

**Becky:** Good evening, everyone, and thank you so much for joining our webinar tonight. We're going to be talking tonight about how navigating prostate cancer is a team effort with oncology nurses, social workers, and other health care professionals. We're really going to dive into those other questions beyond "What is my treatment?" Because, as we know, there's so many other issues that patients and family are navigating.

So, it's going to be a really, really great session tonight hosted by Alicia Morgans of Dana Farber Cancer Institute. So, thank you all for taking time out of your evening tonight to join us. I'd like to thank our gold-level supporters of our webinar series, Lantheus and Veracyte. Thanks so much for making this happen. And I'll just note that all views expressed during the webinar are those of the speakers, and don't necessarily reflect our sponsors' views.

So, in case you're not familiar with PCF, I'm just going to give a brief overview. So, we were founded in 1993, with the mission of reducing death and suffering from prostate cancer. We do this by funding researchers around the globe, both team science and individual researchers—we call young investigators—who are really emerging into the field of prostate cancer research and bringing new ideas to the field.

Many of the therapies used today were developed with early-stage funding from the Prostate Cancer Foundation. And the good news is that with patients living longer, thanks to the therapies and early detection, now research on optimized nutrition, exercise, and cognition can help improve patient's quality of life. So, we are also funding research in that area. And obviously Dr. Morgans is one of those researchers in survivorship who's done a tremendous amount to advance that part of the field.

We also have educational resources for patients and families. You can go to [PCF.org](http://PCF.org) to request patient guides, view past webinars. We have a virtual patient and caregiver summit coming up on June 29th that's going to focus on localized prostate cancer. So, you can register for that at [PCF.org/patientsummits](http://PCF.org/patientsummits). And we have a new-ish partner website called Prostate Cancer Patient Voices that highlights the voice of the patient. So, there you can listen to patients and caregivers telling their stories in their own words.

If you feel inclined, you can support our mission through a donation in any amount. We funded more than \$27 million in research awards in 2023 and including Dr. Yang of Dana Farber Cancer Institute, who is featured there on your screen. And all of our speakers tonight are from the Farber in Boston. Go to [PCF.org/donate](http://PCF.org/donate).

So, I'd like to, without further ado, go ahead and introduce our speakers. Dr. Alicia Morgans is a GU medical oncologist. She's a medical director of the survivorship program at Dana Farber. She's a clinician and investigator with expertise in clinical trials, patient reported outcome measures, and she's also a PCF awardee multiple times.

We're grateful for her past and continued efforts in patient education, as well as provider education through our partner site, UroToday. We're also joined by Max McMahon, who is a clinical social worker at Dana Farber. He specializes in men's health and aging in the oncology setting. Max has also worked as a hospice social worker, and his clinical interests include sexual health and prostate cancer, end of life care, and addressing existential themes. He attended Bates College and has a Master's of Social work from Boston University. So welcome Max.

And I'd also like to welcome Stacy Walker. She received her Bachelor's degree from the University of Pennsylvania and her nursing degrees, including her masters, from Simmons. She worked for seven years in geriatrics and long-term care prior to transitioning to oncology. She actually worked at the Farber while in school and then later returned as a nurse practitioner. And her clinical interests include all GU cancers, particularly prostate and kidney cancers. So welcome, Dr. Morgans, welcome to Max and Stacey. And I'm going to turn it over to Dr Morgans, who's going to lead us through some general discussion topics. If you have a question, please type it in the Q&A box at the bottom of your screen, and we'll get to as many as we can. Thank you so much.

**Dr. Morgans:** Thank you, Becky, and thank you, everybody, for being here today. Max and Stacy, thank you as well. I think this is the first time we've had you on a PCF webinar. So, we are really just thrilled to have your expertise joining in with all of the patients and all of their questions.

And please, everyone, as you are listening, as you come up with questions, please write them in and let us know where you want us to kind of go with our ongoing conversation. I think we're really excited and happy to take on anything that you have related to this topic and any questions that you have, and we'll do our best to answer.

I would say that a lot of times our experiences based in our own past experience, whether that's here at Dana Farber or at other institutions. And so, it may be slightly different where you are, where you're receiving care. but do just sort of take our insights as you can and then, you know, adapt them as you need when you're talking to your own practitioners and thinking through your own situation.

And everybody's a little bit different in every, and every clinical situation is a little bit different. So hopefully this at least will be a place to start. So again, thank you Max and Stacy for being here. And we'll dive right in with some of our discussion topics, which I think are hopefully going to be really helpful for people.

Now, Stacy, you are a nurse practitioner. And you know, that is a little bit different than being a nurse. And so I think I'd like to start off just sort of thinking through "Who is a nurse practitioner?" "Who is an oncology nurse?" What's the difference in terms of training and background, and how do these different roles actually function on an oncology team? Because I would imagine many patients and their caregivers and loved ones are going to be interacting with actually nurse practitioners and with oncology nurses in their experience with cancer care.

**Stacy:** Yeah. So, as you mentioned, I'm a nurse practitioner, which means I am a nurse who has done additional schooling and I have my master's and have the ability to diagnose and prescribe, as opposed to RNs - nurses who who are generally kind of working off of us and the MDS, in terms of making diagnoses and such.

