

Coping with Cancer, COVID and Other Illnesses by Erin Rafter

Hi, everyone. Well, thanks for coming tonight. So my name is Erin Rafter. Well, I'm the Children and Family Program Director at The Gathering Place. If you're not familiar with The Gathering Place, we are a nonprofit cancer support center here in Northeast Ohio. We have two physical locations in Beachwood and in Westlake. We've been around for about 22 years now. All of our services are completely free of charge to individuals and families dealing with cancer. And we provide a wide range of different types of programs. And so when I had the opportunity to talk about this, I was excited and I'm honored to be invited to do this. As I'm going through the information, I'm probably going to default to talking about cancer because that's what I do all day. But the information when I tried to put this together, I tried to keep it general enough so it would include and I'll talk about COVID, and I'll talk about just other illnesses, whether it's a chronic illness, whether it is an acute illness, how these different strategies and things can apply when you're talking with kids. And then at the end, I'll be talking about just how can you help?

So a lot of it depends on your role with the child, with the family, whether this is a personal role or professional role. And then just some resources that I'm aware of. I'll be just kind of talking about, I have a couple of things pulled up online that I'll try and switch over to just so I can show you guys what I'm talking about. But I'll also say it out loud as far as what type of resources I'm talking about. And then I'll also provide my email at the end so if you have further questions or you could benefit from the services that we offer at The Gathering Place, you have a contact person.

So as far as the kind of general topics that I was going to cover with you guys today. So, one, when it comes to illness, whether it's cancer or something else, like the challenges that typically children and families encounter, the developmental reactions to illness. So with that, I will say with these, I have kind of age ranges spelled out when I'm talking about these. But the big thing to be thinking about is developmentally where that child is at, because you could have a twelve year old who is functioning much higher than twelve. You can have a twelve year old who's functioning at a much lower level than their age. So a lot of times it's really you are the expert on your kid. So based on where they are at developmentally, keeping that in mind, the impact that an illness can have on school and behaviors, and then how can you help? What can you do? That's usually the biggest thing that people want to know is just what can my role be and what's going to be helpful. So when it comes to challenges that kids and families encounter when there is an illness or a major stressor, I would be remiss if we didn't talk about just how many challenges there have been, not even just this past year, but these past two years.

And so we have to keep that in mind because at least I know where at the Gathering Place we have been trying to get through these past two years. We've talked about how having cancer is hard enough trying to have cancer in the middle of a pandemic or we also do grief services. So grieving through a pandemic, it's a whole different experience. And so any trauma, any loss, any major stressors, it's going to be seen through a different lens because it isn't just, well, everything else is normal and predictable and now this happened. It's there's so many other things that were not normal or predictable and now here's one more thing. So that can also because as the adult, you are also going through all of those changes and those challenges. So it's affecting how you're coping with it, which is also going to affect how you try to help your child cope with it as well. Obviously, we had COVID and with COVID, with cancer, obviously, there's still a lot of unknowns that can happen, but we have a lot more information about cancer and there's a lot more information that is out there to be able to access and resource.

COVID was something new. So with COVID, we were all learning as we were going. And because of that, it could be hard to try to plan and look ahead and come up with a routine and be predictable because there were still so many unknowns. With kids these past two years, there's been so many changes and challenges with school. A friend of mine who's a teacher had sent me this graphic that it was just showing the grades that kids are in now and then the last grade that they were in, that was "normal". So for a third grader, the last normal school year was kindergarten. So if we think about that, it's just like, oh, my goodness. So that can also have a huge impact on how a child is functioning. So then when there is something else that has happened, some other stressor, it's keeping that in mind. Even the thing that we would usually kind of rely on as being the normal routine at school, even that was different. So that can really impact how a child is functioning. And if we think about just at a school, how many different support systems there are in place, the different resources, all of that was impacted.

