# Demystifying Palliative Care (Supportive Care)

Palliative care is often confused with hospice. Very few people are aware that palliative care deals with the quality of life of patients who have a life threatening disease. This would include psychological, social problems in addition to preventing or treating the symptoms and side effects of of disease or treatment. We are talking to Shirley Otis-Green, Clinical Director of Consulting Services with the Coalition of Compassionate Care of California to demystify palliative care and understand the various aspects that are involved.

**Full Transcript:**

**Priya Menon-** Good afternoon, everyone, and welcome to CureTalks. I am Priya Menon, Scientific Media Editor of CureTalks joining you from India. This is CureTalks' 113th episode. On CureTalks today, we are talking about demystifying palliative care; and on the panel we have Lori Puente who is a myeloma caregiver to her husband, Dave, who was diagnosed in 2008. She writes an excellent caregiver blog called Riding The Wave. We also have Liz Salmi who is a brain cancer survivor, blogger, and Director of Communications for The Coalition for Compassionate Care of California, a non-profit organization dedicated to making sure all people with chronic or serious illnesses receive education on advanced care planning and have access to high-quality, patient-centered palliative care. Next on the panel is Cynthia Chmielewski, a multiple myeloma survivor, advocate, and member of the Philadelphia Multiple Myeloma Networking Group. She is a trained mentor and participates in several online communities. Today's co-host is Gary Petersen, multiple myeloma survivor, advocate, and editor of myelomasurvival.com. Gary is very active in several online myeloma communities. I extend a very warm welcome to the panel.

**Priya Menon-** Recent studies suggest that medical care for patients with advanced illness is characterized by inadequately treated physical distress, fragmented care systems, poor communication between doctors, patients, and families and enormous strains on family, caregiver, and support systems. Palliative care focuses on relieving suffering and achieving the best possible quality of life for patients and their caregivers. Palliative care is often confused with hospice. Very few people are aware that palliative care includes dealing with psychological, social problems in addition to preventing or treating the symptoms and side effects of disease or treatment. We are talking to Shirley Otis-Green, Clinical Director of Consulting Services with the Coalition for Compassionate Care of California to demystify palliative care and understand the various aspects that are involved. Shirley is also a research consultant for psychosocial oncology specialization program at the University of Louisville, Kent School of Social Work, and the Founder of Collaborative Caring. Shirley's educational research and consultation efforts focus on quality of life, palliative care, leadership development, and the creation of meaningful organizational change. Welcome to CureTalks, Shirley, great to have you with us.

**Shirley Otis-Green –** My pleasure! Thank you so very much for this opportunity.

**Priya Menon-** I'll now hand over to Gary to begin with the discussion. Before that, I would just like to remind the listeners that we have…, we will be addressing questions sent in to us at the end of the discussion. If you have a question you would like to ask, please press 1 on your keypads and we can bring you on air to ask them. You can also email the question to priya@trialx.com or post the question on curetalks.com. With that, its over to Gary. Gary, you are on air.

**Gary Petersen –** Yes. Thanks a lot and Shirley Otis-Green, you have the most initials after your name of anyone I have ever seen. (Laughter) MSW MA ACSW and OSW-C, which is Master's of Social Work, Master's of Arts, Academy of Certified Social Workers, and Oncology Social Worker Certification. So, I…, I think you won by at least four or five letters.

**Shirley Otis-Green –** The more letters, the more sign of security.

**Gary Petersen –** Well, I would say probably, is this your first year out of school?

**Shirley Otis-Green –** As it turns out, no.

**Gary Petersen –** Okay. In any event, thank you so much for being with us today because I know that, you know, I can’t speak from a position of ignorance on this subject. So, I apologize for that, but I do know that in my own writings, I wrote about, you know, a good defense is as good as a good offence and I can’t remember, it was like Yogi Bear or somebody like that said that that offences, Bear Bryant it was, offenses fill the seats, defenses win championships and palliative care and supportive care is what I have come to understand it to be in some respects that supportive care is just as important and…, and not like if you would clear up something for me and I am sorry even I have to ask this question, but I’d always thought that palliative care was, you know, the same thing as hospice. So, could you please explain the difference for me and for the audience as well? What is the difference between hospice and palliative care?

**Shirley Otis-Green –** Well, thank you so much for asking. I think for many of us these are words that we may not be that familiar with or if we become familiar with them, we may not have a deep and full understanding even if there is a slight familiarity. I love to think of palliative care in a broader sense…, in a broader term really and its about improving quality of life, addressing the psychosocial, spiritual, physical, emotional needs that a patient may have and looking at the multi-dimensional aspects of suffering from an inter-professional approach and so what that means is its always a collaborative team effort. Palliative care is best understood as a team sport and so be able to have…. I am sorry?

**Gary Petersen –** Yeah. So, its palliative care, I thought it was palliative. I’m sorry I was saying wrong.

**Shirley Otis-Green –** No, you know, not at all. I think its a tomato-tomato sort of thing. I think just the regional differences come in. So, I don’t think there is a right or wrong to the pronunciation, that’s it. I am from Minnesota, so I say lots of things funny.

