Overcoming the Stigma of Urinary Incontinence
Learn tips for opening a patient-provider dialogue about this embarrassing condition.

By Jolynn Tumolo

For many women, urinary leakage unleashes a floodgate of fears: I'm getting old. The next step is long-term care. What if it's cancer?

Embarrassment and shame add to the burden, along with a lack of comfortable vocabulary to discuss what's happening "down there." Combine that with a visit to a busy health care provider who is unfamiliar with advances in incontinence treatment - and unenthusiastic about opening another can of worms during the visit - and you soon have a stigma smothering a life.

It's no surprise, then, that federal data show fewer than half of people who experience incontinence voice their symptoms to health care providers without first being asked. "It's sad," says Diane A. Smith, NP, president and clinical director of UroHealthcare in Philadelphia. Smith specializes in treating patients with incontinence. During her 25 years focusing on this population, she has seen countless situations improved and lives turned around. She shares the story of a 79-year-old woman who recently heard her speak and then made an appointment with her. After about four visits, the woman had gained enough control to plan a trip she thought she'd have to cancel. She was also able to ramp up her volunteer hours at a local hospital.

"She has really contributed back to the community, back to her family and back to herself. With treatment, her options were changing, and she was changing her life," Smith explains. "Just imagine, for every person like that, how many others could have been helped? I think a lot about the people who have this condition who never really get help from anyone."

Altered Lives

Jane Hastings began experiencing symptoms 5 years ago at age 58. "It was insidious. It was so gradual," says Hastings, who lives in Minneapolis. "I noticed I was getting up more at night and having some urgency and frequency. I thought I was way too young for this."

Hastings was unable to sit through a movie, avoided late afternoon meetings when symptoms began to increase, and memorized the locations of bathrooms in every store she frequented.

Altering schedules and habits to deal with incontinence is common in women of all ages. An anesthesiologist and runner who had given birth to her first child told Smith that she was prepared to give up running if necessary to avoid the leak of urine that inevitably worked its way down the length of her leg. The NP used biofeedback to teach the woman Kegel exercises and fitted her with a pessary to use when running. Within 2 months, the patient had resumed running and regained the physical and emotional benefits of a cherished pastime.

Exercise, work, social activity, emotional wellness, sexual function and even preferred living arrangements are threatened by episodes of incontinence. A common time for falls in older adults, Smith notes, is at night on the way to the bathroom.

Adding insult to injury is the fact that it does not have to be that way, says Helen Carcio, NP, owner of the Health & Continence Institute in South Deerfield, Mass. "It is absolutely unacceptable," she declares, "that elderly women who could still be active in the workplace are shamed into the isolation of their homes or are forced into institutionalized living because of urinary leakage."

Smith, whose patient population includes women and men living in skilled nursing facilities, has seen depression diminish as incontinence is controlled.

"One patient has started participating in facility activities and has started making home visits, which her family couldn't handle because of..."
her incontinence,” Smith says. “Her depression has lightened, and it's been exciting. Some people think there's nothing we can do for frail older adults. Well, there's a lot we can do for them. It starts with appropriate assessment and treatment.”

**Don't Tell, Don't Ask**

Diane Newman, NP, codirector of the Penn Center for Continence and Pelvic Health at the University of Pennsylvania Medical Center in Philadelphia, sees a varied population that often shares a troubling experience: delayed treatment.

"I see women of all ages and cultures," says Newman, coauthor of *Managing and Treating Urinary Incontinence* (Health Professions Press, 2009). "What is disturbing is that they have suffered with it for years."

The lack of patient-provider dialogue devoted to incontinence is the result of more than simple embarrassment on the patient's part. An early silencer is women's willingness to tolerate general discomfort, or what Carcio calls "the bother factor."

"Women are well used to pads, having had menses for half their lives. They are well used to the discomforts of pregnancy. Many just accept their incontinence as a normal part of aging, just one more inconvenience to put up with along with their new glasses, their cane or their walker," she says. "It's shocking to see how many women with daily incontinence episodes state they are not bothered by it. It just becomes the norm."

The availability of self-management products such as pads or diapers allows the condition to continue unchecked. Slowly but surely, it stakes a growing claim on a woman's lifestyle. Before long, the stigma sets in, and what began as disinterest can turn to dread.

"They see it as a sure sign of aging - that the body is failing," Carcio says. "Many elderly women say they don't want to be like their mothers."

For women who do initiate discussions with their health care provider, many are frustrated by a lack of response.

