

The Gifts That We Share

Caring For My Parents With Alzheimer's



Marilyn Cahill

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The Gifts That We Share or Caring For My Parents With Alzheimer's

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*Do not dwell on the past; do not
dream of the future; concentrate the
mind on the present
moment...Buddha*

Dedication

This ebook is dedicated to caregivers...

To all of those who have dedicated their time, their effort, their kindness and compassion in caring for those who are no longer able to care for themselves.

This ebook is dedicated to caregivers because whether they are family, friends, or volunteers who care for someone; or whether the caregivers are paid for their services – I believe they are the true heroes of our society.

On many occasions, I have accidentally eavesdropped on conversations (one-sided, many times) of a PSW (Personal Support Worker) or a nurse, or a CCAC (Community Care Access Centre) staff member, or a physiotherapist (or other health care occupation) attending to a person with a dementia-related disease and may I inform you that so often the kindness and compassion that shone through their actions and words often brought tears to my eyes. I have heard personal care workers sing to their residents; I have witnessed nurses holding hands and “dancing” (or rocking back and forth) with their patients; I have glimpsed staff members hugging a resident while whispering words of comfort. I believe caregiving is one of the most valuable and worthy connections that we will form in our lifetimes. Many caregivers have found their true calling or purpose in life.

Because of them, I dedicate this ebook. Thank you.

Introduction

I think a lot about why I would want to write this book. I feel that I have so much to pass on to other caregivers who have just begun this journey. I want to help family and friends learn how to connect with someone who has either Alzheimer's disease or a dementia – really connect – so that they can still experience the “essence” of the person, even when that person can no longer communicate or care for themselves. I desperately want caregivers to learn how to live in the moment – to let go of the fear of the disease and just be at one with that person in the Now. I want caregivers to experience joyful moments throughout the journey and learn to love and forgive and accept forgiveness from that person with Alzheimer's. (Yes, persons with Alzheimer's can forgive – even when they cannot communicate. It's about loving energy.) And finally, I want caregivers to let go of the fear, guilt, resentment and anger and just be – to learn “if you want to get love, you have to give love.”

And lastly, I hope to dispel a fear that Alzheimer's disease is the worst thing that could happen to a loved one; it's not. The disease, like so many other diseases and illnesses, leads to death – and that is a fact of life. Alzheimer's disease is not pretty; neither is cancer.

As a caregiver, my story is not that unusual; in fact, in 2012, there were 15.4 million caregivers alone (Alzheimer's Association. (2013). *Alzheimer's Disease Facts and Figures*. Accessed February, 2014, from: <http://www.alz.org>). I meet other adult children every day who are caring for their parents; many of my friends have been full-time caregivers and many of them have cared for loved ones in their own homes. Some, like myself, looked after both parents (or a parent or a spouse) for a period of time in the home and then have had to make the difficult decision of “letting go” and moving their loved one into a long-term care facility. If there are over 15 million caregivers, chances are in our own circle of influence – many are caregivers.

Like many others who look after a loved one, I am neither a nurse, nor am I a personal support worker. I have no experience in any of the professions of “caring” for patients in any way. My story is not that different from other caregivers – I write from a newly-retired Canadian woman's perspective (living in Ontario). My sister, my mother (in her 80's at the time) and I cared for my father when he exhibited signs of dementia (later, a physician in the emergency ward told us that it was probably Alzheimer's disease – my father, and my mother who was POA (Power of Attorney) at the time, refused to allow us to take my father to a physician). In the last few months of my father's illness, my mother began to have hallucinations and exhibit paranoia and when my father died, we had barely returned home from the funeral when my mother showed further signs of a dementia, too.

Because my experience looking after my father was too heartbreaking to face again, I became determined to do it differently. Since I felt I hadn't done a spectacular job the first time around – I was worn out most of the time – I decided that there must be a better way. There is. The journey is still challenging and wrought with sadness and grief, but it's also one of understanding and acceptance; and for me, that has made a world of difference.

My sister laughed when I told her that I was going to write about our experience of caring for both our parents – she worried that it wasn't very healthy to want to re-live a painful experience. I disagree.

What I do know is that something inside me keeps telling me to do this. And one thing I have learned is that I must listen to my inner voice.

My inner voice is the gift that I received (or *found*) after my father died and my mother became ill. It is not the only gift that I received; I received many others and continue to do so. But the greatest gift that I received is my inner voice became more vocal. And since I believe that we all have a spirit, I now know that my inner voice is really just another word for spirit or my soul.

Caregiving is a unique and profound experience – an awakening; an awakening or realization that we are all here on earth to look after each other as we are all connected. Some of us learn the lessons and are open to the “gifts;” while others do not learn the lessons and do not understand why I would call the experience – a gift.

Since I have opened my heart and my mind, I have discovered and heard new stories of love and kindness and how they transform our lives, each and every day. When you are on “high alert” for new experiences, they fall into your lap! In fact, my mother's hospital roommate was in her room for only a few hours, when the roommate's daughter told me a beautiful story that resonated with me. Since her mother had become ill with dementia, various family members would crawl into the bed with her mother and snuggle up beside her until she fell asleep. On one of these occasions the granddaughter said to her grandmother while lying beside her, “Grandma, do you know who I am?” My mother's roommate answered, “No, I don't know you. **But I can feel the love.**”

This ebook is written for those of you who want to learn the lessons and be open to a new form of communication or connection with your parent – a deeper, more profound way of communicating in understanding the behaviours, because the behaviours of a person with Alzheimer's becomes the “new language” – that is how the person communicates now. If you want to learn the “new language,” you will need to interpret the behaviours and learn to “read” your loved one.

If you intend to communicate or continue to “connect” with your loved one, you will need to open your mind and your heart; we absorb our most profound and transforming lessons when we are open.

Allow me to warn you that caring for a loved one will change your life!

When I read Bolte Taylor’s book, *My Stroke of Insight: A Brain Scientist’s Personal Journey* (2006, Penguin Group) I was inspired by the author’s description of personal energy. She spoke often of how a visitor, or attending physician or nurse, would either bring their positive (and sometimes kind and loving) energy into her hospital room, or that at other times they would bring their negative energy and how it would “suck” her energy and leave her listless and fatigued. Her story roused questions in my mind about patients and their needs and led me to wonder...

What if a person with Alzheimer’s can understand people, but intuitively, not intellectually? What if a person with Alzheimer’s can hear you and want to say things but cannot? What if we sat down with our family member who has Alzheimer’s and looked into their eyes and said words of comfort, “Please don’t be afraid. You are not alone. We will go through this journey together. I will ensure that we take time to understand each other. This isn’t the end of the world...but it is now a different world.”?

What if we followed the theme of the movie *Avatar* and we embraced the words and what those words mean...“*I see you.*”? (If you haven’t seen the movie, the words “*I see you*” are used as a greeting; metaphorically and literally, a person sees or understands in a physical and spiritual sense who the other person is.)

What if our words and acts of understanding could transform the disease from one of fear and loss into a journey of “connection” with our loved one – who is no longer in the world of sense and reason, but who has entered into a new realm of sensitivity and emotion? Now that’s a radical thought! Or, is it?

Lastly, when I owned my children’s clothing store in my past life (before looking after parents) I often would re-iterate to my staff – “Whenever a customer is unhappy, just look them in the eye and say sincerely “What can I do to make things right?” Now I believe that similar words can soothe someone who has Alzheimer’s. Because most of the time, I have learned that our customers did not want the moon, they only wanted to be *heard*. They wanted to know that we understood that they were not happy; that they wanted us to validate their feelings. And, I believe that the person with Alzheimer’s wants the same thing. It’s what we all want – validation – to know that we matter.

Take time to stop the busyness of your life, take time to be in the stillness of that moment – “Dad, you matter to me...whatever it is that you need or want, we will help you as much as we can. All is well.”

You will see the frustration drop. You will notice the person's body will relax and lose its rigidity.

We want to know that we matter still. Our loved ones, our parents, our husbands and wives – all of them just want to know that there is still a joyful life ahead.

You can make that happen – and that's why caregiving is a gift. It's a gift to them and it's a gift you give yourself.

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Chapter One

What is Alzheimer's Disease?

Alzheimer Society of Canada's website <http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Dementia-in-canada> informs us that

“According to a 2012 study commissioned by the Alzheimer Society of Canada, the number of Canadians living with cognitive impairment, including dementia, now stands at 747,000 and will double to 1.4 million by 2031.”

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www.alzheimer.ca

A Statistics Canada report (Sinha, Maire. (2013) *Portrait of Caregivers, 2012*) identifies that *“in 2012, about 8.1 million individuals, or 28% of Canadians aged 15 years and older, provided care to a family member or friend with a long-term health condition, disability or aging needs.”*

Further, the report states *“Ailing parents were the most common recipients of care, with 39% of caregivers looking after the needs of their own parents and another 9% doing so for their parents-in-law.”*

Those statistics are staggering and suggest that there are a whole lot of people out there – caregivers – who are probably overwhelmed and stressed. How do I know? I know because I have walked that path and understand the challenges of caring for someone who has Alzheimer's disease or a form of dementia. The path is challenging because the symptoms alone are challenging, not to mention the physical decline of an aging loved one.

If you were to ask a caregiver what is the most difficult issue to contend with on a daily basis, many would argue that it is the loss of memory and cognitive impairment. It exhausts the person with Alzheimer's *and* the caregiver. The loss of memory leads to sadness, frustration, guilt, anger and resentment – on the person's part *and* the caregiver's.

Thankfully, the more we learn and more informed and educated we become about this disease, the more we are able to cope with new and better ways of communicating with someone who lives with Alzheimer's. When we learn ways to cope with behaviour changes and other cognitive decline, as caregivers, we can learn to *accept* the disease and its demands.

Alzheimer's disease is only one kind of dementia, but it is the most common. It is a disease or condition that develops when nerve cells (neurons) in the brain either die off or no longer function as normal. Because of the neurons dying off or changing, the brain no longer functions as it should – causing memory loss

(one of the most common symptoms that is initially noticed), behaviour changes and impaired thinking. Ultimately, the brain changes lead to an inability to manage the most basic fundamental body functions; for example, swallowing, walking, and the inability to toilet without help.

Alzheimer's disease is a fatal, progressive and degenerative disease and is the most common form of dementia.

There are other forms of dementia including **Vascular Dementia** (often known as post-stroke dementia) which is caused by microscopic bleeding and blood vessel blockage.

Another form of dementia is **Dementia with Lewy Bodies**. Lewy Bodies is an abnormal clump of the protein alpha-synuclein in the part of the brain called the cortex.

According to an article *About Dementia; Types of Dementia: Dementia with Lewy Bodies* (last updated January, 2014) Accessed September, 2013, from <http://www.dementiaguide.com> the symptoms of Lewy Body Dementia are somewhat similar to Alzheimer's disease, but occur out of order. The website explains the differences between the two diseases:

“One way to understand the symptoms of dementia with Lewy bodies is that while they are similar to those of Alzheimer's disease they occur out of order. The symptoms of Alzheimer's disease occur in a fairly characteristic order in relation to the stage of the illness. In Alzheimer's disease, some symptoms are very common when the disease is mild, but others usually do not occur until later, when the dementia is in a moderate or late stage. For example, hallucinations are common in Lewy body dementia. The hallucinations typically consist of seeing things that are not there. In Alzheimer's disease generally, hallucinations occur late (e.g. in the severe stage), but in dementia with Lewy bodies, they usually occur early when the dementia is in the mild stage. In fact, in Lewy Body dementia, hallucinations can be the first sign of the dementia. (It should be noted that patients with early hallucinations also have particular problems with visuospatial function).”

The website www.dementiaguide.com further lists symptoms of Lewy Body Dementia:

- *Large changes in attention and alertness (one day able to hold conversation, next day completely unable).*
- *Other indications of fluctuation are episodes of staring blankly, especially if it occurs to such an extent that you find yourself touching or even shaking the person you care for so that they will "snap out of it".*
- *Daytime sleepiness can be another sign of fluctuation.*

- *Another important set of symptoms of Lewy Body Dementia reflect its overlap with Parkinson's disease. Parkinson-like symptoms (for these symptoms, doctors often use the term "Parkinsonism ") include bent posture, shuffling walk, and the tendency to fall. In fact, recurrent falls can be an early feature of Lewy Body Dementia.*

Because Alzheimer's and Lewy Body Dementia are so similar the symptoms can fool or confuse some of us who are armchair analysts (me!). My mother's dementia follows Lewy Body Dementia *and* Alzheimer's disease and because she refused to go to her physician once she exhibited some symptoms, to date she has still not been formally diagnosed. During her eleven month hospital stay, I did notice that most attending physicians wrote on her medical chart words such as: "seems to be confused" or "memory loss" and because of her age (nearing ninety years) formal tests were not done.

Let's continue with other forms of dementia:

Frontotemporal Lobar Degeneration (includes Pick's Disease) – Nerve cells in the front and side regions of the brain are affected.

Parkinson's Disease (problems with movement are common symptoms) – The alpha-synuclein clumps are in a deeper area of the brain causing degeneration of the nerve cells that produce dopamine.

Creutzfeldt – Jakob Disease – rapidly fatal disease thought to be caused by mad cow disease.

Normal Pressure Hydrocephalus – caused by the buildup of fluid in the brain.

What is common in all of these forms of dementia is that there is **cognitive impairment** because of dying or changing nerve cells in the different parts of the brain.

Alzheimer's disease is a progressive irreversible brain disease that destroys memory.

Alzheimer's disease can affect anyone – any gender, any race, any nationality, any religion and any socio-economic background. Statistics show that most people who are diagnosed with Alzheimer's disease are over the age of 65. As we age, the rates of dementia increase significantly.

Here are some facts about the disease according to www.wikipedia.com

Alzheimer's disease is the most common form of dementia; there is no cure. The disease progresses and eventually leads to death.

Alzheimer's disease can onset earlier, but most cases occur over 65 years of age. In 2006, there were 26.6 million sufferers worldwide.

Alzheimer's affects everyone differently, but there are some symptoms that are similar to all:

- Confusion
- Irritability
- Forgetfulness and memory loss
- Aggression
- Mood swings
- Language difficulties
- Withdrawal from society
- Decrease of bodily functions (which eventually leads to death)

After diagnosis, life expectancy averages 7 to 10 years. Tests can evaluate the disease and a brain scan can be done. To date, there is no cure.

Throughout this ebook I will suggest that you visit different websites as thankfully, there are thousands and thousands of sites. (I just Googled the term "Alzheimer's disease" and received 81,500,000 responses.) Many of these websites are terrific – informative and supportive. I suggest that you visit reputable and credible sites; there are many of them. At the end of this ebook, you will find a list of websites that I have visited over the last few years.

One website that I think is a "keeper" is www.alz.org – this website is so good that when I refer it to friends or acquaintances that need help with understanding the disease (usually they have a family member that has been diagnosed with Alzheimer's disease) they usually email me a huge thank-you. I feel so grateful that I found this website so that I can pass it on to others.

If you want to understand the disease and its affect on an individual's brain, please check www.alz.org and click on the "Brain Tour" slide show: *Inside the Brain: An Interactive Tour*. (Visit www.alz.org/alzheimers_disease_4719.asp) In easy to understand language and clear photos you will begin to understand the irreversible damage that Alzheimer's does. We can learn from the slide show that when the brain changes, it eventually shrinks in size – affecting all functions. The cortex shrivels up – damaging areas involved in thinking, planning and remembering. And we also begin to see and understand that the hippocampus is especially affected by shrinkage. The hippocampus involves forming new memories and so now we know why our loved ones who have Alzheimer's just can't remember that you visited yesterday. Or, that they cannot remember that

they are not supposed to walk now **without** support. Those lessons have just not been learned or retained. (It's one of the reasons that we must not ask our loved ones to press the "call bell." They just can't remember that function. During a stay in the hospital, my mother would repeatedly pick up the telephone (not press the call bell) to summon one of the nurses. Her roommate kept reminding her that the telephone was not for that purpose. But, my mother continued to pick up the telephone and yell into it, "I am ready to go to the washroom now." The phone was dead, of course.)

In the early stage of Alzheimer's disease, "plaques and tangles" (that term that most of us have heard about) begin to form in areas of the brain that involve memory and learning, and thinking and planning. That explains why the person with Alzheimer's has so much difficulty remembering how to itemize a grocery list, or why the person suddenly seems confused about the simplest of directions, or why my mother suddenly would tell me that the school bus no longer dropped off children outside her house. I reminded her that it was summer and that the school buses didn't run in the summer. She looked blankly at me and asked, "Why don't the school buses run in the summer?" (She had even forgotten that school is out during the summer.)

In the mild to moderate stage of Alzheimer's disease brain areas that are related to speaking and understanding speech are further damaged. Also, the person with Alzheimer's finds it difficult to sense where his/her body is in relation to objects around them. (Depth perception, as well as other dimensions, has been further compromised.)

At this stage, there is more confusion and more memory loss that leads the person to have difficulty in the workplace and in social situations. At this stage, my father refused to go out. He wouldn't articulate this but he refused to leave his house. He also could not carry on a conversation, nor would he be even interested in any visitors or their conversations. It was not unusual for him to just get up from the dinner table and leave the room. (Yes, our guests were usually stunned, especially those guests who were visiting him, specifically.)

In the advanced stages of Alzheimer's disease, most of the cortex is severely damaged. Patients lose the ability to communicate, to recognize family and friends and to care for themselves.

I urge you to visit www.alz.org and click on Alzheimer's disease, then click on "Brain Tour" – it won't take you very much time to view the short video, but it is well worth the understanding of the brain and Alzheimer's disease.

- Dementia eventually affects all aspects of a person's life, including **how the person thinks, feels, acts and reacts to his environment.**

The Three Stages of Alzheimer's Disease

There is thought to be three stages of the disease – early, moderate and advanced. Although symptoms are somewhat similar for patients, many symptoms overlap from one stage to another which can cause confusion of which stage the person with Alzheimer's is in. A person with Alzheimer's can move from one stage to another slowly or gradually or there can be a rapid decline from one stage to the next. For most patients, the prognosis is 7 to 10 years on an average. Many live longer than ten years, and some die long before seven years. Many other factors determine life span.

For most, once the disease advances in the brain, behaviour changes increase, abilities will decrease and loss of memory will increase as the brain is affected. Once a learned behaviour has been lost, it is difficult for someone with Alzheimer's disease to re-learn that behaviour.

Because Alzheimer's affects the whole family, it is imperative that we learn everything we can about the disease and its symptoms. Why? I believe (and so do experts) that knowledge will help us with our **communication skills and coping skills**. Our loved one is not at fault when they forget your name. Nor are they at fault when they leave the fridge door wide open. The brain is changing. What we take for granted...what comes natural to us...all of that has been lost with your parent. Try to imagine what that feels like – you say something or do something – and now your parent or loved one is staring at you. You sense their fear from their body language and the look on their face, “Oh, oh. What did I do? What did I say? What's wrong with me?” We can only imagine how frightening that internal struggle must be, deep within. As caregivers, it is our responsibility to assuage the person's fears and doubts. When you don't know what is happening, just be still. Say “It's okay, mom. It's okay.” Or say nothing. Just rub their arm, hug them or hold them. Allow your parent to *feel* – don't discount his/her feelings and emotions.

Caregiver Tip: Remember: The disease has taken his/her ability to think, feel, reason, act and re-act to his environment.

Most websites and research agree on the list of early or mild onset of symptoms:

Early signs:

- Memory loss
- Speech and language difficulties (searching for a word)
- Poor judgment
- Confusion
- Irritability
- Taking longer than usual to complete daily chores or tasks

- Trouble handling money and paying bills
- Loss of spontaneity and sense of initiative
- Mood and personality changes/mood swings
- Increased anxiety and aggression

Many families are slow to recognize changes and/or acknowledge them and their loved ones, themselves, have difficulty accepting that they are ill. Your parent suspects something is wrong but often resists going to the doctor for a diagnosis. Once the diagnosis is made, the family and parent usually find it easier to cope. In a small way, the truth sets us free. We can begin to cope instead of covering it up. (That does not mean that your loved one is not impacted greatly from the news!) Let's remember that fear comes from the unknown.

In the **Moderate Stage**, symptoms become more pronounced:

- Wandering
- Agitation
- Increased memory loss
- Shortened attention span

Caregiver Tip: More supervision and care must be given at this stage. You will need to modify the home for safety reasons. I have included many lists of modifications and home adaptations in the chapter, entitled "Day to Day Caregiving."

In the final or **Advanced Stage**, symptoms include:

People with Alzheimer's in the advanced stage are unable to walk, talk or dress themselves. They are unable to toilet or bathe without assistance. They do not have control over their bowel movements. Many can no longer recognize people, including family and loved ones. Communication can be impaired to the degree that many communicate by grunts, shouting out, or groaning.

Most people do not die of Alzheimer's disease, but of *complications from falling or respiratory illness.*

Some of the most difficult challenges that a caregiver will face are the constant losses – sometimes you will feel like you have been “pummeled” on a daily basis. Alzheimer’s disease is a thief – it literally robs the patient of beloved memories and personality; it robs the mind of its ability to reason, articulate, recognize and remember. Slowly, but surely, our loved one seems to disintegrate before our eyes. That hurts. It’s painful to watch a man of strength and determination, wit and character lose those characteristics each day. Over a few short months, a person can lose his ability to converse with you (never mind, advise you or inspire you like the old days!). When our loved one depends on us for everything, including daily dressing and feeding, the relationship is profoundly affected. (And unless we recognize these emotions as natural, we can become highly stressed.)

When my mother became more and more ego-centric as her world shrank, I found that I actually went through a stage where I resented that she no longer asked how I was doing. I found that I would sit beside her and think “Aren’t you the least bit observant that I am exhausted? That I look like crap?” My mother of the old days would have declared dramatically “My goodness, Marilyn, have you looked in the mirror lately? What is your problem? You are a mess!” I actually wanted her to say that I looked like crap. At least I would know she cared! (Thankfully, I have since learned not to take things personally; and that it isn’t about me, it’s about the person with Alzheimer’s!)

When we are barraged with constant losses, it takes a toll on our health because loss represents grief, an “anticipatory” grief that is constant for many months, if not years. I can’t tell you how many times I drove home after a day of caring for my father, shoulders scrunched up, holding back the tears. I would pull myself together when I arrived home, hoping my husband wouldn’t notice my tear-soaked face. Grief is like a wave and it overwhelms you at the most inopportune times, especially if one stockpiles their emotions, not wanting to allow them the light of day. I would reason that there was plenty of time to grieve *after* my father had died (What the heck was I crying about...he was still here, wasn’t he?). Nonetheless, when we are participants in this show, when we are first-hand observers of the slow decline of our loved one, it is painful and we mourn everyday.

I cried uncontrollably the day my father was admitted to a long-term care facility. I went into the nurse’s office to fill out paperwork and glancing up, I noticed that the ambulance attendants were wheeling my father’s gurney into a room down the hall. My father looked puzzled and scared...he looked like a small child. I began to sob. And sob. (Two or three years of bottled-up emotions poured out of me in that poor nurse’s office.) Then the nurse handed me a box of Kleenex. Well, if you have ever visited someone in a hospital or long-term care facility, you will have noted that the Kleenex boxes are miniature replicas of a normal-sized box. (I call them “mini-me Kleenex boxes.”) At least that is my excuse when I tell you I went through the whole box of Kleenex. That poor nurse. I found it difficult

to look at her the remainder of my dad's stay at the home. She had seen me at my most vulnerable.

Elisabeth Kubler-Ross, M.D., in her ground-breaking book *On Death and Dying*, calls this grief – “anticipatory grief.” *Anticipatory grief* is the grieving that takes place **before** a patient dies. Unfortunately, the nature of the disease only heightens the number of opportunities to grieve; hence, the reason I used the word “pummeled” earlier. As a caregiver, you can feel like you can't face one more loss and then, your loved one will say or do something (unwittingly, of course) that hurts you one more time.

Piece by piece, the person loses his cognitive abilities and memories; piece by piece, family members lose their loved one. It is the nature of the disease – that slow and gradual loss – that is the very reason why we grieve throughout the whole process. So many “mini-deaths”. So many losses.

But that is why the experts encourage caregivers to learn as much as they can about Alzheimer's disease in order to understand the symptoms and the reasons behind the losses. And, of course, with knowledge and understanding, comes acceptance.

“When we know better, we do better.” Mayo Angelou

When we understand that anticipatory grief is normal, and that it's okay to feel bad or even angry, then we can *accept* our emotions. Acceptance is really the key to this disease. For me, I learned that in acceptance, I can let go of the suffering. Some very wise Buddhist once said “Pain is inevitable; suffering is optional.”

In acceptance, we let go of the pain and suffering and we open up to the reality of “what is.” We can't change the diagnosis or the prognosis, but we can change our attitude. Once we change our attitude about the prognosis, then and only then, can we learn to be in the moment and fully experience the time that is left with our loved one. It may not be today or tomorrow, but in time we can learn to appreciate the gift that has been given to us when we become caregivers. It is a privilege to look after a loved one. Be open to accepting the gifts of kindness and compassion. Enjoy the opportunity to bond and strengthen your relationship with your loved one. Learn to open your heart and forgive and be forgiven. Learn to live in the moment and enjoy the now – accept who your loved one has become right now. Sit still with them, hold their hand, put your arm around them, take them for a walk and just talk to them...you will be surprised and amazed how transformative these small acts of acceptance will become (accepting the person exactly as they are right now!). And you will be surprised that when you look deeply into your parent's eyes that the essence of that person is still there. (My dad had a twinkle in his eye until the very end when he died of a stroke-induced coma. Two weeks before he died, he had sat up in his wheelchair and sang

Perry Como's hit "Fly Me to the Moon" – just those five words – and I was transferred back in time to my parent's kitchen, my dad belting out the words of his favourite performer.)

And I am happy to write that as of today, my mother is still alive (fairly healthy at age 90, although wheel-chair bound) and on many good days she is feisty just as she was in her youth. Even when she is telling a story that no one understands, she is still exhibiting the essence of who she was (and still is). To me, that is a mystery, but a beautiful one, no less. I have come to believe that although we might lose our memories, we will never lose the essence of who we are. That essence or soul or spirit or whatever you might call it...lives on. When we take the time and effort to connect with our loved ones during this journey, we are able to connect with their spirit – and that is what makes the journey memorable and transformative.

The Trajectory of the Illness – Alzheimer's Disease

I recently completed two palliative courses and learned a lot of information about death and dying. Mostly I learned that we did just about everything wrong when we looked after my dying father a few years ago.

I learned so many things that I still consider the course information as a "gift" that I gave myself.

One of the most important things that I learned was that my mother, my sister and I could *not* cure my father or *halt the progression* of the disease. (Intellectually, I knew that. But, sub-consciously, I believed we could change the inevitable. My heart just couldn't accept that he had Alzheimer's.)

Secondly, I learned that we attempted to do too much. During the courses, we often discussed the "domains" of an illness: The family and patient are affected by domains of issues which include disease management, physical, psychological, social, spiritual, practical, end-of-life care, death management, and grief and loss.

Imagine my horror when I realized that the three of us in my family attempted to manage all of the domains of issues. Of course, I didn't even know this stuff – so how could I do better?

What I want you to know is this: Caregiving is a huge responsibility with many hats. Too many hats. Your head will hurt.

In retrospect, I feel comforted in the knowledge that we did so much and most times, did it well. And, I am completely at ease and without any guilt today that we could not do more.

When it came time to make more difficult decisions about my mother's care, two years after my father died, the process and the journey was easier. We knew that we did not have the wherewithal to do it again. The tank was empty. Did that make my sister and I feel sad? Yes. Did that make us feel guilty? No. We had learned something in the last journey and that was that Alzheimer's disease eventually beats a patient down. That, no matter how much you try and reverse or halt the disease, the disease (like many diseases) marches forward until the end. We also learned that in the end you either ask for help or you sink.

So now I want to tell you that the trajectory or journey or timeline of Alzheimer's disease is long, gradual and slow.

