

# Barrow Normal Pressure Hydrocephalus Program Patient Handbook





# Barrow NPH Program Patient Handbook

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# Welcome to the Barrow Normal Pressure Hydrocephalus Program

We're very pleased you've chosen the Normal Pressure Hydrocephalus (NPH) Program at Barrow Neurological Institute for your care. Barrow is an international leader in the treatment, research, and education of brain and spinal diseases, conditions, and injuries. Led by President and CEO Michael T. Lawton, MD, one of the world's top neurosurgeons, the Institute is one of the busiest centers for neurology and neurosurgery in the United States.

The Barrow NPH Program is home to a dedicated, multidisciplinary team that is well versed in the diagnosis and treatment of NPH. Our experts in neurosurgery, neurology, neuropsychology, neuro-rehabilitation, neuropathology, neuroradiology, and neuroscience nursing are committed to providing you with individualized, state-of-the-art clinical care so that you can get back to your daily life as soon as possible.

For most patients, the journey with NPH is more of a marathon than a sprint. While we're here to guide you through every step of this journey, know that you and your care partners will also play an important role in the process and your outcome. We encourage you to prioritize your health by focusing on adequate sleep, balanced nutrition, and regular exercise.

While your case is certainly not our first experience with this diagnosis, we recognize that it is yours. To help you and your care partners better understand NPH, we've assembled this handbook. It covers everything from general information about NPH to what you can expect throughout treatment and recovery. Please note that because every patient is unique, not everything described in these pages will necessarily apply to you.

At the end of this handbook, you'll find space to keep track of your appointments and jot down any questions you have for your clinicians. We hope this handbook will help you and your loved ones stay informed and organized throughout your journey at Barrow.

Sincerely,  
Barrow NPH Team



# Barrow Normal Pressure Hydrocephalus (NPH) Program

The Barrow Normal Pressure Hydrocephalus (NPH) Program is home to a dedicated, multidisciplinary team that's highly experienced in providing evaluation, diagnostic testing, and treatment for individuals with NPH. Our clinical team collaborates with research specialists, and facilitates educational programs to advance the diagnosis and treatment of this condition. The Barrow NPH team is committed to the continuity of care of each individual throughout the course of treatment, including discharge planning and correspondence with other physicians who may be involved in your care.

Our NPH team includes specialists from the following groups:

- Neurology
- Neurosurgery
- Neuropathology
- Neuro-Rehabilitation
- Neurological Research
- Neuroradiology
- Nursing
- Neuropsychology

# International Patient Program

We understand that because NPH specialists are few and far between, patients often travel to receive the specialized care they need. If you are traveling to Barrow from another state or country, we encourage you to contact our International Patient Program.

The ***International Patient Program*** is committed to making your treatment at Barrow Neurological Institute as easy as possible. Our first priority is to reduce any stress and uncertainty you may be feeling. We aim to go beyond your expectations to ensure that you and your loved ones are comfortable so that you can focus on your treatment and recovery. During your stay, we'll seamlessly blend your medical needs; individual preferences; and cultural, linguistic, and religious expectations into a tailored experience that makes Barrow feel as close to home as possible.

Our team is here to help you before, during, and after your treatment and can assist you with the following:

- Scheduling clinic appointments and diagnostic tests
- Making hotel/lodging arrangements
- Assisting with hospital admission and insurance verification
- Assisting with financial estimates and payments
- Communicating with hospital physicians and staff before and after your stay
- Finding a local worship/religious center

For more information about our International Patient Program, please contact:

**(602) 406-3867**

**BarrowInternationalProgram@CommonSpirit.org**

# Types of Specialists

You may interact with several different clinicians and staff before, during, and after your stay in the hospital. These specialists may include the following:

**Neurologist:** A doctor who specializes in diagnosing and treating diseases of the brain, spinal cord, and peripheral nerves without surgery.

**Neuropsychologist:** A doctor with special training in assessing whether a person is experiencing changes in their thinking abilities or behaviors due to a disease or an injury of the brain.

**Neurosurgeon:** A doctor who specializes in diagnosing and treating diseases of the brain, spinal cord, and peripheral nerves with surgery. To treat NPH, a neurosurgeon typically places a shunt device inside the brain to drain excess fluid to an area of the body, usually the abdomen, where it can be reabsorbed.

**Physiatrist:** A doctor who specializes in physical medicine and rehabilitation. In other words, this doctor helps patients regain function and independence.

**Physical Therapist:** A clinician who focuses on the assessment and improvement of a patient's physical movements. In general, physical therapy consists of exercises, stretches, and manual therapies (e.g., massage), all of which are tailored toward a patient's specific needs and goals.

**Nurse Navigator/Coordinator:** A nurse who serves as your primary contact person, helping to connect with your care team throughout your treatment journey and get your questions answered. This person can also help you find other support resources.

**Nurses and Nurse Practitioners (NP):** The nurses and nurse practitioners at Barrow have special training in the neuroscience field. Their role is to care for you at the bedside and work with your doctors to ensure your needs are met. Our nurse practitioners are also committed to educating you about your condition.

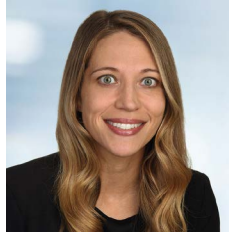
# Meet Your Team

To learn more about our team of NPH experts or to request an appointment, please call **(602) 406-6262**.

## Neurologists



Justin Hoskin, MD



Kamala Saha, MD

## Neurosurgeons



Kris A. Smith, MD



Kerry Vaughan, MD



Andrew Yang, MD

## Neuropsychologists



Krista Hanson, PhD



William Schultz, PhD



Alexander Tröster, PhD

## Physical Therapists



Sharon Hayden, PT



Marie Kruse, PT

## NPH Coordinator



Antonio Green

## Clinic Supervisor



Deanna Hernandez

# NPH Overview

Normal pressure hydrocephalus (NPH) describes an abnormal buildup of cerebrospinal fluid (CSF) within the cavities of the brain, which are called ventricles. Every day, the average adult produces about one pint of CSF, which cushions the brain from injury and carries nutrients to and waste products away from the brain. In NPH, the CSF pathways become blocked and CSF accumulates. This abnormal buildup causes the ventricles to become enlarged, but it usually does not raise pressure within the skull beyond normal limits, hence the name “normal” pressure hydrocephalus.

## What Causes NPH?

The cause for the majority of NPH cases is unknown. In some cases, NPH can develop as the result of some type of injury to the brain. This can include head trauma, a bleed within the skull, or a tumor or cyst in the brain. NPH is also a possible complication of brain surgery.

## Signs and Symptoms of NPH

Three main symptoms are characteristic of NPH: difficulty walking, mild dementia, and impaired bladder control. Because these symptoms are also associated with the aging process and other neurological diseases, such as Alzheimer’s and Parkinson’s disease, people with NPH may go undiagnosed or misdiagnosed for years.

**Gait disturbances** – These can range in severity from mild imbalance to the inability to stand or walk at all. Your gait may be widespread, short, slow, and shuffling, or you may have trouble picking up your feet. Gait disturbance is often the most pronounced symptom and the first to become apparent.

**Mild dementia** – This can look like a loss of interest in daily activities, forgetfulness, difficulty dealing with routine tasks, and short-term memory loss.

**Impairment in bladder control** – This can range from urinary frequency and urgency in mild cases to complete loss of bladder control (urinary incontinence) in more severe cases.

## Diagnosing NPH

The Barrow NPH team is highly skilled in prompt and accurate diagnosis of NPH, as well as identifying whether someone is a candidate for shunt surgery. Whether you have already been diagnosed with NPH or suspect you are experiencing this condition, our team will create a treatment plan designed specifically for you.

Diagnostic tests may include the following:

**MRI CINE Flow Study:** This is a type of magnetic resonance imaging (MRI) that evaluates the flow of cerebrospinal fluid (CSF) around the brain, brainstem, and/or spinal cord. This test typically takes at least 30 minutes, but it is safe and painless. MRI uses radio signals and a very powerful magnet to create a picture of the brain. It can detect if the ventricles are enlarged, as well as evaluate the CSF flow and provide information about the surrounding brain tissues. MRI provides more information than a computed tomography (CT) scan and is therefore preferred in most cases.

**Lumbar Puncture (Spinal Tap):** After the administration of local anesthesia, a thin needle is passed into the spinal fluid space of the low back. Removal of CSF is performed to see if symptoms are temporarily relieved. Improvement of symptoms suggests that a patient will respond positively to shunt surgery.

