



How to Understand and Help the Person with Dementia

A Practical Guide For Carers And Families

By Dr. Hamed Al Sinawi

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Foreword



Oman has triumphed over the recent years in furnishing medical intervention to its people. Along such quest, the country has instituted many eradication and prevention programs. Such development has able to lessen Oman from most of the challenges triggered by traditional enemies of public health, namely communicable diseases. However, it appears it would be premature to celebrate our success in communicable diseases. Instead, the clouds of non-communicable are rapidly assembling in our landscape. With increased living standards, many Omanis are living longer and naturally, some of tend to succumb to challenge of old age and the frailty that entail.

With the entrance of diagnostic tools, there is strong indication that the country is now coming to grip with disorders that compromise one's memory, thinking, language, judgment, and behavior, such as dementia. These disintegrations often lead to erosion of our identity. Being irreversible and progressive in nature, dementia literally devours different parts of the brain. As the disease progresses, the afflicted individual would have multiple physical, emotional and behavioral problems.

In the past decades a lot of understanding of mechanisms triggering the development of dementia has been proposed. Many promising pharmacological interventions have emerged. But as yet, being progressive and irreversible condition, dementia appears to be impervious to 'cure'. Therefore, more efforts are needed outside of the 'medical paradigm'. Hence, the importance of empowering the caregivers via self-help approach comes to the forefront.

This booklet which has amassed evidence-based practical guide for caregivers and the public, aims to disentangle the mystery of dementia using simple language, without the confusing medical jargons. Being a self-help guide, it aims to empower the caregiver on what is going on with their loved ones and some tips on how to cope. The afflicted loved one may lack awareness of their predicament and therefore it is the family that incurs all the burdens and distress of 'burying' the person they previously knew and trying to develop a relationship with literally a 'stranger.' Such stranger could have been once a father, mother, sister, brother or simply enduring partner, colleague or friend. This Booklet has the potential to empower the caregiver to deal with less affable stranger who was once seemingly own 'blood', to use Omani metaphor.

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Introduction



Dear patients and carers

Alzheimer's disease and other dementias are considered one of the most important challenges facing older people throughout the world, and one which prevents those suffering from it from engaging in their normal everyday activities. The accompanying behavioral problems experienced by people with senile dementia often lead to tension and pressure for their carers who have to witness their beloved ones behaving in ways which frustrate their attempts to help and take care of them. At present the available medications are not effective in "curing" this disorder but merely slow down the speed of deterioration.

The aim of this guide is to simplify Alzheimer's disease, explain the signs and symptoms and discusses the role of the carers in looking after their loved one with dementia. This guide also provides some practical and helpful suggestions to help the carers' in the process of looking after their ill relative on day to day basis. I hope that this booklet will answer some of your questions and increase your understanding about Alzheimer's disease and dementia in general. Additional copies of this book are available from the Old Age Psychiatry Team, Department of Behavioural Medicine, Sultan Qaboos university Hospital.

I hope you find this booklet useful, please feel free to send us your feedback

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Oman's Alzheimer's Society



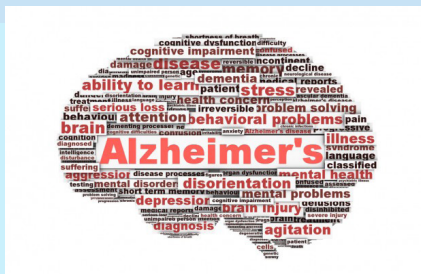
The Alzheimer's Society was born officially on 7th April 2013 (even though its members met regularly for the past year). The Walkathon held on that day had an objective of bringing awareness of Alzheimer's disease to the society. Judging by the responses and number of people who attended, it can be considered a success.

