

MEMORIAL HERMANN
MISCHER NEUROSCIENCE INSTITUTE AND
CHILDREN'S MEMORIAL HERMANN HOSPITAL

HYDROCEPHALUS EDUCATION



Children's
MEMORIAL
HERMANN
Hospital

Mischer
Neuroscience Institute

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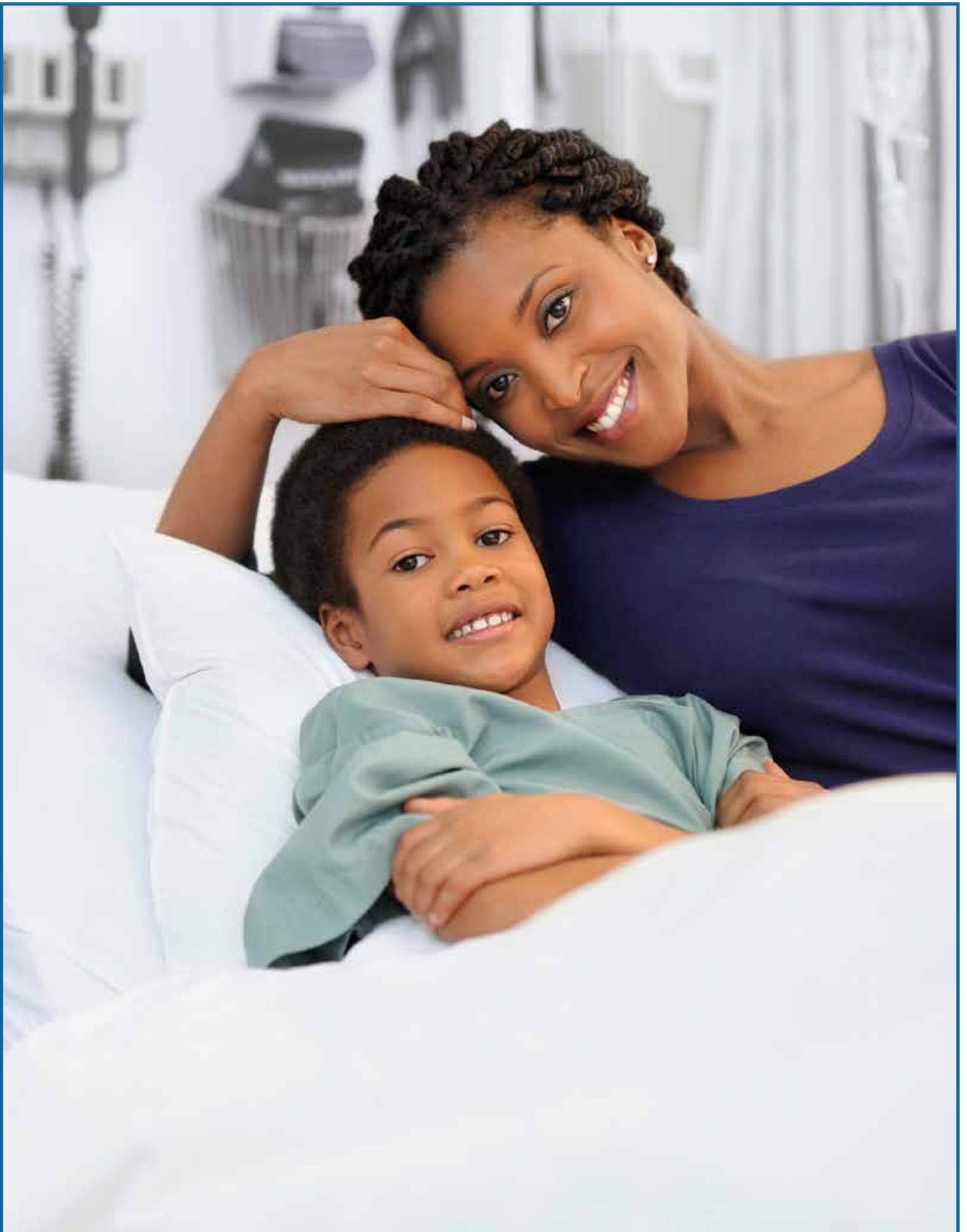
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Introduction

IT CAN BE DEVASTATING FOR FAMILIES WHEN A CHILD IS DIAGNOSED WITH A CHRONIC CONDITION SUCH AS HYDROCEPHALUS, LEAVING PARENTS FEELING OVERWHELMED AND FRIGHTENED. HOWEVER, REMARKABLE ADVANCEMENTS HAVE BEEN MADE IN THE WORLD OF PEDIATRIC NEUROSCIENCE, AND WITH EARLY DIAGNOSIS AND TIMELY TREATMENT MANY CHILDREN CAN RECOVER SUCCESSFULLY.

