

Living Beyond Cancer

Coping with Pain and Fatigue

Guest: Garth Graebe

Lauren Hixenbaugh (00:01):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh, the Coalition Manager for Mountains of Hope. Living Beyond Cancer is a series of podcast created for cancer patients, survivors and their caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and is produced by the West Virginia University Cancer Institute's Cancer Prevention and Control. Today is slightly different as we are recording in multiple locations. So please forgive any of our tonal differences. Today's topic is coping with Pain and Fatigue; our guest today is Garth Graebe. Garth is the Director of the Occupational Therapy Faculty outpatient clinic at WVU. We are so glad to have Garth with us today. Do you want to start off the podcast with telling us a little bit about your position at WVU?

Garth Graebe (00:50):

Sure. I'm on the faculty of the Division of Occupational Therapy in the WVU School of Medicine. In addition to teaching, I also see clients in our outpatient clinic that is faculty-run.

Lauren Hixenbaugh (01:03):

Great. We're glad to have you as a part of our team here at WVU and like I said, we're thrilled to have you with us today to kind of talk about this topic and take a deeper dive about pain. A lot of folks, you hear the word pain, you think you understand what that means. So maybe you can tell us a little bit more about what causes pain. We hear the terms acute and chronic a good bit, and if you want to explain that the difference there for folks.

Garth Graebe (01:31):

Sure. Pain is the body's way of telling us that something's wrong. If I put my hand on a hot stove, the pain alerts me that something is wrong. Acute pain is just the pain that lasts until the body heals itself. Again, if I have burned my hand, once that burn begins to heal, the pain starts to lessen and when it's completely healed, the pain has gone away. That's acute pain. Chronic pain on the other hand is pain that never really goes away. It sometimes can get better, but then it can get worse as well. So it kind of ebbs and flows.

Lauren Hixenbaugh (02:11):

So acute pain is pain that will come and then go away and chronic means it's lasting. Is that correct?

Garth Graebe (02:20):

Yeah, that's pretty much correct.

Lauren Hixenbaugh (02:22):

So when we're working with cancer patients, what are they looking at as far as pain goes?

Garth Graebe (02:28):

Well, a cancer patient is going to experience both acute and chronic pain. Typically, in my experience though, when I'm working with cancer patients, we're dealing more with the chronic pain, the pain that ebbs and flows, but doesn't quite go away.

Lauren Hixenbaugh (02:41):

That's the main reason that we're talking today is how to handle that chronic pain and what are some ways beyond medication that we can manage that, and folks are dealing with this maybe for years and years and years. So what can they do to manage that pain?

Garth Graebe (03:01):

Well, that's just it. There's actually two parts to non-pharmacological management of chronic pain. The first part is just the day-to-day management of it, being able to live and manage our pain. The second aspect of it is coping with the pain. So they both kind of go hand in hand, but the coping with it is just tolerating. Whereas the management is actually being proactive and figuring out ways to get through your daily tasks and activities with as little pain as possible.

Lauren Hixenbaugh (03:36):

How did they do that?

Garth Graebe (03:38):

Well, with coping with pain, we tend to rely a lot on relaxation techniques so that people can learn how to relax and be calm. As stress increases and as our anxiety increases so does pain. The other part about coping with pain is that everyone tolerates pain differently. So what someone may consider severe pain, another person might consider moderate pain. So knowing what your pain tolerance is and working within that pain tolerance is one of the keys to living with chronic pain. The second part on the management of the chronic pain as an occupational therapist, what we tend to do is we try to analyze a person's daily activities and the tasks that they're doing. One of the techniques that has been very beneficial is keeping a pain journal so that you can go back and you can say, on this day I was doing this and my pain went up significantly. Or on this day I was doing these activities and my pain wasn't as bad as it was before. So knowing that, we can then go back and tailor our days around our pain. So in other words, we let pain be our guide.

Lauren Hixenbaugh (05:05):

I like the idea of the journal. So like you said, folks can go back and see what is causing them pain. Then in that journal, are they also writing down the things that are relieving some of that pain?

Garth Graebe (05:18):

Sure. Yeah, and again, if we're talking about non-pharmacological, then we're going to look at ways that their pain seem to be relieved or a little bit more tolerable besides taking a pill to look at what did you do that made the pain better. Did you sit for 10 to 15 minutes and meditate? Did you try the relaxation techniques? Did you exercise? Those kinds of things.

