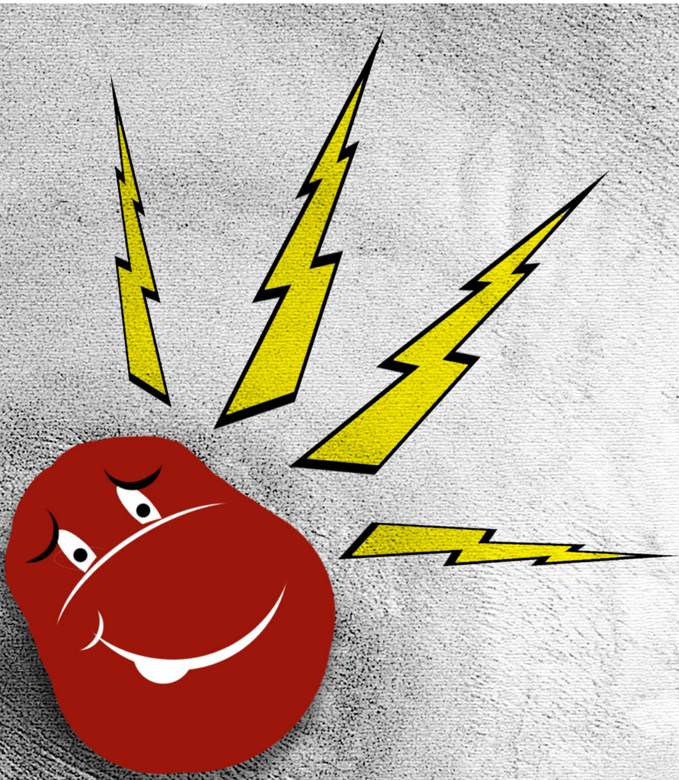
We Call Our Stoma “Sparky”

Survival tips for those who care for ileal conduit-ers



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We call our stoma Sparky.

Well, to be honest, I call our stoma Sparky. My husband, who’s the one with the stoma, was slow to the party. When I first dubbed that bright red, little bald-headed guy “Sparky,” my husband rolled his eyes. But eventually he mellowed, and now “Sparky” gets a little smile every time.

Smiles are worth their weight in gold.

“Sparky” worked for us because it was as ridiculous and incongruous as we could possibly conjure at the time. In retrospect, I probably should have given it a little more thought. The Red Baron? Little Pecker? Little Red Riding Cap? Anything for a laugh. Ileal conduits are tough.

Let me start with our back story, and then I’ll get to the survival tips that could prove helpful. (Skip to the back, page 22, if you want to get straight to the tips. I’ll never know.)

Tips and a checklist of items to have on hand, page 22.

Prologue

Our back story...

Every story is different, of course. I tell ours for any parallels that could be helpful.

My husband made it more than 70 years without seeing the inside of a hospital as a patient. Then, about four years prior to his bladder removal, he had a fairly routine procedure to remove a bladder stone and resect the prostate. Recovery was short but brutal. (Now I would have actually named the catheter — maybe something like Lucifer). Blood clots continued seemingly forever, and were met with assurances that that was a normal outcome.

The clots stopped, but when they started again, a few years later, my husband thought they were residuals from that earlier procedure. As a result, too much time passed before it was all checked out.

A routine annual urinalysis showed blood in the urine. Then came a speedy CT scan and a follow-up doctor's visit scheduled a week later. It's never good when the doctor calls the day after the CT scan and says he wants to see you right away. The scan showed multiple tumors in the bladder.

From there, the path was set. Because of my husband's extensive scar tissue from that earlier procedure, our urologist inserted a scope under general anesthesia in the hospital. The hope was to go in, see what was there, remove all the tumors, follow with chemo in the bladder if need be, and be done with it. No need to talk about other options so early.

That procedure was estimated to take about an hour. I was alone in the waiting room, by choice. (Tip number one: If people offer to keep you company, might as well take them up on it.)

By the time the second hour passed, I started to get anxious. It's possible I was freaking out. For dozens of others in the waiting room, doctors in scrubs came out and said things like, "He did great." Or, "Everything was perfect." Or, "She's absolutely fine." Smiles all around. After about two and a half hours our surgeon came out and said, "Let's go talk in the consultation room." Not good. Not good.

He said that when he went in with the scope, there were so many tumors he didn't even know where to start. He removed what he could. Most were "soft" and appeared non-aggressive. But there was one area, in the back of the bladder, that was worrisome. He tried to remove that as well, but it looked like it was extending through the wall of the bladder and he didn't want to risk breaching the lining, so he got what he could, and biopsied *what remained. Not good. Not good.*

I knew even then that nothing would be the same, but of course had no idea what that actually meant.