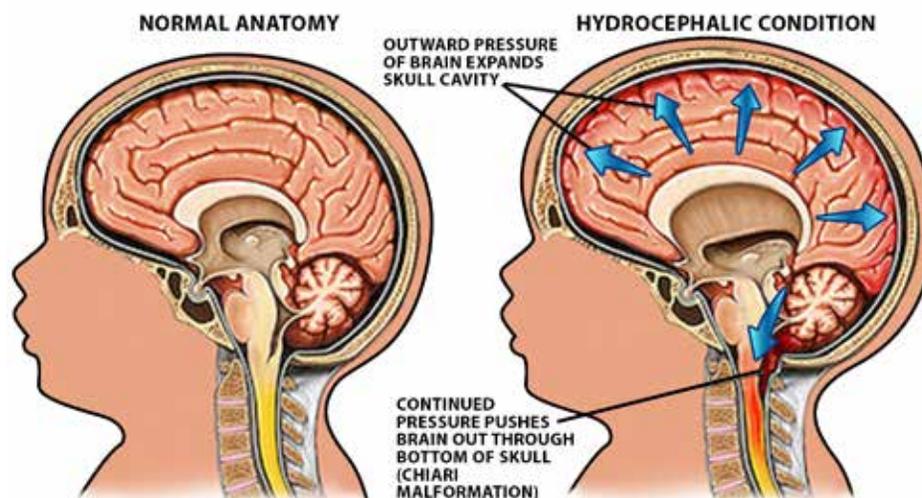
The multidisciplinary team at the Mischer Neuroscience Institute (MNI) at Children's Memorial Hermann Hospital has developed a comprehensive, coordinated program for the care of pediatric hydrocephalus patients. From specially trained, affiliated pediatric neurosurgeons and neurologists to our experienced and compassionate nursing staff, our team is dedicated to providing exceptional care.

This guide has been provided to help you and your child navigate the journey to optimal recovery for hydrocephalus. Along with learning about treatment options and expectations for hydrocephalus patients, you will find important resources, clinical details and helpful suggestions for rehabilitation.



What is Hydrocephalus?

HYDROCEPHALUS IS A CONDITION THAT OCCURS WHEN AN ABNORMAL AMOUNT OF CEREBROSPINAL FLUID (CSF) ACCUMULATES IN THE BRAIN. CSF IS A CLEAR, WATER-LIKE FLUID THAT IS VITAL TO PROTECTING THE BRAIN AND SPINAL CORD. WHEN THERE IS TOO MUCH OF THIS FLUID, IT WILL POOL IN THE BRAIN AND CAUSE INCREASED PRESSURE WHICH LEADS TO AGE-DEPENDENT SYMPTOMS. BECAUSE OF THE INCREASED AMOUNT OF FLUID VISIBLE IN IMAGING STUDIES OF THE BRAIN, A TERM OFTEN USED TO DESCRIBE HYDROCEPHALUS IS “WATER ON THE BRAIN.”



In addition to providing cushioning for the brain and spinal cord, CSF delivers important nutrients while also transporting waste which is eventually absorbed into the bloodstream. When the brain is functioning normally, CSF flows through channels called ventricles, circulates around the brain and spinal cord, and then is absorbed into the bloodstream via large veins called sinuses. Hydrocephalus occurs when there is a blockage within the ventricles or the pathway back into the bloodstream. Rarely, it can also happen when the brain produces too much CSF.

If left untreated, hydrocephalus can lead to a myriad of health problems, including a loss in physical and mental abilities, brain damage and even death. Thankfully, the prognosis for patients can be very good with early diagnosis and treatment.

Causes of Hydrocephalus

HYDROCEPHALUS CAN BE PRESENT AT BIRTH (CONGENITAL) OR IT CAN OCCUR AT ANY TIME DURING A CHILD'S LIFE (ACQUIRED) AS A RESULT OF AN INJURY OR ILLNESS, INCLUDING A HEMORRHAGE, MENINGITIS, TUMOR, CYST OR HEAD TRAUMA. WHILE SOME CHILDREN DEVELOP HYDROCEPHALUS WITH NO KNOWN CAUSE, SOME OF THE MOST COMMON CAUSES OF HYDROCEPHALUS ARE DETAILED BELOW.

Congenital

Aqueductal stenosis is a narrowing or blockage in one of the passageways of CSF in the brain and can be caused by infection, hemorrhage or tumors.

Neural tube defects are birth defects of the brain and spinal cord. Spina bifida is the most common neural tube defect.

Arachnoid cysts are fluid-filled sacs that can occur anywhere in the brain.

Dandy-Walker syndrome is a congenital brain malformation involving the cerebellum and the fluid-filled spaces around it.

Chiari malformation is a brain abnormality that causes the cerebellum to protrude into the space normally occupied by the spinal cord.

Acquired

Intraventricular hemorrhage is bleeding in the ventricles, the major fluid-filled space of the brain.

Meningitis is an inflammation of the meninges (the membranes that cover the brain and spinal cord) and is typically caused by a virus or bacteria.

Head trauma occurs when an injury damages the brain's tissue, nerves or blood vessels.

Brain tumor is any abnormal growth within the brain.

