

# Transcript of Tom Caprio podcast episode

[00:00:00] Welcome to We Really Need to Talk, a podcast about the conversations we could be having with our loved ones. These are conversations with the power to improve the way we live, the way we age, and the way we die. Talking about what we want for the end of our lives is not easy. Found it to be useful and powerful and suspect that others may as well.

My name is Elizabeth Bergman, associate Professor of Gerontology at Ithaca College. And I'm Lisa Richards, the program coordinator for the Finger Lakes Geriatric Education Center. We are co-hosting this podcast from the studio at Ithaca College where we work together in the Gerontology Institute. We spend our days immersed in teaching, studying, and developing programs on topics many would prefer to avoid altogether or maybe just whisper about fearfully.

We have seen firsthand time and again the consequences of not talking about the end of life, but we've also witnessed the power of [00:01:00] talking about it, and that is our motivation for making this podcast.

Welcome back to, We Really Need to Talk. We're so glad you made the decision to listen. Today we're going to talk about the healthcare system, specifically about palliative care and hospice. We'll learn about what they are, when and how to access them and more.

So we'll start by introducing our guests today. We have Dr. Thomas Capo, who is a professor of medicine, geriatric psychiatry, dentistry, clinical nursing and public health sciences at the University of Rochester Medical Center. He's also the Chief Medical Officer for the University of Rochester Medical Home Care, and the medical director for the UR Medicine Hospice.

He also oversees the Geriatric Workforce Enhancement Program funded by the Federal Health Resources and Services Administration. [00:02:00] This program provides education and training related to geriatrics, palliative care, and dementia care for healthcare professionals and family caregivers across New York State.

We are so fortunate to have him here with us today. He is a busy guy. So let's get started. Thank you so much for having me here today. Really happy to have

joined you, and this is such an important topic. Thanks. Thanks, Tom. Let's start with some basics. First of all, what is geriatrics? So that's a great question.

Geriatrics usually refers to the discipline of geriatric medicine, so that's a medical specialty. So I'm a physician that specializes in geriatrics. Sometimes we call that a geriatric, similar to, if you can think about a pediatrician takes care of children. Geriatrician is really focused on the healthcare needs of older adults.

And so we care for patients as they age, and there's particular, we know challenges and diseases that are associated with. That the specialty of geriatrics really focuses on, okay, on that [00:03:00] track, we know that there aren't enough geriatricians in the country. What's going on there to. Yeah, that's a real need I think for our country.

The American Geriatric Society, which is our largest kind of professional society of geriatricians. They've done some studies on this and they're reporting that there's less than 7,000 certified geriatricians in the United States currently. So that's far below the number to meet the need of older adults across the country.

So if you look at the demographics, there's more than 54 million older adults in the country and less than 7,000 geriatricians. And the other challenge with that is that many of the geriatricians, like myself, we are actually not engaged in full-time clinical practice. In other words, We do teaching and administration and other things.

Only about half of those 7,000 or so are really seeing patients as their full-time professional responsibility with it. So that really creates a gap. And some of the estimates are that we're gonna be short of about 30,000 geriatricians by the year 2030. So it's really [00:04:00] hard to kind of catch up and be able to meet that sort of need and that.

Particularly when you consider that for physicians that we're training to be specialists in geriatrics, the new geriatricians, we only train about 250 of them a year in the entire country. So you can do the math there. It's going to really exceed our capacity to be able to meet those sorts of needs. So I think that for many of us in the field of geriatrics, we really looked at the fact that we have to really create a transformation across the entire kind of healthcare work.

To really be sensitized to the needs of older adult patients. Really what I term is geriatric size, a lot of the healthcare system, so utilizing a lot of the expertise of

geriatricians and not just the physicians, but really geriatric specialists at nursing and pharmacy and rehabilitation, to be able to transform the system to be able to meet these kind of unique needs of the older adult patient.

Thank you. And given what you just described, we are really fascinated by the [00:05:00] fact that you have a twin brother who is also a geriatrician. Can you tell us a little bit about how that came to be? Absolutely. Yeah. So I have my brother, Tony is a geriatrician as well. We did some of our training together.

