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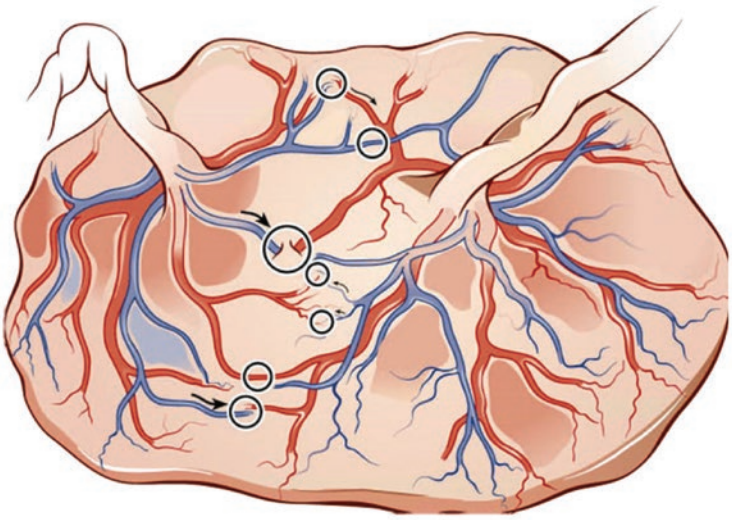


Twin-to-twin transfusion syndrome

Information for prospective parents

Introduction

You are pregnant with monochorionic twins in which twin-to-twin transfusion syndrome has been diagnosed. This brochure provides you with more information on this condition, the available treatments and the outcomes to be expected so that you are better able to choose which treatment is best for you. We have also included several testimonials from people in the same position as you. We hope that these can provide the necessary help or support.

WHAT IS TWIN-TO-TWIN TRANSFUSION SYNDROME?

Monochorionic twins are monozygotic twins who share a common (monochorionic) placenta. This common placenta always contains various blood vessels that connect the circulatory system of one baby to that of the other baby (figure 1). As such, the babies are constantly exchanging blood for as long as they remain together in the womb. In principle, this transfusion of blood does not pose a problem, as long as it remains balanced. However, a blood transfusion imbalance leading to twin-to-twin transfusion syndrome (TTTS) will occur in one in ten monochorionic twins.

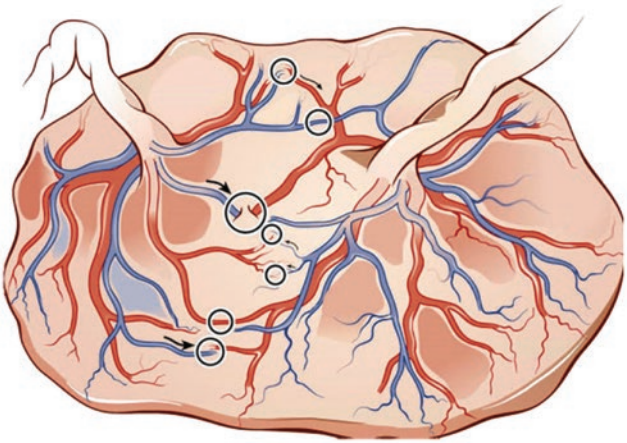


Figure 1: Drawing of the placenta with monochorionic twins. There are various blood vessel connections that connect the circulatory systems of both babies to each other (circled).

In TTTS, one of the babies passes too much blood to the other. The baby receiving this excess blood is called the recipient. The excess blood will cause the baby to urinate more often, resulting in excess amniotic fluid; a condition also referred to as polyhydramnios (poly = too much; hydramnios = amniotic fluid).

This is because the amniotic fluid is formed by the babies' urine. The excess will leave you feeling bloated. The other baby will have too little blood as it is transferring blood to the recipient. As such, this baby is called the donor. As a result of this imbalance, the donor will urinate less often causing a shortage of amniotic fluid. Consequently, this baby will suffer from oligohydramnios (oligo = too little; hydramnios = amniotic fluid).

In normal circumstances, the depth of the amniotic fluid will measure around 4 cm. TTTS is only diagnosed when an ultrasound shows that the recipient has an overly full bladder and the amniotic fluid depth measures more than 8 cm (prior to the 20th week of pregnancy) or more than 10 cm (after the 20th week of pregnancy), while the donor baby has a small or empty bladder and the amniotic fluid depth measures less than 2 cm (figure 2). In TTTS, the membrane that separates both amniotic sacs is difficult to see and sits tight against the donor baby. In addition to the difference in amniotic fluid, the babies often grow at different rates, with the recipient being bigger and the donor being smaller.

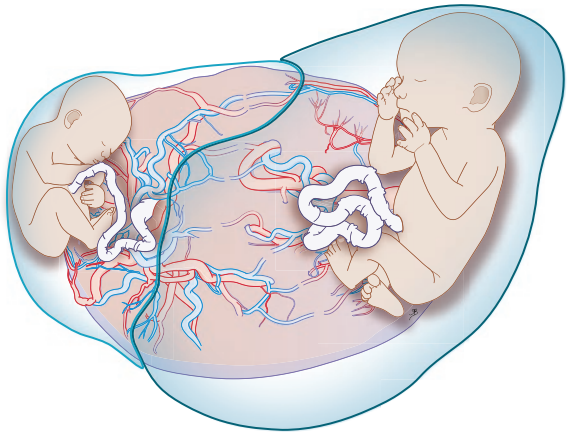


Figure 2: Drawing of twin-to-twin transfusion syndrome (TTTS), showing the donor with little or no amniotic fluid on the left and the recipient with excess amniotic fluid on the right. Blood vessel connections between the babies are always clearly visible in TTTS.

TTTS can be broken down into five different stages:

- ✗ In stage 1, a small bladder is visible in the donor.
- ✗ In stage 2, the bladder is empty in the donor.
- ✗ In stage 3, abnormal blood flow occurs in one or both of the babies.
- ✗ In stage 4, there are signs of heart failure in the recipient, such as fluid under the skin, around the lungs or in the belly.

In most cases, the condition does not go through the five stages in chronological order. For example, stage 1 TTTS might suddenly transition to stage 5 TTTS, without passing through stages 2, 3 and 4. Instead, the stages should be taken as an indication of how severely the babies are affected.

WHAT TREATMENTS ARE AVAILABLE AND WHAT IS THEIR OUTCOME?

In around 90 percent of cases, TTTS occurs before the viable period, between the 16th and 26th week of pregnancy. Without treatment, TTTS almost always results in the loss of one or both babies. On the one hand, the excess amniotic fluid may cause your waters to break, triggering labour at a time when the babies are not yet viable. It is possible for babies to survive from 24 weeks onward, but TTTS often leaves babies severely ill. This means their chances of survival are very limited if they are born much too prematurely. On the other hand, the donor may pass away spontaneously in the womb due to a shortage

of blood, or the heart of the recipient may fail due to an excess of blood. If one of the babies passes away, this may cause the other baby to pass away as well, or the other baby may suffer brain damage as both babies share the same circulatory system. As such, treatment is recommended in most cases.

In stages 2, 3 and 4, immediate treatment is best. Waiting to see how the condition will develop is only possible in stage 1 if the recipient is not suffering a significant excess of amniotic fluid. In 40 percent of stage 1 TTTS pregnancies, the condition spontaneously improves, meaning surgery may be avoided. In around 30 percent, stage 1 will deteriorate, and in a further 30 percent, the condition will persist and treatment is recommended. In stage 1, it is not always clear whether it is better to start treatment immediately or whether to wait and see if there is any spontaneous improvement.

The available treatments for TTTS are laser surgery with amniotic drainage, amniotic drainage alone or an umbilical cord occlusion. Below and on the following pages, we will run through the different treatment options and provide more detail on their expected outcomes.

LASER SURGERY WITH AMNIOTIC DRAINAGE

What exactly does laser surgery involve?

Laser surgery tackles the cause of TTTS. It is a keyhole procedure in which we make an incision of around 3 mm in the abdominal wall. Through this incision, we insert a small tube down into the amniotic sac of the recipient. A camera is then inserted through the tube, and a laser is used to seal off all blood vessel connections between the babies (figure 3). Afterwards, we draw a line between all sealing points from one side of the placenta to the other, so that the babies are fully

separated and no longer able to exchange blood. At the end of the surgery, we also drain off the excess amniotic fluid (usually one to two litres) so that the recipient baby's volume of amniotic fluid and the size of the abdomen are both returned to normal. Laser surgery is always combined with amniotic drainage. The procedure usually takes around 60 minutes. We'll close up the incision with a single stitch and/or surgical tape, which can be removed after one week.