I called all the kids and my sister and brother-in-law, a retired urologist on the East Coast. He kept reiterating that removing the bladder was a last resort and there were all sorts of intermediate steps that could be taken.

The local surgeon told us to wait for the results from the pathologist.

Recovery from that procedure was duly excruciating. The catheter remained very difficult, and the pain from urinating through it was awful. My husband did not want to go through any more procedures that would require another Foley catheter.

The pathology report was not good: High-grade cancer, though there was no evidence it had breached the bladder lining or spread beyond it.

Now came the options. You had them too. The surgeon could go back in and try to remove the tumors that remained. Chemo or radiation could attack them. All the alternatives involved going back in with the scope, dealing with the post-op catheters, and still risking the cancer spreading.

My husband, age 76 at the time, was clear-eyed. He said if he were younger, he might have tried some of those intermediate procedures. But at his age, he just wanted the cancer gone. There would be a lifestyle change, but it would be a small price to pay to remove the need for future bladder procedures, and feel confident he was cancer-free.

Once the decision was made to remove the bladder, as you know, there were three options: reconstructing a new bladder from intestine, using intestine to create an internal sac, or directing the urine to an external bag. You'll hear enough technical terms from others. I'm giving you the lay version.

The external bag is the least aesthetically appealing, and has its own challenges, but it seemed to us to have the lowest risk of complications. At this stage of his life, my husband felt the least complicated and least risky procedure seemed best. He knew he could deal with the lifestyle option, despite having no idea what that actually meant at the time.

So that's how we arrived where you are, though you likely took a different path. It's helpful to know that the Bladder Cancer Advocacy Network (BCAN) has great resources and videos to answer your questions: www.BCAN.org.

Now for some tips...

Topics included:

You've decided on an ileal conduit. Now what?

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You’ve decided on an ileal conduit. Now what?

WE ALL HAVE ONE THING in common: Doctors, nurses and other professionals would tell us as much as they knew at great length, but in the end, despite their best efforts, we had no idea what was in store.

We asked questions, but didn’t know enough to ask the right ones. Will my husband need new clothing? No, the bag is flat and will fit under whatever he wears. For some reason, it didn’t occur to us that the bag would have to be changed every several days. We didn’t find that out until after the surgery. It makes sense. And it’s do-able. But these are some of many things that are helpful to know in advance. I’ll get to more in a minute.

* * *

Choosing a hospital and surgeon

CHOOSING THE RIGHT HOSPITAL and surgeon is far more critical for this procedure than any other step in the process. We were lucky.

The urologist who had taken care of my husband up to this point strongly recommended that we take the two-and-a-half hour drive to Los Angeles to have the surgery, where it would be done by a surgeon and a center that does this type of procedure on a regular basis. He gave us names of a variety of excellent doctors but said if he were having this done, he’d go to a name he gave us. “He’s a great guy, you’ll like him a lot, and you’ll be in the best hands,” he said.

We made the appointment to meet with that surgeon. While we were waiting in the office, the surgeon’s assistant came in to take some information, and we chatted. He said, “Where I studied, they do this procedure about 50 times a year. Here they do it 200-250 times a year.” We were sold. We wanted someone who had seen every complication, every variation, and someone who does this specific procedure on a regular basis.

That’s how we went with the doctor we were told was the best of the best ***at this procedure***. Having said that, we know of many patients who went to other hospitals and were extremely pleased with the procedures and excellent outcomes. You just need to be sure you are comfortable with your surgeon. Ask about after-care services and accessibility, which can prove critical and could be a factor in your choice as well.

Much later we talked to someone who had received his ileal conduit at a highly renowned hospital in New York City, performed by the chair of the urology department. The differences in procedures and post-op care would curl your hair, and the complications this other gentleman endured seemed to us to be unnecessary. He made the best choice possible at the time, and went with the urologist he considered tops.

Most important tip: Choose a surgeon who has done this procedure often, continues to fine-tune his practices, and has an excellent reputation. Make sure you feel comfortable with your choice. Our surgeon clearly wants to be considered the very best in this field and that’s a good thing because he has a vested interest in positive outcomes. Also, our center was a research hospital, so data on every aspect of the operation was gathered and important – pain management, length of stay in the hospital, outcomes, etc. If you have access to a research institution, that’s a consideration as well. Your success is their success.