**Gary Petersen –** Oh, you are from Minnesota?

**Shirley Otis-Green –** Minnesota.

**Gary Petersen –** Minnesota. Okay, go on. I am sorry. I am from Wisconsin, so I understand.

**Shirley Otis-Green –** Oh, Wisconsin. Yeah.

**Gary Petersen –** Wisconsin. Yeah. From Milwaukee. Near Milwaukee.

**Shirley Otis-Green –** Nice! Nice! We have a lot in common. I can see.

**Gary Petersen –** Here you go.

**Shirley Otis-Green –** But, I think if we think of palliative care as that broader construct, I think hospice then is a subset within that or a philosophy and an approach to care within the…, the larger confines of palliative care. So, palliative care can be thought of as an extra layer of support and its something that’s appropriate for a patient or their family to receive concurrence with their disease-modifying treatment. Its something that can be simultaneous to getting chemotherapy or radiation treatment or whatever the…, the physician might be recommending for any person who has a serious illness. Hospice, on the other hand, is something that’s more appropriate for a person who might have terminal diagnosis of less than six months to live and we can think of hospice as, in the US at least, as defined as a Medicare benefit and so its really a kind of transition in the approach to care. So, a person no longer is likely to be receiving chemotherapy or other disease-modifying treatment when you are on hospice, but you can have palliative care simultaneous to having those treatments. So, palliative care is the larger, again a broader term and hospice would be for a smaller subset of people who have more advanced illness. Does that help or does that muddy the waters a little bit?

**Gary Petersen –** No. No. Its… No, it certainly does to kind of explain it. Can…, can palliative care or palliative care, tomato-tomato, can it be considered the same as supportive care or is that element of palliative care as well?

**Shirley Otis-Green –** I think…., I think what has happened is that because that term “palliative care” was kind of popularized really from our friends in Canada and they took that term and began using it and the field, you know, has adopted that term, but its not a word that comes to the New York, you know, a US person’s tongue, for sure and so there has been… Unfortunately for some people who may just hear the term, it would often label their illness and it became conflated with hospice care or end-of-life care and so as a reaction to that, a lot of programs might call their service supportive care or comfort care. You’ll hear all kinds of different phrases, though they are usually synonyms for palliative care and just have maybe been used because people were confusing that term and weren’t sure how to pronounce it or how to spell it or what it meant and so, you know, created a term that they thought might be more user friendly.

**Gary Petersen –** Okay. Thank you. I was treated at a multiple myeloma center. I have…, I have cancer and they had a world class supportive care program with a Director that would actually head the whole thing and…, and that included teaching me and my wife who is my caregiver what we needed to do during transplant, recovery, and post transplant and, you know, it is something, at least the education of my wife since I thought I was going to do okay, ended up saving my life and…, and as a result, you know, I definitely see the need for that and that’s why I asked that question with regard to supportive care, but one thing that we have, you know, at least a lot of cancer patients have is, you know, the threat of the life-threatening aftermath of treatment, meaning that, for example, part of my supportive care was, I took an antifungal, an antibiotic, and an antiviral and I had provided as a, you know, a replacement for my immune system, which was basically gone for a while. So those are the kinds of things that myeloma patients and even cancer patients in general need to support them during this time and not really something that’s part of this palliative care. Is that correct?

**Shirley Otis-Green –** Right. So, the goal of palliative care is to improve quality of life and improve function and so if its not about the…, the disease-modifying treatment. Those are the fancy stages that your doctor might use, so its not about trying to cure the illness. Its about trying to help the person to have the best possible quality of life while they are trying to cure the illness and so palliative care is all about symptom management and being able to look at what are the longer-term impacts of the treatment options that might be going on and being able again to be that active layer of support for the person and their family members that again have that person in the context approach. You mentioned your caregiver was a big part, of course, of your getting through that experience and that ordeal and so, the supportive care team or palliative care team is going to look at not just that patient’s needs but the family’s needs as well and be a support and liaison for them with the rest of the treatment activities that are going on and if you suggest being able to be part of the longer-term followup because many people are like yourself, they go through the treatment and, you know, are, you know, going perhaps decades in the survivorship and still struggling though, perhaps with some of the fallout from those original treatments and the palliative care team can…, can address pain management and…, and other symptoms concerns throughout that whole process.

**Gary Petersen –** Okay and with regard to just cancer patients or, you know, who have transplants like a lot of blood cancer patients, you know, often times they don’t die from the disease. They die from infections and internal bleeds and specifically with regard to my own disease, that’s the case. How would palliative care help prevent these conditions from ending our lives?

**Shirley Otis-Green –** Oh, that is really important question. One of the things that we kind of assume is that palliative care would necessarily be associated with an extension of a person’s longevity, but it turns out that there are now numerous studies that show in fact that having a good quality palliative care service on board early to support the person dealing with the quality of life concerns, pain management, symptom management needs that they might have, not only helps improve their quality of life and, you know, it makes them feel better as they are going through the process but actually helps them to live longer. Some of those early studies that have come out now from 2010 and subsequently since then were done with cancer patients. Lung cancer patients were some of the first that showed all kinds of…, of dramatic results, but it was really… Its not surprising, in fact its kind of intuitive really when you think about it as a lay person, it makes sense. Right? If we feel better, we actually can be perhaps more engaged with the treatment. We can have the treatment go longer and…, and, you know, deal with it better and so we can get the full…, full benefit of the treatment and it also allows us if we feel better to be able to exercise more and…, and that helps us to ward off infections and…, and again they have just better health overall and that is certainly related to longevity. So, I think that the connection with palliative care and length of life is again becoming ever clear for different types of diseases and illnesses and that's a great benefit obviously of…, of looking at palliative care and talking to a physician team about adding that to the mix of the care that a person is receiving.

**Gary Petersen –** Oh, thank you very much for that. I know its very, very important for a lot of cancer patients, so, you know, that kind of support from, you know, after the initial treatment is very important to keep this going. So… Yeah.

**Shirley Otis-Green –** Right.

**Gary Petersen –** What I would like to do now is turn it over to our panel of very talented and experienced panelists. Would you like to start, Lori Puente?

**Lori Puente –** I would, Gary. Thanks for having me on again on CureTalks. Its always such an honor. Can you guys hear me okay?