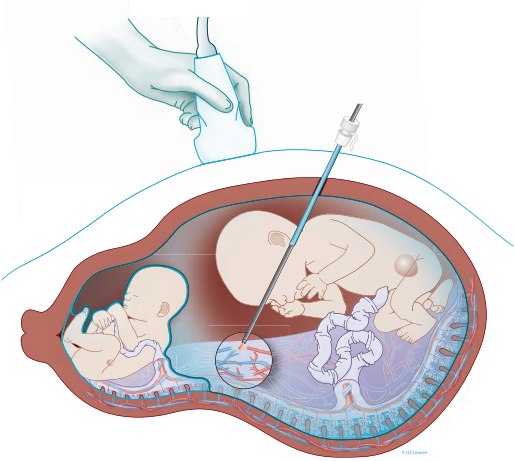


Figure 3: Drawing of a TTTS laser procedure. Using a small camera, the blood vessel connections between the babies are detected and sealed off with a laser.

Will I be awake during the surgery?

The surgery will take place under sedation in the operating room of the maternity unit. You will be given intravenous sedatives, but you will not be under general anaesthetic and you will be breathing independently. A local anaesthetic will be applied to the skin. If TTTS occurs after the 28th week of pregnancy (which is rare), we usually administer an epidural anaesthetic (a back injection) so that we can quickly carry out an emergency caesarean should one of the babies be in trouble.

During the surgery, you will lie comfortably on a heated mattress. The anaesthetist will remain with you throughout the whole procedure. You will be asked not to eat or drink before surgery: from six hours prior to the procedure, you may only have small sips of water.

How long will I need to stay at the hospital?

You will spend a total of two nights in the high-risk pregnancy unit: one night before the procedure and one night after the procedure. The night before the procedure, you will be given a heparin injection to prevent the formation of blood clots in your legs, as well as medication to stop premature labour if necessary. We will take a blood sample to determine your blood group and iron levels and to check for clotting.

The morning before the surgery, we will administer an intravenous drip with antibiotics, and you will be given a medicine to protect your stomach. After the procedure, you will remain in the maternity ward for observation for around two hours. During this time, you will be offered a light meal. If everything is in order, we will return you to the high-risk pregnancy unit where you will spend another night.

The morning after the procedure, we will take another blood sample to ensure you are not suffering from anaemia. We will also perform an ultrasound to see how the babies are doing. If everything is as it should be, the intravenous drip will be removed and you will be able to leave the hospital in the afternoon.

What are the risks of laser surgery for me?

The laser procedure will have little physical impact on you. The chance of severe complications is very small (smaller than one in

100). In very rare cases, bleeding may occur that requires a blood transfusion, or an infection in the amniotic fluid may require the pregnancy to be terminated.
You are likely to feel much better after the surgery because the major distension of your abdomen will disappear. We usually recommend two weeks off work, during which you should only perform light activities. If you suffer any loss of blood or fluid, any fever, period-like pain in your lower abdomen or a decrease in the movement of your babies, you should contact your gynaecologist immediately.

The surgery has no impact on your fertility or on any future pregnancies.

What are the risks of laser surgery for your pregnancy and your babies?

Laser surgery does have a significant impact on your babies and your pregnancy. Following laser surgery, there is a 65 percent chance that both babies will survive, a 20 percent chance that one of your babies will survive and a 15 percent chance that both babies will not survive.

The main reason why one of the babies may pass away after laser surgery is that too little placenta remains (usually for the donor) or that the heart of the recipient fails due to the sudden decrease in blood supply. Because the blood vessel connections are sealed off, the surviving baby is protected and no negative consequences should be expected for this baby. If one of the babies dies in the womb, this usually happens during the first 24 hours after surgery. As such, if the ultrasound the day after the procedure shows both babies are doing well, this is a major step in the right direction. It is also possible that

both babies are born extremely prematurely, and that one of the babies doesn't survive as a result.

The main reason why there is a chance both babies might pass away is that we make an incision in the amniotic sac of the recipient during the laser procedure. The recipient's amniotic sac is already vulnerable due to its sudden expansion and often has minor tears as a result. The 3 mm incision we make in the amniotic sac might cause the sac to rupture completely, which could trigger labour. If you enter labour before completing a 24-week term, the babies will not yet be viable. There is a 10 percent chance that labour will start prior to the 24th week of your pregnancy. If this happens, the babies will not yet be viable as they are unable to survive outside of the womb. There is a further 10 percent chance that labour will start between the 24th and 28th weeks. In the event of such extremely premature birth, the babies do stand a chance of survival outside of the womb, but there is still a chance they will not make it if they have not fully recovered from the transfusion imbalance. There is nothing you can do yourself to prevent a miscarriage or extreme premature birth. The procedure may also cause the amniotic sac to detach from the abdominal wall which would increase the chance of a miscarriage. In addition, there is always a chance that we are unable to seal off all blood vessel connections, and that both babies pass away as a result. All in all, the evidence shows that both babies pass away in about 15 percent of cases.

In very rare cases, a hole in the membrane between the two babies will cause both of them to end up in a common amniotic sac. In this event, you will need to give birth by caesarean as the umbilical cords of the babies might become entangled.

How is the rest of the pregnancy monitored if both babies survive?

If both babies survive the surgery, your pregnancy will have to be closely monitored as the transfusion problem reoccurs in 5 percent of cases. In the vast majority of cases, the problem will be resolved definitively.

If a new imbalance should occur, this will probably no longer manifest in a difference in the volume of amniotic fluid but rather in a difference in the number of red blood cells between the babies. In this event, one of the babies will have a pale appearance due to a deficiency of red blood cells (anaemia), while the other baby will have a very reddish appearance due to an excess of red blood cells (polycythaemia - poly = too much, cythaemia = cells). This condition is called Twin Anaemia Polycythaemia Syndrome or TAPS. Unlike in TTTS, babies with TAPS both have a normal volume of amniotic fluid. The difference in red blood cells is detected during an ultrasound by measuring the blood flow speed in the brains of both babies. In TAPS, the anaemic donor will have a very high blood flow speed, while the polycythaemic recipient will have very slow blood flow. Often, another difference will be apparent in the placenta, with the donor's part being very white and swollen and the recipient's part being very dark and thin. TAPS usually develops a few weeks after the surgery because very fine blood vessel connections that could not be sealed off remain (figure 4).

If any large blood vessel connections remain unsealed, TTTS may return. In this case, the recipient will once again end up with too much amniotic fluid, while the donor's amniotic fluid does not increase. In very rare cases, the process may be reversed, with the former donor receiving too much amniotic fluid and the former recipient receiving too little.

Both TAPS and recurring TTTS require further treatment as both conditions jeopardise the well-being of the babies. The choice of treatment type will depend on the term of the pregnancy, the severity of the condition and the options for further surgery. The first step taken in TAPS is usually a blood transfusion for the baby suffering from anaemia. If TTTS reoccurs, one option to consider is a repeat of the surgical procedure. If the babies have survived to a viable term, we may also decide to induce birth.

To ensure TAPS or reoccurring TTTS is detected in good time, weekly ultrasound scans should be performed during the first month after surgery. During these scans, we will check the volume of amniotic fluid and the blood flow speed in the brains of both babies. Usually, it takes around two weeks for the donor to refill his/her amniotic sac to a sufficient level and for both babies to reach a normal level of amniotic fluid. We will also check the growth, brain development and heart function of both babies, and we make sure that both babies remain in their own amniotic sacs. If all developments are positive after the first month, we can move back to fortnightly ultrasounds.

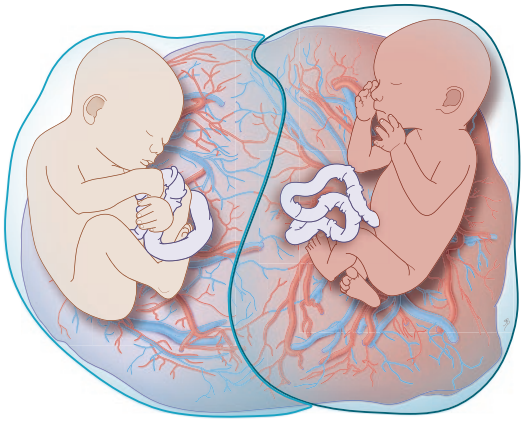


Figure 4: Drawing of Twin Anaemia Polycythaemia Syndrome (TAPS). The donor has a pale appearance due to anaemia (left), while the recipient has a very reddish appearance due to excess red blood cells (right). In TAPS, only minute blood vessel connections remain between the babies.

