## Tips and additional resources



This document offers tips and resources that were presented in the Alzheimer Society of B.C.'s webinar, "<u>Accessing care services during COVID-19</u>". This content was developed for people who are caring for someone living with dementia and were accessing care services before COVID-19, or are in need of additional services at this time.

COVID-19 has caused many unexpected changes. At the Alzheimer Society of B.C., we have continually adapted and reviewed how best we can provide support and education across the province. We have extended the hours of the <a href="First Link® Dementia Helpline">First Link® Dementia Helpline</a>, increased the number of outgoing support calls and implemented check-in calls with group members. We are also providing weekly dementia education webinars and have developed new <a href="COVID-related information resources">COVID-related information resources</a> for people affected by dementia.

Many of the families we support have been impacted by the changes in the care services provided by health authorities during COVID-19. As the pandemic continues to unfold, there remains questions that we do not know the answers to. For example, we do not know when visits will be allowed in long-term care facilities, or what day programs will look like when they open again. What we do know, however, is how hard the recent changes and challenges have been for many people living with dementia and their families.

### **Conversations with a case manager**

Case managers coordinate care and services for people with complex health needs to support them to live at home independently. They develop and review care plans and add additional support or care if needed. They will be up to date on the latest changes in the health-care system and what services are available during COVID-19. In order for them to know how to best support you and care for the person living with dementia, the case manager needs to know:

- What has changed?
- What has become too difficult?
- What safety concerns are present?
- What does the person living with dementia need to be well?
- What do you need to best support the person living with dementia?

Consider these questions beforehand and have a list prepared before meeting with your case manager. This will help you to guide the conversation and ensure you've told them what they need to know about your circumstances so that they can accurately assess the care needs and provide appropriate care services.

#### Additional resources:

- "Accessing Services" webinar
- Arrange for care on the government of B.C. website: www2.gov.bc. Click on Health > Accessing
  Health Care > Home and Community Care then, on the left, click "How to arrange for Care."



# Tips and additional resources



### Making an informed decision

It's important to seek out the right information to make an informed decision around accessing services.

- 1. **Get organized**. Identify the challenge or need. Consult with people that you trust to gain other ideas and another perspective. Make a list of everything you want to ask of your health-care provider and points you want to make.
- 2. **Prepare for meeting.** Consider who you need to speak with about a specific matter. Before an important meeting or phone call, take time to think about your purpose. When the call or meeting is over, what do you want to have accomplished?
- 3. **Keep records.** Record decisions made and who you spoke with. If somebody is going too fast for you to take good notes, politely ask them to slow down or wait. Or, if your phone is set up for audio recording, be sure you tell the person that they are being recorded.

Every time you talk to someone, write down the details in a notebook, or a file. Be sure to keep track of:

- Who you talked to (name, job title, phone number).
- When you spoke to them.
- What you talked about.
- What action they said they would take.
- What action you agreed to take.
- Whether you need to call them back and when.

#### Additional resources:

- "Getting Organized" Advocacy Fact Sheet
- "<u>Dealing with Conflict</u>" Advocacy Fact
   <u>Sheet</u>

## Facing a difficult situation

If you aren't comfortable with a decision made about the person living with dementia's care, consider the following strategies:

- Make sure you understand the whole situation. Ask questions, listen carefully and get all of the details.
- **Gather your thoughts** before a conversation. Make notes and focus on the facts as objectively as possible.
- **Humanize the concern.** Make sure the person you are talking to (or writing to) understands the effects of the situation on the person living with dementia and their family.
- Avoid arguing but be persistent. This can be hard to do. Don't get pulled into an argument.
- **Express your appreciation.** It is a difficult and stressful time for the health-care providers as well. They are doing the best the can in unprecedented times. Acknowledge those that help you.



# Tips and additional resources

#### When services are restarted

The organization that is delivering your home care will have measures in place to ensure the client and worker are safe. As a recipient of home care services, you can call the home care provider to discuss your safety concerns and what you can do to work together.

#### Consider the following questions when calling your home care provider:

- What is your policy on handwashing?
- When do your staff wear PPE (personal protective equipment)? What can I expect?
- What guidelines or safety measures are being followed?
- What happens when a worker is sick?
- What type of training do your staff receive on COVID-19?
- Who is responsible for providing the PPE? Have staff received training to use PPE properly and safely?