Lauren Hixenbaugh (05:48):

Okay and are there additional methods beyond this?

Garth Graebe (05:52):

Sure. But again, everybody's different and we tend to tailor what we do. An example would be that if we find out that someone is spending a lot of time in the mornings doing a lot of activities around the house, and then the rest of the day they're in so much pain that they can't do anything, then we'll work on techniques to conserve our energy. We'll also work on techniques to make things simpler. It's what we call work simplification. There's multiple ways to do any task. If we can figure out a way that's easier and uses less energy, then we'll be able to get more done in a given day.

Lauren Hixenbaugh (06:34):

Great. That's definitely important for these patients to relieve some of that pain. So are these techniques typically effective for folks?

Garth Graebe (06:43):

Yeah, they're universally effective. Again, because pain is so individualistic, then one technique that works for one person may not work for another person. When I'm working with patients, we try to figure out what works when, and that way we can decide, okay, this is what we have to do during these activities and this is what we have to do during these other activities.

Lauren Hixenbaugh (07:11):

Can you give us maybe an example? Somebody walks into the clinic and they have this type of pain. Can you give us like a real-world example maybe?

Garth Graebe (07:22):

Sure. Let's take the example of someone who is preparing a meal. When they prepare the meal, they stand at the counter cutting vegetables, and then they move between the counter and the stove back and forth. They're expending a lot of energy in doing this. By the time the meal is prepared, they're in so much pain that they can't even enjoy their meal that they made. So using some of the techniques, we may change this around so that when they're getting food prepared, cutting vegetables in the such, let's say we sit at the kitchen table and cut the vegetables by sitting down, you use much less energy. Another technique would be to employ maybe a little cart that we can put the vegetables once they're cut onto a cart. We can put all of our ingredients on that cart and wheel it over to the stove so that we're spending less time

going back and forth. The idea again, is to figure out a way that we can get the task completed, but using as little energy and as little stress on our body as we possibly can.

Lauren Hixenbaugh (08:36):

Okay. Yeah. I think that's really helpful to kind of get a visual of and it seems like a lifestyle change, some of it.

Garth Graebe (08:45):

It's not so much, I don't think it's so much a lifestyle change. It's more of what I would call like a lifestyle re-engineering. So we're really not changing our lifestyle. We're just doing things a little bit differently. Once we start doing that and again, using those real-world examples, when I work with clients, they'll come back and they'll tell me that they tried some of these techniques and they're really helpful and after a while, they don't even think about it. It just becomes habit.

Lauren Hixenbaugh (09:17):

So I'm thinking about this person, cutting vegetables and typically we would say, oh, my back hurts or my knees hurt. Let's take some pain medication and keep on trucking. So are there any benefits for them choosing the non-pharmacologic pain management?

Garth Graebe (09:38):

Well, the biggest benefit is using less medication. So if we can save the medication for those days when the other techniques don't seem to be quite enough, not enough to help it, then we can use the techniques in combination with the medication. That's what I've found to be the most effective is instead of just relying on medication or relying on a specific technique, we work in combination. One of the things I wanted to mention to you, and this isn't necessarily a bad thing, but most people don't take rest breaks correctly. So let me ask you, when do you take your rest breaks?

Lauren Hixenbaugh (10:26):

When I'm exhausted.

Garth Graebe (10:28):

Right. What if you took those rest breaks before you got exhausted? In other words, proactive rest breaks, where we take a rest break, but when we're not even really feeling that tired, that way your energy can charge up a lot faster. We can think of energy like a car battery. If it gets too low, it's going to take a long time to recharge. If it gets a little low and we take a rest, then it recharges quickly. If it gets too low, it may not recharge at all.

Lauren Hixenbaugh (11:02):

I'm thinking this is sort of like giving them power back. Once they learn how to manage the pain, then they can say, okay, I can conquer this day because I know if I do X, Y, Z, I won't be

exhausted and I won't be in pain at the end of the day. And I feel like that would be motivating for folks.

Garth Graebe (11:23):

Well, one thing that I wanted to mention since we were talking about proactive rest breaks and things of that nature, and I'll mention this is whenever I'm dealing with clients and I'm doing an initial eval, I'll ask them questions like, what do you like to do for fun? I always get, well, I used to do. When I hear, I used to do then as an OT, the wheels start turning and it's like, ah, why did they stop? Oftentimes they say, well, I can't do that anymore because it hurts too bad. So that's what OT is and we sit there and we think, okay, how can we get this person back to doing what they used to do?

