



COLORECTAL AND PELVIC
RECONSTRUCTION SERVICE

Adjustment to diagnosis

Information for families

Adjustment to Diagnosis

Colorectal and Pelvic Reconstruction Service (CPRS)
Information for families

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Acknowledgements

We are indebted to the contributions of the many families that are cared for by the CPRS team. This resource is for all families affected by colorectal and pelvic conditions.

About this booklet

The Colorectal and Pelvic Reconstruction Service (CPRS) at The Royal Children's Hospital (RCH) Melbourne is leading the way in colorectal and pelvic care in Australia.

We aim to deliver the highest quality clinical care to children and families with colorectal and pelvic conditions. We play a vital role in increasing the awareness, understanding and knowledge of these conditions in the community and work collaboratively to educate health care professionals.

This booklet has been developed to support parents and carers of children who have colorectal and pelvic conditions. The CPRS seeks to establish a healthy relationship with all families, as we believe this enables the best care possible. The content of this booklet has been developed based on the extensive clinical experience of the authors and the most recently published evidence for these clinical conditions.

Everyone learns differently. Some people like to read instructions, some like to learn by having information explained to them, and many like to do both. Please tell the members of the CPRS team if you are finding any information in this booklet difficult to understand.

Introduction

The diagnosis of your child's colorectal condition may initially feel confronting or distressing for you and your family. This booklet aims to provide you with information on what you may expect following your child's diagnosis and some strategies that may help you and your family cope.

The CPRS team includes surgeons, paediatricians, clinical nurse consultants, stomal therapy nurse consultants, a clinical psychologist, a social worker and a child life therapist, who are all able to provide advice and support for you and your child.

Initial reactions

After your child's initial diagnosis you may experience a range of different feelings, including shock, disbelief, sadness, or a combination of all these things. There is no right way to feel.

It is completely normal for parents to feel grief. Grief may include feelings of loss, anger, fear and guilt that come and go over time. You may find you are happy and content one minute, and quite teary and sad the next. Each person grieves in their own way and in their own time.

Some parents, may question whether they did something to cause their child's colorectal condition. It's important to remember that congenital colorectal conditions may occur without any known reason. Although feeling guilty is common for some parents, it is not not beneficial to you or your child. It is important to acknowledge these feelings, but let them go. Try to focus on something positive and beautiful about your child.

You may find yourself thinking a great deal about what the diagnosis means for your child as they grow.

Thinking about the future is a normal response to working through what the diagnosis means. We recommend trying to take one step at a time, one day at a time. The CPRS team will be available to help you understand what to expect as your child grows.

If you feel comfortable, sharing how you feel about your child's diagnosis with someone close to you, may be helpful. This could be a trusted friend, or family member.

Reactions may also differ between partners. Making time to talk together and share how you feel is an important way to understand what each person is going through. It may also bring you closer together as a team to support your child.

The CPRS clinical psychologist and social worker are available to visit you on the ward or following discharge to talk through any challenging feelings.





Celebrating your baby

For many children with a colorectal condition, the diagnosis may occur soon after birth. You may have been separated from your baby while your baby receives treatment at RCH. This experience is likely to be far from what you had expected, and therefore, quite challenging emotionally. Despite there being tubes and wires physically present, your baby will still thrive from your love and attention, as if they were at home.

There are many things you may do in hospital to bond with your baby. These may include time for skin-to-skin cuddles, positive touch, talking and singing. Your baby will also learn your voice, and this will help to soothe them through their time in hospital. Try to remind yourself that there will be plenty of time to spoil your baby and develop your own rhythm and routine as a family.

It may be easy to take an overwhelming focus on the medical side of your baby at this time. Try not to let this define your family. Remember, this is only one aspect of your child's life. Beyond their condition, they are a little person ready to be loved and raised by you.

You should trust your parental instincts and do whatever feels natural to you to try and connect with your child, even in hospital.

It is normal to feel that it is hard to bond during the process of adjustment, especially as you are learning a great deal about their surgical and medical care needs, and things are quite different to what you had expected. There are a number of people that may provide gentle guidance in feeling connected with your baby. This includes the ward staff and members of the CPRS team.

The CPRS team may refer you to the RCH Infant Mental Health team. This team specialises in helping parents bond with their young child whilst in hospital. A little help in this area may go a long way at this time.

Gaining knowledge

You will be visited by a number of medical professionals after your child's diagnosis. It is important not to put too much pressure on yourself to remember everybody's name and understand all of the medical information that you receive. There will be plenty of opportunities to talk further with members of the CPRS team, who will clarify anything you are uncertain about.