COMMON FACTS ABOUT HYDROCEPHALUS

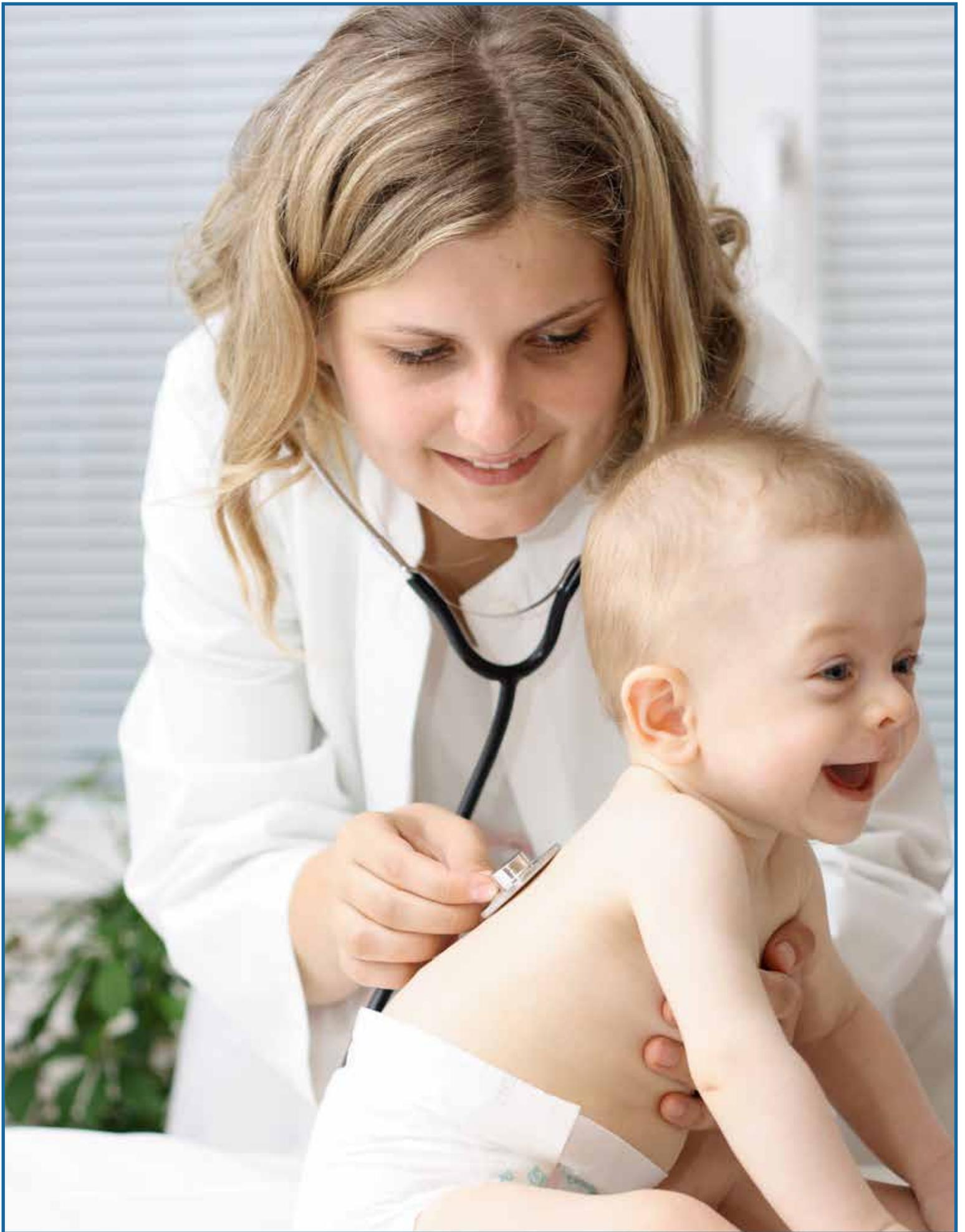
- Hydrocephalus can occur at any stage of life, but most commonly affects a fetus, baby or young child.
- It is estimated that hydrocephalus affects 1 in 500 children, making it slightly more common than Down syndrome.
- Hydrocephalus is the No. 1 reason children undergo brain surgery.
- While there is no known way to prevent hydrocephalus, many children with hydrocephalus can have great outcomes with appropriate treatment.
- Hydrocephalus is a life-long condition and affects more than one million people in the United States.

Types of Hydrocephalus

THERE ARE TWO TYPES OF PEDIATRIC HYDROCEPHALUS – COMMUNICATING AND NON-COMMUNICATING.

Communicating hydrocephalus means that the flow of fluid is blocked after it exits the ventricles. It's called “communicating” because the ventricles remain open and the CSF can still flow freely. This type of hydrocephalus is most often caused by a deficiency in the body's ability to absorb CSF into the bloodstream after it circulates around the brain and spinal cord. In rare cases, communicating hydrocephalus may occur as a result of an overproduction of CSF.

Non-communicating hydrocephalus (also referred to as “obstructive” hydrocephalus) occurs when CSF cannot properly flow through the ventricles, generally indicating a blockage at a site within the ventricular system or between it and the subarachnoid space. The most common type of non-communicating hydrocephalus is aqueductal stenosis.



Signs and Symptoms

SYMPTOMS OF HYDROCEPHALUS VARY DEPENDING ON THE CHILD'S AGE AND THE PROGRESSION OF THE CONDITION.

