Going home after brain tumour surgery

A guide for patients, families and caregivers

Read this guide to help you:

✓ manage your self-care when you return home
✓ cope with changes after surgery
✓ learn more about changes in your ability to exercise and be active
✓ learn more about changes in your ability to think or speak

The information and resources inside will help you and your loved ones find the support you may need and make the transition to home easier.

This guide is for information only.
It does not replace the advice of your surgeon and health care team.
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This guide was created by a team of health professionals who provide care to people after a brain tumour. Try to read the parts of this guide that are most important to you at any given time. You may not want to read the entire guide at once.
Getting the diagnosis

Getting the diagnosis of brain tumour can be overwhelming. The diagnosis may be difficult and unexpected. It is normal to grieve. You may feel anger, sadness, and fear or experience a period of denial.

How can I best cope with my diagnosis?

✓ Get the right amount of information for you
You may want as much information as possible from the start, or you may wish to learn things slowly over time. Let your health care team know what is right for you.

✓ Get information from reliable sources
For example, your health care team, a public library or a UHN Patient & Family Library.

✓ Prepare for possible changes in your energy level, strength, speech, memory and thinking
This booklet and the resources at the end can offer you information to help you with some of these changes.

✓ Accept help from others
A strong support system will allow you to better cope with any challenges you may face. Don’t be afraid to ask for help.

✓ Take part in activities that you enjoy
Do something you enjoy that helps you to take your mind off your worries.

✓ Set small goals
Take one step at a time. Remember there are many things that you can enjoy and accomplish each day.

✓ Be patient
You may have to wait for results and meetings with your health care providers to get the answers you need about your diagnosis and treatment. It’s normal to feel anxious while you wait. Use this time to find support and take care of yourself physically and emotionally.
Attend support groups

Brain tumour support groups allow you to share your experiences with others in a safe and relaxed atmosphere. See the Resource section for a list of support groups.

Get help from a trained counsellor

Ask your doctor to refer you to an appropriate service if you feel that you are not coping with your diagnosis despite all your efforts.

Practice stress management

There are many classes, videos and mobile apps that can help you learn different meditation and relaxation techniques. Your hospital Patient and Family Library or your local library can help you find some of these resources.

What is Advance Care Planning?

Advance care planning is a process of making plans about your future health care.

It includes:

1. Appointing a person (or more than one person) who will act on your behalf. This person is called a Power of Attorney (POA). A Power of Attorney for personal care is someone you trust and legally choose to make health decisions for you if you are not able of make them for yourself.

   If you do not have a Power of Attorney for personal care, a Substitute Decision Maker (SDM) will make decisions on your behalf, according to a list set by the government.

2. Expressing your wishes about care that you want or may not want. This is called an Advance Care Directive. An Advance Care Directive is a document that guides your POA or SDM on what medical treatment and care you want and do not want if you cannot speak for yourself. Your POA or SDM will share this information with your health care providers.

   See the list of resources at the end of this booklet to help you plan and write down your wishes.
Making your home safer after brain tumour surgery

It is important to do all you can to stay safe at home while you recover from your brain tumour surgery and cope with your condition. Here are some tips and suggestions that may be right for you.

Moving around

- Do not wear just socks or slippers when walking around the house. Wear proper fitting shoes with good soles and ankle support.
- Take away any loose rugs. Secure carpets to the floor.
- Move electrical cords out of the way.
- Make sure hallways, stairs and rooms are free of clutter.
- Make sure there are solid hand rails all the way along the staircase.

Lighting

- Make sure there is enough light in all rooms, especially over the stairs. Leave a light on at night in areas such as the bathroom or hallway.

In case of emergency

- Have smoke and carbon monoxide detectors on each floor. Test them regularly to be sure they work.
- Put telephones in rooms that you use often or carry a cell phone with you.
- Consider using a medical alert system if you will be home alone. Search the Internet under Medical Alert Systems for companies that offer this service.

