

Understanding the Dementia Experience

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Introduction

Alzheimer Disease and other dementias slowly steal all memories and abilities that have been learned since infancy - a process of progressive, permanent amnesia. All dementias are characterized by progressive brain failure due to brain cell deterioration and brain cell death. There is no cure for dementia. As the brain deteriorates, the person's ability, understanding and behaviour go through many changes. Often people with a dementia such as Alzheimer disease are seen as individuals with behaviour problems.

It is important to reframe how people with Alzheimer disease are viewed. Firstly, they are people with an altered view of reality due to the Alzheimer disease. Secondly, they are people whose behaviour can change, depending on how we interact with them. In order to know how to interact with a person with dementia, it is important to understand what they are experiencing as a result of having dementia.

Once we understand the dementia experience, and no longer view people with dementia as having behaviour problems, we see their behaviour as appropriate within the context of the dementia. This allows us to approach their care without fear. We can then deliver palliative care, care appropriate to someone with a fatal illness, with love and kindness.

For those readers who have Alzheimer disease, or whose family members have Alzheimer disease, this is very difficult reading. Please remember that you have a lot of living left to do. You will need to find different ways to do things, but it is important to look for joy and hope every day. There is an enormous amount of research being done on dementia, with new research being published daily, and lots of reason to hope for new treatments being available.

There is joy to be found in one's friends and family, in the beauty of nature, in the enjoyment of daily events, and in shared laughter. There is pride and contentment to be found in caring for a loved one, even though they have changed and become unable to do the things they did in the past. So please read to understand, and then turn your thoughts to the positive.

In this document, the emotional effects of this illness, on the family, have been woven into the discussion of the changes of the disease. During family teaching sessions, it is clear that certain parts of this material evoke a strong emotional reaction. At that point, we stop and discuss their emotional responses. Therefore, the discussions of the emotional effects of this illness on the family have been deliberately placed with the emotional state of the family reader in mind. In order to be useful to high-school level grandchildren in the family, wherever possible the use of medical terminology has been avoided or carefully defined.

Also, the changes that take place in the person's abilities have been followed through to the end conclusion, in order to illustrate how everyday life changes as the disease progresses to the later stages.

This wholistic approach may frustrate those who appreciate information being organized into categories such as stages, deficits, symptoms, warning signs (i.e., a reductionist framework). There are many excellent sources in publication, which are organized in exactly that way. However, a wholistic approach works well in individual family sessions when describing the physical, emotional and psychological changes of people with Alzheimer disease to their family, so, for that reason, it has been replicated here. This text attempts to allow the reader to vicariously experience the phenomena of dementia - the confusion, anxiety, fears and realities of having Alzheimer dementia, in order to deepen our logical and emotional insight and understanding.

Memory Processes

When we talk about Alzheimer disease, we discuss main types of memory processes.

Immediate memory is that which you use in conversation to remember what has been said just during the time period of the conversation. Typically, people with Alzheimer disease are able to use their immediate memory until the disease is fairly advanced. Therefore, they can usually have a coherent and socially acceptable conversation. Often, people who do not live with the person with early Alzheimer disease will think that because they can have a good conversation with the person, there is really nothing wrong.

The **short-term memory** fails early in Alzheimer disease. Therefore, although the person may be able to use their immediate memory to have a reasonable conversation, they may not remember the details of the conversation, or that the entire conversation took place, even just a few minutes later. This is the type of memory that you use to remember the last week or so. If you tried, you could probably track back for about a week, remembering everything you did, and all the meals you ate. You would not be able to do this if you were trying to remember back six months; to remember that far back we use a different memory process.

Short-term memory is also the memory process that allows you to do many things at once, to do "multi-tasking". When you are cooking breakfast, you can remember how long the eggs have been boiling, when the frying bacon needs to be turned, when in the process to turn on the coffee and start the toast, and when you can fit in peeling the oranges. A person with short-term memory deficit can concentrate on only one thing at a time, and if a second thing distracts them, the first may leave their consciousness completely. For example, one lady related how she set a nice hot meal on the table and she and her husband, who has Alzheimer disease, sat down to eat. During the conversation, she asked her husband if he would weed the garden at the side of the house. Leaving his hot meal on the table, her husband got up, went out the side door and started to weed the garden. When she went out to ask him to come in again, she discovered that he had completely forgotten that he was in the middle of eating a meal, after he started to think about the garden. You can see from this example that many caregivers eventually learn to curtail the spontaneity of their conversation, and instead evaluate the effect of what they are going to say, on their loved one, before they say it. Short-term memory loss thus creates stress and tension in the household in the early stages of the illness.

Many people have noted that repetitive questioning (the same question being asked many times in a row), the hallmark of short-term memory loss, seems to increase when the person with Alzheimer disease is emotionally upset or worried about a specific situation.

To remember back months, or many years or decades, we use our *long-term memory*. An intact short-term memory is necessary to make new long-term memories. After the short-term memory is affected, the individual with Alzheimer disease does not usually make many new long-term memories (with the occasional exception of emotionally-laden and/or procedural memories, to be discussed later). Additionally, the long-term memory is slowly erased in a chronological sequence, with the most recent memories disappearing first. So, if a 75-year-old has had Alzheimer disease for two years, they may have vague memories of their last 15 years or so, but clearer recall of their first 60 years. As their disease progresses, they may have access only to their first 50 years, then 40, then 30, and so on, until they go back to their childhood memories. This is not an orderly reversal – the person may remember more or less on different days and at different times during the day. (Not all types of dementia affect the memory in the same way, frontal lobe and vascular dementia, for example, may leave most of the memory quite intact in the initial stage of the illness.)

This results eventually, in the person with Alzheimer disease thinking they are much younger than they actually are. It is not as though they realize they are, for example, 81, but they can only remember their first 30 years. Instead, it is as though they are the person that they were at age 30. Consequently, they are confused, because they may not recognize their family, since they are looking for the individuals they were sharing their life with at age 30.

One might compare our reality to a jigsaw puzzle. We have all the pieces in place, and we are able to see the whole picture. The longer a person has Alzheimer disease, the more pieces are missing, and the more difficulty they have in understanding the picture. However, it is human nature to try. Therefore this person may look at their 30-year-old daughter, and decide that she must be their sister, and therefore call their daughter by her aunt's name. Not being recognized is hurtful and grievous for family members. However, understanding that the person with Alzheimer disease is desperately trying to put them into context may bring some understanding and emotional comfort.

As the person with Alzheimer disease continues to be relegated to living in their own past by the advancing of the disease process, they eventually pass through their own childhood. It is extremely common for people with Alzheimer disease to be looking for their parents, and to be very distressed if they are told that they are long dead. Thinking of the context of the person with Alzheimer disease, it is as though one is telling a 10-year-old that their parents are suddenly dead. They become sad and upset. Then, because of their short-term memory difficulty, they ask again for their parents, being unable to remember that this conversation took place a few minutes ago. If they are again told that their parents are dead, their anxiety and sadness is increased. They may become angry, because they "know" perfectly well that their parents are not dead (within their version of reality). The events of their parents' deaths are no longer in the memory of the person with Alzheimer disease.

If another person continues to insist that the parents are dead, the person with Alzheimer Disease may experience an escalation of their frustrations and emotionality to the point that they may lose their temper completely and "explode" in what has been termed a "catastrophic reaction". This is best avoided, as it is emotionally painful for the person with the disease and their carers. No amount of convincing will allow a person with dementia to grasp and accept another person's reality. An understanding of the changes in memory and psychological processes is basic to understanding the altered reality of people with dementia and in helping them to avoid emotionally painful situations. One lady with Alzheimer dementia is told, whenever she talks about her parents, that they are in Florida. She misses them, but she is glad they are having fun in a nice, warm place. There is a family connection to Florida in her remote past, which makes this story plausible. Many researchers have written about the value of the validation of the experience and beliefs of the person with dementia, whether or not it is in agreement with generally accepted reality.

Think of the situation that you are in right now. If someone were to tell you that some element of your reality is not true, you would laugh and think they were being ridiculous. If they continued to insist on a different version of reality than you are experiencing, you may become very annoyed, and eventually very angry with them. This is similar to a person with Alzheimer Disease being told that they are wrong about something they feel is obviously true. ***The long-established habit of trusting their memory is the first instinct of people with dementia, just as it is in people without dementia.***

Insight

If the person with dementia has an intact ability to have insight into their own behaviour, they will recognize that their memory is poor. They will go off to get something, arrive in a room, and not remember why they went there. Their spouse will ask them to get three things at the store, they will remember one, or forget to look at the list they were given. Their frustration is enormous.

For the person whose insight has been destroyed by their disease process, things will not seem normal, but they may express it by blaming others for the things that are going wrong. They are feeling distress, are unaware of anything about themselves that may be causing the distress, so they look elsewhere for the explanation. The loss of the ability to realize that there is anything wrong is called anosognosia. These people are not "in denial"; they honestly are not able to realize that they have a disease that is causing them problems, because the part of the brain that allows reasoning is being damaged.