So, when - in your kind of experience with the team generally, the first line is the nurse. And our nurses are incredibly well trained in and with extensive background in oncology. They can often answer all of your questions without needing to come to us. But, as is within their license, they pretty much always run everything by us, you know, even if it is just a "This is what I told them." "Let me know if, you know, if you suggest any changes." But our nurses will generally be the ones that are answering your messages in, you know, in the online portals and the ones that you're talking to about symptoms and being kind of your first line. We have multiple nurses on the team, and you likely would as well, especially if you are kind of on treatment.

We have our nurse - we call them nurse navigators - often places call them program nurses or oncology nurses. And they're kind of the ones in the clinic with us answering the phone calls, maybe even coming into the patient - into the exam rooms and seeing you in clinic.

And then there are the infusion nurses. So, we call infusion here at Dana Farber - infusion is anything that's happening over on the infusion side, which can include injections as well, such as Lupron and degarelix. And so, the infusion nurses are separate from our program nurses or nurse navigators and they're the ones that would be seeing you, giving kind of during your active treatment. So, for us, and again this might be different elsewhere, but you would see the doctor or medical oncologist or a nurse practitioner or physician assistant, and then go over to an infusion nurse who would be providing the actual hands-on care of therapy.

Our nurses are great at contacting through, again, through the portals or through the phone - generally whatever is more convenient for you as a patient. And that's the - our roles.

**Dr. Morgans:** Great. Thank you for that. And I would just add, you know, I work really closely with many nurse practitioners and physicians assistants.

And I would say, you know, you may find in your care that sometimes you see the doctor and sometimes you see the nurse practitioner - a physician's assistant - and, you know, at least the way that we operate, you're essentially getting the same care regardless of who you're seeing. And I think it's really important, at least in our teams, and I think in teams in many centers, that we are truly teams.

So, you know, whether you're seeing me or whether you're seeing Stacy in our clinic, you're probably getting the same answer, the same recommendations and what's really interesting is when I see a difficult patient, I talk to Stacy and say, "Stacy, what would you do?" "How do you think about, you know, kind of helping support this really complex situation?"

And Stacy does the same. And we do that with the other doctors on the team, the other nurse practitioners, the other physicians' assistants. So, it is really, I think, important - we all have a label, but essentially the doctors, the nurse practitioners, and the physicians' assistants are sort of one level of providing care. As Stacy said, that we write prescriptions, we kind of think about differential diagnoses.

And, you know, how do we diagnose these different problems, how do we treat these different problems? And the nurses are in their own sort of situation, where they're often doing symptom management and refill requests, and trying to get people lab work and trying to kind of coordinate as the glue between all these levels. And then sometimes we have also administrative folks who are helping us get outside records and different things like that.

So, there are many different people on the team. And I think it's really important that if you say to yourself, "Well, I'm seeing the nurse practitioner, but I haven't seen the doctor in a while. You're probably seeing the nurse practitioner because she knows you best or he knows you best, and they're actually doing an amazing job. And I often feel like the right hand of Stacy Walker. It's definitely not the other way around.

So, in any event, that's my view on these levels. But, Max, also a key member of the team, can you tell us a little bit about who the social workers are and what do they provide, in terms of the team, of the patient, and how does a patient engage, you know, are you or social workers like you, people that, you know, patients should think about being able to call on?

**Max:** Yeah. Thank you so much, Alicia. And thank you, Becky and PCF for having us. I think, you know, social workers in the oncology setting were less common than nurses.

And so, I really, you know, I encourage all of you on this on the Zoom tonight to really think about sort of these larger resources. And every institution is going to be different with their social work resources.

But essentially, my work is thinking about what are concrete resources that patients may need. And also really the psychosocial supports and resources.

So, time of diagnosis, or change in status, or rising PSA, or your testosterone has dropped and you're feeling bummed out, or you're feeling nothing, or you're feeling sad. My role is really to sort of help patients walk through some of the experiences they have with treatment, with diagnosis, with maybe change of status, and really kind of spend time unpacking and listening to the concerns of the patient, ideally to guide them towards something that is supportive.

So that could be a referral to our psychiatry department if we think medication may help, it could be access to a support group, it could be a discussion with a spouse or with children, it could be coaching you as a patient on how to have conversations in your own life. So really, I think, you know, social workers are sort of this "catch-all" a little bit for the non-medical supports that patients need.

And that might be a resource to the pharmacy office or access management, which is our insurance folks who sort of process insurance and the financials. So, you know, I think it's really important to think about, you know, as patients, to really think about what are the things that I'm sort of struggling with, with diagnosis or treatment and who else on this team can I access.

And I really encourage all of you to sort of talk to your whomever - your kind of primary provider is and say, "Oh, is there a social worker or a resource specialist that I could talk to because I'm having a hard time getting to appointments, or I'm having a hard time paying, or I'm really depressed, or my wife is having a really hard time, or I have no libido and I'm having a hard time with that."

So again, the social work role is really to sort of hold some of the psychosocial and resource needs of patients and help work through those things and also guide towards the most supportive resources.

**Dr. Morgans:** So, Max, just to continue up on that for one second. So, you've talked about a couple people. So, you know, obviously our teams are complex.

