

The Dementia Companion Handbook

A guide for supporting conversations with your healthcare team



Contents

How to Use This Companion Guide.....	4
Importance of Guide.....	4
Before Your Appointment.....	8
Important People in My Life	8
Your Diagnosis	11
“All About Me” Overview	14
My Personal Life.....	14
Likes and Dislikes	16
During Your Appointment	20
Medications	20
Questions about your medications.....	23
Drugs that didn’t work for you.....	23
Drugs you’re allergic or intolerant to.....	24
Your Healthcare Team Log.....	26
Who is part of your Healthcare Team?	27
Question Log	31
Chronic Conditions Questions.....	33
Your Care Plan	36

After Your Appointment	40
Monitoring Your Health	40
8 Steps After a Diagnosis of Dementia	43
Planning for the Future	46
Choose a Substitute Decision Maker	46
Make Advanced Directives	48
Decide on a Power of Attorney	49
Other Planning For the Future Resources	50
Safety & Driving Resources	52
Additional Resources	54
Mental Health & Support Resources	56
Support Groups	57
Community Resources	59
Alzheimer Society of B.C.	59
Family Caregivers of BC	60
Caregiver Support & Resources	64
Information for people who may be supporting you	64

How to Use This Companion Guide

Importance of Guide

Purpose:

This guide is designed to help you learn about the changes that occur while living with dementia. You may experience changes that affect your ability to complete thoughts, find words, and remember information and directions. This guide was developed to help you track and write down any important information that you learn from your healthcare visits.

How to Use the Guide:

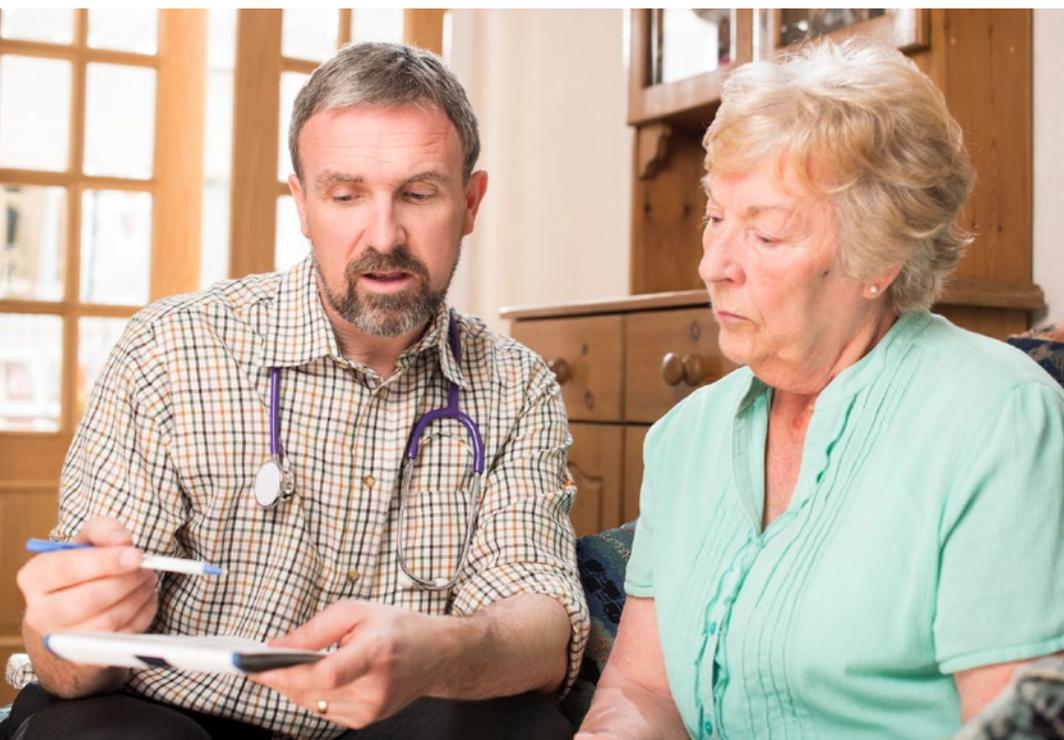
The information in this booklet will help you with your care. It will also help you share important information with your healthcare team. You may find it helpful to have a primary caregiver, close family member, or friend read through this guide to learn about your experiences.

