

FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

Adolescents and adults with Spina Bifida

Independence

Being independent is an important life skill. For young people with Spina Bifida, learning to be as independent as possible will help to create more opportunities in life. This can be a lot to manage when there are also the usual issues of puberty, self-identity and making relationships.

What are some of the issues for young people with Spina Bifida?

Health

Regular clinic visits are important to maintain overall health. For young people living with Spina Bifida it is essential to have good routines. This will set the young person up for a lifetime of looking after themselves. There is a "Living well with Spina Bifida" fact sheet that covers this in more detail.

By doing some form of regular physical exercise issues of weight, independent mobility and good mental health can be managed. For more information and advice about this see the fact sheet – "Weight management and diet" and "Physical activity with Spina Bifida".

Social activities

Meeting up with friends or meeting new people will help to build self-esteem, confidence and personal relationships. Parents or carers may need to help or encourage the young person to get started.

Finding work

Finding a job can be a scary task for anyone. Guidance and support is available to help you. A good place to start is the local Centrelink office. (see www.centrelink.gov.au)

Driving

Being able to drive will help your independence and job options. Cars can be changed to suit your needs. More information about learning to drive and changes that can be made to cars can be found through the Roads and Maritime Services website (see www.rms.nsw.gov.au) and specialist driving centres. Your Occupational Therapist will also be able to help,

Transition to adult services

The transition to adult services is an exciting step for a young adult. Looking after your own health care may need some guidance. The "Living well with Spina Bifida" fact sheet is available for more information. From the age of 15 you can get a Medicare card. (See www.medicareaustralia.gov.au)

Adults

Going to an adult Spina Bifida clinic will give you a chance to talk about any issues you might have about your health. They can also speak to you about:

- Independence
- Relationships
- Sexuality
- Jobs and study
- Leisure activities.

The Northcott Spina Bifida adult resource team can help with the transition to adult services.

There is another fact sheet about "Relationships, sexuality and fertility" you may like to read. Ask your doctor if you have questions.

You can find more information about adolescents and adults with Spina Bifida at:

- Northcott Spina Bifida Adult Resource Team, www.northcott.com.au
- Continence management and Spina Bifida: Download the handbook to help you manage incontinence www.spinabifida-incontinence.info
- Roads and Maritime Services: Learning to drive information available at Roads and Maritime services www.rms.nsw.gov.au
- Australian Government Department of Human Services: Offers help looking for work or applying for a Medicare card. Centrelink also provides a variety of helpful services, www.humanservices.gov.au
- Reach Out is a great online resource about youth mental health and services. www.Reachout.com

Remember:

- There will be a lot of new information. Your red book is a great place to keep all of your health information.
- Remind health care professionals of any allergies you may have, especially to latex.
- Understand when and where to ask for help when you need it
- From the age of 15 you can get a Medicare card.