The people with insight are often able to discuss the fact that they have Alzheimer disease, and the difficulties they have associated with it. They may become depressed and they may grieve as they grapple with the enormity of their diagnosis. These people may need help with their depressive symptoms, possibly including medication.

People without insight, on the other hand, will deny adamantly that anything is wrong, because they are no longer capable of rationally recognizing what is happening to themselves. They trust their memory and therefore feel that if their lives are topsy-turvy, someone else is responsible, because they have no memory of causing the difficult situations themselves. Acceptance of their view of reality is crucial in avoiding arguments. It is very difficult, for a child especially, to accept that a grandparent cannot control their tendency to making accusations which are not the truth. This takes many months of patient explaining by other adults in the household.

The person with Alzheimer disease has no choice but to experience a different reality, in terms of where they are located, or should be, when it is in time, and whom they are with. They may sit in their home of fifty years and demand to be taken “home”, because they expect to be in their childhood home. Trying to insist that their reality is wrong and yours is right will only produce anxiety and agitation, as they are not capable of remembering your version of reality and internalizing it.

Some families have described their loved one with Alzheimer Disease as engaged on a restless search for reality and “the known”, which they can never find. These people are rarely happy. Many spousal caregivers describe the person with Alzheimer disease as only happy at times that they are out – for a drive, to a restaurant, at the market, etc. It may be that they are happy only when they are away from their residence, and away from the environment in which they have a sense of frustration, despair and injustice at no longer being able to function at home. There are no demands on their disappearing skills when they’re out for a drive. In contrast, others with dementia have said they are only really happy and secure when they are at home and feel quite nervous when they are out. One lady would agree to go to a musical play in another city only if her name and address and that of her daughter were pinned on her coat; she knew she wouldn’t be able to get herself home if they became separated in the crowd. Each individual has unique needs.

What To Do?

Firstly – answer their emotional appeal – if they are looking for their mother and father, are they feeling worried and insecure? Try to *reassure* them. You may say something within the context of their reality such as “Your Mom and Dad are away for a while” or “are staying with Aunt Susan and Uncle Terry for a while. They love you very much”, followed by a hug and a smile. This would be much more soothing than the frown they would see on your face if you argued with them. (All of us feel upset if someone else frowns at us). Some people view the search for “Mom and Dad” as a clear message that the person with dementia is feeling uncertain and lost and is looking for emotional security. Doing whatever you can to help them feel emotionally secure, within the context of your special knowledge of your loved one, may alleviate their emotional pain.

Secondly, use *distraction*. Use the fact that people with Alzheimer disease can only keep one thing in their mind at a time, and give them something else to occupy their thoughts.

Something with emotional appeal will be more effective. A soothing ritual of a cup of tea. Playing with the dog. Something meaningful and pleasurable to them. Pull them gently into whatever activity you are doing to socialize ("I would really appreciate your help chopping the vegetables"; "would you mind handing me the nails while I fix this shelf?" etc.) Take them on an emotional memory by "interviewing" them about their early life. If you know their childhood stories – you will be able to say – "I remember you telling me..." and reminisce as if you were there yourself. Tell them a funny story (e.g. "Remember the story that Aunt Minnie used to tell about sneaking into the house just before midnight, and turning back the grandfather clock one hour, only to have it strike '23'? "). Such conversations may bring back remote childhood memories that could be quite enjoyable for the person to talk about. Often people with Alzheimer disease, who spontaneously talk about only the same few stories over and over again, can be triggered to remember other memories by specific questions, comments or the reminiscence of others. When you do this you are helping the person with Alzheimer disease feel joy and contentment instead of emotional pain, and you will enjoy your day considerably more as well.

More About Memory

Although the patterns of response mentioned in the previous two paragraphs are effective, they are difficult to do when you are feeling an enormous amount of grief at the situation in which you find yourself and your loved one. It is important for you to find support in your grieving, to have people to talk to who will help and support you as you dwell with this disease.

The memory loss patterns described above are not absolute. People with Alzheimer disease have good days and bad days. At some times, they will seem to be in the present, at other times back 30 years, at other times, back 70 years. It is very challenging for others around them to continuously adapt to the time frame that the person is forced to be in, by the disease, however, the ability to do so creates a supportive emotional environment for the person with Alzheimer disease.

In addition, some "memories" that the person has may have actually happened to someone else, or came from a book, and instead they recall these things as something they did. When this happens, it truly stuns the family with disbelief as they are sharply reminded of the enormous changes that are taking place as a result of the Alzheimer disease. For example, one lady, a widow who developed Alzheimer disease, started talking to her family and friends about her past hobby of playing tennis. This was very disturbing to her children as it had been their father who was the tennis player, and their mother had never picked up a racquet. She had a huge store of memories of tennis games, but did not remember that it was someone else who had played them.

Many people with Alzheimer disease describe a heightened ability to remember their very early years. This happens for some in the early part of the illness. One fellow said he could remember conversations with his mother and father word for word, which had taken place

when he was six or seven years old. (When asked if this was upsetting, he said, "No, it's kind of a nice visit!"). A lady was shocked when she suddenly remembered the day her sister came home from the hospital as a newborn. She was only 18 months older than her sister. Some people surprise their elderly siblings with the extent of their recall of their early family life. The explanation for this phenomenon in some people is unknown, but it is quite common to hear it described.

Since the short-term memory is affected early, many people who are developing Alzheimer Disease are misunderstood, because they cannot remember what took place five minutes ago, but they can remember what took place 60, 70 or 80 years ago, often with great detail. For this reason, family and friends may suspect that the forgetful person really does know, but is pretending not to remember. They may say to themselves, "If he can remember what happened when he was five, why can't he remember what we talked about ten minutes ago?" Until one understands that different memory processes and pathways are involved, the memory problems of Alzheimer disease can be very puzzling.

Those events in which the person with Alzheimer disease is emotionally invested may be remembered more easily. The things most easily dropped from short-term memory seem to be the mundane day-to-day details of daily living. However, many people do not forget having their driver's licence taken away. Happy emotional times, like the job promotion of a son, or the birthday of a grandchild, also often have enough emotional impact to be remembered, at least for a time. This phenomenon is known as *emotionally mediated memory*.

Here is an example of the emotions helping a person with middle stage Alzheimer disease establish a new long-term memory. A fellow told of reluctantly leaving his wife behind, and making their annual trip "home" to the east coast alone. His wife had been diagnosed with Alzheimer disease for about six years, she did not always recognize him, and she spoke very little. She felt very insecure travelling in the car and usually insisted on returning home after approximately half-an-hour. She was disappointed that she wasn't going on the trip, but he hoped that her faulty memory would protect her from some of the sadness at missing the trip. When he returned, he thought that his wife had forgotten that he had left her behind. However, the first time he cooked fish, she said, "you went home without me". The smell of cooking fish triggered memories of the east coast trip she had missed. The memory came back only when she could smell fish cooking. This led to such a strong negative emotional reaction in her that he eventually had to stop cooking fish altogether.

Some people use these exceptions, the few instances of a person with Alzheimer disease laying down new, emotionally mediated memories, as evidence that there is no disease process. They may say to themselves "If she can remember the kind of car we just bought, that proves that her memory is still working and she has no disease. She is putting all this on just to be difficult." It is important to look at the whole picture, and the long-term patterns of the person's memory processes, rather than a few specific instances.

When a person has some insight into their inability to remember things, they sometimes seem to continuously “kick-start” their memory by almost obsessing on a future event. For example, if they are told there is a doctor’s appointment coming up, they may frequently verbalize the worry that they should be leaving for it, or the worry that they may have missed it. They may do this many times a day until the appointment. Often, family members wait until such appointments are quite near to tell the person with Alzheimer disease about them, and thus help them both avoid that stress. One can see by these examples that the person with Alzheimer disease lives with a fairly high anxiety level. This is another reason we suggest using a calm, reassuring approach to help them control their anxiety level.

Arguing or finding fault with their inabilities, expecting them to “pull their socks up” or “get a grip on themselves” are perfectly normal reactions, until you realize that the person has Alzheimer disease, and therefore no longer has the control to adapt to the everyday pressures of their environment. One fellow intended to delay telling his wife, who had Alzheimer disease, that they were going away to a cottage as they had done for many years. However, one of his adult children told her three weeks before the event. For three weeks she packed and unpacked their clothing, and had it strewn in all rooms of the house. He put up with the disorder with good nature, as he knew that only going to the cottage would eventually stop it.

