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Proem 00:53

the way i become about dying

Michael P. Funk 2002

i am not things.
i am sum of things,
guessing that i'm part of God,
wondering if there's some place
where my soul will go
from where I might look down
with advantages my eyes did not have
and see the tops of trees
which I used to walk beneath for
shelter from rain and sun,
and see the way things go together
like continental tracts of land
punctuated by water and lights
and roads and other concrete artifices

I am, this very moment dying
from headache tumors that
erase my cognitive ability so that I might
be retarded when I wake up tomorrow,
or I might know answers,
or I might still be guessing

or I might be you
you who likes to taste,
you who recognizes the smell of yourself,

you who have hurt and loved and not loved,
you who are dying,
wearing my skin, walking around with my soul.

Our boy, Mike, the poet, lived from May 17, 1976 to November 18, 2002. He would have been 44 this month. So far, reportedly, at least 65,000 people in the U.S. have died of Covid19. Each death is one. Losing a child – agony. We grieved and celebrated Mike together – his families and communities. I'm in awe at the creativity of many grieving for those dying of Covid19. Still, you gotta grieve, one way or another.

Introducing Judy Thomas 03:10

I'm grateful to Judy Thomas, CEO of the [Coalition for Compassionate Care of California](#) for joining me for this conversation recorded in early March about end-of-life and palliative care at the start of this intense Covid pandemic. The Coalition is a statewide collaboration of healthcare providers, consumers and policymakers working to improve care for people of all ages in the face of serious illness. Judy is an attorney with over 25 years' experience in healthcare and public policy. She was recently appointed to the California Master Plan on Aging Stakeholder Advisory Committee. She was recognized as a Practice Change Leader by the John A. Hartford Foundation and Past President of National [POLST](#) (Portable Medical Orders).

We know what end-of-life is. What is palliative care? Palliative care is patient- and family-centered care that prioritizes quality of life by anticipating, preventing and treating symptoms associated with serious illness while addressing physical, intellectual, emotional, social and spiritual needs. Generally, palliative care is provided by an interdisciplinary team of physicians, nurses, social workers, chaplains and other specialists working together to provide patients an extra layer of support, regardless of age or stage of their serious illness. Studies show palliative care results in better patient and family satisfaction, improved home safety and medication management, and can be provided alongside curative treatment, helping patients, families and caregivers through challenging times.

Palliative care in Covid19 world 05:15

Health Hats: Judy Thomas, thank you so much for joining me today. I've been thinking about you a lot lately. I was going to see you next month for the palliative care Summit, but I guess not. I was on two calls this morning already. The first call was with the CDC (Centers for Disease Control), where I'm involved with initiatives related to clinical decision support - the evidence-based tools that clinicians, patients, and caregivers use to make decisions together about medical care. I've noticed before this past month how little the conversation is about palliative care. Now they're pulling together the electronically available or could be electronically available guidelines for people making decisions now in this Covid19 world. I'm co-leading a workgroup that's related to the at-home angle - not the emergency department, the ICU, EMS, acute care. I'm thinking about what's the biggest thing that people are dealing with every day as this insanity unfolds: Do I want extreme measures? Maybe I'm not dying, but I'm really sick, I want palliative care. It's time to think about what we want, because of the risk now. I'm old; I have MS, I'm on immunosuppressants. I'm at risk. How are you seeing the focus on palliative care shifting or rising or changing in this bizarro space?

Judy Thomas: That's a great question. I think you've hit on a lot of topics in that question. I'd like to start at a high level and then drill down. I see this whole situation with the Coronavirus at a very high level helping us think about what works well in the world and what needs to change. Certainly, it's hitting the healthcare system hard. It shows the cracks in everything. Hopefully, through this process, light will come through those cracks, and we'll end up with a better healthcare system. The tension is that palliative care is still a thing, separate, siloed, and newish. We haven't figured it out yet.

Health Hats: How crazy is that?

Judy Thomas: It's crazy. Palliative care happens on so many levels because it's a movement, and it's an actual healthcare delivery system. There's dynamics as to different ways it is or isn't infiltrated into healthcare writ large. We are one breath away from a healthcare emergency or a condition that could turn into a healthcare emergency. It's not those people who are terminally ill or those people who have a diagnosis. It is all of us in this boat together. This is humanity, mortality, the people we love. We're dealing with this every day. How do we integrate this more into the way we think of health, public health, personal health, determinants of health? Certainly, your work, Danny, that shift away from the healthcare system being in control to a partnership with the individual at the center. There's a lot of opportunities here. The situation is reminding us and highlighting the importance of helping people. Some people are at the beginning of the palliative care movement who know this or have some experiences with it, but now it's becoming universal. Right now, there's a lot of stress. So I'm not sure people are thinking clearly and seeing the path through, but as that starts to clear, people will begin to realize and feel, 'I want to be empowered in this situation.'

