Understanding Palliative Care with Dr. Matthew Tyler

Candace Dellacona: Welcome to the Sandwich Generation Survival Guide. I am your host, Candace Dellacona, and I am here today with Dr. Matthew Tyler, who is a dual certified internal medicine and palliative care doctor, and also the founder of How to Train Your Doctor, which I'm sure our listeners already know about because he has thousands of followers on Instagram, on Facebook, on YouTube. So welcome Matt.

Dr. Matthew Tyler: Thank you so much for having me. It's good to be here.

Candace Dellacona: It's great to have you. I just said to you before that I think I have more questions for you than I've ever had for any other podcast guests, so I'm so glad to welcome you here today. Why don't you tell our listeners a little bit about who you are and what, How to Train Your Doctor is all about.

Dr. Matthew Tyler: Sure.

What Palliative Care Is

Dr. Matthew Tyler: So I am a full-time hospice and palliative care physician, and I work in the hospital. I work in our cancer treatment center. And for those of you who are unfamiliar with palliative care palliative care is a medical specialty that provides support in anything related to the stressors or symptoms related to a serious illness like cancer or heart failure or dementia. And the real big picture goal of palliative care is to give you the best quality of life possible. And so I am often meeting with families, patients, caregivers, at very difficult times in their life, faced with big decisions about medical testing, treatment interventions, which ones make sense, which ones feel like maybe they're a bridge too far? And I help function as a sounding board to make sure that these patients and their families have the information they need to make tough decisions and the emotional support to think through those help provide some. Guidance on how to make a plan to move forward.

Candace Dellacona: And so how did you come to transition to find your, calling? Because, for those of you out there listening, the way that I found you, Matt, was through Instagram because you were putting out such amazing and helpful and enlightening information, even for someone who is tangentially related to this world. How did you come to How to Train Your Doctor? Tell us a little bit about that process and what you hope to do.

Dr. Matthew Tyler: Yeah.

Why Dr. Matthew Tyler Started Social Media

Dr. Matthew Tyler: So my foray into social media and talking about all topics related to palliative care came from two big issues in our field of palliative medicine. One issue is that people don't meet us early enough in their illness. Palliative care often gets called in, way too late compared to when we could provide the most support. The other observation being that even if we were getting called a hundred percent of the time the way we wish we would, there aren't enough of us to go around and you can't scale people as well as you can, scale views on social media. And so my hope by getting into social media was just to show people what palliative care is all about and how it can be helpful. The big goal that people would start to kind of speak up and ask for palliative care, demand palliative care from their medical team to be part of the support on their team.

Candace Dellacona: Amazing. I recently had a guest on the podcast, and one of the topics we were talking about was the concept of supportive care, which is obviously beyond the medical treatment, let's say that someone is receiving for cancer. And so I love topics like this because it really addresses the person as a whole and often the family as a whole.

Palliative Care vs Hospice

Candace Dellacona: I think one of the things that I've noticed with a lot of families is the confusion between palliative care and hospice. So how do you explain the difference to families and their patients about the difference? And you sort of touched on this as a two part question is how and when should the palliative care ideally begin?

Dr. Matthew Tyler: Yeah, so I find easiest to differentiate palliative from hospice care in that palliative care is needs based and hospice care is prognosis based. So you are eligible for palliative care from the moment you receive a serious illness diagnosis. So the moment you're getting advanced dementia or a cancer diagnosis, if you have concerns related to the quality of your life, how treatment's gonna impact that, and how the disease is gonna treat that how well it's gonna work, how it's gonna make you feel, you're eligible for palliative care. And we have, there was a landmark study back in 2010 that showed patients who got connected with palliative care at the beginning of a stage four non-small cell lung cancer diagnosis. You know, we all sort of figured if you get connected to palliative care early, you have a better quality of life, which ended up being true. But the kicker was that those folks ended up living longer with a better quality of life with less intense treatment than the folks who got palliative care later on or never. And palliative care, again, needs based, if you have concerns about quality of life with an underlying serious illness you should be asking for palliative care. You should be expecting it, but definitely asking for it. Hospice care on the other hand is prognosis based. Meaning at the end of the day it's an insurance benefit that you are eligible to use if you have an underlying illness for which, if it runs its expected natural course, your doctor believes that your time is six months or less.