In the bathroom

- Install an 18 inch grab bar vertically on the faucet wall of the bathtub above the tub rim to hold on to when getting in and out of the tub.
- Use a bathseat if you are feeling tired or you are having problems with your balance.
- Use a handheld shower hose to reach all parts of your body easily.
- Use a non-skid bath mat inside and outside the bathtub or shower.
- A raised toilet seat, with or without arms, makes it easier to use the toilet.
**In the bedroom**

- Keep a phone and light by your bed.
- Make sure there is a clear path from your bed to the bathroom.
- Make sure your clothes are in a place that is easy and safe for you to reach.
- Get out of bed slowly to keep your balance.

**In the kitchen**

- Keep the things you need within reach.
- Use kettles and small appliances that turn off by themselves, such as a microwave.
- Do not stand on stools, ladders or chairs.
- Sit to prepare food.

**If you use the stove:**

- Turn pot handles to the back of the stove. Use pot holders to prevent burns.
- Consider using the back element instead of the front element.
- Make sure stove dials are clearly marked.
- Use a timer to remind you to turn off the stove.
How to stay safe when you go outside your home

- Make sure there are outdoor lights over entrances and paths.
- Avoid sidewalks that are not clear of ice, snow and wet leaves.
- Avoid going out when the weather is bad.
- Wear boots with a rubber sole and good treads in the winter and when it rains.
- Only cross the street at traffic lights and crosswalks.

When can I drive?

For many people, driving is our link to the outside world. We drive to our friends and family, the grocery store, the movies, activities we love to do and many other important destinations. Sometimes, a brain tumour can lead to changes which may make it unsafe for us to drive a car.

These changes may include:
- Muscle weakness, fatigue or both
- Problems seeing
- Seizures
- Reduced ability to focus on the road and traffic
- Side effects from medication, like feeling very drowsy or tired

In most cases, it is best not to drive until your follow-up visit with your surgeon, about 6 weeks after your surgery. If you still have any of the above changes at the time of your visit, you will be asked not to drive.

Ask your doctor whether it is safe for you to drive if:
- You are taking narcotic pain medication
- If you have had a seizure during the past 6 months
Who else can help me decide whether it is safe for me to drive?

If you have questions about your ability to drive safely, talk to a member of your health care team about a referral to a Driving Assessment Centre. The Centre staff will check how you are driving and may suggest ways to adapt your car so that you can drive safely.

If you are not able to drive after your brain tumour surgery, there are other ways you can get where you need to go. See the Resources section for alternate options for driving.

What about intimacy and sex?

It is common to have concerns and questions about sex and sexuality during and after brain tumour treatment.

For example, you may experience one or more of the following:

- Less interest in, or energy for sex
- Pain that interferes with sex
- Trouble with positioning or body movements
- Changes in arousal (difficulty having or maintaining an erection, vaginal dryness, difficulty having an orgasm)
- Less feeling in certain body parts

Your relationship with your spouse or partner may be affected by the stress of your diagnosis or any changes in mood and personality caused by your brain tumour. Feelings of closeness may also change because you or your spouse or partner is suddenly the caregiver in the relationship.

If you have experienced any of these changes, you are not alone.
What can couples do?

Remember that intimacy is more than just physical sex.
- Show affection and touch often.
- Spend time cuddling, kissing and touching.
- Enjoy holding hands and simply relaxing together.
- Read together in bed.
- Say, “I love you” to your partner every day.

Communicate with your partner
- Talk openly about your worries and anxieties related to intimacy and try to listen to your partner without interrupting.
- Talk about things you can do and enjoy together as a couple.
- Work together as a team. This can help you feel more secure and in control.

Be creative
- Go on dates together.
- Be playful. Wear clothing and lingerie that make you feel confident and sexy.
- Guide your partner and explore your desires together.
- Try new positions.
- Don’t be shy to try using sex toys. There are plenty on the market.

