INCONTINENCE

When the patient begins to wet himself or have his bowel movements in inappropriate places, urinary or fecal incontinence exists. One of these embarrassing conditions often occurs without the other. Urinary incontinence usually appears first, typically around Stage 6 of the disease, and it always causes anger, resentment, humiliation and great distress for the patient, the caretaker and the family. It is one of the major reasons families become exhausted, are no longer able to cope with the problems of home care, and make the decision to place the patient in a nursing home.

Incontinence is not a disease but a symptom. It must be investigated by a physician because frequently it can be treated. Some the conditions that can cause urinary incontinence are infection, enlargement of the prostate, weak pelvic muscle tone, bladder obstruction, side effects of drugs, severe constipation and dehydration. Fecal incontinence may be caused by infection, obstruction, dehydration, medication, lack of exercise and improper diet.

When family members are trying to decide the best approach for treating problem of incontinence in an elderly person, they must consider the type of incontinence and its probable cause. The first step in helping an incontinent person is therefore to find out why it is happening. A doctor can obtain a medical history and give a thorough physical examination to diagnose the cause of the problem. In some cases, such as when infection is the cause, proper treatment will totally clear up the problem.

If a doctor has decided that the incontinence is due to the progression of Alzheimer's Disease, it is important for both you and family members to always remember this: it is the disease that is causing the incontinence. The Alzheimer's Disease victim is not at fault; he should not be blamed or scolded for urinating or defecating in his clothes or on the floor. He does not have the ability to control his toilet habits. Anger and irritability toward the patient will not help the situation.

When the AD person begins to have toileting problems a written diary of these incidents should be kept. An occasional episode does not mean the patient is unable to control his toileting habits.

When incontinence begins, don't try to control it by limiting the amount of fluid the patient drinks. Insufficient liquid intake will produce urine that is too concentrated, causing irritation of the bladder. The opposite approach is recommended, in fact, and you should encourage the patient to drink fluids (at least 1-1/2 quarts, or six cups, of liquid daily), especially since the AD patient frequently forgets to drink or is not aware that he is thirsty.

If the patient is urinating or defecating in inappropriate places, e.g., a waste-paper basket or shoebox in a closet, this may be simply because he can't find the bathroom. Clearly marking the bathroom with an eye-catching sign or picture may help. At night, leave the bathroom light on and the door open so that the patient can easily find the bathroom.

Sometimes the patient does not recognize the need to "go" immediately or moves too slowly, and therefore wets himself on the way to the bathroom. Or his clothes maybe too difficult to manipulate, resulting in a "bathroom accident." To minimize the chance of an accident, place a urinal or commode near the patient's bed, especially if the toilet is some distance from the patient; and see that he dresses in clothing having Velcro tape instead of buttons or a zipper. The simpler the clothing, the better.

When a person is incontinent, establish a toileting program: remind the patient to go to the bathroom every two hours and give him special reminders upon awakening in the morning, after meals and before bedtime.

As Alzheimer's Disease progresses, the patient may forget what to do after he enters the bathroom, even when he is aware of the urge to "go." When this occurs, provide simple instructions for the patient. The patient may also need help wiping himself and flushing the toilet.

As the disease progresses, the patient may not be able to express his toileting needs, but generally he will indicate his needs in other ways, such as picking at his clothes, pacing and restlessness. To best serve the patient, the caregiver must understand both his verbal and nonverbal language.
As the incontinence becomes more difficult to control, it may be necessary to use protective bedding and disposable diapers.

It is worth emphasizing, in closing this section, that even though incontinence is highly unpleasant for all concerned, it is important for the caregiver to try to be calm and accepting. No matter how demented the patient may be, he probably is embarrassed and humiliated by his incontinence and needs your reassurance. (See Appendix B for a medical perspective on various aspects of incontinence.)

**SLEEPING DISTURBANCES**

Recent studies have shown that patients who wander at night and have sleep problems are the most troublesome to caregivers. Current treatment for these symptoms is primarily the use of sleeping medication, which works well for a short period but loses its effectiveness very quickly. Many patients seem to be more confused after taking some of these drugs and may experience other side effects, such as incontinence and unsteadiness while standing.

