

How Childhood Cancer Touches the Entire Family

Nancy Cincotta, MSW, LCSW, ACSW, BCD
May 23, 2007 • 1:00pm ET

- KEY:** Inaudible/unintelligible words/phrases are underlined.
- OPERATOR:** Hello, everyone, and welcome to *How Childhood Cancer Touches the Entire Family*, 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 The Leukemia & Lymphoma Society we thank you all 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, *How Childhood Cancer Touches the Entire Family*. Today's program is a part of the Society's *Focus on Childhood Cancer Education Series* and is funded by The Leukemia & Lymphoma Society. We thank our speaker Nancy Cincotta for sharing her time and expertise with us today and for her dedication to serving families touched by childhood cancers.
- You all should have received a packet of information that includes brochures about some of the Society's services, a flyer for our publications, *Emotional Aspects of Childhood Blood Cancers* and *Learning and Living with Cancer*, and Nancy Cincotta's biography. We encourage you to look through the 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 in your packet. If you can please return that form in the envelope provided to claim your one hour of credit. All other program participants may use the envelope to return your program evaluation.
- After our keynote presentation we will open up the program to questions from all of you, our telephone audience. And we have just about over 1,200 individuals participating today, via telephone from all over the country, in addition to several international participants. International participants are from Ethiopia, Fiji Island, India, Venezuela, Iraq, Lebanon, Mongolia and Pakistan. We welcome you.
- If we're not able to get to your questions today, you can call the Society's Information Resource Center, which we refer to as the IRC. It is a toll-free number, which is 1-800-955-4572. That number is on the material that was included in your packet. Dialing that number will connect you with an

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CARSON PATTILLO: information specialist, who can answer your questions or help you obtain more information. We encourage you to call the IRC to order materials specific to your needs. The regular hours for the IRC are 9 AM through 6 PM Eastern Standard Time, Monday through Friday.

We're also audio taping and transcribing today's program for future posting on the Society's Web site. And the program archive will be available for you to access in several weeks on the Society's Web site.

The Leukemia & Lymphoma Society provides critical information and support to all patients, families and caregivers touched by blood cancer. And the Society has 67 chapters nationwide, and three in Canada, and offers a comprehensive array of free services to patients and families touched by leukemia, lymphoma and myeloma. The Society's mission is to cure these cancers and provide support for patients and their families. We hope today's program is a step forward in providing up-to-date information and resources for childhood cancer survivors and their caregivers, the whole family.

I now have the pleasure of introducing our guest speaker Nancy Cincotta. Nancy has been a social worker since 1979, having been a child life specialist before that, and working as a clinician, manager, researcher, writer and educator focused primarily on the needs of children with cancer and related illnesses and their families. And she currently is the Psychosocial Director at Camp Sunshine, a nationally based retreat program for families of children with life-threatening illnesses and bereaved families, in Casco, Maine. Ms. Cincotta's primary clinical and research interests are related to how children and their families cope in the face of serious and life-threatening illness, demystifying the emotional journey children and their families' face, once a child is diagnosed with a life-threatening illness. And the resilience of the burdens of her profession in working with seriously ill children and their families. And her current research centers on the role of hope in the lives of parents facing the illness of their children. It's such a pleasure to have Nancy with us. Nancy, I'd like to turn the program over to you.

NANCY CINCOTTA: Thank you very much. It's so exciting that there are 1,200 people on the line. Even more exciting to me is that, of those, 400 are family members facing a childhood cancer, that experience. I think that for all of the 800 professionals and for myself, what I would really like to say is although I am the speaker on this call, it really is the families who go through this process, who are the experts, and who have been our teachers in how it is that you cope with childhood cancer.

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NANCY CINCOTTA:

At Camp Sunshine I am honored to be in the position of doing all of the mental health programming and running groups, sometimes as large as 60 families or 60 parents in the room. Last year we saw 754 families, and it really is the voices of families that I hope to get across a bit today. It is, again, an honor to be here.

I wrote an article on the psychosocial issues in the world of children with cancer 16 years ago, and I just wanted to read you a paragraph from that article because it still holds true in my thinking about childhood cancer. Childhood cancer is a family disease since it affects everyone in the family's system. Illness engenders stress internally and externally because it alters the relationship of the individuals to their environment. So the child with cancer, this includes families, school and friends, the total environment of the child. The child's adaptation to illness is complicated by the coping responses of the adults and the children who are part of the child's world. In view of the dependence on and the influence of children on those around them, emphasis must be placed on the needs of those significant to the child.

So we're talking about the impact of childhood cancer on the family and really it is parents who are primary players in the coping of children with cancer. If a parent is not doing well or is struggling, it is even more complicated for a child. And think about what I'm saying if a parent is struggling. When your child is diagnosed with cancer, your world falls apart. In that moment it is probably news that you have ever had to hear in your life. And the impact of that diagnosis on parents, on families, can be devastating. And while you are dealing with perhaps this most devastating news, there is an expectation that you will come to learn everything that you need to learn and make decisions, choices, and begin the treatment for your child immediately. So it is an overwhelming time. And I think that every parent would agree that the period of diagnosis, the date that your child is diagnosed, is a date that stays with you for the rest of your life because it's a time when, whether it is a quick time to diagnosis or it's been a complicated diagnosis to come to, where your life and your world is suddenly changing. You are suddenly in transition from a world where you had a healthy child and certain goals and expectations, to a world where at least for a period of time, you are going to be dealing with the upheaval of figuring out treatment for your child, figuring out a hospital plan, trying to understand what to do with your other children and really trying to integrate this issue into your life.

