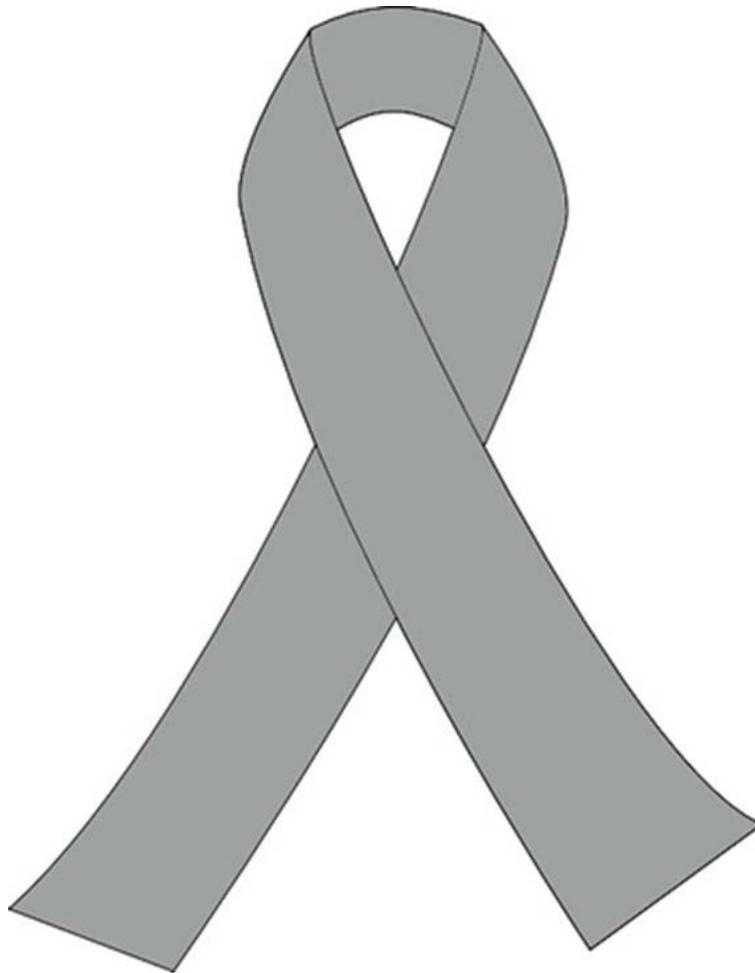


Smilow Cancer Hospital Brain Tumor Program



Yale
NewHaven
Health
Smilow Cancer
Hospital

Yale **CANCER
CENTER**
A Comprehensive Cancer Center Designated
by the National Cancer Institute

WELCOME TO OUR BRAIN TUMOR PROGRAM

Welcome to the Smilow Cancer Hospital Brain Tumor Program. We understand the diagnosis of a brain tumor can be quite scary, but we are here to offer help and support along the way.

Our Brain Tumor Program is the *only* multidisciplinary team providing comprehensive brain tumor care in southern New England and has gained regional, national, and international recognition. It comprises a group of specialists dedicated **exclusively** to the care of patients with all types of brain tumors, including tumors originating from the brain (i.e. glioma, glioblastoma), its covering (i.e. meningioma), or its nerves (i.e. schwannomas), as well as brain metastases from other cancers in the body.

Our physicians offer unparalleled experience, knowledge, and compassion necessary for the diagnosis and treatment of brain tumors. The Brain Tumor Program includes experts from the disciplines of Neurosurgery, Neuro-Oncology, Radiation Oncology, Neuropathology, and Neuroradiology. In addition to physicians, the Program includes Advance Practice Providers (i.e. Physician Assistants, Advanced Practice Registered Nurses), nurse coordinators, practice nurses, and clinical research coordinators (see *Glossary*). All team members work together to deliver the most effective, comfortable, and personalized care. The expertise of the Brain Tumor Program covers all the critical components to successfully manage patients with brain tumors including: comprehensive evaluation and diagnosis, genomic profiling of the tumor, the latest treatment options, thorough follow-up, and extensive psychosocial support. The group meets weekly at a multidisciplinary Tumor Board Conference to discuss each patient's diagnosis on an individual basis, arriving at the most appropriate treatment plan for each person. Because of Yale Cancer Center's dedication to research and education, the program members are leaders in their respective fields, who in addition to providing the most advanced standard of care, also provide the most innovative therapeutic options.

This guide is designed to provide you with information you may need as

you begin your journey from diagnosis through treatment. We hope that you will find this information helpful and thought-provoking. Please use the table of contents to navigate through this information. Lined paper has been provided for you at the rear of this booklet so that you might collect your questions concerning your illness experience at Smilow. You will find a business card holder where you can start to build your personalized team. Feel free to add your reports to this binder so that you will have a comprehensive record of your journey right at your fingertips.

Remember that you and your family are the most important members of our team. By working together, we can provide the best outcome for you. We encourage you to ask us any questions and let us know how you are feeling throughout the treatment process. This information is to serve as a quick resource, but it is not intended to replace advice given to you by your healthcare provider.

We are here to help you navigate through your journey, so please feel free to call us with any questions at:

203-785-2791 (Brain Tumor Surgery)

203-200-1638 (Neuro-Oncology)

203-200-2100 (Radiation Oncology)

Sincerely,

The Brain Tumor Program Team
Smilow Cancer Hospital

Table of Contents

1	<p>WELCOME TO OUR PROGRAM</p> <ul style="list-style-type: none"> • Meet Our Team: A Glossary of Providers • Navigating Smilow • Parking and Directions • What to Bring With Me
2	<p>UNDERSTANDING YOUR DIAGNOSIS</p> <ul style="list-style-type: none"> • Coping with Your Diagnosis • Precision and Personalized Medicine for Brain Tumors: Genetic Testing
3	<p>BRAIN TUMOR SURGERY</p> <ul style="list-style-type: none"> • Who We Are • What to Expect • Frequently Asked Questions Regarding Brain Surgery • Where to Find Us • How to Contact Us • Pre-Operative Planning (Before surgery) • Post-Operative Instructions (After surgery)
4	<p>NEURO-ONCOLOGY</p> <ul style="list-style-type: none"> • Who We Are • What to Expect • Frequently Asked Questions Regarding Neuro-Oncology and Clinical Trials • Where to Find Us • How to Contact US
5	<p>RADIATION ONCOLOGY</p> <ul style="list-style-type: none"> • Who We Are • What to Expect • Frequently Asked Questions Regarding Radiation Treatment • Where to Find Us • How to Contact Us
6	<p>SUPPORT SERVICES</p> <ul style="list-style-type: none"> • Support Groups • Patient Services • Survivorship Clinic • Financial Resources
7	<p>RESOURCES: MY TIME AT SMILOW</p> <ul style="list-style-type: none"> • My Medication Log
8	<p>Extra Notes and Card Holder</p>

1: WELCOME TO OUR PROGRAM

MEET OUR TEAM: A GLOSSARY OF PROVIDERS

Our Brain Tumor Program includes different types of care providers from several specialties who work together to provide comprehensive and patient-focused care for people with brain tumors. Our team meets weekly as a group to ensure clear communication and seamless coordination of care.

The following can serve as a glossary or reference for terms you may encounter in the sections below. Below are descriptions that define the people you may meet along your journey, and the roles they play. **Please understand you may not need or encounter all types of providers listed below.** Every diagnosis and treatment plan is patient-specific—which providers you see is different for every patient. Additionally, oncologists listed below can also provide care for patients with non-cancerous brain tumors and other abnormalities of the central nervous system.

Doctors: Referred to as Attending Physicians, these highly specialized practitioners are ultimately responsible for your care and oversee the team of care providers listed below. They have completed specialty training and are solely dedicated to treating patients with brain tumors and issues with your central nervous system.

