

# Reporter's Guide to Bowel Incontinence

## Shining a Light on a Hidden Medical Problem

The magnitude of the prevalence and burden of incontinence is masked by silence. Breaking that silence is a challenge that few medical disorders or diseases face.

International Foundation for Functional Gastrointestinal Disorders



## **Dear Reporter or Medical Writer:**

The International Foundation for Functional Gastrointestinal Disorders (IFFGD) is pleased to provide you with the *Reporter's Guide to Bowel Incontinence*, your comprehensive resource on this deeply hidden condition. You may be surprised at how common and widespread incontinence really is.

IFFGD was founded in 1991 with a mission to educate, raise awareness and improve care for conditions that many find hard to talk about, let alone live with. Incontinence affects people of all ages; it is a symptom with many different causes. It exacts a tremendous toll on those with the condition, their families, and society at large.

In December 2007, with vigorous encouragement from IFFGD, the U.S. National Institutes of Health (NIH) conducted an NIH State-of-the-Science Conference on Prevention of Fecal and Urinary Incontinence in Adults. The conference resulted in a strong statement by the NIH about the huge unmet need of those who are affected by incontinence. The NIH Panel reported that fewer than half of individuals experiencing incontinence report their symptoms to healthcare providers without being prompted. The secrecy and distress surrounding these issues erode the quality of life for millions, and hamper scientific understanding and development of prevention and treatment strategies.

The Panel reported, raising public awareness is a priority to aid in prevention and to help reduce the stigma associated with incontinence. People experiencing incontinence need to know that they are not alone, that incontinence does not have to be a part of aging, and that the condition can be managed. Being able to talk about it is the first step in both prevention and treatment.

This *Reporter's Guide to Bowel Incontinence* is designed to provide you with accurate information and to help you cover the condition. In the guide you will find:

- In-depth information about incontinence
- Frequently asked questions
- A glossary of medical terms
- Suggested story angles and reasons for writing about incontinence

In addition to referring to this informative guide, I also encourage you to suggest that your readers visit IFFGD's website at **[www.aboutincontinence.org](http://www.aboutincontinence.org)** or call us toll free (in the U.S.) at 888-964-2001 if they want to learn more about incontinence. IFFGD is a nonprofit organization dedicated to informing, assisting, and supporting people affected by gastrointestinal disorders. We have been working since 1991 to broaden understanding about gastrointestinal disorders and support research.

IFFGD welcomes your calls, and we look forward to working with you as we continue to shed more light on incontinence.

Sincerely,

Nancy J. Norton  
President and Founder  
IFFGD

# Incontinence: A Background Guide

- 2 Introduction
- 3 What is incontinence?
- 3 How common is incontinence?
- 4 Who is at risk for developing incontinence?
- 4 Living with incontinence
- 5 Impact on society
- 6 Why does incontinence occur?
- 8 Incontinence in women
- 9 Incontinence and the elderly
- 9 Management and treatment options
- 12 Summary
- 13 More about incontinence
- 14 Glossary of terms
- 16 FAQs
- 17 Story ideas
- 19 References

## Introduction

Few talk about it, so you may find it surprising that so many people live with incontinence. In fact bowel incontinence, the inability to control bowel movements, occurs in 6-10% or more of the general population. We will often refer to it simply as 'incontinence' throughout this publication.

Incontinence imposes tremendous burdens on those who suffer with it, their families, and society. Yet, there is a lack of adequate understanding of how to prevent and treat incontinence.

It is often assumed that incontinence is a condition limited to the elderly. This is incorrect. At least 6% of adults under the age of 40, men and women, in the community are affected by bowel incontinence.<sup>[1]</sup> In nursing homes, the numbers dramatically increase to an average of 45%.<sup>[1]</sup> This is a major concern as the projected population growth over the next 10 years is about 35% for those aged 65 or older.<sup>[1]</sup>

People of all ages struggle with incontinence – men, women, and children are affected. Yet as diverse as these individuals may be, they often share a common secret about this hidden disorder that challenges social and cultural norms, and affects nearly every aspect of their daily lives. Most will go to great lengths to hide their incontinence from virtually everyone – friends, co-workers, even their own doctor. Living with incontinence can have profound personal costs. Everyday activities, such as those that involve leaving the home, may become daunting or even impossible. The world of the individual with incontinence may become gradually smaller day by day, eroding opportunities, potential, and relationships until the impact becomes devastating.

