

7. SURVIVORSHIP

*P*atients diagnosed with brain tumors go through a very difficult and life-threatening experience. This chapter examines what it means to be a brain tumor survivor.

The brain is the essence of who we are. It controls our thoughts, emotions, communication, movements, and organ functions.

A brain tumor diagnosis usually turns the patient's world upside down. For everyone involved, the brain tumor experience is a journey into an unknown land filled with uncertainty. Through the diagnosis, treatments and follow-up visits, there's much to learn and cope with physically, emotionally, and spiritually.

Patients may want to know when treatments will end, symptoms will stop, and when or if they will be healthy again. At some point, patients will usually ask the question, "Will I survive this disease?" and "When will I know that I'm a survivor?"

"SURVIVOR" DEFINED

What is the definition of a brain tumor survivor? Before the 1960s, the term "survivor" was primarily used for family members whose loved one died of cancer.* The

definition changed when patients began living longer due to new radiation and chemotherapy treatments. The medical community began to use "survivor" to describe those who lived for at least five years after their diagnosis or the end of their treatment.

This definition is not accurate for patients who may live more than five years, but are not cured. Some patients may go into remission, requiring treatments many years later. It is wrong to suggest that some patients triumph, and others lose the battle against brain tumors. Treatments may fail the patient, but the patient never fails the treatment. This is why the National Coalition of Cancer Survivorship (NCCS) introduced the following definition of survivor, "From the moment of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor."

You are a survivor—from the moment of your brain tumor diagnosis until long after treat-

ment ends. How does that feel to you? It is important to know that not everyone takes on this definition. "Survivorship" is a dynamic process, and everyone deals with his or her brain tumor differently. You may feel uncomfortable calling yourself a survivor after your treatment ends, or you may wait until you are disease free. You may use the term when you feel some normalcy in your life, or avoid the term altogether.

STAGES OF SURVIVORSHIP

Brain tumor survivorship involves much more than the label "survivor." Survivorship is an ever-changing process, an experience of living with, through, or beyond brain tumor disease. The concept of survivorship includes everything in life that changes as a result of the diagnosis and its aftermath. Many patients struggle to make sense of the changes and to feel a sense of order in life. Fitzhugh Mullan, MD, a physician and

* Editor's Note: This chapter makes several references to cancer. That is because sources for this article included the National Coalition of Cancer Survivorship and the National Cancer Institute, as well as cancer patients and survivors. Not all brain tumors are malignant. However, because of the unique nature of brain tumor disease and its consequences, we feel that the information presented here is relevant to all brain tumor patients and survivors, including those with a benign diagnosis. Please keep this in mind as you read through the chapter. It may be helpful in places to substitute the words "brain tumor" for the word "cancer."

cancer survivor, wrote an essay entitled “Seasons of Survival: Reflections of a Physician with Cancer.” In it, he inserts some structure into his cancer experience by proposing the following three survival stages.

Acute Stage

Acute stage includes the time from diagnosis through the beginning of treatment, when the focus is on the physical disease. Patients and caregivers struggle to navigate their situations and may rely heavily on their oncologists (or neurologists) for information. Supportive services like health care professionals and family support systems are widely available to help patients through this process.

Extended Stage

Extended stage begins when and if the patient responds to treatment. Patients and caregivers may feel positive yet uncertain. Fear of recurrence is often present. Recovery focuses on the physical, emotional, and psychological effects of treatment. Mixed emotional extremes are common. Medical services are no longer available on a regular basis. Patients and their families usually rely on community and peer networks for support.

Permanent Stage

Permanent stage refers to the long-term stage of survival, when a level of trust for health and life returns to the patient. The outside world praises the patient for his or her recovery. However, the patient must manage the long-term physical and psychological effects of the disease. Survivors

may require continued care by specialists with knowledge about long-term and late effects of their disease and its treatments.

The process of brain tumor survivorship involves many feelings: anger, sadness, cognitive fatigue, the fear of seizures, and the hope that treatment will destroy the brain tumor and enable the patient to reclaim his or her life.