Prenatal hydrocephalus is most often diagnosed between 20 and 24 weeks of gestation, when an ultrasound shows the abnormal dilation of the fetus's ventricles and CSF pooling. Infants and babies who are younger than one year may appear to have an abnormally shaped head that is unusually large. Because the bones in the skull of babies have not yet fused together, the skull may expand and protrude to accommodate the excess buildup of CSF. Other symptoms may include bulging at the "soft spots" and/or exaggerated swollen veins on the head, vomiting, sleepiness, irritability, a downward cast of the eyes and seizures.

Older children often have different symptoms because their skulls have long since closed and are no longer able to expand to accommodate the buildup of CSF. Since their heads do not become enlarged, hydrocephalus is not as visibly recognizable. Symptoms in older children most often include the sudden onset of severe headaches accompanied by vomiting. They may also exhibit loss of bladder control, irritability, sleepiness, seizures, and loss of balance, motor skills and memory. Visual difficulties such as decreased visual acuity, a downward cast of the eyes, double vision or repetitive eye movements may also be noted.

What to Expect – Initial Evaluation

Your child's healthcare team may use a number of tools to detect or confirm the diagnosis of hydrocephalus, depending on your child's age and symptoms. Generally, temperature, pulse and blood pressure will be measured. Blood tests may be necessary if surgery is being considered. The physical examination may include measuring the size of the head, feeling the fontanelle (soft spot) of the head in babies, and assessing eye movements and motor function. Older children may also be tested for speech, coordination, attention and memory difficulties. An eye exam by an ophthalmologist may be ordered, as a careful exam of the eyes may provide evidence of increased pressure in the brain.

COMMON DIAGNOSTIC TESTS FOR HYDROCEPHALUS

While the physical examination provides your child's physician with much needed information, additional tests may be necessary to confirm the diagnosis as well as the degree of hydrocephalus. These diagnostic tests provide more detailed information regarding treatment. The following tests are available 24 hours a day and on weekends. Some common tests include:

Ultrasound

An ultrasound is an imaging test that uses sound waves to detect structures within the body and then translates those sound waves into pictures. This test measures the size of the ventricles of infants whose soft spots have not yet fused. During the test, the technician slowly moves a probe around the outside of the infant's head. Ultrasound is also commonly used to take images of a fetus inside a mother's womb and abdomen. It generally takes around 15 minutes, requires no sedation or radiation exposure, and is painless.

Computed Tomography (CT Scan)

A CT, or CAT scan uses a computer system to give detailed, cross-sectional views of brain tissue for physicians to analyze. During the test, the child lies on a table with his or her head in a large, donut-shaped machine that takes pictures of the brain. Occasionally, contrast dye may be injected into a child's body. Contrast helps certain areas of the brain show up better on X-rays. A CT scan generally takes five minutes to complete and is painless. For patients who are too critically ill to leave the room, Children's Memorial Hermann Hospital has a state-of-the-art portable CT scanner to perform CT scans at the bedside.

Magnetic Resonance Imaging (MRI)

An MRI is a test that uses a strong magnetic field and radio waves to give physicians a 3-D picture of the brain. An MRI can be used for a more in-depth look of the brain than other imaging methods. During an MRI, which is painless, the child may require sedation because he or she must lie completely still within the MRI scanner for approximately 45 minutes or longer depending upon the specific sequences ordered by your physician. In order to obtain the best quality image, some patients, especially young children, may require general anesthesia. It is important to be aware that some types of shunts must be reprogrammed after the MRI scan and before the child leaves the hospital.

Quick Brain MRI

A Quick Brain MRI, or Fast Brain MRI, is an abbreviated MRI in which only a handful of images of the brain are taken. It can be performed within 5 minutes, requires no sedation or radiation exposure, and is painless. Children's Memorial Hermann Hospital is one of the only facilities in the region with the capability and equipment to perform this test. It was created for children who require multiple scans during childhood with the goal of reducing overall radiation exposure. In some cases, a standard MRI may still be necessary.

Shunt Series

A Shunt Series is a set of X-rays (skull, chest and abdomen) that can reveal a break or disconnect in the shunt tubing and is painless.

Treatment Options

THE BEST TREATMENT FOR YOUR CHILD WILL DEPEND ON A NUMBER OF FACTORS, INCLUDING HIS OR HER AGE, OVERALL HEALTH AND THE CAUSE OF THE CSF BUILDUP.

Shunt

Surgically implanting a shunt is the most common treatment for hydrocephalus. A shunt is a device that contains a flexible tube and valve system that drains CSF from the brain into another part of the body such as the abdomen or chest cavity where it can be absorbed into the bloodstream.

Shunting can be a highly effective treatment option. However, shunt malfunctions may occur after placement for a variety of reasons. Most children with shunts will have to undergo one or more subsequent surgeries when the shunt malfunctions. Shunts can also become infected, most commonly within the first three months after placement. Strict protocols have been implemented at Children's Memorial Hermann Hospital to minimize the risk of shunt infection.