Medical and surgical treatments can help some individuals with incontinence. In addition, management plans can assist in maintaining a measure of control to help those affected carry on their normal activities.

Despite the impact of incontinence, embarrassment and lack of knowledge about the condition – by patients and physicians – and about management and treatment options often prevents individuals from receiving appropriate care. Individuals too often struggle alone with a debilitating secret.

There is a need to lift the veil of silence masking the occurrence, prevalence, and burden of incontinence. Raising awareness will make it easier for people to talk about incontinence and seek the help they need to prevent or manage this common condition

## What is incontinence?

Bowel incontinence is the involuntary leakage of liquid or solid stool. It is a chronic and unpredictable symptom, which can be caused by many conditions. Some individuals with incontinence might feel the urge to have a bowel movement, but be unable to control it until they can get to a bathroom. Others may lack sensation, and stool may leak from the rectum unexpectedly. Bowel incontinence is also referred to as fecal incontinence, soiling, or lack of bowel control. The term ‘anal incontinence’ refers to the loss of intestinal gas, as well as solid or liquid stool. Incontinence of gas is embarrassing and can be socially isolating.

---

*“We are learning that chronic gastrointestinal symptoms and disorders are important risk factors for incontinence,” said William E. Whitehead, PhD, Professor of Medicine at University of North Carolina at Chapel Hill. “Up to a third of patients with irritable bowel syndrome (IBS) report episodes of fecal incontinence. Those with diarrhea are 3–4 times more likely to experience fecal incontinence.”*

## How common is incontinence?

Bowel incontinence is very common. It occurs in 6% of women younger than 40 and increases to 15% of women aged 40 and older.<sup>[1]</sup> Between 6% and 10% of men experience fecal incontinence, with a slight increase with age.<sup>[1]</sup> Individuals with incontinence are often reluctant to report their symptoms; therefore, the condition is believed to be widely under-diagnosed and hidden in our society.<sup>[2]</sup>

---

*“People are reluctant to talk about incontinence. They may be too embarrassed or at a loss of how to describe the symptom to their physician,” said Nancy Norton, President of IFFGD. “They may talk around it saying they have diarrhea, rather than revealing unexpected loss of stool or being afraid to leave their house. It helps when the doctor takes the lead to probe a little deeper. Simply asking, ‘Do you notice leakage or soiling in your clothes; do you change plans because of your bowel function?’ may be all that is needed for the patient to open up.”*

## **Who is at risk for developing incontinence?**

Many otherwise healthy, active men, women, and children live with incontinence. Although it is associated with aging, incontinence is not a normal part of the aging process and people of any age can develop the condition. Nonetheless, being female and older age are generally recognized as risk factors. Other general factors that place persons at risk include neurologic diseases, stroke, diabetes, inflammatory bowel disease, irritable bowel syndrome, multiple childbirths in women, and episiotomy during childbirth.<sup>[1]</sup>

## **Living with incontinence**

It can be difficult for those who do not struggle with incontinence to understand how it can affect nearly every aspect of an individual’s daily life.<sup>[3]</sup> Being incontinent in public might be a sufferer’s greatest fear and individuals with incontinence must live with the uncertainty of never being sure when an episode might strike. Regardless of whether incidents occur once a day or once a month, the burden of dread remains constant.

Many individuals with incontinence begin to adapt their lives to accommodate unpredictable symptoms. They may begin by limiting food intake, with the idea that if nothing goes in, then nothing will come out. When leaving the house, they may wear dark clothes, carry with them absorbent products, a change of clothing, and supplies for

cleaning themselves. They may find themselves planning their day around maintaining easy and rapid access to a restroom in order to prevent public episodes of incontinence and the feelings of embarrassment and shame this would provoke.<sup>[3,4,5,10]</sup>

The personal impact of incontinence becomes even more profound as sufferers begin to withdraw from social situations in order to keep their problem hidden.<sup>[6,10]</sup> They may participate in fewer and fewer social and work activities. It is not uncommon for a person with incontinence to limit or even entirely avoid activities that most of us take for granted, such as shopping, going to the cinema, dining out, or sexual intimacy.<sup>[7,10]</sup> For some who have incontinence, it can become difficult to even walk out the front door, let alone ride in a car, bus, or airplane.<sup>[8]</sup> Their world becomes increasingly smaller day by day. The withdrawal may be so gradual that it's barely noticeable, until one day there comes a recognition of how isolating or disabling it has become.<sup>[1,9]</sup>

Incontinence is generally treatable,<sup>[7]</sup> yet, most individuals with incontinence never discuss the condition with their doctor.<sup>[7,10,9]</sup> It can be very difficult to broach the subject of bowel incontinence with a doctor and it is thought that embarrassment<sup>[4,9,11]</sup> and lack of knowledge about treatment options<sup>[7]</sup> prevent individuals from receiving appropriate care.