**Gary Petersen –** Yeah. We can hear you great, Lori.

**Lori Puente –** Okay, great! Shirley, its just so heartwarming to hear all of this, I have to say. I also am one of those that has been very confused about palliative care because in 2001 in dealing with my mother's cancer and hospice care, palliative care and hospice was used in the same sentence, you know, would you like one…, one or the other and that sort of…, sort of situation, right, and at the time it was presented palliative care in the hospital versus hospice at home. So, it wasn't even really… It may have just been the evolution of…, of and that was 16 years ago almost. You know what I mean, its obviously evolved and as I have come to kind of been curious about it, it seems as if hospice used to be the umbrella that palliative care was under and now its more like palliative care is the bigger umbrella that hospice is under and so, I think I got that right and I think you actually did a great job of clarifying that with Gary's questions. Is that basically my correct understanding?

**Shirley Otis-Green –** I think you gave several good points in that, Lori, and not to beleaguer the history too much, but the modern hospice has developed some…, Great Britain in England, some years back and it was really a reaction to the medical invasion of that, but that's it. You know, obviously if you look back just a few more generations, you know, most people would have died at home and most physicians would have been palliative care physicians. They would have been coming out to the home and think of the kindly doctor or midwife or, you know, whoever would have been involved from that village or small community to the, you know, kind of almost lay folks, you know, in the medical field who did come and offer comfort and support to the patient and family in their home and…, and try to help them to feel better, dealing with whatever they were facing and knowing that whether they got healed or not was "in god's hands" and not in theirs and as the medical world became more scientific and more rigorous and there were more treatment options and, you know, more recently there was a medical invasion of physicians and…, and their training and teaching and then it became more likely to be in a hospital setting and there were great strides made in terms of people which would have previously perhaps resulted in their death now having the potential for cure, longer life and those are great things, but unfortunately, physicians, the medical world has lost sight of some of the benefits that palliative care had always offered and…

**Shirley Otis-Green –** …so with that medical invasion, there was a reaction that resulted in the hospice movement and that became more focused on care outside of the home and addressing the needs of the actively dying and saying, you know, we need to make sure that…, that we don't lose sight of the whole person, you know, that's going through this illness even if we can't cure the disease and so as you suggest, hospice was, you know, kind of the, if you think of a pendulum, you know, that was kind of the farther swing of the pendulum away from care in the hospital to care at home and that was hospice and then again if you suggest a few years of…, of that, there is the recognition that it shouldn't be an either/or. That kind of a crazy construct, you know. It shouldn't be, you get your care in the hospital, we are…, we are not really caring about you as a whole person. We are treating the liver in 206 and it was like…, or you get, you know, Mrs. Smith gets her, you know, care in her home and in your community, but why is it an either/or and so…

**Lori Puente –** Right.

**Shirley Otis-Green –** …palliative care was attempting to straddle both and have a foot in both sides and to have an academic and research and evidence informed practice, guiding the management of the care and recognizing that again there is this whole person around the liver in room 205 and then you are able to say, we can provide care in inpatient setting congruent to the care that they might be getting otherwise, but we can also do this in the home or in the community and that's from where the focus is moving now, is palliative care in a community setting. So, the good news is that it really is meant to be the best of both worlds and to be able to be the.., the…., again the overarching umbrella to whatever…, whatever the setting or the situation that the patient is in, to be able to offer that relief of symptoms.

**Lori Puente –** Wow! Its…, its like a resurrection. You know, my grandfather was born at the turn of the last century and his father was a cigar maker in the rural…, poor rural area of Tennessee. He was 6 and they were six boys and it was the community that came and checked on the family every week a couple times a week and took care of them and they truly had food because the…, the wife was taking care of him and it took, you know, diabetes which most people didn't even know that was then and there was no treatment and its interesting to hear how we are kind of coming full circle, you know. We…, we leave…, we leave the lay person and the midwife and the country doctor for big medicine and then suddenly we find that big medicine really can't address those other areas that are very important. So, this is really…, this is really wonderful and I, like Gary, my husband was treated back East where the care in the institute in the facility was almost like palliative care. You know, I have my doctor's telephone number, his direct line, his APN's telephone numbers and direct lines and emails and a home nurse and a 24-hour, you know, hotline and, you know, and then I come home to California and I have to, you know, beat my way through the dins at the door to be able to get communication to someone that will help me and its frustrating. So, its almost, I feel, as we may be heading in to more treatment for my husband who is in a relapse situation that I may be wanting to set up a palliative care team for us when we are in Sacramento because I don't really feel like I need it when we go back to the center because they seem to be set up for it and so, with that in mind, how does a person get a palliative team together even if its just temporarily for the recovery period of a major treatment, you know, modalities and so forth? How…, how do you even begin that process?

**Shirley Otis-Green –** Great question. So again, you know, I…, I just want to reach out and say I am sorry about the relapse. I think you have been…

**Lori Puente –** Thank you!

**Shirley Otis-Green –** For me, the really important point as a caregiver or as a person who is, you know, dealing with a thousand issues, one would like to think that you wouldn't have to also be reaching out to find the right care for your…, your loved one and yet, as you all know, so recognizing that I think engaged patients who are engaged from a caregiver, the best strategy is literally to ask to say, you know, I…, you know, today I was listening to this webinar. I was talking to the friends and family. I have heard the term palliative care. Does your program offer palliative care service and if so, how do we connect with them? Unfortunately again, I think being your own advocate is the best advice that I can give. I would like to think that every patient in the future… Our Coalition works really hard with the goal being that in the future a patient who is diagnosed with a serious illness is going to have a palliative care service as, you know, as part of the normal way care is delivered, that there is going to be access to these care providers and that we are going to do a better job of being able to make sure that the main, we might call it making air quotes here, but we might call generalist palliative care that those…, those skills are taught to the generalist care providers so that, you know, again having good communication skills and being able to, you know, have a supportive team present that that isn't something that's reserved only for people who again have the most severe symptoms and the most complex medical situation. You know, ideally… Sorry?

