“An Engaged Caregiver” (Rochelle Prosser, RN, CLNC) [#101]

Brad Power
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“As a nurse, I was the one to do the caregiver services. Having to be that person to navigate their care, knowing that there isn't any treatment available at the time of their diagnosis. I needed mental health services, but nobody offered it to me. They just assumed that because I was a caregiver, I didn't need to have that struggle, I didn't have those issues that regular caregivers go through in terms of finding quality and balance in life.” – Rochelle Prosser

“Some of the behaviors that you see are because of the drugs. It's not that your loved one has changed, it's the drug that you're dealing with, and how to communicate best with that person while they're in that event. It's looking at it with a different lens, without blame.” – Rochelle Prosser

Meeting Summary

Family members can make a huge difference in the outcomes of the care of their loved ones.

How can you be an effective caregiver for your loved ones? What does an engaged caregiver look like?

Rochelle Prosser, RN, CLNC, founder and CEO of Orchid Healthcare Solutions, the Prosser Cancer Library, and founding member of the CancerX Moonshot, is uniquely qualified to be a role model as an exceptional caregiver to help family members navigate their care. She brings a special combination of (1) a professional background as a nurse (30 years), (2) her role as a caregiver to family members with cancer, and (3) her knowledge of data science. Rochelle spent 15 years assisting multiple family members through harrowing cancer journeys. Her daughter was diagnosed at age 4 with a rare brain cancer. The standard of care had a very low success rate, so Rochelle did the research and pioneered an alternative treatment. After 10 years, her daughter achieved remission this year when most patients with a similar diagnosis don't live past 12.

Rochelle created Orchid Healthcare Solutions to give back and help vulnerable populations and communities of color navigate their oncological journeys so they have the care and resources she had to fight so hard to find. She didn't want anyone else to have to go through what she went through. She offers an approach to cancer survivorship, a software platform, and a decision-support system for clinicians. She works with her patients and doctors, often explaining treatments to doctors that they may not know about. She also sits on a federal council on health IT.

What are the challenges that caregivers to cancer patients experience in navigating the care of their loved ones?

Caregivers to cancer patients face all the challenges that patients face:

- **Knowledge to participate in care decisions**: Lack of knowledge about the disease and testing and treatment options, access to trustworthy sources of information
- **Treatment selection and access:** Access to therapies (off label, reimbursement), acute care in cancer treatment; managing comorbidities along with the cancer
- **Effective communication with healthcare providers**: knowing what you need to let the doctors know about, overcoming reticence to honestly share what you are experiencing
- **Administration:** Navigating the complex and dis-integrated medical and payment system

Caregivers also face unique challenges:

- **Emotional distress and anxiety**: helping their loved ones overcome fear, trepidation, concerns about altered body image, the impact on relationships – for example, overcoming a family history where going into the hospital means you may walk in, but you're coming out feet first; maintaining a marriage with the stress of cancer
- **Finding mental health resources** (for the caregiver, as well as the patient)

What can you learn from Rochelle Prosser’s experience as a very knowledgeable caregiver in navigating cancer care?

- **Get mental health support as a caregiver**: There are things that you have to negotiate within your marriage, within your parenting style, within civil engagement, with this individual who has cancer. Some of the behaviors that you see are because of the drugs. It's not that your loved one has changed, it's the drug that you're dealing with, and how to communicate best with that person. It's looking at it with a different lens, without blame. Most people don't know what to say when a loved one or a friend is diagnosed with cancer. There are tools, such as game cards to help the conversation, mindfulness tools, and tools to help your loved one get off the couch.
- **Manage side effects aggressively**: Exhaust all resources to stabilize the patient, then get restorative treatments
- **Search for quality care**: No two cancer centers are equal, and no two community centers are equal. What you will receive in these settings is based on the pharmacy formulary that they have contracted that will allow you to have access to treatments and therapeutics.
- **Explore financial sources**: There are plenty of resources out there at the government level that are not being shared. No one should have a seven figure medical bill. If you're 65 and older, they pay you while you have cancer. It's not a death benefit. You don't have to be disabled to receive it.
- **Step back as a caregiver**: Let your loved one be in the driver’s seat of their care.

What should you do?

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- Review the personal experiences of empowered and engaged caregivers and patients, like Rochelle Prosser, to provide guidance on your journey
- Work with your providers to make sure they understand your needs and priorities
- Connect with Rochelle Prosser for discussion about support options as you navigate your care decisions, especially if you are a caregiver

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Meeting Notes

KEYWORDS

caregiver, daughter, drugs, patients, doctor, cancer, brain, prostate cancer, treatment, husband, nurse, surgery, knew, child, rochelle, room, journey, tumor, brain cancer, dealing

SPEAKERS

Rochelle Prosser (74%), Jeff Dwyer (14%), Brian McCloskey (6%), David Plunkett (3%), Brad Power (3%)

SUMMARY

Cancer patients and caregivers face challenges of managing cancer treatment and survivorship, such as needing emotional support, mental health resources, and effective communication with healthcare providers. Advocacy, access to quality care, and support systems for both patients and caregivers are important solutions. The personal experiences of caregivers and patients can provide guidance, for example, working with your providers to understand your needs and priorities, personalizing your care, and seeing examples of empowered patients and caregivers and interdisciplinary collaboration and knowledge sharing.

