



The following is a transcript of the question-and-answer portion of our virtual event, Community Conversations: Finding your Voice at the End of Life, which took place on March 10, 2021.

Question: Does HOP provide palliative care to individuals not yet needing hospice care?

Answer (Dr. Tim Short, Chief Medical Officer): We have an arm now called [Piedmont Care, which is home-based palliative care](#). They take care of patients that are not yet in hospice, patients that have serious, life-limiting illnesses, usually with a life expectancy of a year, or two, or three, and the focus of palliative care in that setting is on improving quality of life. Palliative providers are experts in symptom management, so they see people with all kinds of diagnoses and associated symptom burdens, tending to that to improve quality of life. They're also really skilled at these challenging conversations. So, they will help families have these conversations upstream well before it might be time to consider hospice. There's lots of living to do with serious illness, just as there's lots of living to do when you're in hospice.

Q: End of life is not just a medical event; our family dynamics are really challenging. How can your team help us deal with that?

A (Michael Williamson, LCSW, social worker for hospice and palliative care): We work with families, in a way, as much as we do with patients, from my perspective. I see family members just as often, and work with them in a counseling role, as does Liz (chaplain) and our nurses, as well, giving a lot of counsel to people. Family members, too—we help guide them. We want them to feel in control, as much as they can, to have what we call autonomy. We want to make sure patients have the ability to decide what they wish for. And families need a lot of guidance in that, so we participate with everybody, with anybody that wants to participate, in terms of family, are involved in those conversations.

A (Liz Forney, chaplain in the field for hospice patients): I think one of the gifts we can offer, as part of a team, is that we're not actually part of that family system. We know that a lot of the dynamics that have happened because of injuries, and pain, intended or unintended. Sitting as a neutral, compassionate presence can begin to bring those to light, and we don't really have any investment in outcome, so we can begin to allow each one to have their voice and maybe allow one another to hear each other in a fresh way.

A (Jenny Hunter, RN, nurse for patients in our northern region): The two words that come to mind when I hear that question about challenging families is facilitation and boundaries. Michael and Liz know how to talk to people! I can help you with your nausea, but I don't know always know those conversations. So it's great that we can have team meetings and when a patient or family member says "oh, we have all this stuff going," I can suggest, "how about I have our social worker and chaplain come to the next meeting? You bring in whoever you want, and they can help facilitate that conversation." It makes it a little safer than the family doing it on their own. The other thing I can do is set some boundaries for them, to help them visualize what that might look like and make some suggestions to help with those challenges.

A (Dr. Short): Well, I might be the only one who grew up in a perfect family (*laughter*). Families are messy. And when you put them under stress, you see both the strength and resilience and beauty, and you can really see the dysfunction and shattering of families. And that's what we encounter day in and



day out. I think what you're hearing here is this kind of team-based care, family-focused care is the best way to address the complexities of a patient and their family with serious illness, pre-hospice or with hospice.

Q: Do you have a recommendation for an optimal time to introduce palliative care physician to an oncology patient with progressing disease?

A (Dr. Short): This goes back to that [Temel study](#), where, in the study, which was done about 10 years ago. It took patients with cancer and entered them with palliative services at the time of diagnosis. And then they took a control group and followed both groups – one that had palliative support and one that did not – and they followed them forward for a couple of years. There wasn't any impact on the treatment decisions, of what kind of chemo regimen they get, etc. They matched them up and then they followed them forward. What they found was that, as I said earlier, the patients with palliative support lived longer, lived better, stayed out of the hospital, and cost less money to the system as a whole. And it was simply because of this attention on symptom management and for the support of real conversations, as well. So, my answer would be the sooner, the better. Many oncologists are open to a collaborative relationship with palliative doctors. Some of them still see palliative as pre-hospice or the same as hospice, and they're not ready for that yet. But if you're finding yourself walking beside a loved one with cancer, and you're worried about symptoms that aren't well-controlled, or "where are we in this? Let's have a real talk here!"—that's a good time to ask the oncologist, "what do you think about asking a palliative colleague to fold into the care here?"

