SUPPORTING FAMILY CAREGIVERS
NO LONGER HOME ALONE

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Managing Urinary Incontinence

Practical tips for home-based care.

This article is part of a series, *Supporting Family Caregivers: No Longer Home Alone*, published in collaboration with the AARP Public Policy Institute. Results of focus groups, conducted as part of the AARP Public Policy Institute's No Longer Home Alone video project, supported evidence that family caregivers aren't given the information they need to manage the complex care regimens of family members. This series of articles and accompanying videos aims to help nurses provide caregivers with the tools they need to manage their family member's health care at home.

The articles in this new installment of the series provide simple and useful instructions that nurses should reinforce with family caregivers. This article is the second of two that provide an update on urinary incontinence and its management in older adults. It includes an informational tear sheet—*Information for Family Caregivers*—that contains links to the instructional videos. To use this series, nurses should read the articles first, so they understand how best to help family caregivers, and then encourage caregivers to watch the videos and ask questions. For additional information, see *Resources for Nurses*.

A major challenge in family caregiving is supporting older adults who are experiencing urinary incontinence (UI), or the leakage of urine that occurs beyond a person's control.[1-3] UI commonly occurs in people who require complex care (those who have dementia, for example) and can be a significant burden for family caregivers.[4] Providing care to someone with UI can be emotionally and physically exhausting, resulting in social isolation, frustration, and a higher likelihood of nursing home placement.[5-7] Yet, many family caregivers say they aren't given the education and support they need.[8] Studies show that family caregivers desire a better understanding of UI, advice on practical issues (regarding toileting skills and selecting appropriate absorbent products, for example), and support from health care providers to improve the care they provide.[7,8]

This article and the corresponding videos were developed as resources for nurses, enabling them to provide education and support to people who have UI and their family caregivers. Also included are practical tips to help caregivers manage the daily challenges of UI (see *Information for Family Caregivers*).

OVERCOMING TREATMENT BARRIERS

Because of embarrassment, many older adults with UI and their caregivers are reluctant to seek medical care.[7,9,10] To help dispel the social stigma associated with UI and facilitate open communication with caregivers, nurses should portray UI as a health problem amenable to treatment.[8] They should explain what UI is and how it's managed in a clear, straightforward way, being mindful that family caregivers may not initiate these discussions and older adults may not wish to acknowledge they're experiencing these symptoms.[8]

Common misconceptions about UI may lead to additional treatment barriers.[10] Many older adults and family caregivers, for example, believe UI is an inevitable part of growing older.[11] Although changes that occur in the bladder and surrounding structures over time can predispose older adults to developing UI, the condition should never be considered a consequence of aging.[3] Additional factors, such as dementia and functional impairments, can affect an older adult's ability to remain dry. In people who have dementia, changes that occur in the brain can lead to a loss of the ability to control urination and a limited understanding of socially acceptable times to urinate.[12] Physical limitations can also affect a person's ability to manipulate clothing and make it to the toilet before a leakage occurs.[12]

Family caregivers and older adults may also erroneously believe there are no treatments for UI.[13] There are now a variety of treatment options that extend beyond surgical intervention and the use of medication, pads, or incontinence briefs. In older adults, first-line treatment strategies focused on changing lifestyle and toileting behaviors (timing

An older adult with UI rests on an absorbent underpad her caregiver has placed on the bedding to protect it from urine leakage. Photo courtesy of the AARP Public Policy Institute.

trips to the bathroom, for example) can be very effective in managing leakages and improving quality of life.[3, 14, 15]

Finally, during emotionally challenging and stressful times, family caregivers may mistakenly attribute bladder leakage to defiant or intentional behavior.[13] Nurses should acknowledge family caregivers' frustrations and provide reassurance that UI is an involuntary act.

ECONOMIC IMPACT

The cost of purchasing UI products and doing laundry for people with UI can be overwhelming.[7, 16, 17] Each caregiving situation is unique and defined by the extent of UI symptoms and the presence of other health issues. Financial support may be available through Medicaid, some private insurers, the U.S. Department of Veterans Affairs, and state or community-based programs. Although Medicare (Parts A and B) and Medigap (supplemental insurance) don't cover the cost of UI supplies, some Medicare Advantage plans (Part C) offer additional benefits.[18, 19] In most states, Medicaid covers UI supplies.[20] Caregivers should contact their state Medicaid office for further details regarding specific guidelines.

