

Snapshots™



CAREGIVER'S HANDBOOK

Name	
Date	



TABLE OF CONTENTS

INTRODUCTION	3
GLOSSARY OF TERMS	4
STEP 1: Getting Started	8
STEP 2: Having the Conversation	10
STEP 3: Getting Organized	12
STEP 4: Preparing for Incapacity	16
STEP 5: End-of-Life Wishes	18
STEP 6: Listing Care Contacts	22
CAREGIVER RESOURCES	24
SUMMARY	26

INTRODUCTION

A caregiver is anyone who gives care and assistance to a person who requires help due to chronic physical or mental health issues. The caregiving role may be one of the most difficult some of us have to assume. Caregiving requires a multi-disciplinary approach that encompasses many aspects of life such as healthcare, daily living activities, transportation, finances, and emotional well-being.

The purpose of the Caregiver's Handbook is twofold: Provide an up-close look at the caregiver's role so you can determine your suitability for it and to provide the necessary steps to develop a viable care plan. A care plan is an expression of a loved one's wishes, values and beliefs that you can easily reference to help and guide you in your decision-making when it comes to the person in your care.

A final thought: there is no right or wrong way when it comes to the format of your loved one's care plan. ***Nor should your care plan be viewed as a legal document or be viewed as a replacement to any existing documents.*** Its value lies in the process: gathering the information, having the conversation and getting everything documented. When complete, you'll feel more confident as will the loved one in your care.

GLOSSARY OF TERMS

Throughout this handbook you may come across terminology that is unfamiliar to you. Reference this glossary at any time you need clarification.

A

Assisted living	A type of residential living that provides supportive services, such as housekeeping, communal dining, and in some cases personal care assistance to seniors who require help with daily living.
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C

Capacity and incapacity	A person is capable of giving or refusing consent to care or medical treatment if he or she is able to understand the information relevant to making a decision with respect to the consequences of that decision or lack of decision. A person is unfit to make decisions about their medical care if he or she is unable to understand the information relevant to a medical decision and the consequences of such decision. Capacity is to be assessed by the healthcare practitioner who is proposing the treatment or plan of treatment (which may include the withdrawal of treatment). A person will be able to appreciate the consequences of the decision if he or she is able to acknowledge that the condition for which treatment is recommended may affect him or her, to understand how the proposed treatment or lack of treatment could affect his or her quality of life, or to explain why he or she is making a decision in a manner that aligns with the person's previously expressed values – this provides another check on capacity. Where a decision contradicts the person's previously expressed values or beliefs, this may indicate that the person is unable to appreciate the consequences of the decision.
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Capacity assessment	A capacity assessment is an evaluation of a person's mental capacity to make decisions about property and personal care.
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Cardiopulmonary resuscitation (CPR)	Describes the emergency procedure used to revive someone when their heart and/or lungs unexpectedly stop working. CPR can include repeated compressions to the person's chest and rescue breathing to inflate the person's lungs and provide oxygen.
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Certification of death	A signed document stating the cause of death. Certification of death can only be completed by a physician or nurse practitioner. The death certificate must be completed within 48 hours of death.
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Care plan	An advance care plan, no matter how specific, is an expression of a person's wishes, values and beliefs. These wishes, values and beliefs must be discussed with healthcare providers and they cannot replace informed consent regarding healthcare decisions. Informed consent must be sought by healthcare providers from a capable patient or the Substitute Decision-Maker (SDM) if the patient is incapacitated. Completing an advance care plan is voluntary and can take many forms.
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Care planning Advanced care planning, as the name suggests, is planning in advance for decisions that may have to be made prior to incapacity or at end of life. People may choose to do this planning formally, by means of advance directives, or informally, through discussions with family members, friends and healthcare and social service providers, or a combination of both methods.

Comfort measures Actions taken to relieve pain or discomfort physically and psychosocially.

Community support services Services provided in or through the community, such as transportation, shopping, housecleaning, and yard maintenance.

D

Decision-making capacity Decision-making capacity requires that the patient be informed of his or her condition, prognosis, proposed treatments and alternatives and that the patient understand the risks and potential benefits of each alternative and the consequences of choosing a particular alternative. A physician must determine that a patient is capable of giving consent and must obtain consent from a patient before providing treatment. A physician is entitled to assume that a patient is capable of giving consent unless there are reasonable grounds to believe otherwise.

Do Not Resuscitate (DNR) Refers to a written medical order that documents a patient's decision regarding his/her desire to avoid cardiopulmonary resuscitation. DNR should not be mistaken as do not treat; it is specific only to CPR.

