



Pediatric Oncology Survivorship: Beyond the Physical Effects

Ms. Alicia Patten

Greetings and welcome to our program, “Pediatric Oncology Survivorship: Beyond the Physical Effects”. The Leukemia & Lymphoma Society exists to find cures and ensure access to treatment for blood cancer patients.

Our vision is a world without blood cancer. For more than 60 years, LLS has helped pioneer innovation, such as targeted therapies and immunotherapies that have improved survival rates and quality of life for many blood cancer patients. We advocate for patients, survivors, and their families, helping them navigate their cancer treatments and ensuring that they have access to quality, affordable, and coordinated care.

We’re fortunate to have as our presenter Dr. Allison Spencer Bechtel. Dr. Bechtel is a hematology/oncology physician at Nemours Children’s Specialty Care in Jacksonville, Florida. She is the director of the Jacksonville Oncology Survivorship Program, which manages over 400 patients who are 2 years or more off treatment. Allie’s goal is to address all aspects of her patients’ care, including physical, mental, and social effects of their previous oncology treatment. She spends the remainder of her clinical time caring for patients with benign hematology as well as treating oncology patients, the majority of whom have leukemia and lymphoma.

Allie completed her medical school at A.T. Still University in Kirksville, Missouri, and her bachelor of science degree in Biology Honors in her hometown of Kingston, Ontario, Canada, at Queens University. Thank you, Allie, for volunteering your time and sharing your knowledge with us. I am pleased to turn the program over to you.

Allison Bechtel, DO, FAAP

Thank you for having me. Looking forward to speaking to you all today.



Disclosures

- None

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Disclosure

Just the obligatory slide. I just wanted to let everyone know that I have no disclosures, financial or otherwise.

Objectives

- Understand the current growing population of pediatric oncology survivors
- Understand the common long-term effects for all pediatric oncology patients, regardless of their treatment plan or course
- Understand potential risk factors for common long-term medical side effects
- Understand resources available for patients with medical long-term effects and when referral should be considered

Objectives

So, today my goal is to help everyone further understand the current growing population of pediatric oncology survivors, understand the common long-term effects for all pediatric oncology patients—that's regardless of their treatment plan or course. To understand potential risk factors for common long-term medical effects, and to also take a quick glimpse of the resources available for patients of medical long-term effects and when referrals should be considered.

Pediatric Oncology

- 2019: estimated 11,060 new cases for patients age 0-14
 - Overall survival 85-90%
- Incidence rates have increased
 - 6%/year
- Remains the #1 cause of death from disease
 - 57% of all children up to 19 years of age

Number of Childhood Cancer Diagnoses Per Year
Total = 15,780, Age 0-19

Cancer Type	Percentage
Acute Lymphoblastic Leukemia (ALL)	20%
Brain and Central Nervous System	18%
Hodgkin Disease	8%
Non-Hodgkin Lymphoma	7%
Acute Myeloid Leukemia (AML)	5%
Neuroblastoma	5%
Bone Tumors	4%
Thyroid Carcinoma	4%
Wilms / Kidney	3%
Germ Cell Tumors	3%
Rhabdomyosarcoma	2%
Retinoblastoma	2%
Melanoma	2%
Other	16%

Source: American Cancer Society, Cancer Facts and Figures (2014)

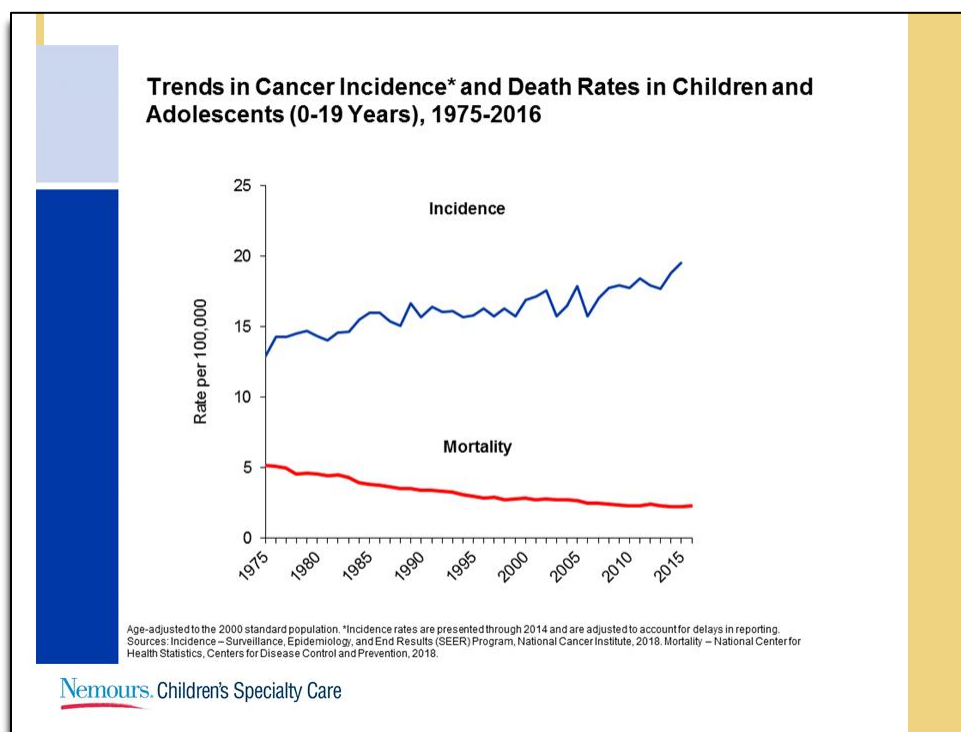
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Pediatric Oncology

So, before I discuss late effects, I always like to try to paint a picture of childhood cancer, survival rates, and the evolution of treatment success. According to the National Cancer Institute, an estimated 11,060 children will be diagnosed with cancer in the United States from birth to 14 years of age. Our survival rate has dramatically improved in the last 50 years, starting at about 10% now to aid upwards of 90%, depending on the resource that you look at.

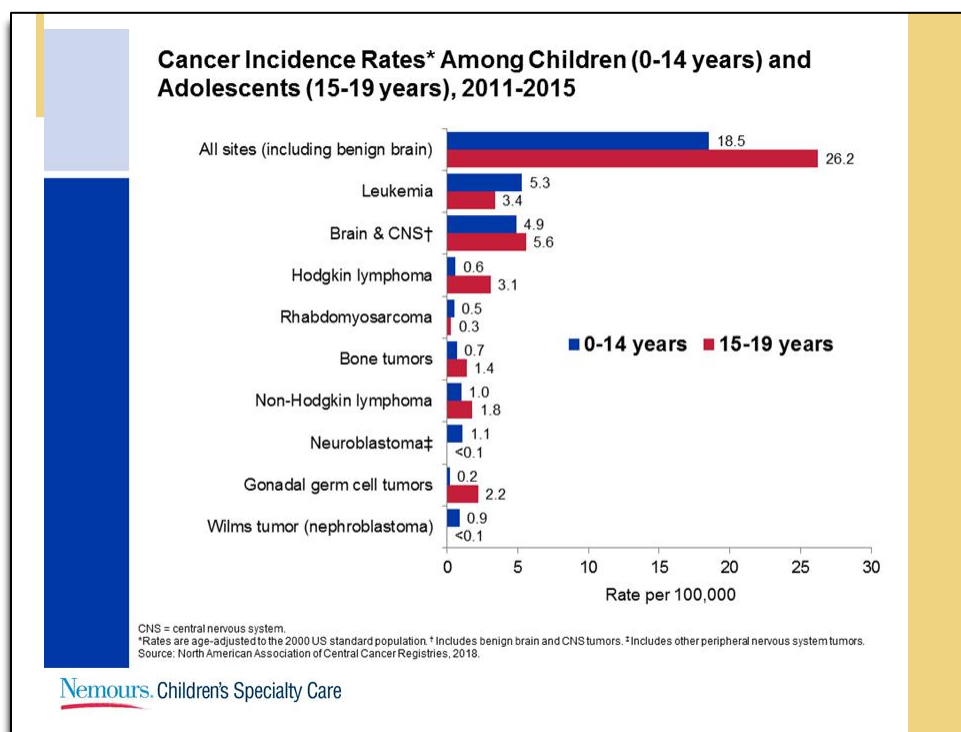
However, it remains the number one cause of death from disease at 57% of all childhood cancers for the 0 to 19 age range. This is more than all the other diseases combined. For overall cause of death in pediatrics, cancer is typically second to fourth, depending on the age group evaluated, always behind unintentional injury.



Trends in Cancer Incidence and Death Rates in Children and Adolescents (0-19 Years), 1975-2016

The next series of slides that I have obtained from the American Cancer Society Cancer Facts website, they present the burden of cancer among children and adolescents in the United States. Cancer incidence and mortality trends in children from 0 to 14 years and adolescents being just 15 to 19 years are quite similar. Since 1975, cancer incidence rates have been increasing slightly, by about 0.7% per year, while cancer death rates have decreased by more than half.