And again, in your individual institution, your team may be a little bit different based on the resources and the strategies that, you know, your group has around supporting all of these patient needs. But you mentioned financial counselors, and you also mentioned, I think, additional forms of psychosocial support, even psychiatry. So, can you say - can you sort of explain from your perspective, you know, who are these folks that might be of importance to patients who are coming through?

And we know financial toxicity is something that has really been, I think, more recognized, but has always been an issue in prostate cancer and in any cancer. So if you could touch on those two groups of people, it'll be really, really helpful

**Max:** Sure, Alicia. Sure. Yeah. You know, I think the social worker's role is to really assess what is the primary concern of the patient.

So, you mentioned financial toxicity. You know, if a patient comes to me and says, "Max, I'm having a really hard time paying to come to appointments, or I don't have a - I don't have any, like, petty cash, I don't have food." I mean, those are real concerns that many patients have. So, that's something I may assist with because we have resources and a resource specialist within our team who might be able to help out with a gift card or transportation options.

And I like to think of resources as, you know, each institution - sort of home institution - has resources affiliated with it. But then you're going to have, you know, municipal and regional resources. And then, of course, national resources, which may be available, to the patient. So that's my role is to sort of help figure out what are those resources that can help specifically with the financial and kind of lifestyle piece.

And then I think from the psychosocial perspective, it's really assessing how is someone doing, with treatment, with diagnosis, with dealing long-term, you know, and that's my role is really to work with the rest of the team, with Alicia, with Stacy, with others, to assess, "Well, do we think this is sort of normal functioning given what we see or is this unusual? Right?" So, we're very used to working with anxiety, but sometimes anxiety can really get in the way of treatment, or anxiety can be crippling. So, in a case like that it's really consulting with our other providers - at the Farber, we have psychiatrists who will prescribe medications. I don't prescribe directly. And so it's having these other consultations with psychiatry, maybe psychology as well.

Sometimes it's a young adult program. Most big centers have young adult programs. And really as a team, trying to come up with - a team and you as a patient - trying to come up with what is - what are all the supports that we can offer you that will be helpful. And so oftentimes it's sort of digging below the surface to figure out what else can we offer that might not be apparent to the patient when they first walk in the door.

**Dr. Morgans:** So that's really important, I think, just acknowledging that sometimes digging is needed. What I would say to everybody on this program is not that anyone is trying to withhold anything, or that they're trying to not offer you something, but, you know, cancer centers and cancer providers often have all kinds of different support around. And I'm going to ask Stacy about some different supports on the clinical side, or more of the sort of medical - medicine - medication side, I guess I should say, in a moment.

But, you know, there's a question in here. You know, "I didn't realize I had access to social workers." Well, at Kaiser - Kaiser is a big, big organization. And it's actually a fantastic organization, from what I know and understand in terms of cancer care. And I would be surprised if there are not social workers where folks that can provide similar type supportive services and needs assessments - which is often what is so helpful about our social work team.

You know, they help, they listen to all of the things that someone is dealing with and say, "okay, this person can use some financial support, and this person can use some psychosocial support, and this person can use or - psychological support, I should say. This person might need to just kind of link back in with their clinical team because they have questions that are really important for the nurses there."

So, maybe that person needs just counseling and perspective on coping. And that might be provided by the social worker herself or himself. And actually, we're so lucky Max has actually launched a sexual health support group because obviously in prostate cancer, that's a really big issue that many of our - if not all of our - patients have to think about. Even if it's not important to them at this moment, it may be important in the future, perhaps could have been important in the past, and something that they want to revisit.

In any event, there are lots of needs. And social workers are amazing at understanding the breadth of opportunities available to patients to support them. So, I would suggest for anyone who says to themselves, "Well, I'm just not sure if I might - I need help in this area, but I don't know who to ask." I would ask your team - if you have a social worker who could help you with that needs assessment. If not a social worker, then a nurse may be able to help as well.

You know, there are a lot of people on your team. And I hope, as the doctor even, that I'm able to sort of listen to some of peoples' needs and try to help connect them. But no one person is going to be the person to know the right answer for every question you have. And so that's why we have teams.

So, thank you for asking that question about Kaiser, and really giving us the opportunity to think about, you know, how do we access this? Social workers are probably available in most organizations that provide care for cancer. So, just ask, and if the social worker is not the right person for you, that social worker can probably tell you who you need to talk to because they're really, really good at that.

Alright. So, Stacy, I know that you prescribe a lot of medications. And I know that some of those medications interact with other medicines or are hard to get because they're extremely expensive. So, I wonder, can you speak a little bit about, you know, the pharmacists and how patients may interact with them? What your interaction with is with them?

But how would a patient know the pharmacist? And also about maybe the interaction between pharmacy and prior authorization teams, or financial counselors, and how does that happen? Because some of these medicines are ridiculously expensive and I think one of the most important things for anybody to recognize with prostate cancer is nobody can afford \$15,000 a month or \$13,000 a month as a cost for cancer medication or anything like that.

I mean, that is well, well over my mortgage, just to be clear. So, that is not something we would expect anyone to pay. So, you're not unusual or crazy or strange to have to talk to somebody about some of the costs of these medications. Anyway, Stacy.

**Stacy:** Yeah. And I would, you know, I would just start by saying I encourage everyone. If you have a medication that is high cost, not to just assume that you need to - that you need it because - or that you need to pay that.

