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Welcome to Yale Cancer Answers with your host Doctor Anees Chagpar. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week it’s a conversation about end of life and palliative care. Elizabeth, I think there are at least some misperceptions about what exactly is palliative care. Can you tell us a little bit about that? I mean it goes all the way back to previous presidential elections when people were talking about death panels. Is that really what we’re talking about? There’s a lot of misperceptions.
Palliative care is a medical subspecialty, that’s really focused on the comprehensive care of patients with serious illness and the support of their caregivers and family members. We’re involved from the time of diagnosis all the way through an illness, whether that’s a terminal illness or whether they’re working towards curative therapy, we’re there to help support the families as well as the patients. Oftentimes we help with symptom management and support, but also with communication support, support for the medical teams caring for the patients as well. So this is not hospice, you’re going to die, let me help you to go blissfully into the good night, right? Tell us about the difference, because I think that people really get confused between palliative care which you said starts at the time of diagnosis and can even be used for people...
who are undergoing therapy for curative intent versus Hospice. So what’s Hospice?
Hospice is care that’s really focused on end of life where a patient’s prognosis is 6 months or less and that’s really focused on the comfort based care of the patient rather than any curative disease. Most Hospice care is provided in the home setting, with families serving as primary caretakers.
Although some Hospice care is delivered in a hospital setting or in a nursing facility or even inpatient, Hospice care is a form of palliative care in that we’re really focusing on the support of patients and families facing serious illness, but Hospice care is really directed towards the end of life and symptom support rather than curative directed therapy. One important thing I think for people to understand is that difference because often people will have pain or they’ll have nausea, or they’ll have some sort of issue or an emotional issue and somebody will say,
maybe you oughta talk to some of the palliative care team. People and people will go, Oh my God, what do you mean? Am I dying? Which is not the same.

You also specialize in end of life and for a lot of patients, especially patients with cancer, that’s something that they don’t really want to think about, but they are forced to kind of think about it. Tell us about what that’s like. When you say I think the patients don’t want to think about it, I think that is in many cases true. But oftentimes patients do think a lot about it and may not have the tools or may not have the comfort level to speak to certain providers or family members about that so in a lot of cases, I feel that we’re having these conversations that families and patients often want to have and may have been thinking of having for a long time, but just didn’t have the outlet or the support to have these tough conversations. And I think that a lot of people are just scared they don’t know what to expect and that makes the conversation very difficult.
So how do you start having that conversation? Each and every patient in each and every circumstance is very different. Obviously there is a lot of fear, and apprehension about care at the end of life, and about confronting end of life. But that isn’t always the case for every patient. There are many patients that I speak to that have very clear wishes about what they want at the end of life, and in particular what they don’t want at the end of life. There are a lot of fears that people are willing to talk about. For instance, fear of uncontrolled symptoms of pain, fears of abandonment, feeling that their doctors or other members of their care team may not continue to care for them if they quote, you know, give up or stop focusing on disease directed therapy, and that’s not at all the case. There’s always support for patients, and there’s always things that we can do to help them cope with their illness, cope with their symptoms, and support them along this really
One of the things that I think people may have fears about is what happens after death. Whether they come from a spiritual background or religious background or not, I believe that may play into that apprehension. Talk about how you broach that topic.

And how exactly does that conversation go? That's a big question.

