

## PATIENT PROFILE

### Nancy Norton

#### *Living Hour to Hour with Fecal Incontinence*



Nancy Norton

On many days, Nancy Norton can only plan her life hour by hour. When she was 35, while giving birth to her son, Nancy experienced a fourth degree perineal tear (a tear extending from the vagina to the rectum). The injury included damage to the anal sphincter muscles, which play a critical role in controlling bowel evacuations. As a result, for the past 28 years she has lived with fecal incontinence, which is the accidental passing of solid or liquid stool or mucus from the rectum.

Nancy's incontinence was revealed when, shortly after giving birth, she was hosting friends and family at her home in Milwaukee to see her new baby. "I was sitting in a chair, and I just stood up and had stool running down my leg," she recalls. Like many women who have experienced similar injuries, Nancy was caught completely off guard. Mortified and alarmed, she contacted her doctor immediately, telling herself, "I need to find out what's going on here."

When Nancy first contacted her health care provider, the response she received conveyed a practically dismissive tone. She was told there was a flu going around, and perhaps she just had an upset stomach. While Nancy felt her doctors were seeing her incontinence as little more than an inconvenience, she was starting to suspect that it was something more serious than the flu. When the condition did not improve, she underwent two rounds of surgery with the hope that repairing the injured tissue would be enough to resolve her incontinence. The first repair broke down, however, and the second repair was not successful. Nancy gradually began to realize that she might be facing a long battle with incontinence. "After waking up for months, hoping that this day was going to be the day when everything was going to work right," she remembers, "it starts to sink in that this is not changing." With no easy answers, Nancy felt stranded. "I was like a lot of other people, where it was a result of an obstetrical injury, and you just automatically assume that it can be fixed. But when the attempts to fix it don't work, then what do you do?"

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That time was especially challenging for Nancy because she had also just become a mother. "Here's this new little baby," she says, remembering those tough first days of parenthood, "and I was trying to be

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a mother while going back in the hospital for surgery. It was overwhelming.” She faced juggling many major changes in her lifestyle at once: being a new parent, changing her diet, trying always to be near a bathroom, and bringing a bag of extra clothes and cleaning materials whenever she went out. “I was learning how to live with this new body, and being a new mom, and caring for the needs of my son,” recalls Nancy. As a result of her experiences, she now understands the importance of not only addressing the medical issues associated with fecal incontinence, but also thinking about its effects on family and personal life.

## **Fecal Incontinence: A Hidden Condition**

Nearly 18 million U.S. adults—about 1 in 12—have fecal incontinence, commonly referred to as bowel control problems. The high prevalence of this condition may seem surprising, but this is probably because most people who have fecal incontinence are reluctant to talk about it, and health care providers rarely screen for it, so it is significantly underdiagnosed. Besides feeling too embarrassed to discuss episodes of fecal incontinence, patients are also mired by the suspicion that their health care providers will not be able to help them, or they may just despondently accept the condition as a “normal” part of aging.

While fecal incontinence is more common in older adults, it can affect people of any age. Several factors can increase the risk of a bowel control problem, including: diarrhea; urgency, or the sensation of having very little time to get to the toilet for a bowel movement; a disease or injury that damages the nervous system; injury to the pelvic floor (the muscles, ligaments, and tissues that support the uterus, vagina, bladder, and rectum), which may occur during a difficult childbirth; and poor overall health from multiple chronic (long-lasting) illnesses. Other risk factors include depression, being physically inactive or overweight, or having type 2 diabetes.

Regardless of the cause, a serious case of fecal incontinence means a life that revolves around being near a bathroom, Nancy explains. This might mean only being able to make plans for the next hour or two at a time, which has the tendency to feel as if the incontinence is controlling a person’s daily life. “Most people don’t even think about the process of defecation, but you end up focusing almost 24/7 on controlling your bowels,” she says. To make matters worse, accidental bowel movements carry such a social stigma that, rather than seeking help, many people with fecal incontinence painstakingly attempt to hide their symptoms with accessories like absorbent padding and deodorant sprays, or they try to manage the condition through changes in their diet that are not always healthy. They especially become very conscious of how much food and water they are taking in—sometimes to drastic levels. “A lot of incontinent people will think, ‘If nothing goes in, nothing will come out,’” Nancy explains. “Well, that’s not a healthy way to live. But it’s those kinds of things that naturally go through your mind to try to control fecal incontinence.”

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Instead of leading a secret life, Nancy chose to keep looking for answers. After her surgical repairs failed to cure her incontinence, she set off to find doctors at some of the country’s best medical institutions who may have other ideas for treatments. Some suggested more surgery, which Nancy was reluctant to try; others suggested a less familiar type of therapy called “biofeedback.” Biofeedback, which teaches patients how to control bodily functions, is used for a number of conditions; for fecal incontinence, it is designed to educate people on the muscles that

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control bowel evacuations. It improves the awareness of sensations in the lower intestine by using tools such as small inflatable balloons in the rectum, which assist in teaching people with fecal incontinence to coordinate the sensation of rectal filling with squeezing of the external sphincter muscle. Another aspect of biofeedback involves special sensors which measure bodily functions and deliver information to health care providers, who use the readings to help their patients make beneficial changes. Research sponsored by the NIDDK has provided encouraging results supporting biofeedback as an effective method for treating fecal incontinence.

