Navigating the World of Alzheimer's Disease: An Educational Guide for Family Members

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Abstract
Alzheimer's Disease (AD) is a condition which deteriorates the brain and results in a form of dementia. Its the sixth leading cause of death in the U.S. and its symptoms have significant impact on both individual with AD and their caregivers. Family members are often confused and overwhelmed with an AD diagnosis. This thesis incorporates a comprehensive literature review that addresses four significant areas of need for individuals with AD: Feeding, communication, behavioral, and activities of daily life. The booklet highlight the importance of family education as they navigate the unfamiliar road of AD.

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NAVIGATING THE WORLD OF ALZHEIMER'S DISEASE: AN EDUCATIONAL GUIDE FOR FAMILY MEMBERS

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What is Alzheimer’s Disease?

Alzheimer’s Disease (AD) is a neurodegenerative condition, that results in a form of primary dementia. Dementia is characterized by progressive deterioration of memory and other cognitive domains such as attention, and executive functioning, which comprises of communication skills and ability to perform Activities of Daily Life (ADLs). Giving its progressive nature, those with Alzheimer’s disease, will continue to experience worsening of symptoms until their inevitable decease.

Cause

Alzheimer’s disease is the sixth leading cause of death in the U.S., but the research of its cause is still underway. Experts believe this disease develops as a complex result of not one, but multiple biological factors such as age, family history, and the presence of the APOE-e4 gene. It is important to note that Alzheimer’s disease affects not only the individual, but also their family and caretakers as the disease currently has no cure.
Stages of Alzheimer’s

Alzheimer’s disease consists of three main stages in which individuals present a spectrum of symptoms. Early stage Alzheimer’s consists of general forgetfulness when trying to find the right words, remember new names, recall something one just read, and misplacement of items. Once an individual has reached middle stage Alzheimer’s, they will experience mood swings, have a change in sleeping patterns, start to wander, and forget personal identifiers such as their phone number and address. By late stage Alzheimer’s individuals will need round the clock care as they lose awareness of their surroundings and happenings, as well as their ability to communicate, walk, chew, and even swallow. Nearing the end of their life, individuals with Alzheimer’s become highly susceptible to infection, especially pneumonia due to their inability to properly swallow. Many individuals with Alzheimer’s die as a result of aspiration pneumonia, severe dehydration, and malnutrition because they no longer to eat or drink.
Importance of Education

Family members often become responsible for providing daily care for their loved ones with Alzheimer’s. Such responsibility can become overwhelming for anyone, especially for those with little to no knowledge or experience with the disease. Therefore, it is crucial for family members to receive education on Alzheimer’s disease in order to competently navigate the unfamiliar road ahead.

This guide aims to provide key information to family members in four major areas of difficulty among individuals with AD: Feeding, ADLs, Communication, and Behavioral issues. The information provided in this guide is intended to:

✓ Eliminate confusion
✓ Alleviate anxiety
✓ Build confidence
✓ Provide support
✓ Foster empowerment
✓ Cultivate and allocate advocacy
Feeding Difficulties

Individuals with Alzheimer’s often have issues meeting their nutritional needs as their disease progresses. Decreases in food/fluid intake may be caused by a slew of reasons, including but not limited to:

- Depression: your loved one may feel lonely, worthless, and ultimately lose hope, resulting in a loss of appetite and weight.
- Communication Issues: as Alzheimer’s worsens, your loved one may no longer be able to communicate that he/she is hungry or thirsty.
- Motor Issues: as the disease progresses, your loved one’s fine motor skills, including gripping normal sized cutlery, holding a cup steady, or sucking from a straw, may deteriorate and result in the inability to feed him/herself.
- Pain: common issues which may cause your loved one pain and detour him/her from eating include, but are not limited to, poor fitting dentures, sore gums, painful teeth, digestive issues, muscle fatigue, soreness, and stiffness.
• Fatigue: your loved one may lose concentration while eating, experience coordination issues, and fall asleep during meals due to fatigue.

  • Medications: certain medications may cause nutritionally counter-productive side-effects. These may include fatigue, nausea, lack of appetite, constipation, bloating, dry mouth, etc.

• Physical Activity: your loved one may experience weight loss due to inactivity, as he/she is unable to exercise enough to stimulate appetite.

• Change in Dietary Preferences: taste often diminishes due to the aging process and memory loss may cause reversion to favorite childhood foods.

• Loss of Appetite: inevitable symptom that your loved one will experience when nearing the end of life.