* * *

Pre-surgery

OUR SURGEON RECOMMENDED taking very specific protein supplements a week prior to surgery to build up the immune system. The case of supplements was only available from the hospital. The hospital also provided us with special heavy-duty sterile wipes to remove bacteria from every portion of the body just before reporting for surgery. Ask your doctor about those if they aren’t offered to you. Every precaution helps.

We were instructed to visit the hospital a week or so prior to the surgery, where my husband was tested and evaluated and questioned by various departments and medical professionals, and measured for his eventual bag placement. The day ended with a class conducted by ostomy nurses. They are the best. The class was filled with good information, but it’s a lot of information to absorb. As a patient you truly have no idea what's in store. Keep in mind that the nurses are the best resource for your questions. They deal with the after care and have seen it all.

My husband had asked his surgeon if he would be able to go to a very important event about two months after surgery. (Full disclosure: this "event" was a cross-country drive to tailgate at a Rutgers football game, normally a highlight of my husband's year. Our kids fly in to join us. It's a big deal. But this year was going to be the biggest ever because it was the first year Rutgers was in the Big Ten and the first home game was against arch rival Penn State. We had lived in Pennsylvania for many years and it seemed like half the people we knew were either Penn State alumni, faculty, or fans, so a number of people were going to join us at this tailgate. My husband had been planning for it and looking forward to it ever since the schedule was announced, long before his diagnosis.) When he asked the surgeon if he'd be able to go, the surgeon said, "Two months after surgery?" Pause. "Maybe."

When we asked the ostomy nurses at the pre-surgery class the same question, their answer was: "He will definitely be able to go. But he won't want to."

One of my friends thought that was a cruel response because it dampened hope, but we saw it as exactly the opposite: helpful, encouraging, honest. First, we knew that physically he would be able to do it. But if he didn't feel like going (which seemed absolutely inconceivable), we would know that that was an expected reaction, not a catastrophic change of outlook and mark of despair. So remember: In the beginning, the patient will not feel like doing things he or she once loved. That will pass.

* * *

At the hospital the day of surgery

WE DROVE DOWN TO L.A. the night before surgery and stayed in a hotel because we had to be at the hospital at 5 a.m.

While being prepped for surgery at the hospital that next morning, my husband continued to crack jokes. As others were being wheeled out of our area and into operating rooms, he turned to one of the interns and asked, “Do they ever wheel anyone back in?” When they were about to give him sedation he pointed to me and said, “Give some to her – she needs it more than I do.”

Then they wheeled him out and I remember being quite certain nothing would be the same again. Little did I know how very much that was true. For one thing, he didn’t crack jokes again for a very long time. But now he does – so just hold tight.

I was told the surgery would take four or five hours. When it rolled into six and then seven, I became very anxious, but the updates from the nurses were all positive. This time my son from Phoenix was with me in the waiting room and that was hugely helpful. My daughter from the East Coast kept calling for updates. I sent texts to our other two kids, who asked to be kept up to the minute. Finally the surgeon came out and said everything went well and that my husband was in recovery. Exhale.

After what seemed like an eternity we were told my husband was in his room and we could go there. When we entered, my husband seemed to be completely out. Motionless. Eyes closed. My son said, “He looks pretty good.” I said, pretty loudly, “No he doesn’t.” A nurse came in at that moment and I asked when my husband might be awake. The nurse said, “He’s awake now. You can talk to him.”

He was fragile, weak, in pain. He couldn’t even bear the sound of my son and I talking to each other (conveyed by a finger to his mouth as in “shush”). His first words were “This is the hardest thing I’ve ever done.”

My husband was a high-level administrator. Seeing him in that state was devastating. Of course I knew he would recover and improve, but you have to prepare yourself for that first sight and for the patient’s reaction.

It turns out that even with his eyes closed, my husband kept seeing faces on the walls and the ceiling for his entire hospital stay, likely a residue of the anesthesia. He told me later he couldn’t even stand the smell of the room, though I smelled nothing. This period can be rough.

* * *

Hospital stay

I CHOSE TO STAY in the room with my husband for the entire time, in a chair that converted to a bed. I would do it again. I wanted to see what the nurses did and how they cared for him, knowing I'd have to do it very soon. If you make the same choice, be prepared to be sleep-deprived and stressed. I continue to think it was worth it.

In my husband's case, the pain was fairly well managed. They asked constantly how much pain he was feeling on a scale of one to ten. His always hovered in the 3 or 4 range, thanks in large part to a device our surgeon hooked up to the incision site that pumped pain relievers to the exact area that needed it most. That and the traditional painkillers kept the worst at bay.

