



Connecting the World to Fight Twin to Twin Transfusion Syndrome
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THE TWIN TO TWIN TRANSFUSION SYNDROME FOUNDATION'S MOST FREQUENTLY ASKED QUESTIONS

1. Can TTTS happen in fraternal twins?

The answer is no. TTTS occurs in twins that share a single placenta (monochorionic), which means they must be identical and monozygotic (single egg). Identical twins can have separate placentas (dichorionic), which on occasion implant very close to each other in the uterus and seem to 'fuse.' TTTS cannot happen with fraternal twins that each have their own placenta or identical twin placentas that fuse together. *Chorionicity (how many placentas) can and should be determined by ultrasound as early as possible in multiple pregnancy.*

2. What are Acute and Chronic TTTS?

Acute TTTS is a transfusion that happens quickly, typically after 30 weeks of pregnancy without much warning. It can also happen during labor in a vaginal birth, or after the cord of one baby has been clamped.

Chronic TTTS is the more common type of transfusion that happens over time with signs that clearly show on ultrasound, or with symptoms that the mother can identify herself. Usually these cases are diagnosed at 15-20 weeks. Monochorionic twin pregnancies are always at-risk and never in a safe zone for TTTS. TTTS may occur at any time during pregnancy.

3. Can you prevent TTTS?

The early pregnancy events responsible for TTTS are in place before the mother knows she is pregnant, i.e., there is no primary prevention for TTTS. It is not caused by hereditary, genetics or by anything the parents did or did not do, nor caused by anything the babies are doing because they are innocent bystanders to events in their placenta. Recently, some investigators in Pittsburgh have taken research done by Dr. De Lia (in Milwaukee) on maternal malnutrition and its treatment in TTTS one step further. They started all mothers of monochorionic twins on aggressive nutritional therapy in early pregnancy, and found fewer and less severe cases of TTTS, when compared to a control group.

4. Does a high 'nuchal translucency' score mean my monochorionic twins will go on to have TTTS?

There is not a clear answer here, but just plan for frequent ultrasounds to look for signs of TTTS, because all monochorionic twins are at-risk. Researchers have found that a discordance (difference) in NT of 20% or more is found in about 25% of monochorionic twins. In this group the risk of early fetal death or the development of severe TTTS is more than 30%. Conversely, if the discordance is less than 20%, the risk of complications is less than 10%. Obviously, the majority of these twins still do fine.

5. What is the difference between TTTS and an abnormal placental sharing (discordance) problem?

Placental sharing refers to how much of the single (monochorionic) placenta belongs to each twin, to provide it with the oxygen and nutrients needed to thrive in the womb. It is determined by events early in pregnancy, and will not change throughout the pregnancy. Doctors can only guess what the placental share is for each twin, but unequal sharing will cause size differences (weights) at ultrasound. Finally, examination of the placenta after birth can document placental shares that differ. *Intrauterine growth restriction (IUGR)* of one identical twin occurs more often because of a small placenta rather than TTTS. Size differences over 20% need to be watched carefully, and some twins will need to be delivered if the twin with the smaller share stops growing, regardless of gestational age.

TTTS refers to all the consequences of a *transfusion of blood* from the donor twin to the recipient twin, through abnormal blood vessels in the shared (monochorionic) placenta. The ultrasound in TTTS shows excess amniotic fluid in the recipient and less fluid in the donor who may be 'stuck,' possibly some size difference related to the transfusion, and heart and Doppler abnormalities. All monochorionic twins are connected by blood vessels, but the majority have either no or two way flow of blood between them. About 20% of the time, TTTS will occur because there is a one way or imbalanced flow of blood in the shared placenta. *Some twins may have both unequal placental shares and TTTS.*

6. What is SIUGR?

This stands for selective *intrauterine growth restriction* of one identical (monochorionic) twin, and is typically caused by unequal placental sharing. On ultrasound scan the IUGR twin is in the 10th percentile or less for weight, and often has absent or reverse end diastolic flow (AREDF) on Doppler studies. When the amniotic fluid levels are normal for the larger baby, there might not be a clear TTTS diagnosis due to this. Again, twins can have placental share problems that might cause SIUGR, as well as TTTS at the same time

7. Is there anything I should do to determine if my twins are at risk for TTTS?

Yes. You need to follow the steps on our homepage and find out if your twins share the same placenta - known as *monochorionic*. Monochorionic twins are identical twins with a single placenta, which contain blood vessels that connect them. Fifteen to 20% of monochorionic twins develop TTTS. If the doctors are not certain how many placentas there are, you should be followed as if it was monochorionic to be safe. Then, use the ultrasound questions and make sure that you are seen every week from 16 weeks through delivery of your babies even if you are not diagnosed.

