

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'How to Address Physical, Emotional, and Cognitive Challenges of Cancer with Palliative Care'***

#### **Description:**

Join us as we speak to Dr. Areej El-Jawahri, a physician researcher at Massachusetts General Hospital and Associate Professor of Medicine at Harvard Medical School. In this episode, Dr. El-Jawahri shares the wonderful benefits of palliative care for both blood cancer patients and their families. Often erroneously associated with hospice or end of life care, palliative care can be started at any point after diagnosis and has shown many benefits with being started early in treatment. In palliative care, the physical, emotional and cognitive challenges after a cancer diagnosis are addressed by a specialized team of providers, leading to a more comfortable experience through treatment and beyond.

#### **Transcript:**

**Elissa:** Welcome to *The Bloodline with LLS*. I'm Elissa.

**Edith:** I'm Edith.

**Lizette:** And I'm Lizette. Thank you so much for joining us on this episode.

**Elissa:** Today, we will be speaking to Dr. Areej El-Jawahri, a physician researcher at Massachusetts General Hospital, and associate professor of medicine at Harvard Medical School.

Dr. El-Jawahri is an oncologist specializing in the care of patients with hematologic malignancies and those undergoing hematopoietic stem cell transplantation and adoptive cellular therapy. Her goal is to improve the quality of life and care for patients with hematologic malignancies and their families.

Her research interests include investigating patient reported outcomes, developing interventions to enhance patient-centered decision making, and designing supportive

palliative and digital health interventions to improve the care of patients with hematologic malignancies.

She serves as the Director of Blood and Marrow Transplant Survivorship Program, the Associate Director of the Cancer Outcomes Research and Education Program, and the Director of Digital Health at Massachusetts General Hospital.

Welcome Dr. El-Jawahri.

**Areej El-Jawahri, MD:** Thank you. Nice to see you guys and I'm excited to be here.

**Elissa:** So, to get started, let's learn a little bit more about you. How did you start in the field of medicine and studying hematological malignancies?

**Dr. El-Jawahri:** Yeah. So, my first interest in oncology came from my residency training actually. I was taking care of patients with leukemia, a specific patient with leukemia who happened to be in her early thirties, who was admitted to the hospital to start chemotherapy for leukemia. And I was struck by the immense physical and emotional symptom burden that she was experiencing during this very prolonged hospitalization.

This is a young woman who literally woke up one day feeling a little bit tired and the next day she was admitted to the hospital facing a life-threatening illness and being told that she will need to be in the hospital for the next 4-6 weeks to receive therapy, and this is the beginning of a very long journey towards stem cell transplantation.

So, this process really allowed me to see the immense burden that our patients with blood cancers face day to day in terms of both physical symptoms they experience as they go through treatments, including side effects such as nausea, vomiting, diarrhea. But, also, the social isolation they feel during these prolonged hospital stays. And on top of that, obviously, dealing with the anxiety of a new cancer diagnosis and a long journey towards a potential for a cure.

And in the process of seeing that experience I knew, honestly, I wanted to be an oncologist caring for patients with blood cancers mainly to really provide a level of support to help patients not only get through this intensive treatment and, hopefully, cure them of their underlying illness but, also, provide them the necessary skills to support them and allow them to effectively cope with their illness during their hospital course and, honestly, up to survivorship into the times when they were cured of their disease and are back to some kind of normalcy after such a life-threatening diagnosis.

**Elissa:** Our episode today is on palliative care. Could you give us the actual definition of what palliative care is, and then why it is so important to patients?

**Dr. El-Jawahri:** Absolutely. So palliative care is specialized medical care for people facing a serious illness. It's really focused on providing patients with relief from the symptoms and the stress of serious illness, both physical and psychological stress of serious illness, with the goal of improving the quality of life of patients and families.

It's provided by specialty trained team of doctors, nurses and other specialists who work together with the patient's other doctors, such as the oncologist, to provide, really, an extra layer of support for patients during the illness course.

