



Managing Incontinence: A survey of those who live with it

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319



International Foundation for Gastrointestinal Disorders (www.iffgd.org)

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Many otherwise healthy, active people suffer from incontinence or loss of bowel control. Fecal incontinence (FI) is also called bowel incontinence. It strikes men and women of all ages and involves the accidental loss of solid or liquid stool. Incontinence is a long-term, stressful, and limiting disorder. An effective treatment and management plan for incontinence minimizes episodes and allows individuals to regain a sense of personal control. Treatments are tailored to address each person's specific symptoms and may include a number of approaches.

In 2010, IFFGD conducted an online survey to help explain what it is like to live with and manage incontinence from the point of view of those who experience the condition. A total of 142 individuals completed an Internet-based survey between September and December, 2010. All indicated that they experience FI *not* caused by irritable bowel syndrome (IBS) or other intestinal diseases. Ninety-seven (68%) of the survey responders indicated they had never been diagnosed by a physician; forty-five (32%) responders indicated they did have a physician diagnosis. Responders were recruited primarily from the International Foundation for Functional Gastrointestinal Disorders (IFFGD) websites.

Key Findings

Reported Characteristics of Bowel Control/FI Problems:

- About two-thirds of the responders suffer from the symptoms of FI but have *not* been diagnosed; one-third have been diagnosed.
- Almost half of diagnosed patients and more than one-fourth of those not diagnosed experience a loss of bowel control 4 or more times per week.
- More than half of all responders experience loss of bowel control primarily during the day, and for most, the stool is usually loose/watery.
- Close to two-fifths of diagnosed FI patients and almost half of undiagnosed individuals say the severity or frequency of their FI changes throughout the year.
- FI patients who are diagnosed typically report that the condition "often" or "always" interferes with their daily activities; those who have not been diagnosed are more likely to say it "rarely" interferes.
- The majority of responders say they missed social activities in the past 3 months due to their FI.

Interaction with Physicians

Most of the people who had a diagnosis of FI talked to their physicians within 3 years after their symptoms first began. Typically, these individuals consulted 1 or 2 physicians before receiving a diagnosis; and more than one-third visited 3 or more physicians before receiving their diagnosis. Most talked first about it with a Primary care physician or OB/GYN, although the largest proportion are currently treated by a gastroenterologist. One out of five said their doctors have not specified a cause. Those who know a cause most frequently mention either an obstetrical injury or a rectal injury. The majority of responders in this survey had not been diagnosed with FI. They gave a variety of reasons for this, most often saying:

- They are too embarrassed to bring it up.
- They feel they can manage the condition on their own.
- They have mentioned it, but their physicians implied there is not much to be done about it or it is a normal part of aging.

Treatment

Responders diagnosed with FI were asked about how their FI was being treated by their physician, choosing from a list that included: changes in diet; over-the-counter anti-diarrheal medicine; fiber; stool softeners; over-the-counter laxatives; prescription laxatives; enemas; biofeedback or Kegel training; surgery; or colostomy.

- Patients diagnosed with FI and who use the treatments listed in the survey have spent, on average, \$250 per year on these treatments.
- The majority of patients are using diet and/or medications to relieve their FI.
 - Most patients like this treatment approach because it is something they can do themselves.
 - More than one-third of patients using this approach feel that the treatment does not really improve their conditions.
- Three-fourths of FI patients agree with the statement, "Even if I follow my treatment exactly, there seems to be times when it is not working." More than two-thirds agree that, "No treatment for FI works completely." Two-thirds agree that, "It is comforting to know that there are other people who suffer from FI."

Detailed Findings

Making the Diagnosis

A diagnosis is the first step in putting together a treatment plan for incontinence. Patients need to speak with doctors candidly about bowel symptoms and doctors need to ask frankly about loss or leakage of stool. Once incontinence is identified in a person, the cause, severity, and treatment plan can be established.

- Over two-thirds (68%) of the responders suffer from the symptoms of fecal incontinence but have *not* been diagnosed.
- Patients diagnosed with FI typically have had the condition for more than 3 years, while those who have *not* been diagnosed tend to report time periods of less than 3 years.
- The largest portion of patients who have been diagnosed with FI were diagnosed more than 10 years ago (38%). The largest portion of patients *not* diagnosed report a time period of 1–4 years (36%).
- Patients under the age of 55 are more likely than are older patients to say they have had FI for more than 10 years (30% vs. 11%), while older patients are more likely than younger patients to have had FI for 1 to 3 years (45% vs. 25%).

