

# Moving on...



**INFORMATION TO HELP YOU  
TRANSITION TO THE  
ADULT WORLD**

**This resource has been developed and collated by:**  
**Julie Dicker - Spina Bifida Clinical Nurse Consultant and**  
**Christine Byrne - Social Worker**  
**The Children's Hospital at Westmead**  
**and**  
**Anita Fisher and Mary-Louise Cuy**  
**Northcott Disability Services**  
**2008**



# Introduction

This resource has been designed for adults with Spina Bifida. It contains relevant information and contact details to assist you to access services in the adult world. It is not, however, a substitute for advice from your health care professionals. If you have any concerns regarding your health, contact your General Practitioner or Spina Bifida specialist.

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# Adult Spina Bifida Resource Team

The Spina Bifida Adult Resource Team is a new initiative funded by NSW Health and commenced in August 2009. The team, which consists of a Clinical Nurse Consultant and a Senior Occupational Therapist, aims to provide clinical consultation, education, support and preventative health strategies to adults with spina bifida across NSW health services.

The team will focus on facilitating and coordinating the effective transitions of young people with spina bifida from paediatric to adult health services and aim to reconnect any adult who has been lost to adult health services after moving on from paediatric services.

It is a state wide service and some of the aims of the service are to:

- Assist any young person making the move from paediatric to adult services
- Orientate any young person to their new adult health service
- Assist with any medical concerns as well as provide education and support to any adult with spina bifida
- Linking adults to appropriate health services as required
- Promote healthy lifestyles for all clients with Spina Bifida
- Attend all adult Spina Bifida Clinics across NSW
- Education to community services about spina bifida

If you would like to contact the team you can reach them by phone or email:

Joanne Brady  
Team Leader/CNC  
Ph: (02) 9472 5214  
Mobile: 0418 429 960  
[joanne.brady@northcott.com.au](mailto:joanne.brady@northcott.com.au)

Jade Baynes  
Senior Occupational Therapist  
Ph: (02) 94725215  
Mobile: 0418 408 738  
[jade.baynes@northcott.com.au](mailto:jade.baynes@northcott.com.au)

# Adult Spina Bifida Clinics

## **Westmead Hospital**

**When:** 3<sup>rd</sup> Wednesday of every month

**Contact:** June Kelly (Wednesdays) to make an appointment

**Phone:** (02) 9845 7800 (Department of Rehabilitation Medicine) or  
(02) 9845 5555 (page 12545)

## **Royal Prince Alfred Hospital - Camperdown**

**When:** 1<sup>st</sup> Wednesday of every month

**Contact:** Alfredo Inton on (02) 95159815 to make an appointment

**Phone:** (02) 9845 2769 (Tuesday to Friday)

## **Prince of Wales Hospital – Randwick**

**When:** 4<sup>th</sup> Tuesday of every month

**Contact:** ‘Adult Outpatients’ to make an appointment

**Phone:** (02) 9382 0400

## **Concord Hospital**

**When:** 2<sup>nd</sup> Tuesday every month

**Contact:** ‘Reception’ to enquire on how to make an appointment

**Phone:** (02) 9767 7233

## **Camden Hospital**

**When:** 3<sup>rd</sup> Thursday of every month

**Contact:** ‘Outpatient Department’ to enquire on how to make an appointment

**Phone:** (02) 4654 6376

## **Royal Newcastle Centre**

**When:** 2<sup>nd</sup> Monday each month

**Contact:** Fax GP referral to 49214811

# Spina Bifida Outreach Clinics

Currently Spina Bifida Services at The Children's Hospital, Westmead and Sydney Children's Hospital, Randwick run yearly Rural Outreach Clinics. The Children's Hospital Westmead run clinics at Coffs Harbour and Tamworth and Sydney Children's Hospital Randwick run clinics at Dubbo and Wagga Wagga. Presently both adults and children with Spina Bifida are able to attend these clinics. However, we are in the process of working with local clinicians within these areas to have all adult patients seen locally enabling better connections with local health services. Therefore paediatric services seeing adult patients will eventually cease. We will ensure everyone is kept well informed when these changes occur.

The clinics are currently held in collaboration with Northcott Disability Services. You can contact one of these Northcott regional offices for more information about the clinics, details of clinic dates and to make an appointment.

**Northcott Coffs Harbour  
Regional Office  
Phone: (02) 6651 2366**

**Northcott Tamworth  
Regional Office  
Phone: (02) 6766 5755**

**Northcott Dubbo  
Regional Office  
Phone: (02) 6882 1099**

**Northcott Wagga Wagga  
Regional Office  
Phone: (02) 6921 1996**



# Health Issues for Adults with Spina Bifida

An **Adult Spina Bifida Clinic** provides a holistic service for people living with Spina Bifida. That means that they can help you discuss all your health matters. Examples of such health matters are listed below.

- Regular medical check ups (for example, yearly renal ultrasound and shunt checks)
- Ongoing continence management
- Prevention and management of pressure areas
- Mobility needs (such as wheelchair prescription, orthotics and footwear)
- Lymphoedema of lower limbs
- Pain management
- Stomalthrapy
- Genetic counselling
- Housing
- Employment
- Advocacy
- Social and recreation activities
- Relationships, family planning and fertility issues
- Referrals and liaison with other services such as General Practitioners, medical specialists, allied health services and Northcott



If you decide not to attend an Adult Spina Bifida Clinic your other option is to visit your **General Practitioner (GP)** regularly. There you will need to get referrals to appropriate medical specialists for individual health issues.

# Managing your Health Care visits

It is important for you to be an active member of your health care team. Here are some tips on how you and your doctor/health clinic can become partners in improving your health care.

## Preparing for your Appointment

- Keep a list of contact details for your health care providers in a place where you can access them.
- Often it helps to keep a notebook record of medical reports, medications, operations and test results.
- Carry your Medicare card, Spina Bifida Health Checklist and other health care information with you at all times.
- Ask what information the health care provider will need, such as x-ray films, test results, and medical records.
- If you have a case manager or community worker, you may want to ask them to come to your appointment with you for support.
- Try to be at your medical appointment at least 15 minutes early to check in. This helps you to complete your visit as quickly as possible.

## Give Information – Don't wait to be asked!

- You know important things about how you feel and your health history. Tell your doctor what you think they need to know.
- It is important to tell your doctor some personal information – even if it makes you feel embarrassed or uncomfortable.
- It's OK to speak openly with your health care providers.