The sleep of Alzheimer’s Disease patients seems to deteriorate as the patient grows more confused and demented. Daytime sleep also increases as the disease progresses; patients are often seen “nodding off” during the day. This frequently accompanies the wandering and confusion at night and, in more serious situations, night-day reversal.

It is beneficial for all concerned if the patient is kept active during the day with exercise and activities that engage his interest. If medication is given to tranquilize the patient, discuss with the family or doctor whether the time of day the medication is given will have any effect on his sleep patterns. Eliminating caffeine beverages from the diet may also be helpful.

When it is bedtime, try to establish a routine. Be sure the patient uses the toilet before bed. A warm non-caffeinated beverage maybe desirable. Pull down the shades and set up a night light. The patient will sometimes find soft music soothing.

If the patient wakes during the night, he maybe looking for the bathroom. A night light left on in the bathroom may be helpful. Frequently the patient may seem more confused than usual when he wakes during the night. He may not be able to see well in the dark and may forget where his bed is. Sometimes the patient will forget how to get back into bed, where to put his head, what to do next. A soft, soothing manner will help convey to the patient that everything is safe and secure. The caregiver may find this difficult to do after being awakened several times each night, but it is important to be gentle and calm with the patient. If this conduct continues for any length of time, the situation should be discussed with the family, agency and the doctor.

Sometimes the patient will refuse to go back to bed and want to sit on the sofa or in a recliner. At other times he might be fully dressed and dozing on the couch. When this happens, it is best not to disturb the patient. Be sure that the doors are secured and that the patient is safe from all possible hazards.

**SEXUAL PROBLEMS**

Sexual problems are not very common, but when they do occur it can be embarrassing if the behavior is not understood. Interest in sex usually decreases in patients with dementia, but as in all other areas, every person is different. Occasionally, some patients may become more sexually active. Such activity may appear from time to time and can be a direct result of brain changes. If this is the case and it becomes a management problem, it should be discussed with the doctor and family.

In the earlier stages, inappropriate language may be used that is completely out of character for the person. This is probably because the normal social customs are no longer remembered as important to the patient. The patient is not responsible for what he is saying; it is the result of the disease. The best response is to ignore the words and try to redirect the patient’s attention to something else that might interest him.
Sometimes the patient may become suspicious or paranoid, accuse the spouse of having an affair or become mistrustful of conversations, especially telephone calls. The patient may accuse the HHHA of having sexual activity with the spouse. The accusations may hurt and provoke anger, but again it is important to remember that this patient has a disease and the behavior is a symptom of that disease. It is not useful to argue with the patient or to try logically to change his mind. Again, distraction, reassurance and sense of humor will be effective in redirecting this behavior. Sometimes the patient is missing the touching, holding and affection that might have been present in his life before he became ill.

Sometimes a demented person will continually remove his clothes or expose himself in public or try to masturbate in inappropriate places. Again, the behavior is a result of confusion and disorientation, not maliciousness. If the patient continually unzips his pants, providing him with pants with only an elasticized waistband and no zipper may alleviate the problem. If a female patient frequently removes her dress, clothing with buttons in the back may help.

If a patient exposes himself and masturbates in front of others or makes offensive gestures, avoid having a negative overreaction. Try to be very matter of fact, and try to distract, i.e., offer him a snack. The behavior is a symptom of this disease. Keep written records and discuss this behavior with the agency.

**SUNDOWN SYNDROME**

It has often been noted that the time of day seems to affect the patient’s behavior. For example, many patients seem to grow more restless and agitated in the late afternoon. This phenomenon is frequently described as the “sundown syndrome.” Scientists are not sure why it happens. The patient cannot control his behavior.

If the caregiver notices this behavior pattern in any patient, it is a good idea to plan the day’s activities so that fewer expectations are made of the patient at this time of day. For example, schedule doctor’s appointments or shopping trips for earlier in the day, when the patient is less tired. Make sure that an exercise period is planned for the patient during the day. Make an attempt to reduce the hustle and bustle of the dinner hour. Late afternoon may be a good time for you to play quiet music and turn off a loud television set. Generally, reducing the stimulation in the environment will prove helpful in managing the person at this time of day.

If the patient becomes agitated, try to distract him with a form of quiet activity, i.e., looking at a family photograph album.

If all attempts fail, do not argue with or restrain the patient. Reassure him you are there to protect him.