Candace Dellacona: So the magic number for hospice is the anticipated expectation or prognosis of six months or less, which should be a pretty good indicator why palliative care is not the same as hospice. And so you know when you are someone who requests the palliative care piece, can a patient also be provided the curative treatments or the treatments that you had been receiving for cancer all along?

Dr. Matthew Tyler: Yeah, absolutely. The best part about palliative care is that you can get it alongside all your other treatments. So as I mentioned, I take care of folks in the cancer treatment center and I'm working alongside the oncologist. They're doing the chemo, the immunotherapy, and I'm doing the symptom management, the emotional support, the planning for the future. We work together. One of my pet peeves about how people talk about palliative care is when we talk about people going palliative care or people that are in palliative care is I worry that it perpetuates a misconception that palliative care is like a choice that you have to make in lieu of something else.

You don't have to give up anything to get palliative care. It's an, it's extra support and almost everyone I work with says they could use some extra support.

Candace Dellacona: I think I've never heard anybody say that they're good. And they don't need that extra help. If anything, the reason why this podcast exists, the reason why your social media platform exists and it's so successful is because people are starved for resources and don't know where to begin.

Dr. Matthew Tyler: Yeah.

What Palliative Teams Do

Candace Dellacona: When you think of palliative care, or maybe when I think of palliative care, I should say, and perhaps some of our listeners, you know what sort of care and things do the palliative care teams most commonly manage on behalf of a patient? Can you give us some examples?

Dr. Matthew Tyler: Yeah. A standard palliative care team should include multiple disciplines on the team. Meaning docs, nurses, social workers, chaplains, ideally. And so how palliative care can help will depend on, who amongst the team you're working with. But high level palliative care should be able to provide some insight and guidance on how to manage you know, physical symptoms, emotional needs, how you're coping with things, your kind of spiritual and existential things like how this illness is kind of impacting how you see yourself in the world, the universe, and think about the bigger picture. They can also help with planning for the future, getting your wishes in writing, if you would find that sort of thing helpful. Talking to your family about what's going on, kinda getting them to rally behind your wishes and coordinating care with the other medical specialists and making sure that we are all on the same page about what we're doing and why we're doing it, what to expect.

Candace Dellacona: Yeah.

Why the Confusion Persists

Candace Dellacona: And why do you think there seems to be, aside from, let's say staffing issues and the fact there are not enough palliative care team members to go around, what is the resistance or the perceived resistance would you say among other professionals and among families when it comes to like this dialogue and why is there so much confusion? Do you, you thought about where that's come from?

Dr. Matthew Tyler: Obsessively yeah how long we got.

Candace Dellacona: Exactly.

Dr. Matthew Tyler: I think there's a lot of pieces to the access to care issues when it comes to palliative care and connecting when we should be connecting. Part of that is that palliative care did, at its core, come from the Hospice movement. Hospice was here first. The modern day hospice came about from, at least in the US the Reagan era. Hospice as a philosophy goes back much further, but the Medicare hospice benefit was a Reagan era thing.

Candace Dellacona: Identified during the 1980s for purposes of hospitals getting paid or care providers getting paid for the care provided under the hospice umbrella.

Dr. Matthew Tyler: Right. Right.

Candace Dellacona: Okay.

Dr. Matthew Tyler: And palliative care as a board certified medical specialty is even newer. Again, people were doing palliative care and providing patient-centered holistic support for a very long time. But as a board certified specialty that didn't come about 2008.

Candace Dellacona: Wow. Okay, so it's really new.

Dr. Matthew Tyler: Yeah. It is new. And with that comes the, there's we're kind of in between generations of medical people right now. And there, there are doctors practicing right now that just straight up didn't have exposure to palliative care when they're in training. And again, that's a factor, not an excuse.

I think we've caught up with lots of other innovations in medicine and that were a lot newer than 2008. So there's it's a piece. I think there is a, palliative care, being tied to hospice care in the name right. I'm board certified in Hospice and palliative Medicine. So there is that by tying them together, there's this conception that they must be relatively the same thing, and that can be a barrier to understanding that they're similar but not the same. And then you've got just a general cultural barriers that no one really wants to think about, talk about death and dying. It's still heavily stigmatized. It's not really something people are quite proactive about. It's something that we just sorta keep to the side until we absolutely need to. So there's not a lot of hunger in the general population to necessarily get ahead of this and learn about this. Although I think that's changing, but it's certainly a barrier for many.

