

Childhood Cancer Survivorship: The Family's Journey Forward

Nancy F. Cincotta, MSW, LCSW, ACSW, BCD
May 29, 2008 • 1:00pm

- OPERATOR: Hello, everyone, and welcome to *Childhood Cancer Survivorship: The Family's Journey Forward*, a free telephone education program. It is my pleasure to introduce your moderator, Carson Pattillo.
- CARSON PATTILLO: Thank you, and hello, everyone. My name is Carson Pattillo. I am the Vice President of National Education Programs for The Leukemia & Lymphoma Society. On behalf of LLS, we thank you for choosing to spend this hour with us today. We welcome all of you.
- The Leukemia & Lymphoma Society appreciates your participation in today's program, *Childhood Cancer Survivorship: The Family's Journey Forward*. Today's program is a part of the LLS *Focus on Childhood Cancers Educational Series* and is solely funded by The Leukemia & Lymphoma Society.
- We thank our speaker, Nancy Cincotta, for sharing her time and expertise with us today and for her ongoing dedication to serving families touched by childhood cancers.
- You all should have received a packet of information which includes a welcome letter, an agenda, Nancy's biography and some brochures about some of the LLS services and programs. We encourage you to look through those materials at your leisure if you have not already done so.
- You will also find in your packet an order form for The Leukemia & Lymphoma Society's materials and an evaluation form for you to fill out for today's program. For nurses and social workers, you can receive continuing education credit for today's program. We have included an evaluation form marked specifically for you. You can claim one hour of credit for participation in today's program.
- For your convenience we also have an Online Participant Evaluation Center. By going to www.LLS.org/eval, you can complete your evaluation online. I will provide a code for professionals at the end of our program today.
- After our keynote presentation, we will open up the program to questions from all of you, our telephone audience. We have over 1,100 individuals registered for today's program via telephone from all over the country, in addition to several international participants from the Fiji Islands, India, Iraq, Kenya, Lebanon and Singapore.
- If we are not able to get to your questions today, you can call the LLS Information Resource Center, which we call the IRC. It's a toll-free number.

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CARSON PATTILLO: The number is 1-800-955-4572. Dialing that number will connect you with an Information Specialist, who can answer your questions or help you obtain more information. The Information Resource Center's hours are between 9 AM and 6 PM Eastern Standard Time, Monday through Friday.

We're also audiotaping and transcribing today's live program for future posting on the LLS Web site and the program archive will be available in several weeks for you to access on our Web site.

I now have the pleasure of introducing our speaker, Nancy Cincotta. Nancy has been a social worker since 1979, having begun her professional career as a child life specialist and as a clinician, manager and educator, she has focused on the needs of families of children with cancer and related illnesses and bereaved families. Ms. Cincotta is the Psychosocial Director of Camp Sunshine in Casco, Maine. Camp Sunshine is a nationally based retreat program for families and children with life-threatening illnesses and bereaved families. Ms. Cincotta is interested in demystifying the emotional journey faced by children and their families once diagnosed with a life-threatening illness and exploring the burdens encountered by the resilience of professionals working in this area. Her current research centers on the role of hope in the lives of families with seriously ill children.

Nancy, we're so pleased you have joined us again today. You're back by popular demand. I'd now like to turn the program over to you.

CINCOTTA: Thank you very much, Carson.

I do apologize to people on the line, that I do have a cough, so hopefully that won't sound so funny in the teleconference. And I want to thank The Leukemia & Lymphoma Society for giving me the opportunity to join you again.

In pediatrics, cancer is a family illness as it impacts every member of the family. So cancer survivorship, from the diagnosis forward, is about those family relationships, and also the professional relationships encountered in the journey.

For some families, their doctors, nurses, social workers and child life staff become to feel like family and for a period of time families spend more time with the medical staff than they often do with their other family members and friends. I mention this now because this call is a combination of professionals and families on the line, and I want families to understand that as professionals it is our privilege to be let into that family unit. And it carries for us tremendous

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CINCOTTA: responsibility. We become experts by virtue of the time we spend with you as families, sharing and learning from your experience.

Families go from being independent, autonomous, seemingly in control of their own destiny and then are faced with this diagnosis of having a child with cancer. The response to that is one that can be where family members can feel overwhelmed, frightened, dependent, confused, somewhat lost in the world, so in a matter of moments everybody goes and has blood tests done or biopsies done and generally people leave situations without a diagnosis of cancer. But in that moment when the biopsy comes back or the blood test comes back, life changes. Not just for the child at that diagnosis, but for everybody in the household of that child, for the parents, for the siblings, for the grandparents. It does seem like, and we've heard people talk a lot about how you go from being in one situation to finding yourself in a situation that can feel crazy. And to reiterate again, it really is about what happens to normal people when they find themselves in an abnormal situation.

You question how you regain your composure after the diagnosis, how do you learn how to make decisions and make decisions quickly, how do you begin to think clearly once it feels like your world has been turned upside down, how do you maintain your family, how do you continue your employment, who do you rely on, what do you say to your children and how do you say it? Do you tell them that they have cancer and how do you tell them?

