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We support twins, triplets and more...

COMPLICATIONS IN YOUR PREGNANCY
WITH TWINS, TRIPLETS AND MORE:
A GUIDE FOR PARENTS

CONTENTS

FOREWORD

This booklet is designed to help you to understand some of the conditions associated with twin, triplet and higher-order pregnancies. Although these complications are rare, we hope the information in this booklet will help you understand what to expect if you are diagnosed with any of these conditions. In recent years, professionals' understanding of these conditions and the best treatments for them has improved, thanks to research to help expand doctors' knowledge. However, there is still more to learn, and Twins Trust is committed to supporting research to improve outcomes for twins, triplets and more.

Twins Trust has partnered with St George's Hospital in London to create the Twins Trust Centre for Research and Clinical Excellence, which is carrying out research into complications which affect twin, triplet and higher order pregnancies, and share their expert knowledge with other health professionals. The TTTS/Multiple Pregnancy Registry, which collects data about complicated pregnancies, alongside research studies into specific conditions like Twin Anaemia Polycythaemia Sequence (TAPS) and selective Fetal Growth Restriction (sFGR or sIUGR), are helping doctors to understand the treatments which give babies the best chance of being born healthy following a complicated pregnancy.

Since 2015, Twins Trust has also funded research studies in partnership with the British Maternal Fetal Medicine Society (BMFMS) in an effort to make all twin, triplet and higher order pregnancies safer, and since 2016 has worked with maternity units across the country to improve the care they offer, with evidenced improvements in pregnancy outcomes.

More information about how to support this vital work can be found in section 7 of this booklet.

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INTRODUCTION

Finding out that you are pregnant with twins, triplets or more can be a time of conflicting emotions for parents. The excitement and joy are usually mingled with thoughts about the practicalities of caring for more than one baby and concerns about the increased risks for the mother and babies. Parents often feel scared and overwhelmed, especially if they later discover the babies share a placenta and are at risk of developing additional complications.

Although there has been great progress in diagnosing and treating complicated pregnancies, it can be hard for parents of twins, triplets or more to find information about the conditions they may be at risk of or diagnosed with. We hope this booklet will help you to understand more about the conditions, and direct you to other sources of information and support.

Being pregnant with twins, triplets or more can feel isolating, particularly if there are complications. As well as providing information, this guide also shares the experience of parents who have had complications during pregnancy. We hope that by reading other parents' stories it will help you to feel less alone.

It is normal to feel anxious, but please try to remember that most parents go on to have healthy, happy babies. Reading this booklet is one of the best things you can do right now – making yourself aware of the warning signs, preparing for possible outcomes and being prepared in case you need to make informed decisions if any complications develop in your pregnancy.

This booklet covers four complications which are specific to twin and higher order pregnancies: Twin-to-Twin Transfusion Syndrome (TTTS), Twin Anaemia Polycythaemia Syndrome (TAPS), Twin Reversed Arterial Perfusion Sequence (TRAPs), and Selective Intrauterine Growth Restriction (sIUGR) also known as Selective Fetal Growth Restriction (sFGR). Information about other pregnancy complications is available on the Twins Trust website **https://www.twinstrust.org/complications** or in our *Healthy Multiple Pregnancy Guide*. If you have any concerns about your pregnancy, you should always seek advice from your midwife or doctor.

If you would like to speak to somebody, please contact Twins Trust or any of the organisations listed at the back of this booklet. We wish you the very best during your pregnancy, birth and the many years to follow.

TYPES OF TWIN AND TRIPLET PREGNANCY

The complications which might affect a pregnancy and the ways in which different pregnancies are managed differ depending on how many babies there are and whether or not they share a placenta. Pregnancies with a shared placenta are at risk of complications which do not affect other types of pregnancy. In rare cases, some babies might also share an amniotic sac, which carries additional risks. In any pregnancy with a shared placenta or amniotic sac, you should be monitored closely by a team of specialists, who can pick up complications early if they occur.

The different types of twin and triplet pregnancy are explained below:

Dichorionic Diamniotic (DCDA) Twins

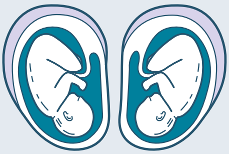
With DCDA twins, each baby has its own placenta and own amniotic sac. Two thirds of DCDA twins are non-identical (dizygotic), and about one third are identical (monozygotic). Because they have separate placentas, dichorionic twins are not at risk of TTTS, TAPS or TRAPs, but they can experience other complications and it is important that you attend all your antenatal appointments.

Monochorionic Diamniotic (MCDA) Twins

MCDA twins share a placenta and an outer membrane, but move around in separate bags of water (amniotic sacs). Because of their shared placenta, there is a risk of TTTS and other complications, and these pregnancies should be monitored more closely to check for early signs of any complications.

Monochorionic Monoamniotic (MCMA) Twins

With MCMA pregnancies, the twins share a placenta but also share an amniotic sac. Because they share a single sac, the twins are at risk of their umbilical cords becoming entangled, which can interfere with their food and oxygen supply. Delivery is therefore usually recommended for MCMA twins at 32–34 weeks by Caesarean section. Because they also share a single placenta, MCMA pregnancies are at risk of complications like TTTS. MCMA twins are very rare – only about 1% of monochorionic twins are MCMA.



DICHORIONIC DIAMNIOTIC (DCDA) TWINS

2 placentae and 2 sacs

MONOCHORIONIC DIAMNIOTIC (MCDA) TWINS

1 placenta and 2 sacs

MONOCHORIONIC MONOAMNIOTIC (MCMA) TWINS

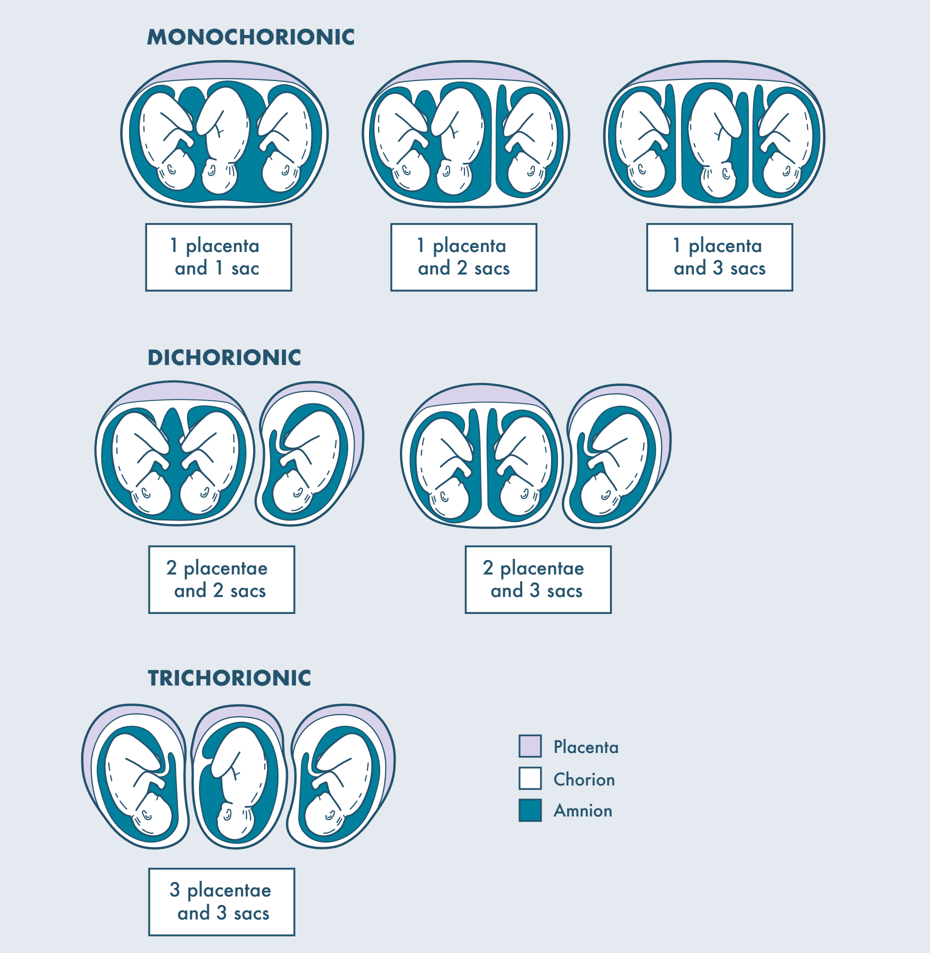
1 placenta and 1 sac

▨ Placenta
☐ Chorion
■ Amnion

Triplet and higher order pregnancies

Triplets can be monochorionic (sharing one placenta), dichorionic (two babies sharing a placenta and the third with its own separate placenta), or trichorionic (each baby has its own placenta). All triplet pregnancies are carefully monitored, but you should have more frequent appointments in a pregnancy with a shared placenta compared to a pregnancy where each baby has its own separate placenta. Like twins, triplets sharing a placenta can also share an amniotic sac, but this is very rare and if this is the case for your pregnancy you should receive individualised care from a specialist team of health professionals.

Similarly, higher order pregnancies may have a combination of shared or separate placentas (for example, a quad pregnancy could have up to four placentas) and babies which share a placenta can, rarely, share an amniotic sac.



MONITORING FOR COMPLICATIONS

Because there is a risk of complications with all twin and triplet pregnancies, but especially those which share a placenta, there are guidelines in place for antenatal care that will ensure you are monitored closely for signs of any complications. Any pregnancy with a shared amniotic sac should be seen by a specialist team who can provide individualised care for your pregnancy.

The care you receive will depend on the type of pregnancy you have. The Twins Trust website has a checklist so you can make sure you're receiving the proper scans and information at each appointment. You can download the checklist at **www.twinstrust.org/antenatal-care**.

There are two main guidelines for twin and triplet pregnancies in the UK. These are the NICE guideline NG137 on twin and triplet pregnancies, and the RCOG Green Top Guideline 51 on the Management of Monochorionic Twin Pregnancies. Your health professionals should follow these guidelines throughout your pregnancy.

In particular, you should look out to see if these key points are being followed:

- You should expect to be seen in a twins/multiples clinic run by a team of doctors, midwives and sonographers who have training and experience in twin and triplet pregnancies.
- You should be given a schedule of the appointments and scans at your first appointment. The importance of each one should be explained to you.
- The team should explain to you what to look out for if you go into labour early and what to do about it.
- If you think there is a problem during pregnancy, or you think you might be going into labour, you should be seen by a doctor experienced in the care of twin pregnancies. They should review you and are likely to scan your babies to check they are well.
- If you give birth and your babies are small or poorly, you and your partner should be asked about the care you would like them to be given, with advice from a neonatal care doctor. You should be involved in all decisions about what happens to them.

(MBRRACE-UK, 2020)

If you are unhappy with your care at any point during your pregnancy, you can ask to transfer your care to a different hospital.

For more information on what to expect during your pregnancy, download Twins Trust's Healthy Multiple Pregnancy Guide from the Twins Trust website.

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Section one:

TWIN-TO-TWIN TRANSFUSION SYNDROME (TTTS)

WHAT IS TTTS?

Twin-to-twin transfusion syndrome (TTTS) is a rare, but potentially fatal, condition that affects about 10-15% of twins that share a placenta (monochorionic twins), as well as higher order pregnancies with a shared placenta. It can appear at any time during pregnancy, but most commonly before 24 weeks' gestation.

It arises because there are blood vessels connecting the placenta that the twins share. Usually, these blood vessels allow blood to flow evenly between the babies so that each baby receives the same amount. However, in TTTS, part of the blood flow is diverted from one 'donor' twin to the other 'recipient' twin in what is effectively a blood transfusion (hence the name).

A lack of blood supply can affect the donor twin's growth so they are smaller than average. The recipient twin is usually larger and has a higher blood volume, which can strain their heart as it works harder to pump the extra blood.

To compensate for the excess blood, the recipient twin often produces a large amount of urine which is then passed out as amniotic fluid (the water around the baby). In contrast, the smaller donor twin can have a reduced amount of amniotic fluid; occasionally it can become stuck against the wall of the womb if there's very little surrounding fluid.

WHO DOES TTTS AFFECT?

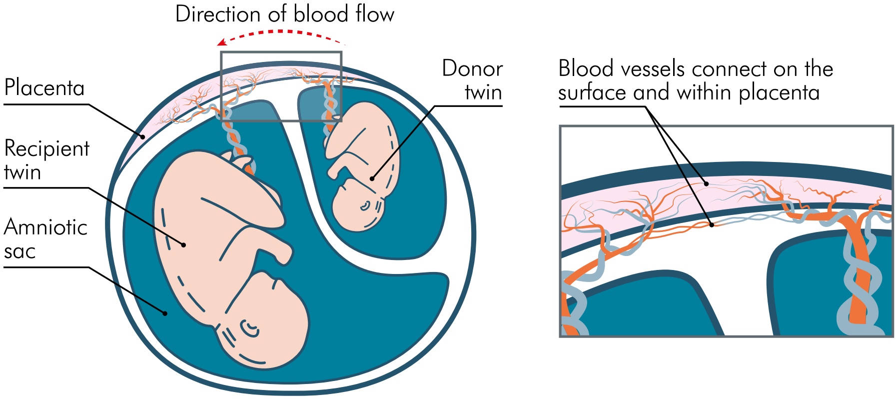
TTTS only affects twins, triplets or more who share a placenta. Twins with a shared placenta are referred to as monochorionic twins because they share an outer membrane (chorion).