- **Neurosurgeons:** Surgeons who are specialized in the surgical treatment of brain tumors.
- **Neuro-Oncologists:** Neurologists who are specialized in the medical management of brain tumors and issues of the central nervous system. This usually, but not always, involves chemotherapy.
- **Radiation Oncologists:** Sometimes referred to as therapeutic radiologists, these doctors are not radiologists, but rather doctors who are specialized in using different types of radiation to treat central nervous system tumors. They determine the most appropriate type and dosage of radiation based on several factors specific to each patient. Radiation treatments can be performed alone or in combination with other treatment modalities.

Neuroradiologists: Radiologists who are specialized in reading various imaging tests (i.e. computed tomography (CT), magnetic resonance imaging (MRI), etc.) of the brain, spine, peripheral nervous system, head and neck. Their interpretation is fundamental in diagnosing and understanding the growth pattern of brain tumors.

Neuropathologists: Pathologists specialized in reading pathology slides of brain and central nervous system tissue. The neurosurgeon removes a piece of the tumor, which is then given to the neuropathologist for microscopic evaluation. Pathologic analysis is important in providing a meaningful diagnosis and has implications for prognosis and further, if any, treatment. More specific genetic testing is performed on every brain tumor at Smilow.

Fellows: Medical doctors, undergoing specialized training, who work closely with attending physicians within a department. Fellows are exposed to a multidisciplinary team of brain tumor specialists so that they can learn all the components to comprehensive care within this specialty. Patients will often interact with fellows in the hospital and outpatient clinics. The fellows are supervised closely by the attending physicians, but have already completed their residency training.

Clinical Support: There are many people who contribute to the flow of patient care and provide care and support for our patients.

- **Advance Practice Providers (APPs):** APPs include both Physician Assistants (PAs) and Advanced Practice Registered Nurses (APRNs). These providers can function independently, often seeing patients in their own clinics, in collaboration with a doctor. Alongside the nurses of our department (see below), APPs are often the team members routinely returning your calls and answering your questions. You can expect to see and hear from them often.
- **Nurses:** All nurses work to provide comfortable care including symptom management and patient education. Their accessibility to patients, experience, and collaboration with other medical professionals makes them a very important resource to patients. You can expect to hear from nurses via phone or within outpatient clinics. We have two types of nurses working within our team:

- **Practice Nurses:** Generally, the first person to return your phone call, they can provide patient education, coordinate care, and assist with any paperwork you may require.
- **Nurse Coordinators:** A specialized nurse who collects your health information and better prepares you for your first visit with our doctors. They can help guide you through your treatment, while educating you of available resources and assistance.

Clinical Research Coordinators: These individuals are helpful in explaining and managing the numerous clinical trials for patients with brain tumors. They are fundamental in the consent and overall process of enrolling and maintaining patients on clinical trials.

Senior Administrative Assistants: They are the contact people for our offices and are responsible for the scheduling and management of your appointments and other diagnostic testing. They help coordinate all aspects of your care. Clinical receptionists in Smilow also help facilitate such appointments.

Other Clinical Support: Throughout your care, you will encounter and converse with countless team members who are responsible for the administration of your therapy. You may encounter infusion nurses, medical assistants, and radiation therapists, for instance, throughout your treatment at Smilow Cancer Hospital. Psychologists and religious providers (also called pastoral care) are also available at your request. These team members work closely with your prescribing physicians and often become familiar faces that you see upon each visit. Additionally, you may meet with research staff members, focused on learning from patients cared for by the Smilow Brain Tumor Program and educating the medical science community. We also collaborate with other departments and providers of Smilow to assure that your time at Smilow is comfortably productive. You can find a list of these free services within the *Support Services* section of this binder. There are countless individuals who will play a critical role in your care. We encourage you to ask about each team member and the role they play.

Social Workers: Licensed clinical social workers are available to help you and your family cope with illness, discuss your concerns, and connect you to a variety of hospital and community resources. They also help facilitate support groups for patients, caregivers, or loved ones.

NAVIGATING SMILOW: My Time With the Smilow Brain Tumor Program

Patient-centered brain tumor care takes place within Smilow Cancer Hospital. The multidisciplinary team of healthcare providers works to create an atmosphere that places each patient at the center of the team, giving you and your family the strongest voice in the process. Your time and collaboration with our team is grounded in dignity, respect, active participation, and support. Located within historic New Haven, Smilow Cancer Hospital has built its walls around the needs of our patients and strives to deliver friendly, efficient services upon your immediate arrival. Visits with our providers take place within Smilow. New and established patients are seen in the following clinic locations:

Brain Tumor Surgery
Smilow Cancer Hospital
35 Park Street
8th floor
New Haven, CT 06510

Neuro-Oncology
Smilow Cancer Hospital
35 Park Street
8th floor
New Haven, CT 06510

Radiation Oncology
Smilow Cancer Hospital
35 Park Street
Lower Level (LL)
New Haven, CT 06510

In the event that you may need to report to a different location within the hospital, additional information will be provided. We strive to make the time with our team as convenient and efficient for you as possible. Contacting the Smilow Brain Tumor Program can be accomplished weekdays from 8:00AM-5PM via the following contact information:

Brain Tumor Surgery: All Appointments, Questions, & Concerns: 203-785-2791

Neuro-Oncology: All Appointments, Questions, & Concerns: 203-200-1638

Radiation Oncology: New Patient Consultations: 203-200-2000
Questions & Concerns: 203-200-2100

Additional contact information and department specific location descriptions can be found within each department's allocated chapter of this binder.

PARKING & DIRECTIONS: SMILOW CANCER HOSPITAL - NEW HAVEN

I-95 TRAVELING NORTH OR SOUTH (AIR RIGHTS GARAGE)

Exit 47 to Route 34 west to Exit 1*. Follow North Frontage Road and turn left into the Air Rights Garage immediately after you exit. Parking is reserved for patients on the 4th floor of the garage; please bring your ticket with you for validation. Please enter the building from the 4th floor of the parking garage, take the elevator to floor 3, and then walk through the bridge to Smilow Cancer Hospital.

I-91 TRAVELING SOUTH (AIR RIGHTS GARAGE)

Exit 1 to Route 34 west to Exit 1*. Follow North Frontage Road and turn left into the Air Rights Garage immediately after you exit. Parking is reserved for patients on the 4th floor of the garage. Please enter the building from the 4th floor of the parking garage, take the elevator to floor 3, and then walk through the bridge to Smilow Cancer Hospital.

TO THE MAIN ENTRANCE AND VALET PARKING (35 PARK STREET, NEW HAVEN)

I-95 travelling north or south and I-91 travelling south: Route 34 west to Exit 1*. Follow N. Frontage Road and turn left onto Park Street, Smilow Cancer Hospital main entrance and valet parking is on the left, before you reach Howard Avenue.

WILBUR CROSS PARKWAY (RTE. 15) TRAVELING SOUTH

Exit 59 to immediately after tunnel. Right at end of ramp. Merge onto Whalley Ave at light. Stay on Whalley until you see signs for Yale-New Haven at Park St. Follow hospital signs, then make a left turn onto S. Frontage Rd. Enter the Air Rights Garage on your right. Parking is reserved for patients on the 4th floor of the garage. Please enter the building from the 4th floor of the parking garage, take the elevator to floor 3, and then walk through the bridge to Smilow Cancer Hospital.

MERRITT PARKWAY (RTE. 15) TRAVELING NORTH

Exit 57 to Route 34 east into New Haven. Right on Ella T Grasso Blvd (Rte. 10) and left onto S. Frontage Rd. (Legion Ave) Enter the Air Rights Garage on your right. Parking is reserved for patients on the 4th floor of the garage. Please enter the building from the 4th floor of the parking garage, take the elevator to floor 3, and then walk through the bridge to Smilow Cancer Hospital.