You might want to write down questions and information you want to discuss with your doctor. Bringing the companion guide to appointments will help you write down your conversations with your care team and the plans you make with them. If you print your guide, you can use a binder to keep all the pages and resources in one place.

Guide Sections:

This guide is organized into convenient sections that can help determine the best care while living with dementia. This companion guide is divided into sections to fill in information before, during, and after you meet with your healthcare team.

To access paper copies of the resources provided in this guide, type out the website links into your web browser.



Before Your Appointment

Before Your Appointment

Important People in My Life

Below is the contact information of important people in my life (primary caregiver, family, friends, and/or neighbours)

Name: _____

Relationship: _____

Number: _____

Address: _____

Name: _____

Relationship: _____

Phone number: _____

Email address: _____

Name: _____

Relationship: _____

Phone number: _____

Email address: _____



Important People in My Life



Before Your Appointment

Important People in My Life

Below is the contact information of important people in my life (primary caregiver, family, friends, and/or neighbours)

Name:

Relationship:

Phone number:

Email address:

Your Diagnosis



Your Diagnosis

List your dementia-related diagnosis and other health conditions. This information might be helpful when attending health care appointments. If you have to visit the Emergency Department, you can use this checklist in the link to help get ready: Be Ready for an Emergency Department Visit tinyurl.com/ER-visit

My Dementia-Related Diagnosis:

Other Health Conditions:

“All About Me” Overview



“All About Me” Overview

My Personal Life

I prefer to be called:

(e.g. First Name, Nickname, Mr., Mrs., Miss, etc.)

I was born on: (e.g. March 3, 1947)

I was born in: (e.g. Vancouver, Canada)

**Single, partner, married, widowed, or
longstanding relationship(s):**

Relationship:

Name:

We've been together since:

My children's names are:

My children live in: (e.g. Calgary, Canada)

My grandchildren's names are:

My grandchildren live in: (e.g. Calgary, Canada)

I have a pet(s): (e.g. cat, dog, fish, etc.)

My pet's names are:

Some activities that kept me busy in the past are:
(e.g. jobs, hobbies, etc.)

Some activities that keep me busy now are:

I want others to know that in the past, I:
(e.g. played baseball, loved to dance)

Likes and Dislikes

What makes me more comfortable is:

(e.g., always have glasses on, hearing aid in, having a cup of tea, etc.)

What makes me feel happy is:

(e.g. conversation topics, sports, music performances, etc.)

Things I like are:

(e.g. foods, activities, conversation topics, music, etc.)

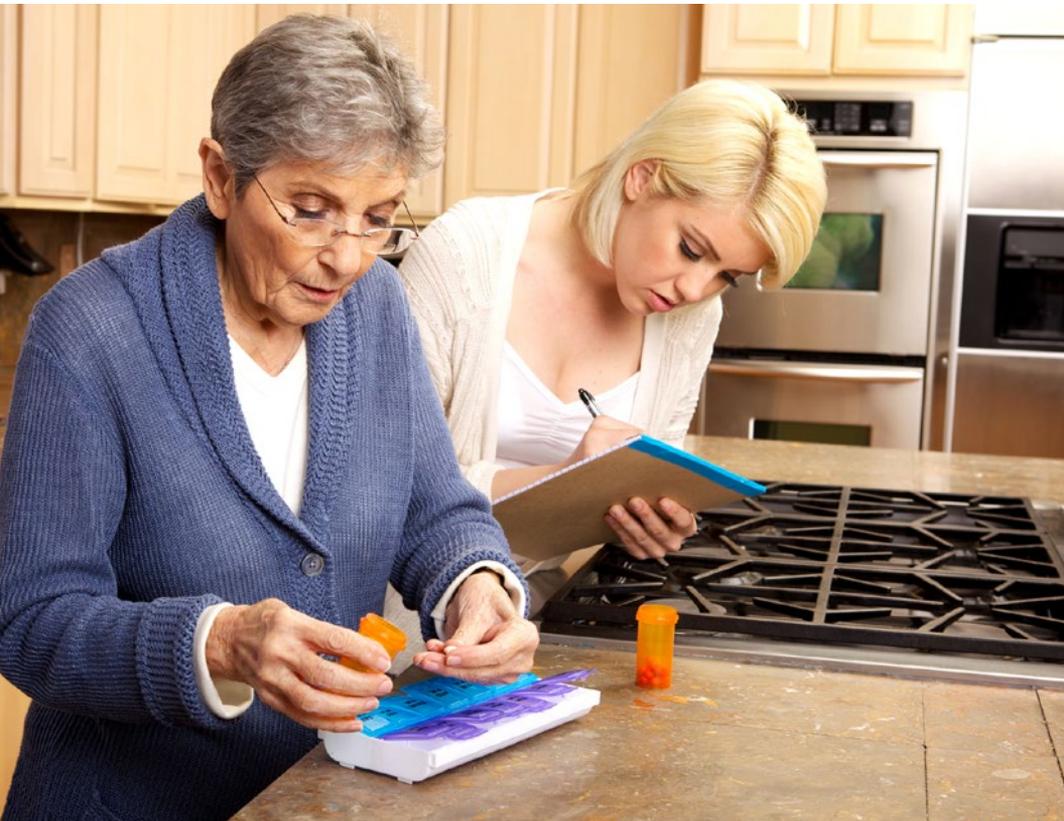
Things I dislike are:

(e.g. foods, activities, conversation topics, music, etc.)

During Your Appointment



Medications



During Your Appointment

During your healthcare visit, ask your nurse practitioner, family or specialist physician about the complementary Coordinating Dementia Tool. It is accessible to providers on most electronic medical record (EMR) systems.

Medications

In the table below, write down the medications your doctor has prescribed to you and why you are currently taking them. You can also list your previous vaccinations and non-prescription health products. For example, you could write down if you have received your COVID-19 vaccine or if you're taking iron supplements.

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drugs I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Drug I Currently Use	Date I Started	Doctor & Type of Doctor
	YYYY/MM/DD	
Reason I'm on This Drug		

Vaccination	Date of Vaccination

Non-Prescription Drugs or Health Products You Use
 (e.g. vitamins, minerals, or protein drinks)

Questions about your medications

If I have questions about your medications, the New Medicines: Questions to Ask the Doctor tinyurl.com/Ask-Doctor form can help with writing down questions and answers for when you meet with your healthcare team

Drugs that didn't work for you

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drug That Didn't Work	Date you Stopped	Doctor
	YYYY/MM/DD	
Reason/Side Effects		

Drugs you're allergic or intolerant to

Drugs you're allergic to	Reaction	Doctor

Your Healthcare Team Log



Your Healthcare Team Log

This section is where you can write down the various types of health care professionals included in your care. You can use the “Current Recommendations” column to write down any instructions or actions you might be given from your healthcare team. Your healthcare team may change over time, and you can cross out or remove any team members’ names who are no longer involved in your care.

Depending upon your health conditions, your care team might include many different health professionals. Check off what providers are involved in your care and you can write their name and role in the table on the next page.



Who is part of your Healthcare Team?

(Check all that apply)

Family Physician

Nurse Practitioner

Neurologist

Psychiatrist

Geriatrician

Psychologist

Nurse

Endocrinologist

Oncologist

Other:

Cardiologist

Physiotherapist

Dentist

Optometrist

Audiologist

Dietician

Occupational
Therapist

Social Worker

Speech Therapist

Name	Role (e.g. Physician, Physio, etc.)	Date
e.g. Dr. Joe Smith	e.g. Hematologist	10/11/22
Recommendation(s) e.g. Please take 1 iron pill once a day.		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Name	Role	Date
Recommendation(s)		

Question Log



Question Log

Over time, questions might come up that you want to ask your doctor or health care team. This section allows you space to write down any questions and answers for easy reference the next time you have a healthcare visit. For example, “What type of dementia do I have?”, “What symptoms can I expect?”, etc.