When will I give birth if both babies survive?

If both babies survive, you will usually give birth around week 32 or 33 of your pregnancy (two months before your due date). As mentioned above, there is a 10 percent chance of losing the babies before the 24th week of your pregnancy. On top of that, 10 percent of mothers give birth between week 24 and week 28, 25 percent between week 28 and week 32 and 55 percent after week 32. Births between weeks 24 and 28 are extremely premature. Babies born this prematurely have a long way to go before being safe and healthy. In Flanders, doctors will involve parents of babies born between weeks 24 and 26 in the decision whether to provide intensive care to such extremely premature babies, or whether to provide comfort care only.

Babies born before week 32 are usually admitted to a neonatal intensive care unit (NICU). As such, you will usually need to give birth in a hospital that has one of these units available. Babies born between weeks 32 and 36 who do not need intensive care are usually looked after in a neonatal unit (N*). Only babies who weigh more than 2.5 kg and who are born after 36 weeks of pregnancy will be able to stay with you in the maternity ward.

Can premature birth be prevented?

There is nothing you can do yourself to reduce the chance of premature birth. Usually, we only recommend that you avoid excessive physical activity and stress. If you'd like to keep working and your job is not too demanding, it's often best to continue working until week 28 or 30. Bed rest is not helpful and might even increase the chances of premature birth. It may also lead to major complications such as depression, osteoporosis, and blood clot formation in the legs.

There are no proven treatments for preventing premature birth. However, it is possible to gauge the chance of premature birth to some extent by measuring the length of the cervix during an ultrasound. If there is no shortening of the cervix, the chance of premature birth is small. One thing we cannot predict is your waters breaking spontaneously.

Is it still possible to give birth to my twins naturally after laser surgery?

After laser surgery, it is still possible to give birth to your twins naturally, on the condition that the lower baby is turned with his/her head downwards, both babies remain in their own amniotic sac and both babies are healthy. Women who have already given birth naturally before have the best chance of a smooth natural birth of their twins. As with all twin births, we recommend an epidural so that we can perform an emergency caesarean if necessary. It's best to bear the possibility of a caesarean section (figure 5) in mind, as only a little under half of twins are born naturally.

If you have not started labour spontaneously by week 35 or 36 of your pregnancy, we will usually induce birth as the shared placenta will have fewer reserves after laser surgery and will often no longer be able to sustain both babies after that point. The bigger the babies grow, the more nutrition they will need, and the higher the chance the placenta will no longer be able to meet their needs.

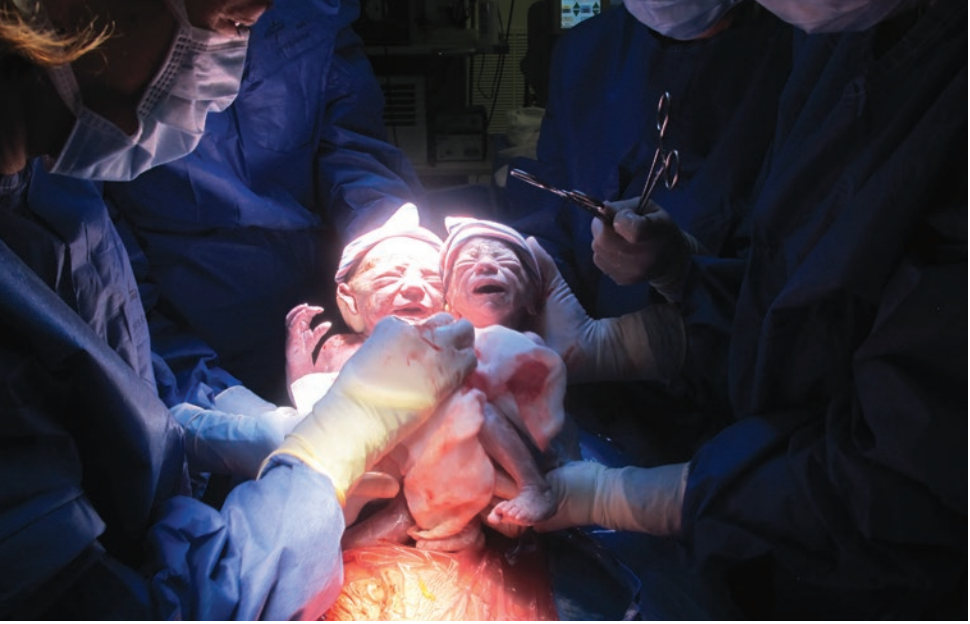


Figure 5: Photo of a caesarean section at the birth of monochorionic twins. The babies will be wrapped in warm sheets, and the umbilical cord will only be cut after one minute if possible so that the babies can continue to get as much blood and as many stem cells from the placenta as possible.

What if only one baby survives after laser surgery?

If only one of the two babies survives, the imbalance cannot return, and the baby will be monitored in the same way as during a single pregnancy. The deceased baby will remain in the womb and will be born at the same time as the healthy baby. The deceased baby does not pose any risk to the other baby as the blood vessel connections between the two will have been sealed off. Using ultrasound, we will keep checking whether the deceased baby remains in his/her own amniotic sac and whether there is any tangling of the umbilical cords. Often, this will be difficult to deal with emotionally because you will not have had a chance yet to say goodbye to your child. When you deliver, you will feel joy at the birth of a healthy baby, but also sadness at the loss of your deceased child. We will support you as best as possible during this time.

If only one of the babies survives, you will usually only give birth around week 34 or 35, and you have a higher chance of giving birth naturally. If you have not entered labour spontaneously by week 35 or 36 of your pregnancy, we will usually induce birth as the part of the placenta that remains for the surviving baby will often no longer be able to provide all the nutrients needed beyond that point.

What are the children's long-term prospects after laser surgery?

Disrupted brain development prior to birth is detected in one in every 50 TTTS babies. As such, we schedule an ultrasound and MRI (magnetic resonance imaging) scan for all patients around week 30 to check the development of the brain. It takes until week 30 for the brain to have developed sufficiently for us to be able to detect any abnormalities. If the all-clear is given after these checks, you have conquered one of the biggest hurdles of your pregnancy: you will have made it to week 30 without any brain damage occurring. However, if we do expect any serious problems for the development of your child on the basis of these scans, you still have the option to terminate the pregnancy.

Nine out of 10 children treated with laser surgery for TTTS develop normally in the long term. One out of 10 children will fall behind at some point. These developmental problems may be due to the condition itself, to the laser surgery or to premature birth. Delays may occur in mental development (such as learning disabilities or delayed language development), but also in coordination (walking, fine motor skills etc.) or in both. One complication typical of TTTS is spastic paresis or cerebral palsy which occurs in one in 30 children after laser surgery. Cerebral palsy causes one or more groups of muscles to stiffen, for example in the legs and/or arms, which may cause problems with sitting, walking, writing or eating.

A number of these development problems can be predicted by carefully monitoring brain development through ultrasound and the MRI scan at 30 weeks. However, developmental delays due to premature birth are more difficult to predict.

AMNIOTIC DRAINAGE

What exactly does amniotic drainage involve?

Amniotic drainage only treats the symptoms of TTTS. In this procedure, we merely drain the excess amniotic fluid through a needle inserted into the amniotic sac of the recipient. This decreases the distension of the abdomen and the chance of miscarriage or extremely premature birth. The imbalance in blood exchange continues to exist, and excess fluid will reoccur in the recipient's amniotic sac. As such, the problem with this procedure is that it usually needs to be repeated after one or two weeks.

Will I be awake during the surgery and how long will I need to stay at the hospital?

Amniotic drainage is a simple procedure performed in the operating room of the maternity unit under light sedation and a local anaesthetic of the skin. Using a fine needle, we usually drain one or two litres of amniotic fluid, which will relieve the distension of your abdomen, leaving you feeling much more comfortable. The needle site will be covered with a plaster which can be removed after a day. Amniotic drainage is a day surgery procedure, meaning you are admitted to hospital in the morning (without having had any food or drink) and will be ready to leave by the afternoon.

In which cases can amniotic drainage prove useful?

As amniotic drainage usually only treats the symptoms of TTTS while the condition remains, it is possible that the babies' health will deteriorate. A major study has also shown that laser surgery is the better treatment for TTTS. As such, amniotic drainage is not our first choice of treatment for TTTS.

