Mayo Clinic Q&A - Dr. Carrie Thompson - Lymphoma Survivorshi...

SUMMARY KEYWORDS

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SPEAKERS

Dr. Halena Gazelka, Dr. Carrie Thompson, Narrator

- Narrator 00:01
 Coming up on Mayo Clinic Q&A,
- Dr. Carrie Thompson 00:03

There's over 60 different subtypes of lymphoma with really different characteristics in terms of is it curable versus is it not? Is it a chronic indolent, slow growing lymphoma that we can treat and put into remission but expect that it will come back versus is it one of these very aggressive diseases but curable with aggressive treatment?

Narrator 00:27

Lymphoma is a cancer of the lymphatic system, an integral part of our immune system. This type of cancer can begin anywhere in the lymphatic system, but often starts in the nodes of the neck, chest, or underarms.

Dr. Carrie Thompson 00:40

As we effectively treat more and more patients, we have more and more patients surviving and more and more patients living with chronic lymphoma as well.

Dr. Halena Gazelka 00:49

Welcome everyone to Mayo Clinic Q&A. I'm your host, Dr. Halena Gazelka. Lymphoma is a cancer of the lymphatic system. It's a part of the body's germ fighting network. It includes the lymph nodes, the spleen, the thymus gland, and the bone marrow. The goal of lymphoma

treatment is to destroy as many cancer cells as possible and bring the disease into remission. Advances in treatment have increased lymphoma survival rates, but life after lymphoma can be complicated. Here to discuss lymphoma survivorship with us today is Mayo Clinic hematologist, Dr. Carrie Thompson. Welcome to the podcast, Carrie.

- Dr. Carrie Thompson 01:29
 Thank you. Thank you for having me.
- Dr. Halena Gazelka 01:32

Well, thank you for being here. This is a great topic, because it is true that we see more and more survivors of many types of cancer, lymphoma being just one of them.

- P Dr. Carrie Thompson 01:43

 Yeah, that's right. It's a really good, you know, problem to have, if you will, on how to manage some of these short and long-term effects of lymphoma treatment. As we effectively treat more and more patients, we have more and more patients surviving, and more and more patients living with chronic lymphoma as well.
- Dr. Halena Gazelka 02:06

 Well, let's just jump right in to what you just said, short and long-term effects of treatment of lymphoma. What do people experience, and what are they concerned about?
- Dr. Carrie Thompson 02:15

Well, it's complex because there are so many different types of lymphoma. So, I think that's where we should start with. There's over 60 different subtypes of lymphoma with really different characteristics in terms of is it curable versus is it not? Is it a chronic, indolent, slow growing lymphoma that we can treat and put into remission but expect that it will come back, versus is it one of these very aggressive diseases but curable with aggressive treatment? So, very much depends on the individual and what type of lymphoma they have. But if we think about those who have the most common form of lymphoma, diffuse large B cell lymphoma, it tends to behave in a fairly aggressive way, patients tend to be pretty sick at the time of diagnosis and then go through fairly aggressive chemotherapy with the hope of cure. So, in those patients when they're finished with treatment, generally the treatment has been kind of tough. So, a big part of the recovery is just getting that physical strength back, as well as the mental aspect of kind of processing everything that somebody has been through over that last six months because sometimes it doesn't really hit until after you're done with the treatment.

Dr. Halena Gazelka 03:47

What are people most worried about, do you find, after they complete treatment for lymphoma?

Dr. Carrie Thompson 03:52

The number one concern is really the risk of relapse. And again, it depends, does somebody have an indolent lymphoma where we do expect relapse at some point, or one of the more aggressive lymphomas where we really are going for cure up front like diffuse large B cell lymphoma or Hodgkin lymphoma. But really, it is that fear of recurrence. Once somebody has been through treatment, they certainly don't want to be faced with having to do that all over again. So, that fear of recurrence and which sometimes spills over to really being, you know, very appropriately vigilant about all health issues, and managing how do you find that balance between watching for symptoms that may suggest recurrence versus living with that uncertainty in a comfortable way to move forward from what's been a really challenging part of somebody's life.

