Caregiver Summit Transcript

0:02:51 Speaker 2: Good morning, good afternoon, and welcome to this virtual summit on the prostate cancer caregiver perspective. My name is Becky Campbell, and I'm the senior manager of medical content here at PCF. We've got an amazing program that I'm excited to share, but first, I'd like to take a moment to thank everyone for joining today and for taking time out of your day. It's really because of your interest and your support that we put on these events, so we really appreciate your interest and your attendance, whether you're here because you're a patient who's newly diagnosed and you'd like to learn a little bit more about what's ahead for you and your caregivers, or maybe you're a caregiver who's supporting someone with advanced prostate cancer and you're looking for resources to help, we we're glad that you're here today. I'd also like to thank our wonderful panelists.

0:03:44 Speaker 2: They are spending part of their day with us because they are passionate about patient and caregiver education, and they have a wealth of experience in a variety of fields. And we also have a patient and caregiver here today who are generously sharing their experiences. We have a great technical team behind the scenes, so I'd like to give them a shout out as well…I'd like to briefly review our goals. Here's what we're gonna cover today. We'll briefly talk about the landscape of caregiving, who is a caregiver, what's the type of responsibilities they have. We'll have our patient and caregiver join us to talk about their journey in localized prostate cancer. We'll talk more about issues specific for spouses or intimate partners, sexual side effects, managing that. Some resources to help. We'll talk about the caregiver journey in advanced prostate cancer, and, some of those unique issues that are faced.

0:04:46 Speaker 2: We'll then move into talking about other types of caregivers and including children and issues unique to that situation. And then last, although these threads will go throughout the 90 minutes today, I want to focus our last section on caring for the caregiver and offering some support and resources for them. Because it could be a challenging journey…I'd like to thank Novartis for their support of this event, for helping make it possible. And just note that all views expressed represent those of our speakers…Just a few procedural notes. If you have questions, please type them using the Q and A function at the bottom of your screen. We can't address individual medical questions, so please, don't include personal information. And we'll get to as many questions as we can with our fantastic panelists. And then finally, if you do need to drop off or anything, a link will be emailed to you with the recordings from today, as well as the links to additional resources that we mentioned during the program…

0:05:58 Speaker 2: In case you're not familiar, I'd like to give a brief introduction to the Prostate Cancer Foundation. So our organization was founded in 1993 with the goal of reducing death and suffering from prostate cancer, as well as extending lives and improving quality of life. We've done this primarily through funding research. Currently more than 2000 projects around the world, and many of the therapies used today were developed with early-stage funding from PCF. And we've also been funding research to improve survivorship, so nutrition, exercise, effects of treatment on quality of life, to improve those long years of healthy life that we hope many patients will have…We also have a number of educational and informational resources. You can go to pcf.org to get our free patient guides, sign up for newsletters, view webinars and summits. All of these recordings live on our website.

0:06:59 Speaker 2: And, you can also join an online support group. I'm excited to note that we are launching a new pcf.org in Q1 of this year. So the website will be a lot more user-friendly, easier to navigate, and I'd also like to call attention to our partner site, prostatecancerpatientvoices.com. This is a newer resource. It features a number of interviews with patients and clinicians, as well as, actually the panelists on our show today, are also featured on this website. So it's another way to explore information and patient experiences across the prostate cancer journey… I'd like to introduce our amazing panelists. Today we have Alicia Morgans, Dr. Alicia Morgans is our host. Um, she has been a wonderful friend to PCF and Prostate Cancer Patient Voices in terms of education.

0:07:50 Speaker 2: So you may be familiar with her. She's a GU medical oncologist at Dana-Farber and directs the survivorship program. She has expertise in a number of areas including clinical trials, patient reported outcomes. Her research interests include side effects of systemic therapy, the vast number of complications that patients can experience, and how to address those. Ad she has received two PCF Challenge Awards and a Creativity Award. So, thank you Dr. Morgans…We're also joined by Dr. Sharon Bober. She is a psychologist and founding director of the sexual health program at Dana-Farber. She's an associate professor in the Department of Psychiatry at Harvard Medical School. And her interests primarily center on cancer, survivorship, sexual health, and quality of life. Thank you, Dr. Bober. And then our third panelist…Ms. Brenda Martone. She is an adult nurse practitioner at the Robert H. Lurie Comprehensive Cancer Center at Northwestern University. She's been an oncology nurse for over 36 years, and an advanced practice oncology nurse since 1998. Her focus for the last 17 years has been GU oncology with a focus on prostate cancer, and she has presented nationally on topics including advanced prostate cancer and advanced bladder cancer. Welcome, Ms. Martone.

0:09:22 Speaker 2: …So we're going to move into our first segment that I like to call the landscape of caregiving. And I want to set the stage by talking about some of the basics and defining some terms when we talk about caregiving. You know, this can be a very broad term, and I want to acknowledge that obviously caregivers could encompass parents caring for children. There are people caring for relatives with other types of illnesses such as dementia, just a whole host of people that are doing medical caregiving. Today we are going to focus on caregiver issues related to prostate cancer, but I want to acknowledge that it is a broad scope and many people are doing just this tremendous work out there. I'd like to turn this over to Dr. Morgans and our panel to start us off with an introduction to the caregiver landscape. So Dr. Morgans, Dr. Bober, and, Ms. Martone.

0:10:20 Speaker 3: Thank you so much, Becky, and thank you so much, Sharon and Brenda for being here with all of us today to talk through some of these things. You know, I think, as Becky said, there are a lot of people who are involved in the lives of individuals with prostate cancer, who we do need to think about as potential caregivers. And and I'd love to start off with Brenda just casting a wide net. Who are some of the people that you see in clinic who might be considered caregivers for some of the patients that we take care of?

0:10:55 Speaker 4: I've seen patients, daughters, that come with patients all the time. There can be aunts, uncles, sister-in-laws, brother-in-laws, obviously significant others and grandparents, some–well, not grandparents, but grandchildren sometimes come in and play a role. And so I think whoever is sitting next to that patient or messaging from home or being involved in that person's care is definitely a caregiver. And one of the things I'm also very cautious about for myself is never to assume who's sitting next to that patient. So I always ask, “Who's with you today?” Because I don't want to make the wrong assumption. And it's just nice to acknowledge everyone who's sitting there so they can feel comfortable and confident when they want to share something just to let them know they're invited as part of the visit.

0:11:50 Speaker 3: Absolutely. I remember some of the patients that we've shared over time, and sometimes it's just a good friend. Sometimes it's a paid caregiver who ends up being with somebody for so long that they end up being a good friend as well. But friends can also play these roles. You know, Sharon, you work really on intimacy, sexual health issues, and I'm sure that you've seen a number of people's sort of ideas and roles in that way can be affected by some of the caregiver responsibilities that they may have and some, and the way that their relationship is changing, perhaps somewhat going from a partnership. And sometimes that partnership is still maintained and should be, and hopefully is, but it can also–the dynamics can shift sometimes when someone is feeling more like a caregiver. I wonder if you can comment on that and how those dynamics can really make things complicated sometimes.

0:12:51 Speaker 5: Sure. I think that's exactly right. You know, one of the things we often talk about is, as prostate cancer, somebody said to you recently, well, you know, it's a “couple's diagnosis,” and in so many ways it is. And at the same time, you know, couples often, have to be very flexible because there's a lot of roles that change. You know, people have to play a variety of different roles they may not have played before. And I think that's totally true, that when you are really in the middle of a kind of an intense patient caregiver role on both sides of that, it's also sometimes hard to shift back to just being romantic partners or co-parents or friends, right? When you're kind of in the middle of something kind of hard around other roles. So I would say that in general, this is not something that gets talked about a lot, and I think that for lots of couples, it's not always easy or obvious to be able to kind of make these changes or switches in roles on a daily or weekly basis.