Lauren Hixenbaugh (12:12):

Yeah. Back to their life. Absolutely.

Garth Graebe (12:14):

Right. Especially when they say, what do you like to do for fun? They say, well, I used to. So that means that they're probably not having as much fun, right? Life is supposed to be fun.

Lauren Hixenbaugh (12:29):

Yeah. One of our previous podcasts she talked about, I think it was Dr. Megan Burkart. She talked about a patient that had sent her Christmas card and said, the doctors kept me alive, but you gave me my life back. I think that's a really powerful statement. And I truly think that's what you're talking about, giving people their life back and giving them the power to say, I need to take a pause today so that I can enjoy the rest of my day. That's really powerful.

Garth Graebe (13:07):

Yeah. I worked with that same client. One of the things that they used to love to do is gardening and they had stopped planting flowers. Well, by the time we were finished, they were not only planting flowers. They had landscaped their whole yard.

Lauren Hixenbaugh (13:23):

That's wonderful.

Garth Graebe (13:24):

So she sent us pictures of her sitting on the ground on a mat in the evenings, early evenings when it was cooler outside with her oxygen and she was planting flowers. So those are the kinds of things that maybe you don't think about sitting on the ground to plant flowers. She didn't, she wouldn't do what most people do. Just kind of bend over and dig a little hole and plant a flower. That was exhausting to her.

Lauren Hixenbaugh (13:54):

It is hard.

Garth Graebe (13:55):

So those are just some of the simple things that we do. Then we stop and we don't have to.

Lauren Hixenbaugh (14:02):

That's wonderful. I, like you said earlier, I truly think you're giving people their life back and not having that anxiety about, I'm in pain this morning and tonight I have something I enjoy doing in the evening and I know I'm not going to be able to enjoy it because I'm in pain. Do you find that you're decreasing anxieties when you are working with folks?

Garth Graebe (14:26):

Sure. That's a very big point. Anxiety, stress, anxiety, worry, those are those cognitive things that really make pain worse. So when we're talking about coping with the pain learning to reduce anxiety, learning to reduce our stress does wonders as far as being able to cope with the little pain that we have. So if we understand that worrying about it and getting anxious about it thinking this is going to hurt, it will. But if instead we relax and we approach things in a more calm manner and we're mindful of what we're going, then we take that piece of that puzzle away.

Lauren Hixenbaugh (15:16):

So I'm also thinking about the patient and even the survivor as well and their families. Are there any resources that both patients and families members should recognize?

Garth Graebe (15:31):

Well, the American Occupational Therapy Association on their website, aota.org has a lot of resources for patients, families, and anyone that would be interested. They're broken into sections and there are complete sections on pain management and dealing with chronic pain as well as dealing with cancer.

Lauren Hixenbaugh (15:52):

Good. I think giving folks, like we said, the power to kind of shape their lives and also having the resources available to them again, I think that gives them the let's them be advocates for their life and their own health care and that sort of thing. So resources are a huge piece when we talk about healthcare and especially this non-pharmacologic pain management. One of the other questions that I saw when I was kind of researching this topic is some folks using these methods of pain management, as well as traditional methods. Could you talk a little bit about that?

Garth Graebe (16:29):

Sure. Like I said earlier, using them in combination, if we can manage our pain levels so that we don't have to rely on medications, that that's going to be huge. Another factor that we typically

run into is when people say I don't have enough energy to exercise, or it hurts too much to exercise. Studies show that pain levels actually go down when we exercise. We're not talking about going to the gym or running laps, we're talking about just getting some aerobic exercise, taking a walk around the block, walking around your house. As we strengthen the muscles around our joints, then they can tolerate carrying our bodies and we have less pain as a result. The worst thing people can do is just sit on the couch and watch television because their body's going to continue to get weak and their pain is going to continue to increase.

Lauren Hixenbaugh (17:33):

I'm glad you were specific about the different kinds of exercise because the next podcast that we're going to have is with Dr. Nicole Stout, and she's going to get really... we're going to do a deep dive into exercise and what that means for folks. So that's great that you mentioned the different modes of exercise for folks.