Medications may need to be reviewed. Report behavior to family, agency and doctor.

**HALLUCINATIONS, DELUSIONS AND CATASTROPHIC REACTIONS**

Delusions and hallucinations are both described in the dictionary as sorts of false perceptions. Delusion refers to a false belief held as a result of a mental illness. Hallucination is defined as a false perception of the reality of objects or events (in *The American Heritage Dictionary of the English Language*), i.e., hearing, seeing or smelling things that are not there. These behaviors could be classified as “psychotic” in other settings, but when they occur in an AD patient, they appear to be the results of the cognitive decline taking place in the patient, and should more appropriately be termed “pseudo-psychosis” of Alzheimer’s Disease.

In the AD patient, these symptoms are reality, and are not false. The woman who serves tea to thirty children every day truly sees the children.
Hallucinations that may be Encountered in the AD Patient

Visual hallucinations: Many times a patient may see strangers coming to attack him, or may see dead relatives. These “people” he sees are very real to him. Don’t argue with the patient. Reassure him that you are there to take care of and protect him.

Auditory hallucinations: Often patients will hear people, or imagine that people are speaking about them. They may sometimes carry on conversations with these people. Don’t try to stop the patient. To the patient, these people are very real. Always be reassuring to the patient.

Delusional Behaviors that may be Encountered in the AD Patient

The “House is not one’s home” delusion: The patient is home, but still wants to go home. He may attempt to pack a bag, or may try to leave. Many times, attempts to stop the patient or to reason with him may result in anger or even violence. Don’t try to argue with the patient. Try to distract him by saying you will take him tomorrow, or that it is too late or dark outside.

The “People are stealing things” delusion: Many times the AD patient hides objects and forgets where he put them. He will accuse others of stealing the objects. An obvious psychological explanation for this behavior might be that the patient really believes people are stealing from him. Reassure the patient by offering to help him look for the misplaced objects.

The “Spouse is an imposter” delusion: Because an AD patient in time can no longer recognize a relative or spouse, a frequent delusion is that persons are imposters. In some instances, anger at that person may result. In one case, the patient called her husband “stupid;” said that her real husband had been very smart, but that he had died.

The Delusion of Infidelity: Often a patient will accuse his wife of being unfaithful, and accuse her of assorts of sexual goings-on with other men. The only suggestion we have is not to argue with the patient; do not reason with him. It is best, in most instances, to ignore what the patient is saying.

Catastrophic Reactions

A catastrophic reaction, when applied to AD patients, is an overreaction to any situation or condition. The patient may react to having too many people around him, to loud noises such as police sirens, or to being asked to do a task that is too difficult for him. The patient may become agitated, angry, or very stubborn. When any situation becomes too overwhelming to the AD patient’s diminished cognitive ability, he may overreact. The homemaker-home health aide should try to be aware of the types of situations that might cause such a reaction, so that this behavior can be avoided. The patient should not be taken anywhere where there may be lots of people, such as a big party. By the same token, the H-HHA should see to it that not too many people visit at the same time. If the aide notices that a task becomes too frustrating for the patient, he should stop him from doing that task.

If the patient does become very agitated, use some of the suggestions outlined in the section above, “Agitation/Restlessness.”

Delusions, hallucinations and catastrophic reactions can, in many cases, be controlled with medications. The homemaker-home health aide should bring these behaviors to the attention of the family, the agency, and the doctor.

ORAL HYGIENE

Healthy gums and teeth are important to the health of the patient and to insuring a proper diet. If a patient has ill-fitting dentures or mouth sores he maybe unable to chew. Daily brushing for the patient who has his own teeth is important. Help him by preparing the brush and toothpaste. If he has forgotten how to brush, show
him. Be sure dentures are cleaned and removed daily and that gums are checked for irritation. If you note any problems, gum sores, reseeding gums, bleeding gums, etc., notify the agency and the family.

**DRUG MANAGEMENT & MEDICATIONS**

There is no medication at this time that has been proven effective for either the prevention or cure of dementia. However, physicians have become more experienced in using some of the tranquilizer and psychotropic medications to manage the difficult behavior that some dementia patients exhibit. Some difficult behavior problems might be hallucinations and delusions that cause extreme anxiety, belligerent attitude with aggressive behavior, depression, extreme agitation or sleeplessness. Demented persons tend to be extremely sensitive to drugs, but if monitored very carefully by the physician life can be much easier for the patient, the family and the aide.