PARKING INFORMATION

VALET PARKING

Valet parking is available at the entrance to Smilow Cancer Hospital at a rate of \$7 for the first hour, \$2 per additional hour, and up to \$15 maximum. When you are ready to leave, call the valet captain at 203.688.2538 (after hours, call 203.688.6076) with your claim check number. Patients receiving radiation therapy qualify for free valet parking and are asked to bring their parking tickets to each treatment so that they can be validated.

AIR RIGHTS GARAGE

The Air Rights Garage is open 24 hrs. a day and is located between North and South Frontage roads, straddling York St. Parking is reserved for Smilow Cancer Hospital patients on the 4th floor of the garage, with direct access to the Park St. building. Take the elevator to the 3rd floor of the Park St. building to directly enter Smilow.

Parking tickets must be validated at the location of the visit. This will reduce the fee to \$4 (up to 24 hours) when parking at the Air Rights Garage.

****Parking escorts are available all day, every day – Call Protective Services at 203.688.2500.*

WHAT TO BRING WITH ME

Our Brain Tumor Program strives to provide quality care while remaining sensitive to and respectful of your life outside of Smilow Cancer Hospital. Coming prepared to each visit helps assure timely care and reduces your wait time. Please bring the following items with you to each appointment:

- ❖ CDs of any recent neuroimaging (MRIs, CTs, PETs, etc.) you received at a facility other than Smilow Cancer Hospital, Yale Medicine, or Yale New Haven Health
- ❖ Updated medication lists including over the counter and herbal medications (a medication log is provided in this binder)
- ❖ A list of questions and concerns you have collected since your last visit
- ❖ Your parking ticket (for validation purposes)
- ❖ This *Smilow Brain Tumor Program Binder*

We strongly encourage all patients to bring a family member, loved one, or friend with them to their appointments. Your network of supporters becomes a crucial component of your care. We recognize your loved ones as an integral part of our team who can keep you company, listen to copious amounts of information alongside you, and provide us insight into helpful information that a care provider may not witness outside the hospital. This is perhaps the most important thing to bring with you.

2: UNDERSTANDING YOUR DIAGNOSIS

THE EMOTIONAL IMPACT OF A BRAIN TUMOR DIAGNOSIS

Coping with your Diagnosis

When you are first diagnosed with a brain tumor, you may feel scared, uncertain, worried, confused, or angry. You may have trouble listening to, understanding, or remembering what people tell you during this time. This is especially true when you first learn of your diagnosis. Accepting the diagnosis and figuring out how it fits into your life is challenging. As you face the many demands of your tumor and potentially treatment, you may look more closely at your personal and family values, your religious beliefs, and what's most important in your life. This can help you with decision-making.

While everyone handles their diagnosis differently, there are a number of common concerns that many people have. These concerns could be anything from understanding your diagnosis and treatment, to managing finances, talking to your children about your diagnosis, family planning and fertility concerns, genetic counseling, and anything in between. We are here to help. Please bring any and all concerns to your care team, and we can set you up with the appropriate resources. We have dedicated social workers, care coordinators, psychologists, and religious providers who will work with you closely to navigate through these concerns and determine suitable solutions. In addition, support groups are a wonderful way to find out what has helped other patients and families cope, and/or talk with other people who are diagnosed with the same type of tumor.

Many people find it is helpful to face the reality of a new or scary situation if they learn as much as they can about it. Knowledge can help lessen the fear of the unknown. You can learn a lot about the type of tumor you have and its treatment by being your own advocate. Finding good sources of support can help you take control of the situation and make informed decisions. These tips can help you make your medical appointments as useful as possible:

- Make a list of questions to ask your healthcare team.
- Bring a family member or friend along to appointments. They can serve as an extra pair of ears, help you remember things later, and give you support.
- Take notes. If someone uses a word you don't know, ask them to spell it and explain it.
- Ask your healthcare team to explain anything you don't understand.

Your feelings (mental health) deserve the same degree of care as your body (physical health). Please tell your care team what you need from us to address any concerns you may have.

PRECISION AND PERSONALIZED MEDICINE FOR BRAIN TUMORS: GENETIC TESTING

The vast majority of brain tumors are not hereditary, meaning other members of your family are not at risk. The tumors, however, have changes in their DNA that other healthy tissues don't have, called genetic mutations, which can make them cancerous. These genetic mutations make every single case exclusively unique and distinct from other individuals. Identification of these genetic mutations can be helpful for a physician making the patient's personalized diagnosis, treatment plan, or prognosis.

Genetic testing uses cutting-edge technologies to identify genetic mutations to better understand the brain tumors. The Yale Department of Neurosurgery is one of the most world-renowned centers for its rapid application of advanced genomic technologies to diagnose brain tumors, paving the way to their personalized treatments.

The genetic testing process can be quite complex and usually applies to the testing of the tumor itself rather than the person when dealing with brain tumors. If, however, your personal and/or family history meets any of the risk factors as determined by your care provider, consider seeing a certified cancer genetic counselor for a personalized risk assessment and a discussion of the appropriate testing options. The Smilow Cancer Genetics and Prevention Program is a component of Yale Cancer Center. All of our genetic counselors are graduate-trained and certified by the American Board of Genetic Counseling.

3: BRAIN TUMOR SURGERY

Who We Are

The first doctor a person often meets after receiving a new diagnosis of a brain tumor is a neurosurgeon. At the Smilow Brain Tumor Program, our neurosurgeons are specialized brain surgeons who **only perform surgery for patients with brain tumors**. The importance of having neurosurgeons with dedicated expertise and experience in brain tumor surgery cannot be emphasized enough. Moreover, our dedicated staff includes an APRN, nurse coordinator, and administrative assistant who are accommodating and committed to providing exceptional, compassionate, and supportive care.

What To Expect

While this is our practice and what we do every day, we understand how scary the prospect of brain tumor surgery can be. Please know you are in the best hands and we will do our very best in successfully treating you from a surgical standpoint. Our surgeons strive to **remove as much tumor as safely as possible so that an accurate diagnosis and positive outcome can be obtained**. They make every effort to be as aggressive as possible with their surgical approaches without sacrificing your safety. Tumor removal is done by a procedure called a “craniotomy,” which involves an incision, or cut, into the scalp. Once the skull bones have been exposed, a few holes are made and connected to create a bone flap, which is temporarily removed from the rest of the skull. The incision and bone flap are made closest to the area of the tumor, which is based on a very special neuronavigation system. Neuronavigation is like a GPS system or map that helps to localize the tumor. The goal of a craniotomy is to remove all, or as much of the tumor as possible. When the procedure is complete, the bone flap is typically placed back and secured in place with titanium plates and small screws.

Preserving neurological function and quality of life is our top priority. The use of intraoperative advances, such as neuronavigation (i.e. the GPS system), neuromonitoring (to monitor motor and nerve function), and awake surgery techniques, when indicated, is available and used routinely at the Smilow Brain Tumor Program. Our hospital is simply unmatched in these capabilities. The thought of awake surgery can be intimidating, but our surgeons only perform this when necessary and it allows them to remove “inoperable” tumor in “eloquent” brain, or areas responsible for speech or motor function. They, along with neuroanesthesiologists, or anesthesiologists who are specially trained at delivering anesthesia to patients with neurological diseases, have detailed protocols that allow this type of procedure to be consistently successful and allows the patients to remain comfortable and without pain.

Our brain tumor surgeons offer sound clinical judgment and insight into when removal of a tumor is too dangerous. In those circumstances, diagnosis is still important when designing a treatment plan and our neurosurgeons will recommend a stereotactic (i.e. MRI-guided) biopsy. A biopsy is a procedure used to remove a small amount of tumor tissue so it can be examined under a microscope. Similar to a craniotomy, this too requires an incision and hole in the skull, though it is usually smaller, and also uses neuronavigation (i.e. the GPS system). For other tumors, focused radiation with gamma knife radiosurgery can be beneficial and our neurosurgeons work closely with radiation oncologists in those circumstances (see Radiation Oncology section). Laser thermocoagulation, a procedure that uses the direct placement of a laser under MRI guidance to burn and kill the tumor cells is used mainly for “inoperable” brain tumors.

