

**Alzheimer's Disease
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trivial plane
to the spiritual
or personal plane.
I had to face
the absolute horror of the
'A' word,
and I began a dialogue
with my existence...**

*—D. Cohen**

**SECTION 6:
MAINTAINING YOUR SPIRIT**

6

* Cohen, D. "The Subjective Experience of Alzheimer's Disease: the Anatomy of an Illness as Perceived by Patients and Families". *American Journal of Alzheimer's Care and Related Disorders Research*, Vol. 6, No. 9, 1991.

6

MAINTAINING YOUR SPIRIT

IN THIS SECTION OF THE WORKBOOK, YOU WILL LEARN ABOUT:

- the things that determine quality of life
- managing challenging symptoms
- maintaining hope when facing dementia
- the importance of spirituality as you face dementia

QUALITY OF LIFE WITH DEMENTIA

Quality of life is defined as a person's sense of well-being that stems from satisfaction with areas of life that are important to them.

Morris Fridell writes, "But the greatest challenge to Quality of Life in Alzheimer's disease is the darkness of the future... The spectre of the dark future of advanced Alzheimer's disease is a significant challenge to Quality of Life in mild Alzheimer's disease. The usual response is to make decisions that must be made...and then avoid thinking about the future. I believe that this approach tends to distort life and to be unsuccessful in eliminating fear."*

He then goes on to say, "The first step in recovery of quality of life is emotional safety. The goal is to recover from anxiety or depression and be strengthened in warding them off, to learn basic coping skills, to do basic advance planning, and to find some enjoyment in a simpler and more present-oriented life style."**

The following pages will highlight **three** key factors in maintaining your spirit so that you can still experience good quality of life:

- Managing Challenging Symptoms
- Hope
- Spirituality

Life is not a dress rehearsal. Remember to enjoy it every day.

* Fridell, M. "Awareness: A Personal Memoir on the Declining Quality of Life in Alzheimer's". *Dementia*, Vol. 1, No. 3, 2002, pp. 360-361.

** Fridell, M. *Dementia Survival: A New Vision*. <http://members.aol.com/MorrisFF/Vision.html>

MANAGING CHALLENGING SYMPTOMS...IN ORDER TO IMPROVE QUALITY OF LIFE

Keep in mind that any changes caused by the disease are not going to happen to you suddenly. You will have time to adjust your lifestyle and to find help when you need it. Keep in mind that some days will be better than others. Do what you can on a given day.

Memory changes

Memory aids can help reduce the demands on your memory:

- Put important things like money, keys and glasses in the same place every time.
- Routine is important—have a regular way and time to do things.
- Do one thing at a time.
- Write reminders to yourself.
- Make a daily list of what you need to do and keep it realistic!
- Posting a weekly calendar of activities on the wall can be useful. Mark off days on a calendar.
- Keep important numbers by the phone where you can see them. Include emergency numbers, as well as your address so that you can refer to them quickly.
- Keep a day planner next to the phone to write appointments in. Get into the habit of checking it regularly.
- Label cupboards or drawers with words or pictures to remind you where things are kept.
- Carry your name, address and phone number in every coat pocket, or put the information on a bracelet
- Label photos with names of people important to you and the role they play.
- Mark the route to the bathroom with reflector tape to make night time visits less problematic.
- Put an oven mitt in the middle of the floor to remind you the oven is on.
- Noisy timers will remind you something is on the stove or in the oven.
- Electrical appliances used frequently should all have automatic shut-offs.

- Ask your pharmacist about help with medication such as using bubble packs.
- Try using talking clocks.
- Tell people you have a memory problem—ask them to repeat or explain things.
- Leave a set of house keys with a trusted neighbour.
- Make a memory book of information that is important to you and keep it with you at all times. This book can be kept in a pocket (“pocket pal”) or hip pouch. It may contain:
 - » important phone numbers, including your own and any that may be needed in an emergency
 - » people’s names
 - » a list of things to do
 - » appointments
 - » a map showing the location of your home
 - » any thoughts or ideas you want to hold on to

Changes in abilities related to day-to-day living

When there is impaired processing capacity in the parietal lobes of the brain, it becomes more challenging to do things independently. To combat this you can:

- Focus on the things you can do, not the things that have become too difficult.
- Experiment with ways to modify activities. Flexibility is the key—find other ways to get the job done.
- Research various aids that may be useful.
- If you are having problems with one activity, try something else.
- If something seems too difficult, take a break.
- If you no longer enjoy reading, try talking books, audiotapes, and videotapes.
- Take your time and ask others to give you time.
- Ask for help and take it. Often people are wanting to know how they can help.
- Ask others to assist with difficult tasks.
- Check into services to help with household chores, meal preparation and banking.

Write a love letter sharing precious memories to your children, spouse and friends. Save for a future time.

