



braintumour
foundation
OF CANADA

1st Edition

Brain Tumour Caregiver Handbook

A guide to what it means to be a caregiver,
what to expect, and how to manage.

Copyright © 2019 Brain Tumour Foundation of Canada

All rights reserved. Printed in Canada. No part of this book may be used or reproduced in any form or by any means, or stored in a database or retrieval system, without prior written permission of the publisher.

Making copies of this book is against the law.

For more information or to receive a free copy of this handbook,
please contact us:

Brain Tumour Foundation of Canada

205 Horton Street East, Suite 203

London, Ontario N6B 1K7

Telephone: 519-642-7755

Toll Free: 1-800-265-5106

Order this free resource online at www.BrainTumour.ca/requestinfo

Our Promise to You

At Brain Tumour Foundation of Canada, you will find accurate, up-to-date, and free information to help you and the person diagnosed with a brain tumour. Additional programs and services include:

- Educational events to help face and manage a brain tumour diagnosis.
- Critical support through one-on-one, pediatric and support group services.
- Research funding into the cause of and potential cures for brain tumours.

How You Can Help

Brain Tumour Foundation of Canada is funded entirely by the generosity and support of many individuals, businesses, and organizations motivated to make a difference for the brain tumour community throughout Canada.



You Can Give By:

General Donation – A single or monthly gift designated to support the area of your choice or allocated by the organization to where the need is greatest. Donations can be made online, by phone, or mail.

Tribute Gifting – Tribute gifts, either in memory or in honour of someone special, are a meaningful way to recognize a loved one.

Hosting a Community Event – Organize and run an event in your community with proceeds benefiting Brain Tumour Foundation of Canada and help Canadians affected by a brain tumour.

Legacy Giving – When updating your will or your life insurance coverage, leave a legacy by including Brain Tumour Foundation of Canada as a beneficiary.

About Brain Tumour Foundation of Canada

An estimated 55,000 Canadians currently live with a brain tumour and an additional 10,000 people are diagnosed each year. That is 27 new diagnoses per day. Thousands of people affected by brain tumours find emotional support and comfort through Brain Tumour Foundation of Canada while gaining a better understanding and knowledge of their disease.

Brain Tumour Foundation of Canada is the only national not-for-profit organization committed to reaching every Canadian affected by a brain tumour through support, education, information, and research. We are led by a dedicated team of volunteers, patients, survivors, family members, health care professionals, and staff, determined to provide hope and support during the diagnosis of a brain tumour and beyond. We work collaboratively to serve the needs of all Canadians affected by every type of brain tumour; adult, pediatric, non-malignant, malignant, or metastatic.

Services, Programs & Resources

One-on-one and group support is available to any Canadian affected by a brain tumour.

Educational events such as webinars give you the opportunity to learn about recent developments in areas such as brain tumour treatment and quality of life topics.

Brain Tumour Handbooks provide a wealth of information about treatment options, long-term effects, and an overview of brain tumours. These handbooks are available in English and French (print copy shipped free in Canada or available electronically) and the following are offered:

- Adult Brain Tumour Patient Handbook
- Pediatric Brain Tumour Patient Handbook
- Non-Malignant Brain Tumour Patient Handbook
- Caregiver Brain Tumour Handbook

You Are Not Alone

Caring for a loved one living with a brain tumour diagnosis is an act of love that draws on many strengths, offers many rewards, and may also require you to take on some new and significant responsibilities. While the Brain Tumour Caregiver Handbook does not provide all the answers, our hope is that you will feel supported and find the personal stories and practical suggestions helpful as you care for the person diagnosed with a brain tumour.

If you don't know where to start, a call to Brain Tumour Foundation of Canada is always a good place. We offer many support programs offered to caregivers including:

In-Person Adult Support Group – A valuable opportunity for people with a brain tumour and their family members or friends to share experiences and gain peer support in a safe and relaxed atmosphere.

Caregiver Virtual Support Group – Gain peer support in a safe, relaxed atmosphere from the comfort of your home.

Closed Facebook Support Group – Gain access to an active group of Canadian brain tumour patients, survivors, parents and other caregivers who offer resources, ask questions, and share stories of hope and support.

BrainWAVE Pediatric Support Program – For families with a child (19 years of age or younger) who has been diagnosed with a brain tumour. Several times a year, in various areas of Canada, BrainWAVE families can meet and relax through fun activities such as trips to sports events, historical sites, and other family attractions.

One-one-One Support – Our social workers are available to chat with by phone or email Monday to Friday from 8:30 am – 4:30 pm (EST).

For information about donating to Brain Tumour Foundation of Canada or to learn about the programs and services offered please call 1-800-265-5106 or visit us at www.BrainTumour.ca



Acknowledgments

A great big thank you to everyone involved in creating this very important resource for caregivers. In 2017, Brain Tumour Foundation of Canada launched a survey to learn from caregivers across the country. The information gathered from this survey helped us create this Brain Tumour Caregiver Handbook.

The committee involved in this resource helped create content and shared personal and professional experiences while providing practical tips and suggestions to other caregivers.

The Brain Tumour Caregiver Handbook Committee included:

- Janet Fanaki, Caregiver and Caregiver Story Content Writer
- Karen Metcalfe, Caregiver
- Laurie Gallinger, Caregiver
- Kyle Dobson, Caregiver
- Marie Scheifele, Caregiver
- Debbie Pires, Caregiver
- Nelson Pires, Caregiver
- Theresa Acchione, Caregiver
- Rosie Cashman, Nurse Practitioner

A special thank you also to:

- Dr. Matias Mariani, PhD, C.Psych of Mariani and Associates for providing content on the cognitive effects of brain tumours and treatment.
- Dr. Chad Hammond, PhD, Program Manager, Advance Care Planning in Canada for providing content on advance care planning in Canada.