OUTLINE

Cancer patient experiences, navigating treatment, caregiver struggles, and relationship dynamics.

- Rochelle Prosser shares her personal journey as a nurse who became a caregiver for two cancer survivors, her daughter with a rare lung cancer and her husband with metastatic (stage IV) prostate cancer.
- In 2007-2008, her husband received tamoxifen and anthracite for prostate cancer, with a 100% cure rate after 3 doses.
- In 2014, her husband was diagnosed with a prostate cancer recurrence, which had metastasized to his bladder, despite previous treatment with vincristine and carboplatin.
- Her daughter was diagnosed with incurable brain cancer at age 4.
- Her daughter received similar treatments to her husband, including carboplatin and Temodar, but failed quickly due to increased brain swelling.
- Her husband was diagnosed with aggressive prostate cancer at the same time, and they had to navigate his fear, trepidation, and altered body image while also dealing with the impact on their relationship.

Cancer treatment challenges and a mother's emotional struggle.

- She describes challenges of caring for a child with cancer while also working as a nurse.
- Her experience as a neural trauma ICU nurse helps her advocate for her daughter's care.

- She requests drugs to sedate Kayla, but becomes tired and her 10-year-old son takes over.
- Her children babysit Kayla while she sleeps, despite her volatile emotional state due to medication.

Mother's 15-year journey as a caregiver, nurse, and advocate for her daughter's rare cancer treatment.

- Rochelle Prosser shares her experience with alternative medicine.
- Her husband needs surgery, but the doctor pushes it to September, causing concern for his health.
- Her daughter underwent various treatments, including an experimental drug that had promising results.

Brain cancer treatment and care, with a focus on interdisciplinary knowledge and replicable clinical programs and cancer treatment disparities.

- Rochelle Prosser describes how her experience caring for a daughter led to the development of replicable clinical programs in chronic disease management.
- Her work with the National Institute of Health resulted in the adoption of their COVID outreach program.
- She reveals her experience of the variability between cancer centers and community centers.
- She advocates for access to resources and government protections.

Cancer survivorship, caregivers, emotional support, and mindfulness.

- Rochelle Prosser discusses inadequate emotional support for cancer patients and caregivers.
- Caregivers need to understand and communicate with loved ones undergoing cancer treatment with empathy and patience, recognizing their changed state due to drugs, and avoiding blame.
- David Plunkett shares his experience with anger and emotional changes due to prostate cancer treatment.
- Rochelle Prosser emphasizes the importance of mental health support and community organizations for cancer patients.
- She shares her personal experience with communication challenges between patients and doctors.
- Her husband struggled to understand medical terminology, leading to frustration and a need for education.
- Her husband was hesitant to discuss his medical concerns, so she took steps to help him become the driver of his own care.
- She reflects on the challenges of being a caregiver, including not being afforded the opportunity to simply be a wife or mom, and the need to rebuild trust in her relationships.

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Prostate cancer treatment options and challenges.

- Jeff Dwyer shares his experience with prostate cancer, including his journey with radiation treatment, and his personal struggles with comorbidities and drug side effects.
- He seeks advice on managing end-of-life care and finding adequate care and support for his cancer treatment.

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TRANSCRIPT

Brad Power
Welcome to another meeting of the Cancer Patient Lab. This is a weekly series where we have honored guests who lead us in a discussion. Today that's Rochelle Prosser. I'll introduce her in a minute.

This is not medical advice. This is for information purposes only. We try to arm people with information they can take to their medical team.

We are a patient-led, all volunteer community, and we would welcome any donations of time or money.

A quick intro to Rochelle: Rochelle has an amazing story of her cancer journey with her daughter, husband, and father. She's a nurse by training, and she's been in the patient navigation space for some time, helping people navigate cancer and applying the lessons that she derived from her experiences as a caregiver to her daughter and husband, as well as her nursing background. She is based in Miami Gardens, Florida.

Rochelle Prosser 2:01
I am the spouse, mother, and daughter of cancer survivors. My husband is a two-time cancer survivor of lung and prostate cancer. My daughter is a long haul cancer survivor in brain cancer. In total, it has been 15 years that I have dealt with direct family involvement with cancer, as well as now I am navigating my father who has been diagnosed with metastatic stage four prostate cancer to the bone, the lungs, the heart, and the lymph nodes. It is rather devastating news. But he's still around. He's still kicking. OJ Simpson recently passed away, and my father is still trucking along. It is due to certain medical technology advances that are available, but he is in a different country, and is not afforded all that we are able to have here in the United States. Navigating that minefield for oncology tourism is something I never thought that I would be in. But here I am today dealing with that.

