



Stress Urinary Incontinence In Cystic Fibrosis – Can We Talk?

By Laura Mentch

Urinary incontinence, the involuntary release of urine, is a common problem for girls and women with cystic fibrosis. Men and boys with CF also experience incontinence, but less frequently. An October 2015 study reported the prevalence of incontinence in CF for ages 12 and over as 68% in women and 11% in men¹. This article will focus on stress incontinence in CF with specific suggestions and resources for women; many of which may be helpful for men.

Earlier *CF Roundtable* articles have brought our attention to incontinence, repeating the guidance to do Kegel exercises to strengthen the pelvic floor muscles. Other types of incontinence, urge and overflow, are most often associated with menopause and aging.

Coughing is a significant cause of incontinence. The abdominal muscles contract with coughing or sneezing, putting pressure on the bladder, which forces open the urinary sphincter releasing urine in drops or gushes. The muscles of the pelvic floor are pushed outward. Can you feel the action of these muscles when you cough?

Pelvic muscles support the pelvic organs and bladder, like a hammock. With frequent and severe coughing, these muscles weaken and become less effective. The pelvic floor muscles surrounding the urethra, vaginal opening and anus are also stressed. Strengthening these muscles can reduce incontinence.

Our Experience with Incontinence

Though it can be part of our every-



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day lives, we seldom talk about incontinence with family, friends or health-care providers. However, this topic comes up in Internet discussion among women with CF. When the door is opened, we share our frustrations along with practical and creative ways we address this problem. What women with CF say about incontinence: “It’s so upsetting and embarrassing.” “This is definitely one of the more humiliating things about CF.” “I always wear panty-liners because I pee myself if I cough too hard.” “I ALWAYS have pads in my purse.” “Sometimes I wear two pairs of underwear.” “I cough harder at home and while I’m doing breathing treatments and usually that is when it happens. Usually I just change clothes.” “I often pee when I vest.” “If I’m walking and I have to cough, I stop walking so I can concentrate on holding it in.” “The only thing I have known to try is Kegels and so far it hasn’t worked. Maybe I haven’t

done it right. Sometimes I feel like I need Depends. It’s pretty embarrassing.” “My research nurse tells me this happens because Kegels aren’t enough for us to be doing and we need to do pelvic floor exercises, whatever those may be.” “This is the reason I do not work out in a gym.” “I love to run but I leak the entire time, it is uncomfortable.” “I swear it happens more during that time of the month.” “My hospital bathroom is a laundry room.” “I feel like it is one of those annoying side effects of CF that no one tells you about.” “I haven’t talked to my doctor about it yet. I never think it’s a big enough issue or I have too many other CF-related things to worry about.” “I guess it’s not bad enough yet to say anything.” “ANOTHER thing for me to bring up at clinic.”

Incontinence can be distressing, affect our quality of life and further complicate our days. We compensate by wearing panty-liners, pads, incontinence underwear; by altering our activity, reducing fluid intake and limiting the strength of our coughing. We often carry this problem (along with pads or extra clothes) silently without telling

¹Gina Reichman, Veerle De Boe, Johan Braeckman & Dirk Michielsens (2015): Urinary incontinence in patients with cystic fibrosis, *Scandinavian Journal of Urology*, DOI: 10.3109/21681805.2015.1096826

PRACTICAL SUGGESTIONS

- Avoid bladder irritants such as alcohol, coffee and tea
- Maintain healthy fluid intake, especially water
- Support your pelvic floor when coughing with muscle contraction or placing your hand under pelvic floor muscles; some women sit on their foot or heel to support the pelvic floor during airway clearance.
- Keep coughing. Effective airway clearance is vital in cystic fibrosis care.
- Don't stop at every bathroom, "just in case."
- Avoid "hovering" above the toilet seat while urinating. Sorry, Mom.
- Adopt healthy posture for urination: feet on the floor, lean forward with breasts lifted up.
- Urinate before treatments or PFTs.
- Maintain fecal continence and avoid straining with bowel movements.
- With trampoline exercise, "jog" instead of jumping with both feet.

those close to us, including our CF care providers. If you experience incontinence, bring it up at your clinic visit. It will increase an awareness of the problem and encourage our nurses and doctors to learn about resources that can help. The good news is there is help.

Support for Incontinence

Kegels. Kegels are the incontinence mantra. Begin by finding and contracting the muscles that stop the flow of urine* and passing gas. Contract only these muscles, not those of your legs, buttocks or abdomen. Sitting with a folded washcloth under your vulva can help you isolate these muscles.

(*avoid squeezing the pelvic muscles while urinating; doing so will compro-

mise the normal process of urination)

There are two ways to perform Kegel exercises:

(1) quickly contract and squeeze these muscles, and

(2) contract, squeeze and slowly lift up, up, up and hold for a count of five.

Practice and repeat ten times at least three times each day.

If you are unsure if you are correctly practicing Kegels, search for instruction online, visit a gynecologist or find a women's health physical therapist.

I recommend these websites and their newsletters for help with Kegel exercises:

<https://www.pelvicexercises.com.au/>

[kegel/](https://urogyn.coloradowomen-health.com/patients/kegel-corner/)

<https://urogyn.coloradowomen-health.com/patients/kegel-corner/>

"The Knack." Tighten and lift your pelvic floor muscles BEFORE sneezing, coughing, laughing or lifting to avoid leaking urine during these activities that put pressure on the pelvic floor.

Posture. Keep your spine straight and upright during airway clearance to support the muscles engaged in coughing.

Incontinence Products. Before reaching for Depends, consider Poise products (panty-liners and pads) or protective underwear designed to hold urine.

Women's Health or Incontinence

Physical Therapy. Women's Health Physical Therapists are specially trained to help women of all ages and use specific techniques for incontinence. This therapy is especially helpful during and after pregnancy. Make an appointment with the Physical Therapist at your CF clinic or find a Women's Health or Incontinence PT at www.apta.org.

Urogynecology. Urogynecology is a specialty within obstetrics and gynecology. Urogynecologists have highly specialized training in surgical and non-surgical treatment of pelvic floor disorders, including incontinence. <http://www.findurogynecologist.com/> ▲

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FACTORS ASSOCIATED WITH URINARY INCONTINENCE IN WOMEN

- Pregnancy and childbirth
- Age
- Obesity
- Changes at end of the menstrual cycle
- Medication
- Disease, e.g. diabetes
- History of pelvic or abdominal surgery

ADDITIONAL FACTORS FOR WOMEN WITH CF

- Persistent and violent cough
- Coughing during airway clearance & PFT
- Pulmonary exacerbation
- Prednisone
- Increased hydration with IV antibiotics
- CFRD