



Preparing for Surgery

Preparing for neurosurgery can be difficult; we hope to provide suggestions for preparing to meet with a neurosurgeon and what to expect before, during, and after your surgery, should you have surgery.

This guide can be printed or downloaded to your device. There are links to external sites; if you have a paper copy, all links are available to type into your browser.

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Months/Weeks Before Surgery

Finding your neurosurgeon: Researching neurosurgeons who have experience with cavernous malformations can be difficult. Cavernous Malformation Canada can provide support in your search and may have suggestions for neurosurgeons with cavernous malformation knowledge and expertise in your area; please contact prem@cavernousmalformation.ca for more information. A member of your healthcare team (Family Doctor, Neurologist, Nurse practitioner) will complete a referral to a neurosurgeon. If you would like a second opinion, your healthcare team may need to complete another referral.

Once you have an appointment, they may ask that you bring all your medications or a list of your medications to the appointment. The team will review your medical history and examine you. It is recommended that you bring a support person to your appointment. It is helpful to have a list of questions to ask the neurosurgeon. See [Questions to Ask Your Neurosurgeon](#) (pg. 8) for suggestions.

Family and Friends: Preparing your family and friends for what to expect and how they can support you. Things like childcare, meal planning, providing care, helping with household chores, caring for animals, and transportation to appointments. It is recommended to discuss whether your family and/or friends will be able to support you post discharge, see [Discharge from Hospital](#) (pg. 5) for more information.

Employment: Talk to your employer about time off; you do not have to disclose information about your diagnosis or treatment. You may need accommodations when you return to work. Review the types of support offered at your workplace, such as short-term and long-term disability.

Financial: You or your partner may have an interruption in your earnings. There are income replacement programs you may be eligible for through the federal government or your province. See, [Financial resources](#) (pg. 9) for federal and provincial financial resources for which you may qualify.

Advance Care Planning: Your plan includes goals of care designation order and your personal directive or health care directive. Advance care planning allows you to document and plan your values, wishes and preferences for the type of healthcare you want. Your healthcare team may ask you questions about your wishes and decision-making, they may also refer to this as a green sleeve. A green sleeve is a green folder that holds your advance care planning forms and will be attached to your hospital chart.

- **Goals of Care Designation (GOC or GCD)** is an order that your health care provider will complete with you, these are your medical instructions and interventions on how you wish to be cared for if you were unable to tell your care team yourself.
- **Personal Directive** is a legal document that records who you want to make decisions on your behalf. Some provinces/territories use different terminology such as advanced directives, health care directives, substitute decision maker or power of attorney.



It is important to talk with a healthcare provider before making an advanced care plan to ensure it's clear and specific. **Each province/territory have different forms and laws, please see [Advance Care Planning \(pg. 10\)](#) for a list of resources.**

Arrangements: If you are having surgery out of your city or town, you may need to book a flight and hotel. Arrange your hotel for you and your family/friend early. It is suggested to review their cancellation policy in case you need to make any changes to your reservation.

Flights/Airlines: It is recommended to obtain travel/flight cancellation insurance should there be any changes to the surgery date or your expected discharge date. If you require a wheelchair, let the airline know.

Some airlines require paperwork confirming you are fit to fly. This information is available on the airline website.

- **West Jet** [Travelling with health concerns](https://www.westjet.com/en-ca/health) (https://www.westjet.com/en-ca/health)
- **Air Canada** [Medical approval](https://www.aircanada.com/ca/en/aco/home/plan/accessibility/medical-approval.html#/) (https://www.aircanada.com/ca/en/aco/home/plan/accessibility/medical-approval.html#/))
- **Flair Airlines** [Flair Airlines - Support](https://flyflair.com/support) (https://flyflair.com/support)
- **Porter** [Flying with medical conditions and medication](https://www.flyporter.com/en-ca/travel-information/disability-assistance/medication-and-medical-conditions) (https://www.flyporter.com/en-ca/travel-information/disability-assistance/medication-and-medical-conditions)

Hope Air is a charity that helps Canadians in financial need fly to medical treatments. For more information see [Medical Travel Assistance Program | Hope Air \(www.hopeair.ca\)](http://www.hopeair.ca)

Weeks and Days Before Surgery

Preparing your hospital bag. Here is a list of suggestions for your hospital stay- [Packing for the Hospital](#)(pg. 12)

Upcoming appointments: You may have presurgical appointments, arrange for transportation (if needed) and it is recommended to have a support person with you.

