

## Creating Memories of a Brief Life

It's no longer considered 'dysfunctional' to mourn an infant's death.

By Amy Kuebelbeck

Excerpted from *"Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life"* (Loyola Press).

Like those who sought to reclaim respect for childbirth as a natural process rather than as a medical procedure, some people are now attempting to do the same with death. A nascent "dying well" movement is emphasizing dignity, hospice care, better pain management, and other approaches that allow for the profound spiritual and emotional growth that can happen at the end of life—both for the person who is dying and for the ones left behind.

Similarly, we are now also on the cusp of a significant cultural shift regarding infant death.

Parents are beginning to be encouraged to cherish and honor their children in tangible ways, and they are finally being allowed to grieve. Driven by the persistent efforts of bereaved parents, who began actively seeking reform in the 1970s, many hospitals have adopted more sensitive practices and offer support groups and professional counselors for parents who experience miscarriage and infant death. Efforts also are under way to improve care for parents who experience losses earlier in pregnancy; for example, some parents are lobbying for hospitals to provide options other than routine incineration for disposing of babies' remains. Several national organizations now exist, including the National SHARE Pregnancy and Infant Loss Support Inc., founded in 1977 by Sister Jane Marie Lamb, O.S.F., and now based in St. Charles, Missouri. The Compassionate Friends group exists for parents who have lost a child of any age.

Inspired by Richard Paul Evans's best-selling book *The Christmas Box*, about a fictional woman mourning at the angel monument that marks her young daughter's grave, communities around the globe are erecting angel statues as memorials to babies who have died. Memorial sites like these are giving parents—especially those who do not have a gravesite to visit—a physical place to grieve. Even parents whose babies died many years ago are seeking out these memorials for solace, grateful that after so much time someone is finally acknowledging their loss and their sorrow.

Fewer parents today must endure the death of a baby. The infant mortality rate has dropped considerably in the United States since the early 1900s, when an estimated 10 percent of all babies died before their first birthday. The rate is now less than 1 percent. But that still represents a lot of babies—and a lot of grieving parents. About twenty-eight thousand infants a year die before their first birthday. About a million U.S. pregnancies end in miscarriage or stillbirth every year, with about twenty-seven thousand of those babies dying during the second half of pregnancy.

In part because of the loving work of parents whose profound loss was minimized or ignored in the past, many newly bereaved parents are now encouraged to hold their child's body and to view that tender act as healthy and natural. They are invited to create memories with their child: to rock their baby, to give their baby a name, and to take photographs of their baby. If the idea of taking photographs is too painful for the parents to contemplate, hospital staff sometimes take pictures and keep them on file in case parents want to see them later. Nurses help parents collect priceless mementos such as handprints, footprints, and a lock of hair. Parents are encouraged to hold a memorial service of some kind and to wait until the mother is physically able to attend.

Caregivers are often awed by parents' capacity to love the pure essence of their child, even if the baby has obvious physical malformations. Many parents are able to acknowledge their baby's physical imperfections while also lovingly noticing the parts that formed perfectly, perhaps long eyelashes, graceful fingers, a nose like Mom's or a chin like Dad's.

These parents will not be leaving the hospital with a baby, but unlike far too many heartbroken mothers and fathers in the past, they will at least be recognized as parents of a unique, irreplaceable child.

