





You are NOT alone.

Understanding Hydrocephalus

A Guide for Adults

Hydrocephalus Association



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WE ARE HERE TO HELP



We provide one-on-one support and can connect you with trained peer support volunteers.

It's common to feel overwhelmed with a new diagnosis of hydrocephalus or when you're living with the condition.

Find answers on our website!

- Newly diagnosed resources
- Living with Hydrocephalus section for every age and stage of life
- Physicians' Directory
- Explore tha Hydrocephalus Resource Library for trusted information, tools and resources



info@hydroassoc.org
for support, resources, and answers to your questions.

(888) 598-3789
to speak directly to a staff member.

@hydroassoc

Dear Reader,

Welcome to our dedicated resource aimed at helping you understand hydrocephalus and find the support you need. Whether you're just beginning to grasp the complexities of the condition or have been living with it for some time, we're here to assist you along this journey.

Living with hydrocephalus can evoke a myriad of emotions - from initial confusion and frustration to eventual relief and acceptance. It's entirely normal to feel overwhelmed, but it's important to know that seeking support is a positive step forward. Rest assured, we're here for you every step of the way.

Within this guide, our goal is to offer clarity and support, addressing your questions and concerns with warmth and empathy. Whether you're the individual navigating hydrocephalus, a caring partner, a concerned relative, or a supportive friend, this resource is tailored to meet your needs.

Through personalized assistance and connections with peers, volunteers, and medical professionals, we endeavor to empower and uplift those affected by hydrocephalus.

Always remember, you are not alone. Together, let's navigate this journey with strength, resilience, and hope.

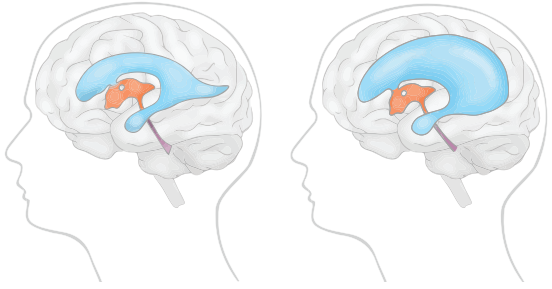
Hydrocephalus Association

What is Hydrocephalus?

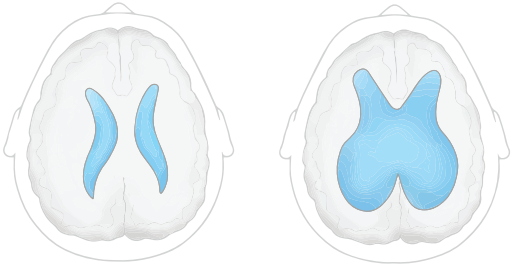
Hydrocephalus comes from the Greek words hydro meaning water and cephalus meaning head.

Hydrocephalus is a condition in which there is a build-up of cerebrospinal fluid (CSF) within cavities in the brain known as ventricles. Hydrocephalus happens when there is an imbalance between the amount of CSF produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and increases the pressure inside the head.

Most of the CSF is produced in the ventricles and the choroid plexus. It then circulates through the ventricular system and gets absorbed into the bloodstream. This fluid is in constant circulation and has many important jobs, including surrounding and protecting the brain and spinal cord from injury and harm. Cerebrospinal fluid also contains nutrients and proteins necessary for the nourishment and normal function of the brain and carries waste products away from surrounding tissues.