He's now located in North Carolina and stayed here in New York. And he specializes in geriatrics as well. And was interesting that we both ended up in that similar career trajectory. It's not real usual. I think that many people going to geriatrics begin with no less twins going into that.

But I really think that a lot of this was shaped by our family experiences and I think that really speaks to common thread that is across many people's stories about how are they working with older adult patients and clients, is that oftentimes there is. Central component or theme of their family experiences.

And certainly for my brother and myself, we grew up really in a household. My parents were very much active caregivers for relatives and others that either didn't have children or were, had struggles with dementia and other [00:06:00] sorts of things. And so I really had that kind of role model. I think early on as I was, it was.

Growing up, I also was very fortunate to have my grandparents that I knew and saw some of the changes that were occurring with aging. I had an adopted set of grandparents that lived next door to us as well, and I saw them age in place. And some of the challenges, and then like many families is that Alzheimer's disease and other dementias really affected, our family as well.

And so we saw, the challenges that came up with that. So I was interested in medicine because of many aspects of the caring profession of the science behind medicine. But I think a lot of those kind of experiences both for my brother and myself have seeing the challenges in terms of aging, but also the respect and really the service that my parents provide as being caregivers for relatives as we are growing up was really set the stage I think for how I envision my future career and trajectory.

I love this. I'm trying to get these documentary film students here at DCA College to listen up and somebody needs to make a movie about you and your twin brother. I think. Yes, and I'm so [00:07:00] fascinated by it as well, and it's

consistent with these conversations that we've been having in the context of this podcast.

The more people we talk to, the more we hear that getting into this work is a function of the early life experiences and the family experiences that people have had, and the real appreciation for the need for skill and care and expertise at the end of life. Tom, tell us what an average day is like for you.

That's a good question. I don't think I have an average day . I think that's part of the challenge of answering that, but, As I look at what I do day to day is that for many of us in the field of geriatrics is that we do many different things, and that's what I like about the field as well.

And what my job looks is the fact that I do have my hands in a bunch of different things that range from clinical care, direct care patients to teaching. To research, to administration. I'm an academic geriatrician, so I work at an academic medical center and we have a lot of [00:08:00] those opportunities and we have a lot of different trainees and students that, that come through and are learning from us.

And so that, that really challenges me each day of being on my toes of thinking about how I can be the best role model and teach her and also take care of the patients and support their caregivers as well. It's not unusual, the fact that many of us in geriatrics are what I would say leadership positions within health systems is because it, with geriatrics is that I really consider us is that we're experts in kind of chronic disease management and helping patients of navigate through the system.

We're experts in terms of what we call transitions of care, so moving between different care settings. So I have colleagues that work in the hospital, in the nursing home, the assisted living and home care. And that's part of the training that we get as geriatricians is that we work across all of these different kind of care setting.

So we have a appreciation understanding of some of those kind of unique opportunities and challenges and what are the needs of the patients in those settings. And so many times we're tapped in terms of these kind of leadership roles. I have my leadership role in home care and hospice [00:09:00] because we have that kind of expertise, that toolkit, if you will, to understand what some of those kind of components are that are really necessary to be able to provide the best care that's age friendly is the terminology we use for our older adult patients.

So Tom, I think we're gonna switch gears a little bit here, and I know you'll have no problem talking about what we're gonna ask you next. So can you tell us what is palliative care and how is it different from hospice? That's a great question, Lisa. I think that's probably the most common question that I get is what's the difference between palliative care and hospice?

And it is important to understand is that they are very closely related and what I really see is complimentary in many ways. But there, there are distinct differences. That I think everybody needs to understand to be able to appreciate what sorts of services and what sorts of supports and things that individuals can receive through palliative care and through hospice.

So the thing that they have in common, really at the most fundamental level is that they do really focus [00:10:00] on things like pain and symptom management, really focusing. On an individual's, what we call goals of care, what's important to them, what did they have as their kind of hopes and wishes? So we try to frame everything that we do around those kind of main concepts.

These are individuals that are receiving particularly palliative care, are those that either have very serious illness or chronic illness, and it can also be life threatening illness. And really the focus is, Supporting those individuals and their families and caregivers as they navigate these kind of challenging times with it.