My journey began with my husband. At the time they were giving tamoxifen and anthracicline for lung cancer patients way back in 2007 and 2008. There was this wonderful new treatment coming out with vincristine (chemotherapy), carboplatin, and cisplatin (platinum-based drugs), that had a 100% cure rate after three doses. We had to make a choice very quickly after having a lobectomy to remove the actual cancerous portion of his tumors of his lung cancer and decide whether we should go at it at a stem cell level. Or do we just say, “Take the win. He's had the surgery. He should survive.” The data showed that even though you did the lobectomy and had the surgery, you still had a resistance rate of about 67% to 80% in African Americans, so we chose to go ahead with the platinum-based drugs. After three doses, he was fine. That was in 2008.

We got to the five year mark, and in 2014 he was diagnosed with prostate cancer, which is one of the secondary cancers that can evolve from platinum-based cancers. The other ones are retinal disease or a retinal detachment in the eye. But at the time, we didn't know that that was a possibility because no one knew what these drugs and their side effects would hold. When I looked back at his PET scan, you could see it right there. His whole bladder lit up like a glow worm. It was so bright, it overshadowed his prostate. But at the time, it was hot too. I'm not sure if he had a single source, or he already had metastatic disease when we treated his lung cancer, but the vincristine and carboplatin certainly helped to delay the symptoms of his prostate cancer. He had adenocarcinoma of the prostate, which was extremely aggressive. The only option he really had at the time was surgical removal, because the immunotherapies that were just coming through bore out that it didn't work in the African American population. There just wasn't enough evidence at the time to say that that was a good choice. They already knew that the radiation treatment didn't work with African Americans, because at the time, they were doing Gamma Knife and photon beam. What people needed was proton beam radiation. That wasn't even developed in 2014.

He didn't tell me that he had prostate cancer in January of 2014. My daughter was diagnosed in March of 2014, just after she turned four, with primal myxoid astrocytoma of the brain. We always wondered if that was a fallout from him, from my husband receiving platinum-based chemotherapy, which we now know, it wasn't. It was truly just a fluke of the germ cell development of the brain. But we know this now, but at the time, I had a lot of parental guilt in saying, “My husband took this treatment, and maybe we had children too soon. Maybe we did something wrong.” I lived with that a lot, knowing that my four-year-old was diagnosed with this incurable disease that was through the optic nerve. It was in all the cellular regions of the brain. It was in the third ventricle of her brain. It went through the pons, which is the brainstem. And it went through the hind. All of the organic growth, very vital centers of where your brain development occurs, that's where her cancer was.

We found that it was 12 centimeters around. Maybe if you put two grapefruits together, you might get to 12 centimeters, but that's an average of the size that I can think of. She also had metastatic disease going down her spine. She truly wasn't going to survive.

I had to rely on everything that I knew in neuro-trauma ICU, to get her through that, because acute care in cancer just doesn't exist. Whether you're in a community center, or whether you're in a cancer treatment center, they just don't do that well. That's one of my pet peeves that I really am striving today to fix. There's this notion, “Let's let it simmer there for 72 hours, and if they're still alive in 72 hours, then we're going to do something.” That is just abhorrent and wrong. I truly believe that just because you have a terminal illness does not mean your life is terminal, or expendable. We should exhaust all resources to intervene to stabilize you, because once you're stabilized, then you can receive restorative treatments.

About a month after my daughter came out of the ICU, the doctors basically sat me down and said, “We went to all of the people you told us to talk to, and they told us to listen to you. You have a long term history with some of these docs of 20 years. Basically they do everything that you say. I have my pen, and here are my notes. Tell me what to do, and we'll do it.” That's how I started my cancer journey with both of my family members, my husband and my daughter. I was the expert in the room. As a nurse, I was the one to do the caregiver services. Having to be that person to navigate their care, knowing that there isn't any treatment available at the time of their diagnosis.

I needed mental health services, but nobody offered it to me. They just assumed that because I was a caregiver, I didn't need to have that struggle, I didn't have those issues that regular caregivers go through in terms of finding quality and balance in life. I was still working and practicing as a nurse at the bedside. Because the treatments my daughter had, which were very similar to my husband, she received carboplatin, vincristine, and then something else called Temodar (temozolomide, an oral chemotherapy medication for brain cancer). She became neutropenic very fast, which meant that I could no longer practice at the bedside and bring home anything to her. It was too risky.

I had to reinvent myself in the midst of trying to maintain healthcare insurance, maintain employment, and maintain a roof over my family's head. We had two other children at the time that were older.

Conventional treatment failed my daughter very quickly. The Temodar caused her to have increased brain swelling. We had to stop the clinical trial after the first 30 days. We ended up at St. Jude's.