E

End-of-life care End-of-life care assists people who are facing imminent or distant death (including advanced life-limiting chronic conditions) to have the best quality of life possible until the end of their life regardless of their medical diagnosis, health condition or age. End-of-life care supports the needs of patients, families and caregivers until the last phase of life and into grief and bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support. End-of-life care should include discussions about advance care planning, treatment plans/goals of care, consent and related decisions.

H

Home care	Home care encompasses a full range of nursing, rehabilitation, and crisis personal support services offered by a provider in a patient's home or community. In Canada, healthcare delivery is publicly funded and administered differently by each province and territory.
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I

Informed consent	A person has the right to consent or refuse treatment, admission to a healthcare facility or personal assistance services, if they have the mental capacity to do so. The person must have the capacity to understand and appreciate the consequences of a healthcare decision. Healthcare providers cannot interpret and follow a patient's advance directive or advance care plan directly. They must get informed consent from the patient or Substitute Decision-Maker (SDM) if the patient becomes incapacitated. Physicians may rely on advance directives/an advance care plan as evidence of prior capable wishes in an emergency situation if no SDM can be contacted in time.
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L

Long-term care	Care received in an institution such as a nursing home.
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P

Personal support worker	Simple daily tasks like taking a bath, feeding, getting dressed, or simply getting around can be difficult for many who rely on caregivers. To assist with these tasks, many caregivers enlist the help of Health Care Aides (HCAs), Community Health Workers (CHWs), and Personal Support Workers (PSWs). With this kind of personal support, those in your care can remain safe and comfortable in their own home and maintain a life with dignity.
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Power Of Attorney (POA)	A POA is a written document that legally enables another party to act on the principal's behalf in various areas such as financial affairs management. In the case where a deceased person had a POA or POAs, the executor needs to contact those parties and inform them of the death since POAs cease to have effect upon the principal's death.
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Power Of Attorney (POA) for personal care	A POA for personal care is a written document in which the person who's being cared for gives another person the power to make decisions about their personal care if they become unable to make these decisions on their own. Personal care may include healthcare, medical treatment, diet, housing, clothing, hygiene, and safety.
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STEP 1:



GETTING STARTED

Most often, the caregiving responsibility falls upon a family member or friend for informal care. If you decide to become a loved one's primary caregiver, you'll need a care plan. To get started, there are a number of actions you can take. The first is building a care team followed by an assessment of support required.

The care team

Creating and implementing an effective family care plan must include the input and support of your loved one, family members, friends and professionals. If possible, the entire team should be involved in putting this plan in place.

Members of the care team may include:



Family



Physicians (primary care physician and specialists)



Friends and neighbours



Lawyers



Home care and home healthcare professionals



Financial advisors



Social workers



All team members do not necessarily need to be present for the initial meeting, but having them participate may help to convince a resistant loved one that it is time to address their current and future needs. It's important to keep your extended family informed as the situation changes from stage to stage.

Caregiver support

Caring for an ailing parent or loved one is a situation that will test your emotions, physical strength and patience. A good place to start when talking about the need for caregiving is to determine the level of care needed. The types of caregiving support provided to a loved one covers a broad spectrum of activities.

The most common types of support are:

- ▶ Helping with housework and household maintenance chores
- ▶ Helping with transportation, grocery shopping, and banking
- ▶ Checking up on them by telephone
- ▶ Communicating with healthcare professionals on behalf of another
- ▶ Contacting community service organizations
- ▶ Helping arrange for home healthcare or hospice services
- ▶ Providing emotional support and personal care activities

STEP 2:



HAVING THE CONVERSATION

It's never too early to begin discussions regarding long-term care plans with parents, relatives, or a spouse. Many seniors avoid discussing their care needs and future plans with their family members although this is a crucial first step for successful care planning. Begin by having an honest and frank discussion with the sole purpose of contributing to your loved one's prolonged security and quality of life. Here are some suggestions to help you conduct a successful conversation:

Timing is everything

- ▶ **Choose a time when there are no distractions or other obligations**
Be sure to include any family members who wish to participate.
- ▶ **Share your concerns and feelings**
Maybe you've noticed that your loved one seems to be struggling to maintain their household and make appointments and is having difficulty driving and/or paying bills on time.
- ▶ **Stress your role as an advocate**
Assure your loved one you want to fulfill their wishes. Stress how much they can depend on you and that you want to maintain their way of life and need their help to make the right decisions.
- ▶ **Listen to their concerns and wishes**
Record their wishes to validate their concerns.
- ▶ **End the conversation with a plan**
Include them in the preparation of their own care plan.