In most cases in life when you have something as dramatic happen to you emotionally, you would understand that there would be a recommendation that would say, don't make any major life decisions in the next six weeks because

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NANCY CINCOTTA:

emotionally you're in a fragile place. But when your child is diagnosed with leukemia or with other types of cancers, you're suddenly in that place where you are taking that feeling of being numb or being hit by a truck, you're overwhelmed, you're confused and you are moving into a treatment plan.

Thankfully, children with cancer are in the fortunate position of having sophisticated teams of medical practitioners, physicians, nurses, social workers, psychologists, child life specialists, who specialize in the treatment of childhood cancer and who have gone on this journey with many people before them. So there is an interesting thing. It is kind of the worst of times, yet it is a time when you are expected to make major decisions.

There are a lot of common themes for families. And one of the interesting things is that in many situations in life as a parent, you have the support and the resource of other parents to look to for information. When you first have a child in and of itself it is a wonderful, yet overwhelming, journey and there are an abundance of books and things out there. The concept of when you become the parent of a child with a life-threatening illness and how you parent that child and who you become is still something where there are many resources that we have developed in our society, but is still something that it's not what you learn about growing up, it's something that you suddenly are faced with and that you need to learn about.

I think there are ways in which it changes your identity as a parent. You expect as a parent that you will be able to protect your child from many different things. Suddenly you're faced with an illness and you are faced with some of your own sense of insecurity that you've not been able to protect your child. I think there are many challenges emotionally at the beginning, where although there was nothing that you did that caused your child to be diagnosed with the illness that they have, where you may feel guilty as a parent. You may feel responsible. You may feel incapable because you couldn't prevent it. And yet you also feel as though you must do what you can now in the interest of your child and taking care of your child and getting your child the best treatment possible.

The diagnosis poses many different challenges and different issues. When I sit in the room at Camp Sunshine and I have many parents in front of me, I always ask the question of what issues would be interesting to talk about. And it is amazing the similarity that seems that people experience in their lives and that they would like to talk about. There are always issues about what happens to a couple when your child is diagnosed with cancer, how do you make decisions together, how

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NANCY CINCOTTA: do you take on the challenge, what roles do you take on. You may have spent years in thoughtful planning of having children and which parent was going to work and who was going to take on what task and what responsibilities, and suddenly that planful decision that you made really may change dramatically and may change within the context of a day.

How you function as a couple, how you do think may work very well when you are doing the normal tasks of parenting, but suddenly you are focused with dealing with medical issues, issues of who has the medical insurance, who feels emotionally able to be at the hospital or in a better position to care for a child while they're going through treatment. All of those things change and some of the direction that you were going in changes.

There's some joking obviously sometimes about how men deal with things and how women deal with things and some of those things may not be always drawn along gender lines, but more around personality lines, depending on what kind of copers you are and what kind of ways you have developed previously in your life in dealing with situations.

If you have a situation where one adult is really vested in learning all the information that's out there and that's how they understand how to cope, versus somebody who really needs to not have all the information, but needs to do things in pieces as information evolves to them, then it's complicated. Because you already have an example of two different kinds of copers trying to face the same pattern together.

There are many issues for siblings and how you deal with siblings when you have a child with cancer, what you do, how you do, how you involve the siblings, whether or not you include them in the treatment process, whether or not you find ways to maintain life the way it has been for them, to not alter their schedule.

There are personal issues that you face. Suddenly this brings up many existential thoughts. When you have time to think. But first the results – the issues of how you deal with the many tasks ahead.

One of the ways in which parents find comfort whether your child starts walking at the same time as another child or toilet-trained at the same time as another child – is by talking to other parents and having that partnering. There's a kind of isolation that can set in when you have a child who's diagnosed with cancer because that natural cohort may not be there, so there may not be somebody always readily

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NANCY CINCOTTA: able to ask the question and you may feel disconnected from the people in your world and the people who've been there for you for support before.

You can be overwhelmed by information and also startled by the people around you. Sometimes the diagnosis of childhood cancer in a family can change the relationships that you have with other people in your family network and in your friend network. Again, the rules on how families and friends learn how to cope with leukemia or a childhood cancer are also not clear and set in stone. So sometimes family members and friends have difficulties trying to figure out how they should deal with you, how they can be involved, how they can be helpful. And it's complicated because a family may not feel as though they can easily reach out because they're in the middle of doing all of the work that needs to be done and the care for a child with cancer. So it's an overwhelming time and it happens all at once.

In some ways life stops. You feel like the life you have currently known has stopped. And then in some other ways life is excelling at a tremendous rate. You are involved with a team that is working with you very assertively, you get to know a lot of people, you get to suddenly feel things and experience things that you haven't experienced before. It may not all be bad, but is in the context of something moving quickly that you have to adapt to.

There are day-to-day concerns in dealing with a child with cancer. What do you say, how do you say it, when do you say it, what kinds of words do you use, what language do you use. It's very complicated. It is difficult sometimes to understand what the limits of honesty are with the child and the different ages of a child can affect again the child's understanding of things. Honesty is really the best policy and one that I think is adhered to throughout the country, but honesty that works in relationship to what the child's age and the child's development status is.

