SUMMARY

WHO DOES TTTS AFFECT?

Twin-to-twin transfusion syndrome (TTTS) occurs in about 10-15% of identical twins who share a placenta (monochorionic twins). It can appear at any time during pregnancy, but most commonly before 24 weeks gestation. TTTS can also develop in triplet or higher order pregnancies that include monochorionic twins.

WHAT IS TTTS?

TTTS arises because there are blood vessels within and on the surface of the shared placenta connecting both twins. Usually, these vessels allow blood to flow evenly between the babies, but in TTTS the blood flow is unbalanced, resulting in a ‘donor’ twin donating blood through the placenta to a ‘recipient’ twin.

WHAT ARE THE WARNING SIGNS?

Symptoms for mothers to look out for include: sudden weight gain; feeling breathless at rest and having palpitations; uncomfortable or tight tummy; thirst; spotting; feeling early contractions; and back/leg pain. If you are at all worried, please speak to your doctor or midwife.

WHAT ARE THE TREATMENT OPTIONS?

If your TTTS is mild, 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 intervention, such as laser surgery or amnioreduction (draining excess amniotic fluid from around the larger recipient twin).

WHAT CAN YOU 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 lots of families have happy outcomes. Below is some advice from parents who have been in your situation:

• Only worry about tangible things
• Talk to your medical professionals if you’re worried
• Be cautious of internet coverage of TTTS
• Be aware of the warning signs
• Ask to attend antenatal classes earlier in your pregnancy
• Do the tours of neonatal wards (NICU/SCBU/HDU)
• Speak to your doctor if you are experiencing pain or discomfort
• Talk about your own needs and emotions with your midwife
• Ask as many questions as you want
• Remind your health professionals to keep you in the loop
• Don’t presume there will be ‘joined up thinking’ between health professionals
• Talk to your partner and offer each other support when you need it
• Speak to medical experts or families who have experienced TTTS
• Continue to voice your concerns when you get your babies home, if there are things you are worried about
• And finally... try to stay positive.

FOREWORD

In recent years, there have been steady improvements in our understanding of Twin to Twin Transfusion Syndrome (TTTS) and much greater clarity in how best to care for patients and babies. In tandem with these developments, our families highlighted the need for additional information and support, reporting that all too often they felt that were left to fend for themselves at what can be a very emotional and worrying time.

Thanks to the fundraising efforts of parents who had babies with TTTS and support from the James Tudor Foundation, we have been able to produce this new parents’ guide and two compilations of parents’ inspiring stories (all three are available for free from our website at www.tamba.org.uk/TTTS); and set up a peer-to-peer support network of parents who have experienced TTTS who offer support online via the Facebook: Twin to Twin Transfusion Syndrome Support Group or by phone on 01483 304442. If you would like clinical information and guidance then you should in the first instance speak to your own medical team. We have also produced a list of regional centres, who conduct laser therapy, at the end of this guide or you can contact our sister charity, the Multiple Birth Foundation who are also listed. We sincerely hope that you benefit from this additional support, but please do keep feeding back to us with your thoughts and ideas.

Once again our sincere thanks to all those families that have supported our work either through fundraising or through the feedback of their own experiences. Whilst there is still much more to be done, with your help we hope to continue to improve our families’ experiences for many years to come.

Best wishes, Keith Reed,
Tamba CEO

Please note that each TTTS pregnancy is very different. The positive 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.
SUMMARY

WHO DOES TTTS AFFECT?
Twin-to-twin transfusion syndrome (TTTS) occurs in about 10-15% of identical twins who share a placenta (monochorionic twins). It can appear at any time during pregnancy, but most commonly before 24 weeks gestation. TTTS can also develop in triplet or higher order pregnancies that include monochorionic twins.

WHAT IS TTTS?
TTTS arises because there are blood vessels within and on the surface of the shared placenta connecting both twins. Usually, these vessels allow blood to flow evenly between the babies, but in TTTS the blood flow is unbalanced, resulting in a ‘donor’ twin donating blood through the placenta to a ‘recipient’ twin.

WHAT ARE THE WARNING SIGNS?
Symptoms for mothers to look out for include: sudden weight gain; feeling breathless at rest and having palpitations; uncomfortable or tight tummy; thirst; spotting; feeling early contractions; and back/leg pain. If you are at all worried, please speak to your doctor or midwife.

WHAT ARE THE TREATMENT OPTIONS?
If your TTTS is mild, 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 intervention, such as laser surgery or amnioreduction (draining excess amniotic fluid from around the larger recipient twin).

WHAT CAN YOU 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 lots of families have happy outcomes. Below is some advice from parents who have been in your situation:

- Only worry about tangible things
- Talk to your medical professionals if you’re worried
- Be cautious of internet coverage of TTTS
- Be aware of the warning signs
- Ask to attend antenatal classes earlier in your pregnancy
- Do the tours of neonatal wards (NICU/SCBU/HDU)
- Speak to your doctor if you are experiencing pain or discomfort
- Talk about your own needs and emotions with your midwife
- Ask as many questions as you want
- Remind your health professionals to keep you in the loop
- Don’t presume there will be ‘joined up thinking’ between health professionals
- Talk to your partner and offer each other support when you need it
- Speak to medical experts or families who have experienced TTTS
- Continue to voice your concerns when you get your babies home, if there are things you are worried about
- And finally... try to stay positive.
INTRODUCTION
Finding out that you are pregnant with twins or triplets can be a time of conflicting emotions for parents. The excitement and joy is usually mingled with thoughts about the practicalities of caring for more than one baby and concerns about the higher 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 twin-to-twin transfusion syndrome (TTTS).

TTTS affects 10-15% of identical twins that share a placenta (monochorionic twins). When twins share a placenta, one baby sometimes has a smaller share which may result in the baby not growing as well. In addition, there are usually blood vessels connecting the babies, allowing the flow of blood from one baby to the other. Most often, this does not cause any problems, but in some cases one baby can receive much more blood than the other. It is important that the pregnancy is closely monitored so that if the condition becomes serious, the most suitable treatment can be considered.

Although there has been great progress in diagnosing and treating TTTS, it can be hard for parents to find information about the condition. This booklet will hopefully be a useful resource for you and it complements the recent work on TTTS produced by the Multiple Births Foundation (MBF) and the Royal College of Obstetricians and Gynaecologists (RCOG). For an in-depth medical explanation of the condition and suggested treatments, please refer to the MBF’s (2010) ‘Information for Parents when Twins Share One Placenta’ and the RCOG’s (2008) ‘Management of Monochorionic Twin Pregnancy’. If you have any concerns, you should always seek advice from your midwife or doctor.

Being pregnant with twins can feel isolating, particularly if there are complications such as TTTS. As well as providing information, this guide also shares the experience of parents who have had TTTS. We hope that by reading other parents’ stories you feel less alone.

It is normal to be worried, but please try to remember that many parents go on to have healthy, happy babies. By reading this booklet, you are doing one of the best things you can right now – making yourself aware of the warning signs, preparing for possible outcomes and being able to make informed decisions about TTTS. If you would like to speak to somebody, please contact Tamba or any of the organisations listed at the back of this booklet. We wish you the very best during your pregnancy, the birth and the many years to follow.

CONTENTS
• Introduction
• What is TTTS?
  • Who does TTTS affect?
• What are the warning signs?
• What are the complications?
• What care should I expect during my pregnancy?
  • What are the treatment options?
  • What might happen to my babies?
• How and when will my twins be born?
  • Bereavement: coping with loss
  • What can you do?
• Parents’ stories: happy endings
  • Recommended reading
  • Where to get further support
• List of hospitals conducting laser surgery
INTRODUCTION

Finding out that you are pregnant with twins or triplets can be a time of conflicting emotions for parents. The excitement and joy is usually mingled with thoughts about the practicalities of caring for more then one baby and concerns about the higher 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 twin-to-twin transfusion syndrome (TTTS).