0:13:58 Speaker 3: Absolutely. I think especially as sometimes our patients are younger or sometimes they're older, and as you mentioned, sometimes there are–they have other responsibilities to take care of children. You know, we certainly see patients with prostate cancer who are in their forties and may have, you know, young children, all the way up to people who might be still caring for their grandchildren. certainly have patients in that situation or who started families later in life. So they themselves are caregivers, but now also are being cared for. And so all of these roles can shift and can cause dynamics that I think it's important for caregivers, for patients, for everyone to be able to feel comfortable and confident talking about, because people like Sharon, people like Brenda, hopefully the doctors on the team too can help sort of sort through some of the complex feelings that may arise in some of these settings. I would love to also, invite on Wendy and Stu as patients who are–not patients, a patient, a partner, to see what their thoughts are in terms of how their relationship and this was years ago. Tell your story how your relationship was affected by the diagnosis and by this new kind of caregiver partner role that you may have found yourselves in.

0:15:29 Speaker 6: So Stu and I have, I mean, we met in ‘03. Stu's initial PSA was done in ‘05. His diagnosis was in ‘06. So our relationship was relatively new. And I think that it was not the way you planned to start a marriage, but in terms of how it affected us, I think that it probably strengthened it because we had to work together on something so serious. And I mean, I think the hardest thing initially was, I think that there's a difference between a patient and what a patient is experiencing and what a caregiver or loved one experiences. You know, it's like anything else, unless you're going through something, you don't really know what it's like. And so as a caregiver, your whole focus is on just, you know, you're aiming for a cure, you're aiming to, treat the disease in a way that you don't have to deal with it again.

0:16:51 Speaker 6: And especially in something like prostate cancer, where the side effects will affect quality of life, you have to sort of understand that the patient is going to be looking at it from a different perspective. So I had to understand that it wasn't quite as simple as saying to a doctor, “well, what should Stu do, in just doing it?” It involved seeing many different types of doctors and educating ourselves through research, through online groups, through going to conferences, reading books, you know, whatever it was, so that we could really attack the larger picture in terms of deciding what was best for and what Stu was most comfortable doing.

0:17:43 Speaker 3: You raised such an interesting point, Wendy, because I see countless people in my clinic who, the caregiver says, “Well, let's just take it out. Let's just get rid of it. Let's be as aggressive as possible. Let's just do everything kitchen sink style.” And then the patient says, “Well, I feel like I would like to take a more moderate approach,” or “I would like to do this,” or “I prefer radiation, not the surgery, for X, Y, and Z reasons.” And it's really interesting that you bring up that, you know, everybody's coming to the table from a different perspective, and it takes a really strong caregiver and a really, I think, a thoughtful relationship and partnership to be able to share different sides and also then to move forward as a team with the treatment at the end of the day. And I wonder, Stu, if you have thoughts or comments on that and how–any advice you have for patients who are trying to navigate, maybe a caregiver or a partner, who wants to approach things a little bit differently than the way that they may wish to approach something.

0:18:54 Speaker 7: Sure. In fact, Wendy and I just discussed this, given that prostate cancer is, I don’t know if it's unique, but dealing with the comorbidities of various treatments is really important. And it's not just dealing with the disease, but it's dealing with all the unintended side effects and consequences of what you decide. And it's, you know, it's very personal. I, for me, I really didn't want to deal with surgery, so that was sort of the point of view that I was coming from. So that definitely colored, you know, my outlook and, you know, and how we navigate it. But yeah, I mean, I think both the caregiver and the patient have to be cognizant of each other's, point of view and what they're thinking and just to be aware that they're, you know, that to me that's what's, you know, fairly unique about prostate cancer, is that there's so many decisions to be made and there's so many avenues you can take. It can be overwhelming, and it's just this decision after decision that has to be made, and it can be very challenging.

0:20:18 Speaker 3: Absolutely. You know, Sharon, I wonder if you can comment on some of the changes that some of the treatments may have in terms of the partnership. You know, I wouldn't necessarily think of it as a caregiver relationship, a partnership, you know, where a patient and and partner, their intimacy may be very changed by some of the treatments, actually most of the treatments that are applied. How do you have conversations with couples in that initial period as they're trying to sort things through and adjust to the effects of some of these therapies on their relationship?

0:20:58 Speaker 5: So Alicia, are you referring to sort of after people have made their initial treatment decisions and are sort of thinking about, or facing, some of the impact of the treatments?

0:21:10 Speaker 3: Yeah. The reason I am, yes, and the reason I am is because I think at least in our system, you end up seeing people typically after those decisions have been made. If you have advice for people, would be great. If you have advice for people who are just facing those decisions fresh and haven't made the choice yet, that would be great to hear, too. I think in our system, at least in most cases, you're seeing people after those decisions are made and now they're trying to adjust to what may be a new normal for some period of time, if not indefinitely.

0:21:39 Speaker 5: Yeah, no, thank you for the question. Well, first of all, I would say that to your point, and I, because sometimes I do see folks after they've gotten a diagnosis, and while they're sort of in the middle of trying to figure out which avenue to go down, and I think Wendy and Stu sort of spoke to about some of that, how you saw many doctors or, you know, when you were trying to figure out what to do. Um, I just wanna say I appreciate your point that as much as couples may often feel very close and very connected, it's interesting how in the moment, it's also very normal that, you know, patients and, and partners aren't always exactly on the same page in terms of decision making, right? That it's actually a process where people are trying to identify their goals and needs and values.

0:22:31 Speaker 5: And, you know, although, you know, in the big picture, I think everyone agrees the goal is to be alive and get on the other side of cancer for a very long time. You know, it is interesting how in the moment, sometimes there's a sense of stress or conflict, you know, that couples may not be, you know, we can't assume people are always on the same page and that it really takes, I think it just–it's important to just give each other time to be able to really sort of talk to each other, right? About what individual needs are, as well as needs are for a couple, right? And I think that, you know, I just really appreciate that, as a partner, often the immediate feeling is “let's just do everything we can to make sure you'll be okay.”

0:23:19 Speaker 5: And from the point of view…of the person going through the experience, you know, it's also complicated, right? People are thinking about “what is this going to mean for me, for my body, for my function, for how I'm going to be in the world?” So, you know, certainly one of the things we know that is incredibly common are changes in sexual function and body image and erectile function. I mean, all of the things that people are probably familiar with in terms of so many of the treatments. But I will say even so, we also know that often, there are so many things to deal with when you are starting treatment, and there are so many things that feel very pressing to be able to plan for and get ready for that. Some of the expected side effects around erectile function, around sexual function, around, just sexuality in general, don't often make it to the top of the list, you know?

0:24:17 Speaker 5: And one of the pieces that I often hear are a feeling or a comment later, “gosh, I wish I had been a little more prepared for some of these side effects. I wasn't, I just, I wasn't really prepared for what it would mean. I didn't–someone might have mentioned it in passing, but I didn't really get it.” I think in general, what I would say is that in the sense that this really is a couple's experience, we know that, partners and caregivers do better if they are able to be communicating regularly, if they're able to, on a very regular basis, find time, not just to be working on like, kind of the functional mechanics of getting through each day, but to really also put time aside to be able to check in and really ask, “Where are you right now?”