Caregivers should also explore purchasing options that can help to defray some out-of-pocket costs. Nurses can encourage family caregivers to purchase products online, buy in bulk at wholesale clubs, or consider home delivery of incontinence supplies.[18, 21] Free shipping offers and discreet packaging also make online purchasing appealing. When purchasing in local stores, caregivers should stock up on supplies when they are on sale.[18] They should know to save all receipts, because they may be able to deduct the cost of UI supplies on tax returns.[18, 19]

Another option are "diaper banks," which provide incontinence supplies to older adults who can't afford them. These supplies are distributed through local nonprofit organizations, such as churches, the United Way, and senior centers, all of which can be a valuable resource.[22] A list of available diaper banks by state can be found at http://simonfoundation.org/resources/directory-us-diaper-banks.

ABSORBENT PRODUCTS

A variety of absorbent products are available to help family caregivers effectively manage UI. However, the use of these products should not take the place of a thorough assessment and treatment of UI when it is possible and desired by the person and family.[3, 23] The purpose of absorbent products is to contain urine, so it doesn't accidentally leak onto clothing, bedding, or furniture, thereby decreasing negative sequelae and optimizing quality of life.

There are two main categories of products: those worn on the body and those used to cover furniture and other items.[23] There is no clear consensus regarding the most effective products. Nurses should work with families to determine which products are the most comfortable and discreet while also providing the maximum coverage needed for the type and amount of incontinence. Products are either disposable or reusable. The former are single use, containing moisture-wicking materials that keep the skin and surface dry. The latter are usually made with cotton or polyester and have an absorbent core and outer layer that prevent urine from soaking through.[24]

Disposable products are generally less expensive, but costs add up if used long term.[25] Most have adhesive strips, which secure absorbent pads to garments, helping to ensure a proper fit. Some disposable protective underwear offer greater absorbency without adding a lot of bulk. Though useful for traveling, disposable products may be challenging to discard in public toilets. Product manufacturers are now working on innovations, such as biodegradable materials, to make disposable pads more environmentally friendly.

Reusable products, which are available in a variety of styles, colors, sizes, and shapes, resemble regular underwear. These products take up less storage space compared to disposable products. However, because the up-front costs of purchasing these products may be higher, choosing the wrong product can be an expensive mistake. Reusable products are

Table 1. Commonly Used Absorbent Products for Adult Incontinence[23, 27]

Type of Product	Description	Indication	Considerations
Pantyliners, perineal pads, male incontinence guards	• Pantyliners and perineal pads are similar to feminine hygiene pads and attach to underwear with an adhesive strip • Male incontinence guards are pads with an adhesive strip that attach to brief-style underwear	Light to moderate urine leakage	• Preferred for discreetness • More effective protection for urine leakage than feminine hygiene pads • May be difficult to adhere to boxer-style male underwear • Products made with superabsorbent polymers are recommended
Protective underwear	• Similar to cloth underwear, these have an elastic waist and are made with absorbent material • Sometimes called "pull-ups"	Moderate to severe UI	• Most popular • Helpful for people who have dementia, who frequently remove absorbent products
Adult incontinence briefs	• Similar to a child's diaper • May have a built-in wetness indicator • Elastic waist has self-adhesive strips that can be refastened	• Moderate to severe UI • May be recommended for people with UI and fecal incontinence	• Often used in those who are bedridden • Reusable products should be avoided • Products made with superabsorbent polymers are recommended
Underpads	Absorbent underpads that may be placed on bedding or furniture to protect from urine leakage	• Severe, constant urine leakage • Nighttime urine leakage	• Disposable underpads are recommended for use with wearable products (such as perineal pads) • Reusable underpads may be used with or without wearable products

typically not recommended for those with heavy urine loss or fecal incontinence.[24] In addition, they may not be as effective at wicking away moisture on the skin's surface, potentially causing more skin complications than disposable products.[25, 26]

The most commonly used absorbent products are described in Table 1.[23, 27] When recommending products, nurses should consider the volume of urine loss, cost effectiveness, timing and frequency of leakages, comfort, fit, ease of use, and preferences of the older adult.[27] For instance, people who experience heavy leakages at night may benefit by using waterproof pads that protect their bed linens or chair pads that protect furniture. Pilot testing a few products may be the best way to determine a person's needs and preferences.