TTTS affects 10-15% of identical twins that share a placenta (monochorionic twins). When twins share a placenta, one baby sometimes has a smaller share which may result in the baby not growing as well. In addition, there are usually blood vessels connecting the babies, allowing the flow of blood from one baby to the other. Most often, this does not cause any problems, but in some cases one baby can receive much more blood than the other. It is important that the pregnancy is closely monitored so that if the condition becomes serious, the most suitable treatment can be considered.

Although there has been great progress in diagnosing and treating TTTS, it can be hard for parents to find information about the condition. This booklet will hopefully be a useful resource for you and it complements the recent work on TTTS produced by the Multiple Births Foundation (MBF) and the Royal College of Obstetricians and Gynaecologists (RCOG). For an in-depth medical explanation of the condition and suggested treatments, please refer to the MBF’s (2010) ‘Information for Parents when Twins Share One Placenta’ and the RCOG’s (2008) ‘Management of Monochorionic Twin Pregnancy’. If you have any concerns, you should always seek advice from your midwife or doctor.

Being pregnant with twins can feel isolating, particularly if there are complications such as TTTS. As well as providing information, this guide also shares the experience of parents who have had TTTS. We hope that by reading other parents’ stories you feel less alone.

It is normal to be worried, but please try to remember that many parents go on to have healthy, happy babies. By reading this booklet, you are doing one of the best things you can right now – making yourself aware of the warning signs, preparing for possible outcomes and being able to make informed decisions about TTTS. If you would like to speak to somebody, please contact Tamba or any of the organisations listed at the back of this booklet. We wish you the very best during your pregnancy, the birth and the many years to follow.
WHAT IS TTTS?

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

It arises because there are blood vessels within and on the surface of the shared placenta connecting both twins. Usually, these 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 cope with the extra blood supply.

To compensate for the excess blood, the recipient twin often produces a large amount of fluid. In contrast, the smaller donor twin can become stuck against the uterus wall with little surrounding fluid.

Source: Multiple Births Foundation (2010)
Designer: Will Lucking
WHAT IS TTTS?

Twin-to-twin transfusion syndrome (TTTS) is a rare, but potentially fatal, condition that affects about 10-15% of monochorionic twins. It can appear at any time during pregnancy, but most commonly before 24 weeks gestation. It arises because there are blood vessels within and on the surface of the shared placenta connecting both twins. Usually, these 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 cope with the extra blood supply.

To compensate for the excess blood, the recipient twin often produces a large amount of fluid. In contrast, the smaller donor twin can become stuck against the uterus wall with little surrounding fluid.

WHO DOES TTTS AFFECT?

TTTS only affects twins or triplets who share a placenta. They are referred to as monochorionic twins because they share an outer membrane (chorion) – the technical term is MCDA and MCMA twins. The diagrams below show the different types of twins.

### MONOCHORIONIC DIAMNIOTIC (MCDA) TWINS

MCDA twins share a placenta and an outer membrane, but move around in separate amniotic sacs. MCDA pregnancies are at risk of TTTS.

### MONOCHORIONIC MONOAMNIOTIC (MCMA) TWINS

With MCMA pregnancies there is no dividing membrane and so the twins are at risk of cord entanglement, which can hinder the babies’ movement, development and potentially result in death. Delivery is therefore usually recommended for MCMA twins at 32-34 weeks by caesarean section. MCMA pregnancies are also at risk of TTTS. MCMA twins are very rare – only about 1% of monochorionic twins are MCMA.

### DICHORIONIC DIAMNIOTIC (DCDA) TWINS

DCDA twins have their own placenta and amniotic sac. DCDA twins are not at risk of developing TTTS, because they do not share a placenta. Two thirds of DCDA twins are non-identical (dizygotic), and about one third are identical (monozygotic).


WHAT ARE THE WARNING SIGNS?

During your first ultrasound scan, the sonographer will look carefully to see if your twins have one chorionic membrane. If so, your pregnancy should be closely monitored with ultrasound scans, so that if TTTS starts to develop it is diagnosed and suitable treatment considered. Warning signs on ultrasound in twin babies include:

- Different amounts of amniotic fluid around the twins. The donor twin may have very little amniotic fluid, while the recipient has a lot. This is known as the polyhydramnios (high levels of fluid) / oligohydramnios (low levels) sequence
- 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 cord and within baby to decide on the severity of TTTS if it is diagnosed)

THERE ARE SEVERAL SYMPTOMS TO LOOK OUT FOR IN MOTHERS:

- 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
- Spotting
- Feeling early contractions
- Back pain and leg pain due to the build up of fluid

You may find it difficult to know whether you should be concerned about some of your symptoms, especially if this is your first pregnancy. If you are at all worried, please speak to your doctor or midwife. Some parents recommend making a fuss if you need to, because unless you are under the care of fetal medicine specialists, not all health professionals are as aware of the condition, the symptoms and potential outcomes..

Scan image at 18 weeks which shows Ashley, the ‘stuck twin’ (right) and Cameron (left) with polyhydramnios
WHAT ARE THE WARNING SIGNS?
During your first ultrasound scan, the sonographer will look carefully to see if your twins have one chorionic membrane. If so, your pregnancy should be closely monitored with ultrasound scans, so that if TTTS starts to develop it is diagnosed and suitable treatment considered.

Warning signs on ultrasound in twin babies include:

• Different amounts of amniotic fluid around the twins. The donor twin may have very little amniotic fluid, while the recipient has a lot. This is known as the polyhydramnios (high levels of fluid) / oligohydramnios (low levels) sequence
• 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 cord and within baby to decide on the severity of TTTS if it is diagnosed)

THERE ARE SEVERAL SYMPTOMS TO LOOK OUT FOR IN MOTHERS:

• 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
• Spotting
• Feeling early contractions
• Back pain and leg pain due to the build up of fluid

You may find it difficult to know whether you should be concerned about some of your symptoms, especially if this is your first pregnancy. If you are at all worried, please speak to your doctor or midwife. Some parents recommend making a fuss if you need to, because unless you are under the care of fetal medicine specialists, not all health professionals are as aware of the condition, the symptoms and potential outcomes.

Scan image at 18 weeks which shows Ashley, the ‘stuck twin’ (right) and Cameron (left) with polyhydramnios

WHAT ARE THE COMPLICATIONS?
TTTS ranges in its severity from mild to severe. If left untreated, TTTS can result in the following complications inside the womb:

• slow growth and development in the donor twin
• anaemia in the donor twin
• heart failure in the recipient twin (from pumping too much blood)
• too much amniotic fluid in the recipient twin, leading to the membranes rupturing too early
• premature labour
• death of one or more of the twins

The care for all women with a monochorionic pregnancy should be based on a policy agreed with your 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 that the condition is deteriorating. If you have symptoms of more severe TTTS, you should be referred to a fetal medicine unit for the most suitable treatment in your individual case.

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 or fetal hydrops (abnormal swelling due to excessive accumulation of watery fluid) in the recipient.


TTTS can also be described as ‘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 quicker, due to sudden differences in blood pressure between the twins in the last three months of pregnancy or during delivery. 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.
BEING AWARE OF THE WARNING SIGNS: WILLIAM AND ALEX'S STORY
SARAH DEVONS

On 9th April 2009 William and Alexander were born, but their story started much earlier than this ... As usual I got pregnant very easily and went for my first scan at 16 weeks. It was immediately clear that I was carrying twins. As there was not a history of twins in the family, we were shocked to say the least. We only wanted number three, but got number four at the same time. Never mind, we thought, loads of people have twins.