Every brain tumor surgery, regardless of the tumor’s aggressiveness and technique for removal, is performed in our state-of-the-art operating rooms within Smilow Cancer Hospital. Every brain tumor surgery is performed with the assistance of neuroanesthesiologists (anesthesia doctors specializing in the care of patients with brain tumors), as well as with neurosurgery dedicated operating room technicians and nurses. A 3 Tesla MRI machine is located within the operating room, allowing surgeons to obtain neuroimaging of the same detail as other MRIs while a patient is undergoing surgery. This allows our neurosurgeons to obtain real time feedback on the surgery, and better guides the surgeon to perform the most complete tumor resection as safely as possible. Ultrasound is also routinely used with brain tumor surgery. These techniques do not expose the patient to radiation but help make the surgery more safe and successful.

After surgery, you will be cared for in our Neurosciences Intensive Care Unit (NICU), Neuroscience Step-Down Unit (SDU), and on our neurosurgery floors of the hospital. We have dedicated ICU specialists with expertise in managing patients with neurological disease. Specially trained, neurologically focused nurses care for our patients to provide the most comprehensive, safe, and individualized care. Most patients who have had a brain tumor removed will go home, on average, 2-3 days after surgery. Patients who undergo a biopsy often go home the day after surgery. Most patients are discharged to home, and in some cases, may require additional care, including OT (occupational therapy), PT (physical therapy), speech therapy, and nursing assistance (i.e. VNA, visiting nurse aides). A small proportion of patients may need to go to a rehabilitation center. Rest assured, we have experienced care coordinators and physician assistants who make every effort to make this transition flawless and timely.

Brain surgery, as with any type of surgery, requires time to recover. Recovery is different for everyone and depends on many factors including the overall health of the person, location of the tumor, involvement of the brain, blood vessels or nerves involved, and whether the person had disabilities related to the tumor before surgery. At the time of discharge from the hospital, you and your caregivers will be provided with detailed written and verbal instructions about the transition to care at home. The instructions include incision care, prescriptions for medications, an appointment for a

post-operative visit with the surgeon, and telephone numbers for any questions or concerns that may come up after discharge.

Specific recommendations regarding incision or wound care, seizure medicine, when it is safe to exercise or drive, and other relevant and important information is given on an individual basis. Likewise, returning to work is also discussed for each person based on progress. We are happy to take care of any necessary paperwork from your employers and other care providers. We ask you kindly give these forms to our nurse coordinator.

FREQUENTLY ASKED QUESTIONS REGARDING BRAIN SURGERY

Is brain surgery painful?

Actually, not really. Surprisingly, patients tolerate brain surgery quite well. The brain itself does not sense pain. Usually only some pain remains near the incision in the scalp and sometimes in the jaw or the neck depending on where the incision is.

How is my skull put back into place?

This is a very common question and concern. We use small titanium plates and screws to reattach the bone flap (i.e. the part of the skull removed to access the tumor) to the rest of the skull.



Titanium allows patients to have subsequent MRIs and go through airport security without difficulty. This is secure and people never have to worry about the bone shifting. Sometimes, if tumor is invading the bone flap, the bone will be left off with a larger piece of titanium mesh covering in its place.

Am I going to lose neurological function after surgery?

In the vast majority of cases, there is no long-term loss of function. However, people who have tumors compressing (putting pressure on) or involving “eloquent” or important functional brain or nerves, and especially those patients who have disabilities before surgery, could have worsening disabilities after surgery, at least temporarily. Important (or “eloquent”) functional parts of the brain include those responsible for language, motor function (ability to move around), and sensation. This usually relates to swelling and is

managed with medications. Our neurosurgeons thoroughly discuss risks and benefits of surgery on a case-by-case basis and specific expectations related to you and your surgery will be discussed. Please feel free to ask questions. It is helpful to have family or friends present for the discussion.

What are the major risks of brain tumor surgery?

As with any other type of surgery, bleeding risks can be increased in patients with bleeding disorders or in patients taking anti-platelet medications such as aspirin. The risk for infection can be increased in patients with diabetes. Other risks are related to the location of the tumor and the involvement of the brain, nerves, arteries, and veins and the function they serve or the area of the brain they supply. Remarkably, brain tumor surgery is tolerated quite well.

When will I learn if my tumor is cancerous and when can I start additional therapies if necessary?

We get a preliminary diagnosis the day of surgery and share this with you and your family. The final diagnosis usually takes about a week to return and genetic testing can take up to two weeks. Not to worry, if additional treatment is needed it is not started before this two weeks to allow for wound healing and recovery. So you are not missing out on anything during this recovery period!

How do I know if I need additional therapies?

Pathology results tell us your diagnosis. Once your pathology is available (and at this time you are usually out of the hospital), we present your case at our multidisciplinary Brain Tumor Board Conference. There, our group of brain tumor specialists decides on the best course of therapies, if any, are needed for you and discusses with you afterwards. If additional therapies are needed, then referrals are made to the appropriate doctors.

Where To Find Us

Our brain tumor surgeons see patients on the 8th floor of Smilow Cancer Hospital. After exiting the elevator, do not go over the overpass bridge, but rather our clinic is at the end of the hall in the opposite direction. A directory with office locations is located above all elevator buttons in the event you find yourself lost. Look for the large fish tank in the center of the waiting room. After checking in at the front desk, our team will then help you navigate the floor and get you to your appointment.

Brain Tumor Surgery Office Hours of Operation:

Monday through Friday
8:30AM-5:00PM

Our Brain Tumor Surgery Clinic: Smilow Cancer Hospital 35 Park Street 8 th floor New Haven, CT 06510	Our Mailing Address: Yale University School of Medicine 15 York Street LLCI 8 New Haven, CT 06510
--	--

How To Contact Us

Your brain tumor surgery team can be reached at: 203-785-2791

Please call this number for appointments, questions, concerns, or to speak with your nurse.

Between the hours of 5 PM and 8:30 AM, and on weekends and holidays, the on call answering service is available to respond to any emergencies or urgent needs.

PRE-OPERATIVE PLANNING: BRAIN TUMOR SURGERY

Your surgery will be arranged for you by our coordinators and you will receive a call with a date and time. All brain tumor surgeries are performed on the 3rd floor of Smilow Cancer Hospital; no brain tumor surgery is performed at the St. Raphael's Campus.

Before surgery, you will be asked to undergo pre-operative testing. **The Pre-Admission Testing (PAT) Department** is located on the **first floor** in the **East Pavilion of Yale New Haven Hospital - York Street Campus**. A chest x-ray, electrocardiogram (EKG) and blood work will be done and you will meet with an anesthesiologist. **Please bring a list of all the medications you are currently taking with you to this appointment.** This visit can take up to 2 hours so please plan accordingly. Their number is **203-688-5860**. You may also be asked to obtain medical clearance from your primary care and specialty physicians (i.e. cardiologist), if appropriate and specified.

On the morning of surgery, please check in at the **PAT Admitting Office**, via the **20 York St. entrance** to Yale New Haven Hospital. **Arrive at least 1 hour before your scheduled surgery.** If surgery is scheduled for 7:30am, please arrive and check in by 6:30am. Please allow extra travel time for parking/weather. A short video outlining this process can be viewed at <https://www.ynhh.org/videos/your-day-of-surgery-at-the-york-street-campus.aspx>

You will then be guided to the 3rd floor where you will meet your neurosurgeon, nurses and anesthesia team. You will change into a hospital gown and an IV will be started. Family and friends can keep you company during this time.

