

Dr. Hurley - DTRF 2022 Patient Meeting Webinar #3

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Jeanne Whiting: Hi everybody. Welcome to our final webinar of the day. We're focusing on FAP and desmoid tumors. Our first presentation here will be I'm sure involving mental health and psychological issues that we all deal with regardless of whether we are in the FAP category or not.

But the first presentation is by Dr. Karen Hurley, PhD, clinical psychologist at Cleveland Clinic, the title being, Building Resilience, Psychosocial Issues in Desmoid Disease. Dr. Hurley, I'll turn the time over you to get started.

Dr. Karen Hurley: Thank you so much. And I hope everybody can hear me. Good.

So, I am a clinical psychologist by training. I have specialized in hereditary cancer risk for 20 years. So what you'll be hearing today is kind of a synthesis. Of both research on psychosocial issues faced by people with all kinds of hereditary cancer risk conditions, including FAP.

But also my experience of sitting in the room with many people who have struggled in a very personal way with the challenges placed in front of them by both FAP and also desmoid disease in particular, which is our focus today. So I am going to pop my slides up.

Jeanne Whiting: While you're doing that, I'd just like to announce that during this webinar the chat will be open but not monitored.

In other words, you can chat and post comments as you like, but if you have any questions for the presenter, they need to be communicated through the q and a from the q and A icon at the bottom of your screen. So we will monitor that and pass those questions on to the presenter at the end of her presentation.

Thank you.

Dr. Karen Hurley: Thank you so much. And I believe I am set up and you can see my slides. Is that correct?

Jeanne Whiting: Yes.

Dr. Karen Hurley: Wonderful. Okay. Okay. So, you know, resilience. So first of all, I wanna say that I have no conflicts of interest to disclose. Any photos that you see in this presentation do not depict any actual patients so that you know that we've been attentive to privacy.

So, resilience is a word that has become more common in terms of talking with people about challenges that they face in all arenas of life. And you, we've probably heard it even more in relation to COVID in the last couple of years as COVID has put a second helping of stress on all of our plates, regardless of what we had going and whether we asked for it or not.

So, Resilience. You know, one way that people commonly think about resilience is that it's a characteristic or a trait so that some, that some people have and some people don't, so that people who are resilient seem like there's some kind of invincible hero or maybe that there's some kind of special magic that they have or some kind of special fairy godmother who has bestowed this magic on them to create that sense of resilience.

But if you've been living with disease for a while, you've probably had the experience of people looking at you and saying, Oh, you're so strong for getting through this when you didn't really ask for this situation to be put in front of you. Rather, resilience is something that comes when we need it.

In fact, research shows that most people in the face of a psychological challenge are resilient. But it's important to recognize that it's a process. It doesn't happen necessarily all at once. And it's not innate, but rather, and these are the words of a psychologist who has put a lot of study into resilience.

The way that she puts it is that resilience is not rare or special, but it comes from the everyday magic of ordinary and normative human resources. So in non

psychology speak, it means that we all have access to this, but maybe we don't know that until we have to. So one way to think about this is, you know, when you, when we get a cut, you know, you see the little girl with the boo-boo on her elbow, right?

Once we have a boo-boo you know, things start to happen right away. The blood starts to clot. Certain skin cells start to form to cover over the cut or the tear, and then within a week or two, you can't even tell that it happened. We don't know that our bodies are capable of doing this until it actually happens.

And in psychology we have similar processes that are mental coping resources that we don't really know we have until they're called upon in stressful situations. So one of the first things we need to do in any kind of challenging situation is to name the challenges. What is it that makes this path difficult in order to then say what are, you know, what is being called, what we are being called to cope with as part of becoming resilient.

So the, you know, if we look at desmoid disease in particular, it poses challenges that are not only outside of the ordinary experience of most people. It's also out of the experience of most of the other people who see the providers that you see. We'll be hearing from a couple of our medical experts later on who treat a number of people, including people with desmoids.

And one of the most confusing things about desmoids is that they are technically benign, which means that they're not cancerous, but, you know, but regardless, they can still cause considerable harm. And so this makes it confusing to communicate to people who are supporting you through this process, but may even cause confusion with doctors who are not specialists who may be unfamiliar with this disease.

Another thing that is confusing is that you may be receiving treatments that are also given to cancer patients. Again both of my colleagues who will be following me can speak much more to this but it does kind of blur the lines. So, one of the things that I say when I'm talking to cancer patients is that cancer does not color inside the lines because of the unexpected ways in which it can manifest.

But even within cancer land, desmoids do not color inside the lines. One thing that can happen with desmoid disease, and these, this is true of medical challenges in general, is that you may be going along this way and then your disease comes this way and knocks you off track. So, if you start to experience functional problems, things that you can no longer do because of extent of

disease, this may thwart goals that you're in the process of achieving, be that building family work goals, education other types of personal goals that are important to you.

