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Understanding Extremely Premature Birth

Checked against current guidelines by the Juniper Foundation editorial team. Not yet reviewed by a clinician.

This sheet is for families whose baby was born, or may be born, extremely early. It explains common terms and gives you questions to bring to your baby's care team.

What "extremely premature" means

A full-term pregnancy lasts about 40 weeks. A baby born before 37 weeks is premature, or preterm. The World Health Organization (WHO) uses the term **extremely preterm** for babies born before 28 weeks. Some other organizations draw the line at a different week, so you may see other definitions. Babies born this early usually need care in a neonatal intensive care unit (NICU) for weeks to months.

Gestational age is how many weeks and days of pregnancy have passed. Your baby's team will often say it as, for example, "25 and 3," meaning 25 weeks and 3 days.

Why babies born this early need so much help

At this stage, many of a baby's organs, such as the lungs, brain, gut, and eyes, are still maturing. Common challenges include:

- **Breathing:** the lungs may not make enough surfactant, a substance that keeps the air sacs open. Babies often need breathing support.
- **Apnea of prematurity:** pauses in breathing because the brain's breathing control is still maturing
- **Bleeding in the brain:** called intraventricular hemorrhage (IVH)
- **Bowel injury:** necrotizing enterocolitis (NEC), a serious illness of the intestines
- **Eyes:** retinopathy of prematurity (ROP), abnormal blood vessel growth in the back of the eye
- **Infections**, because the immune system is still developing
- **Keeping warm and feeding**, which take time to learn

Not every baby has every problem. Many problems are treated, and some resolve as the baby grows.

Every baby's path is different

Outcomes for babies born extremely early vary widely. They depend on much more than the number of weeks. Your baby's team knows your baby's details and can explain what they are seeing. The NICHD Extremely Preterm Birth Outcomes Tool gives research-based estimates that families and doctors can look at together. It is based on babies born some years ago at research centers, and it is meant to support conversations, not to be the only basis for decisions.

The NICU journey often has good days and setbacks. That is common, and it does not always mean things are going badly.

Decisions you may be part of

When birth may happen near the earliest point at which babies can survive, families are sometimes asked to take part in decisions about care at birth. These can include full intensive care or comfort-focused care. Hospitals differ in what they offer at the earliest weeks, so ask what your hospital's approach is. These are shared decisions with your care team. You can ask for time, for an interpreter, for a chaplain or social worker, and for the conversation to be repeated.

Questions to ask the neonatology team

- What are the biggest concerns for our baby right now?
- What does a typical next week look like?
- How can we take part in care and in daily rounds?
- What would change the plan?
- Who do we call for an update, and when is a good time?
- Can we meet the social worker and lactation consultant?

Taking care of yourselves

The parent who gave birth is recovering too. Keep your own follow-up visits and know your warning signs. Ask to be screened for depression and anxiety, and accept specific offers of help.

Where to learn more

- Premature birth by gestational age

- Periviable pregnancy and birth
- Common neonatal conditions
- NICHD Extremely Preterm Birth Outcomes Tool, nichd.nih.gov/research/supported/EPBO
- WHO: Preterm birth, who.int

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