



Morgan Stout:

Now I would like to turn it over to Darrell, to talk a little bit about his experience with a parastomal hernia.

Darrell:

Thanks, Morgan. Thanks, Dr. Poulouse. So I noticed the hernia starting probably within the first year. And since that time, I've lost a bunch of weight, so when you mentioned overweight being a factor, that kind of lit a light bulb in my experience. And as I continue to lose weight, the parastomal hernia seems to have increased, and now there's a definite dome. There's very little pain, or there's an occasional pain that I do experience usually when I'm lifting something, or right after I've lifted something. But it doesn't really bother me, and I don't seem to notice any challenge with the flow of urine through my urostomy or any problems otherwise. I did wait for my doctor to approve even going back to the gym, but I had stopped... I had minimized working out prior to my cystectomy and as again, I was overweight and I had neoadjuvant chemotherapy, so energy was down, so I did kind of limit working out then as well. At the beginning, I started looking at the hernia belt, what I found was that... I currently use a Stealth Belt regularly, and I think some of their experiences, it definitely does assist in relieving or supporting a hernia. And my urologist says that many of his patients use Stealth Belts as well. So in a nutshell, that's kind of my experience with a parastomal hernia. I think there are others that may have a bit more pain.

Dr. Poulouse:

Thanks Darrell, thanks for sharing that. I think that story is a really compelling one. And again, congratulations for all you've been through. And it's one of those things that I can only imagine having undergone what you've gone through, and then thinking about all the things about taking care of the cancer, and now you got to deal with this. And I think it came up in the chat too, that maybe we should be more informative of our patients, when you have these discussions about doing these operations about some of the potential ramifications of having the ostomy and having hernias. Because I think, well, kind of what you're getting at this point in your care, this is the thing you're dealing with. And so knowing about that beforehand, I think we do a poor job as surgeons informing our patients of these kind of ramifications. And we're working on addressing that, and building more of an awareness around this. I do thank you also, for sharing your point about the weight changes and how it impacts things. I'm curious, as you lost weight, were you able to notice the hernia more?

Darrell:

Yes.

Dr. Poulose:

And how long did you say have you had the hernia for?

Darrell:

Probably four years and I just celebrated five years since my cystectomy.

Dr. Poulose:

Wow. Congratulations.

Darrell:

Thank you.

Dr. Poulose:

That's great. And it's a situation like I was describing, not ideal of course to have the hernia, but if it's not causing a lot of symptoms and you're not having much leakage and certainly it's not impeding the urine flow, that's an okay situation. And unfortunately, there are a lot of surgeons out there, especially hernia abdominal core surgeons, who may recommend to someone like you, "Hey, why don't we go ahead and fix it?" I would strongly advise against that, mainly because it's not an ideal scenario, but we know that if you go in and fix it, you can often change it to more of a bigger deal when the hernia comes back, which we know it will come back at some point, when your situation wasn't that bad to begin with. You just got to be careful about when to do the surgery itself.

Darrell:

And that's been kind of the discussion that my urologist and I have had. That if it's not bothering you, let's wait because it is, again, major surgery to repair it.

Dr. Poulose:

Yes, exactly. And I would definitely agree with your urologist. It's one of those things where you just got to be careful before you make that recommendation to do the operation.