0:25:09 Speaker 5: “How are you right now? What do you need right now?” And I know that seems maybe obvious, but when–especially at the beginning and there's such a frenzy, and as you said, people may also be having to figure out how to manage their own treatment while they're working or taking care of an older parent or managing grandkids, there's a lot of ways in which, we kind of don't take care of ourselves, right? Because there are so many other things that we need to be–so many fires have to get put out immediately. And I guess what I would say for anybody who's gone through this probably has a sense about this. It's kind of a marathon, it's not a sprint, you know, and we really need to be helping couples, I think from the beginning about how to get ready for what's going to be a long haul.

0:25:56 Speaker 5: And that means figuring out how to take care of yourselves. That means being able for caregivers to be able to acknowledge that they have needs and that those are valid, for both partners and patients to both be able to assess where they are at and what they need, not just working as a couple, but for themselves keeping like fuel in the fuel tanks, you can have energy to keep going forward. You know, in general around the sexual changes, I would just say that it is not only about erectile function. I want to just sort of put that out right now. When I think about sexuality and intimacy after prostate cancer, we know that people have a profound experience that is as much about feeling like a man, perceived masculinity, the experience of feeling whole in your body, the experience of being able to give and receive pleasure changes.

0:26:53 Speaker 5: You know, it is not only about whether you can get an erection or keep an erection, although that is a part of it. And I also want to just say that all of the research that's been done has been very clear that caregivers actually struggle right around sexuality and intimacy. Not only around just general function, but actual sexual function, right? Often, you know, there are so many ways in which this kind of process and kind of illness can affect both partners. So in that sense, it's important to also be able to really, as I said, just be very regularly finding time for each other to check in emotionally and to communicate. I don't take that for granted, and I don't think we always give each other permission to do that when it seems like on the surface there's always something “more important.” But that is really important for the long haul to have time on a regular or daily basis to do a kind of a check-in like that.

0:27:53 Speaker 3: I think that's such an important message, not just the check-in piece, which is such a good thing. I feel for relationships, probably regardless of a prostate cancer diagnosis, I feel like I can take that one home and use that tonight with my husband and my family. But I think it's also really, really important to reiterate this marathon, not a sprint. Because prostate cancer is a long-term diagnosis. The survivorship piece is a long-term process. And even when prostate cancer is incurable, it's in most cases going to be a process that we are dealing with over potentially years and years of time. And it is a lot to have as a mental burden to constantly be at the highest level of anxiety, stress, cortisol, you know, emergency indefinitely. It's really important to be able to process some of that and take it day by day in chunks that are manageable, in timelines that are manageable and, and that we can kind of process and plan for.

0:28:55 Speaker 3: You know, Wendy, I know when Stu was initially diagnosed, and I think we said that this was 17 years ago or so, so this…has been a marathon for you and Stu, what are some of the things that you did? What are some of the roles that you played? What are some of the activities that you engaged in to try to help him through that initial diagnosis and fact-finding phase where, you know, you were trying to figure out what do we do? What's our timeline? How do we, you know, at least start in step one of this process?

0:29:29 Speaker 6: Going back that a long way, I think that what I did was, I tried to be there for every part of what we were dealing with. We went to a conference together, we went to every doctor appointment together. We talked about it afterwards. And then I think we even early on tried to make time to do some fun things together. Um, certainly, like you said, it was a long journey. There were lots and ups and downs. And I think also just speaking to what you talked about with relationships, you know, fear is a powerful thing. Whether you're afraid, you know, I mean, I still 18 years later feel nervous every time Stu has to get a PSA test, and I worry like the next–after he takes it every hour before he gets the results are very nerve wracking. And that's many, many years later and many ups and downs. But I think that, you know, we did get better at keeping it sort of compartmentalized a little bit, for lack of a better word, so that when Stu was treated for his recurrence, we were able to say, “Okay, we know we're dealing with this, so we're going to take a one week vacation before the treatment so we have time to just be together and enjoy it,” which we did. And I think that that took us years to..

0:31:04 Speaker 7: Yeah.

0:31:05 Speaker 6: Sort of perfect–

0:31:06 Speaker 7: <laugh>. No, I was going to say, we also, with each step in the process, I think we talked about, “Well, if things don't go the way you intend or hope for, you know, what are we going to do?” And we kind of joked about a lot of things, you know, especially when you're talking about, you know…side effects of, you know, intimacy and so on. So, I think just being able to address that openly with each other and to be, you know, upfront and to try to, you know, look at it sort of lightly in a way. You know, I mean, because you have to not sense to you. Yeah. I mean, not that you can be prepared for anything, but it's certainly something that I think it's good to think about. Because things can certainly go awry. And, you know, the more I think that you've at least given it some thought ahead of time, I think you'd be better off.

0:32:07 Speaker 3: You know, Stu, I'd love to hear from your perspective, what were some of the things that Wendy did that as a caregiver, as a partner in the process that you said, “Wow, well, I'm just really grateful that she's here for me in this way.”?

0:32:23 Speaker 7: Well, obviously she was, she–number one, she was always there. She's an incredible researcher and, you know, she'll leave no stone unturned. So she's a great partner. I'm not as detail oriented as she is, and she would just go through and read through research papers or find particular doctors and, you know, I felt like we worked well together. Because, you know, she would find out, let's say, about a particular doctor, even there were times I remember, you know, I had called the…I don't remember who it was, but you know, somebody out in California or Washington state, I can't remember who it was. You know, someone that she had found. And actually the other amazing part of that was that somebody out in these far flung areas would actually get on the phone and talk with me, which was, I found incredibly amazing <laugh>. So, but that, that was a really big part of it, that she was able to research and be very supportive. And…she wasn't trying to direct the ship in a sense of saying, “You ought to do this,” or “You ought to do that.” I don't think you've ever said anything like that to me….

I didn't wanna be responsible <laugh>.

So, just, you know, being always there and always supportive and being really smart.

0:33:56 Speaker 3: Yeah, you know, I love that that's the kind of partnership that you have and had, I find in my clinic, and it may be sort of a male-female thing, or it may just be, you know, patient versus somebody who's very slightly removed, but still part of it. But sometimes it can be too much for the patient himself or themselves, to take on all of that research to dig in. When we're–when you're living in it, it can be hard to then dig in more and more and more and more. And some people cope that way through intellectualization, through research and through study, but not everyone does. And sometimes it's hard, very hard for the patient themselves to do that.

So it's wonderful that your partner, that Wendy copes in that way, that information gathering is part of her coping strategy and part of the way that she processed your illness and that really worked for you.

0:34:54 Speaker 3: Wendy, I just want to follow up though, too. I think you mentioned that you were sort of another set of ears, another set of eyes and ears at the visit to try to help get that information and then support Stu. How–do you have any guidance or any suggestion for how others can do that? Because when we're in clinic, when I'm in clinic, I so appreciate having a family member, a loved one, a caregiver there who can be that second set of eyes and ears to take notes, mental or actual, or just to be a sounding board to flesh out some of the topics that we talk about and to dig into some of these things. Do you have any suggestions or guidance for others who are trying to also do that, supporting their loved one who is the patient?

0:35:40 Speaker 6: I guess, and not even just in terms of what happened with Stu and myself, but I know from friends that are supporting, I have one friend now supporting a sibling. You have to sort of–it's great to take notes. You cannot believe, I mean, there were times I even recorded things because you miss a lot. So it's really–and Stew's done it for me with other medical issues I've had–the person who was in the patient will hear things differently and remember things. So I think it's important, but at the other hand, I think you also have to be respectful of the patient. So Stu had no trouble with me asking any question I wanted or asking for clarity. There were times I even reached out to his doctor without Stu on the email, just because I didn't–I wanted to get an answer before I discussed it with Stu.

