

Dr. Lynn McPher...: Hello, this is Dr. Lynn McPherson, and welcome to Palliative Care Chat, the podcast brought to you by the Online Master of Science and Graduate Certificate program, at the University of Maryland. I'm very excited to have as my guest today, Erin Galyean, who has written a book, hold on to your hat, called the Badass Advocate. Any book with the name badass in it sounds like my kind of book. Erin, welcome to our podcast. How are you today?

Erin Galyean: Thank you. I love that opening. I'm great. How are you?

Dr. Lynn McPher...: I'm very well, thank you. So what's the scoop? Who is Erin Galyean, and what led you to write a book with that kind of a barn burner title?

Erin Galyean: Yeah, that's a great question. Let me give you my background. I grew up in the suburbs of Philadelphia. I grew up in a nice family. I was one of three children and when I was 20 years old, my father was diagnosed with non-Hodgkin's lymphoma, and he ended up dying 10 months after his diagnosis, so pretty quick. And during that time, it was 1997 when he passed away, and I was in college, so I didn't do a lot of the care giving and advocating for him, it was mostly my mother and my sister, but of course, losing my father was a big, terrible occurrence in our family. He was just the lifeblood. He was a lot of fun. He's the guy you go to a party and he's the person everyone wants to hang out with because he's so much fun.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: So it really was hard for us, but of course we managed to move on. We went through the grieving process and of course we still miss him today, but that also made what happened a few years ago even harder. So in, I guess it was 20 years later, because it was 2017, my sister, Megan, who's also my best friend, was diagnosed with three diseases. So she was diagnosed with non-Hodgkin's lymphoma as well. And the non-Hodgkin's lymphoma caused an autoimmune disease and the autoimmune disease cause a lung disease called bronchiolitis obliterans, which is a mouthful. Most people know that lung disease as popcorn lung, that's been in the news in the last few years. So really shocked to our family because my sister, she was a college athlete, not at the time, but she was always healthy and in shape and doing all the things that you should do just to stay healthy.

And so it really caught us off guard, but the cancer that she had, the form of non-Hodgkin's lymphoma that she had was what they say is the good kind, if you want to put it that way. It was very curable, and so it was a positive outlook until we found out that she had that lung disease, the lung disease is very rare and it is really difficult to treat. So it's one time in life when you don't want to be rare is when you have a disease. So as time progressed, my sister's health just deteriorated very quickly, like my father. She ended up passing away 13 months later, so three days before her 48th birthday, she's a mom to two young girls.

And so really difficult time and going through that again was heartbreaking, especially for my mother, if you can imagine.

And for me, I had to have something good come out of something so tragic. And so one way I've felt that I could deal with it was by writing a book. And I did advocate for my sister. I was not her primary caregiver, my mother and my sister's husband were, but I did advocate from afar. So I live in Dallas, Texas, and my sister, she lived in Charleston, South Carolina, and my mom lived down the street. So even though I couldn't be there to take care of her all the time, I could advocate for her from far away.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: And just to give you a brief background, my entire career has been in pharmaceutical sales, so I was a rep, and now I'm in training, and I train reps how to speak to physicians, that's my job. So I realized that my knowledge of being a trainer and having pharmaceutical sales background really was an advantage, and that I could help others by teaching them what I've learned, not only through my father's illness, but my sister's illness, and why not share that wealth of information so people who have a loved one who gets sick with a serious illness can start off their journey strong. I certainly did not feel like a badass, so that title is ironic because you never feel like a badass when you're going through it, you feel scared and overwhelmed and frustrated and all these emotions are going on. So my goal is to help people feel like at the end of their journey, and hopefully it ends a positive, not like my family's story, but that you feel like a badass and you did everything you could for your loved one, no matter how that story ends.

Dr. Lynn McPher...: Yeah. I think it's a badge of honor. My residents always said that if I was a dinosaur, I would have been a badass SRS, which I take as a point of pride. But I'm curious, did either your father or your sister have hospice or palliative care?