# Managing your Health Care visits

## Get Information – Ask Questions!

- It's important to ask questions. If you do not, your doctor may think you understand everything.
- Write down your questions before you visit.
- You may want to bring someone with you to help you ask questions and understand and/or remember the answers.
- Ask your doctor to draw pictures if that might help explain something.

## Take Information Home

- Ask for written instructions or take notes. Use your Personal Health Care Record to keep your notes in one place.
- Ask for copies of your medical tests and reports.
- Some doctors don't mind if you bring a tape recorder to help you remember things. But always ask first.
- Your doctor may also have brochures, audiotapes or videotapes that can provide you with information. If not, ask how you can get such material.

## Once You Leave the Doctor's Office – Follow Up

- If you have any questions, call your doctor.
- If your symptoms get worse, or if you have problems with your medication, call your doctor.
- If your doctor said you should see a specialist, make an appointment.
- If your doctor wants you to have tests, make appointments and have the tests done.



If you had tests and do not hear from your doctor, call for your test results.

# My Medical Information

What type of Spina Bifida do I have? .....

How does it affect me? .....

.....

Do I have a shunt? .....

When was it last replaced? .....

Who is my Neurosurgeon? .....

How often should I have renal tests? .....

.....

.....

How do I look after my bladder? .....

.....

.....

How do I look after my bowel? .....

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.....

Am I at risk of skin damage? .....

How do I look after my skin? .....

.....

Do I need a Podiatrist for my feet? .....

What are my allergies? .....

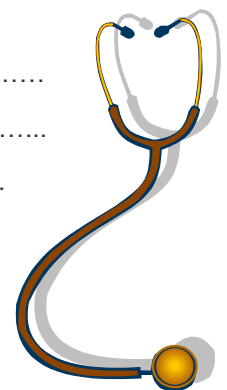
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What medications do I take and why? .....

.....

.....



# My Medical Information

What are my dietary needs? .....

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What are my mobility issues? .....

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Do I have any personal health records? .....

## My Local Doctor

Name: .....

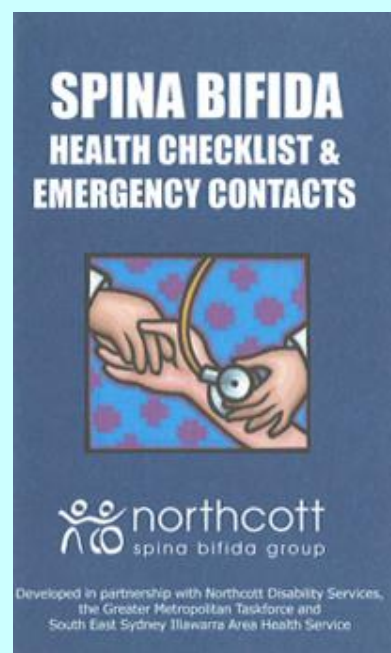
Address: .....

Phone Number: .....

## Spina Bifida Health Checklist and Emergency Contacts Card

This card is a useful place to store important medical information and contact details. The advantage of this card over larger health diaries is that it folds down to credit card size with a plastic cover and can easily fit within a wallet or purse. The card contains specific information about Spina Bifida as well as space to record health and emergency contacts to assist people with Spina Bifida to better manage their health. It would be useful to work alongside medical staff to complete the relevant information.

The cards are available from your Spina Bifida Clinic or by contacting the Northcott Spina Bifida Group Phone: (02) 9890 0990



# Spina Bifida Transition Checklists



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.

## Checklist: Learning what’s ahead

Young person entering high school

### **During Clinic visits:**

- You will receive information about transition & why you need to move to an adult service when you are 18 years old.
- Transition checklists explained
- Learn how to start being responsible for making decisions about your health & have a good basic understanding of your condition & how to manage it
- Ask questions during your appointments
- Understand how puberty affects your condition
- Discuss future realistic goals for your age group (education, sport, social activities, & increasing responsibility)
- You and your family are provided with the opportunity to discuss any concerns about transition.
- Introduction to transition website: [www.health.nsw.gov.au/gmct/transition](http://www.health.nsw.gov.au/gmct/transition)

### **Achieve outside clinic visits: -**

- Discuss health history with your parents
- Discuss with school your post school options
- Make connections with support groups
- Find your own GP- one you feel comfortable with.
- Ask the Spina Bifida Clinic Coordinator at your hospital to send transition plans to your GP.

# Spina Bifida Transition Checklists

## Checklist: Taking Action

### *Young person 14-16 years old*

#### **During each clinic visit:**

- Set goals for the future. (Eg- driving, employment & social activities)
- Make some decisions about ongoing health care and who might provide it.
- Start asking why & how your medication works
- How your medication interacts with drugs & alcohol
- Start attending part of your clinic appointments without your parents. This normally happens when you are about 15 years old
- Be prepared for staff to talk with you about your sexual health
- SB Clinic Coordinator confirms that you have seen GP since transition commenced
- Occupational Therapist to discuss updating any equipment that you require e.g. wheelchair
- Parents are given time to discuss any transition concerns.

#### **Achieve outside clinic visits:**

- Start seeing your GP alone at least some of the time
- GP to preform a comprehensive health review
- Obtain your own Medicare card
- Start filling your own prescriptions
- Make an appointment with disability officer at Centrelink, to discuss eligibility for financial support after your 16th birthday.
- SB Clinic Coordinator to send transition update to GP.

# Spina Bifida Transition Checklists

## Checklist: Moving On

### *Young person 17-18 years old*

#### **During each clinic visit:**

- Attend at least 1 clinic appointment with your Rehabilitation Specialist by yourself
- Transition Folder "Moving On" provided to you
- Meet with the Adult SB Resource team and discuss the differences between child & adult services
- Has read or gone through Moving On booklet with SB clinic coordinator
- Continue to discuss future goals
- Confirm you have a good understanding of medications/side affects & why they are taken
- Confirm there is a good understanding of your condition
- You are now actively involved in decisions about your care
- Parents encouraged to discuss any concerns.

