

Alzheimer's Disease: Managing Fluids, Nutrition & Incontinence

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Purpose The purpose of this course is to provide a guide to management of fluids and nutrition, urinary incontinence, and fecal incontinence for people with Alzheimer's disease.

Goals Upon completion of this course, the healthcare provider should be able to:

- Discuss symptoms of Alzheimer's disease.
- Describe characteristic behavior at the 7 stages of Alzheimer's.
- Describe dietary issues relevant to each of the 7 stages of Alzheimer's.
- Describe at least 5 changes that affect diet.
- Describe the nutritional health checklist.
- Describe the 4 classifications of the National Dysphagia diet.
- Discuss assessment tools for urinary incontinence.
- Describe the components of a bladder diary and a bowel diary.
- Discuss bladder training.
- Describe at least 5 types of incontinence products.
- Discuss the 7 types of stool according to the Bristol Stool Chart.
- Discuss bowel training.

Introduction

Alzheimer's disease is the most common cause of dementia in the United States, affecting approximately 5.4 million people. An estimated 14.9 million people provide unpaid care for Alzheimer's patients, usually family members such as a spouse, daughter, or son. Alzheimer's disease rates increase with age; so, as the population continues to age, healthcare providers in all settings must have an understanding of dementia and tools to manage care and educate others about care.

Alzheimer's disease is characterized by progressive dementia, usually beginning with short-term memory loss and progressing to a variety of symptoms [**see CE course Alzheimer's Disease**], which can include:

- Impaired judgment.
- Disorientation.
- Confusion.
- Behavioral changes.
- Difficulty understanding, reading, and using language.
- Dysphagia.
- Incoordination and inability to walk.
- Incontinence.

Dementia may occur with a number of different disorders as well, and symptoms are often similar. For example vascular dementia has similar but usually less pronounced memory loss while dementia related to Lewy bodies tends to fluctuate and may involve tremors, muscle rigidity and visual hallucinations. Fronto-temporal dementia causes more pronounced changes in personality and difficulty using and understanding language. Regardless of the cause; however, people caring for those with any type of dementia face similar challenges.

Alzheimer's disease is primarily a disease associated with aging. One in 8 (13%) of those over age 65 has Alzheimer's disease but by age 85, 43% have Alzheimer's. Incidence according to age includes:

- <age 65: 4%.
- 65 to 74: 6%.
- 75 to 84: 45%.
- 85+: 45%.

One of the most critical challenges facing caregivers is the constant need to monitor those with Alzheimer's disease because needs and abilities can change, literally overnight, as the brain deteriorates.

Providing adequate fluids and nutrition

In the early stages of Alzheimer's, people are usually able to manage their diets and meal preparation. They may forget to buy bread or leave the salt out of a recipe, but they generally eat and drink adequately—or at least as well as they did before the onset of dementia.

Overview

As dementia progresses, a number of changes may occur that affect diet, not necessarily in order:

- People may forget about eating and begin skipping meals and fluids. The first sign may be an unexplained loss of weight. People may develop urinary infections and constipation because of dehydration.
- People may forget they have eaten and eat repeatedly or drink large amounts of fluids, sometimes resulting in urinary incontinence. They may begin gaining weight, sometimes rapidly.
- People may eat only a few different items rather than a well-balanced diet. Many people begin eating primarily sweets and other junk foods, such as potato chips, partially because they like the foods but also because these foods are easy to access and don't require cooking.
- People may not chew food adequately or may eat very rapidly, increasing the risk of choking.
- People may experience dysphagia, with recurrent episodes of choking and aspiration. This usually becomes more pronounced in later stages of Alzheimer's.
- People may forget to do mouth care, resulting in caries, or may forget to wear—or refuse to wear—dentures, making chewing solid foods problematical.
- People may become confused about using the stove or microwave and unable to cook for themselves.

Whether caring for a person in the home or in a licensed facility, such as a hospital, the first step in managing diet and fluids is observation—direct observation. Asking a person with Alzheimer's to report may or may not get true information. The person may not remember and may report what he or she thinks is true or may, in fact, simply lie to try to placate the other person in some way. Judgment is impaired with Alzheimer's.

Case study 1*

Sally discovered that her mother-in-law Nancy was losing weight and

hadn't been eating regularly. Because Sally was only able to come by in the evenings, she ordered Meals-on-Wheels for Nancy. Nancy replied enthusiastically when Sally asked her about the meals, so Sally assumed all was well.

About 2 weeks after the meals started, Sally decided to help clean out Nancy's refrigerator and opened the refrigerator door to find the shelves piled high with all of the meals Nancy had been receiving, untouched.

*Names in case studies have been changed to protect privacy.