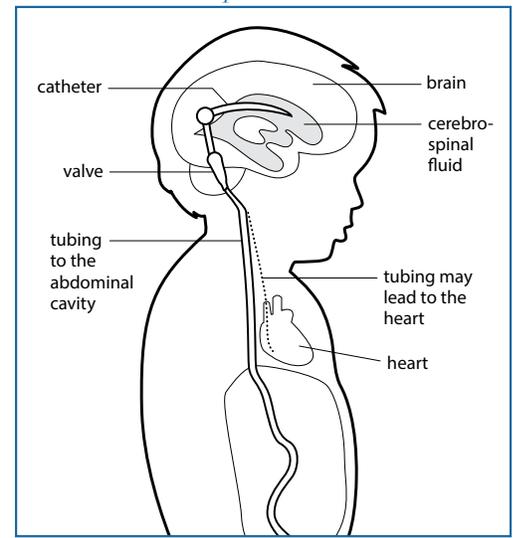
There are three basic components of a shunt:

- A catheter (or tube) that is inserted into the brain ventricles
- A valve that regulates the flow of CSF
- A longer catheter that carries the CSF to another part of the body

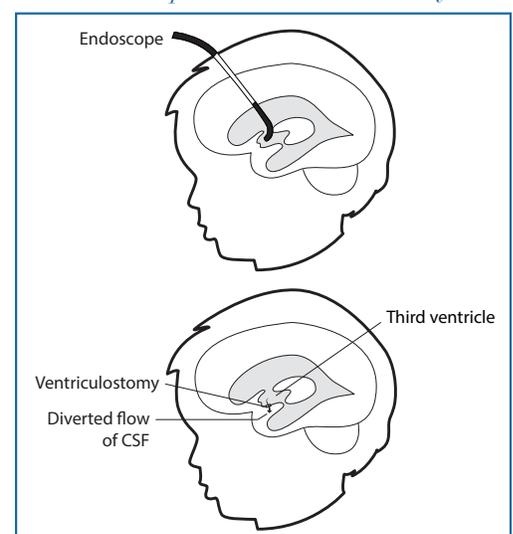
Endoscopic Third Ventriculostomy (ETV)

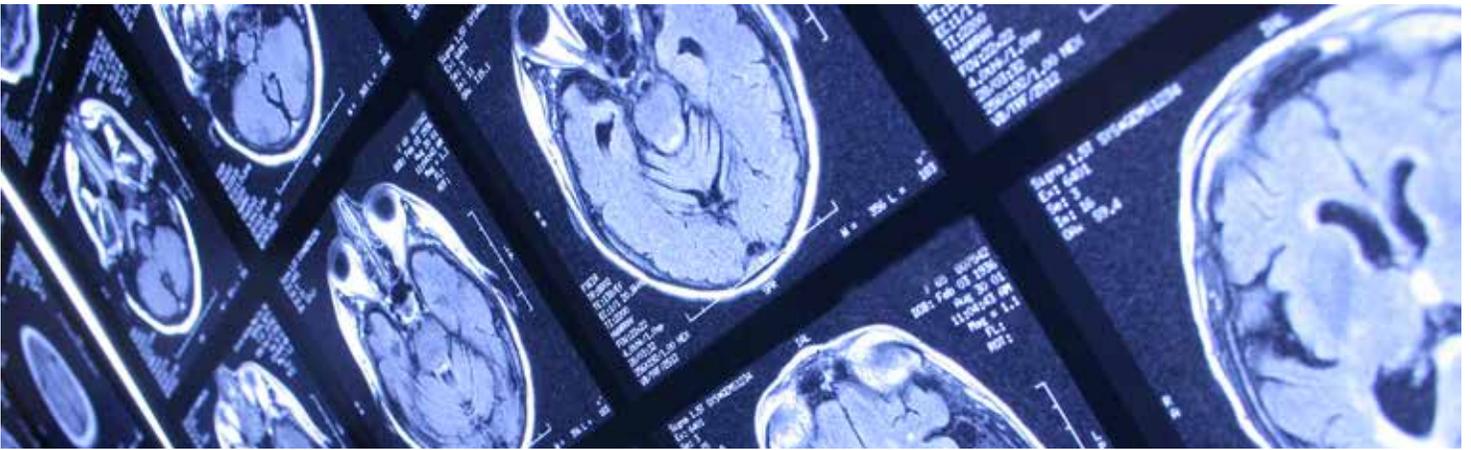
Some children may be candidates for a minimally invasive surgical procedure called ETV. The best candidates have non-communicating (obstructive) hydrocephalus and most commonly have an obstruction preventing fluid from passing between the third and fourth ventricles of the brain. An ETV creates an alternate channel for the flow of CSF and is an alternative to shunting. During this procedure, the neurosurgeon uses a very small camera and tiny surgical tools to create an opening which provides an alternative route for CSF and bypasses the fluid obstruction. The surgery takes approximately 30 minutes and most children recover quickly with no additional surgical intervention required. In some cases, the opening will close and the procedure must be performed again or a shunt may be required.

Ventriculoperitoneal Shunt



Endoscopic Third Ventriculostomy





Other Endoscopic Treatments

Our expert team of affiliated physicians is nationally recognized for their innovative endoscopic treatments for pediatric hydrocephalus that go beyond ETV. Pediatric neurosurgeons at Children's Memorial Hermann Hospital are among only a handful of physicians in the country who are extensively experienced in using minimally-invasive techniques with every possible case, including the following:

- Septostomy
- Aqueductoplasty
- Choroid plexus coagulation
- Cyst fenestration

Septostomy is a procedure in which the surgeon makes a tiny incision in the septum pellucidum, which is the membrane that separates the two lateral ventricles. This procedure may be performed in place of a shunt in some cases or may be utilized in place of adding a second shunt for children with non-communicating ventricles.

