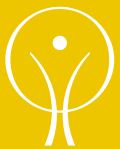


Sharing knowledge. Sharing hope.

Living with a Brain Tumor

A GUIDE FOR BRAIN TUMOR PATIENTS



American Brain Tumor Association

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A Word About ABTA

Founded in 1973, the not-for-profit **American Brain Tumor Association** has a proud history of funding research, providing patient services, and educating people about brain tumors. Our mission is to eliminate brain tumors through research and meet the needs of brain tumor patients and their families.

We gratefully acknowledge Deneen Potter Hesser RN, BS, OCN for the writing of this pamphlet and Gary Hill PsyD, LMFT, CSADC, Wilmette, Illinois for technical review. Dr. Hill is the National Director of United Behavioral Health. He is also a clinical psychologist with a four year old son who has had a brain tumor. We are grateful to Dr. Hill for having brought his insights and psychological expertise to this booklet.

We also thank the patients and families participating in brain tumor support groups across the country who shared “For the Sake of Each Other.”

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Dedication



This booklet is dedicated with love to Bette M. Kapson, whose life was a song of joy and an inspiration to us all. We appreciate her family's generous support of the American Brain Tumor Association.

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Introduction

“You have a brain tumor...”

Perhaps you expected the diagnosis. The headaches were just a little too often, a little different from most headaches. You forgot a few things...and then a few more things. There was that vague feeling that something just wasn't right.

Or, maybe you didn't have the slightest idea. Everything was fine until the seizure. One day your life was routine — the next day you were trying to make sense of the doctor's words: "...brain tumor."

It may help to know a few basic facts about brain tumors:

- A brain tumor is an abnormal mass of cells growing in, or on, the brain.
- Each year more than 186,000 Americans are told they have a brain tumor.
- There are different types of brain tumors. Some are cancer, many are not.
- Treatment depends on where the tumor is located, the type of tumor, your age, and your general health.
- Each year, researchers learn more about brain tumors and the best ways to treat them.

In the pages that follow, we share suggestions from others who have been diagnosed with a brain tumor. Some of the ideas may work for you, or you may think of new ways to face your illness. As you begin this new path in life, please know that you are not alone.





Learn to Ask Questions

Whether you just heard the diagnosis, are beginning treatment, are a long-term survivor or somewhere in-between, you probably have questions. For many, the first step in coming to grips with the diagnosis of a brain tumor is to begin to ask questions.

Give yourself permission to verbalize your concerns. Ask questions of your health care team! Your doctors and nurses are familiar with your individual situation, and can respond with personalized answers which cannot — and often should not — be provided by outside sources.

Following diagnosis, your questions may focus on the disease and its treatment. Later, you may have questions regarding your daily activities, nutrition, rehabilitation, or medications. At any point in your care, however, if the topic causes you concern it deserves to be addressed.

How do you go about remembering all your questions? Purchase a small notebook. Begin to keep a list of questions. Put the topics that are most important to you at the top of your list. Bring the notebook when you visit your doctor, and write down the answers to your questions (or ask the doctor if you may tape record the answers.) It can also help to take someone along to your visits. A family member or friend can give your moral support, and they can help you remember what is told to you.

During your visit, ask for written information on the topics of concern. There are booklets, pamphlets, fact sheets, medication cards, videos, and various other educational materials that will help you understand your disease. Keep a folder with your notebook, and place your resources into it as you collect them. Record telephone numbers or organization names in the notebook along with dates you made contact, and the name of the person to whom you spoke.

Each time you leave your doctor's office, be sure you understand the instructions given to you. What do you do next? When is your next appointment? If you are scheduled for a scan, do you know when and where to go? Ask the nurse to write important dates and instructions in your notebook. Tapes a small calendar to your folder, and you've created your own personal resource center.

What Happens Next?

During your first visit, your doctor probably ordered additional tests. Scans of the brain, such as MRI or CT scans, are done for anyone suspected of having a brain tumor. Additional tests depend on the type of tumor suspected.

If possible, bring someone with you to your scan appointment. Let them drive or arrange for transportation. Ask them to carry insurance forms or receipts for you; while moving from area to area in the hospital it is easy to misplace papers you will later need. A family member or friend can give moral support and can listen for things you want to remember later.

Once the tests are completed, it will take a few days before you learn the results. If you are going to your doctor, take your notebook with you. If the doctor is going to call you, keep your notebook near the phone.

Many people do not remember much of their conversation when the doctor first tells them they have a serious illness. Try to come away with answers to a few questions. With these questions answered, you begin to participate in your care.

- Where is the tumor located?
- What do we do next?
- Until we know more, should I continue my daily routine? Driving a car? Exercising?

When Will We Know More?

After looking at your scans, your doctor will recommend the next step. There are different types of brain tumors, and different ways of treating those tumors.

The following are questions you might ask your doctor about your treatment:

- Can the tumor be operated on?
- What are the risks in removing this tumor?
- Are there treatments other than surgery?
- If the tumor cannot be operated on, what treatment is recommended?
- Can treatment wait? How long?
What might happen without treatment?