Most importantly, it's really important to know that palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

So often people hear the word "palliative care" and sometimes they misconstrue that as thinking that this is actually hospice care or end-of-life care. But that's a big misconception. This field is actually focused on providing patients with an extra layer of support to help them cope with an illness, a serious illness that's impacting them regardless of whether the goal of therapy is to cure the disease or not to cure the disease.

**Elissa:** So, I'm sure one of the other preconceptions of palliative care is about pain management. Is that something that you deal with then with palliative care for patients?

**Dr. El-Jawahri:** Absolutely. So often palliative care clinicians have expertise in complex symptom management including pain management. But I would say palliative care is more than just pain management. I think one of the things that we've learned over the years about the expertise that palliative care clinicians bring to the table, it includes helping patient address symptoms both physical and psychological. So, symptoms such as pain, nausea, vomiting, diarrhea, fatigue, these are very, very common symptoms that our patients with blood cancers deal with on day-to-day basis.

And, also, palliative care has a lot of expertise in helping patients manage the emotional symptoms of dealing with this illness; the fear and the uncertainty about the future, anxiety, depression and feeling sad during the illness course.

And the third aspect that I think is really important to highlight about palliative care is that studies have actually shown that palliative care clinicians have a lot of expertise in helping patients cope effectively with a serious illness. So, providing patients with a structure and the skill set to promote effective coping strategies in the face of serious illness.

And, lastly, I should say that palliative care clinicians are really great about communicating and coordinating care. So, they work very closely with the oncology clinicians to ensure that extra layer of support is there for patients and their families during this illness course.

**Elissa:** There's a lot of talk in the cancer community about following treatment. So, when treatment ends it can be an emotional breakdown for patients. So, is having palliative care at some point throughout your treatment more beneficial to the patient so that they can continue after their treatment and be in a better place emotionally? And, also, is it something that can continue on once the treatment ends?

**Dr. El-Jawahri:** This is such great point because I do think one of the things that we have learned is that often our patients who go through the acute phase of illness, go through the initial therapy, go through a stem cell transplant or go through chemotherapy, they often feel lost in translation during that transition phase into survivorship. And a lot of that lost in translation is actually stemming from the fact that they still are having some symptoms related to their treatment. They're worried about what the future would hold. They're worried about whether this cancer is going to come back. And they're also thinking about how they can actually translate and make sense of this experience, make some meaning out of this experience, this life-threatening experience, to really help them live their life to the fullest moving forward.

And I do think that palliative care clinicians, when they're involved early in the course of illness, can actually understand better patients' values, what matters to them, and can actually help them plan better for that transition phase. And often our palliative care clinicians who actually see all our patients early in the illness course can play instrumental role in that transition to survivorship for patients with blood cancers and their families.

**Elissa:** That's great.

**Lizette:** Yeah, we hear that a lot of blood cancer patients, they don't emotionally realize what has happened to them until they hit a point where they're in remission. So, all through their treatment journey they've just been like on an auto pilot. And I think that palliative care's really important, like you just said, earlier on for a blood cancer patient to be able to cope with their diagnosis and not wait till later on.

**Dr. El-Jawahri:** That is absolutely true. I think what we learned is that humans have their fight or flight response that turns on, their stress response that turns on when we're faced with a life stressor such as a diagnosis of cancer. And we completely go into auto pilot survival mode. And the reality is a lot of the emotional processing of the

cancer experience then waits until the very end, and in many ways becomes very overwhelming at the very end of treatment and the end of therapy.

And so, part of what palliative care does, it facilitates some of that emotional process while going through this experience. But, more importantly, provide patients and families a structure to think about and make sense of these feelings, to allow them to develop adaptive coping strategies, effective coping strategies that can apply not only for the stress of the cancer experience, but also the stress of the transition to survivorship or, honestly, other stressors that impact their life.

So, I do think early involvement of palliative care, and we know, actually, from studies that early involvement of palliative care in the care of patients with blood cancers improve a wide range of outcomes.