Gradually gain information about your child's diagnosis from reliable sources. Not everything you find on the internet is based on reliable scientific research. You might find yourself searching the internet for information to help you feel more in control of what is happening. However, to learn more about the condition your child has been diagnosed with, we recommend using the evidence-based resources provided by the CPRS team.

Having regular contact with the CPRS clinical nurse consultants and asking plenty of questions may help to make sure that you have the most accurate information for your child's condition. This will help you to come to terms with the diagnosis and to move forward as a family.



Sharing

When you are ready, talking to family and close friends about your child's diagnosis is an important way to help you and others understand what is going on for your family. This may help you feel less alone during the journey. The amount of support you have from others, like your partner, family and friends, might also affect how you feel. Having encouraging support will help you feel more positive.

Helpful support may be emotional (a friend to talk to, a shoulder to cry on) or logistical, like offering childcare for siblings or providing cooked meals to your door.

Some families may feel embarrassed at sharing their child's colorectal condition with others. The bowel and bottom are parts of the body that are not openly talked about and something that many of us take for granted. You may find it hard to know the right words to use. The CPRS team will help guide you in the types of explanations that you may feel comfortable saying to family and friends.

It may be helpful to write down or practise what you would like to share with your family and friends before you speak with them. Some families may find it easier to share through an email. Everyone's approach will be different.

Close family members may also feel a sense of concern and uncertainty. Encouraging them to read through the CPRS information booklets may help their understanding of your child's colorectal condition. These may also help to start conversations with you about your child's condition.

Siblings

It may be hard to juggle the hospital with providing care for your child's siblings. Some younger children may become worried at the thought of their brother or sister in hospital, being away from you while you attend to their new sibling in hospital or seeing them need ongoing care at home. Reassuring them that their sibling is okay, and maintaining normal routines as much as possible, may help.

When sharing the diagnosis with your child's siblings, it may be helpful to choose a time and place free from distractions. It is important to use language that they understand. The amount and type of information you give will depend on your child's developmental level, as well as their personality. However, for all ages, simple, factual language is best. For younger siblings, it may also be helpful to use toys, such as baby dolls, to help explain how their sibling's body may work differently.

When you arrive home, you may carry out ongoing care, such as bowel washouts or stoma bag changes. Thinking about how younger children interpret what happens when these cares are carried out is important. Providing simple explanations and letting them know they are not harmful, may be reassuring.

Encourage your child to ask questions and check back in with them over time, providing opportunities for ongoing discussion as well as correcting any misunderstandings.

If you are unsure how to answer a question they have, it may be helpful to say that it's a great question and you are going to have a think about it or write it in a list for the CPRS team!

The CPRS clinical psychologist provides focused support to families, including siblings, in adjusting to their child's colorectal condition. Please contact the CPRS clinical nurse consultants if you would like to know more information.

Example phrases to use with a younger child:

"When baby was growing inside mummy's tummy, before they were born, their tummy and bottom grew a bit differently."

"The doctors had to do an operation to make sure that baby's poo could come out and didn't get stuck inside."

"Baby's nappy still needs to be changed but their poo comes out in a different spot."

"Baby is very safe and has doctors and nurses to help look after them."



Self-care and getting support

Your child's diagnosis is likely to come at a very vulnerable time for you, immediately following their birth. Your physical and emotional wellbeing will need to be supported as much as possible at this time. Be kind to yourself and take each day as it comes.

You may find that during your stay in hospital, you need to feel a sense of control and only focus on the medical management of your child. It may be hard to slow down and reflect on your emotions. You may worry that if you do, you won't know how to contain these emotions. By working through overwhelming feelings, you will be better equipped to face challenges and adjust to your child's diagnosis. The CPRS clinical psychologist may also provide help on how to process and cope with these.

You will hear the CPRS team discuss the importance of self-care. Self-care includes eating well, sleeping/resting whenever you are able to, and/or taking brief breaks away from your child's room during their stay in hospital.

Self-care is very important, as this recharges you to manage the care of your child's condition. The CPRS social worker will often talk to you about this on the ward.



Ideas for self-care:

- The hospital is surrounded by a large park which may be utilised for walks, play dates with siblings, sitting in the sun and taking some time out.
- Finding some quiet time, if only for five minutes every day, is vital. Take time to let go and quieten your mind. Breathe deeply.
- Utilise your friends for support. They could drop meals at your door or just be a listening ear.
- Keep up family routines, wherever possible, as these are great opportunities for connection and cooperation.

