

Dear Shine Member

Living with spina bifida presents many challenges – not least because many people have limited understanding of the condition.

On the back of this page, you'll find a letter about your condition, describing some of the ways spina bifida might affect you.

If you feel it would benefit you, please add your details at the top of the letter and hand this into your GP surgery, where it can be added to your medical records for future reference.

The letter may help you if you're finding it tricky to explain some aspects of your condition.

Yours,



Gill Yaz
Health Development Manager, Shine Charity

Letter regarding patient: First Name.....Surname.....
Address.....
Postcode..... Date of birth.....

Dear GP

This letter has been given to you because your patient has spina bifida. This can affect many systems and organs of the body, and its effects are not limited to musculoskeletal concerns. There may be aspects of health that need to be monitored regularly, to prevent ill health. In Shine's recent survey of adult members with spina bifida, only 19% of patients with spina bifida report receiving regular checks with their GP.

Urinary tract

Around 85% of people with spina bifida aperta, and 50% of people with skin-covered/occult lesions have neuropathic bladder issues. Overactive bladder symptoms such as **urgency or frequency** may be underreported; quality of life can be much improved on treatment. Neuropathic bladder can lead to renal impairment, regular blood tests can help detect this at an early stage. There is evidence that people with spina bifida are more susceptible to bladder cancer, at a younger age, (commonly 30s or 40s) and presenting at a later stage than people without spina bifida. If your patient presents to you with -

- Haematuria
- New, recurrent UTIs
- Pelvic pain
- New difficulty passing intermittent catheters

Then we would urge you to consider referring your patient for investigations, to exclude bladder cancer.

Skin and tissue health

Affected circulation, mobility/gait, body shape, continence and skin sensation may all contribute to **pressure/moisture lesions**, which can develop rapidly and heal slowly. Because of reduced sensation and cognitive issues, people may not seek help promptly leading to more severe lesions and complications such as osteomyelitis and sepsis. Cellulitis and lymphoedema are also common in people with spina bifida. Treatment of **lymphoema** with pressure hosiery is very effective and can prevent loss of mobility and independence.

Children with spina bifida may need regular and prompt replacement of **orthoses**, to prevent pressure sores and support optimum ambulation.

Obstructive sleep apnoea

Adults with spina bifida appear to experience obstructive sleep apnoea more commonly than people without spina bifida. In our survey, 10% had been diagnosed with OSA, but a further 63% reported symptoms. Since many people with spina bifida aperta may also have cognitive difficulties, such as reduced processing speed, and memory issues, OSA may exacerbate these, reducing independence.

Pain

Most of our members report living daily with pain and discomfort. Because of this, they may need prompting to engage with screening for breast, cervical or bowel cancer, or BPH, as they may put symptoms down to general aches and pains

For further information, or if have any questions about the condition, please visit shinecharity.org.uk/spinabifidaforgps, contact us on 01733 555988 or firstcontact@shinecharity.org.uk

Yours,



Gill Yaz
Health Development Manager, Shine Charity

Supported by