“Palliative Care for Advanced Cancer” (Tom Smith) [#32]

Brad Power
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“Be honest with yourself, and be honest with your providers about symptoms you're having. If a bone hurts, please tell somebody about it. If you're short of breath, please tell somebody about it.” – Tom Smith

Meeting Summary

Advanced cancer patients experience many mental and physical symptoms from the disease, including pain, depression, anxiety, nausea, constipation, neuropathy, urinary problems, and sexual problems, and their family also experiences mental stress. To relieve these symptoms and improve quality of life for both the patient and the family, palliative care provides medications, nutritional changes, relaxation techniques, and emotional and spiritual support.

Dr. Tom Smith has a unique perspective on how people experience advanced cancer because he is not only a physician treating patients with breast cancer, but he is also a prostate cancer survivor. He has been a pioneer in bringing palliative care to cancer patients and to the mainstream of medical practice.

What is palliative care?

Palliative care can be thought of as addressing three circles of services around the patient and family:

1. **Symptoms** (physical and mental): such as pain, depression, anxiety, how you're coping, nausea, constipation, urinary problems, sexual health problems, erectile problems.
2. **Support**: Who's supporting you on this journey? Do you have enough support? Who's family for you? Are they available nearby? Do you need help with activities of daily living? Do you have a religious or spiritual community?
3. **Advanced care planning**: Do you need a living will? Do you have an Advanced Directive? If you got so sick that you couldn't speak for yourself, who would you want to make medical decisions for you?

What are the benefits of palliative care?

When cancer patients are seen by palliative care alongside their oncologist they live longer, and they live better. You've got this whole team whose job is to relieve your symptoms. They may check in with you once a week. Are you bothered by pain? Are you bothered by shortness of breath? Are you bothered by nausea? Fix those things, and people live six months longer than if they didn't have the palliative care team involved. The data also show that palliative care does a better job when it is involved early in the care of patients, rather than waiting until the last three or four days before they are going to die and scurrying around trying to relieve their pain. Every advanced cancer patient should be seen by palliative care within eight weeks of diagnosis.

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How should I behave to best manage my symptoms?

Be honest with yourself, and be honest with your providers about symptoms you're having. Be open. If a bone hurts, or if you're short of breath, tell somebody about it. If you're having feelings of depression, anger, or frustration, it's much easier to share those with somebody. Get some help with them. Some people don't want to be a bad patient, and they think that if they complain too much, then the doctor is going to stop their therapy. That's not the case. The providers need to know so they can help.

What are some tips for addressing various physical and mental symptoms?

- For **neuropathy**: menthol, scrambler therapy, auricular acupressure, or ear acupressure.
- For **hot flashes**: Oxybutynin (Distropan) works for men and women. Other drugs, such as Gabapentin (Neurontin), Duloxetine (Cymbalta), and Venlafaxine (Effexor), work for women but have almost no effect for men. Embr Wave bracelet. Structured breathing. Stellate ganglion block.
- For **anxiety**: Gabapentin, mental health care professional.
- For **orgasms for men**: silicone-based lubricant.
- For **total pain management**: yoga, meditation, meditation apps, e.g., Calm, ThisIsKara.
- For **androgen deprivation therapy**: exercise.

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Meeting Notes

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SPEAKERS
Tom Smith (65%), Brian McCloskey (10%), Anonymous Caregiver (9%), Kevin Fordney (8%), Rick Stanton (5%), Mike Yancey (3%).

Brian McCloskey (0:03):

We are honored to have Dr. Thomas Smith from Johns Hopkins join us today. He is going to be speaking to us about palliative care. What makes Tom so unique is that he is not only a physician, but he is also a prostate cancer survivor. If anyone can understand what patients go through, certainly Dr. Smith can from both sides of the fence.

Often patients don't necessarily want to talk about palliative care because we always have hope. That's why this topic is so important because we are in a serious situation where palliative care may very well be part of our future.