So when a child is diagnosed the impact is on that whole community of the child, so that is school, peers, sports activities, all of the things that make children who they are. And certainly on their siblings. I think that some of the complication is how do you then deal with each of those auspices in creating the best possible climate for your child.

It's also interesting to think about so, here your 8-year-old child is diagnosed with leukemia, when the dust settles, what is the existential journey for your child? How is your child at the end of the day different than he or she might have been had they not been diagnosed with leukemia? How has the diagnosis of cancer

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NANCY CINCOTTA: influenced – how does it influence the choices your child makes along the way? What are the strengths that your child experiences as a result of this experience? For many children, there's a tremendous amount of growth which occurs during the experience. How does the diagnosis influence who parents are and how they regard their children during the course of treatment and throughout the course of their lives? There's a long-lasting effect in how everybody looks at the child with cancer in the family.

Some of the complications for siblings are that they are often a lesser priority when a sibling is ill. They are often not given clear developmentally appropriate information about the sibling's illness or treatment plan. Not because it is of intent, but because when you're trying to organize all the information you don't often, I think, find yourself in a position of thinking well, should my seventh grader be here with us when we meet the physician. You don't even know what you're going to be expecting in meeting the physician sometimes. So siblings are not always involved in discussions about the illness and the decision-making or in professional discussions the same way that children with cancer are. So already there starts to be a way in which children develop differently because children with cancer are living through the experience, but they also have access to professionals. And many programs have sibling programs and special sibling projects and there are organizations out there who are available to help siblings as well. But regardless of the efforts that are put forth for siblings, it is true that they will not spend the same amount of time and have the same exact exposure as the child on treatment.

For parents, the juggling and the taking care of siblings becomes a primary concern. And then there are the emotional issues that go and are complicated with that if a parent is away from home for a long period of time and they come back and their child has become more independent than they might have wanted them to be, because they were not there or different issues that evolve. I think it is always a constant juggling for parents to try to meet the demands of both healthy children and children with cancer as they work through the course of treatment. I think parents need to be given a lot of credit for all of the efforts that they make on behalf of all of their kids and to recognize that there are limitations in what any parent can do at any situation.

But children and adolescents generally need information that is age-appropriate, for the information to be repeated, so they can assure comprehension of it. They need verbal and visual preparation related to medical routine and procedures. They need to express their own feelings, their own words, and what they understand

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NANCY CINCOTTA: about other people's explanations. Well-meaning, wonderful people sometimes say things that kids don't understand. So kids need prompt, accurate, clear, understandable information and age-appropriate descriptions and interventions.

I can tell you a funny story. We had a wonderful psychosocial program where a child was prepared to be a bone marrow transplant donor for another sibling, for her sibling, and at the end of the day when that family was leaving this child was upset. And when it was further explored why the child was upset, she said, "Gee, I feel bad, I can't help my brother," and her parents said, "What do you mean? You're going to be the bone marrow donor, that's the best thing that you can do." And the child said, "But I don't have a bow and arrow." So in that child's world, in the world of the young child, bone marrow wasn't a word they understood, but bow and arrow was a word that they did. So sometimes even the simplest things can be things that cause trauma in unnecessary moments for kids, so language is a very important feature in working with kids.

So you think about things that can enable coping. I think that recognizing your own strengths as a family, to realize that however it is you come to a childhood cancer diagnosis, you have lived a life before that point. You have dealt with problems before. There are ways that you have been a copier. What kind of a copier are you and what strengths can you use?

It's actually always good to become somebody who becomes active in problem-solving and in decision-making, so that if there's an issue about something that should happen around a medical procedure or something that should happen about a sibling's schedule, if they should come to a procedure, to feel like you can make an active decision in problem-solving for a lot of the little details because really the treatment of a child with cancer is a series of little details and the more active you can feel in problem-solving, the more positive you can feel about the whole experience.

Partializing things is a wonderful thing to do, to make everything in life smaller. To deal with today, to deal with this procedure, to take one day at a time, one step at a time. To learn information in absorbable units. There's so much information out there and with the Internet there's even more information. But there is a limit to how much one mind can learn in a given day. So just try to break that down and learn what you can at a given time.

And to pace oneself. It's a long journey. The childhood cancer experience, the leukemia treatment protocols could be two years, could be three years, and so it's the kind of thing that you can't do everything in a day and you need to learn

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NANCY CINCOTTA: how to have the stamina for the long haul. It is much more of a marathon than it is a sprint.

Finding ways to be together as a family, new ways, old ways. Whether it's for a minute or for an hour, to feel like you're together in the storm. So when you're making choices about siblings, even though you want life to be as normal as possible, maybe there is an acceptance that life is not necessarily normal when a child has leukemia or has cancer, and maybe if you can miss out on a little bit of your academic life rather than feeling like you've lost the connection to your family, so you're always making choices in how to deal with treatment and each of the components of treatment.

You need to believe in your own strengths. And sometimes you have to, in the middle of a difficult time, force yourself to see your own strengths. You can do it, you have done it, you are doing it.

Find an advocate, someone who can support you if you need it. Find someone for support, unconditional support. The treatment of childhood cancer is not something that anyone should ever have to go through alone.

You know, value the process. So childhood is a joy and working with children is an amazing experience. Children are so much different than adults. And families are so much different in the involvement, in the care of their children. But to have out there the thought that these are the days of your life. So not to wish them away. Not to just get through them. But to seek joy and hope and pleasure and fun.

