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# PATIENT AND CAREGIVER HANDBOOK

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**NAVIGATING HEALTH CARE:**  
Finding your way in Oxford

*Health care can  
be complicated:*

*We are here to help*

## Welcome

Being a patient or a caregiver is not easy. You aren't given a choice about your situation, you may be unsure about what your symptoms mean, and really, you just want to feel better and get on with your life.

On top of that, you are likely navigating different appointments, tests, procedures, referrals and follow-ups. Those are likely to involve a variety of people, organizations, and locations.

It may not take long for you to feel overwhelmed and uncertain about what to do or where to go. That's where we hope this guide will give you some practical advice to help ensure you have a good health outcome and positive experience along the way.

This guide is only meant to be a starting place. Many health care organizations have their own patient guides about specific conditions. You should consult them and follow more specific guidance as needed.

To navigate this guide, we have divided it into different sections:

- Appointments
- Tests
- Procedures
- Ongoing Care and Care Transitions
- Caregiving
- Taking Care of Yourself
- Sharing Your Experience
- Troubleshooting
- Supports and Resources

### Disclaimer:

This document is not to be used as, or in place of, medical advice. Always consult with your health professional.

## OVERALL SUGGESTIONS

- Keep a folder for your medical information, including emergency contacts, important phone numbers or emails.
- Keep a journal of symptoms, thoughts, and questions. Use a calendar for important dates.
- Have a clearly written out description of family history and past medical issues/conditions.
- Write a formal plan for your wishes and have a will. Have a conversation with your family about this and designate who you trust.
- Understand what your insurance covers and what it does not.
- Have a curious mind and be as patient as possible. Your journey may not be linear.

## Appointments

### Before the appointment

- Be clear on the purpose of the appointment. Is this your first consultation or are you meeting with a specialist? If it is an appointment with a specialist, make sure relevant information/results have arrived.
- Write down your symptoms and questions beforehand.
- Write down what you are currently doing to manage symptoms. What helps, what makes it worse?
- Bring a list of medications and any supplements you take, along with over the counter health products including herbal, write down the schedule you take them (how many times per day, how do you take them such as with or without food, as a pill or as a shot).
- Make a plan for how you will get to/from the appointment and any related expenses like parking or taxi/bus fare.
- Coordinate your visit with a caregiver, family member, or neighbour joining you. They can be a second set of ears, ask questions, and take notes.

### At the appointment

- Be active in your care. Ask questions and share any concerns you have.
- Ask for easy to understand information and/or reputable places for more information. See if there is a condition-specific patient guide.
- Ask what wait times to expect.
- Understand what the next step is and who will take it.

### After the appointment

- Call around to understand what the expected wait list may be.
- Fill a prescription, if necessary.
- Schedule tests, follow-up appointments, make a symptom journal and keep a calendar.
- Make a list of appointments, health care providers names, other relevant information. Use consistent calendars (or shared calendar) with a loved one.

#### Helpful questions to ask:

- What's the most likely cause of my symptoms?
- Are there other possible causes?
- Do I need any tests to confirm?
- Is my condition temporary or chronic?
- What treatments are available, and which do you recommend?
- I have other health conditions. How can I best manage these conditions together?
- Are there restrictions I need to follow, such as avoiding certain activities?
- Should I see a specialist? If so, whom do you recommend?
- Are there brochures or other printed materials I can have? What websites do you recommend?

## Tests

Being a patient requires a certain amount of curiosity about what is happening and why. Your health care team may ask that you undergo tests to get to the bottom of what is happening and why. Here are some suggestions when going through tests:

- Ask if there is any information on the test or issue under investigation.
- Ask whether OHIP covers the test or how much is covered.
- Ask if there are any risks or side effects with undergoing the test.
- Ask if any preparation is required, like fasting.
- Ask if medications can still be taken or should be held off until after the test is over.
- Ask how you will get the test results and approximately how long to wait.
- Ask for follow-up, should you call their office, or wait for a call from them? What should you do if you don't hear anything?
- Ask if you will be able to drive or will you need to arrange for a driver?

## Procedures

Similar to tests, going through procedures requires a certain amount of patience and calm to deal with some of the uncertainty that comes with this experience.

Here are some suggestions when going through procedures:

- Ask what options exist.
- Understand what the risks of treatment may be.
- Understand what the risks of not having treatment may be.
- Ask if there is any information on the procedure or issue under investigation.
- Ask whether OHIP covers the procedure or how much is covered.
- Ask how invasive the procedure is.
- Ask, what should I anticipate in terms of recovery?
- Ask if there are pain medications required during/after the procedure.
- If home care is required, ask if there are any waitlists for home care.
- Ask whether any preparation is required, like fasting.
- Ask if medications can still be taken or should be held off until after the procedure is over.
- Ask if you will be able to drive or will you need to arrange for a driver?

## Ongoing Care and Care Transitions

On occasion, your care team may consist of people from different parts of the health care system. For example, you (or your loved one) may be seeing a family doctor, then hospitalized, then return to receive care at home. Or your loved one may be in hospital waiting for placement in a long-term care home.