Date:

Question:

Answer:

Chronic Conditions Questions

Date:

Question:

Answer:

Date:

Question:

Answer:

Date:

Question:

Answer:

Date:

Question:

Answer:

Please feel free to print additional pages of the Question Log if you have more questions for your care provider.

Your Care Plan



Your Care Plan

In this section, you can write down what your health care team tells you to do following your health care visit. You can write down if you have another appointment or if you have to go for additional tests. You can also write down any referral information.

The health care provider said:

Your next visit is with:

The date of your next visit is:

You are being referred to see (e.g. Cardiologist):

The health care provider's name is:

You should get a:

blood test

x-ray

MRI

CT scan

ultrasound

prescription

other:

**Information on where to get these tests/
prescriptions:**

Clinic/Hospital Name:

Address:

Phone Number:

Please feel free to print additional pages of Your Care Plan if you would like to write down notes after each health care visit.

After Your Appointment



Monitoring Your Health



After Your Appointment

Monitoring Your Health

Your doctor might ask you to track and monitor certain health information at home. You can use this section to write down any important information you are monitoring. You can write down any symptoms or health changes that your health team wants you to track. Your caregiver, family member or friend can help with monitoring these changes.

Recommendations	Start Date	Time Frame change is occurring (check below)		
e.g. track your blood pressure	Apr. 05/23	Daily <input type="checkbox"/>	Weekly <input checked="" type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>
		Daily <input type="checkbox"/>	Weekly <input type="checkbox"/>	Monthly <input type="checkbox"/>

8 Steps After a Diagnosis of Dementia



8 Steps After a Diagnosis of Dementia

This checklist is based on the First steps after diagnosis [tinyurl.com/After-Dx](https://www.tinyurl.com/After-Dx) from the Alzheimer Society of Canada.

Steps you can take to live well with dementia	Check list	Links to Learn more
Recognize that you are going through a variety of emotions		Learn more about managing emotions and stress. tinyurl.com/Manage-Emotions
Learn about dementia		Learn more about dementia. tinyurl.com/About-Dementia
Seek help and look for support in the community		Contact your local Society. tinyurl.com/Find-Support Find programs and services that can help you. tinyurl.com/Find-Programs

Steps you can take to live well with dementia	Check list	Links to Learn more
Explore treatment options		Learn more about how to treat dementia. tinyurl.com/Treat-Dementia
Recognize that you have a disease that affects your abilities		Learn more about managing the changes in your abilities. tinyurl.com/Manage-Changes
Tell people		Learn more about talking about your diagnosis. tinyurl.com/Talk-Dx
Plan for the future		Learn more about planning your future. tinyurl.com/Plan-Future
Take care of myself		Learn more about living well with dementia. tinyurl.com/Living-Well

Planning for the Future



Planning for the Future

Over time, making important decisions about finances and care may become more challenging. As these changes occur, there are many choices that you can make to ensure that your wishes are recognized and valued.

Choose a Substitute Decision Maker

Changes in your health can make choices with your care, finances, and other important decisions more challenging. However, there are several things you can do to ensure your desires are communicated, heard, and respected.

After speaking with your doctor, you might want to write down the name of a substitute decision maker. This person can voice your opinion and speak on your behalf if you cannot speak for yourself. This is important as they can speak to the care you want to receive versus the care you might receive.

When choosing a substitute decision maker, consider their availability to fulfill their role. It is important that they respect, understand and value your wishes.

Name:

Phone number:

Email address:

Once you have chosen your substitute decision maker, you might want to talk with this person about healthcare and financial decisions that are important to you.

Representative Agreement

Discuss and pick a substitute decision maker: A Representation Agreement, which names my substitute decision-maker for future health-care decisions.

Resources

Nidus: Representation Agreement | Nidus Personal Planning Resource Centre and Registry tinyurl.com/Represent-Agree

Family Caregiver of BC (FCBC): Advanced Care Planning tinyurl.com/A-Care-Plan

Make Advanced Directives

Respecting your values and wishes in health care decision-making is important. It is a good idea to make an advanced directive when you are well to ensure that your wishes are respected during your care.

Discuss and document Advance Directives:

A “living will” or “advance directive” that describes my wishes for healthcare and end-of-life care in the future, including palliative options.