How do you get up in the morning and move forward? I often find myself sitting in a room with between 30 and 60 parents at Camp Sunshine and I sit in that room often in awe of the energy and the willingness of the range of things and intimate things that parents are willing to talk about. But one of the most common things I hear from parents is when they say that people will look at them and they will say to them, "I don't know how you do it." And in response to that do you think if your child was diagnosed with cancer, "What do you mean, how do you do it?" The answer is really that you have no choice but to do it.

So in feeling like whatever choice there is, is not there, the question becomes, what do you do? And I think that the remarkable thing is that children are resilient, parents are resilient and it is amazing, not just the strength that people find to endure the journey of treatment, but also the way in which some people grow and thrive in the face of tremendous adversity.

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CINCOTTA:

We've used the analogy before, you suddenly become part of a club, a club that you never wanted to belong to, certainly don't want to be part of, but once you're there, what do you do about it? And you think about what happens when you find yourself in a new place. Sometimes in life if you're taking on a new thing, whether it's becoming a parent, it's a new academic career, there are books and courses and things which allow you to acclimate to what those things are about. Well, in this club you don't really have time to prepare. So even if the books are written, and there are many great books and resources out there that you can learn about from the Information Resource Center at The Leukemia & Lymphoma Society, but in fact you don't have time to read the book. There is the sudden expectation that you will in fact be in this club and know the norms and acclimate pretty quickly.

So one of the things I'd like to talk to you about is the story of Holland. And I wish I could see you shaking your heads on the line if you know that story. It's a story that I've heard from a number of parents and it is in some ways analogous to some of the thought of what life is as you move forward with a child with cancer.

So the theory is, and I don't know who wrote this, but I do have copies available should anybody want, that you're planning a trip, you're planning to go to Italy, you're planning a vacation of a lifetime and you take out all the books, you learn the language, you have scouted it out, you've got the map, you know where you're staying, you know what you're doing, you've made all the connections, you've been planning it for years, maybe even decades. And then you get on the plane, you go and you find yourself – and you get off the plane and in fact you're not in Italy, you're in Holland. The people are nice enough, there's interesting wooden shoes, the tulips are beautiful, but you didn't want to go to Holland, you were going to Italy. So Holland is beautiful, but you're still there, feeling like you were supposed to have gone to Italy.

And I think that the cancer journey is a complicated one. It is not only a negative journey, but it is a changing of expectations and a sense of loss of where you were before you got to that world.

So how do you acclimate to a world where your child has leukemia, where your child has some kind of cancer? Acclimate is probably not the right word because acclimate almost makes it seem as though there's time to do that in the process. But what are the things that enable you to get through the process?

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CINCOTTA:

A child once told me that chemotherapy was like a school and that he learned much more from chemotherapy than he'd ever learned from going to school.

So if you think about everything you need to in those first weeks and months in response to this diagnosis, you find yourself learning a lot, not understanding some things, trying to learn how to understand the things that you don't understand, needing to make decisions, often within the first 24 hours, about protocols, about treatments, about the center you're going to be served at, about the physician you meet, a medical group in one moment, and seemingly in the next moment you are suddenly signing off on protocols and details that are going to mean the difference between life and death for your child.

In the mental health world, people will tell you that if you experience a crisis, it would be advisable to not make any decisions within six weeks of that crisis. Don't make any major life decisions. Well, the reality is in the cancer world, six weeks is a real luxury and you're making decisions often within the first six hours, nonetheless the first six weeks.

So what are the common themes in the journey of childhood cancer? Well, there is the impact of diagnosis. The word cancer is very prevalent in our society and although there are thousands and thousands and thousands of childhood cancer survivors, those are not the images that are conjured up often when you hear the word cancer for the first time. So there's the impact of the diagnosis. Really having your breath taken away and then regrouping and trying to understand what it means and what it means for your child.

In a family it also means the impact on the parents and then the impact on the children and how you interface between the two as a parent. How you begin to cope yourself, almost immediately, so that you're in a position of then being able to help your child and your children.

How do you explain cancer to a child and then how do you deal with siblings as well? We live in an era of tremendous amounts of information and everybody has information. Kids have information, adults have information, so the sharing of information honestly and openly and quickly is again one of the more pressing things.

How do you manage information and make quick decisions? What if you're somebody who takes time in making decisions? Not everybody is so quick to look at the facts and then think gee, this is what I should do. But actually you need to learn how to manage information quickly, how you look at your finances.

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CINCOTTA:

Many people, the whole country, is overextended in money, but all of a sudden you may be facing the treatment and the needs of your child. Who knows where you are in your career when this happens as a parent. How do you rearrange your work, your career, your profession? Do you still think of those things that way, once you're sitting with this information about your child?

I've heard a lot of people talk about their changes in their relationship with work, their desire to work, their ability to push harder and focus on work. And the ability for work to both be supportive, but over the long haul, how do you deal with that?

One of the interesting themes in the journey of childhood cancers, almost everybody needs help. It's the very rare family who can go through this without getting help from somebody, from organizations, from communities. Yet the question is, do we ever learn how to accept help? People are often uncertain about how to ask for help and even more uncertain about how to receive help. And then the people who are offering and receiving on the other ends are also not necessarily so clear, how do you do it, what do you do, how do you help people?