So, for example, we know that early involvement of palliative care clinicians in the care of patients with acute leukemia at the time of diagnosis improved patient-reported quality of life, their psychological distress, both their depression and anxiety symptoms, and even reduces the risk of post-traumatic stress and the trauma of this diagnosis for these patients.

So, clearly, having palliative care involved early can provide patients with the ability to process some of this experience, both emotionally and cognitively, and allow them to cope in better ways with a really difficult diagnosis.

**Lizette:** Yeah, that's so important, especially to know that studies have shown how palliative care can be so positive in a person's life while they're going through such a large stressor, right?

**Dr. El-Jawahri:** So true, and I can't stress out enough this importance of distinguishing palliative care from hospice care or end-of-life care. While hospice care and end-of-life care could be parts of palliative care, and important parts for patient who, unfortunately, have disease that progresses, that requires support with end-of-

life care planning. I will say a lot of our work has focused on actually integrating palliative care clinicians in the care of patients receiving curative therapy like stem cell transplantation.

Again, the goal of getting through stem cell transplant is to cure the illness. So, for these patients, when we integrate a palliative clinician as part of their care team, we see a lot of the same benefits that we see in patients with leukemia. Drastic improvement in quality of life, better management of symptoms, including pain, nausea, diarrhea during the hospital stay for stem cell transplant, and better coping, more adaptive coping for these patients, that translates to better emotional well-being and less psychological distress, specifically depression, anxiety, and post-traumatic stress, up to even 6 and 12 months after the transplant course.

So, clearly, having palliative care clinicians involved even during just the transplant hospital stay for these patients, have sustained benefits beyond the actual transplant experience. So, we know this type of care model and integrating palliative care as part of our support team during the illness course can really make an impact for our patients and families.

**Elissa:** Is there a movement to get palliative care more out there to the public so that if for some reason it's not brought up at the hospital, if patients will know to ask for it? I was an AML patient; it wasn't something that was brought up. I, frankly, was one of them that associated with end-of-life care, so I did think about it. And it sounds like it would have been very beneficial because I'm also one that kind of broke down completely after treatment ended.

And so how do we get that word out better throughout the hospital systems including our academic centers?

**Dr. El-Jawahri:** It's such an important point you raised because I think this misperception equating palliative care with end-of-life care is not just on the behalf of the patients or the perspective of the patients, we see this actually even in our

academic centers with our oncologists. So, a huge part of what we're trying to do is actually educate our oncology clinicians, our community oncologists, regarding the benefits of early palliative care for patients with blood cancers, showing and demonstrating to clinicians the benefits of palliative care in terms of improving the quality of life and the lived experience of these patients is probably our biggest way to actually change the paradigm care of these patients.

What I'd love to see in the future is, honestly, having palliative care consultation being part of routine care; this is just what we do for our patients with blood cancer facing this serious diagnosis.

This podcast is certainly also a step forward. I do think we need to educate everyone around us; patients, caregivers, clinicians, about what palliative care really is, what type of domains that palliative care can actually cover in terms of improving patient's quality of life. And what can they do to actually benefit patients and families.

And in doing so, I think we will start a movement to really allow our patients and empower our patients to actually ask for palliative care consultation, ask for the symptom management expert to help you deal with this illness. Ask for the psychological symptom management expert to help you deal with this illness.

So, I do think we have a long way to go, but I hope even this podcast is going to start the process of us thinking about palliative care differently and really positioning ourselves in a place where integrating palliative care in the care of patients with blood cancers is simply the norm. This is what we would do for all of our patients.

**Elissa:** Yes. And part of this podcast is empowering patients to be their own advocates, and we really want them, no matter where they are in their treatment, to step in and ask about it if they are not getting palliative care and find out how that can be beneficial.

One of the things you talked about was having a very specialized palliative care team. Is this something that most hospitals have available anywhere? Is this only at academic centers? Do you then work with social workers and doctors and nurses to provide that care if they don't have that care team?

