

## Your Meningioma Diagnosis

Written by Nancy Conn-Levin, M.A. and Lorraine Rubino-Levy, R.N., B.S.N.

Medical Advisor: Peter McL. Black, M.D., Ph.D.

Sponsored by the Brain Science Foundation

You have just been told that you have a brain tumor and suddenly, everything in your life has changed. Questions fill your mind. What is a meningioma? Can this tumor be cured? What kinds of treatments are available? How much of a risk to life and health are you facing? How will you discuss this with your family and your employer? Will your life ever return to the way it was before?

The first step in learning about your diagnosis is to stop and take a breath. As you face this medical challenge, remember that you are not alone. Thousands of people are diagnosed with meningiomas each year. Many of them have successful treatments, allowing them to return to a productive and satisfying life.

A meningioma (meh-ninn-jee-OH-mah) is a type of tumor that develops from the meninges (meh-NINN-jeez), the membrane that surrounds the brain and spinal cord. There are three layers of meninges, called the dura mater, arachnoid and pia mater. Most meningiomas are categorized as benign tumors. However, unlike benign tumors elsewhere in the body, benign brain tumors can cause disability and may sometimes be life threatening. In many cases, benign meningiomas appear to grow slowly. This means that depending upon where it is located, a meningioma may reach a relatively large size before it causes symptoms. Other meningiomas grow more rapidly, or have sudden growth spurts. Some meningiomas are classified as atypical or malignant tumors. There is no way to predict the rate of growth of a meningioma, or to know for certain how long a specific tumor was growing before diagnosis. Although most people develop a single meningioma, it is also possible to have several tumors growing simultaneously in different parts of the brain and spinal cord. When multiple meningiomas occur, more than one type of treatment may have to be used.

Meningiomas appear to develop about twice as frequently in women as in men, although they can occur in both sexes and at any age. They are the only variety of central nervous system tumor diagnosed more often in women than in men. According to the most recent statistics from the Central Brain Tumor Registry of the United States (CBTRUS), meningiomas are the most common type of primary brain tumor. Unlike a metastatic brain tumor that spreads to the brain from another site in the body, a primary brain tumor originates in the central nervous system. It is estimated that about 26% of primary brain tumors are meningiomas.

In rare cases, when a meningioma is causing symptoms that present a threat to life or health, immediate treatment may be needed. The most common treatment for a meningioma is surgery (removal of all or part of the tumor). Different types of radiation are also being used for treatment of selected meningiomas. Each type of treatment has some risks and benefits, and not every treatment is possible for every meningioma. The size and location of the tumor(s), your age and overall state of health, and which medical center you choose for your treatment will influence this decision. Several major medical centers in the United States will review copies of medical records, MRI and CT scans, and other information to provide a free or low cost "second opinion" about brain tumor treatments.

After treatment, follow up care is very important. Unfortunately, meningiomas sometimes reoccur after surgery or radiation. Recurrent tumors may develop in other parts of the brain or spinal cord, which means that they can cause symptoms that are different from the original meningioma. Follow up MRI or CT scans every one to three years are an important part of long term health care for anyone who has been diagnosed with a meningioma. There is no way to predict whether or not anyone with a meningioma diagnosis will develop a recurrent tumor, or how quickly any untreated meningioma may grow.

The only known risk factor for meningiomas is previous exposure to ionizing radiation of the head, such as that which may have occurred during treatment for a prior brain tumor. Some people with a disease called Neurofibromatosis (NF) appear to have a higher rate of developing meningiomas and other tumors called acoustic neuromas (more accurately known as vestibular schwannomas). Certain chromosomal abnormalities have been associated with meningioma development. Except for those instances, there is no way to know why any individual develops a meningioma.

Although the cause of these tumors is most often unknown, there are certain factors that may affect meningioma growth in some people. There is evidence that in women, exposure to elevated levels of female hormones may promote meningioma growth or recurrence. The risks and benefits associated with the use of hormonal medications (i.e., birth control pills, hormone replacement therapy, infertility treatments, etc.) or pregnancy must be carefully reviewed in women who have been diagnosed with meningiomas.

Here are some initial suggestions that may help you make a decision about meningioma treatments, and take care of yourself during this challenging time:

Get information from sources you can trust. There are several charitable organizations that help people with brain tumors, plus their family members. A resource list is included at the end of this booklet.

Respect your feelings. If you are uncomfortable with any doctor or other health care provider, don't be afraid to talk with another physician, therapist, etc. Making choices about brain tumor treatments is one of the most significant decisions that you will face, so it is especially important to feel comfortable with your medical team.

Get at least one "second opinion" about your treatment plans. Some people with meningiomas find that several doctors suggest the same treatment for their tumors, while others may encounter different suggestions from each person that they consult. Take advantage of the opportunity to get free or low cost opinions from brain tumor specialists at major medical centers.