That was the time when my husband told me he had prostate cancer, which was May. He knew in January. My daughter was diagnosed in March. He told me in May that he had adenocarcinoma of the prostate that was extremely aggressive and showed me the pathology reports and had me talk to his oncologists who were quite upset at him for not doing something about it. But I understood where he was. In his family history, when you go into the hospital, you may walk in, but you're coming out feet first. That was his history of his family's access to health care. That is not our normal now. But that's what he knew, coming into the healthcare system. I had to deal with his fear. I had to deal with his trepidation. I had to deal with his alteration and body image and machismo and being that virile husband that he's supposed to be for me. We had to talk about how our relationship would be after this process and come to an agreement on that. That it's okay. That was when I was 42. He was 15 years older than me. Being that young, he knew the implication it would be for me. He was worried about having a marriage after his surgery. Is he going to have a spouse that's going to be there? I had to assure him I was not going anywhere. But those conversations don't come easy. Most often, your marriage is disrupted, especially if you have a child added into that mix of having cancer.

I had to choose who I was going to help. Of course, I helped the four-year-old. Off we went to St. Jude, Tennessee, from South Florida. I had to leave my husband behind, taking our older children with us, who were 10 and 12 at the time. It was hard.

I found myself realizing that in cancer centers, even in pediatric centers, they have an outpatient model, which is now called the “hospital at home,” or “parent place”, where they give you treatment. You go to your respective room, whether it's at Ronald McDonald House or “the delta center”, or whereever it is that your accommodations are, and you care for your child. You cook for your child. You provide meals. However, if your child needs inpatient care, or has to go again into an ICU, they literally didn't have enough staff to manage that.

When my daughter went into total organ failure during that time, and she was unresponsive, and she just had vital signs, it was really hard. I brought her in and said, “If you give me a bag like a flight nurse, so that I can manage her IV, I can keep her pressures up, and I can get her to the morning. I prefer her to be in the hospital. But it looks like you're not going to admit her.” They said to me, “As a neural trauma ICU nurse, we know who you are. Her best chance of survival is keeping her in your care.” I said, “This is not happening again.” They said, “No. I need you to understand. We read the notes. Your prior oncologist is really mad at you, but what you're doing is right. We're going to overlook that and rely on your experience. We have this bag over here that you're talking about. Just tell us what orders you want. We will make sure the drugs are in the bag. Before she leaves, we will put her in your care. If she's still here in the morning, we will start to do another plan.”

I sat there. I had my two older children standing right there watching this. I could not show emotion. I could not tell them verbally how I really felt. I had to be the parent and the caregiver and the person with the answers for my family. I asked for all these things just to make sure that I could keep her pressure for her heart and and maybe some additional pressors to make sure that her blood flow to her brain would continue. I asked for heparin (blood thinner), just in case I discovered she had a clot. Just some things to keep her going until morning.

What ended up happening is I got tired, and my 10-year-old son had to take over. The drugs made Kayla very volatile emotionally. She was trying to break out of the room and run out. My two other children were like, “Mom. Are her number stable? We can babysit her, but you need to sleep for an hour. You just need to sleep. We understand what's going on. But if we run into a problem, we will wake you up. But it's three o'clock, and you need to sleep.” We took turns and Kayla was running laps in the room because she was on epinephrine and all these other drugs as a four-year-old. She was also on dexamethasone (a steroid). If you have an idea of what dexamethasone does to a person, she is just not who she is.

She survived. By the morning, she was eating and drinking, downstairs causing all kinds of trouble with the room staff. Our appointment was at three o'clock in the afternoon. By the time we got over to the three o'clock in the afternoon appointment, I had disconnected most of her IV fluids, and she survived. The doctor came in, and he said he couldn't believe it was the same child because she was talking. She was walking. She had control over her bodily functions. She was fine. He said, “I don't know what you did. I'm not going to say I don't care what you did. But I hope that you wrote down what you did, because someday someone is going to come up to you and ask you, what did you do to save this child's life? And you need to say this to the rooftops because what you're doing is throwing conventional medicine on its head without surgery, without doing debilitating things, and she will be fine. I knew that if I put her in your care she would be fine.”

After that we stayed another two months. Then we went home.

In July my husband needed surgery. He refused to do it until I got back. On my way home, I called his doctor's office to schedule the surgery. They had pushed it all the way to September. I said, “How long do you normally let patients with aggressive adenocarcinoma of the prostate sit?” They said, “We usually take it out within two weeks.” I said, “It's been three months, and now you're pushing it out to September. I don't think he's going to be here if we wait until September.” She said, “Well, frankly, ma'am, he won't do it until you come home.” I said, “I'll be home. This is Thursday. I'll be home Monday morning. Can we schedule it for Tuesday?” She's like, “No. We'll schedule it on Monday.” I said, “No. I have to put my daughter back on chemo. I have to get there Monday at seven o'clock to get her on her chemo. Can we do this Tuesday? Her life depends on her chemo as well.” I explained to them that I was in Tennessee, and she said, “Okay. We'll do it for Tuesday, six o'clock in the morning, but you have to be there.”

I drove from Tennessee to Miami. It took me three days to get through because my daughter was so critical. She had her chemo. The doctor apologized to me for putting me through that and said I was right, and he would follow what I had to say.

The very next day I had to leave my daughter in the care of her brother and sister to have my husband have a prostatectomy. Then we came home.

My daughter's journey took 10 years. It finally ended when we went for a second opinion to Memorial Sloan Kettering in 2018 and her VP shot failed. On the tip of the shot was four tumor cells from the inside of her tumor that they told me was dead, which it wasn't.