If your doctor suggests that you enter the hospital, write down the name of the hospital. Many doctors are on staff at more than one facility. In your notebook, write down the day and time you are to go to the hospital. Find out which department to go to when you get there. Ask your doctor's secretary for any papers that you should bring to the hospital. Also, if your insurance company requires advance notification, make the appropriate arrangements.

Second Opinions

Not everyone wants, or needs, a second opinion. But, if speaking to another doctor would make you feel more comfortable, feel free to do so. Second opinions are considered standard medical practice. A consultation can help you further understand your disease and your treatment options. Or, perhaps your insurance company requires a second opinion before they cover a surgical procedure.

Most important, be sure it is safe to delay your treatment long enough to obtain a second opinion.

If you decide to seek another opinion there are several ways to do so. Many doctors are willing to suggest a specialist, and may even make the appointment for you. Most hospitals offer physician referral services — they can help you find members of their medical staff with expertise in treating brain tumors. If your insurance requires you to stay within a network of providers, contact your insurance company to learn which network doctors have the experience you need. If you choose to be treated “out of network,” what are your responsibilities? Or, you may already know of another doctor you would like to consult.

Call the doctor’s office and ask their procedure for obtaining a second opinion. Ask for a list of the medical records that will be needed and the best way to have them delivered. In the next chapter, we explain how to obtain those medical records.



Obtaining Your Medical Records

To obtain a second opinion, you'll need your medical records. The laws for doing so vary by state. Many states allow medical records to be released directly to the patient. Other states require that medical records be sent directly to the consulting physician.

The quickest way to obtain those records is from your doctor's office. Copies of pathology reports, operative reports, and consultation reports as well as records of office visits are generally kept in the doctor's office. They also keep the written reports from scans, but may not store the actual scans. There may be a charge for providing a copy of your records.

If your doctor does not have your scans, call the Radiology Department where the scan was done. Scans, x-rays, and myelograms can be copied. Never send an original through the mail! Since there is a sizeable fee to copy scans, get a list of the exact scans needed.

Pathology slides are usually stored in the Pathology Department of the hospital where the surgery was performed. Some slides can be copied. To obtain your slides, call the hospital and ask for the Pathology Department. Again, there may be a charge to duplicate the pathology slides.

Written records of hospitalizations are kept in the Medical Records Department of the hospital for several years. Afterward, they may be copied into electronic files or microfilm and archived. If you need these records, call the Medical Records Department and ask for assistance. They will need to know:

- the name you were hospitalized under
- your birth date
- your social security number
- the approximate date of your hospitalization
- the list of the reports you want

Some doctors store reports and scans in electronic files. The files can be transferred electronically, copied onto a CD, or printed as traditional records. The consulting doctor can tell you which version s/he prefers.

Some hospitals require a written authorization from the patient to release the records. Again, there may be a charge for copying the records.

Find out if the records will be released to you or sent to the consulting doctor. If you are to pick up the records, where and when will they be available? If the records are to be forwarded, give them the consulting doctor's name, address, and telephone. Find out when the records will be sent and by what method. If you are not able to pick up the records personally, consider using a company that has a "tracking system" for packages.

Call the consulting doctor's office and tell them when your records will arrive. Ask if the doctor will consult with you over the telephone, or should you make an appointment? Be sure to allow enough time for the doctor to review your records prior to your visit.

When you pick up your medical records, you may (naturally!) be curious about what they say. Many people are tempted to read their medical reports before giving them to the doctor. Realize that they are written in technical medical terms. Understandably, you may be worried if you do not understand the reports. Don't invent your own meanings! If you are concerned about anything in your medical records, write it down in your notebook. Ask your doctor or nurse to explain what you do not understand.



Reacting to the Diagnosis

When things slow down a bit, the enormity of the situation becomes real. Naturally, you may have very negative feelings about this disease and the changes it is causing in your life. Living with your brain tumor means learning to re-direct those feelings into productive responses. And, don't be surprised if you notice these reactions from your family or friends. That, too, is normal.

When you hear the diagnosis, you and your loved ones will probably experience many of the same emotional reactions: denial, anger, resentment, depression, resignation, and acceptance. At first, many people go through a state of temporary denial. You may feel traumatized and depressed. While you cannot forget the news you just received, it is common to become numb and hide or deny your initial feelings. The denial can last a few days to a few weeks, or even a few months. This initial stage is a very common reaction.

As time passes, denial often evolves into a feeling of anger. The thought "Why me?" is common and you may feel angry for a while. Life may feel very unfair. Some people develop a sense of resignation about living with their brain tumor and the physical or emotional changes that may come with the diagnosis. You may feel resentment because you have this disease and other people around you do not. For some people, this resentment may turn into depression. This is usually temporary. However, if the depression deepens and affects your relationships or your ability to function on a day-to-day basis, then it is important to seek professional help.

