

Special Care Problems: Urinary Incontinence

The principal author of this pamphlet is Linda Duffy, MS, RN, Nurse Practitioner, Geriatric Research, Education and Clinical Center (GRECC) of the Department of Veterans Affairs Medical Center in Minneapolis, Minnesota.

This pamphlet is part of a series on dementia-related diseases. This series was prepared by Kenneth Hepburn, Ph.D., GRECC, of the Department of Veterans Affairs Medical Center, Minneapolis, Minnesota.

Loss of bladder control is known as "urinary incontinence". Urinary incontinence occurs commonly among people with Alzheimer's disease and other dementing illnesses. At first, there may be only a problem once in while. The person may not be aware of the problem at all or may be very upset by it.

Loss of bowel control, or "bowel incontinence," may also occur. This most often happens late in the course of the disease. Bowel incontinence, though, is a totally different problem, and a less common one. One type of incontinence can occur **without** the other. Each type of incontinence poses special care problems for you, the caregiver.

Urinary incontinence may sometimes be caused by health problems. Infections in the bladder or the rest of the urinary tract, drug reactions, or even some psychological conditions can cause wetting problems. Many of these causes will respond to treatment. Bladder control may improve once these other problems are treated. All cases of urinary incontinence should, therefore, be evaluated promptly by a doctor. Even if the incontinence is caused simply by progressing Alzheimer's disease itself, your health care team should have ideas on how to cope with the problem.

As a caregiver, you will play a key role in helping your health care team members. They rely on what you observe and report about the person in your care. Then, too, you are the one who will carry out any prescribed treatment or manage any care plan.

You are also the one who has to live with the problem. You will need to find ways to ensure the patient's comfort and to cope with the extra work the wetting creates. You will also need to deal with your own feelings about what is, for most of us, a sensitive issue.

All these add up to a hard task, and you will surely need help. Don't be afraid or embarrassed to ask for it. Keep in mind that your health care team forms another link in the care network you must set up to meet both the needs of the impaired person and your own needs. The rest of this pamphlet offers ideas for dealing with urinary incontinence problems and for finding additional help you might need. For information on dealing with bowel incontinence, see the pamphlet in this series entitled Special Care Problems, Part 5: Bowel Incontinence.

Observation and Diagnosis

If a person suddenly develops urinary incontinence, the doctor will want to see the patient promptly to learn the nature of the problem. You will need to watch for signs of a pattern to the problem, signs of a worsening trend, or signs of any side effects from prescribed drugs. After hearing your reports and perhaps doing some tests, the doctor will be better able to make a final diagnosis. Then any needed treatment can be planned, and you can work out a care routine together.

In giving daily care, try to observe the patient closely during urination. You can help the doctor greatly by answering the following questions.

Questions:

Until lately, has the person been able to use the toilet alone? Or was help needed?

When you first noticed the problem, did it seem to come on all at once? Or did the loss of control get worse little by little?

Has the person ever had a problem like this in the past?

Is this a regular problem, or does it only occur once in a while?

Does the problem occur mainly at night or mainly during the daytime? Or does the problem occur day and night?

In the course of a normal day, when (and how often) does the person urinate?

Is the person just leaking or dribbling instead of completely emptying the bladder?

Is the urine stream a strong one?

Does a longer than usual amount of time pass before the urine begins to flow?

Does the person wake up wet? Every morning or just some mornings?

Does the wetting occur when the person is in the bathroom or on the way there?

Does there seem to be pain or burning? Does the person complain about itching?

Can you detect any odd odor or color of the urine? Does there seem to be blood or pus in the urine?

Have you noticed any changes in the person since the wetting began? (Does the person seem more upset or confused than usual? Have you noticed any change in sleep habits or appetite?)

Were any changes made recently in the person's home or routine?

Does the patient smoke? How much? Have there been any changes recently in this habit?

How much does the person drink each day? (Figure out the number of cups or glasses of liquid the person drinks in a normal day.) How much is consumed just before bedtime?

What kinds of fluids are consumed?

How many cups of coffee, tea or cola does the person drink each day? How many at dinner-time? **How** many late in the evening?

Does the person drink alcoholic beverages? When are these drinks taken?

Have you learned any ways to help prevent the wetting?

Is the person aware that a problem exists? If so, does the person seem not to care, or is the problem causing upset or worry?

Is the problem mainly that the impaired person chooses places other than the bathroom to urinate (places such as corners, garbage cans, closets or the outdoors)?

Your doctor may have other questions or comments about your situation.

Note: Be sure your doctor knows all the drugs being taken by the impaired person. This includes all over-the-counter drugs and any pills given to the patient by family or friends.

Treatment and management

Once you have a clear diagnosis of the problem, your doctor can treat those symptoms that can be helped. If any effective treatment exists, you may be asked to carry it out at home. Treatment may be as simple as cutting out drinks with caffeine or giving the person less to drink before bedtime. Or you may be asked to give certain medicines. Once again you will also be asked to observe the person carefully for results and for any new changes.

Solving the problem or finding a care plan that works for you and the person in your care may take time. The prescribed treatment may not work at all, or it may only partly work. Perhaps no good treatment even exists for your special case. The cause of the incontinence may simply be the progressing disease itself. Even so, you and your health care team should still work together to find ways to manage the care problems that remain while helping the impaired person get as much out of life as he or she can.

