



**national bereavement
care pathway**
for pregnancy and baby loss

Scotland

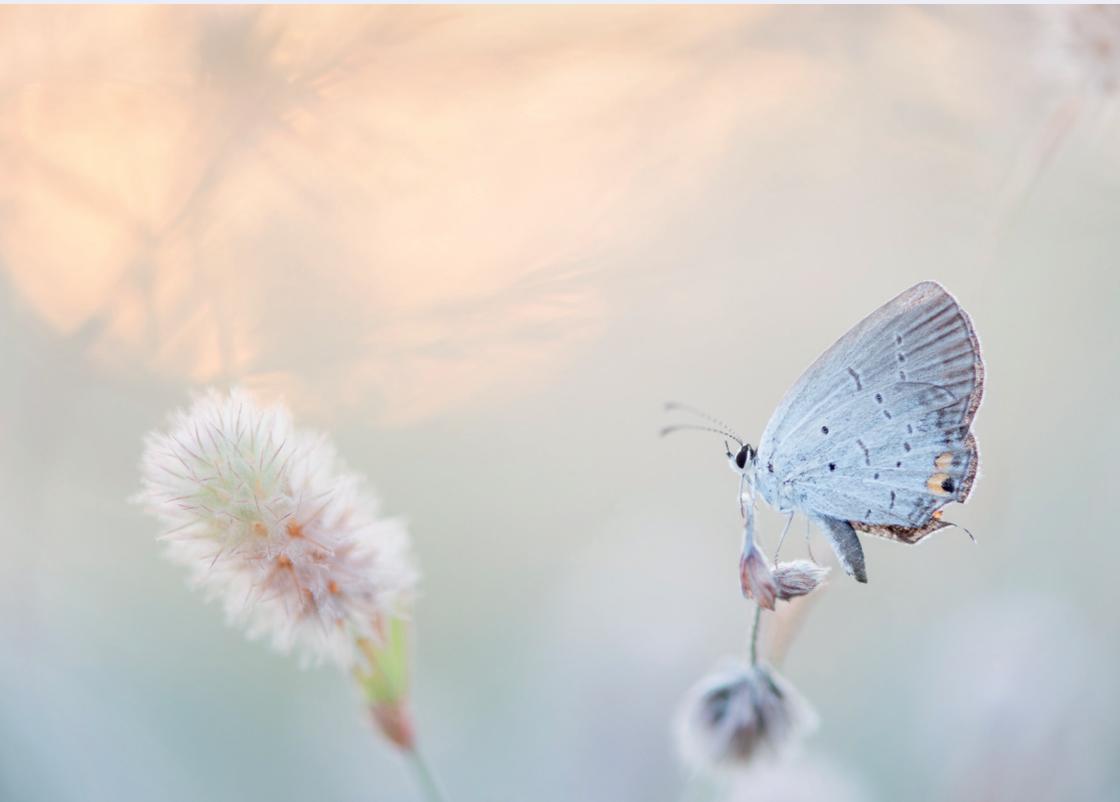


Twins trust.
**Bereavement
Service**

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

TWIN AND MULTIPLE BIRTH

Further Bereavement Care Guidance for Health Care Professionals



Introduction



Twins Trust Bereavement Service offers support to families who have experienced the death of a twin, triplet or more. You can find details of all of their support on their website.

This supplementary information has been written as a result of a Bereavement Care Report undertaken in January 2022, looking at bereavement care before, during and after pregnancy.

We aim to provide all of the specific twin and triplet material together to make it easier for health care professionals to access and find the relevant information.

We have created this guidance, focussing on the death of a baby or babies from a multiple pregnancy, to support the five existing

bereavement care pathways that make up the NBCP: SUDI, Neonatal Death, Stillbirth, TOPFA and Miscarriage, Molar and Ectopic Pregnancy.

The death of a twin, triplet or more can add a complicated layer to the grief, whether it is one or both twins or one or more babies from a multiple pregnancy.

Please read this guidance in conjunction with the relevant individual care pathway for the babies you are caring for. This provides greater detail that relates to both singleton and multiple pregnancies.

As with the singleton pregnancy guidance, continuity of care, parent-led care and consistency is vital for good bereavement care.



**This guidance has been created by
Twins Trust to support the five existing
bereavement care pathways**

Terminology

Throughout this guidance we are referring to twins, triplets and higher order multiples, but we may use the words twins and/or triplets throughout.

Miscarriage



When one baby has died and one baby is alive it is important to continue to refer to the pregnancy as a twin or triplet pregnancy and not to revert back to calling it a singleton pregnancy, as this can be very upsetting.