Candace Dellacona: So, going back to like your first point, right? When it comes to the actual care providers, if they are, esteemed enough and have enough years under their belt, it was not part of their medical training.

Dr. Matthew Tyler: Right.

How to Ask for a Referral

Candace Dellacona: And so when you think about that from a caregiver's perspective or our sandwich generation members that are listening that are at the bit to get these questions answered because I know they struggle with these things.

When you have a care team that perhaps doesn't have the training on it. How do you suggest they bring the subject up with the care team? Do they just say, I want a palliative care consultation with the team that must be here at the hospital?

Dr. Matthew Tyler: That's where I'd start. Yeah. To say I'd like a referral to palliative care if you are taking care of someone who is in the hospital asking, do you have a palliative care team here? If so, i'd meet them. That's all you should have to do. If you're meeting with your doctor in clinic, asking for a referral to a nearby palliative care team would be a great place to start.

Candace Dellacona: And I think it's important to think about too, is that's a big piece of advocacy, right? Particularly if the patient, him or herself or themselves cannot articulate things like that or it's something that they perhaps haven't thought about independently. And the other thing you brought up is that <u>even</u> your title saying that you're board certified in palliative care and hospice, and tying it together with that moniker and the stigma of that. How do you see your role as a practitioner to untangle that, to take the stigma out of it? I think you're doing it by, by being out there every day on your How to Train Your Doctor platform.

But are there other things that you're doing that you see in your everyday life, either with patients or your colleagues about trying to un unravel that for them and unpack it?

Dr. Matthew Tyler: So we're speaking specifically about stigma amongst medical professionals?

Candace Dellacona: Yeah. And stigma among the moniker of like palliative care and hospice tied together. So like to the outside world, whether you're the patient or you're another professional that maybe hasn't been trained in it or resistant to it, or you're so focused on curing, you don't wanna think about things like that.

Dr. Matthew Tyler: I think about that in the same way or if you're familiar with the innovation adoption curve. Are you familiar with that term? So there's this concept of a bell curve, right? You've got the early adopters, the folks that sort of follow behind when someone else has shown this is a thing. And then you've got the folks who are you're never gonna do the new thing.

And you think about like telephones, right? You got the folks out there the proud few or the first ones in line for the very first iPhone. You've got the rest of us that maybe by like the iPhone four or five or six were like, oh, maybe this is gonna be a thing and maybe get rid of my Blackberry. And then we followed suit at that point. And then you got those folks who, if they still sold them, they would have a rotary phone.

And I use the same concept when thinking about palliative care that's in my practice. Going through the work in the hospital and the clinic, I am looking for the folks who get it and that really don't need rigorous convincing education that this just inherently a good thing and that this is, by all metrics, standard of care in many respects now. And I reach out to them and say, how can I help? And how can we do more work together?

A great example at our hospital was that we started as a hospital based team only. We were only seeing folks in the hospital to talk about symptom management, care goals, care coordination, that sort of thing. And the oncology group came to us and said, we love how you're taking care of our patients in the hospital. We would love it even more if you came to clinic and saw our patients in clinic too. Tell us what you need. We'll make it happen.

Candace Dellacona: Wow.

Dr. Matthew Tyler: And yeah, there was no doors needed to be beaten down at all. They saw the work. They got the work, and so we said, yeah we're there. Let's figure this out. It, meanwhile we got, residents coming to me once a week at least saying, so-and-so primary care doctor oh, we've been trying to convince them to get a palliative care referral. They just won't do it. I'm like, I say, okay, like there's just some folks that's at some point we move from, can't get it, won't get it. You've done the education you've given the talks, you've given the grand rounds. I've done all that and at some point folks just don't want to practice a different way, and there's only so much you can do so I'm always one that believes in you lean into your champions. Grow. Grow with the people that you know wanna grow with you and the will follow.

Candace Dellacona: Yeah, I mean, I think that's good advice. And when you think about, the family in general. Aside from the practitioner's perspective, a lot of things that families struggle with in the context of the medical world and as advocates in the sandwich of the sandwich generation is communication and decision making.

And that's in a bit of my wheelhouse when it comes to signing documents where you're appointing people to make decisions, and I know that families often feel really overwhelmed by medical information. Just in general, the diagnosis and what to do and what comes next and what should happen and what could happen if this doesn't work, kind of thing.