Our initial urologist back home had warned us that many surgeons now keep patients as few as four days after this surgey. He told me that since we live so far away, I should make it clear I did not want to be discharged that soon. As I watched the nurses measure fluids from drains, help my husband walk, give him shots, I didn't need any convincing that four days was an insufficient time to put me in charge.

But my husband was dubbed a "superstar." He walked the day after surgery, with help. He was able to eat solid foods almost immediately. He had been a notoriously bad patient up to this point, but he was so determined to leave that hospital on time that he was willing to do whatever they asked of him. Medications helped him start the full digestive process on schedule, and his walking became strong and steady. When the occupational therapist came to evaluate him before release, she said he walked better than she did.

Ostomy nurses arrived to train me in changing the bag. Again, this was the first I had heard that that would be necessary. My husband's blood pressure had been high during recovery, so he was given diuretics to help bring it down, increasing the flow of urine. That made changing the bag a real challenge. The nurses calmly showed me what to do, and I knew immediately there were too many steps, too many parts, too many judgment calls. I wrote down what I was told, but still was pretty sure I could not do it. The written instructions they provided were only helpful if you already knew what to do. I was in a bit of a panic. I asked that they show me again the next day, and they did.

My confidence level did not rise.

Then my husband had a “picc line” inserted into his arm so that when we went home, visiting nurses could give IV fluids every other day for two weeks without having to insert an IV line every time. When they inserted that line in the hospital, the room was cleared and the man who inserted the line wore what looked like a white HAZMAT suit. The picc line goes into a vein that goes directly to the heart, so any lack of sterilization could be lethal. Great. I was not going near that thing.

I was also told that the little bulb still attached to a tube in my husband’s stomach was a drain that had to be emptied every few hours, and the fluids had to be measured and recorded until we returned for the post-op visit.

I would also have to give a daily injection of a blood thinner every day for 30 days post surgery so that my husband didn’t develop any blood clots. The sites of the shots had to vary each time: left arm, right arm, left stomach, right stomach, left hip, right hip. The shot had to be given at the same time each day, within a one-hour window.

I had never given a shot in my life. When our cat needed B12 shots, I took him to the vet every week, because I couldn’t even do that. When I was a little girl I had a long list of things I wanted to be when I grew up. Nurse was not among them. I was always utterly grateful there were others who very much wanted to do that. Thank goodness for all of them! All this is to say I knew there was no way I was going to be able to take care of my husband after only four days in the hospital.

Our surgeon always traveled with a large entourage of residents, so even though he was always approachable and attentive, talking to him with the others around could be intimidating. I decided to work on the resident and med student who were always nearby. I started early making the case for an extra day, assuring them I couldn’t possibly do what needed to be done. They kept saying it was up to the doctor.

On the morning of the fourth day, just before the doctor came for rounds, my husband, who was miserable in the hospital, made his first strong pronouncement: If the surgeon said there was no further medical reason for him to stay in the hospital, but if he had to stay because I made that happen, he would not forgive me.

So I popped a quarter of a Xanax (I needed to stay calm, but realized I was going to have to function well and drive the long drive home).

As a result, I was composed enough when the surgeon looked over my husband and said, "You're great. Good to go." Deep breath.

The nurses taught me how to give an injection. I asked to give my husband one in the hospital room while they watched, just to be sure. Practicing on a styrofoam cube wasn't going to do it for me. There was a ton of paperwork – more than you can imagine. Sheets for logging things. Instructions. Booklets. Prescriptions. Bags of supplies.

We had a caseworker who was setting up the visits from the visiting nurses and the apparatus for the IV fluids. There was some crazy issue with our insurance for the IV drip that took hours to resolve. We finally left the hospital at 3 p.m. On a Friday. In Los Angeles.

What should have been a two-and-a-half-hour drive took four. The nurses had failed to give my husband his final pain meds, so after an hour he started to get very uncomfortable and there was nothing I could do. He had a travel bag attached to his tube, so that wasn't an issue. We were both exhausted and happy to pull up into the driveway, a little before 7 p.m.

* * *

That first night home

ONCE WE ARRIVED HOME, my husband just wanted to go to sleep. Me too. Our bedroom is upstairs but we had agreed that we would sleep in a downstairs bedroom at first. The most immediate challenge was that no amount of pillows or blankets could get my husband comfortable. He was used to an adjustable hospital bed. He was physically miserable. It was our first crisis and it loomed large.

Then he thought of the reclining chair in the family room. It worked. It was a little small, but he could get comfortable enough to sleep that first night, and I could sleep on the couch next to him.