Days Before and Day of Surgery:

Your neurosurgery office or presurgical appointment will provide you with presurgical instructions. These may include:

- Fasting instructions, such as no food or drink after midnight
- Know the time of your surgery and when you need to be at the hospital and where to go when you get to the hospital.
- Medication instructions-you may have to stop or temporarily discontinue some medications)
- You may be asked to shower with antimicrobial soap.
- Packing last minute items for the hospital: (photo ID, health card, medications or list of medications, CPAP if you use one, toiletries).
- Remove jewelry and piercings, it is best not to bring to hospital to avoid misplacing. Remove contact lenses, nail polish.

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- You may be scheduled to have an MRI the day before or the morning of your surgery.

Surgery

Admitting

- You will be given instructions for admitting- you may be admitted the night before or the day of. You will be asked to provide your health card, and they may ask you questions; from there, they will give you instructions on how to get to the pre-op area.

Pre-Op

- Once you complete the admitting process, you will be sent to the pre-op area. Here, you will be asked to change into a hospital gown, have your vitals checked, and blood work may be completed. They may start your intravenous (IV) line at this time.
- Once you are ready for surgery, the anesthesiologist and the neurosurgeon may greet you. The operating room nurse will greet you and help to calm you through the process.

Operating Room

- You will then move to the operating room. If you will be sedated for your surgery, general anesthetic will be administered through your IV.
- Once you are asleep, they will insert a catheter to drain your bladder. They will also adjust your position depending on where you are having your surgery.
- They may shave or cut a portion of your hair.

Post-Op

Once your surgery is complete, you are brought to a recovery area or ICU for close monitoring. Here, you will be connected to several monitors to check your heart rate, blood pressure, oxygen, respiration, medication etc. You may still have a catheter in. You may also have a compression device on your legs, which helps with blood flow to other parts of your body. Your health care provider will administer assessments to assess things like cognition, movement and sensations and these may continue for the duration of your stay.

These assessments include but are not limited to:

- **Mental Status Exam:** To assess your cognition, you may be asked questions such as: “Do you know the date? Do you know where you are? Do you know your name?”.
- **Motor Function:** You may be asked to push and pull with your arms and legs against the health care provider's arms.
- **Sensory Exam:** The healthcare provider will check your ability to feel, and this may be done over different parts of your body with various items such as a pin (to assess pain), a cotton swab (for light touch), and ice (for temperature).

You may experience some pain as the anesthesia wears off. It is important to let the nurse know.



Days After Surgery

If you were admitted to ICU, you may be moved to another unit, such as a neurosciences or stroke unit. Here, you will continue to be assessed and monitored by your healthcare team. You may be asked to get up and move around, and the rehab team (Physiotherapy, Occupational Therapy) may meet with you to help determine your needs.

- **Discharge planning:** Your healthcare team may discuss discharge planning. Some surgeries require longer stays, and some people are discharged after a few days. You may need more inpatient rehabilitation and could be transferred to a rehab unit, or you may be referred to another facility that specializes in rehabilitation.

Discharge From Hospital

You may be discharged home or to an inpatient rehabilitation facility depending on your needs. Some people stay with family or friends or will have family or friends stay with them to help with additional support.

Before discharge, it is recommended to discuss services and resources that you are eligible for with your healthcare team. This may include homecare support, outpatient rehabilitation appointments, and medical equipment such as toilet seat bars, grab bars, a shower chair, wheelchair, walker, and cane.

Determining Your Needs at Home

It is important to identify and discuss all your care needs related to your health and well-being with your healthcare team. This could include:

Transportation: You may have follow-up appointments with your family doctor, rehabilitation, surgeon, and other specialists. You may need support getting to these appointments, especially if you require mobility aids.

Mental Health: If you would like or require support around your mental health, you could be eligible for support through your health region.

Medication Management: you may need reminders for your medications or support picking up your medications. Many pharmacies provide delivery services as well as blister packing to help with organizing your medications.

Household Chores: you may need support with cooking, cleaning, laundry, etc.

Physical/Personal Care: you may need support with toileting, showering, and dressing.

Physical rehabilitation: outpatient or inpatient rehabilitation programs.

Identifying Where You Will Be Discharged

Depending on your needs you may be discharged to an inpatient rehabilitation facility, this will be discussed with you during your stay. If you do not require inpatient specialized care, the team will discuss discharge to home or with your family/friends.



