

**Antenatal
Results &
Choices**

**Twins trust.
Bereavement
Service**

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



TERMINATION FOR MEDICAL REASONS

specific to twins and multiples



FOREWORD



Twins Trust has partnered with Antenatal Results and Choices (ARC) to produce this booklet. A huge thank you to Dr Surabhi Nanda, Consultant in Maternal Fetal Medicine at Guy's and St Thomas' and Clinical Trustee at Twins Trust, for her contribution.

A note on the language we use in this booklet

We acknowledge that you may be pregnant with twins or triplets, but we may refer to twins in this booklet to include all multiple pregnancies.

We use the terms baby, babies and parents throughout this information. This is because most people who contact us use these words. However, we know they don't feel right to everyone. If you contact us for information or support, we will take the lead from you in what language you prefer.

We understand that the word termination can sound harsh and clinical to some people. However, it is the correct medical term, so we have chosen to use termination throughout this booklet.

We know that Termination For Medical Reasons (TFMR) in twins is complex and it's hard to cover

every scenario, but we have tried to be as inclusive as possible.

We acknowledge that everyone will cope in different ways and hope you will find the information useful, but we realise that you may need to choose which information and support is helpful to you personally.

Selective reduction is a medical term you might hear to describe TFMR in twin and multiple pregnancies. Selective feticide may also be a term that you find difficult to hear but it is the terminology that some health professionals use and might be found in other literature.

If you are reading this booklet in regards to selective reduction of a triplet multiple birth pregnancy, not for medical reasons, you will find information here on the Twins Trust website: twinstrust.org/selective-reduction

INTRODUCTION



Finding out that you are pregnant with twins, triplets or more can be a time of conflicting emotions. The excitement and joy are often mixed with concerns about the practicalities of a multiple pregnancy and consequently, worries about the increased risks for the mother and the babies. Parents can often feel scared and sometimes overwhelmed by these prospects.

Modern fetal medicine can enable parents to find out more about the type of multiple pregnancy they are carrying; for instance, whether they are identical or non-identical and whether they share the same placenta (monochorionic) or not (dichorionic) and whether they are in the same amniotic sac.

This information is important as it can provide doctors with an insight into how great the risks of the pregnancy are, and any management options available to deal with any potential problems which may arise.

There is also the possibility that scans, or other tests, may show that one or more of your babies is not developing as expected. As a result, you may be presented with the option to have a Termination For Medical

Reasons (TFMR) of one or more of your babies. We know this can be a very distressing and confusing time as you consider your next steps.

We hope this booklet will help you to understand more about what might be involved when TFMR is offered in a multiple pregnancy. It is not designed to replace detailed conversations with your healthcare team, as each case will be unique.

It is very important that you are cared for by fetal medicine specialists who have expertise and experience in dealing with complicated twin pregnancies and related procedures.



I was pregnant with non-identical twins, a much-wanted pregnancy, and at the 20-week scan severe anomalies were found in one twin, the other looked healthy. With one sentence from the sonographer, your life changes forever. It's hard to describe the shock."



We first had TFMR mentioned to us when I was 16 weeks' pregnant. Thomas was very very small, low fluid, with brain and heart abnormalities. Triploidy was suspected. I was so shocked by how casually the doctors mentioned it and the terms that they used were so clinical. They were telling me that one of my much-wanted babies was not going to survive and the weight of that didn't seem to register with them."

THE IMPACT OF UNEXPECTED OR DIFFICULT NEWS



If you have just been given the difficult news that you may need to consider a TFMR in your twin pregnancy, we are sorry. It is not a situation that is spoken or heard about much and you may feel very alone. In the world of baby loss, it is an area which is often overlooked and yet it is something that thousands of parents face every year. We hope that this booklet will provide you with helpful information about what might be ahead if you decide to have a TFMR.

Going in for a scan happy and excited, then receiving the news of a condition in one or both of your twins or triplets can be very shocking. Suddenly your pregnancy is going

in a very different and difficult direction. For many parents/families, finding out that a condition may have an impact on your baby's/babies' chances of survival or quality of life can be devastating news. It can be very distressing to confront the possibility of TFMR. However, not everyone feels like this: there is no right or wrong and you may find yourself with lots of conflicting emotions.

