

## Accessing Palliative Care



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**Libby:** Finally, I wanted to circle up and talk about accessing palliative care. I think patients come to palliative care through a number of different mechanisms. What that means is while there's not one right way, that means there's no wrong way.

When thinking about outpatient palliative care, depending on one's insurance, it's possible that a referral could be needed. But oftentimes that is not the case anymore, which is great. Still, I think if you have a primary care physician or an oncologist of either medical radiation, urologic, et cetera, talking to that provider is a great starting place. Just ask for a referral. They very well may have people with whom they are already collaborating and they can get you referred to that team and get you established.

Also, there's a resource, which is a website provided by CAPC, which is again the Center to Advance Palliative Care, called [getpalliativecare.org](https://getpalliativecare.org), a simple enough name. This is a way that you can let your

### How to connect with palliative care?



- Outpatient
  - Your primary care or oncology team are a great starting place - ask for a referral
  - Let your fingers do the walking: <https://getpalliativecare.org>
- Inpatient
  - Typically, if someone is hospitalized their main medical team will need to request any/all consultations on their behalf, including palliative care.
  - However, if it's something you want or need, just ask your medical team
- At home
  - Home palliative care is variable - some areas have great home palliative care and some do not
  - However, if your area is lacking, you can always go to [www.prepareforyourcare.org](http://www.prepareforyourcare.org) to begin educating yourself about some important conversations, and then discuss with your PCP or oncologist

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fingers do the walking, to investigate what resources may be nearby or perhaps nearby a family member or a loved one who you think might benefit from palliative care.

I will warn you this is not all-inclusive, and I'm embarrassed to say this, but my own outpatient palliative care team, which is quite a large one, to be perfectly honest, compared to many institutions, with five outpatient palliative care physicians, three nurses, and an administrative person, our team is, embarrassingly enough, not listed on [getpalliativecare.org](http://getpalliativecare.org). I don't know why that is. Although after realizing that in the past few weeks, I certainly will fix that.

But one thing that I would recommend is that if you see an inpatient palliative care team listed at the institution with whom you or a family member, a loved one, et cetera, gets your care, you could certainly inquire with that team to see if they have outpatient palliative care resources. If their program's anything like mine, they may say yes and be able to direct you there.

On an inpatient basis, I will say I do think that often the primary medical team is the gatekeeper for consultation. I think that if a patient requests a palliative care consultation for more support, I think it's pretty unlikely that they would decline to place that consult. But it may be something that you might have to ask for because inpatient palliative care consultation is rarely done automatically for hardly any patient population.

Sometimes it is within the context of a study, and there are some programs, for example, a clinical transplant team, that sometimes people do get automatic consultations, but it may just be something you have to ask about. Even talking to your nurse, physical therapist, your social workers, your inpatient case manager, anyone who's really a part of the medical team could probably help communicate with your primary medical team about that consultation.

Thinking about home palliative care, this is more variable. It's really interesting. I think it doesn't just have regional variation. It really has variations depending on the metropolitan area. There are some home palliative care services that are available. Often they're a part of a hospice organization. Sometimes you just can get access to palliative care at home, but sometimes not.

What I would say is that if you have interest in some of the conversations that palliative care might lead to. For example, thinking about your goals, thinking about your values, thinking about documentation that you might need, like a power of attorney or a living will, an advanced directive.

There's this wonderful resource that I listed here for you called [prepareforyourcare.org](http://prepareforyourcare.org) that has not only educational videos in English and Spanish, but also a link to, within the United States, the state-specific forum for a lot of these important medical decisions that might need to be communicated. For example, a healthcare power of attorney. It's pretty cool. As of the spring of 2018, every state had documents that were directly linked to that.

If you were to go to [prepareforyourcare.org](http://prepareforyourcare.org) to educate yourself or a family member or a loved one, then that would spark great conversation with your primary care physician, your oncologist, anyone else that's an important part of your healthcare team, also your family members. Consider [prepareforyourcare.org](http://prepareforyourcare.org) as another resource either instead of or in addition to meeting with someone depending on what your local resources are.

I know a lot of Boy Scouts in my life, and so I think that it's important to be prepared whenever possible. I want to give a little bit of anticipatory guidance based on what I've experienced. Specifically, I just want to mention that there are still lots of misconceptions about palliative care, including and especially among medical professionals.

I think the reason I bring that up is to tell you that sometimes you could be the person in the room who has the most knowledge about palliative care, even after you've listened to this webinar. I mean that very seriously and literally.

What that could mean is if you ask someone for a palliative care consultation, that provider might have a misconception about palliative care, conflating it with hospice and would say, "Oh, you don't need that yet. You don't want palliative care cause we have lots of treatment options available to you," or something along those lines.

I think, again, what that means is not necessarily that it's not actually an appropriate set of resources for you because if you've made it to the end of this, then you know that it's just for people who have a serious illness, any age, any stage.

What that means is that you should not be deterred. You get to be the educator and educate your provider. Well, I can imagine that, being on the other side of the stethoscope, it could feel awkward to ask for something anyway. I think doing so really could result in educating your provider when you could say, "Well, I understand that I still have treatment options available, and I'm so glad, but I'd like a consultation anyway," or even by further educating your provider and saying, "I've been reading about it and it looks like it's for anyone with a serious illness. How about this? Put in a consult and I'll report back to you and tell you how it goes."

The truth is that your doctor, your advanced practice provider, we work for you, you're the boss. If it's something that seems important or helpful, it's okay to ask anyway. But self-referral is often possible, too.

In conclusion, so we can get to your questions, palliative care is a pretty holistic medical care focused on quality of life for anyone facing a serious illness. It's appropriate for any age, any stage in a serious illness. It can and often should be given alongside standard, even really aggressive urology and oncology care, even with the intent to cure. The hospice is a special form of palliative care that's limited to people who have a life expectancy of six months or less.

## Be aware . . .

- There are still many misconceptions about palliative care, including among medical professionals.
- This sometimes leads to providers reacting by saying, "It's not time for that yet," or "You don't want palliative care, you still have treatment options available."
- If this occurs, do not be discouraged. This just means that you get to be the educator!
- If you think palliative care would help you, it's ok to ask for a referral anyway. Remember, ***your doctor works for you!***
- You could consider clarifying by saying, "I've been reading about it and it sounds like it's for anyone with a serious illness. I don't want to change anything else, just add another layer of support. I'll report back about how it goes!"



Also, palliative care has a potential to improve outcomes that are really meaningful, like quality of life and symptom control. There's great palliative care research that's ongoing and will continue to be. I think if I have anything to say about it, there will be increasing palliative care research at the intersection with bladder cancer, and that you can find nearby palliative care providers with [getpalliativecare.org](https://getpalliativecare.org). Now I think we can probably open it up to questions that Stephanie will curate.

## Conclusions

- Palliative care is medical care focused on quality of life for patients facing a serious illness.
- Palliative care is appropriate for **any age and any stage** in a serious illness.
  - Can be given alongside standard and even aggressive urology care, including surgery, radiation, chemotherapy, etc.
  - Hospice is a specific form of palliative care limited to those with a life expectancy of  $\leq 6$  months

## Conclusions

- Palliative care has the potential to improve outcomes that matter to you, like quality of life
- Exciting palliative care research is ongoing and the field is evolving rapidly, hopefully including research at the intersection of bladder cancer and palliative care
- You can investigate nearby palliative care providers and resources at <https://getpalliativecare.org>

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