## Impact on society

Incontinence results in substantial economic costs to society. Absenteeism and impaired performance while at work limit productivity and employment opportunities.<sup>[6,11]</sup> Individuals with bowel incontinence miss approximately 15 days of work or school per year because of their condition and

---

*“I know from listening to patients how devastating to a person it can be,” said Dr. Adil E. Bharucha, professor of medicine at Mayo Clinic College of Medicine, in Rochester, MN. “There needs to be more open discussion and awareness among doctors and patients alike about preventing, recognizing, and managing the symptom.”*

an estimated 13% cannot attend work or school at all due to the condition.<sup>[12]</sup> For older people, bowel incontinence often results in early institutionalization because family members have difficulty coping with the problem at home.<sup>[6,11]</sup>

### *Conditions that Contribute to Bowel Incontinence*

- *Childbirth*
- *Constipation*
- *Diarrhea*
- *Irritable bowel syndrome (IBS)*
- *Inflammatory bowel disease (IBD)*
- *Neurological disorders*
- *Pelvic or anal surgery*
- *Pelvic floor dysfunction*
- *Radiation treatments for certain cancers*
- *Spinal cord injury*
- *Stroke*

## **Why does incontinence occur?**

Continence depends on properly functioning muscles and nerves in and around the rectum and anal canal. Any condition that interferes with these complex mechanisms may result in incontinence. Childbirth, constipation, diarrhea, irritable bowel syndrome (IBS), inflammatory bowel disease (IBD), pelvic or anal surgery, neurological disorders or injuries, and radiation treatments for certain cancers are some of the conditions that can affect continence.

- **Muscle damage or weakness**

Incontinence can be caused by injury to the ring-like sphincter muscles at the end of the rectum. The sphincter muscles normally stay tightly closed and keep stool in the rectum. If weakened by injury or disease, stool can leak out. In women, for example, the damage may happen as a result of complicated childbirth. Hemorrhoid surgery and other anal surgeries can also damage the sphincter muscles.

- **Nerve damage**

Nerve damage can impair sensation and muscle control. An individual with nerve damage may not feel the need to use the bathroom and stool may leak out unexpectedly. Nerve damage can be caused by complicated childbirth, long-term straining to pass stool,<sup>[13]</sup> spinal cord injury, stroke, and neurological diseases such as diabetes, multiple sclerosis (MS), and Parkinson's disease.<sup>[2,14]</sup>

- **Diarrhea**

Bowel control can be overwhelmed by a sudden or urgent need to pass loose stool, especially if muscle or nerve function is also impaired.<sup>[15]</sup> This can be a devastating symptom for individuals with chronic gastrointestinal conditions that cause diarrhea, such as irritable bowel syndrome (IBS) or after gallbladder surgery.<sup>[16]</sup>

- **Constipation**

Long-term constipation can lead to the formation of a hard mass of stool in the colon. Liquid stool can seep around the mass and be difficult to control.<sup>[17]</sup> This is the most common cause of fecal incontinence in children. In some cases the presence of liquid stool may lead to misdiagnosis and treatment for diarrhea, which only worsens the underlying problem.<sup>[15]</sup>

### *Bowel Incontinence is Widespread*

- *Approximately one-half of people with MS develop incontinence.<sup>[9]</sup>*
- *Up to one-third of individuals with IBS and diarrhea experience incontinence.<sup>[15]</sup>*
- *One study found that 31% of women with incontinence first experienced symptoms before the age of 40.<sup>[3]</sup>*

- **Pelvic floor dysfunction**

The pelvic floor is a group of muscles that not only supports the pelvic organs within the pelvis and lower abdomen but also plays an important role in defecation and maintaining continence. If pelvic floor function is disturbed, normal bowel control may be disrupted. An inability to adequately relax the pelvic floor muscles during defecation may lead to incomplete evacuation, which may also predispose to fecal incontinence. Pelvic surgery, pregnancy, or vaginal childbirth can contribute to development of a pelvic floor disorder.<sup>[18]</sup>

