



INFORMATION FOR YOUNG PEOPLE

Information about Transition from Children's Health Services to Adult Services

What is Transition?

It is the planned move from health services for children to health services for adults.

As you mature from being a child to an adult you outgrow the expertise of children's (paediatric) health service and need to find an appropriate adult health provider. This is a really important issue if you have a chronic condition that will require ongoing treatment. When health professionals in the children's service start discussing transition with you they are talking about getting ready to start seeing adult services. Transition does take time. People will usually start to bring up the topic of transition when you become a teenager.

When Does Transition Occur?

Transition is a process that occurs over many years. This allows time for you and your family to plan your future health care with your health team. You need time to learn new skills that will increase your independence; say good-bye to the children's service and have time to adjust to a new team and the way they do things.

The people in your team will usually start talking about your move to adult services when you:

Are in high school *or*

When you are about 13 years old

or

Close to when you are diagnosed (if you are an older adolescent)

(adapted from NSW Transcare Project
& GMTT Brain Injury Rehabilitation Directorate Paediatric 2004 Transition Project, NSW)

Help With Transition??

www.rch.org.au/transition

Search this website for:

- ⇒ Fact sheets for young people, their families and clinicians
- ⇒ Reference list, including websites
- ⇒ Transition checklists

For further information discuss
with your health care team at RCH.

Taking Charge of Your Health Care



Your Rights (& Responsibilities)

Whenever you seek medical advice or treatment you can expect health workers (including doctors) to:

- ⇒ Take you seriously and treat you in a respectful manner
- ⇒ Provide clear information and explain what is happening in words that you understand
- ⇒ Involve you in any decisions made about your care and any plans for treatment including stopping care or changing treatment
- ⇒ Include a friend or family member during your appointments, if that's what you want
- ⇒ Give you the chance to ask questions about things that are important to you
- ⇒ Respect your privacy and confidentiality
(There are legal limits to this in respect to your safety or the safety of others. Ask your doctor/ team members what these limits are.)
- ⇒ Let you know how to look at your medical record and make sense of it
- ⇒ Let you know how to make a complaint

If you are 16 or under, your doctor or other members of your health team might need to ask for your parent's permission before determining a path of action for your treatment. The team member should discuss this with you first.

Responsibilities

Health workers in adult facilities will expect you to take more responsibility for yourself. They will expect that you:

- ⇒ Understand your condition and its treatment and are able to explain this to health professionals when required
- ⇒ Keep a copy of your health record
- ⇒ Know the warning signs that mean you need urgent medical help
- ⇒ Follow treatment plans given to you by your doctors that you have agreed to
- ⇒ Show up to appointments on time
- ⇒ Know how to get referrals or prescriptions when required
- ⇒ Know how to order and take care of special equipment you might need
- ⇒ Understand how Medicare and your medical insurance work

Complaint?

If you were unhappy about the way you have been treated by any health care staff there are steps that you can take – you can make a complaint!

It is always a good first step to talk first with the person/people involved. Tell them what you experienced and what you want done about it. If you do not want to approach the health staff member yourself, perhaps find someone else on the team that could help you.

If you don't get anywhere, or need some extra help to do this, contact the RCH Consumer Liaison Officer 9345 5676 who can help you.

Differences Between Child and Adult Health Services

Growing up with an illness or disability raises issues that other people your age don't face. One important issue is the question of transition from your childhood medical service provider to those who will look after your adult medical care. While it may sometimes seem difficult and upsetting to have to leave the children's team, it is a great sign that you are becoming an adult. This change will happen as a normal part of the care you receive for your condition.

Differences

There are many differences between child and adult health care settings. One main difference is the amount of independence you will be given. With independence comes the need to learn about your condition, speak up about any concerns you have and seek advice when you need it. As you become an adult you will be learning how to do more things for yourself and therefore not need your parent's help as often. The adult services will treat you as an adult and will expect that you have some independence and are able to do many things yourself.

