FOURTH EDITION

CARING FOR DIABETES in children & adolescents

Editors: Geoffrey Ambler, Fergus Cameron, Karissa Ludwig
Illustrated by Karissa Ludwig

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Introduction

Caring for diabetes in children and adolescents is a challenging task for families and their health professionals. Education and knowledge are essential elements in being able to look after your child's diabetes from day to day and in special situations.

This resource aims to provide this information for you. It will help you revise and build on your knowledge from your diabetes education and also serve as a ready reference when new situations arise.

While teaching will differ slightly between different diabetes centres, the content has been contributed to and edited by health professionals from major children's diabetes centres in Australia: therefore it reflects a common approach and practice.

This resource also takes into account the current guidelines from the National Health and Medical Research Council (NHMRC) and the International Society of Paediatric and Adolescent Diabetes (ISPAD) and assists with their practical application.

This fourth edition includes significant revisions and updates, particularly on new technologies such as continuous glucose monitoring and hybrid closed loop insulin pump therapy. Parents, grandparents, friends and other carers, as well as young people with diabetes, will find this book useful. We hope it helps you.

Please note: The information in this resource has been carefully checked and is believed to be accurate at the time of production. If you are unsure of whether any particular information is appropriate or applicable to your child, you should check with your diabetes team first.

Brand names or trade names are used for clarity in places throughout the book. It is recognised that these are the registered property of the respective companies.

Chapter 1

Diabetes – the basics

This resource will help you and your family learn about diabetes and will be useful to look up when you need to check information at home. It has been written by health professionals who have extensive experience in caring for children and adolescents with diabetes. This first page gives some key points about diabetes; these points are covered in detail later.

What is diabetes?

Type 1 diabetes is the common form of diabetes in children and teenagers and occurs when the pancreas is unable to make enough insulin. Insulin is a hormone which allows the body to use glucose in the blood as energy. The glucose in the blood comes mainly from the food we eat and from stores in the liver and muscle. When a person has diabetes, the blood glucose level rises because of the lack of insulin and they become unwell with the symptoms of diabetes. These symptoms include excessive thirst, excessive urination, weight loss and dehydration. Type 1 diabetes always requires insulin treatment.

Type 2 diabetes is a different form of diabetes that is less common in children and teenagers but common in adults. The pancreas can still produce insulin but the body is resistant to the insulin working. Type 2 diabetes is discussed in more detail in Chapter 14. Type 2 diabetes may not need insulin treatment.

There are some other rarer forms of diabetes which your healthcare team will discuss with you if relevant. In all forms of diabetes the primary goal is to control and normalise blood glucose levels.

Why does diabetes occur?

Some people carry genes that make them more likely to get diabetes. Type 1 diabetes develops in these people only when something triggers the immune system to start damaging the pancreas. The word "autoimmune" is used to describe the process in which the body's immune system acts against some of its own tissues, such as in diabetes when the immune system acts against beta cells in the pancreas. Triggers to type 1 diabetes are believed to be factors in the environment, but are still not well understood.

Important risk factors for type 2 diabetes include genetic factors and being overweight with an unhealthy diet and not enough exercise.

Treatment of diabetes

The care of children and adolescents with diabetes requires a team of specialised health professionals who educate your child and family in diabetes management and help you and your family look after the diabetes.

The main aspects of type 1 diabetes care are:

- Replacement of insulin by giving insulin injections several times each day or using an insulin pump
- A healthy food plan, with a regular intake of carbohydrate-containing foods
- Frequent or continuous monitoring of blood glucose levels
- A healthy amount of exercise
- Regular review by the diabetes team
- Maintaining long-term health and minimising risk of any complications

The main aspects of type 2 diabetes care are:

- Achieving and maintaining a healthy weight
- A healthy food plan
- A healthy amount of exercise
- Control of glucose levels by oral or injectable medications if needed; insulin may or may not be needed
- Regular monitoring of blood glucose levels
- Regular review by the diabetes team
- Maintaining long-term health and minimising risk of any complications

The aim is that children and adolescents with diabetes and their families will be happy, healthy, well-adjusted and grow up and develop normally in all respects.

Chapter 2

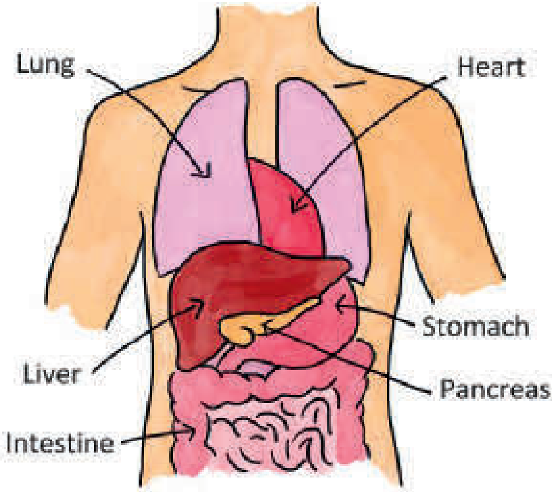
The pancreas, insulin and diabetes

Key Points

- **In type 1 diabetes the pancreas can't make enough insulin, causing the blood glucose to be too high**
- **Diabetes in children and adolescents is usually type 1 diabetes and needs treatment with insulin by injection or insulin pump**
- **Frequent passing of urine, thirst, drinking a lot, weight loss and tiredness are the common symptoms of diabetes**
- **We don't fully understand what causes diabetes, but genes and triggers in the environment are likely factors**

Insulin and the pancreas

Insulin is a hormone produced by special cells (called beta cells) in the pancreas. Hormones are chemical messengers that circulate in the blood, sending messages to other parts of the body. The pancreas is located deep in the upper part of the abdomen, behind the stomach.



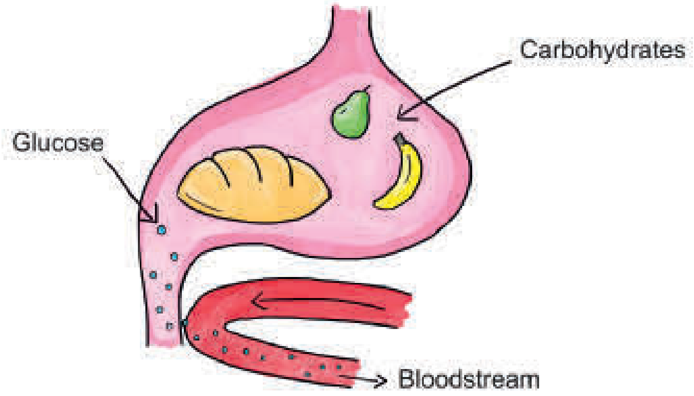
The pancreas has two main functions:

1. Digestion of food – the pancreas produces enzymes that are released into the bowel after a meal to help digestion of food. Diabetes does not affect this part of the pancreas.

2. Production of hormones – there are groups of cells in the pancreas called islets of Langerhans that produce a variety of hormones – insulin and glucagon are two important ones. These hormones help to regulate energy in the body. In diabetes, the main problem is that the cells that make insulin (the beta cells) are damaged and therefore blood glucose levels become elevated. The glucagon producing cells also become damaged which adds to the loss of glucose regulation later, even when insulin is being replaced. This is because glucagon's function is to help increase blood glucose levels if they become too low.

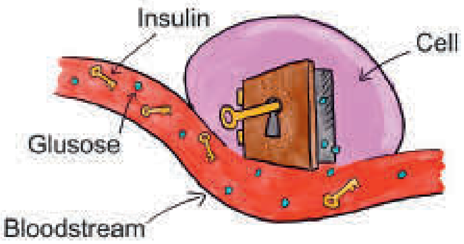
Insulin, food and energy

After we eat, the food is digested in the stomach and the upper part of the bowel. The nutrients from the digested food are taken into the bloodstream. The carbohydrates (sugars and starches) in our food are broken down into glucose which enters the bloodstream. This glucose is used immediately for energy or can be stored in the liver or muscle as a substance called glycogen. Glucose can be released from glycogen when needed and glucose output from the liver and muscle contributes to blood glucose levels, as well as food that has been eaten recently.



Digestion of carbohydrates and absorption of glucose into the bloodstream

We need insulin to help the body use glucose from the bloodstream for energy. Glucose is the major energy source for the cells of the body, but normally glucose can only pass from the bloodstream into cells if insulin is present. If there is no insulin, blood glucose levels will be high but none of the glucose can be used for energy since it cannot enter the cells. Insulin has been described as being like "a key that unlocks the door of cells" and lets glucose in to be used for energy.



How insulin helps the body use glucose from the bloodstream for energy

Ketones are other substances that the body can sometimes use for energy if it cannot use glucose. In people without diabetes, ketones start to be produced from fat as an alternative energy source when supplies of glucose are becoming low, such as during fasting or illness. This can sometimes be the case in people with diabetes but usually in diabetes, production of ketones means there is a lack of insulin and the glucose that is present in the blood is unable to be used for energy. You will learn more about ketones in Chapter 10 'Sick days'.

What is diabetes?

Diabetes mellitus (often just called diabetes) occurs when the body cannot produce enough insulin, or when the insulin that the body makes does not work properly. The name comes from the ancient Greek word 'diabetes' meaning siphon or running through (referring to the passing of large amounts of urine) and 'mellitus' meaning honey-like (referring to the sweetness of the urine due to excess sugar as identified by ancient physicians).

There are two main types of diabetes and some other less common forms:

Type 1 diabetes mellitus is the type that is more commonly found in children and adolescents and occurs because the pancreas loses the ability to make insulin. People with type 1 diabetes need insulin treatment to stay alive. In the past, type 1 diabetes was sometimes called insulin-dependent diabetes mellitus (IDDM). Most of this resource is about type 1 diabetes, but there is also a section on type 2 diabetes.

Type 2 diabetes mellitus usually affects older people but is increasingly being seen in younger people. It is often associated with a sedentary lifestyle, high-energy food intake and being overweight. There is also a strong genetic component. People with type 2 diabetes make some insulin but the insulin does not work well (insulin resistance). Type 2 diabetes can often be controlled by changes to diet and weight control but may need tablets or injectable treatments (insulin or other agents). Type 2 diabetes is covered in more detail in Chapter 14 'Type 2 diabetes'.

Other types of diabetes occur much less commonly and are usually associated with other conditions that damage the pancreas (usually called secondary diabetes). There are also some rarer genetic forms of diabetes. When diabetes is diagnosed, tests will usually be done to clarify the type of diabetes present, especially if there are any features that are not typical of type 1 diabetes.

What causes type 1 diabetes?

The cause of diabetes is complex and not fully understood. We do know that diabetes occurs because of a combination of a person's genes and some things in the environment. If a person who has inherited the tendency to develop diabetes comes in contact with a trigger in the environment, then diabetes may develop. The triggers are poorly understood, but may be common things in our environment which are harmless to most people; for example, common viruses or things that we eat. The trigger may be different for different people.

If diabetes is triggered, the body's immune system which normally protects us from infections, begins to attack the beta cells of the pancreas. The immune system seems to have been tricked into thinking that the beta cells are foreign to the body and starts to destroy them, causing a decrease in insulin production. It can take from a few weeks to a few years for all of the beta cells to be destroyed. Type 1 diabetes is an example of an autoimmune condition.

The pancreas has many beta cells to spare, so symptoms of diabetes do not occur until more than 90 per cent of the cells have been destroyed. This means it is difficult to tell if someone is developing diabetes (i.e., it is difficult to tell they are in the prediabetes phase) until the symptoms of diabetes occur. Special blood tests can detect people in the prediabetes phase and are being used for research and diabetes prevention trials. At this stage there is no treatment proven to stop diabetes developing, but this is an active area of research.

It is important to remember the following points:

- Diabetes cannot be caught from another person. It is not contagious.
- Type 1 diabetes is not caused by eating too much sugar or any other foods.
- There is nothing you could have done to prevent your child from getting diabetes. It was something that was going to happen anyway.
- Your child cannot grow out of type 1 diabetes. It does not change to type 2 diabetes as they get older.

What are the symptoms and signs of diabetes?

When diabetes develops, glucose levels rise above normal, often as much as five to ten times normal. Excess glucose spills over into the urine, drawing water with it and causing excessive passing of urine and dehydration. Thirst increases as the body tries to compensate and the young person may drink large amounts of fluid.

Weight loss is common over weeks to months since the body cannot use glucose for energy and instead starts to break down fat and muscle. Excessive tiredness and mood changes are common because the child is feeling unwell. Breakdown of fat causes chemicals called ketones to accumulate in the blood and this can cause abdominal (tummy) pains, nausea and vomiting.

Common symptoms of diabetes are:

- frequent passing of urine
- increased thirst and drinking
- weight loss
- tiredness
- mood changes

Other possible symptoms include:

- oral or vaginal thrush or skin infections (these organisms thrive in a high glucose environment)
- abdominal (tummy) pains
- decreased school performance because of feeling unwell
- excessive hunger

Diabetic ketoacidosis (DKA)

When the diabetes comes on quickly, or is found late, the child can become very ill. Glucose and ketone levels become very high in the blood and there is severe dehydration and loss of salts from the body. This is called diabetic ketoacidosis and is life-threatening and requires urgent hospital treatment.

The onset of diabetes can be especially rapid in babies and young infants, and symptoms and signs may be less easily noticed than in older children.

How is diabetes diagnosed?

In most cases the diagnosis of diabetes is simple. If symptoms suggest diabetes, your doctor will perform a blood test and a urine test (looking for glucose levels and ketones). Normally the urine contains no glucose; glucose only spills over into the urine when the blood glucose is high, so glucose in the urine is highly suggestive of diabetes. A high blood glucose level is used to confirm the diagnosis. In most cases no other tests are necessary, but occasionally in doubtful cases a diabetes specialist may recommend other tests.

Other blood tests are done at the time of diagnosis to confirm the type of diabetes. These are called diabetes antibodies and are markers of the autoimmune process described above. Other common autoimmune conditions that may be associated with type 1 diabetes are also screened for – in particular thyroiditis and coeliac disease.

If you have a relative or friend with symptoms that sound like diabetes, advise them to see a doctor without delay and to ask specifically to be tested for diabetes. Early diagnosis can prevent severe illness with diabetic ketoacidosis.

Can the pancreas recover?

Many treatments have been tried to stop the damage to beta cells in the pancreas, but at present there is no safe or effective way to do this. This is an active area of research. When insulin treatment is started, the pancreas is able to rest and recover to some degree, but not enough to produce all the insulin the body needs. For a time, the child's own pancreas may continue to produce up to half or more of the insulin needed by the body and this period is called the 'remission phase' or 'honeymoon period'. This can be a period where children require quite small doses of insulin. Unfortunately the damaging processes in the pancreas are irreversible and continue. Over a period of time, from a few weeks to many months, the pancreas becomes unable to produce any insulin and all of the body's need for it must be met by injection.

How common is diabetes?

Each year in our population about 25 children per 100,000 develop type 1 diabetes (for children aged less than 15 years). Diabetes can come on at any age in children, but around 10 to 12 years is most common and it is also quite common around 4 to 6 years. It is estimated that there are around 7000 children and adolescents in Australia with type 1 diabetes under 15 years of age. On average, at a high school there will be one student per 500 with diabetes and in primary schools about one student per 1200.

Our population has an intermediate incidence of type 1 diabetes compared to other countries around the world. Incidence is low in Asian populations (less than one half of our incidence) and highest in Finland (approximately double our incidence). The differences probably relate to genetic factors. The incidence of type 1 diabetes is gradually rising around the world and the reasons for this are not clear.

What are the risks for other family members?

While inheritance of genes contributes to the risk of diabetes, the risk for other family members developing diabetes is still generally low. The long-term risk of a brother or sister developing diabetes (assuming no type 1 diabetes in any other close family members) is about 6 per cent. In an identical twin the risk is much higher, at least 35-50 per cent. If there is more than one person with type 1 diabetes in the immediate family, risks for other children will be higher.

For parents with diabetes, if the mother has diabetes the risk for a child is 3 to 4 per cent, but if the father has diabetes the risk may be 6 to 9 per cent. If both parents have type 1 diabetes the risk for a child is 10-25 per cent. Remember that diabetes is not contagious – the risk relates to genetic factors.

If there are other autoimmune conditions in close family members (for example, autoimmune thyroid disease or coeliac disease), diabetes risk may be greater than the figures quoted above.

Common questions and answers

Why does insulin have to be given by injection or pump? Why can't it be given in tablets?

Current insulin preparations cannot be given by mouth because the insulin is destroyed by the acid in the stomach. Researchers are working to develop insulin-like medications that can be taken by mouth. The tablets that some people with type 2 diabetes take are not insulin tablets and do not work in type 1 diabetes. Other ways of giving insulin are actively being researched.

Should we have our other children tested for risk of diabetes?

Many people worry about the increase in risk of other children in the family getting diabetes. Blood testing is available to look for diabetes antibodies and higher risk genes and this is an active area of research. One problem at present is that if a high risk of diabetes is found in another child, there are no proven treatments to prevent it. There are continuing studies on possible preventions. Your doctor and other diabetes team members will be able to give you the latest information on diabetes screening and prevention trials.

Why is the cause of diabetes still not fully worked out?

We know that diabetes is caused by a combination of genetic factors and factors in the environment. Both of these are very complex. The genetic risk seems to relate to a complex combination of many genes, rather than just a few. Some of the factors in the environment that may trigger diabetes have been suggested, but how these may trigger diabetes is still not fully understood.

Can I decrease the risk of diabetes in my other children?

No factors have been clearly proven to alter diabetes risk, although some studies are in progress. Discuss the latest information with your diabetes specialist.

Will my child be able to come off insulin later in life?

No. Type 1 diabetes requires life-long insulin therapy. Not until a cure is found will it be possible for people with type 1 diabetes to stop insulin treatment.

Chapter 3

What to expect at the time of diagnosis

Key Points

- **The diabetes team includes your child and family, a diabetes doctor, diabetes educator, diabetes dietitian and social worker or psychologist**
- **Your child will start feeling well again soon after starting insulin**
- **Learning about diabetes and starting to come to terms with the diagnosis are your most important tasks during the first few weeks**

The diabetes team

Diabetes is a condition which is best cared for by a team. The team members interact closely, but all have their special areas. Your child and family are an important part of the team that help look after the diabetes. At the hospital and clinic, you will meet the health professionals who make up the rest of the diabetes team:

- A diabetes doctor, who is a specialist in the medical care of diabetes in children and adolescents. In hospital, young doctors in training (called residents, registrars and fellows) work with the diabetes specialist.
- A diabetes educator (or nurse educator), whose main role is to teach your child and family all about diabetes and how to care for it now and in the future.
- A diabetes dietitian, who focuses on food and nutrition.
- A diabetes social worker or psychologist, who helps families cope with the diagnosis of diabetes and the impact it has on their lives. Where there are other psychological stresses for which people need help, other professionals assist the team, such as a psychologist or psychiatrist.
- The hospital ward and outpatient nursing staff, who care for your child at the hospital and help with teaching.

All of these health professionals provide education, counselling and advice at the time of diagnosis and in the subsequent months and years. The team help you start to come to terms with the shock of the diagnosis and help you learn how to cope. The aim of diabetes education is to give your child and family the knowledge and skills to be self-reliant in the care of diabetes.

Diabetes requires frequent adjustment of treatment for different situations and with growth and development. The diabetes team continue to help you with this at follow-up visits and by telephone or email if there are concerns between visits. As children mature, they gradually gain more knowledge and take on more responsibility for their diabetes. They are helped by education at clinic visits, educational updates for families and activities such as diabetes camps.

Remember that your child and family are an important part of the diabetes team.

The aim of the whole team is to help keep the diabetes well controlled so that it can be kept in the background of your lives. We want to keep your child well-adjusted, happy, healthy and safe. We also like to work in close cooperation with your family doctor (GP) and other people who may be involved in your child's care such as the local paediatrician or other local health professionals – these people are also often part of the primary diabetes team.

What happens at diagnosis

When your child is first diagnosed with diabetes, the most important things are:

- to start insulin treatment under medical supervision so that blood glucose levels can be lowered safely and appropriately.
- to give your child and family support while you are coming to terms with what has happened.
- to give your child and family time to learn about the management of diabetes, with the close support of the diabetes team.

There are different approaches to the first week, depending on the preference of your diabetes centre or hospital and your child's particular circumstances. In some cases, children will be admitted to hospital initially, while others will have all of their care as outpatients. Regardless of the local approach, management principles will be similar and a good outcome will be expected. Your diabetes team will guide you and explain what they feel is the best approach for your child and family.

Outpatient stabilisation

Many children are not admitted to the hospital at all and receive their initial education at the hospital as an outpatient. During this time you will learn the basics about diabetes care and insulin treatment will be started. Arrangements will be made for you to come back to the diabetes centre each day for several days for a program of education and stabilisation and then for more sessions over the next few weeks. Nursing staff will assist with the first insulin injections until you have acquired those skills.

Hospital admission

Children with newly diagnosed diabetes will always be admitted to hospital if:

- they are quite sick initially with diabetic ketoacidosis or other illness
- the family lives too far away to travel to the hospital each day
- the child is very young
- there are difficulties with language or the family has other special needs
- there are other reasons that the diabetes team feel need a stay in hospital

The aim is always to keep the hospital admission to the minimum time possible and continue further education and stabilisation out of hospital. With children, it is best for a parent to stay at the hospital during this time.

Other things that happen in the first week

Children with diabetes will generally be feeling well within a few days of starting insulin treatment. A diagnosis of diabetes is understandably a major shock to the child and the family and it takes some time to come to terms with this. It is important to reassure your child that she or he will become well and remain well. Often in the first 24 to 48 hours everyone in the family is feeling shocked and totally exhausted, so trying to get some rest is important.

Whether or not your child is admitted to hospital, the first week will be busy with education sessions and learning activities. The diabetes team will try to arrange specific times for educational sessions to allow families to fit this into their schedules. It is critical that all care-givers make themselves available for this initial education. Arranging some time off work may be necessary and a letter can be provided to your employer to help with this.

Also, during the first few days families are advised about the equipment they will need at home for diabetes management and arrangements are made for these to be obtained. Some families may qualify for special allowances or a health care card and arrangements are made to apply for these.

At first, the diagnosis of diabetes and all the things you need to know about diabetes may seem overwhelming. By the end of the first week, families will be starting to feel more confident to care for the diabetes. There will always be ongoing support and guidance from the diabetes team.

Common questions and answers

I was worried when the hospital said my child did not need to be admitted and we went home after the first insulin injection, to return the next morning. What if something happens at home?

The diabetes team carefully selects which children are suited for outpatient stabilisation. Families are briefed in the basic skills and given clear and simple advice. If they are worried they can call the diabetes team or present to the emergency department after hours.

Can we see our family doctor for follow-up of our child's diabetes?

Your family doctor is very important in your child's overall health care; however you must also have regular visits to your diabetes team. International recommendations and best practice are that children with diabetes should be seen at least 3 or 4 times each year by a team with specialised knowledge and experience in children's diabetes. The diabetes team keeps in touch with your family doctor so that he or she is fully informed about the diabetes. Your family doctor's role in the diabetes management is to develop a care plan (so you have access to all the services your child needs), manage vaccinations, minor illnesses, travel needs etc. As well as your regular visits to your diabetes team, you should see your family doctor regularly about the diabetes care plan. If you don't see your family doctor regularly it is difficult for them to help you when you need them.

Chapter 4

Adapting to living with diabetes

Key Points

- It is normal to feel a range of emotions at diagnosis and throughout the diabetes journey.
- Diabetes diagnosis often signals significant lifestyle changes and changes in routine. It is normal for the whole family to take time to adapt to this.
- Most diabetes services have a social worker or psychologist to help support these changes, if not you can request to be linked in to community supports.
- The diabetes team can help you access support services or financial assistance if required.

Coping with the diagnosis – first feelings

Being told that your child has diabetes is often a big moment for the whole family. It often leads to significant lifestyle changes and changes in routines. It is quite normal to feel a mixture of emotions at this time. Some common emotions are:

Shock: You may have a feeling of unreality. You feel you are operating on 'automatic' and that the news hasn't hit you yet.

Overwhelm and Denial: Your child may pretend that they don't have diabetes or refuse their medications. You may find yourself wishing diabetes away or regularly rescheduling clinic appointments because you're not in a headspace to talk about diabetes with the diabetes team or feel like you're 'not doing well enough' with diabetes cares. A sibling may want things to 'go back to normal' and may rebel against the new family routines.

Anger: Your child may think, 'Why am I the one that has to have diabetes?'. As a parent, you might feel angry at the doctor or nurses or at a family member. You might be angry that your lifestyle has had to change or that you have to come to regular appointments. A sibling may be angry that they feel like they are missing out at times when their parents must focus on diabetes care.

Sadness: For your child, this may be sadness that they need to have a daily diabetes routine. As a parent, you may be sad that the life that you thought your child would lead has changed. A sibling may be sad that their brother or sister has to have medication every day, or that the food your family eats has changed.

Fear: Your child may find the new diabetes routine scary with injections and fingersticks. As a parent, you may experience a sense of uncertainty and worry around the impact diabetes will have on their life and future goals and ambitions. Siblings may fear that they may also be diagnosed with diabetes. As you learn about diabetes together as a family and put your new skills into practice, some of these fears and concerns begin to fade.

Guilt: A child may think they have done something to cause their diabetes, or may feel that their diabetes is a burden to the rest of the family. As a parent, you may blame yourself for your child having diabetes. A sibling may feel guilty that they're not the one with diabetes, or worry they did something to cause their brother or sister's diabetes.

Relief: Your child may feel relieved that there is a reason why they have been feeling unwell recently. As a parent, you may feel relieved that there is a plan for how to help your child to feel better. Siblings may feel relieved that there is a professional team to help support your family during this difficult time.

The emotional experiences that you, your children and your community have are all valid and are individual to you. It is normal for it to take some time for you and your family to work through all the emotions triggered by a diagnosis, but take hope that you and your family are resilient and will find a 'new normal'. With support from your team, caring for diabetes will become a part of your family life.

Adapting as a family

It is normal for each member of the family to take time to process a new diagnosis of diabetes.

Parents and Carers

The shock of a new diagnosis of diabetes can put stress on family and close relationships. You may find yourself being irritable and flaring up easily. Remember that you are all under stress and everyone's responses to stress are different. Accepting these differences is an important part of supporting each other.

Parents' concerns often include fear of low blood glucose levels and grappling with the day-to-day diabetes care routine. You may worry about long-term complications and that you are not doing a good enough job with the diabetes. There may be a tendency to be over-protective. Sometimes it is frustrating that others do not understand the amount of work involved in looking after someone with diabetes and having to re-explain the condition to the child's new teachers, friends and others. It can take a while to adapt to and accept the diagnosis. Try not to put the pressure on yourself to have everything right or to know everything about diabetes, as this is impossible and may be too overwhelming.

The responsibility for day-to-day diabetes care ideally needs to be shared with a partner or another close person. To share the practical tasks is to share the emotional burden.

Parental Self Care

It is important to acknowledge that finding out your child has diabetes is, for most parents, quite a big shock. For many parents, the idea of their child having to take daily medication (especially injections or fingersticks) has never been a possibility before. Additionally, the adjustment required to adapt to the idea that your child has a lifelong condition is hard, and carries with it a number of different – and often difficult – emotions.

Your children will look to you as to how to process this big life event. Because of this, it is important that you make sure that you prioritise your self-care. Small steps like making sure that you are eating and drinking sufficiently, getting enough sleep and having some time by yourself are important. This also role-models to your children that it is important to take care of yourself. It is also okay for you to express your emotions about the diagnosis. This lets children know that it's also okay for them to feel whatever emotions they are feeling too.

Having a major life event, like a new diagnosis, can also make pre-existing stressors feel even bigger. This might include practical stressors (like household finances or pre-existing illness in the family) or more emotional stressors (like a history of mental health concerns such as depression and anxiety). Please don't hesitate to raise these things with your diabetes team to help navigate different support options available to you.

The Child

Your child may experience any of the feelings already described. Like you, they need someone to talk to and at times need encouragement to share their feelings. You may do this by acknowledging your feelings first, which then gives them permission to express theirs. As their parent you are the best person to help them through this difficult time because you know them so well. At times they may also benefit from being able to speak to someone such as a social worker or psychologist.

It is important that a young person's identity does not become defined by diabetes. It can be tempting to ask your child what their blood glucose levels are as soon as they walk through the door after school. Children do not want to identify themselves as a 'diabetic' with nothing else to offer or share. Try asking about other things first, like how their day went, to assist building your relationship and communication. Adolescents especially have been known to say that the only thing they talk and argue about with their parents is the diabetes. It is important to find ways of communicating about the diabetes without having diabetes being dominant.

Children may feel different from their friends and feel their life is ruled by diabetes and routines. They may be reluctant to let people know they have diabetes or be embarrassed to test blood glucose or eat when needed. Teaching your child how to discuss their diabetes with friends can support diabetes acceptance among the child and their peers.

Children may become more dependent on their parents at a time when they would otherwise be becoming more independent. They may also worry about the extra demands their diabetes places on the family. It is important the child is aware that diabetes care is a family approach and are supported to learn age-appropriate care routines to support development of their own self-care skills.

Siblings

It can be hard to know what to tell brothers and sisters of a child who has been diagnosed with diabetes. It's important to provide them with age-appropriate, honest information about what is going on for their sibling.

When information like this is kept secret, it can make the person with diabetes feel like their diagnosis is something to be scared or ashamed of. Also, if they are not given any information, siblings tend to make up stories that are much more horrible than what has actually happened – and this usually centres around them doing something wrong.

A simple explanation like *'Susie had to go to the hospital because her body wasn't making energy. This is called having diabetes. But now she takes medication called insulin to help her have all the energy she needs'* is a great starting point. Encourage questions and try not to make a 'big deal' out of the diagnosis. We want your children to know that the adults are in control and they don't need to worry.

Allowing siblings to reflect on their own experience and feelings during the diagnosis can support the siblings to feel understood and not left out in times when the parent must focus on diabetes cares.

Remember, in order for the new routine to be sustainable, you and your family (including siblings) need to work together as a team. This can be hard for children (especially if they're used to a double serve of ice-cream after dinner!) but is important for family harmony and to reduce the risk of 'diabetes burnout'. Siblings can also be a really great help. For example, depending on their age, siblings can watch for hypoglycaemic symptoms or help writing in the log book.

Wider Family and Friends

Having people around us who support us is a great strength in managing a chronic illness like diabetes. But it can sometimes be hard to know where to start with explaining to them what has happened or what diabetes is. It might be a good idea to provide your friends and family with some of the information you have received from the treating team about what diabetes is. This will not only help them to understand what is going on for you and your family better, but will also provide a good starting point for conversations with you about diabetes.

It is also a good idea to help include people in your child's diabetes care as appropriate and as you and your child feel comfortable. This helps everyone feel like they're part of a 'diabetes team'. If there is a relative or friend that your child has regular days out or sleepovers with, you can develop a plan with them on how your child's diabetes will be managed while in their care. These are normal parts of growing up and we don't want your child to miss out because of their diabetes. If you need some help around having these conversations or how to plan for your child to spend time with family or friends please ask your diabetes team for some tips or resources.

Age-appropriate Independence

When your child has diabetes, particularly in the initial stages after diagnosis, it is normal for you to want to keep them close to ensure they stay healthy and well. However, it is also important to remember that the long-term goal is for them to have a rich and fulling life not inhibited by their diagnosis.

Age-appropriate independence refers to allowing children to build and develop skills reflective of their stage of growth and development. In day-to-day terms this might include encouraging your toddler to tidy up their toys after play or allowing your teenager to go to the movies with friends. In regards to diabetes, this might include a primary school age child doing their own fingersticks or a teenager doing their own injections or pump adjustments.

Encouraging age-appropriate independence not only increases your child's self-confidence and sense of self-worth, but reinforces the idea that your child is just like all other children – despite their diabetes diagnosis.

It is important to note that age-appropriate independence does not mean 'hands off' supervision of diabetes cares. It is vital that you remain an integral part of the 'diabetes team'. This might look like sitting down with your teenager once a week for pump downloads, supervising your child's injections or double checking that they have their diabetes equipment before they go to school.

It can be tricky to work out where the line is between age-appropriate independence and ensuring that your child is practicing good diabetes cares. This is particularly common around periods of transition, such as your child heading to primary school, high school, or the senior years of high school. If you need help or support in finding the 'middle ground' please don't hesitate to talk with your diabetes team for ideas and strategies.

Expectations about diabetes care at different ages and stages of development is discussed further in Chapter 16.

School and Other Activities

Going to school and having after school activities are a normal part of most children's day-to-day routine. After a diagnosis, it is important that your family incorporate diabetes care into your child's normal routine as soon as possible. However, it is also normal to feel some anxiety about placing your child in another adult's care.

Children with diabetes are able to do almost all of the things other children can who don't have diabetes, with some planning and preparation. This includes playing sport, going to friends' houses, school camps and sleep overs. To be confident leaving your child in someone else's care, it's important to build and maintain a trusting relationship with the other adult. Part of this is having a clear plan for diabetes care that both you and the other adult agree on. Regular catch-ups with your child's teacher, dance instructor, football coach etc. are often helpful.

Your Diabetes Educator will assist you in making a diabetes school plan to help the school manage your child's diabetes. This is discussed in more detail in Chapter 15.

It is important to talk through with your child what they can expect when they go back to school or to after school activities. For example, discussing with them who they would like to tell about their diagnosis and how to have this conversation. You could also problem-solve how they would answer questions people might have. It is also important that your child knows how to tell their teacher if they feel like they're having a hypo or need some help, where they will do their diabetes cares and which adults can help them. Having these conversations will make them feel more confident about going back to their school and activities as soon as possible.

Mental Health

Although diabetes is seen as a physical condition, it can very much impact your and your child's mental health. Therefore looking after your mental health is just as important as the rest of the physical diabetes care routine. It is normal to have emotionally 'up and down' days when dealing with diabetes, but should the down days become more frequent it may be worth speaking to a mental health professional.

Mental health conditions that can arise in children with diabetes and diabetes 'burnout' are discussed in Chapter 16 and Chapter 19.

Supports

There are many sources of support for children and families living with diabetes.

Diabetes team

Your diabetes team is here to support you at this time. Most diabetes centres arrange for discussion about adjusting and coping with diabetes through the social worker or psychologist with the team. You can also access these services through your family doctor if needed.

This support is especially important at the time of diagnosis, but also later. Sometimes situations can arise where aspects of diabetes are too much for your child or family to cope with at the time. You should not feel reluctant to ask for help in these situations.

If you are feeling overwhelmed by the amount of information you have to take in, talk to the people teaching you. They will understand that at times it is best to slow things down. Don't be afraid to ask about something again if you don't understand the first time.

Diabetes community

Meeting other children and families can also often be very helpful – you learn how others face similar challenges and ways they have found to deal with them. Local diabetes organisations or your diabetes team can put you in touch with other families. You may also meet them at education days or other functions. Diabetes camps can be a way for your child to meet others their own age with diabetes and to begin to become more independent and self-reliant in a carefully supervised environment. Diabetes camps are discussed more in Chapter 18.

The internet and social media

We know there is a lot of information online about diabetes and a lot of social media support groups. While these can be a great help to a lot of families, at times the volume of information can leave people feeling confused and like they never 'get a break' from diabetes.

If something online is making you feel stressed or worried, it is okay to have a break from it or make some 'rules' about when and for how long you would engage with them for. If you have questions or concerns about something you have read online, your best source of up-to-date, evidence-based information is your diabetes team.

Chapter 21 includes a list of diabetes resources you may find helpful.

Financial assistance

Because of the extra care and costs associated with a child with diabetes, there may be some avenues for extra financial assistance. This includes support from Centrelink, such as a Health Care Card, Carer's Allowance or Carer's Adjustment Payment, or support from the National Diabetic Service Scheme (NDSS).

Eligibility changes from time to time and may vary in different states. Your diabetes team will advise which allowances it may be possible to apply for. In Australia, latest details can also be obtained from Centrelink and your diabetes care team.

If you are struggling to meet the practical or financial demands on caring for a child with diabetes, please don't hesitate to speak with your diabetes care team about what supports may be available.

Common questions and answers

What is the role of Social Workers in supporting people with diabetes?

The main role of a social worker is to help families to adjust to the new diagnosis of diabetes and to support you during your time working with the diabetes team.

Social workers are important to help the diabetes team get to know you and your family. This helps the team tailor your diabetes management plan to match your lifestyle. They can also help by providing families with information about things like Centrelink payments and support groups. Importantly, social workers can provide emotional support to you, your child and your family and can assist with practical problem solving of issues that may arise in diabetes management (e.g., needle phobias, adjusting daily routines, avoiding diabetes 'burnout').

My child wants to stay over at their best friend's house but I'm worried that they won't be safe enough. What can we do?

Children with diabetes are able to do all the things their peers are able to do – with some forward planning. It is normal to feel nervous about your child becoming more independent, however we don't want them to feel like their diabetes 'holds them back'. Please talk to your diabetes team about how you and your child can plan together to make these activities a success.

My 10 year old is very capable and independent. When can I let her do all her diabetes cares by herself?

Well done to your 10 year old for building their confidence in participating in their diabetes cares! However, even when children and teenagers are able to do many aspects of their diabetes care, it is important that their parent or carers remain closely and actively involved. This is not only because children can make mistakes (either with doses or forgetting things) but also because we know the mental burden of having diabetes can be great. Sharing the responsibility with your child, no matter their age, lets them know that they are not alone and that you're in this together. This is likely to increase diabetes cares compliance and their overall health and wellbeing.

I'm worried that my child's BGL's are 'bad' because they are not trying hard enough. How can I motivate them to take better care of their diabetes?

Diabetes is a complex illness in that it uses numbers and target ranges to help with management. This can sometimes make people think that there are 'good' and 'bad' numbers or that control is always easy. It is important to remember that there are no such thing as 'good' or 'bad' numbers, but just data that helps to tell you, your child and the team what to do next.

Remember that a child with diabetes often has to make many more decisions and shoulder additional responsibility compared to other children of their age and stage of development. It is important to remain actively involved in their diabetes management to share the burden. If you feel like your child is experiencing diabetes 'burn out' and is struggling to do all their diabetes cares, reach out to your diabetes team.

Chapter 5

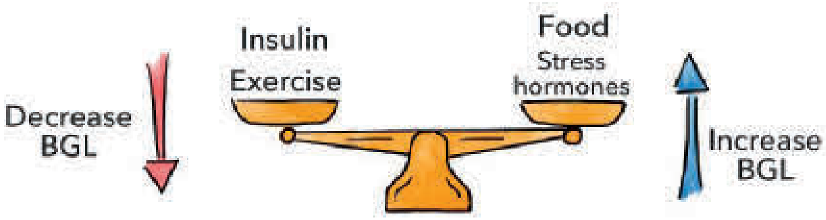
Insulin treatment

Key Points

- Insulin therapy is required to replace the insulin that the body cannot make.
- Insulin has to be given by injection or insulin pump into the fat layer under the skin (subcutaneous). It cannot be given by tablets, since digestion destroys the insulin. Other ways of giving insulin could be possible in the future.
- There are several types of insulin which are used for different purposes:
    - Short or rapid acting (bolus) insulin is used to cover meals
    - Long acting (basal) insulin is used to cover background requirements of the body
- Insulin pumps only use rapid acting insulin, which is given continuously to provide the background (basal) insulin and in ‘bursts’ (boluses) to cover meals and correct high glucose levels.
- Insulin requirements (total daily insulin needs) will change over time as they are affected by factors such as age, growth and puberty. After diagnosis, much lower insulin doses are often required for a period of time (honeymoon phase).
- Your diabetes team will recommend an insulin plan that suits your child’s individual needs (age, food intake, activity level) and your preferences.
- It is important to understand correct injection technique, rotating injection (or pump set insertion) sites, appropriate storage of insulin and safe disposal of pen needles (sharps).

Managing diabetes

The management of diabetes is a balance between factors which lower blood glucose (mainly insulin and exercise) and those which raise blood glucose (mainly food and stress hormones). Managing diabetes is all about understanding these factors and learning to make adjustments for them. Details of all of these aspects are given in later sections.



Factors that must be balanced in diabetes management

Different types of insulin

A variety of insulin types are available, which can be administered via injection (usually multiple daily injections) or an insulin pump (see Chapter 13). Available insulins differ in their profile of action – that is, how quickly they start to act, when the maximum effect is and how long the effect lasts. The profile of action is determined by how quickly the insulin breaks down into single molecules and is absorbed from under the skin and also binding with carrier proteins. Your diabetes team will discuss with you what they feel is best for your child at the time of diagnosis. Later on, it may be necessary to change insulin types or use an insulin pump, as different things suit different children at different ages and stages of development.

Before the 1980s, all insulin was extracted from the pancreases of pigs (porcine insulin) and beef cattle (bovine insulin). In the 1980s it became possible to make human insulin synthetically in the laboratory. These are identical to natural insulin and are highly pure. Laboratory made human insulin has largely replaced animal insulin in the treatment of type 1 diabetes and animal insulin is no longer available in Australia.

Just before the new millennium a number of chemically modified insulins became available called insulin analogues. These have been designed to have better properties which improve the diabetes management in many people. We are likely to see more specially tailored insulin types become available in the future. The availability of different insulins gives your doctor a wider choice of insulins to match your child's needs at any particular time.

There are two main types of insulin action. **Bolus** insulin refers to the 'burst' of insulin that is required to cover a meal and/or correct a high blood glucose level. **Basal** insulin refers to the insulin that covers the background requirements of the body (i.e., should always be present). This is discussed in more detail later.

Insulin is given in one of two ways:

- **Injections:** the usual injection routine is a combination of rapid or short acting (bolus) insulin and long acting (basal) insulin. Injections are usually given 4 times per day (occasionally 2 or 3 times per day in special circumstances). The table on page 26 summarises the different types of insulin in common use. Some books use the term 'intermediate acting' insulin. Here we include these insulins in our long acting (bolus) insulin category as this is the terminology in common use.

- **Insulin pumps:** only rapid acting insulin is used in pumps (i.e., no long acting insulin). An insulin pump delivers insulin continuously in small amounts (basal insulin) with bursts of insulin (boluses) activated by the user to cover meals and correct high glucose levels.

Insulin types used in Australia

The table later in this section lists the types of insulin available in Australia that are commonly used in young people and gives a guide to their characteristics. All insulins are synthetic human insulins or human insulin analogues. The timing characteristics of the insulins shown are a guide only – there is much variation between different children, at different doses and different ages and you may find they work differently in your child. Your diabetes team will decide which insulins are best for your child and discuss this with you.

Rapid and short acting (bolus) insulins

These are insulins that are absorbed quickly into the body after the injection and are used as part of the insulin plan for most children and adolescents. Rapid acting insulins are also used in insulin pumps which deliver insulin continuously.

The rapid acting insulins in this category (Humalog, NovoRapid, Apidra and FiASP) have been designed to be absorbed more quickly than the original short acting or regular human insulins (Actrapid, Humulin R). Rapid acting insulins have the convenience of being able to be given shortly before a meal. They may cause less hypoglycaemia in some people because of their shorter duration of action. On the other hand, rapid acting insulins do not suit all people well as they may be too sensitive to the rapid onset of action or the insulin action may not last long enough.

Long acting (basal) insulins

These have a slower onset and a longer duration of action. Most people on insulin injections have these once or twice a day as part of their insulin plan. These insulins have characteristics that slow their rate of absorption and action. The long acting insulin analogues glargine (Optisulin, previously called Lantus) and insulin detemir (Levemir) offer significant advantages compared with older long acting human insulins and are now in widespread use. People receiving their insulin through an insulin pump do not use any long acting insulin, but need to have some available at home in case of pump malfunction (see Chapter 13).

Pre-mixed insulins

Pre-mixed combinations of rapid or short acting and long acting insulins are available but are not used frequently in children and adolescents. This is mainly because the ratios of the two types of insulin often need to be changed in children and this cannot be done when they are pre-mixed. There are some situations where they can suit young people or are the best compromise and your diabetes team will discuss this with you if needed.

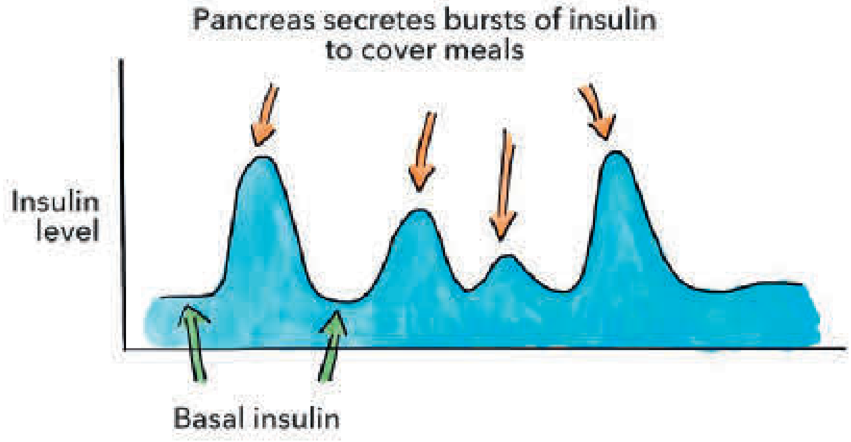
Insulin Type	Preparations and manufacturer	Onset of action	Peak of action	Duration of action
Bolus insulins				
Rapid acting insulin analogues	NovoRapid (insulin aspart, Novo Nordisk) Humalog (insulin lispro, Eli Lilly) Apidra (insulin glulisine, Sanofi-Aventis)	15-30 minutes	1-2 hours	3-5 hours
	FiASP (faster acting insulin aspart, Novo Nordisk)	5-15 minutes	0.5-1.5 hours	3-5 hours
Short acting insulins	Actrapid (regular human insulin, Novo Nordisk) Humulin R (regular human insulin, Eli Lilly)	30-60 minutes	2-4 hours	5-8 hours
Basal insulins				
Long acting insulins	Protaphane (human isophane insulin, Novo Nordisk) Humulin NPH (human isophane insulin, Eli Lilly)	2–3 hours	4-12 hours	8-24 hours
Long acting insulin analogues	Levemir (insulin detemir, Novo Nordisk)	1-2 hours	No pronounced peak	20-24 hours
	Optisulin (insulin glargine 100 units/mL, Sanofi Aventis), previously called Lantus	2-4 hours	Relatively peakless	20-24 hours
	Toujeo (insulin glargine 300 units/mL, Sanofi Aventis)	6 hours	Relatively peakless	Up to 36 hours
Mixed insulins				
Mixed insulins	Rapid / long acting mix: NovoMix30 (Novo Nordisk) Humalog Mix25 (Eli Lilly) Humalog Mix50 (Eli Lilly) Ryzodeg (Novo Nordisk)* Short / long acting mix: Mixtard 30/70 (Novo Nordisk) Mixtard 50/50 (Novo Nordisk) Humulin 30/70 (Eli Lilly)	30 minutes	4-12 hours	8-24 hours

*Ryzodeg contains the ultra long acting insulin degludec which has a duration of action up to 42 hours.

The types of insulin listed in this table are those in common use. These may change over time as new types of insulin are released. Your diabetes team will advise you on the best insulin options for you.

Different patterns of insulin dosage

Ideally, the insulin doses given would mimic the levels produced by a normally functioning pancreas. That is, a small background level of insulin (basal insulin) with pulses of insulin action at times of meals or snacks, as shown in the figure.



With injections, we aim to approximate the body's requirements by using a combination of rapid or short and longer acting insulins. Usually injections are given four times per day, but occasionally a simplified regimen will be used where two or three injections per day are given. The closest way at present to simulate the pancreas' normal secretion pattern is to use a continuous insulin pump (see Chapter 13).

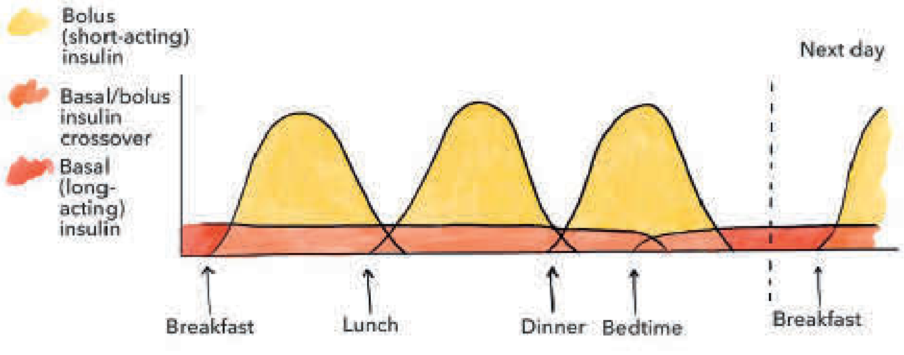
The following describes some commonly used patterns of insulin injections. Your diabetes team will advise on the most appropriate insulin plan to start with and for subsequent treatment. The initial plan could change later, depending on how well it works, your child's age and other variables.

Four times daily injections – basal-bolus or multiple daily injections (MDI)

In this routine, people have:

- Before breakfast: rapid or short acting insulin (meal bolus)
- Before lunch: rapid or short acting insulin (meal bolus)
- Before main evening meal: rapid or short acting insulin (meal bolus)
- Once or twice daily (before breakfast and/or bedtime): long acting insulin (basal insulin)

This routine is often referred to as a basal-bolus injection plan or multiple daily injections (MDI). Commonly about 40 to 45% of the insulin is given as long acting (basal) insulin and the rest is divided up in the rapid or short acting (bolus) doses. This offers very good flexibility for insulin adjustment and when part of a comprehensive diabetes management plan has been shown to have advantages for diabetes control. It is the commonest starting insulin plan for older children, adolescents and adults. It is also commonly used in younger children, although they will need assistance with injections, particularly at school.



A basal-bolus or MDI injection pattern

There are different ways of applying and adjusting this insulin pattern which can be summarized as:

1. **Flexible carbohydrate and insulin adjustment (flexible multiple daily injections)**

   In this method, pre-meal insulin doses are adjusted from day to day based on variations in carbohydrate intake and activity patterns. There is no exact formula for how this is done. It is based on a person's experience and judgement of how food and activity affect their BGLs and involves making small increases or decreases from their usual doses according to the circumstances of the day.

2. **Insulin to carbohydrate ratio (ICR)**

   This is a further extension of flexible day to day adjustment in which the pre-meal insulin dose is calculated according to the amount of carbohydrate that will be eaten and whether a correction for a high blood glucose level is needed. A bolus advisor meter, App or card is used.

3. **Conventional MDI with consistent carbohydrate intake**

   In this pattern, a person has a fairly consistent carbohydrate intake on a day to day basis and tends to keep the pre-meal insulin doses fairly constant from day to day.

All of these methods can be applied well and which one is used is often a matter of the recommendations of your diabetes team and your personal preference. These methods are further discussed in Chapter 6 and Chapter 12.

Two or three times daily injections (simplified injection regimens)

In some children and adolescents, a two or three times per day injection plan may be recommended. This may depend on factors such as age, ability to give injections (e.g., at school) and motivation. Although a multiple daily injection regimen is best for most children, these simpler injection plans can work well in some cases.

A variety of 2 and 3 times per day injection plans can be used. Different plans will suit different children and your diabetes team will advise what they think is best at any time in consultation with you and your child. These injection plans usually involve long acting insulin being given either before breakfast or before bed, or sometimes both, and rapid or short acting insulin being given before breakfast and at afternoon tea or dinner. Your diabetes team will explain the details.

Other patterns of insulin dosage via injection

Many other patterns of insulin dosage may be used, depending on individual needs. Those described above are in most common use. It is common in the honeymoon or remission phase (in the first months after diagnosis) that less rapid or short acting insulin is needed, sometimes none at all for a time. As times goes on however, this will again be needed.

Insulin pump therapy

Insulin in type 1 diabetes is increasingly being given by insulin pump therapy. This involves a small computerised insulin pump which delivers insulin continuously via a small plastic cannula that is inserted under the skin and changed every 2-3 days. The user or a carer activates the pump to give insulin to cover meals or to correct the blood glucose level. Usually pumps are used in combination with continuous glucose monitoring systems (CGMS). Newer model pumps have the ability to alter the insulin delivery rates to adjust the blood glucose level automatically. Insulin pumps use rapid acting insulin only. Patients using an insulin pump do not have to give insulin injections, except in special circumstances.

Insulin pumps are an option for most children and adolescents with type 1 diabetes. Your diabetes team will discuss suitability and timing of pump therapy for your child. After the diagnosis of diabetes, it is common for children to be on injection therapy for a time and then progress later to insulin pump therapy if that is agreed to be appropriate. However, insulin pump therapy can be started at any time. Insulin pumps are covered in detail in Chapter 13.

What is the right pattern and dose of insulin for my child?

The doses, type and timing of insulin injections or whether an insulin pump is used are individually decided for each child. The appropriate doses of insulin are those which keep the blood glucose levels and the overall diabetes control in the desirable range. This varies greatly between individuals depending on body size, duration of diabetes, types of insulin being used, puberty, food intake and exercise.

Here is a general guide to total daily insulin needs in children and adolescents:

- **In the honeymoon or remission phase:** 0.2 to 0.5 units of insulin for every kg of body weight per day.
- **Children beyond the honeymoon phase:** 0.7 to 1.2 units of insulin for every kg of body weight per day.

- **Adolescents:** May require much larger doses, up to 1.5 units or more of insulin for every kg of body weight per day.

For example, Kristine is a 10 year old girl who weighs 36kg. Her usual insulin doses are approximately 6 units of Apidra before each main meal and 14 units of Optisulin (glargine) pre-bed. The total insulin per day is approximately 32 units which is 0.9 units/kg/day, within normal expectations.

Devices for insulin injections

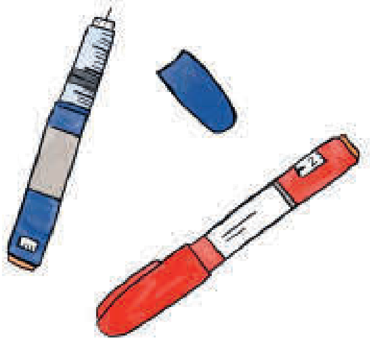
Insulin has to be delivered into the fatty layer under the skin (subcutaneous layer). Insulin can be given by:

- Injection with an insulin pen
- Continuous infusion using an insulin pump (see Chapter 13)

Insulin pens

Insulin pens are devices that are pre-filled with insulin or are loaded with pre-filled cartridges. Current pens hold 300 units of insulin which allows for multiple doses of insulin to be given before the cartridge or pen needs changing. At injection time, the dose of insulin is dialled up on the pen and administered. Pens cannot mix different types of insulin together, so if more than one type of insulin is needed at the same time of day, more than one pen injection is needed. Some pens can be adjusted in half unit increments which is often useful for toddlers and young children.

All major insulin manufacturers have pen devices available for their insulins. Generally 4mm pen needles are recommended for use in children and young people, however 5 or 6mm needles are available if required. Pens or insulin vials must never be shared with another person because of the risk of spreading serious diseases such as hepatitis or HIV.



How to give an insulin injection

Checking the insulin before injecting

The vial, cartridge or insulin pen should be checked for:

- The expiry date.
- The date you opened or started the insulin cartridge or bottle (write this on the calendar or on the insulin bottles when you open them), since any opened insulin vial or cartridge should only be used for a maximum of 4 weeks, then discarded. Often parents of very small children using small doses of insulin will open new pens/vials on the 1st of each month.

- The name – are you giving the correct amount of the right insulin? Different insulin types have colour coded cartridges, but if your insulin pens look similar, mark them clearly so you can easily tell them apart.
- The appearance: different insulins may have a different appearance in the vial or pen.

Clear insulins:

Most currently used insulins have a clear appearance (like water) whether they are long, short or rapid acting. If your insulins should be clear, do not use any vial or pen that is cloudy, discoloured or otherwise altered from the usual appearance.

Cloudy insulins:

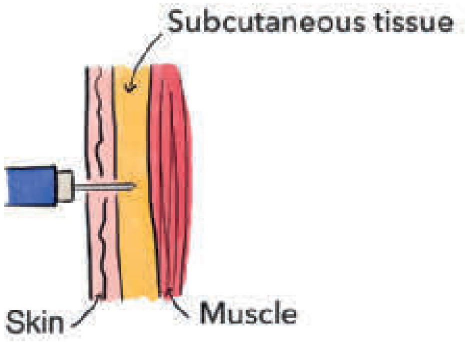
Some particular long acting and mixed insulins have a cloudy appearance in the vial (e.g., Protaphane, Humulin R, Mixtard). These types of insulin need to be mixed well before use. Do not use a vial or pen if the insulin is flaky, clumped, discoloured or cannot be mixed properly.

Giving an injection with a pen

This will become an easy and routine procedure after a while, but the steps are listed here to help with learning. You will be taught how to load and use your particular brand of pen by the diabetes team.

1. Wash hands.
2. Check that you have the correct insulin pen (have your pens clearly marked) and that there is enough insulin remaining in the cartridge for the current injection. You must use a new needle for each injection.
3. If giving a cloudy long-acting or mixed insulin, be sure to mix the insulin well by inverting the pen 10 to 20 times. The cartridge contains a glass ball which mixes the insulin. Do not shake the pen as this will damage the insulin. Clear insulins do not need to be mixed.
4. Prime the pen (get rid of any air bubbles). Dial up a 2 to 4 unit dose and, holding the pen vertically, inject into the air to expel air bubbles (air shot) and to prime the pen. The pen is primed if drops of insulin without bubbles are coming from the needle. If not, keep repeating this procedure until a bubble-free stream of insulin is achieved with the air shot.
5. Dial up the required dose.
6. Select the injection site.