0:36:39 Speaker 6: But I think you have to be–you have to let the patient sort of guide you as to are you there to just take notes or how active a participant they want in meetings that they attend. Because I think there are some people that would say like, “I don't want you asking a lot of questions.” They just don't feel comfortable with questioning a doctor. Whereas other people will say, you know, “Ask whatever you want, because the more information I gather, the better.” But I think it's really ultimately, something that you have to sort of come to an agreement on if you're supporting someone during any doctor appointments, tests, et cetera.

0:37:25 Speaker 7: Also, I think, as a patient, everything you hear, especially when you're meeting with a doctor, is sort of filtered through your own experience. And to have someone else there who only has your best interests in mind is extraordinarily important and really, really valuable.

0:37:45 Speaker 3: Well, this is, I guess to get to another point with only the best interests in mind for the patient, but something that can be really hard. I don't know your personal habits in terms of exercise and diet, strength training, aerobic exercise, you know, eating vegetables and lean sources of proteins. But I can tell you that <laugh>, these are not easy things to do for anybody, but they are absolutely recommended for many of our patients with prostate cancer to really kind of keep them physically and mentally in the best place possible. We got a question through the chat that I think is just really, really key to one of the main issues that sometimes caregivers, loved ones are those people on a day-to-day basis to encourage that exercise, to encourage that healthy diet. Do you have any experience with that, Wendy and Stu? And if so, <laugh> any guidance to avoid disputes during that encouragement?

0:38:51 Speaker 6: Well, we didn't have disputes, but no, he thought he was going to cure himself.

0:38:55 Speaker 7: We tried <laugh>, believe me <laugh>. So I don't know where to start with this.

0:39:01 Speaker 6: Well, no, initially you thought that if you changed your diet, you could cure the…

0:39:05 Speaker 7: Cancer, which I did. So I cut out all meat…and all dairy, and went on a, like a heavy soy diet, cut out ice cream, which was extraordinary torture. Yeah. That's just, I don't recommend that to anyone… Yeah, we definitely went down that road and tried it and…

0:39:26 Speaker 6: And it did lower your cholesterol.

0:39:28 Speaker 7: It lowered my cholesterol. It didn't cure prostate cancer, unfortunately. That's what we were hoping for. At least I was, yeah, <laugh>. But yeah, we try that. I mean, exercise, that's something both Wendy and I naturally do anyway. So that wasn't a big ask for either one of us really. That's just part of our daily life anyway, so, you know, that was fine. But definitely the diet thing, we tried…

0:39:59 Speaker 6: Oh, we still–yeah, I mean, struggle with finding–Stu's more lenient about diet than I am <laugh>. And it's, you know, it's a constant focus of how much of what to eat. The ice cream is still a challenge. But I think that it is something that now more so than even 17 years ago, is considered certainly a part of changing your life once you have a cancer diagnosis.

0:40:33 Speaker 3: Yeah. So I will chime in from from my clinic because this is definitely something that people talk about. And I have loved ones who say, “Well, he just wants to sit on the couch.” Especially when people are on androgen deprivation therapy. When we use medicines to take away somebody's testosterone, in many ways, it zaps their energy, can cause them to feel fatigued and can zap their motivation to really do things beyond that. You know, sometimes when people get a cancer diagnosis, they can have low mood or even depression, which also zaps your–really your motivation to do things. So, what I always encourage is, of course, if somebody isn't motivated because they may have low mood related to a diagnosis of depression, it's important to get to the bottom of that, to talk with an individual's doctor, with that individual of course, and say, “These are my concerns.”

0:41:24 Speaker 3: I wonder if–low mood, diet changes, sleep problems. These can all be aspects of a depression diagnosis, and investigate that because we can treat depression. And if that is underlying a lack of motivation to move, treatment can help that person get moving again. But when it comes to, you know, encouraging people to do that physical activity, which in truth can give them more energy and help their mood pretty substantially, small steps, systematic approaches to small amounts of exercise at first, increasing incrementally over periods of time are really the best way from my perspective. Because if you do small amounts and sustained work with slight increases over time, you can sustain the activity. And it is change that lasts and is durable that really I think is most effective in helping people over time. Like Wendy and Stu said, they still fight with ice cream.

0:42:22 Speaker 3: I personally–right now, it's Girl Scout cookie time, guys. I am really suffering. It's really hard to not engage. There are these things that we just really love. And so, little small steps, recognizing that there will be downfalls, there will be ice cream once in a while, get back on it the next day and do your best and keep going on from there. But good luck to all caregivers who are trying to continue to motivate in a kind way. And also, you know, mirroring that activity, doing it yourself with the person can also be really, really helpful. So before we wrap up this section, Stu, I wonder if you can share a little bit about your prostate cancer journey. There are some questions–as much as you feel comfortable sharing, just to understand kind of what is the status of your cancer right now so that people can put that in context, if that's okay with you to share.

0:43:14 Speaker 7: Sure. It began, let's see, what, when I was 47…

0:43:22 Speaker 6: 20 years ago.

0:43:23 Speaker 7: Yeah. Went to an internist who had done a PSA test, had no idea even what that was. And even though she was doing it, and she said, "Gee, your PSA is a little elevated." And we promptly ignored that until a year later when we went back to the same internist, had another test done. She said, "Hey, your PSA is elevated."

0:43:44 Speaker 6: "Go see a urologist."

0:43:45 Speaker 7: "Go see a urologist <laugh>." So this time, well, it still took a couple of months to listen to her, right? But we eventually went and, well, you take over please.

0:43:57 Speaker 6: Okay, <laugh>. So then, about seven months later, Stu was diagnosed and then we did our research and about six–so it was all together two years from the first test, to Stu chose to do brachytherapy. And so with low dose brachytherapy, it takes a while to see the PSA come down. And Stu was not coming down very quickly. And then about 17 months after his PSA started going up, which initially we thought was a bounce, but then his PSA actually over the next five months went higher than it was pre-treatment. So, he had an MRI and then ultimately another biopsy. The biopsy didn't find cancer. And then a month after that, his PSA started going down, it took Stu seven years from treatment to reach his nadir. And then a year after, you know, and then they were testing yearly, and the next test has started inching its way up. So for then the next seven years, it started going up very slowly. He had a PSMA test in 2020 that was negative, in 2021 it showed cancer. He had a biopsy and there was cancer. The good thing about the PSMA test was that it showed it was localized. So then he had high dose radiation to treatments. That was three years ago. And he's– after the first like six month test, he's been basically at less than 0.05 since. So there were a couple ups and downs in there,

0:45:55 Speaker 3: <laugh>, that's for sure. Yeah, and they sound small looking back, but they are definitely little mini earthquakes, if not major earthquakes when they happen. And I'm glad that you have each other. And I'm glad that you are sharing with us. So let's shift gears a little bit and really talk to Sharon and Brenda for a few minutes around some of the specific experiences or, I guess stressors, that can happen that can stress both the patient and the caregiver as we go through some of these things. Brenda, I wonder if you can comment on what are some of the effects that people can experience, whether they're emotional. We kind of alluded to some sexual health effects. What are some of the things that people experience when they go through treatment for prostate cancer that patients and caregivers need to be aware of and kind of prepare for?

0:46:48 Speaker 4: Definitely all this, most of the side effects occur because of taking testosterone from a normal range down to undetectable or super low pretty quickly. So I like to explain that, you know, the person getting the treatment is going to most likely have hot flashes.

These can be bothersome, more frequent, more intense in the beginning. Over time, these can mitigate, but we do have strategies. If they are bothersome, I let them know that their muscle mass is going to go down, because of the metabolic changes that are happening without that testosterone, I explained that testosterone is basically the engine. And so because the muscle mass is going down, they're also going to be more prone to gain weight in certain areas of their body. That includes kind of the midsection. Depending on the person and the treatment, sometimes there can be some, you know, breast enlargement or tenderness.