When we know the illness trajectory (the decline of the patient and what will happen) it helps in a small way to feel as if we have some control and that, as caregivers, we feel better equipped to meet the upcoming challenges and demands of the illness – forearmed. The illness trajectory is one that takes a prolonged gradual decline (typical of frail elderly people with dementia). Every facet or domain will be affected: psychologically (patient may become depressed); socially (patient will become reclusive or stop socializing with friends); spiritually (patient will feel frightened and bewildered about his future); physically (gradual loss of memory and abilities); and practical (patient will no longer be able to look after day to day management of appointments, groceries, home maintenance, etc.) Each of these facets will need to be addressed over time.

In an article, Authors Scott A. Murray, Marilyn Kendall, Kirsty Boyd and Aziz Sheikh, *Illness trajectories and palliative care*. April 30, 2005, from: <http://www.ncbi.nlm.nih.gov/pmc/?term=PMC557152%2FBMJ>, the authors remind us that the illness journey is long, slow and takes its toll:

“This third trajectory is of progressive disability from an already low baseline of cognitive or physical functioning. Such patients may lose weight and functional capacity and then succumb to minor physical events of daily social “hassles” that may in themselves seem trivial but, occurring in combination with declining reserves, can prove fatal. This trajectory can be cut short by death after an acute event such as a fractured neck or femur or pneumonia.”

“Again, all of this information is to support the patient and the family in making decisions – short-term and long-term ones – about the future. Family members can face end of life care and decisions that revolve around end of life in the early stage of ALZ Disease, rather than waiting until the patient cannot give any input. Don't be afraid to seek help and advice from CCAC, spiritual advisors, physicians and health and social services.”

As caregivers, when we don't understand the effects of the disease on an already aging, fragile elderly person, we are confused about how the patient may die. Most elderly patients are susceptible to falls (a symptom of many diseases of the aging – thanks to frail bodies, frail bones, attempts to walk without support, homes that are not adapted to the aging population, and walkers and other contraptions that are not conducive to patients with cognitive decline, hence, no idea how to use them.). I think that, as caregivers, we assume that our patient or loved one will die of Alzheimer's disease. Not necessarily. As Murray, Kendall, Boyd and Sheikh pointed out in their article "*Illness Trajectories and Palliative Care*,"

"This trajectory can be cut short by death after an acute event such as a fractured neck or femur or pneumonia."

In other words, it's not the Alzheimer's that takes the patient in the end; it's other daily "hassles" that lead to death. (Albeit, it *is* the disease, itself, that furthers the frailty (and, hence, vulnerability) of the patient.)

Planning ahead is the key to a healthy acceptance of the disease. Ask your parent the difficult questions (while you can):

- Where do you want to die? If not at home, where? In a hospital, in the nursing home? Hospice?
- Resuscitation status is a sensitive issue, but an issue that will need to be addressed. Ask your parent his/her thoughts about dying – do they want life prolonged? If done sensitively and compassionately, this discussion can be thoughtful and informative.
- Don't be afraid to hear your parent/loved one discuss death. Get over it! Your parent is going to die and wants to talk about it. When we change the subject or avoid it, we hurt our loved one. At the very least, let them talk. Learn to listen. Stop talking. Just listen.

Okay, I sound wise, don't I? Not. I learned all of this during palliative course sessions. Fooled you, didn't I? But seriously, death is an uncomfortable subject. It takes practice to talk about it...but, all of us can learn lessons from the patient if we just sit still and listen. It is one of the greatest gifts that you can give a dying person.

I think it's so important that we learn, as caregivers, that we can't do it all...that we must ask for support. Instead, as caregivers, we try to do it all – manage all of the domains of issues – spiritual, physical, psychological, practical, etc. – and in the end, we stretch ourselves too thin and we do not manage any of the

domains of issues well. Instead, when we know this stuff (and no excuses now, I just told you) perhaps we should just handle two or three issues and do those well, really well. Wouldn't our loved one be better off? Of course. Someone (say, a volunteer) who just visits with the person with Alzheimer's – plays cards, reads aloud, listens to music and holds his/her hand – only handles the visits and activities – that volunteer will do his/her job with joy, patience and enthusiasm and the person benefits. Or, someone (say, Uncle Jack) decides that one or two times a week, he will drive our loved one to the doctor's appointments, the hospital for tests, and the clinic for blood work. When he picks up our loved one, he is in a good mood and upbeat attitude – lots of laughs along the errand route. Doesn't that help elevate our loved one's mood? Of course. And what if a personal care worker (who is completely at ease and confident in her/his job) visits two times a week to bathe and wash our patient's hair? I call that "win/win." (As a caregiver, you rest!)

In these small acts of kindness - asking for help and receiving it...we add a quality and joy to our *patient's* life's journey. As caregivers, we try to do it all and really end up not doing any of it well – because, quite frankly, we are just too tired and overwhelmed. If you only learn one thing when you read this ebook – please learn this lesson. You can't do everything!

I learned this lesson the difficult way – by attempting to be Super-caregiver! Guess what? There is no award – unless there is an award for the most fatigued and worn out!

Strangely enough, on this very topic (do one or two jobs but do them well) I was walking one morning on my usual route when I happened to walk by a home where a woman had just driven into the driveway to pick up an elderly gentleman who was on his porch waiting for his ride. I heard her yell to him when she opened the door to assist him into the car. She greeted him and yelled, "Well, hello, love...isn't it a beautiful, gorgeous day. I can't wait for us to go on an adventure!" Now, I ask you and be honest...wouldn't you like that joyful woman to drive you to your doctor's appointment? Or do you want to be escorted by the caregiver who is grumpy and exhausted? Ha! Joy wins out!

Chapter Two

Does My Parent/Loved One Have Alzheimer's Disease?

With permission from Alzheimer Society of Canada here is the list of the warning signs. Available from <http://www.alzheimer.ca>

10 warning signs

To help you know what warning signs to look for, the Alzheimer Society has developed the following list:

1. Memory loss that affects day-to-day function

It's normal to forget things occasionally and remember them later: things like appointments, colleagues' names or a friend's phone number. A person with Alzheimer's disease may forget things more often and not remember them later, especially things that have happened more recently.

2. Difficulty performing familiar tasks

Busy people can be so distracted from time to time that they may leave the carrots on the stove and only remember to serve them at the end of a meal. A person with Alzheimer's disease may have trouble with tasks that have been familiar to them all their lives, such as preparing a meal.

3. Problems with language

Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute words, making her sentences difficult to understand.

4. Disorientation of time and place

It's normal to forget the day of the week or your destination -- for a moment. But a person with Alzheimer's disease can become lost on their own street, not knowing how they got there or how to get home.

5. Poor or decreased judgment

People may sometimes put off going to a doctor if they have an infection, but eventually seek medical attention. A person with Alzheimer's disease may have decreased judgment, for example not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.

6. Problems with abstract thinking

From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a cheque book. Someone with Alzheimer's disease may have significant difficulties with such tasks, for example not recognizing what the numbers in the cheque book mean.

7. Misplacing things

Anyone can temporarily misplace a wallet or keys. A person with Alzheimer's disease may put things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.

8. Changes in mood and behaviour

Everyone becomes sad or moody from time to time. Someone with Alzheimer's disease can exhibit varied mood swings -- from calm to tears to anger -- for no apparent reason.

9. Changes in personality

People's personalities can change somewhat with age. But a person with Alzheimer's disease can become confused, suspicious or withdrawn. Changes may also include apathy, fearfulness or acting out of character.

10. Loss of initiative

It's normal to tire of housework, business activities or social obligations, but most people regain their initiative. A person with Alzheimer's disease may become very passive, and require cues and prompting to become involved.

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www.alzheimer.ca

Have you read the list of warning signs of Alzheimer's disease and you are still unsure if your loved one has Alzheimer's or a dementia-related disease?

- Call your loved one's physician, or nurse (if you are not POA, they may refer you to your own physician)
- Call CCAC – Community Care Access Centre
- Call the local Alzheimer's Society office
- Call friends and family members and make some inquiries into your loved one's behaviours – in most cases, other people have noticed distressing signs that something is amiss. You are not alone!
- Visit one of the 88,000 websites on the Internet – the truth is out there!

Most aging seniors are aware of these changes in the early days of the onset of a dementia so they become very clever in disguising the truth. Our parents are aware what the symptoms mean and that scares them into covering up the truth. My mother would cover up my dad's confusion, loss of memory and language difficulties – she would insist that he was fine and that my sister and I were exaggerating his problems. In retrospect, I realize that she was in denial and the rest of us just bought into that story. We didn't want to face the truth any more than she.

When my mother exhibited signs of dementia, my sister and I recognized many of the signs at a much earlier stage; this time we were cognizant of her behavioural changes, but we decided to allow her to stay in her home until her dementia progressed. (Once again, we visited our mother two, sometimes, three times a day to ensure that she was eating well; driving her to appointments; cleaning her house; ensuring that my mother was taking her prescriptions.) When she fell down the basement stairs (even though we did her laundry for her and repeatedly asked her not to go downstairs), the decision was made for us. This is a similar scenario for many families who are struggling with aging parents.

Chapter Three

Help! I Need Somebody! Or, Where to Turn to For Help

There will come a time during the caregiving process that you will be completely overwhelmed and question every decision that you make. You will begin to wonder if you are doing the right thing or if you are actually hindering or stalling the care and health of your parent.

If I can offer only one piece of advice to any caregiver, it would be to ask for support and help. Don't wait until you are exhausted and have your own health issues – that's too late.

Who or where do you ask for help?

If you live in Ontario, Canada, one of the first calls you should make is to **CCAC: Community Care Access Centre** in your local area. If you visit the website CCAC, you can enter your postal code and the appropriate centre and address will appear. You can search their website and find information on various, pertinent topics: Care in the Home (for the person who wishes to remain in his/her own home); Care in the Community (the various agencies and teams in your community that offer more options and resources for you and your family); and Long-Term Care Options (how to understand your options and receive support in your decisions, including help with admission and eligibility). A dedicated CCAC staffer will assess your parent's needs and set up a schedule of support and visits. They will also give you information and support you in drawing up a plan for the future: Financial concerns, Long-term Residence, whether your parent (or you) needs respite, and they will discuss nutritional needs, and occupational therapies, re-fitting your home, etc. etc. If you have any financial concerns about the affordability of long-term care facility in the future, they will go over the costs and your options.

You will give a huge sigh of relief and let go of many of your fears – because fear comes from the unknown. When you don't know your options, when you feel like you are losing control...you will begin to feel fear! Knowledge (that is information and support) *is* power.

Visit www.ccac-ont.ca.

When I first heard about CCAC, I visited their offices in person. I had an informative visit with one of the staff but I was informed that since my mother was POA (Power of Attorney) for Personal Care, that I would have to have her permission for CCAC to visit our home for an assessment visit. It took many months for my sister and me to convince my mother to allow them to visit.

If I had to do it again, I would have done it differently. I tried to convince, argue, cajole my mother to allow CCAC access to our family home and I now believe that my parent's generation is too private to allow that. I didn't take her feelings and emotions into the decision – I should have sat down and allowed her to tell me her expectations and then we could have talked about her short-term and long-term goals for caregiving for my father. And now that (when you know better, you do better) I have more insight into the dynamics of this family issue, I would have given my mother the information, visited CCAC offices with both her and my sister, and had a family discussion over a good meal. With the support of the personal care workers' daily visits, and the nurse's bi-weekly visits, at a much earlier stage of my father's illness, I truly believe that all of us (including my father) would have benefited from the support.

Instead, CCAC didn't visit our home for the initial assessment until nearly the end of my father's journey. Even when the personal care workers visited three times a day, every day, my mother would sometimes send them home without allowing them into the home – I had to be on the look-out for their cars at all times as I would cringe when I heard the door shut. Sometimes, I would leave her with my father, feeling secure that the personal care worker was to arrive at any moment – only to find out the next day that my mother told them that “my husband is sleeping, you aren't needed.” Fortunately, after a couple of failed attempts to visit, these wonderful, caring (and wise) PCWs (Personal Care Workers) would call and inform me that they were in the driveway. Wonderful – they were onto Mom. I would wait at the door and greet them. With open arms!

CCAC – Home First

CCAC – under the umbrella of CCAC, there is a new Ontario program called “Home First” a program which allows seniors to return to their home after a hospitalization stay rather than a long-term care facility. At the very least, it allows seniors and their families to have time to make decisions about the future care while at home. The program allows seniors to live independently in their own home which is the ultimate goal of most families.

Ultimately, the decision to stay in your own home or go to a long-term nursing home is contingent on many factors:

- Level of care needed (priority one)
- Level of care available to assist from family
- Level of care available to assist patient from neighbours and friends (church members, etc.)
- Is the home safe and secure? Can changes be made to make the home wheelchair accessible, etc?
- Level of income (can one afford the extra assistance)
- Is the patient eligible for funding or financial assistance?

Once this has been determined (and I suggest that you sit down with your loved one and family and discuss this thoroughly) then you can contact the CCAC office and request assistance. The office will send a representative who will help you complete an application for assistance. Some communities will vary in their services and their programs. If your loved one is hospitalized, a social worker will visit the person and family and set up an interview which will assess the needs and expectations of the patient. For many families, this will be the first opportunity to completely accept the reality of their parent's situation and likewise, the parent will also have to accept the reality, too.

There are many services that CCAC can provide, sometimes bi-weekly, weekly, and even daily, depending on your parent's needs. You may receive help in light housekeeping, toileting and transfer of patient, bathing patient, feeding, etc.

(All of which helps immensely when you and your loved one are worn out.)

In addition to personal support worker visits, CCAC can assist if you and your parent are eligible for home care visits (light housekeeping, laundry, driving to appointments, banking, etc.). CCAC can also help you with an application for transportation, if necessary.

Caregiver Tip: As you can see from the different services, CCAC is a change agent for anyone who is overwhelmed with decisions and choices of care.

If CCAC determines that your loved one is eligible for assistance, you and your family will need to act as a team with the CCAC staff that visits and cares for your parent or loved one.

We found that note-taking is imperative (CCAC will note all visits and actions taken each visit) by the family caregivers. My sister and I made notes and kept each other up to date with all facets of my father's care, including meals, food and liquid intake, toileting, etc. When the personal support worker and the nurse visited, we ensured that we kept them apprised of all daily activities and any physical or behaviour changes. If my father slept more or ate less, we informed them. When my father had fallen a number of times, it was the caring staff of CCAC who gently persuaded us that we could no longer care for him at home. It became evident that either we needed a live-in full-time nurse, or I was to move into my parents' home full-time. After visiting my parents' home for more than two years on a daily basis, and many sleep-overs, I was too worn out to opt for moving in. With sadness, grief and much guilt, my sister and I broke the news to my mother that Dad would need to go to a long-term care facility. Worn out months ago, my mother agreed. (Note to readers: My mother still announces to all visitors that I put my father into a long-term nursing home and that I turned around and put her into one, also. Those are the kind of "misinterpreting the truths" that will make you crazy. One learns to "detach" themselves from those kinds of statements. Don't take it personally.)

There are many other services in the community to help and support your family as the trend nowadays is to allow the aging senior to stay in his/her own home. Don't stress out and become overwhelmed. If necessary, visit a physician, a nurse, a social worker (in the hospital), your church, or look for a support group. Call your friends and ask around. As I mentioned in the opening pages, many of us have been affected by Alzheimer's disease or know of someone who has a dementia-related disease.

Open a telephone book or Google community services in your community, Google "Aging in the Home," or Google "My aging parent has a dementia – who can I turn to?" As I mentioned earlier, there are thousands and thousands of sites that are focused on the aging parent who has a dementia, and caregiving.

If your parent is a veteran, there is financial support for health care, nursing home care, nursing care, prescriptions, foot care, medical devices, etc. Visit <http://www.veterans.gc.ca/eng> and determine whether or not your loved one is eligible for assistance. CCAC will also help you fill out the application for assistance. If you are eligible, Veterans Affairs also offers a Long Term Care program and Veterans Independence Program to assist veterans to stay in their homes as long as possible. (Also, if your parent is from an "Allied Country" they may still be eligible.)

Recap: Various Agencies/Services to turn to:

- CCAC (Community Care Access Centre)
- Respite programs
- Care sitter, neighbour, friend, family members to help out during the week
- Share the Care program – visit the site and learn how to set up one of your own programs (Chapter Eight – Share The Care – www.sharethecare.org)
- Life-Enrichment classes for seniors (an opportunity for caregiver to rest)
- Home health services
- Adult care center (again, a respite for caregiver)
- Private care
- National organizations e.g. Alzheimer's Society - Educate yourself as much as possible! Alzheimer's Society has a loan program for mobility monitors (person with Alzheimer's might wear a monitor which sets off an alarm if they either get out of the wheelchair or out of bed)
- Outings designed for seniors
- Assisted Transportation: Lambton Elderly Outreach, Care-a-Van, Voyageur Transportation (contact CCAC, your physician, hospital, or long-term care facility) The cost is minimal and well worth it.

- Foot and nail care; hair salon (Some entrepreneurial hair dressers do make “house calls” – do a Google search. That is a service I would have been willing to pay for my mother!)
- My optician came to my mother’s room to allow her to try on different frames. We were pleased with the personal service.
- Dental Hygienists – will make personal visits to seniors
- Medic Alert – a paid service in which the person with Alzheimer’s wears a bracelet or necklace with an alarm. If the patient falls or has an emergency, the patient presses the alarm and the service company is alerted. The company makes the appropriate phone call to acquire help and assistance for the patient.
- Please note that the person who has Alzheimer’s disease in moderate stage will have trouble remembering the purpose of the medic alert bracelet.
- Lastly, ensure you check with the patient’s insurance policies, or professional unions. My father was a carpenter and paid into a union; his insurance covered many services. Also, check for affiliations such as Moose, Elks, etc.

Caregiver Tip: If you are overwhelmed and have no one to turn to, please do not hesitate to confide in your own personal physician as most of us have been affected by aging parents (including your physician!) and they will advise you of your options. Sometimes just the act of sharing your story is enough to help you feel better. And a different perspective from a medical professional is very valuable. (We all need to learn to listen to our physicians; usually we are too busy talking about our own experiences that we forget to hear their wisdom! My own physician told me a personal story to help me accept that my own father resisted going to his physician. She did not break any confidentiality agreement; she merely shared a personal story. I was grateful for her wisdom and understanding.)

Caregiver Tip: My sister and I were too tired (and busy) to inquire about support groups while we were caring for my parents. When my mother went into a long-term care facility I happened to notice that support groups for family members were offered regularly at the facility. In time, I learned that a support group for families of persons with dementia was also offered. The local Alzheimer’s Society office also offers seminars and meetings that support and offer strategies for coping with Alzheimer’s disease. In the name of self-care, find some time and attend one of these support groups. The more that we know...the better we can cope!

Chapter Four

Have a Plan – For Present and Future

In the previous chapter, I urged caregivers to sit down and have a discussion with their loved one about the future. Here is a list of issues that you will need to discuss honestly and openly with your family. Find a quiet time and talk about the big issues – death and dying. Once Alzheimer’s disease (or any dementia) has progressed to the moderate stage this can be a very difficult discussion. Do it earlier than that.

Prior to any decisions, consent is required. If the person is capable of two things: understanding the information regarding the necessary decisions *and* understanding the consequences of the decisions, then the person is deemed “capable.”

If capable, the person can make life and death decisions. If not capable, then a “substitute decision maker” will need to step in and make the decisions.

For the substitute decision maker to make decisions, he/she will need **Power of Attorney for Personal Care (POAPC)**.

Now it’s imperative to stress that a substitute decision maker make his/her decisions on behalf of the patient – taking the patient’s known wishes under consideration. (Having previous discussions and conversations with the patient; understanding the patient’s belief and value system.)

If the substitute decision maker does not know the patient’s wishes, then he/she must act in the best interests of the patient. Often, this will mean that the substitute decision maker will confer with the medical team – that is, the attending physician, CCAC, and the social worker.

In Ontario, A Power of Attorney for Personal Care (POAPC) is a legal document that names the person responsible for the personal care of the patient; that is, health care, safety, hygiene, etc.

A Living Will is a legal document that outlines the patient’s wishes for his future care.

N.B. The substitute decision maker comes into effect only when the patient is no longer capable of making decisions.

A Power of Attorney for Property is a legal document designating a person or persons to make financial decisions on the patient’s behalf. The **Power of Attorney for Property (POAP)** can make decisions (when the patient is deemed “incapable”) regarding finances, home and possessions.

Note: These documents must be signed and dated when the patient is capable.

- **Legislation will differ outside of Ontario.**

Allow me to stress that if these issues are too sensitive to discuss within your family (for whatever reasons), then ask for support and guidance from CCAC, social worker, attending physician, or nurse – all of whom can assist you in this difficult conversation, and in the planning. (Trust me on this: CCAC staff is well-versed in how to handle these difficult topics. They literally will take the burden from your shoulder and handle it for you. From our experiences, we cannot say enough good things about these caring individuals. I also found the hospital's social worker extremely supportive.)

Good communication skills are necessary, as well as a high level of trust and openness. If this is not possible within your family, ask for help.

Specific questions to assist the conversation might be:

- Do you have a Power of Attorney for Personal Care?
- Do you have a Power of Attorney for Property?
- Who would you like to make decisions for you if you become ill and are not capable?
- Have you written a Will? A Living Will?
- Ask your parent/loved one about his preferences if they need to be hospitalized and can no longer live alone in the home. Ask them what would be their choices – perhaps your family has made presumptions and your parent does not want to live alone in his/her own home.
- Where do you want to die? If not at home, where? In a hospital? In the nursing home? In a hospice?
- Resuscitation status is a sensitive issue, but an issue that will need to be addressed. Ask your parent his/her thoughts about dying – do they want life prolonged? If done sensitively and compassionately, this discussion can be thoughtful and informative.
- Are there treatments that you would not want to have in the future?
- Don't be afraid to hear your parent/loved one discuss death. Get over it! Your parent is ill and wants to talk about it. When we change the subject or avoid it, we hurt our loved one. At the very least, let them talk. Learn to listen. Stop talking. Just listen.

Prepare Ahead (Remember: You are the patient's advocate!) Here is a checklist:

- ✓ POA (Power of Attorney) for personal care and POA for property (you will need to have this done at a lawyer's office or you can pick up papers at CCAC)
- ✓ Prepare Wills
- ✓ Banking (If your parent is still able to make banking decisions, discuss having your name added to an account to pay bills for them.) You and your parent will need to visit the bank representative together.
- ✓ Talk to family – ensure everybody is on the same page and understands the patient's actual state of health and the prognosis of the disease.
- ✓ Put a long term plan in place: Visit CCAC and fill out an application (you will need your parent's signature or POA's signature)
- ✓ Look into VAC (Veteran's Affairs Canada)
- ✓ Realize that in the future, your patient will need to be put on a long-term facility wait list (CCAC will help you with this). There is a long waiting list (sometimes one to two years) so look ahead.

In addition, ensure that someone in the family (preferably the POAP) is aware of the location of passports, Wills, medical insurance, driver's license, income tax records, mortgages, and other such documents. (My uncle kept important papers in well-labeled files in a filing cabinet. He telephoned my husband and asked him to come to his house and take note of his files. When my uncle died, his daughter (my cousin), who lived out of town, was very grateful when my husband informed her of the whereabouts of her father's documents. She was relieved.) In addition, ensure that a family member is informed of bank accounts and safety deposit boxes.

Realize that decisions (such as selling the house and selling the car) will arise in the future. If your loved one needs to go to a long-term care facility, you will need to either sell off furniture and possessions or distribute them to family as chances are there will not be enough space to move the furniture to the new home. You will want to know ahead of time the items that your loved one cherishes and ensure those possessions are saved for the move. The sooner you have this discussion, the more likelihood that your loved one can participate in the decisions. These decisions are much more difficult and emotional when the person with Alzheimer's cannot contribute his/her wishes. Do not wait until it is too late – a person with Alzheimer's disease in moderate to advanced stage cannot logically determine a plan for his/her future. (Every decision will become gut-wrenching!)

- What will happen in the future?
- Who can I turn to if my loved one becomes seriously ill?
- If my loved one falls and needs more assistance, what will we do?

- My loved one has fallen and has been hospitalized; the attending physician advises that my loved one *not* return home alone. Who will look after my parent or loved one? Will we need to see about long-term care? A nursing home?
- Which nursing home?
- If there is an emergency, who do I call?
- If there is a DNR (Do Not Resuscitate) in place, do not call the ambulance. Call either your attending physician or have this pre-planned.

If you parent's wish is to die in the home, family members need to know that a "Do Not Resuscitate" form has been signed. Family will need to know not to call 911; unless a crisis arises prior to death that can only be handled in an acute care facility. If an ambulance is called, ensure the DNR form is given to the paramedics; the DNR wishes of the patient should also be relayed to the hospital and staff. You might need a couple of copies of the form.

Caregiver Tip: A DNR (Do Not Resuscitate) form has to be signed by the physician to make it a medical directive; otherwise, medics are still required to initiate CPR.

When planning ahead, you and your family will also need to look into long-term care facilities. This will be a difficult and arduous journey. Why? Because most caregivers do not want to put their parent or loved one into a long-term care facility; in fact, most of us have promised our loved one that we will not do that.

That makes for a difficult, heart-breaking decision to "break our promise." I know of only one friend who when asked to promise that her parent could die in her own home, she responded that she would only promise to do her best and when the circumstances arose and she could not longer do her best, then she would have to make other decisions. A very brave and smart response! Most of us are neither. (Ha!)

Recently I read a wonderful and thoughtful article written by Carol Bradley Bursack, Editor-in-Chief of a website devoted to aging elders and issues, www.eldercarelink.com, a division of QuinStreet, Inc. I have added it here for your information.

The following article is located at <http://www.eldercarelink.com/Assisted-Living/Stepping-Stones-in-Care-Needs-Assisted-Living-Combines-Help-and-Social-Life.htm>:

"Stepping stones in care needs: assisted living combines help and social life"

"Drop the Guilt: You've Honored the Spirit of Your Promise"

“A fact of modern life is that many people live longer than they would have a few decades ago, but many of the survivors live in less than ideal health. Modern medicine has brought people a longer life. Your mom wouldn't be alive today if diabetes couldn't be managed as well as it can be now.

The caveat, however, is that many of these survivors, while happy to be alive, need a great deal of assistance to stay that way. What, in the past, was often a year or so of caregiving to one's parents as they declined in health, has become five, ten or more years, much of it spent while caring for growing children and holding down a job.

While you are happy that your parents have lived longer, you have worried a great deal. You took on the extra care they needed out of love. But the time came when you couldn't do it alone anymore. That's when you hired some in-home help for your mom.

Now, even that isn't enough. You will have to listen to the doctor and put Mom in a nursing home. You have toured the homes in your community and one near you is really very good. You approach your mom with much trepidation.

Sigh! She doesn't remember what she had for lunch, but she remembers that you promised you wouldn't put her in a nursing home. Now what?

Talking to Your Elder: You May Need a Third Party

Family dynamics remain as long as family members breathe. This is your mother. You love her and want the best for her. You know that for her health and safety, a nursing home is the answer. But she's your mom and you still want to please her. So, you need a plan.