**Dr. El-Jawahri:** Yeah. So, actually, most academic centers and community centers do have some access to at least inpatient palliative care clinicians. I would say the outpatient palliative care practices are continuing to grow. Most academic centers do have access to an outpatient palliative care practice, but there's still not enough palliative care clinicians to see all of our patients facing serious illness.

So, I do think there are other ways to get some of the benefits of palliative care and some of the other support and providing an extra layer of support through other providers in our community if you don't have access to specialty palliative care.

And some of the providers that I think of that can really be helpful throughout the illness course for patients with blood cancers include our wonderful social workers, our psychologists, who really do have a lot of expertise in helping patients cope with their illness. In fact, a lot of actually the emotional and psychological support that palliative care clinicians actually stems from education that we've learned from our psychology and social work colleagues, so I do think that's an important piece.

Our nurses are actually the biggest advocates for palliative care, but also have a lot of training in managing patient symptoms. So, I do think nursing involvement can really make a difference for our patients and their families.

And the last thing I would say is that we also have a responsibility across really our institutions nationally to really think about how we should be thinking about training our oncology clinicians to deliver high quality palliative care.

And what I mean that is really training our oncology clinicians on how to address the physical and psychological symptoms of this illness. And this could be training our

oncologists, our oncology nurse practitioners and physician assistants, our nurses to allow more access for patients to palliative care-oriented care that's really focused on addressing the entire needs of the patients, not just what chemotherapy to give, how do we deal with the side effects of these chemotherapy but, also, how do we really improve the lived experience of our patients and families.

**Elissa:** Yeah. The emotional experience of cancer can just be all across the board for patients. And I think a lot of patients, like myself, went through chemotherapy and their treatment with a very positive attitude. And so, it wasn't something that was approached for some patients because they weren't looking depressed, and they weren't looking like they were having a difficult time with this. It does seem something that would be just so beneficial to address the whole patient.

There is so much talk about holistically addressing a patient and the whole person, and all of the different aspects that treatment can bring because it isn't just physical.

**Dr. El-Jawahri:** It's absolutely not just physical, and I do think that in thinking about the whole person, to your point, I don't think we should be focusing on just trying to provide emotional support for patients who are depressed or who are super anxious. This is a really hard experience for everyone, right. Facing a cancer diagnosis, no matter who you are, puts a huge level of stress on the patient, the family, their support system, and we should just acknowledge this is hard. And if it's hard, then we need some support to help us get through it and process it and make sense of it. And that's perfectly normal.

And so, I do think acknowledging that and thinking about those needs as critical and foundational to cancer care, as much as figuring out what chemotherapy to give to cure the illness

And the last thing I really do want to say about this is that we often focus on obviously, the experience of our patients living through this. This is also a really hard experience for our caregivers, the family and friends of the patient dealing with this

illness. We know from research studies that caregivers have high caregiving burden, a huge quality of life deterioration as they watch their loved one's struggle with the illness course, and also have a lot of emotional needs while they're also trying to manage the many responsibilities including caring for their loved one.

And so, I do think one of the benefits of palliative care that we don't talk about as often is, actually, studies have shown that palliative care can also help our caregivers of patients going through blood cancer treatment. In part by, again, providing them with the space and an extra layer of support to help them cope with the illness, and really manage their resources to be able to be a good advocate for the patient, but also take care of themselves during this process.

**Elissa:** Yeah, that's one thing that I feel like it is sometimes forgotten. And we try to educate as best as we can that the caregivers do need help themselves. They need emotional help, they need an outlet, they need self-care. And so, it's really great to hear that palliative care can be beneficial to caregivers as well, and I hope the caregivers listening to this podcast will approach their treatment center, the doctors, and ask for palliative care for the patient, and hopefully benefit themselves with that as well.

**Dr. El-Jawahri:** Absolutely. We know that our caregivers provide the majority of care for our patients with cancer and our patients with blood cancer. So, taking care of the caregiver really helps everybody, right. It helps the caregiver feel better and be able to be a more effective advocate and caretaker for the patient. And it also improves patient outcomes. So, we know that taking care of the caregiver and having the caregiver be empowered to also take care of their needs, can actually impact the entire care continuum. Can improve both caregiver and patient outcomes.