0:47:51 Speaker 4: The other things I talk about is, again, because testosterone is being dropped super quick as opposed to a person going through menopause where our bodies get a chance to kind of slowly adjust mood swings, irritability, agitation, those are all–can all be like related to testosterone. And the changes in the hormone balance as well as, you know, other things can play a factor into that. You know, in terms of diagnosis, any time that a person starts treatment and these changes to the body are going on, I often remind my patients, caregivers, whoever's with them at the visit, that their body is changing. And it's a sense of loss actually, and there can be mourning because the, you know, these changes you have absolutely no control over. They're basically happening, you know, depending on when your diagnosis is. If it's later in life, you've kind of defined what your body is, what it is, how you can expect things to be, and now everything is different.

0:48:58 Speaker 4: So acknowledging not only sort of the laundry list of things to expect, but what those things and how they may impact that person. And again, the sexual dysfunction, things like that. Oftentimes, you know, I will say the changes that may happen include, you know, erectile dysfunction. You know, they, I often say to loss of libido, but you know, they're not going to feel as horny as usual. So if there is a partner that is wanting to, you know, be more sexually intimate, I want to say, you know, sometimes that can create some stressors because the patient actually getting the treatment may not really care that much about things and acknowledging that that's normal. The other thing I mentioned too is that there can be changes, actually physical changes to the genitalia. So, you know, not everyone is going to have these, but you know, often, you know, I've had patients come back and say, “Well, you know, everyone talked about the hot flashes, the loss of muscle mass, maybe the weight gain, but is it normal that, you know, I'm finding that there are changes to certain sizes.”

0:50:14 Speaker 4: And, you know, I try not to omit that, because I want everyone to kind of know ahead of time what might be there. I also think by me bringing that to the table at the beginning in a very non-judgmental, open way, I hope that opens the door for patients, family members, depending on who their caregiver is, to feel comfortable to ask questions and bring this up. I know we've alluded to the fact that this is truly a marathon. And so what, you know, you start off a marathon super strong, you're focused maybe on getting treatment going, you know, trying to get things under better control. You get into your stride and, you know, maybe certain things start to become more of a concern that weren't addressed early on. So addressing them, you know, as they come up. And also, we're going to have those rough periods of time, you know, maybe we get, again, this is super simplistic, but maybe, you know, we get a cramp or we have to take a, you know, we have to dial down our stride a little bit.

0:51:16 Speaker 4: So that just alludes to, sometimes things may not be going as planned, or we need to make adjustments and just letting–I always let patients know there are multiple ways to address things. Not everything requires a medication. Not everything requires an intervention that will, you know, require another visit to another provider. You know, there are some things that can be done dietary wise. Stu mentioned he kind of focused a lot on soy, and we do encourage that in our patients, because sometimes that can help mitigate some of the hot flashes. So just, I think, just being open and laying things out and then coming back to things. So again, I know this is sort of long-winded, but you know, when patients come back and, you know, we find out how they're doing and if they say everything's great, then I always follow up with, “Okay, well, are you having hot flashes?”

0:52:13 Speaker 4: I go through a whole review of systems just so I can open that door again in case something is bothering them [that] they didn't feel like they should bring up in the visit, or maybe they don't feel it's as important, or maybe they just don't feel like they have the time. And I want to make sure that they feel that all of their needs are being addressed. And there's not a wrong question, there's not a silly question. And if they're not comfortable asking me, or if I can sense maybe they're not comfortable with a caregiver in the room, I can certainly make up a reason to have that person step out. If there's something that they want to discuss with me, just, again, I just want them to feel like, you know, their care is complete and that we're here for them, and that they can, you know, bring up whatever it is they want to bring up. And that hopefully together as a team, we can come up with a solution that's compatible with that, the patients and the care caregiver's goals, I should say that everything sort of aligns as best we can.

0:53:16 Speaker 3: Thank you so much for that, Brenda. Wow, lots of great things for us to think about. I think one thing I would just pull from that before I ask my next question is that, you know, Brenda did mention that, sometimes people, even though they love their loved one or their caregiver, or their partner or their friend or whoever it is, maybe they don't feel completely comfortable going into all of the things that they're experiencing with another person there. And that's human nature in a lot of respects. It doesn't mean that the person doesn't care about or love their their loved one, but as a caregiver, you can always offer, “I'm happy to step out for a minute,” or if you really sense that the person there doesn't want to ask you to leave, you could always say, “Oh, you know what?”

0:54:04 Speaker 3: “I have to use the restroom. I'm going to step out for a minute and give them that opening to potentially share something that they may feel uncomfortable about.” Maybe there isn't something to share, but you know your partner, you know, your loved one. Maybe they just need a little bit of space and maybe they'll bring it to you at another time or bring it back to you after they have a solution. But sometimes that can be really valuable for a caregiver to offer that space, that time with the clinical team if it's needed. You know, Sharon, I would love to hear your thoughts. Now, I know that your specialty is in intimacy in sexual health, but I also know that you're a therapist, and I would love to hear your thoughts on what Brenda said about mourning changes in your body, whether they're related to hormone levels that are really low, whether they're related to radiation or surgery, cancer treatment causes changes. And it can be really normal actually, to feel different and actually feel sad about that. I wonder if you have any suggestions or comments for patients or for caregivers who are trying to support somebody through that.

0:55:11 Speaker 5: I appreciate you, first of all, I appreciate Brenda using that word “loss,” and I appreciate, you, Dr. Morgans, sort of coming back to that because I think that speaking about grief and loss is one of those things that can feel kind of taboo. You know, there's an enormous amount of focus on gratitude. I'm all, you know, on gratitude. But, you know, I think that sometimes what gets lost in the mix is that we can be incredibly grateful for what we have and grateful for being alive and grateful for our treatment and not, or simultaneously, feel an incredible amount of grief and loss. And that, I don't think our culture is great at allowing people to have the kind of complexity of emotion, at least in a publicly, outwardly stated sort of way. There are things, you know, we're so supposed to feel good about, and there are things that we don't talk about.

0:56:07 Speaker 5: And, honestly, grief and loss is part of that, right? So I would just say that for many men and partners in general, even just being able to name the feeling right around grief can be incredibly freeing. You know, often when I'm meeting with folks, and I will use that word, people kind of look at me and they say, “Oh my God, you're right. That's what this feels like.” Right? It just–because it's more than sad, right? It, it is a kind of a sense of loss, as you said, which feels permanent, right? There are certain things that may be altered forever. And I think it's just really important to be able to acknowledge and, and validate that some of that is a sense of grief, which people learn to how to live with, right? It's not about trying to pretend it's fine.

0:56:59 Speaker 5: And I think, in fact, that's actually very freeing because when we can acknowledge some of that, it then paves the way for us to be able to then say…”how do we find a way forward? How do we create a new chapter given the loss that I'm also carrying?” And that really goes for partners and caregivers as well as for patients. So I think that's probably one of the things that's not easy to talk about, but is incredibly freeing. I often think of it as a kind of a bag of bricks that we carry with us. And if you can take that brick out of the bag and leave that on the side, because you don't have to feel bad about feeling that it's just part of what you're feeling, it lightens the load a little bit, which is good.

0:57:47 Speaker 5: I also just wanted to add something, if it's okay–to something that Brenda was talking about. Because I was thinking a lot as Brenda was talking about, you know, these issues around sexuality. And I know that's something I'm thinking about. And again, not so much just about the mechanics of sex, but about intimacy broadly. One of the things that I have been struck by seeing couples for many years in this context is that partners are incredibly conscientious about not wanting to upset the other person. And often in the best of intention to try to somehow protect each other from feeling upset. It's interesting how couples often end up living in a much more kind of roommate, friend-like companionate way, because this whole issue around intimacy feels really fraught, right? It's like partners don't want to upset.