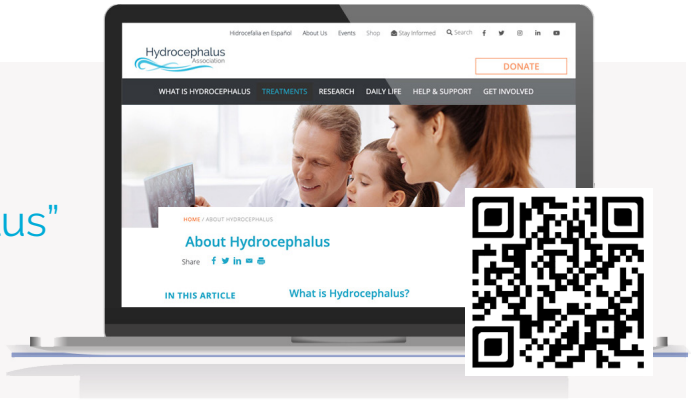


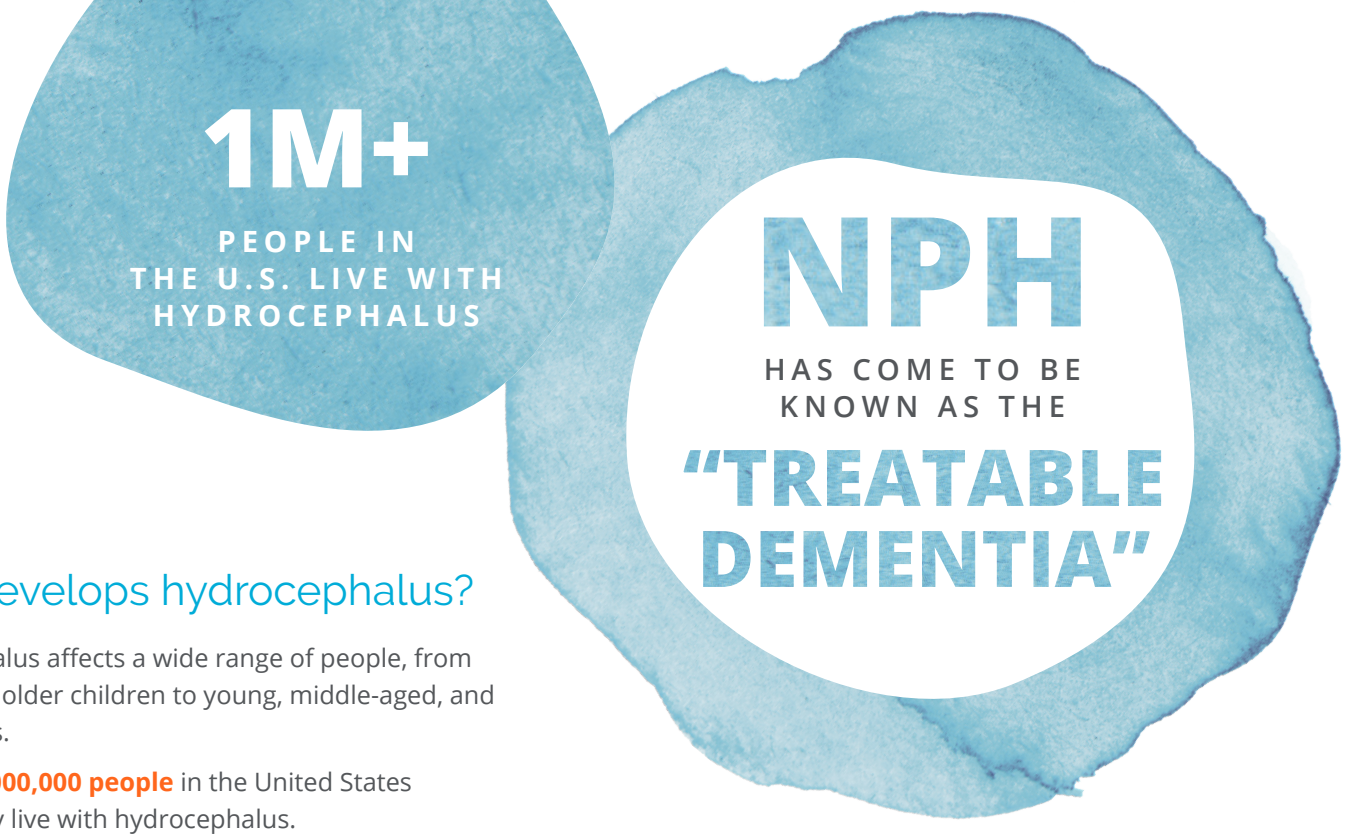
Normal Ventricles | Enlarged Ventricles



Normal Ventricles | Enlarged Ventricles

Want more details?
Visit our "About Hydrocephalus" page on our website.