WHAT ARE THE WARNING SIGNS?

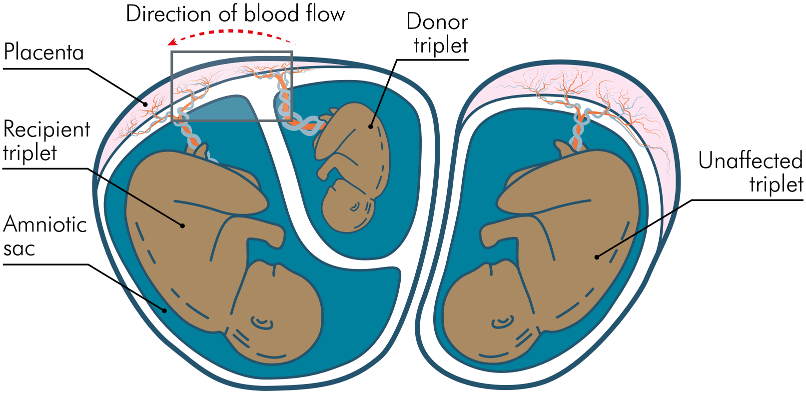
During your first ultrasound scan, the sonographer will look carefully to see if your twins are monochorionic or dichorionic. If they are monochorionic, or you have monochorionic or dichorionic triplets, they should be closely monitored with ultrasound scans, so that if TTTS starts to develop it is diagnosed and suitable treatment considered.

It is important to attend all your appointments so that any early signs of complications can be picked up. You can download a checklist to ensure that you're receiving the right scans and information throughout your pregnancy at **www.twinstrust.org/antenatal-care**.

TTTS IN TWINS



TTTS IN TRIPLETS



Warning signs on ultrasound in monochorionic twin babies include:

- Different amounts of amniotic fluid around the babies. The donor baby may have very little amniotic fluid, while the recipient has a lot. This is known as oligohydramnios (low levels of fluid) and polyhydramnios (high levels of fluid).
- Significant size difference – a difference of less than 15% between babies is considered normal.
- Abnormal blood flow (a special scan called a Doppler is used to measure blood flow in the babies' umbilical cords and within the baby to assess the severity of TTTS once it has been diagnosed).

Mothers should look out for several symptoms:

- Sudden weight gain due to excess fluid – getting noticeably bigger in a short space of time, sometimes even within 24 hours
- Being breathless at rest and having palpitations (unusual heartbeats)
- Feeling that your tummy is tight, uncomfortable and/or the surface looks shiny
- Increased thirst
- Feeling early contractions
- Back pain and leg pain due to the build-up of fluid

The care for all women with a monochorionic pregnancy should be based on a policy agreed with their doctor or the local (or regional) fetal medicine specialists. Women with mild TTTS may not develop any of these complications or require treatment. However, TTTS is unpredictable and your pregnancy will be closely monitored for signs of improvement or deterioration. If you have symptoms of more severe TTTS, you should be referred to a fetal medicine unit for the most suitable treatment.

TTTS can also be described as either 'chronic' or 'acute'. Chronic TTTS occurs in the early months of pregnancy (12-26 weeks) and tends to develop slowly over time. Acute TTTS often happens much more quickly, due to sudden differences in blood pressure between the twins in the last three months of pregnancy or even during labour.

Regular monitoring is important for both types of TTTS, although acute TTTS can develop very quickly so it is important to be aware of the warning signs of TTTS and to contact your hospital if you are at all concerned.

WHAT CARE SHOULD I EXPECT DURING MY PREGNANCY?

There is no such thing as a typical TTTS pregnancy. Each pregnancy will be treated on a case-by-case basis, depending on the severity of the condition and what is right for your pregnancy.

However, the Royal College of Obstetricians and Gynaecologists has provided the following guidance for the care of monochorionic twin pregnancies.

The Different Stages of TTTS – The Degree of Severity

Stage I:	**The mildest form of TTTS with high levels of amniotic fluid around one baby and low levels around the other.**
Stage II:	**The donor now has no urine visible in its bladder.**
Stage III:	**Either the donor twin or recipient has abnormal blood flow patterns shown by the scans which assess the blood flow (Doppler scans).**
Stage IV:	**This is characterised by the development of heart failure in the recipient twin. This can sometimes cause hydrops (abnormal swelling due to excessive accumulation of watery fluid) in the baby, which can be seen on the scan.**

WHAT ARE THE TREATMENT OPTIONS?

If your TTTS is mild (Stage I), you may require no treatment and it is possible that the condition will remain stable or improve. Your pregnancy will be closely monitored and, if TTTS becomes more severe, your doctors may recommend treatment.

The choice of treatment will depend upon the stage of TTTS and how far into the pregnancy you are. Your doctor will discuss with you which treatment options are appropriate to your situation and what is involved, the risks and possible outcomes of each option. Some of the most common treatments for TTTS are described below.

Amnioreduction

Amnioreduction involves draining excess amniotic fluid from around the larger recipient baby, using a fine needle which passes through the mother's abdomen. The procedure does not treat the cause of TTTS, but it can help stabilise the pregnancy by giving more space to the smaller donor ('stuck') baby and reducing the risk of premature labour. You should also feel more comfortable once the excess fluid is removed.

The procedure usually takes around half an hour. You may need to stay in hospital for a short time afterwards, although some hospitals let patients return home the following day for bedrest.

Amnioreduction is suited to acute TTTS at late stage in pregnancy, and is not thought to be as effective for Stages III and IV. Success rates vary between hospitals and the stage of TTTS, but the procedure is generally associated with a:

- 66% chance of survival of at least one baby;
- 44% chance of survival of both babies;
- average delivery at 29 weeks;
- a 15-25% risk of long-term neurological disability for surviving babies.

The procedure may need to be repeated if excess fluid starts to build up again and the risk of complications, such as bleeding, infection or injury

10-13 Weeks: Ultrasound Examination	If twins are diagnosed at the first ultrasound examination, the sonographer doing the scan should check whether the babies share a placenta – the chorionicity scan. This first pregnancy scan may be earlier in some cases, for example if the mother has had fertility treatment, bleeding, or any other health concerns. A photo record of the membrane attachment to the placenta should be kept in the case notes. If there is any doubt about chorionicity, a second opinion should be sought, ideally from a specialist, before 14 weeks. After this stage, it becomes more difficult to work out on scan whether or not twins share a single placenta. Many parents also choose to have the screening test for Down's syndrome – the nuchal translucency scan, which involves measuring the thickness of the fluid lying under the skin at the back of the neck.
14-24 Weeks: Ultrasound Scans Every 2 Weeks	All monochorionic pregnancies should be monitored by ultrasound examination every 2 weeks from 16 weeks, although these scans may be more frequent if the pregnancy is complicated or there is greater cause for concern. The scan will look for early signs of TTTS and check the growth of the twins. If any signs of TTTS are detected, you could be referred to a regional fetal medicine centre with experience of caring for and treating TTTS. In some cases, you may continue to be seen by your local hospital if they have an agreement with the regional unit. At 18-22 weeks an anatomy scan is done to check your babies are developing normally and look for any abnormalities in the babies' structural development and growth.
24+ Weeks: Ultrasound Scans, Doppler Studies and Discussion About Birth Options	All monochorionic pregnancies should continue to be monitored by ultrasound examination every 2 weeks, but after 20 weeks Doppler studies should also be used to look for signs of poor blood flow through the umbilical cords and placentas of the babies. The benefits and risks of different types of birth should be discussed by 28 weeks and the mother and doctor should come to an agreement that she is happy with. It may not be advisable to have a vaginal birth if the first baby is lying breech (bottom-first), the mother has had a previous Caesarean section or if there are other clinical concerns requiring a Caesarean section. TTTS and birth is discussed later in this booklet.

to the membranes, or premature labour, increases slightly with each amnioreduction.

Laser Ablation

Laser ablation therapy involves finding every blood vessel connecting the babies and closing them to prevent the flow of blood from one baby to the other. The surgery is conducted under local anaesthetic or spinal, so you should be awake and, if you wish, able to watch the procedure and your babies on an ultrasound screen.

The procedure begins by inserting a needle and thin hollow tube into the fluid sac of the recipient (larger) baby. The needle is removed before a small telescope (fetoscope) with a thin laser fibre is inserted through the tube. The fetoscope finds all the blood vessels in the placenta that link the blood flow between the two babies. The laser is then used to seal these blood vessels. Each baby stays connected through its own umbilical cord to its main source of blood and nutrition; but the blood can no longer flow from one baby to the other through the placenta.

The extra fluid around the bigger baby is usually drained afterwards. Depending on the complexity, the procedure can take between 45 minutes to two hours.

Laser ablation is generally considered to be the most effective treatment for TTTS. If every blood vessel is found and the two blood supplies completely separated, the procedure only needs to be done once. In the largest medical trial of different treatments for TTTS, the following outcomes were observed for pregnancies treated by laser therapy:

- **at least one twin survived in 73% of cases;**
- **a risk of long-term disability in the surviving babies of around 5-10%.**

Success rates are likely to be higher if TTTS is less severe. Your fetal medicine specialist should be able to talk you through the possible outcomes, based on the unit’s statistics.

A comparison of the different treatment options found that laser ablation was more likely to result in good outcomes for both babies and the mother than other types of treatment (The Cochrane Review, 2008). The Royal College of Obstetricians and Gynaecologists recommends that severe cases of TTTS should be treated by laser ablation rather than amnioreduction (providing the pregnancy is less than 26 weeks’ gestation).

Selective Feticide

In a few cases, the only way to prevent the loss of both babies is to close off the blood flow to the sick baby’s cord, a procedure known as selective feticide. This option is a last resort and means that this baby will die in the womb, but should provide a better chance of survival for the other baby.

WHAT MIGHT HAPPEN TO MY BABIES?

Although a TTTS pregnancy is stressful and it is natural to feel worried, please be assured that many families go on to have two healthy babies at the end of it. In the last section of this guide, our families share their happy outcomes. We hope these stories give you hope and comfort at this anxious time.

However, your doctor will probably also have explained that not every pregnancy with TTTS results in two healthy babies born full-term. This section covers what can happen to babies with TTTS during pregnancy, birth and in the long-term.

While your babies are inside you, possible concerns include slow growth and anaemia, as well as more severe complications such as generalised soft tissue swelling (hydrops), brain damage or heart failure. In severe cases, one or both of the babies may not survive. We have support for families who find themselves in this very sad situation, which you can read about in section six of this booklet.

Another possible outcome is that your babies may be born early, either because the doctors decide the babies have a better chance of survival outside the womb or because you go into early labour. For further information on the risks associated with prematurity, please see Twins Trust's Parents' Guide to Neonatal Care.

Surviving babies born following TTTS during pregnancy often have good long-term outcomes. Many babies are born healthy, especially with recent medical advances in treating the condition. Often the only indication that babies have had TTTS is a minor difference in size or colouring at birth.

However, this is a condition which can cause long-term health concerns in a few cases. Disability can occur due to prematurity or the effects of TTTS on babies' hearts, brains or kidneys inside the womb. Your doctor will discuss these risks with you.

Your babies should be examined by a paediatrician soon after they are born and any health concerns are usually found (or verified) at this time. If you have any worries about their mental or physical development, please speak with your doctor or health visitor and they can reassure you or monitor their progress.

WHAT CAN I DO?

If you are diagnosed with TTTS or find out you are at risk of developing it, first of all, try to stay calm. Please remember that many families have happy outcomes following a pregnancy affected by TTTS. By reading this guide, you are already taking the first steps to prepare for the rest of your pregnancy and birth.

The best thing you can do for your babies is attend all your appointments so they can be monitored, and speak to your doctor about the different treatment and birth options for your pregnancy. You can access a checklist of all the scans and information you should be receiving at your appointments on the Twins Trust website: **www.twinstrust.org/antenatal-care**, and your doctor may offer you additional appointments depending on your individual pregnancy.

If you experience any of the symptoms listed, or you feel that something isn't right during your pregnancy, it's always best to raise it with your health professional so they can check you for any complications.

You can read about Kyran's experience of TTTS on page 38, and Keziah's experience of TTTS and TAPS on page 46.

Section two:
TAPS

WHAT IS TAPS?

