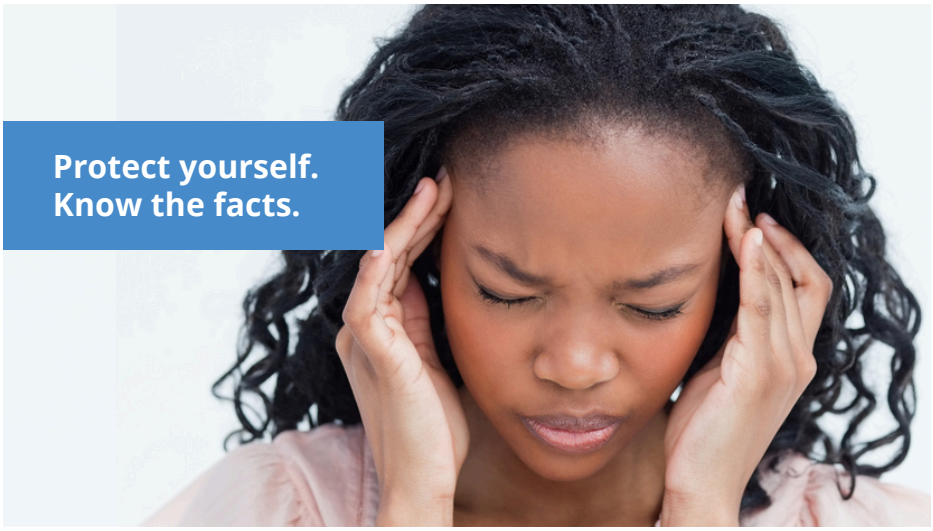
HYDROCEPHALUS CANADA

Championing Spina Bifida & Hydrocephalus Communities

Understanding

Hydrocephalus



Protecting Your Control Centre

Your brain is the most important organ in your body. Containing billions of cells, your brain constantly shares messages through trillions of pathways so you can do all that you do. It controls essentially everything from coordinating your movements and thoughts, actions and reactions, feelings and memories, to speaking, breathing and sleeping.

Your brain is protected by your skull, three layers of cushiony membranes, and an essential clear liquid called cerebrospinal fluid, or CSF. When CSF flows freely, it delivers important nutrients and chemicals from the blood, removes waste products, and provides a protective cushion for your brain.

What is Hydrocephalus?

When too much CSF accumulates, it causes a chronic neurological condition called hydrocephalus. This condition can cause serious damage to your brain and its ability to process information.

Currently, there is no cure for hydrocephalus. In some instances, treatment may not be necessary. However, those individuals are carefully monitored to detect changes that may need attention.

What Causes Hydrocephalus?

CSF is continuously produced inside the four ventricles, or chambers, of the brain. Normally, the fluid flows from one ventricle to the next before exiting the brain and being absorbed.

However, when the amount of CSF increases because flow to the outside of the brain is interrupted or blocked, the ventricles swell and put pressure on the brain.

Challenges Associated with Hydrocephalus

How hydrocephalus affects someone differs from person to person. The resulting challenges depend on:

- what caused the hydrocephalus
- how long the condition has been present
- if there is any brain damage, and how extensive the damage is
- if there are any other associated complications
- what treatment was provided

Because it affects the brain, hydrocephalus can cause a wide range of symptoms ranging from difficulty breathing, poor muscle coordination and mobility challenges to problems with vision, fatigue, headaches, seizures, incontinence and hormonal imbalances.

Challenges with learning, social skills, memory and problem solving are among the most common complications of hydrocephalus. Individuals with the condition may require modifications to the way they are taught, especially when it comes to learning new things at school or work.

Does Hydrocephalus Cause Brain Damage?

Hydrocephalus is a very serious condition that, in most cases, requires medical attention. In some instances, if left untreated, it can cause permanent brain damage. For some people, delaying treatment can cause lasting injury to the brain, so getting an accurate diagnosis and the appropriate treatment as soon as possible is critical.

Types of Hydrocephalus

Excess CSF present in a newborn baby is called **congenital hydrocephalus.** It may be caused by genetic conditions or influences that affect the development of the fetus while it is still in the mother's womb. Congenital hydrocephalus may be caused by blockages, cysts or spina bifida. As many as 90% of people with an open neural tube defect (ie. spina bifida) also have hydrocephalus.

When hydrocephalus develops after birth, it is called **acquired hydrocephalus**. Babies born prematurely are at a higher risk of developing the condition but this can happen at any age. Acquired hydrocephalus can also develop after a head injury, stroke, brain tumor, meningitis or other factors that we can't explain. It is important that we all learn to watch for symptoms of hydrocephalus in people of any age and seek medical attention when we think that someone may have the condition or a shunt malfunction.