Major tip: **Prepare to use or borrow a recliner or rent a hospital bed.**

That next day, on the phone, my brother-in-law the urologist said, "Hang up right now and call a local company that rents hospital beds." Problem was, it was a Saturday and all the companies were closed for the weekend. When my son called from Phoenix and I told him about the issue, he searched online and found a larger reclining chair on Amazon that would be delivered quickly. Black would have matched, but it wouldn't arrive until Tuesday. A brown one would arrive Monday. I ordered it. It came in a large box and had to be assembled. My neighbor was happy to help put it together and I will always be grateful. I'm not good at asking for favors, but I learned.

Next early tip: Get a toilet seat extender. Hospital rooms have raised toilet seats. The act of sitting down onto a normal toilet seat just doesn't work right away when you've had this procedure because the muscles required to do it are not themselves. It can be very painful. I went to the drug store and bought the last toilet seat extender in stock. You can get that ahead of time so you don't have to worry about it during those first crazy days.

And they are most definitely crazy. It can be overwhelming. For the patient, at first, expect pain. Expect frustration. Expect despair. Try to keep firmly in mind that all these things are temporary and life WILL return to normal.

My husband was always accustomed to being in charge, to taking care of himself, to being strong. It was very, very difficult to be totally dependent at first, and it tore him apart to see me running around trying to do everything. But we made a pact that first day, when things seemed to hit rock bottom, that we were a team, in this together, and that he would do all he could do and I would do all I could do, and that's how we would get through it. Team Shelton. That worked for us; maybe it will work for you.

Another tip for how to get through: Keep lists, in two places if need be. You may think you can remember which medications were given at what time, and when it's OK to give the next painkiller, but things can get crazy and if you're like me you can be hard on yourself if you forget something. Lists are very very helpful – you don't have to worry about remembering. You just have to remember to fill out the list. I wrote down when the various meds had to be given (there are several and they are all on different sequences). I checked off when I gave an injection, and which site I gave it that time. I wrote down the amount of drainage, when the nurses were coming, which digestive aids were given, you name it. Lists everywhere. And of course you'll need shopping lists for food and supplies. Try to be efficient when you go out – your energy level is important to the patient as well.

Also: **Have hand sanitizers or hospital gloves everywhere and use them constantly.**

* * *

IV fluids

FLUIDS ARE ESSENTIAL. My husband was not great at drinking liquids, and it was a real struggle for him to fill his daily quota. Even with Boost and Ensure and soups and other liquids, it's hard to get enough down. (If your doctor didn't tell you this ahead of time, stock up on Boost or Ensure or whatever protein drink is palatable. Eating and drinking are tasks to be done, but can be difficult at first.)

Back to IV fluids: Our surgeon's office arranged for visiting nurses to come and set up the IV drip system every other day for two weeks. But the nurse wouldn't sit there for the hours it took to drain, and at the end of the process, it had to be disinfected, flushed, and disconnected. This is that line that goes directly into the vein to the heart, so it was a very scary thing to have to do. I wrote down the instructions carefully and followed them to the letter, but it was still worrisome. OK, terrifying.

Our IV apparatus wasn't working correctly and the first time it took more than eight hours to empty. Various nurses tried to fix that problem on subsequent visits until one finally did. Fortunately, she gave me her cell phone number in case anything else arose, and that was the day that the tube started to fill with blood. Turns out the fluids weren't draining down because the IV tubing was crimped at the top, and blood was coming out the arm instead to fill the vacuum. The nurse talked us through how to remedy the situation over the phone, and all was well.

So get a phone number, if you can, for a visiting nurse. I only used the number that one time, but it was a lifeline.

* * *

JP Drain

IF THE PATIENT you are caring for has a JP drain (a clear little rubber bulb attached to a tube that goes inside the abdomen and fills with fluids from the surgery), it has to be drained often. Be prepared to empty it and measure the output every several hours. There was so much to be doing that I sometimes forgot to write down the time and amount, especially in the middle of the night. Still, I tried as best I could to be as accurate as possible, assuming this was as critical as everything else being done. When we went for our post-op visit a week and a half after surgery, though, all that was needed was the daily total of fluid. Maybe if the totals fell outside some parameters, the other information would have mattered, but that wasn't the case. If you are tasked with doing this, ask beforehand what information is critical, so you don't have to stress about parts that are not.