- *Ask your doctor to back up his words and help you explain to your mom that a nursing home is necessary and will be okay.*
- *If your mom has a friend in a local nursing home, it may be worth considering that home for your mom, even if the facility isn't as convenient for you as the one you are considering. Then, that friend could become an ally in convincing your mom that the move is a good thing.*
- *Reassure your mom, and yourself, that you will still be her caregiver when she is in the nursing home. You will still be part of the care team. If the nursing home you are considering shuts out family in the care plan, you don't want to go there. But these days, most homes have care plans and families are a part of that. Many have regular care meetings that involve family.*
- *Help your mom pick out her favorite objects to take along - photos, art, gifts from loved ones - they all help. If some furniture will fit in the room, let her choose what to take.*

- *Take her shopping, if she can do it, to pick out some new clothes and let her tour the home and see the beauty shop and other amenities. Try to make it an adventure if you can.*
- *Remain firm, citing the doctor's orders. Our parents' generation usually held doctors in great esteem.*
- *Tell her that her safety is very important to you and the rest of the family and that she is no longer safe at home.*
- *Don't back down. Reassure. Remind her that she will once again have a chance to make friends. She's likely been quite isolated in her home. She will have peers to talk with and eat with. She will also have meaningful activities.*
- *Look for a home that stresses person-centered care and tell her about that. Let her know that these days the person is the focus in good homes, and you've found the best one you have in your area. Most nursing homes are quite different than what she has in mind.*
- *Once she is moved, make good on your promise. Be there for her during the transition. Expect some depression and a period of adjustment. But don't show any wavering and don't accept guilt. If she brings up the "promise," you must tell her that such a promise was made out of love, but unwise. You have done all you can to not put her in a nursing home, but life throws us curve balls. We can't foresee the future. Promise or no promise, there really isn't any choice in the matter."*

I have included this article because I wish I had read it when my sister and I had to make the decision to move our father into a long-term care facility. Thanks to websites such as www.eldercarelink.com these gut-wrenching decisions are a little less complicated.

Chapter Five

Day to Day Caregiving – Looking After Your Loved One in the Home

Caring for your parent in their home will become one of the most challenging jobs that you have ever undertaken. Don't let that scare you or deter you. There will be many moments that you will savor and remember for the rest of your life. To this day, I can close my eyes and I am right back in my parents' bedroom...my Mom dozing in a side chair, my Dad in bed staring at me while I am talking to the air (or so it seemed, sometimes). But, then my Dad would smile and I would feel such peace that even in the midst of the dreaded word "Alzheimer's" I would feel like I was so lucky to be sitting there with the two of them.

In retrospect, I now realize that I carried around a lot of guilt at that time when I cared for my parents because the truth is...I never really liked the job. There, I've said it. I didn't actually like the job of caregiving (that is, the day to day practical stuff). I felt like a fraud whenever a friend or acquaintance would recognize my "sacrifice" – I felt such guilt that I compensated (you guessed it!) by working harder. (I am much more suited to supporting the person with Alzheimer's disease in other areas of care: such as visiting, talking, spending time doing an activity, etc.) In hindsight, I realize now that it was not so much that I disliked the practical day to day caregiving of my father, but it was the daily confrontations with my mother that was so stressful. When I look back at our experiences, much of the resistance on my mother's side, I now believe because I know better, was probably due to her own illness and fatigue – which I did not recognize. It was very challenging to care for someone when you met resistance and denial every day – not from my father, ironically. But that aside, I hope our experiences can help someone else who is new to this journey. (Be alert for the underlying reasons for your emotions – when you shine the light on those reasons, you will begin to understand yourself...and that can lead to deep and profound compassion for yourself and others.)

In the course of this ebook, I write about "domains of issues" – physical, social, psychological, spiritual, disease management, practical, end of life issues and grief and loss. Day to day caregiving falls under the "practical" domain; in other words, looking after the necessary day to day needs of the patient: toileting, bathing, feeding, laundry, errands, and so much more. The caregiver spends most of the day attending to the person's practical needs and those very issues are not only time-consuming but physically draining. If you can follow some tips and strategies to make the patient's home more adaptable, the day's routine and schedule will run smoother.

Three words to remember about daily routines:

- Safety
- Structure
- Consistency

Safety in the home becomes paramount because as we have learned from many experts and physicians, many people with a dementia fall and are hospitalized. Modifications will be necessary to ensure the home is safe; therefore, I have included some suggestions that will help prevent falls and accidents in the home.

Prevention of Falls

The elderly are prone to falling and slipping in their homes. That's a fact. Statistics show that one in three over the age of 65 fall or slip. Unfortunately, once an elderly person falls and needs medical help, the experience can be life-changing. Often, family members call such an experience the beginning of the end. Persons with any dementia are particularly prone to falling as their visual perception is limited and their balance is diminished.

World Health Organization says that:

“This risk level may be in part due to physical, sensory, and cognitive changes associated with ageing, in combination with environments that are not adapted for an aging population.”

WHO also reiterates that ...*“In addition, those individuals who fall and suffer a disability, particularly older people, are at a major risk for subsequent long-term care and institutionalization.”*

WHO. (2012). *Falls*. Geneva, World Health Organization (Fact sheet no. 344; <http://www.who.int/mediacentre/factsheets/fs344/en/index.html>, accessed 17 January 2014)

Our elderly parents who *do* fall will often experience an increase in cognitive impairment – in other words, they will begin to exhibit more dementia-like behavioural changes (after the fall). When my father fell trying to descend the stairs, he was taken by ambulance to the emergency department of the local hospital where we were told by the residing physician that if he was admitted that he would probably not leave. He also warned us that his cognitive abilities would decrease as the new surroundings would exacerbate his condition. We chose to take him home as we did not want that to happen. Two years later, my mother fell down the basement stairs when she was attempting to do laundry. (Repeatedly, we had warned her not to go down the stairs; we had put up a sturdy railing; we did the laundry for her!) Physically, both of my parents recovered from their falls although my mother never did return to her home – she

was in the hospital for 11 months at which time she entered a long-term care facility.

It is imperative that we take precautions to prevent falls and slipping. Yes, accidents will occur in spite of the precautions. **Here is a list of safety precautions and tips that I have gathered over the last few years:**

Caregiver Tip: Walk around the entire house – notice anything that might trip your loved one; items that might get knocked over easily, items that the person with Alzheimer’s might bump into; lastly, fix all those worn-out areas in the rug or at the edge of the rug or in the doorways that continually trip up family members over the years. (For example: the coat tree that topples over at the slightest movement)

Bathroom

Install hand-held shower nozzle

Grab bars by the toilet

Grab bars in the bathtub

Grab bars in the shower area

(Install them correctly – ask an expert how to ensure they are sturdy and never coming out of the wall)

Install a raised seat toilet (toilet is raised to accommodate seniors)

Shower chair/bench

Bath lift (you can buy these online or at your local specialty shop/services/products for the aging)

Bath transfer bench

Non skid bath mat (in tub)

Eliminate scatter rugs/mats on floor

Eliminate standing towel racks (decorative, but not fixed to the floor, hence dangerous)

Increase lighting

Add a night light or leave light on all night long

Eliminate locks (some patients lock themselves in and can’t get out)

Re-set the water tank to a moderate temperature (many seniors scald themselves when using water)

Eliminate all drugs, old prescriptions, pills, etc. and cleaning products from the cupboards

Bedroom

Most specialty shops that service aging seniors, or “medical equipment” shops sell various beds, mattresses, pillows for the patient.

Bed rails

Grab bars at the side of the bed

Hospital bed (in later stage)
Foam bed wedges
Memory foam mattresses and pillows
Memory foam pads
Trays that swing over the bed
Pressure relief mattresses
Increase lighting
Eliminate clutter and any area scatter rugs
Ensure electrical cords to lamps are hidden

Kitchen

Eliminate scatter rugs
Replace (or remove) old appliances to ones that have an on/off automatic switch
Unplug appliances
Unplug stove (or install a separate power switch for stove)
Replace heavy pots and pans with either lighter ones, or eliminate them to reduce any opportunities for patient to cook (if unattended).
Rubber grip pads for easy opening of jars
Install either revolving shelves for hard-to-reach items or a lazy Susan
Store items on shelves for easy access – eliminate all items on the top shelves which encourages patient to over-reach
Eliminate cleaning products under the sink – or install a lock on the cupboard door (the kind that prevent children from opening cupboards)
Increase lighting

Living Room

Eliminate electrical cords, or hide them – ensure they do not trip your patient
Lift chair – a patient sits in the recliner, and the recliner lifts them out of the chair
Remove scatter rugs that trip up patient
Remove all clutter or small tables (etc) that could trip patient or impede traffic flow
Fix any door entrances where oftentimes the transition is uneven at the floor level.
Increase lighting

Stairs

Install railings both sides of stairs throughout the home.
Remove rugs if threadbare and uneven.
Add non-slip treads to wooden stairs.
Increase lighting.
Gate in front of the stairs to deter patient
Add light switch at the top and at the bottom of the stairs

Exterior

Increase lighting

Ensure steps are secure and any needed repairs are done

Install railings both sides of the steps

Install non-slip treads to wooden steps

If sidewalks have large cracks, fix cracks or repair any broken concrete

Remove any plants, leaves, debris or trailing ivy from steps

Misc

Replace light switches with the larger, easier to use ones that are now available at any hardware or home store

Eliminate all hazardous products in the home. (including the garage)

Pill organizers

Electronic alerts/medic alerts

Phones designed for seniors

Socks – seamless, non-slip (specialty medical supplies)

Shoes/slippers – Velcro fastener

Foot care – see physician, CCAC, medical supply specialty shop

Lotions and creams for skincare (to prevent bedsores) – see physician, CCAC, and medical supply specialty shop

Gloves (medical supply specialty shop)

Bed pan

Commode (portable toilet)

Some Suggestions to Help Facilitate the Day's Routine:

Similarly, some changes and adaptations can be made in all areas of the home to facilitate the day's routine and I emphasize that routine is necessary. (A person with dementia does not like change! Change confuses him and can precipitate symptoms.) Don't be surprised if some of these changes are recommended when our patients are in the palliative stage.

Set up the bedroom to work for you and your patient. You might need to rent a hospital bed that can make things a little easier for both of you. (Check medical equipment specialties for rent in the yellow pages.) When your patient becomes bed-ridden, you might have to consider adding an eggcrate mattress to prevent bedsores. (Bedsores are very serious with the ailing, bed-ridden patient – try to prevent them at all costs. Fortunately, the personal support workers (and nurses) that visited my father were extremely supportive and made many recommendations.)

Ensure the room is filled with cherished items and mementos from the other areas of the home – your patient may spend a lot of time in the room and you want to make the room as cozy and comfortable as possible. Bring in photos of family members, well-loved books and music.

You might want to hang a bulletin board for cards, inspirational sayings, poems, photos, etc. Be creative and think of the patients favourite things. Allow grandchildren to help you with this – home “art” and children’s projects will bring a smile to anyone’s face.

The bedside table should be appropriate height to the bed to make it easy for the patient to access. A drawer should store toiletries such as mirror, comb, brush, body lotion, Kleenex. A second drawer could store a bedpan and/or urinal, as well as incontinence pads. We bought a box of straws and put it in the drawer, too. Add a bell – if the patient can ring it.

Allow room for a comfortable chair and foot rest – a recliner (especially the automatic ones). If the room is spacious enough, add a second chair for visitors.

Add extra lighting – up the wattage! (See Chapter Seven, article about Dementia and Lights)

You will need a few more items to outfit the bedroom – add a back rest, plenty of pillows and foam for adjusting the height of your loved one’s legs, etc. Bed sores are difficult to heal so do whatever needs to be done to prevent them. You might want to have a discussion about this with the CCAC’s personal care workers (Community Care Access Centre) and nurses that visit. They will enlighten you on the do’s and don’ts of caring for a bed-ridden patient. Ask the experts how to move the patient, how to get him out of the bed, how to help toilet him, and how to shower or bathe him. You are not expected to know this information unless you are in the medical profession, so ask for advice. Don’t be embarrassed. The CCAC staff is only part of the team – you are also on the team! You still matter.

There is an excellent book called “*Caring for Loved Ones at Home: An Illustrated easy-to-follow guide to short or long-term care,*” Harry Van Bommel, 1999, Published by Resources Supporting Family and Community Legacies Inc., Scarborough, Ontario, that is a simple, easy to understand, how-to. The author is very explicit and forthcoming about caring for a patient in his/her home. His drawings are rudimentary but excellent in describing how to change a bed when the patient can’t get out of the bed (my mother and I changed the bed often – but helped my father to a chair before we changed the sheets...who knew that you could maneuver the patient to either side of the bed and voila! change the sheets?); how to put the bedpan under the patient, how to remove the bedpan, how to give a sponge bath...well, like I said, explicit, but it’s all part of the day to day routine and unless you are in the medical profession, I would assume that you have not ever had to do any of these tasks before which is why the

rudimentary drawings are so helpful. I think this book is a keeper. Quite frankly, I wish I had read this book when I was caring for my father. It would have helped me tremendously. If you would like to read Mr. Van Bommel's book, he has permitted me to include in my ebook a direct link to a free online copy of this informative book; please go to Harry Van Bommel's website:

http://www.carelibrary.com/Care_Library/Caring_for_Loved_Ones.html

Bathing and Showering the Person with Alzheimer's

If your loved one is not bed-ridden, as a caregiver, you will need to assist in bathing and/or showering him/her. For many with Alzheimer's, a bath or shower is a frightening experience. Many are very oppositional when it becomes bath day. You will need patience and need to be highly considerate and respectful of the patient. There were many days that my father would outright refuse to bathe or shower and my mother just went with the flow – she gave in to him. Eventually we learned that some days my father said “no” to all requests, and on other days, he would be more compliant.

A few tips on how to bathe/shower a patient:

- Place a plastic bath seat into the tub (you can buy them at medical supply shops); bath or grab bars should be installed earlier. Also, add a non-skid bath mat. Many falls occur in the bathroom.
- Have a shower hose installed (you can buy extra long ones).
- Prepare in advance – draw the bath water, ensure moderate temperature and set necessary toiletries close by, including soap, shampoo, towel, face cloth, razor and bath robe.
- If showering, sit the patient on the bath seat (you might want to give a towel to the patient to allow for privacy) and ensure the water is at a moderate temperature. Try to shower the patient as quickly and as efficiently as possible to prevent chills. Again, ask CCAC, nurse, or PSW how to shower properly.

Sponge Baths

You might want to just sponge bath other days of the week as depending on the physical ability of the patient, a shower or bath is a challenge for most of us. My father would need to be led to the bathroom, and seated, but once on the bath seat, he washed himself (as long as you handed him the soapy facecloth and told him to wash himself down). Every patient is different. Even near the end of his life, the personal care workers told me that my father could still manage certain tasks.

- Assemble all toiletries, towels, face cloth, soap, electric razor and body lotion. (Have house coat and warm clothes near by.)
- Fill a basin with warm water and place beside the bed on a bedside table. Help your patient sit up in bed, preferably with his legs hanging over the side of the bed. You might want to put towels around the patient in case the water drips onto the bed sheets.
- Wash his face and neck first and then dry. Slowly work down the body, only wetting one area at a time. This keeps the patient from catching cold or a draft. Ensure you dry between the toes well and in creases of the body. Wet areas can lead to chafing and eventually bed sores. At all times, you need to prevent chafing and bed sores as the patient is susceptible to them because of the amount of time spent in bed and lying down.
- Be respectful and considerate of a patient's embarrassment.

When CCAC began to visit my parents' home on a daily visit, bathing and toileting were the two responsibilities that my mother and I abdicated; I was thankful as I did not enjoy that part of the day to day care (or practical domain). I am so grateful that personal care/support workers do their jobs so well.

Dressing the Person with Alzheimer's

At the risk of sounding like a parrot, again treat your loved one with respect and consideration. When a person with Alzheimer's can no longer look after his/her own personal and practical needs, it is highly embarrassing for them. They are often ashamed at their loss of control – it is one of the reasons why they exhibit anger and frustration to cover up their shame. Please don't assume that just because of their disease that they no longer care about these issues.

Attempt to make the act of dressing as easy as possible – easy to pull-on pants, looser tops or sweaters with zippers or Velcro fasteners. Often buttons are too difficult to manage so you will need to adapt to your patient. My mother has difficulty with zippers and cannot manage them, but finds buttons still easy to manage. My father could handle neither. Every person is different and although the symptoms are similar for many – patients are at varying degrees of the stages and some strategies work for some and other strategies do not.

Experts tell us to allow the patient to dress himself. Assemble the pieces of clothing ahead of time and display them in order of tasks, i.e., first underwear, then pants, then top, then sweater. Because bending over is too difficult for the patient, you might need to put on their socks and shoes. (I went to the local shoe repair and bought a heavy-duty shoe horn for this purpose.) Switch to non-skid slippers and non-skid shoes with Velcro fasteners that are available at most shoe stores and department stores.

Ensure that you do not rush the whole experience of getting dressed as that only creates tension and will ensure that the task takes much longer. (And if my mother was writing this ebook, she would remind you “don’t be bossy” – her words, not mine.)

Interesting enough, I recently read a fascinating article by Serena Gordon (Fri., Sept. 6 Health Day News) on a website called <http://www.healthday.com> entitled, “*For Some With Alzheimer’s, Occupational Therapy Can Bring Welcome Relief*” in which the author points out that adapting occupational therapies or strategies to cope with patients with Alzheimer’s is a matter of distinguishing which abilities are still strong in the patient (what strengths can we build on) to enable the patient a sense of control in their daily life.

Apparently, when we hand the underwear to the patient and then the pants and then the top, something kicks in (procedural memory) and the patient remembers how this is done. This allows the patient to dress himself and maintain a sense of dignity.

These strategies are life-affirming and change the patient and the caregiver’s experiences.

To read Serena Gordon’s complete article (*For Some With Alzheimer’s, Occupational Therapy Can Bring Welcome Relief*) please visit: <http://consumer.healthday.com/cognitive-and-neurological-health-information-26/alzheimer-s-news-20/for-some-with-alzheimer-s-occupational-therapy-can-be-a-big-help-673993.html>

Eating/Feeding

Alzheimer’s disease affects patients’ eating habits differently – some begin to over-eat as they literally forget that they have eaten and will eat again and again unless someone stops them. Some caregivers have had to actually lock the fridge. Other patients under-eat – they forget *to eat*. And for others, their appetites wane and eating no longer interests them. Many aging seniors (without any dementia) fall into this category.

In the earlier stages of my father’s illness, I began to drop in daily to check in on my parents; it was to ensure that they were both eating well. I had noticed that both my mother and my father ate very little. So, I would drop in at breakfast time and make them breakfast. My mother, who hadn’t slept throughout the night due to my father’s wanderings, would lie down on the couch and nap for most of the day. In a short span of time, I went from dropping in once or twice a day (sometimes three times) to an eight hour shift daily. Meals became my bane. No matter what I served them, no one ate. My mother was too tired to eat and my father just refused to eat.

So I bought my first blender and began to make smoothies for them. At first, the smoothies were more like milk shakes (with a few spoonfuls of protein power and other good stuff from the health food store). Then, I began to add fresh fruit, frozen fruit and yogurt (with a few spoonfuls of protein powder and other good stuff from the health food store). What can I say? The smoothies were a hit! (To this day, my husband and I still drink smoothies every morning although we have graduated to green vegetables and fruits.)

Through trial and error, I learned that the heavy meals we grew up on – meat, potatoes and vegetable and dessert – no longer interested my aging parents. I began to prepare simple meals that my father could feed himself. Omelets or fried egg sandwiches, toasted sandwiches, chicken fingers, rice pudding in a cup, grilled cheese, cheese slices, ham slices, cherry tomatoes, celery and carrot sticks, bacon on a bun, etc. – any food that didn't require cutlery. (If person has a difficulty swallowing or choking, these foods might not be easily chewed. Instead, you should check with the experts on your "team" and ask for nutritional diet suggestions.)

Since eating preferences will vary, you may want to modify my meal suggestions (unless you actually *like* rice pudding in a cup). Aside from what meals you might prepare, here are a few "eating" tips:

- Finger foods
- Smoothies and milk shakes for the fussy eater
- Ice cream at all times (any time of the day) – Ha! Gotcha! (But I am really not kidding!)
- Invest in a box of straws
- Use a pasta bowl instead of a plate – it stops the food from slipping and sliding away
- Buy a cup with a lid such as a travel mug (they sell them at the dollar store)
- Buy an apron (it doesn't look like a bib – which my mother thinks is embarrassing)
- Most physicians and nutritionists will tell their patients to drink "Ensure" or a nutritional supplement. (Both my parents refused any enriched drinks.)
- In the late stage of Alzheimer's disease, choking can become a problem. Be on the look out for any difficulty swallowing. If that happens, inform the doctor immediately.

Lastly, if your parent is wild about a certain drink (such as tea), serve it in a china cup – just invest in a few of them. The ritual of tea drinking is big in our family (my parents are British) and so we still honoured the tradition right up until my dad's final days. I brought a china cup to my mother's hospital room and transferred her hospital "tea" into her own cup whenever I visited. As the weeks flew by, I began to make tea at home for her and brought up a thermos. Of course, I transferred the tea into her beloved china cup. Her roommate leaned

over one day and told me that she was jealous of my mother's china cup. So, I brought her one the next day. You'd 'a thought I gave her a million dollars. Folks, it's always about the simple pleasures in life – even when we are 90 years old. (I truly believe the simple act of drinking a cuppa' is one of life's true pleasures.)

Keep your “team” up to date: Keep a notebook!

Try to keep a journal or note book of your parent's habits, activities and food and liquid intake during the day. The notes are helpful for two reasons:

Firstly, you can remember details to inform the physician and keep him/her abreast of any changes that might indicate a progression of the disease or changes in the usual routine. Also, keep the physician informed of sleep behaviours, eating habits and escalating behaviour changes. Obviously, if CCAC (Community Care Access Centre) is involved in the care of your patient, they will need to be informed of this information, also. (Think of the process as a team function – you are one part of the team and you need to keep everyone on the team informed.)

Secondly, you and your family will chart the patient's daily routine, activities and behaviours and that will enable you to notice “patterns.” These patterns in the patient's behaviour will help you determine how to schedule your day – you can now adapt the day's routine to the patient's good and not-so-good times throughout the day. For example, you will soon notice after charting or note-keeping that your loved one is very compliant and willing to take part in activities in the morning – a good time to make appointments outside of the home or to go visiting or run errands.

You have also observed that during late afternoons and early evenings, your loved one becomes more difficult or oppositional. (He becomes stubborn and unwilling to do anything.) Obviously, you will learn that this is not the time to make a doctor's appointment or run errands. (My mother could not cope with more than one errand as she would tire early. I learned that taking her to a doctor's appointment or getting blood work done was her limit. Stopping at the grocery store or running other errands was just too tiring for her.)

With minor adaptations to his/her moods, you will find that the daily routine runs much smoother. You will also begin to notice that certain activities upset or calm your parent. Perhaps soothing music calms the person with Alzheimer's, or not. (My sister once brought in a Celtic CD to my father's room. He seemed to enjoy the music so we played it often for a few days. One morning when I arrived for my “shift”, my sister informed me “Whatever you do, don't play the Celtic CD. Dad becomes really agitated when it is playing. That was the end of that.)

Perhaps you have noticed that the television irritates or upsets your parent. Television shows particularly can confuse someone with Alzheimer's disease, especially if the person is experiencing delusions or hallucinations. A person with Alzheimer's can have a particularly difficult time discerning reality from fantasy when watching television. My mother rarely watches the TV but when she does I have noticed an increase in her "wild stories."

So, who knew that note-taking was so helpful? (Teachers? Students who are writing exams? Nurses? Doctors? The people who invented "Post It" notes?)

And don't be fooled: Many days my notes consisted of scribbles on the back of a scrap of paper. But my intent was there. (Besides, I am hoping that you will do better.)

Wandering or Getting Lost

I will write about a symptom called "Wandering" in Chapter Seven "Symptoms," but in the meantime if your parent wanders, their welfare and safety is compromised.

Install safety child-proof locks on your home. Tack up a sign that says "STOP" – that alone can deter your loved one. You might need to distract a wandering patient or re-direct them. Walk with them; get them busy; talk about something they like to do. Re-direct their attention.

Consider installing one of those gates that we used when our children were babies/toddlers – install one at the top of the stairs and another at the bottom of the stairs. (But please keep in mind the agility of your patient. Even though my father was nearly 90, he could easily have climbed over a gate to access the stairs.)

If your parent repeatedly leaves the home, disguise the door or put a chair in front of it. Install a heavy duty deadlock and keep the door locked at all times. Also, lock the screen door. Consider a big red stop sign and tape it to the door. Add chimes or an alarm that rings when your loved one leaves. You will need to experiment as some adaptations will work better than others. (When I stayed the night at my parents' home, I began to move heavy furniture at the top of the stairs to block access – it worked for a short time. Eventually my father learned to move the heavy desk to the side and he 'scoted' through the opening.)

Read the section "Wandering" in the next chapter, entitled "Symptoms" as I have expanded on the steps to take to keep your loved one safe.

U.T.I. - Urinary Tract Infection (The symptoms of UTI will fool you.)

On a number of occasions my sister and I have noticed profound changes in my mother's mood and dementia. It took us a long time to correlate the changes in her behaviour with a urinary tract infection. Once we figured that out we now look for the signs of a UTI. What kinds of signs? Well, we have noticed a sudden increase in her bizarre story-telling, increased paranoia, dramatic mood swings and more than normal confusion.

Now, we have learned from the past that any of those signs (especially if one of her visitors or PSWs comment on her behaviours also) usually signifies a UTI. When we assume she might have an infection, we relay the information to the residing head nurse and ask for a test to be completed immediately. The sooner the test results show positive, the sooner my mother will be administered medication for the infection.

If you are a caregiver, chances are that you might not be aware that more often the elderly suffer (especially women) from urinary tract infections.

Since an elderly person (and especially a person with Alzheimer's disease) can no longer tell if they have an infection, here are the warning signs, according to <http://www.aplaceformom.com/blog/?s=learning%20the%20common%20warning%20signs%20of%20a%20uti%20in%20a%20senior%20citizen> Dana Larsen. (March 2012) *The Unlikely Connection Between UTIs and Dementia*:

"Learning the Common Warning Signs of a UTI in a Senior Citizen:"

- *Not being able to do tasks the senior could easily do a day or two before*
- *A feeling of being over-tired*
- *The onset of elderly urinary incontinence, or not being able to control the involuntary leaking of urine*
- *Urine that appears cloudy*
- *Urine that appears bright pink or cola colored, which is a sign of blood in the urine*
- *Strong smelling urine*
- *A fullness in the rectum, for men*

As I mentioned earlier, look for signs of confusion, increased unusual changes in behaviour, etc. In other words, don't assume that the unusual behavioural changes are evidence of an increased dementia.

According to experts, UTIs are potentially harmful and even deadly for the elderly as an untreated urinary tract infection can lead to "sepsis" – poisoning in the bloodstream.

It's imperative to detect the likelihood of an UTI as soon as possible and have the person be tested and put on antibiotics. In a few days, the symptoms should disappear.

Medications (How to ensure your parent/loved one is taking them correctly.)

When my father was in his mid-seventies, he contracted macular degeneration. His attitude of acceptance was exemplary and we never once heard him complain about the disease. He announced that he had "enjoyed life, seen a lot, was a lucky man; so if I die tomorrow, I am content." But, then he followed that announcement with another one: "I am done with doctors. That's it. No more."

So, the fact is that he was not on any medication. None. Zero. (The physician at the long-term care facility was in disbelief.) Why do I tell you this? We never had to worry about his medications or mis-use of them because there were none to monitor. On the other hand, my mother who also didn't like visiting the physician had heart problems and was on a number of prescriptions to regulate her heart and blood flow. She had to visit her doctor every other week to ensure her blood count was within an acceptable range. (And had blood work done twice a month.) She fought going to the lab for blood tests and resisted any appointments with the doctor. It was a struggle each and every time and left both my sister and I exhausted with the confrontation each week over an issue that should have been elementary (but not in my mother's mind).

I later learned that persons with a dementia often resist physician's appointments – it might be found out that they are experiencing some memory loss and other symptoms. Now I believe that my mother was a classic example of "If I don't go to the doctor's and if I don't take my medications...therefore, I must be well." In spite of medications and physician appointments giving my sister and I nothing but hassles, we realized very early on the journey that her medications would need to be closely monitored and tracked.

If your parent or loved one is taking medication, it is imperative that you sit down with the physician and pharmacist and summarize all medications, the dosage, and the times of the day that medication is dispensed.

