



CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

A Chat With Paralympian Noah Grove

By: Renee Wooding

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Cool Kids Campaign is fortunate to have Noah Grove on our team as a Fall, 2021 intern. Noah is a student at Towson University who has first hand experience with childhood cancer. Noah first encountered a leg abnormality at 3 ½ years old and ultimately received a diagnosis of osteosarcoma. He endured painful chemotherapy for nine grueling months. Noah's parents were advised to have his left leg removed for the best outcome and quality of life - his left leg was amputated on June 8, 2004 following his final chemotherapy treatment.

Noah did not let his amputation stop him from participating in sports. When Noah was introduced to sled hockey at the Kennedy Krieger Institute, he really found his passion. He went on to compete in the 2018 Paralympics and helped his team bring home the Gold by defeating Canada. In June of 2021, Noah and his team won the World Para Ice Hockey Championships in Ostrava, guaranteeing a spot to defend the Gold in the 2022 Paralympic Games in Tokyo.

Noah is always eager to share his experience if it will help others. In this interview, he shares some insights and tips for families dealing with childhood cancer.

Q: You were quite young when you were in active treatment for cancer; did this impact or delay your ability to start kindergarten?

A: I was still undergoing treatments when I started kindergarten. I went to a private school and they allowed me to take work home with me or to the hospital for treatments.

Q: Did you have any accommodations at school?

A: I had none up until this year in college. I didn't really know what chemo brain was until recently but looking back at how things were for me in school it was something that impacted me and I wish I knew about sooner so that I could have gotten help.

Q: Were you made aware that chemo could have longer term impact on memory and brain processing? Was this ever an issue for you?

A: This wasn't a topic that was actively discussed by my family and the doctors because I had always done well in academics. I was an A-B student through high school so nobody ever thought to check for any cognitive effects of chemo. It wasn't until college when I really started struggling. I switched majors twice, had to retake courses, and eventually settled on taking a light coursework which ultimately extended by college academic timeline but helped to keep a balanced schedule and set myself up for success in school.

Q: You maintain such a demanding schedule between your hockey travel, practice and school. How do you stay on top of everything. What tips can you share to keep life in balance?

A: It's really difficult. There are days that I don't get everything done that I want to and that's okay. It's about improving everyday. I am still working on time

management and using reminders in my phone and writing big things down is what has helped me the most. I try to do the most urgent things first and slowly chip away at assignments that are due in the future. Even ten minutes a day studying or doing an assignment can save you a lot of time later.

Q: What are your professional and athletic plans for the future?

A: I am really interested in family policy and research. I hope to use my experiences at Cool Kids to help find possibly another internship down the road and even go on to graduate school. As far as hockey goes I want to play until I no longer can. The longer I have played hockey the more in love I have fallen with it and I want to continue to play as long as possible.

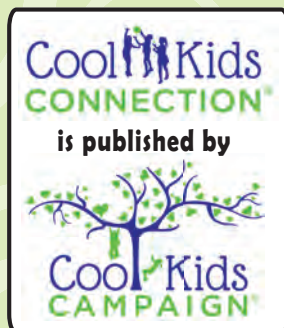
Q: What message would you most like to send to kids dealing with a cancer diagnosis? And do you have tips you'd like to share?

A: Cancer sucks. It is going to be hard to get through but you are stronger and you have to stay positive. Make sure you are nice to everyone. Your parents, your doctors, and your nurses are all stressed and sometimes they need something to cheer them up a bit so remember to be nice, it will go a long way.

Q: What tips would you share with parents dealing with their child's cancer diagnosis and treatment?

A: When there is a pediatric cancer diagnosis it isn't just a diagnosis for your kid, it's a diagnosis for you, your whole family, and support system. Everyone is affected. Make sure to take some time between working, researching, taking care of your kids, talking to doctors, and juggling life to take care of yourself. You will not come out of this the same person you were before and that's okay.