One thing that can be misunderstood is the habit many people with Alzheimer disease have of *covering up* for their lack of memory. They may spend an evening with good friends, laugh and chat and seem very appropriate, and then afterward ask their wife on the way home “Who were those nice people?” How could the person with Alzheimer disease be so dishonest as to spend a whole evening with people and pretend to know them? From an early age, we are all taught to “cover” our memory lapses by pretending to know, until we do remember, in order to remain socially graceful. If you meet someone on the street, and you remember their face, but not their name, you will usually chat with them until you do access the memory of their name, and not let them know that you ever forgot. If you can get away with it, you will move into talking in vague general terms in order to cover up your memory lapse. You do this because in our society, it is considered rude to forget something important like a person’s name, or significant events that happened to them. So we hide our forgetfulness to avoid hurting the feelings of others. People with Alzheimer disease have not lost this long-ingrained habit; they just need to use it much more often than they ever have before. People with memory loss are not able to control when they forget something, and they may remember it one day and forget the same thing the next day.

You will feel extreme shock and sadness that your loved one with Alzheimer disease can no longer remember your friends or family. You may also feel embarrassed and tend to withdraw from friendships. Because of the great emotional toll on both of you, it is better to tell friends about the illness, seek their understanding, and maintain a social life together as long as possible. If the person with Alzheimer disease reaches a point where they refuse to socialize, it is good for you to maintain friendships on your own. You need the strength that comes from strong supportive friendships and relationships with others. This is particularly true since the person with the disease is not able to fill the role of your companion in the same way they did

in the past. One lady, whose husband had recently been diagnosed in the early stage, said, "Even when my husband is sitting in the chair right beside me, I miss him."

Memories which are deeply ingrained seem to last longer. So, for example, someone who has lost the memory of most of the last 35 years of their life may still remember the names of their young grandchildren for quite a while. Unfortunately, this disease eventually robs us of every memory, and every bit of learning that we have ever accomplished. In the late stage of the illness, family members often feel that the person with dementia has no idea who they are. However, recent research has found that people, who have seemingly forgotten family members, still have a measurable emotional reaction when family enters the room, which they do not have when a stranger enters. The reaction used in this measurement was galvanic skin response, the same measure of emotionality used in lie detector tests (the available reference for this work at time of writing was a verbal communication from Dr. Guy Proulx, Baycrest, Toronto). Is there recognition on some level that the person with Alzheimer disease is unable to show, verbally or non-verbally? It may be so. One lady, whose husband is in the late stage of dementia, says she feels her husband does not know her, but her daughters tell her that his eyes follow her everywhere in the room. Another lady relates that her husband, who no longer talks, occasionally has a brief smile and on rare occasions puckers up for a kiss. He is also noticeably more content with music playing. Assuming that there is recognition on some level would seem reasonable in this situation.

The ability of people with Alzheimer Disease to establish new memories is being actively researched at present. Cameron Camp and his associates at the Menorah Park Centre in Ohio have developed a method they call "Spaced Retrieval", which allows someone to help a person with Alzheimer disease develop new habits. This method consists of taking a simple one-step task and working with the person with Alzheimer Disease to practice it (retrieve the memory repeatedly over spaced amounts of time). The practice sessions are kept positive, with no pointing-out of mistakes, but giving the correct information each time (termed "error free"). Paradoxically, people are able to develop new habits, such as using a walker correctly, but they do not remember being taught. This valuable new method is starting to make a difference to the daily lives of many people with early or middle stage Alzheimer Disease. It is quite evident to those who work in long-term care settings, that people with dementia are able to get accustomed to new procedures. Spaced Retrieval is a training process that allows others to formally access the retained ability of people with dementia to have new procedural learning. (www.myersresearch.org)

It is human nature to teach someone how to do something when they cannot do it. If a person with Alzheimer disease no longer knows how to do up a button, they may have lost that ability for good. Teaching them how to do up a button in an ordinary way will result in frustration for you and a sense of failure for them. If they can be taught using the method of spaced retrieval, they may regain some abilities with your assistance. Their disrupted short-term memory has resulted in difficulty in learning new things, or in relearning knowledge that the Alzheimer disease has destroyed. However, all of us who work with people with Alzheimer disease have seen evidence of new memories being laid down. A person who is admitted to a

nursing home may learn the location of their room, and how to get to the dining room after a few months. People with Alzheimer disease talk about not being able to recall the contents of the newspaper article or book chapter they have just read. They forget the content, but remember the emotional experience of forgetting it. We are just beginning to explore the possibilities of teaching new or forgotten material to people with Alzheimer disease, and there is hope of making an impact on their daily lives which may last for months or even a couple of years.

While spaced retrieval can help people learn, or relearn, simple tasks, it cannot reverse the loss of the ability to think rationally, to memorize, to think in the abstract, to have insight, to consider many facts at once in order to solve a problem, or to assess the feelings of one's own body and reach a conclusion about what one should do next in order to resolve difficulties.

Abstract Thought

Abstract concepts, such as numbers and arithmetic, become difficult early in the disease. Very often, one of the first indicators of a dementing process is mismanagement of finances and an inability to add and subtract in order to manage a cheque book. When combined with the deficit in short-term memory, this may result in debts not being paid, or being paid many times over. Often, people with Alzheimer disease will pay for purchases with a bill or two, ask if it is enough, and trust that they are receiving the correct change. It is difficult, but important, for family to be sure that the person is not being taken advantage of by another who does not have their best interests at heart, or is working for their own personal advantage, rather than protecting the interests and assets of the person with dementia.

Language and Communication

Language difficulties take many forms. Aphasia means the loss of language, and can include both speech and comprehension. Usually, this happens gradually as the Alzheimer disease progresses. Any one of these skills may be affected: understanding what others are saying; knowing what things are called, being able to put one's own ideas into words, or, being able to think of the words you want and use them to communicate what you want to say. The disease robs people of their vocabulary and their grammar. All of us grope for the right word on occasion. When language is affected, the frustration of word-finding difficulties is magnified many times. People may use a similar word – such as salt when they mean sugar, or they may describe the thing that they can't name – for example, a cup may be described as "the thing that I drink out of".

This difficulty in naming things is compounded by a difficulty in just knowing what things are. A person with Alzheimer disease may look at a fork, turn it over, and put it down, not knowing what it is or what one would use it for. The knowledge that they developed in childhood, about forks and their use, has disappeared. Agnosia means a total or partial loss of the ability to recognize familiar objects or persons through sensory stimuli as the result of organic brain damage due to the dementia. Any of the senses can be affected - an inability to identify

something by sight would be termed visual agnosia. An inability to identify something by touch is called tactile agnosia. The loss of the ability to interpret perceptions combines with the loss of language to make communication and understanding more and more difficult.

The people close to the person with Alzheimer disease often correct mistakes in language. This frequently provides a source of irritation or tension between them. All of us are somewhat offended when people tell us that we are wrong. It is an irritation that we have to make an effort to get over. Also, pointing out that someone is wrong is not something the rest of us do lightly. People with Alzheimer Disease make very frequent mistakes; as time goes on, they are almost always wrong. Having those mistakes pointed out to them causes a lot of stress, and their stress builds each time they are corrected. Continuous patterns of negative and scolding interaction may lead to anger and/or withdrawal on the part of the person with the disease. Long-time caregivers often talk about how they learned to "just let things go", rather than correcting every mistake.

People with dementia who are having language difficulties sometimes appear to be deaf. If you think of the sounds that come out of your mouth as just that, sounds, you can realize that the person to whom you are speaking is organizing those sounds into words, and giving those words meaning, in order to understand what you are saying. Further, they are integrating the meaning of your communication with the other things they know in order to evaluate your words. When someone cannot sort the sounds into meanings, your words become meaningless, as though they were listening to a language being spoken that they do not understand. One fellow described his experience with this by saying, "It's not just that I need a hearing aid: I need a descrambler!"

The problem of comprehending what others have said is made worse when the person with dementia is in a room with many people talking at once. People with dementia and language impairment are unable, as they once were, to isolate the words of one person in order to carry on a conversation when many other people are talking. Families may see the frustration this causes the person with dementia, as their loved one retires to a room alone during a family gathering, as they leave the church to sit in the car to avoid all the chit chat after the service, or, as they refuse to go to restaurants or malls where there is so much auditory and visual stimulation to process that they are totally overwhelmed and perhaps frightened. One lady in the very early part of the disease described being overwhelmed when in situations where many things are going on at once. She said she felt very insecure and anxious if she were anywhere in town besides her own home.

People with Alzheimer dementia are best able to communicate when they are in a conversation with just one other person, they are face to face, and there are no other visual or auditory distractions in the area (such as television, radio, crowded malls, or other people having conversations).

