

Mayo Clinic Q & A - Hospice Care

📅 Thu, 11/11 10:24AM 🕒 17:12

SUMMARY KEYWORDS

hospice, hospice care, mayo clinic, ashley, patient, care, hospital, palliative care, oxygen, jennifer, people, visits, lynn, life, developed, illness, palliative medicine, caregiver, medical staff, preemie

SPEAKERS

Jennifer Larson LaRue, Lynn Evenson, Narrator, Dr. Halena Gazelka

N Narrator 00:00
Coming up on Mayo Clinic Q&A,

J Jennifer Larson LaRue 00:03
Many people think that hospice is a last resort. But in fact, hospice can provide so much care and comfort in all aspects of the end-of-life experience for both the patient and the family, so that it helps that very difficult, painful time go more smoothly.

N Narrator 00:17
Hospice Care is a special kind of care that focuses on the quality of life for people who are experiencing a life-limiting illness and their caregivers. Today we'll meet a mother who lost her daughter to a rare disease, and how hospice helped her and her family through that very difficult time.

L Lynn Evenson 00:35
To keep Ashley's memory alive, I want to tell her story. And I want to make it open to people to understand and learn what hospice is really about, and how he can make a big difference, not just for the patient, but for the caregiver as well.

D Dr. Halena Gazelka 00:50
Welcome, everyone to Mayo Clinic Q&A. I'm Dr. Halena Gazelka. November is National Hospice and Palliative Care Month, a time to recognize the important work these programs do to help patients and their families when a cure is not possible. Today, we have a great program for you. We have the story of one

family's journey through illness, and their wish to help educate others about the advantages of hospice care. Joining us to share her daughter's story, is Lynn Evenson. And also with us today to discuss hospice care is Mayo Clinic psychotherapist Jennifer Larson LaRue. Welcome to the program, ladies.

L Lynn Evenson 01:29
Thank you.

J Jennifer Larson LaRue 01:30
Thank you. Good to be here.

D Dr. Halena Gazelka 01:32
Lynn, how kind of you to come on today and share with us your daughter's story. Thank you for being here.

L Lynn Evenson 01:39
Yeah, it's a pleasure. I'm really excited about linking Ashley to something that I felt was really important in her medical care.

D Dr. Halena Gazelka 01:50
Wonderful. Jennifer, could we start with you, and first before we start off today, define what is hospice and what is palliative care and how are they different?

J Jennifer Larson LaRue 02:01
Well, Dr. Gazelka if we think of a trajectory of care with life-threatening illness, palliative care can be involved at any point to help with overall quality of life, navigating through the many difficult and often confusing decisions and situations that arise with such an illness. The goal of palliative care is to provide the best possible care, of course, both tailored to a specific patient circumstances and situation. Palliative care can help a lot with pain management, symptom management, social services, and spiritual care issues, for example. And hospice on the other hand, comes into play more when there is a more limited time of life expectancy, and the focus has shifted from curing the overall illness or issue to managing the symptoms and circumstances at the end of life.

D Dr. Halena Gazelka 02:49
Well, you know, Jennifer that I have a passion for this topic because I am a palliative medicine physician, and I've served as one of our hospice medical directors for Mayo Clinic. So, I believe firmly in the power of palliative medicine and hospice as well.

J Jennifer Larson LaRue 03:04
Absolutely.

D Dr. Halena Gazelka 03:05
Lynn, thank you for being here. Again, I'm so sorry for your loss. Would you tell us a little bit about Ashley and her journey?

L Lynn Evenson 03:13
Sure. Well, Ashley was born prematurely in 1987, February. There were a lot of difficulties with the pregnancy. And so, she was a preemie. And we were seen at University of Minnesota for her illness. We moved to Chicago after that. And she just wasn't catching up like preemies normally would. And so, she developed an ear infection when she was about 14-months-old, and she got dehydrated and sick. And so, we ended up going to a major university hospital down by Chicago there. And the doctors couldn't really figure out what was going on. She was only in the fifth percentile at 14 months. So, she was pretty small. So, we had all these kinds of specialists come in and a neurologist came in and he looked at her and he said, I know what she has, it looks like she has Cockayne syndrome. And then he left the room, and my husband and I just kind of looked at each other and we ended up actually going down to the University Library to figure out what it was. Then we had to have a biopsy done to confirm the diagnosis. And that came back six months later as positive for Cockayne syndrome. So, Ashley developed somewhat normally as a child, but her body was aging prematurely. So, we went through a lot of things with her vision, with her bone density, osteoporosis, things like that, that normally what you would see in the elderly. She lived at home with us through school actually. And when she was 18, and she stayed three more years in the school until 21, she wanted to try living on her own. So, then we put her in assisted living because I felt that I couldn't give her the socialization and everything she needed once she was out of school. She held her own. I mean, we had hospital visits and lots of specialist visits and everything because obviously it's a rare syndrome that she had. And then she started going downhill in about, I don't know, when she was about 26-27. She started losing her mobility. She had to go to a walker, then to a wheelchair. And then in May of 2018, she developed pneumonia, and it was found at that time, after she'd been in critical care for 10 days, that she had significant lung disease. They didn't know if it was a form of genetic emphysema or they were calling it COPD, they weren't sure. But she was then on four liters of oxygen 24/7 after that continuously,