Finally, a sense of acceptance sets in as people realize the brain tumor is a reality. You slowly come to grips with the diagnosis, and hopefully, begin to plan your life in a constructive and meaningful manner. This is the time to reassess your values, think about how you want to live your life, and look at your career choices. Find ways to maintain positive, close, and loving relationships with your family and the significant others in your life.

It may sound strange, but some feel that their personal lives change for the better after a major diagnosis. It does make people re-evaluate their lives, often in a much more positive direction. If you use every minute of the day in a valuable and meaningful manner, there is much to hope for and look forward to.

Remember, as time passes, there are no magical patterns for dealing with your emotions. One day you may feel better, and the next day feel upset again. Not everyone shows their emotions, nor does everyone experience the same feelings.

Telling Family and Friends

Spouses or significant others may feel a sense of loss as they assume the role of caregiver, or seem bewildered as they take on responsibilities previously handled by the other person. Every marriage survives by a set of “unwritten” rules that partners live by in their every day lives. During the years of marriage, spouses take on certain roles, such as caretaker or provider within the family. They work out the labor issues for the household, and establish guidelines for their intimate relationship and personal friendships. The diagnosis of a brain tumor can change those rules. Neither spouse may know exactly how to react to each other, especially if caretaker and provider roles have changed. Some couples find they start feeling uncomfortable with each other, not as close, and sense they are losing the intimacy of their relationship. You may begin arguing or disagreeing with each other. At this moment, there is a temptation to pull further apart. Don’t let this happen!

Just like the news of a major medical diagnosis is disruptive to a person’s personal and family life, it can equally be an opportunity for renewal, hope, and a new sense of relationship. Talk with your spouse about the changes in your lives. Acknowledge the need for flexibility now, and find some rules that you can both agree upon and live by. If you have a difficult time doing this seek the advice of a trusted friend, a religious advisor, or a professional counselor. A professional social worker or psychologist can also help in this process. Counseling can help you adjust your relationship, and guide you through adjusting to the medical diagnosis.

Think about the ways you’ve handled previous crises in your life. Are you comfortable sharing your concerns? If so, to whom do you usually turn for support? Do you prefer sharing with a close family member or a close friend, or do you turn to those you may not know well, such as a counselor or a support group? Do you find comfort in religion? Think about the methods you normally use to deal with problems. Even a long shower, relaxing music, or meditation techniques can be of help now, too.

As you move further into the brain tumor experience, you’ll begin to find resources you didn’t know existed. There are people willing to help — you are not alone. Reach out, learn as much as you can, and become an active participant in your health care. Begin by eating healthful meals, even when you’re not very hungry. Moderate exercise (if approved by your doctor) can help fight fatigue, depression, and improve your sleep. If you wish, allow yourself to feel unhappy — but realize there is help available to those whose sadness is consuming or excessive.

Life is about to change. For many, it helps to share the situation with others. Your family and friends can offer support, or help you think through your options.

Telling your family that you have a brain tumor isn’t easy. If you are uncomfortable sharing your news, consider a family conference with the doctor. When you speak to your family, remember that written information about brain tumors is available. That information can help you and your family understand your disease and the treatment options. Just like you, your family needs time to understand and accept the diagnosis. A family that understands your illness and respects your decisions can be tremendous support.

Social workers can help you talk to your family and help your family live more comfortably with the diagnosis. Most hospitals have social work departments. You can also find social workers and counselors at community centers, local social service agencies, local health departments, or schools.

If friends offer help, now isn’t the time to be shy! Groceries, laundry, driving car pool, dinner on the day of your doctor’s visit, weeding the garden — the possibilities are endless. Start a Wish List of things you “wish” you had the time to do. When someone offers help, reach for your list!

Although many people will be supportive, there will be friends who simply find it difficult to deal with your illness. Not knowing what to say, some people may avoid you or avoid conversation with you. There is nothing you can do to change this. With time, you’ll develop a circle of friends with whom you are comfortable.

Changes also may occur within your family system. As a previous chapter of this booklet explained, there are stages of acceptance of the diagnosis. They are: denial, anger, resentment, depression, resignation, and acceptance. Your family may also go through these stages as they react to, and accept, the news of your diagnosis. Your spouse may begin to worry more, or wonder how things will be taken care of. Children may begin to worry about the family member who has the tumor.

Family conferences can help keep your family strong and close to each other through difficult times. Directly, frankly, and honestly discuss

what the diagnosis means. Your family may have questions, or they may be worried about you. Address their concerns. If you are feeling fatigued or need someone to help out with a task you usually do, share this with your family. It is important for them to feel a sense of belonging, and for them to be involved in the sharing of responsibility. If you or your family are having difficulty adjusting to the diagnosis, family therapy may be helpful. A trained and professional therapist, especially one specializing in treatment of chronic illness or grief reactions, may be just the support your family needs to guide them through this crisis.

Talking to Children

If you are a parent with young children, you will need to address your children's concerns. Sensing something unusual, children may use their imagination if they are not told the truth. Their invented explanations may be worse than the truth.

