

Alzheimer's Caregiver Support Group:
Facilitator's Guide

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In collaboration with

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ON AGEING
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Introduction

Caring for a loved-one with dementia is a challenging and exhausting experience, not only physically but also emotionally, psychologically, and spiritually. Being a caregiver can be very isolating. Due to a lack of respite care, many caregivers find few opportunities to take a break from caregiving and to get out of the house, and as a result they often have little contact with social support structures. For these reasons, many caregivers feel not only overwhelmed but also alone in their struggles. Such isolation and hardship can take a heavy toll on caregivers' physical and mental health and wellbeing. Caregiver support groups can help.

Caregiver support groups bring individual caregivers together to talk about their experiences and feelings, share stories of caregiving successes and failures, learn information about the dementia disease process, tips for caregiving skills and stress management, and to get connected to helpful local resources. Additionally, participating in a caregiver support group has been shown to improve caregiver physical and mental health [21].

The National Council on Ageing and Mercy Care Centre realize the tremendous burdens and sacrifices of dementia caregivers. In an effort to lighten the strain on dementia caregivers, these two organizations are working together to create a caregiver support group program in Belize.

This facilitator's guide is the product of collaboration between the National Council on Ageing, the Mercy Care Centre, and nurse practitioner students from Seattle University in Seattle, Washington, USA.

What is Dementia?

Alzheimer's and dementia basics

Dementia is a general term used to describe the decline in mental functioning that is associated with many diseases, including Alzheimer's. Many people think of memory loss when they hear the term dementia—this is a common symptom. Symptoms of dementia also include the loss of other mental and cognitive functions, like of thinking and reasoning skills, judgment, language, and behavior[15]. **Alzheimer's (AD) is the most common form of dementia.** AD accounts for up to 80% of dementia cases. It is a general term for memory loss and the loss of other abilities, the loss of which eventually interferes with daily life.

Alzheimer's is not a normal part of aging. The greatest risk factor for dementia is advanced age and the majority of people with Alzheimer's are over 65, but it is NOT just a disease of elders. Some 5% of cases occur in people in their 40's and 50's. This most usually has a genetic component and is known as “early onset.”

Alzheimer's worsens over time. Dementia/Alzheimer's is a progressive disease; symptoms gradually worsen. Memory loss is mild in early stages, but in later stages Alzheimer's can rob individuals of the ability to carry on a conversation and respond to their environment. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others. Survival can range from four to 20 years, depending on age and other health conditions. **Alzheimer's has no current cure.**

Causes

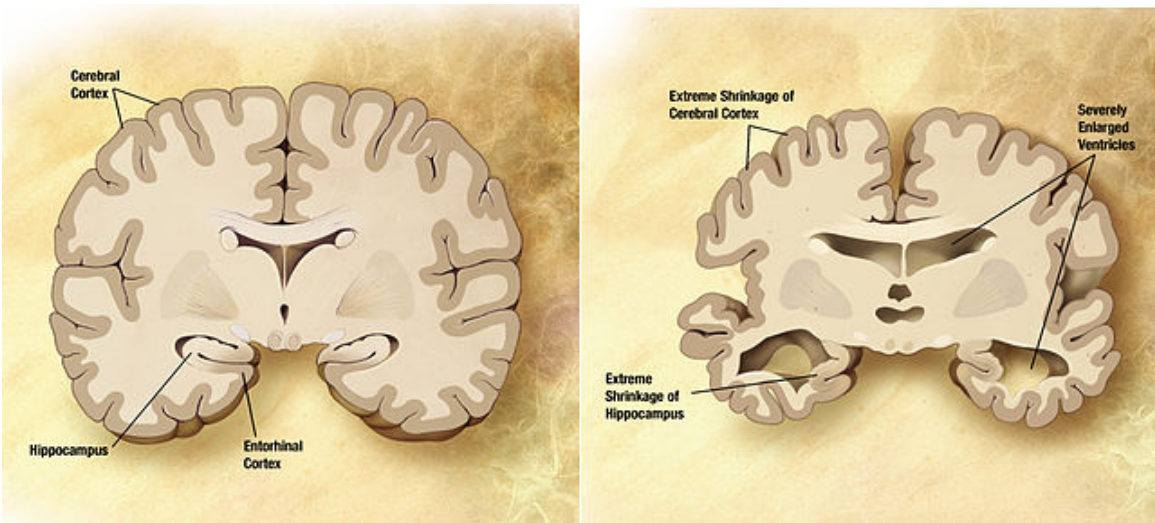
Dementia is caused by damage to brain cells in the form of what are known as beta-amyloid plaques and tangled tau proteins. This damage interferes with the ability of brain cells to communicate with each other. Without normal communication, thinking, behavior and emotions can all be affected.

While the exact cause of dementia is not fully understood, there are a number of risk factors that put certain people at higher risk of developing dementia in later life.

Risk factors for developing dementia
Advancing age is the #1 cause
Smoking
Excessive sitting/sedentary lifestyle
Depression
Sleep apnea
Delirium
Prior head injury
Type II Diabetes
High blood pressure
Obesity
Isolation
Chronic stress
Cardiovascular disease

[1]

The brain has many distinct regions, each of which is responsible for different functions (for example, memory, judgment and movement). When cells in a particular region are damaged, that region cannot carry out its functions normally. The image below from the US National Institutes of Health (2008) shows the extent of the damage that occurs to brain tissue over the course of the disease:



Different types of dementia are associated with particular types of brain cell damage in particular regions of the brain.

Alzheimer's disease: The region of the brain called the hippocampus is the center of learning and memory in the brain, cells in this region are often the first to be damaged. Memory loss is the earliest symptom of AD.