My personal experience began when my mother seemed to forget where she had kept her things. We did notice this forgetfulness, all of us in the family assumed that it simply due to old age senility. Subsequently and gradually she started forgetting where she was (physical location), could not recognize the people around her, often repeating questions that we had already answered her. At this stage we realized that this was not simply a matter of senility, we then took her to various doctors for consultations. The initial diagnosis was "dementia"; only to be confirmed much later that it was indeed Alzheimer's. The disease changed her personality completely; we didn't know what to do or how to handle her and ourselves. It was and still is hard watching her decline. I would spend the whole day watching her walking from one room to another not knowing what she wanted, and she didn't want people to do things for her because throughout her life, she was someone who was highly organized both on her personal as well as professional life. She had been a trained teacher (after completing her Secondary School education); she became a Headmistress and finally an Inspector. Her personal life was a life of refinement in her duties to her family, society, soft-spoken,

articulate, forgiving, always finding good in others, seldom criticizing people; instead often invoking Allah to guide that individual. It is extremely hard for me to write these words by referring to her in the past tense, because she is still physically alive. However, the reality is really not there anymore.

It was important to me to share my experiences with others so that they may learn (and I also) about the emotional upheaval resulting from having a close family member afflicted by Alzheimer's. Therefore I started to look for people here in Oman with the same problem as mine or who went through such experiences in the past. We made contacted met, initially once every fortnight then once a month. We were just a group of caregivers and health care professionals each of one of us had a family member with the disease or worked with patients who had it. At that time we called ourselves the Alzheimer's Support Group, where one of our major objectives was giving each other support. Now I am very proud (humble) we have established Alzheimer's Society in Oman.

AlSayyida. Thubayta Al Busaidi
Deputy chairperson, Oman's Alzheimer's Society



WHAT IS ALZHEIMER'S DISEASE?

What is Alzheimer's disease?

Alzheimer's Disease is an organic brain disorder named after German doctor Alois Alzheimer who was the first person to describe the disease in the year 1906. Subsequently, Doctors and scientists have discovered and learned a great deal more about this disease.

The onset of Alzheimer's disease tends to be accompanied with decline in the brain cells leading to memory, thought and behavioural problems. Such impairment tends to have net effect on the sufferer including difficulties in performing activities of daily living, continue to pursue their hobbies and their social interactions. Alzheimer's disease is a progressive disorder leading to increased deterioration of the sufferer all social situations. According to statistics by the World Health Organisation Alzheimer's disease is the fourth cause of death among people in developed countries. There is increased evidence that Oman is not immune to vagary of dementia.



Alzheimer's disease has no "cure" at present

The treatment currently available including medications reduce the signs and symptoms of the disease. These coupled with various other services and interventions can improve the lives of millions of sufferers who have to adapt to this illness. There are continuing and increasing efforts at the scientific/world level aimed at finding better ways and means for treating this disorder and minimising its effects on patients



What are the most common forms of dementia?

Dementia is a general term used to describe memory loss and other mental processes occurring to an extent sufficient to impair/interfere in the daily lives of people suffering from Alzheimer's disease which forms 60-70% of known cases.

A) Vascular dementia is the second most common form of dementia after Alzheimer's disease. It is caused by problems in the supply of blood to the brain

The symptoms of vascular dementia begin suddenly, for example after a stroke. Vascular dementia often follows a 'stepped' progression, with symptoms remaining at a constant level for a time and then suddenly deteriorating. Some symptoms may be similar to those of other types of dementia, such as Alzheimer's disease. However, people with vascular dementia may particularly experience:

- problems with speed of thinking, concentration and communication
- depression and anxiety accompanying the dementia
- symptoms of stroke, such as physical weakness or paralysis
- memory problems (although this may not be the first symptom)
- seizures
- Periods of severe (acute) confusion.

