

Guidelines for Discussion Group
For People with Early Memory Loss

compiled and written by

Jennifer Ghent-Fuller RN MScN
and
Ike Veenstra BA RSSW

Alzheimer Society of Cambridge
940 King Street East
Cambridge, ON Canada
N3H 3P3

Autumn 2004

Revised
December 2005

Table of Contents

	Page
Table of Contents	2
Introduction	5
Week One	6
Reaction to the Diagnosis	7
Think Happier Thoughts	8
Love Yourself First	9
Week Two	10
Frustration	11
Manage Life's Stresses	13
Dealing with Depression	14
Shopping	15
Using the Telephone	16
Pace Yourself	17
Week Three	18
Being Angry at Oneself	19
Learning to Accept Help	21
Handy Reminders	22
Hug Someone	24

Week Four	25
Grief	26
Cooking	29
Benefits of exercise	30
Guidelines for Exercising	31
Laughter One of the Best Things in Life	32
Week Five	33
Lower Caffeine in Your Diet	34
Anxiety	36
Keeping Healthful Attitudes	37
Thought for the Day	43
Week Six	44
The Impact on Your Family	45
Yoga at the Table	47
Telling People	50
Volunteer Companion Program	52
Getting Lost	53
Advance Planning	54
Other Financial considerations	56
Continuing Power of Attorney	57
You Cannot Make the Sun Shine	58

Week Seven	59
Guilt	60
“I’m OK”. Affirm yourself.	61
Tips to Prevent Falls	62
Around the House	64
Forgive Yourself	65
Week Eight	66
Stay Positive	67
Doing Things	68
Expect Respect	69
Introduction to a Sample Letter	70
Sample Letter to Give to Friends and Family	71
How to Stay Young at Heart	74
References	76

Introduction

This guideline for discussion is an 8-week education program evolved over a four-and-a-half-year period. Initially the "Early Memory Loss Group" at the Alzheimer Society of Cambridge was a general discussion group, with ad hoc teaching and clarification of Alzheimer disease information provided by the facilitator, Jennifer Ghent-Fuller. After two years, some formal teaching notes were made. Ike Veenstra came on board as a co-facilitator during the fourth year of our Early Memory Loss Group. At that point, we developed our 8-week formalized program, and changed the name of the group to the Early Memory Loss Education Group (we have since added an Early Memory Loss Support Group to our chapter program for the graduates). The first members in our program were adamant that they did not want to be just told that they may have negative feelings, they also wanted ways to cope with these feelings and to become positive in their outlook. Many alterations have been made over the past years in response to the feedback received by the participants, and we will continue to let the program evolve. We are now mid-way through the fifth year of our program, and have received very positive responses.

We have attempted to write material that will help people with Alzheimer disease and related dementia regain a sense of control in their lives. Experience has taught us not to initiate discussions on three areas – future nursing home care, the burden of their caregiver, and future worsening of their health. However, these topics have been raised by participants on occasion and we do then discuss those issues in a most sensitive manner, either in the group, or individually after the group, depending on the situation.

There are three general themes to the material: "Coping with Changes In Yourself", "Managing Forgetfulness", and "Guidelines for Living". Items from each theme have been distributed into each of the weekly agendas. Our design is to have a broad variety of topics each week to spread out discussion of the emotive issues. We have also built in some repetition, which we have found taps into their procedural memory to facilitate retention.

Attendance is very high. We have typically run the groups with 4 – 6 participants and 2 facilitators. At each 1.5 hour session, we serve (decaffeinated) coffee and tea, water and a snack at each group. The group is held at the Alzheimer Society office. We ask them to complete a survey at the end of the program. The materials are put in a 5/8-inch binder, with tab dividers for each week, and a copy is designated for each participant. We ask them to leave the binder in the office during the program, and then they are presented with their binder at the eighth class to keep. Occasionally, we have run over into a 9th week, as we fell behind schedule due to lots of discussion (we let the discussion flow, and never try to stay "on schedule"). The group often wanders off-topic and enjoys spontaneous reminiscence and discussion. – JGF Dec. 2005

A testimonial: "[Before] it was like running your thoughts off the wall - nobody was listening. Here, we're one of the club, born into it. Here, we are able to talk to other people who are going through the same thing, the same problems." (Group member)

Week One

Reaction to Diagnosis

People often react to being told they have Alzheimer disease by refusing to believe it. Sometimes they feel emotionally numb.

How do you cope with these feelings?

1. Accept them as being normal. Most other people would feel the same way.
2. Be patient with yourself. You will learn to cope.
3. Take one day at a time.
4. Think of other difficult times you have been through. You found the strength to deal with other difficulties.
5. Believe in yourself. You will find the strength to deal with this disease.
6. Can you think of other people who have coped with a difficult situation in a way that inspired others?¹

¹ Coping with Changes in Yourself-Item 1

Thinking Happier Thoughts

People who are having a difficult time sometimes spend a lot of time wishing their life could be the way it used to be.

