



WHEN A LOVED ONE
IS INJURED, A UNIQUE
TYPE OF GRIEF MAY
BE FELT LONG BEFORE
THEIR DEATH

expecting the Unexpected

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Death is an inevitable part of life. But despite the certainty of it, most people don't live with the day-to-day anticipation of themselves or a loved one dying. Some people, however, are faced with circumstances that leave them no choice but to anticipate it.

Anticipated deaths are usually the result of a disease or advanced age. But sometimes they are the result of an injury, such as one suffered in an alcohol-related crash. And when the death of a loved one is expected, family members can begin to feel the effects of the loss well before the death occurs.

This anticipatory grief is an emotional and psychological journey toward the ultimate loss. And whether that journey takes months, years or even decades, it can be a roller-coaster of emotions, adjustments, hope and preparation.

Learn how the catastrophic injuries of a happily married woman, a young man in the prime of his life and a sweet baby girl took their loved ones on a journey of anticipated death and grief.

Adjusting to a New Reality

Married in 1969, Donald and Lois Pinnow had begun building a long, healthy life together. But four years into their marriage, tragedy struck.

As they were headed home from dinner on a warm June evening in 1973, a drunk driver hit their car from behind at nearly 110 miles per hour. Lois was thrown from the vehicle and, in the initial 48 hours after the crash, doctors didn't know if she would live.

Lois did survive, but with her back fractured in six places, she was left paralyzed from the chest down. Donald and Lois's plans for their present and future lives were shattered, but they were determined to go on.

After six months in the hospital, Lois and Donald moved in with Donald's parents. "I continued to work and my father helped to care for Lois when I wasn't home," he says. "But most of her needs were taken care of by me."

Together, they worked to help Lois to become as independent as possible. But the reality was that, because of her injuries, Lois faced a lifetime of painful and difficult medical conditions.

According to Patti Homan, Ph.D., LPC, a program director at Pathways Center for Grief & Loss, after a catastrophic injury, there are many adjustments to be made, including dealing with the anticipated grief over the loss of present and future plans.

"[After an injury] the process of building a new 'normal' life occurs, which can be jam-packed with struggles and stressors," Homan explains. "Sometimes the stress, burdens and worries cover up grief reactions. The grief gets lost."

But what often doesn't get lost is hope.

Constant medical advances and an individual's religious beliefs, resolve and optimism all play a role in the journey of anticipatory grief.

Keep Hope Alive

Maria Garcia was seven months' pregnant when a drunk driver slammed into her truck. And though she was suffering from a broken leg, fractured ribs and punctured lungs, Maria was more concerned about her baby.



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"I kept telling my husband, Steve, that something was wrong with the baby," she says. "I could feel our baby twisting around over and over again in pain."

Hours after the crash, little Monica Leanne Garcia was born 10 weeks early and weighing only three and a half pounds. Unable to breathe on her own, Monica was placed in an incubator and attached to a respirator. Doctors were not optimistic about her survival. In fact, they gently suggested to a shocked Maria and Steve to end all life-support measures.

But baby Monica had other ideas.

"When I said her name, she opened her eyes. When I held her tiny hand, she squeezed," Maria says of her child. "We believed it was a sign from God and we told the doctors that she was going to live."

"Life and hope go hand in hand," Dr. Homan says. "It is hope that actually carries families through the challenges."

Rhonda Larissa also knows of this hope.

Her 21-year-old son, Jason Fowler, was involved in a 2002 crash that left him paralyzed from the neck down.

"I can't describe the total shock and disbelief I felt when the doctor told me," Rhonda recalls. "Most important though, I was extremely grateful and relieved that he was alive."

Dr. Homan says, "When families' lives are turned upside down, they do not perceive how many more days, months or years they have with each other. There is simply hope to live another day together."

And with these life changes, sometimes what families hope for also changes.

For example, instead of the typical hopes that parents have for their children's future, their focus is shifted toward more immediate, practical accomplishments such as rehabilitation. "We all hoped and prayed that some day Jason would walk again—and we all believed that a miracle would happen," Rhonda says.

It's this hope that often helps the injured person adjust and even thrive in his or her new life.

"We settled into a comfortable routine and Jason's friends often visited," Rhonda says of Jason's life after he came home from the hospital. "He even learned how to use a special computer that allowed him to control his bed, lift chair, phone, DVD player and overall bedroom environment. He began to smile again."

Without question, hope is a crucial aspect in coping with anticipatory grief. But it's also a balancing act with the realities of the daily grind and overall roller-coaster ride of caring for someone with a catastrophic injury.

Too Busy to Grieve

When baby Monica was finally able to go home, she weighed only five and a half pounds. She was also blind and mostly in a vegetative state.

"Her skull never fully developed," Maria explains. "One section of it was the shape of a volcano and full of brain fluid. But she recognized our voices and she loved for me to sing 'Who's the Prettiest Baby in the World?'"

With continuous medical appointments, home healthcare services and the need for constant monitoring, caring for Monica was, at times, exhausting. This daily grind is one of the factors that can have an impact on the anticipatory grief journey.

"Life cannot be the same as it was prior to the crash and injuries often dictate everyday activities, which can be time- and work-intensive," Dr. Homan says. "Sometimes there is so much to do that there isn't time to process feelings and emotions."

Donald, who cared for Lois for nearly 30 years, says, "For me, the hardest part was the hospitalizations. At minimum, she was hospitalized every three years and each time she was in the hospital for at least six months."

Then there was their child to care for.

Donald and Lois's son, John, was diagnosed with Asperger's syndrome, a form of autism. "The disorder is tough and, when he was young, he ruled the family," Donald says. "There was a lot of frustration in trying to raise him. But at 33, he's brilliant and doing very well."

Despite having a full-time job and a special-needs child, Donald continued to care for Lois day in and day out. And he pretty much did it alone.

"I received some support from my parents, but not too much from her family," he says of his daily life. "Not having the family support was depressing for me. I would call her family a lot, but I think they were in denial. She was in really bad shape. The lack of support from the people around me, mostly family, really upset me."

In November 1999—25 years after the crash—Lois's health sharply declined. Suffering from dysplastic anemia, diabetes and kidney failure, her legs had to be amputated. And for the next six years, Lois spent most of her life in and out of hospitals due to infections.

For the last two years of Lois's life, Donald says that their day-to-day routine was grueling.

"On Mondays and Fridays we went to the doctor's office. On Tuesdays and Thursdays she had kidney dialysis. And on Wednesdays she needed wound care," Donald recounts their schedule. "She used to say, 'This is too much for you; it's not fair,' and I would tell her, 'It might not be fair, but I'm doing it and you are alive.'"

Loved ones living with anticipatory grief don't need to be reminded to expect the unexpected when it comes to dealing with daily living. But it helps to remember that it's natural for emotions to take some unexpected twists and turns.

"Families learn to adjust to a completely changed life," Dr. Homan says. "It's normal to periodically 're-grieve' all that is lost while still focusing on daily living."

Preparing for the Worst

At some point though, hope and the daily grind give way to the preparation for death.

In a way, anticipatory grief involves a series of grieving episodes in which the significance of an anticipated loss is considered and reconsidered. In other words, anticipatory grief is the ongoing process of preparing for the death.

But, Dr. Homan says, "No one wants their loved one to die and no one is ever really prepared. There is always a degree of utter disbelief when death occurs."

In fact, multiple factors contribute to anticipatory grief, and the situation is even more complex when anticipated loss is put in the overall context of the family. Each family member may be at any point in their grieving journey. Some may not have begun to grieve, while others are actively preparing for death.

Lois certainly was at a different place than Donald. Having worked as a registered nurse, Lois understood things about her condition that Donald did not, things that would ultimately impact her longevity.

"She talked a great deal about her dying before I would," Donald recalls. "She prepared me as well as anyone could, but I didn't want her to die."

**OPEN COMMUNICATION
AMONG FAMILY MEMBERS AND
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DIFFICULT AND PAINFUL. BUT
THE GRIEF CAN BE SHARED.**

Then there are those who don't have as much time to prepare.

Three years after Jason was paralyzed, he had to be hospitalized for ongoing staph infections. Extremely weak and barely able to tolerate continuing antibiotic therapies, Jason's prognosis was not good.

"The doctors told us that Jason was terminal, that he had less than six months to live," Rhonda tearfully recalls. "Jason was always focused on regaining feeling below his neck, and we all hoped for that miracle. We had no thoughts of a terminal diagnosis or impending death."

Jason was again brought home from the hospital, but this time his family focused not on building a new life for Jason but on his end-of-life care, which included hospice care.

Hospice care focuses on comfort care through pain and symptom management. The team of hospice professionals assists the dying patient and family members with the emotional, psychological, psychosocial and spiritual aspects of dying.

With the support of their hospice team, Jason and his family were able to spend some very special days in the comfort of their home.

"We needed to know that we provided the best care possible for Jason," Rhonda says. "With the assistance of our hospice team, I know we did."

When It's Time to Say Good-Bye

Caring for a dying person is complex because of the multidimensional experiences for the person whose life is ending and for the family members. Expressing love and reassurance for the person who is dying is a normal part of family grieving, and so is the emotional pain that comes with the impending loss.

"Jason openly shared his thoughts and feelings about dying," Rhonda says of her son. "At first, he was fearful of making it into heaven, but with reassurance, he slowly realized that he was 'right with God.' He was at peace, and even planned his own funeral, including picking out his pallbearers, songs and ministers."

Open communication among family members and the dying person can be difficult and painful. But the emotions of grief can be faced together. This often is the most difficult aspect of the loss, particularly if expression of strong emotions is not encouraged within the family.

"When grieving, everyone's needs are different," Dr. Homan explains. "It is

important for family members to share and tune into each others feelings. But this is not always achievable. It is also important to loosen expectations and give 'grace and space' for each other's needs."

For the person dying, saying good-bye is especially significant.

During his last days and through loving hospice care, Jason's family valued the opportunity to honor and celebrate him and his life. They also had the opportunity to say and do the things that mattered most to Jason. And to him, his good-bye was that he wanted to take one last ride in a pick-up truck with his best friend and his brother—one of his favorite activities.

Sadly, Jason was never strong enough to withstand the trip. He died of complications from his injuries four years after the drunk driving crash.

"To honor Jason's last wish, we placed his casket in the back of a pickup truck and drove it to the gravesite," Rhonda tearfully explains.

Through this last gesture, Jason's family was able to grieve and comfort one another while celebrating his life.

"Saying good-bye doesn't mean forgetting or letting go," Dr. Homan explains. "It is important for families to embrace memories and find meaning. For many, you are who you are because of your life experiences with your loved one who died."

Maria had a much different, but an equally significant opportunity to say good-bye to Monica.

Four days after Maria and her husband brought home their newborn baby boy, Stephen Lee—a child doctors had told her she could never have due to injuries she'd experienced as a result of the drunk driving crash—15-month-old Monica started having seizures.

"As we rushed her to the hospital, she clung to me," Maria says of her last moments with her only daughter. "She had more than 20 seizures in the car and I knew that my baby was going to die. Before she took her last breath, she looked up at me and said, 'mama.'"

It was the first and last word baby Monica ever spoke—she died in her mother's arms before they reached the hospital. It was Monica's good-bye to her mother.

Accepting the Inevitable

Even the expected may not happen when expected. Lois died in March 2006—nearly 33 years after the crash that left her permanently injured. Her death certificate states that she died of complications from the injuries she sustained in the crash.

After Lois's death, Donald sank into a deep depression. Feeling as if he had no one to talk to or anyone who would understand his grief, Donald went to hospice bereavement groups. But, he says, "They didn't help me. The people in the groups I went to were much

Help for Your Journey

Anticipated death and grief can be emotionally and physically difficult. Here are some tips to help you cope.

- Set aside time for yourself to rest and renew.
- Tune into your own reactions and needs.
- Incorporate things that have helped you cope with difficult times in the past.
- Be careful not to impose your own assumptions and expectations on your loved one.
- Know that emotions may increase and intensify over time.
- Find healthy ways to express your feeling as they arise.
- Rely on family and friends for support.

older and had lost their husbands. There was no continuity between them and me as far as I was concerned."

Talking with other drunk driving victims/survivors also seemed insufficient to Donald. "A sudden death is different from death after long-term care," he points out. "This was my wife and I cared for her. Many people think she died of a disease, but my wife was killed."

We all know that death is an inevitable part of life, and we have expectations about what is and is not an acceptable end. For those like Maria, whose child survived a traumatic drunk driving crash only to die later of injuries sustained in the crash, grief is intensified because the death of a child is considered to be the ultimate of untimely deaths.

But when Donald, Rhonda and Maria's journey of anticipated grief turned into their personal grief journey with the death of their loved one, they had to learn to adapt to yet another aspect of anticipated death—life without their loved one. And although each family is unique, they share common feelings and needs. Each family wants to know that their loved one received the best care possible. Each family wants to know that their loved one had the chance to receive the most current and effective treatments to prolong life. And each family needs to know that they and their loved one got the chance to say good-bye in a meaningful way. ■