**Physical Therapy Evaluation:** This examination is performed by a physical therapist (specializing in balance disturbances) in the early stages of the diagnostic process to obtain a baseline assessment of the patient's gait, balance, level of functional ability and fall risk. The same exam is performed before and immediately after the lumbar puncture (L/P) is completed to document improvements in mobility and to assist in determining if the procedure was beneficial from a functional mobility stand point.

**Neuropsychological Test:** This test involves a series of questions used to determine if there is a change to thinking abilities, mood, or behavior due to hydrocephalus.

## Treating NPH

There is no known way to prevent or cure hydrocephalus. Fortunately, NPH can often be successfully treated with a special shunt that drains excess CSF away from the brain to another part of the body, usually the abdominal cavity, where it can be reabsorbed. This shunt is programmable, meaning the rate of flow can be adjusted externally using a special magnet, rather than with additional surgeries. This maximizes the potential benefit of the shunt for each individual. The shunt tube is about 1/8 inch in diameter, and it is made of a soft and pliable plastic that is well tolerated by body tissues. Shunt systems come in a variety of models but have similar functional components.

## Possible Complications With Surgery

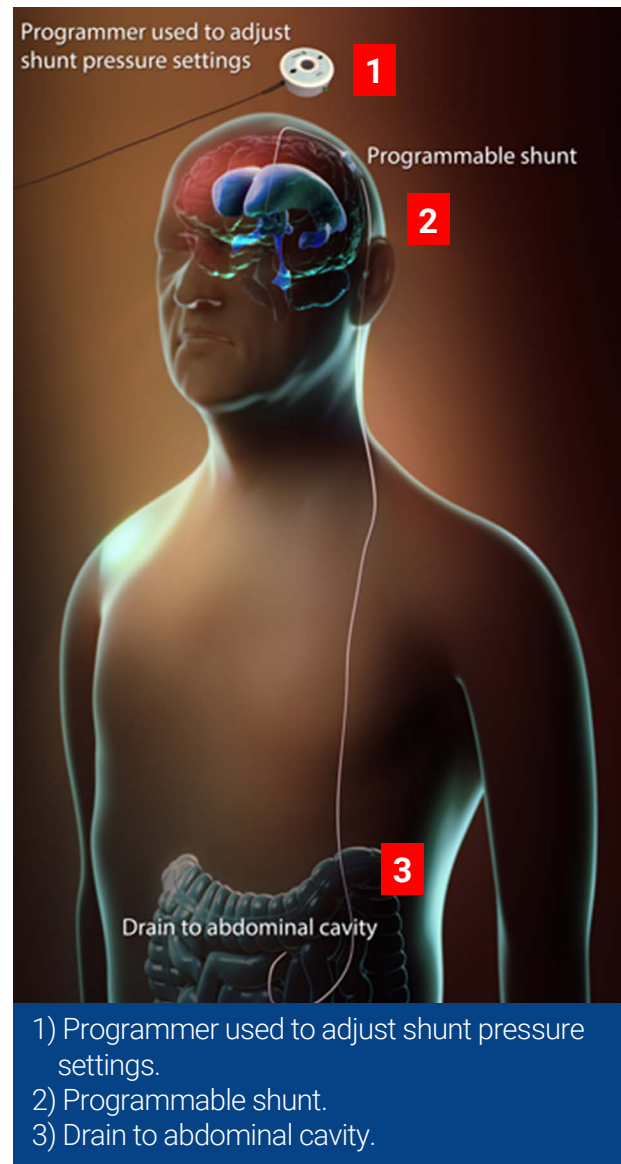
Although shunt surgery is a relatively simple neurosurgical procedure, the decision to undergo insertion of a shunt should not be taken lightly. As with any operation, it's important to weigh the potential benefits with the risk of complications.

The possible complications of shunt surgery can be grouped into those related to the actual operation and those that occur days to years later. The risks of shunt surgery itself include those of general anesthesia and actual placement of the shunt. These risks include death, coma, stroke, hemorrhage, and infection. Fortunately, the risk of encountering serious life-changing complications is relatively small. Your neurosurgeon will discuss these risks with you and answer your questions.

The most common problem with shunt systems is that they can become clogged. This can occur hours or years after the operation. For patients with NPH, a shunt obstruction is usually discovered when the original symptoms recur. Fortunately, shunt obstructions in NPH are relatively rare and do not often result in serious problems.

The most serious complication that can occur following insertion of a shunt is a subdural hematoma, also known as a blood clot. Because most shunts drain CSF from the center of the brain (the ventricles), this may cause the surface of the brain to pull away from the skull, thus stretching and tearing blood vessels on the surface of the brain. The symptoms of a subdural hematoma vary from increasing headache to paralysis, or even coma or death. Shunt-related subdural hematomas most commonly occur after a fall, even one involving only a minor bump to the head. Therefore, a patient with a shunt for NPH should not hesitate to seek medical attention if abnormal symptoms develop.

## Outcome & Recovery



Higher success rates for NPH surgery have been reported from medical centers with greater experience in treating this condition, like Barrow Neurological Institute. It is important to note that if initial success is followed by a recurrence of symptoms, it may be due to a shunt failure or the need for shunt pressure reprogramming.

## **Rate of Improvement**

The symptoms of gait disturbance, mild dementia, and bladder control problems may improve within days of shunt surgery, or they may take weeks to months to resolve. There is no way to predict how fast, or to what extent, improvement will occur. It is also not possible to make general predictions about how long the improvement will last, as the course of clinical improvement varies for each patient. Some patients seem to reach a plateau, while others improve for months but then seem to decline again. Unfortunately, there are no guarantees.

Generally, patients with an implanted shunt system are not restricted in their daily activities, except those involving great physical exertion. Your doctor will discuss with you any restrictions that may be advisable. Most patients with hydrocephalus can look forward to a normal future. Shunts are expected to perform reliably over a long period of time. However, because hydrocephalus is an ongoing condition, patients do require long-term follow-up care by a doctor. Regular visits will help your neurologist identify subtle changes that may indicate a shunt problem. We encourage patients and care partners to become familiar with the signs and symptoms of shunt malfunction, as described below.

## **Shunt Adjustments**

At Barrow Neurological Institute, our neurosurgeons use programmable shunts for the treatment of NPH. These shunt valves can be easily adjusted to control the amount of CSF that is drained. Inadequate drainage prevents improvement in symptoms, while too much drainage can lead to headaches and increase the risk of complications. As noted earlier, you may need one or more shunt adjustments to obtain the maximum benefit of your device while minimizing the risks of over-drainage.

Shunt adjustment is a simple, noninvasive procedure which involves placing an external device over the shunt valve to change the shunt setting. This can be done in a physician's office. Both your neurosurgeon and neurologist have undergone training to make these changes.

## **Shunt Revisions**

Occasionally, patients with shunt systems require revisions. A revision is a surgical

procedure to modify, repair, or replace a shunt system due to complications or changing patient conditions. In cases where a change in shunt pressure is needed, a programmable shunt system can be reprogrammed externally—without the need for surgery.

## **Symptoms of Shunt Malfunction**

- Headache
- Vision problems
- Difficulty speaking
- Irritability/personality change
- Mild dementia
- Extreme sudden fatigue
- Difficulty waking up or staying awake
- Loss of coordination or balance
- Return of gait disturbance
- Incontinence

This list of symptoms is for your reference only and is not intended to be used as a diagnostic tool. If you are in doubt about your condition, or that of your loved one, please consult your physician immediately or go to the nearest emergency room.



# Just Diagnosed With NPH; Now What?

If you have been diagnosed with NPH and identified as a possible candidate for shunt surgery, you will be referred to one of our neurosurgeons who specialize in NPH. You may also be referred to one of our clinical neuropsychologists to undergo a baseline assessment of your ability to understand and process information. This type of testing is performed to provide realistic expectations of cognitive function after surgery.

## Your Neurosurgery Consultation

When you meet with your neurosurgeon, you may want to ask the following questions:

- What is the reason for my surgery?
- How urgent is my surgery?
- What will my surgery entail?
- What are the possible complications of my surgery?
- What should I expect during the recovery process?
- How long should I take off of work?
- Who will manage my medications and supplements after surgery?
- What medications should I stop taking before surgery?
- Will any of my other medical conditions affect my recovery or length of stay in the hospital?
- Will any testing I recently had done be repeated before surgery (MRI study, EKG, chest X-ray)?
- Do I follow up with the neurosurgeon, neurologist, or both?



Also, please be sure to discuss any allergies you have to food, medications, or products (e.g., latex).