How do you change this pattern of thinking?

1. Tune into your thoughts occasionally. Are you having sad thoughts?
2. Make a conscious decision to make yourself feel happier.
3. Feel pleasure in going through your daily routines.
4. Recall a time when you felt supported and nurtured. Tell the story to yourself or someone else. Experience that feeling again.
5. Think of something you like about yourself. Feel proud of yourself.²

² Coping with Changes in Yourself-Item 2

Love Yourself First

Lucille Ball said, "Love yourself first and everything else falls into line. You really have to love yourself to get anything done in this world." These are smart words. Not only will you feel better about yourself, others are very attracted to a person brimming with self-worth.

Please remember, everyday, so many people believe in you...make sure you're one of them!³

³ Guidelines for Living - Item 1

Week Two

Frustration

Frustration is a common feeling, especially when speaking to others or listening to them.

How can you help yourself cope with your frustration?

1. Accept that these changes are part of your life now.
2. Give yourself permission to make changes if you need to. Find things that do work for you.
3. Take control.
 - If you need more time say – “Please wait”.
 - If you are having trouble understanding – say – “Please slow down”, or “Please tell me again slowly with different words”.
 - If other people are jumping into doing things for you when you don’t want help say- “Thank you for wanting to help but I am ok doing this on my own”.
 - If you need help say – “Can you help me?”

4. Smile. It is hard to feel frustrated when you smile!⁴

⁴ Coping with Changes in Yourself – Item 3

Manage Life's Stresses

It is important to be able to handle the stress of everyday life. Otherwise, common hassles will turn into major obstacles.

Stress may also cause you to do things that give pain, such as tense your muscles, grit your teeth and stiffen your shoulders.

The first step in breaking this pain-stress cycle is to realize that stress is your response to an event, not the event itself. It's something you can control.

That's why events that are stressful for some people aren't for others.

For example, forgetting something may leave you anxious and tense because you use it as worry time. Another person, however, decides to relax and not worry about forgetting something.

Understanding that you have control over your stress can help you develop positive strategies for dealing with stress.⁵

⁵ Guidelines for Living – Item 2

Dealing with Depression

Considering the many changes associated with Alzheimer Disease, it is understandable that you may feel sad or unhappy.

Don't carry the burden alone. Talk to people who can help you deal with your feelings.

Try some activities that can help take your mind off your worries, for example, playing your favourite music, gardening, taking a walk, caring for pets. These activities can have a beneficial effect.

Sadness that lasts all day long and makes you feel like you don't want to do anything may be depression.

If the feelings of sadness and hopelessness become overwhelming, make an appointment to see your doctor. Professional counselling may be recommended or medication may be considered.⁶

Adapted from the © Alzheimer Society of Canada 1997-2003. All rights reserved. Web site: www.alzheimer.ca

⁶ Guidelines for Living - Item 3

Shopping

1. Before you go shopping, make a list of what you're going to eat every night for dinner for the next week. Post that meal list on the fridge.
2. Make your shopping list according to what you need for the meals.
3. When you shop, have a pen in one hand to cross items off your list as you go.
4. Keep a blank paper on your fridge too. As soon as you run out of something, write it down so you can remember to buy it on your next shopping trip.
5. Cross off the days on your weekly meal list right after you've made those meals. This will also help you know what day it is.⁷

⁷ Managing Forgetfulness – Item 1

Using the Telephone

There are various things you can do to help you with the telephone:

1. Ask people to speak slowly.
2. Get a phone with large numbers.
3. Have a list beside the phone with the numbers you call most frequently.
4. Ask someone to set up a speed dial system so you have only two buttons to push. Colour code your list.⁸



Speed Dial



Anne



Dave



Jane

⁸ Managing Forgetfulness –Item 2

Pace Yourself

For every hour you work, it is an excellent idea to stop for five minutes, have a good stretch and walk about. It will not only be good for your body – it may well increase your productivity.⁹

⁹ Guidelines for Living - Item 4

Week Three

Being Angry at Oneself

One common feeling is to be angry with yourself. "I get down on myself."

How can you stop being angry with yourself?

1. Decide that you don't want to be angry with yourself and that you want to change.
2. Listen to your "self-talk" – your own inner thoughts about how you are doing.
3. Negative self-talk builds from the opinion of others and yourself over many years. Decide to replace it by supporting and encouraging yourself!
4. Consciously change your thoughts. For example, stop yourself from thinking "I am bad because I can't do as much" to "I am good because I am trying my best in a difficult situation."
5. Be your own best friend. Decide to like yourself. Smile at yourself in the mirror.
6. Look for the humour in your life. Rent a funny movie. Read a joke book.