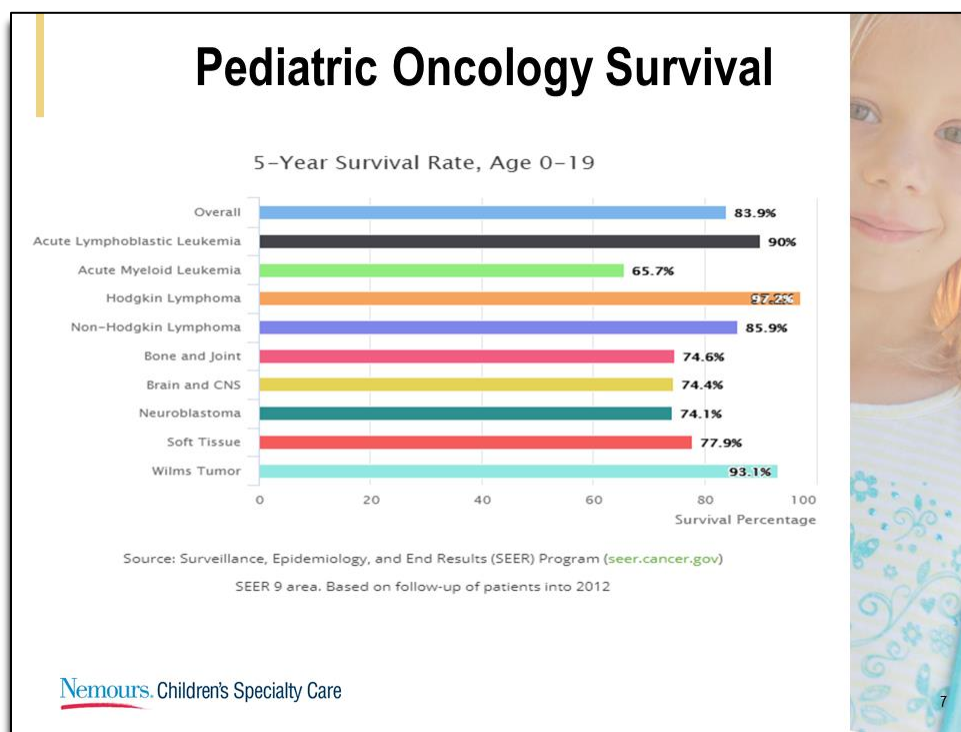
Among children and adolescents combined, so 0 to 19 years, brain cancer has recently surpassed leukemia as the leading cause of cancer death. Although treatment options have improved for both cancers, therapeutic advances for leukemia have been particularly dramatic in a positive direction. From 1975 to 2016, the death rate in this age group declined by about 70% for leukemia compared with 30% for tumors of the brain and other nervous systems. Since brain tumors and leukemia combined are a large number of the patients we treat, understanding their survival and numbers is of help before we discuss potential effects.



Cancer Incidence Rates Among Children (0-14 years) and Adolescents (15-19 years), 2011-2015

This slide shows cancer incidence rates in children from 0 to 14 years and adolescents from 15 to 19 years by cancer type according to the International Classification of Childhood Cancers. This system is more appropriate for children because it categorizes cancers based on the combination of both histology or what you see under the microscope and tumor location rather than just location alone. Leukemia accounts for 28% of all cancers diagnosed in children but just 13% of cancers diagnosed in adolescents.

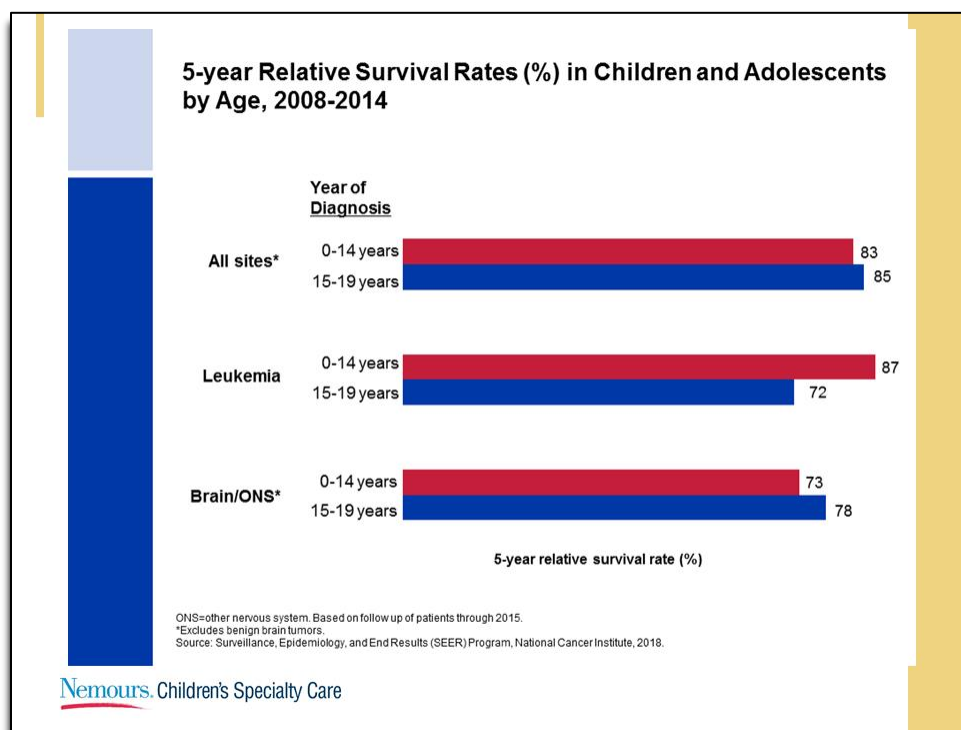
Cancer registries were mandated by law to begin reporting benign and borderline malignant brain and central nervous system tumors on January 1, 2004. Reporting was expanded to include those cancers, because benign tumors or quote unquote “noncancerous tumors” cause disruption to normal function, similar to malignant tumors. And because the prognosis or how well they do for benign and malignant tumors is often similar, I have learned that sometimes what an oncologist would call benign versus, for example, a neurosurgeon is a bit different. But, for the purposes of this discussion, all of these should be included since they can impair function, which is most relevant to me. During 2011 to 2015, approximately one-quarter of all brain tumors diagnosed in children and more than one-half of those in adolescence were deemed benign or borderline malignant.



Pediatric Oncology Survival

While we have made tremendous progress on many diseases, as demonstrated by this graph from SEER in 2012, specifically in leukemia, as I aforementioned, Hodgkin's and non-Hodgkin's lymphoma as well as Wilms tumor—many of these have survival rates greater than 95% in some cohorts. Others, unfortunately, have not fared so well. Many solid tumors and, like I previously mentioned, brain tumors continue to have overall survival rates less than 75% with the high-risk cohorts faring even worse—often well less than 50%.


This graph reflects data up until 2012, and even since then we have made notable improvements in many of these diseases. There's been a lot of progress, but we still have a long way to go. And with this progress is kind of a new era of survivors and long-term effects to be managed.



5-year Relative Survival Rates (%) in Children and Adolescents by Age, 2008-2014

Finally, survival rates are similar for children and adolescents overall but vary by cancer site. For example, the current 5-year relative survival rate for leukemia, as I mentioned previously, is about 87% for children. I probably would argue that it's actually higher now as the most recent study from the Children's Oncology Group was able to quote an even higher prognosis, which is great. But unfortunately, it's only 72% for adolescents.

In contrast, survival for brain and other central nervous system tumors is lower in children than in adolescents. There are a number of reasons for this, both scientific and social. There's some evidence that disease in children versus adolescents, while they have the same name behind them, often have different tendencies, which is why we actually treat sometimes the same disease slightly differently using age as a risk factor. In addition, there's been less enrollment on clinical trials for adolescent group. And therefore, the rate of success has unfortunately not been as robust at the childhood age range.



Pediatric Oncology Survival

- Significant increase in pediatric and adult survivors
- Estimated 429,000 adult survivors (2015)
 - 1/530 age 20-39
- 60% children **will** have late medical effects
- 25% will have a **severe** late medical effect
- Children's Oncology Group Guidelines
 - 20+ members make up panel of experts with hundreds comprising the task force

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Pediatric Oncology Survival

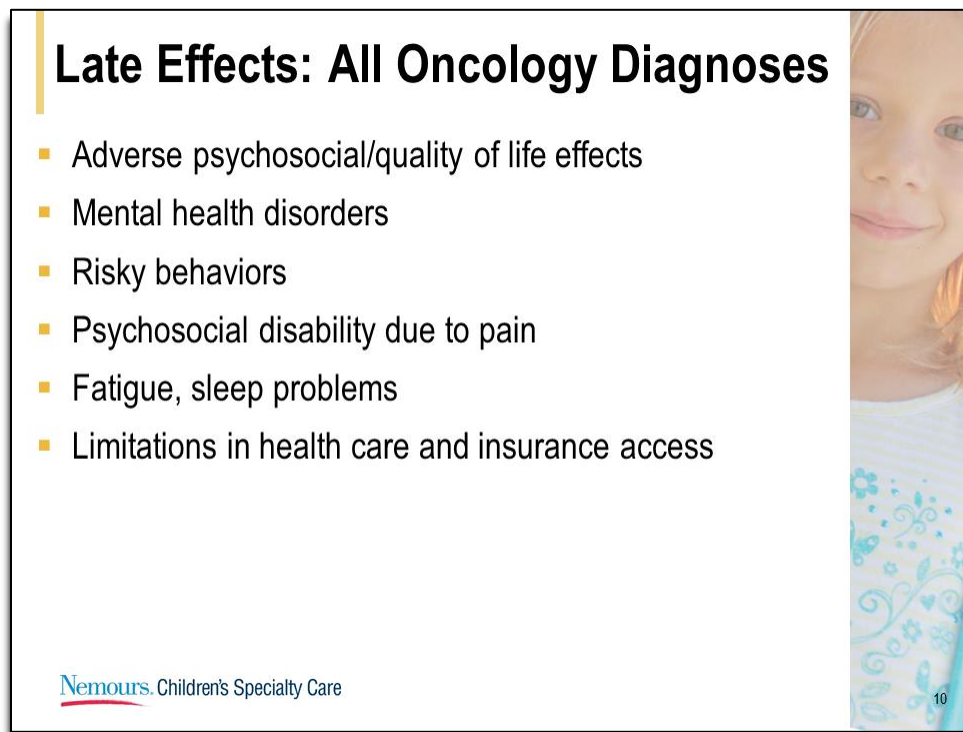
So, just to summarize, our success in pediatric cancer is something that those of us in the field are very proud of. Now, many studies are focused on the fine balance of improvement and outcome and decreasing treatment in length or amount, if able, as well as minimizing toxicity.