- **Loss of storage capacity**

Rectal surgery, radiation treatments for pelvic or colon cancers, and inflammatory bowel disease (IBD) can cause inflammation as well as scarring that stiffens the normally elastic walls of the rectum and lead to urgency and fecal incontinence.<sup>[13,19]</sup> Some women have a reduced storage capacity without these conditions.<sup>[20]</sup>

## **Incontinence in women**

Women are uniquely vulnerable to a number of conditions that may increase the risk for developing incontinence – pregnancy and childbirth, changes in the pelvic floor associated with menopause, as well as hysterectomy and other gynecologic surgeries.<sup>[2,9]</sup> Irritable bowel syndrome (IBS) with diarrhea, and multiple sclerosis (MS), both of which predominantly strike women, can also contribute to the development of bowel incontinence. Although prevalence of incontinence increases with age,<sup>[21]</sup> it is not a normal part of aging. Younger women can be affected, while some older women never develop the problem.<sup>[4]</sup>

The most common cause of bowel incontinence in otherwise healthy women is injury that occurs during childbirth.<sup>[21,22]</sup> Some injuries during childbirth have an immediate effect on continence. However, women who develop bowel incontinence generally do so in their 60's, suggesting that other factors also contribute.<sup>[3,9,23]</sup>

## Incontinence and the elderly

Although incontinence is not considered a normal part of the aging process, as with many other health conditions, the risk for developing incontinence increases with age. Among the elderly, up to 20% of women and 10% of men live with bowel incontinence.<sup>[1,3]</sup>

The burden of bowel incontinence can become overwhelming when combined with other health and mobility challenges this group may face. Studies suggest that incontinence contributes to the decision to institutionalize elderly patients.<sup>[6,11]</sup> In nursing homes, rates of bowel incontinence are nearly 50%.<sup>[24,25]</sup>

## Management and treatment options

Although the physical symptoms of bowel incontinence can be very difficult to live with, it is often the uncertainty of when an episode of incontinence may occur that influences – and in some individuals overwhelms – daily life. An effective management plan for incontinence not only minimizes episodes but also allows an individual to regain a sense of personal control.

Management plans are tailored to address an individual's specific symptoms and often incorporate lifestyle and dietary changes, medication, or bowel management/retraining programs.

### Lifestyle changes – being prepared

Managing incontinence often means being prepared. Knowing what to do when it does happen can help prevent fear from consuming a person's life. For example, it helps to always have cleanup supplies and extra clothes on hand, and although difficult to accept, protective undergarments may be a good idea. Also, people with incontinence should locate the restrooms in public places and make sure that they can get to them easily. Flexibility is important, too, since plans may need to be changed at the last minute.

- **Dietary changes**

Diarrhea and constipation contribute to incontinence for many individuals. In some cases, food choices can be modified to improve bowel function and continence. For example, it may help to reduce or avoid dietary choices that stimulate the gut and may provoke diarrhea such as meals that are too large or high in fat, fried foods, coffee, caffeine, alcohol, and foods containing the sweeteners sorbitol and fructose.

- **Medication**

Medications can help improve diarrhea and constipation or assist in the development of a more predictable bowel pattern. Examples include antidiarrheal medications, fiber supplements, stool softeners, and laxatives.<sup>[7,15]</sup>

- **Bowel management/retraining program**

Bowel management or retraining involves designing a program to help develop a more predictable schedule for elimination and decrease unpredictable episodes of incontinence.<sup>[26]</sup> This may include dietary changes or the use of medication as well as establishing a habit regimen.<sup>[11,15]</sup> It also involves the ability to respond and availability of toilet facilities when feeling the need to have a bowel movement (the 'call to stool'). Incontinence among the elderly in nursing homes could be improved with more toileting opportunities for residents.<sup>[27]</sup>

### *Managing and Treating Fecal Incontinence*

*Management and treatment may include a combination of the following:*

- *Dietary changes*
- *Medication*
- *Bowel management/retraining program*
- *Biofeedback therapy (neuromuscular reeducation)*
- *Surgery to repair muscle damage*
- *Surgery to create a diversion/colostomy*
- *Other newer procedures or devices*

In some cases, it can be helpful to consult a knowledgeable specialist who may be able to shed more light on the underlying symptom mechanisms and help develop a more specific treatment plan.<sup>[15,22]</sup> Depending on the cause and severity of symptoms, a specialist may recommend one of the following treatments: biofeedback therapy, a surgical procedure, or one of the newly developed implants, injections, or devices.