B) Dementia with Lewy bodies (DLB) : this is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for around ten per cent of all cases of dementia in older people and tends to be under-diagnosed. Dementia with Lewy bodies is sometimes referred to by other names, including Lewy body dementia

Dementia with Lewy bodies is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

- A person with DLB will usually have some of the symptoms of Alzheimer's and Parkinson's diseases.
- They may experience problems with attention and alertness, often have spatial disorientation and experience difficulty with 'executive function', which includes difficulty in planning ahead and co-ordinating mental activities. Although memory is often affected, it is typically less so than in Alzheimer's disease.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression, and changes in the strength and tone of the voice.:
- experience detailed and convincing visual hallucinations (seeing things that are not there), often of people or animals
- find that their abilities fluctuate daily, or even hourly
- fall asleep very easily by day, and have restless, disturbed nights with confusion, nightmares and hallucinations
- faint, fall, or have 'funny turns'



Is dementia hereditary?

There are two types of dementia: One is hereditary and this is transmitted via genes of one or both parents. The prevalence rate of this type is about 10% among those below 65 years of age. The second type of dementia is individual and is not hereditary and it affects those who are over 65 years of age.

There are certain causes leading to dementia. These include advanced old age and the presence of specific genes in certain individuals. People suffering from Down's syndrome are particularly susceptible to this form of dementia. There are other lesser causes such as chronic depression and head injuries. A relationship has also been established between the individual's general level of education and intellectual abilities and the likelihood of him or her suffering from Alzheimer's disease. That is, people with lower levels of education and who use their mental abilities less are more likely to suffer from this disease.



Pre-senile dementia

Signs and symptoms of dementia may appear between the ages of 40 or 50 years but this is less common and most cases of dementia occur after the age of 65.

People suffering from pre-senile dementia require additional care because their symptoms occur much earlier in their lives when they are expected to be more active both physically and socially and may still be working or involved in child rearing and have general and financial family roles and responsibilities.



Early signs and symptoms of Alzheimer's disease:

“Ahmed is constantly asking me where I am going, and follows me around the apartment. I have to tell him the same things over and over again, and he jumps every time I come into the room. He refuses to take a shower, and when I tell him it is time to take one, he lies and says he just did it. Yesterday, when our daughter came to visit with her children, he couldn't remember their names.

I kept saying, Ahmed you remember, these are Maya's children. He said he felt dizzy and went to his room. I feel as though I am living with a stranger". A wife caring for a man with dementia .

1. Difficulty in doing/ performing simple tasks such as food preparation or returning things to their places
2. Difficulty in remembering words and changing them with similar words but which do not convey the same meaning or the intended message and this leads to the language or communication of the person concerned becoming vague and not understandable by others
3. Disorientation to time and place and this may lead to the person having great difficulty remembering how to get back to their homes
4. Continuously misestimating things and getting things wrong.
5. Rapid and sudden mood changes without logical reasons for this
6. Changes in behaviour and personality and an increase in anxiety and obsessional thoughts and greater dependence on others
7. Poor motivation re work and life generally leading the individual to spend hours inform of the television or going to sleep.



Who is affected by dementia?

World statistics indicate that about 40 million people are affected by dementia worldwide

Dementia is not a natural part of ageing or a consequence of ageing, however, the longer we live the greater is our chances of developing dementia.

1. For those under 64 years of age, the prevalence rate is under 1%
2. For those aged 65-74 years of age, the prevalence rate is 1.5%
3. For those aged 75-84 years, the prevalence rate is 6.3%
4. For those over 85 years of age, the prevalence rate increases dramatically to 30%



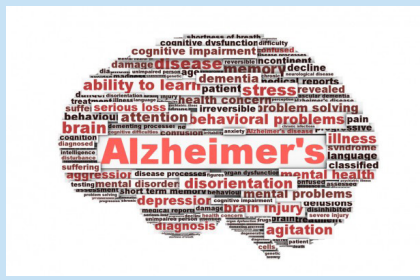
The importance of looking after yourself

Families and carers of people with dementia must take good care of themselves since the care they provide for their relative may cause physical and emotional

pressures amounting to exhaustion which may be very difficult to adapt to. This could lead some carers to forgo their own interests and activities and become socially isolated from the rest of society.

