

Memory Problems?

Find out how these problems affect people diagnosed with Alzheimer's disease & Related Dementias.

- Early signs of Dementia
- Ways to help yourself
- A message to family
- Where to get more information & support

This booklet was created *BY* people in the early stage of dementia, *FOR* people in the early stage of dementia.

We present examples from our own life experiences in user-friendly language. Our hope is that if you can relate to a number of these early signs you will be comfortable approaching your doctor to discuss the situation.

Keep in mind that **YOU** will know something is wrong long before your doctor does. **Don't ignore the problems, ask for help.**

Some memory problems and confusion can be reversed with the proper diagnosis and treatment. Problems may be due to depression, thyroid disease, infections, and drug interactions or other conditions.

If your memory problems are the first signs of Alzheimer's disease or other forms of dementia, **you are NOT alone**. The Alzheimer Society is here for both you and your family members. Information on how to contact the Society is on the back cover.



EARLY SIGNS OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

The examples under each of the "signs" below are quotes from people living with dementia who are members of Early Stage Support Groups in British Columbia.

1. Memory loss affects my daily life activities:

Recent events can quickly slip my mind.

There is a lot of frustration due to misplacing things. I know they are close by but I don't seem to recognize the objects that I'm looking for. Sometimes I could cry.

Conversing is no longer fun. It is difficult because I can't remember what I was going to say, or if it has already been said, I repeat myself.

I seem to hop from one task to another and seldom complete anything. My short-term memory has gone from bad to worse.

2. Familiar tasks are difficult to perform:

Cooking is hard and following a recipe is nearly impossible. It concerns me that I leave stove elements and water taps on.

Sometimes I can't think what I'm supposed to do ... how do I control the temperature in the shower, use the bank machine, the VCR?

When I use the phone, I often punch the wrong numbers. I also have problems with writing and spelling, so now I just don't do it.

3. Problems with language:

Memory lapses take words from me. These are usually names of things.

I lose track of what I am trying to say. Letter writing is difficult too, because I can't remember how to spell familiar words, or they don't look right.

I make unexpected word substitutions. Often the word is close, but not as fitting as the one I had hoped to use before it disappeared. Sometimes I have problems finishing sentences.

4. Becoming disoriented with time and place:

Occasionally I have to pull over while driving because I can't remember where I am going or where I am.

I arrived at the building my meeting has been held in for years, but I couldn't find the regular meeting room. A lady asked if I was lost, but I wasn't. I just couldn't find the room.

I get turned around sometimes; it can be scary.

5. Judgment is poor:

I am more impulsive; speaking out, then wishing that I had taken longer to think before saying something.

I worry about making mistakes and don't participate in activities. Life used to be so easy, now I have to think hard about everything.

I have made so many poor choices lately while buying clothes that I no longer want to shop.

6. Abstract thinking is a problem:

It's hard to do math in my head. Making change is difficult.

Too much information coming quickly makes me anxious and exhausted.

Sometimes I can't think what I'm supposed to do. I think about it, but do nothing. It's like I'm fuzzy in the head.

7. Misplacing things:

I often misplace things after thinking I have put them in a logical place. Then I can't remember my logic.

I put things away, then accuse family members of taking them.

I lose things that are in plain sight. I think the problem is *recognition*, not sight.

8. Changes in mood and behaviour:

While sitting by myself, I can suddenly become anxious or angry for no apparent reason.

I'm more defensive and often don't let people know when I'm struggling. I get depressed easily.

Sometimes I feel frustrated and depressed over my inability to cope and my loss of memory. Memory gaps about past family life are very scary. How can I lose something that is so precious to me?

I cry easily and often feel oversensitive when I have a day with too many tasks to do.

9. 'Personality' changes (or my responses to changes in perception):

Because information overload and crowds confuse me, I often feel fearful. This makes me want to cling to my husband. I need him to be a buffer zone between a confusing world and me.