Some of the information in this booklet might be difficult to read, but our hope is that it may help to prepare you (both physically and emotionally) for what lies ahead. You may already have feelings of grief at losing your healthy twin pregnancy.



“

I walked into my appointment as one person and walked out as someone forever changed. Those walls changed me. All of my hopes and dreams for my twins were dashed in a moment, when a Fetal Medicine consultant sat me down and delivered the grim diagnosis for my much-wanted and loved Baby B. Her diagnosis was poor; and her prognosis was even worse. In that moment, the floor opened up beneath me and I fell even lower than rock bottom. Grief came pouring out of me immediately.”

“

There is nothing that can prepare you for the huge amount of information that comes your way in these complex situations, and it is so unbelievably overwhelming. I just remember feeling like my head was going to explode. I found it really hard to think straight, the emotion was too much at times. It was such an awful mix of shock, sadness and anger... Why me? I just wanted it all to go away.”

TERMINATION FOR MEDICAL REASONS – THE LAW

Regarding your options around TFMR, it can be important to be aware of time limits set down in law.

The Abortion Act 1967 (as amended in 1990) sets out the gestational time limit for most terminations of pregnancy of 24 weeks. The only terminations that can happen after 24 weeks are when the woman's life is in danger or when there is a prenatal diagnosis of a serious condition in an unborn baby or babies.

Two doctors must agree that the condition

diagnosed is serious enough to allow them to offer a termination of pregnancy.

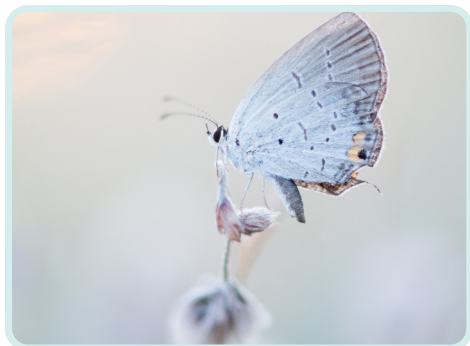
Very occasionally after 24 weeks, a doctor may refuse to offer termination even when the parents involved feel it is the best option for them in their circumstances. If this happens, the doctors must enable parents to get a second opinion. This can be very distressing – Antenatal Results and Choices can provide emotional support in this situation.

TFMR – MAKING THE DECISION



Ending a much-wanted twin pregnancy for both twins or one twin can be a distressing and painful prospect. You had prepared to be a parent to two or more living babies and the idea that this now won't be the case can be hard to come to terms with. It is important that you gather as much information as you can about the condition affecting your twin(s) from expert professionals.

There may be many reasons where the option of TFMR is given as a part of ongoing care for your twin pregnancy. This may be because a physical condition has been suspected or found on a scan, or because a



chromosomal or genetic condition has been diagnosed through genetic testing. You may need to see a team of specialists that could include fetal medicine specialists, neonatologists, paediatric specialists, and geneticists. Sometimes you may be advised to terminate one twin to give the other twin the best chance of survival. Your medical team will give you as much information as they can about the outlook for your baby or babies. Sometimes it can be impossible for them to be certain about what will happen after birth. We know it can be especially difficult to make a decision when there is uncertainty. Only you know what is the best decision for you in your individual family circumstances and in that moment in time. Talking it through with the medical team, possibly getting second opinions and discussing it with family or friends can help. It can also help to talk to someone independent at Twins Trust or ARC. Twins Trust can arrange for you to talk to someone who also had a TFMR during a twin pregnancy. Once you have gathered the information and balanced the risks, you may decide not to have a TFMR.



We didn't have a definite '100% this will happen' diagnosis for our babies. For us we were told there was a high chance they would both either be severely disabled or not make it through pregnancy, but there also was that chance they could have been okay. It would have helped me at the time to know others had to make that decision based on percentages and likelihoods. The fact that we were having twins just made it even harder still as it wasn't just one life, but two that this would impact."