Please note, the above applies to patients who are coming in from home the morning of surgery. **If you have been admitted to the hospital and surgery is scheduled during that hospitalization, all work-up will be done during your hospital stay and you will be transferred directly from your room to surgery approximately 1 hour before surgery.** These situations tend to be more urgent and more specific arrangements may be made.

The following are general instructions if you are coming in from home for surgery; more specific instructions may be given at our brain tumor surgeons' discretion.

1. **Stop taking blood thinning medications and/or supplements at least 10 days before surgery.** Some examples are Aspirin, Motrin, Naproxen, Aleve, fish oil, ginger. Other medications, such as Coumadin, may be held for longer and specific instructions will be given.
2. Call your neurosurgeon before your surgery if you do not feel well or develop any signs of illness, a cold, fever, sore throat, chest pain or difficulty breathing, or if you become pregnant.
- 3 **Please wash your hair before surgery with baby shampoo; a haircut is not necessary.** Our brain tumor surgeons will only shave a small portion of your hair where the incision will be made. We do not shave all of your hair!
- 4 **Do not drink or eat (nothing by mouth) after midnight before surgery.** You may be asked to take your Keppra (if you are on this medicine), or regular blood pressure medications with a small sip of water on the morning of surgery. PAT will inform you what other medications should be taken (i.e. blood pressure medications).

Your neurosurgeon will speak to your loved ones immediately after your surgery and a preliminary diagnosis will be given. The neurosurgeon will speak with you as soon as anesthesia has worn off.

Following surgery, you will be transferred to the Neuroscience Intensive Care Unit (NICU) located in the South Pavilion on the 6th floor. You can expect to spend one night there. There is a lounge for your family's use while you are in the NICU and they may stay overnight with a few members rotating in and out to be with you. Please keep in mind, you may be tired the first night and may prefer no visitors. The following day, you can expect to be transferred to our neurosurgical ward located on either the 6th or 7th floors.

Rehabilitation needs will be assessed after surgery and determined by experts before discharge.

As always, if you have any questions, please do not hesitate to call our clinical nurse coordinator, at 203-785-2791.

POST-OPERATIVE INSTRUCTIONS

The following are general guidelines. Your brain tumor surgeon may give you more specific instructions at their discretion. As always, if you have any questions, please do not hesitate to call our clinical nurse coordinator or APRN at 203-785-2791

1. **Please leave your incision uncovered, clean and dry. Do not apply any antibiotic ointment such as Bacitracin or Neosporin.** You can wash your hair with baby shampoo 5 days after surgery. Wet hair and apply a small amount of shampoo to hair away from incision site. Do **not scrub** over incision site. Rinse, letting soapy water run over incision. Pat dry over incision.
2. **Wash hair daily.** This is a very important part of your after surgery wound care and should begin 5 days after surgery.
3. **Do not take blood thinning medications (i.e. Aspirin, Motrin, Aleve) or supplements (i.e. fish oil) for at least 2 weeks after surgery.**
4. Do not stay in bed. Walking is your best form of exercise and prevents blood clots in your legs. You should not, however, perform any vigorous exercising, but slowly increase your activity each day.
5. If you are taking pain medication stronger than acetaminophen or Tylenol (i.e. Percocet/oxycodone), please be sure to take a stool softener such as docusate (Colace). Likewise, if you are taking steroids (i.e. Decadron/dexamethasone), take medication to prevent acid reflux (i.e. Pepcid, Protonix, Zantac). Eye drops and eye protection may also be important, if specified.
6. Steroids (i.e. Decadron/dexamethasone) will be tapered or decreased slowly over time as instructed before discharge.
7. **You may not drive until you are cleared to do so by your neurosurgeon.** Please note, if you have had a **seizure** or are on seizure medications because of seizure, **you are not allowed to drive by law and certain restrictions are legally enforced.** We recommend you contact your Department of Motor Vehicles for more information.
8. **Staples or sutures will be left in place for 10-14 days.** They will be removed during a follow-up appointment unless otherwise specified. This visit will be scheduled for you before discharge from the hospital. If you have not been given

the date and time and/or the appointment given is not convenient, please call 203-785-2791 during weekdays between 9am and 5pm. Our office can help facilitate appointments with other physicians (i.e. Neuro-Oncology, Radiation Oncology) as well, if necessary.

9. **The tumor will be tested by Pathology and the diagnosis will be determined approximately 7 days after surgery.** These results will be discussed with you during the follow-up visit. If they are available earlier, your neurosurgeon will call you.
10. **We may recommend an initial consult with other members of our team-** such as Radiation Oncology or Neuro-Oncology. ***Do not be alarmed by this.*** It is an effort to give you the most information possible in order to make an informed decision about your care.

Call our Brain Tumor Surgery office (203-785-2791) immediately or come to the Emergency Room for any of the following symptoms:

1. Fever (Temperature greater than 101.5°F), shaking, chills
2. Nausea and vomiting
3. Headache that doesn't go away or is not improved with pain medication
4. New neurological symptoms (i.e. weakness, speech problems), different from before surgery
5. Visual changes, including double or blurred vision
6. Swelling, bleeding, drainage at the site of the incision
7. Seizures
8. Rash
9. Pain or swelling in your legs
10. Chest pain or shortness of breath
11. Constipation not improved with over the counter remedies
12. Any questions or concerns

4: NEURO-ONCOLOGY

Who We Are

Neuro-Oncology, as part of the Smilow Brain Tumor Program, offers advanced and personalized medical treatment for patients with all types of brain tumors. Neuro-oncologists also manage neurologic issues related to cancer, as well as other issues of the central and peripheral nervous systems. Whether newly diagnosed or having previously received extensive treatment, you will work with a team of caregivers to ensure that you receive high quality, personalized care. Neuro-oncologists, fellows, advanced practice providers, nurses, research staff, and administrative assistants (*Glossary, pg. 7*) collaborate to create a comprehensive evaluation and treatment plan that incorporates leading edge therapy with comprehensive psychosocial support. Specifically, neuro-oncologists prescribe the type, amount, and frequency of your non-surgical treatment. How often you see a neuro-oncologist depends on your diagnosis. Additionally, these physicians work to educate you throughout treatment while collaborating with other members of your care team. A neuro-oncologist incorporates all members of his or her team when creating a treatment plan that is patient-centered. The plan is implemented by APPs, nurses, and other providers. Our clinical trial coordinators may also be involved if a clinical trial is deemed potentially beneficial for you.

We often serve as the leaders of your treatment plan team, assuming primary care following brain tumor surgery in most cases, monitoring most aspects of your care well beyond your date of initial diagnosis. Because we will care for you over long periods of time, we will work to gain your trust and determine when treatment or simple surveillance (monitoring your health without treatment) is best suited. Scheduling consistent follow-ups with our department also provides us with the opportunity to update your other providers of your progress. There may be instances throughout your treatment where you only schedule appointments with neuro-oncologists and see other members of the Brain Tumor Program as needed. Rest assured we communicate with them throughout your care.

What To Expect

We understand how scary the unknown can be when facing a diagnosis of a brain tumor. We aim to work with you throughout your care to ensure that you are an active participant in your treatment plan. When you schedule your first appointment with your neuro-oncologist, you will discuss your diagnosis and collaborate to determine a treatment plan most appropriate for you. This plan will be diagnosis-specific, and may include scheduling regular follow-up (i.e. surveillance) MRIs, receiving radiation therapy, participating in a clinical trial, and/or receiving oral or intravenous chemotherapy, biotherapy, or immunotherapy. As a National Comprehensive Cancer Network (NCCN) Member Institution, we are dedicated to following the treatment guidelines that are proven to be most effective. Standard of care, or the current agreed upon recommendations based on clinical expertise, experience and research, is offered to all patients. In addition, clinical trials of novel or new, but approved treatment options, may be offered depending on your eligibility. Please know that you do not have to participate in clinical trials. Standard of care treatment is offered to every patient.