Vascular dementia (which is also a component of AD): damage depends on where the flow of blood to the brain is being interrupted and diminishing the oxygen supply to parts of the brain.

While most changes in the brain that cause dementia are permanent and worsen over time, some treatable health conditions may cause reversible thinking and memory problems.

Treatable health problems that may cause reversible memory loss
Depression
Medication side effects
Excessive use of alcohol
Thyroid problems
Vitamin deficiencies

[1]

Dementia treatment and care

In the case of most progressive dementias, including Alzheimer's disease, there is no cure and no treatment that slows or stops its progression.

Keep your loved one involved and engaged for as long as they are able to be.

Pages 19-37 describe some basic caregiving strategies and skills.

Diagnosis of Dementia

There is no one test to determine if someone has dementia. Your healthcare professional may diagnose Alzheimer's and other types of dementia based on a careful medical history, a physical examination, and laboratory tests.

She will observe to see if the characteristic changes in thinking, day-to-day function and behavior associated with each type are present. Determining the exact type of dementia is difficult, symptoms and brain changes of different dementias can overlap. “Dementia” may be diagnosed without a type being specified.

Warning signs:

- Memory loss that disrupts daily life—one of the most common early signs.
 - forgetting recently learned information
 - forgetting important dates/events
 - asking for the same information over and over
 - increasing need to rely on memory aids
- Challenges in planning or solving problems—
 - changes in ability to develop and follow a plan or work with numbers
 - difficulty paying bills, following familiar recipe
 - difficulty concentrating
 - take much longer to accomplish tasks than usual
- Difficulty completing familiar tasks at home, work or at leisure—
 - trouble driving to a familiar location
 - managing a budget
 - remembering the rules of a favorite game
- Confusion with time or place—
 - losing track of dates, seasons, passage of time
 - sometimes may forget how they got somewhere or why they are there
 - trouble understanding why something is not happening immediately

- Trouble understanding visual images and spatial relationships—
 - difficulty reading
 - judging distances
 - determining color or contrast
- New problems with words in speaking or writing—
 - trouble following or joining conversations
 - may stop in the middle of a conversation with no idea how to continue; repetition
 - may struggle with vocabulary; have problems finding the right word
 - call things by the wrong name
- Misplace things and lose the ability to retrace steps—
 - may put things in unusual places
 - may lose things and be unable to retrace steps to find them
 - may accuse others of stealing—may occur more and more frequently
- Decreased or poor judgment—
 - may experience poor decision making around money
 - may pay less attention to self-grooming
- Withdrawal from work or social activities—
 - may start to remove themselves from hobbies, social activities, work projects, sports
 - may have trouble remembering how to complete a favorite hobby
 - may avoid being social due to changes they are aware of
- Changes in mood and personality—
 - can become confused, suspicious, depressed, fearful, anxious
 - may be easily upset at home, work, with friends
 - may be extremely uncomfortable in unfamiliar situations or locations

Stages of Alzheimer's Disease

Remember: Stages may overlap so it is difficult to place a person in a single stage.

Stage 1: No impairment—this is a normal

The person is not experiencing any memory problems.

Stage 2: Very mild cognitive decline; may be normal age-related changes or earliest signs of dementia

The person may feel as if she or he is having memory lapses—forgetting familiar words; misplacing objects (keys may get put in the freezer). The memory loss is usually chalked up to “getting old.” Family, friends or co-workers will not notice.

Stage 3 Mild cognitive decline; early-stage Alzheimer's can be diagnosed in some, but not all develop these symptoms.

Person will notice increasing difficulty remembering. Family and friends begin to notice. Work performance begins to suffer. Healthcare professional may be able to detect problems with memory/concentration. Common issues include:

- Increasing difficulty coming up with the right word or name.
- Trouble remembering names when introduced to new people or remembering names of people already known.
- Work begins to suffer because of lack of attention.
- Reading becomes a problem. No memory of what they've just read.
- Having greater difficulty social settings.
- Losing or misplacing a valuable object.
- Increasing trouble with planning or organization.
- Increased anxiety as person goes into denial about what is happening.

Stage 4 Moderate cognitive decline—mild or early-stage Alzheimer’s disease

At this point, a careful interview by a healthcare professional should be able to detect symptoms in several areas and more symptoms become noticeable to family and friends:

- Forgetfulness of recent events; won’t remember headlines read that morning.
- Travel to even familiar places causes anxiety.
- Impaired ability to perform mental arithmetic—counting backward from 100 by 7’s.
- Greater difficulty performing complex tasks—paying bills, managing finances.
- Forgetting one’s personal history.
- The person will become more and more withdrawn and moody.
- Will shy away from any task that presents a challenge.

Stage 5 Moderately severe cognitive decline—moderate/mid-stage Alzheimer’s

Gaps in memory and thinking are noticeable to all; begin to need help with day-to-day activities. At this stage a person with Alzheimer’s may:

- Be unable to recall their own address or phone number.
- Become confused about where they are or what day it is.
- Have trouble counting backward from 20 by 2’s.
- Need help choosing proper clothing as they tend to choose inappropriately.
- Remember details about themselves and family.
- Remember names of spouse or children but have trouble recalling names of grandchildren.
- Require no assistance with eating or using the toilet.

Stage 6 Severe cognitive decline—moderately severe/mid-stage Alzheimer’s

Memory continues to worsen, personality changes may take place and they need extensive help with daily activities. Individuals may:

- Lose awareness of their surroundings.
- Remember their own name but not details of their history.
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of their spouse or children.
- Have trouble counting from 1 to 10.
- Start sleeping during the day and become restless at night.
- Increased help needed with daily activities: bathing, going to the toilet, dressing, and sometimes eating.
- Have increasing difficulty controlling their bowel or bladder.
- Agitation, anxiety, delusions, paranoia and sometimes violent behavior.
- Tend to wander.