Hospice takes all of those kind of components that we talked about with palliative care and the focus on those goals of care and pain and symptom management, but it's really palliative care that is focused in on that period of time. That is towards the end of. And so hospice really has this kind of criteria, if you will, or eligibility for it.

That is a general rule of thumb of six months or less prognosis if that disease [00:11:00] process of follows its expected course. And so I really look at palliative care is a very broad concept. Hospice is one component of palliative care that is very much focused as palliative care at the end of life.

Yeah, that makes sense. We get that question a lot too, and we're always a little bit hard pressed to explain. Would it be fair to say that palliative care and hospice are both pretty collaborative in the approach to the patient? And I wonder what you have to say about I always think about why isn't all medicine like this?

Why is there these specialties that are so focused on just one part of the body? Like why? And maybe that's just my own pipe dream, but what are your thoughts about. So I think you bring up all excellent points is that both palliative care and hospice are very much holistic models of care that are accounting for all of the dynamics really, of the patients.

So the psychosocial factors, the physical symptoms they're having, medications that are involved, supporting the families and caregivers, spiritual needs. All of those kind of things are really the focus of palliative care and hospice with. I [00:12:00] really do feel strongly, and this is what I've been championing as part of my career, is that this really should be integrated.

It should be part of standard medical care. But I think you're, you hit upon the right points here is that the traditional medical model has really much very focused in a disease way, in a specialty way of specific organ systems, specific chronic conditions and those kind of things. It's hard at times is that we miss the forest for the trees, so to speak, right?

We are not really accounting for that holistic approach to the patient cause we're focused on that one particular problem. And so I agree with you. I would say that palliative care and hospice are very much complimentary to it. Hospice and we can talk more about this as well is really has implications in terms of insurance coverage and specific services and those kind of things.

And what I mentioned before is that particular eligibility component, that these are individual. Have a terminal prognosis of six months or less is really carving out the group of patients that are eligible to receive hospice [00:13:00] services. And is this generally something that a doctor would bring up or offer, or is it something that a patient and the patient's family would really have to push for?

So unfortunately, I think it's the answer to that question is a little bit of both, right? Is that I think a very well informed consumer, if you will, a patient family member, may be aware of palliative care, may have had prior experiences with their own family with hospice care and that kind of frames.

They're understanding about what some of the services and things that are involved with that. But unfortunately, as we see this across both our state and as well as our national statistics, is that the time that people are receiving things like palliative care and hospice is actually pretty short compared to the time force that we see that they're being treated.

For other diseases, particularly with hospice end of life care, there is a very short, we call length of stay in our programs, right? Is the fact that a lot of times the referral getting the ball moving and having some of these very challenging discussions at times is very late in the disease course.

And so these are folks that, they're already in the dying [00:14:00] process. They may have a lot of symptoms, they may have a lot of challenges there, and at times it really has to be patient. The other family caregivers that are advocating for their loved ones to really get engaged in this kind of plan of care, to be the recipient of palliative care, to be able to address those needs.

That's pretty much exactly why we're doing this podcast, to get people talking about these things more because we know it's so important for people to engage with, their families and the healthcare provider. So Tom, a colleague recently reached out to me asking for some guidance. She explained that her parents were in their nineties.

She's an only child and she wants to be as prepared as possible for the inevitable end of their lives. And she asked me what she could do in advance to prepare. I gave her some resources, some book titles, encouraged her to listen to this podcast when it was released. But I'm curious to know your thoughts about how you might have responded to this question.

So I think first off I would say is that I [00:15:00] compliment your colleague for even having the initiative to begin thinking proactively about it. I think that's really the key first step is to begin these conversations as we've been talking about, to begin thinking, and we call this kind of an advanced care planning process, right?

It's a process. Oftentimes what I see is that for both individual patients and their families, is that it becomes crisis decision making, right? Something has really popped up now, and they haven't had this kind of thoughtful planning in advance, and I would argue is that you don't necessarily make easy or good decisions when you're faced with a crisis like that becomes much more a high stakes kind of conversation.

So I think initiating those conversations is really the most important. So your colleague has older parents that she's worried about in terms of what's gonna play out in the future, is the first thing is that dialogue is having that conversation with your loved ones about what's important to you. What if things change in terms of your health?