It is important to be honest with children. Talk with them, giving them information in words they understand. With very young children, it is often helpful to speak in concrete terms. Describe to them, very simply, "what a brain tumor is." Most young children can understand "It's a lump in the brain that doesn't belong there." Simple drawings may help — and don't worry about being an artist. Tell them what it means to "go to" or "be in" the hospital. Use their questions as a guide to the information they need. Answer what is asked of you. Reply honestly and simply in words appropriate for their age. Remember that very young children have little experience with disease — their first questions may focus on the practical. They may want to know who will prepare dinner or put them to bed.

Give your child a chance to accept this news. It is also very important for parents to try to ensure that routines within the family change as little as possible for the children. Children find the "daily rules of family life" very important. They feel safe and thrive under day-to-day conditions that are easy to predict, are consistent, and make them feel safe. Therefore, it is important that you and your spouse agree not only in what you tell the children, but how to keep their lives as normal as possible. If schedule

changes become necessary, try to make the new schedule repeatable so it becomes a "routine." The sameness will be a comfort to your children.

Older children may link the diagnosis to stories of illness they've heard from friends, or personal experience with grandparents or neighbors. Offer your older child the chance to ask questions or share their concerns. "Is there anything you'd like to ask me?" can be difficult to say, but can open the door to clarifying misinformation as well as providing reassurance.

Some children, especially pre-teens and teenagers, may begin to act out. They may get in trouble, begin to have problems in school, or begin to do things they normally would not do. This is usually a sign that the child is having trouble coming to grips with what is happening within the family. It may be time for more direct action. A serious discussion with the child is very important at this stage. Involve them in the day-to-day family activities. If the behavior persists, they may become depressed — this is a time to seek professional help, such as family therapy. Many families find that after the initial diagnosis children learn to adjust and adapt to the news, especially if the parents are consistent and in agreement regarding family matters.

Most important, remember that children of all ages need to be reassured of your love for them. They need to know that they will be cared for during your illness.

Neighbors and relatives can help keep your children's routines as normal as possible. Plan ahead for special events. If you won't be able to make the school play or watch softball practice, ask an aunt, uncle, or friend to fill-in for you. Although it won't be the same, your child will know that you remembered.

Our social programs can help with additional sample conversations; support groups for parents, children and siblings; and provide a bibliography of reading materials. Our book and video, *Alex's Journey: The story of a child with a brain tumor*, is available from our office. Please call us at 800-886-2282 if we can be of assistance.



How Do I Tell Them? What Do I Say?

These sample explanations can be adapted for your conversations with your children. Change the phrases to match your situation.

“The doctor wants to do some tests to find out why you are getting sick to your stomach and having headaches...” or “The doctor wants to do some tests to find out why I am having headaches.”

“A neurosurgeon is a doctor who knows a lot about the brain.”

“An MRI scan takes picture of your brain, but it cannot see what you are thinking.”

“A brain tumor is a lump in the brain that doesn’t belong there. The doctor is going to operate and take it out. The operation will help get rid of the headaches.”

“A brain tumor is a collection of abnormal ‘cells’ in the brain which are growing out of control. These cells were originally normal brain cells. For no good reason, they started to divide and make more of themselves. This growing collection of cells is called a ‘tumor.’ As the cells continue to make more of themselves, the tumor gets bigger and bigger, like bread baking. Since there is not a lot of extra room in the brain, the tumor may start to squish areas of the brain, causing them not to work properly.”

“With a tumor in there, the computer center of my brain can’t work the way it is supposed to. That’s why I have headaches and seizures.”

“No one knows for sure what causes a brain tumor. They just happen. But we do know that nothing you did, or thought, or said caused the tumor. Nothing you ever wished made this happen. Nothing your brother or sister or friends said made this happen. We also know that you don’t ‘catch’ brain tumors from other people.”

“Would you like to talk about this? Is there anything you would like to ask?”

Above all, reassure your children they are loved and will be taken care of.

For additional suggestions and explanations children can understand, please visit our children’s web site — ABTA Kids — at www.abta.org/kids/home.htm.

From Patient to Patient:

SUGGESTIONS FOR COPING

We thank members of the Wills Eye Brain Tumor Support Group in Philadelphia, the Brain Tumor Support Network of St. Louis, and others who shared for the sake of each other. Their advice:

