

# Normal Pressure Hydrocephalus: A Guide for Patients & Families

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Normal Pressure Hydrocephalus (NPH) is a condition that occurs when excess cerebrospinal fluid (CSF) builds up in the ventricles (fluid-filled spaces) of the brain. This causes pressure on the brain, leading to symptoms that mimic other forms of dementia or movement disorders. NPH can be treated, often with surgical interventions.

## Signs & Symptoms to Watch For

### Common Cognitive Symptoms

- Memory problems, especially with recent events
- Difficulty concentrating or thinking clearly
- Slowness in processing information or performing tasks
- Difficulty with organizing or planning daily activities

### Behavioral & Emotional Changes

- Apathy or lack of interest in activities
- Depression or feelings of sadness
- Mood swings or irritability
- Decreased initiative in social interactions

### Motor Symptoms

- Walking difficulties, such as a shuffling gait
- Stiffness or difficulty with movement
- Frequent falls or imbalance
- Urinary incontinence (inability to control urination)

## Typical Presentation & Progression

### Early Stage

- Mild cognitive symptoms, such as forgetfulness or confusion
- Slight difficulty walking or frequent tripping
- Early signs of urinary incontinence
- Subtle mood changes or apathy

### Middle Stage

- Increased difficulty walking with a shuffling gait
- More noticeable cognitive decline, especially in memory and concentration
- Increased difficulty with daily activities
- Urinary incontinence becomes more frequent

### Late Stage

- Severe difficulty walking or inability to walk independently
- Marked cognitive decline, with significant memory and decision-making problems
- Complete dependence for daily activities, including personal care
- Severe urinary incontinence and possible total loss of bladder control

## Medications FDA-Approved for Cognitive Symptoms

### Symptom-Targeted Medications

- There are no medications specifically approved for treating Normal Pressure Hydrocephalus. However, medications may be used to manage co-occurring symptoms, such as urinary incontinence or mood swings.
- In some cases, medications to help manage cognitive symptoms (e.g., Donepezil for Alzheimer's) may be prescribed off-label.

### Disease-Modifying Therapies

- The primary treatment for NPH is surgical, not medication-based. The most common procedure is the implantation of a shunt to drain excess fluid from the brain and relieve pressure.

## Diagnostic Tests Your Healthcare Team May Use

### Clinical & Cognitive Evaluation

- Detailed medical history, including symptoms and their progression
- Cognitive testing to assess memory, attention, and executive function

### Laboratory Tests

- Blood tests to rule out other potential causes of symptoms, such as infections or nutritional deficiencies

### Imaging Studies

- MRI or CT scans to evaluate the ventricles in the brain for enlargement due to CSF buildup
- A lumbar puncture (spinal tap) to test the CSF pressure and volume
- The imaging studies help to differentiate NPH from other conditions with similar symptoms.

## Planning for the Future

### Healthcare Planning

- Discuss care preferences and goals early on, particularly before surgery if that is an option
- Set up advance directives and healthcare power of attorney
- Plan for the potential long-term care needs after surgery, if applicable

### Legal & Financial Planning

- Appoint a durable financial power of attorney
- Review long-term care insurance and long-term planning for medical costs
- Consult an elder-care attorney to assist with legal planning and estate protection

### Support for Caregivers

- Develop a structured caregiving routine to help manage the patient's needs
- Reach out to support groups and seek caregiver education
- Ensure caregivers have access to respite care and other support services

## National Organizations & Resources

✓ **\*\*Hydrocephalus Association\*\***

☎ 1-888-598-3789 | 🌐 [hydrocephalus.org](https://hydrocephalus.org)

✓ **\*\*Alzheimer's Association 24/7 Helpline\*\***

☎ 800-272-3900 | 🌐 [alz.org](https://alz.org)

✓ **\*\*National Institute of Neurological Disorders and Stroke (NINDS)\*\***

☎ 1-800-352-9424 | 🌐 [ninds.nih.gov](https://ninds.nih.gov)

✓ **\*\*Eldercare Locator\*\***

☎ 1-800-677-1116 | 🌐 [eldercare.acl.gov](https://eldercare.acl.gov)

## Final Notes

- Early recognition and intervention are key to improving outcomes and preventing further damage.
- Surgical intervention can help manage symptoms and improve quality of life for many individuals with NPH.
- Ongoing support and care planning will be necessary for long-term management.