There are approximately 429,000 adult survivors of children's cancer in the United States. That's 1 in about 530 adults age 20 to 39. Even prior to transitioning to the adult world, it's estimated that 60% of children who survive cancer will suffer some form of late effects of which one-quarter will be deemed severe.

The Children's Oncology Group created long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers as a collaborative effort to help guide treating providers, such as myself, for complications of childhood cancer treatment. This has had multiple versions, with the most recent being released in fall of 2018. The intention of these guidelines was to begin use 2 or more years following completion of cancer therapy. Recommendations were made at varying levels of consensus among panel members from a number of subspecialties. While there are some late effects that are more common in specific diagnoses or drug exposure, specific late effects are recognized as high risk for any cancer experience, regardless of what that is.

Today I will spend my time discussing these potential late effects that can occur for all patients who are diagnosed with pediatric cancer, regardless of their treatment course. I intend to address each late effect—potential risk factors that could further escalate their risk—which will then further be divided into patient factors, which I'll explain in a little bit. These include cancer or treatment factors—premorbid or comorbid conditions, which means they had the diagnosis before we met them or while we met them. And we'll also

discuss signs and symptoms for parents and patients to be aware of and methods of prevention, if applicable, as well as intervention and treatment.



Late Effects: All Oncology Diagnoses

- Adverse psychosocial/quality of life effects
- Mental health disorders
- Risky behaviors
- Psychosocial disability due to pain
- Fatigue, sleep problems
- Limitations in health care and insurance access

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Late Effects: All Oncology Diagnoses

So, there are six categories of late effects that the Children's Oncology Group has identified for patients with any cancer experience. They are adverse psychosocial or quality-of-life effects; mental health disorders; risky behaviors; psychosocial disability due to pain, fatigue, and/or sleep problems; and limitations in healthcare and insurance access. So, now we'll discuss these one by one.

Adverse Psychosocial/Quality of Life Effects

- ❖ Social withdrawal
- ❖ Educational problems
- ❖ Relationship problems
- ❖ Underemployment/unemployment
- ❖ Dependent living

Adverse Psychosocial/Quality of Life Effects

Adverse psychosocial and quality-of-life effects is a very broad topic. More specifically, this includes but it's certainly not limited to social withdrawal, which can manifest as patients pulling away from their peer group or not wanting to do social events or outings that they would have previously.

This often stems from the feeling like they cannot relate to their peers anymore after their cancer experience. Also, sometimes patients will have late effects that are physical or mental that impede them from participating in activities in the same way that they did previously. They can also have educational problems. Patient challenges of education can present many ways, including but certainly not exclusive to a decline in IQ, learning disabilities, ADHD, or other more subtle changes, like a decline in grades or taking longer to complete academic tasks, like a test, for example.

Relationship problems: This can be in a number of relationships—most notably though, significant others or partners. This is a result of a number of complicated emotions, including, again, inability to relate or understand the previous or current experience. There's a lot of questions surrounding fertility and a concern, albeit typically very unwarranted, about passing cancer on to future children.

Underemployment/unemployment, this is most often reflected in the fact that a percentage of patients, due to an underlying disability from their treatment or diagnosis, are unable to work as much as they would otherwise. This is more common in brain tumors and soft tissue tumors and is tied to a level of education obtained as well, which is also variable, depending on the patient's diagnosis.


When need for a disability compensation is equalized or taken away, the employment becomes less of a prominent issue. Same as the need for medical follow-up is

continuous for these patients, and at minimum patients will have at least one visit a year—but more realistically multiple—to address any potential effects along with needed tests and scans. And this can be taxing when working full-time.

Finally, dependent living. This is similarly more prominent in the population who require some sort of assistance or have a form of disability. In addition, sometimes it is difficult to make the transition to dependence, particularly when the parent or parents of patients have been so involved in their life for so long in order to ensure that they received what they needed. But now they're being asked to become less involved, and that can be a challenge for many reasons.

Risk Factors		
Patient	<ul style="list-style-type: none"> • Female sex • Young age at diagnosis • Family history of depression, anxiety, or mental illness 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement • Failure to graduate high school
Cancer/treatment	<ul style="list-style-type: none"> • Bone tumor • CNS tumor 	<ul style="list-style-type: none"> • CNS-directed therapy • History of hematopoietic cell transplant
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • Neurocognitive problems • Depression • Physical limitations • Seizures 	<ul style="list-style-type: none"> • Scarring or disfigurement • Vision loss • Hearing loss • Premorbid learning or emotional difficulties

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Risk Factors

So, this is what I was discussing when I was talking about risk factors. So, these are factors that if the patient has one of these, they would be at even further risk of the previously discussed facts. And these are divided into patients. So, something that we generally can't change, something specific to their cancer, the treatment that they have, or a medical condition that they either had prior to meeting us or developed during. So, within this patient population there's a lot of subpopulations that are even higher risk. So, for patients being of female sex; younger age at diagnosis; having a family history of some mental health disorders, specifically depression and anxiety; having then some lower socioeconomic statuses, such as lower household income and educational achievement; or the inability to graduate high school.

These patients, also if they have a bone tumor or a CNS tumor—so that's a brain tumor typically—have a higher incidence of these issues. Or if they had CNS-directed therapy, which really can translate to some type of radiation to the brain, as well as if they got intrathecal or lumbar punctures, where they received chemo to that area. Or if they had a history of hematopoietic cell transplant, also known as bone marrow transplant.

From a medical condition standpoint, those patients that have neurocognitive problems or ability to learn, depression, some type of physical limitation, seizures, scarring or disfigurement, which is more common in our tumors of the bone or the soft tissue, vision or hearing impairment or an issue with learning or emotional difficulties—again, prior to meeting us.

Signs and Symptoms

- Disengagement from activities previously interested in
- Poor motivation
- Decline in school performance
 - Poor attention
 - Difficulty with organization (“executive function”)
 - Poor memory
 - Worsening grades
- Disinterest in pursuit on “next steps”
 - Relationships
 - Employment
 - Dependent living

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Signs and Symptoms

So, what do parents and patients need to look for? If they notice that their child is having disengagement from activities previously interested in, generally poor motivation, decline in school performance, which could include, but again, not exclusive to poor attention, difficulty with organization or what we deem executive function.

An example of this is I often ask patients, specifically, “Do you find yourself that you forget your planner or forget to write something in your planner and then don’t get half done as you used to?” Poor memory, worsening grades, and then the other piece is if they have a disinterest in pursuit of the next step. So, most teenagers can’t wait to move on with their life, but sometimes you’ll find that the patients really just have no interest. And this can be seen in both relationships, employment, as well as dependent living.

Prevention and Intervention

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Referral to psychology
- School liaison or counselor at school
 - Education and vocational resources
- Neuropsychological evaluation (potential 504/IEP needs)
 - School
 - Psychologist
- Involvement in local cancer support systems
 - Adolescent and young adult groups
- Online resources
 - Ex: Americans With Disabilities Act
 - Cancer and Careers

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Prevention and Intervention

So, what can we do? You'll notice a lot of the preventative strategies for everything I talk about today, as well as the interventions, there's a huge amount of overlap. So, I won't repeat myself, but it goes to say that a lot of these things are very important. So, all patients should have a good psychosocial assessment by their pediatrician or survivorship oncologist, like me. I would argue both should be doing it and perhaps this just means it's more likely to be caught.

A good psychosocial assessment is asking targeted questions about how the patient is doing, how they're doing in school, their friends, etc., etc. For some of our patients, referral to psychology can help, specifically if there's a concern that a mental health disorder is contributing, which I'll talk about a little bit later. If the school has a good liaison or counselor, this can be a great resource. And they can also refer them to education or vocational resources to make sure the postsecondary goals are being met.

A neuropsychological evaluation, particularly with school, is really helpful. The Children's Oncology Group actually advises that a large percentage of patients have a neuropsych evaluation by a psychologist. This is not across the board the same for everyone, so some schools will do it but it's not as extensive. And then some psychology departments, such as the one we have here, will do a full half-day of neuropsychologic evaluation. I urge whatever has been done to have evaluated by your oncology group or someone related to your oncology group so you can show that it's thorough and addressing everything it needs. This is important because this is how children get services in school, through what we deem in Florida "504," or an individual education plan. Having involvement in local cancer support systems is certainly helpful, particularly in our adolescent and young adult group. And then there are many online resources that exist. Examples: If the child has a disability, using the Americans with Disabilities Act, and there's also Cancer and Careers.

Mental Health Disorders

- ❖ Depression
- ❖ Anxiety
- ❖ Posttraumatic stress
- ❖ Suicidal ideation

Mental Health Disorders

Mental health disorders. I could spend a full hour talking about this, but I'm going to try to summarize it in just a few slides. So, when I first meet patients and their families and this is prior, at the beginning of their diagnosis, one of the first things I discuss is mental health. I learned very quickly that this plays a huge part during their treatment, and it directly affects the family unit, how the day-to-day life of treatment will look, and also have a huge impact on how their mental health manifests for the rest of their life.

The first thing I do is I give permission for the patient and the family, for that matter, to have feelings. My typical statement is quote, "We just gave you a lot of reason to be depressed or anxious," unquote. I also am a huge advocate for aggressively managing their psyche, seeking regular counseling with a psychologist or counselor and using medication, if warranted, has made a huge difference in patients' ability to cope during their treatment.

In the younger patients where behaviors such as hitting, screaming, temper tantrums, everything you thought as a parent you said so long to once they quote, "Got out of that stage," comes back with a vengeance. I try to delineate between being accepting of emotion but also not accepting of inappropriate actions that prior to the quote "C word," a parent would not tolerate.