Who develops hydrocephalus?

Hydrocephalus affects a wide range of people, from infants and older children to young, middle-aged, and older adults.

- **Over 1,000,000 people** in the United States currently live with hydrocephalus.
- In the United States, **one out of 770 babies** develop hydrocephalus each year.
- There are **more adults** living with hydrocephalus than children.

There is no cure for hydrocephalus, but it can be treated. We are here to support you throughout this journey.

What causes hydrocephalus?

Hydrocephalus can develop for a variety of reasons. You can be born with it or acquire it from a brain injury, infection, or tumor. You can also develop hydrocephalus as part of another medical condition. Visit our website to learn more about the types and causes of hydrocephalus.

How is hydrocephalus and normal pressure hydrocephalus (NPH) diagnosed in adults?

- CT Scan
- MRI
- Lumbar puncture (spinal tap)
- Continuous lumbar drainage
- Intracranial pressure (ICP) monitoring
- Neuropsychological testing
- Gait Assessment

What is Normal Pressure Hydrocephalus (NPH)?

Normal pressure hydrocephalus (NPH) is an accumulation of cerebrospinal fluid (CSF) that causes the ventricles in the brain to become enlarged, sometimes with little or no increase in intracranial pressure (ICP). The name for this condition originates from observations described in Dr. Salomon Hakim's 1964 thesis.

What are the symptoms?

NPH is typically characterized by a triad of symptoms:

- **Gait Disturbance**
  Difficulty walking or making turns, feeling like it's hard to take the first step, balance issues, falling.
- **Cognitive Impairment**
  Problems organizing or planning tasks, hard time multitasking, trouble listening or paying attention, short-term memory issues, feeling withdrawn, talking less, poor handwriting, trouble with simple math calculations.
- **Impaired Bladder Control**
  Trouble "holding it", not able to get to the bathroom fast enough, experiencing accidents.

These three symptoms may not all occur at the same time. They can also emerge at different stages of the disease with varying levels of severity.

Who develops normal pressure hydrocephalus?

- NPH is most commonly seen in **adults aged 60 or over.**
- It is estimated that **more than 800,000 older Americans have NPH,** but fewer than 20% receive an appropriate diagnosis.

Without appropriate diagnostic testing, NPH is often misdiagnosed as Alzheimer's disease or Parkinson's disease, or the symptoms are attributed to the aging process.

What causes normal pressure hydrocephalus?

- **Idiopathic Normal Pressure Hydrocephalus**
  Most NPH diagnoses are considered idiopathic, meaning that the cause is unknown. It is also called primary NPH or idiopathic NPH.
- **Secondary Normal Pressure Hydrocephalus**
  When NPH results from a known cause, it is called secondary NPH. It can be diagnosed as the result of various factors such as head injury, cranial surgery, subarachnoid hemorrhage (bleeding in the brain), tumors or cysts, as well as subdural hematomas, bleeding during surgery, meningitis, and other brain infections.



8
SURGERIES

GARY

DIAGNOSED AT AGE 55

normal pressure hydrocephalus

"I want people to know that normal pressure hydrocephalus is a treatable condition and treatment can improve your life."

How is Hydrocephalus Treated?

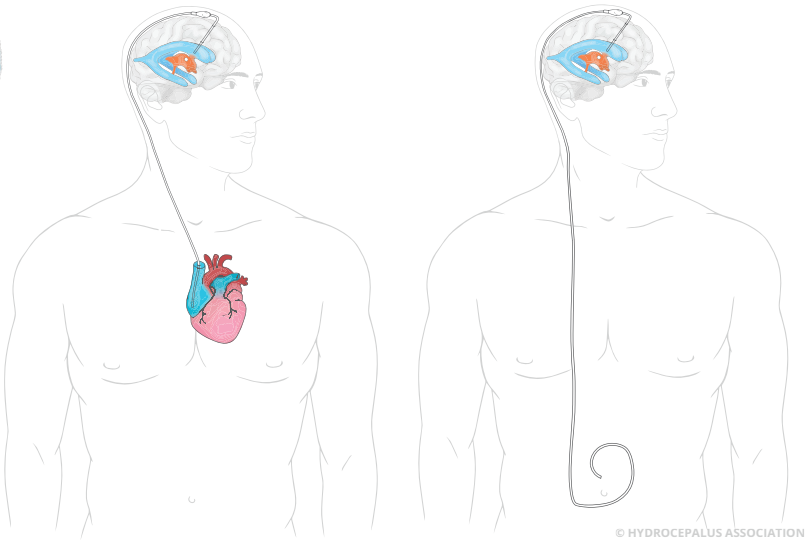
The only treatment options require brain surgery. There are three forms of surgical treatment used to manage hydrocephalus.