TFMR – WHAT MIGHT THIS INVOLVE?



► When BOTH twins have a condition

If both babies are affected by a condition and you decide to end the pregnancy, depending on your gestation, there are usually two methods of termination available.

Surgical termination

Most NHS hospitals can offer a surgical procedure under general anaesthetic up until 13-14 weeks of pregnancy but very few can perform them at later gestations. When an NHS hospital cannot offer a surgical procedure, you should be able to access this free of charge in an independent provider clinic up until 23⁺⁶ weeks.

The providers who offer terminations under NHS contract are:

BPAS: www.bpas.org,

MSI: www.msichoice.org.uk

NUPAS: www.nupas.co.uk.

A surgical termination is carried out using suction or other surgical methods depending on the stage of the pregnancy. It is important to know that the babies are not removed intact so you will not be able to see or hold the babies afterwards. If post-mortem examination of the babies is recommended by specialists after termination, this is not possible with the surgical method.

Medical termination

This method involves a medical induction of labour. It is a two-stage process, initially you will be given drugs to

prepare her body and then, later, to induce labour. The first set of drugs is given to you 48 hours before you are admitted to hospital for the induction of labour and birth of your babies.

If you are more than 21⁺⁶ weeks pregnant (Royal College of Obstetricians & Gynaecologists' Guidance) there is an additional procedure you will be offered to make sure the babies are not born showing signs of life. This involves the babies being given an injection to stop their heart and is performed by a fetal medicine specialist. The medical name for this procedure is feticide. If this service is not provided in your unit, you may be referred to the nearest tertiary fetal medicine unit. After the procedure, you will be given medication to induce (or bring on) labour and will usually be admitted to give birth 48 hours later in your local hospital.

While it is important that you are able to choose which termination method you are best able to cope with, sometimes you may be advised to consider medical termination if a full post-mortem of your babies might provide information that could be important for future pregnancies.

You can find more detailed information on methods of termination here:

www.arc-uk.org/for-parents/ending-a-pregnancy

► When ONE twin has a condition

You may be considering a selective termination because one of your twins has been diagnosed with a structural or genetic condition or there is a complication in the multiple pregnancy affecting one of the babies. Your fetal medicine specialists will discuss with you how your care might best be managed to minimise any harm to the unaffected twin. In this case you will not be able to have a surgical procedure.

You may hear language such as selective feticide or selective reduction used by your healthcare team.

The timing of selective termination

Your fetal medicine doctors will talk to you about when it might be safest to have the procedure, depending on your unique situation. If the diagnosis has been made earlier in pregnancy (perhaps after results from a 12-week scan or a CVS) the doctors will probably suggest it is done as soon as possible. Sometimes if the diagnosis comes after the 20-week anomaly scan, they may talk to you about waiting until 32 weeks in order to reduce the risk of miscarrying the non-affected twin at a time when it is unlikely to survive, however in monochorionic twins this may not be possible. Your Fetal Medicine Specialist will give an idea of

the risk of miscarriage or very early delivery associated with selective termination at various stages in pregnancy.

It can be very difficult emotionally having to wait some weeks for the procedure. Remember ARC and the Twins Trust are available for support. And your healthcare team will help you prepare for the birth of both babies and talk about your memory making options for the twin that has died.

What does a selective termination involve?

The process of selective termination depends on the kind of twin or triplet pregnancy. You would be referred to fetal medicine specialists with expertise in looking after complicated twin pregnancies for this procedure.

In non-identical twins the Fetal Medicine Specialist will inject the twin, who has been diagnosed with a condition, with a drug to stop the heart. The medical term you may hear for this injection is feticide. This is done under continuous ultrasound guidance.