7. If the child is particularly lean you may need to pinch up the skin with the index finger and thumb at the chosen site. The pinch needs to be at least to the depth of the needle, otherwise the injection may go too deep into the muscle layer. This will hurt more and the insulin will act differently.
8. Insert the needle straight into the skin (i.e., at 90 degrees) to its full depth and push the pen button slowly all the way down to push in the insulin. In very lean individuals, injecting at a 45 degree angle to the skin may be necessary to avoid the injection going too deep.
9. Leave the needle in for 5-10 seconds, then gradually let go of the skin and pull out the needle.
10. Always remove the needle from the pen after injection and dispose of in an approved sharps container.



The injection should go just below the skin into the subcutaneous tissue (fatty layer)

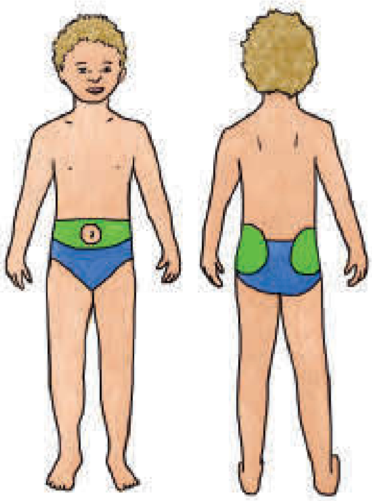
Injection sites

The injection sites recommended are away from large blood vessels or nerves to avoid excessive bleeding or nerve damage. These areas include the abdomen (tummy) and waistline and the upper outer part of the buttocks.

The abdomen (tummy) and upper outer buttocks are the preferred sites of injection because insulin is absorbed more quickly and uniformly from these sites. These areas are also less affected by exercise than other sites. Many children have all of their injections in one of these areas, and by moving around all the available areas on the abdomen or upper outer buttocks, problems of lumps (lipohypertrophy) can be avoided.

In general, rapid and short-acting insulin absorption is quickest from the abdomen, buttocks and thighs. The rate of insulin absorption can be speeded up by exercising muscles – thigh muscles are most affected by this, so you should be careful about injections at this site before exercise. This is not generally a problem with longer acting insulins.

Injections in the arms are generally not recommended, especially in small children who have only a thin layer of fatty tissue beneath the skin here. It is easy for the insulin injection to go too deep and end up in the muscle and be absorbed too fast. However, some diabetes centres may recommend that arms be used at certain times.



Recommended sites for insulin injections

Once you have decided with your diabetes team on the best place for injections for your child, it can be a good idea to use a poster and reward chart to guide this at home, especially for young children. One example is if injections are given regularly in the abdomen (tummy), draw a picture of a child with different sections of the tummy marked with the days of the week. This can help you remember to rotate the sites each day. Too little rotation of injection sites is one of the main problems seen with insulin injections.

Injections are given into the fatty layer under the skin, but they should not go deeper into the muscle layer as this tends to speed up the absorption of the insulin. Standard technique is to give the injection at a 90 degree angle to the skin (i.e., straight in). Some lean children may need to take a small pinch of skin prior to injecting so that the needle doesn't go too deep. Children and adolescents should use a 4mm needle length unless otherwise advised by their diabetes team.

Disposal of pen needles

Used pen needles should be placed in an approved sharps container which needs to be kept out of reach of children. These can be obtained from wherever you get your diabetes supplies (chemist or Diabetes Australia). When full, these sharps containers need to be properly disposed of. Unfortunately, uniform arrangements for sharps disposal do not exist across Australia. Check first with your local council about their sharps disposal arrangements. If satisfactory arrangements do not exist then your chemist will usually be able to dispose of them for you. Do not place pen needles in anything other than an approved sharps container.

Needles, pens, insulin cartridges and insulin bottles should never be shared with others because of the possible risk of contamination and spread of infection.

Insulin storage

Insulin cartridges (penfills) or disposable insulin pens not currently being used are stored in the refrigerator between 2 and 8 degrees C until their date of expiry. They usually have a long storage life under these conditions. If they freeze accidentally, they must be thrown away.

The cartridge or disposable insulin pen that has been opened for current use is generally kept at room temperature, since injections are more comfortable if the insulin is not cold (except hot climates, see below). Opened insulin bottles or pens can be stored in a cool dark place out of the fridge for 4 weeks. Insulin should be discarded after this time since it may not be as effective. In hot climates however, it is advisable to keep all insulin refrigerated including that in current use; allowing 15 to 20 minutes for it to come up toward room temperature may make the injection more comfortable.

Insulin that gets over-heated (e.g., left in a hot car) will lose its effectiveness and should be discarded. Vigorous shaking damages insulin and should be avoided. If you think that your insulin is not working well, perhaps related to storage conditions, discard it and use a new cartridge.

Remember to always have spare insulin of each type on hand.

How long to wait between the insulin injection and eating

Most insulin injections are given before a meal or snack. For rapid or short acting insulins (Humalog, Humulin R, Novorapid, Actrapid, Apidra, FiASP), the injection or pump bolus should ideally be given 15 minutes prior to the meal. Waiting after the injection is generally recommended to allow the insulin to start being absorbed. For some insulin doses such as afternoon-tea or lunch at school, waiting is often not practical so we generally recommend no waiting period for injections at these times if this is the case.

It is important not to wait for longer than the recommended time after giving an injection: if the meal is delayed hypoglycaemia is likely. If the blood glucose level has been trending low just before the injection, waiting is also not recommended. If the blood glucose level has been high, then waiting at least 20-30 minutes or longer (if this is practical) can help the blood glucose levels. Bear in mind that these guidelines are not rigid but should be followed if they fit into the daily routine.

Common injection problems and how to avoid them

Leaking of insulin after the injection

If this occurs regularly, try:

- Holding the skin with a more gentle pinch
- Injecting more slowly and counting longer before pulling out the needle

Slight bleeding and a small bruise

This will occur sometimes because the needle goes through a small blood vessel. It is nothing to worry about and does not stop the insulin from working properly. Avoid injecting into any obvious skin blood vessels (which look like fine blue lines beneath the skin).

Painful injections

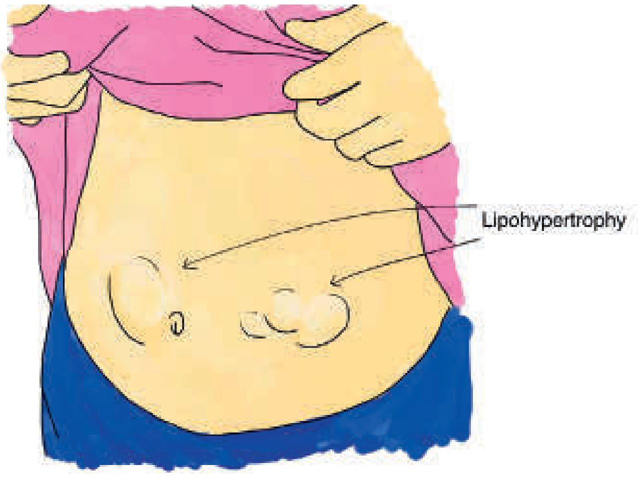
Insulin injections should cause minimal discomfort with modern fine needles. Make sure that a new needle is used each time, because needles start to blunt after 1 injection. Injections can be more painful if cold insulin is being injected. If your insulin has been in the refrigerator, try to remember to take it out of the fridge 15-20 minutes before you want to inject.

If the injection is not being given deeply enough, the insulin may split the deeper layers of the skin, causing pain. If the insulin is being given too deeply, it may go into the muscle layer which can also cause pain.

Some children who are used to only having injections in one area will complain that injections are more painful when they move sites. Often this is a psychological phenomenon and may be avoided by getting children used to using various sites and areas from the start.

Fatty lumps around the site of injection (lipohypertrophy)

This is a common problem when insulin is repeatedly given into the same sites, either by injection or pump. These lumps don’t look good, and more importantly, insulin absorption from these sites is likely to be variable and incomplete. These lumps can be prevented by moving the location of the injection within the same site daily (e.g., moving to a completely different part of the tummy each day) and varying pump sites as widely as possible. If present, these lumpy areas usually go away after several weeks of avoiding giving insulin in that area.



Hot temperature and insulin absorption

The absorption of insulin in some people may be quicker in very hot weather, especially the rapid or short-acting insulin. Some children need less insulin on hot days. Monitoring the blood glucose levels helps you work this out for your child. Insulin absorption and action may also be more rapid if you take a hot bath or shower just after taking insulin, so be careful of this.

Mistakes with insulin doses

It is important to be concentrating and unhurried at insulin injection or bolus times, but occasionally a mistake will occur with an insulin dose. Provided the mistake is recognised, appropriate adjustments are usually easily made. If you are not sure how to compensate, or it is a major mistake, contact your educator, diabetes doctor or hospital for advice without delay.

Errors in insulin doses can be dealt with by thinking about which type of insulin has been given in too large or too small a dose and how long the insulin will act.

- If the mistake has been to give too much insulin, test the blood glucose more frequently and give extra carbohydrate.
- If the mistake has been to give too little insulin, test the blood glucose more frequently and compensate with extra small doses of rapid or short acting insulin.

Common questions and answers

Why are different children on different insulin types?

Insulin treatment has to be tailored for the individual child. Different insulin types suit different children, and this may depend on the age, how long they have had diabetes, their eating and activity pattern and other factors. Sometimes your child may need to change insulin types. Your diabetes team will work out what suits your child best at any time.

My child's insulin doses keep having to be put up. Does this mean his diabetes is getting worse?

No. Doses have to increase as children grow and this is normal. They also increase when the honeymoon period is over, and increase quite a lot during the teenage years.

How does the diabetes team decide how many injections per day my child needs?

This is an individual decision for your child and may change with age and duration of diabetes. The most common management options are multiple daily injections or insulin pumps, since these are recognized to have advantages for long-term diabetes control, reduction of complications and lifestyle flexibility. Your diabetes team will discuss these issues with you and your child.

My child has fatty lumps at the injection sites — is this a problem?

Yes. This is called lipohypertrophy, and is caused by giving too many injections in the one place or putting pump sets in the same area repeatedly. It does not look good and also causes unreliable absorption of insulin. It goes away if these sites are rested. It is prevented by changing the point of injection or pump set as often as possible.

Should I move to a completely different injection site every day?

Insulin is absorbed differently from different areas of the body. The abdomen (tummy) is the best injection site and many use this for all injections. In younger children the buttocks is the preferred site.

My 13-year-old daughter wants to give her injection through her clothes when she goes out so as not to be embarrassed by lifting up her clothing. Will this cause problems?

Although this is not the best practice and cannot be generally recommended, it is better to have the injection through the clothes than to avoid it because of embarrassment. A number of studies have shown no harm from injecting insulin through clean clothing.

I have heard that some people use different types of short acting insulin at different times of day (e.g., short acting insulin (Actrapid or Humulin R) at breakfast and rapid acting insulin (NovoRapid or Humalog or Apidra) at dinner. Also I have heard of people who have long acting, short acting and rapid acting insulin all together at the same time. Please explain?

As a wider range of insulins have become available, diabetes specialists have tried to customise insulin types and patterns to better suit an individual's requirements and gain improved control. Thus, variations from traditional insulin patterns are increasingly used. This requires detailed knowledge of insulin characteristics and should only be done on the recommendation of your diabetes team. As more new insulins become available, more variations in insulin patterns are likely to be seen.

Chapter 6

Food and healthy eating

Key Points

- Children with diabetes need a healthy, varied and nutritious food plan as is appropriate for the whole family
- Controlling blood glucose levels is about matching insulin delivery to the amount of carbohydrate foods that we eat and our physical activity
- Understanding the effect of the amount and type of carbohydrate on BGLs is important in achieving optimal diabetes control
- Learning to count carbohydrates is important for diabetes management
- Different carbohydrate foods affect blood glucose levels differently – the glycaemic index describes this. Try to include some low glycaemic index food in each meal and snack
- Have sensible limits on the amount of food containing added sugar, but some sugar in food is a normal part of a balanced diet
- Have sensible limits on the intake of fats, particularly saturated fats
- Reading food labels helps you work out what to eat
- Healthy eating and an active lifestyle will help maintain a healthy weight
- Encourage water as the healthiest main drink

The food plan (or nutritional plan) for diabetes is really just a healthy way of eating and is good for the whole family.

This section is all about food and diabetes. Your dietitian will go through all of this information with you to ensure you develop a good understanding of the food plan for diabetes. The healthy eating plan that is promoted for diabetes is the same as for all children. Throughout this section you will learn how easy it is to choose and eat good food. The rewards for following a healthy eating plan will be that your child will feel fit and healthy and will grow and develop normally.

Healthy eating

Healthy eating is important for everyone. This means eating a wide variety of nutrient-rich foods from the five food groups. Healthy foods include:

- High fibre breads, cereals and whole grain foods (e.g., multigrain bread, oats, pasta)
- A variety of vegetables, legumes (e.g., beans, lentils) and fruits

- Dairy foods (e.g., milks, yoghurts, cheese and/or alternatives)
- Lean meats, chicken, fish, eggs and nuts
- Poly and monounsaturated fats and oils (in small amounts)

Foods such as packaged snacks, takeaways, chocolates, lollies and soft drinks (including diet drinks) are low in nutrients and best kept as occasional food choices.

It is also important to choose water as a drink instead of juices, flavoured milk, sports drinks, cordial etc., which all have a high sugar content.

The Australian dietary guidelines for children (from the National Health and Medical Research Council) are great a great resource for all people, including children and adolescents with diabetes. They can be found at: https://www.nhmrc.gov.au/about-us/publications/australian-dietary-guidelines

Components of food

Foods are generally made up of a combination of nutrients. Most foods are a mixture of carbohydrate, protein and fat, which all provide energy.

The main nutrients in food are:

- **Carbohydrates:** Carbohydrates are the most important source of energy for the body. Carbohydrates are broken down by the body into glucose. Therefore, carbohydrates have the biggest effect on blood glucose levels compared with other nutrient types. The amount and type of carbohydrate eaten are both very important. Examples of carbohydrate-containing foods are bread, breakfast cereal, oats, rice, pasta, noodles, fruit, starchy vegetables such as potato, corn, sweet potato, taro and most dairy products such as milk, yoghurt, custard, ice cream and soy milk.
- **Proteins:** Proteins are important building blocks in the body and are essential for normal growth and repair of body tissues. They can also be used as a source of energy by the body. It is essential to have protein in food every day. Examples of protein-containing foods are meat, fish, eggs, cheese, nuts and seeds.
- **Fats:** Fats and oils are also essential for growth and development and are an important source of energy. A certain amount is essential for good health but too much or the wrong type becomes unhealthy. Healthier choices of fats are polyunsaturated and monounsaturated fats such as avocado, nuts, seeds, fish and oils such as canola, sunflower, and olive oils. Unhealthier saturated and trans-fats can be found in fatty meats, butter, palm oil, coconut oil, many snack and takeaway foods, pastries and fried foods.

Other nutrients and components of food include:

- **Vitamins and minerals:** These are important for the normal functioning of many body processes. The best way to have a balanced vitamin and mineral intake is through a healthy variety of foods, especially fruit and vegetables.
- **Fibre:** An adequate intake of fibre is important for heart and bowel health and is believed to have a number of long-term health benefits. Choose high fibre and multigrain breads, cereals and whole grain foods (e.g., pasta or oats), as well as a variety of fruit and vegetables.
- **Water:** Water is the most common component of the body. Drinking plenty of fluids is important for general health. Your child should drink more if it is hot and if they are more active or have high blood glucose levels. Water is the healthiest fluid of all to drink.

The Australian Guide to Healthy Eating

The Australian Guide to Healthy Eating provides a basic guide to healthy eating for all people. It emphasises the type of foods that we should eat most, those that we should eat moderately and those that should only be eaten in smaller amounts. This advice applies to all children and adolescents, whether or not they have diabetes.

Based on material provided by the National Health and Medical Research Council

Carbohydrate

Carbohydrate or 'carbs' are energy foods. During digestion, carbohydrates are broken down into glucose and are absorbed into the blood. Blood glucose is the fuel for our body. Blood glucose levels vary throughout the day. They rise after eating carbohydrate and fall as we use the glucose in our blood for energy.

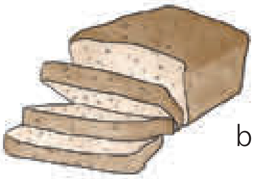
In people without diabetes, blood glucose levels are closely controlled by insulin produced by the pancreas in response to the food they eat. In people with diabetes the amount and type of carbohydrate eaten is balanced with the amount of insulin given. It is important to match the amount of carbohydrates eaten during the day with insulin to keep the blood glucose levels in balance.

The insulin plan for your child will usually be selected based on your child's usual eating patterns and the amount of carbohydrate eaten. Most children (including infants and toddlers) will require three main meals and occasional snacks.

Teenagers or adults may have more flexible eating patterns. It is important to discuss the insulin and food plans with your dietitian to ensure that they work well together.

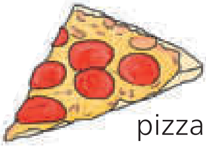

pasta and noodles


cereal

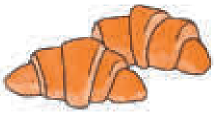

bread


rice

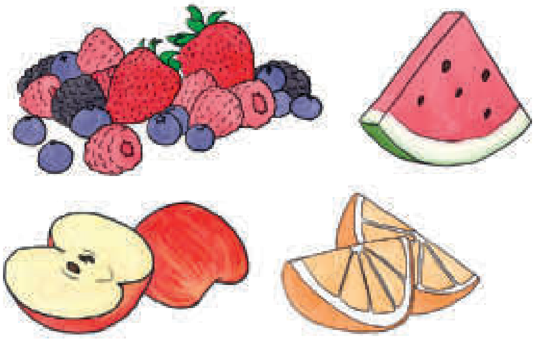

pita


pizza base


savoury and sweet biscuits

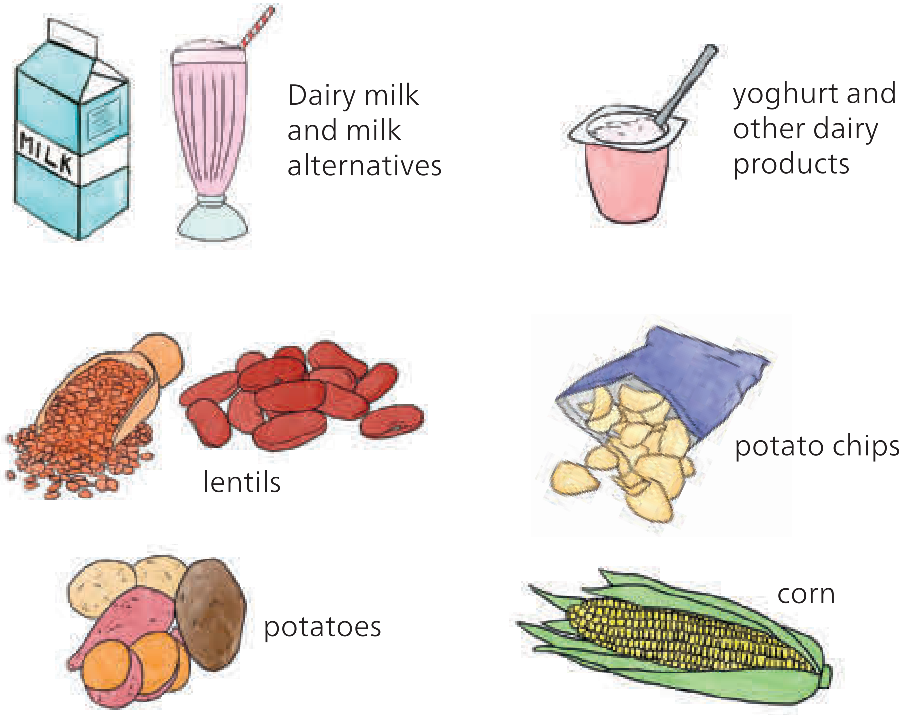

pastries


muffins and cakes


fresh and tinned fruit


dried fruit


fruit juice



These foods provide you with energy and are important for growth and development. Carbohydrates included for your meals or snacks should be matched with your insulin and level of exercise.

Carbohydrate: when, how much and what type?

Understanding these questions is an important part of the diabetes food plan.

The main points are:

1. **Spread of carbohydrate:** The intake of carbohydrate foods should be spread across the day. For most children this will be divided into three meals (breakfast, lunch and dinner) and two or three smaller snacks (morning tea afternoon tea and sometimes supper) at fairly regular times each day. This is appropriate for all children, whether they have diabetes or not.
2. **Amount of carbohydrate:** Regulation of the amount of carbohydrate eaten is important for good results with any insulin plan. Using a simple system to count carbohydrates in grams or exchanges can be a useful guide. Different insulin plans will have different flexibility with meal times and carbohydrate quantity and your dietitian will discuss this individually.
3. **Type of carbohydrate:** The type of carbohydrate also affects blood glucose levels. This concept is called the 'glycaemic index' of food. It is important to include low glycaemic index foods as these may assist with blood glucose control.

When to eat

A healthy eating pattern is to spread carbohydrate intake across the day in regular meals. This is especially important for diabetes management. The aim is to have the insulin action (from injections or pump) matching the carbohydrate intake to keep the blood glucose levels within target as much as possible. Depending on the insulin plan, going too long without carbohydrate during the day may result in the blood glucose level dropping too low.

Overnight when your child sleeps and is not eating, the blood glucose level is maintained because of the carbohydrate eaten before bed, less activity, less insulin acting overnight and ongoing glucose output from the liver.

The meals and snacks required will depend on your child's age, appetite, growth and level of physical activity. Your dietitian will usually advise that your child have three main meals each day (breakfast, lunch and dinner). Often no between-meal snacks are required, but some children may still require morning tea, afternoon tea and sometimes supper. Different insulin plans allow different levels of flexibility around the timing of meals and snacks. Your diabetes team will discuss this with you.

How much to eat

The aim is to eat an amount of carbohydrate that suits healthy nutritional demands, as for any child. In general, children's metabolism is best suited to having a fairly similar intake of carbohydrate each day, which is spread across the day in a similar way.

The current recommendations are that all children and adolescents with type 1 diabetes should count carbohydrates. This is especially important for those using plans with flexible insulin dose adjustment (insulin pumps or bolus advisors). There will always be some variation in carbohydrate intake from day to day, depending on appetite, activity levels and other factors. Counting carbohydrates will compensate for this by allowing the dose of insulin at a meal to match the amount of carbohydrates.

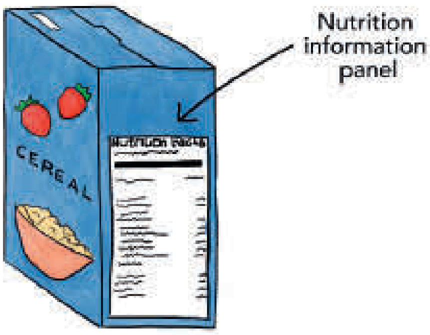
Carbohydrate counting

Counting carbohydrates will help estimate the amount of carbohydrate in different foods, with the aim of helping matching insulin doses to carbohydrate intake. Carbohydrates are generally counted in grams or exchanges.

Counting in grams

The grams of carbohydrate in packaged foods are listed on the nutrition information panel on the label. It is important to know how to read food labels, and these are discussed in greater detail later in this chapter. Your dietitian will also provide a list of the carbohydrate quantities in common unpackaged foods (e.g., fruits and starchy vegetables). The average carbohydrate quantities in a range of common foods are listed later in this section.

Remember that the grams do not refer to the total weight of food, but the amount of carbohydrate in that food.



Counting in exchanges

Counting in exchanges is similar to counting in grams, but it uses a different measure. One exchange of a carbohydrate food is the amount that contains approximately 15 grams of carbohydrate.

1 exchange = 15 grams of carbohydrate

Some people find this method useful because it is easy to remember the number of exchanges in common carbohydrate-containing foods. For example, the following common foods all contain about one exchange (15 grams) of carbohydrate:

- one slice of bread
- one medium banana
- 250 ml of milk
- one medium potato
- one large orange
- 1/3 cup cooked rice
- 1/3 cup cooked pasta

When looking at the nutrition information panel on packaged food, the number of exchanges can be worked out from the number of grams of carbohydrate listed.

Remember that an exchange of carbohydrate does not refer to the total weight of the food, but the amount of that food that contains 15 g of carbohydrate.

The following ranges can help you work out carbohydrate exchanges if information is only listed in grams of carbohydrate

Grams of carbohydrate	Exchanges
7 to 11	½
12 to 18	1
19 to 26	1½
27 to 33	2
34 to 41	2½
42 to 48	3

Carbohydrate content of common foods

Below are examples of common foods with their carbohydrate content listed in grams and exchanges. Guides such as this may be useful when a nutrition information panel is not available e.g. fruits and vegetables. The carbohydrate content listed is a general estimate and will vary slightly with the size of the serve.

This list is not exhaustive; your diabetes dietician will be able to provide you with a more extensive list. There are also carbohydrate counting resources such as the Australian Carbohydrate Counter book which can assist you (https://kidshealth.schn.health.nsw.gov.au/australian-carbohydrate-counter-2020-edition).

Food	Serve (total amount of food)	Carbohydrate in grams	Carbohydrate in exchanges
Noodles/Rice/Pasta			
Pasta (cooked)	1 cup (150g)	42 grams	3 exchanges
Ravioli/tortellini, meat filling (cooked)	1 cup (265g)	34 grams	2½ exchanges
Ravioli/tortellini, vegetable filling (cooked)	1 cup (265g)	30 grams	2 exchanges
Gnocchi (cooked)	1 cup (175g)	51 grams	3½ exchanges
Hokkein or Singapore noodles (cooked)	1 cup (170g)	43 grams	3 exchanges
Rice (boiled)	1 cup (190g)	50 grams	3½ exchanges
Fried Rice	1 cup (165g)	45 grams	3 exchanges
Couscous (cooked)	1 cup (130g)	42 grams	3 exchanges
Gluten free pasta – corn (cooked)	1 cup (148g)	34 grams	2½ exchanges
Breads			
Bread (white, wholemeal, wholegrain, raisin)	1 regular slice	15 grams	1 exchange
Bread roll	Medium (50g)	23 grams	1½ exchanges
Hamburger bun	10-12 cm (74g)	38 grams	2½ exchanges
Hot dog roll	1 roll	28 grams	2 exchanges
English Muffin	Whole (67g)	24 grams	1½ exchanges
Croissant	Large (67g)	22 grams	1½ exchanges
Bagel	12cm (120g)	61 grams	4 exchanges
Lebanese Bread	23cm (85g) 1 whole	45 grams	3 exchanges

Food	Serve (total amount of food)	Carbohydrate in grams	Carbohydrate in exchanges
Chappati	1 large (20cm) 1 medium (15 cm)	24 grams 19 grams	1½ exchanges 1½ exchanges
Naan	1 (95g)	41 grams	2½ exchanges
Taco shell	1 regular (13g)	7 grams	½ exchange
Tortilla	20cm (34g)	15 grams	1 exchange
Turkish bread	1/3 loaf, 12cm	64 grams	4 exchanges
Gluten free bread	1 slice (26g)	11 grams	½ exchange
Breakfast cereals			
Cornflakes	1 cup (30g)	24 grams	1½ exchanges
Rice Bubbles	1 cup (30g)	24 grams	1½ exchanges
Nutrigrain	1 cup (30g)	21 grams	1½ exchanges
Weet-Bix	2 biscuits (30g)	22 grams	1½ exchanges
Just Right	1 cup (60g)	43 grams	2 exchanges
Special K	1 cup (40g)	28 grams	2 exchanges
Porridge (rolled oats w/ lite milk)	1 cup	32 grams	2 exchanges
Quick oats	1 sachet (35g)	23 grams	1½ exchanges
Muesli (natural)	½ cup (51g)	26 grams	1½ exchanges
Up and Go	250mL carton	30 grams	2 exchanges
Vegetables			
Potato (boiled)	Medium	15 grams	1 exchange
Potato (baked)	Medium	18 grams	1 exchange
Mashed Potato	1 cup (245g)	27 grams	2 exchanges
Sweet potato (boiled)	1/2 cup (105g)	16 grams	1 exchange
Corn cob	Medium 12cm	18 grams	1 exchange
Corn kernels	½ cup (85g)	17 grams	1 exchange
Legumes/nuts/seeds			
Baked beans	½ cup (138g)	14 grams	1 exchange
Lentils, cooked	½ cup (95g)	11 grams	½ exchange
Chickpeas	½ cup (93g)	12 grams	1 exchange

Food	Serve (total amount of food)	Carbohydrate in grams	Carbohydrate in exchanges
Kidney beans	½ cup (95g)	13 grams	1 exchange
Peanuts (roasted)	½ cup (78g)	11 grams	½ exchange
Cashew nuts (roasted)	½ cup (75g)	20 grams	1½ exchanges
Fruit			
Apple	Medium	15 grams	1 exchange
Banana	Medium,16cm	22 grams	1½ exchanges
Cherries	1 cup	17 grams	1 exchange
Fruit salad (fresh)	1 cup	15 grams	1 exchange
Grapes	1 cup	26 grams	1½ exchanges
Kiwifruit	1	7 grams	½ exchange
Mandarin	1 small	7 grams	½ exchange
Mango	1 medium	25 grams	1½ exchanges
Nectarine	1 medium	12 grams	1 exchange
Orange	1 medium	13 grams	1 exchange
Peach	1 medium	12 grams	1 exchange
Pear	1 small	12 grams	1 exchange
Pineapple, fresh	1 slice	9 grams	½ exchange
Plum	1	7 grams	½ exchange
Rockmelon	1 cup diced	9 grams	½ exchange
Watermelon	1 cup diced	10 grams	½ exchange
Peaches (can)	10 slices, drained	15 grams	1 exchange
Pears (can)	2 halves	10 grams	½ exchange
Two fruits (can)	½ cup	12 grams	1 exchange
Dried apricots	8 halves	17 grams	1 exchange
Milk and Dairy			
Full cream milk	1 cup (250ml)	16 grams	1 exchange
Reduced fat milk	1 cup (250ml)	15 grams	1 exchange
Flavoured milk	300ml	27 grams	2 exchanges
Soy milk	1 cup (250ml)	15 grams	1 exchange

Food	Serve (total amount of food)	Carbohydrate in grams	Carbohydrate in exchanges
Diet yoghurt (artificially sweetened)	200g tub	14 grams	1 exchange
Sweetened yoghurt (low fat)	200g tub	27 grams	2 exchanges
Ice cream	2 scoops/100mL	10 grams	½ exchange
Takeaway foods and snacks			
Sushi Roll	1 Californian roll	27 grams	2 exchanges
Dim sim, dumpling, spring roll	Small	7 grams	½ exchange
Samosa (vegetable)	1 large piece	43 grams	3 exchanges
Rice paper roll with noodles	1 medium roll	20 grams	1½ exchanges
Pizza (classic crust)	1 slice	32 grams	2 exchanges
Pizza (thin and crispy crust)	1 slice	18 grams	1 exchange
Hamburger	Large bun	41 grams	2½ exchanges
Hot Chips	Small serve	25 grams	1½ exchanges
Vine leaf (meat/rice filling)	1 roll	9 grams	½ exchange
Felafel	1 patty	7 grams	½ exchange
Cakes and pastries			
Banana bread	1 small slice (62g)	29 grams	2 exchanges
Cupcake, iced	Small	25 grams	1½ exchanges
Doughnut, cinnamon	Regular	18 grams	1 exchange
Muffin, homemade	Medium	30 grams	2 exchanges
Pancake	15cm diameter	32 grams	2 exchanges
Choc chip cookie	1 small biscuit	8 grams	½ exchange
Anzac biscuit	1 small biscuit	6 grams	½ exchange
Beverages			
Fruit juice (all)	½ cup (125 ml)	14 grams	1 exchange
Hot chocolate	1 cup	27 grams	2 exchanges
Milkshake	Small, 300mL	34 grams	2½ exchanges

General tips for carbohydrate counting

- To assist with precision of carbohydrate counting, it is recommended that you use standard household measures (measuring cups, spoons and kitchen scales) to help work out serving sizes when you first start learning carbohydrate counting. Afterwards, it is still a good idea to measure foods sometimes to make sure that you are estimating correctly, especially as your child grows and eats more.
- If you are using an insulin pump or bolus advisor, try to estimate as accurately as possible – even a 5 g amount of carbohydrate can make a difference and should be estimated.
- Some meals are hard to quantify the amount of carbohydrate, especially restaurant meals and others where you cannot know the ingredients. All you can do in this situation is make an estimate (under-estimate if anything) and make a correction later if needed.
- For packed meals and snacks from home (e.g., school lunches and snacks), label the amount of carbohydrates of each food individually. Children can then indicate which food items they wish to consume, and supervising adults can add up the multiple foods to figure out the carbohydrate amount for that meal.
- Have lists in the home or lunch boxes of foods the child commonly eats, with the corresponding amount of carbohydrates. This also acts as a reminder to enter the values in to the pump or bolus advisor.
- For cereal, leave measuring cups in boxes or containers to assist with consistent amounts of food and carbohydrate counting.

Your dietitian will suggest an approximate number of carbohydrate exchanges or small range of carbohydrate grams for each of your child's meals or snacks and you can then choose from a variety of carbohydrate containing foods to make this up. For example, a teenager may have 3 to 4 exchanges, or 45 to 60 grams of carbs for breakfast whereas a toddler may have 1 or 2 (15 or 30 grams). In flexible insulin plans and insulin pumps, there is more flexibility and the insulin dose is directly based on the amount of carbohydrate that the person chooses to eat.

Carbohydrate counting is important for diabetes management

Using carbohydrate counting in the diabetes management plan

The above sections have talked about the importance of carbohydrate counting and how this helps to match insulin doses to the amount of carbohydrate that is eaten.

Carbohydrate counting can be used in a number of different ways in meal planning. Your diabetes team will teach you one of these methods, depending on your child's age, insulin plan, eating pattern and other needs. This may change over time. Don't worry if other people you know are using a different plan. The different insulin and carbohydrate plans are outlined below and are discussed in more detail in Chapter 12.

1. Flexible carbohydrate and insulin adjustment ("flexible multiple daily injections")

In this method, the person with diabetes has an understanding of the amount of carbohydrate in foods, their usual carbohydrate intake (which they count using grams or exchanges), their usual insulin doses and activity. They also recognise how their blood glucose levels respond to variation in carbohydrate intake, activity patterns and insulin doses. They learn to adjust insulin doses, especially pre-meal doses, if needed to account for this variation in carbohydrate intake and other factors with the aim of achieving blood glucose targets.

For example, a child who usually has 7 units of NovoRapid to cover their usual breakfast will increase that dose by 1 or 2 units if they are hungry and eat a bit extra.

2. Insulin to carbohydrate ratio (ICR)

An insulin to carbohydrate ratio describes how much insulin is given for a particular amount of carbohydrate. The ICR is individualised depending on each child's insulin requirements.

This type of insulin plan is used for people on an insulin pump or bolus advisor (e.g., a smartphone app). An ICR is programmed into the settings of the pump or bolus advisor by the diabetes team. At mealtimes, the carbohydrate count for the meal is entered and an insulin dose is calculated by the device. The pump or bolus advisor can be programmed for carbohydrate counting in grams or exchanges. Insulin to carbohydrate ratios are discussed in more detail in Chapter 12 and in Chapter 13 'Insulin pumps'.

Some people may use an insulin to carbohydrate ratio to calculate their insulin dose themselves (without a pump or bolus advisor). This is more common when counting carbohydrates in exchanges. In this case they would know how many units of insulin covers 1 exchange of carbohydrate.

For example, a teenager might have 2 units of rapid insulin per exchange (15 g) of carbohydrate before each meal. Therefore, if he eats 3 exchanges he will have 6 units; if he eats 4 exchanges he will have 8 units.

3. Consistent carbohydrate intake ("fixed dosing" of insulin)

In this method, the aim is to have a food plan in which there are consistent amounts of carbohydrate intake for the meals and snacks each day. For example, a child may always like about 3 exchanges of carbohydrate for breakfast, 2 exchanges for morning tea etc. The type of foods can be varied by understanding carbohydrate exchanges. The insulin pattern is designed to match this consistent intake of carbohydrate from day to day.

This method suits people who find they have a fairly consistent intake of carbohydrate from day to day.

All these methods rely on counting of carbohydrates which you and your child will become more skilled at. However, children and families require regular updates to remain skilled at carb counting. Your diabetes team will advise which form of applying carbohydrate counting is recommended and your preferences will be discussed. Diabetes can be managed appropriately with any of these methods, depending on the individual circumstances.

Type of carbohydrate and the glycaemic index (GI)

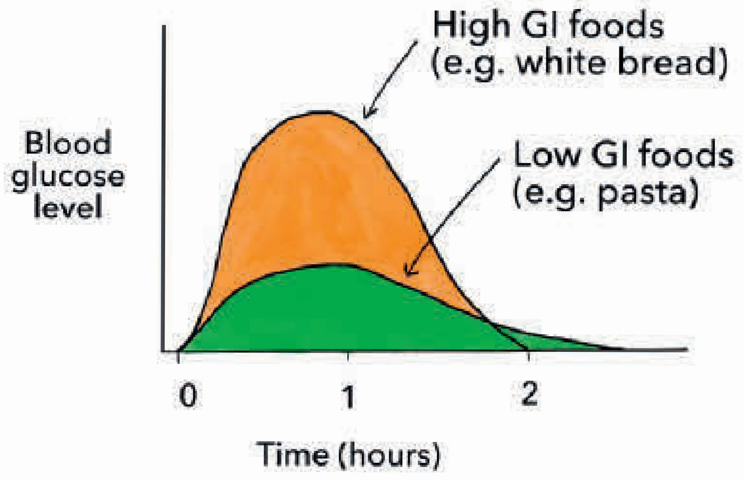
Different carbohydrates will cause your blood glucose to rise faster or more slowly because of differences in how they are digested and absorbed. The glycaemic index (GI) is a ranking of how quickly or how slowly carbohydrates will raise your blood glucose. Foods with a high GI are quickly digested and absorbed and cause a rapid and large rise in blood glucose levels. Foods with a low GI are more slowly digested and absorbed and produce a more gradual rise and fall in blood glucose levels, which is preferable for children with diabetes. We usually consume a mixture of low, medium and high glycaemic index foods at meal times. It is important to try and include at least one low GI food at each meal, or switch to lower GI foods options. This will help achieve more stable blood glucose levels.

Try to include at least one low GI food in each main meal for your child. When the GI is low, the blood glucose rise is slower and lower.

There are a number of factors that influence how carbohydrates are digested, including fibre content, cooking and processing, amount of fat and protein, presence of sugar, type of sugar and type of starch.

Carbohydrate containing foods can be classified as low, intermediate or high GI according to the known effects on blood glucose levels. Foods are given a ranking from 0 to 100. A ranking under 55 is a low GI food, 55 to 70 is medium GI and above 70 is a high GI food. Some packaged foods now include a symbol indicating if they are low GI, but this is not required labelling.

As can be seen in the graph below, the blood glucose rise after eating white bread is much quicker and higher than when pasta is eaten. White bread is a high glycaemic index food (GI greater than 70) and pasta is a low glycaemic index food (GI less than 55). Information like this is available for many foods.



Comparison of blood glucose levels after eating white bread or pasta

It has also been recognised that low GI foods have an important carry-over effect. The benefits of a low GI breakfast will carry over and benefit the blood glucose levels at the next meal. A simple change such as switching to low GI bread and having a low GI breakfast cereal has been observed to significantly improve blood glucose control throughout the day.

It is helpful to consider the GI value when choosing the carbohydrates in a meal. Low GI foods should generally be consumed more often than intermediate or high GI foods. However, it is usual to eat a varied diet that includes low, intermediate and high GI foods.

Common foods with a low, intermediate and high GI:

Low GI foods (GI less than 55)	**Intermediate GI foods** (GI 55 to 70)	**High GI foods** (GI more than 70)
Eat most often	→	**Eat least often**
Pasta and noodles Milk Yoghurt Traditional porridge (rolled oats) Baked beans Wholegrain breads (breads where you can see lots of grains) Doongara rice Sweet potato Apples Pears Peaches Oranges Grapes	Basmati rice Crumpets Bananas Wholemeal crispbread Wheat cereal biscuits Oatmeal Shredded wheatmeal biscuits Pineapple Rockmelon	Puffed wheat White bread Wholemeal bread Baked potato Mashed potato Calrose rice Waffles Jelly beans Watermelon Cornflakes Chocolate rice cereal Water crackers Soft drinks and Lucozade

Note that adding lemon juice or vinegar to a meal (as a salad dressing) can also help lower the glycaemic index of that meal.

Many parents have already noticed that some types of carbohydrate containing foods seem to last longer or always produce a more desirable blood sugar level compared to other foods which seem to be used up before the next meal or snack. This may be due to the difference between a low GI and a high GI food.

The GI should never be used in isolation when making food choices for your child with diabetes. Choosing low GI foods should be combined with a method of carbohydrate counting. The dietary guidelines for children should always be considered when introducing new foods into your child's diet.

What about sugar?

Sugar (or sucrose) is a type of carbohydrate. Sugar can be included as part of a normal healthy diet as long as it is eaten in moderation, especially if included as part of a meal. Foods containing sugar often do not raise blood glucose levels as high as some common starchy foods. Using the glycaemic index, sugar itself has a GI of 65 which is intermediate and many sugar-containing foods such as milkshakes and yoghurts have low GI values. Foods that contain added sugar are often higher in carbohydrate and fats so it is important to read the nutrition information on the packet so that you can decide if it is a suitable food and estimate how much to eat. This will be covered later in this section.

Artificial sweeteners

A number of different artificial sweeteners are available and widely used in products such as diet soft drinks and cordials and other 'diet' or 'low joule' products. These include aspartame (Nutrasweet and Equal), saccharin, sucralose (Splenda), stevia, isomalt and cyclamates.

Artificial sweeteners have been widely used and are generally believed to be safe if taken in moderation.

Products such as diet or no sugar soft drinks and cordials are suitable for people who have diabetes, since full sugar drinks do result in major elevations of blood glucose levels. However, remember that water is the healthiest drink for everyone and diet drinks are best reserved as an occasional item.

Sugar can be included in small quantities as part of a well-balanced, low GI diet, making the use of artificial sweeteners mostly unnecessary. Where sweetening is required in a mixed food or recipe (containing carbohydrate, protein and fat), sugar can often be used. This is because in mixed food, the absorption of the sugar is slowed down by other ingredients.

Products containing the sweeteners isomalt, sorbitol, mannitol, xylitol and maltitol can have a laxative effect if too much is eaten e.g., sugar-free lollies.

Food labels

The labelling of food can be confusing. Some foods or drinks are labelled as 'no added sugar', but they may not be recommended by your dietitian. Whilst some foods may be labelled as 'no added sugar', they can still contain carbohydrates from other ingredients which need to be counted for and matched with your insulin.

Reasonable choices would be food products labelled as:

- diet or low joule cordials and soft drinks
- diet or low joule jelly
- no-oil salad dressings

Diabetic confectionary, ice-cream and biscuits are an unnecessary part of the diet and are not encouraged. These 'special diabetic foods' are often expensive, offer no benefit over the real thing and may contain compounds such as sorbitol which may have a laxative effect.

Try to avoid:

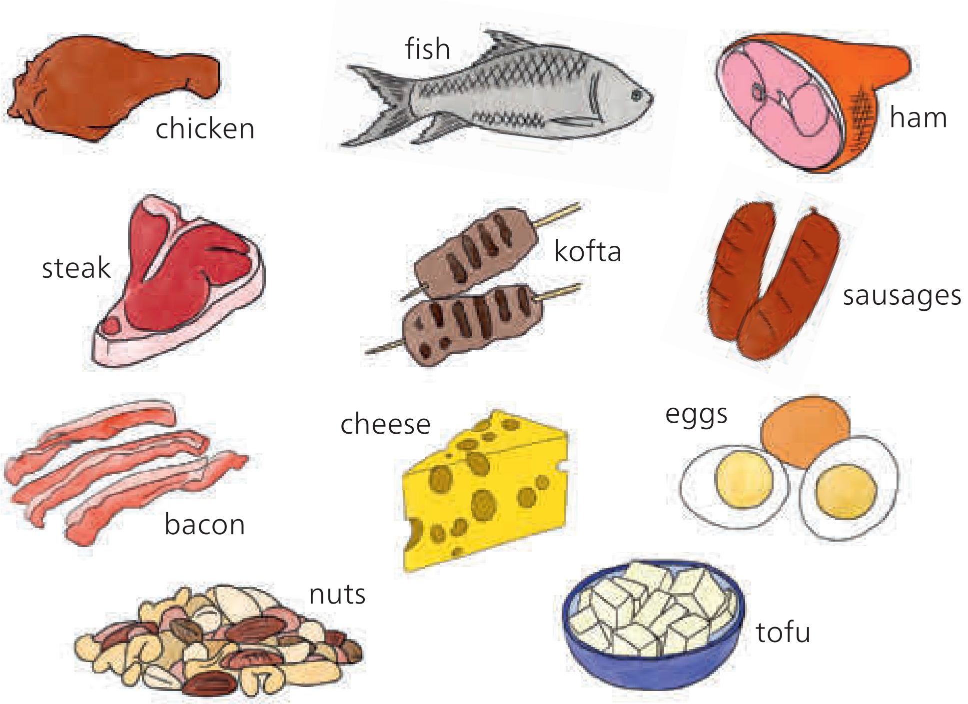
- diabetic or 'no sugar added' cakes, biscuits, chocolates and lollies
- carbohydrate-modified ice-cream
- carbohydrate-modified jams and diet jams.

Proteins

Proteins are important building blocks of the body. Proteins play an important role in growth and repair of body tissue and can also be used as a secondary source of energy by the body.

Protein foods include meat, chicken, fish, cheese, eggs, nuts, legumes and seeds. Some protein foods also contain carbohydrate and fat; for example, milk and yoghurt.

Protein foods can be quite high in fat so it is important to eat foods from this group in moderation as the healthy eating plate suggests. Choose lower fat options such as lean meats and low-fat dairy foods. Try cutting visible fat off and use lean cooking methods such as grilling, steaming, poaching and roasting.



These foods are important for growth and development. We need moderate amounts each day. Choose lean varieties and reduce the intake of saturated fat.

Fats

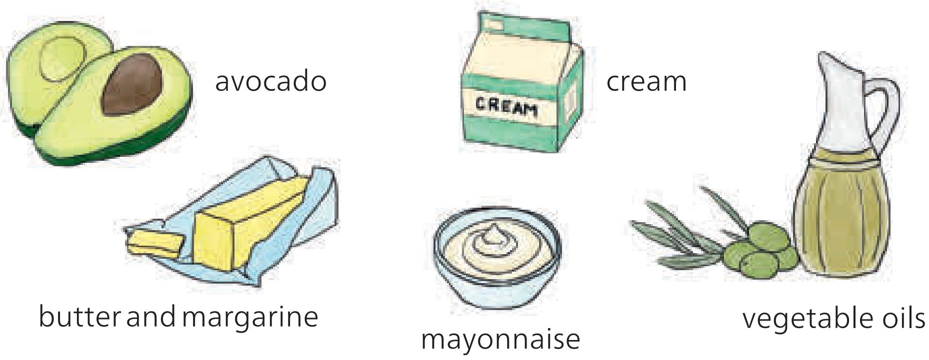
Fats are an important part of our diet and a certain intake is required for healthy growth and development. There are different types of fat in foods, with the healthier choices being polyunsaturated and monounsaturated fats and omega-3 fats. Saturated fats and trans fats are less healthy and should be avoided. Examples of these fats are listed in the table below. It is also important to remember that all fats are high in energy, and if too much fat is eaten, excess weight gain may occur.

Polyunsaturated and Monounsaturated fats (healthier choice)*	**Omega-3 fats** (healthier choice)*	**Saturated fats** (eat less often)	**Trans fats** (eat less often)
Vegetable oils (e.g. canola, sunflower and olive oil) Nuts Seeds Avocado	Fish oils	Fatty meats Butter Coconut oil Palm oil Snack foods Take away foods	Pastries Snack foods Fried foods

*Although polyunsaturated, monounsaturated and omega-3 fats are the healthier choice, they must still be limited to reasonable quantities or excess weight gain will occur.

Why should we eat less saturated fat?

It is important to establish good eating habits from an early age. We know that there is an increased risk of elevated cholesterol and vascular disease in diabetes. Reducing saturated fat in the diet is recommended, not only for people with diabetes but for the general population to reduce the risk of vascular disease. A high intake of saturated fat is strongly associated with high cholesterol and increased risk of heart disease.



Fats and oils can help add flavour and variety. We only need to eat small amounts.

How can we eat less saturated fat?

The best way to reduce saturated fat in our diet is to reduce the intake of fat from meat and dairy foods, packet snack foods and from fats used for frying and baking. Many children's snack foods are high in saturated fat.

Substituting 'healthier' fats such as monounsaturates and polyunsaturates will help to control blood cholesterol levels and reduce the risk of heart disease.

Suggestions:

- Try selecting reduced or low-fat dairy products in place of traditional full fat products. Reduced fat milk is suitable for children over 2 years of age.
- Replace saturated spreads like butter, with monounsaturated and polyunsaturated spreads and oils.
- Try to select low fat options when buying takeaway and select those that are cooked with oil low in saturated fat.
- Avoid deep frying. Oven baking, air frying or grilling is preferred.
- Trim visible fat from meat. Buy lean cuts of meat and lean mince.
- Try to limit takeaways to once or twice a week. Choose healthier choices with more vegetables or salads.
- Watch out for snack foods which are high in saturated fats (e.g., chips, some biscuits and savoury biscuits and dip).
- Ask your dietitian about suitable snack foods or read the snack section in this chapter.
- Try canola, olive or sunola oils which are high in monounsaturates, but these may also need to be limited if your child is overweight.
- Avocados and nuts are high in monounsaturates but still need to be limited to reasonable quantities or excess weight gain may occur.

Do protein and fat affect my blood glucose levels?

Meals high in protein and fat may cause a delayed rise in blood glucose levels 3-6 hours after eating. These meals may require extra insulin in addition to the amount of insulin needed for the carbohydrate component of your meal. Those using an insulin pump may require a different type of bolus, or splitting the insulin bolus (giving part of the bolus before the meal, then giving another bolus few hours after). Speak to your diabetes team for further advice.

Fibre: make sure your child has enough

Fibre refers to material in food which is generally not absorbed, but is very important in keeping the bowel and digestive processes in balance. It also helps keep our bodies healthy by helping to prevent some diseases, keeping our bowels regular and making us feel full. Fibre is only found in plant foods such as wholegrain and wholemeal breads and cereals, brown rice, wholemeal pasta, fresh fruit and vegetables, legumes and pulses (e.g., baked beans and lentils), nuts, bran and dried fruits. Soluble fibre is linked to reducing cholesterol and other forms of fibre (e.g., resistant starch) are linked with disease prevention.

How much fibre your child needs each day will depend on their age.

Requirements for young children (aged 1-8 years):

Grams of fibre per day = age in years + 5

For example, if your child is 6 years old, they'll need 11 grams of dietary fibre per day.

Requirements for older children:

Aim for 20-28 grams of dietary fibre per day

To achieve this, choose high fibre breakfast cereals, wholegrain bread and a good intake of fruit and vegetables. For packaged foods, a high fibre choice contains 3 grams of fibre or more per serve.

Fluids

Having enough fluid intake is part of a balanced healthy eating plan for all people. The best fluid to drink is water. Fresh fruit and some other foods contribute to daily fluid intake. Fluids such as milk and juice contain carbohydrate and need to be counted in your child's carbohydrate intake to ensure adequate insulin coverage. Fruit juices should be limited to no more than one glass per day and consumed in combination with a mixed meal. Diet soft drinks and diet cordials can be included in moderation and will not affect blood glucose levels.

Plenty of fluids are especially important in hot weather and when exercising. During sick days (see Chapter 10), fluid intake is very important, especially if the blood glucose levels are high (water or other carbohydrate-free fluids). When not feeling well, carbohydrate-containing fluids are easier to tolerate than normal foods.

Low carbohydrate foods

Most non-starchy vegetables contain minimal amounts of carbohydrate, provide a variety of vitamins and minerals and do not affect blood glucose levels. Adding these to meals or snacks will increase the overall nutritional quality of your diet and do not affect blood glucose levels when eaten in moderation.

Seasonings such as soy sauce, tomato sauce or garlic can be added for flavour and contain minimal carbohydrate when used in small quantities.

Non-starchy vegetables and some fruits	Seasoning, herbs and sauces	Beverages
Carrot Cucumber Celery Capsicum Mushrooms Peas Zucchini Broccoli Salad greens Tomatoes Strawberries	Vegemite Soy sauce Vinegar Mustard Tomato sauce Worcestershire sauce Stock cubes Herbs and spices Lemon juice Garlic	Tea and coffee Diet cordial or diet soft drink

Note: Eating too much of some of these foods can affect blood glucose

Examples of low-carbohydrate foods

Reading food labels

Learning to read food nutrition labels will be of great help in making food choices. Different products will suit different people, depending on the amount of food they eat, body weight, blood glucose control, blood cholesterol and the amount and type of exercise.

The two main things to consider when looking at a food label are:

- the total amount of carbohydrate (which includes sugar), and
- the amount and type of fat

There are food labelling standards for Australia and New Zealand that all food labels need to comply with. Compulsory information includes energy (kilojoules), protein, total fat, saturated fat, total carbohydrates, sugars and sodium. Total carbohydrate is shown and, beneath this, the amount of the total carbohydrate that is made up of sugars. Total fat is shown and, below this, the amount of that fat that is saturated fat.

Some food packages will display GI information, but this is not compulsory for food labels. Not all foods have been tested for GI value.

Information to look for

Look at the following information in the nutrition panel:

- **Serving size:** Compare this with the amount your child will be eating or drinking. Is your serve size the same as that stated on the package? The serving size is the average serving size of the product but your child may eat more or less than this amount.
- **Fat:** Try to avoid foods high in saturated fat. For snack foods, choose lower fat products -aim for less than 5 g fat per serve or less than 10 g fat per 100 g.
- **Carbohydrate total:** The total carbohydrate includes all sugars and starches, both natural and added. Remember that approximately 15 grams of total carbohydrate equals one exchange of carbohydrate.
- **Sugars:** This tells you how much of the total carbohydrate is sugar. This will include added sugar as well as naturally occurring sugar such as lactose (milk sugar) and fructose (fruit sugar).
- **Ingredients:** When the ingredients are listed on a product they are listed in order of greatest to least quantity by weight. The ingredient which is used most is listed first and that used least is listed last. If sugar or a type of fat is listed first, this may not be a good everyday food choice. Look for added fats and sugars!

Examples of labels

Here are examples of nutrition labels from two products and a guide to the information they contain.

Low fat fruit yoghurt (170g tub)

NUTRITION INFORMATION

Serving size: 170 g Servings per tub: 1

	Average quantity per serving	Average quantity per 100g
Energy	615 kJ (148 Cal)	364 kJ (87Cal)
Protein	13.0 g	7.7g
Fat, total	2.7 g	1.6 g
- saturated	1.7 g	1.0 g
Carbohydrate, total	17.3 g	10.2 g
- sugars	15.6 g	9.2 g
Sodium	54 mg	32 mg
Calcium	175 mg	103 mg

Ingredients: Low fat yoghurt (82%) [Skim Milk, Cream, Live Yoghurt Cultures], Mango Blend (18%) [Mango (50%), Sugar, Water, Vegetable Gums (Fruit Pectin, Locust Bean Gum), Natural Flavours, Acidity Regulators (Citric Acid, Sodium Citrate), Mineral Salt (Calcium Citrate)].

Barbecue Shapes (snack biscuits)

NUTRITION INFORMATION

Serving size: 25 g Servings per package: 8

	Average quantity per serving	Average quantity per 100g
Energy	515 kJ	2060 kJ
Protein	1.9 g	7.5 g
Fat, total	5.6 g	22.4 g
- saturated	1.3 g	5.2 g
Carbohydrate, total	15.8 g	63.4 g
- sugars	0.2 g	0.9 g
Sodium	171 mg	685 mg

Ingredients: Wheat flour, vegetable oil, salt, tomato powder, salt, , yeast, garlic, parsley, sugar, Worcestershire sauce, onion powder, baking powder, natural flavour, vegetable protein extract (from maize), spices, antioxidants (E300, E307b From Soy, E304), Flavour Enhancer (E635), raising agents, flavours (natural, nature identical), spices, vegetable extract, flavour enhancer (E260).

Questions to ask yourself when reading food labels

This example uses the two food labels above.

1. **How much yoghurt is my child going to drink or eat?**

   Your child will eat 170 g if he or she eats the whole tub. Note that the nutrition information is given for this serving size and also per 100 g of yoghurt.

2. **What is the total carbohydrate in this tub of yoghurt?**

   There is 17.3 g in the whole tub (170 g), or approximately 1 exchange of carbohydrate.

3. **What about the sugars in the yoghurt?**

   Sugar is listed as an ingredient and makes up most of the carbohydrate in this product. This is not a problem, since it is mixed with protein and fat in this product which will slow its effect on blood glucose levels. Yoghurt is generally a low GI product (see below).

4. **What is the main ingredient in the yoghurt?**

   Skim milk, since it is listed first in the ingredient list.

5. **Is the yoghurt high in fat?**

   No, it is low in fat and saturated fat. The total fat content is only 1.6 g per 100 g.

6. **Does the yoghurt have a low, medium or high glycaemic index (GI)?**

   This is not shown on the nutrition label. Brief lists of foods and their GIs are given earlier in this section. In general, dairy products have a low GI. Your dietitian can give you more information about GI.