They sent it for replication to Survive, and only one had her full molecular DNA panel. Because medical technology had advanced, we found a new gene, an FGFR gene, that was never recognized before. It's a growth inhibitor. They flew me off to Paris to get this experimental drug W1347. I brought it back. I sat in an IRB review for humanitarian purposes to give it to my daughter. By the time we got through that, she was blind, incontinent, and nonverbal again. We gave her that drug. It broke her bones.

We found out that she had cancer through every cell of her body, from the hair on her head to the soles of her feet and the nails in her feet. She literally lost the melanin in her skin because that's just how much cancer she had in her. But it cured her at the molecular level.

We still had that massive tumor in her head to deal with. That FGFR became the drug classifications of imatinib, which you now hear in brain cancer. Selamatinib is the latest iteration. We started that.

We noticed that we weren't having enough participants there that were people of color or Hispanics. I worked with Memorial Sloan Kettering to bring girls in there, bring black kids in there, black girls and boys, and then expand the population to now that particular humanitarian trial is now a clinical trial. Stage 1, 2, it's almost at stage 3.

The new Selamatinib release is doing a lot of good in brain cancer now.

This is where my story ends. I know it's hard to hear. It's a 15-year journey. We have life dates of 7/15/2014 and 4/18/2014.

Brian McCloskey 24:58
Thank you so much for that overview of your journey.

If you had the time, have you thought about writing a book about your journey?
Because it's really remarkable, as a caregiver, as a mom, and as a nurse.

Rochelle Prosser 25:33
I've had some book offers from some publishers. I didn't have the time. It'll take about nine months from soup to nuts for me to do it. It's just finding the time and making the time to tell the story.

I'm trialing this AI feature that is called “StorilyAI.” You may have seen some posts of me asking people just to try it out. It asked me questions, and then you answer it. You can either put it to voice, or you can do voice-to-text, or you can just type it in. I'm starting to use that now as a tool to help me record the story. But it is dramatic for me. I have to get past the mental health aspect of it as the caregiver, as the wife, as the nurse, to be able to share it in a way that you can hear it without hearing the tears.

Brian McCloskey 26:37
It’s a remarkable story of perseverance. Incredible.

It's really interesting how you were given full authorization to provide drugs in these hospital settings where you weren't practicing.
Tell me about that.

Did you have to sign liability waivers? What did that look like?

Because that seems very unusual. I don't think I've run across any doctors that would even entertain that. We have patients or citizen scientists that are pretty smart about their cancer. But just turning over the keys of the car to the patient is pretty rare.

Rochelle Prosser 27:40
Because of my level of understanding and what I was doing, and the amount of years I've had in it – by the time I was meeting some of these doctors I was almost 25 years in neuro trauma ICU. There really wasn't much that they could tell me. Also, I was working with the doctors that partnered with the NFL and Joe Robbie for the Miami Dolphins. They would come in and have devastating head injuries. We would have to do protocols to preserve the brain, to preserve the spine. The things that I had learned to do and the skills that I had learned to do, I was at such a

higher level, that it was higher than what the oncologist and those skilled in acute care would even understand.

If I could explain it today, if you hear some of my podcasts, I talked about how in these brain cancers we really ought not to do surgery because these tumors actually develop its own new Cradle of Life for these neurons and they develop Astrocytomas, astrocytes, dendrites, and poligocytes that are neuronal-like, but not actually perfect. The more that they move out from the center of the tumor, the more normal they are. They can create new pathways within the brain. We as healthcare providers disrupt this by doing surgery. There is a neuro fold where these brain cells are developed. In cancer patients, in these young children, that neuronal fold ends up turning into a tumor, and then it's adding to this Cradle of Life section. We are actually disrupting the whole propagation of neural cells and neural pathways.

My understanding of the brain is at such a nuanced level, that they quickly realized, after having a conversation with me, that I was my daughter's best keeper. There was no one else better than me to care for her, especially in those acute hours.

Brian McCloskey 30:19
Because you have so much interdisciplinary knowledge, how are these best practices being codified into protocols and being used on a larger scale?

Rochelle Prosser 30:45
While she was going through remission, and all of the journeys, I started working with the National Institutes of Health, not by choice, just by happenstance. COVID allowed the best and the brightest to come and develop tools and develop assessments. When I looked at it from that lens and said, “How can I best protect my daughter, and still meet the confines of work, no longer being at the bedside, but still providing clinical programs that people can replicate?” That's how I had to go.

The National Institutes of Health picked up my COVID outreach program because the company I was working for, we were the only ones that could get into post acute centers, skilled nursing centers, because we put in place an outreach program to call the patients directly on their cell phones. When they shut everything down and locked the doctors out, my nurses were still going strong. I took that from my daughter's journey in saying, “When there is nothing, when you're dealing with a scarcity mentality, how do you make progress in that space?” That's the lens under which I create all of my clinical programs. They're replicable in cardiology, in primary care physician spaces, and now oncology, but really, it is chronic disease management. I bring that because I dealt with understanding the body plus knowing that the brain can be injured too. I really have an in-depth knowledge of how the body works. I bring that to any patients or physicians that I encounter.

