A Gathering of Angels

Seeking Healing after an Infant's Death

> Compiled and Edited by Victoria Leland, RN

In Collaboration with Five Grieving Mothers: Audra Fox-Murphy, Heather Gray, Linda Bailey, Sahnewaz (Tania) Hossain, and Allison Guild



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Gabriel Fox Connor Gray Madison Bailey Lanika Hossain Brennen Guild



I our love could have saved you, you would have all lived forever.

Introduction "A gathering of angels can enlighten the whole world." - Anonymous

id your baby die, leaving you to bear a grief that is so beyond definition that everything in your life has instantly changed and must now be redefined? Has your spark for life been extinguished, your hope for the future vanquished, and your understanding of life shattered? Do you feel like a shell of your former self? Have you searched for a salve for your terrible hurt—in family, friends, prayer, support groups, church, books, drugs, alcohol, etc.—and found help in some measure, but still you walk away hurting, disappointed, and feeling beyond help? If so, I want you to know first that I am truly very sorry for your loss. I can't imagine the depth of the pain you must bear. But, I also want you to know you are not alone in your terrible grief. You are in need of good and special souls. You are in need of angels. Have you found any yet?

I have.

Or is there a special loved one in your life who is grieving the loss of a baby? Do you want to help but don't know how? Are you trying to understand what your loved one must be thinking or feeling? Do you feel inadequate and unable to say or do anything that can help? You also are in need of angels. Have you found any yet?

I have.

Although we live in a medically advanced society, tens of thousands of babies are torn away from life too soon by miscarriage, stillbirth, prematurity, birth defects, SIDs, disease, and accidents. A multitude of young mothers and fathers are left behind to suffer gaping wounds caused by the tragic loss of their babies. These parents live on with an insatiable hunger for clarity as they process what has happened, all the while searching for words of true understanding and for effective solace as they mourn their beloved children. But when they search for help, all too often they find a society that largely underestimates the deepness of their loss. Our society is inclined to dismiss these early deaths and tries to minimize parents' grief, wrongly assuming that because the child lived so short a time, the grief associated with their loss cannot be that great. It is assumed recovery will be brief and life should quickly return to normal. Nothing could be further from the truth. You know this. Good and special souls ("angels") know this. Have you found any angels yet?

I have.

The term "angel" is used quite loosely today, conjuring many different interpretations. For the purposes of this book I am defining an angel in two different ways:

(1) first, as that lovely soul who lived and died in your midst, touched you to your very core, and although gone from you now, continues to leave a legacy of love deep in your heart. It is very evident to all involved that God deemed a very special purpose for their life;

(2) second, as that lovely soul who appears in your life, sometimes briefly, sometimes with longevity, who is compassionately available to you in your grief—someone who doesn't run from it, ignore it, minimize it, or try to fix it. This good and special soul "gets it." No matter how unexplainable and confounding your grief, he or she chooses to walk alongside you in your journey.

Have you found any such angels yet?

I have. I am Victoria Leland, RN (known as "Vicky" to my friends), and I feel compelled to share a unique experience that has permeated the many layers of who I am. It has affected my life as a nurse, photographer, March of Dimes volunteer, writer, Christian, and friend.

Beginning in the summer of 2006 and over the following nine months, a remarkable group of individuals assembled around me. I was working as a bedside nurse in a busy Neonatal Intensive Care Unit (NICU) in Plano, Texas, when five precious babies in my unit died. After nearly twenty years of NICU nursing, I had come to know many wonderful parents and, yes, I had seen many babies die. There was something inexplicably unique, however, in how these five families touched me. Other families came and went and other babies died in my NICU during that time (2006 was an unusually tough year in my NICU). But a spark of true connection ignited when I encountered these five families, especially the mothers.

First there was Audra, a twenty-three-year-old, newly married young woman with so many grand plans for a lovely life with her new husband and first baby. She was a bank teller and her husband was in the army, recently back from a tour of duty in Iraq. Despite all the best medical care they received, their son Gabriel arrived when Audra was only six months into her pregnancy. He did relatively well at first in the NICU, and as he grew it looked as if he'd go home soon. But tragedy struck—part of his intestines suddenly died, leaving him deathly ill. Gabriel lived only sixty-two days, and left his young parents completely devastated.

Shortly after Gabriel died, I met Heather. Heather was a professional engineer who had spent her first ten years out of college building a very successful career and marriage. She and her husband Cole excitedly anticipated the birth of their first child, but he came extremely early into Heather's pregnancy. Connor was born at twenty-four weeks gestation, which is just past the point in a pregnancy when some babies can be saved. Connor struggled from the onset of his brief life, his lungs and immune system simply too immature to sustain him. He died at twenty days of age, leaving his adoring parents completely crushed.

While I was caring for Connor, I also met Linda. Linda was an accountant and mother of twin girls born at twenty-four weeks gestation. Madison died at only two days of age. Kaitlyn, however, survived her premature beginnings after a very lengthy stay in the NICU. Linda and her husband Brendan grieved the loss of one child, while, with their other child, they endured all the stresses and strains that go with a four-month NICU stay. While Linda and Brendan were ecstatic over Kaitlyn's survival, this in no way lessened their grief over the loss of their beloved Madison. Their hopes of raising both twin daughters were shattered, and they were left over-whelmed with grief at Madison's death.

A few months later I met Tania, a native of Bangladesh who had come to the United States as a teenager ten years earlier. She and her husband Sunny were the proud parents of two daughters and Lanika, who arrived twenty-seven weeks into Tania's pregnancy. Lanika did very well in the NICU initially, but at six weeks of age she caught a terrible infection that her frail little body could not surmount. When she died, her parents and sisters were completely overcome with grief. So many of their hopes and dreams for their family died along with Lanika. And a few months later, I came to know Allison, a special education teacher who had excitedly awaited her first child. But complications set in half-way through her pregnancy, and she endured eight weeks of strict bed rest before Brennen arrived at twenty-eight weeks gestation. She and her husband Brian prayed and hoped for his survival, but he lived for only nine days. They walked away from the NICU empty-handed and brokenhearted.

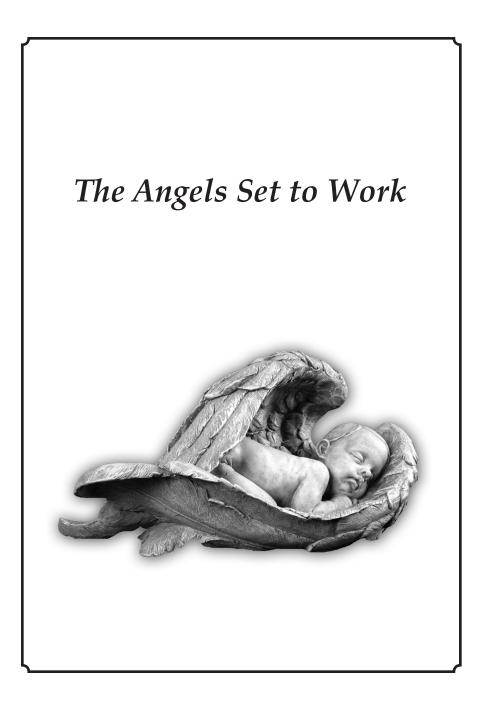
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After these five babies died, I watched with great sadness as their remarkable young mothers plunged into the dark abyss of overwhelming grief, and I could not help but befriend them all. They each moved me, inspired me, touched me—in their motherhood and in their grief—and I felt strongly drawn to each of them. Until that point, I had occasionally befriended parents in crisis in the months and years after their discharge from the NICU. But these five babies and their mothers were somehow very different. Quite simply, I can explain it no other way than that they must have been angels to me. Almost from the moment we first met, they all instantaneously entered a very special place in my heart in ways I find difficult to articulate. I still marvel at this rare coming together of hearts. And I still marvel at them—good and special souls, each and every one.

It is a cold, sad fact that every day in this frenzied rhythm of our twenty-first century existence, babies die. While the busy world might not much have noticed these particular five babies' lives, I did. I remember them. They were angels who gathered in my midst.

And a gathering of angels can enlighten the whole world.

I want to tell you how they enlightened me.



first gathered these five grieving women together shortly after Brennen's death, inviting them each to join me in a volunteer project I was working on for the March of Dimes called "The Path of Hope." They were eager to be involved in something that advanced the cause of healthy babies, and each of them felt the need to do something meaningful that honored the memories of their babies. It took literally no time for Audra, Heather, Linda, Tania, and Allison to form a very special bond and to connect with one another through their grief and compassion. Friendships were easily forged by their common desire to make something good come from the terrible tragedy that had befallen them.

Once that initial March of Dimes project was completed, this group of ladies did not want to stop meeting. They needed one another! They had each experienced feelings of terrible isolation in their grief and learned that our society rarely knows how to help a grieving parent. The group decided to meet regularly, openly share their grief journeys, and then combine their accumulated thoughts into a book. This book would be the legacy of Gabriel, Connor, Madison, Lanika, and Brennen, five angel babies who came and went much too quickly from our lives, but left a deep, lasting impact on us all. We affectionately came to call ourselves the "Good Grief Group," and we set ourselves in earnest to this good task.

The Role of the Fathers

I want to state that the fathers involved here were a large influence in this endeavor. A couple's grief in the aftermath of the death of a baby is most definitely a journey of two. After the death of their babies, Erik, Cole, Brendan, Sunny, and Brian all grieved profoundly. Because of work and other responsibilities, these men were not as available to me as were their wives. When the Good Grief Group focused on this book, these men all supported our efforts. Some of the fathers cared for the children at home after their long work days, enabling their wives to participate in our Good Grief Group gatherings. As the mothers wrote, they often discussed thoughts with their husbands and incorporated a dad's perspective whenever possible. The love of these fathers left a deep impression in many of the words you'll read, and their presence is most assuredly felt between the lines of this book.

First Steps

The first goal I set for the Good Grief Group was to draft a list of what they thought were the fifteen hardest "things" about grieving. At our first book writing gathering, we sat around my dining room table and brainstormed ideas: the mothers telling me everything that was so difficult for them in their grief journey, and me frantically trying to write all their thoughts on a large tablet of paper I'd put up on an easel. In an hour, we filled up more than eight large sheets of paper identifying what they struggled with in their grief.

I worked to condense their eight pages of ideas into fifteen "themes" that would be a good summation of what is most difficult in a parent's grief journey, as identified by these five women. Try as I may, I could not get the long list they voiced to me down to that small a number. I was learning that grief pervades everything, and the difficulties that result are endless. I was able to eventually condense their list to twenty-one broad themes, which they agreed represented their most difficult challenges with grief.

I was clear from the onset with these five grieving mothers that I was not professionally trained as a grief counselor; I would not have the answers to their many probing questions. This did not seem to matter to them. They knew I was hungry to learn, and they were very willing to share their experiences with me. I desired to be a part of this group in order to listen and learn, not advise. I wanted them to teach me about grief so that I could understand it better, be more helpful to them, and eventually assist future grieving parents more effectively.

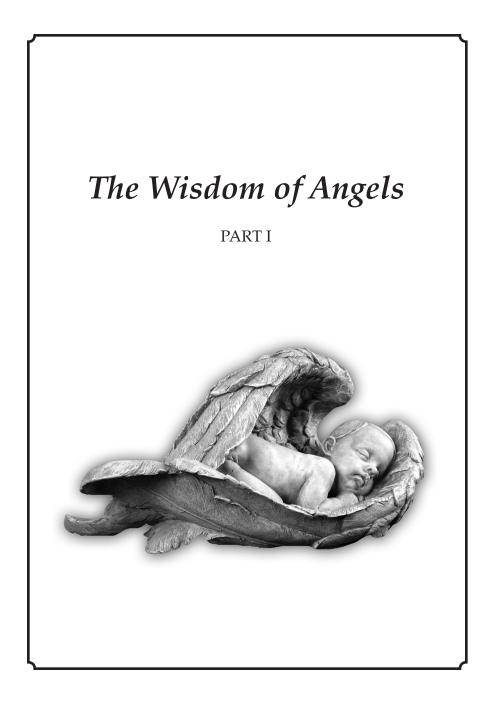
And so, what follows is what our Good Grief Group discussed and identified as our grief themes. These discussions took place over a time frame of about two years. If you read chronologically from the first to the last theme, you will see a progression of these women's grief. The initial eleven themes were written in the first year after their babies died, when their grief was extremely raw and intense. These themes primarily focus on expressing how their grief felt. The next eleven themes were written in their second year of grief, and in them I believe the grieving mothers began to show an acquired wisdom in their journeys toward peace.

How might the following pages be helpful to you? It is our hope that, if you are a parent who has lost a baby, they will:

- Help you clarify your thoughts and understanding about your grief.
- Give words to your grief experience in ways you may not have found yet on your own.
- Bring you some reassurance that you are not strange or going crazy because of the way you think and act after the death of your baby.
- Help you realize you are not alone—we hope to lessen your feelings of isolation as you identify with others.
- Provide you comfort in knowing these six women care and want to help any parent experiencing intense grief.
- Offer you suggestions that may help you in your grief journey.
- Bring you hope that happiness is possible in your life again.

If you are the loving friend or family member of someone journeying through the terrible grief of losing a baby, we hope the following pages will:

- Provide you better insight into this unique type of grief.
- Offer you suggestions that will make you more comfortable as you try to assist your grieving loved one.
- Enable you to effectively help someone you care very much about through their grief.



THEME 1

Grief Defined

Knowing we were going to explore in-depth the experience of their grief, I thought it best if our group effort started by defining the term "grief" itself. I asked these five women, whose grief was still raw and new, "How would you define your grief?" (Allison was two months into her grief, and the others were five-to-eight months into theirs.) Even though they each knew grief intimately, it was not easy for them to define what they were experiencing. How exactly do you define something that defies and permeates everything? I believe they found a way.



Linda Grief is a bottomless void that can never be filled. This void leaves such an emptiness and loneliness within you that, although you may be existing, you're not really living. You may be going through the motions just as you did before, but it's with altogether different feelings. At first, some days it takes all your energy to just exist, but as time goes on, you rediscover the strength to actually live.

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Alliaan I don't think grief can have a definition, because there aren't adequate words to describe it. It's not an emotion; it's a way of life. I don't just wake up in the morning feeling grief; I live it every day. I've heard and like the analogy of the leg amputee—having a vital part of you severed forever, going through many stages of recovery and therapy to learn to walk without it, experiencing intense pain, but eventually beginning to walk again. With grief, the beginning steps are extremely clumsy, and there are falls, frustrations, and disappointments. So much energy is spent on just finding balance so that you don't fall into some deep, bottomless pit. Eventually you can take small steps, which slowly become walking again. Even so, one will never have the same stride they once did, nor even the same ease and confidence in walking they once had. Grief knocked my feet completely out from under me. I am walking again. But my gait will never be the same.



Audra Grief comes uninvited, envelopes your life, and is allconsuming. It's inescapable, although in time we learn to cope with it and compensate. It ebbs and flows, some days fading, and some days, unprovoked and unannounced, it is there, painful as ever. There is reprieve and armor for the struggle—in our inner strength, our faith, and in our experiences of love.

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Arather Grief is almost indescribable. Many people have said to me, "I can't imagine how you must feel." I have learned, for the most part, they really can't. Nor would I want them to—I wouldn't wish this on anyone. Immediately after Connor's death, the grief in me was overwhelming: It was the one emotion that overruled all others. I lived my daily life in total grief, going through the motions of daily life, but feeling nothing but total, overwhelming grief. Now, others outside my grief want me to stop it, and stop it quickly, because it is uncomfortable for them. But I love Connor so much it literally hurts. He is worth every bit of the time and energy it is taking me to grieve his death. My grief is indescribable, but the words I would use in some attempt at defining it would be: okay, natural, life-altering, never gotten over, all-encompassing. Grief defines me now more than I can ever define it.



Tania Grief is the very natural, human process for healing emotional injury. It is individual. When I lost my lovely daughter, I lost my breath. Like my other two daughters, she was everything to me. When she died, I felt there was no way I could breathe without her, live without her. When grief knocked on my door, I could not recognize what life was anymore. Grief affected me completely-emotionally, physically, and mentally. I felt extreme, intense sadness, fear, anxiety, anger, depression, loneliness, confusion, helplessness, isolation, and guilt. I lost, for a while, the ability to feel love or to give love, thinking all the while I was going crazy. But I know I am not going crazy. I just know life differently now. Good things, happy things, are slowly returning to my daily life. I love being a mother to my two daughters at home. They have and always will be great joys to me. But my lovely daughter Lanika died. She lay dead next to me in a box, and I had to put her in the ground and say a final goodbye to her. I am not done with my grieving process. Grief is natural. Grief is individual. And I am not done.

GRIEF DEFINED



REFLECTIONS

FOR THE GRIEVING PARENT: How would you define your grief?

FOR THE FAMILY AND FRIENDS OF A GRIEVING PARENT: What have you learned about grief from these definitions? Is your definition of grief different from your loved one's definition?

Vicky I am an outsider looking in on these women's grief. I have never experienced what they are experiencing. I have not lost a baby. My closest experience to what they are living was when my eighty-four-year-old grandmother, whom I loved and cherished very much, died. My grief over her passing was extremely intense, but it was different from what I see Audra, Heather, Linda, Tania, and Allison experiencing. My grandmother lived a long life, blessing me for over forty years, and although I greatly mourn her absence, my beloved grandmother's death followed a "proper order" in the cycle of life. It is significant that I was given ample time to say goodbye to her. Sometimes I still cry when I recall my lovely memories of her. Yet I know that what Audra, Linda, Heather, Tania and Allison are experiencing is much deeper and more intense than anything I've felt in the wake of my grandmother's death. I have no right to say to these five women, "I know how you feel," because I don't. Their grief over their babies and my grief over my grandmother are two very different types of grief. They can hardly be compared. When I lost my grandmother, I lost a part of my past. When these women lost their babies, they lost a significant part of their future. The grief after the loss of a baby is very distinctive, with its own considerations, challenges, and depths, and it must be acknowledged as such. I want to try to better understand this very unique type of grief, to try to fathom it, so that I can ultimately know how to better help Audra, Heather, Linda, Tania, Allison, and other grieving parents. And so, I will not begin an attempt at defining this type of grief. Although I have dealt with many parents whose babies have died, I confess my ignorance. I have never really listened to their pain. I will open my heart and listen to these five courageous young women, for I know they have much to teach me.