So I think that some of the cancer journey is about being a little bit humble and learning about yourself as an adult and as children, learning about what you need to do for yourself and what you can enable other people to do for you, all the while trying to make sense of what at the beginning sounds like a very confusing story ahead.

I think when you're faced with the diagnosis, you learn about the different styles of coping in your household. Now you may have known those before, because most families face some type of crisis as a growing family. But the diagnosis and treatment of childhood cancer really does clarify for everybody, how they cope, what they need, who they are. And I think of the interesting example, say there are two parents in a household and one copes by seeking information and the other copes by hiding their head in the sand. Both two different styles of coping. You can critique the efficacy of one versus the other, but if you're those two combinations of people now, it's really hard to be somebody who would like to not know everything, if you're living with somebody who really needs to know everything. So even just stylistically there are issues that emerge for couples, issues that emerge for siblings, even understanding and managing your friends and family becomes a complex situation.

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CINCOTTA:

What tends to happen in most families is that both adults don't necessarily cope the same way. Very rarely will you have two optimists, two pessimists. So in some ways people do facilitate each other's coping just by being different in the way that they cope. But there are many issues that emerge for couples along the way. Is there one person who is the primary decision-maker, do people make decisions together, how do they communicate about information, who understands the information, who learns the information, who translates? Is there one family member who becomes more the person to be at the hospital, how do people make decisions about both not just care-taking, but will somebody continue to work, will somebody stay home? So in those early periods there are many decisions that have to be made and they are complicated, but nonetheless people do make those decisions and I think that there is a resilience again between couples, not to just make decisions, but then to change decisions along the way as they need to.

There are many emotional and existential places, again, that you go when your child is diagnosed. You don't necessarily go there in the first days and weeks, but there are moments when you find yourself really dealing with a sense of isolation, a way of trying to figure out how this new normal fits with your life. And again, trying to think through what the private experience you're having is and how you maintain control in an environment that sometimes makes you feel as though you don't have control.

There's an existential crisis often for oneself as an adult and it really does raise issues about the meaning of life, the value of life, what's important to you and where you are, where you are going. Obviously the overwhelming nature of a cancer diagnosis stops many families in their tracks for where they are and all energy goes into taking care of the child initially. Then, with people beginning to learn how to reframe and rethink things along the way, so that there can be some maintaining of family functions as they were previously happening.

So when you think about connections and what happens, you think about families. And I have this concept that I have been thinking about for a long time, that I would call family memory. And interwoven in the fabric of every individual is this concept of family memory. I use it to depict a critical component of family life. A major component of the ongoing existence of a family culture. This is the wealth of knowledge that individuals in a family carry with them about the past and it's carried with them throughout their lifetime. And it serves as a vehicle

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for understanding one's role in the family and the connections among family members. We begin compiling data for this family memory bank at a very young age.

So this is not a very complicated concept and I don't mean to make it sound that way, but the time parents and children spend together, composed of very special routines or even boring routines, becomes stored in the eaves of our minds forever. So these memories are the threads that compose the unique design, different for every family, which serve as one way of maintaining a special connection among family members.

I would like to ask you to close your eyes. The joke of this now in the teleconference is I have no idea whether or not your eyes are closed, so I can't tell if you're cheating or not. Nor can I tell if you're laughing at my jokes.

So I want you to think about what I'm talking about, so it makes sense. Think about memories from your early childhood or your later childhood that stand out in your mind. Some funny family adventure, when the car broke down, a trip to the beach, a roller-coaster, when everybody had the flu and everybody was home sick, getting snowed in somewhere, going out for ice cream, spilling eggs on somebody. Things that maybe are not such a big deal, but in your family something happened and you remembered it and you know that at any moment you could go to your mother or to your sibling and they would remember that experience and you could laugh about it.

So what's kind of interesting is that one of the things that the childhood cancer experience does, is that it changes that memory bank a little bit. For families with healthy children, generally there are happy memories that stand out until like the ages where kids become increasingly independent. So you think about that, like for kids maybe for 10 or 12 years, you have those times, that family time. And some of it is just the time that's off from school or the free time in the house or the crazy things you do.

And so when you think about it, one of the things that happens when you're diagnosed with cancer or some other life-threatening illness is that the family memory changes. Kids get split up for long periods of time, parents often divide and conquer so that someone will be able to stay with the child in the hospital and someone will be home. And some periods of that memory bank time are eaten up by illness memory. So some of the positive memories are changed with negative memories or at least hospital memories. And memories that may be a

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CINCOTTA:

little bit difficult, but also spending inordinate amounts of time apart from one another, family members' experiences become separate and unshared. So siblings may not have that many hours together or that much fun time together and the volumes of memories begin to have different subdivisions.

So when you think about it, the illness in some ways affects the present, but it also takes away a piece of the ability to do what families do, which is to share the past in the future.