Because of that there was a lot of social challenges and isolation. And so typically the types of coping strategies that we try to fall back on and rely on, a lot of those weren't available to people these past two years. So that was a big impact, and that was a big impact on kids. And I think we're just starting to see some of the long term effects of some of that is just how that has really impacted how kids function. The uncertainty with everything, that there has been a lot of loss. And so it's just all these different factors and the financial stressors on a family. So because with that specifically, whether it is cancer, whether it is any other type of medical issue, that medical stressors can be huge. And so because of that, then that can cause sometimes it's not even a trickle down effect. Sometimes it's an avalanche of different changes and things that can happen. So it's also just keeping that in mind. Whether you're the one who's directly dealing with it or maybe you are trying to help support a family who is dealing with that, is that there can be a lot of factors and changes that happen just on the financial side of things.

So those different stress points and family when we are talking about an illness and the stress can kind of wax and wane. So originally the first point is usually when there's a diagnosis, we have seen that anxiety is usually highest at the time of diagnosis. It typically will go down a little bit during treatment. Then we typically see anxiety go back up again at the end of treatment. And so these different stress points based on what is happening with the family, what is happening with the illness, what is happening with treatment. These are all things to kind of keep in mind. So that point of diagnosis, it's a major stress point for families because now you have this information, but you don't know yet what the next steps are. It is scary, it is overwhelming, and it can be almost paralyzing at times because it's like I don't know what the next step is. Once treatment starts, and well, I will take a step back from the diagnosis to the treatment point. Depending on what the illness is, if there are choices when it comes to treatment, there can be a lot of stress as well because we don't know what we're going to choose.

What's the right choice, what's the wrong choice? What are the pros and cons? What are the side effects? There's all these different factors and pieces of information that can go into that decision. With treatment starting, there can be different stress points even within that. So Candy, you mentioned being in the hospital. So it's stressful for the adult. It is stressful for the kid. And so there's that separation piece. And sometimes you know how much time you're going to be separated. Sometimes that's one of those uncertainty things. You don't know how long the parent needs to be impatient. You don't know how long they're going to be gone. Sometimes treatment takes you out of state, so you're not even local. So there's all these different factors that just within that you're trying to do something about the illness. But there still can be a lot of things that are out of your control. Changes in appearance. So someone had mentioned possibly losing hair. There can be weight gain, weight loss, there can be all these different things. And so for younger kids, for kids who might be on the spectrum, that change in

appearance, and even kids who are neurotypical, like, that can be a real stress point because their person looks different.

And so when we're working with kids, the parents who they know they have cancer, but they're not experiencing a lot of side effects we typically see kids "doing okay". For the parents who, because of their treatment, do experience a lot of side effects, that can create more stress for the kids, a lot more questions, a lot more worries. And also sometimes it's that wondering, what are other people going to think? So there can be a lot of just questions or information to go along with that. There can be a lot of routine and mood changes. And so for kids, routines provide that structure. When that routine is thrown off, the kid can be thrown off. We'll talk a little bit more about that as far as the different developmental stages, but also just mood changes. Mood changes in the person who has the illness and for the kids themselves. And we'll talk a little bit more about that too. Stress point at end of treatment. So that can be either due to remission or no evidence of disease. And so a lot of people around the family may be like whoo things are done, but it can be really anxiety producing because it's like, okay, well, what if it comes back?

There can be all these other things that it isn't just a celebration. There can be a lot of long lasting concerns that can come with that or end of treatment because of progression of the illness. And so that then lends to a whole other conversation, whether it's we're looking at quality of life, we're looking at using the word Hospice and what does that mean? And trying to answer and prepare and dealing with any of that anticipatory grief, those different types of things. And then obviously if the person who has the illness dies and that is of course, a huge stress point and can then move into a whole different type of support that the child and the family needs. So when we're talking about developmental reactions, age, I'll just say it one more time. Age and developmental stage are not always the same. So because of that, you can have two 2 year olds who function very differently. And so it really comes down to knowing your child and being able to just kind of keep some of these things in mind. So then that way you can customize it based on the kiddo and what the kiddo needs.