Erin Galyean: Yes. So this is something that I'm really passionate about and I advocate for palliative care. So my father did not have palliative care. So when he passed away in 97, my mom and I have talked a lot about this, it was never brought up to my mom or my father. And we wish we knew about it because when my sister was probably six to eight months into her illness, she was in now the hospital a lot during that summer of 98, I'm sorry, 2018. And we were introduced to the palliative care team. Her doctor was Dr. Jennifer Aaron, who I just adore. And it was a godsend. I wish we knew about it from day one of my sister's illness. And that's what I tell people when I'm part of social media groups, get in touch with the palliative care team as soon as you can, because they will support you. And she made a huge difference in my sister's last six months, eight months of her life. And I'm so thankful, and that's why I advocate for it.

Dr. Lynn McPher...: But it's interesting that a lot of people in our society are very fearful particularly of hospice, but even with palliative care. Why do you think that is? There's a very well-known physician in California who says, "If palliative care were a medication, every prescriber would want to write for it and every patient would want it written for them." So why are people fearful of this?

Erin Galyean: I agree. And I think there's a stipulation, and this is the word that I try to get out from my perspective as a former family patient advocate, is that palliative care is not end of life care. So I think what happens is, and I can tell you from experience with my sister, she was young and we did not want to have the mindset that she was dying. We wanted to be in the fight mode. We're going to get her out of this, we're going to figure out a way, we're going to fight for her. And so when you hear hospice, you think in the mindset of the family, I'm giving up, we are giving up, and that's not the case. With palliative care, it is not end of life care. It is serious illness care. And so I tell people this in my book, and to back up, Dr. Jennifer Aaron wrote the foreword for my book.

She was a great asset to me when I was writing the book, because she gave me that perspective of a palliative care physician and someone who's in and out of the hospital all the time, working with patients. And so I would use her as resource and ask her these questions that maybe I didn't have as much experience in dealing with. And so, she and I would talk about that, that people have this misconception that if you ask for the palliative care team, or if a physician recommends the palliative care team, then they are giving up on the patient. That's so could not be further from the truth. It is comfort care. And even more than that, it is taking care of the mental and emotional health of that patient. And if they're going through a serious illness, believe me, even if they don't like to talk about their emotions, there's a lot going on in that brain.

Dr. Lynn McPher...: Yeah. It's a lot to unpack. So what specifically did palliative care bring to the table for your sister and your family?

Erin Galyean: Yeah. That's a great question. They did a lot of different things. One of the things that sticks out to me, and if there's anyone getting into palliative care, or if you're in palliative care now, is the biggest asset is that end of life conversation. Now I know I just said, it's not end of life care, but you still need to have that conversation when someone has a serious illness. The what if conversation. And now my sister and her husband were really good about planning for that when they were healthy, but it's different when you're actually in that situation. And there's actually a more in-depth conversation that needs to happen than what you have with your lawyers, because you're on it. And so Dr Aaron had a private conversation with my sister, and I only know this because my sister told me not Dr. Aaron, about her end of life care, and what happens if you go on a ventilator.

All those things, all the very specifics, because now it could really happen, and we need to think about what you really want. It's not just a hypothetical when

I'm sitting in a lawyer's office writing up my will just in case. So she had that difficult conversation that, I'll be honest, my sister and I were super close and I didn't have the heart to start that conversation, and I had some very difficult conversations with my sister, that one I just couldn't bring about. I couldn't do it, neither could my mother or my brother.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: And so that was such a blessing that she took on that responsibility in a sensitive way. And she introduced her to something called the five wishes.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: And so you're familiar with this?

Dr. Lynn McPher...: Oh, yes. Uh-huh (affirmative).

Erin Galyean: Yeah. So if there's anyone at palliative care that's not, I highly recommend looking into that. And I have actually a link on my website because if you're not dealing with palliative care team, I think you should have access to it and look over and use that information to your advantage. And so she had my sister fill it out and when I came back into the room, my sister asked me to help her. And it made the conversation a lot easier for both my sister and for me.

Dr. Lynn McPher...: Yeah. Yeah. It's shocking how many people don't have an advance directives.

Erin Galyean: It is.

Dr. Lynn McPher...: When do you think those conversations should start in general in life? 18 year olds don't even want to hear about it. You're a pretty young chicken there, you may or may not have one, but a lot of people your age aren't interested. You wait till you're magically 65 or diagnosed with a serious illness, what do you think?