8422 Bellona Lane, Suite 102
Towson, MD 21204
p: 410.560.1770 • f: 410.560.1775
coolkidscampaign.org

Editor-In-Chief:
Reneé Wooding

Design:
Linda Ports

COOL KIDS CAMPAIGN STAFF:

Chris Federico
President & Founder

Janet Robinson
Director of Operations

Reneé Wooding
Managing Director, Baltimore

Taylor Wilkins
Family Communications
Coordinator, Baltimore

Allison Wilt
Events & Outreach Coordinator,
Baltimore

Jen Dean
Project Administrative Coordinator

Melissa Scott
Managing Director, Charlotte

Carrie Johnson
Family Engagement
Coordinator, Charlotte

Maggie Lantzy
Event Coordinator, Charlotte

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ABOUT THIS ISSUE AND ABOUT COOL KIDS CAMPAIGN

In this issue, we focus on helping your child succeed at school. Many families are not prepared for the academic challenges that can occur as a result of cancer treatment. Anyone who has experienced “chemo brain” knows it’s a real thing! Difficulty with slower processing times, focus and retention can be among the challenges pediatric cancer patients and survivors face. In this issue, we explore these challenges and suggest some ways to overcome them. In addition, our partners at Weis Markets will provide some healthy and delicious recipes for school lunches or after school snacks. And we will hear from Paralympian, Noah Grove, about his experience with cancer.

While we always provide an overview of our Connection content, we thought it was about time we told you a bit more about our organization – Cool Kids Campaign. Founded in 2005, our mission is dedicated to improving the quality of life of pediatric oncology patients/survivors by addressing the academic, social and emotional issues that accompany a cancer diagnosis. Our services are largely provided at our Cool Kids Clubhouses. We currently have a Cool Kids Clubhouse in Honor of Ken Singleton in Towson, Maryland and a Cool Kids Clubhouse in Honor of Dan Jansen in Huntersville, North Carolina (and we have plans for more Clubhouses to come). Here we offer parent support groups, activities targeted to teens, movie nights, summer activities, Smile Celebrations honoring a birthday or treatment milestone and more!

We also offer free use of our vacation homes to Cool Kids families who reside in Maryland and North Carolina and we offer a free overnight camp for Maryland families. In these pictures, you can see the fun that takes place here, but these activities are about more than just fun – we provide a totally accepting atmosphere where all kids can just be themselves at any stage in their cancer journey and siblings are always included. We work hard to help kids overcome social isolation, sadness and the feeling of being an outsider.

We also offer free professional tutoring to Maryland and North Carolina Cool Kids so they can stay current academically and remain in their peer group at school. If you reside in Maryland or North Carolina, we hope you’ll contact us for an application. If you live elsewhere, check the Resource page on our website (www.coolkidscampaign.org) for helpful information and links to other organizations. And follow us on social media – we may be coming to your town soon!

Melissa Scott
Managing Director
Cool Kids Campaign – North Carolina
melissa@coolkidscampaign.org



Reneé Wooding
Managing Director
Cool Kids Campaign – Maryland
renee@coolkidscampaign.org



School Lunches & After School Snacks



Emily Bumgarner, M.Ed, RDN, LDN
Registered Dietitian at Weis Markets
weisdietitians@weismarkets.com

Getting back into the groove of school is daunting, but figuring out lunches and snacks doesn't have to be difficult. There are endless combinations for lunches and snacks that will fit your child's tastes and any allergies.

The Weis Dietitians want to make it simple to pack a nutritious, but also delicious lunch and help with ideas for those essential after school snacks.

SCHOOL LUNCH IDEAS

MINI PIZZAS:

Endless combinations to top an English muffin or bagel

WAFFLE SANDWICHES:

Put your favorite sandwich components on frozen waffles

BENTO BOXES:

Combine an item from each food group into a divided container

THINGS TO REMEMBER WHEN PACKING SCHOOL LUNCHES

The best thing about packing lunches is you and your child get to decide what to include so you can customize to fit their taste and allergies. Remember to include as many food groups as possible in the lunch for maximum nutrition. To

make things even easier in the morning pack lunch the evening prior so all you have to do in the morning is grab and go. While you are at it, don't forget to include an ice pack with any perishable items.