If you and your surgeon agree to move forward with surgery, a date will be selected. Since this is a progressive condition, the surgery is typically not considered urgent. Your surgeon understands, however, that once you have been given an opportunity to improve your quality of life, you want to feel better immediately. Their office will do their best to accommodate your schedule and desire to move forward quickly. In addition to the surgeon's schedule, there are other factors that influence the timeline of surgery. For example, if you see other specialists (e.g., cardiologist, pulmonologist), you may need

clearance from them before you undergo shunt surgery.

# Your Hospital Experience

## When Surgery is Recommended

First, we want to remind you that you're in excellent hands. Barrow Neurological Institute is an internationally renowned medical center, which offers care for people from throughout the world with brain and spine diseases, disorders, and injuries. *Newsweek* routinely lists Barrow as one of the best hospitals in the world for neurosurgery.



Your medical team—including the staff in the operating room, intensive care unit, and regular nursing floor—are highly skilled individuals who strive to provide care with dignity and compassion. The Barrow Neuroscience Tower is a 430,300-square-foot tower dedicated solely to treating neurological and neurosurgical patients.

Once you come to the Barrow NPH Program, you are part of the Barrow family. We care about you!

## Testing Before Surgery

Once a date has been set for surgery, your surgeon's office will schedule a time for you to come in and complete testing in our Pre-Admission Testing Clinic. This may include specific lab work, a chest X-ray, MRI or CT studies, encephalography (EEG) tests, and an examination by one of our hospitalists for medical clearance. We carefully select preoperative tests for each patient to ensure the best and safest care possible.

If you have had some of these tests completed recently, please send the reports to your surgeon's office. Some tests may not need to be repeated if they were done within an acceptable timeframe. Pre-admission testing is important, as the results sometimes uncover other medical conditions that are unknown to patients and may need to be addressed prior to surgery.

The preoperative nurse will interview you, obtain your medical history, review your patient care record, and answer any questions you have at this time. Make sure you bring a list of your current medications (with their dosages), even if you have already provided this list

to your surgeon's office. This list should include both prescriptions and over-the-counter medications.

Hospital registration may also take place at this time. Remember to provide the registration staff with your email address so that you receive an invitation to our **patient portal**. This portal will allow you to retrieve medical records online, which you may share with your other doctors. If your other doctors are not affiliated with our hospital, they will not have access to crucial records that can help them take care of your other medical conditions. The Registration Department staff is responsible for sending you the invitation to this link.

Bring this handbook, and any other paperwork you've received from our doctors, with you to your preoperative appointment.

# Preparing for Surgery

## Diet

Weeks before your surgery, begin eating a balanced diet if you are not already on a specific plan. Eat three to four meals per day.

Decrease your intake of alcohol, caffeine, and cigarettes weeks or months prior to your surgery, if possible. It is not recommended that you abruptly stop smoking days before surgery; doing so can have an adverse effect on your breathing passages.

## Medications

Notify your surgeon if you are currently taking any of the following medications:

- Hypoglycemics (insulin or oral agents)
- Anticoagulants/antiplatelets (Aspirin, Excedrin, Coumadin, Plavix, Heparin, Lovenox, etc.)
- Anticonvulsants (Depakote)
- Anti-inflammatory drugs (Anaprox, Dolobid, Feldene, Motrin, ibuprofen, Naprosyn, Toradol, Vioxx, Aleve, Advil, etc.)
- Natural supplements, such as Vitamin E
- Herbal medications, such as ginkgo and St. John's wort.

Your surgeon may ask you to discontinue some medications before surgery to reduce your risk of complications.

## Planning

Plan your discharge ahead of time. Although a typical stay for NPH surgery is one night, it is possible you may stay longer if any of your providers have concerns about your health.

Taking care of the following tasks before your surgery can make for a smoother recovery at home:

- Identify a companion to help you for a few days after you arrive home.
- Arrange transportation to and from the hospital. Discharge usually takes place by 11 a.m.
- Stock your refrigerator.
- Prepare meals in advance.
- Contact your insurance company to determine your benefits regarding outpatient therapy or medical devices, such as walkers and shower chairs, that you may need once you are home.

- Remove all loose area rugs in walking paths.
- Move any loose cords and/or wiring, and clear the walking paths inside your home.
- Move essentials to the drawers and shelves that are between shoulder and waist level so that you can reach those items without bending over past your waist.
- Notify family and friends when you are expected to be discharged from the hospital to avoid gift deliveries after you have left.
- Ask friends and family not to visit you once home if they suspect they have been exposed to a cold, COVID-19, or the flu.
- If you'd like to keep friends and extended family updated about your recovery, consider creating a social media group or a webpage on a site like [CaringBridge.org](https://www.caringbridge.org).
- If you will not have help when you return home, it's especially important to:
  - ~ Stock your refrigerator and pantry before your surgery.
  - ~ Fill prescription medications in advance, when possible.

## Day Before Surgery

Remove nail polish, jewelry, and body-piercing jewelry before you come to the hospital for surgery.

Your surgeon may request that you take a shower with chlorhexidine the night before and morning of surgery, giving special attention to the area of surgery. You may also be asked to wash your hair with your shampoo of choice when you shower as instructed above. Do not use hair spray, other styling products, lotions, or perfumes.

Generally, patients are advised not to eat or drink after midnight before undergoing surgery. Please consult your surgeon for the restrictions that apply to your specific case.



# Day of Surgery

## Hospital Information You Should Know

### Parking

Patient and visitor parking is available in the Sixth Avenue and Third Avenue garages. Rates are \$1 for up to six hours, \$10 over six hours without validation, and \$1 with validation. Validations are available at the parking concierge desk on the Third Avenue Bridge. Upon request, hospital security will escort you to your car. Valet services are also available.

### Getting Around

The Barrow Neuroplex and Neuroscience Tower are located on Third Avenue, just north of Thomas Road in Phoenix. Our campus is about a 20-minute car ride from Phoenix Sky Harbor International Airport and about a 30-minute drive from Scottsdale's private airport. Public transportation is available in Phoenix, through the Valley Metro bus and light rail services. Campus maps and directions can be downloaded from [BarrowNeuro.org](http://BarrowNeuro.org) or picked up at the parking concierge desk on the Third Avenue Bridge. Wheelchairs are available for patients and visitors who need assistance getting around the campus.



### Insurance

Although the hospital and Barrow physicians accept most insurance plans, we always recommend checking with your insurance company before your visit to confirm your coverage. Your surgeon's office will also verify your insurance coverage prior to your hospital admission.

Patients who plan to receive elective services but who do not have health insurance must make payment arrangements with the hospital and physician before undergoing treatment. The physician's billing office can provide the necessary forms and hospital contact information.

## **Contacting Patients in the Hospital**

Family and friends can call the hospital 24 hours a day at **(602) 406-3000** to reach a patient who has been admitted. Because of governmental regulations, information about a patient's condition can only be shared with individuals legally designated by the patient.

## **Tobacco-Free Campus**

For the health and well-being of our patients, visitors, and employees, St. Joseph's Hospital and Medical Center is proud to be a tobacco-free campus. Tobacco use is not allowed in our buildings or anywhere on our grounds, including parking areas, walkways, and any other outdoor spaces.

## **Visiting Guidelines and Hours**

Visiting hours at St. Joseph's Hospital are between 5 a.m. and 10 p.m. However, visiting hours are subject to change to ensure the safety of our patients and staff. Overnight visitation is restricted to one adult and must be approved by the nurse manager, supervisor, or house manager. Children may visit patients but must be accompanied by and remain with an adult at all times. Certain patient care areas, such as intensive care units, have age-related visitor restrictions. St. Joseph's also reserves the right to limit the number and time of visits. If you are a visitor, we ask for your cooperation if a staff member requests that you and/or other visitors leave the room. This will allow us to fully concentrate on the patient's care and needs. You will be allowed back into the room as soon as it is safe to do so.

## **Café 1895**

Open daily from 6:30 a.m. to 9 p.m.

## **Starbucks™**

Open Monday through Friday: 5:30 a.m. to midnight

Open Saturday and Sunday: 6 a.m. to noon

## **Patient Safety**

To help ensure the safety of our patients, we ask that you do not visit a hospitalized patient if you are experiencing symptoms of a cold, COVID-19, or the flu.

## **Wireless Internet**

Wireless internet is available in most areas of the hospital. The network is GUEST-SJHMC.

## **Patient Relations**

We strive to create an outstanding experience for our patients and their loved ones. If you have any concerns regarding your care, please speak with the nurse manager. If you feel that your concerns have not been addressed, please contact Patient Relations at (602) 406-6200.