Many young people want to know in advance what to expect in the adult service so as to be better prepared. We have tried to list some of the differences for you.

Child Services	Adult Services	Tips
Child health settings are very family focused	Adult services will treat you as an independent adult and may not include your family.	You are entitled to bring someone with you to your appointments and it does often help to have someone else there for support
Questions are often directed towards your parents /caregivers	You will be expected to know about your medical condition. You will be asked questions directly, not your family.	Bring a list of questions and concerns as it is easy to forget when you are sitting there in the doctor's office
There is usually more flexibility with appointments	You will be expected to make your own appointments and keep them at the agreed time.	If you have a lot to discuss with your doctor make sure you ask for a long appointment to have enough time to discuss your concerns.
Many services cost less in the child health services.	There may be added costs and increased charges for some things such as equipment.	Learn about Medicare and what your medical insurance covers.

Financial Issues In the Adult Medical World

Who Pays?

During your childhood your parents paid for any medical costs that were not covered by Medicare. In fact most of your medical care was paid for by hospital and appeared to be free.

As an adult you will need to know about the costs of medical care.

Medicare



You will probably find that you have been covered by your parent's Medicare card. If you are over the age of 15 you are entitled to have your own Medicare card. It may be more convenient and give you more independence if you have your own card.

To enrol for a new card for yourself

- ⇒ Gather up your identification (birth certificate, passport, bank account details)
- ⇒ Attend a Medicare office (with your identification)
- ⇒ Complete a Medicare copy/transfer application form. This form is available from the HIC (Health Insurance Commission) website or Medicare offices.
(You may want to have this already completed before you go into the Medicare office.
If your parents are wishing to enrol on your behalf, both you and your parents need to complete the form.)

When you are going for a check up or treatment it is important that you take your Medicare card with you. Medicare covers the cost of:

- ⇒ All public hospital clinics
- ⇒ Treatment as a public (Medicare) patient in a public hospital
- ⇒ All or part of the costs of treatment by practitioners such as doctors, including specialists, participating optometrists or dentists (specified services only).

To find out more about Medicare and the charging of fees, visit the Health Commission
Website: www.hic.gov.au
or phone 132 011

Bulk Billing

Bulk billing is when the government pays your doctor for your medical. This means you do not have to pay for your appointment. You just have to sign. Some doctors will bulk bill but they do not have to!

Before you make an appointment with a doctor, ask if they bulk bill. If they don't, ask them to explain the costs and how much you can get back from Medicare.

Private Health Insurance

You do not have to have private insurance – it is your choice. There are many private health insurance companies. If you are thinking of taking out private health insurance have a look at what different insurance companies offer and what best suits your needs and budget.

You may find that your parents have you covered with private health insurance. Ask them if this will be transferred to you as an adult.

All private health insurance requires a contribution on a monthly or yearly basis by you. You need to allow for this when budgeting your money.

Pharmaceutical Benefits Scheme (PBS)

Most medicines available on prescription are subsidised by the government under the PBS. This means that the government helps pay for the cost of these medicines so you are charged less.

To be eligible to receive medicines under the PBS you just need to provide your pharmacists with your Medicare card when you have your prescription filled.

If you require a lot of prescription medicine it is a good idea to keep a record of your spending on a prescription record form (available from any pharmacy). When you reach a certain amount of spending on your PBS medicines for the calendar year, your pharmacist can provide you with a Safety Net Concession Card. This entitles you to receive further PBS medicines at a reduced rate for the rest of the calendar year.

For further information on the safety net amount talk with your pharmacist or visit www.hic.gov.au

Specialist Doctors

Specialists such as neurosurgeons, urologists and orthopaedic surgeons may ask you to pay at each visit when you see them in their private rooms. You can then claim some of the money back from Medicare. This is normal practice that you need to be aware of so that you can plan for the expense.