#### **Achieve outside Clinic visit:**

- Look after your equipment; learn how it works & how to get it fixed
- Take your medications without supervision
- Continue filling your own prescriptions
- Make your own appointments with your GP and the adult services
- Ensure you have your own trusted GP & have received a comprehensive health review
- Explore your options for further education training or employment.
- SB Clinic Coordinator to send summary report of paediatric care to young

## A Checklist.. How well do you look after yourself?

As an adult living with Spina Bifida, you are constantly coping with challenges and special conditions. Read over the following list and tick the areas that you think you are good at. You can then follow up on the areas you may need to work on.

- I have an effective bladder management routine.
- I have an effective bowel management program.
- I know the names and dosages of the medications I am taking, their side effects, and when to take them.
- I am prepared to take care of unexpected incontinence issues.
- I talk with someone and get assistance if I need it.
- I wear shoes and socks at all times.
- I check my feet for skin breakdown daily.
- I bathe daily and check my skin for skin problems.
- I am aware of how headaches may be related to my shunt.
- I wear a MedicAlert bracelet if I am allergic to latex.
- I know how Spina Bifida affects having sex.
- I know how to prevent pregnancy and sexually transmitted diseases like HIV.
- I understand how my health condition may affect having children.
- I have regular gynecological check-ups (women).

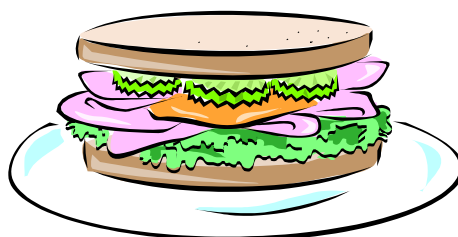
**Be sure to talk to your doctor or nurse at the Spina Bifida Clinic if you need some help with these things.**

# Want to Stay Out of Hospital?

To maintain good health and be as independent as possible with your mobility and activities of daily living, you need to take care of your skin, keep your weight within the normal range, get and attend to your toileting routine.

## Some Tips for Healthy Living:

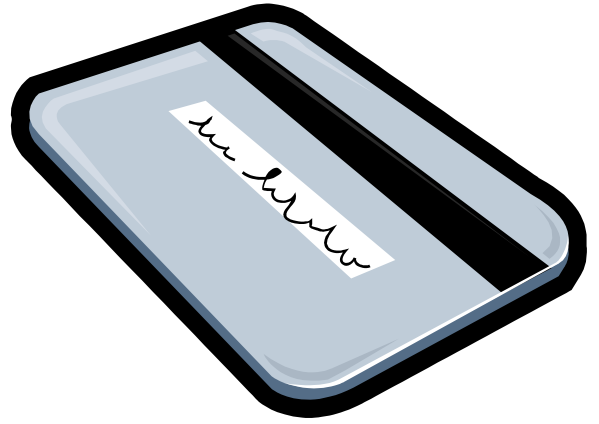
- Have regular kidney tests (ideally these should occur at least once a year). Silent damage can be happening to your kidneys without you being aware of it. The main test is a renal and bladder ultrasound. A blood test that will look at kidney function at the same time is also advisable. Your local doctor (GP) can order for you these tests for you.
- Check your skin on a daily basis for any redness or skin breakdown (don't forget to check your feet!). Treat any cuts, sores or burns on parts of your skin that have poor sensation promptly. Remember, early treatment can help you avoid a hospital admission.
- For any health issues you have, make sure you seek medical attention early. This will help ensure that these health issues do not become more serious.
- Eat healthy, nutritious food and avoid overeating – especially if you are bored. Avoid eating take away food – it is expensive. Try cooking your own meals instead.
- Keep as active as possible and have recreational activities to be involved in.
- Stay positive, laugh lots and have fun!



# Adult Health Services – Who pays?

During childhood your parents usually paid for any medical costs that were not covered by **Medicare** (the public government health care fund).

As an adult, you will need to know about the costs of medical care. All Public Hospital Clinics are covered by your Medicare Card. As an adult, it is important that you get your own Medicare Card and carry it with you.



**Medicare** provides access to:

- Free treatment as a public (Medicare) patient in a public hospital.
- Free or subsidised treatment by practitioners such as GP's, specialists, participating optometrists and dentists (specified services only).

## Contact Medicare

For more information, as well as the location of your nearest Medicare office contact Medicare.

**Website:** [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)

**Phone:** 132 011 (general enquiries line)

## Applying for Your Own Medicare Card

- You will need to gather up identification such as your birth certificate, passport, bank account details etc.
- Complete the Medicare 'Copy/Transfer Application Form'. You can do this at your local Medicare office or fill one out before you go to Medicare. The form is available on the Medicare website.
- Submit the paperwork at your local Medicare office.

# Adult Health Services – Who pays?

## Specialist Doctors

Specialist doctors such as Neurosurgeons, Urologists and Orthopaedic Surgeons may ask you to pay at each visit when you see them in their private rooms. If they do this you need to then claim the money back from Medicare. This is a normal practice that you need to be aware of. Even though you see them in their private rooms, any surgery that may be required can often be done as a Public Patient in a Public Hospital which is covered by Medicare.



## Private Health Insurance

As an adult, you also need to decide whether you want to get Private Health Insurance. Your parents may still have you covered with their insurance. If so, you need to know if this will be transferred to you as an adult.

If you decide to get Private Health Insurance you will be required to pay a fee on a regular basis by yourself. You need to allow for this ongoing cost when budgeting your money. You do not have to have Private Health Insurance – it is your choice!

For more information you can visit **PrivateHealth.gov.au** (an Australian government website) where you can compare information about the private health insurance policies available in Australia.

**Website:** [www.privatehealth.gov.au](http://www.privatehealth.gov.au)

# Continence Support

## Where can I get information and advice about continence?

- Your continence nurse advisor
- Your GP, Specialist, Spina Bifida Doctor or Nurse
- Your local Community Health Centre
- **The National Continence Helpline**  
This is a free and confidential information and referral service staffed by experienced continence nurse advisers that operates from 8am to 8pm weekdays.  
**Phone:** 1800 33 00 66
- **The Continence Foundation of Australia Website**  
**Website:** [www.continence.org.au](http://www.continence.org.au)
- **The Bladder and Bowel Website**  
An Australian Government Website dedicated to bladder and bowel health  
**Website:** [www.bladderbowel.gov.au](http://www.bladderbowel.gov.au)

## What subsidy schemes may assist me with the cost of continence products?

Please note: As of 1<sup>st</sup> July 2010 there will be changes to the current Continence Aids Assistance Scheme.