Ron: Tim, just a quick thought, I just read this quote earlier today. It's that when someone has a life-limiting diagnosis, the saying is, it's always too early until it's too late. Obviously, we believe earlier is better.

Q: Somebody asked a related question: how do you find a palliative specialist?

A (Dr. Short): We are really fortunate in this community. We have a fantastic palliative program at UVA, a fantastic program at Sentara Martha Jefferson, Hospice of the Piedmont has a fantastic home-based palliative care program called Piedmont Care, Augusta has a robust program... so this whole area is very well-equipped with palliative care. Your doctors know us, your doctors know the palliative providers in the area, that's a good place to start. Google it, you'll find us readily, as anyone in today's world does.

Q: What happens once you enter hospice? I was with my father at home while he died; luckily, his neighbor was a hospice nurse.

A (Jenny): A nurse will come out and admit you, which just means she's going to come out and do a little physical and get some information from you and you sign some consents. After that, the team descends upon you (*laughter*) which might be overwhelming at first. But, you'll meet the nurse, you'll get a team and the way I explain it to my patients is that you're the captain of the team, so you call all the shots. I'm gonna be your nurse and I'll handle the medical aspects of things, the nausea, the constipation, pain, all that type of stuff, and be in touch with your doctor. The social worker, like Michael, they handle everything else. They handle the emotional, spiritual, financial, all types of things. We have a chaplain who also helps with the spiritual needs, and we have a home health aide. So, I let them know up front that they're going to have a whole team of people here that you can use as much or as little as you



want. After that, as a nurse, I'll be coming out at least once a week to check on you, see how your symptoms are, and we also talk a lot about goals right at the onset when you sign up for hospice. What is it that you want, would you rather not have a lot of pain and be alert? Are there any events that are coming up that are important to you? That type of thing.

Q: What about after the death – what kind of support do the surviving family members get from a hospice service?

A (Ron): We have very talented grief and bereavement counselors. And when someone passes, a member of our team will reach out to that family and offer grief support. And that grief support can come in many different forms. It can be one on one counseling and it can be group counseling. Our [Center for Grief and Healing](#) [staff] are very skilled at supporting families after death. There are also times when patients that do not receive services from hospice, at the moment, need that grief and bereavement support. And we will welcome anyone that needs that support to take advantage of those services offered by this talented team of counselors. So, we'll not only care for patients and our family members of patients, but also of community members. And the last thing I'll mention, too, we have a [Center for Children](#) and oftentimes [when] children [are] suffering a loss, it's oftentimes from sudden death, or patients that are not on hospice. And they need a lot of support. So, we have a group of therapists that work specifically with children to meet their needs. The Center for Grief and Healing and the Center for Children are supported by philanthropic support. We're very blessed in this community to have donations that come in to be able to allow Hospice of the Piedmont to support our community beyond what it is we do in caring for our patient's families specifically.

Q: The control of symptoms, particularly anxiety, is fundamental to quality of life. How do palliative care physicians address anxiety, pain, and other symptoms so the patients are not feeling excess anxiety? Michael, you bridge both the palliative world and the hospice world. Why don't you start with how do we approach this?

A (Michael): Sure. One of the ways I often phrase it to people in a way that's understandable for people that don't work in the medical field is to say symptoms are kind of circular. If you're having pain, for example, you're often having anxiety or breathing distress. If you're having anxiety, you might feel your pain in a sharper way. So, we want to make sure that we're looking at both and trying to manage all symptoms we have. Luckily, there are a lot of tools that medical practitioners, physicians and nurse practitioners and whatnot have to utilize medically. But then we want to look at the family systems, counseling on all sorts of things, in order to address all the ways that pain can be experienced. Because pain, of course, simply isn't just physical. There's emotional pain or spiritual pain, many things. And we want to make sure that we're touching on and addressing all those issues. Looking at one without the other is not complete and it's not closing that circle. So, we want to touch on all those things we can. And if people are experiencing one, we need to try to focus on that.