Length of Time with FI	Diagnosed	Not diagnosed
More than 10 years	38%	13%
4 to 10 years	27%	26%
1 to 3 years	29%	36%
Less than 1 year	7%	25%

Talking about it

- The large majority of patients (80%) who have been diagnosed with FI talked to their physicians about it within the first three years, including 40% who mentioned it within the first year.
- One-fifth (20%) waited 4 years or more, including 7% who waited more than 10 years before mentioning it.

Time with FI before Seeking Medical Advice	Diagnosed
More than 10 years	7%
4 to 10 years	13%
1 to 3 years	40%
Less than 1 year	40%

Symptom Patterns and Severity

Incontinence can affect nearly every aspect of daily life. People with incontinence live with the uncertainty of never being sure when an episode might strike.

- Patients in both diagnosis groups experience their FI frequently:

Frequency	Diagnosed	Not diagnosed
At least 1 time per week	83%	70%
At least 2 times per week	76%	60%
At least 4 times per week	47%	27%
At least 10 times per week	16%	8%

- The majority of responders (71% diagnosed, 57% not diagnosed) experience loss of bowel control primarily during the day.
- More than half (58% diagnosed, 65% not diagnosed) say their stool is usually loose or watery, and more than one-quarter say that stool consistency varies (31% diagnosed, 27% not diagnosed).

Stool Consistency with FI	Diagnosed	Not diagnosed
Varies	31%	27%
Loose or Watery	58%	65%
Hard or Firm	11%	8%

- Two-fifths (38%) of responders who have been diagnosed with FI and almost half (48%) who have not been diagnosed say that the severity or frequency of their FI changes throughout the year.

Daily Living and Quality of Life

People who experience incontinence endure an emotional burden of embarrassment as well as physical burden of discomfort and disruption of daily living – including work and social activities.

- Patients who are diagnosed with FI most often report that the condition “often” interferes with their daily activities (40%), and the remainder report that it “always” (29%) or “sometimes” (31%) interferes.
- Those who have not been diagnosed most often say that their FI “sometimes” interferes (38%). However, one-fifth (19%) say it rarely interferes.

Frequency that FI Interference with Daily Activities

Frequency	Diagnosed	Not diagnosed
Always	29%	20%
Often	40%	24%
Sometimes	31%	38%
Rarely	0%	19%

Missed Work or Social Activities During Previous 3 Months due to FI

Frequency	Diagnosed	Not diagnosed
Missed work	38%	26%
Missed social activities	73%	55%

- More than one-third (38%) of patients who have been diagnosed with FI and one-quarter (26%) of those who have not been diagnosed say they have missed work in the previous 3 months due to their FI.
- Of those who missed work, more than half (53% diagnosed, 52% not diagnosed) missed 4 or more days due to their FI.
- The majority of all responders say they had missed social activities in the previous 3 months due to their FI (73% of diagnosed and 55% of undiagnosed). Over one-third of those who missed activities because of their FI missed more than 5 activities.

Interactions with Physicians

Plain spoken and direct communication between doctors and patients about symptoms is important to making a diagnosis

and finding the right treatment. Individuals with FI may be hindered by social stigma, discomfort talking about symptoms, or lack of awareness that potential treatments are available.

- Two-thirds (68%) of the survey responders do *not have a diagnosis* of FI from a physician. When asked why they have never been diagnosed by a physician, they most often report that:
 - They have mentioned it to their doctors, but the doctor implied either that there is not much that can be done about FI or that it is a normal part of aging (23%).
 - They are too embarrassed to bring it up to their doctors (20%).
 - They believe they can manage it on their own (15%).
- Of the one-third (32%) of responders who *do have a physician diagnosis* of FI, 38% say they first discussed their condition with their primary care/family physician, followed by 22% who spoke to a gastroenterologist, 13% to an OB/GYN, and 11% to a colorectal surgeon.
- More than one-third (36%) of patients with FI are currently being treated by a gastroenterologist, 24% see a colorectal surgeon for treatment, 22% are treated by a primary care/family physician, and 7% by an OB/GYN.
- Most patients consulted more than one physician before they were diagnosed as having FI.

Number consulted	1 doctor	2 doctors	3-4 doctors	5 or more doctors	Do Not Recall
Percentage of Patients	22%	33%	37%	4%	4%

- Most patients diagnosed with FI (20%) report that their doctors attributed their bowel control problems to an obstetrical injury, followed by 16% who mention an anorectal injury, and 9% who mention a spinal cord injury.
- Almost one-fifth of patients (18%) indicate that their doctors did not mention a reason for their bowel control problems.
- Only 44% strongly agree that their doctor is sympathetic and listens to them.