When making an appointment don't forget to ask how much it will cost and how much you will get back from Medicare!

To find out more information about the costs of health care:

- ⇒ Talk with your medical team
- ⇒ Visit the Health Insurance Commission website: www.hic.gov.au
- ⇒ Talk with your pharmacist
- ⇒ Visit a Medicare Office or phone them on 132 011
- ⇒ Contact the pharmaceutical benefits scheme on 132 290

Making the Move: Checklist for Young People

To make life a little easier, some people find having a list of 'things' to be achieved very helpful. It can be very satisfying to tick off what you have already achieved and jog your memory of what still needs to be done. Using this idea the checklist below has been developed for you to use as you start to think about, and make the move to, adult health services. The more you know the better prepared you will be to make the move when the time comes.

The checklist is broken into 2 sections;

- ⇒ Some things to think about as you are **starting out** with the move to adult services.

This usually starts from 13 years old.

- ⇒ The things that would be useful to aim for when you are **getting closer** to moving to the adult services.

This would occur anywhere between the ages of 16-19 years old, usually after Year 12.

But how do you achieve some of these things that are listed?

Let's face it; sometimes it is hard to talk to doctors and other health care professionals! To help you out with this another fact sheet has been included on 'Communicating with Health Care Staff'. It is hoped that this will provide you with some tips to help you get the information you need from them.

Starting Out

Use this checklist when your health care team start talking to you about the move to adult services. This usually starts when you are about 13 years old.

- Start to learn about your disability or condition
- Learn the warning signs that mean you need emergency medical help
- Know who to call in an emergency
- Make sure you understand your medications, what their names are, what they do and when you take them.
- Start taking more responsibility for your own self care (such as cleaning your equipment, doing your exercises and taking your medications without being reminded)
- Take an active role in your appointments by asking questions
- Talk to your doctor about how smoking, street drugs and alcohol interact with your condition or the medication you are taking
- Talk to your doctor about difficult topics such as the changes in your body, puberty and contraception
- Ask your team to explain to you why you are having a test and the results of the tests
- Know about any allergies you have
- Ask your parents to wait outside the room so you can have some time alone with your health care team members.
- Learn how to have a prescription filled
- Talk to your doctor about transition, how and when you should move to adult services, your options and what differences to expect in the adult service
- Ask your health care team about where to get more information about your condition or other young people with disabilities

But life is not all about medical stuff!

Non – medical things to think about

- Think about what job you want to do after you finish school, especially when you are selecting your subjects.
- Start exploring your options for further education or training.
- Find out about other young people who have a disability, if you have an interest in this.
- Take on more responsibilities (chores) at home to increase your independence.
- Discuss with your doctor any restrictions there may be on playing sport.

Getting Closer

Use this checklist to build on the skills you already have, as you are getting closer to making the move to adult services. This usually occurs between the ages of 16 - 19 years old.

- Know about your disability or condition
- Know when you need emergency medical help
- Know who to call in an emergency and how to get in contact with them
- Learn how to make your own appointments and start making them
- Meet privately with members of your health care team
- Know how smoking, alcohol and street drugs interact with your condition and medication you are taking
- If you haven't already, talk to your doctor about birth control, how/if your condition may affect your fertility and genetic information you need to be aware of
- Tell your doctor if you are feeling low or having trouble at school or home
- Learn what tests you need to have, why and how often

- Ask for copies of medical tests and results as well as a verbal explanation
- Fill your own prescriptions
- Order the supplies for your equipment and know how to maintain it
- Enrol for your own Medicare card and find out about private health cover.
- Learn about how to maintain a healthy lifestyle with exercise and eating healthily
- Know what differences to expect in the adult service
- Start meeting with new adult doctors to 'check them out' before you have to switch
- Know your health history. (See below – My Medical History)

Non – Medical things to think about

- Find out if there are any restrictions on you learning to drive
- Find out if you are eligible for financial support from Centrelink
- Think about your career interests, decide on what you will do after school finishes and find out what steps you have to take gain the further education or training you may need for this
- Think about how you will keep in touch with friends once school ends
- Remember to enrol to vote when you are 18 years old

My Medical History

Most of us will have to see new doctors at some stage of our lives. This can be for many reasons; you move to a new area or you develop a condition where you need a referral to a new specialist. As you make the transition from child to adult health services you will need to see a new adult doctor. All new doctors need to have a good understanding of what your past health has been like. When you see a new doctor they will ask about major health events in your life.

