Brain tumor guidebook

For patients and caregivers

Sentara®

Introduction

According to the American Brain Tumor Association, there are more than 700,000 people in the United States living with a brain tumor today.

At Sentara, we know that finding out you have a brain tumor is frightening and overwhelming for both patients and their loved ones. For this reason, we have a dedicated care team that provides our patients with education and assistance throughout their journey.

Understanding what happens when a brain tumor is found can help patients partner with their care teams and feel more comfortable and informed.

We encourage you to learn all you can about your brain tumor.
The Sentara Brain Tumor Guidebook includes:

- Basic overview of the brain and its functions
- Information on types of brain tumors and common imaging procedures
- Treatment options
- What to expect before and after treatment and/or surgery
- Resources for you and your caregiver(s)
- Questions to ask your care team at the end of each section
- Common terms
- Note-taking section at the end of the guidebook

This guidebook is a reference for you to gain a basic understanding of brain tumors and to provide information on valuable resources to you and your caregiver(s). Your team may change any of the general guidebook recommendations based on your unique needs.

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Meet the team

There are many different team members that you may interact with after your tumor diagnosis. Each team member has a different role in your care. Your specific team will be determined by your diagnosis and the Sentara facility you are visiting. You may or may not meet each of the team members listed below.

Neurosurgeon

Neurosurgeons are physicians specialty trained in surgical procedures of the brain, spinal column, and nervous system. If you have brain surgery, your neurosurgeon will be the team member who either biopsies (see page 30) or removes the tumor. A neurosurgeon may have other physicians assist with your tumor resection if necessary.

Medical Oncologist

A Medical Oncologist is a physician who is specialty trained to treat cancer and tumors. Medical oncologists use various medicines, such as chemotherapy, to treat cancer and tumors.

Radiation Oncologist

A Radiation Oncologist is a physician who is trained to treat solid tumors. Radiation oncologists use radiation therapy, such as stereotactic radiosurgery or protons, to treat these tumors.

Otolaryngologist (ENT)

Otolaryngologists (also known as Ear, Nose, and Throat surgeons) are physicians specialty trained in surgical procedures of the head and neck. Some brain surgeries require the assistance of an otolaryngologist to approach brain tumors, particularly those tumors that are approached through the nose and sinuses or through the ear and temporal bone.

Endocrinologist

An Endocrinologist is a physician who specializes in treating disorders and conditions of the hormones.

Anesthesiologist

If you have a surgical resection or biopsy, an Anesthesiologist or a certified registered nurse anesthetist (CRNA) will be the one to make sure you are asleep during the procedure. They administer general anesthesia and will monitor your vital signs and breathing during the procedure.

Radiologist

A Radiologist is a physician who reviews imaging such as X-rays, CT scans, and MRIs. You will likely never meet this team member.

Pathologist

A Pathologist is a specialized physician who may diagnose your tumor type. They do this by reviewing the biopsied sample under a microscope. You will likely never meet this team member.

The tumor diagnosis may take 2-4 weeks (or longer) as multiple physicians may have to review the sample before a final diagnosis is determined.

Hospital Medicine/Critical Care

If you are admitted to the hospital, a general medicine physician or critical care physician will likely manage your medical care and needs during your stay.

Advanced Practice Provider (APP)

Advanced Practice Providers (APP) are Nurse Practitioners (NP) or Physician Assistants (PA) who have completed advanced education and training. They work with physicians and help provide care during your procedure, hospital stay, and office visits.

Palliative/Supportive Care Team

Providers who specialize in supportive care are available to help with decision-making, symptom management, and goals of care.

Bedside Nurse

If you are admitted to the hospital, a Registered Nurse (RN) or Licensed Practical Nurse (LPN) will deliver your bedside care. These licensed and trained professionals will be responsible for administering medications, assisting with daily activities, and monitoring and assessing you. As you recover, if you have any concerns or questions during your stay, always let your nurse know, and they can assist with getting you answers.

Patient Care Technician

If you are admitted to the hospital, Patient Care Technicians (PCTs) will assist the nursing staff with your care.

Integrated Care Manager (ICM)

If you are admitted to the hospital, you may be assigned an Integrated Case Manager (ICM). They help assist you with transition plans after hospital discharge. They specialize in discharge planning, verifying insurance coverage, and helping to coordinate your care.

Physical Therapist

Physical Therapists (PTs) are licensed and trained professionals who will assess your general mobility, ambulation, balance, stair climbing (if needed), etc. They are available both in and out of the hospital.

Occupational Therapist

Occupational Therapists (OTs) are licensed and trained professionals who focus on self-care abilities (bathing, dressing, feeding, toileting, home management, activities of daily living, etc.). They are available both in and out of the hospital.

Speech Therapist

Speech Therapists are licensed and trained professionals who assist with speaking, feeding, and swallowing. They are available both in and out of the hospital.

Respiratory Therapist

Respiratory Therapists are licensed and trained professionals who provide respiratory medications and care. They are available both in and out of the hospital.

Nutritionist/Clinical Dietitian

Nutritionists and Clinical Dietitians monitor and assess nutritional status and provide education on healthy choices throughout your brain tumor journey. They are available both in and out of the hospital.

Medical Office Staff

Staff members at medical and surgical offices will assist with making appointments and answering questions. Many of these staff members are Medical Assistants (MAs) and work under the direction of your care team.

Radiology Technologist

Radiology Technologists perform the scans/imaging ordered by your provider to view your tumor, such as MRI and CT scans.

Patient Navigator

A Patient Navigator may be available after a surgical resection or biopsy of your tumor. They can assist with providing postoperative care instructions and can help navigate you through your inpatient stay.

Oncology Nurse Navigator

An Oncology Nurse Navigator is available for patients with cancer. They can help coordinate care and provide education and resources for patients and their families. They help with communication between patients, family members, and the care team.

Oncology Social Worker

An Oncology Social Worker is trained to address the emotional, physical, and social concerns that can come with a cancer diagnosis. They support patients, families, caregivers, and friends by connecting them with community resources and providing counseling.

Chaplain

Sentara Chaplains encourage spiritual health through compassionate care every day. Focusing on what matters most to you, chaplains offer interfaith emotional and spiritual care for people of diverse religions and faiths and those who find meaning in other ways.

Patient Advocate

To help facilitate open communication, Sentara hospitals employ Patient Advocates – staff members who serve as liaisons between patients and family members and the appropriate hospital staff. Patient Advocates field questions about hospital services or level of care and provide patient rights and hospital policies and practices.

Notes

My brain tumor

My brain tumor

While this guide is an informational and educational resource, it is also a tool for you to use in documenting and detailing your own individual diagnosis, care team, and treatment plan. Use the following section to write down your diagnosis information, as well as contact information for your care team.

My diagnosis and tumor location

My diagnosis is ____

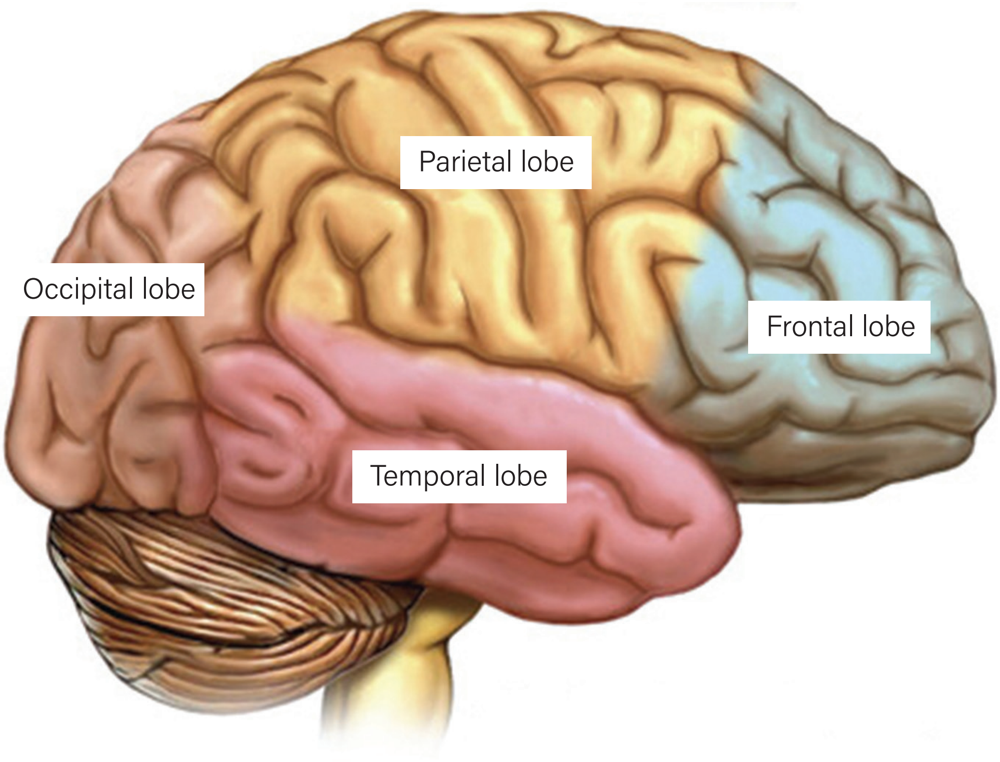
____

____

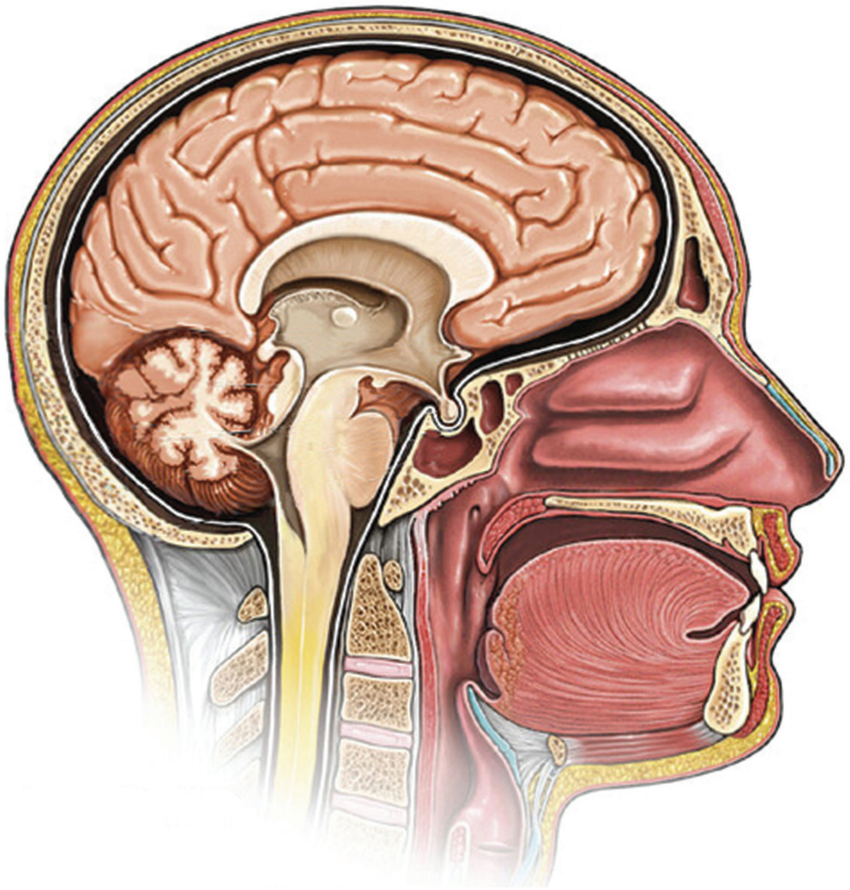
____

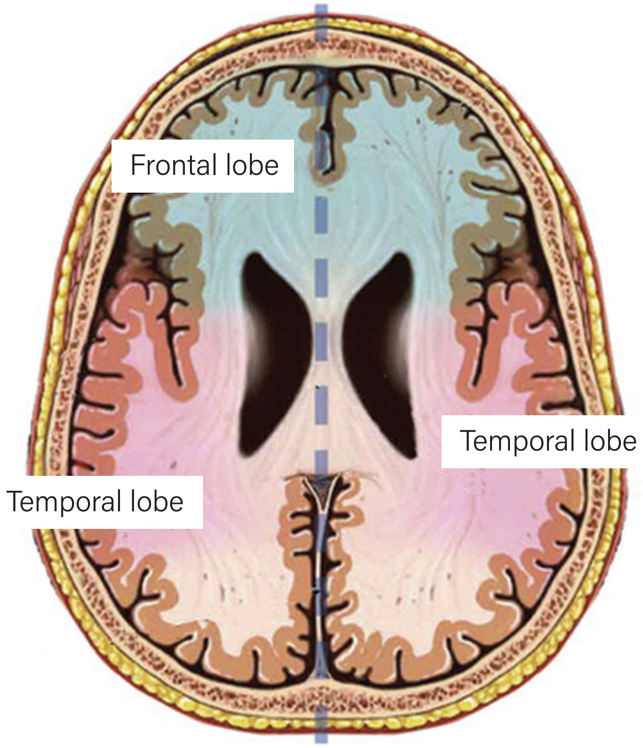
Have your team circle your tumor location using these diagrams. Please refer to the common terms section on page 59 for details on the labels on the illustrations.