AFTER SCHOOL SNACK IDEAS

NO-BAKE ENERGY BITES:

Sweet, but full of protein and fiber

PARFAITS:

Layer your favorite yogurt, cereal and fruit

DIY TRAIL MIX:

Choose your favorite items and combine them in a zip top baggie

THINGS TO REMEMBER ABOUT AFTERNOON SNACKS

Most kids come home from school looking for something to snack on, but be sure to keep portions small so dinner is not spoiled. Use this time to include extra nutrition by incorporating two or three food groups into one snack. Make it easy on yourself and the kids by keeping easy to grab items in the pantry, fridge or on the counter.

**Check out our recipe for
NO-BAKE ENERGY BITES
on the following page!**



Find current and past editions
of the Weis HealthyBites Magazine at:
healthybites.weismarkets.com

No-Bake Energy Bites

*This recipe is a Weis Dietitian favorite! All ingredients get tossed into one bowl and combined.
Kids love getting involved by mixing and rolling the bites.*

INGREDIENTS:

1 cup Weis Quality old-fashioned oats
1/2 cup Weis Quality creamy peanut butter
1/2 cup ground flaxseed
1 tsp Weis Quality vanilla extract

Any 3 mix-ins:

- 1/2 cup dried cherries, raisins, blueberries or cranberries
- 1/2 cup unsalted chopped almonds, pecans, walnuts, pistachios or peanuts
- 1/2 cup crushed whole-grain pretzels or cereal
- 1/2 cup dark chocolate chips
- 1/4 cup coconut flakes



DIRECTIONS:

Place all ingredients in a large bowl and stir until well combined. Cover and refrigerate for 30 minutes so the mixture is easier to shape. Using clean hands or a cookie scoop, roll mixture into 25 (1-inch) balls. Refrigerate in an airtight container for up to 1 week.



—cook at
HOME
with the

WEIS DIETITIANS

Visit the Weis Markets Facebook Events page to learn more and register for our interactive virtual cooking classes for kids and adults! All classes are **FREE** of charge for Weis Market's Preferred Shopper's Club Card holders.

Seeking individualized nutrition counseling? Our Weis Dietitians also offer **FREE** tele-nutrition services!
Email weisdietitians@weismarkets.com to schedule an appointment.

Nutrition
& WELLNESS

weis

PUZZLES AND GAMES

Fall

Word Search

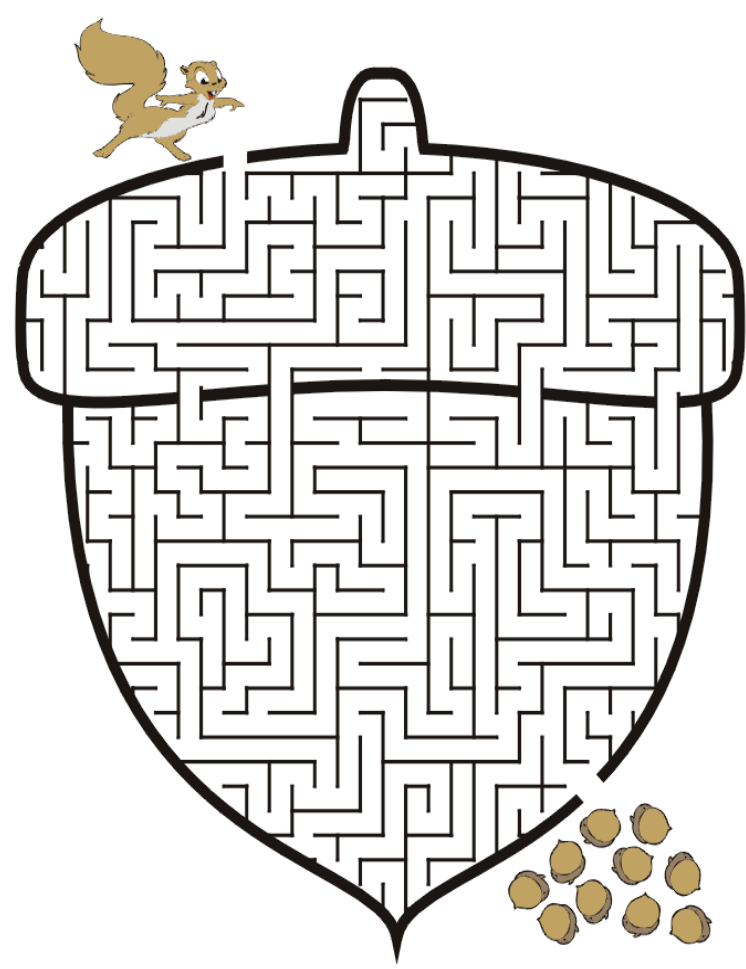
R	A	C	O	R	N	X	S	N
N	E	F	A	E	L	Q	C	I
D	U	T	Q	X	U	V	A	K
H	U	T	A	I	C	H	R	P
A	C	C	R	E	S	U	E	M
P	D	R	K	A	W	R	C	U
P	E	N	U	S	A	S	R	P
L	C	Q	I	K	U	W	O	E
E	S	N	E	W	J	A	W	A
K	C	A	T	S	Y	A	H	R