0:58:45 Speaker 5: They're, you know, upset each other. Like, if he can't get an erection, I don't want to make him feel bad, so I don't want to like try to hug because then I don't know what'll happen or in the other way. You know, a patient will be like, “Well, there's the last thing I would want to do is give my partner the impression that like, this is gonna lead to something. Because it can't lead to anything. So I don't want to get started.” You know, there is an amazing amount of avoidance of all things intimate, right? Because often people are concerned or afraid that if it kind of can't go the way it would have gone in the past, right? That what might have looked like foreplay or something in the old days would be taken–would be misinterpreted. You know, what I'm often struck by is that couples often have an enormous need for connection and intimacy.

0:59:33 Speaker 5: But often end up living with this kind of elephant in the room between them. And I would just say that, you know, there's a way to work through that, right? That even if in the short term or longer term, that sexuality or sexual activity or romance, whatever you want to call it, may look different. What often concerns me is that people feel kind of sometimes lonely, right? In a relationship, even though they feel close in certain ways. But it's sort of like, there's, not really a repertoire for how to be able to sort of be connected or feel intimate without feeling like, “Oh my goodness, it's going to lead to something that's going to end up being distressing or being frustrating or being upsetting.” And I think that I'm just calling that out because I see that all the time, and I don't think it's something that gets enough attention.

1:00:27 Speaker 5: I think the, you know, clear next step to dealing with that is by just being able to talk about that, right? It's incredible how many couples are able to reach a very different place of connection by just being able to have this conversation, right? By being able to say, “Gosh, I just miss feeling close in that way. I know things are different than they used to…you know, they're different than they were, or maybe they, for right now, that's not something we can deal with exactly.” But on the other hand, it feels very all or nothing, right? It's very black and white. And, I guess I just really want to invite people to consider that even though things may be different, the sense of connection, intimacy, sensuality, romance doesn't have to be all or nothing. And I think that that's an important message. And again, I think there are lots of ways that we can sort of think about how to expand that or make that experience more expansive. But couples, you know, we, as humans, have that capacity to be flexible. But sometimes we need a little guidance or a little support or a little push. And I think it's worth mentioning.

1:01:37 Speaker 3: Very, very worth mentioning. So thank you for going through that, Sharon, and talking about these things that if we just acknowledge them, maybe we can take one of those bricks out, set it by the side of the road, or let the elephant just leave the room please. <laugh>. So, really, really important. So thank you. Brenda, I think just getting back to the side effects, I think patients and their caregivers know this, too, can sometimes have side effects from their treatment, radiation, surgery, sometimes hormonal therapy to contributing obviously, that are embarrassing urinary symptoms like urinary leakage, incontinence episodes, accidents, bowel urgency, or even leakage that can happen, again, related to the treatment. These are things that are hard to talk about. I wonder, from your perspective…is there anything that someone can do? Is there value in a caregiver helping to support an individual to talk about this with their doctor team to explore whether there might be something there that could be helpful in fixing some of these problems?

1:02:53 Speaker 4: Most definitely. I often tell patients that I'm either speaking to on the phone or seeing in the clinic, that unfortunately I'm not a mind reader. So if, you know, if people don't bring things up or they don't feel comfortable saying something, I'm going to try to find out information if I'm able to in other ways. And, you know, again, me going through and specifically asking them questions about any symptoms they may be having. Again, if they say they're great, and, you know, sometimes I'll look over at the caregiver and I'll get this look, that kind of lets me know that maybe that's not entire picture and explore that a little bit more, I can, I often ask for permission from the patient if I can ask the caregiver a question or just to follow up. The other thing, again, by asking specific things, I'm hopeful that will help open the door for them to be able to say, “Yeah, I'm getting up like eight times at night, you know, and my sleep sucks and I'm super tired and I can't really concentrate during the day,” or, you know, “Every time I sneeze I'm starting to leak some urine.”

1:04:04 Speaker 4: “And it's embarrassing. I don't want to have to wear any sort of protection” and, you know, the old phrase used to be, I don't want to have to wear a diaper or a pad, but that's really a misnomer now because there's so many different things that can be done, or so many different choices you have where it's not that you're wearing more protective underwear if that's the case. Yes, during radiation, we all know that no matter how hard or how cautious the radiation oncologist is in aiming the beam, there's parts of the body, the intestines that you know, will become irritated. And so you might be having diarrhea that may not be controlled, and this may limit your willingness to be out in public because nothing is more embarrassing, obviously, for anyone to have some sort of accident out in public, or what strategies can we do, speaking to, you know, radiation that can be very complicated, too, in having to have a full bladder and an empty colon.

1:05:14 Speaker 4: You know, so there are challenges there that can be very frustrating to patients. And I think just sort of, like I said, always being comprehensive, always listening, being very observant, asking whoever's with them, you know, “Is it okay if I check to see if I agree?” You know, depending on who the partner is, you know, the joke sometimes can be that that partner knows the other partner better than anybody else, but I certainly don't want to make assumptions and sort of speak for that person. But, I think also sometimes just being quiet, like I can ask questions and get answers, but sometimes I don't think as providers, we often feel comfortable just sitting back for what might seem like an hour, but it's only seconds to kind of let questions digest, let the person think about that, let them be able to recall if there was an episode or an incident that was bothersome to them.

1:06:21 Speaker 4: And, you know, let them share that… at their own time I think is also helpful. And then again, if things are brought up, discussing strategies that we can help to see, is there something we can do? We may not be able to make everything go away and stay away with a symptom, but maybe we can reduce the frequency that you're up at nighttime. Maybe there are things that we can investigate that would help with, you know, frequent–if you're having diarrhea, maybe there's something that we can do or some adjustment that can be made that the symptom becomes less bothersome. And again, that all, you know, less bothersome symptoms also reflects in improved quality of life and just general wellbeing and feeling good about the treatment that you're getting or the decisions that you've made. And I also tell people nothing is written in stone.

1:07:16 Speaker 4: So just because we have this plan, just because we're doing this today, we have to be flexible and make adjustments. Because what we know is true, maybe in terms of a medication or a dose for someone, doesn't mean that that's the right dose for that person sitting in front of me or that patient. So letting them know that adjustments could be made to treatment if things aren't really all that tolerable, it doesn't mean treatment's going to be taken away. And it certainly doesn't mean you have to suffer through if treatment is expected to be, you know, a year, two years, or even lifelong looking at, you know, things that can be done to mitigate some of these symptoms and side effects is so important for the patient, the caregiver, the family, just everyone which, I think that's what we all offer with each of our unique roles on a clinical team. What one person may miss, the other may pick up. So I'm glad we have this comprehensive team always looking at patients.

1:08:18 Speaker 3: Wonderful. Well, thank you for that, Brenda. Just to address some of the questions in the chat, I want to share that. Yes. Hormonal-lowering medicines, taking testosterone levels down very, very low with androgen deprivation therapy does cause multiple things, including shrinkage of the testicles and shrinkage of the penis. There are not easy ways to fix or reverse that, but it is something to talk to your urologist about. One piece I do want to share related to side effects is that there are different types of urologists. There are the urologists who do surgeries to remove prostates. Those are urologic oncologists, so cancer directed urologists. But there are a totally different group of urologists who actually work on men's health issues. Things like erectile function, urinary leakage after prostate cancer surgery, and these individuals, maybe the right type of urologist to engage with. If you are having a lot of leakage, if you are having erectile dysfunction because they have the expertise to perhaps put in an artificial valve that stops the urinary leakage or give you maybe strategies around injections for erections or even a prosthesis that can be implanted in the penis to allow you to have pretty normal erections basically on demand.