Major parts of the brain



Cross section of the brain





My care team

Please use this page to write down contact information for your care team members.

Specialty____

Dr.________________________ Phone number____________________

Specialty____

Dr.________________________ Phone number____________________

Specialty____

Dr.________________________ Phone number____________________

Specialty____

Dr.________________________ Phone number____________________

Specialty____

Dr.________________________ Phone number____________________

Specialty____

Dr.________________________ Phone number____________________

Other care team members

________________________ Phone number____________________

________________________ Phone number____________________

________________________ Phone number____________________

________________________ Phone number____________________

________________________ Phone number____________________

________________________ Phone number____________________

Talking to and working with your care team

You are an important member of your care team! Our goal is to give you the information you need to be informed and engaged in your treatment plan so that together, we can have the best outcomes possible.

Tips for talking to your care team

- Take notes. You may find it helpful to keep a log of conversations you have had with the care team. (There are blank pages at the back of this booklet for you to use).
- Consider using the phone to include others in the conversation.
- Bring a support person with you (friend or family member).
- Let the care team know if you need more information. You can always ask them to repeat what they said, slow down and even explain things differently.
- Talk about your wishes.
- If faith or religion may influence your decisions, you can bring this up with the care team or speak to a chaplain. You may also invite your own religious representative to assist you with making decisions.
- Ask for the best way to contact the care team if you think of other questions later.
- Write down your questions. Some common questions are listed on page 12.

What else can you do to help your care team?

It is essential that your care team can contact you at any time to discuss your plan of care and ask important questions. Be sure to:

- Provide the team with the best phone number and a backup phone number so they can contact you.
- Ensure your voicemail is not full so the care team can leave you a message if you cannot answer the call.
- Sign up for Sentara MyChart. This online tool provides secure and convenient electronic access to medical information and healthcare providers. You can get updated information and test results and communicate with your care team outside of the office. Family members can also have access to your healthcare information – if given approval – to enable them to provide additional support.

Please use the link mychart.sentara.com/mychart/signup or the QR code to sign up for MyChart.

Questions to ask about your brain tumor

Being diagnosed with a brain tumor can be overwhelming. You may use the space below to help organize your thoughts and assist with understanding your diagnosis.

What type of tumor do I have?

What is the size of my tumor, and where is it?

Is this a primary brain tumor or a metastatic tumor?

What are my treatment options?

What is my prognosis?

What is the goal of my treatment? Can it be cured, or is it to control symptoms?

What are the risks/side effects of treatments?

What will happen if I don’t have treatment or postpone treatment?

Will I need more tests before treatment begins?

What additional physicians do I need to see?

What kind of resources are available for my tumor? ____________________

____

Can I drive a car? ____________________

____

Can I work? ____________________

____

Can I exercise? ____________________

____

What is my tumor WHO grade, and what does it mean? ____________________

____

Do I have cancer? ____________________

____

- What type of cancer do I have? ____________________

  ____

- Has the cancer spread? ____________________

  ____

- Are my family members at risk of developing cancer? ____________________

  ____

Notes

Brain tumor overview

Brain tumor overview

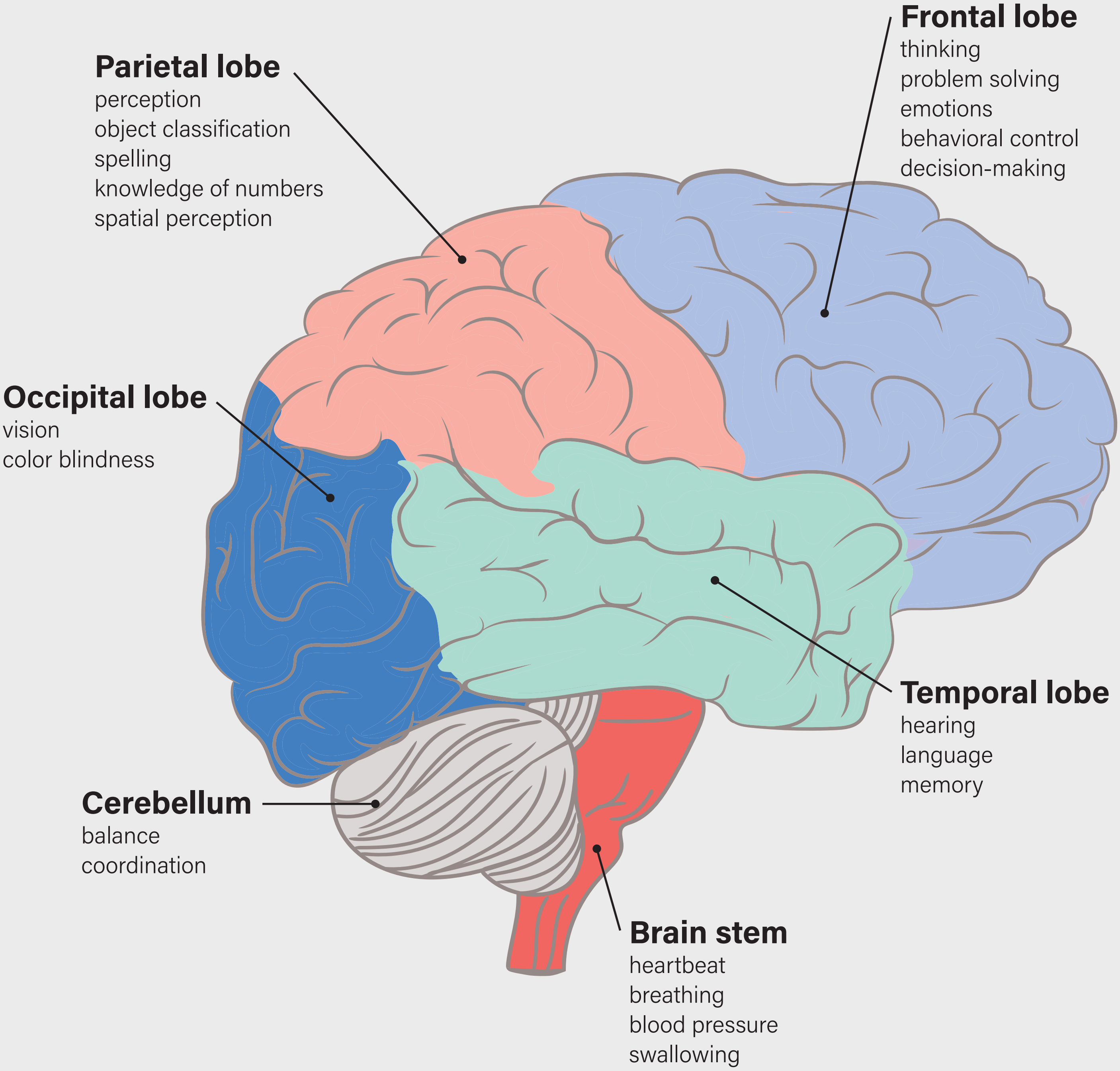
In this section, you will learn more about brain tumors and the diagnosis process. This section also includes common imaging procedures and details on what to expect. When it comes to brain tumors, knowledge is power!

How the brain works

The brain is a complex and vital organ that controls important functions for living. The brain controls emotions, memory, touch, balance, walking, speaking, breathing, and much more.

The image shown here illustrates the different areas of the brain and their functions.

Depending on where your tumor is located, you may have symptoms that affect the normal function in one or more areas of the brain. Each person may have different symptoms from their brain tumor. Understanding where your brain tumor is located and what functions that part of the brain controls can help you and your loved ones prepare for and understand symptoms you may experience.



Frontal lobe
thinking
problem solving
emotions
behavioral control
decision-making

Parietal lobe
perception
object classification
spelling
knowledge of numbers
spatial perception

Occipital lobe
vision
color blindness

Temporal lobe
hearing
language
memory

Cerebellum
balance
coordination

Brain stem
heartbeat
breathing
blood pressure
swallowing

Diagnosis

When a brain tumor is found, it is essential that your doctor finds out what type of brain tumor it is to help develop a treatment plan. Making a diagnosis will consist of the following:

- Your care team will collect your medical history to provide background information about any previous health conditions and family history.
- A neurological exam, also called a neuro exam, will be performed. This is an assessment tool used by your care team to check the function of your nervous system (which includes your brain, spinal cord, and nerves from these areas). For example, your care team may ask you your name, the current date, where you are, and ask you to lift your arms and legs. You may be asked these questions frequently, even if there have been no changes to your neurological status.
- Laboratory tests and common imaging tests may be ordered. You can find more details on imaging types on page 19.
- Based on the results of your testing, a biopsy may be performed. A biopsy will provide you with final pathology results. This information will provide you and your care team with more specific information about your tumor diagnosis.

Tumor Board

Tumor Board is a medical conference that takes place with your care team and other specialists to discuss complex tumor cases. The members of the care team who participate in Tumor Board may be a neurosurgeon, oncologist, radiation oncologist, radiologist, pathologist, and/or specialty nurses. Not every patient's tumor will be discussed at the tumor board conference. Treatment options, such as clinical trials, may be discussed. Patients and family members do not attend the tumor board conference. If your case is presented and decisions are made about your care, you will be contacted by your care team.

Types of brain tumors

Brain tumors come in many forms and can be cancerous or non-cancerous. Your tumor diagnosis is based on the kind of cells that make up the tumor. Below is a general overview of tumor types and the tumor grading system. For specific information about your tumor and diagnosis, please reach out to your care team.

Primary brain tumors

Primary brain tumors are tumors that start in the brain or in the central spinal canal. This means that the tumor started growing in the brain and did not come from somewhere else in the body. Primary brain tumors are assigned a grade. Below, you will learn details about the tumor grading system.

World Health Organization (WHO) tumor grading

Once your tumor is diagnosed, the tumor can be defined by a classification system. Most medical centers, including Sentara, use the World Health Organization (WHO) classification system. Tumors are assigned Grade 1, 2, 3, or 4. The assignment is based on how abnormal the cells are. A tumor grade is a helpful tool for the care team members to communicate efficiently and clearly about your tumor. The tumor grade also helps your care team determine your potential outcomes and treatment options.

Grade 1: Slow-growing tumors that are benign (non-cancerous). Grade 1 tumors are associated with long-term survival.

Grade 2: Slow-growing, but sometimes becomes a higher-grade tumor later. Grade 2 tumors can be malignant (cancerous) or non-malignant (non-cancerous).

Grade 3: Fast-growing, malignant tumors.

Grade 4: Fast-growing and very aggressive malignant tumors.

It is important to remember that tumor grading can change and evolve with time.

Metastatic brain tumors

Metastatic brain tumors are tumors that have traveled from somewhere else in the body. If your tumor is a metastatic brain tumor, this means that you have a cancerous tumor somewhere in your body, and it has traveled to your brain.

You may already be aware of the primary tumor in your body, but if you are not aware of another tumor, you will likely have a full examination (including bloodwork and imaging) by your care team to attempt to find and diagnose the primary tumor. The primary tumor will be somewhere else in your body (for example, in the lungs or breasts).

Malignant brain tumors

Malignant brain tumors are cancerous tumors. These tumors are made up of abnormal cancer cells. Malignant brain tumors are typically fast-growing and can invade other healthy tissues. Malignant brain tumors may require intensive treatment, such as surgery, radiation, and chemotherapy.

Non-malignant/benign brain tumors

Non-malignant (also known as benign) brain tumors are non-cancerous tumors. These tumors are typically slow-growing. While benign tumors are not cancer, in some cases, they can still be a serious medical condition. Some benign tumors can spread to other locations in the body, but this is rare. Some benign tumors require treatment, such as surgery, radiation, and chemotherapy. These tumors can change, grow, or come back even though they are not malignant.

Treatment recommendations are individualized and will depend on your tumor type, location, grade, and extent. Your personal beliefs and goals of care will also help decide what treatment is best for you.

Common imaging procedures

Your treatment team will discuss with you what imaging you will need.

CT (Computed Tomography Scan; Computed Axial Tomography; CAT Scan)

A CT scan uses X-ray technology to take multiple views of the inside of the body. Compared to regular X-rays, a CT scan can take clearer and more detailed images of organs, bones, soft tissue, blood vessels, and other parts of the body.

- How long will it take? **It takes about 10-15 minutes, depending on how many pictures are needed.**

Prior to the test

- Before your test, follow your doctor's instructions regarding any changes to your medications or diet.

At the healthcare facility

- A healthcare professional will explain the test and answer any questions you may have.
- You will remove your clothes and put on a gown or robe.
- You will remove all jewelry, hair clips, dentures, and other objects that could show on the X-rays and make the images hard to read.
- If your CT scan includes oral contrast material, you will need to drink the contrast material at this time.
- You may be given an injection of contrast dye into your vein (Let your doctor know if you have any allergies and/or kidney problems before having this test.).

Description of the test

You will lie (usually on your back) on a movable bed. The bed will slide into the doughnut-shaped CT scanner. Depending on the type of scan, an IV line may be placed in your hand or arm. A saline solution and contrast material may be injected into your vein during the test. The technologist will leave the room. You will be given directions using an intercom. The machine will take a series of pictures of the area of your body that is being studied. Your bed may move slightly between pictures.

MRI (Magnetic Resonance Imaging)

An MRI uses magnetic waves and computers to make pictures of the inside of the body. It can make 2-dimensional and 3-dimensional pictures. These scans are more detailed than CT scans.