Little did we know how different a twin pregnancy is compared with a single pregnancy. Immediately we were under consultant care and because of the type of twins I was carrying, I was scanned fortnightly. My twins shared the same placenta and we were told that the risk of TTTS was likely but it is rare. I was told that if any scan showed an increase in fluid in one of the babies’ sacs this was an indicator of TTTS onset. At every scan we could see a minimal increase, but I was told not to worry. Apparently if the one baby receives more blood it wees more, which in turn produces more amniotic fluid and hence the indicator of TTTS.

My whole pregnancy was entirely different to my previous two. I was incredibly hungry all the time, tired and grumpy. By 24 weeks I had a feeling that something had changed. Call it sixth sense. I was huge, and at first put it down to simply carrying twins, but I was also incredibly uncomfortable, my bump was tight and I looked 9 months, even though I was only 6 months. I had a scan at 26 weeks and my notes did say there was a slight increase in water. My usual consultant was away and I asked the consultant I saw if I should worry. “No,” they said. “It’s fine”.

The following week I went to Centreparcs for a much needed break with the family. By this point my bump was immense. To be honest, I was sure
something wasn’t right, and was convinced I wouldn’t make it through the week. But I did and having spent the week being stared at because I was so huge, we went home. The next week I went for my 28 week scan. Little did I know that our lives were about to change forever.

My scan showed that the water had significantly increased, but because I was 28 weeks, it was too late to treat the TTTS. It is very unusual to be diagnosed with TTTS so late in the pregnancy. Looking back, I wonder if the TTTS had been there earlier, but just not spotted. I will never know. My consultant arranged for me to see her again the following day and told me to bring my bag and be prepared to deliver the babies.

William Hugh and Alexander John Devons were born on the 9th April 2009, pictured here. William was the bigger twin, 1130grms, and had all the water to splash around in, Alex was much smaller, 840grms, and had more or less no water. He had been the stuck twin.

Sadly, two months later on 12th June, Alex died of necrotising enterocolitis, an infection in the intestine. Although the loss of Alex is unimaginable, we have William, a much loved son and brother to my two eldest.

TTTS, although rare, I found out is surprisingly common. I knew of two other mums who had also had TTTS, but you do feel very alone. I suggest to anyone who has TTTS, or is at risk of it, learns as much as they can about it. The signs are so subtle on the scans, but if at any time you think something is wrong, keep asking your consultant. I knew something was not right and had my consultant been at my last scan, I may well have known I had TTTS then, not a fortnight later. Always trust what your body tells you; after all you know it best. If you are diagnosed with TTTS, ask as much as you can, and if you are early enough for treatment, it is very possible that treatment is successful.
I was really enjoying my twin pregnancy (after getting over the initial shock!) but by 28 weeks I was beginning to wonder how I could possibly get any bigger. I was staying in another part of the country with friends when I spent a very uncomfortable night because of pain under my right ribcage and general restlessness.

The next morning I had a small vaginal bleed and so duly went to the local hospital to be checked out, expecting to be sent home reassured. I was surprised to be kept in and given steroids. The separating membrane between the twins was identified on the scan and there didn’t seem to be any clear reason identified for the bleed. Unfortunately that night I went into labour and in the early morning went by blue light ambulance to the nearest hospital.
with two beds for 28 weekers which happened to be our local hospital over 200 miles away!

By the time we arrived, labour had stopped. A midwife commented on polyhydramnios at a scan carried out by the on-call doctor and I was measuring 44 weeks. During that day and night I had the same pain and discomfort in my right upper abdomen and the midwives were having great difficulty picking up the heartbeat of Twin 2 who was positioned there (evidently because of the excess fluid surrounding Twin 2). It was not until the next day that I had a scan carried out by an ultrasonographer who gave us the results we dreaded.

It was TTTS – Twin 1 was motionless at the base of the uterus with the membrane stuck to her and no surrounding fluid and Twin 2 was surrounded by a large amount of fluid and her heart was under strain.

I felt absolutely sick with fear and just couldn’t believe what was happening to us and our twins. I was sent back to the ward where we were told we would wait for an opinion from the local consultant with a special interest in fetal medicine who was presently off-site.

It was plainly not a time to be waiting and so we insisted on an immediate referral to Kings Hospital Harris Birthright Centre. Later that afternoon, Kings made a diagnosis of acute, severe TTTS and told us that the outlook was potentially very bleak. We were given the option of immediate delivery of two very sick premature babies or of laser surgery (not usually performed this late in pregnancy) with a 60% chance of at least one baby surviving. We were also faced with the possibility that Twin 2 (recipient) may have suffered brain damage due to the massive, rapid transfusion of blood.

It was a very difficult decision to make.

We were given some time together in a small room to make a decision. It almost felt like it was happening to someone else but at the same time the possibility of not having our two babies we had hoped for was prominent in our minds.

We decided to accept the laser surgery, wishing it would be a success and give our babies the best chance to recover and have some more time ‘inside’.

The surgery itself was painless but it required some focus to remain still for a relatively long time. It was amazing to see our beautiful babies on the inside.

‘I felt absolutely sick with fear and just couldn’t believe what was happening to us and our twins.’

and would have been very enjoyable had the circumstances been different. The laser separated the abnormal connecting vessels with loud ‘pops’ but no discomfort. The excess amniotic fluid was also drained off after the main procedure. We then waited 30 minutes and had another scan to see that both twins were still alive. I then had a patch stuck on my lower back containing medicines to prevent contractions and we were sent home with an appointment for one week’s time. We were shocked...
at the time that we were sent home and we felt quite alone and uncertain of what the next 24 hours would hold. We went into our local hospital each day for two days to have a heart tracing of Twin 2 to monitor her recovery. On the second day I had persistent cramp-like pains in my legs which continued throughout the day. By the late evening I was having contractions and we went into labour ward, where my waters broke in the early hours. That morning, Sophie Alice (Twin 1 donor) and Emily Rose (Twin 2 recipient) were born by emergency Caesarean Section weighing 2lb14oz and 3lb2oz respectively. They both cried on delivery which was the best sound I have ever heard.

They spent over 10 weeks on SCBU but did not require ventilation and we feel that the 48-hour period post-laser surgery really made a great difference to their condition at birth.

Our experience made us realise that you must be your babies’ advocate and that if you do not feel that you are getting the right treatment or feel uncertain about the advice you are given then insist on seeing the consultant or on a referral to a Specialist Centre. It is important to be well-informed which helps you to feel confident about seeking the best treatment for your babies. We found the message boards on TAMBA extremely helpful both in terms of sharing other peoples’ experiences of TTTS and links to appropriate sources of information on TTTS.

“We found the message boards on TAMBA extremely helpful both in terms of sharing other people’s experiences of TTTS and links to appropriate sources of information on TTTS.”

We feel so very blessed and grateful to the skill of the team at Harris Birthright and at Pembury Hospital SCBU to have two utterly adorable, happy, healthy 2 and a half year old girls today.
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.

10-13 WEEKS: ULTRASOUND EXAMINATION

If twins are diagnosed at the first ultrasound examination, the sonographer 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 by a specialist before 14 weeks.

Some parents also choose to have the screening test for Down’s syndrome – the nuchal translucency scan, which involves measuring the thickness of the fetuses’ necks to see the amount of 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, although these scans may be more regular 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 anomaly 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 AND DOPPLER STUDIES EVERY 2-4 WEEKS

All monochorionic pregnancies should continue to be monitored by ultrasound examination every 2-4 weeks, but after 24 weeks Doppler studies should also be used to look for signs of poor blood flow through the umbilical cords and placentas of the babies.

