

Life with Incontinence

By Cheryle Gartley, as printed in The Lancet

I was 21 years old when I began to leak. It was the dark ages—no advertisements on television, no articles in magazines, no products in drugstores, no continence clinics in the phone directory, no helpful books in the library—no wonder I thought I was alone.

I behaved like the silent millions around me. After a year of dehydrating myself to sit through management meetings at the bank, followed by commuting in rushhour traffic (dehydration headache pounding) to my MBA studies at the University of Chicago, I gave up. I quit the bank, put my MBA on hold, and stayed home. It is claimed that urinary incontinence is not lifethreatening, but the human spirit can die. For a while friends continued to invite me out—but they finally gave up too, buried by the weight of my creative excuses (read lies) to hide my secret.

I did ask for help, or at least I thought I did. I told my doctors that bringing in a urine sample for constant urinary-tract infections was difficult; I would either (1) dehydrate myself before driving to their office, or (2) have an “accident” on the way—either choice, no specimen. The solution suggested? Have someone deliver the sample. Incontinence was still very much in society’s closet, and definitely not being addressed at medical schools.

Time passed in a depressed blur of washing clothes. Then life changed with one event. My mentor telephoned to ask what he or his wife had done that I no longer accepted their invitations—they wanted to make amends. Shocked that I had caused pain, I blurted the truth. His response started the most amazing journey of my life. Not missing a beat he responded that he would: attach a porta-potty to their horse, put a giant sponge on his boat for me to sit on, and build a clothes closet for my use on campus. My assignment? Find out what the female astronauts were using for urine collection and “get a life”.

Right! Simply lift myself out of depression? While I felt totally out of control, I was certain people now experienced me as controlling—self-centred or bladdercentred - neither socialises very well. Incontinence fears had spread into every facet of my life, like weeds infiltrating a garden. It also didn’t help that I’ve always been good at attracting chaos, so why should living with incontinence be different?

It wasn’t, especially when I began to devote my life to promoting continence. On a book promotion tour when my chair, which had been ratcheted up, began to slowly sink 30 seconds into the newscast, a cameraman crawled under the desk, positioned himself on his back, and physically propped it up. I still wonder whether he worried as much as I did about my bladder. I also think about the airport guard inspecting my luggage full of absorbent products who, stunned, slammed it shut. What did he say to the supervisor hurrying to question him? Did the anchorman who asked me: “How does your husband like going to bed with you in diapers?” ever regret this incredible question?

Similar incidents followed me worldwide. On a speaking tour, I thought how wonderful that the Japanese sent so many people to meet my train. Later my translator confided to me they had been alerted by colleagues that the American arrived with a lot of luggage (products again) and that several car trunks were needed.

I recognise that my life has been unique. Most people would not find many positive things to say about their incontinence, but I walk because my bladder misbehaved. It was the first clue that caused a neurosurgeon listening to my lecture to diagnose (and later release) a tethered cord (lipomyelomeningocele). My guest room is wonderfully busy occupied by renowned incontinence experts—and I am privileged to experience medicine from an insider perspective without paying the dues of years of schooling. Best of all, being bladder-challenged has helped me to respond with empathy to patients who seek my help.

People ask whether I'd trade my life as it is to be dry. Hard call, but the answer would probably be no. Yet it is still difficult to self-identify as a person with the stigma of incontinence. And would I give anything if a scientist reading this account solved incontinence so that I could leave the planet totally continent? You bet, and please hurry, so many of us are waiting.