

Unforeseen Gifts: Seeking meaning while caring for children diagnosed with DIPG

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Hey DIPG (because you do not deserve a kind salutation):

You are a terrible and cruel disease. You are rare and aggressive, developing in a critical part of a child's brain, often limiting the ability to biopsy, resect, or treat. You cheat children of the life they deserve. Hearing about your existence is unimaginable as you limit a child's life expectancy to less than a year on average. Given your aggressive nature, children gradually lose parts of themselves, bit by bit. Weakness, difficulties breathing and swallowing, confusion, loss of speech. You trap children in their bodies, and they describe feeling as if their body is an unrecognizable, foreign object. You wreak havoc on families' lives as they try to comprehend the news that their sweet child will not live to graduate high school, become an engineer, get married, have children, and likely not even play in their next baseball game.

The grief starts from the moment families hear your crushing acronym. Parents immediately begin to question their identity and how they will navigate life without their child. Will they be able to parent their other children? Who are they if not a parent to this special child? It becomes nearly impossible to not imagine burying their child and planning their funeral. Siblings feel as if they lost their best friend at diagnosis and also their caregivers as they watch them slowly cocoon in a shell, enveloped with immense grief. Life becomes a ticking time bomb, and the pressure to make every birthday and holiday celebration perfect becomes crippling.

You tear the hearts of pediatric neuro-oncologists around the world as they enter the room to be the bearer of excruciatingly painful news. You make families and clinicians feel helpless as treatment is limited

in fighting against your awfulness. You have turned the worlds of families upside down such that the order of the world no longer makes any sense, and families feel they are constantly reliving a nightmare. Despite how powerful and almighty you feel you are, I want you to know our patients, families, and pediatric neuro-oncology community are stronger.

As a pediatric psychologist who specializes in seeing children with brain tumors, I have walked alongside many children and families impacted by you. Similar to patients and families, I have struggled to find meaning in the midst of the profound despair you create. There are days where there is no meaning to be found in you, and that is okay. With a disease as horrifying as you, sometimes hearts are irreparably shattered. There is no guidebook on coping with you, though I wish there was. My coping style as a psychologist is always evolving. On a daily basis, I am grappling with the duality of the emotional experience fostered by you. It is a tug of war between heartache and gratitude, not gratitude to you, but the resilience of the human spirit in spite of you. Despite the immense physical and emotional pain you cause children and families, I have witnessed unexpected beautiful gifts along these illness journeys. You have illustrated that joy, hope, and love can co-exist with fear, distress, and grief. You have taught me to cherish every little moment and to find joy in the small things. You have shown me what is truly important in life. You have reminded me to hug my loved ones a little tighter, never go to bed angry, and to always take the trip. You have shown me how to weather the storm and taught me about a level of faith and strength I never knew existed.

Many times, I have left the hospital after a day supporting children and families affected by you and felt defeated, helpless, and angry. As a helper, I want to alleviate children and families of the emotional

Abbreviations: DIPG, (diffuse intrinsic pontine glioma); Hey, DIPG (because you do not deserve a kind salutation).

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pain and worries they are carrying. Caring for children and families impacted by you often leaves me with a sense of helplessness. It is extremely difficult to walk into hospital rooms filled with grief, express emotional vulnerability, and open myself to love on a child who I know will not survive because of you. At each visit, I watch the child's functioning slowly fade, and as this happens, I witness the heartache of families as they desperately seek options to prolong time together while prioritizing their child's quality of life. Even though the child loses their ability to communicate or move their arms to give a hug, I find comfort in still seeing the sparkle in their eye, the smirk, the head nod, the blink; the love is always there. It may be expressed differently, but the room remains filled with love. Although you are pervasive and hard to ignore, I do my best to broaden my perspective beyond the changes and losses you unfairly force on children. I try to remember the bell ringing after radiation, the Make-A-Wish pictures and videos, the celebration of small moments where smiles and laughter were shared through tears. You have made me cry more times than I would like to share. But you have also made me smile because even though life is messy and hard, it is also beautiful, even in the cast of your monstrous shadow. My heart is heavy, but it is not just filled with grief. In between the dark and torn spaces, there is love and appreciation for the children who have allowed me to care for them during their tumultuous journey with you. If I did not let down my walls to love on these children, I may save myself from heartache, but it would come at the cost of not getting to witness the lives of extraordinary children. The privilege and honor of caring for children affected by you is worth every ounce of pain.

With a dismal cure rate, you may think you are tougher, but we will not give in. In fact, new experimental research is cracking your armor, and we are beginning to feel a glimmer of hope that new treat-

ments will give children more time to live with you, with the ultimate goal of finding a future cure to overcome you. We will continue fighting the good fight until no child, parent, or sibling ever has to hear the devastating news that their child is diagnosed with you. We will rise up to the challenge because the world is a much better place with our children growing up to achieve their wildest dreams. One day, we will prevail. I hope it is in my lifetime, but if not, I will continue to express my gratitude to the patients, families, and colleagues who have touched my heart and inspired me to face insurmountable obstacles with humility and grace. **Diffuse Intrinsic Pontine Glioma or Determination, Inspiration, Passion, Gratitude.** The first is you, the terrible monster who has placed heavy emotional burdens on my heart. The second is the gifts I have received because of you. Through you, I have sadly learned sometimes it is impossible to find meaning in devastating situations. But I have also learned there can be goodness in the hard. So as I grieve the lives of change-makers whose time was cut way too short, I will dig deep to find gratitude for the unforeseen gifts.

From a grieving yet grateful and hopeful pediatric psychologist, Dr. Megan.

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