- How long will it take? **About 40-90 minutes.**

Prior to test

- Follow your doctor's instructions regarding eating and drinking before the test. This will depend on what part of the body is being examined.

At the healthcare facility

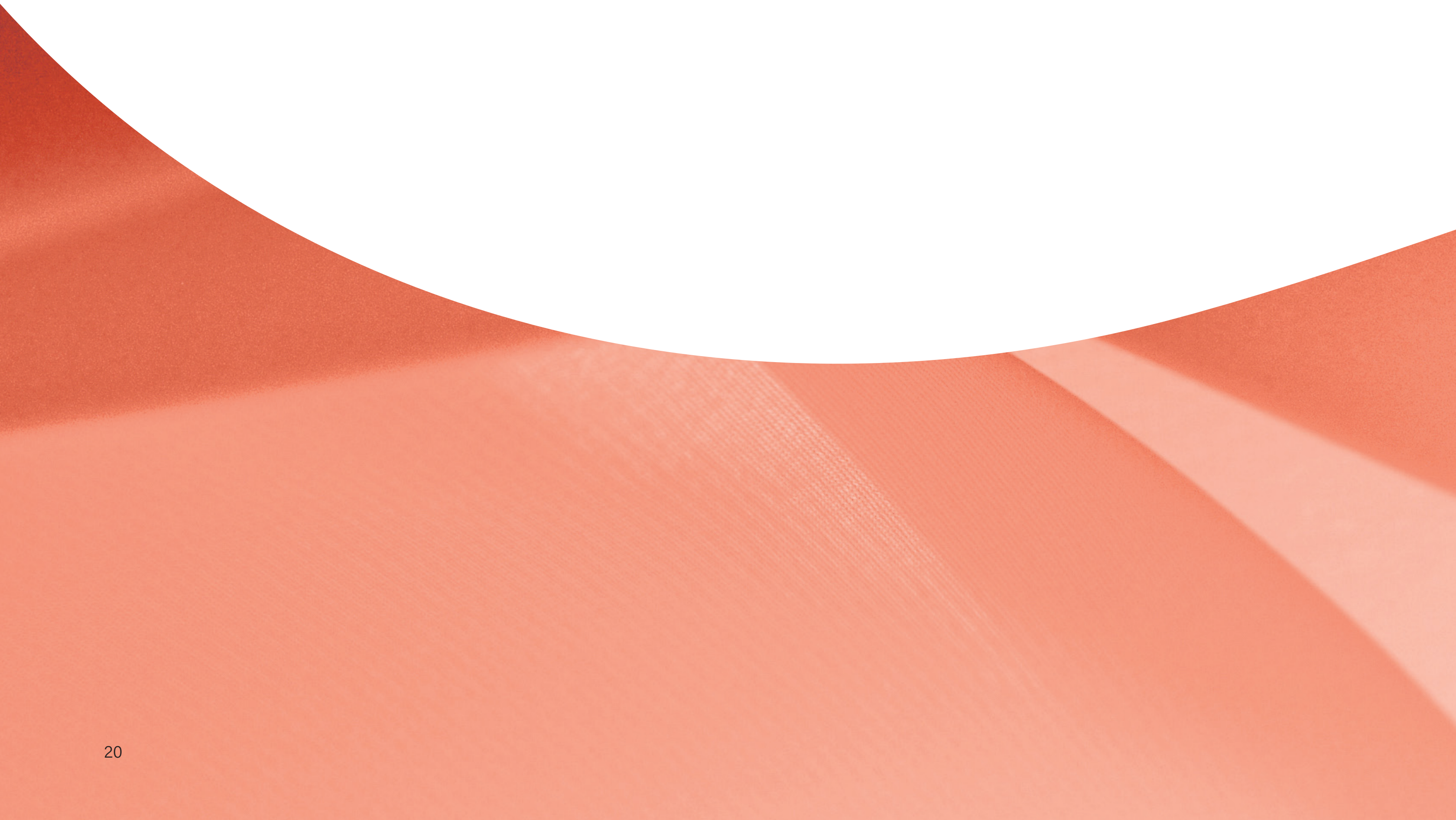
- Your doctor may give you a medication (a sedative) to calm you if you are anxious about the test. If your doctor prescribes a sedative and you are not currently admitted to the hospital, you will need to arrange for a ride home. Be sure to follow your doctor's instructions on when to take the sedative. It may need to be taken 1-2 hours before the exam.
- You will be asked if you have something in your body that would interfere with the MRI, such as: a pacemaker, neurostimulator, aneurysm clips, any metal, previous joint replacements, or surgery, etc.
- You will be asked to remove all metal objects and/or skin medication patches.

You may be:

- Given earplugs or headphones. The MRI machine makes a loud banging noise.
- Given an injection of contrast dye into your vein (Let your doctor know if you have any allergies and/or kidney problems before having this test.).

Description of the test

- You will lie very still on a sliding table. You may have monitors to track your pulse, heart rate, and breathing, depending on your condition. The table will slide into a narrow, enclosed cylinder.
- Notify your doctor if you are claustrophobic (afraid of small spaces) or unable to lie on a flat table.



PET scan (Positron Emission Tomography)

This test makes images that show activity in body tissues. A substance that gives off a tiny amount of radiation is injected into your body. This substance goes to the part of your body that is most active. A machine can then detect where that substance is.

Prior to the PET test

- Wear comfortable clothes.
- Do not eat or drink anything, except water, for at least 6 hours before the scan.
- Check with your doctor about taking your regular medications.
- If you have diabetes, ask the doctor for specific diet recommendations for the test day since this can affect your results.
- Tell your doctor if you are or might be pregnant.

Description of the test

- How long will it take? **Approximately 2 hours.**
- You will be given a radioactive substance. This may be done through an injection, or in some cases you will be asked to breathe in gas. It will travel through your blood to the area of the body being studied. It takes 30-90 minutes for the substance to be absorbed by the tissue. When the substance has been absorbed, the scan can take place.
- You will lie on a table and be moved into a machine that looks like a large, square doughnut. This machine detects and records the energy levels from the substance that was injected earlier. The images are viewed on a computer monitor. The scan lasts about 30-45 minutes.

> “Medical imaging refers to several different technologies that are used to view the human body to diagnose, monitor, or treat medical conditions. Each type of technology gives different information about the area of the body being studied or treated, related to possible disease, injury, or the effectiveness of medical treatment.”
>
> — FDA.gov

Bone scan

A bone scan is a test that detects areas of increased or decreased bone activity. These may indicate bone injury or disease.

Radioactive isotopes and tracer chemicals are used to highlight problem areas.

- How long will it take? **You will be in the scanner for 20-60 minutes. Sometimes another scan is done after 24 hours.**

Prior to the test

- Tell your doctor if you are pregnant or breastfeeding. You may need to discard breast milk for several days after a bone scan.
- Tell your doctor if you have recently had anything that contains barium, such as contrast dye or bismuth.
- Three hours before the scan, you will receive an injection of radioactive tracer chemicals. You should drink plenty of fluids between the time of the injection and the scan. You will also be asked to empty your bladder before the scan.

Description of the test

- You will lie on your back on an imaging table. A camera above and below the table will slowly scan you. You may be asked to move into various positions as the scan is done. It is important to lie still when not told to move. The camera will be able to detect small amounts of radioactivity in the injected material. This will allow the doctor to see areas where there may be bone injury or disease.

Brain tumor treatment

Brain tumor treatment

There are many considerations that factor into the type of treatment that you will receive for your tumor. You, your loved ones, and your care team will be able to discuss the best course of treatment for you. This may include non-surgical and/or surgical options.

Some of the factors that are taken into consideration when deciding on a treatment plan are:

- Location of the tumor
- Type of tumor
- Size of the tumor
- Tumor grade (see page 18)
- Personal beliefs (for example, your values and religious beliefs)
- Goals of care (for example, your hopes, personal goals, and priorities about your quality of life)

Clinical trials

Clinical trials and new treatments are always being developed; if you have questions about your options, ask your care team or go to sentara.com/research to see current trials happening here at Sentara. Clinicaltrials.gov is also available as a resource.

Second opinions

Sentara partners with many care teams so that a variety of treatment options are available for our patients. If you choose to get a second opinion on treatment options or care, we support this decision.

Notes

Non-surgical treatment

Non-surgical treatment

Your care team will review the best treatment options for your specific tumor with you. If your tumor is not able to be removed surgically, there may still be options for tumor treatment.

Some tumors require both surgical and non-surgical treatments as well.

The following section provides non-surgical brain tumor treatment options. If you have specific questions about non-surgical options, please ask your care team.

Chemotherapy

The National Cancer Institute website defines chemotherapy as a type of medicine, given in either a pill or IV, that is used to kill tumor cells and prevent tumor growth.

- Side effects are dependent on the type of drug used, but most patients will experience some degree of fatigue, hair loss (alopecia), and low blood counts. Other side effects are possible. Please speak to your care team about other possible side effects.
- If you are prescribed chemotherapy, it is important to follow up with your medical oncologist to closely monitor for side effects. This is generally done through clinic visits and lab draws.
- There are ways to lessen the side effects of chemotherapy. We encourage you to talk to your care team about any symptoms you are experiencing so we can work to provide you with the best treatment to alleviate your symptoms.

Targeted drug therapy

The American Cancer Society website describes targeted drug therapy as a type of chemotherapy that targets specific tumor cells without affecting normal tissue.

- Targeted drug therapy is generally given through an IV and used in combination with surgery, chemotherapy, or radiation.
- Targeted therapy may target certain proteins, enzymes, chemicals, or blood vessels attached to the tumor.
- This type of therapy usually causes tumor cells to die by blocking how the tumor grows, divides, and copies itself. Targeted therapy may also affect how the body feeds tumor cells (as in the case of targeting new blood vessels attached to the tumor).
- Unlike chemotherapy, hair loss (alopecia) is not a common side effect, but you will likely experience some degree of fatigue.
- Talk to your medical oncologist about specific side effects and their treatments based on the targeted therapy prescribed.

Radiation therapy

Radiation therapy, also called radiotherapy, uses high-energy waves of radiation to kill tumor cells or shrink tumors. Common radiation therapy options are external beam radiation therapy (EBRT) and internal radiation (brachytherapy).

Stereotactic radiosurgery

Radiologyinfo.org defines stereotactic radiosurgery (SRS) as a type of radiation treatment that can accurately target specific areas of the brain using Gamma Knife, CyberKnife, or Proton Beam therapies. SRS is not traditional surgery, as there is no incision.

Optune photo citation: https://www.optune.com/?gclid=CjwKCAjwyNSoBhA9EiwA5aYlb_4OmCBb0tde4rw-oXKAqSYCH1hA1EgFj5hO_

Optune

Optune is a type of treatment that uses electric fields called tumor treatment fields (TTF) to slow down or destroy cancer cells. This is currently only an FDA-approved treatment for one tumor type (GBM – glioblastoma multiforme). Optune is a wearable, portable device. While using Optune, you will have pads, called transducer arrays, on your head for several hours a day for several weeks. This treatment can be done at home. More information about Optune can be found at optune.com.

Common medications

Some medications may be used for treatment and/or to help manage symptoms from your brain tumor.

Steroids

- Steroids are used to reduce swelling of your brain. Commonly prescribed steroids are dexamethasone (Decadron) and methylprednisolone (Solumedrol). The dose of these medications may be decreased gradually by your care team.
- Possible side effects: hunger, sleeplessness, high blood sugar (we will monitor your blood sugar frequently), high blood pressure, and behavior changes.

Anti-epileptics

- Anti-epileptic (or anti-seizure) medications are used to prevent seizures. A commonly prescribed anti-epileptic is levetiracetam (Keppra).
- Possible side effects: irritability, drowsiness, and dizziness.

Pain control medications

- Pain control medications are used to help control pain. Please notify your care team if your pain is not controlled. A commonly prescribed pain control medication is acetaminophen (Tylenol).
- Possible side effects: drowsiness, nausea.

Other side effects are possible. Please speak to your care team to learn more.

Questions to ask about non-surgical treatments

What are the potential risks for my treatment options? ______________________________

____

What are the potential benefits for my treatment options? ______________________________

____

What happens if I don’t do treatment? ______________________________

____

What happens if I delay my treatment? ______________________________

____

What are the side effects of my treatment? ______________________________

____

Will I need more than one treatment option? ______________________________

____

Will I be admitted to the hospital for this treatment? If so, how long will I be in the hospital? __________

____

What is the purpose of this treatment? Will it cure my tumor, or will it help manage the symptoms? _____

____

Will I need someone to help me at home after treatment? ______________________________

____

Surgical treatment

Surgical treatment

If your brain tumor is in an area of your brain where it can be safely removed, your neurosurgeon will work to remove as much of the tumor as possible. If your care team is planning to surgically operate on your tumor, please review the next section.

We understand the decision to have brain surgery is a major life decision, and you look to us for guidance, expertise, and experience that you can trust. Your care team wants you to feel as comfortable as possible with your decision to have brain surgery. On the following pages, you will find brief descriptions of common brain tumor surgical procedures.