Aqueductoplasty is a procedure to expand the opening of a narrowed aqueduct of Sylvius, the channel which connects the third and fourth ventricles of the brain. The most common cause of congenital hydrocephalus is aqueductal stenosis. This occurs when the passageway between the third and fourth ventricles – the aqueduct of Sylvius - is narrowed or blocked. When a child has an isolated fourth ventricle, CSF becomes trapped and creates pressure on the brain stem. In these cases, an aqueductoplasty may be performed to enable communication between the third and fourth ventricles of the brain.

Choroid plexus coagulation is a groundbreaking technique that is performed to decrease the production of CSF. The surgeon places a small cautery device into the endoscope to obliterate the choroid plexus, the substance in the brain which produces the majority of CSF.

Cyst fenestration may be performed in children with arachnoid cysts or other types of cysts. This endoscopic procedure also eliminates the need for a shunt, as the surgeon makes tiny incisions in the cyst walls to create channels for CSF flow.

Meet Our Team



David I. Sandberg, M.D., F.A.A.N.S., F.A.C.S., F.A.A.P.

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Lillian Sprague, P.A.-C.

Physician Assistant,
Division of Pediatric Neurosurgery,
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Paula Maldonado

Medical Assistant,
Division of Pediatric Neurosurgery,
UTHealth Medical School

Who is...

BELOW IS A LIST OF CAREGIVERS WHO MAY BE PART OF THE MULTIDISCIPLINARY TEAM THAT CARES FOR YOUR CHILD.

Pediatric Neurosurgeon: A highly trained, specialized physician who focuses on treating diseases of the brain and spine which require surgery in children.

Pediatric Neurologist: A highly trained, specialized physician who focuses on treating diseases of the brain and spine which do not require surgery in children.

Physician Assistant: Also known as a PA, practices medicine under the supervision of a licensed physician.

Medical Assistant: Works closely with your child's pediatric neurosurgeon in the outpatient clinic to take your child's vital signs, identify details about their condition, and arrange diagnostic tests and surgeries.

Nurse: Provides daily clinical care, such as assistance in taking medications, bathing, dressing and toileting. He or she works closely with you, your child and the healthcare team. The charge nurse works closely with the bedside nurse to assist with your child's care and is usually responsible for the operations of the unit. A team lead is a nurse who works closely with the charge nurse and bedside nurse to advocate for any clinical, medical or patient satisfaction needs.

Pediatric Dietitian: Works closely with your child's healthcare team to develop an individualized nutrition plan. Dietitians also may perform nutritional screening, calorie counts, nutrition education and counseling.

Pharmacist: Advocates for the safe and effective use of medicines across the continuum of care for your child, from admission through discharge. They provide information about medications and carefully monitor all treatment that involves drug therapies. Working in conjunction with other healthcare professionals, they play a vital role in ensuring your child's safety.

Physical Therapist: An expert in maintaining and improving the movement of joints and limbs. He or she will suggest special exercise and techniques to improve your child's muscle control and balance.

Occupational Therapist: An expert in helping children learn to perform daily tasks on their own and learn new, practical skills for everyday life.

Speech-Language Pathologist: An expert in helping children with speech and language difficulties learn ways to communicate and deal with swallowing problems.

Child Life Specialist: Works collaboratively with other healthcare team members to help children, adolescents and families understand and cope with hospitalization. The Child Life Specialist provides important information to help you and your child prepare for medical and surgical procedures. He or she also provides emotional support through safe and fun activities, therapeutic play, developmental interactions and recreational opportunities.

Case Manager: Responsible for reviewing admission and discharge plans. He or she will coordinate both events based on individual patient needs and educate you and your family members.

Social Worker: Assists patients and family members in planning ways to deal with social, emotional or financial problems that may arise during hospitalization. He or she also may assist in discharge planning.

Transitional Care Coordinator: Helps patients and family members understand clinical terms and manage treatment and post-treatment expectations. He or she also communicates with other team members and coordinates teaching needs.

Chaplain: Helps patients and family members cope with grief, feelings of loss of control, depression, desire for religious sacraments, short-term counseling needs and loneliness. The chaplain also offers spiritual support to people of all faiths.

During the Hospital Stay

There are various levels of care at Children's Memorial Hermann Hospital depending upon your child's condition, other underlying medical issues and the type of treatment required. Throughout their stay, hydrocephalus patients may receive care in more than one unit as changes in their condition occur.

UNITS

Pediatric Intensive Care Unit (PICU)

The PICU provides comprehensive and continuous care to our most critically ill children. A child will be transferred out of the PICU once his or her condition improves and less monitoring is required.

Neonatal Intensive Care Unit (NICU)

Our Level III NICU is equipped to care for critically ill infants and premature babies born as early as 23 weeks gestation and weighing as little as 1 pound. Our Level I and II Neonatal Special Care Units provide intermediate care for newborns who are less critically ill and require less intensive support.