Your past can help predict the future. Knowledge of your past health helps your doctor make decisions about what may happen in the future or what is the best option to take. It also helps your doctor if they know about your past health so they don't 'double up' on things that have already been done. For example, there may be no use trying a medication if you have already tried it before and it did not work; or having another x-ray on the same arm.

Most young people need to ask their parents about their medical history, especially things that happened when they were very young. Below is a table of what to include in your medical history. Why not sit down with your parents and fill it in! When you go to your new doctor take this with you so you will be prepared for the questions you will be asked.

Most doctors should provide a summary of your medical care of your time at the paediatric hospital. This will be sent to the adult hospital; you should ask for a copy of this, for your own records.

Birth

Birth weight: _____ Were you born early? No Yes

How many weeks? _____

Any problems at birth?

Serious Illnesses

Illness	Date/age	Length of illness

Hospitalisations and Surgeries

Date/age	Procedure/Why	Length of stay in hospital

Immunisations

Immunisation	Date		
Diphtheria, tetanus, whooping cough (DTP)	1.	2.	3.
Polio (OPV or Sabin)	1.	2.	3.
Measles, Mumps, Rubella (German measles) (MMR)	1.	2.	3.
Haemophilus Influenzae type b (Hib)	1.	2.	3.
Hep A	1.	2.	3.
Hep B	1.	2.	3.

My Current Medical Conditions:

Current Medications

Medication	What is it taken for?	How much (Dose)	How often is it taken?

Current local doctor (GP)

Name :

Practice address:

Phone number:

Communicating with Health Care Staff

Let's face it; sometimes it is hard to talk to doctors and other health care professionals!

So here are a few pointers to help you get the information you need from them.

- ⇒ Know your rights and responsibilities.
- ⇒ Ask questions!
(Remember: There is no such thing as a stupid question)
- ⇒ If you do not understand something ask them to explain it to you again.
(It is their job to make sure you do understand the information)
- ⇒ If you need help, ask!
- ⇒ Say what you think – be honest!
- ⇒ Write down what the staff tell you so you will remember when you get home.
- ⇒ Phone if you have questions after your appointment.
- ⇒ Bring someone with you (for support and to help you remember what was said).
- ⇒ Ask your parents to wait outside the room if you want to discuss a 'personal matter' with the staff.
- ⇒ Ask your doctor to tell you everything.

Hints for Finding the Right Doctor for You

Everyone is different. Some people you 'click with', some you don't!

It is the same with doctors or other health care professionals. You need to find the right one for you.

The right doctor/health professional for you should:

- ⇒ Be someone you can talk to about difficult topics (such as body changes and sexual health)
- ⇒ Make you feel that you are being listened to
- ⇒ Make you feel comfortable
- ⇒ Value your opinion
- ⇒ Talk and/or act on your concerns
- ⇒ Be someone you can ask questions of and know you will get an honest answer
- ⇒ Not mind you asking about their background and experience
- ⇒ Encourage you to get a second opinion if you want one
- ⇒ Discuss options with you
- ⇒ Make you feel they are in control of your treatment with you as their partner

The Role of the Case Manager in Transition

Some adolescents who have a chronic illness have a case manager at some stage during their treatment. This person was the one who helped you and your family to work out what your health care management goals were and what services you needed to reach them.