- **Biofeedback therapy**

Biofeedback therapy for incontinence involves reeducating muscles and nerves using special sensors to help a person change bodily functions they are usually not aware of. Working with a trained therapist can help to modify or change abnormal responses to more normal and effective patterns.

- **Repair surgery**

Surgery to repair the anal sphincter may be an option for some people who have not responded to less invasive treatments and have muscle damage but functioning nerves.<sup>[28]</sup> However, improvements appear to deteriorate over time.<sup>[29]</sup> Different techniques can be considered depending on the type or extent of damage.

- **Newer treatment options**

Other newer treatments are being developed to improve continence. These range from nerve stimulation in the lower pelvic area, to implants, and injection of bulking materials.<sup>[13,28]</sup> There is hope through research that additional therapeutic options will be developed for patients with incontinence unresponsive to treatment.

- **Diversion surgery**

Some individuals with severe incontinence who have had no success with management plans or treatments choose to have a colostomy. Stool leaves the colon through a surgically created opening in the abdomen where it is collected in a pouch. A colostomy does not restore continence, but it can give individuals control over defecation and may allow them to resume normal activities.<sup>[7,30]</sup>

Although current management and treatment options do improve the quality of life for individuals with incontinence and can mean the difference between social isolation and a productive life, these measures do not guarantee a return to complete continence.<sup>[22]</sup> Even after initial success with biofeedback or surgery, many patients do not retain the post-treatment degree of continence long-term.<sup>[7]</sup> There is a great need for research aimed at finding innovative treatments to improve lives of affected individuals.

## Summary

Incontinence can have devastating effects on an individual's quality of life. At least 6% of the general population has episodes of bowel incontinence, and individuals of all ages are at risk for developing the problem – men, women, and children. Many different conditions contribute to the development of incontinence and treatment is usually tailored to address an individual's specific circumstances.

The effects of this hidden condition extend far beyond the physical symptoms. Sufferers often withdraw from their social and professional activities to hide the problem from everyone in their lives. Millions suffer in silence, unaware that their condition is *not* uncommon and that help is available.

Although bowel incontinence is generally treatable, if not always curable, embarrassment and lack of knowledge about the condition and treatment options keep many individuals from receiving appropriate treatment and support. Instead, sufferers are left to face alone the many challenges of living with and managing the condition.

## *More about Incontinence*

*International Foundation for Functional Gastrointestinal Disorders (IFFGD)*

*P.O. Box 170864*

*Milwaukee, WI 53217*

*888-964-2001 (toll free in the U.S.)*

*414-964-1799*

*[www.iffgd.org](http://www.iffgd.org)*

*IFFGD is a nonprofit education and research organization whose mission is to inform, assist and support people affected by gastrointestinal (GI) disorders. We offer educational materials about GI disorders and publish “Digestive Health Matters,” a quarterly journal for the general public. For information about bowel incontinence, visit our website at [www.aboutincontinence.org](http://www.aboutincontinence.org).*

*Education and awareness can help break down the barriers that block millions from seeking care. Here are some key messages:<sup>[1]</sup>*

- You are not alone – incontinence is common across all ages*
- You do not have to just “live with it”*
- Some medical conditions that cause incontinence can be treated*
- Incontinence does not have to be a part of aging*
- There are various management and treatment therapies to help improve continence*
- You should tell your doctor*

## Glossary of Terms

**ANAL CANAL OR ANUS:** The lowermost portion of the large intestine.

**ANAL INCONTINENCE:** Any leakage of liquid or solid stool or excessive leakage of gas.

**BIOFEEDBACK THERAPY:** A painless neuromuscular reeducation tool in which a therapist, using special sensors to monitor functions that we are usually not aware of, helps to change abnormal functions to more normal and effective functions.

**BOWEL:** Intestines or gut.

**BOWEL CONTROL:** Ability to delay defecation or passing of intestinal gas in a controlled manner.

**BOWEL INCONTINENCE:** Inability to delay defecation in a controlled manner.

**BOWEL MANAGEMENT OR RETRAINING:** A program to help develop a more predictable schedule for elimination and decrease unpredictable episodes of incontinence. It may involve normalizing stool consistency, usually through dietary changes; establishing a regular time for elimination; and stimulating emptying on a regular basis.

**COLOSTOMY:** A surgically created opening of the colon to the abdominal wall, allowing the diversion of fecal waste.

**CONSTIPATION:** Reduced stool frequency, or hard stools, difficulty passing stools, painful bowel movements, or lack of satisfaction after defecation.