Survivorship can teach a new appreciation of the world, oneself, and others. The awareness of the impermanence of life can make it much more precious. And even when a cure is not possible, there may be an opportunity for healing. Treatments focus on the elimination of disease, while healing focuses on psychological and spiritual wellness.

INFLUENCES ON SURVIVORSHIP

There are several key factors that may be related to brain tumor survivorship:

- Physical factors including age, gender, type and stage of brain tumor, treatments, and progression of disease. Children older than age three tend to have a higher survival rate than infants, and adults below the age of 45 do better than older adults. Tumors that are slow growing generally have a better prognosis than aggressive tumors.
- Side effects such as cognitive disorientation, physical limitation, disfigurement, and disability. In general, less severe side effects allow for a better quality of survivorship.
- Psychological factors influenced by age, previous experience with

illness, psychological strengths and weaknesses, coping mechanisms, prior history of depression, anxiety and other mental health issues, self-esteem, and personality traits like independence and motivation. These factors affect a person’s outlook on life.

- Social factors including race, gender, ethnicity, religious orientation, education level, employment history, financial stability, available social support, and the patient’s role in his or her family, such as being a spouse, parent, or child. Social factors affect a person’s ability to get health care as well as the quality of care.

DEALING WITH EMOTIONS AND GRIEF

Brain tumor patients experience different types of loss throughout their journey: from the loss of hair, to the loss of various levels of cognitive functioning, the ability to take part in certain activities, relationships, self-esteem, and innocence. People affected by brain tumors often endure emotional pain and suffering from these losses. Relaxation activities like deep breathing, imagery, meditation, and light exercise can help ease stress. Survivors with severe emotional stress should consider seeking assistance from a mental health professional.

Intense emotional suffering caused by loss is called grief. Processing grief can be a long journey for patients and caregivers. Hidden grief can manifest itself in emotions like anger, guilt, anxiety, helplessness, and sadness. Everyone grieves in his or her own way. However, psychol-

ogists believe that once grief is recognized, those mourning go through the following steps: accepting what has been lost, experiencing the pain associated with the loss, adjusting to the new environment, and moving on.

Several studies and surveys show that survivors need emotional support, especially reassurance. Many brain tumor patients welcome the opportunity to express themselves and share their experiences. Caregivers and friends can play an important role by educating their loved ones about the grieving process and by encouraging them to verbalize their feelings. Many patients and their families benefit from attending support groups. NBTF can help you locate a brain tumor support group in your area.

POST-TRAUMATIC STRESS DISORDER AND POST-TRAUMATIC GROWTH

Some brain tumor patients may perceive their diagnosis and its accompanying treatments as a traumatic event. Post-traumatic Stress Disorder (PTSD) is a term for an anxiety disorder that may result from a severe trauma. The diagnosis of a life-threatening illness or learning of one's child's diagnosis can be traumatic. Symptoms of PTSD include fear, helplessness, and horror, re-experiencing the event, avoiding reminders associated with the event, and increased stressful responses for at least one month.

Studies suggest that some childhood brain tumor survivors, their parents, and adult survivors experience PTSD. Brain tumors are

unique from other traumatic stresses because of the neurological effects and the uncertainty of recurrence. If you think that you might have PTSD, you should consider seeing a psychologist who can provide you with a clinical diagnosis and professional assistance through your trauma.

Post-traumatic Growth (PTG) is a term for the positive life changes that can come from trauma. PTG is considered to be the opposite of PTSD. For some patients and caregivers, the brain tumor experience inspires them to question their beliefs, attitudes, life goals, and relationships. This period of re-evaluation, which can at first be traumatic, may ultimately create positive changes. Studies suggest that brain tumor survivors who endure trauma grow from their ordeal. Specific areas of PTG include appreciation of life, personal strength, and improved ability in relating to others.

A long-term glioblastoma survivor describes positive changes coming from his journey:

“It was five years ago when I was diagnosed with a brain tumor and, based on statistics, given a rather dire prognosis. The irony is that I, like others in a similar situation, have come to refer to my disease as a gift because it was a wake-up call. And it was not, ‘Hey, wake up, you’re going to die.’ It was, ‘Hey, wake up, you are alive.’ Wake up and recognize the preciousness of this moment and all the wonderful moments life so generously and graciously gives you.”