- 1** Take advantage of help offered to you, and don't be afraid to **ask for help**.
- 2** **Get a second (or third) opinion** from doctors who specialize in brain tumors. To be an effective advocate for yourself, you'll need information about the options open to you.
- 3** **Ask your doctor** this question: "What questions should I be asking that I don't know I should be asking?"
- 4** Don't be afraid to **talk about your fears** and feelings — you are not alone! People do care, and will help.
- 5** **Always have faith...**and depend on the faith of others. Ask family and friends to pray for you...I believe a person prayed for gets well quicker.
- 6** **Set short term goals** so you can feel good about your progress.
- 7** **Find one thing good** about each day.
- 8** Laughter and humor help. **Smile a lot.**
- 9** **Share your feelings** with your family and friends so they understand what you are dealing with. If you have difficulty verbalizing your feelings, try writing letters to share your thoughts.
- 10** **Find purposeful things to do** — a daily morning walk with a friend; lunch once a week with your grandchild.
- 11** **Keep a journal** — a special place all for yourself.
- 12** Decorate a small box with bits of costume jewelry, brightly colored paint, wonderful pictures from old magazines.
Put your worries in it, and tightly close the lid!
- 13** **Be kind to yourself.** Take a bubble bath, go to a ball game, take a nap on a lazy Sunday afternoon.
- 14** **Set your own limits**, not those expected by others.
- 15** Know that symptoms usually worsen in the darkened evening hours. This is generally when everyone is tired and defenseless, and at their worst. **Arranging for outside support or visitors in the evening may help.**
- 16** **Confide in someone.** It helps to know you are not alone.
- 17** **Start a gratitude diary** — each day write down something for which you are grateful.
- 18** **Find a spiritual leader.** Researchers find that people who attend services regularly have healthier immune systems.
- 19** If you are having a difficult time living with your brain tumor, **reach out for professional help.**
- 20** If you are angry, **do something physical.** Take a long walk, play basketball, pound on a pillow.
- 21** Don't worry about repaying favors — **accept help without feeling guilty.**
- 22** **Read** — about brain tumors, new treatments, and about brain tumor survivors.
- 23** **Set a goal and work toward it.**



Nurturing the Caregiver

When someone we love is ill, we want to do everything we can to help. Sometimes, however, the demands of caregiving combined with the ongoing stress of everyday life can seem like a lot to cope with all at once. We express our appreciation to the Department of Behavioral Medicine at the Chicago Institute for Neurosurgery and Neuroresearch, Chicago, Illinois for providing the following suggestions for coping with caregiver stress.

DELEGATE RESPONSIBILITY

Don't do everything yourself if there are others in your family who can help. Sit down and discuss what each member of the household — including children — can do and develop a schedule of responsibilities. Take into account each person's ability, maturity and availability. Remember that not everyone can, or should, be directly involved in caring for the patient; there will be other tasks which also need attention. Look beyond the immediate relatives for help — even those further away can participate on some level. Finding others to handle family tasks will give you more time to care for your loved one and yourself and, thus, help reduce stress.

LOOK FOR HELP OUTSIDE THE HOME

If there are no other members of your household or relatives close by, look to friends or members of your church or social group. Often, people want to help but are not sure what they can do. Be prepared to respond to their offers. Try to determine the time, money, or energy commitment they are willing to make and give them one or two suggestions that fit their level of commitment. Some people may be available on a one-time basis to run an errand, baby-sit, or help with a particular household chore. Others may be available more regularly or for longer periods of time. Ask for help with grocery shopping, cooking and freezing meals, yard work, household repairs, driving car pool or driving to therapy appointments. Those living further away may be able to help with financial needs, filing insurance claims, or searching for support resources.

If people offer help at a time when you really do not need it, tell them how much you appreciate their offer and their friendship. Suggest they ask again in a few weeks, or ask if you may call on them if your needs change. You can also suggest they help in some less tangible way such as making a visit, saying a prayer, or lending a supportive ear when you need it.

BE ASSERTIVE

Learn to say no. Set limits on your time. Be realistic about what you can and cannot be responsible for right now. Consider asking friends to visit during hours that are convenient for you and your loved one. If you find yourself with visitors who sometimes “wear-out their welcome,” ask if you might use the time during their next visit to run errands.

TAKE TIME FOR YOURSELF

Take time to get away from caregiving for at least a few hours each week or longer, if you can. Home health care agencies and caregiver groups offer respite caregivers — someone to stay with your loved one for a few hours. Use the time to do something for yourself. See a movie, get a haircut, go shopping, walk in the park, attend religious services, or simply take a nap! It can be difficult to leave your loved one even for a few hours, especially if they are very ill, but it may be the most important thing you do for that person and for yourself. Taking this time is not being selfish. Rather, it is critical in order for you to continue caring for your loved one’s physical and emotional needs in a loving and helpful way.

DISCUSS YOUR FEELINGS

You may find it helpful to share your feelings with a supportive listener such as a family member, close friend, clergy member, professional counselor, or members of a support group. Sometimes it helps to let that person know that you don’t expect answers or solutions, just a sympathetic ear. If you are seeking advice, look for someone who will continue to be supportive even if you decide not to take the advice given.

GIVE YOURSELF PERMISSION TO ASK QUESTIONS

The words “brain tumor” can be overwhelming. It’s common for families to make a visit to the doctor, hear terms and phrases they’ve never had in their vocabulary before, then be asked to make a decision. Back at home, there may be a flood of doubts as to what was heard and whether it was understood.

If you have questions about the information your family was given, call your doctor. If you did not understand something that was told to you, or you have additional questions you forgot to ask, call your doctor. Your doctor believes you understand everything that was said unless you speak up. And, having answers to your questions can be a great stress reducer.