Usually, only very small doses are needed, but even these small doses sometimes produce side effects. Some patients may have a negative response and become agitated. Some unpleasant side effects may be a dry mouth, drowsiness, difficulty in walking, tremors and falling, and constipation. Sometimes these drugs are effective for a short period of time, and sometimes the patient's condition changes and he may no longer need the medication. Sometimes even after a drug has been discontinued, it may take some time for the body to be clear of the drug, sometimes even as long as four weeks. These effects are all carefully monitored by the physician with your assistance and observation of the patient’s behavior.

Always be sure the medication is kept in a safe place out of reach of the patient. Some medications may be given before meals, some after. Never argue with the patient about taking medication. If the patient has trouble swallowing pills, some medications may be given in liquid form, others can be crushed and mixed with apple sauce or cottage cheese. Always report any change in the patient’s condition to the family, agency and physician.

**CREATING A SAFE ENVIRONMENT**

The more an individual is impaired by Alzheimer's Disease, the greater is his chance of having an accident or being injured in an unsafe environment. Therefore, the homemaker-home health aide has to be alert when caring for the patient, to see that he does not hurt himself or anyone else. Since the patient is not responsible for his actions it is up to the individual who is caring for him to make the environment safe in order to avoid accidents. If the aide is working in a home where there are family members, they should be consulted about arranging the house to make it “accident-proof.” Use checklist (see Handouts below) to ensure the safety of the home environment.

The three basic principles to keep in mind when going about making the house safe are to keep the environment SIMPLE, UNCLUTTERED and UNCHANGING. However, the surroundings may have to be changed as the patient’s condition worsens, for example, walkways may have to be widened if the patient requires a wheelchair.

*IMPORTANT: If the patient is a smoker, the homemaker-home health aide should keep the cigarettes and matches, and stay with the patient while he smokes. Even if the patient is a non-smoker, matches should be out of his reach.*

For the wanderer, as mentioned before, it is recommended that the patient wear identification that cannot be lost or stolen. In fact, since one never knows what to expect next from the patient, it may be wise to have all dementia patients wear this type of identification. A medic-alert bracelet or necklace is often recommended as well. However, for the chronic wanderer, the safest identification is “camp labels,” with the patient’s name and phone number sewn into all clothing, even socks. (See Session IV, “Wandering.”)
Travel and Vacations

Another source of confusion for patients is being taken to strange places. Even though he may have been there many times before, a patient often will not remember having been there, so it seems like a strange place to him. It is suggested that the patient stay at home with the H-HHA, and that the family caregiver(s) take vacations alone or with others. This not only benefits the patient, since confusion may lead to aggression, but is a good respite for the family caregiver(s). The safest place for the patient is at home, in the familiar, simple, uncluttered atmosphere in which he is most comfortable.

TAKING CARE OF YOURSELF

The problems faced by the caretaker of patients with loss of intellectual functioning, or dementia, can often be overwhelming. Answers to the simplest questions about how to manage these patients are often missing in the medical literature. When you care for an AD patient, you may feel tired, overburdened and unappreciated. Fatigue, discouragement, anger and guilt are all normal feelings that you may experience. Thus, it is essential that you find ways to care for yourself (diet and exercise), to manage stress, and not exhaust your own emotional and physical resources. Pursue your hobbies and interests during your free time.

Homemaker-home health aides working in the homes of a family coping with Alzheimer’s Disease often become surrogate members of the family. They share the burden, come to love the patient and the family, and also grieve over the decline and loss of the patient.

Grief can make you feel sad and depressed. However, sharing your feelings with your supervisor who understands your job can make you feel more comfortable. This, in turn, will enable you to better care for the patient. Remember, the agency is your back-up and support system.

There may be no cure for Alzheimer’s Disease, but your understanding of the way this illness affects the patient’s emotions and behavior can make a difference in the quality of life of the patient.

AGITATION/RESTLESSNESS

Agitation maybe expressed in the Alzheimer’s Disease patient in many forms. Pacing, moving up and down constantly, fidgeting with clothes, being verbally abusive, cursing, screaming, pushing, biting, scratching and striking out at people are all signs that the patient is agitated. One or more of these symptoms are often found in AD patients during the course of the disease, though not all patients demonstrate them.

