First of all, it’s important to recognize that any changes you are experiencing in your mind, emotions and personality at this time are absolutely NORMAL.

The second thing to recognize is that living with the diagnosis and treatment of a brain tumor is an extremely difficult and challenging task for patients and their families. There is, initially, the shock of the diagnosis followed by the necessity of determining treatment plans, and of course, the treatment itself. Added to these challenges is the fact that you may experience very real changes in your mind, emotions and personality.

These changes may result from the brain tumor itself, or from treatments such as surgery or radiation. They can affect your ability to process information, communicate with your family and loved ones, remember things, and perhaps even doing basic daily living tasks. Your whole personality and identity can be affected.

You may not be totally aware of these changes as they can often be quite subtle. However, those around you - family, friends, and caregivers - may notice these differences and find them quite upsetting. This is particularly true with personality changes.

Some of the changes you may experience are:

- **Processing information and thinking:** This can result from fatigue associated with treatment, or it can be the result of the tumor itself. You may find yourself becoming distracted, you may have difficulty concentrating or find it difficult to learn new things.

- **Communicating:** These challenges can range from difficulty “finding the right word” to problems understanding what is being said, writing, or carrying on a conversation. As we are all social beings, these problems can be extremely frustrating.

- **Remembering things:** Short term memory can be affected resulting in problems remembering things, including remembering to do routine tasks. You may also experience difficulties learning new things.

- **Performing basic tasks:** This can be the result of problems associated with difficulties with physical coordination on top of memory problems. You may forget to do a task, or the basic steps in how it is done.

- **Psychological changes:** These are probably the most difficult changes and they occur in approximately half of patients. These can be the result of having to cope with the emotional impact of a life changing medical condition as well as the physical and mental fatigue of a brain tumor and its treatment. While the most common psychological change is depression, you may notice increased irritability, anxiety, sadness, apathy, euphoria, sudden mood changes, anger, or uncharacteristic behavior. Such changes are absolutely normal under the circumstances.
How is Brain Function Evaluated?

A neuro-psychologist (PhD) should be part of your multi-disciplinary medical team. This is the person who can determine whether changes in particular brain functions have resulted from the tumor and its treatments, and therapies that may be of help, such as cognitive rehabilitation or psychotherapy. This assessment is referred to as a neuropsychological evaluation.

Coping With These Changes

A number of strategies can help you cope with the challenges that affect everyday activities, communication and interpersonal relationships.

- **Join a Support Group:** Talk to your medical team about a support group that can help you work through issues related to your brain tumor, get tips on coping, and provide emotional support.
- **Write Things Down:** Use a notebook to keep track of things, including people’s names and tasks that need to be done.
- **Streamline Your Routine:** Keep everything consistent: your schedule, where you put things, routes you take. Now is the time to keep everything as simple as possible.
- **Give Yourself a Break:** Make arrangements at work or school to shape things to your needs, including enough time to do tasks and for rest. You may also need to “dial it down” to relieve the pressure of trying to perform at your prior pace or level. A notebook and a consistent, streamlined routine can greatly help matters.
- **Turn it OFF:** You may find that background noise from a television, radio, or electronic devices is extremely distracting. If so, the OFF button is the path to silence and improved concentration.
- **Delegate:** If someone offers help for a task you don’t enjoy doing, take them up on the offer! Even better, have a list of things that need to be done, so family and friends know where you could use their help. This way, you can focus on healing and the things you enjoy doing. Two resources to help you with delegation are:
  - Meal Train [http://www.takethemameal.com](http://www.takethemameal.com) to sign up to bring a meal is: [http://www.takethemameal.com](http://www.takethemameal.com)

We at the EndBrainCancer Initiative understand your needs and can assist you in getting you the support you need. Please remember that you are not alone. Contact us today.
[www.endbraincancer.org/we-can-help/](http://www.endbraincancer.org/we-can-help/)
Other Suggestions for Coping

- Anything that will make you calmer and more relaxed, especially activities you enjoy
- Exercise, take a walk, or join a class at your local treatment center. Your medical team can help direct you to appropriate exercises and classes for cancer patients.
- Consider prayer and/or spiritual guidance
- Do yoga, stretching, or relaxation exercises
- Talk it out with someone sympathetic
- Listen to music you enjoy
- Take up a hobby you like or join an art class

Focus on Things That Bring You JOY

- Only you know what these are
- Make a list and make time do them
- Ask others for help
- Spend more time with your loved ones
- Visit a favorite spot
- Reading
- Sunrise/sunset
- Outings with friends
- Keep a journal

Seek professional Help: Such as a Counselor or Social Worker

Finally, Remember That What You Are Experiencing is NORMAL.

As one brain tumor patient put it:

“I learned patience, compassion, tolerance - all within myself. I used to be a perfectionist with myself and I have since learned that it's okay to leave a bit of dust on the end table”.

“It is okay to grieve who we once were. Sadness, joy, grief, anger, acceptance....they are all part of the process. But the knowledge that what you are experiencing is normal is what will help you the most.”
Coping Strategies and Ideas: Daily Routine

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__________________________________________________________________________________
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__________________________________________________________________________________

Coping Strategies and Ideas: Other Activities

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Things that bring me JOY!

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The EndBrainCancer Initiative is here to offer help and HOPE, provide access, and guide you through this journey. All of our services are provided free of charge.

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