* * *

Swollen areas

I WOULD WAGER THAT anyone who has casually and coarsely referred to someone as having "big balls" has no concept of what the real thing can look like. As I understand it, gravity pulls bodily fluids to their nearest, lowest point, and if you are a man who has had pelvic surgery, the point where fluids congregate is the scrotum. On my husband's third day in the hospital, when the ostomy nurse was showing me how to change the bag, she spotted the situation. "Oh – I wish they had… well, no matter, now we have to deal with this."

I don't know who "they" are, or what she wished they had done. There was no point in asking. But it was a BIG issue. My husband and I, had never seen anything like this, and joked later that any elephant would have been proud. Who knew the scrotum could stretch out to that size? Think enormous. It sounds funny in retrospect but at the time it was not a joking matter because of the heaviness, discomfort, and the heat. The ostomy nurse put crushed ice in a baggie, wrapped it in a washcloth, and placed it so that the scrotum was elevated. Much like elevating legs can relieve the swelling of ankles, elevation seems to help in this more sensitive spot as well. And the ice helped cool the heat. I honestly don't remember how long it took to return to a normal size, but we used ice for elevation many days at home – maybe as much as a week. Again, take heart. Normal size returns. And then you can exchange knowing smiles whenever anyone says someone has "big balls."

* * *

Daily shots

AH, THE SHOTS. OUR SURGEON prescribed a shot of Lovenox every day for 30 days to avoid blood clots. My husband told me that if I were the one who needed a shot a day he wasn't sure he could do it. I told him if my life depended on it, he would rise to the occasion. That's what I was doing — you do what you have to do. Every doctor I talked to beforehand said it was very easy to do and wouldn't be a problem. Maybe for you it won't be. For me, it was a real challenge.

The device itself is easy. Even the generic comes pre-dosed and disposable. You insert the needle, push down the tab on top, and when the medication discharges, the needle recedes immediately back into the tube and you dispose of it in a Sharps container. The visiting nurses all thought it was cool. (I had them do it on the days they came if it was the right time of day). My husband was a good sport. Sometimes I hurt him and sometimes I didn't. My technique was not ideal. The nurses all advised me to pinch a "good hunk" of skin before inserting the needle. One time I pinched too small a hunk, and the needle went clear through, squirting the medicine into the air. No dose that day. Believe me, I am not the one you want for a nurse. Still, I kept telling myself that as bad as I was, there had to be others equally challenged and yet their spouses managed to live through it. I actually told myself this several times a day. Day 30 was a happy day for both of us, because it was the final shot.

But — we later spoke with someone whose doctor had not prescribed shots after this procedure and the patient did end up back in the hospital with a blood clot, so the shots can be vital. You do what you have to do.

* * *

Diet and intestinal issues

MY HUSBAND WAS PLACED on a special diet in the hospital (called an “ostomy diet” on the menu) – basically, no raw fruits or vegetables or anything hard to digest. Everything else was fine. After two days I noticed he was given a tray with a normal diet. I asked the nurses their thoughts, and they agreed that it could be helpful to stay on the ostomy diet – it helps the digestive tract get through its trauma more easily, they said. I kept him on that diet when we got home, which was easy enough because he didn’t feel like eating much anyway. That’s where Boost and Ensure come in handy. He knew he had to eat to get strong, and his number one request for supper, amazingly, was halibut – bland, soft, easy to get down, no strong taste to deal with. He asked for cooked carrots, too. We both lost weight.

We were told it was OK to eat anything a week or so after surgery, but in my husband’s case, eating things more difficult to digest continued to cause problems, so we ended up staying away from raw fruits and vegetables for a few weeks more.

My husband ended up losing about 20 pounds. We were told it is not uncommon to lose up to 30 pounds. Though he tried his best to eat what was necessary, his appetite was weak and almost nothing seemed appealing. Soup worked best, and it was good as a fluid as well. It took several months until he was able to slowly gain back a pound here and there. His appetite increased and food started tasting good again. It took a long while.

Digestive problems are an issue after surgery. For sure. You will be warned about this, but not enough. Despite daily stool softeners and milk of magnesia, narcotic painkillers cause constipation and it can be terribly uncomfortable. We added prune juice, upped the milk of magnesia, even used some suppositories. It got so serious we were given a prescription for something stronger. As warned, once these measures finally start to work, they cause the opposite problem. Diarrhea can be very serious because it dehydrates you, which we were warned from the beginning is to be avoided at all costs. So then you deal with that condition, and bring back the constipation. Back and forth. Back and forth. It sounds like no big deal, but believe me it is a very big deal, especially when everything else is going on. Maybe it was a coincidence or the passing of time, but once we added Probiotics to the mix, everything leveled off. I would recommend using those from the very beginning. You want to be on as even a keel as possible, to minimize the discomfort. For us, Probiotics made the difference.