From the 1<sup>st</sup> July 2010, the **Continence Aids Assistance Scheme (CAAS)** will be replaced by the **Continence Aids Payment Scheme (CAPS)**.

### 1. Continence Aids Payment Scheme (CAPS)

This scheme is exactly the same as the continence aids assistance scheme with the same eligibility requirements. The only significant difference will be that it will be a direct payment into your bank account. You will be paid the entire amount for the year in one payment. You will no longer be required to

# Continence Support

purchase your products from a nominated supplier which is what you or your carer does now. This will increase flexibility and choice about where and when you purchase your incontinence products.

What you will need to be careful about is when that direct payment is placed in full into your bank account that you don't spend it on anything else as you will not get any more money for continence products and health staff will not be able to supply you with products if you have run out.

For more information about the changes to this scheme please go to [www.bladderbowel.gov.au](http://www.bladderbowel.gov.au)  
Ph: 1800 33 00 66 (National Continence Helpline)

## **2. Northcott Spina Bifida Group** (a division of Northcott)

If you are a financial member of the Spina Bifida Group (\$20 per year) you may be eligible to receive a subsidy for catheters, pads, Conveen anal plugs, orthopaedic shoes and boots up to the value of \$300.

**Phone:** (02) 9890 0990 for more information.

## **3. Provision of Appliances to Disabled Persons (PADP)/ENABLE**

PADP can help you with the provision of continence products once your CAAS money has been fully utilised for the year. To discuss eligibility and apply, contact your continence nurse advisor or your local PADP lodgement centre.

**Phone:** 1800 362 253 (1800 ENABLE) for more information.

**Website:** [www.enable.health.nsw.gov.au](http://www.enable.health.nsw.gov.au)

#### 4. **BrightSky Australia** (through PARAQUAD NSW)

If you do not qualify for any of the above schemes or you need extra continence aids or supplies, BrightSky provides a cost effective service for this equipment.

**Phone:** 1300 88 66 01

**Fax:** 1300 88 66 02

**Webstore:** [www.brightsky.com.au](http://www.brightsky.com.au)

#### 5. **Ostomy NSW**

If you have an ileal conduit (wear a stoma bag for urine) or have an appendico-vesicostomy you are eligible to join the Ostomy association for your supplies. There is a yearly membership fee, payable on July 1<sup>st</sup> every year. You need to order your supplies monthly.

**Phone:** (02) 9542 1300

**Fax:** (02) 9542 1400

**E-mail:** [ostomy@bigpond.com](mailto:ostomy@bigpond.com)



# Equipment for Life

When you were younger any mobility equipment that you needed was probably organised through an Occupational Therapist at your children's hospital or school.

As an adult you may find that you will need to replace old equipment that you have had for years. If your needs have changed, you might also require different types of equipment that you have not used before.

Such equipment might include a:

- Wheelchair (manual or power)
- Walking stick/s
- Pressure care cushion
- Hoist
- Mobile shower commode
- Electric bed
- Pressure care mattress
- Scooter



## How can I get new equipment?

An Occupational Therapist can help you to find the equipment that is the right fit for you and your lifestyle. They can recommend options and assist you to trial equipment, so that you can choose what works best for you. They can then assist you to apply for the equipment, most likely through the Program of Appliances for Disabled People (PADP) scheme.



# Equipment for Life

## What is the PADP Scheme/ENABLE?

The Program of Appliances for Disabled People (PADP) is a NSW Government scheme that assists people with disabilities by providing appropriate equipment, aids and appliances. The program is financially means tested for people over the age of 16 years. Most people on a Disability Support Pension qualify. People who receive assistance through PADP are required to make a contribution of \$100 towards the cost of the items they receive.

## What else can an Occupational Therapist (OT) help me with?

- Home modifications
- Activities of daily living assessments
- Travel training
- Vehicle modifications
- Workplace assessments
- Community access



## How can I contact an Occupational Therapist (OT)?

- Talk to your Spina Bifida doctor or nurse or Jaie Thomson, the Senior Occupational Therapist for Adult Resource Team.
- See an OT at your local public hospital or community health centre. See the NSW Health website for locations.

**Website:** [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

- Contact an OT at Northcott Disability Services.

**Phone:** (02) 9890 0100

- The 'Australian Association of Occupational Therapists NSW' website has a listing of OT's in private practice (these OT's charge a fee for service).

**Website:** [www.otnsw.com.au](http://www.otnsw.com.au)

- Talk to your General Practitioner (GP)

# Wheelchair Access at Home

If you use a wheelchair, your home may already be modified/altered so that you can get into the house and access all the rooms you use. However, if your home has not been adapted or you are planning to move into your own house/unit, modifications may be needed.

## What types of modifications might my home need?

- A ramp to either the front or the back of your house
- Wider doorways for easier wheelchair access
- Changes to the toilet/bathroom to support your privacy and independence with toileting and bathing
- Changes to the kitchen to ensure your maximum safety and access

## How do I organise modifications?

To start the process you need to contact your local Occupational Therapist (OT). If you do not know an OT or you have not seen one for a long time you can contact Northcott on **Phone:** (02) 9890 0100, or talk to your doctor. An OT will meet with you to discuss what needs to be altered so that you can access all the rooms in the house/unit. They will let you know who needs to be contacted and the forms to be completed. The OT will also write a report with drawings to assist you with your application.

## Who pays for the modifications?

If the Department of Housing owns the house/unit, they pay for the alterations. If you or your family owns the house/unit, there are Government Schemes to help share the costs.



The free book "**Housing for Living**" by The Master Builders Association gives lots of good design ideas. For more information, **Phone:** (02) 8586 3519.

# School is Finished – What Next?

After school you will begin to look at career options for adult life. This might involve looking for work, learning more skills or pursuing further education. Below are some options and supports that may be helpful when planning your future goals.



## Post School Programs

DADHC provides two Post School Programs for eligible young people with a disability; Transition to Work and Community Participation. You apply for these programs in your last year of school, usually by September. Phone the Post School Programs Infoline for more information.