So how do you see or what do you do with respect to your palliative care team to help the patients clarify what their goals are, if they have a hard time communicating that? Do you have any advice for that?

Dr. Matthew Tyler: Yeah.

Training Doctors to Talk Goals

Dr. Matthew Tyler: And it's I'm glad you asked this 'cause this sort of reflects how, what, How to Train Your Doctor means to me compared to when I started this. So I, I started doing social media and videos back in 2022 under the handle How to Train Your Doctor. And at the time I was very much focused on giving patients and caregivers like phrases or questions to bring to the medical team to be better self advocates, engage in these complex conversations. And I, I love the idea of it. But I was repeatedly hearing from folks, Hey I'm asking for this stuff. I'm asking my doctor to have a bigger picture conversation. They keep shutting it down what am I supposed to do? And after hearing about enough, I've shifted really what I'm trying to

Candace Dellacona: What are, so what were the conversation starters? So tell us a little bit about your tips that you'd provide to those people.

Dr. Matthew Tyler: Yeah so the training got back to the notion that, as we talked about palliative care being relatively new in the medical field, so to our complex medical decision making communication skills. And the reality is doctors don't get trained in complex medical communication. We get trained in complex diagnoses and treatment,

Candace Dellacona: In treatment, yeah.

Dr. Matthew Tyler: making difficult decisions that don't have a medically speaking black and white, right or wrong answer. Medical decisions that are highly dependent on patient preferences and trade offs they're willing to make or not make as human beings. We're not trained in that. That it is happening. I think the younger generation of doctors coming through are getting exposed to more of that. But it's still more of the exception, not the norm. And again, I promise I'll answer your question when I talk about training, when I talk about How to Train Your Doctor, it was more with that in mind where I was trying to help patients and their caregivers nudge their doctors into these conversations, knowing that doctors weren't really taught how to initiate those necessarily.

Candace Dellacona: Yeah. So the burden on the family or the patient really.

Dr. Matthew Tyler: For a lack of any better alternative

Candace Dellacona: all due respect, right?

Dr. Matthew Tyler: Yeah. We can't snap our fingers and kind of change the medical culture.

Candace Dellacona: no, of course not.

Dr. Matthew Tyler: Uh, And a lot of patients and caregivers presume that if there was something serious to talk about, their doctor would bring it up.

Candace Dellacona: True. Absolutely true.

Dr. Matthew Tyler: And that is sometimes true but not always true. And in many times, the doctors look into the patients and their caregivers to float out big questions before they, they jump in because they're worried about upsetting them or giving them too much more, too much

Candace Dellacona: so interesting. It's just to go back to that so if you think about it in practical sense, and I've been there as a family member we're like relying on the doctors to be telling us like, okay, what does this mean? And then the doctors are waiting us on us to ask those big questions.

And often both parties walk away okay, as the caregiver or the advocate, I guess if they thought I needed to know something, the doctor would've told me. And then the doctor leaves the meeting saying if they had questions about what this meant, they probably would've asked. That, that's sort of what you're saying.

Dr. Matthew Tyler: Yeah. So the early mission of How to Train Your Doctor was, prompting patients and caregivers to say, Hey, doc a quality of life is really important to me and I'd like to talk more about how this illness is gonna impact my quality of life and what changes should I expect?

What decisions should I prepare for? Let's talk about getting a backup decision maker in writing. I'd really like to know about prognosis. Can you gimme some, a general ballpark about what to expect? And it was, and I think I was offering those questions through the lens, through the personal lens that if someone asked me those questions, I would love to engage with them in a conversation about that.

And I'd have thoughtful answers to hope. Hopefully I'd have thoughtful answers to give them in exchange for sticking their neck out there to ask those things.

Candace Dellacona: As a trained palliative care doctor though, so you were much more, you had the faculty to answer those direct questions, whereas other physicians, perhaps not.

Yeah.

Dr. Matthew Tyler: And at the same time, knowing that a lot of my colleagues were not powertrain, are still, willing to jump into those conversations when prompted. But at the same time there's a lot who aren't. And when do caregivers and families and patients stick their necks out to ask the questions? They really do just. Get shot down. Like, I don't talk about that, or don't worry about that. One day at a time, just like garbage like that is not particularly helpful. And so over time I've really shifted like the training of How to Train Your Doctor that I really am speaking to these days is more so just getting the palliative care referral from your doctor and training them to reach for palliative care and to pull 'em onto your team. Because that team is equipped to talk about the hard stuff and synthesize the information and put it into the context of what matters most to you and help you plan for the future to keep you in the driver's seat of your life for as long as possible. And that's really become, I think A more realistic and B, easier for people to wrap their arms around when they're already, neck deep and medical life as it is and dealing illness.

