### My Caregiver Handbook

### Helping you on the care journey



The experience of care can be complex, confusing and challenging-but also very rewarding.



# Navigating the care experience

We've created this booklet as a way of helping you navigate the healthcare system more efficiently and easily—and to ensure that you can take the best possible care of yourself and your loved one. It's an acknowledgement that the experience of care can be complex, confusing and challenging—but also very rewarding.

It is also an acknowledgment that caregiving alone, without a proper network of support, can lead you down a difficult path of physical and emotional exhaustion. We know you can do anything you set your mind to, but no one person can do everything.

Pharmacists and their teams of professionals can be great allies as you navigate the care experience. This handbook provides information about how you can work with your pharmacy team to get the very best for you and the person in your care.

We hope that you find this handbook–and other resources available at **TevaCaregivers.com**– helpful. If you have any questions, please speak with your pharmacist, who is there to help.



### Common healthcare terms you may hear

As you meet with various healthcare providers, including your pharmacist, you may hear words or concepts that are unfamiliar to you. Never be embarrassed to ask a healthcare provider to re-explain something that they have said. How well you understand something will affect your ability to act on that information.

Here are some of the most common words or expressions you might hear when talking with healthcare professionals:

- Acute: a disease with an abrupt onset and, usually, a short course
- Chronic: a persistent or recurring illness or ailment
- Degenerative disease: a disease marked by progressively worsening quality or function
- Diagnosis: identification of an illness or other problem by examination of the symptoms
- Mandate of incapacity: a legal document giving someone else the right to make health decisions on a person's behalf if they become incapacitated
- Palliative: treatment that does not cure but can relieve pain and other symptoms
- Power of attorney for property (sometimes called a "continuing," "enduring" or "general" power of attorney, or "representation agreement," depending on your province or territory)<sup>1</sup>: a legal document giving someone else the right to act on a person's behalf to carry out certain legal acts related to the administration of their property (paying bills, withdrawing money from a bank, etc.)

- Prognosis: the likely course of an illness or ailment
- Remission: lessening or disappearance of the signs of an illness or ailment
- Side effect: a secondary, typically undesirable effect of treatment
- Symptoms and clinical signs: indications of an illness or ailment perceived by a patient and that can be detected by a healthcare professional who examines the patient





# Understanding your support network

Many caregivers feel alone in the care experience. You don't have to. Finding the right balance between your involvement and involving others is usually the best path to ensure your health and the well-being of the person in your care. After all, healthcare professionals work with assistants to help them give the best care to their patients.

The following diagram will help guide you to the various supports that are available to you. Have a look, and ask yourself if you are accessing all the help that's available or close to home.

- Patient's team: Friends, family members, neighbours-they can all help. From simple tasks like giving you some time off to driving the person in your care to a medical appointment, other people can share in the responsibility.
- Professional team: Caregivers sometimes need to make legal and long-term financial planning decisions. It's wise to build relationships with accredited professionals who can advise and guide you in situations that require specific expertise. For example, a lawyer can help guide you through the process of seeking a power of attorney in the event that the person in your care is no longer able to make decisions for themselves. A lawyer can also assist your loved one in assessing their legal capacity and executing a power of attorney while they still have capacity, allowing you to carry out certain legal acts related to the administration of your loved one's property.
- Healthcare team: As a caregiver, you will meet many healthcare professionals. By providing referrals, your family doctor is most often the starting point for expanding your healthcare support network. Some of the professionals you'll work with, such as social workers or nurses, will provide in-home support. You can track all of these professionals using our "Tracking My Support Network" document, available on TevaCaregivers.com, and share the information with your pharmacist.
- Community team: Many community organizations exist to help caregivers. Most commonly, caregivers will turn to health charities to get more information on the illness or disability. But remember, social support services can often help with meals, housecleaning, time off from care (respite), and even legal or financial advice, among other supports (see page 6 for information about how to access these services).

For information on caregiver support resources, visit **TevaCaregivers.com**.



- Specialists
- Public health services
- Hospital team
- Lab
- Home care team (includes care coordinator, personal support worker, etc.)
- Complementary health professionals (includes dietitian, physiotherapist, etc.)
- Senior residence or assisted living facility



### Helpful resources

## Here are some free resources that will help you access regional, provincial and federal supports.

### Huddol

Huddol is a community dedicated to all caregiving and health topics. Through this easy-to-access online experience, you can talk with experts and meet other caregivers like you. Learn, share and connect to a caregiver support network. To access Huddol, visit **huddol.com**.

### Provincial caregiver support organizations

The following provincial organizations provide support services to caregivers (you do not need to be in the same province to access these resources):

- Family Caregivers of British Columbia (familycaregiversbc.ca): 250-384-0408, 1-877-520-3267 (toll-free in BC only)
- Caregivers Alberta (caregiversalberta.ca): 780-453-5088, 1-877-453-5088
- Ontario Caregiver Coalition (ontariocaregivercoalition.ca; online only)
- L'APPUI (Quebec; lappui.org/en): 1-855-852-7784
- Caregivers Nova Scotia (caregiversns.org): 1-877-488-7390



### Government of Canada–Benefits for Caregivers

The Government of Canada offers information on benefits, tax credits and other assistance to caregivers. Visit canada.ca/en > Money and finances > > Managing your money > Life events and your money > Caring for someone who is ill or disabled.

The site also offers a "benefits finder" at **canada.ca/en > Benefits > Benefits finder**.

#### Resources listed by province and by health condition

We've put together a list of resources available in your province, as well as a listing of support groups for various healthcare conditions. Find these and more at **TevaCaregivers.com**.