Stage 7 Very severe cognitive decline—severe/late-stage Alzheimer’s

The final stage of the disease:

- Lose their ability to respond to their environment.
- Speech becomes non-existent.
- Total incontinence.
- Become unable to control movement—unable to walk or turn self in bed.
- Need help with most of their daily personal care—eating, using toilet.
- May lose ability to smile, sit without support, hold up head.
- Reflexes become abnormal.
- Muscles become rigid and swallowing is impaired.

[2]

Impacts on Caregivers

Caring for a patient with a dementia is a full time, around-the-clock job. Caregivers of dementia patients face incredible amounts of physical, emotional, psychological and spiritual strain. The act of caregiving in-and-of itself is enough to increase the mortality rate among caregivers [7]: so great are the burdens on dementia caregivers that four out of every ten dementia caregivers do not outlive the loved-one they are caring for [17].

There are a number of reasons that the strain of caring for a dementia patient is so great:

- Family and friends may not know how to act around the person with dementia, so may no longer feel comfortable visiting. As a result, caregivers can become socially isolated. This isolation and loneliness may be worsened if the caregivers have no help at home, making it difficult to leave the house and socialize.
- As the disease of dementia progresses, patients often have disturbances in their sleep-wake cycles. They are often awake and wandering in the middle of the night. This makes getting a good night's sleep nearly impossible for caregivers, adding sleep deprivation to their long list of hardships.
- Caregivers of dementia patients face not only the physical decline of their loved one, but also the emotional and psychological decline. As the dementia progresses, patients' personalities and temperaments can change. They may say mean things that they never would have said before the disease, repeatedly ask the same questions or engage in frustrating behaviors, or even act violently toward their caregivers. Caregivers often feel they are left caring for someone whose former positive, loveable characteristics have been replaced by an unrecognizable stranger. Struggling with this kind of change and ambiguous loss causes many caregivers to suffer from clinical depression.
- Caregivers often give up their entire lives, 24/7, to caring for their loved one. This can lead to reduced opportunities for exercise and self-care, which can lead to deterioration of pre-existing health conditions and development of new health problems.

Because of these factors, and because caregivers often put the needs of their dementia patients before their own, caregivers are at risk of becoming “the hidden patient” (Ballard, 2006). As mentioned previously, the health and well being of the dementia patient is directly tied to the health and well being of his or her caregiver. Even though the life of the caregiver is of equal value to that of the dementia patient, the needs of the caregiver are often subsumed by those of the patient. Caregivers’ work is tremendously difficult and they often have no one to advocate for them, nor the time to advocate for themselves. For these reasons, we must be extra vigilant to the health and needs of our dementia caregivers.

Benefits of Caregiver Support Groups

Caregiver support groups have many benefits for both caregivers and patients. As mentioned in the introduction, studies have shown that caregiving takes a heavy toll on caregivers' mental and physical health [4, 7,17, 21,22].Studies have also shown that the health of the patient with dementia is directly related to the health of his or her caregiver: the healthier the caregiver, the healthier the patient, and vice versa[22].

What some of the specific benefits of support groups for caregivers?

Benefits of support groups for caregivers
Normalization of the caregiving experience
Social support
Emotional support
Reduced isolation
Sharing success stories
Learning from other caregivers' mistakes
Sharing caregiving tips
A safe place to discuss difficult emotions
Appropriate outlet for feelings like anger, guilt, grief, shame, and frustration (these feelings are all a <i>normal part of the caregiving process</i> but non-caregiver friends and family may not be able to relate to or understand these feelings).
Learning factual information about the dementia disease process
Getting connected to useful community resources

Facilitating a Caregiver Support Group

Emotional Support & Factual Information

Research indicates that support group participants, in addition to benefitting from the social and emotional support of the group, value support groups as a place to learn more factual information about dementia [21]. Increased education about dementia makes caregivers more effective: they are better able to respond to patients' needs when they understand and can anticipate them. Furthermore, studies have shown that caregiver depression decreases as caregiver education about dementia increases, and when caregiver depression decreases, patient outcomes improve [22].

Types of information support group attendees may find helpful include:

- different types of dementia and how they progress and evolve over time
- how patients' symptoms may vary with the type of dementia they have and the particular stage of the disease they are in
- what to expect as the disease progresses
- basic caregiving skills, techniques, and strategies
- self care and stress management
- referrals to relevant, useful community resources

Leading a Support Group

Studies have shown that caregiver support groups do not need to be led by an experienced caregiver in order to be effective for participants [21]. In fact, support group facilitators don't even need to have previous healthcare experience to be effective facilitators [21]. So what makes a good facilitator? Successful, effective support group facilitators have some of the following qualities:

- Empathetic
- Supportive
- Non-judgmental
- Good listener
- Knowledgeable about dementia
- Effective teacher

- Regularly solicit feedback from participants

Successful support groups have leaders with these qualities, and they also have predictable structure, boundaries, and routines. Here are some guidelines for the general structure of a support group meeting:

- All participants, including the facilitator(s), should be seated in a circle
- Introductions: Each meeting should begin by going around the circle and having each participant introduce him or herself, sharing such information as:
 - Name
 - Whom they are caring for (spouse, parent, friend, etc.)
 - What type of dementia their patient has (if known)
 - How long they have been caregiving
- Housekeeping items: After introductions is a good time to address any housekeeping items that need to be discussed with the entire group (scheduling issues, announcements, etc.)
- Check-ins: After housekeeping, participants should be invited to share how they have been doing since the last meeting. Rather than going around in a circle, such check-ins should be impromptu. In other words, participants should only share if they feel comfortable doing so. Things participants may wish to share during this time include questions like: What challenges have they faced? What successes have they had? Importantly, participants should also be asked to reflect on moments of joy or positive experiences.
- The bulk of the meeting should have a theme determined by the facilitator each week. Some potential themes include:
 - a common idea raised during check-ins (for example, if many participants mention feelings of anger during check-ins, that emotion could be explored more deeply during this part of the meeting)
 - a predetermined topic prepared by the facilitator (for example, dealing with feelings of guilt, or discussing one of the factual topics listed above)
 - guest speaker (for example a local healthcare provider, professor, or representative of a community organization working with dementia)
 - informational video or other relevant presentation

- Closure: the facilitator should bring each meeting to a close, using a final thought, exercise for the week, quote, poem, prayer, etc.

