

Dear Shine Member

Living with normal pressure hydrocephalus (NPH) presents many challenges – not least because many people have limited understanding of the condition.

We have created a letter about your condition, and what to do if your condition begins to change. 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, if your condition has worsened (ie your walking / balance), if you think your shunt isn't as effective as it was previously in managing your symptoms.

Yours faithfully

Gill Yaz



Head of Health - 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 **normal pressure hydrocephalus (NPH)** or is suspected of having NPH. NPH is the only potentially treatable cause of dementia, so its prompt identification and treatment is important for the best outcomes. NPH usually occurs in older adults and is characterised by progressive-

- gait disturbance (shuffling, magnetic-type gait)
- cognitive decline/dementia, and
- urgency, frequency and incontinence of urine (and sometimes faeces).

Insertion of a programmable ventriculoperitoneal (VP) shunt is the most common treatment for NPH. Careful patient selection, either through imaging or tests such as extended lumbar drainage, helps ensure surgery is offered to those most likely to see improvement after a shunt placement. Frailty rather than age is also a factor in patient selection.

The thin silicon tube diverts CSF from the ventricles to the peritoneum and this is thought to reduce the distortion of the brain tissue above the enlarged ventricles and relieve symptoms. Shunts sometimes malfunction and for people with NPH, a return of their previous symptoms would be reported. In addition, as NPH progresses, it may be necessary for the setting of the programmable shunt to be altered at their neurosurgery centre if their symptoms to begin to worsen. Complications of shunt surgery include subdural haemorrhage, but shunt infections and blockages are less common in older adults than in children.

Patients who have been immobile prior to shunt surgery would often benefit from Physiotherapy and Occupational Therapy to aid their rehabilitation. Bladder symptoms are less likely to improve than ambulation of cognition, so ongoing support from the local Continence Service may be needed. Input from Social Services Care services may also be needed.

Not all patients will improve after shunt insertion, and those that do may find their symptoms returning over time. However, many people find even small gains in their function greatly improves their quality of life, function and health.

Unfortunately, not everyone will be offered surgery, because of frailty/comorbidity, or because tests show their condition is unlikely to improve. There are also patients who decline the offer of surgery. These patients will require a great deal of care, multi-agency support and symptom management as their condition progresses.

Shine provides support for people with NPH, and information and e-learning via our Professionals' Membership.

Further information is available on our website : www.shinecharity.org.uk – and you may also wish to join Shine as a Professional Member.

Professional members can contact our specialist teams for information and advice, can access our CPD accredited e-learning modules, and can order and download copies of all Shine resources to support both those diagnosed with NPH and their carers. Shine Membership is free and you can [register online](#), by phone, or e-mail using the details below.

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 faithfully,



Gill Yaz

Head of Health- Shine