There are many theories as to the cause of agitation. It may be due to the chemical alterations in the brain or caused by the recognition of losses by the patient. It may be part of depression, anger or anxiety, or of overmedication; or it may just be an unexplained part of the illness. It is also possible that the patient builds up unused energy due to lack of exercise, and restlessness may result.

Restlessness, pushing or screaming may also be a sign that the patient is not feeling well. He may have a fever or gas or be constipated. At times, restlessness may be a part of the depression or anxiety the individual feels when he can’t find a wanted object or is unable to complete a task. At this stage, the patient will find it increasingly difficult psychologically to deny his memory loss, and instead of withdrawing, he may become agitated. It is important to remember that in some instances agitation maybe avoided by the proper prevention and intervention. Maintaining a safe environment that is constant, avoiding confusion that may be caused by loud noises or crowds, and asking the patient to do only those things that he can do successfully (not asking patient to tie his shoe when he can no longer do so) are examples of preventative measures. Others include not contradicting him, not confronting him, maintaining a calm voice and manner, and being patient.

Some of the interventions or strategies that may calm the agitated patient are speaking softly and gently; patting him; and diverting him by singing a song, playing a game, offering him a sweet, or playing some music. Sometimes rocking him back and forth gently while speaking softly is very effective.
Sometimes nothing seems to help. Remember, it is the disease that is causing the annoying behavior, and the patient has no control over it. If his restless behavior cannot be managed and controlled to a tolerable level, describe it to the family and doctor. Observe when it happens, what helps and what doesn’t. Be sure to keep a written record of your observations. The physician may want to try medication, so that the patient can be maintained at home. Don’t hesitate to contact your agency supervisor for additional suggestions.

### Wandering

Wandering is a major problem and one of the most frequent reasons, along with incontinence, that families make the decision to place their confused relative in a nursing home. The afflicted person is in a dangerous situation when he wanders off alone, because although he may look perfectly healthy, his ability to comprehend danger and make the appropriate judgment no longer exists.

A patient who wanders requires constant supervision and a secured environment. When dealing with such a person, the rule is “expect the unexpected.” The most passive patient may get up and wander off when you least expect it.

It is unwise to try to forcibly stop a person who is wandering. Instead, walk with the person and gently distract him with something else of interest, e.g., a snack, rest, activity, etc. Sometimes the frequency of wandering can be reduced if the AD patient is allowed to play out his plan, while observing a point at which alternative suggestions can be offered in a supportive, guiding and non-corrective way!

There are many reasons a person may begin to wander. For example, wandering may be expected to occur after the patient moves to a new home, since he finds it difficult to learn new information. In this situation, he may also be grieving about giving up his own apartment now that he is living with a family member, such as his daughter. Wandering may also be a result of boredom and restlessness and the need for more exercise. Or wandering may occur when the patient is upset, because he no longer recognizes familiar places as he once did. He may attempt “to go home” even while he is in his own house. The patient is living in the past and may attempt to leave to do the same activity as in the past, i.e., go to the office. Try to understand his feelings and get him to express himself and talk about it.

The person who wanders needs to be reassured and given clues as to where he is. Do not argue or confront this patient, especially if he is severely demented; correcting him may make him feel he is being criticized, and his anxiety and agitation may increase.

The patient’s environment should be made as safe as possible. Secured windows and locked doors are essential. Sometimes additional locks are placed at the bottom of the door, where the Alzheimer’s Disease patient would probably not look. Bells or electronic signals are also sometimes installed. Special doorknobs are available from hardware stores that require special manipulation to be opened.

Every patient should wear an identification bracelet at all times. The bracelet should be securely fastened. Identification in a coat or wallet may be used as well, but not alone. The AD patient will often lose his coat or wallet easily if he wanders.

It is a good idea to have a recent photograph of the patient readily available. If the patient does wander away and get lost, the photo can be helpful to the police who, in most communities, are now trained to be on the alert for these confused individuals and to help them return to their homes.

If the patient wanders off, stay calm and notify a family member. The family member, in turn, should notify the police, and then return home to be near the telephone number on the patient’s identification bracelet in order to receive the call when the police find the patient. If the family member is not available, call the police without delay.