Emotions

Emotions stay fairly intact in the person with dementia. They continue to feel the whole array of emotions: happiness, sadness, joy, grief, and so on. What changes is the amount of control they have on the expression of their emotions. When well, most of us can sit in a room and feel a strong emotion, such as anger or joy, but hide it from any one else, so no-one knows how we feel, and we can control what we say to mediate the expression of that emotion. This type of control is no longer available as dementia progresses. For this reason, people with Alzheimer Disease are seen to have emotional swings. It is important to realize the effect you have on the emotions of the person with dementia. They are extremely sensitive to your body language (and your spoken language), and may easily react with anxiety to a frown on your face or tension in your voice. As you develop an awareness of their reaction to your moods, you will become adept at being sure you are not communicating anxiety. If you do, take a few minutes to gather your thoughts, calm down, and then approach them again with a distraction or a different approach. As the disease becomes more advanced, people with dementia become unable to express their emotions with their facial muscles, or it may not occur to them to hug. They may respond negatively to the noise and confusion of many people present. Young children, particularly, need to be given an explanation that "Grampa still cares, he just can't show it."

Time

The person with Alzheimer disease loses the ability to use *time* in a meaningful way fairly early in the illness. This includes the ability to know the meaning of what time it is, what day of the week, month, season, or year. A person may not remember having breakfast, and telling them that it is 10:30 and well past breakfast may work for a couple of minutes until their short-term memory fails, and they ask again about breakfast. They may not recognize the feeling of fullness in their stomach as indicating that they don't need to eat again, as they are no longer able to connect bodily sensations to the meaning of those sensations. The inability to tell time is also compounded by being unable to interpret other external cues in their immediate environment. Seeing that it is dark outside, may not help them realize that it is not breakfast-time and they should go back to bed until it's light.

An example of this is a story about a bus driver. He started work at eight in the morning, however, as his sense of time eroded with the beginnings of his Alzheimer disease, he began to arrive at work earlier and earlier. He knew that his ability to tell time was not functioning, so he began pushing himself to get out the door as soon as possible after he woke up. The anxiety caused him to wake earlier, and after a few months he was regularly showing up for work about 4 A.M. (Note the similarity with seeming "obsessions" described earlier).

It is often tasks that are repeated daily that are confused when the time element is taken into consideration. Making the bed one day blends in with making the bed every other day. Forgetting that a day has passed in between, one fellow repeatedly demanded of his wife why she had messed up the covers as they had just finished making it. The food will go bad in the

refrigerator because they do not remember how many days it has been since they bought it. People will carefully take their medication, and then do it again half-an-hour later, forgetting they have previously taken enough for the day. People with a dosette will do the same, forgetting what day it is. Checking the day off on a calendar may not be a reliable compensation if they don't remember what the date is, as they go through the day. Some people may be able to rely on something in the environment to repeatedly check the date, such as yesterday's paper, or a date and time function on a watch. Others may forget to check the date and time. One person established the procedure that only his wife could make an X on the calendar to show that each day was over. With that one assist, he was still able to take his own medications. However, once the person has proved unreliable in taking their medication, they need help to do so. If they live alone, counting the pills that should be left or checking with the pharmacist about the frequency of prescription renewals will let you know if they are accurate in medicating themselves.

Apathy

Apathy is the term used when a person with Alzheimer disease experiences the loss of drive or the inability to use *initiative*. The part of the brain that controls initiation of activity or communication is damaged. People who have this, need to rely on other people cueing them in order to be involved in conversation or in activities. Families talk about their frustration because the person just sits and stares at nothing for long periods of time, and feel that they should be using their time for some purpose. When this occurs, it is important to identify who has the problem. Is the person with Alzheimer disease being harmed by sitting for long periods, or is it the caregiver's discomfort with this change in the person's state that is the issue? The apathy is caused by the disease process. As long as the person is receiving adequate nutrition, is getting sufficient exercise spaced throughout the day, and is sitting in a soft comfortable chair so they are not at risk to develop pressure areas, and they seem content, are not showing signs of anxiety stemming from boredom, then their condition should be accepted. Periodic stimulation and pulling them into engagement with activities and conversation are useful, however, the person will not exhibit full-time engagement with those around them and their environment as they had previously.

Geographic Disorientation

Alzheimer disease also causes an inability to recognize one's surroundings. This *geographic disorientation* begins with an inability to find one's way around the community. People with Alzheimer disease may go down a street that they have known for 50 years, and suddenly, none of the buildings look familiar. They may recover their memory in a few hours, until the next episode of 'blankness', but eventually, their memory of the geography of their community is gone permanently. People who are still driving may possess driving skills, but at some time reach a point at which they are reliant on another person to be in the car with them to give them directions. This geographic disorientation progresses until they are unable to find the way around their own neighbourhood, and later, unable to navigate to find rooms in their own home.

There are obvious safety concerns because of geographic disorientation. When a person with dementia has geographic disorientation and their memory is on a backward trek, they may start walking or driving to a home that they lived in decades ago. Since they have memory loss, they may be heading for a place in a different city or a different country, and they become easily lost. The geographic disorientation may mean that they drive around for hours until something looks familiar and they find their way home. Diana Friel McGowan, in her book "Living in the Labyrinth", a first hand account of having dementia, describes these episodes. Later in the illness, people are no longer able to recover and find their way home. They are likely to travel in a straight line (perhaps because of tunnel vision, to be discussed later), over the path of most resistance (rather than turn to stay on the road, they will go over fences, across fields, or into dense bush to stay in a straight line). Because of this, when a person with more advanced dementia goes missing, it is an extreme emergency. Alzheimer Canada completed a project on this topic entitled "Search is an Emergency", to help Long Term Care Facilities prepare for the eventuality of a resident who goes missing. This was inspired by extensive work and lobbying by retired Ontario Provincial Police Officer, Ted Phillips, whose article "When Residents Go Missing: Over-reaction is justified, under-reaction is inexcusable" can be found in the May/June 2000 issue of the journal Long Term Care).

Since people usually have well-ingrained habits of carrying their purses or wallets, it is a good idea to have them carry family contact information even before they are at risk for being lost. The Safely Home: Alzheimer Wandering Registry exists to help the authorities search for people with dementia who are lost (Applications for the Wandering Registry can be obtained from any Chapter of the Alzheimer Society, or ordered from the Alzheimer Canada web site – www.alzheimer.ca). Since no pictures are attached to the Wandering Registry at present, it is also advisable to have up-to-date pictures of the individual on hand – both of the face and also full-length, in order to show body shape and posture (this will help searchers spot a person a distance away). Some people put a notch in the soles of their loved-one's shoes so their footprints can be distinguished easily. [GPS technology has offered other possibilities since this paper was written in 2002].

People whose geographic disorientation has extended to the point that they are not able to find their way around their own home cannot be left alone, for fear that they may inadvertently walk out the door to the outside while trying to find the way to the bathroom, for example. One woman put a picture on the bathroom door, so whenever her husband called that he could not find the bathroom, she could call out – "It's the door with the picture of the hockey player on it!", and thus avoid running upstairs herself to show him the door. However, she still could not leave him at home alone; he needed to be reminded each time. In one instance, he went out the back door in February, with no coat or boots, because he thought it was the way to the bathroom. Even when he was outside, he could not rationally connect the facts that there he was standing in snow and he was outside and cold with the fact that the bathroom couldn't possibly be there.

Many people who do not recognize their home are restless to "stop visiting" and return "home". They may be concerned about who is paying the bill for them to stay in "this place".

Reassurance given in a way that does not contradict their current view of their reality is difficult to give. Being positive and confident, rather than anxious, helps when reassurance is being given. It is vital to avoid arguing and reasoning. Without an intact memory, it becomes increasingly less possible to follow a reasoned argument as the disease progresses. Distraction may be helpful in these circumstances. Try a distracting ritual, such as feeding the birds, which can last a long time and is emotionally engrossing.

The geographic disorientation extends from an inability to orient themselves in their community, in their neighbourhood, in their own home to eventual disorientation to their own body. Think of a small child learning what their hand is, what their arms and feet and legs are. Later they learn how to put their limbs into clothing.

If you think of a toddler just learning to dress themselves, and then push the thought back to before that stage of development, you will arrive at an understanding of the adult with Alzheimer Disease who loses one skill after another in putting on their clothes. Forgetting the geographic layout of their body, general loss of episodic and procedural memories, and apraxia (discussed below) all contribute to a developing inability to dress. People become uncertain of the way to dress themselves – often putting their feet into sweater sleeves, or putting things on backwards. For example, one fellow became unable to cooperate with his wife as she dressed him because he forgot that he needed to raise his foot off the ground in order to get it into the trouser leg. Instead, he pressed his foot into the ground. He remembered that there was something he needed to do with his foot, but pressed down instead of pulling up. His wife at first thought he was being uncooperative on purpose, but then realized that she had to change her tactics and have him sit to put clothing on his lower body. Also think of a very young infant who has not yet learned the identity and appropriate movements of their hands and arms or feet and legs. The appropriate movements required in dressing are forgotten. At a later point, a caregiver will have to pick up their loved one's hand or foot and place it in the clothing. This is an illustration of the theory that people with Alzheimer disease experience a regression back through their childhood development (see Reisberg, B. et al. *Retrogenesis: Clinical, physiologic, and pathologic mechanisms in brain aging, Alzheimer's and other dementing processes*. *European Archives of Psychiatry and Clinical Neurosciences*, 1999; 249(S3): 111/28-111/36).