My sister and I made a chart on the computer and listed all the medications, dosage, and time of day administered.

We printed off a few charts and each of us took the sheet whenever we visited the physician, blood lab, hospital, etc. In fact, we kept one in the home and we each carried one in our purses. That was particularly handy when visiting emergency in the early hours of the morning. Obviously, after a doctor's visit, we made any changes to the chart if the physician changed medications.

My sister also bought pill boxes with the days of the week and every Sunday afternoon she would re-fill the boxes with the appropriate dosages per day. Many of our friends have the pharmacy dispense packages that do this task for you. When you have many responsibilities, it is one less task to do.

Obviously, it will become the family's responsibility to ensure that their parent is taking the medications properly. My sister checked the pill box daily and if there were any inconsistencies (wrong day of the week empty; some pills missing or not, etc.) she would note it and we would call the doctor's office. We did find out that my mother would actually throw the pills into the garbage - so that is another tip...be nosy at all times! Check the trash containers in the kitchen (under the sink) and in the bathrooms. In spite of the disease, our patients become very sly in hiding medications. In their minds they mistakenly think that if they don't take the pills, they are "okay" and not ill.

Caregiver Tip: Look for pills that your loved one might have thrown away. Also, if you look carefully you might find pills wrapped in Kleenex in the trash; or in my mom's case, pills would be on the floor near the baseboard – she had dropped them and then would forget that she dropped them and then not take them. In her mind, she had swallowed them. They also get the days mixed up, so if you ask them if they took their medications, they answer "yes" – although they took them yesterday, not today! Yesterday is today in their minds! If they swallowed the pill on Monday, that counted for every day of the week! (Begin to think like them to understand them! Or, are you really confused now? Ha!)

If this problem persists and your parent is not taking the medications properly, you will have to administer them yourself. Family members will now need to ensure that your loved one takes his/her medications at the appropriate times. A telephone call might not be enough. You will need to drop in and oversee this task. Another suggestion might be to request help from a neighbour or volunteer. Or contact CCAC, physician or attending nurse for help and suggestions. Over-medication or under-medication – both are troublesome and might be an indicator that your parent needs full-time assistance.

Caregiver Tips: Medications

- In the early stages of the disease – telephone and prompt your parent to take his/her medications.
- In the moderate stage of the disease, a telephone call will not suffice. You will need to put a better plan in place. Your family members will need to take turns and drop in to ensure that your parent takes his medications. If that is not feasible, especially for those of you who are out of town, you will need either a reliable neighbour or recruit a volunteer to be responsible for medications.
- Clean out the medicine cabinet – ensure there is nothing in the cabinet or in the house that will confuse the patient. Persons with Alzheimer's

disease often confuse bottles and prescriptions – they cannot read labels properly and are confused easily.

Persons With Alzheimer's Disease and Money Matters

Simply put, the person with Alzheimer's disease has cognitive decline; his brain has changed. The simplest of tasks have become too difficult to manage.

There will come a time when a family member (Power of Attorney for Personal Property) will have to begin to look after the parent's money matters. The POA will need to pay the bills, handle receipts and invoices, file taxes, write cheques, and so forth which will mean the POA needs access to the parent's bank account.

The change-over will be extremely difficult for everyone in the family – this will represent loss of independence for your parent. For anyone, even a person with Alzheimer's, the loss of controlling their own money is a big blow!

This is huge, people! There are two major "biggies" when dealing with aging parents and this is one of them – loss of control regarding money. The second "biggie" is ...drum roll, please...when your parent can no longer drive! Most seniors will confess that these two issues represent a huge loss of independence to them. (It is not any different for the parent with a dementia.)

Try to be compassionate and allow your parent or loved one some control in their life. Look for ways that you can "give in" to your parent and allow them this – dignity! Your parent/loved one is very aware that you have taken over the reins of their whole life – allow them the dignity to make some of their own decisions. Obviously, when it comes to safety and physical well-being, you will have to take control, but there are many issues that you can be lax about – let go of the need to control everything – the person's attire; what foods he/she eats (or doesn't eat); leisure activities; etc. There are many days my father did not want to leave his bedroom and we went with the flow. (He didn't say much, but the looks on his face did the talking!)

Allow me to tell you a story about control and dignity...A wonderful, caring personal care worker at the long-term care facility where my mom lives once raced after a resident with dementia who had walked outside of the building into the parking lot. At first, a gentleman went racing after him and took his arm to steer him back into the building; the resident shrugged off the gentleman's hand and became visibly angry. The personal support worker came up behind the two of them and gently called out the resident's name...which stopped him dead in his tracks. She then motioned to the gentleman to leave and she took over. I watched mesmerized as she magically transformed the resident's mood. How

did she do that? She soothingly started to talk about the cars in the parking lot, while slowly re-positioning him towards the building's entrance doors. She asked the resident if he had wanted to take a walk to see the cars, and what a wonderful day it was to look at all of the different cars – the red Focus, the black Chrysler and the gray van. The resident and she continued the talk about cars while she gently maneuvered him into the building. He didn't know what a force she was! (The gentle art of persuasion in effect.) Yes, it took a little longer than insisting that the resident return to the building. But, she allowed him his dignity. **Not once did she remind him that he wasn't allowed outside on his own.** It would have been pointless anyway, since he would *not* have remembered the next time in any event.

Caregiver Tip: Here is a list of things that we did to ensure our parents' home was more comfortable and "safer" – or what you might call "Coping strategies" – (I have included a couple of things that I wished we had done. The last two points (such as "lists" taped on the mirror) my mother refused to allow. She was in denial (that my father had Alzheimer's) and thwarted many of our attempts to help my father. There was no apparent reason (to us) to what she allowed and didn't allow.)

- TV schedule on coffee table and remote – list channels and favourite TV shows – be very explicit. For example, write a note: "Coronation St. is on channel five at 7:00 pm"
- List of "How-to's" For example: How to turn on the microwave; How to turn on toaster oven (discourage use of stove or oven – unplug them or disconnect them.)
- Switch to electric kettle with automatic off switch.
- Change telephone to one with a pad with extra large numbers.
- Make a list of often-used telephone numbers and names; include emergency numbers, too. (Ensure the most used numbers are on speed dial.) Ensure there is a telephone on each level of your home. (That will prevent your parent rushing down the stairs to answer the telephone.)
- Think of buying the Alert services where your loved one wears a remote to access help.
- Remove scatter rugs/mats; ensure there are no slippery floor areas in home; install hand bars in long hallways, stairs, in bathroom by the toilet and in tub/shower area. Also ensure there are no scatter rugs to slip on in bathroom. Put a non-skid rubber mat in bathtub/shower stall and install a bath seat in tub/stall. My mother had a floor towel rack that was flimsy –

which we found out when we noticed my father used it as a support, as the rack (and my father) would begin to topple over. I removed the towel rack and hid it many times, but my mother kept finding it and re-positioning it in the bathroom. These are the little things that can drive you mad, unless you sit down and communicate your fears. Or, go out and buy a safety bar and have it installed in that *exact* location.

- Clothing – non-skid slippers, shoes (running shoes are best) with Velcro straps for closure.
- Pull-on elastic waist pants for easy access. Scrubs are good. Ditto sweat pants. (Yes, even if you have never, ever seen your father in sweat pants! Tell him all the athletes wear them; he should, too.)
- Put out clean towels and face cloth in bathroom daily. (Easy access is key to everything.) Assemble shampoo, soap, towels, clean clothing for bathtime. (Keep in mind that if you leave the room to look for an item, your parent may fall.)
- Meal menu – easy to heat foods or no heat required are best. Think of children’s school lunches – small containers of yogurt, fruit, ice cream, rice pudding, etc. Anything that does not require reheating in the oven. (My mother told me that she would never endanger herself by cooking on top of the stove. I believed her. When we sold the house and had to empty it of her possessions, I looked in the kitchen cupboards for the set of pots and pans. I only found lids. To my horror, I realized that she had used the pots (they must have burned and she could not clean them) and had thrown out the evidence of her “accidents.”)
- Library – large print books, audio books
- Magnifier – you can go to the Canadian Institute for the Blind office and ask for tips for the aging senior who has visibility issues. (My father began to use a huge magnifying glass that helped him in his early days of macular degeneration.)
- Increase the light wattage to ensure more clarity and light. As soon as my parents started hallucinating, we added more floor lamps to those areas. (And I didn’t even know the term “visuoperceptual difficulties”.)
- Calendars – buy a big one with large type and large squares – add daily notes and routines and reminders; well-used telephone numbers; prompts. Remind your loved one/parent if someone’s birthday is soon. Make notes of doctor’s appointments. Keep your loved one in the loop – remind him of special occasions and celebrate them. Never assume that because your

parent/loved one cannot remember; therefore, it doesn't matter. It matters!

- Add typed lists of daily routines in appropriate rooms. For example, on the bathroom mirror the list might be: wash face, dry face, comb hair, brush teeth.
- Print out a daily routine or schedule. For example: Eat breakfast, clean dishes, put away dishes. Get dressed. Do light housework – dust living room. Read and have a snack. Prepare lunch. Clean lunch dishes and put the dishes away. Have a nap. Watch news on channel five at 5 pm. Prepare dinner. After dinner, put dishes away. Another example.: “Our neighbour, Sam, is visiting after dinner. After Sam goes home, prepare for bed.”
- Note any doctors' appointments or hospital visits. Add hair appointments and expected visits or outings. Ensure that you go over the schedule with patient and ask them if they would like to add or change anything. These simple gestures help give the person with Alzheimer's disease some control in their life. If they don't want to do a particular thing, ask what their preferences are. It's important that there are not any surprises. Surprises represent change! **And patients do not like change.**
- Print out words and tape the appropriate word to objects as a prompt – for example, tape the word telephone to the telephone; or tape a list of the items that are in a cupboard; for example – print the types of items that are in the bathroom medicine cupboard (lock away any prescriptions, etc.)
- Similarly, print up the items kept in the fridge. The patient will know where to find items and where to put back items.

Look For Joy

There are many activities that you and your loved one can share together, but you will need to alter your expectations. Try to spend time and be in the moment. In other words, try not to become so distracted that you are with your parent in body only; your mind is somewhere else or making up a “to do” list. Stay engaged with your parent and give them the gift of yourself – your attention. And, strangely enough, when you stay in the “now” of the moment, you will begin to let go of the stress of caregiving and just begin to enjoy the presence of your loved one.

- Photo albums – my mother's favourite activity

- Allow patient to sort through a box of photos – either spend time looking and talking about the photos or allow patient to help you make a family album
- “Play” with coins – yes, money! Patients like to look at the coins, pile them in stacks, or just move them around. I have no idea why except that I have found from my limited experience that the aging parent (with dementia) seems to “love” money.
- Put money and a wallet and a purse on the table, and a patient will fill the wallet, put the wallet into purse. Take it out. Start over. (My mother loves it when I pull out her purse and wallet.)
- Fold items in a drawer. Take out the sweaters or underwear and allow patient to re-fold them. Exchange wire hangers for plastic hangers in the closet and allow your parent (mother) to help.
- Sort books on a shelf. Study each cover. Ask the patient if there is a favourite book that they would like to have to keep by their bedside.
- Look through picture books together. Think coffee table books – landscapes (of a particular favourite location); animals; children.
- Read aloud. Some people like the newspaper read aloud.
- Have a sing along – oldies, but goodies! Print out the lyrics to some songs and go for it. (Large font.) Forget about your voice. Just sing out loud because you will be doing much of the singing...ha!
- Jewellery box – sort through the jewellery, talk about the stories behind the pieces.
- Ask friends and family for extra jewellery pieces to stock; books; photos.
- Think activities that are simple – but attempt to tie into a favourite pastime or hobby
- Spend time outdoors in the garden, a park or take a walk. The outdoors restores us – allow time in your day to sit and just be.

Caregiver Tip: Ensure that the activity you share with your parent is one that is enjoyed. Don't assume that all persons with a dementia want to sort buttons or look through albums. My mother is very quick to remind me if the activities are unacceptable to her. She once reminded me that “I never liked to do that when I was young. Why on earth do it now?” Be alert to changes in their likes and dislikes – sometimes, they no longer want to do an activity because they cannot do it. They want to “save face” so they tell you they dislike that activity.

I have included a wonderful list of activities to help facilitate communication with elderly residents when visiting them in Chapter Ten: Letting Go (How to transition your loved one to a long-term care residence) from *Gentlecare: Changing the Experience of Alzheimer's Disease in a Positive Way* (Jones, M. 1999, Hartley & Marks).

Remember to look for joy and do what makes you happy; give energy to what makes you happy, passionate, and that honours you. Don't put your energy into feelings of fear, anger, resentment and other negative emotions.

You will experience many moments of letting go, of saying goodbye to a piece of your past memories. These are bittersweet moments...and they hurt. You are grieving, slowly but surely, every single day. Eckhart Tolle calls these moments “mini deaths” – moments when you have a glimpse of reality – that the person you love is no longer there...when you find your loved one fast asleep on the couch during the morning or afternoon; when you realize that your loved one no longer asks about your day; instead, they only talk and care about their day (the world has shrunk for them – and your daily activities or comings and goings no longer matter to them); when your loved one needs assistance to do the most menial and simplest of daily chores; when your loved one no longer is able to write a cheque or balance a cheque book or make a telephone call.

That is all part of the journey - the growth and self awareness of the individual caregiver. We are on a journey and just like any other journey; we will experience highs and lows. (And let us not forget that our loved one is also on their personal journey.)

The first time that my father asked me to show him how to fill out a cheque, I dutifully obliged without a thought to its importance. When it came to money my parents were old school, that is, they didn't believe in owning charge cards or debit cards. Instead, they paid by cash for most items and services. Like many others of their generation, only when it was absolutely necessary did they remit a payment by post. Otherwise, my parents piled into the car and drove to the necessary office to pay a bill (and later this became my job to drive them).

In short, my father didn't write many cheques so that when he first asked me for assistance in completing a cheque, I didn't give it one thought. It was only when I found the cheque in his desk that it struck me odd – then I realized that the cheque that I had completed for him was his “visual aid.” I was puzzled at first, still in denial. I put the thought out of my mind, but it lay there in my subconscious mind (poking at me occasionally).

There were other signs of early dementia that we all ignored. (In our case, we assumed any abnormalities of behaviour were due to my dad's progressive macular degeneration. We presumed that if he couldn't see one of his grandkids, then that must be the reason he doesn't recognize them.)

My sister, my husband and I often took my parents on Sunday outings which was a treat for both my parents – and let's be honest, an outing is also a reprieve and rest for us. My Dad especially enjoyed one of us driving instead of my mother (who was a terrible driver – but that's another story) – Bayfield, Sombra, Grand Bend, Port Stanley (local southwest Ontario haunts that are both charming and scenic) were our destinations most Sunday afternoons. My father had contracted macular degenerative eye disease early in his mid seventies, so that my mother inherited the driver's seat; unfortunately, sometimes I think my father regretted

that more than the actual disease itself. He often “back seat drove” while she completed their list of errands; he all the while giving directions and unsolicited advice throughout the trip. (I bet that is a familiar story with many other families.) Needless to say, when I took over the chauffeur’s seat, he and my mom were thankful.

I had another glimpse into this insidious disease when on one of these trips to Port Stanley, in the middle of December, that when we returned to my parent’s home and I drove up to their house (I had not even stopped the car yet), my father jumped out of the car. The fact that my father was unharmed at the time was a testimony to his body’s strength and flexibility; my dad was 88 at the time.

My sister and I were stunned – our father had just leapt out of a moving car. We rushed to help him up and he joked “I’m desperate for a cup of tea.” Well, my father’s sense of humour could always win us over and once again, we both filed away the incident and did nothing. We were still in denial. (I know. You are saying “Duh!”)

In January, almost two months after the car incident (the jump as we called it!) my father announced that he no longer would be taking any more day trips in the car. Within a couple of weeks, a second announcement – he no longer would be going *anywhere* in the car. In fact, it became clear to my sister and I that Dad would not venture **outside of the house**. (When asked why, he replied, “It’s scary out there.”)

After watching my father take his daily constitutional or walk for as long as we could remember, he stopped going outside. He became frightened of the outdoors; the following summer we coaxed him outside onto the back porch and he relented only to position his lawn chair beside the back door. That was the last time that he went outdoors. The next time was when he was taken by ambulance to the hospital in August of that same summer.

I have a photo of my mom, my dad and I standing beside the car in Port Stanley on that fateful day when he jumped out of the moving car. I look at it often because when I look into my dad’s face he looks so carefree and normal, even laughing. I love that photo.

Chapter Six**It's About Learning a New Language – Alzheimer "Speak" (Communicating with persons with dementia who have language difficulties)**

When my mother entered the long-term care facility, after a few months, I asked her how did she like her "new home" and she replied in the usual manner of someone who is lucid most times but still struggles to articulate herself.

She responded to my question: "Well, it's a fine place, and I am fine. But the home and myself *just don't go together.*"

Quite frankly, I think that pretty much sums up her feelings and might I add...quite accurately!

I have noticed over the past years in my (albeit, limited) experience that persons with memory and cognitive losses express themselves in a somewhat convoluted way; nevertheless, they do convey their emotions and feelings just not in a typical fashion. For instance, my father would frown and furrow his forehead and no one would mistake his intentions, even though he didn't utter a word. My mother who is much more talkative (and always has been) chats up a storm to any willing listener (and sometimes not so willing listeners...ha!). And no matter what she is attempting to say the message is somewhat garbled. It is sometimes upon reflection that I figure it all out. When you listen enough to a person with cognitive impairment, you do become able to discern the meanings and thoughts eventually. Often there is a thread to their story that links one conversation to another. Unfortunately, most people, including family and friends, do not have either the time or inclination to make the discernment.

For example, during a conversation my mother asked about my husband's baseball game and I replied that his team won the game although my husband didn't play due to his knee surgery. She nodded. Soon afterwards she turned to me and inquired, "Did he get a lolly?" I was completely puzzled. Didn't have a clue. But as we sat in silence, I went over the earlier conversations and thought about the activities of her morning schedule. She had volunteered to me that a group of them had gone on a morning walk and were rewarded at the end of the walk with icicles. She didn't call them *icicles*, nor *freesies*. She called them frozen sticks but I am still fairly young enough to remember those from my past. So suddenly I had an insight...icicles were frozen "lollies" or "lollipops." She was making the leap that if she was rewarded with an icicle, surely John's baseball win warranted a "lolly." So like an excited child who has just figured out how to spell "cat - c-a-t" I turned to her and said "Eureka! I got it!" Okay, I didn't yell "Eureka" but I was pretty proud of myself. So I asked her if she meant to say that John deserved a "lolly" for his baseball team's win? "Of course," she replied, calmly. I replied, "No, he didn't receive a "lolly" but I will definitely forward your suggestion to his team – everyone deserves a reward after a little exertion." She

thought about what I had just said and then remarked, “Well, I would imagine at his age, he puts forth a lot more exertion than just a little.” Well said, mother. (Yet, at other times, she will insist that my husband (who is 61) is in his early twenties...but “aging well.” Yes, my husband loves her for this.)

Experts inform us that someone with Alzheimer’s disease loses the ability to retrieve certain words or language to express themselves – they often struggle with how to express their thoughts. You can easily watch their faces and see the frustration on them. My mother (as did my father) substitutes words which are often used in a highly “creative” manner. She might relate an event that occurred at the dining room table and want to name her other three table mates...she will describe them as “you know, those people who roll up beside me.” What she means to recite are their actual names, but she can’t remember their names so now her brain substitutes the names with a *description* of them - the three ladies who are in wheel chairs who are beside her at the dining table. If you weren’t aware of this, you might be totally confused throughout the whole story and wonder who the heck or what the heck are people who roll up? Is someone harassing her? Is there a rolling gang of mischief makers in the nursing home? Do they sidle up to someone and demand Kleenex? (Yes, my mother doesn’t go anywhere without her faithful box of Kleenex on top of her lap. My sister and I keep her cupboard well-stocked with boxes of tissues even though the staff has assured us that Kleenex is supplied!!)

- Creative substitutions are the mainstay of any conversation. There are other clues that one will pick up on when having a conversation with a person with Alzheimer’s disease.

The website http://www.alz.org/search/results.asp?q=care%2Fdementia-communication-tips-asp&as_dt=i#gsc.tab=0&qsc.g=care%2Fdementia-communication lists other changes or what I call mutations or “riffs” in the conversation (*Communication and Alzheimer’s*):

- *Difficulty finding the right words*
- *Repeating the same words or phrases again and again*
- *Substituting words that sound similar*
- *Inventing new words to describe familiar objects*
- *Easily losing train of thought*
- *Difficulty organizing words logically*
- *Reverting to speaking in a native language*
- *Using curse words (a strange quirk of diseases that sap language skills)*
- *Speaking less often, or even not at all*
- *Relying more on nonverbal gestures to compensate*

All of which make conversations quite interesting. I often think a linguist would have a field day. I often run home and write down something my mother has said because it is so interesting that it is almost “genius”. Normally it takes a few seconds or even minutes for me to make sense of her puzzle but I do get there eventually. Sometimes it wows me how imaginative or how clever the substitution or invention is. She once told me that ever since the new sergeant had taken over the building (she never calls it home) that the allotments had become small. I puzzled over that one for a number of visits. Then it hit me. The sergeant, of course, was the new director and the allotments were the portions of food at meal time. (Who’d a thunk?) And I felt ashamed that I had confessed to my sister that Mom was talking about the war again. (Sergeant...war...get it?) (And no, the portions were not smaller.)

There are many ways to help someone communicate or express themselves but patience and understanding are the keys to any conversation. Most importantly, continue the conversations. Do not give up on your loved one and allow them to go into silence. It is enough that they have to contend with frustration and disappointment on a daily basis; don’t allow the conversation to discontinue. Try to remember at all times: **Your loved one is still there deep inside. They just can’t get it out for you to see that. And that frustrates them and leads to anger, repetition, withdrawal, depression and so it goes...**

Here are some more tips from <http://www.alz.org> (Click onto Caregiver Centre, then click “Communication”) in furthering the conversations or helping your loved one to communicate. With permission, I have included some of those tips:

- *Be patient and supportive.*
Let the person know you're listening and trying to understand. Show the person that you care about what he or she is saying and be careful not to interrupt.
- *Offer comfort and reassurance.*
If he or she is having trouble communicating, let the person know that it's okay. Encourage the person to continue to explain his or her thoughts.
- *Avoid criticizing or correcting.*
Don't tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if it helps to clarify the thought.
- *Avoid arguing.*
If the person says something you don't agree with, let it be. Arguing usually only makes things worse — often heightening the level of agitation for the person with dementia.
- *Offer a guess.*
If the person uses the wrong word or cannot find a word, try guessing the right one. If you understand what the person means, you may not need to give the correct word. Be careful not to cause unnecessary frustration.

- *Encourage unspoken communication.*
If you don't understand what is being said, ask the person to point or gesture.
- *Limit distractions.*
Find a place that's quiet. The surroundings should support the person's ability to focus on his or her thoughts.
- *Focus on feelings, not facts.*
Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may provide clues.

In the later stages of Alzheimer's disease, when your parent or loved one is less communicative, you will find that conversations decrease substantially. But still you must have patience and understanding that the person may still want to express their feelings or emotions, but that language is now very difficult for them.

- *Identify yourself.*
Approach the person from the front and say who you are. Keep good eye contact; if the person is seated or reclined, go down to that level. (Don't tower over them.)
- *Call the person by name.*
It helps orient the person and gets his or her attention. Ongoing communication is important, no matter how difficult it may become or how confused the person with Alzheimer's or dementia may appear.
- *Use short, simple words and sentences.*
Lengthy requests or stories can be overwhelming. Ask one question at a time.
- *Speak slowly and distinctively.*
Be aware of speed and clarity. Use a gentle and relaxed tone — a lower pitch is more calming.
- *Patiently wait for a response.*
The person may need extra time to process what you said.
- *Repeat information or questions as needed.*
If the person doesn't respond, wait a moment. Then ask again.
- *Turn questions into answers.*
Provide the solution rather than the question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"
- *Avoid confusing and vague statements.*
If you tell the person to "Hop in!" he or she may interpret your instructions literally. Instead, describe the action directly: "Please come here. Your shower is ready." Instead of using "it" or "that," name the object or place. For example rather than "Here it is" say "Here is your hat."

- *Turn negatives into positives.*
Instead of saying, "Don't go there," say, "Let's go here."
- *Give visual cues.*
To help demonstrate the task, point or touch the item you want the individual to use or begin the task for the person.
- *Avoid quizzing.*
Reminiscing may be healthy, but avoid asking, "Do you remember when?"
- *Write things down.*
Try using written notes as reminders if the person is able to understand them.
- *Treat the person with dignity and respect.*
Avoid talking down to the person or talking as if he or she isn't there.
- *Convey an easygoing manner.*
Be aware of your feelings and attitude — you may be communicating through your tone of voice. Use positive, friendly facial expressions and nonverbal communication.

http://www.alz.org/search/results.asp?q=care%2Fdementia-communication-tips-asp&as_dt=i#gsc.tab=0&gsc.q=care%2Fdementia-communication

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I have found through experience with both parents that “how” I say something becomes more important than what I actually said. In other words, a person with dementia can easily misinterpret a conversation but clearly will remember your emotions or “energy” when you spoke. My mother often ignores my words, but will say “You seem happy.” Or she might chastise a staff member because of their “attitude.” I will gently remind my mother that the staff is merely trying to help her out of her chair and she will ignore the command, but obsess about how difficult someone is. Someone else could say the exact same words and my mother would become compliant. It’s eerie how an individual with Alzheimer’s cuts through the conversation and goes straight to the heart of the matter. (It’s mind blowing.)

I have also learned that individuals with a dementia need to be recognized and valued – do not speak over them or act as if they are not in the room. Allow the person his time to speak. Learn to listen. In the palliative course, we learned “WAIT” which is an acronym for “**W**hy **A**m **I** **T**alking” still.

When my mother is telling me a story, she often forgets her thought half-way through her conversation. (And many times I am not sure of the story, the characters, the point, etc.) But I will allow my mom to recover her thought for a few seconds, and most times, she will not remember her story, so I gently remind her or re-cap what she has just said. She will smile and nod, “Oh, yes, that

story...” And she will continue. This allows my mom (and other persons with Alzheimer’s) to maintain their dignity and self-esteem.

Whenever a person with Alzheimer’s is talking to you, ensure that you give them your full attention...even if you are unsure of what the person is actually saying. Many residents and staff have told me that they are unsure of what my mother is talking about; I smile and always say “Yes, isn’t it lovely that she is still telling us her stories.” Don’t let the conversations stop.

Caregiver tip: When conversing with someone who has a dementia-related disease, try not to ask questions that the person cannot answer. Even the simplest of questions is now difficult for them. For example, because they have no short-term memory, they will not remember what they had for breakfast or the previous dinner. Many times, the day’s activities have been forgotten.

Instead, prompt them with the answer and allow them to “expand” on the answer. For example, you might say “Today is Tuesday and Tuesday is bath and wash hair day. Your hair looks lovely; did you enjoy having it washed today?” Now your parent is pleased to be complimented (hey, don’t we all love a compliment?), feels good about themselves and can expand the conversation about the experience of “bath day.” Believe you me – bath day usually elicits lots to talk about!

Caregiver Tip: An interesting note – I have noticed with many of the residents in the long-term care facility where my mother lives that many of them still like to “preen.” No matter how advanced their disease, no matter what stage they are in, they still like to be fussed over – they like to go to the hairdresser and they like their nails painted. Many of them smile or their faces light up if you compliment them. When I give my mother a hand mirror to hold, she won’t let go...she is too busy looking at herself. Other residents have leaned over to their daughters to ask them to re-comb their hair or adjust their scarves. It’s quite amazing – even my father who was almost blind, partially deaf, and didn’t verbally communicate, would smile when we told him his latest haircut looked good. On one occasion, I complimented a resident in the long-term residence on her newly-permed hair – she grabbed my hand and smiled (and wouldn’t let go). What made this action remarkable was that the resident had symptoms of a stroke – she did not speak or acknowledge people. But, she was clearly delighted that I had complimented her! (These are the moments when I feel so blessed that I have had the experience of caring for my parents – the people I meet are memorable!)

