



ACI NSW Agency
for Clinical
Innovation

INFORMATION FOR PARENTS/CARERS

About Transition from Children's
Health Services to Adult Services

 **TRANSITION**

**CHILD
ADULT
HEALTH
SERVICES**

What is Transition?

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

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

When Does Transition Occur?

Transition is a process that occurs over many years. This allows time for you **and your child** to plan future health care with your health team. **Your child** will need time to learn new skills that will increase **their** 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 child's team** will usually start talking about the move to adult services when your child:

⇒ Is in high school

or

Is about 13 years old

Or

Or

Close to time of diagnosis (for older adolescents)

Help With Transition?

The ACI Transition Care Network has developed a range of generic tools to aid transition:

- ⇒ Fact sheets for young people, their families and clinicians
- ⇒ GP resource kits
- ⇒ Reference list, including websites
- ⇒ Transition checklists
- ⇒ Webpage www.aci.health.nsw.gov.au

The Network Manager and Coordinators continue to;

- ⇒ meet with key clinicians to identify service needs
- ⇒ encourage young people to have a say in what is needed to improve the current system
- ⇒ collect data on current transition programs and service gaps

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The Role of Parents and Caregivers

Transition to adult health care for young people with chronic illnesses is a process not a single event. Moving from a familiar child environment to adult health services impacts significantly not just on the young person and members of the health team, but parents, caregivers and other family members and friends.

Your son/daughter's health care team considers you a vital part of the planning process during transition.

As a parent/caregiver your role has been to help your child gradually assume responsibility for their own health care as they develop into an adult. You will find that your role does change from that of being the primary care provider, to providing emotional support as your adolescent learns to manage their own life and health care needs.

This can be difficult for some parents/caregivers. They have said that they feel 'left out' of their adolescent's health care as the staff increasingly talk directly to the young person and ask their opinion, rather than asking the parents. Remember that your adolescent is able to display these independence skills because of your support and help. The skills that they are displaying will help them become an independent adult.

As a main support provider for your adolescent, you are still able to play a very important role during transition. They will still require your help with many things. They will need to know about their past medical history, you can help them pick a new doctor, talk to them about the timing of transition and continue to teach them about life in the adult world.

If you do need some help remember to ask. You are an important part of the transition process!

When to Move?

This is often one of the first questions that parents have when the topic of transition is first raised.

Successful transition requires collaboration, planning and coordination of services and therefore should begin early. Discussions about transition are usually initiated at the time the young person starts high school.

From a parent/carer's perspective the following issues around timing of the move need to be carefully considered:

- ⇒ Although most facilities have a cut off age for treatment at child services this should be negotiated with your facility as part of your young person's transition plan. Developmental age, social maturity and educational stage all need to be considered.

- ⇒ Capacity of the adult facility to provide appropriate care is important. Most adult facilities do not have schools on the premises and this may impact significantly on the young person should they require frequent or lengthy hospitalisation

Important Issues in the Transition Process

The process of transfer to adult facilities requires careful planning around the following issues:

- ⇒ Selection of new health professionals and building a trusting relationship with the new team
- ⇒ How and when to say goodbye to the children's team, including how important medical information will be transferred to the new team.
- ⇒ Selection of the adult facility (with consideration of location, capacity to manage the condition and access to educational and vocational facilities).
- ⇒ Guardianship issues (if appropriate) and the role of the carer when the young person is totally dependent
- ⇒ Issues relating to money and equipment needs; billing, supply of medications and supply of essential medical items and equipment
- ⇒ Availability of outpatient facilities
- ⇒ The young person's attainment of independence and knowledge of their own needs

Recording Important Health Information

Your son/daughter will be required to know about their medical history. When seeking medical help most young people will be asked their medical history, such as immunisations, illnesses, operations. For young people with a chronic illness this information is very important to impart to the adult health care providers. If you have not already, it would be beneficial to sit down with your son/daughter and recall and record their medical history for them, especially about what happened in their younger years. Try to write this history down for them.

Many child health facilities provide special health folders for young people with chronic illnesses. Ask your child's medical team for one!

Recently the Department of Health developed the 'My Health Record', a red book similar to the child blue book. This is available from your health service. It provides an easy, concise health record, which can be updated by both patients and health professionals.

Many services are now developing transition packages, which contain information about the transition process and assessments to help you and your son/daughter set goals for transition. We suggest that you discuss transition issues with your health team and ask them to help you access important health related information about your son/daughter's medical management.

We have included a copy of the fact sheet "My Medical History" that is part of the transition information for young people. The fact sheet contains information that most new health professional will require about your son/daughter. Although the table below is directed towards young people, they may require your help with some of the answers, especially the things that happened when they were young. Try to make some time to go through this table before your son/daughter visits their new health care professional.