Brian McCloskey 32:48
What's interesting is that you have knowledge of brain cancer and prostate cancer. Here at the Cancer Patient Lab, we help patients with prostate, brain, and pancreatic cancers. We've

learned that there can be knowledge shared across cancer settings that may not be very well known. That's a benefit to what we offer.

I'm curious what you have learned about the similarities between prostate and brain cancer, where there are these “aha moments” about, “I learned something in one of these settings that can be applied to another setting.”

I'm curious if you've run across those instances?

Rochelle Prosser 34:09
I learned that no two cancer centers are equal, and no two community centers are equal. What you will receive in these settings is based on the pharmacy formulary that they have contracted that will allow you to have access to treatments and therapeutics. There's a municipality component to it, based on your zip code, on what the municipality will even pay for, even when the hospital says “Yes” or “No.” That's under the 340E program which has been in place for perpetuity, but it's set as a safety net. Based on your zip code, your municipality will dictate what care you can receive, or whether you can travel out of your county, your zip code, or your state.

I had no idea. I was literally taking my child anywhere. I felt like the sun. I've been everywhere. I literally was that person in that post office, but it was a cancer for the cause, cure for the cause journey. I didn't realize that I was setting up networks and ecosystems, not just for the cancer centers, but also for the community centers to expand their treatments. Because if nobody knows what you have, it gets shelved prematurely, or maybe we don't know the full gamut of the side effects that it could cause and even know it's helpful to somebody else as an adjacent treatment. But if we don't put a mitigation plan in place to identify what those treatments are, and what it causes in comorbidities, meaning, does it give you high blood pressure? Does it give you urinary stasis? Does it give you GI upset? Those types of things become chronic diseases after you survive, which is added stress in the survivorship realm, and added cost to a family or an individual that has exhausted the resources. I had no idea. These are the things that I learned.

I also learned that there were plenty of resources out there at the government level that are just not being shared. I put it as part of my program to provide that to patients. If you contact me, I will give that to you. Because no one should have a seven figure medical bill. I was in it for 10 years. That's just for my daughter. I could have sold everything, which is what they want you to do. They want you to sell everything, liquidate your assets, liquidate your 401Ks and 403B's, liquidate your stocks and bonds, and all of those things. But you actually don't have to.

Brian McCloskey 37:24
There are government protections them against that?

Rochelle Prosser 37:27
Correct. If you're 65 and older, they pay you while you have cancer. And no, it's not the death benefit. It's real money. You don't have to be disabled to receive it.

Brian McCloskey 37:39
It would be over and above anything that you might be receiving from an employer?

Rochelle Prosser 37:44
Correct. As long as you're 65 and older.

David Plunkett 37:56
Are you seeing any improvement in emotional support for both patients and for caregivers? Is that getting any better over time?

Rochelle Prosser 38:11
I honestly thought there was no program for emotional support for caregivers and patients because of the big public outcry that is happening now from physicians, to nurses, to patients. Apparently, there was something there. It was woefully inept because they didn't understand that cancer survivorship is part and parcel and should be thought of at the beginning of treatment, not at the end. In the end, you've missed all of these opportunities.

There is a reconstruction going on in mental health, and who it should be applied to. Unfortunately, it's just not being done well. I've started talking about it more often and saying, “If the shoe were on my foot, what were the things that I could have used?” Then sharing that publicly and saying, “Do you feel the same?”

There has been such a groundswell that I'm having a conference in August to talk about oncology mindfulness, because it's different from just mental health. We can go to our spiritual advisors, and they can talk about mental health and prayer and all of these things. But when somebody is terminally ill, there is an actual governing body called palliatology (palliative care) that we don't discuss. It's not psychiatry. It is helping with death and dying, dealing with the loss of a loved one, caregiver, or the loss of themselves. It's a whole different framework than just going through Freudian egos. Most times people don't even know what to say when a loved one or their friend is diagnosed with cancer. Having that proper support. There are tools, little game cards to help the conversation, little mindfulness tools to help your loved one get off the couch or just accept that, they brush their teeth, that's halfway there.

Some of the behaviors that you see are because of the drugs. It's not that your loved one has changed, it's the drug that you're dealing with, and how to communicate best with that person while they're in that event. It's looking at it with a different lens, without blame. It's equating it to smoking cessation, and saying that because tobacco has nicotine, and nicotine is extremely addictive, you literally cannot blame the smoker for smoking, because they're an addict. It equates that to oncology. The drugs that they take change who that person is, the person who you met and fell in love with is not the person that is standing in front of you after a cancer treatment, and they may never be that same person again. There are things that you have to negotiate within your marriage, within your parenting style, within civil engagement, with this individual.

