

BECOMING YOUR OWN ADVOCATE: A GUIDE FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CARE PARTNERS

WHAT IS SELF-ADVOCACY?

Self-advocacy is the ability to speak up for yourself, a family member or another individual. It involves understanding what support or accommodations you need and effectively communicating this to others. When advocating for someone else, it's important to ensure that their voice remains central to any decisions or actions. Self-advocacy empowers individuals to stand up for their values, interests, well-being, safety, and personal growth.

EXAMPLES OF SELF-ADVOCACY

- Seeking help from your doctor
- Requesting easy to read signage at a local theatre
- Applying for a disability tax credit
- Asking for dedicated seating areas with low lighting and reduced noise levels in a restaurant

Tips for Advocates

A. BE INFORMED



Know the Person's Wishes: Discuss and clarify the person's wishes for future care as early as possible, and continue these conversations as the disease progresses. Understanding their preferences will help you advocate effectively. Resources to support these discussions and help navigate difficult conversations are linked at the end of this document.



Collect Basic Information: Document details like the person's social insurance number, health-care numbers, doctor's contact information, prescriptions, passwords, and other essential information.



Importance of Enduring Powers of Attorney and Advanced Care Planning: Having an Enduring Power of Attorney (EPA) and an advanced care plan is crucial. These legal documents ensure that the person's wishes are respected and decisions are made on their behalf if they become unable to do so.

B. BE EFFECTIVE



Be Proactive and Organized: People living with dementia interact with many healthcare and service providers. Being proactive and organized helps keep track of their care. Store medical records in an online folder or keep physical copies in a folder to bring to appointments and ensure someone else knows where to find the information.



Prepare Your Story: Have a short, practiced introduction that explains the person's situation to medical staff and others. Example: "My mother, May Chow, is in the middle stages of dementia. She is 86 and used to run a grocery store. She is lonely and losing her English skills. It's crucial for her to live in a care facility with Cantonese-speaking residents or staff."



Keep Careful Records: Record dates, names, contact details, and important information from conversations, both electronically and in-person. Create a timeline to track events.



Make a Business Card: Create a card with your contact information to leave with key people involved in the person's care. Example: "Leanne Cohen (Aaron Cohen's daughter) cell: 555-1234 home: 555-4321 email: leannecohen@email.ca."



Prepare for Each Phone Call or Meeting: Before important calls or meetings, outline your purpose and goals. Make a list of questions and points to address. Record the names, job titles, and callback number of those you speak with and ask them to slow down if needed.



Think Ahead: Proactively address potential problems. Example: Mark, supporting his aunt who lives independently, gave his contact information to key people in her community and set up automatic payments for her bills to prevent issues.

C. BE RESPECTFUL AND KNOW YOUR LIMITS



Avoid Arguing: Remain calm when communicating. Practicing what you need to say aloud before meetings or phone calls can help. Write a draft of emails or letters and review them with fresh eyes before sending.



Figure Out Your Strengths: Identify the areas where you feel confident, such as managing finances, organizing appointments, or assisting with personal hygiene. Knowing your strengths can help you focus your energy effectively. Be open to seeking help with tasks you find more challenging.



Get Help: Don't try to do everything alone. Seek help, take breaks to avoid burnout, and reach out for support with self-care. Arrange for someone to act as your substitute if you are unavailable and leave their contact information with relevant parties.



Ask Questions and Seek a Second Opinion: Never hesitate to ask questions or request a second opinion. It's important to fully understand the situation and the options available. Being informed empowers you to make better decisions.

REMEMBER: ADVOCATING FOR YOURSELF OR SOMEONE LIVING WITH DEMENTIA IS ABOUT ENSURING THEIR VOICE IS HEARD AND THEIR WISHES ARE RESPECTED. STAY INFORMED, ORGANIZED, AND PROACTIVE.

For more advocacy resources, visit:

PLEIS-NB Website - <https://legalinfonb.ca/>

Family Care Conference Question Prompt Sheet - https://spaltc.ca/wp-content/uploads/2021/05/QuestionPromptList_EN.pdf

Advance Care Planning Canada - <https://www.advancecareplanning.ca/resources/tool-kits-and-guides/>

All About Me - <https://alzheimer.ca/sites/default/files/documents/All-About-Me-en-Alzheimer-Society.pdf>

If you have questions or want to learn more, please reach out to us!

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