TAKE CARE OF YOUR OWN BODY

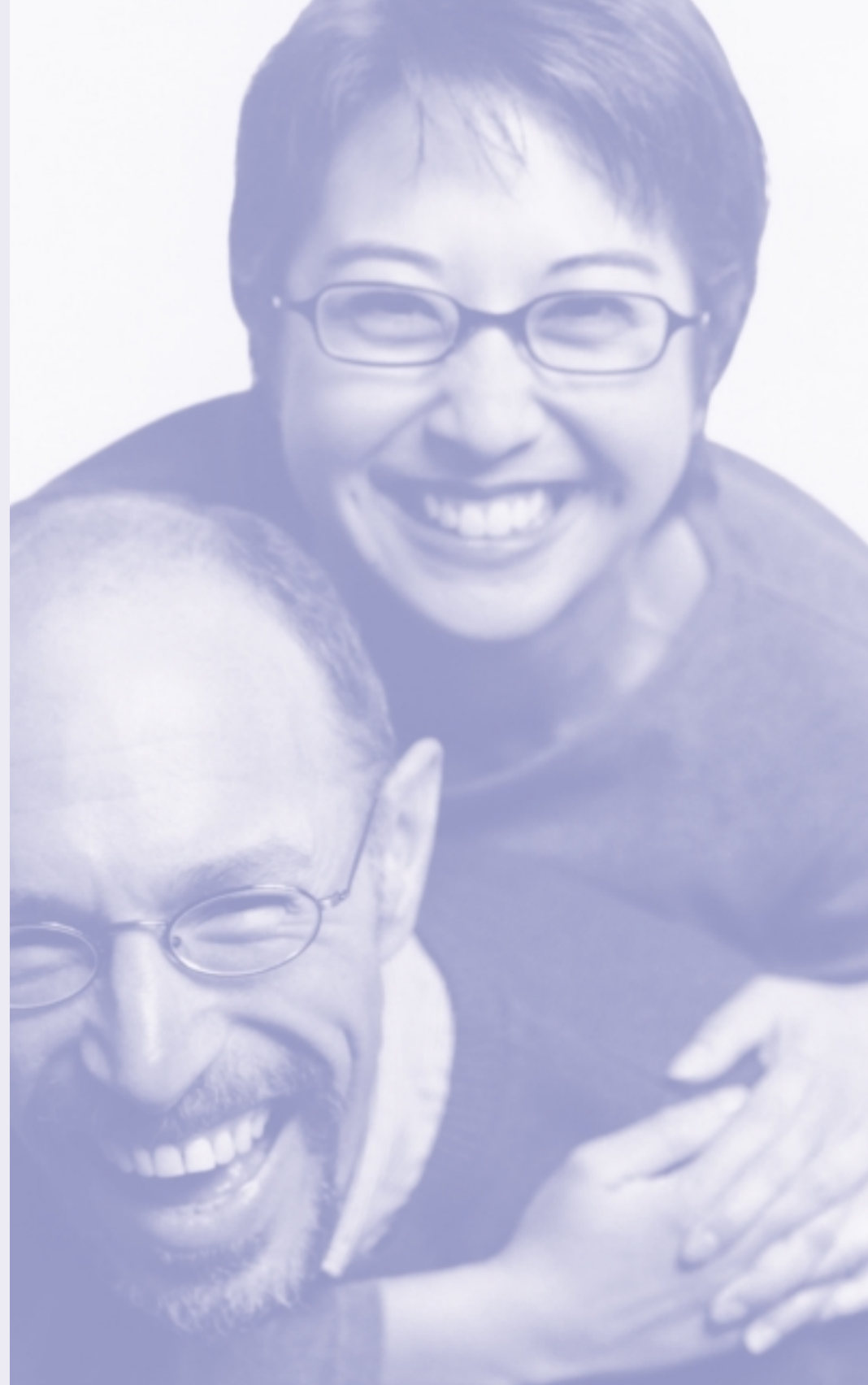
It is not uncommon for caregivers to provide the best care possible for the patient while neglecting their own health. Doing so leaves the caregiver vulnerable to exhaustion and disease. To avoid stress-related illness, pay attention to your own physical needs by making sure you eat a healthy balanced diet, exercise, sleep regularly, and find time to relax. Most important, don’t put off your own medical and dental checkups.

REACH OUT FOR SUPPORT

Caregiver stress can become dangerous to both the caregiver and the patient. There are many services available which can help prevent caregiver “burn out” or provide assistance to those in need. Home healthcare agencies, hospices, respite programs and adult day-care services all offer alternative forms of caregiving. The National Family Caregivers Association, which can be reached at 800-896-3650, can help you learn more about those programs. The Family Caregiver Alliance provides an online caregiver support group accessed at www.caregiver.org. And, remember there are medical professionals who specialize in dealing with stress, who can help you rebuild your coping skills into healthy resources. Your doctor can make a referral for you.