Your care goal becomes managing the impaired person's toileting in a way that preserves his or her comfort and self-esteem as much as possible and saves you extra work and trouble.

Coping Techniques

The following ideas may be helpful to you. Discuss these with your doctor or nurse and make a plan. If a plan doesn't seem to be working, discuss the problems you are having and any ideas you may want to try. Keep at it until you have a plan that works.

Support groups offer you another valuable resource. Other members may well have excellent suggestions, based on their own experiences, for managing the problems you are facing.

Finding the bathroom or toilet easily.

Help the impaired person find the bathroom or toilet easily. Try visual cues like arrows, a sign on the bathroom door or a brightly painted door. Try night lights in the hall, the bathroom and the bedroom. Consider trying a bedpan or commode chair to bring the toilet closer to the person, if you think that would help.

Make sure the bathroom feels safe...

and comfortable to the impaired person. Is the room warm enough? Is the room well-lit but not glaring? Think about putting up support bars or handrails to help the person when standing up or sitting down. Be sure, too, that the toilet seat is stable and at a good height for the person. You can buy a devices that can change the height of the seat, if need be. A few magazines and/or a battery-operated radio in the bathroom may also help.

Review the person's daily habits ...

and take advantage of any patterns or cues to plan ahead. For instance, does the person usually need to urinate first thing in the morning or after drinking products with caffeine in them?

If you observe the person closely you may also see that he or she acts a certain way just before the accidents. Sometimes the person may rock back and forth, become restless, touch or hold the genital area, or begin unzipping clothes. In all these cases, being aware of the pattern will help you take the person to the toilet before an accident can occur.

Make changes in the daily routine if need be.

Consider having a man sit down to urinate rather than stand. This will reduce accidents due to poor aim of the urine stream. Keep clothing simple and easy to remove. Two-piece outfits may be changed most easily. Only the soiled half needs to be removed. Since many people react to caffeine by needing to urinate more urgently or more often, you may want to restrict the use of these drinks or stop offering them at all. If the person wakes up wet in the morning, you might want to restrict the fluids the person consumes in the evening. Also make sure he or she goes to bed with an empty bladder.

Note: Do **not** greatly restrict the total amount a person drinks during the day. Lack of enough water can cause serious problems. You should also be very cautious about the over-the-counter drugs such as cold remedies. These drugs may have harmful side effects. Some may cause new problems or mask symptoms that need treatment. Check with your doctor before using any drug.

Set up a pattern ...

of taking a person to the bathroom at regular intervals. Aim for a pattern of taking the person to the toilet about every two hours. If night wetting is still a problem, you may want to try different patterns of waking the person once or twice during the night to use the bathroom. This will clearly disrupt your own rest, though. You may be better off using some of the supplies suggested in the next section and letting the person sleep through the night.

Supplies that can help you cope

If your efforts have not worked as well as you might have wished, you may want to try some of the special clothes, supplies and equipment designed for persons with problems of incontinence. These products may be found in discount stores, drug stores and medical supply houses.

In addition to the grab bars, handrails and adjustable toilet seats mentioned earlier, a number of other products can help an incontinent person. To name a few, these include adult diapers, liners, slipcovers, sheets, wet-proof mattress covers, "chux" bed protectors, external (condom) catheters for men that may be attached to a leg or bed bag and pads for women. Some may be washed and reused. Others can be thrown away after one use. Some products are more absorbent than others because they contain a gelling material. These products may be expensive. You will need to weigh what you can afford to buy against the amount of help and relief these products offer you as a caregiver.

Your doctor, nurse or pharmacist can describe these products and help you decide what would work best for you and stay within your budget. They should also be able to tell you where you can find these items in your area.

Be sure to include the cost of all such items in your planning. Shopping for the best price will help you control costs. If you decide you want to try a piece of equipment, think about renting it for a trial period rather than buying it outright. For major items, you may find that renting the piece, even over a long period, is still cheaper than buying it.

Living with the problem

If the person for whom you provide care has become incontinent, then your caregiving role has grown. If no treatment works, you still have to cope somehow with the problem. You will need to observe the patterns of the problem and to work with your doctor or nurse on a good care plan. You need to figure out ways to plan ahead and prevent the problem, if possible. You may also need to comfort the patient and clean up if the plan does not work.

As with other parts of your caregiving task, seek help with incontinence problems. Besides working with your health care team, don't be afraid to ask your family and friends for help. They can fill in for you at times. They can find out where to buy incontinence supplies and shop for the best buys. You may also want to try hiring help, either in your home or in a respite care facility.

Finally, as in all aspects of your caregiving, don't ignore your own needs and feelings. Even if you can remember that the impaired person is not causing problems on purpose, dealing with incontinence may make you feel any number of emotions: shock, anger, disgust, shame or a sense of being overwhelmed. Then, too, you might feel guilty for feeling this way. Try to keep in mind that the trouble is not the result of your being a poor caregiver. The problems are part of the disease itself and part of the caregiving role. Other people have had similar troubles, so do not feel you must keep your problems and feelings to yourself. Speak to a friend or family member, a counselor or member of the clergy, or join a support group. (The Alzheimer's Disease and Related Disorders Association may be able to help you find a support group near you. Ask your health care team or a local hospital for a

referral.) At times like this, sharing what you feel can be very helpful.