Be an assertive medical consumer and don't hesitate to ask questions. Your interest in learning more about any diagnosis, possible treatments, and related topics will not threaten a good doctor, nurse, or other health care provider. Encourage a family member or close friend to accompany you to medical appointments. This allows another person to discuss any information with you after the appointment is over.

Don't be afraid to ask for help and support. Coping with a brain tumor can be a very challenging experience in many ways. This may involve dealing with physical symptoms, emotional stress, financial concerns, changes in family dynamics, and altered spiritual needs. Most friends and family members will want to be supportive of your needs. They will appreciate your letting them know how to be helpful. Specific requests for help (i.e., Please bring dinner for us on Tuesday; Can you drive me to the doctor's office?) are especially

effective. This includes asking for hugs when you need them!

At any time of stress, the worst thing to do is to stop taking care of yourself. Coping with any type of brain tumor diagnosis is something most people never imagine having to do. Making choices about treatments that can have serious complications, and adjusting to a lifelong health concern requires time and energy. For most people, life after a meningioma diagnosis will be different, but it may also be filled with some unexpected benefits. Many brain tumor survivors report an increased awareness of the blessings in their daily lives, and a new sense of appreciation for their survival.

This information is intended to help you learn about your meningioma diagnosis and some treatment options, plus how to care for yourself throughout the experience. Please share this booklet with your family and friends to help them have a better understanding of your concerns.

### **About the authors**

Nancy Conn-Levin, M. A. (health educator) and Lorraine Rubino-Levy, R.N., B.S.N. (registered nurse) are meningioma survivors who provide support and information to others affected by these tumors.

Peter McL. Black, M. D., Ph. D., Medical Advisor, is Neurosurgeon-in-Chief, Brigham & Women's Hospital and Children's Hospital, Boston, MA, Chief of Neurosurgical Oncology, Dana Farber Cancer Institute, Boston, MA, and Franc D. Ingraham Professor of Neurosurgery, Harvard Medical School.

*For more information about brain tumors, contact these charitable organizations:*

#### **American Brain Tumor Association**

2720 River Road  
Des Plaines, IL 60018

Toll free: 800-886-2282  
Voice: 847- 827-9910  
Fax: 847-827-9918  
<http://www.abta.org>

#### **Brain Tumor Foundation of Canada**

620 Colborne Street, Suite 301  
London, ON N6B 3R9  
Canada

Voice: 519-642-7725  
Fax: 519- 642-7192  
<http://www.btfc.org>

#### **The Brain Tumor Society**

124 Watertown Street, Suite 3-H  
Watertown, MA 02472

Toll free: 800-770-8287  
Voice: 617- 924-9997  
Fax: 617-924-9998  
<http://www.tbts.org>

#### **Central Brain Tumor Registry of the U.S.**

3333 West 47th Street  
Chicago, IL 60632

Voice: 630-655-4786  
Fax: 630- 655-1756  
<http://www.cbtrus.org>

### **The Healing Exchange BRAIN TRUST**

T.H.E. BRAIN TRUST  
186 Hampshire Street  
Cambridge, MA 02139-1320

Toll free: 877-252-8480  
Voice: 617- 876-2002  
Fax: 617- 876-2332  
<http://www.braintrust.org/meningioma>

### **National Brain Tumor Foundation**

414 Thirteenth Street, Suite 700  
Oakland, CA 94612-2603

Toll free: 800-934-2873  
Voice: 510-839-9777  
Fax: 510- 839-9779  
<http://www.braintumor.org>

### *Disclaimer*

*This booklet contains basic information about meningiomas and conventional treatment options, plus suggestions for self-care following a brain tumor diagnosis. It is not intended to be a substitute for medical care, or to be used as a way to diagnose or treat any medical problem.*

*If you or someone you know has symptoms that might indicate any illness, please contact a health care provider.*

*The telephone numbers and other contact information for organizations listed above may be subject to change.*

### Acknowledgments

Funding for the development and distribution of this booklet and other educational materials has been contributed by The Brain Science Foundation. Technical assistance was provided by Elizabeth Noll, Director of Neurosurgical Research Affairs, Brigham & Women's Hospital and Children's Hospital, Boston, MA.

Copyright © 2002 by Nancy Conn-Levin, M.A. and Lorraine Rubino-Levy, R.N., B.S.N.  
All rights reserved.

The Meningioma Project  
Boston Neurosurgical Foundation  
300 Longwood Avenue  
Boston, MA 02115  
<http://www.boston-neurosurg.org>

### **Online Support and Information**

The Meningioma List is an online group provided by The Healing Exchange BRAIN TRUST, a charitable organization that helps people affected by brain tumors and related conditions. Hundreds of meningioma survivors and their family members exchange email messages through this group, sharing support and information with each other. There is no charge to subscribe and members can participate as much or as little as they choose. For more information about The Meningioma List or to subscribe, please send your name and the email address at which you would like to receive messages to:

[nconnlevin@braintrust.org](mailto:nconnlevin@braintrust.org)