Introduction to Palliative Care

It's a place for people that the traditional hospital system has kind of done their thing. They have tried everything. they might still be trying, but you're passed from one specialist to another to, another, to.

You know, you could have dementia, that you might also have stage four cancer. And so the neurologists and the oncologists are kind back and forth and maybe they're not talking to each other.

So a good palliative care physician comes in to kind of help bridge those gaps. And then it acts as a bridge to give patients really good, high quality care where they have a doctor who they, have his cell phone number, which we experienced earlier.

and is on call, and you can call them at any time. So if you're not sure if he should go to the emergency room, you could call the doctor. If you need to be seen, instead of having to go out to a doctor's office, the palliative care physician, at least in our model, comes into your home or wherever you are at.

I know for like my mom with dementia, it's really hard to get her to doctor office for something as simple as a UTI, which happens quite frequently. So having a doctor that can actually go into the facility or send a nurse, if we assume it's a UTI, send the nurse get the sample, you know, start her on a broad spectrum antibiotic.

And then once we have the culture back, then we figure out what needs to be done next. Welcome back to this episode of the Think Well, Age Well podcast.

I'm your host, Dr. Heather Sandison. Today, we're talking about something that can feel difficult to approach, but that ultimately can be an incredible act of love.

Making sure the people we love know how we want to be cared for if serious illness or cognitive decline changes our ability to speak for ourselves. We were originally going to be joined by Dr.

Bob Uselander as well, but in a very fitting reflection of the work that he does, Dr Bob was called away to support a patient and their family at the end of life.

We are sending our thoughts to them as they make challenging decisions today. I'm very grateful to be joined by Katie Powers, a healthcare strategist, educator, and advocate dedicated to helping individuals and families feel more informed and empowered as they navigate some of life's most complicated healthcare decisions.

Katie serves as program director of the Empowered Endings Foundation and chair of The San Diego Dementia Consortium. She also comes to this work from a deeply personal place.

Katie is the daughter of a mother living currently with frontotemporal dementia. So today we're going to talk not only about advanced care planning and dementia, but about what it is actually like to be the family member navigating those decisions and how having difficult conversations earlier can ultimately create more clarity, connection and peace for everyone involved.

Katy, thank you for being here and welcome. Thank you for having me. So I want to start talking about your mom. Can you tell us a little bit about you mom and her journey with frontotemporal dementia and what the first signs were that something wasn't right and how this path, what this paths to the diagnosis and then now care for her has looked like for you and your family?

Sure. My mom was diagnosed about four years ago with dementia. And the first signs were pretty obvious to me because I worked in the health care field.

But my dad was very reluctant to admit that there was anything wrong. I think the final straw was when it was during COVID. and I had to go to the emergency room via ambulance because i was really sick.

And I was at a Sharp Memorial. So I needed to be picked up and I didn't have my phone with me. The only phone number I knew off the top of my head was my mom's.

And so I called her and said, mom, can you come get me from the hospital and bring me home? And she said sure. And then I'm sitting there waiting for the longest time in the parking structure, because during COVID, you had to sit in this weird line.

And so I call from the security guys' phone again, and I said, Mom, where are you? And she's like, oh, I am in parking the structure. Turns out she was at Rady Children's Hospital.

just a few doors down, but I'm obviously not a child. And so I was not quite sure what she was doing there. But shortly thereafter, she had her license taken away.

You know, from there, it just kind of has been a steady decline. And becoming the daughter of someone with dementia, especially with the work you do professionally in this field, how did it change you?

Well, I think for the most part, it really gave me a lot of empathy for other people that are living with Dementia, Alzheimer's, any type of cognitive impairment.

It's one of those things where you don't understand it, you can't it until you actually are living with someone that you love that's going through it.

And seeing my mom losing her a little bit every day has been the hardest thing in the world for me. And I have my sister, but she doesn't live close. So, you know, it's just one of those things where you, I see it every day.