Stress Management Tips

- Laugh.
- Set priorities. Don't try to do everything.
- Separate a task or problem into manageable parts:
 - 1 Specify the problem.
 - 2 List possible options with pros and cons for each.
 - 3 Choose a plan and list steps necessary to accomplish it.
 - 4 Establish a timetable and take action.
- Pick your battles. Not every difference of opinion or argument is worth winning.
- Relax your need for control. You'll save your own energy.
- Pace yourself. Stop before you become too tired or frustrated with a person or situation.
- Make lists, and use a date book or calendar.





About Support Groups

Webster defines support as “to carry, to endure bravely or quietly, to promote the interests or cause of, to provide a basis for the existence or substance of comfort.” Support can take many forms. It may be your loved one helping you through your illness. It may be a neighbor who mows your grass or cooks a meal for you. It may be a child who sits beside you and never says a word. Or it may be the feeling of not being alone which patients and family members alike may find in a support group. We thank Deborah Brunelle, AD, BSN and David Anderson, MD, co-facilitators of the Central DuPage Hospital Brain Tumor Support Group in Winfield, Illinois for sharing these guidelines for selecting a support group.

FINDING THE RIGHT GROUP

Through networking with patients and families, you’ll meet other people learning to live with a brain tumor. There are other families traveling this path — exploring resources, facing treatment choices, and finding ways to approach their concerns. They meet in support groups to share experiences and be there for each other.

If you think you’d like to “try out” a support group meeting, how do you go about finding a group?

Begin with the nurses and social workers at the hospital providing your treatment, or call the social work department of hospitals close to you. Ask what type of support groups meet at the hospital or in the area. You may receive varied responses.

Brain tumor support groups are organized specifically for those with brain tumors. Most brain tumor groups welcome both patients and family members or friends. Some focus on adult tumors, others on childhood tumors.

Cancer support groups or **cancer wellness groups** are more abundant, thus, it may be easier to find a meeting location close to you. Cancer groups offer information, support and nutrition information for cancer patients. Brain tumor patients facing radiation or chemotherapy may find valuable support and wellness resources within the cancer community.

Head injury support groups welcome brain tumor patients, treating the trauma of brain surgery as a head injury. Families interested in learning more about memory retraining, speech, or rehabilitation services often find shared concerns within head injury groups.

Once you learn the type of groups available, ask for telephone numbers to each group so you can call to learn more about how the groups are run.

The American Brain Tumor Association maintains a nationwide database of support groups. Call us at 800-886-2282 for a list of groups in your state.

FORMAT OF THE GROUP

When you reach the group's contact person, there are several questions you might wish to ask:

- Who sponsors the group?
- Where and when does the group meet?
- What is the format of the meeting?
- Who facilitates the group? Is there a medical professional available to answer general medical questions that may arise?
- How many people with your type of tumor are currently attending the group on a regular basis? If this not a brain tumor support group, do a majority of the members have concerns similar to yours?
- What percentage of members are newly diagnosed? In treatment? Have completed treatment?
- Is the meeting open to patients, family members, friends, or all?
- How many people usually attend the meetings?

Some groups specifically focus on the person with the tumor, others meet the needs of both patients and family members. In many groups, all members meet together then “break-out” into smaller groups of patients, spouses, caregivers, children, parents, etc.

Some groups offer support-only, and may be run by someone who has experienced a tumor or by a mental health professional. Education-only groups are usually run by health care professionals who develop a



program with set educational goals. The information is then presented over several weeks with set “start” and “stop” dates. The program may be repeated several times a year. Some support groups offer an educational speaker, followed by an opportunity to share experiences of the last few weeks and introduce new members.

Most formal support groups rely on a facilitator who keeps the program focused, redirects the conversation when the topic begins to stray, and provides resources when necessary.

WHAT TO EXPECT

Although many people join support groups to find someone who has shared the same experience, think about what you expect from the group. How do you expect to benefit, and what are you comfortable sharing with the group? The members will be interested in learning your experience and what brought you to the group. They may ask about the treatments you’ve had, or ask if you’ve had similar experiences to theirs. You are welcome to share as much, or as little, information as you are comfortable sharing.

YOUR FIRST MEETING

The first support group meeting you attend may bring on fears and anxieties that you were unaware you had. It isn’t easy to enter a room of strangers and share information about yourself. How do you reduce those anxieties?

Sometimes, a family member or a friend will attend the meeting first and bring back a feeling for how the group is run. Or, it may be helpful to take someone with you to your first meeting.

Remember that everyone in the group went through a “first meeting.” This is a good chance for you to listen and observe. There is no obligation for you to stay through the entire meeting nor to return a second time. If the group did not meet your expectations, consider sharing that information with the leader following the meeting. Facilitators welcome feedback. It helps them make changes in the way the group works, allowing it to grow according to the members’ needs. If you feel good about your first meeting, be sure you know the date and time of future meetings. Ask members if there are any special upcoming events such

as health fairs, educational programs, or Brain Tumor Awareness Week activities. Find out about other programs offered in the area — relaxation classes, healthy-cooking demonstrations, music therapy sessions, etc.

BEING A GROUP MEMBER

Very quickly, you’ll learn the usual pattern of your group’s meeting. A welcome, the facilitator’s introduction, time to share experiences followed by a social break. Or perhaps your group begins with an invited speaker, followed by a question and answer session.