**Phone:** 1800 761 030.

- **Transition to Work** is a time-limited program which aims to support and improve employment outcomes for school leavers who can transition to work within one or two years. The program assists school leavers with a disability to develop skills that will help them move into employment, vocational education and training or higher education.
- **Community Participation** aims to assist young people with a disability to develop the skills they need to work towards their goals, increase their independence and participate as valued and active members of the community. The program has been developed as an alternative to paid employment or further education in the medium to long term. The program can be offered individually or in a group environment.

## Career Information Centres

These centres offer useful information for job seekers. They can help you with material and decisions about education, training and employment options. They can also refer you to specialist officers within educational institutions who assist people with disabilities.

**Phone:** (02) 9209 1661

# School is Finished – What Next?

## Disability Employment Services

The Disability Employment Network (DEN) provides specialist employment services to people with a disability who need ongoing assistance to find and maintain employment. DEN is delivered by a network of organisations around Australia. To find out more about the DEN programme you can contact a **Centrelink** Disability Support Officer, **Phone:** 13 10 21.

To search for a Disability Employment Service near you, visit the **Jobaccess** Website or phone Joabaccess.

**Website:** [www.jobsearch.gov.au/public/providers](http://www.jobsearch.gov.au/public/providers)

**Phone:** 1800 464 800 (to speak to a JobAccess Adviser)



## Further Study

### ▪ TAFE NSW

TAFE employs specialist Teacher/Consultants for Students with Disabilities to ensure they have equal access to education and training at TAFE NSW campuses. The specialist Teacher/Consultants can support prospective students with pre-course counselling and assistance with the enrolment process, as well as assist with classroom support and assessment modifications.

**Phone:** 131 601 (TAFE NSW Information Centre)

**Website:** [www.tafensw.edu.au/students/support/disabilities.htm](http://www.tafensw.edu.au/students/support/disabilities.htm)

### ▪ University

NSW Universities have disability officers. You should seek advice and assistance from these officers when preparing to apply for a place. Contact the relevant University for more information.

### ▪ Scholarships

You may be eligible for money from Paraquad, Northcott or SpineCare (a division of Northcott) to help cover the cost of your study. Contact the following services for more information:

**Northcott and SpineCare:** (02) 9890 0100

**Paraquad:** (02) 8741 5600

# Centrelink...How can they help?

As a person with a disability you may be entitled to assistance from Centrelink.

This may include:

- Financial support such as Mobility Allowance, the Disability Support Pension or Educational Supplement.
- Employment assistance

**Centrelink Disability Officers** can advise you about the payments and services you may be entitled to receive. They can also refer you to the right person or organisation to assist you.



For information, assistance and appointments with a Disability Officer visit your nearest **Centrelink Customer Service Centre** or **Phone: 13 27 17**.

**Website:** [www.centrelink.gov.au](http://www.centrelink.gov.au)

## Handy Hints for Phoning Centrelink

- Don't hang up. Your call will be placed in a queue so if you do hang up and redial you will end up at the back of the queue again.
- Have your details ready next to the phone. You will need your Customer Reference Number and any Centrelink letters or papers you may want to talk about.
- If someone else is calling for you, they must have your permission. You either send Centrelink your permission in writing or you must be with them at the phone.
- Mobile calls are charged at mobile rates.



# Getting Around...Transport

## Taxi Transport Subsidy Scheme (TTSS)

This scheme subsidises the travel cost for participants, allowing them to travel by taxi at half fare. The maximum subsidy that can be claimed per trip is \$30. For information on how to receive this discount for taxi transport, contact the scheme.



**Phone:** 1800 623 724 (toll free)

**Email:** [ttss@transport.nsw.gov.au](mailto:ttss@transport.nsw.gov.au)

**Website:** [www.transport.nsw.gov.au/concess\\_grants/ttss.html](http://www.transport.nsw.gov.au/concess_grants/ttss.html)

## Mobility Parking Scheme

This is available through the Roads and Traffic Authority (RTA) and gives authority for people with a significant mobility problem to park their car in a parking space reserved for people with disabilities. Forms can be obtained at any RTA office.



**Phone:** 13 22 13

**Website:** [www.rta.nsw.gov.au](http://www.rta.nsw.gov.au)

## Learning to Drive

The RTA website contains information on vehicle modification standards for people with a disability in NSW.



**Website:** [www.rta.nsw.gov.au/registration/downloads/vsi/vsi\\_dl1.html](http://www.rta.nsw.gov.au/registration/downloads/vsi/vsi_dl1.html) (go to information sheet 21)

For further information on car modifications and gaining your license, refer to the supplement pamphlets included with this booklet.

# Money Problems?

As adults, we generally get our own income by working or receiving a pension. We use this income to pay our everyday living expenses. Such expenses might include things like rent, food, phone, internet, and transport. Initially, learning to budget our money and pay larger bills can be hard.

## Example:

You have a mobile phone and have just received a bill for \$300 which you can't afford to pay. There is interest charged on this account, so each month the bill keeps getting bigger. If you don't pay it, you will have your phone disconnected.



## Need help?

If you are having problems paying your bills and would like to talk to someone about how to better manage your money, you can get advice from one of the following free services.

### Financial Counsellors Association

Phone: 1800 808 488

Website: [www.financialcounsellors.asn.au](http://www.financialcounsellors.asn.au)

### Wesley Credit Line Financial Counselling Services

Phone: (02) 9951 5544

Website: [www.wesleymission.org.au/centres/creditline](http://www.wesleymission.org.au/centres/creditline)

### Salvation Army Moneycare

Phone: (02) 9633 5011

Website: [www.salvos.org.au/need-help/financial-troubles](http://www.salvos.org.au/need-help/financial-troubles)



# Leaving Home

One day you will probably decide that you want to move from your parents' home. You may want to set up a home of your own or share a house with other people. This can be an exciting time in your life, but it is also a huge step that requires a lot of preparation.

## What do I need?

- A house/unit in an area close to family, friends and services I use.
- Savings in a bank account and an income, preferably from a job.
- To have learnt some Independent Living Skills like:
  - Cleaning
  - Cooking
  - Washing
  - Ironing
  - Traveling
  - Budgeting
  - Food shopping
  - The self confidence to manage your home and services



## Can I live in a Department of Housing residence?

You may be eligible for a house/unit from the Department of Housing. The general waiting list for housing is approximately 7-8 years, but you can apply once you turn 18. If your family home is not very well suited to your disability needs (for example wheelchair access), you may be eligible to receive Priority Housing, which could reduce the waiting list to 2-3 years. You can obtain a Housing Information Pack from your local Department of Housing office or contact the Department for more information.