In the **home environment**, observation can include sitting with people when they eat or sharing a meal, watching them prepare meals, checking the refrigerator and cupboards for food supplies, and even checking the garbage to see if food is being wasted. If people aren't able to shop for groceries, someone may need to help them or make arrangements for home delivery of groceries.

In a **licensed facility**, observation includes staying with people while they eat—rather than just putting a tray of food in front of them—and watching how they handle the food. This is especially important when people are first admitted. Observation also includes noting carefully how much people eat or drink during the meal. If half of the food is left on a plate, then the task is to figure out why. It may be because of personal food preferences or it may be that the person is unable to cut food into bite-sized pieces or may be unable to chew certain foods.

Additionally, people should be carefully observed as they eat and drink:

- Do they cut food, such as meat, into bite-size pieces or put large pieces into their mouths?
- Do they avoid eating certain foods? Which food? Why?
- Do they handle utensils correctly? Can they cut meat or other foods with a knife?
- Do they gulp food and liquids or chew and swallow adequately?
- Do they tend to choke on foods or liquids?
- Do they spill fluids or drop food? If so, why? Do they have tremors or are they inattentive?

Dietary consideration by stage

While there are a number of methods of staging Alzheimer's, the 7-stage classification system used by the Alzheimer's Association is more specific than some others and incorporates other classification systems, such as pre-clinical, mild, moderate, moderately severe, and severe and early stage, mid-stage, and late stage. It's helpful to consider diet and nutrition in relation to staging while keeping in mind that there is much variation among those with Alzheimer's disease or other forms of dementia.

Stage 1	No impairment/Pre-clinical. While changes are taking place in the brain, people function without evident impairment.
Stage 2	Very mild cognitive decline. People may note they are forgetful or forget words but can usually function within normal limits.

People at these beginning stages usually are able to shop, prepare meals, and eat with no assistance—assuming there are no other major health obstacles.

This would be an ideal time to take note of people's meal preferences and habits. Do they, for example, like to eat their large meal at midday or in the evening? Do they like tea or coffee? Do they cook? Do they buy a lot of prepared foods? Do they have food allergies? What foods do they like or dislike? Is their diet adequate? Unfortunately, most people exhibit no symptoms or only very mild forgetfulness in these stages, so potential caregivers and healthcare providers aren't aware that a problem may develop.

Because incidence of Alzheimer's jumps markedly to 45% for those 75 and older, a good strategy would be for family and healthcare providers to include this type of dietary information in observations and health histories for those in their late 60's or early 70s or those beginning to exhibit mild forgetfulness.

A dietary assessment (including amounts) usually includes a 24-hour record of intake for a "usual" day. While diet may change somewhat, people usually vary their eating habits little from day to day. Of particular concern is daily intake that includes adequate protein, whole grains, 5 or more servings of fruits and vegetables, and 3 servings of dairy foods.

While the standard recommendation for water is “8 glasses a day,” the reality is that foods and beverages also contain water, and many people drink far less than this and are adequately hydrated. A better guide is to check skin turgor, urine concentration, and mucous membranes for hydration.

However, caregivers need more concrete advice, so aiming for 6 to 8 glasses of fluid (including water) daily is advisable. Tea and coffee provide the same liquid as water. However, some juices, such as the popular mixed vegetable juice, are high in sodium, which may increase thirst and the need for water.

The Nutrition Screening Initiative for the Elderly developed a checklist that is useful when assessing diet. An answer of “yes” to any of the following statements suggests a potential nutritional problem.

Nutritional Health Checklist

- I have an illness or condition that made me change the kind and/or amount of food I eat.
- I eat fewer than two meals per day.
- I eat few fruits, vegetables or milk products.
- I have three or more drinks of beer, liquor, or wine almost every day.
- I have tooth or mouth problems that make it hard for me to eat.
- I don't always have enough money to buy the food I need.
- I eat alone most of the time.
- I take three or more different prescribed or over-the-counter drugs per day.
- Without wanting to, I have lost or gained 10 lbs. in the last six months.
- I am not always physically able to shop, cook, and/or feed myself.

Stage 3

Mild cognitive decline (Early stage). Short-term memory loss becomes evident to others and people begin to have trouble remembering names, reading, managing money, and planning and organizing. They may misplace belongs and have trouble functioning in a work or social environment.

At stage 3, people may begin having some difficulty with food preparation, especially if a number of steps are involved, but generally

can manage to eat with no difficulty although some people may begin to forget about eating or forget that they've already eaten.

In the home environment, one indication of beginning problems may be that shopping and food preparation are becoming inconsistent. For example, a person may have 8 boxes of cereal because he forgot he already bought cereal. Staples may be missing. The refrigerator may be full of half-rotted food, empty of food, or crammed solid with food. When fixing dinner, a person may cook just one thing, such as a potato, and eat just that and nothing else. People may say things like, "I'm getting too lazy to cook" or "I wasn't very hungry."