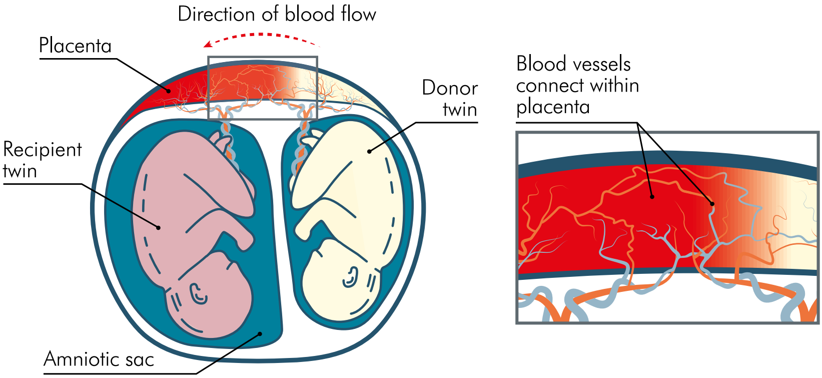
TAPS stands for 'Twin Anaemia-Polycythaemia Sequence'. This is a condition found only in pregnancies where twins or triplets share a placenta. Anaemia means not having enough red blood cells (which contain haemoglobin, the red substance that carries oxygen) in the blood. Polycythaemia is the opposite – when there are too many red blood cells in the circulation. Small blood vessels can form in the placenta between the babies, connecting their blood supplies, allowing a slow passage of blood from one baby to the other. These are smaller than the connecting blood vessels seen in TTTS. This can cause the baby donating the blood (donor) to become anaemic (low blood levels), and the baby receiving the blood (recipient) to become polycythaemic (high blood levels), which can lead to overload and strain on its heart.

TAPS can be more difficult to diagnose than TTTS, as there is no difference in the fluid volume around the babies. It can develop on its own, or after laser therapy for TTTS.

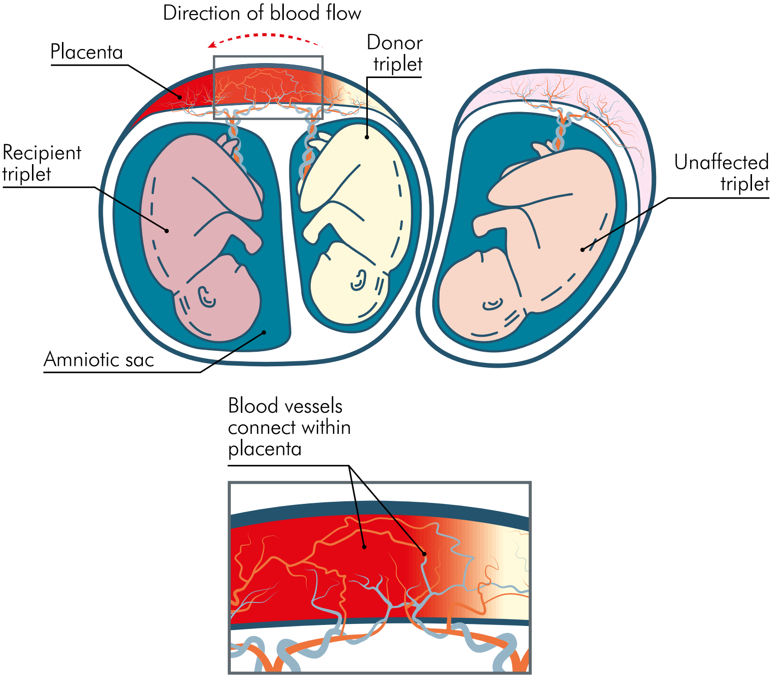
WHO DOES TAPS AFFECT?

TAPS is a rare condition that can affect monochorionic twins (or any higher order pregnancy where babies share a placenta). It can occur spontaneously or following incomplete laser treatment for Twin to Twin Transfusion Syndrome. Small blood vessels in the placenta connecting the circulations of the two babies may allow blood to leak through from one baby (the donor) to the other (the recipient). Pregnancies where the babies each have their own placenta (dichorionic twins and trichorionic triplets) are not at risk of TAPS.

TAPS IN TWINS



TAPS IN TRIPLETS



WHAT ARE THE WARNING SIGNS?

The mother rarely has symptoms from TAPS – it is something that is detected through an ultrasound scan of the babies.

The Doppler scan measures how fast blood is flowing through the babies' blood vessels, in particular the Middle Cerebral Artery, one of the blood vessels in the baby's brain. If a baby is anaemic, the blood is thinner and flows faster. If a baby is polycythaemic, the blood is thicker and flows more slowly. If the Doppler scan finds fast blood flow in one twin and slow blood flow in the other, then TAPS is diagnosed.

It is important to attend all your appointments so that any early signs of complications can be picked up. You can download a checklist to ensure that you're receiving the right scans and information throughout your pregnancy at **www.twinstrust.org/antenatal-care**.

Sometimes if TAPS is not picked up during pregnancy, but is suspected after the babies are born, it can be diagnosed postnatally by checking the babies' bloods and sending the placenta to be examined for tiny connections between the blood vessels.

WHAT COMPLICATIONS MIGHT OCCUR FROM TAPS?

Because it is the red blood cells that carry oxygen around the body, the anaemic twin has to try harder to pump enough blood and oxygen around the body. If the anaemia is severe, this may lead to heart failure. Because the recipient twin's blood is thick, this can lead to blood clots (thrombosis) in the circulation; it can also lead to heart failure because the blood is harder to pump around the body.

TAPS is usually graded into 5 different stages; Stage 1 is the mildest form while Stage 5 is the most severe.

WHAT CARE SHOULD I EXPECT DURING MY PREGNANCY?

TAPS is a rare condition, so you should be cared for in a Fetal Medicine Unit with expertise in managing the complications of twin and more pregnancies.

Your babies will have regular scans, at least every 2 weeks. The Doppler blood flow in the babies will be measured. In addition, the growth and amount of water (amniotic fluid) around the babies will be measured to distinguish TAPS from TTTS or other complications.

Each pregnancy will be treated on a case-by-case basis, depending on the severity of the condition and what is right for your pregnancy. However, the Royal College of Obstetricians and Gynaecologists has provided the following guidance for the care of monochorionic twin pregnancies.

10-13 Weeks: Ultrasound Examination	If twins are diagnosed at the first ultrasound examination, the sonographer doing the scan should check whether the babies share a placenta – the chorionicity scan. This first pregnancy scan may be earlier in some cases, for example if the mother has had fertility treatment, bleeding, or any other health concerns. A photo record of the membrane attachment to the placenta should be kept in the case notes. If there is any doubt about chorionicity, a second opinion should be sought, ideally from a specialist, before 14 weeks. After this stage, it becomes more difficult to work out on scan whether or not twins share a single placenta. Many parents also choose to have the screening test for Down's syndrome – the nuchal translucency scan, which involves measuring the thickness of the fluid lying under the skin at the back of the neck.
14-24 Weeks: Ultrasound Scans Every 2 Weeks	All monochorionic pregnancies should be monitored by ultrasound examination every 2 weeks from 16 weeks, although these scans may be more frequent if the pregnancy is complicated or there is greater cause for concern. At 18-22 weeks an anatomy scan is done to check your babies are developing normally and look for any abnormalities in the babies' structural development and growth.
24+ Weeks: Ultrasound Scans, Doppler Studies and Discussion About Birth Options	All monochorionic pregnancies should continue to be monitored by ultrasound examination every 2 weeks, but after 20 weeks Doppler studies should also be used to look for signs of poor blood flow through the umbilical cords and placentas of the babies. The benefits and risks of different types of birth should be discussed by 28 weeks and the mother and doctor should come to an agreement that she is happy with. It may not be advisable to have a vaginal birth if the first baby is lying breech (bottom-first), the mother has had a previous Caesarean section or if there are other clinical concerns requiring a Caesarean section.

WHAT ARE THE TREATMENT OPTIONS?

If you develop TAPS, your twins or more will be monitored regularly by ultrasound scan. If the babies are well enough, this monitoring may be all that is required (this is called expectant management). If the health of either baby is affected by the TAPS, it may be necessary to deliver the babies early. If it's too early to deliver the babies, and expectant management is not a suitable option, other treatments may be necessary; these include laser ablation, intra-uterine transfusion and exchange transfusion.

Laser ablation therapy

Laser ablation therapy involves finding the small blood vessels connecting the twins and closing them to prevent the flow of blood from one baby to the other. The surgery is conducted under local anaesthetic or an epidural/spinal, so you should be awake and, if you wish, able to watch the procedure and your babies on an ultrasound screen.

The procedure begins by inserting a needle and thin hollow tube into the fluid sac of one baby. The needle is removed before a small telescope (fetoscope) with a thin laser fibre is inserted through the tube. The fetoscope finds all the blood vessels in the placenta that link the blood flow between the two babies. The laser is then used to seal these blood vessels. Each baby stays connected through its own umbilical cord to its main source of blood and nutrition; but the blood can no longer flow from one baby to the other through the placenta.

Intra-uterine transfusion

Intra-uterine transfusion (IUT) involves giving a blood transfusion to the anaemic baby while still inside the womb. You will usually be given a small injection of local anaesthetic in your abdominal wall to numb the area. Then a fine needle is inserted into the womb. The position of the needle is followed by watching it on the ultrasound scan. The needle is inserted into the anaemic baby's umbilical cord, and the baby given a blood transfusion through the needle.

Intra-uterine exchange transfusion

The polycythaemic baby's blood is too thick – if necessary, this can be treated by exchange transfusion. In this procedure, a needle is inserted into the polycythaemic baby's umbilical cord, as described above. Some blood is then taken from this baby. This blood is then replaced by a similar amount of saline (salty water), effectively diluting the baby's blood.

WHAT MIGHT HAPPEN TO MY BABIES?

TAPS is associated with short-term and long-term health implications, although not much data on long-term health outcomes has yet been collected.

It may be necessary to deliver the babies early because of TAPS. If this happens, the babies may need to spend some time in the neonatal unit because they are premature.

Some evidence shows that there may be a small risk of long-term complications such as neurodevelopmental impairment or deafness after TAPS, especially for donor babies. However, the evidence is not yet clear and more research is needed to show exactly what the long-term outcomes are.

HOW AND WHEN WILL MY BABIES BE BORN?

If the TAPS is mild, your babies may be born at the usual time, i.e. 36 weeks for monochorionic twins. In this situation, vaginal birth may be possible, depending on other factors, such as the position of the babies. But if TAPS is affecting the babies' health, it may be necessary for the babies to be born early; in this situation, Caesarean section is more likely. Your doctor can discuss the different options with you and the benefits or risks of each. You should have this discussion by 28 weeks of pregnancy.

WHAT CAN I DO?

If you are diagnosed with TAPS or find out you are at risk of developing it, first of all, try to stay calm. Please remember that many families have happy outcomes following a pregnancy affected by TAPS. By reading this guide, you are already preparing yourself for the rest of your pregnancy and birth.

There is nothing active that you can do to prevent or treat TAPS yourself. The most important thing is to make sure you attend your regular scans with the specialists who can detect TAPS if it occurs, and advise you on the best course of action.

You can access a checklist of all the scans and information you should be receiving at your appointments on the Twins Trust website: **www.twinstrust.org/antenatal-care**, and your doctor may offer you additional appointments depending on your individual pregnancy.

You can read about Keziah's experience of TTTS and TAPS on page 46, and Penny's experience of TAPS in a triplet pregnancy on page 50.

Section three: TRAPS

WHAT IS TRAPS?

TRAPs is a very rare condition that occurs in monochorionic twin pregnancies (or higher order pregnancies where a single placenta is shared). TRAPs occurs when one fetus develops normally whilst the other fails to develop, and there are blood vessels that form in the placenta which connect them. The fetus which hasn't developed (which your doctor may refer to as the 'acardiac baby') will continue to grow, but will not look like a fully formed baby or be able to live on its own. Usually this fetus will not develop a heart, head or arms. The developing baby pumps blood not just around its own body, but also into the undeveloped fetus. Eventually, it may begin to show signs of strain and heart failure due to this extra demand on its heart; these signs can be detected by expert ultrasound scan.

WHO DOES TRAPS AFFECT?

Twin Reversed Arterial Perfusion sequence (TRAPs) is a very rare complication that is specific to monochorionic twin pregnancies, or higher-order pregnancies with a shared placenta, and occurs in roughly 1 percent of these pregnancies.

WHAT ARE THE WARNING SIGNS?

