

# SHARED EXPERIENCES

Suggestions for living well with Alzheimer's disease



## Planning for the future

Planning for the future is one of the positive steps you can take to help you and your family prepare for the challenges that having Alzheimer's disease will bring.

You may still be independent, but as the disease progresses, your ability to make your own decisions will decline. Talk to family members, close friends and health-care professionals now about your needs and wishes for the future.

### Topics to discuss

- Work, retirement and volunteer activities
- Money and legal matters
- Living arrangements
- Health-care and personal care planning

Speaking about these matters now gives everyone an opportunity to bring their concerns out into the open and develop some solutions. This can help to reduce potential conflicts in the future. Planning for the future may bring you comfort in knowing that you will have some control over your life and quality of life as the disease progresses, and that your wishes are known by the people who will be making decisions on your behalf when you are no longer able to. It may also reassure all those involved that decisions made respect your wishes and needs and honour your personal values and beliefs.

### Work, retirement and volunteer activities

If you are still working, consider talking to your employer about Alzheimer's disease and your symptoms. Before doing so, be aware of your employment rights and options. Do not quit work until you have been fully assessed and can make choices and access employee benefits where available based on a correct diagnosis. Cutting down on your hours and responsibilities may be an option, or you may have to stop working. If you own your own business, you will want to plan for its future.

Volunteering may give you an opportunity to continue using your skills and participate in activities that you have always enjoyed.

### Money and legal matters

Talk to your family. Make sure your money matters will be in the hands of someone you trust—a family member or close friend.

You may wish to arrange for a trusted relative or friend to be authorized to legally make financial decisions on your behalf once you are no longer able to. This person may be called a power of attorney or representative. Terms and legal requirements vary by province. Talk to a lawyer about naming someone to look after your financial interests.

Pull together all of your legal and financial documents such as bank accounts, mortgages, insurance policies, pension plans, RRSPs, investments, ownership of home, car, real estate, and business. Putting someone you trust in charge of these documents now helps protect your assets later. Make a will, if you have not done so already.

### Living arrangements

For now, you may be living on your own, with a family member or with a close friend, and may need little or no assistance with daily living. As Alzheimer's disease progresses, you will find that you need help with activities such as cooking, housekeeping, shopping and transportation. Talk to family members and friends to see who would be able to help you with these tasks.

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Your local Alzheimer Society can provide information and referrals to community and social services that are available in your area.

As your abilities change, there may also have to be changes in your living arrangements. Perhaps a family member could come to live with you. Or, you could move to live with someone else.

There may come a time when you need to be in a safer environment or require more assistance with daily living. There may be options in your community such as live-in companions, assisted-living homes, supportive housing, retirement and long-term care homes. Find out what is available. Arrange a visit. Go with a family member or friend and ask questions.

## Some questions to ask

### Is the residence Alzheimer-friendly?

- Are staff members trained to care for people with Alzheimer's disease?
- Can you walk safely indoors and outside?
- Does it have a home-like environment?
- Are the rooms private or shared?

### What is the care philosophy of the residence?

- Does it focus on the person's needs?
- Can it accommodate your personal preferences for food, routines and activities?

### What kind of medical care does the residence provide?

- Can you continue to see your own doctor?
- Is there a doctor on call?
- How often does the doctor visit?
- Can you meet the doctor?
- How are medical emergencies handled?

### What kind of personalized care is available?

- Can you choose menus?
- Can you bring your pet?
- Can you bring your own furniture?
- Is there a hairdresser that comes into the home?

Changes to the living environment can be stressful for everyone concerned. Looking into the options now and discussing the choices ahead of time can help relieve some of the stresses of decision-making.

### Health-care and personal care planning

Just as you can name someone to look after your financial interests, you can also name someone to make health-care decisions for you when you are no longer able to do so. This person may be called a substitute decision-maker or power of attorney and may or may not be the same person helping you with your finances. Terms and local requirements vary by province. Contact your local Alzheimer Society for more information.

Let the person know that you have chosen him or her to act on your behalf on matters relating to your health and personal care. Topics to be discussed may include medical treatments, caregiving options, housing options, and end-of-life care.

### Why is this important to discuss now?

As the disease progresses, your substitute decision-maker will have to make decisions about your care. For most people, making decisions on behalf of someone else is difficult. By talking to your decision-maker now about what level of care you do and do not want in the future, you may reduce the person's anxiety when it is time to make those choices. You will also have the comfort of knowing that your future care will be in good hands and that your wishes will be respected.

If you think it would be helpful, write down your wishes. Some provinces have legally-recognized documents in which you can set out the type of care you wish to receive. The name and wording of the document varies from province to province. Your local Alzheimer Society can help you find out if your province has legal documents regarding planning for future health-care.

Even if you choose not to write things down or draw up a legal document, talk about these matters. Your verbal wishes can be just as valid. Let those closest to you know what you want and what you do not want for your future health and personal care.

When planning for the future and discussing health-care options with your family and substitute decision-maker, you may want to discuss your options with your physician care team.

There are three main categories of treatment: extraordinary medical care, conservative medical care, and comfort or palliative care.

### Extraordinary medical care

In extraordinary medical care, the goal is to prolong life using all available types of treatment. This could include using kidney dialysis for kidney failure, tube feeding when swallowing is no longer possible, or cardiopulmonary resuscitation (CPR) to restart the heart.

### Conservative medical care

With conservative medical care, the goal is to maintain or improve the current state of health. This could include using blood pressure medication to treat high blood pressure, insulin for diabetes, or setting a fractured hip.

### Comfort or palliative care

The goal of comfort or palliative care is to give comfort when there is no treatment for an illness and death is near. Pain control is a priority, as is emotional and spiritual support for the person and his or her family.

More than anything else, planning for the future is about communication. Talk to the people who are going to be involved in your care – whether it be your husband, wife, son, daughter, another family member, close friend, doctor or the members of your health-care team.

### Additional resources

For more information, please refer to the following print materials. These are available from the Alzheimer Society or on-line at [www.alzheimer.ca](http://www.alzheimer.ca).

- *Decision-making: Respecting individual choice*
- *Ways to help: Assisting families living with Alzheimer's disease*
- *Caregiving options: Considering long-term care*

For more information, contact your local Alzheimer Society or visit our website at [www.alzheimer.ca](http://www.alzheimer.ca).