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ABOUT CANCER


CANCER SUPPORT
COMMUNITY.



10 TIPS TO LIVING WELL WITH
A Brain or
Spinal Cord Tumor

The journey through a brain or spinal cord tumor diagnosis is different for everyone. There is no single roadmap. Whether you are a patient or a caregiver, we hope that these tips shared by other survivors will help make your journey easier.

1. Take one step at a time, and make one decision at a time.

Life with a brain tumor can feel overwhelming. Yet, with small steps you can find your best path. Before making major decisions, talk with a variety of medical experts, patient navigators, and brain tumor advocates. Don't trust everything you read online. Ask all of your questions. In time, you can collect the information and support you need to make good financial, medical, and personal decisions.

2. Find a treatment team you trust.

Your team might include a neurosurgeon, neuro-oncologist, radiation oncologist, medical oncologist, neurologist, endocrinologist, nurses, social workers, and patient advocates. Trust comes from being able to talk openly with your team and believing they can help. Try to get a second opinion at a brain tumor center. Treat this like an interview to find the best experts for the job. Your team should help you care for your mind, body, and spirit.

3. Use a notebook to keep track of your symptoms, answers to questions, and next steps.

Ask someone to help you keep notes. Look back at your notebook to

help you remember and track how you're doing over time.

4. Accept help when it is offered.

Day-to-day life and tasks can become harder. Ask others for the help you want and need. Often, your friends and family will feel good offering assistance. An online scheduler (see Resources) can help you and your loved ones stay organized and informed.

5. Reach out to other brain tumor survivors.

It's comforting to talk with others who understand what you're going through. You and your loved ones don't have to feel lonely, helpless, or hopeless. You can connect with others through the Internet or a local support group.

6. Seek support from a patient advocate.

A trained advocate can help you navigate through many parts of the cancer journey. They can help manage insurance issues, find resources, and help with legal documents such as your will, medical directives, and estate plans. Many cancer centers offer, or can refer you to, a skilled advocate or patient navigator.

7. Learn to relax and find a new perspective.

A brain tumor diagnosis is life changing. Be

aware of your feelings and how you handle them. You can calm yourself with deep breathing, journaling, exercise, or creative activities. If you feel worried or depressed, consider talking with a social worker or therapist. You can learn to manage your feelings and find a sense of calm. Take time to think about your life goals and self-image. Explore what's important to you and what makes you feel happy. Focus your energy on things that improve your well-being.

8. Find ways to feel in charge of your life. At times you may feel frustrated by changes to your work, school, and family life. Take action. Work with your medical team to come up with a plan that gives you as much control as possible over your treatment and care.

9. Focus on nutrition and exercise. Every small step you take to eat better, get more exercise, and find

more humor in life can make you feel better. Eating well will give you more energy and nutrients to help your body. Exercise can lift your spirits, boost your energy, and reduce stress. Even when you feel tired, you can set reachable goals for healthy eating and exercise (example: a 10-minute walk).

10. Remember that hope is possible. It may help to focus on family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, hope can still make each new day better in some way. Plan to do something that makes you smile. Accept that some days will be better than others, but you can continue to enjoy the small, special moments.

CancerSupportCommunity.org/Brain has more information and tips on coping.

RECOMMENDED RESOURCES

Accelerate Brain Cancer Cure
202-419-3140
www.abc2.org

American Brain Tumor Association
800-886-2282
www.abta.org

American Society of Clinical Oncology
888-651-3038
www.cancer.net

Cancer.gov/ClinicalTrials

CancerCare
800-813-4673
www.cancercare.org

Musella Foundation for Brain Tumor Research and Information
888-295-4740
www.virtualtrials.com

MyLifeLine.org
888-234-2468
csc.mylifeline.org
Inform loved ones and schedule their help.

National Cancer Institute
800-422-6237
www.cancer.gov

National Brain Tumor Society
800-770-8287
www.braintumor.org

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org.

Cancer Support Helpline®

CANCER SUPPORT
HELPLINE
888-793-9355

Whether you are newly diagnosed with cancer, a longtime cancer survivor, or caring for someone with cancer, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Monday-Friday from 9 am - 9 pm ET.

Cancer Experience Registry®

CANCER EXPERIENCE
REGISTRY

The Registry is a community of people touched by cancer. The Registry collects, analyzes, and shares information about the experience and needs of patients and families. To join, go to www.CancerExperienceRegistry.org.

Frankly Speaking About Cancer®

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ABOUT CANCER

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

Support at local CSCs and Gilda's Clubs

Almost 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

Open To Options®

Open to
Options

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting a local CSC or Gilda's Club providing this service.

The Living Room, Online

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

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