Dr. Halena Gazelka 04:58

And I can imagine you see patients across that spectrum. What are some effective coping strategies that you've noticed in individuals who seem to manage that fear well?

Dr. Carrie Thompson 05:09

Yeah, absolutely. There are very, everyone has different experiences. But in in those who manage well, I feel like there's a few things that we can take away from their experience that has helped them. First thing is being open to talking about it. And oftentimes, that's with a friend, family, a loved one. But sometimes it's really helpful to talk to somebody who's been through a similar experience. I find that particularly for our younger patients, you know, a patient who, let's say, has Hodgkin lymphoma, they're in their 20s, or 30s, and cancer is not something that most people experience or are talking about. So, finding somebody through either your cancer center or one of the national organizations like Leukemia & Lymphoma Society, or Lymphoma Research Foundation, to talk to somebody who's had a similar experience can be just really helpful to get through that. The other thing, a couple more things, finding that you know, what we call their new normal. We know that life isn't going to go back to exactly how it was before lymphoma. How could it? You've had this, you know, really major experience in your life, and may have still some side-effects from therapy or the disease itself. So, learning to live with that and embrace that new normal, and be patient and kind with yourself as one is regaining strength. And then the last one, I'll add that I think studies really back up, is being physically active. One thing is that many people feel is that, you know, their body has let them down. Cancer has come and been such a disrupter, and strength oftentimes goes down, you may have other challenges, it's recovering from surgery for those who have that and such. But physical activity not just improves quality of life and fatigue, but also in our studies showed that those who are more physically active during survivorship, it's associated with a lower risk of relapse. So, we really encourage everybody to be physically active during that survivorship period, because there's so many benefits.

Dr. Halena Gazelka 07:42

That's fascinating. That's a great incentive to get on the treadmill.

Dr. Carrie Thompson 07:48

Exactly when, you know, so much of cancer feels out of somebody's control. So, to have a tool that somebody can really own and manage themselves, I think it's great.

Dr. Halena Gazelka 08:03

Carrie, do you have any suggestions for what individuals could ask their doctor, or their physician, or provider about survivorship after lymphoma? Or what to expect after treatment?

Dr. Carrie Thompson 08:14

Yeah, I think some of the logistics of what happens next is a really important conversation to have. We know that individuals as they go through treatment, they have a certain routine, you know, it's every three weeks chemotherapy, meet with your care team, go have chemo, and then that repeats time and time again. And so, at the end of therapy, where hopefully we have good news, you're in remission, the scan looks great. Losing that routine can be kind of challenging. So, having a clear idea of what are the next steps? Do I require scans moving forward? We know that in lymphoma, most lymphoma patients actually don't require scans, but regular follow-up visits, laboratory studies, physical exam, what symptoms to watch out for, and then are all important things that patients should know. And then how to coordinate with your primary care physician is also very important. Who's going to do the regular other cancer screening that's necessary such as mammograms, colonoscopies, how often should a patient see their primary care physician? And how will that care be coordinated? Those are all really important questions to ask.

Dr. Halena Gazelka 09:30

You mentioned earlier that there are many, many types of lymphoma. So, there are many, many types of treatment for the different lymphomas, but are there any common short-term and long-term side-effects of lymphoma treatment?

Dr. Carrie Thompson 09:46

Yes. The one short-term effect that does get better with time but can be very bothersome, is peripheral neuropathy. So, that is this, you know, numbness and tingling feeling that can happen in the fingertips and the toes. It's directly related to some of the chemotherapy drugs that we use. And that can be quite bothersome. We do expect that a fair number of patients will experience hopefully just mild symptoms. But, like I said, it can be quite bothersome. Thankfully, that does get better with time, and in the vast majority of patients that neuropathy does resolve. But unfortunately, we don't have a magic pill to make it go away or go away faster. So, that's one that requires some patience. But we do expect for it to get better with

time. The other one is definitely fatigue. Chemotherapy is tough. The chemo that we use in lymphoma does tend to cause a fair amount of fatigue. And again, that's where that exercise can really be helpful. And it doesn't need to be training for a marathon or anything like that. Most of the studies in cancer survivorship and exercise has been in walking programs, for example, or mind-body techniques like yoga. So, really just doing a regular walking routine and working your way up as you recover can be very useful. Those are the short-term effects. And then long-term, one thing we do worry about, which is an effect seen in patients who receive a certain type of chemotherapy in the class called anthracycline chemotherapy can be long-term cardiac or heart effects. Those are things that generally don't happen early, it's something that happens 5, 10, 15 years down the road. And so, that's where that coordination with primary care physicians to know that this is a potential late effect is very helpful. Again, it's seen in the minority of patients, but those who have pre-existing cardiac conditions are at higher risk, or certainly those who have also received radiation to the chest are at higher risk.