It's a little bit easier for me to handle her decline. My sister who sees her every couple months, It is much harder. So I try to do everything that I can to prepare her for what she's going to see, what to expect when she sees mom the next time.

And that just radiates through me in the work that i do.

Katie's Mom and the Dementia Journey

Because when I have one of our patients that has dementia, I might be doing the assessment with Dr. Bob, and I'll look around the home and notice that there's a piano.

And I immediately think to myself, hey, we need to bring in our music therapist because this would be really helpful for this patient. or they have a beautiful garden full of roses or whatever flower they love, then maybe the next time we stop by or nurse visits, I'll text the nurse and say, hey, make sure you pick up a bundle of flowers for Mrs.

Jones when you go out to see her next. And so there's little things that just kind of creep in that I don't think I would have noticed or I wouldn't have done before without the experience.

Were there things that you thought you understood professionally that felt really different when it was happening to your own family? 100%. I thought I knew just about everything about dementia.

I'd been to all of the classes, I had gone through all the workshops, and I've gone to Teepa Snow. And oh my gosh, it's the biggest slap in the face when that actually happens to you.

you all of a sudden forget everything that you've been taught and you remember pieces of it, but there's just things that, you have to go back and relearn because now you're actually having to do it.

You know, the hand under hand. method and I'm like, yeah, I know what that is, but I've never actually done it before. And probably you haven't done when you're cranky and tired and triggered and, and upset because mom's not listening and she's, you know, trying to like trying, to get her in the shower is a challenge.

you hear about it, but then when you're actually doing it yourself. So pretty much everything went out the window. I had to really relearn and re immerse myself into everything dementia related so that I have a better understanding.

Honestly, didn't know how dementia was even diagnosed, which is really sad. But I thought it was just an MRI or something. And it's so much deeper than that.

So yes, a lot changed. Very complex. Are there conversations in your family that you wish you had had earlier? I think this is one of those heartbreaking things about dementia, and as it creeps up, is that families often realize there were questions they wished they'd asked when their loved one was still very clearly cognizant and able to answer them.

Did that happen in you family? Absolutely. One of the things that came up probably around the time that we knew that my dad is going to be 80 this year, my mom is 75. And so probably two years ago, we started noticing that dad was no longer able to really care for her by himself.

Yeah. and she started getting frustrated with her because of her incontinence and I would be around them and i would overhear him yelling at her, because she peed on the floor or you know had an accident or the bathroom was a mess and, I just said whoa like we need to do something.

So we had those conversations then, but there was nothing in her advanced healthcare directive. There is nothing her plan, nothing about what happens if mom gets dementia.

there's no direction whatsoever. So dad and I literally had to figure it out on our own and we have to guess as to what mom would want. Did she want to stay home with in-home caregivers?

Did you want move into a community, a memory care community? And she eventually did have to move in to a Memory Care facility here in Escondido. And it's okay.

But, you know, I tour just about every single one in San Diego County and I had my top five that I liked. I'm curious. And for other people who are looking or considering this, and I was sure the answer for a lot of people is I would love to move into memory care if that reduces the burden on my loved ones, right?

If that's the easiest for them, but only if it fits a set of criteria, because there's a spectrum of what that reality can look like, of day-to-day life might look in a place like that.

So what were your criteria? How did you decide? Well, for me, even though before mom's dementia, I had toured plenty of facilities, but never through the lens of a daughter looking for a place for mom.

And so I hadn't to go back and retour a lot of places and I went specifically looking at their memory care units. The feeling that I got when I walked in, I wanted to know what the residents were doing, how they looked.

Did they seem happy? Did the seem content? What kind of activities did they have going on? Was there, were they just slumped over in wheelchairs, sitting there doing nothing, being force fed?

You know, there was just so many things that had seen in various situations and The one thing that touched my heart the most was when I toured one facility and one of the residents came up to me and she just had a nice conversation with me.

And she didn't know me, but she asked for my phone number and I told her that I was looking for mom. She said, oh, okay. If I call this number, can I talk to your mom?