D Dr. Halena Gazelka 06:11
Lynn, could you tell us a little bit about how Ashley came to be enrolled in hospice and what kind of services she received. What was that extreme like for all of you?

L Lynn Evenson 06:21
She had developed pneumonia in 2018, May of 2018. And she ended up in critical care at Sacred Heart Hospital in Eau Claire, and she was in there for 10 days. At that time, we were told that she had a significant lung disease, which nobody knew how, where developed or anything like that. So, she was put

on oxygen, and she was on four liters of oxygen continuously. Then in February of 2019, she developed pneumonia again, and we were back in the hospital over in Luther in Eau Claire. And she was in there for five days on oxygen. And at that point, we started to bump up her oxygen a little bit. July of 2019, she started really having a lot of issues with breathing, any exertion and stuff. End of July, we had to put her in the hospital because her saturations were running so low with any activity she couldn't breathe. So, she was in the hospital in Menominee for five days. That's when we were told that her lung disease was so significant that there wasn't really anything they could do for her. Basically, the doctor said she was actively dying. And they said to us, well you know, we can't do anything for her here. What do you want to do? Do you want to leave her here? Do you want to take her home? Do you want her to go back to her apartment? And I asked her, and she said she wanted to go back to her apartment. And so, we set up hospice with Mayo, and they got everything together for us, like in 24 hours, her bed, you know, all the equipment she needed in her apartment. When she left the hospital she was on 15 liters of oxygen. And no portable oxygen generator does 15 liters. So, the most we could get was a 10 liter one. So, that was kind of hard. But she lasted two weeks on that. But it was two weeks of hospice. And, you know, after going through the whole thing, I thought it would have been nice if it would have been six months of hospice for her. Because I think her quality of life would have been better, and it would have been less stress on me. And my whole, I started thinking about it, and I thought, you know, nobody really said to me, you know, let's see if hospice can come in and help you as well as Ashley. And I thought, yeah, that would have made a big difference. So, you know, my whole point behind this is I don't think that education is out there for the patients as well as medical staff. I don't think a lot of doctors think of hospice as a quality of life care treatment versus a last resort type treatment. And so, I thought, you know, to keep Ashley's memory alive, I want to tell her story. And I want to make it open to people to understand and learn what hospice is really about, and how it can make a big difference. You know, it's not just for the patient, but for the caregiver as well, because I believe it would have been so helpful for me if we would have known in February that she should have been on hospice versus July in 2019.

D

Dr. Halena Gazelka 09:49

Can you tell us a little bit about the services that Mayo Clinic Hospice Care offers?

J

Jennifer Larson LaRue 09:53

Sure. I should say how long do you have to answer that question, but Mayo Clinic Hospice Care offers care such as skilled nursing, aide visits to help with activities of daily living, chaplain visits and social work visits. Some of the Mayo Hospice agencies also provide complementary therapies such as music therapy and massage therapy. All of the Mayo Hospice agencies also provide volunteers to help with a wide variety of things that the patient or family may need or want. Bereavement care is also offered to families after a patient dies. And that's in place for roughly a year after that. I will add too that hospice is a Medicare benefit that also provides medical equipment and medications that will keep the patient comfortable at the end-of-life. It really is holistic patient and family centered care provided in a place where a person feels most comfortable in their own home.

D

Dr. Halena Gazelka 10:50

I think, Jennifer, that's one of the brilliant concepts of hospice is that it ministers to the entire individual, and to their family as well. And coming from the field of pain medicine, where I know so much is affected by the physical, that I love that concept. Tell us about why early referral to hospice is important for individuals.