7. **Are the 'barbecue shapes' an appropriate carbohydrate food for everyday eating?**

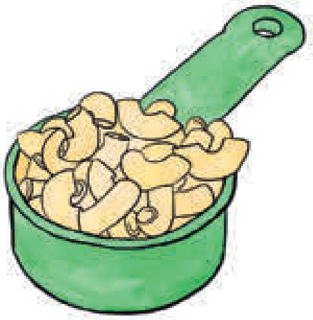
   The shapes do contain carbohydrate. However, they also contain 22.4 g of fat per 100 g (i.e., they are 22.4 % fat). Foods with more than 10 g per 100 g should only be eaten occasionally and in moderation. The shapes are also high in sodium (salt). Thus, the shapes should be regarded as an occasional food to be eaten in moderation and not an everyday food.

8. **How many of the Barbeque Shapes make up one 15g exchange?**

   You cannot tell this from this nutrition label. Some nutrition labels might tell you how many biscuits make up one serving, but not in this case. You could estimate by knowing that the pack is made up of 8 x 25 g servings, each serving containing 15.8 g of carbohydrate or about 1 exchange. Alternatively, weighing reveals that there are approximately 13 biscuits per 25 g of the product or per exchange of carbohydrate.

9. **Do I need to weigh and measure everything?**

   We recommend that initially, you take the time to use measuring cups or kitchen scales to assist with carbohydrate counting and knowing your usual portions. This is important as the amount of insulin you inject is determined by the amount of carbohydrate you eat. We recommend you re-check your measurements every 6 months or so to make sure you are accurate, particularly as appetites can vary with growth and age.



Ingredients in disguise

Fats and sugar are sometimes called by other names in ingredient lists. Use the following lists to see how many different fats and sugars are contained in your food choices.

Fat is also known as:	Sugar is also known as:
vegetable oil/fat	sucrose
animal fat/oil	glucose
shortening	dextrose
copha	malt
lard	maltose
tallow	glucose syrup
chocolate	corn syrup
palm oil	molasses
coconut oil	golden syrup
milk solids	fruit syrup
ghee	fruit juice concentrate
	honey

Nutrition claims on food labels

Food packaging and advertising use a number of terms to make claims about the product. They may not always mean what you think. If in doubt, read the nutrition panel which helps you work it out for yourself.

- **Lite or light:** May refer to colour (e.g., light olive oil), salt content (e.g., lite chips) or to fat content. This can be confusing, so check the nutrition panel.
- **No added sugar:** May still contain fruit sugar (fructose) or milk sugar (lactose). Check the nutrition panel for the carbohydrate content.
- **Cholesterol free or low cholesterol:** Cholesterol free does not mean fat free. Cholesterol is only found in products of animal origin. Avocados, for example, are cholesterol free but not fat free.
- **Low joule:** The food or drink has been artificially sweetened, but may still contain carbohydrate. Check the nutrition panel.
- **Diet:** Products that have a lower energy content (kilojoules or kJ) than other similar foods (e.g., diet yoghurt).
- **Carbohydrate modified:** A sugar alternative such as sorbitol is used. Check the nutrition panel for carbohydrate and fat content. These foods still contribute energy to the diet and are not necessarily suitable alternatives.

- **Low fat:** The food contains less than 3 g of fat per 100 g.
- **Reduced fat:** The fat content has been reduced but the food may still be high in fat (e.g., reduced fat cheese). These may still be fine to eat, but consider how much and how often you eat them.
- **No added salt or reduced salt:** There has been no salt or less salt (sodium) added to the food.
- **High fibre:** The food must contain at least 3 g of fibre per average serve.
- **All natural:** A very non-specific claim. Read the nutrition label.
- **Toasted or oven baked:** Check the fat content of these foods. It may still be quite high.

Calculating the amount of carbohydrate from a recipe

There may be some favourite recipes you enjoy which you'd like to calculate the amount of carbohydrates for. This section helps you identify the amount of carbohydrates per serve.

Step 1: List all the ingredients

Step 2: Identify the carbohydrate containing foods

Step 3: Write down the quantity of each carbohydrate e.g., 1 cup, 1 tablespoon

Step 4: From the carbohydrate content tables, books or apps, calculate the grams of carbohydrate in the recipe

Step 5: Add up the total number of grams in the recipe

Step 6: Divide the total number of grams by the number of serves it makes. This gives you the amount of carbohydrates per serve.

Ingredients	Contains Carbohydrates?	Carbohydrates in grams	Carbohydrates in exchanges
8 sheets Fresh lasagne sheets	Yes	190 grams	13 exchanges
Meat and vegetable filling			
300g lean mince	No		
1 large onion, chopped	No		
1 garlic clove, chopped	No		
1 cup chicken stock (low salt)	No		
2 sticks celery	No		
1 small head broccoli	No		

Ingredients	Contains Carbohydrates?	Carbohydrates in grams	Carbohydrates in exchanges
2 chopped zucchini	No		
500g mushroom	No		
2 capsicums	No		
320g canned kidney beans	Yes	43 grams	3 exchanges
White sauce			
1 tablespoon margarine	No		
2 tablespoons plain flour	Yes		
1 cup light milk	Yes	15 grams	1 exchange
Chopped parsley	No		
Tomato sauce			
1 x 425g can 'no added salt' tomatoes	Yes	22 grams	1.5 exchanges
2 tablespoons tomato paste	Yes	5 grams	
Chopped basil	No		
Total Carbohydrates		**275 grams**	**18.5 exchanges**

The total amount of carbohydrate in this recipe is 275 grams (18.5 exchanges), and makes 8 serves (one large lasagne will get sliced in to 8 equal sized portions). If your child eats one serve, this will give 275 / 8 = 34 g of carbohydrate, or 18.5 / 8 = 2.5 exchanges per serve. If they eat 2 serves it will be 77g or 5 exchanges.

Advice for specific age groups

As children grow and develop, the initial meal plan will require adjustment. The management of diabetes varies greatly at different ages and stages of development.

Infants and toddlers (under five years)

Breastfeeding is encouraged for infants with diabetes. Breast milk or human milk substitute formula remains a major nutrient source until one year of age. Solids may be introduced at four to six months.

Fussy eating, food fads and food refusal are common in toddlers and when these occur in a child who has diabetes this can cause great anxiety for parents. It is not unusual for a toddler to eat erratically and be unpredictable, but usually with persistence and a consistent approach, more regular eating patterns can be established.

A structured routine of three main meals and two small planned snacks such as morning tea, and afternoon is ideal. Avoid continuously eating (i.e., grazing) throughout the day, as this makes blood glucose interpretation more difficult. Grazing throughout the day may also lead to your toddler refusing to eat at main meals, which causes more stress. Speak to your dietitian about appropriate amounts of food at main meals and snacks.

The meal environment is important in establishing good eating habits in children. TV, computers, electronic devices such as smart phones or tablets, and other distractions should be turned off and everyone should sit at the table for at least 15 minutes, even if not choosing to eat. If a young child will not eat at the meal they should still stay at the table and hopefully will start to eat. If not, they can be offered something after the meal, although that still needs to be a healthy food choice. Meal times for small children should be limited to approximately 20 minutes per meal.

If a young child asks for food between meals/snacks, offer water, low carbohydrate nutritious foods (vegetables like carrots, cucumber, tomatoes or beans) or try distraction techniques, e.g., reading a book, playing a game.

As healthy eating habits for life are being established by the whole family, a variety of food colours, tastes and textures should be promoted. Encourage your infant or toddler to have the same family meals, modify to ensure appropriate textures, cut in to bite-size pieces, minimise the use of chilli and salt. To guard against parents becoming slaves in the kitchen, toddlers should be given a simple choice between one food or another e.g., 'we are having toast for breakfast this morning, would you like peanut butter or avocado on it?' rather than asking 'what would you like to eat?'.

School-age children

Children's energy needs are constantly increasing with rapid growth and activity. Energy intake nearly doubles from 6 to 12 years of age. Regular review of meal plans is therefore essential. Eating patterns tend to be more regular at this age and most children adapt well to having three main meals. If hungry, they may also have two or three snacks during the day if appropriate for their age and growth.

Meal and snack routines should be incorporated into the usual school timetable where possible. Depending on the amount of carbohydrate at planned snack times such as morning tea or afternoon tea, extra insulin may be required. School-age children are encouraged to carry 'hypo food'. For exercise, reducing insulin doses to minimise the risk of hypoglycaemia is preferable, while some extra carbohydrate for exercise may also be required. School-age children need to be guided about choices from the school canteen and fast foods. Also, avoid swapping of food at lunchtime which is common, since swaps may have different carbohydrate quantities or be less suitable choices. As children may go to sleepovers, camps, or parties, appropriate food choices should be discussed with the supervising adults.

Adolescents

Adolescence is a natural period of establishing independence and of rebellion; managing diabetes is one more thing to rebel about. Growth is rapid, lifestyle is more irregular and there is often more snacking, staying out late, eating out and fast foods. The issue of alcohol use may also arise. The desire for independence can cause resentment of restrictions, particularly if food is the focus.

Routine, nutritious meals are important, especially through periods of rapid growth to prevent excessive snacking in the afternoon or evenings. Depending on the amount of carbohydrate at snacks, extra insulin may be required. On an insulin pump, foods containing 5 grams, or ½ exchange of food need to be accounted for to allow insulin delivery. Those on flexible multiple daily injection plans, speak to your diabetes team about when extra insulin injections may be required for mid-meal times.

Adolescents on multiple insulin injections or insulin pumps enjoy the flexibility of being able to adjust daily routines to match their lifestyle. Accurate counting of carbohydrate is important in order to take advantage of this flexibility. It is important that healthy food choices and routine meals are still reinforced. Undesirable practices such as skipping insulin, over-restricting food intake to reduce weight or episodes of binge eating are often seen in this age group.

Children's parties and special occasions

We all love eating out, parties and celebrations. They are important for children's social development and diabetes is no reason to miss out. For these occasional times, the meal plan can be relaxed without affecting overall diabetes control.

- The number one rule is HAVE FUN! Parties are special for all children.
- Before the party, chat to your child about what foods may be there and what they may choose.
- Encourage savoury food choices (e.g., chips, popcorn, party pies and sausage rolls). Allow some high sugar foods such as birthday cake or ice-creams.
- Provide the host with simple instructions about 'hypo' management (e.g., symptoms and how to treat) and reassure them that high sugar foods occasionally will do no harm.
- It is easy to have diet or no sugar soft drinks and diet cordials at parties for everyone to enjoy.

If blood glucose levels are high after the party, don't be tempted to restrict intake at dinner, as this may result in a low blood glucose level later in the night. Offer healthy carbohydrate food choices at the evening meal, test the blood glucose level before bed and give extra snacks if needed.

Sometimes children eat less food at parties because they don't think they can eat party food or they are too busy playing. If this is the case and there have been lots of active games, it is important that your child has a good supper before going to bed to avoid overnight hypos. They may need to eat extra supper if they ate little at the party.

If you are holding the party you can easily control the food provided. Remember to plan lots of active games. Children don't expect all high sugar foods and anything that is a novelty is fun enough. Try a theme or dress-up party with foods to match (e.g., American baseball and hot dogs, Mexican tacos or a Hawaiian pool party).

Provide a variety of food choices including fruit and vegetable platters with dips (e.g., hummus, guacamole, salsa), or cheese and crackers. Party bags can include a range of arts and craft activities, seeds to grow vegetables, socks and the option of small amounts of lollies or chocolates. Encourage your child or adolescent to be open about what they eat as this may help you understand variations in blood glucose levels.

Healthy takeaways

Takeaway food can be a part of a healthy eating plan for your child, particularly if you select foods lower in fat and sugar. Add extra salad or vegetables wherever you can.

Examples of healthier choices of common takeaway foods include:

- **Sandwich bar:** Multigrain rolls, bagels, focaccia, pita bread, sandwiches and so on, filled with lean meat, chicken, fish, egg, baked beans, avocado or cheese and salad.
- **Pasta or pizza parlour:** Pasta with tomato-based sauces; lasagne; thin-based pizza; vegetarian pizza topped with tomato, onion, capsicum, pineapple, mushrooms and a light sprinkling of cheese.
- **Salad bar:** Fresh salads such as coleslaw, potato, tabouleh, pasta, bean and rice; low fat yoghurt; fruit smoothies; fruit salad; pita bread, rolls and sandwiches; milkshakes.
- **Chinese:** Steamed rice or noodles, stir-fried dishes, steamed dim sims.
- **Japanese:** Noodles or rice with soup, sushi or sashimi.
- **Lebanese:** Kebabs with meat or chicken and salad, falafel rolls.
- **Hot food or takeaway shop:** Hamburger – plain with salad, steak sandwich, grilled fish, BBQ or charcoal chicken, chicken burger, baked potato, chunky potato wedges, mashed potato and gravy, soup with a roll, toasted sandwiches.
- **Cafe:** Multigrain bread, wraps, pita bread, sandwiches, quinoa salads and so on filled with avocado, eggs, lean meat, chicken, fish, and salad.

Adapting recipes

You will still be able to use your favourite recipes for meals and snacks. Some modification may be necessary to reduce the fat or sugar content. Discuss this with your dietitian if unsure.

Suggestions in cooking

- Halve the sugar in your usual cake recipes (e.g., if the recipe usually has one cup sugar, change it to half a cup). Sugar is still necessary for taste and texture and it doesn't cause a big rise in blood glucose levels if included as part of a balanced diet.
- Try to use polyunsaturated or monounsaturated margarine, canola or olive oil in cooking in place of butter, lard or dripping.
- Try to use low fat ingredients where possible (e.g., low fat cheese and milk).
- Try to incorporate some low GI foods in your ingredients whenever practical (e.g., oatbran, dried apricots, muesli, yoghurt, fruits).

Snack ideas

It is important to have some variety in the foods that your child eats. Planned snacks are a great opportunity to increase the overall nutritional quality (amount of vitamins and minerals) of your child's diet. Include lean protein (e.g., lean meat, chicken, fish, eggs, or cheese) and some low carbohydrate vegetables. Some children get into a habit of very limited choices which they then tire of. Depending on the amount of carbohydrate in the snack, extra insulin may be required.

Here are some ideas:

- Raw vegetables such as cucumber, carrots, celery, or capsicum and dip – tzatziki, hummus, eggplant, guacamole, salsa or mix low fat yoghurt, creamed cottage cheese or ricotta with french onion packet soup mix or peanut butter
- Fresh fruit or fruit salad – try it with yoghurt
- Low fat yoghurts – put a container in the freezer for about an hour to make a delicious frozen snack
- Bread, muffins, raisin bread, crumpets or bagels with toppings or fillings such as avocado, peanut butter, tuna, lean meat, egg or cheese

- Vegetable soup
- Baked beans or spaghetti on toast, jaffles
- Microwaved popcorn or on the stove with a tiny amount of oil
- Pretzels or rice crackers – plain or flavoured
- Bagels or pitta crisps
- Fruit smoothie – mix low fat milk, low fat yoghurt and fruit
- Hot chocolate drink – low fat milk and cocoa mix or a couple of teaspoons of Milo in milk
- Crackers: water crackers or other light cracker biscuits with toppings such as lean meat, chicken, eggs, cheese, fish, avocado or peanut butter
- Low fat ice-cream
- Light flavoured milk or milk with flavouring

Ask your dietitian for more snack ideas.

Diabetes and coeliac disease

People with type 1 diabetes have an increased risk of developing coeliac disease. Coeliac disease affects approximately 7 per cent of children with diabetes.

Coeliac disease is a condition where the lining of the small intestine (or small bowel) is damaged due to a sensitivity to the protein gluten, found in the grains wheat, rye, oats, barley and triticale. The damaged lining of the intestine makes it very difficult for the body to absorb nutrients from food and can result in weight loss, poor growth, lack of energy, diarrhoea and a swollen belly. However, in children with diabetes, there may be no obvious symptoms of coeliac disease. Children who have diabetes and undiagnosed coeliac disease may be more susceptible to hypoglycaemia or more variable blood glucose levels due to unreliable absorption of food.

A blood test can be done to screen for coeliac disease. If this screening blood test is positive, a small bowel biopsy will usually be recommended, as this is the only way to confirm the diagnosis. A gluten-free diet (GFD) is the only accepted treatment for coeliac disease.

The gluten-free diet means removing wheat, rye, barley and possibly oats and products made from these grains. Alternatives such as quinoa, rice, corn, potato or soy-based products, fruit, dairy and other gluten-free food items are used to meet carbohydrate requirements. Commencing a gluten-free diet will allow the lining of the small intestine to recover, improving absorption and promoting normal growth and development. Where a child has coeliac disease, special resources are available to help. Families can join the Coeliac Society and obtain more of information and support.

Common questions and answers

How accurate do I need to be with the amount of carbohydrate foods?

Managing diabetes works best when there is accurate matching of insulin doses to carbohydrate intake. Thus, it is worth working on this and doing the best you can. Sometimes it is not easy, e.g., unfamiliar foods or restaurant meals, but at home you can more easily estimate accurately by using scales and reading food labels as needed. Keep a list of your child's commonly consumed foods with the amount of carbohydrates to assist. Other tools to assist with counting carbohydrates include lists, books, or apps which your dietitian can provide.

What should I do if my child's blood glucose level is high at meal or snack time?

The approach varies according to the circumstances and whether the child is treated with injections or a pump.

Injections: The meal or snack should be given as usual, but if they are not very hungry then eating a little less is fine. Not giving food when a child is hungry just because the blood glucose is high is not recommended and may be interpreted as punishment. If insulin is due at the time, giving extra rapid or short-acting insulin is a good idea – the amount required can be advised by your diabetes team, or obtained from your bolus advisor. If an insulin dose is not due, you should also consider giving an extra injection of rapid or short-acting insulin so that the BGL does not stay high. If the blood glucose remains high or there are ketones in the urine, refer to the section on sick days. If this is happening regularly, then it is more appropriate to review overall insulin doses.

Pump: a correction can easily be given with the pump, either with a meal or snack, or in-between. The pump will guide this dose when the glucose level and carbohydrate count are entered.

What happens if my child eats too much carbohydrate at a meal or snack?

This will happen sometimes as appetite varies. If it is significantly more than the expected, blood glucose levels may be elevated, but usually only for a few hours. If your child is more active and eating more, then it usually balances out well, since extra carbohydrate is needed when more active.

If your child is on a pump, the extra carbohydrate can be bolused for after the meal or a correction dose given later if needed.

If on injections and the additional carbohydrate has caused significant hyperglycaemia, an insulin correction dose can be given, as discussed in Chapter 12.

What if my child does not want to eat?

Your child may be feeling unwell or just not hungry. On many insulin patterns, e.g., pump or multiple daily injections, the meal can often be delayed until the child feels ready to eat provided that the BGL is fine. Work at establishing routine eating patterns as discussed earlier in this chapter and avoid feeding young children too often, since this may reduce appetite at routine meal and snack times.

Sometimes it is reasonable to offer substitutions of food, but this should not be for "junk foods" and be careful of setting up a pattern where you become a slave in the kitchen, trying to cater for all whims. Offer a limited number of healthy choices e.g., 'would you like yoghurt or banana instead?'

Just after diagnosis my child was very hungry and eating a lot, but is now less hungry. Why is this?

At first, the body has to make up for the weight loss before the diabetes was treated. After that the appetite usually decreases back to normal. Your diabetes team will advise and also guide you with any insulin adjustments that may be needed at the time.

Will my child become overweight as a teenager or adult because they have diabetes?

No, but this is possible if the balance between food intake, insulin and exercise is not right. Genes are also a factor, so if there is a tendency to being overweight in the family, there is increased risk. Sensible, healthy eating, particularly keeping the diet reasonably low in energy and fat, and adequate exercise are the keys to avoiding gaining too much weight. If you are concerned about your child's weight, speak to your diabetes doctor and dietitian who can help to get the balance right.

Is it OK to have artificial sweeteners?

Sweeteners such as sorbitol in diabetic sweets should be kept to small quantities only, since diarrhoea and tummy cramps may occur. Artificial sweeteners are widely used in diet drinks and cordials and if taken in moderation are safe and acceptable. Some sweeteners (e.g., Splenda, stevia) can be used in baking, but using ordinary sugar is a reasonable alternative since in a mixed food type the effects on blood glucose levels are likely to be small. Extensive use of artificial sweeteners is not necessary because sugar can be used in moderation as part of a healthy, balanced diet without upsetting diabetes control.

My son has been working hard at the gym and would like to start taking protein supplements to build muscle. Will this affect his diabetes management?

Building muscle mass requires a combination of extra food intake and resistance training. The body can only use small amounts of protein at a time, so the best approach is to increase his protein intake throughout the day (spread out between meals and snacks). Good options include eggs, lean meats, nuts, fish, or cheese. He should also make sure to take appropriate amounts of insulin so his body absorbs all of his food to help with muscle growth.

Whilst there are many popular muscle building supplements available, most of these don't have scientific evidence of their effectiveness. Some of the protein supplements on the market may also be contaminated with other substances, which can interfere with diabetes management.

Chapter 7

Monitoring diabetes control

Key Points

- Diabetes monitoring can be divided into:
    - Monitoring of blood glucose levels throughout the day
    - Monitoring of blood (or urine) ketones when the blood glucose is high, or the child is unwell – see page 84
    - Monitoring of long-term control using the Haemoglobin A1c and "time in range" (if using continuous glucose monitoring) – see page 83
- Check the blood glucose level (BGL) preferably four to six times per day, or more often if needed
- Vary the times of checks sometimes to know what is happening at different times
- Check at night periodically
- The target range for blood glucose levels is between 3.9-10 mmol/L. However, the preferred range may vary depending on when you take the reading, generally:
    - Before meals 4 to 7 mmol/l
    - After meals and before bed 5 to 10 mmol/l
    - at 3am 5 to 8 mmol/l
- Your diabetes team may give you individualized targets which are slightly different to these
- You must keep a record of BGLs, either a record book or electronically via a software platform advised by your diabetes team. Without a record of the BGLs you have taken, you and your diabetes team cannot adjust your treatment!
- Check the blood (or urine) for ketones if:
    - Your child is unwell, especially if the BGL is > 15 mmol/l
    - Your child is well but the BGL remains persistently above 15 mmol/l over a few hours of checking
    - If using an insulin pump and BGL > 15 mmol/l, always check for ketones (refer to Chapter 13)
- Continuous Glucose Monitoring (CGM) is an increasingly used method for measuring glucose levels
    - It can provide information about the glucose trend throughout the day and night
    - It is required for use of hybrid closed loop pump systems
    - An alarm at or below a specific low glucose level can provide a safety net, especially overnight
    - CGM does not entirely replace fingerstick glucose checks and cannot be relied on in all situations

Blood glucose monitoring

Blood glucose measurements are important to:

- monitor daily blood glucose control and allow insulin adjustment
- detect high or low blood glucose levels so that treatment can be given if needed
- monitor and treat diabetes during illnesses and exercise.

Blood glucose meters (glucometers)

An accurate blood glucose meter is essential for management of diabetes.

A variety of blood glucose meters are available from different manufacturers. These currently all rely on a drop of blood from a fingerstick being placed on or drawn into a special strip from which the machine reads the blood glucose level.

There are two main types of meter available:

- **Bio-electric meters:** The glucose in the blood generates an electrical current on the strip. This current is converted by the machine to a blood glucose level.
- **Reflectance meters:** The glucose in the blood changes the colour of the test strip. The machine reads the colour of the strip by reflecting a light beam from it and converts this into a blood glucose reading. This technology is older but is still available.

Your diabetes educator will guide you as to the most suitable blood glucose meter for your child – different meters may suit different children and families. When choosing a meter you may consider different features such as size of the meter, size of drop of blood required, price and memory. Other features may include the ability to transfer readings to computer programs or mobile phones, the ability to provide insulin dosing advice (see Chapter 12) or to link with an insulin pump or continuous glucose monitoring device.

Special points about blood glucose meters

- All available machines will give satisfactory readings if used properly. All can be prone to errors if not used correctly.
- If you are concerned about the performance of your meter, contact the manufacturer for advice or ask your diabetes team.
- Most meters can give falsely low readings if too small a drop of blood is used.
- Your educator and the meter instructions will guide you as to the size of the drop required.

- Meters all have a limited life span and may become more troublesome or unreliable after three to four years of use. Within this time it is recommended that you upgrade your meter.
- Meters are mechanical devices and can break down or be damaged. It is a good idea to have a spare meter as a back-up.
- Machines have a temperature range within which they are meant to operate and can be less accurate when used outside this range.
- No meter is as accurate as a laboratory blood test but they are accurate enough to guide diabetes management. Accuracy is within 10 to 15 per cent when used correctly.
- A number of meters can store readings which can be accessed from the memory and downloaded to a computer or to a smart phone via Bluetooth.
- Blood glucose meter memories and downloads are not a substitute for keeping a more complete diabetes diary or electronic log book – this is still important as it allows recording of insulin doses and notes to be made about any other issues affecting the diabetes on a daily basis. Such information is important to allow informed adjustments.
- Some glucose meters can be programmed to provide advice on insulin doses, or can sync with a mobile phone app which can provide this advice. The doses are based on settings provided by your diabetes team which are entered into the meter or the app. These are called 'bolus advisors' and are discussed in Chapter 12.

Obtaining the blood sample – lancet devices (fingerstick devices)

A number of lancet devices (also called fingerstick devices) are available and your educator can advise which is best for your child. The part that pricks the finger is called a lancet. Very fine lancets cause less pain and damage to the fingers and are recommended for use in children. Some devices allow the depth of penetration of the lancet to be varied which can reduce discomfort in some children.

When should we check the blood glucose?

The amount of blood glucose monitoring needed varies from person to person and from time to time, however more monitoring of BGLs is generally associated with better control, since there is more information available on which to base insulin adjustments. Very young children often need more frequent checks and children of all ages need to check more if the diabetes control is unstable. Intermittent blood glucose testing is likely to be increasingly overtaken by continuous blood glucose monitoring systems.

Recommended monitoring

If CGM is not being used, the BGL should be checked four to six times per day to give a picture of what the levels are like over the 24-hour period, but sometimes more frequent checks are required. It is unwise to do less than 4 BGLs per day. These checks are required to maintain the BGL in a safe range and to identify problems early. There are times when BGLs should always be checked (e.g., before main meals) and times when BGLs should be checked only as required (e.g., overnight).

Times to check BGLs

Always (every day)	
Before breakfast	This is called the fasting/waking BGL. It helps determine if the overnight insulin dose is correct.
Before all main meals	This helps determine if the dose from the previous meal was correct (for lunch and dinner). If the pre-meal blood glucose level is above the target range a higher mealtime dose of insulin can be given (a correction dose).
Before bed	A blood glucose level between 5 to 10 mmol/l is desirable at bed time. If the blood glucose level is less than 5 mmol/l, an additional snack is needed for most people.
As required	
Overnight (e.g., 11pm and 3am)	This is not practical every night, but up to once per week is recommended. This is especially important if: • morning blood glucose levels have been low • long-acting insulin doses have changed • your child has had a very active day or • there were low readings during the evening. The blood glucose level should be 5 mmol/l or higher before bed and throughout the night. If you find abnormal night readings, you must make adjustments and keep monitoring until BGLs become satisfactory. Contact your diabetes team if unsure.
Exercise	Exercise can lower the blood glucose level so BGLs should be checked before, during and after exercise (Chapter 11).
Sick days	Illness can cause high or low blood glucose levels. BGLs need to be checked more frequently during sick days (Chapter 10)
A low BGL (hypo) is suspected	Hypoglycaemia must be detected and treated immediately (Chapter 8)
After meals (post-prandial check)	Although checking BGLs before main meals is standard, it is also important to sometimes check BGLs after meals to make sure that the pre-meal dose of insulin was adequate. If you are not checking after meals, there is the possibility of large glucose rises which will contribute to less satisfactory overall control and to a risk of complications. Check sometimes 2 hours after breakfast (before morning tea), 2 hours after lunch (before afternoon tea) or 2 hours after dinner (before supper). The target is to have a BGL in the range 5-10 mmol/l at these times.

Performing a BGL check and recording

1. Set-up of the meter will vary according to the manufacturer's instructions, which should always be followed. Make sure strips are not past their use-by date. It is important that the date and time are set correctly in the meter since this helps you and your diabetes team when assessing BGLs. Be careful to check and reset the time and date if needed after battery changes.
2. Wash and dry hands or the other area to be pricked. This is important to avoid infection and so that food or drink residue does not give a falsely high reading. This is a common reason for an unexpected high reading.
3. Ensure that a relatively new lancet is being used. The points of lancets dull very quickly, causing more discomfort and damage to the fingers. Preferably change the lancet for every BGL check or at least once per day.
4. Prick the finger on the sides of the finger tip (see illustration). Avoid pricking the tops or the pads of the fingers as repeated pricking in these locations can cause loss of fine touch sensation. Spread the finger pricks around different fingers so thickened areas do not develop. Some children prefer not to use certain fingers (e.g., the second or index finger).

Where to perform fingerstick glucose checks

5. Squeeze an adequate drop of blood onto the strip. If the strip you have sucks up the blood, make sure that you hold it against the blood droplet for enough time to draw a good sample. Remember, meters can give errors if too little blood is placed on the strip.
6. When the BGL result is available, record this in your blood glucose record along with any relevant notes. Even though most meters have memories for a number of blood glucose readings, it is important to keep a record book or electronic record to allow patterns of readings to be examined and make other notes about insulin doses, food, activity, illness and so on which may be affecting readings. The record book (either manual or an electronic version) is a very important resource for you, your doctor and educator to assess progress and help make adjustments.

If you are using an insulin pump or a bolus advisor mobile phone app, the blood glucose level should be entered into the pump or into the app. This will assist with calculation of an insulin dose and will store the glucose reading as an electronic record. Some meters used with pumps or mobile phone apps will sync with the pump or mobile phone and automatically store the BGL in the electronic record (see Chapter 12 and Chapter 13).

Continuous glucose monitoring systems (CGMS or CGM)

These are a range of devices that measure the glucose level in a space under the skin – the subcutaneous tissue glucose level. This is a fairly accurate reflection of the fingerstick (blood) glucose level, though it is not always exactly the same. The subcutaneous tissue glucose level can lag behind the blood glucose level by several minutes, but this difference is usually not long enough to cause problems in day-to-day diabetes management. CGM works best if worn consistently. Wearing CGM consistently can help with diabetes control.

There are 2 main types of CGM: real time CGM and flash glucose monitoring.

Real time CGM

The system includes three main components:

- A sensor which is worn by the child, usually on the tummy, upper buttocks or back of the upper arm. The sensor includes a small filament which is inserted under the skin to measure the glucose levels. Each sensor generally lasts between 6-7 days and can only be used once.
- A transmitter which sends the data wirelessly from the sensor to the receiver. Transmitters are reusable.
- A receiver, often a mobile phone or an insulin pump, which displays the glucose level and the glucose trend (whether the glucose level is rising, falling or staying the same).

CGM does not eliminate the need for fingerstick glucose checks: most types of CGM still require calibration with 2 to 4 fingerstick glucose levels per day. CGM also cannot be relied upon in all circumstances such as if your child is unwell, or if there is a very high or low sensor glucose reading on the CGM. Certain medications can make the glucose readings on some CGM systems less reliable. For example, paracetamol may cause falsely high readings. Your diabetes team can tell you which medications may interfere with your type of CGM.

You should always check a fingerstick glucose level if:

- Your child is unwell
- Your child has symptoms of hypoglycaemia, even if the glucose level on your CGM is normal
- The CGM is reporting a low or very high sensor glucose level
- Your child has taken medication which may interfere with the sensor glucose reading

Advantages of CGM

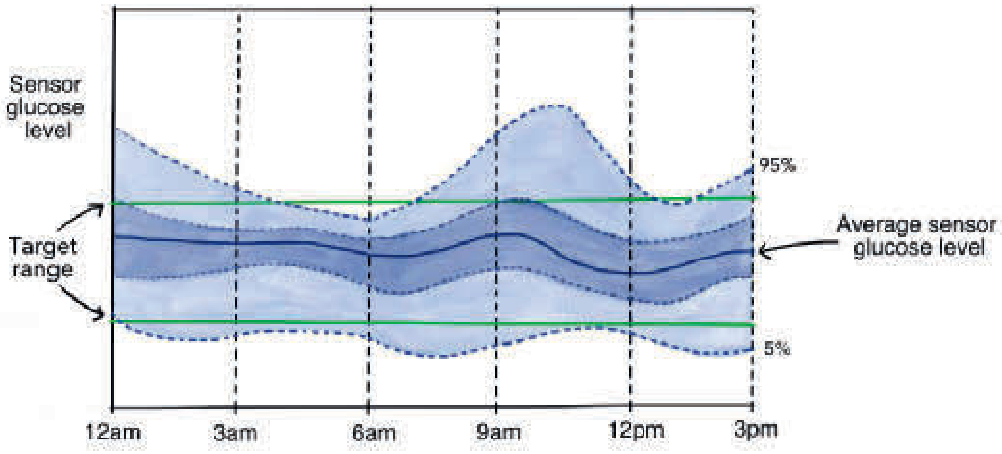
- CGM provides a glucose trend (whether the glucose level is rising, falling or staying the same) in addition to the glucose level. This can allow you to adjust your child's management accordingly.
- Alarms can be set for when the glucose level is above or below the target range or if a rapid change in glucose level is occurring. This provides a safety net to help detect and prevent hypoglycaemia (particularly overnight).
- The CGM data can be viewed remotely (e.g., on the mobile phone of a parent when the child is at school).

- Some types of CGM can sync (wirelessly communicate with) a pump to allow the pump to automatically adjust how much insulin is given depending on the blood glucose level (hybrid closed loop) – see Chapter 13.
- CGM gives much more information about blood glucose patterns. This increases the ability of the diabetes team to adjust your child's treatment to suit their needs.

Disadvantages of CGM

- Some children get skin reactions to the adhesives used to stick the sensor to the skin. There are various options to address this which your diabetes team can help you with.
- Alarm fatigue: some families find frequent alarms from the CGM intrusive. The alarm settings can be altered to minimise this, and some alarms can be turned off entirely.
- Accuracy: sometimes the CGM readings are inaccurate. This can be addressed by calibrating your CGM. Occasionally the sensor will need to be replaced. Certain medications such as paracetamol can give falsely high readings on some CGM systems.
- CGM systems are expensive. There are government subsidies available in some countries to enable CGM use in children and adolescents with diabetes. You should discuss this further with your diabetes team.

Any issues with continuous glucose monitoring should be discussed with your diabetes team and with the device's manufacturer. Many problems can be fixed relatively easily and should not be a reason to stop using CGM.

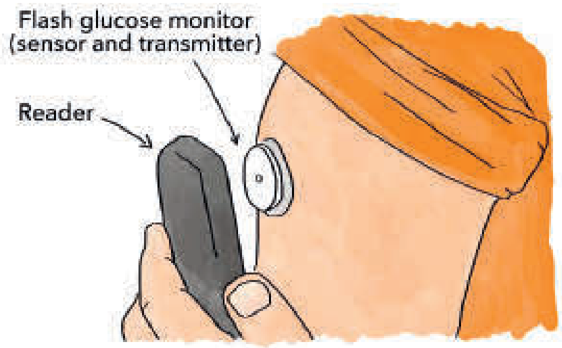


An exampling of a BGL profile from a CGMS device

Flash glucose monitoring systems

This is a different type of glucose monitoring which is similar to CGM. Flash glucose monitoring still measures the glucose level in the same way (subcutaneous tissue glucose), but the sensor glucose level is only displayed on request, rather than continuously. The child wears a sensor on their upper arm and the glucose level is obtained by swiping a reader over the sensor. Even though no continuous real-time data displayed, a glucose trend for the past 8 hours can be seen with each sensor glucose check.

Flash glucose monitoring systems do not alarm for high or low glucose levels like real-time CGM and it cannot sync with an insulin pump. The system does not require calibration with fingerstick glucose levels and the child can wear each sensor for up to 14 days before it needs to be replaced.



A flash glucose monitoring system worn on the upper arm

How to interpret and respond to CGMS information

When using CGMS, the glucose trend is just as helpful as the glucose level itself. When CGMS provides a sensor glucose level, it also indicates whether the glucose level is rising (slowly or rapidly), falling (slowly or rapidly) or staying about the same. Most systems use a type of arrow to indicate this. Examples of this are shown in the table below. The glucose trend can help you decide on how to act on a sensor glucose level. The time of day and relationship to food, exercise and insulin doses are important factors in interpreting the data.

CGMS arrow indicators			**Glucose trend**	**Over-night**	**Pre-meal** (about to eat, more than 3 hours since last meal)	**After meal** (early, first 90 minutes)	**After meal** (late, second 90 minutes)
Medtronic	Dexcom	Freestyle Libre					
↑↑ or ↑↑↑	⇡● or ⇈●	↑	**Rising or Rising rapidly**	Take action	Probably fine	Probably fine	Take action
↑	●	↗	**Rising slowly**	Probably fine	Probably fine	Probably fine	Take action
—	●	→	**Steady**	Probably fine	Probably fine	Probably fine	Probably fine
↓	●	↘	**Falling slowly**	Take action	Probably fine	Probably fine	Probably fine
↓↓ or ↓↓↓	● or ●	↓	**Falling or Falling rapidly**	Take action quickly	Take action	Take action	Probably fine

Probably fine: no action needed except normal surveillance if the glucose level is in (or close to) target range. If glucose is above or below target range extra insulin or glucose may be required.

Take action: watch carefully, check again soon with fingerstick BGL; extra glucose or insulin may be needed

Take action quickly: confirm with a finger stick reading and treat with glucose or insulin as needed

It is important to remember that both the glucose level and the glucose trend should be taken into account when deciding whether action is taken. For example, if the glucose level is well above target and the glucose trend is steady, an insulin correction is still required.

The rate of glucose rise or fall indicated by the arrows varies slightly between different types of CGMS, but generally:

Rising or rising rapidly – glucose is rising by at least 3.3 mmol/l over 30 minutes

Rising slowly – glucose is rising by around 1.7-3.3 mmol/l over 30 minutes

Steady – glucose level is not increasing or decreasing by more than 1.7 mmol/l over 30 minutes

Falling slowly – glucose level is falling by around 1.7-3.3 mmol/l over 30 minutes

Falling or falling rapidly – glucose level is falling by at least 3.3 mmol/l over 30 minutes

Other important principles with CGMS

- It takes time to gain experience and understanding of CGMS.
- Initially people are often surprised at how much fluctuation in BGL they see.
- Don't over-react to changes.
- Initial recommended settings for the alarms are 3.9 mmol/l for the low alarm and 10 mmol/l for the high alarm. These numbers may vary between different diabetes centres.

What are the target blood glucose levels?

The blood glucose level of a person without diabetes is quite tightly controlled within a range of approximately 3.5 to 8 mmol/l. In people with diabetes, blood glucose levels are likely to be more variable and it is not possible to always keep the blood glucose within this range.

Target blood glucose ranges are recommended to keep blood glucose levels as near as possible to the normal range, without the risk of too many low readings (hypoglycaemia). Generally, the target blood glucose range is 3.9 to 10 mmol/l. The ranges vary a little for different ages and vary depending on when the reading is being taken. Each child should have their targets individually determined with the goal of achieving a value as close to normal as possible.

At bed time the recommended target range is set a little higher to reduce the chance of hypoglycaemia at night. The blood glucose level should be checked regularly in the late evening or overnight (2 to 3 am). Levels above 5 mmol/l in the late evening and overnight are desirable.

Recommended target ranges

The target range for blood glucose levels is 3.9 to 10 mmol/l.

The preferred level within this range may vary depending on when you take the reading, generally:

Before meals:	4 to 7 mmol/l
After meals and before bed:	5 to 10 mmol/l
at 3am:	5 to 8 mmol/l

Your diabetes team may give you individualized targets which are slightly different to these depending on local practices or your individual circumstances.

Realistic expectations and problems with blood glucose levels

While we would like to have all blood glucose levels within the target range, this is rarely possible. Blood glucose levels may vary for many reasons, including variation in food, activity, insulin absorption and mood. Some of these are predictable and some totally unpredictable.

Aim to have as many readings as possible within the target range, but accept that this is often not possible. Realistically, most people achieve only 60 to 80 per cent of readings within the target range. Unless the out-of-range readings are very high, this pattern is still compatible with good overall control. Of course, when more than a few readings are out of the target range, it is important to explore why. Too many readings or constant readings outside the target range mean insulin doses need reviewing and perhaps other aspects such as food and exercise. If most readings are within the target range then the overall control is likely to be good.

There are also certain times when some people find control more variable or difficult, such as during school holidays, when travelling or in the winter months when activity may be less. All you can do is try to adjust factors within your control and consult your diabetes team if things are too difficult or not settling with time.

It is important not to use judgmental words like ‘bad’ to describe your child’s blood glucose levels. Usually a level above or below the target range is beyond their control and it is important that they do not feel they are being judged by their levels (e.g., you are ‘bad’ if you have a ‘bad’ blood glucose level). For levels outside the target range it is better to talk simply about above or below target blood glucose levels.

It is important that parents maintain a degree of supervision over blood glucose monitoring and recording that is appropriate for the child’s age. Understandably, children can tire of blood glucose monitoring and recording. Unless supervised, this can become too infrequent, be done carelessly, be poorly recorded or not done at all. There can be the temptation for children to ‘fudge’ results by writing down or entering a reading without checking the BGL or by writing down readings that will better please their parents or diabetes team. This often occurs in otherwise responsible children and indicates the difficulties that diabetes can pose. A sympathetic approach with firm guidance and a spirit of teamwork will often prevent or overcome such problems. Reviewing the meter memory and meter downloads are useful to check on the accuracy of recording.

Unstable blood glucose levels

When blood glucose levels are unstable, there are a number of things to think about and check:

- Do extra blood glucose monitoring to get a better idea of the day's readings and allow patterns to be seen.
- Is the blood glucose technique correct?
- Make sure your child is washing and drying their hands well before the check, or using a mini-wipe. Wet hands will cause dilution of the blood sample and a falsely low reading.
- Are all the insulin doses being given? Some older children and teenagers may forget injections or pump boluses and need reminders and supervision.
- If your child is on insulin pump therapy and levels are suddenly high, check to see that the pump is operating and check the line and cannula.
- Is the insulin being given into lumpy sites? Check the sites and move away from lumpy areas. This is an extremely common problem. Insulin absorption can vary by up to 25 per cent from day to day, even in healthy injection sites. This variability is made worse if injection sites are lumpy.
- Is the insulin out of date or has it been affected by extremes of temperature? This is especially common in summer and when away on holidays.
- Is the carbohydrate intake variable or uncontrolled? This is also a very common issue.
- Are appropriate adjustments of food and insulin being made to cope with sports and exercise?
- Are emotional factors upsetting your child? This can contribute to stress, poor adherence with diabetes routines and unstable blood glucose levels. Ask your diabetes team for advice.
- Is your child unwell with an infection or other illness? Consult your doctor if this may be the problem.
- Sometimes the reason for unstable blood glucose levels is not clear and it is a matter of waiting for a pattern to emerge. Contact your educator or doctor if you are concerned.

Monitoring of overall diabetes control

Haemoglobin A1c

Haemoglobin A1c measurement is a blood test which should be performed about every three months to look at overall long-term diabetes control. It is discussed more in Chapter 17.

Time in range

This is a measure of diabetes control used for people on continuous glucose monitoring. It calculates the percentage of time spent in the target range (3.9-10 mmol/l). The goal is to have a time in range of above 70%. This is discussed further in Chapter 17.

Ketone checking

Checking for ketones is necessary if the blood glucose is persistently elevated above 15 mmol/l or during periods of illness.

Always check for ketones in the following circumstances:

- If your child is unwell and the BGL is above 15 mmol/l.
- If your child is well, is using injections and the BGL remains persistently above 15 mmol/l over a few hours of checking.
- If using an insulin pump and BGL is above 15 mmol/l, always check for ketones without delay (refer to Chapter 13).

If a child using injections is otherwise well and has one BGL above 15, it is not necessary to check for ketones right away. Recheck the BGL in about 2 hours and check for ketones then if the BGL remains above 15 mmol/l. Regardless of whether it is necessary to check ketones, you may still decide to give a correction dose of insulin if the BGL is high (see Chapter 9 and Chapter 10).

Ketones can be checked in blood or urine. Checking the blood for ketones can give an earlier warning of ketones and is likely to be more accurate. Nevertheless, checking urine ketones is quite adequate in most situations.

Not all blood glucose meters have the ability to check for ketones. It is important to ensure that you have the correct meter and strips to check for ketones. Urine strips also detect glucose which appears in the urine if blood glucose levels are high, but the main point of urine testing is to detect ketones.

When ketones are present with a high blood glucose, this means more insulin is needed. This is discussed in detail in Chapter 10.

Non-invasive blood glucose monitoring

Non-invasive glucose monitoring has long been a goal, i.e., a method of measuring the BGL without having to prick the finger or place a probe under the skin. Instead, the glucose measurement is taken through the skin without puncturing it. Current techniques include using light, ultrasound, electrical signals, or measuring the heat generated by glucose metabolism.

This technology has been an area of research for many years. A range of devices have been released over the years but were pulled from the market, mostly because the glucose levels were unreliable. Several non-invasive glucose monitoring devices are being tested overseas but they are not yet approved for use in Australia.

There are still concerns about the accuracy of glucose readings from these newer devices. Many factors can affect a non-invasive glucose measurement including skin colour, sweat, light (indoor vs outdoor) and movement. Some devices use a combination of the different non-invasive measurement techniques to attempt to overcome this. All of the non-invasive devices still require calibration with fingerstick glucose levels.

Although none of the current devices are available for use in children with diabetes, this is an active area of research. Your diabetes team will keep you informed of new developments and their progress.

Common questions and answers

How accurate are blood glucose meters?

Blood glucose meters are not as accurate as laboratory blood glucose measurements, but if performed correctly, the degree of accuracy is perfectly fine and within 10 to 15 per cent. Many meters will give inaccurate results (read low) if not enough blood is applied. Using the same meter consistently will decrease any variation that occurs between different meters.

My child only checks their BGLs twice daily, at breakfast and dinner. Is this OK?

No. The minimum number of BGLs that are required for safety and to guide insulin adjustment is 4 per day and at least one overnight BGL a week. Children can tire of BGL monitoring and it is very important that you encourage and support your child to do their BGL checks.

My son will not keep a diabetes record book as he says the readings are all in the memory of his blood glucose meter. Is this a problem?

Some glucose meters can provide an electronic record, but the readings generally need to be downloaded to a computer before patterns can be seen. When a book is used, many readings are easily seen and give immediate feedback on how the diabetes is going. This means that it is easier to recognise when things go wrong and make adjustments. A bolus advisor app can provide an electronic logbook however it is important to ensure all of the glucose readings are being saved in the app. If preferred, computer-based versions of log books can be used.

It is important that you support your child/adolescent whenever they are doing their BGLs at home. Help them by writing the result in the book or recording it in the app for them. This also allows you a chance to review the results in a non- threatening way. You should review your child or adolescent's BGLs at least once a week.

For pump users, the pump system can serve as a complete record, provided that all BGLs are entered into or transferred into the system.

I worry that I cannot get all of the blood glucose readings in the target range. What am I doing wrong?

Probably nothing. It is impossible to get all readings in the target range in diabetes. There will always be a number of readings above, and occasionally some below. If most of the readings are in or near the target range you are doing well. If many readings are outside the target range, insulin doses need to be reconsidered. Your doctor will arrange a haemoglobin A1c check every three months which gives a check on overall diabetes control.

Does it matter if my child does not wash his hands before a blood glucose reading?

Yes, this could be a problem as food or drink particles on the fingers may give a falsely high reading and infection is more likely. If soap and water are not available, wet wipes are a good alternative. Make sure the hands are dried properly before checking.

My child has favourite fingerstick sites. Does this matter?

Yes. Favourite spots will often get thickened scar tissue and tend to hurt less, but the fingerstick sites will heal more slowly and infection may be an increased risk. The fingerstick sites should be spread around different fingers and always remember to use the sides of the fingertip. Some people do prefer not to use certain fingers and this is fine as long as they are being spread around a reasonable amount.

My child has difficulty getting enough blood for a fingerstick check. Any suggestions?

Make sure the fingers are warm and that the fingerstick is done in the correct position where blood can be squeezed toward the end of the finger. If blood is being squeezed toward the end of the finger you should see it getting redder, not paler. It may help to keep the finger below the level of the heart when doing a check. Some lancet (finger stick) devices have an adjustable setting – try adjusting this to a greater depth.

Should we be using CGM? Our son is not keen on the idea.

CGM has become more reliable in recent years. Many children and adolescents in Australia have started using it since the Australian Government began subsidising the devices in 2017. Good diabetes management can still occur with sufficient fingerstick BGL monitoring, so if you are not keen to pursue CGM, concentrate on getting a good amount of monitoring by fingerstick and looking for patterns. However, CGM can assist with additional glucose profiling and is especially popular amongst some pump users. It is also an option to use CGM for occasional periods for extra information, rather than continuously. Ask your diabetes team for the latest information.

My CGM and fingerstick glucose measures are different. Which one should I believe?

The fingerstick (blood) glucose level is generally more reliable than the CGM glucose level. This is because the CGM measures the glucose in the layer beneath the skin (the interstitial glucose). This glucose level can 'lag' behind the blood glucose level by several minutes. If your CGM indicates the glucose level is changing rapidly, this lag time may explain the difference between the sensor and fingerstick glucose levels.

If the fingerstick glucose level is consistently very different to the CGM glucose level, you should calibrate your CGM (if your system can be calibrated) or change the sensor. If these problems persist you should speak to your diabetes team and the manufacturer of the CGM system.

Remember, you should always confirm a high or low sensor glucose level with a fingerstick before treating.

If my child's BGL is normal does this mean they can't have ketones?

Ketones can occur if your child hasn't eaten for a prolonged period. They can also occur if your child's body hasn't been able to absorb enough nutrients due to vomiting or diarrhoea. These are sometimes called 'starvation ketones' and happen when there is not enough insulin **and** glucose. In this situation your child needs both carbohydrate and insulin. Starvation ketones are generally not as concerning as ketones seen with high blood glucose levels. This is discussed further in Chapter 10.

Chapter 8

Hypoglycaemia (low blood glucose levels)

Key Points

- Hypoglycaemia (a hypo) occurs when the blood glucose level is less than 3.9 mmol/l, or where there are symptoms of a hypo at a level close to this.
- Main causes of hypos are exercise, missed or delayed meals, not eating enough carbohydrate, or having too much insulin.
- To treat a mild or moderate hypo give approximately 0.3 grams per kilogram of body weight (or 10 to 15 grams total) of fast-acting carbohydrate (sugary food) such as:
  - glucose tablets or glucose gel 10-15 grams (not tablets in children under 5 years)
  - Lucozade 60-120 ml
  - ordinary soft drink or cordial 125-250 ml
  - fruit juice 125-250 ml
  - sugar or honey (two to four teaspoons)
  - jelly beans – 3 to 6 large or 6 to 12 small jelly beans (not in children under 5 years).
- The amount of glucose needed to treat a hypo depends on a child's size, insulin plan, recent insulin doses and recent exercise.
- In a severe hypo, the child may be extremely drowsy or disorientated or become unconscious or have a fit.
- To treat a severe hypo:
  - Do not give anything by mouth
  - Lie the child on their side
  - Give an injection of glucagon. Give 0.5 ml if preschool age, 1 ml if school age.
  - Call an ambulance if the situation does not improve quickly or you need help.

Hypoglycaemia (commonly called a hypo) occurs when the blood glucose level is too low. There is some debate in medical circles about an exact "cut-off" value that defines hypoglycaemia, however for practical purposes most would agree with a level of less than 3.9 mmol/l. Hypos can be graded according to whether they are mild, moderate or severe. Mild hypos are common and nearly all children experience these at times. Fortunately, severe hypos are rare, but you need to know how to deal with them just in case.

Symptoms of hypos

A hypo is a blood glucose level of less than 3.9mmol/l, or if your child has one or more of the following symptoms at a level near 3.9 mmol/l:

- paleness
- shakiness
- headache
- sweating
- feeling hungry
- dizziness
- heart pounding
- irritability, change in mood
- lack of concentration
- confusion, vagueness
- crying
- weakness
- blurred vision

Your child may show other symptoms, but these are the most common.

In severe hypos the blood glucose is very low. The child becomes very drowsy, extremely disorientated, aggressive, unconscious or may have a fit or convulsion (see below).

Infants and young children are usually not able to indicate that they feel unwell and may show few signs. Parents or carers may only recognise subtle signs such as paleness or irritability – if in doubt check the blood glucose level.

Hypo symptoms occur for two reasons:

1. The body produces chemical messengers (hormones) to attempt to raise the blood glucose level. Adrenaline is the main one and causes most of the symptoms.
2. The brain is not getting enough glucose to keep working normally.

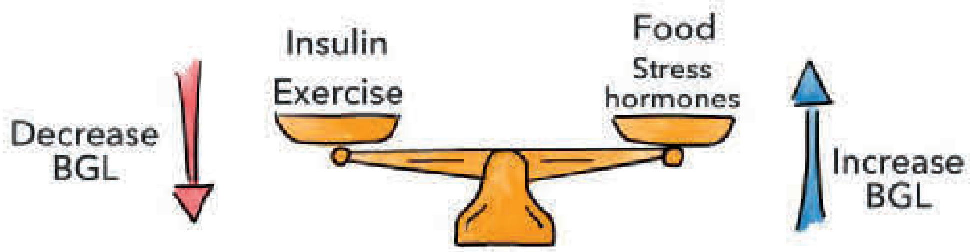
Unfortunately there is no foolproof way of recognising a hypo. When in doubt, checking the blood glucose level will tell you what is happening.

Not everyone feels the same when their blood glucose level is low and the symptoms and signs may not always be the same. However, most people with diabetes learn to recognise the feelings they have when their blood glucose is too low. Occasionally, some people have difficulty knowing because they don't feel different at all.

What causes hypos?

With diabetes, the blood glucose could drop low at any time, but a hypo is often related to an imbalance between insulin, food and exercise. To understand this, it is helpful to recall how each of these affects the blood glucose:

- insulin lowers blood glucose
- carbohydrate in food raises blood glucose
- exercise usually lowers the blood glucose



The main causes of hypos are:

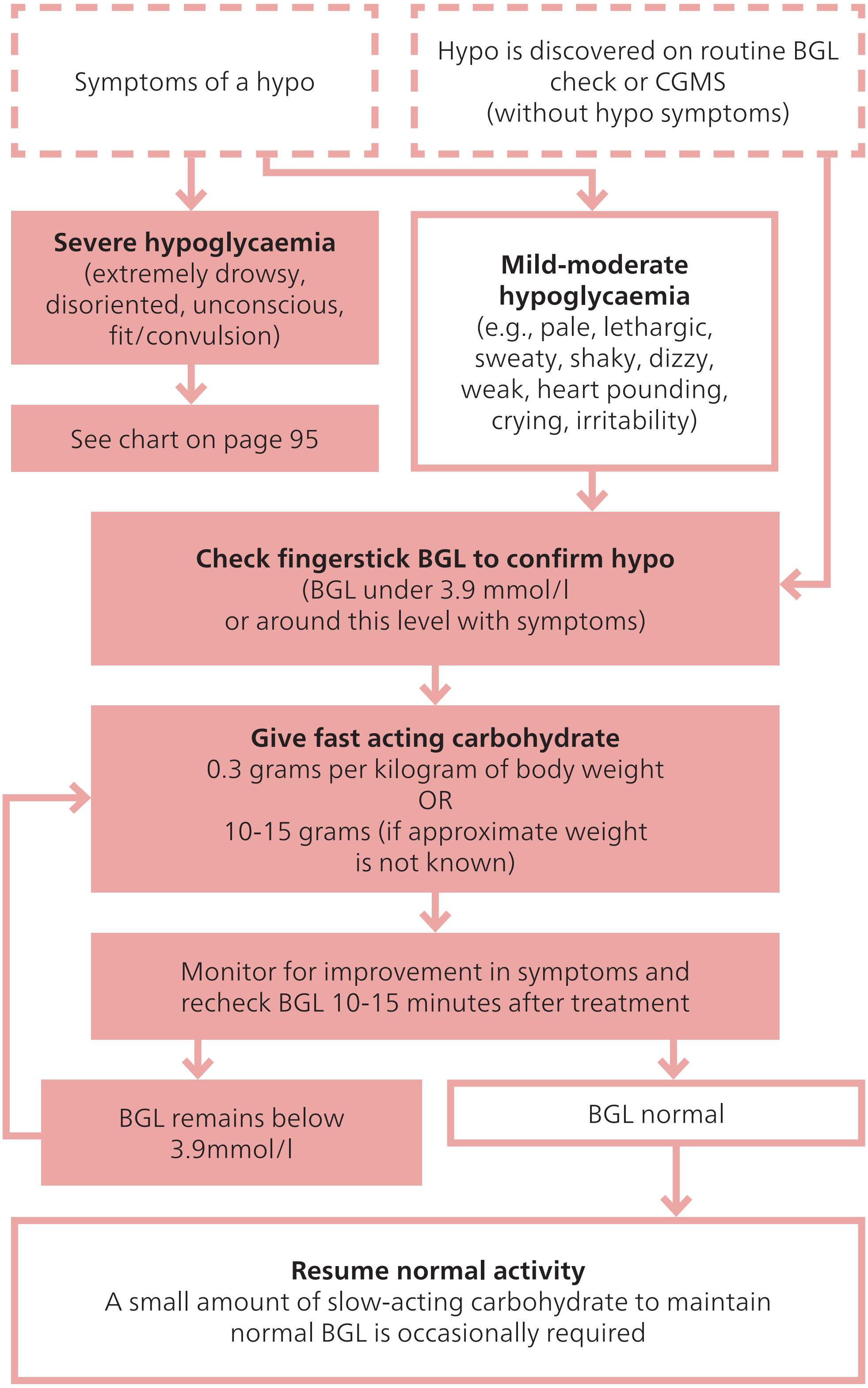
- **exercise, without decreasing the insulin or without eating extra carbohydrate**
- **missed or delayed meals, or eating too little carbohydrate at meals for the insulin dose given**
- **a recent dose of insulin was too much for the body's needs**
- **alcohol intake (see the section on adolescents in Chapter 16).**

Hypos can occur unexpectedly and for no obvious reason. Hypos are usually mild and the treatment is simple but sometimes they can be severe.

