

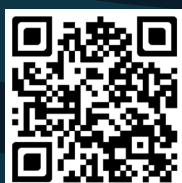
A CLINICAL REFERENCE FOR HEALTH CARE PROVIDERS

Pediatrician's Guide to **HYDROCEPHALUS**

Recognizing complications, supporting families,
and caring for the whole child.



Hydrocephalus
Association



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HYDROCEPHALUS ASSOCIATION

We are here to support you.

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What is Hydrocephalus?

Hydrocephalus is a condition in which cerebrospinal fluid (CSF) accumulates in the brain's ventricles, potentially increasing intracranial pressure. There is no cure. Treatment most commonly involves surgical placement of a shunt system to divert CSF from the brain to another part of the body, usually the abdomen. Some children may be treated with endoscopic third ventriculostomy (ETV), a surgical treatment that creates an alternative pathway for CSF flow and may eliminate the need for a shunt. Both shunts and ETVs can fail at any time and require prompt evaluation if symptoms of increased intracranial pressure occur.

SIGNS AND SYMPTOMS OF A MEDICAL COMPLICATION

It is important to be aware of potential medical complications related to the treatment of the child's hydrocephalus. Complications can appear gradually over time or suddenly, creating an emergency medical situation. If not recognized in a timely manner, a child could sustain brain damage.

Common Signs in a Child With Hydrocephalus

- ☐ Increased head size or rapid head growth
- ☐ Bulging fontanelle
- ☐ Poor feeding/loss of appetite
- ☐ Vomiting
- ☐ Headache
- ☐ Vision problems
- ☐ Irritability
- ☐ Tiredness
- ☐ Personality changes
- ☐ Loss of coordination or balance
- ☐ Fever
- ☐ Redness or swelling along the shunt tract

Early or Gradual Signs Noted by Caregivers and Teachers Over Ways or Week

- ☐ Decline in academic performance
- ☐ Changes in attention, focus, or engagement
- ☐ Difficulty with memory
- ☐ Decreased motivation
- ☐ Difficulty following directions
- ☐ Increased sensitivity (emotional, visual, or sound)
- ☐ Changes in feeding, engagement, or development (infants and toddlers)

Subtle, unexplained changes from baseline should always be taken seriously.

WHEN TO CONTACT NEUROSURGERY

Prompt neurosurgical evaluation is recommended if any of the following occur:

- ☐ Headaches, vomiting, lethargy, or irritability
- ☐ Vision changes
- ☐ Seizures
- ☐ Developmental or academic regression
- ☐ Fever with concern for shunt infection
- ☐ Swelling or redness along the shunt tract
- ☐ Changes in head circumference or neurologic exam

Caregiver concerns should always be taken seriously.

EVERY CHILD IS UNIQUE

Hydrocephalus presents differently in every child. This includes their symptoms, strengths, needs, and challenges.



Growing Up with Hydrocephalus

IMPACT ON DAILY LIVING

Children may experience **migraines and/or chronic headaches, vision problems, fatigue, ADHD, chronic pain, neck stiffness,** and **challenges with balance and/or coordination.** These challenges can impact school, social interactions, and overall daily functioning. Symptoms may also fluctuate depending on how the child is feeling and CSF drainage.

MENTAL HEALTH & SELF-IMAGE

Children and adolescents with hydrocephalus may experience **anxiety, depression, social challenges,** and **self-esteem concerns.** Routine screening and early referral to mental health providers can support emotional well-being, and open discussions about self-image and social experiences are important.

COGNITIVE, LEARNING, & BEHAVIORAL IMPACT

Daily life and academics will differ from child to child. Some children may thrive without interventions. Others may benefit from therapies, academic accommodations, or additional social and emotional support.