Resources

Alzheimer Society of B.C.: Decision-making and respecting independence [tinyurl.com/Decision-Make](https://www.tinyurl.com/Decision-Make)

Nidus: Advance Directive | Nidus Personal Planning Resource Centre and Registry [tinyurl.com/Advance-Direct](https://www.tinyurl.com/Advance-Direct)

Decide on a Power of Attorney

There will be a time when you can no longer make legal or financial choices for yourself. During this time, a family member, caregiver or healthcare provider may need to make decisions for you. The person you pick to act on your behalf will need to know your wishes so they can honour them and take action for you.

Discuss and appoint a Power of Attorney:

Talk to my friends, family and/or caregiver to ensure that someone I trust will manage my financial matters. Write down a Power of Attorney authorizing someone to make legal or financial decisions on my behalf.

Resources

Nidus: Enduring Power of Attorney | Nidus Personal Planning Resource and Centre Registry tinyurl.com/Power-of-A

Who should we contact for this information?

Name:

Phone number:

Email address:

Other Planning For the Future Resources

Alzheimer Society: Planning for our future
[tinyurl.com/Plan-Future](https://www.alz.ca/plan-future)

Nidus: Personal Planning Resource Center
and Registry www.nidus.ca/

Family Caregivers of BC: Advance Care
Planning with a Focus on Representative
Agreements [tinyurl.com/Advance-Plan](https://www.familycaregiversofbc.ca/advance-plan)

Advance Care Planning with a Focus
on Advance Directives [tinyurl.com/
Advance-Plan-2](https://www.familycaregiversofbc.ca/advance-plan-2)

Safety & Driving Resources



Safety & Driving Resources

Living in a comfortable and safe place can help you live well with dementia. Living with dementia can affect your safety but there are ways to help you manage your risk. Your environment must be safe so that you can be independent. Your abilities to do activities like driving might be impacted. You might want to learn more about these changes and how you can stay safe.

Information on how to keep safe, live well and prevent disorientation can be found below:

- Making our environment safe
tinyurl.com/Env-Safe
- Living safely and independently
tinyurl.com/Live-Safe
- Disorientation and getting lost
tinyurl.com/Dis-Lost
- MedicAlert medical ID bracelet
tinyurl.com/MedicAlert-CA

Information about driving and dementia can be found below:

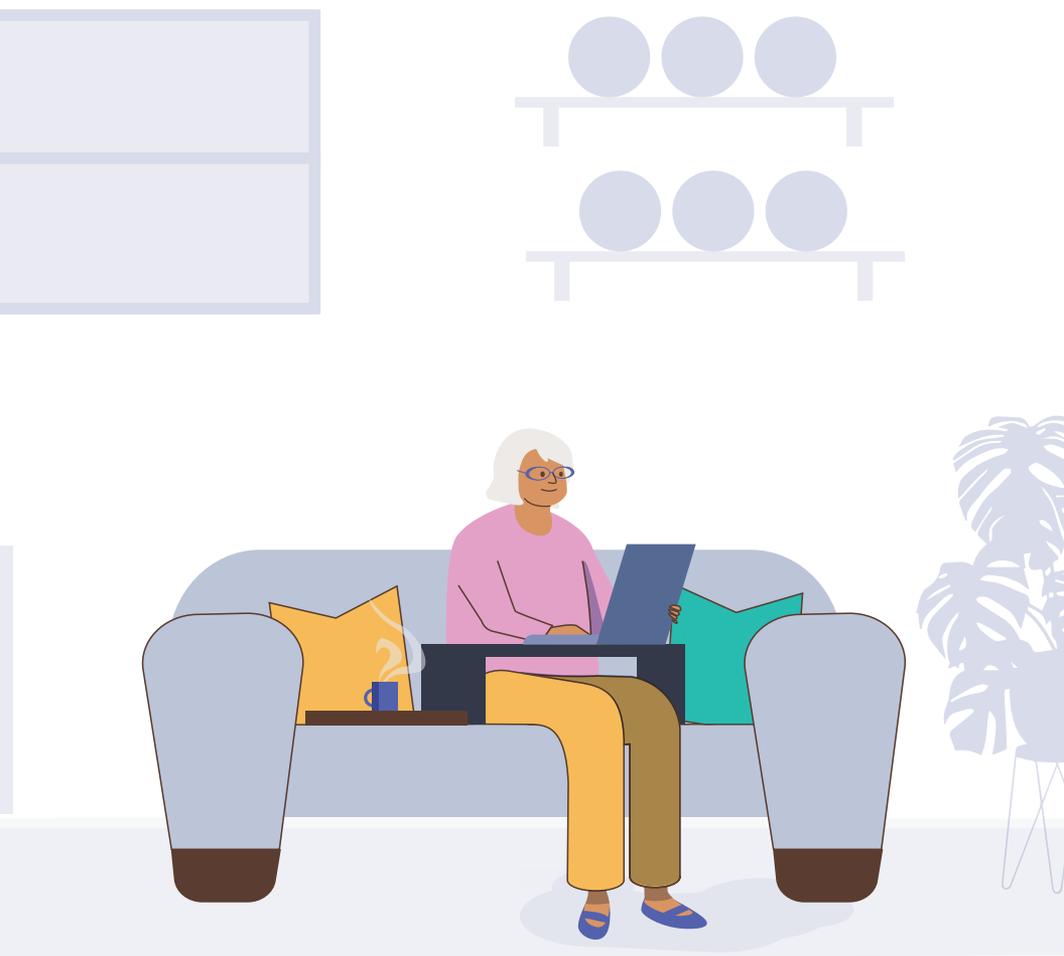
- The Driving and Dementia Toolkit
tinyurl.com/Drive-Tool