Table of Contents

Adjusting to the New Normal..... 1

 Realistic Reminders for the Caregiver..... 1

 Managing Emotions and Expectations..... 2

 A Caregiver’s Perspective: Debbie & Nelson..... 3

Accepting Help..... 6

 What Can Others do to Help?..... 6

 Other Ways to Help a Caregiver..... 8

 What Happens If the Help Stops?..... 9

 A Caregiver’s Perspective: Marie..... 10

Finding the Right Words..... 12

 Conversation Starters..... 13

 Talking to Your Child Diagnosed with a Brain Tumour..... 16

 A Caregiver’s Perspective: Karen..... 17

Advance Care Planning 19

 A Caregiver’s Perspective: Kyle..... 20

Practice Self-Compassion..... 22

Practice Stress-Reduction Techniques..... 23

 A Caregiver’s Perspective: Theresa..... 24

Caregivers – A Vital Member of the Team..... 26

 A Caregiver’s Perspective: Janet..... 29

Cognitive Effects of Brain Tumours and Treatment..... 31

 Memory Loss..... 31

 Sleep Difficulties..... 32

 Strategies to Support Cognitive Effects..... 32

 A Caregiver’s Perspective: Laurie..... 34

Tips for Long-Distance Caregivers..... 36

Bill of Rights for the Brain Tumour Caregiver..... 38

Adjusting to the New Normal

Be gentle on yourself! Adjusting to a new normal after a loved one is diagnosed with a brain tumour can be challenging at times. This new normal is a continuous process for the person diagnosed, the caregiver(s), as well as family and friends.

It's true that life is no longer as it once was, and a new normal has begun. Caring for someone with a brain tumour entails significant responsibility and stress. Often just making it through the day is a tick in the win column. As you give more and more of yourself, your time and energy, it is important to remember that you are only one person and cannot be everything to everyone.

The new normal means rearranging your daily schedule to accommodate all concerned. The new normal can even interfere with your meal prep, exercise routines and hobbies. It's those routines we've been locked into that make it hard to adjust.

Realistic Reminders for the Caregiver

Here are some gentle reminders and suggestions to keep in mind as you manage your own energy levels:

Be kind to yourself – This is a difficult time in your life, and you may be reading this resource from cover to cover on the same day your loved one was diagnosed, or you may be reading it months after the diagnosis because it feels like you haven't had time to breathe. And that is okay! Do what you feel is right from moment to moment. Go at the pace that resonates with you, not what might have worked for someone else.

Practice self-compassion – One day at a time, often one minute at a time. There is no one way to care for a loved one. This will be a trial and error process, so be gentle on yourself and find a way that works for you and the person you are caring for. Do your best to avoid criticizing yourself, especially if you feel that you are not doing enough.

Don't second-guess past decisions when you receive new information – This is an easy trap to fall into, the "if only" game. You are doing your best and expectations of yourself beyond that are just

another drain on you. While others can be critical, it is often our internal critic that is most difficult to tame; this takes time and practice.

Take time off without feeling guilty – Arrange for someone to step in as a helping hand. All caregivers need a break at times, even if it just allows you to take a drive, go for a walk or grab a coffee with a friend.

Think of yourself as an information gatekeeper – Discuss how much should be shared with others. What you are comfortable sharing may be different than what they are willing to share.

Find someone to switch on / off with – Being able to unload, debrief, or just cry with a friend, family member or therapist who listens without judgement and provides suggestions when appropriate, is a valuable support person. Keep these people close!

Attend to your own health needs – Get proper rest and nutrition. Exercise regularly, even if it's a 10-minute walk to get some fresh air. To provide the care your loved one needs, you need to care for yourself.

Integrate fun into your life – Integrate fun activities to do as a family. Perhaps it's a movie, or games night at home with snacks, or going for a drive somewhere new. These are low-stress activities that will nurture joy and bring you closer together. Allow yourself this time.

Schedule – Develop a calendar to let family know when it is ok to visit and when you need space.

Managing Emotions and Expectations

It can be easy to become the caregiver of everyone involved; however, it's important to keep your focus on yourself and your loved one. It's about balancing your needs and energy levels as well. Try to only socialize and spend time with positive people. Being with someone who questions your actions or decisions is not helpful and can be destructive.

You are doing the best you can with the information available to you.



Debbie & Nelson: A Caregiver's Perspective

At some point, everyone in Debbie's family of four has been the caregiver. Debbie herself had a brain tumour, her husband had kidney cancer, her eldest daughter was born with a physical disability affecting her mobility, and then her youngest daughter Sammy was diagnosed with a brain tumour. Debbie has a unique perspective as both a brain tumour survivor and caregiver. This heightened her fear when Sammy was also diagnosed with a brain tumour.

At some point, each of them has learnt to care for each other.

Debbie...

Debbie was on a phone call in 2003 when she switched the receiver to the other ear and thought the person was speaking in Latin. On the other ear, everything sounded normal again. Her brain tumour, an acoustic neuroma, caused the problem. As a result, she has lost some hearing, has no ear drum in one ear, and suffers frequent debilitating headaches.

At the time, Debbie and Nelson were still dating. Despite having been given an option to walk away, Nelson stepped up and became Debbie's caregiver and boyfriend. "I told her that I'd do what it takes. I tried to make sure that we still had things to do together so I bought an Xbox so that we could play together. It became a way to forget about being sick for a while and she surprised me by really enjoying the games!" said Nelson.

"It wasn't easy, but I did what I could to keep the house in order so that she didn't have to stare at dirty dishes, learnt how to take the best care of her that I could, and still found time for some fun times." They later married and had two children.

Debbie's advice to caregivers.

Advocate for the person: "If you see something you don't think is in the best interest of the patient, say something!"

Encourage the person – "Practice new skills in fun ways. When being trained to re-use her left hand, we found ways to make the training fun and then rewarded Sammy with a Starburst that she had to unwrap using her left hand. Whatever we could do to make it fun."

Understand that things will not be the same – "Our daughter recovered very well, but still can't manage being in loud, crowded, noisy places and can't process things the same. She is still adjusting to her 'new normal' and is sometimes anxious and overwhelmed."