ACORN
APPLE
DUCKS
HAYSTACK
LEAF
NUT
PEAR

PUMPKIN
RAKE
SCARECROW
SQUASH
SQUIRREL
SWEATER
WIND

Try to find all of the hidden autumn related words in the puzzle above.
Remember, words can be diagonal, vertical, horizontal, frontward or backwards.

Help the squirrel through the maze to find its acorns



SUDOKU

Place a number between 1 and 4 in each empty cell so that every row, every column and every 2x2 box contains all the numbers 1 to 4.

1

	1	4	
	4	2	
	2	3	
	3	1	

2

3					5
	5			2	
6					1
1					3
	3			5	
5					2

3

	2			4	
4					2
		3	6		
		2	1		
6					3
	3			6	

ANSWERS:

1

4	3	1	2
1	2	3	4
3	4	2	1
2	1	4	3

2

2	6	9	4	1	3
7	6	1	9	5	2
6	9	2	5	4	1
1	4	5	6	2	9
9	2	6	1	3	4
5	1	4	2	3	9

3

1	9	4	6	5	2
5	2	7	1	9	3
7	5	1	2	9	6
6	2	9	6	5	1
2	1	3	9	4	5
9	4	5	1	2	3

BRAIN TEASERS

COUNT HOW MANY OF EACH PICTURE YOU FIND.
WRITE YOUR ANSWER ON THE LINES BELOW EACH PUZZLE.

I SPY HALLOWEEN



I SPY THANKSGIVING



FUN FACTS!



Ten Nutty Facts About Squirrels



Now you might be thinking, what could be so interesting about a squirrel? I see them all of the time all over the place. All they do is bury nuts and steal birdseed, right? What's so special about them? Well, there is a lot more to these furry mammals than meets the eye.



Squirrels are not so similar to rats, but like rats, they are rodents.



The more than 200 different species of squirrel live all over the world.



They belong to the Sciuridae family, and are native to every continent, with the exception of Antarctica and Australia.



Just like rats and mice, a squirrel's front teeth will continue to grow throughout its life. This makes them great for chewing and gnawing.



Have you ever noticed that squirrels have large eyes? These help them to see where they are going when climbing trees and escaping from other animals who might attack them (predators).



Most tree-dwelling squirrels prefer to live alone. They will, however, group together during especially cold weather.



Gray squirrels are masters at finding their buried nuts. Thanks to their wonderful sense of smell, they usually recover around 80 percent of all the nuts they bury! The 20 percent that they don't get to eat will usually grow into oak trees.



Squirrels are born blind.



Squirrels can find food buried beneath a foot of snow.

