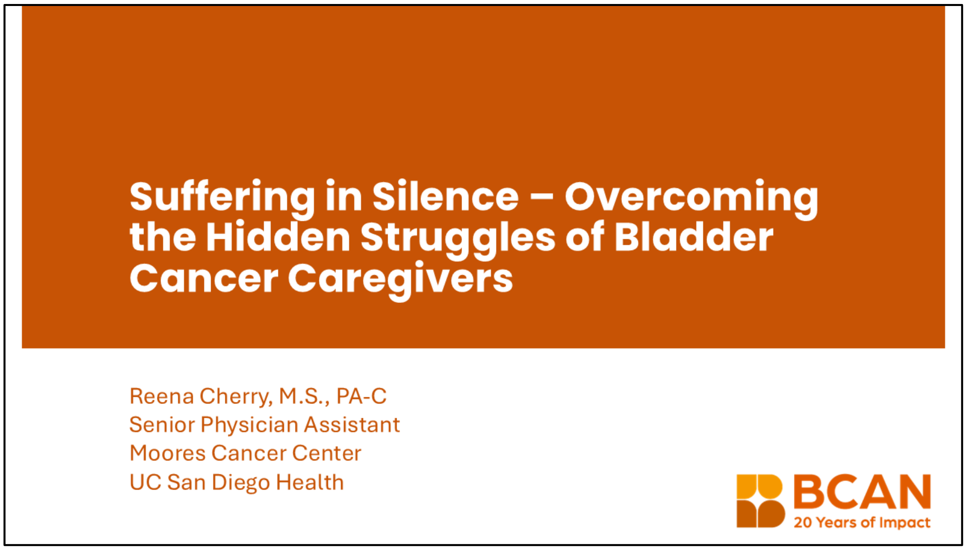
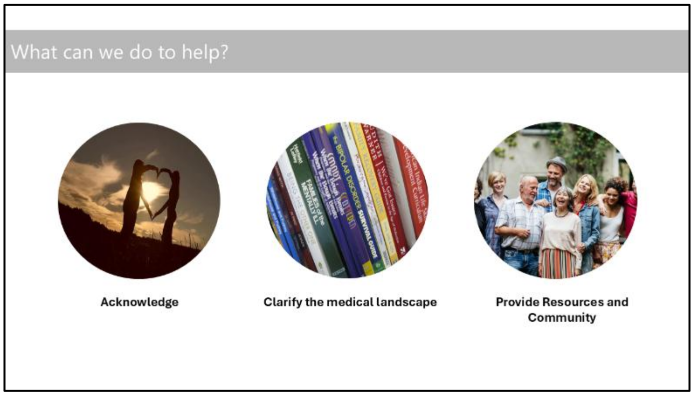


Suffering in Silence – Overcoming the Hidden Struggles of Bladder Cancer Caregivers

Reena Cherry, M.S., PA-C
Senior Physician Assistant
Moores Cancer Center
UC San Diego Health

BCAN
20 Years of Impact

Reena Cherry:



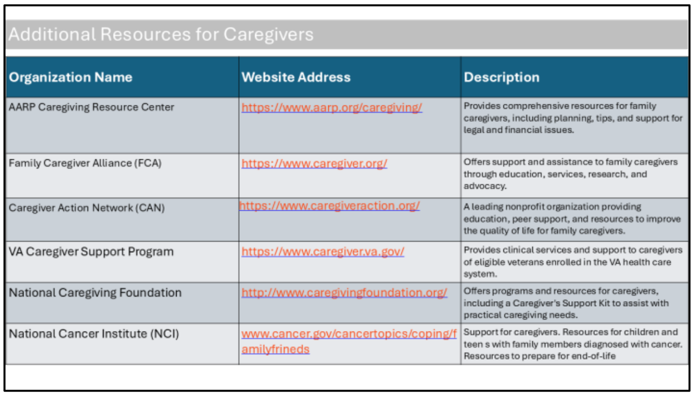
What can we do to help?

All right, what are some of the tangible ways we can help? The first is that we have to start addressing and acknowledging caregivers, and we have to acknowledge them with intention.