Many of the families and carers of people with dementia find it difficult to adjust and adapt to the changes in their relationships with the person with dementia.

This booklet offers a number of ideas to help you in understanding your special needs and the times when you may need help from others



LOOKING AFTER YOUR SELF

Each of us has strengths and weaknesses. Accordingly, each of us deals with the daily pressures including caring for someone with dementia in different ways.

The following points may help you to stay in good health.

1. What you can do to stay in good health:
2. Taking exercise like walking on a regular basis
3. Ensuring that you take a diet suitable for your needs.
4. Learning how to relax
5. Staying in touch and maintaining regular contact with your friends.



Your feelings

Caring for someone with dementia may affect your feelings and these negative feelings may surface from time to time.

Feelings of guilt, anger, frustration, sadness love, loneliness, helplessness, anxiety and general boredom.

Many of the carers of people with dementia suffer from feelings of loss. Such feeling remains with them throughout the development and deterioration of the situation of their relative. This could lead to feelings of great loss of their relationships with other family members. These feelings could linger on even after the death of the person with dementia.



Anxiety and confrontation

Each of us has his/her own way of dealing with crisis and pressures. Sometimes the anxiety may manifest in the form of bodily or physical symptoms such as fatigue and weariness. These pressures could affect the carers emotionally giving rise to feelings of great sorrow and sadness.

The signs and symptoms of exhaustion and weariness resulting from caring for someone with dementia could take the following forms:

- ☛ Loss of appetite for food
- ☛ Indigestion
- ☛ Headaches

- ☛ Mood changes
- ☛ Feelings of restriction and annoyance
- ☛ Slowed/laboured thinking
- ☛ Sudden bouts of anger

You may find the following strategies helpful in minimising and preventing yet more exhaustion and for dealing with stress and anxiety.

- ☛ Talking to friends
- ☛ Consulting a medical doctor
- ☛ Psychiatrist or clinical psychologist
- ☛ Joining a group or association of carers of people with dementia



How to explain dementia to others?

Many people do not understand dementia and how it affect the sufferer and his family and this means most often avoiding social gatherings because of fear of embarrassment that may arise due to the behavior of the sufferer, or because they do not know what to say when such a thing happens.

1. Tell friends and family as soon as possible
2. Take or accompany other family members to the doctor so that
3. They can answer any questions they may have



Friends and family

Friends and relatives may react in different ways to the person suffering from dementia. Some may continue to visit regularly, try to understand and help whilst others may accept what is happening but stop visiting.



Communication

Inability to communicate effectively with others is one of the most difficult and frustrating problems for the person with dementia. S/he may find great difficulty in understanding what is being said as well as great difficulty in expressing their feelings in a suitable way/manner.

Practical ideas/suggestions

1. Avoid conversations which contain many questions requiring an answer.
2. Use short and simple sentences and phrases.
3. Try to use hands movements and facial expressions to help the person with dementia to understand what is happening/going on.
4. Avoid noise and noisy gadgets such as radio and TV.



Personal Hygiene

The person with dementia may forget to how to take care of her/himself ad his/her personal hygiene and this aspect of care could become one of the biggest challenges creating problems and difficulties to both the sufferer and carers

Practical ideas/suggestions

- Ensure that sufferer has privacy when using the bathroom
- Ensure that washing and bathing is simple and explain every step.
- Make sure that the bathroom is warm and comfortable

Ensure that the environment is safe by providing suitable mats to prevent sliding and falling, and suitable handles fixed at appropriate heights to help the sufferer and use a suitable bath chair as necessary

- Arrange regular visits to the dentist to ensure that dental health including healthy gums and suitable dentures are available if required
- You may need assistance in cleaning the sufferer's teeth or his/her dentures
- Remember that it may not be necessary to have a daily bath



Nutrition

“At first, Mom would forget to eat. This was easy to manage by making her a plate of food and she'd eat. Then she started eating less and more slowly. Verbal reminders while she was eating handled this situation. Then Mom declined to where my father or I would feed her. This too eventually became a struggle as she would take bites of food, chew for a short time, and then forget to finish chewing or to swallow. We finally went to blended foods and liquid supplements. Mom had always made it clear that she didn't want

“artificial means to keep her alive-this included a ventilator and/or feeding tubes”. We honored her wishes and did the best we could. Feeding Mom would take an hour or more per meal.”