Now that you are in transition, you may find that you need a case manager. Depending on how services are organised in your area, this person might either be from the child or adult health service. Your case manager does much the same sort of thing in either service. They are your main support and contact person and should be able to help you work out the best health care plan possible. Some of the things that they can help you with are as follows;

- ⇒ Helping you set goals so that you can achieve what you want to
- ⇒ Advising you about possible services
- ⇒ Talking with services, your solicitor, insurer etc
- ⇒ Advocating on your behalf
- ⇒ Keeping everyone informed about things
- ⇒ Educating you and your family about the transition process
- ⇒ Helping you become more independent

Many young people report that their case manager was the most valuable person that they met during their transition to the adult world. It's their job to try to help you with things that you find difficult, so don't be too shy to ask them for help whenever you need to.

Centrelink

Centrelink is a Federal Government organisation that provides many services including employment services and financial assistance.

Your parents may already receive some help from Centrelink and as you get older you may become eligible for financial assistance from Centrelink.

There are many different types of assistance including disability payments, mobility allowances, youth allowances and help with paying rent. There are strict criteria that you need to meet to be eligible for payments.

You may be surprised by what you are eligible to receive!

There are many different payments and all have different criteria. This can make it confusing and hard to work out what you may be eligible for. Therefore, it is advisable to speak with someone from Centrelink directly.

There are a couple of ways to get in touch with Centrelink;

⇒ **Contact the Centrelink call centre** – they will be able to talk with you over the telephone and advise you of what services you may be eligible for. They can also send you out an information package and application forms for the different payments.

Once you receive the forms, fill them out as best as you can and post them back to Centrelink or drop them into your local Centrelink office. Centrelink will then contact you to discuss what assistance they are able to provide for you.

If you have access to a computer the website is:

<http://www.centrelink.gov.au>

⇒ **Make an appointment to see the Disability Officer at your local Centrelink** – if you want to speak with someone personally about your entitlements or are having trouble filling out the Centrelink forms or working out what you want, make an appointment to see the Disability Officer. You can make an appointment to see the Disability Officer at your local Centrelink office by contacting the Centrelink Appointment Line.

⇒ **Call into your local Centrelink office to pick up the application forms** – You should know what you are entitled to before you go in to pick up forms.

Be aware that Centrelink will ask you for some personal information, especially financial information. It is important that you fill in the forms honestly and keep Centrelink 'up to date' with any extra income you may earn or receive.

When you apply for financial assistance through Centrelink you may also be eligible for other services provided by Centrelink. These include being eligible for assistance through the Disability Employment Service. These services provide information as well as training and support to find and keep a job. If you think these services might be able to help you or you want some more information about what they can offer, make sure you talk with someone at Centrelink about these services.

For Further Information Contact Centrelink;

Disability, Sickness and Carers line 13 27 17
(For Information on the disability support pension, career payment, mobility allowance, sickness allowance and carers allowance)

Appointment line 13 10 21
(Ring this number to make an appointment with someone at your local Centrelink Office)

Youth and Students line 13 24 90
(For people who are studying)

Centrelink's website www.centrelink.gov.au

More Centrelink contact numbers are in the white pages

Education, Training and Employment

Some people find that when it comes time to leave school they have no idea of what they want to do with their life. There are also people who know exactly what they want to do but they may not know how to go about it. There are many options available but it could take you a while to work out what you want to do in relation to further education, training or work. If you start to think about this while in high school you should have enough time to look into your options, to find something that you are really interested in.

Education and Training

University - is an option for some people considering further education. There are many courses throughout many universities in NSW. To gain entry into university you have to meet certain criteria. If you have a course in mind, talk with your school counsellor about the eligibility criteria and how to apply to the university.

All people who undertake study at a university are asked to contribute to the cost of their education through HECS (Higher Education Contribution Scheme). These payments can be deferred, meaning you can pay for the cost later when you start earning money.