1 Shunt System

The most common way to treat hydrocephalus is by surgically implanting a device called a shunt.

A shunt is a flexible tube placed into the ventricular system of the brain. Its purpose is to redirect the flow of cerebrospinal fluid (CSF) to another part of the body, most often the abdominal cavity, where it can be absorbed. The shunt system has a valve that maintains CSF at normal pressure within the ventricles.



Adult with VA Shunt

Adult with VP Shunt

2 Endoscopic Third Ventriculostomy (ETV)

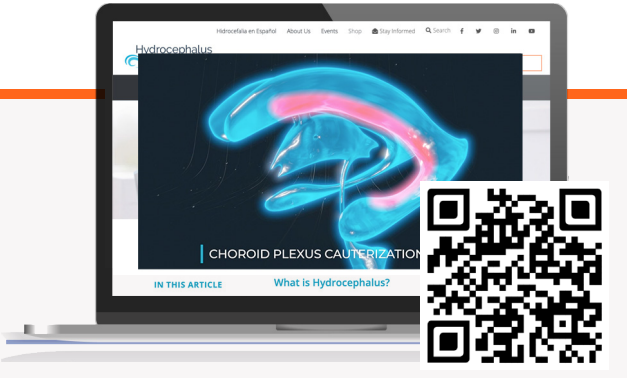
A second surgical treatment option is a procedure called Endoscopic Third Ventriculostomy (ETV). An endoscope is used to puncture a hole in the membrane on the floor of the third ventricle to open a natural pathway. This allows CSF to flow out of the ventricles and around the brain, bypassing a blockage. An ETV is an alternative to shunting for some cases of obstructive hydrocephalus and may be useful in other cases as well. This treatment option is not suitable for everyone, and it is typically used for patients over the age of two.

3 Choroid Plexus Cauterization (ETV/CPC)

The third treatment option involves the addition of Choroid Plexus Cauterization (CPC) with ETV. The choroid plexus is a network of vessels in the ventricles of the brain where CSF is produced. The neurosurgeon uses a device to burn, or cauterize, choroid plexus tissue to reduce the amount of fluid being introduced into the ventricles. The fluid then passes through the opening made during the ETV and into the space surrounding the surface of the brain. This treatment is primarily used in children under two.

Your neurosurgeon should be able to provide you with a reliable estimate of the chances of success in your specific case before an ETV or ETV/CPC operation.





Watch the different surgical treatments for hydrocephalus in our animated video.

Signs and Symptoms of a Complication

Hydrocephalus can be treated with surgery, but the treatment options can include complications.

Understanding the signs and symptoms of a shunt failure or the closure of an ETV is critical. Symptoms can vary considerably from person to person, but within an individual, repeated failures often show similar signs. If there is a sudden problem with the shunt or ETV, symptoms can appear quickly and may be life-threatening, requiring immediate medical attention. As you become more familiar with potential complications, you'll better recognize and understand possible issues in yourself or your loved one. Trust your instincts to guide you in making the best decisions.