Candace Dellacona: But I think what you've done with How to Train Your Doctor is, a movement by groundswell, which is, maybe it wasn't the most efficient way to try to have the other practitioners step in. But putting that information out there, you're creating more educated patients and families. So I think by virtue those, the doctors who are perhaps behind the eight ball a bit will be brought up alongside with everyone else, and hopefully there'll be some catch up there.

Handling Family Disagreements

Candace Dellacona: Communication is so important with decisions like this. And one of the things that I talk about with clients when we're signing, let's say healthcare proxies, for example, here in New York. You're only allowed to appoint one agent and then one successor agent. You can't have two agents because in the event of a disagreement, what do doctors do, right? So how do you help family members when, you know there's conflict? And do you have suggestions to help families navigate these really difficult situations where some loved ones may disagree about the type of care being received, let's say medicine to manage pain, but the patient isn't alert or something like that. Do you have any suggestions for those folks out there looking for that?

Dr. Matthew Tyler: Yeah, so navigating family disagreements about how to proceed with medical care. I'll say, there's always gonna be fringe cases. I'll answer this from the lens of my experience that most family members, even when they disagree, they're advocating for their loved one, the best way that they know how, and that we all have our loved one's best interest at heart when we into these conflicts and that's why they get so heated.

Putting aside all the sheisty stuff we've seen about financial conflicts of interest, 'cause I think those are far away minority cases compared to what's usually going on, which is people are scared, people are confused, they're not medically trained, and they're just trying their best. Uh, and in those situations, I think what is the most helpful starting point is requesting a family meeting from the medical team.

It's much easier to do in the hospital, but you can organize it in clinic too. But really setting aside a time to have everyone who has a vested interest in this medical care plan on the family side, medical side. To really sit down and make sure that we're all operating from the same playbook. What is going on? What changes are common with the disease? What decisions are on the table? And also what are the expectations from these different interventions? Do we have the same information about how feeding tubes help or hurt folks with dementia, for example? Yeah we're pushing mom to do chemo, but is the oncologist even offering chemo? Let's sort this out first and let's sort out what they think about the benefits or not of said treatments? And I would say most of the time when we have to just gather in one room or whether that be physically or virtually and have one conversation, most of this confusion and disagreement dissipates.

Beyond that, as often as I can, I try to bring back the patient voice into the conversation. And if the patient can't speak for themselves, I think there is a common trap question that medical folks will ask or that families will ask of themselves, which is, what would mom want? What would dad want?

And I think that is a very sticky question because when you're very sick, even dying, what most people would say they want is to get better, be stronger,

Candace Dellacona: Yeah. Yeah.

Dr. Matthew Tyler: go back home. And it leads us down this road of, talking about things that aren't really possible and sidesteps needing to make some really difficult decisions. And what we really need to do in these sorts of situations where this disagreement is come back to the person and their core values and how they prioritize what's most important to them. And so rather than asking, what would mom want, what would dad want, I'd say, if your dad could, understand the situation as we've laid it out to you, what would they say? Tell me what they'd say about what's going on here. And, yeah, because it really, I think we get much too fixate on outcomes and choices before spending some time with values and priorities and the process of just prioritizing what matters most. And if we spend some time talking about what matters most to this person, trade offs to be willing to make or not make for more time and what to do next is gonna be a lot easier to sort out. And again, conflict is, tends to dissipate a lot more once we start with, okay, medically, what's possible? What are the trade offs here? And then what trade offs is this person willing to make? What would they say about this?

Candace Dellacona: Right, right.

Values Based Decision Makers

Candace Dellacona: I think, you bring up a really great point about what would mom or dad say about this and when I have clients sign their advanced directives from a healthcare perspective, one of the questions I ask them when they're considering certain agents to be the one to speak for them is, I wanna make sure that the person you're appointing is a good advocate for you and not a shrinking violet with doctors. And can ask for the attention.