**Phone:** 1800 629 212

**Website:** [www.housing.nsw.gov.au](http://www.housing.nsw.gov.au)

# Leaving Home

## What if I need help with personal care and cleaning?

There are services in the community that can assist with this. For more information, contact **Home Care NSW**.

**Phone:** 1800 350 792

## What if I need some help to learn skills for independent living?

If you want to move out of your parents home then it may be a good idea to consider spending a year living in accommodation with a bit of extra support, before you move into your own place.

Northcott has two transitional accommodation services, which provide support to people with disabilities to learn to live independently.



- **Merrylands Independent Living**

A residential program that offers an opportunity for people to live in their own accessible unit with drop in support from services such as Home Care. A Living Skills Educator is also available to support you to learn the skills you may need when you move into your own home.

**Phone:** (02) 9890 0100 for more information.

- **Woodbine Transitional Service**

A residential program that operates from a shared house in the Campbelltown area. Residents are supported to develop skills for independent living. While Merrylands does not provide any overnight staff, Woodbine has staff to assist with personal care and living skills training during the day and throughout the evening.

**Phone:** (02) 9890 0100 for more information.

# Relationships, Sex and Parenting

The ability to love and be loved does not change when a person has a disability. You are a sexual being and you have the right to express your sexuality. The challenge lies in discovering and accepting your own sexuality so that you feel free to share yourself with others.

As time passes you may find that you have many questions about your body, your sexual parts, persons of the other sex, forming relationships, intimacy, sexual intercourse, safe sex, contraception, fertility, pregnancy, folate, healthy babies and more. You will also want to know how your disability may affect these things.

All of these questions are extremely important and you need to continue to ask them until you understand the answers. Who can you comfortably discuss these important and, at times, embarrassing issues with?



## Help may be available through:

- Your mum and/or your dad
- Your GP (General Practitioner)
- Your Spina Bifida doctor or nurse
- Family Planning Australia (FPA) Health Clinics  
They provide specialised services for people with disabilities.  
**Phone:** 1300 658 886 (FPA Health Line for reproductive and sexual health questions)  
**Website:** [www.fpahealth.org.au](http://www.fpahealth.org.au)  
**Mail order resources:** [www.fpahealth.org.au/resources](http://www.fpahealth.org.au/resources)
- A Community Worker from Northcott Disability Services  
**Phone:** (02) 9890 0100

# Counselling Services

Sometimes we experience things that upset us and make it hard for us to feel good about ourselves and others.

Problems might involve things like:

- A boyfriend or girlfriend
- Family
- Work or study
- Hating the way you look
- Feeling sad or alone

It is often good to talk about these things with a family member or a friend, but sometimes you don't want to talk about it with someone you know.

If you would like to meet with a counsellor face to face, you can contact your local community health centre. You can also talk to your local doctor about any issues you may have and they may discuss referring you to a counsellor.

Northcott Disability Services also has social workers and community workers that you can talk to. They can also help you find a counsellor in your area.

**Phone:** (02) 9890 0100 to speak to a Northcott worker.



**Free telephone counselling is available 24 hours a day through:**

**Lifeline**

**Phone:** 131 114

**Salvation Army Careline**

**Phone:** (02) 9331 6000

# Abuse and Neglect

If you feel that you are being badly treated by another person in a way that makes you feel threatened, or you want to report the abuse of someone you know, you should contact one of the following services:



## The Police

If you or someone you know is being abused or at risk of abuse, you can call or visit your local police station.

**Phone:** 000 (Emergency only)

**Website:** [www.police.nsw.gov.au](http://www.police.nsw.gov.au) (for contact details of your local police station)

**NSW Police Force Assistance Line (PAL):** 131 444

If you are a victim of a crime, other than life threatening or time critical emergency situations, this assistance line allows you to report crime over the phone.

## National Disability Services Abuse and Neglect Hotline

This hotline is for people with a disability, as well as their families and carers, to report abuse or neglect received while accessing government funded services (such as respite, supported employment, accommodation and community services).

The Hotline is a free service and can be contacted from 8am until 8pm, 7 days a week. Anonymous reports are accepted.

**Phone:** 1800 880 052

**TTY:** 1800 301 130

**Translating and Interpreting Service:** 131 450

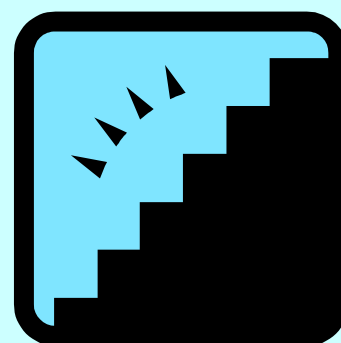
**Website:** [www.disabilityhotline.org](http://www.disabilityhotline.org)

# Disability Discrimination

Disability discrimination is where a person is treated unfairly because of their disability. If you feel that you are not being treated properly because you have a disability, you might be experiencing discrimination.

## Example:

The toilets at your work are not wheelchair accessible and when you talk to your boss about making them easier for you to use, he says he can't make any changes and you will have to learn to use them as they are.



For information about disability discrimination and how to make a complaint, contact one of the following organisations:

## Disability Complaints Service

Assists people with a disability make complaints about services.

**Phone:** (02) 9319 6549

## NSW Disability Discrimination Legal Centre

Assists people to understand disability discrimination legislation.

**Phone:** (02) 9313 6000

**Website:** [www.ddlcnsw.org.au](http://www.ddlcnsw.org.au)

## The Australian Human Rights Commission

Individuals can lodge complaints of discrimination and harassment with this independent national institution.

**Phone:** (02) 9284 9888 or 1300 656 419

**Website:** [www.humanrights.gov.au](http://www.humanrights.gov.au)

# Legal Advice

If you need advice about a legal problem you are having, you can get free advice from the following services:

## Legal Aid

Legal Aid provides a range of services to people who need advice, assistance and representation, and who qualify for legal aid.

**Phone:** (02) 9219 5000

**Website:** [www.legalaid.nsw.gov.au](http://www.legalaid.nsw.gov.au)

## LawAccess NSW

This is a free government telephone service that provides legal information, advice and referrals for people who have a legal problem in NSW.