I occasionally become disproportionately angry which is completely unlike me.

An evening out with our friends can be cut short when I am overcome with a desire to be by myself. Yet I am a 'people' person.

I used to like to go out to malls and restaurants but now I don't like crowds, so we don't go.

10. Loss of stamina, interest, initiative:

I put off shopping trips, then when I do go it's overwhelming.

I can do two or three things, no more. The mental effort exhausts me.

I didn't feel listened to by my doctor, so I stopped talking to him. Even family members don't appreciate there is something wrong. No wonder I give up. I spend lots of time thinking about doing tasks, but end up doing nothing.

BE AN ADVOCATE FOR YOURSELF

One way to help yourself is to be an advocate. If you are concerned about any of the early signs, go to the doctor. If you don't get help, ask to be referred to a specialist. You need to speak up in order to have your needs met.

The following comments are excerpts from a presentation made by Marilyn (a member of the Early Stage Support Group) at the Alzheimer Society of B.C. 2000 Provincial Conference.

Being an advocate is to make your needs known and work towards having those needs met. An important basis for being able to speak up for yourself is a strong self-image. This gives you the sense that you have the right to respect, to fair treatment, to consideration from others and to have your needs met.

People with serious memory problems can go through an identity crisis as they come to terms with changes in their abilities. Over time I came to realize that I was the same person as before, but I now have a disability that I have to work around and I may need help from others in expressing my ideas and getting my needs met. Believing that you are the same person as before is important to having a full life.

Who can be an advocate?

- **Family and Friends** – those who are closely involved with my needs and wishes.
- **Peer Support Groups** – can offer non-judgmental discussion, help to clarify issues and give moral support. Members don't need to be able to communicate well. Being helped by and helping others is a very powerful way to make people feel properly valued as part of a community.
- **Alzheimer Societies** – can provide information and resources, respond to early stage problems by bringing us together and finding experts and advisors to help. They can also act as advocates for people who have no family nearby.

Medical Profession – can encourage their patients to join a local peer support group and seek advice from the Alzheimer Society. This will help the person deal with feelings of frustration, isolation and depression. I urge physicians to take action as early as possible for our best benefit and to push for better drug treatments and research studies for us.

The following are some examples of ways I advocate:

- I make sure doctors and other professionals explain things to me slowly and with diagrams if needed.

- I do volunteer work with the Alzheimer Society. It gives me the opportunity to make wonderful friendships and a strong sense of self-worth. It makes me feel useful at a time when I can no longer be in the workforce. My volunteer work includes: radio broadcast, presentations to professionals and family members on Alzheimer's disease.

OTHERS HELP ME ADVOCATE

People who share my goals and help me to do all that I can do for myself are also advocates for me.

What do I want in an advocate?

- Someone who is caring, understanding, honest, trustworthy, capable and has respect for me.
- Someone who will listen and ask me different times in different ways to make sure they understand.
- Someone who has the ability to understand the issues and to communicate accurately my needs and wishes when and where I can't.
- Someone who will give me the respect to **LET ME SPEAK FOR MYSELF WHENEVER AND WHEREVER POSSIBLE.**

WHERE TO GET SUPPORT

Join an Early Stage Support Group in your area.

** If there isn't one, get one started.*

** Take charge of your health!*

Early Stage Support Groups are a place for relaxed discussion. Supported by the Alzheimer Society numerous groups have formed to encourage mutual support and sharing of information.

These groups are invaluable to their members.

Some comments from group members:

I always feel good after chatting here.

I look forward to this meeting.

One of our members was feeling down. I think we picked her up. After all, that's what this group is all about.

My time is well spent here. We talk and encourage one another while laughing at ourselves on occasion. There is a good feeling of camaraderie amongst us since we understand both our feelings and our needs.

HANDY TIPS – WAYS TO HELP YOURSELF

These tips are used by members of the Early Stage Support Groups.

Keep track of appointments & things.