But not so strong that they are substituting their wishes for the patient's wishes. And that's what you said. And there's a real balance there, right? Between advocating and being super strong and then maybe shutting out the voice of the patient and always going back to what does the patient want?

Dr. Matthew Tyler: Yeah I was just the other day talking to a patient who was thinking about changing the names on their healthcare Power of Attorney document, and they had their sister on there and they were like my sister lives outta state, so I think I might I pick this friend who lives close by instead to be my healthcare private attorney. And I said look, it's certainly, it's helpful to have a healthcare surrogate who is available locally and could come to the hospital. God forbid you're hospitalized, but far more important to have a backup medical decision maker who just understands your values and your priorities and step up to make potentially like really high stakes life or death decisions. Because it's your POA, your power of attorney, is rarely ever making easy decisions or low stakes things. It's when you're so sick that we need to have a thoughtful conversation about, quality of life versus living as long as possible and different decisions.

Those are the things that power of attorney most commonly gets called in to do. So ideally, pick someone who can speak as if they were you and will, speak up to make tough decisions if need be.

Candace Dellacona: And just for clarification purposes, so you're in the Midwest and so in some states in the Midwest healthcare directives are called medical or healthcare powers of attorney Here on the East Coast, they're mostly referred to as healthcare proxies. When Matt is referring to a power of attorney making a decision for medical purposes, it's a medical power of attorney.

Spiritual and Cultural Beliefs

Candace Dellacona: And one of the things that you said at the top of. Our discussion was talking about the spiritual piece, right? Because you were talking about the whole person and viewing the whole person in a way that takes into account their quality of life. So how do you help patients incorporate, let's say cultural beliefs or their spiritual concerns?

Here in New York people of the Jewish faith even have a halachic living will which is governed by Judaic Law. How do you help patients incorporate those beliefs maybe that you're not familiar with, into their care plan?

Dr. Matthew Tyler: Yeah, so I think a couple things on that front. As a as a physician, a specialty physician at that, I think the best place to start is by asking. I try to highlight and make a habit of asking, how are you spiritual, religious? Many people are and many people are not.

But for folks who are, I'll ask you, how does that fit into your medical care right now? Is there anything that's important to know about how your spirituality or religious beliefs might impact your medical care? And that is typically where, folks who are Jehovah's Witness may, say no blood transfusions.

And I think similar to your question, if there's anything important to know, I have to keep an open mind 'cause I don't know how they all work for people. But I make a point to ask and if there's ever, a particular decision we need to make, and I'm not sure how religious beliefs fit in and nor is the patient, we always encourage 'em to reach out to their community, religious leaders and get their input whenever possible too. 'Cause we don't, the nice thing about my job is I don't have to know all the answers. And often I try to connect 'em with the folks who do.

Candace Dellacona: Of course. And reminding them that they can do that, that those are, certainly great questions for them to ask.

Turning the topic a little bit.

Insurance and Coverage Basics

Candace Dellacona: There's been a lot of talk, especially at the beginning of the year of, healthcare coverage and the logistics related to Medicare and private insurance and how people pay for things. So is there something from a physician's perspective, that you'd like to share with the listeners about what families maybe should know about insurance coverage as it relates to their access with palliative care?

Dr. Matthew Tyler: Unfortunately, like everything in healthcare that what your coverage looks like will depend on your plan. So you your big ones that are being your private insurances or a Medicare Advantage plan that's run by a private insurance or traditional Medicare, speaking to the 65 and over population here.

So palliative care referrals are just like any other specialty referral. So, if you need a referral versus if you can self-refer, what's your copay gonna be and all that stuff will be as relevant as it is for anything else you're getting in your healthcare right now.

Candace Dellacona: A referral, like a traditional referral as you'd think if you need a referral for an orthopedic doctor.

Dr. Matthew Tyler: Yeah. For most people, yeah, you do have to get a physician referral. And there are a plan, I think PPO some PPO plans do allow you to self-refer. So If you have a self, it's always good to know how your insurance works in general to avoid nasty surprises.

But I would always check to see if you can, if you have a plan that allows you to self-refer. If you do have a plan that requires physician referrals for palliative care, I was, I just had a, someone asked me about this the other day, but they they said, well, what if you're getting cancer treatment and you ask your oncologist for a palliative referral and they say, no, you don't need that. What do you need palliative care for? And, or what do you do? And in situations like that, you don't need that specific doctor's referral. You can go to your primary care doctor or your geriatrician and get a referral through them if you like. Or you can talk to the social worker or nurse and have them, apply a little like inside pressure.