## **Hospital Phone List**

NPH Program	(602) 406-6262
Registration	(800) 643-1219
Main Hospital	(602) 406-3000
Preoperative Center	(602) 406-3192
Hospital Security	(602) 406-3363



# What do I bring with me to the hospital?

Please **do** bring the following to the hospital:

- Complete list of medications that you take at home, including dosages and frequency
- Insurance card and means to pay hospital copayment
- Identification
- Living wills and advance directives
- Test results:
  - ~ If you have had a chest X-ray within the last year, notify your surgeon to avoid unnecessary testing. Also, please tell your physician if you have had an EKG (electrocardiogram) test completed within the last month. Your surgical team will want to see the results of this test.
  - ~ If you have experienced any medical challenges, such as cardiac, renal, or respiratory conditions, please make sure that your specialist for that condition is aware of your upcoming neurosurgery. These physicians must “clear” you for surgery; that is, they must provide a written release stating that your condition does not prohibit you from undergoing surgery.

Please **do not** bring the following items to the hospital:

- Unnecessary valuables or jewelry
- Medications from home. Hospital policy prohibits patients from receiving medication from outside the hospital for safety reasons.

# Preoperative Department

You will be asked to arrive at the hospital hours before your surgery is scheduled to begin. This time allows the hospital staff and physicians to ensure everything is in place for your surgery and answer any last-minute questions from you or your loved ones.

You will be asked to remove your eye glasses, contact lenses, and dentures, if applicable. Your dentures may be placed back into your mouth in the recovery room when you are awake and alert. You will also be asked to remove all jewelry, so we recommend leaving it at home. Hearing aids will not be removed until you have arrived inside the operating room to ensure that you can communicate with the surgical team until you drift off to sleep.

You will meet many members of our staff during the time before your surgery. Your surgeon and their assistant will check in with you to see how you are feeling and complete all hospital tasks. These tasks include explaining the procedure, answering all questions, and obtaining signed consents.

In addition to your surgeon, you will meet the neurosurgery resident assisting your surgeon, your OR nurse, and your anesthesiologist. It may seem like everyone is asking you the same questions repeatedly, but we want to ensure nothing gets overlooked and everyone understands your medical condition and overall health. The surgical team also has requirements to carry out, such as asking you what procedure you expect to be performed. The surgeon or their assistant will mark the side of the body they will be entering for your procedure. An intravenous catheter may be placed in your arm to administer medication to relax you before you are taken to the operating room.

At this time, you will also meet the nurse program coordinator—if you haven't already. The coordinator will discuss the treatment and recovery guidelines designed by the team to ensure your recovery is a positive experience.

A successful surgical outcome is not only dependent on the expertise of the surgeon; your commitment to following recovery instructions is just as important.

If you are being considered for a research project, you may be introduced to a research nurse at this time. Determining factors for research participation include the type of condition and symptoms you have, as well as your demographic. If you meet the criteria for a research project, you will sign a consent form after receiving a thorough explanation of the project.

Doctors improve surgical techniques, develop new technology, and identify safe medical therapy through research studies. Even if these research studies may not benefit you personally, they could help others in the future.

You always have the right NOT to sign a research consent form without feeling the need to explain your decision. Your care is not affected if you choose not to sign the research consent form.

## During Surgery

### Neurosurgical Waiting Room

While you are in surgery, your loved ones may wait in the neurosurgical waiting room on the second floor of the hospital.

The front desk staff in this area should be notified if your contact person wishes to leave the premises in case a member of the surgical team needs to speak with them. After the surgery is completed, a member of the surgical team will speak to your contact person. Children are welcome to visit once you've been admitted to the general nursing floor. Neurosurgical procedures tend to be longer than other procedures, and the lengthy wait can be challenging for young children.



### Operating Room

You will be in the operating room longer than the actual time for surgery, as the anesthesiologist will need time to care for you before and after surgery. It is best to relay this to your loved ones so they don't worry.

## Recovery Room

Your personal contact in the waiting room will be notified once you are transferred to the recovery room from the operating room, and again when you are to be transferred to your room. Visitors may be permitted in the recovery room at the discretion of the recovery room staff. You will remain in the recovery room for one to two hours while you awake from anesthesia. While we do our best to avoid delays in transferring you to your hospital room, delays do sometimes occur due to emergencies and other unforeseen circumstances.

As you recover, your nurses will monitor your neurological status and vital signs. You will be asked to state your name and answer other questions to assess your mental status. You will be connected to a cardiac monitor, a pulse oximetry machine to measure the oxygen in your blood, a temperature gauge, and an oxygen mask.

Medication may be ordered to control your pain. Please ask for this medication when you feel uncomfortable, especially during the first few days after surgery. If you wait until the pain worsens, the medication ordered by your doctor may not be able to control your pain. If you are concerned about becoming dependent on narcotics, please discuss this with your surgeon before surgery. Non-narcotic medication is available, and it is often sufficient to control pain.

Please notify your nurse if your pain is not adequately addressed. Because many patients feel nauseated after a surgical procedure, medications are available in the recovery room to help prevent this unpleasant side effect.

You may have a variety of intravenous and arterial lines, which may remain in place for a few days or until hospital discharge.

# While in the Hospital

## Intensive Care Units (ICU)

If you require close monitoring, you may be assigned to an ICU after surgery. On these units, there is usually one nurse for every two patients.

In the ICU, your team will encourage you to increase your activity level as tolerated. This will help you avoid complications associated with temporary immobility, such as gas pains, bed sores, decreased lung capacity, and blood clots. You will be asked to reposition your body by turning over or moving your arms and legs, to take deep breaths, and to use an incentive spirometer to flush anesthetic agents from your lungs. Showers are permitted after your surgeon provides a written order.



Your nurse will assess your neurological status at predetermined times to ensure you recover as expected. Your assessment will include various questions to test your alertness. You also may be asked to move specific parts of your body.

Food and liquids will be introduced slowly, beginning with ice chips and advancing to more substantial foods as tolerated. At this point, you may need neuro-rehabilitation treatment to assist with your recovery, such as speech, occupational, and/or physical therapy. These services may continue throughout your hospital stay and after hospital discharge in an outpatient setting. Social work, case management, and pastoral services are available on request.

Tubes that drain fluid from the surgical site may remain in place for as long as four days and will be removed at the discretion of your surgical team. Tests, such as radiographic studies (MRI, CT) and laboratory tests, may be performed in the days after your surgery.

Please relay to your loved ones that flowers and live plants are not permitted in the ICUs.

## General Nursing Units

Your surgeon may determine that your condition does not require ICU monitoring. If this is the case, you will be admitted to the general nursing floor instead. Private and double rooms are available in these areas.

On general nursing floors, your activity will be increased to avoid muscle weakness and other complications of immobility. Some patients are out of bed the same day as surgery. Services such as physical, speech, and occupational therapy may be provided.

Diet will be advanced as tolerated. Small, frequent, balanced meals will help you heal faster and regain your normal energy level.

While you are in the hospital, many different types of doctors from different areas of medicine may visit you.



A typical hospital admission for patients undergoing NPH surgery is one overnight stay, which may be in the intensive care unit (ICU) or the regular nursing floor. The length of stay in the hospital, as well as the need for the ICU, is ultimately determined by your surgeon and based on your overall health and any existing medical concerns.

Once you are ready to leave the hospital, please remember to notify your loved ones and take all of your belongings with you.

The hospital's case managers and social workers are available to help you identify needs that you may have after discharge from the hospital. These needs may range from renting wheelchairs to arranging home health care and outpatient therapies.

# Discharge From the Hospital

Your physician will let you know the day you are expected to be discharged from the hospital in advance so you can arrange transportation.

Prescriptions for pain control and other medications will be provided prior to your discharge. You may not feel the need to fill these prescriptions right away, but it's important to have your medications available if the need arises.



Discuss with your physicians the possible interactions between the medications you are taking. Avoid drinking alcohol, driving, and operating any other heavy machinery while taking medication for pain.

On the day of discharge, you will receive your paperwork and be ready for discharge by 11 a.m. If possible, please notify your ride the

night before your anticipated discharge to ensure a timely pickup. If your ride is unavailable before 11 a.m., you may wait in the Discharge Lounge. Home medical equipment, prescriptions, and lunch boxes can be delivered to this area, if necessary.

As you recover, honor your physical limitations and allow sufficient time to heal before resuming normal daily activities. Ask your surgeon for specific limitations on lifting weight. We generally advise gradual exercise, which may look like walking before returning to usual gym activities.

Taking baths, swimming, or otherwise submersing your incisions into any body of water is discouraged until your incision is healed. This typically means at least 14 days after surgery. Wound care is prescribed by your surgeon.

We know our recommendations for recovery may seem restrictive, but they're based on our experience in treating thousands of patients just like you.