So when you think about that, and the reason that I bring this up here, is because this is a very interesting concept about how you think about how you go through the cancer process with your child. And you think about what the role of building memories and what some of the therapeutic interventions or some of the wonderful things that families can and do together, happen during the course of the illness treatment.

People always ask the questions, should I bring the siblings to the hospital, should I keep life as normal, should I do this, should I do that. And I think one of the interesting things is that you'll hear everybody say I want to keep life as normal as possible for my children, I want to keep life as normal as possible for the sibling, but the reality is that life is not normal once your child is diagnosed with cancer.

That does not mean that life will not be normal again or will not face a new normal, but the reality is that period of time of treatment is an atypical time. And perhaps the focusing on family memories and the focusing on time people can spend together, the Thanksgiving dinner made in the hospital, the day a child misses from school to be at clinic to support their sibling or to see that their sibling isn't going to a better world where they're getting millions of things and that the sibling who stays home isn't being deprived of a life-changing experience. That the opportunity to build memories, create memories and to have fun becomes a really critical component of the pediatric oncology arena. So that when people are creating a party or referring a family to a wish program or having a camp experience, that those experiences need to be seen as in concert with normal child development and the normal building of family ties and family memories. So the opportunities should be there, not just for the child who is sick, but for all of the children, so that they can continue to have what is a normal life of children together, but in this case it wouldn't be in the same arena. It would be in the hospital, it would be at the clinic, it would be on a particular trip.

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CINCOTTA:

So I guess I want you to hold onto that idea of creating memories and creating opportunities for families to share some more of their life together.

I'd asked a number of families to describe for me kind of quality of life after cancer treatment. And I just wanted to read you this person's response.

This is a mom and she said, "after cancer treatment," is to use an analogy for her of post-traumatic stress syndrome with military returning home, "there are so many emotions and issues to deal with that appear opposed and are not well understood by anybody who hasn't joined the club. Elation and fear are everyday undercurrents that just do not go away. A non-medical driven, bipolar, day to day existence. Life is different because every member can't help but look through the cancer lens. From the outside people seem to think that everything is what it was before diagnosis. Each member of our family is in a different place on this journey."

When you're talking about kids, you're talking about so many developmental issues that come into play. The age of the child who's diagnosed and the sibling ages make a very big difference in what children understand and how children can understand.

If you take anything from this teleconference today, I would ask you to think that not only do children need age-appropriate explanations of what their diagnosis is and what their treatment is, but that as children grow those explanations need to grow with those children. So maybe annually or what works in one's own family, that children need to revisit the idea, both children on treatment and siblings. Siblings often feel like the whole treatment thing is a big surprise being kept from them and they need to be involved in the knowing and the understanding of what the child's diagnosis is and what the treatment is. But what a child understands at 2, 4, 6 or 8 are very different than what they understand at 10, 12, 14 and 18. So sometimes children are given an explanation at the time of diagnosis, but that explanation stays in their heads as the same age as it was when they were diagnosed. So again, the conversations can be different at different ages and the conversations need to grow as children grow.

For children, play is their work, school is their work, and those are places where children can find great benefit in the understanding and the coping with their illness. So I would invite your children into a conversation about their illness and if it's a younger child I would have that be the vehicle for that to be play.

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CINCOTTA:

There are many, many issues that come for families with kids with leukemia and other life-threatening illnesses related to school and school issues. There's a whole series up on the Internet from The Leukemia & Lymphoma Society related to educational and school issues, which are downloadable and really helpful for people to learn more about what to expect and where to expect it.

So again, I would think that when looking at issues related to childhood cancer, they always need to be seen through the lens of the developmental age of a child.

For families, there are different stages of family development that also impact on where a family is at, how they deal with the diagnosis. And I'm going to give one simple example.

Many families have young children who are diagnosed with cancer at a time when they may have only one child, they may be thinking about how many other children they will have, and their life becomes challenged by the cancer diagnosis. And those questions about do I go on to have other children, am I going to be able to cope with that and to cope with this, what can I do with my life, those questions all become part then of what are the challenges imposed for families with kids with cancer.

Families respond to social support and to having a community of people to ask questions. Most people benefit from the support of other people in most activities that they do in life. So in the cancer community, that is not any different. So that people benefit from the mothers' support of other mothers, fathers' of other fathers, kids with kids, siblings with kids. And one of the things that we've really found to be very helpful is that not only groups of children having the ability to help each other, but if you have a sibling who has cancer, if you find yourself in a support group with another child who has cancer, but is not your sibling, you can learn so much and you can find yourself compassionate at a whole different level, when you find yourself in a room with somebody else in the same situation as your sibling.

So quality of life after treatment is in fact – there's another statement that I want to read to you. I know that we are running close to the time now. One of the things of the re-entry into the non-cancer world, after you've been on treatment, "I think the main issue" – I'm reading from a family's quote – "I think the main issue we have had to deal with as a family is the out of control feeling of not knowing what the future holds and thinking that at any moment, at any second,

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CINCOTTA: perhaps when we least expect it, this cancer thing could rear its ugly head again and mess with everything." So not knowing I think is the most challenging and then balancing this with living fully in the present moment.

One of the things that families really learn to do during their cancer journey is how to appreciate every day and how to live every day to the fullest.