What are you thinking about in terms of particular goals in mind? [00:16:00]  
And everybody has wishes and goals. There, There may be goals in the future of looking even just a few years down the road for, a grandchild's marriage or a special sort of event and those kind of things, and trying to frame that around there, but also being realistic about what are some of the current kind of help, challenges and things that person is dealing with.

And getting a sense about, how much is too much? How much is that we beginning to cross into this threshold? This person perceives that they're suffering through this process. So they have chronic pain, they have chronic illness, they have functional limitations that is, is limiting their ability to travel and to play golf and do those sorts of things.

All of those things begin to erode into what a person's perception of quality of life. And so that's really the first step is that kind of conversation, to have that openness with it. And I can tell you is that with my own family, I particularly remember my Italian grandparents that were very hesitant to talk about some of these things, right?

And some of it was a cultural, and probably a generational overlay to it is that they felt like if you [00:17:00] talked about these things about getting sick or dying, is that you would have that or somehow bring bad luck on you as well. And we have to move beyond that, be respectful of that, but get a.

About how we can engage in some of these meaningful conversations. So that would be the first step. And then the second step is really the fact that those conversations then lead to completing some of this kind of advanced care planning documents. The thing I think about the most important is a healthcare proxy.

A healthcare proxy form allows you to designate someone on your behalf to speak for you. If you're not able to do that for. In the context of medical decision making and really everybody needs that. It doesn't matter about in terms of your illness, it doesn't matter in terms of your age, is that is a powerful document that empowers that person to really speak in your voice if you're not able to.

But it's also a high stakes kind of opportunity, right? Because we think about the fact that you are having to entrust that person. It has to be a person who knows your wish. It has to be a person that really is going to advocate on your behalf to make sure that your [00:18:00] wishes are being followed and honored with it.



And so that really becomes one of the most important pieces of information. And related to that, the healthcare proxy is that sometimes people, as they're completing their wills and other documents, they may appoint a durable power of attorney for healthcare. And that is in, in some ways very equivalent under the law in terms of thinking about having a designated person.

We call 'em an agent that's gonna act on your behalf. So either the healthcare proxy or the durable power of attorney for healthcare, I think is the most important kind of things to do. And then there can be discussions, particularly with your doctor about, What makes sense in terms of other advanced directives?

So I think about, like in New York state, we have the medical orders for life sustaining treatment or mult form that are medical orders. So it has to be done in conjunction with a physician that would outline specific kind of treatment interventions and reflect what your wishes are about things like.

Resuscitation. So the, we call it cardiopulmonary resuscitation, chest compression, shocking the heart, those kind of things. Ventilator [00:19:00] support. So being on a breathing machine to be able to support life that way and other wishes, other kind of things that may be relevant to that particular person's health status and what you think about for the future.

We can't anticipate all issues for the future. And so that is where, going back to the healthcare proxy or the power of attorney is, That gives you a person to be able to respond as those situations change in the future. So really important point to begin those kind of conversations and complete some of those documents.

Thanks Tom, and it hearkens me back to this. I keep saying starting is the hardest part, right? And so that was another point that I made to my colleague when she reached out that, that thinking about this and starting these conversations, really it can be the hardest part of this whole process and.

So that's why we're doing this podcast and encouraging people to get started

until we're faced [00:20:00] with the reality of end of life decision making, either together with or on behalf of a loved one. Many of us know little about what's involved, aside from what we see on say, television dramas. Tom, do these shows reflect reality and what do they get right or what do they get wrong?

So that's a great question, Elizabeth, in terms of what we see from the Hollywood approach, televisions and movies and those kind of stories that unfold. The challenge with that is that it's largely inaccurate. A lot of times that this is to further a storyline, to create some drama and plot twists and those sorts of things, and we.

We know that there's a lot of kind of the media out there that shows that a person has, let's say, a cardiac arrest. So their heart stops, right? And they have to be, they either receive chest compressions or they're shocked and they wake up immediately and they continue their dialogue and conversations.