While you certainly are going to pick your battles as a parent, it's crucial to stick to your guns and be as consistent as you are able. Why does this matter? You want a good human at the end of this, and while it is so very easy to just let everything go because now they have cancer. This theory, unfortunately, backfires big time when it comes to raising a respectful and somewhat well-adjusted child and eventually adult. Now I say all this completely understanding that I am not in a parent's shoes, and I get to walk out of the room after 20 minutes. But, as the individual who sees patients afterwards and still

cares for patients during treatment, I can say there’s a lot to be said for compassionate and consistent parenting, even during a chaotic time.

So, the four categories that are found at an increased risk in patients who have had cancer are depression, anxiety, posttraumatic stress, and suicidal ideation, with the latter two being much less common but are still at a higher percentage when compared to the rest of the population.

Risk Factors		
Patient	<ul style="list-style-type: none"> Female sex Family history of depression, anxiety or mental illness Not in a relationship Poor social support Perceived poor physical health 	<ul style="list-style-type: none"> Lower household income Lower educational achievement Failure to graduate high school Unemployment No health insurance
Cancer/treatment	<ul style="list-style-type: none"> CNS tumor 	<ul style="list-style-type: none"> CNS-directed therapy History of hematopoietic cell transplant
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> Chronic pain Permanent hair loss 	<ul style="list-style-type: none"> Scarring or disfigurement Premorbid learning or emotional difficulties

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Risk Factors

And then subpopulations that are even higher risk, again, you’ll see some overlap from previous. If a patient also has poor social support or is not in a relationship, that can be deemed an increased risk factor. CNS tumors, again, and CNS-directed therapy, if they received a stem cell transplant, if they have a history of chronic pain or permanent hair loss—that can also increase your risk. Again, a lot of these are similar to the previous.

Signs and Symptoms

- Increased emotional lability
 - Tearful
 - Angry
 - Short-tempered
- Disinterest in previously enjoyed activities
- Social isolation
- Nausea
- Heart palpitations
- Poor sleep (more or less)/fatigue
- Increased or decreased appetite
- Change in weight
- Nightmares of previous cancer experience

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Signs and Symptoms

So, signs and symptoms. I have learned just asking a patient if they're depressed or anxious won't get you very far. And if you ask more specific questions, you tend to capture more children.

So, the way I usually phrase it: Are they increasingly emotionally labile, which can manifest as a lot of things? Tearful, more so generally in females. Males can more manifest as being angry or short-tempered. Again that's not consistent, but just common things being common. If a patient has a disinterest in previously enjoyed activities, they're socially isolating themselves. Sometimes it only manifests as gastrointestinal symptoms like nausea or abdominal pain. If they have heart palpitations, that can be consistent with an anxiety. If they have poor sleep, which can be more sleep or less sleep or just generally fatigued, change in appetite in either direction, a change in weight, or if they're having specific nightmares of their previous cancer experience, that would lend itself to a PTSD-type picture.

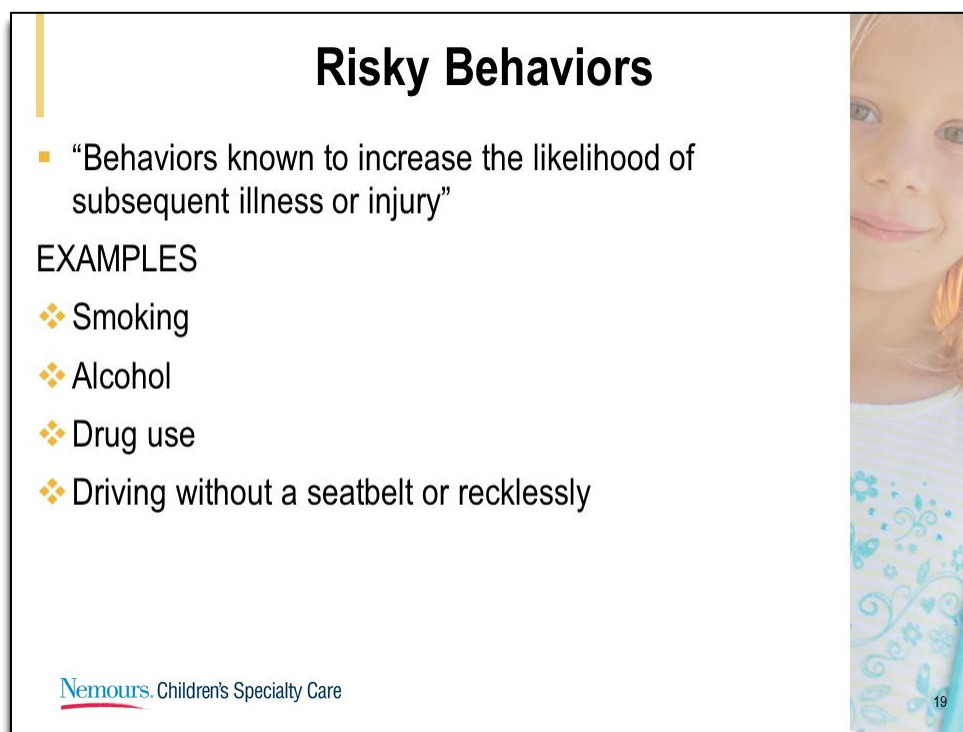
Prevention and Intervention

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Referral to psychology/psychiatry
 - Psychiatrist necessary if psychotropic medications required
- School liaison or counselor at school
- Evaluate parent for posttraumatic stress
- Involvement in local cancer support systems
 - Adolescent and young adult groups

Prevention and Intervention

So again, what can we do? These kids need really specific questions asked of them. There are very few patients that are going to come forward, walk into your room, and say, “I am anxious and depressed.” But I found that if I asked specific questions, it seems like at least a third of the patients I ask have some symptoms. If you’re so lucky to have a great psychologist or psychiatrist that you have access to, a referral to this is of benefit. A psychiatrist is necessary if psychotropic medications are required. Not all patients need that. Some can be managed very appropriately getting psychotherapy or counseling. This can be done by a psychologist. In some cases, it also can be done by a school counselor. It kind of depends on the severity. If you have a psychologist that is specific to the cancer experience, that is always really helpful. We are very lucky to have that here, so they can—in the context of their experience—give them good psychotherapy.

You also want to evaluate the parent for posttraumatic stress. So, a child is often the product of their environment. Sometimes kids are predisposed, but then also, if the parent has had a lot of posttraumatic, it may be deflecting to the child. And again, having some local support systems is really helpful, especially when the patients, again, are having this, “I don’t feel like anyone understands what I went through.”



Risky Behaviors

- “Behaviors known to increase the likelihood of subsequent illness or injury”

EXAMPLES

- ❖ Smoking
- ❖ Alcohol
- ❖ Drug use
- ❖ Driving without a seatbelt or recklessly

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Risky Behaviors


So, risky behaviors. I find this one to be probably one of the more difficult ones to deal with. So, risky behaviors is defined as a behavior known to increase the likelihood of subsequent illness or injury—so nice and vague. Risky behaviors in patients who have had cancer are surprisingly common and, to me, for a few specific reasons. Superficially, you would think, “Why would an individual who’s already been handed an unfortunate and frankly unlucky situation be more reckless with their life?”

Well, adolescents and in reality, really most humans are not wired this way. The thought process is that, “If I was unlucky enough to get cancer, why would something else bad happen to me?” Or, I survived cancer so I can survive anything. There’s a lot of overlap with some of these choices and mental illness as well, and often alcohol and drug use can be a method of self-medicating and an attempt to numb those feelings that they’d rather not deal with. So, risky behaviors are rather broad. The things that I typically discuss most notably are smoking, alcohol, drug use, and then driving without a seatbelt or recklessly.

Risk Factors

Patient	<ul style="list-style-type: none"> Adolescent/young adult (at diagnosis or follow-up) Male sex 	<ul style="list-style-type: none"> Lower household income Lower educational achievement Psychological distress
Cancer/treatment	<ul style="list-style-type: none"> None 	
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> None 	

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Risk Factors

So, the subpopulations that are increased risk are probably not super surprising. So, adolescents and young adults are at higher risk of reckless behavior anyway, so we just increase them more. And that's both at diagnosis, or if in follow-up, they're adolescent—males more so than females. And again, some of the socioeconomic risk factors, such as lower household income and educational achievement.

Signs and Symptoms

- Increased signs of anxiety or depression (outlined previously)
- Withdrawal from previous activities
- Increased car accidents
- Declining school attendance

Signs and Symptoms

So, things to watch for. This is pretty obvious. So, if they do have increased signs of anxiety and depression, you do want to note that cause that does increase the risk of reckless behavior. If they're having, again, a withdrawal from previous activities. If there are increasing number of car accidents, your radar should also go off. Or if they're having declining school attendances this sometimes can be a reflection of increased alcohol or drug use. Not always, but certainly something to think about.