8. Why can my donor twin become a recipient and the recipient a donor?

The events in the monochorionic placenta in TTTS don't always make sense, but this can happen and the twins' roles reverse. We often hear about this after laser surgery, because the doctor doing the surgery does not obliterate all the connecting blood vessels, which happens to be then actual goal of the laser surgery as developed by Dr. De Lia. Separation of the twins' placental circulations is the only way to maximize the chance for their healthy survival in severe TTTS. We hear too many stories, that for whatever reason, this is not the case. In TTTS, classically one baby is larger and dark red while the other is smaller and pale. There are sets of twins born with one dark red and small, and the other larger and pale. This is an example of the reversal of their roles.

9. Is there anything I can do if my twins develop TTTS?

If you have a TTTS diagnosis, start reading the information on horizontal rest and nutrition. Studies show that all mothers with TTTS have metabolic problems, so you can start this right away. These steps will even benefit the babies. Many moms of monochorionic twins start this even when they are not yet diagnosed. Follow the Create a Medical Plan suggestions and make sure that you receive preventative care. We believe that preventative care for TTTS is medically necessary care.

10. Do all TTTS twins need placenta laser surgery?

No. Although placental laser surgery is a remarkable advance in the fight against TTTS, it is best used for moderate to severe (stages III and IV) TTTS, or twin size differences (discordance) of 40% or more, because there are procedure-related risks. Our medical advisors generally prefer comprehensive therapy for TTTS, which may include amnioreductions, horizontal rest, nutritional supplements, a cervical cerclage (stitch), and laser therapy. Many TTTS couples do choose this approach and are amazed with the outcome without laser surgery. If the TTTS is severe or if it appears to worsen over time, the surgery is performed up to 25 weeks. Other couples may want to have the surgery right away. You have to educate yourself on the criteria laser doctors each has for when, why and how they would do the surgery, and make a decision. For example, if the recipient has an 11cm pocket of amniotic fluid, but the donor still has a 3cm pocket, you might not qualify for laser surgery. However, an 11cm pocket is an indication for the amnioreduction in order to make the mother more comfortable and prevent her cervix from shortening. All laser surgeons perform an amnioreduction after the procedure to restore the pocket to normal levels. There is a range to TTTS, and there is value to all the treatments depending on what you and the babies need. Don't rush the decision and use the Foundation's 15 Most Important Questions to determine the degree of TTTS affecting your babies.

11. Is the laser surgery experimental?

No, it is not experimental and is almost always covered by insurance. It was introduced 20 years ago (by Dr. Julian E. De Lia) and has been performed thousands of times throughout the world. However, various centers have modified the surgical technique and instruments (which may be considered experimental) in various ways that, more often than not, lowered the overall survival and healthy survival rate of the twins.

12. Will Medicaid pay for 'out of state' placental laser surgery?

Both private insurance and Medicaid will typically pay for the procedure. It is important for the local, referring physician to first get the approval for the surgery.

13. If one of my monochorionic twins is lost inside me, what will happen to the other one?

Frequently doctors say that if you lose one baby, you will lose the other. But this happens only in about one-third of the cases. Most of the babies go on and are just fine, especially if the loss is before 30 weeks. The health of the surviving twin can be assessed inside the uterus by ultrasound and MRI. It is better to continue the pregnancy if you find out you have lost one and avoid prematurity problems in the survivor, unless this twin is in distress.

14. Does TTTS affect identical twins after they are born?

Not usually. TTTS is a disease of the placenta during pregnancy. Once the babies are born, they no longer 'donors' or 'recipients' in a TTTS. There can be health concerns for the babies due to prematurity, or from the effects of TTTS inside the womb, but these are usually verified or detected at birth or soon after by the pediatricians.

15. Should I deliver my monochorionic twins by cesarean section or vaginally?

This is a personal choice between you and your doctor. Many mothers may choose a c-section before labor begins, so their babies are born quickly, with pediatricians present who can handle complications related to prematurity, TTTS or any other problems with the babies. Occasionally an acute TTTS can occur in labor. There may be reasons for an early delivery such as lack of growth in one baby, or one or both twins go into distress for any reason, or the babies' lungs are mature and may be 'safer out then in.' The mother's womb might not respond at earlier gestations to induction of labor so a c-section is needed. Mothers wanting vaginal birth should have the babies' heart rates monitored closely for signs of acute TTTS, and be prepared for an emergency c-section if needed.

16. If I had a TTTS pregnancy once, am I at increased risk for TTTS in a future pregnancy?

Sometimes families are prone to have twin gestations, but these are typically fraternal or non-identical twins. The chance of having TTTS in a future pregnancy are likely the same as the first (about 1 in 1,000 pregnancies) and do not increase.

17. What if I've been told that there is no hope for my babies diagnosed with TTTS?

This may have been the case 25 years ago, but there is tremendous hope now for your babies. TTTS has been the focus of a few serious researchers and their work, who had to overcome the prevailing pessimism at the time to create a new reality for your babies. All you have to do is read the Foundation's web site, and see what former TTTS couples on our message boards have to say. You will know that your babies can make it, and be healthy. Never give up. We are here to help you.