

SUPPORTING FAMILIES WHO RECEIVE A PRENATAL DIAGNOSIS

Pregnancy should be a time of joyful expectation. But what if the baby is believed to have a disability or a life-threatening health condition? Prenatal screening is quickly becoming a routine part of obstetric care, in many cases using a simple blood test to screen for such conditions. Because of the growing frequency of this testing, parents are increasingly told by their doctors of potential problems with their pregnancies and are encouraged to abort, or to have additional tests done to determine a diagnosis.

It is worth noting that a screening is meant to detect the *potential* for a disability or illness and is not diagnostic. A diagnosis requires further testing, and there is evidence that screenings are not as accurate as many believe them to be. Additionally, even with further testing, doctors sometimes misdiagnose a baby who is then born completely healthy. Often, however, the diagnosis is accurate.

For parents, the news of a prenatal diagnosis is crushing. They may not know what to do or where to turn. They may anguish over what medical decisions would be best for their baby and wonder how to approach the rest of the pregnancy. All too often, they are advised by physicians, and sometimes by family, to schedule an abortion. Tragically, many parents are told that it would be best for everyone, including their baby, to have the abortion—even late in the pregnancy. Many feel great pressure to do so and may fear continuing their pregnancy.

In some cases, the diagnosis may indicate that the baby is expected to die before or shortly after birth. As parents face the heart-rending knowledge that their *hello* may also be their *goodbye*, those around them may wonder how to provide the best support.*

"I felt numb from hearing the diagnosis, and my reaction was to do anything to get out of this pain." — Christina¹

A model of care has been developed specifically for families whose infant is likely to die before or after birth. Often called "perinatal hospice," it's a way of caring for both the baby and the baby's family before, as well as after, birth.² The word *perinatal* refers to the time before and after birth; hospice is specialized care for anyone diagnosed with a serious illness, most often in the final stages of life. Perinatal hospice is not a place; it's a form of support provided by many hospitals and high risk obstetrical practices, in addition to ordinary maternity care.

It includes specialized prenatal care, help with planning for the baby's delivery, and a focus on the baby's comfort after birth. This comfort care includes components such as attention to feeding, warmth, time with the family, and medical treatments when needed. Perinatal hospice nurtures the baby's life for as long as he or she lives. Depending on the diagnosis, some babies live long enough to be cared for at home by their family—sometimes for months or even years. Perinatal hospice provides a model of care that respects the baby's life from conception through natural death. It also honors the baby's family and provides precious moments together—whether the baby is inside or outside the womb—which can be cherished forever.

For Friends and Family

Suppose you have friends or family who recently received a prenatal diagnosis for their unborn child. You may want to be there for them but don't know how. In an effort to ease the sorrow of their loved ones, some people may be tempted to suggest to the parents that abortion is the answer. However, many parents who carried their children to term say that protecting their baby and honoring his or her natural life, no matter how brief, was profoundly healing.

When parents say "yes" to life for their child, they are saying "yes" to the most loving and healing path for all involved. When God invites us to draw close to him by following his commandments (Jn 14:15), he does so because he wants what is best for us. By saying "yes" to life for their child, which is morally good and right, parents are placing their trust in God and embracing their child and the life their child has been given for as long as it is given.

Remember that both the mother and the father deserve our concern. Some may try to comfort parents with comments such as "God needed another angel" or "You're young; you can have another one." Most parents do not find these comments helpful; they want *this* baby. We can help parents by acknowledging their baby, using his or her name, asking about their hopes and plans for their child's birth, and most of all, by *affirming their exceptional role as the parents they already are*.

For the Parish Community

As with any member of your parish who is experiencing a serious illness or death in the family, you can offer practical support like help with meals, babysitting, housework, or yard work. The time between the diagnosis and the baby's birth is filled with medical decisions and plans—for the birth, baptism, recording precious moments together, and even a funeral, if the baby's death is expected. Long before the baby is born, parents may be overwhelmed by their unexpected situation and may welcome the practical support and prayers of the parish family.

For Clergy and Pastoral Care Workers

A very important role is played by clergy and pastoral care workers in helping families who face a diagnosis indicating their child is likely to die before or shortly after birth. When discerning how to minister to such families, they should be aware there are many factors that go into determining the best options of care. To know the particular needs and struggles of a family, it is essential to maintain close, regular contact with the parents.