[10]

Support groups will gain and lose members over time. People who have just become caregivers or only recently learned of the support group will join, and those who are no longer caregiving, or who no longer feel that they are benefitting from the group, will drop out over time. Both the arrival and departure of group members is significant and should be recognized as such:

New participants should be welcomed by the group, and facilitators should make a special effort to reach out to these members as they are the most vulnerable to stop attending before they are able to realize the benefits of participation. New participants should be helped to see both the benefits they can reap from participation, as well as the ways in which other participants will benefit from their presence.

Likewise, departing members' contributions over the course of the group should also be recognized with a special goodbye. Because all participants are experiencing issues of grief and loss as part of their caregiving roles, it is especially important for all group members—both those departing as well as those staying behind—that there is appropriate closure associated with group members' departure. All participants should be given an opportunity to say thank you and goodbye to departing members at the end of their final meeting. This could include sharing an anecdote about how the departing member has been helpful to them, a word of advice, or simple “thanks” or “good luck”.

Challenges

One common challenge that support group facilitators face is participants who either speak too much, dominating the discussion, or don't speak at all. Facilitators should never force participants to share when they are not comfortable. Rather, they can invite quieter participants to share by making open-ended invitations such as, “I'd like to give those of us who haven't shared yet today a chance to do so if they would like.” Statements such as this do not put shy participants on the spot, but do create space for participation by indirectly signaling to more talkative participants that now is a time for them to quietly listen.

An essential strategy for keeping groups running smoothly and ensuring that participation is beneficial for everyone involved is to regularly solicit feedback from participants. If caregivers aren't finding the group useful, they will not continue to give up their precious time to attend. If they are unhappy with the way things are going and see no way to improve them, they are likely to stop attending without saying why. On the other hand, if support group participants feel that their opinions of the group are valued and respected, and that their feedback will be taken into account and acted upon, they are much more likely to share both their suggestions for what's going well and what they would like to see change. It's likely that if one participant has a concern about something, other participants also share that concern, making this kind of feedback especially valuable for facilitators.

Soliciting this kind of input from caregivers can be done in a number of ways:

- Build it in to the routine of the group. For instance, at the closure of each group, invite participants to share feedback: share one thing that worked well for them about the group today, and one thing that they would like to see different next time.
- Make yourself available to participants outside of the group for feedback
- Have an anonymous suggestions box: participants may feel more open to sharing feedback if they can do so anonymously.

Encourage participants to share feedback both in terms of what is working well for them and what they would like to see change.

Basic Caregiving Skills

Communication Tips

No matter how difficult it may become or how confused the person may appear, continued communication with your loved one is very important.

Changes are unique to each person with Alzheimer's. In the early stages of dementia, the person's communication may not seem very different. He or she might repeat stories or not be able to find a word. As the disease progresses, a caregiver may recognize other changes such as:

- Using familiar words repeatedly
- Inventing new words to describe familiar objects
- Easily losing his or her train of thought
- Reverting back to a native language
- Having difficulty organizing words logically
- Speaking less often

Teepa Snow is a leading expert in working with loved ones with dementia. Her “Positive Physical Approach” [17] involves three primary initial aspects: **Visual; Auditory; and Touch**. As described below, before you attempt to engage your loved one in conversation or completing a task such as bathing, it is important to first engage him or her on all three of these levels.

Initial Approach of Person With Dementia:

Approach your loved one from the front, pause at the edge of public space (at least 6' away); call them by name, identify yourself by name. Greet with open palm up.

After your person acknowledges you, extend your hand to theirs. Shake hand, and change to underhand grip.

Move slightly to one side, out of direct range.

Keep good eye contact; if the person is seated or reclined, go down to that level (still slightly to one side).

Call the person by name.

It helps orient the person and gets his or her attention.

Use short, simple words and sentences.

Lengthy requests or stories can be overwhelming. Ask one question at a time.

Speak slowly and clearly

Use a gentle and relaxed tone — a lower pitch is more calming.

Patiently wait for a response.

Your person may need extra time to process what you said.

Repeat information or questions as needed.

If the person doesn't respond, wait a moment. Then ask again.

Turn questions into answers.

Provide the solution rather than the question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"

Use direct, literal statements.

Tell your person exactly what you need and mean for them to do. Describe the action directly. Use the name of an object (e.g. "here is your HAT"), it is a good reminder.

Be patient and supportive.

Let your person know you're listening and trying to understand. May eye contact and show the your loved one that you care about what she is saying. Be very careful to not interrupt.

Offer comfort and reassurance.

If he or she is having trouble communicating, be patient and tell them it's okay.

Encourage your loved one to continue with her thought.

Avoid criticizing or correcting.

Listen and try to find the meaning in what is being said. Do not tell your person that he is wrong. Repeat what was said if it helps to clarify the thought.

Avoid arguing.

Arguing will make things worse and further confuse him. It may heighten agitation and frustration.

Offer a guess.

If the person uses the wrong word or cannot find a word, try guessing the right one. Be careful to stop at a couple of guesses, repeated guessing can elevate the level of frustration your person feels.