Commonly Affected Cognitive Areas

- ☐ Sustained attention
- ☐ Working memory
- ☐ Self-monitoring
- ☐ Problem-solving
- ☐ Initiation
- ☐ Organization
- ☐ Sequencing
- ☐ Transitioning
- ☐ Motor functioning
- ☐ Comprehension
- ☐ Developmental delays

What This May Look Like

- ☐ Forgetfulness or difficulty with routines
- ☐ Trouble following directions
- ☐ Inconsistent academic performance
- ☐ Difficulty starting or completing tasks
- ☐ Rigidity in thinking
- ☐ Difficulty with transitions
- ☐ Trouble retaining information taught (short-term memory)
- ☐ Inability or confusion on how to start a task or worksheet
- ☐ Getting lost frequently or easily, both physically and academically
- ☐ Deficits in fine motor and gross motor skills
- ☐ Conversing excessively and freely, but lacking depth in conversation
- ☐ Difficulty making or keeping friends

How This May Present by Age

In **infants and toddlers**, this may present as developmental delays, feeding challenges, or reduced engagement. In **school-age children**, it may appear as learning, attention, and academic challenges. In **adolescents**, difficulties may include executive functioning, independence, and planning.

Subtle Changes Matter

Monitor for subtle changes in cognition, behavior, or daily functioning, as even gradual changes from baseline may be clinically significant.

NEUROPSYCHOLOGY & SCHOOL SUPPORT

Referral to neuropsychology is recommended for **learning concerns, behavioral challenges,** or **academic decline.** In **infants and toddlers**, the focus is on developmental monitoring and early intervention, while in **school-aged children**, this often includes formal neuropsychological testing, and in adolescents, support may focus on accommodations and transition planning. **Results can guide IEPs and 504 Plans,** as well as targeted supports and accommodations.

SCHOOL, SPORTS, & DAILY ACTIVITIES

Most children can fully participate in school and activities. Encouraging normal participation, when appropriate, is important. Helmets should be used for activities where there is a risk of head injury, and neurosurgical guidance should be followed for contact sports.

MAGNETS SAFETY

Devices with magnets should be kept at least two inches away from programmable shunt valves. Examples include tablets and covers, electronic devices, and toys with magnets. This is especially important in school and everyday environments where these items are commonly used.

Managing Your Patients

CO-OCCURRING CONDITIONS

Hydrocephalus can be present with these conditions:

- ☐ Spina Bifida
- ☐ Cerebral Palsy
- ☐ Seizures/Epilepsy
- ☐ Brain Tumor
- ☐ Dandy Walker Malformation
- ☐ Chiari Malformation
- ☐ Autism

IMMUNIZATIONS & ROUTINE CARE

Routine vaccinations and dental care are safe for children with hydrocephalus. Antibiotic prophylaxis is not required for dental procedures.

CONSTIPATION & SHUNT FUNCTION

Constipation can increase intra-abdominal pressure and contribute to distal shunt malfunction. **Encouraging hydration and increasing dietary fiber** can help, and stool softeners may be used when appropriate. It is also important to monitor for worsening neurologic symptoms.

HELPFUL TIPS FOR MANAGING YOUR PATIENTS

- ☐ Monitor for signs of shunt malfunction, ETV failure, or infection
- ☐ Take caregiver concerns seriously
- ☐ Watch for subtle changes in behavior or function
- ☐ Monitor development, learning, and emotional well-being
- ☐ Support referrals and school accommodations
- ☐ Screen for co-occurring conditions
- ☐ Monitor head circumference and watch for changes from the child's growth curve.
- ☐ Encourage routine eye exams to help identify signs of increased intracranial pressure.

COORDINATED CARE

Children with hydrocephalus may be followed by:

- ☐ Pediatric Neurosurgery
- ☐ Pediatric Neurology
- ☐ Endocrinology
- ☐ Rehabilitation therapies (PT, OT, speech)
- ☐ Neuro-ophthalmology or ophthalmology
- ☐ Neuropsychology

IMAGING CONSIDERATIONS

When ordering an MRI, always document the presence and type of shunt and valve. Be aware of **programmable valves**, as post-MRI reprogramming may be required.

PRECOCIOUS PUBERTY

Children with hydrocephalus may be at increased risk for precocious puberty due to hypothalamic or pituitary involvement.

Signs to Watch For: Early breast development or testicular enlargement, rapid growth, early onset of menstruation, and behavioral or mood changes may be observed. Referral to pediatric endocrinology is recommended if concerns arise.

TRANSITION PLANNING

Begin preparing early for transition to adult care by teaching self-management skills and helping patients understand their shunt and symptoms. HydroAssist® can support symptom tracking and communication with providers.



HA is Here to Support You.

As a healthcare provider, you play a critical role in guiding patients through the complexities of hydrocephalus. Visit our resources for providers.

RESOURCES
FOR HEALTHCARE
PROVIDERS