Amniotic drainage is only recommended when laser surgery is not possible in stage 1. We may be unable to perform a laser procedure because the blood vessel connections are not sufficiently visible. In some cases, we may be unable to see these connections because the placenta is entirely situated on the anterior part of the womb or because the amniotic fluid is bloody. Bloody amniotic fluid may be caused by bleeding during pregnancy or following the insertion of a tube for a planned laser procedure. In stage 1, there is a one-in-three chance that TTTS is resolved following a single drainage procedure. The second case in which amniotic drainage may be preferable to laser surgery is when TTTS occurs after the 28th week of pregnancy. In this case, laser surgery is often not recommended, but amniotic drainage might allow the babies to grow in your womb for a few weeks more.

What are the risks of amniotic drainage?

The risks involved in the procedure itself are very limited for both the mother and the babies. There is a one in 100 chance of your waters breaking, usually in the days following the surgery. As such, we recommend one week off work during which you should only perform light activities. Amniotic drainage has no impact on your fertility or on any future pregnancies.

How is the rest of the pregnancy monitored after amniotic drainage?

Given the fact that TTTS will not disappear, we will need to carefully monitor the rest of your pregnancy. We will schedule an ultrasound check-up a few days after the amniotic drainage to see if there has been any improvement. We will also carefully monitor the health of both babies as they will remain connected to each other after the procedure, the imbalance remains in most cases, and they are still dependent on each other for their individual well-being.

UMBILICAL CORD OCCLUSION

What exactly does umbilical cord occlusion involve?

During an umbilical cord occlusion procedure, we will use a fine tool to seal off the umbilical cord of one of the babies (usually the recipient). This will cause the baby in question to pass away without causing any harm to the other baby. As TTTS requires the presence of two babies, the imbalance will disappear immediately upon the passing of one of the babies. Just like laser surgery, we will make a

3 mm incision in the abdominal wall during this procedure to insert a tube down into the recipient's amniotic sac. Using ultrasound, we will seal off the umbilical cord in three different places so that the other baby does not lose any blood and remains protected (figure 6). At the end of the procedure, we drain the excess amniotic fluid so that your abdomen returns to its normal size. The procedure usually takes around 60 minutes. We'll close up the incision with a single stitch and/or surgical tape, which can be removed after one week.

Will I be awake during the procedure?

The surgery will be performed in the operating room under sedation and a local anaesthetic of the skin. From the 28th week of pregnancy onward, we will often administer an epidural too so we can perform an emergency caesarean if necessary.

How long will I need to stay at the hospital?

Aftercare is the same as for laser surgery. You will need to stay in the high-risk pregnancy unit for two nights. We will perform an ultrasound to see how your surviving baby is doing the day after the surgery, and you will be able to leave the hospital during the afternoon.

In which cases is umbilical cord occlusion recommended?

As this procedure results in the loss of one of your babies, umbilical cord occlusion is not our first choice of treatment for TTTS. However, we may recommend this procedure if one of the babies is displaying a severe anomaly or when laser surgery is not possible in

an advanced stage of TTTS. During stage 2 to 4, there is a very high chance that both babies will pass away if laser surgery cannot be performed. In this case, a decision may be made to occlude the umbilical cord of the recipient. If this is done, there is a good chance that the donor baby will be born healthy.

If the donor shows any severe anomalies, occlusion may also be performed on the donor's umbilical cord. In this procedure, we will need to remove the excess amniotic fluid from the recipient first so we can fill the donor's amniotic sac to create enough room to perform the surgery (figure 6). Preferably, we will make the incision in the amniotic sac of the baby whose umbilical cord will be sealed off. Consequently, if any loss of amniotic fluid should occur after surgery, this fluid will come from the deceased baby and the healthy baby will retain sufficient fluid. In most cases, any loss of amniotic fluid will stop spontaneously as no additional amniotic fluid is produced.

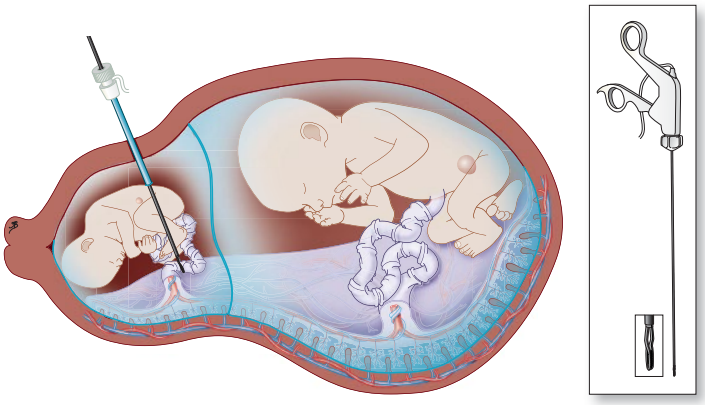


Figure 6: Drawing of an umbilical cord occlusion on the donor baby. The recipient's excess amniotic fluid has been drained (right), and fluid has been added to the donor's amniotic sac. Through a tube in the amniotic sac, a fine tool is used to occlude the umbilical cord.

What are the risks of umbilical cord occlusion for me?

Umbilical cord occlusion has little or no physical impact on you. As with laser surgery, the chance of severe complications is very small (lower than one in 100). In rare cases, severe blood loss or an infection of the amniotic fluid might occur. In most cases, we prescribe two weeks off work. If you suffer any loss of blood or fluid, any fever or period pain or a decrease in the movement of your babies after the procedure, we recommend that you contact your gynaecologist immediately. Of course, this surgery will have an emotional impact. Additional psychological support is available at any time. The procedure itself does not have any impact on your fertility or on any future pregnancies.

What are the risks of umbilical cord occlusion for my pregnancy?

Occlusion has a serious impact on your pregnancy and the surviving baby. There is an 85 to 90 percent chance that the remaining baby will survive. In 5 percent of cases, the healthy baby will pass away in the womb, either because too little of the placenta remains, or because a hole has formed in the membrane between the two babies and their umbilical cords have become entangled. In 5 to 10 percent of cases, the surviving baby is lost due to miscarriage or premature birth, most often due to your waters breaking.

As with laser surgery, there is nothing you can do yourself to prevent any premature breaking of your waters. Any fluid leaking from the amniotic sac of the deceased baby will usually stop spontaneously. This does not cause any harm to your healthy baby whose amniotic sac remains intact and who will retain a normal level of amniotic fluid.

How is the rest of the pregnancy monitored after umbilical cord occlusion?

It is impossible for the imbalance to return after an umbilical cord occlusion and your baby will be monitored in the same way as during a single pregnancy. The deceased baby will remain in the womb and will be born at the same time as the healthy baby. This does not involve any risk for the surviving baby. During ultrasound scans, we will always check whether the deceased baby remains in his/her own amniotic sac and whether there is any tangling of the umbilical cords.

When will I give birth and can I still do so naturally after umbilical cord occlusion?

In most cases, the healthy baby will be born naturally after 35 to 36 weeks. There is an 80 to 90 percent chance that your baby will be born after 32 weeks. If you have not started labour spontaneously by week 36 of your pregnancy, we will usually induce birth as the part of the placenta that remains for the surviving baby will often no longer be able to provide all the nutrients the growing baby needs beyond that point.

What are the child's long-term prospects after umbilical cord occlusion?

In the long term, most children who survived an umbilical cord occlusion are healthy. Developmental delays occur in one in every 25 children. A number of these problems can be detected by carefully monitoring brain development through ultrasound and an MRI scan at 30 weeks, as with laser surgery. However, developmental delays due to premature birth are more difficult to predict.

WHICH TREATMENT IS BEST?

Without treatment, TTTS usually results in the loss of both babies, especially if the bladder is empty in the donor baby. As such, taking no action is not an option in most cases. The laser procedure in which blood vessel connections are sealed off offers the best chance of two healthy babies and is the first choice in terms of treatment as a result. In 65 percent of cases, both babies will survive, and in 20 percent of cases, one baby will survive. There is a 15 percent chance of losing both babies. After the surgery, your pregnancy will need to be monitored closely as the imbalance may return. You will usually give birth around week 32 or 33. Ninety percent of children who received laser treatment for TTTS will develop normally.

Amniotic drainage, the procedure in which excess amniotic fluid is drained, is only recommended for stage 1 TTTS when the donor is still able to urinate and laser surgery is not possible, or when your pregnancy has already passed 28 weeks. Your pregnancy will have to be closely monitored as the babies are still connected to each other, and the condition remains present in 60 percent of cases.