Be practical
- Use the bathroom before you have sex if urinary incontinence is an issue.
- Take medication for pain, but check with your doctor or pharmacist about what is right for you and to avoid any medication interactions.
- Plan to have sex at times when you have more energy.
- Have lubricants nearby.
- You may choose to take a bath to feel refreshed and relaxed.

Live healthy
- Exercise and healthy eating boost energy, mood and self-image. This can help with your overall interest in and energy for sex.
- Relaxation techniques can reduce stress anxiety and muscle tension.
What types of changes might I experience after my surgery?

This picture shows the different parts of the brain and some of the body functions each part controls.

It is not possible to predict the exact changes you may experience after your surgery, but location, size and type of tumour will play a role.

For example:

- If the tumour is in your cerebellum, you may have problems with balance or coordination.
Changes in exercise and activity after your brain tumour surgery

Will my brain tumour affect my physical activity level?

Your brain tumour may or may not change your physical activity level.

This will depend on:

• The location, size and type of tumour
• How well you recover after your surgery
• Side effects of any medications you may be taking

What should I think about before exercising?

• Know what movements you can do safely.
• Listen to your body.
• Be aware of how you feel as you exercise or do an activity. For example, a headache or feeling very tired is usually a sign that you are doing too much, too soon.
• Choose activities that you enjoy. Exercises should make you feel better, not worse.

What might help me to keep going?

• Exercise with a friend or family member.
• Remember that any amount is better than none.
• Drink plenty of water, unless advised otherwise.

What types of exercises are helpful for me to do?

Walking is the best exercise — indoors or outdoors — if safe to do. Continue any exercises your health care team has suggested for you.
Here are some examples of exercises you may want to try. Talk to your doctor or physiotherapist to make sure they are safe for you before you start. Make sure you exercise safely. For example, do your exercises with someone next to you or use a railing or other support.

<table>
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<tr>
<th>Strengthening exercises</th>
<th>These can be everyday tasks such as:</th>
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<td></td>
<td>• Sit to stand, stairs, seated marching, seated leg straightening, chair push-ups</td>
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<th>Dexterity and coordination</th>
<th>Use exercises that are right for your level of coordination, such as:</th>
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<td>• Picking up safety pins, rice granules, writing, keyboarding and texting</td>
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Do the following while sitting:

• Tap your feet, make circles with your feet, roll a ball under your foot, try to place or throw items at or into a target, such as a garbage bin

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<th>Balance</th>
<th>Some examples are:</th>
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<td>• Heel/toe walking along a straight line, standing on one leg</td>
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What activities can I do at home?

Try to slowly return to your everyday activities once you get home.

• Take part in preparing simple meals, such as cutting and chopping vegetables.
• Do some light household work like folding laundry, washing dishes.

Increase your fitness by doing these everyday activities.

Talk to your doctor before you:

• Lift, push or pull anything heavier than 10 pounds (5 kilograms)
• Go to the gym or do your regular exercises
Using your energy wisely after brain tumour surgery

It’s important to your recovery to save your energy and use it for the most important things you need to do.

How can I use my energy wisely?

Spread your activities throughout the day
- Spread out the work
- Do work over several days, instead of all at once.
- Divide big tasks into small steps that you can manage.

Plan
- Make a list of activities you need to do ahead of time.
- Make sure you plan time for breaks.
- Plan to do the hardest tasks when you have the most energy.

Set priorities
- Set realistic goals that you can achieve.
- Do important things first.
- Leave other tasks for later or for someone who can help.
- Learn to say “no”. Do not worry about pleasing others.

Make it easier
- Sit when possible.
- Take many short breaks during any activity.
- Learn to take breaks before you get tired.
- To help you rest, take slow deep breaths.
- Keep things close. Store items you use most often within easy reach.
- If you have to carry something in your arms, hold it close to your body.
- Use aids to save energy; for example, a reacher, jar opener, trolley.
- Make sure you can reach things easily to avoid fatigue and injury.
Changes in your thinking and your memory after brain tumour surgery

It is common to experience changes in your ability to think or your memory because of a brain tumour. These are also called cognitive changes.