This first appointment is dedicated to working with you to determine the treatment plan that is most appropriate for your diagnosis and personal preference. We will also introduce you to the various complementary services offered at Smilow Cancer Hospital that can be used in conjunction with your medical care (*section 6*). If you and your doctor decide that treatment with medication is appropriate for you, you will return to our clinic regularly for your treatments and for follow-up care. Our team works to provide the best personalized care for you.

Depending on the specific characteristics of your tumor or neurologic issue, your neuro-oncologist may prescribe systemic therapy. Systemic therapy (or medications that treat the whole body) can include intravenous (IV) chemotherapy, antibody therapy (also called “immunotherapy”), and/or oral (by mouth) chemotherapy; patients may receive more than one type of systemic therapy.

If chemotherapy is recommended, you will have an educational session with one of our specialized medical oncology nurses. During this session, you will receive specific information about the chemotherapy drugs that have been prescribed, as well as any additional medications that you may need to take to help with side effects of the chemotherapy. Chemotherapy is usually an outpatient treatment, self-administered at home or in the Infusion Center on the eighth floor of Smilow Cancer Hospital. Our team of doctors, APPs, and nurses will carefully monitor you. If you are to receive IV chemotherapy, you will be seen by your primary neuro-oncologist or one of our APPs during your time in the Infusion Center. The entire team of providers, however, is involved in the planning and execution of every step in your treatment plan. The length of each treatment may differ depending on which medications you are receiving.

Treatment is given in “cycles,” which are usually 1 to 4 weeks in duration. Your oncologist will tell you how many cycles are planned. Oral chemotherapy, if elected, is

a convenient chemotherapy option that patients can take in the comfort of their home while following their treatment schedule. Chemotherapy treatments given by IV may last up to 6 hours, depending on the medicine used, however many infusions only last 1-2 hours. We encourage you to dress comfortably for chemotherapy treatment, as you will be sitting for variable amounts of time. You may want to bring layers of clothing to put on in case you get cold. Additionally, you may have friends or family members in the Infusion Center with you. You may eat before and/or during chemotherapy. Many of our patients take this time as an opportunity to read, watch TV, work, play games on a computer, do word puzzles, or just rest.

This information is a brief overview of the types of treatments that may be offered by your neuro-oncologist. Please understand this may not apply to you. If it does you will be presented with more individualized written information on the medications and specific details that will help you during your treatment.

Any questions can also be directed to your team at 203-200-1638.

FREQUENTLY ASKED QUESTIONS REGARDING NEURO-ONCOLOGY and CLINICAL TRIALS

What are clinical trials?

Clinical trials are research studies that explore new medical strategies, treatments or devices, and how well they work. Trials are extremely important for advancing medical knowledge and care for our patients. They combine the standard of care with new medications or treatment regimens to try to improve how we treat patients with brain tumors.

Should I participate in a clinical trial? Am I a guinea pig?

Some patients have concerns about participating in a clinical trial. You are not a guinea pig. Standard of care (i.e. the current and most updated recommendations for treatment) is always offered to patients. Participation in a clinical trial depends on many factors, including your preference, eligibility (do you meet criteria needed to participate), and your doctor's medical opinion. Many people find it helpful to know all of their treatment options, while others may find the information overwhelming. If you are interested in participating in a clinical trial, please ask your team to assess your eligibility. We will discuss which trials you may be eligible for, and the pros and cons of each versus standard of care. Through discussion with your team, we will help you make the best decision for you.

What if I am receiving a placebo (i.e. not the research drug)?

No matter what kind of trial you are on, **every** patient receives the standard of care treatment specific to his or her diagnosis. This means that, even if you are on a clinical trial, you will never be in a situation where you **only** receive a placebo medication.

Where To Find Us

Our neuro-oncologists and their staff see patients on the 8th floor of Smilow Cancer Hospital. After exiting the elevator, our clinic entrance can be found at the opposite end of the overpass bridge. A directory with office locations is located above all elevator buttons in the event you find yourself lost. Brain tumor surgery and neuro-oncology are conveniently located in the same space. Look for the large fish tank in the center of the waiting room. After checking in at the front desk, our team will then help you navigate the floor and to your appointment.

Neuro-Oncology Office Hours of Operation:

Monday through Friday
8:00AM-5:00PM

Our Neuro-Oncology Clinic: Smilow Cancer Hospital 35 Park Street 8 th floor New Haven, CT 06510	Our Mailing Address: Yale University School of Medicine 15 York Street LLCI 920 New Haven, CT 06510
---	--

How To Contact Us

Your Neuro-oncology team can be reached at: 203-200-1638.

Please call this number for appointments, questions, concerns, or to speak with your nurse.

Between the hours of 5 PM and 8AM, and on the weekends and holidays, the on-call answering service is available to respond to any emergencies or urgent needs.

5: RADIATION ONCOLOGY

Who We Are

Radiation therapy is part of the multidisciplinary team and often an important part of a multiple treatment approach (i.e. surgery, chemotherapy) to managing brain tumors. Radiation may be prescribed to prevent or significantly delay tumor recurrence (i.e. regrowth). All types of radiation therapy are available and are provided by an experienced staff of highly skilled professionals. Radiation treatments are prescribed and overseen by a specialized radiation oncologist. Other providers, such as fellows and APPs, may also provide care overseen by your designated attending physician. Behind the scenes, medical physicists and dosimetrists work with the radiation oncologists to prescribe very precise and accurate treatment plans. Our nurses and radiation therapists coordinate the actual delivery of care.

What To Expect

Different types of tumors require different types of radiation and our physicians are experts in determining which type is appropriate and when it should be used. The following is a basic overview. Your radiation oncologist will provide more specific information to you as each patient is treated on an individual basis.

STANDARD FRACTIONATED OR IMRT (Intensity Modulated Radiation Therapy)

This standard type of radiation is often used to treat patients with various types of brain tumors, including tumors originating from the brain (i.e. glioma, glioblastoma), its covering (i.e. meningioma), or its nerves (i.e. schwannomas). Typically, this type of radiation is given over several days, for several weeks. Giving a small amount of daily radiation, called “fractions,” rather than a few large doses, helps to protect normal body tissues. Weekend rest breaks allow normal cells to recover. The total dose of radiation and the number of treatments you will need will depend on the size and location of your tumor, type of tumor, your general health, and any other treatments you may be receiving. If you had surgery, radiation treatment usually will not start for at least four weeks after your surgery date. If you had a biopsy only or did not have surgery, treatment may start sooner.

To plan your radiation treatment, a CT scan will be performed after your initial consultation appointment. This scan, called a “simulation,” will take about 30 minutes. You will be fitted with a custom mask that you will wear during radiation treatment each day. This allows for precise treatment with your head in a reproducible position every day. After you complete the simulation, it may take 1-2 weeks for treatment planning before you actually start.

When your treatment begins, the radiation therapist will use some marks placed on the mask to locate the treatment area. You will lie down on a treatment table. For each radiation session, you will be in the treatment room about 15 minutes, but you will be getting your dose of radiation for only about 1 to 5 minutes of that time. Receiving external radiation treatments is painless and invisible, just like having an x-ray taken. You will need to remain very still during the treatment so that the radiation reaches only the area where it's needed and the same area is treated each time. You don't have to hold your breath and should continue to breathe normally during treatment. The radiation therapist will leave the treatment room before the machine is turned on. The machine is controlled from a small area right outside the treatment room. You will be watched on a television screen in this control room. You may feel alone, but please keep in mind that you can be seen and heard at all times by the therapist who can talk with you through a speaker. The machines used for radiation treatments are very large, and they make noises as they move around to aim at the treatment area from different angles. The machines are being moved and controlled by your radiation therapist at all times. They are checked constantly to be sure that they are working correctly. If you do feel ill or uncomfortable during treatment, please tell your therapist and so the machine can be stopped.