Biofeedback helped Nancy regain some control over her daily life. “Biofeedback really helps you understand the physiology of how things work, about muscle groups and coordination of those muscle groups, so even though I am still incontinent, I feel like I have some kind of control,” she says. It helped her learn how to be prepared and to think about what she needs to take with her during the course of the day. Even then, adjustment back to a daily routine required small steps. She would start by leaving her home for just a short period of time. She would ask herself, “could I be away from the house for an hour comfortably without being near a bathroom?” She forced herself to take a class at a university because it put her in a social situation where it would be difficult to be able to get up and leave. She made an effort to “get back out there and do things” that wouldn’t result in her being overcome with anxiety, which can raise the sense of needing to be near a bathroom. To be out in public and have access to a restroom is not always easy, says Nancy, but “as an incontinent person, you learn how to navigate through life in a different way.”

## **Advocating for Others**

As a result of her experiences with fecal incontinence, her struggles with finding proper care, and her

continuing journey through life with the condition, Nancy founded the International Foundation for Functional Gastrointestinal Disorders (IFFGD), a nonprofit education and research organization that helps people affected by gastrointestinal disorders. “I thought, I can’t be the only one who is having these kinds of issues,” she says. After IFFGD was established, “we had people calling us with every gastrointestinal condition you can think of because there was no other place for them to go.” Since its start in 1991, the IFFGD has been a source of educational information, support, and assistance for people who suffer with functional gastrointestinal and motility disorders, including fecal incontinence and irritable bowel syndrome.

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Even with a resource like the IFFGD, raising awareness of fecal incontinence is not an easy task, primarily because of the negative public perceptions of the condition. In a sense, fecal incontinence is a hidden disability, because the anxiety associated with it is an enormous burden, yet people tend to suffer in silence, or they rarely leave their homes. Travelling becomes an even bigger problem. Nancy knows “the anxiety of not being able to get out of your seat for the last half an hour [of a flight], and you just hope that everything is fine. Or checking into a hotel room early because you want to get into your own room and have your own bathroom.” Even taking care of simple errands like going to the grocery store becomes an exercise in preparedness, as people with fecal incontinence

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must be constantly aware of where the restrooms are. Even then, they must bring extra supplies, such as incontinence wipes, because public restrooms are ill-equipped to help someone clean themselves after an episode of incontinence.

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The fear of having an accidental bowel movement in public can also be debilitating to someone’s social life, especially if they are too embarrassed to explain why they cannot attend a gathering. Nancy is all too familiar with the questions that go through the mind of a person with fecal incontinence when asked to go out: “Do I feel comfortable enough to explain that I may not be able to make it? I might not be able to go to church, or sign up to volunteer for something; am I comfortable enough in explaining why I’m not there?” For the most part, says Nancy, people are understanding, but they do not necessarily comprehend the nature of her condition. People with fecal incontinence, she says, have to decide: “Are we going to venture out? How do we plan our day? What are we going to need? How are we going to handle [the incontinence]?” When accidents do happen, they can be psychologically crippling. “It’s a very emotional experience when it happens, particularly in public,” says Nancy about fecal incontinence. “It’s enough to stop a person in his tracks, and then you don’t want to go back out there again. You don’t want to put yourself in that situation, because society is not always kind to people who are incontinent.”

## **Hope Through Research and Awareness**

Nancy believes that perception of fecal incontinence has improved slightly since her diagnosis almost

3 decades ago, but there is still much work to be done to raise awareness among medical caregivers and the public. Since 2011, the NIDDK has managed the Bowel Control Awareness Campaign, which provides current, science-based information about the symptoms, diagnosis, and treatment of fecal incontinence, including resources such as advice for talking to doctors and links to professional and voluntary organizations for help and support. In August of 2013, the NIDDK hosted a workshop entitled “Developing a Clinical Research Agenda for Fecal Incontinence,” where a panel of experts discussed major issues in the diagnosis and treatment of fecal incontinence, and future research directions. There were also discussions about raising public awareness of fecal incontinence to make it easier for patients with the condition to come forward and seek treatment.

Nancy continues to live with fecal incontinence. But, as an advocate for millions of people who are affected by a largely secret condition that seizes control of their daily lives, she has shown the courage to confront negative perceptions and inspire hope in what many would see as a hopelessly distressing situation. She credits her biofeedback therapist and a strong network of people close to her as vital components to help her cope with incontinence. She says her husband, a co-founder of IFFGD, “has been by my side from the beginning, never wavering, always there to help me every day.” She also has a group of supportive friends who understand her difficulties with social gatherings. “They’re always saying things like, ‘What can we all do that Nancy can do?’ And that really means a lot to me. And I have been very thankful.” She adds, “But this is something that is not going away, and there are a lot of people who really need help... [They are] living with fecal incontinence and are really doing the best they can to manage it.”