I hate that phrase, “live like you’re dying” – I say: Live like you’re alive, and re-think what your definition of alive is.

— Tony, patient
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Quality of Life

Generally, people who are well informed about their illness, treatment, and resources for support, are more able to make decisions that take into account their quality of life and overall wellbeing.

THINGS TO REMEMBER

- You and your loved ones can learn to adjust to a new perspective on life.
- When problems arise, consider active coping strategies (see p. 48), to identify solutions that you can live with.
- Value support from others with experience.
- Take the time you need to experience your grief.
- Think about how to get help for your immediate caregivers, to avoid them from “burning-out”.
- Find a sense of peace and meaning in your life by tapping into your spirituality and/or other things that bring you comfort.
- Make plans for the future, with realistic intentions and without regret.
When you feel overwhelmed about your diagnosis (or any problem for that matter), it’s useful to think about how you react in difficult situations. Many people find that an “active” coping style reduces stress and improves their focus when they try to solve serious problems.

When you are making treatment decisions and learning how to manage your diagnosis, consider your quality of life. You have to define what “quality” means to you, then take reasonable steps to bring you closer to your quality of life goals.

It helps to recognize that you don’t have to sort everything out at once. It may take some time to deal with each issue that you face, so ask for help if you need it. It is likely that your doctor or nurse will know who you can contact for additional support.

### ACTIVE COPING

- Define the problem: break it into smaller parts
- Decide which elements of the problem you can control, and which you can’t
- Look for advice and information to address the problem
- Make a plan and take action to deal with the problem
- If the problem cannot be solved, try to adopt a new perspective to make it an issue you can live with
- Acknowledge your feelings
- Find a support group or counselor
- Build relaxation into your schedule (Yoga, exercise, music, reading)

### Coping with the Fear of Recurrence

The risk of recurrence is one issue that people diagnosed with a brain tumor genuinely fear. The goal of treatment is, most often, to prevent recurrence for as long as possible, but for how long is unknown.

One of the best safeguards for your quality of life is to be familiar with and follow the post-treatment monitoring plan set by your medical team. The earlier a problem is detected, the more options you may have for re-treatment. If additional treatment is suggested, consider the possible risks and benefits of treatment, and it’s often helpful to get a second or even third opinion before deciding what to do.

One of the hardest realities for most of us is the unknown. When you allow thoughts of tumor recurrence to disturb your ability to enjoy life, or to depress you, then it’s time to get help.
CHAPTER 5 / QUALITY OF LIFE

How you feel can have implications on your quality of life and the way you experience your diagnosis. It’s important to stay in touch with your feelings and seek support when you need it.

THE VALUE OF SUPPORT

By developing a new perspective on life, no matter how awkward or foreign it may initially feel, it has helped many people come to terms with the unknowns in their lives. They may find peace and new meaning. They realize they may need to shift priorities and focus on ways to enjoy life, and each moment in it, differently.

It sounds cliché, but if you can focus on keeping a healthy lifestyle and spending more time doing things that make you and others in your life feel happy, it makes a difference, and can push the fear of recurrence away. It’s valuable to focus on what you can control, such as your highest quality of life, rather than to focus on what you can’t control, such as cancer recurrence.

How you feel can have implications on your quality of life and the way you experience your diagnosis. It’s important to stay in touch with your feelings and seek support when you need it.

EXPRESSING YOUR EMOTIONS CAN

• Decrease anger or feelings of hostility
• Improve self-confidence and assertiveness
• Improve feelings of empathy, interest, and humor
• Improve energy (reduce fatigue)
• Improve overall quality of life

Get the Support you Need

There are many ways to get the support you need. Part of the challenge is accepting that you’d like support, and that it’s okay. If you already have people you can talk with and lean on, use them. If you’d like to find people who understand, seek them out. Knowing that you have people to talk with about difficult emotions is essential when coping with a brain tumor.

Support Groups

No one understands the experience of someone affected by a brain tumor more completely than somebody else in the same situation. That is the basis of support groups.

Support groups serve several functions. They give patients and families opportunities to talk with knowledgeable people, including health care professionals, who can educate them and provide information about their disease.
They offer emotional support and practical insight to help cope with the crisis of a brain tumor diagnosis. And they can smooth the transitions that patients and families must make as they deal with unfamiliar environments, such as hospitals and outpatient clinics.

**Professional Counseling**

Many people benefit from personalized help in dealing with emotional stressors. To find a counselor or psychiatrist with experience in helping people with cancer, specifically brain cancer, again ask your doctor or nurse. Often, the treatment center’s social worker or a spiritual leader can offer guidance at no additional cost.

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**GREAT RESOURCES FOR SUPPORT GROUPS**

For more information on support groups, talk with the social worker or nurse at your treatment center or ask:

- **National Brain Tumor Society**
  [www.braintumor.org](http://www.braintumor.org)
  NBTS offers information about one-on-one and online support specifically for brain tumor patients with links to several other organizations that can help.

- **T.H.E. Brain Trust**
  [www.braintrust.org](http://www.braintrust.org)
  T.H.E. Brain Trust offers a large variety of online support groups for specific brain tumor types and caregivers.

- **Imerman Angels One-On-One Cancer Support**
  1-877-274-5529
  [www.imermanangels.org](http://www.imermanangels.org)
  Imerman Angels carefully matches a person touched by cancer with someone who has fought and survived the same type of cancer. Personalized matches are also provided for cancer caregivers.

- **Cancer Support Community**
  1-888-793-9355
  [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)
  CSC offers on-site or online support groups for a variety of cancer types and caregivers.

- **American Cancer Society**
  [www.cancer.org/treatment/supportprogramsservices/index](http://www.cancer.org/treatment/supportprogramsservices/index)
  ACS offers a search tool to find cancer support groups located in or near your zip code area.