With that, I think what I would like to do is to go back to Carson and think now about some of the questions and answers for the audience.

CARSON PATTILLO: Thank you so much, Nancy. Such an informative presentation and your compassion, insights, knowledge come through, they shine through, so thank you for all that you said.

It is now time for the interactive part of our program, the question and answer session. And before the operator gives instructions for all of you to enter the question and answer queue, I would like to remind all of you that because we have so many on the line, for everyone to benefit, if you can please try to keep your questions general in nature and Nancy will provide an answer general in nature. Your phone line will be muted after you ask your question, so that Nancy can respond.

Operator, can you please give instructions to our telephone participants, so they can queue themselves for the question?

OPERATOR: To participate in the call by asking a question, please dial star-1 on your keypad. We will take questions in the order they are received. Be aware that due to time constraints, we can only take one question per person. Once your initial question has been voiced, the operator will transfer you back into the audience line. Again, to participate in the call by asking a question, please dial star-1 on your keypad.

CARSON PATTILLO: Thank you. Let's take our first question, please.

OPERATOR: Our first caller is Jeannie from Florida.

JEANNIE: I hope I don't frighten anyone, but I am a 30-year survivor of Hodgkin's disease and I had no centers back then to tie into. And I'm still looking for my club members. There of course are other members that have had an illness, but with the late effects that I constantly have to deal with – fortunately, I've had no reoccurrences. But the late effects of the massive amounts of radiation that I did suffer, and I also went on to have children, keep me in a frightened mode of quality of life. And these things that you're explaining, the emotional effort, I'm

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JEANNIE: still trying to find in my community who can help me identify the difference between an adult woman going through an illness as an adolescent, to what is reality in my emotional state every day. Because I do have children. And I also have two grandchildren. And it is quite frightening. But like you said, Nancy, the emotional status of living life to its fullest. Yes, I've learned to be able to do that, but I still seek out where the information is. Where are there people like me? Being that I did survive a childhood cancer as an adolescent. That's why I'm calling in today. And I hope that I don't frighten anybody, but I also hope that I give hope to others as well. I keep looking, I keep asking, where is the group that I belong to? If anyone knows of anyone like me, I would appreciate somebody to contact me.

CINCOTTA: I think that it's wonderful to have you on the line and I wouldn't worry, if I were you, about frightening anybody. And I think that you should give the operator your contact information because in fact, one of the things that happens when you run the program that we run at Camp Sunshine, and I'm sure for The Leukemia & Lymphoma Society, is that you do have people who are coming back 20 and 30 and even 40 years later in situations where they're looking both for medical information and also for people who are in their cohort. It is, I think, truly one of the most common components of human nature, is to want other people who have gone through what you've gone through and come out the other side. And I think that if we can play a role in matchmaking people, that would be great.

I think that it is also true that sometimes if you are a trailblazer, it is much more complicated emotionally because you didn't grow up having that cohort and you didn't grow up having that independent support. But this is an exciting time in the cancer world and there are many people alive, as many years down the road as you, so I think that is our call to action, to help people connect with each other. And I think that it's really great to hear from somebody who is a 30-year survivor.

CARSON PATTILLO: Thank you for that, Nancy, and also thank you, Jeannie, for being on the line. And just voicing what you just voiced, reassured many that may be in a similar situation as you. There are organizations out there. And just from The Leukemia & Lymphoma Society's perspective on – if you have access to the Web or your children or grandchildren can help you gain access to the Web site. On our Web site we have a bulletin board and you can communicate with other patients and survivors that are in a similar stage as you. That might be the second step. But today was your first step. So thanks again for being on the line.

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CARSON PATTILLO: Let's take our next question, please.

OPERATOR: Our next question comes from Lorna in Canada.

LORNA: Good morning. My 11-year-old son finished 39 months of chemo six months ago. His prognosis from day one was excellent. He was a textbook patient. He is experiencing anxiety now and it seems to be snowballing. Aside from talks of his own mortality, be those conscious or subconscious, he has also experienced the death of many friends and one just a few days ago. We are going to get him into counseling soon, but I'm wondering what hope can we have for emotional normalcy for him and how common is anxiety for these kids?

CINCOTTA: Thank you so much for calling. I think that is it very common for kids to – either during treatment or after treatment – to experience anxiety at some point. They have been through – you know, when you think about even how they were prepared going into it, for everybody, you hit the ground running. So you don't have that anticipatory time to prepare and to even think about how you will cope about the situation. You just deal with those 39 months of treatment.

I think that it is very, very common, unfortunately, for children with cancer to meet other kids along the way who do not survive. And I think that is one of the issues for kids, that they have to deal with in their growing up and their feeling sometimes even, how come I survived and they didn't survive, and feeling guilty about that. Or worrying, in fact, about their own survival. So the anxiety has some ways in which it can be expressed and people can tap into to identify what your son is actually feeling and what the anxiety is coming from.