Keep a gratitude journal to record all the things that made you happy or thankful today.

- Simplify your living space and your life.
- Consider sorting out your closet and dresser drawers to make it easier for you to choose what to wear.
- Consider purchasing clothing that is simpler to put on.

Changes in mood

- If you get frustrated when things are not going well, blame the illness, not yourself.
- If you are depressed or have other worrying feelings or thoughts, your doctor may be able to help.
- Sometimes talking to a counsellor who knows about dementia helps.

Changes in the ability to talk to others

Finding the right words to express your thoughts may become harder. Understanding what people are saying will also be difficult at times.

- Take your time.
- Tell people you have a problem with thinking, communicating and remembering.
- If you did not understand a statement, ask the person to repeat it.
- It is okay to ask over and over again.
- If too many people or too much noise bothers you, find a quiet place.
- If you lose a thought, let it go. It is okay if you forget—it may come back.

HOPE...AND THE EXPERIENCE OF ALZHEIMER'S

Hope is the belief in what is possible. It is what nourishes us during difficult times. With dementia, you can be struck by spells of discouragement, fear, or disillusionment. Hope may feel a bit elusive.

We hope because it is essential to our quality of life. When we hope, we are willing to get up more times than we fall down. We are willing to give ourselves one more chance, again and again. With hope, whatever the outcome, we can go on.

One reason to hope is an awareness of work underway to treat or cure Alzheimer's disease. Scientists are continually researching new medications to slow disease progression and enhance functioning. New drugs are currently under investigation. In the last decade, there have been tremendous advances in research. Each new finding builds on previous ones. Scientists are optimistic that each advancement is moving towards prevention or a cure.

Another reason to hope is that those working in long-term care are developing far more loving, creative, and dignified ways of caring for individuals whose disease is very advanced. We can feel encouraged that in the future, we will be in the presence of loving and caring people who understand our condition and needs at all stages of the illness.

With the advances in communication technologies, people around the world are collaborating and sharing their discoveries, ideas, and experiences related to the many aspects of Alzheimer's disease and related dementias. Everywhere in laboratories, community settings, support groups, households, and in our every day lives we can find seeds of hope.

Finding Hope*

Does everyone always hope?

No. Hope fluctuates for every person. We can experience more or less of it on any given day or during any given period. When our hope is weak, that does not mean we are weak. Times of illness or unwanted change are particularly hard on hope.

* Adapted from: Jevenc, R. F. & Miller, J. E. *Finding Hope: Ways to See Life in a Brighter Light*. Fort Wayne, Indiana: Willowgreen Publishing, 1999.

If I am low on hope or feel I have no hope, can my hope return?

Yes. Sometimes, it is as if our hope has gone into hiding and one day it re-emerges. As with a physical injury, time and effort can help restore hope. Each of us must make the choice to reclaim our hope. It is not just handed to us. We must reach for it.

Here's the critical question: *How do I learn to hope?*

There are various ways you can learn to find, keep, and build hope. Some ways will work better for you than others. The only way you will know which ones work for you is by experimenting. Some ways will work better on certain days or at certain stages in your life. You will figure it out as you go along. Keep in mind that “hoping” is seldom an overnight success. It’s more like a lifetime adventure.

You might have to experiment to find a way that works for you.

- Throw the hope switch. Hope to hope.
- Notice signs of hope. Spring always follows winter.
- Listen to hopeful voices—talk to people with a positive attitude.
- Look back. Think about a time in your life when you felt especially hopeful. You can feel hopeful again. Why? Because you have done it before. You have had the experience of hope. You have got the makings.
- Expect to find hope where you least expect it—hope may find you.
- Break the silence that often accompanies times of low hope or no hope. You may break your silence by opening up to another or by writing for yourself. However you do it, you will head towards hope.
- Borrow hope from others, from your beliefs, from songs, readings, stories, movies, or even dreams.

- Let out the artist or the clown in you.
- Sometimes, when we are unable to feel hopeful, we need others to offer encouragement, or to shed a brighter perspective on a situation. This is the reason why people go to support group meetings.
- Many find hope in seeing the growth and maturity of children and grandchildren that they helped usher into the world. They are an extension of life that continues on. In the face of one's own illness or mortality, the company of family can inspire hope.
- For those with limited or disconnected families, it can be comforting to establish a sense of extended community—a network of even one or two significant people whom you know will see you through the ups and downs, and with whom you can share your hopes and fears. True communication and understanding between people is one of the most powerful ingredients in a recipe for hope.
- Some people put inspiring photographs or paintings on their walls or desks. Some hang posters with cheering thoughts or carry notes with affirming words.
- Practice. Then practice some more. You practice by: naming hope whenever and wherever you find it; by highlighting hope as you come across it; by taking hope in; by expressing it; by preserving it.
- Search for what is meaningful in your life. Right next to it you will find what gives you hope.