How do you do that? So if you need to squirt a doctor with a syringe or you need to take time to plan fun, to note the fun, to chronicle the fun, to kind of live a life. A simple technique would be at the end of every day to note kind of the joy and the sorrow. So what was the worst part of every day? But to end on what was the best part of every day, so that you have the moments and the connection and you don't lose them in the middle of being in the battle.

Take time for your children. Take time for yourself. Even five minutes. Families will always say there's no time to be alone, there's no time to take time. Here's a normal simple suggestion, but as a parent, I think you understand this well, which is just close the door when you go to the bathroom. Give yourself five minutes of time alone. There's a way of reframing the situation to kind of – you think about do you have a bunch of lemons or do you have lemonade. Is a syringe a negative thing because it's a needle or do you ask if you can keep an

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NANCY CINCOTTA: empty syringe and put finger-paint in it so that you can make it a fun thing. On a day that you go in for chemotherapy, can you bake cookies at home that night, so maybe then what your child remembers is the cookies versus the chemo.

Somehow creating a dialogue. Acknowledging the burden of chemo, while at the same time acknowledging the power of chemotherapy. Keep the story of what's going on very precious. Seek support, seek your allies.

I think one parent mentioned to me earlier today the importance of accepting all types of help. Help that you would not have imagined that you would need and that you wouldn't have thought of accepting before, but do not turn away help. Because even if you don't need certain things today, you may need them tomorrow. And again, in pacing yourself, you don't know what you need.

Communication is paramount, working with the medical team. The medical team community with you. Creating avenues to enhance communication in your life. And sometimes that means slowing down communication. Many people develop a caring bridge or care pages, where they can put their child's story and they can kind of enter those details at the end of the day, so they don't have to be calling hundreds of people to give them information.

For resources that you don't know information about, you've got information in your packet where you can contact The Leukemia & Lymphoma Society and they will be able to give you lots of information.

Many families have said to me one of the recommendations should be to tell people to go to Camp Sunshine because it's a place where we are creating communities of families of kids with cancer, so that people can help each other, inform each other, support each other.

You think about simple ways of enhancing communication. So if you have one parent who's home taking care of a child and another parent who's working during the course of the day, rather than walking in at the end of the day and hearing everything that happened during the day at once, calling an hour before arriving home, either from work or in the car, so that you can again partialize the information that you're being given. Information is empowering, but sometimes if it comes to you all at once or at the end of a very frustrating day, you may not be able to hear it.

Find a group. There are groups in your communities, groups through The Leukemia & Lymphoma Society, groups through Camp Sunshine. Again, a place where people can find support and connection with each other.

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NANCY CINCOTTA: Now do parents cope differently than other parents with their kids? Absolutely. Every family is unique, every family – whoever they were before treatment and preexisting patterns of communication in the family are not going to change. Do things get better when somebody is having to deal with a childhood cancer diagnosis? Actually I think in some cases the cancer experience can help communication. I think initially it can exacerbate communication, but there are more adults, more professionals, more role models, more opportunities to communicate. Because often many other things in life that get in the way of families spending time together go away for a period of time, so that there is an opportunity for people to talk, to learn. And because you're dealing with complicated issues it really does force communication at times. But the avenues, the things which enhance communication are things that people need.

When you think about where do families go emotionally after their children are diagnosed with leukemia or other childhood cancers, there is a changing of priorities, a search for meaning in the lives of families. There is a process of accepting that life is finite and perhaps as a result you value life more and you integrate yourself differently in the community. Maybe you look at every day and live every day to the fullest. The concept of maintaining hope and joy in your life regardless of what you're going through is an important one and on the American Cancer Society Web site there are strategies for maintaining hope and enhancing hope in your life.

I wanted to, before we open up to questions, I wanted to give you some secrets that I feel like I have learned in my time at Camp Sunshine. And I also want to say that again, even though we're just touching on topics, there'll be opportunity to talk in the later part of this call and also in other ways after the call is done.

So some of the secrets that I've learned sitting and listening to parents and to children are that most marriages are complicated. Often mothers want to be in charge of their child's care and they are reluctant to have substitutions called in. So even though it may be overwhelming, it really may be part and parcel to the role of motherhood.

Most children talk more than their parents think they do and understand more than they let their parents know. And that it is not an issue of how much a child loves you if your child talks to a social worker or a nurse or a physician more than they talk to you. It's often a protective issue on the part of a child. But children are very sophisticated and have a great depth of understanding.

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NANCY CINCOTTA: Children are children first in dealing with their cancer. And the cancer is secondary to their needs and their desires as children. Unfortunately, teenagers are also teenagers first, so they may not always be completely honest with their parents.

Children of all ages have great capacity to cope, to understand, to be resilient.

Parents are remarkably resilient, even if they don't believe it at first. I often hand out a survey where I ask parents what they have learned about themselves and their children over the course of their cancer treatment and 95% of people will come back and tell me that they are stronger than they thought they were, more resilient than they thought they were.

Fathers have a lot to say and feel the impact of their child's cancer quite profoundly. And given the correct environment, they will talk and even cry about it and again, many programs don't have opportunities to reach out to fathers in the same way, but for the programs that are retreat-based, there's an opportunity to work with fathers in a particular way.

Sleeping patterns change when a child is diagnosed with cancer. People don't often talk about this. But many parents don't sleep through the night out of concern or monitoring of their child. And more families than talk about it, that hear the concept of the family bed after their child is diagnosed with cancer.