Maybe one of the biggest questions that we have as human beings, right? And I'm glad you brought this question up because I can talk a bit about the wonderful team with which we work. We have dedicated physicians, nurse practitioners, nurses and also social workers and chaplains, both inpatient and outpatient, as well as a dedicated art therapist and a dedicated psychologist who only focus on patients that are at the Cancer Center, not end of life necessarily, but anywhere throughout their cancer journey. Supporting them in this regard, so many patients do have a lot of
what we call existential distress or spiritual concerns. That’s something that all palliative care providers are adapted at identifying and discussing with their patients. But in particular, we rely upon our spiritual care providers and our social workers and chaplains for those particular needs that patients may present with. That doesn’t mean that patients necessarily have a strong religious belief, or they may not identify it as spiritual or existential distress. That’s sort of our jargon that we use to talk about these things, but you know, fears about what happens next with finding meaning in their life and their current experience is thinking about legacy. You know what’s important to them now? What’s important for them to leave behind and pass forward, and sometimes that presents in anxiety or sometimes that presents in thinking more about the spiritual or deeper aspects of really the human experience. So that’s a big question and we try to
address that on an individual level.
I’ve had many patients that really don’t identify with any particular religion or identify themselves as either, you know, generally spiritual or atheists, or relapsed Catholic, as many people say. But there are many different ways to kind of talk about these things and provide comfort and support and just a shared sense of humanity facing these questions and concerns. and when you talk about, the questions about leaving a legacy. I think the other thing that happens at the end of life that people may be thinking about is relationships, either relationships that require mending things that have happened, that you know have not been resolved, and how to deal with those relationships, particularly as you face the end of life because we all have relationships where there may have been some strain. There may have been, you know, people have fights, bickering or whatever, and then you’re facing this
inevitable event and you may want to find closure in that.

Is that part of what your team can help people with?

How do you do that?

Yes, absolutely. And again, I think when we talk about palliative care we talk about all these kind of larger issues and larger questions.

And when I think about how it’s implemented and how it unfolds day to day, it’s such an individual experience.

So I think one thing that we’re particularly adept at is identifying these relationships. These legacy concerns that people may have. Sometimes they’re linked to physical symptoms. To be honest,

I’ve had patients that you know, their blood pressure goes up, their heart rate is high, they have headaches and day after day you kind of notice there is always a certain time of day when certain people are visiting.

You know what’s going on with those. People they have been hospitalised many, many times and they want to make amends with a loved one that maybe they have been
separated from for whatever reason.

Or want to reconnect with children or spouses or make a lifelong commitment.

We’ve had several marriages in just the past year, both of patients and a family member and just, you know, solidifying that link or recognizing these missing pieces in people’s lives or these important components of closure of legacy for them, and helping to facilitate that.

A big part of that comes into play with children, with guardianship. With financial planning and we actually have a program where we have a partnership with the Yale Law school and there’s a partnership that’s facilitated with the palliative care service and social work where we can help provide some legal systems to patients that may need it, for instance, to help provide assistance with guardianship or paperwork to help give people peace of mind that maybe they’ve been unable to obtain through the usual measures because of illness. Because of repeated hospitalizations.
Helping patients get married in the hospital or helping facilitate a ceremony so that they can really make a concrete demonstration of their family ties and that brings so much peace and closure and that does more than any medication that I could certainly provide. We rely heavily on our palliative team for that, and in particular our social work and Chaplin team. You certainly don’t think of palliative care services as being, palliative care services as being, wedding court. But it is cool that you really do take a holistic view of what are the things that are important in this person’s life, that they want to celebrate, that they want to amend, that they want to get done before the capstone of their life, right? And even thinking back on different capstones that they’ve had in the past. Are they proud of what if they spent their lives cultivating and practicing and what’s important to them? And so I think as physicians, we tend to think about illness and end of life from a very
medical viewpoint as we should.

But really, from a patient perspective and from a human experience, there’s really so much more

I think with palliative care we help obviously with the symptom support with the communication support we have the time to really sit down and delve into these deeper issues and help resolve and support patients at times of crisis.

And great sadness, but also there’s such an opportunity for joy for meaning, and I think that’s what keeps all of us doing what we do.

I was at a conference several years ago now, and it was a career fair for students, and they were thinking about different specialties.