Tom Smith (1:18):

Let me tell you a little bit about my prostate cancer story. I was on an active surveillance trial here at Johns Hopkins because my PSA was rising steadily. It got to 5.8 when I was 66, so I had a radical prostatectomy. Open procedure. I went for a jog the next day and ran a 25K in the mountains a month later, with a hemoglobin of about 10 and a half – maybe not the smartest thing to do. I had a recurrence within a year. My PSA started to rise. It turns out I have an ATM mutation, the ataxia telangiectasia mutation, a deleterious one, which means it's likely to behave badly. In mine, so far it has behaved intermittently badly. So it came back within a year. I got androgen deprivation therapy with leuprolide (Eligard and Lupron Depot both contain leuprolide as the same active ingredient.) and bicalutamide (Casodex) that you take for six months, and then I got eight weeks of radiation therapy. I had a really difficult time with the androgen deprivation therapy. It made me depressed, and I couldn't sleep because I had hot flashes that were terrible. I would wake up every 45 minutes at night. So I went seven or eight months with no sleep, which also contributed to my depression. The depression got so bad at one point that I actually admitted myself to the hospital so I wouldn't kill myself. That can happen. I had depression when I was a resident, but I hadn't had it for 40 years. And suddenly, when my testosterone dropped to zero, it came back again. Interesting. And then the bicalutamide gave me pretty significant interstitial fibrosis of my lungs. I'm the eighth reported case of it in the literature. Along with my medical oncologist, I wrote up my story. It can cause inflammation of the lungs in about .03% of people. I was one of those people. It dropped my pulmonary function from about 100% of normal down to about 50% of normal. I went from somebody who was an

ultra marathon runner to somebody who couldn't go up a flight of stairs without stopping and huffing and puffing. It's recovered about 70%, which is enough to jog at a 14 minute mile pace for a couple of miles, but it's not enough to do any of the things that I used to do. Then, unfortunately, within a year of the radiation therapy, I recurred again, with my PSA rising, and it has continued to slowly rise. I had such a difficult time with the first therapy and nearly died, that I am not anxious to do any repeat therapy. I have had a Prostate Specific Membrane Antigen scan. The good news is that it didn't show any lumps or bumps that could be radiated. We did the Orioles trial here. They somehow configured the trial name to be Orioles where they irradiated all the little spots that could be seen as oligometastatic disease, as it's called. (Oligometastatic prostate cancer is generally defined by presence of five or fewer metastatic sites on imaging. It is a transitional state between localized and widespread metastatic disease.) That seemed to delay the rest of the disease from coming back. They didn't find any spots to radiate. The bad news is that I'm sure it's in my bone marrow, and I'm going to end up with multiple bone marrow mets sometime within the next year or two, or three.

Brian McCloskey (5:36):

Do you know what your Gleason is?

Tom Smith (5:40):

I was 3 plus 4. Not something that you would expect to recur, but it's that ataxia telangiectasia mutation. I had a germline mutation, meaning one normal and one abnormal gene. When we looked at the actual cancer, there was no ATM protein whatsoever. The cancer had lost the other normal ATM gene, which means it's probably going to be pretty aggressive when it starts to grow. My PSA is only up to 1.8. But I'm sure it'll be 3.6 in six months, and then 7 after that in six months. So that's where I am prostate-cancer-wise.

I see a lot of prostate cancer patients here in my clinic because I'm an oncologist, as well as a palliative care doctor. It's like seeing the ghosts of Christmas past, present, and future, but not having Jiminy Cricket, so that I can change the future.

I got interested in palliative care about 30 to 35 years ago. It grew on the shoulders of hospice. Hospice was started in the 1950s in England by Dame Cicely Saunders, who was a nurse and then a doctor and a social worker. She set up residential hospices, when people were dying, like when they had six months or less to live. There wasn't much in the way of treatment. You would come, and you would stay there, and you could get morphine, and there was a chaplain for all faiths. I have a picture of the English coast with the wind blowing through the white curtains. A really nice place to be. In the US, when it was set up, President Reagan expanded the hospice program, and Secretary of the Interior James Watt set it up as a home-based program. You would have specially trained nurses come out to your house under the direction of a doctor to manage pain symptoms and things like that. But you had to have a 50/50 chance of dying in the next six months in order to qualify. They didn't hold you if somebody lived seven months, but if somebody lived a year then you might be disenrolled from hospice. They really paid attention to

pain, depression, how people were coping, how their families were coping, making sure that if there were life events that needed to happen that those life events were talked about and made to happen.

