



You are
NOT alone.

Understanding Hydrocephalus

A Guide for Families

Hydrocephalus
Association

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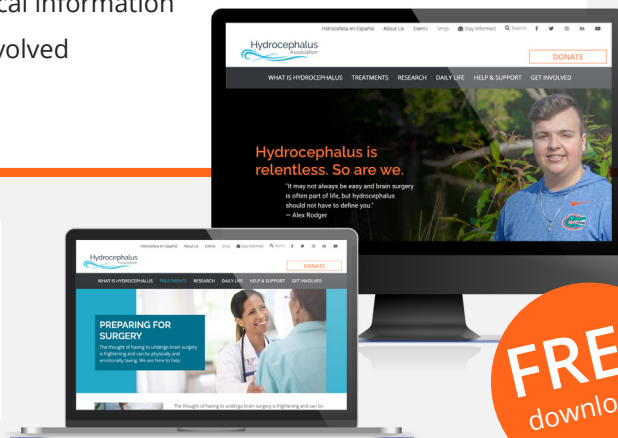


WE ARE HERE TO HELP

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
- Updated medical information
- Ways to get involved



FREE
downloads!



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



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.

Raising a child with hydrocephalus or living with the condition yourself 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 loving parent, 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.

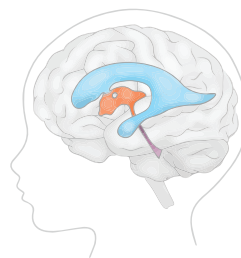


What is Hydrocephalus?

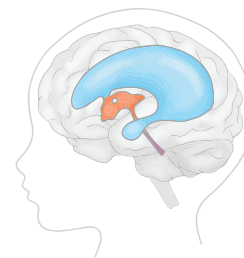
Hydrocephalus comes from the Greek words **hydro** meaning water and **cephalus** meaning head.

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.

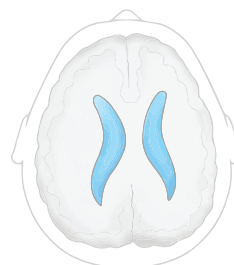
Most of the CSF is produced in the ventricles and the choroid plexus. It then circulates through the ventricular system and gets absorbed into the bloodstream. This fluid is in constant circulation and has many important jobs, including surrounding and protecting the brain and spinal cord from injury 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.



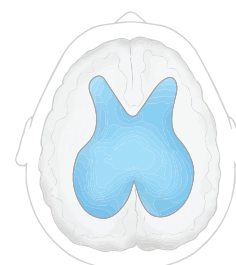
Normal Ventricles



Enlarged Ventricles



Normal Ventricles



Enlarged Ventricles

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



1M+

PEOPLE IN
THE U.S. LIVE WITH
HYDROCEPHALUS

1

OUT OF

770

BABIES DEVELOP
HYDROCEPHALUS
EACH YEAR

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.

WHILE THERE ARE
COMMONALITIES

**EACH CHILD'S
JOURNEY**

IS UNIQUE

How is hydrocephalus diagnosed in infants and children?

- Measuring a baby's head circumference
- Neurological evaluation
- Ultrasound
- CT scan
- MRI

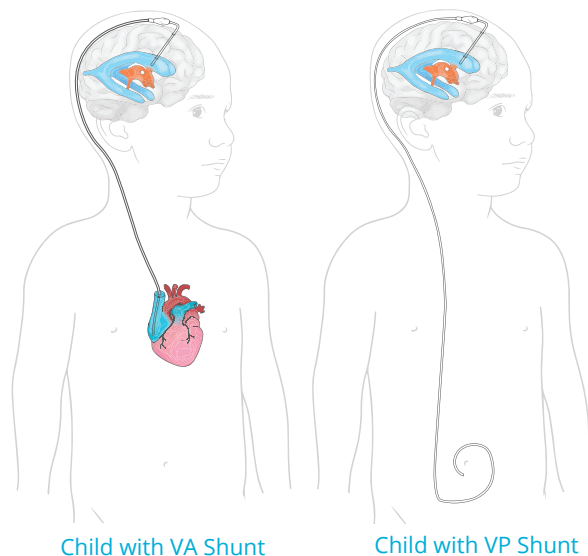
How is Hydrocephalus Treated?