You can also use the Government of Canada "benefits finder" tool to see programs for which you are eligible. Visit **canadabenefits.gc.ca** to access this tool.



# Preparing for a meeting with the pharmacist

Pharmacists are your allies. They can help you understand the health condition of the person in your care and support you in your role. Getting the most out of your partnership with the pharmacy team means being prepared for visits. Here are some tools that can help.

# Preparing for your first meeting with the pharmacist

The first time you visit a pharmacy, you will want to bring certain information and a list of questions that you have prepared in advance.

For this first visit (or if you have an important update on the person's condition or a new prescription), be sure to talk with the pharmacist to find out a good time to discuss your concerns, rather than just dropping in. This will ensure that the pharmacist has set aside enough time to speak with you.

Download "My Pharmacy Checklist" at **TevaCaregivers.com**; this form will make it easy for you to gather the information you need before your first visit.

# Preparing for a regular meeting with the pharmacist

When you make a return visit to the pharmacy, share with the pharmacist any information that you think is relevant to the condition of the person in your care:

- Take notes that include your observations or concerns.
- Report any change in the condition of the person in your care, whether better, worse or just "different." For ideas about what you should look for, see suggestions on pages 9-10.

The pharmacist can also answer questions about your own health.

- Talk about how you are feeling.
- Ask about your own health, and seek advice.

Remember: when it comes to health or treatment, no question is too small, and every question is important.

# What do I do and when: How to best respond to problems or issues\*

When you're taking care of yourself, you often know what doesn't feel quite right. This can be more difficult when you're supporting someone else. Whether the problem is age-related or linked to a particular health issue, the person in your care may have trouble communicating when there is a problem. The following points will help you know what to look for and how to react under different circumstances.

If the person in your care expresses discomfort, or if you observe something that you feel is wrong or is a noticeable change, take notes and evaluate the situation so that you can decide what to do. Look for any of the following changes and be sure to mention them to healthcare professionals.

### Physical changes

- Fever
- Pain (very local or more general)
- Sleep (insomnia, fatigue, change in sleep patterns)
- Skin condition (itchiness, pimples, change in colour)
- Weakness or loss of strength
- Appetite/digestion (no appetite, too much appetite, constipation, diarrhea, bloating, nausea)
- Headaches
- Nausea
- Dizziness (feeling lightheaded, frequent discomfort, fainting)

\* Remember: when in doubt, always take more precautions. Speak with a healthcare professional on your care team (or, in most provinces, call 811 for advice from a health line), or, in more urgent situations, call 911 to seek immediate help.

### Behavioural and psychological changes

- Mood (highs and lows)
- Attention/concentration (lack of focus, poor memory, disorientation or confusion)
- Negative thoughts (depression or anxiety)
- Aggression

#### Functional changes

- Changes in hearing
- Changes in vision
- Changes in mobility
- Inability to get up from a chair

Maybe you've noticed other symptoms or side effects either described by your pharmacist or not mentioned above. Note them here.

What I see	How often I see it

If the health condition of the person in your care is improving, be sure to note that and share the good news with your pharmacist.



## Signing a power of attorney\*

To act on someone else's behalf, at the pharmacy or the bank for example, you need written permission. While the person in your care can verbally authorize the pharmacy to share information with you, we recommend getting that permission in writing, so you can use it in different places.

A power of attorney should include the following information:

- The date on which it is created
- The name of the appointer or donor (the person on whose behalf you are acting)
- The name of the attorney or attorneys (your name and that of other caregivers who will have access to information)
- A description of the responsibilities assumed by each person
- The signature of the appointer
- The signature(s) of one or more witnesses, depending on your province or territory (each province and territory has its own rules about who can and cannot be a witness)

At **TevaCaregivers.com**, you can download a template for a power of attorney (or equivalent) that you can fill out and share with your pharmacist or other healthcare professionals.

\* A "power of attorney for property" is different from a "power of attorney for personal care" (sometimes called a "proxy," "directive" or "representation agreement," depending on your province or territory). Powers of attorney for personal care are required in the event that the person in your care no longer has the ability to make their own decisions. Powers of attorney for personal care may be more common in situations of mental health issues or cognitive decline. These should be discussed with your family doctor or a legal advisor.



## How your pharmacist can help

You can depend on your pharmacist and their team for a range of supportive services. The pharmacy is more than just a place to pick up medication; the pharmacy team can help you navigate many important aspects of the care experience. Consider some of the following ways in which they can help.

### Information about an illness or disability

- Ask for information about a health problem, diagnosis or new treatment options.

#### Information about your health

- Get health tips and recommendations for how to better manage your own health.

### Managing medications

- Ask about different medication options.
- Discuss how to streamline the medication schedule that the person in your care follows.
- Report issues with medications, such as side effects, and discuss alternatives.
- Get a prescription renewed or extended directly from your pharmacist.
- Ask for a record of medications.
- Get helpful tools and strategies for managing when the person in your care cannot self-medicate or refuses to take their medications.

### Other health-related aids

 Ask the pharmacy team for help when shopping for other health products, such as mobility aids or devices to adapt a home.

#### Coordinating care

 Pharmacy staff can help you communicate with other members of your healthcare team.

The pharmacy team can help you navigate many important aspects of the care experience.

Get more information and resources for caregivers at TevaCaregivers.com

<sup>1</sup>Disclaimer: this document contains certain legal information that is not legal advice. It is not a substitute for legal advice, and you should always consult a legal professional if you require legal advice or have legal questions regarding yourself or your loved ones.

This handbook is not a substitute for medical advice or treatment. Always consult a healthcare professional if you have questions regarding medical advice or treatment for yourself or your loved ones.