REMAINING HOPEFUL

Brain tumor patients have a right to remain hopeful in the fight against their illness and its aftermath. Hope is a powerful concept and coping strategy that empowers patients to look beyond the moment and into the future.

One brain tumor patient expresses the importance he places on a positive outlook:

“I have no question that the mind-body connection is very real and can affect the outcome of our illness. I do not intend my outcome to be translated as a cure. Some people will get better while others will have periods of remission. Whatever time remains—and I base this on many, many conversations with patients as well as my own experience—it will be higher quality if we engage our mind’s ability to affect our attitude.”

However, hope does not necessarily translate into being cured.

Kendra Peterson, MD, a neurologist with much experience working with brain tumor patients, explains:

“It is important to explore what other things a patient hopes for, for example: freedom from pain or other physical symptoms, maintaining maximum independence for as long as possible, participation in a particular family event or gathering, making peace in a troubled relationship, dying with dignity or dying at home. What people hope for frequently changes throughout their lives and at the end of life, but rarely do they stop hoping.”

SUPPORT GROUPS

A support group is a meeting of patients, family members, and others, who are dealing with the same issue or illness. Support groups are usually led or facilitated by a health professional, such as a social worker, psychologist, or nurse. Support groups can be in person (often held at a hospital) or online, where members communicate by email.

Support groups serve several functions. They give patients and families opportunities to talk with knowledgeable people, including health care professionals, who can educate them and provide information about their disease. Support groups let individuals know that they are not alone. They provide a chance to talk with people who are in or have survived similar situations. Support groups can offer emotional support and practical experience to help cope with the crisis of a brain tumor diagnosis. And support

groups can smooth the transitions that patients and families must make as they deal with unfamiliar environments, such as hospitals and outpatient clinics.

Support groups are free of charge. Most of them have no requirements about regular attendance or participation. People can choose to come or not, stay as long as they like, and feel comfortable about participating or just listening to others in the group. Support groups are not all the same. Some can be intense and emotional, others fun and energizing.

Support groups are not for everyone—at least not consistently for everyone. It depends on the person and his or her particular feelings at any particular time. However, when a person and family have to face the diagnosis of a brain tumor, it is important to realize that everyone involved may benefit from having someone to talk with. It is

often important to have a person who is not emotionally involved who can offer an outside perspective. The National Brain Tumor Foundation (NBTF) always recommends counseling, whether one-on-one or for the family. We and others across the country are helping professionals get support groups started, specifically for brain tumor patients, in a number of geographic areas. To see if there is a group in your area or for information about online support groups, call NBTF at 1-800-934-2873 or visit our website at www.braintumor.org.

MANAGING FOLLOW-UP CARE

Brain tumor patients need to receive the best quality of care available. Quality care may be found at local hospitals or may require travel to a well-known brain tumor treatment center, depending upon the diagnosis. Some patients do not want to receive treatments far from home. A second opinion from a major oncology center can confirm the best local treatment plan. See the NBTF fact sheet *Issues to Consider When Choosing a Brain Tumor Treatment Center* for more information.

Tips for Doctors' Appointments

Doctors' appointments can be very stressful for patients and caregivers. The exchange of information can be more difficult than most people realize. Here are some tips to help you get the most out of these important meetings:

- Take someone to medical appointments that can ask the doctor questions, understand what



Members of the Sacramento area Brain Tumor Support Group staff an information table at a resource fair.

was talked about during the appointment, and discuss it with you afterwards.