Umbilical cord occlusion is never our first choice of treatment as it results in the loss of one baby. Occlusion should only be viewed as a second option in stage 2, 3 or 4 when it becomes apparent that laser surgery is not possible or when one of the babies is severely ill. The rest of your pregnancy will be monitored as if you were carrying a single baby, and you will usually give birth around week 35 or 36. In 95 percent of cases, children will develop normally.

However, some parents opt for umbilical cord occlusion over laser surgery as the chance of extremely premature birth before 32 weeks is smaller than following laser surgery (10 percent compared to 35 percent), resulting in a lower chance of developmental problems. Other parents may choose not to seek treatment and to terminate the pregnancy, which is permitted up to 24 weeks.

The best treatment for TTTS depends on your own specific circumstances. Every TTTS pregnancy is different, and every parent has different needs and expectations.

Dealing with TTTS and the available treatments does not have any impact on your fertility or any future pregnancies, but in many cases, psychological support will be required to reinstate your confidence that pregnancies can run their course without any problems and ensure that anxiety and sadness do not get the better of you.

We hope this brochure has helped you better understand TTTS, the available treatments and their outcomes. If you still have any questions after reading this brochure, please do not hesitate to ask us so that we can provide you with the necessary information.

TESTIMONIALS

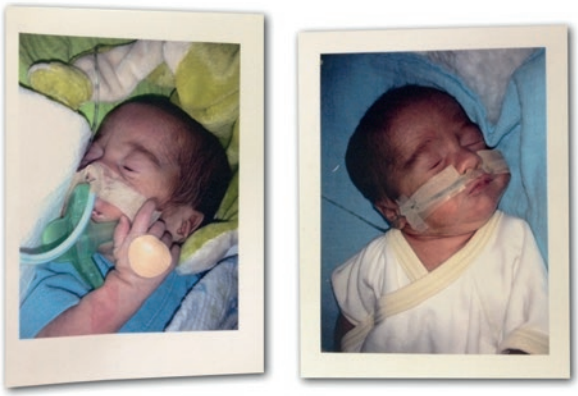
Oxtraordinarily ordinary!

We were trying for a third child. After our first consultation at University Hospitals Leuven, we didn't have a care in the world. We'd been through this before and everything felt comfortably familiar. While we were in the waiting room, a poster inviting parents expecting twins to an information evening caught our eye. My husband jokingly said: 'Hopefully we're not leaving with a leaflet for the twins evening today!' 'That would be quite something, right?' When our turn finally came, I hopped onto the table and pulled up my t-shirt, excited to hear that tiny heartbeat once again. The staff asked us whether we were ok with the midwife performing the ultrasound. 'Of course,' we said. 'This is our third child; we know the drill by now!' I remember feeling the cold gel, looking at the machine and hearing that typical sound. The midwife was strangely quiet. I panicked a little as I was expecting at least a few words of reassurance. After a few minutes – which felt like an eternity – I picked up the courage to ask if everything was ok. 'Yes', the midwife said. 'Everything's fine – with both of your babies!'

And that's how our extraordinary adventure started (with a leaflet for the twins evening in hand!). We went from ultrasound to ultrasound, became experts in twin-to-twin transfusion syndrome, made drawings to explain TTTS to our family and friends, became familiar with the doctors and assistants at the gynaecology unit, learned to put our faith and that of our twins in professional hands and above all, we tried not to lose sight of each other and the twins' big brother and sister during this roller coaster ride.

I wanted to decide on names for the boys really early on; I was certain my babies would make it through, come what may! My husband was a little more cautious and wanted to protect and look after our family, as the future of our twins remained uncertain. We went through laser surgery and a brain scan. Luckily, we didn't have to make any heart-wrenching decisions afterwards; the results were very encouraging.

Eventually, Cas and Jules were born via an emergency caesarean, after 30 weeks and 5 days of pregnancy. Cas weighed 1.640 kg and Jules was 1.340 kg. We explained to the big brother and sister that their little brothers would not be coming home immediately and that they would need to grow big and strong at the hospital first. They nodded to say they understood and carried on playing, but of course, they could sense that all kinds of things were still in the balance. Next, we went through a period in which we felt we were always falling short. Mano (3.5 years) was going to school and wanted to tell everyone who would listen about her new brothers. Lou (1.5 years), a wild teddy bear, really needed structure in his life, and a generous helping of hugs. Which incubator do I visit first? Who do I give kangaroo care to today? Do I have time for both of the twins and can someone else pick up Lou and Mano from school and daycare? When do I pump breast milk? Whose care do I take part in? Then, there was the Christmas play at school, fancy dress clothing that had to be sourced, Lou who had to be potty-trained... 'Switch off my brain and ignore those pangs of guilt' was my survival strategy!



During the day, I coped pretty well, but when everything went quiet at night, I struggled. After 7 weeks, Cas was allowed to come home, and another 7 weeks later, Jules arrived home too. The festive season passed

by in a haze, but on 19 January, our family was finally all complete and at home! That's when another strange process started: we had to really get to know these boys we'd spent weeks watching and praying over. All those monitors and clocks telling us whether they were doing well and when they needed feeding were gone, and I had to learn to rely on my maternal instinct once again – even though that maternal instinct was exactly what I had to switch off to make it through the past few weeks and months. Slowly but surely, I allowed my motherly heart to thaw, and an avalanche of emotions came over me. An occupational therapist from KOOKOS, the Brabant home counselling service, regularly visited with exercises for Cas and Jules and words of encouragement. She was just one of the many lovely people surrounding me, enabling me to feel that everything was ok, that we were doing well and that I could feel confident about the future. When people ask now how we got through those days, I'm still not sure exactly what to say. Maybe it was because we accepted the extraordinary start as just another ordinary situation?

In the meantime, Cas and Jules have grown into two plucky 4.5-year-old toddlers. Next year, they'll be starting their third year of nursery school. I never dreamt we would get this far, but then again, I always did exactly that: I kept hoping that everything would be just 'ordinary' one day. They have loads of fun together and are really physically attached to each other. Sometimes, they could not be more different: Jules can sit and draw for hours, while Cas is slaying imaginary enemies with his big brother like a Power Ranger. Other times, they're both football heroes, winning the World Cup in the garden. At night, they crawl into bed together and share the mischief they've each been up to. 'Twin-to-twin', the common name for the syndrome, has really taken on a special meaning: they're connected for life. As their 'new baby' cards said: 'both unique, unique together'. That's how it feels, every day. One final message for all mothers and fathers who are not sure what's in store for them: it's not naive to have hope; in fact, hope is the most beautiful gift you can give to your twins. Stay strong!


Cyriel and
Pol

'Pregnant? Congratulations! Would you like to book your first ultrasound?'
The main thing you want to hear during that first ultrasound is that your baby is exactly where it should be and that its heart is beating...
'Can you see that too?' the midwife asked the student sitting in during the scan. 'Yeah, there are two babies, right?'
...and the other thing is whether you're having just one baby or more, of course!
That photo is actually the most beautiful ultrasound photo we've got. The first in a long line where they both still managed to fit in a single image.
Later on, the photos became a little less idyllic. For most other couples, every ultrasound is a happy reunion with their baby (or babies), but for us, every ultrasound was a moment where we held our breath and hoped for positive news.
That's because at 16 weeks, an amniotic fluid imbalance was detected. Finally, you're starting to feel relieved that you're feeling less nauseous, and you build up the confidence to tell everyone that you're pregnant — and then this kind of news dampens your enthusiasm. According to the statistics, there's an even higher chance than during the first three months that you'll lose at least one of your babies. That's followed by a series of situations in which you, as parents, have to make heart-wrenching choices, with statistics on the chances and outcomes of each option being the only thing to rely on. As long as our babies were healthy and we didn't see them suffering, we kept choosing them both.

Pol and Cyriel received successful laser surgery. Even at that time, we knew exactly who was who – they both had their own story. After two weeks, and against all expectations, it was donor Pol, and not recipient Cyriel, who presented us with a dilemma. His heart was still able to circulate blood, but its right ventricle had stopped working.

This wasn't a problem as long as I kept supplying him with oxygen as a mother, but he would struggle to survive in the great big world outside of my womb.

Once again, we had to prepare ourselves for a tough choice: we could either allow Pol to grow in my womb until the end of my pregnancy, with an increased chance of complications for Cyriel, or we could let Pol go to give Cyriel the best chance at life.

Pol was still in good health at that time, and we couldn't face giving up a healthy baby. As a parent, you keep talking to your child, explaining to them their heart needs to beat just a little differently... you never lose faith in the strength of your own children.

