

Continuing your pregnancy when your baby's life is expected to be brief

You may have just received prenatal test results that reveal the heartbreaking news that your baby is not expected to survive very long after birth. This news is shocking, confusing, devastating.

*How can this be?
What do I do now?*

One option is to continue your pregnancy and embrace whatever time you may be able to have with your baby, before and after birth. A growing number of parents are welcoming this option.¹

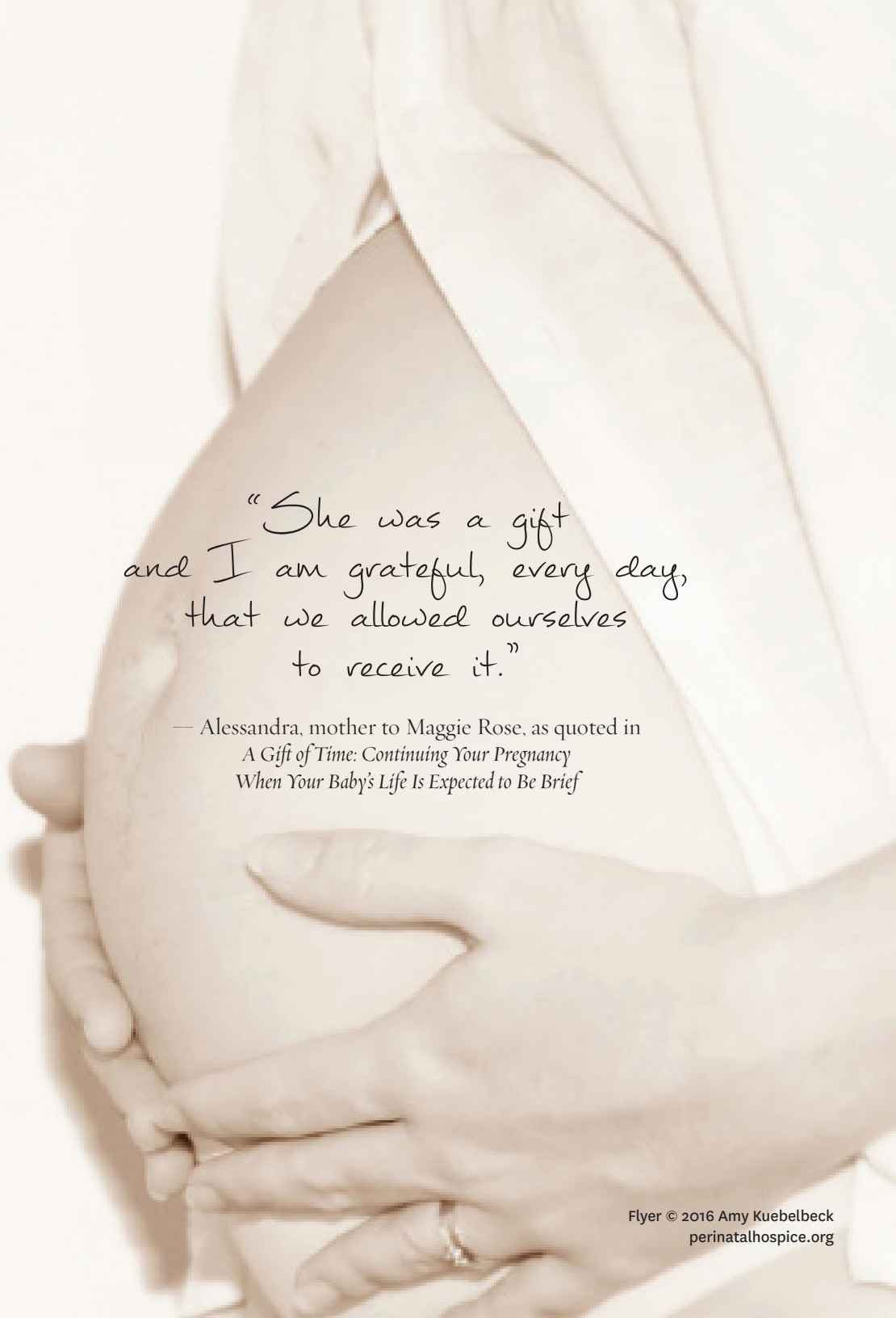
If you are considering this path, much support is available² and you are not alone. Many hospitals offer specialized care for families like yours, providing support throughout the remainder of the pregnancy and providing exceptional care for the baby and family during and after birth. Sometimes called perinatal hospice or perinatal palliative care, this support includes planning for your baby's birth, making preliminary medical decisions about care for your baby after delivery, providing emotional support for the family, and assisting with memory-making such as photography. Palliative care follows the baby's lead and can also include medical treatments if needed to improve the baby's life. You can ask your caregivers if they have a program, or visit perinatalhospice.org to see if there is a program near you. Even without a formal program, you can work with your caregivers to create a loving experience for you and your baby.³ You still have a profound opportunity to parent your child. Parents who have traveled this path before you have found that it can be a beautiful, deeply meaningful, and healing journey.

Continuing the pregnancy is not about passively waiting for death. It is about actively embracing the brief, shining moment of this little life.

¹ "The science suggests that perinatal palliative care is welcomed by parents and is a medically safe and viable option." Wool C. State of the Science on Perinatal Palliative Care. *Journal of Obstetric, Gynecologic & Neonatal Nursing*. 2013 Apr 11.

² See perinatalhospice.org for many resources for parents and caregivers, including an international list of nearly 300 programs.

³ See *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* by Amy Kuebelbeck and Deborah L. Davis Ph.D. (Johns Hopkins University Press, 2011).



*"She was a gift
and I am grateful, every day,
that we allowed ourselves
to receive it."*

— Alessandra, mother to Maggie Rose, as quoted in
*A Gift of Time: Continuing Your Pregnancy
When Your Baby's Life Is Expected to Be Brief*