I think that the question of – it sounds like you're already getting treatment – and the question of when is it good to get help and what kind of help is out there? There are both connected to treatment centers and then connected to cancer agencies, there's a cadre of well-versed clinicians who understand the cancer process. I think that for all kids there may be a time when they could benefit from some type of individual treatment. There also is a tremendous benefit of group treatment because many kids experience some of the same emotions and I would check to see if in the location near you there is such a center.

But I think that it is part of the process and for many kids there is a period of working through that anxiety and working through the understanding of where they are and what happened to them and how that is different than the experience of some of their friends. And also dealing with and mourning the loss of friends who they've become connected to along the way.

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CINCOTTA: There are programs – I will do a one minute – Camp Sunshine serves as a retreat for families of kids with cancer and there are very common themes in our kids' program and in our parent support group. And it's a program available to people nationwide, regardless of where you live, to either come to the program in Maine, come to the program in Wisconsin, and be part of that growing effort. It is very nice for kids to be able to have a cohort of other kids who have gone through the same issues.

So I think that you've done a great job in identifying the need for help now. And sometimes I think people question for a very long time if their children need help. If your child is showing signs of anxiety or depression, it is of great benefit to connect them with somebody who can just help them deal with those issues and kids really do, when put in the situation, talk and express and deal with the issues they've encountered.

CARSON PATTILLO: Thank you, Lorna, for your question. Let's take our next question, please.

OPERATOR: Our next question comes from Pamela in New York.

PAMELA: I actually do not have a family member nor am I a survivor, but I do have friends who have a little boy who's 6 or 7, have gone through this. I actually own a learning center in New York and my question is more post-treatment for these kids. I've read a lot about developmental issues that can occur or may be occurring because of the radiation and the chemotherapy, and I'm just wondering if you've heard of any programs specifically and you know of their efficacy with these kids, so that they don't struggle through their childhood, through their teen years and even into their adult life, so that they can actually get those skills, closer to a normal functioning level, so that they can have a fuller functioning adult life.

CINCOTTA: That's a great point and a great question. I think that we are seeing that a lot of children on some of the leukemia protocols and other protocols are experiencing different learning problems. There are a couple of different issues. Some children experience learning problems because of the issues that they face in missing school, not being caught up with their cohorts, some of the emotional issues around medical care and their situation, when given added support when treatment is done or during the course of treatment, is that they are frequently in the position to be able to catch up.

There are other children who, because of radiation and chemotherapy, intrathecal medications, are experiencing other problems. And I think that it's very well known in the leukemia population to now be versed in understanding those

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CINCOTTA:

problems. There are lots of recommendations for kids to have learning evaluations very early on, at the beginning of their treatment, to be able to understand where they are baseline at that point and then to be able to understand later in the process where they are and to become connected to neuro-psych people and education people, connected to the treatment center, who have a strong sense of what is happening in the protocol and then what the implications are for that, and providing the supports in place.

That being said, I don't think this is an area that is still one which is perfect in the world and that people like The Leukemia & Lymphoma Society, who are kind of leading the initiative with this, with their back to school program and with their online resources for educational programming, but that this is a very, very important issue. And that it is overwhelming often for parents at the beginning of a process, when they have a child who's diagnosed with leukemia, to be focused on all the other issues that a child may face. But it's a very important issue and there are, in fact, protocols that have been developed and support that is out there for kids, so that it becomes important.

And one of the places to start with that would be to start at The Leukemia & Lymphoma Society Web site with the back to school program and all of the initiatives. There are tremendous materials that are available that would help any child who's had cancer or any other life-threatening illness, but certainly if a child is experiencing any educational problems.

And the message to families would be really not to wait. If you notice that your child is experiencing any type of regression in their learning, any issues in learning, behavioral issues that seem to be not connected to something else, but may well be connected to learning issues, so that the idea would be to seek help early and to start even with The Leukemia & Lymphoma Society.

CARSON PATTILLO:

Pamela, thank you for the question. Let's take our next question, please.

OPERATOR:

Our next question comes from Marianne in Ohio.

MARIANNE:

To follow up with what you just said, it makes a lot of sense to us. We are not waiting. We know exactly what our son might need for support in the future because he has already had two neuro-psych reports done. But what happens is we have this wonderful document, but we bring it to the school and we bring it to other people in our community, and I just think they believe we are looking for problems or being slightly neurotic. And I think we're doing a really good job finding a balance, but I'm looking for any insight because we are seeing the signs

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MARIANNE: and our son does have anxiety, based on all that he's been through. Looking for advice of how to not just appear like we're looking for attention, looking for more than we need.

CINCOTTA: How old is your son?

MARIANNE: He is 11.

CINCOTTA: I think that you have touched on again one of the very complicated issues for families. My experience at camp is often to hear stories of families, knowing that their kids need help, even being armed with the information, and then struggling with the world to understand and support that information before there is kind of an ensuing crisis, where it becomes apparent to everybody that a child is having problems.

So that one of the pieces of advice really is to both be consistent and not to feel as though you need to stop advocating, even if it appears as though to the world you're advocating too much. Because in fact, advocating for your child is something that is very important to do and it sounds like you have already begun that journey.

