

Fatigue and Other Symptoms After Brain Tumour Treatment

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Fatigue is more than simply “being tired”

- ❑ Fatigue is a debilitating, persistent loss of energy and endurance
- ❑ Fatigue affects the whole body
- ❑ Symptoms may not be relieved or improved by sleep
- ❑ Especially when chronic or severe, fatigue can have a profound effect on quality of life

Fatigue is often misunderstood

- ❑ Common among survivors of many brain tumour varieties
- ❑ May develop following neurosurgery, chemotherapy and/or radiation treatment
- ❑ May also be associated with brain tumours prior to treatment
- ❑ Sometimes amplified by other medical issues
- ❑ Fatigue symptoms can be overlooked when they are present with chronic illnesses

Fatigue can vary in intensity

- ❑ Different levels of fatigue, range from mild to severe
- ❑ Fatigue can interfere with a person's ability to carry out activities of daily living
- ❑ Physical and cognitive symptoms are unpredictable
- ❑ Effects of fatigue may change from day to day, or at various times throughout the day
- ❑ Symptoms may include sudden, overwhelming feelings of mental, emotional or physical exhaustion

Why does fatigue develop?

- ❑ A variety of illnesses and other factors can either cause fatigue to develop or make symptoms of fatigue worse
- ❑ Anemia, side effects from medications, hypothyroidism, insomnia, depression, dehydration, poor nutrition, stress overload and chronic pain can all be linked to fatigue
- ❑ Sometimes fatigue is idiopathic (unknown cause)
- ❑ A thorough medical examination is always the first step in evaluating and treating fatigue
- ❑ Treating other illnesses or medical conditions can sometimes improve fatigue symptoms

How can fatigue be manifested?



Most discussions of fatigue focus on PHYSICAL symptoms and effects

- Reduced energy level
- Diminished strength or endurance
- Difficulty falling asleep or waking up overnight
- Changes in balance and coordination
- Lower capacity for work
- Muscle aches

Attentional Fatigue & Cognitive Symptoms

- ❑ Less well known, but can be equally devastating
- ❑ Reduced ability to concentrate and understand
- ❑ Inability to process new information
- ❑ Difficulty with decision making and problem solving
- ❑ Organizational abilities may be reduced

Other aspects of Attentional Fatigue

- ❑ May feel overwhelmed by ordinary activities
- ❑ Easily distracted, shorter attention span
- ❑ “Brain Fog” – reduced mental clarity
- ❑ Unable to manage simultaneous tasks
- ❑ More effort needed to meet minimal goals because of challenges focusing attention
- ❑ May have only a few symptoms or any combination

A. B. I. & Associated Challenges

Brain Tumour Survivors can experience many signs of Acquired Brain Injury, including the following cognitive and physical effects:

- ❑ Memory loss (especially short term memory)
- ❑ Difficulties with processing or retaining new information
- ❑ Changes in problem solving skills
- ❑ Diminished ability with mathematics
- ❑ Distractions from sensory input (noise, light, crowds, background movement, other “ordinary” activity)
- ❑ Changes in coordination, balance and agility

Suggestions for Support & Coping Resources

- ❑ Many local and national nonprofit organizations provide information and resources for brain tumour survivors and their loved ones
- ❑ Take advantage of educational materials, support services and other resources provided by international groups as well
- ❑ Share what you learn about these resources with your health care team, so that you can help educate them about brain tumours and related issues

For More Information About Brain Tumours

- ❑ American Brain Tumor Association
www.abta.org
- ❑ Brain Science Foundation
www.brainsciencefoundation.org
- ❑ Brain Tumour Foundation of Canada
www.btfc.org
- ❑ Central Brain Tumor Registry of the US
www.cbtrus.org
- ❑ National Brain Tumor Society
www.brainumor.org

Brain Tumour Support Groups

- ❑ Professionally led (nurses, social workers, etc.)
- ❑ Self-help groups (mutual aid organizations)
- ❑ Discussions, guest speakers, social connections, can become an “extended family”
- ❑ Available in many parts of USA & Canada
- ❑ We all can learn from each other!

Online Support Groups

- ❑ Available 24/7, no geographical limitations
- ❑ Each type of group has advantages and limitations
- ❑ Mailing lists: Deliver email messages, either sent individually or in digest form once a day
- ❑ Bulletin boards: Can read messages at any time, may have to log in and use password to participate
- ❑ Chat rooms: Real time conversation via computer

Importance of Finding Support

- ❑ As few as two people can become a support group for each other
- ❑ Finding someone that understands your challenges can be very meaningful
- ❑ Whether by phone, email or in person, don't hesitate to reach out to others
- ❑ You can't have too much support!
- ❑ Listening to someone else's brain tumour story can be rewarding and inspiring

Coping with Fatigue Can Be Exhausting!