So some of these may be delayed that you're able to resume later, or in some cases a goal may no longer be feasible and then have to be changed or let go of entirely. . Another thing that happens, it, and again, we'll get more data on this in the next presentations is that, you know, desmoids do have a tendency to come back and with any situation in fear of recurrence, again, this is similar to what is faced by cancer patients, although not in exactly the same way.

It is natural to feel anxious in this situation. You know, when you're focused on something that threatens your wellbeing, threatens your sense of goal and purpose and identity that it is uncomfortable. When we feel anxious, we feel discomfort and we want to get rid of that discomfort. People also will go to worst case scenarios, and so your mind starts racing ahead to the what ifs that keep you up at night. And then people get into situations where their thoughts start chasing thoughts. So you may you know, be thinking about worst case scenario. You start going online to look at research, and then you have, and then maybe you're arguing back and forth with yourself about how much you need to be anxious or worried, but it creates a cycle of racing thoughts or repetitive thoughts that can be bothersome.

Another thing that can happen is if you're going through a cycle of maybe getting some treatment, then you get scans and then you have to wait, see if things come back and get more scans, is that this winds up being kind of a rollercoaster of hope and disappointment. Now, rollercoaster is something that we usually get on.

You know, because it's entertaining or fun, but this is a rollercoaster that no one asks to be on, but it can be quite steep at times. And add to that sense of anxiety. So some of the feelings that people can have is you know, for feeling angry that you did so much and still don't feel well because of desmoid disease.

For FAP patients, you know, the fact that you undergo a a colectomy, which is a very major procedure and that doesn't take care of everything that that FAP presents that can be problematic. Or if you have if you have sporadic desmoid disease. But if you're the kind of person who eats well and exercises and has done so much right and you still don't feel well anyway, it's almost like some kind of you know, contract has been violated that that you tried to live, you know, you've been trying to live well. Sometimes you know the fact that no one

can promise you that things won't come back or they can't promise you the way a surgery might turn out, can lead to feeling lost.

Like no one's there for you. You can feel demoralized by being knocked off track, especially if that happens more than once. And then you know, if you've gotten some treatment and you're on the road to recovery, there is a sense of vulnerability. Is it okay to be hopeful again and to form new goals, having had the experience of being knocked off track.

So with all of that said you know, you know, there's a lot of advice out there about coping with anxiety in general and coping with stress, but dealing with these challenges that are outside of ordinary experience we need to really take a closer look at what's going to be helpful at this level of anxiety, vulnerability, and stress.

So one thing that you might hear from a lot of people is staying positive. So, you know, believe me, if we could give hope or positive thinking as an injection, we absolutely would. But the thing is that being positive is not something that we can easily give. and that it actually can put pressure on people when someone tells you to stay positive, you know, thinking that if you know, just eliminate enough of your negative thoughts that it'll keep you well you know, So what that does is that it makes people vigilant about some of those other feelings that we talked about, like feeling lost or vulnerable or angry, and then people start feeling bad about the fact that they're having feelings about their disease.

So what do we do instead? So it's important to recognize that resilience is a process and that there are things that happen along the way to regaining your balance and figuring out how to have your best quality of life possible given what's going on. So typical things that happen to people after they've had a medical challenge -

Number one is sometimes you'll hear people talk about gaining new priorities. You can ask yourself what's important to you now given the changes that you've been through. There's also this idea of recalibration. What's your measure of a good day? Maybe, you know, if you were, if you're athletic and you were a runner and you could run five miles, and maybe that's not within reach right now, a good day still has to be within reach, even if it's just getting down to the end of the driveway to the mailbox and back.

You still need to be able to set a goal that has a little bit of a challenge to it. And, but that is within reach enough so that you can feel positive about that

particular day. It leads people to question more generally, how do you define quality of life? And that can feed into this idea of re, of reassessing what your priorities are.

And then there's also a very interesting process that happens about refocusing. You know, when you have medical challenge, you might look, you might be more focused on what you can't do but then there's a gradual shift towards what you can do. So one illustration of that is if you're aware of the Peter Matisse, I was tutoring a student.

This was back when I lived in New York. And I learned that she was interested in an art. So we took a, we were looking at a book and Matisse came up and when he as he got older, he became too ill to paint, and that's when he started doing collages with the help of an assistant. And some of his most famous and beloved works come from this period when he was able to shift from what he couldn't do to what he.

So then I asked my student, she was nine years old. If you broke your arm, let's make a list of things you can and cannot do after you break your arm. So she was able to list she could, she wouldn't be able to cook, wouldn't be able to paint walls. I assume there was a renovation at home going on at the time.

Hang stuff up, move your arm, do sports. What could you do? You can pour water in a cup. Well, yes you can, right? You can use your phone, you can cook, but it would be different. And then I asked her, So when you think about what you can't do, how do you feel sad? How do you feel when you think about what you can do, feel happy.

