For many parents whose baby dies before or after birth, their tragic loss comes as a sudden, unexpected, blinding shock. Just as their world is shattering and they may feel as though they can barely breathe, they are asked to make immediate decisions. Accepting the offer of beautiful and healing portraiture from Now I Lay Me Down to Sleep requires a soul-baring leap of faith. Caregivers who gently offer the option of photography to these stunned parents, photographers who discreetly and skillfully capture parents’ grief and love, and parents who bravely open their broken hearts to strangers all join together in a profound encounter that will bring consolation for years to come.

For a smaller but growing number of parents, their shock came many weeks or months earlier, when prenatal testing revealed the devastating news that their baby likely would die before or soon after birth. The shock and terrible heartbreaking is the same. But these families often find that the advance warning gave them a gift—a gift of time to absorb the news, time to celebrate the baby, time to make plans for the baby’s birth as well as the baby’s likely death. For many of these parents, an essential element of their plans is photography.

I was one of these parents. In 1999, midway through my pregnancy with my third child, my husband and I received the crushing news that our baby had an incurable heart condition and would likely die within days of birth. We gradually absorbed the news and began to make plans. This was six years before NILMDTS was founded, and the idea of taking photographs of a dead or dying baby was still considered macabre; most people were horrified by the idea.

Online support for grieving parents was essentially nonexistent. Facebook and Twitter hadn’t even been invented yet. There was virtually nothing for people like me who had received a life-limiting prenatal diagnosis and were continuing their pregnancies. But in my desperate search for information, I stumbled across a little handbook about stillbirth. In it was a low-quality, poorly composed, amateur snapshot of a mother and father cradling their stillborn baby. The photo was so powerful that it made me weep. And it made me want photos for myself.

I decided that I wanted pregnancy photos too, even though at that time photos of bare pregnant bellies were still considered slightly scandalous—something only for celebrities like Demi Moore, whose nude pregnancy photo on a 1991 Vanity Fair cover was groundbreaking and controversial.

I found a local photographer, Claudia Danielson, who specialized in elegant black-and-white images of pregnant women and newborns. She had never photographed anyone in a situation like mine before, but her heart was overflowing. She said how sorry she was and that she felt honored to help us honor him. Our session with her, when I was

The photo was so powerful that it made me weep.

And it made me want photos for myself.
eight months pregnant, was filled with a spirit of joy and commemoration. It felt sacred.

And when it came time for Gabriel to be born, I had already instructed my mom and sisters and a close friend to bring their cameras and take as many photos as they possibly could, even if they thought what was happening was too sad. I even took photos myself. Although I wish I could have had the kind of professional-quality photos offered by NILMDTS, I am deeply grateful for the photos I do have. They capture Gabriel’s brief life—9 months before he was born, and 2-1/2 peaceful hours afterward—in ways that words cannot.

Since then, I have helped spread the word to parents and caregivers about ways to support parents like me who receive a life-limiting prenatal diagnosis and wish to continue their pregnancies and embrace the baby’s life for as long as it may last.

In addition to writing my books Waiting with Gabriel and A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief, I work to advocate for perinatal hospice, also called perinatal palliative care. This is a model of care that, like NILMDTS, developed after I needed it but is now helping countless other families.

As prenatal testing continues to advance, more families are finding themselves in this heart-rending situation. For parents who choose to continue their pregnancies, perinatal hospice and palliative care provides support from the time of diagnosis through the baby’s birth, life, and death, caring for the baby as well as the family with dignity and love.

Perinatal hospice is not a place. It can be thought of as “hospice in the womb” (including birth planning and preliminary medical decision-making before the baby is born) as well as more traditional hospice and palliative care at home after birth (if the baby lives longer than a few minutes or hours). It includes emotional support for the family and basic newborn care such as warmth, comfort, and nutrition, and it can also include medical treatments intended to improve the baby’s life. Perinatal hospice can easily be incorporated into standard pregnancy and birth care.

As of this writing, about 250 perinatal hospice and palliative care programs have been developed around the world and are listed at perinatalhospice.org. Perinatal hospice is a beautiful and practical response to one of the most heartbreaking challenges of prenatal testing.

Perinatal hospice is ideally suited for photography. Parents who choose perinatal hospice have the gift of time to absorb their baby’s diagnosis and prognosis and to make decisions and plans.

They have time to realize that although their original hopes for their baby’s life have been destroyed, they still have a profound opportunity to parent their child and create new hopes: hope that their baby will be loved, hope that their baby will be treated with dignity in life as well as in death, hope that their baby will be remembered. They have time to learn about remembrance photography and NILMDTS, time that allows them to move beyond what can sometimes be an initial reluctance about this kind of photography. They have time to schedule a pregnancy photo session and perhaps develop a relationship with a specific photographer for the birth. They have time to intermingle their grief with joyful anticipation of their baby’s arrival—and photography is often a key part of their excitement.

Whenever I hear from a pregnant woman who has received a devastating prenatal diagnosis and is waiting with her baby, just like I was back in 1999, my basic advice is always the same: Embrace this time with your baby, write a birth plan, and make plans for photography. A photographic record of this fleeting time together before and after birth is, truly, a gift.

Amy Kuebelbeck, a former reporter and editor for The Associated Press, is author of the memoir Waiting with Gabriel: A Story of Cherishing a Baby’s Brief Life (Loyola Press, 2003) and lead author of A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life Is Expected to Be Brief (Johns Hopkins University Press, 2011) along with Deborah L. Davis Ph.D. She edits the website perinatalhospice.org and posts at facebook.com/perinatalhospice and on Twitter at @PerinatalHospic. She lives with her family in St. Paul, Minnesota.