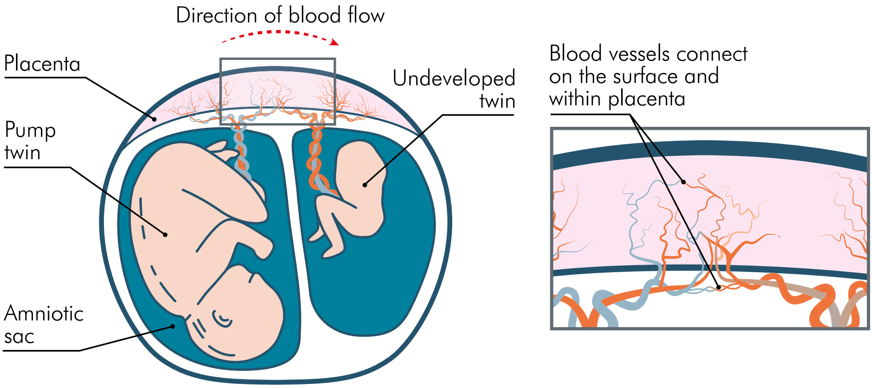
The mother is unlikely to have any unusual symptoms when TRAPs develops. TRAPs is a condition that can be detected only by ultrasound scan.

It is important to attend all your appointments so that any early signs of complications can be picked up. You can download a checklist to ensure that you're receiving the right scans and information throughout your pregnancy at **www.twinstrust.org/antenatal-care**.

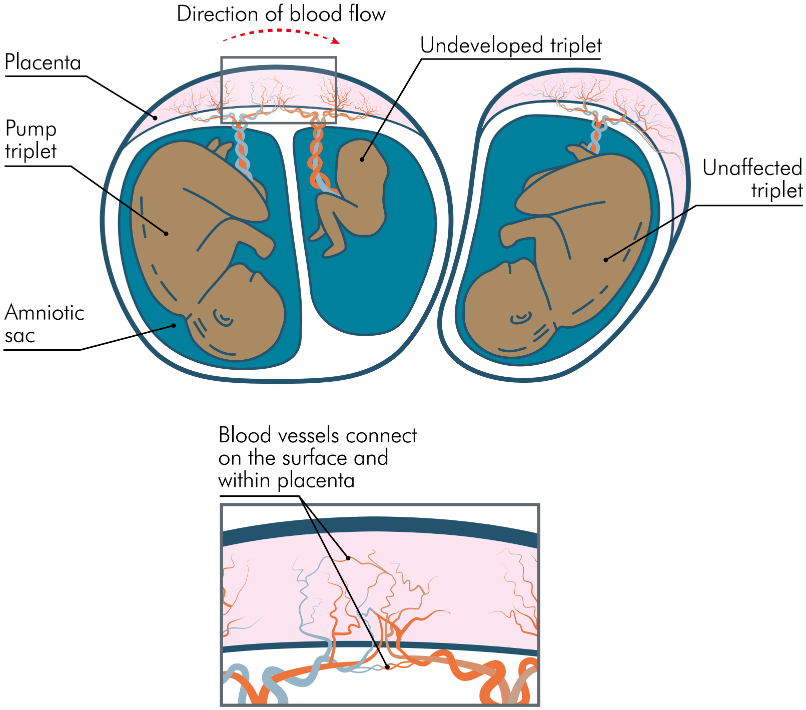
In advanced cases, polyhydramnios might develop and the mother might develop symptoms similar to those of TTTS:

- Sudden weight gain due to excess fluid – getting noticeably bigger in a short space of time, sometimes even within 24 hours
- Being breathless at rest and having palpitations (unusual heartbeats)
- Feeling that your tummy is tight, uncomfortable and/or the surface looks shiny
- Increased thirst
- Feeling early contractions
- Back pain and leg pain due to the build-up of fluid.

TRAPS IN TWINS



TRAPS IN TRIPLETS



WHAT COMPLICATIONS MIGHT OCCUR FROM TRAPS?

In a TRAPs pregnancy, the undeveloped fetus will not survive. There is also a risk that, without treatment, the healthy baby may develop heart failure or even die in the womb, due to the strain of pumping blood into the undeveloped fetal mass.

TRAPs carries a risk of preterm labour (either spontaneous, or because the doctor believes the safest course of action is to deliver the baby early). There is also a high risk that the healthy baby will not survive if TRAPs is untreated; however, every case is different and your doctor will be able to advise you of the best course of action for your individual pregnancy.

WHAT CARE SHOULD I EXPECT DURING MY PREGNANCY?

TRAPs is a rare condition, so if you are diagnosed with it you should be cared for in a Fetal Medicine Unit with expertise in managing the complications of twin and more pregnancies.

Each pregnancy will be treated on a case-by-case basis, depending on the severity of the condition and what is right for your pregnancy. However, the Royal College of Obstetricians and Gynaecologists has provided the following guidance for the care of monochorionic twin pregnancies.

WHAT ARE THE TREATMENT OPTIONS?

Occasionally, TRAPs is discovered later in the pregnancy and, provided that the developing baby is well, you may be closely monitored without intervention.

However, it is more common that TRAPs is discovered earlier and treatment is needed. Laser therapy involves blocking (occluding) the umbilical cord of the undeveloped fetal mass. This stops the flow of blood from the developing baby into the undeveloped mass, which eases the strain on the developing baby, allowing it to recover and continue developing normally.

This treatment is conducted under local anaesthetic or spinal, so you should be awake. The procedure begins by inserting a needle and thin hollow tube into the fluid sac of the undeveloped fetal mass. The needle is removed before a small telescope (fetoscope) with a thin laser fibre is inserted through the tube. The fetoscope finds the umbilical cord of the undeveloped fetus. The laser is then used to seal the blood vessels in this umbilical cord, effectively stopping the blood flow.

Following the procedure, the developing baby will continue to be monitored closely.

10-13 Weeks: Ultrasound Examination	If twins are diagnosed at the first ultrasound examination, the sonographer doing the scan should check whether the babies share a placenta – the chorionicity scan. This first pregnancy scan may be earlier in some cases, for example if the mother has had fertility treatment, bleeding, or any other health concerns. A photo record of the membrane attachment to the placenta should be kept in the case notes. If there is any doubt about chorionicity, a second opinion should be sought, ideally from a specialist, before 14 weeks. After this stage, it becomes more difficult to work out on scan whether or not twins share a single placenta. Many parents also choose to have the screening test for Down's syndrome – the nuchal translucency scan, which involves measuring the thickness of the fluid lying under the skin at the back of the neck.
14-24 Weeks: Ultrasound Scans Every 2 Weeks	All monochorionic pregnancies should be monitored by ultrasound examination every 2 weeks from 16 weeks, although these scans may be more frequent if the pregnancy is complicated or there is greater cause for concern. At 18-22 weeks an anatomy scan is done to check your babies are developing normally and look for any abnormalities in the babies' structural development and growth.
24+ Weeks: Ultrasound Scans, Doppler Studies and Discussion About Birth Options	All monochorionic pregnancies should continue to be monitored by ultrasound examination every 2 weeks, but after 20 weeks Doppler studies should also be used to look for signs of poor blood flow through the umbilical cords and placentas of the babies. The benefits and risks of different types of birth should be discussed by 28 weeks and the mother and doctor should come to an agreement that she is happy with. It may not be advisable to have a vaginal birth if the first baby is lying breech (bottom-first), the mother has had a previous Caesarean section or if there are other clinical concerns requiring a Caesarean section.

WHAT MIGHT HAPPEN TO MY BABIES?

In a TRAPs pregnancy, the undeveloped fetus will not survive. There is also a risk that, without treatment, the healthy baby may develop heart failure or even die in the womb, due to the strain of pumping blood into the undeveloped fetal mass.

If laser treatment is successful, however, your healthy baby should recover and develop normally from then on. This baby will continue to be monitored closely throughout the rest of your pregnancy. If your doctor thinks it will be safest for your baby, they may recommend early delivery.

HOW AND WHEN WILL MY BABIES BE BORN?

It is often fine for your healthy baby to be born vaginally. If there are remaining concerns about this baby, however, Caesarean section may be recommended. When this baby is born, the undeveloped fetal mass will be delivered at the same time. If the umbilical cord of the undeveloped fetus has been closed off by laser treatment weeks earlier, it may have shrunk and been partly reabsorbed by the body, so may be quite small.

Your doctor may recommend that your baby is delivered early if they believe this is the safest course of action. You will be advised based on your individual pregnancy.

WHAT CAN I DO?

If you are diagnosed with TRAPs or find out you are at risk of developing it, first of all, try to stay calm. Please remember that many families have a healthy baby following a pregnancy affected by TRAPs. By reading this guide, you are already preparing yourself for the rest of your pregnancy and birth.

There is nothing active that you can do to prevent or treat TRAPs. The most important thing is to make sure you attend your regular scans with the specialists who can detect this very rare condition, if it occurs, and advise you on the best treatment.

You can access a checklist of all the scans and information you should be receiving at your appointments on the Twins Trust website: **www.twinstrust.org/antenatal-care**, and your doctor may offer you additional appointments depending on your individual pregnancy.

You can read about Dannielle's experience of TRAPs in a triplet pregnancy on page 39.

Section four:

SELECTIVE INTRAUTERINE GROWTH RESTRICTION (SIUGR)

also known as Selective Fetal Growth Restriction (sFGR)

WHAT IS SELECTIVE INTRAUTERINE GROWTH RESTRICTION?

Just like singletons, sometimes twins and multiples are smaller than expected for their gestational age. Most twin, triplet or more babies will be slightly different in size, but sometimes one baby is significantly smaller than the other/s and doesn't grow as well as it should. This is called 'selective' growth restriction (sFGR or sIUGR) and can be detected by regular ultrasound measurement of the babies' sizes. This is usually due to its placenta failing to give it enough food to grow normally. Growth restriction can be detected on ultrasound scans when it is noticed that the is a significant difference (more than 10%) in weight between the babies. It may also be seen that the affected baby is not growing along its own lines as expected on the growth charts. The blood flow measurements (Dopplers) in the umbilical cord and within the affected baby may also be abnormal, and the amount of water (amniotic fluid) around this baby may be reduced (oligohydramnios).

Sharing a placenta poses extra risks to the babies. Often this can be due to complications of monochorionic twin pregnancy like selective Fetal Growth Restriction (sIUGR) where one twin is smaller than the other.

sIUGR is associated with stillbirth and disability and affects one in seven monochorionic twin pregnancies in the UK, although we know less about pregnancies where this happens early (before 24 weeks of pregnancy).

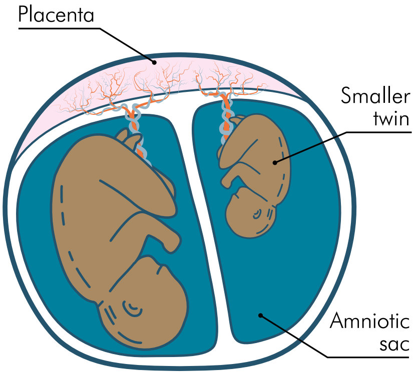
Sometimes babies affected by TTTS are also affected by sIUGR, but these are separate conditions. While TTTS is mainly related to the unequal volumes of blood shared by babies across their shared single placenta, growth restriction is related to the size, function and each baby's share of the placenta.

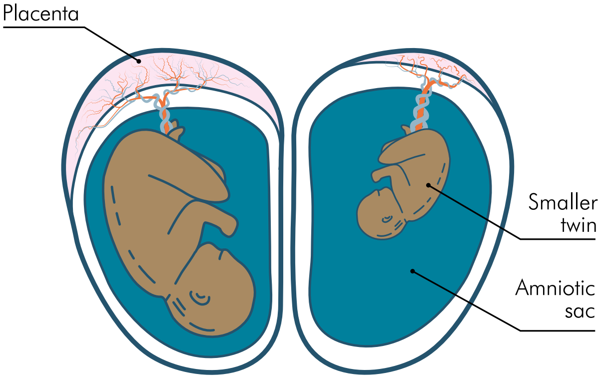
WHO DOES SIUGR AFFECT?

sIUGR can happen in multiple pregnancies where each baby has its own placenta (dichorionic twins and trichorionic triplets) and also in twin or higher order pregnancies where babies share a placenta, but the causes and treatment are different in each case. Selective fetal growth restriction occurs in 10-15 percent of twin, triplet or more pregnancies.

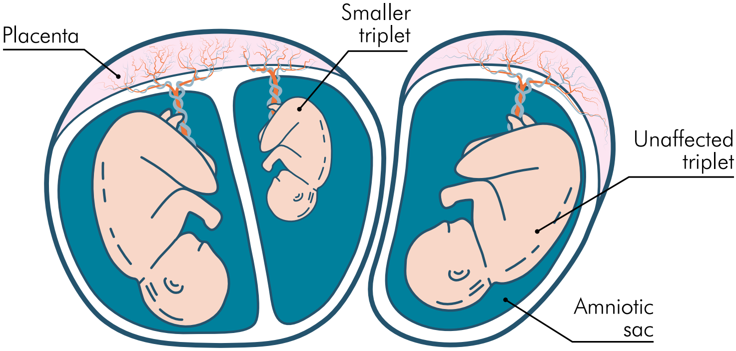
Section four:
SELECTIVE INTRAUTERINE GROWTH RESTRICTION (SIUGR); ALSO KNOWN AS SELECTIVE FETAL GROWTH RESTRICTION (SFGR)

SIUGR IN TWINS





SIUGR IN TRIPLETS



WHAT ARE THE WARNING SIGNS?