There are many organizations out there for help, but I would contact the local Leukemia & Lymphoma Society because I know many people who've had the experience of connecting with their local Leukemia & Lymphoma Society and having that person help them through some of the issues that they face, both at the school and in the community. And it is even helpful, even more helpful sometimes, to have a group willing to go out to the school to address these issues and to have people come onboard. Because even though this is becoming common knowledge in the cancer community, it is much less so the common knowledge in the education programs.

There are many, many back to school conferences, initiatives out there by The Leukemia & Lymphoma Society. And it's even helpful to invite your child's teachers and the people who do testing at the school to attend those meetings because it's almost like opening up a whole new area of information.

So I would encourage you to keep doing what you're doing and use The Leukemia & Lymphoma Society for help.

CARSON PATTILLO: And Marianne, to follow up with what Nancy was saying, if you call the 1-800 number, the Information Resource Center number, 1-800-955-4572, that

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CARSON PATTILLO: number is on the materials in your packet, you can speak with one of our specialists to support you and reaffirm what you're doing as positive and wonderful, but can also give you the contact of your local chapter in your area. And that person in the local chapter is called the Patient Services Manager, who can be your conduit in your armor in getting information out on behalf of your son and supporting your son. So please reach out to us, we are here for you and hopefully can assist you.

Let's take our next question, please.

OPERATOR: Our next question comes from Kathleen in New Jersey.

KATHLEEN: I have a grandson, Nancy, that is 3½ and was diagnosed with ALL leukemia [acute lymphocytic leukemia] on November 3, 2007. So he was going to the clinic, CHOP, the Children's Hospital of Philadelphia, but a branch in Voorhees. And he would get transfusions, he would have to get the blood and some other kind of blood and the ANC counts would come down and his mom wouldn't let anybody in or anybody out. And my son – she seems to be able to confront the fact that he has cancer, but I don't think my son has ever been able to really accept the fact that his son does have cancer. And then when he lost his hair I thought oh, well, maybe he'll realize it now. But I just think he's expecting a miracle before his three and a half years is up, where his therapy – and then that way he won't, hopefully, he'll never have cancer again. And his demeanor is he's very demanding, uncontrollable behavior and craves enormous attention, but only from his mother. He will not let her go. He does not let my son near her. He tells him to get away. And then I think my son maybe isn't accepting it because he feels isolated.

CINCOTTA: So I wish this was, Kathleen, the first time I was hearing this story. But thank you for calling with this information.

I think that sometimes, depending on the roles in the family and the situation in the family, that mothers are frequently the people who go to clinic and are around, particularly younger children, during that intensive period of chemotherapy. And that they become the object for the child who is there, both to express themselves and that it is almost like there's a partnership in going through treatment together.

It sounds like there are some complicating factors. And I do think that – I've had the experience of a father who was a very lovely man, sitting in the car throughout the three years of his child's cancer treatment, not being willing to

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CINCOTTA: come in to the center. And I think that there are more natural opportunities for women when they are at the centers to talk with other mothers and to have the experience of the connection with other people and also to have the direct information from physicians and nurses. So that when you're the parent who is not at treatment, you then get the information through another person and sometimes then the burden is placed on the person giving the information. So that I think it just makes it very, very complicated.

I think when you're a grandparent and you're watching this for your own family, you, of course, want to do whatever you can do to kind of make it better and it's a three and a half year course of treatment, so it's a very long time.

I don't want to always sound like a commercial exclusively for The Leukemia & Lymphoma Society and for Camp Sunshine, but one reality is that one of the things we've really come to see, particularly with men in the program at camp and I believe in some of the group programs for parents at The Leukemia & Lymphoma Society, that men really benefit from the opportunity to be in a room with other fathers and to hear what the experience has been like for them and also to break down some of the barriers for trying to understand and trying to accept the reality of a child's diagnosis and what the treatment and what the three and a half years of treatment would be. So perhaps there could be a resource for your son in one of these programs.

For all of the situations we've talked about so far, families are welcomed to apply to Camp Sunshine, where it is a retreat that has a psychosocial program, so there is a group program that runs five of the days that people are at camp and many of these issues are discussed. And I just think that in some situations it is harder for fathers to be in the information in the same way that mothers are in it and that they actually benefit from outreach and support around those issues. So my hope would be that there could be a resource for him out there.

CARSON PATTILLO: Thank you, Kathleen, for your question. Let's take our next question, please.

OPERATOR: Our next question comes from Jennifer in Idaho.

JENNIFER: This is Jennifer in Iowa. My question is my husband and I, when you talked about how couples differentiate in dealing with cancer, my husband was more the optimist and I was the one dealing with it with our daughter. And I was at the time pregnant with our son. And it was a lot to deal with alone, all on my own. And to do all the things. And now after she has been off cancer treatment for two years, there seems to be almost a void there because we didn't focus on our

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JENNIFER: marriage so much, but more on our children. How do you get past these difficulties within your marriage?

