

Advocacy happens anytime we seek to make a change at an individual, community or national level. Self-advocacy refers to what we do to improve a situation for ourselves, a family member or another individual. Seeking help from your doctor, requesting easy-to-read signage at your local theatre, applying for a disability tax credit or asking a restaurant owner for dedicated seating areas with low lighting and reduced noise levels are examples of self-advocacy.

Sometimes, people living with dementia are unable to make their needs and wishes known, so somebody else must speak to others on their behalf. **The main job of an advocate is to communicate.** Advocating effectively can include a telephone call, a one-to-one appointment, an email or a letter. If you are advocating for someone else, it is important to ensure that the voice of the person remains at the center of any action or decision you make.



Advocacy in action

Norah, 85, who was living with early-stage dementia, fell in her apartment and broke her hip. It was a couple of days before her nephew, Mark, found out that she was in hospital and went to visit. She was very confused and upset when he arrived but calmed down when she saw him. He had to shout because she had lost her hearing aid. A nurse came in and remarked that she was surprised at how differently Norah behaved with her nephew, and how much better she seemed. The staff hadn't realized that she was living with hearing loss. They thought that she was uncooperative due to her dementia. Mark helped them to see that she simply couldn't hear what anyone was saying.

Once through her surgery, Norah made it clear she wanted to return home. Mark enquired about accessing home support services but instead learned the hospital social worker was planning to transfer Norah to a long-term care facility. As Norah's advocate, Mark was committed to ensuring Norah's wishes about her personal care were fulfilled. He compiled all details of the situation by talking to her doctor, surgeon, hospital nursing staff and the hospital social worker. He then contacted the Home and Community Care office in his Health Authority to share these details and get the appropriate level of care organized for Norah to be discharged and return home. Through determined effort and perseverance, Mark was able to successfully advocate for Norah's wishes.

Not all cases are as straight forward as the example above. It can take a long time to advocate for yourself or a person living with dementia. The following page details some key tips and important things to remember when you are acting as an advocate for someone. Find more advocacy resources at alzbc.org/advocacy.

Tips for advocates

Know the person's wishes: If you are advocating for someone on the dementia journey, take some time to discuss their personal wishes for future care. Clarifying and confirming what they want will help you plan ahead and advocate effectively. For example, if you know they wish to remain at home, you can focus your efforts on accessing home support services that meet their needs. You may consider becoming their legal representative or Power of Attorney to make decisions on their behalf when they are no longer able.

Be proactive and organized: Someone living with dementia will interact with many people in the health-care system – from family doctors, to gerontologists, social workers, case managers and care staff members. Often these departments are unconnected, meaning you will need to share your story several times. Practise your introduction and the key points you wish to raise. Consider storing your medical records in an online folder or keeping physical records in a folder that you can bring to each appointment. Being organized from the beginning will help you stay informed.

Keep careful records: Just like Mark in the example above, make sure you know who you need to talk to and how to get in contact with them. Record dates, names, contact details and important information when you have conversations, both electronically and in-person. Create a timeline to keep track of events and use it as a visual tool to explain your concern. If you are told a response will take 10 working days, make note of that. If you don't get a response, you can follow up as you have already noted the name of the person and how to contact them. Having these records will remind you what actions you need to take and help reaffirm your point if you are doubted or dismissed.

Identify a solution and manage expectations: If you are facing a challenge, spend some time considering the solution you are advocating for. These are different for everyone and vary from case to case. For example, if you are overcharged, the solution would be a refund. Make sure to manage your expectations and advocate for realistic solutions. Sometimes this means persevering and other times it means being willing to compromise.

Avoid arguing

Try as much as possible to remove the emotion from your argument and maintain calm when communicating your needs and humanizing the concern. Practise what you need to say aloud before making a phone call or take a few deep breaths before entering a meeting. Write a first draft of an email or letter, but don't send it right away. You may be more objective if you take a break and then review the message with fresh eyes. This will give you an opportunity to ensure you haven't left out anything important and your focus is on the facts, not your emotions. If you are advocating for someone, describe how the issue is impacting them, but also try to understand the issue from the perspective of the organization you are dealing with. For example:

"I understand you have many people to look after in addition to my father, which must be difficult when you are so understaffed. However, it's important to him that he is dressed in a clean shirt every morning, as this was his routine his entire life."

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 (Monday to Friday, 9 a.m. to 4 p.m.)
- **Punjabi:** 1-833-674-5003 (Monday to Friday, 9 a.m. to 4 p.m.)