Because we have all sorts of options, and sometimes the option is looking for an alternative. But most of the time the option is finding a way to get it more - or at a more appropriate cost. And so, you know, what we do - what my role there, after prescribing, it goes to our pharmacy team, they start the prior authorization process. If there is a prior authorization needed, we have a special team that does prior authorizations, and it gets bounced back. We look at the copay, if it requires a - if it gets denied - again, you know, a lot of patients panic because they get a letter from their insurance company saying it's been denied.

What my role in that case, I write many letters of medical necessity. I have templates you wouldn't believe! And so sometimes it takes a little bit of time, but often we get things covered that initially are denied. And then once it is - once it is covered, it's often still has a high co-pay.

So there are all of the - you know, we have a whole team dedicated towards financial assistance for, specifically for medication. And so, what that looks like is, you know, finding out if the drug company has a special program to help with copay assistance, if the - if our - if we have a cost matching program. There's all sorts of different ways that we see financial help, whether it's through the insurance, through the drug company, through our organization, through outside organizations like Max mentioned there being kind of national organizations that sometimes help with these things.

So, that's often where it gets kind of pushed to one of our resource specialists or our social workers to know kind of what else is out there in terms of being able to get a co-pay card, for example. So, there are lots of options. You know, and I would mention that I don't see a lot of this in in prostate cancer, but even sometimes not just the medications for treatment, but sometimes medications for side effects too that we prescribe, they can sometimes have high co-pays.

And so again, I just encourage you, if you ever come across that you go to your, you know, local CVS or drugstore - or whatever drugstore of choice, to pick something up, and there is a high co-pay, don't immediately assume that you need to pay that. There are often alternatives, that we use regularly and safely that just aren't, you know, necessarily our first go to. But we would look for an alternative if something is a high cost for you.



**Dr. Morgans:** Sorry, I was having trouble unmuting myself. Sorry about that. So, that's absolutely true. And I would suggest when it comes to supportive care meds - and I was just trying to paste this into the chat, which is why I was having trouble unmuting - and I am not able to paste something to everybody - but I wanted to just alert everyone to a website called GoodRx.

This is a website that - actually, so little did I know, until I actually was in medical school, that every pharmacy can actually sort of think about the cost to income ratio on any given prescription. And so they set the amount. Thank you for putting that in there, Becky. They set the amount of markup that they're going to have on any given prescription, anything in that they carry.

So what GoodRx does, is it sort of looks at every pharmacy in your area and for a particular medicine and will tell you what the cost is. And it just does a cost comparison. And it actually provides coupons for many, many medications that maybe it has some sort of agreement with Walgreens or Walmart or Costco or CVS or who knows what, but it might have that agreement so that the thing that costs \$700 at pharmacy X costs \$10 at pharmacy Y, and you don't know until you go into this thing and it does all the comparison and offers the coupons.

So, for especially - for supportive care medicines, GoodRx I think can be really helpful. It also can be helpful with abiraterone, which is a medicine that we often use the other name for that is Zytiga. But the other thing that is really, really helpful for patients with prostate cancer is that Medicare this year, 2024, set a cap on the out-of-pocket costs for pharmacy benefit for, you know, the copay stuff that we have to do, which I believe for medicines that are still, not generic - so still brand name, is, I believe, \$3,300 a month. Please do not hold me to that. It might be \$3,500 a month or - a year! Guys, that's \$3,500 a month is ridiculous. Sorry about that. \$3,500 a year is still actually quite high when we break it down month to month, but can be manageable for patients in a way that is way better than, you know, \$35,000 for the year.

So, it could be potentially more manageable. And when we get into 2025, I believe that cap is somewhere around \$2,200 a year - a year. So that's somewhere around \$200 a month. And that's all out of pocket for medications that are not generic. So this is really important for us to think about and to know.

So, things are getting better. And that's good for people with prostate cancer. But the folks from the financial assistance team can be extremely helpful. And pharmacy interfaces with them as well as with the team, like Stacy said, and says, "Hey, Stacy. I need a letter of medical necessity. I need, you know, a letter to share that this has to happen and sort of rebut that refusal or denial from the insurance and Stacy and her team - and people like Stacy, so nurse practitioners, physicians assistants or sometimes pharmacy teams, nurse teams, whoever it is at your center - can rebut those denials and can get you covered. And I think that happens more often than we expect. So, just know that prior authorizations are

attainable. It just it does take effort, but usually the effort is not necessarily on the patient part.

Sometimes there's some financial forms you do need to fill out, but a lot of times it's your team that's going to bat for you, and they are going to do everything they can to get that medication for you. So, anyway, Medicare is making changes. Your team is supporting you. So do ask. And I just want to mention also, that it looks like some of the folks who are on the webinar have been helped by social workers and I just want to give a call out. It says that, you know, social workers I've spoken with really helped me through some anxiety. Social workers are phenomenal. They're not just needs assessments. They do help a lot with strategies around coping, thinking about, you know, prioritization, thinking about family, thinking about supporting children or loved ones as you're also supporting yourself.

So social workers are sort of "Jacks of all trade," and really amazing to have on your team. So do ask for them. I have not worked in a center that has not had access to a social worker. I do think that they're, you know, commonly recognized as incredibly important members of the team and so are probably available where you are.