About 30 to 35 years ago there were four or five of us in the oncology community and a couple of geriatricians, Diane Meier in particular, who said, “Why should you have to wait until your last six months of life to have somebody pay attention to pain, coping, depression, anxiety, all those things?” We were clearly the lunatic fringe of oncology back then. The idea that you would tell somebody that they had a terminal illness, oh, my goodness, 40 years ago, that was verboten. Then ideally, you would give somebody some notion that they might die so that they wanted to go back and see where they grew up, if they had to make up with their long lost brother, their kids that they were estranged from, get their financial house in order. People didn't do that because they didn't have any idea what was going to happen to them. So we thought, “Why not have open and honest communication? And let's talk about symptoms and try to fix everything that we can.” So now when I think about palliative care there are probably half the patients that we see who are not dying of their illness at all. I see a lot of people with chemo-induced neuropathy, and we have some special ways to treat that. We see a lot of people with nausea and vomiting. We see everybody who gets a heart transplant and everybody who gets an artificial heart. Because you have a whole team coming in – doctors, nurses, nurse practitioners, social workers, chaplains, pharmacists – and saying, “How can we help? What are the things that are bothering you? And how can we help?” What's not to like about that? So I'm trying to move away from palliative care being just hospice, and for the last couple of weeks of life, to palliative care.

I think of it as three circles around the patient and family because the family is always involved. The first is symptoms. it's pain, depression, anxiety, how you're coping, nausea, constipation (anybody who takes a good pain medicine is going to get constipated), urinary problems, sexual health problems, erectile problems. I didn't mention all the things that I had to do with urinary and rectal incontinence and inability to get an orgasm and all the things that they never told me about and radiation therapy. So that physical stuff and mental stuff first.

The second layer is support. Who's supporting you on this journey? Do you have enough support? Who's family for you? Are they available nearby? Do you need help with activities of daily living? Do you have a religious or spiritual community? That's part of taking care of you.

The third big layer is advanced care planning. Do you need a living will? Do you have an Advanced Directive? If you got so sick that you couldn't speak for yourself, who would you want to make medical decisions for you? We call that the durable power of medical attorney. I'm in the oncology clinic right now. If I walked around and identified 10 people with less than a year to live, I would bet fewer than one or two would have that durable power of medical attorney identified in the chart. I tell people it's all a heck of a lot better to figure those things out Thursday afternoon at 2:00 in the daylight, rather than at 3:00 in the morning in the emergency room when you haven't discussed it at all. I'm a breast cancer doctor and some of my breast cancer patients do extraordinarily well, and others die of their illness. I ask people, “Do you have

any strong feelings about advanced life support, like being on a ventilator? Having CPR done?” Some of my patients will say, “I've led a great life. I'm ready to go. The past couple of months haven't been so good. I've made all my peace. Just let me go when my time comes, let God and nature take its course.” And I have other people who say, “Do everything you can to keep me alive until the last possible moment.” But you're never going to figure those things out. I can't guess those things. I guess wrong about half the time. And if you leave it to your relatives, your relatives will be way over aggressive compared to what you are. Multiple studies have shown that if you leave it to your wife or your kids in particular, that they're more likely to want you to be on a ventilator than you would want to be yourself. So it's better to have those things written down if you can.

The other point about palliative care is it sounds grim because people equate it with hospice. But there are now multiple studies that show that when cancer patients are seen by palliative care alongside their oncologist they live longer, and they live better. You've got this whole team whose job is to relieve your symptoms. Maybe check in with you once a week, to get some patient-reported outcomes. Are you bothered by pain? Are you bothered by shortness of breath? Are you bothered by nausea? Fix those things, and people live six months longer than if they didn't have the oncology team involved. That translates into anywhere from six to 12 people alive at the end of the year. Who wouldn't wouldn't be alive if they didn't get that care? Symptom management is really, really important. If your doctor or nurse practitioner isn't doing a great job of managing your symptoms, ask for some more help.