32 WEEKS: DISCUSSION ABOUT DELIVERY OPTIONS

The benefits and risks of different types of delivery should be discussed by 32 weeks and the mother’s view should be considered. It may not be advisable to have a vaginal delivery if the first baby is lying breech (bottom-first), the mother has previously had a caesarean section or if there are other clinical concerns requiring a section. TTTS and birth is discussed later in this booklet.
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 intervention.

The choice of treatment will depend upon the stage of TTTS and how far into the pregnancy you are. Your doctor will tell you which treatment options are appropriate to your situation and discuss 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 twin, 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’) twin 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, although it can take up to 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 less advanced stages of TTTS 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% survival rate of at least one baby;
- 44% survival rate of both babies;
- average delivery at 29 weeks; and
- a 15-25% risk of long-term neurological handicaps 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 to the membranes, or premature labour, increases slightly with each amnioreduction.

LASER ABLATION

Laser ablation therapy involves finding every blood vessel connecting the twins and closing them to prevent the flow of blood from one baby to the other and the possible risk of transfusion. The surgery is conducted under local anaesthetic or an epidural, so you should be 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) twin. 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 linking the two babies, before the laser burns the vessels and seals them off. Each baby stays connected through the umbilical cord to its main source of blood and nutrition.

The extra fluid around the bigger twin 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
I was so scared and not just about what was going to happen to the babies, but also about having laser surgery done to me. It ended up being a most surreal experience. The anaesthetic administered was described by the anaesthetist as like have a few large gin and tonics – you are aware of what is going around you but you don’t really care! So true!

Emma Richards

TTTS. If every blood vessel is found and the twins’ blood supplies completely separated, the procedure only needs to be conducted 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% cases;
- a risk of long-term handicap in the surviving babies of around 5%.

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 positive 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).
Laser surgery was done under local anaesthetic - it was not an especially painful procedure, just a bit uncomfortable when the laser and endoscope was put into the womb through my abdomen. The thing that was truly amazing was that we were able to see the video images of the boys on a screen as the surgery happened. They looked completely fully formed, just tiny, and they were keen to be on camera, which meant they kept on getting in the way of the surgeon as he tried to laser through the shared blood vessels in the placenta.

As well as the treatment of the blood vessels, one and a half litres of excess amniotic fluid was drained, and the individual amniotic sacs were cut through so that the boys shared a sac instead, enabling Iestyn to have some fluid around him at last and not be quite so shrink wrapped!

The surgeons (amazing men, the boys have their names as middle names) were very pleased when they scanned again an hour or so after the surgery and things already seemed to be improving. Gethin’s heart scan was also looking more normal, and the boys were not showing any signs of distress. We were kept in overnight, and the scan in the morning showed things were continuing to improve. We were discharged, and came back once more, a week later, to Queen Charlottes, before we were handed back to our local hospital in Oxford.
Laser surgery was done under local anaesthetic - it was not an especially painful procedure, just a bit uncomfortable when the laser and endoscope was put into the womb through my abdomen. The thing that was truly amazing was that we were able to see the video images of the boys on a screen as the surgery happened. They looked completely fully formed, just tiny, and they were keen to be on camera, which meant they kept on getting in the way of the surgeon as he tried to laser through the shared blood vessels in the placenta.

As well as the treatment of the blood vessels, one and a half litres of excess amniotic fluid was drained, and the individual amniotic sacs were cut through so that the boys shared a sac instead, enabling Iestyn to have some fluid around him at last and not be quite so shrink wrapped!

The surgeons (amazing men, the boys have their names as middle names) were very pleased when they scanned again an hour or so after the surgery and things already seemed to be improving. Gethin’s heart scan was also looking more normal, and the boys were not showing any signs of distress. We were kept in overnight, and the scan in the morning showed things were continuing to improve. We were discharged, and came back once more, a week later, to Queen Charlottes, before we were handed back to our local hospital in Oxford.

SELECTIVE FETICIDE
In a few cases, the only way to prevent the loss of both twins 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 the 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 tissue swelling (hydrops), brain damage or heart failure. In severe cases, one or both of the babies may not survive.

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 spontaneously because you go into labour. For further information on the risks associated with prematurity, please see Tamba/Bliss’s (2010) Parents’ Guide to Neonatal Care.

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

However, this is a condition which can cause long-term health concerns in a few cases. Physical and mental handicaps 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 and physical development, please speak with your doctor or health visitor and they can reassure you or monitor their progress.

“A year on, we are exhausted but very grateful parents … hang on in there and don’t give up hope!”

Katrina Rowan-Wilde

also have explained that not every outcome involves 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, concerns include slow growth and anaemia, as well as more severe complications such as generalised soft
Our two beautiful girls were born by Caesarean at 34 weeks and 5 days, weighing 3lb 1oz and 3lb 13oz. After our babies were discharged from hospital, they have continued to see the consultant to monitor their progress. We have had concerns following our donor twin’s head scan and a different shaped head and rapid head growth, but as both seem to be happy progressing babies and that us parents have larger than average head size, they haven’t had to have further tests. Our donor twin is still being seen by the hearing screening department but again nothing significant found. The recipient twin has been ahead with just about everything; our donor having a heavy head/stiff neck has found it hard to lift her head up to crawl. We saw a physiotherapist and with time, this has corrected itself enough to stop attending. At 16 months, the recipient is walking and the donor is just starting to. The recipient twin remains heavier and taller and we were told that the donor may catch up in six months, in their teens or never.
HOW AND WHEN WILL MY TWINS BE BORN?

Premature birth is a concern with TTTS. Try to prepare yourselves for the possibility that your babies may need to spend a bit of time in a neonatal unit, even if they are born around their due date. These units are also known as Neonatal Intensive Care Units (NICU), High Dependency Units (HDU) and Special Care Baby Units (SCBU), with the main difference being that the level of medical care needed is more intensive in NICU and HDU. Many hospitals run tours of the neonatal wards so that parents can meet the staff, see what the equipment and tiny babies look like and ask any questions. For more information on prematurity and neonatal care, please see Tamba/Bliss’s Parents’ Guide to Neonatal Care.

When twins share a placenta, many doctors recommend delivering the babies by caesarean section, usually between 34-36 weeks (37 weeks being considered ‘full term’ for twins). Vaginal delivery is possible with monochorionic pregnancies, although it is advised that your babies’ heart rates are continuously monitored using electronic surveillance for any signs of distress.

If Acute TTTS is detected, your doctors will suggest an emergency caesarean section. The Royal College of Obstetricians and Gynaecologists recommend that in monochorionic twin pregnancies, doctors and parents should have a discussion around 32-34 weeks about what mode of delivery and care would be best. The benefits and timing of a C-section delivery will need to be balanced against the recognised difficulties and hazards of a section for the mother, as well as the risks for premature babies.

“’ We couldn’t fault the care we received ... we felt like we were on the top of the priority list and nothing was left to chance. ’”

Michelle and Cormac Cassells

www.tamba.org.uk / 021
We have 3 children - a 7 year old boy, and twin boys who are just 2. The boys were born naturally (gas and air) at 38 weeks, and weighed 5lb 1oz and 5lb 2oz. Jack was very pale and quiet, whereas Oliver was very red and loud. The midwife did comment to my husband at the end of the birth that the placenta was very thick and healthy on one side and very thin and pale on the other, but this information was not passed on and it was ‘thrown away’.