And I said, well, if I'm with her, you can. And it was just the sweetest interaction. It really touched my heart and it made me feel like this person is happy here.

For me, it's more about the feeling. You know, also, of course, the regular criteria, how many carryovers per resident, you know that type of thing. I wanted to make sure that there was enough staff and that they were trained in dementia, which surprisingly a lot of them are not.

Yeah, you know, here in San Diego, staffing is challenging, right? There's a high cost of living. We certainly had Marama here and in VISTA for a while in memory care community.

And that was one of our biggest challenges was finding adequate staff and then having them stick around long enough to train and have them have the skill set that they needed because it is a often an entry-level position.

It's very challenging, but yes, so many of the things that you talked about. I mean, I'm bringing up these experiences of walking into places and it's like, what hits you immediately?

The culture, the smells. what people are doing. Are they all watching TV? Is it sparse? Right? Everybody in their rooms isolated from each other watching tv or are they engaged and interacting?

And there is a spectrum out there. And I should say today, right, there are days when people You know, there are different people on staff and sometimes they're more tired and, sometimes, they are more jazzed.

And, yeah, so it's challenging, right? And it is challenging to own and operate and run a community like that. It is hard. But there's people who do it really, really well and some who, you know…

It's not quite the place that feels right for mom. Yeah. I definitely have a pulse on which ones feel right and are done right. And I wish I could put a list together of criteria for other people, but I think the biggest thing is just how, how does it make you feel when you walk in there?

That gut punch. Yeah. It's, it's mostly intuition and just sitting back and observing, looking, paying attention to details, spending as much time there as you can.

I think is important too. So you can have a meal there. How's mom doing there? She's doing pretty good. You know, she has her good days and her bad days, but her decline is happening, you know day by day.

And the facility she's at, I would say is pretty. It's not my number one choice, my dad is the resistance and refuses to move her because the spent all this money on furniture and blah, blah blah and it's just a battle.

And these are some of the very real dynamics that come up, right? I've certainly seen it from my perspective of, you know, we've got a spouse, a couple of adult children, maybe an in-law, and everyone's got their opinion.

And there's the financial considerations. There's logistical considerations of how far is it from me? So how often am I going to get there if it's another 15, 20 minutes out of the way versus right around the corner?

I mean, there is that gut sense that you get when you walk in.

Choosing Memory Care and Family Dynamics

The friends, right? Like you described this woman who came up to you and asked for your phone number, asked if she could call and talk to your mom. It's like, this woman might be a friend to my mom.

There might a connection here. Whereas another place, it might not feel like there's that, that potential. I know when my moms talked about it, she's, like well, if there is someone there, I already have some community.

Maybe that helps. And so then, you know, does it make sense for it to be a little bit further away? There's just an

endless number of things that you could discuss.

And then the complexity of the dynamics within a family is a whole nother level. Right. How do you navigate it? Well, one thing that was nice is I took my dad to an advanced healthcare planning seminar and I was actually speaking on a panel at the same seminar, so he came to see me speak.

But in the process, I looped him into this advanced health care planning talk. So he and sat there and listened to this presentation by Dr. Mitz Tomita.

And it was great because when they were going through the advanced healthcare directive and healthcare agents and I elbowed him and said, dad, who's your healthcare agent?

And he's like, your mom. And I said what? She doesn't have capacity anymore. So I thought, okay, write that down. You need to change that. You know, I've got all the documentation that I am my mom's health care agent so I can actually make decisions on her behalf.

But, you know it's been a battle and my parents are of that age. They're baby boomers that They went to the attorney and they got all the paperwork done 10 years ago and so that should be sufficient and things have changed since then.

And so now things need to be changed and that is what I'm constantly working on with my dad. An advanced care plan is particularly important when there's either high risk or soon after someone receives a dementia diagnosis.

When do you think families should start that conversation? And then as you just alluded to, how often should we be checking in and updating them? Well, one thing that we did at Empowered Endings recently was start a program called the Clarity Path.