- Keep a notebook with questions and concerns, and write down notes from the meeting.
- Take a tape recorder and ask the doctor if you may tape the conversation.
- Request to meet with the doctor in a private room with the door closed. This is especially important for brain tumor patients, who may be more easily distracted than other people.
- Tell your doctor at the beginning of the meeting if you have several questions, and ask the most important questions first. Ask the doctor to schedule a longer appointment for next time if necessary. Ask when you can talk on the telephone about your immediate questions if there is not enough time during the meeting.
- Ask if your doctor works with a health care provider, such as a nurse practitioner or physician's assistant, whom you can contact if your doctor is unavailable.
- Express yourself clearly and directly, and ask for what you want or need. Let the doctor know when you have heard enough or want more information. Ask for additional resources on specific topics.
- Repeat what you heard the doctor say, and ask him or her to explain things in simpler terms if you don't understand.
- As a last resort, consider finding a new doctor if your needs are not being met.

NCCS has a free resource available called *Cancer Survival Toolbox*. It has information about communicating, finding information, making decisions, solving problems, negotiating, and standing up for your rights. Contact the NCCS at 1-877-NCCS-YES (1-877-622-7937), or visit www.canceradvocacy.org.

SPECIFIC QUESTIONS ABOUT FOLLOW-UP CARE

After treatment, patients need monitoring or follow up with a member of their medical team who knows the original diagnosis and treatment history. This person can determine how often and for how long follow-up care will be necessary.

Important questions to ask your neurosurgeon, neuro-oncologist, or neurologist about follow-up care:

1. **How often should I see you or other members of my health care team for follow-up visits?**
2. **What follow-up tests should be done and how often?**
3. **What symptoms should I be concerned about?**
4. **Who should I contact if I develop those symptoms?**

MEDICAL HISTORY AND RECORDS

Patients and their primary caregivers need to have basic knowledge about tumor type and treatment history. It empowers patients and their caregivers to make better medical decisions. This information can be organized in a notebook, portable file holder, or even a binder dedicated to med-

Medical records patients should keep

- The type of brain tumor you were diagnosed with and copies of pathology reports
- Date of diagnosis and treatment history, including surgical reports, sites and levels of radiation, types and amounts of chemotherapy and any other drugs, lab reports, and doctor and hospital names with contact information
- MRI reports, and copies of scans if possible

ical history and records. It should be shared with new doctors.

Patients have the right to see and to get access to their medical records. The process of viewing medical records involves signing a release form. Fees may be charged for copies of records and scans. Get copies of films, disks, and reports as soon as possible. The best time to request these copies is when the tests are first given. Take your medical records with you to appointments. Keep duplicates for second opinions and in the event that your copies should get lost in the mail or elsewhere.

HEALTH INSURANCE, COSTS, AND FINANCIAL ASSISTANCE

Brain tumor treatments, tests, and doctors' appointments can be a financial burden for patients and their families. It is extremely important for patients to have health insurance that will offer some medical coverage.

Patients may want to ask a caregiver, family member, or close friend to help them manage their

health insurance. Having a designated health care advocate can make a big difference in the type and quality of care a patient receives. Because there are so many different types of health insurance plans, it is important for patients and their caregivers to understand the scope of their insurance coverage. Your insurance company can provide answers to questions about your policy and available coverage. Your state insurance office has information about how and where to get new insurance.

Sometimes coverage is denied by health maintenance organizations (HMOs) or employer-sponsored plans. There is usually an opportunity to appeal the decision by making claims such as medical necessity. Even simple claims that were processed incorrectly may require several phone calls and letters to resolve, which takes time and energy. At times like these it is especially worthwhile to have a caregiver, family member, or close friend who can assist with insurance issues. Patients may need to reserve their energy for taking care of themselves and getting stronger.

For more information, call NBTF and request a copy of our health insurance fact sheet, or download a copy from the web site at www.braintumor.org.

RETURNING TO WORK

The period after diagnosis and during treatment can involve changes when patients and their caregivers redefine expectations and family roles. Brain tumor patients may leave their jobs or reduce their work hours dur-

ing this period. Later, many patients can and do return to work. Other brain tumor patients, however, cannot work at all, or can only handle some of their former responsibilities.