In identical (monochorionic) twins, selective termination is performed when one baby is very sick and places the other in danger of death or permanent



I remember walking out of the first appointment at the tertiary hospital we had been referred to, with a leaflet called 'Selective Feticide'. Just looking at the name on the front of the leaflet made me feel sick. How could I even consider this for a baby I had wanted so much? I found some of the medical terminology so hard to stomach."

brain injury. In these cases, the best course of action may be to stop the blood supply to the sick baby in order to protect the healthy one. There are different technical procedures that your fetal medicine specialist may perform depending on your circumstances. You may hear terms such as Intra-fetal or interstitial laser, Radiofrequency ablation (RFA), Cord occlusion or ablation, Cord resection and Fetoscopic laser ablation and selective reduction. Don't be afraid to ask your doctors to explain exactly what is involved.

You will normally be able to go home the same day of the TFMR. It is advised that you speak to your healthcare team about what will happen with the baby that has died in utero in order to help prepare you with what might happen at the birth.

What are the risks of selective termination?

Depending on when the procedure is performed, the primary risk is miscarriage of the whole pregnancy.

In identical twins, there is a varying chance of compromise to the unaffected twin depending on the timing and the technique of the procedure. This may range from a 50% chance of death of the unaffected twin in cases like TRAP sequence with intra-fetal laser, to around

a 5-10% chance with radiofrequency ablation. Your fetal medicine clinician will guide you through what is the best procedure in your unique circumstances depending on the ultrasound findings, and the stage of pregnancy.

In non-identical twins, usually the fetal medicine specialist will offer the procedure before 16-18 weeks when possible. The chance of the miscarriage when the procedure is performed at this stage in pregnancy is around 8% above the background risk. This risk of miscarriage or very early labour can increase to around 15-20% if the procedure is offered mid pregnancy (beyond 18 weeks).

To prevent the chance of the unaffected baby being born dangerously early in pregnancy, some fetal medicine units will offer the procedure after 32 weeks. There is a variation in practice across the country, as legally two doctors must be in agreement for the procedure this late in a pregnancy.

If your doctors do not agree to perform the procedure at this stage, you are entitled to a second opinion. We acknowledge that this circumstance can be extremely distressing, and you can contact Twins Trust or ARC for support.



For the next several weeks, I was grieving the loss of my baby who was still very much alive. Every scan was so bittersweet: I was so happy to see my beautiful Baby B and tried to soak up every moment in seeing her because I also knew that she would be born sleeping. My grief was an avalanche, and it began with the diagnosis. It was swift and immediate; my heart had never experienced anything like it before and never will again."

“

At 16 weeks our Twin B was diagnosed with multiple anomalies that would lead to a very short and painful life. We made the difficult decision to have a selective reduction. However, to preserve our healthy Twin A, we would not have the procedure done until 31 weeks. Those 15 weeks in limbo were the darkest, loneliest time in my life. I was physically ill and mourning the loss of my baby who was still very much alive and growing inside of me. Every scan I attended was atrocious, admiring my beautiful baby while knowing her fate. It was something that is so profound that it is difficult to put into words.”

WHAT MIGHT HAPPEN AFTER SELECTIVE TERMINATION?

Birth, delivery, bereavement aftercare and follow up

We are aware that there is variation in care across the country. We are also aware that there are many different scenarios when it comes to twin pregnancies and the complications. We have tried to describe some of the scenarios you might expect but you may not find your exact situation here. Please ask your healthcare team any questions you have.

You will be sent home with some advice of what to expect physically and what to look out for including signs of labour. Mild discomfort or crampy abdominal pain is quite common, and you can take

paracetamol for this. If your waters break or you have bleeding or regular painful contractions, we would recommend you contact your nearest maternity unit. The chance of infection from the procedure to you is very low, and as such, this procedure is done as an outpatient (usually similar to your scans) and does not require antibiotics.

You will be invited for an ultrasound scan usually a week after the procedure to ensure the wellbeing of the unaffected twin. Depending on the scan findings, you may have further follow-up scans. Many units may continue to offer care under the twins' team.

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To begin with, I was terrified about what it might be like to see my baby who had died inside me, after he was born. But after speaking to someone else who had gone through a similar situation, I made the difficult decision that I wanted to see my baby. The overriding love and pride you feel for your baby/babies when they are born, even dead, is incredible.”