**CONTINENCE:** Ability to delay defecation or passing of intestinal gas in a controlled manner.

**DIARRHEA:** Passing loose or watery stools.

**EPISIOTOMY:** An incision made in the skin between the vagina and anus meant to enlarge the vaginal opening during childbirth in order to prevent tearing and to facilitate delivery of an infant.

**FECAL INCONTINENCE (FI):** Involuntary leakage of liquid or solid stool.

**FORCEPS:** An instrument shaped like tongs that may be placed around an infant's head to help guide it out of the birth canal during delivery.

**HEMORRHOIDS:** Swollen veins or tissue in the anus or nearby within the rectum.

**INFLAMMATORY BOWEL DISEASE (IBD):** Chronic gastrointestinal disease that causes inflammation and ulcers in the gastrointestinal tract. The most common types are ulcerative colitis and Crohn's disease.

**IRRITABLE BOWEL SYNDROME (IBS):** A chronic functional bowel disorder in which abdominal discomfort or pain is associated with defecation or a change in bowel habit. Typically it includes intermittent and recurrent abdominal pain accompanied by diarrhea, constipation, or alternating episodes of both.

**MANAGEMENT PLAN:** Management plans for bowel incontinence incorporate a number of strategies to minimize episodes of incontinence and allow individuals to regain a sense of personal control.

**NEUROLOGICAL DISORDERS:** Disorders that affect the brain, spinal cord, nerves, or muscles.

**PELVIC FLOOR:** A group of muscles that support the pelvic organs, participate in defecation, and help maintain continence.

**RECTUM:** The lower end of the large intestine, leading to the anus.

**SOILING:** Staining or soiling undergarments with stool.

**SPHINCTER:** Ring of muscle that opens and closes.

**URGENCY:** Having very little time between feeling the urge to have a bowel movement and the need to pass stool.

## FAQs

**What is bowel incontinence?** Bowel incontinence is the inability to delay defecation in a controlled manner. It is also referred to as fecal incontinence, anal incontinence, soiling, or lack of bowel control.

**Why does incontinence occur?** Many conditions can contribute to the development of incontinence. Childbirth, constipation, diarrhea, irritable bowel syndrome (IBS), inflammatory bowel disease (IBD), pelvic or anal surgery, neurological diseases, traumatic injuries, and radiation treatments for certain cancers are some of the conditions that can affect continence.

**Who is likely to develop incontinence?** Many otherwise healthy, active men, women, and children live with incontinence. Although it is often associated with aging, it is not a normal part of the aging process.

**How common is incontinence?** At least 6% of the general population lives with incontinence. It occurs in 6% of women younger than 40 and in 15% of older women.<sup>[1]</sup> Between 6% and 10% of men experience incontinence, with a slight increase with age.<sup>[1]</sup> Individuals with incontinence are often reluctant to report their symptoms, therefore, the condition is believed to be widely under-diagnosed and hidden in our society.

**How is incontinence managed?** Management of incontinence often involves dietary changes, medication, or bowel management/retraining programs. Individuals should work with a knowledgeable healthcare professional to develop an individualized management plan.

**Are there treatments that can restore continence?** Depending on the cause and severity of symptoms, one of the following treatments may restore continence: biofeedback therapy, a surgical procedure, or one of the newly developed implants, injections, or devices.

**Can incontinence be cured?** Continence cannot always be restored. Even after initial success with biofeedback or surgery, many patients do not retain the post-treatment degree of continence long-term.<sup>[7]</sup> There is a great need for research aimed at finding innovative treatments to improve lives of affected individuals.

**What is the personal burden associated with incontinence?** The impact of this hidden condition extends far beyond the physical symptoms and can have devastating effects on an individual's quality of life. Sufferers often withdraw from their social and professional activities to hide the problem from everyone in their lives. It is estimated that millions suffer in silence.

## Story ideas

### *One of the Best Kept Health Secrets*

At least 6% of adults in the general population live with bowel incontinence. Because individuals with bowel incontinence are often reluctant to report their symptoms, the condition is believed to be widely under-diagnosed and hidden in society.

### *Individuals Do Not Receive Treatment for Common Health Condition*

Bowel incontinence is generally treatable; however, embarrassment and lack of knowledge about the condition and treatment options keep individuals from receiving appropriate treatment and support. Instead, sufferers are left to face alone the many challenges of living with and managing the condition.