Anonymous Caregiver (16:23):

I'm originally a techie, and I left tech because I had people in my personal life who were dying of misdiagnosis on the medical side, but then also in the mental health side undertreated, men in particular. I'm a behavioral health clinician now. You may appreciate that I did my training at Cancer Support Community, who were some of the pioneers in recognizing the stigma, and the fact that quality of life matters. As you just showed, you can get a longer life, not only better quality of life. That's my background. I'm also on a committee at UCSF representing patient needs. I stay involved with the staff and the physicians there but also other patient advocates in prostate cancer.

I want to upvote something. I've noticed there's something about the language and how people approach the concept of palliative care. UCSF, for example, names their palliative care service Symptom Management Service. So simply having a different brand name to attract patients to it maybe can help remove that stigma and that association with hospice care.

Tom Smith (17:53):

I'm with you on giving it a different name. Half of my colleagues think we should be calling it supportive care, or supportive oncology, and half think it's a medical specialty named palliative care. We don't call cardiology by some other name. So it's an issue of some contention. When the group at MD Anderson renamed their service from the palliative care service to the

Supportive Oncology Service, some of their referrals went up by 25% because patients really don't know what palliative care is, or the very few who do usually equate it with hospice. But doctors are so afraid that it just means their patients are going to die that they don't refer until pretty close to the end. That's one of my biggest bugaboos is that the data all show palliative care does a better job when we get involved early in the care of patients, rather than waiting till the last three or four days before they die and then scurrying around and trying to relieve their pain.

Anonymous Caregiver (19:16):

Wow, that's news to me that the bigger hurdle is overcoming physician resistance to refer, more than patient willingness to uptake the services.

Tom Smith (19:27):

It's physician resistance. It's been studied multiple times, and doctors are still equating palliative care with hospice care.

Anonymous Caregiver (19:36):

Maybe also they are equating it with the notion that “I failed as a physician.”, as opposed to, “They are part of my care team.”

Tom Smith (19:44):

You're absolutely right. I'm an oncologist, and one of the delusions that oncologists often have is that they failed the patient, or the patient failed the chemotherapy, when in fact the chemotherapy failed the patient. Or if you just did things a little bit differently, everything would have changed the outcome when most often it's the natural history of the disease. The group at UCSF has been one of the biggest palliative care supporters for the last 10 years, 15 years probably. What they showed was that at their cancer center, just two years ago, only 9% of cancer patients get referred for palliative care, even though they were a well established group. Most of those were referred less than three months before they died. So we trained our docs here to try to get everybody who's seriously ill with advanced cancer to be seen by palliative care within eight weeks. I helped write the position paper for the American Society of Clinical Oncology based on multiple randomized trials, where half the group got cancer care alone and half the group had cancer care along with palliative care. The group that got the combined care did so much better, and their surviving relatives did so much better, that we suggested every advanced cancer patient be seen by palliative care within eight weeks of diagnosis.

Anonymous Caregiver (21:39):

That's very consonant with what we've found on the psychosocial side. That's why the Cancer Support Community, for example, partners with providers of physical medical care to make sure

people are getting comprehensive whole person care. I want to thank you so much for including the family members and that support circle in it. My own personal experience shows that often the caregiver (the family caregiver, because they're not paid to do this), the family bears often more stress than the patient, and including them in the support circle is so important to help them help their loved one.

Tom Smith (22:17):

Absolutely. What I teach here is you look the patient in the eye and say, “You've had your world turned upside down. How are you coping with all of this?” And then you have to listen, which doctors aren't necessarily so good at doing. So you listen to what they say. And then you physically turn and look at the family and say, “You know, your dad or aunt is really pretty sick. How are you coping with this illness?” And they'll tell you if they’ve got financial toxicity, can't pay for the transportation, pay for the help, or used up all their family medical leaves. They still don't feel like we're doing a good job of providing care at home. What can you do to help? Our team comes in.