In the lead-up to the birth it can be very normal to feel anxious about giving birth to a baby or babies that have died.

Parents have told us about conflicting emotions at the time of birth, particularly if they have a surviving twin. It can be difficult to celebrate the birth of the unaffected twin and mourn the death of the other baby at the same time.

Depending on what gestation you had the procedure and the length of time to delivery following the procedure will affect how your baby will look. In some early cases there will not be a baby to see. In later gestation you

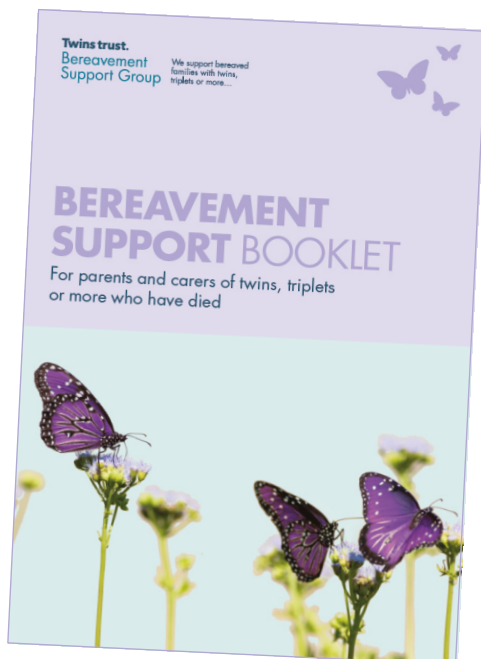
would give birth to both twins either vaginally or via caesarean section following a discussion with your healthcare team. There is no right or wrong in these situations. If you are unsure about seeing your baby you could ask for them to be wrapped in blankets to hold in your arms, or you could ask the midwives to take photographs to keep in your notes in case you change your mind about seeing them in the future. Depending on your individual circumstances your medical team may discuss post-mortem investigations with you, as some results may have an implication on future pregnancies.

Memory making and funeral arrangements

You can find lots of helpful information around memory making and funeral arrangements in Twins Trust's Bereavement Support Booklet: twinstrust.org/bsg-booklet

- Memory making – After your baby or babies die – some ideas: Page 18
- Arranging the funeral or memorial: Pages 29-32

Information is also available on the Twins Trust website here: twinstrust.org/memory-making



Certificates of birth

Baby loss certificates are available for free in England to anyone who has lost a baby, including those before 24 weeks of pregnancy (or 28 weeks if the loss was before October 1992).

You can choose whether or not to request one:

www.gov.uk/request-baby-loss-certificate

At Twins Trust we have certificates of birth available that you can download from our website: twins trust.org/birth-certificates



Paula Gallacher – Bereavement Midwife at the John Radcliffe Hospital, Oxford



We work very closely with our Fetal Medicine Unit who update us of all women who have a multiple pregnancy who are having to make difficult decisions due to the complex nature of the pregnancy. They are given the option to speak to a Bereavement Midwife prior to birth to discuss choices and options and talk through any questions they have. It is also reassuring for them to have a named contact and sometimes we would arrange to see them prior to birth to have those face-to-face personal contacts rather than just discussing over the

phone. Sometimes we can be present at the birth to support the family, especially if an elective date is given. We are able to then support with paperwork and legalities (if indicated) and memory making but this is very individualised based on the family's circumstances and wishes. We endeavour to make this time as memorable as we can so families can spend unlimited time with both babies in our dedicated bereavement suite in order to treasure this short but beautiful time with their new babies."

FOLLOW UP AND COUNSELLING

A few weeks after delivery you will be invited to discuss the events around your pregnancy and the reasons for TFMR with your consultant. In some cases, this will be relevant for planning the next pregnancy. You should continue to have ongoing support from the bereavement team; some units will offer additional support with

bereavement counselling and/or training psychologists. If there is a provision for this, the bereavement team should be able to share details.

If you want to explore access to private counselling the ARC helpline team can help you find someone who might be appropriate.