And our faith was repaid during the next ultrasound: Pol's right ventricle had fixed itself. His blood was flowing just as it should, and everything seemed to be stabilising. In addition, his amniotic sac, which had become detached during the surgery, had reattached itself. Finally, we were faced with an 'ordinary' pregnancy: just what

we needed! But it didn't last long. At 24 weeks, recipient Cyriel's waters broke. He was in the amniotic sac through which the surgery was performed. The chance that the babies would be born right at that moment rose enormously. Yet another dilemma presented itself. What if the babies were to be born now? Would you like us to help them make it through? Luckily, we received excellent guidance on every choice we were faced with.

The next few weeks were very tense, and the rest of my pregnancy played out full-time at the hospital. At 28 weeks, Pol's waters broke as well. They certainly knew how to keep things exciting, our little rascals! Still, they were able to top up their own amniotic fluid independently, and they kept swimming around without a care in the world.

At 33 weeks, the tension got too much. Blood in the amniotic fluid isn't too much of a problem in itself, but at 33 weeks, the time came to relieve me from my motherly role as the only person responsible for the well-being of my babies. The twins were born at 33 weeks and two days. We received the best possible care from the awesome team in the neonatal unit. But honestly speaking, their premature birth was the least of our worries. Our most difficult weeks were already well behind us at that point. Of course, we spent as much time with them as we could, because we had been a team for such a long time, and as the saying goes: 'never change a winning team'! We're still a team today, and we hope to remain a team for many, many years to come.

Elena and Daria

My partner and I really wanted a child, but in September of 2017, I was told that it would be difficult for me to get pregnant naturally. We visited a fertility clinic to see if we could start treatment, but it turned out we wouldn't need to after all – completely unexpectedly, I was five weeks pregnant. We were over the moon! When we attended our first ultrasound two weeks later, we were told there was a tiny heart beating away nicely.

Not one, but two

My partner was always joking that we'd probably have twins, so we went home feeling a little relieved. Everything looked good, and the next ultrasound had been scheduled for week 12 of my pregnancy. What we didn't know at that point was that our lives would never be the same again after that second scan. Five weeks later, the gynaecologist seemed a little surprised when he saw the ultrasound images. It turned out I wasn't just pregnant with one baby: we were having twins after all!

At first, I was so shocked that I started crying. I was scared we weren't ready for two babies. The gynaecologist also told us that one of the babies was smaller than the other, but that we shouldn't be too worried about this at that point of my pregnancy.

Once we'd managed to process the big news, we were absolutely thrilled. We were expecting two babies, identical twins. How wonderful! Our gynaecologist immediately scheduled an appointment with the twins team at University Hospitals Leuven, who would be monitoring the rest of my pregnancy. At our next consultation, we were told the babies were monochorionic diamniotic twins, and that it was possible there might be an imbalance in their blood transfusion. I had always assumed these kinds of complications were possible, but surely not in our miracle babies.

Stay hopeful

Around week 13 of my pregnancy, we found out we were expecting two girls. We were asked to come for an ultrasound in week 15 as our smaller baby was not catching up in terms of growth. During the scan, we were told that not everything was going as smoothly as we thought and that our smaller baby was unlikely to catch up. I wasn't ready to accept that our wonderful story would come to an end after just a few weeks. What we didn't know at that point was just how quickly things could go wrong. After the scan at 15 weeks, we had to come for a check-up every three to four days. Every time, we were told the prospects weren't great, but we stayed hopeful regardless.

We were told that we might need to give up one of our babies to give the other one a chance. Regardless, we decided to give both of our girls a chance, and a few days later, that turned out to be the best choice we could have made. My placenta was on the front of my ab-

dominal wall, so surgery to split it into two was not an option. Laser surgery to seal up the smaller baby's umbilical cord was also out of the question. We were told giving up the bigger of our girls, Elena, was our only option – but we simply couldn't do that!

Our dream shattered

Over the next two weeks, I scoured the internet for information. I lost confidence in our doctors: it was 2017, and I couldn't believe there was nothing that could be done about our situation. I wanted to save our girls. I started forcing myself to eat more; lots of protein and unsaturated fats. But it didn't make a difference: on 20 December, I could no longer feel Elena. She would always tickle me on the left underside of my tummy when I got out of bed, but that day, there was nothing. I could still feel some movement on the right, but during the afternoon, I realised I had barely felt anything at all. I waited for another few hours as I didn't want to give up that easily, but that evening, I finally found the courage to tell my partner our dream might be over.

We drove to A&E, where we were told that Daria had passed away and Elena's heartbeat had slowed down significantly. The next day, I was induced, and on 21 December, I gave birth to our twins, after just 18 weeks. They were both fully formed. Elena was the larger of the two, 20 cm and 260 g; she was pale and looked exhausted. Daria was just 16 cm and 160 g, and her skin was very red from all the blood she had got from her sister after her heart had stopped beating. Both of our girls fought for a long time.

Unfair

Later, it turned out that as well as twin-to-twin transfusion syndrome, our girls suffered from a big imbalance in their share of

the placenta. Daria only had one-fifth of the placenta to herself, so neither of my girls had much chance of being born healthy, right from day one. Daria's umbilical cord was very thin and embedded in the membranes of the placenta. We were unable to save our girls: everything went wrong. One thing I learned is that sometimes there is nothing you can do. It's important for expectant parents of twins to realise that even when everything seems to be going fine, things can still go wrong all of a sudden. Parents have to be ready to choose between life and death, and sometimes to choose one baby over the other.

Our girls live on in our hearts. They allowed us to be a mother and father for the first time. I have learned what real love feels like, but also what real loss and sadness feel like. During this time, I received a lot of support from my partner and our friends, but also from contact on social media with people in the same situation and parents who had lost their twins.


Fred and
Magnus

14 June 2018. The house is a sea of blue, yellow and orange with all this birthday bunting and balloons. Magnus turns five today! While we're handing out chocolate cake and fruit juice to his class, Magnus is getting hugs from his friends. It's great to see how big he's growing. He also gets a big kiss on the cheek from his teacher.

Magnus has brought in a book to show his classmates the pictures of his birth. Pictures of a tiny baby with red skin, full of wires and tubes in an incubator, with sunglasses to protect him from the light... His teacher looks surprised. She didn't know that Magnus was born so prematurely. When it comes to intelligence and coordination, she always thought he was completely normal, if not a little mature for his age, emotionally speaking. Secretly, I'm relieved that everything seems to be going well and we've not had any major issues.

Magnus also tells his friends about Fred, his little brother who was in the tummy with him, but who passed away and is now a star up in the sky. He's telling the story in an easy and relaxed manner as if he's talking about the most normal thing in the world. When I look at him, I fill with pride, because he's had to fight hard, but he's turned into a big, smart, charming and honest child.

30 May 2013. I've been pregnant for 28 weeks with our twins. Until recently, my pregnancy was going smoothly, but over the last week or so, I'm finding it a bit trickier. I feel nauseous and bloated. The gynaecologist in Antwerp said I need to rest and take it easy for a while. It's a Friday afternoon, and David and I have just been to start our gift list. We've waited a long time to do so, because we were told several times in no uncertain terms that being pregnant with identical twins is always risky, especially in the first part of the term up to 26 weeks. Now that we've got past that milestone, it feels like a minor victory. After we're back from the shops, David sets off for Brussels Airport. He's planned a

trip with some of his friends before our twins will be taking up all of our energy and time. I'm due for my monthly check-up at University Hospitals Leuven, so I set off as well. Even getting in and out of the car is getting a lot more difficult. My belly feels like a balloon that's about to burst.

At University Hospitals Leuven, I'm examined by one of the assistants. He seems surprised at what he finds and immediately calls his supervisor. The latter is in no doubt: despite being in an advanced stage of my pregnancy, this is a clear case of twin-to-twin transfusion syndrome. Of course, the news comes as a shock to me. The only thing I can think of is what they told us at the information day: if you've got TTTS, doctors can perform laser surgery and there is a good chance that everything will be alright. Or that's how I remember it, at least. The doctor says that she'd like to perform laser surgery as soon as possible because both of my babies are severely ill and that I should ask David to come back from his holiday. Luckily, he isn't on the plane yet, so as soon as I tell him the news, he promises to hurry down to the hospital. I can tell from his voice that he's not overly worried either. It feels like we're both holding on to the hope that everything will be ok in the end, and that neither of us has realised just how serious the situation is.

