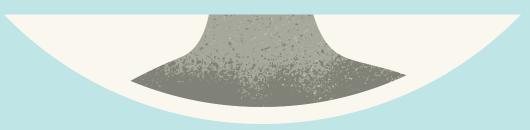


# **SEASONS OF CHANGE**

Stories of Hope After Loss



These stories are dedicated to the children and teens who have lived and died courageously in the face of cancer. We acknowledge the loving parents who have shared their stories. May we choose to honor the lives of our loved ones by living lives that our children would have wanted for us.

May we also live boldly and bravely, just as our children have.

"When all the world appears to be in a tumult... the seasons retain their essential rhythm. Yes, fall gives us a premonition of winter, but then, winter, will be forced to relent, once again, to the new beginnings of soft greens, longer light, and the sweet air of spring."

Madeleine M. Kunin

# **SEASONS OF CHANGE**

Stories of Hope After Loss

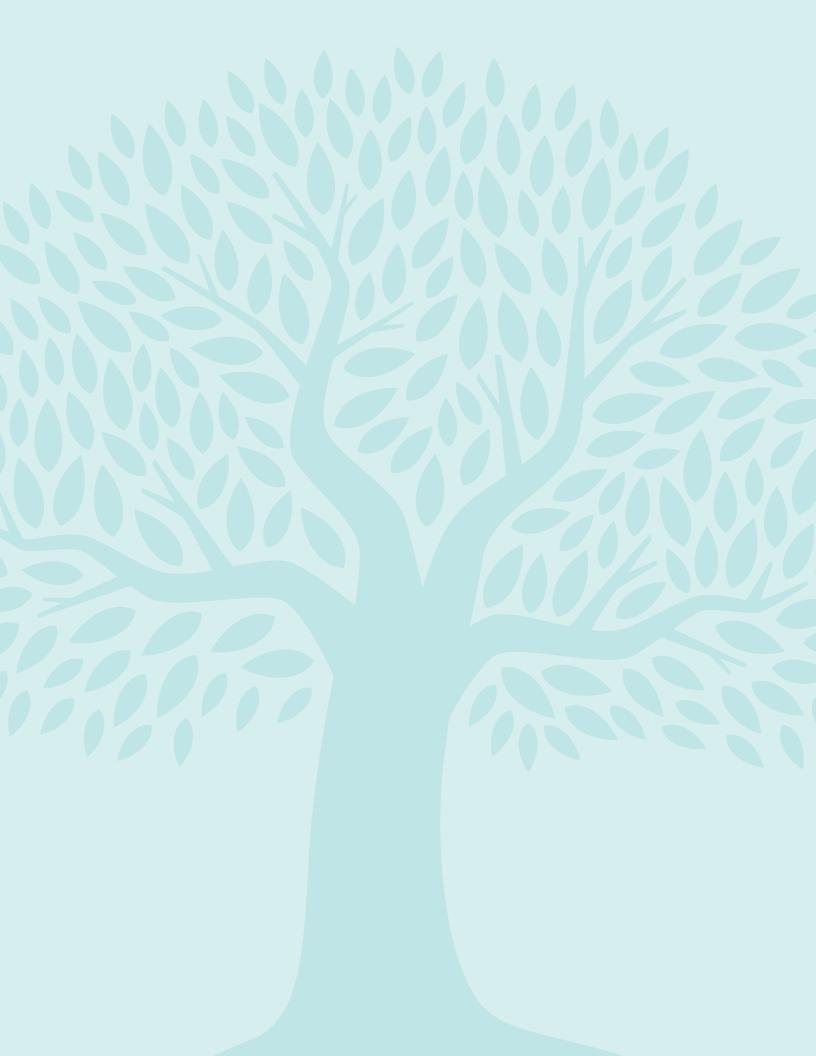


Contributed by bereaved St. Jude family members

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Dear Parents,

Grief is hard work on a regular day. You will find that holidays and other special days present unique challenges to your ongoing grief process. You are not alone. We are St. Jude bereaved parents who have also had to navigate our way through these seasons of change. Each St. Jude parent and family member who contributed to this sensitively-written and compassionate book has experienced the death of a child. Our hope for you is that, by sharing moments in our journeys and some of the things we learned about grief along the way, you may be comforted in knowing you are not alone in your journey and that you might feel a little less lost.

Seasons of Change is divided into four sections: Days Ahead, Relationships, Milestones, and Holidays. Each section has one or more questions for you to reflect on as you read through each topic. If you find journaling helpful, we encourage you to write your thoughts. However, if you prefer not to write, you may want to take time to think or maybe to share your reflections with someone else. Everyone grieves differently, and everyone has different ways of coping. It's most important to do what feels most helpful and comfortable.

We recommend that you choose sections or topics you feel ready to read rather than reading this book straight through. Some of the topics may be better to read at a later date, in the moments you need them.

If you would like to talk to another St. Jude parent who has experienced the grief of losing a child, please contact the grief support coordinator to discuss the Quality of Life Mentor Program. Her information and more resources can be found in the back of this book.

St. Jude Children's Research Hospital

Quality of Life Steering Council



In the days after the death of your child, you find that life as you knew it no longer exists. Places and things that just a few days ago were familiar now appear oddly foreign and strange. Friends and family who were once close and understanding now may seem as though they speak a language you don't understand.

There is the constant presence of grief while you attempt to go about the tasks of figuring out a new identity, new roles, and changed relationships. At times, you may find yourself searching for distractions from your grief while at other times immersing yourself in it. You wonder how you will survive without your child.

Take each day one at a time, knowing that there is no timeline to your grief.

#### Questions for Reflection

- What memories do I want to carry with me as I live out each day?
- How has my grief changed what's most important to me?
- Grief looks different for everyone. What does grief look like in your life?



Grief is a normal response to losing a loved one, and it is a very individual process. Everyone grieves differently, for different amounts of time, and with different intensity. Some common responses to losing a child include, but are not limited to **shock**, **sadness**, **fear**, **anger**, **guilt and regret**, **loneliness**, **anxiety or ongoing worries**, **and less desire to spend time with others**.

#### Seeds for the Soul

- Embrace the emotions you feel during your grieving process. These are natural and normal. Don't be afraid to acknowledge them. Grief is normal.
- Grief is a personal process. Figure out how you grieve and how you
  express that grief. If something doesn't seem right, don't be afraid to
  ask for help.



# **GRIEF IS NORMAL**

# Sarah, mother of Austyn

And just like that, 5 weeks have gone by. That's 35 days, 840 hours, 50,400 minutes since I've last held my baby in my arms. Most of the time I feel like I can barely come up to breathe, and then another wave of grief knocks me completely back under only to feel like I'm drowning again. It's an awful, awful feeling. The emptiness I feel is overwhelming.

I miss your smile. I miss hearing you laugh. I miss your sweet voice. I miss folding your little clean clothes. I miss seeing your face in my rearview mirror as I'm driving in my car and seeing the sun hit your face just perfectly as you stare back at me. I miss your hugs. I miss your kisses. I miss brushing your hair. I miss giving you a bath at night. I miss making your food. I miss reading you books. I miss painting with you. I miss playing babies with you. I miss singing to you. I miss holding you. I miss rocking you. I miss every single thing about you, Austyn.

Today, I took my grandma to the grocery store, and I had 3 different people stop to ask if I was "Austyn's mom." I love hearing that. In fact, being "Austyn's mom" is and will be forever my greatest accomplishment in life. My broken heart smiled. It smiled really big today. In fact, we have had many people stop us over the last few weeks and tell us how Austyn has forever changed them. I could talk about my girl all day, and I'm honored that people approach me to share how Austyn has impacted their lives.



- Grief affects the whole person. It cannot be solved with facts or information.
- Grief is persistent and unpredictable. It requires you to be patient and gentle with yourself.
- Certain things trigger strong grief reactions.
- In sickness, our children became our teachers. They continue to teach us even now.



# **EVERY DAY IS MONUMENTAL**

#### Amber, mother of Stellan

I'm sorry you are reading this, and I'm sorry I'm writing this. I'm sorry we each have lost a child. We have been touched by anger, confusion, and sadness that is truly unbearable in so many ways. It's not the circle of life, and I will never understand why our dear children were touched by these illnesses. Our job is to protect our children, and this was a booboo neither you nor I could fix.

My son was 2 months and 26 days old when he passed—a beautiful redheaded baby boy who was, sadly, born with a very rare tumor. I never knew him not to be sick. Most of his life was spent in the hospital. I miss him terribly but was truly blessed by each minute we spent together. What have I learned?

Every day is monumental. Every day there is hurt and a void like no other. After 13 months, I can report progress in my healing and acceptance, yet the pain still lingers. And frankly, I do not want it to go away completely. Sure, some days are better than others, but grief requires we take them one day at a time.

I've learned that I am deeply disturbed by certain things. I'll never know how my son's voice would have sounded. I'll never put him on a school bus. I'll never see the man he would have become. And as much as these things torture me, I also experience and hang on to the beautiful memories. I saw him smile. I kissed his tiny lips. I held his little hands. We endure such a range of emotions, we are sure to be strong and weak as need be.

I've also learned there are situations that trigger my strong emotions. I seem to see little redheaded boys everywhere. Have there always been so many diaper commercials on television? There always seems to be a baby at the grocery store who will not stop staring at me. And of course, there was the first time someone asked if my twin girls were my only children. Right then and there I decided to open myself to this stranger. "No ma'am, I have a little boy who lives in heaven." People really don't know what to say, but I've learned to respect their effort in trying.

With all my heart, I believe the love between a parent and child is the strongest love. The bond is unbreakable. I will always love my son and will think about him every day. I believe he taught me my duty is to live, even if that means living with a hole in my heart. He taught me that every moment is sacred and must be appreciated. He taught me to keep on keeping on, to follow my heart. For it is within our hearts that our children reside alive and well.



- Sometimes just talking about your child and remembering the sweet times you had are healing for you. The stories you tell are not only good for your soul but allow others the opportunity to see how wonderful your child was.
- Stigma can surround counseling and going to counseling. However, counseling is a great resource that can be a tremendous step in your healing process. Don't be afraid to find what helps you heal.