Mild to moderate hypoglycaemia

The flowchart on the following page outlines treatment for a mild to moderate hypo.

What to do for a mild or moderate hypo



Fast-acting carbohydrate will raise the blood glucose level quickly. This should be something that can be eaten or drunk quickly and easily and contain glucose or sucrose.

Examples of fast-acting carbohydrate (hypo treatment)
10 to 15 g of glucose tablets or glucose gel (take care with the amount as these may come in different sizes and strengths; tablets are not suitable for children under 5 years of age)
60 to 120 ml Lucozade (Lucozade contains 18 g glucose per 100 ml)
125 to 250 ml (approximately half to one cup) orange or fruit juice or ordinary soft drink (not a diet drink)
2 to 4 teaspoons of sugar or honey
3 to 6 large, or 6 to 12 small jelly beans (note, this is approximate since a variety of sizes are sold). Jelly beans, other sweets or glucose tablets are not advised in children under 5 years due to choking risk

Examples of fast-acting carbohydrate for treatment of hypoglycaemia

Some people find through experience that they may need to follow the fast-acting treatment with one exchange or serve of slow-acting carbohydrate to help maintain the blood glucose level. This is not necessary in most cases, especially in pump users.

Examples of slow-acting carbohydrate
One slice of bread
One exchange or serve of plain biscuits
One apple or one banana
250 ml (1 cup) milk

If a meal or a snack is due within half an hour of the hypo, give fast-acting carbohydrate to treat the hypo then recheck the BGL. If the BGL has corrected, you can then give insulin (if due) and give the meal or snack.

Important points about hypos

- Thinking about why the hypo occurred is important in deciding how much treatment to give – more glucose / carbohydrate treatment is likely to be needed if an insulin dose or bolus has just been given or if vigorous exercise has been occurring.
- Foods to treat hypos should always be carried by the family or child or be readily available (e.g., with the teacher at school, in the car or in a handbag).
- When a young person is having a hypo, they should remain supervised until recovered and should not be left alone at any time. The hypo treatment should be with the child or brought to the child; the child should not be sent away to get the hypo treatment.
- The person should wear an identification bracelet or necklace indicating that they have diabetes or at least carry some form of identification (e.g., wallet card) indicating diabetes.
- Babies and toddlers may require less carbohydrate to treat a hypo – your diabetes team will discuss this with you. Teenagers and adults need more carbohydrate than young children to treat a hypo.

- Infants and young children are best given fluids to treat hypos initially. Jelly beans, lollies or glucose tablets may be a choking risk.
- Always keep a close eye on your child after a hypo. If the child is not improving after 10 to 15 minutes, recheck the blood glucose level and repeat the hypo treatment if necessary.
- Avoid the tendency to over-treat mild hypos, as this causes large blood glucose peaks (sometimes called rebound highs) that will affect overall control. A hypo can provoke a strong urge to continue to eat in some people, so be mindful of this. If using an insulin pump and the child is hungry after a hypo, you must bolus as normal for the carbohydrate to be eaten once the BGL has corrected back to target.

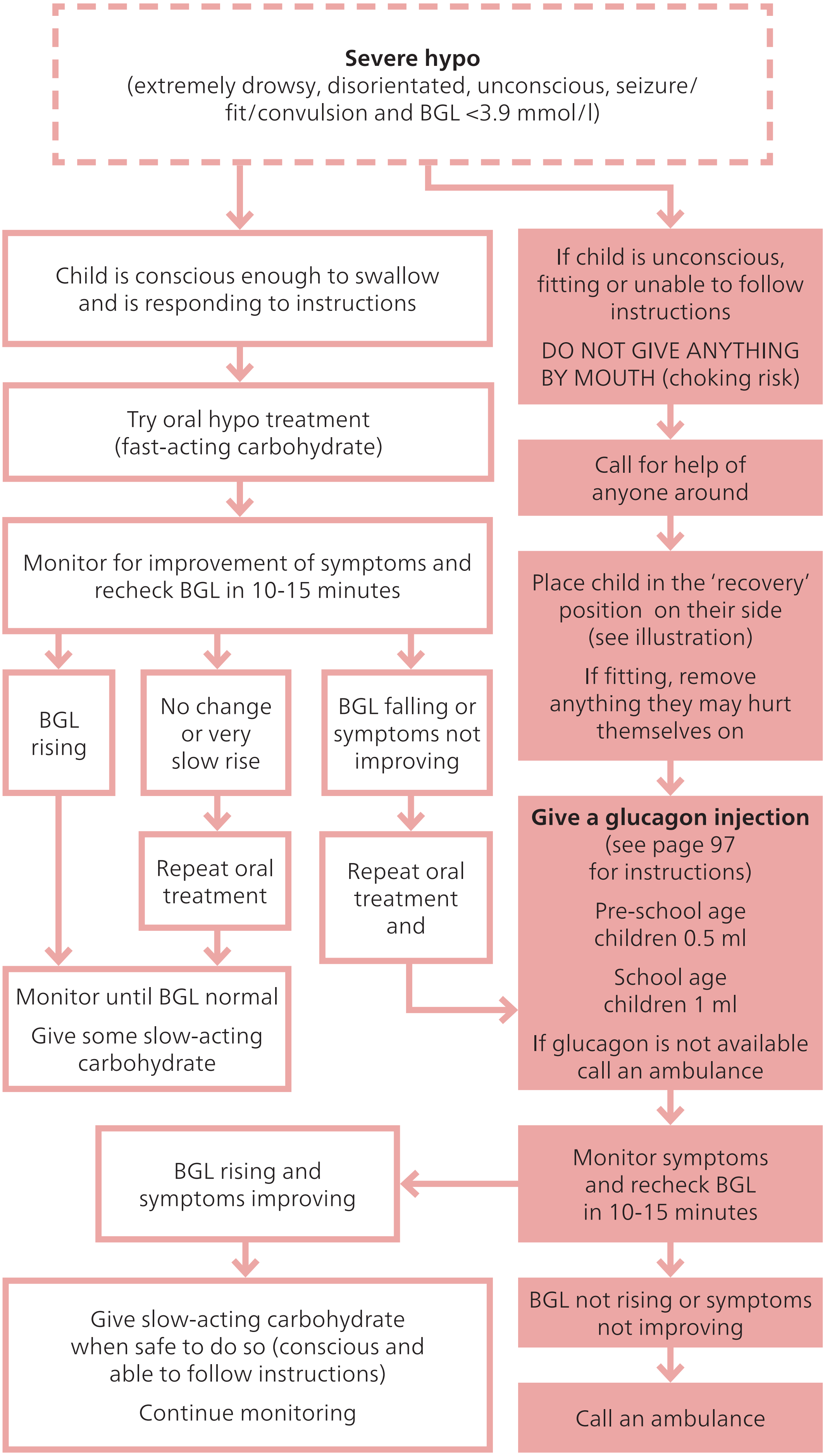
Severe hypoglycaemia

Symptoms of a severe hypo:

- Extremely drowsy or disoriented
- Unconscious, or
- Having a fit or convulsion

Management of severe hypoglycaemia is outlined in the flowchart on the following page.

What to do for a severe hypo



Important points about severe hypos

- A judgment needs to be made about whether or not to try treating with sweet foods or drink. The child needs to be conscious enough to be able to swallow. If the child is too drowsy or disorientated to understand what you are saying or does not respond to simple instructions then nothing should be given by mouth.
- **Do not try to give anything by mouth if the child is unconscious or fitting – glucagon is needed.**
- The 'recovery' (coma) position is the safest position for someone who is unconscious. It protects their airway and helps prevent them choking. See the illustration below for the correct position. Do not place a pillow under the child's head. If the child is having a fit or convulsion do the same thing. Do not attempt to place anything in the mouth. Lie the child on their side and stop them from hurting themselves.

Correct position to place an unconscious child

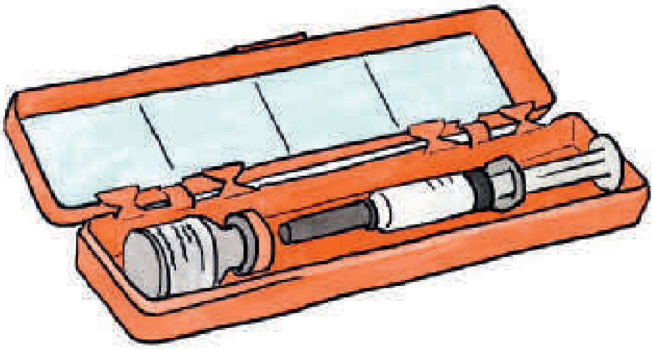
- Glucagon is a life-saving treatment for severe hypoglycaemia. Glucagon is a hormone that raises the blood glucose level by making the liver release its store of glucose. All families should keep glucagon at home and carry it when they travel.
- If two adults are available one should stay with the child while the other gets the glucagon. Don't be afraid to give the glucagon – it can't do any harm, it can only do good in the case of a severe hypo. Your child cannot overdose on glucagon so don't hesitate to give it. Continue to monitor BGLs after giving glucagon, the BGLs will rise in approximately 5-10 minutes.
- Call an ambulance if the situation does not improve quickly or you need help. The emergency number in Australia is 000 and in New Zealand is 111. The ambulance officers will decide if your child needs to go to hospital or is recovering satisfactorily.
- If your child uses an insulin pump the pump can be disconnected (using the quick-release) although this is not essential.
- Always contact your diabetes team for advice after a severe hypo. It is important to think about why the severe hypo occurred and how to prevent further episodes.

Giving a glucagon injection with the GlucaGen hypokit (Novo Nordisk)

The GlucaGen Hypokit contains a synthetic form of glucagon and comes in a kit with everything that you need. Remember to check the expiry date of your glucagon periodically and obtain a new supply just before the old one expires. While keeping or using expired glucagon is not recommended, if you find that the glucagon is past its expiry date and a severe hypo occurs, you should still give the glucagon as it is likely to work and will cause no harm.

A glucagon injection is given as follows:

1. Remove the orange cap from the bottle.
2. Remove the grey needle guard.
3. Inject all the sterile water from the syringe into the bottle containing the powder (the glucagon). Leave the syringe in the bottle.
4. Swirl (don't shake) the bottle with the syringe in it until the glucagon has dissolved (leave your finger on the plunger to stop it coming back).
5. Draw up all the glucagon (1 ml) for a school-age child, or half the glucagon (0.5 ml) for a pre-school age child.
6. Inject into the front of the thigh or buttock (upper, outer part of buttock) just as you would an insulin injection. You will see that the needle is longer than an insulin needle so that the glucagon goes in deeper to the muscle layer where it works best.
7. Do a blood glucose level.



A GlucaGen (glucagon) Hypokit

Recovery from a severe hypo

- The child will usually wake in about five to ten minutes. If a fit has occurred it is usually short and does not cause permanent damage.
- When the child is awake, give sips of ordinary soft drink or other sweet drink and when possible follow this with some slow-acting carbohydrate food. Try to avoid over-feeding and be guided by BGL levels.
- A severe hypo or the glucagon treatment can make your child vomit. They may also have a headache. Continue to give sips of sweet drink.

- Monitor the blood glucose level frequently (every 15-30 minutes).
- Your diabetes educator should be contacted when next available.
- Do not omit the usual insulin injection after the hypo but seek medical advice as to ongoing insulin doses if unsure.
- Blood glucose levels are often high soon after a severe hypo. This should not be treated with extra insulin.
- The ambulance should be called if things do not improve quickly or you just want some help – state that your child has diabetes and has had a severe hypo and is fitting or unconscious. The ambulance officers will help as needed, but if the child is recovering well, a trip to hospital is not always necessary.
- Remember to replace your glucagon as soon as possible.

Mini-dose glucagon treatment

Mini-dose glucagon is a special way of using low doses of glucagon by subcutaneous injection when there is a continuing tendency to low glucose levels, but not severe hypoglycaemia. This is in a situation where your child is unwell, but not seriously unwell and not persistently vomiting. This is also discussed in Chapter 10. This treatment is not commonly used anymore, however it can help you get through a difficult period of lowish BGLs and may help avoid a trip to hospital. Your diabetes team will advise if this might be appropriate for your child.

For severe hypoglcemia (drowsy, coma or seizures), it is very important however, that full doses of glucagon are given as outlined above and not mini-dose glucagon.

How often do hypos happen?

Many hypos are preventable; however, mild hypos are common. A person with good diabetes control may have a few mild hypos each week. Severe hypos are much less common and many children with diabetes never have a severe one. Hypos (especially severe hypos) are becoming less common as the technology for monitoring glucose levels and insulin pump technology improves.

When a hypo occurs, it is always wise to consider what may have caused it. This is usually delayed or missed food or increased activity or exercise without taking more food or less insulin. Some hypos happen for no apparent reason.

If any of the following are happening, it is likely that insulin adjustment is needed and if in doubt you should contact your child's diabetes educator or doctor:

- More than three or four hypos per week, especially if no reason evident
- Hypos are tending to occur at the same time each day
- Any severe hypo
- Night hypos, especially if no reason is evident

Night hypoglycaemia

It is important to remember the possibility of hypos at night. They are more likely to occur after a lot of exercise during the day or if the child has eaten poorly or is unwell. Sometimes children wake with hypos at night, but often they can sleep through and the hypo remains undetected. Recurring night hypos can be dangerous and contribute to memory and concentration problems. Fits or convulsions at night are a risk. The following will help to prevent or minimise night hypos:

- Regularly checking the blood glucose level at the child's bed time or in the late evening aiming for a level of 5 mmol/l or above. If less than 5 mmol/l, some extra slow-acting carbohydrate should be given, for example 5-20 g. The amount needs to be judged according to the circumstances of the day and past experience, e.g., give more if the child has had a very active or low BGL day, less if the BGL is close to 5 mmol/l, more for larger children etc.
- If BGL is less than 3.9 mmol/l before bed, treat as a hypo with fast-acting carbohydrate. Depending on the situation (as above), this may be followed by slow-acting carbohydrate. If low during the evening, it is wise to re-check the BGL at 2-3 am.
- Some need to have a higher target BGL before bed – your diabetes team will advise if this is needed.
- Occasionally (e.g., three or four times per month) check the blood glucose level when the child is asleep in the late evening (around 11 pm) and/or at 3 am. The blood glucose level should generally be above 5 mmol/l overnight.
- Pre-bed, late evening or overnight blood tests should especially be considered if the child has exercised a lot that day or evening, has eaten poorly, is unwell or if the long-acting or dinnertime insulin doses have recently increased.
- Some families find it necessary to reduce evening insulin doses after sport or exercise to prevent delayed night time hypos (see Chapter 11) or, if using a pump, to use a lower temporary basal rate overnight.
- Alcohol intake increases the risk of night hypoglycaemia.
- Some children in the honeymoon phase (soon after diagnosis) may have lower BGLs overnight (e.g., 3.5 to 4 mmol/l) which is not hypoglycaemia because their pancreas is still producing some insulin. Your diabetes team will discuss this with you.
- CGM is excellent for monitoring overnight glucose levels continuously and allows alarms to be set. Pump models that use CGM as part of a hybrid closed loop system reduce the risk of hypoglycaemia significantly as the system can adjust insulin delivery to reduce the risk.

Hypoglycaemia unawareness

This means that hypoglycaemia is occurring (as measured by BGL or observed by others), but the person with diabetes is not aware of it.

Toddlers and young children frequently do not sense hypos well or cannot tell you about them and therefore detecting hypos relies on those caring for them. Children will gradually learn to recognise and express their hypo symptoms. After a hypo, encourage them to tell you how they felt to help them learn.

In older children and adolescents, hypoglycaemia unawareness can develop if they have a period where they are having too many hypos or frequent overnight hypoglycaemia. This arises because the body's defence mechanisms against hypos (such as adrenaline) reset their level at which symptoms will be produced. This can be a dangerous situation because severe hypos may come on suddenly without the usual warning. If hypos are occurring without symptoms, you should contact your doctor or educator for advice. Fortunately this is a fairly uncommon problem with modern diabetes management and can usually be fixed by adjustment of insulin doses. Avoiding lots of hypos or long hypos minimises the risk of hypo unawareness arising. It is usually necessary to run the blood glucose levels a little higher for a period to restore normal hypoglycaemia awareness.

Newer technology for hypoglycaemia prevention and management

There has been a rapid expansion in recent years in technology aiming to prevent hypoglycaemia or detect it early enough to avoid a prolonged or severe hypo.

Continuous glucose monitoring systems (CGMS or CGM)

CGMS have the ability to detect hypoglycaemia or a rapidly dropping glucose level. Alarms can be programmed to alert the user to a low glucose level and when they are rapidly approaching hypoglycaemia. This is particularly useful as a safety net to detect hypoglycaemia at night – see Chapter 7.

Sensor-augmented insulin pump therapy and hybrid closed-loop

Some types of CGMS and insulin pumps can 'communicate' with each other so that insulin delivery can be automatically adjusted to avoid hypoglycaemia. A low glucose suspend ('suspend on low') is where the pump stops delivering insulin when the CGM sensor detects hypoglycaemia. A predictive low glucose suspend ('suspend before low') is where the pump stops delivering insulin when the algorithm calculates that the user is rapidly approaching hypoglycaemia (to avoid the hypo).

One step further is hybrid closed-loop therapy, when the basal insulin delivery from a pump is constantly adjusted to keep the sensor glucose level in the normal range. These pump features are discussed in detail in Chapter 13.

Intranasal glucagon

Baqsimi (Eli Lilly) is a type of glucagon that can be given through the nose (intranasally). It has been developed as an alternative to the injectable form for treating severe hypoglycaemia. Many families may find giving an emergency medication intranasally easier than giving an intramuscular injection. At the time of publication of this book, Baqsimi had been approved for use overseas but was not yet available in Australia. It is likely to become available in the near future.

Common questions and answers

My four-year-old doesn’t have many hypos, but when he does, he doesn’t seem to recognise them. What should I do?

Young children are often not good at recognising hypos, and even if they do feel ‘funny’ they may have trouble knowing what this is or expressing it. With time they usually learn what it feels like and are able to tell you. When a hypo occurs, after treating it spend a few moments asking how the child felt and whether they felt any symptoms. This can help the learning process.

CGM would also be helpful to detect hypoglycaemic episodes and identify patterns.

My seven-year-old daughter seems to be having hypos at school every morning and asking the teacher for jelly beans. The teacher says she looks OK, but treats it as a hypo because she is worried. What should I do?

It may be hypoglycaemia, but some children can go through a stage of saying they are low to get lollies. The only way to sort out what is happening is to test the blood glucose at these times, and where possible always test before treating a hypo. It may also be wise to change the hypo treatment you have available at the school (e.g., juice boxes are a good alternative).

How many hypos is too many?

Most children have occasional mild hypos, often up to four per week. Usually there is a logical explanation such as extra activity or eating less. If more than this number is occurring, if there is no explanation for frequent hypos or there are any severe hypos, some adjustment to the diabetes management may be needed. Contact your educator or doctor if unsure.

I have heard that glucagon can make children vomit. Should I try not to use it if possible?

In a severe hypo where the child is unconscious, fitting or too drowsy or uncooperative to take anything by mouth, you must give glucagon in the full recommended dose. It can do no harm and will raise the blood glucose. It is true that afterwards there can be some nausea and vomiting but that can be easily dealt with.

My daughter gets a bad headache after hypos. What should we do?

This is not uncommon, and the best thing to do is rest. If necessary, a dose of paracetamol will help.

My 15-year-old son is very particular about his diabetes control and always has excellent blood glucose levels. In the past three weeks he has had three major hypos which came on without warning. Luckily we were there to treat him. What is happening?

This is hypoglycaemia unawareness, and can happen if the blood glucose levels are generally running too low. The body does not produce a hypo response until the blood glucose becomes very low, and then it is too late for the person to respond. The problem can be corrected by adjusting the insulin so that the blood glucose levels are in a more normal range and he may need to run his BGLs a little higher for a while. If this is happening you need to contact your educator or doctor as soon as possible.

We worry about our daughter having a hypo at night, and possibly having a fit. How can we avoid this?

The risk of night hypos can be minimised by checking the blood glucose before bed, and if the level is less than 5 mmol/l or falling rapidly, having some extra supper. It is wise to periodically check some blood glucose levels at night, either in the late evening or middle of the night. It is especially a good idea to test in the late evening or overnight if your child has exercised a lot that day, eaten less or is not well. Reducing the evening dose of insulin after vigorous sport or exercise will also help reduce the risk of night hypos. For some insulin plans, having some supper is important to reduce the risk of night hypos.

The availability of CGM (continuous glucose monitoring) also allows night BGLs to be monitored and can be used regularly or occasionally to check the overnight BGL profile. Pump systems with hybrid closed loops control overnight BGLs extremely well and significantly reduce the risk of night-time hypoglycaemia.

How can we tell if our child is having a hypo at night?

Children sometimes wake up if they are having a hypo and they may have a bad dream. If your child has had a restless night or wakes up feeling unwell you should be suspicious of hypos and think about overnight testing. Some night testing is recommended for all people with diabetes.

Chapter 9

Hyperglycaemia (high blood glucose levels)

Key Points

- **When blood glucose is above 15 mmol/l:**
  - **Try to identify possible reasons**
  - **If your child is unwell or if the blood glucose remains above 15 mmol/l, test the blood (or urine) for ketones**
  - **If blood glucose remains high and there are ketones present, extra insulin is needed**
  - **Drink extra (sugar-free) fluids**
  - **Pump users must always respond to high BGLs without delay**

Hyperglycaemia or a high blood glucose is when the blood glucose is higher than the target range. Target blood glucose ranges were discussed earlier, but are included here as a reminder.

Recommended target ranges

The target range for blood glucose levels is 3.9-10 mmol/l.

Preferred ranges at particular times include:

Before meals: 4 to 7 mmol/l
After meals and before bed: 5 to 10 mmol/l
at 3am: 5 to 8 mmol/l

Nearly all people with diabetes have some blood glucose readings above the target range. Often this will be just a short-term rise (a few hours) and then the blood glucose levels fall to the desirable range.

Why blood glucose levels may be high

There are a number of reasons why the blood glucose readings may be high. These include:

- Eating extra carbohydrate foods.
- Less exercise than usual.
- Sometimes temporarily during or just after vigorous exercise (stress effect).
- Measuring the blood glucose too soon after a meal – usually wait two hours after eating.

- The insulin dose may be too low or may have been forgotten.
- Emotion, such as excitement or stress.
- Infection or other illness.
- Glucose on the fingers will give a falsely high reading; if this is suspected, wash the hands and re-check the blood glucose level.
- Insulin pump users – there may be a problem with the infusion set or function of the pump (see Chapter 13).

What to do about high blood glucose levels (above 15 mmol/l)

A high blood glucose is a cause for concern. If the BGL is over 15 mmol/l then you should try to find a cause (from the list above). If the BGL has been elevated for more than 2 hours or there are symptoms such as thirst, increased urination, excessive tiredness or feeling unwell then ketones should be assessed.

Usually an injection of rapid or short acting insulin (or correction bolus for pump users) should be given to return the BGL to the normal range. The only times that extra insulin should not be given is if the high BGL is due to a stress response during or immediately after exercise (the BGL will usually come down by itself) or if it was due to sugar on the fingers. If your child is due to have a meal soon (e.g., within the next hour) and is otherwise well, you may wish to wait and incorporate the correction insulin dose into their usual mealtime dose (rather than giving the two injections close together).

If BGL remains persistently elevated (above 15 mmol/l) for a number of hours and is not corrected, the following are likely to occur:

- symptoms such as increased thirst, increased urination and excessive tiredness.
- ketones are likely to develop.
- the child could become sick with ketoacidosis (see Chapter 10 ‘Sick days’).

General responses to high BGLs are similar, but there are some differences according to whether treatment is with injections or an insulin pump. This is outlined below and in more detail for pump users in Chapter 13.

Do the following with any high blood glucose levels:

If receiving insulin via injections

- Repeat the blood glucose level in about 2 hours. You may have given an extra injection or may be expecting a spontaneous fall – in either case a repeat BGL is a good idea.
- If your child is unwell (e.g., fever, vomiting, listless etc) or if repeat blood glucose level is still above 15 mmol/l, then test for ketones.
- If the blood glucose is above 15 mmol/l and there are ketones present, extra insulin is needed (see Chapter 10 'Sick days').
- Even if ketones are not present, consider giving an extra dose of rapid or short-acting insulin to correct the BGL – again, follow the guidelines in Chapter 10 and Chapter 12.
- Drink plenty of fluids when the blood glucose is high; drink water or diet (sugar-free) drinks. This helps to lower the blood glucose and prevent dehydration.
- Try to identify possible causes (e.g., illness, missed insulin dose or others as above).
- Look to see if there is a pattern of the blood glucose rising at the same time each day – in this case an increase in the appropriate insulin dose should be considered.
- Avoid strenuous exercise if the BGL is high, especially if ketones are present. If the body is lacking in insulin, exercise will not bring the BGL down (see more information in Chapter 10 'Sick days' and Chapter 11 'Exercise and sport').
- It is important to check the blood glucose level after an extra insulin dose to make sure it is satisfactory. Be careful with giving extra doses of short-acting insulin before exercise (the exercise may bring the glucose level down), in the evening, at bedtime or overnight. At these times it is essential that the BGL is checked 2 to 3 hours later.

If receiving insulin via a pump

- High blood glucose levels always need to be addressed without delay in pump users, since there is no pool of long-acting insulin in the body to help protect against ketosis and ketoacidosis.
- Full details are given in Chapter 13, but outlined here
- If BGL is above 15 mmol/l, do the following:
  - Immediately check for a problem with the infusion set or pump delivery.
  - Check the blood for ketones (urine ketones if blood strips are not available).
  - If ketones are negative (less than 0.6 mmol/l in blood or negative or trace in urine), a correction bolus can be given with the pump. If there is any doubt about the infusion set, this should be changed.
  - If ketones are positive (more than 0.6 mmol/l in blood or small, moderate or large in urine), a correction dose of insulin should be given with a pen. Refer to the flowchart in Chapter 13 for dosing advise. Do not rely on the pump at this point – regain control with injections and then sort out any pump or delivery set problems later.
  - Think about causes as outlined above, e.g., missed boluses.
  - Drink extra fluids (water or sugar-free) and avoid strenuous exercise until the BGL is settling.

Common questions and answers

My three-year-old receives insulin via injections and sometimes has blood glucose levels around 16 to 18 mmol/l. Should I give him extra insulin at these times?

Usually, yes. High BGLs are usually caused by insufficient insulin for the food that has been eaten. This is corrected by an appropriate extra dose of insulin or 'correction bolus'. If he is well, check the BGL 1-2 hours later. If BGL remains above 15 mmol/l, or he is unwell in any way, check for ketones. If the blood glucose stays up or there are ketones present or he is unwell – refer to the guidelines in Chapter 10 'Sick Days' and Chapter 12 'Insulin Adjustment'. Check with your doctor or educator if unsure.

When we check our daughter's blood glucose level before supper and bed it is often high, but this is only about one hour after her dinner. What should we do?

The blood glucose will often be elevated just after a meal. Leave the test until at least two hours after a meal where possible, even if this means testing after she has gone to bed. This is a better guide to whether the insulin needs adjusting.

My son's BGLs are often high despite increasing the insulin dose, and my educator suggested that he may not be giving his insulin. I am not happy about this suggestion because my son is a good boy and he knows that he needs his insulin.

Insulin omission happens at times, not only with children and teenagers but adults as well. Children and adolescents will sometimes omit insulin if they are not helped or supervised with their injections or pump boluses. The reason children and adolescents miss some insulin is due to an inability to prioritise and plan because they have not yet reached this stage of brain development. This inability to do injections or boluses without assistance is not the child/adolescent being 'bad'; it is expected if they don't receive enough help and supervision. Also, giving insulin every day is hard work and to do it in the long term, the person needs support from their family and friends.

We recommend that you support your child or adolescent on a daily basis with their injections or pump boluses. When at home, the pre-meal BGL and the meal content should be discussed together and entered into the record book, pump or bolus advisor app. There can be discussion of the appropriate dose of insulin and the need for any adjustments and the dose can be checked and administered. Cross-checking doses will reduce errors and ensures that they are done accurately. Children and adolescents should not go away into another room unsupervised to test BGL or deliver insulin. At school, it is also best when possible to have someone assisting with supervision of BGL monitoring, recording and insulin administration.

My 12 year old daughter is on an insulin pump. If the BGL is a little high before bed (for example 16 mmol/l), can we just wait to see if it settles overnight?

No, this situation needs attention now. Insulin pump users do not have any pool of long-acting insulin in their system, so are prone to more rapid development of ketones or ketoacidosis if there is interruption to insulin delivery. Check the infusion set and pump for delivery issues, check the blood (or urine) for ketones and sort out the situation as outlined here and in Chapter 13 before going to bed. An additional BGL check during the night is also likely to be needed, but progress can also be monitored via CGM (if using).

Chapter 10

Sick days

Key Points

- Illness may cause high blood glucose levels or low blood glucose levels:
  - Infections with fever often cause high BGLs
  - Gastroenteritis (vomiting and diarrhoea) illnesses often cause low BGLs
- If high blood glucose levels are not treated, ketones will develop and your child could become very sick with diabetic ketoacidosis (DKA)
- Treat the underlying illness. See your doctor if concerned
- Measure blood glucose more often, every two hours at first
- Drink more fluids:
  - Sugar-free fluids if the blood glucose level is above 8 mmol/l
  - Fluids containing carbohydrate if the blood glucose level is below 8 mmol/l.
- Check for ketones regularly if the blood glucose level is above 15 mmol/l
- Do not omit or stop insulin: if blood glucose levels are low, less insulin may be needed.
- If the blood glucose level is above 15 mmol/l and ketones are present, extra rapid acting insulin is needed – this section tells you how to work out the extra dose. Sometimes extra insulin will be needed if the BGL is 8-15 mmol/l.
- Insulin pump users need special precautions – more detail in Chapter 13
- Call for advice or go to the hospital if:
  - you are unsure what to do
  - vomiting persists
  - you are unable to keep the blood glucose level above 4 mmol/l
  - you are unable to get blood glucose level below 15 mmol/l with extra insulin doses, or unable to clear ketones
  - the child is becoming more unwell
  - you are worried or exhausted or don't know what to do next

Sick days – introduction

Children and adolescents with well controlled diabetes are not at greater risk of getting sick with infections or other illnesses. However, when children with diabetes do get sick, much greater care and attention is required. If the guidelines in this section are followed, most sick days can be dealt with at home.

Sick days can cause:

- **High blood glucose levels**

  These are more common during illness, particularly in viral illnesses with fever (e.g., influenza or a bad cold) or in bacterial illnesses (e.g., tonsillitis or ear infections). The blood glucose levels rise as 'stress' hormones are released to help the body cope with illness; however, these stress hormones work against insulin and the normal insulin given does not work as well (insulin resistance). Blood glucose levels will often still be high even if the child's appetite is poor because of continuing release of glucose from the liver.

- **Low blood glucose levels**

  This is likely to occur in stomach and bowel illnesses (gastroenteritis) with nausea, vomiting and especially diarrhoea but without other general symptoms such as fever. The blood glucose levels are low because the child's appetite is often decreased and the food and drink that is taken is not being well absorbed.

If, during illness, high blood glucose levels are not treated:

- Ketones will develop in the blood .
- The body is likely to become dehydrated (high blood glucose levels drag fluid out of the body into the urine).
- Severe illness with diabetic ketoacidosis (DKA) may occur – see below.

Knowing how to manage sick days should prevent any major problems like this developing.

The goals of sick day care are to:

- prevent dehydration.
- prevent diabetic ketoacidosis (high levels of sugar and ketones in the blood).
- prevent hypoglycaemia (low blood glucose levels).

What are ketones?

Ketones are chemicals in the blood which come from the breakdown of fat. The body makes ketones as an alternative energy source to glucose in some situations. When there are ketones in the blood they will also be found in the urine and thus a urine test can also be used to identify ketones.

Ketones in the blood usually indicate that there is too little insulin in the body.

Two situations can occur:

1. **Glucose levels are high:**

   This is the commonest situation. Even though the blood glucose level is high, the body cannot use glucose for energy because of the lack of insulin. Thus, fat is broken down to form ketones as an alternative energy supply. This can happen during illness or when insulin doses are too low or have been missed. When the blood glucose is high (above 15mmol/l), ketones in the blood or urine are a warning sign that the body needs more insulin. If ketones continue to build up, the child can become very sick with diabetic ketoacidosis.

2. **Glucose levels are normal or low:**

   Here the body is lacking insulin **and** glucose. These are sometimes called **starvation ketones** and they can happen in stomach and bowel illnesses with vomiting and diarrhoea where not enough carbohydrate is being absorbed. In this situation more glucose intake is needed, so that insulin doses can continue to be given to turn off ketone production. If this extra glucose cannot be taken by food or drink, a stay in hospital may be needed. In illnesses with low blood glucose levels, insulin doses should not be stopped or omitted, but may need to be lowered (see below).

	Reason for raised ketones	**Action required** (see flowcharts on pages 115 and 117 for details)
High BGL	Lack of insulin	Requires extra insulin
Normal BGL	Lack of insulin **and** glucose (starvation ketones)	Requires additional carbohydrate and usual insulin doses
Low BGL	Lack of insulin **and** glucose (starvation ketones)	Requires additional carbohydrate. May require reduced insulin doses (do not stop insulin)

Ketones generally do not need to be checked in diabetes when the blood glucose level is low, provided there is a clear reason for the low glucose levels (e.g., poor intake, vomiting or diarrhoea). This is because the treatment for the low glucose level would be the same either way (give carbohydrate and continue insulin, possibly at reduced doses).

Ketone levels should **always** be checked in an unwell child with a raised BGL.

What is diabetic ketoacidosis?

Diabetic ketoacidosis (DKA) is a serious illness that occurs when the blood glucose and ketones in the blood are very high and the person becomes very dehydrated, often with nausea, vomiting, abdominal pain, laboured breathing and unusual smelling breath (similar to nail polish remover or acetone). The blood becomes too acidic because of a build-up of ketones and there is great loss of body salts and fluid. DKA occurs when high blood glucose levels and a lack of insulin are present for many hours due to illness or missing insulin doses. DKA requires urgent hospitalisation and treatment. Untreated DKA can cause severe illness or death.

How to check for ketones

Checking for ketones in the blood

Meters are available that allow for measurement of ketones as well as glucose in the blood.

Measuring the blood ketones is a similar procedure to measuring blood glucose, except a different strip is inserted into the machine. The machine will report the amount of ketones (beta-hydroxybutyrate) in the blood as a number. These numbers can help you tell if there are no ketones, small, moderate or large ketones according to the table below.

Blood ketone reading (mmol/l)		
	Less than 0.6	Negative or trace only
	0.6 to 1.5	Small to moderate ketones
	Above 1.5	Moderate to large ketones (the higher the number, the more ketones)

Refer to the information below for how to respond if there are small, moderate or large ketones in the blood, depending on the BGL. Extra insulin is likely to be needed.

Checking for ketones in the urine

Urine ketones are generally only measured if blood ketone measurement is unavailable.

This is done using urine test strips, as follows:

1. Check the expiry date of the ketone test strips. Some brands of strips also measure the amount of glucose in the urine, which will be high if the blood glucose has been high. Out-of-date strips or strips that have not been stored well-sealed may not work properly. If the strip does not read negative before you use it, it is spoiled and should not be used.
2. Let some urine run over the test strip by passing urine directly onto the strip or collecting a small amount of urine in a container and dipping the strip.
3. After the time specified on the test strip bottle, compare the colour of the strip with the chart on the side of the bottle. Timing is important to get the correct reading.
4. The urine ketone reading will be either:

   Negative – no colour change

   Trace – just a slight colour change (slightly pink)

   Small (+, 1 mmol/l or 10 mg/dl also shown on bottle)

   Moderate (++, 5 mmol/l or 50 mg/dl also shown on bottle), or

   Large (+++, 15 mmol/l or 150 mg/dl also shown on bottle)
   – strong purple colour

Checking the colour of a ketone strip against the chart on the bottle

When to check for ketones

Always check for ketones in the following circumstances:

- If your child is unwell and the BGL is above 15 mmol/l.
- If your child is complaining of tummy pains or nausea, vomits, is breathing heavily/panting or has 'smelly breath'.
- If using injections and the BGL remains persistently above 15 mmol/l. Recheck the BGL in about 2 hours and check for ketones then if the BGL remains above 15 mmol/l.
- If using an insulin pump and BGL is above 15 mmol/l, always check for ketones without delay (refer to Chapter 13).

When to re-test:

- Follow the flowcharts on pages 115 and 117. In general, if ketones are present on the initial check and BGL remains above 15 mmol/l, check again for ketones in about 2 hours. Checking for ketones more often than this is usually not helpful.

Always be concerned when ketones are present and the BGL is above 15mmol/l. The more ketones there are, the more cause there is for concern.

Guidelines for sick days

1. Take care of the underlying illness: Children often get minor illnesses, but with any significant illness your doctor should be consulted for advice.
2. Relieve symptoms: Paracetamol or ibuprofen can be used to treat fever, headaches or other discomfort. Your doctor may also advise other medications for specific illnesses. Many medications for children are available in sugar-free formulations (e.g., paracetamol, most antibiotics); however, even if they contain sugar the amount is not sufficient to cause problems and the medication should be given as prescribed. Some continuous glucose monitoring systems are unreliable if paracetamol has been given. Blood glucose checks should be done by fingerstick in these cases.
3. Measure the blood glucose more frequently – every two hours initially, but every hour if the blood glucose is low.
4. Check for ketones if the blood glucose level is more than 15 mmol/l. If any ketones are present, continue to check each two hours or so for ketones until negative.
5. Drink more fluids:
   - If the blood glucose level is more than 8 mmol/l, drink water or sugar-free drinks.
   - If the blood glucose is less than 8 mmol/l, drink liquids containing carbohydrate (e.g., fruit juice, normal soft drinks, icy poles, normal sweet jelly).
   - Give your child small drinks frequently, rather than large drinks occasionally.
   - Often there will be no appetite for food – don't worry about this, but make sure to keep up plenty of fluids to avoid dehydration. As a guide try to get your child to drink half to one cup of fluid over each hour.
6. **Do not stop insulin.** It is especially important that long acting insulin (or basal insulin for pump users) is still given. If blood glucose levels are low, you may need to lower the usual doses of both long acting (basal) and short acting (bolus) insulin. Pump users may run a lower temporary basal. Sometimes in this situation insulin doses may need to be reduced by 30 per cent or more.
7. Give extra insulin: If the blood glucose level is above 15 mmol/l and ketones are present, extra rapid insulin is needed. Sometimes extra insulin will be needed if the BGL is 8-15 mmol/l and there are persistent ketones – see the flowcharts in this chapter. Continue to check the blood glucose and ketones about every two hours until the blood glucose falls and the ketones are negative.
8. Avoid strenuous exercise when unwell, especially if ketones are present.
9. When teenagers or young adults who predominantly look after their own diabetes are unwell, parents should resume care and supervision, as the teenager may be too unwell to make appropriate decisions. Extra support and care from all around is helpful. It is often best to check the blood glucose and ketone status of your adolescent for yourself, as it may have been falsely reported to you, forgotten or not recorded at all by the young person when unwell.

Call your diabetes team for advice if:

- vomiting is frequent or persistent (more than two or three vomits may mean hospital admission is needed, especially in young children).

- blood glucose levels cannot be kept above 4 mmol/l.
- blood glucose levels cannot be kept down below 15 mmol/l after extra doses of insulin or unable to clear ketones.
- your child is becoming more unwell or develops other symptoms (e.g., abdominal pain, drowsy, confused, deep or heavy breathing).
- you are very worried or exhausted or do not know what to do next.
- your child is very young.

If you are unable to contact your diabetes team or are worried that your child is very unwell you should present to your local Emergency Department.

Giving extra insulin during sick days

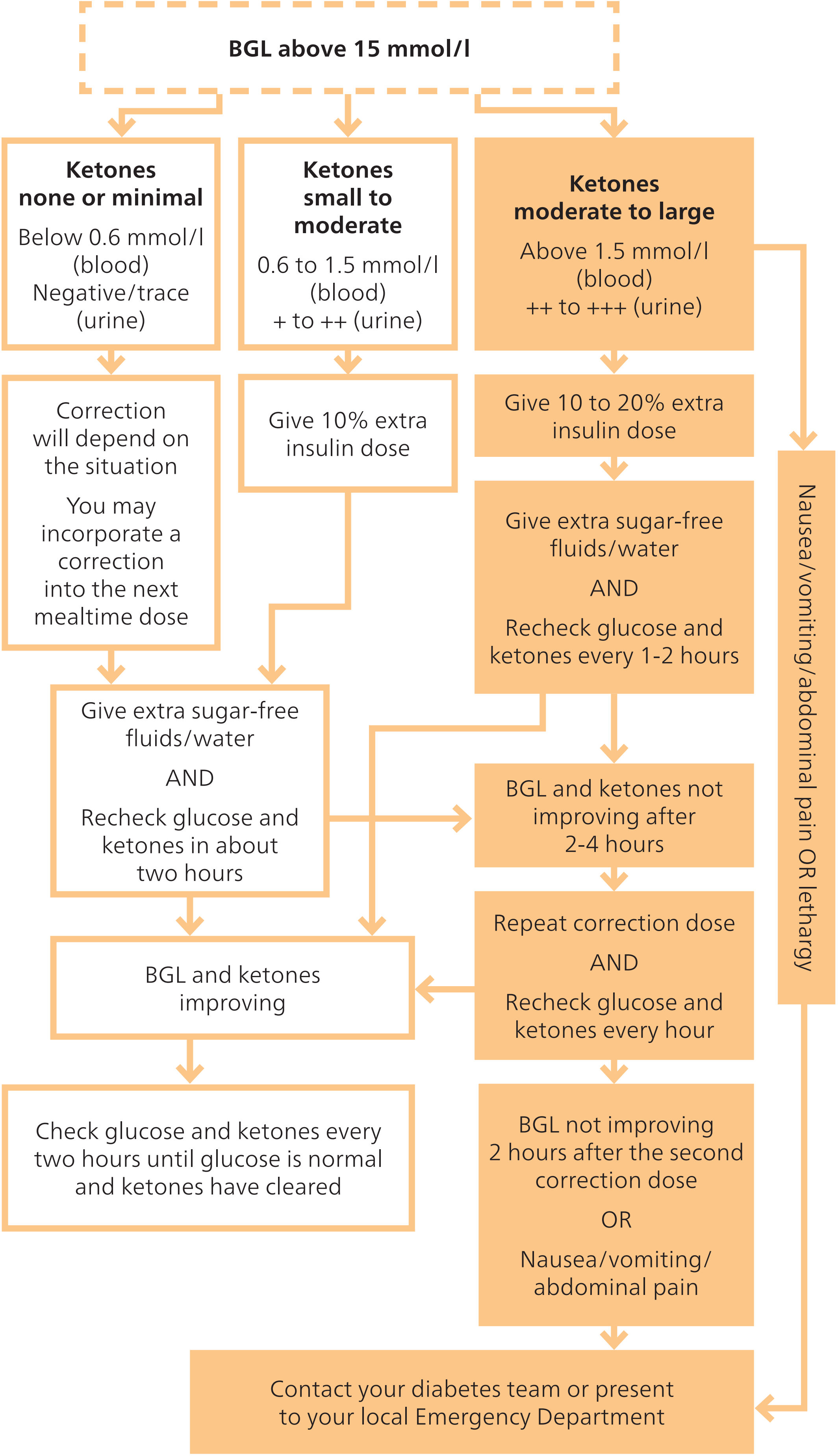
- Extra insulin is needed if the blood glucose level is raised and ketones are present. Don't wait until the next insulin dose is due – give an extra dose right away. The flowchart on the next page will guide you about this.
- Use rapid-acting insulin only for extra doses. Do not use long-acting insulin for these extra sick day doses.
- **Extra doses are calculated as 10 or 20 percent of the total daily dose** (provided in the flowcharts). Use the smaller dose in the range first or if you think your child is very sensitive to the rapid acting insulin.
- Glucose and ketones should continue to be checked regularly (around every 2 hours) until glucose is normal and ketones have cleared.
- Repeat doses of rapid acting insulin may be required if the glucose and ketone levels do not improve.
- Insulin pump users will use correction doses through the pump if there are no ketones or with a pen injection if ketones are present – specific details are given in Chapter 13.

Guide to extra insulin doses and monitoring for sick days

The flowchart on the following page outlines sick day management for hyperglycaemia (glucose above 15 mmol/l). Guidelines for low glucose levels are discussed later.

If your child's glucose level is normal or only mildly raised (between 4 and 15 mmol/l) you should follow the general sick day management advice outlined above. Remember, you do not generally need to check ketones unless your child's BGL is above 15 mmol/l.

Sick day management of high glucose levels



Example of extra dose calculation

Usual daily doses:

Breakfast: NovoRapid 7 units, Optisulin 12 units

Lunch: NovoRapid 6 units

Dinner: NovoRapid 5 units

Total daily dose = 30 units

A 10% extra dose would be 3 units of NovoRapid (rapid-acting) i.e., 10% of the usual total daily dose

A 20% extra dose would be 6 units of NovoRapid (rapid-acting)

Remember only rapid acting insulin should be used for correction doses.

Basal (long acting) insulin on sick days

In some cases it may be necessary to increase the basal insulin during an illness where BGLs are persistently raised.

- Pump users may increase the temporary basal by 25% or more if required (set for 4 to 6 hours then review).
- People using injections may also need to increase the long-acting (basal) insulin dose. Remember that the higher dose of basal insulin given by injection will usually last for 24 hours. It is a good idea to discuss an appropriate adjustment with your diabetes educator.

Illnesses with low blood glucose levels

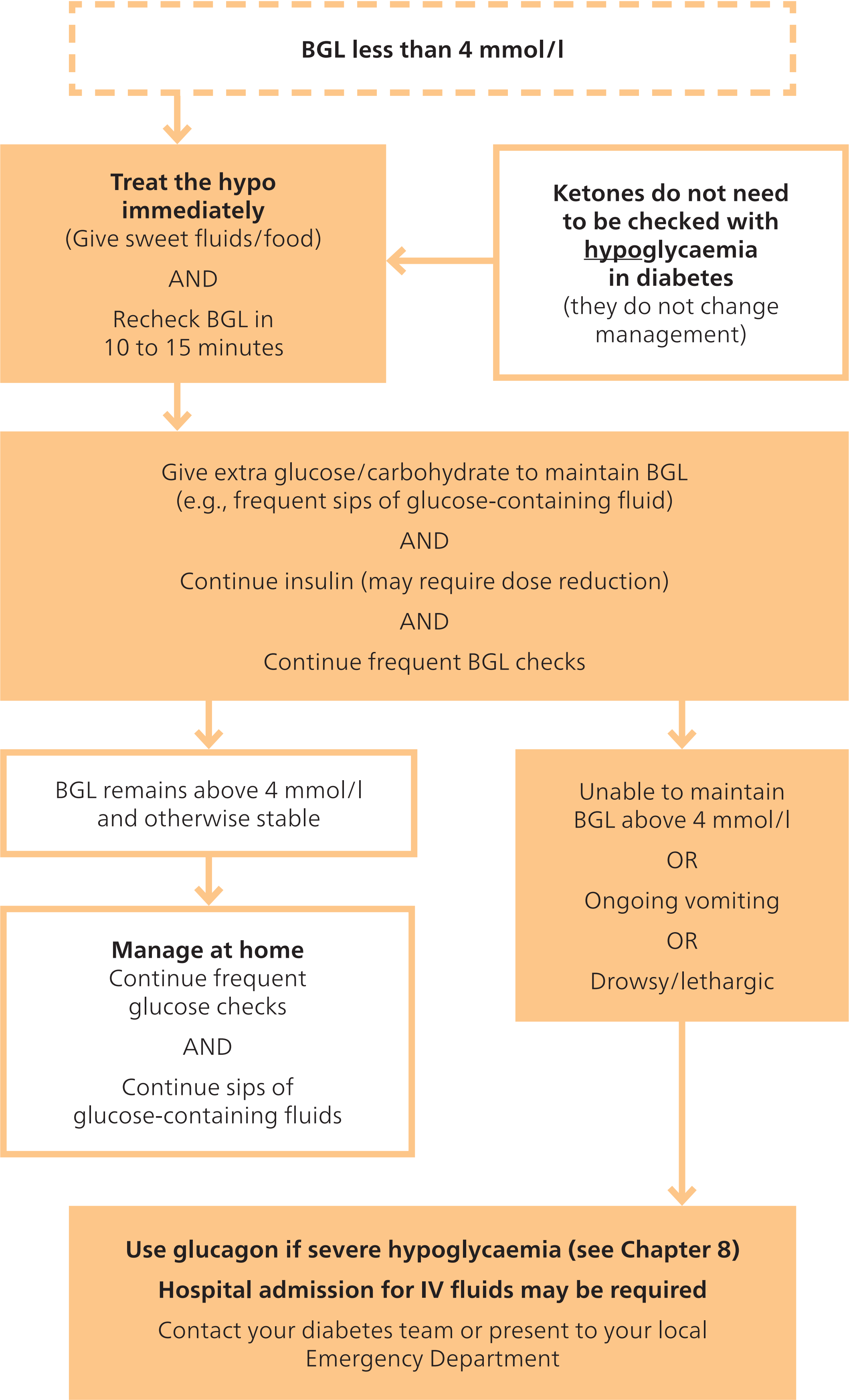
As discussed above, many illnesses will raise blood glucose levels, even if the appetite is less than usual. This is the most common situation. Some illnesses, however, cause blood glucose levels to be low and these are usually gastroenteritis illnesses (tummy upsets) where nausea, vomiting and diarrhoea are the main features. Blood glucose levels are low because there is less carbohydrate intake and the food that is eaten may be absorbed poorly. There may be ketones (usually small amounts) in the blood in this situation – these indicate that supplies of glucose are running low in the body. You do not need to check for ketones if the blood glucose level is low as this will not change your management. The body still needs insulin, especially the long acting (basal) insulin, in these situations as well as extra glucose from carbohydrate.

Electrolyte replacement solutions (e.g., Gastrolyte or Hydralyte) can be used and help to replace fluid and electrolyte losses. The solutions contain relatively small amounts of glucose, usually around 15 g or one exchange per litre, so additional carbohydrate may be needed.

In these situations, still follow the sick day guidelines as above. In some cases where symptoms persist, there is dehydration or the blood glucose level cannot be kept above 4 mmol/l, hospital admission may be required.

The following flowchart outlines sick day management for low blood glucose levels (glucose below 4 mmol/l).

Sick day management of low glucose levels



BGL less than 4 mmol/l

Treat the hypo immediately
(Give sweet fluids/food)

AND

Recheck BGL in 10 to 15 minutes

Ketones do not need to be checked with hypoglycaemia in diabetes
(they do not change management)

Give extra glucose/carbohydrate to maintain BGL
(e.g., frequent sips of glucose-containing fluid)

AND

Continue insulin (may require dose reduction)

AND

Continue frequent BGL checks

BGL remains above 4 mmol/l and otherwise stable

Manage at home
Continue frequent glucose checks

AND

Continue sips of glucose-containing fluids

Unable to maintain BGL above 4 mmol/l

OR

Ongoing vomiting

OR

Drowsy/lethargic

Use glucagon if severe hypoglycaemia (see Chapter 8)

Hospital admission for IV fluids may be required

Contact your diabetes team or present to your local Emergency Department

Adjusting insulin doses for low glucose levels

If things are improving but the blood glucose levels are tending to stay low, insulin doses should be reduced. Do not stop the insulin. You may need to reduce the dose of both long and rapid acting insulin.

Rapid acting (bolus) insulin:

- If you are using a bolus advisor or insulin pump for meals and your child has vomiting or diarrhoea, it is reasonable to reduce a suggested dose by 30% or more as their carbohydrates may not be absorbed well.
- If you are using fixed doses, you will need to take a 'best guess' approach to dose reduction depending on your child's intake, symptoms and blood glucose level. It is always better to give a more cautious dose initially and give an extra top-up dose later if needed in this situation.

Long acting (basal) insulin:

- It is very important to always give long acting (basal) insulin, though you may consider reducing the dose if the glucose levels are persistently low.
    - People using injections may reduce the dose by 25% or sometimes more if required.
    - Pump users may use reduce the temporary basal by 25% or more if required (set for 4-6 hours then review).
- Basal insulin is vital to prevent ketones from developing, especially if much less rapid acting insulin than usual is being given.

Do not cease insulin! If insulin is ceased entirely it can lead to diabetic ketoacidosis.

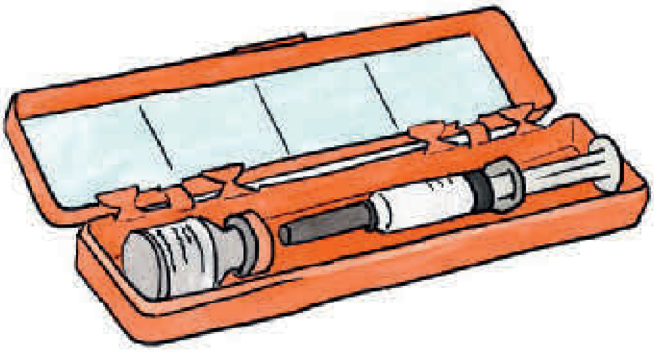
A reduced insulin dose may be required for a number of days as it takes some time for the bowel to recover. Insulin doses may be difficult to judge in this situation, and if in any doubt, contact your diabetes team for advice.

Mini-dose glucagon

Glucagon is a medication that is usually used for emergency treatment of severe hypoglycaemia in diabetes when the person is unable to safely eat or drink or is unconscious or fitting. Glucagon raises the BGL, mainly by releasing glucose from the liver and in such situations can be life-saving. All families must have glucagon at home and know how to use it.

Mini-dose glucagon is less commonly used however some families find it effective if their child is not tolerating enough oral intake to maintain a normal glucose level. Sometimes children with diabetes experience illnesses which are not severe, yet their BGLs are low (under 4 mmol/l) and they are reluctant to eat or drink enough to raise the BGLs up to satisfactory levels. This is especially common in young children and toddlers. The mini-dose glucagon protocol has been developed as a way of raising BGLs in such circumstances until the child is eating or drinking better.

Your diabetes team will discuss whether mini-dose glucagon is appropriate for you and will provide a protocol for how to use it. You MUST NOT use a mini-dose glucagon protocol if your child has severe hypoglycaemia – decreased consciousness or fitting – a full dose of glucagon is needed urgently as described in Chapter 8.



Foods and fluids for sick days

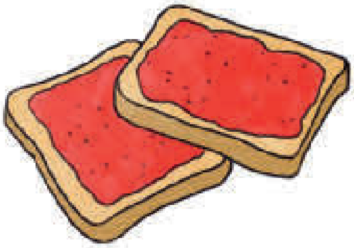
When the blood glucose level is above 8 mmol/l use low calorie or sugar-free fluids, such as:

- water
- diet cordial or diet soft drink (shake bubbles out or allow to go flat)
- diet jelly

When the blood glucose is below 8 mmol/l carbohydrate-containing foods or fluids will be required, such as:

Food	Drink
Jelly beans Toast or bread Plain sweet biscuits Ice-cream, icy poles Yoghurt Sweet jelly Banana, orange	Ordinary soft drink Juice Milk with added chocolate powder Tea or water with honey or sugar

Any carbohydrate-containing foods or fluids may be used, but it is a matter of trying to use foods and fluids which your child will tolerate while sick.



These fluids are not generally suitable for children with significant dehydration. Any child who may be becoming dehydrated should be assessed at hospital and may require admission and an intravenous drip. Signs of dehydration include dry/cracked lips, reduced urine output, dry tongue, sunken eyes and dizziness when standing up suddenly.

Surgery and anaesthetics

Like any child, a child with diabetes may require surgery or a procedure with an anaesthetic at some time in their life. These can be performed safely, provided that appropriate precautions are taken and the diabetes is cared for during this period by staff experienced in childhood diabetes. Not all hospitals have this expertise. You should always discuss any planned procedures with your diabetes specialist who will be able to advise about appropriate arrangements. Your surgeon will look after the operation and surgical care but you need the involvement of your diabetes team to look after the diabetes.

Even minor procedures will require admission to hospital, although sometimes the stay can be for only one day. Surgery is best performed first thing in the morning. An intravenous drip containing glucose is usually required to cover the period before, during and after the operation where your child cannot eat or drink.

For minor procedures, insulin will be given by injection or a pump will continue to be used, with doses adjusted as needed. For major procedures or emergencies, an insulin infusion will be given through an intravenous drip. More frequent blood glucose monitoring is required and the blood glucose levels are likely to be more variable. Continuous glucose monitoring systems cannot be used during the surgery or during recovery so fingerstick glucose checks will be required. The aim is to avoid major hypos, prolonged hyperglycaemia, dehydration or other complications.

If you have any doubts about arrangements for surgery or a procedure, you should contact your diabetes team without delay.