Rick Stanton (23:29):

I am an advanced prostate cancer patient currently on Pluvicto and abiraterone. You're telling a compelling story, but as a member of the advanced prostate cancer people (men) on this call, I think we're probably all saying “Yeah, that sounds great, but what could I be doing differently? What could palliative care help me with?” I am not really sure what it could help me with at this stage. I have the power of attorney stuff down. Long range planning – I could probably do a better job. I don't really have a long range plan. But other guys will want to know what they can do. Could it do anything for us now? Maybe help with my hot flashes. They aren't that bad. I get them about every two hours. What I'm wondering is: how can we personalize this discussion a bit to us guys?

Kevin Fordney (25:09):

Rick, can I respond to that? This will be three years into my journey come January. After the first year, I switched my insurance, and I wanted to get hooked up with the Knight Cancer Center in Portland, Oregon. I live in Vancouver. I was very pleased with my oncologist. But I found I was expecting too much of my oncologist. She is so busy. I would get 15 minutes to 30 minutes with her, and her specialty is my cancer. So I went through a situation where I had some pain. I was put on hydrocodone that I shouldn't have been put on. I had extreme constipation. I was looking for the nurses connected with my cancer doc to help me, and I said I need to broaden out my team. I was told about palliative care, and I got started with them. In the same way that we're hearing here, Andrea, the gal that I work with, said that so many people equate it with hospice. Anyway, I got started with her. I have a monthly pre-scheduled virtual meeting with her every month. The thing she's done for me is get me off of heavy duty pain meds. I won't get into every detail. But my point is she is somewhat like a counselor. She's become almost a virtual friend. She understands me holistically. Her notes are impeccable. She remembers how I was the

month before, and right now I'm having no pain. But a couple of months ago, I went on some ibuprofen and took care of some inflammation without doing a pain med. I asked what I should do if I travel, and I want to feel good, she said, “We may send you with a bottle of prednisone, or we'll send you with something.” I get 30 to 45 minutes with her just talking about quality of life. “How is it now? How might it be in the future? What can you do?” Before she put me on the ibuprofen, she checked with the cancer doc to make sure it's okay with what I'm doing. Bar none, she's the most fabulous member of my team. I can't lose my cancer doc, but I look forward to Andrea every month. And I know where she's going to help me down the line. She wants me to get a naturopath because I had some neuropathy. But the docs want to make sure if you take a supplement, it's okay with what you're doing. The idea of building out the team well beyond the oncologist is one I agree with, and I want to heartily endorse that the number two person on the team should be palliative care.

Tom Smith (29:13):

Thank you for the endorsement, and I would love to clone Andrea and distribute her around the country. A couple of things that come to mind. One is what you can do today. One is to communicate with your partner. “How are you coping with me being sick?” Oftentimes partners don't ask. Hopefully they'll tell you, and maybe you will be honest with them and help them.

The second are some physical symptoms. For neuropathy, there's a woman named Marie Fallon in Edinburgh, who had two patients come in and said, “I put 2% topical menthol on my hands and feet, and it really helped my chemotherapy-induced neuropathy.” I send people to the drugstore to get something called mineral ice. It's 2% menthol, and it doesn't work all the time, but it can really take the sting and the numbness and tingling sometimes out of the chemotherapy-induced neuropathy. We also have two other ways of treating it here. One is this machine over on the side that is called scrambler therapy that works really well. We do auricular acupressure, or ear acupressure. I work with my colleagues at the School of Nursing, and we did 15 people to start with, and we saw a 50% reduction in their pain, numbness, tingling, and stiffness. Now we're doing a much larger trial. So that's promising.

Hot flashes are a real bane of existence. I'm a breast cancer doctor. I have put more young women into menopause and caused hot flashes than I'd ever care to imagine. So I figured when I got them, it was just fair play. Somebody was getting revenge on me. The things that work for women don't seem to work very well for men. Gabapentin (neurontin) seems to cut hot flashes in 70% of women, but it doesn't work hardly at all in men. Cymbalta (duloxetine), same thing. For women it works well, but it doesn't work for men. Venlafaxine (Effexor) has almost no effect for male hot flashes. The one thing I found that helped me, and I wrote a letter to the New England Journal of Medicine about, was something called Oxybutynin (Distropan). It has two uses that are approved by the FDA. One is for bladder spasms, and the other is for people who sweat too much. I was really at wit's end with my hot flashes, and within two hours of my first dose of oxybutynin, I stopped sweating. I still would get a little warm in a triangle on my back. But I just wouldn't drip sweat off my eyebrows. I'd be doing a procedure in the clinic, and I'd be dripping sweat off my eyebrows onto the surgical field. That's not good. We did a 150-person

