

Scott: Welcome to the Three P's of Cancer Podcast where we'll discuss prevention, preparedness, and progress in cancer treatments and research. Brought to you by the University of Michigan Rogel Cancer Center. I'm Scott [Reading 00:00:11]. We're here with the University of Michigan Rogel Cancer Center Director for patient and family support services, Donna Murphy. Can you talk about ancillary services for cancer patients, their families and caregivers?

First, let's meet Donna. She's a licensed master of social worker and has been at the university for 21 years. Donna has been part of the patient family support services since 2005, and the director for the last four years. Donna, can you tell us what exactly patient and family support services are?

Donna Murphy: Sure. The patient family support services is a group of providers, therapists, people trained in the psychosocial part of dealing with health and healing. In this case with cancer. The resources are really designed to help a patient connect the mind, the spiritual part of healing with the physical part. So, for example, we have art therapy, music therapy, guided imagery, and mindfulness. We have a specialist who manages the needs of the parents who are ill, who have concerns about their children. We also have a chaplain. We have individuals specifically that'll deal with anxiety, and depression, and if necessary find medications that will help with that. We have a patient education program. We also manage the volunteers in the cancer center. And so, that makes up other range of people that provide resources, sometimes written, sometimes in talk, sometimes in the actual doing of activities to help heal.

Scott: Wow. That sounds like a lot of services that could be beneficial to patients and their families. So, you mentioned something about children a minute ago. Is there a good way to let children know or are there avenues to let people into their cancer diagnosis?

Donna Murphy: Absolutely. There's some pretty detailed information on how to share illness and changes in someone's health. A parent, a caregiver with the child and it's really based on the age of the child, how you would do that. We absolutely support and recommend as does the research that you let people in early, a lot of times not knowing what to say might be a barrier to telling people. Privacy and the way that you manage your personal needs sometimes are a barrier as well. We do find that when people reach out and other people know, like experience of dealing with the ups and downs of the diagnosis can be really helpful when other people are there. As someone that you would trust, and certainly being on the same page with other people about your needs and desires, I think that patients sometimes share experiences where they feel overwhelmed, but they also don't know what to do with all of the people reaching out.

And sometimes having a spokesperson or that advocate identified as you go on the front end of a health ... pretty critical health situation is helpful. That that person can relay information to the people worried and waiting, mostly to help. And so being really specific with the kinds of things you might want help with or

the things that are needed. For example, when we talk about kids, someone that needs a ride from school every day, and we can help shape what that could look like with someone. So they're worried and concerned about that part of that day, if they're not home for that piece, is getting taken care of the same way every day from a reliable source. And that person who's doing that task is usually more than happy to commit to that.

So it's one example of how an unmet need or a fear that, let's say, a parent might have, could be addressed by saying this is what I need. And then having a way to get that done, maybe by someone else who will arrange for that. We do you find that the support with other people in another person's life who is ill is sometimes the most valuable part of their coping.

Scott: So, obviously there's resources for patients to be able to access, to get that help?

Donna Murphy: Absolutely. We have specialists specifically. There's one in a role of families facing cancer, and that individual as a child life specialist. Very highly trained in development and also in working with adults and sort of looking at the needs of the family. Our therapists in all of our areas are trained to have those and identify those discussions about the needs that come up psycho socially. We might be making, let's say, art, maybe painting or a tile project, or something that is repetitive and soothing. Sometimes we find that that's when a person can easily talk, different than sitting face to face with them and asking pointed questions. And so everybody that we have that works in the psychosocial domain is someone who's specifically trained in dealing with critical health issues, how they affect the emotional realm and what might be needed as a support for that individual. And we, we feel very fortunate that we have those resources here.

Scott: So, through these different resources you mentioned art therapy, guided imagery. Are those activities that are there just to kind of kill time, or can you explain a bit more about how those kind of activities are beneficial for patients and caregivers?

Donna Murphy: Sure. I think we know that basically the pleasure center of the brain is what drives a lot of what we do. Certainly the arts things, that soothe or calm, prayer and meditation, those are things that many people talk about being meaningful throughout their life. Certainly at a time in crisis. Sometimes the confusion and the chaos that might come from a pretty calm or stable life, and then this sudden diagnosis of cancer, or the threat of your life changing dramatically, made not have you reach for those like you might have in the past when you're well. And so we want to prompt people and remind people that these resources are helpful. They're helpful in working through feelings. They're helpful in soothing the sensory system, certainly visual, tactile, auditory. We think about music therapy, using music to heal, to slow a heart rate down, to give you energy, to allow you to write, for example.

Coupling, let's say, music with art or making of some sort, where your hand and eyes are connecting, a body mind sort of connection and making, is a very powerful experience. And when we go into things like guided imagery, meditation, prayer, which have a lot of privacy and purity. No one's really going to analyze your thought or the imagery that allows you to feel soothed. And yet a highly personalized approach to that, for example, our guided imagery would work with a script for someone who may find standing in a tall pine forest listening for the sound and the wind. Listening for needles falling, for example, that might be worked into a script based on their words. And this agreed upon script.