Carers of people with dementia have to ensure that their relatives have a good diet suitable for their needs and this presents another challenge. The person with dementia may have loss of appetite or he may be unable to masticate or swallow the food or drink taken/offered to him. Sometimes the person with dementia may develop excessive appetite and may show preference to sweets. They may also suffer from a dry mouth.

Practical ideas/suggestions:

- Offer small light meals such as cheese, natural yoghurt, dried fruit which does not need much preparation or cooking
- You may want to seek advice from a nutritionalist/ dietician or medical doctor.
- If there is difficulty in swallowing seek advice from a speech therapist



Urinary Incontinence

Urinary incontinence may create difficulty and be painful to both sufferer and carer. Ensure that all medical tests and investigations have been made in order to arrive at

correct diagnosis and to assess the situation since there are many cause of urinary incontinence. Any person could develop this condition and it may be possible to find an easy and simple solution. Urinary incontinence and constipation could cause urinary tract infections and it may be related to diabetic mellitus.

Practical ideas/suggestions:

1. Ensure that the person with dementia has sufficient intake of fluids.
 2. Reduce intake of caffeine and replace this with other fluids/drinks or decaffeinated drinks.
 3. Encourage the patient to use the toilet before meals and before going to bed and to use clothes that can be easily taken off.
- Ensure that there is adequate lighting during the night so that it is easy to find the toilet.



Sleep

Sleep problems and difficulties are common among people with dementia. Sleeping habits and patterns may change so that they sleep during the day and stay awake

at night. It is also possible that they may need to sleep fewer hours than previously.

Some older people may wake up at night to use the toilet but the person with dementia may lose his way returning to bed.

Practical ideas/suggestions

1. Keep a sleep diary to record times of sleep and number of times the person awakes
2. Discuss sleeping problems with the doctor who may make some suggestions regarding medications and the times when they should be taken
3. Depression can cause sleep problems so consult the doctor to ascertain if the person with dementia is suffering from depression or not
4. Make specific regular times for sleep
5. Ensure that the bedroom is comfortable and is adequately lit.
6. Reduce alcohol and caffeine intake.
7. Offer a light meal, herbal tea or warm milk drink before the person goes to bed.



Challenging or difficult Behaviour

Behaviour is a response to the feelings, circumstances and events in the individual's environment. The person with dementia may be unable to understand the changes to his brain functions resulting from dementia and may therefore be unable to understand what is happening around him or to express his feelings.

Among the factors that may affect the individual's behaviour are:

Type of dementia

- Low level skills and abilities previously and now
These traits
- Communication and motivation skills/skills need to engage people around the individual
- Among these factors are preoccupation or obsessions which could lead to explosive reactions in the person with dementia and this could lead to anxiety provoking behaviour or behavioural problems/difficulties
- These behavioural problems may become linked to other factors and situations including;
- Effect of the health and safety of the person with dementia
- Causing exhaustion to the families and carers
- Effect on the health and safety of others



Wandering

This may occur for various reasons:

1. Becoming lost or disoriented
2. Looking for people or places from the past enjoyment of walking
3. Discomfort such as tight clothes or wanting to find a toilet
4. Physical changes which have occurred in the brain that may cause a feeling of
5. Restlessness and anxiety
6. Being bored, restless or upset.

Practical ideas/suggestions

- Look for a pattern to the wandering.
- Is it aimless wandering, agitated pacing, or wandering away?
- Look for a reason. Is the person disoriented or confused?
- Does he or she believe there is something they have to do? Exercise such as walking may help if the person is bored.
- Take the person for regular visits to favorite places.
- If the person is seeking something or someone from their past or feels they have a task to perform, then alternative activities to meet these needs could be planned.