- ❑ Especially when the causes and effects of fatigue are either misunderstood or unknown, finding encouragement and understanding can be difficult
- ❑ Positive self-care techniques can improve overall health and may reduce symptoms
- ❑ Use the following suggestions as a starting point, and develop your own plan which incorporates the techniques that work best for you

Sixteen Healthy Suggestions for Coping with Fatigue & Other Symptoms

1. Pay attention to your diet.

Some people plan 5 or 6 small meals throughout the day to meet their nutritional needs. Be sure to utilize all food groups. Maximize nutrients by eating fruits and vegetables in a rainbow of colors. Lean protein, complex carbohydrates and small amounts of healthy fats are all important to good nutrition.



2. Drink enough water.

Hydrate, hydrate, hydrate!

Dehydration can increase symptoms of fatigue. Plan to drink water before or with every meal, and also throughout the day. Keep water handy and limit beverages with caffeine (coffee, tea, cola drinks, etc.) which are dehydrating. Drinking enough water is important for many bodily functions.



3. Avoid inactivity.

Talk to your medical team about incorporating gentle exercise in your daily routine. Walking, stretching, swimming or water exercise, Tai Chi, circuit training and other forms of activity can actually improve fatigue for many people. Find ways to keep on moving!



4. Get adequate sleep and rest.

While daytime naps can be helpful at times, limit them to under 30 minutes daily so they do not reduce nighttime sleepiness. Going to bed and waking up at the same time each day helps your body develop a regular sleep routine. Keep a quiet, calm, restful atmosphere in your bedroom. Lie down and rest when you feel tired.



5. Learn and apply energy conservation techniques.

One of the most important coping techniques is learning to conserve and manage a limited amount of energy. Make lists. Decide to do only those activities that are most meaningful or important. Use “free time” wisely. Be efficient and learn to pace yourself.



6. Avoid sensory overload.

Look for a quiet place to recover from overstimulation or avoid it entirely when possible. Limit time in front of a TV or computer screen. Be aware of sensory input from noise, light, movement, crowds and other sources. If you cannot have a conversation with background noise (from radio, TV, other people talking), find a proactive solution such as changing location, muting the TV, or asking people to be quiet for a moment.



7. Recognize your energy level and adjust activities accordingly.

Listen to your body! Postpone demanding tasks when you are having difficulty with physical or cognitive symptoms of fatigue. Rest and recharge yourself before you become completely exhausted. Find a place to sit when you are feeling unsteady. Use handrails on steps. Move carefully and slowly when needed.



8. Identify your priorities and be aware of how you spend time every day.

Time is limited for everyone. Daily life can so easily become overwhelming. Learn to focus on people and activities that are most meaningful and important to you. Make conscious choices when planning your schedule. Let your daily activities and commitments reflect your values.



9. Surround yourself with positive people.

One of the most powerful positive influences can be simply spending time (or talking with) people who help you feel better about things. Attitudes are contagious! Optimistic feelings tend to multiply. “Look for the good” whenever possible. Minimize negativity of all types.



10. Embrace your spiritual connection.

Spirituality can be a powerful part of health and healing. Connect with personal and family traditions, explore faith communities and congregations, or celebrate the Universe in your own way. Prayer and meditation can be comforting.



11. Develop an attitude of gratitude!

Notice the positive things around you each day and learn to say “thank you” for whatever brings you joy. Celebrate your blessings! Keep a list of people, places and things that make you smile. Enjoy photos of loved ones or scenes that evoke happy memories. Keep a journal and describe enjoyable experiences to recall later.



12. Learn to ask for help.

Asking friends and family to help (and being willing to accept their help) can free up energy to use for other tasks. Be as specific as possible when you make a request for help. People who care will want to do something to make things easier for you. Imagine if the roles were reversed... how would you feel?



13. Allow yourself to say NO.

Especially if you have reduced energy and endurance, it's important to minimize your "things to do" list. Learn to say NO to any requests that you cannot – or do not want – to do. Set aside energy for healing and to cope with any unexpected demands.



14. Laugh, sing, smile, create, enjoy!

Making time for humor, music, creative arts, and other sources of pleasure each day may improve your quality of life. Be sure to include activities where you “lose track of time” and can feel relaxed. Use creative activities to recharge your batteries!



15. Use stress management and relaxation techniques to help reduce fatigue.

Breathing exercises, muscle relaxation, visualization and imagery can help reduce stress. Use 5-minute stress breaks. Journal writing allows you to keep notes about your feelings and symptoms. Over time, this too can become a tool to help manage fatigue. Reducing stress can also help improve overall health.



16. Acknowledge your fatigue related challenges.

Being honest about how fatigue affects your life can help you cope more effectively. Use communication techniques. Be patient and gentle with yourself, especially when things are difficult. Remember, "This too shall pass."

In summary



- ❑ If you are coping with the effects of brain tumour related fatigue, remember...
YOU ARE NOT ALONE!
- ❑ Coping techniques, positive self-care and working closely with your healthcare team all can help improve your quality of life

Wishing you good health



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