Additional Pediatric Units

The Children's Center and the Roger & Debbie Clemens Pediatric Wing are designed for children who require hospitalization but whose conditions are not life threatening. Youngsters who need extra attention—for example, post-transplant patients or those with gastrointestinal problems or seizures—receive treatment in the Children's Special Care Unit (CSC).

HELPFUL NUMBERS



Pediatric Neurosurgery Appointments with Drs. Sandberg and Fletcher

832.325.7234

Child Life Department

713.704.2066

Department of Case Management and Social Work

713.704.4190

Main Hospital Number

713.704.4000

Neonatal Intensive Care Unit (NICU)

713.704.2900

Patient Relations

713.704.4540

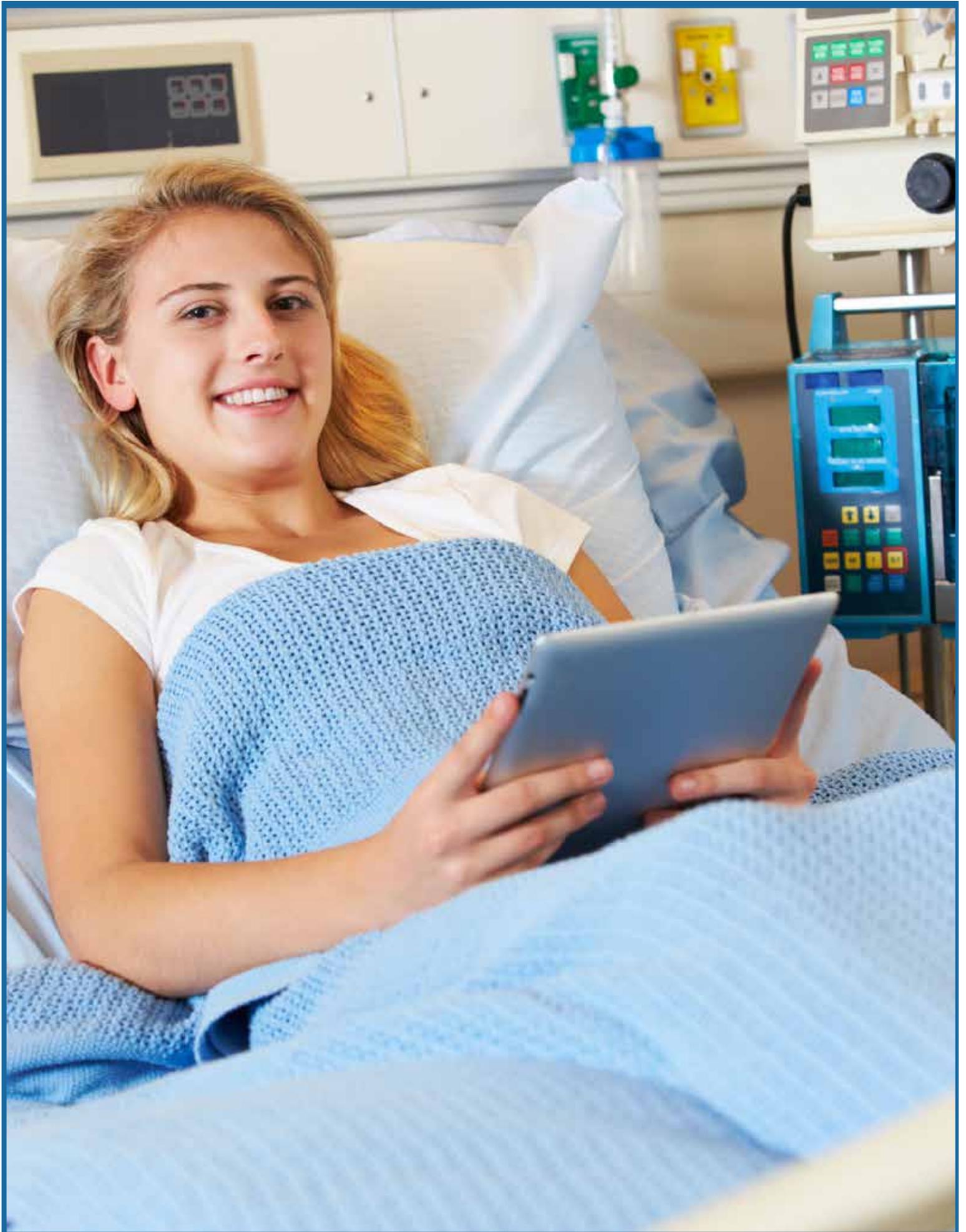
Pediatrics Floor

9th Floor 713.704.4991

10th Floor 713.704.2170

Pediatric Intensive Care Unit (PICU)

713.704.2238



Discharge, Care and Rehabilitation

Your child's caregiver team will begin working on the discharge process early on during your child's hospitalization to ensure the transition home is as seamless as possible. Before you leave, your child's physician, physician assistant and nurse will talk with you about your child's follow-up care, including medications, diet and how to care for him or her at home. If you have questions or concerns, please be sure to ask.