Adults

- Headaches
- Nausea and/or vomiting
- Excessive tiredness
- Difficulty waking up or staying awake
- Vision problems
- Irritability
- Changes in behavior or personality
- Decline in academic or job performance
- Loss of coordination or balance
- Difficulty concentrating or focusing
- Signs of infection, such as fever, redness, or swelling at the shunt site

Older Adults with NPH

- Mild dementia (forgetfulness, confusion, trouble thinking or focusing)
- Loss of bladder control (trouble "holding it")
- Difficulty walking
- Poor balance
- Falling
- Feeling withdrawn or talking less
- Mood changes
- Return of pre-treatment problems
- Signs of infection, such as fever, redness, or swelling at the shunt site



AMY

DIAGNOSED AT AGE 17

acquired hydrocephalus

31
SURGERIES

"You never know how strong you are until you are faced with really challenging circumstances, and see yourself come through those things over and over again. I think it makes you stronger every time, and gives you a different perspective on what is actually difficult in life."

5 Steps to Live and Thrive

Navigating life with hydrocephalus can present its challenges, but with the right knowledge and support, you can lead a fulfilling life.

Below are five essential steps aimed at empowering you to maximize your well-being with hydrocephalus. From education and finding the right medical team to understanding treatment options and building a strong support network, these steps will guide you towards resilience and well-being. Let's embark on this journey together, equipped with the tools and resources to conquer any obstacles along the way.

1 Educate Yourself

Empower yourself and your loved ones by learning about hydrocephalus, its symptoms, and treatment options through our wealth of educational resources.

2 Find Your Doctor

Identify experienced specialists and prepare for appointments using our resources to ensure you receive the best care possible.

3 Understand Your Treatment

Familiarize yourself with available treatment options to make informed decisions in collaboration with your medical team.

4 Navigate Daily Life

Gain insights from articles, videos, webinars, and events to effectively manage hydrocephalus in various aspects of your life.

5 Build a Support Network

A support network can provide encouragement and understanding as you navigate this journey. We have online and in-person groups around the country to connect you with others who understand your experiences.

Want more details? All the information you need is on our website.



ALEX

DIAGNOSED AT AGE 28

obstructive hydrocephalus, inoperable brain tumor

3
SURGERIES

"Hydrocephalus has made me face some of my toughest fears. It has shown me how adaptable I am and also how optimistic I can be even under the most dire circumstances. It has also made me more compassionate, empathetic, humble, and giving."

Adult Resources

We're here to help you live live your best life.

Online Resources

Discover resources on our website, including articles and videos, covering topics such as traveling, employment, relationships, headaches, and more.

HydroAssist®

Download our mobile app to manage your treatment history, record changes, maintain a symptom diary, securely store scans, and invite loved ones to view or manage your account.

Online Support Groups

Meet other adults in one of our online communities, including virtual meetings for those in their 20s, 30s, women 40 and older, and men breaking barriers.

HydrocephalusCONNECT

Get matched by email or phone with a trained volunteer who has walked a similar path and is ready to listen to your concerns and share reliable information to answer your questions.

Hydrocephalus Stories

Explore our library of stories, written firsthand by individuals living with the condition.

National Conferences: HA CONNECT

Immerse yourself in the power of connection, where you can engage with peers and experts in sessions that are designed to provide resources, support, and an inclusive environment.

Ask the Expert Video Series

Gain expert guidance from leading medical professionals, providing you with knowledge and in-depth answers to common questions.

Webinars

Join experts to stay up-to-date with the latest topics and developments in hydrocephalus.

Research

Your story matters. Share your unique journey with scientists engaged in clinical trials and gathering insights from our patient registry, HAPPIER. Get involved and help move research forward.



MERLIN

1 SURGERY

DIAGNOSED AT AGE 58

normal pressure hydrocephalus

"Life is for living and I try to live my best life on a daily basis. My mantra is *Strength, Resilience and Triumph.*"

NPH Resources

We're here to help you live your best life.

Online Resources

Explore a range of resources on our website, including medical information, articles, and videos that address treatment options, related conditions, rehabilitation strategies, and more.

HydroAssist®

Download our mobile app to manage your treatment history, record changes, maintain a symptom diary, securely store scans, and invite loved ones to view or manage your account.

Online Support Groups

Join our online community and virtual meetings to connect with peers in an inclusive space, sharing experiences and providing support.

HydrocephalusCONNECT

Get matched by email or phone with a trained volunteer who has walked a similar path and is ready to listen to your concerns and share reliable information to answer your questions.