Some of what we are about is helping people understand and normalizing what people do and what people experience. Even though they may be reluctant to begin a conversation, most children and adults are eager to talk about their cancer experience and find relief even in discussing difficult issues. In some situations mothers, fathers, children will all talk to other people more than they will talk to each other.

There is a new normal that people talk about when their child has been diagnosed with cancer. And I think that some of that new normal is really the sense of many things you have to do. This is not a club you would choose to belong to, this is not something you would want to do, but once you're in the middle of it and once you are going through treatment and you meet people who are kind and reaching out to you and you are having conversations and talking about intimate details about life that you may not otherwise have talked about, that you do feel like you have a secret, that you learned something about life that maybe other people don't realize it, don't realize so quickly.

That doesn't mean you wouldn't give this all away if you had a choice, but that there are ways and personal ways, that there are things that you learn about

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NANCY CINCOTTA: yourself and your family and your commitment to each other. And even in the sense of joy in life that you might not have otherwise talked about.

There's a power in people becoming parts of groups. There are many resources out there for families. The Leukemia & Lymphoma Society is a tremendous resource for families on back to school initiatives, on information services for financial support. CureSearch is a Web site that offers tremendous information on all aspects of childhood cancer. And Camp Sunshine itself serves as a tremendous resource nationally. We'll be running 27 programs this year in Maine. And it is a retreat for families of kids primarily with cancer and other life-threatening illnesses. We'll run three programs in Wisconsin and one in Arizona this year. And it blends kind of joy, hope, and psychosocial programming. We're creating a community for families of kids with cancer to find friendship, community and in essence to find parts of themselves. And again, to maintain joy and hope.

I think this is probably the time when I'm supposed to stop and we open it up to discussion. Yes?

CARSON PATTILLO: Absolutely. Nancy, thank you so much for such an informative presentation. So touching and grounding and encouraging, I'm sure for all those that are on the phone.

And now we're going to open up the phone lines so people can ask direct questions of you. It's the interactive part of our program, the question-and-answer session. And before the operator gives instructions for the audience to enter the question-and-answer queue, I'd like to remind all of you that because we have a little over 1,000 people participating on the line, for everyone to benefit, if you can please try to keep your questions general in nature, so Nancy can provide an answer general in nature. And your phone line will be muted after you ask your question, so that Nancy can respond.

Operator, if you can please give instructions to our telephone participants, so they can queue themselves to ask a question.

OPERATOR: To participate in the call by asking a question, please dial star-1 on your keypad. We will take questions in order that they are asked. Please 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.

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CARSON PATTILLO: Whenever you're ready we'll take our first question, please.

OPERATOR: Your first question is from Karen in New Jersey.

KAREN: Hi. My son is a cancer survivor, having had a bone marrow transplant in the spring of 2006. In the course of his three years of treatment, my young children grew into teenagers and I now have a 17-and 15-year-old. And I'm wondering more about them. While they understand what happened, they are angry and disillusioned and I'm discouraged for them. And I'm wondering if you have any thoughts on how specifically to help teenagers.

NANCY CINCOTTA: Teenagers are both wonderful and complicated. I think that the joy in teenagers is sometimes that we've known them for all of those years before they become teenagers. I think that it is very, very common for families who experience bone marrow transplants and treatments where they've had to be away from home for the siblings to, again, grow to be more independent and to learn to do things by themselves. And I think that at times the teens then resent their parents when they come back into the situation and want to regain control, establish boundaries and perhaps have children be where they were, either before they left or where they should be now. And in fact, often kids are more independent than their age.

In the pediatric oncology world we often have family meetings about diagnosis and about coming off treatment. In the survivor world it becomes important also to have that type of meeting, where you have the whole family present and you're able to have honest and frank discussions about what the experience was like and what it was like giving voice to the children who were not necessarily there for all of the medical treatment, but who had their own experience, so that their experience becomes valuable.

There are also programs out there. There are many survivor programs. There are both the regular programs at Camp Sunshine and the off-treatment program, where there would be an opportunity for children to be able to express some of those feelings and meet other kids who went through that experience. I think as a parent it's very complicated because you feel as though you've done everything for your kids and now when the treatment is done and you should be able to have some ability to move forward, what happens is it is a safe time for your other kids to express their feelings.

There are ways to work through it and resources for people available out there, but it is a complicated time and a time strategically where, while you still have

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- NANCY CINCOTTA: children who are teenagers, there's an opportunity to have them in the house and have opportunities to meet and discuss many of the issues and try to work through some of the feelings that they went through.
- CARSON PATTILLO: Karen, thank you for the question. We will take our next question, please.
- OPERATOR: The next question is from Kim in Virginia.
- KIM: Thank you for taking my call. We have a son who was very blessed, had lymphocyte-predominant Hodgkin's disease, which means a short treatment for him. It took longer to diagnose than to actually treat. So we spent all the fall, at doctors' offices, for pretty much the entire day, week-long hospital stays and things like that. He is getting ready to turn 8, but we have two daughters who are also – one will be 6 this summer and another one will be 5 in November. And we have been noticing extreme behavior in the daughters. Just excessive stuff with behaviors around the house, acting out, getting into things that they know they're not supposed to do. And it's been very frustrating. And I don't know if other families experience this or what we can expect to be doing with this. And it's just very frustrating. We could really use some guidance on this one.
- NANCY CINCOTTA: Thank you, Kim. I think siblings are one of the harder issues for families to face. I do think when the child is in the middle of active treatment and when parents are involved in it, it is a harder time for siblings to express their feelings. There is a natural time when things slow down and things get a little bit calmer in the house, for siblings to act out and to begin to find ways – and they're going to be different depending on the age of the child – to express their feelings.
- Sometimes the ability to identify that, to have kids be able to understand even what the experience was for them, because I think it's very confusing, particularly for younger kids, to understand what happened to the family that they had and what was happening at the time and then all of a sudden you would have things change.
- Now I do think that for many kids, 6, 7, until under the age of 9 or 10, a lot of kids can find value in having opportunities to play out and act out some of their experiences. I don't know if there are resources, but many centers have sibling resources that may have psychosocial staff who are available and able to help with those issues.
- Again, I would also think sometimes when treatment is over, people think they should not avail themselves of certain resources like camp programs or wish programs. But that's actually a great time to do it. And we didn't mention