Encourage the person to talk – "In the same way that the caregiver needs to listen, the patient needs to communicate what they really need, so that the caregiver can take the best possible care of them."

Daughter Sammy...

Sammy had been a competitive dancer since the age of four, so Debbie knew that something was seriously wrong when Sammy said she couldn't keep up anymore, saying "Mommy, my feet won't do what I want them to".

After many visits to multiple doctors and symptoms including weight loss, headaches and a swollen face, Debbie continued to advocate for her daughter and her pediatrician referred her to a neurologist. Five minutes into that appointment, when Sammy's eye started jumping during a simple eye tracking test and she had fallen over during a balance exercise, they knew something was seriously wrong. Sammy was sent for an emergency MRI which revealed a juvenile pilocytic astrocytoma (JPA) compressing her brainstem.

Following her 18-hour surgery, Sammy was told she wouldn't be able to dance again. Debbie told her: "Never accept what they tell you. Listen to it, absorb it, then prove them wrong." Recently, Sammy was awarded third place overall in her category!

Nelson's advice to caregivers.

Accept that it will be hard – "A caregiver needs to understand that this is very, very hard. Your mind needs to be prepared for that from the start, so that you can plan. That way, if it's easier than you think, it will be a relief."

Give yourself permission – "It can overwhelm you like a tidal wave, then you can end up being the one that needs help. Give yourself permission to feel bad / guilty / overwhelmed. It's okay to give yourself a moment to deal with it, but then get back to what you've got to do! You will be surprised at what you can do."

Listen – "Really listen! Your instinct is to help, but you don't necessarily know what the person needs. Debbie had terrible headaches, where her head would lock, she couldn't move, and her skin felt like it was on fire. I learnt to be there, not to touch her, not say anything, just sit next to her and just be there."

Accepting Help

Stress and grief prompt different reactions in individuals. Some people have a great need to share their feelings and others may become withdrawn. Allowing those who love you to share in the experiences of caregiving has many benefits, even aside from the obvious one of lightening your burden of caring.

If family members offer help, take them up on their offer. It may provide focus for them and an outlet for their grief and mixed emotions.

Keeping busy and being task-oriented can be therapeutic for some people. The person living with a brain tumour diagnosis may also appreciate the demonstration of care and affection from others.

What Can Others do to Help?

People often want to help but don't know how. Here is a list of suggested tasks you can ask others to help with:

Fundraise – It's hard for many caregivers to ask for help – especially if it's related to finances. Many people love organizing events and often communities will rally to raise funds for families who may need help with finances while someone is going through brain tumour treatment.

Help in and around the house – For instance; laundry, dusting, clean the kitchen or bathrooms, vacuum, walk the dog, shovel the driveway and walkway, cut the grass, help with fixing odds and ends that may accumulate and are in need of some tender loving care.

Grocery shop or prepare meals to freeze – Asking a friend or neighbour to call or text when they are going to the grocery store; or batch cooking / baking to stock your freezer.

Provide childcare – Set times throughout the week that are most helpful for you.

Run errands – For instance, going to the pharmacy to pick up medications, pick up groceries or dry cleaning, drive children to and from school, daycare, or extra-curricular activities.

Assist with medical appointments – It is often helpful to have a friend provide a ride to medical appointments or pick up prescriptions.

While these things may seem unimportant at times, when they do get done, it will help with easing into your new normal. Bringing family and friends into the circle of care allows others to show their love, reduces isolation, and strengthens emotional bonds.

Brain Tumour Foundation of Canada provides information on a variety of topics in the form of online presentations and resources about brain tumours. This information is available to help you make informed decisions about treatment, to learn about ways to improve quality of life, and to make connections with the brain tumour community. Learn more at www.BrainTumour.ca



Other Ways to Help a Caregiver

When someone asks, “How can I help?” or “Let me know how I can help?” consider printing this list off to give to your friend, family member, neighbour or colleague who offers to help. Alternatively, you can create your own list that is personal to you and your loved one.

Sometimes it’s difficult to think of tasks or ways to help when asked on the spot – this list takes that responsibility away from you as the caregiver and offers your supportive network concrete ways to help:

- Arrange to take vehicles in for an oil change or tune up
- Be the driver; head out for a scenic drive
- Call or text when going to the grocery store; offer to pick up and drop off items needed
- Drop off favourite magazines
- Drop off funny movies
- File and organize paperwork. Create forms or documents to help with organization of emergency phone numbers, appointments etc.
- Fill the bird feeder
- Help with laundry
- Make a playlist of favourite music
- Meal prep or invitation for a home-cooked meal
- Mow the lawn
- Offer to visit with the person diagnosed with a brain tumour while the caregiver runs errands
- Pick up and drop off kids at school or extracurricular activities.
- Rake leaves
- Share a gift card to a local restaurant or coffee shop
- Shovel snow

- Start a food chain with others interested and willing to help
- Take the dog for a walk
- Water plants

Tip to your friends and family who want to help: Offer your time. Be very specific with your offering (i.e.) "I am all yours from 9:00 am – 11:00 am on Saturdays" or "I can walk your dog every day at 4:00 pm when I get home from work."

This list is to remind you there are creative ways people in your life can help and reduce workload and stress.

This list is to remind you there are creative ways people in your life can help and reduce workload and stress. To print this list, please go to www.BrainTumour.ca/caregiver



What Happens If the Help Stops?

Sometimes your friends, family members, and neighbours return to the demands of their busy lives and may forget the impact that a brain tumour diagnosis has had on you and your family.

Encourage people to continue to include you in plans or offer specific suggestions for how they can help. But know that we cannot make people help or care in any precise way. This can be frustrating and hurtful. Be open to other ways that they and others may offer to be involved in your life.

Along with changes in family relationships there may also be changes in friendships. Sometimes the people you most counted on for support are not the ones who come to your aid. The disappointment associated with this realization may be balanced by the pleasant surprise at the individuals who do choose to offer help.



