

Since the time paper was first written, my brother has passed away of complications related to pneumonia. Macen Clay Holderman passed away at 2:45 p.m. on the 27th of September.

My Brother Macen

My brother Macen was always a bit of a whiner, so nobody thought anything of it when he started complaining about a pain in his leg the early winter of 2014. It was probably just an excuse to skip soccer and play more Call of Duty with friends. Sure, this excuse had lasted a bit longer than others, but we reasoned his often complained about “growing pains” were nothing to worry about. After he had been limping for about a month, my concerned parents finally decided that this pain might be something more serious, perhaps a torn ligament. Their concern turned out to be justified.

Macen was diagnosed with osteosarcoma, an aggressive form of bone cancer, on April 15th of 2014 at Denver Children’s Hospital in Colorado. At the point of diagnosis, the cancerous, bony tumors, which originally started in the left knee, had spread to my brother’s lungs, and though his doctors saw little reason to quote what they referred to as ‘meaningless statistics,’ I looked up the survival rate for metastatic osteosarcoma on St. Jude’s Research Hospital’s website. His diagnosis carried about a 30% survival rate at 5 years (St. Jude, 1). The doctors at Denver Children’s explained that my brother and our family had a rough fight ahead of us. Treatments for my brother would involve five different types of chemotherapy, a modified amputation of his left leg known as a rotationplasty, a lung surgery known as a lobectomy, and an intermittent trip of almost 500 miles between Denver Children’s (where surgeries and new treatments would be performed) and our home in Albuquerque, New Mexico. Despite these challenges, my brother’s medical team was confident in Macen’s strength, and his ability to overcome this disease.

Treatment was hard on both my brother and the



My brother Macen Clay Holderman, driving his Jeep using a modified sling to hold his leg up.

rest of our family. Through the next two years we would work to stay strong despite the constant fear, stress, and anxiety that my brother’s disease caused all of us. In the autumn of that year my brother had a rotationplasty performed to remove a tumor, and just a few months later Macen had two lobes of his lungs (and about 60 tumors) removed by surgeons in Denver. During treatment, my brother lost all of his hair, became increasingly weak and sick, and completely changed in personality. Some days, he was braver, stronger, and more compassionate than anyone else I have ever known. Other days he was reclusive and petulant, clearly exhausted by the tedious and painful treatments he was undergoing. For my part I began to drift away from my family, and

the better part of my senior year of high school was spent hiding away from my home in coffee shops, pretending my constant studying wasn't some coping mechanism designed to hide my anxiety and growing dread from my siblings and parents.