randomized trial in women. There are lots more women with hot, significant hot flashes than men, and 50 got placebo. They got about a 20% reduction in hot flashes, which is what you see with placebo. The other group got two and a half milligrams twice a day. The other third group at five milligrams twice a day and the placebo group went like this stayed about the same. The oxybutynin group dropped by 70% with the number and severity of hot flashes. So it's become my go-to drug for men with hot flashes, and even women with hot flashes. So we published.

Rick Stanton (33:40):

Are there side effects?

Tom Smith (33:43):

It can make your mouth dry, and it can make you feel a little fuzzy-headed. So you try to cut down to the minimal size that will do it. But if you just Google oxybutynin and hot flashes, you'll come up with a couple of papers showing that it works pretty well. You might have to convince your colleagues to print out the paper and show it to your oncologist, but I'm pretty sure he or she will be willing to give it a try because we handed it out like water for bladder spasms and neuropathy.

Brian McCloskey (34:36):

The Embr Wave bracelet is something I got involved with maybe over a year ago. It's a little device that you wear on your wrist and it sends pulses of warm and cool from a ceramic plate on the bottom of your wrist. You can dial it up or dial it down. It didn't really work for me, but there are other patients who have said that it works great for them. I don't know if you've heard of it. But for those on the call that are really afflicted by hot flashes, this is something you could think about.

Tom Smith (35:21):

Structured breathing seems to help too. 15 minutes of deep breathing, deep exhalation, deep breathing, deep exhalation, much like yoga, that seems to help a lot of people and is completely natural, not taking a drug.

Rick Stanton (35:46):

Once a day, or how does that help for like an hour, or how does that work?

Tom Smith (35:52):

It seems to help throughout the day, even at night. It may not take them from 20 a day to zero a day, but it might take them from 20 a day to 12 a day or something like that. You can also do a stellate ganglion block on the nerve that controls some of your sweating back here on your

neck. I was almost going to do a do-it-yourself job in the mirror here. With ultrasound, you can stick a needle back there avoiding all the big arteries and veins and important stuff, stick it right into the stellate ganglion gap and nerves and inject some local anesthetic. And for many women and for some men that seems to work for hot flashes really well and is remarkably safe.

Anonymous Caregiver (36:57):

On the topic of gabapentin, speaking on the psychology side, it is little known but also effective in men who struggle with emotional regulation issues. I've seen it used effectively off-label for people who tend to have large and cascading chain reactions. People experiencing psychological pain can intensify their experience of physical pain and vice versa. Gabapentin, at least what I've seen on the mental health side, can be effective for those who have comorbid psychological experiences or formal diagnoses. I don't know if you've seen that used in your setting yet.

Tom Smith (37:49):

Yes. And we did a trial with women with anxiety, Gabapentin versus placebo, and it helped pretty substantially. Start with 300 milligrams at night. Try that for three days. Then go up to twice a day, then go up to three times a day and then escalate it if need be. It makes a lot of people sleepy. So it's not a great drug for everybody. But it can really help with anxiety and mood stabilization. Good point.

Anonymous Caregiver (38:22):

My experience too is if you're at the point of needing Gabapentin for psychological pain medication, that's a clear indication you probably need a mental health care professional on your team, right?

Tom Smith (38:36):

Yes. I saw a therapist for quite a while and continued to see my psychiatrist because my life has changed dramatically. I can't do the things that I used to do.

The other pointer that I can give is that I sat in on a support group and the woman who was leading it said, “One of the things men can do who have trouble getting orgasms is use a silicone-based lubricant rather than any other because it gives you a lot more sensation.” I can really attest to that. Rather than olive oil-based or any other type of oil based lubricants, silicone-based ones are much thinner. And it really feels much more natural.