# **FINDING SUPPORT**

### Leticia, mother of Arianna

As a newly bereaved mother I was completely lost! I was broken, defeated, depressed, and hated being around people. At the same time, I was terrified to be left alone. I learned early which people made me feel better about myself and those who didn't. I tried really hard to be around others who truly wanted nothing but to help.

The first year was rough, really rough! In the beginning I was completely against counseling. I just couldn't wrap my head around ever healing or being counseled by someone who had never met Arianna or me. All I could see was me walking into an office once a week, being asked how I was doing and always having the same answer, "Horrible." My husband was in counseling and had been asking for our family to go to this bereavement camp. If I wasn't going to counseling I definitely wasn't going to sing "Kumbaya" in the woods with a whole bunch of people I didn't know.

About 10 months into my grief, I truly was falling apart and was watching my 6-year-old do the same. I was tired of being sad and had no idea how to help my daughter. I finally "broke" and called a counselor. To be completely honest, it was weird at first, but after about the third time of telling Arianna's story, I felt different. I got through the story with fewer tears. The sixth time was better and by about the eighth time, I felt even better talking about her.

I finally agreed to go with my family to the bereavement camp. The first day was rough, and I was so nervous. I wanted nothing more than to jump on a plane and head home. My husband asked me to give it one more day, so I did. The second day was fun. Telling all these strangers about my daughter felt good. For that day, it felt like I was keeping her alive.

I realized that telling others about Arianna, allowing others to help us, or going to a camp in the woods was not torture. It was a way to keep her alive in our lives in a healthy way. I remember laughing at a story about Arianna I was telling a friend and for the first time realizing our little family just might be on the road to healing.



- Sometimes we find the best things in unlikely places. Don't be afraid to look for a community in different places. You never know what you could find when you're not looking.
- Staying connected to any sort of community is helpful. Although it may take time, keep looking for people who support you and love you. The impact of this community can be life changing.



# STAYING CONNECTED

# Lisa, mother of Trevor

After the death of our 4-year-old, Trevor, I suddenly felt physically and emotionally alone. My days that were once consumed with taking care of Trevor and interacting with people suddenly came to a stop.

I was invited to join a women's Bible study at a local church where we had met several people during Trevor's journey. I felt close to these people since they supported us in our time of need, and we were new to the Memphis area. Although I wasn't sure I was ready to join a Bible study, I did feel it was a way to stay connected to the people who supported me during Trevor's cancer journey. Now, 4 years later, those women are my best friends.





- Plant a tree or a butterfly garden at a favorite family gathering place (perhaps at Grandma and Grandpa's house or at another family member's house where you had many gatherings).
- Plan a butterfly release at a favorite vacation spot with the entire family.



# **FAMILY GATHERINGS**

# Wendy, mother of Nick

My husband and I both come from large and very close families. We often get together for special occasions like campouts over a summer holiday, family reunions, weeklong vacations, or family getaways over a long weekend during the winter months.

In August 2006, while our extended family attended the wedding and reception of our nephew and his new bride, our immediate family was at St. Jude. Nick had relapsed and was back to begin the long and terrible process of a bone marrow transplant. The transplant never happened because on that day, while our family at home toasted the newly married couple, Nick was in emergency surgery after suddenly suffering a brain bleed.

It was difficult news to share when we finally reached our family back home in Ohio. They had just rejoiced together at a wedding, and now we were giving them the most devastating news they had ever received. After hearing the news, my sister went out into the garden at our parents' home and found a smooth oval stone. On it she wrote the name I called Nick when he was little, "Nicky Adam Sweetheart," and placed it in the garden among the bleeding heart plants that had been a favorite of my grandmother. That garden became a place of remembrance for my family as just 8 months later we placed an angel statue in the same garden after my sister died.

My husband's parents have a more difficult time sharing and showing their grief, which was hard for my husband and me. We were hurting so badly and did not feel the same support from his family as we did from mine. Months after Nick died, friends of my inlaws showed up at their home with a weeping cherry tree to plant in their front yard as a symbol of their loss and grief. One of Nick's favorite things to do at Grandma and Grandpa's house was to climb trees. This simple gesture became such a meaningful expression of their grief that when, several years later, deer threatened the life of the tree, it was extremely upsetting for Nick's grandparents. The tree was saved, is growing strong, and in many ways has helped my husband's parents work through their grief.

Since the time when Nick died, our family has continued to get together for special occasions. It has been crucial for us to continue to find ways to both laugh together and cry together. Our family gatherings can never be the same again, but in many ways, when we are all together, we feel Nick is there with us in the laughter of his cousins, the stories of his aunts and uncles, and the hugs from his grandparents.



- Just as every death is different, so is every healing process. Others may encourage you to clean out your child's room, but only you can decide when you're ready for this bit of closure. Do what feels right to you when it feels right and not a moment before. Likewise, it's OK to clean it out sooner rather than later if that's what feels right to you.
- Don't wait for an overwhelming feeling of now is the time, for it may not come. Instead, honor the small moments here and there. Give away clothes and toys when you're ready and if it feels as though you'll never be ready, keep them. That's OK, too.



# RECLAIMING THEIR ROOM

# Cayce, mother of Will

Though each of our 3 sons had their own rooms, we'd often find them all bunked together in the mornings. At night, my husband and I would tuck each boy in his own bed in his own room, knowing that as soon as we retreated downstairs, the nightly bed shuffle would take place.

As Will's cancer progressed and he became more immobile, his room became the default room. All of the playing, plotting, whispering, arguing, fighting, and shenanigans happened there. When it was time to sleep, the pillows and blankets were dragged from the other bedrooms into Will's room, and that's where our 3 sons slept.

Lots of magic happened in that room in those last few weeks. Will's big brothers were always around, quietly doing their thing as a parade of friends and family gathered to say goodbye to our sweet child. Will's dog, Nellie, was always there, curled up at the foot of his bed. My husband and I even slept in there on an air mattress. We had the world's longest slumber party, and I wouldn't have changed a thing.

Our priest came to visit daily. He'd let himself in the back door and make his way upstairs to find us. One day, about a week before Will died, Father Val asked him what he was most looking forward to about heaven. Without a moment's hesitation, Will looked at the "Are you experienced" poster on his wall and said, "Meeting Jimi Hendrix."

Will's room is full of many of our most cherished memories. For a couple of years, his room remained untouched. The décor was still 8-year-old boy. It wasn't that we were against making changes. We just didn't have a reason to, nor did it feel like it was time to do so.

After a while, the bedding was replaced with something more suitable for adult company though his Cars bedding wasn't disposed of. It's folded in the linen closet and is often the favorite go-to blanket when one of the big brothers wants to nap.

As a child's room naturally evolves over time according to his interests and age, so has Will's room, even though he's gone. It is a lovely room, reserved for guests. It's not called a guest room, however. It will always be "Will's room." It has lovely, mature furniture and bedding. Real art hangs on the walls, and the bathroom is tastefully done.

Will's favorite clothes still hang in his closet, and, yes, the Jimi Hendrix poster still graces the wall.



- Moving after you have lost a child can be one of the most difficult steps to take. Before you go, take your time to go through your child's items that are particularly meaningful.
- Unpacking may be as difficult as packing. As you are once again faced with your child's items, you may find yourself crying and laughing at the same time.
- Give yourself as much time to do this as you need. Realize it takes time for a place to feel like home. Be patient, as it may take even longer after you lose a child.



#### MOVING

#### Katie, mother of Sean

Moving is never a simple task, even under the best of circumstances. Moving after you have lost a child can present a whole variety of emotions.

Depending on the circumstances of the move, you may find yourself looking forward to the possibility of a "fresh start," a new location, friends, and opportunities. However, even if the move is for a good reason, feelings of tremendous sadness can surface. It may be very difficult to leave all that was familiar to you and your child—your home with all its memories and the support of family and friends who knew your child and your journey.

Packing, and possibly going through your child's belongings, may be an enormous burden. Even if you are not doing it yourself, watching someone else put so many cherished things in boxes may have its own difficulties. If your child is buried, feelings of guilt may arise about leaving him or her as you move.

We moved 3½ years after our son passed away. I honestly did not know what to expect. We chose to bury our son when he died, and the cemetery was the last place we stopped as we left town. It was a terrible feeling to leave knowing it would be a while before we could return. We have friends who offered to stop by the cemetery for us, but we know it is not the same.

We have since been back ourselves. Seeing little gifts or notes left by friends for our son has brought us comfort knowing someone is stopping by. It is still hard not to be the one visiting his grave on a continuous basis, but we are fortunate to have caring people who will step in for us regularly.

Upon arriving at our new house, we put pictures of our son everywhere and arranged reminders of him throughout the house. For a while, I was sad, in part because of the move itself and also about our son. I have found it particularly difficult because people do not know him. At one point, I said to my husband, "I feel like we lost him all over again." What I have learned, however, is that it is my job to help people get to know him through us. Some people are more receptive to hearing about him than others are, but that seems to be common whenever you meet new people and will be a continuing part in our journey.



- You may become the face of someone who knows and understands loss. Because you do, this may provide a strength and hope that another family or person needs. If you feel strong enough to be there for others, do so. If you don't, give yourself permission to politely decline.
- In honor or in memory of your child and those who helped you
  or those who were not there for you, give to others who grieve. If
  receiving cards comforted you, then send a card. If having people
  with you gave you comfort, be there for others.



# WHY DO PEOPLE CALL ME EVERY TIME SOMEONE DIES?

#### Christine, mother of Catie

Having a child diagnosed with cancer is rare. Having a child die is also rare. Having both may make you an expert in the eyes of others. Since the death of our child we have been called whenever anyone we know learns that someone else has been diagnosed with cancer. We are called often when someone we know learns of a death in the family of someone they know. Having lost a child to cancer does not make you an expert on cancer or death or grief. Having lost a child to cancer may make you an expert on compassion, understanding, and survival.

The bottom line is that death, while it is inevitable, is painful. No one should go through their loss and grief alone, yet many do. It does not matter the size of their family. It does not matter whether their loss was the loss of a child or not—it was a loss. It does not matter whether they have many friends or few friends—they will need someone. Their life changed—as mine has and as yours has. You have experienced something deep and profound, and hopefully you have learned some things about yourself and about grief.

When I went through the loss of our daughter I was in a fog. I only wanted to be with my daughter—the only person I could not be with—and no one else and nothing else mattered at that time. Others were there, but I was not completely there. They were crying and sad, but their sadness was not my sadness. They had not experienced what I had experienced. I was a St. Jude mom who came home, and no one around me knew what it meant to be a St. Jude mom. This made me feel so alone.

A few months after our daughter died, one of her St. Jude friends died. I had to attend that funeral. I did not want that mother to feel the loneliness that I had felt. After a few years and several more funerals, I learned something. It didn't matter whether I was comforting a grieving St. Jude mother or not. What mattered was that I was offering comfort. What mattered was that the person grieving was not alone. This realization continues to astound me. Grieving people are more often than not comforted by the presence of people.

Having lost a child to cancer may make you able to relate to another's unfathomable pain—such as the loss of a loved one. Sharing your grief journey with another helps that person bear the pain and may help you on your own healing journey, which is a journey without an end.



Bereaved parents often describe feeling out of place when returning to life back home: family, work, social gatherings, church, etc. You may find that many of the activities and responsibilities you once had as the child's parent no longer make sense. Your roles have changed.

#### Seeds for the Soul

- We have no other option than to create a "new normal."
- Not only was my child a gift, but the ways his life and death changed me forever are also gifts. My son made me a better person. He made my "new normal" something I could never have imagined, and I will thank him for that every day.



# A "NEW NORMAL"

#### Amber, mother of Stellan

There truly is no easy way to begin to describe how I dealt with my son's death. Part of me has lost touch with the intensity of the pain directly after his passing. I think our minds block that out for a reason so we are able to heal.

The little bit of energy I could muster up went toward taking care of my 5-year-old twins. That included all the normal motherly duties: packing their lunches, brushing their hair, and, of course, remembering the hair bows. By the time I got them off to school, I felt as if I had run a marathon that I had not trained for. The remainder of my day was usually spent alone with what I now know was too much time to think, dwell, and isolate myself. I had never felt such total depletion. All I could do was stay on autopilot for my little girls. I knew they needed and deserved a hundred percent of me, but I was not functioning at a hundred percent. I did the best I could.

Over time, I slowly began creating my "new normal." I decided I did not want my son's death to be in vain. I knew that my response to his death would break his heart, and that broke mine. I continued to pick up the pieces slowly and started to feel a sense of peace that I had not felt before.

I started to think of Stellan's short, sweet life more as a blessing than a curse that had been bestowed upon him. He had brought so much joy and gentleness to me while he was here. He wanted me to have that, so what a beautiful foundation for my "new normal" to be built upon.

I tried to start doing something "normal" every day. Some days it was a shower. Other days it was brushing my hair. My steps were small. There was not only work to be done on the outside but on the inside as well. One day, I was able to look at my twins and feel joy. Finally, and most importantly, I could look at pictures of my son and actually be thankful for the sweet memories he gave me. Although my heart was still in a million pieces, the pieces started to patch together. There are pieces that don't fit together properly, but this is my "new normal."

In creating my "new normal," I began to notice the sweet things Stellan had passed on to me. I became more empathic. I became so unbelievably aware of the beautiful, small things around me and thankful for them like I had never been thankful before. My "new normal" was making me a person I was actually proud of, and I could feel in my heart my son was proud, too. I noticed that people were being drawn to my strength.



Relationships can change after the loss of a child. The stories in this season address the relationships that are lost after the death of a child, the relationships that are restored but are changed, and the relationships that are established. All of our relationships are changed, including our relationship with our deceased child, ourself, our family, our friends, and our community.

#### Questions for Reflection

- How has losing my child changed my relationships? How has it changed me?
- What is my definition of a supportive relationship?
- Have any attempts at support been helpful? How can they be more helpful?



When faced with this painful truth, it helps to honestly acknowledge the new reality and forgive your own limitations and doubts. Seek the companionship of a skilled listener, and find and honor the boundaries that can protect your tender heart.

#### Seeds for the Soul

- Be open with others in your life. Have conversations that explain clearly how you have changed because of the loss of your child and how that is likely to affect both personal and work relationships and also social activities.
- Concentrate on the roles you see as a priority in your life moving forward. What is important for you to do right now?
- Leave yourself open to roles that you might want to pursue again someday.



SEASON 2: RELATIONSHIPS

# **BECOMING THE "NEW" YOU**

### Lisa, mother of Thomas

A couple of months after my son died, I was sitting with a friend at a basketball game that my husband was coaching and that my remaining children were playing in. I must have smiled at something someone said, because my friend mentioned that it was nice to see my smile. I think her words were, "It's nice to see you coming back."

I thought, "Coming back? Like I left the room for a few minutes and now I am back and the party can go on?" What kind of grief "process" is that? Or maybe she meant that since I was smiling in public again that it was some arbitrary indication that my mourning period was over, and everything would go back to the way things were.

A part of me understood what my friend meant, and I suspect if the roles had been reversed, I might have said the same thing. But, it did make me reflect on how my view of my identity had changed. I felt a bit like jello—shaky and very "unformed."

After the loss of my son, I felt changed to my core emotionally and physically—less social, less confident. Whereas I had identified myself in the past as a hard worker who could take on any challenge, I now struggled to summon both the energy and motivation to complete any project no matter how small. I questioned my faith, which had been at the core of my existence from an early age. All the social occasions I once craved were fraught with potential pain, so I avoided them.

My parents especially wanted their daughter back—the one who organized extended family get-togethers and planned Thanksgiving dinners and family trips. I didn't want those roles anymore. I guess I wanted permission to be the person I needed to be in my grief—not someone lost in her own misery or ignoring her extended family and friends—but not the bubbly person from before either.

With some hard conversations, I began to ask for that permission from the people around me. Now, after several years, I feel I am becoming more comfortable with the person I now am and the permanent changes, both positive and negative, that grief brought to my view of myself. I expect that process will continue for quite some time.



It is important to recognize that you and your caregiving partner might experience the intense emotions of the grief journey at different times and in different ways.

- It can be hard to honor your child when you and your partner are grieving differently. It is important to recognize the unique ways your partner grieves, but it is also important to come together so you can create a lasting legacy for your child.
- Make a conscious effort to spend intentional time with your partner so you can reconnect. Through this tremendously difficult time, it is important to have someone you can lean on and trust.



# **PARTNERSHIP**

#### Kevin, father of Catie

One of the things St. Jude strives to provide is a sense of family even in the midst of a battle for your child's life. Families make the best decisions they can about who will accompany their child to treatment in Memphis. For us, we had to split up the family. Christine went with Catie to St. Jude, and I stayed home in Pennsylvania with the other kids.

We managed through all of that during treatment. But, when Catie relapsed and eventually died, coming back together and trying to be a married couple again was a challenge. All of the little disagreements and differences of opinion became magnified through the lens of Catie's death.

I wanted to support Christine. I was even willing to put my own grief aside and care for her and continue to care for our other kids who had lost their sibling. What kept getting in the way was the stupid, everyday stuff from the time that we had been apart. Little things became huge obstacles to overcome, like a picture that had been moved in the house while Christine and Catie had been at St. Jude.

During the 8 months Catie had been in treatment, life had gone on, and kids had grown and changed. This fact was enormously painful and a potential source of division.

In all of this, the possibility existed for Catie's death to have more tragic consequences than it already had. As bad as it was, we needed to make a choice to let it get worse or use it as a rallying point for our family moving forward.

We continually asked ourselves, "What would Catie want us to do?" In asking this we began developing her legacy by honoring her in a way that made her sacrifice, her journey, and her battle have some meaning beyond her death.

Keeping Catie "alive" by struggling through and reconnecting with Christine was hard. Sticking with it and persevering has made us even stronger and also honored all that Catie endured.



- The love and support of a friend is invaluable.
- Grief may change the dynamics of relationships, but it does not have to destroy them.
- Love endures all things.



# **ENDURING RELATIONSHIPS**

# Paul and Paula, parents of Steve

At the end of the school day, Steve came bursting through the door and yelled down the hall, "Mom, Mom!" Thinking something terrible had happened, I ran to him, and he said, "Mom, I've got to clean my room! A wonderful girl is coming by after cheerleading practice, and I want my room neat in case she happens to see it! Mom, she's beautiful! Just wait until you meet her! You will love her!"

Steve was a junior in high school and Laurie a sophomore. A relationship began for them based on respect and love. Steve wasn't the only one to fall in love with Laurie. Paul and I did also. Steve graduated high school and started his first year in college. Within the first few weeks of school he began to have hip, back, and leg pain. Following multiple tests, Steve was diagnosed with chondrosarcoma, a cancer of the cartilage.

He received aggressive treatment for a year and went into remission. But the cancer came back twice more, and Steve passed away in July 1994. Laurie and her parents were with us every step of the way, and Paul and I will always cherish their love and friendship. Laurie continued for her master's degree, still very much our daughter.

One day, Laurie called and told us she wanted to bring someone to meet us. We loved Ryan immediately, and it was evident they cared for each other. Following graduation, a wedding date was announced. We met Ryan's parents, who are so sweet and willing to share their son with us and make us part of their family.

When the wedding day arrived, we were to be at the church early, as Laurie had asked me to assist her with her veil. Paul and I were pinned with corsage and boutonniere, escorted down the aisle, and seated. Steve was our only child, and how precious it was to Paul and me to be made a part of the wedding. A day that could have been so difficult was a blessing.

Ryan and Laurie are still very much our kids, and we now have two beautiful granddaughters who call us Grandpa and Grandma. We are blessed!



Sharing your emotions with your children helps them know someone else feels the same way. These talks can help you feel close to your children and quiet their wondering or worries.

- You can't be all things to all people. Some of the needs your children have can be taken care of by other trusted friends or family members. Others want to help; let them.
- Be patient with yourself and communicate to your children how you feel, not just about the child who died but about them, too.



# HELP YOUR CHILD GRIEVE WHILE YOU GRIEVE

# Christine, mother of Catie

No one can be all things to all people. As a mother, I tried. I knew my kids were hurting and they missed their sister, but we missed her in different ways.

In the beginning, I could have cried all day. I would hear a song, see a picture, or think of her, and the tears would fall without stopping. Many nights I cried myself to sleep wondering if the pain I felt would be my end. In that state, was it possible to support my other children? No, I had to allow myself time to grieve and mourn the loss of my daughter on my own first.

At first, I would allow myself to cry but would limit crying in front of the children. As time went on, I would explain to the children why I was crying. My reason was that I was sad and that I missed their sister because I love her and she was not with us any longer. I would also tell them that I was glad they were with me. I reassured them that I loved them and my sadness did not stop my love for them.

Children tend to live more in the present than adults do. Each of my children experienced and coped with their grief in different ways. One of them would name one of her dolls Catie and play with her. My son did not want to talk about Catie, while my youngest daughter would watch videos of Catie. But while the grief was difficult for each of my children, I realized that my children needed me during this time.

Once I realized that the other children really had a need for a mother, I had to figure out how to be the mother they needed. Just like when they were born, there was no book or owner's manual that explained what they needed or how I could take care of them. I had to listen to them. I had to hear them at their time, and I had to give them my time. They were not going to be visibly sad—they told me they were so happy that I was home with them. Their time of sadness was while I was away, and that is why they were happy, because I was there again to help them through whatever was bothering them.

My loss was different. I had never left our daughter. I became, through our journey, our daughter's nurse, roommate, cheerleader, playmate, and social secretary, and I remained her mother. When she died, I lost the most important life-and-death job I ever had—and I failed to keep our daughter alive. I had to accept this and accept that other aspects of life were valuable, though they might not be life-or-death related. This acceptance would take time.



- We still include James in all of our important family moments, such as holidays, family portraits and other celebrations. When we took family pictures a few months back, we held a picture of James in the photo. That way he is included in our family portrait.
- We talk about James daily and celebrate his birthdays as a family.



# INTRODUCING YOUR CHILD TO A NEW SIBLING

## Rebecca, mother of James

When James was 19 months old, we found out he had a rare form of kidney cancer. We were devastated, to say the least. After James' third birthday, he lost his battle with cancer. I remember thinking, "Our family is gone! How are we supposed to be a family without him?"

Six weeks after James passed away, my husband and I found out we were expecting another child. I had such mixed emotions. A part of me was thrilled to be a mom again, and another part just wanted my son back. I struggled with these emotions for a few months, but eventually I became very excited to meet our new baby. We welcomed Adeline Elise into our family 10 months after James passed away. I was overjoyed to have her in my arms.

My worry then turned to Adeline knowing her brother. How would she ever know what an amazing person he was and how special a child he was? I then realized it was up to me to help her get to know her brother.

As Adeline grew in age, I would show her pictures of James. Once she started learning to speak, I taught her how to say James' name. My husband and I talked to Adeline about James all the time. We would tell her stories, show her videos, and make sure she knew he was her big brother in heaven. When Adeline started playing with toys, we would bring some of James' toys out for her.

As Adeline turned two, she started asking questions about James. At first, I didn't know how to answer her questions. I told her James was very sick, and he had to go to heaven to get well. I also told her she could talk to him anytime, and he would hear her. I began taking Adeline to James' gravesite. She loved to visit her brother. She would sit down on his grave and talk to him. This was another way for her to get to know her brother. Even though she couldn't see him, she felt close to him when we visited. For James' birthdays, we bring a large bouquet of balloons to his gravesite. Adeline lets them go, and we sit and watch them fly away. Once they are gone beyond the clouds, Adeline says, "Mommy, James must have caught them." I love celebrating his birthday this way. We are still remembering how wonderful he was and how lucky we are to have had him in our lives.

Adeline is now 3½ years old. The worry about her loving her brother and knowing him is gone. Sometimes she becomes sad when she misses her brother. I hold her and tell her it is OK to miss him. I tell her how much I miss him as well, and that I get sad, too. I realize as I hold her that she does have a relationship with her brother. It has been 4 years since James left us, and I still feel as though he is a big part of our family and our everyday lives.



- Find ways that help both you and your other children honor the lost member of the family. Although the grieving process is unique to each person, finding a common way to remember someone can help you heal individually as well as create a new relationship with your other children.
- Know that children can grieve differently than you and other adults. Be conscious of the ways your other children are grieving and find ways to support them and love them during these times.



# WHEN A SIBLING BECOMES AN ONLY CHILD

# Maranda, mother of Brayden

There is no pain like having to hold your child as they leave this world without you. It is painful for everyone who loves your child. When my son died in September 2014, I tried so hard to block it out. I think I am still blocking out that pain. For a long time, I didn't want to leave the house. I worked from home and took care of my other little boy. I couldn't completely fall apart. I had my sweet little 4-year-old, Mason, to take care of. He was lost and didn't understand at all what had happened to his big brother, who was also his best friend. We all did everything together. One second we were together, and the next we came from the hospital without Brayden. Our hearts and lives were completely shattered and unrecognizable. Still, life had to go on. I wanted the best for Mason. I wanted his life to be positive and to have some semblance of normal.

What is normal? I know we all ask ourselves that, especially after the pediatric cancer monster enters our world. I think to me, normal was Mason getting to do all the things Brayden didn't. For me, it was Mason not living in a hospital and being able to go to school.

Mason started preschool in 2015. He had such a hard time that first month. He cried every day when I dropped him off. I cried so hard the first day, but I was so proud of him. He had his first day of school, something Brayden never got to do. Then, Mason got sick all of the time and missed a lot of preschool. After that, he started kindergarten, only to spend the whole year sick again. This time with stuff a little worse, he had *C. diff*, and something called reactive arthritis. The reactive arthritis caused him to scream in pain, and he couldn't walk. When he lost the ability to walk, I will admit, it took me back to when Brayden was diagnosed with brain cancer, and I immediately was horrified that it was happening again.

I think my first mistake was assuming there was a normal. I had forgotten, there really isn't a normal out there. There are just families trying to get through every day. Some days are so difficult, and some are so beautiful. We will always celebrate Brayden's birthday in heaven, and his birthday here on earth. We talk about Brayden and remember him all the time. Mason thinks Brayden was amazing and brave, and he is right. Mason decided to be brave just like his big brother, and it has helped him so much. We miss our Brayden, but we see him in many different ways—in a beautiful sunset, in the ocean waves, in the wind, and every so often I can hear him telling me to keep going. I will, Brayden. I will keep striving to be brave like you. We love you, always!



- Depression, sadness, and grief are just as much physical as mental.
   I had always thought of grief and sorrow as emotional experiences and didn't realize how real the physical symptoms are. I was surprised by my altered sense of taste and by the actual pain I felt in my chest.
- It is OK to find comfort in laying shared traditions to rest rather than forcing yourself to try to continue them. My brother and I created this tradition together, and he is no longer here to do it with me. Forcing myself to maintain the tradition without him is just not the same.



## **ADULT SIBLING**

## Quanita, sister of Bilal

I was walking through the ice-cream aisle of the grocery store about 2 months after my brother passed. I had avoided that aisle since Bilal died, because I did not want to see Ben & Jerry's Half-Baked, our favorite ice cream. However, on that day my heart yearned for one more movie night with Ben & Jerry's Half-Baked in my hand. I wanted to remember what it was like when we did it together.

Whenever Bilal or I had a rough day or just needed to relax and unwind after a long day, we would sit together with our own Ben & Jerry's Half-Baked pint in our hands and watch a movie. It was our little tradition. Bilal often bought 2 for himself. He would finish one while we decided what to watch (agreeing on which movie to watch often took a while), and then he would eat one during the movie. Bilal loved it so much that when he got his first paycheck from his first full-time job after high school, he came home with eight pints of Ben & Jerry's Half-Baked ice-cream! Four for each of us. We continued our tradition when I moved away for college. We would Skype one another and play the movie on our laptops simultaneously. When he went to St. Jude, we continued our tradition of movie nights via Skype and, when he was too sick to eat ice cream, I would forgo it as well. The last text on my phone from Bilal asked me to pick up some from the store on my way to the hospital.

As I stood in front of the Ben & Jerry's section of the grocery store that day, my mind raced through all the times we had enjoyed it together and all the times we had fought over who ate whose ice cream. I could feel my head spinning and my breathing becoming more and more labored. I knew I had to buy it quickly and get out of the store or else I would crash in the middle of the ice-cream aisle.

I bought the ice cream and barely held myself together during the 7-minute walk home. I cried as I mindlessly picked a movie because I couldn't fight with Bilal over which movie to watch. I started the movie and put one big spoonful of the ice cream in my mouth. Much to my surprise, I tasted nothing! I swallowed quickly and took another spoonful from deeper in the container and still tasted nothing. Had I just lost the ability to taste sugar? What was happening to me? Had the heavy crying altered my taste perception? Whatever it was, I knew I would never be able to eat Ben & Jerry's Half-Baked again. It will never taste the same. It then occurred to me that our tradition was over. As a farewell to our beautiful little tradition, I finished that pint of ice cream. I cried harder as I got close to the bottom of the container, realizing it was the last time I would ever eat it. I have not bought Ben & Jerry's Half-Baked since then. It is oddly comforting to have put our little tradition to rest rather than trying to continue it without him.



Spirituality is about connection. It is about feeling attached to something that feeds your spirit, adding depth and meaning to life.

A spiritual connection may be with God, with certain people, with a community, with nature, or with special rituals and practices.

## Seeds for the Soul

- Keep a few of your favorite and most encouraging Bible verses where you can see them. Maybe that's printed out on a bulletin board or on the visor of your car or saved on the home screen of your phone. Just keep them in a place you can be reminded of God's promises, when your faith is hit the hardest.
- Play some worship songs or hymns to help you feel more connected and in contact with God. They are often a great time to release some of the emotions He already understands.
- Look for God winks around you. If you keep your eyes open, you may see little reminders of your beautiful child. A butterfly. Their favorite color painted in the sky. Those are ways to personalize a big God, as one who cares about the things that bring you joy and comfort.



SEASON 2: RELATIONSHIPS

# SPIRITUAL CONNECTION

# Tasha, mother of Sydney

About 3 weeks before Sydney died, we were on a drive. We loved our drives. It was a crisp fall day. The sun was shining. The leaves were golden. We held hands and sang along with her favorite songs at the top of our lungs. After a bit, Sydney grew quiet. I looked over at her and spotted a smirk on her beautiful face. When I asked what the smirk was all about, her reply broke my heart and made me thankful, all at the same time.

"I'm just so ready to go home whenever God wants me," she said with a smile. When I asked her if she thought that would be soon, she told me she did. When I asked if she was afraid, she answered, "Oh no. I just know it will be so peaceful there." It was then that she asked this momma to do what seemed an impossible task. She asked me to pray that if God didn't heal her "all of the way" here, she wanted Him to take her home soon.

Later that night as I tucked her into bed, we had another conversation. This time, I told her that although momma and daddy were always there for her, she might be experiencing things that had no earthly words to describe. There were moments when she looked beyond us. Moments when we felt her escape this earth. I told her that in those moments, if she couldn't explain it to us, to remember that God was always there for her.

The smile that lit up her face in that instant, almost blinded me. "I know!" she said. "You know when I pray all of the time? Well, He's right here." "Right here" was beside her where she pointed.

I sat in awe and asked what God looked like. Sydney answered, "I haven't gotten to His face yet. But He holds my hand, and hugs my neck and He whispers in my ear."

All of these years later, I still have difficult days. I'm always aware that a part of me is missing. But I learned so much from my girl, and on those really dark days, I reach out to the One who sits beside me. I pray. And maybe I don't visually see His body there next to me, but I definitely feel Him all around—holding my hand, hugging my neck—and I hear His whispers of love in my heart. That same God is carrying me through my grief and beyond.



- A legacy is something that is left behind as an inheritance or a gift to others. What has your child left as their legacy? In what ways can you carry that legacy forward?
- Honoring your child's legacy might feel extremely overwhelming when you are grieving. Consider that honoring your child's legacy today might be something as simple as getting out of bed.



## **LEGACY**

# Wendy, mother of Nick

When I decided to sign up for the St. Jude Memphis Half Marathon, I knew it would be challenging for this 54-year-old, non-running grandma. I battled through wake-you-up-in-the-middle-of-the-night pain, wicked shin splints, and serious doubt.

The reason I decided to run in the first place was for my son, Nick. It had been an entire decade since he left us for heaven, and I wanted to do something meaningful to remember and honor his life. Raising money to support childhood cancer treatment and research was just the way to do that. I figured it would be emotional training for this specific half marathon, but I had no idea that I would spend many times running in tears. Not because of pain but because I miss my boy or I want my mom or I remember so many other children who have suffered.

Sometimes I wonder why I know so many children who have died. The weight of their memories is not something I take lightly. Some I have known in this life. Some I was not able to meet this side of heaven but have come to know well through their surviving family members. Each one of them has had a part to play in making me into the person I have become.

Several months before the race, I wondered if there was a way, on race day, that I could remember all of these dear children along with the ones who have survived. I decided I would create a race day T-shirt and on that shirt, I would sew ribbons: white for those now gone and gold for the survivors. Each ribbon would bear the name of a specific person who has personally impacted my life. Just a few days before the race, I finished sewing the last of 93 ribbons onto my shirt.

Aside from the 6 months of physical training I went through, there was another side to the preparations that took no physical effort at all. In fact, it only required me to sit still and think. As I carefully sewed each name onto my shirt, I saw their faces and remembered. I gave thanks to God for those who have survived. I mourned again for those who have not. Many times a vivid memory came to mind. Sometimes, I could hear their laughter.

This shirt does not physically weigh much at all, and yet it carries the weight of the world–countless moments, weeks, and years of sickness, suffering, and sometimes profound loss for each name represented and for their families. The loss may not even be death itself but the loss of a limb or the loss of a future dream or the loss of that "before cancer" innocence.

And with each mile I ran, I was privileged to carry each of these dear ones with me.

# **SEASON 3:** MILESTONES 50

As you move through life after the loss of your child, you will encounter markers or milestones that may represent shattered dreams and hopes for a future with your child. Some of the milestones will be expected, and some may take you by surprise, but they will all cause you to ache for your child. Know that you are allowed to experience good things without leaving your child behind.

## Questions for Reflection

- What milestones are especially meaningful to me?
- In what ways would I like to honor my child as I experience milestones?
- Who should be involved in honoring my child's milestones?



- Find a special way to remember your child: planting a garden or a tree, or some other ritual that brings peace and healing to your heart.
- There is hope that each year does become more bearable, but we are never the same people we were before our child's death.



# ANNIVERSARY OF THE DEATH OF YOUR CHILD

# Nancy, mother of Matt

The first anniversary of Matt's death was in the spring of 2009. I had been dreading this day for several weeks and found myself reliving the last weeks of his life, detail by detail. It was surreal, and it felt just like the time before he died. I found myself yearning to touch and hold him again—just to kiss his sweet face and tell him how much I loved him.

I vaguely remember people calling me or seeing me in town saying all those dreaded words: "He is in a better place now," "At least you had him for 25 years," "You need to move on with your life," and "At least he is no longer suffering." It became clear to me that they could not possibly understand the loss, sorrow, and pain that I was feeling. You never get over your child's death; it just becomes more bearable with time.

As more anniversaries passed, I did not find myself crying as much, and I was actually able to think about Matt and some of the positive memories that meant so much to me during his life. The pain and hole in my heart was still there, but I was going through life's toughest journey and beginning to heal. I was able to see a ray of hope that I was going to make it. The flowers began to look pretty again, and the sky was beautiful.

Each year since his death, I plant a special tree to honor the life, strength, courage, and joy that he brought and continues to bring to my life. I often visit the trees and feel his presence close to my heart.



- Find the way that works best for your family to honor your child's legacy each year on his or her birthday, in a way that is most healing for you and your family, such as picking a family ritual that you will do each year to celebrate your child's birth and precious life.
- Talking about your child and telling stories surrounding their birthday can help you remember the special relationship you have with your child.



# ANNIVERSARY OF YOUR CHILD'S BIRTHDAY

# Nancy, mother of Matt

For most families, birthdays are a celebration of one of life's most precious gifts: the birth of our dear children. Matthew used to take birthdays to the extreme. He would celebrate the whole week of his birthday. Although his grandparents and cousins lived far away, our immediate family shared in the joy of his enthusiasm with each yearly celebration.

Matt did not talk to me much about dying when he was sick with his brain tumor. However, he once asked me to promise to have a birthday cake and sing "Happy Birthday" each year in his memory.

The first birthday after his death was like a blur. I certainly did not feel much like celebrating. The pain and deep hole in my heart were unbearable. I went to the local Dairy Queen to get an ice cream cake (this was his favorite!). When I got into the car, I was in tears. The cake said "Happy Birthday Matt," and all I could think of was that I wanted him back to celebrate this special day, personally.

His sister and brother came over that night. We sat in silence for quite some time. It still seemed surreal that Matt was not there to celebrate with us. All of a sudden, I felt a "wind of strength" across my face, and I began to tell stories about some of Matt's birthday celebrations when he was little. In turn, my two children and husband did the same. We were able to laugh about some of the stories. We then sang "Happy Birthday." I could hardly get through the words, but I did it. When we blew out the candles, the moment of the joy from the lights on the cake turned to a deep sense of loss and sadness.

The second year after his death, his birthday celebration was slightly more bearable. I went to Dairy Queen, told stories about Matt, sang "Happy Birthday," and then blew out the candles. I began to feel a sense of peace knowing that Matt would always be there in spirit with us each year as we continued to celebrate his birthday and honor his legacy.

I now understand that although I do not have a physical relationship with Matt, I will always have a spiritual one.

He continues to be close to my heart, and I will always keep his promise and remember this special day. His birth was the happiest day of my life, and I will always cherish that moment. I continue to be on a new journey in my life and continue, after 5½ years, to figure out what the "new norm" is for our family.



- Be proactive. Make a plan. Know what day is the first day of school and plan something special for yourself. Take yourself out to breakfast, take the day off and sleep in, go to the gym or spend the morning with a friend.
- I personally watch the kids get on the bus and offer a prayer.

  Cancer—although it took my sweet 7-year-old daughter—affects only one in every 330 children, so most children will have an average of 18 first days of school in their healthy lives, and if they study hard, one of them will grow up and find a cure for cancer.



# **BACK TO SCHOOL**

# Christine, mother of Catie

Everyone knows that the beginning of anything new is filled with many emotions—hopes and dreams as well as fears and anxieties. The beginning of school is no different. Whether you loved school as a child or were not much of a fan, there was always a day to go back. Thanks to today's retailers, you can't miss this time of year. Enormous pencils are hung from store ceilings. Displays are filled with notebooks and paper, pens and pencils, glue sticks, and crayons at office-supply stores, grocery stores, and the we-sell-everything stores like Target and Walmart. Summer ends, and the first day of school comes each year, whether we are ready or not.

When our children aren't old enough to go to school, we wait and hope they will be ready when the time comes. When the children are old enough there are many decisions to be made, from which school your child will attend to what they will wear. How will they get to school? Will they have the right supplies? Who will be their teacher? Will they be in the same class as their friends? And, most importantly, will they be happy?

All this getting ready can be so much fun or so much work. What does this time of year mean to a parent who has lost a child to cancer? That child will be missing from the first-day-of-school photo. There will be no picking out that first-day-of-school outfit, selecting the perfect backpack, or listening to their hopes and dreams. That child will miss out, and so will you, as their parent.

If there are no other children in the house and you are at home, your home can become too quiet. If you go to work, you will pass and possibly be stopped by a school bus on your way to work.

Each of these opportunities will pull on your heart strings.



- If it is something that would be helpful to you, talk to your child's school about finding a way to commemorate your child at his or her graduation ceremony.
- If it is better for you to stay home and not attend the graduation ceremony, that is also OK. This is a time to do what is best for you.



# **GRADUATION FROM HIGH SCHOOL**

# Wendy, mother of Nick

My son, Nick, died just 3 days before his sophomore year of high school was to begin. My children attended a small private school, and Nick's 20 classmates were more like his siblings. Those first years of our grief were also filled with other kinds of firsts for Nick's friends. One by one, each of them got a driver's license. They attended their first prom. And each one was excited to share the joy of those moments with me by showing off their brand new licenses and their beautiful new prom dresses.

It was a bittersweet time for me. I truly wanted to be happy for the dear friends who had been such a special part of Nick's life. Don't get me wrong—I was so glad that I could share in these momentous occasions with each and every one of them. But I also felt the gut-wrenching stab of sorrow, as each milestone was a reminder of what was supposed to be and now would never happen for my son.

As time ticked away and 2 long years passed without Nick, his friends got closer and closer to graduating from high school. One day they asked if I could meet with them during their study-hall period. I agreed. When we met, I could tell they were having a hard time expressing what they wanted to ask me. They wanted to know if it would be OK to leave an empty seat at graduation where Nick would have been sitting, and they wanted me to speak to them at the graduation ceremony.

That was one of the most difficult things I have had to do. But I did it. I took the microphone, and with my back to the audience I faced Nick's friends, now young adults ready to face the world. The empty chair in the first row seemed so... empty.

At that moment I could not have anticipated the impact my presence would have. Several weeks later, I received a letter from an older sister of one of Nick's friends. She told me that when she was a freshman in high school she had lost a friend in a car accident. She went on to say that her friend's parents were so consumed with their grief that they could not face their son's friends ever again. She told me that when her friend died, she wanted so badly to be with his parents, to cry together, laugh together, and tell stories together. But it didn't happen. And, she felt like she not only grieved the loss of her friend but also the family she had been so close to for so long. It was then that I realized the value of presence. Most of the time there are no words, but your presence can make all the difference.

You may have had to face, or will face in the future, the high school or college graduations of your child's friends. It is a landmark moment in their lives and also for you. Do what feels right for you.



- Be present with your feelings of sadness and loss in relation to never seeing your child graduate from college.
- Think about the conversations you had with your child about their dreams and aspirations and remember all of their accomplishments while they were alive.



# **GRADUATION FROM COLLEGE**

## Bill, father of Matt

From the time my son was born, I often thought about what he might choose for a career when he grew up. Matt was a young adult when he died. He was always gregarious and loved animals. He loved to socialize, and college would have been such a wonderful experience for him. After all, these are some of the best years of a person's life.

In the spring, many families are getting ready for the graduation of their sons or daughters from college. There are many celebrations and excitement about the future. I often wonder what it would have felt like to watch my son walk across that stage to receive his college diploma. I still yearn to have experienced his excitement as he entered into a new chapter in his life.

What would Matt be doing now? Would he be a marine biologist, physician, lawyer, or something else? I know that whatever Matt would have chosen to do, he would have done it with tremendous passion. I would have been very proud of him and can envision the smile that would be on his face. Most importantly, as long as he was happy, I would have been happy, too. After all, isn't happiness the most important thing we should wish for our children?

Although I still keep in touch with many of Matt's high school and college friends, I have to admit it is hard to see them continuing to grow as adults and succeed in their individual careers. I know Matt would have wanted to experience a "first job" too. Now I can only wonder what this experience might have felt like for him.



- Continue to talk about your child, through stories and photographs, for the benefit of your new child.
- You will love the new baby differently, and this child is never meant to replace the child you have lost.



# **HAVING A NEW BABY**

## Keith, father of Josh

The feelings of having a new addition to the family are so powerful! My daughter Ashlyn and son Ethan are very excited. Excited enough to agree to not get any Christmas presents this year, because our baby will be here 2 days before. That should be enough of a gift. Well, we would not do that to them, but it's nice to see them so agreeable.

I am extremely happy about having a baby. I do, however, know that Josh will not physically be here to meet him when he arrives. Granted, they would have been 21 years apart, but I know for a fact that he would've been a great big brother. Why not? He was for Ethan and Ashlyn. In honor of Josh, I would like to give our baby the middle name of Joshua. I think that would be great, and I think Josh will love that as well.

Still, the thoughts do occur. What kind of relationship would they have had? What would it be like? What will this child learn from Josh? I know Josh would "brother-sit" anytime we asked him. Josh absolutely loves children. When he was in the middle of his treatments at St. Jude, he asked a few times, "Will I be able to have kids?" That right there says it all. The love he has for his brother Conner, who is his mom's and stepfather's child, and Ethan and Ashlyn, was very deep and still is.

Our family will never be complete. There will always be that empty spot without Josh here. Having another child does not complete this circle we have, but I know Josh is always with us. Spiritually, we have our complete family, and that's all we need.

SEASON 3: MILESTONES



- Make a scrapbook or special memory box filled with photos and other things that represent your child who died. Give it as a gift to your grandchild, and when he or she is old enough to understand, look at it together and tell them about their aunt or uncle.
- If your child who died was your only child, then you are facing an
  additional grief, the loss of being a grandparent one day. Consider
  volunteering your time as a foster grandparent to a child in need for
  organizations such as AmeriCorps or the American Association of
  Retired Persons (AARP). So many children could benefit from what
  you have to offer.



# **BIRTH OF A GRANDCHILD**

# Wendy, Mother of Nick

One after another, my family has experienced the deaths of many of our dear loved ones in a very short time. My 25-year-old nephew. My dad. My 15½-year-old son. My sister. My mom. And my brother... all in a little more than one decade.

During those same years, my oldest son and daughter both graduated from high school, and then from college. Both got married, and five years later my oldest son was divorced. To suffer so much loss and change in such a short amount of time leaves my head spinning.

When I was beginning to think that things were only going from bad to worse, we got some unexpected news just a month after my brother died. My daughter and her husband were expecting their first baby! As I write this, my first grandchild, a girl, is due to arrive into the world in just 3 weeks.

As I look forward to the birth of my granddaughter, there is an ever-present reality that she will never know her Uncle Nick, and that I will never get to experience the joy of watching Nick get married or be a father himself. I am filled with great joy and anticipation and at the same time with such sadness. But isn't that the way life is after the loss of a child? So many great memories are now bittersweet—laughter and joy mingled with tears and sadness.

My mom had a brother who died when he was young. I never knew my Uncle O'Neil. But because my mom shared so many stories about her brother throughout my lifetime, I feel like I did know him. We, too, will tell stories and share photos, and my granddaughter will know her Uncle Nick.



- Consider making a scrapbook of the important times in your child's life as a way to remember and honor his or her legacy.
- Allow yourself to feel mixed emotions when you see others
  having children and grandchildren. This is a normal part of the
  grief process.
- Remember, you will never forget your child. Continue to talk about your child and tell the stories that are most important.



# **NEVER HAVING GRANDCHILDREN**

# Nancy, mother of Matt

Matt was in the prime of his life when he died at the age of 25. He had only been married for 6 months prior to his death and did not live long enough to have children. When Matt was a little boy, I dreamed about being a grandmother and knew that I would love his children, just as I loved Matt so much. After all, isn't that what every parent wishes for their children?

Many of his friends are now having children, and it is bittersweet for me. Although I am happy that their lives have moved forward, at times mine still feels like it is in a holding pattern. What joy I would have experienced to have a little piece of my son still alive to hold onto and cuddle with. There are so many funny stories about Matt that I would have liked to tell his children. I wonder if his children would have looked like him and had similar mannerisms. Would his child have had his larger-than-life personality? What would his child have grown up to become?

I could picture Matt's beautiful smile as I watched his children grow up. Most importantly, I would have been able to see his children grow up to be wonderful, loving, and compassionate young adults like Matt. Sadly, I will never experience any of these wonderful moments as many of my friends have done.

I realize that I have to find another way to continue Matt's legacy, since he has no children. What will this look like? I never want to forget him. A child would have reminded me of him every day. So many intense emotions.

SEASON 3: MILESTONES



- Give yourself permission not to attend a wedding early in your grief journey.
- Normalize the feeling of being happy for the couples at weddings you will attend, and at the same time, acknowledging the loss for your family.
- In addition to a wedding gift, consider making a donation in the couple's honor to a charity of your choice.



## WEDDING

## Bill, father of Matt

There is a picture that sits on my desk. At first glance, it looks like many photographs taken at weddings. It is a picture of my wife, Nancy, smiling proudly as she dances with our son, Matt, on his wedding day. If you look closely, you can see the scar on Matt's head, and that is when you notice her eyes. Nancy's eyes tell a story that only a mother's eyes can, for she both shows how precious a moment this is and at the same time, knows that precious moments are slipping away.

Matt was a newlywed when he died. His brain tumor, which had been in remission for many months, had returned shortly before his wedding day. He and his fiancée had decided to proceed with their wedding, not knowing what the future might bring. They had begun dating the year before Matt went off to college. After his freshman year and the discovery of his brain tumor, they were together for multiple brain surgeries, radiation treatments, and chemotherapy. Obviously, they had not planned for any of this, but they were in love and wanted to be married.

A wedding can be a tremendous undertaking in the best of situations, but it took on a new meaning given their circumstances. Being married meant a great deal to Matt. In 2008, Matt got married on a beautiful summer day in Maine. He and his wife were able to be together for several months before his death.

I have attended several weddings since Matt died. Initially, they were quite bittersweet. Many involved Matt's close friends and classmates. Sometimes it hurt when they spoke of their future lives together, the excitement of starting a family, and all of the things that should be so exciting at this point in their lives. I was torn between being happy for the new couples and at the same time, sad that Matt did not get to experience this.

Time is slowly healing my grief. I think more often now of the opportunities that his wedding allowed us to share. It was an honor to give a toast while he was alive so I could tell him just how proud I was of him, what an inspiration he had been to me, and how many lives he had touched during his journey. Most importantly, it allowed me to tell him just how much I loved him.

I remember these things at weddings now. They are the celebration of two lives, no matter what the future may bring. That is what Matt would have wanted me to remember.



Loving someone is a choice that can stay with you forever.
 There is always a risk of hurt when we choose to love. Trust that the reward will always be greater and choose love. Even hurt can teach you something.



# **AS TIME PASSES**

# Christine, mother of Catie

When our daughter died she was just a little girl, 7 years old. So sweet and so innocent, the age when parents are still heroes, tears are kissed away and every day is filled with the words "let's pretend." We thought our hearts would break watching our other kids grow up without their sister. We were determined not to allow our grief, sadness, or longing for Catie to cause us to miss the childhood of the other kids.

Each year there were fewer tears shed by each of us. Each year more joy filled our house. Each year we grew more comfortable talking about Catie and sharing stories with the kids who were too little to remember their sister.

We found ourselves in a place we all came to know and accept as safe and secure in regards to Catie and her memories. That all changed one day when the calendar turned and we were all taken by surprise. November 2 was just a day, but for us it was a milestone. It was the day that Catie had been gone longer than she was here. How was that possible? How? Why? All the questions that time had stopped now resurfaced and were once again repeatedly being asked.

All the healing, was it lost? All the pain was new again and yet familiar. This time it would not stay with me as long, but it was as real and difficult as the first time, and I had no idea it was coming. This day didn't affect only me; it also had an impact on all of us. While this day took me by surprise it also prepared me for Catie's next birthday, which would be her Sweet 16!

Each day that passes we miss something, but we learn something about ourselves, too. We will never get over and finish missing Catie. It is a part of our lives forever. Each moment of pain we go through is just that—a moment of pain. Each moment of pain is another sign that we love and miss our sweet girl. That is why my favorite quote about loss and grief is:

"All the art of living lies in the fine mingling of letting on and holding on." Havelock Ellis



Anticipating a special holiday, anniversary date, or birthday can sometimes be more stressful than the actual day. Don't be afraid to be honest and express your sadness over missing your child. Also, don't be afraid to laugh and share great memories. These are all normal feelings that will come and go, just as the seasons do.

We encourage you to find the things that are right for you and your family to do. You might want to hold on to some of your traditions or let some go and start new ones. Get rid of the things that increase your stress. Get more rest and take extra time for yourself—you will need it. Plan ahead and find ways to include and remember your child on these special occasions. And finally, hold fast to those who are most precious to you. Remember that they, too, are missing your child.

#### Questions for Reflection

- How have holidays changed? Have any aspects stayed the same?
- What are helpful ways that I can anticipate holidays?
- What holidays are helpful for my grief? What holidays may be harmful for my healing?



- Give yourself a break. Vacations are like everything else after the death of your child: You need to figure them out and see what works best for you.
- Share the vacation with your child. Tell him or her what you like best or what you think your child would most enjoy.



## **VACATIONS**

## Kevin, father of Catie

When most people think of vacations, they think about getting away from it all. Going somewhere where the day-to-day of their normal lives is replaced by something entirely different. A vacation is equivalent to an escape for many.

To a bereaved parent, escape can seem like a pretty good idea at times. Yet escaping the reality of having lost a child is not easy and carries with it the added guilt of having a good time without your child. A vacation—doing anything fun, exciting, happy—is somehow not consistent with mourning. In addition, vacationing takes us out of the supportive environment where we do not have to tell the story of our child to a place where normal questions like, "So, do you have any children?" or "How many children do you have?" can lead to pain.

Vacations can also dredge up memories if you are returning to a vacation spot you used to frequent with your child or separation anxiety if you are going to a destination your child never experienced.

The reality is that vacations, like holidays, anniversaries, etc., can be challenging. Being aware of the potential pitfalls will prepare you for most of the feelings that may come your way. Vacations are not, in fact, escapes from reality; they are your reality in a different ZIP code. Remember to take care of yourself, remember that it is OK to have fun, and most of all remember to honor your child by loving those that he or she loved the most–yourself!



- Try to focus away from all the death-related parts of Halloween to the more light-hearted traditions such as pumpkin carving, scarecrows, mice, cats, and similar observances.
- For some Christian denominations, if Halloween is too difficult or you choose not to celebrate this holiday, you may consider celebrating your child's life on All Saints Day, which is the first Sunday after Halloween.



# **HALLOWEEN**

## Lisa, mother of Thomas

For our family, Halloween was always a significant holiday. It had always been a favorite of mine as a child, and I definitely encouraged the boys to enjoy all aspects of the holiday. The boys ordered costumes months before Halloween and wore them many times before the actual holiday. We had parties and celebrations many times in the weeks leading up to Halloween.

What was once an enjoyable time of festivities became very complicated by many issues, most notably the closeness of Thomas' passing to the holiday. Before he died, he had selected a costume for that year's Halloween celebration, and I ordered it as a show of faith that he would, indeed, be able to wear it. The costume came while he was in the ICU, and he never actually got to see it. Of course, when Halloween rolled around 3 weeks later we had 2 other children we needed to continue to make memories with, but our grief was so raw. The costume itself was large enough for me to wear that Halloween, so although we didn't feel much like celebrating, we were able to have some semblance of a traditional Halloween while still honoring Thomas. It was difficult but had some qualities of healing.

The second layer of difficulty in the celebration of Halloween is the fact that the whole holiday is centered on death. After losing Thomas, I found it quite difficult to be confronted by gravestones, skeletons, zombies, and all the markers of death while still trying to deal with the death of my child. It seemed like everyone else was celebrating something that was our biggest nightmare.



- Take the time in the days leading up to Thanksgiving to think about some blessings in your life. Think about a wonderful memory of your child as well as one positive thing that has happened recently. It doesn't matter how small the blessing is; it is about looking for and finding something positive to celebrate.
- Make a point of doing one thing in memory of your child for someone else for Thanksgiving. Donate a turkey to a food bank in your child's name or spend an hour feeding the homeless and look for an opportunity to tell someone you help about your child.



## **THANKSGIVING**

## Kevin, father of Catie

Thanksgiving is a uniquely American holiday when we stop as a people and count our blessings. For parents who have had a child battling cancer and who have lost that child to the disease, blessings seem harder to count, as they are somehow harder to find. For Thanksgiving in 2008, we were gathering as a family in Memphis to celebrate. Unfortunately, on Tuesday as family began to arrive, we learned that Catie's tumor was back and that treatment would be suspended. The doctors simply told us to cherish the time we had left. Counting blessings that Thanksgiving was a difficult task. Thanksgivings since then have been reminders of that Thanksgiving, and as a result, they could have been tainted.

As with most milestones and life in general, attitude, perspective, and choice can make all the difference in the world. Birthdays, holidays, anniversaries, and in this case, Thanksgiving provide us, the parents of a child who has preceded us in death, with opportunities to celebrate our child's life rather than her death. Rather than marking Thanksgiving with mourning and sorrow in the knowledge that our child is no longer physically with us, we have marked this holiday with remembrances of Catie's life and the joy she brought to us in the short time she was here. In addition, we have made a point to celebrate with those around us, choosing to look at the blessings of those still with us.

Thanksgiving will always be a day where I shed a tear or two in remembrance of Catie and the Thanksgiving we spent in Memphis, but it will also always be a day when I count the many blessings still in my life, when I cherish the people around me. It will also be a day when I count among my blessings St. Jude and their tireless efforts to work toward a day when no parent ever has to face what we face today. Choosing to look hard to find the blessings on Thanksgiving is a way I can honor Catie and her life.



- Many families hang stockings on the fireplace during Christmas. If you are
  having difficulty thinking of hanging the stocking of your child who died
  or seeing it empty on Christmas morning, consider filling it with things
  your child would have loved, such as movies, music, or gift cards. Give
  these things as gifts to each other or share them together.
- Adopt a child or family at Christmas in your child's memory. Consider giving gifts and food to others in need.



# **CHRISTMAS**

## Bill, father of Matt

The holidays can be very difficult after the loss of a child. We, as parents, struggle with our own raw grief during a holiday such as Christmas. Yet, we often feel we must "carry on" for the sake of our child's siblings, family members, and friends.

We put our own emotions aside and often feel isolated during the celebration of the holidays. I remember thinking, "How could this be such a joyous occasion when such a terrible thing has happened to us?" There is no simple answer to this question. As the years have passed, I have learned to understand that these feelings are normal, and I have slowly again begun to appreciate the spirit of Christmas.

I recently read a story I found quite helpful. The family of a young boy with a brain tumor had been told this past October that he probably only had a few weeks to live. The child wanted to spend Christmas at home but probably would not live long enough to see the holiday. Members of his community found out about his wish, and when the child flew home to the small city where he lived, the gazebo and trees in the town were covered with Christmas lights. People in his hometown piled shaved ice against the child's apartment for snow. Hundreds of people, some in Santa hats, showed up on motorcycles.

The young child was able to enjoy this through his window, and he was able to pass many of the gifts that he received on to those in need. His classmates also came to visit him. He passed away before Thanksgiving, just 2 weeks after returning to his hometown.

It is important that we embrace this spirit during the holidays. I have learned to give myself time to heal. It is true that Christmas will never be the same. In our home, we started a tradition of keeping a small Christmas tree up all year, filled with Matt's favorite ornaments. This has allowed us to celebrate the spirit of Christmas and Matt throughout the year.



- Get a New Year's noisemaker and at midnight, make so much noise with it that your child hears it.
- Make a New Year's resolution that you will do something special for yourself each day to take care of yourself in honor of your child.



# **A NEW YEAR**

## Kevin, father of Catie

For many people, New Year's Eve and the beginning of a new year marks a fresh start. New Year's resolutions, new diets, and a general sense of putting away the old, starting anew, and replacing old habits with new ones are all hallmarks of this holiday. For parents who have lost a child, New Year's can be a heart-wrenching time of marking yet another milestone celebrated without their child. Like birthdays and anniversaries, a new year can be another stark reminder of the hole left in our lives, hearts, and homes.

However, because New Year's embodies a sense of renewal and change, it can also provide an opportunity for parents, grandparents, and siblings to begin to grow beyond the loss and grief and begin to see the hope of a new existence beyond the child's loss. New Year's can delineate a point in time where grief begins to become a motivation for change and growth. A specific date on a calendar can provide the impetus to move from mourning a death to honoring a life.

Catie died January 25, 2009, so the last New Year's with Catie was tainted by the last days of her battle with cancer. The next New Year's was almost a year removed from her death but provided us with a specific opportunity to begin to look ahead. The New Year's since have not been the raucous, joyous occasions immortalized by Dick Clark, but we have managed to make each year since Catie's passing more and more of a celebration by focusing on those around us and honoring Catie by moving forward with the passing of time.

We honor Catie with each choice we make to look to the future rather than the past. Every time we offer a smile to a child facing the battle Catie lost, every time we speak at a fundraiser and tell the people who are supporting St. Jude to keep doing it so that the Caties of the world stop dying, and every time we show our sadness instead of hiding it from the people we love, we honor our daughter and what she endured.

We make her sacrifice meaningful rather than meaningless, because we tell her story and try to make the ending better for the next kid.



- Some traditions are harder to keep than others. Keep the ones that are easier to keep and let go of the ones that feel unbearable.
- Words can't describe the unique emotional experience of feeling both joy and sorrow at the same time. It may take a while, but allow your heart to experience it without any interference from your brain.



# THE FIRST EID

## Quanita, sister of Bilal

As the month of Ramadan was coming to an end, I was dreading the final day of celebration, Eid. It was our family tradition to get ready in the morning and take a family photo before heading to the mosque for the service. How could we take a family photo without Bilal?

The morning of Eid, Mom and I went through the motions of our usual traditions. We had a nice breakfast, put on new clothes, and got ready to go to the mosque. We were both aware of skipping the ritual of taking a family photo before leaving for the mosque, but neither one of us said anything. I was relieved that mom didn't bring up the family photo, and I can only assume she was, too.

After spending the morning at the mosque, we came home. Mom made traditional Eid food, and we ate together in silence while watching TV. Then, the phone calls started coming. Our family from around the world were calling us to say Eid greetings. Some family members who called us from the other side of the globe had stayed up very late or awakened very early to be able to call us on the day of celebration to talk to us.

After a few hours of phone calls, and just as we were getting ready to call it a day and be done with it, the doorbell rang. I answered the door and my face lit up with a smile as my eyes teared up. My aunt's family had driven 10 hours from California to visit on the day of the celebration, so we wouldn't be alone. They had left right after the prayer and spent most of Eid traveling just to be able to end the day with us. They wanted us to all be together for whatever little bit of this special day remained.

While our hearts ached for Bilal, I couldn't help but feel grateful for the outpouring of love from everyone. The Eid ended up being the happiest while also the saddest one yet. It was a unique experience to be able to feel 2 very strong and opposite emotions at the same time.



- Feel free to choose ways that are helpful to you and your family to remember your child.
- Allow yourself permission not to visit the grave if it is too difficult.
- For some, visiting the grave may be very comforting.
- Allow family members a choice on what is best for them—choosing or not choosing to visit the gravesite.



## **EASTER**

# Ed, father of Thomas

Easter is a bittersweet time for our family. Thomas loved Easter. I remember so many times of egg painting and hunting, and the sheer joy on his face as he ran around looking for them. Those memories make me both smile and cry.

For me, Easter also brings a time of hope. In the Christian tradition, the Easter story is an account of how God overcomes death, provides eternal life, and prepares a home for his children. I love the word "home." As a child of God, Thomas closed his eyes in this world but opened them at home. No matter how heavy my grief, I am always comforted knowing he is home, safe in the arms of Jesus.

One time, I went by Thomas' grave. I have to admit that I had only gone to his grave a few times since his death. It is too hard to bear. Sometimes I get such a longing that I have to go by just to be closer to him. As I squatted next to his grave, through the tears I noticed a small baseball bat someone placed there, perhaps an angel.

It was heartbreaking to see the grass had covered his grave. It hit me hard knowing so much time had passed since he was with us. My life seems like a mess sometimes, trying to manage family, life, and an ever-present grief. Those walking this path know what I mean. At times it can be overwhelming.

Standing beside the grave I noticed I was alone at the cemetery. The cars sped by on the interstate, and life continued to go on. Where were they all going? It seems this world can get us twisted in so many directions. Up seems down, down seems sideways, forward turns out backwards. The grass-covered grave is but a doorway through which we must all walk.

In Ecclesiastes, King Solomon wrote, "Better to spend your time at funerals than at parties. After all, everyone dies, so the living should take this to heart. Sorrow is better than laughter, for sadness has a refining influence on us." A wise person thinks a lot about death.



- If you are not able be in the celebratory mood on the actual date of Mother's Day and your mother or mother-in-law is still living, discuss possibly choosing another day close to Mother's Day to celebrate your relationship with them. A simple explanation is all that is needed, and a less emotionally charged day is best for everyone.
- If you lost your only child, you continue always to be a mother. It's important to find the best way to be present with your feelings on Mother's Day.



# **MOTHER'S DAY**

# Lisa, mother of Thomas

Mother's Day is charged with many emotions once a mom has lost a child. No matter what your plans might be, it continues to remind you of the change in your role as a mom.

Mother's Day concentrates our thinking on what it means to be a mom, how that role is defined, and what it means for now and in the future. For myself, it was difficult to deal with the increased awareness of loss that the day brought while still trying to enjoy the children who remained. The physical relationship with one of my sons was missing, but his brothers still needed to celebrate the relationship I had with them, and I needed that also. Still, it was hard to get one less hand-drawn picture or homemade card, one less hug. I found that my mind so easily focused on what wasn't there, and I had to make an effort to remind myself of the blessings of my other children.

Also, it was difficult to be the person in charge of making sure my own mother and mother-in-law had a special day. In the years before I lost my son, I was the one who cooked meals for them or planned outings to honor them. After my loss, however, I found myself unable to fulfill that role. I needed space and freedom to attend to my own loss and concentrate on my remaining children.

With time, all these mixed feelings have become easier to manage, but I think Mother's Day will always be a day of very conflicting emotions.



- If you are not able to be in the celebratory mood on the actual date of Father's Day and your father or father-in-law is still living, discuss possibly choosing another day close to Father's Day to celebrate your relationship with them. A simple explanation is all that is needed, and a less emotionally charged day is best for everyone.
- If you lost your only child, you continue always to be a father. It's important to find the best way to be present with your feelings on Father's Day.
- You may consider finding another way to celebrate Father's Day that will honor your child's legacy.
- Pick an activity that you and your child used to do and do it on Father's Day. If you used to read to your child, take out a special book, sit down and read it aloud, and allow yourself to feel your child's presence with you.
- If you have other children, take the time to focus on being their dad on Father's Day.



# **FATHER'S DAY**

# Keith, father of Josh

For me, it has not been the same since Josh passed away. This is the one day we would set aside for just him and me to spend together. It didn't have to be anything extraordinary, just as long as we were together. Being a father to him was enough of a privilege in itself.

The first Father's Day without him was only 4 days after he passed away in June 2007. We had gotten home from St. Jude June 5. That day, I still had it in my mind that I was to pick him up in the morning from his mom, Kathy. That was our tradition. Now, I had to change that. I was very emotional that day, and all I could think of were the things we did the year before and other years on this day. I felt empty and really did not want Father's Day at all. I was hoping it could be just another day.

I have 2 other children, Ethan and Ashlyn. They tried to make it a special day for me. All I could do was play along and pretend I was happy. As the day went on, I did find myself focusing on these 2 beautiful children and my wife, Jodi. As difficult as it was, I managed to gather the energy, spend this day with them, and actually have fun doing it.

Father's Day will never be the same without my son Josh here, but I know that he is with me especially on this day as on many others, giving me the strength to celebrate with my family.



Every story matters, even stories of those we love who no longer walk this earth with us. Finding meaning and purpose looks different for everyone. Finding meaning and purpose in your child's story allows you to build a new relationship with your child that will carry them forward with you into the future by honoring their life.

- Find what sets your heart on fire. This can be anything from art to volunteer work to a career change, but it is important to find meaning in something that excites you. When you find what excites you, you will be able to remember and honor your child in a new way.
- Out of this terrible tragedy, my family and I have become better and stronger. By living our lives in a way that honors Arianna, we keep her spirit with us.



# FINDING MEANING

# Enrique, father of Arianna

Finding purpose and making meaning of our struggle has been important for me since losing Arianna. My priorities shifted during our fight with Arianna's brain tumor, and, after her passing, I pursued a career at ALSAC, the group that promotes St. Jude fundraising and awareness. I would never say I have found my dream job, but, more importantly, I have found my purpose in life. I'm doing everything within my power to try and ensure that no family ever feels the pain we have endured in losing our child to childhood cancer.

My family has always been in the forefront of every decision I have made and everything I have done. The only thing that has changed a bit is that now I also do everything honoring not only Arianna's memory but also remembering her fight. And, I never forget the struggles we have endured as a family.

Working at ALSAC is so fulfilling for me because within the walls of St. Jude is the only place I feel Arianna with me, and I get to feel that daily. I have so many good memories there, and when walking around the hospital, I get to relive those memories. I love that I get to work with patient families daily and get to see them make great memories at ALSAC events like my family did.

I think I provide a whole new dynamic to my work team that wasn't there before. I speak the same language, if you will, as the patients' parents. Although patient survivors are on the team, they were children when they went through treatment. As a patient parent, I can help navigate tough situations that only a parent who has been in the thick of a fight at St. Jude would understand.

I like to think that if Arianna were around as an adult and had survived her fight, she would be proud of the family we have become. We not only honor her life through my new career, but we try and be kind as she always was to everyone she met.

We honor her kindness each year on her birthday by doing 8 random acts of kindness in honor of each year we had her with us. This helps us look forward to what would probably be an extremely sad day. I think since it's filled with love and kindness, the day is a little easier for us.

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ATTENTION: If you speak another language, assistance services, free of charge, are available to you. Call 1-866-278-5833 (TTY: 1-901-595-1040).

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-866-278-5833 (TTY: 1-901-595-1040).

تنبيه: إذا كنت تتحدث باللغة العربية فيمكنك الاستعانة بخدمات المساعدة اللغوية المتوفرة لك مجانا. .يرجى الاتصال بالرقم 1-866-278-5833 (الهاتف النصى:1-400-595-10).



The course you will take on your journey with grief is only faintly predictable. As with the seasons, a cycle exists. But, seasons are also unpredictable—freezing winds when one expected warmth; uncomfortable, sticky heat when one expected a cool breeze; and the winter day that feels like spring. Think of your grief as changing seasons through the years and take comfort in knowing that you are not alone in your journey.

#### Resources:

Lisa Clark, PhD, St. Jude Grief Support Coordinator
Phone: 901-595-2658 Email: lisa.clark@stjude.org

www.stjude.org/bereavement

Quality of Life Service
St. Jude Children's Research Hospital
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