A (Liz): In my experience, people often have some anxiety about unresolved family issues, things that they haven't expressed forgiveness for or asked forgiveness for. And that's some of the work that we can do as spiritual counselors. And sometimes people have been told some really scary things about the afterlife. And there's an opportunity there, to ask what have they heard, what do they believe? What are some other ways of thinking about that? Just to open up to some of those things. Sometimes the anxiety is just about feeling like there's no one you can safely say it to. And we become safe people for



you to be able to say what needs to get said, to have a sense of peace and comfort and resolution at the end of life.

A (Dr. Short): This is a great question because I think it illustrates how important it is that we, as health care team members, offer both clinical competence and compassion. And if we're not competent at good symptom management, tending to whether it's anxiety or pain or shortness of breath or sleep disturbance, we can't really get to the more important, deeper, richer aspects of palliative and hospice medicine, those matters of the heart, those issues that you're touching on: relationships, closures forgiveness, etc. So, it's a great question. I think it also raises the issue of what's important to people when they're staring down the barrel of mortality. And that's where a lot of this anxiety circles around what's important to people at the end of life. First is comfort. And so, this question of anxiety about being uncomfortable is very, very common. Second is control. They want a sense of control of their destiny, and they lose all sense of control. Often, they come into the hospital setting and all control is yanked away from them unintentionally. But absolutely. And the third thing that is most important to people staring down the barrel of mortality is they're worried about their family. They are making decisions oftentimes more about their family than about themselves and their greatest fear, the greatest fear of somebody facing dying, is a fear of abandonment, is the fear of being alone. This is where anxiety finds its energy, in these realms, and why it's important for interdisciplinary team to approach these complex issues.

Q: I see your care team includes a chaplain. Will you be attempting to convert someone who is not religious? What denomination are your chaplains?

A (Liz): That's a really beautiful question. And the answer is no, we are not in the conversion business. We're really in the caring and compassion business. And so, when I enter and meet family and patients, my standard intro is, "hi, I'm Liz. I'm a chaplain, which means I'm here for your emotional support and your spiritual care. However you define it." All of our chaplains want to meet people where they are and care for them in whatever system of faith or just view of the world they have. We do have good relationships with all of the Catholic parishes. So, if that's a really important thing, to have a sacrament at end of life, we can make that happen. We also cultivate many interfaith relationships. We have a Jewish chaplain on staff, and we are in conversation with both Buddhist and Imam folks. So, if that's your tradition, we will make sure that you're cared for in that way. One of the challenges at end of life is that folks often haven't been able to attend the of their church and they've gotten disconnected. So, we help that connection happen.

Q: How do you suggest we start these conversations earlier with family members that are often not ready to have them?

A (Jenny): I mean, my kids are in their 20s and we start talking about it now. Of course, it helps that I'm a hospice nurse, but intergenerationally, even with my mom and my kids, her grandkids, we have these conversations. So, if you think about it, we are all dying. We all have that in common, every single one of us. Sometimes humor helps. And so just in in the course of a lazy day, it can be brought up. "Have you ever thought about what do you think you want to do when you die, Mom? Do you want to be buried? I just thought about that. What do you think?" And so, I think when we're in a healthy state, that's when we need to start talking about it.