7. Listen to soft music, especially before bed-time. This will help you be calm.
8. Think of a time you felt peace and serenity.¹⁰

¹⁰ Coping with Changes in Yourself – Item 4

Learning to Accept Help

1. Learn how to ask for help from others.
2. If you are like most people, you don't like to ask for help. It is hard to accept help when it is offered.
3. However, it is also true that if you are like most people; you feel good when you are able to help others.
4. Please remember that others feel good when they help you.
5. So you are helping them, too.
6. How do you react when others insist on helping you when you don't want help? For example, you could say, "Thank you so much for wanting to help me, but I really need to do this by myself." Be kind, but assertive.¹¹

¹¹ Coping with Changes in Yourself – Item 5

Handy Reminders

1. Do difficult activities at your best time of day.
2. Carry your name, address and phone number, and those of your family with you at all times.
3. Have a place where you always put important items —your wallet or purse, your keys, your glasses, your watch.
4. Use one pin number for all accounts. Try to pay most bills by automatic deduction at the bank.
5. Find two people you trust to help you with your finances.
6. Make a list of questions for your doctor.
7. Use a reminder chart for things you want to do every week – for example – go for three walks.
8. If you forget something, or have difficulty doing something, do not dwell on it, but return to it at a later time.
9. Get a dry-erase white board for reminder notes.

10. Keep things that you are doing currently out in the open where you can easily find them.
11. Do one thing at a time.
12. A place for everything, and everything in its place.
13. Try to establish a daily routine.¹²

¹² Managing Forgetfulness - Item 3

Hug Someone!

It is always a good idea to reach out to your friends and family in a positive way. We all can get so busy we forget how good it feels to give a good old-fashioned bear hug. It feels equally good to get one. What are you waiting for? Start your own hug campaign today.¹³

¹³ Guidelines for Living – Item 5

Week Four

Grief

Grief is a deep sorrow because of the loss of a loved one, or because of the loss of something that is dear to us. Loss of health causes grief.

We all react to this loss with grief. Grief is normal.

The grieving process is hard to work through. It is possible to feel grief from the past, all over again.

You may experience grief as a result of being diagnosed with Alzheimer Disease or similar diseases.

People experience their grief in different ways. Some people experience grief in a very emotional way.

They may become irritable, angry, frustrated, sad, or express yet other emotions. These expressions of grief are like a mirror of the feelings they have inside.

Other people experience grief in a physical way. They may feel like they were punched in the stomach or in the chest.

People with a physical type of grief reaction may like to talk or do things. Someone may tell stories about his dog that just died. A different person may want to clean the house or fix the fence.

Both men and women may have an emotional, or a physical, or a mixed reaction to grief.

There is no right way or wrong way to express grief. It is all normal.

It is helpful for all to find safe people to speak about their reactions to grief. These safe people could be family, friends or counsellors

Time often helps people to live with the pain of grief.

It is important to remember that every member of the family reacts to grief in a different way. This makes grief a complex family matter.

Different grief reactions need to be respected and accepted.

People who live with Alzheimer Disease and similar diseases live with many losses.

The worry of future losses often causes fears and grief.

The community does not always understand the grief and fears of people with Alzheimer disease. It is the job of us all to change this.

Live each day to the fullest.

Enjoy the present.¹⁴

¹⁴Includes adaptations from: "Beyond Gender" by Dr K. Doka 23/02/05 London, ON
Coping with Changes in Yourself – Item 6

Cooking

1. Put all your ingredients on the counter before you start. As soon as you use each ingredient, put it away in the cupboard or fridge.
2. Use a loud, noisy timer to remind you that you have something on the stove. Set the timer when using the stove or microwave to remind you to take the food out.
3. Use an electric kettle and iron with an automatic shut-off.
4. Put an oven mitt at the door of the kitchen when you turn on the stove. When you see the oven mitt on the floor, you will remember that the stove is on.
5. Put a reminder note on the inside of the front door – “Have I turned off the stove?”¹⁵

¹⁵ Managing Forgetfulness – Item 4

Benefits of Exercise

There are many well-documented benefits of people who have Alzheimer disease exercising. Exercise improves strength, endurance, and cardiovascular health and also helps control blood pressure. Exercise also reduces the risk of falls and fractures.

Staying active also:

- improves energy, stamina and mood
- improves sleep
- promotes regular bowel and bladder function
- helps maintain flexibility and balance, reducing the risk of serious injury from falls
- helps maintain the ability to do other daily activities, such as housework and self-care
- gives one a sense of well-being
- creates emotional calmness through a sense of familiarity and accomplishment

Guidelines for Exercising

- choose an exercise program that you are comfortable with
- wear loose-fitting clothes and comfortable, supportive shoes
- remember to warm up – before any activity, walk for a few minutes and then do gentle stretching exercises for the upper and lower body
- if you can find a partner to exercise with, do so
- establish a regular routine – exercise at the same time of the day if possible, and keep the sequence of activities the same each time
- plan for success – do exercise that you are easily able to do and that you enjoy
- play music while you exercise
- have fun!¹⁶

¹⁶ Guidelines for Living – Item-7 Adapted from alzheimerdisease.com

Laughter One of the Best Things in Life

It has been written that children will giggle and laugh up to 400 times a day. Adults, however, are laughing more like 12 to 15 times daily. Or less. What happened to the funny side of life? Learn from the kids - get your laugh quota up. Take life less seriously. It will make you feel great.