Types of surgical procedures

Biopsy

A biopsy is a surgical procedure where a small amount of tumor tissue is removed to confirm a diagnosis. This can be done with craniotomy surgery (described below) to remove some or all of the tumor or as a standalone procedure to get a definitive diagnosis.

The small amount of tissue removed during a biopsy will be sent to the laboratory. The laboratory can quickly get a preliminary diagnosis from a frozen sample. The preliminary diagnosis is not a final diagnosis. The frozen sample may be used by your surgeon to determine whether it is safe to continue removing tumor tissue. The final diagnosis will be determined once the specimen is sent off for further testing.

Pathology results

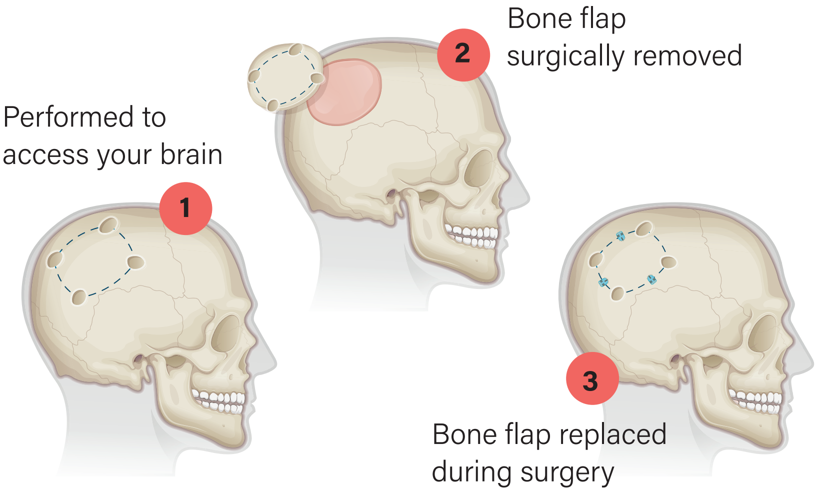
If a biopsy of your tumor tissue is completed, your surgeon will send the tissue sample for testing to get a final tumor diagnosis. The tissue is sent to a pathologist who thoroughly examines the sample to ensure an accurate diagnosis.

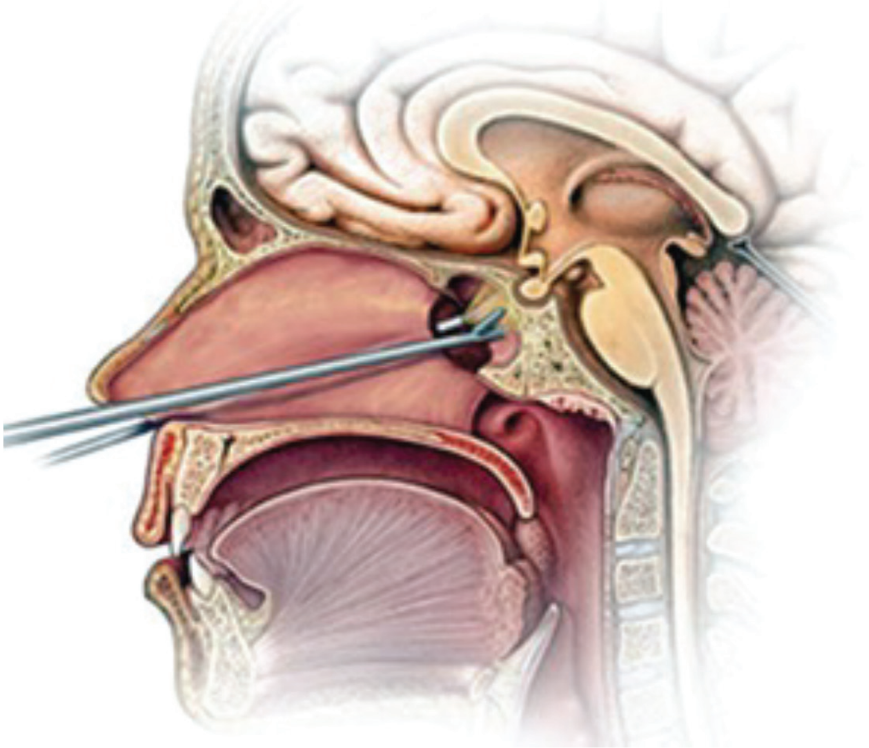
It can take up to four weeks for your pathology results. You will likely be discharged from the hospital before receiving your final tumor diagnosis. Depending upon the results, the tumor may need to be sent for additional testing (which may take longer). **Please note – if you are on MyChart, you will likely receive your results before your postoperative appointment.** You may see your results before your physician. Please contact your surgeon's office if you receive the results so that you may further discuss your plan of care. Otherwise, your care team will likely discuss these results at a postoperative appointment.

Craniotomy

A craniotomy is a type of brain surgery where a part of the skull is removed to get to the brain. During the surgery, your neurosurgeon will remove some or all of the tumor tissue, and a small amount will be sent (biopsy, described above) to confirm your diagnosis. Please see the "Pathology results" section above for more details. At the end of surgery, the removed piece of skull is put back in place and secured with plates and screws.

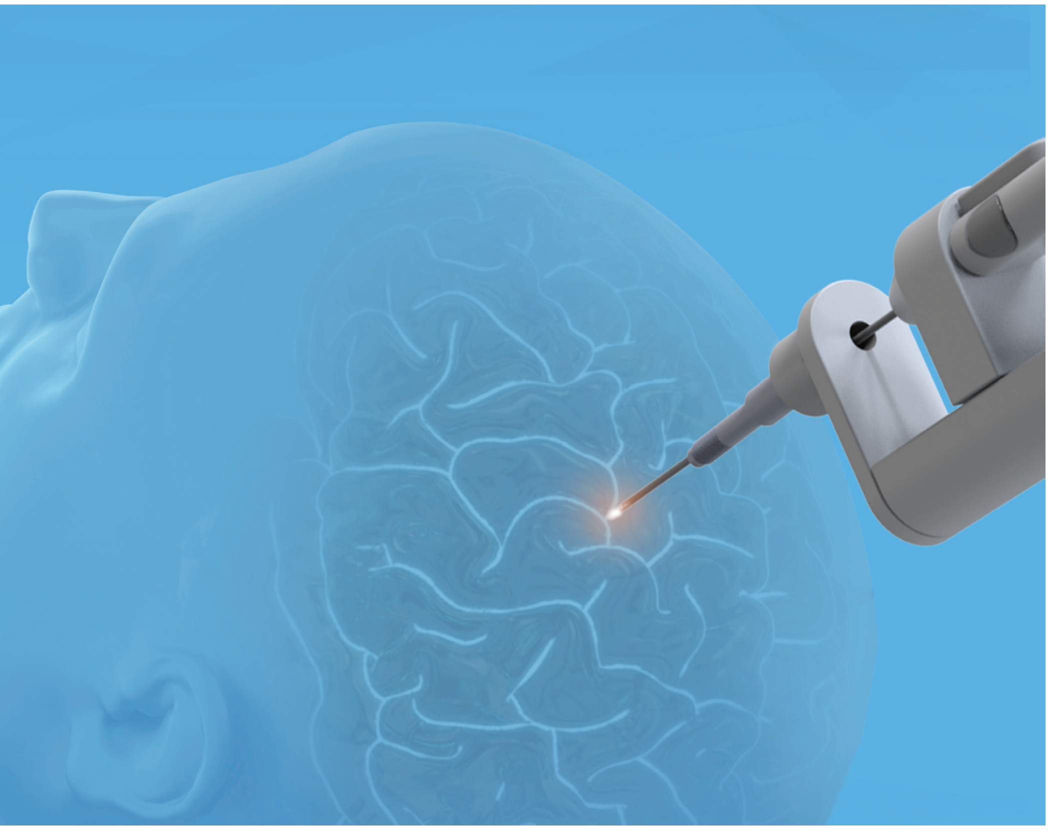
An example of a craniotomy procedure is pictured to the right. The surgical incision size and site may differ from the photo depending on where your tumor is located and the size of your tumor.





Endonasal surgery

Endonasal surgery is a common surgical approach used to remove tumors located at the back of the nose, for example, pituitary tumors. This is usually performed by an ear, nose, and throat (ENT) surgeon as well as a neurosurgeon. The surgeons will go through the nose to access your tumor. An example of endonasal surgery is shown to the left.



Laser Interstitial Thermal Therapy (LITT)

Laser Interstitial Thermal Therapy, abbreviated LITT, is a procedure in which the surgeon uses a laser to ablate (or destroy) tissue. As noted by the National Institutes of Health, this procedure is minimally invasive and has a short recovery time. LITT is only used for certain brain tumors, so ask your provider if you would be a candidate for this procedure.

How to prepare for surgery

It starts with healthy choices and good nutrition

Improving your health before surgery can help to lower your chance of postoperative complications. Please see the "Improving your health and wellbeing" section on page 45 of this guidebook for more information. Also, please ask your care team and surgical team what you can do to improve your health before surgery.

> If your surgery is not preplanned, the planning for surgery will occur during your hospital stay.

Preoperative visit

You may have a preoperative appointment at your surgeon and/or primary care physician's (PCP) office. This is a good time to ask any last-minute questions about your surgery. Your surgical team will discuss your tumor and what to expect during your surgery and hospital stay.

Certain imaging (MRI, CT scan, X-ray, etc.) and blood tests may be required before your surgery. Your care team will update you on what is needed and how to complete the testing.

Preoperative planning

You may receive a preoperative phone call from a nurse who will review your medications with you and ensure that you are ready for surgery. They will confirm the time of your surgery with you and the time that you need to be at the hospital. They will review which medications to stop taking and which medications to continue taking. They will also review when to stop eating and drinking before surgery.

Make sure to discontinue all anti-inflammatory medications such as aspirin, Motrin, and naproxen. There are other medications that can cause increased bleeding, such as Vitamin E, turmeric, garlic, fish oil, etc. If you are taking a blood thinner, you will need special instructions from your physician on when to stop this medication.

You may need to stop taking herbal supplements or vitamins, as some may interfere with other medicines. If you take herbal supplements or vitamins, ask your doctor if you should stop taking them before surgery.

Night before and morning of surgery

Skin preparation

Your skin preparation includes:

- Shower and wash your hair before surgery
- Do not shave your surgical site within three days of your surgery

Depending on your surgical site, your head may be shaved during surgery. If you want to have your head shaved before surgery, please do so at least three days before your surgery.

When to stop eating and drinking

You will be given specific instructions about when to stop eating and drinking before surgery. You will likely be told not to eat or drink anything after midnight on the day of your surgery.

What to bring to the hospital

You are encouraged to bring comfortable clothes and personal hygiene items to use (deodorant, toothbrush, etc.). If you use a CPAP machine, please bring it with you to the hospital and know your settings. You should bring your hearing aids, dentures, and glasses if you use them. If you bring any item that has a container, please bring the container for the safekeeping of your item or device.

Please do not bring electrical items such as fans or electric blankets for safety reasons. You may bring battery-operated items. Cell phones, laptops, and tablets are permitted for use in your room. Remember to bring chargers for those items. A family member or friend may bring the devices to you once you are admitted to a room after surgery.

Please DO NOT bring to the hospital:

- Jewelry
- Valuables
- Large amounts of cash

Helpful things to have while in the hospital:

☐ Items that might ease your anxiety or pass the time, such as reading material, cell phone, etc.
☐ This guidebook to use as a resource
☐ A copy of your advance directive (living will) if you have one
☐ Your insurance card, driver's license, or photo I.D.
☐ If your insurance requires a copay and you have not already taken care of it prior to the day of surgery, it may be collected at the time of your arrival. Please bring a payment source to pay the copay if necessary
☐ A payment source to pay for any prescriptions that may be needed at discharge (DO NOT bring large amounts of cash)
☐ Comfortable clothes to wear when leaving the hospital after surgery
☐ CPAP, if you use one. Know your settings and bring all the parts. We will provide the water. If you are having endonasal surgery, check with your doctor to see if you will still be able to use your CPAP while recovering from surgery.
☐ Current medication list, including all over-the-counter medications and supplements you take
☐ Implant information if you have any implants in your body (for example, pacemaker information)

Reminder — Please remove fingernail and toenail polish, including acrylic nails, before surgery. Please remove any hair appliances before surgery.

Day of surgery

If your surgery was planned, you will arrive at the hospital as you are instructed in your preoperative phone call or surgery letter. Prompt arrival allows staff sufficient time to prepare you for surgery.

Preparation for surgery includes:

- A nurse and an anesthesiologist will ask you questions
- A nurse will start your IV
- Your surgeon will visit you to mark your surgical site and answer any questions you may have.

Anesthesia

Your anesthesiologist and/or certified registered nurse anesthetist (CRNA) will review all information needed to evaluate your general health, including your medical history, laboratory test results, allergies, and current medications.

The anesthesiologist will answer any further questions about your anesthesia. Intravenous (IV) fluids will be started, and preoperative medications may be given if needed. Once you are in the operating room, monitoring devices will be attached, such as a blood pressure cuff, EKG, and other devices for your safety. At this point, you will be ready for anesthesia. The anesthesiologist (or CRNA) will be with you throughout your entire surgical procedure to monitor your vital signs and administer medications to keep you sedated.