Garth Graebe (17:55):

Sure. And when we're talking about exercising, people always will say, if we're talking about a cancer survivor, I can't breathe well, I can't do things that well, I don't have that much energy, I've got chronic pain and you're asking me to exercise, but exercise is just activity and that's what's important. Even if we, like I said, even if we get up and walk a few laps around our house, on the inside, that's better than nothing. I'm sure Dr. Stout will give a lot more detail as far as using exercise to combat pain. But it's just really important. It's just an important piece that we don't want to stop doing the activities that we enjoy or that bring us pleasure. We may just do them a little bit differently, but the key is to remain active and actually just to participate as fully as possible in our lives.

Lauren Hixenbaugh (18:58):

That's a powerful statement. So one of my favorite questions, because I think this opens it up to any patient that you've had. Is there a common question that you get?

Garth Graebe (19:08):

A common question? I typically get the most common question is how can I do more? I really miss not being able to do this. For example, I had a gentleman who said, "I really miss playing with my grandchildren." Well, there's no reason that they shouldn't play with their grandchildren. We just changed the way they did it and we incorporated some rest breaks within the activities. They came back and they said, "I spent the whole day with my grandson and we had a great time." So those are the things that make what I do rewarding, but it's also rewarding for the client because they're getting back to doing the things that they once enjoyed and had stopped doing.

Lauren Hixenbaugh (20:01):

Absolutely. I think we keep going back to the same we're just giving them their life back and I think that's a great theme for every podcast for sure. We hear this new term of mindfulness. Is

that something that you feel like people are partaking in? Do you feel like you're working with folks on that sort of thing?

Garth Graebe (20:22):

Yes. Mindfulness is actually when you hear that term, there is an actual protocol called mindfulness. It's a psychological protocol to help people to learn how to relax. There are many, many relaxation techniques. They all have three things usually in common. One is to engage the mind, the second is to relax the body and the third is to let the mind relax as it's being engaged. All the different techniques and there's lots of these available. There are apps for cell phones and for iPads and computers to help you with different relaxation and meditation techniques. But when you boil it down, they all have the same three elements. The reason that there's so many varieties is because everyone likes one variety versus another one. So people have individual preferences and what they enjoyed doing is something that they're going to continue to do. If it's something that they don't enjoy or they view it as a chore, chances are, they're not going to stick with it. So looking at the different relaxation techniques, learning how to actually let your entire body and your mind relax is really a key to coping with not only pain, but just the anxiety and stress in general and we can all use that.

Lauren Hixenbaugh (21:55):

Certainly especially cancer patients and survivors, and for that matter, their caregivers as well. That could certainly be a great family activity to be mindful together.

Garth Graebe (22:09):

Sure. A lot of these things can be done in group formats. So when we're talking about a group, the family can be a group and set aside some time as a family to just relax and be present in the moment.

Lauren Hixenbaugh (22:28):

Yeah, absolutely. Well, as we begin to wrap up today, I just want to take a minute and kind of revisit for our listeners some of our points. So if listeners remembered one tip at today's podcast, what would you hope it would be?

Garth Graebe (22:47):

The one tip would probably be to learn how to conserve energy, by sitting down to do task and by taking rest breaks before we need them. That would be the one tip that I would hope that everybody would get.

Lauren Hixenbaugh (23:02):

And we talked a little bit about resources earlier. Are there any additional resources and how can people get in touch with you or the clinic?

Garth Graebe (23:12):

Sure. Most occupational therapists are trained in dealing with pain and chronic pain, as well as other aspects and getting back to life. So if people are having difficulty finding an occupational therapist, they can always contact me at area code (304) 293-3600. We can even set up an appointment to get together for a consultation.

Lauren Hixenbaugh (23:44):

Okay, great and just another resource for folks. If you want to find out more information about Living Beyond Cancer, you can just visit our website at moh.wv.gov or you can visit the WVU Cancer Institute at wvucancer.org. Living Beyond Cancer also has a Facebook support group and you just go in the Facebook search bar and type Living Beyond Cancer and we have a wonderful group. We have about 150 members at this point, which we're really excited about. Folks are very supportive and kind, and especially sharing some inspirational quotes and things of that nature and supporting one another. It's a really great group.

Living Beyond Cancer would like to thank Garth Graebe for joining us today, as well as our listeners. We hope that you'll continue to join us.