What You Need to Know About Travelling if You Have a Brain Tumour

For people affected by a primary brain tumour

Read this resource to learn:

- · What you need to know before you decide to travel
- What are the medical risks of travelling with a brain tumour
- What you need to do if you decide to travel
- · Questions to ask your health care team





What you need to know before you decide to travel

Are you thinking of travelling?

Many people with a brain tumour decide to travel and have an enjoyable time doing so. Before you decide to travel, it is important to know about the medical risks of travelling. It is also important to know what you can do to travel safely.

Talk to your oncologist (cancer doctor) about your plans

Talk to your oncologist (cancer doctor) before you decide to travel. Your tumour may have caused changes to your body and your thinking. These changes may make it harder to travel.

You may have some of these changes to your body. For example:

- weakness
- trouble walking
- be unsteady on your feet
- low energy and stamina (you may become tired more quickly)

You may have changes to your thinking. For example, you may:

- have trouble with your memory
- be unable to find your way in a new or busy place
- have trouble making plans
- have trouble planning important tasks like taking your medicine
- have trouble speaking with or understanding others

Your oncologist will help you decide if you are well enough to travel and will discuss the medical risks.

In helping you decide if you should travel, your oncologist will look at:

- your overall health
- your medical history
- the medicines you take
- the symptoms (signs) of the cancer you have
- your treatments
- the side effects from treatment

What are the medical risks of travelling with a brain tumour?

A medical risk is something that could make your symptoms or illness worse. These are some risks people with a brain tumour may have:

- A lower seizure threshold
- Increased risk of infections
- Increased risk of blood clots

People with a brain tumour have a lower seizure threshold. This means you have a greater chance of having a seizure (fit of uncontrolled movements) than people without a brain tumour.

Make sure to talk to your oncologist about your risk for seizures. Make sure you take the medicine you have been given to help control your seizures.

Many brain tumour treatments may lower or weaken your immune system. Your immune system is your body's system for fighting infections. If your immune system is weak, it can increase your risk of getting infections. Depending on your treatment, there may be times where your immune system is stronger or weaker. Ask your oncologist when it is best for you to travel.

Travelling long distances can increase your risk of getting blood clots. People living with cancer have a greater risk for a blood clot than people without cancer. If you decide to travel and will be sitting for a long time, here are a few tips to help prevent blood clots:

- · Avoid alcohol.
- · Drink lots of water.
- Take a short walk every 1 2 hours. You can do this in the aisle of a train or plane or stop your car and get outside.
- Stretch your legs often.
- Wear anti-embolic stockings (stockings that help with blood flow). Make sure they are the proper fit and do not cause pain or discomfort. You can get these stockings from your local drugstore.

Think about changing your travel plans

Talk about your travel plans with your:

- health care team
- your caregiver
- · anyone else you will be travelling with

These people will help you understand the risks and benefits of your travel plans.

If your travel plans involve too many medical risks, think about changing your plans.

For example:

- If you want to visit family or friends, could they come to visit you instead?
- If the place you want to visit does not have the medical care you may need, could you visit a place that does have the medical care?
- If the place you want to visit means travelling for a long time, could you visit a place that is closer?
- If the trip involves a lot of walking, think about renting a wheelchair or rollator walker (a walker with wheels, brakes and a seat).
- If you have trouble with thinking skills, can a trusted friend or family member travel with you?
- If you are too ill to travel outside Canada, is there a place you could travel to inside Canada?

What you need to do if you decide to travel

If you decide to travel, here are some things you can do to travel safely.

Bring important medical information with you

When you travel, there is important medical information that you should bring with you. You will need to get this information before you leave for your trip. You should carry this information with you when you travel:

- Your diagnosis (your disease or condition).
- A copy of your oncologist's notes about the treatment you are getting.
- The names of all the medicines you are taking. You can get this from your pharmacy.
- The amount of medicines you take (dosage). You can get this from your pharmacy.
- A copy of recent imaging (like a MRI, CT scan, x-rays). You can get CD copies from the medical imaging department at the hospital where your imaging was done.

- Contact details of your health care team. For example your:
 - oncologist
 - family doctor
 - palliative care specialist

If you need medical care while you travel, the health care team that sees you will need this information to know about your illness.

Bring enough of your medicines with you

When you travel, bring enough medicines for the time that you are away (plus extra in case of travel delays). Call your doctors if you need a refill of your medicines before you leave for your trip. Your doctors (who see you in Ontario) cannot send prescriptions (medicine ordered by a doctor) to pharmacies outside of Ontario.

If you run out of medicines while you are away, you will only be able to get a prescription from a local clinic or hospital. You will need to bring all your medical information and reports to get a prescription for your medicine. Getting your prescriptions will likely cost money.

Pack your medicines (in the original labelled containers) in your carry-on baggage. That way you have your medicines, even if your checked luggage gets lost.

Think about getting travel medical insurance

Travel medical insurance covers any medical costs you may have while you are outside of Ontario.

Travelling outside of Ontario (but in Canada)

Your Ontario health care (OHIP) will pay for some but not all of the medical costs if you become ill. OHIP only covers the cost of emergency health services. Emergency health services are for health conditions that need to be treated right away.

You may need private travel medical insurance for other costs such as:

- prescription medicines
- ambulance services
- emergency transport back to Ontario by ambulance or air

Not all provinces cover the cost of the same prescription medicines. Also, you may not be able to get some medicines in certain provinces. It is important to take enough medicines to last you during your trip.