A loved one will usually open up about their preferences if you begin by sharing your own.

Preparing the care plan

A care plan should highlight a loved one's wishes and priorities and the person receiving care should be able to participate as much as possible. To help you steer the conversation in the right direction, we've put together some initial questions to help you get a better understanding of their priorities.

Do you want to remain at home as long as possible?

If so, would you hire in-home care at some point?

Would you want someone in the family to be your full-time caregiver?

How do you feel about moving to assisted living or a nursing home?

What are your values and beliefs regarding your quality of life and longevity?

What are your wishes for end-of-life care?

Do you have a living will, advance directive or Do Not Resuscitate (DNR) order in place?

Have you designated someone as a medical and/or financial Power Of Attorney (POA)?

Do you have a trusted advisor or attorney?

STEP 3:



GETTING ORGANIZED

Taking on the role as caregiver comes with serious responsibilities, and the best way to prevent problems is to gather all documentation ahead of time before a medical crisis strikes. Keeping information organized can also help you to communicate better with healthcare providers and be a better advocate.

Personal Information & Health Record

Loved one's full name					
Address					
Primary language		Phone		Cell	
Date of birth		Place of birth		Gender	
SIN		Passport number			
Driver's license number		Health card number			
Email					

Medical Information

Blood Type					
Allergies					
Major surgeries (include date)					
Chronic health problems					
Smoker	Y/N				



When locating the many documents, account numbers and tax information, use a checklist to make note of the information and consider sharing the list with the rest of the care team to ask them if you've missed anything. They'll feel included and may just be aware of an item unknown to you.

Document gathering

Legal

- Certificate of birth, marriage, divorce/separation, citizenship
- Will and any codicils (amendments) to the will
- Power Of Attorney
- Living will and power of attorney for healthcare

Financial

- Insurance policies (life, health, home, etc.)
- Contracts or rental agreements
- Titles to real estate, cars, boats, and other hard assets
- Charge, debit, and banking cards
- Credit card and charge account names and numbers
- Financial asset statements, RRSPs, non-registered accounts, RRIFs, TFSA, etc.
- Appraisals for personal property
- Tax information and tax returns from the past three to five years
- Receipts from property taxes and other large recent payments

Medical

- Do Not Resuscitate directive or other medical orders
- Most recent medication list
- Most recent lab results

Other

- Keys to house, office, safe-deposit box, post office box, etc.
- Combinations to safe or lock
- List of recent employers, dates of employment, terms of employment
- Internet passwords, access codes, PINs
- Jewelry and other valuables
- Instructions on how to care for pets, plants, house or dependent



HOME SAFETY ASSESSMENT

Ensuring your loved one’s safety within their living space is crucial to their prolonged health and happiness. Use the following checklist to assess the safety and suitability of their home.

Inside and outside the home	Yes	No
Check smoke and carbon monoxide detectors	<input type="checkbox"/>	<input type="checkbox"/>
Check that the house number outside is clearly visible from the street – in case of emergency	<input type="checkbox"/>	<input type="checkbox"/>
Install sensor lights outside for pathways and doors	<input type="checkbox"/>	<input type="checkbox"/>
Have flashlight in accessible locations such as night stands, kitchen	<input type="checkbox"/>	<input type="checkbox"/>
Make extra set of keys available with family or neighbours	<input type="checkbox"/>	<input type="checkbox"/>
All rooms	Yes	No
Install night lights in bedroom, bathroom, hallways, stairs, etc.	<input type="checkbox"/>	<input type="checkbox"/>
Ensure that steps and pathways around the house are clear of clutter and tripping hazards	<input type="checkbox"/>	<input type="checkbox"/>
Clear pathways and clutter (electrical cords small furniture) to avoid trips or falls (remove loose rugs)	<input type="checkbox"/>	<input type="checkbox"/>
Install or secure handrails in stairways	<input type="checkbox"/>	<input type="checkbox"/>
Get rid of unstable furniture that can cause falls (stools, rolling chairs, three-legged table, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Check that lighting is adequate in rooms, hallways and replace burnt out lights or add lights to rooms	<input type="checkbox"/>	<input type="checkbox"/>
Switch door handles to lever style (easier for elderly)	<input type="checkbox"/>	<input type="checkbox"/>
Remove or disable locks from doors within the house	<input type="checkbox"/>	<input type="checkbox"/>
Arrange furniture to facilitate mobility	<input type="checkbox"/>	<input type="checkbox"/>



Regularly inspect your loved one's home for potential hazards and security of doors and windows.