But you do need to ask. So, let me just ask Stacy and Max and - lets put this out there - so when you have so many cooks in the kitchen, so many members on the team, it can be hard to think through, "What does communication look like?" And I think we have had some questions on this. You know, how often do teams get together?

Are they sitting in a room having lunch talking about everybody? Or are they having like big tumor boards - and that's a weird sounding word to people who are not in medicine, but it essentially is a meeting where we go through images, and pathology, and treatment options, and plans and have lots of team members there. And we talk about what's the best strategy for this patient? Or how is this happening?

How often is communication happening? What does that look like in real life? So, I wonder, let's start with you, Stacy. What does communication look like? Does it vary along the course of the treatment plan? Does it need to change and become more frequent, less frequent over time? what does it look like for you?

**Stacy:** So, I think it, you know, it does depend on the treatment - the treatment plan, kind of if someone is progressing versus whether someone has stable disease.

You know, we are very lucky to work in a scenario - Dr. Morgans and I are frequently, you know, or generally in clinic together when we're working. So, there doesn't necessarily need to be a formal, you know, meeting every week. We see each other, you know, twice a week. And so, we're just discussing the patients that have active things going on that we are following up on.

And as I do with the other physicians that I work with as well. I do, you know, I think, for the - for patients who have, kind of a lot of changes to their care, and are having, you know, are either having some distress or having a lot of complications, or honestly, even if they're not medical complications - if there are a lot of social factors going on that we need to be aware. We communicate a lot online. You know, we have kind of ongoing threads with what's going on with the patient, so that everyone can be kind of - everyone on the team, including social work, including the nurses, everyone can be kind of looped in at once.

I will say, at least on our team, our nurses, again, going back to those nurse navigators - or program nurses - are really kind of our glue. And keeping that conversation going. I think especially because they are the most - getting kind of - talking to the patients the most on the side outside of clinic.

But our conversations, aren't - they're generally not formal. You know, they're very informal and frequent. About the patients and then in the formal sense, it's, you know, if we need a significant treatment change. And then we have something - like Dr. Morgans mentioned - tumor boards, where we're looking at it with a group, with an interdisciplinary group, saying, you know, people maybe from radiation oncology or nuclear medicine looking at scans together, coming up with a plan together, to make sure that our next treatment option is the best one, that kind of everyone agrees - know what all of the treatment options are, but making sure that our next one is the best one.

**Dr. Morgans:** Great. And Max, how does communication work for you? Because you're not in clinic with Stacy or with me. You - I actually have seen you in clinic sometimes, so I know you are! You are sometimes there. I just don't know why you're there, when you're there, but it's always a joy to see you there! When you are there! So, how does it happen when you're not necessarily in the same physical space all the time - and you can't be, with all of the different docs that that are - you know, and nurse practitioners and physicians assistants - who are supporting the patients that you also support.

**Max:** Yeah, Alicia. I think, you know, it's interesting to think about communication. I think patients don't realize how much we talk about them behind the scenes. And I think ultimately that's a good thing, right? So, if it's minor adjustments to medication, or I meet with a patient and they're - they want to hold a med, they want to stop a medication for a while.

You know, that's a consultation that I'm going to have with you, or with Stacy, or with the nurse navigator. So, I think, you know, the way I try to communicate, I think, as Stacy said, is there's a lot of informal communication behind the scenes and that's, you know, sometimes an email, sometimes on our EMR system, sometimes it's a phone call or text.

And it's always remarkable to me how much communication is happening behind the scenes. And just in the work rooms, in clinic, and there's so much of that. And I think often patients worry that, "Well, what if what if my doctor or my nurse isn't sharing this information?" And, you know, I think really in - on a good team, we're communicating pretty regularly.

It's not all the minutia of care, but certainly, if a patient expresses some concern about treatment, or a concern about an interaction with a provider, you know, I'm going to come back to the team and say, "Oh, this is what their experience might be like." The other thing I'd say, which I think that's really important with prostate cancer, is to remind, you know, everybody on this call that, again, in a system - in an ideally working system - medical oncology would also be talking with radiation oncology and surgeons and urologists.

And I think people - patients often worry that we're not doing that. And just to say that we really constantly are when there's treatment decisions that have to be made, you know, patients going to a different specialist and the specialists are talking behind the scenes on what they think is really the best course of action. And, but again, my approach is really to be responsive to the clinicians, to the providers on the team.

I sort of serve you, and Stacy, and everybody else, but I also serve patients. So, I'm really trying to listen to all the voices in the room to figure out what's going to be most helpful.

**Dr. Morgans:** Great. Thank you, Max. And I think one thing that I would suggest, because even the most perfect system, if you ask a question and you're trying to get it answered and you haven't heard an answer within 72 hours, maybe reach out via the portal or phone call and say, "Hey, this was an open question. This was something that - a loose end. This was a lab that I never heard back on. This was a scan that I never really heard about, or a pathology reevaluation that I never heard about." Reach back out. Because, even in a perfect system, sometimes the ball is dropped. And I would say, you know, that is extremely rare, but I always, always, always advise patients if you haven't heard back from somebody on my team within, you know, usually 4 or 5 days, please let me know, because either I didn't send a message, or I didn't follow up on something, or someone else didn't.