And one of them came up to me and asked me, how could anybody do palliative care and end of life? Because I mean it’s just such a depressing field

and I came back and I asked one of our palliative care physicians about that, and she said, well, the two greatest moments are life and death,
and those are inevitable. And there's something important about being there for patients at those two times, absolutely. I mean, it's truly an honor to be with patients that are going through difficult times wherever they are along their journey of serious illness and certainly at end of life and the way I see it is it's not just about the patient but also about their family and caregiver and what happens after the patients pass and their bereavement. How they look back upon the patient's illness. Did they feel supported? Cared for. Did the patient feel that things went in a way that they wanted things to go. Were their wishes respected, their goals recognized and appreciated and valued. So I know for many people it does seem like a very sad topic and there is a lot of loss and grief. But our team finds a lot of meaning and a lot of joy and we do this because it's a passion. I don't think any of us
woke up
the last day of college
and said, I’m going to be a palliative
we find our way into this field
for a reason and we’re generally
a pretty happy bunch,
We’re going to talk more about
how you care not only for the
patient but also for their family
after we take a short
break for a medical minute.
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This is a medical minute
about colorectal cancer.
When detected early,
colorectal cancer is easily treated
and highly curable and as a result,
it’s recommended that men and women
over the age of 50 have regular
colonoscopies to screen for the disease.
Tumor gene analysis has helped improve
management of colorectal cancer
by identifying the patients most
likely to benefit from chemotherapy
and newer targeted agents,
resulting in more patient
specific treatments.

More information is available at yalecancercenter.org.

You’re listening to Connecticut Public Radio. Welcome back. We are discussing end of life and palliative care and right before the break Elizabeth was telling us that this is really not necessarily a morbid field that part of her job is to really care for and support and at times even bring joy to patients at a really important time in their life.

And it’s not just the patient, right Elizabeth, it’s also, you know, caring for the family and the caregivers.