Because a prenatal diagnosis offers the gift of time to prepare, you can discuss parents' hopes and plans ahead of time. Making the time to talk and pray with them, as well as your gentle presence, can witness to the infinite worth of the life—however brief—of this beloved child of God.

A prenatal diagnosis often raises deep spiritual questions for parents. They may be hearing statements about God "taking" their baby, which can be very difficult and challenging for them. Many parents are comforted by the thought of God being with them and their baby throughout their experience, as well as by the thought of God lovingly caring for their child until they meet again. It may therefore be helpful for you to speak to them on this topic and help them to reflect on it themselves.

Parents also often want to have their baby embraced by the Church, and every effort should be made to initiate their child into the Church through the Sacraments of Baptism and Confirmation. Some parents may also request the Sacrament of Anointing of the Sick in order to obtain healing graces for their child. However, clergy should be aware that this sacrament would not be applicable in this situation. The primary purpose of the Sacrament of Anointing of the Sick is spiritual healing; once a child has been baptized, the need for spiritual healing no longer exists because original sin has been remitted, and he or she is incapable of committing personal sins until the age of reason. If you receive such a request, you might consider offering a general blessing of the child.

There are also other means by which clergy can extend the Church's loving embrace. The *Order of Christian Funerals* and the *Roman Missal* include variations to accommodate children who died shortly after birth, as well as the burial of unbaptized children whose parents intended to have them baptized. As each situation is unique, clergy can refer to the *Order of Christian Funerals* and the *Roman Missal*, as well as *Pastoral Care of the Sick: Rites of Anointing and Viaticum*, to obtain guidance on how to care for the baby and his or her family.

Clergy and pastoral care workers can also help parents by directing them to perinatal hospice care—a life-affirming, practical response to prenatal diagnoses. If there is no program nearby, you can offer additional support to them as they create a perinatal hospice experience for their family. It is also worth noting that, in such situations, many funeral homes offer services at a reduced rate, or even for free, and parents may be grateful for your support or guidance in making funeral and burial arrangements for their baby. Many resources regarding prenatal diagnosis and perinatal hospice are available for parents as well as caregivers, and it may be helpful for you to familiarize yourself with what is available on the local and national levels.*

If someone we know has received a prenatal diagnosis, let us ask the Holy Spirit to work through us. May the families of these little children be strengthened and comforted by our affirmation of the truth that their child's life—however long or short—is worth living.

"The first weeks after David's diagnosis, never in my wildest dreams did I imagine how wonderful and rewarding this journey would be. Yes, it was painful and sorrowful, but I could not imagine the joy that would also be a part of this. David has left us with so much more. I am so blessed to have lived and experienced this little life." — Christina³

*There are support programs and resources across the country, as well as online, to help families that have received a prenatal diagnosis of a disability or life-threatening illness. For more information, please visit www.goo.gl/PZFFXo⁴ for a non-comprehensive list of such resources or contact your diocesan office for Family Life or Respect Life Ministry. A list of diocesan Respect Life Ministry offices can be found at www.usccb.org/about/pro-life-activities/diocesan-pro-life-offices.cfm.



www.usccb.org/respectlife

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1 Quoted from *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* by Amy Kuebelbeck and Deborah L. Davis (Johns Hopkins University Press, 2011). Used with permission. Name changed for privacy.

2 N.J. Hoeldtke, B.C. Calhoun. "Perinatal hospice." *American Journal of Obstetrics and Gynecology*. September 2001; 185(3):343-348.

3 Kuebelbeck, Davis. *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief*. Used with permission. Names changed for privacy.

4 Full URL: www.usccb.org/about/pro-life-activities/respect-life-program/2015/supporting-families-who-receive-a-prenatal-diagnosis-resources.cfm



Secretariat of
Pro-Life Activities

United States Conference of Catholic Bishops
3211 Fourth Street NE, Washington, DC 20017-1194
Tel: (202) 541-3070 Fax: (202) 541-3054
Toll-free order number: (866) 582-0943
www.usccb.org/respectlife www.facebook.com/peopleoflife