

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.