Erin Galyean: I think the younger, the better. So for me, I do probably have more than the average person because I've lost a father and a sister. My dad was 53, by the way, I didn't mention that. My dad passed away at 53, my sister at 48, or almost 48. And so I have a different mindset than I think most people my age, but I don't think the average 40 year old has those things. I think it's especially as soon as you have children, you seriously need to start thinking about that, or if you have a spouse, what does that look like?

Dr. Lynn McPher...: So who should read your book, do you think, obviously I'm assuming you think family members of someone with a serious illness should read it. What's in it for them? What is in your book that will give them some guidance?

Erin Galyean: Yeah. So in my book I lay out eight badass strategies I call them.

Dr. Lynn McPher...: Okay.

Erin Galyean: They are very easy to follow, because I have the trainer background, I understand how you want to get right to it. You don't want to beat around the bush. So it's very tactical strategies that you can follow right along. So things like building a support team, what does that look like? You should not have to care or advocate for a patient on your own, even if you're an only child, I give you ideas of ways that you can pull in other people in the community and get that support that you need so you're not alone. I also talk about how to ask questions to physicians, not about specific questions because everyone's healthcare experience is different, but how to formulate good questions. In fact, I had a colleague who, her father had a heart attack soon after I wrote this book. And so I gave her an advance copy and she shared it with her mother and the doctor at the end of her meeting said, "I have to tell you, you asked really good questions."

And that made me so proud because the daughter who I work with said, "My mom doesn't always stay focused, and that helped her to give her tips of how to stay focused during that conversation and ask the question she needed to ask in order to move forward and make good decisions."

Dr. Lynn McPher...: But do you think most physicians welcome that level of questioning?

Erin Galyean: Say that again? Do I think what?

Dr. Lynn McPher...: Do you think most physicians are open to those kinds of questions from patients' family members?

Erin Galyean: Yes. I do. So it's not aggressive necessarily, it's how to ask open-ended questions versus close-ended questions. How to maneuver it, that if you don't understand something, don't just move on. So I think what happens a lot in this society is we put physicians on such a high pedestal that sometimes we get intimidated and we don't want to look dumb. And so we may not understand something because physicians use medical jargon not to so they sound so smart and talk above our heads, it just comes natural to them.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: So if that happens, and you're in a situation where you're advocating for a patient and you don't understand what the physician just told you, you could be making the wrong decision. So you have to clarify and you have to pay very close attention to what the physician is saying and asking questions about what those terms are so you can make better informed decisions. So I really dive into that and how you can ask the questions and practice those skills.

Dr. Lynn McPher...: I'm always shocked to read the data about the level of numeracy skills among the lay public. Numeracy is how illiterate you are with regard to numbers. So if

an oncologist, for example said, if we go with chemo number one, you've got a one in 10 chance. If we go with chemo number two, you've got a one in 12 chance. Most people don't understand which is the better odds.

Erin Galyean: Yeah.

Dr. Lynn McPher...: I think people might be embarrassed to say, could you break that down for me? Could you unpack that?

Erin Galyean: Absolutely.

Dr. Lynn McPher...: Yeah.

Erin Galyean: I do think that's very common. I know that I've been in that situation and it really takes... And I think that being a trainer has helped me to learn, you know what? That's not what's important. And that what's important is that you understand the situation and you can help your loved one, especially if they're conscious and able to make decisions, you can help them make the best decision for their situation. And you have to ask those questions and we don't, I don't think we do. And so I want to give them permission and say, it's okay.

Dr. Lynn McPher...: Yeah. Well, even if you're a Rhodes scholar, when someone tells you, I'm sorry to tell you, you have cancer. Your mind just completely goes on the blank and you don't hear anything after that.

Erin Galyean: You're so right. So I use this example when... So I've been lucky enough that I've never had a serious illness like cancer, but I went through fertility. And when I was in the fertility office, I remember the physician telling me all these things that were going on with my body after I got testing done, and my husband couldn't come to that appointment. And I came home and my husband said, "So what did he tell you?" And I said, "I have no idea," [inaudible 00:15:28]. So in my book, I actually talk about recording those conversations with the permission of the physician, of course, or the healthcare provider.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: And it's not to catch them doing something wrong, it's so you can walk away and listen to it again and say, Oh my gosh, I didn't even hear that. And you know what? I don't know what that means, but I need to call back and ask, or clarify the next time we meet, depending on how urgent it is. And we did that as a family, because not everyone shows up to those doctor's appointments. And I can't tell you how well our support team works to fight for my sister's health, because we were all on the same page because we had the same recording that we could listen to and dissect, and figure out what's the next move? What are the next set of questions we need to ask?

