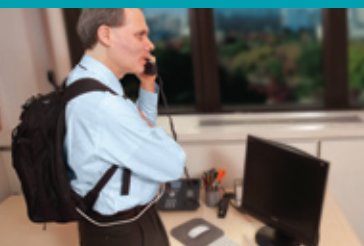


Faces of Short Bowel Syndrome



PATIENT PERSPECTIVES

"A Day In The Life"

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What is Short Bowel Syndrome?

Short bowel syndrome (SBS) is a condition in which a large part of the small intestine has been removed by surgery. The remaining section cannot absorb enough nutrients and fluids from food for the person to maintain good health. SBS also can be caused by disease or injury that prevents the small intestine from functioning properly despite a normal length.

What causes SBS?

SBS often is a consequence of surgery due to a disease or injury such as Crohn's disease or ischemia. It also can be the result of a birth defect and other complications in the newborn period that may lead to intestinal surgeries early in life.

What are the most common symptoms of SBS?

- Diarrhea
- Oily or sticky, often foul-smelling stool (known as steatorrhea)
- Abdominal pain
- Weight loss and malnutrition
- Dehydration
- Fatigue and weakness
- Flatulence
- High output into an ostomy bag (in patients with an ostomy)

How is SBS treated?

There are different ways of treating SBS. Dietary considerations are important. Many patients with SBS may need nutrition and fluids, either through a feeding tube directly into the stomach or small bowel (enteral nutrition) or through an IV inserted in a large vein (parenteral nutrition). There are also surgical options which include techniques designed to lengthen the amount of remaining bowel (lengthening procedures) and small bowel transplantation. Treatment often is determined by factors such as the amount and section of bowel remaining as well as the health of the individual patient.

What are the goals of SBS treatment?

The main goal is to ensure that people with SBS get the nutrition and fluid that they need. Doctors also will focus on treating and preventing complications of SBS that may occur. Another goal is to help patients regain a more normal life. That may mean returning to work, enjoying time with family and friends, or reducing dependence on parenteral support.



Ibrahiem

Age: 33

I think few people my age have endured what I've had to struggle with for the past five years. After suffering serious complications from surgery to remove my colon, my doctor said I had less than a one percent chance of living. I was only 28 years old. Luckily, I beat those odds. But now, I am living with the physical and emotional limitations of short bowel syndrome (SBS).

“My life changed after surgery”

Unlike most people with SBS, I have not been living with Crohn's disease for many years. My diagnosis came quickly with a single operation. Five years ago, my doctor said that ulcerative colitis put me at a very high risk of developing cancer. As a young man, I didn't want to take the risk so I opted to have my colon removed. But there were serious complications with the surgery.

“I wasn't prepared for a life receiving parenteral nutrition (PN) 11 hours a day for six days a week”

I have always been an active person. Some said I was even on track to play college basketball. So when I was diagnosed with SBS, I wasn't prepared for a life receiving parenteral nutrition (PN) 11 hours a day for six days a week. PN is important. I need it to survive. But I wish I could turn back the clock to when I could freely live my life. I can't go through a normal day or night without the IV lines and equipment getting in my way. Occasionally, I wake up in the middle of the night to use the bathroom, only to accidentally rip out my IV. It's painful and frustrating.

“I've been reduced to being a spectator”

What I would give to play just one more game of basketball. I used to play for hours. But I know now that I may never step back onto the court again. Or even jump in a swimming pool or hang out on a beach without my shirt on like every other guy. I've been reduced to being a spectator because I can't risk developing an infection, and I also want to keep my health issues somewhat private.

“I must plan every detail of my day – down to the hour”

I miss being spontaneous – being able to grab a drink with friends or run off for the weekend on a moment’s notice. Now, I must plan every detail of my day – down to the hour. My entire social life is packed into every Saturday night because that’s the one night I am free from PN. Trying to balance it all – the family dinners, parties with friends or even dating – is nearly impossible.

“I am never well enough to work as hard or as long as other people in my family”

My family and friends are always accommodating. But I know that the slightest issue with my condition can put any of my social plans in jeopardy. Recently, I planned an overnight trip to Michigan with friends. I was ready to go but my apparatus wasn’t. I ended up developing an infection and spent a very disappointing weekend confined to my home. Thankfully this time, I didn’t end up in the hospital. That’s my biggest fear. Most times when I do get an infection, I’m sick for at least a week and sometimes even a month. I can’t work, I can’t see friends, I can’t go anywhere or do anything when I have an infection. I’m lucky to work for a family-owned business. It allows me to be flexible when I need time off. But I’m still frustrated because I am never well enough to work as hard or as long as other people in my family.