Throughout your treatment, your radiation oncologist will regularly check on the effects of the treatment. Please note that you may not notice or be aware of any changes during your radiation treatment. Our nurses and doctors are available by phone at any time should you have a question or concern.

For more information about radiation at Smilow, please watch the following video at: yalecancercenter.org/radonc

GAMMA KNIFE STEREOTACTIC RADIOSURGERY (GKSRS)

This more focused type of radiation is typically used for brain tumors which arise from other tumors in body, also known as metastases, but can be used for certain types of primary brain tumors described above. Other benign (non-cancer) conditions, such as vascular malformations, are also treated this way.

GKSRS uses narrow beams that are delivered from multiple angles. This allows a very high dose of radiation to be delivered to a small spot. GKSRS is usually given as a single treatment in a one-day, outpatient setting.

The team that provides GKSRS includes a radiation oncologist, a neurosurgeon, a physicist, and a nurse. Each provider offers his/her expertise to the treatment plan for each patient. On the day of treatment, a stereotactic headframe will be placed on your head by a neurosurgeon, using a local anesthetic and possibly a sedative. Before treatment can proceed, a new set of images to guide treatment will be obtained while you are wearing the headframe, such as an MRI or CT scan. These images are sent to a dedicated computer where the treatment plan is developed by the physicist, radiation oncologist, and neurosurgeon.

The same headframe that was placed at the beginning of the day before the imaging is then used to position your head for treatment. This allows for accuracy within less than one millimeter. You will lie down on a table with the headframe attached to the table. The length of treatment depends on the number and size of tumors being treated but is generally 1-2 hours. Afterwards, the headframe will be removed and you will be discharged home. There is no prolonged recovery time; most patients resume their normal activities within 1-2 days. Pain is often minimal and can be managed with over-the-counter medications such as Tylenol and Ibuprofen. You will see the neurosurgeon and radiation oncologist for follow-up, which will include periodic additional imaging of the brain as well as clinical assessments of benefits and side effects.

FREQUENTLY ASKED QUESTIONS REGARDING RADIATION TREATMENT

What is radiation treatment?

The use of high-energy rays or particles to treat disease is called radiation therapy. Special equipment is used to aim the radiation at tumors or areas of the body where there is disease. Sometimes it's called radiotherapy or irradiation.

How does radiation treatment work?

High doses of radiation can kill cells or keep them from growing and dividing. Radiation therapy is a useful tool for treating cancer because cancer cells grow and divide more rapidly than many of the normal cells around them. Although some normal cells are affected by radiation, most normal cells appear to recover more fully from the effects of radiation than do cancer cells. Doctors carefully limit the intensity of treatments and the area being treated so that the cancer will be affected much more than normal tissue.

What are the side effects of radiation?

Side effects of radiation therapy most often are related to the area that is being treated. With radiation treatment to the brain, this can include fatigue, skin redness, and hair loss. Your doctor and nurse will tell you about the possible side effects and how you can manage them. Many side effects can be controlled with medication. They usually go away within a few weeks after treatment ends. However, some side effects can last longer. Many patients have no side effects at all.

Will I lose my hair?

Radiation therapy can cause hair loss, also known as alopecia, but only in the area being treated. Radiation to your head may cause you to lose some or all of the hair on your scalp. Many patients find that their hair grows back again after the treatments are finished. The amount of hair that grows back will depend on how much radiation you receive and the type of radiation treatment your doctor recommends.

Can I drive myself to and from radiation?

Many patients are able to drive to and from their radiation treatment appointments. However, driving may not be recommended for some patients due to symptoms such as fatigue or seizures, or side effects resulting from strong pain medication. Talk to your doctor about your specific symptoms and treatment plan.

Will I be radioactive after radiation treatment?

External beam radiation therapy does not cause your body to become radioactive. There is no need to avoid close contact with other people because of your treatment.

How do I take care of myself during radiation?

Be sure to get plenty of rest. Sleep as often as you feel the need. Your body will use a lot of extra energy over the course of your treatment, and you may feel very tired. Fatigue can last for several weeks after your treatment is finished. Try to eat a balanced diet that will prevent weight loss. Your nurse will discuss specific skin care instructions with you. Be sure your doctor knows about any medicines you are taking before starting treatment.

Where To Find Us

The department of radiation oncology is happy to offer free valet parking during your radiation oncology visit. Please park outside the main entrance of Smilow. Our staff will validate your parking ticket in the waiting room at each visit. This is available exclusively during radiation oncology visits. We are located on the Lower Level (LL) of Smilow Cancer Hospital. You will see the door to the office's waiting room immediately after exiting the elevator. A directory with office locations is located above all elevator buttons in the event you find yourself lost. Look for the large fish tank in the center of the waiting room. After checking in at the front desk, our team will then help you navigate the floor and get you to your appointment.

Radiation Oncology Office Hours of Operation:

Monday through Friday
8:00AM-5:00PM

Our Radiation Oncology Clinic:	Our Mailing Address:
Smilow Cancer Hospital 35 Park Street Lower Level New Haven, CT 06510	Yale University School of Medicine 15 York Street LLCI 920 New Haven, CT 06510

How To Contact Us

Radiation Oncology: New Patient Consultations: 203-200-2000
Questions and Concerns: 203-200-2100

** Emergency radiotherapy is available on a 24-hour basis via a staff radiation oncologist, a radiation therapy resident, and a registered radiation therapy technologist.*

Our physicians also treat patients at several other locations, including:

McGivney Cancer Center (Hamden): 203-867-5622

Trumbull Radiation Oncology: 203-337-8700

Lawrence + Memorial Cancer Center (Waterford): 860-444-3744

Shoreline Medical Center (Guilford): 203-453-7170

Griffin Hospital (Derby): 203-732-1280

6: SUPPORT SERVICES

Support Groups

We provide an opportunity for patients and their caregivers to interact with one another in a supportive environment. Our support group provides an opportunity for patients, friends, and family members to share common concerns related to the many challenges associated with being diagnosed with and treated for a brain tumor.

- **Brain Tumor Support Group**

Date/Time: 3rd Monday of each month at 3:00PM

Location: 55 Park Street- seminar room behind the auditorium

- **Caregivers Support Group**

This group offers an opportunity to meet other caregivers in a relaxed, supportive environment where you can confidentially share your feelings, experiences, and stories of hope and learn ways to cope.

Date/Time: 1st + 3rd Thursday of each month at 5:00PM

Location: 1st floor of Smilow in the Patient and Family Resource Center

- **IMPACT: A Support Group for Young Adults Living with Cancer and Beyond**

The **IMPACT Support group** for young adults with cancer is for patients and cancer survivors who are between 18-39 years old and will help discover how young adults cope with the same issues and concerns. The group also discusses resources, helpful tips, and skills to help one another survive and thrive during and after their diagnoses.

Date/Time: The 3rd Thursday of the month from 5:30pm-7pm

Location: Children's Hospital, 2nd floor, room CH290

Patient Services

Social Work

Social Work is available for patients throughout the continuum of care, from diagnosis through survivorship or bereavement. We help patients and families adjust to a diagnosis, in addition to discussing concerns related to the illness, treatment, and prognosis. Social Work can advocate for you, can assist with advance care planning and decision-making, as well as with referrals to community resources. We facilitate support groups for many cancer types as well as for young adults with cancer and family and friends. Professionally facilitated groups by Licensed Clinical Social Workers can assist group members in feeling less isolated, gaining a sense of control and mastery, being cohesive and supportive to one another, as well as assuring that any information and resources brought into the group are appropriate and accurate. Please ask your care team for additional information about how to contact the social worker who will be working with you and your family or call the Department of Social Work at 203-688-2195.