CINCOTTA: I think that one thing to know is that you're in a situation that many, many, many, many parents of kids with cancer are in. So that it is not something to believe that your relationship is particularly more complex or troubled or complicated than many of those of the people around you. The way that families often survive is pulling together in the interest of the kids and doing what needs to be done and then there is that one person who goes off and is at the hospital alone and finds themselves at least feeling more alone in dealing with the experience. And I think that sometimes it takes treatment to end and people to find themselves feeling separate from each other, to begin to then work towards things that would in fact be helpful, to bring them together.

I think that couples counseling at a time when the family can do it can be a tremendously helpful avenue to just get the discussion going again about what happened and what was the experience. Because often what happens is people have the experience and they never go back and relive it or deal with it. And I think the same way that I was talking before, about how kids are at developmentally different places, so that they need kind of a more enhanced version of what the story was. Well, I don't think that's necessarily so different for young families, that have not lived through all of life's tragedies together and they are facing this tragedy. And the skills that people innately have to deal with this or kind of you go into survival mode to do what you need to do. So to be an environment where someone else would bring the conversation back to what happened at diagnosis, what happened in those years after, what were the feelings, what was each person feeling. Perhaps it was a very lonely journey for both people and that maybe there are ways to make it less lonely now, to kind of go back, relive it and find a feeling of relief that you did live through that period. You got done, you needed what you needed to get done, and now the time is there for you to take care of each other and to take care of the relationship. And to talk about it and to open communication about the experience.

CARSON PATTILLO: Jennifer, thank you for the question. Let's take our next question, please.

OPERATOR: Our next question comes from Emma in California.

EMMA: Good morning, thanks for taking my call. I have a daughter who is now just a year over treatment from acute lymphoblastic leukemia and we've been lucky enough to have psychological support through two professional psychologists

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EMMA: who work with our hospital. And I thought it was interesting that Nancy focused a lot of her talk on treatment and the need for support during and immediately after diagnosis. What I'm finding now is, for a start, we're at risk of losing the two psychologists we have because they've just lost their funding, so trying my best to do what I can to get fund-raising grouped together, because my daughter does, a year and a half after treatment, still have psychological issues. I think a couple of the other families have mentioned this, the fears of her own mortality, she has body image issues because she often became bloated with all the chemotherapy, and all those sorts of things that are impacting her life. As well as the ongoing impact on the rest of our family's life. And I'm finding it difficult to find resources post-treatment. All the while you're in treatment, you have the support of the doctors, the hospitals, the schools are a lot more empathetic. What I'm finding is post-treatment, is you almost become isolated again. And if we lose our two psychologists, we'll pretty much be on our own unless I can get the funding together to keep these psychologists onboard. And also to try and institute a long-term follow-up clinic in our area because long-term follow-up clinics are few and far between, I'm finding. And it's not just the psychological aspects that concern me, but also the physical and other aspects that are now becoming much more understood with more children surviving from cancer diagnosis.

CINCOTTA: How old is your daughter?

EMMA: She's just turned 8. She was diagnosed in February of '05, just before her fifth birthday.

CINCOTTA: I think that you are on target with everything that you have just said. There are increasingly more follow-up clinics, but they are still more scarce than treatment programs. So that it does behoove people to either in their own centers, work to getting a follow-up treatment program working, or to identify in your area a follow-up treatment program. Because you're absolutely correct, for both the medical issues and the psychological issues, you want to be able to have that resource.

Now hopefully they will not let go your two psychologists, but I hear that issue and concern and I know that in healthcare today there are issues with support services. You know, an active parents group is also a very important feature to helping preserve services and also to giving your child a reference group for other kids who've gone through. I think again, kids groups for kids starting in that 8 to 12 group, where they are both expressive and creative and are able to play and

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CINCOTTA: talk through various issues, would be a wonderful opportunity for your daughter. And I think that in fact, that survivors need as many services as kids on treatment. And I do think that that is something that it becomes worth partnering with the many organizations that are out there and doing that. And there are coalitions of survivor agencies, but I would do what you are doing and I would continue the search for a survivor program that would then also be able to offer other support services around it. And I would look at programs like Camp Sunshine and the off-treatment program and even the programs that have children still on treatment, because a year off is not very far off. And some of the services should still be available that are available to others. Carson?

CARSON PATTILLO: Emma, thank you for the question. And thank you all for your questions.

Our program has come to a close. The time was too short. If you can all please help me thank Nancy Cincotta. We are so grateful that she has donated her time to us today. Nancy and I hope that many of your questions were answered and that the information provided will assist you and your family in your next steps.

A reminder to all of you to fill out your program evaluations. Or if you are a nurse or social worker, to fill out your continuing education credit form. And you can return the evaluation in the envelope provided. We do encourage you to complete your evaluation online by visiting www.LLS.org/eval. Nurses and social workers must enter a code to obtain your credit. That code is PEDS56OC. You may also mail your evaluation in the envelope provided, if you choose to do so.

Our Information Resource Center is open. Do not hesitate to contact us if you have further questions. Our master's level specialists are available to provide you with more information, can link you with your local chapter. And again the number is 1-800-955-4572.

On behalf of The Leukemia & Lymphoma Society and Nancy Cincotta, I'd like to thank you all for sharing your time with us today. Good-bye and we wish you well.

OPERATOR: This concludes today's conference call. You may now disconnect.

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