Dealing with Incontinence
Physically and Emotionally

Definition of incontinence: Inability to control bladder or bowels.

Resources:

- The 36-Hour Day
- The Mayo Clinic Guide to Alzheimer’s Disease
- HDIS.com (Home delivered incontinence supplies – try a variety pack to see what products suit your needs the best) www.hdis.com

The books listed above address the physical aspects of incontinence and agree that, with planning and the use of a variety of incontinence products, urinary incontinence can be a manageable part of the disease process. As with all things related to dementia, patience, calmness and understanding will go a long way.

Things to know:

1. Incontinence is almost always a part of Alzheimer’s Disease.
2. Other things can cause incontinence, so when it first appears it is advisable to talk to your medical practitioner. While it will be part of the process at some point, be sure to rule out or treat other causes.
3. There are things you can do that may keep incontinent incidents to a minimum for awhile.
   A. Follow a bathroom routine. Provide reminders every 1-2 hours, if necessary.
   B. Place a picture of a toilet and the word TOILET on the bathroom door.
   C. Keep the bathroom door open with a night light on so the person can find the bathroom more easily.
   D. Watch for nonverbal signs that might indicate the need to use the bathroom.
   E. Some caregivers find that tape on the floor in the shape of arrows leading to the bathroom is helpful.
   F. Avoid clothing with complicated fasteners.
   G. Do not limit fluid intake. Dehydration is common for people with dementia. Hydration is critical for proper kidney function.
   H. Sometimes, urgency of needing to use the bathroom combined with slowed mobility make it difficult to get to the bathroom in time. Use of a portable or bedside commode can reduce incontinence episodes and reduce fall risk as well.
What is not always addressed in the literature is the emotional and physical toll that incontinence takes on a family caregiver. This certainly varies by caregiver, by stage of disease and level of incontinence, and by how willing your loved one is to let you assist them with toileting issues. It adds one more unpredictable variable to the mix.

So, how to cope? A few ideas:

1. Connect. Find a support group, if you haven’t already. No one knows incontinence like other caregivers, and they know the tricks of the trade. They also understand the challenges, and why this issue can be so wearisome. No need to reinvent the wheel. If you are unable to get to a support group, find support online. A couple of places to start:
   - [http://alz.org/living_with_alzheimers_message_boards_lwa.asp](http://alz.org/living_with_alzheimers_message_boards_lwa.asp)

   Also, connect with chapter staff. We have learned a lot from caregivers (both family and professional) over the years, and can brainstorm with you about Your particular situation. Agitation and aggression around this issue are not uncommon. Call us! 1-800-292-3900.

2. Plan ahead. Addressing incontinence can be tiring. You are on your feet more, guiding your loved one to the bathroom, physically wrestling with undergarments and clothing changes, purchasing supplies, and doing more laundry. Try to plan ahead as much as possible, with supplies and clothing changes close at hand. Add the waterproof mattress pad to the bed and use extra bedding at strategic places to minimize total bed linen changes. You may be able to develop a toileting schedule for awhile, and can plan outings accordingly. Bring supplies with you, and learn where public or family restrooms are readily accessible.

3. Reprioritize/Get help. Priorities often shift, and as incontinence becomes an issue you may find that your priorities change in a couple of ways:
   a. This issue requires time and energy. What can you give up? Perhaps this is not the year to try to plant a garden, or worry about the weeds. Can you minimize some house work, paperwork, meal preparation? In other words, something has to give.
   b. Health and hygiene need to be addressed, but not always by you. If you can afford to pay someone to assist you, either by providing hands-on care or by relieving you of some other responsibilities so you can provide the hands-on care, this is the time to do it. Include family members in a discussion about changes in symptoms and what this means practically. Enlist their help, if possible.
4. Plan for a move. Bowel incontinence and caregiver fatigue are two of the top reasons people move their loved one to a facility. Sometimes, having a plan can relieve some stress. While you may not need to use it right now, it can help just knowing that you are prepared in this way, should you find yourself overwhelmed. Consider a short-term respite stay in a facility for your loved one as a way to get some rest and try out another arrangement. I realize this could mean a large financial cost, but it may be well worth it – an investment in your own well being.

Questions? Concerns? Comments? Please call or e-mail me at 1-800-272-3900 or laurel.kerr@alz.org.