Encourage unspoken communication.

If you don't understand what is being said, ask the person to point or gesture. You may want to design a simple picture board with commonly used tasks or words.

Limit distractions.

Find a place that's quiet. The environment should support the person's ability to focus.

Focus on feelings, not facts.

The emotions being expressed are more important than what is being said. Try and interpret the feelings behind the words (which may not be the one she is trying to find). Tone of voice and other actions may provide clues.

Refocusing Attention

For your loved one, loss of control and confusion can lead to insecurities about many things so that events are blown out of proportion. They interpret things from a fearful perspective, which may lead to incorrect notions and suspicion:

- Rain on the roof—someone is trying to break into the house.
- A misplaced item—has been stolen.

Remember these key concepts when attempting to redirect your loved-one's attention from a distressing thought:

- Validate whatever the person is feeling
- Do not attempt to be confrontational or try to reason with them
- Refocus on another task and away from the situation that is causing the anxiety

Examples:

Offer to help find her "stolen" purse and suggest you and she have something nice to drink after you've located it.

Tell Auntie that the noise she heard is probably raindrops but you'll check to be certain, refocus by telling stories, or reminisce about a family time.

Helping to Prevent Depression in Your Loved One

Unfamiliarity with tasks, surroundings and people can lead persons with Alzheimer's disease to become agitated and aggressive. To try and prevent this, do your best to help control their surroundings:

- Keep the noise and the crowds around them to a minimum.
- Make sure the room is not too light or too dark; or too hot or too cold.
- Monitor sounds and noise levels.
- Replace all glassware with plastic.
- Try and remain calm in all activities and to not rush.

If your loved-one gets agitated they may become aggressive toward you and/or start throwing things. It is hard but you must remain calm and try to redirect the focus.

- Be compassionate.
- Do not scold, argue or attempt to reason with them.
- Find out if they are hungry, thirsty or need to use the bathroom.

Their behavior may be the result of physical discomfort or a silent infection such as a urinary tract infection find out as much as you can from them...then use your detective skills.

It may be the result of a medication side effect. Review medications with the doctor or nurse.

Dealing with Combative Behaviors

One of the most challenging aspects of caring for a loved one with dementia is dealing with their unpredictable behaviors. Understanding the nature of the type of dementia is critical to understanding and responding to behaviors.

Example: Fronto-Temporal Lobe Dementias— rare neurodegenerative dementia

Since the frontal lobe of the brain controls our “higher, executive” functioning, have that part of the brain diminish means that a person may lose those controls sooner. He may say unexpected, rude or odd things. Behavior is often impulsive. They have a tendency to lash out. They have lost their “filters.”

As Lisa Gwyther, a clinical professor at Duke Medical Center says, “Even in the most secure environments, unprovoked combative or unsafe behavior may occur without warning.” [11]

In all forms of dementia changes in behavior may be brought on by
Physical discomfort
Over-stimulation
Trying to complete a too complicated task
Communication frustrations
Unfamiliar surroundings and/or social situations

Triggers must be identified or the problem may worsen.

The most common triggers for combative behaviors
Fear
Misperception of a non-existent threat
The inability to communicate desires
Frustration about a multitude of issues
Depression

Your loved one most likely will exhibit aggression out of frustration because their familiar world is no longer familiar; not much makes sense to them anymore.

Here are a few tips to minimize the likelihood of aggressive behaviors:

- Learn the signals, verbal and non-verbal, that your person demonstrates as signs of increasing agitation—clenched fists, rapid eye movements, hand gestures, muttering, louder and louder voice.
- Divert attention—offer treat or favorite “comfort” item to them.
- Create a “memory box” and have it available to remind them and distract them
- Do not make demands but ask for their help with some small task
- Allow plenty of time to complete the task
- Change your person’s environment; it may be they are overstimulated and need a quiet space
- Slow down your own actions; lower the register of your voice; stay calm
- Avoid letting them watch loud, action television shows; play soothing music instead

What to do if your Loved One Becomes Combative

Agitation:

- Slow down, speak in a soothing voice
- Offer encouragement, praise them on...their pretty blouse
- Use visual cues—adjust the light in the room to a lower, more calm inducing level
- Back away from them; ask permission to approach
- Repeatedly reassure them that they are in a safe place and you are listening to them
- Ask them to help you—redirection
- Offer them a “safety object,” ask if they like to rest in their room
- Let them know you will stay with them until they feel safe

Catastrophic Reactions: Reaction way out of proportion to the situation

- Always use a calm approach; keep relaxed and non-threatening
- Use positive communication; be open and friendly
- Call your person by name and establish eye contact with them; let them know who you are
- Speak slowly and clearly
- Do NOT confront; do NOT ask for an explanation
- Speak in short, uncomplicated sentences
- Provide frequent reassurance
- Touch them only to guide them to a safe place; if touch has a negative effect—back off

Do NOT “gang up” on a person about to lose control; they can be triggered to become even more physically aggressive. Restraining someone does NOT reduce aggression, it may escalate it.

The Ten Absolutes:
Never argue: agree—no matter what the issue
Never shame; distract instead
Never say “remember?”; use reminisce
Never say “you can’t”; use “do what you can”
Never try to reason; divert attention
Never lecture; reassure
Never say “I told you already”; take a deep breath and ...tell them again
Never command or demand; ask politely
Never force; reinforce

And...

The 5 R’s
Remain calm
Respond to feelings
Reassure the person
Remove yourself
Return later

[5, 6, 9, 11]

When dealing with physical aggressive behaviors:

Use the above techniques to try and diffuse whatever the situation is. If you feel as though you are in danger of injury, remove yourself from the situation. If your person is escalating, try and calm them before they become physical; make sure there are no objects in the vicinity that can be used to for self-harm or to harm you.