Common questions and answers

When my son gets ear infections and has a fever, he eats much less. Should I lower his insulin doses?

Illnesses with fever and infection often make the blood glucose levels higher than normal, even if the child is not eating well. This is because of glucose output from the liver, which is exaggerated when the body is stressed and lacking in insulin. The body is also more resistant to insulin during times of stress. You should check the blood glucose levels more often and continue the usual doses of insulin. Sometimes extra insulin will be needed. Some illnesses make the blood glucose levels lower, especially vomiting and diarrhoea. If this happens, less insulin may be needed – monitor more often and check with your doctor or educator if unsure.

How do extra fluids help when my child is sick?

High blood glucose levels can cause extra fluid losses through passing more urine. Extra fluid helps replace this and helps the body clear ketones.

My daughter has only had diabetes for three months and this is her first illness since the diagnosis. We don’t feel confident about giving extra inulin. What should we do?

It is natural that you will feel anxious and uncertain about dealing with sick days, especially at first. Use the guidelines in this section. If worried or unsure, call your doctor or educator who will guide you; this can usually be done over the telephone. If you are worried overnight you can present to your local Emergency Department.

If my child is sick and does not feel like eating, what can I do?

Measure the blood glucose level more often. Try to give carbohydrate-containing fluids or foods that are easy to swallow (e.g., jelly, custard, ice-cream). During sick days, if the blood glucose level is above 8 mmol/l, low calorie or sugar-free fluids should be used. If the blood glucose level is below 8 mmol/l give carbohydrate-containing fluids or food.

Do children with diabetes get ketones whenever the blood glucose is high?

No. If the child is well and the blood glucose is high from eating more than expected or perhaps because of mood or emotion, then usually there will be no ketones. It is only when there is not enough insulin in the body that ketones develop, and this is more likely at times of illness. Ketones are likely to develop if the BGL is high for more than a few hours.

My seven-year-old daughter with diabetes needs to have her tonsils removed. I have been advised that this can be done in our local private hospital, even though they do not have a children’s section. What should I do?

Surgery on children with diabetes should only be performed in hospitals in which there is experience in looking after children with diabetes at these times. Usually this will be a major children’s hospital or general hospital with a paediatric section. Your diabetes specialist needs to be involved in the planning and during the time in hospital. Contact your diabetes team for further advice about how you should proceed.

Chapter 11

Exercise and sports

Key Points

- Exercise usually lowers blood glucose levels, but sometimes they rise for a short time during or just after strenuous exercise
- Measure the blood glucose before exercise and frequently during any prolonged exercise, or check the sensor glucose regularly if using continuous glucose monitoring
- For exercise, there may be a need to lower the insulin doses, eat extra carbohydrate or both
- Delayed hypos can be a common problem after strenuous or prolonged exercise – measure the blood glucose, lower the insulin and eat extra carbohydrate after exercise if needed
- Planning ahead helps minimise any problems
- Continuous glucose monitoring can be very useful for monitoring glucose trends with exercise

Benefits of exercise

Exercise is very beneficial and is encouraged for all children. With appropriate knowledge and precautions, exercise and sports can be undertaken without major concerns in children and adolescents with diabetes. There are a number of professional sports people with diabetes.

Exercise:

- helps keep the body in good shape and at an ideal weight
- helps people feel well and happy and is an important social activity
- helps keep the heart rate and blood pressure lower
- gives you more energy
- strengthens muscles and bones
- helps you get good control of diabetes.

Children and adolescents should do around 60 minutes of moderate-to-vigorous physical activity per day. In infants and young children, general activities and play provide adequate exercise. As children grow older they are increasingly active and will often wish to become involved in group or individual sports. Older children and adolescents who have a tendency to be inactive and do not wish to play sports should be encouraged to incorporate some regular exercise into their routine (e.g., walking, swimming). Children with diabetes should not be limited in their activities and should be encouraged to participate in sports and physical activities. Learning sports when you are young gives you skills that are much harder to develop as an adult.

Although children with diabetes can participate in most activities, some activities should be approached with caution for people with diabetes. Some activities require a medical certification prior to participation which will take into account factors such as the overall diabetes control and the frequency and severity of hypoglycaemia. Solo activities are particularly problematic as it is important to have a companion who knows about diabetes and can help in an emergency.

Higher risk activities for people with type 1 diabetes include sports where recognising or treating a hypo could be difficult. These include unsupervised water sports (e.g., surfing, sailing, scuba diving), sports involving heights (e.g., rock climbing, hang-gliding) or motor racing. With proper planning, supervision and good diabetes control, many of these activities are still possible for people with type 1 diabetes.

How exercise affects blood glucose levels

Exercise usually lowers the blood glucose level (during and after exercise) but occasionally it may cause the blood glucose level to rise.

Exercise lowers the blood glucose level because:

- the exercising muscles use more glucose as fuel.
- exercise makes the body more sensitive to insulin (i.e., the same amount of insulin has a greater effect).

Lowering of blood glucose levels can occur during the exercise and for some time after, often up to 12 to 16 hours.

Exercise may increase the blood glucose level because:

- some of the body's other hormones rise during exercise (e.g., adrenaline) and increase glucose output from the liver.

The way blood glucose changes with exercise may depend on the type of exercise. Exercise also affects everyone a little differently. Because everyone is different in the way their body will respond to a certain activity, learning your child's own response to each type of exercise by observation and extra BGL monitoring is important.

Guidelines for exercise and diabetes

Planning can make diabetes management safer and easier during exercise. Although exercise should ideally be planned, this is often difficult to achieve in young children.

Things to think about before exercise

✓	**Type of exercise** (how long or strenuous will the exercise be?)	Short or low-level exercise may require no adjustment, whereas prolonged or vigorous activity will require reductions in insulin and/or extra carbohydrate.
✓	**Snacks and hypo treatment**	High GI snacks and food or drink to treat hypoglycaemia must always be available during exercise.
✓	**Supervision**	Ensure a supervising adult (teacher, coach, Scout leader) knows that your child has diabetes. Provide them with simple information and guidelines for what to do if there is a problem, which is most likely to be a hypo.
✓	**Access to communication for emergencies**	Always ensure there is a way to call for help if a problem occurs during exercise (e.g., a mobile phone).
✓	**Diabetes identification**	Your child should have diabetes identification (e.g., ID bracelet) on them during exercise in case of an emergency.
✓	**Injection sites**	Insulin is absorbed more quickly from parts of the body that are exercising (e.g., arms and legs). The abdomen (tummy) is the best place to have insulin injections before exercise or, as a second choice, the buttocks.

Glucose monitoring around exercise

Fingerprick BGL or flash glucose monitoring:

- Glucose level should be checked before, during and after exercise.
- Additional checks during prolonged exercise.

Continuous glucose monitoring (CGM):

- Sensor glucose checks before, regularly during and after exercise.
- Fingerprick confirmation if the sensor glucose is rapidly changing or the result is unexpected.
- Ensure predictive alerts and low glucose alarms are activated.

How to adjust for exercise

Most forms of activity lasting more than 30 minutes are likely to need consideration of adjustment to insulin dosing or food. This can depend on many factors, such as usual activity patterns, intensity and type of exercise, when you are exercising, type of insulin plan and recent insulin doses. This general advice applies to most forms of exercise which lower the blood glucose level. Advice for situations where the blood glucose level rises with exercise are discussed later.

Adjustment for exercise may require:

1. **Reduction in insulin doses** acting during and sometimes after exercise

   and/or

2. **Additional carbohydrate** before and during the exercise

For planned exercise, particularly in older children, insulin reduction is an appropriate first step. For unplanned exercise and younger children, a common first step is to give some extra carbohydrate.

Prolonged exercise will usually require a combination of insulin reduction and extra carbohydrate.

Insulin adjustment for exercise

Insulin reduction is often the appropriate first response to exercise.

Reasons for reducing insulin doses include:

- Not wishing to eat or drink too much before sport.
- Extra carbohydrate may not be enough to avoid hypos.
- Older children and teenagers are likely to exercise more intensely.
- Extra food with exercise can contribute to unnecessary extra calories and excess weight gain.
- Prolonged exercise or high activity periods (e.g., sports carnival days or school camps).

However insulin reduction as a first step is not practical in all cases, especially when extra exercise is spontaneous or unplanned e.g., it may not be possible to predict when a toddler will be very active.

Guidelines for adjusting mealtime (bolus) doses

Which dose to reduce

Generally, reduce the insulin dose that is acting at the time of the exercise. Rapid-acting insulin generally peaks within 30 to 90 mins of being given, so there is a higher risk of hypoglycaemia if exercise is happening at the same time as the peak of insulin effect. This applies to rapid-acting injection and pump bolus doses.

	Morning exercise	Afternoon exercise	Evening exercise
Rapid-acting dose adjustment	Reduce breakfast insulin dose	Reduce lunchtime insulin dose	Reduce dinnertime* insulin dose (or afternoon-tea bolus in pump users)

*Even if dinner is eaten after the evening exercise, a reduction in the dinnertime insulin dose is still often required.

With evening exercise a reduction in overnight (basal) insulin dose may be required. This is discussed below.

How much to reduce it by

The mealtime insulin dose generally needs to be reduced by 20-50% depending on the type of exercise.

- In high intensity or prolonged exercise, a dose reduction of close to 50% may be required.
- In lower intensity or shorter duration exercise, a smaller dose reduction of around 20% may be required.

Over time you will learn what dose changes work best for your child with different types of activity.

Other tips:

- Rapid-acting insulin (Novorapid, Humalog, Apidra, FiASP) should be used instead of short-acting insulin (Actrapid, Humulin R) around exercise where possible.
- Caution should be used when giving a correction dose prior to exercise as the blood glucose will probably fall naturally with physical activity. If a correction dose is required, a similar principle should be applied to dose reduction (20-50% reduction from usual correction depending on the type and duration of exercise).
- It is important not to reduce the insulin doses too much as this may cause prolonged hyperglycaemia which can worsen overall diabetes control.

Guidelines for adjusting long acting or basal insulin doses

The long acting insulin dose (injection) or basal rate (pump) may need to be reduced for:

- Prolonged or unusual activities (e.g., school camps, hiking, skiing).
- Evening exercise (to avoid delayed hypoglycaemia overnight).

The long acting or basal insulin should be reduced by around 20-50%, depending on the situation. This can be done via a temporary basal if your child is using an insulin pump. Specific advice for pump users is discussed below.

For some children it is necessary to have different doses of insulin on different days depending on their activity levels (e.g., lower dose on weekends with sporting activities). Insulin pumps can do this by having several different basal profiles programmed. Your diabetes team can help you make a plan for these times.

Extra carbohydrate before and during exercise

If you wish to adjust by taking extra carbohydrate, the following table is a general guide to the extra carbohydrate which should be taken before and during exercise. You may find that you modify this a little for your child after you gain some idea of their pattern with particular types of activity. If insulin is also being reduced, the extra amount of carbohydrate needed will be less.

It is usually best to have the extra carbohydrate 20 to 30 minutes before exercise (except if you are using an insulin pump in AutoMode – discussed below). The extra amounts are in addition to the carbohydrate your child usually has during the day. Your child should not have additional insulin to cover this extra carbohydrate.

Exercise type	Blood glucose level before exercise	Extra carbohydrate	
		Before exercise	During exercise
Short duration (under 30 minutes) or **Low intensity exercise** (e.g., slow walking, yoga)	Less than 7 mmol/l*	15 grams (1 exchange)	Not required
	7 mmol/l or above	Not required	
Moderate intensity exercise (e.g., swimming, jogging, tennis)	Less than 7 mmol/l*	15 to 25 grams (1 to 1.5 exchanges)	15 to 25 grams (1 to 1.5 exchanges) per 30 to 40 minutes
	7 to 10 mmol/l	15 grams (1 exchange)	
	Above 10 mmol/l	Usually not required	
Strenuous exercise (e.g., basketball, hockey, football, strenuous cycling)	Less than 7 mmol/l*	15 to 30 grams (1 to 2 exchanges)	15 grams (1 exchange) per 20 to 30 minutes
	7 to 10 mmol/l	15 grams (1 exchange)	
	Above 10 mmol/l	Usually not required	
	Above 14 mmol/l	Strenuous exercise should be avoided if glucose is above 14 mmol/l & ketones are present	

*If BGL is under 5 mmol/L, delay exercise until BGL is above 5 mmol/L and rising.

Remember: less carbohydrate than this may be needed if insulin has been reduced

The above carbohydrate suggestions are for an average 40 to 60kg young person, but should be adapted for the individual child. As a general rule of thumb, young adults require:

- 0.5 to 1 grams of carbohydrate per kg of body weight each hour during moderate exercise.
- 1 to 1.5 grams of carbohydrate per kg of body weight each hour during strenuous exercise.

These are a starting guide only – you will discover with time how much carbohydrate will be required for different types of exercise.

Ideas for extra carbohydrate before and during exercise

Many carbohydrate foods are suitable before and during exercise, but here are some popular ones:

- juice
- milk
- sports drinks
- yoghurt
- fruit
- fruit bar or muesli bar
- biscuits

Exercise with an insulin pump

The pump is best left on for exercise (with appropriate adjustments), but for vigorous, contact or water activities the pump will need to be disconnected. The general principles outlined above for diabetes management with exercise still apply: target glucose levels can be maintained by reducing insulin doses or increasing carbohydrate intake. Management using a standard insulin pump (or manual mode) is slightly different to using a hybrid closed-loop insulin pump in AutoMode.

Standard insulin pump (manual mode)

1. Pump-on for exercise (with reduced basal rates)

This is the most ideal scenario. As a starting point, use the temporary basal rate to reduce the basal rate to half the usual rate (a 50% temporary basal) for the duration of the exercise and for one hour after. If the exercise is planned, the basal rate can also be reduced for 1 to 2 hours beforehand. Additional carbohydrate (not bloused for) may be required e.g., 8 to 15 grams (half to one exchange) every 30 minutes or so, often best in the form of juice or sports drinks.

2. Pump-off for exercise

The set allows the pump to be easily removed for contact and vigorous sports or for swimming. **The pump can usually be disconnected for up to 2 hours if exercising.** Once reconnected, if the BGL is above target, a half-strength correction (i.e., 50% of the pump's recommended correction) can be given.

The glucose level should be checked after an hour off the pump. If the BGL is rising at that point, then the pump must be reconnected and a half strength correction given. The pump can then be disconnected for the next hour of exercise.

As discussed above, after vigorous and prolonged exercise (especially in the evening) **a reduction in the overnight basal rate may also be needed**. A temporary basal rate can be used for this, using a 20-30% basal rate reduction as a starting point.

Hybrid closed-loop insulin pumps in AutoMode

Different strategies are required for exercise when using a pump in AutoMode. Key differences include:

1. **Temporary target:** The temporary basal option has been replaced by a 'temporary target' (temp target) in pumps using AutoMode. Setting a temp target means that the target glucose level (which is usually 6.7mmol/l) is set slightly higher (8.3mmol/l). The higher glucose target means the pump will be less aggressive in attempting to lower the glucose level during exercise which provides a buffer to avoid hypoglycaemia. The temp target can be set for the duration of the exercise and for a period of time after exercise as required. Young children might use a temp target all day on high-activity days such as sports days.
2. **Avoid early carbohydrate-loading:** Carbohydrate loading will cause the glucose to rise if it is done too far in advance of exercise. A pump in AutoMode will attempt to correct the rising glucose by providing extra insulin (microboluses). This could increase the risk of hypoglycaemia with exercise.
3. **Suspend the pump during prolonged disconnection:** If a pump in AutoMode is disconnected for more than 30 minutes the insulin delivery should be suspended. This is important because otherwise the algorithm that calculates the insulin adjustments in AutoMode will take this insulin into account (it will assume the insulin has been given). It is important to remember to resume the insulin delivery (turn the suspend off) when the pump is reconnected.

If the pump on AutoMode is disconnected for activity, hyperglycaemia should be corrected upon reconnection as described above.

Delayed hypoglycaemia after exercise

Delayed hypoglycaemia is common for up to 12-16 hours after significant exercise. This is because the muscles can continue to use more glucose than usual and the body is more sensitive to insulin after exercise. If there has been prolonged or intense exercise throughout the day then delayed hypos are very likely. This is especially concerning when hypoglycaemia occurs overnight. Overnight hypoglycaemia may also occur after evening exercise.

Strategies to prevent overnight hypos after exercise

- Blood glucose testing before bed and overnight. If the blood glucose level is less than 5 mmol/l at bed time some additional long-acting carbohydrate should be given. It may also be necessary to check the blood glucose level later in the evening or overnight. Continuous glucose monitoring with low glucose alarms can help detect and prevent overnight hypos and hybrid closed loop pump systems will suspend or reduce insulin as needed.
- Reduce long-acting or basal insulin dose on the day of strenuous exercise (usually by 10-30%).
- Reduce the dinnertime insulin dose after evening exercise. Note that this may reduce hypos in the early part of the evening but is less likely to prevent delayed hypoglycaemia.

High glucose with exercise

Some types of exercise cause the glucose to rise transiently, either during or soon after exercise. This usually happens with quick, high-intensity exercise such as sprinting or weight-lifting. Sprinting just prior to routine exercise has even been suggested as a “hypo avoidance” strategy for some people.

Hyperglycaemia from exercise usually resolves on its own and doesn’t require an insulin correction dose. Often the glucose level will improve around 30 to 60 minutes after cooling off and having some water. If an insulin correction is given, it is important to be very cautious with the dose (give a much lower dose than would usually be required). Unnecessary or over-correction of hyperglycaemia after exercise can cause severe or prolonged hypoglycaemia.

Even if an insulin correction is not given, people who get hyperglycaemia during or soon after exercise are still at risk of delayed hypoglycaemia overnight.

Some people may find that the stress of a competition also raises their blood glucose more than a similar level of activity would during training. It is important to monitor glucose frequently on these days so that you become familiar with your child’s response.

Exercise adjustment examples

The following are examples of some common adjustments. Since exercise and response to it will vary so much in different children, only extra monitoring and trial and error will determine what works best for your child. Your educator and doctor are experienced in advising about these adjustments if you need help.

Example 1

Sarah is a three-year-old girl who attends preschool two mornings per week. She is tending to have low BGLs at preschool in the late morning because she is more active than at home.

Adjustment:

It was found that she is quite hungry at preschool and giving some extra carbohydrate at preschool solved the problem. If this had not been successful, reducing the morning insulin dose (if using injections) or use a temporary basal/ temp target (if using a pump) on those days would need to be considered.

Example 2

Aysha is a 14-year-old girl who wishes to attend a dance party on Saturday night from 7 pm to 10.30 pm. She is a keen and vigorous dancer. She is on multiple daily injections using a bolus advisor. She takes Apidra (rapid-acting) for meals and Optisulin (long-acting) 28 units before bed.

Adjustment:

Morning and lunch doses remain the same. Her bolus advisor advises a pre-dinner dose of 14 units of Apidra. The pre-dinner Apidra is reduced to 10 units (30% reduction) and dinner is eaten as usual. Aysha makes sure to have one or two exchanges of carbohydrate per hour during the party (e.g., potato chips, orange juice, cake). On returning home she checks her blood glucose and would have extra carbohydrate if her BGL is less than 5 mmol/l. She reduces her pre-bed Optisulin to 23 units (20% reduction). Dad usually checks her blood glucose level at 2-3 am after a big night out.

Example 3

Alison does 2 hours of dancing on Tuesday evening. She uses an insulin pump on manual mode. Despite using 50% temporary basal during, she still goes low during or afterwards.

Adjustment:

In addition to her temporary basal rate, she has 15g of her dinner carbohydrate unbolused and uses the 50% temp basal rate for 4 hours. This works well for her for this activity.

Example 4

Michael does basketball on Tuesday nights. He uses a standard insulin pump (manual mode). He is often high at the end of the game and corrects. Even though he has an extra snack before bed he is having late evening hypos.

Adjustment:

Michael realises that the correction bolus he is giving after the game may be causing his late evening hypoglycaemia. He stops giving the extra insulin and finds that his post-game hyperglycaemia improves gradually by itself. It is decided also to use a temporary basal rate of 70% for 8 hours and adjust this as needed over the next few weeks based on his response.

When is it unwise to exercise?

People with diabetes should avoid exercise if:

They are unwell

- Exercising when unwell can raise the blood glucose and ketone levels and make your child feel more unwell

The blood glucose level is above 15 mmol/l and ketones are present

- More insulin is needed at this time, not exercise. Exercise will not lower the blood glucose if the body is lacking insulin
- This should be managed as described in Chapter 12 and exercise should only occur when glucose and ketones have normalised

If the BGL is above 15 mmol/l, but the person is well and ketones are negative, mild or moderate exercise is fine (but not strenuous) and will help bring the glucose down. However, it is important to think about why the glucose is high and whether extra insulin might be needed.

Common questions and answers

? Our son tends to have hypos in the night after his athletics days, even though we give him extra carbohydrate. What can we do?

Delayed hypos after exercise are common and exercise can cause blood glucose levels to be lower for some 12 to 16 hours afterwards. Lowering the insulin on these very active days will help – lowering both the mealtime and the long-acting (basal) insulin for full day activities is often required.

? My son had a BGL of 18 mmol/l immediately after basketball last week. Should we have given extra insulin then?

No. High intensity exercise can push the BGL up temporarily during the exercise and for a short period after. This is because of a 'stress hormone' response. Usually the BGL will settle with rest and some fluids. Giving extra insulin at this time is likely to cause a hypo. Check the BGL an hour or so later to make sure it is settling.

My 15-year-old son is a keen surfer. I worry about him having a hypo when he is out in the water. What should I do?

Activities like surfing are potentially hazardous and require extra precautions. Always check the blood glucose level before going into the water and eat some extra carbohydrate (see the guidelines in this section). Some children will lower their insulin doses if planning a very active time. He should always surf with a buddy who knows he has diabetes and what to do for a hypo. He should come in to the beach every 30 minutes or so for extra carbohydrate (one to two exchanges). As an extra precaution, a tube of glucose gel can be tucked into the wetsuit or board shorts in case of an unexpected hypo.

My daughter has a school camp which is going to be very active. What should we do about her insulin doses?

Plan ahead by looking at the activity program and how active it will be. Also ask to see the menus to check for carbohydrate content and number of meals and snacks provided. If the camp is much more active than your child's usual routine, insulin doses often have to be reduced by 20 to 30 per cent overall. Extra carbohydrate will also be needed. Consult your diabetes doctor or educator before the camp if uncertain.

My daughter is sometimes hypo after netball training, but at competition matches her blood glucose levels are often high. Why is this?

Sometimes the stress and excitement of the competition will make the blood glucose high through production of hormones like adrenaline which cause glucose release from the liver. If this affects performance, ask your doctor or educator about some possible solutions.

Chapter 12

Insulin adjustment and bolus advisors

Key Points

- **How you adjust insulin will depend on the insulin dosing plan and the types of insulin being used. Insulin doses often need adjustment.**
- **There are several types of insulin adjustment:**
  - **Pattern adjustment: adjust usual insulin doses because of high or low glucose levels at certain times over a few days or longer periods. Regularly look for patterns in the glucose levels to see if an adjustment is needed.**
  - **Day to day adjustment (flexible daily adjustment): adjust insulin doses taking into account a variation in carbohydrate intake or activity.**
  - **Corrections: giving additional insulin (either as an extra injection or added to a mealtime dose) to help bring a high BGL into the target range. Only rapid-acting insulin should be used to give corrections.**
- **Insulin pumps and bolus advisors use an insulin to carbohydrate ratio (ICR) and insulin sensitivity factor (ISF) to calculate insulin doses based on carbohydrate intake and BGL (incorporate a correction dose). Adjustment using the ISF and ICR are outlined below.**
- **If hypos are occurring frequently, don't delay adjustments**
- **Seek help from your diabetes educator or doctor if you are not sure what to do or your adjustments are not working**

All people with diabetes need adjustment of their insulin over time and also often from day to day. At first this may seem a little confusing, but you will soon find that it falls into place and you will get a good feel for how to adjust your child's doses. Older children and teenagers will also start to think about their own adjustment and can become skilled at it. It is very rewarding and will give you a sense of control to be able to adjust the insulin doses as needed.

In some situations and for some children, adjustment remains very difficult, requiring more frequent contact with your diabetes educator or doctor. Shortly after diagnosis, very frequent adjustments need to be made and these are usually made by regular contact with your diabetes educator or diabetes doctor.

Why does insulin need adjusting?

Insulin doses will need adjusting gradually over time and can often need adjusting day to day. There are many reasons why insulin may need adjusting, including the following:

- As children enter a honeymoon phase shortly after diagnosis, insulin doses decrease
- As children grow, they need more insulin to maintain good control
- Insulin requirements increase more with puberty and the associated growth spurt
- Changes in activity levels from day to day
- Variation in appetite and food intake from day to day
- Change of circumstances, such as holidays, new school, camp etc.
- Sickness (see Chapter 10 'Sick days')

Principles of insulin adjustment

It is useful to think of three main types of insulin adjustments and think of them in this order:

1. **Pattern adjustments to usual doses:** changes to regular doses based on patterns in blood glucose readings over several days or longer.
2. **Day to day adjustments (flexible daily or 'thinking ahead' adjustments):** adjustments to some doses based on what is going to happen that day (e.g., exercise, eating more or less than usual).
3. **Corrections ('fix-up' adjustments):** adjusting a dose or giving an extra dose to correct or 'fix up' a blood glucose reading that is unexpectedly high.

More detail on these three types of adjustment is given in the following sections.

General points are:

- Insulin adjustment requires a knowledge of the types of insulin your child is on, particularly when they start to work and how long they work for (see Chapter 5 'Insulin treatment').
- Overall insulin adjustments are generally based on the recognition of blood glucose patterns over several days, so enough blood glucose readings need to be done to allow this.
- Cautious adjustment steps are made in insulin doses until blood glucose levels in the target range are reached.
- At times of instability or illness it is necessary to do extra blood glucose readings to guide adjustment.
- Recurring hypoglycaemia requires thinking about insulin doses without delay and adjustment if needed.
- Frequent dose changes may be necessary when insulin needs are changing rapidly, in which case your diabetes educator or doctor should be aware and able to help.
- Many insulin plans incorporate flexible dose adjustments on a day-to-day basis to adjust for activity and exercise; this is most suited to multiple daily injection plans or insulin pumps but can be used to some extent in most plans.

- Different insulin plans incorporate corrections in different ways. In some plans corrections are estimated based on your experience and in others a correction dose is specifically calculated using a mathematical formula or bolus advisor.
- Latest insulin pumps can make a number of these adjustments automatically, but are working to similar principles.

Pattern adjustments to usual doses

These are changes to regular doses based on patterns in blood glucose readings over several days or longer.

This may occur:

- when coming out of a honeymoon phase.
- as the child grows and especially as they have their growth spurt with puberty or reach the end of puberty.
- when the child has a general change in activity levels.

Pattern adjustment process:

1. **Look for a pattern**
   - Look at blood glucose levels over a few days or longer to see if a pattern emerges (e.g., high levels before breakfast).
   - Three days of levels above the target range or two days of levels below the target range at the same time of day should make you think about the need for adjustment.
2. **Identify which insulin dose needs to be adjusted**
   - Identify the insulin that is acting to regulate glucose levels at this time of day (e.g., the pre-breakfast level is mostly regulated by the previous evening's long-acting insulin).
   - In general, adjust only one insulin at a time. Adjusting more than one at a time can be confusing.
3. **Decide how much to adjust the dose by**
   - See the guide below for how much to adjust.
4. **Assess the outcome**
   - Wait a few days to assess the outcome of the adjustment before making further changes.

Exceptions to these guidelines are:

- Hypoglycaemia (especially if severe) or periods of increased activity or sick days may require more rapid or frequent adjustment.
- Where your doctor or educator advises more frequent changes.

Identifying which insulin is acting (i.e., which dose requires adjustment) is outlined below using a multiple daily injection (MDI) fixed dosing plan as an example. Remember, fixed dosing insulin plans involve giving a set (fixed) dose of short or rapid-acting insulin with each meal and assume a fairly consistent amount of carbohydrate intake for their various meals day to day. Fixed dosing insulin plans are outlined in more detail in Chapter 5. Most children will be on a more flexible insulin plan, however the same general principles for pattern adjustment apply.

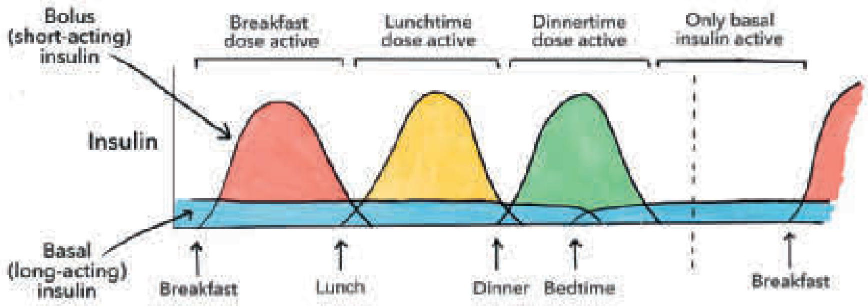
Which insulin dose to adjust based on blood glucose patterns

To decide on which insulin dose to adjust, you must understand which dose is acting at the time of the high or low glucose level. The below graphics indicate the doses for a child on MDI (with once daily long acting insulin) and when each dose will be acting.

Timing of doses:

	Before breakfast	Before lunch	Before dinner	Before bed
Rapid/short-acting insulin dose	✓	✓	✓	
Long acting insulin dose				✓

When each dose is acting:



You can see that:

- Each dose of rapid or short-acting insulin is active for several hours after it is given.

  For example, the breakfast dose will be acting during breakfast and for several hours in the morning. The response to this dose will be reflected in the pre-lunch (or pre-morning tea) blood glucose level.

- The long-acting dose is active throughout the day and overnight. It will usually be the only dose of insulin still acting late at night and early in the morning (provided no extra rapid or short-acting doses have been given after dinner). Response to this dose will be reflected in the late night/early morning BGLs.

Remember, the dose of insulin that needs to be adjusted is the dose that is acting at the time of the high or low glucose level. Therefore:

Time of high or low glucose level	Dose to alter (dose acting at the time)
Before breakfast or overnight	Evening long-acting insulin
Before morning tea or lunch	Breakfast rapid or short-acting insulin
Before afternoon tea or dinner	Lunchtime rapid or short-acting insulin
Before supper or bed	Dinnertime rapid or short-acting insulin

The appropriate dose of insulin needs to be raised or lowered accordingly. For example, if the glucose level is raised in the morning when your child wakes up (before breakfast), the long acting insulin dose likely needs to be increased.

In some MDI fixed dosing regimens there is also a morning dose of long-acting insulin given. The general principles of pattern adjustment remain the same. In this case if the glucose level is abnormal before lunch, the morning long-acting insulin may sometimes require adjustment.

How much should doses be adjusted by?

Insulin adjustment is made in steps based on blood glucose monitoring. The amount by which the dose is changed depends on the current dose.

For example:

- if on 4 units of Novorapid, a 1 unit increase is a 25 per cent increase.
- if on 20 units of Novorapid, a 1 unit increase is only a 5 per cent increase.

Doses are usually adjusted by about 10 per cent of the current dose. If you are unsure, make smaller cautious changes, waiting for several days of blood glucose readings to decide on further adjustment.

Remember that during periods of insulin adjustment more frequent BGLs are very helpful (e.g., four to six per day or sometimes more).

General rules of thumb for adjusting insulin doses:

Dose to be adjusted	Adjust by
5 units or less	0.5-1 units*
5-10 units	1 unit
10-20 units	1-2 units
20-30 units	2 units
More than 30 units	2-4 units

*Pens are available that allow half-unit adjustments.

Note that for some insulin dosing plans (bolus advisors and insulin pumps) the dose of rapid or short-acting insulin is calculated using a formula. Therefore, instead of altering the dose of insulin directly, the settings in the bolus advisor or pump are changed. The same general principles apply: the settings which decide the insulin dose acting at the time of the abnormal glucose level will be changed. For example, if the pre-lunch glucose level is raised, the settings will be changed to make the breakfast dose stronger. This is discussed in more detail on page 144.

Day to day adjustments (flexible daily adjustments)

These are adjustments to some doses based on what is going to happen that day. Examples of this are:

- reducing a dose or doses for sporting activity.
- reducing an evening dose of insulin after a very active day to avoid delayed hypos.
- adjusting a dose to plan for eating more or less at a meal.

If you can anticipate that your child's insulin needs will be more or less than usual on a certain day, then making an adjustment is likely to reduce the chance of highs or lows during the day.

Adjustment for sports and activities

This is also covered in Chapter 11. Extra activity or sport usually requires a reduction in insulin doses, extra carbohydrate or both. Which insulin doses are lowered will depend on the time of the day the sport is played and which insulins are mainly acting then. For example, less short-acting insulin might be given in the morning on days when there is planned physical exercise at school at 9am.

For days when the activity levels will be continually high (e.g., athletics carnival, active camp, bushwalking) all doses may need to be lowered (short and long-acting insulins) and this is usually a reduction by 10 to 30 per cent, depending on the individual. Remember also after very high energy days to reduce the night time dose of insulin to avoid delayed hypos overnight.

In people using an insulin pump a temporary basal rate or temporary target can be used. This works in the same way as altering the long acting insulin injection dose. This is covered in more detail in Chapter 11 and Chapter 13.

Adjustments for meals

The dose of rapid or short acting insulin for meals can be adjusted if need be to cope with more or less carbohydrate intake if that can be predicted. For example, you may know that your child always eats more and ends up with a high blood glucose level after eating pizza for dinner. Therefore, you may find that it helps to increase the rapid-acting insulin dose before dinner on those days to give a better BGL later in the evening.

The extra insulin dose can be decided based on experience (flexible MDI) or calculated using a bolus advisor or insulin pump. These techniques all rely on carbohydrate counting at mealtimes which is discussed in Chapter 6.

How to make insulin adjustments for meals is discussed further below.

Correction doses ('fix-up' adjustments)

This is adjusting a dose or giving an extra dose to correct or 'fix up' a blood glucose reading that is unexpectedly high. For example:

- giving extra rapid or short-acting insulin when the blood glucose level is found to be high before a meal.
- giving extra doses for high readings between meals.
- adjusting for sick days.

Corrections can be incorporated into most injection insulin plans and are used by all insulin pumps.

A correction involves an adjustment (increase or decrease) to rapid or short-acting insulin or an extra dose of rapid or short-acting insulin. If you need to do lots of corrections, then it usually means that the usual doses need some adjustment to prevent the problem readings in the first place. **Correction adjustments are not made with long-acting insulin.**

The amount of correction adjustment (up or down) will vary for individuals but will **usually be around 10 to 30 per cent of the rapid or short-acting insulin dose for that time.**

A formula can be used to calculate a more specific correction dose. This is called using an insulin sensitivity factor (or correction factor) and is described in more detail on page 146.

When an unexpectedly high or low BGL occurs it is wise to re-check the BGL after washing the hands (if high, in case of sugar on the hands) and make sure a good size drop of blood is used so that the meter is reading accurately. Similarly, an unexpected glucose level on continuous glucose monitoring should always be checked on fingerstick.

Adjustment for sick days is a type of correction and is covered in detail in Chapter 10.

Example:

Your child is due to have their usual injection at breakfast time and the BGL is 18 mmol/l, with no ketones. If you know from previous experience that this makes the BGL high for the rest of the day, it would be reasonable to give a little extra rapid or short-acting insulin for the pre-breakfast injection.

Incorporating the types of insulin adjustment into specific dosing plans

Most insulin dosing plans incorporate both **day-to-day adjustments** (for changing carbohydrate intake and physical activity) and **corrections** for high or low glucose levels into each dose of rapid or short-acting insulin. The method used to adjust these doses varies between different dosing plans.

While **pattern adjustments** still follow the general principles outlined above (identifying and adjusting the appropriate dose), the way this is done also varies between different insulin dosing plans.

The method of insulin adjustment for different insulin dosing plans is outlined below for people using:

- Injections by flexible MDI
- Injections using a bolus advisor (as a mobile phone app or a bolus advisor glucometer)
- Insulin pumps

Flexible multiple daily injections (flexible MDI)

In this method, the principles of adjustment based on overall patterns should still be used as outlined above. However, pre-meal insulin doses are also adjusted from day to day based on variations in carbohydrate intake and activity patterns. There is no precise formula for how this is done. It is a type of 'fuzzy logic' that is based on person's understanding of how food and activity affect their BGLs, judgement and past experience. Many people may use much the same insulin doses and have the same carbohydrate intake most days, with only occasional adjustments. Other people find that they adjust doses more frequently. The concept of "correction doses" outlined above is also incorporated into flexible MDI dosing.

The pre-meal injections allow greater flexibility for adjustment, since each of those doses can be adjusted according to:

- the amount of carbohydrate that is going to be eaten;
- any planned activity; and,
- whether the current blood glucose needs correcting (i.e., is higher or lower than desired).

Diabetes education includes discussion of how to make these adjustments and this may be done differently in different centres and by different people. It also requires a good understanding of carbohydrate counting and different effects of different carbohydrates (i.e., the glycaemic index).

In this method, a person has a good understanding of their usual carbohydrate intake for each meal and the amount of insulin usually required to cover that. They then make adjustments of pre-meal doses (up or down) according to the particular circumstances at that time (planned food intake, recent or planned activity, current BGL level) and their previous experience. Long-acting insulin doses are usually not adjusted on a day to day basis, although may sometimes be reduced if needed relating to sport and exercise (see Chapter 11).

Example 1:

Justin is 14 years old and usually has 12 units of NovoRapid before breakfast. Today he has a BGL of 5 mmol/l, but is not very hungry and plans to eat less. He also has Physical Education class at 9am. He decides to reduce his dose to 8 units.

Example 2:

In the same circumstances above, if Justin's BGL had been 14 mmol/l, he probably would have taken the usual dose of 12 units, to assist the BGL to return to normal.

Example 3:

Emma is on a multiple daily injection plan with NovoRapid before meals and Levemir before bed. She knows that on a usual day when she eats a usual breakfast of cereal and toast, she needs 8 units of NovoRapid. However, she sometimes does not feel like eating much for breakfast and only has a glass of milk. She finds that 5 units of NovoRapid works well on these days and her BGL late morning is within target.

Injections using a bolus advisor

A bolus advisor is a variation of the 'flexible multiple daily injections' insulin plan described above. It uses a mathematical formula to calculate the dose of mealtime short or rapid-acting insulin based on the carbohydrate count and the pre-meal glucose level.

Therefore, the dose of insulin suggested by the bolus advisor incorporates the amount of insulin required to cover:

1. the carbohydrates in the meal (a **carbohydrate bolus**) and
2. a correction dose for any hyperglycaemia (a **correction bolus**)

The amount of insulin the bolus advisor suggests will also depend on the target blood glucose level and how long the insulin will be acting (active insulin time). These settings are also programmed into the bolus advisor by your diabetes team. Bolus advisors are not 'set-and-forget' devices. The settings will need to be adjusted over time to match your child's insulin needs.

When using a bolus advisor, a glucose level and a carbohydrate count (in grams or exchanges) must be entered into the device by the parent or child. The bolus advisor will then calculate a suggested dose of short or rapid-acting insulin to be given by injection. You do not have to do the dose calculations yourself – your diabetes team will program individual settings into a bolus advisor which will do the calculations for you. Bolus advisors do not advise on the dose of long-acting insulin.

There are several forms of bolus advisors including mobile phone apps and certain types of glucometers. Some diabetes departments provide dosing tables or wheels which are based on the same concept. The bolus advisor method is derived from the way that insulin pumps calculate doses.

Bolus advisors use the **insulin to carbohydrate ratio** and the **insulin sensitivity factor (or correction factor)** to calculate the insulin dose (discussed in more detail below). Some people find that they prefer to use these formulae to calculate their dose manually instead of using a bolus advisor, which is possible providing they have a good grasp of the concepts.

Insulin to carbohydrate ratio (ICR)

The ICR is a formula used to calculate the dose of insulin required to cover the carbohydrates that will be eaten in a meal. The ICR can be adapted depending on whether you count your carbohydrates in grams or exchanges.

For example:

- An ICR of **10 grams per unit** means that 1 unit of insulin covers 10 grams of carbohydrate.
- An ICR of **1 unit per exchange** means that 1 unit of insulin covers 15 grams (1 exchange) of carbohydrate.

We will use grams rather than exchanges in the following discussion to avoid confusion.

The bolus advisor uses the ICR to calculate the carbohydrate bolus. An example of this calculation is detailed below for your understanding. Remember, you will not need to do this calculation yourself, as the bolus advisor will do it for you.

Example of calculating the carbohydrate bolus using the ICR:

If the person will eat 50 grams of carbohydrate for lunch and their ICR is 10 grams per unit:

50 / 10 = 5 units

Therefore, the bolus advisor would suggest 5 units to cover the carbohydrates for lunch

The ICR is individualised for each person based on how much insulin that person typically requires. **Your diabetes team will calculate your ICR for you and program it into the bolus advisor.** We will briefly describe how the ICR is calculated so that you have a general understanding of the concepts, however you will not be expected to do this yourself. These calculations are based on the total daily dose (TDD) which is the total amount of long-acting and short or rapid-acting insulin your child uses in a day.

How your ICR is calculated

The ‘450 rule’ is an example of how an ICR may be calculated. Different centres may use slightly different rules for this calculation.

This calculation determines how many grams of carbohydrate 1 unit of insulin will cover (i.e., the ICR).

The ICR is calculated by dividing the total daily dose of insulin (TDD) into 450.

For example:

TDD = 48 units

450 divided by 48 = 9.4

Therefore 1 unit of insulin will cover approximately 9 grams of carbohydrate (thus the ICR = 9).

This figure is programmed into the bolus advisor.

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your bolus advisor. This information is presented here so you understand how your bolus advisor is programmed. The ‘450 rule’ does not work for everyone but is a good starting point. These starting doses for your meal carbohydrate boluses will then be modified as needed.

Adjusting the ICR

The ICR can be strengthened or weakened depending on your child’s response (i.e., what happens to their blood glucose level after a meal). Some people also find that the ICR is different at different meals. The commonest variation is people who find that they need a stronger ratio for their breakfast compared to other meals. Your diabetes team will help you adjust the ICR but as you gain more experience you may start to make adjustments yourself.

A good rule of thumb is to **only adjust the ICR by about 10% at a time** and monitor the response. An exception to this is if severe hypoglycaemia is occurring (whereby the ICR may need to be weakened by more than 10%) or if your diabetes team suggests a larger change. How you adjust the ICR will vary depending on whether you are counting carbohydrates in grams or exchanges.

Example (if counting carbohydrates in grams)

If the ICR is 10 grams per unit:

- a 10% weaker ICR would be 11 grams per unit (i.e., 1 unit now covers 11 grams of carbohydrate)
- a 10% stronger ICR would be 9 grams per unit (i.e., 1 unit now covers 9 grams of carbohydrate)

You may notice that **as the ICR gets stronger the number (in grams per unit) gets smaller.** To avoid confusion it is helpful to talk about making the ICR **stronger** or **weaker** rather than higher or lower.

Example (if counting carbohydrates in exchanges)

If the ICR is 1 unit per exchange (i.e., 1 unit of insulin covers 15 grams of carbohydrate):

- a 10% weaker ICR would be 0.9 units per exchange (i.e., 0.9 units now covers 15 grams of carbohydrate).
- a 10% stronger ICR would be 1.1 units per exchange (i.e., 1.1 units now covers 15 grams of carbohydrate).

Most families count carbohydrates in grams rather than exchanges. Your diabetes team will discuss which option is most suitable for you. If you are counting your carbohydrates in exchanges it is important that the ICR in your bolus advisor is programmed in exchanges and any adjustments take this into account.

Insulin sensitivity factor (ISF) or correction factor

The ISF or correction factor is used to calculate a correction bolus. A correction bolus is the amount of insulin required to correct the glucose level back to target. The target blood glucose level is usually 5 or 6 mmol/l. An ISF describes how much (by how many mmol/l) the blood glucose will reduce when 1 unit of insulin is given.

For example:

An ISF of 2.5 mmol/l per unit means that 1 unit of insulin will correct the BGL by 2.5mmol/L

A bolus advisor will use the ISF to figure out how much insulin is required to correct the BGL to the target level. The process is explained below for your understanding, however the bolus advisor will do this calculation for you.

Calculating the correction dose using an ISF can be broken down into 2 steps:

1. **Work out the BGL difference**

   When a BGL is entered into the bolus advisor, the advisor figures out the difference between the current BGL and the target BGL (i.e., how many mmol/l the BGL needs to correct by).

2. **Use the ISF to calculate how much insulin is needed to cover the BGL difference**

   This is done by dividing the ISF into the BGL difference.

Example of calculating the correction bolus using the ISF:

If the ISF is 2.5 mmol/l per unit, the current BGL is 18 mmol/l and the target BGL is 6 mmol/l

BGL difference = 18 – 6 = 12 mmol/l (we want to reduce the BGL by 12 mmol/l)

12 / 2.5 = 4.8 units (the bolus advisor would advise giving 5 units of insulin as a correction)

Remember, you will not need to do any of these calculations yourself. They are all performed by the bolus advisor based on the settings programmed in by your diabetes team.

At a mealtime, the correction bolus of insulin is added to the carbohydrate bolus so that the total mealtime dose covers the carbohydrates and corrects any hyperglycaemia. The bolus advisor will do this automatically if both a carbohydrate count and a BGL are entered in. The bolus advisor can also be used to calculate a correction dose between meals. If your child requires a **correction dose between meals**, the blood glucose can be entered without entering any carbohydrates (or entering '0 grams'). The bolus advisor can then calculate a correction dose.

Negative correction

If the BGL before a meal is lower than desired, the same formula will be applied by the bolus advisor to reduce a bolus dose. Instead of adding insulin to the carbohydrate bolus, some insulin will be removed from the final bolus calculation. This will help bring the glucose level back up to target.

For example:

If the ISF is 2.5 mmol/l per unit, the current BGL is 4 mmol/l and the target BGL is 6 mmol/l:

BGL difference = 6 – 4 = 2 mmol/l (BGL needs to increase by 2 mmol/l to reach target)

2 / 2.5 = 0.8 units (the bolus advisor would reduce the suggested insulin bolus by 0.8 units)

How your ISF is calculated

The '120 rule' is an example of how an ISF may be calculated. Different centres may use slightly different rules for this calculation.

This determines how by many mmol/l the BGL will change in response to 1 unit of insulin (the ISF).

The ISF is calculated by dividing the total daily dose of insulin (TDD) into 120.

For example:

TDD = 48 units

120 divided by 48 = 2.5 (ISF or correction factor)

Therefore the BGL should fall by 2.5 mmol/l for every unit of insulin given

Adjusting the ISF (or correction factor)

The ISF can be adjusted depending on your child's response. An appropriate ISF will bring a high BGL down to target within 2 to 3 hours, without causing hypoglycaemia.

If the ISF is too strong, the correction bolus suggested by the bolus advisor will be too large meaning it will correct too quickly or overcorrect and cause hypoglycaemia. If the ISF is too weak, the suggested correction bolus will be too small resulting in undercorrection and ongoing hyperglycaemia. Your diabetes team will adjust the ISF as required but as you gain more experience you may start making adjustments yourself.

Similar to when adjusting the ICR, a good rule of thumb is to only adjust the ISF by relatively small increments (10%) and monitor the response. It is usually appropriate to watch for a trend over several days prior to making any further adjustments unless severe hypoglycaemia is occurring.

When adjusting the ISF it is important to remember that a**s the ISF gets stronger, the ISF number (in mmol/l per unit) gets smaller**. Therefore, it is helpful to talk about making the ISF **stronger** or **weaker** rather than higher or lower.

Example:

If the ISF is 2.5 mmol/l per unit:

- a 10% weaker ISF would be 2.8 mmol/l per unit (i.e., 1 unit reduces the BGL by 2.8 mmol/l).
- a 10% stronger ISF would be 2.3 mmol/l per unit (i.e., 1 unit reduces the BGL by 2.3 mmol/l).

Example of insulin dosing using a bolus advisor:

Francesca is on an insulin plan with Apidra before meals and Optisulin at bedtime. The diabetes team have calculated an insulin to carb ratio (ICR) of 5 grams per unit and a correction factor (ISF) of 2 mmol/l per unit. Her target BGL is 6 mmol/l. All of these settings have been programmed into her bolus advisor.

Today at breakfast her BGL is 12 mmol/l and she is going to eat 45 grams of carbohydrate. She enters the BGL and the carbohydrate count into her bolus advisor. The bolus advisor suggests a dose of 12 units.

The calculation used by the bolus advisor is detailed below for your interest. Remember, you will not need to perform this calculation.

Carbohydrate bolus:

45 / 5 = 9 units

Correction bolus:

BGL difference = 12 – 6 = 6mmol/L

6 / 2 = 3 units

Therefore the total bolus insulin dose is 9 + 3 = **12 units**

Adjustment using an insulin pump

The methods for calculating insulin doses used by a bolus advisor were derived from how an insulin pump works. Therefore, the concepts of insulin to carbohydrate ratio (ICR) and insulin sensitivity factor (ISF) or correction factor also apply to insulin pumps.

These factors are calculated by the diabetes team in the same way ('450 rule' and '120 rule') and are programmed into the insulin pump. The pump uses these settings and the same formulae to calculate a carbohydrate and correction bolus. Adjustments to the ICR and ISF are made in a similar way to those in a bolus advisor: incremental adjustments followed by a period of observation before making any further changes. Insulin pump settings and adjustments are discussed further in Chapter 13.

Summary of insulin adjustment

Insulin adjustment is an essential part of diabetes care. Think of:

- **Pattern adjustment:** look for patterns that indicate a need to adjust usual insulin doses because of high or low glucose levels at certain times over a few days or longer periods. Look at this regularly.
- **Day to day adjustment (flexible daily adjustment):** think whether you need to adjust a dose or doses now or today to take into account a variation in activity or carbohydrate intake.
- **Corrections:** think about the need for a correction adjustment, especially for correcting a BGL that is too high now.

Insulin adjustment examples

Below are some additional examples of adjustments as discussed above.

Example 1: Pattern adjustment

Jordan, aged 10

		Before breakfast	Before lunch	Before dinner	Before bed
Current insulin doses	Novorapid	4 units		3 units	
	Actrapid		4 units		
	Optisulin				8 units
BGLs	Monday	7.5	12.0	10.5	8.3
	Tuesday	6.5	15.6	6.7	9.5
	Wednesday	8.1	13.2	4.6	7.3
	Thursday	5.8	14.1	7.4	7.9

The blood glucose levels are generally within the desirable range except before lunch. A 1 unit increase in the morning dose of Novorapid should improve the pre-lunch BGL.

Example 2: Pattern adjustment

Claire, aged three

		Before breakfast	Before lunch	Before dinner	Before bed
Current insulin doses	Novorapid	2 units	1 unit	2 units	
	Levemir	3 units			3 units
BGLs	Monday	3.6	9.0	10.5	8.3
	Tuesday	5.1	11.5	6.7	9.5
	Wednesday	3.0	8.6	4.6	7.3
	Thursday	4.0	6.1	7.4	7.9

The blood glucose levels are generally within the desirable range except before breakfast when they are often too low. A 1 unit decrease in the evening dose of Levemir should help the morning BGL be slightly higher and within target. Checking the BGL overnight would also be a good idea until things improve.

Example 3: Flexible, day to day adjustment

Adam, aged 10

Adam has a swimming carnival and is in six events during the day. He finds it hard to eat extra food when swimming a lot. His usual insulin doses are:

	Before breakfast	Before lunch	Before dinner	Before bed
Novorapid	6 units	6 units	4 units	
Optisulin				8 units

His mum lowers his breakfast and lunchtime doses of NovoRapid to 4 units and lowers his dinnertime dose to NovoRapid 3 units. She also lowers his evening Optisulin to 6 units to reduce the risk of a delayed hypo. She makes sure to check the BGL in the late evening.

Example 4: Flexible, day to day adjustment

Louise, aged 16

Louise is having a normal day, but dinner is going to be high in carbohydrate and she is quite hungry. She is on a multiple daily injection plan with Humalog before meals and Levemir at bed. Usually she would have 8 units of insulin before dinner, but tonight decides that 10 units would be a better estimate of her insulin needs.

Example 5: Correction adjustment

Lok, aged 11

Lok is on a fixed MDI insulin plan.

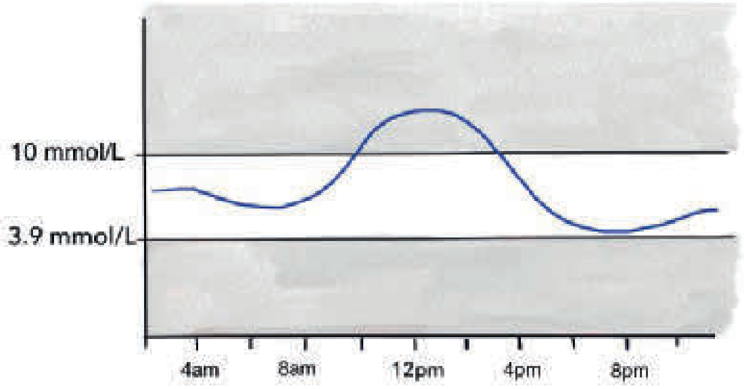
	Before breakfast	Before lunch	Before dinner
Actrapid	8 units	6 units	
Novorapid			7 units
Optisulin			14 units

Lok has a blood glucose level of 22 mmol/l (negative ketones) before dinner. His mother decides to give him 9 units of Novorapid instead of 7 units for dinner (around 30% extra of the current Novorapid dose). His mum tries to find out if there is any reason for the high glucose (e.g., less activity, a missed lunchtime dose or extra or inappropriate food). She also checks Lok's glucose level before bed and overnight to ensure the correction dose was not too strong resulting in hypoglycaemia.

Example 6: Adjustment of an insulin to carbohydrate ratio (ICR)

Marc, aged 13

Marc uses bolus advisor to dose Apidra for his main meals. His ICR is 7.5 grams per unit and his ISF (correction factor) is 2.2 units per mmol/l. He takes Optisulin 25 units before bed. His CGMS shows the following trend for the past few days:



Marc notices that his BGLs always seem high at morning tea but they return to the target range after his lunchtime insulin. He decides to try strengthening the ICR for his breakfast Apidra dose to 7.0 grams per unit. He does not change the ISF (correction factor) because the correction with his lunchtime insulin seems to be working well.

Common questions and answers

Why do insulin needs increase so much in puberty?

Puberty is a time of rapid growth and also hormonal changes. The body needs more insulin as it grows bigger and it is also more resistant to insulin at this time. After puberty and the growth spurt is complete, insulin doses often decrease.

Do I always need to check with my doctor or diabetes educator before adjusting insulin?

No, only if you are unsure. Regular adjustment of insulin is a necessary part of diabetes management and you will learn to do this. After a while many families and teenagers become quite experienced in adjusting the insulin themselves and it is good to be independent. If you don't feel confident, are unsure or it just isn't making sense, contact your educator or diabetes doctor for advice. Insulin can be much more difficult to adjust in some children than in others.

Chapter 13

Insulin pumps

Key Points

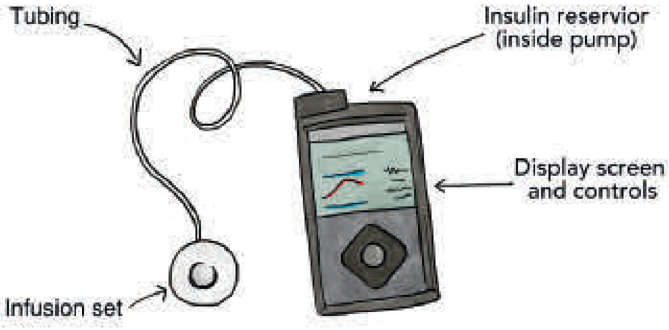
- **Insulin pumps are now widely used in the management of type 1 diabetes and are a core therapy with evidence of significant benefits.**
- **A pump delivers insulin under the skin from an insulin reservoir. The insulin is delivered according to individualised settings programmed into the pump.**
- **Insulin pumps and continuous glucose monitoring systems (CGMS) are being increasingly used in combined systems with increasing adjustment, automation and safety features. The latest generation of devices are called hybrid closed loop systems.**
- **Insulin pumps require frequent input from the pump user (to enter carbohydrate counts and glucose levels and to give boluses for meals or corrections), although successive generations of pumps have enhanced automation and other systems to assist the user.**
- **It is important to still have a supply of insulin pens (for both rapid and long-acting insulin) so that you can switch back to injections straight away if there are any issues with the pump.**
- **Hyperglycaemia in pump users is more concerning than with injections (there is a higher risk of developing diabetic ketoacidosis if the insulin delivery is interrupted)**
- **If the BGL rises above 15 mmol/l on a pump it is vital to check for problems with insulin delivery (the infusion site, line or pump), to check for ketones and manage appropriately (see page 178).**

This chapter explains details of using an insulin pump for diabetes management. However, as there are a number of different brands of insulin pump, the information here cannot be brand or system specific. When your child starts an insulin pump, additional individual information and education will also be given to you by the diabetes team. Remember that information in other chapters of this book is also relevant for insulin pump users.

What is an insulin pump?

An insulin pump is a small computerized device that delivers regulated amounts of insulin continually under the skin. The pump is programmed to give small background doses of insulin **(basal insulin)** continuously throughout the day and night depending on the individual's needs. Each time the person eats carbohydrate, they activate the pump to give a burst of insulin **(meal bolus)** to cover the amount of carbohydrate that they are going to eat. An extra bolus **(correction bolus)** can also be given to treat a high blood glucose level. In this way the insulin pump simulates more closely the way the pancreas would normally deliver insulin.