Marie: A Caregiver's Perspective

Marie's Mom lived with a brain tumour diagnosis for many years. "I was just three years old when she was first diagnosed" explained Marie, "the first diagnosis was of a low-grade tumour, but then it came back at a higher grade tumour 12 years later when I was in high school. Then she needed radiation treatments, as she did 5 years after that, and until she passed in 2016."

"I wasn't always the primary caregiver. When I was in high school, my two older sisters would drive Mom to appointments, or my Dad would. When I was in my twenties my Dad moved to Mexico for his work, but my Mom's brain tumour grew, needing surgery, so she returned to live with me until my Dad returned from Mexico."

Marie shares her experience, despite it being challenging. "It wasn't easy. I was essentially still a kid myself and found it hard to deal with the reversal of roles. I wanted my Mom to still be my Mom."

Marie offers this advice for someone caring for someone diagnosed with a brain tumour.

Be aware of personality changes – "Because of the tumour's location in the frontal lobe, my Mom went through personality and behavioural changes that resulted in impulse buying. This meant that she needed 24 / 7 care and she couldn't understand why."

Be accepting – "The person diagnosed won't see the changes for themselves, so you need to accept that. The disease changes the person they were."

Be frustrated – "It's okay to feel frustrated and resentful. It's common to be angry at the disease that has taken the person that you knew."

Be flexible – "There's no training, no manual, not even this handbook can tell you the best way to take care of the person you are caring for. There is no perfect way. Trust your gut that you are doing the right thing for your loved one!"

Don't get caught up in small details – “I was so concerned about whether my Mom was eating healthy food. Now, I wonder if it was worth the time and energy.”

Laugh – “Allow yourself to laugh at the disease. Mom would say some crazy things. I think laughter got my family through it.”

Be resourceful – “At the end of Mom's life, when she entered hospice, my sisters and I all took leave from our jobs to spend time with Mom. Reach out to find out what the government offers in terms of terminal illness leave or employee insurance.”

Marie now works in radiation therapy, her decision to work in oncology was inspired by her Mom's experiences with a brain tumour diagnosis.

Finding the Right Words

Caregivers often experience higher levels of stress while supporting someone with a brain tumour diagnosis. Uncertain prognosis, prolonged treatment, reduced life span, as well as personality changes and memory deficits are common, either from the brain tumour itself or a side-effect from treatment.

A brain tumour diagnosis is very different from other types of cancer and other non-brain related diseases due to the complexity of supportive care needs, potential personality changes and / or communication challenges.

The one thing that you can do as a caregiver is to keep the lines of communication open. Feelings of anger or frustration are natural and common among caregivers. You may be angry about the way your relationship with the care-receiver is changing, or about your new role as a caregiver.

Many caregivers feel frustrated because of their inability to meet all the needs of the individual or to balance their caring roles and their own personal lives and identity. Some may feel angry about the physical / mental changes the person diagnosed with a brain tumour is experiencing.

If you find yourself getting angry at the person you are caring for, stop and take a break; regular breaks are vital and reaching out for help is just as important.

Conversation Starters

The right level of communication is key; if you are both consumed with talking about the brain tumour diagnosis, treatments, side-effects and so on, challenges will arise for the both of you. If you never talk about the brain tumour diagnosis, then that can become a challenge as well.

Here are some examples to help initiate dialogue around your loved one's brain tumour diagnosis:

- "I notice that when we start to talk about your brain tumour diagnosis this can make you feel uncomfortable. I am here to support you and it really helps me when I know what you need."
- "I feel that we always ignore what is happening with your health and that makes me really scared. I really want to help and support you the best I can, and I am wondering if we can have a chat about what you need from me."
- "I feel like all we do is talk about how you feel. Let's take 10-minutes to think about our next adventure together."

Knowing what to say (and what not to say) when your someone has been diagnosed with a brain tumour is upsetting and sometimes we don't know what to say. Talk to the person to gain an understanding of how they feel and what support would be best for them.

Here are some suggestions for those times you feel stuck for words:

Instead of Saying	Consider Saying
"Don't worry, I'm sure you'll be fine."	"This sounds incredibly hard for you, let me know how I can help." Be a shoulder to cry on. Let people talk, cry, vent and give them time to do so. Just listening, and acknowledging how they feel, can often be enough, because sometimes just knowing someone's there is all they need.
"You don't look like you have a brain tumour."	Sometimes our intent is to give a compliment, yet it doesn't feel this way for the person diagnosed with a brain tumour. Symptoms like fatigue, or impact on memory, and difficulties with communication are all challenging side-effects of a brain tumour. Remember, just because you can't see the symptoms, does not mean they're not there.
"You're such an inspiration! You're so brave!"	Some people we've spoken to have found this type of comment frustrating and impersonal, explaining they haven't asked for this and it was not a challenge they wanted to face. Talk to your loved one and ask if this would upset them. If so, talk about how else you can express your respect for them.
"I bet you are glad treatment's over."	It's easy to assume that just because someone has finished their treatment they'll be happy about it. The truth is, finishing treatment can be a scary time and the long-term effects of treatment can be just as difficult.

Instead of Saying	Consider Saying
"I know someone who had a brain tumour," or "I know how you feel."	"Whatever you decide I'll be here to support you. If you want to talk about it, please let me know."
And when you really aren't sure what to say...	"I wasn't sure what to say but I just wanted to let you know I care / I'm here for you."

It can be unnerving to hear that someone you care about has been diagnosed with a brain tumour, and it's completely normal to struggle with what to say. But honesty and compassion make the best policy, and if you're worried and don't know what to say, you can say that. Saying something is better than saying nothing.

Brain Tumour Foundation of Canada is here with support for anyone affected by a brain tumour, including the person diagnosed, their friends, relatives and caregivers. Support groups provide a safe space to share your experiences, ask for advice, and seek support from others in a similar position.