Regardless of the format, each group will have its own set of guidelines to ensure equal time for each member wishing to share concerns or experiences. The facilitator is responsible for focusing members on the topic at hand and keeping the conversation on track. The facilitator is also there to direct medical questions to an appropriate resource, or make referrals to other support services when warranted.

When you become comfortable with the group, you may wish to ask questions of the group, bring in newspaper articles, or share resources you’ve found. Support group facilitators enjoy suggestions for new programs, involvement in area activities, or general assistance in the everyday running of the group. Perhaps some of your members have special talents — the ability to write a newsletter; experience in public relations; or contacts with companies that may be interested in sponsoring your group. If you have suggestions or want to help, speak up! Someone is always willing to listen.

WHAT HAPPENS WHEN I STOP GOING TO THE GROUP MEETINGS?

At some point in your recovery, you may come to the realization that the group is no longer what you need. Saying good-bye, for any reason, can be difficult. Speak to the facilitator and ask for help in telling the group. Other members may wish to keep in touch with you — give them the opportunity to extend this friendship. Remember: you can always go back to the group when and if you wish. The friendships made will always be with you and your family.



Where Do We Go From Here?

Eventually the frequent appointments for therapy stop, and the dates for follow-up care become further apart. The pace slows, and another period of adjustment begins. It is a time when it can be difficult to do nothing after having done so much.

Your task now is becoming well again. Make appointments for your follow-up doctor visits or scans and mark them on your calendar. Begin to rebuild your life within the guidelines set by your healthcare team. Eat a healthful diet. Exercise within the guidelines given to you by your doctor. Get out — go to the movies, visit museums. See friends. Be very good to yourself! You deserve it. But be patient — getting well takes time.

A NEXT STEP...

As you rebuild your life, you may wish to keep abreast of the newest findings in brain tumor treatment or learn more about the research that will someday lead to a cure. Our web site — located at www.abta.org — offers extensive brain tumor information, treatment and research updates, patient and families stories, lists of family and professional brain tumor meetings, and information about upcoming ABTA events. These materials are also available by calling us at 800-886-2282.

The thread that runs through each of our services and programs is hope. Become involved — join us in some way, to make sure there is a cure, and ultimately, a way to prevent brain tumors. It is through all of our collaborative efforts that progress will be made.

Notes

Request for Information

BUILDING KNOWLEDGE

- ☐ A Brain Tumor — Sharing Hope
- ☐ Tumor del Cerebro — Compartiendo la Esperanza
- ☐ Dictionary for Brain Tumor Patients
- ☐ Living with a Brain Tumor
- ☐ A Primer of Brain Tumors

FOCUSING ON TUMORS

- ☐ Ependymoma
- ☐ Glioblastoma Multiforme and Anaplastic Astrocytoma
- ☐ Medulloblastoma
- ☐ Meningioma
- ☐ Metastatic Brain Tumors
- ☐ Oligodendroglioma and Oligoastrocytoma
- ☐ Pituitary Tumors

FOCUSING ON TREATMENT

- ☐ Gene Therapy
- ☐ Radiation Therapy of Brain Tumors: A Basic Guide
- ☐ Stereotactic Radiosurgery

FOR & ABOUT CHILDREN

- ☐ Alex's Journey: The Story of a Child with a Brain Tumor *for ages 9-13*
 - ☐ Video Format
 - ☐ Booklet Format
- ☐ When Your Child Returns to School

SUPPORT RESOURCES

- ☐ A Bibliography of Books & Resources
- ☐ Brain Tumor Survivor's Guide to the Internet
- ☐ Care Options
- ☐ Emergency Alert Wallet Cards
- ☐ Financial Aid Resources
- ☐ Housing During Treatment Resources
- ☐ Scholarship & Educational Financial Resources
- ☐ Transportation Resources
- ☐ Wig and Head Covering Resources
- ☐ Wish Granting Resources

CONTINUED ON NEXT PAGE

NEWSLETTER

- ☐ Messageline, 3 issues a year
- ☐ Print format
- ☐ Email format

FOCUSING ON SUPPORT GROUPS

- ☐ Organizing a Support Group, A "How To" Pamphlet
- ☐ Listing of Brain Tumor Support Groups by State
Please indicate which state
- ☐ Listing of Bereavement (Grief) Support Groups by State
Please indicate which state

CONNECTIONS — A PEN PAL PROGRAM

- ☐ Connection Coupon: Information needed to match you to a pen pal

PHYSICIAN RESOURCE LISTS

- ☐ Physicians offering Clinical Trials for Brain Tumors in ADULTS
- ☐ Physicians offering Clinical Trials for Brain Tumors in CHILDREN

VOLUNTEER OPPORTUNITIES

- ☐ Please send me information about volunteering for the
American Brain Tumor Association

Name

Address

Apt/Suite

City

State

Zip

Phone *optional*

Email *optional*

*NOTE: If you provide an email address, we will send your newsletter, updates, and other
pertinent information electronically.*



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