So when it comes to our youngest group, so typically infants to toddlers, that zero to two year old age, it isn't that they're going to have a concept of the disease, but they could still hear the words. And throughout this, I'll talk about how it's hard to use the word cancer. It can be hard and scary to use the word COVID. It can be hard to use the word depending on whatever the illness is, but it can be important to do it. Again, I'll just talk about from the perspective of cancer, we talk about with families that when you are trying to explain this to kids, that who would you rather have them hear the word from you or somebody else? Because kids at any age, they are really good at selective hearing. So whatever chores, telling them to go clean up, go put on pants, all of those different things, they magically cannot hear you. The second you think you are having a private conversation, they're like little ninjas and they can hear every word that you are saying. So if you use the word with them, a couple of things happen. One, you are still instilling that trust, that there aren't big things that you're hiding, that you're encouraging them to be able to ask you questions and do these different things.

And so with this youngest group, I think the thing is that they will hear the word at some point. So if you start using the word and getting them used to hearing the word, it isn't as scary. They are very aware of separation and changes in routine. So we used to try to tell parents like keep the routine as much as possible. Now we will say keep the routine as realistic as possible because I think trying to keep everything as much the same as you can, I think that puts too much added pressure on the adults that you might not be able to do. So it's trying to keep it as realistic as possible and then trying to prep the kids for that. So whatever the routine is going to be, it may not be the same as before, but if at least

they have an idea of what it is, they're a little bit more able to adjust to it and kind of get used to it. So there's going to be times when the routine might change and nobody knew that it was going to. But then you can reset and say, okay, well, tomorrow this is what's going to happen.

And sometimes you have to just scale it back to day to day. But at least if there's some preparation, hopefully it can help them adjust a little bit quicker to it. And that can be caregivers. That can be not just the logistics of the routine, but also who is going to be there doing it with them? Is it going to be grandma? Is it going to be an aunt? Is it going to be the babysitter? All those different things just so that they have an idea of who is my person today? And if they have an idea who that person is, it at least gives them a little bit more of a sense of some predictability and some knowing. The big needs that we usually see at this age is, you know, that consistent reassurance, calm tones, allowing them to play. They still need that play time. They still need to be kids. That's how they experience the world. That's how they get their feelings out. That's how they learn. And as I had said, just who will be taking care of them. So that way they know when we move into that next stage of preschool so they can have more of an understanding.

When it comes to the disease and treatment, it's still going to be using simple words. It's still going to be keeping it very simple, very concrete, but at least, again, kind of introducing more of that vocabulary. So when they hear it, they get used to it. And hopefully it isn't as scary. The things from that younger group still carry over, but they can display like some regression of learned skills. There can be some backsliding with some of those things. We look at that as being normal and it doesn't mean that a skill is lost, but it's just kind of you got to rebuild some of it a little bit. There are going to be lots of questions, so many questions at this stage, and sometimes it's the same question over and over again. So with this age group, at times we'll talk about like, books are your friend, having things where even it's written down and there's pictures, there's stuff you can keep coming back to, to revisit, to answer their questions over and over again. Part of that is they're trying to build that concept in their head. And part of it is also they want to know that the answer is the same every time they ask it.

So this way they're like, oh, okay, yeah, that's the same thing they said last time. All right, that's what they told me. I can keep going with this then. The big needs that they have at this age is assistance with expressing their feelings. They're still learning those words. This is, again, where books can be our friend to really help give them those words. But also I think books are the friend of the adults too, because you are probably exhausted. You don't necessarily have the words. So having a book who can do it for you that you can do together, that there's still that closeness and that cuddle time. And sometimes when it comes to harder concepts, you're not looking at each other, you're looking at something else. It can facilitate more conversation. So that is something where we use a lot of books in our groups and things for kids, and we try to have a lot of different things available for parents and grandparents and support people to be able to use as well. They are also huge on play. This is how they work stuff out. A lot of times they're acting out things, they're acting out scenarios, they're acting out situations.

And so we've had parents before who have called us up really worried because they're like, they're making the Barbie go to the hospital and I'm like, that's a good thing. They're trying to figure this out so they can have that mirrored play. And those are those things where we want to keep an eye out for that type of stuff. And it can also be opportunities for conversations and asking a lot. As much as they ask questions, I always encourage the adults to ask questions too. Tell me what's going on here, what's happening here, because this gives you an insight into their little heads and what they are trying to process. So those are big moments. They look little, but they can actually be big opportunities. Also, really just letting them know what to expect. And it could just be day to day. But if they have some idea

of what's going to be happening, where the routine is, what's predictable, it can give them at least kind of a sense of grounding in what can feel kind of chaotic. So for our younger elementary age, for this we can use more clear words when it comes to cancer, when it comes to an illness.

