

Spina Bifida – Living well with Spina Bifida

Disclaimer: This fact sheet is for education purposes only. Please consult with your doctor or other health professional to make sure this information is right for your child.

Why is health maintenance important?

As everyone gets older, we need to take more responsibility for our own health to ensure we continue to live well. Living well with Spina Bifida includes weight control, exercise, regular health and equipment reviews and attention to any warning symptoms. By monitoring your health, it is possible to prevent complications, minimise hospital admissions, maintain your level of independence, and maximise your participation in your community.

Some key concerns are:

- Mobility – our joints, connective tissues and bones experience wear and tear as we get older. You may find that you are not as mobile as you used to be and that you need to use a different mobility aid to help you manage.
- More pressure injuries – this can be caused by a number of different things. Some common problems include poor diet, ill-fitting equipment, weight gain, decrease in mobility and poor continence management.
- Weight gain – It is common for all people to gain weight as they age, this is true for people living with Spina Bifida too. It can be more difficult to participate in physical activity and eat healthily, especially when you move out of home.
- Kidney problems – some adults living with Spina Bifida have trouble maintaining their continence program in adult life. This can lead to very serious health issues such as renal failure.
- Shunt problems – as you get older your shunt also gets older. Don't ignore the signs of shunt malfunction. Know who you would need to see if you start to notice warning signs.
- Medical advice – It is important to have a relationship with your nearest Spina Bifida Service. They can review and make suggestions about your individual situation and will liaise with your chosen General Practitioner.

General tips for what you can do:

- Many adults living with Spina Bifida lead happy, productive and independent lives. There are just a few things that need attention.
- Find a good GP that you can talk to. Link in to a Spina Bifida Service or Rehabilitation Specialist. The Spina Bifida Adult Resource team are a great resource in the community for people over 18. You can self-refer to them at Northcott. Try to have an annual review to stay ahead of any issues related to your Spina Bifida.
- Organise to get your own Medicare card. You can do this at your local Medicare office.
- Monitor your mobility. Be open to changing your mobility equipment to support your body, this may mean that you are able to be more independent for longer.
- See medical specialists urgently if you experience worsening spasms or loss of strength in legs or arms, and it is affecting your ability to walk or transfer.
- Check your skin but in particular your feet and bottom daily. Use a pressure cushion and

wear shoes. If you develop pressure injuries or swelling on the legs see your GP and follow up with your rehabilitation specialist. You should attend daily to self-skin checks and take good care with your hygiene. Use a podiatrist for managing your foot care.

- If you have orthoses remember to check them on a daily basis. They should be reviewed by an orthotist at least once a year. They need to be cleaned regularly & inspected for any signs of wear & tear. Although rare, sometimes the plastic or componentry of the orthoses may break and this could result in a fall. If ill fitting, they could contribute to pressure injury also.
- Have a renal ultrasound every year. Keep up your clean intermittent self-catheterisation program. You might require repeat urodynamic testing and a cystoscopy if you have had an indwelling catheter for more than 15 years. The frequency of testing will be decided by your treating urologist.
- Eat a balanced diet with sufficient fibre (eg. cereals, grain, fruit & vegetables). Remember that you will gain weight more easily so dietary advice may be necessary if you are gaining weight. Exercise regularly to maintain a healthy body weight.
- Ensure you have a regular shunt review by either a neurosurgeon or the Spina Bifida Service.
- Minimise alcohol consumption, recreational drugs and don't smoke cigarettes.
- Know the reason why you are taking different medications and keep track of any changes.
- For women, be aware of the normal look and feel of your breast and see your GP immediately if you notice any new or unusual changes.
- Women over 18 need second yearly pap smear and gynaecological review. Men need regular prostate cancer and related screening. It is important not to neglect aspects of your sexual health.
- Important general health reviews as you age include blood pressure and cholesterol checks, eye tests and blood sugar tests.
- It is important to have regular 6 monthly or 12 monthly dental reviews. In between dental visits good oral hygiene practices need to be maintained.
- Try to find social activities that you enjoy. Get out and about and have lots of fun.

Carer assessment

- It is important to be aware of the physical, mental and emotional wellbeing of your family members. Your family is ageing as well and their health can impact on your health.
- If your care needs have changed, the adequacy of your care should be reviewed.

What's involved with Spina Bifida Service?

- Attending the Spina Bifida Service is an opportunity for you to have:
- Regular medical checkups (for example, yearly renal ultrasound and shunt checks).
- Ongoing advice and consultancy about continence management. There may be new continence products available and get linked in to continence subsidy schemes.
- Education and advice about prevention and management of pressure injuries and lymphedema.
- Review of your mobility needs, such as wheelchair prescription, orthoses and footwear.
- Issues of pain management can be explored and management plans created.

- Genetic counseling, relationships, family planning and fertility issues are discussed in a supportive environment.
- Housing, employment and advocacy advice is available.
- Social and recreation activities are explored with you to ensure you are maximising your community participation potential.
- Referrals and liaison with other services such as GP's, medical specialists, allied health and community services may provide you with additional support in your community.

If you decide not to attend an Adult Spina Bifida Service your other option is to visit your GP (local doctor) regularly. There you will receive referrals to appropriate medical specialists for individual health issues.

Things to remember:

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- Living well with Spina Bifida includes weight control, exercise, regular health and equipment reviews and vigilance to any warning symptoms.
- Know your body and be proactive in managing any changes.
- Make sure you tell new health care professionals about any allergies you may have.
- Use services and supports available to you to maintain your independence.
- Review your equipment on a daily basis. Remember to clean your equipment and keep up with maintenance needs.