People may begin to exhibit changes in weight, either weight gain or weight loss, because of changes in their eating habits. People who live alone are particularly at risk because there is no one else to essentially remind them about the need for an adequate diet. People who don't eat adequately alone may happily eat a hearty well-balanced diet if eating with family or friends, so intervention may include invitations to meals or bringing meals to share. Family members and friends are often willing to do this but unaware of the need until it's pointed out to them.

At this stage, some minor assistance is often needed, such as with an inventory of foods and a weekly shopping trip to the grocery store. Additionally, if cooking is becoming a problem, frozen dinners and easily prepared and eaten foods—yogurt, bananas, pre-cooked meats, deli salads—may be good alternatives.

Someone should check in with people at this stage at least 2 to 3 times a week and sometimes daily, depending on how people are doing. Ongoing supervision is especially important at this stage because problems become more acute and obvious as people near stage 4.

For people in a licensed facility, such as a skilled nursing facility or hospital where meals are served, the primary concern is observing that people are eating and drinking in adequate amounts and eating a well-balanced diet. The need for assistance with eating or drinking is usually quite minimal. People may respond well to eating in a communal setting.

People who have not completed advance directives should be encouraged to do so because they may not be able to in later stages. People should make informed decisions about the type of care they

want at the end of life, such as whether they would want to have feeding tubes.

People should have a thorough dental examination. If crowns, bridges, or dentures will need to be replaced, it's much easier to do so at this stage than when people become more confused and sometimes combative.

Stage 4	Moderate cognitive decline (Mild/early-stage) over 2 to 10 years. Dementia is more obvious to others, but people can usually manage most activities of daily living and manage simple personal affairs, such as shopping. They have decreased knowledge of current events, difficulty with mathematics and multitasking, and may begin to forget personal history and withdraw socially.
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The problems encountered at stage 3 may exacerbate as people enter stage 4. People usually remain able to feed themselves and do simple shopping, but food preparation and maintaining an adequate diet is a concern. Because short-term memory worsens, people may forget food on the stove until it starts to burn, or heat a pan and forget about it and leave the room. With gas stoves, inattention could lead to clothing or potholders catching fire. People may forget how to operate a microwave.

1. Put food in microwave.
2. Press **2-0-0**.
3. Press **Start**

At this stage, signs to help people remember may be useful as long as reading skills remain intact. Signs should be large enough to be easily read, worded simply, and placed in close

proximity to the task.

If a person is not preparing adequate meals and caregivers are unavailable to help, then Meals-on-Wheels is a good choice although (as noted above) someone still needs to monitor people to make sure they are eating the food.

People should be evaluated for nutritional status, especially if their eating habits are poor. In some cases, a dietary supplement, such as Ensure®, is advisable. The amount of supervision needed may vary with individuals, but usually someone should check in with people at this stage of dementia at least 3 to 4 times weekly.

People in licensed facilities should be observed carefully to ensure that they are eating an adequate diet and drinking ample fluids and may need reminders, but they are usually able to eat without assistance once food is presented to them. As people near stage 5, they may begin to have more problems with eating, such as frequent choking.

Stage 5	Moderately-severe cognitive decline (Moderate/Midstage). People are more obviously confused and require assistance with activities of daily living although they can still usually feed themselves and dress, but may not be able to prepare food or may forget about eating. They are increasingly disoriented and may have trouble using or understanding speech.
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It's at this stage that the problems noted at earlier stages become much more evident, and difficulties intensify. People who were forgetful about eating may become frankly anorexic. People who needed directions to use the microwave may no longer be able to follow directions.

At stage 5, most people should not live independently, but many do, and this can pose a tremendous challenge for family and healthcare providers. People are reluctant to leave their homes or become dependent. They may differ in recognition of their own dementia. They may not have family or friends to care for them. Even if someone is aware that her memory is failing, she may cling to the familiar. If a patient's safety is at risk, then adult protective services must be notified so a social worker can do an assessment.

Most people at stage 5 can handle utensils fairly well and can eat and drink with little assistance. If they are unsteady or spill fluids, then cups or drinking utensils with lids should be used. Some people may be able to prepare simple foods such as cereal or use a microwave, but ready-made meals and easily prepared foods are best. Meals-on-Wheels may provide an essential service. Families or caregivers should assist people to shop and stock shelves and refrigerators with easily-prepared or precooked nutritious foods as well as checking to ensure people are eating an adequate diet.

Many people, at this stage, should move from a regular diet to a soft diet because the risk of choking increases, and they may have some difficulty handling a knife to cut meat. Sharps, such as carving knives, may need to be removed from the kitchens if people can no longer

handle them safely. People should sit upright when eating and drinking if at all possible as this lessens the risk of choking.