Small, frequent meals—including foods rich in protein—are encouraged to promote healing. Smoking should be avoided, as it inhibits the healing process by hindering blood flow to your organs and tissues.

The hospital's case managers and social workers are available to help you identify needs that you may have after discharge from the hospital. These needs may range from renting wheelchairs to arranging home health care and outpatient therapies. Please ask to speak to one of these individuals before the day of discharge.

## Discharge Lounge

After you are discharged, we will escort you to our Discharge Lounge. This lounge offers a quiet and comfortable environment with the following amenities:

- Water, coffee, and light snacks
- Comfortable chairs
- Television
- Phone
- Bathroom
- Lockers

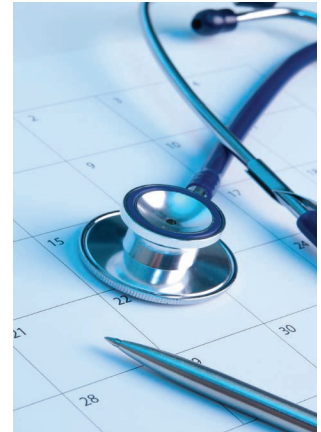
Enjoy the amenities while you wait for your ride to pick you up. If you have chosen to utilize our pharmacy for your discharge medications, they will be delivered to you in the Discharge Lounge. The pharmacist will review your discharge medications and answer any questions you may have. If you are being discharged with any medical equipment, this will also be delivered to you in the Discharge Lounge.

When your family member or caretaker arrives to pick you up, they can check in at the front desk or contact the Discharge Lounge from their vehicle at **(602) 406-2616**. The Discharge Lounge staff will escort you and your belongings to your waiting vehicle.

If you need help arranging a taxi to transport you home, the Discharge Lounge staff will be happy to assist you.

## Follow-Up with Your Doctors

Please note that we coordinate your follow-up appointments with specific timeframes in mind. If you reschedule any of these appointments, please ensure that you allow at least **two to three weeks between the appointments** with your neurosurgeon and your neurologist. Adjustments made to your shunt valve must be done slowly over time to avoid complications of over-drainage. If you see the neurologist less than two to three weeks after your neurosurgeon makes an adjustment to your shunt, your neurologist will NOT be able to make another adjustment to your shunt during this visit.



Your neurosurgeon will ensure your recovery is going as expected. Your neurologist will manage your shunt long term and only refer you back to your neurosurgeon if there is a problem with the shunt down the road. Oftentimes, when we have a foreign device placed in our body, we attribute new symptoms to this device. Your neurologist is specifically trained to evaluate any new symptoms that arise after surgery and determine if it is shunt related or caused by an unrelated condition.

You will have an appointment with a physical therapist after surgery to evaluate your gait/balance and determine if you need ongoing physical therapy. Once the therapist completes this assessment, they will provide your neurologist with recommendations for therapy. Although we understand it may be more convenient for you to seek therapy at a facility closer to your home, if you would like to continue ongoing care with your physical therapist at Barrow, they will be happy to schedule you in their clinic.

If you are receiving therapy at another facility, please **ask your therapist to provide you with a progress note** and bring it to your follow-up appointment with your neurologist. This can help your neurologist make informed decisions regarding your shunt adjustments.

Keep in mind that if you begin therapy at another facility (in the home, at a rehabilitation center, at a skilled nursing facility, or in another outpatient setting) prior to your appointment with our physical therapist, **your insurance carrier may not allow you to see our therapist during this follow-up visit. If this is the case, we kindly request that you contact our NPH clinic to cancel your appointment at least one week in advance. This will allow another patient to accept that appointment time. The clinic can be reached at (602) 406-6262.**

Before your appointments, consider writing down any questions you have. During your appointments, we recommend writing down any instructions given by your physician, such as the need for an annual checkup, future X-rays, or other time-sensitive tests.

## At Home After Surgery

While you will receive specific discharge instructions when you leave the hospital after surgery, this handbook offers some general guidelines for what you can expect during your recovery.

Although shunt operations do not work for everyone with NPH, many people experience symptom relief, which may range from mild to dramatic. These symptoms—including gait disturbance, mild dementia, and incontinence—may resolve within days to weeks following a shunt procedure.

Some patients may require significantly more time to improve. There is no way to predict with certainty who will benefit from a shunt procedure and how long the improvement will last, as the course of clinical improvement varies for each patient. Some patients reach a plateau, while others improve for months but then seem to decline again. A small percentage of patients experience worsening symptoms immediately after surgery, followed by gradual improvement. Unfortunately, there are no guarantees.

Caring for patients with NPH requires a team of physicians rather than one individual surgeon. If you're unsure which physician to contact with questions and concerns throughout your recovery process, please contact the NPH program coordinator.

### You May Experience the Following After Surgery

Postoperative **nausea** may be related to your pain medications. If possible, take your pain medication with food. Eating small, frequent meals and avoiding spicy and fried foods may help reduce nausea.

It may take **six weeks or more for your energy level to return to normal**. You will probably feel fatigued for the first two weeks then notice a gradual increase in energy thereafter. If you experience extreme **fatigue**, notify your doctor. They may order blood tests to evaluate your hormone levels.

**Constipation** is a common problem after surgery due to anesthesia, inactivity, and prescription pain pills. It is helpful to increase your intake of water, fresh fruits and vegetables, fiber, and bran. Also, taking over-the-counter docusate sodium tablets, 100 mg (one to two times per day), can help keep your stools soft. You may decrease your dosage if your stools become too soft.

If these measures do not relieve your constipation, you may take milk of magnesia (one to two tablespoons every 12 hours). If this doesn't work, you may use a Fleet enema or rectal

suppository to assist with evacuation of the rectum. This is preferred over heavy straining. If none of these methods is successful, please notify us.

**Here are some tips to keep your bowels moving:**

<b>What to Do</b>	<b>How Often</b>
<b>Prevent constipation with these:</b>	
Drink more water	Every day
Eat fresh fruits and vegetables	Every day
Walk	Every day
Senokot (8.6 mg tablet)	Daily, one to two times per day, until your bowel movements return to normal
<b>If constipation is not relieved with these measures, you may take:</b>	
Dulcolax (10 mg pill)	Once a day until you have a successful bowel movement
MiraLAX powder (1 capful dissolved in 8 ounces of water)	Drink once every day until you have a bowel movement
<b>If these do not work or if you have not had a bowel movement in three days, try:</b>	
An enema or rectal suppository	Once; an enema or a rectal suppository is preferred over straining

**Wound Care**

- Keep the dressing on your abdominal incision clean and dry. You may have some itching at the incision site. This is a normal part of the healing process.
- Do not apply ointments, lotions, or creams to your incision unless advised to by your surgeon.
- Showers are typically approved by your surgeon within a day or two after surgery.
- Baths, hot tubs, and swimming pools are not allowed until your surgeon approves.
- Avoid peroxide for incisions closed with absorbable sutures, as it will cause the sutures to break down too rapidly. Instead, clean your incision with soap and running water.
- Begin daily hair washing with mild shampoo and conditioner (to ease the tangles) when cleared by the surgical team, usually three days postoperatively.
- Use caution when brushing or combing your hair, as vigorous rubbing can disrupt the sutures.
- If nylon sutures are used for the skin closure, your surgeon will remove them during your postoperative clinic visit after hospital discharge (within 10 to 14 days following surgery).

## Avoid Infection

Keep your fingernails trimmed short. That way, if you happen to scratch your incision, you'll be less likely to cause irritation or infection. Contact your surgeon immediately if any of the following symptoms occur:

- Sudden increase in swelling at the surgical site after the swelling had begun to subside
- Fever or chills
- Colored drainage from incision
- Body temperature greater than 101 degrees without other signs of illness
- Deeply reddened skin (pink skin is normal with healing)

## Activity

Patients recover at different rates from neurosurgical procedures and are encouraged to honor their physical and emotional limitations. It is, however, important to get out of bed and move as soon as possible after surgery to avoid developing problems related to inactivity, such as blood clots or pneumonia. Walk with help if you feel unsteady. Get plenty of rest.

Start **light activity** for the first few days you are home and then gradually increase activity with short walks (with assistance if you feel unsteady).

Plan to be away from **work** for two to four weeks if you have a sedentary job, and six weeks if you have an active job.

Resume **normal daily activities** (including sexual activity) after six weeks, unless otherwise advised by your surgeon.

Do not to lift, push, or pull more than **10 pounds** for 12 weeks after surgery.

Do not do anything that would put you at **risk of head trauma for three to four months** after surgery (such as skiing, snowboarding, biking, contact sports, etc.).

Ask your surgeon for specific limitations on **weight lifting**, swimming, and any other activity involving great physical exertion.