* * *

The bags

THERE ARE MANY MANY TYPES of ostomy bags. Our nurses had the ones they wanted to use; those were the ones we were trained on and those were the ones that were ordered for us. The size of the stoma keeps changing in the beginning, so it makes sense that there isn't a one-size-fits-all solution. But once you know the manufacturer of the bag, you can look online or call directly and ask questions. I found this out quite by accident.

My husband has a bad back and his one relief, and daily joy, had been soaking in a hot tub in the morning, with jets directed to the area of pain. He was resigned to never doing that again. I decided to call the manufacturer of the bag we were using to ask if they made any products that would work in a spa. To my surprise, they said, "Our products should work there as well. Try it privately first [as though we'd go public anyway!], but there shouldn't be any problem with the seal, even in hot water." They were right. Even our surgeon and his residents seemed surprised to learn that when I shared the information at our post-op visit, so it's good information to know.

But there were other benefits from that call. It turns out that the manufacturer – in our case, Convatec — has ostomy nurses on call at all times, and you can ask all sorts of questions. I don't call anymore, but I really took advantage of that phone number in the beginning. After conversations with those ostomy nurses, we experimented with several different types of bags – moldable, one-piece, two-piece, etc. We finally arrived at the one that was best for us. Big tip: Keep trying different types of bags until you find the one that works best for you.

The overnight bag is also important. We knew it had to be flushed with white vinegar every morning, but no one had told us, until I asked, that it should be replaced altogether every two weeks or so. Remember that there is a difference between the travel bag and the overnight bag. The overnight bag is larger and designed so that the patients can turn to either side without a problem while they sleep. It took my husband a while till he began using the overnight bag. He didn't like the feeling of being hooked up to it. But he was up several times a night checking to make sure his bag wasn't too full, so he finally decided it was better to hook up after all. Sleeping through the night is one of the major positive benefits of the overnight bag. No need to get up and go frequently, which had been the case prior to surgery. He'll still unhook it if he wants to get a drink or get up for any reason, rather than walking around with it. Whatever makes the individual comfortable is what you should go with. No one can make those calls for them.

* * *

Post-op visit

AFTER SURGERY, MY HUSBAND HAD several small tubes, called stents, coming out from his stoma and they remained when we went home. I had asked the scheduling secretary what to expect during the first post-op visit, and she said they would remove the picc line for the IV fluids, but that the stents and JP drain would stay one more week until the following visit. That was not the case. When we went for that first post-op visit, a week and a half after surgery, everything was removed – the picc line, the JP drain, and the stents. It was a very good day, made even more so because we weren't expecting it. The first step back to normalcy. It was actually amazing how different that made life right away. My husband was infinitely more comfortable – physically and psychologically — and I had less to measure and fret over. The first hurdle was passed, and things truly continued to improve from that point forward.

* * *

Ups and downs

WE HAD BEEN WARNED repeatedly in advance – by the surgeon, by the resident, by the nurses – that when patients get home, they can actually begin to feel stronger and more energetic somewhat quickly, likely from the adrenaline that's flowing, but there can then be a sharp drop in energy after that. The surgeon in particular stressed this is normal and to contact his office with any concerns. He said many of his patients assumed mistakenly that something was going very wrong and went directly to the nearest Emergency Room. He said ER staffs might not be familiar with the procedure or the recovery efforts, and could make decisions based on their best judgments without taking the needed factors into account. Don't worry if there is a dramatic drop in energy, he warned. This is normal. Clearly this is a major issue for many people, so be forewarned.

* * *

Hernias or bulges

HOPEFULLY, YOU WILL NEVER HAVE to deal with this, but we did. My husband developed a large bulge around his stoma a month or so after surgery. Now he wears a hernia belt that fits around the opening of the bag. The literature says that some people order the hernia belts as preventive measures. Think about it. Judging from the various questions we've asked, it seems like there isn't much that can be done about it. Surgery is an option, but apparently the hernias or bulges tend to come back regardless.

* * *

Clothing

AT FIRST, SHORTS OR LOOSE-FITTING sweats with elastic waists were easiest and worked best. I recommend having a good supply of those. Doctors and nurses were always asking us if we had any problem with leakage or breaking of the bags, and the answer was always no – until it happened. My husband wore normal pants with a belt to our first post-surgical movie. The way he was sitting, the belt of his pants cut off part of the bag so what remained filled quickly, and finally couldn't handle the strain. We had that problem one more time after that first incident. Since then my husband has been very aware of how his belt and bag work together. Sparky is located high, across from the bellybutton (and yes, it will return to being a bellybutton). Yours might not be high, so belt placement may not be a problem. We did order some ostomy underwear at first, but we've found it isn't necessary. Normal clothing works fine. If you're a swimmer or outdoors person, some of the ostomy underwear might work well — basically, the garment has a sleeve or pocket for the bag to stay put. It's worth a try.