Hydrocephalus Stories

Explore our library of hydrocephalus stories, written firsthand by individuals living with NPH and their loved ones.

National Conferences: HA CONNECT

Immerse yourself in the power of connection at HA CONNECT, where you can engage with peers and experts in sessions that are designed to provide resources, support, and a nurturing environment.

Ask the Expert Video Series

Gain expert guidance on NPH from leading medical professionals, providing you with knowledge and in-depth answers to common questions.

Webinars

Stay up-to-date with the latest topics and developments in NPH through our webinars.

Research

Share your unique journey with scientists engaged in clinical trials and gathering insights from our Patient Registry, HAPPIER. You can have a significant impact in driving progress in research and bringing hope to the hydrocephalus community.



ALEX

DIAGNOSED AT SIX MONTHS

congenital hydrocephalus

7
SURGERIES

"Being a part of the Hydrocephalus Association and getting the opportunity to meet new families and tell my story gives me hope that we are getting closer to finding a cure. I look to inspire new members and simultaneously expand my support network."

About HA

The Hydrocephalus Association (HA) was founded in 1983 by parents of children with hydrocephalus. At a time when there was little to no information about the condition, we provided support services and educational resources to individuals and their families. Today we have grown into a national organization and have expanded to include four program areas: support, education, research, and advocacy.

Support and Education

Our team includes staff and volunteers with extensive knowledge and personal experiences with the condition. We provide invaluable assistance and guidance for both people who are newly diagnosed and those who have been living with hydrocephalus. We have a dedicated Medical Advisory Board of clinicians and scientists who advise on the creation of our publications and programs. We are fully committed to providing accurate and trusted information and supporting you and your family every step of the way. Through our resources, events, and support services, we aim to connect you with a strong, supportive community of peers who understand your experiences. Count on us to be there for you as you navigate and manage your condition.

Advocacy

Our Hydrocephalus Action Network (HAN) empowers our community to assure that the federal government is investing adequate funds to support hydrocephalus research for improved treatments and cures as well as appropriate programs that support those affected with hydrocephalus, particularly around healthcare, education, and labor issues.

Research

Our Research Program funds innovative, high-impact research to improve hydrocephalus treatments and to understand root causes. We are the largest and most prominent private funder of hydrocephalus research in the country and support two multi-hospital clinical research networks, the pediatric-focused Hydrocephalus Clinical Research Network (HCRN) and the Adult HCRN (AHCRN), as well as a basic science network, the HA Network for Discovery Science (HANDS), and the Hydrocephalus Association Patient-Powered Interactive Engagement Registry (HAPPIER). Through collaboration with industry, scientists, engineers, and clinicians, we advance treatments, support new devices and drugs coming to market, enhance clinical care, and bridge the gap between basic and clinical science. Since starting our Research Program in 2009, we have supported research to decrease shunt infection rates, 18 drug therapies in various stages of testing, and 2 new patents for drugs. Our research is driving change and creating a better future for individuals with hydrocephalus.

Hydrocephalus Association



TRACY

DIAGNOSED AT AGE 23

non-communicating hydrocephalus

1
SURGERY

"My extremely positive result after ETV surgery has made me want to advocate for and make a difference for others with the condition as well as anyone who faces obstacles in their life."

Voices from Our Community

DOROTHY

DIAGNOSED AT AGE 76 / *normal pressure hydrocephalus*

"NPH has given me a different perspective on life, each day is appreciated. One of my main purposes in life is to advocate for the awareness of NPH. If even one person can avoid what we endured, it's worth time and effort."

1 SURGERY





6 SURGERIES

APARNA

DIAGNOSED AT BIRTH / *congenital hydrocephalus, aqueductal stenosis*

"As someone who has benefited greatly from scientific innovation and as a clinical researcher myself, I have seen the impact that research can have on the lives of patients. Being involved in research and reading about advancements in the field of medicine keeps me hopeful that a cure for hydrocephalus can be found."