If someone cannot safely use a stove but attempts to do so, the stove should be disconnected. Telling someone, "Don't use the stove," and even posting a sign over the stove saying, "Don't use the stove," cannot guarantee that a person at stage 5 will comply. This holds true for other dangerous equipment (such as cars).

In licensed facilities, people may be much more confused than they are in the home environment because they may be overwhelmed by the noise, confusion, and strange faces, especially if they are in pain or are constrained in some way. Therefore, people may need more assistance with eating and drinking than they would need otherwise.

Healthcare providers should assist people with their meals, such as by putting milk into cereal, asking people if they want cream and sugar in their coffee, and cutting meat. Someone may need to stay with a person while he eats or check in frequently to see if the person is eating without difficulty.

Stage 6	Severe cognitive decline (Moderately severe/Midstage) People are obviously confused and unable to take care of themselves. They may experience difficulty with toileting and have incontinence and may have personality changes, do repetitive activities (wringing hands), wander, pace obsessively, and forget recent experience. They may recognize their name but forget personal history and may recognize familiar faces but forget name and relationship. They may have increasing problems with choking and dysphagia.
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People at stage 6 cannot safely live alone or take care of themselves. This means that most of those in the home environment are cared for by family members, such as a spouse or offspring. Those who are not at home have usually been placed in some type of assisted living program.

Eating problems are often much more serious at stage 6. Patients may gulp food, refuse food, inadequately chew food, and choke frequently. They may be unable to chew because they refuse to wear dentures or their dentures fit poorly. Dysphagia is very common. Even soft food may cause choking.

Dysphagia affects about a quarter of hospitalized patients and up to 40% of those in skilled nursing facilities. With disorders affecting the neuromuscular system, such as Alzheimer's, people may experience impaired initiation of swallowing as they chew and move food to the back of the throat.

The pharyngeal swallow reflex closes the larynx and the epiglottis to prevent aspiration, but when this reflex is impaired, food may be aspirated into the lungs. Sometimes people cough as they begin to swallow or regurgitate food into the nose. Other people are able to swallow and the food passes into the esophagus, but they feel choked and cough late in the swallow and may regurgitate food into the mouth.

Some people are able to feed themselves, but others may need some guided assistance, such as by holding onto the person's hand and guiding the spoon to the mouth, or even direct feeding. People may be better able to drink through a straw than directly from a cup or glass.



In many cases, people at this stage spill or drop food when they are eating. Disposable and washable adult bibs are commercially available, but towels or aprons may also be used to protect the clothing. It's easier to use something to protect the clothes than to have to change the clothes or leave the person wearing soiled clothing. Caregivers may not be aware of the

availability of items, such as disposable bibs.



Additionally, non-spillable drink containers that are easily grasped should be used to reduce spillage. Some people may find it easier to eat with tablespoons than teaspoons or may fair better with adaptive utensils, such as spoons with large grips.

At this stage, especially as they near stage 7, people begin to eat pureed or very soft foods, such as scrambled eggs, custards, and soups. Some people eat baby foods, and while they are nutritious, they are not very palatable and are expensive. A better alternative is to use a blender or food

processor to puree food. However, in some cases caregivers just throw a bunch of different foods into the blender making a very unpalatable glop of food, so it's important to advise caregivers to season and keep taste in mind.

The American Dietetic Association developed the National Dysphagia Diet (NND) to standardize descriptions of diets related to dysphagia. Each person should be assessed on an individual basis. Liquids are described as spoon-thick, honey-like, nectar-like, or thin (water-like). In the home environment, caregivers should be provided guidance about appropriate food choices. In a licensed facility, patients with dysphagia may be ordered a diet according to NND classification.

Classification	Foods included	Foods excluded
NND 1 Dysphagia— pureed	Food with no lumps (the consistency of pudding) such as pureed meats, fruits, vegetables, and soups and mashed potatoes (smooth), ice cream, and puddings. Dysphagia mixed is NND 1 diet with one item (such as scrambled eggs) from NND 2.	Scrambled eggs, peanut butter, gelatin, yogurt with fruit (unless smooth and completely blended), and cottage cheese.
NND2 Dysphagia— mechanically- altered	Moist, soft, easily chewed food, such as ground or finely-diced meats, tender vegetables, soft fruit, smooth moistened cereals (cream of wheat), scrambled eggs, pancakes, and juice (thickened if needed). Mechanically soft is the same except that it allows bread, cakes, and rice.	Breads, cakes, rice, peas, corn, hard fruits and vegetables, skin of fruit/vegetable, nuts, and seeds.
NND 3 Dysphagia— advanced	Foods with soft but regular texture, including moist tender meats (fish, stews), cooked or soft vegetables, breads, cake, rice, and shredded (not torn) lettuce.	Hard fruits (apples) and vegetables (raw carrots, celery), corn skins, nuts, and seeds.
No dysphagia	Regular diet with all foods allowed.	No exclusions.