Remember: Your loved one is NOT acting this way on purpose, it is the disease. Try and remain calm, and **respond to the emotion, not the behavior.**

Preventing Stiff Joints and Muscles

These images from the Health Education and Training Programme [12] illustrate some of the ways you can help your person to exercise their joints and muscles to prevent stiffness and contraction due to pain, or lying still for a long time.



Exercise the elbow by gently bringing the hand as close as possible to the shoulder.



Exercise the wrist by moving it around in circles.



Exercise the shoulder by lifting the arm up and bringing it behind the head and gently laying it back as far as possible.



Exercise the knee by lifting the thigh up and bringing it close to the chest as far as possible.

Eating

For our loved ones with Alzheimer's Disease and related dementias, eating related challenges may be a result of:

- **Cognitive issues**—your loved one may not be able to let you know when they are hungry; they don't know how to start eating and once they start, often they just stop eating when they've forgotten what they are doing; they often cannot tell which is food and which is plate due to visual-perceptual challenges.
- **Behavior and psychosocial issues**—depression often causes appetite reduction; they may be distressed or pacing so they can't sit still to eat; and pacing uses up calories they can't afford to waste.
- **Physical problems**—they may be unable to hold and use utensils; they may be too tired; have tremors; have decreased depth perception; they may have dry mouth or swallowing issues.
- **Environment issues**—too much noise, confusion, visual stimulation; poor lighting, uncomfortable temperatures all serve to distract from the business of eating.
- **Food related issues**—too many food choices at once; they may have difficulty eating what is on offer; the presentation of the food may not be appetizing.
- **Chronic disease**—co-morbidities associated with dementia such as diabetes, intestinal or cardiac issues will cause appetite decrease.
- **You, as a caregiver, may feel too stressed and burdened about the time it takes to make certain your loved one eats enough.**

Tips to Ensure your Loved One Gets Enough Calories

View meal times as opportunities for interaction; using a warm, happy tone can start it off right.

- Try to make mealtime calm; be patient, avoid rushing, give your person enough time to finish.
- Be aware of possible frustration, confusion and anxiety; look for ways to diffuse these.

- Finger foods—use them. Make them as nutritious as possible and have them available throughout the day; they promote calorie intake and independence.
- Try to maintain the same mealtime; be flexible as needs change.
- Minimize distraction during the meal.
- Offer foods that are familiar; offer different textures and colors; allow your person to make choices.
- Help maintain hydration by helping your loved one drink plenty of fluid throughout the day; dehydration can lead to many issues—increased fall risk; constipation; electrolyte imbalances→confusion.
- Use adaptive tools as needed—there are available modified utensils available.
- Maintain routine dental checkups; daily oral health
- Be alert—address any potential safety issues; risk of choking—chewing and swallowing problems may arise during the course of the disease.

Remember to take care of yourself! Your needs are just as important as your loved one's, so be sure you are also enjoying a satisfying and nutritious diet.

[13, 16]

Bathing

It is often difficult for persons with dementia to remember hygiene. Included in that is bathing. For a person in an altered mental state to be undressed and cleaned by another person can be extremely frightening and embarrassing. So bathing can be a time of distress and stress for your loved one and you. Here are some tips to remember to help the bathing process go more smoothly:

- If your loved one is taking medications for pain administer those about 30 minutes before bath time. This helps prevent any unnecessary pain triggers.
- Gather supplies: Several large towels (bath blankets if they are available); washcloths; soap; shampoo
- Have a shower chair in the tub so your loved one can sit down while bathing; cover the seat with a towel

- Ask them if they are ready to bathe; do not order them to do so.
- Make sure the room where the bath is to be given is warm
- Play your loved one's favorite music during bath time so it represents a pleasant experience.
- Keep as much of the body as possible covered to avoid embarrassment, you can wash one part at a time.
- Keep her/him warm:
 - keep covered with warm towels as much as possible
 - keep the bath water warm
- You can reduce your person's fear of the bath by:
 - adding non-skid surfaces to everything
 - make sure their feet are on a solid surface and not dangling
 - avoid spraying water directly at any body part as direct spray can be frightening and/or painful; you can put a cloth over the hair and pour water through that to wet hair
 - be sure and communicate each step as you go; tell them exactly what you'll be doing next and why.
 - provide choices throughout bath time; if there is a choice of soap or shampoo, let them choose which. This will give them a sense of control.
 - let them do for themselves as much as possible; hand them the soap and tell them to "wash your arm."
 - put your hand over theirs and guide them in the motions
 - be gentle—an elders' skin is fragile, no scrubbing is necessary and might cause damage
 - be sure and wash those hard to reach, out of the way places where bacteria like to grow.
- Hair Washing:
 - use as little water as possible, and pour it over your loved one's head rather than spraying it
 - make certain to deflect water and shampoo away from the face with a washcloth

- use as little shampoo as possible to cut down on the need for rinsing
- After bath care:
 - check for rashes and sores
 - pat skin dry
 - apply lotion to keep skin soft
 - use powder or cornstarch under breasts and in the creases/folds of skin

Bathing in Bed

Eventually, you may have to bathe your loved one while they are lying in bed. This can seem awkward at first but following these steps can help make the process as comfortable as possible for you and your loved one:

- First, gather supplies:
 - thick towels
 - waterproof sheet if available
 - washcloths
 - soap; shampoo
 - two large bowls—one for wash water; one for rinse water. Fill these with warm water.
- Lay the thick towels under your person; put the waterproof sheet under the towels if you have one
- Cover her with a blanket and undress her while keeping her covered; keep the blanket on her during the bath
- Put the water bowls within reach
- Stand at your loved one's shoulder
- Start with the face; wipe with a warm washcloth; no soap is necessary
- Wash and rinse one side, then move to the other and repeat the process
- Uncover one body part at a time and soap and rinse each; remember—not much soap is used, it's harder to rinse.
- **Make sure you talk to your loved one the entire time; keep her informed of what you are doing
- Wash her genital region last