Feeling like nothing is funny? Work at getting some laughter. Get a funny book by Bill Cosby or a joke book. Rent some hilarious movies like City Slickers or The Pink Panther or videos with Goldie Hawn or Austin Powers or Mr. Bean or John Cleese. Tell some jokes; recall a really funny incident. Go online to find sites on humour, laughter and being jolly. If laughter is good medicine for Patch Adams, it is good medicine for us all. Come on, you can do this!¹⁷

¹⁷ Guidelines for Living – Item 6

Week Five

Lower the Caffeine in Your Diet

Caffeine is a stimulant. It can increase alertness and heart rate. Caffeine can also cause restlessness and difficulty in sleeping. The effects of caffeine begin about 15 minutes after you consume it and last up to several hours.

Caffeine in your diet will raise your anxiety and tension. Caffeine also interacts with medications. All this is harmful to people with Alzheimer Disease or similar diseases. Consider limiting your caffeine intake.

Coffee, tea and cocoa are naturally caffeinated. When caffeine is added to beverages in Canada and the United States, it must appear in the ingredients list on the label. Manufacturers are not required to list the amount of caffeine.

In Canada the amount of caffeine must be listed on the new "Energy" drinks.

When in doubt regarding the caffeine content of a product, read the content label. Amounts of caffeine in a product in Canada may differ from that in the United States.

Coffee is the major source of caffeine for most adults. For children, the major source of caffeine is carbonated beverages and tea.

Caffeine Levels in Some Foods and Drinks

Item	milligrams	Item	milligrams
Energy Drinks (1can)		8-ounce coffee	
Red Bull Energy Drink	80	Dripped	85
Jolt	71.2	Percolated	75
Energy Mountain Dew	roughly 45	Instant 1tsp	75
		Espresso 1 fl. oz.	40
Soft Drinks (1 can)		Decaffeinated	3
<i>American Mountain Dew</i>	55		
Canadian Mountain Dew	0	8-ounce tea	
Colas	38 or more	Black tea	40
Ginger Ale	0	Green tea	40
7 Up	0	Iced tea-ready	30
Orange Crush	0	Instant	28
A&W Root Beer	0	Decaffeinated	4

Items Containing Chocolate	milligrams
Baker's chocolate (1 oz.)	26
Dark chocolate, semi-sweet (1 oz.)	20
Milk chocolate (1 oz.)	6
Chocolate milk beverage (8 fl. oz.)	5
Chocolate-flavoured Syrup (1 fl. oz.)	4

Please note, that for tea and coffee products, the range varies depending on the brewing methods, plant variety and products.¹⁸

¹⁸ National Soft Drink Association (2003), www.nsda.org; Personal Canadian Market Research; Health Canada, <http://www.hc-sc.gc.ca/>

Anxiety

Feeling anxiety is a common reaction to learning that you have Alzheimer disease. There are many other situations, which can also cause anxiety. How can you calm your own anxiety?

1. When you find yourself feeling anxious, mentally yell - **STOP!**
2. Concentrating for a minute on feeling calm will help you deal with any stress.
3. To calm yourself, pause for a moment. Think only about your breathing. If you can, lie down for a few minutes and think only about your breath going in and out.
4. When you are calm, take another look at the problem. Take things slowly. Expect things to go as well as they can, whether you do them yourself or ask for help.
5. Try some activities that can help take your mind off your worries – playing music, taking a walk, studying nature. What has worked for you in the past?¹⁹

¹⁹ Coping with Changes in Yourself – Item 7

Keeping Healthful Attitudes

Healthy Living

Look after yourself! In our society, there is now more emphasis on the individuals taking the time to look after themselves. It is important to think about the basics of staying as healthy as possible.

Exercise

Regular physical exercise is good for the body and good for the brain. Exercise brings oxygen to the brain, reduces stress, and promotes efficient functioning of the body. It also causes the brain to release endorphins; “feel good” chemicals that can make you feel happier. The current recommendation is to do an exercise program 2 – 3 times a week, for 30 minutes each time.

Try “sneaky” ways to increase activity:

- Try parking your car as far as possible from your destination
- Take the stairs, not the elevator
- Walk the dog every day for an hour
- Take up dance classes (or dance in your living room!)

- Make extra trips up and down the stairs
- Rake the leaves
- Do extra gardening
- Put extra physical activity into your daily routine

Eat properly

Malnutrition can contribute to poor health and cause poor bodily functioning and increased illness. Make sure you eat a balanced diet with foods from all the food groups. Try to increase your fibre intake and decrease your fat intake. Poach or broil poultry or fish instead of frying fattier meats. Replacing meat with legumes occasionally provides variety and healthful eating. Deeply coloured fruits and vegetables have more nutrients.