And we know that's not true, that rarely ever happens with it. [00:21:00] The individuals that are experiencing this kind of health crisis where they, where heart stops is. We initiate this process of resuscitation. So that means a person has a breathing tube down their throat that if that rhythm comes back of the heart and they're shocked back into a normal rhythm, they oftentimes are now being transported to the hospital.

They're in the intensive care unit. They're seriously ill, We oftentimes say is the heart never just fails in isolation with it there, so your heart stops. That's a very serious event that has implications for your brain function and your kidney function and everything else. So these are very serious kind of things.

So this kind of just wake up and move on with the story with it and save the day is rarely the real situation that plays out with it. And then oftentimes is that we see in terms of the Hollywood storytelling is that folks are often. Either at their deathbed confession or be able to create closure in terms of any sort of conflict and those kind of things in their life, in those last [00:22:00] few moments before they die with it.

And again, we rarely see that plays out for folks. It's really important that these kind of conversations and this really, I think, change perspective in terms of death and dying within our culture begins to take hold so that we can appreciate this. Really a natural part of life that this is something that is not always comfortable to talk about or to be engaged with when we can feel that we're as prepared as possible for it.

But even when that moment that we're faced with some of these kind of decision making. It can be a real challenge with it. And so it's not always this kind of positive drama and those kind of things that, that we see play out. It can be a real challenge with it and I think the way to address that is, again, going

back to having these kind of conversations early and trying to create this as a more of a normalization of our discussions amongst our families.

Thanks, Tom. So I've shared some other snippets about this experience in [00:23:00] other episodes, but together with my father, I was with my mother during an ICU intensive care unit. Stay that. Culminated in her death in November of 2017. It was a difficult time. It was an emotional time and one of the things that struck me in this context related to language, we, my father and I, were looking for straightforward information and answers to questions that would help us make the best decisions we could related to my mother's care.

We'd had conversations with her. What she wanted, what she didn't want. She did have a living will about which her healthcare providers were aware. But still, we were struggling to make decisions that were in accordance with what she would've wanted or not wanted. And the language that the healthcare providers in the intensive care unit was using was very clinical.

It included a lot of medical jargon that [00:24:00] we didn't understand. We were persistent and ultimately we felt like we did get the information that we needed. But in the moment, and as I think about that experience, in retrospect, I feel like it was harder than it needed to be to get our, her healthcare providers to really just level with us.

And I don't say that to criticize them or disparate to them, and they provided her with really excellent care. But I'm interested in your thoughts about why this happens and how it can be overcome, both at the level of the healthcare system, but also at the level of individuals and families. So first Elizabeth, I wanna thank you for sharing that story.

I can only imagine the challenges you faced in terms of having those kind of conversations and trying to make sense of the situation. And what resonates with me is that I think it's unfortunate that's still all too common. This continues to play out many times, anytime we're interacting with the healthcare system.

I [00:25:00] think the issue about language and sort of the terminology that we use and kind of the narrow perspective of just dealing with that sort of problem. One thing at a time with it from our perspective physician perspective and the provider perspective is something that, many ways it.

I think people have to appreciate is that we've been acculturated into that. So in other words that when I went to medical school, it was like learning a new language. It really was learning a foreign language with it. And I think that's

something important to of keep in mind is that it's a new language that this combination of English and Latin and Greek and all of these sorts of things, and we talk in abbreviations and we spend many years in terms of training across all the healthcare discipl.

Understanding this language and communicating with it, it, I think, allows us to, to feel a sense of sophistication as well. But it also, some of the shorthand and things allows for some efficiency communication. But the problem is that when we think about patients and we think about families that go into an intensive care unit setting, they're like visitors in a foreign land that don't understand the.

And so [00:26:00] that really is, I think, at a system level. This is very much upon us of, as healthcare professionals of thinking through, of not using the medical jargon of trying to cut through a lot of this kind of challenges with it. And some of that I'm beginning to see take place with it is that we're trying to unwind this a little bit and be able to communicate more clearly.

We oftentimes share many components of our electronic health record directly with patients that have a portal and those kind of things. So we have to be more mindful in terms of how the language is used and abbreviations with it. But I think at the individual level, it really comes down to this fact of just being able to pause and to say honestly as well is, can you slow down?