Travelling outside of Canada

If you get ill outside of Canada, OHIP only covers a small amount of emergency health services. For example, if you need to go to an emergency room in the US, it may cost thousands of dollars for your care. OHIP will only pay up to a total of \$50.00 (in Canadian dollars) a day for this service no matter how serious the illness is.

Before you decide to travel outside of Canada, it is strongly advised that you get travel medical insurance. Make sure you fully understand what your travel medical insurance policy covers.

If you do not have insurance, you may end up paying a lot of money if:

- You need medical care while you are away.
- You need to come back to Canada because of a medical emergency.

Even if your oncologist feels you are well enough to travel, it may still be hard to get travel insurance. You may have to:

- Fill in a form about your health.
- Get information from your doctor about any other pre-existing medical conditions (any other illness you already have before you travel).
- Get checked by another doctor (not your own).

It may be hard to get insurance if you plan to travel to a country that has expensive health care costs. It may also be hard to get insurance if you need to take a long flight to get to your destination.

It is important that you give the insurance company all the details about your illness and treatment. If you do not do this, they may not pay for your medical costs if you get ill or injured when you travel.

Make sure your insurance covers all other pre-existing medical conditions you may have (not only your brain tumour).

Remember to always carry proof of your travel medical insurance when you travel. Make sure to let a friend or family member at home know how to contact your insurance company.

If you get medical care while you travel, make sure you get a detailed invoice (bill or list of charges) from the health care provider or hospital. It may be difficult to get the proper paperwork once you return home.

Here is a list of some things to look for when you buy travel medical insurance (this is not a complete list). Your insurance should:

- Pay for you to stay in hospital if you need medical help due to your brain tumour.
- Pay for you to stay in hospital if you need medical help due to a new illness or injury.
- Pay for health care visits like a doctor's appointment outside of Ontario.
- Pay for any prescription medicines you may need if you get ill or injured.
- Pay for any cash advances (emergency money for medical costs) so you
 do not have to use your own money.
- Pay to get you back to Canada for medical care or to the nearest place that has the medical care you need.
- Pay for an ambulance.
- Pay for a health care provider to travel with you if you need to go to another place or country for treatment.

Arrange for any help you may need when you travel

It is important to think about the type of help that you need day-to-day when you are at home. You may have equipment at home like a walker, grab bars or shower chair. You may have a caregiver to help you with activities. You will need to know if you will have this type of help when you travel.

For example, **can you use the washroom safely on a long flight?** Think about if you are steady enough on your feet to go to the bathroom safely. You may have to ask someone that you are traveling with to walk with you to the bathroom. You may also need to ask for help getting on and off the toilet.

Will you need help with day-to-day activities? You will need to know how you will do these tasks when you are away from home. Plan with your caregiver how you will do these tasks when you are away.

Will you have equipment that you use (such as a transport wheelchair, grab bars or a bath seat) where you are staying? Some hotels will have accessible rooms (rooms for people with disabilities) and basic bathroom equipment available. If you plan to stay at a hotel, ask if they can loan you the equipment that you need.

Get help from airlines and travel companies

Before you travel, ask the airline, bus or travel company you book your ticket with about the type of help they can give you. It is common to ask for help from airlines and travel companies if you have a medical condition or disability.

Many people with brain tumours have weakness, trouble walking or have fatigue (tiredness). You may need extra help getting through the airport and on and off the plane.

Possible help often includes:

- Early check-in
- Early boarding (getting on) the plane
- Help carrying your luggage or special equipment (like a walker)
- Use of an airport wheelchair
- Help getting on and off the plane
- · Help with opening or cutting food

For more information about planning your trip when travelling with special needs, visit Canadian Air Transport Security Authority (CATSA-ACSTA) Website: https://www.catsa-acsta.gc.ca/en/special-needs

Questions to ask your health care team

Here are some questions to ask your health care team to help you decide if you should travel.

- Am I healthy enough to travel (by airplane, car)?
- Are there any risks with travelling that I should know about?
- Can you give me documents that explain my diagnosis and treatment?
- Who should I call if I have medical problems when I am away?
- Is there any special help I should arrange?
- Is there a good time for me to travel?
- Is there a time I should avoid travelling?

Remember: You can access your personal health record anywhere, anytime on a computer, smartphone or tablet using <u>myUHN Patient Portal</u>, a secure website for patients of UHN.

Online information and resources

Travelling outside Canada:

Government of Ontario "Travelling Outside Canada" Website:

http://www.health.gov.on.ca/en/public/publications/ohip/travel.aspx

Or call ServiceOntario, INFOline at: 1-866-532-3161 (Toll-free in Ontario only) TTY 1-800-387-5559.

Travelling with special needs:

Government of Canada: Canadian Air Transport Security Authority (CATSA-ACSTA)

Website: https://www.catsa-acsta.gc.ca/en/special-needs

About accessible travel:

March of Dimes Canada

Website: https://www.marchofdimes.ca/en-ca/programs

Travel Checklist: Do you have everything you need?
□ Medical information:
☐ List of current medicines and dosage
☐ Letter or chart notes from your oncologist with diagnosis, imaging and treatment
☐ Contact information for your oncologist, your family doctor and any other doctors you see
☐ Travel medical insurance documents
☐ Any equipment you will need (for example, wheelchair or walker)
□ Enough medicine for your time away packed in carry-on baggage (plus extra in case of travel delays)
☐ This information sheet and any other notes from your health care team for reference
□ Other



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