INFORMATION FOR YOUNG PEOPLE about Transition from Children’s Health Services to Adult Health Services
Transition: The Basics

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

⇒ When you are about 13-14 years old

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

The Network Manager and Coordinators also:

⇒ 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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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 want to ask for your parent’s consent 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 and change appointments if you are unable to attend the appointment
⇒ 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 NSW Ombudsman. The Youth Liaison Officer can help you make a complaint and help you to work out what you want done about it.

For help in making a complaint contact the:

Youth Liaison Officer
NSW Ombudsman
Ph: (02) 9286 1000 or 1800 451 524
www.ombo.nsw.gov.au
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 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.

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 leaning how 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**
- Child health settings are very family focused
- Questions are often directed towards your parents/caregivers
- There is usually more flexibility with appointments
- Many services cost less in the child health

**Adult Services**
- Adult services will treat you as an independent adult and may not include your family.
- You will be expected to know about your medical condition. You will be asked questions directly, not your family.
- You will be expected to make your own appointments and keep them at the agreed time.
- There may be added costs and increased charges for some things such as equipment.

**Tips**
- You are entitled to bring someone with you to your appointments. It does often help to have someone else there for support.
- Bring a list of questions and concerns as it is easy to forget when you are sitting in the doctor’s office.
- If you have a lot to discuss with your doctor ask for a long appointment so you have enough time to discuss your concerns.
- Learn about Medicare and what your medical insurance covers.

To find out more about Medicare and health insurance see the fact sheet “Financial Issues in the Adult Medical World”.
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 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. Many 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.

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!

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.
**Health Care Cards**

A Health Care Card entitles you to reduced cost medicines as well as other concessions (such as reduced costs of public transport, energy/electricity bills and some reductions in health care costs).

You get a Health Care Card automatically on some Centrelink payments. You may also be entitled to a Health Care Card if you are on a low income.

You can apply for a Health Care Card through Centrelink. While you are at it – why not make an appointment at your local Centrelink Office to see what else you might be entitled to!

For more information on Health Care Cards contact Centrelink or look at their website: www.centrelink.gov.au

**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.

You do not need to have private health insurance to see a doctor in private practice. If you do have private insurance it does not allow you to claim any refund for visits to doctors in private practice. Private health insurance will only allow you to get a refund for visits your doctor makes to you if you are admitted to hospital.

To find out more about 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 to 14 years old.

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

This usually would occur between the ages of 16-18 years old.

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 13 to 14 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 - 18 years old.

- Know about your disability or condition
- Know when you need emergency medical help
- Know who to call in an emergency
- 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 & results as well as a verbal explanation
- Fill your own prescriptions
- Order supplies for your equipment and know how to maintain it
- Enrol for your own Medicare card and find out about private health cover.

- Learn 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 fact sheet - 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
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  [ ]

How many weeks?______

Any problems at birth?

**Serious Illnesses**

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<tr>
<th>Illness</th>
<th>Date/ age</th>
<th>Length of illness</th>
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**Hospitalisations and Surgeries**

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<th>Date/ age</th>
<th>Procedure/ Why</th>
<th>Length of stay in hospital</th>
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**Immunisations**

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<th>Immunisation</th>
<th>Date</th>
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<tr>
<td>Diphtheria, tetanus, whooping cough (DTP)</td>
<td>1.</td>
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<tr>
<td>Polio (OPV or Sabin)</td>
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<tr>
<td>Measles, Mumps, Rubella (German measles) (MMR)</td>
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## Family Medical History

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<th>Condition</th>
<th>Relative</th>
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<tr>
<td>Cancer (type)</td>
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<td>Cancer (type)</td>
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<td>Diabetes</td>
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<td>Heart Disease</td>
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<td>High Blood Pressure</td>
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<td>Mental Health (condition)</td>
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## Adverse Reactions to Medications

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<th>Medication</th>
<th>Reaction/ reason for no longer taking it?</th>
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## Allergies

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<th>Food or substance</th>
<th>Reaction</th>
<th>Treatment</th>
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## Treatments tried before?

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<tr>
<th>Condition</th>
<th>Treatment</th>
<th>Outcome</th>
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**My Current Medical Conditions:**

**Current Medications**

<table>
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<tr>
<th>Medication</th>
<th>What is it taken for?</th>
<th>How much (Dose)</th>
<th>How often is it taken?</th>
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**Current local doctor (GP)**

Name:

Practice address:

Phone number:
General Practitioners
(G.Ps)

Everyone should have a local doctor (also called a G.P.). They are a good person to contact first if you start to feel unwell, have some questions about your health or need someone to talk to. G.P’s are often easier to get in to see than a specialist and they deal with many different health issues. A good G.P. will look at your overall health (physical and mental), not just one specific area. If your G.P. does not have all the answers for you they will refer you to an appropriate person, such as a medical specialist, counsellor or dietician.

It is helpful to have a G.P. lined up before you get sick and really need them. They are especially important when you have a chronic illness. People often visit their G.P. more than once a year and form a good relationship with them.

If you do not have a G.P., it is important that you find one as soon as possible. Choosing a G.P. is a personal thing. A good G.P. is someone you feel comfortable talking to, knowing they are listening to what you are saying and are ‘taking you seriously’. It is a good idea to shop around for a G.P. you ‘click with’. Try asking family and friends that live near you if they can recommend a good G.P.