Some foods that seem intuitively to be a good choice for a soft diet, such as soft white bread or cake, are not. Bread that is chewed but not swallowed can become a thick goopy wad in the mouth. People can easily choke on the curds in cottage cheese, another soft food. Thin liquids may run quickly to the back of the throat, causing people to choke or aspirate, so thickened liquids are safer and easier to swallow.



Foods and liquids, such as juices, can be thickened in a variety of ways: cornstarch, flour, egg yolks, and tapioca. Additionally, instant thickeners, such as Thickenup® (which is a modified cornstarch), are commercially available and can be added to any liquid.

Although expensive, ready-to-serve thickened products, such as thickened coffee, milk, water, and juices, are also commercially available. It's important to remind caregivers that water should

also be thickened as caregivers sometimes don't think of water as part of the diet.

Additionally, caregivers often need to be reminded to ensure that people are getting 6 to 8 glasses of fluid daily because, as people's care needs intensify, it is easy for caregivers to forget about offering fluids between meals.

People in licensed facilities usually have fewer dietary options because nutritionists determine an adequate diet, and food is delivered. If the diet seems inappropriate for a particular person, then the nutritionist should be notified immediately. The nutritionist may not have adequate information initially to assess dietary needs so input from other healthcare providers is very important.

In almost all cases, a healthcare provider or family member must stay with the person and assist while he has his meal and must maintain careful records to ensure the person is getting adequate nutrition and fluids. Scheduled offering of fluids, such as every 2 hours during waking hours, should be established because people are often not able to request fluids. Sometimes, people become restless or combative if they are uncomfortable or thirsty.

Stage 7	People are completely dependent and bed or chair bound. They may lose speaking ability and experience frequent
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incontinence. Muscle weakness and rigidity worsens, and people choke easily and experience increasing dysphagia and inability to take oral foods and fluids.

Stage 7 is extremely challenging for caregivers at home and in licensed facilities. While people may vary, many are non-verbal, and providing adequate fluid and nutrition is increasingly difficult. Some people are more cooperative with eating than others, but most reach the point where they are no longer able to take oral foods and fluids because they choke and aspirate or are resistive or nonresponsive. People can easily develop aspiration pneumonia.

At this point, the person's advance directive, if one is available, should guide care and determine whether feeding tubes are placed. In some cases, religious beliefs guide these decisions and must be respected. If there is no advance directive, then the burden of this decision rests on the next of kin if there is one. If there is no family, then the physician may make the decision. Some caregivers believe the decision about a feeding tube is a choice between starving the person to death or allowing the person to continue to live, but it's not so simple.

In fact, studies show that insertion of feeding tubes does not prolong survival, probably because by the time end-stage Alzheimer patients need feeding tubes, they are nearing death already, and this is usually not reversible. Feeding tubes may result in complications and discomfort. Further, studies show that whether patients with end-stage Alzheimer's disease receive feeding tubes depends to a great extent where the people receive care. Large and for-profit hospitals, for example, tend to insert feeding tubes at a much higher rate than smaller rural hospitals that are not associated with medical schools.

People cared for in the home are also less likely to receive feeding tubes. Many people who die at home are under hospice care, and insertion of a feeding tube to prolong the life of a dying patient generally exempts the patient from hospice care.

Managing urinary incontinence

Urinary and fecal incontinence are common problems associated with Alzheimer’s disease, with urinary incontinence generally occurring first. Urinary incontinence usually doesn’t occur until stage 4 or later unless there are underlying causes, such as diabetes, urinary tract infections, stroke, multiple sclerosis, prostatic hypertrophy, cystocele, and Parkinson’s disease.

With the onset of any incontinence, a thorough medical exam should be completed to determine if there is a physical cause that can be corrected or if medications, such as diuretics (such as furosemide), sleeping pills, or anti-anxiety medications, are a contributing factor. Because Alzheimer’s disease is most commonly a disease of the elderly, there may be many things contributing to incontinence. The person or caregiver should complete a simple assessment tool.

Question	Yes	No
1. Do you sometimes leak urine?		
2. Do you feel urgency when you need to urinate?		
3. Do you leak urine when you cough, laugh, sneeze, or strain.		
4. Do you have a history of urinary infection or enlarged prostate?		
5. Do you feel burning when you urinate?		
6. Do you leak urine at night or wet the bed?		
7. Do you continue to dribble urine after you urinate?		
8. Do you have to urinate frequently to avoid accidents?		
9. Do you have difficulty urinating?		
10. Do you wear pads or other materials or briefs to absorb urine?		
11. Do you need to urinate more than twice during the night?		
12. Is your sleep interrupted by urinary leakage?		
13. Does urinary leakage stop you from exercising or being active?		
14. Do you avoid shopping or activities outside of the home because of urinary leakage?		
15. Are you taking any medications?		
16. Do you have painful bowel movements, constipation, or diarrhea?		
17. Is the need to urinate frequently interfering with personal relationships?		
18. Do you leak feces?		
19. Do you sometimes lose control of your bowels?		