I find that if you have had any experience talking with young children while attempting to find out about their day (How was school today? Answer: Fine.), you will need to re-discover those techniques that you used to “mine” information. These techniques will also enable you to find out what your loved one *really* thinks about a situation or an event. Sometimes, I simply state “You seem happy today.” Or “You look very sad today.” And my mother responds with a story.

Most times I cannot follow the story, but always I realize that my mother is relieved to at least talk and have her feelings or emotions recognized.

You will need to learn *how to read between the lines or how to discern their energy about something or someone!* Begin to read their emotions on their face!

And remember, most importantly, that it is not about you trying to solve or reconcile their stories; it's about allowing your loved one the opportunity to talk (or vent). That's all. Just listen and allow them the opportunity to express their emotions. (On the other hand, if your loved one likes to "vent" too often, ensure that after a brief time, you change the subject; distract them; tell them a funny story; bring the pet to visit. My sister reminds me too often that some of the residents (my mother) hold a story and riff on the story as if the subject's on "stuck" dial.)

Have you experienced your loved one repeating something? They will ask you a question; you answer. They will ask again; you answer again. Ask again. And again.

Yes, even though you might become annoyed or irritated (especially in the beginning of the journey when all of this is new) a person with dementia needs patience and understanding. The very fact that your parent is repeating something means *that this is important*. Instead of getting irritated, slow down, take a deep breath and allow the person to talk. Just listen. It beats getting all upset and trying to answer the question over and over.

Try not to interrupt the person with Alzheimer's; let him talk. If you try to give explanations or try to reason with him, the person cannot understand or remember! It's imperative that you don't take this personally. The individual's reasoning abilities, in fact, cognitive abilities are impaired and your explanation will only confuse him further, or worse, make him feel bad about himself. Furthermore, too many choices overwhelm him, confuse him and make him feel worse. So you can understand now that simply allowing the person to talk is sometimes all that is needed. I often just let my mother talk or I simply rub her arm or hold her hand. (My sister was wonderful with my father and now is with my mother...she simply just grins or tells a funny story (with multiple laughs) and my mother just simply laughs along with her. It's quite remarkable to watch. I am mesmerized by it. It's as if the simple act of smiling or laughing elevates my mother's mood. Sue can actually tell any story (when she had a mouse in the kitchen and she didn't want to kill it) and it will transform my mother's mood. Sue has learned that laughter *is* healing energy!)

Many caregivers experience their parent's frustration in the words "I want to go home." It often breaks our hearts to hear a grown person say this simple phrase...*I want to go home*. Our first inclination is to say...*You are home; or, this is your home*. I learned this is not what our parent wants to hear; in fact, it

confuses them. A more appropriate response (a more loving response) might be...*Okay, but let's have a cup of tea first. Or, That sounds like a good idea to me.* And then begin to distract them or go for a walk in the garden and return "home."

There is a difference in the two responses – our first inclination to correct the person confuses the person with a dementia (in their world, they are **not** at home) and in the alternative response, the caregiver has attempted to prevent embarrassment, shame and confusion for the person. Instead, the caregiver has soothed the person's fears. As caregivers (and friends and family), we often forget that the person with Alzheimer's is very aware of our responses – when we argue, disagree, or try to correct them, we cause them shame. (The person with dementia *understands* (or *intuits*) that you are upset...but the person doesn't have the cognitive ability to remember *why* you are upset.)

My mother will often ask me outright, "Do you see the boys in the trees?" I used to be truthful; now I fib. Or, I might answer, "Well, I think that you see the boys; therefore, there must be boys...and I just don't see them." For some reason, that calms my mother.

Sometimes, before we answer, we need to ask ourselves...*How can I allow my loved one to save face?* That makes all the difference.

According to an information tip sheet to help enhance communication between people with dementia and their caregivers (Reprinted from the Alzheimer Society of Canada *Day-to-day Series: Communication*, available at http://www.alzheimer.ca/~media/Files/national/brochures-day-to-day/day_to_day_communications_e.pdf there are a few simple steps to take when having a conversation with a person who has Alzheimer's disease:

- *Set the Stage*
- *Communication is easier if other things are not happening at the same time. For example: if the TV or radio is distracting the person, turn it off.*

- *Get His/Her Attention*
- *Approach the person slowly and from the front. Gently touch the person's hand or arm to get his/her attention.*

- *Make Eye Contact*
- *If the individual is sitting in a chair bend down or sit beside them so they can see your face. Many individuals with Alzheimer have decreased upward eye movement.*

- *Speak Slowly and Clearly*

- *Use simple words and short sentences. Speak slowly and clearly. If the person has a hearing problem, face her and lower the pitch of your voice.*
- *Give One Message at a Time*
- *Do not include too many thoughts or ideas at one time.*
- *Do not give too many choices. Questions that can be answered with “Yes” or “No” are easier than open-ended questions.*
- *For example: “Would you like soup for lunch?” is easier than “What would you like for lunch?”*
- *Pay Attention*
- *Reactions to what you say can give you some idea of how much is understood.*
- *Repeat Important Information*
- *If the person has not understood the message the first time, repeat it, using the same words.*
- *Show and Talk*
- *Show her what you mean as well. For example: if you want an individual to sit down, sit down and motion for them to sit beside you.*
- *Keep In Mind:*
- *Those feelings remain despite the losses caused by Alzheimer disease.*
- *That we all communicate by emotion, expression and touch – holding a hand or smiling when talking can convey more than words.*
- *That everyone wants to be included – it is painful to be ignored because you have difficulty communicating.*

2010. *Day-to-Day Series – Communication.* Alzheimer Society of Canada. All rights reserved. www.alzheimer.ca

Chapter Seven

SYMPTOMS and How to Manage Symptoms While Caring for your Loved One

Since many individuals with a dementia-related disease exhibit some of the following symptoms, but not necessarily all of the symptoms, I decided that it might be easier for the reader if I presented “Symptoms” within this chapter, each in its own section. Hopefully, the reader can access the symptom or symptoms that pertain to his/her loved one.

The website <http://www.therubins.com> reminds us that caring for our loved ones who have a dementia-related illness is different from caring for aging patients *without* dementia:

*“In many ways, taking care of patients with AD is different from assisting patients with only physical ailments. For example, patients with AD have **impaired insight, often misjudging or denying the extent of their physical and mental impairment.** These patients may perceive the intervention of a caregiver who assists them with performing the activities of daily life (ADL) as an indignity and, mistakenly, as an imposition. Consequently, patients with Alzheimer’s disease frequently display behaviors that are disturbing to the caregiver and disruptive to the caregiving process. These include resistance, rejection, agitation, negativism, and verbal or physical aggressiveness and abuse. These behavioral changes are, at least in part, accompanied by changes in neuromotor function. With the progression of the disease, the brain is increasingly less capable of selecting and modifying its responses to various incoming stimuli. Consequently, the body of a patient with AD reacts differently to a variety of external stimuli that act upon it compared to the body of a healthy person. These fundamental changes in neuromotor function profoundly complicate patient care because they limit the patient’s physical capability to cooperate with the caregiver.”*

Caregiver Tip: Mr. Harold Rubin reminded me (when I asked for permission to cite his website) that their website compiles recent information and “current thinking” that may change over time and that I should add a cautionary note that this is not a definitive explanation of behaviour.

Allow me to remind the caregiver that dealing with our loved one’s symptoms is one of the most stressful challenges of caregiving – we are saddened by the symptom, itself, and we are confused as to how to handle the unwanted behaviour. It comes as a shock to many of us to see our parents behave in such ways. That’s why it’s so important to both become informed about the disease and its management *and* to remind yourself to “let go” – of your expectations and of your suffering. Release your resistance to the circumstances, or the reality of your situation. Let go of any expectations and just live in the Present. (It is a

choice: we can either suffer or let go of the suffering and accept the reality.) This acceptance can lead you to awareness of positive energy and our positive energy can transform our relationships and connections with our loved ones. Choose to embrace each day as it unfolds and make the choice to accept yourself as “enough” – remind yourself every day that you are doing the best that you can...and that is enough.

Problem behaviours (or symptoms) are really the person with Alzheimer’s “new” way of communicating now that verbal communication has become more difficult. As the brain cells deteriorate, a patient’s judgment is impaired and language difficulties prevent the patient from expressing himself. The symptoms **are** the way the individual now communicates and expresses himself.

There are various reasons why symptoms manifest:

- Medications (always, always check with physician first when any new symptom manifests).
- A change in the surroundings.
- A change in the actual caregiver.
- A change in the routine and structure of the day.
- Loss of control – The individual has lost control over most segments of his life (someone needs to care for him, bathe him, dress him, and sometimes, even feed him) and this frustrates, and even angers him. Hence, the symptoms.

Try to remember this factor (loss of control) when your parent or loved one is exhibiting unusual behaviour – your understanding this will lead to deep compassion and love for your loved one.

A help guide for those who deal with Alzheimer’s lists a number of factors to help identify what the cause might be:

http://www.helpguide.org/elder/alzheimers_behavior_problems.htm)

- *Try to put yourself in the person's situation. Look at their body language and imagine how they might be feeling and what they might be trying to express.*
- *Ask yourself what happened just before the problem behavior started? Did something trigger the behavior?*
- *Are the patient's needs being met?*
- *Does changing the environment or the atmosphere help to comfort the person?*
- *How did you react to the problem behavior? Did your reaction help to soothe the patient or did it make the behavior worse?*

Smith, Melinda, M.A., Russell, Doug, L.C.S.W., and White, Monika, Ph.D. Last updated: December 2013. *Alzheimer’s Behavior Management: Tips for*

Managing Common Symptoms and Problems. Accessed December, 2013, from: http://www.helpguide.org/elder/alzheimers_behavior_problems.htm (All rights reserved.)

Try to ensure that the home or bedroom is calm and stress-free. And more importantly, ensure that our tone and voice is calming and relaxed. Any negative emotions will affect the person's behaviour and unsettle them. If you want a relaxed person, you will need to be relaxed, too. (I believe Jill Bolte-Taylor's experience of healing energy is a powerful one. See my Introduction.)

Gandhi... “**Be the change you want to see.**” (This quote has become my “go to” support whenever I want to change my emotions.)

Exercise is extremely important in the *prevention* of problem behaviours and in *stopping* them once the individual is exhibiting certain behaviours. Exercise can be a short stroll around the gardens outside, around the block, down to the corner store, or through an indoor mall. If the person with Alzheimer's likes to dance or enjoys music, allow music to move them; even yoga can be practiced while seated in a chair. (I taught my mother the T'ai chi move “wave hands at clouds” and she can easily perform this move while seated...which she loves to do. (It's relaxing. And when I say “taught,” I mean – she mimics my actions.)

Symptom: Losing items and searching for them; Repetition

Patience – you'll need it. Persons with dementia seem to lose items and spend a great deal of time in a search for those items. Often I would visit my mother's home to find her searching frantically for her purse. (For some reason, money, wallets, and purses are a big thing – they are forever obsessing on those items.) She would often find it (No, let me correct myself, I would find her purse!) in the same place that she always left it - beside her lounge chair in her knitting basket. In plain view!

When she fell and was hospitalized for nearly one year, I would often find her searching in her bedside table drawers for her purse. It became such a habit that my sister and I finally took her purse home and just left her wallet. Unfortunately, that didn't prevent her searching. Her wallet was small enough that she hid it throughout the hospital room. Now people, you and I both know that hospital rooms are not very big – how many places could she hide a small wallet? But, when even the nurses told us to take the wallet home, we knew Mom and her money would have to be parted. Well, not exactly. We took the wallet home and left loose change (enough to buy tea and a daily newspaper) in the top drawer. Clever, yes? Nope. The change was always missing. (Not missing, just moved temporarily.) Once again, the nurses asked us to take her money home. It appeared that she would hide the loose change in her clothing and bed linens and the nurses never knew when a toonie would appear at bath time, or drop out of her clothing when she was in her wheelchair on an outing. (She still hides

things under the pillows in her room at the residence. I often find pieces of chocolate nestled in her lingerie drawer – melted, of course.)

I tell you this story only to highlight the lost and search maneuvers that persons with Alzheimer's employ in their daily lives. Frustrating for caregivers? You betcha. But when you know this stuff, it helps us understand why they do what they do. And it is in understanding that our deepest compassion and kindness occurs.

Actually, when the individual hides things, it is usually a behaviour that is masking an underlying fear. What your parent needs is lots of reassurance.

To this day, my mom moves and hides all kinds of small items in her bedside dresser – she isn't hurting anyone or herself. So, why not? It seems to be an activity that she has no control over so we ignore it. Thankfully, all of us (including the staff) know enough to look for any missing item in the dresser. (And we add extra hugs, of course.)

My father didn't hide items (he was partially blind...until near the end of his life, when he became totally blind) but he was obsessed with some things. My mother and he hid their bank books and passports (with some small amounts of English sterling) in a safety deposit box which they stored in a kitchen cupboard. My sister and I would often find him lodged on a kitchen step ladder (stuck!) searching for the kitchen cupboard which stored his safety deposit box. We would have to pry him off the step ladder with promises that we would retrieve the box and allow him to look at his bank book. Once he had sat with his bank book and English sterling for awhile, he would be perfectly content to allow us to store the safety deposit box again. Unfortunately, this game went on one too many times and when we found him standing **on the kitchen counter** one day after an outing with mom, we knew we had to stop the activity. This incident became the catalyst for action – we no longer left him unsupervised. And in a way, my sister and I realized and accepted that my father was very ill and that we needed help. It was that incident that finally convinced my mother to allow us to call the Community Care Access Centre. So, all good – even that scary incident allowed us to ask for help.

Again, because of impaired judgment due to degenerative brain cells, the person with Alzheimer's hides objects for various reasons that often do not make any sense to us unless we take the time to reason the behaviour.

Most people hide items to keep them safe. Think about it. Where would you hide your valuables? In a safe or any location that is hidden or locks or "closes shut." One caregiver mentioned in a forum on the Internet that she sees a direct correlation of the item and the hiding spot. For example, dirty dishes will be found in the bathtub – bathtubs are clean and for washing our bodies. Hence, dirty dishes need to be cleaned (bathtub is clean and that is where we wash up).

A second example that she mentioned is valuables that are hidden in a freezer or refrigerator – the freezer or refrigerator is locked (the door closes). When explained, the individual's actions make a little more sense to us. Often, the individual "stores" items in the cupboard which is where I would find items that should be in the refrigerator, such as milk or eggs.

Tip:

- You may need to de-clutter your home and eliminate too much stimulation. Simplify life and the surroundings.
- Distraction is very important. Use photo albums, calm and peaceful music, peaceful activities. A cuppa is always an antidote in my family! Just saying the words, "Dad, how about a cup of tea?" and he would be transformed.
- Exercise! Go for walk, gentle stretches, stroll around the garden...just help your parent move a little. Experts tell us that some behaviours are symptoms of boredom.
- Remove all dangerous products or lock them up. Eliminate dangerous tools, cleaning products, or items in the medicine chest.
- Check through the areas where they seem "obsessed" in hiding or searching for items. In my mother's case, whenever I visit, I open all the drawers and look for "hidden" items. Most times I find chocolate pieces or cookies within the folds of her lingerie. Once, I even found my sister's "missing" mince tarts. Ha!
- Encourage your parent to hide things in a dresser or box or closet so that you can check for missing items at a later time. (Not while they are present.)
- Check through trash cans before you throw the trash out. If possible, lock the basement door. At the very least, discourage your parent going into storage areas unaccompanied by someone.

Caregiver Tip: When you find "lost" items in inappropriate or "odd" locations, ensure that you do not make it into a big deal. Try not to scold or chastise your parent/loved one. Instead, my sister and I always act as if the search is a game, and we have "won" a prize for finding the item. We laugh often and we might say, "Hey, lucky me, I found your wallet, Mom! Good hiding place, Mom." She smiles and acts as if the hiding place was her plan all along.

Remember:

- When a person is exhibiting certain behaviours, she/he wants and needs reassurance!
- Fear is usually the reason for most behaviours. Hence, repetition is usually a sign that the individual feels insecure or fearful.

Identify the cause of the anxious questions or repetition. Ask yourself these types of questions. Is my mother worried? What is she worried about? Is she worried that I am leaving her? Is my mother in the past – thinking about someone who has died? Try to get into their thought processes so that you can find the words to reassure. Reassure them, stay calm and speak in quiet tones. Perhaps rub their arms or give them a hug. Let them see that you are peaceful and allow your peaceful energy to change their erratic energy. (As Gandhi said, “Be the change that you want to see.” Or, if you want your loved one to be calm, **be calm, yourself.**)

When your parent is excitable or irritated (or repetitive), try changing the subject. Talk about something that he/she loves. Visit a beloved pet. Call the dog and make a fuss of him. **Distraction is key.** (Someone told me that she leaves the room, counts to twenty, and then returns. That tiny act can defuse the individual with Alzheimer’s anger or irritability.)

Determine if your parent/loved one has better times during the morning or evening. Get a handle on his/her optimal time of day. Try to see the cycle and prevent the poor behaviours before they escalate. **Prevention is key.**

Go with the flow! If your parent is telling a story, allow them to talk without interrupting them or trying to correct their version. Yes, patience is a virtue. It is difficult to listen to a story that you know is incorrect especially if your parent’s version hurts your image or someone else’s. Allow for the mixed up version or “untruth”. Experts tell us not to correct them and say “Aunt is no longer alive.” That only heightens the person’s anguish – he is already confused and now he feels that you are threatening his world (which is a world of frustration). Allow the Beatles to inspire you...”Let It Be, Let It Be.” Just breathe. (Okay, another pop song.)

Many persons with Alzheimer’s often repeat over and over “I want to go home.” It doesn’t matter if the individual is at home, or is in a care facility, or a hospital, or staying with a loved one.

When your loved one says these five words, it breaks your heart. But, apparently this is a common refrain of individuals with Alzheimer’s disease – a common preoccupation – “I want to go home.” It signals a person’s stress, insecurity and anxiousness.

There is no point in explaining to the person that they **are** in their home. I believe it is important not to address the words or content but to address the state of the person’s mind. Instead, offer comfort and reassurance.

- Offer reassurance
- Sit them down and offer them a warm blanket
- Play music

- Offer them a cup of tea or hot chocolate
- Sit and hold their hand
- Distract them – tell them a story about the past or pull out wedding albums and look through them together

I read on one website that you can always reassure the person and tell him “Yes, let’s go home. But first, let’s sit and have a cup of tea.” Sometimes the distraction is enough. (My sister and I have used this technique with both parents for years!)

Similarly, sometimes the same techniques (distraction and diversions) help soothe the individual who wants to go to work.

- Give them a job to do. For example, sorting through a basket of laundry, fold and put the laundry away.
- Allow the individual to do the task at his own level of competence – don’t be a control freak if the laundry isn’t folded perfectly, or if the laundry is put into the wrong dresser drawer.
- When the laundry is returned to my mother’s room, my mother helps me put the items away. We also exchange the wire hangers and replace them with plastic ones and re-hang her items of clothing. This simple activity gives my mother a sense of accomplishment. (She took great pride and care in her home.)

My own father often would begin to get agitated around six pm or shortly after dinner. He would point to the ceiling over and over. My mother would be so frustrated wondering what he wanted. We learned that he wanted to go to bed early. He was tired at that time and was looking for the stairs to go up to bed. Pointing upwards was his signal. (I find it interesting that he didn’t know enough to look for the stairs leading up to the second floor...but that he knew that the ceiling was up and that above the ceiling was where the second floor was located!)

Symptom: Memory Loss and Confusion

Memory loss and confusion are caused by progressive damage to the brain cells and certain circumstances and events can worsen the loss. Even a change in routine, can worsen the symptoms.

There are a number of signs of memory loss and confusion and I have listed a number of them in Chapter Nine – “List of Signs that tell you when to know parent/loved one should not be left alone” because many of the signs of memory loss are signs that alert us that our parent/loved one needs more support.

But when you are caring for your parent and living day to day with your parent, you will need to respond in a loving, accepting manner:

- Stay calm
- Try not to re-act to their confusion and become emotional
- Gently say your parent's name and respond to the confusion (a brief explanation)
- Reassure your parent that all is well
- Offer suggestions to the confusion: "I'm your daughter, Marilyn, Dad. You usually call me Mal." Or, "It's snowing outside. We'll need a warmer coat."
- Jog memory with thoughtful reminders. Assemble items before confusion gets worse. For example: If your parent is looking for a lost item in an inappropriate location, go and get similar items (or the actual item) and assemble them on a table. "Dad, here is your wallet and let's look inside now and see if your money is in it?" Don't chastise him for looking for his wallet in the kitchen cupboard or in the bathroom.
- If individual is talking about the past, realize that there is no point in you arguing that event happened many years ago.
- Don't take it personally – If your father doesn't recognize you, gently state your name and tell him that you are his daughter/son. (Recognize that your sadness and grief in moments like these are natural.)

When our mother is confused about facts, my sister and I often repeat her story (but with the correct facts) and pretend that is how she told us the story. Since we have not actually corrected her, just repeated the correct story as if she told it correctly the first time – she often nods and says "Yes, of course, that is what I just said." (Even though she clearly did not!)

When she is confused about my father (now deceased) and tells us that he is upsetting her (which is a frequent theme), we often laugh and say something equally silly. For example, my sister often says "Well, since dad died a couple of years ago, he must have had quite the journey to visit you." My mother stops and becomes quite still and then laughs aloud. And then my sister will suggest a pleasant activity. Obviously, these responses work for us; others might need to find a different response. And let me remind the reader that some days these tactics work and on other days, these same tactics do not work. Go with the flow!

Caregiver Tip: Go for a walk. Whenever you or your parent/loved one is tired or feeling overwhelmed...do something that you both enjoy. (Remember when we read a favourite story to our children to allow them "quiet time" to settle down after a "challenging" day; the person with Alzheimer's disease, or any dementia-related disease, needs "quiet time" also. Find the activity that gives you peace. For our family, peace is in nature, gardens, sitting outside, long walks, strolls in the park – if there is a tree or shrub nearby, count us in! Birds? They are a must! Butterflies? Bonus!)

Symptom: Aggression

Unfortunately, anger and aggression often lead to the caregiver's inability to cope; thus, the individual with Alzheimer's is moved to a long-term care facility. It's so imperative that the caregiver gets support and information about the underlying issues that lead an individual to these unwanted symptoms: Does the person feel threatened? Has something changed in the environment? Is the person in pain? Is the person thirsty or hungry? Sometimes, the person with Alzheimer's is so frustrated that he is not being understood (yes, he is aware that others around him are not understanding him) and this awareness of his "not being understood" (and his loss of control) leads to his venting his frustration – hence, aggression or anger.

Caregiver Tip: Above all, identify if your parent is in pain or if the symptoms are caused by his/her medications. Make a doctor's appointment and eliminate that worry.

If we can determine **what triggers the aggression**, then we can make some changes – for example, if the person with Alzheimer's becomes aggressive or angry while in the kitchen, take some time and look around.

You could hang some signs to label items or cupboards, or add visible notes and tape to the fridge. Put a "STOP" sign on door to prevent your loved one from attempting to leave the house. Sometimes (not always), this is enough of a deterrent to prevent the individual's attempts to leave and prevents a potential confrontation with him/her.

Do you remember the account of the personal support worker that diverted (or distracted) the angry resident who had left the building? The PSW had defused a potential angry encounter.

Try a similar diversionary tactic with your parent. For example: Individual is in the kitchen and becoming aggressive – calmly and quietly call out his/her name; perhaps point out his favourite foods and calmly state "I see that you must be hungry since we are in the kitchen. Would you like me to show you some of the foods that are in the fridge? Were you going to prepare yourself a snack? Would you like to help me make a sandwich? Try to determine what has triggered the outburst and then, try to defuse it with a diversion, that is, a snack. (And obviously, please don't inundate your loved one with all of those questions. Choose one question and wait for his reaction.)

If all else fails, leave the room for a few seconds. Count to ten and then return. Sometimes a few short seconds can defuse the situation. (And perhaps, just perhaps, your loved one likes to cook and simply is sad that he no longer can.)

Try calm and soothing words, perhaps a catch phrase that has worked in the past. Never argue or allow yourself to get angry...that does not work! (It might even scare him.)

And try not to find yourself “reasoning” with your loved one. I know for a fact (because that was my “default” response) that reasoning does not work – it only confuses the individual with Alzheimer’s. And reasoning with someone who can no longer reason leads to mounting frustration. The next time when you begin to reason (and the individual doesn’t understand) notice how you begin to feel stress. Change your response. Take it from me. The “reason” button does not work!

To recap, aggression or anger is best prevented in the first place.

- Identify the triggers and then eliminate them as best you can.
- Routine is absolutely necessary.
- Eliminate noises, frenetic activity, clutter; turn the TV off
- Prevent surprises/ or changes.
- Use compassion when you encounter a person with Alzheimer’s or engage in a conversation.
- Stay calm and reasonable. (Use your quiet voice.)
- Initiate a calming activity that usually soothes the individual
- Try ignoring, distracting, and diverting their attention.
- Don’t bully or use controlling tactics – that exacerbates the problem
- Take time out...not the individual, YOU! Care for yourself.

And lastly, here are a few proven distractions that work for some caregivers:

- Music
- Pets
- Cup of hot chocolate/tea/ and cookies (take a break together)
- Read a book aloud (or the daily newspaper).
- Go for a walk in the garden.
- Go for a walk around the block. Spend time outdoors.
- Time out. You, that is. Find someone who will allow you to take a breather occasionally. Ensure that you have breaks throughout the week to allow you to rest, relax, and re-nourish your spirit.

Learn to let go of your need for control – your need to have your loved one follow your routine and your schedule, your meal menu, etc. Sometimes we become control freaks and we are so regimented in all that we do; perhaps that, in itself, is a trigger. (Who knows?)

Symptom: Agitation

Okay, everything that I just mentioned in the above section, “Aggression” relates to the symptom of agitation. Agitation, irritation, anger and aggression are often due to similar causes: any change in the environment which frightens the person with Alzheimer’s (because the individual is more confused in unfamiliar surroundings, or in a cluttered area, or with new people, or what I call the “drama” that some families perpetuate.) Changes in the routine or schedule can cause agitation; misunderstandings due to hearing loss or “misinterpretations”; and lastly, agitation is often caused by pain, fatigue, and over-stimulation. Fear is the true cause – fear resides in the person with Alzheimer’s as he has lost control over nearly every facet of his life.

My mother fights against the residence that she is in every day – she nearly always responds with agitation and anger when she is confronted. She sees many requests for normal daily activities as reminders that she needs support. The simple task of bathing can elicit her frustrations. Simply put, she is rebelling against her reality. Her frustration with her circumstances (that she is in a residence) leads to agitation and impatience with her carers – she will complain, tell wild stories, push them away, and refuse any requests. To say she is “difficult” is not completely accurate. But when she is in this state, I find that I have a deeper compassion for her – I try to understand how her fear is ruling her emotions.

As a caregiver, how do we respond to agitation?

- Stay calm and talk quietly to the individual.
- Open the curtains and allow light into the room. Comment on the beauty of the day. (That’s a diversion that often works for me.)
- Turn the TV off, and ensure the surroundings are calm and peaceful.
- Read the person’s face and body language – ascertain if he/she is in pain, uncomfortable, needs to toilet, room too hot, too cold, etc.
- Go with the flow (unless person is unsafe).
- Allow your parent some dignity (if individual refuses a bath, acquiesce; bathe tomorrow).
- Give plenty of assurance.
- Allow individual to voice her/his frustrations. (Just listen!)
- Try to determine what the “real” issue is about (sometimes, the tone of a request to do something can frustrate my mother...the same request in a gentle, calm voice can get a different response).
- Go for a walk outside.
- Have a cup of tea. (Ha! The antidote for everything.)