**Smoking** delays healing and can cause a wound infection. Reducing this activity, or stopping completely, will improve your chance of a speedy recovery.

**Driving** *is not* recommended until you meet the following criteria:

- You have stopped taking narcotic pain medications
- You do not have visual problems that affect your ability to drive
- You have complete awareness of your surroundings
- You have regained your strength and total control over your fine motor movement

**Bathing:** Showering is appropriate upon approval from the surgical team. Do not immerse the surgical sites on your head or abdomen in any body of water (bath, pool, hot tub, etc.) until the sutures are removed and you have received clearance from your surgeon.

## Nutrition

We recommend eating frequent, small meals (four to six per day), each with a moderate amount of protein, to assist in the healing process. You will receive specific instructions while in the hospital.

Avoid straining hard for bowel movements for three months. Use stool softeners immediately after surgery and include plenty of fluids (six to eight cups of water) and fiber (fruits and vegetables) in your diet. Contact us or your primary care physician to help manage any constipation problems.

## Medications at Home

Prescriptions for pain control and other medications will be provided at discharge. You may not feel it is necessary to have these prescriptions filled right away, but it is important that your medications be available if the need arises. Keep in mind that it is easier to control pain while the intensity is minimal to moderate. If you wait until the pain is significant, the dose you have been prescribed may not be sufficient to manage the pain. Decrease the frequency of the pain medication once the pain subsides. You should transition to over-the-counter medications within a few days of surgery.

### Key Points:

- Discuss with your physicians the possible interactions between your medications.
- Take your medications with food, as many cause nausea on an empty stomach.
- It's common for pain medications to cause constipation, so stool softeners may be beneficial. See "At Home After Surgery" section for more information on this.
- Ask your surgeon before taking medications that contain anticoagulant (blood-thinning) properties, such as ibuprofen or aspirin.
- Vicodin and Percocet both contain acetaminophen (Tylenol). Do not take Tylenol while you are taking these medications, as taking more than 4,000 mg of Tylenol within a 24-hour period can lead to liver damage. Avoid drinking alcohol, driving, and operating any other heavy machinery while taking medication for pain.

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**Oxycodone/Acetaminophen** (Percocet, Endocet)

**Hydrocodone/acetaminophen** (Vicodin, Norco)

**DO NOT TAKE EXTRA  
acetaminophen with these two  
types of pain pills. (Tylenol®)**

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**Oxycodone**

**Hydrocodone**

**Hydromorphone (Dilaudid)**

**Codeine**

**Tramadol**

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You can also take 650 mg of acetaminophen (Tylenol®) every four to six hours, if needed, with these five types of pain pills.

When you feel you no longer need your strong pain pills, you may take ibuprofen (Advil) or acetaminophen (Tylenol) as directed by your surgeon. Acetaminophen (Tylenol) and ibuprofen (Advil) are over the counter—no prescription needed.

## MRI Scans

All of the shunts we use at Barrow are “MRI resistant,” meaning they are compatible with MRI machines. If, for some reason, you have a shunt that is not MRI resistant, you will need to have your shunt examined after any future MRI scans to ensure the magnet has not interfered with the shunt’s settings.



# When to Call Your Doctor

## **Call your neurosurgeon's office or go to the emergency room if any of these occur:**

- Dramatic vision changes (e.g., blurred, double, loss of peripheral)
- Fever of 101 degrees or greater, especially within the first three months of surgery
- Persistent or worsening headaches not relieved with over-the-counter medication and/or a nap
- Jerking/twitching of your face, arms, or legs (seizure activity)
- Difficulty or discomfort in moving your neck, face, arms, or legs
- Significant changes in your behavior or ability to think, such as confusion or difficulty concentrating
- Depression or severe anxiety
- Excessive sleepiness or dizziness
- Significant fatigue that doesn't improve
- Abdominal stitches coming apart
- Redness, swelling, odor, or drainage at your abdominal incision
- Severe abdominal pain
- Loss of bowel/bladder control
- Nausea and vomiting
- Constipation lasting three days and not helped with over-the-counter treatments

Complications of NPH surgery include infection, bleeding, and over-drainage. If you are calling outside of normal business hours and can't reach your surgeon in a timely manner, please contact the nearest emergency room.

# Community Support & Resources

## **Hydrocephalous Association**

Founded in 1983 by the parents of children with hydrocephalus, the Hydrocephalus Association (HA) is the nation's largest and most widely respected organization dedicated to hydrocephalus.

Toll-free hotline: (888) 598-3789

Email: [Info@HydroAssoc.org](mailto:Info@HydroAssoc.org)

Website: [HydroAssoc.org](http://HydroAssoc.org)

## **Mental Health Resources**

American Association of Marriage and Family Therapists

**AAMFT.org**

American Psychological Association

**APA.org**

Health Resources and Services Administration

**HRSA.gov**



# Glossary of Common Terms

**Acquired Hydrocephalus** – Hydrocephalus that develops after birth.

**Acute** – An illness or a symptom that happens suddenly and for a short time. It is the **opposite of chronic**.

**Adult-Onset Hydrocephalus** – Any hydrocephalus that appears in adulthood from any cause, including head injury, stroke, meningitis, or an unknown cause (idiopathic).

**Analgesic** – A medication used to reduce pain. Analgesics include aspirin, acetaminophen, and ibuprofen. Every pain medication has benefits and risks. Specific types of pain may respond better to one medication over another. Results also vary from patient to patient.

**Anticoagulant** – Drugs that help prevent blood clots from forming and are externally administered (IV, oral). They are also called blood thinners.

**Atrophy** – Wasting or thinning of muscle mass.

**Blood Clots** – Blood that has changed from a liquid to solid state.

**Catheter** – The small, flexible tube that is inserted into the brain to allow excess cerebrospinal fluid (CSF) to drain to another part of the body, usually the abdomen, where it can be reabsorbed.

**Central Nervous System (CNS)** – The part of the nervous system that consists of the brain and spinal cord. It connects to the rest of the body through the peripheral nervous system.

**Cerebral** – Of or relating to the brain or intellect.

**Cerebrospinal Fluid (CSF)** – The clear, water-like fluid that surrounds the brain and spinal cord. This fluid provides nourishment, carries away any debris (such as excess protein cells), and protects the central nervous system from injury. It is in constant production, circulation, and absorption. The body makes almost a pint of CSF daily.

**Cerebral Ventricles** – The four chambers of the brain, which are located near the center of the brain and produce CSF.

**Chronic** – An illness or symptom that persists for a long time or constantly recurs.

**Cisternogram (Cisternography)** – A radiographic study of the basal cisterns of the brain after the introduction of an opaque contrast. The basal cisterns are CSF-containing spaces located at the base of the brain.

**Cognitive** – Having to do with thought, judgment, or knowledge.

**Communicating Hydrocephalus** – Also referred to as “nonobstructive hydrocephalus.” This type of hydrocephalus occurs when the CSF pathways and ventricular system are not blocked by anything. Rather, the buildup of CSF appears to be due to a problem with reabsorption.

**Congenital Hydrocephalus** – Hydrocephalus that is present from birth.

**Contrast Agent/Medium** – A substance used in radiography to allow visualization of tissues. This substance is injected into the body through an IV.

**Craniotomy** – Surgery performed on the skull, where a portion of bone is temporarily removed to gain access to the brain.

**CT Scan (Computed Tomography)** – An imaging technique that uses X-ray beams to create detailed images of parts of the body. A CT scan will show if the brain’s ventricles are enlarged or if there is a blockage.

**Dementia** – Deterioration of intellectual faculties—such as memory, concentration, and judgment that interferes with daily activities.

**Dura Mater** – The outermost and toughest of the layers that protect the brain and spinal cord. These layers—the dura mater, arachnoid mater, and pia mater—are also known as the meninges.

**Dysfunctional** – Working improperly or abnormally.

**Edema** – Swelling of a part of the body that is caused by a buildup of fluid. Diuretics may be given as medication for edema.

**Emesis** – Another word for vomiting.

**Endoscopic Third Ventriculostomy (ETV)** – A surgery in which a hole is made in the floor of the brain’s third ventricle. This creates a new pathway for CSF to be absorbed and discarded by the body so that it does not build up and cause symptoms.

**External Ventricular Drain (EVD)** – This device is somewhat similar to a shunt, although it is on the outside of the body. A catheter is implanted into the brain to drain the excess CSF. The flow can be regulated by either raising or lowering the bag into which the fluid is emptied.

**Fixed Shunt** – A type of shunt that has a valve preset for high, medium, or low pressure (within the brain). The pressure setting cannot be changed without further surgery.