So talk a little bit about that. Being a caregiver, I think is one of the hardest jobs that anyone can have. Being a caregiver from my past experience, when I think about myself going through medical school and residency and training, I tend to think about the caregiver as the support person that brings the patient to the hospital that picks up their medications, that helps coordinate things and what I’ve learned through personal experience and what I see every day is that this is really an all encompassing job that you can’t really understand until
We recognize that the caregivers are really the most important people in the lives of our patients, and vice versa and try our best to recognize their value, incorporate them into medical decision making, into conversations, making sure we communicate with them and bring in communication from the medical teams as well as just recognizing that essential role that all caregivers play. And really, the extreme exhaustion and fatigue and distress that this job carries with it. I mean, I can imagine watching a loved one face the end of life and watching them go through everything, treatments, symptoms, ultimately facing their demise, it is a harrowing experience for them while they’re trying to be supportive of the person going through it and I can’t imagine what that’s like. So tell me about how you not only try to support the patient and help them with their symptoms and help them to find peace at the end of life and at the same time,
try to help the caregiver who themselves is going through their own grief and sadness, watching the demise or potential demise of a loved one. I think number one is recognizing their role, recognizing their presence, incorporating caregivers into the communication, whether that be inpatient or outpatient, regardless of whatever serious illness their loved one is facing. We really view the palliative care patient experience as that of a patient and caregiver. Sometimes it’s a family of 20 that’s in the patient’s room, and so we recognize them. They are really integrated into the patient’s care. We involve them in our spiritual care in our social work, we involve them in our symptom assessment. We involve them in every single communication and recognize their expertise. They know the patient better than anyone else, and they always will, no matter how much time we’ve been with them in the ICU setting, or how many labs we’ve reviewed, or how far back into their
0:19:34.372 –> 0:19:35.78 record we’ve gone.
0:19:35.78 –> 0:19:37.97 They know the patient best.
0:19:37.97 –> 0:19:42.17 Our social workers also follow
0:19:42.17 –> 0:19:43.229 patients, families, outpatient.
0:19:43.229 –> 0:19:44.994 They have caregiver support groups.
0:19:45 –> 0:19:47.478 They have bereavement support groups as well.
0:19:49.6 –> 0:19:50.924 It’s a hard job.
0:19:50.924 –> 0:19:52.91 There’s a lot of resources out
0:19:52.989 –> 0:19:55.389 there that social work may also
0:19:55.389 –> 0:19:58.182 connect folks with, both at a state and
0:19:58.182 –> 0:20:00.172 local and national level.
0:20:00.18 –> 0:20:02.196 I fill out a lot of family
0:20:02.196 –> 0:20:03.204 medical leave paperwork.
0:20:03.21 –> 0:20:05.569 Even though any physician can do that,
0:20:05.57 –> 0:20:07.761 but it is time intensive and it’s
0:20:07.761 –> 0:20:09.484 something that many people don’t
0:20:09.484 –> 0:20:11.294 think about until they’re kind
0:20:11.3 –> 0:20:13.326 of asked,
0:20:13.326 –> 0:20:15.678 because they can imagine that you know,
0:20:15.68 –> 0:20:17.696 while the caregiver is the caregiver,
0:20:17.7 –> 0:20:19.728 the caregiver is also the patient.
0:20:19.73 –> 0:20:22.089 Who is a different patient,
0:20:22.09 –> 0:20:24.435 but you know somebody who is also
0:20:24.435 –> 0:20:26.514 going through their own form of
0:20:26.514 –> 0:20:28.524 depression and their own form of
0:20:28.524 –> 0:20:30.507 internal pain and their own issues,
0:20:30.51 –> 0:20:32.598 which only add to the plate
0:20:32.598 –> 0:20:33.99 that they’ve already got.
0:20:33.99 –> 0:20:35.45 That’s already overflowing with
0:20:35.45 –> 0:20:38.006 all of the issues that they have
0:20:38.006 –> 0:20:40.56 to deal with for their loved one,
right? So, recognizing that this is a group effort, not any of this, caregiving is not a single person’s job. And there’s a team of people to help support every patient and every caregiver and if it’s a situation that isn’t safe for their patient or isn’t safe for the caregiver, I’ve had so many caregivers breaking an arm break a leg, they haven’t slept in days and we need to recognize it. You know everyone needs to be cared for here. This is not a one person job. This is a marathon, not a race. And there’s a team of people really here to support you and in the hospital we have a lot of resources, of course, but we also help coordinate outpatient support as well, whether that’s home health aides, visiting nurses, home care, home Hospice support, medical equipment hospital beds, commodes, things like that that will make caregivers lives easier when they leave the hospital. What about your personal health, right? Because as a member of
the palliative care team,
I can imagine how emotionally invested you
are in your patients and how exhausting
just from an emotional burnout perspective
that can be helping all of these patients
and their families with their medical issues,
their symptom issues.
Their emotional issues.
That must be exhausting.
It can be exhausting.
I will not lie.
I think all of us in medicine and
many other fields we work
a lot of hours
and do a lot of good work.
I think it’s important to take breaks
to step away every now and then,
but I think for me one of the key
things that help prevent burnout and
helps with provider and caregiver well
being is I find so much meaning in my
work and a lot of joy in the work that I do.
So seeing a patient that was
in just insufferable pain,
unable to walk,
having trouble eating and drinking,
and two days later he’s up
and walking the halls,
passing me by as I do my notes and
those sorts of things just bring me so much
joy and we do really great work every day.

So that makes the job easier in a lot of ways and I think many people on my team feel the same way.

So it’s intense and it’s important to take time away and whether that’s time with family, doing things that I enjoy outside of the hospital, spending time with people that I enjoy that are on my vacation, I do enjoy time with my patients and my colleagues, of course, but I do find a lot of meaning in the work I do every day.