With laser surgery, everything has to move quickly. I find myself in a sterile room with two doctors busy working on my belly. Suddenly, one of the doctors looks up in shock and says she's unable to detect any heartbeat in the donor baby, our tiny Fred.

For a moment, I'm left hoping I misheard her – perhaps I didn't want to hear her – but straightaway, she confirms my worst fear: that one of our babies suddenly passed away, and that she's shocked herself because this has never happened before.

I start crying and beg the doctor to tell David the news because I

can't do it myself. I simply can't tell him that one of our babies has died. I think that somehow, I feel responsible: after all, it was me who was carrying them. Surely, I should have felt something earlier if they weren't doing well? Why did I not come to Leuven sooner?

That same moment, David arrives at the hospital and runs through the corridors of the maternity ward, full of hope and saying hello to the nurses he encounters along the way. Afterwards, he said that he could already see it in their faces; in the way they didn't really make eye contact because they knew what he was about to find out.

As soon as the doctor tells him about Fred, David collapses. It breaks my heart to see him this way. The next few days are just awful. We need to process the biggest shock of our lives, but it feels unreal because I still look exactly the same and I'm still pregnant. Every now and then, we manage to forget for a while, but then it all hits us again. It's over. We are no longer having twins.

David returns to work two days later; he needs something to occupy his mind and the business he works for gives him exactly that.

I stay at the hospital because Magnus is still alive and needs constant monitoring as he's very sick. Aside from the regular check-ups, my days are filled with crying, falling asleep from pure exhaustion, waking up again and crying some more at all the well-wishes we've received. The room is full of flowers sent by friends, family and colleagues. I don't want to see anyone right now, apart from David and my mother. David is driving back and forth to Leuven all the time. I keep thinking he must feel lonely on those trips.

Soon, the first of a series of hurtful situations occurs, such as a new person on the ward who is complaining all day just because the doc-

tors have told her to lie flat, and concerned family members who want to remove the twin-things from our house to make things more bearable for me. But above all, there's love: in messages, in e-mails, from the doctor who came to see me late at night because I asked her to and from all the nurses on the ward.

The doctor says it would be good for me to go home, to see friends and to talk about what happened. But that's the last thing I want. I feel safe in these hospital surroundings, and I'm terrified of losing Magnus as well without sensing that anything is wrong – yet again. But then, the doctors notice that the surgery has caused some membranes to detach that could choke Magnus' umbilical cord without me ever noticing. So, I end up staying in hospital after all. The tension starts to become unbearable: I really don't want to lose another baby inside me. I want to give birth. However, the doctors are adamant that I should wait until I'm 30 weeks in, to give Magnus the best chance of recovery from the transfusion syndrome. A few days before I reach week 30, it looks like the membranes are closing in around Magnus' umbilical cord, and the doctors decide to schedule a caesarean.

I give birth to a tiny, tiny baby. Magnus is perfect and starts crying immediately. The midwife briefly holds him to my face, but I have no idea what I should be feeling towards that little human. There's still too much sadness. Magnus is taken away immediately and placed in an incubator in the neonatal intensive care unit, on oxygen. David stays with him. He's extremely proud of his son.

Then, I give birth to a dead baby. Fred passed away two weeks ago and it's clear to see: his head is totally misshapen, but his hands and feet are perfect. I don't have the courage to hold him; something I regret to this day as I don't have a single photograph of my second son. What follows next is 54 days of travelling back and forth to the

hospital. I stay with Magnus as much as possible, from early in the morning until late at night. The clockwork functioning of the neonatal intensive care unit is what I've started to rely on now, together with the love and sympathy of my sister who's a nurse on the unit where Magnus is being looked after. I pump breast milk, I help care for Magnus where I can, I give him hugs, and I don't give up.

In the meantime, Fred is cremated. David and I both say goodbye to him for the final time, and we wait on a bench outside until his ashes are ready to take home. The days are quiet and long.

More difficult moments follow: the certificate that suddenly confirms everything in black and white, the family composition document that no longer includes Fred (yes madam, because he passed away, right?), people close to you asking whether you'd like a second child (I already had two), people around you making it through their pregnancy without a care in the world (or so it seems, anyway) and sharing their great news with everyone who will listen.

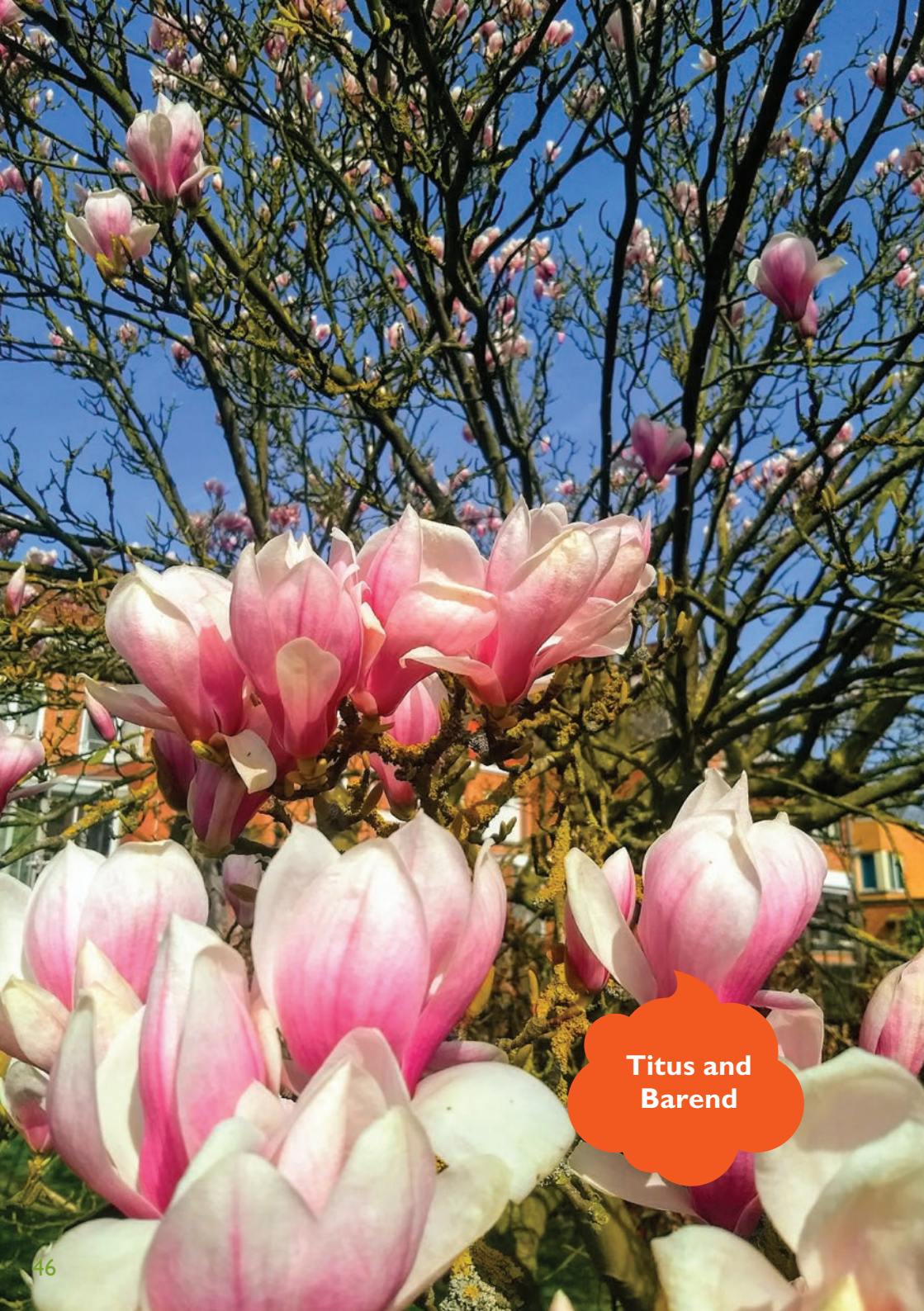
In August, Magnus is finally ready to come home. We're both over the moon, but it's also difficult to say goodbye to the cocoon of safety offered by the hospital for the second time. We arrive at home with a baby who cries all the time and who we don't understand. Now, I know that he was crying for my attention; my full and undivided attention. Because at the time, my heart was still heavy with our loss. I spend more time thinking about Fred than about Magnus, and he can sense that. He's crying for me to put him first. I start to feel less and less sure of what I'm doing as a mother. For over six weeks, machines and nurses did something that I couldn't do as a mum, and something that should be the most ordinary thing in the world: care for my son. Once Magnus is home, I need to rediscover my maternal instinct, and I struggle to do so. It's a very unhappy period for both me and Magnus.