MAKING THE DECISION

Your capabilities, needs, and the advice from your physician and neuropsychologist should all be factors considered when deciding whether or not to return to work. Your physical and mental condition are also important. Your condition will be affected by the size, location, and type of tumor, as well as the treatments received. A neuropsychologist can anticipate problems you might have at work, and provide strategies to help you compensate. The biggest challenge you may experience when returning to work is that some tasks may be more difficult.

Strategies to help the patient prepare for returning to work and adjusting after starting:

- If necessary, seek cognitive training and assistance from a neuropsychologist.
- Consider going back to work part-time to start. Many patients make the mistake of going back to full-time work too quickly.
- When accepting a new job or going back to an old one, be honest about your needs and expectations.
- Organize your environment so that it helps you do your job well. You might want to arrange an enclosed workspace and use earplugs to avoid distractions. It might help to create checklists, keep a calendar of appointments, and

employ auditory and visual cues such as appointment reminders from your computer or color-coded files.

- Relearn tasks through repetition and modeling.
- Prioritize work assignments.
- Understand your limitations and adapt.
- Work with your employer to make reasonable accommodations in the workplace.

AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act of 1990 (ADA) prevents job discrimination for disabled individuals. If a person with a disability can perform the essential duties of a job, the employer cannot discriminate in the hiring process. By law, the employer must also make reasonable accommodations for people with disabilities.

FEDERAL AND STATE DISABILITY PROGRAMS

Temporary and permanent benefit programs offer financial assistance for those who cannot return to work. A hospital social worker or local social services agency can provide more detailed information and possibly assist with the application process.

Medicaid

Medicaid is a health insurance program for eligible people below a designated income level. It is jointly funded by federal and state governments. Each state has different eligibility requirements. For information about Medicaid

coverage, visit www.cms.gov or call your local Department of Social Services.

Medicare

Medicare is a federal health insurance program for eligible individuals aged 65 or older, people with permanent kidney failure, and disabled people under the age of 65. Disabled applicants must have been receiving Social Security Disability Insurance (SSDI) benefits for 24 months to qualify. The Medicare hotline has information about state counseling and assistance programs and about the Health Insurance Portability and Accountability Act (HIPAA) of 1996. HIPAA is a law that offers protections against employers who exclude employees from group coverage or who increase insurance costs because of an employee's medical history. Call 1-800-MEDICARE (1-800-633-4227), or visit www.medicare.gov or <http://cms.hhs.gov> for more information.

Social Security Administration

The Social Security Administration offers two programs for people with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Both programs define disability as "a medically determinable impairment which results in marked and severe functional limitations and which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months."

Social Security Disability Insurance (SSDI) is not based on need. SSDI is based on money deducted from a worker's paychecks. For more information about SSDI, call 1-800-772-1213, or visit www.ssa.gov/disability.

Supplemental Security Income (SSI) is a need-based program. Past contributions to the Social Security system do not affect eligibility. For more information about SSI, call 1-800-772-1213, or visit www.ssa.gov.

Department of Veterans Affairs

Veterans Health Administration offers eligible veterans and their dependents medical treatment based on financial need. Call 1-877-222-VETS (1-877-222-8387), or visit www.va.gov.

For more information on issues related to work and disability programs, call NBTF at 1-800-934-2873 and request a copy of *Returning to Work: Strategies for Brain Tumor Patients*, or download a copy from the web site at www.braintumor.org. Click on "Patient Info," then "Publications."



This chapter was written by Jeannine Walston, and we are very grateful for her assistance.

North American Brain Tumor Coalition

The North American Brain Tumor Coalition (NABTC) is a network of charitable organizations representing almost 200,000 patients, family members, and friends. NABTC is committed to eliminating brain tumors and improving the quality of life for those affected by brain tumors. NABTC represents the interests of its community by raising public awareness about this issue. NABTC advocates for increased research funding, access to specialized care, and other issues affecting the brain tumor community.

NABTC also participates in meetings and programs at the Food and Drug Administration (FDA), the National Institutes of Health (NIH), and other federal agencies. NABTC works with organizations representing patients with life-threatening illnesses to improve research and the delivery of health care. NBTF is a member of the NABTC. For more information about NABTC, visit www.nabraintumor.org.