

HYDROCEPHALUS

Information for Patients, Parents and Families

This booklet explains hydrocephalus in children and adults, including normal-pressure hydrocephalus, and the two main surgical treatments: endoscopic third ventriculostomy (ETV) and ventriculoperitoneal (VP) shunt insertion.

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Precision, integrity and compassion

What is hydrocephalus?

Hydrocephalus is a condition in which cerebrospinal fluid (CSF) builds up within the fluid-filled spaces of the brain, called the ventricles. The ventricles enlarge and may place pressure on the brain or interfere with normal brain function.

CSF normally circulates through and around the brain and spinal cord. It cushions the nervous system, carries nutrients and helps remove waste products.

Why does it occur?

- A blockage in the normal CSF pathways
- Reduced absorption of CSF
- Bleeding within or around the brain
- Infection such as meningitis
- A brain tumour, cyst or congenital abnormality
- Prematurity-related intraventricular haemorrhage
- Head injury or previous brain surgery
- Occasionally, no clear cause can be identified

Hydrocephalus in babies and young children

- Rapid increase in head circumference
- An unusually large head
- A tense or bulging fontanelle (soft spot)
- Prominent scalp veins
- Downward-looking eyes
- Poor feeding or repeated vomiting
- Irritability or excessive sleepiness
- Seizures or delayed development

A baby who becomes unusually sleepy, feeds poorly, vomits repeatedly or develops a tense fontanelle needs prompt medical assessment.

Hydrocephalus in older children

- Headache, often worse in the morning
- Nausea or vomiting
- Blurred or double vision
- Difficulty looking upwards
- Problems with balance or walking
- Decline in school performance
- Behavioural change or increasing sleepiness
- Seizures or loss of previously acquired skills
- Urinary incontinence

Hydrocephalus in adults

- Persistent or worsening headache

- Nausea and vomiting
- Blurred or double vision
- Increasing drowsiness or confusion
- Memory or concentration difficulty
- Difficulty walking or maintaining balance
- Weakness or reduced level of consciousness
- Urinary incontinence

Rapidly developing hydrocephalus can be a medical emergency, particularly when there is increasing drowsiness, repeated vomiting or reduced consciousness.

Normal-pressure hydrocephalus (NPH)

Normal-pressure hydrocephalus mainly affects older adults. The ventricles become enlarged, but the pressure measured at a single lumbar puncture may be normal or only intermittently raised.

The three typical symptom groups are:

1. Walking difficulty

- Slow walking with short, shuffling steps
- Difficulty initiating walking
- A feeling that the feet are stuck to the floor
- Unsteadiness when turning
- Frequent falls or increasing need for a walking aid

2. Cognitive change

- Slower thinking
- Reduced attention or short-term memory
- Loss of motivation
- Difficulty planning or organising daily activities
- Increasing dependence on others

3. Bladder disturbance

- Urgency or frequency
- Difficulty reaching the toilet in time
- Urinary incontinence

Not every patient has all three features. Walking difficulty is often the earliest and most prominent symptom. NPH can resemble Parkinson's disease, Alzheimer's disease or other conditions affecting older adults, so careful assessment is essential.

How is hydrocephalus diagnosed?

- Detailed medical and neurological assessment
- Measurement of head circumference in babies
- Developmental assessment in children
- Examination of the eyes and optic nerves
- CT or MRI scan of the brain
- Assessment of CSF flow or pressure in selected patients

Additional assessment for suspected NPH

- Formal walking and balance tests
- Memory and cognitive assessment
- Lumbar puncture or large-volume CSF tap test
- Temporary lumbar drainage
- Lumbar infusion testing in selected cases

Improvement after temporary CSF removal may support the diagnosis and help estimate the likelihood of benefit from shunt surgery. No single test can predict the outcome with complete certainty.

Treatment options

Treatment depends on the patient's age, the cause of hydrocephalus, the location of any obstruction, previous surgery, imaging findings and general medical condition.

1. Endoscopic third ventriculostomy (ETV)
2. Ventriculoperitoneal (VP) shunt insertion

Endoscopic third ventriculostomy (ETV)

ETV is an operation that creates a new pathway for CSF to flow out of the ventricles. Using a small camera called an endoscope, the neurosurgeon makes an opening in the floor of the third ventricle. This allows CSF to bypass an obstruction and circulate through an alternative pathway.

Who may benefit from ETV?

- Aqueductal stenosis
- A tumour or cyst obstructing CSF flow
- Certain congenital abnormalities
- Selected cases of shunt malfunction
- Other forms of obstructive hydrocephalus

ETV may be suitable for children or adults, but it is not appropriate for every type of hydrocephalus. Success depends on age, the cause of hydrocephalus, previous bleeding or infection, previous shunt surgery and the anatomy shown on imaging.

What happens during ETV?

- The operation is performed under general anaesthesia.
- A small scalp incision and a small opening in the skull are made.
- The endoscope is guided into the ventricular system.
- A controlled opening is created in the floor of the third ventricle.
- The new CSF pathway is inspected before the wound is closed.

Potential advantages

- No permanent shunt tubing or valve
- No abdominal incision
- Avoidance of some long-term shunt complications
- No need for valve adjustments

Possible risks

- Bleeding or infection
- Seizure
- CSF leakage
- Injury to nearby brain structures or blood vessels
- Memory or hormonal disturbance
- Failure to control hydrocephalus
- Closure of the opening later
- Need for a VP shunt or further surgery
- Very rarely, severe neurological injury or death

An ETV can stop functioning months or years after apparently successful surgery. Symptoms of hydrocephalus may then return and require urgent assessment.