The Weight of Childhood Death

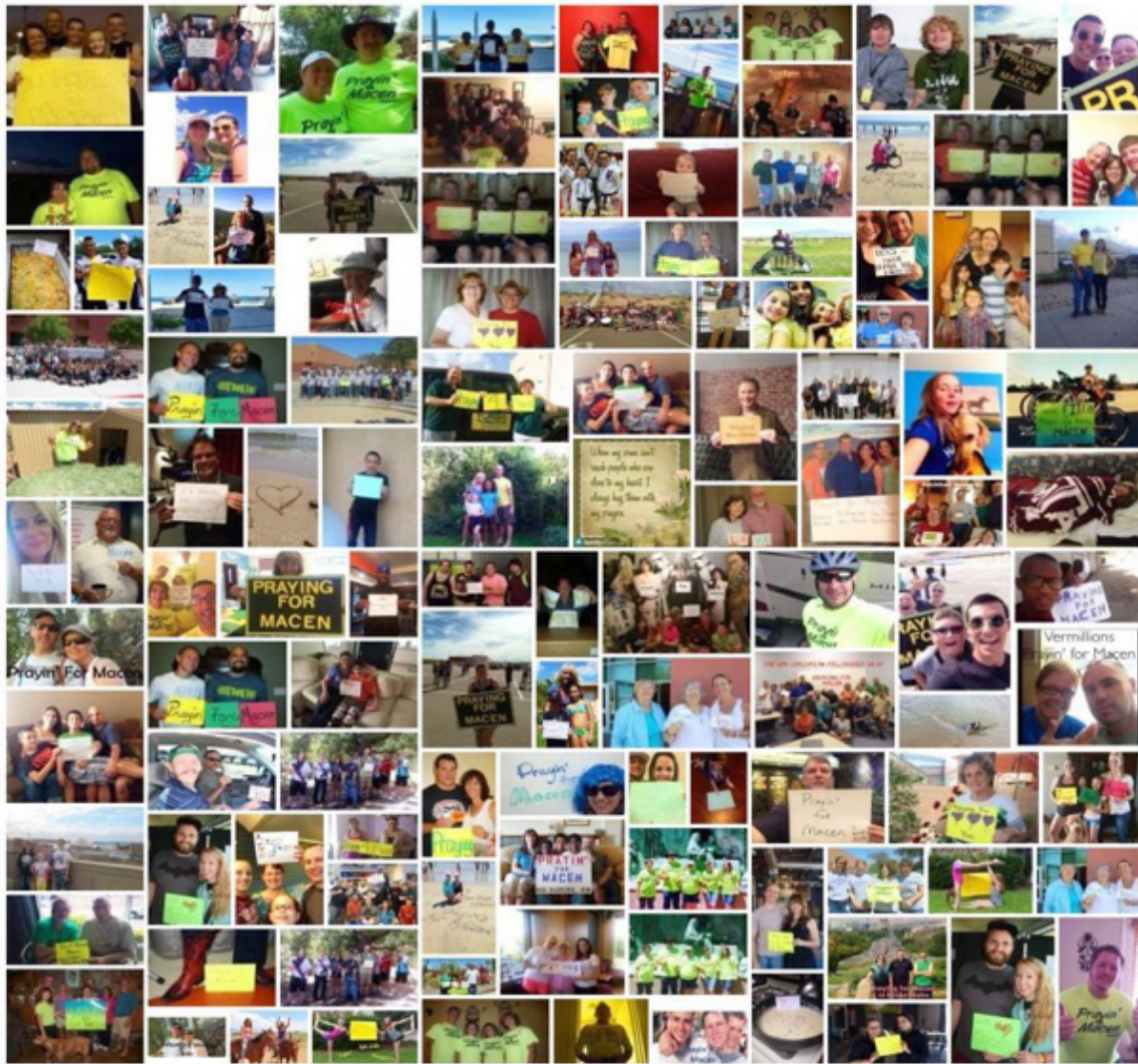


A professional photograph of my family, taken right before my brother began treatment for osteosarcoma.

The story of Macen and the rest of my family is far from unique. From genetic disorders to aggressive cancers, terminal pediatric illnesses and high mortality diseases affect thousands of children and their families every year. The CDC's "National Vital Statistics Report" lists "congenital malformations, deformations and chromosomal abnormalities" as a leading cause of death for children under the age of 5, and childhood cancer as a leading cause of death for children between the ages of 5-18 (Xu, et al). For many of these diseases, curative treatments are not available, and patients have no or very little hope of recovery. Watching as a sibling or child suffers through these diseases and coming to terms with the fact that this loved one will likely die is a shattering and traumatic process. Terminal pediatric illnesses often leave many families unable to cope with the loss as siblings lose one of the closest emotional connections of their early lives and parents risk losing "basic aspects of a parent's identity" (Edelstein qtd. in Buckle and Fleming, 1). Furthermore, parents may be unable to care competently for their other children, further increasing the burden on siblings of children with pediatric diseases.

What set my family's story apart during my brother's struggle with cancer was the immense support and care that we received from our church and local communities. Through a network of friends, churches, and relatives we received prayers, fundraising, and support from literally thousands of people. When a difficult treatment period arose, our church organized meals to be brought to our house. When my brother had trouble with stairs after his rotation-plasty, friends helped to build a bedroom on the first floor of our two-story house. When the family had to travel yet again to Denver, people donated us their spare airline miles and extra tickets. The outpouring of concrete support to my family was an amazing and constant wellspring of hope that pushed us through tough times, especially keeping my parents going as they fought for their son's life.