Precautions to take

- Try a lock the main door to the house.
- Advise neighbors about the wandering, and ask them to let you know if they notice him or her wandering.
- Have a recent photograph to give to the police in case the person gets lost.



Repetitive talk and actions

1. People with dementia may repeat actions and may constantly ask questions or say the same thing over and over again.
2. Repetitive actions and talk are very frustrating.

Causes can include:

- *Forgetting they have just asked a question.*
- *Anxiety, forgetting the answer*
- *Insecurity, and being confused by people, places or events.*

Practical ideas/suggestions

- Have the doctor check for a medical condition or medication side effects.
- Distract the person with other enjoyable activities.

- Avoid reminding the person that they have asked the questions.
- Use memory aids for people who can read, such as a daily schedule.
- Try giving a different response or turning the questions into a discussion.
- If the person has lost the ability it may be best not to discuss plans until necessary.
- Try to understand why the person is repeating the question or behaviour. Responding to the underlying behavior might help.



Over-reactions

You may find that the person with dementia may sometimes over-react to a trivial setback or a minor criticism. They may become very agitated or stubborn, scream, shout, make unreasonable accusations or laugh or cry uncontrollably.

This tendency to over-react is part of the disease.

Coping with this behavior can be very difficult and often a matter of trial and error. Remember that the behavior is not deliberate; it is out of the person's control and they are possibly quite frightened by it. They need your reassurance even though it may not appear that way.



Aggressive behavior

A person with dementia in some circumstances may be verbally abusive or become aggressive to the point of physical violence. This may occur when the person is misunderstood or provoked.

Attempts to physically restrain an aggressive person may produce a violent response.

Causes can include reactions to humiliating situations or people, frustration at not being able to complete a task, fear of unfamiliar surroundings or situations and reactions to the behavior of others.

Practical ideas/suggestions to prevent the behavior

- Have the doctor check for a medical condition or medication side effects.
- Avoid putting the person in situations that may produce anxiety, fear or disorientation.
- Try to prepare the person by explaining what is going to happen or where you are going.
- Try to avoid arguments. It can be better to agree with what the person says or does and then try distraction or humour or provide friendly help.
- Try to use encouragement, praise and affection

rather than criticism anger or frustration.-

Be aware of any warning signs that the person is becoming agitated.

- Ensure your own protection; leave the room or house and go to a safe place until the outburst is over.

Ideas to respond to the behavior

- Do not try to restrain the person.
- Avoid approaching until the person has settled down; stay out of reach.
- Try to avoid making the situation worse by shouting, abusing or touching the person.
- Try reacting in a calm voice or with reassuring words.
- Give the person time to settle down.
- Avoid punishment after the event.
- The person is unlikely to remember what happened and the punishment will not be helpful.
- Try to remember that it is the
- Illness and not the person causing the behavior.
- Seek assistance from a professional such as a doctor if you feel the need to Respond with aggression.



Suspicious and Accusations

As the person with dementia becomes increasingly forgetful or confused, he or

she may misplace or lose possessions or be unable to recognize familiar people or objects. Others may be accused of stealing their money or other possessions. Other accusations can be linked to personal relationships such as the claim that their partner is being unfaithful. They may become confused and accuse their partner of being someone else.

Practical ideas/suggestions:

- Check that the suspicions are incorrect.
- Try not to take false accusations personally. These accusations are associated with the brain damage and are not able to be controlled by the person with dementia.
- Try to keep the environment as familiar as possible.
- If possible keep a spare set of things that are often mislaid, such as keys or a wallet or purse.
- Distractions may help, Try to learn the person's favorite hiding places.
- Try to identify any pattern to the behaviour, such as accusations about a particular person, or the time of day it usually occurs. This may give some clues about why it happens – and what to do about it.