1:09:34 Speaker 3: But it is a surgical procedure to have that prosthesis placed. So these are conversations to have with your urologist. It is worth having them. I think, caregivers, please support your loved ones to have those conversations, because you can feel better. And it's–but you have to ask the questions. Just as Brenda said, people won't know to refer you there if you don't let them know. And then gastroenterologists or other supports, perhaps medical oncologists can help with things like hot flashes by using medicines in addition to things like Effexor, maybe oxybutynin, maybe acupuncture, maybe some other strategies or things like GI distress, frequent bowel movements and those kinds of things. Maybe you'd need to go see a specialist there. So do talk about those issues with your teams. Let's shift gears a little bit, and let's talk for a moment about one of the other questions that came in and put this in the framework of even advanced prostate cancer. That's not curable. Perhaps. You know, we may find that it's harder to cope or very hard to cope in a situation where a cancer diagnosis is going to be with us for the rest of our lives. Also, of course, hard to cope with a cancer diagnosis that we think might be cured as well. But Sharon, we did get a question about spirituality. Spirituality and kind of what role, if any, does this have to play when people are trying to cope and manage, especially maybe with long-term challenges like incurable prostate cancer?

1:11:01 Speaker 5: Yeah, I mean, I think that for people who have a strong religious or spiritual affiliation, where that is a source of strength where there's a source of community which is very supportive, we know that spirituality is really one–is a very major source of strength and healing for everyone, right? Well, not just patients, but also for caregivers. And I would say, again, it's both, you know, I think in terms of one's personal relationship with a spiritual being and also often in the context of a community, which can be incredibly powerful, I would say, that's a good example of something which is helpful for some folks and not necessarily helpful for others. Right? So, what I think is important is to be able to identify what your needs are, right?

1:11:58 Speaker 5: Sometimes people may, for example, not have been particularly connected to a practice, whether that's every, you know, could be a meditation practice, could be a church-based spiritual practice. And in the context of illness or lifelong illness that all of a sudden is something that they realize could be a major source of strength. You know, what I would really invite people to, again, consider is, is that this is a time where we can reflect on what we need, you know, and I think this is just as important for caregivers as it is for patients. And I will also say it's not always the same for both, right? Sometimes we see within a couple, you know, partners and caregivers share, for example, a spiritual home. And sometimes they don't, you know, sometimes there is something that may be more valuable for one than the other.

1:12:53 Speaker 5: And I think what's important here is, at least from my perspective, not to judge, right? Not to be trying to prescribe that, but more about inviting people to really figure out what it is they need and to value the fact that taking care of yourself is just as important as taking care of other people. And so, you know, because if we don't have, as I said, gas in the gas tank, and energy to be able to take care of ourselves, it's really hard to consistently day by day, show up for other people as much as we want and need to do that. But certainly appreciating that spirituality, whether it's in a more organized way or in a more individual way, is absolutely an incredible too for those who find it useful.

1:13:44 Speaker 3: Great. Well, thank you for that. You know, let's continue kind of focusing on caregivers. We're focusing a little more on advanced disease, but I'd like to invite Wendy and

Stu back because this is not something that's specific to advanced disease or to localized disease. Wendy, you are an expert communicator with doctors. And we heard as we were first just chatting, that you, you know, interviewed many doctors to find the right team to support you and to have that good communication, not just with the doctor, but with the team. Can you tell us a little bit–any advice you have for caregivers, for partners who are trying to help choose the right doctor for their partnership for this diagnosis, and also how to optimize that communication and that ability to reach out when you need it and share that information, ask for information when it's time?

1:14:44 Speaker 6: I think that, you know, one of the things that we came to realize, because we had a couple of situations where friends or people we knew came and asked us, like they were newly diagnosed, "What do we do? Where do we start?" Is that you have to recognize that, you know, so we may have spoken to or met with eight to ten doctors, but you really have to focus on who you feel comfortable with. So…and that you can, I think, tell pretty easily, you know, it has to be a good fit, how much information they share with you, the type of questions they ask you, the type of opinions they have and how they back them up. So you can sort of see because you have to have a lot of trust and confidence in who you choose for your treatment.

1:15:46 Speaker 6: But, you know, sometimes it's as simple as saying, "How do I communicate with you if I have a question?" And you'll see how accessible they are. Are you communicating directly with them how much staff they have? And the interesting thing that we found is that when we would sort of give an abbreviated list to friends of these are doctors we think you should see before you make a decision where you're going to be treated, they didn't have the same opinions that we did about the doctors. So it's a very personal decision. It isn't just saying, "Oh, who's the top doctor where I live, in our case, New York City," or "What's the top hospital?" You come to realize that it's a more personal interaction on that level. And that's really important to acknowledge for yourself. And it has to work, I guess, for both people in the relationship, that they feel comfortable. And maybe for a caregiver, you want to feel that you're being acknowledged by that professional and that that you are included in the conversation.

1:17:08 Speaker 3: Absolutely. And just a follow up question, I know you're the primary partner and caregiver, obviously of Stu, but do you have children who might also have–maybe adults now–but who might have participated in this? You know, sometimes people have adult children who want to be heavily involved and, you know, do you have any experience with that or any advice for how others beyond that direct romantic partner can also serve in that caregiver role?

1:17:41 Speaker 6: In our case, I think it was not so much as a caregiver in terms of meeting with doctors or anything, it was more for support for us. So that if Stu was going in for a biopsy, we have five kids between us, you know, one or two might say like, "Oh, I'll come and keep you company if you want while you're waiting." Or they would check in more or remember more like, "Oh, he is having a test. Let me offer support. What can we do?" And that's more probably because of the timing of where they were in their life at the time. They were, well, they were all out of the house or already, right? They were out of the house, but they were in college starting careers. So they were sort of different from, let's say, when Stu and I were dealing with our parents being ill and having medical issues, and we were older, so we had more time and yeah, availability.

1:18:44 Speaker 6: But I would say in terms of support, they were there and were also very close to my sister and her husband, and they were also very supportive. And especially in the times of crisis that we went through, because I also was thinking as I was listening that a lot of times, this isn't the only issue we're dealing with. Stu had other health issues. I had, we had all four of our parents had gotten ill and passed away during this 17…you know, there's a lot going on. So it's not always that you're dealing with just one issue. And so that can sometimes complicate things, but I think that when you're trying to find care, you have to make sure that that particular caregiver and as well as the treatment feels right to you.

1:19:41 Speaker 3: Great advice. Definitely great advice. Now, let's shift a little bit. I think a lot of times when we're talking about advanced prostate cancer, incurable prostate cancer, there are standard treatments, and then sometimes there is the opportunity to consider clinical trials. These might be standard treatment plus something extra that to be even more strong and more effective. Sometimes it's standard treatment and we're trying to decrease the treatment burden, but maintain the effectiveness or the impact of that treatment, but just try to decrease the symptoms that can come from it and everything in between. I wonder, you know, it's not uncommon that a partner has to or has the opportunity to support someone as they're considering a clinical trial. Brenda, do you have advice on how partners might help support patients who are thinking about clinical trials to feel comfortable, to feel confident, to feel supported, to feel like it's a safe option for them?