Kitchen	Yes	No
Remove any spoiling food from kitchen and refrigerator	<input type="checkbox"/>	<input type="checkbox"/>
Remove clutter from kitchen countertop	<input type="checkbox"/>	<input type="checkbox"/>
Clearly mark "OFF" position for stove and oven using red tape, permanent marker or nail polish	<input type="checkbox"/>	<input type="checkbox"/>
Bedroom	Yes	No
Place a telephone close to bed for easy access at night	<input type="checkbox"/>	<input type="checkbox"/>
Install night lights for trips to bathroom	<input type="checkbox"/>	<input type="checkbox"/>
Bathroom	Yes	No
Ensure bathrooms have bath mats to reduce slipping on wet floors	<input type="checkbox"/>	<input type="checkbox"/>
Install grab bars in the bathroom (close to shower and toilet)	<input type="checkbox"/>	<input type="checkbox"/>
Add a rubber mat in shower to reduce slipping	<input type="checkbox"/>	<input type="checkbox"/>
Consider a bath seat in the shower	<input type="checkbox"/>	<input type="checkbox"/>
Consider clearly labelling "HOT" and "COLD" faucets	<input type="checkbox"/>	<input type="checkbox"/>

STEP 4:



PREPARING FOR INCAPACITY

As you collect the information you need to develop an appropriate care plan for your loved one, it will be necessary to determine their ability to remain safely independent. It will also be important to understand your loved one's strengths, weaknesses, and areas of concern. Seniors can have a number of limitations that can impact their daily lives.

You may want to schedule a capacity assessment for your loved one, which is normally conducted by their doctor or health professional. It will be used to determine your loved one's capabilities and mental capacity, as well as a baseline in their care plan.

Substitute Decision-Maker

It's important to note that your loved one should also officially appoint someone to act as a Substitute Decision-Maker (SDM) if the time comes when they cannot make their own medical decisions. That person should be identified in a written document (e.g., Power Of Attorney for Personal Care or other instrument) and should be included in your care plan. Doing so will ensure that their decisions are made by the SDM of his or her choosing.



Above all, approach the capacity assessment conversation as an opportunity to include your loved one in the decision-making. Stress that you're concerned about their welfare and there are real risks you want to protect them from including elder fraud, isolation, physical constraints and mental constraints.

Capacity assessment

Here are some visual cues that your loved one may need a capacity assessment:

List	Checked
Spoiled food that doesn't get thrown away	<input type="checkbox"/>
Missing important appointments	<input type="checkbox"/>
Unexplained bruising	<input type="checkbox"/>
Difficulty getting up from a seated position	<input type="checkbox"/>
Difficulty with walking, balance and mobility	<input type="checkbox"/>
Uncertainty and confusion when performing once-familiar tasks	<input type="checkbox"/>
Forgetfulness	<input type="checkbox"/>
Poor personal hygiene	<input type="checkbox"/>
House and yard need care	<input type="checkbox"/>
Stacks of unopened mail	<input type="checkbox"/>
Late payment notices, bounced cheques and calls from bill collectors	<input type="checkbox"/>
Poor diet or weight loss	<input type="checkbox"/>
Loss of interest in hobbies and activities	<input type="checkbox"/>
Depressed or low-energy temperament	<input type="checkbox"/>
Forgetting to take medications, or taking incorrect dosages	<input type="checkbox"/>
Unexplained dents and scratches on a car. To retain a driver's license, some provinces require that drivers, when they reach a certain age, retake a road test and pass it. Is it time to take away the keys?	<input type="checkbox"/>

STEP 5:



END-OF-LIFE WISHES

When someone in your care is approaching the end of their life, there are a number of options – medical and personal – to consider. The following set of questions and statements are designed to help you better understand end-of-life wishes so you can take the right courses of action and provide the right care.

Medical decisions

What should be the goal of treatment?

- More time Comfort Mobility Lucidity

How might those goals change if you were extremely ill and in pain?

How aggressively should doctors act to keep you alive?

If you were extremely ill and the prognosis bleak, would you want:

- | | |
|---|---|
| <input type="checkbox"/> Hospitalization | <input type="checkbox"/> Artificial hydration |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Resuscitation |
| <input type="checkbox"/> Artificial nutrition | <input type="checkbox"/> Ventilator |

Comfort

What might bring you comfort if you were at the end of life?