- Conversations about dementia and driving
tinyurl.com/Converse-Drive
- Driving and transportation
tinyurl.com/Drive-Transport

Information about BC Transit handyDART service can be found below:

- HandyDART Information
tinyurl.com/handyDart
- HandyDART & HandyCard Application Form
tinyurl.com/handyDart-Form

Additional Resources



Mental Health & Support Resources



Mental Health & Support Resources

You might notice that your mood changes from time to time. It is natural to experience mood changes at times as you notice changes in your skills and abilities. You may be feeling nervous, scared, or overwhelmed about your future. You are also probably wondering where you can get support and what your future looks like. Below are some useful resources that discuss mental health and support:

- Managing Emotions and the Stress of Living with Dementia
tinyurl.com/Manage-Emotions
- Changes in Mood and Behaviour
tinyurl.com/Changes-Mood
- Delusions and Hallucinations
tinyurl.com/Delusions-H
- Managing the Changes in Your Abilities
tinyurl.com/Manage-Emotions
- Dementia Information – What does it mean for me?
tinyurl.com/Dementia-Info

Support Groups

Dementia can leave those with the disease and their care partners feeling isolated. It is important to know that we are not alone. There are other people to share the journey with us. The Alzheimer Society of B.C. and Family Caregivers of BC has many support groups that can help. Check out these support groups:

- Alzheimer Society of B.C. – Support Groups [tinyurl.com/Support-G](https://www.alzheimersocietybc.ca/support-groups)
- Family Caregivers of BC – Support Groups [tinyurl.com/Support-Care](https://www.familycaregiversbc.ca/support-groups)



Community Resources



Community Resources

Living with dementia and other chronic conditions can be challenging. It is important to recognize that you do not have to face this alone. This section provides resources and contact information that can help support you.

Alzheimer Society of B.C.

The Alzheimer Society of B.C. is the only provincial charity dedicated to supporting people affected by dementia. Working in communities throughout the province, the Society supports, educates, and advocates for people living with dementia and enables research into the disease. The most direct way to access programs and services [tinyurl.com/Find-Programs](https://www.alzbc.ca/Find-Programs) or information, including on formal referrals for health-care providers, is by calling the First Link® Dementia Helpline.

First Link® Dementia Helpline

If you have questions about Alzheimer's disease or other dementias, call the Alzheimer Society of B.C.'s First Link® Dementia Helpline for information and support (toll-free):

- English: 1-800-936-6033
(Monday to Friday, 9 a.m. to 8 p.m.)
- Cantonese and Mandarin: 1-833-674-5007
Punjabi: 1-833-674-5003
(Monday to Friday, 9 a.m. to 4 p.m.)