And it's a six week program that's guided by Dr. Bob and takes people through an advanced health care directive from start to finish, but includes questions like what's most important to you?

What, what thresholds, What are your threshold? Do you want to. continue living if you no longer can feed yourself or, you know, I mean, it's very, very in depth and it takes you through so many things that I wish my mom had answered for me because now I just have to guess.

So I'm going through this first cohort of the clarity path with Dr. Bob and 20 other people so that when I get done, I will have an advanced healthcare plan for my daughter.

She's 15 now, so she's not my healthcare agent. down the road, uh, she'll have a good idea of what I want and what honors my wishes. And that way she and my healthcare agents can know that they're doing what want.

and those decisions were made long before any cognitive decline took place and they should be reviewed often. I would say every year would be ideal, but every couple of years, or if there's any change of condition, Would be a good bucket with your taxes.

Like that chore that nobody wants. I mean, if you're healthy and everything is going fine, there's probably no need to go back and revise much. But I would say the most important thing is making sure that your healthcare agents are identified and that you've spoken to them and you had conversations with each of them.

And keep those conversations going. You might be friends with someone now, but maybe haven't talked to him in five years when they have, they get a call and might have to make a decision on your behalf.

So maintaining those relationships with your healthcare agents is crucial too. Or updating them, yeah. Yes. I guess we're kind of describing the risk of waiting, right?

In your dad's case, your mom is no longer able, she no long has the capacity to be his healthcare agent. So that

needs to updated. God forbid he ends up in the hospital unable to make decisions for himself and you could not step in because legally you're not that person.

Right. And I'm the only daughter that lives here. He has two daughters from a previous marriage. So the three of us are healthcare agents for my dad now, but they both live in Utah.

I am the one person that's local for both mom and dad. proximity is important. What should we actually have in place? So I think the advanced care planning, I know at least in my mind, it's this alphabet soup of, like we talked about an agent, there's the pulse form, There's these legal documents, how do we make sense of this?

And is there a checklist, especially in this course that you and Dr. Bob are working on, working through? I wanna take a moment to share something really exciting with you.

This is something that's been a long time coming for us. At Sulseri, our mission has always been to make dementia rare and optional, to give people real tools, real answers, and real hope when it comes to brain health.

But one of the biggest barriers we've seen over the years is access. So many people need this care. They're motivated, they're ready to do the work, but they simply haven't been able to afford it.

And this is why I'm incredibly excited and proud to share that we are now participating in Medicare's Guide Program. This means that for the first time, eligible patients can receive ongoing support for cognitive decline, Alzheimer's and dementia through Medicare, with significantly reduced out-of-pocket costs and support from caregivers.

We are not just opening the door, we are expanding our team to meet this need. We now have two new nurse practitioners trained in our functional root cause approach to brain health.

They're working alongside us with our teams to deliver this care in a way that's personalized, comprehensive, and deeply supportive. This is about reaching more people earlier and staying with them longer on their journey.

It's about supporting caregivers who have been carrying too much for too long. And it's about making sure that the cost is no longer a reason that someone doesn't get the care that they deserve.

If you or someone you love is experiencing memory loss or cognitive decline or has been diagnosed with Alzheimer's or dementia, I want you to know that there are options and that now there's more access than ever before.

You can learn more and see if you qualify by visiting salseri.com or calling 760-385-8683. This is just the beginning and I'm so honored and excited to be able to bring this announcement to you today.

Yes, absolutely. So you can either go through a course, which I would highly recommend. You can also get together with an estate planning attorney that has specialized in this type of work.

But, you know, we offer it through the practice. Dr. Bob will sit down with anybody. We pull all the medical records. what's going on with conditions and maybe some precursors to something that might come up in the future.

And Dr. Bob will actually sit down with a person or a couple and do a complete advanced healthcare directive with them, which includes all of the forms, all the check boxes.