Anonymous Caregiver (39:42):

On the topic of trying to reduce the stigma of getting help, or with coping, or what we like to refer to as “adjustment.” We have this diagnostic bucket we can use and still get insurance

reimbursement for your counseling or your flat out psychotherapy. It's called “adjustment disorder". The “disorder” is because we call it disorder if it's creating subjective distress or functional impairment. The idea is that a cancer diagnosis is an adjustment. It's an adjustment for the family, whoever is dealing with a change in life circumstances like this. It's a provisional diagnosis often because you want to do a full clinical workup and figure out what all is going on. A really easy way to enter this is to just recognize it's natural to frame this as an adjustment and get help.

Tom Smith (40:58):

The other thing that we really stress, as part of sort of total stress and total pain management is meditation or yoga - one or the other. I have in Epic, which is our electronic medical record, a smart phrase that lists all the sites where you can get free meditation help. I personally find the Calm app very useful because it's 10 to 12 minutes, and that's about my attention span. It doesn't fix the pain, but what it does is fix my reaction to it. It doesn't ruin my whole day. I mean, what I see so many people with chemo-induced neuropathy, whose feet burn and tingle, are numb and cold, all at the same time. The first thing they do when they wake up in the morning is put their feet down on the floor, and they say, “Damn, my feet hurt.” Why do they hurt? They hurt because I got chemotherapy. Why did I get chemotherapy? Because I had rectal cancer, I had prostate cancer, right? And it puts you in this PTSD spiral as I call it. This leads to catastrophizing. Today's going to suck just like yesterday. If you can break that cycle, either by fixing the symptoms, or fixing the reaction to it, saying, “Hey, my feet hurt, but that means I'm still alive and my nerves still work, and I'm going to walk some today.” So if you can fix that reaction, you can sort of nip that catastrophizing part in the bud. It can be really helpful for people

Rick Stanton (43:01):

You mentioned a Calm app. Is that something you have on a phone?

Tom Smith (43:09):

I do it on my iPhone. Just go to the App Store. Download Calm. You get the first seven days free, and then I think it's like $40 a year. It's pretty inexpensive. Actually, anybody at Johns Hopkins who's faculty or staff or student gets it free. We believe so strongly in it that the whole university gets it free. She has a little bit of a Long Island accent. So I like that too. But she'll have you concentrate on your breathing to start with. LeBron James has a whole series of meditations on there about sports, and living the life that you want to lead. They're from the UCLA Mindfulness Awareness Research Center, MARC, at UCLA. Just Google that. It has a whole bunch of free meditations on it. You'd be surprised at how many of our consultations are actually to teach somebody meditation. And if you told me that five years ago, I probably would have dropped that. And there's another one called This Is Kara (thisiskara.com). It has about 25 different meditations, each from about 15 minutes to 20 minutes long. It's like, “I'm feeling

lonely. I'm feeling depressed. I'm feeling fatigued." And you can click on those, and she'll lead you through a meditation that might help you with each of those specific feelings or symptoms.

Rick Stanton (45:21):

Mike Yancey, how are you doing?

Mike Yancey (45:56):

I'm getting spinal cord compression. I've been through radiation before, but I'm still going to have some soreness for quite some time. I have unfortunately become concerned about cracking the vertebrae, so now I'm on limited duty. Projects are all over the place, and it frustrates the heck out of me.

Rick Stanton (46:24):

Limited duty on what?

Mike Yancey (46:26):

They're letting me lift anything much more than 10-15 pounds. Don't know how long it might go on. Frustrating.

One of the issues is that this lesion on my back was a non-PSMA-producing lesion. That's a red flag in and of itself. The good thing is it had not not morphed to small-cell neuroendocrine. That was one of my fears.

Tom Smith (47:39):

Amgen is working on a drug for neuroendocrine prostate cancer. I think it's in clinical trials right now, and from what I'm told, it looks pretty promising.

Brian McCloskey (47:55):

You know the name of it, Tom?

Tom Smith (47:57):

No. Just had a number.