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.



2 Endoscopic Third Ventriculostomy (ETV)

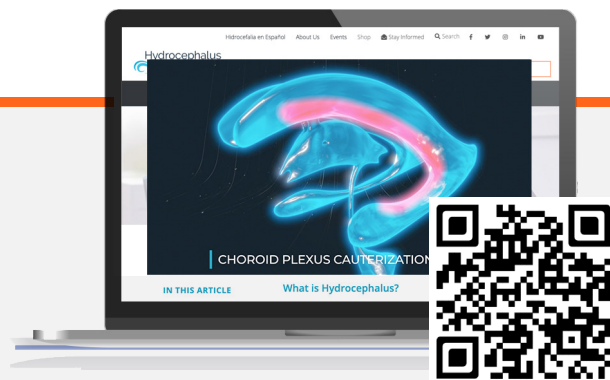
A second surgical treatment option is a procedure called Endoscopic Third Ventriculostomy (ETV). An endoscope is used to puncture a hole in the membrane on the floor of the third ventricle to open a natural pathway. This allows CSF to flow out of the ventricles and around the brain, bypassing a blockage. 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.

Infants and Toddlers

- Increased head size or rapid head growth
- Bulging or tense fontanelle (soft spot on the baby's head)
- Prominent scalp veins (infants)
- Headaches (toddlers)
- Vomiting
- Loss of appetite or feeding difficulties
- Excessive tiredness
- Difficulty waking up or staying awake
- Vision problems
- Downward deviation of eyes
- Irritability or fussiness
- Loss of previous abilities
- Developmental delays or missed milestones
- Signs of infection, such as fever, redness, or swelling at the shunt site

Children and Young 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

UNTREATED

DUKE

DIAGNOSED AT 2 WEEKS

compensated hydrocephalus

“

My best advice: find your support people, advocate for your warrior, and surrender to the unknown while always celebrating the now from the rooftops, because you can't believe what miracles and lessons lie around the bend.

”

Emily, mother

3

SURGERIES

HAWKINS

DIAGNOSED AT 3 MONTHS

acquired hydrocephalus

“

It was such a whirlwind — from diagnosis on Monday to brain surgery on Thursday.

”

Drew and Sarah, parents



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.



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SURGERIES

CAROLINE

DIAGNOSED IN UTERO

spina bifida (myelomeningocele)

“Hydrocephalus has made me stronger because whenever I want to do something, I trust myself enough to get it done. While it may look different, I am still able to do what I love. I know that hydrocephalus does not define who I am. It only pushes me to try new things and not to give up on anything.”



Resources for Families

We're here to help your child live their best life.
As your child grows, our resources grow with you.

Online Resources

Our website includes medical information, informative articles, firsthand stories, videos, and more, providing parents guidance and valuable perspectives to navigate every stage of your child's journey.

HydroAssist®

Download our mobile app to manage your child's treatment history, record changes, track their symptoms, and securely store scans. HydroAssist® is a great tool for families to manage their child's care together.

Free Downloadable Toolkits

Download our toolkits, featuring a Medical Summary, Teacher Guides, and a Toolkit for Transitioning Medical Care.

Online Support Groups

Meet other parents to gain insightful perspectives, shared experiences, and support and friendship.

HydrocephalusCONNECT

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

National Conferences: HA CONNECT

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

Webinars

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

Research

Your story matters. Share your family's journey in our patient registry, allowing scientists to gather insights into our lived experience and to identify gaps in needed research. Get involved and help move research forward.



APARNA

DIAGNOSED AT BIRTH

*congenital hydrocephalus,
aqueductal stenosis*

6

SURGERIES



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.



Resources for Kids and Teens

We're here to help children and teens live their best life!
Our resources aren't just for parents.

PenPal Program

Foster lasting friendships through our PenPal program, designed for children aged 7 to 12.

HydroAssist®

Download our mobile app to manage your treatment history, record changes, track your symptoms, and securely store scans. HydroAssist® is a great tool for youth and parents to manage care together.