• Swallowing Issues: your loved one may experience dysphagia (swallowing difficulties). Signs of dysphagia include: coughing/choking when eating, need of extra time/effort to eat, drooling/food spilling from the mouth, sounding congested or having a wet/gurgly voice after eating, frequent bouts of pneumonia, or unintentional weight loss. A swallow evaluation is by a speech-language pathologist is recommended to determine if dysphagia is present.
Feeding Strategies

The following are strategies for individuals with Alzheimer’s who experience feeding difficulties. Keep in mind that swallowing skills must be taken into consideration by the care team before introducing any kind of feeding strategies.

1. Increase Fluid Intake - stimulates hunger, prevents dehydration and UTIs.
2. The Hand-Under-Hand Technique - allows individuals with poor motor skills to receive the assistance needed while still participating in the activity.
3. Use Restroom Before Meals - will reduce bathroom breaks during meals that distract your loved one from eating.
4. Oral Care – healthy gums and secure dentures reduce pain in the mouth that detour from eating/drinking.
5. Dinner Before Dessert – increases the likelihood that nutritious foods will be eaten before your loved one is full.
6. One Item at a Time - reduces the chance of your loved one feeling overwhelmed.
7. Offer Snacks – eating small items between meals increases total caloric intake throughout the day without ruining appetite for meals.
8. Easy Exercises - more physical activity throughout the day increases appetite. Stretch, walk, or fully extend arms and legs while sitting.
ADLs Difficulties

Individuals with AD will forget and lose the ability to perform normal day to day tasks. Your loved one may show signs of difficulty with more complex tasks such as managing finances, medications, shopping, preparing meals, and doing housework first.

As the disease progresses, you will begin to see further difficulty in the following areas:

- Mobility: getting around with or without an assistive device.
- Transferring: moving oneself from sitting to standing.
- Toileting: getting to the toilet/commode/urinal before becoming incontinent.
- Bathing: washing/rinsing/drying of all areas of the body.
- Dressing: making appropriate clothing decisions and taking clothes on/off.
- Applying Personal Products: applying deodorant, perfume, moisturizer, etc.
- Hair Care: washing/rinsing/drying, combing, and styling of any hair.
- Oral hygiene: brushing/flossing teeth, using mouth wash, placement/removal/ and cleaning of dentures, swabbing gums, etc.
- Eating/Drinking: the ability to feed and consume liquid by oneself.
ADL Strategies

The following are general strategies, ranging from early to late stage, for individuals with Alzheimer’s who experience difficulties with completing the activities of daily living. Keep in mind that each individual is different and therefore the amount of assistance needed and the rate at which it will be required will vary.

1. Develop a daily routine and checklist of daily tasks.

   Your loved one can cross out each task once completed.

2. Focus on one task at a time.

3. Use a monthly calendar to keep track of all important dates and appointments and cross out each day as it occurs.

4. Keep grocery lists on the fridge for easy reminder to add items as they run out.

5. Place toothbrush in cups labeled AM and PM after each use.

6. Use a pill box that is labeled with each day of the week and AM/PM or an electronic one that only opens at certain programmed times. **Important: your loved one may not be reliable to take medication on his/her own, even with assistive devices. With the progression of the disease, consistent monitoring is required for medication intake.**

7. Lay out clothes for next day on the end of the bed or hang on bathroom door.

8. Keep any assistive ambulation device directly next to the bed for easy access.
Communication Difficulties

As Alzheimer’s progresses the individual’s ability to communicate will decline.

Difficulties to expect from early to final stage of AD may include, but are not limited to:

- Finding the right word
- Using similar words repeatedly
- Describing familiar objects rather than naming them
- Substituting intended words with a related word
- Switching beginning sounds between two words
- Using made-up words in place of target words

- Organizing words logically
- Forming sentences
- Repeating stories
- Feeling inundated by excessive stimuli
- Easily losing train of thought
- Reverting to speaking a native language
- Speaking less often
- Understanding long sentences
- Following normal rate of speech
- Taking literal meaning of irony/joke
- Reading any written material
- Spelling/writing words
- Understanding number concepts
Communication Strategies

The following are general strategies to initiate better communication between you and your loved one with Alzheimer’s.

1. Careful Approach – find a quiet place, stand in direct line of vision, introduce yourself, and address loved one by name.

2. Keep it Simple – speak directly to your loved one, use short sentences/phrases, ask yes/no questions one at a time.

3. Be Patient – give the individual ample time to respond.

4. Easy Instructions – provide step-by-step instructions and model tasks for your loved one.

5. Be Precise – speak slowly and clearly, give visual cues, and clarify his/her message by repeating what he/she said.

6. Go Beyond the Words – listen to his/her tone of voice, watch gestures, look for physical signs of pain etc.

7. Clarify – instruct your loved one to point or gesture if you don’t understand and tell him/her directly if you still don’t understand.