**Lori Puente –** It does seem as though…, it does seem as though it would unburden the APN and the physician that are meeting with you to set up your treatment, right, and unburden the infusion nurses because now you are sitting there a week later with a bunch of questions that you didn't have at the time…

**Shirley Otis-Green –** Right.

**Lori Puente –** …you were in the doctor's office and so you are trying, you know, their kind of a captive audience because they are treating your loved one and you are, you know, struggling with things that you want to know. I know as a very engaged caregiver and when I go to the big center, I am part of the team. When I come home, I am kind of viewed a little bit as an interloper and it took me a long time to do the Lori schmooze to be able to impress upon them the fact that I am…, I trust them and I acknowledge them, but I think this thing I finally got through to them was I said, I only have one patient and I am an expert. You have a whole bunch of all different kinds of diseases and treatments that you are dealing with. So, I am not asking you a question or asking for some service from you out of the blue. You know, I have done my…, I have done my due diligence and it took a while to where, you know, the doctor was continually backing me up that they finally come up and ask me now, but…, but and I…, and I get it, but it would have been so much easier if I had a terminal, if you will, a person that I could have been in communication with that could…, that they knew that was part of their system, right, and said, oh, well, you know, if Shirley's involved with Puente, she's asked us to, you know, run his blood panel before they start or, you know, those kinds of things.

**Shirley Otis-Green –** Right.

**Lori Puente –** Its like a palliative care person could unburden the medical care team of the stuff they are doing, you know…

**Shirley Otis-Green –** Absolutely.

**Lori Puente –** Yeah. So, would you say that the person…, the first person to ask might be…, to ask if there is a social worker at the hospital, that's another thing a lot of people are unaware of, that there is usually a social worker at the hospital and if its big enough, there is an oncology social worker and I learned that…, yeah, I learned that back at the big facility because it was actually one of our consultation stops because we had to meet with the social worker and I was like, really, you know, and it was like, it was refreshing. It was, she was there to advocate for us and here's my card and my number and here are multiple places to stay and do you need any financial help and you know what it means, she took care of all those things that you worry about. That's not the job of your doctor.

**Shirley Otis-Green –** Exactly! Again, its that team approach that…, that really is the hallmark of palliative care, that they try to, again the literature and the research that's being done is trying to piece out, what…, what are the qualities that make this so powerful. What is it that makes this more effective and really useful for patients and family and then can, you know, lead to such good results and…, and certainly one of the things that keeps consistently coming out is the…, the team approach because what you have already mentioned in terms of being able to have a liaison, have a facilitator, have a navigator and making air quotes on all of those terms, but having someone that you know you can reach out and touch base and who can follow you across settings and time, that's so powerful…

**Lori Puente –** Its very powerful.

**Shirley Otis-Green –** …lost in the system, making sure that you have access to the resources that you need. Sorry?

**Lori Puente –** And you are right and there are times when I am very certain about what's occurring with my husband but he is not and he just wants me to check. You know, he wants me to take that extra step and then if I don't really have to go bother, I have to go through two people to get to the APN, to get the question answered and I know what she is going to say because I already know the answer…

**Shirley Otis-Green –** Right.

**Lori Puente –** …but, it…, it would be nice to have that person that…, that they are more willing and they understand that there are these concerns and these fears and these uncertainties that may be for the caregiver and maybe for the patient, maybe both or…, or in this case just one and its that extra person that my husband sees that is credentialed, you know, this is the person. This person is a nurse. This person is a doctor, you know, and it just helps him to validate what I am saying and anyway, one other thing, so ask a social worker at the hospital I guess or ask a nurse and then the other thing I wanted to know was, an alternative to the next person, but I wanted to know, do palliative care personnel have extra training in that area?

**Shirley Otis-Green –** Well, I love that question.

**Gary Petersen –** Lori, so that first piece was one question?

(Laughter)

**Gary Petersen –** You are my Lori Puente.

**Lori Puente –** I…, I didn't know I was limited, Gary.

**Gary Petersen –** No, well, you know, to the hour, we got to give Liz and Cindy some time.

**Lori Puente –** I know. I know. Okay.

**Gary Petersen –** Could you please…, could you please answer her last question and…, and we will make it short…, shorter than the first question.

**Shirley Otis-Green –** Again, I…, I so appreciate you highlighting the social worker and to your point in regard to training, that's again what the Coalition works really hard to try and do is to offer training so that…, that people are not misidentifying themselves as the palliative care when they may not have expertise and extra training in that, but it is definitely its own professional field. A physician can be board certified in palliative care. There is a board certification for nurses. There are certifications for social workers. There's even now certification for chaplain. So, it is a subspecialty of the field in and of itself. I am…, I am fortunate to be the…, the co-editor of The Oxford Textbook of Palliative Social Worker. There is literally a body of knowledge there. You know, there's books and articles and…, and expertise that we expect someone to have before they call themselves that, but unfortunately people in some circumstances or situations may say that they have a palliative care team when it really is just a doctor or just a nurse, sometimes it is not even different disciplines and they may not be board certified or have special training. So, that's kind of a caveat to the beware circumstance, but yes, on to the next question.