Here are some suggestions that may help you with the following situations:

- Admitted to hospital
  - Make sure you know who the providers are on your care team
- Discharged from hospital
  - Make sure you don't leave without a clear discharge plan
- Receiving home care
  - Make sure you know who is coming into your home and why

Regardless of your situation, it is important to be actively involved in your care during these care transitions. During care transitions, exchange of information can be challenging, so ensure your care team understands your circumstances. Ensure your caregiver is also involved in developing your care plan. Ask for a clear discharge summary for instructions. Let them know if you have concerns about going home. If you do not have a family doctor (or nurse practitioner), let your care team know that you don't have anyone to follow-up with. Ask for a single number you can call if you have any questions or concerns.

For some information specific to returning home from a hospital, Ontario has a [Hospital to Home Patient Guide](#) to help you during this time.

## Caregiving

If you are a caregiver, this can be challenging physically and emotionally. You can develop your own health issues as a result and may need support to manage the care of your loved one. Here are some things that may help you:

- Make sure that you are involved in the care planning of your loved one so that you are not surprised and caught off-guard.
- Identify yourself to the care team, including leadership and let them know the role you hope to play in your loved one's care.
- Understand if you are being asked to play a more formal role in the care of your loved one, like changing dressings or administering medication. Ensure you have been shown and are prepared to do these tasks.
- Ask where to learn more about the health issue your loved one is dealing with, how best to support them, and what are some supports or resources for caregivers (for example, counselling, support groups, workshops).

## Taking Care of Yourself

Being kind to yourself may be the last thing you think about when you are dealing with health issues, but remember that the uncertainty and anxiety of managing your health can take a toll.

Here are some suggestions to help you deal with this stress:

- Do some research on services available in your community.
- See if there are any peer support programs where you can speak with others in your situation. You may benefit from their experiences and lessons learned.
- Breathe deeply, exercise, go for a walk, and meditate to clear your head.
- Speak with your loved ones.
- Consider seeking counselling, therapy.

If you're having difficulty and aren't sure what to do, you can call Telehealth Ontario. A registered nurse will take your call 24 hours a day, 7 days a week. This service is free and confidential. • **Toll-free: 1-866-797-0000**

You can also call Reach Out 24/7 to speak with someone directly about any mental health concerns you may have. • **Toll-free: 1-866-933-2023**



Reach Out is a bilingual, 24/7 information, support and crisis service for people living in Oxford, Elgin, Middlesex and London.

519-433-2023

[www.reachout247.ca](http://www.reachout247.ca)

**ONE #  
ONE CALL**

Finally, you may wish to call Connex Ontario to help you navigate many resources and services that may exist. • **Toll-free: 1-866-531-2600**

## Learning From Your Experience

### Patient Experience

Many health organizations offer feedback surveys where you can comment on your care experience. These are often looked at to understand what you went through and whether you have any suggested improvements to care. Make sure you ask for a survey if one is not offered to you. Your feedback helps to ensure those making health decisions understand the needs of those they are serving.

### Patient Engagement

Many health organizations have now created volunteer opportunities for patient and family advisors to actively participate in designing and implementing programs, projects, and policies. Ask the organizations who are providing your care if you can get involved to share your experiences and ideas about where opportunities for improvement may exist. The knowledge that patients and caregivers provide can ensure health organizations are well in tune with patient values.

## Troubleshooting

If your health experience really isn't going well, you may wish to file a concern or complaint. Health care organizations typically have a patient relations process where you can document your issue and it will be investigated. Ask any organization for more information about how to do this, as processes vary depending on sectors of care. Regulatory colleges are in place to file concerns or complaints about individual practitioners.

## Resources and References

Lots of great resources exist out there. Here are a few local and provincial ones to help get you started. Do some research on ones that are helpful to you.

[South West Health Line](#)

[South West Self Management Program](#)

[Ontario Caregiver Organization](#)

[The Hub for Parent Caregivers](#)

[Ottawa Hospital Research Institute Decision Aids](#)

[Cleveland Clinic – Questions to Ask Your Doctor](#)

## Patient Declaration of Values

In fall 2021, we look to collaborate with the Oxford County community to develop a community-wide Patient Declaration of Values. This document will outline expectations of patients, families, and caregivers when it comes to participating in care, so your input to develop this will be essential! Stay tuned to our website and social media for ways to share what matters to you!

## Who Are We? Join Us!

We are the Oxford and Area Ontario Health Team, consisting of approximately 20 different health organizations along with patients, families, caregivers, and clients who are coming together to integrate our services, all with the intention of improving health care in our region. If you want to help shape improvements in your local health system, **join us** by emailing [info@oxfordandareaohht.com](mailto:info@oxfordandareaohht.com)



## Visit our Website

To learn more about how health care is integrating in Oxford and Area, please go to our website at [www.oxfordandareaohht.com](http://www.oxfordandareaohht.com) and sign up for our newsletter. Another way to stay informed is by visiting us on Twitter [@oxford\\_ohht](https://twitter.com/oxford_ohht)

## Feedback

We would love to know what you think of this handbook. Was it helpful? Would you suggest any improvements? Please complete a survey by clicking [here](#).