Water

Make sure you get your 6 to 8 glasses a day

Two-thirds of your body is made up of water. That means it is the most vital nutrient needed.

Water plays many roles in keeping you healthy. It helps to digest food so you can absorb the nutrients you need. It gives you an important source of minerals like magnesium and calcium.

Water moistens the mucous membranes and lubricates the joints and cools the body through perspiration.

Try to get the equivalent of six to eight glasses of water daily. Don't wait until you feel thirsty to get that all-important drink. Keeping a large glass of water by your kitchen sink and another beside the bathroom sink is a good way to jog your memory to keep well hydrated.

Avoid the problems that dehydration can cause!

Take your medications as prescribed

Your doctor has prescribed medications, which are expected to help you. If you feel that they are not helping, or that they are causing side effects, talk about your concerns with your doctor.

If you go to more than one doctor, be certain that each of your doctors, and your pharmacist, has a current list of all the medications you take, including vitamins and other medications, such as aspirin, antacids or sleeping remedies that do not require a prescription.

If you have forgotten to take your pills, consult your pharmacist about how to get back on track.

Avoid Excess Alcohol

Some studies have found that one drink per day may be beneficial. However, even one small alcoholic beverage daily may be too much, depending on your health status and medications.

More than one alcoholic beverage per day may cause damage to the cerebral cortex, the seat of memory, learning, reasoning, intelligence and emotions. Please consult your doctor to find out what the best option is for you –avoidance or moderation.

Avoid smoking and second-hand smoke

Smoking constricts blood vessels, making less blood, oxygen, and nutrients available to the brain. It also replaces oxygen in the blood with carbon monoxide, a chemical that damages brain cells. If you smoke, talk with your doctor about assistance in quitting. If you live with someone who smokes, ask them to smoke on the balcony or porch, outside.

Breathe Deeply

The oxygen you breathe nourishes the brain. Many people, especially as we get older, are shallow breathers. Here is a helpful exercise to breathing more deeply by expanding the bases of your lungs:

- Inhale to the count of four.
- Hold for a count of seven.
- Then exhale slowly to the count of eight.

Get enough sleep each night

Most people need at least 7 or 8 hours of sleep per night. If you are having difficulty sleeping, try to adjust your environment or habits to increase your sleep time. You should feel rested in the daytime. However, napping in the daytime is helpful as long as you are active, eating well and generally looking after yourself.

Have your hearing checked.

Hearing loss can interfere with daily activities. You may need ear wax removed, or you may need a hearing aid.

Achieve and maintain a healthy body weight.

Carrying too much weight can increase your risk of high blood pressure, high cholesterol, diabetes, heart disease, stroke, some cancers, gallbladder disease, and arthritis in weight-bearing joints.

A high-fiber, lower-fat diet along with regular exercise can help you lose weight and keep it off.²⁰

²⁰ Guidelines for Living – Item 9

Thought for the Day

Love who you are.

Someone else will always be smarter.

Their house will be bigger.

They will drive a better car.

So let it go,

And love you and your circumstances.

To the world you might be one person, but to one person you just might be the world!²¹

²¹ Guidelines for Living – Item 10

Week Six

The Impact on Your Family Relationships and Your Friendships

You will go through many changes with your illness. One of these changes will be the way you remember things. As a result of memory loss, you may have different memories for events than your family or friends.

What can you do when you remember things differently?

You could ask that people not correct you or argue with you every time you have different memories than theirs. Would that work for you?

You could ask your family and friends to be patient when you are unable to remember something. Would you feel comfortable asking people to be patient?

Other changes you will go through involve speaking to and listening to your family and friends.

Would you feel comfortable asking people to speak more slowly?

How do you feel about people helping you when you can't find the right word?

Would you be comfortable asking your family and friends to help you if you are getting into difficulty?

What can **you** do to help your family and friends?²²

²² Coping with Changes in Yourself – Item 8

Yoga at the Table

Shoulder relaxation:

While sitting at the table, interlace your fingers behind your head. Relax your elbows and shoulders. Breathe and stretch your elbows back.

Hand stretches:

Place hands with palms together and fingertips up, move fingers in all directions and stretch. Squeeze fists tight. Then, stretch your fingers wide. Interlace your fingers and rotate hands.

Neck rolls:

Drop your head to one side. Roll it around in a wide circle, and then switch directions.

Lower back stretch #1:

While sitting, interlace your fingers below your knee. Bend your leg up and stretch your forehead to your knee. Switch legs.

Lower back stretch #2:

Cross your left leg over your right. Place your right hand or elbow on the crossed knee. Gently turn your back and look toward your left side behind you. Switch legs and twist the other way.

Lower back bend:

Stand up. Grab the edge of your desk or table, and step back a little with your feet shoulder width apart. Let your upper body stretch down, relaxing your head on the table.

Don't hold your breath!