I get pregnant again soon. The doctor told me that a new pregnancy would offer comfort; that new life would bring happiness, and that's exactly what happens.

When Oscar is born, I suddenly realise what it's like to give birth without any worries and to feel nothing but love straightaway. At the same time, I still feel it's all very unfair, and I'm angry about what me, Magnus and David had to go through. It's only at that moment that I'm able to close the chapter of my first pregnancy.
We're five years on now, and I still hope from the bottom of my heart that Magnus is able to deal with it all now and in the future as well as I've been able to. Later, when he's older, I want to apologise to him once again for the difficult start we had and explain to him that I couldn't have done anything differently.

Magnus and Oscar are the best of friends, and I'm extremely happy with my beautiful family. That might sound like a cliché, but I really am. At the end of May every year, we pause to think about what happened and David and I go out for a meal or on a trip. The sadness is easing, but it will always be there, somewhere in the background.

Recently, friends of ours lost a baby early in their pregnancy. With our experience, we were able to support them through every step of the grieving process and they really appreciated that. It was good to see that everything we've been through wasn't for nothing.


Titus and
Barend

In December of 2009, we received some fantastic news: I was pregnant again, and this time, it was twins! A whirl of excitement started that day: after two pregnancies and two healthy children, our family would be complete with another two babies. However, it didn't take long for a few minor ailments to crop up – though they seemed fairly normal at first. At just 16-18 weeks, my belly was already the size of someone who had carried full term, and it caused me a lot of discomfort. An ultrasound showed that even at that early stage, the balance of amniotic fluid between the two babies was unequal. That same day, the regional hospital referred us to the twins unit at University Hospitals Leuven where it was immediately apparent that the situation was worse than we thought. From the moment we arrived, the staff clearly explained all the potential outcomes. Two days later, I'd already had laser surgery. That was the option that offered the best chances at that time of bringing two healthy babies into the world. Still, we were conscious of the fact that things could take a turn for the worse, even though you use all your energy to hope for the best in moments like this. The staff at the high-risk pregnancy unit offered us the best care we could have asked for, and we were given all the information we needed to prepare for what could still lie ahead.

The first few days and weeks after the surgery went as well as they possibly could, and the ultrasound scans during that period gave us hope. At every check-up, we gained a little more confidence, even though the potential risks were repeatedly mentioned.

Regardless, at 24 weeks, the inevitable happened: my waters broke and labour started almost immediately afterwards. Next, we went through the most intense 24 hours of our lives. An impressively strong team surrounded us with the best possible care, and the midwife did not leave our sides for one moment. The team tried everything medically possible to hold back the birth of our boys, but de-

spite their efforts, the twins were born at that extremely premature stage. Sadly, they were not strong enough yet to make it on their own. Shortly after their birth, they passed away peacefully. The birth of our sons was a moment in which life and death came together. My memories of the days after their birth are hazy; the only thing I felt was disbelief. We needed a lot of time to come to terms with the fact that the unthinkable had happened.

Again, the team of midwives and the high-risk pregnancy unit stayed right by our side during this time, not only to sort out the practical side of things, but also to make sure we could say goodbye properly to Titus and Barend. In our period of mourning, we were supported by the presence of our families and the entire team.

Titus and Barend would have turned six in the spring of 2018. In our garden, the magnolia tree that blossoms at that time of year reminds us of the hope and sadness that we carry inside us. Every spring, the petals fall off.

Jomar and Willis

Finding out your twins have TTTS certainly comes as a shock. Suddenly, you're left with so much uncertainty and anxiety: will they both survive, or will we be left with only one baby or perhaps none? Our twins, Jomar and Willis, were in stage 1 of their TTTS. What made our situation extra scary is that we were not eligible for laser surgery. My placenta was on my front abdominal wall, and there were too many blood vessel connections between the babies making the surgery too risky to perform. We were given other options: we could choose to terminate the pregnancy or choose one of our babies. It was impossible for us to make that choice ourselves: we would be wondering for the rest of our lives what it would have been like to have two babies. In the end, we chose to take no action and to see what happened for as long as our babies remained in stage 1. The difference in their amniotic fluid was significant, but luckily, our donor baby's bladder continued to function. We had twice-weekly check-ups with the twins team at University Hospitals Leuven. It was a stressful period in which many a tear was shed. At every ultrasound, we faced a tense wait to find out whether both of their hearts were still beating.

Once we got past 24 weeks, the staff prepared us for a new potential situation: that one or both of our babies could be born prematurely by caesarean. We had a consultation with the neonatology specialist who told us that we could still opt for palliative care only. Again, we faced a whole host of difficult choices.

Still, my pregnancy continued to progress. After 31 weeks, the balance of amniotic fluid had nearly been restored, but the circulation in the umbilical cord of our donor baby was not as it should be. As a precaution, I was admitted to the hospital where the twins' heartbeats were monitored three times per day. It wasn't exactly enjoyable, but the fact that the babies were being monitored on a daily

basis and that the twins team were ready to jump in when the time came to give birth certainly was a big weight off our minds.

In the end, the babies held out until week 35 and I was able to give birth naturally. According to the doctors, this was an extraordinary outcome: the babies managed to resolve the problem themselves meaning they were only born one month prematurely. Two healthy boys who had to spend a couple of weeks in an incubator without any real issues: they just needed to gain a little weight before they could come home with us.

ALARM SIGNALS

You can contact us at any time in the following situations:

- ✗ Fever, feeling generally unwell, redness around the wound in the week after treatment.
  These symptoms could be a sign of infection.
- ✗ Strong feelings of period-like pain that come and go in your lower abdomen, loss of blood or fluids.
  These symptoms could be a sign of (premature) labour.
- ✗ Fewer baby movements than you are used to
  These symptoms could be a sign that your babies' health is deteriorating.
- ✗ Any other symptoms
  If you are worried about any other symptoms, feel free to contact us.

During working hours, you can contact us via the obstetrics office: tel. +32 (0)16 34 22 00.

In the evenings or during the night, you can reach us via the E 496 maternity ward:
tel. +32 (0)16 34 36 04

You can also e-mail us on: twins@uzleuven.be

As we are continuously trying to improve outcomes for TTTS twins, there are a number of research projects in which you can take part if you wish to do so. For more information on these projects, please contact the doctors on the University Hospitals Leuven twins team or pick up a flyer from the gynaecology and obstetrics ultrasound centre.

If you would like to provide financial support to twins research, you can do so via the patronage fund for twins research. Donations can be made to account number IBAN BE45 7340 1941 7789; BIC code: KREDBEBB in the name of KU Leuven, under reference 'for EQQ-MCLL01-O2010'. For donations over 40 EUR, you will receive a tax certificate. For more information on donations, feel free to contact the KU Leuven University Fund on +32 (0)16 32 37 39.

NOTES AND QUESTIONS

You are bound to be left with some questions after reading all of this information. Sometimes, it can be difficult to remember these questions and ask them during a consultation. You can write your questions down in the space below and ask them at your next consultation, or in an e-mail to twins@uzleuven.be.

RELIABLE WEBSITES AND INFORMATION

The internet offers a wealth of information, but not all of that information is up-to-date or comparable to your situation. This may leave you feeling confused. You can ask us to provide you with details of reliable websites and information at any time.

It is often nice to know who exactly was involved in your treatment at University Hospitals Leuven. You can make a note of the names of the medical staff who looked after you in the space below:

Gynaecologist: . . . . . .

Paediatrician: . . . . . .

Midwife: . . . . . .

Social worker: . . . . . .

Other: . . . . . .

Design and realisation
This brochure was compiled by Prof. Liesbeth Lewi, gynaecologist and head of the twins care programme at UZ Leuven; Amber Dhaene and Elise Degreef, obstetrics students at Vives Kortrijk; Dr Isabel Couck, gynaecologist and PhD student; Nele Thijsen and Kathleen De Neef, both midwives and founders of the information evening for parents of twins; Nancy Henrotte, Goedele Timmerman and Kathleen Depré, case managers on the foetal medicine team, in cooperation with the communications team. A special thank you goes out to the parents who kindly shared their stories.

You can also find this brochure on www.uzleuven.be/en/brochure/701044.

If you have any comments or suggestions regarding this brochure, please send them to communicatie@uzleuven.be.

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