

CHAPTER 5

JOY IN THE MOURNING: RETURNING TO JOY

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In my sixty years of life, I have come to recognize that grief comes with every important loss we encounter. I have also come to understand that the more important or precious the loss, the deeper and more profound the grief will be. My journey has been one marked by important losses, all of them different and very precious. It has been equally marked by the important and precious losses encountered by others. The journey has changed me forever, and ultimately has led me through the pain to my life's passion and work – becoming a grief counselor called by God to give birth to the “Joy in the Mourning”® Center for Life Losses.” I want to share with you the story behind the ministry to which I have devoted my life until God says “enough” or takes me home.

As a very small child, I remember sitting under our dining room table one night crying because our tropical angel fish was dying. Another time a bird was killed by one of our cats. My only consolation came from a precious older next-door neighbor who brought a bouquet of climbing roses from her fence and helped me have a “funeral” for the bird. When I was older, another not-so-nice neighbor intentionally poisoned my favorite cat. I keenly remember the anger and utter helplessness I felt as I witnessed such senseless suffering in another living thing. When I was in second grade, a classmate told me about her parents' divorce. She was the only child I knew who had experienced divorce, and I felt her pain as she told me how much she missed her daddy. I learned from her that grief can be about losses other than death.

I knew very early in my life that I wanted to help people. My journey toward that goal began one Christmas when, as a four-year-old child, I remember receiving my first nurse uniform – a bibbed white apron with a red cross on the bib and a white cuffed

cap bearing a black stripe on the cuff – and a “doctor kit.” The uniform had been lovingly hand-sewn as a gift to me by the wonderful neighbor next door who was more like a grandmother than a neighbor. From this point on, most of the time my dolls (as well as my little sister and playmates) became my “patients.” The playhouse that my father built for us in the back yard was more often a “hospital” than the house it was intended to be. We had a surgery suite in the bike “garage” behind the little house. When I was older, my father even allowed me to use one of his camera lighting tripods as a pole for intravenous fluid administration. It worked just fine with a peanut butter jar taped to it complete with plastic tubing from my dad’s fish aquariums!

As a young girl, I recall reading the “Cherry Ames” and “Sue Barton” nurse stories with delight. I dreamed of wearing a white uniform and cap and of somehow changing the world by easing pain and suffering. After high school, I chose to attend one of the last hospital-based diploma nursing schools in the country, the Watts Hospital School of Nursing in Durham, North Carolina. It was “practical,” much less expensive than going to college, and my family doctor said that the best nurses he had ever worked with came from there. As student nurses, we lived in a dormitory on the hospital campus, took our classes there, and worked daily in the hospital except on weekends. I was fascinated by what I was learning about disease processes – and also what I was learning about caring for each patient as a whole person, not as just a diseased liver or ruptured appendix.

Critical care nursing held a particular fascination for me, and after graduation in 1971, I became an intensive care nurse. I got married that summer, and my husband’s career moved us frequently. Over the course of time, I lived in five different states. In each new place I found a job, and it always involved some kind of intensive care work. Though I loved what I did, the “fit” was never exactly right. I’ve described it as feeling like a “square peg” trying to fit into a “round hole.” However, in every setting, I found that my work always involved crisis, grief, and loss. Somehow I was drawn to patients who were critically ill or dying, and their fami-

lies. I felt their experiences of loss keenly. Over the course of time, their stories of loss became intertwined with my own.

Early in my career, while living in Michigan, the first story unfolded. I met a wonderful couple while working in ICU. The husband was my patient, and he was critically ill from complications following a heart valve replacement. The new valve had become infected, and there was no way to heal the infection because the valve was not living tissue. There was also no way to replace the infected valve with a different one because the infection would have to be eradicated before a new valve could be put in, and my patient could not live without a valve in place. I was drawn in an incredible way to him and his wife. They had been given the news that he would not have long to live. They were Christians, very authentic in their faith, and their faith inspired me. It was solid even when the things they prayed for did not happen as they had hoped.

All of us were praying for a miracle. My patient rallied for awhile. Even now I recall happily the day that he felt like eating a hamburger, and also the one in which he was able to move to a room, no longer in ICU, where I continued to visit him frequently. His condition worsened after Thanksgiving that year. He and his family were told that he probably would not survive until Christmas. The miracle we received in answer to our prayers was not that he lived, but rather that he lived meaningfully while he was dying. Another miracle was that he lived long enough to spend Christmas with his family in his hospital room. I was blessed to have been a part of the life of this family. It was a window into how love and faith work during crisis and dying, and it was one of the most touching and humbling experiences I have ever had.

Another significant episode in the Michigan ICU was a midnight interaction I had with a mother who stationed herself at the side of her three-year-old daughter. The child had somehow gotten out of the house and behind the family car as the mother was backing out of the driveway to go to the store. She had backed over the child, and the little girl was dying from crush injuries. I remember the mother's tear-stained face as she said bleakly, "God must not want me to have a little girl. I'm a terrible mother! He is punishing me for running

over her.” I recall feeling totally helpless, not knowing what to say to her or how to help her. All I could do was cry with her.

In the mid 1970s, we moved to Illinois where I had my first “taste” of neonatal intensive care. Neonatal intensive care, the care of critically ill and premature newborn babies, was a relatively new specialty, and from the moment I started learning about it, I was “hooked.” I remember a couple who had tried multiple times vainly to have a child. Each pregnancy had resulted in a miscarriage or early stillbirth. Finally, a precious and very tiny little boy, barely one pound in weight, was born to them. He was extremely premature and precariously alive. His lungs were severely underdeveloped. Over several months, he struggled to survive, and a mechanical ventilator was necessary to give his body the oxygen it needed. Though he grew and gained weight, the months of having to be on the ventilator took their toll on his lungs. The lung damage was so severe that he was never able to come off the machine, and he ultimately died. Over the months of his short life, I grew very close to his parents, and I found myself again immersed in the process of loving and losing as we moved together through his life and death.

In that same hospital, a baby girl came into the world, resuscitated after having been born without a heartbeat. She was severely brain-damaged and was never able to breathe on her own. She had wonderful parents, but she could never go home with them because she could never come off the ventilator. At this time, home care for medically-fragile children was non-existent. The hospital cared for her until her death several years later. Her parents had to process the loss of what might have been in order to accept and adjust to what was. It was an ongoing sorrow for them because of losses that related not only to her medical fragility and brain damage, but also to the lost dreams of having her home and having the opportunity to simply be her parents.

In the late 70s, while living in Tennessee, I worked in a pediatric intensive care unit and began to learn what a difficult and different kind of grief it is for parents and grandparents when a formerly healthy child is suddenly in critical condition or dying, or when a

medically fragile or chronically ill child's condition worsens. During this time, I was also experiencing losses of my own. Seven years of infertility finally culminated in a pregnancy, but the pregnancy ended almost immediately with a very early miscarriage. I was at home alone when the miscarriage occurred. I remember being on the floor with my arms around the toilet bowl, weeping into it, knowing that a nearly-microscopic baby was in there somewhere amid the blood clots, and not wanting to flush the toilet, while knowing I had to.

My husband and I went through infertility testing and discovered that the problem was with me. We were told I would probably never be able to have a baby. So we began the process of adoption. After waiting for over a year on a state adoption list, we learned about a baby that was going to be born and placed for private adoption. Things went well for three months. The baby was born – a little girl. The evening before we were to bring her home, her mother changed her mind about the adoption. For me it felt like having gone through a pregnancy and then experiencing the death of the baby two days after giving birth. I was devastated – and angry. I could not understand why God would allow us to come so close – and then not let us have her. I was angry with every pregnant woman I saw. I was angry every time I cared for an abused child or for a baby born addicted to drugs because of its mother's addiction. I couldn't understand why they could have babies, and I could not!

At this point, I decided to go back to school to get a bachelors' degree in nursing. If I couldn't be a mother, I believed I could do something meaningful with my career if I had a college degree. It was during this educational interlude that I took my first class in death and dying. Mortality and loss were discussed and examined in multiple ways. I read Elisabeth Kubler-Ross's foundational book, *On Death and Dying*. My class even visited a funeral home and talked in depth with the mortician there. I was intrigued by this mysterious and deep thing called mortality and how it intersected with life and death.

In the early 80s, after receiving my degree, to my joy and amaze-

ment I became pregnant and was able to carry the baby to term. During labor, complications resulted in an emergency Caesarean delivery. My son was born not breathing. The birth was silent and terrifying. I was fully awake during the delivery, and as they lifted him from my womb, I could see that his color was blue. He was whisked out of the room for resuscitation. I had worked with enough babies to know that everything about his future depended on how long he had been without oxygen and how long it would take for him to breathe. The resuscitative efforts were successful, and he lived, but he spent the next twenty-four hours under observation in the special care nursery. I now understood on a very personal level the experience of terror when a child's life is hanging in the balance. I also understood the anxiety that resulted from watchful waiting that would show us whether or not he had suffered any brain damage at birth. To my relief, his physical and mental development were normal. However, until he finally walked at fifteen months, I could not be sure that he was really going to be all right.

After my son's birth, I began to work at Duke University in the NICU. Two experiences there changed my life and the direction of my work forever. The first was the birth of a little baby boy named Jonathan. He was born with a severe birth defect that required immediate surgery to save his life, and he had to be on a ventilator for a very long time after the surgery. I fell in love with this little boy – and with his parents. It was through their experience, and my experience with them, that I learned how to truly help parents to be parental in an intensive care setting. There were many complications following Jonathan's surgery. The complications were unavoidable. All of them resulted from treatment necessary to save his life but that caused other problems over which we had no control. I now saw through the window of closeness that developed with his parents, a first-hand, long-term experience of the grief that comes from having a child who is much-loved but critically ill – and then chronically-disabled. To this day, I am still in touch with Jonathan's mother, and I eagerly follow the progress of his life through her Christmas letters.

The second life-altering experience was the short life of a tiny

infant born with a heart malformation that could not be corrected and was incompatible with life. After multiple resuscitations, she finally died. I vividly remember going into the staff lounge, beating my fist on the wall, and saying angrily out loud to God, “Why do I stay in this insanity? This hurts too much!” I have never heard God speak to me audibly, but immediately after my question, I “heard” words in my mind that I knew were not my own thoughts. The words were, “You do it for their families.”

At that moment it was as if a conception took place – the conception of a dream that would later become my life’s work. I knew that I couldn’t “fix” the pain of parents. I also knew that medical science wasn’t powerful enough to always save or “fix” lives so that the outcomes were always good. I realized that it was the “magic” of walking with people through the most dreadful experiences of their lives that made the difference for them. I couldn’t change their circumstances. I could not save or heal their children, but I had the power to change how they experienced these things. And I could bring with me the power of God’s love and compassion. The burning desire of my heart was to make a difference in the lives of as many families as I had the opportunity to touch.

In the meantime, in my own life, another life event had occurred. My father had a stroke. It caused complete paralysis of his right arm and partial paralysis of his right leg. My mother cared for him at home for the remaining years of his life. I watched her live out her love and commitment to him, and I also watched how her faith in God sustained her and gave her strength. For the last few years of my father’s life, I was fortunate to live close enough to my parents that I was able to go home frequently to help my mother care for him. I vividly remember the Christmas before Daddy died. He was having trouble breathing, and he had lost a significant amount of weight. He and I spent Christmas Eve together in the emergency room. He was dehydrated and received intravenous fluids, after which I was allowed to take him back home. During this time, he and I had the most meaningful and important conversation we had ever had – about his wishes when the time came for him to die. One wish was to be at home and not in the hospital when he died.

He shared that he did not want to be kept alive by machines or artificially fed in any way. He also told me that he had made his peace with God – finally having settled some questions he had struggled with over the years concerning the deity of Jesus Christ – and then he shared with me his assurance that he would go to heaven after he died. As we discussed these things, he was fully lucid and seemed to be entirely at peace.

After that conversation with my father, my mother, sister, and I all agreed that we would abide by Daddy's wishes to the extent possible. I tried to get his doctor to order hospice care for him, but he said he couldn't be certain that my father's condition was terminal. He said he couldn't order hospice care unless he could be sure Daddy would die within six months! I could *look* at him and tell that he was dying! I told the doctor that, if he would support us as we provided hospice care for Daddy, if he would not pressure us to put him in the hospital, and if he would come to the house to pronounce him dead, we would continue to allow him to be Daddy's physician. However, I also told him if he could not promise that support, we would change doctors. He was able to agree to this.

My father died quietly on February 13, 1985, not quite two months after our conversation in the emergency room. He never had to go to the hospital again, and he was never fed artificially. My mother remained his primary caregiver, with me and my sister visiting as we could on the weekends to help her. He went into a coma one morning and died just after 4:00 PM that afternoon. I was en route, trying to get home to be with him. About fifteen minutes out, I felt impressed to pray that God would allow Daddy to die peacefully and not let him have to suffer a long time. When I arrived at my parents' home, I was met at the door by a deacon from their church who told me that Daddy had died just a few minutes earlier. What a comfort it was to me to realize that I had been praying for him at the moment he died, and that God had taken him home within that single day and without suffering.

At the time of my father's death, my son was a month shy of his third birthday. We did not take him to the funeral, but I did tell him that Grandpa had been sick for a very long time, and that he

had died. The night of the funeral, as I was tucking him into bed, he asked, “Mommy, what’s ‘died’?” I had always been told that, when a child is big enough to ask a question, he is big enough to receive an honest answer on a level he can understand. I tried to think of a way to explain death to such a small person. The story I told him, and the little game I played with him to help him understand that dying is not the same as sleeping, seemed to satisfy him.

It was not until he was ten years old that I realized how important the story had been for him. One night he repeated to me the story I had told him so many years before and asked lots of questions about his grandfather. I realized then that the story needed to be published to help other children. In 2005, the little book “*Mommy, What’s ‘Died’?*” *The Butterfly Story* was published with my son as its illustrator. Since its publication, it has been used in public schools, in hospices, and in funeral homes. More recently I have adapted the story to help grieving children in third world countries. It has been used successfully in several different countries by International Christian Hospice in the incredible work they do to train church volunteers to help those who are dying, and their families.

After my father died, another devastating loss in my personal life was the death of my marriage and subsequent divorce four years later. During the separation, I moved to my hometown to live with my mother, and returned to school to get a master’s degree in nursing, specializing in parent-infant nursing and focusing specifically on crisis and grief intervention with families of critically ill or dying infants and children. I remember being told by one of my professors, “You will never get a job as a nurse doing that.”

Undaunted by her discouraging words, I graduated in 1989 and went to work in the NICU at Baptist Hospital in Winston-Salem, North Carolina. I loved the work I did with families. I learned how to provide support for families whose babies were dying – and how to include them in everything that was happening along the way. I remember specifically being with the parents of a six-month-old baby boy who had such severe lung damage that he could no

longer get enough oxygen, even with the ventilator. They were given the option of taking the breathing machine off and allowing him to die. After they had received this news, they asked me to come into the room with just the two of them. I remember that we sat in silence for a while. It was a heart-wrenching time for all three of us.

The mother finally asked me, “Linda, if he were your baby, what would you do?” I breathed a prayer, and I was given words again in my head that went something like this: “We have technology that can prolong life and often save it. But the same technology that can prolong life can also prolong suffering when the outcome is not going to be life. You have done absolutely everything as parents that you can do to give your son every chance at life. So have the doctors and everyone who has cared for him over the months. I think he is telling us that he can’t do it anymore and that he is too tired to keep fighting. I think he is dying, and that no matter what we do, we can’t keep that from happening. I also believe that he is suffering because of the lack of oxygen. To take the breathing machine off would allow him not to have to fight anymore. He could just be a little baby, without tubes for the first time, and allowed just to be held in the warmth of your love as he slips away. That would have to bring him so much comfort – to be held while he dies rather than dying in a bed hooked up to all these machines and intravenous tubes.”

They chose to remove the machines. His daddy held him while we took away all the tubes. He then carried him to a family room where he and his wife – and other family members – had the opportunity to be together, holding him, kissing him, and loving him from this life into the next. He lived for several hours. It was precious and meaningful time for them – and for me. I was in the room only to check on them at intervals and to check the baby’s heartbeat and breathing. He appeared to be comfortable and not suffering. They were suffering, but there was a peace that did pass understanding in that room, and there was something comforting to them in just being able to care for him during those moments at the end of his life. Several months later I received a card from his mother re-

calling how meaningful the experiences of both his life and his death had been to them.

In 1991, I moved to Columbia, South Carolina – a casualty of a corporate “downsizing and reorganization.” I went to work again in NICU. About six weeks after the move, I realized that the work I was doing was not a good “fit” for me – again the “square” peg trying to fit into a “round” hole. I turned in my resignation and immediately started looking for other work while working out my three-month probationary commitment. I decided that, if I couldn’t find something in my specialty area of grief and crisis, I could work comfortably in pediatric home health care. I interviewed at another local hospital. There were no clinical specialist positions open at that time, but I was told that budget preparations were underway for the next fiscal year, and if approval came for the position, I would certainly be their choice for working with new parents as a clinical specialist/educator on the maternity unit. I thought it sounded like it could really be fun, especially after all of the stresses and losses of the previous six years.

I discovered soon that God had a very specific plan for me and that, as I was experiencing all the “bumps,” crises, and losses in my own life, He had been laying out a plan that only He could have engineered. The week after my last day at the previous hospital, I received a phone call offering me a job in the newborn nursery at the hospital that was considering me for the clinical specialist position. I was asked to meet with my new supervisor after my first day of orientation so that we could “write the proposal” for the position they were hoping to secure. When I met with her, I asked, “So, we are going to write a proposal for my working with new parents, right?” She said, “No – remember all those ‘unusual interests’ of yours in your resume (grief, loss, crisis)? We have decided we want you to do all those things, as well as educational programs for parents. What do you think?”

What did I think? I think it was a miracle straight from the hand of God! The proposal was approved, and that October I started my new role as the clinical nurse specialist for perinatal family care in the area of the hospital that cared for women and children. It soon

expanded to crises with infants and children in the emergency room as well. God used this experience to show me two things. First, He can do anything He wants to do (even when “nobody will ever hire you to do that” as my former professor said). He has a plan and purpose, and He will do it. Second, I learned that this work was the most rewarding, amazing, exhausting, and satisfying work I had ever done. I now knew beyond a shadow of a doubt that God had called me to it and had prepared me for it. It was a perfect fit for this “square peg!” I had finally found the right hole!

And – as a special gift, God also gave me a new husband. Several years earlier, Jim had experienced the death of his wife Sandra following a battle with breast cancer. From the beginning of our marriage, he has shared my dreams, encouraged my vision, and supported my work.

I worked at the hospital for five years, at which time there was another corporate restructuring. My job was eliminated, not because it wasn't valued, but because it didn't provide revenue. (I discovered that insurance doesn't pay to help families through crisis, grief, and loss.) Though this was disappointing, God had shown Himself so faithful during other hard times that I knew I could trust that He would continue to lead me.

He used an “anonymous donor” to give money to the hospital foundation, specifically to be used for “bereavement care.” I was asked to become a self-employed clinical nurse specialist working under a contract with the hospital to continue to provide services to families who experienced critical situations and deaths related to their children. My current work *Joy in the Mourning*® was the result. Psalm 30:5 says that “Weeping endureth for the night, but joy cometh in the morning” (KJV). My husband wept when I told him the name that God had given me for this work. He said, “That's true: You cry through the long night of grief, but if you do good mourning, you come back to your joy.”

Since 1996, when *Joy in the Mourning*® started, I have been back to school – this time at Columbia International University, earning a master's degree in clinical counseling. I wanted to be able to do more for people who experience all kinds of life losses than

I could as a nurse. I am now a licensed professional counselor who specializes in losses of any kind. As my own life experiences have taught me, there are many kinds of losses other than death. The most exciting part of my work is that God has moved it into another chapter. Joy in the Mourning® Center for Life Losses was founded in 2002 and is a developing non-profit organization. Our mission is to provide programs and people to help individuals and families return to the joy of living after any kind of life loss. I am so excited to be a part of what God wants to accomplish through this ministry.

As I write, I reflect on the past two years. During that time, my mother died from dementia, and I experienced the “empty nest”—two more significant losses. My life has been a wild ride, and it isn’t over yet. However, every experience, no matter how painful and difficult, has been used by God in my personal life and in the work I am doing. I wouldn’t trade a minute of it, and I would be willing to go through all of it again to have learned the lessons He has taught me and to be doing the work I am doing. I serve an amazing God! To Him be all the glory!

Questions for personal reflection and/or discussion:

1. Linda’s vision of a life of helping others started very early, when as a child she imagined herself a nurse, and then developed the characteristics to match the calling. When you were a child, what did you imagine yourself doing as an adult, and to what degree have you been able to fulfill that vision?

2. While nursing, Linda was drawn toward helping those in extremely difficult situations. What characteristics does it take to function well in that kind of setting? Describe people who have helped you in difficult times.

3. Linda’s story involves multiple losses, including infertility and

an adoption that was called off at the last moment. How might you have (or how have you) responded in similar situations?

4. Review the chapter with a view toward identifying and listing all the losses Linda describes. (In a group setting, have someone compile these for the group.) If there are other kinds of losses not mentioned in the chapter, that you or others in your group have faced, add them to this list, then share briefly what happened, and how they have affected you over time.

5. Linda has experienced a renewal of hope and fulfillment of her dreams to establish a ministry to help others because God specializes in reversals, using our weaknesses to help us become strong in Him, and comforting us in all our troubles so that we can comfort others in any distress with the comfort we, ourselves, have received (see 2 Cor. 1:3-4). How have you seen this truth express itself in your own experience?