

Aging with Spina Bifida



It's a known fact that the general population is getting older and most people - including those with Spina Bifida and/or Hydrocephalus will enjoy a longer lifespan than previous generations.

As intensive treatment and studies of Spina Bifida and Hydrocephalus did not really begin until the early 1960's, it is only recently that relatively large numbers of people with these conditions have been assessed.

When young people leave education and leave paediatric services, they often find that much of the responsibility for monitoring their general health lies with themselves.

Dr Gillian Hunt, who has studied Spina Bifida and Hydrocephalus for more than 35 years, told said: "One of the main priorities in caring for yourself is to keep appointments with your GP or hospital consultants.

"Even if you are quite well it is important to check blood pressure, urine and eyesight every year. When you see your doctor - even if it's about a minor ailment - ask them to check your blood pressure, which is also an indicator for kidney problems."

One of the best ways to detect shunt problems is by having your eyesight checked by an optician. A squint is often symptomatic of intracranial pressure. The optician will also check the back of your eyes as well.

Dr Hunt added: "Don't ignore headaches or neck aches - they may well be caused by intracranial pressure. Similarly, frequent headaches and sickness could be symptoms of shunt problems."

People with Spina Bifida and Hydrocephalus experience the same issues as anyone else as they age, but they can be prone to a number of specific problems.

The effects of ageing for people with Spina Bifida may be expected to include weight gain, more pressure sores, blood pressure problems and reduced mobility.

Weight gain can be one of the most debilitating problems and is a major threat to health. Dr Hunt advised: "If you use a wheelchair you use far less energy than someone who is mobile. It is important to stick to a healthy diet.

"Weight gain affects not only the patients, but the carers too, as they can be worn out by the stress and strain of lifting a heavy weight. So it could mean that the weight gain could cause the patient to go into a care home. If you can stay slim, you will be more active and independent, and you'll have more fun," she added.

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Inactivity can lead to osteoporosis (brittle bones), so it's important to include foods rich in calcium and vitamin D in your diet. Skimmed milk and low-fat yoghurt are good sources of calcium, while exposure to sunlight provides us with an active form of vitamin D.

It is not uncommon for wheelchair users to report that their muscles tire more easily and they frequently experience significant bone and joint changes. They may have used certain muscle groups to the maximum over the years - but this shouldn't deter anyone from doing physical exercise, which does help to build strong bones and muscles, and also boosts psychological well-being.

Lead as active a life as possible, and try to get out and meet people. Ageing can be difficult for everyone, not just people with Spina Bifida and/or Hydrocephalus. But taking care of your health, and making sure you seek support when you need it, will help you to live a full and active life. Contact your SBHI Family Support Worker for advice and support.