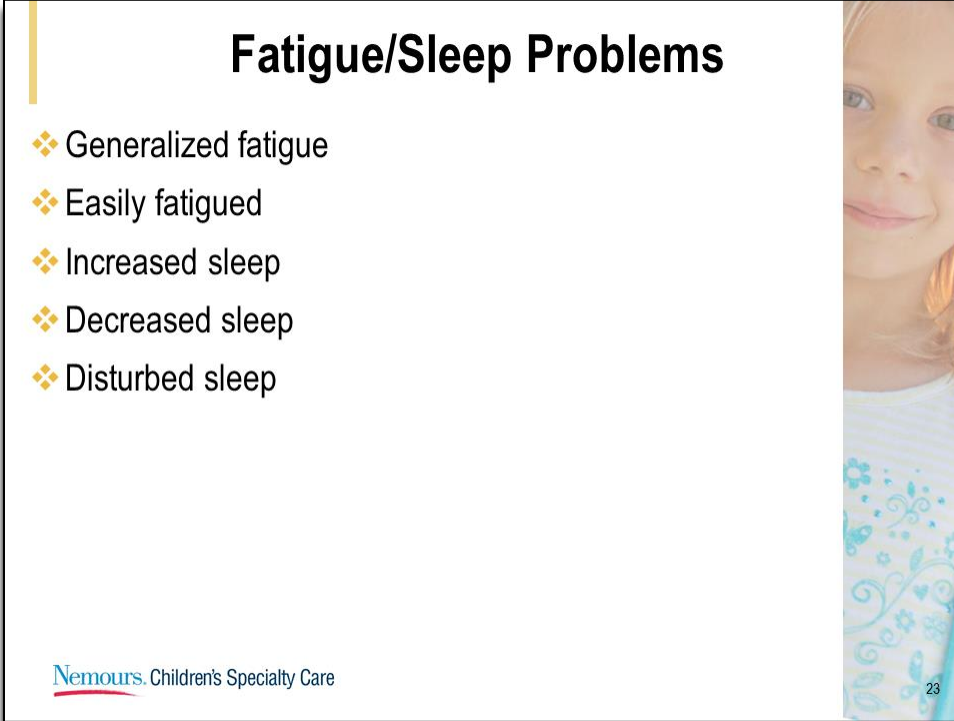
Prevention and Intervention

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Appropriate anticipatory guidance about increased risk
- School liaison or counselor at school
- Refer to resources for smoking cessation and/or drug and alcohol use
 - Smokefree.gov
 - Alcoholics Anonymous

Prevention and Intervention

So, for prevention and intervention, again, similar to before, you want to get a good assessment of these patients. For me, the big thing is I try to address it head-on before it even starts, which I'm sure mortifies parents on a regular basis cause I'm doing it younger and younger. But what I do want to do is educate the patient and parent about their increased risk when they're young. And as the patient gets older, part of the history being obtained ideally should be without the parents to ensure nothing is being hidden. This can be really hard for our parents as they have been, as I mentioned previously, very involved in every aspect of their child, especially in the oncology clinic.

However, patients may divulge more information without the parents there, and then we can ensure they get the necessary help they need. There is patient and provider confidentiality, but if a patient is in potential harm of themselves or others then I'm obligated to report to the parents. Otherwise, it's a matter of working through it with the patient and what's the best way of seeking help and, hopefully involving the parent as well with their permission. These can be very sensitive topics, but we want to encourage patients to feel like they can share everything so we can help them. And there are a few specific resources that are available, including smokefree.gov as well as Alcoholics Anonymous.



Fatigue/Sleep Problems

- ❖ Generalized fatigue
- ❖ Easily fatigued
- ❖ Increased sleep
- ❖ Decreased sleep
- ❖ Disturbed sleep

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Fatigue/Sleep Problems


So, fatigue or sleep problems. This is something that I feel like most people on this earth suffer from to some extent. But saying that, we have learned that those that have a cancer diagnosis—even more so. It can manifest in many forms. It can be general fatigue with often unclear cause, which is very frustrating for patients and families. Or it can be because they've been inactive during their diagnosis for a variety of reasons and, therefore, the activity level wasn't what it was. Some are more easily fatigued either due to a medical diagnosis or sometimes, again, without an obvious clear cause.

In addition, sleep has been added to the most recent Children's Oncology Group Survivorship Guidelines in this most recent edition in 2018. And like many things, the challenges can manifest in many ways. Poor sleep is also a common symptom in many mental health disorders, so isolating this issue is actually very difficult at times.

Risk Factors

Patient	<ul style="list-style-type: none">• None	
Cancer/treatment	<ul style="list-style-type: none">• CNS tumor	<ul style="list-style-type: none">• Pulmonary radiation
Premorbid/comorbid medical conditions	<ul style="list-style-type: none">• Depression• Obesity	<ul style="list-style-type: none">• History of sleep disturbance



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Risk Factors

So, patients that are at increased risk—those that have CNS tumors, if they've had pulmonary radiation, depression, obesity, or history of sleep disturbance either during or prior to treatment.

Signs and Symptoms

- Inability to participate in previous activities
- Falling asleep during the day
- Difficulty falling asleep
- Difficulty falling back asleep
- Increased number of awakening during sleep

Signs and Symptoms

So, things to look for. Again, if they're unable to participate in previous activities secondary to their fatigue, if they're falling asleep during the day. And I always note it's really important to get a sense: Are they falling asleep Monday through Friday at school because they're bored, or does it happen on the weekend as well? If they have difficulty falling asleep or they're able to fall asleep but then they wake up and can't fall back asleep, that's helpful to figure out cause sometimes what medications we use will be a little bit different. Or if they're having a lot of awakening during sleep.

Prevention and Intervention

- Ensure no other underlying physical source of fatigue
 - Anemia
 - Endocrinopathies (ex: thyroid)
 - Nutritional deficiencies
 - Cardiac disease
 - Pulmonary disease
- Referral to specialists if medical effect is contributing
- Referral to psychology or counselor if mental health is contributing
- Good sleep hygiene (no screen, consistent time)

Prevention and Intervention

So, this is a little bit more difficult to prevent, but from an intervention or workup standpoint it's really important that whoever is seeing the patient for the fatigue, that they rule out any other physical source. So, things like anemia or low red cells.

Endocrinopathy is most, most notably, I'm sorry, is thyroid. That can often have signs of fatigue. Certain nutritional deficiencies, albeit pretty rare, should be looked at. If they have cardiac or pulmonary, so heart or lung disease, secondary to their chemo, if they're not functioning well, you certainly can have fatigue from that. If any of these medical effects are noted, you do want to refer to the appropriate specialist.

If nothing else is coming up but you think mental health is contributing after some targeted questioning, psychology or counseling may be of value. And then the final thing is sleep hygiene, which is always easier said than done, so things that none of us probably practice. No screen in the room, having a consistent bedtime, ensuring adequate amount of sleep. Arguably, teenagers require the most sleep of anyone. The whole 8-hour rule kind of gets thrown out the window, but you do want to make sure they're having good-quality sleep.

Psychosocial Disability Due to Pain

- ❖ Common complaint DURING treatment
- ❖ Acute and/or chronic pain
- ❖ Multifactorial

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Psychosocial Disability Due to Pain

So, pain is a very complicated symptom for many reasons. And in the medical field, we have for many years had a really difficult time quantifying pain and, therefore, rely on patient report, which of course is really dependent on the patient. Pain can manifest many ways. Patient's ability to cope with pain is quite variable and, again, multifactorial. During treatment for cancer, pain is often an expected side effect of either their cancer, treatment, or often both. Therefore, we use pain medication really often. There's typically some hesitancy from families, particularly in the current environment of narcotic addiction. Saying that, it doesn't seem that their use leads to increased use long term. However, it is important, particularly if the pain becomes more chronic in nature that the pain is addressed more globally.

Risk Factors

Patient	<ul style="list-style-type: none">• Female sex	
Cancer/treatment	<ul style="list-style-type: none">• CNS tumor• Hodgkin lymphoma• Vincristine exposure	<ul style="list-style-type: none">• Amputation• Limb-sparing surgery• Radiation to bone/joint
Premorbid/comorbid medical conditions	<ul style="list-style-type: none">• History of osteonecrosis	



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Risk Factors

So, the subpopulations that are at increased risk of long-term psychosocial pain are those that are female, those that have a CNS tumor, Hodgkin's lymphoma, vincristine exposure, which is given to a lot of our patients. If they've had an amputation, they can have what's called phantom pain quite often. Limb-sparing surgery, so in our bone tumors most frequently. And then if they've had radiation to their bone or joint or if they have a history of osteonecrosis, which is secondary to steroid use—so, most commonly in our leukemia patients.

Signs and Symptoms

- Pain symptoms are limiting patients' ability to participate in their typical activities

Signs and Symptoms

So, signs and symptoms are pretty obvious. They have pain and their treatment is done, then I would argue this is an issue, and especially if it's limiting their ability to participate in their typical activities that make them happy.


Prevention and Intervention

- Ensure good psychosocial assessment, including impact of physical symptoms on emotional outcome, by pediatrician or survivorship oncologist
- Psychological consultation if chronic pain is present
- Psychiatry consultation if psychotropic medications needed
- Pain rehabilitation clinic
 - Focus on tackling pain symptoms from all aspects (physical, mental, and emotional)

Prevention and Intervention

So, what can we do? Again, a good psychosocial assessment, including how are these symptoms affecting the patient. And a lot of teams now have pain management specialists that typically have an anesthesia background. We are really lucky here to have that. And I think they've given us some good change in management plans, and also an avoidance of narcotics, if able. It's not always realistic up-front, but it certainly is the goal long term.

You do want to get psychology involved, especially if it's a chronic pain, because there's a lot of underlying mental health that overlaps with pain. And it's sort of what came first: the chicken or the egg? So, our pain team has their dedicated psychologists, and we often will loop them into psychology. And if you think medication of the psychiatric nature is going to be needed, then you're going to want to get psychiatry involved, too. In our more extreme or severe cases a pain rehab clinic is really of value, and those patients are going to have their pain symptoms tackled from all aspects, which to me is the best way to do it.



Limitations in Health Care and Insurance Access

- Finding a physician that is comfortable managing a more complicated young patient
- Ongoing copays
- Multiple visits/tests
 - With escalating costs when patients' income is little to small
- Transition of insurance at certain age/life point
 - Already established condition → potential increased cost

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Limitations in Health Care and Insurance Access

So, insurance. This is often a word when we hear it that we, or maybe I, inadvertently cringe. It's often a barrier or a nuisance to obtaining what providers feel is appropriate care. And for families, it's really a necessary evil of their family's experience when their child was undergoing treatment for their cancer.