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> Music and stories | <input type="checkbox"/> Visitors |
| <input type="checkbox"/> Massage | <input type="checkbox"/> Silence |
| <input type="checkbox"/> Prayers | <input type="checkbox"/> Solitude |
| <input type="checkbox"/> A particular pet | <input type="checkbox"/> Other _____ |



As important as the end-of-life conversation is, it's just as important to put it in writing. Keep in mind, other medical, legal and professional documents will be considered first.

When I am dying, the following are important to me:

- Keep me comfortable
- Take out all tubes and lines that are not adding to my comfort
- Have my family and friends with me
- Offer food and drink, if I am willing
- Stop medications that do not add to my comfort
- Attend to my spiritual needs
- Other _____

The place where I would like to spend my last days if possible:

- At home, which for me is: _____
- In hospice
- In hospital
- Other _____

Please care for my body by ensuring the following:

- Burial
- Cremation



The following is important to me:

(practical matters, family concerns, spiritual care, etc.)

I would like my family and friends to know and remember these things:



When asking your loved ones about their end-of-life wishes, often they are unclear about what their wishes are – allow them to take their time to identify what matters most.

Other wishes and thoughts

(write down anything that would help others understand and support you at the end of life)

NOTES:

STEP 6:



LISTING CARE CONTACTS

List known persons currently contributing to the care of your loved one such as a general practitioner, medical specialists, health/community care providers, financial and legal advisors, Substitute Decision-Maker (SDM), family members, volunteers or friends who provide assistance.

Emergency

Name	Relationship	Cell Phone	Home Phone	Email

Medical	Name	Address	Phone	Email
Primary physician				
Secondary physician				
Dentist				
Physical/occupational therapist				
Nurse				
Caregiver				
Pharmacy				
Other				



CAREGIVER RESOURCES

Educating yourself as much as possible about the medical, emotional, physical, social and spiritual dimensions of ageing will better prepare you to recognize and understand your loved one's experiences and challenges. Below is a range of websites, articles, handbooks and other materials that can help you learn more about being a caregiver and caregiver-related services.

Government and non-government bodies

- ▶ [Canadian Coalition for Seniors' Mental Health](#) – Promotes the mental health of seniors by connecting people, ideas and resources.
- ▶ [Carers Canada](#) – Enhances the quality of life for carers through partnerships and advocacy.
- ▶ [The Caregiver Network](#) – Online learning network supporting family caregivers and their loved ones.
- ▶ [National Seniors Strategy for Canadians](#) – Promotes, debates and explores policy options that can support the development of a National Seniors Strategy.
- ▶ [Guide to Seniors Housing in Canada](#) – Connects families to a range of senior living options.
- ▶ [Coping with chronic illness and end-of-life care](#) – Guide to mental, emotional and social health topics.
- ▶ [Substitute Decision-Maker Form](#) – Consent form to disclose personal health information and appoint an SDM.
- ▶ [Veterans Assistance](#) – Services, support and information for Veterans on health and well-being.

Snapshots Life Event resources

- ▶ [Executor's Handbook](#) – Provides solid overview of estate settlement as well as a range of useful information and tools to expedite executor responsibilities.
- ▶ [Will Planning Checklist](#) – Highlights a range of issues to consider when writing a will.
- ▶ [Power of Attorney article](#) – Defines and provides an overview of POAs for property and personal care with a link to a POA for personal care.
- ▶ [Personal and Financial Logbook](#) – Organizes a range of personal and financial information.
- ▶ [Long-term-care resident co-payment rates in Canada](#) – Lists costs province-by-province for basic, semi-private and private rooms.



Arm yourself with knowledge, and don't forget to ask for help from the healthcare system, family, friends and neighbours.

Home care

- ▶ [Seniors healthy living](#) – Provides strategies and information to help seniors stay healthy.
- ▶ [Home Care Services](#) – Explains how to get help for patients and seniors living at home.

Senior housing

- ▶ [A Place for Mom](#) – Connects families with seniors housing.

Health information associations and services dedicated to specific ailments

- ▶ [Alzheimer's and Dementia](#)
- ▶ [Depression](#)
- ▶ [Diabetes](#)
- ▶ [Parkinson's Disease](#)

SUMMARY

After you've created a care team, had discussions about your loved one's wishes and collected the required documentation – legal and otherwise – you have constructed a viable care plan. Take it with you when you visit doctors, healthcare providers and the rest of your care team to assist in their understanding of your situation and the person in your care. As a final thought, caring for a loved one is a situation that will test your emotions, physical strength and patience. Taking care of yourself is one of the most important – and one of the most often forgotten – things you must do as a caregiver. When your needs are taken care of, the person you are caring for will benefit too. That means more time together and hopefully less worry.

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