To be a child that's coming through this, they have a sense of lack of control on top of everything else. How do you parent that? You are hearing the seven sides of Sybhil (of “The Exorcist”) coming out of this child. It takes a different lens. It's more than just being patient. It's a level of understanding that this person has been through hell, and they probably have PTSD (post-traumatic stress disorder). The best way to handle it is not by yelling, screaming, and shame. I hope that helps.

David Plunkett 42:22
I can certainly sympathize with a lot of that. I've been on ADT (androgen deprivation therapy) for a number of years now. I've recognized some changes in my emotional landscape. I am much quicker to anger than I ever was before. I'm also quicker to tears, but anger is what I have the most trouble dealing with. For me, the hard part is learning to deal with it, not through isolation, but through other, more active means. On the other hand, in practical terms, I am a lot more careful when I get out on the road. What I don't want to get into is road rage. It's an ongoing process.

Rochelle Prosser 43:13
With that traveling 32 hours to try to get to New York with a dying child in the back, I practiced road rage a lot, so I can totally understand.

Brian McCloskey 43:26
If you try bipolar androgen therapy, you definitely don't want to get anywhere near a highway or road. And dexamethasone (a steroid), for that matter. That's an evil drug.

Rochelle Prosser 43:47
This is why I say that in cancer, it really takes a village, and it's a village of specialists, not just the oncologist that you're dealing with. You need those ancillary specialists, the mental health specialists called “a palliotologist”. You need your community organizations.

David, I would encourage you to go find, “I Love You, Man.” That's an organization you might want to find. They're really great. They're specifically for men, and it's only for men. You might have some kinship there to help you with the anger issues and self acceptance of where you are having prostate cancer.

If you're just not yourself, there's a certain thing that you want to do, and sometimes it works and sometimes it doesn't, and that really changes the dynamic in your relationships, whether you're married or not. You have to negotiate that. You have to talk about it. You've got to bring that person in. Sometimes their answer is, “No”. When that answer is “No”, that takes an emotional toll on you.

We have now been married 25 years. I wouldn't say that it was a beautiful marriage, because 15 years of it is dealing with cancer. It was very difficult, whether it was with him alone or with him and our daughter. We had very differing ideas on what cancer treatment should be. The most glaring moment was when the doctor came up to me with the paper and the pen, and asked me what to write down, and my husband was like, “He's up to no good. Obviously, you can just cut it out.” I was like, “You cannot cut out the person's brain stem. You will kill them.” It just wasn't sinking in for him. I started talking and said, “Okay. We're going to do an osmotic drip. This is the rate we're going to do. We're going to put a brain bolt in at this diameter and put the catheter to this extent. My husband turned to me and said, “Who the F did I marry?” I was like, “You married a smart person. But you really need to stop talking now, so I can tell this doctor the right thing.” There is a whole dynamic that we had to “come to Jesus” with. Although I'm not a doctor, the doctors respect me.

David Plunkett 46:41
I've experienced it a little bit from the support side as well, when my grandmother was going through kidney failure. She would have a consult with a nephrologist, or her cardiologist, and they would say, “Well, how are you doing? What's new?” She would reply, “Oh, I'm fine. Nothing new.” I’d look at her and I say, “Tell the doctor what's been going on. This happened, and that happened, and this happened.” It's very hard to get a patient to overcome that reticence.

As a patient, I have experienced that myself, and I have to talk myself through, “This is what I need to let the doctors know about.” There's still an existing need for mental support and education for patients. It's hard to get them to do that.

Rochelle Prosser 47:28
More of it is the person that's in the room (the caregiver), while they're talking to the doctor, they don't want to hurt you. They don't want to hurt their loved one that's in that space. Or maybe they're going to talk about something while that individual is in the room that they did not want to share with their family member, or maybe they're talking about their family member themselves.

I had to stop going in the room, and I made an agreement with the physician, that if something really concerning happened, I would either contact him about my loved one, which is my husband – I'm talking about my husband here – or he would contact me. In order to make my husband get out of that fear, I had to put him in the driver's seat of that. If he forgot to talk about it, I made another appointment and had him write it down, put it in his phone, put it in his wallet, put it in places where he would remember to go to it and take it out. “Okay. Yeah. I wrote that down. Here are the questions.” I had to help him become the driver of his care.

I do that with my daughter right now, now that she's 14. I do that with her now to be the driver of her care. If we're going to talk about sex, I leave the room. Because as a mom, I really shouldn't be in that conversation anyway, other than saying, “She needs to be on birth control”, or “We want to have a family planning strategy.” “Okay, endocrinologist, take it away from there.” She can make that relationship and say, “I'm comfortable with this person”, or, “I'm not comfortable talking with this person”.

My husband shared back with me on that was, “Hey. Can you stop calling the doctor? You're calling the doctor, and we're bringing up things that I hadn't even considered, and it makes me uncomfortable.”

Eventually, when you come out of your shell and are more capable of understanding what's going on with you, and having that solidarity, you, the caregiver, need to pull back and allow that space and privacy to happen, and understand that the caregiver should be just that – a caregiver. I wasn't afforded that. That's the thing that I missed through this whole journey was that I should have just been a wife. I should have just been a mom. I was not afforded that opportunity. That construct was severely disrupted for 15 years within my marriage and within my relationship with my child who's 14 now, and I have to build back that trust.