How this impacts our patients is a moving target for many reasons, and I do not mean this to be a political statement. I'm Canadian. I don't talk about politics, but insurance companies provide care. Who are able or want to enroll, etc., is to some extent dictated by the current regulations and laws.

In addition, many patients transition out of being under their parents' insurance plan as they are also transitioning out of their pediatric program, which is really a challenge in and of itself, so they're learning to navigate paperwork and check boxes and function independently all at once.

When I meet families, I try to start the transition process a few years before they transition out, which, in our program, is their 21st birthday. This includes, but certainly not exclusive to, teaching patients about their diagnosis, medications that they take and ones that they have previously taken, their ongoing risk—as well as ensuring they have appropriate care lined up for when I move their care to either an adult oncologist or, more likely at that time, a family doctor or internist. I usually just start the discussion a couple years in advance, particularly since most patients are only seeing us annually when they're in their late teens. This is so they can ensure they have an adult provider that is comfortable and able to care for them before I see them for their last visit. We also provide a summary of their care and their ongoing monitoring to make sure that everything is in writing and easily transferable to the next medical provider.

Risk Factors		
Patient	<ul style="list-style-type: none"> • Unemployment 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement
Cancer/treatment	<ul style="list-style-type: none"> • Testicular cancer • Higher cumulative alkylators (ex: cyclophosphamide, ifosfamide) • Combinations of alkylators 	<ul style="list-style-type: none"> • Treatment with MOPP • Cyclophosphamide for conditioning for transplant with radiation to abdomen/pelvis, tests, brain • Unilateral orchiectomy
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • None 	

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Risk Factors

Those that have a more difficult time transitioning and navigating the healthcare field are those that are unemployed, have a lower household income or educational achievement, those that have had testicular cancer, higher chemos of alkylating agents or combination of alkylators, or a unilateral orchiectomy.

Prevention and Intervention

- Early discussion by Survivorship Oncologist
- Active involvement by patient in their care EARLY on
- Online resources
 - Centers for Medicare and Medicaid Services (CMS)
 - Patient Advocate Foundation
 - Healthcare.gov
 - Cancer Legal Resource Center

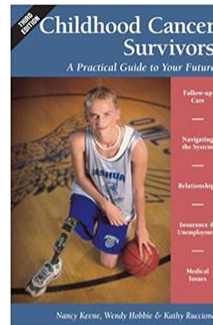
Prevention and Intervention

In terms of prevention and intervention, it's really, really important that we talk about this early. This should not be a discussion on their 20th birthday, or 1 month till their 21st birthday. So, the survivorship oncologist needs to address this with the help of social work, if available, so that they can get it done in a timely fashion. It's really important to involve the patient early on. Again, this is a difficult transition for parents. So, they've been in charge of their child's care and had to be their advocate for many years, and now I'm really putting things on the patient. So, it's certainly a moving target. It's not all going to happen at once, which is more reason it should be started early.

There are a lot of great online resources that can be made available to families: Center for Medicare and Medicaid Services, or CMS. There's multiple advocacy groups that have information online for parents and patients so they can learn to advocate for themselves, which really will bode well for them no matter where they go: healthcare.gov in terms of finding insurance centers. And then also, there's a lot of legal resource centers as well, including the Cancer Legal Resource Center.

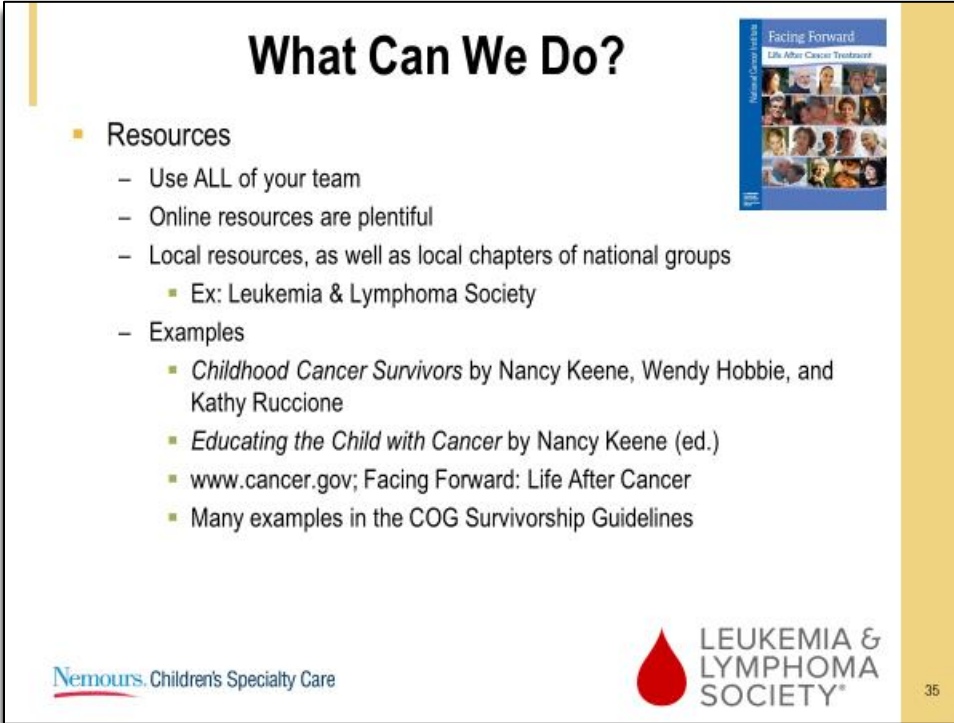
What Can We Do?

- Discussions need to be ongoing
 - At diagnosis
 - During treatment
 - Long-term follow-up
 - Transition




What Can We Do?


So, what can we do? It's really crucial that survivorship or after treatment is a longitudinal discussion. At the beginning, most families appropriately remember a small portion of any discussion and simply put, their focus is curing their child at that time. However, once the shock has begun to wear off, it's completely appropriate to, in conjunction of talking about their current treatment plan, to discuss ongoing management after treatment is complete. Many families and patients do worry about these things, but it just frankly takes a back-burner when everyone is truly in survival mode. So, unless the oncologist brings it up the parents are not going to. However, if it is addressed on an ongoing basis, the transition to survivorship care will be more smooth and effective.




What Can We Do?

- Resources
 - Use ALL of your team
 - Online resources are plentiful
 - Local resources, as well as local chapters of national groups
 - Ex: Leukemia & Lymphoma Society
 - Examples
 - *Childhood Cancer Survivors* by Nancy Keene, Wendy Hobbie, and Kathy Ruccione
 - *Educating the Child with Cancer* by Nancy Keene (ed.)
 - www.cancer.gov; Facing Forward: Life After Cancer
 - Many examples in the COG Survivorship Guidelines



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What Can We Do?

So, as I've been developing our survivorship program here in Jacksonville, I've become more versed in the many resources available both in person or locally, as well as online. The nurse I work with and myself, with the help of our AYA physicians, social workers, and child life team, were able to create a multiple-page document of online resources, some of which I mention today as they give valid and appropriate information about everything from late effects, to scholarships, to finding an advocate for insurance, and each individual's employment rights.

In addition, most major cities that have an oncology center have local support either through their local charities or with national groups, such as The Leukemia & Lymphoma Society. This allows parents and patients to connect with like-experience and -minded individuals. This can be exceptionally helpful even when they are well past the active treatment phase.

Levels of engagement are going to vary for each individual, and there's really frankly no right answer. But what is crucial is an attentive parent, and as they get older a self-aware patient who is in tune with potential concerns to watch for. Particularly as the patient is farther away from treatment, we are less likely to link a concern with previous treatments. But if something seems off, I encourage patients and/or parents to contact their physicians. Sometimes this can be appropriately addressed by the pediatrician or family physician or sometimes by the oncologist—or often it's a team approach.

References

1. Children's Oncology Group: Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancer. Version 5.0. October 2019
2. American Cancer Society. Cancer.org
3. SEER Data

References

Thank You!
QUESTIONS



Thank You! Questions

And this concludes my presentation.

Ms. Alicia Patten

Thank you so much, Allie, for providing us with this great information.

It is now time for the question-and-answer portion of our program. We have received some pre-submitted questions from patients and caregivers alike and have contacted LLS through our online LLS community or have spoken to our Information Specialists.

Our first question: “How important is continued psychosocial care in terms of anxiety and coping as treatment ends?”

Allison Bechtel, DO, FAAP

It’s really important. So, anxiety doesn’t stop when you stop taking chemo. I would argue it probably gets worse. And I actually tell parents and my older kids that the second scariest day is the day they stop treatment because now we’re not doing anything for their cancer. So, I think it’s really important to address that specifically and the fears surrounding stopping treatment. There’s also fear with leaving your oncology team because you’ve seen them once a week for forever or however often and now it’s getting spaced to weeks and months. So, that can provide a lot of anxiety.

The other thing that’s really important is I meet a lot of kids that are teenagers that got treatment when they were 4 or 5 years old. They remember very little. They’ve had a perfectly functional year or years. And then they hit high school, they’re old enough to understand what they went through, and they totally crumble.

And part of it, I’m sure, has to do with they’re teenagers and they’re type A and they want to, do really well in getting into college, etc. But part of it is now, either they know someone who’s older and has gone through cancer treatment has either not fared so well or gone through a lot, or they are having major, “Holy moly, I could have died!” And so, I think saying that the anxiety is only during treatment is really naive, and it’s really important to continue to be addressed. And if it happened during treatment, I can promise you it’s not going to go away as soon as you move on into the nononcology world. It may get worse before it gets better.