What problems might I have if I have cognitive changes?

If you have cognitive changes, you may have trouble:

- Keeping your train of thought while talking or performing a task
- Remembering things
- Doing more than one thing at a time, such as cooking and talking on the phone
- Working with numbers
- Doing tasks quickly

How can I best manage changes in my ability to think and remember?

1. Memory aids

| Make lists | ✓ Write a to-do list each morning. Cross off each item after you have done it.  
|           | ✓ Keep a running list of groceries you need to buy on your fridge. |

| Make notes | ✓ Choose 1 notebook or 1 place on your cell phone to keep important information, such as:  
|           | • the names and phone numbers of your doctors, family and friends  
|           | • any questions for your doctor, or other member of your health care team  
|           | • any answers you receive from your health care team  
|           | • any detailed or complicated information |
Simplify

- Keep the people you call most often in the “Favourites” section of your cell phone’s Contact List, or on a list by your phone.
- Set up your bills to be paid automatically.

Use timers

- Learn how to use the timer on your cell phone, iPad™ or other electronic device.
- Set the timer when cooking.

Keep a calendar

- Write down all your appointments on a small calendar which you keep with you.
- Learn to use the built-in calendar and ‘reminders’ on your cell phone or computer.

2. Involve family and friends

- Bring someone to your appointments to take notes and help you remember any information. They are also an important moral support.
- Ask them to become your “memory partner” and to give you reminders.

3. Organize your environment and your day

- Try to do the same things at the same time each day.
- Create a weekly schedule to keep track of what you need done.
- Try to complete one task before starting another.
- Organize your space. Return things to their proper place when you are finished.
- Keep frequently used items where you can easily see them.
- Use a pill organizer or have your pharmacy put your medicines in a blister pack.
4. Exercises for your brain

Just as exercising your body makes you stronger, scientists are learning that exercising your brain improves your memory, concentration, and other cognitive skills.

Here are some things you can do to keep your brain active:

- Review the day’s events out loud or write them down before you go to sleep at night.
- To improve your memory and attention, focus on any nearby object and then try to recall as many details as you can with your eyes closed.
- Try some ‘brain games’ such as Scrabble™, puzzles, or checkers. Numerous websites and mobile apps have ‘brain fitness’ games. These are often free.
- Take part in a mentally challenging activity that you enjoy, such as:
  - Reading and writing letters or e-mails
  - Group activities, like a choir or a book club
  - Trying something new, such as a support group
- Do your routine tasks in new ways
  - If you are right-handed, use your left hand to draw or pick up small items

Physical exercise, eating healthy and getting enough sleep all help to keep your brain working at its best.
Changes in speaking and communication after brain tumour surgery

What can I do if I am having problems speaking or understanding?

You may have trouble communicating with others, or reading and writing, because of your brain tumour. This may be very hard to cope with and leave you feeling angry, discouraged or depressed.

How can I speak to others more easily?

- Take your time
- If you can’t recall a certain word, try using a different one
- Use gestures or point to things
- Use simple words and short sentences
- Take a break and come back to it later
- Have a sense of humour. It’s hard to be stressed when you are laughing!

What can I do if my speech is slurred?

- Move your mouth more when you speak. This helps to make each sound clearer
- Speak loudly and slowly
- Say every sound of each word. Be sure to say the last sound of words
- Make “key words” stand out. Say these words louder, with more emphasis
- Take a deep breath from your belly before speaking

Is there anything else I can do?

- If possible, make sure that people can see your mouth when you talk
- Make eye contact
What can I do when I can’t find the right word?

Show the object you are trying to talk about in different ways. For example, draw it or pretend to use it. You can also say what it’s used for or describe how it looks.

**Being tired can make it harder to communicate.**

Here are some signs that you are tired:

- You have trouble concentrating.
- You forget most of what you hear or read.
- It’s harder to find the right words.
- The muscles in your face get tired or weak.
- You start to slur your words.
- Your voice changes. For example, it may get softer.
- It’s harder to breathe when you speak.
My loved one has trouble speaking and understanding when we talk. What can I do to make it easier?