**Lori Puente –** Thank you, Shirley.

**Gary Petersen –** Lori, thank you so much and you are so intelligent and asked those great questions. I find it very difficult to…, to bring it to an end, but I…

**Lori Puente –** No, I was…, I was ready to come to an end.

**Gary Petersen –** Okay. Thanks, Lori.

**Lori Puente –** Thank you, Gary.

**Gary Petersen –** As always. Okay. Liz Salmi! Liz, welcome to CureTalks and welcome to the palliative care conversation. Are you there?

**Liz Salmi –** Thank you. Yes, I am here. Thank you for having me and this is, like you said, my first time on this chat. So, I am very thankful to be a guest and I see most of the other patient guests are from the myeloma community and so I am here representing two perspectives. One, I am a brain cancer survivor. I have been living well with brain cancer for the last eight years and I kind of treat it like a chronic condition. Yeah, and my disclaimer is, I also work for Shirley, who is our clinical guest. So, I…, I do know a thing or two about palliative care since I work with Shirley quite often and so some of my questions might sound kind of like a ringer, its like certain things that I am like, I want to make sure people know this. So, just generically, Shirley… Oh, go ahead, Gary, you were going to say…

**Gary Petersen –** No, no, no. You ring away.

**Liz Salmi –** Okay. Okay. So, I just wanted, Shirley, could you really specifically outline what services are offered as part of palliative care? It really seems generic, like what is it exactly and how can patients ask for it and…, and can palliative care helps families too?

**Shirley Otis-Green –** And you'll notice that that was one question, Gary. Right?

**Shirley Otis-Green –** No, again I think its yes, yes, yes and yes. So, palliative care is very much because of that…, that person in context mindset, it is definitely for the family as well as the patient and that's one of the things that sets it apart as one of the things that makes it really special is that its all about helping the person to recognize the impact of what's going on, you know, outside of just the confines of the hospital or the clinic situation. So, saying how can we support your loved ones as they support you through this. You ask in regard to how, again what kinds of services palliative care might offer. One of the best ways to think about palliative care, I think, is its relational and so its about communication and again like Lori was mentioning, be able to have someone that you can turn to and ask the really hard questions and…, and having the patient and family come together often in a family meeting. Sometimes there…, there's again different terms that you might use for this, but the idea that the family meeting itself is the intervention of palliative care is a way of thinking about this. So, it might be that a primary care provider would say, you know, we are going to call a family meeting and I am going to turn this over to the palliative care team to…, to set up and run and there would be a physician perhaps, a palliative care nurse, and a palliative care social worker, perhaps a chaplain. They will bring their team together and have the patient with their loved ones, the key people that are going to be helping to make decisions, perhaps people that are the surrogates on advanced directive forums.

**Shirley Otis-Green –** Again, the patient might bring their children or their…, their parents, or their siblings, you know, get whoever the most important people are. We had family meetings where there were, you know, the person brought their pastor and, you know, again a next door neighbor, someone again that…, that might be their caregiver. So, the idea is that this office and opportunity for clarification about what the person's illness is, what their prognosis might be, what treatment options they might have. These meetings can be called shared goals of care meetings where the idea is to outline what the trajectory of the illness might be, what kinds of supportive services can be useful as that person goes through that, being able to identify what we call anticipatory guidance and being able to say, well, if the illness follows such and such a path, it is likely to cause these disturbances or these discomforts or these problems and being able to anticipate those coming down the pipe and offer team approach to try and address those. So, being able to have that fuller perspective is a really important part of what the palliative service can offer.

**Liz Salmi –** Nice! I actually… You mentioned, Shirley, in there and said advanced directive and I actually had a question about that. So, I have had two brain surgeries and before both surgeries, my doctors asked me to complete an advanced directive document. Can you explain to me what an advanced directive is and how that process of advanced care, planning, and documents might relate to palliative care?

**Shirley Otis-Green –** That's an important question. The advanced care planning process is really something we at the Coalition think of as…, and what we would like to see at least as a normal life event. Just when a person gets…, becomes an adult and they, you know, get their driver's license and registered a vote, we'd like to think that advanced care planning will just become a normal part of what went down as responsible adult, but advanced care planning often in a hospital or in relationship to a serious illness or a treatment like brain surgery, you know, is tied in to help us make decisions on your behalf if we…, if you are not able to tell us what you might like. So, we can think of that in the…, in the…, as a way to ensure that the care that you get is really the care that you would want and in a setting that you would want. So, it goes back to that shared goals of care idea and palliative care service is especially useful for advanced care planning purposes because they…, they usually have the time. They are not the seven-minute clinic visit that you often get. Again, a family meeting is often an hour or sometimes even more. So, a relatively in-depth conversation about the values and the things that matter most to the patient and not so much about specific, do I want to have this or that, that who should make decisions for me if I can't and what should be the goal of the treatment options that I am looking at and, you know, what kind of parameters or guidance can I give to that person and to my treatment team so that we can ensure that the care that I get is the care that I want in the new setting that I would be more comfortable. So, its a really…, its often tied into palliative care and palliative care physicians, doctors and nurses, social workers would in their palliative care training would have special training in communication around advanced care planning and advanced directive.

**Liz Salmi –** In listening to the first part of the podcast and Gary was talking about his experience with myeloma and he mentioned, you know, ongoing as a survivor or something, he needs…, there are certain medications he needs to worry about and is related to his condition and he mentioned antifungals. Now, that's really interesting. That's something you need to take, whereas my cancer is totally different, but there are equally weird things I need to worry about and I think weird in a nice way. So, the side effects of brain tumors and brain cancers are really complicated. For example, I have to take an anti-seizure medication so I don't have seizures and when I first started taking this…, dealing with my condition and learning about it, I tried up to six different anti-seizure medications over a three-year period to find the right dose that worked for me and is really complicated working on that with my neuro-oncologist and then also after brain surgery I was on chemotherapy for two years and the first antinausea medication I was given didn't work for me at all and it was kind of this back and forth relationship I started with my neuro-oncology nurse practitioner where I had her phone number and I would call her and I was like, "I am still nauseous. This is not working" and we tried all these different medications to eventually nail down the one that worked for me and when…, when you have palliative care being related to, you know, symptom management, I think about my symptoms of seizures and nausea during treatment and, you know, I felt like my oncology team did a great job of dealing with that symptom management, but none of them ever called it palliative care, but looking back, knowing what i know now, I am like then we were practicing palliative care, but no one ever called it that. Can you…, is there a reason why my doctors and nurses may have never actually used the phrase "palliative care?"