Ms. Alicia Patten

Our next question is, “Should a child see a dietician regularly as they may have digestive issues or weight issues?”

Allison Bechtel, DO, FAAP

I don’t think they need to see a dietician regularly, but I will tell you that certain patients are at higher risk of having obesity, especially patients with leukemia or brain tumors, so I certainly address weight when I see patients. I look to see if they have a healthy weight for height. I personally address a lot of it on my own, but if it’s available and the family has interest, a dietician certainly is going to help because they’re going to take a different approach. So, I think it’s of value but I don’t think it’s necessary.

Ms. Alicia Patten

Our next question is a two-part question. “After years of remission, do children need to visit with their pediatrician more often?”

Allison Bechtel, DO, FAAP

Not more often unless there are particular concerns. So, typically, a pediatrician as they’re older, will see you once a year and then our clinic at minimum will see everyone

once a year. Obviously, if they have other late effects that are relevant to their cancer, they may need to see a physician more often. Whether that be the pediatrician or a specialist kind of depends on what it is, but I wouldn't say just having a cancer diagnosis warrants seeing their pediatrician more than what would be scheduled of their siblings, for example.

Ms. Alicia Patten

The second part of this question is, "When do they return to seeing their pediatrician versus the hematologist/oncologist?"

Allison Bechtel, DO, FAAP

Yeah, this is always a difficult question, and I'm sure it depends on the center. So, for us, once they're diagnosed, typically every single question with few exception or issues until they're done treatment will come to the oncology team. Once they are done treatment—and especially once their central line is out—we typically direct to the pediatrician first. And there's a few reasons for that. One, [of the] most common thing they're going to be calling about is a fever, worry for infection. And we do like to try to protect our patients, if we can, that are getting treatment, so the pediatrician's office actually would be the best place.

The second is, which is this is really hard for parents, is the more common things that they're going to be dealing with, the pediatrician is actually going to look at that at a better scope than the oncologist will. We're very biased. We think everything is something bad. But chances are, even though they've had a cancer diagnosis, that they actually have something that could be treated appropriately by the pediatrician.

Ms. Alicia Patten

Our next question is, "Is survivorship oncologist a specialty that only some centers have?"

Allison Bechtel, DO, FAAP

This is a bit of a relatively new field I think, depending on who you talk to. So, how every center deals with survivorship I think is a little bit different. In the very big centers, everyone has at least one survivorship physician. It is now advised by the Children's Oncology Group that all patients off treatment, which is about 2 years for most places, should be seeing a survivorship oncologist. And so, I would argue the majority of centers in the United States that are part of Children's Oncology Group—and any other country that is part of that—will have survivorship programs. What that looks like is a bit variable still. So, I think the majority do at this point. And I suspect over the next 10 years that the places that don't will, as long as they have the staff to support it.



The screenshot shows a slide titled "LLS EDUCATION & SUPPORT RESOURCES" with a red vertical bar on the left. The slide lists several resources with corresponding icons: Information Specialists (with a photo of a woman on a headset), Free Nutrition Consults, Caregiver Support, Free Education Booklets, Free Telephone/Web Programs (with a photo of a man at a computer), Live, weekly Online Chats, and LLS Community. At the bottom, it says "BEATING CANCER IS IN OUR BLOOD." and the LLS logo.

LLS EDUCATION & SUPPORT RESOURCES

- Information Specialists
 - EMAIL: infocenter@LLS.org
 - TOLL-FREE PHONE: 1-800-955-4572
- Free Nutrition Consults: www.LLS.org/nutrition
- Caregiver Support: www.LLS.org/caregiver
- Free Education Booklets: www.LLS.org/booklets
- Free Telephone/Web Programs: www.LLS.org/programs
- Live, weekly Online Chats: www.LLS.org/chat
- LLS Community: www.LLS.org/community

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Ms. Alicia Patten

Our next question is, “Can my child still get immunizations?”

Allison Bechtel, DO, FAAP

The short answer is yes. The literature or scientific data is not particularly great on when you should restart. It’s anywhere from 3 months to 6 months, depending on who you talk to. So, if we’re talking about the survivorship population, absolutely. They should be getting immunizations unless there’s another reason. And I will be honest: Our oncology clinic really appreciates when you get immunizations because the challenge that we’re now dealing with is some outbreaks of diseases that previously didn’t exist. And if you’ve been exposed to those and are coming to your regular follow-up and there’s patients on treatment, that actually can be a risk. So yes, I would encourage all patients, unless there’s another reason, to get their immunizations.

Ms. Alicia Patten

Our next question actually touches upon something you said earlier, which is a question that we get here at LLS a lot about cancer being contagious. When someone asks you, “Is cancer contagious?” how do you answer that?

Allison Bechtel, DO, FAAP

So, cancer is a cell that is growing improperly, and there’s no way that that can be passed on. I think another question that often gets addressed in our clinic that a lot of patients think about but don’t ask, which I don’t know if “contagious” is the right word, but a lot of patients worry that they’re going to give the cancer they had to their future child. And there’s a lot of things I understand floating around the Internet that are consistent with that. But with very few exceptions, cancer is not contagious nor is it inheritable or can be passed along.

Now, there are some that are. Usually, that would have been addressed by your oncology team early in diagnosis based on a good history and some other testing, potentially. But the majority of childhood cancer we have no good reason for it, and we can't get it from someone else either.

Ms. Alicia Patten

Our next question is, "I'm pregnant. Can I still be around my child when they are getting chemo?"

Allison Bechtel, DO, FAAP

So, the short answer is yes. I'm probably not going to be able to answer this completely, but the only thing that we advise with parents that are pregnant is that a lot of chemo is secreted into the urine. And so, we actually have the moms not change the diaper for the first few hours after it's given. And I'm not sure that's something specific, and I'm sure that would [be], what we call center dependent. But generally speaking, yes, they certainly can be around their child. But I would ask your individual oncologist about that and their preference.

Ms. Alicia Patten

Our next question is, "Are there any supplements or nutrition components that can be used during treatment to alleviate some of these effects?"

Allison Bechtel, DO, FAAP

I wish. So, nutrition is something, I think, I get asked more often than anything else on patients during treatment. And my understanding as to why, which makes sense, is a parent feels very out of control in a lot of this and they want some method of feeling like they're helping their child besides, obviously, bringing them to their appointment.

So, there is nothing we know of that nutritionally specifically helps with either making the cancer go away more likely or with effects. What we do know is that a child that has a relatively healthy weight is going to fare better from a medical standpoint—both beating their disease and managing effects—than a patient that is undernourished or low weight.

So, I think that's the most important thing is to try to get food in. Now I will tell you on the late-effect side, I always then have to have the discussion with family that I understand 2 years ago we told you, "Eat anything you want, just get food in," and now I'm telling you, "Please eat less and eat better." And that can be really challenging. So, our first choice is good food and healthy food. Our second choice is any food. But unfortunately, there's no specific nutritional supplement or food that is going to make this better or worse. I wish. That would be awesome. I look forward to when that exists.

Ms. Alicia Patten

Me too. Our next question is, "My child is getting therapy as part of a clinical trial. How does this differ from treatment that is not part of a clinical trial?"

Allison Bechtel, DO, FAAP

Good question. So, a clinical trial is they're asking a medical question to see if some change is better than what is currently offered to all patients. So, I think the best way I explain it to family in most places in the United States are part of the Children's Oncology Group. And for the last 50 years, they've had clinical trials for almost every disease and most of them it's that there's been data from other studies showing that some type of change is promising. And once we have enough information, we usually will compare

that specific change to what is considered what we call “standard of care,” which typically is the previous study what was deemed to be the best.

And so, a clinical trial means that you are involved in the research of asking that specific question. Sometimes that means that there are two slightly different therapies available on that clinical trial and you’re randomized, which is really just a computer flipping a coin and you are going to be on one treatment versus the other. And sometimes it’s that the outcome was so good previously that everyone is going to be on the same arm and they’re just watching to make sure that the small amount of data from the previous phase 3 trial is as good with bigger numbers.

So, being on a trial simply means you’re getting either the standard of care or the standard of care plus or minus a small change to see if treatment can be better. And because of people’s involvement of clinical trials, that is why we do so well in children’s oncology. So, if you can be involved in one the people before you and after you are also very thankful, as are we.

Ms. Alicia Patten

Our next question is, “How can I best support my child during treatment?”

Allison Bechtel, DO, FAAP

I think the best thing a parent can do is to be their parent. So, that’s different for everyone. I am not a parent, and I usually disclose that fairly quickly, understanding that I don’t know what it’s like to be one. I know what it’s like to be a daughter and a sister and all of those things, but I’ve never been a parent. But I think from what I’ve seen is that it’s really easy for parents to kind of everything they’ve believed to do as their parent can completely go out the window. And I kind of alluded to this when I talked about behavior.

So, it’s really easy to not discipline your child for 3 years during leukemia treatment. That ends up backfiring. And I understand that having a child with cancer comes with a lot of guilt, and I usually address that in the first few hours of meeting a family: that this is not anything that had to do with pregnancy or what you fed them or how they are as a human—any of those things.

And so, I think a parent trying to be their child’s parent just as they were the hour before they met us. If they can do that, I think that, honestly, alone is probably the best thing that they can do because none of this is going to feel normal and parents always tell me there’s like a before and after cancer. It’s never going to be the same again, but I think trying to keep some normalcy the best you can in the context of getting done what needs to be done is really of value. And I think those are the families and the kids that do the best is that life kind of moves on despite cancer as best they can.

Ms. Alicia Patten

Our next question is, “How do I collaborate with my primary care physician about my past treatment and monitoring long-term side effects?”

Allison Bechtel, DO, FAAP

I think the big thing is going to see your pediatrician every year. The pediatrician should know all of your history and the oncologist should be keeping them updated through. Usually, now the good thing about electronic medical records is, for example, our pediatricians get our notes every year. But just being honest about side effects and also trusting the pediatrician.

