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14

ESSENTIAL
Things to
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CANCER
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“I just want to be treated like everyone else.”

Childhood cancer affects roughly 250,000 kids, like brothers Jakob and Channing, each year.

These are wise words from 8-year-old Jakob Nielson, an energetic boy living with leukemia in Clinton, Wisconsin. Jakob just started third grade, and unfortunately, his family is all too familiar with childhood cancer. His twin brother, Channing, went through the same type of leukemia just a few years earlier.

Yes, the Nielson family has been through cancer twice. Yet, they don't focus on anger or sadness. They've chosen positivity and hope. And best of all, they want to help others do that too.

Childhood cancer affects roughly 250,000 kids each year worldwide. It's one of the

most frightening, anxiety-ridden and stressful situations that a child can go through. So when it touches a student in your school, it's critical that you're ready.

The twins' mother, Alyssa Nielson, has seen how important the school experience has been for her two boys. Below, she joins two counselors who have personally dealt with childhood cancer. Together, they offer up powerful advice on how to cope with this topic at your school in what might very well be the making or breaking point for one of your students. Read, absorb and *do* these things. The doctors and nurses might be the ones saving their lives, but your influence at school has a tremendous effect as well.

“They already feel like their life is different, so do whatever it takes to let them be like other kids.”



1. “Kids need school. It helps normalize their lives.”

Kelly Kaminski is the school counselor at Clinton Elementary School, where Jakob and Channing attend school. She knows firsthand how important it is for kids with cancer to maintain their normal routines as much as possible. Like Jakob said above, he wants to be treated like any other kid, and being able to participate alongside his friends is really important. “When the child is able to come to school, try to normalize their day as much as possible,” Kaminski says. “They already feel like their life is different, so do whatever it takes to let them be like other kids.”

TAKEAWAY: Let your assumption be that the child will want to be treated like any other student. When you have to make accommodations, do so with the intent of normalizing the experience as much as possible. If a child has to be out for a considerable amount of time, for example, consider regular Skype visits with his or her classroom so that the child can continue to see—and be supported by—his or her peers.

2. “Establish a plan as soon as possible.”

Within days of Jakob being diagnosed, Alyssa Nielson had set up a plan with the staff at Clinton Elementary School that covered overall communication, missing school, accommodating appointments and monitoring Jakob’s health throughout the day. Nielson says it’s never too soon to start having these conversations, and that it’s helpful to have considered some of these questions before a diagnosis ever happens at your school.

TAKEAWAY: Your critical-illness plan (often called a 504 plan) is just as important as ones you make for fire, tornado and other emergencies. Does your school have a plan for homebound tutoring, for example, if a child becomes critically ill? In creating your plan, consider networking with other schools to see how they handle similar situations.

“... a quick email telling me that my child is having a good day is nice.”

3. “You have to have a point person.”

Parents like Nielson have an endless number of people they have to communicate with, including doctors, counselors, their family, friends and the school. The more the school can do to streamline communication with just one or two staff members, the easier it will be for everyone involved. “You can’t all be calling the mom for every little thing,” Kaminski says. “Find a way to coordinate the communication.”

TAKEAWAY: Assign a point person who is readily available and comfortable coordinating communication between teachers, administrative staff and the family. This might be the school counselor, or the child’s classroom teacher if that helps to maintain the sense of normalcy.

4. “There is no such thing as too much communication.”

It’s easy to establish a plan up front, but the communication between staff and parents has to be ongoing. Remember that the family of a child with cancer needs to keep a close watch on their child for their overall health. Nielson’s philosophy is: The more communication, the better. “Regular meetings between parents and staff members help me feel more comfortable. But even a quick email telling me that my child is having a good day is nice.”

TAKEAWAY: Schedule regular check-ins with the student’s parents—whether the child is able to attend school or is out due to his or her stage of treatment. If the child is in school, make a point to share non-cancer-related updates too, such as a book or activity the child enjoyed. If the child is out of school, share regular updates from the child’s classroom along with your wishes for continued healing.