OVERCOMING ODORS AND MESSINESS

Controlling and preventing unpleasant odors are common concerns of family caregivers.[17, 28] Fear of unpleasant odors and embarrassment can lead to social isolation and anxiety.[29] A frequent and mistaken practice of people who have UI is to limit fluid intake, which leads to highly concentrated, dark urine that may have a strong odor.[30] Foul-smelling urine may also result from a bladder or urinary tract infection. Certain foods or medications can also affect the color and odor of urine.[31] Nurses should encourage family caregivers to discuss any abnormalities with their health care providers.

Maintaining proper hydration daily can minimize strong urine odors. Unless fluid restrictions have been recommended, a person should consume six to eight glasses (eight ounces each) of fluid daily.[30]

Caregivers should be taught that the area protected by a pad or incontinence brief should be cleansed regularly, thoroughly rinsed, and patted dry. The use of no-rinse or foam cleansers may be more effective at reducing incontinence-associated dermatitis than soap and water.[26] Following incontinent episodes and toileting, special care should be taken to wipe the area from front to back to prevent cross contamination and infection. Applying moisture barriers after each cleaning (creams or ointments containing zinc oxide, for example) can be an important step in the prevention of skin breakdown.[32]

Information for Family Caregivers

Managing the Older Adult with Urinary Incontinence (UI): Tips for Self-Care

Taking care of yourself.

- Relieve stress—it can make you a better caregiver. Find ways to help manage stress, such as scheduling time alone, walking, or meditating.
- Recognize you're not alone—UI is a common challenge for caregivers. Attend support group meetings or use social media to gain strength, support, and advice from others.

Communicating with the care recipient.

- Broach the topic of UI when you're alone with the care recipient.
- Don't use shaming or demeaning language (such as the word "diapers" for absorbent products).
- Avoid nagging and arguing about toileting.
- Ask the care recipient the following questions; the answers will be helpful when describing the problem to health care providers:
  - Do you have difficulty making it to the bathroom in time?
  - Do you need to urinate more than every two hours or more than eight times a day?
  - Do you use the bathroom more than once each night?
  - Are you using anything—such as toilet paper, a paper towel, or a pad—to protect your clothes from accidental urine or bowel leakage?

Seeking help from health care providers.

- Ask your primary care provider for assistance.
- If necessary, seek a referral to a bladder care specialist for evaluation and management. This might be a continence nurse specialist, a urologist who specializes in continence issues, or a urogynecologist.
- Keep a bladder diary that details how often and when the person urinates during the day and night and when she or he is having bladder or bowel accidents. Also list the amount and type of fluids typically ingested in a day, as well as all prescription and over-the-counter medications. Bring this record to provider appointments.

Family caregiver instructional videos about UI can be found on AARP's website:

🎥 Managing Incontinence: How Family Caregivers Can Help
http://links.lww.com/AJN/A165

🎥 Managing Incontinence at Home
http://links.lww.com/AJN/A166

🎥 Helping Someone to the Toilet
http://links.lww.com/AJN/A167

🎥 Seeking Emotional Support: Managing a Family Member's Incontinence
http://links.lww.com/AJN/A168

🎥 How to Talk with Someone About Incontinence
http://links.lww.com/AJN/A169

🎥 Selecting Incontinence Products
http://links.lww.com/AJN/A170

🎥 Managing Incontinence for Those with Difficulty Getting Out of Bed
http://links.lww.com/AJN/A171

For additional information, visit AARP's Home Alone Alliance web page:
www.aarp.org/nolongeralone.

TOILETING TIPS

Toileting in public places can be a source of concern for caregivers, leading to social isolation and limited travel.[21] Advance planning can be helpful to minimize stress and promote social interactions outside of the home environment.[21] Caregivers should be encouraged to pack two separate bags in advance with all the supplies they may need. This may include wipes, gloves, a change of clothing, incontinence pads, and a plastic bag for soiled products.[21] One bag can be kept in the car, in case it's needed. Caregivers should carry the other bag to ensure they're ready if a leakage occurs.[8, 21]

When traveling, caregivers should seek out family or companion bathrooms, which tend to be larger and can accommodate more than one person at a time.[21] Caregivers who are of a different gender than the care recipient may also want to consider carrying a sign that can be attached to the outside of a public bathroom stall door, alerting others to the caregiving situation.[21] Planning for access to bathrooms during the course of a trip, ensuring that travel seats are near bathrooms, and making frequent stops for toileting can help to reduce anxiety.[21]

STRESS MANAGEMENT

Relationships between caregivers and care recipients can be complicated when age and gender differences exist. In addition, drastic changes in roles (adult children who've become the caretakers of their elderly parents, for example) can be a source of embarrassment and suffering for caregivers, particularly when the caregiver assumes duties previously managed by the care recipient.[7]