The boys both came back to the ward with me, and we had three days of them not wanting to feed much, and the doctors having great difficulty getting blood samples. Several doctors and consultants saw me with my ‘two tone’ babies during this time, and commented on the difference in colour, but when they asked about the weights of the boys, they said no more. On the third day, the midwives were obviously getting concerned about the difficulties in feeding (although they were subtle about this, and didn’t alarm us). They bathed the babies and tried to get them latched on, but there was nothing really happening.

When the doctor once again failed to get a blood sample from Oliver (his blood clotted whilst coming out as it was so thick), another consultant was called who immediately realised that the boys were suffering from TTTS and rushed us all to SCBU.

Jack rallied well and was allowed back to the ward with me the next day, but Oliver needed a day in the incubator, and then slowly reducing levels of light therapy which mean he stayed down the corridor in SCBU for the next 10 days. Both boys are now fine, and further check-ups on their development have shown them to be doing well.

Blood taken from his belly button and water put in, he was placed in incubation and had light therapy to help the high levels of jaundice that were being caused by his body breaking down some of the excess red blood cells.

Jack was given a blood transfusion to help his anaemia. Oliver needed more care - he had
BEREAVEMENT: COPING WITH LOSS

Sadly, TTTS is a potentially fatal condition and not all twin pregnancies end with two healthy babies. If you have lost one or both twins, we are very sorry for your loss. We have produced an accompanying booklet ‘TTTS & Bereavement’, which includes parents’ experiences of bereavement and some practical advice. Tamba’s bereavement support group (BSG) has also produced a free booklet on ‘Multiple Loss during Pregnancy, Birth and in Infancy’. The BSG is run by parents for parents – all the befrienders have lost one or all of their multiples.

They know how special it is to have fallen pregnant with twins and the complicated emotions you will be feeling right now. Tamba are here to listen and help. If you are finding it difficult to discuss what you are going through with your family and friends, please contact BSG via the website (www.tamba.org.uk/bsg) or phone Tamba’s Twinline (0800 138 0509) or the Tamba office (01252 332344).

“...It is still early days as I am only 18 weeks ... I know that until I am holding them both in my arms we are not out of danger.”

Amanda Dunworth
TTTS: WHAT CAN YOU 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 lots of 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 this 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 TTTS was.”

Be cautious of internet coverage of TTTS. “Where I found it to be very beneficial and reassuring was reading about successful outcomes of other TTTS pregnancies. However, a number of sites I felt presented a very negative picture of TTTS and had a number of inaccuracies of the prognosis.”

Be aware of the warning signs. "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. Queen Charlotte’s were able to guess it was TTTS by just looking at Abby.”

Ask to attend antenatal classes earlier in your pregnancy. “We think that couples experiencing TTTS (especially if it is your first pregnancy) should ask their obstetrician/GP/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). “Tour NICU and SCBU and speak to paediatricians in advance, just in case an emergency delivery is needed. 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 not 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 TTTS, 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?, is it TTTS?, what symptoms do we need to look out for? etc”

Remind your health professionals to keep you in the loop. “A diagnosis of TTTS seems to lead to a large number of medical professionals becoming involved, who may communicate effectively with each other, but leave parents feeling sidelined.”

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 of TTTS. As the twins were roughly the same size (unusual for twins suffering from TTTS), 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 TTTS. You can also talk to other parents going through the same situation on Tamba’s messageboard, as well as the support group for parents on Facebook or by phone on 01252 332344

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”.

And finally ... try to stay positive. “Although TTTS is 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 TTTS, 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.”
I found out I was expecting twins at 18 weeks + 6 days – an earlier scan had missed the second baby. The following day I was diagnosed with twin-to-twin transfusion syndrome. It was a huge shock – we had only just found out we were expecting two little girls, and now we faced the possibility that we might lose one or both babies.

The obstetrician and in particular the midwife were really wonderful and supportive. The doctor outlined our options – laser surgery, draining amniotic fluid, or doing nothing (though he made clear that without any treatment I would most likely go into labour within three weeks and lose both babies). We decided to go for laser surgery as it had the best chance of success.

At the time (July 2005), laser surgery wasn’t available in Ireland, so we went to King’s College in London. We had a long day of waiting, detailed scans and blood tests, before surgery was performed. I was given a painkiller but was awake throughout the procedure which took half an hour. I was then sent back to a private room to rest. Within about half an hour I felt kicking, and started crying with relief. However it was hard to be sure that I was feeling both of them and we had to wait for a scan to confirm the good news – both babies survived.

We returned home to Dublin the next day and went straight to our own hospital where a scan confirmed both babies were still doing fine. I was monitored with scans once or twice a week for the rest of my pregnancy. We had scares at 28 weeks and 31 weeks where it looked like the babies would have to be delivered due to the deterioration in the blood flow to the smaller baby, but each time it improved at the following scan. In the end I made it to 35+6 before the babies were delivered by planned Caesarean section.

Rachel weighed 6 lbs 4 oz and Sarah weighed 3 lbs 14 oz. Despite the fact that they were identical twins, they didn’t look alike at all due to the big weight difference. Rachel spent just one night in NICU being monitored, then she was on the ward with me and went home with me on day 5. Sarah needed tube feeds and stayed in NICU/SCBU for 15 nights. We were so thrilled when she was able to come home, 2 weeks before her due date, and we were all together as a family.

Rachel and Sarah had a shaky start in life but they never looked back. They both grew quickly and although Rachel is still a centimetre taller and two pounds heavier, the difference between them is not noticeable at all and most people struggle to tell them apart. At four and a half, they are two of the happiest and healthiest little girls you could meet. In fact they are both very tall for their age and people constantly assume they are older than they are.
I found out I was expecting twins at 18 weeks + 6 days – an earlier scan had missed the second baby. The following day I was diagnosed with twin-to-twin transfusion syndrome. It was a huge shock – we had only just found out we were expecting two little girls, and now we faced the possibility that we might lose one or both babies.

The obstetrician and in particular the midwife were really wonderful and supportive. The doctor outlined our options – laser surgery, draining amniotic fluid, or doing nothing (though he made clear that without any treatment I would most likely go into labour within three weeks and lose both babies). We decided to go for laser surgery as it had the best chance of success.

At the time (July 2005), laser surgery wasn’t available in Ireland, so we went to King’s College in London. We had a long day of waiting, detailed scans and blood tests, before surgery was performed. I was given a painkiller but was awake throughout the procedure which took half an hour. I was then sent back to a private room to rest. Within about half an hour I felt kicking, and started crying with relief. However it was hard to be sure that I was feeling both of them and we had to wait for a scan to confirm the good news – both babies survived.

We returned home to Dublin the next day and went straight to our own hospital where a scan confirmed both babies were still doing fine. I was monitored with scans once or twice a week for the rest of my pregnancy. We had scares at 28 weeks and 31 weeks where it looked like the babies would have to be delivered due to the deterioration in the blood flow to the smaller baby, but each time it improved at the following scan. In the end I made it to 35+6 before the babies were delivered by planned Caesarean section. Rachel weighed 6 lbs 4 oz and Sarah weighed 3 lbs 14 oz. Despite the fact that they were identical twins, they didn’t look alike at all due to the big weight difference. Rachel spent just one night in NICU being monitored, then she was on the ward with me and went home with me on day 5. Sarah needed tube feeds and stayed in NICU/SCBU for 15 nights. We were so thrilled when she was able to come home, 2 weeks before her due date, and we were all together as a family.