- Dr. Halena Gazelka 12:11
 - I was just going to say earlier that it seems counterintuitive to think that if you're tired, that exercising might make you feel better, but it's true.
- Dr. Carrie Thompson 12:20

It is true, it is true. And it is hard to hard to imagine. But I tell people to consider your energy to be like a bank account. And let's say you have \$100 a day in that account, and over time you're going to gain money. So, eventually you're going to be up to 150 and 200. But early on, you're going to have to budget, budget that energy and figure out how do you want to spend that time. And so, some should be doing some physical activity, because that will pay off in the long-term. But in the short-term, you may have a big event, let's say, a family wedding, that's gonna take \$80. So, that may be a day where you're not doing a whole lot in the morning and you're really having to budget that time and then the next day, you may be making up for it. But over time, that budget will grow as long as you're putting the effort into it to get those deposits in the bank.

Dr. Halena Gazelka 13:21

That's a great analogy. I love that. How can survivors of lymphoma prepare for life after treatment?

Dr. Carrie Thompson 13:32

That's an excellent question. And that's a hard question to answer because lymphoma tends to be like all cancers, unexpected. And so, how can you prepare for something that you've never experienced before? I think the communication with your treatment team is one of the most important things to help individuals prepare for what life is going to be. Also, those connections with others who have been through cancer treatment before. That may be somebody who has been through a different kind of cancer treatment, or maybe a lymphoma patient. It really depends on the individual situation. There are some nuanced situations, though, for individuals

who, let's say are in the workforce, and how to manage transitioning back to work if you've taken time off of work or had a modified work schedule during chemotherapy. Again, that's talking with your physician or your provider care team on what do I expect, and how can I ease back into this? What's life going to look like post treatment? It's interesting because we talk about a lot of negative side-effects and of course nobody would wish lymphoma or any other cancer on anybody. But what I find very inspiring as a lymphoma physician, are some of the silver linings that individuals experience.

Dr. Halena Gazelka 15:07

I love silver linings, Carrie. Now you're talking my language.

Dr. Carrie Thompson 15:14

It has a term in research, post traumatic growth, which is kind of the flip side of post-traumatic stress disorder. So, post traumatic growth is where people have these individualized positive effects that happen after lymphoma or another traumatic event. And I've seen all sorts of really amazing changes that people have made in their lives. And the studies show that, you know, some people find certain relationships are enhanced after going through this, because facing a life-threatening event forces you to really examine your life and prioritize certain things and deprioritize others, or find, you know, real excitement in career or career changes, also. So, those are the things that I just find so, so inspiring and amazing what our patients experience after lymphoma.

Dr. Halena Gazelka 16:18

I'd never heard that term before post-traumatic growth. But I love that. We focus so much on the negatives, like you said, I love that focus on the positive. I'm going to read more about that.

Dr. Carrie Thompson 16:28

Yeah, we can't take away, you know, the event that happened, somebody had lymphoma or a different kind of cancer. And we can't control that, but it happened. And so, what can people control is the response to that, and us taking that opportunity to really examine, okay, I've just been through this, what helped me, what didn't? What do I want moving forward for myself in my health, and that's physical health, mental health, emotional, spiritual health. So, it's an opportunity to make really positive changes.

Dr. Halena Gazelka 17:06

Carrie, let's talk for a minute about support systems. No one goes through cancer treatment in a vacuum. Obviously, it interrupts and affects every area of their life. So, what can caregivers, family, friends, co-workers do to help prepare for lymphoma survivorship?

