# HYDROCEPHALUS CANADA

Championing Spina Bifida & Hydrocephalus Communities

# 

Idiopathic Normal Pressure Hydrocephalus



Protect yourself. Know the facts.

It is amazing what that shunt valve can do! Within two days, he was walking through the halls in the hospital and lifting his feet right up off the floor. His balance was great and he didn't lean to one side anymore.

-- A quote from Lorraine about her husband, Frank who had shunt surgery for iNPH.

#### What if we could reverse dementia?

Idiopathic Normal Pressure Hydrocephalus (iNPH) affects the brain and is considered to be a potentially reversible form of dementia. It occurs when too much cerebrospinal fluid (CSF) accumulates in ventricles (chambers) of the brain and can cause serious injury. Sometimes, this condition occurs with little or no increase in intercranial pressure.

When CSF flows freely, it delivers important nutrients and chemicals from the blood to the brain, removes waste products, and provides a protective cushion. However, too much CSF can cause serious damage and significantly impact our ability to move, think and function normally.

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 - and are not getting the treatment they need. A delayed or incorrect diagnosis can be devastating and cause irreversible damage to the brain. iNPH affects more than 1 in 200 adults over the age of 55. The cause is usually unknown.

As many as 70,000 Canadians may be living with undiagnosed iNPH. This means thousands of people, who have much to live for, may be unnecessarily losing their independence, time with loved ones and admitted to long term care facilities prematurely.

## **Recognize the Signs of iNPH**

Older adults are most-often affected by iNPH. They typically suffer from three symptoms associated with mobility, memory and bladder control.

#### **Bladder Control**

Loss of bladder control can range from urinary frequency and urgency in mild cases to complete loss of control in severe cases.

## Mobility

The ability to walk properly is usually the first and most pronounced sign of iNPH. Those affected may walk with their feet spread widely apart and take short, shuffling and slow steps. People with iNPH will say it feels like their feet are heavy or stuck to the floor. They may have trouble picking up their feet and be more likely to trip or fall.

#### Memory

When someone loses their interest in daily activities, becomes forgetful, has difficulty performing routine tasks, and experiences short-term memory loss, these are often assumed to be signs of aging. However, in some cases, these challenges may be caused by iNPH and need to be investigated.

# The Proper Treatment Can Give You Back Your Life

The good news is that when iNPH is diagnosed early and managed properly, it is possible to stop the damages caused by the condition and regain function. In some cases, symptoms that resemble dementia and are robbing people of their quality of life can even be reversed.

Specific testing for iNPH can only be done by medical or surgical professionals with specialist skills. If enlarged ventricles are identified, referral to a neurologist can be made by your family doctor.

The neurologist may do an exam that includes evaluation of how you walk, process information, speak and if you have any bladder issues. They may also order an MRI, CT scan or test related to your cerebral spinal fluid (CSF) such as a lumbar puncture (spinal tap).

Neurosurgeons may recommend a shunt as treatment for iNPH. Shunts help redirect cerebrospinal fluid (CSF) from the brain to other parts of the body. The goal of this procedure is to have the brain's ventricles return to a more normal size and relieve symptoms of normal pressure hydrocephalus.



# Remember....

The good news is that when iNPH is diagnosed early and managed properly, it is possible to protect those who are being affected. In some cases, symptoms that are robbing people of the quality of life they deserve can even be reversed.

Speak with your doctor as soon as possible if you, or someone you love, is experiencing challenges with:

- memory
- mobility and
- bladder control

If you, or someone you love, is experiencing these three issues, ask your doctor if iNPH could be the cause and if testing for iNPH is appropriate. Your doctor can start the process by requesting a CT scan or MRI of the brain.

# Get the Help you Need

If you suspect iNPH, make an appointment to see your doctor and take this information sheet with you. An early diagnosis can be the difference between an active, independent life and one full of challenges and disabilities.

I started to feel like I was walking on gum, like I could not lift and place my feet properly. I was shuffling along. Over time, I required a walker and then a wheelchair. I started having problems with balance, fatigue, incontinence, increased irritability and a noticeable decline in my ability to think and process information.

-- Gilda, diagnosed with iNPH at 62

# 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



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