There are in-person groups, groups that meet online, and Closed Facebook Support Groups. Find out more about all the ways that Brain Tumour Foundation of Canada offers support at www.BrainTumour.ca/support



Talking to Your Child Diagnosed with a Brain Tumour

A child's level of understanding can be underestimated, it is important to be honest and build trust with your child as you go through the process of diagnosis and treatment. Your child's age and maturity should help you determine how much information and detail to disclose. Discussing the diagnosis openly allows your child to ask questions about what is happening and helps the child express any feelings they may want to share.

Sometimes, reading stories encourages discussion with young children. If you are caring for a child diagnosed with a brain tumour, Brain Tumour Foundation of Canada offers a free children's storybook called *A Friend in Hope*. This story takes you through a little girl's diagnosis of a brain tumour through the eyes of her best friend Danny. Alternatively, if it's an adult in your family that has been diagnosed with a brain tumour, sometimes parents utilize this book as a guide to talk to younger children about brain tumours in general.

*To order *A Friend in Hope*, please visit
www.BrainTumour.ca/storybooks.*

*And for age appropriate language, please
refer to www.BrainTumour.ca/caregiver*





Karen: A Caregiver's Perspective

Karen describes her fourteen-year old daughter Mckenna as happy and quirky.

She was always even-tempered as a young child, but when she was almost five, she started exhibiting unusual symptoms like not being able to bend her head back, vomiting, and complaints about neck pain.

In 2010, Mckenna was diagnosed with a non-malignant brain tumour called a juvenile pilocytic astrocytoma (JPA). She underwent two surgeries in London, Ontario, which is a two-hour drive from their home in Windsor.

"It was a time of crisis for us," says Mckenna's mother Karen.

"In addition, we have another child who we also needed to consider."

To focus on Mckenna while also accommodating her younger brother Blake, Karen and her husband leaned on her parents to have him for sleepovers and other support. This time allowed them to put 100% attention on her, while Blake's grandparents did the same for him.

Karen shares several other helpful tips for parents.

Practice mutual respect – "My husband and I respected each other's feelings and how the other deals with things. We were never at odds with one another this way."

Take help from others – "People would ask us what they could do to help, and we would give them suggestions. Remember that it makes people feel good to be able to help."

Manage the possibilities – "Deal with the facts in front of you because there are so many things that you may never need to deal with."

Responsible Googling – "Limit your research to reputable sources like Brain Tumour Foundation of Canada and well-known medical sites."

Set-up success for life – “You can’t have a brain tumour and not think something will give. Be proactive in setting up an Individual Education Plan (IEP) at school, appointments with neuropsychologists, child-life specialists, and setting up mental health services in advance.”

Don’t make the hospital a scary place – “We ensured that our son was just as much a part of the experience as Mckenna. The Child-Life Specialists included him in crafts and games.”

Social media – “We maintained Mckenna’s privacy and did not share her experience on social media. Instead, we designated a friend who emailed our support network with news, updates, etc.”

Take breaks – “Go for a half-hour walk and don’t feel guilty about self care.”

Mckenna now leads a healthy life. One of her passions is selling glitter tattoos as a fundraiser for Brain Tumour Foundation of Canada, while her mother is the coordinator for the Brain Tumour Walk in Windsor, Ontario. “What happened to Mckenna continues to shape our daily outlook in life,” says Karen. “You don’t want to relearn the lesson that life is precious.”

Advance Care Planning

Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate.

Advance Care Planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself.

It means having discussions with family and friends, especially your Substitute Decision Maker – the person who will speak for you if you cannot speak for yourself. It may also include writing down your wishes and talking with health care providers and financial or legal professionals.

One thing is for sure, advance care planning is NOT only for the person diagnosed with a brain tumour, it is important for all of us (regardless of health status) to go through the process of advance care planning and have open dialogue with our loved ones about future wishes.

In Canada, the best resources and current tools for advance care planning are found online with the Speak Up Campaign. The Speak Up Campaign is part of a larger initiative for Advance Care Planning in Canada and is overseen by a National Advance Care Planning Task Group comprised of individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organizations.

For the most up-to-date tools and resources used by province, please visit www.AdvanceCarePlanning.ca



Kyle: A Caregiver's Perspective

During the Christmas holidays of 2014, Kyle and his wife Leanna were walking their dog and thought that life couldn't be more perfect. They were spending the holidays nestled in the Canadian Rockies. In May, their son was born and as Kyle puts it, "things were going so well."

Earlier that year, Leanna complained about headaches and was believed to be suffering from postpartum hormone changes. On January 1, 2015, a scan confirmed that she had a Grade 3 anaplastic astrocytoma.

Surgery, radiation and chemotherapy followed but the tumour came back in December 2016. She went back on daily chemo the following month, which caused a great deal of swelling and severe headaches.

She was prescribed a high dose of steroids which, following prolonged use, caused Cushing's Syndrome which ate away at her lean muscle and caused insomnia, moon face, and a buffalo hump on the back of her neck.

With her illness and side effects, Leanna was not able to care for their son and Kyle took on the role of the primary family caregiver.

"It was a massive transition to be caring for her, our son, and the dog," he says.

Adding to the stress was the fact that he is a private person. It was difficult discussing with others, and family and friends did not know how to bring up the subject.

Kyle felt fortunate to work for a company that supported mental health, which educated all employees to be sensitive to such issues. "It was a huge relief to know that my employer and co-workers supported me and Leanna. It was one thing I didn't need to worry about."

Kyle tapped into Brain Tumour Foundation of Canada for help and offers the following advice:

Develop systems – “I’m an engineer and my job is all about developing strategies. As much as you can, outsource the day-to-day tasks like meals. In our case, we registered our son for daycare earlier so Leanna could rest, and I could focus on caring for her during the day. It was a worthwhile extra cost.”

Seek help for yourself – “Whether it’s supportive counselling or medications for your mental health, talk to your medical professional. I battled through my anxiety because that’s what guys are supposed to do. After some time, I asked my family doctor for help and started taking medication, which made a huge difference. Remember – as a caregiver, you need to take care of yourself in order to be able to take care of those you love.”