I don't understand. And I don't think any healthcare professional would take any offense to that of just saying, I don't understand. I need you to repeat that or go through that. No, no different than if you're having a hard time following somebody that's speaking a different language than you and that you catch a little bit of it, but you want to be able to ask for some clarifications along the way.

But it's something that, [00:27:00] that definitely, I think, is still a persistent issue, and it's a, it's really persistent of being polite about it but asking about, Oh can we just pause here? I don't understand. Or I need some more input about this. Or, what's your perspective on this? There's a lot of expertise of many of these kind of specialists and other healthcare professionals that can help inform, I think good decision making.

And I think that many times, and I'm very guilty of this as well, I always try. To catch myself is that we make assumptions that people understand more than what they may actually do. So we have to do that sort of check in. What are your questions, what's your understanding? And that's really what I like as a clinician, is to be able to ask, what's your understanding?

What have you been told is going on with it? And just changing those kind of dynamics. Really changes that whole conversation and I can appreciate what you're saying. My wife was in the intensive care unit, was receiving care and fortunately things worked out very well for her in the end. But I was a physician in the hospital that I trained in and still encountered those kind of challenges informed about what the [00:28:00] medical situation was.

These are my colleagues that I knew, and it was challenging in that aspect. So I can only imagine in terms. Any other individual that is trying to navigate these kind of challenges about how challenging it is. And I think that's where you just again, have to slow down, pause and ask for clarification.

Yeah, I think that, not to try to outdo everybody with stories here, but I have an ICU story too about my father and it's not, it wasn't so much about the language that the medical professionals use, but it was about trying to get them to adhere to his wishes what he wanted. It was one of those situations where it was like the one doctor who could fix the one thing would come in and we spent, three or four or five days, clearly he was dying and people kept coming in and I can fix his lungs and I can fix his.

There was maybe one person who we felt we could really talk to and would listen to us, and it was one of the nurses. And we heard later that she got in trouble, for suggesting that we might need to talk to a social worker or something. And I just, that's what really [00:29:00] led me down this path to getting very interested in.

Teaching people more about those situations you're gonna be in and helping you understand that you do have a voice and that you can ask questions and you can say, I don't understand and what is going on. And it was such agony for my brothers and sisters and I that I just left that, it changed me really, it led me to the Gerontology Institute.

And so anything that we can do to empower people to ask the questions or get the documents or make them understand that they can really, they can help someone to fulfill their last wishes and do what they want at the end, but it's gonna, it's not always easy. I think you're right, Lisa, is that it's not easy and thank you for sharing those challenges that you experience.

Is that It's all too familiar to me though, unfortunately, is that there's of this compartmentalization, we often talk about silos of just looking at our own kind of issues and there's this process that I often term as therapeutic momentum that

occurs, in other words, is that there's always something more we can do and once the train's on the tracks, it's moving full speed.[00:30:00]

There's very little opportunity to just slow down to be able to pull back, to take the train into the station and pause and ask some of those kind of questions along the way. And in many ways, and I appreciate this, working in an academic medical centers, that we have all these really brilliant specialists that are specialists in their particular areas, their domains, where it would be the heart and the lungs or kidneys and those kind of things.

And that we become, I think, very focused within the medical model, particularly with American. Focusing in on that one sort of organ, focus in on that one kind of challenge with it. And we have amazing sort of technologies and medications and things to address that. But again, not missing the big picture, I think is the point that you're raising and making sure that we are, that we're responding to that individual's needs and wishes.

This is really where I think that this movement of palliative care, and I'll label it that way, of palliative care, is an attempt to address that, to look at a more holistic kind of approach to patient care. And to be able to, take a leadership role in some ways of unifying all of [00:31:00] these different kind of inputs from specialists and others to be able to help as a navigator, if you will, for the patient and the family.

But going through some of these very kind of complex decisions and making sure at the end of the day that we're being patient person centered in terms of our decision making process. That sounds pretty ideal. And always those moments are fraught when things are happening and you have family dynamics and people around that might grasp onto some kind of hope.

You know that, oh, if we could fix this thing, then maybe he or she'll be okay. And that's the kind of stuff that comes up. Even if you have a healthcare proxy, even if you have documents on file, there's always gonna be those family dynamics and people who you think might act a certain way when they're faced with this kind of situation might act completely outta charact.