A (Dr. Short): I find many families also fall into that conversation driving home from a funeral from a friend or something like that. Something happened to somebody. And it prompts you, saying, “if this was me, I wouldn't want this, or I would want this.” That can be a that can be an opportunity to fall into that conversation. I think the other advice I would give, if you're struggling and you feel like we really need to have this conversation, but they're really recalcitrant and avoidant, this is where forms and advanced directives might be helpful. You know, can we just fill out this form? And we all know that the forms themselves don't really translate to impacting care at the end of life. It's the conversations around the form. But sometimes they can be a good facilitator to get a conversation started. And we have we have a robust, active, collaborative right now in our community, the Central Virginia Community for Advanced Care Collaborative. And there's forums and you can get them online. You can get them at any of the hospitals, you can get them on our website. [We use Five Wishes](#). It's a beautiful form that can facilitate a little bit more conversation. So can the [POST form](#) here in Virginia, the more robust advance care directive, it's an excellent way to stimulate a conversation. Anybody else want to chime in on that one?

A (Liz): I was just going to say I resonate with Jenny's expression and that the posture of curiosity, rather than going at it from sort of a morbid sober, like, just to be like “I wonder, you know, have you ever thought of...” just in a light, warm, curious way, is a great way to open the door.

A (Dr. Short): Yeah, I agree with the curiosity and humility... and I would add that are ways that invite discussion, you know. So, I'll tell you the other thing that I've seen, for my family, has been a few television shows or movies that really speak to the heart. “This is Us,” I mean, there are some powerful scenes in there that have prompted my wife and I to go to spaces that we wouldn't have gone otherwise.

Q: What's the difference between different hospices?

A (Ron): Well, we're very proud of being in this community for the past 40 years. We are the only community based, not for profit, and we are governed by a board of trustees who take their role in working with a community asset very, very seriously to assure that it is sustaining. I think the thing that differentiates Hospice of the Piedmont are the things that I mentioned earlier. We go well beyond just caring for our hospice patients and we care for the community, caring for people that have grief issues, caring for children that wouldn't have a place to turn. There's Music by the Bedside and massage therapy and pet therapy, things that Hospice of the Piedmont will offer our patients that go above and beyond the traditional delivery of care. So, we're very proud of some of the initiatives that we're doing to go beyond simply providing hospice care. And I think that's a differentiation as a not-for-profit provider in our community.

A (Dr. Short): Well, thanks, and I will add to that we have [a robust program for our veterans](#) that is just a beautiful program. We are embarking on a death doula program and training of death doulas, as they are able to reach people that don't reach hospices for various reasons. So, we really are looking to care for community.

Dr. Short: Ron, before you close, I'd just love to take this opportunity to apologize that we couldn't get to all the questions. There were a lot of questions rolling in and thank you very much for those. And, just to say thank you for your engagement, I can tell by the quality of the questions in this room, there's a lot



of wisdom in this room and a lot that we have to learn from you, just as we learn every day, and have the privilege of learning every day from the families we get to take care of. Ron, would you like to close up?

Ron: Well, I simply want to say, what a good conversation. And I want to I want to finish the way I started, by saying thank you. We all know talking about death is uncomfortable. And here you were, listening and engaging in this conversation. It takes some courage to talk about end of life for yourself or for your loved one. It will take many more community conversations to break this tyranny of silence and find our voice at the end of life. We look forward to more conversations, these community conversations events will be held quarterly. Our next one will be in June. We'll send you an email and get the word out to the community and hope that you'll join us again. This session was recorded and we'll post it on our website, if you would like to share it with others. Also, if you'd like to talk to someone, please reach out to us. You can call us at the office at 817-6900, or you can go to our website and [click on "Contact Us"](#) and we'll be sure to connect with you.

I want to say thank you to my coworkers for the work they do every day. I am so fortunate to work with 200 colleagues that are so talented, so committed to serving our patients and families facing serious illness, death, and grief for all of us at Hospice of the Piedmont. We are grateful to have the privilege of sharing this journey with our patients and families. I want to thank Dr. Short, Jenny, Michael, Liz... thanks for sharing your wisdom. Also, I want to thank Brandon Sutherland from WIN Technologies who helped produce this program, and my colleague Rachael Palm, who coordinated all the details to bring this program to you. We're looking forward to our next community conversation in June. Finally, I will say, Ken, I love you and I miss you. Thank you, everyone.