"When I brought it up to my gynecologist, he said, 'Oh, Jane, anyone who has had three children is entitled to some of those symptoms,'" remembers Hastings, a master's-prepared RN and former parish nurse. Two years later, she came across a continuing education brochure about bladder control and learned about Medtronic's InterStim. She made an appointment with a urologist, got the implant and today works as a patient advocate for Medtronic.

"Many patients tell me that even when they brought it up to their primary care provider, nothing was done," Smith says. "Most of the time, patients find me on their own or after they hear me talk. It's unfortunate."

Smith blames provider passivity on ignorance about the impact of incontinence and ignorance about treatment success through behavior modification, therapy and medications. But she doesn't accept it.

"When you consider that overactive bladder is more common than diabetes, hypertension and asthma, I think we need to screen for it," she says. "We have a responsibility to ask."

When other health issues are the focus of an appointment but the patient identifies incontinence symptoms, make another appointment to address the incontinence directly, Smith advises. Do not dismiss the concern or the issue. If an NP is unsure how to help patients with incontinence, the National Association for Continence (www.nafc.org or 800-BLADDER) can identify local providers for referral.

**Putting It Into Practice**

To maximize response and minimize embarrassment, be simple and direct when asking patients about incontinence. Keep in mind that many don't know what incontinence means, so questions such as "Have you leaked urine in the last 3 months?" "Do you lose urine when you sneeze?" and "Do you have trouble making it to the restroom without leaking?" are more appropriate than "Do you experience any incontinence?"

Janine J. Sherman, NP, a women's health nurse practitioner at Southwest Ob/Gyn in Houston, places incontinence questionnaires in the office waiting room. If a patient indicates a problem, she follows up. If not, Sherman asks specific questions to screen patients throughout
the visit.

"I bring it up very casually, and I mention the importance of Kegel exercises and hormonal changes that might occur during perimenopause that can contribute to the problem," says Sherman, coauthor of *Start Talking: A Girl's Guide for You and Your Mom About Health, Sex or Whatever* (Bayou Publishing, 2008). "I often relate the issue back to myself because I have had three vaginal births, which is the most common reason for incontinence."

The National Institutes of Health (NIH) recommends that providers address four specific issues when asking about a patient's experience with incontinence: frequency, volume, degree of "bother" and interest in treatment. To help dispel the stigma, NIH is reaching out to patients with the messages that they're not alone and that incontinence doesn't have to be a normal part of aging. Carcio recommends asking questions about incontinence symptoms at every well woman visit and including education about pelvic floor exercise. About 89% of women do not perform Kegel exercises properly, she says. "They do not know it's a rectal squeeze."

Public events are vital in spreading hope and dispelling stigma among people in the community, she adds. Nurse practitioners can talk to groups at community centers and other settings. Approach the issue openly when speaking, Carcio advises, and with a sense of humor when possible.

Most NPs agree that when it comes to the silence surrounding incontinence, societal changes are heading in the right direction.

"Direct-to-consumer advertising has helped people become better informed about urinary incontinence and available medications, and about appropriate incontinence products," Newman says. "Treatments - particularly behavioral interventions, medications and surgery - can be successful in 8 of 10 people."

Newman points out that consumer media outlets are paying more attention to the subject of incontinence. In 2008 alone, she was interviewed by *USA Today*, *O Magazine* and *Ladies' Home Journal*.

"I think on the whole the public is still embarrassed by it," Smith comments. "But it carries less of a stigma than it did 25 years ago."

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**Patient, Provider Satisfier**

Think patients don’t care all that much about urinary incontinence symptoms? Helen Carcio, NP, owner of the Health & Continence Institute in South Deerfield, Mass., once treated a woman who was so pleased with Carcio’s care that she gave her a diamond ring. Despite the NP’s protests, the patient refused to take it back.

The gesture spoke volumes to Carcio, who is holding on to the ring in case the patient's family one day asks for its return.

Diane Smith, NP, president and clinical director of UroHealthcare in Philadelphia, has also been the recipient of lavish gifts. She received a ruby ring from a woman who went from daily accidents and severe prolapse to comfort and dryness.

Jewels aside, the nurse practitioners say the real sparkle is in the satisfaction they get from helping patients with incontinence.

"There isn't a day that I don't think I've made a difference in somebody's life," Smith says. "Everybody looks for the meaning of what they're doing in their life. And helping people with this issue is definitely worthwhile."

~Jolynn Tumolo