- Wash around the labia
- Be gentle

To shampoo your loved one's hair in bed:

- Place a soft, plastic bowl near your person's head; lift the head slowly to the edge of it
- Wet the hair and wash with an easy to rinse shampoo
- Rinse and dry

Toileting

If possible, set up the bathroom to make it as easy as possible for your person to get on and off the toilet. Have a raised toilet seat and grab bars if that is feasible. Try and be aware of signals that she/he needs to use the toilet:

Nonverbal cues that your loved one may need to use the toilet
Agitation
Fidgeting
Tugging on clothes
Wandering
Touching genital area

Other tips for successful toileting include:

- Try and take the person to the bathroom on a regular schedule. Every 2-3 hours is a good schedule.
- If your person needs help removing clothing-- help her/him by moving slowly, saying what you are doing, encouraging them to help.
- Remind her that she needs to pull down her pants or lift skirt before sitting.
- Don't rush; allow time to empty bowel and bladder. It may take a minute to get started. Go back in a few minutes or stand just outside the door in case they need help.
- Hand toilet paper to use. You will eventually need to do this part for them. Using infant wipes is easier than toilet paper.

- Assist in getting clothing back in order.
- Put a sign with a picture on the door. Keep the door open when not in use so person can see the toilet.
- If possible, use commode chair or urinal by bed at night to reduce the risk that your person will get up and fall in the night.
- Often an elder will, for fear of incontinence, stop drinking water and become dehydrated which increases the risk of falls and urinary tract infections. Make sure they are drinking plenty during the day. Limiting fluids in the evening may help cut down on falls at night.
- Keep path to toilet free of obstacles and objects that could possibly be mistaken for a toilet.

Moving a bedridden person

You need to know how to move a bedridden person if you are on your own. If your loved one is unable to assist, it is better to have two people to help with moving her/him, but this is not always possible. When transferring your loved one from the bed to a chair, use the procedures shown in the illustrations below. This will help to protect you and your loved one from strain and injury.

1. Roll the patient on one side



2. Move the patient to the side of the bed. Ask the patient to bend legs and to prop on the same side elbow



3. Hold your hands on the patient's pelvis, ask to raise him/her buttocks. Sit patient on the edge of the bed with feet flat on the floor



4. Stand in front of the patient and hold both shoulders. Keep patients feet flat on the floor



5. Help patient raise bottom from the bed and rotate him/her towards the chair



6. Transfer from bed to chair. Hold patient by shoulders and knees



Shifting to Avoid Sores

A **bedridden patient** is one who is too sick to get out of bed at all, or only for short periods.

To prevent bedsores, you should do the following:

- Help the your person out of bed and into a chair from time to time if possible.
- **Lift** the patient up off the bed slowly — do not drag the person's body as it breaks the skin. Ask a family member to help you — two people can do this much more easily than one, and it is safer for everyone...you and your loved one.



- Encourage your loved one to move around in the bed as much as they are able to. If they cannot move, change their position on the bed frequently, if possible every one or two hours. Use pillows or cushions to help them keep the new position.
- Keep the bed sheets clean and dry. Put a soft, cotton towel under your person for extra padding and absorbency.
- Look for damaged skin (change of color) on the back, shoulders and hips every day. Massage the back and hips, elbows, heels and ankles every day with any soothing cream or oil. This helps to prevent 'bed sores' from developing.

[12]

Caregiver Self-Care and Stress Management Techniques

Caregivers experience a great deal of stress and often have little or no time to themselves to relax [17]. This stress takes a toll on caregivers' health, which affects their ability to be effective caregivers and ultimately impairs the health of the very loved-one they are caring for [22]. Therefore, it is important for the sake of the caregiver as well as the patient that caregivers find ways to take care of themselves and manage their stress.

What are some signs that a caregiver may be over-stressed?

<i>Physical</i> indicators of caregiver stress
Constant fatigue or lack of sleep
Weight gain or weight loss resulting from change in eating habits
Tight muscles, clenched jaw, sensation of overall tension
Joint pain
Frequent headaches, stomach aches, or other, new physical problems
Shaking, jerking, hyperactive reflexes
Startle easily
Eye discomfort or strain

<i>Social</i> indicators of caregiver stress
Not getting out of the house much
Not talking to or interacting with others when out and about
Getting angry or irritable with other people
Getting sad
Wanting to go back home as soon as you go out
Ignoring family, friends, and people you usually love to be around
Limiting contacts, ignoring friends' and family's attempts to connect
Losing interest in things that you used to enjoy

[17, 24]

Caregiver support groups are one great way for caregivers to get some time out of the house, away from the patient, to emotionally vent and unwind. However, caregiver support groups may not be effective or accessible for every caregiver. The following is a list of strategies caregivers may use to help manage stress:

- Be willing to ask for and accept help from others (see page 39 for suggestions on how to ask for help from family and friends).
- Make sure to eat a healthy diet and get exercise as frequently as possible.
- Make sure to attend to your own physical and health needs as well as those of your loved-one. Keep regularly scheduled doctor and dental appointments.
- Hold reasonable expectations for yourself. You may not be able to keep your house as clean, do the laundry as regularly, or keep up as well with other day-to-day responsibilities. That is ok.
- Set reasonable limits and make them known to the people in your life. Don't be afraid to say "no" to requests that you are unable or unwilling to meet.
- Make a point of keeping company only with friends who make you feel good. If spending time with someone makes you feel worse, not better, limit the time you spend with that person. Maximize the time you can spend with people who make you feel happy.
- Go for a walk.
- Have a cup of decaffeinated coffee or tea (with a good friend if possible!).
- Take a bath, or soak your hands and/or feet in a tub of cool water.
- Stretch.
- Read a chapter of a book you enjoy.
- Do something that makes you laugh.
- Garden.
- Reflect on favorite past memories.
- Listen to music or other soothing sounds.
- Sing a favorite hymnal.
- Sit in the sun.
- Say or read a prayer.
- Write in a journal.