5. “Offer homebound learning or tutoring.”

Miriam Matz is both a mom of a child going through cancer and a child psychologist. She’s been on both sides—helping a child cope with a diagnosis and also doing everything she can to help her own child, Ellie, who is currently 7 and receiving treatment in Pennsylvania. She reminds schools that a child’s lack of attendance at school is out of their control. “A parent shouldn’t have to worry that their child is missing out because they don’t feel well enough to be at school,” Matz said. “Homebound tutoring is really important.”

TAKEAWAY: Look into what services your district offers for critically ill children. If resources are limited, consider video tutoring or offering homeschooling support. Try to align the curriculum as best as possible to what’s happening in the classroom.



PHOTO CREDIT: ISTOCK.COM/DINIC

“... a video or book might work for explaining cancer to classmates.”

6. “As the situation changes, so does your approach.”

Many children dealing with leukemia have years of treatment. Kaminski has dealt with Jakob and Channing from as young as 4K to now third grade, and those ages are very different. As the child gets older or their needs change, so should the school’s approach. “A child’s needs change over time,” Kaminski says. “As they get older and more mature, learn how to communicate with them and their peers in a different way.”

TAKEAWAY: Use age-appropriate education. For instance, a video or book might work for explaining cancer to classmates in the younger grades, but older students will be able to learn more about the disease itself and how it affects their friends. In these instances, consider bringing in a child life specialist or nurse from the local hospital.

“Remember that they might be experiencing things like fatigue, pain or weakness.”



7. “Many side effects are invisible.”

As a psychologist, Matz knows that many side effects go unnoticed. She says it’s important to be proactive about what is going on beyond the surface. She’s seen how kids can try to hide those difficult emotions. “The child may be putting forth a huge effort to mask their needs in a school environment,” Matz says. “Remember they might be experiencing things like fatigue, pain, weakness, anxiety and inattentiveness.”

TAKEAWAY: Take a deeper look. How is the child eating at lunch? Is he or she participating in class? Check in with the family to see what sort of side effects the child may be experiencing, but also talk to the child directly. A more comfortable chair, for example, or a chance to take a rest in a quiet space in between activities might make a big difference.

8. “Anyone can be that person that connects with a child.”

Both Nielson and Kaminski remember a special moment that Jakob had last year with the school’s secretary. “She had been through cancer herself, and she told Jakob she knew what it felt like to lose your hair,” Nielson says. It was such a memorable moment for Jakob, and he would often stop into the office to say hello to this staff person and use her as support. Even though Kaminski is the counselor and naturally talks with a lot of the kids, she says it’s important to remember that sometimes connections can come from the most unexpected, delightful places.



TAKEAWAY: Let the student naturally find those little rays of sunshine in his or her day. They will gravitate to certain staff members and friends more than others. Encourage this—let them find comfort wherever it feels right.

Back to School

Siblings are often affected profoundly when a brother or sister is diagnosed with cancer.

9. “A team effort makes a huge difference.”

Once you have an initial plan in place, everyone needs to be on board. Jakob’s school created a 504 plan, and anyone who crosses his path during the day received a copy, from his classroom teacher to the school nurse to the art teacher. “This was an unfamiliar situation for our school,” Nielson says. “But the staff reached out to me to obtain information, ideas and other resources. It was nice to know my family would be taken care of and that my child would be able to safely attend school.”

TAKEAWAY: Everyone needs to be on the same page. Don’t just send out an email or form on what the plan is. Make sure the plan for an individual student is readily available to anyone who needs it. And if it changes, make sure everyone is updated.

10. “Err on the side of kindness.”

Childhood cancer is enormous in its implications, and there are many, many things going on at home, in treatment and outside of school that teachers and administrators just don’t see. If a child is missing work or having behavior problems, Matz says it’s best to go straight to the parent. “Please ask what is going on before you give out consequences to the student,” she says. “It’s important to hold all kids accountable, but having the whole picture can allow you to do this fairly.” This means keeping other family members in mind too. Siblings are often affected profoundly when a brother or sister is diagnosed with cancer, so anything the school can do to reach out to them is especially helpful too.