Rachel and Sarah had a shaky start in life but they never looked back. They both grew quickly and although Rachel is still a centimetre taller and two pounds heavier, the difference between them is not noticeable at all and most people struggle to tell them apart. At four and a half, they are two of the happiest and healthiest little girls you could meet. In fact they are both very tall for their age and people constantly assume they are older than they are. They are the best of friends and are looking forward to starting school in September.
THE MIRACLE OF AVIA AND ELIA DOZA
ASNAT DOZA

Before I start to tell our TTTS story, I want to say that both our daughters survived and are progressing extremely well. They are a year old and they have already brought us great joy and happiness. We smile at them with amazement every morning, and they are the last thing we look at before we go to sleep. They are our very own miracle, and I doubt we will ever see anything more amazing!

TTTS was showing in our case on the first baby scan at week 11, and was originally mistaken as Down’s syndrome. A second scan by a senior consultant a few days later confirmed TTTS. Our centre was very much aware of the syndrome and immediately booked us a series of weekly scans. We were offered to terminate the pregnancy since the chances of positive pregnancy outcome were lower than average. But the consultant suggested that no-one can tell how this pregnancy will develop. The situation stayed stable for a further seven weeks. Every scan showed slight changes in the TTTS, but it was still only monitored and no action was required.

Early in week 18, we were told that the water pools had changed dramatically and the level of TTTS was changed to level 2. We were very upset. Further tests that afternoon revealed that the deterioration suggested level 3 TTTS and that an intervention was now imminent. Our centre could no longer support our case and so we were referred to Queen Charlotte’s Hospital in London for a laser ablation.

The weekend between the scan and the laser ablation was the worst weekend of our lives. Our household which is normally a happy noisy place became very quiet. Anxiety was in the air. We all had many things to organise - babysitters for the children we would leave behind, food and instructions to friends who
we had something to eat anyway. The husband and I had no appetite, but in a nearby shopping centre. Both my husband and I had no appetite, but we had something to eat anyway. The operation took 32 minutes. We saw everything on the screen and the whole process seemed like it was out of a science fiction movie. 45 minutes later we were told both babies survived the operation and that the TTTS seemed to be improving. It was delightful news. The following morning the donor baby was seen moving during the scan. She was ‘unstuck’ and in a pool of water. While we were delighted, it was clear we are not out of the woods yet. Many things could still go wrong.

Queen Charlotte’s released us a week later, and we were followed by our local centre for the rest of the pregnancy. There was a high risk of miscarriage in the following six weeks, so I decided on bed rest. Even though some consultants suggested it would make no difference, I felt I had to try and do something. TTTS seemed to have been resolved, but the donor baby had a lot of catching up to do.

On week 26 I was hospitalised with bleeding and water leakage. It was a nightmare. TTTS, even though it was resolved, meant the babies were unlikely to be viable. Somehow we all kept positive, but looking back at ourselves I can’t quite understand how we managed.

The babies chose to arrive at week 28 + 7 hours. It was an emergency caesarean. Avia the ex-recipient was born 2 pounds 14 ounces and Elia the ex-donor was only 1 pound 14 ounce. A dear friend described it as: “less than a bag of sugar”. Look at them now!
Our first scan was at 12 weeks. The sonographer immediately told us we had ‘two for the price of one’! She referred us to a consultant there and then. The consultant told us that as we had identical twins, it would be a high risk pregnancy and that there was a possibility of complications. She explained that we would have far more scans and checkups than a standard pregnancy. She booked us in for our next scans at 16 weeks, 18 weeks, 20 weeks and 22 weeks, as well as coordinating follow-ups with consultants. All was fine until we went for our 20 week anomaly scan and we thought our biggest decision at that point was to find out if we were having boys or girls! As she scanned the babies, she said there was quite a difference in size, that there had been a slight difference two weeks ago, but now the difference in size had become quite significant and this could be an indication of Twin to Twin Transfusion Syndrome (TTTS). After the scan, the consultant explained to us what TTTS was and we understood that it meant our babies’ lives were at risk. She said she would need to refer us to Kings College Hospital to see the experts who would confirm for sure that we had TTTS. Kings confirmed that we did have severe TTTS and qualified for laser surgery. The doctor told us that our twins each had a 30% chance of survival.

"Try not to focus too much on the statistics and possible outcomes, take each day at a time."
Our first scan was at 12 weeks. The sonographer immediately told us we had ‘two for the price of one’! She referred us to a consultant there and then. The consultant told us that as we had identical twins, it would be a high risk pregnancy and that there was a possibility of complications. She explained that we would have far more scans and checkups than a standard pregnancy. She booked us in for our next scans at 16 weeks, 18 weeks, 20 weeks and 22 weeks, as well as coordinating follow-ups with consultants.

All was fine until we went for our 20 week anomaly scan and we thought our biggest decision at that point was to find out if we were having boys or girls! As she scanned the babies, she said there was quite a difference in size, that there had been a slight difference two weeks ago, but now the difference in size had become quite significant and this could be an indication of Twin to Twin Transfusion Syndrome (TTTS).

After the scan, the consultant explained to us what TTTS was and we understood that it meant our babies’ lives were at risk. She said she would need to refer us to Kings College Hospital to see the experts who would confirm for sure that we had TTTS. Kings confirmed that we did have severe TTTS and qualified for laser surgery. The doctor told us that our twins each had a 30% chance of survival and the highest risk at this stage was perishing during surgery or miscarriage following the procedure, most likely within the first week. We had to sign a disclaimer that removed all blame from the hospital if the procedure failed and our babies died. I was given three forms of painkiller, a suppository, an oral and a local anaesthetic, but the tube which was forced through my skin was fairly large (it had to be big enough to get the laser and a camera though). It was fed into the fluid sack that the biggest twin was in and we were able to watch on a screen as he moved the camera round. We saw both our babies from the inside which is a view most parents don’t get to see!

We also watched as he severed the blood vessels that joined our twins. There were 12 in our case and one of them was a very large one. He was very good at trying to put me at ease during the procedure, making jokes about the quality of the food from the hospital café and asking if I wanted him to cut the twins’ toenails while he was in there! His assistants then drained 1.5 litres of fluid from around the bigger twin, which made my stomach feel far less stretched! We then had to wait in a side room for a few hours, after which point they scanned me again and said the babies were still alive, although I was still bleeding from the wound, so they asked me to stay for a little while longer to make sure the bleeding stopped. It was a very long day and a very worrying time! We had arrived about 9.30 that morning and didn’t leave until after 7pm!

We returned to Kings the following week and they were able to tell us that both babies were still alive and twin 1 had some fluid round him and was beginning to grow again! We were very grateful for the good news! We were warned it was likely they would arrive early. Our milestone was to get to 30 weeks and every week after that would be a bonus. We continued to have weekly scans at Kings until 30 weeks, at which point I was referred back to my local hospital. Occasionally, after that, my local hospital would ask me to go and get scanned at Kings again, as they wanted a second opinion that they were still growing ok, given the circumstances.

I was told to give up work at 28 weeks in order to rest and keep my feet up as much as possible in order to try to prevent premature delivery. I had to go to the hospital for fetal heart monitoring twice a week from about this time. I was also
given steroid injections at 31 weeks to mature the babies’ lungs in case they arrived early.

At 35 weeks (on a Monday) my consultant said he thought it was time we delivered the babies and he booked me in for a caesarean the following Monday. Although Kings had said they thought all the joining vessels had been severed so it was probably safe to deliver vaginally if I wanted, my local hospital was not happy to do this.

In the week leading up to delivery, I had an appointment at the hospital to attend almost every day, which I thought was funny because I had been told to rest as much as possible! On my next appointment for fetal heart monitoring (Wednesday), twin 2’s heart rate dipped so I was admitted immediately. It felt like the start of the end! The doctors decided that as long as twin 2’s heart rate did not dip any more, they would continue with the plan to deliver on the scheduled date but keep me in hospital until then. We did not know it at the time but it seems twin 2 had stopped growing and this gave twin 1 time to catch up on his size!