3 SURGERIES



JAMES

DIAGNOSED AT AGE 28 / *acquired hydrocephalus, TBI*

"The biggest piece of advice I would give to someone who has been newly diagnosed is to pay attention to your body. Pay attention to what doesn't feel right and get it addressed with your doctor as soon as possible. On the flip side, try not to allow yourself to get too paranoid if at all possible and continue to live your life and do what you enjoy."



2 SURGERIES

MARIO

DIAGNOSED AT AGE 71 / *normal pressure hydrocephalus*

"The advice I would give to someone who is newly diagnosed is to be assertive, ask questions, and get a second opinion if you are in doubt."



20 SURGERIES

SIERRA

DIAGNOSED IN UTERO / *congenital hydrocephalus, spina bifida*

"The advice I would give to someone newly diagnosed is, to do your research, understand as much as you can about your condition, and never let it stop you from living your dreams."



1 SURGERY

PETER

DIAGNOSED AT AGE 65 / *normal pressure hydrocephalus*

"I do have a different perspective on my life and my family's lives. I pay much more attention to my health and the health of others. After speaking with many people over the last thirteen years who have been diagnosed with NPH, I have come to realize how important it is to keep my body and mind in the best shape possible."



5
SURGERIES

LIAN

DIAGNOSED AT 5 WEEKS / *congenital hydrocephalus, preemie*

"We are our own healers. If you can bring even just one small shift into your experience, you have the opportunity to change your life."

15
SURGERIES



KEVIN

DIAGNOSED AT BIRTH / *congenital hydrocephalus*

"Helping others navigate hydrocephalus helps me guide my own journey towards finding purpose; whether that be to help find a cure for hydrocephalus or build the best community of compassionate warriors."



18
SURGERIES

JAMIE

DIAGNOSED AT 4 MONTHS / *congenital hydrocephalus*

"Living with hydrocephalus has had its challenges, disappointments, and setbacks. But it has also introduced me to an amazing community of dedicated and resilient people, including fellow patients, physicians, and researchers. This community brings me so much hope for the future of hydrocephalus care. Most of all they remind me that none of us are alone on this journey with hydrocephalus."



LAUREN

DIAGNOSED AT AGE 24 / ***obstructive hydrocephalus***

"Never stop advocating for yourself or your loved one. Stay faithful, resilient, and determined, and remember you have a community here who understands!"

1
SURGERY



LAURIE

DIAGNOSED AT AGE 62 / ***normal pressure hydrocephalus***

"Through the years, I have learned much about living with NPH. I am truly grateful to the Hydrocephalus Association; whereby, I can attend Zoom support group meetings, meet new friends, and on the website read information regarding my condition."

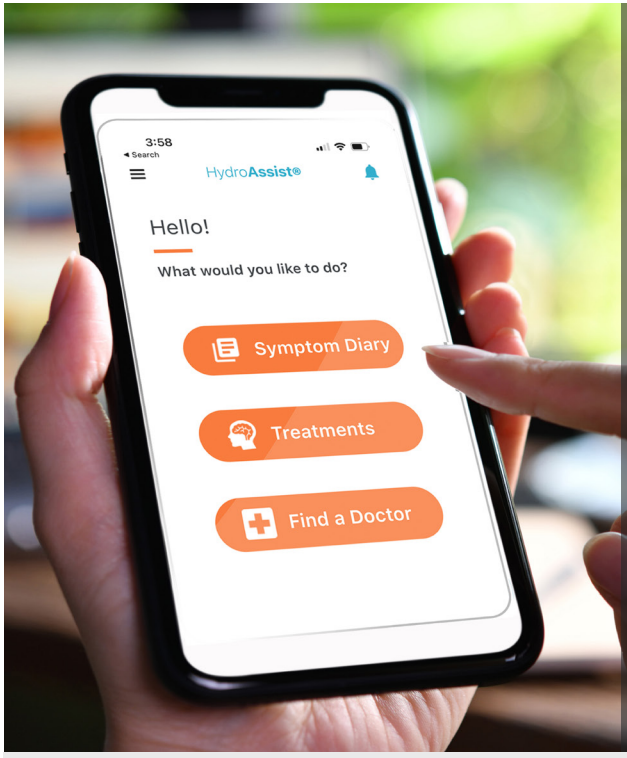
2
SURGERIES

To read more about these personal journeys, please visit the community section of our website.