Keep a journal – “I started keeping a journal to write down my thoughts. It makes you feel better when you get them out of your head and onto the paper. ”

Access the brain tumour community – “Here we found a community of people who really understood our situation and made us feel part of the community. Find brain tumour events and support in your area.”

“It’s tough being a caregiver, but I am grateful to share my story as a way to help other people.”

Practice Self-Compassion

Once we accept and acknowledge our feelings, we can get a handle on addressing them. Self-compassion is the act of having empathy for oneself. Self-compassion has nothing to do with a pity party or weakness, and everything to do with acknowledging the reality of how we are feeling to help cope with challenges more effectively and constructively.

The practice of self-compassion offers a way to forgive yourself for perceived mistakes or experiencing certain feelings; it allows you to acknowledge and comfort yourself during difficulties that may arise as part of your role as a caregiver.

Self-compassion is a non-judgmental curiosity about and warm acceptance of how we are doing, with the intention of supporting ourselves accordingly through those feelings, just as we would someone else. It enables us to reduce our stress by more effectively identifying and addressing our needs.

Practice Stress-Reduction Techniques

Many caregivers have trouble taking care of their own needs as they provide so much care for the needs of others. Whether you feel guilty for taking time out for yourself, or if you just feel like you don't have the time to take, consider this perspective: If you don't take care of yourself, you won't have anything left to give!

Be mindful – Take a few minutes a day to practice being mindful focusing only on what's going on in the present. Try taking a short walk or lay down and instead of thinking about what's worrying you, pay attention to your senses – what you see, feel, hear, smell. This can make a huge difference in your emotional and physical well-being.

Breath focus – Deep breathing is a simple, yet powerful relaxation technique that can be practiced almost anywhere and provides a quick way to get your stress levels in check. Deep breathing is the cornerstone of many other relaxation practices too.

Repetitive vocalization – For this technique, you silently repeat a short prayer or phrase while practicing breath focus. This method may be especially appealing if religion or spirituality is meaningful to you.

Laugh – Watch a funny TV show, hang out with friends who make you laugh.

Listen to music or dance – Music can act as a wonderful, stress-reducing backdrop to everyday tasks, or have a one-person dance party! It feels great!

Meditate – While quick meditations are great for dealing with acute stress, a regular meditation practice will help build your overall resilience to stress.

Write it down – Gratitude may help relieve stress and anxiety by focusing your thoughts on what's positive in your life.



Theresa: A Caregiver's Perspective

Theresa was very close with her father.

In 2001, he passed away at age 47 from a twenty-month battle with a glioblastoma (GB). Only two years before she also lost her older brother in a car accident.

It was a volatile situation when her father was diagnosed with GB. His diagnosis was difficult for various family members to process and it sent them into crisis mode.

At the time, Theresa was 26 years old and had to step into the role of caregiver and advocate for her father.

"I became his voice when he couldn't speak," says Theresa.

"I was so close with my dad. He was the easiest person to care for."

With the mental and physical toll that caring for her father took, Theresa believes that she suffered from post-traumatic stress disorder (PTSD) for nearly two years after his death. Insomnia, grinding her teeth and an inability to focus were some of the symptoms she had experienced.

She feels blessed that she was able to be there and care for her father, but "being a caregiver was all-consuming".

Theresa shares some advice for those caring for a parent or a loved one.

Get respite – "My aunt, mom, grandmother and I had a system for caring for my dad - 2 days on and 2 days off. This meant there was always someone with him and allowed two of us to have a break."

Access a support group – "My parents are from a small town. At the time of my dad's illness, we didn't know about brain tumour support groups but found them helpful afterwards. When I moved to Calgary, Alberta I started a support group where patients and caregivers met monthly. This was therapeutic for me."

Know when to act – “When it becomes a safety issue and you can’t care for them any longer, know when to go to the hospital.”

Designate a Power of Attorney – “I was my father’s POA for health care and really advocated for what he would have wanted in his care.

Choose someone who puts the patient first – “As well, “there are many tough decisions to make and conversations to be had that should be done ahead of time while your loved one is of sound-mind.”

Be there for them – “Everything the person could once do is taken away from them. Help them by doing it with dignity, respect and happiness.”

Practice self-care – “My self-care was spent going out for coffee with friends. I didn’t take proper care of myself and if his illness had lasted any longer, I don’t know if I could have survived it. Go for walks or meditate – the more you care for yourself the better you will feel.”

Theresa cherishes the final moments she spent with her father, and she keeps his memory alive by telling stories about him to her own children.

“I’m letting them know what a great person he was and that he would have been the best grandpa.”

Caregivers – A Vital Member of the Team

As the primary caregiver, you are a critical member of the person's health care team. In addition to reporting and monitoring symptoms, caregivers help organize medications and medical appointments, provide comfort and emotional support, while overseeing all the usual demands of work, school, and home.

Your care contributes significantly to your loved one's health and well-being and facilitates the health care team's efforts to provide professional care. As we discussed in previous chapters, your role as a caregiver may at times cause stress and challenges resulting in financial, physical, psychological, or professional hardship.

Learning how to navigate the health care system and accessing resources will make your job as a caregiver easier and less stressful. Look for guidance from your health care team, including your family doctor and benefit from the expertise of professionals. For example:

If you have a concern about	Speak to
Treatments, side effects, complementary therapies	Oncologist, nurse, or pharmacist.
Work or financial issues	Social worker
Spiritual or religious issues	Clergyman, pastoral care professional, social worker, or counsellor.
Nutrition	Dietitian, oncologist or nurse.
Speech, language, or swallowing problems	Oncologist or nurse. A referral to a speech language pathologist may be helpful, and in some centres an occupational therapist can help as well.
Visual problems	Oncologist, nurse, optometrist, or ophthalmologist.