#### Remember that you can also do your part to keep home care workers safe:

- Wash your hands regularly.
- Let the home support worker know if you're sick. Take the appropriate steps to stay in a separate room.

#### Additional resource:

• Route65: "Is home support still safe?"

## **Accepting services**

Consider these tips to empower the person living with dementia to accept care and help from others:

- Encourage a health-care provider to attach a photo of themselves smiling onto their PPE. Wearing masks and other PPE obscures a home care provider's face, making them harder to recognize, not able to communicate a smile and, in some cases, appear frightening to a person living with dementia.
- If necessary, ask the health-care provider to speak slower and clearer, as a mask can muffle their voice and make them more difficult to understand.
- As a care partner, you could try wearing a mask yourself to help familiarize the person to them.
- Care partners can stay with the person living with dementia while they receive care. This may help to reassure the person if they appear anxious or fearful. If doing this, ensure that you maintain the recommended physical distance from the care provider. You may also need to help with communication if the person living with dementia has trouble understanding what is being said to them.



## Tips and additional resources

### Supporting a person living in long-term care

The visiting restrictions in place because of COVID-19 have created a challenging situation for many families. Many people who are caring for someone who lives in a care home have expressed how visiting restrictions have made it increasingly difficult to stay involved. It is important to try to see the big picture and recognize that the restrictions are in place to protect the people who live in care homes.

**This is a difficult situation to adjust to.** Ask yourself these questions:

- 1. What do I need to be OK with the current situation?

  This could be through regular updates from staff, seeing the person through a window or on camera, or hearing their voice over the phone.
- What can I do for the person in care?
   Work with staff at the care home to determine what you can do to help stay connected, such as by sending emails, letters and photos.



#### Additional resources:

- Caring for someone at home
- Caring for someone in longterm care

## Make a caregiver back-up plan

As a caregiver during the COVID-19 pandemic, it's important to have a back-up plan in case you or someone else who provides care or support were to become sick. Connect with other family members or friends now to identify a back-up caregiver. In times of uncertainty it can be reassuring to know there is a back-up plan. Make sure the designated back-up caregiver is fully equipped to take care of the person living with dementia. The back-up caregiver should know where to find everything they will need to care for the person living with dementia and where to access the following information:

- Medication information and schedule.
- Important phone numbers (e.g. doctor, case manager, home care worker).
- Chronic health conditions.
- Groceries and supplies list.
- Routines, preferences, lifestyle needs.
- Location of any important documents.

#### Additional resource:

Ready, Set, Plan – for Care Partner Absence



## Tips and additional resources

### Self-care and managing the changes

It is important that caregivers take care of themselves. You are the most important person in the life of a person living with dementia. Self-care is vital to staying well and will be even more important during these heightened times of stress, change, and uncertainty.

#### Additional resources for caregivers self care:

- Strategies for self-care
- Self-care and caregiver resilience during COVID-19
- "Staying healthy in a time of change and uncertainty" webinar
- "Building caregiver resilience" webinar

#### Tips for taking care of yourself

**Stay positive**. Remind yourself that the current situation is temporary. Try to think about the positive aspects of your life. Practice gratitude daily.

**Stick to a routine**. Both you and the person living with dementia will benefit from a regular and predictable daily routine. Schedule physical activity, rest, social time, and purposeful activities into each day.

**Stay connected.** Regular phone calls or visits over Skype can help you and the person living with dementia to maintain the feeling of being connected to others. Consider your options for staying in touch.

**Avoid information overload**. It is important to stay informed but too much information can become overwhelming. Limit your news to reputable sources and consider setting a time limit or schedule.

**Get support for yourself**. It is important that you get support for your own experience. Identify a trusted family member or friend who you can call when you are feeling overwhelmed, frustrated, sad, or lonely.

### **Alzheimer Society of B.C. Resources**

The First Link® Dementia Helpline is for anyone affected by dementia, whether professionally or personally. Helpline staff and volunteers give people the support they need, when they need it.

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

For further information and support, visit the Alzheimer Society of B.C. website:

- COVID-19 and dementia resources
- Upcoming webinars