So words that they might hear chemo, radiation, surgery, those types of words, you can use them. And I'll give you a couple of resources at the end that can help to explain some of those things. But whatever the treatment might be, that whatever the diagnosis is, it can be beneficial to use those words because that way they're hearing them, they can have the chance to ask some questions. Sometimes kids don't have questions right away because they got to take it in first and kind of think about it. So just because we have one conversation doesn't mean we're one and done a lot of times it means coming back to it and checking in with them to see if they have any questions. And I'll say from this point on with kids and their ages, that just as adults have the instinct to want to protect kids, kids have the exact same instinct to want to protect the adults around them so they could have questions, but they might not ask you because they don't want to make you sad, they don't want to make you mad. They don't want to put that on you. So one thing that we encourage adults to do is when you're having the conversation, letting them know you can ask questions.

If you don't want to ask me about it, you could ask Grandpa, you could ask your teacher. And these are adults that you've talked to ahead of time to know, are they okay being that person. But I cannot tell you how many families we've had who have talked about kind of their nine and up, particularly, that when they ask do you have any questions the kid is like nope, but then they hear from the teacher that a question has been asked or they hear from the school counselor or they hear from the coach or their kid's friend's parent that a question came out. And so that's okay. It's good that they're asking, but that's why you want to make sure that that kind of inner circle of people knows what's going on and has the right information. So if that question comes up that kid can get an answer and can get a consistent answer for what you're also telling them. But we've had parents like, they won't ask me anything.

I'm like that's okay. At least they're asking. So that at least they're getting the information somewhere and they're getting those questions out. They're not just rolling around in their heads because a lot of times, just like adults, kids can kind of think of the worst case scenario. And it's much better that they have the concrete information so you can rein those in, any of those worries and all the what ifs. Anticipate changes and try to help prepare that child. These kids, particularly in this age group or this developmental stage, are more sensitive to the physical changes in adults. So very aware of hair loss, very aware of changes in weight, very aware of differences in energy levels. As I said, lots of questions and might not ask the parent. They still have that magical thinking. So again, this is why I think it can be so important to have adults who can answer their questions and check in with them because we've had kids who they think, well, I yelled at mom and then two weeks later she got diagnosed that I was really mad at her. And now this happened. So they can make these connections that we would think, why would they think that?

But they do. And so sometimes we can see regression, we can see acting out or we see it go the other way. And all of a sudden you have a nine year old who's trying to parent everybody because they're looking for some sort of control. So it's really just trying to figure out those boundaries and what's helpful and what they can do that can be helpful but they don't have to take on inappropriate responsibilities. Their big needs, clear communication, clear expectations, giving them permission to have fun, giving them permission to be with friends, giving them permission to still be involved in sports, telling them that we still want those things to happen as much as they can, making sure they have appropriate information, expressing and normalizing feelings and time and attention. It might not be

from you, maybe it's from some other adults, but just so that they're getting some of that special time. So our ten to 13 year olds, those preteens, a lot of the time, first of all, you're trying to tease out how much of it is just being a preteen, how much of it is stressed from the illness. And honestly, sometimes you don't get an answer to that.

You're just then trying to manage their reactions to things. So again, explaining the illness as clearly as possible, I think particularly with this age and up, because starting in this age group, access to computers, access to the Internet, if they have their own devices, if they're not getting the answers from you, they're going to look for the answers. So you want to make sure that you're giving them appropriate information. In our groups with the kids this age and up, we say the Internet can be our friend. The Internet can be our worst enemy as well. And so even you can have two people who are diagnosed with breast cancer and have very different treatment plans, very different outcomes, very different results. So you want to know what's going on with your person, not what you're finding online. So trying to make sure that they have appropriate information, giving them resources so it can be if you have more questions, let us know. If we don't have the answer, we will try to help you find it. You know, that you can empower them a little bit, but also making sure it's still within those appropriate boundaries. And again, keeping routines and activities as realistic as possible.