It is important to discuss your options with your healthcare team and family/friends before your discharge. Suggestions to ask your healthcare team and family/friends:

- Could there be any risks to returning home? If so, what types of risks?
- What challenges may I face? (physical, emotional, financial)
- Can I live alone?
- Can I reside with my family/friends? Can they provide the appropriate care, and do they know what the risks or challenges may be?
- What type of rehabilitation do I need? Are there any costs associated with my rehabilitation?

Changes to Your Environment

After brain or spinal cord surgery, you may need to make temporary or permanent changes to your environment. These changes could include moving furniture to enable mobility or having supportive equipment (shower chair, toilet bars, raised toilet seat, grab bars etc.) It is important to bring up any concerns or questions with your care team as an occupational therapist can perform a functional assessment to determine what types of barriers you may face, as well as create a treatment plan to support your goals and needs.

Managing Your Care at Home

You may require assistance with personal care (showering, dressing etc.) or homemaking (cooking, cleaning, laundry etc.) You may qualify for services from your health region to help support you in your home. Each health region has different community services and supports, it is important to discuss what services are available to you with your health care team.



Rehabilitation and Therapy

During your stay at the hospital, you will encounter various healthcare professionals who will support you in your recovery. The rehabilitation team will help to facilitate your recovery and help identify any needs or accommodations you may need to maintain your independence and well-being. Below is a list of terms you may encounter when discussing your rehabilitation goals.

Inpatient Rehabilitation: Can be located on a unit within the hospital or at an alternate location. You will receive therapies (on the unit or at another location) to improve your overall functioning to support your independence and well-being. You may be transferred here, if you need more support in your recovery, but no longer require acute, specialized care.

Outpatient Rehabilitation: Once you are ready to go home (from the hospital or inpatient rehabilitation) you may be referred to an outpatient rehabilitation program, here you will continue to work with a rehabilitation team on therapies that will continue to support your recovery goals.

Physiotherapy (Physical Therapy): A physiotherapist assesses physical movements and implements therapies catered to specific goals to help restore movement and functioning. You may also have a physical therapy assistant, who will help to implement your treatment program.

Occupational Therapy: An occupational therapist will assess activities of daily living (bathing, toileting, dressing, ambulating, eating, grooming), as well as providing support with cognition, memory, sleep, fatigue and sensory processing. They will help with tools, therapies or devices that will support your independence in the community. You may also have an occupational therapy assistant to help conduct your treatment plan to support your therapy goals.

Respiratory Therapy: A respiratory therapist specializes in the evaluation, treatment and care of people who are experiencing difficulties with breathing or are at risk of complications related to breathing.

Speech Therapy: A speech-language pathologist provides assessment and evaluation to those experiencing swallowing or communication difficulties. They will provide therapies to help improve speech, language, voice, fluency, and swallowing functions to support effective communication and improve your quality of life.

Recreation Therapy: A recreation therapist works with people to enhance physical, social and emotional well-being through recreational activities and experiences.

Neuropsychology: A neuropsychologist specializes in understanding the relationship between the brain and behaviour. Their role involves (but is not limited to):

- assessment and diagnosing disorders related to brain function. Some assessments may be completed months after your surgery.
- Conducting comprehensive evaluations to help identify strengths and weaknesses related to cognitive areas (memory, attention, language, problem-solving)
- Providing therapy and interventions to improve cognitive and emotional functioning.

Physiatrist: A medical doctor who specializes in helping patients with physical disabilities or impairments to improve their function, mobility, and quality of life.

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Questions to Ask Your Neurosurgeon

- Why do I need surgery?
- What is your experience with cavernous malformations?
- How many patients with cavernous malformation have you seen?
- Have you performed surgery on someone with a cavernous malformation before? How many have you removed surgically?
- (If you have brainstem or spinal cord cavernous malformation) How many of these were in the brainstem or spinal cord?
- What will happen if I don't have surgery?
- How soon do I need to have surgery?
- What are the possible risks of surgery?
- What are the benefits of surgery?
- Should I get a second opinion?
- What other specialists will be a part of my surgical team?
- How long will the surgery take?
- Will I be left with any permanent deficits following the surgery?
- What do I need to do to prepare for surgery (changes in medications, diet, or activity)?
- What types of medication will be given to me during my surgery? After surgery?
- (If you are travelling from outside your community) When can I travel home by plane?