**Gait** – A manner of walking.

**Generic** – Nonproprietary, or not protected by trademark registration. A drug not protected by a trademark is also called by its scientific (generic) name, as opposed to the proprietary or brand name. For example, acetaminophen is the generic term for Tylenol.

**Hereditary** – Transferred via genes from parent to child.

**Hydrocephalus** – An abnormal buildup of cerebrospinal fluid (CSF) in the ventricles of the brain. The fluid is often under increased pressure and can compress and damage the brain. Hydrocephalus can arise before or after birth.

**Incontinence** – Inability to prevent discharge of urine and sometimes feces. Urinary urgency or incontinence is a common symptom of normal pressure hydrocephalus.

**Intraventricular Hemorrhage (IVH)** – A bleed within the ventricular system of the brain (also referred to as a brain bleed).

**Lateral Ventricles** – The two “C-shaped” cavities in the brain—one on each side.

**Lethargy** – A condition marked by drowsiness and an unusual lack of energy and mental alertness. It can have many causes, including illness, injury, or drug effects.

**Lumbar Drain** – A lumbar drain is used in a variety of circumstances, including testing whether a person might be a candidate for long-term shunting of CSF. In patients diagnosed with NPH, prior to placing a permanent shunt, a lumbar drain can be used to gauge if the patient will respond to the shunt. This is a procedure done in the hospital (it may take one to four days to complete).

**Lumbar Puncture** – See “*Spinal Tap*”

**Lumbar Tap** – See “*Spinal Tap*”

**Meningitis** – Inflammation of the meninges, the three protective layers (membranes) that envelop the brain and spinal cord.

**MRI** – Short for magnetic resonance imaging. This is a noninvasive test which uses radio signals and a powerful magnet to show the anatomical structures of the brain. It can reveal enlarged ventricles and evaluate CSF flow.

**Noninvasive** – A procedure for diagnosis or treatment that does not require insertion of an instrument or device through the skin or a body orifice.

**Normal Pressure Hydrocephalus (NPH)** – A form of hydrocephalus where the ventricles are enlarged but there is no obstruction within the ventricular system. The cause appears to be that the used CSF is not being reabsorbed and discarded by the body like it's supposed to be.

**Over-Drainage** – A condition where too much CSF has been withdrawn from the cerebral ventricles. Symptoms are usually noticed after a patient is upright for a while and typically include a severe headache in the morning, within about 30 minutes to an hour of getting out of bed. The headache may be combined with nausea, dizziness, and vomiting. Over-draining can result in "slit ventricle syndrome."

**Peritoneal Cavity** – The area of the abdomen, below the diaphragm, where the intestines are located.

**Prognosis** – A forecast as to the probable outcome.

**Programmable Shunt** – Type of shunt where the physician can raise or lower the amount of CSF taken from the brain. The setting is changed by means of a magnetic device placed over the shunt; no surgery is involved.

**Progressive** – Increasing in scope or severity, advancing, or going forward.

**Quality of Life** – Refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. The term "quality of life" is often used in discussions of treatment options.

**Recurrence** – The return of symptoms.

**Reservoir** – Part of the shunt where the CSF is stored and then released periodically.

**Revision** – An operation performed to replace one part of the shunt or the entire shunt system.

**Rule Out** – Term used in medicine, meaning to eliminate or exclude something from consideration for diagnosis.

**Shunt** – A mechanical device implanted to drain excess CSF to another part of the body where it can be reabsorbed and discarded. There are many types, and the neurosurgeon will choose the one that is best for each patient. The most commonly used shunts are: ventriculoperitoneal (VP) shunt, ventriculoatrial (VA) shunt, ventriculopleural (VPI) shunt, and lumboperitoneal (LP) shunt.

**Spinal Tap** – (Also called a “lumbar puncture” and/or “lumbar tap.”) The insertion of a hollow needle to remove some of the CSF, either for pathological testing (e.g., for infection), or to relieve some pressure and see if the patient improves.

**Under-Drainage** – This occurs when not enough of the CSF is withdrawn. Symptoms usually arise when the patient is reclining or lying down. The patient may wake up with a headache, which generally disappears after the patient has been upright for 45 minutes to an hour.

**Urinary Incontinence** – The unintentional loss of urine.

**Valve** – Mechanical device in the shunt which regulates the flow of CSF by opening and closing.

**Ventricles** – See “cerebral ventricles.”

**Ventriculopleural Shunt (VPI)** – Type of shunt where the catheter drains CSF into the pleural space, which surrounds the lungs.



## Patient Resource Guide

We've designed this guide to help you take an active role in your care, keep your medical information organized in one centralized location, and communicate your health information to your providers clearly, efficiently, and accurately. We also hope it will help you make the most of your doctors' appointments.

Filling out this guide may take some time initially, but it will save you time in the future because you will have all of your medical information in one place. If you do not have all of your health information now, start with what you do have. Take your notebook with you to all appointments, procedures, and hospital visits.

The more information you can provide for your doctors during your appointments, the better your doctors can understand and address your health care needs.

Keep in mind that Barrow and St. Joseph's Hospital provide access to your medical records through an online patient portal. Once you provide your email address to the hospital staff in the Registration Department, you should receive an invitation to access the patient portal. If you have questions regarding hospital records, please call **(877) 621-8014**.

# My Information

Name	Date of Birth	Blood Type	Height	Weight
Address	Home Phone		Work Phone	
	Cell Phone		Fax Number	
	Email Address			
Social Security Number	Medicare Number	Part A <input type="checkbox"/> Yes <input type="checkbox"/> No	Part B <input type="checkbox"/> Yes <input type="checkbox"/> No	

Primary Insurance	
Plan Name	
Address	
Phone	
Group #	
Policy #	
Insured Name	
Insured Employer	
Insured SSN	Insured Date of Birth

Secondary Insurance	
Plan Name	
Address	
Phone	
Group #	
Policy #	
Insured Name	
Insured Employer	
Insured SSN	Insured Date of Birth

Emergency Contacts Name & Relationship	Address	Phone

# My Barrow Treatment

*My neurosurgeon is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*My neurologist is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*My physical therapist is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*My neuro-ophthalmologist is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*My neuropsychologist is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*My physical medicine and neuro-rehabilitation physician is:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*Other contact:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

*Other contact:*

\_\_\_\_\_ Office Phone:\_\_\_\_\_

# Barrow Treatment Team Clinics

## Neurology

### **Kamala Saha, MD**

Normal Pressure Hydrocephalus Clinic  
240 West Thomas Road, Suite 301  
Phoenix, AZ 85013

**Office** (602) 406-3596  
**Fax** (602) 406-5926  
**Contact** Antonio Green

### **Justin Hoskin, MD**

Normal Pressure Hydrocephalus Clinic  
240 West Thomas Road, Suite 301  
Phoenix, AZ 85013

**Office** (602) 406-3596  
**Fax** (602) 406-5926  
**Contact** Antonio Green

## Neurosurgery

### **Kris Smith, MD**

#### **Surgical Director, Barrow NPH Program**

Barrow Brain & Spine  
2910 North Third Avenue  
Phoenix, AZ 85013

**Office** (602) 406-7750  
**Fax** (602) 406-6398  
**Contact** Diane Dorsey,  
Michele Mercado,  
Edna Ramirez

### **Andrew Yang, MD**

Barrow Brain & Spine  
2910 North Third Avenue  
Phoenix, AZ 85013  
Phoenix, Arizona 85013

**Office** (602) 406-3181  
**Fax** (602) 406-6398  
**Contact** Diane Dorsey,  
Michele Mercado,  
Edna Ramirez

## Clinical Neuropsychology

### Alexander Tröster, PhD

Barrow Neurological Institute  
222 West Thomas Road, Suite 315  
Phoenix, AZ 85013

**Office** (602) 406-3671  
**Fax** (602) 406-6115  
**Contact** Ernestina Carrillo

### Krista Hanson, PhD

Barrow Neurological Institute  
222 West Thomas Road, Suite 315  
Phoenix, AZ 85013

**Office** (602) 406-3671  
**Fax** (602) 406-6115  
**Contact** Ernestina Carrillo

### Wil Schultz, PhD

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**Fax** (602) 406-6115  
**Contact** Ernestina Carrillo