Referrals may also be made to a number of RCH services (where applicable):

- WADJA Aboriginal Family Place
- Pastoral Spiritual Care
- Child Life Therapy
- Infant Mental Health
- Maternal and Child Health Services
- Starlight Express Room for siblings
- Family Services

Please remember that when you go home you are not alone. If you need further support in adjusting to your child's diagnosis, please contact any of the following team members:

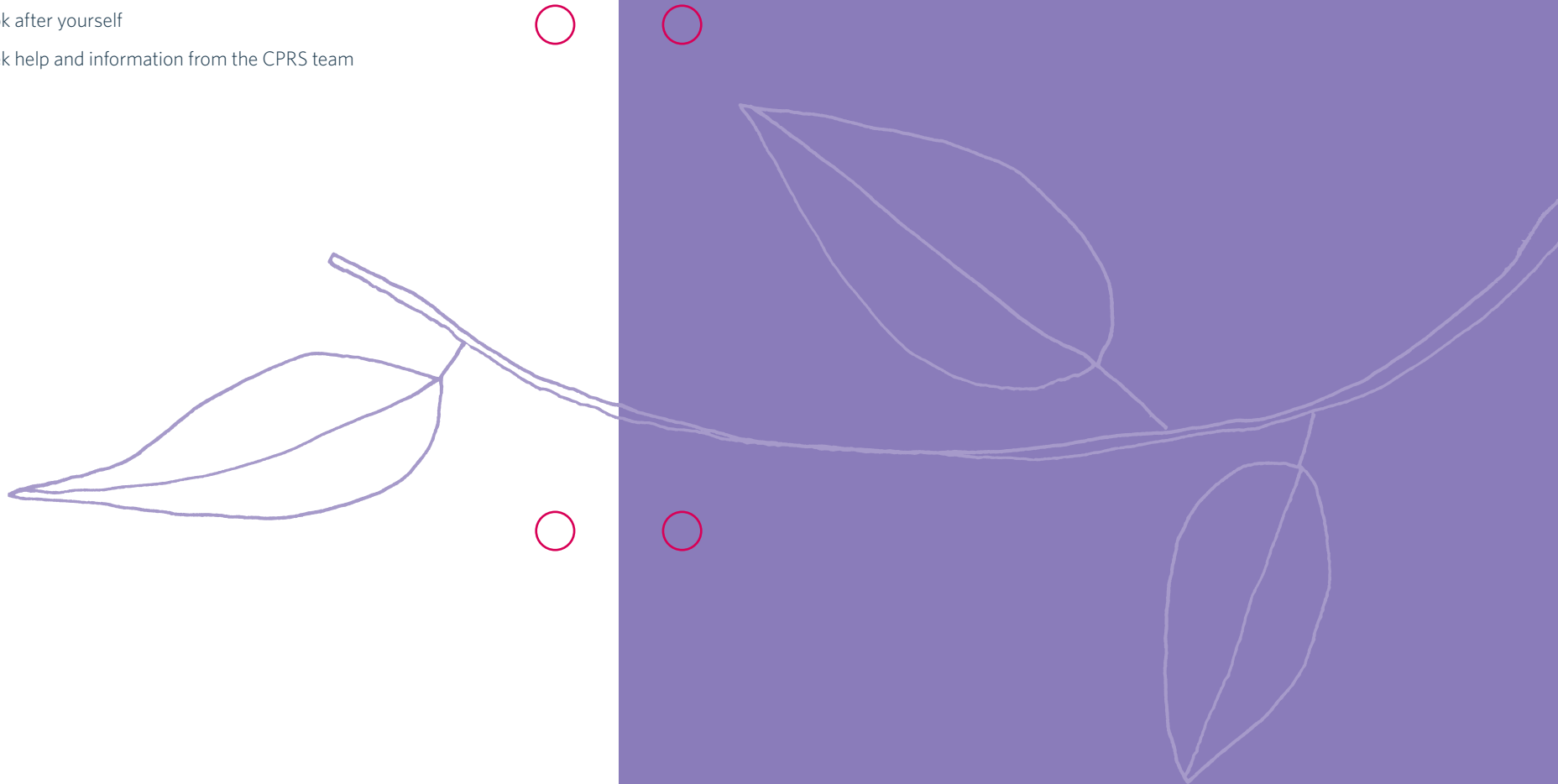
CPRS clinical nurse consultants:
colorectalnursingcnc@rch.org.au

CPRS clinical psychologist:
colorectalpsychology@rch.org.au

CPRS social worker:
colorectal.socialworker@rch.org.au

Summary

- Experiencing a range of feelings is normal
- There is no right way to feel
- Enjoy time with your child
- Try and talk to people close to you about your child's diagnosis
- Look after yourself
- Seek help and information from the CPRS team





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