Abstain from Preconceived Ideas about "Chemo Brain"

Children diagnosed with cancer, what comes first to mind? Chemotherapy, loss of hair, debilitation? Remember the silent side effects that chemo/radiation has on a developing brain. Memory loss, short attention spans, and daily routine tasks are sometimes left unspoken. Parents of school-aged children who have had cancer and are returning to school must reach out to hospitals and homecare staff to utilize virtual learning.

Absence Does not Make Other Student Hearts Grow Fonder

Unfortunately, both cancer and the side effects may be at the core of your child's treatment, but what about your child's social support system? Children may miss years of schooling during treatment of Leukemia and brain cancers. Think about the emotional toll on a 5-year-old who has a brain tumor. The physical, mental, and social role this plays in early childhood through the teenage years can be complex. This blog should shed light on certain educational system stereotypes of children in cancer treatment and/or remission. Kids know they are different post-chemo and it hurts them internally not to be at the level their peers are.

Be a Precative Advocate, so School Staff can Pass it on

You have probably heard the cliché an ounce of prevention equals a pound of cure. Preparation is important while advocating for your child prior to their first day back to school, after perhaps having years of absence. This is a lot to consider all at once while caring for your child as he/she is fighting cancer. As you may be already aware, anticipating future milestones could stabilize their emotional well-being now, rather than waiting until there's an issue later. Your child would be grateful to continue socializing with school friends, peers, and teachers; your child could be free to be who they are-uniquely, without self-doubt.

In Charge Before Dis

Discharge planning begins at hospital admission, so don't hesitate to ask for psychological referrals, or state programs that may provide more support for your child's mental/social health. Ask your child's teacher to pre-educate the class on general childhood diseases and its implications. You don't need to disclose your child's private health information, but their teachers should promote inclusion among peers, in an effort to avoid potential bullying. Your child deserves equal treatment from their peers and teachers without prejudice. They've been through so much already to add increased anxiety about reentering the classroom.

Schools and Staff Judging a Book by the Cover

Here is a list of possible false beliefs/stigmas your child's teachers may have unknowingly regarding students with pediatric cancer or remission:

- "Special Education" is non inclusive of children with pediatric cancers
- Chemotherapy causes total brain dysfunction
- Assuming a child that is free of cancer doesn't require extra time to complete assignments
- Treatment is complete; therefore, no additional assistance is required
- Preconceived ideas/opinions of children's health solely based upon outward looks/behaviors

Mind Over Body, or Body Over Mind?

A previous patient suffering from a neurological disease would psychosomatically (mind over body control) hide pain symptoms when family was present. Healthcare professionals, are taught to never skew pain levels based upon patient behavior. Pain scales should be documented subjectively, not *our* observations. It's imperative for your child's educational and social health and wellbeing that teachers understand this. If teachers are unaware of the different needs of childhood cancer survivors, then students are also.

Long after pediatric cancer survivors are in remission, there is a risk of the following body changes an adolescent may have:

- Underdeveloped/overdeveloped growth
- Acquired bone fragility
- Respiratory Disease
- Sterility

Relationships With Peers is Priority for Future Adulthood Independence

As parents, you may be caring for your child's physical well-being, and this is super important. Please don't forget about their mental, social and emotional health. Depression can be silent, your child/adolescent may be able to disguise how they're truly feeling. Anxiety, Post Traumatic Stress Disorder (PTSD) and low self-worth are also hard to pinpoint in a young child/adolescent. Bullying and isolation may be your child's only friends (causative of their self-depreciation), which is heartbreaking.

"I was inside all the time with cancer and everything, so going outside and playing …was difficult and joining in with other kids because when I was in the hospital, I hadn't been

really able to interact with kids that often, then going into school and meeting new kids was hard." (15-year-old survivor)

"She was chronically shy; I think as a result of the treatment…she was hesitant about interacting with children her own age." (parent of an 11-year-old survivor)

Misrepresented, Without Help

One parent from another similar study, said their child was deemed to have "special needs" in order for the child to have extra school support. Another was unable to get extra support at all. However, some parents would rather not divulge their child's medical information, which is understandable and their right under the law (HIPPA). The only exception to the rule is having parental consent to disclose that private information, or create a more generic approach as mentioned below.

If teachers, principals, staff and other students are unaware of these continuous side effects from chemotherapy, then how can kids be assured of a smooth transition back into school?

Where's the Evidence Proving Unawareness of Bullying

Research interviews of bullying composed of 73 pediatric cancer survivors (age ranging from young children, teens, to early adulthood), including 60 of their respective parents. Types of pediatric cancers evaluated in this study were: leukemia, lymphomas, Ewing sarcoma, brain and bone tumors, and testicular cancer. The results are eye-opening:

- About 40% of pediatric cancer survivors admitted to being bullied
- Parents were mostly unaware their child was, in-fact, bullied
- Parents concluded that students lacked total insight about the effects of pediatric cancer treatment
- School programs that helped peers understand the toll it takes on a survivor's social skills reported less bullying and promoted friendship building

"I never experienced any teasing or bullying…they were all just genuine, loving, and caring people…they knew exactly what I was going through. They weren't ignorant." (20-year-old survivor)

Preventative Approach Regarding Bullying in School

Protective, *proactive* parents should foster visitation from friends at the hospital during treatment (unless restricted for treatments), encourage virtual chats, even cell calls. Hospitals and schools could combine after school activities/social clubs, so pediatric cancer patients can develop their social skills and feel confident and included. Parents

should also be attending teacher conferences, where staff can simply be informed and address bullying in the classroom. The **Camp Quality puppet show** was a successful anti-bullying tool, giving survivors the chance and skill to defend themselves. The science has proven that pediatric cancer survivors, now adults, are thriving better than survivors who had no outside help inside school.

Silence Taunting Ignorant Groupings Mean Alienate

Think back to your childhood years as bullying may have been a part of it, almost always because of how you looked, dressed, and interacted with others. Imagine having cancer, chemo, silent side effects, body image changes, hair loss, regressed social cues and brain development on top of it? Children are resilient warriors, who suffer with cancer. But, as the results showed, most younger children didn't verbalize any bullying. Perhaps they were unable to understand they were being bullied? Or, the child survivor tucks it away for a later, yet definitive day. Let The Sassy Carmen Foundation guide you, your family and, most importantly, your child through these treacherous years, *absent* of bullying and stigma.

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