So to have someone guiding that process, a palliative care physician would be really ideal. Yeah, I agree with you. I think in some ways it's really about masterful kind of skills brought to family meetings. That's what we talk about with palliative care, to be able to navigate some of those things because, we don't wanna extinguish hope and [00:32:00] there, there is always hope in situations that seem very dark and very negative with it.

The question is what are we hoping for and what is the realistic kind of expectations? What is the clinical realities of what we're seeing? And then I think also at the end of the day, really tapping into the experience, the expertise of the clinicians that are around there in, in your general experience.

What happens? What plays out from here is this a person that is confronted with serious life-threatening illness that's going to have ongoing very severe, significant functional impairments that may not be able to return home, may not be able to enjoy the same sort of quality of life or the same scenario beforehand.

And when are we reaching that sort of threshold of what I'll label is suffering for that person? How do we be able to navigate that to be ensuring that it's not what we want and hope for, but it's what respecting what that person's individual wishes and goals are so that we can be the representative in terms of their voice.

And this is [00:33:00] really where the healthcare proxy comes in to be able to ensure that they are part of the conversation when they can't be. And because of that serious, And I think that's the overarching goal to be able to cut through a lot of this because that therapeutic momentum I talked about, there's always something more we can do.

The question is, should we be doing that? What is gonna be the benefit versus the burden of those particular interventions?

So as a healthcare proxy, Tom, as someone who might. Designated to help make decisions in place of a loved one or on behalf of a loved one. What are some of the most common procedures or interventions that we may be asked to make decisions about for a critically ill loved one. That's a good question.

It's what is the healthcare proxy being faced with in terms of making decisions and their role within this decision making? I think the most common scenarios, and again, everything is a little bit different [00:34:00] based upon, the clinical scenario, but. I think the most common scenarios is really focused on decisions that are either treatment decisions about either trials of particular interventions, so let's say this is particularly medications or antibiotics or those kind of things, initiation of specific therapies.

So this could be reflected in, let's say, a decision making around a do not resuscitate order, where that person would not want attempted resuscitation, cardiopulmonary resuscitation, chest compressions, those kind of. But they hadn't expressed that previously in advanced directive, that healthcare proxy can

then be empowered to be that what we call surrogate decision maker, step into that role for that particular patient and be able to complete those directives.

Or it could be initiation of other types of treatments. So you think about a ventilator, a breathing machine, right? And so that involves having a tube down the throat and having a machine that helps support breathing with that. For some individuals that are faced with really serious illness, they have underlying lung [00:35:00] disease and those kind of things.

This may require a long term support on a breathing machine or it may not be as beneficial. And so maybe that's a decision that we don't even wanna initiate that's going too far in terms of what that person's wishes were or other decisions about, let's say dialysis because the kidneys are failing and those kind of things.

So those are the scenarios. The challenge is that we don't always know or can predict what kind of scenario is gonna be specific to. So this is where the healthcare proxy or that healthcare agent is really a dynamic kind of process. It's a person that, for me, as a physician, can actually speak to that person that knows that patients well, presumably knows them best, understands what their goals of care are, and can provide perspective to me so that I can make.

Recommendations about what's the next step along the way in terms of treatments, because we're really in this kind of gray area when we talk about this, is that these are seriously ill individuals that can't speak for themselves, that are having probably complications along the [00:36:00] way from medical issues, underlying disease process, those kind of things.

Even though we can do certain things is that incrementally in small amounts, it may only be moving in one direction towards recovery, and some decisions could actually be moving in the other direction where it's actually prolonging a dying process for that person or increasing their suffering because of pain and other symptoms and things.

And so it's an important kind of relationship and a dialogue that occurs between that healthcare agent and the clinical team that is treating that patient. To be able to get a sense about what is best for this person based upon knowing them, based upon what their goals are, those kind of things. And we oftentimes talk about the healthcare agent, or that healthcare proxy is using what we call substituted judgment.

So in other words, they're literally going into the shoes of that person and speaking with their voice as part of this dialogue of decision making and those



kind of things. So it's a, it's. Incredibly important, a really powerful role. If you [00:37:00] think about a great responsibility that you are taking on to be your advocate for that, your loved one, and to be speaking on their behalf when these medical decisions are coming up.