So you can either go through the clarity path with us, with the group, or you could sit and I do it one-on-one with Dr Bob. Oh, or an estate planning attorney, if you're not in San Diego.

An estate-planning attorney. What's the difference between an advanced healthcare directive and a PULST form? I don't even know that. The Pulse form is the pink form that is basically the directions for what to do in case of an emergency.

They're usually on file with the hospital. And so it covers the very basics of, you know, DNR, do not resuscitate, feeding tube. various, you know, very simple kind of, if you're going to save someone's life or if your not.

Yeah, If you are going make those heroic efforts. Correct. Yeah. And then choosing a healthcare agent. You've talked a bit about this, but I think many of us automatically name our spouse or the oldest child without really thinking carefully about what we're asking that person to do.

Right. So like you mentioned, you're in town, right? That's an important consideration. Some people, obviously you do this professionally as well. Your deep in this so you have a much more nuanced understanding than someone who works in sales and marketing or something else.

That is right. It's entirely different.

Advanced Care Planning and Legal Documents

And so what should we consider when we're choosing someone to make some of these most important decisions on our behalf? What are the qualities that we would look for?

For me, what I considered was number one, I'm not married. So I am a solo ager right now. And so I don't have a spouse necessarily to name. I didn't know that that would even be the best person.

in the first place because a spouse is obviously going to be very emotional, very frightened, and very scared. They obviously love you and are going try to do everything they can to keep that person alive.

And some of that sensibility of honoring a person's wishes might not be in their space and their availability at that moment. So, you know, I also see, just can I, want to double click on the spouse conversation because I always see that people are often, right, they're married, in the same age bracket, so they are both in their late seventies and the overwhelm of technology, of medical interventions, the complexity of the medical language, it's like they don't, even if they have cognitive capacity, that capacity required for this role is sometimes just outside of what they can do.

Yeah. I think it needs to be someone that you're close with, that knows you and understands you, but can also take a step back and kind of remove themselves from the emotional part of this.

Detachable. Yeah, I had a conversation with my sister about my end of life wishes. And I told her that if I end up with dementia, like mom has, that I want to, and it will be in my advanced healthcare directive, but I elect to voluntarily stop eating and drinking.

When I get to a certain threshold and I said, as my healthcare agent, you know, Jen, can you do that? And she said, I don't know. I didn't think so. And that was heartbreaking for me to hear.

But I mean, that's my only sister. She said well, maybe I could do it, but can we put somebody else on there? Sometimes you can get an honest answer from her, right?

Yeah. Because the last thing you want to do to her is have her in what feels like an impossible position, right? It is an impossible position especially voluntary stopping eating and drinking.

It takes seven to ten days for a person to pass and that's a long time and a lot of waiting for the family. Fortunately, the patient, it's done properly with the right medical care.

It's painless, you know, for the patients, but it is very painful for family. So I elected to have one of our death doulas that works with us as my health care agent.

because she knows me, she know the industry, the lingo, how to advocate, exactly what needs to be done. If I'm in a memory care facility, She knows to pull me out, bring me somewhere home so I can go through the process that I

need to go.

The same thing goes for if I end up with an incurable cancer or disease that has less than six months to live. I would like to elect to go through medical aid in dying and die with dignity on my own terms, surrounded by my family, and surrounded my love in the environment that I want to be in.

I don't want die in a hospital. Don't wanna die at a still nursing facility. So it will all be outlined. But yes, the right person is very important. You know, I had two deaths close to me personally in the past year and one was my sister-in-law who was only 38 and was diagnosed with bowel cancer on September 15th and she passed away in ICU on Sept.

30th. It was just absolutely unbelievably heartbreaking, left behind her two boys. And it was tragic. She was in right place for what was happening, Right.

But because she was so young, nobody saw that coming in two weeks. Right? But she didn't have a chance to say, no, I'd rather be at home. I rather not be hooked up.

You know, and they were so wonderful in the ICU. They, they took everything off and the boys came in and were able to see goodbye to their mom. Talk about it.

