

Part 3: How can caregivers help when their loved one needs bladder removal?

A graphic for a webinar series. It features a dark grey rectangular area on the left containing white text, and a white rectangular area on the right containing an orange sunburst logo. The text on the left reads: "Patient Insight Webinar Series", "Enhanced Recovery in Radical Cystectomy: Exploring The Caregiver Experience", and "Brandon Sterling, PhD, APRN, AGACNP-BC, CCRN, CMQ".

Patient Insight Webinar Series

Enhanced Recovery in Radical Cystectomy: Exploring The Caregiver Experience

Brandon Sterling, PhD, APRN,
AGACNP-BC, CCRN, CMQ

Patricia Rios:

Thank you, Brandon, for a fabulous presentation. You really took us from understanding what the enhanced recovery programs are and the pre/post, during surgery, very comprehensive to also sharing information about your research. In fact, one of the questions in the chat is if we can share a link or reference to your study because it sounds really good. So we'll try to get that from you and send it out. So thank you for sharing that with everybody, and also for helping us promote some of the resources we have available on our website as well as the Inspire platform. For those of you that are listening, if you haven't had a chance, please check out the chat. In the chat, we have some of those links like the Inspire platform as well as other resources. And we'll continue to put them in the chat throughout the remainder of this webinar.

I also want to encourage you if you have any questions for Brandon to go ahead and use the Q&A feature. And with that, I'm going to transition to some of the questions that we got from the audience, Brandon. One of them comes from this gentleman who says, "What specific questions, and of whom, should a prospective cystectomy patient ask in order to find a provider and team who will follow an enhanced recovery program?" Part one. And part two is, "Is there a widely accepted set of ERP guidelines and roadmaps and assessment criteria?"

Brandon Sterling:

Yes, that is an excellent question. So in my experience, typically it's the larger academic medical centers, they are the ones who follow enhanced recovery. So I want to say large academic medical centers, MD Anderson, Sloan, Dana-Farber, Mayo, they all tend to follow those guidelines. Now, if you want to ask your team specifically, I would ask them, "Hey, here we are about to do the surgery, is your focus on enhanced recovery? Do you know what enhanced recovery is?" And that could be a deciding factor in you having your surgery at a community hospital versus going to a larger academic medical center, because a lot of it is just resources. You have to have the resources to really implement the enhanced

recovery. And then, oh, excuse me, from a provider standpoint, not only do you have to have the urology team on board, but you have to have the anesthesia team on board.

You have to have the patient care units on board, because it's a whole movement. Because back in the day, the nurses would just give narcotics like it was candy. So when I first started in my role at MD Anderson, that was actually an issue where the nurses would just do what they'd always done. So it was more so of me having to reeducate the unit staff like, "Before you give that narcotic..." Well, after a while, we just removed it from the post-op order, so you didn't even have access to it. But it was a lot of education, a lot of collaboration between all of the different disciplines.

And then in regard your question of if are there published guidelines? Yes. You can actually Google scholar enhanced recovery, radical cystectomy, and there are a plethora of articles that are available to you to really examine each of the elements. Now, I didn't go into the minute details and drug classifications. I really did a broad overview, but I will say that those patients who have their surgery at a center who does enhanced recovery, that like I said, they will tend to have decreased hospital stay, they will have decreased narcotic use.

They tend to have decreased readmissions because they already have the resources and the communication platforms in place to talk to the teams, if needed. Because in my eye, in my purview, if we can get you into the clinic before you need a readmission, that's where I would rather you be. Do we need to bring you in to give you a small infusion of saline to stabilize you and hydrate you before sending you to the emergency room? That's the key. That's the goal.

Patricia Rios:

Thanks for answering that. And I want to transition to a topic you covered around empowerment of the patient. So this question came up, "How do you encourage patients to learn to care for their own stoma or bags? And is it generally better for the patient to do it themselves?" As you mentioned, many caregivers offered to help, but what happens if a bag needs change and the caregiver isn't around?

Brandon Sterling:

Yes. I actually had many caregivers in my study reference this. And they were like, "Well, it's kind of on this timeline." So once you're at home that first few days and they're acutely recovering from surgery, it's like, "Oh, yes, I'm here. I can help." And then they slowly transition to where it's like, "Okay, we've now discovered the size of the stoma and this is the size of the stoma it's going to be for a while. So here are the scissors, and now I want you to cut it and now I want you to do this task." And a lot of them basically detailed how it was a transition period. And it got to the point where it's like, "Well, it is time for a stoma change, so I'm going to watch you."

So again, it all goes back to that teamwork and just having that unsaid understanding like, "Yes, I'm here to help you, however, you have to learn it on your own. That way you can be independent." And the patients, they said kind of pushed back from time to time, but once they got that idea of, "Oh yes, maybe there will be a day you won't be here with me." Or, "I have to do distance travel." Or, "I want to go biking." Or, "I want to do an activity independent of you, so I do need to eventually learn it for myself." So that's actually an excellent question.