Being a family caregiver can be difficult under any circumstances, but UI management is especially demanding. The physical and emotional demands of washing and changing sheets and clothing daily or several times a day, along with knowing that a loved one is experiencing discomfort and embarrassment, can cause fatigue, stress, and musculoskeletal strain. Caring for someone who has incontinence requires patience, compassion, and empathy. It can be helpful for caregivers to recognize that experiencing conflicting emotions (sadness, confusion, anger, being overwhelmed) is normal.[7, 33] It's important for nurses to encourage family caregivers to remain calm and communicate in an honest, understanding way during times of frustration, such as when a care recipient refuses to use the toilet or is combative about needed care. It can also be helpful for caregivers of people who have cognitive impairment or dementia to attend a support group or educational class to learn useful approaches to communicating successfully with care recipients.[34] Friends and other family members may also be called upon to provide emotional and physical support.[7] If financially feasible, hiring someone to assist with care may relieve some of the caregiving strain.

Caregivers should be encouraged to prioritize self-care.[35] Family caregivers often limit their social lives and positive, health-promoting practices, such as exercise, which can contribute to burnout.[36] Talking with other caregivers online or in person can be a valuable source of support and provide advice about how to improve the caregiving situation (tips

Resources for Nurses

Managing Incontinence: How Family Caregivers Can Help[a]
http://links.lww.com/AJN/A154

Managing Incontinence at Home[a]
http://links.lww.com/AJN/A155

Helping Someone to the Toilet[a]
http://links.lww.com/AJN/A156

Seeking Emotional Support: Managing a Family Member's Incontinence[a]
http://links.lww.com/AJN/A157

How to Talk with Someone About Incontinence[a]
http://links.lww.com/AJN/A158

Selecting Incontinence Products[a]
http://links.lww.com/AJN/A159

Managing Incontinence for Those with Difficulty Getting Out of Bed[a]
http://links.lww.com/AJN/A160

[a] Family caregivers can access these videos, as well as additional information and resources, on AARP's Home Alone Alliance web page: www.aarp.org/nolongeralone.

Additional Resources

Alzheimer's Association
www.alz.org

Family Caregiver Alliance
www.caregiver.org

National Association for Continence
www.nafc.org

Simon Foundation for Continence
http://simonfoundation.org

for purchasing affordable products, for example).[37, 38] The National Association for Continence and the Alzheimer's Association have message boards on which caregivers can ask and answer questions, as well as newsletters and additional resource materials (see *Additional Resources*). ▼