But just the contrast with one of my best friends lost her father recently, and he had pancreatic cancer and chose the medical aid in dying. And his grandkids were there doing a puzzle next to him.

He drank. He was able to drink the juice and he signed some paperwork right before to make sure his wife and kids were all taken care of and that there were no question marks and they had flowers everywhere and felt very celebrated and it was this very peaceful process.

It felt chosen and the juxtaposition between the two was so striking for me. And then, you know, of course in our worlds, we hear about sort of the, all the chaos that can come with resisting death.

So I'm curious how you document what actually matters to you. so that people know, so everyone knows, there isn't tension in the family. What pieces are most important about what we communicate and how we communicated?

Well, the clarity path that I'm going through right now documents we have a platform online where it has to see different questions. And then you can literally click a button and start talking and it'll type in your answer, which I love because otherwise I'd be typing away.

Um, and I can actually express my true feelings and then I couldn't go back and edit it later, of course, but It gets how I'm actually feeling in that moment when I've been asked that question out on paper.

So the most important thing is I think to have it written down. And it can be something as simple as writing a letter to your family. Some people have recorded the video.

There's different ways that you can do it, but there's nothing that has to be legally documented except for the voluntary stopping eating and drinking that has to be documented prior to cognitive decline.

So this might be an opportunity like through a video or a letter where you might describe things like, what does dignity mean for me? How important is independence?

Yeah, we go through that in a flirty way. Awesome, amazing. So you have a list of questions, like things that come up for as I was kind of preparing for this conversation.

It's like We talk a lot about meaning and purpose and what gives us joy at different stages of life often will change. So what would an acceptable quality of live, what amount of purpose, dignity, meaning, joy would look like quality

versus I'm ready to go.

How do we give our families enough of that? I mean, can you ever so that they can make a decision for a scenario that we maybe didn't anticipate? I don't think you can ever come up with every possible scenario out there because, like you just mentioned with your sister-in-law, had this very tragic illness come on suddenly and a very quick death afterwards.

And I'm sure that someone at that age probably didn't have a whole lot of planning done. I think it comes later in life that we start thinking about it.

And for me, I thing mine is going to outline a lot about dementia because of my mom. But I also understand that that is the one piece of this, that if I do want to elect to die with dignity on my own terms, whether through voluntary stopping eating and drinking or through medical aid and dying, I have to have that documented prior to any cognitive decline.

So that will be in mind very clearly. But I think that there are lots of questions. There's lots The clarity path, I think, is going to be a really beautiful thing for people to go through and experience because it does bring up a lot of those questions.

It brings joy and there's different adjectives that you can pull from a list and things that describe you. And then you kind of pick your top five and then talk about what does that look like for you?

And binary, compassion, love. Yeah. you know, a couple others, but what does compassion mean to me? And what is love mean me and, you now, caring for others which is a huge thing for me.

So I would want those things honored and remembered. about who I am. This, I mean, you're the Clarity Path. I want to sign up, i want do it. i'm sure a lot of people listening do.

Let's share right now how do people find out more about this Clurity Path program.

Choosing the Right Decision-Maker

You can go to the website. It is www.claritypath.org. TheClarityPathBelieve.com. OK. We'll put it in the show notes so that everybody can find it. And I think what you're describing, I'm sort of addicted to personal growth anyways, but it just sounds like a really neat opportunity to go through this within group and take the time to be intentional about this, which for me is kind of a carrot.

But I thing for some people, they might be like, yeah, no, not going to take time do that. So I do want to bring up the stick here. The what if, if you don't, do these things.

If you don't have a clear path, if you Don't Have This Documented, what happens when siblings or other family members are disagreeing about what their loved one would have wanted?

What do we do when there's all this burden and conflict, financial, emotional, logistical, like, you know, caregiving, as you well know watching your dad go through it being a thick in it with your mom, there is ripe room for conflict and disagreement.