Additional Suggestions for Parents

- Where will I wait during the operation?
- How will I know when the operation is over, and where will my child be when I can see them?
- What are the long-term effects of the surgery on my child's development?
- Will my child be in pain and how will it be managed after the operation?
- When will my child be able to eat?
- When will my child be ready to go home?
- How long will it be before my child can return to regular activities (school, playing, sports, etc)?
- How do I talk to my child about the surgery?
- Is there a healthcare team member that can help prepare/support my family and child for surgery?



Financial Resources

211

211 connects people with the appropriate information and services to enhance Canada's social infrastructure and enable people to fully engage in their communities. The service is free, confidential, and available 24 hours a day by phone, chat, text, and internet. Call or Text 2-1-1 or go to their website, [Help Starts Here - 211.ca](http://211.ca) (211.ca)

Canadian Red Cross

The Canadian Red Cross is a leader in supporting Canadians to remain living in their homes safely and with dignity through innovative and compassionate community health services.

[Community Health Services in Canada - Canadian Red Cross](https://www.redcross.ca/how-we-help/community-health-services-in-canada/)

<https://www.redcross.ca/how-we-help/community-health-services-in-canada/>

The Canadian Red Cross has a health equipment loan program. See [Health Equipment Loan Program](#) to determine whether this resource is available in your community.

(<https://www.redcross.ca/how-we-help/community-health-services-in-canada/health-equipment-loan-program>)

Government of Canada

The Canadian government offers a variety of program that you may qualify for. For more information please see [Government of Canada's Benefits website](http://www.canada.ca/en/services/benefits.html) (www.canada.ca/en/services/benefits.html)

Hope Air

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Province/Territory Government Sites

Each province and territory have financial benefits and resources that you may be eligible for.

- [Government of Alberta](https://www.alberta.ca/) <https://www.alberta.ca/>
- [Government of British Columbia](https://www2.gov.bc.ca) <https://www2.gov.bc.ca>
- [Government of Manitoba](https://www.gov.mb.ca/) <https://www.gov.mb.ca/>
- [Government of New Brunswick](https://www2.gnb.ca/) <https://www2.gnb.ca/>
- [Government of Newfoundland and Labrador](https://www.gov.nl.ca/) <https://www.gov.nl.ca/>
- [Government of Northwest Territories](https://www.gov.nt.ca/) <https://www.gov.nt.ca/>
- [Government of Nunavut](https://www.gov.nu.ca/en) <https://www.gov.nu.ca/en>
- [Government of Nova Scotia](https://beta.novascotia.ca/) <https://beta.novascotia.ca/>
- [Government of Ontario](https://www.ontario.ca/) <https://www.ontario.ca/>
- [Government of Prince Edward Island](https://www.princeedwardisland.ca/) <https://www.princeedwardisland.ca/>
- [Gouvernement du Québec | Government of Quebec](https://www.quebec.ca/) <https://www.quebec.ca/>
- [Government of Saskatchewan](https://www.saskatchewan.ca/) <https://www.saskatchewan.ca/>
- [Government of Yukon](https://yukon.ca/) <https://yukon.ca/>