Put music and that could be used over and over again. And once someone has that, and has rehearsed that, and has said that out loud, it's something you can call up almost automatically by just closing your eyes or concentrating. There's just a simple example of what we like to do when we bring someone forward. The art therapy sessions are very individualized. We know that when people do this, especially with color, especially with movement and different textures. Choosing a meaningful object that once it's done carries with them the power or the meaning of that experience when they were ill. Might also be a container of some sort or mementos, or things that are important are kept. For example, a box, or a book, or a card that was made. A piece of art that we frame. Those are all ways that someone can express fear, worry, anxiety, hope, joy, excitement in a way that is pleasurable and meaningful.

So, we often find that people that are ill have more free time than they were used to, and sometimes people are like, "Well, what can we do? How do we keep ... What should we do today? How we'll keep you busy." We want to make sure that people are choosing activities that matter to them. That have a sense of freedom of time. You know, when we get lost in an activity. There are no strings attached, you don't have to do it. It's freely chosen, and it carries meaning and it brings joy, and that you're not doing it for someone else.

Scott: Well, Donna, that's a lot of creativity that people can get involved in. What if you're not creative, like myself, and I'm more into either exercising. Are there other kind of complimentary or integrative therapies or exercise that would be also helpful?

Donna Murphy: Absolutely. There's great evidence for things like Yoga, which also might not be everyone. But in any yoga studio a Yogi would be able to nurture the pace that you're at. So, Yoga is an excellent mind body connection. I think walking, especially when people aren't feeling well, as long as they're stable, with a little help. Walking is a great way to begin to rebuild endurance, or to catch your breath after a difficult treatment and come back. There's a lot of body work that can really be powerful in healing. We know the evidence base massage is great. For people in treatment, we definitely ask that that person is cleared through their physician, so that physical touch and manipulation doesn't interfere with sort of like a platelet development or count.

But there are massage therapists that are specifically trained for oncology work. And so looking for those specialists in your area. Things like Reiki, healing, touch. A lot of our patients talk about those being incredibly beneficial. And certainly acupressure, acupuncture, there's numbers of ways physically that people ... Usually this thought of reengaging because the change is in their body, and wanting to get back to their endurance, working through fatigue. In all of those things, you'd be working with your oncologist to say how much, or when am I ready? Especially if there has been surgery. But that idea of getting back on track, getting to a certain fitness level, getting your stamina, and managing the team are almost always goals of a patient who's been through a lot of drug therapy, and potentially surgeries, and try to recover for that.

Again, we would say, whatever that doctor, or nurse practitioner, or physician's assistant, or your nurse recommends. And then take a slow and steady approach to that.

Scott: That's a lot of really good information and a lot of different activities, it seems like that can be helpful. But how is participating in a PFSS type program helpful and beneficial to cancer patients?

Donna Murphy: I think it [inaudible 00:12:50] junks that physical care that they're receiving. The physical and medical side to someone's cancer is the most important reason why they come. The other resources that are here really work with the mind and body. And the professionals we have doing that work, whether they're social workers, psychiatrists, art and music therapists, guided imagery, meditation, spiritual care is a huge component, as well as supporting the family. I think these are all ways that, in addition to the things that are happening and on behalf of the disease in your body to help eradicate and heal, we want to bring that mind in, and we want to bring the spiritual side of that in. To connect it all, to make sense of it all.

We often find that people will share at some course of their care about how their life starts to be redefined. Like, re-narrated. Here's this thing that happened and I wasn't expecting it. Asking people to live in the unknown, especially with the diagnosis of cancer, there's a lot about it that we can't define. Timeframes, the way it's all going, we're dependent on scans and other resources to tell us how it's working. And that waiting is sometimes debilitating for people, and so we want to train people, and teach people, and talk to them in real time while they're getting treatment, if we can. To do other things with your mind and you body, to help, and soothe, and calm, and do other things that help with the worry and the waiting.

Scott: So, by doing that, does that potentially help with a quicker recovery, or help with the healing process?

Donna Murphy: I think there's a lot of research that shows that yes it does. And that hope, of all things, is one of the most healing powers. When we do things that matter, that are pleasurable, we release chemistry ... The chemistry in our brain releases

dopamine for one, releases substances that help us heal and bring pleasure. And in a happy state we function better than in a worried and anxious state. And if we can move it, and again, those are big, tall orders that ... What we ask someone to endure when we give them the diagnosis is really incredible. Loss of work, loss of function at times, loss of roles that you might have had, the worry about other people stepping in and the roles that you did carry. So, we really see this in families and with parents, and so we want to give them tools.

We want to teach them tools, and these are tools for life, not just tools they're getting through cancer. If we expose you to like let's say art, and you had said earlier you're not creative, but I would argue that point and sometimes we do. And sometimes we see this amazing outcome. And I will add that we have a gallery that's for patients in the cancer center. The patients show their art and they work with an outstanding art therapist to create that art. Some of them are artists before their cancer, and some will share that their art changes dramatically once they have that diagnosis. They might even move to a completely different medium, or someone who's never engaged comes forth with prolific artwork. I can think of multiple examples of artists we've had in our gallery that way. And so we always want to take a shot at that person who says, "That's not for me," and we will. And sometimes we ask for permission to come back.