So what happens? What happens when we don't have it written down? Well, when you don' have written it down, then basically what happen is if there's an emergency, you go into the ER and their job is to save your life unless they're told otherwise.

They're going to intervene, they're gonna crack your chest open, They are going put you on feeding tubes and ventilators, paddles on your chests. That's what their job is to do.

And so they do that and they then send you onto the next stage, which is either home or to you know, a specialist,

refer you to a specialists, and then from there, it's treat, treat treat until there is no more treatment.

Yeah, so that can be a painful slog through a lot of medical intervention that not everyone is interested in getting. It's expensive, time consuming, all consuming.

Right. And for the right person, that's the thing. But it's not the right thing for everyone. Right. And so making sure that that's spelled out is important.

I want people to understand palliative care and hospice from you, you being so in it with Dr. Bob. So I think that we should just start with a definition.

What is palliate of care in hospices? Because I so many people in their mind, it means we're giving up. It means, we are preparing for death. And it's more nuanced than that.

So what do you wish families understood? And can you just give us what is palliative care? What is hospice? Sure. Well, the definition of palliate means to relieve symptoms.

So, you know, my best way of defining palliative care is it's a place for people that the traditional hospital system has kind of done their thing. They have tried everything.

they might still be trying, but you're passed from one specialist to another, to You know, you could have dementia, but you might also have stage four cancer.

And so the neurologists and the oncologists are kind of back and forth and maybe they're not talking to each other. So a good palliative care physician comes in to kind help bridge those gaps.

Then it acts as a bridge to give patients really good high quality care where they have a doctor who they, have his cell phone number, which we experienced earlier.

and is on call and you can call them at any time. So if you're not sure if he should go to the emergency room, you could call a doctor. If you need to be seen, instead of having to go out to a doctors office, the palliative care physician, at least in our model, comes into your home or wherever you are at.

I know for like my mom with dementia, it's really hard to get her to the doctor's office for something as simple as a UTI, which happens quite frequently.

So having a doctor that can actually go into the facility or send a nurse, if we assume it is a UCI, send the nurse get the sample, you know, start her on a broad spectrum antibiotic.

And then once we have the culture back, then we figure out what needs to be done next. Right, without having to amplify her disorientation and dehydration.

Right. Or lose her at the hospital, which my dad has done. Yeah, right. Lose her where she literally is so disoriented she's lost, doesn't know how to get back from the bathroom, or have her get an infection that she succumbs to because the hospitals is an easy place for that to happen.

Right. Yeah. And then hospice is, you know, really geared more towards somebody who is less than six months to live, and it is Medicare covered. Palliative care, like in our model, is not covered by insurance.

It's private pay. Then hospices is covered, by Medicare. So they come in and typically you have, maybe a nurse visit a couple times a week, LVNs a And they provide like the hospital bed, the commode, you know, all of the equipment that you might need for that, kind of end of life stage.

And hospice when it's done well is amazing. And we're lucky here in San Diego. You guys are a palliative care, not hospice. So is there a hospices company here that you recommend working with?

You know, I really love a couple. One of them is Seacoast Hospice and Comfort and Peace has been really good. Yeah. Agreed. Your personal story here, it's so much of what defines you at this age and your career even.

and it brings that compassion, that thoughtfulness. And there's a lot of ambiguity, I think, it comes up with dementia that I'd like to give voice to.

Because you're often grieving changes in someone while they're still physically there. I'm curious what you've learned about loving your mom through these chapters and your dad.

Yeah, loving him has been a little harder than loving mom, to be honest. But, you know, I think there's a term called, gosh, what is it? Grief, anticipatory grief.

Yeah. And, you know, there's something so real about that because you are literally losing somebody every single day.

Palliative Care, Hospice, and End-of-Life Choices

It's not like something sudden like a car accident and someone's just gone. Every single you're feeling that loss. I got my first few gray hairs and I didn't know what to do.