During surgery

Brain surgery can last anywhere from a few hours to many hours. During your surgery, visitor(s) are directed by hospital personnel to the appropriate waiting room. It is important for your visitor(s) to register with the waiting room receptionist so that the surgeon/OR team can contact them during and after surgery. You will be asked to provide a contact number for the visitors. At the end of the operation, the surgeon will discuss your surgery with your visitor(s) and answer any questions they may have.

We will attempt to accommodate as many visitors as possible in the waiting rooms. However, it may be necessary to ask some visitors to stay in the main lobby. If there are changes in the postoperative room assignment or operating room schedule, it may be necessary to move visitors between different waiting rooms.

What can I expect during surgery?

- Your hair may be shaved in the area of your surgery.
- A bladder catheter (Foley catheter) is a small tube placed in your bladder to drain urine and help monitor the function of your kidneys. If you need to have a bladder catheter, this will be placed in the operating room after you have been put to sleep under general anesthesia.
- The anesthesiologist or CRNA is responsible for your comfort and sedation during your surgical procedure. They will manage vital functions in the operating room, including heart rate and rhythm, blood pressure, body temperature, and breathing. The anesthesiologist is also responsible for giving IV fluid when necessary.
- Your surgeon will close your surgical incision with staples or sutures (stitches). The area of your surgery will be wrapped with a head wrap made of gauze. Your surgeon will remove this around 48 hours (about two days) after surgery unless otherwise stated by your care team.

Drains

It is possible that you will have a drain inserted into your head during surgery that will remain in place until your surgeon determines it can be removed. The drain will be removed before you leave the hospital.

There are different types of drains that could be inserted during surgery. Examples of some of these drains are below, however, they can vary by surgeon.

Jackson-Pratt (JP) drain

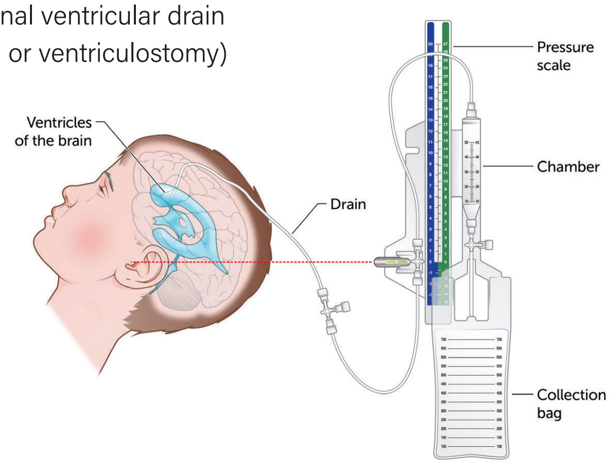
You may have a JP drain inserted to collect and drain blood after surgery so that the blood does not collect in your head. Your nurse will monitor the drain output every 4-6 hours. The surgeon determines when the drain will be removed.

Jackson-Pratt (JP) drain

External ventricular drain (EVD or ventriculostomy)

An EVD is a temporary drain that is placed in the ventricles of the brain. CSF (cerebrospinal fluid) will be collected in the drainage system, and output will be monitored hourly by the bedside nurse. An EVD is also used to monitor the intracranial pressure (ICP), and the nursing staff will monitor the ICP continuously. An EVD allows for CSF to be drained outside of the brain instead of inside your body.

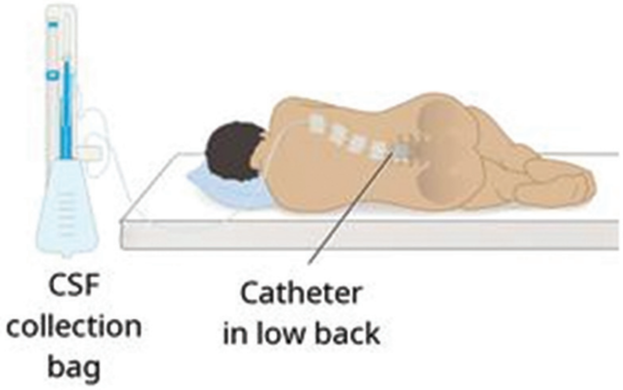
External ventricular drain (EVD or ventriculostomy)



Lumbar drain

You may have a drain inserted during surgery to collect and drain cerebral spinal fluid, also called CSF. A lumbar drain may be placed in your lower back to remove CSF or to monitor the pressure of the CSF. Draining the CSF can decrease the pressure around the brain and spinal cord. Your care team will decide when the catheter can be removed.

Lumbar drain



After surgery

After surgery, you will be moved to an intensive care unit (ICU). Highly trained nurses will be at your bedside to closely monitor your recovery. Once you are settled in your room and awake from anesthesia, your family will be allowed to visit you.

A typical stay in the ICU is one or two days. However, there are several reasons why you may need to spend more time in the ICU. If you require a longer stay in the ICU, your doctors and nurses will inform you and your family.

If you are admitted to the ICU with a breathing tube in your mouth (intubated) and connected to a ventilator (breathing machine), you will be lightly sedated so that neurologic checks can be performed (detailed on page 17). This means that you will have medication that will help to keep you calm, and the nurses will ask you simple command questions, i.e., wiggle your toes and give a thumbs-up. If your breathing tube remains in place, there is a possibility that the nurses will apply restraints to you for your safety. It can be dangerous if a patient removes their breathing tube while sedated. The restraints can be removed when the breathing tube is removed.

What to expect in the intensive care unit (ICU)

- You will be monitored by nurses continuously.
- You may have an arterial line (a small catheter that is usually placed in an artery in your wrist) for continuous blood pressure monitoring.
- You may have a small tube (catheter) in your bladder to drain your urine and to help monitor the function of your kidneys. The catheters are usually removed shortly after surgery or when ordered by your doctor.
- Your skin will be assessed daily.
- You may be placed on oxygen.
- You will be considered a fall risk, and you will not be able to get out of bed without assistance/supervision.
- You will have frequent blood draws and monitoring of your labs.
- The head of the hospital bed will likely be elevated. This is to help prevent swelling.
- Neurologic exams will be performed frequently (see neurological exam section on page 17).
- You may have a postoperative scan of your head: an MRI, a CT scan, or both.
- If appropriate, you will begin to work with physical, occupational, and possibly speech therapy. The therapy care teams will make recommendations for your recovery and safety.

Transition out of the ICU

Expected time spent in the ICU and the hospital will depend on your postoperative recovery.

After being in the intensive care unit, you may go directly home or move to another unit once you are medically stable and no longer need ICU-level care.

What to expect in an intermediate care (IMC) or medical-surgical (med-surg) unit

- Frequent neurological checks and vital signs by nursing staff and care team.
- You will still be considered a fall risk.
- Therapy (physical, occupational, speech) will continue to work with you if necessary.

Postoperative medications

You may be placed on multiple medications after surgery. You will get information on what these are and why you need them. Feeling discomfort after surgery is normal, especially at the incision site. We will do everything we can to ensure your comfort. Please see the following section for more information on common postoperative medications.

Common medications

You may or may not be placed on these medications postoperatively. Your care team will decide the best medications for your treatment while considering your health history. Your care team will review your specific medications with you.

Steroids

- Steroids are prescribed to help reduce swelling. These medications will be decreased gradually by your care team.
- Possible side effects: hunger, sleeplessness, high blood sugar (we will monitor your blood sugar frequently), high blood pressure, and behavior changes. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed steroids are dexamethasone (Decadron) and methylprednisolone (Solumedrol).

Anti-epileptic

- Anti-epileptics are used to prevent seizures.
- Possible side effects: irritability, drowsiness, and dizziness. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed anti-epileptics medications are levetiracetam (Keppra) and lacosamide (Vimpat).

Anti-nausea

- Anesthesia can cause nausea; these medications can help to make that feeling go away. If you are feeling nauseated, make sure you let your nurse know.
- Possible side effects: headaches, constipation/diarrhea, drowsiness, confusion, urinary retention, or dry mouth. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed anti-nausea medications are ondansetron (Zofran) and promethazine (Phenergan).

Antibiotics

- Antibiotics are used to prevent and/or treat infection.
- Possible side effects: mild skin rash, upset stomach, nausea, loose stools. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed antibiotics are cefazolin (Ancef) and vancomycin (Vancocin).

Constipation prevention

- Constipation can be a side effect of anesthesia and certain medications. Bowel management medications are used to prevent and/or treat constipation.
- Possible side effects: bloating, gas, cramping, loose stools, diarrhea, nausea, rectal irritation. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed bowel management medications are polyethylene glycol 3350 (MiraLAX) and senna (Senokot).

Remember — Always follow the instructions provided by your doctor and pharmacist when taking any medications. Keeping track of the time that you take all medications is helpful. Set reminders on your phone or write down what time your next dose of medication is due so that you don't miss a dose or take too much of an important medication.

Pain control medications

- Pain control medications are used to help control pain. Please notify your care team if your pain is not controlled.
- Possible side effects: drowsiness, nausea. Other side effects are possible. Please speak to your care team about other possible side effects.
- A commonly prescribed pain control medication is acetaminophen (Tylenol).

Nasal spray

- If you have endonasal surgery, you may have nasal sprays for postoperative comfort.
- This may be administered frequently while you are awake to relieve congestion and help keep your nose moist. This will also help to minimize headaches and drain old blood and mucus.
- Possible side effects: runny nose, sneezing, coughing, headache, nasal and/or eye irritation. Other side effects are possible. Please speak to your care team about other possible side effects.
- Commonly prescribed nasal sprays are saline nasal spray (Ocean Spray) and oxymetazoline (Afrin).

You may have other medications that are prescribed to you. If you have any specific questions about your medications, please ask your nurse or contact the care team member who prescribed the medication to you.

Possible surgical side effects and complications

After surgery, it is possible that you may have side effects or experience a complication. Your surgeon will discuss the risks of surgery with you. We will do everything we can to minimize these risks. We will provide education on how to recognize signs and symptoms of a complication and who to contact if you have concerns.

While you are in the hospital, your nurses will monitor you closely for signs or symptoms listed below:

- Headaches
- Nausea and vomiting
- Neurological changes
- Facial swelling
- Cognitive and behavioral problems
- Seizures
- Deep vein thrombosis (DVT) (blood clots in the arms or legs)
- Pulmonary embolus (PE) (blood clots in the lungs)
- Stroke (blood clots or bleeding in the brain)
- Infection
- Pneumonia

How to lower your chance of postoperative complications

Please see the Improving your health and wellbeing section on page 45 for more information on how to lower your chances of postoperative complications.

Reminder! Don't touch your incision! If you must touch your incision, please make sure your hands are clean.

Postoperative care

Incision care and showering

You may have one or more incisions after your surgery. The incision type will be based on the type of surgery that you have. Your care team will review instructions on how to care for your incision and when you are allowed to shower.

Craniotomy care

The incision(s) may be closed with either staples or sutures (stitches), and these will be removed at your follow-up appointment about two weeks after your surgery.

You may shower with mild soap and shampoo, but avoid touching your incision.

- Do not allow the shower head to spray directly on the incision.
- Use a cup to pour water gently over the incision for rinsing.
- Pat the incision dry after showering with a clean, dry towel and then avoid touching your incision after this.
- Do not put any products in your hair or any creams, ointments, or lotions over the incision site.
- Do not submerge your head (do not dunk your head in a bath, swimming pool, or hot tub) until cleared by your surgeon.

You may apply ice packs to the incision to assist with swelling and discomfort.

Do not allow anything to rub against your incision (for example, sunglasses can easily rub against the incision).

Avoid having your hair colored or permed for 4-6 weeks after surgery.

Endonasal care

Your nose may be packed with a dissolvable nasal packing postoperatively. Continue to use saline nasal spray to help relieve congestion and keep your nose moist. This will also help to minimize headaches and drain old blood and mucus.

Do not submerge your head underwater until you are cleared by your surgeon.

Follow the ear, nose and throat (ENT) precautions:

- No nose blowing
- If you need to sneeze, sneeze with your mouth open
- Do not use a straw
- Do not use your CPAP machine

Please contact your surgeon's office if you are having clear or bloody drainage from your nose.

Do not strain while having a bowel movement. This can create pressure in your head. It is important to take stool softeners and laxatives so that you are not constipated after surgery.

Activity after surgery

Getting up and moving after surgery is a very important step in the healing process. It will help to prevent pneumonia, blood clots, and problems with your bowels and bladder.

Therapy and your bedside nursing team will help you get up and move around after surgery. You will want to avoid any strenuous activity until you have been cleared by your surgeon to do so. Walking for exercise is okay.

Do not try to lift, push, or pull more than 10 pounds after surgery. Do not do anything that could put you at a higher risk for head trauma; this includes:

- Do not drive until you are cleared by your surgeon.
  - We recommend staying out of the car except for your drive home from the hospital and your drive to your post operative appointments.
- Do not participate in any high-risk activities such as skateboarding, snowboarding, biking, or contact sports after surgery until cleared by your surgeon.

Eat a well-balanced diet. Eat high-fiber foods (such as fruits and vegetables) and drink plenty of water (6-8 cups a day – unless otherwise stated by your doctor) to avoid constipation.

If you have any specific activity or diet questions, please ask your surgeon.