In sIUGR the mother usually has no symptoms. This is why it's so important to scan twins, triplets and more to watch their growth. Sometimes when a placenta is not working properly (causing growth restriction), it may be associated with high blood pressure (pre-eclampsia) in the mother. This is why it's always important to have your blood pressure checked and your urine tested for protein regularly.

It is important to attend all your appointments so that any early signs of complications can be picked up. You can download a checklist to ensure that you're receiving the right scans and information throughout your pregnancy at **www.twinstrust.org/antenatal-care**.

WHAT COMPLICATIONS MIGHT OCCUR FROM SIUGR?

sIUGR can lead to such poor growth in the baby that it's safer for it to be born early, so that it can feed normally outside the womb. Severe growth restriction can lead to death of the baby in the womb.

WHAT CARE SHOULD I EXPECT DURING MY PREGNANCY?

sIUGR can be serious for one or both babies and a specialist assessment is recommended. Frequent ultrasound scans will assess the weight difference between the babies, the blood flow measurements (Dopplers) in the umbilical cords and within the babies, and the amount of water (amniotic fluid) around each baby. Abnormal blood flow to the babies (the Dopplers) is associated with risk of complications. In most cases the blood flow measurements are normal, and in this case the babies are likely to do well with careful monitoring for the rest of the pregnancy. If the blood flow measurements are not reassuring, a specialist will explain treatment options to you; which may include early delivery of the babies.

There are specific guidelines for the care that twin and triplet pregnancies should receive. You can download a checklist to ensure that you're receiving the right scans and information throughout your pregnancy at **www.twinstrust.org/antenatal-care**.

If your twins are monochorionic, they will follow the Royal College of Obstetricians and Gynaecologists (RCOG) Green Top Guideline number 51 on the Management of Monochorionic Twin Pregnancy: **https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg51/**

All twin and triplet pregnancies should also follow the National Institute for Health and Care Excellence (NICE) guideline NG137 on twin and triplet pregnancy: **https://www.nice.org.uk/guidance/ng137/**.

WHAT ARE THE TREATMENT OPTIONS?

Close monitoring by ultrasound scan is essential. Currently, the only treatment for sIUGR is to deliver the baby; this of course means delivering all of the babies at the same time. If one of your babies is diagnosed with sIUGR, your pregnancy will be followed closely with frequent ultrasound scans. You may reach a point when the doctors advise you that it is better for the baby to be born (so that it can feed normally outside the womb) rather than stay inside where it's not receiving enough from the placenta. Depending on how severe the growth restriction is and how many weeks pregnant you are, this birth will often be by Caesarean section. If sIUGR happens at an early stage in pregnancy, sometimes a decision will be made that it is preferable to allow that unwell baby to die in the womb, rather than deliver all the babies that early, and risk death or disability of them all due to being delivered so prematurely.

There are three main ways of managing monochorionic twin pregnancies with sIUGR:

Expectant Management

Firstly, a watch and wait approach (also called expectant management). The difficulty with this approach is that the smaller twin could die in the womb, which can then lead to developmental damage or the death of the larger baby/ies.

Selective Feticide

The second option is a procedure can be performed which blocks the umbilical cord from the smaller twin to the placenta and as a consequence leads to the death of the smaller twin (also known as selective termination or selective reduction). This allows the larger twin to continue growing and gaining maturity, hopefully being born at term (after 37 weeks of pregnancy).

Laser Ablation

The final option is for laser to be used to completely separate the twins' circulations. This method protects the larger twin in the event of the death of the smaller twin, but increases the risk of death of the smaller twin.

We do not yet have good evidence on the best way of managing sIUGR in twin pregnancies, so women and their partners are offered different management options depending upon where they live and who they see. It is also clear that there are gaps in what we know about sIUGR. We have already set up a UK national registry of complicated twin pregnancies to collect information about pregnancy outcomes.

WHAT MIGHT HAPPEN TO MY BABIES?

If sIUGR is not too severe, it may be possible for the pregnancy to continue with close monitoring until the babies are born at the usual time. In this case, the baby will usually feed normally after birth and catch up to its normal weight after some time. If the growth restriction becomes severe, it may be necessary for the baby to be delivered, even if this is early. In this situation, the benefits for the growth restricted baby of being delivered early must be balanced against the risks of prematurity to the healthy babies forced to be born early too.

HOW AND WHEN WILL MY BABIES BE BORN?

As described above, the babies may need to be born early, depending on the severity of the growth restriction and how far pregnant you are.

Caesarean section may be necessary if your doctors feel that the restricted baby is not healthy enough to survive the extra demands of labour.

WHAT CAN I DO?

By reading this guide, you are already preparing yourself for the rest of your pregnancy and birth. The best thing you can do is attend for the regular ultrasound check-ups of the babies. Make sure that you have the usual regular blood pressure and urine tests. When there's so much focus on the babies, sometimes the more routine pregnancy checks for your own wellbeing may be missed.

Voice any concerns you have to your midwife and doctor.

You can access a checklist of all the scans and information you should be receiving at your appointments on the Twins Trust website: **www.twinstrust.org/antenatal-care**, and your doctor may offer you additional appointments depending on your individual pregnancy.

You can read about selective growth restrictionin a monochorionic pregnancy in Ella's story on page 36 and Gemma's story on page 41. Mel's story of a dichorionic pregnancy with selective growth restriction is on page 43. You can also read about Maria's experience of selective growth restriction in a triplet pregnancy on page 48.

Section five:
PARENTS' EXPERIENCES

Each complicated pregnancy is very different. The stories in this guide are included at our parents' request so you do not have to search the internet for real life examples. Your experience may be completely different, and your medical team will be best placed to explain possible outcomes and challenges.

ADVICE FROM OTHER PARENTS

If you are diagnosed with a pregnancy complication or find out you are at risk of developing it, stay calm; remember that many families have happy outcomes.

Below is some advice from parents who have been in your situation:

- **Only worry about tangible things.**

> *"With so many uncertain and potential outcomes of the condition, it would be very easy to end up being fraught with anxiety. Therefore, I would only worry about something if it was definite. I started to read up on cerebral palsy when this was mentioned as one possible outcome, and my mind started to go into overload. I stopped reading and decided I'd continue only if one of the babies developed the condition."*

- **Talk to your medical professionals if you're worried.**

> *"Solicit as much information as possible from the doctors and have open and honest discussions. I developed a peace of mind when I felt fully aware of the situation and fully understood what my babies' condition was."*

- **Be cautious of internet coverage of pregnancy conditions.**

> *Where I found it to be very beneficial and reassuring was reading about successful outcomes of other complicated pregnancies. However, a number of sites I felt presented a very negative picture and had a number of inaccuracies of the prognosis."*

- **Be aware of the warning signs, if there are any, and attend all your appointments for regular monitoring.**

> *Our tip on how to spot acute TTTS is: If the shape of the bump suddenly (over the course of a few days) changes significantly. In our case, Edward was pushed up above Lefty, so that the shape of Abby's bump pushed out abruptly, almost unnaturally, at the top. Our hospital were able to guess it was TTTS by just looking at Abby."*

Not all pregnancy complications have visible warning signs, so the best thing you can do is attend all your appointments. You can check which appointments you should be having at **www.twinstrust.org/antenatal-care**, but if you have a complicated pregnancy you may be offered extra appointments.

- **Ask to attend antenatal classes earlier in your pregnancy.**

> *We think that couples experiencing complications (especially if it is your first pregnancy) should ask their obstetrician, GP or midwife if they can go to antenatal classes early, as the probability of premature birth is very high. We were months off our first antenatal class when I had the boys at 24 weeks, and I genuinely didn't have a clue what to do during labour."*

- **Do the tours of neonatal wards (NICU/SCBU/HDU).**

> *Ask if you can have a tour of NICU and SCBU and speak to paediatricians in advance, just in case your babies need to spend some time there. Knowing what to expect should this situation have happened was very useful. It also makes the whole thought of what happens when your babies arrive a lot less scary."*

- **Speak to your doctor if you are experiencing pain or discomfort.**

> *"Although I did know I was carrying twins, I dismissed the back pain I was feeling. It was only because I had a regular check-up booked that it was discovered – if it had been a week or so later, I may have lost both babies. In addition, if a stay in hospital or bed rest is enforced, make sure you take antithrombosis medication!"*

- **Talk about your own needs and emotions with your midwife.**

> "With a complicated pregnancy, the appointments quite rightly focus on the care of your babies. However, because you may be visiting a special fetal medicine unit in a different hospital to your local hospital, your name may slip through the net in terms of midwife appointments locally. I only knew who I should be seeing as I had had a previous pregnancy."

- **Ask as many questions as you want.**

> "There is an awful lot of information to take in at an extremely emotional time. If you don't understand or if you need it repeating for the tenth time, just say so. I felt a bit silly asking some of the questions I did, but was never made to feel that way!" and "I was always worried about asking questions as I was both nervous of hearing the worst and I had been told to think positively about how things were going. Always ask – e.g. why are the babies being induced?, what symptoms do we need to look out for?, etc."

- **Remind your health professionals to keep you in the loop.**

> "A diagnosis seems to lead to a large number of medical professionals becoming involved, who may communicate effectively with each other, but leave parents feeling side-lined."

- **Don't presume there will be 'joined up thinking' between health professionals.**

> "The concerns of the antenatal department were obviously not passed on to the 'birthing team' and they were not looking out for the signs. As the twins were roughly the same size, the birthing team presumed things were ok, and ignored other signs such as the colour difference and the appearance of the placenta."

- **Talk to your partner and offer each other support when you need it.**

> "Pull together – never stop yourself from looking forward and having hope. Also try and make everything that happened stand for something positive – we know our marriage is built on a strong love that won't crumble."

- **Speak to medical experts or families who have experienced complications.**

You can also talk to other parents going through the same situation on Twins Trust's forums, or call Twinline for a listening ear (open weekdays between 10am-1pm and 7pm-10pm on 0800 138 0509).

Continue to voice your concerns when you get your babies home, if there are things you are worried about.

> "Hopefully there will be few or no long-term implications of the TTTS, but it is always better to mention something and be reassured or have a difficulty dealt with appropriately, than to worry about worst case scenarios."

Some parents may have concerns about their children's development following a complicated pregnancy – if you have any worries it's best to speak to your GP who can make a referral if needed.

Speak up if you're not happy

If you're not happy with your care you can ask to be seen at a different hospital. If your local hospital doesn't have a specialist twins clinic, they may provide you with shared care, where they consult with a specialist team to provide the right care.

And finally... try to stay positive.

> *"Although we had a rare condition and there are only a few doctors with extensive experience, we had complete confidence that the doctors had the knowledge and experience and were advising and treating us in our and the babies' best interests. This reassurance with our doctors really helped us to remain positive. Although the news of twins, let alone complications, was incredibly surprising, it was in the best interests of the babies to act quickly. Again, it is important to feel confident with the care being received."*

Ella's Story

Selective Intrauterine Growth Restriction in Monochorionic Twins

In 2017 I fell pregnant with twins. We were scanned at 12 weeks and were told it was an identical twin pregnancy: MCDA twins where they share a placenta but have separate amniotic sacs.

At 16 weeks I had a scan at the hospital. The sonographer started scanning my stomach but soon left the room before very quickly returning with a senior colleague and telling us to go to another room for a more thorough scan. The scan was conducted by the doctor in silence. She told us that one of our twins (we had decided not to find out the sex) was growing at a normal rate, but the other was much smaller and there was an issue with the placenta.

The doctor told us that our twins had a rare condition called Selective Intrauterine Growth Restriction (sIUGR) and we would need to be referred to a specialist hospital and speak to the consultant there about what the options were. As MCDA twins share a placenta there is more risk to the pregnancy than if they have separate placentas. She explained that our smaller twin had an unequal share of the placenta and the blood wasn't flowing through their umbilical cord properly. She said that unfortunately we may have to prepare ourselves that our smaller twin may not survive as they were so small, and that as their placenta is shared the bigger twin would also likely die in this scenario due to the drop in blood pressure. She mentioned that selective feticide could be an option in order to save one of the twins. We were then referred to a hospital in London for an appointment two days later.

I remember it being a very stressful and lonely time. As we are a military family, we don't live close to our friends and family, and after the excitement of announcing a twin pregnancy it was absolutely horrible to have to say to loved ones that there was a serious problem with the pregnancy. There wasn't much information online at the time either.