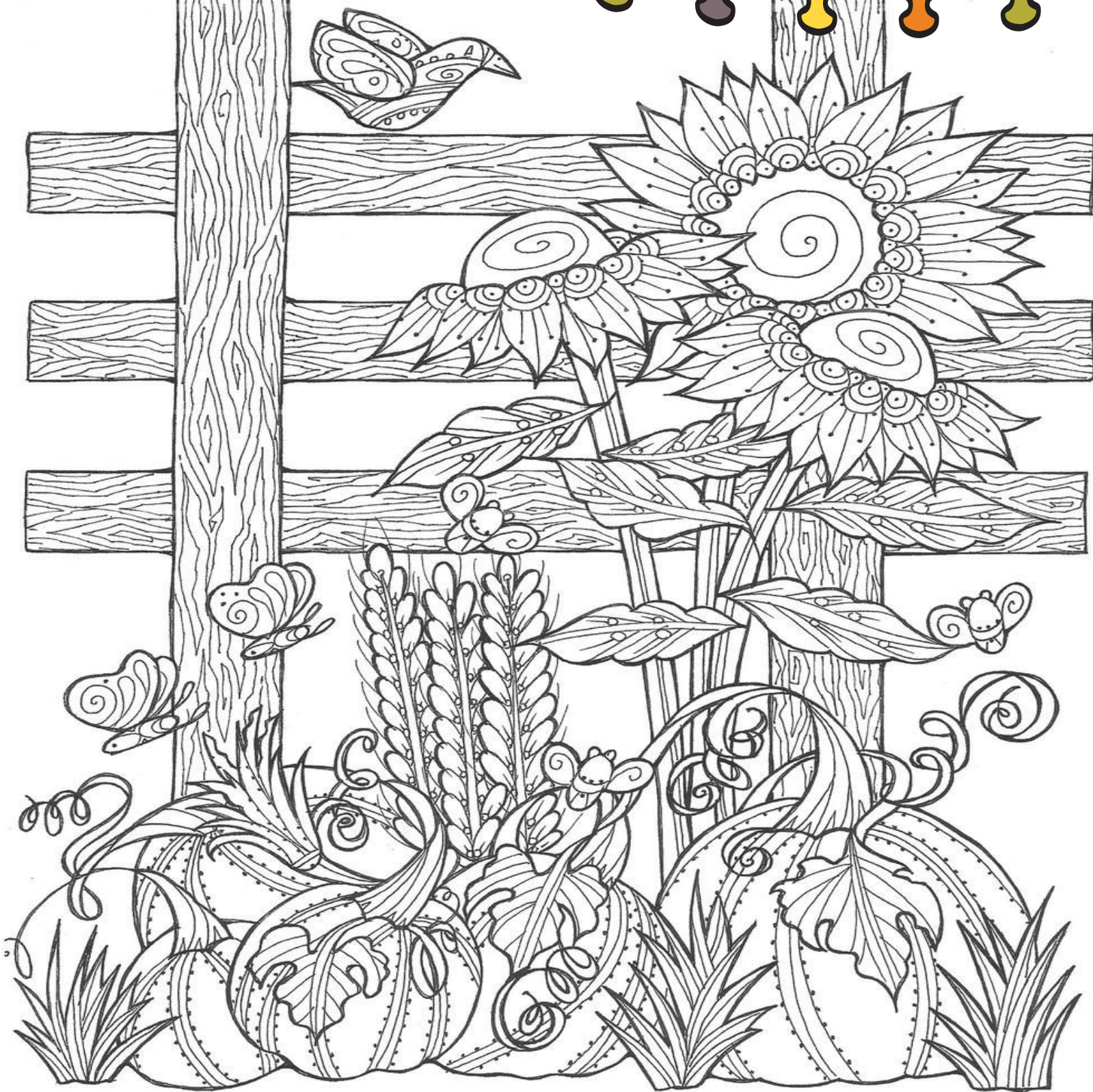


The hind legs of squirrels are double-jointed, which gives them the ability to run up and trees very quickly.



MOTHER SQUIRREL WITH HER NEWBORN.

COOL COLOR ME





IT DOESN'T MATTER if it's your kid's first day of kindergarten or if it's the first day of their senior year of college, going back to school in the fall always stirs up nerves for parents and their kids. Not to mention the fact that it can take about 3 to 6 weeks for the dust to settle and for students to get into a rhythm with their classes. But what happens if your student never settles in, and learning becomes an ongoing struggle? What can you do to help them?

There are some more traditional things that you can do like sitting down with the school learning specialist, checking to see if your student has a visual or auditory impairment, getting your student evaluated for any cognitive or emotional issues, but then what? Not everyone can pay for a specialty school, program, or tutor, but there are some little things that you or your student can do to keep on track.

