

Navigating Life with A Brain Tumor

Behind the scenes of the American Academy of Neurology's new book for patients and caregivers.

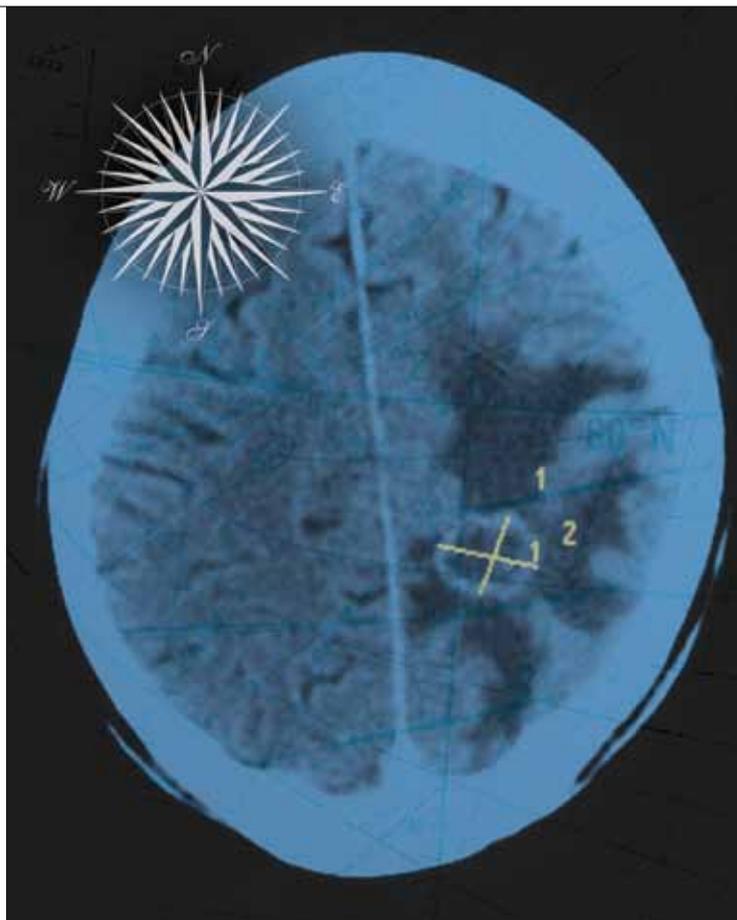
BY TODD FARLEY

Brain tumor" is not a phrase anyone wants to hear, especially from the lips of a doctor. It's a diagnosis that often engenders fear first, questions later. Patients may wonder, "Exactly what is a brain tumor? Where did mine come from? Is it cancerous? Will I survive?"

Because people who receive a diagnosis of brain tumor are usually very anxious, they may be unable to fully absorb medical information and advice. Answers from doctors can be staggeringly complex, while websites and chat rooms provide such a jumbled flood of opinion and "fact" that the newly diagnosed can be easily overwhelmed.

A NEW TOOL FOR MANAGING TUMORS

That's why the American Academy of Neurology (AAN) decided to publish *Navigating Life with a Brain Tumor*, a new resource for patients and caregivers and the second in the AAN's series of *Neurology Now*™ Books. (See box, "Neurology Now Books," in Resource Central, page 36.) The book was co-authored by Lynne Taylor, M.D., Fellow of the AAN, neuro-oncologist, director of palliative care at Tufts Medical Center



in Boston, MA, and member of the *Neurology Now* Editorial Advisory Board; Alyx Porter, M.D., director of neuro-oncology at the Mayo Clinic in Arizona; and Diane Richard, a professional writer. (A neuro-oncologist is a doctor who specializes in cancer of the central nervous system.)

Helping to educate brain tumor patients on the reality of their conditions was particularly important to the AAN as well as to the book's authors and editors, especially since knowledge—when put to good use—can be a powerful tool in itself. "An informed patient is a more effective communicator and therefore better able to participate in shared decision making with his or her physician. And here's the most important part: Patients with more knowledge are better able to manage their condition, resulting in better outcomes over time," stresses Lisa Shulman, M.D., professor of neurology at University of Maryland School of Medicine, Fellow of the AAN, editor-in-chief of *Neurology Now* Books, and member of the *Neurology Now* Editorial Advisory Board.

"Having all this information can make a patient's appointment with his or her doctor much more meaningful," Dr. Porter says.

The authors wanted to "meet patients where they are," says Dr. Taylor. "We wanted to help neurology patients and their families and caregivers understand the common symptoms that can occur with brain tumors—to explain those symptoms and why they may be getting them. Plus, we wanted to give a big-picture view of treatment options such as chemotherapy, radiation therapy, and surgery without getting too detailed about specific drugs."

"Patients want to be able to feel not only like they understand

everything, but also that they can contribute to what's going on," adds Dr. Porter. "This book is another tool to make this transition as they begin to fight their tumor."

HONEST OPTIMISM

A mass of abnormal cells in the brain, brain tumors are classified as cancerous (malignant) or noncancerous (benign). They come in many types, with more than 120 already identified. (See box, "Brain Tumor: The Basics.")