### *Bowel Incontinence: Common Reason for Nursing Home Admission*

Although it is not a normal part of the aging process, the risk for developing incontinence increases with age and may lead to early institutionalization.<sup>[11]</sup> It is one of the most common reasons for nursing home admission<sup>[2]</sup> and affects nearly 50% of nursing home residents.<sup>[24,25]</sup>

### *As Baby Boomers Age, Bowel Incontinence to Become Greater Health Burden*

As we age, our bodies are at greater risk of developing many conditions, including incontinence. The baby boomer generation, now beginning to enter their 60's, may soon cause an increase in the number of individuals living with bowel incontinence and be responsible for a rise in the burdens associated with the condition.

### *Women and Bowel Incontinence*

Women are uniquely vulnerable to a number of conditions that increase the risk for developing incontinence – pregnancy and childbirth, changes in the pelvic floor associated with menopause, as well as hysterectomy and other gynecologic surgeries.<sup>[2,9]</sup> Irritable bowel syndrome (IBS) with diarrhea and multiple sclerosis (MS), both of which predominantly strike women, can also contribute to the development of incontinence.

### *Few Pregnant Women are Educated about their Risk for Incontinence*

The most common cause of bowel incontinence in otherwise healthy women is obstetrical trauma, leading to muscle or nerve injury.<sup>[21,31]</sup> This happens most often during more complicated deliveries involving forceps and episiotomies, and many experts believe that injuries may be reduced by limiting their use.<sup>[23,32]</sup> A survey in the U.S. revealed that most new mothers received no information from their doctor about risks associated with episiotomy (51.3%) or the possibility of developing bowel incontinence (80.6%).<sup>[33]</sup>

## References

1. Landefeld CS, et al. National Institutes of Health State-of-the-Science Statement: Prevention of Fecal and Urinary Incontinence in Adults. *Ann Intern Med.* 2008 Feb 11 [Epub ahead of print].
2. Nelson RL. Epidemiology of fecal incontinence. *Gastroenterology.* 2004 Jan;126(1 Suppl 1):S3-7. Review.
3. Bharucha AE, et al. Prevalence and burden of fecal incontinence: a population-based study in women. *Gastroenterology.* 2005 Jul;129(1):42-9.
4. Kuehn BM. Silence masks prevalence of fecal incontinence. *JAMA.* 2006 Mar 22; 295(12):1362-3.
5. Garcia JA, Crocker J, Wyman JF, Krissovic M. Breaking the cycle of stigmatization: managing the stigma of incontinence in social interactions. *J Wound Ostomy Continence Nurs.* 2005 Jan-Feb;32(1):38-52. Review.
6. Miner PB Jr. Economic and personal impact of fecal and urinary incontinence. *Gastroenterology.* 2004 Jan;126(1 Suppl 1):S8-13. Review.
7. Madoff RD, Parker SC, Varma MG, Lowry AC. Faecal incontinence in adults. *Lancet.* 2004 Aug 14-20;364(9434):621-32. Review.
8. Norton NJ. The perspective of the patient. *Gastroenterology.* 2004 Jan;126(1 Suppl 1):S175-9. Review.
9. Hawes SK, Ahmad A. Fecal Incontinence: a woman's view. *Am J Gastroenterol.* 2006 Dec;101(12 Suppl):S610-7. Review.
10. Bharucha AE, et al. Symptoms and quality of life in community women with fecal incontinence. *Clin Gastroenterol Hepatol.* 2006 Aug;4(8):1004-9.
11. Bharucha AE. Fecal incontinence. *Gastroenterology.* 2003 May;124(6): 1672-85. Review.