If the person answers yes to some of the questions on the assessment tool, then a more detailed assessment should be completed to ascertain exactly when and how much incontinence is present. In early stages, the person should be able to answer questions, but in later stages (stages 4-7), caregivers may need to provide information.

Informational questions

1. How often do you have urinary/fecal accidents?

2. How extensive is your incontinence?

Does it soil or wet underwear only, run down your legs, soil outer clothing, pool on the floor, or remain contained by absorbant products?

3. How often do you have accidents at night and how much leakage do you have?

Does urine or feces wet or soil only incontinent product, wet or soil bedding, wet or soil nightclothes, or wet or soil the additional areas, such as the floor?

Diet should be evaluated as well. Some drinks, such as colas, coffee, and tea have diuretic properties that may exacerbate or cause incontinence. Some people drink excessive amounts. Drinking fluids in the late evening may increase nocturnal incontinence.

Case study #2

Sarah's mother Ellen began having incontinence during the night. She would get out of bed and urinate on the way to the bathroom or urinate on a chair in the room or into the wastebasket. Sarah was up 2 or 3 times during the night, cleaning up, scrubbing the floor, and changing her mother's clothes. Sarah tried to put disposable briefs on her mother, but Ellen almost immediately tore them off and stuffed them into the bedside stand.

Finally, Sarah began to keep a record of when Ellen was incontinent and discovered a pattern, Ellen usually got up between midnight and 2 AM and again in the very early morning between 4 and 6, so Sarah set an alarm for midnight and 4 AM and woke her mother up and took her to the bathroom at those times.

Additionally, Sarah moved her mother's bed close to the bathroom door so that Ellen only had to take a few steps and put a grab bar on the wall between the bed and the bathroom door. These changes reduced her mother's nocturnal incontinence by about 85%. Sarah also went to the hardware store and bought a plastic runner and placed it on the floor leading from the bed to the bathroom so any

leakage went onto the runner instead of the hardwood floor.

Managing incontinence, as with all things associated with Alzheimer's disease, requires careful observation to determine patterns. When does it happen? How does it happen? Why does it happen? Is it associated with anything? Clearly, Ellen needed to urinate at night but was confused. While getting up twice during the night was a burden for the caregiver, it was less of a burden—and certainly less frustrating—than getting up 2 or 3 times to wash and change her mother and clean urine off of the floor night after night.

Observation includes observing behavior before and at the time of incontinence as often people exhibit clues that they need to urinate, especially at stage 5-7. For example, people may become restless, pull at clothing, moan, or repeat the same phrase before episodes of incontinence. One woman would call out "It's late, it's late, it's late" repeatedly when she needed to urinate. As language skills become impaired, people may have increasing difficulty stating their needs.

Some people are incontinent because they forget where the bathroom is or can't reach it in time. If, for example, a person's bed or favorite chair during the day is not close to a bathroom, it might be moved or a commode or urinal placed close by. The environment should be simplified—clutter removed for the pathway to the toilet and throw rugs removed. Sometimes placing a brightly colored toilet seat cover on the toilet may help people with advanced dementia find the toilet more easily.

Sometimes people are incontinent because they physically have trouble sitting on a low toilet or getting up, so using an elevated toilet seat with arm supports as well as grab bars may make it easier for them. Clothing may be too tight or difficult to remove. Other people have reduced sensation and don't realize their bladders are full.

People may also develop strange ideas that must be accommodated as trying to use reason is usually not successful. For example, one woman at a daycare center absolutely refused to sit on the toilet because the toilet seat was black: "I won't sit on that black hole!!!" She had no problem sitting on a toilet with a white toilet seat. Most likely, it was not the color so much as a change in her perception that made her fear the black toilet seat.

Bladder training

Bladder training is an exercise for both the person who is incontinent and the caregiver in many cases and usually involves scheduled urination. A period of observation should precede bladder training to ascertain if the person has any control of urination and to determine what, if anything, triggers incontinence.

A bladder diary should be kept for 3 to 5 days if possible to record all urinations and episodes of incontinence so that the pattern of incontinence can be assessed. The **bladder diary** should contain:

- **Time:** This helps to determine the pattern of urination, both for controlled urination and incontinence.
- **Amount:** Output is usually estimated as small, medium, or large.
 - A small amount (up to 30 mL) may dampen underwear.
 - A moderate amount (30 to 60 mL) may overflow the undergarment and run down the legs.
 - More than 60 mL usually results in clothes being soaked and urine running onto the floor or onto furniture.
 - In a supervised environment, such as a licensed facility, urine may be measured when possible.
- **Intake:** This is important because the timing and amount of liquids may be contributing to incontinence.
- **Incontinence:** The sensation at the time of incontinence (urgency, burning, no sensation) should be recorded as well as the activity.