And I just wanted to go color my hair and so I've got a box of like really dark brown hair color and somebody was like, wow, you look really harsh. I said, I didn't know who to ask, like I don't have my mom there.

And so there's times when you just really miss her and I miss here every day. I call her every, day I put an Alexa in her room so I can just drop in and that way she doesn't really have to worry about trying to dial on her phone or anything.

that rarely happens, or if it does, it's at like 2 a.m. or something random. And then with dad, I think I just have to remind myself every day to be compassionate because he's also grieving the loss of the wife that he has known and had for four years.

They got married when I was five or six. So, you know, It's challenging, but I thing just leading with love, not being quick to be upset or judge or. Yeah.

Try to put yourself in the other person's shoes. Well, maybe you're answering this question already, but is there a practical thing that families can do today and maybe every day?

Practical thing to do every, I think for me the most important thing is for to be in communication with both my mom and my dad and sister every because that's the family, that is the core family that we have left.

And also my daughter, she's not doing as well with this whole thing with my mom's dementia. It's really hard for her. But at the same time, I don't push it with her because she is grieving the loss of her grandmother.

So everyone's grieving and we have to just understand and You know, check in. Check in with people. I check-in with my dad every day. It's just a text message or something.

Yeah. And that was something that surprised me about my sister-in-law's death is that everyone in the family processed it really differently, right? Her grandma lost her daughter.

The girl's dad lost their sister. There was everyone that, of course, her boys lost, their mom, and everyone's going through it in a different way. Everyone's got their grief and it's not just about grieving on your own.

It's about showing up for the people who are still there. Right. Yeah, and acknowledging and I think being considerate of their process and that they're going to go through it a little differently.

Yeah. I want to flip 180 degrees here. You do. So I wanna acknowledge you spend so much of your personal and professional life thinking about dementia, caregiving, a serious illness and life's hardest transitions, including the end of life.

But what brings you joy right now? Oh, that is such a loaded question. Well, you've been thinking it with this clarity path process. Right? I feel like you have a little leg up on most people.

I think right now what brings me the most joy is getting out and connecting with people face to face, not just, you know, sitting, spending too much time in front of my computer.

I like to do meetings outside coffee shops and go to lunch or even go take a walk on the beach with someone and just chat with them while we're walking down the Beach.

So I try to just keep it as normal as possible, but at the same time, remember to take care of myself. And my phone automatically shuts off from 10 to seven in the morning for a reason.

So don't override. Yeah. There's the only people that can override it are my dad and my sister. Not even doctors. Katie, thank you for being here and especially for be willing to share not only what you know and have learned professionally, but your experience as a daughter in this.

One of the things I really hope that people take away from this conversation is that advanced care planning isn't about death. It's really, it's about love.

It's about knowing someone well enough to understand what makes life worth living for them and then caring enough about those people we may someday leave in charge of these difficult decisions that we don't make them guess, that Right.

And dementia makes these conversations just particularly precious because we don't always know how long we're going to have the ability to clearly express our wishes.

Right I think, and please jump in and correct this if I didn't get it quite right, but the invitation from today's conversation is do not wait for a crisis.

Do not for the moment you think you need this. Ask the questions, tell people you love what matters to you, write it down, make a video, right a letter and then revisit the conversation as life changes.

Correct. Katie, I am so grateful to for you for work that you're doing for families navigating dementia and the end of life and serious illness and also for the way that you're honoring your own family's experience and making this path a little clearer for those that will come behind you.

Grief, Joy, and Final Takeaways

Your work is so important and I know not always easy, but I couldn't be more grateful that you're here in our San Diego community doing this, offering these services and making a really hard part of life a little easier for people.

Thank you. It's a labor of love. I can tell. So to everyone listening, please share this episode for someone who you think needs to hear it so they can open up those conversations and reduce the suffering associated with end-of-life.

Until next time, keep taking good care of your brain, your body and those you love. Be well. Thank you so much for listening to the Think Well, Age Well podcast.

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Until next time, keep thinking well and aging on purpose.