Patricia Rios:

Thank you, Brandon, I also liked that you talked about rehabilitation as part of the enhanced recovery program. Could you talk a little bit more about that role throughout the different phases, post-surgery and what they should be looking for in terms of patient? And what if that's not offered? What kinds of tips can you provide to the patient so they could take advantage of that service?

Brandon Sterling:

Oh, that is a great question, and prehab... Okay. So the thing is, once you make all your appointments, and this is very true of MD Anderson, it's almost like all your appointments have to align perfectly for you to be seen in all one day. And maybe that PM&R professional may not be available to you. We get a lot of patients who are out of town, so it then becomes... It's like, "Well, we depend on you to do your own activity." And I always would tell patients, "Just think simple."

Again, we don't expect you to go out and get a gym membership. We don't expect you to go start CrossFit. And when it comes to increasing activity, you can start by walking to your mailbox and back. Okay, you've met that milestone and you feel comfortable. Okay, well let's do it twice. Okay. Well, now let's go walk to the stop sign. So it's all about your personal ability and safety. Okay, safety, safety, safety. There is no expectation for you to start doing box jumps or dead lifts, what I was doing when I injured myself. You have to use common sense and you have to do what's safe.

And unfortunately, given again, the resources of that facility, you may not have access to do the prehab, but just keep it simple and just do things that are within your physical realm. No need to go above and beyond, or go crazy to injure yourself. And then you just continue that same program after surgery. And one thing that I would really like to highlight and I want to mention is sometimes it's the small ones, just you drinking that shake, "I couldn't tolerate a full shake yesterday, but I drunk a full one today." Or like I said, you being able to walk down at the end of the driveway, "I couldn't do that before because I was too uncomfortable." So accept the small wins. And then like I said, just think smart, think safe, and do what you need to do to recover and make sure that you of course, consult with your team. Because again, we don't expect you to go out running marathons pre-surgery, or post-surgery.

Patricia Rios:

I love that. I love the celebrating those small wins and taking one day at a time. So our focus today is around caregivers, and I think those on the call are here because they have a loved one. But what about those individuals who are not as fortunate to have someone living with them or close to them? What other resources are there to set them up for equal health outcomes as those who have someone living at home with them?

Brandon Sterling:

Oh, that is a great question and that is one of the biggest challenges we have in healthcare. Because sometimes it's not that they can't help, they just don't have the time because they have to work. If I could wave my magic wand, I would advocate for all caregivers to be compensated some type of way. Because ultimately it's a full-time job and it's a full-time job you can't leave because they live with you, in certain circumstances. But in the case that you are single or you don't have support, that's when it's a great team, you need to voice that immediately to your surgery team. And then they can get a social

worker in because depending on the benefits you have available to you, they can get someone to come to your home and check on you. Or you can have an in-person caregiver that can be provided through different resources and different volunteer organizations. So the big thing on that is just making sure you communicate that to your team. And that would always be one of my three questions. Do you have a home? Do you have a ride? And do you have food?

Patricia Rios:

Thank you for covering that. I think that is sometimes things that we take for granted. I would say that on the BCAN website we have a list of support groups. And I want to encourage, if you haven't had a chance to look at that, to browse and find a support group near you. We have our female focus support group once a month, and that information is there as well as Inspire. So those who are a little bit isolated, don't feel that way. There is support and plenty of resources available to connect you to what's available in your community. And we have run out of time, and with that, I have one last question for you, Brandon, to close us off. Are there any thoughts, last comments that you want to share with our listeners as we talk about this topic of enhanced recovery program and caregivers?

Brandon Sterling:

I just would want to leave you with, if you can inquire about the existence of enhanced recovery program. Because remember, many teams aren't explicitly calling it enhanced recovery, they're calling it my outstanding surgical journey. But you can still inquire about the elements just to say, "Hey, I heard about this enhanced recovery, are you doing it?" And then when you look at it at a granular level, they'll be like, "Yes, we're doing this, but we don't actually call it that." And then as far as the caregivers, I just wanted to say be encouraged because you are one of the pillars of the care provider team. And as I was saying about the eye test, you are the first line of defense to keep your loved ones safe in the home environment. Because as much as I love my patients, and as much as I love taking care of them, I can't be at your house, so we depend on the caregivers.

And just if your gut is telling you something isn't right, you should definitely reach out to the team and advocate and then leave it up to us to take it from there. Because one thing that I've always leaned on in my experience as being a nurse for it's like 16 years this year, is I would always ask the caregivers, "Well, how did they look to you? How do you think they're doing?" And that was always a cornerstone because sometimes they'd be like, "Oh, they're looking great." And it would be my first time meeting the patient, I'm like, "Oh, well if this looks great to you, then okay, we look great." Or they would be like, "They don't look so good." And I was like, "Hm, I was thinking the same thing, so let me go in my tool bag to see what we can do to figure out what's really going on." So just be encouraged, know that you're not alone, and again, use those BCAN resources as you go through the surgical journey with your loved one.

Patricia Rios:

And that is an excellent way to end today's webinar. Brandon, thank you so much. We're so fortunate to have you with us today. Thank you for everything that you're doing for our bladder cancer community. Thank you again for joining us, and we'll see you next time.

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