And we just want to know, so we can get this taken care of and get it moved on for you. And usually that actually doesn't happen. But I so appreciate that patients know that they are - they are welcome to be that second check and sort of, you know, hold us all to that standard because if I would ever forget to send something, or forget to put the order in, or forget whatever it is, because we're all human.

It is so important. Ultimately, just that the job gets done. Right? That the question is answered, the scan is done. The lab is ordered, whatever it is. And so, please never feel intrusive with your team to making sure to circle back. "Close the loop," as we say. We often say that at Dana Farber. Just "close the loop" to make sure that everything is - the boxes are checked, the i's are dotted, the t's are crossed, and we can go on from that.

So, you are a part of the team, too. And it's important for you to feel confident and empowered to make sure, when things aren't done, that you circle back, and tell people, "Hey, I'm just not - I just want to follow up on this, make sure it's done." So, one thing that I think is really important, and I know where we are - gosh, the time is flying.

Second opinions can make people really, really stressed. And we get many second opinion requests at Dana Farber. And our patients at Dana Farber often get second opinions somewhere else. You know, Stacy, I wonder if you can sort of share, from your perspective, what does it mean to get a second opinion? Is that something people should feel self-conscious about?

Stacy: I encourage people to get second opinions. And = both in my professional life and my personal life. I have, you know, encouraged family members to get second to second opinions. And I truly think that, you know, at most providers, I hope, I know - certainly I do feel that I want my patients to have all of the information. And to be able to make an educated decision that is best for them and whether that decision is made based on a plan, based - sorry, I should say, if the decision of where they get treated is made based on their connection with the provider, the proximity to the clinic, or what the plan is that they're offering, it should be the right one for them. And I can't guarantee that I'm going to be the right one for everyone.

And so I really encourage people to hear all of the information, to meet as many people as they need to, in order to feel like they are getting the right treatment for them. And again, even if it's just to confirm what you heard from someone else, you know, that that's the right plan.

And I will say, you know, I will just add, we often stay in touch with people who get second opinions with us but get treatment elsewhere. Just to be able to check in from time to time and say, you know, this is going on. Do you think, you know, this is still the right path? Sometimes they'll come in and have an additional meeting but continue to get their care elsewhere. And, again, I encourage that, and I feel you should be empowered to do that as well, wherever you are.

**Dr. Morgans:** Fantastic. Thank you. Thank you for that, Stacy. I think it's important to hear that from medical team members.

I am never offended when someone gets a second opinion. I see many second opinions myself, and sometimes the first opinion is not - just not the right fit. For whatever reason. It might just be that we're too far away, or we're too complex, or maybe we are the right fit and the folks closer to home are not the right fit.

It's all what's best for the patient. So never, never, never feel stressed about that. So just a quick circling back to resource support. There's a question about, you know, "I haven't heard about resources at my institution necessarily. Should I expect that I'm going to hear about them, Max? And what if I have specific needs, and I don't feel like I have access?"

Are there online supports? Are there other supports? What do you think about this, Max? You know, if someone doesn't hear about all of the supports up front, should they keep asking maybe and see what else is available based on their needs?

**Max:** Yeah. Great question. And you know, I'm very honest with the patients that I work with, which is sometimes, "we don't do a great job in our bigger institutions about telling patients what all the resources are." And that's because they are very specific depending on needs. So, I think that, you know, Alicia, you mentioned sort of being a good advocate, and I think all patients, you know, if you have something that is a real need to feel comfortable to ask someone. Because often, resources aren't disseminated or explained as well as they should.

And that's for a lot of different reasons. But again, often there are national supports, there are particular grants that open up. Prostate cancer is a little tricky because sometimes we have less national funding than other cancer types. But it can be seasonal, too, or different time of the year, different funds open. So, I think again, what I would say is, each institution is different.

But to ask, you know, your team, your nurse or your doctor, or even at check in, you can say, "Hey, is there a resource office? Is there a specialist? Is there a social worker who can help with, you know, whatever the issue may be?" and you'd be surprised at what may be available.

**Dr. Morgans:** Thank you for that.

So, Stacy, quick question about other people who are involved in the cancer journey. You know, sometimes the caregivers need support. Sometimes the life transition is causing, you know, whole families to need support, or kids to need support. Even though, you know, prostate cancer often happening in older adults, sometimes it's happening in younger people, and sometimes older people have young kids.

And so there are all kinds of different needs that can happen associated with family and family members. You know, what do you advise when people are either going through these transitions that can be particularly traumatic to families or when they're going through, you know, pretty typical prostate cancer transitions and needs? But families are - they need extra support.

How do we in cancer care support families through some of the challenges that occur in prostate cancer?

**Stacy:** I send them to Max. No, I - but truly, you know, I have had this recently, you know, where I have a - we're seeing patients that are younger and younger, you know, and to your point, as you mentioned, we can have older patients that have younger children.

So, there's no age limit on that. But I have referred a patient's daughter to social work, to help with some of those concerns, and I really, I truly just loop in social work as much as possible. And I encourage patients to bring their, you know, significant others and their families to appointments so that they can ask questions as well.

I think sometimes a lot of the anxiety comes from feeling out of the loop of what's happening and getting information second hand can be really, it can be really difficult. But that being said, you know, I always like to mention it's always the patient's choice who there in the room with them and who gets that information.

