



GETTING CONNECTED

Transferring to Adult Health Services
And Gaining Independence

INFORMATION FOR YOUNG PEOPLE With Diabetes

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What's this all about?

The following information sheets have been put together from a number of sources, to assist young people with diabetes who are:

- about to leave home and live independently,
- moving away from the area for employment or education,
- transferring from a paediatric diabetes service and moving across to an adult service.

These moves can occur at a time of much change, and this can be scary for some and exciting for others.

It is hoped that the information contained within the following pages will help to make this change in your life a little smoother and give enough knowledge to keep your diabetes on track while travelling the road to independence!

Differences Between Child and Adult Health Services

Growing up with diabetes raises issues that other people your age don't face. One important issue is the question of transfer from your childhood medical specialists to those who will look after your adult medical care. For some it may seem difficult and upsetting to have to leave the children's diabetes team, especially if they have known you for many years.

There are many differences between child and adult health care services. One main difference is the amount of independence you will be given. With independence comes the need to learn about your diabetes, speak up about any concerns you have and seek advice when you need it. As a young 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.

Differences - continued

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



Adult Services

Adult services will treat you as an independent adult and may not include your family.



Tips

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.

Checklist

Use this checklist to identify the skills you already have, and the areas where you may need to increase your knowledge before you leave the paediatric clinics.

- Know about your diabetes and how to manage sick days
- Know the symptoms for hypos and hyperglycaemia
- 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
- Know how smoking, alcohol and street drugs interact with your diabetes
- If you haven't already, talk to your doctor about contraception and how diabetes might impact on fertility and pregnancy.
- Talking to your doctor about feeling low or having trouble at study or home or work
- 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
- Start meeting with some 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

- Remember to declare your diabetes in applying for your driving licence.
- Find out if you are eligible for financial support or any concessions from Centrelink
- Think about how you will keep in touch with friends once school ends
- Remember to enrol to vote when you are 18years old!

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

Responsibilities

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

- ⇒ Understand your diabetes 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 if applicable, 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

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 and 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.

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 cover for medical costs varies according to the type of insurance cover you are paying for.

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 Physicians, Endocrinologists, Eye and Foot Specialists 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! Some specialists may be willing to bulk bill and you may need to discuss this when you make your appointment.

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

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. When you make the transfer 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 '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.

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:

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 tells 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 emotional problems)
- ⇒ 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

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, 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

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 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. TAFEs are also great people to help negotiate some support, if you find you need some for your course. 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.

The ATLAS Program assists students through the transition from school to employment. There are only limited places available and some criteria you need to meet. All applications close in May and have to be done through your school. If you want some further information on this program talk with your school counsellor or principal as you have to get in early.

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.

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.

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

Often when you finish high school there may be the need for you to leave home either for training and employment reasons, or because you are keen to live independently. You may find that in the past you have taken for granted some of the jobs your parents did to help you manage your diabetes, and when you are living independently from your family may be unsure of what exactly you should be doing to keep your diabetes on track.

More than just getting scripts

Just as you have rights and responsibilities (as listed on page 14), your doctor has a duty of care to all people he sees and ethically is expected to ensure that he provides reasonable care for all his clients.

It is unfair to expect you can turn up at the doctors just seeking a script for your insulin without providing some information to the doctor on your diabetes control. It is a good idea to write down a few days blood glucose readings off the memory of your meter and take these along with you.

The routine checks that are going to let you know how things are going and whether you have your diabetes on track are listed below:

- 3 monthly HbA1c – a blood test that gives important information about long term control
- Eye check – once a year, this can be done by an Optometrist if you have no eye problems, and the optometrist is able to put in eye drops to dilate your pupils.
- Urine test for your kidney function – once a year
- You should have your blood pressure and cholesterol checked 6 monthly
- The condition of the nerves and blood vessels in your feet should be checked regularly and your Diabetes Educator or GP can do this.

Sometimes your GP may overlook that you have not had a test done recently and you should feel comfortable enough to remind them.

Seek out a diabetes team or centre!

Most large regional towns and cities will have a diabetes centre based at the main hospital. Many of these provide a service where at one visit you may see a Dietitian, a Diabetes Educator and Specialist Doctor who are able to arrange all of the above tests, and you will be bulk billed.

Professionals working at these centres are also great contacts in times of emergencies such as sick days, broken diabetes equipment and providing advice if things are going haywire. The best way to find out if there is such a service near you is to ring the hospitals in the area and ask if they have a diabetes service or clinic.

Need more info?

- Ask your GP or endocrinologist
- Diabetes Australia 1300 136 588
- Contact the Diabetes Centre at your closest hospital or community health centre

Look on the web:

- www.diabeteskidsandteens.com.au – a great website covering all sorts of issues, including a special site for teens
- www.realitycheck.org.au – another site that provides information for young adults with diabetes
- www.health.nsw.gov.au/gmct/transition – a health site that looks at transition needs

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