**Phone:** 1300 888 529

**Website:** [www.lawaccess.nsw.gov.au](http://www.lawaccess.nsw.gov.au)



# Multicultural Services

Community services should provide support to people from a variety of backgrounds. However, if you would like information and support from services with specific skills in helping people from culturally and linguistically diverse backgrounds, contact one of the following organisations for advice:

## **Multicultural Disability Advocacy Association (MDAA)**

MDAA aims to promote, protect and secure the rights and interests of people from a non-English speaking background with a disability and their families and carers in NSW.

**Phone:** (02) 9891 6400

**Website:** [www.mdaa.org.au](http://www.mdaa.org.au)

## **Ethnic Communities' Council of NSW (ECC NSW)**

ECC NSW is a non-government peak body representing many organisations and people from the multicultural community in NSW. The primary roles of the council are advocacy, education and community development.

**Phone:** (02) 9319 0288

**Website:** [www.eccnsw.org.au](http://www.eccnsw.org.au)

**Email:** [admin@eccnsw.org.au](mailto:admin@eccnsw.org.au)



# Recreation and Leisure

Recreation time is a great opportunity to have fun, meet new people and pursue activities that interest you. Listed below are some contacts which may be useful when searching for activities.

## Social and Recreation Groups

### Northcott Adult Recreation Service

This service enables people with physical disabilities to participate in leisure and recreational activities of their choice. These may include camps, group activities and one off events. For more information or to refer yourself contact Northcott Adult Recreation.

**Phone:** (02) 9890 0100

**Email:** [recreation@northcott.com.au](mailto:recreation@northcott.com.au)

## Sporting Groups and Fitness

### Wheelchair Sports NSW

Wheelchair Sports NSW supports and conducts a wide range of wheelchair sporting events and programs for athletes of all ages and skill levels, in both Sydney and across most of the state.

**Phone:** (02) 9809 5260

**Website:** [www.wsnsw.org.au](http://www.wsnsw.org.au)

### New South Wales Push and Power Sports Inc.

This sports organisation caters for disabled athletes of all ages and gender using either power drive or manually powered wheelchairs. The sports that they currently play are Wheelchair Rugby League and Balloon Soccer.

**Phone:** 0439 583 249

**Website:** [www.pushandpower.org.au](http://www.pushandpower.org.au)

# Recreation and Leisure

## **Burn Rubber Burn**

Burn Rubber Burn is an exercise program developed for individuals with a spinal cord injury (including Spina Bifida). It is a circuit based exercise program incorporating resistance and cardiovascular training, focusing on health and wellbeing.

For all enquiries please contact Simone Robinson Di Francesco on:

**Phone:** (02) 93825623 or 0402776868

**Email:** [simone.robinson@sesiahs.health.nsw.gov.au](mailto:simone.robinson@sesiahs.health.nsw.gov.au)

**Website:** [www.pycnsw.org/mosparts/burnrubber](http://www.pycnsw.org/mosparts/burnrubber)

## **Leisure and Recreation Websites**

### **D-Ability**

This is a disABILITY Leisure, Arts, Sports and Lifestyle Web Guide. The site gives you direct links to the websites of people and organisations from across the world, people with a multitude of backgrounds and abilities.

**Website:** [www.D-ability.org](http://www.D-ability.org)

### **Active Places**

This is a geographically-aware search engine identifying physical recreation, sport and cultural activities, appropriate contacts and accessible facilities for people with a disability.

**Website:** [www.activeplaces.com.au](http://www.activeplaces.com.au)

## **Art**

### **Accessible Arts**

Accessible Arts is the peak arts and disability organisation across New South Wales. It promotes and provides opportunities for people with disabilities to participate in arts and cultural activities and to develop as professional artists.

**Phone:** (02) 9251 6499

**Website:** [www.aarts.net.au](http://www.aarts.net.au)



# Police, Fire and Ambulance

Triple 0 (000) is an emergency hotline service to be used in life threatening or urgent situations. 000 calls are free from any phone. This includes payphones, mobile phones and even disconnected mobile phones.

If there is an emergency and you need help from the Police, Fire Brigade or Ambulance contact one of the following numbers.



**Emergency Services Phone: 000**

**TTY Phone: 106 (hearing / speech impaired)**

## Tips for Phoning Triple 0 (000)

- 000 calls are answered by an Operator who will ask which service you need.
- Simply answer 'Police', 'Fire' or 'Ambulance'.
- Your call will then be forwarded on to the department you requested.
- Once you have been connected to the appropriate service, stay on the line and give as much information to the operator as possible.
- You will be asked about the location of the emergency. It is a good idea to memorise your home address and the address of other places you spend significant time at, in case of an emergency.
- Stay calm and speak slowly.
- Remain on the phone until the operator tells you that they have enough information.

# Useful Contacts



<b>Centrelink Disability Services</b> Website: <a href="http://www.centrelink.gov.au">www.centrelink.gov.au</a>	13 2717
<b>Contenance Aids Assistance Scheme (CAAS)</b> Website: <a href="http://www.intouchdirect.com.au/healthcare/caas.htm">www.intouchdirect.com.au/healthcare/caas.htm</a>	1300 366 455
<b>Commonwealth Carelink Centre</b> (Information centre for people with a disability and their families) Website: <a href="http://www.commcarelink.health.gov.au">www.commcarelink.health.gov.au</a>	1800 052 222
<b>Disability Council of NSW</b> Website: <a href="http://www.discoun.nsw.gov.au">www.discoun.nsw.gov.au</a>	(02) 9211 2866
<b>Department of Housing (NSW)</b> Website: <a href="http://www.housing.gov.au">www.housing.gov.au</a>	1800 629 212
<b>Home Care Service of NSW</b> (Information, Referral and Assessment Centre)	1800 350 792
<b>Independent Living Centre NSW</b> Website: <a href="http://www.ilcnsw.asn.au">www.ilcnsw.asn.au</a>	(02) 9890 0966
<b>JOBMATCH</b> (A job service for people with disabilities)	(02) 9890 0970
<b>Northcott Disability Services</b> Website: <a href="http://www.northcott.com.au">www.northcott.com.au</a>	(02) 9890 0100
<b>Paraquad</b> Website: <a href="http://www.paraquad.org.au">www.paraquad.org.au</a>	1300 886 601
<b>Spina Bifida Group of NSW</b> Website: <a href="http://www.northcott.com.au/spina_bifida_group.php">www.northcott.com.au/spina_bifida_group.php</a>	(02) 9890 0990
<b>TAD (Technical Aid to the Disabled)</b> Website: <a href="http://www.tecnicalaid.org.au">www.tecnicalaid.org.au</a>	(02) 9808 2022
<b>Wheelchair Accessible Taxi Service</b>	1800 043 187

# Information on Spina Bifida

## Books

### **Health Guide for Adults Living with Spina Bifida**

*Published by the Spina Bifida Association.*

This book provides health information and resources to help you manage your health and prevent further complications.