At our first appointment at the second hospital the consultant was lovely and reassuring and told us that I was going to be scanned every week, either there or at our local hospital, and the plan would be to try and get me to 32 weeks and then deliver locally where our twins would have a 4–5 week stay in NICU. I was lucky to receive excellent care from all the doctors at both hospitals who were always kind and empathetic, especially when I had to go to scans alone due to my husband's work commitments.

Everything carried on like this for the next few weeks, we had weekly scans where the size difference between our twins remained stable and everyone seemed cautiously optimistic so I started to relax and hoped I would make it to 32 or even 34 weeks.

> **"...It was scary and nerve-wracking but days went by and they moved from NICU to special care..."**

At a scan at 29 weeks in London we were told that twin A's growth had slowed and that the placenta wasn't working as efficiently as before. The consultant said that the twins would need to be delivered imminently. They didn't have two neonatal beds at that hospital that day so we would have to go back to our local hospital to have the babies. I can't remember the journey at all, but we made it to the hospital and tried to prepare as best as we could for an immediate C-section.

We were then told that the local hospital wouldn't be able to accommodate us for the birth as Twin A was too small for their neonatal ward (Twin A's estimated weight was 800g) so they rang round other hospitals trying to find us a bed. I could hear them on the phone calling hospitals that were up to 100 miles away from where we lived which was very anxiety inducing. Luckily the hospital which was able to take us was much closer. I was transferred by ambulance and had daily scans for the next few days to try and prolong the pregnancy for as long as possible but had a Caesarean 3 days later.

The Caesarean was an incredibly positive experience. The room was full of medical people which I found reassuring and at this stage I just couldn't wait to find out the sex of the twins. A doctor had explained exactly what would happen during and after birth so I felt as calm as you can in that situation. The birth went without incident and I was able to hear the cries of my sons as they were born and see them very briefly as they were whisked off to NICU.

Later that evening I was able to see them properly, Simon was 1.4kg and Alistair was 880g. Simon was very red and they were diagnosed with TTTS, this had never been picked up on in pregnancy. They both had jaundice and needed high flow oxygen to help them breathe. It was scary and nerve-wracking but days went by and they moved from NICU to special care. Simon was moved to the local special care as it was closer to home, but Alistair stayed at the hospital where I gave birth for a few more days. My husband had to drive round trips between our home and the two hospitals to see us all and deliver expressed milk to both boys, which was very hard until we were all reunited at the local SCBU. Simon came home after 6 weeks which was amazing but hard with Alistair still in hospital. Eventually after 9 long weeks, Alistair was ready to come home too. He was on oxygen 24 hours a day due to chronic lung disease caused by his early birth, which he needed for a further 8 months. An amazing nurse called Julie helped us at home.

Until recently the boys were under speech and language therapy but have recently been signed off and don't seem to have any other long-term effects from their sIUGR or early births. They are now lovely little three-year-olds who love dinosaurs, Hey Duggee, playing with trains and singing! ■

Kyran's Story

Surrogacy and TTTS

We entered into a surrogacy agreement with our wonderful sister-in-law back in 2019 and embarked on our journey to fatherhood. We fell pregnant in June 2020. As our previous attempt was an ectopic pregnancy, we had to go for an early scan at six weeks pregnant at the hospital. Our surrogate had to attend the appointment alone due to the coronavirus restrictions, and was told that our baby was actually two babies and they were in fact identical!

We were ecstatic. Our dream had come true. The pregnancy then ran smoothly, we had a gender reveal party on a Saturday (at 20+3) with a small group of family and friends and were delighted after much anticipation to find out we were having GIRLS?! The weekend flew by and we had a hospital scan to attend on the Monday.

Our surrogate and Ryan attended the scan, at which the sonographer made them aware she could not see any fluid around twin two and there was no visible bladder. She expressed her concern and gave a possible diagnosis of twin-to-twin transfusion syndrome (stage 2) and rushed us to a Fetal Medicine Unit. There they confirmed the diagnosis and spoke to us about the risks of the surgery and the chances of one or both babies surviving. We were absolutely terrified. They then performed the fetoscopic laser ablation surgery and fluid reduction on twin one's sack, and this fluid was then put into twin two's sack. We had an ultrasound afterwards to confirm both heartbeats were still active. We then had to wait two weeks for the second scan to confirm both babies had survived, and we were relieved when we found out the operation was a success!!!! We were then regularly scanned at the Fetal Medicine Unit to check the babies blood flows to the cerebral and umbilical artery. At 27 weeks our surrogate's waters broke. She was hospitalised on bed rest for three weeks which was very difficult. At 29+6 she gave birth to our two beautiful baby girls, Skylar & Aria Morgan-Trodden. They weighed 2lb 2oz & 2lb 4oz. They are now in NICU and have been for 3 weeks. They are alternating between bottles and nasal feeds, have had three brain scans, and the doctors and nurses seem really impressed with their progress and weight gain. We are still on our journey but as a little family we couldn't be happier. ■

Dannielle's Story

Triplets with TRAPs

Please note, this story mentions an acardiac baby (a baby who does not fully develop in the womb and cannot survive after birth).

We found out we were pregnant in November 2018. We booked a private early scan and were told we were having identical twins, our babies were sharing a placenta, and we were currently around 7 weeks and 5 days pregnant. The sonographer informed us she was a little concerned with a grey area and that there could be a 3rd baby but could not tell as it was such early days.

Over the coming weeks everything was going well within the pregnancy. Then, a few days before our 12-week scan, I began to have a light bleed. I was advised to get checked out and went to the hospital to be scanned. The sonographer began to scan me and could see the 2 babies on the screen with healthy heartbeats. This was such a relief, but she could not see a reason why I had been bleeding. A few minutes later, which felt like a lifetime, she informed us that she believed she knew the reason for the small bleed. On the screen she showed us our 3rd beautiful baby. Unfortunately compared to our other 2 babies the blood flow was a lot slower and they had a lot of amniotic fluid around them. Our local hospital informed us that they would be referring us to a Fetal Medicine Unit.

At 13 weeks and 4 days we arrived there unsure of what to expect. The consultant began to scan my growing tummy. After a few minutes our worst fears became reality – our 3rd baby didn't have a visible heartbeat. Our other 2 babies had strong heartbeats and were growing well.

We were taken to a side room where the consultant informed us again that there was no visible heartbeat in the 3rd baby. She continued to say that all 3 of our babies shared the same placenta and would be known as identical triplets.

> **"...Our babies are our little miracles..."**

Due to the pregnancy being such a high risk she told us there was a high chance that I could miscarry all my babies, so the next couple of weeks were critical. I was referred to my local hospital to have 2-weekly scans to see how the babies were developing. Then at 19 weeks and 5 days the sonographer noticed that baby number 3 had become larger than the previous scan and detected blood flow within baby number 3, so again I was referred to the Fetal Medicine Unit.

At 20 weeks pregnant we had our appointment with a fetal medicine specialist, who informed us that our pregnancy was a complex and high-risk case, and that fetus C had a rudimentary heart and was in effect an acardiac fetus. He explained the options we had going forward. We could continue the pregnancy and see how it would go with weekly scans and my care transferred to the Fetal Medicine Unit. The following 2 options involved surgery on the fetuses and placenta with a high chance of potentially losing one or both of the viable twins. The doctor then went on to say that he had spoken with two other specialists who agreed with the options, and there was no obviously correct route of action. We decided that, as babies 1 and 2 were doing well, not to intervene with surgery and to monitor the pregnancy weekly at the Fetal Medicine Unit.

The professor told me that the only time they would really be worried and would have to intervene would be if Fetus C was to become bigger than A and B.

Over the following weeks I travelled to the hospital every week to monitor the pregnancy and see how the babies were doing. We did not know what they would be seeing on the screen, but at each scan we could clearly see two strong heartbeats.

At my regular weekly growth scan at 26+5 weeks, we could see that over the last week Fetus C had grown 5 weeks in the space of a week and was now bigger than Fetus A and B. My consultant informed us that the 2 babies were roughly around 2lb each. Due to the growth in Fetus C and the complications of what we now know was TRAPs, they would be looking at delivering the babies at 28 weeks to give them a better fighting chance of survival. As each week passed, they didn't know whether they would continue to see two strong heartbeats.

At 28+4 weeks, on the 23rd April 2019, our 3 babies were delivered via caesarean section. First was Edee weighing 2lb 2oz, second was Eldora weighing 2lb 5oz and lastly was our beautiful Effie born sleeping. We were able to see Edee and Eldora for a few seconds before they were whisked away to the neonatal unit.

Over the next 11 weeks it was a very surreal experience; our babies were in neonatal and special care, and they were so poorly we did not know whether they would make it home. They faced many challenging experiences including both fighting off sepsis, needing breathing support, multiple blood transfusions, heart murmurs and suspected NEC. Our babies are our little miracles and were finally well enough to come home just before their due date.

I have written our story to help raise awareness of TRAPs to anyone who has been through or experienced similar pregnancies. Edee and Eldora will be known to most people as identical twins, but they are identical triplets. As the girls get older, we will always tell them about their sister Effie and how they are 1 of 3. We often visit Effie at her resting place which we call Effie's Garden.

We cannot thank the fetal medicine specialist, our consultant and all at the hospital enough for the love and care they showed us through this journey. They truly are amazing, and without them we would not have Edee and Eldora here with us today. ■

Gemma's Story

Our sIUGR twin pregnancy

I was six weeks pregnant, it was two days after Christmas and I had started to feel some pain. I knew something was different and we were booked for an emergency early scan. It turned out there was definitely something different... twins! What a shock! With two older children aged 3 and 5, it was not what we were expecting at all. The sonographer explained that we were having Monochorionic Diamniotic (MCDA) identical twins as she could see the membrane between them and one shared placenta as it was so early on. She described the risks that come with this type of pregnancy and twin-to-twin transfusion syndrome (TTTS) was mentioned.

We went to our regular 12-week scan and twin two was noticeably smaller, but it wasn't until our 18-week scan that the sonographer went quiet – she seemed to be spending an extra bit of time examining the babies. Eventually she said she could see 'draping of the membrane' between the two of them and that twin two had less fluid in their amniotic sack. She went on to explain that these were signs of TTTS, as it meant more amniotic fluid around the larger twin was making the membrane 'drape' onto the smaller twin's amniotic sack. We were immediately referred to a Fetal Medicine Unit. We had to wait two days for an appointment, which was agony. I just lay down on the sofa for those days, I barely moved I was so worried. I googled a lot.

When we got to the hospital, the sonographer was very reassuring. He spent about an hour scanning and re-scanning, checking the blood vessels and measuring every part of the babies. Eventually he gave us the news we weren't expecting – your babies have not got TTTS but we believe they have something called selective Intrauterine Growth Restriction (sIUGR).

He told us that sIUGR meant an irregular sharing of the placenta – their egg had split unevenly, meaning that one twin had a larger share than the other. This twin would get more nourishment, more blood and oxygen than the smaller twin. The smaller one would have to work harder to get what it needed and would be smaller all the way through the pregnancy and at birth.

We were told we had to return in two weeks' time so they could double check the babies were growing normally for babies with sIUGR. This was

> **"...I just lay down on the sofa for those days, I barely moved I was so worried..."**

a long two weeks. I had a wedding to go to in between and it was hard to explain to people when they asked how the babies were doing. Most people felt concerned for the smaller baby. It was a difficult time to feel positive, even though we had been told they did not have TTTS, as there was not as much information about sIUGR available and we had to google most of what we wanted to know.

When we returned, the sonographer measured the babies once again. All their stats were in keeping with the previous two weeks and they were growing nicely, albeit unevenly. What a relief!

From then on, we were scanned every two weeks to make sure that the babies continued to grow at the correct rate. At every scan we were willing the smaller twin to grow the most – I even spent time working out the percentage difference between the babies weights, every time they were measured, it was all I could think about. All the way through the babies continued to grow normally for each of their sizes and it was decided that I would be able to have a natural birth. That was until my 32-week scan when we discovered the smaller twin's growth had slowed right down and they booked me in for a planned c-section at exactly 34 weeks. I was glad that we had an end date in sight and I was able to have steroid injections in advance which would help to develop the babies lungs and lower the chances of them having breathing difficulties once they had been born.

We finally got to our c-section date and two healthy babies were born weighing 5lb 12 and 4lb 1. They were both whisked off to the neonatal unit and I didn't see them for quite a few hours. The larger twin was being monitored but was really in there to support the smaller twin, who needed a bit more help breathing and monitoring, was noticeably smaller and redder in colour. It was soon clear though, that they were progressing perfectly and were quickly moved from high dependency to special care. As I had decided not to breastfeed, they learnt to suck from a bottle very quickly and we were allowed home after only five days!