Because each patient's journey with a brain tumor is different, *Navigating Life with a Brain Tumor* is organized as a reference book. "We didn't really envision the book to be read cover to cover," Dr. Porter says. "We hoped patients and caregivers would look through the table of contents at various times in their journey and pick the various topics that were of most use to them."

Navigating Life with a Brain Tumor provides specific information on the various treatment options, whether through surgery, radiation, or medication. The authors makes clear that a "cure" for brain tumor rarely occurs, and mostly only in the case of meningiomas and pituitary tumors. (Meningiomas are tumors arising from the cells that cover the brain and spine, called the meninges; they are often diagnosed by accident and are typically benign. Pituitary tumors can be completely removed in surgery and don't usually return.) Because most brain tumors exist within the delicate tissue of the brain, completely removing them is difficult, if not impossible. Instead, most brain tumor treatments are an attempt to minimize the size of the tumors and their symptoms and to help patients live a "neurologic progression-free survival," as the book states.

Addressing the issue of prognosis—predicting probable outcomes, such as how long one will live with a tumor—was a particularly important aspect of the book for Dr. Taylor. She notes that medical literature in the 1950s to 1960s was evenly distributed between articles on diagnosis, treatment, and prognosis, while today it very heavily emphasizes only diagnosis and treatment. "Many neurologists now treat long-term survivors of brain tumors. There is a lot of nihilistic thinking out there that if you are diagnosed with a brain tumor, there's nothing more you can do. So we wanted the voice of the patient and the long-term survivor to come through," she says.

Of course, anyone honestly addressing the prognosis of brain tumor patients can't shy away from death, which the authors do not. The book addresses the possibility of dying, hospice care—even how a patient actually passes away as a result of a brain tumor. While such information might be perceived as dark, it was absolutely necessary to the book's legitimacy.

Brain Tumor: The Basics

- ▶ **What is a brain tumor?** A brain tumor is as a mass or growth of abnormal cells in the brain.
- ▶ **How are brain tumors classified?** Tumors can be either noncancerous (benign) or cancerous (malignant). Primary brain tumors are tumors that begin growing in the brain. Secondary (or metastatic) brain tumors begin as cancer in another part of the body before spreading to the brain.
- ▶ **How many people are diagnosed with brain tumors?** Approximately 180,000 brain tumors are diagnosed in the United States each year, including both malignant and benign. Roughly 40,000 are primary tumors and the rest secondary. The National Cancer Institute estimates 23,000 Americans will be diagnosed with brain cancer in 2012, and nearly 13,000 will die.
- ▶ **What causes a brain tumor?** Primary brain tumors result from a genetic mutation in certain nerve cells in the brain (neurons) that causes them to grow too quickly. Secondary brain tumors result only after cancer has grown in another part of the body and then moved up to the brain.
- ▶ **What are the symptoms of a brain tumor?** The symptoms that result from a brain tumor vary depending on type, size, and location but can involve headaches and nausea; hearing, vision, or speech difficulties; problems with balance; loss of sensation in the limbs; seizures; changes in personality; and general confusion.
- ▶ **How are brain tumors diagnosed?** Brain tumors are diagnosed through neurologic exams, such as checking a patient's vision, hearing, balance, and coordination; imaging technologies, such as MRI, CT scans, and PET scans; and biopsy or surgical removal.
- ▶ **What treatments are available?** Treatment for brain tumors varies by patient depending on his or her personal health and the size and location of the tumor. Regular treatments, however, include surgery (the physical removal of some or all of the tumor), radiation therapy (the use of radiation to attack malignant cells), and chemotherapy (the use of drugs to battle the growths).

"We talked to a lot of our patients about that, and they said if you don't write the truth, we won't respect it," Dr. Taylor says. "They said 'of course it's dark, it's difficult, but don't disrespect us by making the book light and frothy.'"

"None of us are trying to sugarcoat the prognosis or the gravity of what we're talking about here," Dr. Porter agrees, "but at the same time, what I think inspires me is seeing patients transition from a place of fear to a place of empowerment and grace and bravery."

THE VOICE OF THE PATIENT

The authors of the book present a strong case for patients to be advocates for themselves, by keeping copies of their own files, assembling the medical team they want, and having the courage to ask questions of their doctors.



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—ALYX PORTER, M.D.

“What we hoped to do was drive the point home that it takes a team, and the patient is an active member of that team,” Dr. Porter says. “Brain tumors are rare, so physicians who are specialty-trained to take care of brain tumor patients aren’t that common, meaning at times it might be worthwhile to seek a second opinion.”

The book includes advice on how to get a second consultation, encouraging brain tumor patients to do what’s best for them even if it may seem awkward or make them uncomfortable. “That’s based on the common questions we get asked,” Dr. Taylor says, “or more commonly, after meeting with me, somebody will ask my nurse, ‘how do I go about getting a second opinion and will that hurt her feelings?’”