Dr. Lynn McPher...: Mm-hmm (affirmative). What are some more of your strategies of the eight badass strategies?

Erin Galyean: Yeah. I also talk about gaining and applying powerful knowledge. So going back to what you said, how people don't know, you may be an expert in your field, but you may not be in healthcare. And so a lot of times you're thrown into this situation, you're caught off guard, even being in healthcare myself on the sales side, on the pharmaceutical sales side, I didn't know anything about my sister's lung disease and I'm in respiratory, but it still is a rare disease I knew nothing about. So I made sure to do research and not just me, but as a support team, we did research. And I think that's really important. And then once you do that research, if your loved one has a rare disease, especially if they have a rare disease, go find the experts.

So a family friend of ours did some research and she kept finding a name in her research, Dr. Kiersten Williams. And what I did was I said, you know what? I'm going to reach out to Dr. Williams. I don't know this woman, but it's worth a shot. And that's another badass strategy is how you advocate for someone is getting that second opinion, doing your research, following up. And so I reached out to this doctor and I'm still in contact with her today, she did not know my sister. She actually was in another State and she replied to me, she was an expert in bronchiolitis obliterans. Now she was an expert in pediatrics, but she still knew a lot about this disease. And the number one thing, I'll never forget what she said. At this point in time, my sister was losing weight rapidly and she could not gain weight. And she was getting so tiny, she was about 80 some pounds. She was five, two.

Dr. Lynn McPher...: Mm-hmm (affirmative).

Erin Galyean: And so you can't fight a disease if you're weak. And so that was her advice. She said, the first thing you need to do is get her a feeding tube. And we had just talked about this with my sister's pulmonologists not too long before, and they said no, because they didn't want to open her to infection. And then when we came back with Dr. Williams recommendation, that changed. And it's one of those things that those pulmonologists had good intentions, but you don't know what you don't know. And if you have someone as an expert in that disease that can advocate and say, no, this is what they need, because I'm experiencing this, that changes the other physicians mindset. And she did get a feeding tube. And I think that Dr. Williams helped my sister live probably another four or five months because of that advice.

Dr. Lynn McPher...: Wow, that's impressive.

Erin Galyean: And I'll take those four or five months.

Dr. Lynn McPher...: You bet. You bet. Any disease that ends in obliterans that can't have a good ending, right?

- Erin Galyean: Right.
- Dr. Lynn McPher...: Just the name right there. So is there any benefit to palliative care people reading your book?
- Erin Galyean: Absolutely. I think that, one, it's a great resource for them. This is how I look at the palliative care team. Of course their number one priority is the patient.
- Dr. Lynn McPher...: Mm-hmm (affirmative).
- Erin Galyean: But they also, if they're getting into palliative care, if they're new to it, they have to realize that the family is also there and they need your help too. You are a wealth of information and they probably don't know how much of a wealth of information you are. They most likely will not ask you questions because they don't even know everything that you know, so they don't even know that they should go down that road. So you could recommend my book certainly to the family, but if you read it yourself, I think it will give you the perspective of the family, especially if you've never been on that side of the pain that they go through, the anxiety, the lack of knowledge and experience, especially if this is their first rodeo with having a sick loved one. And it's not just the family, it could be a good friend. It could be anyone that's there for that sick person [crosstalk 00:19:43].
- Dr. Lynn McPher...: ... Hospice and palliative care, we do consider the patient and the family as a unit of care. We're probably the best in healthcare doing that.
- Erin Galyean: I think you are, I think you are. And because just my experience with Dr. Aaron and her team, they included my sister's children. They made these really cool little thumb artwork that I still hold on to mine, that they made for the children, but I cherish mine because it has my sister's thumbprint on it. They made the hospital, which is a scary place that nobody wants to go to, especially if you're under the age of 18, and they made it a little bit more lighthearted.
- Dr. Lynn McPher...: Mm-hmm (affirmative).
- Erin Galyean: They really, and Dr. Aaron actually gave me her cell phone number at the time. And this is way before she wrote my book. This is right when my sister was sick and I was able to reach out to her and ask her advice on a few things. I didn't abuse that, but every once in a while, I did maybe twice reached out to her because I was desperate.
- Dr. Lynn McPher...: Palliative care people are awesome [crosstalk 00:20:36].
- Erin Galyean: They're incredible.
- Dr. Lynn McPher...: ... One thing I learned from Dr. Charles Dutton, I spent a couple of weeks at San Diego Hospice when he was there. And I remember we were rounding on a

