



Fact Sheet:

Caring for Someone with Incontinence: Emotional and Social Issues

When asked, many family and partner caregivers say that heavy incontinence would tip their decision towards moving a loved one to a nursing home. What makes this such an emotionally difficult turning point? Incontinence can be the last straw in a stressful caregiving situation. Covered below are some of the issues that make incontinence so difficult to deal with, and tips on how to cope with these concerns.

Resistance

What should you do when your loved one is resistant to using pads or protective underwear? An individual asked to use incontinence products daily may feel that they are no longer capable of taking care of themselves at the most basic level. Their response to you might be one of denial, anger, refusal, or passive inaction.

Coping: It is important to talk with your loved one in a calm, understanding, and honest way about how their incontinence is affecting you and your ability to provide the best possible care for them. This can make acceptance easier—of the incontinence as well as the incontinence products. If the care receiver lives with a mental or cognitive condition like dementia, learn the best approaches by taking a class or attending a support group where you can learn useful tools for more successful communication.

Be tactful; walking in and saying the house

smells may offend the care receiver and cause a defensive response rather than one of cooperation.

Embarrassment

You might feel a sense of embarrassment not only for yourself but also for the care receiver. It's hard to be responsible for caring for someone, like your parent, in this very personal and often invasive way. If you are caring for someone of the opposite sex, it can be awkward having to see, touch and care for their private areas. If you are caring for a parent of the same sex, it may still feel like you're invading their privacy. And finally, there is compassion for the loss of dignity felt by a loved one who now needs care at this level.

Coping: Talking it out with supportive family, friends, or professionals can be helpful. Acknowledge your uncomfortable feelings. Hire a home care worker or recruit another family member or friend to provide care when is too hard for you to do.

Reactions

Caregivers are often not at their best when dealing with incontinence. It might feel like the care receiver allowed an incontinence episode to occur on purpose to punish you. You might find yourself getting angry or impatient, especially if help is needed at an inconvenient time, such as when preparing

dinner or sleeping. The cost of incontinence supplies can be a concern in the budget of the caregiver/care receiver. And if the care receiver is not cooperative, it puts even more strain on your relationship with them. Some people may also have physically reactions and discomfort to bodily fluids and odors.

Coping: Admitting to your discomfort is a good first step. Pretending this is not an issue for you, if it is, only makes matters worse for both you and the care receiver. Know that the care receiver is not trying to make your life harder; they have no control over what is happening. This is difficult for them, also. Seek out help through an in-person or online support groups, from a friend or family member who has had a similar experience, or from a social worker, nurse, occupational therapist or other health professional.

Emotions

You might find yourself getting angry or resentful for having to deal with this situation. Maybe it's just too hard for you to do. Sometimes it may feel easier to just not clean someone up, but this is neglectful of the care receiver and puts the care receiver at risk for skin breakdown and infections, particularly urinary tract infections.

Coping: Acknowledge the many feeling you might have about dealing with incontinence and ask for help. Support groups, either in-person or online, can offer you both emotional encouragement and tried and true practical strategies. No doubt other caregivers will share their research and experience with various products. Get product recommendations from your doctor, pharmacist, or an occupational therapist. Seek out products that make it easier for you and the care receiver. Consider hiring a personal care aide or allowing other family members help whenever they can. You don't have to do it all.

Physical Limitations

Mismatched body types, physical disability, or age or disease-related physical weakness may make providing incontinence care for your loved one difficult. A small person trying to help a much larger person out of bed might risk hurting their back or straining other muscles. You might be at risk for falling when roused in the middle of the night to aid the care receiver in getting to the bathroom or using a urinal. And the lack of sleep that results from getting up several times during the night will definitely affect your functioning and capacity to cope the next day.

Coping: If you are caring for someone with a physical disability, such as paralysis or weakness, make sure you have a physical therapist or occupational therapist teach you how to use your body so that you don't hurt yourself while trying to help the care receiver. Work with your physician to make sure any plan of care includes what YOU need as well as what the care receiver needs. It's OK to acknowledge your own limits and set limits when something might be harmful to you.

Planning

Going out with someone who is incontinent takes some advanced planning. Caregivers and care receivers often become socially isolated because of concerns about dealing with incontinence outside of the home setting.

Coping: Prepack two small duffle or shoulder bags with everything you might need such as incontinence pads, wipes, gloves, change of underwear, and other supplies you require. Be sure to include a couple of plastic bag to stash soiled products. Keep one bag with you and one in the car, just in case. If traveling, look for a family/companion bathroom that allows two people to go in together. Or carry a laminated flyer that you can affix to the

entrance of a public bathroom that says, for example, “wife caring for disabled husband inside.” Know that in some states, like California, a state law allows a family caregiver or paid attendant of either sex to assist a care receiver in a public bathroom. Arrange to have a seat near the bathroom in an airplane or on other transportation. Keep in mind where bathrooms are on an outing, which will reduce anxiety for both of you. Stop by a restroom frequently, even if the care receiver has not said they need to go.

Time and Resources

Incontinence makes the caregiver’s job harder in many ways. Incontinence product leaks, their inconsistent usage, or even lack of use when called for, will result in more loads of laundry and more time consumed cleaning up the bathroom and around the house. Additional time is required if help is needed to bathe your loved one after a urine or bowel accident. As personal care takes more and more time, you may find yourself growing less patient and more frustrated. These feelings are only compounded if cleaning and bathing demands occur throughout the night leaving the caregiver without adequate sleep. Increasing time demands needed for incontinence care will influence when more help is needed, for example, recruiting another family member or hiring an attendant, and possibly considering whether it’s time to look into residential care placement. Additional factors that cannot be overlooked are the cost of incontinence care products, and the effort involved to monitor and purchase all necessary supplies.

Coping: Hiring help can take some of the strain off of the caregiver. Many caregivers suggest searching online to find the best price for incontinence supplies and for finding coupons to help reduce the cost at the store. Don’t hesitate to ask another caregiver—in person or on an online caregiver support groups—for their suggestions on the best places to buy

products. You may ultimately decide that placement is the best choice both for you and the care receiver—even if you promised never to move them to a nursing home. Then the caregiver can return to being a partner, adult child, friend, sibling and not only the personal care attendant. The change from loving partner to caregiver can result in grief, guilt and depression. Taking care of your own needs is most important in being able to care for someone else.

You are not alone . . .

It will be easier for you, as a caregiver, as well as for the care receiver if you can make incontinence care as natural as possible. It is, after all, very common—25% of women and 15% of men experience incontinence at some point in their lives. Get a medical evaluation to see whether there is something that can be done to decrease the urgency of needing to use the bathroom, and to find out if a treatable condition can be identified, such as a urinary tract infection or prostate problem. Discuss with the care receiver’s physician whether medication or bladder training would be effective in this situation. Above all, seek out and get help from family, friends, and paid help if possible so it is not entirely on you to do all of the care.

Resources

Southern Caregiver Resource Center
891 Kuhn Drive, Ste. 200
Chula Vista, CA 91914
(858) 268-4432 | (800) 827-1008 (in CA)
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include: information and referral, counseling, family consultation and case management, legal

and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance
National Center on Caregiving
(415) 434-3388 | (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities.

Urology Care Foundation: American Urological Association
www.urologyhealth.org

National Association for Continence
www.nafc.org

Incontinence Support Center
www.incontinencesupport.org

Recommending Reading

Fact Sheets

Caregiver's Guide to Understanding Dementia Behaviors

Hiring In-Home Help

Taking Care of YOU: Self-Care for Family Caregivers

Caregiving and Ambiguous Loss

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