Scott: I don't think you'd be hanging my stick figures up anytime soon.

Donna Murphy: You could make an awesome gallery.

Scott: Barring actually putting a gallery event up for me. This is all great, great service here. It sounds like the University of Michigan Rogel Cancer Center. Well, what if I don't live in the Ann Arbor area, or I'm not being seen as a patient here? What should I be looking for to try to find these kinds of services?

Donna Murphy: Well, I think what we do know is there's just prolific resources out there. A lot of them are online. So, in terms of support and connection, it would be really trying to identify in your area what's there specific to cancer. We have amazing resources with cancer support community and guilders club leukemia, Lymphoma Society, American Cancer Society. So, those global resources are there. There's a number of online connections support. There's peer to peer support. I think of Imerman Angels and other global resources that help match people with the same or similar background and experience.

As far as activities, and this is what I am amazed at, in this cancer center where all of our patients are outpatients in this center, thousands of them. We'd rather see you connecting to those resources in your community. Why come and use a medical model in your approach to art making, or let's say Yoga and yet at the same time sharing your experience and your story with the resource you're connecting to is a really powerful and important part of the patient voice, and getting what you need? And so I would say, looking really at yourself to say,

"What? I've got this treatment, and I've got these side effects. Or I've got this timeline in my mind. What would make it better?"

And those are the same things you would probably say before cancer. I love gardening. I love flowers. I love collaging. I love talking on the phone with my friend. Whatever that happens to be, you should do more of it. Sometimes we withdraw because we're overwhelmed and we've got you sometimes have rigor to go back into the routine that made us feel fulfilled. And with worry, that's hard to do. With hope and feeling optimistic, you're more likely to engage. And so it might just be, sometimes even creating an accountability partner. Someone who will say to you, "What have you done for yourself today? Or have you done something that has brought you joy? Have you pulled out your journal? Are you doing your writing? Have you been out to the garden? Can we go to the museum? Would you like to take in a movie?" So that someone who has their eye on how you're doing with those things is sometimes helpful.

Scott:

There's all these resources here at the University of Michigan as well as in the communities, does this cost? I mean [inaudible 00:19:43] we talk about being worried and doing these things to help with that worry. I mean, finances is one big worry that patients, I think, have. So, to add onto that, that can sometimes be even more troublesome.

Donna Murphy:

So for example, here, a lot of the resources that we have are of no cost to the patient. So we do a great deal of work with philanthropy to make that sell. I think that's true for other cancer resources. Certainly, in the cancer support communities, Guilders Club, American Cancer Society, leukemia, lymphoma. A lot of programming that might happen at that community level, the regional level is supported and funded. So, hopefully, those resources are no or low cost. Like, for example, at our local Y and I think it was a national program called Live Strong at the Y, there's scholarships to pay for eight or 10 week sessions to do some conditioning, and getting that endurance back.

And if that may not be so in your community, there might be people who would work with you that way if cost was an issue. I think that what is really more important is to look at the meaningful piece of something that might cost nothing. Reading, listening to podcasts, music, things that are available on the web, movies and ... While those might be more passive, sometimes they're great activities when you're not feeling well. And the more active things we can do, like walking, doing an activity with a friend so that you have the emotional support, and the ability to talk out some of your feelings. Meeting someone for a cup of coffee and seeing if they'll pay for it. So that social part and being connected costs nothing, but it's sometimes a really hard part.

And I do want to add this because people talk about it a lot. They talk about it in support groups and in therapy, that sometimes their range of friends change. I've heard it said, friends become strangers and strangers become friends. And for the difficulty that some people have talking about cancer, we're reaching back to someone. They're often surprised that the people they thought would

come forward. And I think it's just a reminder to say that, it's not easy for anybody to deal with the words or the diagnosis, but there are people out there that would love to be that person for you. But you have to be able to say or help someone help you with being able to say, "You know, I need someone right now. I need to talk right now."

And so we really want to encourage that you connect rather than isolate. And when we're wounded and sick, we kind of as a species we want to isolate. And so I find that the people that talk about their feelings related to being diagnosed, and facing all of that and what that might mean, is that I'm being social and being connected and doing some things out in the community are ways is to be aware that there's more, there's more. It's like being outside or being at night and forgetting to look up and seeing the stars. And then when you do, you're like, "Whoa, I forgot to look up." To find it in the simple things, to find meaning in this simple things that can bring you joy but also have you remember, is vast.

There's a big world out there. There are caring good people out there to reach out to them. To know who they are first and then reach out to them.

Scott: Great. Well, Donna, I really appreciate all the quality information that you've given us and appreciate you taking the time today.

Donna Murphy: Well, it's my pleasure.

Scott: Thank you for listening and tell us what you think of this podcast by rating and reviewing us. If you have suggestions for additional topics, you can send them to cancercenter@med.umich.edu. Or message us on Twitter [@umrogelcancer](https://twitter.com/umrogelcancer). You can continue to explore the three P's of cancer by visiting rogelcancercenter.org.