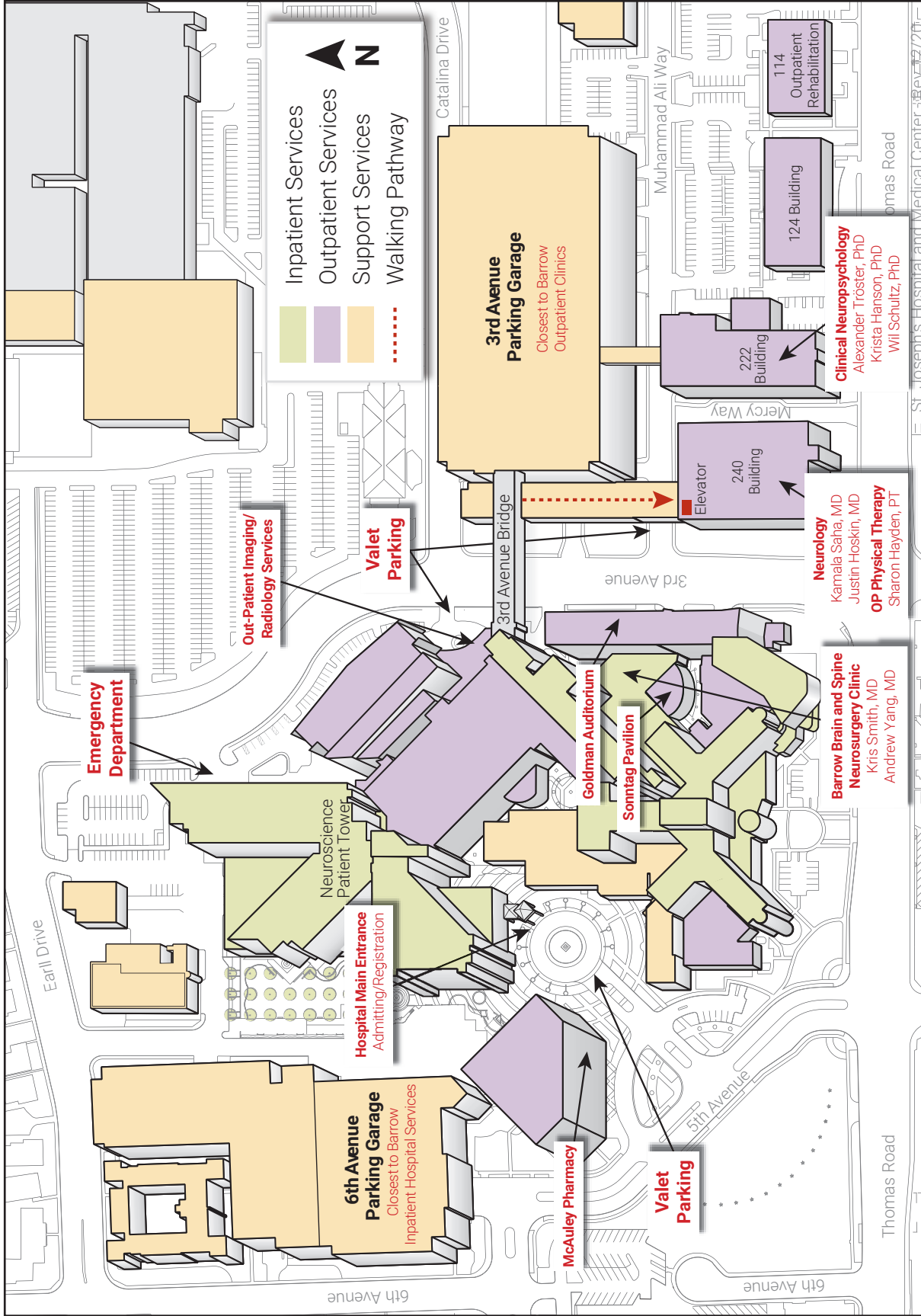
## Outpatient Physical Therapy

### Sharon Hayden, PT

Barrow Neurological Institute  
240 West Thomas Road, Suite 303  
Phoenix, AZ 85013

**Office** (602) 406-5266  
**Contact** Felicia Tso

# Campus Map



# Contacts

Obtain business cards from, or list contact information for, your health care providers and the facilities where you receive care. Keep track of your medical record number or account number at each office, hospital, or medical facility where you receive treatment to make it easier when you request medical records, inquire about a bill, and make appointments.

<b>Health Care Provider or Facility</b>	<b>Address</b>	<b>Phone Number &amp; Contact Person</b>	<b>Office Hours</b>	<b>Medical Record Number or Account #</b>

# Pharmacy Information

Please include at least one 24-hour pharmacy, if possible.

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

<b>Pharmacy</b>	Hours
Phone	Fax
Address	

# Prescription Insurance Information

Insurance Name	ID #	Group #
Address	Phone	Fax
Insured Name	Employer	
Insured Social Security Number	Insured Date of Birth	
Benefits, Co-pays, and Deductible		







# Medical Records

Use this section to keep copies of your medical records, including:

- X-ray (radiology) reports
- Operative (surgery) reports
- Pathology reports
- Laboratory results
- Consultation reports
- Reports or records pertaining to your health

Most medical facilities require written consent signed by the patient to release medical records. Keep in mind that St. Joseph's Hospital provides access to your medical records through a *patient portal*. Once you provide your email address to the hospital staff in the Registration Department, you should receive an invitation to access the patient portal. See next two pages for details. If you have questions regarding hospital records, please call **(877) 621-8014**.

# Dignity Health “My Portal” - Getting Started

“My Portal” by Dignity Health provides a convenient and secure online platform, where you can access your hospital health information and communicate with your care team.

## It’s as easy as 1-2-3!

1. Provide your email address when you register or during your hospital stay.
2. Check your email for an invitation to enroll in the patient portal, and click on the link provided.
3. Follow the quick, easy steps to complete your enrollment and start managing your hospital health records online.

## Need Assistance?

If you are having difficulty accessing your patient portal, please call **(844) 274-8497**.



# Access Your Patient Records Online

## **Features of the Online Patient Center:**

- View lab results
- Read and download discharge instructions
- See a list of your procedures and conditions
- Review your medications and allergies
- View upcoming appointments and add them to your personal calendar
- Read a summary of your visit

# Radiology Information

There are many types of radiology exams (also called radiographic studies). Radiographic studies are evaluated by a radiologist, who then creates a report about their findings. It is recommended that you always obtain a copy of the radiology report for your records.

<b>Type of Radiology Study</b> (MRI, CT, angiogram, ultrasound, nuclear medicine study, etc.)	<b>Date of Exam</b>	<b>Health Care Facility Address &amp; Phone Number</b>	<b>Medical Record Number</b>	<b>Do you have a copy of the radiology report?</b>
				Y N
				Y N
				Y N
				Y N
				Y N
				Y N
				Y N



# Making the Most of Your Doctors' Appointments

## Making the Appointment

- Confirm the location of the office when scheduling your appointments, as some doctors may have more than one office.
- Confirm that the office accepts your insurance, even if you have seen the doctor previously.
- Ask whether you need to arrive early to fill out or update paperwork.
- Ask if you need to bring your radiology exams (MRI, CT, etc.) to your appointment. It is usually necessary to bring all available exams to the first consultation. If the doctor recently ordered an exam, they will often have a copy of the report, but they may not have seen the actual images.

## Preparing for Your Appointment

Use this handbook to write down information and keep track of appointments, phone numbers, questions, instructions, and medications. Bring it with you to every appointment.

### **Put the following information in this handbook:**

- All of your surgeries, including the name of the operation, the date, the name of the doctor, and the name of the hospital
- Allergies to foods and medications, and the type of reaction
- All medications you are currently taking. Include the dosage of the medication and the frequency that you take it.
- Your pharmacy information: name, address, phone number, and fax number. If your pharmacy is not open 24 hours, keep the name of a 24-hour pharmacy handy in the event that you need a prescription after regular business hours.
- A copy of your radiology exam reports, medical test results, and other medical information. If your doctor needs the information for their records, ask them to make a copy—always keep the original copies.
- Business cards for all of your specialists and any facilities where you receive care

## Attending Your Appointments

We recommend bringing another person with you to your appointments. It is often difficult to hear, understand, and remember everything the doctor tells you, especially if you are feeling anxious, overwhelmed, or physically unwell.

Bring your notebook, list of questions, and radiology exams (including reports). During your appointments, briefly jot down answers to your questions. Collect a business card from each specialist or medical facility.

Ask the staff for your medical record number or account number, and record it in your notebook. Each medical facility maintains a specific medical record number or account number for each patient. Providing this number when you request records or radiology exams, inquire about a bill, or even make an appointment will help you navigate the system much easier.

# Appointments

Date	Time	Name of Health Care Provider or Facility & Specialty	Address	Phone Number & Contact Person	Special Instructions or Directions

# Appointments

Date	Time	Name of Health Care Provider or Facility & Specialty	Address	Phone Number & Contact Person	Special Instructions or Directions

















[BarrowNeuro.org](http://BarrowNeuro.org)