- Put an oven mitt in the middle of the floor to remind you the oven is on.
- Use post-it notes to remind you of important things to do or to remind you how to operate appliances (e.g. steps to warm up food in the microwave).
- Keep a day planner next to the phone to write appointments in.
- Use a weekly dispenser for pills.

Exercise both physically & mentally.

- Read the paper to keep your mind active.
- Take up swimming or regular walking.
- Join a choir, the mental stimulation is good and it lifts your spirits.

Participate in social activities.

- Stay involved with hobbies and interests.
- Volunteer your time to help someone else.

Stay independent & safe.

- Carry your name, address and phone number in every sweater and coat pocket, or buy a bracelet to put this information on.
- Write HOT above the hot water tap in the shower or glue a red disk on the tap. Use arrows to indicate ON.

Put your affairs in order.

- Make a Representation Agreement (in B.C.) or Power of Attorney to say what you want for your future care.
- Write a love letter to your children, spouse, and friends sharing precious memories. Save for a future time.
- Write a family history. Some stores sell books with questions that prompt you for details.

Keep in contact with your doctor.

- Find out about the use of vitamins to stay healthy.
- Ask about new prescription drugs for dementia (they may help reduce some symptoms).
- Keep a list of things that happen and your responses to any medication so when you have your appointment, you can bring the doctor up-to-date.

Work on your attitude -- think positive!

- Keep your sense of humour (or develop one!)
- Write a gratitude journal to record all the things that made you happy or thankful today.
- Who cares if you forget? There is no test at the end of the task or the day. Enjoy!

Life is not a dress rehearsal.

Remember to enjoy every day!

A MESSAGE TO FAMILY MEMBERS & FRIENDS

Please don't correct me. I know better -- the information just isn't available to me at that moment.

Remember, my feelings are intact and I get hurt easily.

I usually know when the wrong word comes out, and I'm as surprised as you are.

I need people to speak a little slower on the telephone.

Try to ignore off-hand remarks that I wouldn't have made in the past. If you focus on it, it won't prevent it from happening again. It just makes me feel worse.

I may say something that is real to me but may not be factual. I am not lying, even if the information is not correct. Don't argue, it won't solve anything.

If I put my clothes on the chair or the floor, it may be because I can't find them in the closet.

If you can anticipate that I am getting into difficulty, please don't draw attention to it, but try to carefully help me through it so nobody else will be aware of the problem.

At a large gathering, please keep an eye on me because I can get lost easily! But please don't shadow my every move. Use gentle respect to guide me.

Sometimes you give me the message that you think I am faking these problems. What you don't see is my terrible confusion and my hurt knowing how you feel.

I don't mean to frustrate you. I know you get impatient and tired of telling me things three times in a row. Please be patient.

Ask me what I think or want. Don't assume that you know.

Believe I still love you, even if I am having trouble showing it.

Traditionally, professionals and caregivers have mostly known the middle to late stages of dementia which has led them to see the person as incapable of making their own decisions or managing their own affairs.

For many people, signs of dementia appear many years before the late stage of the disease. What can be done to meet the needs of those in the early stages of dementia when we know that something is wrong and it is getting worse?

Often people try to hide their confusion and embarrassment. However, some of us have chosen a different course!

Early Stage Support Group members draw strength from sharing concerns with each other. It is simply a time to talk, listen, laugh and maybe even shed a tear with others who truly know the experience of living with dementia.

If people knew how much this monthly meeting means to those of us who participate, these groups would spring up all over the country.

To find out more, contact the Alzheimer Society nearest you. See the back cover for details.

If you have concerns about memory problems, contact your physician and the Alzheimer Society nearest you.

Alzheimer Society of B.C.:

Tel: 604.681.6530

Toll Free: 1.800.667.3742

Web: www.alzheimerbc.org

Other Provinces, contact the Alzheimer Society of Canada:

Toll Free: 1.800.616.8816

Web: www.alzheimer.ca

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