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NANCY CINCOTTA: wishes on the call, but for everyone, the opportunity to plan a wish trip and to go on a wish trip might be a time for the family to be able to have some time and connection positively around the illness.

I also would recommend coming to a retreat program like Camp Sunshine, where you can have the ability for the siblings to hear other siblings and when you can hear other parents talk about the issues and how they do it.

It's also a time to create special time for all of your kids, now that treatment is over. To create an alone time for each sibling, each child with each parent, so that there can be special moments that are happening.

And I think that as kids get older, both kids on treatment and siblings, there becomes an importance in discussing what the experience was, what everybody felt, what everybody went through, as kids get older. Because developmentally they can understand more. So it's not a static thing where you deal with it today and then it's done. It's the kind of thing that you deal with for years to come at each different developmental plateau for your children, both the siblings and the child with cancer.

CARSON PATTILLO: Kim, thank you for the question. Nancy, I'd like to ask you, if we move to the parents. Many times a parent, if a child is in treatment in the hospital, they'll take shifts and watch the child and sometimes emotional and physical intimacy can be affected. Could you touch on that just a moment, on the importance of that? Or the stressors of that.

NANCY CINCOTTA: I think that during the course of treatment itself it's complicated for parents to find time for each other, emotionally or physically. I also think that depending on who each parent is, sometimes one parent is more comforted by emotional closeness and sometimes a parent is more comforted by physical closeness. So that sometimes people are just not on the same page and sometimes they're just too tired to be able to deal with those issues.

Finding opportunities for parents to be with each other is a wonderful gift that both friends and family members can give for parents who have really long stays in the hospital, just so parents can talk to each other. I think that it is confusing because there are times when a child is in the hospital where staff may feel it's great for parents to leave for a little while and to be away. But parents will talk about the burden that that stress creates sometimes, too, that they don't feel like they want to leave their child for a minute while they're in the hospital. So sometimes it's actually fun to try to create some kinds of opportunities for

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- NANCY CINCOTTA: parents, even in the hospital, where they can have time to have a meal together or they can have a plan where one walks the other to the car at the end of the day, so that they have those few minutes together. And where parents can have a chance to remember the strengths of their partner and the connections to their partner and what they do.
- I think that for many families it is not until treatment is over that they actually regain the connections and stability to each other and to that adult relationship. I think that encouraging kids to be kids and adults to be adults is also a helpful thing and developing activities that maybe can involve also both the entire family, but that may have a component where parents are allowed to have the opportunity. Again, in some of the retreat program, we, and I know that other programs, create, even in the context of a family program, an evening that is just for adults to be together. And it's an opportunity for kids to sleep out and be separate from their parents as well. So that sometimes families really need help because there is no time, where there are no other resources or life is too complicated.
- Also for some people they don't even realize that they don't have that time because they are so busy with the tasks of what is happening. Getting people to talk about it, getting people to talk to each other is a pretty wonderful thing that I think that many professionals can also help adults achieve during this time. Because sometimes people get so consumed with cancer treatment, understandably, that everything in life pales in comparison. So even having a family create a game night, where it is the parents against the kids, is an opportunity to bring some of that normal relationship time back.
- CARSON PATTILLO: Excellent, excellent ideas. We'll take another question from the audience, please.
- OPERATOR: Your next question is from Megan in Florida.
- MEGAN: I was wondering, you were talking about some sibling programs. The only ones that we're familiar with over here – I have two other social workers that are here with me – is the Super Sibs program. So I was wondering if there were any other specific programs or Web sites that you knew specifically for our siblings.
- NANCY CINCOTTA: Super Sibs is certainly one that I would recommend and I think that the information service at the end of the call may have other Web sites. Very program-specific, and I don't know if this is true for some of your hospitals, there are a lot of hospitals that have program-specific sibling days and sibling camps. There are a number of camps around the country that offer a sibling week. Like the Hole in the Wall program in Connecticut. And I believe that there are actually

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NANCY CINCOTTA: other programs around the country where this is a sibling week exclusively for the needs of sibs.

Now there are some camp programs that allow the children and siblings to come together and I would recommend those and the family camp concept programs because it gives an opportunity – one of the things that we have seen in our group work program is you allow – I run groups with siblings and kids together and they get to hear other kids with cancer talk about their things and kids with cancer get to hear other siblings. It is amazing the energy that comes and the questions that come. And the honesty of the kids. Where one kid will say, "Yeah, I did that to manipulate the situation so I could get my way," and somebody else will chime in about something they did. So I think that some of them are even just creating the natural environment.