Jeffrey, I saw you laughing a few times on some of the things that I've said. Would you like to share?

Jeffrey Dwyer 50:45
I'm in my fifth year of prostate cancer. I have taken a lot of those journeys myself. When you say some of those things, it kindles me to remember when I felt some of those issues.

I am at a point now where I'm going to be investigating palliative care. But I have taken none of the drugs. None.

I have had a prostatectomy. I'm a Gleason 9 stage group 5. When I had biorecurrence, I could not get proton beam treatment. “Impossible.” You're coming to this with total ignorance. But when nobody's telling you about this particular means of treatment, that's not right. I wanted to investigate it, and I did. Eventually, in the middle of COVID, 2022, I went to the University of Pennsylvania. Self referral. Dana Farber fortunately said, “Well. You can do it right here at Brigham and Women’s. You could do it right here at Mass General.” I said, “No, you can't. You can't get proton beam for prostate cancer in New England.” Nobody talks about it. So I ended up going to Philadelphia for almost three months to get my radiation, and it knocked back the PSA. The doctor was wonderful. She said, “If it recurs, come back again.”

I'm at that point now with a slowly rising PSA, and because of comorbidity of coronary artery disease, the only reason I haven't been on hormone therapy was because as soon as they saw that report from Mass General Cardiac that said, “This guy is borderline open heart surgery,” which then happened. I had that surgery. And that was a bitch to recover from. People told me that it wasn't that much. Well, that's not true. It was.

I couldn't have home health care people come in because we were right in the middle of COVID. So your local nurse cardiac home rehab sees seven people that day. I'm going, “This makes no goddamn sense at all.” Instead of it being maybe a six month rehab, it was two years. And in the middle of that I had to go to Philadelphia and go through the radiation and fortunately, the radiation was targeted. They were able to do it on my prostate bed, my iliac chain, and the one met that had just appeared after a PSMA PET scan at Dana Farber on my sacrum.

In my fifth year, I'm in limbo. When I hear about the drugs, I have probably 25 friends either through this group, or personal friends that I've seen suffering from the side effects of the interaction of the side effects of the drugs with their other diseases.

I learned I had osteoporosis, when my spine collapsed, and I have five compression fractures now.

I learned recently that I have interstitial lung disease. I'm going through the tests next week to find out which one. When I'm looking at the list, I have four terminal illnesses, for Christ's sake. I've got to manage those. My wife and I've been managing where we live to get ready for home hospice care, which is going to be next week, or am I gonna be able to survive? Who knows? But I know that we've done pretty well, so far.

But I know I'm going to be sitting there in the room with my oncologist. He's gonna say, “Well. Now you should take Lupron. You should take this one. You should take that one.” I'm gonna go, “Jesus Christ. I just don't want to go in that direction.” I'm just trying to figure out how to do it. I'm not as frightened about dying; I'm more frightened about being totally debilitated while I am dying.

Rochelle Prosser 56:49
I totally understand that. Care should be given in the way, manner, and preference of how the patient wants. Period. It shouldn't be forced or visited upon you. First of all, I'm sorry that you've had to go through this. It is very difficult hearing your friend's story while you're going through this. I am coming from the standpoint of totally understanding what you're going through, after living it myself. I understand the journey. We can certainly have a conversation after this offline. I'm happy to assist you in that.

But for yourself right now, and for the rest of the group: if you can travel to where you trust your provider you should go ahead and do that, because clearly you trust this person in Philadelphia. In Philadelphia, you will have more services than you have where you are right now.

Jeffrey Dwyer 58:01
I live in Western Massachusetts. My regional hospital in Western Massachusetts was purchased by Mass General Hospital, which is the largest health chain in Massachusetts. In fact, it's the largest employer in Massachusetts. I'm fortunate because all of my doctors that I see for heart, for osteoporosis, for everything, are affiliated there. But I also know that there are certain basic restrictions on that. Dana Farber sits out there by itself. I moved because of the radiology, after having the prostatectomy when my doctor told me, “No. We don't do that kind of radiation.” I moved to Dana Farber, and I was fortunate. I did some research and found a good medical oncologist, but they have their limitations too.

I'm trying to realize that they have to work within the standard of care because of the liability issues with it.

This group has done some wonderful things for guys with bipolar androgen therapy and using estrogen instead of some of the ADT drugs, which then allow you to rebuild your bone mineral density, but they're really hard to obtain. Because as soon as you bring it up in that 20-minute window or 30-minute window you've got with your medical oncologist, they will say, “No. We don't do that.” I don't want to lose these caregivers, but I also don't want to be told, “Since we don't do that, this is what we've got to offer you. We don't have a, b and c. We have d, c, and f.”

Rochelle Prosser 1:00:07
You're not alone in your struggles, but you're also not alone in finding the pathway to caregiving and care delivery in the way that you want it. You're welcome to reach out to connect with me.

Jeffrey Dwyer 1:00:39
Thanks.