The insulin pump has a **reservoir** in it which is loaded with **rapid-acting insulin**. No long-acting insulin is used. The reservoir is driven by the computerized pump mechanism. This is attached by a plastic tube to a special plastic or thin metal needle **(cannula)** which is inserted under the skin usually of the abdomen or buttock region. This cannula, the tubing and reservoir has to be changed every 2 or 3 days which is easily done at home (this is called a set change). The pump can be disconnected for short periods (up to 2hrs) e.g., to have a shower, swim or play football, but in general it remains attached to the person 24 hours a day.



The features of different insulin pumps vary greatly. Some pumps are able to receive glucose readings directly from a continuous glucose monitoring system (CGMS) and many pumps can temporarily stop giving insulin to avoid hypoglycaemia when the CGMS predicts the glucose is dropping too quickly. Some pumps have the ability to alter how much insulin is being given to match the sensor glucose levels (hybrid closed loop system). These features are discussed in more detail below.

It is important to remember that, no matter what special features a pump has, **insulin pumps are not automatic**. All insulin pumps require input including glucose levels and carbohydrate counts with food, and require careful thinking and adjustment around exercise. Young children require parents or carers to operate the pump, but older children and teenagers become increasingly independent in operating the pump. In general, a pump requires as much work and thinking about diabetes as injections, but with a number of potential benefits. It is important for the person with diabetes to be motivated themselves to go on a pump rather than being talked into it by others.

Your diabetes team will discuss with you if your child may be a suitable candidate for a pump and help you to consider possible advantages and disadvantages. It may come down to personal views and preferences as to whether people with diabetes like the idea of an insulin pump. It is important to remember that modern insulin injection plans can still give most people good diabetes control if they concentrate on the routines and management of their diabetes.

Outline of insulin pump therapy

In general, people on insulin pumps manage their diabetes as follows:

- Basal rates (background insulin rates) are established that suit different time periods throughout the day. Most people have between 4 and 6 different basal rates, but occasionally more. The pump delivers this insulin continuously. New pumps adjust basal rate insulin delivery when in AutoMode.
- Bolus insulin doses are given for meals and snacks. The amount of carbohydrate that is eaten for a meal or snack needs to be fairly accurately estimated in grams or exchanges. This amount is entered into the pump, allowing the pump to calculate the amount of insulin required.
- Correction doses can be given at meal times or other times if the BGL is higher than desired at the time. The pump calculates a correction dose based on the BGL entered into the pump. In some cases the pump receives glucose levels automatically from the CGMS which can be used to calculate a correction dose.
- The pump still needs a number of glucose levels per day to function properly. The blood glucose level should be tested at least 4 to 6 times per day, or at any other time there is concern, but some CGMS systems require less. Even if CGMS is sending glucose levels to the pump automatically, most pumps still need the pump user to act on these levels (e.g., to give corrections) at least several times a day and to enter some fingerstick glucose levels for calibration.
- High blood glucose levels must be taken very seriously and action taken quickly to correct this, because there is no long-acting insulin being used.
- The pump can be disconnected for short periods throughout the day e.g., contact sport, shower, swim, but usually not for more than 2 hours.
- The insulin reservoir, tubing and infusion cannula need to be changed every 2 to 3 days, but sometimes more often.
- Frequent contact with the diabetes team is needed initially, but this later settles into a standard 3 monthly review if all is going well.
- Record keeping is important to monitor progress and to recognize the need for adjustments. Most systems upload data electronically to the cloud now and this can be accessed by your diabetes team for reviews.

Potential advantages of insulin pumps

For people who successfully make the change to a pump, there are a number of potential advantages. These are discussed below.

Better blood glucose control and HbA1c

Many people experience smoother blood glucose levels and a fall in HbA1c with pump therapy, but not all. Hypoglycaemia is less common in general with pumps, although it remains a significant risk. Pumps may help stabilize diabetes for people who work hard at their diabetes yet have difficult and unstable blood glucose control.

More accurate insulin delivery

The pump delivers insulin very accurately and simulates more closely the way a healthy pancreas works. Insulin absorption is much more predictable than with insulin injections. The pump can be accurately programmed to match the changing needs of any individual, and some pumps can even adjust the insulin delivery based on the glucose readings from the CGMS. Only rapid-acting insulin is used in pumps.

Flexibility and lifestyle benefits

The insulin delivery of the pump can be altered to allow for many variations in routine, eating patterns and exercise. This allows the times and amounts of meals to be more flexible and allows sleeping in and other variations in routine to a much greater extent. It also more easily allows for adjustments on sick days if the person is not eating or is needing extra insulin. Many people enjoy how easy and discreet pumps are for delivering insulin, compared to giving insulin injections with a pen.

Potential disadvantages of insulin pumps

There are a number of potential disadvantages of insulin pumps for some users.

Being permanently attached to a 'machine'

Some people do not like the thought of having to be attached to the pump almost constantly. The pump can be worn on the belt, kept in a pocket or concealed under the clothing in a pouch. A quick-release connection allows the pump to be disconnected easily for short periods e.g., a shower, swim etc. Nevertheless, some people cannot adapt to this permanent dependence on a machine.

Frequent input from the pump user

Insulin pumps need a lot of input from the user. Pump users who are not using CGMS need to be prepared to do 4 to 6 blood glucose tests a day, sometimes more. This is needed to ensure that the pump rates are correct, to help work out how much of a bolus dose to give at meal times and to minimise the risk of high blood glucose levels and ketones developing. Continuous glucose monitoring systems (CGMS) can help reduce the burden of fingerstick testing, and some systems can communicate the sensor glucose levels directly to the pump. Despite this, all pumps (even pumps linked to CGMS) require frequent input from the pump user for entry of carbohydrate counts for meals and giving correction boluses.

More rapid development of ketones or ketoacidosis

When a problem occurs with insulin delivery by the pump, ketones and ketoacidosis can develop much more quickly because there is no reservoir of long acting insulin in the body. Pump users are taught to watch for this and how to respond. This is another reason why more frequent BGLs need to be done by pump users. In case of pump malfunction, people always need to have insulin pens available to switch temporarily to at any time needed.

Skin infections or irritation

Because the cannula is left under the skin for up to three days, irritation or infection at the site can sometimes occur. This can be minimised by appropriate and careful technique. Occasionally, some people are sensitive to the adhesive or tapes which can cause skin irritation. There are a range of different tapes and topical skin preparations available to address this.

Cost

Your diabetes team will discuss how pumps may be accessed through private health insurance or government subsidies. Partial subsidies are available from the Australian Government for pump purchase as well as NDSS subsidy of consumables.

Diabetes management on a pump is a team effort

Most older children and teenagers adapt to the pump very quickly and are often quicker to grasp new technologies and gadgets than their parents. However it is very important that parents or other carers stay closely involved and interested in their child's diabetes. Just having a pump does not mean that more responsibility for diabetes management can or should be shifted onto the child or teenager.

The degree of involvement of parents and other family members will vary between different families. It may seem rather obvious to state these things but sometimes teenagers or parents perceive starting on a pump as a handover of responsibility for care to the teenager themselves. This is not the case and this needs to be a gradual process over many years with parents maintaining an active role and interest. In general parents should continue to have a role in:

- Checking and assisting with techniques of reservoir filling and infusion set insertion.
- Assisting with adjustment of basal and bolus doses, including adjustments needed for exercise.
- Ensuring that adequate BGL monitoring is being done and recorded and that other record keeping is maintained.
- Assistance at times of high BGLs or sick days.

- Assisting with assessing carbohydrate content of foods and other aspects of food planning.
- Assistance with ensuring that an insulin pen with rapid-acting insulin is available and carried at all times.
- Assistance with management of hypos and ensuring adequate provision is taken to avoid or minimize risk of hypos.
- Assistance with communications with pump team and in organising and attending hospital visits.
- Assistance in setting up device-specific software and uploading pump data prior to an outpatient clinic visit.
- Assistance with maintaining adequate supplies of insulin (including availability of long-acting insulin), reservoirs, infusion sets, batteries, tapes etc.
- Any other general aspects of diabetes and health management.

Steps in commencing insulin pump therapy

Suitability for a pump

This will be discussed with you by the diabetes team and it is important for you to find out as much as you can in preparation. The diabetes team will provide you with information and the internet is another good source. You and the diabetes team will need to make a joint decision about whether or not to start on an insulin pump. Ultimately, it is your diabetes specialist that makes the recommendation for commencing a pump, so they must be involved in your discussions.

Two important factors for suitability are a demonstrated ability to monitor blood glucose levels at least 4 to 6 times per day and a motivation to achieve and maintain good diabetes routines and control.

Preparation for starting on the pump

Once you and your diabetes team have decided that you are suitable for a pump, the diabetes nurse educator will assist with the arrangements which need to include:

- Discuss with the pump team how arrangements will be made for purchase of the pump and ongoing supplies (e.g., through your health fund).
- Arrangements will be made for pre-pump education with your diabetes team. You may be given specific tasks to complete (e.g., reading or online education) before the date of the pump start.
- A date will be arranged for the pump start. This is done as a full day outpatient visit. The person with diabetes and at least one parent or guardian need to be present also. Much of the time is spent on technical training about the pump and pump therapy.
- The diabetes team will set the starting doses of insulin for the basal and bolus doses; these will be adjusted, especially over the first few days as things are settling in.

Wearing the pump

You will receive full instruction on the operation of your pump during your pump start. Details are all contained in the instruction guide that comes with your pump and you should keep this for reference. You will soon become very familiar with all of the commonly used features on the pump.

It is important that the pump wearer is comfortable in where and how they wear the pump. The various options will be discussed with you by the pump educator. Various cases, pouches and accessories are available, including:

- Belt pouches and clips.
- Pouches that are worn under the clothing, including waist pouch, thigh pouch, leg pouch, bra pouch and sports guard pouch.
- Pouches can also be sewn into clothing, e.g., pyjamas.

Remember that the pump will have to be accessed to give boluses for eating and the site needs to be accessible to check for any problems.

Many children simply carry the pump in their pocket and this is simpler and more convenient than using pouches etc. This is possible by making a small hole in the seam of the pocket through which the tubing can be passed.

Infusion sets and tapes

The pump delivers insulin via an infusion set which has a cannula on the end of it and is inserted beneath the skin. The insulin, reservoir and infusion set need to be changed at least every 2 to 3 days, sometimes more often.

Your pump team will advise on the most appropriate type of infusion set for you. There are a variety of sets available from different manufacturers with different features, cannula lengths and tubing lengths.

It is usually most convenient to insert a new set after a bath or shower, when the skin is clean and dry. This should be at least 3 hours before bed. The reason for this is so that there is adequate time before bed to ensure that the new set is working properly and BGLs are satisfactory.

Full instructions on loading insulin and inserting the particular set type will come with each set and will be taught by your educator. Please note the importance of hand-washing and a clean environment for changing a set. It is best to change a set in a relaxed and unhurried environment.

Site selection and rotation

The abdominal (tummy) area is a good area since insulin absorption tends to be most consistent. Avoid the belt-line and waist-line, any place that clothing would rub and avoid a circle of about 4 cm around the umbilicus (belly button). Other sites can be used including the upper, outer buttock or the thigh.

The site (including reservoir and infusion set) needs to be changed if there is any redness, irritation or suspected problem with insulin delivery. Move well away from the previously used site.

Disinfecting the skin and avoiding infection

Before inserting the infusion set it is important to wash your hands well with soap and water and disinfect the skin area using the recommended antiseptic. It is important to use careful technique not to contaminate the insertion site after it has been cleaned or any of the equipment. Infection at the site is a risk if appropriate precautions are not taken. Any soreness, redness or swelling at the infusion site indicates a need to insert a new infusion set at a new site without delay and remove the old set. Full instructions are included with each infusion set. Make sure you clean the top of insulin vials with an alcohol swab when filling a new reservoir.

Tapes and skin preps

Special skin preps and tapes are available for people who have sensitive skin or if you need the tape to be extra sticky. It is important for the infusion set to be well secured to avoid accidental dislodgment.

Infusion site and set problems

With care, infusion site problems can be kept to a minimum. However, most people will experience a problem at the infusion site at some time. Possible problems include:

1. **Dislodgment, blockage or kinking of the cannula**

   This will happen from time to time, again more commonly with vigorous activities and especially after direct knocks to the cannula site. You may see the tape or cannula dislodged or sometimes leakage of insulin. Often the first indication that something has happened to the site is high BGLs. Unexplained high BGLs always requires a full check of the insulin reservoir, pump, tubing and site. When no explanation is evident, the insulin, reservoir and infusion set should be changed anyway as this is the most likely cause of the problem.

2. **Sets not adhering well**

   Vigorous activities and sweating make this more likely. Some special preparations are available if needed to help tapes stick more strongly. Different types of sets and tape will sometimes stick better on some people. For any set adhesion problems consult your Pump User Manual, pump company customer care line or your diabetes team.

3. **Infection**

   Tenderness, redness, swelling or pus at the cannula site may all indicate infection. If this occurs the site must be changed without delay. Antiseptic or antibiotic creams may be required or sometimes oral antibiotics. The chance of infection is minimised by careful handwashing and disinfecting when inserting the cannula and keeping the area generally clean.

4. **Irritation or allergy to tapes**

   The tapes used have low allergic potential, but some people may be sensitive to them. Different sets and tapes are available if this is the case. Your diabetes team may also suggest other techniques to reduce irritation such as barrier products or low dose steroid sprays onto the skin.

   Establishing a good general skin care routine including using hypoallergenic (less irritating) soap, drying the skin thoroughly after bathing and moisturising regularly is important. Pump wearers must be particularly careful to remove an 'old' set gently: never rip the set off. Gently and slowly remove the set, perhaps using an oil-based product to assist removal.

5. **Air bubbles in the infusion tubing**

   It is important that the insulin is at room temperature prior to filling the reservoir. Make sure you spend time tapping the air bubbles out during the filling and priming procedure. Check that the tubing is well attached to the reservoir. Tiny bubbles (like champagne bubbles) do not affect the BGLs. The air itself does no harm; rather it is the insulin that is missed when air is infused that can cause the problems.

6. **High blood glucose levels after a set change**

   If after a set change, blood glucose levels become high or a correction bolus does not work, it is likely that there has been a problem with the insertion of the set. Check the site for any insulin leakage, blood in the first part of the set or other problems. Check that the tubing does not have large amounts of air in it. Check for any error messages on the pump and that the pump is operational. Sometimes in lean people at certain sites, where there is not much of a fatty layer beneath the skin, the cannula tip may hit up against the muscle layer and this stops proper delivery of insulin. Pain at the time of insertion and afterwards will often occur if this is the case. Some people who are too lean on the abdomen will use the upper buttock where there is more of a fatty layer.

If no other easily fixed problem is found, the set must be changed again.

When in doubt, change the set.

Disconnecting and reconnecting the pump

1. Disconnecting

Most infusion sets contain a quick release feature that allows the pump to be disconnected for short periods e.g., vigorous sport, shower etc. Ordinarily the pump should not be disconnected for longer than 2 hours.

The pump must be disconnected for taking a bath as the temperature of a bath will damage the insulin in the pump. The pump is usually disconnected for very vigorous sports, contact sports and swimming. A completely waterproof pouch is available for other watersports.

What to do with a pump when it is disconnected will depend on the type of pump. For some models the pump should stay running but for other models the user will need to ‘suspend’ the pump while it is disconnected. The pump should be kept in a place that is safe, clean, cool and dry. Your diabetes team will advise you on the correct approach for your pump.

2. Reconnecting

When reconnecting, make sure the pump is re-started if it was suspended. If any of the connections have become contaminated during disconnection, wipe with an alcohol wipe before reconnecting. No priming dose is needed when reconnecting, whether or not the pump was suspended.

Insulin types

Only rapid-acting insulin is used in the pump. This means that **there is no long-acting insulin reservoir in the body** and this is why a pump or infusion set problem can lead quickly to rising BGLs if not detected.

The rapid-acting insulin that is infused by the pump forms only a small reservoir under the skin which is almost all absorbed over 3 to 4 hours. Unless a bolus of insulin has recently been given this will be only a very small amount of insulin.

Your pump contains a feature that allows the estimated duration of action of insulin to be set for each individual, as part of the insulin on-board and bolus wizard features (see later). Usually this is set at approximately 3 hours and your diabetes team will advise what is best for you, taking into account your individual circumstances and pump model.

Setting the pump rates

The pump team will program your initial pump settings, including adjustment of any alarms and safety features required. A maximum bolus dose and maximum basal rate will be programmed for each individual to prevent the possibility of accidentally giving too much insulin; these will need to be changed over time as a child grows and needs more insulin.

In the following sections, details and examples of calculating pump doses are given. Initially these calculations will be done by your pump team. With experience, you will get a feel for how to adjust pump rates yourself.

Starting rates and total daily dose of insulin

Your starting doses will be individually set by the diabetes team, however the following gives a guide as to how this is calculated. The pump delivers **basal insulin** continuously 24 hours per day for background insulin requirements. On top of this **boluses** or bursts of insulin are given to cover carbohydrate food intake **(carbohydrate bolus or carb bolus)** or to correct high blood glucose levels **(correction bolus)**.

The total daily dose that the person is having on injections often needs to be reduced by approximately 20%, because the pump is a more efficient method of insulin delivery. Between 35 and 50% of this is given as basal insulin over 24 hours and the rest becomes the bolus doses for food (see calculation below).

Basal insulin

Most people have about 35 to 50% of their total daily insulin requirement given as basal insulin. At first this can be divided evenly across the whole day with the same amount given every hour, but usually we start with a pattern that has 4 or 5 basal rates which takes into account small variations in the need for basal insulin at different times of the day. The individual basal pattern needed is strongly influenced by age and puberty.

When setting and adjusting basal rates an important principle is that the basal rate needs to change 2 to 3 hours before the desired change in insulin effect.

Example of basal insulin calculations:

- A person is having 60 units of insulin per day in total while receiving injections (total daily dose on injections = 60 units).
- For changing to a pump, the dose is reduced by 20% = 48 units. This is their new **total daily dose (TDD)** for their insulin pump.
- Basal insulin: 45% of TDD = 22 units per day = 0.9 units per hour (or your team may set a number of basal rates which vary slightly around this rate).

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand the principles of how your pump is programmed.

Bolus doses

On top of the basal doses of insulin, boluses or bursts of insulin are needed. There are 2 types of bolus:

1. **carbohydrate bolus** (also called carb bolus or meal bolus) – to cover the amount of carbohydrate that is going to be eaten.
2. **correction bolus** – an extra bolus to correct a high BGL back down to target levels.

Insulin pumps use a mathematical formula to calculate the insulin bolus doses. Several specific settings need to be programmed into your pump to enable the pump to calculate an individualised dose.

These include:

- The **insulin to carbohydrate ratio (ICR)** which calculates the carbohydrate bolus.
- The **insulin sensitivity factor (ISF or correction factor)** which calculates the correction bolus.

Other settings which the pump uses to calculate doses include the **target blood glucose level** and the **insulin-on-board** or **active insulin time** (how long the insulin will be acting). These will be discussed further below.

In the early stages of having a pump your diabetes team will decide on these settings, program them into the pump and make any necessary adjustments. It is helpful for you to understand how the ICR and ISF work so that you can eventually learn to make adjustments yourself.

Carbohydrate boluses using the insulin to carbohydrate ratio (ICR)

The insulin to carbohydrate ratio (ICR) is a formula used to calculate the dose of insulin required to cover the carbohydrates that will be eaten in a meal or snack. For example, an ICR of 10 grams per unit means that 1 unit of insulin covers 10 grams of carbohydrate. The ICR is individualised for each person based on how much insulin that person typically requires.

The insulin pump uses the ICR programmed into the pump settings to calculate the carbohydrate bolus. An example of this calculation is detailed below for your understanding. Remember, you will not need to do this calculation yourself, as the insulin pump will do it for you.

Example of calculating the carbohydrate bolus using the ICR:

If the child will eat 50 grams of carbohydrate for lunch and their ICR is 10 grams per unit:

50 / 10 = 5 units

Therefore, the insulin pump would calculate 5 units to cover the carbohydrates for lunch

Some people find that this ratio is different at different meals (they need different doses of insulin to cover the same amount of carbohydrate at different times in the day). The commonest variation is people who find that they need a stronger insulin to carbohydrate ratio for their breakfast compared to other meals.

The ICR is individualised depending on each person's insulin requirements. **Your diabetes team will calculate your ICR for you and program it into the insulin pump.** We will briefly describe how the ICR is calculated so that you have a general understanding of the concepts, however you will not be expected to do this yourself. These calculations are based on the total daily dose (TDD) of insulin which is described above.

How your ICR is calculated

The '450 rule' is an example of how an ICR may be calculated. Different centres may use slightly different rules for this calculation. It is used to calculate the approximate ICR your child will require.

The ICR is calculated by dividing the total daily dose of insulin (TDD) into 450.

For example:

TDD = 48 units.

450 divided by 48 = 9.4

Therefore 1 unit of insulin will cover approximately 9 grams of carbohydrate (thus the ICR = 9).

This figure is programmed into the pump.

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand how your insulin pump is programmed. The '450 rule' does not work for everyone but is a good starting point. The starting ICR used to calculate the meal carbohydrate boluses will be modified as needed over time.

Some people prefer to count their carbohydrates in exchanges rather than grams (1 exchange = 15 grams). In this case the ICR settings in the pump are programmed as 'units per exchange'. Therefore, if you have an ICR of 1 unit per exchange, the pump will deliver 1 unit of insulin for every exchange of carbohydrate. If your ICR is programmed in exchanges instead of grams, it is important to take this into account when adjusting the ICR (discussed later).

Most families count carbohydrates in grams rather than exchanges. Your diabetes team will discuss which option is most suitable for you.

Some pumps allow different types of boluses to be set for certain circumstances. Most people will use a **normal bolus** in which the bolus is all infused almost immediately, usually over a minute or so. This bolus is still only absorbed into the body over 3-4 hours. However the pump can also be programmed to give a dual wave bolus (sometimes also called combination bolus) or a square wave bolus. A **dual wave bolus** gives a specified percentage of the insulin immediately with the remainder given over a longer period of time. A **square wave bolus** spreads the total amount of bolus evenly over the time specified. This is discussed in more detail later.

Before any bolus it is wise to check, if possible, that your pump reservoir has plenty of insulin and there are no problems with your tubing or site by taking a quick look at all of these. This ensures that you check these things regularly.

Correction boluses (using the insulin sensitivity factor)

A correction bolus is an extra bolus given at any time to correct a blood glucose level that is unexpectedly high. Often this is given before a meal or snack as this is when the BGL is done, in which case the correction bolus is added to the meal bolus. The pump calculates the amount of insulin to bring the BGL down to a preset **target blood glucose level** (usually 5 or 6 mmol/l).

The **insulin sensitivity factor** (ISF or correction factor) is used by the pump to calculate the correction bolus. The ISF describes how much (by how many mmol/l) the blood glucose will reduce when 1 unit of insulin is given. For example, an ISF of 2.5 mmol/l per unit means that 1 unit of insulin will correct the BGL by 2.5 mmol/l.

An insulin pump will use the ISF to figure out how much insulin is required to correct the BGL to the target level. The process is explained below for your understanding, however the insulin pump will do this calculation for you.

Calculating the correction dose using an ISF can be broken down into 2 steps:

1. **Work out the BGL difference.**

   When a BGL is entered into the insulin pump, the pump figures out the difference between the current BGL and the target BGL (ie. how many mmol/l the BGL needs to correct by).

2. **Use the ISF to calculate how much insulin is needed to cover the BGL difference.**

   This is done by dividing the ISF into the BGL difference.

Example of calculating the correction bolus using the ISF:

If the ISF is 2.5 mmol/l per unit, the current BGL is 18 mmol/l and the target BGL is 6 mmol/l

BGL difference = 18 – 6 = 12 mmol/l (we want to reduce the BGL by 12 mmol/l)

12 / 2.5 = 4.8 units (the pump would calculate 4.8 units of insulin as a correction)

Remember, you will not need to do any of these calculations yourself. They are all performed by the insulin pump based on the settings programmed in by your diabetes team.

At a mealtime, the correction bolus of insulin is added to the carbohydrate bolus so that the total mealtime dose covers the carbohydrates and corrects any hyperglycaemia. The pump will do this automatically if both a carbohydrate count and a BGL are entered in.

Many people have different correction factors for different periods of the day. For example, a gentler correction factor may be desired overnight when a young child may be more sensitive to insulin.

Remember: if BGL is unexpectedly high it is important to check that there are no problems with the pump and infusion site and to check for ketones (see page 178). Corrections will not work if the insulin is not being delivered!

How your ISF is calculated

The '120 rule' is an example of how an ISF may be calculated. Different centres may use slightly different rules for this calculation. It is used to calculate the approximate ISF or correction factor your child will require.

The ISF is calculated by dividing the total daily dose of insulin (TDD) into 120.

For example:

TDD = 48 units

120 divided by 48 = 2.5 (ISF or correction factor)

Therefore the BGL should fall by 2.5 mmol/l for every unit of insulin given

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand what your pump is doing. Also, the '120 rule' does not work well for all people, especially the very young and other special circumstances. It gives a starting point from which adjustments can be made by you and the diabetes team.

Insulin-on-board (active insulin time)

Pumps assist by keeping track of how much insulin has been delivered that is yet to act. i.e., insulin sitting under the skin that is to be absorbed and act over the next 3 to 4 hours. The computer algorithms that do this are slightly different in the different pump brands, but the principles are similar. The key is setting a factor that suits the individual for estimated duration of insulin action – usually in children this is set to approximately 3 hours. It is important to understand that the characteristics of the insulin cannot be changed – this setting reflects how long the insulin acts for an individual which can vary accordingly to age, size and other factors. Your diabetes team will advise the suitable settings here.

Thus, when using a correction bolus, the pump will take into account when the last correction bolus was given and how much of that will still be acting (i.e., will the BGL still be falling without the need for an extra bolus). This will allow an adjustment of the correction bolus to be made to avoid the BGL dropping too much and causing a hypo (i.e., will avoid what is termed 'insulin stacking').

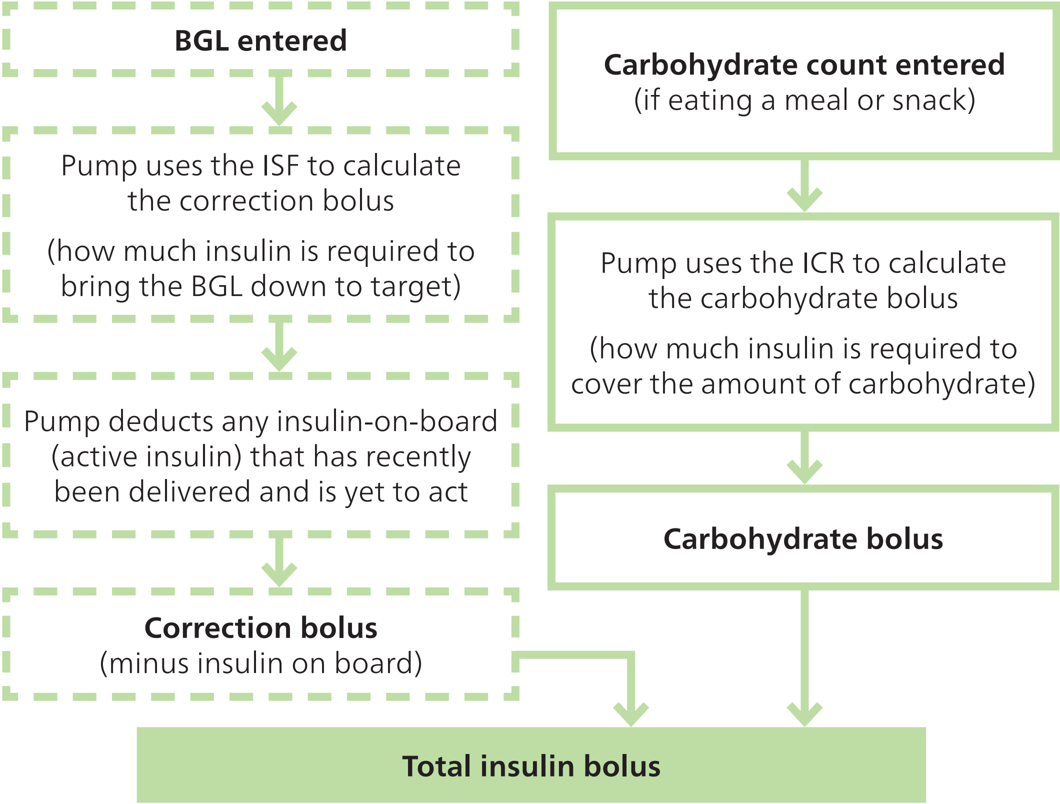
As an approximation, 25-30% of a rapid-acting insulin bolus dose is absorbed each hour. Therefore after 1 hour 30% is absorbed, after 2 hours 60% and after 3 hours 90%.

Example:

A correction bolus of 5 units is given 2 hours before the BGL was found to be 20 mmol/l. Insulin duration has been set for 3 hours in this person's pump. The pump then calculates that approximately 60% of this previous dose has been absorbed, therefore 40% (=2 units) is still to act. Thus, the pump would suggest reducing the next correction bolus by 2 units. (This example assumes that you have checked there is not an insulin delivery or site problem and that the carb bolus was correct).

Bolus calculator summary

We have discussed how the pump software assists the calculation of a bolus dose to cover the carbohydrate in a meal and also a blood glucose correction. Here is an overview of how the pump calculates the total insulin bolus:



Negative correction

This is when the BGL entered into the pump is **below** the target glucose level. In this case the ISF is used to calculate how much insulin should be **subtracted** from the dose to bring the glucose back to target. The pump will take this amount away from the carbohydrate bolus to calculate the total insulin bolus.

Adjusting the pump rates

The pump rates that you start on are likely to be adjusted over the first few days or weeks and then from time to time depending on age, growth, changes in activity and diet etc. The aim is that you will gain experience in making these changes and your diabetes team will always be available to guide you.

Adequate blood glucose testing and keeping good records is essential to allow adjustment of insulin pump therapy. Electronic records of blood glucose levels entered into the pump and insulin doses administered are stored in the pump and can be accessed through software provided by pump manufacturers. The diabetes team will need to access these records to make adjustments to the pump settings. It is important to download the records from your pump to the computer prior to your clinic visit so that the diabetes team can access the information. Your diabetes team and the pump manufacturer will advise you about how to do this. Continuous glucose monitoring (CGM) can also assist with pump adjustments and may be recommended by your diabetes team.

Adjusting basal rates

Most people will end up on more than one basal rate for the 24 hour period. This takes into account different basal insulin requirements at different times of the day. **The total daily amount of basal insulin is usually between 35 and 50% of the total daily dose (TDD)**, sometimes a little higher or lower in certain circumstances. If your total daily basal insulin is outside this range you may have an imbalance and should consult your pump team.

Certain scenarios may suggest that the basal rate is too high or low:

Basal rate is too high	Suggested by: • Frequent hypos at a similar time of day • A drop in BGL when a meal is skipped • The need for excessive food intake to avoid frequent hypos • Excess weight gain
Basal rate is too low	Suggested by: • Frequent raised BGLs at a similar time of day • A rise in BGL when a meal is skipped • The need for frequent correction boluses for high BGLs

Generally, a basal rate should keep the BGL steady (or lower the BGL only slightly) when no carbohydrate-containing food is eaten. There are simple ways to check if a basal rate is appropriate.

To test the night time basal rate:

- Give the last insulin bolus (i.e., dinnertime bolus) at least 4 hours before bed.
- No more carbohydrate should be consumed after dinner until morning.
- Test the BGL at bedtime: it must be in the target range of 5-10mmol/l. If the BGL is above or below target range manage as required and delay basal testing until another night.
- Test the BGL at 2 or 3am and on waking.
- A good basal rate will keep the BGL level overnight or drop it only 1 to 2 mmol/l.

To test the basal rate during the day:

- Start the test when the BGL is in the pre-meal target range (between 4 and 8 mmol/l).
- Have a carbohydrate-free meal and therefore have no mealtime bolus.
- Test every 1-2 hours for 5 hours.
- A good basal rate will keep the BGL level or drop it only 1 to 2 mmol/l over this period.

If the blood glucose rises above target during any of these tests, increase the basal rate covering that time slightly, usually by about 10% of the existing rate.

If the blood glucose falls more than slightly (1-2 mmol/l) during any of these tests, decrease the basal rate covering this time slightly, usually by about 10% of the existing rate.

Remember that **changes in basal rates need to be made 3 to 4 hours before the desired change in insulin action** because of the lag in effect of absorption from under the skin.

Adjusting carb boluses

Your diabetes team will give you initial settings for your ICR i.e., the setting in your pump that indicates how many grams of carbohydrate is covered by 1 unit of insulin. This may have to be adjusted from time to time depending on how well it is working.

A correct carb or meal bolus is that which returns the BGL to within 2 mmol/l of the starting BGL after about 3 hours. If a low occurs within this period then a weaker carb bolus setting is needed. If the low occurs within 1 to 2 hours of the bolus a larger change will be needed than if it occurs between 2 and 4 hours after the bolus.

A good rule of thumb is to only adjust the ICR by about 10% at a time and monitor the response over several days. An exception to this is if severe hypoglycaemia is occurring (whereby the ICR may need to be weakened by more than 10%) or if your diabetes team suggests a larger change. How you adjust the ICR will vary depending on whether you are counting carbohydrates in grams or exchanges.

If carbohydrate counting in grams:

If counting carbohydrates in grams, **as the ICR gets stronger the ICR number gets smaller** (i.e. the number of grams covered by 1 unit of insulin reduces). To avoid confusion it is helpful to talk about making the ICR **stronger** or **weaker** rather than higher or lower.

For example, if the ICR is 10 grams per unit:

- a 10% weaker ICR would be 11 grams per unit (i.e. 1 unit now covers 11 grams of carbohydrate).
- a 10% stronger ICR would be 9 grams per unit (i.e. 1 unit now covers 9 grams of carbohydrate).

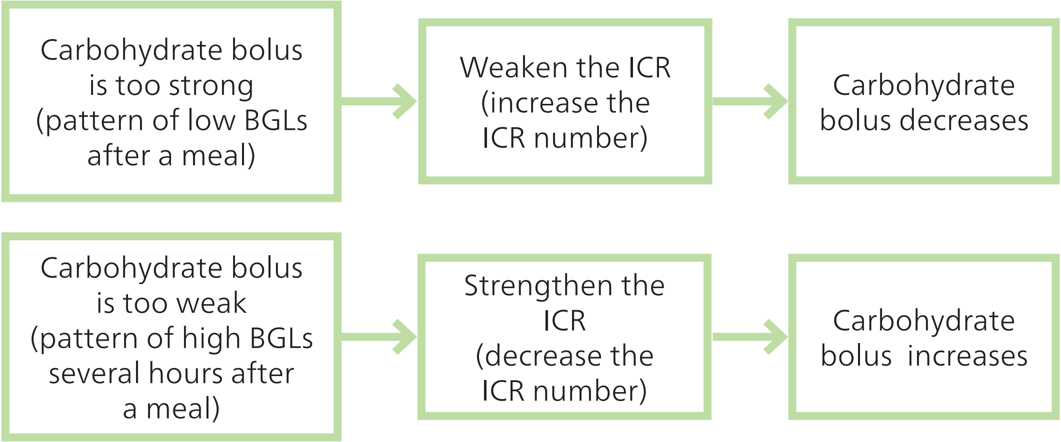
Example:

John's glucose level is dropping below target after lunch. This means his lunchtime ICR is too strong so the insulin dose calculated by the pump is too high. John's current ICR is 10 grams per unit which is weakened to 11 grams per unit.

If John eats 50 grams of carbohydrate at lunch:

- At an ICR of 10 his pump calculates a carbohydrate bolus of 5 units
- At a weaker ICR of 11 his pump now calculates a carbohydrate bolus of 4.5 units

Key points (if counting carbohydrates in grams):



If carbohydrate counting in exchanges:

The opposite is true if counting carbohydrates in exchanges. In this case as the ICR number increases the dose gets stronger.

For example, if the ICR is 1 unit per exchange (i.e. 1 unit of insulin covers 15 grams of carbohydrate):

- a 10% **weaker** ICR would be 0.9 units per exchange (i.e. 0.9 units now covers 15 grams of carbohydrate).
- a 10% **stronger** ICR would be 1.1 units per exchange (i.e. 1.1 units now covers 15 grams of carbohydrate).

Most families count carbohydrates in grams rather than exchanges. Your diabetes team will discuss which option is most suitable for you. If you are counting your carbohydrates in exchanges it is important that the ICR in your pump is programmed in exchanges and any adjustments take this into account.

It is very important that you understand which direction to adjust the carbohydrate factor if needed. If in doubt, check with your diabetes team.

Adjusting the correction factor or insulin sensitivity factor (ISF)

These settings will also be calculated by your diabetes team at the time of the pump start, but will need to be adjusted from time to time.

An appropriate correction factor will bring a high BGL down to target within 2 to 3 hours, without causing hypoglycaemia.

If the BGL is not coming down adequately with one or more corrections, this suggests that a stronger correction factor is needed. If the BGL comes down too much or too quickly, this suggests that a weaker correction factor is needed. Generally, make a change of about 10% of the current factor and then evaluate that over several days.

Remember that **the lower the ISF, the stronger the correction**. Therefore, a young child who needs less insulin will have a weaker ISF (higher ISF number) than an older child who requires more insulin. The following examples illustrate a correction dose for a BGL of 20mmol/l using a different ISF:

A 4 year old might have an ISF of 8 (1 unit of insulin lowers the BGL by 8 mmol/l).

Therefore, to come down from 20 mmol/l to 6 mmol/l, the pump would suggest (20-6)/8 = 1.75 units of insulin.

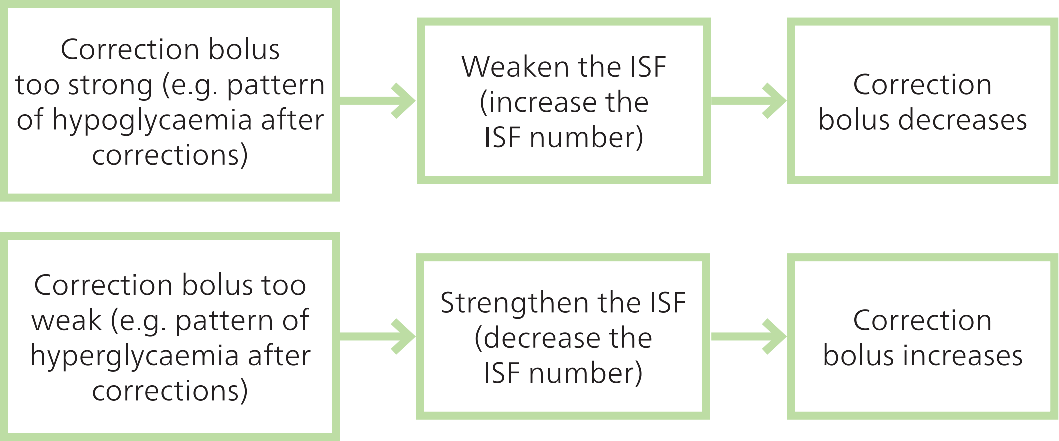
A 15 year old might have an ISF of 2 (1 unit of insulin lowers the BGL by 2 mmol/l).

Therefore, to come down from 20 mmol/l to 6 mmol/l, the pump would suggest (20-6)/2 = 7 units of insulin.

When making adjustments it is helpful to talk about making the ISF **stronger** or **weaker** rather than higher or lower.

Therefore, if the correction given by the pump is too strong (causing hypoglycaemia), the ISF needs to be weakened (so the ISF number needs to increase).

Key points for ISF adjustment:



It is very important that you understand which direction to adjust the correction factor (ISF) if needed. If in doubt, check with your diabetes team.

Keeping a record of pump rates and changes

Pump settings will change from time to time and it is important that you keep a written or electronic record of these. This is because if the pump is damaged or fails, you need to know what to program into a replacement pump when it arrives. We suggest that you regularly perform a pump download to keep an electronic copy of these records.

Monitoring and target ranges

Blood glucose monitoring

Successful use of a pump requires an adequate amount of blood glucose monitoring, usually 4 to 6 per day but preferably more. This information is required to know how to adjust pump doses and to detect unexpected high readings and possible insulin delivery problems. It is strongly recommended that insulin pump users also use continuous glucose monitoring systems (CGMS), however fingerstick BGLs are still required to calibrate the CGMS and to confirm any very high or low sensor glucose readings. Insulin pump users should have a meter that can also measure blood ketones.

It is important to keep a detailed record of blood glucose levels, ketone tests, basal rates and boluses, carbohydrate exchanges and exercises. This is usually done through the pump itself. Software provided by the pump manufacturer allows the records on the pump to be downloaded onto a computer. Your diabetes team can then access these records via the internet and help make any adjustments. This system relies on consistent use of the pump: all glucose levels need to be entered into the pump, even if no bolus is about to be given. This allows the pump software to contain a full BGL history which is important for reviews and adjustments. Some types of CGMS can automatically send the sensor glucose levels to the pump, which makes record keeping easier.

At first, a total of 8 BGL or CGM readings combined will be required routinely per day, with extra readings if something of concern is happening. The usual times will be:

- Before breakfast
- Before morning tea or 2 hours after breakfast
- Before lunch
- Before afternoon tea or 2 hours after lunch
- Before dinner
- Before supper or 2 hours after dinner
- Late evening
- 3am

Later this may be able to be reduced to 4 to 6 BGLs per day by omitting routine 3 am readings and one or more of morning tea, afternoon tea and supper. It is essential however to always check the BGL before main meals so that you can ensure that the correct bolus (carb bolus ± any correction bolus) is given.

BGL targets

The target range for blood glucose levels is between 3.9-10mmol/L. However, the preferred range may vary depending on when you take the reading, generally:

- Before meals 4 to 7 mmol/l
- After meals and before bed 5 to 10 mmol/l
- at 3am 5 to 8 mmol/l

Continuous glucose monitoring systems (CGMS or CGM)

Continuous glucose sensors are available which can be used alone or integrate with some pumps. CGMS is strongly recommended for all pump users. These sensors use a thin filament placed under the skin, much like a pump set is inserted, and sense the glucose level in the layer under the skin. This is then converted to a blood glucose value and is displayed on the device. More information about CGMS can be found in Chapter 7 ('Monitoring diabetes control'). Integration of CGMS with insulin pumps is discussed in more detail below.

Sensor-augmented pump therapy

There are several features that only become available when a pump and CGMS are used together. These can help make diabetes management safer and easier. It is important to know that not all types of insulin pump are compatible with all forms of CGMS and that some features are only available on certain pumps. Your diabetes team can discuss the various CGMS and insulin pumps with you.

Low glucose suspend (suspend on low)

This is when the insulin pump automatically stops delivering insulin when the sensor glucose level falls below a certain limit. This low limit is programmed into the pump and is usually around 3.4-3.9 mmol/l. This is a safety feature that can help prevent severe hypos.

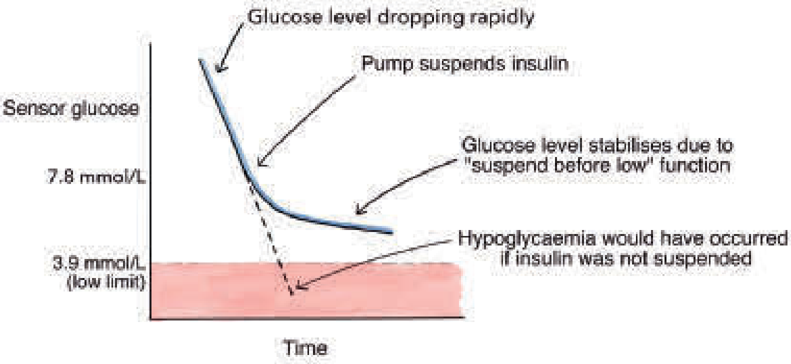
Predictive low glucose suspend (suspend before low)

A pump with this feature can be programmed to stop delivering insulin when it predicts that a hypo is likely to occur within the next 30 minutes.

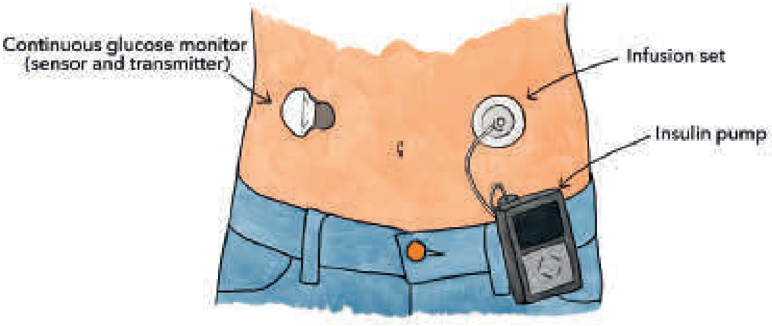
Here is an example of how one brand of system is programmed to deal with low BGLs:

The pump will suspend when the glucose level is within 3.9 mmol/l of the programmed low limit and is likely to drop within 1.1 mmol/l of the low limit within 30 minutes. To figure this out the pump performs a calculation based on the current sensor glucose, the sensor glucose trend (how rapidly the glucose is falling) and the programmed low limit.

In the graph below, the 'low limit' programmed into the pump is 3.9 mmol/l. The CGMS detects that the glucose is falling rapidly. When the sensor glucose reaches 7.8 mmol/l (3.9 mmol/l above the low limit) the pump temporarily suspends insulin delivery to avoid hypoglycaemia.



When the glucose level is back within the normal range the pump will recommence insulin automatically. The pump user is often unaware that the predictive low glucose suspend has happened. When the predictive low glucose suspend feature is turned on it is important not to attempt to interfere with the function by suspending the pump yourself or treating a hypo that hasn't occurred yet. This will likely cause the glucose to rise above the normal range.



Insulin pump with CGMS device which communicates wirelessly with the pump

Hybrid closed loop (AutoMode or SmartGuard)

A closed loop system is when a pump and CGMS are able to automatically manage the glucose level without any input from the pump user. This is not currently possible but is an area of ongoing research. **Hybrid** closed loop systems are systems which can manage some of the glucose levels automatically but still require some input from the pump user.

In recent years, hybrid closed loop technology has become available on some pumps in Australia. This is called "AutoMode" or "SmartGuard" on the Medtronic system. Other systems are currently being developed.

When an insulin pump is in AutoMode it can adjust the basal insulin delivery based on the glucose level detected by the CGMS. The basal insulin delivery will increase or decrease to keep the sensor glucose within target range. In this way, the pump provides insulin corrections automatically. Using complex algorithms, the pump is able to 'learn' over time how much insulin is required to maintain the glucose within the normal range. Thereby, a pump can adapt to each individual's needs.

Some input from the pump user is still required. Carbohydrate counts still need to be entered into the pump with meals and snacks and a mealtime bolus needs to be administered. Glucose levels that are very high also require manual correction.

Pumps with hybrid closed loop technology still have the ability to function as a normal pump would when AutoMode is switched off. This is called manual mode. All of the usual settings for basal rates, carbohydrate factors (ICR) and correction factors (ISF) are programmed into the pump so that it can work in manual mode. These manual settings need to be kept updated over time.

The hybrid closed loop system does not work well if there is prolonged significant hyperglycaemia. If significant hyperglycaemia is not corrected manually the pump will "exit" AutoMode and will continue to function as a normal pump would (manual mode). This means that there will be no further automatic adjustments to the basal rates until the situation is resolved by the pump user. A common reason for exiting AutoMode is a missed carbohydrate bolus causing the glucose level to rise after a meal. After the glucose level is back within target range, AutoMode can be recommenced.

A hybrid closed loop system can reduce some of the burden of diabetes care but it is not a 'set and forget' system. It still requires a motivated user to ensure it is functioning appropriately. Using this system requires additional training by your diabetes educators. If you are interested in this system you can discuss with your diabetes team whether it is right for you.

The information provided here about sensor augmented and hybrid closed loop systems is necessarily general in nature, since available and anticipated systems will all have system specific algorithms, settings and procedures which will be taught to users and families when they commence the system.

Measuring ketones

It is important to measure ketones whenever the BGL is 15 mmol/l or above. High blood glucose with ketones indicates insulin deficiency which needs to be acted on without delay (see later). In these situations, continue measuring ketones every 2 to 4 hours until they disappear.

Ketones are best measured in the blood using particular blood glucose meters that measure BGL and can also measure blood ketones with separate test strips. The measurement of blood ketones is preferred as this gives a much earlier warning of ketosis and changes in ketone levels. Ketones can also be measured in the urine using ketone test strips if blood ketone testing is not available.

Food and carbohydrate counting

It is a good idea for all people starting on a pump to be reviewed by the diabetes dietitian before the start date and there will usually also be dietary education during the pump start process.

There are some particular points about food for pump users:

Carbohydrate counting

Counting carbohydrate quantities (in grams or exchanges) is particularly important for people using pumps. It is very important to know how many grams of carbohydrate or exchanges (one exchange = 15 grams of carbohydrate) you are about to eat, since the bolus of insulin is adjusted accordingly. In general, all carbohydrate eaten should be bolused for, unless there is a specific reason not to, e.g., when treating a hypo or before sport. For more information about carb counting see Chapter 6, page 44.

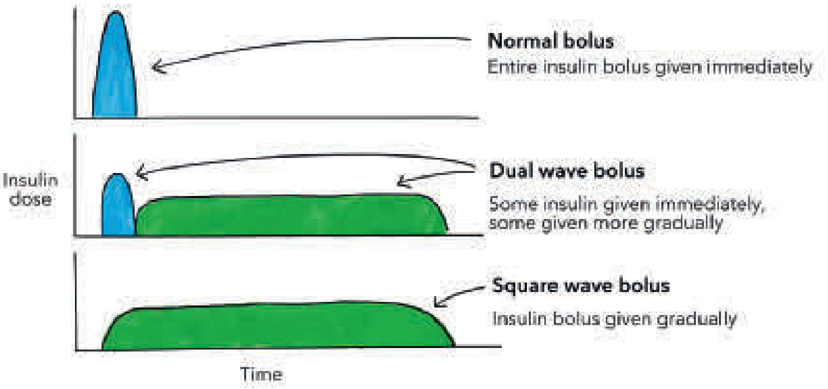
Square and dual-wave boluses

You will probably notice that different carbohydrate-containing foods have different effects on your BGLs, even if the carbohydrate count is the same. This is the concept of glycaemic index (discussed in Chapter 6) and usually relates to how quickly the carbohydrate is absorbed after the meal.

Some pumps have an option to give the carbohydrate bolus in different ways to help manage these different types of carbohydrate. It should be noted that hybrid closed loop pumps do not have these options.

Dual wave (combination wave) bolus: a proportion of the calculated insulin dose is given immediately and the remainder is delivered gradually over a longer period (e.g., 50% immediately and 50% over the next 4 hours). A low glycaemic index meal / high fat meal usually responds well to a dual wave bolus because the carbohydrate is absorbed slowly and over a longer period of time.

Square wave bolus: the calculated insulin bolus is given over a longer period of time as set by the user, without an initial bolus immediately. This can be useful for a long meal or extended snacking and is also helpful for some individuals with delayed gastric emptying (rare in young people).



Flexibility with food intake on a pump

- Pump users do not have to eat between-meal snacks.
- Meals and snacks can be more flexible, but avoid the temptation of having no routines as this will make good control difficult to maintain.
- Be careful of the temptation to eat lots of extra snacks. Even though with a pump these can be covered with extra insulin boluses, they will lead to excessive weight gain.
- Healthy balanced eating and regular exercise are important in assisting with blood glucose control and maintaining a healthy weight.

High blood glucose levels and sick days

High blood glucose levels

High blood glucose levels will occur from time to time and have to be taken very seriously in pump users, more so than people on injections. This is because pump users do not have any background reservoir of long-acting insulin and diabetic ketoacidosis can develop more quickly.

It is essential for pump users to always carry rapid-acting insulin in a pen that can be given if there are problems with the pump or infusion set.

Reasons for high blood glucose levels may include:

- Problems with the infusion site, cannula, tubing, reservoir, insulin or pump – ALWAYS CHECK FOR THESE FIRST
- Extra carbohydrate intake, not adequately covered by a carb bolus
- A missed carb bolus
- Illness e.g., infection, causing BGLs to rise
- Basal rates or carb boluses are too low

In the event of an elevated BGL (15 mmol/l or above), do the following:

1. Immediately check for problems with the pump or delivery system

- ✓ Check the infusion site: any redness, swelling or leaking?
- ✓ Check along the infusion line: any kinks or leaks?
- ✓ Check the pump reservoir: is there still enough insulin?
- ✓ Check the pump: any error messages?
- ✓ Consider insulin problems: has it expired or could there be temperature damage?

If there is any doubt about the insulin, infusion set or cannula, change these and insert in a new site without delay.

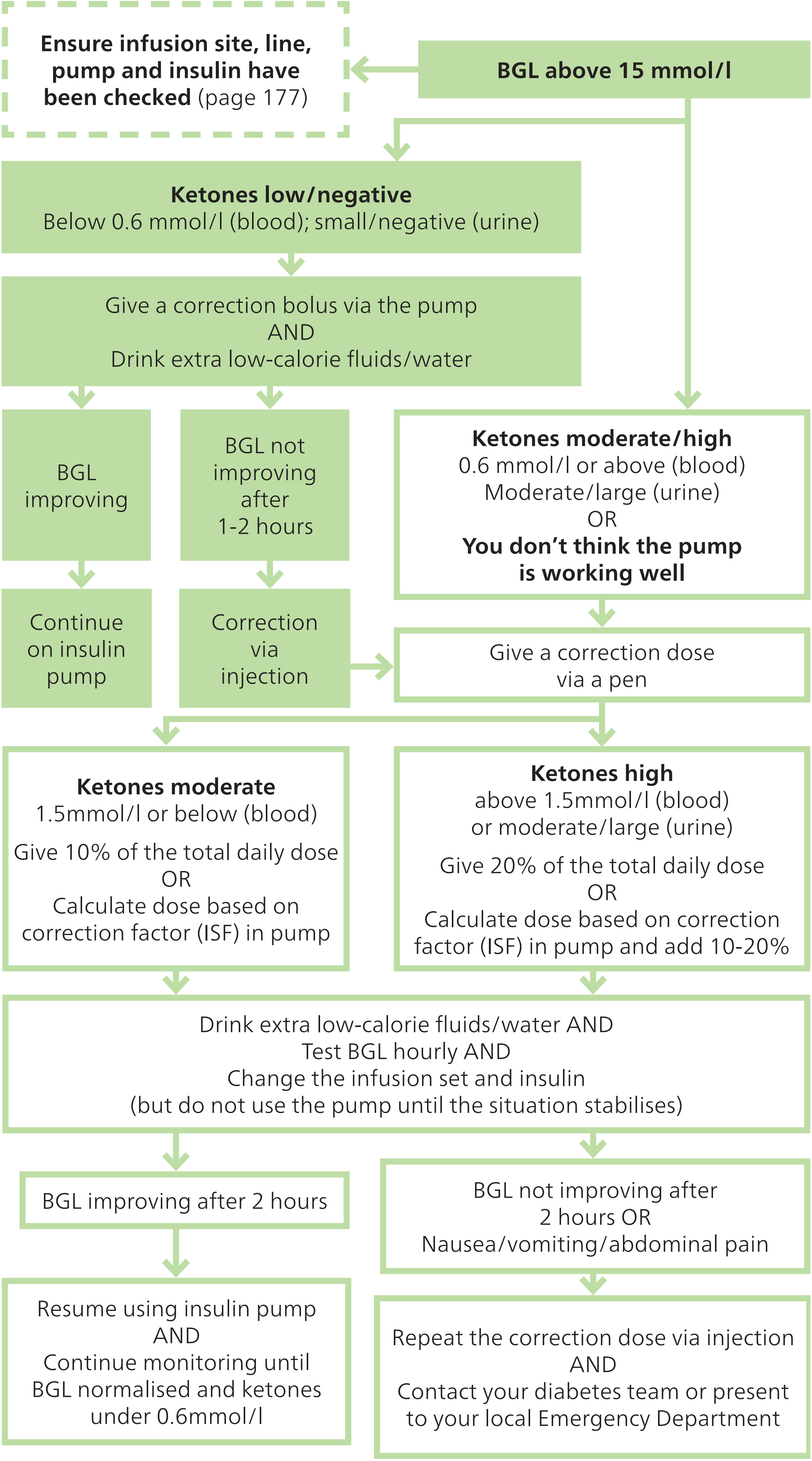
The operation of the pump can be checked by DISCONNECTING your infusion set and setting a priming dose of 5 units and watch for drops coming out of the line.

If you don't think your pump is working, remove the pump and infusion set and proceed to give an injection of rapid-acting insulin with a pen or syringe. Contact the pump manufacturer's helpline.

2. Check for ketones if BGL is 15 mmol/l or above

High ketones indicate that you may have a pump delivery problem or be developing a significant illness. How you proceed will depend on the ketone result (see flowchart on the next page).