So, it's really easy for parents to think every single new symptom is their cancer because the last time it was something, it was their cancer. But I think trusting the pediatrician to think through the noncancer things first, obviously, disclose anything you're worried about. And the pediatricians always have the ability to pick up a phone and talk to us, and we can kind of talk through things. And most of the time it isn't something concerning. But I think the big thing is just, letting [them] know your concerns. Be honest about your anxiety, which all parents have after all of this, and, try to work through what would be the more common thing for their pediatrician. And then obviously, if there are concerns then they reach out to our team and try to see if there's anything else that needs to be done in the context of their treatment.



LLS EDUCATION & SUPPORT RESOURCES

- **• LLS Podcast, *The Bloodline with LLS***
Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: www.thebloodline.org
- Education Videos**
Free education videos about survivorship, treatment, disease updates and other topics: www.LLS.org/educationvideos
- **• Patti Robinson Kaufmann First Connection Program**
Peer-to-peer program that matches newly diagnosed patients and their families: www.LLS.org/firstconnection
- What to Ask**
Questions to ask the treatment team: www.LLS.org/whattoask
- Other Support Resources**
LLS Community, discussion boards, blogs, support groups, financial assistance and more: www.LLS.org/support

LLS Education & Support Resources

Ms. Alicia Patten

Our next question is, "How do we address the issue of fertility regarding treatment?"

Allison Bechtel, DO, FAAP

Well, I think that's one thing that we have learned in the oncology world that is not done as well as we would like, but there is a movement to make it more of a priority. So, it's kind of a twofold answer. One is, obviously, the people I'm speaking to now all are postdiagnosis, but we need to do a better job of offering or disclosing things up-front. And it's sort of the, "I don't remember 50% of what you said to me, so even if you offered fertility or told me that was going to be an issue, I don't remember it." That's possible. But we really do need to try and make it a priority. Obviously, life first, but having good fertility options is important.

I think on the back end, it kind of depends on a few different things. It depends on the risk. It also depends on the age of the child. And I have 16-year-old boys that are losing sleep over their inability, potentially, to have children. And then I have, 18-year-old girls

that look at me and say, “I’m never going to have children, why do you keep asking me?” So, I think the important thing is kind of getting a gauge as to where the family and more importantly, where the patient is, and then you can start offering options.

So, there are certain lab tests now that can be sent that, albeit not perfect, give you a general gestalt about fertility abilities or for females what we call “ovarian reserve.” That’s really helpful to get an idea. Obviously, we have patients that are at higher risk than others, so trying to stratify them. There’s some really good websites that actually do that, particularly through Livestrong, but there’s also other websites that do a great job of doing that. But that’s just a generalization.

So, sometimes it’s helpful for them to also meet reproductive OB/GYNs, which we’re lucky we have one here. So, we’ll often refer them so that they can be looped in so if for some reason later on they either want to be tested or want to egg harvest, if that’s relevant, we have them established.

So, it’s a sensitive, but really important topic. I think you have to address it head-on, but you also have to gauge where the family’s at, too. And that’s something that, honestly, I’m still working on. And I think overall we’re trying to do better as an oncology society addressing it up-front but then also having a good system on the back-end.

Ms. Alicia Patten

Our next question is, “What are common side effects that will most likely continue after treatment stops?”

Allison Bechtel, DO, FAAP

Every kid’s different, so I’m not sure I can give a “most likely.” And I don’t know if we have great data to say, “This is the most common side effect.” Personally, I think the most common side effect is anxiety and depression. And I think the reason for that is, one, lots of kids have it despite meeting us and, two, I think we underdiagnose it.

In the months that I have been specifically in a survivorship role and really making this a main discussion point, my psychology referrals have been really impressive. And I don’t think that’s because, all of a sudden, we have a spike in anxiety and depression in our clinic. I think it’s because a lot of it gets missed because it’s subtle. And I think a lot of kids are scared to talk about it or they’re embarrassed, or they think it’s not normal to think all of these things.

And it’s not to say it’s not normal, but it’s something that should be addressed, because the way I phrase it to kids is, “I don’t want you to not have emotions, but I do want you to start learning how to appropriately cope with those so that you can function as a human being.” And sometimes it can be very paralyzing to have some of these feelings, which are pretty real especially when they’re old enough to understand what they went through whether it be months or years ago.

So, I think to me, that’s probably the most common side effect that I see long term. And I think it’s actually the hardest ones to diagnose honestly, cause I just think we don’t think about it. We’re really good at thinking about physical effects because those are obvious or I can find them in a lab value, but mental health is a totally different can of worms.

Ms. Alicia Patten

Great point. Our next question is, “My child is having difficulty coping with their diagnosis. Where can I turn to get help?”

Allison Bechtel, DO, FAAP

I think that depends on where your child's being treated. I can't speak to every center, that kids are treated at, but I would argue most have some type of psychology support. And while there is stigma against having a psychologist involved, I promise you it pays for itself in spades no matter how embarrassed or you don't want to give that label. So, I think the first thing is asking your oncology team if there is psychology help.

The second option, you know, child life is often present in oncology groups, and I think they often are a nonthreatening individual that can help work through some of that stuff. Obviously, different training, but I think still is good at that. Most places should have a social worker, so the social worker may be able to refer to outside services. And then depending on what school the child goes to or how old they are, often there's counselors at school as well.

So, I think it kind of depends on where you are and also what's convenient. So, having a school counselor's great cause you can do it in the context of school, but then some kids don't want someone knowing they're going to therapy because, again, for reasons I don't totally understand, there's a stigma against having some type of feeling.

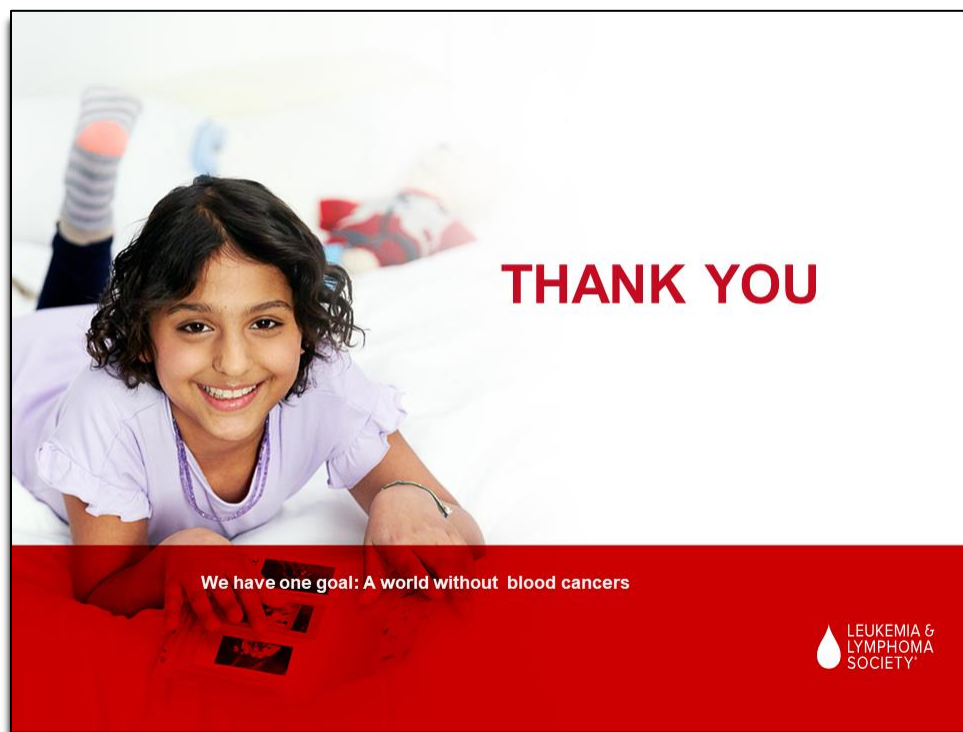
So, I think you got to just talk to your oncology team and see what's available and also be willing to do some legwork because, unfortunately, sometimes that's a bit insurance-driven in terms of what type of support you would be eligible for from a payment standpoint and who will pay for what. But you got to just speak up is, I think, my first piece of advice and see what's available where you are.

Ms. Alicia Patten

Absolutely. Our last question is, "Can cancer stunt growth?"

Allison Bechtel, DO, FAAP

It's kind of a broad question, so I guess the easy answer is yes. But it really depends on what you got for treatment and where your cancer was. So, the cancer we see most commonly of growth tissues is brain tumors, and that's based on the location—and also, if they get radiation to their head. So, it's certainly possible. It's not a guarantee. Your growth chart should be looked at every visit by your survivorship oncologist as by your pediatrician. And if there are concerns with that and/or going through puberty, then that should be addressed by referral potentially to the endocrine or hormone doctor.



Thank You

Ms. Alicia Patten

That concludes the question-and-answer portion of our program. Thanks, Allie, for sharing your time and knowledge with us. We appreciate your dedication and commitment to patients and caregivers throughout their cancer journey.

For those looking for more information about childhood cancer, please visit www.LLS.org/childhood cancer. If you have additional questions, please call an LLS Information Specialist at 1-800-955-4572. Information Specialists are available to speak with you Monday through Friday from 9 AM to 9 PM Eastern Time, or you can reach us by email at infocenter@LLS.org. We can provide information about resources, personalized clinical trial assistance, and nutrition consultations and answer other questions you may have about diagnosis, treatment, and support.

LLS also offers financial assistance programs to help individuals with blood cancer. For more information about our financial support, please visit www.LLS.org/finances. We'll also include the resources shared by Allie.

On behalf of The Leukemia & Lymphoma Society, thank you for listening and we wish you well.