Scheduled/ Prompted urination

Scheduling of urination may vary according to need. For example, if a person is incontinent only at night, like Ellen in the case study above, then scheduling urination at bedtime and at specified times during the night may be adequate. If incontinence occurs at various times, day and night, then the goal is to prevent incontinence by emptying the bladder on a regular basis—at the same times each day—to establish a routine. This is especially important in the earlier stages of Alzheimer's as having an established routine in place may help as the dementia increases and training is more difficult.

People should urinate immediately upon arising and immediately before going to bed at night. With many people, eating and drinking

trigger the need to urinate, so scheduled urination should usually be done both before and after meals. Initially, people should attempt to urinate every hour during waking hours. If this controls incontinence, then the time should be lengthened to every 1.5 hours and so on. Most people with any degree of dementia and incontinence should attempt to urinate at least every 3 hours.

In the home environment, a caregiver may need to remind a person to urinate. Alarms that can be programmed to ring at certain times throughout the day are available commercially to help people remember as one problem with incontinence is that people simply forget to go to the bathroom until the need is urgent. In a licensed facility, prompted urination is usually necessary, with a staff person reminding the person and assisting her.

Some people are simply unable to control incontinence, regardless of attempts at bladder training. These people may need to use incontinence products around the clock. Patients with overactive bladders or bladder spasms may benefit from anticholinergic medications, such as oxybutynin (Ditropan®) or tolterodine (Detrol®). Oxybutynin transdermal patches, which are applied to the skin and changed every 3-4 days, are available and may work well for people who are forgetful about taking medications.

Incontinence products

Products intended for menstrual fluids (such as Kotex®) are not adequate to contain urine or feces, so people must begin by choosing the correct product. Absorbant pads for incontinence are graded according to the degree of incontinence they can contain. Briefs and adult diapers are sized, usually from XS to XL, although sizing is not always consistent from one brand to another. People with dementia or their caregivers may need guidance in choosing the right products.

Some products are intended specifically for males and some for females, so it's important for people to read labels. While early incontinence products were essentially adult diapers—and these are still often used for bedridden patients—there are many more options available now.



There are many considerations:

- Is the product comfortable to wear?

- Is it too bulky for the type of clothes the person usually wears?
- Does the product make noise (swishing) when the person walks?
- Is the product absorbant enough to prevent leakage?
- Does the product have a color-change strip to indicate it needs to be changed?
- Does the moisture barrier work in all positions: standing, sitting, and lying.
- Is the product easy to change.
- Does the product provide odor control?
- How much is the estimated weekly cost of the product?

Products include:

- **Disposable briefs/panties** that fit like regular underwear. There is a wide range of types. If a person doesn't like the feel of one brand or refuses to wear one type, sometimes switching to a different brand may work. Washable briefs/panties made of cotton or nylon with built-in padding are also available but are usually most effective for light or moderate incontinence. Some panties have pockets into which absorbant pads are inserted.
- **Incontinence pants** fastened with snaps or tabs (such as adult diapers) are also available. Some require inserts of absorbant pads. Some products are plastic backed, especially those intended for night-time use.
- **Absorbant pads** come in a variety of shapes and sizes, from thin panty liners to thicker absorbant pads.
- **Disposable underpads** are flat, plastic-backed pads that are often placed on chairs or beds to protect them.
- **Disposable wipes** especially intended for incontinent adults are available to help cleanse the skin, but they are essentially the same as baby wipes, which may be less expensive and more readily available. People should be advised to that those without perfume are less irritating to the skin.
- **Waterproof mattress coverings** should be advised for anyone with incontinence. These are readily available and often marketed for allergy control. The mattress cover should completely incase the mattress because sometimes people urinate whiile sitting on the side of the bed and urine can run

down and soak into the mattress. Box springs should also be covered.

Some waterproof mattress covers have fabric over the plastic, but it's better to use those that are completely plastic and can be washed while in place. It's easier to remove and wash a mattress pad than it is to remove the mattress cover and wash it. However, they should be covered with a mattress pad for comfort and air flow.

- **Skin barrier products** may be necessary to prevent skin breakdown, especially with moderate to large amounts of incontinence. Products include barrier wipes, protective ointments, pastes, and creams. Petrolatum-based products often contain vitamins A and D. Some products contain zinc oxide. Some products are marketed specifically to protect against urine and some to protect against feces.