Fast forward two years and we now have two very energetic toddlers – the smaller twin even walked before the larger twin, which we definitely weren't expecting. They have both surpassed themselves and are developing just like any other toddler. They still have a 3lb difference between them and this will become less and less noticeable as they get older, but it has certainly helped us to tell who is who in all the baby photos! ■

Mel's story

sIUGR in Dichorionic Twins

My husband and I found out I was pregnant at the end of January 2020. We'd been trying a few months but it was still an exciting surprise! We decided to have an early private scan at 8 weeks just to check everything was ok, as neither of us quite believed I was actually pregnant because I felt fine! Whilst being scanned the sonographer brought up the image on the screen of a little baby with a heartbeat. We were amazed! She said, "Everything looks fine, and if I just move the image over here, you'll see baby number 2 – congratulations you're having twins!" WHAT! We burst out laughing, swore quite a lot and that's when realisation hit!! I was pregnant with TWINS!!!

My pregnancy was great (I was one of those annoying glowing pregnant ladies!) until I had a routine 28-week scan which highlighted an abnormal result for Twin 1 – the blood flowing through the umbilical cord was restricted and the baby was measuring slightly smaller in size, so I was referred to the Fetal Medicine department for a more detailed scan 5 days later. Within that time, I had a consultant appointment and my blood pressure was a bit high, coupled with the abnormal scan, it was decided I needed the detailed scan that day at a bigger hospital to ensure everything was ok. The consultant spent quite some time taking measurements, listening to blood flow and taking pictures of her findings on the screen, and then said that twin 1's placenta wasn't working efficiently so it wasn't getting enough blood. This meant there was growth restriction too. Twin 2 was absolutely fine as they were DCDA twins (separate sacs and placentas). The consultant said I'd be admitted to hospital and wouldn't be leaving until I had the babies. Wow. It was only July, the babies weren't meant to come until September! That was not what I was hoping for at 28+5 weeks pregnant. I had steroid injections to help the babies develop their lungs and conversations were serious that I could need an emergency C-section any day.

Once on the ward I had monitoring to trace the twins heart rate to ensure they weren't distressed. I spoke with the NICU team about what to expect when they were born, and I was having lots of tests. All VERY scary considering I felt absolutely fine and just went into hospital for a routine appointment.

The days and then weeks passed, with daily scans and heart rate monitoring, and even though the babies (especially twin 1) were tiny, the tests, scans and monitoring was very consistent. The doctors wanted to get me to 32 weeks as that's a bit of a developmental milestone for the babies.

At 31+5 I had another scan where they took measurements of the babies. Twin 2 was growing nicely but twin 1 barely at all, so it was decided after the weekend and at 32+1 I'd have a C-section.

> **"...The consultant said I'd be admitted to hospital and wouldn't be leaving until I had the babies..."**

My husband met me in theatre and there were a lot of staff busily preparing for the arrival of our two tiny babies. The Caesarean was strange, brutal and I felt like a spectator asking lots of questions about what was happening – it didn't feel like it was happening to me. Within 15 minutes of the surgeon starting, the first twin was born – twin 2, a girl, weighing 4lb 6oz! She was held up so we could see her and she let out a cry, but she quickly went to the paediatricians for her checks. Then the smaller twin was being pulled out but amazingly still in her sac! It was incredible to see! Twin 1 was held up – another girl!! She weighed just 2lb 9oz, so was really tiny. She too let out a cry and was then seen to by the paediatricians. They both needed a bit of oxygen and warmth but they were breathing independently which was reassuring. After 10 minutes or so, they said they were taking the girls through to NICU. They brought them to me to see them for a few seconds before disappearing off and my husband followed to keep up to date with their progress. It was such a shame to not have contact with the girls and so I felt quite disconnected to begin with, but I knew the importance of them getting to NICU quickly.

The twins were in the High Dependency Unit (HDU) in incubators with tubes blowing oxygen up their noses and all sorts of wires attached to them. They were tiny, just laying on their tummies working hard to breathe. The nurses said they were very responsive to the oxygen and their temperatures had stabilised after being in the incubators. They were being tested for jaundice and they had feeding tubes in their mouths to start giving them milk. I had expressed a small amount of colostrum but didn't have enough yet for them, so they had donated breast milk through their tubes until I was producing enough. Expressing was the one thing I could actually do for my babies so I was determined to do it.

We decided on names – Matilda for the bigger twin and Evelyn for the smaller – Big Tilly and Little Evie! We managed to have our first cuddles with Tilly a day after they were born and Evie the day after that. Both girls responded well to the oxygen and that was reduced over the next few days. They both needed a tube in their veins to receive nutrition as their digestive systems weren't tolerating the milk too well – it just meant they could have nutrients and grow a bit easier. They both needed light therapy to help with jaundice and they were maintaining their temperature well in their incubators.

Surprisingly, even though Evelyn was much smaller than Matilda, their treatment wasn't too dissimilar and they were progressing well without any surprises.

The girls were in HDU for 10 days before being transferred to Low Dependency. Evie just had to put on a bit more weight to come out of the incubator and we were introducing breast feeds with them both.

Luckily the hospital had a home tube feeding program so we could be discharged with their tubes still in as long as they were progressing with breast feeds too. Matilda was discharged first after 4 weeks but Evelyn stayed in for a further week – that was by far the hardest week of them all. It was tough to be looking after Matilda at home but then going to the hospital daily to see and try and feed Evelyn too.

We had support from a wonderful community nurse visiting us at home and after 2 weeks the girls had their feeding tubes taken out as they were fully breastfeeding!!

Both girls have continued to put on weight well, there's still a small weight difference between them but now at 5 months old and still exclusively breastfeeding they weigh a huge 15lb 13oz and 12lb 12oz! They're hitting their milestones for their corrected age of 3 months and they're smiley, happy, chatty girls. ■

> **"...It was tough to be looking after Matilda at home but then going to the hospital daily to see and try and feed Evelyn too..."**

Keziah's Story

TTTS and TAPS

I was 13 weeks pregnant when I found out I was having monochorionic diamniotic twins. These are identical twins that share a placenta, but have their own individual sacs. Everything looked healthy, and the joy was indescribable.

I was booked in for a routine scan 3 weeks later and at 16 weeks was diagnosed with twin to twin transfusion syndrome known as TTTS. It was such a shock. All the excitement of carrying twins was now gone in just a couple of weeks and, at Stage 2 already, I had a high chance of losing them both. After a missed miscarriage the year before, the thought of losing two more babies was heart-breaking. TTTS meant the blood wasn't flowing evenly between the two of them. The one baby, the donor, had less blood flow and was becoming smaller in size. She was dehydrated and couldn't wee. Her bladder was really small and the amniotic fluid began to get less around her. Meanwhile, the other baby, the recipient, had too much blood flow and was getting too big. She was trying to wee the excess fluid, and had a big bladder and too much amniotic fluid around her.

I had an urgent referral to a Fetal Medicine Unit and an appointment the following day to meet the consultant. The next few weeks were crucial and I was being scanned every few days to see if both babies had a heartbeat. Making it a day at a time and scan by scan was all I could focus on.
I was advised after a few weeks I would need laser ablation surgery. The odds of the operation being successful would increase if it was done further into gestation, but at borderline stage 3, it was unknown whether both babies would survive a few more weeks to wait. I was asked if I wanted to terminate my pregnancy, but this was never an option for me to consider.

We were lucky to have been referred to one of only a few hospitals in the country that have the specialist care for TTTS and offer the surgery. My placenta wasn't in the ideal position so it made access even more difficult. A laser beam was used to laser the blood vessels in the placenta to help share the blood flow evenly and help the babies grow at the same rate. I had 2.5 litres of excess amniotic fluid removed from around the bigger baby. I had it done with local anaesthetic and sedation, and my husband could hold my hand the whole time.

After the surgery we had to wait several hours to know initially if the girls had made it through the operation, and then the weeks to follow I had an increased risk of internal bleeding and miscarriage. I just felt like everything was against me. A few weeks later I was told I had made it through the most critical part, but still only had 50% chance of keeping both babies and it was likely they would face complications as a result of TTTS.

Every week the difference in size began to level out. At each scan as soon as we saw two heartbeats, two bladders and two even fluid levels, we would start to relax. I found the scans difficult. As soon as that jelly went on to my tummy I would be terrified they were going to tell me something bad. Some scans I barely opened my eyes for and others I couldn't take my eyes off the screen just praying they would be okay.

At 24 weeks pregnant I had an MRI scan to check the babies' brains for any side effects from the surgery. We went to see a neurologist at the hospital who explained one baby had had a stroke in the womb at 12 weeks so way before surgery. He was able to discuss the parts of the brain that may have been damaged, but wouldn't really know the long term effects until birth or even into childhood.

> **"...Every day I am grateful for how blessed we were..."**

We were asked again if we wanted to terminate our pregnancy following the stroke, although terminating one baby would likely result in the fatality of both. The answer was always no, no matter the severity or the circumstances we would be faced with, but we had to sign all the paperwork anyway to accept what we had been told.

At 28 weeks, I also developed TAPS. Twin anaemia polycythaemia sequence is another complication of TTTS and caused the twins to suffer from an imbalance in red blood cells and haemoglobin, so we were then being monitored closely again to ensure this stayed within a certain level. Because of my TTTS and TAPS complications I was advised not to go past 36 weeks gestation, however, my waters broke at 32 weeks and I had an emergency C Section under general anaesthetic.

Matilda and Felicity were both born weighing exactly 3lb 7. After all of that, they were the exact same size. They went straight to intensive care. It was a few days before I could cuddle my daughters and caring for them through incubators was hard. It broke my heart we couldn't stay with them, and feeding them through tubes and cannulas was difficult. At their lowest weight they weighed 2lb 7 and 2lb 4. After 5 weeks we were able to come home with 2 (albeit tiny) healthy, gorgeous girls.

Over 4 months with my battle with TTTS, I had 28 ultrasound scans, 2 MRIs, 6 steroid injections, 1 transfusion, 1 stroke in the womb, 1 fetal laser ablation surgery, 1 amnioreduction procedure, 1 emergency C section and then almost 5 weeks in Neonatal Intensive Care. As well as the usual symptoms of a multiple pregnancy!

It was the scariest experience to go through, but because of the consultant and his team at the Fetal Medicine Unit, I have two healthy daughters that, at almost aged 3, show no complications of the journey they went through. Every day I am thankful to him and grateful for how blessed we were. ■

Maria's Story

sIUGR in a triplet pregnancy

I became pregnant naturally, but I paid for and received a private scan around 12 weeks as the previous year I had 2 miscarriages, my bump was big, and I just felt like something was different or wrong and then found out I was carrying triplets. Got seen within 2 days by the consultant at my local hospital where it was all confirmed by them. Due to the nature of a multiple birth I was given a lot of information about risks associated with the pregnancy. They more or less said that the singleton had its own placenta and should do well and would be more rare to have complications than that of the monochronic – diamniotic twins. As these were sharing a placenta they were the ones to look out for. They explained the complications that can arise in monochorionic pregnancies and they are due to unequal sharing of blood, blood volume, placental nutrients or a combination of these. Complications such as TTTS, TAPS and SIUGR may present and because these situations require different therapies and can sometimes be helped, the best thing to do was to monitor closely the growth of the babies.

It wasn't until a scan at 22 weeks that they picked up an issue with triplet 1 the singleton. He was small, not overly but just enough to give them caution to monitor him closely. After all my worrying during my pregnancy about the twins it was the singleton who was now in trouble.

At a scan with the multiple birth specialists at 26 weeks, they informed me that Triplet 1, the singleton, had placental dysfunction and reversed end diastolic flow which basically meant blood should flow forward but in extreme circumstances it can reverse direction. They also diagnosed him with IUGR which is growth restriction usually linked to reverse flow. I was then bombarded with information and stats of survival chances and what options were available to give the other 2 babies the best chance of surviving as they were doing so well. I had not expected this, the singleton was the baby who should have been ok, but now he was diagnosed with growth restriction and below the 5th centile. What did this mean? Because of the reverse flow and the growth restriction, my baby was more than likely suffering from malnutrition and reduced oxygen to the body and brain.

As I was only at 26 weeks things were not looking good and delivery was very risky. My husband and I decided we wanted 3 babies from this pregnancy and the best option to try and help triplet 1 to survive was to deliver the babies the next day via emergency Caesarean. We were told how this was putting the other 2 babies at risk as they were healthy and growing as they should. We had decided to tell the doctors we wanted to give triplet 1 the chance to survive, but honestly, I didn't know how I felt. He was very poorly and I worried if I was going to end up causing harm to the 2 healthy babies as a result.