Hallucinations

Having hallucinations means seeing or hearing things that are not there.

Hallucinations can make the person frightened or agitated. Sometimes people with dementia may misinterpret or misidentify people or objects and this is not hallucinations. Some hallucinations may be ignored if they are harmless and do not cause the person to be distressed. They may reflect underlying feelings. Try to identify what these might be.

Practical ideas/suggestions

- Have vision and hearing checked.
- Have the doctor check for a medical condition or medication side effects.
- Ensure that rooms are well lit and there are no shadows that can be mistaken for objects. If the person seems frightened quietly reassure them.
- Encourage the person to explain what they are seeing or hearing, and discuss this with them.



Caregivers support group for Alzheimer's patients

The caregivers support group of Alzheimer's patients is an effective way to provide advice and guidance to carers by providing an opportunity

to connect with others going through the same circumstances and exchange practical ideas on how to deal with the patient and vent feelings of stress and depression, which may be caused by the pressures resulting from the provision of care for the patient.

The first group was founded to support the caregivers of Alzheimer's patients in the Sultanate in August 2012 and the group is made up of approximately 8-12 people from the families of Alzheimer's patients and caregivers who meet every two weeks and aims to meetings:

1. simplify the medical information of individuals by explaining the symptoms of Alzheimer's disease, how it progresses and how to deal with different behaviors.
2. Enable individuals to share personal experiences in how to deal with the difficulties associated with providing care for Alzheimer's patients.
3. To participate in various educational events to and contribute to the development of various programs to develop ways care Alzheimer's patients like Day care for the patients and caregivers training project.

If you are interested in joining the care of support group, please email us as at senawi@squ.edu.om

Life with an Alzheimer's patient

Each one of us has a reason for writing about something; be it for fame, for money, for entertainment or simply just for the sake of writing something that perhaps others may find interesting; the list of reasons is endless. One can find a million and one reasons for writing about anything.

I have only one reason for writing this article; sharing. In sharing there is hope that others may benefit, may avoid pitfalls, may be encouraged to continue to give of themselves whilst performing obligatory tasks or difficult, soul wrenching, emotionally draining tasks that befall and test them during their daily lives.

How does Alzheimer's differ from many other diseases?

The most important difference between Alzheimer's and many other disease is that "the victim usually has no idea what is happening". It is left to the family to witness in sadness and helplessness the slow disappearance of person they had known, had shared their lives with, laughed with, cried with and loved.

What to do when it starts ?

1. Acceptance: Once the disease has been diagnosed, accept the fact. This will be very helpful for you and the patient allowing you to come to terms with the condition and start to prepare for the future. It is also very important to let the people around you know the reality of the situation.
2. Plan ahead. Once you are aware of how Alzheimer's affect a person, think ahead and be ready for the changes that will follow. (both in the short and long term)
3. Maintain health of patient: Do your utmost to keep your patient healthy (ensuring that any medication for any ailment is regularly administered; provide good healthy food, balanced diet, expose them to fresh air as often as practical, etc)
4. Personal preparation (physically and emotionally):: There will be behavioral and personality changes in the patient; initially losing the ability to perform complex tasks, then later, even simple tasks. Be ready to guide the patient and carry out these tasks on their behalf. Do not

give them the impression that he/she is either hopeless or clumsy.

5. Understand the disease and stages of progression: Search for & read all the available information that you can about the disease. Find others who went through or are going through a similar or same ordeal and ask them questions. Obviously discuss your case with relevant doctors who will assist you with professional advice. Join a society if one is available. It is important that gain confidence through understanding that you are not alone.
6. Creation of a supportive environment: Patients may forget the names of common objects. It will not help to reprimand they will not benefit from an argument; it will make them sad and depressed. Show them love, don't make them feel silly. Give them emotional/spiritual support. If the patient is young and is able, engage him/her in interesting activities and expose them to social interaction with understanding people.