Managing hyperglycaemia on an insulin pump



BGL above 15 mmol/l

Ensure infusion site, line, pump and insulin have been checked (page 177)

Ketones low/negative
Below 0.6 mmol/l (blood); small/negative (urine)

Give a correction bolus via the pump
AND
Drink extra low-calorie fluids/water

BGL improving

Continue on insulin pump

BGL not improving after 1-2 hours

Correction via injection

Ketones moderate/high
0.6 mmol/l or above (blood)
Moderate/large (urine)
OR
You don't think the pump is working well

Give a correction dose via a pen

Ketones moderate
1.5mmol/l or below (blood)
Give 10% of the total daily dose
OR
Calculate dose based on correction factor (ISF) in pump

Ketones high
above 1.5mmol/l (blood)
or moderate/large (urine)
Give 20% of the total daily dose
OR
Calculate dose based on correction factor (ISF) in pump and add 10-20%

Drink extra low-calorie fluids/water AND
Test BGL hourly AND
Change the infusion set and insulin
(but do not use the pump until the situation stabilises)

BGL improving after 2 hours

Resume using insulin pump
AND
Continue monitoring until BGL normalised and ketones under 0.6mmol/l

BGL not improving after 2 hours OR
Nausea/vomiting/abdominal pain

Repeat the correction dose via injection
AND
Contact your diabetes team or present to your local Emergency Department

It is very important to give correction doses via injection rather than via the insulin pump when ketones are high. That way you can be 100% sure that the insulin is going in. If there is a problem with the insulin delivery and you continue using the pump, your child could develop diabetic ketoacidosis (DKA) and become very unwell.

Remember:

- Changing the infusion set and replacing the insulin is important if the ketones are high because hyperglycaemia and ketones are commonly caused by pump or infusion set issues.
- Extra rapid acting insulin doses may be given every 2 hours as needed. Once the BGL and ketones are improving the correction doses can be given via the pump.
- If you start using the pump to correct after giving an injection, the pump does not know how much insulin was given by injection and when. You may need to consider reducing the correction bolus suggested by the pump if an injection was given within the past 3 hours.
- The body is less sensitive to insulin when high ketones are present. This is why the suggested correction dose is higher when there are more ketones present. This is also why you might need to add 10-20% to the correction dose calculated using the pump's correction factor when ketones are high.
- If at any time your BGL remains high, ketones persist or you develop nausea, vomiting or abdominal pain, call your diabetes team urgently or proceed to hospital immediately.

Example:

10 year old Kate tests her BGL on waking and finds the level to be 21 mmol/l and her ketones 1.5 mmol/l. On checking, she finds that her set has become dislodged. Her TDD on the pump averages 36 units and her correction factor is 3.5 (meaning that 1 unit of insulin lowers the BGL by 3.5 mmol/l when correcting). She needs to give a pen injection and can calculate this in one of 2 ways which usually gives a similar suggested dose:

1. 10% of TDD which would be 3.6 units. She opts for a dose of 4 units

   or

2. Using the correction factor from the pump, to bring the BGL down from 21 to 6 mmol/l, calculates as (21-6)/3.5 = 4.2, so again 4 units.

Sick days

Sick day management is covered in detail in Chapter 10. Important points are summarized here, especially as they apply to pump users:

- Illnesses can cause high blood glucose levels (usually viral or bacterial infections with fever), or low blood glucose levels (usually gastroenteritis illnesses).
- Have a sick day kit available which should include: extra supplies for BGL and ketone testing, rapid-acting insulin and pen or syringe, glucagon for injection, sugar-containing and low-sugar fluids, a thermometer, medication for fever, e.g., paracetamol, contact numbers for your doctors and pump team.

- **Never omit insulin.** Even if you are unable to eat you still need to have some insulin (see below for adjustments). Keep the pump on unless you have switched to insulin via injections.
- Test the blood glucose more often, every 2 hours or so during the illness.
- Test for ketones in the blood (preferred) or urine whenever the blood glucose is above 15 mmol/l and continue checking every 2 to 4 hours until ketones are cleared.
- Treat the underlying illness – see your doctor if the cause of the illness is unclear or you are very unwell or becoming sicker.
- Drink more fluids (water or low calorie) if the BGL is high and/or ketones are present. This will help the BGL fall and ketones to clear.
- Parents or partners should take over or assist with management and decision making if the person on the pump is too unwell to make appropriate decisions.

If blood glucose levels are high (above 15 mmol/l):

- Give extra boluses of insulin to bring the BGL down – use pump or pen depending on whether significant ketones are present as outlined in the earlier flowchart. Extra doses may be required as often as every 2 to 3 hours.
- It will often be necessary to also increase the basal insulin rate during an illness where BGLs are tending to be high. Use the **temporary basal rate** to increase the basal to 125 to 150% of the usual basal; set this for 4 or 6 hours initially and then review based on BGL progress.

If blood glucose levels are low:

- Treat hypos in the usual way (Chapter 8).
- If you are eating and drinking less your meal boluses will be less anyway. If you are not absorbing food well because of the illness, carb boluses may need to be even less than your usual ratio – consider weakening by 25% in the first instance.
- If BGLs continue to trend low, it may be necessary to reduce the basal rate. Use the temporary basal rate to decrease the basal rate to 50 to 75% of the usual basal rate; set this for 4 or 6 hours initially and then review, based on BGL progress.
- In pumps with AutoMode (hybrid closed loop systems) the temporary basal has been replaced by a temporary target. This is a slightly higher glucose target than usual, meaning the pump will be less aggressive in attempting to correct hyperglycaemia. This provides a safety "buffer" to prevent hypoglycaemia on sick days.

Call for help or go to the hospital if:

- Persistent nausea or vomiting or becoming more unwell.
- Unable to clear ketones.
- Unable to keep BGL below 15 mmol/l or above 4 mmol/l.
- You are worried, exhausted, too unwell to decide on doses or just don't know what to do next.

Sick day examples

Example 1:

Sarah is unwell with tonsillitis. Despite eating little her BGLs are running high. Corrections have partially worked.

Her mum runs a temporary basal rate of 150%, initially for 4 hours, with frequent BGL monitoring.

Example 2:

Mario has gastroenteritis. Vomiting has stopped and he is drinking but still has some diarrhoea. He sips Gastrolyte during the day.

His mum finds that adequate BGL is maintained using temporary basal rate of 50% until he starts feeling better that evening.

Hypoglycemia

Overall, most successful pump users have less hypoglycaemia, particularly less episodes of severe hypoglycaemia. However hypos are still a very important issue. Hypoglycaemia management is discussed in Chapter 8.

If your child is having frequent or recurrent hypos on an insulin pump this will usually mean that there is a major problem with basal rates or bolus doses. Reduce your total daily dose (TDD) by 10% by reducing your basal rates and weakening your carbohydrate bolus and correction factor (insulin sensitivity factor) all by about 10%. Contact your diabetes team for further advice: a recalculation of your basal rates and bolus doses will be needed.

Exercise

Since exercise generally lowers the blood glucose during and after, adjustments are made by having less insulin, more carbohydrate, or a combination of both. The insulin pump is best left on for exercise but for vigorous, contact or water activities the pump will need to be disconnected. Advice on pump management during exercise is outlined in Chapter 11.

Pump discontinuation – using injections again

If you need to remove or stop using your pump for any reason, you need to start having insulin injections. This will be both rapid acting (bolus) and long-acting (basal) injections, so you need to have these available for when they may be needed.

All people on pumps need to carry rapid-acting insulin with a pen at all times. Long-acting insulin needs to be readily available but not necessarily carried with you.

It is very important that you keep a written or electronic record of your current pump settings somewhere in case the pump breaks-down and has to be replaced. You need to know these settings to re-program the pump. We give the following disconnection advice:

1. Short periods of disconnection

If disconnection from the pump is only going to be for part of a day, use doses of rapid-acting (bolus) insulin via a pen every 2 to 3 hours in a dose that gives you your basal requirements for the next 2 to 3 hours, covers your carbohydrate intake and gives any correction that is needed. In this case, use the rates and formulas from your pump.

2. Longer periods of disconnection

If disconnection is necessary for a longer period, you will need to switch to a combination of long-acting (basal) and rapid-acting (bolus) insulin. You must always have supplies of these available.

Disconnection doses

Calculations are made from the usual average total daily dose (TDD) on the pump.

Basal insulin

Long acting insulin (Optisulin or Levemir) should be given to cover the basal insulin needs. Optisulin is given once daily (usually before breakfast in younger children or before bed in teenagers) and Levemir may be given once or twice daily.

The long acting dose is about 35-50% of the usual average total daily dose (TDD) on the pump.

Remember that these insulins have a duration of action approaching 24 hours, so if you reconnect your pump within 24 hours of a long-acting dose, basal rates may need to be run at or close to 0 until the injected long-acting insulin effect has worn off (use temporary basal rate feature, for example at about 10% temporary basal).

Bolus insulin (carbohydrate and corrections)

For carbohydrate and corrections use a rapid-acting insulin pen (NovoRapid, Humalog, Apidra, Fiasp).

The doses can be calculated in 2 different ways:

1. Using the carbohydrate and correction factors (ICR and ISF) that you use in your pump.
2. Using 50-65% of the insulin total daily dose (TDD). This is split into 3 pre-meal injections of rapid-acting insulin.

Suggested disconnection dose plan

	Pre-breakfast	Pre-lunch	Pre-dinner	Usually once daily (pre-bed or pre-breakfast)
Rapid-acting insulin	15-20% of TDD	15-20% of TDD	15-20% of TDD	
Long-acting insulin				40-50% of TDD

- This is a starting point only and adjustments are then made according to monitoring, food intake, exercise etc. Extra monitoring is essential to guide these adjustments, including overnight monitoring initially, since this is a significant change to therapy.
- Consult your diabetes team if you are not sure or having trouble adjusting the doses.
- It is a good idea to get a copy of the updated disconnection doses at every visit with your diabetes team.

Most frequent challenges for pump users

Having type 1 diabetes presents many challenges for young people and their families. Here is a list of the commonest issues that arise with pump therapy. Knowing these might help you avoid some problems.

1. Bolus problems – missed, late or poorly estimated

Forgetting to bolus is the commonest problem we see in insulin pump therapy, especially in teenagers. There are many reasons for this relating to human nature and behaviour, which need to be explored for each person. Missed boluses are a major reason for poor diabetes control and families need to work to ensure optimal bolusing. Every time a food bolus is missed, this is also a missed opportunity for a correction bolus. If diabetes control is suboptimal and there are significant missed boluses, this can lead to inappropriate adjustment of pump basal rates or other settings – usually the bolusing problem should be addressed first before making any other adjustments.

2. BGL checking

Not enough BGL checking is a common issue. A minimum of 4 BGL tests per day is recommended, but preferably more. Checking before eating main meals is always important because it allows a correction bolus to be added to the meal bolus. Remember always to do extra checks around exercise, sick days and occasionally at night. There is strong evidence that people who do more BGL checking have better diabetes control.

Continuous glucose monitoring (CGM) can help when BGL checking is a barrier, but any abnormal sensor glucose levels still need to be acted upon appropriately.

3. Pump setting adjustments

Sometimes it can be difficult to know which settings need adjustment in your pump over time – basal rates, carbohydrate boluses or correction boluses or perhaps all. In general, as children grow, all insulin dose settings need to be increased proportionally (i.e., increased basal rates, stronger carb ratios and stronger ISF or correction settings). You will gain experience with this over time and your diabetes team will continue to guide you. An important principle to remember is that most settings and ratios should not vary widely from those discussed earlier and most individuals do not require complicated rate settings.

4. Response to hyperglycaemia and sick days

It is very important to have a practiced response to high BGLs and sick days, as covered in other sections. This is important to avoid diabetic ketoacidosis and other problems and hospital admissions.

5. Site and set issues

The most common problem is forgetting to change the set every 2 to 3 days. After 3 days, insulin absorption characteristics change and BGLs become less stable. If there are problems with the sets not sticking well or skin reactions, your diabetes team can advise on other options.

6. Back-up plan for acute events

Have a plan for when something goes wrong. This includes knowing how to respond quickly to high levels, sick days, hypoglycaemia etc. It also involves knowing who to call if your pump fails and how to temporarily change over to injection therapy. For pump technical issues, contact the pump company. For diabetes management and health issues, contact your diabetes team.

Obtaining supplies and service back-up

Mostly supplies will be obtained via the NDSS through your Pharmacy. The supplies that will be routinely needed are:

- infusion sets
- reservoir
- alcohol wipes
- pump batteries (some models don’t use standard batteries)
- pump battery caps (generally needed every 6 months)

Some people may purchase additional special tapes if needed for sensitive skin etc. Supplies are readily available and shipped quickly but try to always keep at least a month ahead with your supplies to avoid running out. Insulin is provided on prescription via your doctor and pharmacy as usual.

In the event of pump breakdown, damage or other malfunction you need to revert to insulin injections without delay as per the ‘Pump Disconnection’ information above. Contact the insulin pump company as soon as possible for technical support. Usually it is possible to obtain a replacement pump fairly quickly.

Common questions and answers

My 15-year-old son is erratic with his routines, often forgets his blood glucose testing and has overall poor diabetes control. Should we buy him an insulin pump in an attempt to improve his control?

No. Your son has difficulties with the basic routines of diabetes which are unlikely to be helped by a pump. Using a pump is likely to be more risky for him under these circumstances. Pump users need to be highly motivated and prepared to do four to six BGLs per day or sometimes more. Work with your diabetes team to improve your son's basic diabetes routines in an attempt to get improved control on his insulin injections.

My 11-year-old daughter works hard at looking after her diabetes and usually has a HbA1c around 8%. Her doctor is very happy with her progress. She read about insulin pumps on the internet and would like to go on a pump. Should we do this?

Your daughter sounds well motivated and would be a good candidate for an insulin pump. While her control level is reasonable, it is above the recommended target. It is possible that this could be improved with a pump and there would be other potential advantages in terms of flexibility of routines, meals and lifestyle. Ask for more information from your diabetes team. Even if she chooses not to go on a pump she should be able to achieve good diabetes control with insulin injections.

Our son is now 13 and he has had unstable diabetes control since he was diagnosed as a toddler. We have worked really hard at attempting to stabilise things and our doctor and diabetes team have tried many different insulin combinations and doses. He is always prepared to do as many tests as needed and is generally good with his food. Could a pump help us?

You should discuss this with your doctor and diabetes team, but your son sounds like a person who could benefit from a pump as long as he felt this was good idea.

Chapter 14

Type 2 diabetes

Key Points

- Type 2 diabetes can occur in young people
- Important risk factors for type 2 diabetes are genetic factors and being above a healthy weight with an unhealthy diet and not enough exercise
- Type 2 diabetes can usually be treated with weight management, a healthy eating plan, regular daily physical activity and tablets, but insulin or other injectable medication may also be needed
- Family support is essential in order for a young person to achieve the lifestyle changes required

Most of this resource focuses on type 1 diabetes since most children and adolescents with diabetes have type 1 diabetes. Overall, however, type 2 diabetes is by far the most common form of diabetes in the community (80 to 90 per cent of diabetes) and predominantly affects older people. There is great concern about the global increase in the incidence of type 2 diabetes. Unfortunately, the age of onset of type 2 diabetes is falling and we are seeing an increase in type 2 diabetes in children and adolescents.

A number of factors increase the risk of developing type 2 diabetes, including genetic factors (ethnic background and family history), being above a healthy weight and low physical activity. For young people, this is often accompanied by excess screen time and poor sleep habits. It is a priority to help young people diagnosed with type 2 diabetes to achieve a healthy weight by improving their diet and eating habits, along with increasing physical activity.

What is type 2 diabetes?

In type 1 diabetes, the main problem is insulin deficiency, with the pancreas being unable to make insulin. In type 2 diabetes, the main problem is resistance to insulin. The pancreas is able to make insulin, often in large amounts, but the insulin is not able to work well because the cells of the body are resistant to its effects. Sometimes later in type 2 diabetes, the pancreas becomes exhausted and insulin resistance and insulin deficiency are both present.

Why do people get type 2 diabetes?

One of the major risk factors is being overweight or obese. Young people most at risk are those who have central obesity, meaning that they carry a lot of extra body weight in the tummy or abdominal region (often called 'apple shaped').

There is a strong genetic contribution to type 2 diabetes, which tends to run in some families. It is clear that there are certain ethnic groups that have a particularly high risk of type 2 diabetes, especially if they become overweight. Some higher risk groups include South Asian, Indigenous Australian, Maori and Pacifica. There are also some less common forms of type 2 diabetes which affect non-obese people and usually they have strong family genetic risk factors.

As well as seeing an increase in type 2 diabetes in adolescents, doctors are also seeing an increasing number of young people with obesity and insulin resistance which is likely to go on to develop into type 2 diabetes unless it can be reversed. This is called metabolic syndrome, insulin resistance syndrome or pre-type 2 diabetes. In addition to being above a healthy weight, it is also common to have a particular type of skin appearance called acanthosis nigricans. This is a dark brown, velvety marking that is most common around the back of the neck but can also occur in the underarms, groin and elbows. This skin appearance is a very strong marker of insulin resistance and risk of type 2 diabetes.

Diagnosis of type 2 diabetes

Type 2 diabetes can present with the same symptoms as type 1 diabetes, including excessive thirst and urination, tiredness and even diabetic ketoacidosis. The symptoms of type 2 diabetes usually develop gradually, whereas in type 1 diabetes, they can develop rapidly. Many people with type 2 diabetes have no symptoms at all and are only diagnosed after screening on a routine medical check which finds a high blood glucose level or glucose in the urine. Because of this, people with type 2 diabetes may have had the disease for many years unknowingly and can have significant complications already present at the time of diagnosis.

Treatment of type 2 diabetes

Type 2 diabetes requires careful lifelong management which includes healthy lifestyle choices alongside the treatments prescribed by the diabetes team. Some people with type 2 diabetes can do well with dietary improvement, exercise and weight loss and may not require other treatment, at least not for a number of years.

However, most will eventually require additional treatments which can include oral medications (tablets), medications by injection, insulin or a combination of treatments. All of these aspects are discussed later in this chapter.

Achieving a healthier lifestyle for the whole family

Lifestyle changes include both regular physical activity and a healthy, nutritious eating plan. Improving sleep habits and reducing sedentary behaviour/screen time is also a very important part of a healthy lifestyle. If the young person smokes, this should be ceased as it increases the risk of vascular complications (see Chapter 19).

Establishing a daily routine in discussion with your adolescent is a very helpful place to start. This should include realistic, consistent wake and sleep times, regular mealtimes, time for daily physical activity and agreed upon limits for electronic media use/screen time. Adequate sleep is vital for all young people and poor sleep has been linked to obesity. Regular sleep patterns should therefore help adolescents to get the recommended 8-10 hours of sleep per night.

It is important to involve the whole family in making lifestyle changes. This includes eating healthy meals together as a family and exercising together (e.g. going for a walk after dinner). This will help the child or adolescent adhere to the changes, follow their diabetes action plan and will provide health benefits for the whole family. When parents follow the same healthy lifestyle plan, they provide a positive role model for their child.

It is also important to avoid blame when goals are not reached (e.g., weight loss or blood glucose targets). Instead, provide positive reinforcement and encouragement for healthy behaviours, as any measures that improve health and wellbeing are valuable.

Weight management

Being above a healthy weight can make it difficult to manage diabetes. Adults who are overweight need to lose weight and this alone may help manage diabetes. In children and adolescents who are still growing, some may need to lose weight, but for some the goal may be to maintain the same weight or reduce the rate of weight gain over time. As children grow taller, their weight then becomes a better balance for their height and age.

Mealtime routines and healthy eating

Healthy eating is important for managing type 2 diabetes, improving weight, controlling blood pressure and blood glucose levels, and reducing blood cholesterol levels if raised. The principles of healthy eating for type 2 diabetes are to:

- Understand the sources of carbohydrate and how they affect the blood glucose levels.
- Reduce total energy and choose an appropriate amount of quality carbohydrates to help with weight loss and blood glucose control.
- Avoid all sugar-sweetened drinks such as soft drinks, juice, cordial, energy drinks, flavoured milk and iced tea.
- Choose snack foods carefully and in small amounts, as many are highly processed, low in nutrition, high in calories and high in refined carbohydrate.
- Eat fruit (2 serves) and vegetables (5 serves) each day.
- Reduce foods high in saturated fat.
- Eat regular meals.
- Improve food skills (such as meal planning, food budgeting, cooking) so you do not have to rely on processed, pre-prepared and takeaway foods.

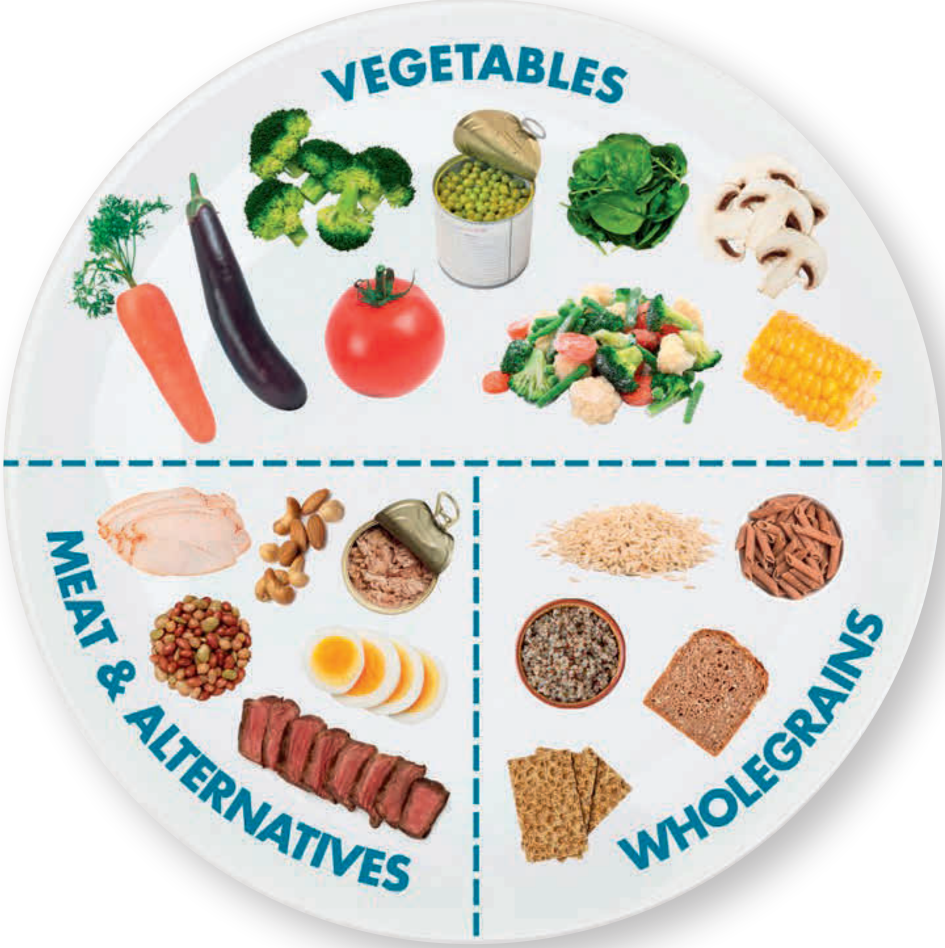
The healthy eating portion plate is a good guide for the whole family to follow. Children and adolescents still have unique nutritional needs for growth and development that must be met, so speak with the diabetes dietitian in your team about what is best for your family.

Family meals should include:

- A variety of vegetables, fruit and legumes (e.g., baked beans, lentils, chickpeas).
- High fibre breads, cereals and grain foods (e.g., quinoa, pasta, low GI rice).
- Low fat dairy foods (e.g., lite milk, lite cheese, low fat yoghurt).
- Protein foods (e.g., eggs, nuts, lean meats, poultry and fish).
- Healthy fats and oils (e.g., olive oil, canola oil, polyunsaturated or monounsaturated spreads).

Extra foods such as packet snacks, takeaway food, chocolate, bakery items, lollies, biscuits and ice-cream should be kept to occasional, small treats.

Limiting the availability of packet snacks and high-energy foods (such as frozen chips/nuggets/potato crisps/biscuits) at home will make it easier for your child or adolescent to follow the healthy eating plan. Do not bring soft drink or other sugary drinks into the family home. Diet drinks should also be limited. Water and lite milk are the best drink choices.



Regular reviews with a diabetes dietitian will help your child and family make small, sustainable changes towards a healthy family diet. Carbohydrate is an important part of all healthy eating plans for children, however there is some evidence that in type 2 diabetes, a diet lower in total carbohydrate (with choices being high in fibre and low GI), with a slightly higher protein and monounsaturated fat intake, may improve blood glucose control and metabolic measures. The dietitian will discuss these options with you. Studies remain ongoing about the long-term benefit of very low energy diets for young people, such as using meal replacement shakes or intermittent fasting for a short period of time. Any restrictive diet must be carefully planned and supervised by your child's dietitian.

Physical activity

Daily physical activity is an important part of managing type 2 diabetes. Regular exercise has many benefits including helping you achieve a healthy weight, increasing glucose uptake by cells, helping insulin work better, improving general fitness, mood and wellbeing. Your diabetes team will discuss a suitable activity plan with you. This should focus on enjoyable and achievable exercise goals and include activities that involve other family members.

Moderate exercise is an amount which makes you puff a bit but you should still be able to carry on a conversation during the exercise. Aim for at least 60 minutes of moderate exercise per day. Walking is an excellent form of exercise and is best done with a friend or other family member for companionship and safety.

As a family, it is important to discuss and agree upon reasonable limits being placed on the time children spend in sedentary activities such as recreational screen time (e.g., video games, television, tablets and smart phones) as research has shown a strong relationship with the time spent on these devices and obesity. Recreational screen time should be less than 2 hours per day.

Those with type 2 diabetes treated with insulin need to remember that hypoglycaemia is more likely with exercise. It may be necessary to reduce insulin doses on days of strenuous exercise as suggested in Chapter 11. Test the BGL more frequently as a guide. Your diabetes team will advise depending on the exact details of your treatment.

Those with type 2 diabetes who are not on insulin do not have a risk of hypoglycemia with exercise, so no special precautions are needed.

Monitoring and follow-up

People with type 2 diabetes require blood glucose monitoring, regular haemoglobin A1c checks and regular follow-up by their doctor and diabetes team. This is similar to type 1 diabetes, although the frequency of monitoring and follow-up may vary, depending on the treatment required. Target BGLs are tighter than for type 1 diabetes (usually 4 to 6 mmol/l before meals and up to 8 mmol/l after meals) and the target for the HbA1c is less than 6.5%.

Screening for complications – blood pressure and lipids

The diabetes team will arrange for appropriate checks for various complications such as eye, kidney, nerve and foot problems. It is also very important to have regular blood pressure and blood lipid (cholesterol) checks and have treatment of these if needed.

Medications for type 2 diabetes

It is important to remember that type 1 diabetes cannot be treated with tablets and always requires insulin therapy. For type 2 diabetes there are a range of tablets and injectable medications that may be effective, either as single medications or in combination. However, type 2 diabetes may also require insulin. Detailed explanation is beyond the scope of this resource, but a brief summary is given here. Your doctor will advise which is most appropriate for the individual and give full information about potential benefits, side effects and other issues. The medication recommended may change with time.

There are several types of medications used for type 2 diabetes treatment. Not all are currently approved for use in young people. Combinations of some agents are used.

Metformin

This medication aims to overcome insulin resistance by making the body more sensitive to insulin. It also improves the blood glucose levels by reducing glucose release from the liver. It is usually the first choice for overweight adolescents with type 2 diabetes and can be very effective in combination with the healthy lifestyle measures described above. Metformin can come in a long acting form taken once per day or a regular form taken twice daily. Metformin can cause some gastrointestinal side effects like nausea, abdominal (tummy) pain and reflux, but these improve after a week or so if the medication is taken consistently. Hypoglycaemia is unlikely with metformin because of the way it acts.

GLP-1 analogues e.g., exenatide (Byetta), dulaglutide (Trulicity), liraglutide

These are a newer class of medications that work to control blood glucose through a variety of mechanisms including increasing insulin secretion and slowing down digestion. These medications are given by injection under the skin (subcutaneous) anywhere from twice daily to once weekly, depending on the specific medication. They are occasionally used in adolescents with type 2 diabetes that isn't controlled on metformin and insulin. GLP-1 analogues may also assist with weight management.

DPP-4 inhibitors e.g., sitagliptin

These are another newer class of medications that are taken by mouth and are sometimes used in type 2 diabetes in adults, but are rarely used in younger people.

Insulin

As outlined above, insulin treatment may be needed in young people with type 2 diabetes, either from the time of diagnosis or at any time. It is important not to delay the use of insulin if other treatments are not able to control the diabetes well. Insulin may be used in combination with some of the other medications.

Less commonly used medications

There are a variety of medications that are used in adults with type 2 diabetes but are not generally used in young people. This is usually due to concerns about tolerance, side effects and effectiveness. These include thiazolidinediones (e.g., pioglitazone, rosiglitazone), sulphonylureas (e.g., gliclazide, glibenclamide, glipizide, glimepiride, tolbutamide), meglitinides (e.g., repaglinide) and SGLT2 inhibitors (e.g., dapagliflozin, empagliflozin, ertugliflozin).

There are also medications which alter the absorption of certain food types. Acarbose is a medication that slows the absorption of carbohydrate foods which can help prevent rises in blood glucose levels. Orlistat is a medication that blocks absorption of about 30 per cent of the fat that is eaten. This does not specifically treat the diabetes but may help diabetes management in people having major problems achieving weight control. These medications are not usually used in young people due to gastrointestinal side effects (bloating, diarrhoea) and nutritional concerns.

Bariatric surgery

Bariatric surgery refers to weight-loss surgical procedures such as a sleeve gastrectomy or Roux-en-Y gastric bypass. These procedures are occasionally performed in adolescents (15 years and older) with severe obesity and associated medical issues such as type 2 diabetes that don't respond to other treatment options. Bariatric surgical procedures have a beneficial effect on weight and can improve control in type 2 diabetes, but can also result in nutritional deficiencies or the need for further surgery. These procedures are still relatively rare in adolescents in Australia at the time of publication of this book.

Sick days and type 2 diabetes

Extra care is needed if you are unwell. Similar principles apply to sick days for type 1 diabetes, especially if you are being treated with insulin (see Chapter 10). Here is a summary of sick day management for type 2 diabetes:

- Check the blood glucose more frequently.
- Keep taking usual insulin doses and other diabetes medications.
- Metformin should be withheld during severe illnesses that require hospital admission or severe gastroenteritis with profuse vomiting or diarrhoea.
- If you take insulin, you may need extra doses during illness if BGLs are above BGL target– see Chapter 10.
- If you take insulin, you may need reduced doses during illness if BGLs are below BGL target.
- Keep drinking fluid to avoid dehydration – sip on fluids containing some carbohydrate (e.g., juice) if the BGL is under 8 mmol/l. If over 8 mmol/l, you should use fluids that do not contain carbohydrate (e.g., water, sugar-free lemonade).
- Keep eating small, regular meals if possible.

Contact your doctor, diabetes team or hospital if:

- You cannot keep the BGL below 15 mmol/l or above 4 mmol/l
- There is persistent vomiting
- The person is getting sicker
- You are worried and don't know what to do

Type 1 and type 2 diabetes (combination)

Occasionally people can have combination forms of diabetes with features like both type 1 and type 2 diabetes. These people may be treated with a combination of insulin and a medication to improve insulin sensitivity, such as metformin.

Screening for insulin resistance and type 2 diabetes

Since progression to type 2 diabetes may be prevented, it is recommended that young people with risk factors be screened. Australian/New Zealand guidelines recommend screening from the age of ten (or from the start of puberty if puberty starts earlier) if the child or adolescent is overweight or obese and has one or more of the following risk factors:

- a close family history of type 2 diabetes.
- the child or adolescent's mother had gestational diabetes during the pregnancy.
- high risk racial or ethnic group.
- signs of insulin resistance (e.g., acanthosis nigricans skin changes).
- other conditions associated with the 'metabolic syndrome' (e.g., high blood pressure, high cholesterol, polycystic ovarian syndrome).
- using psychotropic medications (e.g., anti-anxiety medications, antidepressants, mood stabilisers or antipsychotics).

Screening can be done with a fasting blood glucose level or HbA1c. The child or adolescent may also have an oral glucose tolerance test (which involves drinking a glucose-containing fluid and monitoring the blood glucose level over a two-hour period).

Major efforts are being put into programs to prevent obesity in young people and to detect the early warning signs that will lead to a high risk of type 2 diabetes. Young people who are overweight and have the acanthosis nigricans skin appearance as described earlier should always be assessed for insulin resistance and type 2 diabetes.

Common questions and answers

My 13-year-old son is overweight and has been diagnosed with insulin resistance. Is it inevitable that he will go on to get type 2 diabetes?

No. He has the opportunity to prevent or delay this by changing to a healthy diet, exercising more and reaching a weight that is within the healthy weight range for his age. This can often be difficult to achieve and requires long term commitment from the whole family, so you should seek the advice of your family doctor, dietitian and other health professionals as needed.

My 14-year-old daughter has had type 1 diabetes for three years. She is on large doses of insulin and our diabetes specialist has suggested adding a tablet (metformin) to her treatment. Does this mean her type of diabetes has changed?

Your daughter probably has one of the ‘combination’ forms of diabetes. Insulin treatment is still essential, but insulin resistance can be a major problem which can be helped by adding a medication like metformin to make the body more sensitive to insulin. This would only be done on the advice of a diabetes specialist.

My four-year-old son has type 1 diabetes and is on four insulin injections per day. When he is an adult will he be able to be treated with tablets instead of insulin, like his grandmother?

No. Your son will always require insulin replacement because he has type 1 diabetes in which the pancreas cannot make insulin.

My 15-year-old daughter has type 2 diabetes like her father, and is treated with metformin tablets. Do I need to watch for any side effects?

Metformin is generally a safe medication, provided that certain precautions are taken. You will be advised about these by your diabetes team. Metformin should not be used in people with any major liver or kidney problems. If your daughter has a significant illness (e.g., one requiring admission to hospital), the metformin should be stopped and you should contact your doctor without delay. There is a risk of a serious complication called lactic acidosis if metformin is continued during major illness. Metformin also should not be taken with some other prescription medications and X-rays with iodine contrast should be avoided. Your doctor will advise on all of these issues.

My 12-year-old daughter is 10 kg over the healthy weight range for her age and I have been told she has mild type 2 diabetes. I am putting her on a strict diet with the aim of losing the 10 kg over the next three months. Is this the best approach?

Weight control is an important aspect of type 2 diabetes management and involves exercise and diet management. However, it is unrealistic and unhealthy for your daughter to rapidly lose this much weight at this time in her life. A much safer approach would be for your daughter to stay at the same weight while she gains height or lose weight gradually. Then, as she has her growth spurt, her BMI (Body Mass Index) will gradually transition into the healthy range for her age. It is important that any weight loss be sustained for the long term, rather than regained later on.

Chapter 15

School and diabetes

Key Points

- Planning ahead helps minimise any problems with diabetes at school
- Remember the hypo pack for school
- The teacher and school need to have information about diabetes and your child
- Talk to the school and make sure they have the information they need

It is normal for parents to feel anxious about sending their child to school after a diagnosis of diabetes. You want to feel that your child is in safe hands while at school. Your child may also be worried about returning to school and especially about the management of the diabetes and being different. With planning and support, the child can participate safely in all school activities and can have a productive and fun time at school. The approach required will vary considerably depending on the age of the child.

Below are some points to think about for your child at school.

Information and education

Principals, teachers and office staff need to receive information about diabetes. This should include basic information on food, exercise, hypos and sick days. Most importantly, the school must receive a school diabetes management plan for your child, which can be provided to you through your diabetes centre. Diabetes Australia (as1diabetes.com.au) can provide additional information such as school resources, teacher & student webinars etc.

At the time of publication, Diabetes Australia and the National Diabetes Services Scheme (NDSS) were rolling out a Diabetes in Schools program to support schools in managing type 1 diabetes. The program involves both online and face-to-face training for school staff.

It is important for you to go to the school, make sure they have this information and run through it with your child's main teacher and other appropriate staff. It is also important to advise the child's teachers that relief teachers need to know about the diabetes. Speak to your child's teachers regularly about your child's general progress and any possible concerns related to the diabetes.

It is best to assume that the teachers will not have any knowledge about diabetes, so start with a basic summary. Common misconceptions about diabetes are that older children fully understand diabetes and should be totally self-caring or that activity should be restricted. It is important for the teachers to understand that these are not true.

School staff are often happy to assist with or supervise insulin injections, insulin pump boluses and blood glucose checking once it has been explained and shown to them. There is additional training available to the school teachers via Diabetes Australia and your diabetes team can assist you with sourcing such programs. School staff also have an important role in ensuring that the child with diabetes is eating their food and in watching for hypos and assisting with hypo treatment.

Who is responsible?

It is important to know who is responsible for different aspects of your child's diabetes care while they are at school. Having a clear understanding with the school from the start can help prevent any miscommunication or misunderstandings down the track.

Generally, the responsibilities are as follows:

Parent/guardian responsibilities

- Notify the school of the diabetes diagnosis and any relevant changes to the treatment plan
- Provide a school diabetes management plan to the school
- Educate the appropriate school staff about diabetes management and the support required (your diabetes team can support you in this and additional resources can be found online at as1diabetes.com.au)
- Provide diabetes supplies (insulin, pens, needles, sharps disposal container, glucometer, strips, hypo packs etc.)*
- Monitor diabetes supplies (including expiry date of insulin) and ensure they are replenished

School staff responsibilities

- Be aware of the diabetes diagnosis
- Understand and help enact the school diabetes management plan
- Know where the diabetes supplies are kept
- Ensure information is disseminated across appropriate staff

Healthcare team responsibilities

- Work with parents to make a school diabetes management plan and assist in keeping it up to date
- Help provide plans for special circumstances (e.g., school camp)

*Older children will often carry their diabetes supplies with them. For younger children the supplies will often be kept in a specific place (e.g., the school office). Hypo treatment packs (discussed below) should be kept in an accessible place at school for children of all ages.

Hypoglycaemia (hypos)

Teachers and office staff need to know how to recognise and treat hypos. Hypo food should be readily available and hypos treated where they occur, rather than needing to send the child somewhere else. A child with a hypo should never be sent alone to obtain their hypo food or left alone during a hypo. If initial hypo treatment is not effective it can be repeated each 15 minutes until the child recovers. Your child or the teacher should let you know if a hypo has occurred at school.

Make sure there are hypo packs at school (e.g., with the class teacher and in the staffroom).

Contents of a hypo pack

1. Name of the child.
2. List of contents.
3. Written descriptions of hypo symptoms in your child.
4. Instructions for how to treat a hypo.
5. Fast-acting carbohydrate such as juice boxes or jelly beans.
6. Parents' and hospital contact numbers.

All this information should also be documented on the child's diabetes management plan provided to you by your diabetes team.

In general, school staff do not take on the responsibility of giving glucagon injections. In the event of a severe hypo an ambulance will be called and the paramedics will administer glucagon. For specific occasions such as school camps glucagon training can be provided to the school teachers if staff are willing to be trained to give glucagon.

A child with diabetes should never be sent to the sick bay unsupervised and never be left alone if they are having a hypo.

Insulin doses and glucose testing at school

Children generally need to have insulin injections at school or use an insulin pump. How this is managed will depend on the type of therapy and the age of the child:

- Older children and teenagers can usually take responsibility for their own blood glucose checking and insulin injections or pump bolusing.
- Some children will require provision of a place where they can keep their glucometer and insulin pen and go for an injection.
- Younger children will need supervision with blood glucose checking and insulin injection or bolusing with a pump. School staff are usually happy to assist or supervise with these provided that they have been appropriately briefed.
- For school staff to perform blood glucose checking or give injections or boluses requires negotiation and appropriate education and training.
- The level of assistance needed will vary and this can be negotiated with the teacher and school, with the assistance of your diabetes educator or Diabetes Australia if needed.

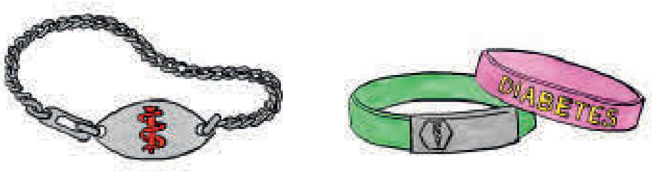
School diabetes management plans

A school diabetes management plan generally includes information about your child's insulin administration plan (injections or a pump), when BGL checking should occur and whether they are using continuous glucose monitoring. It also contains information on hypo symptoms and treatment and what to do in the event of high glucose levels. You can modify the plan to match your child's symptoms of a hypo. The management plan should also contain contact information for the parents and the diabetes team.

If you agree, you can add your child's photograph to the diabetes management plan. This could be used for the school staff room and contains information on hypo symptoms and treatment. Please be mindful your child may not wish their photograph displayed in public spaces so have a conversation with them and the school beforehand.

Identification

The child should always wear a medical identity necklace or bracelet, stating they have diabetes. Children may also need identification for the school bus indicating that they may need to eat on the bus.



Examples of diabetes alert wrist-bands

Food

In younger children the teacher may need to ensure that all of the meals are eaten on time and that food is not given to, or obtained from, other children. Meals and snack times should be at the same times as other children. Occasionally an additional snack may be necessary just before going into school in the morning. With planning, your child can order lunch from the school canteen. Parents need to be informed if there is going to be a change in meal times at school for a special event.

Exercise

Any moderate or strenuous exercise is likely to need extra carbohydrate unless you have planned with your child to reduce insulin doses (see Chapter 11). Your child will still be able to join in special events such as parties, swimming carnivals, sports days and excursions but you need to know about these events in advance so that you can plan ahead.

Letting others know

Encourage your child to let the teacher know if they are feeling unwell or having a hypo. In general, it is best that classmates know about the diabetes, but some children prefer to have only a few friends know. This will vary between individuals and with the age of the child. Friends with some knowledge about diabetes can be excellent 'buddies' and help out with hypos and so on.

If your child requires injections or blood tests at school they may wish to do this in privacy and the school should help make arrangements for this. Careful negotiation with the school will usually result in them being very helpful. Bear in mind, that it usually works best to give the school a small amount of essential information rather than over-loading them with instructions and less relevant details.

Participation

The child with diabetes should be allowed to participate fully in all activities (e.g., sports, excursions, sports days, carnivals and camps). Some of these will require special liaison and preparation by parents. The diabetes educator will help with special advice, depending on the circumstances. Staff involved in these activities should know about the child's special needs.

Behaviour and discipline

The child with diabetes should be treated the same as other children, as much as possible. The child should be disciplined in the normal way; however, they should never be detained at mealtime or after school. You need to be informed if your child is going to be late home.

If they need extra snacks, to test blood glucose, to take insulin or have extra trips to the toilet, they need to be allowed the time. However, avoid drawing unnecessary attention to their condition.

Blood glucose levels and effects on learning and examinations

Teachers should be aware that when a child has low blood glucose levels, or after low blood glucose levels, concentration, behaviour and school performance may be affected. Tiredness, irritability and lack of concentration can occur with either high or low blood glucose levels. Fortunately, these problems are usually minor and occasional.

Special provisions are available for children sitting external examinations. Forms supplied by the school should be filled in well in advance. Provisions are made for blood glucose testing during exams and extra time for testing, hypo treatment and recovery if necessary. If diabetes causes major problems during an examination, students can apply for consideration under the Misadventure and Illness provisions.

High blood glucose levels

If blood glucose levels are high, extra trips to the toilet to pass urine are often needed and the child should also be allowed to drink as much water as they like. The school should inform you if high blood glucose levels, excess urination or thirst persists.

Sick days or emergencies

If your child becomes sick at school, you should be contacted. If you are not contactable, then the child's diabetes team should be contacted for advice.

For any emergency situations (e.g., unconsciousness, convulsions), the teachers should know how to lie the child in the coma position and call the ambulance and tell them that it is a child with a diabetic emergency. These measures are detailed in Chapter 8 and in your school diabetes management plan.

Common questions and answers

My son is reluctant to tell other children that he has diabetes. How should we approach this?

Children vary in this. Some children don't mind everyone knowing, but some prefer only a few close friends to know. It is good if your child can have a few close buddies who know he has diabetes and a little bit about hypos, so that they can tell an adult if there is a problem.

My child will be starting school soon. How do I go about making sure the teacher knows what to do about the diabetes?

Planning ahead is important. Visit the school and discuss with the teacher or principal. The school needs to have written information about diabetes and you also need to tell them the particular details about your child's routine. Arrange for hypo packs to be at the school, and make sure the school knows how to contact you. Usually this is enough, but if there are particular concerns, contact your educator who may be able to arrange additional resources for the school.

My nine-year-old son is starting to come home with half of his lunch left in his bag, and has had low blood glucose levels some afternoons. What should I do?

Talk to your son about why this is happening. Sometimes a simple change of food choices may work – variety is important as is food that is easy to eat. Perhaps let him order lunch from the canteen some days for a change. Sometimes they are too eager to start playing and 'don't have time' to eat their lunch. You may need to visit the teacher and check that lunch is supervised, and reinforce how important it is that he eats all his lunch after his lunchtime insulin. It is quite common that children with diabetes are allowed to leave the classroom 5-10 minutes before lunch so that they can attend to their diabetes routines and then meet with their friends to have lunch and play. This can be incorporated into the school diabetes management plan.

I worry about what will happen if my child has a severe hypo at school. The teachers say they are not able to give glucagon. Is this a problem?

The school will know to call an ambulance in the event of a severe hypo and paramedics will give glucagon or a glucose injection.

Chapter 16

Different age groups and diabetes

Key Points

- Diabetes affects children differently throughout the age groups
- Different issues arise at different ages

Toddlers and preschoolers

Preschool children are imaginative thinkers and are in what is called the trust stage and fantasy stage. During this stage parents look after all aspects of the diabetes, but a gradual increase in participation in diabetes routines is encouraged. It may be helpful to play games around the diabetes procedures, gradually letting the child help (e.g., fingersticks, choosing the injection or infusion site, pressing the plunger during injection). Letting them practise on their dolls or teddy bears is very helpful.

Young children often have difficulty recognising hypos, but there is a gradual increasing recognition of hypo symptoms which should be encouraged by discussion about feelings at the times of hypos. Hypos are more risky during this age because the toddler is unlikely to recognise or be able to treat them and therefore the child requires constant supervision by a responsible person.

Children may have some understanding of foods they can eat, but apart from giving simple choices control needs to be taken by the parents or carers. Young children have little concept of time and their routines need to be controlled. Even toddlers and young children should have a pattern of fairly regular meals and snacks and the pattern of 3 main meals and 2 or 3 snacks per day works well.

The family should all sit together at mealtimes with minimal distraction (e.g., turn off television) and try to make mealtimes a positive social interaction. This often encourages better participation and eating from children.

During this time the aim is to keep blood glucose levels in the target ranges discussed earlier, however numerous factors can lead to unstable blood glucose levels (e.g., teething, immunisations, variable appetite, activity and sleeping patterns and minor childhood illnesses). Blood glucose levels are usually much more variable in young children. For this reason, many parents find continuous glucose monitoring helpful at this age.

Insulin pumps can be very useful in this young age group (see Chapter 13). Parents often find that an insulin pump helps reduce some of the variability and allows them to cope better with the variable eating and other factors at this age. Pumps can be locked so that young children cannot activate the settings. Infusion sets are more usually placed on the buttocks, although interference with the set seems very infrequent since children gain an early understanding of the importance of their diabetes therapy.

School-age children (6 to 11 years)

Children of this age are concrete thinkers, curious and sociable. They have also become more objective and are increasingly responsible. Participation in diabetes care increases; however, supervision is still generally required with all aspects of diabetes management. Children of this age are acquiring the necessary fine and gross motor skills but lack the maturity and knowledge to take on the full responsibility. They need to be carefully supervised in their diabetes care and adults need to make sure that insulin doses are accurate and are all given, whether by injection or insulin pump.

During this age range children usually start doing their own fingersticks, often from quite a young age. Many will wish to start trying some of their own injections from around nine to ten years or sometimes earlier, although they should not be forced if they are reluctant. Children gradually become more aware of time and can learn to take greater responsibility for eating food at a set time. Knowledge about food increases rapidly. This age group is usually able to recognise hypos and seek treatment.

For children of this age on a pump, they will actively participate in set changes and some may do this by themselves, with supervision. Often from 9-10 years of age, children will also estimate their meal boluses and operate the pump themselves, although supervision is still needed.

Additional factors that can affect blood glucose control include mood, growth, variation in food intake, sports, parties, childhood illnesses and variable routines at school.

Adolescents

Adolescence is a time of major physical and psychological change and increasing independence. However, behaviour and degree of responsibility vary enormously during this period. Body image is very important and peer pressure can lead to denial, self-neglect and risk-taking behaviour.

Adolescents should be increasingly taking over responsibility for their diabetes care but continue to need help and supervision. Often during early adolescence, further education is required, directed primarily at the adolescent, rather than at the parents. Additional education about things such as alcohol, puberty, sexuality, drugs, smoking and complications is necessary. Adolescents should increasingly recognise the importance of good blood glucose control to prevent complications. Adolescents are often capable of quite independent operation of a pump, although teamwork with the family and general supervision are still always advised.

If the diabetes was diagnosed at a young age, often the initial education was mainly directed to the parents. It is important to have some formal education directed to the adolescent at this time so they are equipped with the information to move gradually towards increasing self-care and independence.

Adherence and general management issues

Some adolescents begin to resent routines. Also, poor or variable cooperation with food, insulin injections or pump boluses and monitoring can become a problem. Unfortunately it is common to see adolescents doing little or no glucose monitoring and becoming variable in their routines. Faking or fudging of blood glucose levels is not uncommon as the adolescent tries to 'satisfy' their parents and health professionals by having some reasonable readings in their record. Usually this is temporary and is discovered when the blood glucose meter or CGMS is downloaded or the HbA1c is out of keeping with the reported blood glucose readings. An insulin pump download may show minimal glucose levels being entered which is often a sign of missed glucose checks. It can be a difficult time for families as questions over trust and honesty arise. Continuous glucose monitoring can support the adolescent with their glucose monitoring and can help improve accountability.

Insulin omission (forgetting or deliberate) is also reasonably common at this age. With insulin pumps, it is often the food boluses that are missed, particularly at school. Insulin omission is obviously quite serious as it leads to poor control and risk of serious illness with diabetic ketoacidosis.

Remember that poor adherence to diabetes management is not always directly linked to diabetes issues. Sometimes children and adolescents may be angry or sad with other areas in their life, such as poor body image, lacking school performance, conflict with significant relationships and low self-esteem. Additionally, some children and adolescents may manipulate insulin doses and other routines in an attempt to control weight. This is not the right way to achieve weight loss and can cause more problems with the diabetes.

Parents and adolescents need to continue working as a team for diabetes management through the teenage years. This is strongly encouraged, although a more subtle, hands-off approach is needed than in childhood. Studies have shown that handing over total control too early and lack of involvement with diabetes by parents in the teenage years is associated with poorer control and other difficulties, including 'burnout' in adolescents. Clearly the degree of involvement will be differently negotiated for different families. Compromise is needed on many issues at this age, including diabetes. Keeping lines of communication open between parents and teenagers is important. The diabetes team will work to support and guide teenagers and their families and may tend to be listened to more than 'nagging parents'.

Even though negotiation and reasoning are important, if dangerous practices such as insulin omission, poor insulin dose decisions or insufficient BGL monitoring are occurring at any age, parents or caregivers need to take control and directly supervise and monitor all aspects of diabetes care. Sometimes it is even necessary to take over some of the diabetes procedures, just as at the time of diagnosis. Your diabetes team will provide support as best possible, but they cannot take over the parental role.

These certainly can be difficult years for diabetes management and control may not be optimal. However, there is light at the end of the tunnel and with greater maturity in later adolescence there will hopefully be improved motivation, interest and cooperation with the diabetes management. Remember also that many young people with diabetes sail through the teenage years with no major problems.

Transition to independent adult care and adult diabetes services

This process is usually started in the clinic when your teenager starts seeing the doctor or other health professionals without a parent. By late adolescence, it is necessary for the person to have gained independence and confidence in looking after their diabetes. In late adolescence (usually between 16 and 18 years), it will be necessary and appropriate to move from a children and adolescent diabetes service to an adult service. It is important that this step be well planned and successfully made.

Your diabetes team will advise and assist at the appropriate time and discuss the various options in your locality.

Appropriate career options

Some professions (such as the defence forces, commercial pilot, police, fire brigade) are not usually open to people with diabetes and they need to know this when considering career options. Organisations such as Diabetes Australia can assist with further current information.

Growth and puberty

The growth spurt and changes of puberty result in much higher insulin requirements and it is important to try to keep up with this by appropriate monitoring and insulin adjustment. Adolescent girls may have higher and more variable blood glucose levels around the time of the menstrual period, but appropriate monitoring will guide the necessary insulin adjustments.

Weight issues

It is often during adolescence that concerns arise about excessive weight gain, especially in girls but also in boys. Teenagers are very conscious of body image and this is contributed to by peer influences and the media. Sometimes teenagers will manipulate their insulin doses in an attempt to avoid weight gain or lose weight. This is a poor strategy which usually fails and leads to poor diabetes control and long-term weight gain. Your diabetes team are aware that this is a very important issue at this age and want to work with young people to avoid this.

The diabetes team try to take a preventative approach and it is important that there is not an overt focus on diet or weight as this can worsen the problem. Growth will be monitored and if concerns occur with weight there are a number of effective strategies. These include additional advice about the food plan, changes to types and patterns of insulin and increasing exercise.

From time to time teenagers, more commonly girls, start to restrict the amount of food they eat because of concerns about body image and weight. Any such concerns should be discussed with the diabetes team who will reinforce concepts of healthy, sensible eating and normal body image. Additional help will be sought if needed, but hopefully the situation can be contained before it becomes more serious.

Smoking

Smoking needs to be actively discouraged from an early age. Smoking is a health risk to all people, but particularly to those with diabetes because of the increased risk of diabetes complications, particularly vascular disease. Children and adolescents are more likely to take up smoking if adults in their home smoke.

Drugs

Illicit drugs or unprescribed drugs are damaging to the health of all adolescents, but represent an added danger in those with diabetes through their effects on conscious level, insight and judgment, appetite and body metabolism.

Mind-altering drugs make it difficult for people to recognise hypoglycemia and to have correct judgment about treating hypos, food and insulin doses. Some drugs increase appetite, causing high blood glucose levels.

Alcohol

Alcohol can be dangerous and unhealthy for adolescents. For people with diabetes there are additional problems with alcohol. Delayed hypoglycaemia is a risk because alcohol blocks glucose production by the liver. Impairment of the senses by a combination of alcohol and hypoglycaemia is very dangerous. Alcohol can also contribute to excess weight gain and increased blood lipid levels.

Discussion about alcohol will be included at an appropriate time in diabetes education. Alcohol intake cannot be condoned below the legal age limit; however, it is recognised that teenagers will often experiment with alcohol at an earlier age. Young adults who choose to have alcohol should be advised how to do this responsibly and minimise risks:

- Drink in moderation only; one to two drinks maximum at any session and avoid drinking daily.
- Select beer or dry wines in preference to other things. Low alcohol beer is a preferable option. Avoid sweet wines, fortified wines, spirits and liqueurs. If drinking ‘pre-mixed’ drinks, diet options are advised.
- Always eat some carbohydrate before drinking and continue to have a regular carbohydrate intake during the period of drinking and afterwards.
- A responsible person who is not drinking and is aware of the type 1 diabetes should be present in case of emergency.
- Diabetes alert identification should be worn.
- Blood glucose levels should be checked regularly, especially before going to bed and overnight if concerned. Ensure a level above 5 mmol/l before bed and if below this or borderline, eat extra carbohydrate. A reduction in overnight insulin of around 20-30% is often appropriate to avoid overnight hypos after drinking alcohol.
- Arrange for a responsible person to wake the person the next morning at an appropriate time, to see that all is well.

Contraception

This is an important general issue in adolescence and will be discussed by the healthcare team at an appropriate time. If contraception is required, condoms are recommended for both contraception and protection against sexually transmitted diseases. Intra-uterine devices are not recommended for young women with diabetes. The oral contraceptive pill can be used by young women with diabetes without significant extra risk, unless there are certain complications such as high blood pressure, lipid abnormalities, vascular disease or blood clotting disorders. Unplanned pregnancies in women with diabetes pose major extra risks to their own health and the health of their baby.

These comments are of a general nature only and if contraception is required, the issues should be discussed in detail with your GP, diabetes doctor or educator.

Driving

Unpredictable or severe hypoglycaemia is the main hazard to driving however the authorities also need to know that there is adequate general diabetes care and that there are not serious complications that would make driving hazardous. On applying for a learner's permit, forms will be issued to take to the doctor for a medical report and medical examination. The wish to obtain a licence will sometimes be an incentive for adolescents to improve aspects of their diabetes care. Doctors have a legal obligation to recommend against the granting of a licence if the requirements are not being met. A report from the diabetes doctor is usually needed every two years for a standard licence renewal.

With a responsible attitude, driving is generally safe. The blood glucose level should be checked immediately before driving and food for treating hypoglycaemia must be available in the vehicle.

Diabetes alert identification

All people with diabetes should wear a bracelet or necklace indicating that they have diabetes. A variety of alternatives are available so an acceptable style can usually be found. At the very least, a card should be carried in the wallet or purse indicating that the person has diabetes. Teenagers often need to be reminded about this.

Ear piercing, body piercing and tattooing

These are choices for individuals and their families to make. Skin infections and infection of piercing sites are much more common if BGLs are high and diabetes is in poor control. Aim to have good diabetes control before considering this and have it done by professionals only. See your doctor or diabetes team if you have questions before or after.

Common questions and answers

My two-year-old's blood glucose levels seem to vary a lot. I think this is because some days he eats really well and other days just doesn't seem interested in food. What can we do?

This is common at this age and blood glucose levels do vary more. Offer simple choices if not eating well, or carbohydrate-containing fluids. Avoid the temptation to offer treats instead of healthy choices – give simple choices of acceptable foods e.g., 'Would you like yoghurt or banana?'. Sometimes if your child goes through a phase of less appetite, lowering the insulin dose may be necessary – discuss with your diabetes team. Insulin pumps may be helpful in smoothing control in such situations.