When to call your surgeon's office:

- Temperature greater than 101˚F with chills, sweating, or shaking
- Changes in your incision - significant swelling or redness around the incision
- Increased drainage from incision
- Foul odor or cloudy color drainage from the incision
- Uncontrolled pain
- No bowel movement in 3 days
- Fall without injury or loss of consciousness

When to call 911:

- Chest pain
- Shortness of breath
- Fall (with pain, injury, or loss of consciousness)
- Seizure activity
- Facial drooping, weakness on one side of your body, speech difficulty, eyesight changes, or loss of balance

Questions to ask about brain surgery

Deciding to have brain surgery can be overwhelming. You may use the space below to help organize your thoughts and assist with understanding your surgery.

What is the goal of my surgery? ______________________________

____

What are the risks of surgery? ______________________________

____

What are the common complications? ______________________________

____

What medications will I need to stop taking before or after surgery? ______________________________

____

How long should I expect to be in the hospital? ______________________________

____

Will I need someone to stay with me after surgery? ______________________________

____

Will my head be shaved? ______________________________

____

How big will my incision be? ______________________________

____

Will I have restrictions after surgery? ______________________________

____

Will I be able to drive? ______________________________

____

How long will it take to recover from my surgery? ____________________

Will I have a drain inserted during surgery? If so, how long will this stay in? ____________________

What is the chance the tumor will come back if resected (or removed)? ____________________

What happens if I choose not to have surgery or delay surgery? ____________________

If I choose not to have surgery, what resources are available to me? ____________________

How to manage your care at home

How to manage your care at home

This section focuses on guiding you through managing your care at home. Your active participation in your care plays a strong role in your overall health.

Monitoring symptoms and health changes

A brain tumor can affect many parts of your body, and it can cause emergencies to occur at any time. Please call 911 immediately if any of the following occur:

Seizures

Seizures can happen for many reasons. They can happen suddenly and can last for various amounts of time. If you have a seizure, you may lose your awareness of your surroundings, shake, twitch, not be responsive, become limp, and/or become stiff.

Please have your loved ones review the following steps to take if you have a seizure:

- Place them on their side
- Do not stick anything in their mouth
- Protect them from injury and protect their head
- Do not restrain their movements
- Time the seizure (note what time it started and record how long it lasts)
- Call 911 immediately

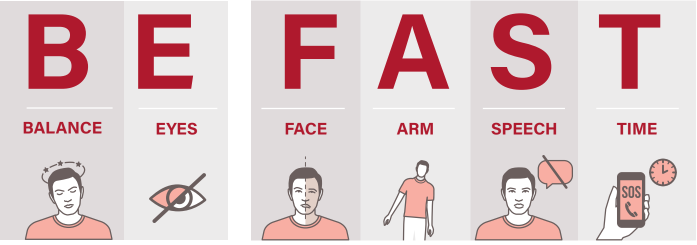
Having a brain tumor increases your risk for seizures. Please ask your care team if it is okay for you to drive a car.

Strokes

A stroke is when you have a ruptured blood vessel or a clot in your brain. Strokes can be life-threatening and need to be treated quickly. Please note when the stroke symptoms start.

Call 911 immediately if you or your loved one experiences any of the following signs/symptoms of a stroke:

- Sudden loss of balance
- Sudden visual loss
- Sudden onset of facial drooping (uneven smile)
- Sudden weakness on one side of the body
- Sudden speech difficulty



Changes in the level of consciousness

If you or your loved one seems confused, is not acting right, or if their behavior is different (agitated or inappropriate), please call 911 or go to the closest emergency room.

Falls

If you fall and get hurt, please call 911 immediately. Brain tumors may alter your balance, and you may become more likely to fall.

Tips to avoid falls:

- Be aware of all floor hazards, such as pets, small objects, and uneven surfaces.
- Provide good lighting throughout your home. Install night lights in the bathrooms, bedrooms, and hallways.
- Keep extension cords and telephone cords out of the pathways. Do NOT run wires under the rugs; this is a fire hazard.
- Do NOT wear open-toe slippers or shoes without backs. They can lead to slips and falls.

Improving your health and wellbeing

Living a healthy lifestyle is important, especially after being diagnosed with a brain tumor. There are resources available to assist you with making positive changes to your health.

Smoking cessation

Quit smoking.

- Smoking can cause an increased risk of infection.
- Smoking can slow or complicate your recovery from treatment and can be harmful to your health.
- Smoking reduces the size of your blood vessels and decreases the amount of oxygen circulating in your blood.
- Vaping is considered smoking, and you should stop vaping before and after surgery.
- If you use marijuana, please discuss it with your care team.
- If you would like resources to help you stop smoking, please visit smokefree.gov or call 1-800 QUIT NOW (784-8669).

Drug and alcohol use

Quit illegal drug use.

- Illegal drugs can cause an increased risk of infection.
- Illegal drugs can slow or complicate your recovery from treatment and be harmful to your health.
- Illegal drugs can worsen the symptoms of your brain tumor.
- If you use illegal drugs regularly, you should discuss this with your care team.

Alcohol use guidelines

- Alcohol use can slow or complicate your recovery from treatment and can be harmful to your health.
- If you drink alcohol often, please reach out to your care team for specific guidelines.
- If you would like resources on how to stop using illegal drugs and/or quit drinking, please visit samhsa.gov.

Exercise

- If you are able, try to incorporate low-impact exercise (such as walking) into your daily routine. Please follow your care team's recommendations about exercise and activity. Reach out to your care team about any specific restrictions that you may have.

Dietary changes

- Nutritionists and dietitians are available within the Sentara system to assist you with healthy eating habits and dietary changes.
- Eat a well-balanced diet and drink water for hydration.
- Eating a well-balanced diet with enough calories, protein, vitamins, and minerals will help to keep you strong and healthy.

Questions to ask about managing your care at home

For patients

Who do I call if I have a question about my care?

Who can I talk to if I need support?

How will I know what is normal and what is something concerning?

Who can I talk to about more dietary recommendations?

Are there any activities I should avoid?

How often should I follow up with my care team?

Do I need to get imaging done regularly?

What resources are available?

Will I need any special equipment or assistive devices?

For caregivers

Please see the caregivers section for questions to ask and more, starting on page 55.

Resources

Resources

This section is a tool kit filled with valuable information. We are here to help you work through emotional adjustments, share your diagnosis with others when ready, and answer practical questions related to healthcare decision tools and insurance along the way.

Emotional adjustments and support

It is perfectly normal to feel different emotions after being diagnosed with a brain tumor. Talking about your feelings with your doctors, nurses, or family may be helpful. We have additional specialty-trained care team members who are available to assist you and your loved ones when needed.

Anxiety, fear, and emotional distress

Anxiety (a feeling of worry or unease), fear, uncertainty, anger, and sadness are common feelings that patients and loved ones sometimes have when coping with a tumor diagnosis. These are normal responses.

Changes in the ability to keep up with family duties, loss of control over events in life, changes in the way you look, or simply the shock of a brain tumor diagnosis might lead to feelings of fear or anxiety. A person could feel uncertain about the future and concerned about suffering, pain, and the unknown. Some people mourn the changes in their bodies and the loss of the healthy future they may have expected. Fears concerning loss of independence, changes in relationships with loved ones, and becoming a burden to others may overwhelm the patient and complicate family life.

Loved ones may have these feelings because they, too, are uncertain about the future or maybe even angry that their loved one has a brain tumor. Please see the caregiver section of this guidebook, on page 55, for more resources for a caregiver.

Sometimes, a person with a brain tumor may become overly anxious, fearful, or depressed and may no longer cope well with day-to-day life. If this happens, it often helps the patient and family to get help from a professional therapist or counselor.

If you recognize that you are showing the signs below, please reach out to your care team or to the crisis helpline (988):

- Feeling anxious and overwhelmed to the point of panic
- Trouble thinking, solving problems, or making decisions (even about little things)
- Being agitated, irritable, or restless
- Feeling or looking tense
- Concern about "losing control"
- An uneasy sense that something bad is going to happen
- Trembling and shaking
- Being cranky or angry with others
- Feeling unable to cope with tiredness, pain, nausea, and other symptoms
- Trouble sleeping or restless sleep

Please reach out to the crisis helpline (988) if needed.

Telling loved ones about your diagnosis

Being diagnosed with a brain tumor can feel scary and overwhelming. The side effects of your brain tumor may make it harder to communicate. While allowing others to help balance the practical and emotional challenges of this diagnosis, figuring out who to tell about your diagnosis and how to tell them may feel overwhelming.

When you are ready to tell others you have a brain tumor, consider using these helpful tips*

- Check in with yourself first and let us know how you feel about telling others. Are you ready to tell others? Are you ready to tell your children?
- You are in control of who you tell, when you tell them and what you tell them. It is okay not to tell everyone everything.
- Prepare by having a supportive person available to process with afterward if you are anticipating a hard conversation and/or prepare by having coping skills or grounding techniques ready afterward to help you decompress/process.
- Bring a supportive person with you if you think it might be beneficial to have them there, and they already know about your diagnosis.
- Think about your boundaries ahead of time. What information is something you want to stay private? What are you willing to share?
- Plan out your responses if you think it will be a difficult conversation or anticipate your reactions to unhelpful comments from friends or family members.
- Consider when you tell others. Would it be beneficial to wait until after you have your treatment plan and know what the next steps are?
- Be honest. It is okay to say you do not have all the answers.
- Consider using a messaging system to manage written communications and updates. Consider if you would like to ask someone to help you with this task.

*Source: Dana-Farber Cancer Institute and the National Cancer Institute.

If you have children in your life, figuring out how and when to tell them about a brain tumor diagnosis can feel particularly scary. While our natural instinct may be to protect children by hiding distressing information from them, children are observant and may sense that something is off. We can help lower children's anxiety by talking about the diagnosis in a developmentally appropriate way that helps them understand what to expect.

Consider the following when talking to children about a brain tumor diagnosis:

- You know your children best and know the best way to communicate this news with them.
- If you have a partner, make sure you both are on the same page and consider your partner's response and role moving forward with helping your children process while you go through treatment.
- Consider when you tell them. Have you told other adults in their lives who might share or ask them about your diagnosis? Do you want to make sure you are the one to tell your children personally? Would you like to have someone else with you for support during the conversation?
- Share with your children if there is a trusted adult who knows about your diagnosis who they can go to other than yourself or a partner to talk about your diagnosis and what they might be feeling.
- Consider their age and what language would be age-appropriate.
- Let your child lead the conversation and be guided by what concerns your child might bring up.
- Depending on their age and understanding:
  - Emphasize they did not cause you to get a brain tumor by their thoughts or behaviors
  - It is not contagious – they cannot get sick from your brain tumor
  - Welcome them to still share when they feel sick or not well and need help
  - Reassure your love for them
- Consider preparing them for some of the symptoms you might experience and how your behavior/roles/responsibilities might change or shift within your family.
- Give them time to process the news.
- Your child could benefit from continuing their regular routines
  - Emphasize that they are not responsible for you or caring for you throughout your treatment.
- It's OK to cry or show emotion during the conversation. It can normalize these feelings for your children and allow them to be comfortable sharing their emotions with you.
- If you think your child is struggling more than you expected, have a conversation with them. Ask them what they are feeling and if there is something that will help.
- Watch their behaviors – this can tell a lot about how they could be processing the news.
- Consider reaching out to your child's pediatrician, a therapist, or utilize community resources such as support groups or camps that could help if your child is consistently struggling.
- Connect with the child's school, teachers, and/or school counselor for further support and resources as well.

While sharing your diagnosis can be stressful, communicating with others can help you build support both emotionally and practically as you navigate your medical care.

Community support

Although brain tumors seem like a rare occurrence, they are common. You are not alone. There are support groups and community resources available for you and your support system throughout your journey.

Sentara offers the Supportive Care Clinic. Supportive Care Services is Palliative Care.

Supportive Care Services is a medical specialty in an outpatient setting that focuses on improving the quality of life for patients experiencing a severe illness. Supportive care services can help with physical symptoms such as pain, shortness of breath, and depression, as well as provide emotional support to you and your family. Supportive Care Services are available during any stage of your illness and can be provided while you are receiving treatment for your illness. You do not need a referral to schedule an appointment with the Supportive Care Clinic. You can schedule appointments for yourself. Please call 757-624-0300 if you would like more information or would like to schedule an appointment.

Supportive Care Services/Palliative Care differs from Hospice

Hospice is a care plan that focuses on quality of life and liberal symptom management. Hospice care is a valuable part of medical care for patients who are approaching the end of life or who wish to focus on symptom management only. Supportive Care Services, on the other hand, are available to you at any time during your illness and do not depend upon whether your condition can be cured.

Oncology social workers

Oncology social workers are located throughout the system and can provide acute crisis counseling and help you transition into a long-term outpatient counseling program. Ask your care team for more information.

There are national programs with many support resources available.

The American Brain Tumor Association (ABTA)

ABTA.org | 800-866-ABTA (2282)
ABTAcares@abta.org

National Brain Tumor Society

BrainTumor.org | To connect with their personalized support and navigation team, email PatientNavigator@BrainTumor.org

Local resources

There are local support groups and organizations available. Please reach out to your care team to find out more about these organizations.

Social media resources

Many patients and caregivers choose to join Facebook groups for brain tumor patients. There are local groups, national groups, and international groups available. Please note, we do not recommend taking medical advice from these groups and they should only be used as a resource for support.