J Jennifer Larson LaRue 11:15

I think an early referral to hospice is really important because of that coordinated holistic care that's provided. Ironically enough, studies have shown that people live a little longer when palliative and hospice care are involved, mainly because of that coordinated, holistic approach. I think many people think that hospice is a last resort. You've probably heard that phrase used before as well. But in fact, hospice can provide so much care and comfort in all aspects of the end of life experience for both the patient and the family so that it helps that very difficult, painful time go more smoothly, I think.

D Dr. Halena Gazelka 11:54

Jennifer, if there are listeners today who are interested in more information about hospice, how might they find that?

J Jennifer Larson LaRue 12:01

I would say the best way that people can connect with hospice care, Mayo Clinic Hospice Care, for example, is across the midwest. And the best way to find information would be to go to either to the main Mayo Clinic website, www.mayoclinic.org, or the Mayo Clinic Health System website for those listeners in Wisconsin or other regions outside of Rochester, SE Minnesota. Or just check with your primary care provider for more information too. They should be able to direct you to the appropriate agency that way as well.

D Dr. Halena Gazelka 12:36

What else do you want our listeners to know about hospice care, Lynn?

L Lynn Evenson 12:41

You know, I really love the fact that I could get a hold of anybody 24/7. That was, as Ashley's disease progressed, especially with her lungs, and she was in an assisted living facility, and she wanted to go back there after she got to the hospital last time. And the staff were great. But I had to train the staff what to do for her and with her. When she was put on oxygen, I was taught how to use the oxygen generators, to take her SATs, everything like that. And then I had to in turn, had to go and train them. And there were times in that 15 months that I would get calls in the middle of the night, I would get in the car, I would drive over there, because they didn't know what to do for her. And I think, like I said, if I had known that the hospice was an option, I certainly would have felt better knowing that there was somebody I could call immediately who could come and take care of her. And I think a lot of people don't understand that that's available for the caregivers as well as the patient. And I don't know for sure, but I wonder if a lot of medical staff don't really understand that as well.

D Dr. Halena Gazelka 13:55

Good point. Probably not.

L Lynn Evenson 13:56

Yeah, and I think medical staff maybe need to hear more about patient stories and how hospice has helped them, and, you know, improve their quality of life at the end, where it's not so much about, you know, trying to catch up with care, but making it comfortable care for people.

D Dr. Halena Gazelka 14:19

I love the point that you made about 24-hour availability, because so often individuals who are very ill, and they're not on hospice, their families don't know what to do other than call the emergency room or call 911 and summon an ambulance. And a lot of times people spend time in hospitals that they prefer not to if they were given the choice.

L Lynn Evenson 14:42

Right. Yeah. And I don't, like I said Ashley wanted to be in her own apartment.

D Dr. Halena Gazelka 14:46

Yes.

L Lynn Evenson 14:47

It did get near the end there, it was almost two weeks before she passed, and the social worker had said to me, because I decided to give her her medications every two hours. She was on lorazepam and morphine to help her breathing because she just couldn't breathe. And at the two week point the social worker said, you know, we need to think about maybe putting her back in the hospital. And I agreed with her, you know, and we didn't have to, it didn't end that way. But, you know, somebody's kind of guiding me and saying you don't, it's okay, you know?

D Dr. Halena Gazelka 15:25

Yeah.

L Lynn Evenson 15:26

And so, it's nice to have somebody to have your back. I guess that's the best way to put it. Because a lot of times you don't know if you're making the right decision. Because obviously, I've 32 years of medical background with Ashley, but I'm not a doctor.

D Dr. Halena Gazelka 15:47

Well, it sounds like you took care of her beautifully, Lynn. Thank you for sharing with us. Jennifer, any last words for our listeners?

J

Jennifer Larson LaRue 15:53

I just wanted to reiterate that those early referrals to hospice care, just as Lynn, you know, very eloquently has shown us, those early referrals to hospice are so, so important for that reason to care for the patients and the families both the best way that they can.

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Dr. Halena Gazelka 16:14

I couldn't have said that better myself. Wonderful. Thank you for being here today. Our thanks to Lynn Evenson for being here today to share her daughter Ashley's story. And to Mayo Clinic psychotherapist, Jennifer Larson LaRue, who works in hospice for joining us to talk about hospice care today. I hope that you learned something I know that I did. We wish each have a wonderful day.

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Narrator 16:40

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