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 well, 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 event 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 'doubling 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.

Birth

Birth weight: _____ Were you born early? No Yes

Any problems at birth?

How many weeks? _____

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.

Family Medical History

Condition	Relative
Cancer (type) _____	
Cancer (type) _____	
Diabetes	
Heart Disease	
High Blood Pressure	
Mental Health (condition) _____	

Adverse Reactions to Medications

Medication	Reaction/reason for no longer taking it?

Allergies

Food or substance	Reaction	Treatment

Treatments tried before?

Condition	Treatment	Outcome

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:

Fostering Independence

The process of transition is ideally occurring at the same time as parents are fostering increased independence in their adolescent. The goal of all parents is to continue to provide emotional support while gradually easing themselves out of the role of direct care provider.

Although 'letting go' may be difficult, especially for parents of young people with a chronic illness and/or disability, it is still important that the young person be encouraged to develop a realistic level of independence for their age, abilities and limitations. Gaining independence is a natural progression in their development. Parents and other family members are role models for a child at all stages of development. Your son/daughter will learn new skills from your actions. It is never too early to start imparting knowledge and teaching your child skills they will need as they develop.

Some of the skills your son/daughter may be required to demonstrate in an adult health care setting include:

- ⇒ Talking with their health care team about their concerns and treatment plan
- ⇒ Time management
- ⇒ Handling money
- ⇒ Stress management and coping skills
- ⇒ How to access information, resources and equipment
- ⇒ Knowledge of their condition, medication and other important health information
- ⇒ Ability to be an assertive and effective advocate on behalf of themselves
- ⇒ Self care techniques related to daily living activities
- ⇒ Development of a social life
- ⇒ Health and wellness knowledge; including nutrition, fitness and personal safety
- ⇒ Educating professional and clinicians on their medical history and their needs

It is important to give young people ample opportunities to see these skills modelled for them as well as practice the new skills.

Looking After Yourself

Being a parent or carer of an adolescent is a difficult task. As your son/daughter is developing and finding their place in society your role is changing. Being a parent of a child with a chronic illness or condition adds new dimensions and challenges to this stage of development. There is a constant struggle between providing guidance to your adolescent son/daughter without too much pressure.

Added to this is the need to consider leaving the children's service, which is often a difficult task. You have probably built up a long term, trusting relationship with the health professionals and may feel ambivalent about moving onto another service, wondering if the adult service will be able to meet your son/daughter's needs.

Given that the adult services require the young person to be independent, you may feel 'left out' by the adult teams when they do not volunteer information about your son/daughter's progress. It may be very hard for you to step back and let your son/daughter and their doctor control their medical path. Give yourself time to come to terms with this.

It is very important, as part of your son/daughter's transition plan, that you have an opportunity to have your feelings expressed. You will be teaching your adolescent new skills and providing emotional support for them during this time. If you are worried about some aspect of the transition process it is imperative that you raise your concerns with a member of your son/daughter's health care team. If you are not supported it will make it harder for you to positively support your son/daughter through the transition.

Financial and Medical Decision Making

By the time you reach 18 years old, you are legally able to control your own affairs. But sometimes people are unable to make decisions about how they will live or how to arrange their financial affairs due to their disability. They need help from others to make these decisions on their behalf. This fact sheet explains the role of decision makers such as a person responsible, a guardian, money managers and financial managers.

Financial Help

The Supreme Court of NSW has ruled that you are capable of managing your own affairs if you are able to manage more than your household bills now and in the future. You do not have to be able to manage complex financial affairs (Supreme Court of NSW HvH 20/3/00)

There are systems in place to help your son/daughter manage their money if they are finding it a bit difficult. Many people with a disability can be supported to manage their own money. A family member, friend or a disability worker can often assist people with a disability to manage their finances. A family member could even become a joint signatory on a bank account. This means they can deposit or withdraw money from the person's account. They could also receive Centrelink payment on the person's behalf.

If there is someone acting on someone else's behalf there are strict legal rules for the management of the person's money.

The manager of another person's money must;

- ⇒ Keep the money in a safe place.
- ⇒ Not make any profit from being the money manager.
- ⇒ Spend the money in a way that directly benefits the person.
- ⇒ Hand back the money if the person asks for it, if they have a basic understanding of the value of money (even if the money manager considers that the person may spend it 'foolishly').

If the money manager breaks these rules they may be committing a crime.

If there are no informal arrangements (family or friends looking after your son/daughter's money) or if these people are not respecting the rules and your son/daughter are not able to look after their own money by themselves, a financial manager may be appointed by the Guardianship Tribunal.