[ClinicalTrials.gov Identifier: NCT04702737 -

Official Title:	A Phase 1b Study Evaluating the Safety, Tolerability, Pharmacokinetics and Efficacy of Delta-like Protein 3 Half-life Extended Bispecific T-cell Engager AMG 757 in Subjects With De Novo or Treatment Emergent Neuroendocrine Prostate Cancer
Actual	June 10, 2021

“Palliative Care for Advanced Cancer” (Tom Smith) [#32]

Study Start Date :	
Estimated Primary Completion Date :	October 3, 2023
Estimated Study Completion Date :	April 10, 2026

Mike Yancey (48:06):

My particular mutations have a very high probability that they’re neuroendocrine. That's why I'm trying to stay on top of this thing. That's good to hear that there are some things in the pipeline potentially.

Brian McCloskey (48:20):

Tom, any key takeaways?

Tom Smith (48:46):

I think I've said most of them. Being from Baltimore, and Francis Scott Key and the Star Spangled Banner, and all that, I would say, “Don't give up the ship.” You want to stay alive now, but you want to stay alive for advances coming three months down the line, six months down the line, a year down the line, waiting for somebody to crack the code even more.

Be honest with yourself, and be honest with your providers about symptoms you're having. If a bone hurts, please tell somebody about it. If you're short of breath, please tell somebody about it. I have a fair number of guys who don't want to be a bad patient, and they think that if they complain too much, then I'm going to stop their therapy. That's not the case. I just really need to know. I don't want somebody's vertebrae to collapse. I don't want their femur to break. It's much easier to fix those things before they happen than wait for them to happen.

Brian McCloskey (50:00):

That's great advice.

Anonymous Caregiver (50:02):

Can I add to that and say the same thing is true with your psychology? What are the thoughts that are going around in your head? From a therapist's perspective, it's the same thing. If you have insight, if you're noticing symptoms, or if you actually know what you're saying to yourself, tell someone. This is the whole other companion profession that's designed to help heal you and make you whole.

Brian McCloskey (50:27):

Tom, you said you see breast cancer patients as well. We hear a lot about the difference of how women and men take on this disease. Can you talk a little bit about that. It helps all of us contextualize how to manage this. What's different between men and women?

Tom Smith (50:55):

I think women are more likely to talk amongst themselves and talk with their doctors and nurses. They're more likely to seek psychological helpers, or counseling help than guys are. We see it as a sign of weakness. For 16 years, we've been running retreats for patients with metastatic disease and their partner, starting with breast cancer, and now with colon cancer, and we did our first one for prostate cancer metastatic couples. That was about six months ago, when everybody worried that we would have a hard time getting the men to open up, but after about 30 minutes, it became obvious that we were going to have a hard time getting the men to shut up.

Anonymous Caregiver (51:49):

Men need someone to create that opening that they're willing to follow. Right?

Tom Smith (51:56):

Yeah. Just be open and honest. I couldn't agree with Kerri more. If you're having feelings of depression, anger, frustration, it's much easier to share those with somebody. Get some help with them.

Brian McCloskey (52:18):

I have two questions. One is on one side of the pendulum, and the other is on the other side of the pendulum. Early in my disease, I was very concerned about controlling my cancer. I began to take hormone therapy, and then I was also super concerned about how hormone therapy was going to affect me physiologically. I wanted to be able to monitor not only my PSA to understand cancer progression, regression, etc., but also physiologically how I was metabolizing these drugs and its effects on me. Are there advances in this space? Where's the digital self? Where are we on that front?

Tom Smith (53:12):

The PSA is still the best for most of us. The PSMA scan is an advance in that you can see earlier spots that you might radiate and prevent them from seeding other spots. Although the data from that is not yet fully mature. I don't see any other ways that I know of to sort of monitor yourself.

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If you are on androgen deprivation therapy, it is vitally important that you exercise. You lose 15 to 17% strength in your legs. You can maintain most of that if you go to the gym, you lose some arm strength, although not nearly as much as the leg strength. Your chest wall stays the same and that's hardwired not to change. But if you're on androgen deprivation therapy, do whatever sort of exercise you can at least three to five times a week just to maintain it.

Brian McCloskey (54:32):

This is very different from some of our other discussions, and very complementary. Thank you so much, and we may follow up with you if we have other questions, if that's okay.