Caregiver Tip: Always rule out physical pain or reaction to medications. You know what I am going to suggest. Yes! Make a doctor’s appointment.

Symptom: Irritability

Irritability is not based in actual memory loss (it's not a cognitive symptom), but in the inability to control their emotions and the frustrations that well up within themselves. Irritability becomes a factor because the person with Alzheimer's lacks the insight of why caregiver is trying to control them, and it is this misunderstanding that leads to many symptoms, including irritability. (Many sites differentiated between irritability, agitation, and anger. I believe that most caregivers won't care what the symptom is called...only that some compassion and understanding (on the caregiver's part) will be needed to deal with these symptoms.)

Therefore, caregivers need to recognize triggers that set off irritation.

- Encourage your loved ones to do activities that they like and are successful at, as opposed to cajoling them into activities that they do not want to do.
- Too much stimulation or too little stimulation (when a person with Alzheimer's is in sensory overload, he/she becomes very resistant to any requests).
- Loud, bossy behaviour will send my mother up the wall – she will resist anything that a caregiver suggests if the caregiver is not calm and patient.
- Persons with Alzheimer's will resist activities that are fearful to them – their response is often irritation or aggression. Once a caregiver realizes the individual is frightened or fearful, the caregiver can modify their actions. A caregiver can begin to soothe or dispel the fears.
- Individual might be uncomfortable (room temperature), constipated, in pain, tired, bored or have a mild infection (UTI). There is often a reason why someone is irritated or agitated. You will need sleuthing skills.

I have noticed that when my mother becomes irritated with a staff member at her facility that it is always centered on an issue that she doesn't completely understand. For example, she becomes very irritated when staff insists that she puts her night clothes on for bed at an early hour. She insists that she doesn't want to go to bed early, so she resists when they try to dress her for bed. Instead, when she is calmly and quietly told that she can put her nightgown on but that does not mean that she needs to be in bed, then my mother accepts that. Unfortunately, when she isn't told that clearly enough, she panics and gets highly agitated over bedtime routines. On the other hand, my father loved his bed (and sleep!) and looked forward to all naps and bedtime. He was totally compliant when told it was bedtime – too bad he didn't stay in bed (but that's another issue – night wanderings!)

I have found that the easiest and the fastest way to my mother's compliance on any issue is to merely ask her what she wants. Now, there's a novel thought. Too bad I didn't learn this lesson early on the journey, but alas, no.

Now I am not suggesting that we give in to her demands because many of them are not reasonable: “I would like my car keys so that I may drive myself home,” “I would like to move into an apartment and live alone,” or “I can walk without support so please take your hands off me.” And although she is in a wheelchair, she often tells me to put her coat on because “I would like to walk down the street and catch a bus to another apartment.”

No, I am suggesting that when we seem to concede a point or give in, we allow the person some dignity. We can always say yes and leave (without actually fulfilling the demand). Many of the personal support workers use this strategy: “No, of course you don’t need to take a bath today.” (Knowing full well that it isn’t bath day, the personal support worker allows the resident to have control.)

Caregiver Tip: Irritation is often caused when the person with Alzheimer’s feels that everyone is controlling them. (This is true, caregivers are in control.) Have compassion and allow your loved one some dignity and yes, some control...give in to them when safety and health is not an issue. Does it really matter if your parent/loved one wants to dress a certain way or eat or not eat a certain food? My mother often makes an outrageous demand and both my sister and I agree and say, “Yes, let’s do that; not today, but tomorrow.”

Symptom: Wandering

According to the Web, six out of ten patients with Alzheimer’s disease will wander.

Sometimes, the symptom “wandering” is one of the first “tangible” signs that our parent/loved one is ill. I have heard many stories of adult children that never realized that their parents had a dementia-related disease until the parent became lost or confused outside of the home. Many times they found out through a neighbour or an apartment building’s super or caretaker. For the person with a dementia, the person often becomes confused about their surroundings or environment. My father once asked my mother “Where are we?” when they were standing in their local grocery store. Other times, he had asked me “Where is the bathroom?” while standing two feet away from it.

Some individuals with Alzheimer’s go outside and are immediately confused – the newer environment triggers confusion, restlessness, agitation and fear. As caregivers, be on the look out for these responses. Gently take their arm, and guide them towards your destination. Give words of reassurance: “We are going home now, Dad.”

There are many tips on reputable sites that remind caregivers to keep the home safe and secure; to create a routine that prevents the need to wander; ensure

basic comfort needs are met – toileting, room temperature, etc.; and use diversions and distractions to prevent the symptom.

Here are some more tips to prevent wandering:

- Camouflage doors and door knobs (Paint them the same colour as the walls) Many long-term care facilities and hospitals use this technique. Some facilities paint a mural on the wall and the door is cleverly disguised.
- Tape a STOP sign on the front and back doors of your home.
- Hide keys, coats and shoes. (Unless the person goes outside without wearing shoes or coat – which is often the case.)
- Use devices that signal if door is opened (simple bell might work or electronic device or alarm). Hang chimes or bells.
- Install bright sensor light at the exterior entrances to your home. Ensure that the light is bright enough that when triggered, you are alerted that the person with Alzheimer's has left.
- Tell your neighbours of the person's tendency to wander.

If your parent/loved one does wander and does get lost:

- You'll need a list of telephone contacts of people to call for help, including neighbours, friends, and police.
- Contact the Alzheimer's Society and ask for suggestions.
- Keep an updated photo ready (and medical information) for police.
- Keep a list of places where the person may wander. (Do this ahead of time at the first sign of symptom.)
- Provide the person with ID jewellery.
- Provide a MedicAlert bracelet.
- Provide the person with a GPS tracking device.
- If you cannot locate your loved one, call 911.

Thankfully, my father never attempted to leave the home...he was too frightened of the outdoors, but he did wander throughout the home during the middle of the night. When my dad would begin to wander throughout the night, my mother would get up in the night, and just sit in a chair and watch him. She learned very early in his disease that confronting him and trying to cajole him back into bed would not be successful. When I stayed the night, I followed my mother's behaviour. I helped my father down the stairs (since he would attempt the stairs whether anyone helped him or not) and then he would just wander from room to room, touching items, stopping, and then repeating his actions over again. I sat down in a chair and dozed on and off. Surprisingly, when he was ready to return to bed, I would sense the change in his movements and become fully awake and alert. Then, I would help him up the stairs and back into his bed. I learned this technique from my mother. She said it was her attempt to just "go with the flow."

Caregiver Tip: If your parent is wandering, learn to “read” the behaviour and routines...what is it he is looking for? Is it the bathroom? (Perhaps he begins to wander immediately after dinner...he might need to use the washroom.) When my father “wandered” throughout the night, my mother astutely told us that he was locking up the house (touching the door locks), turning off lights, and ensuring that the stove was turned off – all of which was his routine for many years previous to his illness.

Symptom: Sundowning

Sundowning is a term that describes the state of confusion that occurs at the end of the day as the sun goes down. Persons with Alzheimer’s disease and other dementias might seem normal throughout the day and then as the evening progresses, they might exhibit restlessness, agitation, wandering, or complete confusion. Or, an individual might see hallucinations or become quite paranoid and difficult to handle.

My father exhibited confusion during the day and not as much at the end of the day – the complete reversal of what is normally found. In fact, my sister and I would disagree about our father’s condition because we observed him at two different times of the day. She dropped in to help our mother look after him after work at dinner time; I dropped in during early morning and stayed a good part of the day until my sister relieved me around five pm. He was confused and stayed in bed most of the day; he needed complete support and aid. Strangely enough, about four pm he would want to come down the stairs for a meal and sit at the dining room table and say a few things. My sister saw him when he was up and talking. For the longest time, she insisted that Dad was able to stay in the home without help. She couldn’t understand my insistence that he was gravely ill! One Saturday afternoon when she was caring for my father while I took my mother out to do errands, she had a first-hand glimpse into his confused state of mind. He had an episode where he crawled around on the floor looking for something which to this day still upsets my sister to even think about.

There are many factors that may lead to sundowning:

- Older people need less sleep
- Not enough exercise throughout the day
- Too much sleep during the day
- Coffee, stimulants
- Poor lighting, increased shadows which cause visuoperceptual difficulties to increase (see Chapter Seven, Symptoms: “Hallucinations”)
- A faulty “internal body clock” – day and night turned around
- Change in surroundings, change in caregivers
- Individual is over-tired and now becomes agitated

Coping Strategies for Sundowning or other sleep issues:

- Install better lighting and night lites
- Ensure safety locks or alarm devices alert when doors are opened
- Limit naps during the day
- Limit snacks before bed
- Prepare dinner to eat early evening, not late hours.
- Ensure individual exercises throughout the day and ensure there are plenty of activities available. Boredom can lead to restlessness.
- Maintain a restful and calming bedtime routine. Speak calmly and quietly to individual; use words of reassurance.
- Eliminate noise, TV, loud music or any changes in routine.
- Try to figure out what it is that causes the symptom and try to make changes to prevent the symptom before it begins.
- Lastly, ensure that your parent's doctor is aware of the symptom. (Ha! You saw that one coming, didn't you?)

Caregiver Tip: If your parent is wandering throughout the night, do not confront or startle him. Ask him what he needs. Don't argue or cajole him. Reassure him. Try to patiently lead him back to bed. If your parent does not want to go to bed, allow him to pace but only under supervision. Experts tell us that sundowning and night restlessness typically do not last past the middle stage of Alzheimer's disease.

It has been suggested on many websites that if a person with Alzheimer's is in a long-term care facility that the staff *change of shift* during the early evening might also contribute to an individual's sundowning. The increased activity of the staff and the change in the daily routine are both factors that heighten the person's sensitivity to changes in his/her environment. (Individuals with Alzheimer's are extremely sensitive to any change.)

Harvard Health Publications published a fascinating article about the effects of better lighting for persons with Alzheimer's disease entitled, "*Bright lights, less dementia?*" Excerpted with permission from Special Health Report: [A Guide to Alzheimer's Disease](#), published by Harvard Health Publications (Issue Date: 2011), Harvard University:

A unique study offers another strategy for improving symptoms of dementia. People who have dementia often have a diminished ability to track or react to day and night transitions. Both light from the environment and the hormone melatonin are necessary for normal circadian rhythm (the 24-hour sleep-wake cycle).

Researchers studied 189 residents in 12 assisted-care facilities, most of whom had dementia. Some residents received doses of bright light between 9 a.m. and 6 p.m., some took supplements of melatonin or placebo pills, and some received

both treatments. A fourth group received no treatment. Almost all of the participants completed at least a year of the study.

People in the facilities with bright daytime lighting appeared to have less progression in their dementia. They had 53% less of a decline in physical function scores, and 5% less decline in memory test scores, compared with the average decline at dimly lit facilities. Patients exposed to bright light were also 19% less likely to develop depression during the time of the study.

People who took melatonin without bright light frequently complained of depression and were more likely to become socially isolated. This suggests that melatonin alone is not useful. However, when melatonin and bright light exposure were combined, depression rates were not higher than expected, and after several months of use, sleeping patterns seemed to improve. There was longer uninterrupted sleep, less frequent episodes in which residents were up out of bed at night, and somewhat less agitated behavior, according to researchers, who reported their findings in JAMA in 2008.

For people with dementia and for their caregivers, the use of bright lights is a simple, safe change. It may be helpful to combine light therapy with melatonin for people who have difficulty getting to sleep or staying asleep. These findings could improve the quality of life for people with dementia and ease strain on those who care for them.

For more information visit: www.health.harvard.edu

Note: Harvard Health Publications does not endorse any products or medical procedures.

These kinds of studies about Alzheimer's disease and other dementias are not only fascinating, but they give us hope that other strategies will be discovered and support the treatments for persons with Alzheimer's (and caregivers) in the future.

Symptom: Sleeping Too Much

For my father, the main part of his day was spent in the bedroom. Since he often was restless and wandered through the night, he slept a lot during the day. If at all possible, try to change that – if an individual sleeps less during the day, it is hoped that they will tire during the evening and sleep better throughout the night. At least, that is the goal. In our case, we lost the battle. As a stubborn man, my father would nap consistently whether or not we discouraged it. We moved an armchair into the small bedroom and replaced some of his clothing in the dresser with easy to slip on clothing. A television might have been a nice addition, but my father had stopped watching television very early in his illness. Since he had a progressive eye disease called macular degeneration and was almost blind, books and magazines were no longer enjoyed. Most of the time we either played

CD's or we just sat in the armchair and talked to him. Rarely did he respond to us, although he occasionally made a funny quip or two which would always delight us and the glimpse of what our dad used to be like would send us laughing and crying simultaneously. In spite of how bleak this sounds, both my sister and I still talk about how peaceful and serene the room felt and that we were happy and content just to sit with him. (He might not have responded to us, but he was always attentive.)

Many studies seem to show that Alzheimer's disease affects the sleeping cycles of patients: circadian rhythms - daily cycling of body temperature, sleep, wakefulness, and metabolism - are sometimes disrupted in older adults and some evidence suggests that these disruptions may be worse in persons with Alzheimer's, and other dementia-related diseases. Hence, our loved ones have disrupted sleep patterns: sometimes the days and nights are turned around and sometimes individuals sleep more often throughout the day and sleep for short intervals only during the night. For a caregiver, this is one of the most difficult symptoms to handle because as we all can imagine, if your loved one does not sleep – you will not sleep either. Unfortunately, caregivers who are not able to sleep throughout the night, will burn out sooner, rather than later.

In my humble opinion, it is probably one of the leading factors in the decision to have a loved one go to a long-term care facility – caregivers just cannot handle the daily challenges when exhausted and worn out. (Please do not feel ashamed that you no longer can handle the demands of caring for someone after a long length of time – we are all human and we do not have unlimited resources of health and wellness. We must be aware of when our bodies and our minds are telling us..."it's time...I have nothing left.")

Symptom: Depression

Science is not clear what the relationship is between Alzheimer's disease and depression. The symptoms are very similar so it is important that if your loved one exhibits signs of depression that you visit the doctor.

Typically individuals with Alzheimer's exhibit depression in the early onset of disease and the middle stage only.

Medications can help someone who is living with depression and enhance their quality of life; medications can help a person with Alzheimer's deal with the diagnosis of Alzheimer's disease in the earlier stages.

When my father died, my mother exhibited many signs of depression which obviously my sister and I attributed to his death. In retrospect, the signs of depression (along with hallucinations and some delusions – TV talking to her, etc.) completely fooled my sister and I. We assumed my mother was dealing with my father's death in her own way (albeit unusual.) When she visited the

doctor, she insisted that she was “just tired and worn out.” (Please remember that our aging parents are very good at hiding their symptoms...they can fool anyone in the early stages. My mother fooled us and we had already been down this journey with my father.)

An article written by the Mayo Clinic Staff entitled *Alzheimer's or depression: Could it be both?* <http://www.mayoclinic.com/health/alzheimers/HQ00212> lists some symptoms that are similar for both depression and Alzheimer's disease:

- *Loss of interest in once-enjoyable activities and hobbies*
- *Social withdrawal*
- *Memory problems*
- *Sleeping too much or too little*
- *Impaired concentration*

According to the website <http://www.mayoclinic.com/health/alzheimers/HQ00212>, physicians must rely heavily on caregivers and family members to relay important information about symptoms as persons (with Alzheimer's) have cognitive impairment and are unable to discern or express their symptoms. According to the article *Alzheimer's or depression: Could it be both?*:

“If a person with Alzheimer's displays one of the first two symptoms in this list, along with at least two of the others within a two-week period, he or she may be depressed.”

- *Significantly depressed mood — sad, hopeless, discouraged, tearful*
- *Reduced pleasure in or response to social contacts and usual activities*
- *Social isolation or withdrawal*
- *Eating too much or too little*
- *Sleeping too much or too little*
- *Agitation or lethargy*
- *Irritability*
- *Fatigue or loss of energy*
- *Feelings of worthlessness, hopelessness or inappropriate guilt*
- *Recurrent thoughts of death or suicide*

Source: Mayo Foundation of Medical Education and Research. All rights reserved.

Because the symptoms for depression are somewhat similar to the earlier symptoms of Alzheimer's disease, this is a good opportunity to remind the reader that a physical check-up is imperative – let's not assume that we have the answers about our parents' health. There are too many armchair analysts in the world, in my opinion. (I should know – I am often accused of being one.)

Symptom: Apparitions/Hallucinations (Or Visuoperceptual Difficulties)

Sometimes my father would see “apparitions” or people from the past. Neither my sister nor I was much bothered by these moments of “clarity” or shall I say, “Non-clarity”. On one occasion my mother was napping and I was sitting reading a book while my father lay in his bed. Suddenly he sat up and pointed towards the corner of the bedroom. I did nothing. And although he rarely spoke more than a few words at a time, he said aloud “Well, hello, Jack.” And hey to you, Hooky.” He had a big, goofy grin on his face and I didn’t want to spoil his moment remembering his older brother (dead many years) and his buddy from the Second World War (also deceased). He continued looking towards the dark corner and grinning from ear to ear. It seemed as if he was listening.

Obviously, there was no one there in the room with us so I allowed my dad his few minutes with the ghostly reminders of his past and then I asked him, “Well dad, do you feel better?” He nodded and lay down again.

I told my sister about the unusual event and she just shrugged it off. Apparently she, too, had witnessed him point to the shadows in the room and name people from his past. (He was not on any medications.)

Another afternoon, I was helping him get up out of bed and he stopped and pointed to the doorway. “Three men,” he said quite agitated. “Who? Who?” I inquired. He shook his head. That was the only episode that I felt was a little eerie. Later I told my sister that I wondered if “Death” came with two assistants and that thought had us hysterical. Macabre? Yes. (You have to laugh at this stuff or you will soon be the one in bed seeing shadows and tall figures in doorways yourself! Besides, my dad had a fantastic, wry sense of humour and we both quipped “Geez, he’d have loved these jokes.”)

Strangely enough, after my father died and my mother was slowly showing dementia signs herself my mother began to dread sleep. When we discussed this with her, she confessed to Sue and me that she saw three men in the doorway at night just before she fell asleep. “Oh, no!” we thought. Not the three men again! Nothing would convince her that the three men did not visit her room every night. We tried hanging dream catchers in the window (the natives believe that they catch the spirits that are roaming around). We tried the occasional sleep-over (but let’s face it...we had just spent the last year or two looking after my father. The sleep-over had worn out its luster!). Nothing seemed to allay her fears. Finally I blurted it out to the doctor during her bi-weekly appointment and he felt sorry for her (or me, I’m not sure). He prescribed a few mild sleeping pills and warned her that there would be no repeats! She still occasionally sights the three men in the doorway but those hallucinations have morphed into many others.

Interestingly enough, the “three men” always wore black suits, according to my mother, and one was very tall – almost the height of the doorway. The other two were variant heights but shorter. They wore hats and ties and sounded very nattily attired, but as my sister, Sue, wryly noted to me, “Easy for you to critique them. They are not scaring the hell out of you each night.”

Much later (too late to help us deal with my father’s hallucinations) we did learn that illusions and delusions are quite common symptoms with both Alzheimer’s disease and dementia.

According to, Harold Rubin, MS, ABD, CRC, <http://www.therubins.com/> , *Illusions and Delusions - Part II - Dementia and Delirium*"

“Psychotic features associated with dementia involve altered perceptions, which may include hallucinations, misperceptions and delusions. Hallucinations, when present, are most commonly visual (actually see things that are not there as opposed to thought broadcasting or thought insertion). Typical misperceptions include inability to recognize oneself in a mirror and an inability to distinguish a real person from a TV image. Delusions are most commonly paranoid and relate to the ideas of theft, abandonment or infidelity.”

Further, the author explains, in the article *Illusions and Delusions in the Elderly – Part I:*

“Delusions are commonly seen in conjunction with dementia. Simple delusions of theft and vague suspicions directed at relatives are commonly observed. It usually represents an attempt by the amnesic patient to explain the loss of articles that have been misplaced. Unable to remember losing the object, the demented patient imagines an explanation involving theft by someone close at hand, often a caregiver. Many of the delusions that evolve from the visual experience of imaginary visitation can be viewed as an attempt to make sense out of bizarre. This input nonetheless seems real to the patient (if there are strangers in the house, they must be there for a purpose).”

(Please note that Harold Rubin reminds us that he is not an expert in any of the issues reflected on their web pages, but rather investigators who report on current scholarly results. I quote his website because I found his information enlightening to me as a caregiver...I hope that it offers some insight and information to the reader if they (like me) stressed over the symptom of hallucinations as much as I did.)

My father’s illness advanced rapidly and his hallucinations seemed to go away after a few months. By the time he was in a long-term care residence, his

hallucinations disappeared totally. (Now we understand that hallucinations and delusions are usually symptomatic of early and moderate stages of Alzheimer's disease, and not the later or more advanced stages.)

In contrast, my mother's hallucinations come and go, and paranoia has set in. When my father died, her hallucinations (which now I realize are not always hallucinations) progressed rapidly. Along with the three men in the doorway, she also complained of boys in trees, people in her backyard and that the people in the television set were talking back to her or worse, laughing at her. The final blow was when she marched me outdoors into her backyard and proceeded to point to the donkey! I spent many fruitless hours trying to reason with her; later, I learned that I reacted in the worse possible way! (That is why I am writing this e-book....because when you know better, you do better.)

When I look back at my conversations with her during the 2011 curling season (yes, we are both fans of curling), I actually cringe at my behaviour. Many a day I would insist that the curlers were not looking at her, nor talking to her. She would acquiesce in agreement with my logic. But to her, the curlers were communicating with her and the subject came up time and time again.

Now I have learned better...those hallucinations are not necessarily "hallucinations" but instead, she is probably experiencing visuoperceptual difficulties. That is, many patients with dementia have visual problems due to normal aging, macular degeneration and/or damage to the visual system (perhaps because of the progressive disease).

Visual "mistakes" are made since often the patient's disease (the deterioration of the brain cells) prevents them from seeing something and then interpreting it correctly (and many times, they do not name it correctly because of their language deficiencies).

I have learned to differentiate between misperceptions or visual mistakes that my mother makes – my mother "sees" a person sitting in the (unoccupied) chair (but there is a winter coat on the chair) – and a true hallucination (seeing something that is not there) – my father sitting beside her bed (no one is sitting beside her bed, there is no chair, and my father died a couple of years ago). Most of us, like me, make assumptions about the disease and we are just wrong!

Caregiver Tip: Discern whether your parent/loved one is seeing something that is clearly not there or whether they have insight that the hallucination could not possibly be real. For example, my friend's father was on medication during a hospital stay and saw "bugs crawling on the ceiling." When my friend asked him about the insects, her father replied, "Well, I see them...but how can that be? I think I must be dreaming because surely there are no bugs in this room." My friend consoled her father..."You're right, Dad. It must be the medication." (Our

loved ones with dementia-related diseases are seldom able to make that distinction.)

According to Alzheimer's Society (UK), Fact Sheet 527, *Sight, perception and hallucinations in dementia*, there are many problems that occur between what is *visualized* and what the patient *perceives* as "reality" (Reprinted with permission from Alzheimer's Society (UK). (Last Reviewed: October 2012). Fact Sheet 527, *Sight, perception and hallucinations in dementia*. Accessed September, 2013, from: <http://www.alzheimers.org.uk/factsheets>):

- **Illusions** – *what the person sees is a 'distortion of reality'. This may result from a particular characteristic of the object, such as its surface being shiny or it being the same colour as the wall behind. An example might be seeing a face in a patterned curtain.*
- **Misperceptions** – *what the person sees is a 'best guess' at the inaccurate or distorted information the brain has received from the eyes. This is usually the result of damage to the visual system due to diseases such as glaucoma. For example, a shadow on the carpet could be mistaken for a hole in the floor.*
- **Misidentifications** – *damage to specific parts of the brain can lead to problems identifying objects and people. For example, distinguishing between a son, husband or brother may become difficult.*

Hallucinations do occur more often in patients with Lewy Body Disease and those with Parkinson's, but Alzheimer patients also do exhibit some hallucinations.

Delusions also appear to be more common in patients with Lewy Body Disease or Parkinson's related dementia; up to 70% of Lewy Body Disease patients have delusions.

Ensure that hallucinations and delusions (and paranoia) are reported to the physician as the symptoms could be due to illness (stroke), medications and/or eye disease. It goes without saying that an eye check-up should be made for the patient and ensure that eye glasses are of a recent prescription and cleaned on a regular basis.

Here are a few tips that I have learned to use while caring for my father and my mother:

- Avoid talking or laughing or whispering while near the person with Alzheimer's – if that does occur, then ensure that you explain clearly to your parent the exact nature of the discussion (otherwise, your parent

- assumes/deludes herself/imagines/misperceives a story or complete fabrication).
- No loud, violent TV.
 - Don't argue in front of the person with Alzheimer's.
 - Do not have loud conversations close by – my mother misinterprets most conversations and events that occur in the hallway outside her door.
 - Help them look for missing items that they insist are lost or stolen.
 - Try to have duplicates of the lost items (for example, extra wallet, loose coins, etc.).
 - Don't argue with your parent or try to reason with them.
 - Just listen to the “story” and try to eliminate the items that have been “misidentified.”
 - Increase the lighting in the room.
 - De-clutter the room.
 - Hang clothing in closets – a draped coat is always misidentified as a person. Also, pillows or cushions are often misidentified.
 - Go with the flow – sometimes you have to distract them as nothing else comforts them.
 - Watch the person's movements and adapt – Eg. my mother slowly moves her teacup forwards and I realize that she is going to misjudge the table. I move the table towards her or I gently take the teacup from her hand.
 - Place an item into the person's hand. Otherwise, they will misjudge the distance and not retrieve it.
 - Say aloud what the item or object is before you place it in front of them.
 - Identify people who enter the room (Oh, look, Mom. Here's your good friend, Margaret.)

For more informative facts about visuoperceptual difficulties and hallucinations, please visit the website <http://www.alzheimers.org.uk/factsheets> and check out the many topics relating to dementia/Alzheimer's disease. (There are many fact sheets explaining different issues about Alzheimer's disease and I think it is a true find to anyone who wants to understand the complexities of this disease.)

I think the above-mentioned website does a great job of describing why an individual with Alzheimer's sees things that aren't there. To recap, objects are visually seen but the impaired brain cells (and damage to the visual system) misinterpret what the objects are. Hence, the individual will insist that a draped sweater over a chair is a scary animal; a housecoat hanging on a hook becomes a really tall, frightening person; trees that move in the breeze become children in the trees. A mirror or shiny object, even a glass vase that reflects light in the room, will conjure up a frightening scene or “dancing people on the ceiling.” What we have labeled “hallucinations” are actually visuoperceptual difficulties – clearly an error on our part as caregivers. Hallucinations are rarer than

visuoperceptual difficulties but do occur in many types of dementia, most specifically Lewy Bodies Dementia.

In a similar fashion, the person with Alzheimer's will misunderstand their own conversations with family members or staff and even misinterpret and remember "overheard" conversations or snippets of conversations incorrectly. Many a visit with my mother includes a bizarre re-telling of a story that I know has an element of truth in it somewhere, but mostly based on erroneous facts and misunderstandings. Many residents will overhear staff talking in the hallways, misinterpret the gist of the conversation and later will relate a wild story to a family member. My mother insisted that "she was going to move to another home because the sergeant said so." Nothing we said could allay her fears or comfort her. Weeks later I learned that there was a new director at the nursing home and that the director had introduced herself to many of the residents. My mother's impaired judgment led her to believe that the director was the "sergeant" and that some of the goals that the director stated were misinterpreted to mean "changes." Because my mother cannot discern truth from fiction sometimes, she insisted that the sergeant was moving her to another location.