Managing fecal incontinence








Fecal incontinence related to Alzheimer's disease usually occurs in the later stages, stage 6 and stage 7, although it may occur earlier in some individuals. Flatal incontinence is more likely to occur as early as stage 3 and is actually quite common with older adults in general.

As with urinary incontinence, fecal incontinence may be caused by other factors than the disease, so a thorough history and examination is indicated. Fecal incontinence can be caused by medications, diet, chronic constipation and impaction, sphincter damage, and functional disabilities that prevent the person from getting to the toilet in time to defecate.

A **bowel diary** should be kept for 3 to 5 days if possible to record all defecations and episodes of fecal and flatal incontinence. The bowel diary should contain:

- **Time:** This helps to determine the pattern of controlled defecation, fecal and flatal incontinence.
- **Type:** The type of bowel movement should be noted, using the Bristol Stool Chart as a helpful guide. The type of stool can provide information about cause, such as inadequate fiber in the diet or inadequate fluids.

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

- **Amount:** A small amount usually only soils undergarments while moderate to large amounts may soil clothing or run down the legs, depending on the consistency of the stool.
- **Abnormal findings:** Any blood or excess mucous in the stool should be noted as well as the need to splint about the rectum in order to pass stool.
- **Fecal incontinence:** Report should include type, amount of stool, and activity the person was doing at the time.
- **Flatal incontinence:** All incidences should be noted, including time and activity.
- **Food and fluids:** Intake is especially important to help determine if incontinence is related to foods or fluids.
- **Drugs:** All prescribed and over-the-counter drugs and supplements should be recorded, including time and dosage.

Bowel training

Bowel training can be extremely challenging when people enter later stages of Alzheimer's because they may be both confused and uncooperative. A better plan is to establish good toileting habits when people are in earlier stages because whatever problems they had at stage 1 to 4 are like to exacerbate at later stages. Most people who develop Alzheimer-associated fecal incontinence also have urinary incontinence.

Bowel training includes scheduled defecation—especially avoiding delayed defecation. About 20 to 30 minutes after breakfast in the morning is a good time for most people as drinking warm liquids and eating stimulate peristalsis. However, scheduling may also be done after other meals if that is more convenient for caregivers, depending on the person's usual pattern of defecation.

People should be positioned sitting upright with knees elevated slightly and leaning forward if possible. Initially, some stimulation may be necessary to promote defecation. This may include digital stimulation or a rectal suppository, such as glycerine. While stimulus suppositories, such as Dulcolax®, may be necessary at times, they should be avoided as much as possible.

If people can cooperate, they should be urged to strain as though having a bowel movement. For people who are very confused, the caregiver may need to provide a demonstration or gently apply pressure to the abdomen—depending, of course, on how cooperative people are.

Modifications in diet may be necessary. Many people have inadequate fiber intake and may need to increase whole grains, fresh fruits, and vegetables to relieve constipation. Bulk forming foods, such as bran cereal, bananas, rice, tapioca, yogurt, and oatmeal should be offered. People who are often constipated may be helped by adding daily bran and prunes or prune juice to their diets although they should be added slowly to diet to avoid diarrhea. Some foods that may contribute to diarrhea include dairy products, fatty and greasy foods, some artificial sweeteners (containing sorbitol and mannitol) and fruit juices.

Medications Many older adults should take daily **stool softeners**, and they may be necessary for those with Alzheimer's disease, especially if stools tend to be hard. **Bulk formers**, such as Metamucil® and Benefiber®, swell in the intestines

and help to lubricate and soften the stool, but they may result in constipation if people don't have an adequate fluid intake, so they should be used with caution in patients with dementia. Bulk-formers may also result in increased flatulence.

Laxatives, such as Milk of Magnesia®, should be avoided as much as possible because they interfere with the pattern of bowel movements and have decreasing effectiveness. Additionally, they may cause cycles of constipation, diarrhea, and impactions. People with a history of frequent laxative use may need to be weaned away from them.

Antiflatulants, such as Beano® or simethicone, may help to reduce flatulence. When taken in small doses, people rarely have side effects.

Incontinence products Incontinence products for fecal incontinence are similar to those for urinary incontinence [see above], especially since people are often incontinent of both urine and feces.

Conclusion

When caring for people with Alzheimer's disease, foresight and planning ahead is extremely important to ensure people's safety and health. Diet must be monitored carefully at all stages.

Skin in care is a primary consideration with all types of incontinence. The skin should be cleansed after each episode of incontinence, but frequent washing with soap and water may be irritating and drying to the skin, increasing the risk of skin breakdown, so using products especially intended for incontinence care is a better option.

No-rinse cleansers sometimes contain skin barriers as well. For example 3M One-Step Skin Care Lotion® contains dimethicone to provide a temporary breathable moisture barrier. A combination of products, include antiseptic skin cleansers and skin barriers may be necessary if skin is denuded.

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