



June 2024

Normal Pressure Hydrocephalus (NPH)/ Dementia Coordinator

Thank you for your interest in the role of Normal Pressure Hydrocephalus (NPH)/Dementia Coordinator. This is an exciting brand new role to lead on the development of the NPH/ Dementia service within Shine and work with partners to increase awareness of this condition.

Shine has a membership of over 14,000 members living with spina bifida and/or hydrocephalus and associated conditions and over 6,500 associated members.

In the last year Shine has seen a 25% increase in members who are living with NPH across England, Wales and Northern Ireland over the last year. There are currently just over 600 members living with NPH, plus their carers registered, but we are expecting this to continue to rise as awareness and diagnosis of the condition grows.

To help us listen to our members living with NPH/ Dementia, understand their needs and be the lead support in England, Wales and Northern Ireland outside of the NHS, we are developing a NPH/ Dementia service specifically for Shine members.

What is Normal Pressure Hydrocephalus?

Normal Pressure Hydrocephalus (NPH) is a condition which mainly affects people over 60.

A clear fluid, cerebrospinal fluid (CSF) is constantly produced and absorbed, and flows through chambers within the brain, (ventricles) and around the outside of the spinal cord. CSF protects the brain and spine, provides them with nutrients, and removes toxins.

When more CSF is produced than absorbed, hydrocephalus occurs. In NPH the ventricles become enlarged by too much CSF building up, although the pressures inside the head are often found to be normal. The condition is associated with several symptoms, including difficulty walking, cognitive impairment/dementia, and urinary incontinence.

What causes NPH?

In many people, the cause of NPH is not known but it is usually associated with older age.

In some people NPH can be caused by a previous head injury, a bleed in the brain, or because of infection or a tumour blocking the flow of the CSF. In some cases, the cause can be reduced CSF flow owing to stenosis (narrowing) of the aqueduct which is a part of the ventricular system. In NPH the excess fluid and enlarged ventricles press on the blood vessels and brain tissue. This can alter the way the brain works and prevent the brain from removing toxins. These

toxins can then build up in the brain and begin to harm brain cells, leading to dementia and loss of brain volume.

Normal Pressure Hydrocephalus Symptoms

Increasing difficulty walking is often the first symptom noticed. The pattern of walking (gait) can become slow and shuffling, with difficulty picking the feet up (sometimes described as 'magnetic gait' or 'sticky feet') or a wide based stance.

Cognitive impairment in NPH may appear to be like Alzheimer's but it generally progresses at a slower rate, and usually follows difficulties with walking rather than being the first symptom to appear. In addition to memory difficulties, there may be problems with attention and slowness of thought.

Many people also experience issues with their mental health, such as depression or anxiety, or with regulating their mood, becoming agitated, angry or frustrated.

Urinary leakage is more common than bowel leakage, but some people may have either or both. People with bladder involvement describe urgency and frequency of needing to pass urine, with sudden leakage.

Headaches and fatigue may occur and can vary in intensity between people. There may also be a wide range of neurological symptoms such as numbness, tingling or weakness in any of the arms, legs, or face.

The new NPH/ Dementia Coordinator role

We are looking for a dementia specialist.

You will be an expert in your field and will understand the challenges of receiving a life-changing diagnosis in later life, have been working directly with older people (ideally face-to-face) who are living with dementia, and their families. You will also demonstrate knowledge and experience in the changes to behaviour, physical health and mental health that accompany dementia/ NPH.

You will be an experienced, skilled, organised and dedicated new member joining Shine's Services' team to develop and lead our new NPH/ Dementia service, working alongside our Health Team and our regionally based Support & Development Workers.

As the driving force of this new service, you will be creating a clear framework for delivery, providing quality information, advice and guidance to members and their families, building

strong networks with national, regional, and local existing dementia/relevant support services and be Shine's dementia and NPH specialist.

You will work to raise awareness of NPH, by building relationships with key stakeholders, working with the NHS and delivering the annual NPH awareness week, with the next one due in May 2025.

If you are interested in this role the full Job Description and Person Specification is available. If you would like to have a chat about the role in more detail or have any questions, please give me a call on 07879 322751 or email me on gill.valentine@shinecharity.org.uk

Thank you again for your interest in this role

Gill Valentine
Director of Services