So, to recap...persons with Alzheimer's disease do not see and interpret things the same way that we do...their brains take in and mis-interpret visual information causing them to *misjudge* distances, dimensions, depths, colours, items, events, and circumstances.

I hope this information about visual perceptual difficulties helps you not only understand their actions and reactions to events and circumstances, but also helps you cope with the person's behaviour. Once we understand that a person with Alzheimer's cannot walk into a dark room without some fear, then we can adjust our own behaviours and reactions. For instance, we now know to ensure lighting is better – add light bulbs with higher wattage. Ensure that clothing is stored in a closet, out of the way, not draped over a chair. De-clutter the rooms, especially the person's bedroom. Remove mirrors or other "high glare" items. If an individual is frightened of an area of a room, walk over to that area and touch items. Explain what they are. If your loved one is still frightened, just remove the item.

More tips to help a person with Alzheimer's who has visuoperceptual difficulties:

- As a caregiver, learn to adjust to the person's walking difficulties. Anticipate that shiny floors will appear wet or look like water to the person with Alzheimer's. Grasp the person's arm and ensure you are supporting him across the floor.
- Similarly, the lines or delineation from carpet to flooring will confuse them. Many hesitate at doorways for this reason. Continue to support your parent and remind him that the floor has transitioned from carpet to floor.

- Staircases will also become a factor. Prompt your parent to hold the railing and prompt him each step. If there are two steps, you might offer that information. For example, “We are approaching steps, Dad. There are two of them. Take a moment to stop and look at them before you attempt to step up.”
- Patterned floors, ditto! (Patterned floors are confusing and completely frighten a person with Alzheimer’s!)
- Trees or shrubs that move in the breeze – become moving people!
- Roof-top chimneys or stacks - are seen as “people” (my mother always points to people atop roofs and often laments that parents should not allow their children to climb houses)
- Mirrors are particularly frightening to persons with visuo-perceptual problems. Sometimes, my mother would see herself in the mirror and turn to me and say “I can’t go in there. Someone is in the room” I would have to remind her that the person is she! (Usually I laughed when I said it...she would think about what I just said...then see that I was smiling...then she would grin and laugh!)

Visuo-perceptual difficulties also account for why it is so difficult to “sit” a person who has Alzheimer’s – they are often resistant to sit. The reason is that the individual cannot see what they are sitting down upon. To our parent, he/she sees or perceives a hole that is just too dark or deep. Even the distance to the toilet seems far, far away to them. Now that you know this you can offer your arm as support and you can *slow down*. Take a tip from the personal care workers. Watch them when they transfer your loved one. They offer support (plant themselves firmly first), they offer words of assurance, and calmly and slowly help the individual. They do not rush the individual. Speed is *not* the name of the game. Safety is!

My mother often calls the hallway outside of her room – the “mall.” She would often refer to another resident’s room down the hallway as “down the street.” This could be deemed “language difficulties” but I believe that she perceives a long area of space and, therefore, interprets it as a street. (We live in houses that are lined on a street; the residents’ rooms are lined in a corridor. Similar?)

I have spent a great deal of time on the symptom “Hallucinations and Paranoia” because I believe that it is a symptom that troubles the family a great deal – for our family, we struggled whenever my mother spoke of boys in the backyard with guns, or my father and his friends coming into her room and raiding her closet (my father is now deceased). My guess is that other adult children struggle with the same issues. It is completely natural for us to feel sadness, shock and grief when our loved ones make such accusations. And, these allegations and accusations trouble us – we are not only shocked and saddened to hear these wild statements, but we are totally overwhelmed in how to deal with them. When they first occur, we reason with our parents (Now mother, you could not have seen a donkey...here let’s go outside and I’ll show you proof.).

With more information and understanding, I have learned to accept this as one more thing to have compassion for the person who has a dementia.

Why do hallucinations disappear by the end of the second (moderate) stage of Alzheimer's disease?

During the first and second stage, apparitions and hallucinations are often a prominent phenomenon but seem to disappear near the end of the moderate to advanced stage. Why is this? Sadly, because the person's cognitive abilities have further diminished – the cortex is now severely compromised. With physical abilities on a decline and mental capabilities declining, the individual now enters the advanced stage of Alzheimer's disease. Some caregivers have expressed that their parent, once difficult to manage, is now compliant and easier to look after. That is only because the individual is more bed-ridden and less inclined to converse or take part in daily activities. I have read that some caregivers (especially those who care for their spouses) are quite saddened when the hallucinations stop – they are very aware now that the disease is worsening.

Chapter Eight

Self-Care/Caregiver Fatigue

If you want to take care of others, then first, you must take care of yourself. Every therapist or expert (or armchair analyst) will attest to that.

If you ever wondered why a caregiver is so tired and distraught, allow me to take a moment to list the number of challenges/chores/tasks that a caregiver meets on a daily basis.

The person with Alzheimer's must be assisted in getting up out of bed, and then helped in toileting, bathing, dressing and feeding. Sometimes the individual is either in a wheelchair or uses a walker or cane so heavy lifting or supporting the individual is necessary many times throughout the day (and night).

Throughout the night the individual will need assistance in toileting and sometimes the bed linens will need to be stripped and laundered. (And if your parent has incontinence, pajamas will need to be changed, too.)

If your parent has the night and day turned round (which is common), then the caregiver will be awakened throughout the night and on "high alert" to listen for the night wanderings. Unfortunately, the individual is often ornery at this time and more difficult. Ultimately this translates into less sleep for everyone.

During the day, meals, laundry, and housekeeping will need to be attended to and some of those responsibilities will need to be done more than a few times a day – meals, snacks, drinks, toileting, personal care; repeat.

Now if that isn't a big enough challenge, the individual will still need to have regular medical check-ups, blood work or hospital appointments, and prescription pick-up. (If you can, have your pharmacy deliver prescriptions.) In addition, banking and financial matters will need to be taken care of, along with house maintenance, garden work and more. As a caregiver, those responsibilities will probably fall on your shoulders. (Many caregivers that I have met over the last few years lament that they receive little help from other family members.)

Last, but not least, a common symptom of Alzheimer's disease is forgetfulness/memory loss/confusion which means that most of the daily tasks will need to be done with cajoling and subtle manipulation so that the individual will oblige. Many will be stubborn, angry, aggressive and demanding at times as their world is changing too quickly for them to understand and their loss of control will terrify them. Many stubborn acts or willful acts are the sole result of their fear – this is the only way for them to express their loss of control. It sounds bizarre

but if we understand why they are acting the way they are, then perhaps we can have more compassion, kindness and understanding.

Oh, and did I mention, that the list of challenges or daily chores will all be completed while juggling your other life – you do still have one, don't you? Your own family, work and life needs will still matter and finding a balance will be the highest priority now.

Caregiver fatigue will involve many symptoms: fatigue, sleep deprivation, anxiety, and stress. There's good news and bad news now. The good news is that "when we know better, we do better" – and that's what this ebook is all about. My heartfelt intent is that you have the knowledge and the facts about this disease and about caregiving and the importance of self-care. The bad news is that if you ignore these symptoms and don't find a balance in your life, your health may suffer. (Statistics do show that a high percentage of caregivers burn out.)

Resentment, anger and guilt are all by-products of caregiving. The terrible trio: *resentment, anger and guilt*. Learn to recognize these emotions within you and give them attention. It is natural and human for all of us to feel these emotions when we are caregiving on a long-term basis; what is not natural (or helpful) is to ignore, deny or refuse to accept them.

I have since learned to ask myself questions: "What am I feeling? Where did that feeling come from?" Then, I allow myself to feel the emotion – all the time acknowledging the emotion and the reasons for the emotion. I remind myself "It's okay that you feel anger. Just ride it out." And soon, the emotion will lessen. Yes, it takes practice but it is the healthy way to accept ourselves for who we are. We're not perfect; we are whole. I am not justifying being angry – I am allowing that at times we may feel anger and that's okay. My acceptance of all my emotions allows me to let go of them *before* they grow or cause harm.

Our anger or resentment is usually a red flag to remind us that we are off balance – that we need to pay attention to an issue that hasn't yet been accepted or resolved. For instance, my anger was due to watching my father become someone different – I was angry with the circumstances. And, I missed the "old dad" of years ago. So instead of recognizing my sadness and accepting the new reality, I just continued to feel anger, resentment and stress. I also recognize that my resentment came from the overwhelming feeling that I no longer had "my" life – that it was out of control. I was scared that I would be spending my retirement years looking after parents for the rest of my life. All of these emotions are natural when we are caregiving; if I had sat still and recognized and accepted my feelings and emotions, I would have realized that I was over-tired and needed more support. (And that in spite of the demands of caring for my parents, I could still enjoy a happy and joy-filled life.)

One of the biggest myths or misunderstandings about caregiver's stress and fatigue is that the stress stems from the actual "caregiving." (Day to day care leads to fatigue, yes.) I agree that the stress comes from the difficulties and challenges of caregiving and **not having enough information or support**. But most of all, I believe that the caregiver just doesn't take care of her/him self while caring for the patient. For some reason, many of us (I have my hand up; in fact, I'm waving it like an obsessed fan.) ignore our sleep deprivation, our fatigue and our health issues while looking after someone. I read online that a caregiver quipped "I'm too tired to look after myself! That just takes time and effort that we don't have."

But if we could at least stop and recognize that we are caregiver fatigued (I think that is an actual term) then and only then, can we stop and begin to address the symptoms before they become health issues.

Caregivers need more information and they need more support. That's really why I am writing this ebook because I didn't have any information when my family went through this challenge. We were tired and confused **most** of the time and felt emotionally exhausted **all** of the time. The day my mother gave her permission to allow CCAC to enter our lives was a day of relief! My sister and I felt like the cavalry had arrived to save us. (I was like a child with my nose at the front door while waiting for their arrival. "CCAC is coming. CCAC is coming.")

When we begin to look after ourselves, we can begin to accept the journey and finally learn to embrace it – that is full acceptance of "what is." Once we learn to accept the situation, we begin to experience a full life again. I say this because I believe that it is the non-acceptance of our reality which hurts us the most. The truth is our loved one is dying and we grieve every day.

We must learn that it's okay to ask for help; that it's okay to ask questions; that it's okay not to have the answers; it's okay to admit guilt and frustration; and it's okay to grieve *before* our loved one has died. We're human. Many of us are not nurses, physicians, personal support workers or of any medical profession; we are from all walks of life and do not know how to do this job. We learn as we go. And many of us (myself at the time) feel like we are not meeting the challenges – we feel like failures (and that is a pretty crummy feeling when we think we have had a pretty good life up until this point). I wish that at some point someone would have told me that it was *normal* to feel this way; that would have made all the difference to me. Instead, I stressed. (My friend (a nurse) reminds me that even if you are in the medical field, you still feel that you're supposed to have all the answers; hence, feelings of guilt and inadequacy prevail.)

Caregiver Tip: I will suggest a wonderful support - Dr. Robert Buckman's book "*I Don't Know What To Say...*" – *How to Help and Support Someone Who Is Dying*. Dr. Buckman reminds us that when a patient and his family learn of a terminal illness (or chronic) illness, that it is normal to experience a wide range of

emotions, and that it is natural to grieve *before* our loved one has died. This is another book that I wished that I had read while my father was ill; alas, I read it a couple of years after he died.

Take up meditation, yoga, T'ai chi, breathing exercises (relaxation) or just go for a walk along the river or in a park. Be close to nature and breathe in fresh air (no matter the weather) – all of which alleviates stress of both the body and the mind. Above all: Love yourself; don't blame yourself or take on guilt for experiencing emotions of resentment or feeling fatigue and burn out. Begin to remind yourself over and over again..."I'm just doing the best that I can. And that's enough."

Accept help – don't become a martyr or play the victim – that's toxic and that toxic feeling feeds the "poor me" or "I hate this job" stage (oh yes, that stage will rear its ugly head at some point – honestly). My intent in writing this ebook is to alleviate and lessen that stage and help you through it.

Accept help – from family, neighbours, friends, physicians, Alzheimer's Society, CCAC, nursing staff, people who smile at you, people in the grocery store who bump their cart into your cart...yes, you want to get to the acceptance stage so that you can welcome and encourage ALL support or offers of assistance. (These offers of support are "gifts" – do not refuse them.)

Learn to take care of yourself by taking more stuff off your plate: hire a cleaner (or pay your niece or next-door neighbour's teenager to clean your house); ask for help with maintenance work, gardening and errands; explore meal alternatives (Meals on Wheels); eliminate unnecessary tasks; free up your calendar and pare unnecessary engagements. In short, simplify your life while you have the responsibility of caregiving. Stop trying to do it all; instead, share the load.

In fact, have you heard of "Share the Care"? Neither had I until I completed two palliative courses. I learned that such a program does exist and exists to do exactly what it says...share the care (of looking after a loved one). Many years ago, communities pulled together, shared their resources and rallied around to support a family in need. Parish or churches would hold gatherings and congregations would offer to bring meals to the family, do errands, cut the lawn, fix the eaves, and so much more. And let's not forget, the ladies of the church would take turns just dropping in to make tea and offer up a serving of comfort and cheer. Not a bad idea, right?

Well, "Share the Care" is a program based on that premise. Organized in 1995, founded by Sheila Warnock and Cappy Capossela, a group of women decided to join together and "share the caregiving" of their terminally-ill friend (Cappy Capossela) – their experiences, knowledge, and know-how are the basis of a model so that other people can form their own groups to care for a loved one who is either elderly, disabled, chronically ill or terminally-ill. The website is

packed with enlightening stories and how-to information. It is worth a visit! And once again, the website is a reminder that caring for a loved one is a supremely challenging job and one that should be shared by many, and not by one alone!

Please take some time and visit this informative website

<http://www.sharethecare.org/index.html>

Peace comes from within. Do not seek it without.” Buddha

Stress De-Busters: Another List (I hope lists do not stress you out.)

- Look for joy in the small things (I relish and am grateful for every little thing now. Learn to pay attention. When we “pay attention to the smallest of details”...we begin to see miracles everywhere.)
- Healthy snacks such as nuts (magnesium), smoothies, raspberries, oranges, blueberries, green tea and oatmeal are a few foods that decrease anxiety (drop the habit of binge eating or drinking)
- Essential oils – lavender, lemons, coconuts - I can just catch a sniff of lemons or coconut oil and I am transported – they are “happy” essential oils
- Sip lemon water throughout the day – lemons are anti-bacterial, and a cleansing agent. Lemon juice lowers blood pressure by strengthening blood capillaries.
- Just call a friend – experts say just a few minutes of “bitching” is enough; don’t dwell too long on your issues or you will only begin to dwell in misery.
- Go for a walk (Exercise)
- Garden – nothing gives me more peace than tending to my garden
- Add a birdbath to your backyard – watch the birds, and smile
- Breathe – just breathe – five seconds in, hold five seconds, breathe out five seconds; repeat
- Be in the present – just sit still. (That’s all. You don’t have to do anything.)
- Flex and release – tighten your muscles and then release them
- Quiet the brain – do breathing exercises; be mindful of the present moment
- Friends – go out and share your feelings
- Humour – Laugh (Find and do things that make you laugh out loud.)
- Take a break, go on a vacation, or relax and rest for an afternoon
- Take a daily nap (even if only for ten minutes)
- Get plenty of sleep (sleep is restorative!)
- Take up yoga (yoga is beneficial to the body’s organs and glands)
- T’ai Chi restores the body’s balance – and it exercises the brain

- Nature – go for a walk by the water, collect autumn leaves, make a snowman – take a lesson and follow the play of a child
- Treat yourself – buy yourself a cookie or a cupcake; visit the library and settle in for a good read; type up a quote that makes you feel good and hang it at your desk or beside your bed (I cut out pictures of blue butterflies from magazines and use them as book marks.)
- Be kind to yourself – reassure yourself (because no one else will say the right thing as much as you!) pat yourself on the back often
- Volunteer (I know what you are thinking “What? Is she crazy? Isn’t caregiving enough?) – think of helping others in any capacity (My husband and I and our friends volunteer for the local jazz festival, a fundraiser for our local organ donors association.) I believe it’s important just to stop thinking of yourself and your “world,” instead, go and live in another’s world. It will change your perceptions and attitudes! Oh, it’s also a lot of fun.
- Lastly, remember that studies now show evidence that long-term stress can be a factor of Alzheimer’s disease. (Yikes: There’s a good reason for all of us to ensure we practice balance in our lives.)

At this present moment, I am writing the Chapter entitled “Self Care” with one eye on the television – the curling trials are on, and curling is one of my passions. (No, not to play the sport. Just to watch on television.) When the program ends, I will go for my daily, long walk along the river. I will practice being present in the moment – I will be grateful for the natural sights: I will look upwards at the geese forming their beautiful “V’s” in the sky as they fly to sunnier climes; I will stop and watch the geese (who can’t afford to fly to sunnier spots) frolic in the river; I will nod and smile at other brave souls, weathering the bitter cold of the winds along the waterfront. I will be “present.”

Self care is an important issue that is particularly close to my heart. I have learned the hard way that giving your all to caring for aging parents is not smart – it’s harmful to your body. Physically, mentally, emotionally and spiritually I always felt drained. My doctor diagnosed my ailments and fatigue due to a compromised endocrine system. To put it in layman’s terms, my body could not turn off the cortisol due to the constant stress. I am not advising caregivers to throw in the towel; not at all. In fact, I hope that caregivers everywhere can learn some helpful tips, ask for help and support and take care of themselves – while they help their loved one stay in the home because that is the ultimate goal of most of us (until it is no longer possible).

Thankfully, I have recovered and feel well-rested and lucky; lucky to have learned some valuable lessons about life, compassion and self care. I had forgotten that compassion and kindness begins at home. It begins with me! We must look after ourselves first, with love and compassion; then, and only then, can we turn to others and look after them.

So, here's my list of important lessons about self-care:

- We cannot take our physical, mental, emotional, and spiritual health for granted.
- That if we do not "honour" our own health, how can we "honour" another's?
- That all (yes, all) of my stress was due to one simple fact: I did not accept my reality.
- The longer we resist (what is happening around us), the longer our suffering will persist.
- Set limits. Learn to say "no."
- Learn to say "yes." Enjoy each moment. We get only one chance at life.
- Enjoy every day (If that is not possible, then stop and feel grateful for ten things before you go to bed. If you cannot think of a gratitude list, then just name one thing: Say, "Thank you. I'm here.") Find joy in the simplest of moments: a hot cup of tea; a sunset; a light rain; the changing sky; children playing; an elderly couple holding hands; spending time with someone you love.)

Simple, right? So simple that I now shake my head. How could I have not understood these lessons? Well, that is something I have also learned along the journey (of life)...all of our challenges can lead to greater knowledge and insight – *if* we choose to accept the lessons. Acceptance in everything as it happens. (You don't have to *like* what happens; just accept it.)

Now I take time to restore my spirits when I feel depleted. I take time-outs and enjoy any activities that I am passionate about. What gives me great happiness may not excite another. But when we completely lose ourselves in any hobby or passion, we will find that sense of contentment and peace, even in the midst of adversity. My sister and I like to dance and we get together with some friends to dance for a couple of hours a week – we feel like kids again. (It's a wonderful feeling – try it, you'll like it.) My husband loves baseball. Some of his baseball team mates will practice hitting balls after the ball season is over. They like to play (I mean, hit balls) until the snow flies. He has said many times over, "Gosh, when I am hitting the balls, I feel like a kid – I just love it."

The point is that we each are different and our hobbies and pastimes will also differ. Try to spend time doing something that you love and makes you feel like you are a kid again. Laughter and hanging out with our pals gives us meaning in life. And it is so important to find meaning in life while you are caregiving; if you can share it with your loved one that will be even more special.

Remember that it is not the destination that is important in life; it's all about the journey. Even when you are faced with a painful journey, look for brief moments of peace, contentment or happiness. And, yes, even laughter. Accept that you

are doing the best that you can and be content with that, alone. That acceptance will transform your life and you will become open – open to life’s lessons.

Mother Theresa said “*God does not command that we do great things. Only little things with great love.*”

During the last few hours when our father was dying, my sister and I stood by the window in his room and happened to see the sun begin to rise. Suddenly, there was a huge noise outside, under his window. We both looked at each other and smiled – dozens and dozens of birds - blue jays, cardinals, sparrows and finches were chirping, as if on cue. We stood fixated at the window as our eyes welled up. We both agreed that we had never felt such love permeate a room.

We were “open” to receiving the love and peace of that moment.

CHAPTER NINE

How long can a person with a dementia-related disease live independently in his/her own home?

I do not know of many adult children who have parents who asked to go to a long-term care facility. It takes a very courageous and strong-willed individual to make that difficult, self-less decision.

Most aging seniors want to live in their own homes until the end of their lives. Wouldn't you? Be honest.

Unfortunately, individuals with dementia-related diseases have impaired cognitive thinking; therefore, logic and reason will not be part of the conversation about this touchy issue. If you and your parents have a plan in place – one that outlines what to do when the aging parent can no longer live alone in his home – then feel blessed and grateful that the difficult decisions will not have to be made by you and your siblings.

If there is no plan or if you and your loved one have waited too long and now the decision is in your hands, how will you know *when* it's time to move your parent into a long-term care facility?

Experts agree that *with support* many individuals in the mild to mild-to-moderate stage of Alzheimer's can live alone. Physical safety is a strong determinant. Is your loved one safe in the home?

Experts tell us that with structure, daily routines and much support from family and outside agencies, yes, living in the home is feasible.

Do neighbours drop in and check on your parent? Are family members close by and available on a daily basis? Are medications properly dispensed? Is there a plan in place for meals, laundry, light house-keeping, home maintenance, and daily errands? Does someone drop in and visit just to talk? Does someone telephone daily to ensure the person is safe and well? Is shopping done by a volunteer? Does someone take your parent to the medical appointments?

All of these tasks can be supported by a volunteer, neighbour or family member. If CCAC is involved, they might send a nurse once a week to follow up on medical issues. A PCW (personal care worker) might drop in two or three times a week to assist in giving a bath or washing the individual's hair. In my limited experience, I have found that CCAC makes a huge impact (they are a change agent) and can ease the fear of leaving your loved one alone in the home.

When both my husband and I were working full-time before my father became ill, my husband's mother fell when she was 90 years old. (She broke her hip.) She

did not want to go to a long-term care facility; instead, my husband and his sister's family ensured that his mother's home was retro-fitted to enable her to stay in the home. After a three month convalescence in a care facility, she returned home – alone. She lived in the home alone for another four years before she died of cancer. The fact that she was able to live alone was remarkable. But she did not exhibit any signs of dementia, only the frailty of aging. My husband and I and my sister-in-law delivered meals daily; my brother-in-law and husband maintained the grass and garden. Home maintenance was also handled by my brother-in-law. Doctor and hospital appointments were handled by my sister-in-law and her husband, too. In short, with the support of neighbours, friends and family, my mother-in-law was able to live in her home until the last few months of her life.

List of Signs that tell you when to know parent/loved one should not be left alone

I have written from a daughter's view of caring for both my father and my mother while they stayed in their own home. After my father died, my mother lived alone in her own home for another two years. My sister, my husband and I shared the responsibilities (my husband did most of the maintenance and yard work). There were many conversations about whether or not my mother should be left alone. Because we were with my father daily for at least three years (even longer if you count the daily meals and check ups) I think our family became more alert and aware of my mother's earlier symptoms of Alzheimer's disease. Unfortunately, after a fall my mother suffered a broken wrist and fractured pelvis and was hospitalized for eleven months.

We had already seen my father's reaction to a long-term care facility (not good), and so we were very cautious when it came time to decide if my mother could be left alone, or needed more care. (We were still dropping in on a daily basis – sometimes up to three times a day.) But at the end of the day, a caregiver or family member has to go on instincts. There are many signs to look for to determine if your parent is coping on their own – be on high-alert at all times.

Our own mother exhibited few of the signs listed below – she kept an immaculate home (I cleaned it, but she followed me around dusting, etc.); dishes were always cleaned and put away; the fridge was filled with the foods that we had bought (I drove her to get groceries once a week); my sister ensured her medications were taken properly (although she often found them on the floor, etc.); she seemed to eat the meals that we brought over or prepared for her. But when I cleaned out her house after she was hospitalized, I realized that the new pots and pans that she bought a couple of years ago were missing. I instinctively knew that she had burnt them and had thrown away the evidence. I also noticed that bills (although paid...by me!) were filed in odd places. Items were in closets

or dresser drawers that just seemed strange. When I realized that she was not coping as well as we had thought, I felt very sad that I had not noticed these signs. Then I realized that she had coped very well, in spite of her progressing disease. Now we are thankful that she had time in her home after my father died. It would have been very sad and difficult for her to go into a long-term care facility soon after his funeral. I'm thankful she was spared that.

Once my mother fell and was hospitalized, it was as if the wheel fell off. Her dementia seemed to progress rapidly and her "coping" skills of everyday activities deteriorated quickly. The question of whether she could return to her own home was non-negotiable!

Recognize signs that your aging parent is NOT coping in their own home – alone:

- Messy or untidy home (perhaps even dirty)
- Hoarding (some people have piles of clothing or newspapers throughout the home)
- Dirty dishes (your parent used to clean the dishes after each meal)
- Dirty fridge or food going bad (ensure they are eating the meals that you bring over; open the fridge and do an inspection)
- Empty fridge (someone who is coping well realizes they will need to call for someone to take them to get some groceries)
- Consistently out of food staples
- Not eating well
- Not hungry, poor appetite
- Stove spills, smells of burnt food, etc (check the garbage for burnt food or pots and pans)
- Unsafe hazards in home
- Parent is unkempt looking (my father did not like to shower or wash his hair; rarely wanted to put on clean clothing – these are all signs of a progressive dementia)
- Disengages from society and family (my father shunned all outside contact)
- Resigns from social groups, friends
- Refuses invitations (neither of my parents wanted to see friends or invite anyone over)
- Gives up hobbies or has no interest in activities that used to be enjoyable
- Accidents in home – laundry tub overflowed, bathwater run over (my mother unplugged the freezer and I found it one-third full of water one day – all the food ruined)
- Telephone off the hook
- Television is "on" but not working properly – "snow" showing on screen
- Becomes isolated, contrary, depressed
- Becomes anxious
- Becomes aggressive

- Mood swings
- Personality changes
- Medication abuse – not taking medicine, throwing it out, taking pills incorrectly at wrong times of the day, forgetting to take medications or skipping doses
- Alcohol abuse

As an advocate for your loved one, it is your responsibility to be investigative, so look for the evidence of the above listed traits. Become nosy and ask questions of your family and neighbours, also. (Yes, check the trash can.)

Remember, if you confront and question your loved one, he/she will deny any problems. But please remember that they are probably aware that they are forgetting things and they are terrified so that they will deny and refuse to accept that there *are* problems.

And most of all, please remember that you are not alone. Contact one of the many agencies that I recommended in Chapter Four; call Community Care Access Centre; Alzheimer's Society; your physician; a social worker; or your loved one's physician.

Sometimes the most difficult thing about making decisions is fear! Face your fears and get more information. Information and support will lessen the fear and release you from guilt. (Fear is the basis of most unwanted emotions, including anger, guilt, and frustration.)

When to know it is time for a long-term care facility or in-home, full-time nursing (It's about safety!)

Whether or not you leave a parent or loved one alone in the home or apartment is always a safety issue.

Is my parent safe when he/she is left alone? Am I frightened that something might happen? Do I have reason to believe that?

The previous page lists many facets of the progressing dementia but most importantly ask yourself these questions (and be honest):

- If an emergency occurs, is my parent able to telephone 911? Does my parent understand that concept? (When a social worker asked my mother this question, she answered "I would call Marilyn if something happens. But I don't know her number." When asked "Wouldn't you dial 9-1-1, Gwen?" She answered, "No, why would I bother them when Marilyn will come over right away.")
- Does my parent know how to use the telephone? Can my parent telephone me or another family member? Do they call on a regular basis?
- Can the patient recognize danger?
- Does the patient wander and get lost? Does he/she forget the home address?
- Is the patient unpredictable? If an emergency occurs, are you certain of your parent's ability to handle a crisis?
- Has your parent/loved one become very aggressive with either you or a family member? If your parent/loved attacks you (or a family member) that is an alarming sign! Please call your physician immediately. A person with Alzheimer's or a related dementia could harm someone. (That is usually a call for immediate removal – caregivers should not endanger themselves!)