patient, and at the end of that encounter, instead of saying, do you have any questions? He looked the patient in the eye and said, "What questions do you have for me?"

Erin Galyean: So that is an example where you just gave as an example of the questions that I tell the family members to ask instead of a close-ended to do you, are you, will you, which ends with naturally yes or no. If you change into open-ended, which is what he did, what questions, then it gets your brain thinking differently. And the person on the other end will go, what questions do I have? Oh, okay. I'm supposed to have questions. Let me start thinking of them versus no, I'm okay. I don't know.

Dr. Lynn McPher...: And if you feel more welcomed to ask the question as well.

Erin Galyean: Yes. Less intimidating, right? Instead of, do you have any more questions? And really I'm hoping you say, no, it sounds like I want you to ask me questions, so what are they?

Dr. Lynn McPher...: Yeah, absolutely. Well, I will say I went onto Amazon to check out your book and I'm a Kindle unlimited girl, and I see it's part of my plan. So I downloaded it.

Erin Galyean: Yes. Oh great.

Dr. Lynn McPher...: Yeah. So people have unlimited, they're welcome to do that. And you can purchase it from Amazon, any place else, or is Amazon the best place?

Erin Galyean: Yeah, Amazon's great. And I also am on barnesandnoble.com, and walmart.com. So you can find me any of those places. And I would say, check out my website too, I have a lot of free resources on there. So, if you want to see what else can help you and support you, like I said, I have the five wishes, but I've a lot of other things. And I also have some blogs. So I have others who have either been caregivers, patient advocates, or patients themselves. I also have them write guest blogs about their experience, that might be helpful for some palliative care physicians, just to see the perspective of the patient or the caregiver. We're a team. And I think the sooner that the family members realize that, I know palliative care physicians do, but the families come in and they realize, we're not against each other, we're all together working for the same thing. And [crosstalk 00:22:41].

Dr. Lynn McPher...: You know that we have our online master of science degree in palliative care. And one of the overriding principles is transdisciplinary care. So in other words, if the chaplain comes in, or the social worker, or the nurse or the pharmacist, instead of the physician, regardless of who's in the room, I believe that we should all be cross-trained enough to at least get the ball rolling. Certainly chaplaincy is not my area of expertise, but I can tap dance some pretty long ways before I say, let's go get the chaplain on this one or the social worker or whatever. And I expect the chaplain to be able to speak a little bit about

constipation, which I can fix in a New York minute, because that's where I live, is the drug therapy. I think that's very, very important. What is your website?

Erin Galyean: Yeah, the website is www.badassadvocate.com. Very easy, just like the book.

Dr. Lynn McPher...: There you go, you censure that, badassadvocate.com. Any last thoughts you'd like to share with our listeners?

Erin Galyean: I just want to thank anyone in palliative care because I have a special place in my heart for palliative care physicians, nurses, anyone on the team, what you're doing is amazing, and same with hospice, I don't even know how you do it, but you are amazing people, and I'm so thankful that my sister was blessed with the palliative care team. And that's why I'm such an advocate for it. In fact, palliative care month was November, and I remember Dr. Aaron's like, "I didn't even know there palliative care month. I love how you advocate for the palliative care." And so my sister and my dad both went to hospice and those people are amazing as well. So just thank you for everything you do because we need you.

Dr. Lynn McPher...: Thank you. And thank you for your efforts in writing your book. And I'd like to thank you for spending a little bit of time with us today in our podcast.

Erin Galyean: Thank you for having me.

Dr. Lynn McPher...: Oh, of course, this is Dr. Lynn McPherson and this presentation is February 2021, University of Maryland. For more information on our completely Online Master of Science and Graduate Certificate Program in palliative care, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.