And that's why we're doing this podcast, really trying to encourage and empower people to have that dialogue, have those conversations feel safe to do that in advance so that we don't find ourselves in a crisis situation and not really sure about what we can. Best do to honor someone

based on your many years of experience. Tom, what are one or two things that we can do most importantly, to assure that we receive the care that we want and to avoid the things that we might not want as the end nearest for. So I think the most important things I would share with your listeners is the first is have the conversation with those you [00:38:00] love, regardless of age, regardless of your health status.

This is important conversations for everybody. We know that our health, our lives can change in an instant. There can be a trauma that occurs. There can be a car accident, there gonna be a stroke or a heart attack, or those kind of things that can occur suddenly. Or there can be things that we know as part of a disease, progression of cancer, of heart disease, of those kind of things that eventually we will be confronted with kind of end of life decision making.

Having a comfort level amongst your loved ones to have this kind of conversation, I think is the key first step with it. The second thing I would say is to really complete the healthcare proxy or the durable power of attorney for healthcare. That's gonna be critical to really, from a legal standpoint, empower that person you trust to be able to speak on your behalf if you are not able to.

And it's important to keep in mind, is that healthcare proxy really only becomes. Activated, if you will, if you as an individual can't speak for yourself with it. So there's always a partnership. There's always that support, but we're always trying to plan for [00:39:00] kind of the worst case scenario. We don't necessarily know what that means for the future, for all of us.

So having those kind of conversations, having that person that you trust to be part of that decision making is key. And then the final point I would just add to that is that don't go it alone either, is that this is really. Having conversations, having trusted resources amongst, in terms of your healthcare team, having an advocate that's a family member of loved one.

To be able to navigate some of these challenging discussions as well is important. And always ask questions if you don't understand something, if you need people to slow down or repeat stuff. I think asking that questions and really challenging in some ways, again, in a respectful way, but challenging in some ways the status quo that I think in many.

That medicine has provided that we do speak in jargon. We do end up having all of these kind of challenges of just talking about our little section of the universe in terms of healthcare and sometimes missing the big picture. And so sometimes it's really the patients and the families themselves have to of bring us back into that [00:40:00] reality of thinking about the big picture in making sure that we're doing the best for that person.

What haven't we talked about, Tom, that you would want our listeners to know? I think we covered a lot of ground with it. The points that we raised about having discussions early is really key with it, and I'm so appreciative that you're doing podcasts like this to be able to get the word out, to be able to have this kind of dialogue so that we can really raise the level awareness about not only the challenges and things that occur in terms of medical illness and end of life care, but also the opportunities that exist for us.

To be able to express our care to our loved ones by being engaged in these conversations. This has been so fantastic to have you on today. It's, you're such a wealth of knowledge about all this stuff, which makes sense considering what you do. Is there anything else you wanna add for our listeners?

I just want to thank all the listeners for joining and to thank both of you, Elizabeth and Lisa, for having me as part of this podcast today. I really appreciate being able to get some of [00:41:00] this message and to have this discussion with you. We're grateful to you, Tom, for all of the work that you do. As you described earlier in the podcast, the with patients and families, with trainees and students.

Through your leadership of the Geriatric Workforce Enhancement Program at the University of Rochester, your service to the community as well. And I should note that the University of Rochester's Geriatric Workforce Enhancement Program funds the Finger Lakes Geriatric Education Center, and through that, this very podcast.

So thanks so much to you for all that you. I know your time is incredibly valuable and we're grateful to you for having shared some of that with us today. Thank you so much. Thank you so much for listening to, We really need to talk.

You'll find more information and links in the show notes. We hope you'll continue to tune in as we talk with end of life experts and champions of tough conversations, who will teach us more about the important questions and how to ask them of our loved ones and healthcare providers.

We hope you'll [00:42:00] subscribe on Google, Apple, Spotify, or wherever you get your podcasts. Our contact info is also in the show notes. Drop us a line and let us know your thoughts, your questions, or ideas you have for future episodes. Or just say hello and remember starting is the hardest part, but we really do need to talk.