And I also think that if people work in a program where there isn't a sibling day or a sibling opportunity, that that would be a great innovation to create, where gee, you just allow siblings time on their own to come in and be with the professional staff and to do whatever they want to do creatively at clinic, so that the energy is about them and the energy about being a sibling.

There are also a number of books out there for siblings and we can have a list available at the Information Resource Center at the end of the call.

CARSON PATTILLO: Thank you very much. We'll take our next question, please.

OPERATOR: Your next question is from Melissa in Indiana.

MELISSA: My daughter is 9 years old. She has ALL leukemia and she'll be finishing and getting her port out June 15. We've been taking her to the free cancer center in Illinois, but we aren't getting a breakthrough, she doesn't want to talk about cancer, she doesn't want to have anything to do with it, not be involved. We had a bit of a breakthrough where she kind of owned some of her feelings a little bit. She's a little frustrated that Daddy is more at work, so he's not able to spend more time with her. But as far as addressing any kind of – with her cancer – is it normal and is it okay for her to not want to talk about her cancer, to not be involved? To totally clam up and not want to discuss it. Or is it something we should pursue more?

NANCY CINCOTTA: Great question. Kids are really, really different. You have some kids who are real talkers and some kids who really don't want to say a word about all of that. Are the feelings there, are the thoughts there? Most probably. Is it normal for her to do what she's doing? Absolutely. And I think that in the range of normal we have

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NANCY CINCOTTA: to understand that different kids – like if you think about everybody as adults, there are probably of the 1,200 people on this call, some people who are talkers and some people who are not.

One of the interesting things for kids is just providing them the opportunity in an ongoing way. For kids who are 7, 8, 9, talking may not be the vehicle, but writing really may be. I am stunned – and we always know that drawing and expressive activities are places for people to have the opportunities to do – some easy ways for the family, if you want to create activities where maybe everybody draws a picture of what the cancer experience has been or what it has been on-treatment or life before treatment, life now and the envisioning of life after treatment. If you had every adult and every kid in the household just draw those three stages, you would be surprised at the stories which come out.

It's also again – every center has different people, but there are often centers who have people who are very adept in expressive arts, whether that is child life people, art therapy people, social work people, to be able to help kids have an opportunity to engage in some play material around their illness.

One of the things that's really true for 9 year olds – they're going to be 10 year olds, 11 year olds, 12 year olds – and you can create a day or a time where you allow for the conversation. Sometimes it's three months after treatment has ended or six months after treatment and pulling out the cards that you got or the photos or photo albums of the experience, where children at later stages will come and talk about it. Or bringing kids to programs and having them in an environment where there's other kids around them who have cancer and have the experience. So it isn't about adults always trying to talk to children about experiences, but also where other kids who may be kids who are very verbal about it do talk about it, so in fact even if they choose not to talk about it themselves, they will hear what other kids have to say and they will make the connection of other people who've gone through the experience.

I think all kids want to be the same as the kids around them and they want to be part of a group, so some of the joy again, kids' camps and family camp, Camp Sunshine are wonderful opportunities to create a natural, fun, happy environment where, in fact, just everybody around you is somebody who has lived through an experience that you have lived through. And it's the normalizing of that experience and the acknowledging of that experience that kids need.

CARSON PATTILLO: Melissa, thank you for participating today. We'll take another question, please.

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- OPERATOR: Your next question is from Marcie in Massachusetts.
- MARCIE: Hi, thank you for taking my call. Our niece was just diagnosed with ALL on May 1, so she's in the beginning stages. She's in an induction stage with her chemotherapy. And we've noticed that she is very disconnected, much like the last caller. On Sunday she wouldn't talk at all, which isn't really her attitude. She seems already pretty depressed. She's rather precocious, so we're not really sure what she is understanding. She's not talking and she's saying things that are concerning, particularly, to her parents, like she doesn't want to go to the gift shop unless they can bring her a wheelchair. And that's clearly not her and she doesn't need a wheelchair. So what are some things we can do to help quell her fears at this time, and to also help her parents understand what she's going through?
- NANCY CINCOTTA: I think there's a lot of things. How old did you say she was?
- MARCIE: She's 6.
- NANCY CINCOTTA: So at an age – and one always needs to think about the ages of kids – I think sometimes when kids are sick or when they're – I don't want to say sick – when they're diagnosed with leukemia or with some type of cancer, I think it's hard to understand what the boundaries of the illness are emotionally. They know that there's been a lot of attention, there's treatment that they have to do, and I think that to begin with that some kids will in fact push to understand what the boundaries are of what they can and can't do. So whether it's asking for a wheelchair or wanting to stay in bed or not wanting to participate, they may feel that they have an illness that is such that they can't do those things. And so they want to see what will be supported in their behavior and what will not be supported.
- I think that it is great for kids to have an ally, an advocate, a nurse practitioner, a childlife specialist, a social worker in their center, that they come to understand as uniquely available for them, to help them think about what their treatment is, what they need, what they're doing. I think that it is also okay to give kids permission to be upset and to be reactive in having gotten this diagnosis and to having to go through treatment, but also making very clear that during this time we are still going to have fun as a family and we are going to do fun things and here are our future expectations and this is what we're planning for this time and these are things we're going to do.
- Kids need messages that life is going to continue, that this is not going to be all about the illness and that this is going to be temporary. And when you are 6 it is much more difficult to understand what temporary means and what it means

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NANCY CINCOTTA: that this is going to be a component of your life and not all of your life and not forever. Because at 6 today is really important and what you can do today and what you can achieve today.