Symptoms in Infants with Hydrocephalus:

- head enlargement
- fontanel (soft spot) bulging when baby is upright and quiet
- prominent scalp veins appearing unnaturally full
- vomiting (especially projectile)
- irritability, change in personality and sleepiness
- fever
- seizures
- downward deviation of the eyes (sunset eyes)

Symptoms in Toddlers with Hydrocephalus:

- head enlargement
- headaches and seizures
- vomiting (especially projectile) irritability, change in personality, sleepiness
- unable to concentrate
- fever
- lethargy/listlessness
- blurred or double vision
- loss of previous cognitive or motor abilities
- delayed development in walking and talking
- poor coordination or balance

Symptoms in Children with Hydrocephalus:

- headaches and seizures
- vomiting (especially projectile)
- irritability, change in personality
- tiredness, difficulty waking up from sleep or staying awake
- blurred or double vision
- loss of coordination or balance
- impairment of cognitive or motor performance
- decline in academic or work performance

Symptoms in Young and Middle-Aged Adults with Hydrocephalus:

- chronic headaches not relieved by pain medication
- visual disturbances
- fainting
- vomiting
- incontinence
- gait disturbances: clumsiness, difficulty walking on uneven surfaces and stairs
- cognitive problems: becoming dependent on lists, declining in academic or work performance

Symptoms in older adults:

When diagnosed in older adults, hydrocephalus typically results from either high pressure in the skull or a condition called idiopathic normal pressure hydrocephalus (iNPH) which is a reversible form of dementia (see next page).

NOTE: headaches experienced by toddlers, children and adults that are at the front and sides of the head and are generally severe upon waking in the morning, or following a nap, and may be relieved by sitting up.

If you or someone you know is experiencing symptoms related to hydrocephalus, seek medical attention as the condition can become life-threatening.

Treatment of Hydrocephalus

Treatment usually involves surgically implanting a shunt system. These systems include:

• **a catheter** (a flexible tube made of sturdy plastic) which diverts excess CSF away from the brain. One end is placed inside a ventricle and the other ends in another area of the body where the CSF can drain and be absorbed such as the belly, heart or lungs.

• **a one-way valve** that controls the rate at which the CSF drains.

While shunts can provide relief, they can also be problematic. They tend to be subject to mechanical failure, infection and blockages. Catheters sometimes need to be adjusted or replaced. Some people will have dozens of brain surgeries to manage shunt challenges. 40% of shunts placed in children fail.

Balancing the Flow of CSF is Critical

In some instances, if too much CSF is released (over-draining), the ventricles can collapse and cause damage to blood vessels.

In other instances, if too little CSF is released (under-draining), hydrocephalus symptoms may continue or reoccur. Over-drainage and under-drainage of CSF can be managed by adjusting the drainage pressure of the shunt valve. If the shunt has an adjustable pressure valve these changes can be made by placing a special magnet on the scalp over the valve to avoid brain surgeries.

Instead of a shunt, some people can undergo a procedure called endoscopic third ventriculostomy (ETV). ETV surgery uses a very small camera called a neuroendoscope to see inside the ventricles and create a small hole in the third ventricle. This hole allows CSF to flow out of the blocked ventricle.

Can hydrocephalus be cured?

Hydrocephalus is a chronic condition. That means there is no cure and, in most cases, the person affected will live with the condition for life. If hydrocephalus develops because of a brain tumour, sometimes removing the tumour will allow CSF flow to return to normal.

For most people, hydrocephalus is treated with a shunt. When treatment is successful, the ability to think and a person's lifespan can be similar to those of the general population.

iNPH |
A potentially reversible form of Dementia

iNPH, or Idiopathic Normal Pressure Hydrocephalus, usually affects those over the age of 65. Those impacted tend to have a triad of symptoms which include challenges with walking, memory and urinary incontinence.

The greatest challenges with iNPH are getting an early and accurate diagnosis and the proper treatment. If treated early, iNPH and its debilitating symptoms may be reversed. Unfortunately, too many people with iNPH are not being diagnosed - or are misdiagnosed with diseases associated with aging, such as Alzheimer's, dementia or Parkinson's disease.

As many as 30,000 Canadians may be living with undiagnosed iNPH.

hydrocephalus.ca

About Hydrocephalus Canada

Our goal is to empower individuals impacted by hydrocephalus to experience the best life possible. We believe everyone affected by hydrocephalus:

- has the right to our attention, compassion and commitment
- has value and deserves to be treated with dignity
- requires and deserves access to safe, effective care
- benefits from, and offers benefit to, collaborative communities
- has the responsibility to help everyone understand hydrocephalus

Our Current Efforts are Focused on:

- creating a Canadian Hydrocephalus Strategy
- increasing awareness of hydrocephalus
- advocating for solutions to support prevention; early, accurate diagnosis; access to appropriate treatment; optimal outcomes; and, ultimately a cure
- developing education and support tools for patients, caregivers, healthcare professionals, policy makers and media
- establishing supportive communities that encourage inclusive, proactive conversations and activities, and
- funding meaningful, breakthrough research

HYDROCEPHALUS CANADA
Championing Spina Bifida & Hydrocephalus Communities

Call us at 416.214.1056 or
Canada wide tollfree 800.387.1575
Email info@hydrocephalus.ca

Charitable Reg. #10799 9310 RR0001

HYDROCEPHALUS CANADA

Championing Spina Bifida & Hydrocephalus Communities

Learn how you can get involved. Contact us to help make a change.

Call us at 416.214.1056 or
Canada wide tollfree 800.387.1575
Email info@hydrocephalus.ca
Web hydrocephalus.ca