Candace Dellacona: Right.

Dr. Matthew Tyler: it's often the nurses and the social workers and chaplains who understand the ins and outs of palliative care more so than the doctors and many times and can know how to like, say the thing to get the thing that you need

Candace Dellacona: Right, the right words and phrase it the right way.

Dr. Matthew Tyler: Yeah. Yeah, you know, there are a lot of avenues you can go that way.

Hospice Benefits and Gaps

Dr. Matthew Tyler: And, but while we're on the topic of insurance I do wanna call out that hospice works a lot differently when it comes to insurance coverage. And I think probably the main things you know about hospice care is it's all covered through traditional Medicare. So even if you have an advantage plan, if you're moving to hospice care, you get kicked back over to traditional Medicare. And in, in that case, your Medicare hospice benefit covers everything provided by the hospice agency. The nursing visits the social work visits, the medications, the equipment like the bed and the wheelchair, the oxygen, that's all covered by your Medicare hospice benefits.

Candace Dellacona: Which is amazing. I think one of the things that leads to some confusion for my clients anyway, and I think just in the public at large is that when someone is, fits the category of hospice and they receive the hospice, I guess diagnosis, if that's the right terminology, there's also an assumption that they'll receive home care services through hospice. I think what's really important to distinguish for people is that the care that you receive is actually a nurse, which is considered skilled care to come in and check up on you, but that does not, hospice does not automatically cover the home care attendant role, which is the activities of daily living, which are often really needed with someone who's on home hospice but is not covered through home hospice and Medicare.

Dr. Matthew Tyler: Yes, this is a major gap in the Medicare benefit in general. As you said it's most noticeable when it comes to hospice care. But as you're getting at, there's no scenario where Medicare will pay for private in-home caregivers. Which is a real shame as often that is the difference between being able to live the rest of your life in your own home or having to, to move to a nursing home and spend all your money and apply for Medicaid and have Medicaid pickup the bill from the nursing home.

But that is a major gap that I am talking to families about on a almost daily basis these days. And you're right. It's an expectation. If you're sick enough to need hospice, then most people find themselves needing 24 hour supervision and are shocked to learn that there's no mechanism through most major insurance plans, including Medicare, to get that sort of support.

Candace Dellacona: And people in the sandwich generation are often those that are filling that gap and trying to pull that need, whether it's a daughter or in my case, I was a niece trying to coordinate all of that. So yeah, I mean it's really helpful to know that in advance and understand that there can even be a significant financial burden with that.

What Families Wish They Knew

Candace Dellacona: You've been so generous with your time, Matt and I only have one more question and then I promise I will let you go. What do families often say to you, that they wish they had known sooner about palliative care and hospice and anything under your umbrella?

Dr. Matthew Tyler: Most people ask why we haven't been involved sooner is really the big thing. One, one of the other common questions that families would ask is really just, what should I be asking? When you're thrown into this situation, you know, caring for a parent who's getting sicker, for most people, they're doing this for the first time and for most people, they're not medically trained and they have no idea what's normal and what's not.

And especially in medicine where the whole thing's a dumpster fire, medicine doesn't function like a business or a law firm or these other operations that just make more logical sense. And there's an order to things that just, it's not the same in medicine and it's hard to reality check yourself if you're not familiar with the territory. For most people, once they meet us, they ask where have you been? Like, why weren't you involved sooner? And that's why I am on social media talking to people about palliative care. So they know to ask for us sooner. 'Cause there's a good chance that they're gonna bring it up before their doc does.

Final Thanks and Wrap Up

Candace Dellacona: I started this podcast because I wanted to provide resources as I said and you are the perfect example of someone who shares his knowledge to people that really need it and are searching for it, and you're helping people like me and the sandwich generation survive and thrive and figure it all out.

So from the bottom of my heart, thank you so much for taking time away from your schedule today to share all of your knowledge with us. And we're gonna have all of your social media profiles in our show notes, so that our listeners can follow along and learn as much as I have from you. So thank you so much for being here today, Matt.

Dr. Matthew Tyler: It was a pleasure to be here. Thank you for having me.

Candace Dellacona: Yeah, my pleasure.