**Elissa:** That's great. So, we talked a little bit earlier a lot about how some patients and caregivers can erroneously associate palliative care with end-of-life care or hospice care. Could you delve into any other misconceptions that are around?

**Dr. El-Jawahri:** I think that's probably main misconception that people have. I do want to highlight that, obviously, as our patients and their families face a life-threatening illness there are a lot of fears and uncertainties about their cancer diagnosis. There's a lot of uncertainty about the future and what the future holds.

And another piece that we know patients and families struggle with is really understanding their illness and fully understanding their prognosis. And, I often have patients say to me, "Well I wish I knew this. I wish I knew this about this illness. I wish I knew that about illness." And one of the things that we've learned also about integrating palliative care early in the illness course is that it can help really improve patient's illness and prognostic understanding. Somehow our palliative care clinicians can actually work as almost translators between our oncology clinicians and patients and families by providing a place and a space for patients to process the information they learned from the oncology clinicians.

Sometimes patients also want to share different aspects of their fears and worries with a palliative care clinician rather than their oncology clinician. Not because they don't trust their oncology clinician, but because they really would like to have a place to be able to talk about their fears about the future outside of the oncology clinical setting where their goal is to, I want to get through this illness, I want to get better.

And so, one of the things I would say to know about palliative care is that because of their expertise in helping manage and navigate a serious illness across the continuum of cancer care, they've also developed really amazing expertise around communication, and helping patients really understand their illness. Understand what to expect during the illness course, and also cultivate their prognostic awareness and their prognostic understanding of what the future will hold.

**Edith:** Doctor, you mentioned that patients can start palliative care at any point in their treatment. What do you look for when you refer a cancer patient to start palliative care?

**Dr. El-Jawahri:** So, I think what we look for is what are the actual needs that these patients have, what are the supportive care needs of these patients? Are they struggling with any physical symptoms that are difficult for us to manage alone as oncology clinicians, and having an expertise of a clinician who knows how to do complex symptom management could help us?

I look for patients who are actually looking to process their illness and deal emotionally and cope more effectively with their illness. And I think about those patients as good referral for palliative care to help them cope, both during the illness course and even thinking about these coping skills and their application later on.

And I also sometimes send patients that I feel like need really a lot of help understanding their illness better, understanding their prognosis better. Or patients who are struggling to think about the what if scenarios. Often in these situations, when we're faced with our own mortality, we have a million questions about what ifs. What if this treatment doesn't work? What if the second treatment doesn't work? What do I do if I become really ill and I can't manage some of the things that I want to manage day to day? How do I support my family?

And these are really important questions that often, if we don't address them, they eat on us and we don't process them, and they become the elephant in the room often. And so, many ways people sometimes avoid these difficult questions but, often, actually addressing these questions head on with the help of a palliative care clinician, can allow you to process and actually plan for the best-case scenario, for the worst-case scenario, and for the most likely scenario. So, you're prepared for what this illness brings, and people feel much more empowered and at peace with dealing with this illness.

**Lizette:** You're so right yeah. One person said they didn't want to know what would happen if the treatment didn't work, just like you said. And then their therapist said, "Well, let's talk about it. What would happen?" And then they went into plan that their

doctor would help them come up with a different treatment plan and they would do that. And so, the person did feel empowered. They felt that there was options out there, which is something that we don't often think that we have, right?

**Dr. El-Jawahri:** That's exactly right. I think often we avoid the difficult questions but, first of all, we think about them all the time. So, it's not like that's an effective strategy. We keep thinking about them.

And second, sometimes the answers are easier than you think, and not asking the question is, in itself, a problem. And so being able to ask the question and facilitate a conversation can actually bring us a lot of comfort and peace in knowing what are the possible pathways with this illness and how do I prepare for the future.

**Lizette:** And how does a patient get palliative care? Does a patient or their caregiver have to ask for it all the time? It doesn't seem like it's routinely offered to everyone at this point.