* * *

Life a few months out

AS I WRITE THIS, we are eight months out of surgery and pretty much back to normal. ("Though normal isn't so great," as my husband likes to quip.) Let's call it the "new normal." My husband's weight is back to a good level. Having the bag has become routine for him, and changing it has become routine for me. You have to do some planning if you go away, and make sure you have all the supplies you need, but that too becomes normal, like packing your underwear or toothbrush. It's part of what you do. My husband considers the bag a small price to pay for being alive, and is happy to be free of the discomfort he had beforehand. His attitude was remarkably positive from the very beginning and I do believe that made a big difference, and helped me stay positive as well.

We never did get to that first Rutgers Big Ten game against Penn State. It was true, as the nurses had warned us, that my husband did not want to drive out for it. But all the kids and grandkids came from near and far, along with some friends, to "tailgate" under a scarlet canopy in our backyard, so it was even more fun – all the festivities without the long drive. We've traveled since then, and all has been fine.

There's no easy way through this healing process other than just to get through it. But I'm told that our story is pretty typical, so I can assure you that you WILL get through it, and life will be back to normal. Believe me, if I could do this, you can do this. We are all — patients and care-givers alike — amazingly resilient. Even our new buddy Sparky agrees.

* * *

Tips

1. If people offer to stay with you in the waiting room, might as well take them up on it. You might think it's better to handle it all alone, but the moral support can prove very helpful.
2. Choose a surgeon who has done this procedure often, continues to fine-tune his practices, and has an excellent reputation.
3. Ask about pre-surgical nutritional supplements and sterilizing wipes.
4. Prepare to use or borrow a recliner or rent a hospital bed when you first get home.
5. Have shorts or sweats with elastic waists on hand.
6. Have a big supply of Boost or Ensure or whatever protein drink the patient likes best.
7. Get a toilet seat extender.
8. Keep lists, in two places if need be.
9. Have hand sanitizers or hospital gloves everywhere and use them.
10. Get a phone number for a visiting nurse, if you can find one that doesn't mind being called.
11. When you first get home, expect pain, frustration, despair. Try to keep firmly in mind that all these things are temporary and life WILL return to normal in time.

12. Check out the Bladder Cancer Advocacy Network website at http://www.bcan.org/. Also, the BCAN Connection is a helpful information line and the Survivor2Survivor connects new patients with those who've been through it: 1-888-901-2226 ext, 207.
13. There may be ups and downs in attitude and energy level. Dips are normal and not cause for extra concern.
14. Try and try again several types of bags until you find the one that works best for you.
15. Change the overnight bag once or twice a month.
16. Try Probiotics for digestive problems (in addition to stool softeners and milk of magnesia).
17. Ask your doctor if a preventive hernia belt is a good idea for you.
18. Ask for help when you need it. People don't know what to do and are happy to have some concrete way to be useful.
19. Remember that time is your friend, and you WILL both return to normal living in a few months.
20. Name that stoma, preferably something ridiculous, so you have the upper hand. You'll view it differently forever.

* * *

A checklist for stocking up before surgery:

- ☐ A good supply of hand sanitizers or hospital gloves
- ☐ A toilet seat extender
- ☐ A reclining chair or a rented hospital bed
- ☐ Loose-fitting sweat pants
- ☐ Priobiotics, milk of magnesia
- ☐ Boost, Ensure, or whatever protein drinks are preferred.
- ☐ Soups and liquids
- ☐ White vinegar

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“Sparky” is filled with helpful recommendations and tips, covering ...

- You’ve decided on an ileal conduit. Now what?
- Choosing a hospital and surgeon
- Pre-surgery
- At the hospital the day of surgery
- Hospital stay
- That first night home
- IV fluids
- JP drain
- Swollen areas
- Daily shots
- Diet and intestinal issues
- The bags
- Post-op visit
- Ups and downs
- Hernias
- Clothing
- Life a few months out

Praise for Sparky

“This book is full of important information and sprinkled with humor making it a must-read for all patients who will require similar surgery.” — **Michael B. Fisher**, M.D., Founder and Director, Santa Barbara Diabetes Resource Center

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