Though, in general, support is available for most families dealing with high risk pediatric diseases, issues of the family are often rightfully dwarfed by weight of the patient's own trauma. From groups of families struggling with similar illnesses I've learned that, while not unheard of, the level of support my family received from the point of my brother's diagnosis onward is quite rare. Many families do not have the strong communities that my family relied on, a deficiency that can be quite damaging to families dealing with and recovering from pediatric illness. In the book, *Family-Centered Psychosocial Care in Pediatric Oncology*, authors and clinicians Lory Weiner and Maryland Pao discuss both the importance of the family in pediatric care and the lack of support often given to families in these critical situations. They argue that family members, especially siblings, experience many of the same psychological reactions to a cancer diagnosis as the patient does, and therefore need support for these symptoms (Weiner and Pao, 1). However, the current support for families dealing with high risk pediatric illness is generally insufficient for allowing families to heal, recover, and eventually thrive in the wake of devastating illnesses and the loss of a child. Distancing of families from support structures, a lack of consensus on therapies for family recovery, and the high visibility of the patient's illness all culminate to negatively impact families experiencing the death of a child. To better serve these families, effective strategies for helping them



A collage of people supporting my brother. Many of them are wearing T-shirts saying "Praying for Macen."

through their grief need to be developed, agreed upon, refined, and put into practice.

Anticipatory Grieving

In finding the best ways to guide families through their grief, it is helpful to delineate the pattern that grieving for a terminally ill loved one typically follows. In her book, *When a Brother or Sister Dies* Clair Berman, herself a survivor of the death of a sibling, summarizes the process of grieving as experienced by children she has interviewed. "They grieve when they learn of the condition, they grieve as the illness progresses and when the patient regresses they grieve anew when death claims its victim." (31) Berman delineates here the difference between the grieving that happens before the death of a patient and the grieving

that follows that death. In what she calls "anticipatory grieving," Berman states that siblings and other family members "live in the shadow of death," (32) constantly "bargaining" (32) for more time with their loved one while simultaneously and subconsciously making attempts to distance themselves from their loved one. These reactions to terminal illness present barriers to families trying to make the most of their remaining time with the patient, as well as to the ability of families to remain stable in the face of their loved one's disease. These challenges include siblings' inability to appreciate their own problems in light of the overwhelming "world of war" and "medical crisis" that is overtaking the lives of their brother or sister. As one surviving sibling remarked, the everyday, normal

struggles of her life were “just not up there on the list of priorities” (Berman, 34). As parents, extended family, and friends cluster around the affected child, siblings can feel increasingly marginalized, with serious deleterious effects to their academics, health, and their relationship with their siblings. With regards to academics, a study by Barbara L. Wolfe of the University of Wisconsin-Madison titled “School Outcomes of Chronically Ill Children and Their Siblings: A Multivariate Approach” found that, among other things, children with chronically ill siblings saw reductions in metrics like attendance, test scores, and even IQ over the course of their sibling’s illness (Wolfe, 6). The report hypothesizes that these effects are due to the reduced attention afforded to these children by their parents, who become more concerned about the illness their other child is battling (Wolfe, 11).

As someone who is currently experiencing the fallout of a terminally-ill sibling, and after reviewing interviews of many in the same position, it seems that almost nothing besides cursory grief counseling is being done to alleviate the effects that a terminally-ill child has on their siblings during the illness. Claire Berman recommends that extended family and close friends take time to discuss with siblings of terminally-ill patients the problems that they are going through, instead of the status of their brother or sister (35). She also advocates guiding children in developing identities outside of being a sibling to the dying child, such as recognizing their talents, or future aspirations. These social interventions could be suggested by medical care staff, religious leaders, or grief counselors, and when paired with traditional grief counseling (usually discussions about the process of grieving and the deceased) these measures could be simple and effective ways of guiding these children through the loss of their siblings.

A further supplement in assisting siblings of terminally ill children during their brother or sister’s illness is to provide financial or logistical help to parents of these children. Worries about planning trips to hospitals, family finances, and even things like cooking and cleaning can distract parents from taking proper care of their unaffected children. Organizations like the American Cancer Association, Relay for Life, and small community organizations such as local churches all currently offer these services. Along with this,

options for respite care, professional care of an ill-patient that provides temporary respite for the primary caregiver, are both useful in allowing parents to spend time with their other children, and are provided by many non-profit and government organizations.