**Shirley Otis-Green –** Great! A great observation! One of the many things I like about you, you have got good observation. I think…, I think that that's kind of speaking to the point I was making about generalist palliative care, that we like to think that we didn't throw the baby out with the bath water even during that time of the science, you know, as I have mentioned historically how there was that…, that change and it maybe was more of putting the emphasis on a different syllable, but doctors hopefully have always been trained and always had a responsibility to address pain and suffering, but it did seem to get for many folks kind of backburner on their first several decades unfortunately and so depending upon when a person went to school and what kind of medical program that they might have studied in or again nursing program or social program, they may or may not have had as much focus on…, on these areas, but certainly there…, there were always, you know, great doctors and great teams and great providers who attended to these…, these issues, but.., but it was…, its been inconsistent, that…, that some again do that better than others.

**Shirley Otis-Green –** So, the fact that you had a really dedicated staff that worked with you to make sure that you got eventually, you know, the right strategy to address your nausea, you know, it is the goal that a person will always have that kind of attention. Unfortunately, you may have gone to a place where you might not have had somebody to care that much and struggle that hard and.., and try so many different techniques and wrote so many different prescriptions and titrated them differently and made different cocktails of them and said, oh, somebody who maybe would have given up earlier and that's where the problem comes in. So, good palliative care has…, has…, had never totally gone away and then, you know, and now that it is resurfacing again, unfortunately now everyone still knows about it or has access to those skills, but…, but again many people do. So, it may be something that…, again a doc would say, well, this is just what being good medicine is all about and so they didn't see it as they are stuck with things and…, and…, and then palliative care might be reserved more for folks to get really serious complex and difficult to manage themselves. They wouldn't necessarily be for the routine person under the routine circumstance. Some docs now are…, are double board certified, so they could be an oncologist who also, you know, specializes in that and then also has a specialization in palliative care and, you know, that kind of gives you the best of all worlds, right? So, there may be then a difference in how you can help people to train and how they identify those services.

**Liz Salmi –** Okay. Well, I thank you and I am going to yield before so the next panelist can ask their questions.

**Shirley Otis-Green –** Thank you!

**Gary Petersen –** All right. Thank you. You…, you did an excellent job, Liz. So, thank you so much for your first time. You did wonderful. Cindy Chmielewski and I never get her name wrong, Cindy, are you online?

**Cynthia Chmielewski –** I am here. Can you hear me, Gary?

**Gary Petersen –** How are you doing, Cindy?

**Cynthia Chmielewski –** I am doing well. How are you doing, Gary?

**Gary Petersen –** I am doing okay. I am still digging out of the Hurricane Matthew.

**Cynthia Chmielewski –** Well, I saw some of the pictures there.

**Gary Petersen –** We're almost done digging actually, so…

**Cynthia Chmielewski –** Okay. Hi, Shirley! How are you doing?

**Shirley Otis-Green –** I am great. Thank you!

**Cynthia Chmielewski –** So, one of the benefits of going last is many of your questions have already been answered by the panelists in front of you. So, what we…

**Gary Petersen –** Cindy, you are never at loss for words.

**Cynthia Chmielewski –** Yes, I know. Thank you, Gary. I always come up with a question, right?

**Gary Petersen –** I know that. One, no…. More than one.

**Cynthia Chmielewski –** That's why you kept me last.

**Gary Petersen –** No.

**Cynthia Chmielewski –** Okay. So, Shirley, do all cancer centers have formal palliative care teams or some do and some don't? Is it something like if I asked for in my cancer center, they would have or could you talk about that?

**Shirley Otis-Green –** Yeah. That's such an important point. Unfortunately, in today's world, we do not necessarily all have equal access to the same quality care and that would be the same if you were asking about cardiology services or, you know, neuro-oncology services or whatever it might be. There's been an increase in penetration in palliative care fairly recently and so just in the last decade, there has been an enormous number of new programs being established. I would say that hospital beds over a certain number, so, you can say, over a hundred beds. I think we are…, the…, the US average now is pretty close to 75%. So, there has been an enormous number of programs that have delineated that service, but if we were sat on the other side, we know that most of those programs are understaffed. In fact, social media has been replete with a storage of research just recently published that looks at how the pipeline is not sufficient for the numbers that we need and that again many programs have difficulty in identifying and finding those well-qualified, well-trained specialists in this area. So, the good news is that people are recognizing that there is a need, but the bad news is that there may not be sufficient numbers of people who need that thing.

**Cynthia Chmielewski –** Okay and thinking about that, are palliative care services covered by insurance?

**Shirley Otis-Green –** Excellent point again. The rubber hits the road in in terms of ,can I access it and can I pay for it. At this point, we can truthfully say and optimistically say that insurance does cover palliative care, but again depending upon where one's getting their care and what kind of coverage they might have, I can't as confidently say that there will be a gap somewhere, but it is something that's a covered service. So, whether you have Medicare or Medi-Cal, whether you have Medicaid, depending upon where you might live, you have, I am making air quotes for Obamacare or something through the Affordable Care Act, any of the…, the governmental programs, VAs, again all of those programs have palliative care built in to their service provision. So, insurance will cover them. If you…, if you have any of the Blue Shields or Blue Cross or any of the Blues, you are going to be covered and so most of the programs of private insurance will follow the Medicare or Medicaid guidelines and again will offer the same kinds of things. So, yes, typically and again, it is a covered service, but if you have a co-pay with your regular insurance, you will have a co-pay and probably with palliative care as well.