- **American Brain Tumor Association**
  [www.abta.org](http://www.abta.org)
  ABTA offers a list of brain tumor support groups by state, with a zip code search.

- **Musella Foundation**
  [http://virtualtrials.com/list.cfm](http://virtualtrials.com/list.cfm)
  Musella Foundation offers online support groups for people affected by brain tumors.
RELATIONSHIPS

Talking about your Diagnosis

Many people, understandably, find it difficult to talk about their diagnosis with others. First you’ll have to decide who you need to tell – and what you want to tell. You may decide that you have different groups of people that you’ll talk with about different things. It can help you feel better, and the people you talk with will also feel good as they find ways to help and support you.

There are people who will be directly affected by your experience (family members, close friends, your boss). These people should know what you’re going through so they understand the stressors that you must face, and the schedule changes that you’ll experience.

Children sense and know more than adults often give them credit for. Children will overhear telephone conversations, pick up their parents’ anxiety, blame themselves, and fear the worst if they are given no information. When a parent has a brain tumor, the natural desire is to protect the children through silence – but that usually backfires and makes things worse.

Young children up to the age of eight will not need a great deal of detailed information; older children and adolescents will need to know more. In a two-parent household, try to talk to each other first, to determine the best way to talk to your children. If single parents are feeling a bit anxious about the conversation, they may want to ask a relative or friend to be present.

Although no one wants to alarm children, there is nothing wrong with crying when a crisis happens. Crying is normal and healthy.

QUESTIONS ABOUT HEREDITY

Only 5-10% of brain cancers are hereditary. If you have questions about your family history, we suggest the following:

- If you have multiple family members diagnosed with brain tumors or have concerns about starting a family after having a brain tumor yourself, consider a consultation with a genetic counselor. He or she can access the latest genetic information related to the specific tumor type in your family and advise you accordingly.
- Share your family’s medical history with your kids and help them become good medical historians as their own future health is monitored.
How your Diagnosis Impacts Others

Different people will react differently to your news; some will be eager to help, while others will withdraw and not know what to do.

It is not uncommon for a serious diagnosis to produce changes in personal relationships. This is because it is stressful, because brain tumors can change a person’s personality, and because they can leave people unable to function the way they used to. Relatives and close friends may find behavioral changes hard to deal with.

On the other hand, many feel that their marriage or relationship is strengthened through the process of dealing with a crisis together. They are grateful to have each other’s support.

When friends and family want to help, it can be useful to put together a list of tasks that are easy to delegate. Be specific about what you need: a drive, help with shopping, help making phone calls.

Keep in mind that most people offering help are eager to do something—and by allowing them to be supportive, they will feel appreciated. Similarly, it’s important not to over-use supportive people; take note of when they need a break.

As a caregiver, it’s important to know that your loved one may not be aware of how their behavior impacts you. You must be able to find the support you need to take care of yourself. You will need all the strength you can get.

— Candice, caregiver
Humor

Is a brain tumor humorous? No, but learning to laugh at life’s challenges has been shown to help people cope better with difficult situations. Being able to find humor in life can be calming when dealing with a brain tumor diagnosis.

Humor therapy is an actual science. It is used to improve quality of life, provide pain relief, encourage relaxation, and reduce stress. The physical effects of laughter include increased breathing, increased oxygen use, short-term changes in hormones and certain neurotransmitters, and increased heart rate.

Most often, finding the humor in life is something you and your friends can focus on anywhere, anytime.

SPIRITUALITY

The crisis of a brain tumor diagnosis often helps people gain insight into their beliefs and spirituality. Each of us holds beliefs about life, its meaning, and its value, whether we participate in a religious tradition or not. Prayer may be comforting and help you feel less alone.

Some people find comfort in their spiritual beliefs while others question their faith, possibly feeling distressed by the idea that the illness might be a punishment for some past sin or lack of faith. Having doubts and being angry are normal responses.

It can be helpful to talk to your pastor, rabbi, imam, or a spiritual counselor in your community. Members of religious and spiritual communities also may provide practical help, such as assistance with transportation, meals, and visitation services.
MAKING PLANS FOR THE FUTURE

Hope is a powerful concept and coping strategy that empowers people to look beyond the moment and into the future. Your sense of “hope” can change over time. It’s not about being positive all of the time, but about trying to view things from a positive perspective as much as possible.

When you make plans for the future, keep hope in mind. Make reasonable plans based on your well-being at the time. Patience is important. Simple plans can be appreciated just as much as larger goals for the future.

GAIN A NEW PERSPECTIVE...

- Remember to do things that make you happy
- Spend more positive time with family, friends, and loved ones
- Seek a more meaningful job
- Volunteer to help others (like becoming a brain tumor advocate)
- Focus on your health: quit smoking, eat better, exercise more
- Become more spiritual, whatever that looks like for you

It has been six years since my diagnosis and treatment. I have dedicated my life to helping those going through cancer or caring for someone going through cancer. There is so much that a person like myself can do to help.

— Greg (from the National Brain Tumor Society’s Story Corner)

GET INVOLVED TO HELP OTHERS

National Brain Tumor Society, www.braintumor.org
Accelerate Brain Cancer Cure, www.abc2.org
Imerman Angels, www.imermanangels.org
CANCER SUPPORT COMMUNITY’S FRANKLY SPEAKING ABOUT CANCER SERIES

Cancer Support Community’s Frankly Speaking About Cancer: Brain Tumors program is part of a national education program that provides support, education, and hope to people affected by cancer and their loved ones.

Frankly Speaking About Cancer booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis, and survivorship issues.

For more information about this program, the Frankly Speaking About Cancer series or Cancer Support Community, please visit our website at www.cancersupportcommunity.org or call us toll-free at 1-888-793-9355.

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