**Dr. El-Jawahri:** We are working really hard to make offering this routine a reality. And the way we're doing this is, honestly, by conducting multiple studies that have really established that the addition of specialty palliative care clinicians to the leukemia team, for example, in the care of patients with leukemia, and to the transplant team and the care of patients with transplant, can really improve patient outcomes.

And so, we are hoping that these data are actually going to push for palliative care integration as just routine clinical care for patients with blood cancers, specifically these patients. And I do think that's going to happen more and more.

I can tell you that in my conversations with institutions across the country there are multiple institutions that are just making this part of their process. That when a patient is admitted for stem cell transplant, they will see the physical therapist as soon as they come in, they will see the palliative care clinician as soon as they come in, and the palliative care clinician will continue to follow them throughout the illness course. And

they will see the nutritionist and the other care members that provide that extra layer of support. It takes a whole team to take care of our patients and their families.

Until this becomes a reality across all of our centers and institutions, I urge patients and families to first know that palliative care does not equal end-of-life care. And two, to ask simply for a consultation or a visit with a palliative care clinician, ask for a referral from your oncology clinician. You can even bring it up, as I heard in this podcast, that palliative care clinicians can make me feel better, can I get a referral to palliative care.

And I do think that will work and I think will allow patients to increase active engagement in their care, and it empowers them to really seek the care that they want. And that's true for our family members and our caregivers.

**Elissa:** I'm curious. We talked about when to start palliative care, but when does it end? At what point in their treatment, or after treatment, do they stop working with the palliative care team and maybe transition to just a therapist?

**Dr. El-Jawahri:** It's often actually directed by the experience of the patient and their discussion with their palliative care clinician. And it really depends on their needs. So, we have some patients, for example, with blood cancers that have some needs after they go through treatment. Some symptoms that really are still there that require some management. And the palliative care clinician will continue to work with the patient until they feel like they're in a good place with a lot of the physical and emotional symptoms.

And sometimes we have a conversation between the patient and the patient tells the palliative care clinician and says, "I think I'm good to go. I think I'm in a good place, I'd like to come less and less to the cancer center because it will be nice to have a break from coming and seeing my medical providers all the time." And that's perfectly fine. I think there is no set time when palliative care has to simply stop being involved

in the care of these patients. But it's really a conversation between the patient and the palliative care clinician, and it's tailored to their needs

**Edith:** So, Doctor, on our patient podcast home page we have a quote that says, "After diagnosis comes hope." What would you say to cancer patients and their families to give them hope for a more comfortable treatment?

**Dr. El-Jawahri:** Oh, that's a hard question, that requires a lot of thinking. I will say that cancer is a difficult journey, and, at the same time, you do not have to suffer alone. We can help you manage and deal with this illness course and effectively cope with it in the best way possible. And provide hope not just for a cure of cancer, but a hope for better symptom management for less distress, for a higher sense of meaning and gratitude at the end of this cancer experience. And whatever doesn't break you makes you stronger.

**Elissa:** I love it. Well, thank you so much, Dr. El-Jawahri. I think this was wonderful, getting out all the information about the benefits of palliative care, and how important it is at any stage of the cancer treatment to, hopefully, earlier on, where we do hope that it is something that becomes, kind of more out there, and that patients will take advantage of it. And we really hope that all the patients and caregivers listening today will immediately be going to their care team and asking about it if they do not already work with a palliative care team.

So, thank you again so very much. We really appreciate your time today.

**Dr. El-Jawahri:** Thank you for having me.

**Elissa:** And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia and Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the show



notes or at [TheBloodline.org](http://TheBloodline.org). This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better.

The survey is completely anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you: financial support, peer-to-peer connection, nutritional support and more.

We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to [LLS.org/PatientSupport](http://LLS.org/PatientSupport). You can also find information about palliative care at [LLS.org/Treatment](http://LLS.org/Treatment), and then look under "types of treatments".

All of these links will be found in the show notes or at [TheBloodline.org](http://TheBloodline.org).

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode.

We look forward to having you join us next time.