TAKEAWAY: Our lives at school are busy ones, with many obligations and demands pulling at our time. But when you’re dealing with a family struggling with cancer, put away your phone, turn away from your computer, and give their situation 100 percent of your focus, love, and attention. They will be grateful for it.



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11.

“Be a leader in communicating with the other kids.”



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Nielson believes it’s up to the school to lead the way in communicating with other students. It’s important to talk to the parents to know how much they are comfortable sharing, but many kids would rather talk about it than not. “I know it helped Jakob feel more comfortable at school,” she says. “He knew the students were learning about what he was going through. This made it less scary and more understandable for all of them.” Nielson also recommends that classmates view the movie *Why, Charlie Brown, Why?*, which is about a Peanuts character being diagnosed with cancer. (You can watch the full series on [YouTube](#).)

TAKEAWAY: Don’t wait for other students or their parents to come to you with questions. As long as the family is OK with open communication, lead the way in talking to your school.



12.

“Come up with creative ways to keep the child included.”



One of Jakob’s favorite ways his school kept him engaged while he was gone for appointments was something called “Monkey in My Chair.” (You can learn more about this program [here](#).) Classmates would put a stuffed monkey in Jakob’s chair while he was out, and they’d take it along to art, gym and other places so the kids would remember him throughout the day. “It helped the students to remember to include Jakob when he returned, and it helped him to know he wasn’t forgotten when he missed school,” Nielson says.

TAKEAWAY: Technology is a pretty powerful tool. Consider setting up a Google Doc where students can contribute to a shared journal. Or use a class email to send cards or pictures sharing what the class is doing. These little things really help students feel more involved.

“Sometimes a small gesture can make a huge difference for a family dealing with cancer.”



13.

“Encourage your staff and students to be advocates.”

The Leukemia & Lymphoma Society has many ways you can get involved at the school level, including a program called Pennies for Patients, a three-week program for elementary and middle schools where students collect change and raise funds online while learning about service and philanthropy. Nielson helped execute this program twice at the twins’



school, and she said it was a great success. “It was a huge boost for both my boys to see their school participating in something that affected them,” she says. “The other students got to learn about what they were going through, and it was so neat to see the kids realize that working together in a small way can actually have a huge impact.”

TAKEAWAY: Find a way to bring awareness to your community about childhood cancer. The Leukemia & Lymphoma Society has chapters all over the country, and they’re always willing to help execute a fundraising or awareness campaign.

14.

“Let people help.”

This piece of advice comes from Channing, Jakob’s brother, who went through leukemia at a young age and finished up treatment while in first grade. He says, “Sometimes cancer is scary, but if you let others help you, it’s not as scary.” This is a very good and real reminder of just how important it is to offer that help.

TAKEAWAY: Sometimes a small gesture can make a huge difference for a family dealing with cancer, whether it’s organizing a meal train, sending a Starbucks gift card, or just letting the child and parents know they are in your thoughts. Make these gestures often, with the hope that soon the child will be a healthy member of your school community.

12

Great Books to Help Talk to Students About Childhood Cancer

Jacob Has Cancer: His Friends Want to Help

by Heather Cooper, Heather Paschal and Melanie Williams

Best for: **Grades PreK-3**

This is a special coloring book published by the American Cancer Society for the friends and classmates of children with cancer to help them learn what cancer is, what their friend may be going through, how they can help and how much their help will mean to their friend.



The Brave Souls Club

by Danielle Viverito

Best for: **Grades PreK-3**

This inspirational story seeks to provide an answer to the question “Why me?” asked by kids who are battling illness and disease. This positive story will hopefully leave the reader feeling like an inspirational hero and an official member of the Brave Souls Club.