- Say “yes” to hope. No one plans to develop a chronic illness. But illness happens. Life does not always turn out the way we wish. When that happens, what do we do? Live with it? Fight it? Ignore it? Give in to it? There may be a reason to take any of these stances at one time or another. The hopeful response, however, is different. Hope says “yes.”
 - » Yes, there is a way to handle everything.
 - » Yes, I can deal with whatever that has been handed to me.
 - » Yes, the unexpected can bring joy as well as sorrow.
 - » Yes, misfortune can be a cause of growth as well as grief.

- Some people talk about living in the moment—access the potential for opportunity in each day.
 - » Today, I can meet with friends.
 - » Today, I am going to enjoy this quiet time when I can watch the world go by out of the window.
 - » Today, I can go to my Tai Chi class.
 - » Tonight, I can be warm by the fire.

Living with hope

“Searching to find what to be thankful for, I had to remind myself that anything with an end has a beginning. I could be thankful that we live in the 21st century, and now there is medication that helps many of us slow symptoms and I do have the benefit of an Early Stage Support Group. Medication has allowed me to continue functioning at a reasonably healthy level and while Mild Cognitive Impairment has progressed to Early Alzheimer’s disease—I still feel smart, inside.

I continue to read (who cares if I make mistakes), walk, sing, and do word-finds because I believe it is important to keep busy. Remember the old adage, “If you don’t use it, you lose it.” I can no longer follow a recipe, but I can still whip up a mean stir-fry! My husband has become a greater support than ever before and bless him for his helpfulness. We now grocery shop as a team and he has taken on the responsibility for putting my pills into their weekly dispenser, then of course, he has to remind me to take them. One of the nicest things he has done for me is to hire a cleaning lady twice a month. This makes my life much easier. We still have a good life, only now we have to work around the challenges of Alzheimer’s disease.”*

SPIRITUALITY

The search for meaning and purpose during stressful life events knows no religious or spiritual borders. It is a quest as natural to the human condition as the quest for food and shelter.

People have a spiritual dimension in their lives. It is the essence of every person whether or not they have a religious faith. The ability of the human spirit to find meaning and purpose in life is remarkable—even amid tremendous challenges and hardships.

Human suffering can lead people in two opposite directions: promoting spiritual growth or diminishing the human spirit. Religion and spirituality offer pathways to find meaning in life, even after a diagnosis of a dementing illness. Like any terminal illness, a diagnosis of dementia brings with it a reordering of priorities. It can be a time to take stock of one’s life and focus on the legacy one wishes to leave behind. **

* Contributed by an Early Stage Support Group Member, Kelowna, B.C.

** Snyder, L. “Satisfactions and Challenges in Spiritual Faith and Practice for Persons with Dementia”, *Dementia*, Vol. 2, No. 3, 2003, pp. 299-313.

“Having Alzheimer’s disease made me face ultimate realities, not my bank account. My money, my job and other parts of my life were trivial issues that restricted my growth, my spiritual growth. Alzheimer’s disease transferred me from what I call the trivial plane to the spiritual or personal plane. I had to face the absolute horror of the ‘A’ word, and I began a dialogue with my existence, a dialogue with my life and my death.”*

If you have a spiritual life, it need not end with a dementing illness. It can be supported and affirmed. With appropriate physical care, you may need to look for support to:

- maintain faith practices and contact with faith groups
- express and demonstrate affection
- mark special occasions and make every day special
- talk about distress
- speak about your spiritual life

List some of the important people or resources to help you with sustaining hope and your spiritual life.

“So, like persons with incurable cancer or ALS [Amyotrophic Lateral Sclerosis], we with Alzheimer’s can come to a place where the disease is part of our lives but doesn’t define us. Then we can continue on with the basic tasks of our lives, with, say, singing our own songs or developing our relationship with God.”**

* Cohen, D. “The Subjective Experience of Alzheimer’s Disease: The Anatomy of an Illness as Perceived by Patients and Families”, *American Journal of Alzheimer’s Care and Related Disorders Research*, Vol. 6, No. 9, 1991.

** Friedell, M. <http://members.aol.com/MorrisFF/LossOfSelf.html>

ARE YOU FINDING IT HARD TO:

- **COPE WITH RECEIVING YOUR DIAGNOSIS ?** **YES/NO**

- **PROCESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA?** **YES/NO**

- **FINDING AND MAINTAINING HOPE?** **YES/NO**

- **MAINTAIN YOUR SPIRIT?** **YES/NO**

- **MAINTAIN YOUR FAITH PRACTICES?** **YES/NO**

If the answer is yes to any of the above questions, consider:

- contacting the Alzheimer Society of B.C. to join a support group (see Section 7)
- contacting the Alzheimer Society of B.C. to access education programs