“They literally had to cover me in ice bags from head to toe”

After returning home following my colon surgery, I’d get infections so easily, that it felt like I lived at the hospital. Granted, I was happy to be home, but I knew that if a week passed without being in the hospital, I’d definitely be there next week. All of the nurses and other staff knew me by my first name. What I’ll never forget about those times are the 105 degree fevers I would get. It was scary, because they were very difficult to get under control. They literally had to cover me in ice bags from head to toe to reduce them.

“One night during the week without PN would be amazing. I might even be able to balance my personal relationships again”

I will always do my best to live a full, active life but the difficulty is finding the time to do it all. Reducing my dependence on PN would really change my current situation. Even lowering the volume of PN would help. If there were a treatment that could reduce my PN, then that might give me an entire day of my life back. One night during the week without PN would be amazing. Then I could actually do things during the week that other people my age take for granted like going out with friends or watching a ballgame at the stadium and not on my TV. With more time, I might even be able to balance my personal relationships again. That would mean the world to me.



Laura

Age: 47

All my life, I've cared for other people – my husband, my children, and even my patients in my work as a gastrointestinal (GI) nurse. So it was difficult for this caregiver to become the patient.

“It was tough accepting my diagnosis”

As a GI nurse, I saw how Crohn's disease could take away a person's quality of life. Then I learned it for myself firsthand as someone with the condition. And it wasn't easy experiencing what my patients had to endure. In the back of my mind, I always knew that I would likely be diagnosed with short bowel syndrome (SBS), especially considering the severity of my disease and the 17 surgeries I had undergone to remove parts of my intestines over the last 30 years.

“I felt so isolated from the world”

All those years caring for SBS patients helped prepare me for the dreaded day when I was diagnosed with the disease. But it never prepared me to actually walk in their shoes.

At first, I was on parenteral nutrition (PN) for 12 hours a day, seven days a week. In those early days on treatment, I felt so isolated from the world. I now am on PN three days each week for 10 hours a day and supplement it with hydration through an IV. I've learned to carry my nutrition around the house and even have hooks in the kitchen for my hydration, so I can at least get back a sense of my former self. Thankfully, I have been able to continue working a modified schedule, even though it's working with employees instead of patients. Because I work in a hospital, I am constantly aware that I'm at risk of contracting a serious infection. Although I do my best to avoid it, I usually get an infection at least once or twice a year. And because I need to be hospitalized, that means days and weeks away from the work I love.

“I still have dreams of one day getting back to a normal work schedule”

Watching my patients slowly deteriorate over the years has served as a reminder of what lies ahead for me. Since being diagnosed and put on PN, my greatest challenge has been remaining emotionally strong and positive each day – with my work and my family – in spite of my future. I still have dreams of one day getting back to a normal work schedule. But for now, I have to be content with working only three days a month.

“A treatment that may lower the amount of my PN would make a world of difference”

Being around other people with SBS has actually helped me brighten my own perspective. Every day, I am working harder to live my life to the fullest and am encouraging other people to do the same. While my dependence on PN has slightly decreased over the years, I am hopeful for the day when I can get more freedom from it. A treatment that may lower the amount of my PN would make a world of difference. It would mean being hooked up on treatment for two or four less hours each day, or even getting nearly an entire day back – to enjoy an afternoon with my family, an evening with friends, or maybe even someday, a day back with my patients as their nurse.



Gail

Age: 71

I retired 17 years ago ready to enjoy my golden years. After working for more than 40 years, and many with Crohn's disease, I looked forward to my new freedom – spending time with friends, taking care of my grandchildren, and traveling. I even had one last dream vacation planned back to Hawaii. But then I was diagnosed with short bowel syndrome (SBS) and all those plans were put on hold.

“No one really understood what I had to endure”

The reality of my diagnosis, and the necessary dependence on parenteral nutrition (PN), replaced my dream of a carefree retirement. I was devastated. At first, I was confined to my house, forced to receive 20 hours of PN every single day. Although my family and friends were there to support me, no one really understood what I had to endure.

“I cannot stay out too long because of my PN schedule”

In the early days of my diagnosis, the long hours and days on treatment left me feeling isolated and depressed. I have been able to reduce my PN a bit recently and am able to go out more with friends and family. But I cannot stay out too long because of my demanding PN schedule, which requires me to receive treatment seven nights each week for 10 hours at a time. And the strange looks I get when people see all the equipment I must carry doesn't make it easier. I'd love to go out to parties again, especially for New Year's Eve. Long holidays, however, are especially difficult. One Christmas Eve, the pump broke on my PN equipment. It nearly ruined my entire holiday.

“I haven't been able to truly accept my condition and treatment”

The lost hours, the broken plans, the canceled trips – they've all added up and really get me down. I haven't traveled by airplane in two years because carrying all that equipment through security and on the plane is just too much to handle. And besides, I'm too afraid of suffering a serious infection while far from home. But I am hopeful that one day I might regain some of my time and freedom back. A treatment that would give me back just a night or two a week would greatly improve my life. Maybe even one day, I can travel again.



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