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REFERENCES

1. Abrams P, et al. The standardisation of terminology in lower urinary tract function: report from the standardisation subcommittee of the International Continence Society. *Urology* 2003;61(1):37-49.
2. Gotoh M, et al. Impact of urinary incontinence on the psychological burden of family caregivers. *Neurourol Urodyn* 2009;28(6):492-6.
3. Wagg A, et al. Incontinence in frail older persons. In: Abrams P, et al., editors. *Incontinence: proceedings of the 6th International Consultation on Incontinence, Tokyo, September 2016*. 6th ed: International Consultation on Urological Diseases and the International Continence Society; 2017. p. 1309-442.
4. Gorina Y, et al. Prevalence of incontinence among older Americans. *Vital Health Stat 3* 2014(36):1-33.
5. Maxwell CJ, et al. Predictors of nursing home placement from assisted living settings in Canada. *Can J Aging* 2013;32(4):333-48.
6. Morrison A, Levy R. Fraction of nursing home admissions attributable to urinary incontinence. *Value Health* 2006;9(4):272-4.
7. Santini S, et al. Impact of incontinence on the quality of life of caregivers of older persons with incontinence: a qualitative study in four European countries. *Arch Gerontol Geriatr* 2016;63:92-101.
8. Bliss D, et al. Health literacy needs related to incontinence and skin damage among family and friend caregivers of individuals with dementia. *J Wound Ostomy Continence Nurs* 2013;40(5):515-23.
9. Hayder D, Schnepp W. Urinary incontinence—the family caregivers' perspective. *Z Gerontol Geriatr* 2008;41(4):261-6.
10. Lobchuk MM, Rosenberg F. A qualitative analysis of individual and family caregiver responses to the impact of urinary incontinence on quality of life. *J Wound Ostomy Continence Nurs* 2014;41(6):589-96.
11. Jung HB, et al. A current perspective on geriatric lower urinary tract dysfunction. *Korean J Urol* 2015;56(4):266-75.
12. Skelly J, Flint AJ. Urinary incontinence associated with dementia. *J Am Geriatr Soc* 1995;43(3):286-94.
13. National Association for Continence. *Incontinence myths: six myths about incontinence*. n.d. https://www.nafc.org/incontinence-myths.
14. Diokno AC, et al. Effect of group-administered behavioral treatment on urinary incontinence in older women: a randomized clinical trial. *JAMA Intern Med* 2018;178(10):1333-41.
15. Talley KMC, et al. Defeating urinary incontinence with exercise training: results of a pilot study in frail older women. *J Am Geriatr Soc* 2017;65(6):1321-7.
16. Subak L, et al. Urinary incontinence in women: direct costs of routine care. *Am J Obstet Gynecol* 2007;197(6):596 e1-e9.
17. Tseng CN, et al. A qualitative study of family caregiver experiences of managing incontinence in stroke survivors. *PLoS One* 2015;10(6):e0129540.
18. MedicareFAQ.com. *Medicare coverage for incontinence supplies*. n.d. https://www.medicarefaq.com/faqs/medicare-coverage-for-incontinence-supplies.
19. Paying for Senior Care. *Financial assistance for adult diapers and absorbent products for seniors*. San Mateo, CA: Caring, LLC; 2019 Jul. https://www.payingforseniorcare.com/adult-diapers/financial-assistance.html.
20. Department of Health and Human Services, Office of Inspector General. *Medicaid payments for incontinence supplies*. Washington, DC; 1995 Nov. OEI-03-94-00771. https://oig.hhs.gov/oei/reports/oei-03-94-00771.pdf.
21. Family Caregiver Alliance. *Caring for someone with incontinence: emotional and social issues*. San Francisco; 2014. Fact sheets; https://www.caregiver.org/caring-someone-incontinence-emotional-and-social-issues.
22. Simon Foundation for Continence. *Directory of U.S. diaper banks for adult absorbent products and incontinence product-related resources*. n.d. https://simonfoundation.org/resources/directory-us-diaper-banks.
23. Lekan-Rutledge D, et al. Promoting social continence: products and devices in the management of urinary incontinence. *Urol Nurs* 2003;23(6):416-28, 458.
24. Gray M, et al. Assessment, selection, use, and evaluation of body-worn absorbent products for adults with incontinence: a WOCN Society consensus conference. *J Wound Ostomy Continence Nurs* 2018;45(3):243-64.
25. Brazzelli M, et al. Absorbent products for containing urinary and/or fecal incontinence in adults. *J Wound Ostomy Continence Nurs* 2002;29(1):45-54.
26. Beeckman D, et al. Prevention and treatment of incontinence-associated dermatitis: literature review. *J Adv Nurs* 2009;65(6):1141-54.
27. DeMarinis M, et al. Absorbent products for incontinence. In: Newman DK, et al., editors. *Clinical application of urologic catheters, devices and products*. New York, NY: Springer; 2018. p. 149-71.
28. Drennan VM, et al. A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatr* 2011;11:75.
29. Brittain KR, Shaw C. The social consequences of living with and dealing with incontinence—a carers perspective. *Soc Sci Med* 2007;65(6):1274-83.
30. National Association for Continence. *Clean and odor free*. 2014. https://www.nafc.org/bhealth-blog/clean-and-odor-free.
31. [No authors listed.] Urine color and odor changes. *Harv Womens Health Watch* 2010;17(10):7.
32. Beeckman D, et al. Interventions for preventing and treating incontinence-associated dermatitis in adults. *Cochrane Database Syst Rev* 2016;11:CD011627.
33. Cassells C, Watt E. The impact of incontinence on older spousal caregivers. *J Adv Nurs* 2003;42(6):607-16.
34. Eggenberger E, et al. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatr* 2013;25(3):345-58.
35. Oliveira D, et al. Health-promoting self-care in family caregivers of people with dementia: the views of multiple stakeholders. *Gerontologist* 2019 Apr 6 [Epub ahead of print].
36. Almberg B, et al. Caring for a demented elderly person—burden and burnout among caregiving relatives. *J Adv Nurs* 1997;25(1):109-16.
37. Hopwood J, et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review. *J Med Internet Res* 2018;20(6):e216.
38. Lauritzen J, et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Database System Rev Implement Rep* 2015;13(6):373-433.