

Dear Shine Member

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

We have created a letter about your condition, how a problem with your shunt might affect you, and what to do next. It also mentions the possible challenges you face living with the condition.

If you feel it would benefit you, please add your details at the top and share this with your GP surgery. To share the letter phone your GP surgery directly and ask them how you can email them a document to be added to your medical records. It will then be available for your doctor for future reference.

The letter may help you if you're finding it tricky to explain how you're feeling and if you think your shunt isn't working properly.

Yours,



Gill Yaz
Health Development Manager, Shine

Letter regarding patient: First Name..... Surname

Address

Postcode Date of birth/...../.....

Dear GP

This letter has been given to you because your patient has hydrocephalus and has a shunt in situ. Insertion of a shunt, particularly a ventriculoperitoneal (VP) shunt is the most common treatment for hydrocephalus. The thin silicon tube diverts CSF from the ventricles to the peritoneum (or less commonly the pleural cavity, or the atrium in VA shunts) and this reduces the high intracranial pressure preventing damage to the brain tissue. Shunts sometimes malfunction and prompt neurosurgical attention may be necessary.

People who have had previous shunt malfunctions may recognise their own 'individual' symptoms of raised pressure, but sometimes new signs and symptoms can present from one shunt blockage to the next.

Symptoms include, but are not limited to:

- headaches, neck pain
- nausea & vomiting
- visual disturbances (typically blurred, double vision, or restricted visual fields, may also include photosensitivity)
- dizziness, drowsiness, loss of consciousness

Signs of shunt infection are similar to malfunction but also include:

- fever
- seizures
- neck stiffness
- erythema/tracking along shunt tubing
- photosensitivity is more common in infection

People with suspected acute shunt malfunction or infection should be seen at a Neurosurgical Unit within four hours of the onset of symptoms.

Shunts can also malfunction over a prolonged period, and symptoms may be less clear, possibly including:

- fatigue, general feelings of being unwell, lethargy
- new or worsening visual or perceptual problems
- changes in behaviour
- decline in academic / mental / cognitive performance

Review by a neurosurgeon should be arranged if chronic shunt problems are suspected.

In addition to malfunction, shunts can sometimes siphon away too much CSF over time. Over-drainage can cause the ventricles to shrink and become slit-like as the brain and meninges draw away from the skull. Many shunts have features designed to prevent slit-ventricle syndrome (SVS) but it can still occur, particularly in children, and in adults who had shunts placed in infancy. A suggestive symptom of shunt over-drainage/SVS is recurrent severe headaches that progressively worsen as the individual remains upright and can be relieved by lying down. They may also experience dizziness and nausea. Imaging studies are needed to diagnose SVS, and a referral to neurosurgery for management is appropriate where SVS or over-drainage are suspected.

As well as potential complications, people with hydrocephalus may have challenges living with the condition, these could include:

- headaches - traditional painkillers may not be effective where the headaches are neuropathic in nature.
- speed of processing information
- behaviour, self-monitoring, relationship issues
- memory, planning, organising issues
- anxiety

Should you require more information or have any questions about the condition, please visit

www.shinecharity.org.uk. You can also contact us via Tel: 01733 555988, or Email: info@shinecharity.org.uk

Yours,



Gill Yaz
Health Development Manager, Shine