Cancer’s Reemergence

My brother had a lobectomy on the 14th of August, 2014, removing 65 tumors from his lungs. Though he was theoretically free of cancer at this point, he was kept on chemotherapy until March 18th to kill any small cancer cells that had managed to escape detection. After his treatment had ended, bone scans revealed that my brother was free from cancer, and we celebrated his new designation as being NED (a patient with No Evidence of the Disease). Although Osteosarcoma often comes back after this designation is given, we were hopeful that Macen’s battle with cancer was over, and we looked forward to his reintegration into school, and his continually growing proficiency with his prosthetic.

The return to normalcy, however, was not long lived. On December 6th, 2015, a little over a year from his lung surgery, a routine scan found four masses in my brother’s lungs. He quickly had the tumors removed in another lung surgery similar to the first, and was started on a clinical trial using immunotherapy to attack his tumors. After another bone scan showed continued growth of his tumors, my brother was removed from the trial. He is now undergoing chemotherapy and radiation therapy for tumors in his spine, arm, liver, and lungs. Although we remain hopeful for his recovery, the treatments remain effective, and his doctors have not classified him as terminal, I remain aware of the ever-growing odds against my brother’s survival. When to Hope, and When to Plan

As a child’s illness progresses in severity, the issue arises as to the degree to which hope should be encouraged in parents and siblings. Hope is an important rallying tool, and hope for “beating the disease” can bring great strength to patients, care staff, and the family unit. However, unreasonable hope can prevent parents, caregivers, and siblings, for preparing properly, emotionally and logistically, for the worst-case scenario.

I currently face a similar dilemma with my brother Macen. There is no curative treatment option for

the extent to which his disease has manifested, and it is likely he will not live another five years. Though his illness is not terminal, and my family continues to keep hope alive, I constantly wonder if it is the right time to prepare myself for the worst, while simultaneously feeling fully the guilt of being unable to see his healing as a possibility.

This sentiment is echoed in the interactive piece *That Dragon, Cancer* a first-person exploration of the struggle of creators Ryan and Amy Green experienced as their son Joel struggled with, and eventually died from terminal brain cancer. Like my family, the Greens were and are deeply religious Christians, and like my family, they drew hope and comfort from their religious beliefs. Ryan and Amy faced a disagreement in facing Joel's disease; Amy held hope until the end of Joel's life that he would be delivered miraculous healing by God, while Ryan demanded to feel fully the impending death of his child without the softening of groundless hope. While both parents maintained the overall hope that their son Joel would continue on to a better place in heaven (a belief that I happen to share about my own brother) which certainly brought a measure of comfort, Ryan rejected the tenuous hope for miracles in favor of dealing directly with the emotions of loss, whereas Amy clung to hope for healing as a support in Joel's last days. The work as a whole acutely brings into perspective the ability for such hope to lend strength to families in times of need, and solidify a family narrative around a theme of hope, even while coming to terms with impending destruction.

Support for hope as a coping mechanism has been echoed in the medical community. The American Academy of Pediatric Practices official guidelines on Palliative care, outlined in the journal piece "Palliative Care for Children," suggest that "continued hope for a cure, no matter how unlikely, may be an important coping mechanism" for parents and siblings dealing with pediatric terminal illness.¹ Both Claire Berman in her book *Losing a Brother or Sister* and Jennifer Buckle and Stephen J. Fleming in their book *Parenting After the Death of Child* cite beliefs about the afterlife and religious beliefs in general as useful tools in dealing with the after effects of death. Generally, it seems that hopeful outlooks on the fates of deceased children should be encouraged, though there is not

enough evidence to ascertain whether it is helpful for parents to hold out continued hope for miraculous healing regardless of the odds of their child's recovery.