The book is chock full of anecdotes and quotes from 25 people who have experienced brain tumors in some way, and so it offers an inside look—sometimes humorous, other times sobering and poignant—about what it feels like to be diagnosed with a tumor. One woman who wasn’t overly concerned with her meningioma said she knew she didn’t have much to fear: After all, she said, “I watch *Grey’s Anatomy*.” Another woman whose primary brain tumor returned more than a decade after it was first treated said she didn’t understand how it happened: “Why me?” she asked, “I eat vegetables.” And a man suffering from a glioblastoma (the most malignant of primary brain tumors) explained that along with the serious health issues it was causing him, his brain tumor also seemed to have made a real mess of his golf game.

Navigating Life with a Brain Tumor: A Sneak Peek

Chapter 1

“A Look Inside Your Brain” provides a wealth of specific information on the brain’s structure, including its hemispheres, lobes, and 12 pairs of cranial nerves, to provide patients with the background they need to better understand their condition.

Chapter 2

“Diagnosis” details the specifics of getting a brain tumor diagnosis, whether via MRI, CT scan, angiogram, or biopsy, and explains exactly what patients will undergo during those procedures. For example, CT scans “typically last 10 minutes while you lie on a moveable table that glides smoothly into the center of a doughnut-shaped machine,” while for MRIs, the patient should “expect to lie within the MRI cylinder for about 20 minutes to an hour.” The chapter also addresses the importance of patients being their own best advocates by assembling the team they want, keeping copies of their file, and getting second opinions when desired.

Chapter 3

“Understanding Radiation Therapy” focuses on specific issues patients might face in undergoing radiation therapy, whether relating to where they should get it done (location is important because of the daily drive it will entail), a smell they may experience during the treatment, or other side effects of it.

Chapter 4

“Lifestyle Management” focuses on alternative treatments and therapies that may benefit the brain tumor patient. These include breathing, exercise, nutrition, and sleep advice, as well as specific herbal and dietary supplements that may improve a patient’s life and health. For example, the authors discuss the evidence for or against turmeric, a root in the ginger family, and resveratrol, a pigment found in the skins of red grapes. Chapter 4 also provides information on specific legislation or programs that might help people with brain tumors, including the Federal Family and Medical Leave Act and the American Cancer Society’s program to help defray hotel costs for those who travel daily for radiation treatments.

Chapter 5

“Symptom Management and Palliative Care” addresses specific symptoms brain tumor patients may face, the importance of sexuality and spirituality in coping with cancer, and hospice care for those patients who need it.

Chapter 6

“Care of the Caregiver” focuses on taking care of those people who help take care of brain tumor patients.

Chapter 7

“Planning for Your Future” focuses on nonmedical issues brain tumor patients need to deal with, including financial issues, legal issues, health care directives, and the importance of compiling an emergency notebook. Written entirely by two lawyers, this chapter relates to more than just brain tumor patients and may be included in all future *Neurology Now* Books.

Chapter 8

“Benign Tumors” provides specific information on these less threatening tumors, including meningiomas and pituitary adenomas.

Chapter 9

“Primary Tumors” focuses on these dangerous tumors that begin in the brain. It addresses the three most important things in battling primary tumors—a patient’s age, the specific type of tumor, and how it responds to treatment—as well as specific treatment options that currently exist and may exist in the future.

Chapter 10

“Metastatic Brain Tumors” gives information on the diagnosis, treatment, and prognosis for patients developing secondary brain tumors.

Appendix

The Appendix includes a guide to drugs prescribed for brain tumors, and the glossary offers definitions of key terms.

Starting October 31, 2012, you can buy *Navigating Life with a Brain Tumor* from bookstores, Internet retailers, or directly from Oxford University Press at bit.ly/QUeo8S or the AAN Store at bit.ly/OXhwOu



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—LYNNE TAYLOR, M.D.

The overall tone of the book was due in large part to the work of Diane Richard, a writer brought on board to help Dr. Taylor and Dr. Porter. Although she had never written about the brain before, Richard has always been intrigued by it.

“Neurologic issues affect so many people, so I have a general interest in it,” she says. “It’s just fascinating.”

“Diane took a lot of our awkward, clumsy scientific language and turned it into something with a distinctive voice that echoes that of patients and caregivers,” Dr. Taylor says.

“This book is meant to be extremely accessible,” Richard says, noting that there were “umpteen iterations” of each chapter: “We wanted the book to be useful for the person who is in a stressful situation and needs information in a hurry. We knew people were not going to be reading the whole book from beginning to end; we wanted to make sure it was relevant to readers in many different situations.”

A BRIGHTER FUTURE

Ultimately, Dr. Taylor explains, *Navigating Life with a Brain Tumor* was written to offer patients and their caregivers hope, adding that MRI scans and MRI spectroscopies as diagnostic tools continue to improve, and radiation therapies offer new and improved forms of brain tumor surgery. Citing glioblastoma patients who once only lived a year or two now living “five years, 10 years, in some extreme cases even 15 years,” Dr. Taylor says, “we wanted to make it clear to brain tumor patients that a lot has changed recently.”

Dr. Porter is similarly optimistic: “There’s the real possibility that within my career span we’ll be able to genetically analyze each patient’s tumor and come up with the best chemotherapy regimen for them specifically, as is already being done in breast cancer. I think in the next 20 years that’s where we should be with malignant brain tumors.”

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