Treatments

An effective treatment or management plan for incontinence not only makes episodes less likely, but also allows a person to regain a sense of personal control. Treatments are tailored to each person's specific symptoms. A treatment plan may include more than one method.

Diet and Medicines

- Of those patients who have a diagnosis of FI, the majority (69%) are incorporating diet changes and/or medicine in their treatment plan.
 - Patients report that they like this approach primarily because it is something they can do themselves (71%). Others state that they like it primarily because it is inexpensive (13%) or easy to do (6%).

- When asked what they like *least* about using diet and/or medicines to relieve their FI:
 - 48% say it sometimes does not work, no matter how careful they are.
 - 19% say it is hard to follow.
 - 16% say they miss certain foods.
 - 10% say they don't like the side effects from medications.

Treatment	% of Patients Diagnosed *
Diet/Medicines (Net)	69%
OTC anti-diarrheal	42%
Fiber	33%
Changes in diet	31%
Stool softeners	9%
Enemas	9%
Surgery, such as sphincteroplasty	13%
Biofeedback or Kegel training	11%
Colostomy	2%
None of these	22%

*Individuals may receive more than one treatment

- Forty percent indicate that they look at a lot of websites for help in understanding and treating their FI, and almost two-thirds (62%) indicate that they strongly agree with the statement that "It is comforting to know that there are other people who suffer from FI."

Satisfaction with Treatment

- More than half (56%) strongly agree that "No treatment for FI works completely," and another 13% agree.
- More than two-thirds (69%) of responders strongly *disagree* with the statement, "I almost never have any 'accidents' since I've started/undergone treatment."
- One-half (49%) *disagree* with the statement, "I have good control of my FI."

Summary

It is apparent from this survey that FI dramatically affects the quality of life of sufferers. For many individuals, the condition limits their social activities and affects their work life. Embarrassment and lack of adequate communication between patients and doctors are barriers to obtaining a diagnosis. The degree that FI impacts on daily life may be the key factor in determining whether a patient seeks and obtains a diagnosis. Those with a diagnosis report more frequent episodes and more life impact than those who did not obtain a diagnosis. Patients diagnosed with FI appear to be disappointed with currently available treatments, and over half are unhappy with how their condition and their feelings are sometimes treated by physicians. It is also clear from this survey that there is a considerable number of FI sufferers who do not realize that treatments are available and thus do not seek treatment for it from a physician.

Moreover, subsequent to this survey two new treatments for patients with FI who have failed more conservative therapies

were FDA approved and are now available – InterStim sacral nerve stimulator, and Solesta injectable gel.

Conclusion

Education and awareness can break down barriers to finding care and treatment. The public and healthcare providers need to be more aware of the symptoms, burdens, and treatments of FI. To help address this lack of awareness, in 2011 the National Institutes of Health (NIH) began a new program to help patients and health care professionals feel more comfortable talking about bowel control problems and addressing the needs of patients. The Bowel Control Awareness Campaign has Web resources available at www.bowelcontrol.nih.gov.

Bowel control problems affect an estimated 18 million U.S. adults and the condition is believed to be widely under-diagnosed, according to the NIH. Incontinence is common across all ages; it does not have to be a part of aging. Importantly, there are a number of treatments and strategies to help improve continence. The first step, if you have incontinence, is to talk to your doctor.

IFFGD has many helpful resources. Visit our website at www.aboutIncontinence.org.

About the Publication

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Demographic Profiles of Survey Responders	Diagnosed	Not diagnosed
Under age 65 years	80%	73%
18-34	11%	18%
35-44	13%	12%
45-54	36%	22%
55-64	20%	21%
Female/Male gender	80/20%	74/26%
Employed	53%	50%
Not able to work because of FI	9%	2%
Uninsured	4%	10%
Married or living as married	71%	60%
College degree	54%	43%

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About IFFGD

The International Foundation for Gastrointestinal Disorders (IFFGD) is a 501(c)(3) nonprofit education and research organization. We work to promote awareness, scientific advancement, and improved care for people affected by chronic digestive conditions. Our mission is to inform, assist, and support people affected by gastrointestinal disorders. Founded in 1991, we rely on donors to carry out our mission. Visit our website at: www.iffgd.org or www.aboutIncontinence.org.

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