



Shine

Spina bifida • Hydrocephalus
Information • Networking • Equality

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Older adults with spina bifida – Information for General Practitioners

Introduction

Spina bifida is a developmental disorder of the spinal cord and brain, which usually leads to some loss of neurological function below the lesion. Neuropathic bladder and bowel, reduced mobility and skin sensation are often experienced, along with subtle but significant cognitive impairment associated with hydrocephalus.

As a stable condition, spina bifida has often been viewed as a Paediatric disorder with fairly intensive input during childhood, but little follow-up or monitoring after transfer to adult services.

However, we now have significant numbers of older members with spina bifida who are facing many health issues which, had regular health checks been maintained over these decades, may have been identified and treated at an earlier stage. Furthermore, many adults with spina bifida are reporting a deterioration in mobility associated with Tethered Cord, Chiari, arthritic changes to the neck and shoulders, etc, which detract from their quality of life, independence, and ability to work.

We have produced this information for GPs which we hope will be of help in managing and monitoring your patient, so that common problems can be identified and treated at an early stage.

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Urinary tract

Neuropathic bladder and bowel are noted in approximately 90% of people with spina bifida aperta, and around 50% of people with significant spina bifida occulta. Detrusor sphincter dyssynergia can result in high storage pressure of the urine, ureteric reflux, incomplete voiding (leading to UTIs), which can lead to renal failure, as well as distressing symptoms of frequency, urgency and incontinence of urine. Patients in their 40s who may have been out of follow-up for many years, may have developed an atonic bladder and be prone to UTIs.

Annual blood pressure check, FBC, with urea and creatinine, and renal scans every two years should detect impairment in renal function, and ultrasound of the urinary tract every two years should detect changes in capacity and post-void residual.

Detrusor hyperreflexia can be treated with anti-muscarinics, botulinum toxin, and incomplete voiding by intermittent clean catheterisation. Patients reporting significant neuropathic symptoms would benefit from referral to a Urologist with a special interest in neuropathic problems, to discuss pharmacological or surgical options, and to be taught ISC.

Bowels

Constipation is commonly experienced by adults with spina bifida, owing to loss of sensation in the rectum and impaired innervation of the pelvic floor. However, patients may need careful questioning as to the frequency and consistency of stool, with reference to the Bristol stool chart, as lifelong overloading may lead the patient to view constipation as the norm.

Overflow as a result of impaction may be reported to you as recurrent diarrhoea, as incontinence of faecal fluid will cause more management

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problems to the patient than their constipated state. PR examination may not reveal impaction, and XRay/abdominal ultrasound may be necessary.

There is sometimes a reluctance to take laxatives in case incontinence increases, albeit temporarily, and the patient may need careful explanation of the need to clear out constipated stool to prevent overflow, and checks as to what support is in place or needed to support toileting, cleaning, etc.

Anal irrigation may be an option, and referral to Colorectal service can be made for assessment and teaching of this method.

Tissue Health

Flaccid paralysis of the lower limbs, absent sensation, and poor circulation may predispose a person with spina bifida to pressure sores, cellulitis, and lymphoedema. Because of reduced sensation, these problems may advance significantly before the patient seeks advice.

A regular review of patients with spina bifida could include tissue health checks. Management of pressure sores should include attempts to identify the precipitating factors, and education on changing position throughout the day, as well as appropriate dressings.

Lymphoedema can result in loss of independence, and active management with graduated, fitted hosiery can be very effective. Foot care for adults with reduced sensation and circulation should ideally be as per diabetic patients.

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Mobility

Some adults with low lesions report reducing mobility from their thirties. Tethered Cord may be a factor, and can sometimes be surgically treated. Physiotherapy can also help maintain good posture, improve wheelchair technique, and prevent wear and tear on the neck and shoulders. Correct aids and orthotics can also support mobility. Bone density scans may also be helpful.

Sleep apnoea

In a Spina Bifida Clinic for adults, many cases of obstructive sleep apnoea have been noted. Patients may complain of constant fatigue or poor cognitive performance, with weight gain and oedema. The patient may benefit from sleep studies.

Obesity

Reduced muscle bulk in the legs and hips, with reduced activity, may decrease the basal metabolic rate significantly. Patients with spina bifida may need as few as half the calories of an adult without spina bifida, and weight gain is common. Considerable ongoing support may be needed to reduce weight.

Cognitive factors

Deterioration in cognitive function should prompt a referral to a neurosurgeon to investigate possible decompensating hydrocephalus, Chiari, or shunt malfunction.

Spina bifida often occurs alongside hydrocephalus, and cognition may be impaired in certain areas making it harder for adults to care adequately for their health, and comply with their treatments.

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Memory, motivation, slow processing of information, and a poor sense of passing time may mean problems are presented late, and treatment plans not understood, remembered, or adhered to, even in some patients who appear superficially to be very able. Taking time to check comprehension and writing down instructions can improve compliance.

Mental Health

Anxiety and depression are reported more frequently in people with spina bifida and hydrocephalus than the general population. Cognitive problems, isolation, and incontinence can all have an impact on mental wellbeing. Some talking therapies, such as counselling, may be less effective because of cognitive factors than CBT or other intensive therapies.

Shine relies on people's generosity and support so we can help our clients who depend on us for help and advice - people with hydrocephalus, spina bifida, their families and carers. To donate to **Shine** please visit www.shinecharity.org.uk or call **01733 555988**.

This information has been produced by **Shine's** medical advisers and approved by **Shine's** Medical Advisory Committee of senior medical professionals.

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