1:20:39 Speaker 4: Definitely. This is a good conversation between patients and their partners. I will say if anyone has ever been approached or had the opportunity to participate in a clinical trial, they all include consents. And the consents purpose is basically to give the patient, the caregiver, the partner, as much information as possible so that when they do decide or decide not to, their decision is informed. So when I first started, consents weren't quite as cumbersome as they are now. They used to be five or six page documents. I can tell you with some of the clinical trials that I've talked to patients about, it's not unusual to hand them 30 pages of light reading for them to do. So, you know, that's a lot to sift through and, you know, and also, you know, there's a lot of information in there that's all important, but sometimes being able to help the patient and the caregiver or partner kind of focus on the more unique things about the trial or the side effects, as well as, you know, talking about the risks, the benefits, what's the expectation of the study, kind of trying…

1:21:55 Speaker 4: I try to give them a more kind of brief synopsis. And of course they are to take the consent home to read about it, but there's no right or wrong answer. And I also remind them that if there is an opportunity to participate in a clinical trial, the decision making is the same as if we were talking about another treatment option. So, you know, it's sort of like, “Is this matching with your goals? Does it align with what you're looking for?” You know, “What are your comforts, what are your fears about being in a clinical trial?” You know, patients just like, you know, all of us, we come with preconceived ideas, we have past experiences, we know other people who had a situation that was similar, and this is what happened. So, you know, opening that door and not only with the information or the synopsis, but asking them what sort of concerns may they have or might they have initially about considering this.

1:22:59 Speaker 4: And I think another big factor about, you know, supporting the patient and the caregiver or partner is what's the time commitment with the clinical trial? Some clinical trials can require a lot of extra visits for safety, and that necessarily isn't a bad thing, but do you have the time, do you have the transportation? What barriers might be currently in place that may influence your decision making, even if you're interested in actually participating? And what can we do to help mitigate or remove some of those barriers? And again, you know, the care team is so important. So, you know, the clinical research office, the nurses, the data coordinators, study coordinators, they're often very much involved in answering questions and they're another go-to.

So another resource point that's available. And again, no one should make a decision on the spot. There's time to think about things, there's time to ask the follow-up questions, and we're available to answer any of those questions.

1:24:09 Speaker 4: And, I think, you know, I think it's all about education, conversation and, you know, just the practice that we have every day addressing questions, concerns. The most important person in the room is the patient, the caregiver, the partner. So, you know, and also it's mutual decision making. So it's not me telling the patient what to do and reinforcing, this is all mutual decision making. You know, ultimately it's the patient, the treatment, et cetera, that will happen to the patient with the effects on, you know, the patient and the caregiver. But again, nobody is making a decision for them. And I will tell them, too, when they're considering a clinical trial, that there are eligibility criteria, and these aren't meant to discriminate or do anything. They're meant for safety. So even if there is an interest in a clinical trial, there's certain parameters that have to be met.

1:25:09 Speaker 4: And those could be lab parameters. It could be, you know, are there any other medical conditions as we've alluded to that may not make it the best or the safest option for, you know, for the patient? Or are there medications that they're currently taking? So the clinical trial is an opportunity, but again, we have to make sure it's safe for the patient, there's screening involved, and also make sure that it's something that's feasible for the patient. And, you know, cost, again, depending on where that patient lives. I work downtown in Chicago, a major medical center, and parking is not free, even though it's discounted. So, you know, like I said, looking at different barriers, looking at restrictions, how best can we do something for that patient? And, you know, and again, just making sure they feel comfortable in a conversation and that they feel that there's permission for them to, you know, share their concerns and ask their questions. So I don't know if there's anything else you want me to think about Alicia or a follow up?

1:26:16 Speaker 3: No, that is excellent. And you know, I think your comment about understanding why there might a person–might feel barriers is really, I think, the best place to start. What are your concerns? What are your hesitations? And then if the caregiver, the partner can't answer or help relay any–or allay any of those, you can always reach out to the care team, “These are my concerns. Should I be worried about this?” If they can't say, “Here's how we'll fix that,” or, “Here, you don't have to worry about this,” then maybe it's not the right thing for you. But asking the question is the place to start. And understanding what the barrier is from your perspective as the patient's perspective is really, really important. You know, I think we are definitely winding down here. Sharon, I want to pass to you with a couple of pieces to focus on as you kind of wrap this up.

1:27:12 Speaker 3: A lot of the treatments for prostate cancer, whether they're hormonal lowering medicines or the physical treatments themselves, like radiation or surgery, can lead people to feeling isolated, depressed, alone, just down. And things like support groups are one way that they may have some way to lift themselves up. Caregivers may feel similarly that support groups may be helpful. I wonder if you could speak to that: support groups as a method to try to pull people up and give them a community that understands them and any other ways that they may be able to improve their mood or feel less isolated.

1:27:50 Speaker 5: So quick comment. Thanks for the question about care groups or support groups. I would just say in general, we know that nobody can do this alone, right? And that's partly why we have this wonderful webinar on caregivers, right? Because nobody can do any of this alone. But I would say that it–a couple things. One, I am a huge fan of support groups because I think in general it can be incredibly powerful to have a group of people that, as you said, can help kind of lift you up and sort of be in this together. I will also say, and I'm going to be totally honest about this, not all support groups are supportive. Meaning that you have to kind of find the right group for you. So you know, that may mean that if you are, for example, dealing with you know, you're living with metastatic disease, you may want to be in a group with other people who get that.

1:28:40 Speaker 5: On the other hand, if you are no longer on treatment, being in a group with people that are dealing with metastatic disease may not be helpful to you, right? So I think it's important just to recognize that, like anything, you have to find the right…I appreciate how, I think it was Brenda or Wendy talking about finding the right doctor. You know, I think you have to find the right group, and that means that you might want to check out a group. And if it is great, that's great. And if it's not, I wouldn't give up on groups. I would say, there are a lot of groups out there, right? And I believe that there are excellent caregiver support groups as well. I know through cancer support communities and other places, there is a growing acknowledgement that caregivers need support.

1:29:25 Speaker 5: And there are actual opportunities for caregivers to be able to get together and really be able to share with each other. So I would just say in general, you know, whether it's for sort of general coping and wellbeing, or also thinking about the specific kind of, you know, challenges that men have around the sexual side effects, there are absolutely a number of private Facebook groups. There are a number of support groups available where people are speaking very frankly, very openly about these things. And, I would just say, you know, it's important to acknowledge that, again, not all groups are for everyone. So you have to be open-minded, check it out, and if you don't find that a particular group is the right one for you, don't give up. I would just do a little bit more looking. And the other thing more broadly is just to say that there is support out there, right?

1:30:14 Speaker 5: So beyond groups, there are individual opportunities to get some counseling. There are opportunities for couples to see somebody together to get a little bit of help or support. The main thing here is just to not feel like you have to figure it out by yourself. I think that that's what is wonderful about this webinar and Prostate Cancer Foundation. And,, you know, the message is that you don't have to do this by yourself and to be able to really sort of use the resources that we have out there.

1:30:45 Speaker 3: Well, thank you so much for that, Sharon. Thank you, Brenda. Thank you, Wendy and Stu, I'm going to pass back to Becky so she can close us out.

1:30:55 Speaker 2: Thank you so much, Dr. Morgans, Dr. Bober, Brenda, Wendy, and Stu. This has been just an amazing, amazing 90 minutes, just so much information, and I'm so, so thankful for you all for sharing your experience, your expertise, your time, to all who stayed with us. I hope that this time was valuable for you and that you're taking away some new knowledge or inspiration to help you make decisions about your care with your caregiver, with your patient, with your family. And I'd also like to finally thank Novartis for helping to make this event possible. Look out for an email with links to the recordings. We'll send that along in about a week. We'll have additional information on these topics and the links that we shared in the chat. So thank you once again to our panelists, Wendy, Stu, Dr. Morgans, Dr. Bober, Ms. Martone, have a great rest of your day, everyone, and please be well.