Ventriculoperitoneal (VP) shunt

A VP shunt is a system of narrow flexible tubes that diverts excess CSF from a brain ventricle to the abdominal cavity, where it can be absorbed naturally.

The shunt usually contains

- A ventricular catheter inside a brain ventricle
- A valve that controls CSF drainage
- Tubing that passes underneath the skin
- A distal catheter ending in the abdominal cavity

The shunt is placed entirely beneath the skin. The valve may be felt beneath the scalp but is not normally visible.

Types of valve

- Fixed-pressure valve
- Programmable valve
- Valve with an anti-siphon or gravitational component

A programmable valve can usually be adjusted externally without another operation. Patients should tell healthcare professionals that they have a programmable shunt before MRI, as the setting may need to be checked afterwards.

What happens during VP shunt surgery?

- The operation is performed under general anaesthesia.
- Small incisions are made on the scalp and abdomen.
- A catheter is placed into a brain ventricle.
- The valve is positioned under the scalp.
- Tubing is tunnelled under the skin to the abdomen.
- The abdominal catheter is placed in the peritoneal cavity and the wounds are closed.

Potential benefits

- Relief of raised pressure, headache and vomiting
- Improved alertness or vision
- Improved walking and balance
- Improved bladder control in selected NPH patients
- Support of neurological development in children
- Prevention of further neurological deterioration

In normal-pressure hydrocephalus, walking often shows the earliest and greatest improvement. Bladder and cognitive symptoms may improve more gradually and may not recover completely.

Possible risks

- Shunt blockage or infection
- Disconnection, breakage or movement of the catheter
- Over-drainage or under-drainage of CSF
- Subdural fluid collection or haematoma
- Bleeding, seizure or CSF leakage
- Abdominal pain, infection or organ injury

- Need for valve adjustment
- Need for shunt revision or replacement
- Anaesthetic complications
- Very rarely, severe neurological injury or death

A shunt is a mechanical device and can malfunction at any time. Some patients require one or more shunt revisions during their lifetime.

Before surgery

- Medical and neurological assessment
- Blood tests
- CT or MRI review
- Anaesthetic assessment
- Review of medication and allergies
- Assessment for infection
- Additional tests depending on age and medical condition

Please tell the surgical team about blood-thinning medication, bleeding disorders, fever or infection, previous abdominal surgery, allergies, previous shunts or other neurosurgical implants, and possible pregnancy. Do not stop prescribed medication unless advised by the treating team. Follow all fasting instructions carefully.

After surgery

- Level of consciousness and pupil responses
- Movement and strength of the limbs
- Headache, nausea and vomiting
- Wound condition and temperature
- Fluid intake and urine output
- Signs of infection
- Improvement in the original symptoms

Children will also be observed for feeding, alertness, irritability and developmental behaviour. Pain relief and anti-nausea medication will be given when required. Mobilisation begins when it is safe.

Going home

The length of admission varies according to age, the procedure performed, the cause of hydrocephalus, recovery after anaesthesia, neurological condition and any complications.

Before discharge, the patient or family should understand:

- How to care for the wounds
- Which medicines to take
- Which activities to avoid
- How to recognise shunt malfunction or ETV failure
- When the next clinic appointment will occur
- Who to contact if there is a concern

Recovery at home

Wound care

- Keep wounds clean and dry as instructed.
- Do not apply creams, oils, powders or traditional preparations unless approved.
- Seek advice for increasing redness, swelling, pain, discharge, fluid leakage, wound separation or fever.

Activity

- Resume gentle walking and light activities gradually.
- Avoid heavy lifting, strenuous exercise and contact sports during early recovery.
- Avoid repeated pressing or rubbing over the shunt valve.
- Follow the surgeon's advice regarding swimming, school, work and sport.

Warning signs of shunt malfunction or ETV failure

Symptoms may develop gradually or very quickly. Previous symptoms of hydrocephalus may return in the same pattern as before surgery.

Babies

- Increasing head size
- Bulging or tense fontanelle
- Vomiting or poor feeding
- Irritability or excessive sleepiness
- Downward-looking eyes
- Seizure or reduced responsiveness
- Redness or swelling along the shunt pathway

Children and adults

- Increasing or severe headache
- Repeated vomiting
- Increasing drowsiness or confusion
- Irritability or personality change
- Blurred or double vision
- New walking difficulty, imbalance or weakness
- Seizure or loss of consciousness
- Return of previous hydrocephalus symptoms
- Redness, swelling or tenderness over the shunt
- Fluid leakage from a wound
- Abdominal pain or swelling

Do not wait for a routine appointment if shunt malfunction or ETV failure is suspected. Attend the Emergency Department immediately.

Signs of shunt infection

- Fever
- Increasing headache or vomiting
- Irritability, drowsiness or neck stiffness
- Redness or tenderness along the shunt tubing
- Wound discharge
- Abdominal pain
- Poor feeding in babies
- General deterioration

Long-term follow-up

- Neurological assessment
- Developmental review in children
- Head circumference measurement in babies
- Vision assessment

- School or learning support
- Walking and cognitive assessment in NPH
- CT or MRI when required
- Shunt valve checks and programmable valve adjustments
- Physiotherapy or rehabilitation when indicated

Patients and families should keep a record of the shunt type, valve model, programmable setting if applicable, date of insertion, previous revisions and treating hospital.

Important

Not every patient with enlarged ventricles requires surgery. The decision to perform ETV or insert a VP shunt depends on symptoms, imaging findings, the cause of hydrocephalus, age and the likelihood of benefit.

Neither ETV nor VP shunt surgery can guarantee complete recovery of neurological symptoms that were present before treatment. Always follow the individual advice provided by the neurosurgical team.