Dr. Carrie Thompson 17:25

Yes, caregivers and support systems are so important for our patients. I have a lot of thoughts on this. The first thing, the first piece of advice I'll give is, keep in touch with that person. Just because treatment ended doesn't mean that the side-effects have ended, or the long-term effects, whether that be physical or emotional, have ended the day that treatment stopped. Certainly, that's not the case. But unfortunately, sometimes support really drops off after treatment ends. So, showing up for that person and asking openly, how can I help? Sometimes we have a habit of saying. Oh let me know if you need something. That's not as helpful as saying something very specific, like, hey, I was gonna go grab takeout for our family, let me drop some offer for you as well. Or, if you're interested in grabbing coffee, let's hear how things are going. And then, you know, based on that, making some kind of concrete actions of, hey here are things that I can do to support this individual as they're in this kind of, you know, new normal, like we talked about. The other really important thing for caregivers is to take care of yourself. Being a patient is hard. Absolutely. Being a caregiver has its own struggles and challenges indeed, and the care and focus from others is generally on the patient as it should be appropriately. But that means that the caregiver is carrying a significant burden, oftentimes without support for themselves. So, ensuring that as a caregiver you have some time away from that role, some time to take care of yourself, time to talk to others to manage your own struggles and mental health through the process is exceedingly important.

Dr. Halena Gazelka 19:32

You touched a little bit on this earlier, particularly in terms of exercise, but what can survivors of lymphoma do to improve their overall health?

Dr. Carrie Thompson 19:43

We talk about things that sound like common sense, but there is data to back up some of these common sense things in terms of improving your overall health from potentially reducing the risk of relapse of lymphoma, but also keeping yourself as healthy as you can be should a relapse occur. Or also keeping yourself as healthy as you can be so that you're really mitigating any of those potential long-term effects of chemotherapy and radiation on the heart and lungs and things. So, exercise definitely one of those things, again doesn't need to be hardcore CrossFit or training for a marathon, a walking program. Just anything that gets your heart rate up a bit for 20-30 minutes a day, consistency that goes along way. The other thing is really examining the diet. There is some good data that fruits and vegetables, particularly the cruciferous vegetables, which are the green leafy things, I describe them as everything my children hate. Those are the things that are really good for us, the broccoli, the brussel sprouts. There's some data that those antioxidants in those vegetables do have an anti-lymphoma effect. So, following a really healthy, clean diet, and again, this doesn't need to be an extreme lifestyle change, small lifestyle changes, increasing the amount of fruits and vegetables you eat on a daily basis. Let's say you don't have any with breakfast, add in something with breakfast. Following kind of a Mediterranean type of diet is what we generally recommend. And then again, I can't stress enough the importance of mental health. Going through cancer is a really challenging thing, and that transition from active treatment to survivorship can actually be some of the most challenging emotionally for individuals because it's an abrupt change. There's a lot of uncertainty, there's the fear of relapse. So, just recognizing that, it can be a challenging time, giving yourself grace when you're having those, you know, big emotions around that

time. And then seeking help from a mental health care provider if you are having more overwhelming feelings of anxiety or depressive symptoms during that time, certainly is very appropriate and helpful.

Dr. Halena Gazelka 22:21

This has been a terrific conversation, Carrie. Do you have any last words of wisdom or pearls that you'd like to share with our listeners?

Dr. Carrie Thompson 22:29

Oh, you know, I'm passionate about caring for those who have been affected by cancer. And while it can be a very challenging time, because of the physical and emotional side-effects of treatment, it can also be a really beautiful time in people's lives as there's the opportunity to have this new normal, celebrate the successes of therapy, and really make those lifestyle changes or enhance lifestyle to live the best that you can in this new normal.

- Dr. Halena Gazelka 23:12
 That's great. Thank you for being here, Carrie.
- Dr. Carrie Thompson 23:14
 Thanks for having me.
- Dr. Halena Gazelka 23:16

Delightful. Our thanks to Dr. Carrie Thompson, Mayo Clinic hematologist for being here today to discuss lymphoma survivorship and so much of it applicable to survivorship of every other cancer as well. I hope that you'll learned something. I know that I did. And we wish each of you a wonderful day.

Narrator 23:36

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