Instructions for Managing Pain at Home

Our goal is to make every child's hospital stay as pain free as possible, and pain measurement and management should continue at home. Although pain after an operation, injury or medical procedure is normal and expected, the following guidelines can help your child stay as comfortable as possible once at home:

- Give prescribed medications on time. Do not give more than the prescribed dose.
- Give only the medications that the doctor prescribes or recommends.
- Give pain medications with food to avoid an upset stomach.
- Call the doctor if your child's pain or fever worsens; if unwanted side effects of medication occur, such as rash, itching, vomiting or dizziness; or if you have any other questions or concerns related to your child's condition.

Planning Your Child's Recovery

An important part of your child's recovery is making sure that after you leave the hospital, your child gets all the care he or she needs to get better. A nurse, social worker or discharge planner should help plan this follow-up care. If you have trouble understanding discharge instructions for any reason, ask for the instructions in writing. If you are having difficulty understanding the language being used, ask for translated documents or an interpreter.

Find Out About Your Child's Condition

- Ask about the condition, how soon your child should feel better, and the signs and symptoms you should watch for.
- Find out about your child's ability to do everyday activities like rolling over, crawling, walking, climbing stairs, going to the bathroom and other important activities.
- Find out how much help your child will need during the recovery; for example, whether or not someone should be with your child 24 hours a day.
- Write down any questions you have and ask them before you leave the hospital.
- If you are not confident about how to care for your child after leaving the hospital, or if you have doubts about getting the care needed at home, please speak up. Ask to speak to the nurse in charge, or ask your child's nurse, social worker or case manager if you could be referred to a home health agency that could come to your home to make sure your child's needs are being met.

Find Out About Your Child's New Medications

- Ask for a list of all of the medications your child will be taking at home. The list should include all of the patient's medicines, not just new ones started in the hospital. Check the list for accuracy. You and your child's doctor should also share the list with anyone who is providing follow-up care.
- Ask for written directions about the medicines. Ask if there is any food or drink that should be avoided.
- Tell your doctors, nurses and pharmacists about all the medicines, vitamins and herbs your child usually takes. Ask if there are any of these that he or she should not take with the new medicines.
- Ask about the side effects of the new medicines. Find out what you should do if your child experiences any of them.

Find Out About Your Child's Follow-up Care

- Ask for written directions about physical exercises your child may need to do.
- If your child has a wound, ask for written directions on how it should be cared for.
- If your child needs special equipment, make sure you know how to use it, where you can get it, and whether it's covered by your insurance, Medicaid or other health plan.
- Ask about any tests your child should get after leaving the hospital and who you should contact to get the results.
- Find out about any follow-up visits with your doctor or other caregiver.
- Review your insurance to find out what costs are covered and not covered after your child is discharged, such as costs for medicines and equipment.
- If your child needs home care services, make sure the facility or service is covered by your insurance, Medicaid or other health plan; and that it is licensed or accredited.

WHEN TO CALL YOUR DOCTOR OR 911

Call your doctor, 911 or head to the nearest emergency center right away if your child experiences any of the following:

- Trouble with sucking, drinking or eating
- Fever
- Stiff neck (refusing to bend or move the neck or head)
- Trouble breathing
- Seizures
- Head injury
- Headache or visual disturbance
- Bleeding, drainage or pus at the incision site
- Vomiting
- Confusion or more than usual sleepiness

Outpatient Rehabilitation

Some children diagnosed with hydrocephalus will benefit from long-term rehabilitation therapies and educational interventions, regardless of the treatment they receive. Your child's physician will work with you to prescribe the best short-term or long-term rehabilitative treatment based on your child's individual needs.



Discharge Worksheet

IMPORTANT INFORMATION TO KNOW PRIOR TO DISCHARGE:

I will follow up with the neurosurgeon at:

Pediatric Neurosurgery Clinic

6410 Fannin St.

Suite 950

Houston, TX 77030

Telephone: 832.325.7242

Fax: 713.512.2220

www.mhmni.com

Appointment Date/Time: _____

Prior to my follow-up appointment, I will need (imaging, labs, etc.):

I will be discharged on the following medications:

Special instructions (home health, outpatient therapy, additional follow-up appointments):



Resources

Be An Angel Fund

www.beanangel.org
Telephone: 281.219.3313

Department of Assistive and Rehabilitative Services (DARS)

www.dars.state.tx.us
Telephone: 1.800.628.5115
Toll Free: 1.866.581.9328

Family Services of Greater Houston

www.familyservices.org
Telephone: 713.861.4849

Harris County Social Services

www.csd.hctx.net
Telephone: 713.696.7900

Hydrocephalus Association

www.hydroassoc.org

Hydrocephalus Kids

www.hydrocephaluskids.org

Hydrocephalus Support Group at Mischer Neuroscience Institute

Please contact 713.222.CARE to register
or visit www.mhmni.com/support/

Mischer Neuroscience Institute at Children's Memorial Hermann Hospital

www.mhmni.com

Texas Children's Health Insurance Plan (CHIP)

Telephone: 1.800.647.6558

Texas Department of Health and Human Services

To apply for Medicaid: 1.800.252.8262
Harris County Residents: 713.767.2000





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childrens.memorialhermann.org
713.704.KIDS

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877.75.NEURO (63876)