While in hospital, I was given twice-daily fetal heart monitoring and all was fine until the evening before my scheduled caesarean. At 9pm, just as my husband was planning on going home for his last night sleep as a man without any parental responsibilities, my waters broke!!

The hospital was very busy that night and they told my husband they wanted to move me to Brighton hospital, but he would not allow them to. I was not aware of this at the time! They told us that the babies would be taken straight to SCBU after they were born to make sure they were ok. I was surprised at this, as I had been led to believe that if they were born after 34 weeks they would not need any special care.

Joshua and Matthew were delivered just before midnight weighing 4.4lb and 4.6lb. There were no complications. Because there was another emergency caesarean needed in the room next door, we were allowed to hold the boys for nearly an hour after they were born. The result of this was that they needed a glucose drip when they got to SCBU because they had got cold. They spent 9 days in SCBU before coming home.

They are 18 months old now and are normal toddlers with no obvious difference in size! The advice I would give to other parents is to ask doctors for as much information as they can give you, try not to focus too much on the statistics and possible outcomes, take each day at a time and expect that they will need special care, even if it’s only for a few days. It is all worth it!
given steroid injections at 31 weeks to mature the babies' lungs in case they arrived early.

At 35 weeks (on a Monday) my consultant said he thought it was time we delivered the babies and he booked me in for a caesarean the following Monday. Although Kings had said they thought all the joining vessels had been severed so it was probably safe to deliver vaginally if I wanted, my local hospital was not happy to do this.

In the week leading up to delivery, I had an appointment at the hospital to attend almost every day, which I thought was funny because I had been told to rest as much as possible! On my next appointment for fetal heart monitoring (Wednesday), twin 2's heart rate dipped so I was admitted immediately. It felt like the start of the end! The doctors decided that as long as twin 2’s heart rate did not dip any more, they would continue with the plan to deliver on the scheduled date but keep me in hospital until then. We did not know it at the time but it seems twin 2 had stopped growing and this gave twin 1 time to catch up on his size!

While in hospital, I was given twice-daily fetal heart monitoring and all was fine until the evening before my scheduled caesarean. At 9pm, just as my husband was planning on going home for his last night sleep as a man without any parental responsibilities, my waters broke!!

The hospital was very busy that night and they told my husband they wanted to move me to Brighton hospital, but he would not allow them to. I was not aware of this at the time! They told us that the babies would be taken straight to SCBU after they were born to make sure they were ok. I was surprised at this, as I had been led to believe that if they were born after 34 weeks they would not need any special care.

Joshua and Matthew were delivered just before midnight weighing 4.4lb and 4.6lb. There were no complications. Because there was another emergency caesarean needed in the room next door, we were allowed to hold the boys for nearly an hour after they were born. The result of this was that they needed a glucose drip when they got to SCBU because they had got cold. They spent 9 days in SCBU before coming home.

They are 18 months old now and are normal toddlers with no obvious difference in size! The advice I would give to other parents is to ask doctors for as much information as they can give you, try not to focus too much on the statistics and possible outcomes, take each day at a time and expect that they will need special care, even if it's only for a few days. It is all worth it!

“They are our very own miracle, and I doubt we will ever see anything more amazing!”

Asnat Doza
Now 16 months old, the girls are in perfect health and not a day goes by when I don’t think about how lucky they were to even survive.

Hayley Jeans

My boys are doing so well now; it’s hard to believe I nearly lost them.

Joanne Venn

The girls are continuing to do amazingly well, are very healthy and content babies.

Sarah and Ian Hills
“We would recommend to anyone expecting multiples that they request a tour of their local Neonatal Unit – if you don’t end up there, great, but if you do at least you will be slightly more prepared.”

Heather and Paul Maber
LIST OF HOSPITALS CONDUCTING LASER SURGERY

This list is based on the best information available at the time of publication. If you are concerned and would like to know where your nearest hospital is that conducts laser surgery.

LIVERPOOL WOMEN’S HOSPITAL
Fetal Medicine Unit
Tel: 0151 708 9988
www.lwh.me.uk/html/fetal.php

ROYAL VICTORIA INFIRMARY, NEWCASTLE UPON TYNE.
Department of Fetal Medicine
Tel: 0191 2825836/7
www.newcastle-hospitals.org.uk

THE HARRIS BIRTHRIGHT RESEARCH CENTRE
Tel: 020 3299 9000
www.kch.nhs.uk/services/womens-services/harris-birthright-centre/

QUEEN CHARLOTTE’S & CHELSEA HOSPITAL
Tel: 020 8725 1911
fmu@sghms.ac.uk

THE WEST MIDLANDS FETAL MEDICINE CENTRE
Edgbaston
Birmingham B15 2TG
Tel 0121 627 2683
www.bwhct.nhs.uk/fetalmedicine-home/fmc-aboutus.htm

FETAL MEDICINE UNIT, ST GEORGE’S HOSPITAL
Department of Obstetrics and Gynaecology
Tel: 020 8725 1911
fmu@sghms.ac.uk

FETAL MEDICINE UNIT, BRISTOL
Tel: 0117 342 5470

THE IAN DONALD FETAL MEDICINE Department, Glasgow
[As of September 2010, the TTTS laser service is in the planning stages and not yet available]

WHERE TO GET FURTHER SUPPORT

THE TWINS AND MULTIPLE BIRTHS ASSOCIATION (TAMBA)
The Manor House, Church Hill, Aldershot, Hampshire, GU12 4JU
Admin: 01252 332344
Twinline: 0800 138 0509
www.tamba.org.uk

MULTIPLE BIRTHS FOUNDATION
Hammersmith House, Level 4, Queen Charlotte’s and Chelsea Hospital, Ducane Road, Hammersmith, London, W12 0HS
Telephone: 020 3313 3519
www.multiplebirths.org.uk

BLISS (for babies born too soon, too small, too sick)
9 Holyrood Street, London, SE1 2EL.
Family Support Helpline (freephone): 0500 618 140
www.bliss.org.uk

STILLBIRTH AND NEONATAL DEATH SOCIETY (SANDS)
28 Portland Place, London, W1N 4DE
Telephone: 020 7436 5881 (9.30am – 5.30pm Monday to Friday; and 6pm-10pm Tuesday and Thursday)
www.uk-sands.org

RECOMMENDED READING

www.multiplebirths.org.uk/


Twin-To-Twin Transfusion Syndrome: Parents’ Stories
www.tamba.org.uk/TTTS


www.tamba.org.uk

Twin-To-Twin Transfusion Syndrome: Bereavement Stories
www.tamba.org.uk/bsg

Twin-To-Twin Transfusion Syndrome:
www.tamba.org.uk

Twin-To-Twin Transfusion Syndrome: Bereavement Stories
www.tamba.org.uk/bsg


www.tamba.org.uk

Twin-To-Twin Transfusion Syndrome: Bereavement Stories
www.tamba.org.uk/bsg
LIST OF HOSPITALS CONDUCTING LASER SURGERY

This list is based on the best information available at the time of publication. Please talk to your doctor or midwife if you are concerned and would like to know where your nearest hospital is that conducts laser surgery.