1. Be patient. Give the person enough time to speak.

2. Speak slowly, clearly and use frequent pauses. Your loved one usually needs more time to understand.

3. Take the time to explain or make sure your loved one can follow the conversation. Repeat or summarize if necessary.

4. Use simple language:
   - Short sentences
   - Simple sentences
   - Familiar words

5. Stress the important words in sentences.

6. Accept mistakes in speaking. Do not always fix mistakes.

7. Do not always complete sentences or supply words. Give some words or guess the message if your loved one is struggling or looks frustrated.

8. Accompany what you are saying with gestures or pointing if possible.

9. Ask questions that can be answered with “yes” or “no.” Give choices:
   - “Are you talking about…?” (yes or no)
   - “Is it a…?” (yes or no)

10. Cut out distractions:
   - Keep the room quiet (for example, turn off the TV)
   - Let one person speak at a time
   - Ask one question at a time
   - Don’t interrupt
   - You may want to limit the number of people present at one time or avoid large groups
Who can I contact for help?

There are organizations where you will find many types of support. Each organization offers different programs. Call or check out more than one place or program to see what’s right for you.

Resources by topic

There may be other programs more suited to your needs than the ones listed in this guide. You may want to contact other agencies or programs not included on our list.

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<td><strong>Support Groups</strong></td>
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| Brain Tumour Foundation of Canada (drop-in groups held in many Canadian cities) | Phone: 1 800 265 5106 extension 400  
Website: www.braintumour.ca |
| Gerry and Nancy Pencer Brain Tumour Centre (separate groups for patients and for patients’ families or caregivers) | Phone: 416 946 2240  
Phone: 416 946 2240  
Website: www.uhn.ca/PrincessMargaret |
| Gilda’s Club:          |                     |
| 1. Separate groups for patients and for patients’ families or caregivers.  
| 2. Group for people in their 20’s and 30’s. Topics include dating and sex, parenting and employment. | Phone: 416 214 9898  
Website: gildasclubtoronto.org |
| **Advance Care Planning** | Advance Care Planning resources  
- *Speak Up, Advance Care Planning Workbook*, Ontario Edition, c/o Canadian Hospice Palliative Care Association  
Website: www.advancecareplanning.ca  
www.myspeakupplan.ca |
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| One-on-one and Online Support | **Brain Tumour Foundation of Canada:**  
1. One-on-one support with trained staff during office hours  
2. Online Peer Support Centre (active group of brain tumour community message boards)  
Phone: 1 800 265 5106  
Website: [www.braintumour.ca](http://www.braintumour.ca) |
| Professional Counselling Support | **Princess Margaret Hospital, Psychosocial Oncology**  
Phone: 416 946 4525  
Website: [www.uhn.ca/PrincessMargaret](http://www.uhn.ca/PrincessMargaret) |
| Transportation               | **Cancer Care Ride – Wheels of Hope**  
Phone: 1 888 939 3333  
Website: [www.cancer.ca](http://www.cancer.ca)  
Click on ‘Support and Services’.  
**Toronto Ride**  
Phone: 416 481 5250  
Website: [www.torontoride.ca](http://www.torontoride.ca) |
| Financial                    | **Wellspring’s Money Matters**  
Phone: 416 961 1928  
Website: [www.wellspring.ca](http://www.wellspring.ca)  
**Social Workers, Princess Margaret Hospital, Psychosocial Oncology**  
Phone: 416 946 4525  
Website: [www.uhn.ca/PrincessMargaret](http://www.uhn.ca/PrincessMargaret) |
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| **Medication Expenses**    | **Trillium Drug Program**  
Phone: 416 642 3038  
Website: [www.health.gov.on.ca](http://www.health.gov.on.ca) (Click on ‘Prescription drug benefits’)  

**Social Workers, Princess Margaret Hospital, Psychosocial Oncology**  
Phone: 416 946 4525  
Website: [www.uhn.ca/PrincessMargaret](http://www.uhn.ca/PrincessMargaret) |
| **Home Supports**          | **Community Care Access Centre (CCAC)** has contact information for many agencies which provide personal care and homemaking assistance.  
Phone: 416 506 9888 (Toronto)  
Visit the website for agencies listed by location.  
Website: [www.torontocentralhealthline.ca](http://www.torontocentralhealthline.ca)  
If you live outside Toronto, click on: the ‘Find services in other areas’ for a list of agencies in your area.  