You could have a family where the kids involved in three different sports and all these different clubs and those different types of things. And that might not be realistic right now. So it could be talking with them about we still want you to have as much as we can. Can we pick one sport right now? Can we pick one activity? Can we do something that we know we can get you to and you're going to enjoy it? But it doesn't have to be all of the things. And again, because of just they're being preteens, there can be increased anger, mood, withdrawal. We see a lot more physical symptoms with this age. It kind of starts with the early elementary, too. So their stress sometimes comes out as headaches, stomach aches, body aches, those different types of things. So if that seems to be happening more frequently, it's just keeping that in mind and feeling like, okay, maybe we need to revisit some of the coping strategies and things like that. Grades can change. Those can be impacted. So trying to look at, well, then how can we provide them the resources and the support that they need?

So again, people to talk and listen to them, clear expectations, reassuring them about things and really trying to normalize feelings. Those are all key with this age group. How are we doing on time here? Okay, so developmental reactions, high school. So this is an age where they are in this gray area of independence and can take on more responsibilities, but they know it all and the adults around them do not. And so because of that, you're trying to navigate so many different pitfalls with this age group. So again, really explaining the illness as clearly as you can, talking with them about your own feelings and being honest and trying to encourage them to talk as well. There's that push-pull of that independence. But I think we also run into that concern of, especially with the older end of this age group, when we have had families that have had a diagnosis of cancer and there's like a junior or senior in high school, there can be specific concerns. There could have been a kid who was on the trajectory that they were going to go out of state for school and they're going to do all of these things, and that could be changed or they don't want to leave now.

There could be a lot of different conversations that happen. So that is something to just keep in mind with this age group big changes in behavior. Again, it's hard to tease out how much of it is the age and how much of it is the stressor. So sometimes you don't try to find the reason, you just try to address it. So structure, appropriate limits, having other trusted adults and people to talk to, they're going to turn to their friends. But you want to make sure that there's some other adults too that they can talk with,

because again, addressing appropriate information, correct information, and also that they're having appropriate responses to it, having healthy outlets for their emotions and for stress and really encouraging and supporting their involvement as much as possible in the process. So that way they feel like they're included and however much they want to be included, that they're given some freedom with that. As far as, okay, how can I help? The big part of that is kind of what is your role? Are you the parent? Are you a close family member? Are you a professional? Are you a support person?

Because that impacts how you can help. What does the family want or need? So again, you can have two families dealing with the same diagnosis, but they are going to take very different approaches to it. So we have some families who want everybody to know, want everybody to be on the same page. They are an open book. We have some families who are at the very opposite end of that. Don't want anyone to know. We've had some schools before call us and they're like, we have a family where the parent has had cancer for two years and we had no idea. So if you don't know, you can't help. So that's where it can be a struggle. But trying to respect that as much as possible, it's a sticky wicket when you're trying to navigate those things. Hopefully, if the family is open, then it's really a lot of asking questions. What do they want? What do they need? Because that can change over time. And what does the child want or need? I say that specifically because you can have two kids in the same family, and one of them, again, wants everybody to know and wants everybody checking in and wants to feel that support.

You can have a sibling who doesn't want anybody to ask, wants school to be school, doesn't want people coming up and saying how is so and so doing? And so it's trying to navigate and trying to respect that as much as possible. And then what is available? So in the setting that you are in. So if you are the person who's been diagnosed, then, okay, trying to pull together those resources, you might not need all of them, but it's good to know what's out there. I know with Connecting for Kids, that's something where it's really about the information. Like here's all the things you may pick and choose what you want. And so that can happen with any illness, knowing what's out there, knowing what's available, and then picking and choosing what you may want or need, or if you are a support person, allowing that family to pick and choose what they want or what they need. The other part of that, though, is what are your boundaries. And I say this because particularly those in kind of a professional role, and I'll speak from a school perspective. We have definitely encountered where a school professional will say, okay, I have this child in my classroom, and they're dealing with cancer in the family, but I myself lost my mom to cancer and I don't know how much of a support I can be to them.