Now, clinically for, for us, that means not sweeping caregivers up into what's happening with a patient. Caregivers do, they tend to get swept up with a patient, so we walk into a clinic room, we talk about you know, the treatment, we ask how the patient's doing, we review the treatment plan, and the caregiver does get swept along in that. We have to address caregivers with intention and I'm going to take a minute or two to share with you how I do this, um, with caregivers. If I have a 30-minute slot to see a patient, I usually use about 28 of those minutes and those minutes are directed towards the patient. And then I do a couple of things that I think are very critical. The first thing I do is I look at the patient and I say, "Mr. Jones, would you mind if I address your wife directly for one or two minutes?" 100% of the time, patient will say yes. That does two things. One, I have asked the patient permission to use a couple of minutes of their clinic time in order to speak directly to the caregiver. I have also done this in front of the caregiver, so now the caregiver knows we have permission to talk and they can take up a little bit of space. And then the second thing I do, and I think it's the most important, is I will look at the caregiver, I typically scoot a little bit closer to the caregiver, I do intentionally, um, enter their personal space, not to freak them out, but I want to get into their personal space, and I look at them and I ask, "How you doing?” And almost 100% of the time that I do this, the caregiver will start to cry. Now they can tell typically by the look on my face and the tone of my voice that I already know they're not okay. So, now they don't have to put on airs. They don't have to pretend like everything's fine, “it's fine, we're fine, everything's fine,” they don't have to do that. I've already opened the door because I've suggested to them with my voice and my face and getting close, "I'm pretty sure you're not doing okay." And then I will ask them, and the way that I ask is, "If I had a magic wand and I could wave that magic wand and make just one thing a little bit better for you, what would it be?" And caregivers can very quickly, typically, start to talk about the one thing that is bothering them the most, and we can talk about that thing in one or two minutes, and my goal as a clinician is not to solve all of their caregiving problems, it's to take the edge off of the one thing that's really kinda keeping them up at night. The one thing that's really nagging at them. And it is my intention when I do this that that caregiver leaves that clinic room feeling seen. And that I think is really the crux of acknowledgement. It is interacting with a caregiver in a way that allows them to know we see them. So that's acknowledgement.

The second is clarify the medical landscape. Usually we talk at the patient and at the caregiver about side effects. What I try to do in clinic spaces is to talk about side effects and, and give the appropriate information about what to expect, but then I will also, and again, intentionally turn to the caregiver and say, "This is what it's going to look like for you. “And then I will talk about the, the side effects from their lens, through their lens, from their perspective. "Yes, you know, your husband is going to be moving through immunotherapy. Here's what it's going to look like for you. Probably going to be a pretty, pretty easy caregiving lift. Here are the things that I really want you to focus on. Don't worry about all the other things." And I do that with chemotherapy or I do that with radiation, but I intentionally talk about the side effects through the lens of the caregiver, and that helps them really understand where they're going to need to really be intensely involved, when they have an opportunity to fall back and maybe take care of some other tasks for their other family members or, God forbid, for themselves. Um, so talking about side effects and how the treatment's going to look through their lens, I think, is really critically important. And then lastly, we have to provide resources and a sense of community for our caregivers.

Reena Cherry:



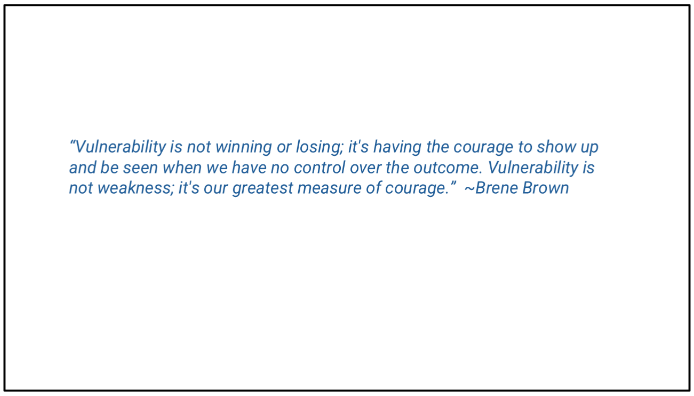
Additional Resources for Caregivers

Organization Name	Website Address	Description
AARP Caregiving Resource Center	https://www.aarp.org/caregiving/	Provides comprehensive resources for family caregivers, including planning, tips, and support for legal and financial issues.
Family Caregiver Alliance (FCA)	https://www.caregiver.org/	Offers support and assistance to family caregivers through education, services, research, and advocacy.
Caregiver Action Network (CAN)	https://www.caregiveraction.org/	A leading nonprofit organization providing education, peer support, and resources to improve the quality of life for family caregivers.
VA Caregiver Support Program	https://www.caregiver.va.gov/	Provides clinical services and support to caregivers of eligible veterans enrolled in the VA health care system.
National Caregiving Foundation	http://www.caregivingfoundation.org/	Offers programs and resources for caregivers, including a Caregiver's Support Kit to assist with practical caregiving needs.
National Cancer Institute (NCI)	www.cancer.gov/cancertopics/coping/familyfrineds	Support for caregivers. Resources for children and teen s with family members diagnosed with cancer. Resources to prepare for end-of-life

This is a list, it's not a comprehensive list of resources where you can go and find specific information that you're looking for with respect to caregiving. Um, you'll notice at the top I have the National Alliance for Caregiving, which is, I want to say it's an extraordinary website, so, um, uh, different categories. So there are people caring for people caring for uh, people over the age of 50, um, gen X, uh, caregivers, LGBTQ caregivers, um, African American caregivers, Asian American caregivers, so they, they've broken this down into many different categories so I think every caregiver can find themselves in the information that they have, and I think it's beautifully organized. But, but there also, obviously, is a whole laundry list of other resources that you can find online.

And as we close, um, I want to acknowledge that caregiving is... It's extremely vulnerable. One of the hardest things we will do as human beings on this earth is to take care of another human being that we love who is sick. And caregivers often feel so vulnerable and I want to change our mindset about vulnerability and Brené Brown, once again, knocked it out of the park and I'll try not to cry when I read this because I cry every time.

Reena Cherry:

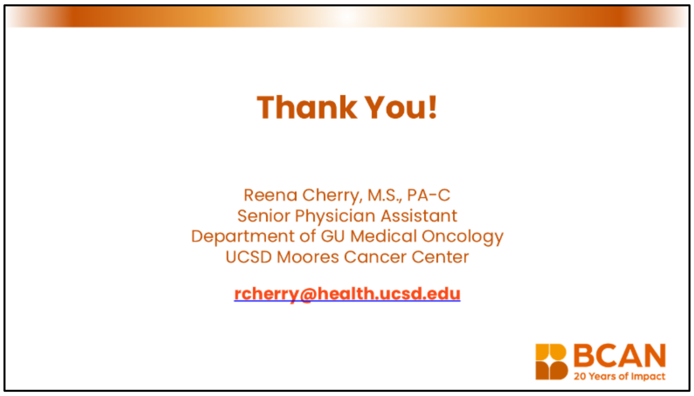


"Vulnerability is not winning or losing; it's having the courage to show up and be seen when we have no control over the outcome. Vulnerability is not weakness; it's our greatest measure of courage." ~Brene Brown

Here's what she had to say about vulnerability. She said, "Vulnerability is not winning or losing. It's having the courage to show up and be seen when we have no control over the outcome. Vulnerability is not weakness; It's our greatest measure of courage." So to all of the caregivers out there, thank you, thank you, thank you, for all of the extraordinary work you are doing to support our bladder cancer patients. You do have a community. We are here to support you and we truly, truly appreciate and value you.

Reena Cherry:

Thank you so much for your time.



Thank You!

Reena Cherry, M.S., PA-C
Senior Physician Assistant
Department of GU Medical Oncology
UCSD Moores Cancer Center

rcherry@health.ucsd.edu

BCAN
20 Years of Impact

SPONSORS:

MERCK
INVENTING FOR LIFE

natera

UroGen
Pharma

BCAN
20 Years of Impact