I was admitted to hospital and prepared for surgery the next morning. I was to receive a scan in the morning on the off-chance triplet 1 had improved. Miraculously he did, he was still poorly but had stabilised to the point where they decided to postpone surgery and scan me daily to keep the pregnancy going for as long as possible. I would never have thought it would be possible, but I made it another three weeks before they finally had to deliver the babies as triplet 1 was starting to deteriorate and wasn't doing very well. I had been in the hospital for over 3 weeks and the day they decided to deliver the babies there was no room in NICU. The day was a blur, and by night time I had been transferred to a hospital over 120 miles from home to be rushed to theatre for an emergency section by doctors I did not know and had never met. On 30th November, 3 boys were brought into the world fighting with everything they had. The twins needed breathing support but were stabilised, but little Reece was not well at just 1lb 10 and was delivered not breathing. He was ventilated and rushed out of the room.

I was devastated and broken in a strange hospital with a team I did not know. My 3 little boys were taken away to be treated, not knowing how they were. They required so much help that it was 2 hours before I received news on their condition.

9 weeks later, we all left NICU with no breathing aids or feeding tubes, the 3 boys were fending for themselves.

They made it, and the 3 of them are now 1 year old happy boys. Reece is still on the 5th centile and will be assessed in the first couple years of life to understand if the reduced blood flow while in the womb will cause any issues with his development but at the moment he seems healthy and happy, and most important of all he is here. ■

> **"...the singleton was the baby who should have been ok, but now he was diagnosed with growth restriction..."**

Penny's Story

Triplets with TAPS

I found out at 9 weeks that I was having triplets during a scan for a suspected ectopic pregnancy. I went from thinking I was potentially losing my baby, to finding out there were three! It was the biggest shock of my life – naturally conceived and with no family history it was the last thing I was expecting to hear. I was the happiest and most terrified I think I've ever been.

I was sent from my local hospital to a hospital in London for my further scans, who at 16 weeks suspected a problem in my identical twins. I definitely didn't appreciate how bad that problem could be. At 17 weeks they formally diagnosed TAPS and I was given three options. The first was to do nothing, monitor it closely and hope that it didn't get any worse. The second was to try and terminate the twins and hope that I managed to keep the singleton. The last was to have laparoscopic laser surgery to try and fix the problem. Although it also had a risk of miscarriage and premature labour, surgery really seemed our only option. I was determined I was keeping all three of my babies. I was booked in for the one-day surgery the following day at a different hospital.

We turned up and sat in the waiting room, before being called in to be prepped for the op. It was all very relaxed and surprisingly informal. We think this was to try and keep everyone calm, to help the procedure go as smoothly as possible. The team were amazing. I was on the bed and had 5 other people around me, plus my husband, before the doctor came in – he assessed where the babies were situated by ultrasound and chose an entry site which was in with T3. All the screens were set up in front of us and so we could see everything the doctor could see and was using to complete the operation. It was mind blowing and scary as hell but I feel extremely privileged to have seen two of my babies long before they entered the world. The surgery itself was relatively painless but I definitely felt bruised not long afterwards and for quite a few days following. I returned to the previous hospital for follow up scans over the next two weeks and slowly the Dopplers started showing improvements. I was left with a very small scar which became a mini stretch mark as my belly continued expanding. But it's a stretch mark I'm immensely proud of – we had major surgery and, thankfully, it was successful. After a few more weeks I was discharged back to my local hospital.

One morning, at 26 weeks, I noticed some excess fluid, so went in to the maternity fetal assessment unit who did a few checks, but decided that everything was fine. I'm pretty sure though that it was the precursor to the following Wednesday night when there was a lot more fluid. Thursday morning saw me back at the hospital where they said my waters had broken. Yet another unexpected event, I had no idea what waters breaking looked like. I didn't think I needed to know already. No one was really sure which baby the waters were coming from, but the assumption was that it was my singleton at the bottom due to the pressure from the other two on top, and so the chance of me going into labour within 24 hours was very high. My local hospital couldn't provide the care needed for such premature babies if they came, so I was transferred to another hospital where I spent the next week and a half on bed rest. Their NICU ran out of bed space, so I was then transferred to yet another hospital. The travel almost brought on labour and I was given all the preparatory drugs for having preterm babies, another scary moment at 29 weeks. Somehow, we managed to avoid them arriving that soon, and I was again on bed rest for another week. It had been determined somewhere along the line that the waters were coming from T3 at the entry site from the TAPS surgery, so at that point the consultant was happy that my risk of imminent labour had reduced enough, and the babies would be old enough, not to need the higher levels of care. I spent one night at my local hospital before finally being allowed home.

I was 31 weeks when I booked my planned C-section for 35 weeks, but the babies obviously heard the conversation and didn't want to wait that long, as that same afternoon I went into spontaneous labour. I arrived at the hospital at 5pm, and by 7.57pm I was a mum of three. It was a complete whirlwind; I don't think I remember the time the decision was made that they were coming out. I was prepped for an emergency C-section. The operating room was so full of people, a different team for each of the babies and me. They did go round and introduce themselves and say what they were there for. I'm hugely grateful to them all but I have to be honest, I have absolutely no idea who those people were, it was way too overwhelming to take it all in. Having the epidural was the most uncomfortable bit for me, leaning as far forward as I could felt like I was squashing the babies. I got a massive case of the shivers afterwards too. But the operation went well, without any issues and all three were delivered quickly. Sadly, because they were so premature, I didn't get to see the babies straight away. And unfortunately, because of the lack of fluid in her sac, T3 had seriously under-developed lungs, which meant she had to be transferred to a different hospital for treatment. They wheeled me round to NICU on the bed to see them all before she left, but I couldn't get close to them yet, and they were mostly covered in tubes and wires. I met T1 and T2 properly the following morning, but it was a few days later on Christmas Day that I was well enough to make the trip to meet T3. The perfect Christmas present.

I feel like my pregnancy was fairly eventful, but ultimately, I loved every second of carrying three babies, and I don't remember all the bad stuff. It took a little while but I'm lucky enough to have three very healthy little people crawling around now, and it's amazing every day. ■

Section six:
SUPPORT FOR BEREAVED FAMILIES

Sadly, these are potentially fatal conditions and sometimes, despite the best treatment, one or more babies may not survive. If this has happened to you, we are very sorry indeed for your loss.

If you do find yourself in this situation, it's important to know that you are not alone. There is lots of support available from Twins Trust as well as other organisations, and we are here for you.

SUPPORT FROM TWINS TRUST

- **Bereavement booklet –** written together with bereaved families, our booklet includes information on the unique death of one or more of your twins, triplets or higher order multiples, subsequent pregnancies and how to remember babies who have died.

Twins trust.
Bereavement
Support Group
We support bereaved families with twins, triplets or more...

BEREAVEMENT
SUPPORT BOOKLET
For parents and carers of twins, triplets or more who have died

- **Online support group**
A special place where families are supported by others who understand the challenges and grief of experiencing the death of one or more of their babies.

- **Befriending service**
Peer-to-peer support from parents and grandparents who have experienced the death of their twin(s), triplet(s) or more.

- **Newsletter**
Families can sign up to the Bereavement Support Group newsletter, sent by email four times a year. These feature personal stories, details of memorial meet-ups and fundraising news.

- **Certificates of birth**
'Always together... forever in our hearts' beautiful words that appear on our new certificates of birth that bereaved families can freely download. (We hope that these certificates will provide families with some comfort and a precious keepsake of baby or babies who are sadly no longer here.)

If you are finding it difficult to discuss what you are going through with your family and friends, or would like to know more about the support that is available, please contact Twins Trust bereavement group coordinator at **bereavementsupport@twinstrust.org** or **https://twinstrust.org/bereavement/support.html** or you can follow us on Twitter **@twinstrustbsg**.

Twins trust.
Bereavement
Support Group

We support bereaved
families with twins,
triplets or more...

Section seven:
RECOMMENDED READING AND FURTHER INFORMATION

RECOMMENDED READING

- **MBF** (2010).
Information for Parents when Twins Share One Placenta.
Multiple Births Foundation: London.
http://www.multiplebirths.org.uk/shop.asp#booklets

- **NICE** (2006).
Intrauterine Laser Ablation of Placental Vessels for the Treatment
of Twin-to-Twin Transfusion Syndrome.
NICE: London.
https://www.nice.org.uk/guidance/ipg198

- **NICE** (2020).
Twin and Triplet Pregnancy.
NICE: London.
https://www.nice.org.uk/guidance/ng137

- **RCOG** (2016).
Management of Monochorionic Twin Pregnancy.
Royal College of Obstetricians and Gynaecologists: London.
https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg51/

- **Twins Trust** (2020).
Parents' Guide to Neonatal Care for Twins, Triplets and More.
Twins Trust: Aldershot.
https://www.twinstrust.org/neonatal-care

- **Twins Trust** (2020).
Complications.
Twins Trust: Aldershot.
https://www.twinstrust.org/complications

WHERE TO GET FURTHER SUPPORT

Twins Trust
The Manor House, Church Hill, Aldershot,
Hampshire, GU12 4JU

Tel: **01252 332344**
Twinline: **0800 138 0509**
www.twinstrust.org

Twins Trust Bereavement Support Group
Email: **bereavementsupport@twinstrust.org**
www.twinstrust.org/bereavement

TAPS Foundation (International)
Email: **hello@tapssupport.com**
Twitter: **@tapssupport**
Instagram: **@tapsssupport**
Facebook: **https://www.facebook.com/tapssupport/**
https://www.tapssupport.com/

TTTS Foundation (International)

Offers support with Twin-specific complications as well as bereavement services and support groups

Email: **info@tttsfoundation.org**
Facebook: **https://www.facebook.com/tttsfoundation**
Twitter: **https://twitter.com/tttsfoundation**
Instagram: **https://www.instagram.com/tttsfoundation**
https://tttsfoundation.org

BLISS
(For babies born premature or sick)
Fourth Floor, Maya House, 134-138 Borough
High Street, London, SE1 1LB

Tel: **020 7378 1122**
Email: **ask@bliss.org.uk**
Email support service: **hello@bliss.org.uk**
www.bliss.org.uk

Multiple Births Foundation

Tel: **020 3313 3519**
Email: **imperial.mbf@nhs.net**
www.multiplebirths.org.uk

Stillbirth and Neonatal Death Society (Sands)
Victoria Charity Centre, 11 Belgrave Road,
London, SW1V 1RB

Tel: **020 7436 7940**
Helpline: **0808 1643332**
Email: **helpline@sands.org.uk**
www.sands.org.uk

Further support: **https://www.sands.org.uk/support-you/how-we-offer-support**

If you have any questions or concerns about your or your babies' health in or after pregnancy, you should speak to your health professional in the first instance. Some parents may have concerns about their children's development following a complicated pregnancy, and if you have any worries it's best to speak to your GP who can make a referral if needed.

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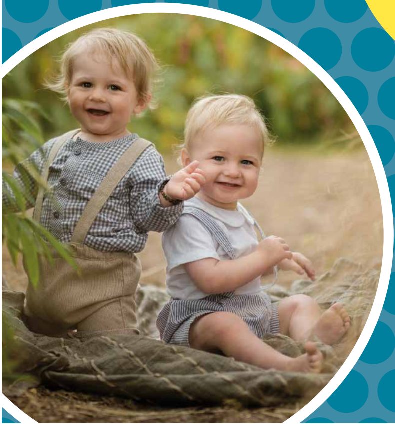
at high street retailers such as **JoJo Maman Bébé** and **Clarks**, cinema trips, holidays and **much more**

RESOURCES
A wealth of information to help you wherever you are on you parenting journey

MAGAZINE
packed full of interesting stories, advice and ideas

twinstrust.org/join



Twins trust.

We support twins, triplets and more...

Twins trust.

Twinline

Need to talk?
We're here

Twinline is open Monday to Friday,
10am to 1pm and 7pm to 10pm

0800 138 0509

asktwinline@twinstrust.org

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www.gift-surg.ac.uk

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HELP US TO SUPPORT MORE FAMILIES

If you've found this booklet helpful, would you consider supporting Twins Trust with a financial contribution? As a charity we rely on our membership programme, fundraising and donations to raise the money needed to provide our services, courses and information for multiple birth families, fund our research and maternity support. There are lots of ways you can get involved to help support families with twins, triplets and more.

The simplest way is to make a regular or one off donation on our website: **www.twinstrust.org/donate**. Or you might want to join our weekly lottery.

Maybe you'd like to have some fun or take on a personal challenge to raise money for us. Creating a fundraising page is very easy (e.g. Just Giving) and you can find fundraising ideas and forthcoming events on our website: **www.twinstrust.org/fundraising**.

If you would like to speak to someone about other ways to support Twins Trust, please email **fundraising@twinstrust.org**.

Twins trust. **We support twins, triplets and more...**

COMPLICATIONS IN YOUR PREGNANCY

WITH TWINS, TRIPLETS AND MORE:

A GUIDE FOR PARENTS

Twins trust.

We support twins, triplets and more...

www.twinstrust.org ☎ **01252 332344** **@twinstrust**

Twins Trust, Manor House, Church Hill, Aldershot, Hants, GU12 4JU

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Registered Company Number: 3688825