And it - and sometimes they don't want to share it all. And that's absolutely appropriate as well. So, it's really, you know, for me about finding kind of what's right for a particular family, but it's getting to know the family well, getting, you know, not just the patient, and being able to guide in that direction.

**Dr. Morgans:** Yeah. And it can be really complicated. So, you know, if you are the person who is seeking support, social work is a great place to start, I think. And I completely agree. I would also say that Prostate Cancer Foundation has a number of Facebook groups that might be of help for younger patients or older patients or, you know, caregivers, or others.

So, check out the Facebook groups. There are also - there are web support, virtual support groups that have been available since the pandemic, mostly. There was a string of support groups through an organization called UsTOO throughout the entire country for a long time, and UsTOO merged a couple of years ago with another organization called Zero.

So, you know, Prostate Cancer Foundation does actually have a great relationship with Zero and what prostate cancer doesn't - what Prostate Cancer Foundation doesn't necessarily have in live weekly support groups, the support groups that are offered virtually through the Zero-UsTOO collaboration actually may help you guys as well. So, take a look at that. And the Facebook groups and everybody has a different social media that they are or are not willing to engage in.

So, take some take a look at that. And Becky is putting some amazing websites up into the chat right now. What's nice about the Zero website, since they merged with UsTOO, and since the pandemic and things have gone virtual, they actually have a support group locator. So, you can put in your zip code, and it'll tell you, you know, what's available locally if you want to go in person.

But it's also nice to just say, "Okay, gosh, I really am free - every single Tuesday. And I want to have a support group every Tuesday, and I don't really care where it is. It just needs to happen at approximately this time of night for me." You can actually find it and say, "Okay, well, this one happens to be in, you know, Colorado, or this one happens to be in Maine, or perhaps in North Carolina, who knows where it is."



But if the time works out, the day works out, and you have an internet connection, there you go. You can participate in that support group. So in some ways, the pandemic, and its increased allowance of our understanding of how things work in that virtual world has been maybe helpful in some ways, bringing us all together for the support that we need.

You know, Max, I think one of the things that people have been struggling with in prostate cancer for years, that we have not necessarily addressed sufficiently, has been sexual health. And I wonder if you have any thoughts on how teams locally and through support groups perhaps, like we just talked about, might be able to help support sexual health and distress associated with sexual health dysfunction, because this has been a complication that, though we acknowledge it, has not necessarily, you know, been supported as overtly as I wish that it were. Especially given, you know, that it's such a ubiquitous problem. What are your thoughts?

**Max:** Yeah. Thanks, Alicia. I think the sexual health concerns with prostate cancer treatment are so primary and they're really hard to talk about. And so, I think there's a relationship and responsibility as providers, that providers have to be asking good assessment questions of our patients. And patients also have to come to us and say, "Yeah, I'm really bothered by the fact that I have no libido, or I don't seem to show any interest towards my wife or, you know, I don't know how she's feeling about that."

So, I really, you know, try to normalize a lot of the realities that patients experience with treatment. And I think we can all do better about having really honest conversations about what are the impacts on intimacy, on sexual function, on sort of men's sense of themselves and, not just men, but their, you know, their partners and their families.

So, these are, you know, going back to this question of "How do we support families, and couples, and spouses?" It's really kind of being able to talk about these issues with providers that patients feel comfortable with, whether that's the oncologist or, you know, somebody who's specializing in really more sexual health domains. But again, these are really important areas.

And, I think, again, there's a responsibility for both us as the practitioners and on patients to say, "Yeah, this is something that's really bothering me. Is this normal? What can I do?" Sometimes we can - there's physiological and pharmacological interventions. Sometimes there may not be, but we can talk about other ways of sort of coping and adapting to some of the sexual health changes.

**Dr. Morgans:** Great. And there might be actually referrals that are needed. So, the urologists that support you in terms of the prostate surgery are actually not usually the urologists - in most centers - that actually support sexual health and rehabilitation. Just because these are specialized areas and, in many practices, they're actually separate physicians who work on those areas. So, it is okay to ask for a referral



to a sexual health specialist or a men's health specialist who might be able to support that rehab and, you know, some supportive services that are not necessarily going to be the expertise of the person who's an amazing surgeon and cancer urologist.

So, that is something to keep in mind as well. One thing, just to mention, social work is not usually something that I have seen as a billable service. I think it's usually a supportive service that is in addition to things that you receive. So, I wonder, Max, can you comment on that? Do you normally bill Medicare? Maybe I am, maybe I'm just completely unaware.

**Max:** So, yeah. So, we don't bill, Alicia, at the Farber. But there are some institutes that do bill. Sometimes patients have limited - they might have six, like, psychosocial sessions that are not billed, and then they have to bill. So, again, I think that's a really good question to ask your treating institute, which is, you know, "What do I have to pay for out of pocket, or what's billed actually? And what's just folded into care?"

So, we're lucky that that, our supportive services, you know, we don't bill.

**Dr. Morgans:** Great. So, that is something to ask your team. But just because it's billed, doesn't mean it's not covered. So, keep that in mind as well, because certainly, once you reach your cap in coverage, you know, you've got your deductible, you've got perhaps a co-insurance. Once you've reached your max out of pocket, which for many patients with prostate cancer is actually going to be reached every year.