If you have a concern about	Speak to
Difficulties experienced by patients with respect to regular activities, like walking, dressing, bathing, household responsibilities	Start by speaking to your health care team – they may suggest an occupational or physiotherapist, physiatrist, or a rehabilitation program. Additional care providers in the home may be appropriate. A handicapped parking permit may also be useful.
Hearing problems	Oncologist or nurse. An audiologist may also be helpful.
Increasing care in the home	Doctor or nurse can suggest help through community nursing, social work, physiotherapy, occupational therapy.
Accessing hospital equipment at home	Doctor, nurse, social worker, community care providers. The Red Cross loans equipment and your health care team can advise you about this.
If memory problems are present or change	Neuropsychologist may recommend a neuro-cognitive assessment.
Going back to work or school after treatment	A rehabilitation specialist can help with strategies for a successful re-entry into your work or academic program. Ask your doctor or nurse about a rehabilitation program to help with impairment in speech, mobility, memory, or thinking.

There are many ways you can be active in the care of your loved one. Keeping the lines of communication open with the person diagnosed, family members, and the health care team is essential. Do not be afraid to ask questions and write down the answers. It is often easy to forget specific instructions when trying to understand everything that is happening. Having answers and instructions written down will often help you manage during difficult times or when fatigued.

Speak to your health care team about ways you can improve and sustain your caregiving experience.

For a suggested list of questions to ask the medical team, please visit www.BrainTumour.ca/caregiver.



Janet: A Caregiver's Perspective

In August of 2016, the beloved Canadian band The Tragically Hip, performed their final concert in Kingston, ON. Their fans gathered across the country to watch the televised event – on cottage docks, neighbour's backyards, and the comfort of their living rooms.

Earlier that year, the band announced their lead singer, Gord Downie, was diagnosed with a terminal brain tumour.

"I remember driving in the car and hearing his doctor on the news," says Janet. "For the rest of the day more information came out about the type of brain tumour he had called a glioblastoma (GB)"

Janet watched the concert with friends at a Toronto movie theatre. Little did she know that less than a month later her 47-year-old husband Adam would be diagnosed with the same disease.

She recalls hearing the news. "There was really nothing good the doctor said, and that really bothered me." Later she turned to her husband and said, "Okay, we know what it is so let's get our team together and deal with it."

Janet still gets emotional thinking about that moment and her fierce determination to help him fight. And it continues today, almost three years later.

As a caregiver, she established several rules and guidelines for their path forward. She shares them here for others to consider:

Build your team – "It's important to have the best medical professionals for YOU. Spend time researching and meeting with specialists in advance of the surgery or treatment to ensure that you are a good match. Do they take time to answer your questions? Do you feel they are good listeners? What kind of care pre and post procedure can you expect?"

Have an outlet – “Spend quality time together, but also find those moments that are just for you. Use it to release tension and the heaviness of your role. Read a book, do yoga, or any other activity that brings you pleasure. Use it to recharge.”

Be honest – “People mean well, and they want to cheer you up when they think that’s what you want to hear. But many times, that’s not what I needed. Give yourself license to say, ‘it’s awful’ or ‘it’s not okay’ and even curse without worrying that it will offend or shock someone.”

Ease financial burdens – “Seek out possible government tax incentives and monthly allowances available to caregivers.”

For parents – “I contacted my children’s school principals and home room teachers to alert them of the situation at home. I also mentioned it to some of their friend’s parents. In case my kids weren’t talking about it, I felt better knowing that others were watching out for them.”

Support in the brain tumour community – “The people that will know what you’re going through the most are those who have been through it too. Find out about counselling, online and support options through Brain Tumour Foundation of Canada.”

Cognitive Effects of Brain Tumours and Treatments

Cognitive deficits can occur because of the tumour, its treatment, or both. Cognition is the process by which a person is aware of, perceives, or comprehends ideas. It involves all aspects of perception, thinking, reasoning, and remembering.

Some of the deficits a person diagnosed with a brain tumour may experience include difficulties with memory, attention, orientation, language abilities, problem solving, and creativity. These functions could be affected either temporarily or, in some cases, permanently.

Depending on the tumour size and location, as well as the treatment given, these changes can be quite unique. If your loved one experiences changes in cognitive function, an assessment from a neuropsychologist can be requested.

Neuropsychological testing provides an in-depth assessment of cognitive and behavioural functions. The examination will test for strengths and weaknesses. Strategies can be put in place to help cope with changes and regain cognitive functionality.

Memory Loss

Short-term memory loss is a frequent challenge reported by people diagnosed with a brain tumour. Often, it is attributed to radiation therapy; however, surgery, chemotherapy and the tumour itself may play a role.

Some short-term memory loss may get better with time, but all too frequently it becomes a permanent reality of daily life. There are many tools you can adapt as a caregiver to help you're the person with short-term memory loss.

Sleep Difficulties

Cognition is a broad term, which encompasses a variety of mental processes including memory, problem solving, language, forward planning, and attention, which can all be differentially affected by inadequate sleep.

A person diagnosed with a brain tumour may have difficulty with sleep patterns at times. There are many factors that can influence sleep such as surgery, anesthesia, chemotherapy, radiation, and medications. Some of these treatments may cause sleep difficulties that last many months.

Because living with a brain tumour changes the course of a person's life, there are many factors that may also contribute to sleep difficulties, such as coping with a life-threatening illness, depression, financial concerns, and family worries.

Encourage your loved one to speak to a professional if you feel these worries are interfering with sleep. Sleep is important for healing and recovery.

Strategies to Support Cognitive Effects

Unless we experience a significant cognitively disabling condition, we may take for granted how much non-essential information we filter out on a day-to-day basis. A brain tumour may result in slowed processing, reduced ability to sustain, divide attention, or multi-task. These issues are sometimes presented from caregivers as concerns their loved one is not listening or ignoring them. This is due to reduced attentional resources and competing with environmental stimuli.