Grieving After Death

Arguably the most acute stage of grieving for a loved one is in the days and weeks directly after they have died. Family members, especially siblings of the deceased, can be aimless, emotionally unstable, and afraid for their own safety in the conclusion of a pediatric terminal illness. As an article from the National Child Traumatic Stress Network points out, children in these situations can even show reactions not easily recognizable as grief. "For example, a quiet toddler may have more tantrums, an active child may lose interest in things he or she used to do, or a studious teen may engage in risky behavior." In addition to these personality disturbances, children may also develop a more intense reaction known as Childhood Traumatic Grief, defined by a pilot study as "A condition in which trauma symptoms impinge on the child's ability to successfully address the normal tasks of grieving" (Cohen, 1). Though this disorder is not Post Traumatic Stress disorder, it does carry many of the same symptoms including, "reliving aspects of the person's death," "avoiding reminders of the death or of the person who died," and "increased arousal and anxiety."

Though feeling saddened and temporarily depressed by the loss of a loved one is normal in childhood, many children and teens do not have the ability to mentally or emotionally process the death of a sibling, especially as a result of terminal disease. If left unaddressed, problems resulting from this bereavement and Childhood Traumatic Grief can lead to children disassociating from their families, leaving communities that previously had offered them support, or becoming emotionally stunted as they grow to adulthood.

Currently most sibling grief after pediatric terminal illness is considered normal unless some visible problem manifests. When a sibling's grief is recognized as problematic, interventions of traditional psychotherapy, such as mindfulness-based cognitive behavior therapy, are used to address problems of behavior, though often times other issues are written off or left untreated. Pilot studies, like the one conducted by researcher J. A. Cohens, have shown great

success using cognitive behavior therapy coupled with joint therapy sessions. These therapies involve both parents and their children, and can lead to significant improvement in the symptoms of childhood traumatic grief, as well as improvement in symptoms of anxiety and depression also present. In addition to these therapies, organizations like the National Child Traumatic Stress network recommend that parents talk often to their children about the deceased sibling, and monitor them carefully for the signs of Childhood Traumatic Grief mentioned above. It should be noted, as Jennifer Buckle and Steven J. Fleming write in their book *Parenting after the Death of a Child*, that parents may also enter a “numb survival” after the death of a child that can make this form of support difficult or impossible for them to provide (35). Monitoring the psychological health of the parents following the death of a child is also imperative to the health of their children. The number of siblings treated after the death of a child for Childhood Traumatic Grief must be expanded as caregivers, community members, and hospital staff become trained in better recognizing its symptoms, and more research needs to be done into the efficacies of certain psychological treatments in alleviating the symptoms of this disorder. Looking Forward and Moving on

After the initial pangs of loss set in following the death of a sibling, the greater challenge faced by survivors is learning to live without their brother or sister, but while keeping present their memory and legacy. In the aftermath of the death of a child, the entire structure of the family unit is tested. Roles that were filled by a departed sibling may fall to another child or be discarded (102-103 Buckle). Parents and siblings alike may feel that the deceased is being forgotten, or left behind by the family. This feeling of losing a connection with the deceased must be metered with a real and urgent need to move out of the shadow of grief and onward into life. At one extreme a family loses its identity as it tries to forget about the lost child, and at the other a family remains paralyzed by fear and loss, threatening the autonomy and function of the parents, and the emotional development of the siblings. Families must strike a healthy balance between these two poles to successfully overcome their grief.

Siblings themselves face a number of unique problems in the wake of losing their brother or sister. As

noted in the article from the National Child Traumatic Stress Network, siblings can face “survivor’s guilt about being alive,” intense regrets about things they did or said to the deceased child, doubts about worldviews, and even personal and irrational blame for the death of their brother or sister. Moving forward children also must reformat their identity, both moving away from association with the deceased, and incorporating ideals and images that their sibling represented.

In the book, *Parenting after the Death of a Child*, Jennifer L. Buckle and Stephen J. Fleming argue that “picking up the pieces of the family requires regenerating the relationship with the deceased child in new terms” rather than simply moving on from it. Claire Berman, author of the book *When a Brother or Sister Dies*, similarly advocates that siblings and parents find ways to carry on the legacy of the deceased, such as organizing blood drives, scholarships, or charities in the name of their departed loved one (114). Berman also advises that families hold onto their deceased loved ones by making scrapbooks, mementos, and other “tangible connections” (113). In all Berman views the role of the mourning family not so much as to function without the deceased, but rather to incorporate the deceased’s goals and memory into their own lives.

