

PREPARING FOR NEUROSURGERY

You recently learned that you are going to have neurosurgery for a brain tumor or similar disorder. There are many questions filling your mind. What happens during brain surgery? How can you help yourself be ready for this type of procedure? What kinds of things can you do to promote your recovery? How can you talk about this surgery with family members, friends and your employer? Will your life return to normal after your treatment has been completed?

As you begin to think about these issues, please stop for a moment and take a deep breath. Even though this is a frightening topic for most people, it is important to remember that experienced neurosurgeons perform hundreds of brain surgeries every year. Many people are able to return to productive lives after surgery for brain tumors, intracranial vascular abnormalities (tangled blood vessels within the brain) and similar conditions that can be treated through neurosurgery.

The text of this booklet is divided into chronological stages that reflect the sequence of events associated with preparing for your surgery. In some cases, emergency neurosurgery is performed very soon after a brain tumor or similar disorder is diagnosed. However if your neurosurgery is not an emergency, you will have additional time to consider many of the suggestions included in this booklet. Many people have weeks or even months between the time of their diagnosis and the date when their neurosurgery is scheduled. This interval may be associated with getting a second opinion, the need for additional testing, making arrangements for surgery or other factors related to determining the best treatment for your condition. Regardless of whether your neurosurgery is an emergency or if you have a chance to make detailed plans ahead of time, there are practical suggestions included in this guide that can help promote your recovery.

Two to Four Weeks ahead of your surgery date:

Within this time period, you may find it helpful to think about some of the effects that will be associated with your surgery and anticipated recuperation period. If you can prepare ahead of time and plan some practical coping ideas, you will be able to focus on the healing process after surgery without being as concerned about daily responsibilities. What kinds of things could you do in advance at home to make things easier when you return from the hospital? Consider what

type of plans might have to be made to make things more comfortable for yourself after surgery. If possible, cook and freeze some meals ahead of time, or ask friends and family members to help provide healthy nutrition during your recovery period. If you are feeling well now, take advantage of this opportunity to catch up with laundry and other household chores so the amount of work needed when you return home will be minimized. Think about purchasing gifts or cards for birthdays or other upcoming events that will occur while you are recuperating from surgery. Make a list of movies to rent or books on tape that can be borrowed from the library. If you have young children or disabled family members who depend on your care, be sure to make alternate arrangements for their well being during your hospitalization and recovery. Reaching out to friends and family members is especially important at this time. If your requests for help are specific (i.e., Can you drive me to the hospital on Thursday morning?), you will be more likely to get the assistance you need.

In addition to making practical plans for household and family responsibilities, it's also a good idea to review financial and insurance information. Preparing advance directives ahead of time brings many people peace of mind before having any type of surgery. These documents include a living will, a legal document specifying which treatments you would like to have (or not have) at any time in the future when you might be unable to make that type of decision. Another advance directive is a health care proxy, which is sometimes called a durable power of attorney for health care. This document allows you to designate a person who will make medical decisions for you in the event that you are unable to do so personally. If you do not specify a family member, friend or other individual to act as your personal health care agent or medical power of attorney, it is possible that some procedures might occur that are not according to your wishes. By making your feelings known about topics such as resuscitation, use of ventilators and nutritional support, or other similar treatments, you can be assured that your personal wishes will be respected in the event you are unable to communicate. Forms for living wills and other advance directives can be obtained at most hospitals.

This is also a convenient time to review your medical insurance, to ensure that all pre-approvals for your surgery have been processed. If you have life insurance or disability insurance policies, you may want to review these as well. Taking advantage of the opportunity to pay bills and arrange for banking needs that may occur after your hospitalization will make things go more smoothly then. If you are feeling well enough to attend to financial concerns like these, it will help you focus on your recovery during the healing process.

If you are employed, it is important to make arrangements for short term and long term job responsibilities that might be affected by your absence. Examples include identifying tasks that could be done by a substitute worker, reviewing ongoing projects with your supervisor, and making plans for a reduced schedule when you are well enough to return to work. Some people find that choosing to return to work with a limited schedule makes that transition proceed more smoothly.