Health insurance

If you have health insurance, we encourage you to explore your health insurance benefits and coverage as you go through your treatment. Coverage and benefits vary from one insurance company to another, and your insurance company will dictate the final determination of your benefits after a claim is processed.

Here are some common terms that apply to almost everyone with insurance regarding insurance coverage.

- **Co-insurance:** The percentage of health care costs an insured patient pays after meeting a health care plan's yearly deductible. For example, an 80/20 co-insurance rate means the insurance company pays 80% of approved healthcare costs, and the patient pays the remaining 20% of out-of-pocket costs. Your deductible must be paid first.
- **Co-pay:** A set fee that an insurance provider requires a patient to pay each time care is received. A specialist's fee may be higher than the PCP's. The co-pay amount is set by the insurance provider, not the doctor's office. Some benefit plans require a co-pay for each radiation treatment.
- **Deductible:** The amount of approved health care costs an insured patient must pay out-of-pocket each year before the health care plan begins paying any costs.
- **Effective date:** The date when your insurance begins to take effect.
- **Out-of-Pocket maximum:** This is the amount of co-insurance you are required to pay annually. Once this amount has been paid, you have met your cap, and the insurance will begin to pay all applicable charges at 100% of the allowed amount. Co-pays and deductibles may or may not apply to this amount, depending on your plan.
- **Precertification:** The process of requesting approval from an insurance plan for specific services before they happen, such as a treatment, procedure, or hospital stay; also called pre-approval.
- **Premium:** The amount a person or company pays each month to keep insurance coverage.

If you have further questions or want to know more about your specific coverage, please call "Member Services"—the telephone number is listed on the back of your insurance card.

If you do not have health insurance, please contact the Sentara billing department to get more information about the financial assistance process or to start a payment plan.

Source: ASCO answers Managing the Cost of Cancer Care: Practical Guidance for Patients and Families http://www.cancer. net/sites/cancer. net/files/cost_of_care_ booklet.pdf

Decision-making tools

What is a legal decision-maker?

A legal medical decision-maker (also known as a medical power of attorney, healthcare surrogate, or healthcare proxy) is an adult who makes treatment decisions for a person who is unable to make their own decisions. Serving as a legal, medical decision-maker does not make one financially responsible and does not affect who can visit your loved one.

Who can make decisions for individuals who cannot make decisions for themselves?

Virginia: In the absence of an Advance Care Plan or Medical Power of Attorney, the default medical decision-maker for a patient lacking decisional capacity is outlined in the Virginia Health Care Decisions Act.

1. A guardian for the patient; or
2. The patient's spouse, except where a divorce action has been filed, and the divorce is not final; or
3. Majority of adult children of the patient; or
4. Both biological/legal parents of the patient; or
5. Majority of adult siblings of the patient; or
6. Any other relative of the patient in the descending order of blood relationship

Scan the QR code or visit the URL for more information.

law.lis.virginia.gov/vacode/title54.1/chapter29/section54.1-2986

Advance care plan information

Healthcare is extremely important to everyone. Wherever you are, whatever the situation, you want to be sure you receive excellent medical treatment. More importantly, you want your medical choices to be understood and honored.

Advance Care Plan (Advance Directive) documents can include your Living Will, which helps the health care team know what your wishes are, and your Medical Power of Attorney or Healthcare Agent, which is who you want to speak for you if you can't speak for yourself.

Please refer to the Advance Care Planning Guide for more information on how to complete an Advance Directive. If you need one of these packets, please reach out to your care team or follow the link below to direct you to the forms needed to complete an Advance Care Plan.

Scan the QR code or visit the URL for more information.

sentara.com/PatientGuide/Forms

Quality of life conversations

People have different opinions about what makes life worth living. It is important to have discussions with your loved one about your quality-of-life goals.

Questions are listed in the following section to help guide the conversation with your loved ones and the care team. Review your wishes with your loved ones so that in case of an emergency or change in your condition, your loved ones know what you want.

This guidebook alone will not be used to make treatment decisions, as this is not a legal document. Not every item on the next page will apply to you, but it is important to consider what you would want in these situations.

Questions to ask your loved ones about decision-making

List or describe things that have the greatest effect on your quality of life. If you can no longer do the things listed, would this change your treatment decisions?

Do you have any emotional or spiritual concerns for consideration?

Do you have a will? Has it been recently updated?

If applicable, what are your wishes for your children/grandchildren?

Have you talked to your loved ones about whether you would want life-sustaining or palliative care measures if you become very ill?

Are you willing to be put on a breathing machine for an extended period?

Is it important for you to be independent and self-sufficient in your life?

Caregivers

Caregivers

It is perfectly normal to feel emotional after a loved one has been diagnosed with a brain tumor. Talking about your feelings with friends, family, counselors, and support groups can be helpful. It is important to remember to take care of yourself. It is normal to feel frustrated, overwhelmed, or upset, but we want you to know that there are resources available to help you and your loved one. Please see the community support information on page 51 for information on what's available to support you and your loved one, or reach out to your loved one's care team for questions.

We encourage you to keep a copy of all your loved one's treatments and a timeline of their care. There is a notes section at the back of this guidebook that you can use for that purpose.

Caregiver fatigue

While caring for someone you love can be incredibly meaningful, it can also be challenging. Caring for someone with a brain tumor can be time-consuming and presents unique challenges, including navigating physical, cognitive, and behavioral changes with your loved one. Sometimes, this stress can lead to fatigue and burnout.

Caregiver fatigue is common and can be experienced in many ways. You may constantly feel tired despite getting enough sleep. You may experience an increase in feelings of sadness, helplessness, and hopelessness. Perhaps you may have trouble focusing or lose interest in doing things you used to enjoy. Often, caregivers who are fatigued find themselves neglecting their own care needs. You may find yourself getting sick more easily or experiencing an increase in anxiety. Changes in mood, such as irritability and impatience, can occur. You might also notice changes in your appetite or sleep.

Caregiving is hard! Remember that your feelings are normal and valid. There are some things you can do to help yourself through this experience.

- **Use your support system.** While it can be hard to ask for help, it is OK and encouraged for you to do so. Identify those whom you trust and can rely on in your network. Also, recognize which tasks you need help with. Choose what is a priority for you to do and what you can outsource to a trusted member of your support system. This may look like asking for help with meals, household tasks, or companionship for your loved one to allow you some respite time.
- **Share with others.** Being a caregiver can prompt many mixed feelings. Acknowledging and naming your emotions can help lessen the distress and help you feel more in control. You can share your story with others that you trust, join a support group, and/or consider journaling.
- **Schedule time for yourself.** We know time is precious and scarce. Self-care can look like many different things, and there is no requirement that it has to take a lot of time. Think about what recharges you and try to carve out a few minutes every day. This can look like a few extra minutes getting ready in the morning or asking a friend to help with your loved one so you can take a short walk.
- **Consider your physical, mental, emotional, and spiritual health.** Caregiving can be physically, mentally, emotionally, and spiritually taxing. Take some time to reflect on what is important to you. Try to carve out time to take care of your own physical and mental healthcare needs. If you are experiencing spiritual distress, consider reaching out to a spiritual advisor that you trust.
- **Talk to a counselor.** A licensed mental health professional can help you process your thoughts and feelings and learn new methods of coping with stressful situations.

How to help in an emergency

If your loved one is seen emergently, we encourage you to provide as many details about your loved one's care as possible. Be ready to tell the emergency room provider the following information:

- What is your loved one's normal level of function? (For example, can they walk around on their own? Are they bedbound?)
- What is your loved one's normal level of consciousness? (For example, are they alert? Confused?)
- What new symptoms are they experiencing? How long have they had these symptoms?
- What medications are they currently taking?
- What is your loved one's brain tumor diagnosis/ tumor type?
- Please provide a timeline of the changes that you have seen in your loved one and note important events in their brain tumor care:
  - If they had surgery, what surgery did they have, and when did they have it?
  - What treatments has your loved one had (if any), and when did they have them? (For example, radiation and chemotherapy)

Changes to look for in your loved one and when to call 911:

Please see monitoring symptoms or health changes on page 44 for signs and symptoms to watch for while caring for your loved one at home.

Please reach out to the crisis helpline (988) if needed.

Questions to ask as a caregiver

Who can help me talk to my loved one about the future? ________________________________

____

Who can I talk to if I need support? ________________________________

____

How soon should I call if I notice a change in my loved one? ________________________________

____

Who should I call if their symptoms worsen? ________________________________

____

What are ways I can support my loved one? ________________________________

____

Who should I call if I am having difficulty supporting my loved one? ________________________________

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Common terms

Common terms

This section consists of terms that you may or may not hear during your brain tumor journey. Not all terms listed below will be relevant to your tumor diagnosis.

A

Acoustic Neuromas
Benign tumor of the hearing nerve (eighth nerve).

Adenoma
A benign growth formed of glandular tissue.

Advanced Practice Provider (APP)
Advanced Practice Providers (APP) are Nurse Practitioners (NP) or Physician Assistants (PA) who have completed advanced education and training. They work with physicians and help provide care during your procedure, hospital stay, and office visits.

Agnosia
Absence of the ability to recognize the form and nature of persons and things.

Amenorrhea
Absence of menses due to causes other than pregnancy or age.

Amnesia
Loss of memory caused by brain damage or by severe emotional trauma.

Analgesia
Loss of sensitivity to pain, loss of response to a painful stimulus.

Aneurysm
Dilation of an artery formed by a circumscribed enlargement of its wall.

Anosmia
Partial or complete loss of smell.

Anoxia
An absence of oxygen.

Anti-Coagulant
A medication that prevents coagulation (clotting) of the blood.

Antidiuretic
An agent that reduces the output of urine.

Aphasia
Difficulty with or loss of use of language in any of several ways, including reading, writing or speaking, not related to intelligence but to specific lesions in the brain.

Apnea
Temporary cessation of breathing.

Arachnoid
The middle layer of membranes covering the brain and spinal cord.

Astrocyte
Cell that supports the nerve cells (neurons) of the brain and spinal cord.

Astrocytoma
Tumors within the substance of the brain or spinal cord made up of astrocytes, often classified from Grade I (slow-growing) to Grade 3 (rapid-growing).

Ataxia
A loss of muscular coordination and abnormal clumsiness.

Atrophy
A wasting of the tissues of a body part.

Attending Physician
A medical doctor who has completed all medical training.

Autonomic Nervous System
The involuntary nervous system also termed the vegetative nervous system—is a system of nerve cells whose activities are beyond voluntary control.

B

Biopsy
Removal of a small portion of tissue, usually for making a diagnosis.

Blood-Brain Barrier
The barrier that exists between the blood and the cerebrospinal fluid prevents the passage of various substances from the bloodstream to the brain.

Bradykinesia
Slowness in movement.

Brainstem
The portion of the brain that lies between the diencephalon and the spinal cord comprises the midbrain, pons, and medulla.

Broca's Aphasia
Difficulty producing speech as a result of damage to Broca's area in the left frontal lobe.

Broca's Area
An area in the left frontal lobe specialized for the production of language.

C

Carcinoma
Cancer, a malignant growth of epithelial or gland cells.

CT Scan (Computed Tomography Scan)
A diagnostic imaging technique in which a computer reads X-rays to create a three-dimensional map of soft tissue or bone.

Cerebellum
The lower part of the brain that is beneath the posterior portion of the cerebrum. It regulates the unconscious coordination of movement.

Cerebrospinal Fluid
Water-like fluid that circulates around and protects the brain and spinal cord.

Cerebrum
The principal portion of the brain, which occupies the major portion of the interior of the skull and controls conscious movement, sensation and thought.

Chiasm (Optic)
Crossing of visual fibers as they head toward the opposite side of the brain. For each optic nerve, most of the visual fibers cross to the opposite side, while some run directly backward on each side without crossing.

Cingulate Cortex[1]
The cingulate cortex is a part of the brain that helps control motor function, error detection, emotion, memory, and pain processing.

Cisterns
Large, cerebrospinal fluid-filled spaces that lie within the subarachnoid space.

Coma
A state of profound unconsciousness from which one cannot be roused.

Concussion
A disruption, usually temporary, of neurological function resulting from a blow or violent shaking.

Contrast
Medium: Any material (usually opaque to X-rays) employed to delineate or define a structure during a radiologic procedure.

Contusion
A bruise: cerebral contusions often involve blood vessels that leak into brain tissue.

Corpus Callosum
The large midline fiber bundle that connects the cortices of the two cerebral hemispheres.

Cranium
The part of the skull that holds the brain.

Craniectomy
Excision of a portion of the skull.

Craniopharyngioma
Tumor arising from the embryonic duct between the brain and the pharynx.

Cranioplasty
The operative repair of a defect of the skull.

Craniotomy
Opening of the skull, usually by creating a flap of bone.

CSF
Cerebrospinal fluid.

D

Diabetes Insipidus
Excretion of large amounts of urine of low specific gravity. The inability to concentrate urine.

Diffuse Brain Injury
Damage to the brain that can affect many parts of the brain, often in a subtle fashion; examples include diffuse axonal injury and inadequate blood flow.

Diplopia
Double vision, usually due to weakness or paralysis of one or more of the extra-ocular muscles.