**Community Navigation Access Program (CNAP)**, a network of over 30 community support service agencies in the Toronto area.  
Phone: 1 877 540 6565  
| **Health and Wellness**    | **Canadian Cancer Society**  
Website: [www.cancer.ca](http://www.cancer.ca)  
Phone: 1 888 939 3333  

**Cognitive Therapy**  
Phone: 1 800 434 2268  
Website: [www.caot.ca](http://www.caot.ca)  
(Go to Find an OT, Under ‘Select Area of Practice, click on ‘Cognitive Rehabilitation’  

**ELLICSR: Health, Wellness and Cancer Survivorship Centre**  
Phone: 416 581 8620  
Website: [www.ellicsr.ca](http://www.ellicsr.ca) |
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<td><strong>Health and Wellness (continued)</strong></td>
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| **Fatigue Clinic** (fatigue related to cancer treatment) | Phone: 416 946 4501 ext. 2363  
Website: [www.uhn.ca/PrincessMargaret](http://www.uhn.ca/PrincessMargaret)  
Go to ‘Patients and Families’. Click on ‘Specialized Program Services’                                                                                                                                 |
| **Look Good Feel Better – Princess Margaret Hospital** | Phone: 416 946 2075  
Website: [www.uhn.ca/PrincessMargaret](http://www.uhn.ca/PrincessMargaret)  
Go to ‘Patients and Families’. Click on ‘Specialized Program Services’                                                                                                                                 |
| **Nutrition**                                | Talk to a Registered Dietitian for free  
Phone toll free: 1 877 510 510 2  
Website: [www.eatrightontario.ca](http://www.eatrightontario.ca)                                                                                                                                                     |
| **OHIP-funded physiotherapy information**    | Phone: 416 591 3828                                                                                                                                                                                                  |
| **Ontario Physiotherapy Association**        | Phone: 1 800 672 9668  
Website: [https://opa.on.ca](https://opa.on.ca)  
Click on ‘Find a physiotherapist’. Type in your city and ‘neuro’ as the specialty                                                                                                                                 |
| **UHN Patient and Family Libraries**         | Visit the Library and ask for a customized health search, and free information  
Website: [www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca)  
  - Search for UHN Patient and Family Education resources                                                                                                                                                                |
| **Wellspring’s Cancer Exercise program**     | Phone: 416 961 1928  
Website: [www.wellspring.ca](http://www.wellspring.ca)                                                                                                                                                               |
University Health Network tries to keep patient education resources up to date, but some information may change. Please contact any agencies that may be listed inside to make sure the information is correct or to find out more about their services.

Acknowledgements and adaptations:


Home Safety section adapted from *How to prevent falls at home and in the community* (D-5165)
by Margaret Liu and Meghan McCormack, 2014

*Home safety* (D-5858) by Occupational Therapy, Toronto Rehab, 2015

*Kitchen tips* (D-5859) by Geriatrics Program, Toronto Rehab, 2015

*Tips for talking* (D-5884) by Lisa McQueen, 2016

*How to have a successful conversation* (D-5894) by Sucheta Heble, 2015

*Signs of fatigue* (D-5883) by Sucheta Heble, 2015

*Tips to speak clearly and be understood* (D-5940) by Andrea Gomes, 2016

*Tips for word-finding* (D-5885) by Sucheta Heble, 2015

This guide has been reviewed by the Patient and Caregiver Education Program