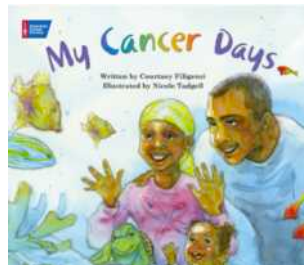


My Cancer Days

by Courtney Filigenzi

Best for: **Grades PreK-3**

Another publication offered by the American Cancer Society. This book assures children with cancer that they are not alone, and it helps them understand that it’s OK to express their feelings.

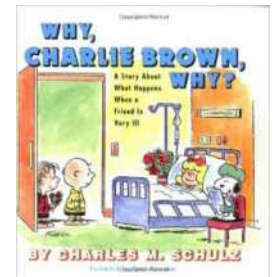


Why, Charlie Brown, Why? A Story About What Happens When a Friend Is Very Ill

by Charles M. Schulz

Best for: **PreK and up**

The Peanuts gang always does a great job when it comes to teaching life lessons, and this book is no different. It helps answer difficult questions and gives kids some peace of mind when they have a friend who is really sick.



Little Tree: A Story for Children With Serious Medical Problems

by Joyce C. Mills

Best for: **Grades PreK-3**

This sensitive, healing story of a little tree that loses some of its branches in a storm is a perfect read for children who have experienced life-challenging illnesses or accidents. After a storm, Little Tree’s branches are badly damaged. She experiences fear, self-blame and worry, feelings that many children with serious medical issues can relate to.

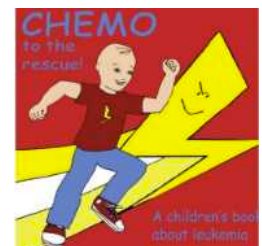


Chemo to the Rescue: A Children’s Book About Leukemia

by Mary Brent and Caitlin Knutsson

Best for: **Grades K-4**

Mary Brent wrote this book with her then-5-year-old daughter, who was being treated for leukemia. Writing this story helped Caitlin come to terms with her illness and treatment and gave her the power she needed to fight and be strong during the difficult times. This is an encouraging book that provides a positive outlook to chemotherapy and hospital life.

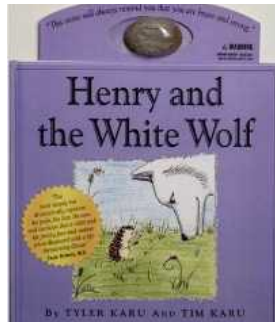


12 Great Books to Help Talk to Students About Childhood Cancer

Henry and the White Wolf

by Tyler Karu and Tim Karu
 Best for: **Grades PreK and up**

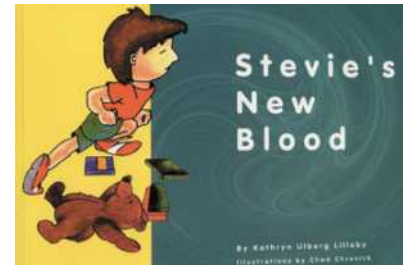
Henry is a sick little hedgehog who must undergo the grueling treatment offered up by the White Wolf. Luckily, he holds a talismanic stone that comforts him and reminds him that the dignity and courage he needs to heal are always with him. This story was written by a teenage sister and brother who drew from their own experience in hospitals.



Stevie's New Blood

by Kathryn Ulberg Lilleby
 Best for: **Grades K-4**

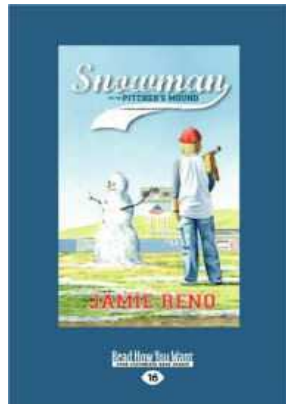
Bone marrow transplant can be a difficult subject to explain to kids, and this book does a wonderful job. Stevie is undergoing a transplant from his sister. It offers a great look, from a children's point of view, at what is involved and what it means to go through BMT.



