Perinatal Palliative Care Pathways: Options for Caregivers to Consider





Learning Objectives

After reviewing this Guide you will be able to:

- Name four pathways for care following the diagnosis of a life-limiting fetal condition
- Consider which pathway, or which aspects of a pathway, would work best for your family
- Bring questions and concerns about the options to your medical team

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Introduction

All expectant parents live with some degree of uncertainty, but the knowledge of a life-limiting fetal condition brings a new level of anxiety and stress. For this reason, it is very important for the parents to consider their goals for their baby and their family and to communicate these goals to the medical team. Some parents will decide that interrupting the pregnancy is their best option. Others will want to have time with the baby, if that is possible, even if it means the use of technology and a long stay in the Intensive Care Unit (ICU). Some will want to try to bring the baby home, and others can't imagine it.

Perinatal palliative care focuses on supporting families that need to make complicated decisions about medical care during the pregnancy and after delivery. Conversations between the caregivers and with clinicians can be complex and emotional—especially when there are differences of opinion about how best to care for the fetus and the pregnant individual. Here Natalia Henner, MD, neonatologist and palliative care specialist, describes four pathways for parents to consider and to explore with their palliative clinicians and other members of the medical team.

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Four Pathways

Interrupt the Pregnancy

For some parents, the uncertainty they face is just too big. The prognosis for the fetus may be unclear, and this may cause unbearable stress. There may be ongoing risk to the pregnant individual. Or the parents simply can't imagine continuing a pregnancy that is likely to lead to the death of their baby. Note: This option may or may not be available to all parents, depending on where they live. Consult your maternal and fetal health specialists about available options.

Perinatal Hospice

Some families choose to continue the pregnancy to its natural conclusion of delivery, which may happen near the due date or sometimes earlier. The medical team works to balance the needs of the mother and the baby, taking cues for care decisions from them. The family usually decides not to pursue treatments involving technology (like breathing tubes or feeding tubes). This option involves uncertainty, because how long natural life will last without technology is different with each baby and medical condition. Some babies can be discharged home from the hospital with support from medical and hospice care teams. Perinatal hospice often works with parents who anticipate their baby dying within hours, days or weeks, who accept the natural disease progression, and who prefer to minimize the use of medical technology or surgeries for their baby.

Pursue All Available Treatment Options

Starting with the approach to prenatal care, the family and medical team aim to treat the baby like any other child with a complex perinatal condition. Families that choose this pathway commonly hope for longer survival with the help of every available medical/surgical therapy. Typically, the baby is cared for in the Neonatal Intensive Care Unit (NICU) or the Cardiac Intensive Care Unit (CICU). For some families, this choice results in a complicated hospital stay and lifelong use of medical technology (such as tracheostomy with permanent mechanical ventilation). Some caregivers may find that this approach meets their goals for medical care, based on their definition of quality of life for their child and family. Others become discouraged by the ongoing "medicalization" of their child and may experience diminishing hope of ever getting their child home. And some families, despite all efforts and due to the severe nature of the baby's condition, still experience the death of their child. Most of these families will still feel positive about their decisions, because they know everything possible was tried.

Hybrid (In-Between) Approach

This pathway is for families that are not quite ready to refuse all intensive treatment (and agree to hospice), but who are also not certain that they want all potential intensive care or surgical interventions for their baby. Together with the medical team, they agree to observe the baby after birth, collect postnatal information (such as imaging, labs, baby's natural state or abilities, opinions of medical subspecialists), and to make decisions about the direction of care from there. This approach may require the use of more therapies (like a breathing tube or medications) at the time of delivery to stabilize the baby so that the medical team and caregivers can have the time to gain clarity about next steps. Through this process, they determine what a baby can do on their own and what the treatment options would be. Some families might choose to stop life-sustaining therapies in the ICU, while others continue towards the path of surgical/medical interventions with the potential to re-evaluate whether therapies change the baby's condition in a positive way.

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There are no right or wrong answers for families facing a life-limiting fetal condition. A palliative care clinician can help clarify what feels right to you and your family, and which pathway best meets your care goals. With this knowledge, you will have greater confidence in making decisions with the medical team. You will also find it easier to consider any changes you wish to make over time.

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