

Questions to Take to Your Prenatal Appointments

A printable question guide for families navigating a Trisomy 18 diagnosis. Use the questions that fit your family's needs, add your own notes, and bring this guide to appointments.

PAGE 1 - UNDERSTANDING A TRISOMY 18 DIAGNOSIS

These questions can help you better understand screening or diagnostic results, ultrasound findings, and what additional information may be available about your baby.

Questions for Maternal-Fetal Medicine (MFM)

- What findings have you identified on my baby's ultrasound?
- Are any of these findings commonly associated with Trisomy 18?
- Are there additional ultrasounds or tests you recommend?
- How will my baby's growth and wellbeing be monitored during pregnancy?
- How often should I expect to see the MFM team?
- Should we schedule a fetal echocardiogram or consultations with other specialists?
- What pregnancy complications should we be aware of?
- What symptoms or changes should prompt me to call your office or go to the hospital?
- Can you help us understand what the findings may mean for pregnancy, delivery, and newborn care?
- When should we begin discussing delivery planning and the hospital where our baby will be born?

Questions for a Genetic Counselor

- Can you explain what Trisomy 18 means in everyday language?
- Do the results suggest Full, Mosaic, or Partial Trisomy 18?
- What can the test results tell us - and what can they not predict about our individual baby?
- If our result came from NIPT or another screening test, what does the result mean and how accurate is it?
- What diagnostic testing options are available to confirm the diagnosis?
- What are the differences between CVS and amniocentesis?
- What are the benefits, limitations, and risks of diagnostic testing?
- Could additional chromosome testing provide more information about the type of Trisomy 18?
- Is this likely to have happened randomly, or could a parent carry a chromosome rearrangement?
- Would you recommend parental chromosome testing or testing in a future pregnancy?
- Can you connect us with reliable Trisomy 18 resources and family-support organizations?

Questions About Testing & Results

- Was this a screening result or a diagnostic result?

- Can we receive a complete copy of the laboratory report?
- What exactly was found on the chromosome test?
- If mosaicism was found, what percentage of tested cells showed Trisomy 18, and from what type of sample?
- Could the results differ between the placenta and the baby?
- Would additional testing change pregnancy monitoring or medical planning?
- Are there ultrasound findings that should be evaluated more closely based on these results?
- Who can review the results with us in detail and answer follow-up questions?

Pregnancy With Trisomy 18

Questions for pregnancy monitoring, fetal cardiology, neonatology, and delivery planning.

PAGE 2 - PREGNANCY WITH TRISOMY 18

Your baby's individual findings and your family's goals can guide conversations about monitoring, specialist care, birth planning, and newborn care.

Questions for Maternal-Fetal Medicine (MFM)

- What findings have you identified on my baby's ultrasounds?
- How is my baby growing compared with previous scans?
- How often will we have growth ultrasounds?
- Will you monitor blood flow through the placenta and umbilical cord?
- How will you monitor amniotic fluid levels?
- When might non-stress tests or biophysical profiles begin?
- What changes or symptoms should prompt me to call or come to the hospital?
- What findings could change the timing of delivery?
- How will fetal growth restriction affect decisions about the pregnancy or delivery?
- Should I deliver at a hospital with a Level III or IV NICU?
- Which specialists should we meet with before delivery?
- Can we begin creating an individualized birth and neonatal care plan now?

Questions for Fetal Cardiology

- What heart differences do you see in our baby?
- Can you explain the findings in everyday language?
- How severe are the heart differences?
- Are there signs that the heart condition is affecting our baby during pregnancy?
- Will we need additional fetal echocardiograms?
- Does the heart condition affect where our baby should be delivered?
- What evaluation will our baby need after birth?
- Would our baby need medication, respiratory support, or another intervention immediately after birth?
- Are catheter-based procedures or heart surgery potentially treatment options for this particular heart condition?
- If surgery could be considered, what factors would determine whether our baby is a candidate?
- Can we meet with the pediatric cardiology or cardiac surgery team before delivery?
- How does your team approach treatment decisions for babies with Trisomy 18?

Questions for Neonatology

- What should we expect immediately after our baby is born?
- Who will be present from the neonatal team at delivery?
- What options are available for stabilizing our baby after birth?
- What types of respiratory support could be offered if our baby has difficulty breathing?
- How will feeding and nutrition be managed?
- What testing will be performed after birth?
- Would our baby automatically go to the NICU?
- When will we be able to hold, bond with, or have skin-to-skin contact with our baby if medically appropriate?
- How will decisions about medical interventions be made?
- How does your NICU approach treatment for babies with Trisomy 18?
- Will specialists evaluate our baby based on their individual medical needs?
- Can palliative care be involved alongside medical or life-prolonging treatment?
- Can we tour the NICU and meet members of the neonatal team before delivery?

Questions About Delivery Planning

- Where is the safest place for our baby to be delivered?
- Is vaginal delivery an option?
- Under what circumstances would a C-section be considered?
- Will our baby be continuously monitored during labor?
- How will changes in our baby's heart rate during labor be handled?
- Who should be present at the delivery?
- Can our pediatric or neonatal specialists be notified when I go into labor?
- What newborn resuscitation options can we discuss before delivery?
- Can our wishes for oxygen, ventilation, medications, or other interventions be documented before birth?
- Can we create a written birth and neonatal care plan that is placed in my medical record?
- What happens if I go into labor at a hospital other than our planned delivery hospital?
- How can we prioritize bonding and family time after birth?
- Can siblings or other family members visit after delivery?
- Are photography, keepsakes, handprints, footprints, or other memory-making activities available?
- Who should we contact if we want to change our care preferences before or during delivery?

This guide is for education and appointment preparation and is not a substitute for individualized medical advice.