One of my favorite and simplest tools to use are dry erase markers. You don't even need to have a whiteboard! As someone with chemobrain, I use these markers these all the time to write notes for myself about when my grad school assignments are due, when I have to meet with people, things I need to buy at the store, etc. - I write these notes on my bathroom mirror, because I know that I'm going to look there twice a day when I brush my teeth, but windows work just as well. If you really want to go all out, they now sell giant dry erase stickers for walls. Writing notes in notebooks is great, but if kids don't open these notebooks outside of school, they aren't helpful. You can pick up a decent pack of dry erase markers at Walmart, Staples, or Amazon. Your kids don't need all the fancy packs with yellow or orange because those colors can be hard to see even on the best whiteboards.

Another great tool is the Livescribe Smartpen. This pen is my number one recommendation for all students! It comes with a special notebook (you can buy extra), that allows your student to take notes while the teacher is speaking, and it simultaneously records the notes and the audio so that the student can review them both at a later time. The audio can be listened to straight from the pen, and both the audio and written notes can be uploaded to your kid's computer. The bonus is that if your child is missing school for a bit, they can have another student use this to take notes for them and then email everything over. You may have to get permission to use this because it is an audio recording device, but a good teacher will see the benefit of allowing your student to use this AMAZING pen. They are a little bit pricey, but they are a long-term invest-

ment, and if you don't have the funds you may be able to convince your child's school to purchase one of them, as a special support device for your student. Without a doubt, this pen helped me survive statistics!

My last recommendation is to set up a Google calendar that you can share with your child. Schools have their portals, and some will connect with Google calendar, but regardless this is a great way to help your students plan out their week and to keep track of their classes and assignments. It will also give you some insight regarding what work they need to tackle and what other activities they have going on outside of school. Some kids will be able to manage this on their own, but for others, this is just a good habit to get into. The bonus is that it can be connected to their phone if they have one and you can help them set up alerts, to remind themselves of what they need to do each day. It's not about being "big brother," it's about giving kids the strategies they need to be successful and slowly transferring the responsibility to them.

You may already have some tips and tricks that you're using with your students, don't stop if they're working for your kid. I've just listed a few options for you to try. Feel free to email me at Erika@brainbodega.com if you have any questions, or to follow me on Facebook for other pointers.



Photo by Volodymyr Hryshchenko on Unsplash



Photo by Santi Vedri on Unsplash





CHEMOBRAIN-

THE ROLE OF ONCOLOGY SOCIAL WORKERS

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If your child is having memory problems and trouble focusing on tasks, finding words or managing daily activities, you are not alone. These are examples of symptoms of “chemobrain,” a possible side effect of chemotherapy that can affect cognitive or thinking abilities. It’s important to talk to your health care team if your child is experiencing any of the symptoms of chemobrain during or after treatment.

SYMPTOMS OF CHEMOBRAIN

- Forgetfulness or memory lapses
- Difficulties concentrating or focusing on tasks
- Trouble recalling or remembering common words or names
- Struggling to do more than one task at a time

Coping with symptoms of chemobrain involves finding ways to help your child remember things better and doing activities that keep their memory sharp. For tips to cope with chemobrain, read CancerCare’s fact sheets titled “Coping with Chemobrain: Keeping Your Memory Sharp” and “Improving Your Concentration: Three Key Steps.” You can find these at www.cancercare.org.

START A HEALTH CARE JOURNAL

If you witness chemobrain or any treatment side effects, starting a health care journal can be helpful. Having a journal or notebook will allow you to keep all of your child’s health information in one place. If your child is experiencing chemobrain, it may be helpful write down the following in your journal or notebook:

- The time and place first witnessed any chemobrain symptoms
- What was your child doing and what symptoms were experienced
- The frequency of chemobrain symptoms
- Any activity that you think helped your child cope with chemobrain
- Any medications your child may be taking
- Any questions you may have for your health care team

Have this journal along any time to you talk your health care team.