My eight-year-old is not showing any interest in giving her own injections. How should I encourage this?

Proceed gently. Children vary in the age that they feel ready to start doing injections or inserting pump sets. Usually they will do their own fingersticks earlier, but many don't start giving injections or pump related procedures until nine or ten or sometimes later. It is important they are involved in diabetes routines from early on, even if it is just helping with some part of a procedure. Gradually, involvement in practical procedures can be increased and they start to take more direct responsibility, with continued supervision.

I was shocked when our educator said that our 14 year old son was not entering blood glucose readings into his pump and missing mealtime boluses. He has always been so reliable. Where have we gone wrong?

You haven't gone wrong. Having diabetes can be particularly difficult in adolescence. Attention to the diabetes may wane and it is more difficult to supervise. Adolescents are striving for independence but are not quite ready for it, especially as far as the diabetes is concerned. Try to establish some agreement with your son about how you may cooperate to help with the diabetes. Sometimes the diabetes team can help negotiate this, since teenagers will often listen more to them than 'nagging parents'. Hang in there – things will improve!

At what age should my teenager start seeing the diabetes team by himself?

There are no definite rules for this and it is a question of when individuals feel comfortable about it. It is usually harder for the parent! Usually in the early to mid-teenage years the diabetes team will start to recommend seeing the young person by themselves first as this is important in the transition to independent adult living. The parent or parents are usually seen with the teenager afterwards and relevant issues discussed.

I don't want to encourage my daughter to drink alcohol but if she does, I want her to do it safely. How can I approach this?

These types of dilemmas are faced by all parents of teenagers. The diabetes team will usually raise the issue of alcohol at an appropriate time, since many teenagers will experiment with it. While not encouraging alcohol, it will usually be explained that adults can have alcohol in moderation in a safe manner by following certain rules. Then, if or when the teenager does try alcohol they have some information about how to do it with minimal risk. It is important to discuss the issue of alcohol in education.

Chapter 17

Follow-up visits and long-term management

Key Points

- Your child needs review by your diabetes team approximately every three months, or sometimes more often
- A diet and education review should occur each year, or more often if needed
- A haemoglobin A1c test should be performed approximately every three months to assess overall control
- The 'time in range' is another measure of overall control for those using continuous glucose monitoring
- Maintaining good long-term control will minimise the problems and complications that diabetes may cause
- Transition to adult services needs to be planned at the appropriate time

The first phase of your diabetes education aims to give you the basics about caring for diabetes at home. Sometimes this will occur during a stay in hospital of several days or may be done as part of an outpatient education program where you spend the nights at home and return to the hospital for several days over the following weeks for further education.

Moving on from this first phase can feel like a big step and will naturally cause some anxiety. However you will get plenty of support and guidance from the diabetes team, especially in the early stages. Your diabetes team is always willing to help, but it is important that you actively seek help from the team when you are concerned or have questions. Otherwise the team may assume that 'all is well'.

Moving on from the first phase

Your diabetes team will assist you in all of these important steps that will prepare you for looking after diabetes at home.

1. **The first phase of education:** the aim over the first few days is to give you, your child and family the basic education about diabetes management. There is a lot to learn and it is impossible to do this all at once. The diabetes team will put a plan in place for further education sessions.

2. **Obtain diabetes supplies:** you will need a range of supplies for diabetes management. Your diabetes team will advise about any different options and where to obtain them. The main requirements are:
   - blood glucose meter (glucometer)
   - blood glucose strips
   - lancet device and lancets
   - blood ketone test strips
   - diabetes record book
   - insulin
   - insulin pens
   - insulin pen needles
   - glucagon (GlucaGen hypokit)
   - medical alert bracelet or necklace
   - sharps container
   - insulin and glucagon prescriptions

   Later, you may need supplies for:
   - Insulin pump therapy, for those using insulin pumps
   - Continuous glucose monitoring, for those using CGM

3. Arrange to join the **National Diabetic Services Scheme (NDSS)** which allows people with diabetes to obtain supplies at concessional prices through NDSS approved pharmacies or Diabetes Australia. The diabetes team will provide you with a form for this. Supplies such as testing strips, lancets and insulin pump consumables (non-reusable parts) are obtained at concessional prices.
4. Obtain information about joining local **diabetes organisations** such as Diabetes Australia and Juvenile Diabetes Research Foundation.
5. **Insulin doses:** You will be advised of the doses of insulin to have at home by the diabetes team and when to phone to get further advice about doses. Insulin doses are likely to change rapidly in the first few weeks and frequent advice from the educator or doctor is usually required to adjust doses.
6. **Contact numbers:** Phone and e-mail are all useful ways to communicate with the diabetes team. The diabetes team will supply these.
7. **Follow-up arrangements:** Usually there will be fairly close follow-up by telephone and/or email. This gradually decreases as time goes on, insulin changes become less frequent and you feel more confident about the home management of diabetes. Remember that if you are concerned, diabetes advice is available from your hospital.
8. **Finishing education:** During the first few weeks, appointments will be made for you to return to the diabetes centre for more education, checks on progress and adjustment of diabetes management. You will have frequent contact with the diabetes team in these early weeks. It is particularly important for the food plan and insulin doses to be reviewed and adjusted if needed during these early days.

Long term follow-up

Regular visits

Regular follow-up visits are important for diabetes. You will get to know your diabetes team well and children will often look forward to visits to the team that they know so well. After the more frequent visits near diagnosis, routine follow-up for most children is three to four times per year. At clinic visits, the diabetes doctor will discuss any questions or concerns you have, look at blood glucose and other records, examine your child and discuss any adjustments or other management that may be needed. You will also see other members of the diabetes team as needed at these visits (diabetes educator, dietitian or social worker/psychologist), but not necessarily at every visit.

A HbA1c should be performed at each clinic visit (three to four times per year) and the 'time in range' will be reviewed for those using continuous glucose monitoring.

Annual review

Usually once per year there will be a more major review paying particular attention to growth, development and puberty, blood pressure, nutrition and checking for any other problems or complications. Once each year it is also recommended that there be a full review session with the diabetes educator and dietitian. Visits may need to be more often for children under five or where there are special concerns about the diabetes.

Most diabetes centres also recommend an additional blood test once every year or two to check that there are no problems developing, such as thyroid problems, coeliac disease or high cholesterol. Your diabetes team will explain this to you.

Complications screening

It is usually recommended to start screening for diabetes complications in adolescence, once your child has had diabetes for 2-5 years. Again, your diabetes team will advise about how this is done and more details are given in Chapter 19 'Complications'.

Recommended minimum follow-up for diabetes

- Visits to your child's diabetes doctor and team three to four times each year.
- More frequent visits will be required just after diagnosis and later if there are concerns about progress.
- Diet and education review yearly with interim advice as needed.
- Haemoglobin A1c test performed three to four times each year.

Diabetes outreach and shared care

Children living in or near the major cities usually see a children's diabetes specialist for regular review 3 or 4 times per year, as well as other members of the diabetes team as needed. Country children may see their local paediatrician or physician for routine review. Also, diabetes specialists from one of the major children's hospitals may visit regional areas or use tele-health (video or telephone conferencing) for diabetes reviews if needed.

For regional families, the aim is for your child to have expert local care as well as periodic review by specialists from the children's hospitals if needed. These arrangements work through the close cooperation of the diabetes teams from country areas and children's hospitals.

Other diabetes supports: workshops, seminars and diabetes camps

In addition to the support and education you have from your diabetes team, there are other avenues for learning about diabetes, updating knowledge and sharing experiences.

Diabetes organisations will often run workshops, seminars or other education programs. These will cover a wide range of topics but sometimes are more specific (e.g., toddlers diabetes support group, seminar for teachers, education session for grandparents and other carers). Details of these are available through your diabetes centre and organisations such as Diabetes Australia and Juvenile Diabetes Research Foundation.

Diabetes camps are also a great way of learning more and helping your child to adapt to diabetes in a fun environment. For younger children, parent and child camps are available in some states and older children and teenagers attend camps by themselves. More information on camps is in Chapter 18.

Goals for long-term management and control

The overall goals of diabetes management are to have:

- normal growth and development
- good social and psychological adjustment
- full participation in school and other activities
- healthy eating patterns
- blood glucose levels in the target range as much as possible (see ‘time in range’ below for CGM users)
- minimal hypoglycaemia or no serious hypoglycaemia
- long-term metabolic control as good as possible as measured by haemoglobin A1c
- reduced risk of long-term complications.

Recommended control targets

Below are realistic recommendations for day-to-day targets (target blood glucose levels) and targets for overall control (HbA1c and time in range). The concepts of HbA1c and ‘time in range’ are discussed in more detail below.

Day-to-day targets (blood glucose levels)	The target range for BGLs is 3.9 to 10 mmol/l
	Within this range the preferred level may vary depending on when you take the reading, generally: Before meals: 4 to 7 mmol/l After meals and before bed: 5 to 10 mmol/l At 3am: 5 to 8 mmol/l
Longer term targets (markers of overall control)	HbA1c under 7%*
	Time in range above 70%

*Individualized HbA1c targets may need to be set for some individuals

What does the haemoglobin A1c (HbA1c) tell you?

The HbA1c gives a measure of overall blood glucose control over the last two to three months. While blood glucose tests give important information about daily variations in blood glucose levels, the HbA1c gives important information about long-term control.

The HbA1c level should be measured approximately every three months when you visit your doctor or diabetes centre.

As red blood cells move around in the bloodstream, the haemoglobin they contain picks up glucose. The amount of glucose picked up depends on how much glucose there is in the bloodstream. If the average blood glucose levels are high over a two to three month period, lots of glucose will stick to the haemoglobin and the HbA1c will be high. If blood glucose levels are mostly within the target range the HbA1c will be in the desirable range. If blood glucose levels are swinging from high to low, the HbA1c may be reasonable, but this is not a good balance. The HbA1c is a little more influenced by recent readings than earlier readings in the two to three-month period.

Daily blood glucose levels and regular HbA1c measurements (approximately every three months) are important in monitoring diabetes control. Diabetes control is judged by both the HbA1c and the blood glucose levels.

People without diabetes have an HbA1c of 4 to 6 per cent but people with diabetes usually experience too much hypoglycaemia if their HbA1c is maintained in this range. Therefore, the HbA1c with diabetes runs higher than the non-diabetic range. The closer the HbA1c is to the non-diabetic range the better, provided that there is not too much hypoglycaemia. The HbA1c can come into the non-diabetic range in the 'honeymoon phase' following diagnosis, but later is likely to run a little higher. The target HbA1c in children and young people with type 1 diabetes is less than 7%.

People often feel frustrated when they can't get all of the blood glucose levels in the target range. This is difficult to achieve. The aim is to get the majority of readings within or close to the target range.

While the above glucose and HbA1c targets are desirable, they will not be possible for some children at certain times. The aim, however, is always to be moving towards the targets – any degree of improvement of control is beneficial.

Relationship between blood glucose levels and HbA1c

The HbA1c is not an average of blood glucose levels. However, there is a good relationship between average blood glucose levels and HbA1c which is approximately as follows:

HbA1c	Estimated average BGL (mmol/l) over last 8-12 weeks
6%	7.0
6.5%	7.8
7%	8.6
7.5%	9.4
8%	10.1
8.5%	10.9
9%	11.8
9.5%	12.6
10%	13.4

It is evident from this table that to have a HbA1c in the recommended target range of under 7%, average BGLs need to be under 8.6 mmol/l.

Time in range

This is a newer way to assess diabetes control in people who use continuous glucose monitoring (CGM). The term 'time in range' refers to how much time each day is spent in the target blood glucose range (3.9 to 10 mmol/l). This is usually expressed as a percentage. Children should spend more than 70% of their time with a glucose level in the target range. This would equate to spending around 17 hours per day with a glucose level between 3.9 and 10mmol/L. A 'time in range' of more than 70% usually means the HbA1c is around 7%.

Using the 'time in range' as a measure of diabetes control has some advantages over using the HbA1c. As discussed above, the HbA1c can be low if the child is having a lot of hypos, which may mask the fact that they are also having a lot of hyperglycaemia. Such variable blood glucose levels (lots of levels above and below target range) means the diabetes is not well controlled. The 'time in range' is a good way to figure out if this is a problem and help address it. In reality, the HbA1c and 'time in range' are used together to form a more complete picture of your child's diabetes control.

Problems with control

The following are signs that there are problems with diabetes control and that a review of management is needed. Refer to Chapter 7 'Monitoring diabetes control' for an approach to unstable blood glucose levels. If the solution is not clear, your diabetes educator or doctor should be contacted for further advice.

Signs indicating problems with diabetes control:

1. Blood glucose levels are often falling outside the recommended range.
2. More than 3 or 4 mild hypos per week especially if the reason is unclear.
3. Hypoglycaemia unawareness; that is the child is not aware of hypos – they are only noted on testing or by others.
4. Any episode of severe hypoglycaemia (e.g., fits or unconsciousness).
5. HbA1c above the recommended range or 'time in range' below the recommended range.

The nature of diabetes is such that there will be periods when blood glucose levels will be stable and other more difficult periods when they fluctuate (see the section on blood glucose levels in Chapter 7). Sometimes, despite everything you do, there will be ups and downs that cannot be explained. This can be frustrating, but usually improves with time.

Insulin omission and other control problems

Diabetes is a challenging condition for young people, their families and health care advisors. It has a unique set of attributes:

- It is a long-term condition with no cure yet possible.
- It requires time-consuming and complicated management from day to day.
- It makes young people feel different from their peers.
- It reduces lifestyle flexibility.
- Problems can develop rapidly if there are management problems (e.g., severe hypoglycaemia or diabetic ketoacidosis).
- There is a risk of long-term complications which cannot be predicted for individuals but is greater if control is not optimal.

It is not surprising that some young people at times find this condition overwhelmingly difficult and become unable or unwilling to adhere to management recommendations, even though they are aware that this is not in the best interest of their health. It is important that young people, their families and health care advisers are aware of the difficulties that can sometimes arise, so they can help get through these times. These problems are more commonly encountered in teenagers who are starting to be more independent, but elements of them are also seen in younger children. The psychological aspects of diabetes in children and adolescents require much more research and understanding.

Problems that may be encountered are:

- insulin omission (forgetting or missing doses)
- problems with blood glucose monitoring
- problems with food
- diabetes 'burnout'

Insulin omission (forgetting or missing doses)

Omission or missing of some doses of insulin is common in teenagers or younger children who are taking responsibility for some or all of their own doses. It is a major contributor to poor diabetes control and a common factor in teenagers admitted with diabetic ketoacidosis. Sometimes this is due to being forgetful or over-busy or distracted. It can be a problem with either insulin injections or insulin pump therapy. The injections or boluses most commonly omitted are those at school. Sometimes the omission is deliberate. Reasons for this may be misguided attempts to control weight, not wanting to appear different at school or psychological disturbance.

Insulin omission is suspected if the HbA1c is in the poor control range (especially if this is so on more than one occasion), if blood glucose levels are persistently high despite apparently reasonable insulin doses or if there is recurrent diabetic ketoacidosis.

If insulin omission is a problem, the diabetes team will explore the possible contributing factors in order to change the pattern. Re-education or counselling may help. Sometimes pump users take a break from the pump and return to an injection plan for a time. Frequently, the diabetes team will ask parents to work much more closely with the young person with diabetes and supervise and assist with all aspects of diabetes management until the situation can be turned around.

Problems with blood glucose monitoring

After many years of blood glucose monitoring, teenagers will sometimes lose motivation and do less or no monitoring. Clearly, this makes diabetes management difficult and contributes to poor control. There may be a tendency to write down false readings in the record book or enter false readings into the insulin pump so as to satisfy parents and the diabetes team, but this will be uncovered when the meter or pump is downloaded or the haemoglobin A1c is found to be high.

Helpful strategies can include compromise on the number and timing of BGLs, re-education and counselling, and teamwork with parents or other family members. Continuous glucose monitoring systems may relieve some of the burden of frequent blood glucose monitoring, but most systems still require calibration with fingerstick checks.

Problems with food

Problems with the diabetes healthy food plan are common and a major contributor to difficulties with diabetes control. Common problems are overeating, excessive treats and snacks and irregular timing of meals and snacks. Food binges may occur and there is an increased tendency to eating disorders in diabetes, such as anorexia nervosa or bulimia. Weight is often a concern in teenage girls and there is sometimes manipulation of food and insulin in an effort to modify this.

These problems require a team approach with special input from the diabetes dietitian. It is important to normalise the food plan as much as possible and help teenagers to sensibly and realistically address any concerns they have about food issues and weight.

Diabetes ‘burn-out’

It is not surprising that the relentless demands of diabetes over long periods can lead to a situation of burn-out in young people with diabetes and their families. Features include a lack of motivation, a lowering of aims and targets, missing or avoiding follow-up appointments and a feeling of helplessness in being able to change the situation. There is an element of burn-out in most of the problems mentioned earlier in this section. All of these things can lead to anxiety, stress or even depression and it is important to address these. Depression can be more common in people with diabetes and is important to act on signs of this, so that the situation can be helped.

There is no easy solution to burn-out, but helpful strategies can include simplifying diabetes routines where possible, sharing the load with family members, re-education, counselling and sometimes psychological intervention. The diabetes team will try to maintain closer contact in order to help motivation, and regular visits with a diabetes social worker or psychologist can be helpful. It is also important for young people to have positive diabetes role models and an understanding of advances in diabetes management that will give them hope for easier management and possible cures, provided these are realistic. Attending diabetes camps can help re-motivate some young people.

For all of these issues, the diabetes team take a non-judgmental approach and bring in other health professionals to help if needed. Diabetes requires a lot of compromise in people’s lives, especially in the teenage years. Often the difficulties are only temporary and are overcome with time.

Transition to adult care

All young people will need to transition to care in adult diabetes services at some time. This should be a planned process in which there is appropriate preparation and time for adaptation.

Your diabetes team will guide you about local transition recommendations and arrangements. Here are some important points in the transition process:

- Transition will often occur between 15 to 18 years of age. However this may depend on whether a young person has left school, availability of local services and their own preferences.
- Transition should not be a sudden event, but a planned process over a period of time which allows education and knowledge to be reviewed and for the young person to adapt to the upcoming change.
- Adolescents transitioning need to be a given a range of possible options for the adult service they could attend and participate in that decision; for example – preferred location, hospital clinic or private service. Some services run joint young adult clinics (with adolescent and adult diabetes specialists) as a way of facilitating transition.
- The diabetes service will arrange for a transfer of relevant medical information to the new adult diabetes team, with the young person’s consent
- It is important that young people do not get “lost” in the transition process, through either not attending the suggested adult service or dropping out early because it is different to what they are used to or because they feel disconnected from their long-term diabetes team. Parents and caregivers have a role in helping to ensure that young people have their appointments and attend them, especially early in the process. Your diabetes team will also have mechanisms in place to monitor the transition process and to try to ensure that successful transition has occurred.
- If there are problems in the process of transition, you should contact your child/adolescent diabetes team to discuss. Sometimes a different centre or doctor may need to be tried, since different services suit different people.

Common questions and answers

How can I get advice about diabetes problems if I am worried?

The first step is to contact your usual diabetes educator, dietitian or doctor, depending on the question. If you can't contact them and the question is urgent, you can go to your local Emergency Department.

We live in a country town a long way from a major children's diabetes centre. How should our child be followed up?

It is a widely accepted recommendation that children with diabetes should see a doctor with specialist experience in children's diabetes about every three months. In country centres the appropriate doctor is usually a specialist paediatrician, or may be an adult physician for older teenagers. Teams from children's hospitals diabetes centres visit some regional areas or provide telehealth and your doctor may recommend you see them for review. Country centres usually also have a diabetes educator and dietitian with experience in children. Find a follow-up pattern that suits you and your child.

Can the haemoglobin A1c be too low?

Yes. A low haemoglobin A1c can be achieved by having lots of hypos, but this is definitely not a good thing. Severe hypos with fits or unconsciousness or hypoglycaemia unawareness become an increased risk if the HbA1c is too low.

My child's diabetes is quite difficult to manage and we can never seem to get the haemoglobin A1c in the recommended target range. What should we do?

The recommended range is the ideal but, for a variety of reasons, not everyone can reach this. The most common reason is that blood glucose levels are higher than ideal at those times of the day when you are not testing. It may also be that the insulin types or timing are not the most suitable for your child at this time. Your diabetes team will be able to help with these issues. Continuous glucose monitoring may also help figure out if there are times when your child's glucose levels are above target range without you realising (e.g., overnight). Your child's treatment can then be adjusted to address this.

Remember that any improvement in haemoglobin A1c is of benefit in reducing the risk of complications (e.g., improving from 9.6 per cent to 9.1 per cent, even though it is not in the target range).

My 15-year-old son has been on four injections per day for several years, and was doing well. Now his control has deteriorated; he seems to be doing less testing and he is often forgetting his lunch-time injection at school. What can we do?

It sounds like there are some elements of diabetes burn-out. Explore the reasons for difficulty with the lunch-time injection. Sometimes this is something simple that can be overcome (e.g., lack of privacy or not enough time). The diabetes team will assess if they can re-motivate your son or if there are other particular issues. A review by the social worker or psychologist may help. Work with your son in a team effort so he is not carrying all of the load of day-to-day management. It is important for parents to stay involved in assisting with diabetes care, even during the teenage years.

Chapter 18

Travelling, holidays, camping and other special situations

Key Points

- **Travelling and holidays should not be restricted because your child has diabetes**
- **Planning ahead will help prevent any problems and ensure that travel and holidays are safe and enjoyable**
- **See your diabetes doctor and educator before the trip – especially for overseas trips**
- **Changes to timing and routines can be dealt with by planning ahead**
- **Diabetes camps and school camps help many kids with diabetes and are fun!**

Preparing for travel

Things to consider

Before travelling it is important to think about:

- length of journey
- possibility of delays
- timing of insulin
- access to medical services and diabetes supplies
- care of insulin and diabetes equipment
- customs regulations in different countries
- changes in types of foods
- changes in activity levels
- changes in medication and sleep routines
- the prevention and management of sickness away from home
- carrying letters from your diabetes team in case they are needed at customs or security checks

Review by the diabetes team

A review by the doctor and educator is advisable before the trip. This is especially important for overseas trips. Diabetes control will be assessed and adjustments made if needed. Appropriate letters will be supplied and advice given about coping with time zone changes. Other issues such as insulin adjustments for activity changes, overseas medical facilities and so on can also be discussed.

Letters and contacts

- Obtain a letter from your doctor or diabetes nurse educator summarising medical information about your child in case you need to seek medical advice away from home. For overseas trips and domestic flights, obtain a letter stating that you will be carrying supplies such as insulin, diabetes devices and/or wearing diabetes technology. This is to avoid any problems at customs or security inspections. You only have to show this going through security if the officer is questioning why you have the diabetes supplies.
- Ask your doctor about suitable diabetes services at your destination. Usually some contact names addresses and phone numbers can be provided for most parts of the world.
- Make sure you have the contact phone and e-mail address of your usual diabetes doctor and educator in case you or others need to contact them about your child.

Immunisations

Ensure your child is up to date with immunisations and has any special immunisations required for travel to particular countries. Allow at least two months for this in case special immunisations are required – your GP will be able to advise about this.

Travel insurance

Obtain travel insurance well in advance. As the insurer will usually require information from your doctor, sufficient time needs to be allowed for this process. Diabetes Australia can provide information about companies providing suitable medical and other travel insurance. It is a good idea to shop around.

Contact with the airline

Advise the airline that your child has diabetes and find out approximate meal times and whether extra snacks are available. It is best not to ask for a 'diabetic diet' as this is often low in carbohydrate and not the type of food kids like. Ask for a kids' meal or a normal meal. It is a good idea to carry food that you like in case there is not enough carbohydrate food on the menu.

Supplies

- Make sure you have enough supplies – insulin, glucagon, insulin pens, pen needles, blood glucose meter and spare batteries, blood and ketone test strips, diabetes bracelet or neck chain, insulin pump supplies and CGM supplies.
- The insulin, glucagon and blood glucose meter need to be protected from extremes of temperature; use an insulated container or packing.
- If you are travelling with an insulin pump, make sure that you have a supply of insulin pens as a back-up and keep a record of pump disconnection doses in the event of pump failure.
- If you are using CGM ensure you have enough glucose testing strips in case there is a problem with the CGM you need to go back to fingerstick monitoring.
- Make sure your child is wearing a diabetes ID necklace or bracelet.
- During the trip, essential diabetes equipment needs to be divided between two separate hand luggage bags in case one is lost. Supplies should not be packed in your luggage in the cargo hold as they may be exposed to extreme temperatures or get lost at the airport.

Preparation in case of sick days

- Prepare a kit for sick day management.
- Revise information on sick day management and hypoglycaemia management.
- Obtain supplies of easy-to-eat carbohydrate for treating hypoglycaemia. Be prepared for long and unexpected delays. Carry supplies of bottled drinks and water if allowed, although there are limits on carrying liquids on some flights.
- For trips to countries where English speaking is uncommon, it may be advisable to have medical letters translated into the local language and also some translations for important requests (e.g., I need to find a doctor; I need sugar quickly). Making contact with the Australian consulate may also be advisable for longer stays or in the case of any difficulties.

Food and hygiene issues

Like all travellers in overseas countries, you need to be extremely cautious with food hygiene. In countries where water supplies and general hygiene are suspect, drink only bottled water, avoid ice cubes and salads, avoid street food sellers and market stalls and brush your teeth with bottled water.

Reference information

Download an electronic version of this book 'Caring for Diabetes in Children and Adolescents' to take with you.

Changes to timing and routines

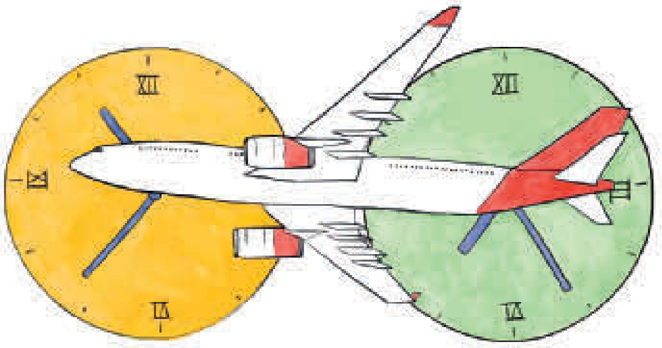
Adjustments can be made when needed to cope with changes in diabetes routines. In general, diabetes control will be smoothest in children when routines are fairly regular; however, there will often be times when routines have to change. Extra blood glucose monitoring in these situations is helpful.

If using injections, thinking about patterns of insulin action and meal times will usually help you work out what to do. Insulin pumps allow the greatest flexibility for changes in routines, although adjustments are still relatively easy on multiple daily injection plans (MDI).

Overseas flights and time zone changes

Insulin adjustments for flights crossing time zones need to be individualised, taking into account:

- the duration of the flight.
- number of hours of time zone change.
- timing of meals, snacks and stop-overs.
- usual pattern of insulin doses.
- time of arrival at destination and plans for that day (e.g., sleeping or active).



Your educator can help you work out a detailed plan and, when possible, you should allow one month's notice of travel if you want help in working out a plan.

General principles are:

- Never omit insulin on flights.
- Do extra BGL monitoring.
- CGMS can assist in making any insulin dose adjustments during your flight.
- Keep one watch on local departure time and one on destination time.
- Set an alarm or arrange to be woken to avoid over-sleeping on the plane or after arrival.
- Higher BGLs are more likely during flights because of inactivity. Be prepared to give extra doses of rapid-acting insulin whenever BGL is above the target range (or additional pump boluses, provided there are no ketones present).

- Low BGLs are more likely if care is not taken to avoid more than the usual overlap of long-acting insulin doses or if less food is eaten because of sleeping more than usual. Be prepared for unexpected hypos.
- Carry additional carbohydrate in case there are delays, late meals and so on.

What sort of insulin adjustments will be required?

- No significant adjustments are required for predominantly north-south travel with less than a two-hour time shift (e.g., Sydney to Tokyo).
- When travelling west, the travel day is extended (e.g., if you leave eastern Australia in the late afternoon you arrive in London at breakfast time after travelling about 24 hours).
- When travelling east, the travel day is shortened (e.g., if you leave eastern Australia in the morning you arrive in Los Angeles earlier the same morning after travelling for 14 hours).

How to adjust insulin for time zone changes

Multiple daily injections (MDI)

Rapid-acting (bolus) insulin

- Continue to take rapid-acting insulin before main meals (about every four to five hours).

Long-acting (basal) insulin

For children who take once daily long-acting insulin, the options are:

- Give the next long-acting dose approximately 24 hours after the previous one, but at a reduced dose, so that you can resume your usual time of day injection at the destination. The time intervals will vary according to your destination, but the first dose at the destination will also need to be reduced if the dose given in transit was significantly less than 24 hours ago. The principle is that you will need about the same amount of long-acting insulin each 24 hours, whether you split it or not.

  OR
- Give the next dose of long-acting insulin at your usual time of day (morning or evening) at the destination, which could be up to 36 hours after the last long-acting injection. This will work satisfactorily, provided that rapid or short-acting doses continue to be taken regularly before meals with top- ups as needed if the BGL is above target. If it is less than 24 hours after the last long-acting injection, give a reduced dose to avoid overlap.

For children who take twice daily long-acting insulin:

- Continue to take it approximately every 12 hours. If your morning and evening doses vary significantly, you can readjust the ratios at your destination. Use extra BGL monitoring to guide dose decisions.

Simplified injection regimens (e.g., 3 injections per day)

- This will vary considerably, depending on the pattern of your insulin plan and the type and number of long-acting insulin doses.
- Start by thinking about your long-acting doses; whether you have this once or twice per day.
- If you have long-acting insulin twice per day, plan to have doses about 12 hours apart; the ratios may need changing at your destination because of time shift.
- If you have long-acting insulin once per day, the options are the same as for multiple daily injections above.
- Short-acting insulin should be given with the long-acting insulin doses that are given before meals. Additional short-acting doses may be required especially if BGL rises above 12-15 mmol/l.
- Some people decide to change to four injections per day (MDI) during their travel to make things simpler and more flexible and this is quite a good idea.

Insulin pumps

- If you are using an insulin pump, you will give boluses as normal. It may be beneficial to set temporary basal rates or temporary targets depending on your BGLs.
- Once you land at your destination change the date & time on your child’s pump to local date & time.

Continuous glucose monitoring systems (CGMS)

- CGMS is safe to use on commercial flights
- If instructed to turn off your CGMS you must comply. Carrying a travel letter explaining that CGMS is safe to use during a flight should prevent this from happening.
- Transmitters can’t be turned off (just switch them to aeroplane mode).

Remember to always change the time on your insulin pump, CGMS and glucose meter when you reach your destination.

Sleeping in

Sleeping in is part of the enjoyment of weekends and holidays. No particular changes need to be made if the later injection time is within 1-2 hours of the usual time.

Unfortunately though, diabetes does not allow your child to sleep in for a long time. Sleeping in for longer can cause problems with low blood glucose levels if overnight insulin is still acting or high blood glucose levels if insulin action is running out. If your child wants to sleep in longer, then you need to check the blood glucose level to ensure that this is safe and then arrange to wake at a set time later. Never take insulin doses in bed and do not go back to bed between taking insulin and eating breakfast. Giving the insulin later than usual in the morning can cause overlap with the evening insulin, so if you do this you should compensate by either moving the entire day's routine later or reducing morning long-acting insulin and/or evening rapid-acting doses.

Getting up earlier

No changes usually need to be made to insulin doses or food plans if the injection time is an hour or less different from the usual time. For earlier starts than this, you can bring the whole day's routine forward with extra testing in the evening to assess the need for any extra food and best insulin dose.

Going to bed later

Checking the pre-bed blood glucose level is recommended and it needs to be above 5 mmol/l. The alternative is to reduce the evening insulin if you know in advance that your child will be up later than usual, especially if they are planning an active evening such as a school dance.

Staying over at a friend's house

Children love to stay over at a friend's house, but with diabetes this can create practical difficulties and anxiety. Some planning can make this possible without problems. The age of the child will make a difference in the planning that is required. If your child stays regularly with friends or relatives, arrange for some diabetes education or for them to read a resource like this one.

If your child can do blood testing and can use pens or give an insulin bolus via their pump, usually all that is required is that the host family receive simple advice about meal requirements and timing and hypoglycaemia. They need to know how and when to contact you. They also need advice about what to do if an emergency arises.

Diabetes camps

Children or adolescents who have diabetes are often very dependent on their parents in caring for the diabetes and often do not know others of the same age with diabetes or do not mix with them. It is not uncommon for children who have had diabetes for a number of years to have never spent a night away from their parents. Diabetes camps are good for children and adolescents for the following reasons:

- They meet, make friends and socialise with other children with diabetes. They will also realise they are not the only person in the world with diabetes.
- They learn to become more independent in diabetes care – a stepping stone toward independent adult living. Children and adolescents learn how to care for themselves and adjust their diabetes care for situations such as increased activity. This often leads to children participating in other camps (e.g., school or sports camps) and being able to have holidays away from their parents.
- They learn more about diabetes in general. All camps have an educational component whether this is formal or informal learning.

- They increase their confidence in social and physical activities in a well-supervised environment.
- They participate in a safe, quality and fun recreational program.

Another important function of camps is to provide some respite for parents from the daily responsibility of looking after their child with diabetes. Many children require encouragement to go to camp initially, but end up having a wonderful time and gain great benefit.

A variety of camps exist in different regions and catering for different age groups.

Children do not normally attend camp alone under the age of nine years. For younger children (less than nine or ten years) there are weekend camps where the child attends with one parent.

Diabetes Australia has established camping standards guidelines to ensure that camps are run in a safe and professional manner. Camps have professional staff with diabetes training. For information about camps that would be suitable for your child, contact your diabetes educator, Diabetes Australia or the Juvenile Diabetes Research Foundation.

School camps

Most children in primary and secondary school will want to attend school camps or overnight excursions, which are usually two to five days long. This often makes people worry about the diabetes care.

Most of these camps do not have any nursing staff, but medical facilities are usually close by. Some parents attend camps as helpers and this may work well, but sometimes children will not want this. Planning ahead should allow your child to attend camp without any major problems.

Preparing for camp

Here are guidelines for preparing for camp or overnight excursions:

- Revise and refresh diabetes skills for your child (e.g., dialling up a dose and injecting insulin using pens, blood glucose monitoring, testing for ketones, changing a pump set and setting a temporary basal rate on their pump). Children need to have basic diabetes skills to attend camp. Your educator will arrange extra education before the camp if needed.
- Obtain the activities and meal program for the camp as early as possible and discuss this with your diabetes educator or diabetes doctor. In most cases activity levels will be higher than usual and lower insulin doses will be necessary. This is usually in the range of 10-30 per cent less than usual doses.

- Discuss the food and meals with the camp organisers. Arrange for extra carbohydrate food to be available so your child can treat hypos and prepare for exercise.
- Provide teachers and/or supervisors with information about diabetes before the camp (see Chapter 15 'School and diabetes'). It is also useful if your child has one or two friends who know about diabetes and hypos and can act as buddies to alert teachers if there is a concern.
- Try to identify one teacher or supervisor who will take responsibility for any extra supervision that your child needs.
- Arrange for a hypo pack or packs to be available at the camp, with instructions for teachers and/or supervisors about its use (see Chapter 15). Usually there will not be staff at such camps who would be able to give a glucagon injection for severe hypoglycaemia but if this occurs the Ambulance Service would be called and paramedics would give glucagon or a glucose injection.
- Make arrangements so your child or a teacher can contact you to discuss blood glucose levels and insulin doses while at camp.

Fasting for religious or other reasons

Healthy nutritional plans and most diabetes management plans rely on regular carbohydrate intake. However, sometimes there is a wish to participate in periods of fasting. Examples include the religious activities of Ramadan and Yom Kippur.

People with diabetes or other significant medical conditions are usually excused from fasting by their religions, but some people will still make a personal choice to fast. Fasting is not recommended for younger children. For teenagers and adults this can usually be done safely, using the following principles:

- Fasting for more than 12 hours is not recommended.
- Think about your insulin plan and in particular which insulin doses are covering food intake.
- For people on insulin pumps, the approach is usually simple. Continue the pump at the usual basal rates. Take meal boluses only when eating and use corrections if needed. If BGL tends to run low while fasting, use a lower temporary basal rate.
- For those on a multiple daily injection plan, continue your usual basal or long-acting insulin. Sometimes this may need a small reduction if total daily food intake is less. Use injections of rapid or short-acting insulin only when eating or if needed for corrections. Be careful about large doses of rapid or short-acting insulin just before sleeping, since this can increase the risk of night hypoglycaemia if the dose is misjudged.
- In all cases, extra BGL monitoring is important to guide adjustment and to guard against the increased possibility of hypoglycaemia.

Common questions and answers

? What should we do if our child gets sick when overseas?

Use the information in this resource on sick day management. If things are not getting better you will need to see a doctor. You may have been given a contact by your diabetes team before leaving home. Otherwise, find the nearest children's hospital, or large hospital with a children's department. If none is available nearby, ask for help to find an English- speaking doctor or a doctor who speaks your language.

? What should we do if our blood glucose meter is lost or breaks down when we are overseas?

Consider taking a spare meter. In many countries it will be possible to purchase a replacement machine, but the meter might read the blood glucose in different units than you are used to (1 mmol/l = 18 mg/dl).

? My nine-year-old wants to sleep over at a friend's house. He cannot yet give an injection. How can we handle this?

This is a good incentive for him to start learning to give injections independently. You can start working on this at home and ask your diabetes educator for help if required. He should be able to confidently test his blood glucose level, dial up the correct insulin dose and give the injection before he sleeps over at a friend's house. Being unable to give an injection should not be a barrier to keep him from socialising.

Chapter 19

Complications and associated conditions

Key Points

- The risk of diabetes complications can be minimised by having good long-term diabetes control
- Screening for complications is important to allow early detection
- It is also important to screen for other diseases associated with type 1 diabetes such as coeliac disease and thyroid disease
- Screening usually involves checking blood pressure, a blood test, a urine test, eye examination and sometimes testing of the nerves
- Smoking increases the risk of diabetes complications and must be avoided

In this section we discuss the long-term complications that can occur with diabetes and what can be done to reduce the risks. Older children and adolescents should be made aware of these gradually, at a level appropriate to their understanding. Risk of diabetes complications increases with longer duration of diabetes, poor blood glucose control, high blood pressure, smoking and if there is a history in the family of diabetes with complications. Complications are rare in children, but good diabetes control from early on is important and helps establish good long-term habits. Modern diabetes management techniques have reduced the rates of long-term complications, but serious complications are still sometimes seen in young people, especially when diabetes control is poor for long periods.

Minimising the risk of complications

- Try to keep the blood glucose levels within the target range as much as possible.
- Aim for a time in range above 70% (if using continuous glucose monitoring).
- Ensure that your child has a haemoglobin A1c (HbA1c) measurement approximately every three months, as a guide to long-term control. The target HbA1c is under 7%, however there is strong evidence that for every degree of improvement in diabetes control, the risk of complications will decrease.
- Make regular visits to your diabetes doctor or clinic. These should be every three months but sometimes more often if control is not good.
- Your child should be physically active and maintain a healthy food plan.
- Discourage smoking. Smoking adds substantially to the risk of diabetes complications.

Screening for complications and associated conditions

Complications screening allows the detection of very early signs of complications. If these are detected early, changes can be made to management that can stop them progressing or even reverse the complications. Early detection and prevention are very important. It is also important to screen for other conditions associated with type 1 diabetes (e.g., coeliac disease).

Screening may be done directly through your diabetes service or you may be referred to an external provider (e.g., a local optometrist, community pathology laboratory).

When does screening start?

Your doctor or diabetes educator will advise when screening should start, but a common guideline is to commence screening for complications once your child reaches early adolescence and has had diabetes for 2-5 years. Screening for other conditions associated with type 1 diabetes starts from the time of diagnosis. Emerging evidence suggests that with modern diabetes management, screening in low risk individuals for some complications may not be needed until later e.g., 15 years of age.

For type 2 diabetes, screening for complications starts at the time of diagnosis.

How often is screening required?

Screening intervals vary between different diabetes services, and also depend on which complication is being screened for. Most centres perform a blood pressure at least annually and routine blood tests and urine samples every 1-2 years depending on risk profile. Eye screening (retinal photography) and other types of screening vary between centres but usually occur approximately every 2 years.

Long-term complications

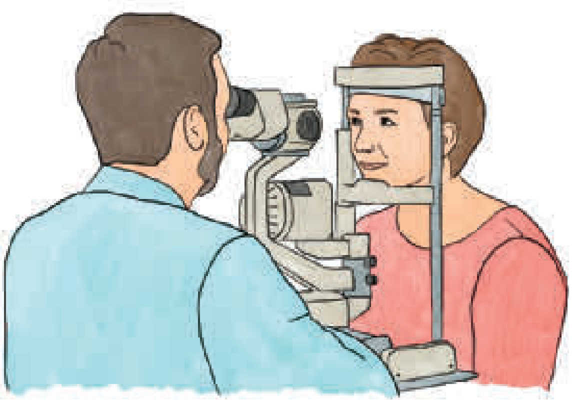
Complications occur in diabetes because of the effects of higher than normal blood glucose levels on small blood vessels, nerves and large blood vessels in the body. Some brief information is provided here on possible long-term complications.

Eye problems

Retinopathy

The retina is the thin layer of tissue at the back of the eye which contains small blood vessels and nerve endings for vision. Retinopathy refers to damage to the retina. Minor changes to the retina are very common after 10 to 15 years of diabetes (non-proliferative or background retinopathy), but this does not impair vision. Of more concern is where there is progression to new blood vessel formation (called proliferative retinopathy). This can threaten vision. The progression of retinopathy is related to poor diabetes control and long duration of diabetes. It can be treated by laser treatment or may require surgery for complications.

Screening for retinopathy can be done by an eye doctor (ophthalmologist) or optometrist.



Temporary blurred vision associated with changes in blood glucose levels

Large changes in blood glucose levels can cause blurred vision and difficulty in focusing. This is common at the time of diagnosis when blood glucose levels which have been running high are brought under control or after a period of stabilisation where blood glucose levels are improved. The blurred vision does not last long and usually disappears after a few weeks. It does not cause any long-term damage. Any change in glasses prescriptions should be delayed for a while after large changes in blood glucose levels.

Cataracts

Cataracts are a clouding of the lens and are more likely to occur in people with diabetes but usually only in older people. These can be successfully treated by surgery.

Kidney problems (nephropathy)

The kidneys filter waste products from our bodies and pass them into the urine. Diabetic nephropathy refers to kidney damage that can be associated with diabetes, which again is a greater risk for people with poorly controlled diabetes over long periods. Risks are greater in those with high blood pressure or who smoke. Advanced nephropathy can cause kidney failure, requiring dialysis or kidney transplantation.

Nephropathy can be detected at an early stage and treated effectively. Screening is done by testing urine samples for leakage of microscopic amounts of protein (called microalbuminuria). If early kidney damage is detected, the treatment is to improve diabetes control as much as possible and medications are given to slow or stop further kidney damage and to control blood pressure.

Nerve problems (neuropathy)

Diabetic neuropathy refers to nerve damage associated with diabetes. Again, the risks are highest in those with poorly controlled diabetes over long periods. Symptoms can include numbness or pins and needles, especially in the feet and lower legs. Neuropathy is rare in young people, but sensitive tests can detect minor neuropathy in young people with only fairly short periods of poor control. In the early stages, neuropathy can be reversed with improved diabetes control. Screening for neuropathy is part of some complications screening programs and is always recommended if there is poor diabetes control.

Vascular disease

Older people with diabetes have an increased risk of heart attacks and strokes due to narrowing of or blockages in large blood vessels. Risks are greater in people with untreated high blood pressure, high blood cholesterol levels or who smoke. Large vessel narrowing can also occur in the penis, causing impotence (problems getting an erection) and in the legs, causing circulation problems.

Adolescents with type 2 diabetes or combination type 1 and type 2 diabetes are at a greater risk of vascular disease at an earlier age.

Blood pressure should be measured at least annually and screening for high cholesterol levels should occur every 1 to 2 years as part of complications screening.

Foot problems

Foot problems (due to decreased blood flow or nerve problems) do not occur in children and adolescents. However, children with diabetes should protect their feet from injury because scarring and other damage could cause problems in later life.

Foot injuries, plantar warts, calluses, corns and in-grown toenails may be more of a problem in children and adolescents with diabetes, since infections are more likely in a high glucose environment and will be slower to heal. Proper care of the toenails is important and shoes should be worn for sports and outside play. Any scarring on the soles of the feet can increase the risk of long-term foot problems. Any foot injury needs to be cared for properly.

It is important that problems with foot alignment (such as flat feet or high arches) are detected in children with diabetes, since these may lead to an increased risk of later foot problems and can be corrected if discovered early. A podiatrist assists with any such problems.

Medical conditions commonly associated with diabetes

People with diabetes are at an increased risk of some other conditions, particularly thyroid gland problems, coeliac disease and more rarely, other autoimmune disorders such as adrenal disease and rheumatoid arthritis. These are conditions with a similar cause to diabetes, where the body forms antibodies against certain tissues and causes them not to work properly (called autoimmune conditions).

People with diabetes may also have skin issues due to irritation from pump or CGM adhesives or from injecting insulin too frequently into one place. Mental health issues are also more common in people with type 1 diabetes, particularly depression and anxiety.

Thyroid problems

An underactive thyroid gland (hypothyroidism) occurs in 3 to 8 per cent of children with diabetes. Symptoms and signs may include tiredness, weight gain, poor growth, problems with diabetes control and an enlarged thyroid gland (goitre). It may be difficult to detect without a blood test. If hypothyroidism occurs it is easily treated by giving replacement thyroid medication in tablets.

Overactivity of the thyroid gland (hyperthyroidism) is also a slightly increased risk with diabetes. Symptoms and signs may include weight loss, nervousness, increased appetite, tremor, problems with diabetes control and an enlarged thyroid gland (goitre). This also can usually be corrected by medications taken in tablets.

Most diabetes centres screen for thyroid problems with a simple blood test every 1-2 years in children with diabetes.

Coeliac disease

Coeliac disease occurs in about 7 per cent of children with diabetes and is another antibody-related (autoimmune) condition in which the body forms antibodies against the protein gluten which is found in the grains wheat, rye, barley, oats and triticale. These antibodies cause damage to the bowel lining which may cause poor absorption of food, poor growth, unstable diabetes and possible development of bowel tumours in later life. In many children, no symptoms may be evident except unstable diabetes control so most diabetes centres screen for coeliac disease at the time of diabetes diagnosis and with a blood test every 2 years or so.

Coeliac disease can be treated by diet changes which involve avoiding the grains containing gluten. This treatment is very effective, but adds an extra difficulty to diabetes care. Advice from a dietitian experienced in the area is essential.

Skin reactions to adhesives from insulin pumps or CGM

Skin reactions such as contact dermatitis can occur due to the adhesives at pump infusion sites and CGM sites. These reactions can be minimised by rotating the sites frequently. Small children with less available space at commonly used sites (abdomen, buttocks) may try inserting the CGM on the back of their arm instead. Ensuring the pump set is changed frequently enough (usually every 2-3 days) is also important. If the reactions persist, your diabetes team can provide advice on barrier products to protect the skin or alternative adhesives that may be used.

If the skin is broken or inflamed there is also a risk of infection. Any sites that are very inflamed, painful or have discharge should be reviewed by your local doctor as further treatment such as antibiotics may be required.

Issues with pump insertion sites are discussed in more detail in Chapter 13.

Lipohypertrophy

These are the “lumps” that appear at an insulin injection site (or pump infusion site) when the same site is used too frequently. When insulin is injected into areas of lipohypertrophy the insulin absorption is unpredictable and it often doesn’t work as well. Rotating the insulin injection sites frequently reduces the risk of lipohypertrophy and ensures the insulin is absorbed properly.

Mental health issues

Mental health issues are more common in children and adolescents with type 1 diabetes than in the general population. These include anxiety, depression and eating disorders. This may relate to the stress associated with managing a chronic medical condition. These issues may persist into adulthood and need to be addressed if they arise.

Mental health conditions can be identified and supported with effective treatments. Learning how to recognise signs and understand these conditions can be an important step in managing diabetes. Should you have concerns about mental health and diabetes please speak to your diabetes care team.

Common questions and answers

My seven-year-old has had diabetes for two years. Does he need his eyes checked?

An eye check is generally not recommended in children at this age. If your child has eye symptoms at any time, a check should be done, but these would be unlikely to be due to diabetes. Sometimes temporary blurring of vision can occur when blood glucose levels are changing a lot, but this soon goes away.

My 15-year-old daughter has had diabetes for ten years and poor control for five years and has some early eye changes and slight nerve changes in the feet. Is this serious?

These are warning signs of the diabetes starting to affect the body and these could progress to become more serious. The good news is that early problems can often be stopped or reversed if control is improved, so this is the most important thing. Any improvement in control, even if only small, is of benefit.

Is the rate of complications decreasing with modern diabetes management?

Yes. Modern diabetes management including new insulins, multiple daily injection plans, insulin pumps and CGMS have progressively reduced the risk of diabetes complications especially in young people. This has led to progressive changes to screening recommendations for diabetes complications, starting later and less frequent. However, it is important not be become complacent and to follow the recommendations of your diabetes team. Major and early complications are still possible in adolescence or young adulthood if attention to diabetes control is poor.

Chapter 20

Research and the future of diabetes management

Key Points

Around the world, major research efforts and funding are being invested in diabetes, with the aims of:

- **Finding a cure for diabetes**
- **Identifying those at risk for diabetes and preventing the onset of diabetes**
- **Improving management techniques until a cure is found. This includes:**
  - **development of new and better insulins**
  - **development of better ways of giving insulin (insulin delivery)**
  - **development of better blood glucose monitoring equipment**
  - **minimising the risk of long-term complications.**

Finding a cure for diabetes

A cure for diabetes would be a treatment method that replaced the insulin-producing capabilities of the pancreas. This would mean that insulin injections would no longer be required and blood glucose levels would be able to stay in the normal range.

Currently, the most promising research is in cell replacement in which insulin producing cells would be injected into people with diabetes. These take over the glucose-sensing and insulin-producing functions of the pancreatic beta cells. These replacement cells could be beta cells from humans or animals, or may be newly created (bio-engineered) cells with the properties of beta cells. There is much interest in the potential of stem cell research as a source of these cells for a diabetes cure.

Much progress is being made in this field, but the main problems are with long-term survival since the cells are easily rejected. Beta cell transplantation has shown some success with improvement in diabetes, however most recipients eventually require insulin again longer term. It still rarely performed and is not yet suitable for children or adolescents with type 1 diabetes. Bio-engineered cells and stem cells are showing promise but also require much more development.

Other areas of research include using immune modulating drugs to try to extend the remission phase ("honeymoon period") by preventing ongoing destruction of the remaining beta cells immediately after diagnosis.

The artificial mechanical pancreas has also been a dream of modern technology and some progress is occurring in this area, particularly with external systems. The hybrid closed-loop insulin pumps are a step closer to making this a reality. Limiting factors to be overcome are the "lag time" in continuous glucose monitoring systems, time taken for insulin to be injected and start to act, and the lack of other adjusting (counter-regulating) hormones such as glucagon. Implanted artificial systems have the additional problems associated with any long-term implanted devices.

Whole pancreas transplants are possible, are often successful and may lead to people coming off insulin injections. However, this procedure has significant risks of permanent health problems or death. It is usually only available to adults with advanced diabetes complications with kidney failure who also require a kidney transplant. Long-term anti-rejection drugs are needed that can have many side-effects. As yet, it is not a suitable option for children and young people.

Diabetes prevention

Medical researchers have aimed for a long time to identify people who may be at risk of diabetes (pre-diabetes) and find a way of preventing diabetes developing. This research involves finding out more about the cause of diabetes, finding ways to predict who may get diabetes and trying treatments that could prevent the onset of diabetes.

Most studies have concentrated on screening relatives of people with diabetes by antibody tests and other blood tests. Where high risk factors are found, experimental treatments have been tried to prevent diabetes. At present, no preventive treatment has been proven to be safe and effective. Some are showing promise and active trials are continuing. Testing of relatives of people with type 1 diabetes is not yet routine, but may become so in future. Screening of all children would be a much more difficult task, but may be possible in the future.

Improving management techniques

Until a prevention and cure are available for diabetes, it is likely that there will be many improvements in the way it is treated. These are likely to include:

Insulin and insulin delivery

- **New insulins:** Manufacturers are continually working on new insulins that work better or have more suitable action profiles. New insulins (e.g., FiASP, Ryzodeg) have been released over the past few years and been helpful for many people. Other new insulins are under development.
- **Inhaled insulin:** Techniques have been developed that allow short-acting insulin to be inhaled into the lungs. This form of insulin has been approved for use in adults overseas. Studies are underway to determine if inhaled insulin is safe and effective in children, but there are several potential issues that may limit its use. Inhaled insulin cannot be used in people with lung conditions such as asthma. The doses available (cartridges) are also relatively large so it would be difficult to give doses small enough for children and to adjust the dose. There is also no evidence on the long-term effect of insulin on a child’s lungs. Even though inhaled insulin is a potential future treatment, it is not currently an option for children with diabetes.
- **Hybrid closed-loop insulin pumps:** This technology uses an algorithm to enable the insulin pump and CGMS to stabilise the blood glucose levels between meals and overnight (a semi-automated system). The pump user still enters a carbohydrate amount and gives a bolus with meals. This technology is relatively new in Australia but is showing great promise. Hybrid closed-loop pumps are discussed in Chapter 13.

Glucose monitoring

- Continuous glucose monitoring systems (CGMS or CGM): This technology has advanced rapidly in recent years. There are multiple systems available which are now more accurate and easier to use. This technology can also link with an insulin pump to provide a hybrid closed-loop system (described above). CGM is discussed in Chapter 7.
- Non-invasive blood glucose monitoring: This refers to monitoring glucose levels without having to puncture the skin. Concerns about accuracy have limited widespread use of these devices. Several non-invasive glucose monitoring devices are currently available overseas for adults with type 2 diabetes but they are not yet approved for use in Australia.

Other areas of research

- **Prevention and treatment of complications:** New drugs and other ways of preventing and treating diabetes complications are in constant development.
- **Information and education:** It is an ongoing goal in Australia and other countries to provide better information and education for people with diabetes.
- **Psychological research:** More research is needed about the way psychological aspects interact with diabetes management and the psychological impact of chronic conditions such as diabetes.

Chapter 21

Resources

A wide variety of sources of additional information are available. Your diabetes team will advise you which additional resources they recommend.

There is a large amount of information about diabetes on the internet. Much of this is useful and interesting, but be aware that the quality of information can be very variable. Always look at the organisation that is running the site as this will be a guide to how reliable the information is likely to be. For example, sites such as the Diabetes Australia, the American Diabetes Association or those of major children's hospitals or universities are likely to be of high quality. A lot of what you may read on the internet will apply to type 2 diabetes, so be careful to distinguish this.

If you come across material you don't understand or that disagrees with what you have been told, discuss this with your diabetes team. If you don't have access to the internet, don't worry. New developments and information are always available through your diabetes team who keep in close touch with the latest information and technology from around the world.

Here are some commonly used sources of information:

Local organisations

Diabetes Australia

Diabetes Australia is an Australia-wide diabetes organisation. They assist with administering the National Diabetes Services Scheme (NDSS), provide advocacy, information and research funding.

www.diabetesaustralia.com.au

The Juvenile Research Foundation of Australia (JDRF)

JDRF provides fundraising, advocacy, information and support for young people with type 1 diabetes.

www.jdrf.org.au

as1diabetes

A NSW and ACT based service which provides information for kids, teens, parents and schools about type 1 diabetes.

https://as1diabetes.com.au/

Diabetes NSW and ACT

A service dedicated to supporting people with Type 1 and Type 2 diabetes in NSW and ACT. They provide education, information, programs and services designed to help people better manage their diabetes. They also run a free helpline 1300 342 238.

https://diabetesnsw.com.au/

Diabetes Victoria

Charity and consumer body for adults and youth with diabetes. Their website contains some resources on diabetes management in youth.

https://www.diabetesvic.org.au/resources

Diabetes New Zealand

A charitable trust that provides fundraising, information and support for people with type 1 and type 2 diabetes.

https://www.diabetes.org.nz/

International organisations

The American Diabetes Association

www.diabetes.org

The National Diabetes Information Clearinghouse of the USA

(a service of the National Institutes of Health)

www.diabetes.niddk.nih.gov

Diabetes UK

www.diabetes.org.uk

Appendix

Quick-find guide

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Common abbreviations

BGL	Blood glucose level
CGM(S)	Continuous glucose monitoring (system)
DKA	Diabetic ketoacidosis
GI	Glycaemic index
GFD	Gluten free diet
ICR	Insulin to carbohydrate ratio
ISF	Insulin sensitivity factor (or correction factor)
MDI	Multiple daily injections

This book will help you look after diabetes in your child or adolescent.

First published in 1998, over 60,000 copies have been sold.

The editors and contributors are experienced diabetes health professionals in Australia. The book reflects their common approach to diabetes care. It is a comprehensive, practical and up to date guide to all aspects of diabetes care, including:

- Insulin therapy and adjustment
- Food and healthy eating
- Insulin pumps
- Continuous glucose monitoring
- Hypoglycaemia
- Sick days
- Travelling, exercise and sport
- Diabetes and school
- Adapting to living with diabetes
- Type 2 diabetes

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