Parenting at a Challenging Time (PACT) Program

The Parenting at a Challenging Time (PACT) Program offers guidance and support to parents with cancer who are concerned about the impact of their illness on their children. We can explain what you might expect from your children and how to talk with children of different ages about cancer and cancer treatment. We can help clarify how well your child is coping with your diagnosis, and if further support is necessary we may guide you on how to provide or seek additional support. Please ask your care provider to contact your social worker for this service.

Integrative Medicine

The Integrative Medicine Program aims to empower our patients with the knowledge and support to improve and maintain quality of life while undergoing cancer treatment. Services offered include: Massage, Reiki, Meditation, Yoga, Essential Oil therapy, Art Expression, Personal Story Writing, and Movement classes. Group classes and individualized treatments are intended to nurture, soothe, and support. Benefits include improved relaxation, sleep, and immune function, as well as relief from anxiety, pain, fatigue, and nausea. Please call 203-200-6129 for more information and scheduling.

Palliative Care

Palliative Care is a comprehensive, interdisciplinary team based approach that focuses on the physical, psychosocial, spiritual, and practical needs of patients and their families facing serious and advanced illness. It is appropriate at any time during a patient's medical experience as an "extra layer of support" even while receiving active treatments. The goal is to improve quality of life, respect personal values and preferences, provide education and support, promote comfort, and relieve suffering. The Palliative Care Program at Smilow Cancer Hospital collaborates closely with your oncology team to provide expert treatment of pain and other physical symptoms, guidance with difficult treatment choices

and transitions of care, assistance with coping strategies and mental health matters, and help with psychological, spiritual, and practical concerns. For more information or to schedule an appointment, call 203-200-2725 or visit yalecancercenter.org/palliative

Volunteer Services

The YNHV Volunteer Services department has several patient and family-centered programs, which provide support and comfort during challenging and often difficult hospitalizations. Programs such as Comfort Companions (providing bedside visits for patients in their end stage of life when family is not available), Oasis for Healing (providing relaxation sessions – Reiki, Light Touch Massage, Guided Imagery), and Pet Therapy (providing therapeutic dog visits) help to relieve some of the stress and discomfort patients and families may be experiencing. In addition, volunteers visit patients to provide prayer shawls, books, magazines, and crossword/word searches, as well as special requests for music at the bedside. There are also volunteers who provide friendly visits to our non-English speaking patients and volunteers who visit patients to review non-medical questions patients and families may have about their stay. For more information on how to access these services, please call 203-688-2297.

Dietary Awareness & Nutrition

Good nutrition is especially important while you receive treatment for cancer. Ask your nurse, medical assistant, or doctor to contact the dietitian for you if you are experiencing loss of appetite, trouble eating, weight loss, changes in bowel habits, or have questions about vitamins, minerals, supplements, or any other nutrition concerns. Patients with dietary restrictions during chemotherapy (i.e. tyramine-free diet) may greatly benefit from a consultation with a dietician.

Our registered dietitians can see you during treatment, help you over the phone, or schedule an appointment. The service is free to patients receiving care at Smilow Cancer Hospital.

Healing Garden

The outdoor healing garden is located on the seventh floor of Smilow Cancer Hospital for patients and families to enjoy. The garden, complete with a stream and benches, provides its patrons with nature's healing qualities.

Spiritual Care

Spiritual Care consists of professionally trained chaplains who visit patients through the hospital to provide emotional and/or spiritual support while showing the utmost respect for patient beliefs and values. Please ask your care team to facilitate a visitation or call 203-688-2151.

The Boutique

The Cingari Family Boutique at Smilow Cancer Hospital offers services and support to meet your needs throughout treatment. Fashion and makeup advice, specialized skin care products, decorative canes, and educational products are at your disposal Monday through Friday, 9:00AM-5:00PM and Saturday, by appointment. For all questions or to schedule an appointment, please call 203-200-CARE.

Lodging

New Haven offers hotels and other accommodations geared toward longer-term stays. Some options are within walking distance of the hospital and many are within a few minutes by car. Please contact patient relations at 203-688-3430 for more information. The Suites at Yale New Haven is a 24-suite hotel offered by Yale New Haven Hospital at the corner of Dwight Street and North Frontage Road in New Haven. For more information, please call 203-654-7500.

Yale Cancer Answers

Tune in to *Yale Cancer Answers* on Sunday evenings at 7:30PM on WPNR for a weekly radio show focused on cancer screening, detection, treatment, and prevention. Hosted by Yale Cancer Center doctors, the show features a guest cancer specialist each week who provides information on the most recent advances in cancer therapy and responds to listeners' questions. Listen to the radio show online anytime at yalecancercenter.org/answers or through iTunes.

Patient and Family Resource Center

An education-rich place to research and obtain information on cancer-related topics and services. Brochures, books, computers with internet access, comfortable chairs, and other helpful information can be found on the first floor of Smilow (North Pavilion 1-300), Monday through Friday from 9:00AM-3:00PM. For more information, please call (203-200-4636).

Survivorship Clinic

WHAT IS THE SURVIVORSHIP CLINIC?

The Survivorship Clinic at Smilow Cancer Hospital is the first dedicated, multidisciplinary resource for cancer survivors in the State of Connecticut to provide patients and their families with vital information on cancer prevention, wellness, supportive services, and the latest health research related to cancer survivorship.

WHAT SERVICES DOES THE SURVIVORSHIP CLINIC PROVIDE?

The Survivorship Clinic provides dedicated support services for cancer survivors. Each survivor receives:

1. A written treatment summary and survivorship care plan tailored to your specific diagnosis and treatments received. This care plan includes information about potential late- and long-term effects, future screening, and surveillance recommendations.
2. A medical consultation with an MD or APRN to review the survivorship care plan.
3. Individualized counseling from a registered dietician and physical therapist to design a personalized plan to help optimize the survivor's health behaviors.
4. Psychosocial support with a private visit with a social worker.

WHO SHOULD COME TO THE SURVIVORSHIP CLINIC?

Anyone at any stage of treatment (active treatment to follow-up care) at Smilow Cancer Hospital is eligible to come to the Survivorship Clinic.

WHEN SHOULD YOU COME TO THE SURVIVORSHIP CLINIC?

In general, most survivors come to the clinic within the first year of diagnosis, as their adjuvant therapies (i.e. chemotherapy and radiation) are finishing and they are entering the "surveillance" phase of cancer care. Even if you are on extended treatment, you can be seen in the Survivorship Clinic.

HOW DO SURVIVORS MAKE AN APPOINTMENT?

CALL 203-785-CARE OR 203-785-2273

Financial Resources

How will I pay for my care? How will I pay for deductibles and co-pays? How will I pay for medication and other medical devices necessary throughout my treatment? How will I manage to pay for everything else in my life? How much time do I need to take off from work?

Treatment for a brain tumor can be costly. It affects your health, emotions, relationships, time, and finances. Regardless of where you are in your treatment, Yale New Haven Health has the necessary resources to better help you plan and pay for treatment costs. Some costs throughout brain tumor therapy are spontaneous and unexpected. YNHH offers financial counseling to patients and families about their bills and cost for therapy.

Please call 203-688-2030

Your social worker can also assist you in addressing your financial concerns and can direct you to programs, which you can apply for assistance. Patient Financial Admitting Service (PFAS), for example, can assist you in applying for state medical insurance or “The Free Care Program.”

Many patients are employed and may require assistance in coordinating a medical leave or taking advantage of their medical benefits. We encourage you to speak with your employer’s Human Resources office or a YNHH social worker so that finances do not become a burden during treatment.

7: RESOURCES— MY TIME AT SMILOW