End-of-life choices 11:14

Health Hats: What freaks me out about the situation now is that my palliative and end of life goals and wishes - I separate those - I'm not saying that palliative care is End-of-Life. They happen to be together in this movement, but they're very different. Right now, my big fear is that I'll be alone because everything is so infectious. The way we're dealing with this now is to keep everybody separate. Sure, there's an infection control part to that - very important. On the other hand, it's hard to advocate for yourself and share your life goals, your function goals, your activity goals, when you're alone in situations where everybody is stressed, everybody's burned out.

Judy Thomas: I love the way that you described the tension that exists. There's a lot of tensions right now for my organization, the Coalition for Compassionate Care, the palliative care movement. We're trying to get the word out that we see the surge coming - the surge of ill people, the number of people going to the hospital, the number of people in ICU and on ventilators. Before that surge comes, let's have conversations. This is the time while you still relatively healthy, and you have the capacity. You're not in that stressful situation to have those conversations. I love the way you talk about it because you are so person-centered. The healthcare team wants to know what treatments to do, what interventions to do, but it really is about how to help you live your life. Who you are and how you want to be treated and make your way through this? You need to have these conversations now. This is the time.

Health Hats: Yesterday, I was on the phone with my son. First, my wife is my health partner and then, if not her, one of my sons. We were talking yesterday on the phone, and we've had these conversations for years, but there's something about right now that feels different. I can say now that I don't want to

be on a ventilator for more than a couple of days. So, where am I on the continuum this minute? I'm not afraid of being dead. I'm afraid of dying. This idea of dying by myself that freaks me out. He's asking me more questions. What do you want? Then he asks how is he going to communicate that to anybody when he can't get in?

Shifting to no-touch telecommunication 15:00

Judy Thomas: Healthcare providers are working on remote conversations as our system went overnight from rare tele, phone call, and video visits to the norm. I've talked to some health plans, and they said, we usually make these decisions in six months, and now we're making it overnight. How to make this happen? How to pay for it? How to help providers bill for it and get paid? Most of our healthcare system is gearing up superfast. In some settings, they don't have as many technology resources to stay connected. It might be harder in a nursing home to have remote connection than if you're in the hospital. We want to get the word out to our healthcare providers so they can be comfortable in having these conversations remotely. One of our palliative care physicians, Michael Fratkin, talks about how he's found that it's even better tele-conversations if you do it right than in person.

Health Hats: That is interesting.

Judy Thomas: Maybe it's a good thing to come out of this.

Health Hats: I filled out the paperwork two years ago. For some reason, this seems like it's either a whole other decision, a different set of choices. You can't just rest on that five years ago you signed your advanced directives paper.

Judy Thomas: That highlights two key points. Reviewing your decisions and naming somebody to be your spokesperson. These decisions are context-specific, and we can't anticipate. Who anticipated the pandemic? You can start to think, 'if I got Covid19, I have an idea of what might happen. What might look that look, how might it progress, how long might it take? If I receive these treatments and survive them, am I going to be able to get back home? How am I going to be? What's my life going to be like? Am I going to have the resiliency to have to continue my life the way that I want it to be?' You're bringing up being alone. There are layers to that. I love how you described earlier the stress even if you have the capacity to make your own decision, you've got the physical condition and a dynamic with your body. It's helpful to have some backup, and somebody to speak for you. What if you don't survive this condition or maybe you get treatment, but then you get off of treatment for a few days, but not get back to your life. Would you rather stay at home in familiar surroundings where your family can still come, or do you want to be in a medical setting? Some people do. Some people want that. We want to know that there's a system for those people who want that. We could do that. We can provide that. We're good at that. For those people who want a different path, there are choices here. And the sooner people think about this and talk about it the more likely they are to be able to go down that path of their choice.

Now a word about our sponsor, ABRIDGE.

Use Abridge during your palliative care or end-of-life conversation with your primary care professional. Push the big pink button, and record the conversation.

Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations.

Guidelines change by the minute. Palliative care, not so much 19:45

Health Hats: Let's go on the other side of this. We're frontline clinicians and we're either an office practice doing telehealth, or we're in the hospital as a hospitalist or an intensivist working the acute side. In this tumultuous time, people are looking for something definite. This is how I should act. When I ask people about end-of-life guidelines, they ask where do you live? They say it's state by state. But if we want to provide these heroic burned-out people who take care of us a quick roadmap that is evidence-based about how they should act, where would you point them?

Judy Thomas: You're talking about how to deal with palliative care in the current setting?

Health Hats: Yes. Because people are describing that are guidelines for protective equipment or whatever. It seems like twice a day; the guidelines are changing. People want guidelines. People talk about who speaks for you, what your goals are, what choices might you make? It isn't quite as frenetic, maybe, as trying to deal with your breathing. All we can do to help people help clinicians, frontline clinicians have a roadmap of how to work with individuals and families. How can we point people?