Caregiving Grief

The lady in the paragraph above also grieved the fact that her husband had lost one more ability. Caregivers may get into a routine and feel that they are on top of their loved one's needs, only to feel devastated that all their efforts have not prevented their loved one from getting worse. There is cumulative grief, mounting up over all the losses and difficult to resolve as you are still reminded of it since you are dwelling with the cause of your grief every day. This grief leads to anger, frustration, resentment, a sense of failure and other severe emotions. There is grievous outrage because the person with the disease is no longer able to help you to meet your needs, because you don't have time to meet your own needs since you're so busy watching out for them, and because you find yourself in so many strange

situations in which you find you have a real loss of control, and you are not able to re-establish control - the situation just has to run its course. Finding people to talk to, especially others who are experiencing the same things, in a support group, or on a caregiver web site may help give you strength to carry on.

It is best to avoid getting into a pattern of substance abuse in order to cope. Caregiving requires a lot of thoughtfulness, creativity, patience and perseverance, and is easier with a clear head. If you are feeling totally overwhelmed, you may need to seek help for support, new ideas or respite (someone else taking over your caregiving for a few days while you rest). Some caregivers find ways to spend time on activities they find stress releasing. Looking after your own stress levels and health is very important.

Some caregivers experience symptoms of depression (for example, problems with sleeping, decreased appetite, increased feelings of irritability, feelings of hopelessness) and sometimes, a family physician may suggest medication, such as an anti-depressant. This medication does not change your situation but may help you to cope more effectively.

Doing Things

Alzheimer disease affects muscle strength and coordination. *Fine motor movement* is affected, causing lack of precision in movements. This may be seen in the first few years as shaky handwriting, or general clumsiness when grabbing or holding things with the hands, or difficulty performing tasks requiring precision.

Apraxia is a loss of ability to initiate purposeful movements and to execute and sequence patterns of movement to carry out specific activities. As well, individuals with apraxia may also have trouble understanding back, front, left, right, up, down, or other relative directions. As a result of these losses, it becomes difficult to do things such as tying shoelaces, doing up buttons and zippers, and any activity involving coordination. Loss of patterns of movement will result in the eventual inability to coordinate hand and leg movements when driving.

In addition to fine motor movement, the Alzheimer disease also affects *gross motor movement*. The most notable change is a lack of strength and stamina in walking. People with Alzheimer disease lose the ability to stride and subsequently take progressively shorter steps. The ability to *balance* is also affected. As this happens, the person develops a slow, shuffling walking gait and starts to become prone to falls. This type of walk is reminiscent of that of a person with Parkinson's disease. In the late stages, the ability to walk is lost.

Myoclonus is an occasional strong and prolonged contraction of skeletal muscles, usually seen only in the late stages of Alzheimer disease. This may happen as an emotional response when the person is startled or stressed. You may pull one way on a person's arm or leg, only to have their limb draw back from you. If you are dressing a person with Alzheimer Disease, you may have the impression that they are being uncooperative. However, they have no such

intent and are unable to control the contraction of their muscles, or release the muscles. The contraction will slowly release in it's own time.

The memories that are affected by Alzheimer disease are not only those for events, but *physical memories* or *automatic abilities* as well. As we progress through childhood and adulthood we learn about doing many things that become so habitual that we do them without conscious thought. Using cutlery, brushing our teeth, washing, toileting skills, grooming, dressing, driving, playing the piano, typing, skiing, skating, riding a bicycle, or swimming are all examples of over-learned or habitual activities that we may have practiced so frequently that we do them easily without conscious thought. Since these skills are over-learned, they are usually maintained in the early stages of Alzheimer Disease.

Grooming and **bathing** are disrupted when the person forgets how and when to do things. They may forget what the steps of washing are. They may forget that they need to wash. They may be unable to remember how much time has elapsed since they last washed or changed their clothes. They may also believe that they are clean and take offence should anyone suggest otherwise. Dealing with such situations in a manner that is kind and jovial, rather than confrontational, is important. One fellow, who needed to help his wife bathe as she was no longer able to do so herself, was puzzled because she was calm and cooperative until he helped her step out of the bathtub, and then she became agitated and wanted to get covered up immediately. As it turned out, as soon as she saw her own reflection in the mirror, she thought there was another person in the bathroom, and she was embarrassed. As you can see, the cause of the distress for a person with dementia is not always readily apparent to the rest of us, who can take intact thought and reasoning for granted.

Control of bowel and bladder are usually affected in the middle or late stages of the disease due to sphincter control, although, some people are affected earlier. Relearning control is not possible (because the short-term memory interferes with learning), and incontinence products are needed. However, if a person who has usually toileted themselves, becomes acutely ill (for example, with pneumonia), they may become incontinent for a time and then recover, especially if they are facilitated in doing so. This incontinence is due to an environmental cause. Facilitation would mean the removal of barriers, such as bed rails or other restraints, and the use of pull-up incontinence products, rather than those with tape fasteners that are difficult to learn to take off and reapply. If the incontinence is due to the disease progression, they may still have sphincter control, but be unable to find the bathroom, and/or remove their clothing, and/or find the toilet to sit down. Guiding the person to the toilet every 1 ½ to 2 hours, and/or helping them with their clothing and sitting on the toilet, and cleaning themselves may help them avoid incontinence. A picture on the bathroom door of a toilet or some other identifying symbol may help a person who gets lost in the house and is unable to find the bathroom, but they may need reminding of the picture every time they are looking for the bathroom. Leaving the bathroom light, and perhaps a hall light, on at night may help them find the bathroom, as well. Finding out what is contributing to a new inability is essential in resolving it. New problems usually arise with deterioration. It is necessary to carefully examine the circumstances in order to pinpoint which deficit is interfering with the performance of a

task, such as toileting, so that the help offered to the person is appropriate and not more or less than what they need.

Although new problems can sometimes be resolved successfully in a way that the person with dementia is able to continue to function, generally they need more and more help. When the person caring for them starts to feel frantic because of the sheer volume of things to do, it may be time to contact your local community care agency to look for outside help.

Some people with Alzheimer Disease say that they have to think out every step to do things they used to do without thinking. One woman related at an Early Stage Support Group, that she could no longer use an escalator and was very unhappy about this. After being coached to slow down and concentrate on the task, she was able to go out and use the escalator the next week. However, she also was wistful that there were things she used to be able to do automatically, and now she had to think about them. (This same lady often said, "I think you're only sent as much as you can handle" – her inspiring philosophy, and her strength, in her journey through Alzheimer disease.)

One fellow related how he would always ask his wife to wash before dinner. One day she didn't return to the kitchen. When he went looking for her, he found her at the bathroom door. She knew she had to go into the bathroom to wash, but she couldn't remember what to do to wash.

Another lady related that the last year her husband planted the annual flowers in their garden, they didn't do very well. The next spring, she discovered that, in the sequence of steps to planting the seedlings, he had neglected to remove them from the plastic seedling holders.

Eventually, people become less adept at their formerly automatic abilities, and finally, will be unable to do them. For this reason, in the middle and late stages, people need help with many activities as they care for themselves or the things in their household. Inabilities with fine motor movement compound the difficulties caused by forgetting automatic physical abilities. One fellow described his frustration as his wife was losing her abilities to do her hobbies. She left many projects in various stages of completion around the house. He said, "If only she would just work on one thing at a time and get it finished!" However, her short-term memory loss was making it difficult for her to remember what she had been working on (and where she had last left it), and her decreasing skills were causing her to make mistakes in her knitting and sewing, so she would put the projects down in frustration. She was unable to work on them and unable to finish them.

Driving

The issue of driving is extremely difficult. Sometimes during testing, a physician will find that the person's spatial skills are such that they need to cease driving immediately. Other times, the family may want to curtail the person from driving because when they sit in the passenger seat while the person with dementia is doing the driving, they find their driving unsafe. One

method of gradually ceasing the driving has been found to work well. A lady asked her husband once a week or so if it could be her turn to drive (her license renewal was coming up). She gradually increased the frequency of asking for her turn until she was doing the driving 80% of the time. Then she started to automatically head for the driver's side of the car whenever they walked toward the car, without saying anything. After about six to eight weeks, her husband always went to the passenger side and never again expected to be the driver. This non-confrontational approach is positive, but not always possible.

Sensory Changes

Two types of changes affect a person's altered perception of the environment through their senses. Firstly, *the memories of the meanings of sensations* may be lost. We are able to sniff the air and think, "flowers" or "something's burning". However, we had to learn those meanings in the past and they will eventually be forgotten with Alzheimer disease.