TALK TO YOUR DOCTOR

If your child has problems with memory and attention, or other difficulties related to chemobrain, speaking with your doctor is an important first step in getting the care you need. Write down your questions and concerns about any side effects and treatment in your health care journal before your next medical appointment. In addition to bringing questions, if possible, bring someone with you to any appointment. Another set of ears can help reduce confusion. Here are questions that may want to ask your health care team:

- What is causing my child’s chemobrain?
- How long do chemobrain symptoms usually last?
- Can you evaluate me to see if my child’s chemobrain symptoms are related to anything that could be more easily treated, such as low blood count or other medications he or she is taking?
- Should we see a neuropsychologist (an expert trained in how the nervous system, especially the brain, controls mental functions such as language, memory, and perception) ? If so, can you refer me to a neuropsychologist to be evaluated?
- What do you recommend we do to improve my child’s memory?

In addition to your health care team, you may want to let friends and family know. You may be relieved talking to someone you trust and they can help you better cope with chemobrain.

THE ROLE OF ONCOLOGY SOCIAL WORKERS

Professional oncology social workers understand the complex issues that arise with a cancer diagnosis. Social workers can help you manage any emotional or practical concerns that may be causing chemobrain and help you develop ways to cope. Talk to your hospital oncology social worker.



Photo by
Bermix Studio
at Upsplash



Holiday season is upon us, which means spending time with family and friends and taking the time to celebrate your traditions. However, sometimes people with cancer and their loved ones can feel 'offbeat' or even excluded during the holidays. In fact, this season can prompt questions such as: How can I celebrate when I have so many other things on my mind? What will my life look like next year? This season can also prompt feelings of anxiety, depression, and even resentment. It can be easy to succumb to these negative feelings and turn the holidays into a time of dread. Adjusting your mindset and sharing these concerns with people you love and who love you can help you feel more connected. "Optimism is the foundation of courage." (Nicholas M. Butler).

There are numerous ways to adjust our mindsets to encourage a more positive approach to our problems. By utilizing a mixture of optimism and realism, we are able to maintain a positive outlook while also bracing ourselves for the worst.¹

Here are 6 ways to become more realistically optimistic:¹

START WITH A POSITIVE NOTE

Starting the day on a positive note sets the tone for the rest of the day: Make your bed, get dressed, make time for breakfast, get the extra whipped cream for your coffee, etc.

SET REALISTIC EXPECTATIONS

There is only so much we as individuals can control and so much energy we can spend on the things we cannot. Modify your expectations to be consistent within those boundaries. You cannot change someone's behavior; you can only control your reaction to that behavior.

ENJOY THE SMALL THINGS

Do not limit your happiness for the big milestones, or the next big event. Acknowledge the little things that make you smile like listening to a favorite song, or your pup greeting you at home after a long day.

BE A POSITIVE ROLE MODEL

What kind of a person do you want your children, friends, or coworkers to emulate? Be that person.

DO SOMETHING CREATIVE

Creativity comes in all shapes and sizes. Find your niche and make time for it, or even turn it into a family activity, and your mindset will shift accordingly.

PRACTICE GRATITUDE

Gratitude is the antithesis of negativity. Think about and appreciate the good things in your life.

Changing one's mindset doesn't happen with the flip of a switch. It takes constant self-awareness and practice to embody more realistic optimism. To practice this mindset change, try this silver linings exercise over the next two weeks.¹

FINDING SILVER LININGS

The purpose of this exercise is to promote a more positive outlook when faced with a difficult situation. It contains the following four steps:¹

1. Shift into a positive mindset by listing five things that are meaningful, enjoyable, or worthwhile.
2. Identify a recent difficulty by describing a recent event that resulted in distress or frustration.
3. Identify costs by writing down the costs associated with the event noted above.
4. Find silver linings by listing at least three positive outcomes of the above difficulty.

By participating in this exercise regularly for two weeks, it is hoped that readers will be more likely to approach challenges with a positive perspective that encourages the spirit of resilience.

Citations.

¹<https://positivepsychology.com/pessimism-vs-optimism/>

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Cami, Relapsed Acute Lymphoblastic Leukemia

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FRONT

BACK



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