LIVERPOOL WOMEN’S HOSPITAL
Fetal Medicine Unit
Crown Street, Liverpool, L8 7SS,
Tel: 0151 708 9988
www.lwh.me.uk/html/fetal.php

ROYAL VICTORIA INFIRMARY, NEWCASTLE UPON TYNE.
Department of Fetal Medicine
Queen Victoria Road
Newcastle upon Tyne, NE1 4LP
Tel: 0191 2825836/7
www.newcastle-hospitals.org.uk

THE HARRIS BIRTHRIGHT RESEARCH CENTRE
King’s College Hospital
Denmark Hill
London SE5 9RS
Tel: 020 3299 9000
www.kch.nhs.uk/services/womens-services/harris-birthright-centre/

QUEEN CHARLOTTE’S & CHELSEA HOSPITAL
Du Cane Road
London W12 0HS
www.imperial.nhs.uk/qcch/index.htm

THE WEST MIDLANDS FETAL MEDICINE CENTRE
Birmingham Women’s Hospital Mackley
Park Road
Edgbaston
Birmingham B15 2TG
Tel 0121 627 2683
www.bwhct.nhs.uk/fetalmedicine-home/fmc-aboutus.htm

FETAL MEDICINE UNIT, ST GEORGE’S HOSPITAL
Department of Obstetrics and Gynaecology
St. Georges Hospital
Blackshaw Road
London SW17 0QT
Tel: 020 8725 1911
fmu@sghms.ac.uk

FETAL MEDICINE UNIT, BRISTOL
St Michaels Hospital
University Hospitals Bristol
Tel: 0117 342 5470

THE IAN DONALD FETAL MEDICINE Department, Glasgow
[As of September 2010, the TTTS laser service is in the planning stages and not yet available]
The Southern General Hospital,
1345 Govan Road,
Glasgow G51 4TF.
Tel: 0141 232 4339

WHERE TO GET FURTHER SUPPORT
MULTIPLE BIRTHS FOUNDATION
Telephone: 020 3313 3519
www.multiplebirths.org.uk

BLISS (for babies born too soon, too small, too sick)
™
0500 618 140
www.bliss.org.uk

STILLBIRTH AND NEONATAL DEATH SOCIETY (SANDS)
Telephone: 020 7436 5881 (9.30am – 5.30pm Monday to Friday; and 6pm-10pm Tuesday and Thursday)
www.uk-sands.org

RECOMMENDED READING
www.multiplebirths.org.uk/
www.tamba.org.uk
www.tamba.org.uk/TTTS/
www.tamba.org.uk/bsg
Twin-To-Twin Transfusion Syndrome:
www.tamba.org.uk
Twin-To-Twin Transfusion Syndrome: Bereavement Stories
www.tamba.org.uk
ACKNOWLEDGEMENTS

We would like to thank all the parents who have shared their experience of Twin-to-Twin Transfusion Syndrome (TTTS), not only those who are quoted, but equally those whose experiences have informed this booklet and whose stories appear in an accompanying booklet of parents’ stories available on Tamba’s website.

These parents are: Stuart and Jo Laidlaw, Heather and Paul Maber, Michelle and Cormac Cassells, Asnat Doza, Sarah and Ian Hills, Rebecca Green, Natasha Fitzmaurice, Joanne and Jason Venn, Claire and Nick van As, Hayley Jeans, Sarah Devons, Emma Richards, Nicola and Gareth Keymer, Debbie Whips, Geoff and Christy Siseman, Katrina Rowan-Wilde, Abby and Steven Cole, Helen and David Willcox, Karen Lintern and Amanda Dunworth.

Thanks also to the following contributors for providing ideas, suggestions and corrections on the drafts of this guide:

Sandra Bosman  Multiple Births Specialist, Midwife, RVI  Newcastle and UK Midwife of the Year 2007
Dr Leanne Bricker  Consultant in Fetal and Maternal Medicine,  Co-Director of the Fetal Medicine Unit, Liverpool Women’s NHS Foundation Trust
Carol Clay  Tamba’s Twinline and Supports Group Coordinator
Margie Davies  Multiple Births Foundation, Midwifery Advisor
Jane Denton  CBE Multiple Births Foundation, Director.
Helen Lalji  Multiple Births Foundation
Judi Linney  MBE, Director of Public Health, Midwife and Health Visitor, Tamba President and mother of twins
Professor Jim Neilson  Professor of Obstetrics & Gynaecology, University of Liverpool, Co-author of the Royal College of Obstetricians and Gynaecologists’ (2008) Green Top Guidelines on the ‘Management of Monochorionic Twin Pregnancies’
Keith Reed  Tamba Chief Executive.
Debbie Ross  Tamba Membership and E-Resources Manager

The Twins and Multiple Births Association (Tamba) is a charity set up by parents of twins, triplets and higher multiples and interested professionals in 1978. It is the only UK wide organisation that directly helps parents and professionals to meet the unique challenges that multiple birth families face.

It undertakes research, campaigns and provides information and support to over 10,000 members and supporters each year. Our work is funded through membership fees, fundraising activities and the delivery of our services. You can download our latest Annual Report and Accounts for 2009-10 now (pdf doc).

Charity Number 1076478, Scottish Charity Number SC041055, Registered Company Number 3688825
THE MANOR HOUSE, CHURCH HILL, ALDERSHOT, HAMPSHIRE, GU12 4JU
TEL: 01252 332344

Whilst every care is taken in providing information, please note that it is of a general nature and that readers should seek professional or expert advice as appropriate to specific circumstances. Tamba does not accept any liability, including liability for any error or omission.
ACKNOWLEDGEMENTS

We would like to thank all the parents who have shared their experience of Twin-to-Twin Transfusion Syndrome (TTTS), not only those who are quoted, but equally those whose experiences have informed this booklet and whose stories appear in an accompanying booklet of parents' stories available on Tamba's website.

These parents are: Stuart and Jo Laidlaw, Heather and Paul Maber, Michelle and Cormac Cassells, Asnat Doza, Sarah and Ian Hills, Rebecca Green, Natasha Fitzmaurice, Joanne and Jason Venn, Claire and Nick van As, Hayley Jeans, Sarah Devons, Emma Richards, Nicola and Gareth Keymer, Debbie Whipps, Geoff and Christy Siseman, Katrina Rowan-Wilde, Abby and Steven Cole, Helen and David Willcox, Karen Lintern and Amanda Dunworth.

Thanks also to the following contributors for providing ideas, suggestions and corrections on the drafts of this guide:

Sandra Bosman
Multiple Births Specialist, Midwife, RVI
Newcastle and UK Midwife of the Year 2007

Dr Leanne Bricker
Consultant in Fetal and Maternal Medicine,
Co-Director of the Fetal Medicine Unit, Liverpool Women's NHS Foundation Trust

Carol Clay
Tamba's Twinline and Supports Group Coordinator

Margie Davies
Multiple Births Foundation, Midwifery Advisor

Jane Denton
CBE Multiple Births Foundation, Director.

Helen Lalji
Multiple Births Foundation

Judi Linney
MBE, Director of Public Health, Midwife and Health Visitor, Tamba President and mother of twins

Professor Jim Neilson
Professor of Obstetrics & Gynaecology,
University of Liverpool, Co-author of the Royal College of Obstetricians and Gynaecologists' (2008) Green Top Guidelines on the 'Management of Monochorionic Twin Pregnancies'

Keith Reed
Tamba Chief Executive.

Debbie Ross
Tamba Membership and E-Resources Manager

The Twins and Multiple Births Association (Tamba) is a charity set up by parents of twins, triplets and higher multiples and interested professionals in 1978. It is the only UK wide organisation that directly helps parents and professionals to meet the unique challenges that multiple birth families face.

It undertakes research, campaigns and provides information and support to over 10,000 members and supporters each year. Our work is funded through membership fees, fundraising activities and the delivery of

Whilst every care is taken in providing information, please note that it is of a general nature and that readers should seek professional or expert advice as appropriate to specific circumstances. Tamba does not accept any liability, including liability for any error or omission.