**Cynthia Chmielewski –** Okay, well that's great to know that it is a covered service.

**Shirley Otis-Green –** Absolutely!

**Cynthia Chmielewski –** I was…, I was reading, I guess, on Twitter because that's where I get lots of my information that apparently the ASCO Palliative Care Oncology Symposium concluded that the sooner a patient is getting palliative care, the better the quality of life and they are only seeing patients no later than eight weeks after their diagnosis in this study and I was just wondering what types of palliative care services can be offered to someone who is newly diagnosed with cancer and how do we not make it scary to them if they associate palliative care with hospice?

**Shirley Otis-Green –** Exactly and that's one of the real challenges, again is that we…, again there's lots of folks that are…, that misinformation becomes a barrier for them. Again, the palliative care sounds like something that again if I am not familiar of, you know, you don't know what you don't know, right? So, it can be simply, you don't understand the benefit or the value or if you have heard about it, again its been correlated with end-of-life care. You could be a little bit off point that yeah, just newly diagnosed. I am going full bore. I want to fight this to the end. There is… No, of course, I am…, I am not interested in "giving up." So, being able to have the service and have the opportunity to work really hard with messaging is…, is what we are always struggling with. We…, we want very much for programs like this. So, thank you, all, for CureTalks to make sure that you included palliative care as part of your…, your agenda for the week and help folks to realize that this is again an extra layer of support for anyone with a serious illness, not at all to be reserved and only for people who are facing actively end of life.

**Shirley Otis-Green –** So, being able to bring this up and normalize this as part of care, that many other studies that…, that you are mentioning that ASCO or other organizations use and they are looking at their guidelines, that the researchers have done in those studies is they said, you know, palliative care is an extra layer of support. Its something that we offer anyone who is newly diagnosed with lung cancer or whatever the study population is and being able to say to neutralize any concerns and…, and be able to say that, you know, in that kind of way is often a very positive step and then being able to explain what palliative care is. So, being able again to say that this is…, my colleagues work with me so that you can have the very best possible quality of life and few of us are…, are going to turn down the opportunity to have, you know, that…, that more comprehensive addressing of our symptoms. Most folks then are saying, well, yeah, that's sure. I'd like to talk to someone about that. So, if it can be skilfully offered, I think you can go a long way towards being able to allay any concerns.

**Cynthia Chmielewski –** Now, I…, I…, I think so too. Now, I don't want to imagine Cancer Society Cancer Action Network and I sometimes get these action alerts, things that I should be acting upon and writing to my senator and representative about and its coming true. Its called the palliative care and hospice education and training app. Do you know anything about that and what is it and is it something that I should be like tweeting out and telling people to support?

**Shirley Otis-Green –** Well, I love you for many reasons and that's just one. So, as we were talking… …the recognition that there is not nearly enough in the workforce and not nearly enough trained folks on any given day to do this good work and so we…, many of the leading professional organizations have gotten together and have drafted legislation that is working its way through Congress as we speak and it is designed to increase the numbers of trained folks. So, this would be legislation that, yes, I would encourage you to support and to encourage your legislative teams to support, the Congress people, to put their support behind us and what it would do is allow additional training resources for physicians and nurses and social workers and others to be able to get the kinds of intensive training that is so necessary so that they can provide us with quality care. The reason your Cancer Action Network would have encouraged you to…, to look into this is because we know that there are more and more folks getting older in the US and those people are more likely to have serious illness coming, you know, into the fore and given that we don't have enough people that are well trained to be able to address their symptom needs, we have a…, a real potential crisis coming down the pike. So, being able to have more people trained to be able to offer good quality palliative care and symptom management is going to be a really important thing as all of us age and have more likelihood of facing cancer or some other serious illness.

**Cynthia Chmielewski –** Great! So, I will tweet out about it and tell people to…, to sponsor and and write to their congress people.

**Shirley Otis-Green –** Thank you.

**Cynthia Chmielewski –** …and my…, my last…, and my last question is, another study I read that…, that patients that had hematological malignancies that were given palliative care, doing their stem cell transplant, had a much better quality of life than patients that weren't offered those services. Can you like describe some specific services that might have been considered palliative care services that could have been provided to these patients so that I just get a better understanding of what they are talking about.

**Shirley Otis-Green –** Well, again, quite probably, a first step would have been those family meetings that I was mentioning earlier. Being able to have and again optimum palliative care providers that have that…, that kind of mindset and approach, so being able to bring together that family with the team and really explore in depth and detail what the symptoms are for that individual person and in that allows us to address those symptoms and the person then to do better. So, being able to look at whether it again would be the stem cell transplant population or again whichever other group, being able to really know what's going on for this individual as you heard Liz describe and Gary mention, depending upon what your illness is, you can have a whole different set of symptoms and so it isn't a case where one size fits all and having someone who has the expertise to really address the particular areas of suffering that's going on for this particular patient and family, that's really the key. So, that a listening ear, that…, that ability to come in and really carefully doing assessment and understand what's going on and then as I mentioned earlier, that idea is the anticipatory guidance, being able to say, wow, a person is on anti-seizure medications. Its likely that there is going to be such and such, you know, sequel that's going to come down the pike and we can maybe anticipate that and maybe there are some things we can do to address that. So, that…, those things go a long way in contributing to increased quality of life.