And so that's healthy to acknowledge those boundaries. And so being able to acknowledge those, whatever your role might be, is then good, because you can say, okay, what am I able to do? What am I not able to do? And maybe there are other people who can do something different. So that is being able to pull together those resources and just knowing as the parent, as the person who maybe is dealing with the illness, what are your boundaries? What are your limits? What are you able to do? And that can change from day to day. So a lot of it comes down to giving yourself some grace and being realistic with what you are able to do. Because if you're realistic with yourself, you're going to be able to be realistic with the kids. And they're going to trust that more than somebody who's trying to tell them, it's fine, everything's fine. Everything's fine, because they're going to sit there and go, Everything's not fine. I know this is not okay. Something's going on, and that can lead to more of those behavior problems or emotional issues that we see rather than that, okay, this is hard, and we're going to try and figure this out.

And this is where we're at today. Kids are going to trust that more. So it's okay to say those things. As far as different resources and things like that. So I wanted to make sure before we wrapped up so just that

we have different groups and things at the gathering place. I'm happy to tell people more about that on an individual basis. There's a lot of different types of support that we offer at the gathering place. So these are different things for adults. Our website is touchedbycancer.org. And so all these things are listed. And so if you yourself are dealing with cancer and you have more questions, our services, as I said, are free of charge, and the majority of our services are open to anyone touched by cancer. So not just the person who's been diagnosed. So I'm always happy to answer more of those questions for people and then all of our contact information there. But I'm actually going to come out of this. So that way I can show you guys. Okay, so as far as different types of resources that are out there, there's a ton of different things, but I want my little thing here.

Okay. There's a great YouTube video that was put together by MD Anderson. So I just wanted to show you because if you type in specifically Kid to Kid: Your Parent Has Cancer, I would say probably eight years old and up. It's from a kid's perspective, but they go through what is cancer, what is chemo, what is surgery. And they do it in a concrete, but it's a professional way. So that is a great resource that's out there. As far as books, so the American Psychological Association has their own publisher, but they have a number of different books that are out there on a number of different topics. One of the ones that we really like is called *Visiting Feelings*. I'd say probably for eight years old and up. I really like it because it just talks about kind of feelings in the general way, but the pictures are really engaging. And for younger kids, there's a whole series called "The Way I Feel". I don't know if you guys can see that. So lots of different topics. They've got probably like six or eight, "When I Feel Scared", "When I Feel Worried", "When I Feel Sad", "When I Feel Angry".

So we really like these because again, for the age group, it's very straightforward, but starts that conversation. There's also for parents there it is. Okay. So there's a book that's out there called "How to Help Children Through a Parent's Serious Illness". This is not cancer specific. It's from a child life specialist perspective, but it goes through just very practical, but it's geared towards parents. So that itself is a great resource. The author is Kathleen McCue, and I do know local libraries have it. We have copies of it, but it is out there and it is available. And the other thing to kind of keep in mind is whether it's COVID, whether it's other illnesses. A lot of times we fall back on more general books, not necessarily specifically about a certain topic. There are a number of books that are out there that are geared towards kids around cancer. But a lot of times it's really just trying to give them the words and the language to be able to identify their feelings and express their feelings, because those are skills they're going to be able to use their whole life. So a lot of times we just really try to encourage parents to use those types of resources.

You can work in talking about some of the other things, but a lot of times it's really more about that resiliency and basic strategies. The other thing that I will say before we kind of move to questions is that if all else fails, if you don't know how to start the conversation, you start with a question. So with your kids or with any kid, you might want to test the waters first to see where are we starting with, what do they know about this before we jump into this bigger conversation? So it could be just asking the question, have you heard the word cancer? And that's the starting point. It gives you an idea where are they at with this before we launch into any of this other stuff and just asking those questions and getting them to kind of just give you that idea where they're at with things, it allows you to read the room basically as far as where they might be with stuff. So if all else fails, start with a question and that way it's at least a starting point and it can feel a little bit easier sometimes for the adults as far as far as like where do I go with this.