Doppler
A non-invasive study that uses sound waves to show the flow in a blood vessel and can be used to determine the degree of narrowing (percent stenosis) of the vessel. A wand is placed on the skin over the vessel that is to be imaged. This study has no risks and is not painful.

Dura Mater
A tough fibrous membrane that covers the brain and spinal cord but is separated from them by a small space. It is the outermost layer of the three membranes.

Dysphasia
Difficulty in the use of language due to a brain lesion without mental impairment.

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[1] https://www.sciencedirect.com/topics/psychology/cingulate-cortex#:~:text=The%20exact%20number%20of%20functional,et%20al.%2C%202008

E

Edema
Swelling in the body.

Electroencephalography (EEG)
The study of the electrical currents set up by brain actions; the record made is called an electroencephalogram.

Endocrine Gland
A gland that furnishes an internal secretion, usually having an effect on another organ.

Ependymoma
A growth in the brain or spinal cord arising from ependymal tissue.

Epidural
Immediately outside the dura mater. Same as extradural. Also, a form of local analgesia and anesthesia, often injected into the outer section of the spinal canal.

Epidural Hematoma
A blood clot between the dura mater and the inside of the skull.

Epilepsy
A disorder characterized by abnormal electrical discharges in the brain, causing an abnormal sensation, movement, or level of consciousness.

F

Frontal Lobe
One of the four lobes of the brain; includes all the cortex that lies anterior to the central sulcus and superior to the lateral fissure.

Frontal Sinus[2]
The frontal sinus is a hollow space in the frontal bone that lightens the skull. Its mucosal lining helps to warm and humidify the air.

G

Gamma Knife
Equipment that precisely delivers a concentrated dose of radiation to a predetermined target using gamma rays.

Glasgow Coma Scale (GCS)
The most widely used system of classifying the severity of head injuries or other neurologic diseases.

Glioma
A tumor formed by glial cells.

Glioblastoma
A rapidly growing tumor composed of primitive glial cells, mainly arising from astrocytes.

H

Hemangioma
An aggregation of multiple dilated blood vessels.

Hematoma
A collection of blood outside the blood vessels.

Hemianopia:
Loss of vision of one-half of the visual field.

Hemiplegia
Paralysis of one side of the body.

Hemorrhage
Bleeding due to the escape of blood from a blood vessel.

Hormone
A chemical substance formed in one gland or part of the body and carried by the blood to another organ, which stimulates functional activity.

Hospitalists[3]
A clinician whose primary professional focus is the general medical care of hospitalized patients.

Hydrocephalus
A condition, often congenital, marked by abnormal and excessive accumulation of cerebrospinal fluid in the cerebral ventricles. This dilates the ventricles and, in infants and young children, causes the head to enlarge.

Hyperesthesia
Excessive sensitivity to touch, pain or other stimuli.

Hypertension
High blood pressure.

Hypothalamus
A collection of specialized nerve cells at the base of the brain that controls the anterior and posterior pituitary secretions and is involved in other basic regulatory functions such as temperature control and attention.

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[2] https://www.sciencedirect.com/topics/psychology/cingulate-cortex#:~:text=The%20exact%20number%20of%20functional,et%20al.%2C%202008;

[3] https://www.hospitalmedicine.org/about/what-is-a-hospitalist/

I

Intra-Arterial Catheterization
Angiography: An invasive study in which a catheter (a small tube) is placed in the artery and contrast material is injected, which makes the blood vessels visible on an X-ray image. The catheter is inserted in the groin into the femoral artery (the artery to the leg) through a needle and is guided into the arteries in the neck and head.

Intracerebral Hematoma
A blood clot within the brain.

Intracranial Pressure (ICP)
The overall pressure inside the skull.

Intraoperative Cisternography
Administration of a contrast dye into the ventricles, which are chambers in the brain that contain brain fluid.

Intravenous (IV)[4]
Something exists, occurs within, or is administered into a vein or veins.

Ischemia
Inadequate circulation of blood generally due to a blockage of an artery.

J

Jugular Veins
The major veins on each side of the neck draining blood from the head toward the heart.

L

Leptomeningitis
Inflammation of the membranes covering the brain and spinal cord.

Lipoma
A benign fatty tumor, usually composed of mature fat cells.

Lumbar Drain
A device (usually a long, thin, flexible tube) inserted through the skin into the cerebrospinal fluid space of the lower back; provides a method of draining cerebrospinal fluid.

M

Magnetic Resonance Angiography (MRA)
A non-invasive study that is conducted with a magnetic resonance imager (MRI). The magnetic images are assembled by a computer to provide an image of the arteries in the head and neck.

Magnetic Resonance Imaging (MRI)
Diagnostic tests that produce 3D images of body structures using powerful magnets and computer technology rather than X-rays.

Medulla Oblongata[5]
The bottom-most part of the brain. Its location is where your brain and spinal cord connect, making it a key conduit for nerve signals to and from your body. It helps control vital processes like your heartbeat, breathing, and blood pressure.

Medulloblastoma
A tumor composed of medulloblasts, which are cells that develop in the roof of the fourth ventricle (medullary velum).

Meninges
The three membranes covering the spinal cord and brain are termed dura mater, arachnoid mater and pia mater.

Meningioma
A firm, often vascular, tumor arising from the coverings of the brain.

Meningitis
An infection or inflammation of the membranes covering the brain and spinal cord.

Meningocele
A protrusion of the coverings of the spinal cord or brain through a defect in the skull or vertebral column.

Midbrain[6]
A part of the brain that functions as a relay system, transmitting information necessary for vision and hearing. It also plays an important role in motor movement, pain, and the sleep/wake cycle.

Motor Cortex
The region of the cerebral cortex lying anterior to the central sulcus concerned with motor behavior; includes the primary motor cortex in the precentral gyrus and associated cortical areas in the frontal lobe.

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[4] Oxford English Dictionary; [5] https://my.clevelandclinic.org/health/body/23001-medulla-oblongata; [6] https://www.verywellhealth.com/midbrain-anatomy-5093684#:~:text=The%20midbrain%20functions%20as%20a,of%20the%20central%20nervous%20system

N

Neuralgia
A paroxysmal pain extending along the course of one or more nerves.

Neuroblastoma
Tumor of the sympathetic nervous system, found mostly in infants and children.

Neurofibroma
A tumor of the peripheral nerves due to an abnormal collection of fibrous and insulating cells.

Neurofibromatosis
A familial condition characterized by developmental changes in the nervous system, muscles and skin, marked by numerous tumors affecting these organ systems.

Neuroma
A tumor or new growth largely made up of nerve fibers and connective tissue.

Neuropathy
Any functional or pathologic disturbance in the peripheral nervous system.

Neurosurgeon
Neurosurgeons are physicians specially trained in surgical procedures of the brain, spinal column, and nervous system. If you have brain surgery, your neurosurgeon will be the team member who either biopsies or removes the tumor.

Nil Per Os (NPO)
Nil Per Os, or NPO, is the Latin phrase that translates to "nothing by mouth." If you are NPO, this means that you cannot eat or drink anything.

Nystagmus
Involuntary rapid movement of the eyes in the horizontal, vertical or rotary planes of the eyeball.

O

Occipital Lobe
The posterior lobe of the cerebral hemisphere is primarily devoted to vision.

Occiput
The back part of the head.

Olfactory Bulb
The olfactory bulb is a part of the brain that detects odors.

Oligodendroglia
Non-nerve cells (see glia) forming part of the supporting structure of the central nervous system.

Oligodendroglioma
A growth of new cells derived from the oligodendroglia.

Optic Nerve
The optic nerve is the nerve responsible for transmitting visual information (your vision).

Osteoma
A benign tumor of bone.

Otolaryngologist
An otolaryngologist is a physician, also known as an ear, nose, and throat (ENT) surgeon.

P

Papilledema
Swelling of the optic nerve head that can be seen in the back of the retina during an eye examination.

Paraplegia
Paralysis of the lower part of the body, including the legs.

Parietal Lobe
The lobe of the brain that lies between the frontal lobe anteriorly and the occipital lobe posteriorly.

Per Os (PO)
Per Os, or PO, is the Latin phrase that translates to "by mouth." If you have medications ordered that are "PO," this means they will be administered orally.

Pituitary Gland
A gland at the base of the brain that secretes hormones into the bloodstream. Those hormones then regulate other glands, including the thyroid, adrenals and gonads. The "Master Gland."

Pons[7]
A section of the brain that links your brain to your spinal cord. The pons handles your unconscious movements and processes (for example, sleeping and breathing).

Post-Ictal (Postictal)
State following a seizure, often characterized by altered function of the limbs and/or mental activity.

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[7] https://www.webmd.com/brain/pons-what-to-know; [8] https://medlineplus.gov/ency/article/001939.htm

Prefrontal Cortex
Cortical regions in the frontal lobe that are anterior to the primary and association motor cortices are thought to be involved in planning complex cognitive behaviors and in the expression of personality and appropriate social behavior.

Premotor Cortex
Motor association areas in the frontal lobe anterior to the primary motor cortex are thought to be involved in the planning or programming of voluntary movements.

Primary Care Provider (PCP)[8]
A physician, nurse practitioner, or physician assistant who sees patients with common medical problems. A PCP's role is to provide preventive care and teach healthy lifestyle choices, identify and treat common medical conditions, assess the urgency of your medical problems and direct you to the best place for that care, and make referrals to medical or surgical specialists when necessary.

Proprioception
Sensation concerning movements of joints and position of the body in space.

Pupil
The black part of the eye through which light enters, enlarges in dim light, and decreases in size in bright light.

Q

Quadriplegia
Paralysis of all four limbs.

R

Radiation Oncologist
A medical doctor who has received advanced training in the treatment of persons receiving X-ray treatment for an illness.

Radiologist
A medical doctor who has received specialized training in interpreting X-rays, CTs, MRIs and performing angiography.

Radiotherapy
Treatment of a lesion with radiation.

Resident Physician
A medical doctor who is still receiving training from attending physicians.

S

Sedation
Sedation is the use of medications to relax someone or make them go to sleep.

Sella Turcica[9]
A bony structure at the base of your brain that surrounds and protects your pituitary gland.

Sensory Aphasia
Difficulty in communicating with language that derives from cortical damage to those areas concerned with the comprehension of speech.

Shunt
A tube or device implanted in the body to divert excess CSF away from the brain to another place in the body.

Skull
The bones that surround the brain.

Sphenoid Sinus[9]
Air-filled sacs on either side of the nasal cavity that filter and clean the air breathed through the nose and lighten the bones of the skull.

Spinal Canal[10]
Also known as the central spinal canal, is a cavity that runs through each of the vertebrae of your spine and contains the spinal cord.

Spinal Cord
The spinal cord is a long bundle of nerve cells and fibers along the spine. It carries messages between the brain and the rest of the body.

Stenosis
Narrowing.

Stereotactic
Originated from the Greek words stereo, meaning three-dimensional, and tactos, meaning touched.

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[8] https://my.clevelandclinic.org/health/diseases/23100-empty-sella-syndrome-ess; [9] https://www.healthline.com/human-body-maps/sphenoid-sinus#1; [10] Oxford English Dictionary; [11] https://www.sciencedirect.com/topics/immunology-and-microbiology/tectum#:~:text=Tectum%2C%20via%20its%20connections%20to,necessary%20for%20survival%20and%20reproduction

Stereotactic Radiosurgery
The precise delivery of radiation to a preselected stereotactically localized target.

Strabismus
Deviation of eye movement that prevents the two eyes from moving in a parallel fashion.

Subarachnoid Hemorrhage
Blood in, or bleeding into, the space under the arachnoid membrane, most commonly from trauma or from the rupture of an aneurysm.

Subdural Hematoma
A collection of blood (clot) trapped under the dura mater, the outermost membrane surrounding the brain and spinal cord.

T

Tectum[11]
A part of the midbrain that controls eye movements, approach, and avoidance movements.

Temporal Lobe
The hemispheric lobe that lies inferior to the lateral fissure.

Teratoma
Tumor or growth made up of several different types of tissue (i.e., fat, bone, muscle, skin).

Thrombus
A blood clot attached to the wall of an artery.

Thalamus
Brain cells that lie in the upper part of the brain stem.

Transsphenoidal Approach
Operative method of reaching the pituitary gland or skull base traversing the nose and sinuses.

Trigeminal Neuralgia
Paroxysmal pain in the face. Pain may be so severe that it causes an involuntary grimace or "tic." Also called Tic Douloureux.

U

Ultrasound
The use of high-frequency sound to create images of internal body structures.

V

Valve
A device placed in a shunt system to regulate the rate and direction of CSF flow.

Vasospasm
Spasms of blood vessels, decreasing their diameter.

Ventricle
The cavities or chambers within the brain that contain the cerebrospinal fluid. There are two lateral ventricles and midline third and fourth ventricles.

Ventriculostomy
An opening into the ventricles of the brain, achieved by inserting a small, thin, hollow catheter. Serves as a means to relieve pressure from the brain and spinal cord.

Ventricular Drainage
Insertion of a small tube into the ventricles to drain cerebrospinal fluid, usually performed when pressure is increased.

Vertebra
Any of the 33 bones of the spinal column.

Vertigo
An abnormal sensation of rotation or movement of one's self or the environment.

X

X-ray
Application of electromagnetic radiation to produce a film or picture of a bone or soft tissue area of the body.

Additional notes

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