It is important to remember that everyone's situation is unique and there is no way to anticipate ahead of time how you will be affected by this surgery. Making choices about any aspects of this experience which you can control will help you adjust to the uncertainty that accompanies preparing for surgery.

One Week ahead of your surgery date:

Many people feel anxious or concerned about neurosurgery as the time for their procedure gets closer. It can be helpful to make a list of your questions and concerns so that you can discuss them with your surgeon and other health care providers. If your surgery will take place in a city away from where you live, please be sure that your primary care physician is kept informed about your progress by your neurosurgical team. This will help promote continuity of postoperative care after you return home.

In the week prior to your surgery, your physicians may schedule an appointment for preoperative testing. In most cases, the process involves a visit to the hospital where blood tests, an electrocardiogram (EKG), chest x-ray and other outpatient tests can be performed. You may also receive a physical examination, either from your personal physician or one of the staff physicians at the hospital where your surgery will take place. Often, part of your preoperative testing will include an interview with someone from the anesthesiology staff. Although he or she may not be the anesthesiologist who will assist during your surgery, you can still discuss your medical history, the type of medications that will be used, possible effects you may notice, and any other concerns. It is important to answer any questions honestly and completely, particularly concerning your exposure to medications (whether prescribed or not), alcohol or any other substances which may affect your reaction to anesthesia. Be sure to discuss any herbal supplements or nonprescription medicines that you may have used recently.

Before you enter the hospital, remember to ask your surgeon or anesthesiologist which medications you may take on the day of your surgery and if there are any special instructions about doing this.

During your preoperative appointments, it is important to ask questions and make notes about the answers. Sometimes a family member or close friend can accompany you to these visits so they can help you recall what was discussed.

Within a week of your surgery is a convenient time to prepare a small bag to take to the hospital. Here are some suggestions for items to bring, as well as items that should be left at home.

When you enter the hospital, please do NOT bring:

- Jewelry or other valuables
- Non-prescription medicines or supplements (unless suggested by your surgeon)
- Originals of any document that has not been copied
- Large amounts of money
- Anything that cannot be replaced or duplicated

What to bring to the hospital:

- Any insurance documents that may be needed, including your membership card, authorization letter or codes, signed claim form (if required), or any similar forms. Ask your insurance representative what might be required if you are unsure which documents to bring. Be sure to make photocopies of any papers that you are taking to the hospital and leave those copies at home.
- Prescription medications in original labeled containers from the pharmacy. It is important to be certain that your surgeon and other members of your health care team are aware of all medications that you are taking.
- Eyeglasses, hearing aids, dentures or other items you will need after your surgery.
- Comfortable lounging clothes, a lightweight robe and non-skid slippers. Many people find it reassuring to wear their own clothing in the hospital as soon as it's practical to do so.

Because your head will be bandaged, items that button down the front are easier to put on and remove. Choose clothing with wide sleeves to allow intravenous (I.V.) tubes and bags to be passed through comfortably. Items made from soft, washable material will be especially practical. Include at least one pair of socks, since it may be cool in your hospital room.

- Personal toiletries (soap, toothbrush and toothpaste, deodorant, body lotion, etc.). Although many hospitals supply these items, you may prefer to bring travel size containers of your usual selections. Some people find it comforting to apply a pleasantly scented lotion or body spray.
- A small spiral notebook, pen and pencil, which can be used for you or your family to write comments or questions regarding your care. This notebook is also a convenient place to record the names of any especially helpful staff members (or any hospital personnel who were not helpful during your stay). Another way this notebook can be utilized is to write down small milestones in your healing process (i.e., took bandages off, sat up in a chair for 45 minutes, able to walk in the hallway for 15 minutes, etc.). A visible record of your progress will be reassuring as each day passes and your strength returns.
- A list of telephone numbers for people that you may want to call. If you are able to make outgoing phone calls, it can be encouraging to have short conversations with family and close friends while you are in the hospital. Be careful about tiring yourself, and “listen to your body” when it’s time to rest. If you are unable to make calls, perhaps a family member or friend can contact other people to let them know how you are doing.
- An inexpensive watch can be very comforting, particularly if you are in a room without a clock. A watch can help you be more aware of when medication is due to be administered, when visiting hours are scheduled, times when nursing shifts change, and other useful information.
- A pillowcase from home can be a soft, familiar addition to your bedding, helping you feel more relaxed while hospitalized.