Snowman on the Pitcher's Mound

by Jamie Reno
 Best for: **Grades 3-6**

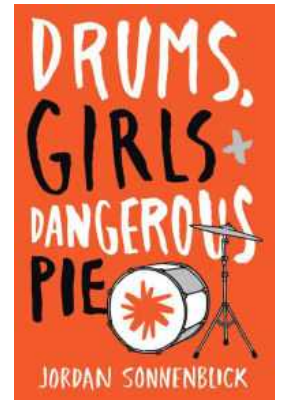
Meet 10-year-old Tyler, whose mom has non-Hodgkin lymphoma. Even though the character who has cancer in this book isn't a child, it's still a really good look at how a child deals and copes with cancer. This fictional story is perfect for kids who are starting to graduate from picture books.



Drums, Girls & Dangerous Pie

by Jordan Sonnenblick
 Best for: **Grades 6 and up**

This fictional story is told from the point of view of Steven, an eighth grader whose younger brother has been diagnosed with leukemia. It's a very honest look at what it's like to have a sibling going through a critical illness.



Secrets of the Cancer-Slaying Superman

by Benjamin Rubenstein
 Best for: **Grades 3 and up**

In order to survive cancer and the awful treatment that comes with it, according to the author—a two-time survivor—you need the right mind-set and a great support system. This story brings a boy's perspective to defeating a killer disease with its lesson of how attitude affects the outcome.



This Star Won't Go Out

by Esther Earl
 Best for: **Grades 7 and up**

Journal entries, letters, sketches, photographs and essays tell the life story of the girl who inspired the character Hazel Grace in John Green's amazing bestseller *The Fault in Our Stars*, who passed away at age 16 after a brave battle with cancer.





School Checklist

If you have a child in your school who has been diagnosed with cancer, it's important to put a plan in place and execute it in a timely fashion. Use this checklist to make sure your school is ready.

WITHIN A WEEK	✓	Designate a contact person. Make sure it's someone the family knows and who is comfortable being the point person.
	✓	Reach out to the family. Don't wait for them to come to you. Make sure you let them know you are proactive about coming up with a plan.
	✓	Talk to your staff. Make sure everyone is aware of the situation, and talk about your critical-illness plan.
	✓	Meet with the family. The child and his or her family should be there as well as any key staff.
	✓	Distribute your critical-illness plan. Anyone who has contact with the child should get a copy of the plan, often called a 504 plan.
WITHIN A MONTH	✓	Communicate with other students. Make sure you've spoken with the parents about whom they're comfortable sharing information with and what they want shared.
	✓	Develop a classroom plan. Outside of the 504 plan, make sure the classroom has a plan for everyday things like missed homework, planning ahead, etc.
	✓	Reassure the family. These first few weeks are stressful. Talk to the family often, even if you're just sharing weekly updates via email.
	✓	Keep notes. You learn so much along the way, and this can really help fine-tune your critical-illness plan. Whether it's through email or just keeping a Google Doc that everyone has access to, try to document your process.
	✓	Identify any communication problems. Not everything is going to be perfect right away. Be open to talking about things that aren't working and adjust as needed.
ONGOING	✓	Check in with staff. How are things working? Who needs more communication? Talk to the staff and continue adjusting your 504 plan as needed.
	✓	Check in with the family. How are things going with the family? How are the siblings? Do they have any other special requests? Try to accommodate as much as possible.
	✓	Check in with the student. Don't focus too much on their illness—that's a job for their parents and doctors. Instead, just interact with them the same way you would do with your other students. If things are off, you'll see it.
	✓	Help establish normalcy. Do everything you can to keep the child's day as typical as possible. Treat them just like you would any other student for most day-to-day things.
	✓	Continue to monitor students. Watch for any potential bullying that could happen as well as any sensitivity that your students might have. If needed, bring in a counselor to talk to your students.

Get Involved in The Leukemia & Lymphoma Society's Student Series



Your school can help support the LLS mission to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life for patients and their families.

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GRACE
Hodgkin
lymphoma
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