

# Other primary care issues for people with spina bifida

## Chapter 7: Health promotion strategies and other clinical issues in spina bifida

*A routine approach to reviewing spina bifida helps clinicians detect problems requiring early treatment and referral. In addition, information, such as dietary and other lifestyle information can help promote a sense of health and wellbeing.*

### Key issues for clinicians

- Attention to general health measures may help prevent significant long term complications of spina bifida.
- Obesity is a major issue in young people and adults with spina bifida and is a significant barrier to independent mobility.
- Self care, including skin care, is an important part of general health for people with spina bifida.
- Peer support organisations can provide important access to resources and support networks.

Early prevention can minimise long term problems<sup>1-3</sup>

The early detection of changes in clinical condition and of any complications from spina bifida is essential. While monitoring of neurological and urological changes have been highlighted in earlier chapters, there are other measures that general practitioners can take to enhance the quality of life for young people and adults with spina bifida.

General practitioners often diagnose changes early, and are able to refer initial problems to specialist centres. Some common problems of which GPs need to be aware are listed below.

### Obesity in spina bifida

Nutrition plays a vital role in spina bifida in terms of general health, bowel function regularity and the prevention of obesity.

Lack of mobility is a major contributing factor to the development of obesity in spina bifida.

Neurological and orthopaedic problems can decrease mobility, resulting in weight gain. This weight gain can result in a further decrease in mobility, contributing to further weight gain. The loss of mobility may be so severe as to result in the person being confined to a wheelchair.

The GP can play an important role in monitoring weight and intervening early to prevent weight gain.

### Promoting exercise, sports and activities

General practitioners can improve the general health of people with spina bifida by promoting the role of physical exercise.

In addition to helping maintain mobility and prevent obesity, sport can be a major opportunity for socialisation, formation of relationships, peer support and meeting prospective partners.

### Skin care — pressure sores and neuropathic skin

Skin problems, often related to immobility, can be a continuing source of morbidity. Early treatment is the key to successful outcomes.

Altered sensation from spina bifida can result in neuropathic, atrophic skin with ulcers and chronic infection. Poor vascular supply and abnormal autonomic function are also common in spina bifida and can contribute to skin atrophy.

Lymphoedema, secondary to immobility is common and can result in skin damage and ulceration.

Care should be taken to ensure that shoes fit properly, and that wheelchairs, general aids and aids to transfer patients do not contribute to skin damage.

Patients may benefit from referral to specialist lymphoedema clinics.

### Latex allergies

Allergies to latex are more common in people with spina bifida than the general population. Reactions can vary between mild reactions to severe anaphylactic shock.

Care needs to be taken to avoid the use of rubber gloves and any other latex items, such as the balloons in catheters. Some hospitals have latex free operating theatres for procedures for allergic individuals.

Clinicians need to remain alert to this possibility and to refer to specialist clinics for advice if the situation arises.

### Self care and hygiene

Cognitive and physical deficits can contribute to poor self care and hygiene. A deterioration in self care may point to worsening underlying medical problems. Patients may need to be taught simple grooming techniques adapted so that they are achievable within the context of any cognitive deficits.

### Social development and educational strategies

Peer support is one of the most important ways in which people with spina bifida learn to adopt healthy behaviours. Encouraging patients to join spina bifida associations can provide opportunities for peer support, which can increase self esteem and personal and social relationships (see list of associations in *Chapter 9*).

### References

1. Hoeman P. Primary care for children with spina bifida. *Nurse Pract* 1987; 22:60–72
2. Spina Bifida Association of Victoria website. [www.sbav.org.au](http://www.sbav.org.au)
3. Lutkenhoff M, Oppenheimer SG. Spinabilities. A young person's guide to spina bifida. Woodbine house: Bethesda 1997

### Case study: building links through community organisations

Toby is a handsome 26 year old man with spina bifida at the S1–2 level. He is in full time employment, had lifelong urinary incontinence, but not faecal incontinence. He presents with the difficult problem of urinary incontinence after he ejaculates. Toby self catheterised in the morning and at night, and used a pad during the day. As a result, he had low self esteem. He attended a spina bifida association meeting where incontinence was discussed.

He was encouraged to attend a spina bifida clinic and was subsequently referred to a urologist.

Urodynamic studies were performed and full continence measures have been instituted. His resulting social and sexual function have greatly increased and he confidently anticipates the prospect of finding a girlfriend.