

# spina bifida

## Passport to success

A manual for young adults with spina bifida about successfully managing your incontinence.

Why is managing your continence so important?

Just as a passport allows you to enter other countries, successful continence management allows you to enter into a full and active life. A life that includes a happy sex life, good health and prevention of serious illness.

Today, most people with spina bifida live well into adulthood. Modern surgical and medical management techniques have made this possible.

Unfortunately, spina bifida never goes away. A successful lifestyle depends on you gaining the maximum amount of independence that you can. Independence to study, work, form relationships and perhaps start a family.

To achieve independence, you must be able to **manage** your spina bifida. And a difficult aspect to manage is your incontinence.

Because you have spina bifida, you should regularly attend a specialist clinic to keep well and to prevent problems from occurring. Prevention is the best way to stay well and happy.

### Outline of the manual

This manual contains:

- this introduction
- tips on how to improve your organisational skills
- facts about managing bladder incontinence: question and answer checklists; managing bladder incontinence; reviewing self catheterisation techniques; urinary tract infection warning signs and case studies
- facts about managing bowel incontinence: question and answer checklists; managing bowel incontinence; diet tips and case studies
- spinal cord tethering
- hydrocephalus and shunt blockage
- sex and having a family
- staying well and preventing illness
- resources.

This manual has been written as a series of commonly asked questions and simple answers. It has a continence management planner at the end to help you organise your daily, weekly and annual routines.

You cannot do it on your own. You need to have a support team around you. There are three important team members:

- specialists at your spina bifida clinic — urologists or 'bladder' doctors, renal or kidney doctors
- your general practitioner
- continence nurse at a spina bifida clinic.

### Better continence, better life: a case study

Sally is 25. She has spina bifida and a shunt for hydrocephalus. She walks with ankle foot orthoses (AFOs — a common type of splint) and uses a wheelchair for longer distances. She is on a clean intermittent catheterisation (CIC) routine for her bladder incontinence. Bowel continence is managed by very careful diet and enemas.

She says:

I loved school and though it was hard, I completed year 12 over 2 years. I didn't go to university or TAFE. Incontinence was my quiet terror word. I was never confident that I had it 100% under control so found it just too hard to take the big steps.

I did some part time work and short courses. I lost contact with good school friends as they moved on or moved away. It was so hard to talk about my incontinence. I got worse. Increasingly, I sat at home. I put on weight. I became a blob. I got a very bad urinary tract infection (UTI) which put me in hospital. Every cloud has a silver lining. I met a great urologist and continence nurse. They basically gave me confidence and forced me to confront the issue.

I went back to basics — better routines for cathing, and a minor operation called a Malone procedure to make bowel washouts more effective and easier to do. This helped me believe in myself a lot more.

What can I say? I am in the final year of a TAFE Business Information Technology diploma; I have an over- hectic social life; I have a steady boyfriend; I am a much stronger person.

### MORE KNOWLEDGE IF YOU WANT IT

This manual does not cover 'what is spina bifida' in detail. The companion manual to this one, *Spina Bifida — Taking Control: Effective Continence Management in Spina Bifida* covers the medical side in detail. It has been written for doctors and nurses to help them provide better treatment. But you can find out more on the medical side by reading it. Both manuals are available on the website: [www.spinabifida-incontinence.info](http://www.spinabifida-incontinence.info)

**Ready to move on? You are taking the first step *now*.**