Here are some general strategies to help address some difficulties:

- Complete tasks during “peak” times of alertness and attention.
- Encourage your loved one to pace themselves and rest as often as needed throughout the day.
- Implement a daily routine to reduce active processing of mundane tasks (i.e.) always leave keys in the same place.
- Make short and long-term goals; break tasks into manageable chunks to be completed in a logical, step-by-step sequence.
- Leave notes in prominent places (i.e.) a list of the morning routine on the nightstand.
- Reduce distractions (internal and external) and avoid interruptions when completing tasks. (i.e.) turning down the TV when speaking to your loved one.
- Reduce the number and complexity of tasks to complete; intersperse easy and fun activities.
- Use alarm clocks, to-do lists, or a daily planner to keep track of medications, tasks, and appointments.
- When communicating with your loved one, engage in communication with the person in front of you and use eye contact when communicating with your loved one as much as possible.
- Draw the individual’s attention by making physical contact (light touch of arm or hand) while calling their name and making eye contact.
- Use sub-vocal reminders and reorientation when completing tasks.

Sub-vocal reminders are when a person practices internal self-talk to help stay in the moment to ensure they do not lose their place in a list of steps they are carrying out. An example would include medication management. If a person must always take their medication before bed, they may be already going through a sub-vocal rehearsal as they are brushing their teeth (e.g. “Ok, after I finish brushing my teeth, I am going to take my medication and then go to bed.”)



Laurie: A Caregiver's Perspective

Laurie and her husband James have been married for fifteen years.

"Our life was full of spontaneous day trips," says Laurie. "James and I really enjoy nature and throughout our marriage have gone on regular hikes, drives without knowing our destination, and day trips to Niagara Falls."

All of that changed in 2013 when James was diagnosed with oligodendroglioma in his frontal lobe. He underwent resection of the tumour followed by 7 weeks of radiation and 12 months of chemotherapy.

What was anticipated to be a few days in the hospital turned into months of rehabilitation for a permanent brain injury. Nothing could have prepared Laurie for the changes that would follow.

"The surgery impeded day-to-day activities for him such as orientation from day and night, confabulation (or misinterpretation of memories), word confusion and an inability to be a full participant in daily household decisions."

"The first year didn't allow for much time or energy to engage in anything outside of the immediate world of appointments. Over time I worked to engage with more activities outside of the home to maintain a sense of self."

Laurie shares what she learned over the years, along with offering advice to other caregivers on dealing with the stress, hardship, and sadness associated with caring for a loved one with a brain tumour:

Stay organized – "I created an Excel spreadsheet with doctors / health care team information, medications and medical expenses that was a real time-saver at appointments with new specialists and hospital stays."

Start a new hobby – "I am an avid paint night goer with friends or on my own. I work on other hobbies indoors during the winter and love gardening in the summer."

Access counselling services – “Don’t be afraid or too proud to engage a therapist. It could be a space to vent all the things you can’t say to your loved one or others.”

Find joy and happiness – “It is a battle to relax into happiness and breathe in the good moments but it’s necessary to get you through bad days.”

Know when to take a long break – “Caregiving is a marathon not a sprint. If you find that you are perpetually exhausted and short breaks aren’t enough anymore, organize some guilt-free time to restore your energy. Trust your ability to care for yourself as well as you do for your loved one. Give yourself what you need so that you can refresh and keep going for the both of you.”

While Laurie works full-time, James is now volunteering at a thrift store and participates in an acquired brain injury program. As challenging as the path has been, she says, “My husband is my best friend and I will do whatever he needs.”

Tips for Long Distance Caregivers

A diagnosis of a brain tumour affects the entire family. A person diagnosed with a brain tumour may need more and more help as the disease progresses.

Today family members often live at some distance from each other. When a relative needs increasing support, caring from a distance presents additional and unique challenges.

If you live an hour or more away from a loved one you care for, you are a long-distance caregiver.

Long-distance caregivers can play several roles for their loved one diagnosed with a brain tumour, here are some examples of how you can help:

- Arrange to stay with the person while his / her primary caregiver takes a long-break or goes on vacation.
- Communicate regularly with your loved one to offer emotional support (writing and phoning them or contacting them with a video application).
- Coordinate information (facilitating the transfer of information between health professionals, conducting searches to find information about clinical trials and treatments, or help navigate local programs and services to meet their needs).
- Establish a local network of contacts you can reach. If the distance is great, organize visits from neighbours, church members, or friends and family on a regular basis, with a follow-up to see how your loved one is doing. Professional caregivers or a volunteer visiting program can also be a great resource for care and companionship when extra support is needed.
- Help get paperwork in order in case of an emergency including wills, substitute decision-maker, power of attorney for personal care, advance care planning etc.

- Help with finances or getting bills paid.
- Keep family members and friends informed.
- Offer to have the home assessed to ensure it is a safe environment.

Schedule a family meeting. You and other family members should discuss what your loved one needs, who can help, and in what ways. Have the meeting by phone or a video application.

Bill of Rights for the Brain Tumour Caregiver

I have the right to...take care of my own health, spirit, and relationships.

I have the right to...seek help from others even though my loved one may object. Only I can recognize the limits of my endurance and strength.

I have the right to...accept help that is offered to me by others.

I have the right to...receive consideration, affection, forgiveness, and acceptance for what I achieve as a caregiver and offer these qualities in return.

I have the right to...get angry, be depressed, and express other difficult feelings occasionally.

I have the right to...take pride in what I accomplish, and to applaud the courage it takes sometimes to meet the needs of my loved one.

I have the right to...protect my individuality and the right to make a life for myself that will sustain me in the time when my care-receiver no longer needs my full-time help.

I have the right to...expect and demand increased awareness and support to find resources to aid me in caring for my loved one.

I have the right to...maintain facets of my life that do not include the person I care for, just as I would if he / she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.



braintumour
foundation
OF CANADA

205 Horton St E, Suite 203, London, ON N6B 1K7

519-642-7755 | 1-800-265-5106

www.BrainTumour.ca



©2019 Brain Tumour Foundation of Canada

All rights reserved. Printed in Canada. No part of this handbook may be used or reproduced in any form or by any means, or stored in a database or retrieval system, without prior written permission of the publisher. Making copies of this book for re-sale purposes is against the law.