In the early stages of the disease, share memories and laughter with them as much as possible

Remember you are assisting a person not a disease

Although a person with Alzheimer's may not be

able to recognize you, he/she is very much capable of receiving love and kindness Personal balance. Try to maintain a sense of compassion, humor, and a willingness to learn new strategies to assist the person with AD, as well as yourself. The person with Alzheimer's disease (and you, as their caregiver) will experience many changes over the course of time. This can be frightening and requires flexibility of thought, deeds as well as personality. Both of you are undergoing a journey through unknown territory. Be kind to the person with AD and yourself.

Be prepared it's a lifetime commitment like bringing up a child. It's your duty; if help comes around take it as blessing; however do not be depressed if no one offers help or comes to visit. For many people, they would prefer to remember the patient as he/she was. Seeing the patient in such a state is emotionally upsetting for some people; therefore they stay away

Common question:

“How long do people with Alzheimer's disease live after developing the disease?”

After a diagnosis of Alzheimer's disease, a person lives from three (3) to twenty (20) years. Many factors

influence how long the patient will live. Knowing the life expectancy of someone with Alzheimer's is valuable information for helping both the patient and his/her family. Above all else, the Quality of life is key to everyone.

Hired help: If you do have hired help to look after your patient, relieve them once in a while. Take charge yourself.

Most importantly, take care of yourself and your emotional, physical and spiritual health. Talk about it to those who are willing and happy to listen. Do have a life of your own, do not be despondent and defeatist by waiting for the worse to happen.

The patient will not get better and it will take many years.

AlSayyida. Thubayta Al Busaidi

A poem for Mum:

All the time you are in front of me, and I in front of you,

Yet you are not the one who you used to be.

I look at your eyes when I am near, I see them blank,

And I would want to know what goes in there.

Amah, do you still see in me your darling daughter,

Or am I someone who is not known, a step farther.

You still smile and you still laugh,

And make me feel that I haven't lost all.

You held my hand and brought me up,

Now it's me who must hold you to live up.

I terribly miss what all we shared,

Yet I know that deep down you still care.

Why else your eyes fill with tears,

Whenever your soul feels I am in fear.

I am here ammi for all your needs,

For doing what I do are best of my deeds.

(By : Mrs. Fatima , caring for her mum who has Alzheimer's)

Summary

In this booklet we discussed the term Dementia and what signs and symptoms appear in the patient who is diagnosed with Dementia, we also discussed the different behaviors that makes it difficult, caring for persons with Dementia. This booklet provide you with practical tips that may help in dealing with such problems and situations.. Some of these tips may work better than others or you may have your own idea that work s with the person whom you care for. Remember every sufferer presents different characteristic and as carers we need to understand them and adjust our actions accordingly in order to minimize stress and exhaustion for ourselves.

Please feel free to share them with other carers.

We hope you find this booklet useful and welcome you feedback on:

senawi@squ.edu.om

References

1. Becoming a carer, a booklet about looking after someone with mental health foundation
2. Coping with dementia , a practical hand book for carers; Alzheimer Scotland .
3. Dementia the caring experience ;australin government department of health and aging

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The Ageing and Dementia Research Group at Sultan Qaboos University

The Ageing and Dementia Research group comprises of faculty members from the Department of Food and Nutrition, Department of Behavioral Medicine, Department of Pharmacology and Clinical Pharmacy, Department of Medicine and Department of Pathology.

Currently we are working on a Research Project funded by The Research Council, Oman (TRC) studying the effect of dietary supplementation on Alzheimer's Dementia (AD), Mild Cognitive Impairment (MCI) and Traumatic Brain Injury (TBI) (RC/AGR/FOOD/11/01).

The Ageing and Dementia Research Group at Sultan Qaboos University invites Omanis (aged 50 – 90 years) to participate in a research project examining the use of international tests in assessing memory and other brain functions

If you are interested, or know someone who could be interested, please contact us.