12. Drossman DA, Li Z, Andruzzi E, et al. U.S. Householder Survey of Functional Gastrointestinal Disorders: Prevalence, Sociodemography, and Health Impact. *Dig Dis Sci* 1993;38:1569-80.
13. National Institutes of Health. Fecal Incontinence. <http://digestive.niddk.nih.gov/ddiseases/pubs/fecalincontinence/#3>. (National Digestive Diseases Information Clearinghouse 2007:accessed 2007)
14. Wald, A. Bowel Problems Associated with Neurologic Diseases. IFFGD Fact Sheet #198. 2006.
15. Lowry, A. Medical Management of Fecal Incontinence. IFFGD Fact Sheet #306. 1999.
16. International Foundation for Functional Gastrointestinal Disorders. *IBS in the Real World Survey - Summary Findings*. IFFGD 2002.
17. Madoff RD. The Etiology of Fecal Incontinence. IFFGD Fact Sheet No. 172, 1995.
18. National Institutes of Health. Pelvic Floor Disorders. [http://www.nichd.nih.gov/health/topics/Pelvic\\_Floor\\_Disorders.cfm](http://www.nichd.nih.gov/health/topics/Pelvic_Floor_Disorders.cfm). (National Institute of Child Health & Human Development 2007:accessed 2007)
19. Katz JA, Orkin BA. Colorectal Cancer and Continence. IFFGD Fact Sheet #308. 2004.
20. Bharucha AE, Fletcher JG, Harper CM, Hough D, Daube JR, Stevens C, Seide B, Riederer SJ, Zinsmeister AR. Relationship between symptoms and disordered continence mechanisms in women with idiopathic fecal incontinence. *Gut* 2005;54(4):546-55.
21. Weber AM. The perspective of a gynecologist on treatment-related research for fecal incontinence in women. *Gastroenterology*. 2004 Jan;126(1 Suppl 1): S169-71. Review.
22. Lunniss PJ, Gladman MA, Hetzer FH, Williams NS, Scott SM. Risk factors in acquired faecal incontinence. *J R Soc Med*. 2004 Mar;97(3):111-6.

23. Davila GW. Informed consent for obstetrics management: a urogynecologic perspective. *Int Urogynecol J Pelvic Floor Dysfunct.* 2001;12(5):289-91. Review.
24. Nelson R, Furner S, Jesudason V. Fecal Incontinence in Wisconsin Nursing Homes. *Diseases of the Colon and Rectum* Vol. 41, No. 10 October 1998.
25. Dey AN. Characteristics of elderly nursing home residents; data from the 1995 National Nursing Home Survey. Advance data from vital and health statistics; no. 289. Hyattsville, Maryland; National Center for Health Statistics 1997.
26. Plummer, M. Strategies for Establishing Bowel Control. IFFGD Fact Sheet #302. 2002.
27. Schnelle JF, Leung FW. Urinary and fecal incontinence in nursing homes. *Gastroenterology.* 2004 Jan;126(1 Suppl 1):S41-7. Review.
28. Norton NJ. Impact of fecal and urinary incontinence on the health consumer: barriers on diagnosis and treatment – a patient perspective. From Prevention of Fecal and Urinary Incontinence in Adults; an NIH State-of-the-Science Conference: Program and Abstracts. 2007 Dec 10-2.
29. Bharucha AE. Summary of Clinical Research Activities – Incontinence. <http://www.giresearch.org/site/gi-research/iffgd-research-awards/2003/incontinence>. (IFFGD 2007: accessed 02/02/08)
30. Lowry, A. Surgical Treatment of Fecal Incontinence. IFFGD Fact Sheet #303. 1994.
31. Whitehead WE, Wald A, Norton NJ. Consensus Conference Report: Treatment Options for Fecal Incontinence. *Diseases of the Colon and Rectum* Vol. 44, No. 1 January 2001.
32. Weber, A. #309-Changes in Pelvic Floor Function at Childbirth and After Delivery. IFFGD. 2005.
33. McLennan MT, Melick CF, Alten B, Young J, Hoehn MR. Patients' knowledge of potential pelvic floor changes associated with pregnancy and delivery. *Int Urogynecol J Pelvic Floor Dysfunct.* 2006 Jan;17(1):22-6. Epub 2005 Jul 8.



International Foundation for Functional Gastrointestinal Disorders  
IFFGD

P.O. Box 170864

Milwaukee, WI 53217-8076

Toll-free: 888-964-2001

Business: 414-964-1799

Fax: 414-964-7176

E-mail: [iffgd@iffgd.org](mailto:iffgd@iffgd.org)

---

[www.iffgd.org](http://www.iffgd.org)

[www.aboutconstipation.org](http://www.aboutconstipation.org)

[www.aboutibs.org](http://www.aboutibs.org)

[www.aboutincontinence.org](http://www.aboutincontinence.org)

[www.aboutgerd.org](http://www.aboutgerd.org)

[www.aboutgimotility.org](http://www.aboutgimotility.org)

[www.aboutkidsgi.org](http://www.aboutkidsgi.org)

[www.giresearch.org](http://www.giresearch.org)



The printing of this publication was  
made possible by a grant from  
Medtronic Foundation.