8. Reassure – Comfort the individual with a gentle touch on the shoulder and tell them you’re there to help.
Behavioral Difficulties

Behavioral issues of loved ones with Alzheimer’s are the leading cause of physical and mental stress for family and caregivers, resulting in severe exhaustion. The following are common behavioral difficulties among those with Alzheimer’s:

- Repetitive Behaviors: repeating stories, questions, or certain motions.
- Wandering: walking aimlessly from place to place.
- Verbal Outburst: impulsive and aggressive oral episodes in which you the individual reacts grossly out of proportion to the situation.
- Physical Outburst: aggression and physical combativeness displayed in biting, pinching, hitting, kicking, punching, etc.
- Sun-downing: as the sun is setting, an individual’s erratic behaviors will increase often due to confusion, anxiety, and fear.
- Transferring Without Assistance: getting out of one’s seat on one’s own even though assistance is required for a safe transition.
- Pacing: walking back and forth at a steady speed often due to stress or anxiety.
- Restlessness: when an individual is unable to relax, usually due to boredom or anxiety.
Behavioral Strategies

The following are general strategies to address the common behavioral difficulties your loved one may exhibit over the course of his/her experience with Alzheimer's.

1. Basic Necessities - verify that hunger, thirst, and bathroom needs are met.
2. First Response – respond to emotions not words, validate feelings, and redirect with another topic or activity.
3. Calm Environment – a quiet room, dimmed lighting, and soft music is soothing.
4. Comfort – comfort your loved one with a sweet treat, warm beverage or blanket.
5. Increase Interactions – prevent boredom and negative behaviors with frequent attention.
7. Change it Up – switch activities or take a break if a situation is too stressful.
8. Alternative Treatments – regulating sleeping schedules is vital in reducing sundowning behaviors; additional melatonin may help your loved one sleep at night and stay awake during the day, and light treatment may reduce sleep disturbances during the night, so your loved one can stay asleep. *Consult with your loved one's doctor for further information and alternatives.*
Commonly Asked Questions

1. How do I get my loved one to stop asking the same question repetitively?

Decrease this behavior with a visual reminder. Instruct your loved one to write the answer down or provide him/her with written cards/pictures. Remind him/her to look at the note/card each time the question arises.

2. Will there be possible swallowing issues in the future with the progression of Alzheimer's?

Yes, swallowing issues are to be expected. As the disease progresses, individuals lose the motor ability it takes to swallow and may ultimately forget how to swallow even if there is no physical reason for them not to.

3. My loved one refuses to take his/her medications. How can I get him/her to take them as needed?

If your loved one refuses to take his/her medication and/or is experiencing difficulties swallowing pills, consult with his/her doctor and speech-language pathologist to see if it is possible to crush the pill in applesauce, pudding, or another food with the same consistency to encourage compliance and facilitate swallowing.

4. My loved one often gets upset with the belief that illogical events are occurring. How should I address their concerns even though there's nothing real to worry about?

It's normal for individuals with Alzheimer's to believe that illogical events are occurring. Confusion may stem from true or fictional events; however,
such thoughts are a reality for your loved one. Therefore, never minimize concerns, rather reassure, redirect, and validate his/her feelings.

5. *Is it okay if I don't understand my loved one to pretend like I do?*

The best communication is direct communication; express your misunderstanding in a reassuring way. This may sound like, “I’m sorry, I’m not sure what you’re saying, but I’m here to help as best I can.”

6. *Can I leave my loved one alone?*

The answer varies; however, if you question his/her safety, it’s better to be safe than sorry. Struggling to care for a loved one and needing a break is normal. Take care of yourself first to prevent burnout. Respite Care or assisted living may be possible solutions.

7. *How can I help my loved one continue to interact with relatives and friends?*

Visiting a person with AD can be stressful if the visitor is unsure how to interact. Arranging reminiscent activities, such as looking at a photo album or recalling shared memories helps the visitor feel more prepared. Such activities also enhance communicative interactions and overall well-being of individuals with AD.

8. *My loved one is experiencing weight loss due to swallowing issues. Is a feeding tube a good option for him/her?*

The decision for placement of a feeding tube belongs to the family members in charge of the individual’s medical decisions, unless an advance directive is in place. *Ask the doctor to discuss the pros and cons of a feeding tube.*
Resources for Family Members

American Speech-Language-Hearing Association – ASHA
http://www.asha.org

Alzheimer’s Association
http://www.alz.org

Bright Focus Foundation
http://www.brightfocus.org

Center for Disease Control and Prevention
http://www.cdc.gov

Family Caregiver Alliance: National Center on Caregiving
http://www.caregiver.org

National Institute on Aging
http://www.alzheimers.gov
or
http://nia.nih.gov
References