Most G.P. appointments are between 1-15 minutes long. If you think you will need longer, ask the receptionist to book you in for a longer appointment time.

Cost of seeing a General Practitioner

The cost of seeing a G.P. does vary (but it is cheaper than seeing a specialist).

⇒ Some G. P.’s “bulk bill” which means they charge Medicare instead of getting you to pay the bill directly (which means you pay nothing).
⇒ Other G. P.’s may ask you to pay the bill. You can then claim this money back from Medicare.
⇒ Be careful though, some G. P.’s charge more than what you can get back from Medicare.

It is always a good idea to ask the receptionist, when you ring up to make an appointment, how much your appointment will cost, how much you get back from Medicare or if they will ‘bulk bill’.

For more information see the fact sheets “Hints for Finding the Right Doctor for You” and “Financial Issues in the Adult World”
Enhanced Primary Care (EPC) - Chronic Disease Management Plans

In 2004 the Federal Government of Australia increased some benefits, under Medicare, to help GP manage the health care of people with chronic medical conditions, including those requiring multidisciplinary care. If you are eligible, this could mean that you may not have to pay for some services or therapies you receive for your chronic illness/condition. It will also mean that your G.P. will be paid (by the government) to help manage your condition and the care you may need by other health care professionals.

To be eligible your G.P. needs to have identified the services and supports you need and write them in a plan. They will then arrange for you to receive these services. The plan team will include your doctor and other health and community care providers. These could include dentists, dieticians, occupational therapists, psychologists, social workers, speech therapists, home nursing and optometrists, to name a few.

You can ask your G.P. if you meet the criteria and qualify for a plan and the Enhanced Primary Care (EPC) Medicare Benefits.

Under the EPC scheme some of the things you may be eligible for a Medicare rebate are:

⇒ Some dental services (up to 3 visits per year) if your dental problem is adding to the seriousness of your chronic condition.

⇒ Services provided by some allied health professionals (such as occupational therapists, mental health workers, physiotherapists, chiropractors, psychologists and speech pathologists).

You must be referred by a G.P. first to access these benefits, so ask them if you qualify. Although you get some money back, some professionals may charge more than you will get back from Medicare, so also talk to your doctor about how much you may have to pay yourself.

For further information about Enhanced Primary Care:


⇒ Ask Medicare for the Medicare Benefits Schedule Book (pages 43-49 November 2004 edition)

⇒ Ask your G.P.
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 sex and body changes)
⇒ 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, health care cards, 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.

⇒ **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, illness and injury 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)

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
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 sheets 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 manage your money if you are finding it a bit difficult. Many people with a disability can be supported to manage their own money. You may find that a family member, friend or a disability worker can assist you to manage your finances. A family member could even become a joint signatory on your bank account. This means they can deposit or withdraw money from your account. They could also receive your Centrelink payment on your behalf.

If there is someone acting on your behalf there are strict legal rules for the management of your money.

The manager of your money must:

⇒ Keep the money in a safe place.
⇒ Not make any profit from being your money manager.
⇒ Spend your money in a way that directly benefits you.
⇒ Hand back your money if you ask for it, if you have a basic understanding of the value of money (even if they consider that you may spend it ‘foolishly’).

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

If you have no informal arrangements (family or friends looking after your money) or if these people are not respecting the
rules and you are not able to look after your money by yourself, 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 relate 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
Education and Training

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.

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 NSW 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.

ADHC has two programs to improve the employment outcomes for school leavers with a disability and provide support for those who are unable to move to the workforce. These programs are;
Community Participation - provides an alternative to paid employment or education for people with moderate to high support needs. The program offers the opportunity for continued learning and life skills development and participation in the community through community based support.

Transition to Work - assists school leavers with a disability achieve employment (open or supported) or enrolment in vocational education and training or enrolment in higher education.

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.
EnableNSW and ADHC

Both Enable and ADHC provide services to people with a disability and may be providing some services for you.

Some of these services, or funding of these services, may change when you turn 16 or 18 years old or when you leave school. It is best to be prepared for these changes rather than finding out just before the changes occur. As you get older you 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 your parent’s 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.

You may be required to contribute a yearly payment (usually about $100) to help Enable with costs.

If you are receiving assistance from Enable it is worth contacting your local Centre to find out if there are any changes that will occur when you 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 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 you receive but most ADHC services will not change when you leave school. There are some exceptions, such as services for school aged young people. This could include some therapies. In such cases you may need to apply for adult services.

When you leave school or turn 18 years old you 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 circumstance.

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

Talk with your local service provider

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)
Work Experience

Work experience is all about trailing 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:

NSW TAFE
website: www.tafensw.edu.au
The Disabilities Unit (02) 9244 5085

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

Job Network
Website www.workplace.gov.au
Telephone 13 6268

New Apprenticeship’s
Website www.newapprenticeships.gov.au
Telephone 1800 639 629

University Admission Centre
Website www.uac.edu.au
Telephone (02) 9752 0200

ADHC
Website www.adhc.nsw.gov.au
Telephone local contact number in white pages (under A- Aging and Disability Department)