CHAPTER TEN**Letting Go (How to Transition your loved one to a long-term care facility)**

It's time to let go and allow others to care for your loved one – it will be a difficult challenge but a necessary one at some stage. As my sister said, "It's time to let go and reclaim our lives." I would like to add that we can now go forward and be the person who we are meant to be...because caring for a loved one will have changed you. We become more compassionate and kinder, yes; but, we have also learned a few lessons about change. Change is vital to a healthy, long life. We must embrace change and not fear it. Be willing to accept this new transition in life as a healthy one for both your loved one and yourself. It does not mean that your job is done. As loving adult children (wives and husbands), we are never done – our relationship just transforms into something different and that's enough – as long as there is still love!

Once you have made the decision to enter your loved one into a long-term care facility, you will need to ensure that your parent's name is on the waiting list – placements can take up to two years. (Hence, I wrote the chapter entitled "Planning Ahead" to remind you to visit CCAC and complete the application form. And, if you did not take the time to read Carol Bradley Bursack's article in Chapter Four, please do read it. Let go of your guilt!)

You and your siblings will now want to visit the different facilities in the area to choose the two or three options that are best suited for your loved one (and the family). There are a number of considerations that are important:

- Person's needs (disabilities, dementia, etc.)
- Cleanliness (is there an odor?)
- Cost of facility
- Location
- Services that are offered
- Meals, nutrition
- Activities that are offered
- Staff – reputation, ask what is the ratio of staff to resident
- Emergencies – how are they handled
- Reputation (ask friends for recommendations)
- Number of complaints (check the website for complaints – they must be listed)
- Family advocacy rights; family committees
- Gardens or outdoor areas (a top priority for our family)

Try to visit during the day when residents are dining or enjoying some of the activities...you will want to see and feel the true essence of the facility. When you go on the tour (you call and make an appointment), try to take note of both

the residents and the staff; look for interaction between the staff and the residents; take note of the light and the comfort of the various areas (you may be spending time with your loved one and a comfortable lounge area is a must!)

Our choice for our mother was based on the cleanliness and comfort of the facility (it felt like a home) and the staff – they were friendly and caring during our visit. In addition, we looked into a couple of empty resident's rooms and they looked lovely – like a studio apartment with a wonderful window view. In addition, the residents were friendly and said hello. Lastly, but a top priority, we loved the outdoor gardens and huge verandah at the front of the building. Many of the residents and their family visitors sit and watch the comings and goings of the neighbourhood throughout the whole summer and fall. We have a choice to sit on the verandah or go into the back gardens – both are bliss!

Before you move your loved one, if at all possible, allow your loved one to visit his/her home before your family sells the family home. I know of many seniors who lament that no one allowed a last visit to the family home and this is particularly heart-breaking for them. (We think we are protecting our loved one from the heartbreak of saying "goodbye" to the family home; instead, our loved ones feel cheated of the bittersweet moment of leaving their homes.)

Your role has changed and you must accept that you are no longer the caregiver for your loved one. Instead, resume your *old role* as daughter, son, sister, brother, wife, or husband. The transition is now about "letting go" and even though it's difficult, it allows you to re-connect with your loved one without the daily challenges or stresses of caregiving. If you want a new role (and you probably are willing to take on some responsibility as you abdicate your old responsibilities) become an advocate for your loved one – health issues, nutrition, quality of care, etc. From my experience (of visiting two different facilities) I have found my role as visitor has become twofold: One, I visit and re-assure my mother that she is not forgotten and that she still matters to her family. Two, my visits are "wellness checkups" as I now am open to her physical state and her mental state; I ensure that she is looked after properly and that her needs are met. As an advocate for my parent, I ensure that if she needs more exercise and fresh air, then my sister and I take her for a walk or sit outside in the garden. We bring her treats (chocolates) and tea; we bring her weekly magazines (although she rarely remembers even reading them); we send her cards and pin them to her bulletin board; we buy new clothes when necessary and toiletries to make her feel good; we leave reminder notes for the staff of her favourite television shows – the name of the show, the TV channel and the time of the show; we bring in shawls and afghans for warmth and familiarity (and coziness) and as a link to her home (ensures continuity and comfort); and we have hung a wall calendar (large print) and made notes of activities and visits. Over time, some of these things have changed (we no longer hang a wall calendar and we no longer bring her books to read). The recliner and television set that we brought to her room in the early days has almost been forgotten – my

mother rarely watches television and does not use the chair, unless she is supervised. (She cannot seem to sit still. She is in perpetual motion for most of the day. This, too, is a common symptom of middle stages of dementia.)

But, it is the visits that ensure that my sister and I are aware of my mother's needs – if you don't visit, you will not be aware of your loved one's needs, wants, or their physical or mental state. Of course, you will miss an opportunity to connect with your loved one – a connection that holds all the possibilities of transformation.

Now that your parent/loved one is in a long-term care facility there are a number of comforts that you can provide to ease their transition:

- Try to have the physician break the news to your parent that he/she must go into a facility.
- Ensure that you either visit the facility ahead of time, or allow the individual (if at all possible) make some decisions about the pieces of (small) furniture, and pictures and decorating accessories that can be moved to their new home.
- Reassure them and try to use words such as: You are moving to a new, small studio apartment, Mom...I think you will enjoy how cozy and comfortable it is. I will call your friends and let them know your new address so that they can visit you.
- Ensure you point out the positives, such as, large window with great view; beautiful gardens; great food in the dining room; monthly day trips to the stores; etc.
- Check out the other names of the residents and if someone is a friend or acquaintance, ensure that you take your parent/loved one to visit them. A friend is important at any age – I know my mother often complains that she doesn't have any friends in the home. (She does. She forgets though because they are new friends and not her friends from the past.)
- Bring pillows and comforters or bedspreads from your parent's home – it allows for continuity and comfort.
- Hang an arrangement on the door of the resident's room – if at all possible, take a walk around the facility and look at other door arrangements and allow your parent to tell you what they would prefer. Our mother loves pink and she loves roses and hydrangeas so my sister and I always ensure we buy "pink stuff."
- If at all possible, try to ensure that you and your family support your loved one on moving day – it helps the person realize that some things will never change – we want to reinforce that we still love them and will support them on this next part of the journey.
- Moving day is an emotional day – be prepared for some tears on your part and your parent/loved one's part. Accept it as part of the journey. (Bring Kleenex.)

- Try to find a quiet moment (when applications are completed; forms exchanged; routines have been noted) and have a nice cup of hot tea or coffee (and cookies, of course) with your parent. Remind them that “this is nice...just you and me!”

I have included a list of activities from the book, *Gentlecare: Changing the Experience of Alzheimer's Disease in a Positive Way* that might help you when you visit as I have noticed that many adult children begin to stop visiting their parents when they are in long-term residences, especially when they have a dementia. Their reasons are varied but I often hear one, in particular: “Well, my parent really doesn't know me and I don't have anything to say or do. Time passes too slowly – I dread the visits.”

As the following list shows, there are many things to enjoy with a loved one with dementia – and as I have repeatedly said throughout this ebook – try sitting and being still. Hold their hand and just be in the moment. Even a peaceful twenty minute visit is appreciated by the person with Alzheimer's (and yourself!). To me, the list below opens up so many possibilities: It reminds us that we are visiting someone who we care deeply about (and we can forget that they have a dementia-related disease) and we can enjoy the moment, the simple moment.

Reference: Jones, M. (1999). *Gentlecare: Changing the Experience of Alzheimer's Disease in a Positive Way*. Vancouver, B.C.: Hartley & Marks, Pages 197-198

Activities related to communication while visiting the elderly:

- *Explain and reassure them about current living arrangements*
- *Bring a bouquet of flowers and talk about them, arrange them together, look at them, hold them, smell them*
- *Help them write to friends and family*
- *Help them prepare a few Christmas cards for special friends and family*
- *Bring a baby to visit*
- *Bring a pet to visit (you will need permission, of course)*
- *Find their favourite reading material and read aloud to them – the newspaper, the Bible, or a daily meditation*
- *Read lyrics of songs*
- *Read old recipes and discuss them*
- *Complete gentle shoulder massage*
- *Massage their hands and feet with scented lotion. Manicure their nails*
- *Wind wool with them*
- *Bring colourful pictures of pets, kids, garden, and food*
- *Pray with them. Sing with them*
- *Promote movement. Walk and talk*

- *Spend five to ten minutes browsing through and discussing large books – barns, horses, gardens, embroidery, the royal family and family photo albums.*

My mother and I spend many hours enjoying photo albums that we have created just for her. Normally she looks at each photo and tells me a story (yes, one that I have heard many times). When she reminisces, it is important for her to find meaning and significance in her life which is vital on the journey of illness. During palliative, patients have a need to find value and worth in their lives now that time is drawing to an end. Looking at photos or photo albums allows a wonderful opportunity for the patient to talk about their life journey. As a caregiver, open your heart and mind...just be there and listen. (Try not to judge or interpret. Just listen.)

Caregiver Tip: When looking through the photo album, point to a picture and say “Tell me about this photo.” That’s it. Your loved one will probably be off and running with a story, or two.

As a caregiver, remember that you are not supposed to “cure” their illness! You aren’t on this journey to prevent what is happening from happening...rather, you are on this journey to comfort and love your parent. That’s all. You don’t need to be a hero. Just be yourself.

Practice being in the Now – allow your mind to be present with your loved one. Many of us find that difficult to do as we want to spend time multi-tasking: yes, I am with my parent, but I am mentally making a to-do list and counting down the minutes when I can pursue another activity. Most of us do that. But if you can let go of the mental activity and just be with your loved one at this present moment, you will appreciate and see the joy in the moment more easily. It’s a learned habit – and you will need to practice it every day. (But, oh, the peace you will feel when you are with your loved one!)

Recently I walked by an open door in the care facility where my mother resides and looked inside. A daughter was visiting her mother and they were both knitting; both sitting in comfortable, cozy armchairs. My eyes welled up when I realized they personified a perfect portrait of a mother and daughter, completely at peace with one another – both enjoying a pastime together – and in the moment.

Chapter Eleven

Questionnaire to Other Caregivers

Throughout the whole year my mother was in the hospital, and in the year and a half that she has been in a long-term care facility, I meet other family members every week. On this journey with our parents, my sister and I have met some pretty amazing people – staff, nurses, personal support workers (these people are super-amazing in my book), volunteers, and lastly, other family members who are visiting their loved ones. In the following questionnaire, I ask the question: “Upon reflection, what was the best thing about looking after your mother/father/loved one?” and I asked this of other caregivers who had to eventually see their loved one go into a long-term care facility. By far and away, the best thing for me was meeting these people...meeting and connecting with people who care for those who cannot care for themselves. Because that is really what this whole journey is all about – connections and relationships. I had the unique opportunity to care for both of my parents and connect with them on a different level and to form a bond that will stay with me for the remainder of my life. And now, I have another unique opportunity to meet other like-minded people. It’s all about giving and receiving – kindness and compassion. That is a gift, my friends.

I wanted to tell you my story but I think it’s important to hear other stories, so I made a list of questions and gave them to other family members who I have met at the residence where my mother resides. (I regret that I did not give the questionnaire to people that I met at the hospital because many of them would have inspired us with their answers, I am sure.)

All of these amazing people, including my sister, gladly supported me in my writing this ebook, and were happy to oblige me with answers to the questionnaire. I have left the questions and their answers in their entirety so that the reader can fully appreciate the comments. I am completely overwhelmed with their responses and so thankful that they took the time to complete them.

You will note that each of us tell a different story...caring for a loved one has many facets. Each situation is unique; each caregiver is unique; each person with Alzheimer’s is unique.

Questions for caregivers –

Sue D. (my sister) cared for both father and mother, both with Alzheimer’s disease

- What were the signs that convinced you that it was time for your loved one to go to a nursing home? Was it a joint decision? Did you make the decision for them? How did you reconcile that? Or, did your parent/loved one have a plan in place ahead of time? Forgetfulness, unable to process information when wanting parent to sign a form, hallucinations &/or illusions. It was not a joint decision for either parent, no plan was in place other than to live forever in their own home. A health issue forced the decision but it was ultimately the children that agreed to it. With parent #1 there was a lot of grief and guilt. There really wasn't time to reconcile it all as he passed away 3 months after admittance to long term care. We spent those 3 months visiting every day, crying once we were leaving in the elevator, spending lots of time thinking about it and obsessing over it and feeling both guilt and grief over what their life has now become. With our mother, having been through it all, it was easier to accept and do things differently, altho we still felt a period of grief that her last days would be spent in a place she had no desire to be.
- In retrospect, what would you do differently? I'm not sure we could have done anything differently for my father (parent #1). I believe you have to go thru all the steps of guilt and grief. There's no way, once you recognize the signs, that there would be any way to have a conversation with your parent about it.
- In retrospect and upon reflection, what lessons did you learn from your journey? It all comes down to one thing.....it is what it is. You can rage, cry, feel guilty etc etc, but nothing will change what your parent is going thru and what you are watching them go thru. It is their journey and for whatever reason it is happening to them. All you can do is visit & try to be uplifting. When you are unable to visit as you are feeling too upset or angry, then give yourself a break and don't visit. We have to allow ourselves to live our own lives and not make their situation become our life.
- Upon reflection, what was the best thing about looking after your mother/father/loved one? With our father, the best thing was that he died 3 months after being placed in a nursing home. He had no quality of life as he couldn't walk, see, hear, & had advanced alzheimers. We felt blessed that he lived until almost age 90 before any health issues and he had a full and active life until then. It was a privilege to be with him at his end. With our mother, and we're going on year #2, we keep visits shorter than with dad & enjoy our time with her. She doesn't ask a lot and we laugh when the illusions allow.....sometimes they're too sad to do that so we laugh when we can.
- Upon reflection, what was the worst thing? It can be a struggle to visit and not see it as your own demise in a couple of decades. I've had to train my mind to not go there. It's extremely difficult to see your loved one decline, to place them in a long term facility and watch them rage against it.
- Self-care is an important issue when caring for a loved one – what did you do to ensure that you stayed healthy and “sane”? I don't believe I was sane when watching my father struggle and placing him in the nursing

home. Fortunately we didn't have to adjust as he didn't last long after that. With my mother we make sure to take days to ourselves and not feel she needs us with her all the time. In staying away, she has joined in activities which she would not do if we were there. And I'm not alone....I'm blessed to have a sister and brother-in-law who are amazing and do more than I do.

- Do you have any tips that might help someone who is beginning their own journey in caring for their loved one in the home? I would tell them that they have to feel what they're feeling without judgment, but after a period of time they have to recognize that it's their parent's journey, not theirs. That they should not feel guilty when they claim their own life back.

Karen F. (Mother had Lewy Body Dementia...combined with Parkinson's Dementia)

- What were the signs that convinced you that it was time for your loved one to go to a nursing home? Was it a joint decision? Did you make the decision for them? How did you reconcile that? Or, did your parent/loved one have a plan in place ahead of time? **Signs that changes were ahead: Her symptoms fluctuated from being mainly lucid, to moments of paranoia and hallucinations. She would call 911 over imaginary break-ins, hear noisy children, see strange creatures (which she named), was falling and injuring herself quite frequently, and her apartment was extremely messy. Placing her in a nursing home was not a joint decision. Many years earlier she had made it quite clear that she never wanted to enter any kind of facility; however, we had toured some of the homes in the area to see what they offered. The decision was actually taken out of our hands by her doctor. She had to be hospitalized for surgery, as her last fall resulted in fractures. Evaluations were done when episodes occurred in the hospital, and the Dr. would only discharge her to a 24 hr. care nursing home. She could no longer stay in her own apartment. Everything was clearly explained to her, and she herself signed all the paperwork...however, she didn't remember any of that later. I felt bad that she was having to go into a facility against her wishes...and knew she strongly blamed me for putting her there...But I also knew that she would definitely require full-time, long-term care in the near future.**
- In retrospect, what would you do differently? I don't know that there's anything I could have done differently. I do feel that she maybe was admitted too early, but at the same time, I knew that I couldn't offer her the complete care that she would need. (dressing, toileting, feeding, mobility issues, etc.) It was hard to judge when that would become necessary, and the application had to be filled out and approved for her to get a bed.
- In retrospect and upon reflection, what lessons did you learn from your journey? **What lessons did I learn from my journey? First of all, that it's**

entirely different when it affects one of your own! The emotional cost is high. This wasn't the same person I had always known. Her ideas and tastes and habits changed. I had to learn to adjust to those changes. It was important not to argue, but rather change topics and move on. Likewise, if she became difficult, (moody and combative) I needed to remove myself from her presence at times. I also needed to make things as pleasant, comfortable, and normal as possible...for both of us. Sticking to a routine was important. But the biggest lesson of all was not to feel guilty.

- Upon reflection, what was the best thing about looking after your mother/father/loved one? The best thing about looking after my mother was that I was able to get much closer to her than ever before. We spent much more time together, and although it could be difficult, it was also very rewarding.
- Upon reflection, what was the worst thing? I guess the worst thing about the whole journey was seeing her upset and crying when she was lucid enough to know that something was happening to her, but not being able to do anything about it. I knew she often felt lonely too, because I was the only one around to visit her. She had always been a very social person, and seeing her mentally and physically deteriorating, not knowing me, and being unable to do things for herself anymore was terribly sad. Conversations became nonexistent, and she lost interest in everything. This isn't how anyone wants to spend their final years.
- Self-care is an important issue when caring for a loved one – what did you do to ensure that you stayed healthy and “sane”? Having friends to talk to helped a lot! I can't stress that enough. They didn't have to be going through the same situation even...just be a listening ear. But advice was welcome. I also tried to schedule visits at times when she was most receptive, and would adjust the length of the visits accordingly. I eventually settled on visiting every other day for an hour or two, and that worked for me. Once again I had to not feel guilty if we went away for a holiday...I knew she was getting the care she required. Going out for dinner, or to the movies, or even a manicure was a good break. Exercise was also important...but I was up and down on that one! (My mother was in a nursing home for eight years. And I was the only family care-giver.)
- Do you have any tips that might help someone who is beginning their own journey in caring for their loved one in the home? Advocate for your loved one! Remember this is their home now, and it's probably a big adjustment for them to make. They must be here 24/7, whereas family and staff get to leave. Personality clashes are bound to happen with other residents and staff members...none of us get along with everyone in this world! Try to participate in events at the home (both of you). Interact with other residents and staff...know what's going on. Make things as homey as possible in your own loved one's environment. Pictures/photographs are a great way for staff to get to know more about the residents too. My mother always loved food and treats from home...I would bring in things

she liked, even occasionally meals from Swiss Chalet and McDonalds! It's fine to stay and have a meal with them too...they enjoy the company at mealtime. Most importantly, make sure the care your family member is getting is up to par and what you want for them. Attend those care plan meetings, and don't be afraid to ask lots of questions and get answers.

Anna G. (Mother has Alzheimer's disease)

- What were the signs that convinced you that it was time for your loved one to go to a nursing home? Was it a joint decision? Did you make the decision for them? How did you reconcile that? Or, did your parent/loved one have a plan in place ahead of time? **I resisted moving mom to a nursing home but I knew I could not care for her for much longer. I kept her home (with me) for 2 years and the responsibility was becoming too great. Also, my siblings lived out of town so that was hard. My family supported the idea, however difficult it was for all, because they worried about both of us.**
- In retrospect, what would you do differently? **I would not do anything differently. I felt honoured to have the opportunity to take care of my mom. I made mistakes or probably didn't handle situations correctly but Alzheimer's is very unpredictable and difficult to understand.**
- In retrospect and upon reflection, what lessons did you learn from your journey? **I'm sure I've learned many lessons but maybe most importantly – appreciate the little things, the moments and the time we have with our parents. Life is short and precious.**
- Upon reflection, what was the best thing about looking after your mother/father/loved one? **The best thing about looking after my mother was the fact that I could give back to her – never as much as she gave us (her kids), however!**
- Upon reflection, what was the worst thing? **The worst thing was to see and experience losses **every day**. Who she was or what she could do...you grieve every day.**
- Self-care is an important issue when caring for a loved one – what did you do to ensure that you stayed healthy and “sane”? **(Anna told me that her friend was a social worker and she often helped her with advice and support and reassurance. Anna also told me that her family supported her and so did her friends. She also went to a support group. Anna also took her mother to Outreach Adult Day Centre which allowed her mother to experience something new, and allowed Anna to have a brief time to herself. Anna also (her physician advised her to contact Alzheimer's Society) took “breaks” when a representative from the Alzheimer's Society would visit her mother.**
- Do you have any tips that might help someone who is beginning their own journey in caring for their loved one in the home? **Contact Alzheimer's**

Society and Outreach Adult Day Centre – find time throughout the week to have respite for yourself. Most of all, ask for, and accept help and support from friends and family.

Luann J. (brother had Alzheimer's)

My brother was in his early 60's when he started showing signs. He owned his own business when he got to where he would have anxiety attacks just thinking of being around anyone. He could not function outside his home. His meds were a problem to him as he'd forget to take them or take too many, and by this time he was sleeping most of the time. It got worse down the road as he would be in a conversation and ask us to be quiet as he could not think of what he was planning on saying.

When other people around him were talking he'd hold his head and ask us to keep quiet as he would lose his train of thought. Dates, time and places just to mention a few were hard for him to deal with. When it got to that point he had to go into a home for caregiving. Then his anger set in and he would turn on me after a period of time helping him and go on to the next person he felt he could trust. He was unable to trust one individual for long periods, as he felt we were turning on him. Then the violent actions he'd show got worse and it was scary being around him at this time as he was a large man. My brother tended to hit himself in the head in anger at himself for not remembering and as he called it being stupid. His walking got worse also so that was the time when a nursing home came up. They talked to him the Friday before he died and told him he'd be going to a nursing home. I feel that's when he gave up and willed himself to die as he could see no life ahead of him. At the age of 67 yrs young he passed away with no medical reason per se.

It's sad because all the medication in the world cannot cure this disease. It's hard on everyone including the patient. On reflection, the worst thing was feeling helpless. To see a loved one suffering within his own mind is stressful. Again, you're helpless and you just have to stand by and show your love even though at times it was very difficult.

Conclusion

Gifts: Life's Little Lessons (Hint: Those lessons aren't so little.)

I have learned many things on this journey. I have learned to have an open and expansive mind – probably the greatest gift that I could give myself. Deepak Chopra reminds us in his book *SuperBrain: Unleashing the Explosive Power of Your Mind to Maximize Health, Happiness, and Spiritual Well-Being*, Rudolph E. Tanzi and Deepak Chopra, that one must cultivate a new attitude about change – be open and willing to change – if one wants to live long and live healthy.

I have learned that aging is natural and that grief is a normal reaction when one's parents age and yes, die. I have learned that our emotions and how we **accept** them is pivotal and even life-changing. As humans, we are not meant to be perfect; we are meant to be whole. Acceptance of all of our emotions – the good with the negative – is the mainstay of a healthy well-being. What does that mean? It means that we need to accept and embrace **all** of our emotions: grief, sadness, anger, frustration, guilt, resentment...the list goes on. From each of these emotions, we will learn and grow. (But first, we must acknowledge the emotion and do some digging...Why am I feeling this way? What triggered my response?)

Along with an open mind, I have opened my heart to kindness, compassion, growth and wisdom...all gifts. And love. I have learned that love is transformative and can change us for the better.

I have learned that living life is all about gifts – giving and receiving. Everything we give out comes back to us, as a gift. Giving and receiving.

What else have I learned? Well, I have learned that a negative attitude breeds negative energy, and that negative energy creates more negativity and so on and so on. Negative energy creates ill health. We store it in our bodies and minds and like a virus, it either flourishes or it just sits there – like mold. Ugly!

We can release negative energy – it's a conscious choice. Decide right now to change your attitude. Begin to cultivate an attitude of acceptance – live in the present and accept what is. If you are feeling anger, sit still and focus your mind on the anger. Practice the act of detachment – sit and watch (like an observer) the emotion. Feel it. Soon, with practice, your mind will analyze the emotion: What emotion am I feeling? What words or deeds triggered that emotion? Why did that hurt me in the past? Why would that hurt me today? What happened in the past that makes me feel this way at present? Is my emotion based in fear? Fear of what?

The act of focusing on the emotion and just “allowing” the emotion is the act of acceptance. And strangely enough, the emotion will dissipate with time. At the

very least, we can stop beating ourselves up. We can remind ourselves that it's okay to feel this way. Love yourself in spite of feelings of guilt, anger or resentment. (And you will discover that love will transform those feelings...in time.)

The upside to all of this is our attitudes will change. Gandhi said "Be the change that you want to see." If you want peace, then *be* peace. If you want to be with your aging parent with love and *not* resentment, then be love.

And for anyone who thinks this is "crazy talk," let me assure you that this kind of thinking works. It worked for me and it can work for you.

When I visit my mother at her nursing home, I no longer see the wheelchairs first and the people second. I no longer see the bins of soiled laundry in the hallways and the cups with straws. Instead, when I visit, I see kindness, compassion and yes, love. I notice the couple in the community room who are holding hands. I hear the personal care worker who is walking, arm in arm, with a resident, all the while talking about the resident's new hair style and how beautiful she is. I notice the housekeeping staff member who is cleaning the floor of the resident's room, while regaling her with stories of her grandchildren. And I notice the activities director who is laughing with pure joy (my mom calls her a "whirling dervish"); the personal support worker who is singing aloud "You are my sunshine" to a resident while she helps him walk to his room; and the physical therapist who is gently cajoling a resident with terms of endearment. I see the love.

My good friend, Janet, told me a story that I have not forgotten. She took her two young grandchildren to see her mother at a nursing home. It was their first time at a nursing home. One of her grandchildren grabbed Janet's leg and hung on for dear life; she was frightened and started to cry. Janet's other grandchild stood in the lobby and then clapped with glee. She turned to Janet and said, "Oh, nanny, look at all the grandmas!"

It's all about attitude! It's all about positive energy!

Lastly, the most important lesson of all that I have learned: our spirit endures no matter what. In this ebook, I referred to Alzheimer's (as many experts do) as a thief; but, in the end, the disease does not rob the person's spirit or "essence" – the true nature of who we are. The dictionary reminds me that "essence" is that sometimes elusive, but "intrinsic or basic nature of a thing...the quality or qualities that make a thing what it is."

At the end of my father's journey, that familiar twinkle in his eye, that same smile, and that same smirk when his lips pursed and he said "oooooh" (as in "oh, I like that.") were still intact. And that is what I am grateful for and makes me smile today – the disease could not take that away from us. Another gift!

I have proof of this every time I visit the home where my mother now resides – as my mother and I visit other residents, their faces light up when we approach them; their smiles touch me as I hug them or pat their arms. I see glimpses of their true nature every day.

When we hold our loved one's hand, let's remember that our parent (or loved one) is still here – their spirit or intrinsic nature still alive. Look into their face and say "I see you." All is well.

Dear Reader,

I trust you have benefited from my experiences caring for a person with Alzheimer's. It was truly a labour of love for me born out of a respect for those who are diagnosed with this disease and those who care for them. In many respects we are all in this together and benefit from supporting each other. I would welcome your comments and specifically how you benefited from the book's contents.

Simply email me at marecahill@gmail.com . I shall attempt to reply to every response but if I can't then consider your comments to be much appreciated.

Take care –

Marilyn

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When I requested reprint permission from many of the following websites, the email recipients often replied with positive words of support as they, too, had grandparents or loved ones who had a dementia-related disease. Often the emails were full of kind and supportive words. I wish to take the time here to thank them for their words of encouragement. Thank you...we are all connected.

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