

The other incontinence: New treatments helping sufferers regain bowel control, decrease suffering, shame

January 25 2013, by Stacey Burling

In an era when people talk about just about anything, fecal incontinence is one of the few medical conditions that is so embarrassing, so disturbing, that people don't even tell their doctors about it.

Sadly, if sufferers talked, they'd find out how common their problem is and learn that new help is available.

In the last two years, two new treatments for the debilitating condition have been approved. They don't cure everybody, but can offer hope to people who are often so afraid they'll soil their pants in public that they won't leave home. Their lives revolve around their unreliable sphincters.

Joshua Bleier, a Pennsylvania Hospital colorectal surgeon, is thrilled to be able to offer something helpful. He has been using a device similar to a heart pacemaker to improve function of [pelvic floor muscles](#).

"I am amazed and so gratified by the fact that these people whose lives have just been hijacked and destroyed by their incontinence ... they're just rescued by this," he said. "It's the best feeling in the world."

Henry Parkman, director of the GI Motility Laboratory at Temple University Hospital, said doctors call [fecal incontinence](#) the "silent affliction." Even when they visit a specialist, patients with it may say they've come due to diarrhea. Doctors are learning that they have to ask.

"If you think that there's embarrassment attached to [urinary incontinence](#), that is just a shadow of the embarrassment surrounding fecal incontinence," said Nancy Muller, executive director of the National Association for Continence.

The National Institute of Health estimates that 12 million Americans have fecal incontinence. The incidence rises with age and experts estimate that 15 percent of those over 70 suffer from the condition. It's a key reason many elderly people wind up in [nursing homes](#).

While most of us associate the need for adult diapers with serious illness and [dementia](#), doctors said they treat middle-aged people who are still working and healthy seniors without cognitive problems. That makes the emotional consequences all the more brutal.

"It can be devastating," said Stephanie Moleski, a gastroenterologist at Thomas Jefferson University Hospital. "It affects self-confidence, personal image. It can lead to social isolation."

Like parents with toddlers, patients have to learn where all the public bathrooms are. Bleier said he had had patients who spent eight hours a day sitting on the toilet.

The problem is more common in women than in men. Women can blame their children. Lengthy labor, especially when deliveries required forceps or episiotomies, is linked to incontinence immediately after the birth and years later when pelvic floor muscles weaken. Prostate cancer treatment is a risk factor for men. Nerve damage from diabetes can also cause incontinence. Stroke and neurological disease patients are at higher risk.

Fecal incontinence can range from what doctors call "leakage" to full bowel movements.

A 79-year-old Bryn Mawr, Pa., man was willing to talk about the problem that left him isolated, depressed, and afraid to leave his house, but his wife vetoed use of his name because she thought it was too embarrassing. He first became incontinent a decade ago after radiation treatment for prostate cancer. His doctor suggested Kegel exercises, which are used to strengthen the pelvic floor, and they did the trick for a while.

Three or four years ago, the problem returned with a vengeance. Sometimes, the man felt he was about to have a bowel movement, but had too little warning. Other times, he didn't feel the stool escape and discovered it later.

He was still working, so he would often have to race to the bathroom. He carried extra underwear and, later, adult diapers. He'd surreptitiously wash soiled underwear in the toilet, wrap it in paper towels, and dump it in the trash. He did the best he could with the odor.

"Nobody would say anything, but I imagine I was not a very popular character at that time," he said.

He had to watch what he ate. Red meat was out and Mexican food caused an "explosive" discharge.

"I had some terrible messes," he said. "It was getting me down. It was very depressing."

His worst experience came while driving his car. He felt the bowel movement starting, but couldn't find a bathroom.

"I was holding it back as hard as I could, but it just broke through like a dam," he said. He turned around and headed home, sitting in the mess the whole time. Then he had to clean everything up. "It was very

upsetting," he said. "You feel very helpless."

His family knew what he was going through, but nobody else. "Those are the issues that you kind of sweat out as a human being," he said. "People don't realize that these little dramas are going on."

The man, one of Bleier's patients, tried the pacemaker device, known as a sacral nerve stimulator. It didn't completely get rid of the problem, he said, but "it makes a big difference."

He said the stimulator gives him more warning time to get to a bathroom and a greater sense of control. "It's really quite a miracle," he said. "You don't have that cloud over your head all the time."

Doctors typically first try dietary changes and Kegel exercises, sometimes coupled with biofeedback.

Jefferson's Moleski said another new treatment is Solesta, a bulking agent that is injected beneath the lining of the anus, narrowing the opening. According to the Food and Drug Administration, the treatment reduced fecal incontinence episodes in half of the patients by 50 percent six months after treatment, but a sham procedure had the same effect for a third of patients.

Moleski said the results are a lot better than previous options and it's a less invasive approach than the pacemaker.

Bleier said that in the past, surgeons could only try to repair the sphincter, but that was painful and would often fail after three to five years.

He considers the new Medtronic pacemaker, InterStim, a significant advance. The device was initially approved for urinary incontinence and

the company applied for the additional use after patients reported that it improved both kinds of incontinence. Bleier said there was some evidence that it could also help patients with chronic constipation.

A Medtronic spokesman said InterStim uses the same technology as a heart pacemaker but paces at a different rate. While a heart pacemaker connects directly to heart muscle, InterStim stimulates the sacral nerves.

Bleier said the device, which consists of a lead wire and a neurostimulator the size of a stopwatch, is implanted on top of a buttock muscle. Patients don't feel it when they sit down and you can't see its imprint under a tight pair of pants. Patients can try the stimulation for two weeks with the pacemaker outside the body before deciding whether to have it implanted, an outpatient procedure. Medicare pays about \$21,500 for the device and treatment.

A Medtronic study of 77 patients found that 40 percent reported complete continence three years after insertion of the device.

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HOW TO REACH THE SPECIALISTS

Joshua Bleier, a colorectal surgeon at Pennsylvania Hospital, implants the sacral nerve stimulator. The number for his physician assistant is 215 829 2082. The front desk is 215 829 2099.

Stephanie Moleski, a gastroenterologist at Thomas Jefferson University Hospital, is at 215 955 8900.

The number for Henry Parkman, director of the GI Motility Laboratory at Temple University Hospital, 215 707 3431

Medtronic, maker of the sacral nerve stimulator, InterStim, gave me a list of local centers that are implanting the device. It is not a comprehensive list, but here it is: Pennsylvania Hospital, Thomas Jefferson Health System, Einstein Medical Center, Christiana Hospital and Kennedy Health System.

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