TAFE also offers many courses for people who want some further education and training. There are heaps of courses offered, vocational as well as interest courses. All TAFEs have disability support people that can assist you to choose a course that interests you. They are also great people to help negotiate some support, if you find you need some for your course. You can get help with things such as note taking or tutoring. TAFE courses do cost money but you may also be eligible for an exemption.

New Apprenticeships combines work with training and at the end you get a recognised qualification. There are many different types of occupations to choose from. Some schools even offer this program as part of your last years of school. You will also get a training wage while you work and study.

Local services may also be available to you that are directed towards people who are not able to access other courses and training. Ask your health care team about any services that are available in your local area.

Employment

There are many employment services, all offering different things. Find out as much information as possible about the services to help you work out what service would suit you the best. Talk with family, friends and professionals who may have used the services. Perhaps a visit to the service could also help you decide if this is the service for you.

Some employment services offer services to provide you with a quick course that will help you be 'job ready'. They then place you in a job but they do not provide any follow up support. There are some employment services that specialise in services for disabled job seekers who offer more. They not only find you employment but also provide you with training on the job and support to help you keep the job.

Below are a couple of employment services that are relevant through out NSW. There are also local employment services about.

Job Network is a network of organisations that help you get and keep a job. Centrelink is able to refer you to a local Job Network member. A list of members can also be found on the Job Network website. In some areas there are employment services for job seekers with a disability.

CRS Australia helps people with a disability or injury get a job. CRS provides information on choosing the right job for you, gaining work experience and training as well as providing on going support. CRS also helps with how to write a job application and a CV and how to prepare for interviews.

The services provided by CRS are free to people who are receiving a Centrelink benefit. You can get more information about CRS from Centrelink or by telephoning CRS.

Work Experience

Work experience is all about trialling a job for a short amount of time to see if it is something that you enjoy or are suited to. It is a trial prior to employment.

Some schools offer work experience. This is usually undertaken for a short period of time and is often not paid.

It is worth asking if employers offer work experience. If they do, make sure you ask whether it is paid, or unpaid and negotiate an exact amount of time you will be doing the work experience.

For more information contact:

CRS Australia

website	www.crsrehab.gov.au
Telephone	1800 624 824

Job Network

Website	www.workplace.gov.au
Telephone	13 6268

New Apprenticeships

Website	www.newapprenticeships.gov.au
Telephone	1800 639 629

National Auslan Interpreter Booking and Payment Service (NABS)

The service will start on 31 January 2005.

NABS is the National Auslan Interpreter Booking and Payment Service. It is funded by the Department of Family and Community Services. NABS is based at the corporate office of Wesley Mission Brisbane, in Brisbane, but it will provide services Australia-wide.

NABS provides interpreters to Deaf and hard of hearing people who use sign language and would like an interpreter for private medical appointments. It is free of charge to Sign Language users and medical practitioners.

The booking service will include interpreting services for both deaf adults and deaf children. It will include situations where there is a deaf adult and a hearing child or a hearing adult and a deaf child attending a private medical consultation. It will also provide interpreters for deaf/blind people.

NABS will operate nationally between the hours of 8am to 8pm, Monday to Friday, excluding all national Public Holidays.

Phone (V)	1800 24 69 45
Fax	1800 24 69 14
TTY	1800 24 69 48
Email	Bookings@nabs.org.au
SMS	0427 671 261
Mail	National Auslan Interpreter Booking and Payment Service 930 Gympie Road Chermside Qld 4032

The new service will provide free interpreting services for your private medical appointments in the following areas:

GP and Specialist Podiatrists or Chiroprodists	Aboriginal Health Workers	
Chiropractors	Audiologists	Osteopaths
Dieticians	Psychologists	Mental Health Workers
Psychiatrists	Occupational Therapists	Speech Pathologists
Physiotherapists	Dentists	Optometrists

ROYAL
CHILDREN'S
HOSPITAL



**For further information
discuss with your RCH Health Team
and www.rch.org.au/transition**