So, something really important to keep in mind as you're, you know, choosing your insurance each year. These would not be something that would add to that additional bill because they would be in your max out-of-pocket cost. So, important questions to ask of the financial counselor of the practice itself and just try to find out what's going on there.

And thank you, Max, because we, you know, we only know what we know, as is very clear and evident there, and every practice is a little bit different. So, just thinking a little bit about end of life, you know, Stacy, as we start to kind of wind down, this is a super challenging phase for everybody.

And some of our patients, unfortunately, do face the need for palliative care, which does not in itself mean hospice - might mean pain control, symptoms support, family support. Could mean end of life care in hospice, but it doesn't necessarily mean that, actually. But these transitions - from active treatment to engaging palliative care while staying on active treatment, to potentially transitioning to palliative care as a primary way to focus on quality of life and improving that quality of life.

Even if we can't actively manage the cancer because it's beyond our control at that point, these are very challenging. How do you work with team members that specialize in those services? And how do patients sort of mentally and actually engage with them in a way that makes sense?

**Stacy:** Yeah. So, you mentioned this, but I just wanted to emphasize again, you know, that there is truly a difference between palliative care and hospice or end of life care.

And I really am a strong proponent of kind of early palliative care. So I tell all of my patients, "all palliative care means is symptom management." They are symptom experts. Often that symptom is pain, but it can be other things, too - other symptoms related to disease or related to the treatments that we have you on that cause side effects.

And they really are wonderful at managing these symptoms. And honestly, the data has shown us that getting people on palliative care early can actually extend life by making quality of life better. So, I really encourage that discussion early on with all of my patients. And that referral early on, if appropriate.

And then when it comes time to talking about the possibility of hospice, you know, that is really more of a, you know, when it's that - again, I like to have that conversation early. And so, I tell people this ahead of time, you know, when it, what it would look like, you know, when we are going to have that conversation so that when it does come up, it's not shocking, you know.

So, and what going on hospice looks like, is and sometimes it's the palliative care without ongoing treatment of the cancer. And so that often involves getting a hospice, accompany, you know, like a visiting nurse, outside agency involved so that you have care at home, or wherever you choose to be.

And that's generally outside of - at least at Dana Farber - that's outside of our organization. But we still stay involved, you know. And we very much want to be involved and want to be, you know, and I like to remind patients that we're never cutting ties. Even if you're not actively getting treatment for your cancer.

And I think that's where, you know, making sure that social work is involved and making sure that the, you know, the nurses are still actively checking in, and that we are still checking in is really important. But generally, our nurses and our administration team is really good at making those referrals on your behalf.

But again, I - two things that, you know, I like to encourage talking about it early. I like to encourage patients to bring it up early, too, if they are considering it. You know, I think sometimes patients are afraid to talk about it, thinking that we will think that they're giving up, or that we are going to give up or what it - but it really is a conversation that is best had early, so that, you know, which it doesn't always mean that a decision needs to be made at that time.

But I encourage patients to never feel uncomfortable bringing up either palliative care or end-of-life care with their provider as that's, you know, that's part of our role.

**Dr. Morgans:** Thank you. You know, if you're going to pursue aggressive care that is trying to control your prostate cancer, why would you not aggressively pursue improved quality of life and symptom management?

That, to me, is a no-brainer. Palliative care - they're the experts on all the symptoms you might ever have and any transition that you might have. You know, oncologists, urologists - they're great at taking care of your cancer. Put them together and you are tackling both ends of that spectrum and really keeping your best life.

So, in the last say, 30 seconds for each of you, anything you would like to say to wish every patient, or family member, or advocate knew as they were going through this process. Max, let's start with you.

**Max:** Oh, boy. Look, I think I just encourage really kind of honest communication, open communication. I think that the hardest things to talk about, we sort of keep private.

And I just encourage all patients and families to understand that we as providers, we're used to listening and hearing your questions, your experience day in and day out. So, please bring up those questions to your treating team and your doctors because they want to know. So, if there's something you're struggling with, there are questions you have. Please, please, you know, let us know because it'll help us help you as well.

**Dr. Morgans:** Thank you. And, Stacy?

**Stacy:** I would just say don't assume that you have to struggle through side effects or, you know, like, fatigue and other things. Just because you're on cancer treatment, we, you know, we want quality of life just as much as you do. And please - and we can't help with things that we don't know are going on.

So please, please talk to us early and frequently about what your symptoms are, so that we can help manage.

**Dr. Morgans:** Wonderful. And last words from me: If you're thinking about a second opinion, just get one. No one's going to hold it against you. Pathology second opinions can be a send out where you don't have to see someone from the institution.

But if you want something like imaging, or recommendations, or guidance on treatment, you just need to see someone else from a different center. And it's really easy, and no one will hold it against you. And Becky, back to you.

**Becky:** Great, thank you so much, Dr. Morgans, Max and Stacy. This has been just a phenomenal hour of really practical information.

This webinar will be up on our website for folks to view. We'll share it on social media. And so appreciate your time and your tremendous amount of expertise. So, can't thank you enough for helping patients around the

US and potentially around the world as well. So, thanks to all and good night.

**Dr. Morgans:** Thank you, everyone. Good night.

**Becky:** Bye bye.