When we tense up, we often hold our breath. By taking a long, deep breath, you relax your body and de-stress your mind.”²³

²³ Adapted from S. Kirk Walsh for Weightwatchers.com
Guidelines for Living – Item 10

Telling People

You may want to tell other people you have been diagnosed with Alzheimer disease or a similar disease. If you tell your friends and relatives, they may be more understanding and helpful toward you.

Telling people is difficult if you don't believe your diagnosis yourself. You may want to wait for a while before you say anything to anyone. Or, you may want to tell people that the doctor has given you a diagnosis, and also tell them that you find it hard to believe.

Each person reacts differently to the idea of telling people about living with Alzheimer Disease. Some people may want everyone to know. Some may only want to tell a few people.

Question:

How do you feel about telling others about your illness?

It is your decision who you want to tell. You may be most comfortable telling the people who are closest to you first. Whenever any one of us gets a major illness, there are people around us who need to know. They may want to find out what they can do to help you. They can give you understanding and comfort.

What good things would happen if you do not tell people?

What good things would happen if you do tell people?

Is it important to have others understand what you are experiencing?

How could you respond if they don't understand?²⁴

²⁴ Coping with Changes in Yourself – Item 9

Volunteer Companion Program

Our Alzheimer Society has a program of providing a volunteer companion for people with Alzheimer Disease.

The volunteers visit people with Alzheimer Disease once a week for a couple of hours.

Together people with Alzheimer disease and their companion may chat, play a game, garden or go for a walk, etc.

You may enjoy participating in this program sometime in the future.

Getting Lost

Sometimes people with Alzheimer Disease will lose track of where they are.

This sometimes happens when the disease is quite new. A period of disorientation may last for a few minutes or a few hours.

You may want to consider enrolling in the Safely Home program provided by the Alzheimer Society of Canada.

There are also electronic devices that can increase your sense of personal safety.

Advance Planning for Your Future Care

For everyone, there is a possibility that they will not be able to make decisions or choices, some time in the future.

Advance Care Planning is a voluntary process. It involves appointing a Power of Attorney for Personal Care.

This allows you to say who will be making decisions on your behalf in the future if you are unable to do so. You are the only person who can appoint your own Power of Attorney for Personal Care, so it is important to do it when you are well.

Once you have appointed people to be your Power of Attorney, you continue to make decisions as long as you are able to.

You may want to specify when the Power of Attorney will take effect, or you may leave that to the judgment of the person you are appointing.

It is a good idea to appoint a second person to act as your Power of Attorney for Personal Care, in the event that the person who is your first choice is unable to do it.

You need to tell your Power of Attorney for Personal Care how you feel, what is important to you, what your values are.

They can then make decisions on your behalf, which follow your choices. Your wishes can be respected, even if you are not capable of making decisions.

A Power of Attorney for Personal Care makes decisions concerning health care, food, living arrangements, clothing, hygiene and safety.

“A Guide to Advance Care Planning” is in your package.²⁵

²⁵ Coping with Changes in Yourself – Item 10

Other Financial Considerations

Everyone living with Alzheimer Disease or a similar disease can complete a Disability Tax Credit Certificate form for their income tax. Use form T2201 to apply for this tax credit.

Caregivers of people living with Alzheimer Disease have special Tax Credits also. Please refer to form RC4064(E). These forms are enclosed in this package.

Some union agreements have health provisions that may assist with retired members. Veterans benefits may also be of assistance.

For those under 65 years of age:

People who are under 65 may be eligible for a federal or provincial government disability pension.

Many employers provide Long Term Disability Insurance and you may be eligible through their program.

If the cost of medications is overwhelming, ask your pharmacist for an application for assistance from the Trillium Ontario drug benefits.

Continuing Power of Attorney for Property

This is the second type of power of attorney. You can appoint one or more people to manage your financial affairs.

You can determine when this Power of Attorney for Property will take effect. You can also restrict the Power of Attorney for Property if you wish.

For example, you may wish to allow your Power of Attorney for Property to pay your bills and reinvest your money, but you may not want them to sell your property.

A booklet is enclosed in this package.

It is best to consult a lawyer when completing both types of Power of Attorney; however it is not absolutely necessary.²⁶

²⁶ Coping with Changes in Yourself – Item 10

You Cannot Make the Sun Shine

None of us can control weather conditions, or what other folks say or do, nor can we control a lot of things in life. However, we CAN control how we react to those things. That ball is always in your court.²⁷

²⁷ Guidelines for Living – Item 12

Week Seven

Guilt

Many people feel guilty because of the changes they and their family need to make to cope with their illness.

Guilt is another example of negative self-talk.

How can you stop yourself from feeling guilty?
Consider taking positive steps, such as:

1. Practice having high self-esteem. Tell yourself – “I am a worthwhile person”, “I am important”.
2. Realize that when others help you, they are raising their own self-esteem.
3. Think of someone whose life you have influenced in a positive way. Feel proud of yourself.
4. Think of something you like about your spouse, a family member or a friend. Tell them how you feel.
5. Think of an obstacle you have overcome. Thank yourself and whoever helped you.
6. Practice! See the next page for an example.²⁸

²⁸ Coping with Changes in Yourself – Item 11

“I’m OK!” - Affirm Yourself

- 1. I am a successful person.**
- 2. It is OK to be proud of myself.**
- 3. I did a great job of taking care of my family.**
- 4. My community benefited from me being in it.**
- 5. I have given strength and support to my spouse, children and grandchildren.**
- 6. My family loves me.**
- 7. I am proud of my strength in adversity.**
- 8. I love to laugh.**
- 9. I have worked hard and I can be proud of that.**
- 10. I have helped many people.**

Tips to Prevent Falls - Fitness

- Keep body weight down. Extra weight on the hips and trunk makes us more top-heavy and unstable.
- Keep leg and hip muscles strong. Do leg raises and side stepping.
- Turn around or change direction slowly.
- Keep knees and hips flexible by moving them through a full range of motion. If balance is a problem, you can do this on a bed.

Challenge your balance system daily by going over uneven ground and around obstacles. Walking in a crowded mall is also challenging.

Tips to Prevent Falls - Be Watchful

- Be aware of uneven edges in the joints in the sidewalks. They are easy to trip on in a poorly lit area.
- At night, take care when moving from brightly lit areas to dark areas, and vice versa. Go slowly. Allow your eyes to get accustomed to the change in light.
- If you have strong bifocals, be careful when you shift your gaze from close objects to those further away.
- After bending over, do not straighten too quickly – the blood pressure in the brain can suddenly drop, causing you to faint.
- Wear shoes with non-skidding soles.²⁹

²⁹ Guidelines for Living - Item 13

Around the House

1. Put a laundry basket in the hall to remind you that you have clothes in the washer.
2. Turn down the temperature setting of the hot water heater – the factory settings can cause severe burns. About 40° C or 105° F is high enough.
3. Write HOT above the hot water taps.
4. Put a sign with the word “OFF” and an arrow ↘ to help remind you to turn off the taps, if you have that difficulty.
5. Put outside or inside lights on timers, so you don’t have to remember to turn them off.
6. Have a reminder bulletin board or white board to write notes about what you need to do.³⁰

³⁰ Managing Forgetfulness - Item 4

Forgive Yourself

Far too many adults are too hard on themselves and suffer untold stress from feelings of guilt.

If you have done the best you can do in any situation, and most of us do, don't beat up on yourself if it didn't have a positive outcome.

If you let someone down and you regret it, say you are sorry, and then move on.

If you couldn't do all you wanted to because you were unable to be superman/woman, let it go.

Be as kindly and forgiving of yourself as you would be to a dear friend.³¹

³¹ Guidelines for Living- Item 14

Week Eight

Stay Positive

Cultivate an upbeat attitude and stay positive.

Happier people handle stress better and can enjoy better health. Count your blessings. Every time you hear yourself saying something negative, turn it around, and rephrase it into something more positive.³²

³² Guidelines for Living – Item 15 – www.successfulaging.ca

Doing Things

What things did you enjoy doing with your free time twenty years ago?

What things did you enjoy doing with your free time in your childhood?

What do you like to do now when you are alone?

What do you like to do now when you are with someone?³³

³³ Guidelines for Living – Item 18

Expect Respect

Expect help, kindness, patience and respect from others.

Keep your self-esteem strong. Don't tell yourself you are doing badly; tell yourself instead that you are doing well despite the disease.

Take things slowly. Expect things to go well, whether you do them by yourself or get help.

Relax.... The less stress you are feeling, the better you will do.

To relax, lie down for a few minutes and think only about your breathing.

If your mind drifts, pull your thoughts back to just thinking about your breathing.³⁴

³⁴ Guidelines for Living – Item 16

Introduction to a Sample Letter

On the following pages you will find a letter of introduction to Alzheimer Disease, which you may copy and send to your family and friends.

Dear Friend:

You are likely reading this letter because you have been told that a person you know and care about has received a diagnosis of Alzheimer Disease, or another form of dementia.

As a result of better diagnostic testing and more information about disease symptoms, there has been a trend toward diagnosing people with dementia earlier in their disease process. As people are being diagnosed at an earlier stage, the general public is more aware of what people with dementia need in order to live their lives normally. With the added benefit of medication, those with a diagnosis will be able to maintain normalcy in their lives with only minor adjustments.

The following are comments given by individuals in the early stages about some of their common concerns:

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

→ **“I make unexpected word substitutions. Often the word is close, but not as fitting as the one I would regularly have used. I sometimes have trouble finishing sentences.”**

→ **“I worry so much about making mistakes that I don’t participate in as many activities as I used to.”**

→ **“I often misplace things after thinking I have put them in a logical place and then I can’t remember my logic.”**

You might feel that some of these concerns are the same ones that you experience from time to time. The Alzheimer Society has information about the difference between normal forgetfulness and memory loss associated with dementia. For those diagnosed with an irreversible form of dementia, the changes are not a normal part of aging, and the symptoms will continue to get worse with time.

You cannot protect your friend from the grief process they will experience as a result of their diagnosis. Nor can they protect you as you will have your own unique way of reacting. You may struggle, on occasion, and feel nervous about making hurtful mistakes in the things you say or do, but the most important gift you can give is the care and support that comes with maintaining a normal relationship.

Sometimes in wanting to protect those you care about, you may inadvertently minimize their experience. People with dementia have suggested that in some of their interactions with well-meaning friends, they felt they were not taken seriously. For instance, in an effort to avoid embarrassment, you might say: “Oh don’t worry about that mistake, it happens to me all the time; it is not your Alzheimer Disease.” While your heart is in the right place, you do not have a disease that is going to get worse.

Or you may say "You don't have Alzheimer Disease." A diagnosis of Alzheimer Disease is made by carefully eliminating any other possible explanation for the symptoms, and doctors are very reluctant to give these symptoms a name unless they are as certain as they can be.

You might want to discuss your friend's comfort with the label of their diagnosis. For instance, your friend may be comfortable using the word Alzheimer's or Dementia or they may be more comfortable referring to their changes using words such as 'short-term memory loss', or just 'memory problems'.

Ask your friend if there are any adjustments that you need to make in the way that you interact with them. If you are comfortable talking about the changes associated with their disease, let the person know this. If you are uncomfortable, you will need to let your friend know this so that they do not think that it is anything they have done.

Below are some comments from those in the early stages about their hopes for your reaction as you move through the disease process with them:

→ **"Try to ignore off-hand comments that I would not have made in the past."**

→ **"I usually know when the wrong word comes out and I am often as surprised as you are."**

→ **"My thinking does not always work as clearly as it used to. I may bump into you on the street, or in the mall, and take a few extra minutes to remember what your name is and my connection to you. As my disease progresses, it will be easier for me if you give me your name and make reference to how we know each other."**

Some people want help to find a word when they are having trouble, and other people would rather just do their best and keep going without being interrupted. Please ask them what they would prefer.

What is of utmost importance, is maintaining a relationship with your friend that is as normal as possible. Because of new treatments or the type of dementia that your friend has, it may be years before the changes are significant enough to move them into the next stage of their disease.

Consider visiting your local Alzheimer Society to browse through their resource library. Any book that is written from the perspective of a person who has the disease will shed insight into the early stages. These books may also provide you with vital information as you support your friend through the many changes they will encounter with this disease.

Some excellent books to read include:

- Alzheimer's Early Stages by Daniel Kuhn
- Living in the Labyrinth, by Diana Friel McGowin
- Show Me The Way To Go Home, by Larry Rose

The Alzheimer Society of Canada's website is also a useful resource and can be reached at: www.alzheimer.ca. Our web site contains a paper entitled "Understanding the Dementia Experience" which can be found at www.alzheimercambridge.on.ca .

Yours truly,

How to Stay Young at Heart

1. Throw out nonessential numbers. This includes age, weight and height. Let the doctors worry about them. That is why you pay them.
2. Keep only cheerful friends. The grouches pull you down.
3. Commune with nature.
4. Enjoy the simple things.
5. Laugh often, long and loud. Laugh until you gasp for breath.
6. The tears happen. Endure, grieve, and move on. The only person who is with us our entire life is ourselves. Enjoy feeling alive.
7. Surround yourself with what you love, whether it's family, pets, keepsakes, music, plants, and hobbies, whatever. Your home is your refuge.
8. Cherish every day.

9. Don't take guilt trips. Take a trip to the mall, even to the next county or a foreign country, but NOT to where the guilt is.

10. Tell the people you love that you love them, at every opportunity.

"Life is not measured by the number of breaths we take, but by the moments that take our breath away."³⁵

³⁵ Guidelines for Living – Item 17
Adapted from George Carlin's Views on Aging

Sources

Alzheimer Society of Canada (2001). Shared Experiences.

Doka, K. "Beyond Gender", lecture given on 23/02/05 in London, ON; adaptation.

Ghent-Fuller, J. (2003) Understanding the dementia experience.
www.alzheimercambridge.on.ca

Gregg, S. Sample letter. Alzheimer Society of Guelph-Wellington.

Stones, Lee. www.successfulaging.ca (Love yourself first; Pace yourself; Hug someone; Laughter, one of the best things in life; Thought for the day; Manage Life's stresses; Keeping Healthful Attitudes; You cannot make the sun shine; adapted**)

www.alzheimercanada.ca (Dealing with depression – adapted)

www.alzheimerdisease.com (Guidelines for exercising – adapted)

www.georgecarlin.com (How to stay young at heart – adapted)

www.hc-sc.gc.ca (Health Canada) Information on caffeine (adapted).

www.nstda.org Information on caffeine (adapted).

www.weightwatchers.ca (Yoga at the Table – adapted from article by S. Kirk Walsh)

* Adaptations in materials were made to suit people with short-term memory loss.