- Know yourself: if you re-energize by being around other people, seek out social opportunities. If you re-energize by being alone, find some time for solitude.

[17, 24]

Caregiving affects almost all aspects of caregivers' lives, and often they feel that they no longer have time to do the things they used to enjoy. Before deciding that activities you used to enjoy no longer fit into your life, consider the following options:

- Is there a different time you can do your favorite things?
 - Perhaps you used to exercise first thing in the morning. Maybe now you can stretch during your loved-one's afternoon nap.
- Is there a different place you can do your favorite things?
 - If leaving the house for extended periods is no longer an option to visit friends, consider inviting your friends to visit you at home.
- Can you spend a different amount of time on your favorite things?
- You may not have the same amount of free time to spend doing your favorite things, but spending a few minutes a day on activities that bring you joy and relaxation is better than no time at all.

[24]

Even simple relaxation exercises that take just a few minutes and require no special props or equipment can be surprisingly helpful.

- Diaphragmatic Breathing:
 - Sit or lie down with a pillow behind the small of your back:
 - Breathe in slowly and deeply, pushing your stomach outward.
 - Think the word "relax" in your mind before you exhale.
 - Slowly let the air out, letting your stomach fall back down.
 - Repeat ten times, remembering to breathe slowly and deeply.

[25]

➤ Progressive Deep Muscle Relaxation:

- Sit in a chair with your back straight, both feet on the floor, and hands in your lap.
- You will tighten the muscles in your body, holding them flexed for 15-20 seconds, and then slowly relaxing them.
- As you release the tension in each muscle, focus on the difference in sensation between your muscle when it is tense and when it is relaxed.
- Start with your forehead and work your way down to your toes, one muscle at a time.

[25]

Ultimately, there are no “rules” about how to take care of yourself. Pay attention to your own physical, emotional and spiritual needs. Do whatever brings you joy, whenever you can fit it in to your unique schedule and circumstances. The journey of caregiving is long and unpredictable—so it’s important to take care of yourself. If your own needs are unmet, you will not be able to adequately care for your loved-one, or anyone else who may rely on you. Remember that your own personal needs are just as important as the needs for the person you are caring for.

Asking for Help

Many caregivers feel isolated and alone in their caregiving journey. Often caregivers feel that caring for their loved one is their responsibility alone. Family and friends who were once a frequent presence may become more distant as the dementia progresses, because they might feel uncomfortable or not know how to act around someone with dementia. Here are some suggestions for how to ask for help:

- Make a list of all the things you could use help with. Your list should include caregiving tasks, as well as other tasks. Some friends and family may feel more comfortable helping you with grocery shopping or housework than with direct caregiving tasks.

- Consider which items on your list are best done by you, and which items are appropriate for family and friends.
- Keep your list handy so that when a family member or friend offers to help, you have a specific task you can suggest.
- Give choices to people who are offering to help. For example, if you need groceries, you could give a helper your grocery list and have them do the shopping for you, or offer to have them stay at home with your loved-one while you go to the store.
- Some family members or friends may feel uncertain of how to act around your loved one because they are unfamiliar with dementia. Providing them with some information about dementia may help put some of their fears at ease. For instance, it may be helpful to share with people that dementia is not contagious, or give them specific suggestions of activities that your loved one enjoys. Even if he or she can't engage in conversation, your loved one may really enjoy being read to or listening to music. Giving helpers specific suggestions can help make them more comfortable in their interactions with your loved ones.

[24]

Local Resources

Health and Allied Services

- **The Mercy Care Centre** provides a holistic approach to the well being of older people in the community. It provides a walk in and outreach medical services with a well-stocked pharmacy. There is a small chapel on site for older persons to find peace and solace. The recreation room/ dining room provides space for games and social activities .It is looking to provide a physiotherapy service this year.
- **The Mercy Kitchen** (in the same compound) provides breakfast and lunch to over 100 older persons daily.
- **Belize Centre for the Visually Impaired(BCVI)** provides a service to all members of the community but offers a reduced cost service to older persons, which includes eye examinations, eye surgery and glasses.

Social and Community

- **HelpAge Belize** provides social support to older persons Monday - Friday at their Centre. A limited home care service is offered each morning to house bound in the community and a variety of activities each afternoon, except Thursday, when a meals on wheels service is offered. Activities include Games, Craft, Exercise, and Fellowship.
- **Belize Red Cross** provides a meals service once per week to older people.
The Mental Health Resource Centre provides day facilities for the homeless and mentally ill, many of which are elderly people. Here they can bathe, change clothes, enjoy a hot meal, watch television, play games and socialize. A laundry service will be provided for the community very soon.
- **Young Women's Christian Association (YWCA)** although primarily offering a service to young women, the YWCA also opens up their facilities to older women who enjoy social activities at the Centre.

- **VOICE Belize City** is an advocacy group of older persons who are based from YWCA but hold meetings at the Samuel Haynes School of Excellence. They advocate for improved services to be provided to older persons including access to better healthcare, financial benefits and transportation.
- **Church Groups:** There are numerous church groups that, from time to time, provide meals for the elderly and the homeless.

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