Secondly, *the interpretation of the sensory information may be altered*. Agnosia is the loss of recognition of sensory information and includes all senses - sight, sound, taste, touch, and smell. For example, one woman became panicked easily while driving in a car because she had the illusion that they were moving straight up rather than along the ground. Late afternoons or early evenings are more problematic for visual perception, as light changes occur at that time.

If, for example, the person forgets what a common sound means, such as the ringing of a telephone, they will exhibit a startle response every time they hear it. Most people who hear a sound they can't identify immediately want to know what the sound was, and get up to investigate until they have solved the mystery. People with Alzheimer disease may have this type of startle reaction to normal, everyday sounds. Thus, they are frequently surprised, and become anxious and in need of reassurance if they become frightened. This is often the reason that people with Alzheimer disease become agitated and restless for no apparent reason. Even though you do not know the reason that they have become anxious, it is important to reassure and calm them, rather than tell them that they have no reason to be anxious. The reason is there, in their reality; it is difficult to find out what it is, and you may not. It is important to validate their emotions and recognize that their emotions are real and appropriate in their reality. For example, one fellow in a nursing home became very agitated every day about 4 P.M. In order to try to understand the cause, someone stayed with him from 3:30 to 4:30. The volunteers, activity staff and the day shift of nurses left at 4, and the evening shift went into report. The unit changed from a bustling hive of activity to the quiet of a deserted library. As it became quieter, he began to pace and shout, "Who's on that line? Why aren't they working?" At one point in his working life he had been a factory supervisor. In his mind, he was back in that time, in that workplace. His interpretation of the sudden silence in his current environment was linked in his mind to his former workplace and he took the absence of activity to mean that the work on the factory line had ceased and felt responsible to get it going again. Listening carefully to the person with dementia and knowing their history are valuable tools to helping them.

Television or radio programs are one example of sounds and visual effects, which may disturb a person with Alzheimer disease who no longer knows the meaning attached to these media. If you can put yourselves into the mind of someone who has forgotten what a radio or television is, you may have a reaction that is not unlike someone from the 1700's suddenly experiencing a television. You may think that the people in the box are looking at you or talking to you, or laughing at you. Unlike the person from the 1700's, you will not be able to learn what that box is and become accommodated to it, because your short-term memory will prevent you from laying down this new memory. Watching a small child become able to use the phone, she went from not knowing what the phone was used for, to thinking that the person who was speaking was actually, magically in the receiver, to finally realizing that she could somehow communicate without the person she was speaking to being present, by using the telephone. The person with Alzheimer disease or related dementia goes through a similar process, but in reverse. This last example is an illustration of how many inabilities (sound recognition, visual recognition, language, abstract thought, etc.) may combine to the point where the person with Alzheimer disease cannot do something they have done for decades, such as use a telephone.

The sense of *smell* may decrease, and the most notable effect when this occurs is a decrease in the ability to taste food. On our tongues, we taste sweetness, sourness, saltiness and bitterness. The rest of our ability to taste can be attributed to the sense of smell. One fellow who lost his sense of smell quite early in the disease, described how he had to force himself to eat, because putting food into his mouth was like putting cardboard into his mouth. This same fellow put 6 – 8 teaspoons of sugar in his tea. He said he couldn't taste the tea or the milk, but he enjoyed the sensation of having hot, sweet liquids. He also enjoyed salty foods and meals that were highly spiced.

Paradoxically, when the disease process is affecting the olfactory centre of the brain, people with Alzheimer disease or related dementias may relate that they detect strong unpleasant odours, when others present cannot. Removing what they see as the cause of the odour is more effective than arguing that the smell doesn't exist. For them, the smell is quite real. Since the origin of the perception of the smell is in their mind, removing the object they see as the cause may have no effect, and distraction or some other comfort measure may work. Arguing will not change the fact that they perceive the smell, but it will raise their anxiety level and may lead to worsening behaviour patterns.

The loss of *visual depth perception*, the ability to see in three dimensions, may mean that people have difficulty navigating stairs, particularly if the same colour carpet that is on the floor also goes down the staircase. Some people have had success putting a contrasting colour of duct tape at the front of each step, so the person with Alzheimer disease can visualize the steps more easily. If a person with Alzheimer disease is looking at a solid black area, or a solid white area, such as a bathtub, they may perceive a yawning bottomless hole. Putting a coloured bath mat down may increase the likelihood that they would be willing to step into the tub. Putting blue food colouring into the water may allow them to see what they are stepping into as well. Generally, with altered depth perception, it becomes challenging to judge how high, deep, long, wide, near or far things are.

The geographic disorientation and difficulties with depth perception combine to lead to an inability to find oneself in space. The person with Alzheimer disease may lack a cognitive map of where their body is in space. This leads to difficulty navigating. They may go to sit down, but miss the chair, as they are unable to judge the distance and relative location of their body to the chair. Spaced retrieval has been used to help people with dementia remember to feel the front of the chair on the back of their legs before they sit down.

Visual acuity is also worsened, and this can hasten the loss of ability to read or tell time or recognize people or things. People whose visual acuity is affected may enjoy reading large print books and later in the disease may still be able to read headline-sized print. It is important to try, as signs may help them find a familiar place in their otherwise confusing environment. Each individual is unique in this regard. (The ability to read is also affected by short-term memory loss - if you can't remember what happened in a story in the previous chapter, your enjoyment of reading a book will be affected. Reading is also affected by decreased language skills - frustration at no longer recognizing many words.)

There is also the development of **tunnel vision**, and the associated decrease in their available peripheral visual field causes people with Alzheimer disease to have problems with going through the environment physically. Other things passing through their visual field from side to side, such as a car on the road may also startle them more easily. We see the car coming "out of the corner of our eye", so we have warning, whereas the person with tunnel vision will not see the car until it is directly in front. Also, they may not connect the sounds they hear with the fact that a car is driving close by. Safety is an important consideration after tunnel vision has developed. People are more likely to trip on curbs or scatter mats, which are on the ground or floor at their feet, as these are no longer in their peripheral vision. The short-term memory, which the rest of us use to remember that there is a curb coming up, may not assist the person with Alzheimer Disease. Many people have mentioned that the family member with Alzheimer Disease likes to walk directly behind them. This may be the easiest place for them to keep track of their caregiver, if their decreased peripheral vision would not allow them to easily see someone walking beside them.

Judgement

The enormous changes in memory, perception, interpretation and understanding lead to changes in the ability to use judgment as the person has used it in the past. A person with Alzheimer dementia may not be able to take everything into account when they make a judgment, and may forget many important factors when making a decision. This may result in embarrassment for the family. One fellow, who had been a very proper gentleman all his life, unzipped and urinated into the water in front of a tour boat loaded with people about to disembark. He was oblivious to the scandal he had created, and, although there had been signs of memory loss, this incident helped the family realize that there was something seriously wrong. This type of behaviour may be also termed disinhibition, but whatever it is called, it is the result of multiple losses in cognition affecting the person's ability to exercise their usual standard of judgment. The inability to exercise judgment in daily life is often seen in the

frequently voiced observation by families that their loved one can no longer choose what to eat on a restaurant menu, or may be perplexed when it comes to deciding between different items of clothing, such as whether to wear the brown belt or the black belt. Even such seemingly inconsequential decision-making tasks may become impossible for some people with Alzheimer dementia.

Hallucinations

Visual or auditory *hallucinations* happen to about half the people with Alzheimer disease and may happen with other types of dementia, especially Lewy body and frontal lobe dementia. Usually the hallucinations are of animals or people. You may be unaware of these hallucinations until your loved one starts talking about the nice dog or cat they saw, or comes into the room when the two of you have been alone all day, saying, "Where did everybody go?" There is no point in arguing that these hallucinations are not real, as they are very real to the person experiencing them. The hallucinations can be very susceptible to suggestion, however. If they are not causing distress, they can just be accepted. If they are distressing, a suggestion that they have been misinterpreted (eg. "Those aren't enemy soldiers, those are Uncle Arthur's hunting buddies") or that they will be gone soon ("Don't worry, he's just leaving") and definite calmness on your part, can be very effective.

Integration of Concepts

The *processing of all information is slowed*. One fellow described his struggle in social settings. He had a great deal of difficulty processing the words that people were saying to figure out what they meant. When he stood talking to a group of friends, he would work hard to figure out what each one was saying, as the conversation went around the group. He would miss a little of what each one said, because, before he had finished understanding what one person had said, the next person would start talking. He was also slower in trying to think of his own contribution to the conversation. Consequently, by the time he thought of what he would say, and how he would say it, the conversation had passed onto another topic. When he said something himself, the others laughed and said, "Where have you been, we were talking about that five minutes ago!" He ended up withdrawing socially, and just concentrated on listening, instead of participating, unless he was in a one-to-one situation.