So on one hand it is very challenging work and it’s important to recognize the potential for burnout. But at the same time I think my life without this work would be significantly lacking. So I enjoy what I do and I know my colleagues feel the same way. That’s so important. We talked a little bit about making sure that when people pass away their wishes are fulfilled in and that they find closure,
kind of put the finishing touches on the things that they wanted to do. Tell us about preparing for end of life because it’s certainly not something that we all like to think about or talk about. And you had mentioned that one of the services that you have, in the myriad of services, was a partnership with Yale Law to help with legal documents? But what kinds of things should people really be thinking about before? Looking at end of life because we all know that it’s coming at some point. It’s coming and we may not want to think about it. We may think that it is, decades and decades and decades away. And so we don’t think about it. But what things should we be thinking about and talking about with our families? I think there are two perspectives to take when you think about preparing for end of life. So there is the caregiver perspective and sort of the practical legal power of attorney perspective, and that’s a hard job.
0:25:16.5 –> 0:25:18.6 so there’s that perspective,
0:25:18.6 –> 0:25:19.88 the more practical sense.
0:25:19.88 –> 0:25:21.48 And then there’s really the
0:25:21.48 –> 0:25:22.799 patient focused perspective,
0:25:22.8 –> 0:25:24.9 which I think is highly individualized.
0:25:24.9 –> 0:25:27.35 So in terms of the patient perspective,
0:25:27.35 –> 0:25:29.42 each and every patient is different
0:25:29.42 –> 0:25:32.658 than what I try to do is just normalize
0:25:32.658 –> 0:25:35.4 whatever is important to them at that time.
0:25:35.4 –> 0:25:37.983 So when patients face their
0:25:37.983 –> 0:25:39.948 mortality or nearing end of life,
0:25:39.95 –> 0:25:42.05 every patient has a unique story.
0:25:42.05 –> 0:25:44.768 Some people are really fixated on, and
0:25:44.77 –> 0:25:46.818 I had one patient who he managed all
0:25:46.818 –> 0:25:48.439 the practical things for his home.
0:25:48.44 –> 0:25:49.488 Everything outside
0:25:49.488 –> 0:25:51.06 of the home was his job.
0:25:51.06 –> 0:25:53.055 Everything inside the home was his wife’s
0:25:53.055 –> 0:25:55.325 job and he said I need to teach her
0:25:55.325 –> 0:25:57.344 how to use the snow plow and this
0:25:57.344 –> 0:25:59.585 was a really key thing for him and I
0:25:59.585 –> 0:26:01.796 thought it was so touching that this was
0:26:01.8 –> 0:26:03.896 how this man lived his life.
0:26:03.9 –> 0:26:05.514 These were the people that he
0:26:05.514 –> 0:26:07.3 cared about and this was his job.
0:26:07.3 –> 0:26:08.874 And
0:26:08.874 –> 0:26:10.97 it may have seemed silly
0:26:10.97 –> 0:26:12.796 to some other people in his life,
0:26:12.8 –> 0:26:14.585 but for him this was really important
0:26:14.585 –> 0:26:16.707 to make sure. He already had all the
0:26:16.707 –> 0:26:18.729 financial things and all the other things.
But his wife needed to learn how to use a snow plow. For other people, it’s a physical legacy, right? So I want so and so to have my wedding ring I want so and so to have my boat, for other people it’s personal physical items that they need to worry about other people. They may have already thought about these things, I’ve paid for my children’s college. but I haven’t really thought about myself and what I want to leave behind or what I need to process so every individual is different. There was a gentleman I took care of many years ago in a very far away place, but he was passing away at a pretty young age and it had a really diverse, exciting life and traveled extensively, he helped plan itineraries for trips that he wanted his family to take that were meaningful for him. This is where I studied abroad. This is where I had my first internship. This is the coffee shop that I used to study at back in wherever and so that was important to him, and we helped him facilitate writing all of these things down and
documenting them.

Everybody is different and I think I try to educate caregivers and family members to respect whatever it is that is important to their loved ones.

So even if you’re kind of rolling your eyes like I don’t care about all of your passwords, I don’t need to know the last four of every bank account.

But for some people, that’s just what they need to process.

I liken it to when you have that nesting instinct when you’re very, very pregnant, you just need to clean out whatever it is you need to clean out. Otherwise you’re going to go crazy.

Support them and normalize that itch, whatever it is.

For people as a caregiver, I was medical and legal power of attorney for my mother, and it was sort of a crash course in all of this.
write down all those passwords.

Keep a running log of all that important information because it is a boatload for people to take care of both if patients are diagnosed with serious illness or unable to participate in medical and financial decisions. I view it from a caregiver perspective and inpatient perspective, but there’s no right or wrong way, and there’s no one way to do it, certainly.

Dr. Prsic is the director of the Adult Palliative Care Program, an assistant professor at the Yale School of Medicine. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at Yalecancercenter.org. We hope you’ll join us next week to learn more about the fight against cancer. Here on Connecticut Public Radio.