National Conferences: HA CONNECT

Experience the power of connection and learning at HA CONNECT, where children, teens, and siblings can engage in Kids Camp, our Teen Track, and interactive sessions. Friendships are made that last a lifetime.

I Can Relate Video Series

Watch our "I Can Relate" video series created by teens and young adults to address the questions most on their minds.

Online Meet-ups

Tailored for this stage of your journey, our online meetings for teens provide a supportive and safe space to connect and share.

Scholarship Program

Apply for our scholarship program which provides financial assistance to young adults pursuing post-high school academic opportunities.

Online Resources

Explore our website for topics specifically for youth including college, healthcare ownership, independence, relationships, and personal stories.

Free Downloadable Toolkits

Download our toolkits designed for teens and young adults to take ownership of their medical care. Fillable PDFs include a Medical Summary and a Toolkit for Transitioning Medical Care.



ALENA

DIAGNOSED AT 3 MONTHS

*congenital hydrocephalus,
aqueductal stenosis*

2

SURGERIES

“

When Alena was diagnosed, we were terrified as new parents. The Hydrocephalus Association welcomed us with open arms. They provided us with the tools, connected us with experts and local families in a similar situation to ours. We are forever grateful to HA and their staff. Thank you for uniting the hydrocephalus community.

We no longer feel alone!

”

Kate and Alex, parents

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 prevent, treat, and ultimately cure hydrocephalus. We are the largest private funder of hydrocephalus research in the country and sustain two 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). Through collaboration with industry, scientists, 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, there is now a 36% decrease in shunt infection rates and over 10 drug therapies are in various stages of testing. Our research is driving change and creating a better future for individuals with hydrocephalus.



LAUREN

DIAGNOSED AT AGE 15

acquired hydrocephalus

6
SURGERIES



My journey has had ups and downs. It was hardest just after I developed hydrocephalus, but I'm happy to say that over five years have passed since my last brain surgery.



Voices from Our Community

AMIYAH

DIAGNOSED AT 1 MONTH / *acquired hydrocephalus arteriovenous brain malformation*

"Parenting a child with hydrocephalus requires strength, patience, and unwavering love. In this journey, remember you are not alone; your resilience is a guiding light for your child's path to triumph over challenges." — *Jacque, mother*

2
SURGERIES



4
SURGERIES



RILEY

DIAGNOSED IN UTERO / *x-linked hydrocephalus*

"It can be scary but stay courageous and always look for the positive. There is a lot of beauty in chaos." — *Alison, mother*

2
SURGERIES



GABRIELA

DIAGNOSED AT 3 DAYS / *acquired hydrocephalus, premie, IVH*

"The NICU doctors have to give the best and the worse case scenarios. That does not make me lose hope. On the contrary, that light in her eyes gives me hope and I remind myself that the brain is very resilient... and so is she." — *Amanda, mother*



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SURGERIES

GENESIS

DIAGNOSED AT AGE 5 / *acquired hydrocephalus, IVH*

"Living with an invisible condition like hydrocephalus can be very frustrating at times. Although I deal with these challenges, I like to remind myself as long as I am hopeful anything is possible, Including a cure or other options for us Hydro warriors."

JACOB

DIAGNOSED AT AGE 2 / *congenital hydrocephalus, aquaductal stenosis*

"When my son was diagnosed, I reached out to HA and was connected with moms who had older children with hydrocephalus. I learned so much, got tremendous support and hope from meeting these moms. I also met their amazing kids - which inspired and comforted me as I thought about Jacob's future." — Susan, mother