Processing visual information is also slowed. One person noted that his wife jumped every time their young grandchildren ran across her field of vision. Slowness in processing the visual input, as well as tunnel vision, contributed to the impression that the children had jumped into place. Many people are surprised to get an answer to a question they have asked the person with Alzheimer Disease, five or ten minutes after they had asked it. The slowness extends into all spheres. One woman related how leaving the house for an outing used to require a half-hour's preparation in the morning. In the months just before her husband went into the nursing home, she could count on a full three hours or more to accomplish the morning's chores of breakfasting, dressing and using the washroom before leaving the house.

In order to integrate some of the concepts described thus far, think for a minute about the constellation of inabilities mentioned earlier, and imagine an elderly man who goes into the washroom in his nursing home and comes out complaining about the other man who won't leave. The nurse goes in with him and finds the washroom otherwise empty. He insists that the other man leave before he does his business. The nurse leaves, frustrated because she cannot make this man understand that there is no one but himself in the washroom. This occurs many times a day, and the man's frustration slowly builds over the days to the point that he 'needs' sedation. Pulling together what you know about the constellation of inabilities, however, you can figure out that this man no longer knows what a mirror is and what it does. Furthermore, his memory has gone backward in time, and he thinks of himself as looking the way he looked in his teens (perceptagnosia). So, each and every time he goes into the washroom, he sees an 80-year-old stranger who refuses to leave as long as he is in there, and therefore he has no privacy. Even if the nurse tells him that he is in the mirror, it will not help, as he has forgotten what the word mirror means, and forgotten the concept of reflections in mirrors, and forgotten what his face looks like in the present. Once the cause of the problem is figured out, the mirror can be covered, and the man will regain his sense of privacy and his frustration and anxiety will decrease. He needs others to work within his reality to help him solve the problem.

Take another instance of a person who has lost the ability to feed themselves well, has lost the knowledge that a certain feeling in their stomach means they are hungry and need to eat, and has lost the ability to understand most words. They are fed a couple of bites, and, seemingly have lost interest in eating. Their short-term memory does not allow them to remember that they are in the middle of a meal. They may not recognise food as food, or connect it with the task of feeding themselves. Someone asks them if they are full. They may hear what sounds like nonsense words – sjopm flrtem wdber – for example. However, wanting to be polite, they may answer a raised inflection in the person's voice with a socially acceptable "yes". This results in their food being taken away before they have had enough to eat. People with Alzheimer disease reach a point where others have to take on the task of assessing whether they have had enough, as they are no longer able to judge their own nutritional intake for its adequacy. They may feed themselves once they get help starting, or they may need to be fed by someone else. They may not recognize feelings of thirst, and may go without drinking for long periods, or work outside on hot days without taking in adequate fluids, risking dehydration.

Other people may overeat, as they fail to recognize the physical feelings of fullness, do not remember that they have just eaten, or are no longer able to exercise their judgement to give themselves adequate nutrition. In some instances, keeping food out of sight, or not having inappropriate food in the house is the only way to cope with a person going through this type of phase. This can cause real conflicts for a caregiver. In one instance a lady had to stop having her delicious cookies and squares available for her grandchildren, who adored them, in order to help her husband who had diabetes and Alzheimer disease, but was no longer able to exercise appropriate judgement in stopping himself from eating as much as he wanted to eat.

This caused grief to this caregiver as she was no longer able to dote on her grandchildren in a way she and they loved.

Geographic and spatial disorientation combine with a failed short-term memory to result in people and things becoming lost. If a person with the disease looks for things where they think they have left them, and is constantly unable to find them, they may get a sense that things are always disappearing on them. If they are convinced that they left an item in a different place, they feel as though someone else has moved it. They may develop a conviction that someone is coming into their house and moving things or taking them. Therefore, they may hide things away. If you found that your car was missing, you would automatically report it stolen. The logic of thinking a missing item has been stolen remains a part of the logic of a person with Alzheimer disease. The difference between you and the person with Alzheimer disease is that they may not accurately remember what things they actually had or where they left them. Family may be accused of stealing things, and this is most stressful. Smiling, being reassuring, and cheerfully offering to help them look are useful approaches. Distracting them into another train of thought as you look may bring an end to the episode.

People with Alzheimer disease gradually stop their household activities such as repair, cleaning, cooking, gardening, etc. as the disease makes the performance of these tasks impossible. The abilities *to plan, organize, and carry out functions* become severely compromised early in the disease. These functions are called *executive functions*, because they require a number of different memories, different skills and the ability to see the sequence of each of the steps of a procedure and their relation to the other steps. Performing duties around the house becomes impossible for the person with Alzheimer disease, even though they appear to be physically capable of carrying out those duties. Take, the example of boiling an egg. One must know what an egg is, that boiling it requires putting water in a pot, heating it to a boil, and leaving the egg in for the correct amount of time. If any one of those steps cannot be performed adequately, the person with Alzheimer disease cannot boil the egg. They may be able to do things for a period of time if the steps are broken down for them (eg. "please put these plates on the table", "please put these forks on the table" etc., rather than "please set the table"), or, if they work side by side with another person doing the same thing; but eventually, this too, becomes impossible. The picture is complicated because the person with the illness has good days and bad days, and, for a while, they may perform the required function on some days, and seemingly refuse to, on others.

Knowing which abilities remain and which inabilities need to be compensated for is important for family members caring for their loved one. It is difficult to step into the personal space of someone with Alzheimer disease and take over a function when they are no longer able to do it. They may do it one day and not the next. They may be offended because they feel they are still capable of taking care of things themselves. Using good humour, showing respect and caring, trying and failing and trying again, the caregiver eventually helps the person with dementia get used to the fact that they need help. Further deterioration means that they are having to start this process all over again. Sometimes family who do not live with the person with dementia are surprised by how much they cannot do. They may say something like "If

you weren't doing so much for Mom, she would be able to do it herself!" Not having been there for all the times Mom tried and couldn't, and not wanting to accept that Mom is as incapable as she is, they end up hurting Dad who has had to accept Mom's inabilities and help her, because he has no choice.

Just as not remembering where they put something can lead a person with dementia to have delusions about people stealing from them, the inability to sense the passage of time may lead to *delusions* about their significant other. If a person thinks that their husband or wife has been gone for a long time, even though they left for just an hour and came back with bundles of groceries, the person with dementia may accuse them of bad behaviour. It is very demoralizing for a hard-working and caring caregiver spouse to be accused of having an affair, but it is helpful for them to realize that the anxiety their spouse is experiencing because of the disease, coupled with their inability to evaluate time, and their lack of judgement may lead to them making hurtful accusations such as this.

Is it any wonder that anxiety, fear and frustration are hallmarks of this disease? The person with Alzheimer disease has lost all anchors and connections to the real world. When you are interacting with a person with Alzheimer disease they may not know where they are, who you are, what you want to do, why you want to do it and how it is done. Unlike you, they are lacking an understanding of their *context*. At the beginning of the illness, most of the person's contextual information is intact. As the disease progresses, they lose more and more of their abilities and their knowledge which they use to evaluate the context they're in. Early on, you may see a person who is functioning well, but who's judgement of what is appropriate to say in a social setting is disturbed. Later, the lack of context may mean that they do not ever know where they are in place or in time, but they do know their main caregiver. They will "shadow" their caregiver, never letting them out of their sight, for fear of becoming completely lost.

Giving personal care is especially intrusive, and trust must be established each and every time that the person with Alzheimer disease is approached. If you feel threatened and someone starts handling you without your permission, you may fight them off. It is a similar situation if someone with Alzheimer disease is fighting the person trying to help them: it may be because they do not understand, or are mistaken, about the context of the interaction, and they feel threatened. The reputation that people with Alzheimer disease have of being aggressive is misplaced. In most cases, the person is merely on the defensive, keeping themselves from harm by someone who seems to be about to do them harm or avoiding a situation they find threatening. You know that they need your help and you feel that they should be grateful. On the other hand, they do not realize that they need help, and may be offended when help is offered. Almost all of "aggressive", or violent defensive behaviour in dementia can be avoided by adapting changes in the way other people interact with the person with dementia. Forceful distraction can be very effective. When her husband gripped her arm too tightly, for too long, one lady pointed behind him and said, "Look at the birds out the window!" By the time he got to the window and complained that he couldn't see any birds, the crisis was over and he had completely forgotten that he was upset about having his medications given to him.

If you send clear signals through your tone of voice, facial expression and relaxed and confident attitude, that you mean them no harm, they may be trust you to the point where you are able to help them with their personal care. People with Alzheimer disease become extremely sensitive to the body language of others, as they no longer possess the judgement and insight to understand the situation, so they evaluate the threat posed to themselves by the frown or aggressive stance of the other. It is important to exaggerate your body language communication to let the person with Alzheimer disease know that you intend them no harm. A smile on your face, a relaxed tone of voice and body stance, a sense of calmness and reassurance, perhaps a hug, all communicate that you mean to help, not harm. If you feel like you're overdoing the positive body language, you are communicating your intent effectively for a person with Alzheimer disease.