Family Caregivers of BC

Family Caregivers of BC (FCBC) is a BC-wide provincial not-for-profit charity dedicated 100% to the wellbeing of family and friends who are the unpaid caregivers of people living with chronic disease, disability, or frailty due to aging. FCBC's mission is to improve the quality of life of family and friend caregivers through support, information, education and leadership.

FCBC's free services include BC Caregiver Support Line, with one-to-one emotional support, health system navigation, information and referral, Caregiver Coaching (by referral); Support Group Facilitator Training and Circles of Care for Caregivers training; and the Online Caregiver Resource Center – a tools and resources website with educational articles, webinars, podcasts, e-learning and more.

FCBC collaborations with the community, health authorities, and government partners to include the family caregiver voice in health care policy and practice toward person- and family-centered health care. More information can be found at www.familycaregiversbc.ca.

BC Caregiver Support Line

Call our BC-wide toll-free Caregiver Support Line at **1-877-520-3267**, 8:30 am – 4:00 pm Monday, Wednesday, Friday and 8:30 am – 7:00 pm Tuesday and Thursday. FCBC staff are experienced in dealing with caregiver situations. We take time to listen to you, which distinguishes us from the busy health care providers you may encounter. We are then able to offer help with:

- Information and referral to resources
- Healthcare navigation
- Emotional support
- Access to support groups
- Access to webinars, articles, and resources specific to your needs

Our goal is to listen with compassion, remembering that while there may be common themes, each experience is different, and so are the needs. For many caregivers, the support they find is simply knowing they are not alone in their experience. We are interested in what you are going through and want to be among the resources you think of for support.

Other Community Resources

Any additional community resources for dementia or other chronic conditions can be written down below.

Organization Name:

Phone number:

Email address:

Website:

Organization Name:

Phone number:

Email address:

Website:

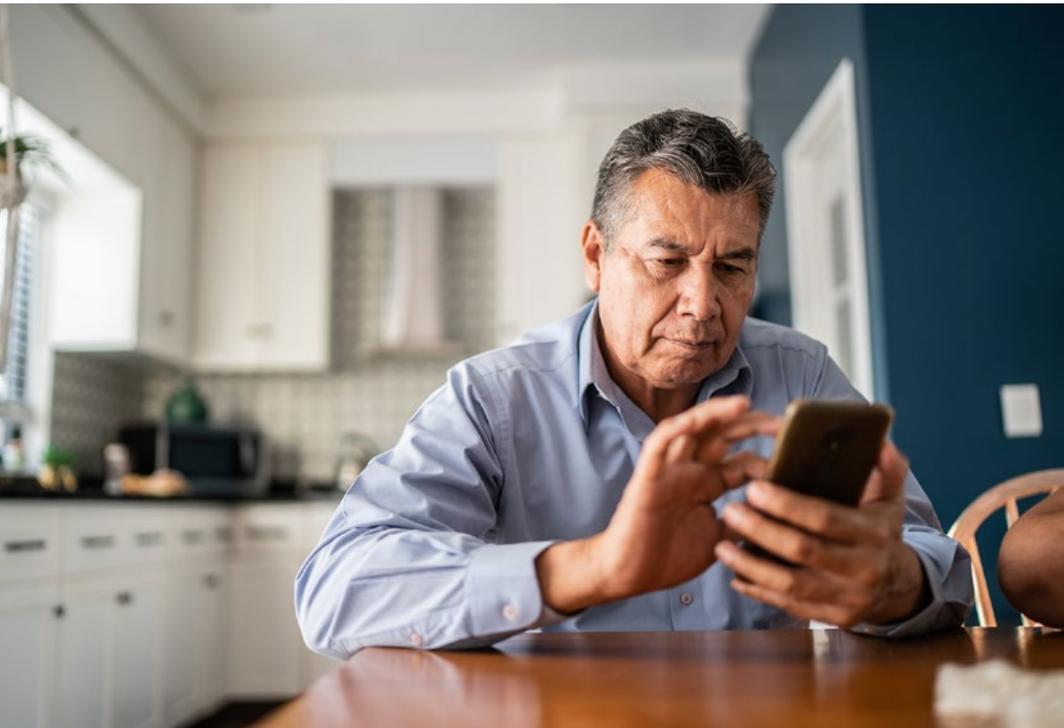
Organization Name:

Phone number:

Email address:

Website:

Caregiver Support & Resources



Caregiver Support & Resources

Information for people who may be supporting you

You are the most important person in the life of someone living with dementia. There are things you can do to help maintain your well-being and health. When possible, it is important to take breaks, like going for a walk. Caregiving is tough physically, emotionally, and mentally. In addition, caregivers require education and support to make informed decisions.

Family Caregivers of British Columbia has many resources and services that are available to you, free of charge:

- Support Groups [tinyurl.com/Support-Care](https://www.tinyurl.com/Support-Care): This is a confidential and safe space offered around a mutual experience of caregiving for a family member or friend. This is a time for reassurance, where caregivers can realize they are not alone.
- One to One Phone Support [tinyurl.com/1-Coach](https://www.tinyurl.com/1-Coach): is provided for unpaid family and friend caregivers by telephone BC-wide and online. We answer calls 8:30am-4:00pm on Mondays, Wednesdays & Fridays, and 8:30am-7:00pm on Tuesdays & Thursdays, and return calls within one business day.

- Caregiver Coaching <https://tinyurl.com/1-Coach>: With a solution focused coaching session, a caregiver can be supported to develop a short-term action plan. By referral from our Caregiver Support Line, a caregiver can meet with a coach 2-3 times.
- Caregiver Learning Center tinyurl.com/Learn-Center: Our Learning Center offers 4 categories: read, watch, listen and take a class. In each of these categories, we address common topics, questions and concerns that we hear from caregivers (e.g. financial, emotional side of caregiving and much more). We provide caregiver resources in the form of articles, tip sheets, flip books, webinars, videos, short on-line courses and podcast episodes.
- Caregiver Connection Magazine and Enews tinyurl.com/Care-Connection: a free quarterly magazine is published by the Family Caregivers of BC. It is full of interesting and informative articles directly related to caregiving issues. You can also sign-up for monthly updates and resources related to caregiving.
- Connection Corner on Facebook Live tinyurl.com/FB-Live-Caregivers: We will be live on our Facebook page discussing current caregiver topics or offering Mindfulness practices. All of our live sessions will be saved to view later if you cannot make it during this time.

The Alzheimer Society of B.C. has many helpful educational resources and support groups to help us with managing and coping with our caregiving responsibilities. Some of these resources are listed below:

- Family caregiver support groups [tinyurl.com/Family-Caregiver](https://www.tinyurl.com/Family-Caregiver): The Alzheimer Society of B.C. offers Family Caregiver Support Groups for caregivers and family members of people living with Alzheimer's disease and other dementias.
- Long distance caregiving [tinyurl.com/Long-Distance-Care](https://www.tinyurl.com/Long-Distance-Care): Today, family members often live at some distance from each other. When a relative needs increasing support, caring from a distance presents additional and special problems.
- COVID-19 tips for caregivers [tinyurl.com/COVID19-Caregivers](https://www.tinyurl.com/COVID19-Caregivers): Explaining COVID-19, hand hygiene and ways to take care of ourselves are just some of the topics that are discussed in this helpful Alzheimer Society of B.C. resource.

More health information, support and advice is offered free of charge by calling 8-1-1. More details can be found on the HealthLink BC Website [tinyurl.com/About-811](https://www.tinyurl.com/About-811).



**Providence
Health Care**

How you want to be treated.

Acknowledgments: This document has been produced in collaboration with patient partners from the Patient Voices Network and caregiver partners from Family Caregivers of B.C.; representatives from the Alzheimer's Society of B.C., Family Caregivers of B.C., and Doctors of B.C., Vancouver Division of Family Practice, Vancouver Coastal Health, Providence Health Care, Home ViVE, and West End Seniors' Network. This project is funded in partnership by Doctors of BC and the BC government through the Shared Care Committee.