So I think it also becomes important to think about the things that this child is capable of, skilled at, interested in and to continue to cultivate those things and those parts of that child's personality. So whether that means if this child is a kid who loves to paint or who loves to do messy things or things with clay, that you keep presenting those opportunities and you try to normalize the activities around this child's day, so that the focus becomes a little bit pulled away from some of the medical treatments.

And that you find support. And for all children, no one has asked this question, but sometimes there's a question about whether or not counseling is a valued idea for children. And I think that everybody knows their own children and when they know they are very different than themselves, I think that when kids get diagnosed with a life-threatening illness, depending on what their medical symptoms are, they really feel not like themselves and they need help understanding what their reaction to the illness is, that they are who they are, that they still have the love and support of the people around them and that they can still make progress and that there is a life plan ahead of them. Particularly for kids who get pulled out of school and who don't have the normal rhythm of what they were doing in life before. It's very frightening, it's very unnerving, to not understand what's ahead of you and what the plans are.

So even if it means saying, "Tomorrow we're doing this, this and this," so a child understands and understands that thing, and I think again, sometimes kids will ask for wheelchairs and they will ask to be in bed not because they are feeling so sick and feel like they can't walk, but because they're wondering both how sick the world is perceiving them and also what are the limits of what they can and can't do.

CARSON PATTILLO: Marcie, thank you for being on. We'll take our next question, please.

OPERATOR: The next question is from Sharon in Arizona.

SHARON: Hi, thank you for this call, this is a great conference. I have a question. For those families that have the rare diseases, the ones that don't have the clear treatment pathway, poor outcomes, what are the additional stressors that you see on both the child and the family? What do you say to those families, how do you guide them? They can't go and just talk to all the people that have ALL. They don't have the best protocols. There's those rare diseases that just – there's nowhere

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SHARON: for these parents to turn. What advice can you give for these parents and to help them with their children?

NANCY CINCOTTA: One of the interesting things that we have also been doing at Camp Sunshine is that we have been working with a number of people who have very rare disorders. And rare has a range. Some which there are 500 people nationwide who have it, like Fanconi Anemia, and then some where there is even a smaller number than that.

I think there are different ways in which people can find support from each other. Some is just in the joining together of people who have rare illnesses and some is in combining the energy of people who have that same rare illness. But I do think that for every child and for every family, there are parallels in some of the emotional issues and I think there are frustrations that there may not be programming and there may not be camaraderie and that it may be harder to understand the future and the treatment protocol of certain rarer illnesses. But I think that some of the same emotional vulnerabilities that people feel and some of the need to be connected and to need to be connected to organizations that understand rare illnesses. So depending again what the subset of the illness is, to help families find people to be connected in those things.

I think sometimes for a kid with a rare disorder – I can give you an example, it may not be as rare as the conditions that you may be thinking about – but we've just recently developed a program for families of kids with Down's syndrome and leukemia because many of the siblings in those situations really – you know, I would meet one at a time in a particular program and they would have no reference group of other people to talk to or to deal with some of the same issues that they were feeling, so we've taken kind of a rare thing and made it a very common thing, by trying to get 30 families nationwide to join in.

I think that it's important for families of kids with rare diseases to know that the National Organization of Rare Diseases is out there, that there are resources out there for people with rare diseases, and that even though a particular rare disease may not be common, that rare diseases are common, and that there are people who deal with the same struggle.

I also think that some of coming to terms with dealing with a rare illness is about dealing with issues of why it is you have this particular thing. Some of those emotional issues are very much the same as some other more common illnesses, but it's an internal journey of understanding your connection to that illness and I think that, again, we could recommend resources around the country for people to connect to people who understand that emotional profile.

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NANCY CINCOTTA: And I would also think that there are probably Internet resources that may be helpful.

I think in situations of rare illnesses it's also times when families may need more help from professionals and people who can be advocates and supportive because it's also at times much harder to get resources for families when people don't recognize the name of the illness right away, even if the illness can be more devastating than a more common illness.

CARSON PATTILLO: Thank you, Sharon, for the question. And specific to blood cancers, The Leukemia & Lymphoma Society has a First Connection program where we can link parents together or siblings together or patients together with a similar diagnosis.

So I thank you all for your questions. Our one hour has come to a close. And please help me thank Nancy Cincotta. We are so grateful that she has donated her time to us today and we thank you for all the work that she does every day in supporting families touched by cancer.

And we would also like to thank all of you, the participants today. We hope that many of your questions were answered and that the information provided will assist you in your next steps.

And a reminder to all of you to fill out your program evaluations and if you're a nurse or social worker, to fill out your continuing education credit form. Feedback is extremely important to us. It helps us to plan the most meaningful programs for you, so your comments and suggestions are greatly appreciated.

And a reminder to all of you also that our Information Resource Center is open. It is our toll-free 1-800 number. Don't hesitate to contact us if you have further questions or need guidance or information. Our Master's level information specialists are available to provide you with more information and can link you with your local chapters or referrals. Again, the number, as I mentioned in the beginning of the program, is 1-800-955-4572.

And on behalf of The Leukemia & Lymphoma Society, I'd like to thank you all for sharing this hour with us. We wish you well. Good-bye.

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

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