**Gary Petersen –** Myeloma teacher, you always do your homework.

**Shirley Otis-Green –** She does!

**Gary Petersen –** Doing a good job this time as well.

**Cynthia Chmielewski –** Okay, Gary, why don't you see if there are any questions from listeners. We have like 3 minutes left.

**Gary Petersen –** Oh, gosh. You normally do that. One thing before we do that is, I was thinking to myself what you have in palliative care because you have an identity problem and hospice is understood and.., and it seems to me like you can have a chart that would say palliative care and below that would be supportive care and another leg would be hospice care so that at least you separate those because I think, you know, just like we said before that, you know, there is just a lot of confusion with regard to what it really means. I mean, we know, you know, we, you know, who have been through supportive care, a number of us understand what that is, but we don't, you know, palliative care was kind of like that's hospice, but its not hospice. There's more to it than that. So, you know, you really have an identity problem that you guys need to work on it. We'd love, you know, for you to find a way to get just like this, you know, program that we've got here, you know, to get the message across, but you know, part of it is just palliative just as a kind of a foreign thing and we as myeloma patients, like Cindy and I, know better than most because everybody assumes that we have skin cancer. You know, nobody has ever heard of multiple myeloma until they get it.

**Shirley Otis-Green –** Yeah and you bring up a really important point and Liz is working out…, it is part of her job with our Coalition to identify a group of engaged patients to help us in doing just what you described. Liz, if you have to take a quick moment to tell Gary a little bit about that good work?

**Liz Salmi –** Well, I know that we have 1 minute left for questions from callers. I'll just say, the…

**Gary Petersen –** No. No. You have a little extra time because we can take an extra 5 or 10 minutes for callers, if you guys can give us more time.

**Liz Salmi –** Yeah. No. I guess the quick answer is we are actually working on something with the patient community, of which I am part of, to actually break down the misconceptions and barriers about palliative care for storytelling where patients who have received palliative care or maybe haven't but wish they had had a chance to tell those stories. There are a lot of different professional associations on the clinical side, such as the American Academy of Hospice and Palliative Medicine, The National Hospice and Palliative Care Organization, organizations like the one I work for which is the Coalition for Compassionate Care, California, who all work with professionals, who all know that and believe that palliative care is the best most person-centered care available. They, like you said, have an image problem and so I believe as a person who kind of wears two hats of being in the palliative care space but also being a patient feel that its almost time for the patient to understand palliative care, to kind of take the charge in spreading the good word among others and this…, doing this podcast today, which is such amazing opportunity to get the word out and demystify palliative care which is the title. We are working on the project to do this storytelling, I can't announce it yet because its not official, but I hope that maybe once it launches maybe we could do another CureTalks and…

**Gary Petersen –** Yeah. You can easily translate it from Canadian into American.

**Gary Petersen –** Okay?

**Liz Salmi –** Okay.

**Gary Petersen –** Minnesota, people from Minnesota would understand it.

**Shirley Otis-Green –** Exactly. Exactly.

**Gary Petersen –** Exactly. So, Priya, could you bring on some of the callers?

**Priya Menon-** Yeah. We are just…, we are getting some questions posted on our CureTalks website, Gary, and the latest one is, let me just read that out for you. I have it. Yeah. Yes. Just came on the website.

**Gary Petersen –** Okay.

**Priya Menon-** Shirley, who is responsible for coordinating the palliative care team with the primary care physician? Is it the patient, caregiver, or someone else?

**Shirley Otis-Green –** Such great questions! I love how thoughtful everyone is. I think you'll find is that there is not necessarily a standardization in regard to how that might…, might look or work. We know that some palliative care programs have a…, the palliative care leader is a nurse and other programs with the physician, other times it even is a social worker or a chaplain. So, there's great variety in that regard and then in regard to who coordinates and how that kind of comes about. Some programs again have it as a consulting service and so a physician has to request him to another physician to make that…, that referral work. So, there is again quite a bit of variability between the different settings, but again the engaged patient is going to ensure that they have asked and made the request and the good news is if lots and lots of folks, there is a ground swell of public request for this when there is going to be more push for the administration of the various programs to ensure that they do have the right people and if they didn't have palliative care service, to say, wow, people are asking for it. We need to get one.

**Priya Menon-** Thank you, Shirley. We have a list of questions. I think we have actually answered quite a few during the discussion. Just one more, that's what I am thinking. Yes. When is the best time during treatment that you should start looking for or consider palliative care?

**Shirley Otis-Green –** What we know from the studies and…, and you heard Cindy mention this too, that the earlier start is better. So, being able to hear the diagnosis of a serious illness and have even as early as your very next visit the opportunity to raise the question of, is there a palliative care service available to me and my loved one, you know, at the center and how do I ask, that's it. So, there is no too early. Many people again upon finding the services of palliative care, you know, if it does come in at the end of their life would say there's only too late, there's not too early.

**Priya Menon-** Thank you, Shirley, and thank you very much. Its like, I think we are almost 5 minutes over our time and that was a very, very informative discussion. I learned a lot because I also have always thought hospice and palliative care was same and until Lori suggested and I started digging up. I never knew that they both are different; and in India, if you see, its almost nonexistent apart from a couple of places. So, this is certainly very useful. I thank the panel, Lori, Cindy, Liz, and Gary for valuable inputs and participation; and the talk is going to be available on CureTalks' website along with a transcript in a couple of days and thank you very much for all this information that has been shared today. Please join us again on CureTalks, which is on 25th of October and this time we are going to discuss skin cancer or melanoma. Thank you very much, everyone.

**Shirley Otis-Green –** Thank you!

**Gary Petersen –** Thank you, Priya, very much.