Advance Care Planning Resources by Province/Territory

- **Alberta:**
[Advance Care Planning | Alberta Health Services](https://www.albertahealthservices.ca/info/page12585.aspx)
<https://www.albertahealthservices.ca/info/page12585.aspx>
Personal Directive [Personal directive Alberta Gov.](https://www.alberta.ca/personal-directive)
<https://www.alberta.ca/personal-directive>
- **British Columbia:**
[Advance Care Planning - Province of British Columbia](https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning), provides you with essential information, they also offer guides in various languages.
<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>
- **Manitoba:**
Advanced Care Planning Workbook: [ACP Workbook PDF](https://wrha.mb.ca/files/acp-workbook-e.pdf) (<https://wrha.mb.ca/files/acp-workbook-e.pdf>)
Health Care Directives: [Health Care Directive | Health | Province of Manitoba \(gov.mb.ca\)](https://www.gov.mb.ca/health/livingwill.html)
<https://www.gov.mb.ca/health/livingwill.html>
- **New Brunswick:**
Health Care Directives: [Health Care Directives Guide](https://www.legal-info-legale.nb.ca/en/uploads/file/pdfs/health_law/Health_Care_Directives_EN.pdf)
https://www.legal-info-legale.nb.ca/en/uploads/file/pdfs/health_law/Health_Care_Directives_EN.pdf
- **Newfoundland and Labrador:**
Advance Care Directive: [How to Make an Advance Health Care Directive](https://www.gov.nl.ca/cssd/files/seniors-pdf-ahcd-booklet.pdf)
<https://www.gov.nl.ca/cssd/files/seniors-pdf-ahcd-booklet.pdf>
- **Northwest Territories:**
Personal Directives: [Personal Directives | Health and Social Services](#)
Examples: [Examples of Personal Directives | Health and Social Services](#)
- **Nova Scotia:**
Advance Care Planning: [Advance Care Planning - Conversations about Serious Illness](https://library.nshealth.ca/SeriousIllness/ACP)
This link offers helpful information and videos for goals of care, personal directive and advance care planning.
<https://library.nshealth.ca/SeriousIllness/ACP>
- **Nunavut:**
Personal Directive and Planning: [Nunavut Personal Directive](https://dyingwithdignity.ca/wp-content/uploads/2023/03/DWDC_2024ACP_NunavutForm_ENG.pdf)
https://dyingwithdignity.ca/wp-content/uploads/2023/03/DWDC_2024ACP_NunavutForm_ENG.pdf
- **Ontario:**
Advance Care Planning: [Ontario ACP Workbook and](https://advancecareplanningontario.ca/acp/acp-workbook)
<https://advancecareplanningontario.ca/acp/acp-workbook>



- **Prince Edward Island:**
Advance Care Planning [PEI Advance Care Planning Guide](#) and [Workbook](#)
<https://www.princeedwardisland.ca/en/information/health-pei/advance-care-planning>
Health Care Directive Form: [PEI health care directive form](#)
https://www.princeedwardisland.ca/sites/default/files/publications/health_care_directive_form.pdf
- **Quebec:**
Directives médicales anticipées: [À propos des directives médicales anticipées](#)
<https://www.quebec.ca/sante/systeme-et-services-de-sante/soins-de-fin-de-vie/directives-medicales-anticipees/description>
Advance Medical Directives: [About advance medical directives](#)
<https://www.quebec.ca/en/health/health-system-and-services/end-of-life-care/advance-medical-directives/description>
- **Saskatchewan:**
Advance Care Planning: [Advance Care Planning | SaskHealthAuthority](#)
<https://www.saskhealthauthority.ca/your-health/conditions-diseases-services/advance-care-planning>
Care Directives: [Health Care Directives | PLEA](#)
<https://www.plea.org/plans-for-the-future/health-care-directives>
- **Yukon:**
Advance Care Planning: [Plan for your future health care decisions | Government of Yukon](#)
<https://yukon.ca/en/health-and-wellness/care-services/plan-your-future-health-care-decisions>



Packing for the Hospital

- Health card and ID
- Any medical equipment or supportive devices you use (CPAP, Cane, wheelchair, walker)

Clothing

- Sweatpants (with elastic band)
- loose zip-up sweaters as you may have IVs and other monitors making it difficult to wear other clothes.
- Comfortable shoes or slippers
- Grip socks
- Bathrobe, Comfortable pajamas
- Underwear

Comfort

- Pillow, Blanket (twin size)
- Ear Plugs or noise-canceling headphones
- Sleep mask
- Neck pillow

Entertainment

- Books, Magazines
- Colouring or activity books
- Audio books
- Pre-Downloaded movies or shows on your device
- Cell phone apps (meditation, games, podcasts, music)
- Change for vending machines
- Notebook
- Snacks

Toiletries

- Toothbrush, toothpaste, floss, mouth wash
- Deodorant
- Lip balm
- Shampoo, conditioner, Body wash, lotion
- Makeup wipes, baby wipes
- Makeup, if you wear it
- Personal hygiene products

Electronics

- Cellphone
- Tablet or laptop (there may not be a television in your room for entertainment)
- Chargers (longer cords are helpful)
- headphones

Miscellaneous

- Family photos
- Mints or hard candies
- Water bottle
- Extra bags to bring items home
- Bag for laundry
- Stuffed animal or comfort items

Additions Suggestions for Children

- Bottles and bottle brush for washing.
- Formula, if used, you may be asked to provide your own.
- Diapers, pull-ups
- Stuffed animals
- Small toys
- Comfort items (familiar items from home, soothers, comfort blanket)



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