So, you know, she's nine years old and she got it. And you know, on, in this schema it looks simple, but just because it's simple doesn't mean it's easy. So, you know, sometimes, especially if you're recovering from a big surgery, this can be, I call it, you know, the FEMA year. You know, it's not going to be pretty, you know, you're sort of, you know, in this process of cleaning up, assessing what could be salvaged of your goals, your body image, you know, things of that nature.

And maybe there are some things that are, you know, kind of out of reach right now and need some cleaning up and maybe some things that, you know, will need to be let go of. So, this is the tough part that comes after the crisis. Whenever he says, you know, you get all the cards and lasagnas in your freezer after a surgery, but then when all of that is done, this is the process that remains.

And so this is in a way what resilience looks like. You know, getting in the mud with the rake and doing the do. Other techniques that can be helpful using positive self-coaching statements. One of the most famous ones is one day at a time. Looks pretty on a coffee mug, but if you think about it, taking things one day at a time, taking those worst case scenarios and breaking them down into manageable chunks is one of the most powerful coping tools that you can use.

You can make up your own. A good one if you have fatigue is if you can't do a lot, do a little right. You get started, maybe you know, and then your energy picks up a little and you can do more than you think you can do. Another one is to say, you know, maybe things look a little daunting, but if one piece falls into place on one day after day, that can build up.

A couple of other things. There's lots of advice out there about dealing with anxiety and you know, like meditation, yoga, things like that, which requires some commitment to learn. But when I'm working with patients, I like to focus on what I call emotional first aid, which are things that you can do that require no practice and that you can do.

And, you know, nobody can tell that you're doing them. These are really good to use. For example, in a waiting room when you're waiting for a to go into for a scan. The first one is called color naming. It's a grounding technique. It's very simple. If you're having an anxious moment, look around your space.

Name three things that are blue. 1, 2, 3. And then you name three more things that are not red, right? That one's green, that one's brown, that one's white. And you can try this for yourself. But there's something about moving from the emotional experience of physiological arousal to this cognitive naming exercise that it may not take all your anxiety away, but it'll give you enough of a break in the anxious thoughts that gives you an opportunity to you know, maybe do some breathing or other things to help you center.

Another one is I call the breath brush. And I developed this after, you know, realizing that when you tell people to take deep breaths, Sometimes people will get more anxious because they'll take a couple of deep breaths, the anxiety doesn't go away, and then they start getting frantic about trying to push the anxiety away.

So instead, I encourage people, if you're having physical anxiety, is to take a normal breath and then imagine that it can travel inwards and find those spots of anxiety within you. And then the breath just brushes very lightly over those

spots. The way that you might do with a feather or brushing a baby's forehead, just very lightly to that a couple of times.

And that can be a soothing sensation. Again, it may not take everything away, but give you enough to go on to get through what you need to do. Other things that you can do, especially if you're having you're in an early recovery, say from a surgery is to look at your level of hassles because we know that hassles like changes in your day to day schedule, getting the kids off to school, figuring out how to do meals and laundry looking at things and identifying what you can simplify because that will help reduce your stress, which we know is a strong driver of negative mood.

It's really important to have respite. Because we know that if if that, if you try to plow through stress without taking breaks, it can actually decrease your tolerance for stress over time. Whereas if you are using if you are feeling stressed, but you're able to take even short breaks, that actually increases your sense of hardiness.

Also one other aspect of stress is that while you're going through an illness, other people are going through it with you. So anything that can help at quality of life, at the family level by, you know, by reorganizing things to smooth out your routines, giving attention to children and helping them have stable schedules, having adult allies who can help you both in terms of providing support and also giving extra attention to the children, again, that can reduce hassles and reduce that feeling of going through this alone.

So, in closing, I wanna say that in dealing with rare conditions like desmoid tumors, is that, these these experiences push you to think about things that most people for prefer not to think about, which is that in truth, all of us are subject to random events. You just may have been. And there's actually no, just in that you've been pushed to think about the randomness of disease in a way that most people are not exposed to.

And that all of us, without exception are subject to hard times. And we and it's truly not predictable how that's going to happen. So if we circle back to our question about what is resilience? Resilience is actually instead of something we have, it's something that we do. This is a the tips that I've been giving you will hopefully help you towards creating good outcomes in the face of the challenges.

And that resilience is always now there's, you know, instead of thinking about it in all or nothing terms of how to make myself feel better, what is one step that

you can take towards getting closer to back on track? And with that, I would love, I would like very much to acknowledge my colleagues at the Weiss Center at Cleveland Clinic.

And I thank you so much for your kind attention.

Lynne Hernandez: Thank you so much, Dr. Hurley. That was wonderful. We really appreciate it. So much great information in here. It looks like we don't have any questions currently, but it's possible that some people might post them as the webinar goes on.