Judy Thomas: With Covid19, the guidelines are changing every few hours as we learn more and more; it's a moving target. But palliative care is still the sound, solid, fundamental principles that we've known and been developing over the last 10, 20 years. It is a mindset: The individual healthcare provider takes care of themselves and understands the best they can what's going on in their own body and where they're at—then creating a place that you can elevate above this chaos and try to create some presence to be with the individual and the family. Presence itself is very therapeutic. The palliative care team has refined and developed to see what's going on in the bigger picture of pain and symptom management. Not just what is happening right here, but what is the trajectory of the condition? The palliative team can help the care team with these conversations. The fundamental place to start is who's going to be the spokesperson for the individual if they can't speak for themselves or even if they can speak for themselves. Anybody who's gotten a serious diagnosis or been with somebody when they got sort of serious diagnosis knows that as soon as the doctor starts talking, your mind is gone. You need extra ears to remember and track what's being said. Having that person named is beneficial to the team. And then after that, helping them think about their life and what's important to them. 'What matters most' can be constructive words for a healthcare provider to think about. If we're clear what matters most to them, then it's much easier to get there.

Health Hats: What matters most? Like what matters most to me is I want to hang out with my grandkids, or I want to play my saxophone, what do I want to get out of life?

Judy Thomas: It depends to some extent to what level of function I want to have? For me, what's most important at the end of the day is being able to have meaningful communications with my family and my loved ones. If I can't have meaningful connections with them, then I don't have quality of life. At the same time, I did have the caveat that it may be important that my life be sustained to my husband. I'm fine with that if he wants to sustain my life, even though it's at the point where I don't have the quality

for me. Because this is about a relationship, not just about me. Health care providers also learn what that disease process looks like as best we know today so that we can educate our patients.

Palliative care, feeling less miserable 25:56

Health Hats: What am I not asking you that I ought to be?

Judy Thomas: We've covered a lot. We could go back a bit. I love how you articulated palliative care and end of life being different.

Health Hats: Let's explore that. How can people be doing palliative care in this emergency, emergency, emergency time; with this overload, this burnout, with the turnover of carers. Thinking about myself as a nurse in the days when I was a frontline, caregiver. It's not any less important. We're all guaranteed to be miserable during this outbreak. Palliative care means that you can be less miserable. You don't think about it when you're healthy, and you're feeling fine. You think about it when you feel like crap, and how do you feel less like crap?

Judy Thomas: I love the way you describe it. You make it tangible and real rather than the word, palliative, that comes from the people who are entrenched in this all the time. We have our own language sometimes. There is so much stress and so many moving parts. It can be hard to stay focused on the true North, but hopefully, palliative care can be that for some people and some providers - to provide space in this chaos. I hope that once we get out of this whole process, we'll be moving towards a healthier, more holistic health system. Maybe we'll have a vision more of how palliative care becomes entrenched or intertwined with our healthcare system. You also talk about services at home and community-based services. That's a real tension, too. We've been trying to push costs of care out of the hospital and into the home. It's hard to be in people's homes and have people going into one home and then visit another person in another.

Health Hats: I'm glad you said that. I'm fortunate that I'm here with my wife, who I love dearly, and we get along great. If one of us gets sick, it's the other one that's gonna take care of us. Lord help us if it's both of us at the same time. How do we best use the medical system when we're at home, and it's just us at home, and we're managing things and trying to be Palliatively sound? Those aren't the right words, but you know what I mean - feel less like crap. The answer to my own question is probably using the telehealth services, be as specific about what you need, what's going on, and where you want to feel less like crap? Is it moving your bowels? Is it breathing? Is it aches and pains? What is it?

Judy Thomas: We know how to deal with those physical issues. The healthcare system is good at that. We have the skill, the knowledge, the tools to address it. So, people should feel like if they're having physical misery, like you said, that an advice nurse or a remote physician visit should happen. You're also bringing up the cracks in the healthcare system: to acknowledge the role of caregivers, family, lay caregivers, not just the medical professionals that help us have good health. You and your wife are the medical teams for each other if something happens. You're the frontline medical team. Our healthcare system needs to be better looking at family members as extensions of the team. Healthcare isn't just what happens in your three-day hospital stay, and then you go off and live your life. Health care is every day. It's how we live our lives.

Health Hats: Judy. Thank you. This is great. Short notice. Thank you very much.

Judy Thomas: It was a great conversation with you, Danny.

Reflections. Simple Gifts 31:30

Trust, time, and talk. Control and connection. The 3Ts and 2Cs. Still key to decision-making, coronavirus or no coronavirus. I thought I knew what I wanted: die at home. Now, I'm not sure. Do I want to put my wife through caring for a Covid positive person? I know I don't want to be on a ventilator at all. I hope someone can hold my hand when I die. How do you do virtual hand-holding? I appreciate that unique organ: skin. Have you discussed end-of-life and palliative care with your family? Do it now.