Person Responsible

Medical and dental practitioners have a legal and professional responsibility to get consent to treatments before treating a patient. If the patient is not capable of consenting to his or her own treatment, the practitioner should seek consent from the patient's 'person responsible'. This is a requirement under the Guardianship Act 1987.

A person Responsible is:

1. A guardian (appointed by the Guardianship Tribunal who has the function of consenting to medical, dental and health care treatment).

If there is no guardian:

2. The most recent spouse or de facto spouse.

If there is no spouse:

3. An unpaid carer who is now providing support to the person or provided this support before the person entered residential care.

If there is no carer:

4. A relative or friend who has a close personal relationship with the person.

If you are the person responsible for someone who cannot consent for themselves you have the right and responsibility to know and understand:

- ⇒ What the proposed treatment is
- ⇒ What the risks and alternatives are
- ⇒ That you can say 'yes' or 'no' to the proposed treatment
- ⇒ That you can seek a second opinion.

The health care worker has the responsibility to give you this information and seek your consent to the treatment before treating the person.

A person responsible cannot consent to treatment that the patient objects to or that is considered 'special medical treatment'. This includes sterilisation operations, terminations of pregnancy and experimental treatments.

Guardians and Financial Managers

In most cases when a person is unable to make decisions about how they will live or how to arrange their financial affairs, their family will provide support and make decisions on their behalf. If there is no one available to make decisions, or if a problem arises with providing support, a person can request that the Guardianship Tribunal appoint a formal decision maker.

The Guardianship Tribunal can appoint guardians and financial managers for people 16 years and over who are incapable of making decisions about their lifestyle and financial affairs. The NSW Guardianship Tribunal can appoint legal decision makers for:

1. Guardianship issues - which relate to decisions about a person's lifestyle and other personal matters such as where they live, services they should receive and what medical and dental treatment they receive.

This person is known as the guardian.

2. Financial matters - which relates to decisions about a person's money and assets.

This person is known as the financial manager.

Guardians can be a family member, a friend or an official called the Public Guardian.

A written application for a guardianship order can be made by a person with a disability, the Public Guardian or anyone with a genuine concern for the welfare of a person.

For more information about the NSW Guardianship Tribunal

Telephone: 1800 463 928

Or visit their website: www.gt.nsw.gov.au

EnableNSW and ADHC

Both Enable and ADHC provide services to people with a disability and may be providing some services for your son/daughter.

Some of these services, or funding of these services, may change when your son/daughter turns 16 or 18 years old or when they leave school. It is best to be prepared for these changes rather than finding out just before the changes occur. As they get older they may also become eligible for some other services.

EnableNSW (previously Program of Appliances for Disabled People PADP)

Enable NSW is a NSW Government program for people with disabilities. It has been established to assist both children and adults with permanent or long-term disabilities live and participate in their community by providing appropriate equipment, aids and appliances. Enable provides a wide range of equipment such as wheelchairs, bathroom aids and feeding pumps.

For children and young people under the age of 16 years there is no financial criteria for the eligibility of assistance from Enable . This means that it does not depend on how much their parents earn. Once a young person turns 16 years old there is a financial criteria that has to be met. Depending on your family situation, this could mean providing a copy of their parent's tax returns, a copy of their tax return or their pension number. Those on low incomes are eligible for more help from Enable but people on higher incomes may also be eligible for assistance with expensive items.

Your son/daughter may be required to contribute a yearly payment (usually about \$100) to help Enable with costs.

If your son/daughter is receiving assistance from Enable it is worth contacting your local Centre to find out if there are any changes that will occur when they reach 16 years old.

For more information on Enable

Look on the NSW Health website: www.enable.health.nsw.gov.au

Phone: 1800 362 253

Department of Ageing, Disability and Home Care (ADHC)

The Department of Ageing, Disability and Home Care (ADHC) is a NSW Government department responsible for assisting people with a disability (and older people) to participate in community life and improve their quality of life.

ADHC provides many services for people with a disability. Some of these are respite care, accommodation support, day programs, therapies and vacation care. These services are often funded by ADHC but may be provided by local services.

There may be some changes to the ADHC services your son/daughter receives but most ADHC services will not change when they leave school. There are some exceptions, such as services for school aged young people. This could include some therapies and vacation care. In these cases they may need to apply for adult services.

When your son/daughter leaves school or turns 18 years old they may become eligible for other ADHC services such as accommodation support.

Because there are many services that ADHC provides, through many local service providers, to many people with a range of needs, it is best to ask them about what will change in your son/daughter's circumstance.

Be prepared for these changes by finding out in advance about what may change. To find out about any changes or what your son/daughter may become eligible for:

1. Talk with your local service provider
2. Contact your local ADHC office

To find out more information about ADHC services:

Look at their website: www.adhc.nsw.gov.au

Find their contact number in your local white pages (under A - Aging and Disability, Department)