As a society, we need to provide the guidance and resources children and families need to regenerate their relationships with the deceased. Grief counselors, medical staff, and community leaders need to incorporate remembrance ceremonies and guidance regarding legacy work in the name of the deceased child into the outreach they provide siblings and families, turning a tragedy into a lasting legacy that can keep the memory of the deceased child alive, and the relationship between the family and the deceased intact.

Bringing it Home

The question of how to revive a family following the death of a child is one that has been with humanity since before we were human. The family is the strongest unit of social cohesion, and while this lends it resiliency, it also means that its failures can impact each of the individual members of the family in a very serious way. For many, especially as we grow up, family forms the base unit of our identity, a constant place of love and security when it seems all

the world is a dangerous place, and because of that, death intrudes on the family in a way nothing else can. The death of a sibling shatters assumptions of belief, safety, and prosperity. It is an all-out assault on the identity of the sibling, on the identity of the parent, and on the idea that "everything will be all right."

As a society and as a community, we owe it to ourselves and to each other to provide guidance and support through adversity as shattering as that provided by pediatric terminal illness. Those in the clergy and in other positions of leadership in the community have the duty to rally physical and emotional support to families in danger of collapse from these threats. Members of the medical community have a commit-

ment to the health and wellbeing of their patients, and a duty towards monitoring and guiding the families of their patients comes with that commitment. Psychologists and counselors have a duty to listen to parents and siblings struggling with the grief before, during, and after the death of a child as well as a duty to provide guidance to those attempting to resolve the connections to their lost loved ones. As a society, as a larger family, we must provide the scaffolding and structure parents and siblings need to restructure, regenerate, and reform their lives in the wake of the pediatric illness. We must enable them to live.

References

American Academy of Pediatric Practice. "Palliative Care for Children." *Pediatrics* 106.2 (2000): 351-357. Print.

Berman, Clair. *When a Brother or Sister Dies*. Westport, CT: Praeger, 2009. Print.
Buckle, Jennifer L. and Stephen J. Fleming. *Parenting After the Death of a Child: A Practitioner's Guide*. New York: Taylor & Francis Group, 2011. Print.

Cohen JA, Mannarino AP, Deblinger E (2006) *Treating Trauma and Traumatic Grief in Children and Adolescents*. New York, NY: Guilford Press. Print.

Kim, Jew. *The Holderman Family*. 2014. Albuquerque, New Mexico. Digital Photograph

National Child Traumatic Stress Network Child Traumatic Grief Committee. (2009). *Sibling Loss Fact Sheet Sibling Death and Childhood Traumatic Grief: Information for Families*. Los Angeles, CA & Durham, NC: National Center for Child Traumatic Stress. Web. 5 June, 2016. http://nctsn.org/nctsn_assets/pdfs/Sibling_Loss_Final.pdf

Osteosarcoma. *Jude Children's Research Hospital*, 2016. Web. 4 Apr. 2008. <https://www.stjude.org/osteosarcoma>.

That Dragon, Cancer. Numinous Games. 2016. Print.

Weiner, Lori and Maryland Pao. *Comprehensive and Family-Centered Psychosocial Care in Pediatric Oncology: Integration of Clinical Practice and Research*. Chichester, UK: John Wiley and Sons, 2012. Wiley Online Library. Web. 12 May 2016

Wolfe, Barbara L. *School Outcomes of Chronically Ill Children and their Siblings: A Multivariate Approach*. Stanford, CA: School of Education, Stanford University. Print. B1-B6.

Xu, Jiaquan, et al. *Centers for Disease Control and Prevention. National Vital Statics Report Deaths: Final Data for 2013*. Hyattsville, MD: U.S. Department of Health and Human Services. February 16, 2016. Web. 12 May 2016. http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf