

Afterthought

Marlene Harris Austin

THE FLASHING RED LIGHTS, which transposed the familiar objects of our yard into illusionary images, seemed no stranger than the events of the evening. Three hours earlier we'd been a happily pregnant couple. Now we were the parents of two critically ill babies. I looked at my husband's anxious face and knew, as his silhouette was blocked from my view by the closing ambulance door, that a part of our lives was closing.

Roy and I had been married a year, members of our ward and community for three months when, on 14 October 1979, I delivered twins three months prematurely. Our son, Anthony, died three days later; our daughter, Elizabeth, born weighing two pounds, spent eight months in the intensive care unit of Boston Children's Hospital. Most "premies" her size are released from the hospital after three months; Elizabeth remained on the respirator nearly that long. A collapsed lung followed, then frequent bouts of congestive heart failure, dangerously unbalanced blood chemistry levels, and finally she was unable to keep down her feedings. Her physical ups and downs became an emotional roller coaster for me. But my crisis was not limited to grieving for Anthony or fearing for Elizabeth.

During the eight months following the birth of our twins, the bishop spoke to me twice—in the foyer. The Relief Society president called me once to get directions to the hospital so she could visit another

MARLENE HARRIS AUSTIN, a BYU graduate, lives in Westford, Massachusetts, with her husband, Roy, and their daughters Jennifer and Elizabeth, who is now a healthy fifth grader. She has published a book of poems, "Daffodils to Thistle Down," and is currently educational director for a butterfly park (the fourth in the USA), maintains her own business, Nature's Fantasia, and writes screenplays.

ward member. Her replacement visited once, as did our home teacher. My visiting teacher, the only person I knew in the ward, seemed uncomfortable, never reciprocated my calls, and finally asked to be replaced. The new visiting teacher never contacted me. Two thousand miles separated us from our families. Our parents' weekly calls and the hand-quilted baby blankets sent by family members could not substitute for the protective shelter of their presence. I felt destitute in a society that had promised to sustain me. It would take many years and laborous study to reconcile Church teachings and my experiences—or rather, my perception of those experiences. Depression and pain permeated those perceptions and the memories that I recall so clearly.

I felt peaceful and calm as we held our son while his sweet spirit quietly slipped from his tiny body. I felt a deep longing for him, a swelling sorrow but also a placid tranquility. This, I thought, was the way truly converted Christians grieved. My testimony of the resurrection and celestial families, my strong faith in God and his love for us would spare me the pain others associated with death. My seminary teacher's words came back to me: "If you have a real testimony and understand the plan of salvation, death will be a joyful event."

But within weeks, the positive feelings gave way to desolating loneliness. Any solace prayer brought rapidly slipped away as I recognized with absolute completeness the implications of my closing words, "Thy will be done." Conversations with my husband helped renew my knowledge of the doctrine concerning life after death but did not reach into the emptiness that engulfed me. Questions overwhelmed me. God had a reason—either a regimented eternal plan or simply a mortal body unable to sustain life. But why Anthony? Why us? If blessings are rewards for goodness, then what are life's difficulties? What had we done to deserve this? Even when you rationally don't believe such things are punishment, it's hard not to think, "If only. . . ." Why did priesthood blessings and joint faith seem ineffective? Consolation from Church members seemed ineffective as I continually feared that Elizabeth, too, would die. Nothing I had ever learned had prepared me for such a devastating ordeal.

Typical conversations with ward members included an inquiry about Elizabeth, a pause for a brief response, then a story about another "premie." Though well meaning, stories of "amazing recoveries" didn't help. Why couldn't our little one make such progress? I wondered. Stories of babies with severe problems sent me into despair. Would Elizabeth, too, develop such problems? I needed to talk, not listen; I needed someone to care about my pain.

After Anthony's death, almost no one acknowledged that we had ever had a son or might grieve for him. Ward members asked about

“our baby.” Some could not remember which had died. Other rigid, unfeeling comments were more than I could deal with, frazzled and depressed as I was. Elizabeth, at seven days, began showing signs of a heart problem requiring either an experimental drug or surgery. When I told a close friend that I wanted my daughter to live, she quickly corrected, “No, you want Heavenly Father’s will for her.” I attempted a compromise. “I want Heavenly Father’s will to be for my daughter to live.” “No,” she replied emphatically, *you want God’s will for your daughter.*” This conversation, like others that followed, left me feeling misunderstood, misjudged, and isolated.

Roy and I had few outlets for our fears for Elizabeth during the many months she remained in jeopardy. Some acquaintances wanted us to see the bright side—“You must be happy that your daughter is doing so well,” we heard—even though her condition was critical. Few took time to find out how she really was. Others ignored my fear and wanted me to do likewise.

I wanted to know more about celestial families. What did it mean to “raise” a celestial child? To feed him? Teach him to walk? Does a child living in paradise need to learn about baptism or repentance? Other questions seemed more weighty. If our son were in such a wonderful place, was it right to keep his sister from joining him?

The question “Why did this happen to us?” had the most distressing possibilities. Was our son’s death and our daughter’s inability to get better somehow related to the way we had been or were living? Several ward members had insinuated that I, because of my weaknesses, was responsible for the situation. When I mastered the lessons I was supposed to learn from this, they said, God would make our daughter better. My first reaction was fear that they were right, but the more I thought about these comments, the angrier I got. Why would God use this experience to teach me patience or trust when others learned such lessons by broken washing machines or hectic Seminary schedules? Would God really put our babies through this to teach us a lesson?

It seemed that everything I heard in Church suddenly took on devastating implications. “You can do anything if you have enough faith,” heard in its many forms, only filled me with anguish. Did I (or we) simply lack faith? Requirements for celestial glory now seemed threatening. Temple marriage had always meant united and reunited families to me. Now the emphasis was the perfection of the family members. I must be perfect to be with Anthony again. But how could I possibly serve others when I didn’t have time to cook? When was I supposed to write in my journal, study scriptures, or become involved in community affairs? My mind was weary and anxious (not faithful)

and filled with anger (not appreciation for those around me). I wanted to scream when we received an article with the line "Worrying is sinful" underlined in red. I felt panicky realizing that I seemed to be rapidly drifting farther and farther from perfection.

By mid-December these feelings, coupled with exhaustion and anxiety, began to affect my health. I frequently lost my balance and had difficulty focusing my eyes—especially on Sundays. Roy suggested that I ignore distressing comments at Church, but nothing seemed to help.

When the hospital social worker who acted as our liaison with the staff asked about my personal health, the floodgates opened. After listening to my story, she explained that good, religious people are not always able to help people in mourning or crisis because they lack experience and because they are coping with their own problems. I felt relieved and revived.

Later I shared this conversation with the woman who had been my visiting teacher, still my only friend. "You talked to the social worker about problems with the Church?" she asked, appalled. "What will she think about the Church now?" I was a traitor.

Subsequent sessions with the social worker were tainted by shame and guilt. Conversations with my "friend" became less frequent and more awkward. But I was not left totally adrift. Two weeks later I received a phone call from Mary, who was to become my confidante. It took the sensitivity of a woman going through strenuous difficulties herself to reach out to me. When I expressed feelings Mary did not understand, she accepted them. When she did understand, she helped me understand myself. Most important, however, Mary cried with me.

Though we had received little emotional support from the ward during Elizabeth's hospitalization, I assumed we could get help with extensive medical care when Elizabeth was released from the hospital. When I talked to a sister in the visiting teaching program, I expected the usual, "You know you can count on the Relief Society." Instead she said, "Oh, you're strong. You'll do fine." Even when I asked, I couldn't get help.

Elizabeth was finally released from the hospital on 16 June 1980. I was elated as I carried her down the hospital steps I had fearfully climbed so many times. But my exultation was short lived. The second night home, she choked, her lips turning a dusky hue we'd seen in the hospital. But this time I was to decide upon and apply any intervention necessary to restore her normal breathing. Should I try chest therapy—pulsating thumps to loosen the secretions that blocked her breath-

ing—or should I force a thin tubing down a nostril to her throat, then try to suck the obstruction out? Her life was literally in my care.

Our stress continued. Elizabeth required oxygen for ten months and had to be fed through a surgically inserted stomach tube. Each of her five daily feedings often extended beyond the usual hour; she frequently regurgitated and had to be fed again, then monitored against choking. I dreaded measuring the seven medications that accompanied each of her feedings. Within weeks the sharp-edged rims of the medicine bottles had cut my fingers until they bled. Fear sent me scurrying each night to her crib to count her respirations. She was at high risk for respiratory infections and Sudden Infant Death Syndrome. The doctors could not guarantee that she would live. I stayed home on Sundays with her, afraid to expose her to infections. I also lost touch with the hospital social worker. Elizabeth's release from the hospital signaled to those around us that life was back to normal, that grieving and worrying were in the past. In spite of Elizabeth's extensive care, I was told to pickle my cucumbers and become a confidante to a distressed neighborhood teenager. Each suggestion pushed me into a deeper depression. With passing months, my pain only intensified. I often fought back tears and longed for just a few moments of respite from the constant pressure and fear.

The thought of my son's small grave covered with snow under a barren maple tree was never far from my mind. But worry about Elizabeth had never allowed me time to grieve, to quietly contemplate or find answers. Now we were on our own with a very sick child, with only winter weather, germs, and hospital appointments to look forward to.

I was alone, sequestered as much by my feelings as by my circumstances. I was separated from my son, frightened for my daughter, and unable to communicate or connect my grief with my husband's grief. In retrospect, I think Mary's deep caring and influence, my husband's and family's quiet support, and the gospel saved me from mental collapse. Though the gospel was a source of strength for me, I felt alienated from its source and the culture created by it. I needed help.

Finally my husband suggested I talk to someone at LDS Social Services. Every week I carried Elizabeth and an oxygen tank tangled with tubing up the stairs to his office. He reinforced some of the concepts the hospital social worker had first shared with me, understood my schism with the Church, and helped me explore my deteriorating relationships with ward members. After nearly a year of counseling, he suggested that I talk with the bishop.

I made an appointment, and on a rainy Sunday I walked into the bishop's office. I remember only his first comment, which interrupted my well-planned dissertation. In one short paragraph, he told me that I had been rude to the sisters and that they had responded to me accordingly.

That night, for the first time during those difficult months, I felt I could no longer go on. I cried, begging my husband to join me in taking our daughter's life, then our own. I felt no darkness or wickedness about those longings. I simply could see no way out, no way to change the situation which (according to the bishop) I had caused. I couldn't deal with my grief any longer. I wanted to be with my son.

Three days after my husband's gentle refusal, the longing left me — but with a new dimension to my devastation. I now understood my potential to do evil. I began seeing a psychiatrist, but real healing did not begin until later, when I met Elaine, then Sandra.

Elaine moved into the ward a year after her three-day-old baby had died. Initially we compared our experiences and shared our grief, but then we began to explore how our experiences affected other facets of our lives. Because of her pain, Elaine had become obsessed with shopping, and the family was on the verge of bankruptcy. She and her husband seldom spoke, but our bishop would not refer her to LDS Social Services. Several weeks later, she tried to commit suicide. She and her husband divorced, then remarried.

Sandra moved into our ward less than a month after her baby died of a congenital problem. I lost contact with her when she and her husband relocated, but many of her comments evoked painful memories and led me to an important discovery: My reactions were normal.

Elaine's and Sandra's responses to loss were startlingly similar to mine. None of us questioned the reality of our babies' external existence or of God, even though we felt a deep loss. We were frustrated by the inability of others to help us and felt misunderstood. We quoted at length similarly painful comments others had made to us. I began to realize that I was not selectively abandoned, nor were my feelings extreme or exaggerated.

Our discussions loosened the unrelenting negativism that had caused me to blot out the kindnesses extended to us. One couple had taken us out to dinner; another had babysat several times; several sisters had driven Elizabeth and me to the hospital for her check-ups; two LDS doctors not only helped save Elizabeth but spent extra hours, precious to any doctor in that unit, giving us emotional and spiritual support. Even being able to recall such things was a breakthrough.

As I began to readjust my perceptions of reality, I understood that my expectations and the expectations of the people in my ward had

been too high. I expected to be the recipient of loaves of lovingly baked bread or to have my house cleaned with a willing smile—like the examples in visiting teaching meetings. My visiting teacher found no reason to clean floors as clean as her own. She'd heard of grief vanquished by prayer and concluded that I did not need comforting. I hoped for an inquiring call—like the calls mentioned in testimonies. Our home teacher seemed to be intimidated by the pain he might encounter. He seemed to find it easier to recall the promises of celestial units and to ignore the agony of broken mortal families. I cried for the wise, loving counsel of a caring bishop—as discussed in *Ensign* articles. The bishop was busy raising money for the building fund and inspecting blueprints. New in his calling, he lacked the training and sensitivity to express his concern or love.

When I realized how inappropriate my expectations were, I was angry at the Church. I had learned those expectations from my fifth-generation Mormon family, from Mormon culture, Mormon meetings, Mormon lessons. I recalled remembering the statement, “The church is the same everywhere. There are always those to love and care about you,” while I fed Elizabeth for the second time in an hour, wondering when I could cook dinner, when I could sterilize oxygen equipment and hold compresses on my baby's inflamed gastrostomy incision. I had quit reading Church magazines because I could no longer relate to the rosy idealism I found there. “We grew spiritually,” seemed to be their most common response to death or despair.

I didn't doubt the truth of such statements, but they were too easy and incomplete. I also had grown. I had learned about the nature of God (he sustained Elizabeth's life, but only after medical experts had been unable to), mortality, and suffering. I had learned, but not in the one-dimensional way the articles portrayed. I found no mention of the searing, agonizing pain that forced growth. The feelings the articles related were those of the first, numbed days before reality became inescapable, or years later after wounds had healed. At best, the articles refer briefly to the depth and duration of the pain that bridges those two eras. These articles and Church lessons had been my guide on bereavement. I had felt betrayed and frustrated at having been ignored, but this later discovery left me incensed. I felt deceived by an organization that required me to remain a dedicated participant if I wanted to have my baby again.

In time I reevaluated our experience. We had been neglected, but for a reason. The only communication I had received from any of the more than 250 who throng to our family reunions had been a survey for a family history. But we did live two thousand miles away. Clearly we needed more support from our ward, but we had recently moved

into a large, transient ward which was adjusting to a new bishopric and the stresses of building a chapel. We may have made ward members uncomfortable, the death and illness in our lives confirming the same possibilities for other ward members. If I had had appropriate expectations, I'd have been less distressed, more easily and comfortably supported. My assumptions about the grieving process and Heavenly Father's will to remove difficulties from our mortal lives elongated my grieving. I had set myself up for failure, and it had come—accompanied by exhaustion and fear. Guilt and questioning had demoralized me even further. I had expected to continue on normally, pleasing everyone I encountered.

My expectations of others were even more unrealistic. I thought ward members could remove my sorrow and solve my problems. I thought they would intuitively understand my feelings, know what to say, when to call, how to support me. This crisis seemed so immense to me that I supposed it would be important to others. I believed that the welfare system succeeded because members were willing supporters. I didn't realize that friendships were an essential part of the network. Roy and I had had little opportunity to build relationships. But I hadn't thought about that as I waited expectantly for the loving support I'd always heard about.

My talks with Elaine and Sandra helped me understand the ward members' expectations. Observers' assumptions (often learned from the same source as mine) were equally unrealistic in their cases. Some had never experienced grief. Sandra was astonished when an aunt repeatedly told her that she and her husband would have as many babies as Heavenly Father wanted to send them, even if they lost them all.

Most people believe, and I probably did too before this experience, that there are right and wrong ways to grieve. Grieving should only last a few weeks or months; if it continues, the bereaved is not "trying" hard enough. Gratitude for what we have or having another baby will chase away sadness. Longing can be eased, the emptiness in our arms and hearts will subside if we don't spend too much time at the cemetery, or if we keep busy. We must learn from our experience to help others.

Staying busy did not keep us from thinking. Sandra found herself baby-sitting a ten-month-old for a week. Relatives felt she needed "a baby to comfort her" when what she wanted was some time alone. When she asked someone to take care of her children, she was told, "I would think you would want them with you at a time like this." Grieving is not only painful but requires time, energy, and a great deal of thought. The rejection I received when I expressed my need to grieve led me to conclude that such needs were wrong. The guilt I felt

produced more depression. In time I have learned that grief is an individual experience; the only rights and wrongs are in being true to myself.

People were uncomfortable with fears about Elizabeth. "Be patient and have faith," I was told, even though our son had died and her LDS doctor had cautioned us about being too hopeful. I couldn't be totally positive about her convalescence; I had hit rock bottom many times when my expectations (and the doctors' estimations) had proven overly optimistic. "Oh, come on. Where's your faith?" one sister remarked when I told her how long the doctor expected Elizabeth to remain on oxygen. I wondered if she wanted our situation to improve so she wouldn't have to think about it. Later I realized that I was upset because she reinforced my own inner fears that my faith (or something) was lacking.

I was moving in cycles. I felt inadequate and worthless. When others did not relieve my pain, I felt ignored, abandoned, and rejected. This led to more self-condemnation and deeper depression. Those who anticipated that I would react with more visible strength were put off by my despair. Each unfulfilled expectation weighed on me.

I spiraled downward. Who had been at fault? Me for expecting? Them for disregarding? Had there been a fault? And yet the pain had been so intense that I had reluctantly stepped into the bishop's new office on a dreary day and had walked out wanting to take my own life. Elaine had gathered bottles from her medicine cabinet; Sandra had not spoken to her husband for two weeks. What did we need that we did not get?

I needed to know that Heavenly Father loved me, that this awful occurrence was not a punishment or a curse. I needed support from those around me to prove that I was worthy of divine love. My husband and I did not starve without homemade bread, but it would have meant a great deal on any one of those cold, dark nights when we came home late from the hospital and I still had to prepare a meal. I needed it to know that someone cared. I didn't need telephone calls to fill my time or answer my questions—they would have helped during those lonely days while Elizabeth was in the hospital when I, finding it too painful to think of Anthony, thought of her and repeated over and over while the laundry swished in the washer, "Breathe, baby, breathe. Beat, heart, beat." Yes, calls would have helped fill my thoughts, but I needed them more to know that someone else thought of me. I didn't have to have help once Elizabeth came home. But I needed someone to show me that I was still valued.

Now that I know these things, what would I do if another Elaine or Sandra moved into our ward? I would treat those who suffer with dig-

nity. Rather than reminding them how much more bravely, trustingly, or rapidly another has healed from a similar experience, I would compliment their strength and show sincere admiration for the way they are sustaining themselves. I would be loving, realizing that those in great need must use their energies to maintain themselves, mentally, emotionally, and spiritually, sometimes at the expense of others' feelings and needs. I would try to rid myself of any impulse to judge others.

Supporting someone in distress means giving your time, opening your heart, allowing yourself to feel another's pain. Don't expect to heal or even cheer one who is grieving. Don't feel responsible to rid them of their grief. Instead, provide a loving, supportive atmosphere in which they can heal themselves. Be patient. Help them realize they should accept themselves and their feelings. Finally, even though we all want to feel needed, wise, and successful, such desires in these situations must become secondary to those of the bereaved.

Knowing what to say can be difficult. But even the wrong words coming from a loving person can be dismissed. Love and acceptance are the key. Mary knew about love, about sharing pain, about listening, about gentle questions that helped find answers.

Linda knew about love, too. A college friend, Linda was a member of a ward that we visited near the hospital. "I heard about your babies," she said as we stood alone in the chapel. "How are you doing?"

"Oh, we're all right," I replied, in the nonchalant act that had gotten me through numerous recitations of our story.

She took my hand, "How are you *really*?"

I couldn't speak, but I didn't need to; her eyes filled as readily as my own, and for that moment I was not alone.