- Pictures of friends, family members and any other photos (or postcards) that you enjoy can be placed in an inexpensive album. Being able to look at the faces of people you care about – or allowing yourself to think about favorite places or familiar scenes in your album – can help you be more relaxed, especially if you are feeling lonely. Remember to bring copies of photos and leave any originals safely at home. If you have a roommate, looking at photos together can be a nice way to share thoughts and experiences.
- If you are able to take a shower while in the hospital, a shower cap will be very useful to cover your bandages. That first shower after your surgery (whether it's in the hospital or at home) will be especially welcome! If you are feeling weak or unsteady, be sure to let the nursing staff know about this before walking unassisted anywhere in your hospital room.
- A magazine or paperback book for “light reading” if you are unable to sleep, or interested in some relaxing material.
- You may want to have a small amount of money available (less than \$10) for a newspaper or other inexpensive item from the gift shop. Some hospitals have volunteers who visit patient rooms and bring items like these for sale. In addition, inquire about rental policies for telephone and television charges prior to your admission. In some hospitals, these fees are paid by cash or check on a daily basis. Other hospitals include these services as part of the room charges.

Although the week prior to your surgery will be very busy, remember to allow time for some relaxing plans with your family or close friends. Doing something enjoyable will help you stay calm during this period of uncertainty and anticipation.

Your surgery day:

The day has finally arrived and now it's time for your neurosurgery. Whether you spent the night before your operation in the hospital, or awoke very early to arrive at the admitting office in the wee hours of the morning, this will be a long day for everyone involved. You will have received orders from your medical team regarding what to eat or drink. Most often, preoperative patients are advised to have nothing by mouth (NPO) after midnight of the night preceding your surgery. You will be able to brush your teeth and rinse your mouth with water without drinking.

Remember to ask your physicians for any instructions about taking your regular medications. Sometimes these medications can be swallowed with a small sip of water. Certain medications may be discontinued prior to your surgery as well.

Before going to the preoperative area, you will change out of your regular clothes and put on a hospital gown. Be sure that all of your jewelry has been removed. If you brought jewelry or other valuables to the hospital, please leave these things with a family member or close friend. Do not wear contact lenses, make-up or nail polish, and remove any loose dentures or other items that could be dislodged during surgery.

While you are waiting in the preoperative area, an intravenous line (IV) may be started. In some hospitals, the IV is not connected until you reach the operating room. Other instruments that measure levels of blood oxygen, blood pressure, and heart rate will be added there. After you have been sedated (asleep), a catheter may be placed into your bladder to drain urine. A tube may be placed in your windpipe to help keep your airway open and ensure adequate oxygen flow while anesthesia medications are being used. If portions of your head are going to be shaved, this is most often done after you are sedated.

Many factors can affect the duration of your neurosurgery, and although your surgeon may be able to estimate the time needed for your operation, sometimes delays occur. Each hospital has its own procedures for notifying patients' family members about the progress of an operation and when it is finished. In some cases, a nurse or other staff member may talk with your relatives in the family waiting area while your surgery is still in progress. Knowing ahead of time how they will be contacted will help family members be calmer while they are waiting for your surgery to be completed.

After your neurosurgery is done, you will be taken to a post anesthesia area. This area can be called a PACU (post anesthesia care unit), recovery area, or it may have another name. Specially trained nurses and staff members will be with you as you awaken, and they will carefully observe your vital signs and other indications of your health. When your pulse, blood pressure, temperature and other signs are stable, you will be moved either to a neurosurgical intensive care unit or another area of the hospital where you can be closely watched for at least twenty-four hours. Ask your neurosurgeon to discuss the special arrangements for postoperative care at the hospital where your surgery is scheduled. Some people are alarmed

to find themselves in an intensive care unit after brain surgery, especially if this has not been discussed with them ahead of time. However after this type of surgery, even patients without surgical complications are frequently observed in some type of specialized area before being moved to a regular hospital room.

One to Three days after your surgery:

During the first few days after your neurosurgery, there will be many changes. When you first return to your hospital room, you may still have an intravenous line, urinary catheter and/or other equipment attached. Some physicians prefer to have their patients use inflatable devices to promote blood circulation in the lower legs and minimize the potential for blood clots. Your surgeon may also utilize elastic stockings for the same purpose. Within a day or two, this equipment may be gradually discontinued, depending on the progress of your recovery. You may be allowed out of bed as soon as the day after surgery, at which time you may be allowed to sit in a chair. Even sitting up may require more effort than you expect. Don't be afraid to ask for assistance if you cannot do these tasks independently. Most of all, remember to "listen to your body" and take each step of the healing process at your own pace. It's important to realize that healing is not a competition and each person reacts differently to the stress of any kind of surgery.

Your physicians will prescribe some kind of pain medication, as well as other medications such as antibiotics (to minimize the chance of infection), steroids (to avoid swelling within the skull), anticonvulsive medications (to avoid seizures) and any other medication that may be indicated. Some of these medications have side effects, so be sure to tell your medical team if you notice any unusual symptoms.

As you begin to regain your strength, you will be allowed to move around and walk in the hallway. Some physicians encourage their patients to be out of bed as much as possible. You and your medical team will discover together what activity level will be best for your individual recovery. If you have concerns or questions, write them in the small notebook that you brought to the hospital so you can remember to discuss these topics with your physicians when they visit your room. Ask your surgeon for guidelines about wound care, as well as when the staples or stitches will be removed from your incision.

During your hospital stay, a member of the social work staff may come to discuss plans for continuing your recuperation at home. This meeting will include questions such as whether or not there are stairs to climb, if you will be home alone at any time, if you need help with activities of daily living, and similar issues. Depending on your condition after surgery, you may also meet with a physical therapist, speech therapist or occupational therapist. Each of these members of the medical team specializes in rehabilitation and their services can be very helpful during your postoperative recovery. In some cases, you may begin receiving one or more of these therapies in the hospital and then continue your therapy at home or as an outpatient at the hospital. Ask your neurosurgeon if you have concerns about rehabilitation services after your surgery.

Leaving the hospital

Some people are able to leave the hospital within a few days after conventional neurosurgery, while others may be hospitalized longer. In most cases, when you leave the hospital after neurosurgery, you will be able to continue your recuperation at home. Occasionally, if more intensive therapies are needed or if you need additional care that cannot be provided by family members, you may go to a rehabilitation center before returning home. The most important thing to remember is to focus on your continuing progress while healing, whether you are recovering at home or in a rehabilitation center.

Once you return home, let yourself adjust to any physical or emotional changes and take one step at a time. It's easy to become overwhelmed by expecting yourself to return to a full schedule of responsibilities too soon or even by something as simple as becoming tired easily. Many people find that limiting both the number of visitors and the length of their visits helps allow an opportunity for naps and quiet rest, both of which are helpful to the healing process. Slowly adding new activities to your daily routine and gradually returning to a more active schedule works best for many people. Be patient with yourself, and most of all, allow yourself to take the time that you need to completely heal from this experience.

This information is intended to help you learn about preparing for neurosurgery, plus how to care for yourself throughout the different stages of that 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 brain tumor survivors who provide support and information to others affected by these tumors. Both of them have received neurosurgical treatment.

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<http://www.brainsciencefoundation.org>

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<http://www.boston-neurosurg.org>

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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

650 Waterloo Street, Suite 100
London, ON N6B 2R4
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: 773-579-0021
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>

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 information for people who are scheduled to have conventional neurosurgery for a brain tumor, intracranial vascular disorder, or any similar condition. The information included here 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.

Online Support and Information

Free online groups are provided by The Healing Exchange BRAIN TRUST, a charitable organization that helps people affected by brain tumors and related conditions. More than two thousand brain tumor survivors, family members and others who are interested in this topic exchange email messages, sharing support and information with each other. To learn about the

BRAINTMR list, The Meningioma List, TOPS (teens of parent survivors) or other online groups, contact:

info@braintrust.org

Additional information about most of these groups is also available at this web site:

<http://www.braintrust.org/services/support/>