

Getting Organized

Make a Plan

When somebody is diagnosed with Alzheimer's disease or another dementia, they and their close friends and family need to plan for the future. Be sure to consult the person with dementia as much as possible. You must respect their wishes and beliefs.

Figure Out Your Strengths

Make use of your strengths and ask for help with things you are not confident handling. (See "Get Help" on next page.)

Collect Basic Information

Write down details like your family member's SIN and health-care numbers, their doctor's contact information, prescriptions, and other information you will be asked for.

Prepare Your Story

You are likely to have to explain certain things again and again to a whole series of people. It's helpful if you have a short, practised introduction that you can give to medical staff, social workers and others, so that they understand who you are and who you are representing.

Example: My mother, May Chow, is in the middle stages of dementia. She is 86. For decades she ran a grocery store in a Vancouver neighbourhood with her husband, John, who died two years ago. Now that John and the store are both gone, she is very lonely. Due to dementia, she is losing the little English she had. It's very important to us that my mother live in a care facility with other Cantonese speaking residents or staff so that she has someone to talk with.

Make a Business Card

If you're trying to support a friend or relative who is still living independently in the community, you may end up leaving your name and contact information with lots of people. A card just makes it easier. You can print them off yourself at home if you have a printer, or you can write out the information and make photocopies.

Example: Leanne Cohen
 (Aaron Cohen's daughter)
 cell: 555-1234 home: 555-4321
 e-mail: leannecohen@email.ca

Prepare for Each Phone Call or Meeting

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?

Make a list of everything you want to ask and points you want to make. When you get somebody on the phone, make sure you write down their name and job title. If somebody is going too fast for you to take good notes, politely ask them to slow down or wait. If your phone is set up for audio recording, be sure you tell the person that they are being recorded.

This is one of 10 **Advocacy Fact Sheets** prepared by the Alzheimer Society of B.C. These fact sheets offer tips on advocating for a family member with dementia. We suggest you read through the series, and then use the resources provided to find more specific information.

Keep Records

Every time you make a phone call or have a meeting or appointment, write down the details in a notebook, a file or elsewhere. Be sure to keep track of:

- Who you talked to (name, job title, phone #).
- When you spoke to them.
- What you talked about.
- What action they said they would take.
- When and how you will know when the action is completed.
- What action you said you would take.
- Whether you need to call them back and when.

It is always helpful to summarize a phone call just before ending the call. Repeat back what you heard and what actions are being taken. This helps ensure you are both on the same page.

If you make an important agreement, try to get it in writing. Staff in government departments change jobs, and people in hospitals and care centres work shifts, so you are always dealing with new people.

You are likely to end up with a lot of paperwork and you'll need to keep it organized. You can use file folders, a three-ring binder, or any other system that works for you. If you're using e-mail, make sure you keep copies of important e-mails — either computer back-ups, paper copies, or both.

Think Ahead

As much as you can, think ahead so you can prevent problems before they happen. Here's an example of being proactive:

Example Story:

Mark is supporting his aunt, who has dementia but is still living by herself in her apartment. The apartment is within easy walking distance of stores, so she doesn't need to drive, and Mark wants to make sure she can manage on her own as long as possible. He knows she is very worried about money and has been arguing with the local stores, sometimes refusing to pay because she thinks they are charging too much. He takes an afternoon off work and goes around giving his contact information to key people: her apartment manager, the manager at the grocery store, the bank branch manager, the woman who runs her favourite cafe, and so forth. In several cases he sets up accounts for her, which he'll make sure get paid.

He also sits down with her and helps her set up her telephone and hydro bill to be paid by automatic bank transfer. He sets up internet accounts for those services so he can log in and make sure everything is fine.

Get Help

Too many people, especially spouses, try to do everything themselves. This can be overwhelming. **Ask for help and take it**—and give yourself breaks.

Have Back-up

Try to arrange for a substitute who can act for you if you're ill or unavailable. If you're planning a trip, be sure to leave your contact information with your "sub," and make sure you've left their name with everyone who needs to know.

Rev: 2012 June