Remember that their short-term memory may not permit them to remember what you are doing when the two of you are part way through a task, such as a bath. People have found it effective to keep chatting throughout the task, as the continued connection and reassurance of a soothing tone helps the person with Alzheimer disease stay calm in a situation they would otherwise find threatening.

You can assist the person with their emotions. The person with Alzheimer disease, particularly late in the disease, lives in the moment, without a context. They are without a perceived past or future. If you help them enjoy the moment, it is a gift of positive emotions. A person with Alzheimer disease, who gets into a bad mood, will stay in that mood long after they've forgotten why they feel that way. Your gift of laughter or pleasure can result in a positive mood that lasts for hours. Laughter at some of the comical situations you will experience is healthy and to be shared with the person with Alzheimer disease by hugging them, or somehow showing that the two of you have shared a special moment. A few people have worried that laughing is inappropriate because of the gravity of the illness, and feel guilty for finding some situations funny. Very experienced caregivers have said, "You have to laugh. If you don't laugh you cry. Sometimes you laugh and cry at the same time."

Individuals with Alzheimer disease are unique in their prior history, beliefs, behaviours and habits. Alzheimer disease progresses at different rates in different people: some succumb to it in as little as two years; others deteriorate slowly over twenty years. The changes that the person experiences at any one time depend on the areas of the brain that have been affected. So, for example, some people develop language changes early in their illness, others maintain their fluency for years. Some develop incontinence very early and are able to completely manage their incontinence products on their own for a long time. Others remain continent for years. Some have insight and intact judgment ability, others do not.

A person with Alzheimer disease has a constellation of inabilities and difficulties that combine to produce the unique pattern of the expression of their disease at any one point in time. Each new inability interacts with the others to produce new challenges for the person with the disease and those supporting them. Whenever the progression of the disease changes the

person's abilities and behaviours, the person affected and their family need to find new ways to cope with their care and daily life events.

Note Written In 2002

Originally, this material started out as a talk based on the video "The Brain and Behaviour", featuring Dr. Helen Creasey, produced by the University of Sydney (Australia) Television Service for the Alzheimer's Disease and Related Disorders Society (ADARDS). The content has grown in depth and complexity (and hopefully insight) thanks to the people with dementia and their families who have shared their experiences with me over the past three years.

A special thanks to Susie Gregg, who shared her article, "The Seven A's of Dementia", to Jane Grieve, who lent her expertise to the comments on caregiver depression, and to Craig Smith for his many comments and suggestions.

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Note Written in 2012

The article above, "Understanding the Dementia Experience" was written to provide an explanation of the pamphlet I wrote for family members in the early months of the year 2000. Originally entitled "How to Interact with a Person with Alzheimer's Disease", it was modified slightly and reissued as "How to Interact with a Person with Dementia (with memory loss) and is reproduced in full below.

The article "Understanding the Dementia Experience" has been freely available by being referenced and posted on many web sites in pdf format. Over the years, I have received many messages of appreciation. However, I would like to say a special and sincere 'thank you', to the lady from Texas, USA who called to ask if it was available in published form. I told her that I was hoping at some time to put it into a book. "Good," she said, "I'm so tired of photocopying it!" I could never have received a higher compliment. The memory of that conversation repeatedly encouraged me and made me smile, as I was expanding the article into a book. Whenever I flagged, that memory helped me push myself to keep writing and rewriting. The book, "Thoughtful Dementia Care: Understanding the Dementia Experience" is now completed and available as an ebook for \$4.99, and will be available in the summer of 2012 in print (www.understanding-dementia-experience.com). In the book I expanded the content of this article and added discussion of many issues which were not covered in the article. The Table of Contents of "Thoughtful Dementia Care" are reproduced at the end of this free ebook.

To those readers who are struggling with the day to day realities of dementia, I would like to convey my sincere best wishes. Many people have told me that the way I understand and

explain dementia has been very helpful, especially to family members, and I hope that others will continue to find it valuable in the future.

The Pamphlet:

How to Interact with a Person with Dementia (with Memory Loss)

A Person with Dementia (Especially those with Alzheimer Disease):

- Likely has a poor memory for recent events
- Gets lost and loses things
- Is restless, anxious and easily distracted
- Has emotional swings
- Has poor judgement
- May be socially inappropriate
- Will forget how to do everyday tasks
- Has difficulty understanding what is said to them
- Will forget what things are
- Has difficulty knowing what to say because they forget words and how to express themselves with language
- Becomes afraid of social interaction

What is needed?

People with dementia need caring people to help them:

- Stay relaxed
- Feel secure
- Feel that you mean them no harm
- Raise their self-esteem

When you care:

- Be aware that how you behave can determine the mood and reaction of the person with dementia
- Concentrate on and adapt to the mood and state of mind of the person with dementia while interacting with them

Use 'Unconditional Positive Regard'

The "Dont's"

- Do not reason and argue
- Do not demand that they reason or problem-solve
- Do not demand that they remember
- Do not demand that they get their facts straight
- Do not correct their ideas or scold them
- Do not reorient them
- Do not think that they are being uncooperative on purpose
- Do not think that they really do remember, but are pretending not to

- Do not use a “bossy” dictatorial attitude in care
- Do not act with impatience

Do

- Enter into their frame of reality, or their 'world'
- Be aware of their mood or state of mind
- Use few words and simple phrases
- OR use no words, just friendly gestures and simple motions
- Do everything slowly
- Approach from the front
- Wait for a slow response
- Constantly reassure them that everything is 'OK'
- Keep people with dementia comfortable 'in the moment' - every moment
- Maximize use of remaining abilities
- Limit TV or radio programs which they may feel are frighteningly real
- Maintain privacy
- Provide a safe physical environment

Language Needs

- Use short words
- Use clear and simple sentences
- Speak slowly and calmly
- Questions should ask for a “yes” or “no” answer
- Talk about one thing at a time
- Talk about concrete things; not abstract ideas
- Use common phrases
- Always say what you are doing
- If they repeat their question, repeat your answer as you did the first time
- Give them a longer time to process information
- Wait patiently for a response
- Be accepting of inappropriate answers and nonsense words
- Speak softly, soothingly and gently

Care Needs

- Recognize that receiving personal care feels intrusive
- Reassure with your tone and manner
- Do one thing at a time
- Talk through the care “play-by- play”
- Be aware of your body language and use it to communicate relaxation and reassurance
- Be sincere
- Use a soft, soothing touch
- Be aware of the individual’s unique triggers
- Be aware that a person with dementia may not accurately judge whether a situation is threatening to them

- They may respond to fear, pain or anxiety by defending themselves with what we call "aggression"
- If they become distressed, stop immediately and allow them time to calm down – don't try to restart the activity right away

You need to change your behaviour to adapt to the dementia because the person with the disease cannot.

Permission is given for the pamphlet above to be freely reproduced if it is used in whole, without anything being deleted or changed. Attribution should be given in very small font to "J Ghent-Fuller, Alzheimer Society of Cambridge, ON Canada, 2000." Your own organizational contact information may also be on the pamphlet.

Books:

1. "*Thoughtful Dementia Care™: Understanding the Dementia Experience*", by Jennifer Ghent-Fuller was first published April 2012. Further information is available on the website, www.understanding-dementia-experience.com. (ISBN-13:978-1480007574; ISBN-10:1480007579). It is available in print as a paperback by ordering individually on Amazon, or can be ordered by bookstores through Amazon. It can be ordered at www.wordsworthbooks.com by telephone. It is also for sale as an ebook on Amazon and Smashwords (as well as many other platforms through those distributors).

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2. *"It Isn't Common Sense: Interacting with People Who Have Memory Loss Due to Dementia"* was published in January of 2013. (ISBN-13:978-1481995993; ISBN-10:1481995995)

"It Isn't Common Sense" was written for those who are just beginning to learn about dementia, as well as those who have experienced severe frustration in trying to communicate with the person with dementia in ways that are less likely to give rise to anger. This book provides a brief, easily understood, orientation to the causes and effects of dementia, assisted by carefully designed on-line search terms, which will lead the reader to explanatory illustrations. Reflective exercises are provided, in order to help the reader to build an empathetic understanding of the emotional context within which the person with dementia dwells (these could be used in a discussion group - purchasers may copy individual exercises for this purpose). Fundamental interaction patterns are explained. Soft cover, Amazon.com, 39 pages.

YouTube Talk - "Thoughtful Dementia Care™ "

The basic concepts of Thoughtful Dementia Care™, described by the author, Jennifer Ghent-Fuller. This talk was filmed at an Ontario Network for the Prevention of Elder Abuse (ONPEA) conference in Thunder Bay, Ontario, Canada on May 9, 2013. The video is presented as Part One and Part Two. Could be used as an orientation to dementia or parts of the video could be played to generate discussion in a group. The table of contents (including time lapsed markers and overhead slides used) of the videos is available on the website www.understanding-dementia-experience.com.

https://www.youtube.com/watch?v=YS4TLdDPz_c