Twins Trust's Bereavement Service

At Twins Trust, our bereavement service supports parents, carers, and their families after the death of a twin, triplet or more, both during and after pregnancy. We have a befriending service which offers peer-to-peer support for those who have experienced a loss.

All of our **volunteers** are parents or grandparents who have experienced the death of their own babies or children that are twins, triplets or more. Some of our befrienders have themselves had a TFMR and we match according to experience.

We have a very active private **Facebook** group as well as a public page, Instagram and Twitter and we send out quarterly newsletters.

Our **bereavement booklet** which is available to download or as a hard copy contains personal experiences, including a TFMR story, information on coping with loss,



The Twins Trust TFMR monthly meetings help me connect with other mums that have/are going through such tragic circumstances like myself. It is a very safe space to talk where everyone understands how I feel."

supporting a bereaved parent, caring for a surviving baby and much more.

We also have **certificates of birth** that bereaved families can download for twins, triplets, individual baby, individual twins and individual triplets.

We have been holding regular **online group**

meetings for anyone who has experienced the death of a multiple, and specifically a monthly TFMR meeting.

Our **bereavement website**

twinstrust.org/bereavement-support includes many more bereavement resources and leaflets, a remembrance page where you can add a memorial for your baby or child, as well as details of any events and fundraising that are happening.

We do not want anyone to feel alone, so please contact us at any point if a TFMR is being considered.

A volunteer at Twins Trust's Bereavement Service

“ I am a volunteer for Twins Trust, and help facilitate some of the support groups too, especially the one specific to TFMR. I found it so incredibly helpful during my own loss and grief to have a volunteer, someone who just ‘got’ how I felt and understood all the crazy thoughts that go on in your head. My volunteer really gave me confidence and helped with ideas of how to remember my babies and how to talk to friends and family about what had happened to me. It also gave me hope for the future. I found the process of TFMR really isolating at the time, and back then, the support group didn’t exist. I think it is such an incredible option to have, to meet other women who have gone through the same life altering and devastating experience, to be able to talk openly, confidentially, and supportively. It is an honour to be able to help run these groups now, and I am happy to talk to anyone who feels it would help them through this extremely difficult time.”

Support with surviving twins

“ For me, I think when you lose a twin the grieving process is more protracted and drawn out. I’m not trying to take anything away from those who have lost one baby, it’s just that my grieving has to be done in between caring for my other baby.”

“ It is difficult to grieve for a lost twin. People seem to expect you to be so pleased that you have a baby that you should somehow get over it more quickly. I look at Joseph and although he is his own person, I also see one half of a pair and I think I will always see that.”



What **Antenatal Results and Choices** (ARC) can offer

ARC has been providing specialised information and support to parents given unexpected or difficult news in their pregnancy for over 30 years. We have a confidential helpline via phone or email (details below). Our small, trained helpline team are not medically trained but have a good overview of screening and diagnostic pathways and where the centres of excellence for fetal medicine are across the UK. We are also very used to the distress and difficult emotions that parents can experience when confronted with a prenatal diagnosis and painful decisions about the future of a pregnancy. We are familiar with the extra complexity parents face in a twin pregnancy. ARC can give you a safe containing place to help you gather information and work out your next steps.

ARC offers specialised support to those facing termination – for as long as is needed. Our bereavement services include online password protected forums, a network of trained peer support volunteers and a range of supportive publications.

ARC works closely with health care professionals and runs a well-established training programme to help equip staff to deliver high quality care through prenatal diagnosis and its consequences.

Helpline: Call (020) 7713 7486 or text 07908 683004 10am – 5.30pm Mon–Fri (evening service Tues and Thurs 8–10pm, please email to arrange call)

Email: info@arc-uk.org

Website: www.arc-uk.org

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TERMINATION FOR MEDICAL REASONS

Twins trust. **Bereavement Service**

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

 www.twinstrust.org/bereavement  bereavementsupport@twinstrust.org

Antenatal Results & Choices

 www.arc-uk.org  info@arc-uk.org

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