3

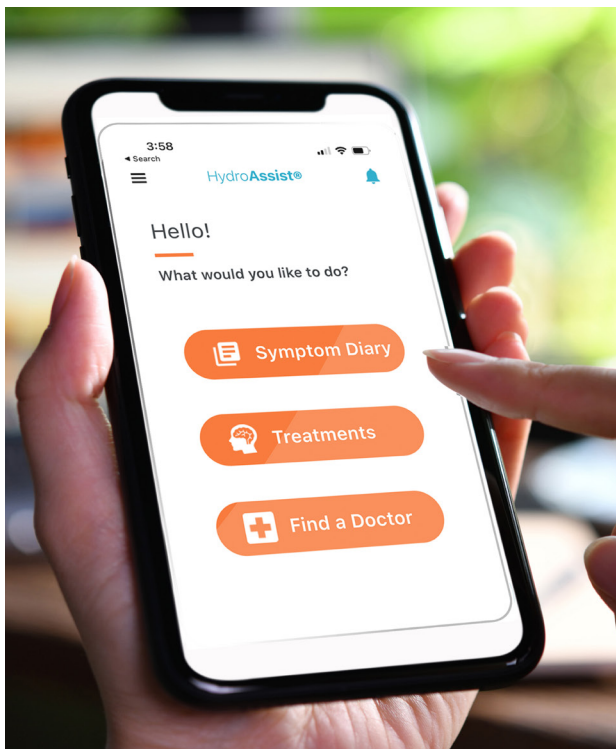
SURGERIES



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



HydroAssist®

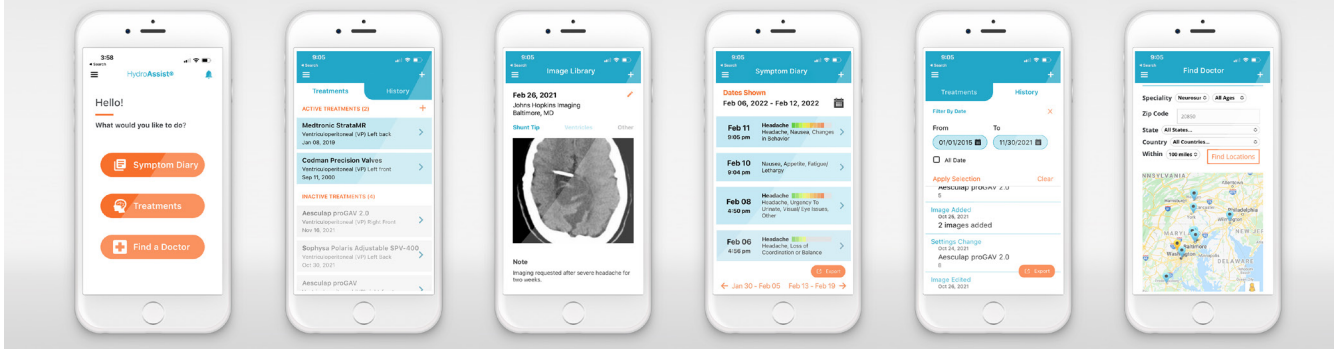


Go. Be. Mobile.

With the HydroAssist® 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.

HydroAssist® 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.



17

SURGERIES

RYDER

DIAGNOSED AT BIRTH

*acquired hydrocephalus,
preemie, IVH*



Hydrocephalus has made me stronger by knowing I can and will get through whatever life throws at me.



KAI

DIAGNOSED AT BIRTH

*acquired hydrocephalus,
preemie, IVH*



I've been very fortunate to not have had any issues related to my hydrocephalus. But it is really hard, and I worry when my brother is having problems.



1

SURGERY

Quotes from Parents

"Our son is thriving as a young adult in part because of the way the HA community has supported him since he was a toddler! Connecting with others locally and attending HA Conferences has been key to this. My hope for the future is that fewer families will face these challenges. Being involved with HA's research efforts, I'm so encouraged that the number of scientists looking for better treatment has exploded! We've already seen breakthrough discoveries and I can't wait for the next ones." — *Tessa*

"I am most proud of my son for loving and living his life to the fullest despite all of the obstacles that he has faced due to his hydrocephalus. I find strength in watching him thrive along with all of the other amazing people with hydrocephalus that we have met on this journey." — *Jessica*

"The journey with hydrocephalus has been...transformative. Realizing that everyone's journey is unique but embracing the fact that we are all in this together has helped me get through the tough times and appreciate all the little things. I find strength in numbers. Find your hydrocephalus community early and surround yourself with the people who will understand and support you." — *Eileen*

"Most days, it's easy to forget that I have a child with hydrocephalus. And that's such a gift: my son is a kid, who does kid things, and makes kid friends, and happens to live with hydrocephalus. It may not feel like it for you today, but there's a whole lot of normal involved in this journey." — *Jason*



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

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