HydroAssist®

GET IT ON Google Play

Available on the App Store

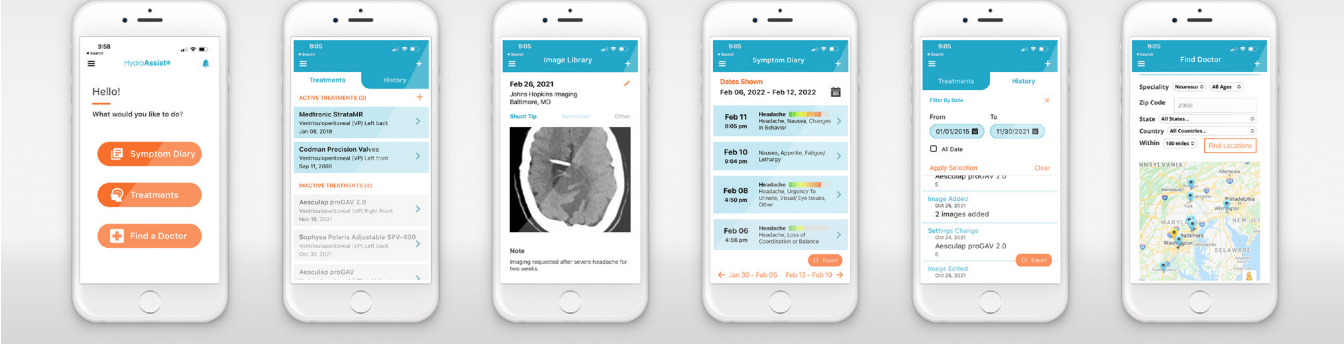


Go. Be. Mobile.

With the Hydro**Assist**® mobile app, you can have peace of mind to go where you want and be who you are. Take your entire hydrocephalus treatment history, images and medical records with you on your mobile device. Track your symptoms and headaches in an exportable journal. Find a local doctor based on your location.

Hydro**Assist**® is perfect for the individual living with hydrocephalus and the caregiver, alike.

Download it for free today.



- The homescreen puts managing your hydrocephalus at your fingertips.
- Easily enter treatments and view your entire history, including active and inactive treatments.
- Upload and store images of your scans and medical records!
- Track headaches and other symptoms.
- Text, email or print your treatments and symptom diary.
- Find a doctor based on your location.



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SURGERIES

GREG

DIAGNOSED AT AGE 12

acquired hydrocephalus, baseball injury

"With hydrocephalus, everyone is different. The effective treatment might not always be 'by the book' and it is important that the person is treated rather than treating the hydrocephalus 'the way it should be'."

Quotes from Adults

"The thing that surprised me the most...was how relatively painless shunt surgery was. As soon as I got home from the hospital, I tackled the laundry that had piled up and life quickly got back to normal. I never had to fill the prescription for painkillers and I was back at work and the gym in less than two weeks." — *Trish*

"Living with someone who has hydrocephalus has its challenges, but remember, you are not alone. Reach out, share your story, seek support, and embrace the journey together. Each day is a step forward, and with love, resilience, and understanding, we navigate these waters as one. Together, we can find strength and hope." — *Natasha, A Loving Wife's Perspective*

"I couldn't be as positive and hopeful about my future if it wasn't for the Hydrocephalus Association and all that they do. The impact they have had on my life is immeasurable." — *Amir*

The future looks bright for managing hydrocephalus. There are brilliant researchers developing innovative technologies, treatments, and medications that will make diagnosis, treatment, and daily life easier for people with this condition." — *Patrick*

Hydrocephalus Association

Mission and Vision

Our vision is a world without hydrocephalus.

Our Mission

Our mission is to find a cure for hydrocephalus and improve the lives of those affected by the condition.

We will accomplish this by collaborating with patients, caregivers, researchers and industry, raising awareness and funding innovative, high-impact research to prevent, treat and ultimately cure hydrocephalus.

Hydrocephalus Association

HYDROCEPHALUS ASSOCIATION

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