### **Enabling Romance**

*By Ken Kroll and Erica Levy Klein*

An illustrated guide to love, sex and relationships for people with a disability.

### **Living with Spina Bifida: A Guide for Families and Professionals**

*By Adrian Sandler, MD.*

Written for families and professionals who care for children, adolescents, and adults with Spina Bifida.

### **Sexuality and the Person Living with Spina Bifida**

*By Stephen Sloan, PhD*

This book focuses on sexual development, sexual activity, and other important issues.

### **Spinabilities**

*Edited by Marlene Lutkenhoff RN & Sonya Oppenheimer MD.*

A young person's guide to coping with the medical, self-care and emotional issues of Spina Bifida.

#### **Please note:**

A number of these books can be purchased at the Spina Bifida Association of America Website.

**Website:** [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

Books are listed under the heading 'Marketplace'.



Copies of a number of these publications are also available for loan to Northcott clients at the Northcott Centre Library in North Parramatta. **Phone:** (02) 9890 0100 to speak to the Librarian.

# Information on Spina Bifida

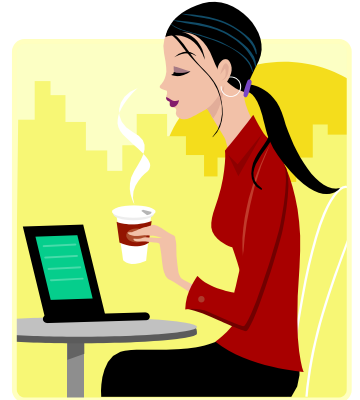
## Internet Resources

### **The Australian Spina Bifida and Hydrocephalus Association**

**Website:** [www.asbha.org.au](http://www.asbha.org.au)

### **Information on Percutaneous Cecostomy using Chait Trapdoor Cecostomy Catheter.**

**Website:** [www.cecostomy.com](http://www.cecostomy.com)



### **Passport to Success**

*Produced by the Spina Bifida Foundation of Victoria and The Royal Australian College of General Practitioners.*

A downloadable manual for young adults with Spina Bifida about successfully managing incontinence.

**Website:** [www.spinabifidaincontinence.info/clientmanual.htm](http://www.spinabifidaincontinence.info/clientmanual.htm)

### **Spina Bifida Body Owners Manual for Adolescents**

*By Glenrose Rehabilitation Hospital Adolescent Services Canada.*

The website contains information from the Adolescent Service's Body Owner's Manual, a binder of practical articles designed and written for teens.

**Website:** [www.adolescentservices.net/bodyownersmanual.htm](http://www.adolescentservices.net/bodyownersmanual.htm)

## Videos

### **Spina Bifida and Continence Video**

Video Package from Spina Bifida and Hydrocephalus Association of Queensland

# Information on Spina Bifida

## Contact People

### Paediatric Services:

**Julie Dicker – Spina Bifida Clinical Nurse Consultant**

The Children's Hospital at Westmead

**Phone:** (02) 98452802

**Email:** [Julied2@chw.edu.au](mailto:Julied2@chw.edu.au)

**Jason Birse – Spina Bifida Clinical Nurse Consultant**

Sydney Children's Hospital Randwick

**Phone:** (02) 93820681

**Email:** [jason.birse@sesiahs.health.nsw.gov.au](mailto:jason.birse@sesiahs.health.nsw.gov.au)

**Sharon Bird – Clinical Nurse**

John Hunter Children's Hospital Newcastle

**Phone:** (02) 49213677

**Email:** [Sharon.Bird@hnehealth.nsw.gov.au](mailto:Sharon.Bird@hnehealth.nsw.gov.au)

### Adult Services:

**Joanne Brady – Clinical Nurse Consultant, Spina Bifida Adult Resource Team**

**Phone:** (02) 9472 5214

**Email:** [joanne.brady@northcott.com.au](mailto:joanne.brady@northcott.com.au)

**Jaie Thomson – Occupational Therapist, Spina Bifida Adult Resource Team**

**Phone:** (02) 9472 5215

**Email:** [jaie.thomson@northcott.com.au](mailto:jaie.thomson@northcott.com.au)

# Spina Bifida Association Websites

## Australia

**Australian Spina Bifida and Hydrocephalus Association**

[www.asbha.org.au](http://www.asbha.org.au)

**Spina Bifida Assoc of NSW**

[www.northcott.org.au](http://www.northcott.org.au)

**Spina Bifida Assoc of QLD**

[www.spinabifida.org](http://www.spinabifida.org)

**Spina Bifida Assoc of SA**

[www.spinabifida.asn.au](http://www.spinabifida.asn.au)

**Spina Bifida Assoc of Victoria**

[www.sbav.org.au](http://www.sbav.org.au)

**Spina Bifida Assoc of WA**

[www.sbawa.asn.au](http://www.sbawa.asn.au)

## International

**International Federation for Hydrocephalus and Spina Bifida**

[www.ifglobal.org](http://www.ifglobal.org)

**Spina Bifida Association of America**

[www.sbaa.org](http://www.sbaa.org)

**Association for Spina Bifida and Hydrocephalus (Britain)**

[www.asbah.org](http://www.asbah.org)

**Spina Bifida and Hydrocephalus Association of Ontario**

[www.sbhao.on.ca](http://www.sbhao.on.ca)

**Glenrose Adolescent Service (Canada) Body Owner's Manual for Young People with Spina Bifida**

[www.adolescentservices.net/index.html](http://www.adolescentservices.net/index.html)

## Example of a Search Engine



**Website:** [www.google.com.au](http://www.google.com.au)

To search; type in the word/words about the information that you are looking for and click on "google search" or press 'Enter'. Example of search words: "Wheelchair Sport NSW" or "TAFE NSW" etc.