Some parents may be distressed about the idea of the dead baby remaining with any surviving baby or babies, conversely, other parents may find this thought comforting. It is also helpful to discuss with the parents how the baby that has died might look at the birth, depending on the gestation of the miscarriage. It is sometimes a regret from the parents, that they didn't see their baby or babies even if they are told the baby has deteriorated. It is important to be open and honest, but to let parents know that they can see their baby (if at all possible). Parents will often feel fearful for their surviving babies and may be worried that this will affect the pregnancy. Some parents will start grieving for their baby straight away while others will be unable to start grieving until after the birth.

At the time of breaking the bad news that one or more of the babies have died, additional time and care needs to be taken to discuss the care of the surviving baby or babies for the remainder of the pregnancy. Parents will often need greater support and reassurance throughout the rest of the pregnancy, and this is especially important if family and friends are focusing on the surviving baby and not really acknowledging their loss. Parents should be offered specialist bereavement

support if one baby has died. Twins Trust provide resources that may be helpful including a **bereavement support booklet** and they are also available to support parents before the birth of the surviving baby. Other charities such as **Sands** also offer support and resources. However, some parents may find that they are not ready to access this support, particularly if they are focusing on the surviving baby or babies.

“
When I went in for my c-section, my consultant made a point of making sure everyone knew I was pregnant with twins. It really made me feel validated.”

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died.

If both or all babies in the pregnancy have been miscarried, it will be important to discuss what will happen next and how the babies might look, depending on the gestation of the miscarriage.

Parents sometimes decide to name their babies or have nicknames for their babies from early pregnancy. This may help parents and their family to talk about their baby or babies in the future. (See Miscarriage Bereavement Care Pathway page 20.)

Termination of Pregnancy for Fetal Anomaly (ToPFA)



Twins Trust has partnered with ARC to produce a **Termination for Medical Reasons (TFMR) booklet** specific to twins and multiples, which is a very comprehensive guide that you may wish to look at.

It is important to recognise that if a TFMR is needed for one baby from a multiple pregnancy, it can impact the surviving twin or triplets, particularly if they are identical. The parents will need to be fully informed about all of the options available to them, including the risks to the surviving baby or babies. Parents will need to be given time to understand and make their decision, as it can be difficult to make it quickly due to the potential impacts to the surviving babies and can sometimes be a regret. The Twins Trust and ARC booklet covers this topic in much greater detail.

The parents should be informed about what the baby that has died will look like after

birth as well as what to expect for the remainder of the pregnancy, and staff should consider that some parents might find the thought of the dead baby in the womb distressing, others may find it comforting.

Parents may need guidance from staff with coming to terms with this: helping them to find comfort in something that seemed so unimaginable to begin with.

If the termination is to be carried out after 24 weeks' gestation, parents must also be told that they are required to register the stillbirth of the baby who has died. Once the TFMR has been carried out it is important to make all staff aware so that the rest of the pregnancy can continue without inappropriate comments or constant reminders to the staff caring for them about what has happened.

The Purple Butterfly sticker may be introduced at the time of the loss to help communication. It is important that staff are aware of the



We found out at 17 weeks that one of our twins had multiple health complications which if he were to survive the birth would cause an incredibly short and painful life. To save him that suffering we felt there was no option besides TFMR. We were asked do we want to do it straight away and risk going into early labour, putting our other twin at risk, or wait until 32 weeks knowing for four long months what was to come. Again, we felt there wasn't really a choice in these 'options'. In the end, I carried them both to 34 weeks and the procedure to end our baby's life happened just before their birth. It broke my heart, but I'll always be grateful I had the extra time to be with him, knowing he was safely cuddled up with his brother for so long."

significance of the 'Purple Butterfly' symbol and its meaning, posters should be displayed in prominent areas to alert people to the symbol. Please see the section below for more details.



I did find medical professionals I came across during the time I was still pregnant after he died were quite unsure of how to classify me. I had a phone call with one doctor when I had Covid and he asked me if this pregnancy was a twin pregnancy or if it was a previous pregnancy of mine. When I said I was pregnant with twins, but one had died, he said, so 'no' then. Doctors/midwives who knew my case always referred to it as a twin pregnancy. It was very important to me that it be acknowledged as a twin pregnancy."

It is important that staff acknowledge the importance of the baby (or babies) who have died and avoid focusing only on the surviving baby or babies

Staff should offer parents scan images of all the babies together, where possible. It may be helpful for any surviving siblings to see these images later on. It is also important to consider that bereavement support may be needed for a long time after the babies are born. Twins Trust bereavement group offers support after the TFMR of one or more babies from a multiple pregnancy, at any time. Parents sometimes decide to name their baby

or have a nickname for their baby from early pregnancy. This may help parents and their family to talk about the baby in the future.

Parents should be offered specialist bereavement support if one baby has died. However, some parents may find that they are not ready to access this support, particularly if they are focusing on the surviving baby or babies.

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died.

If the TFMR is for both twins or all triplets, it is important to explain the procedure and what the babies might look like depending on the gestation. Please refer to the memory making section for ideas for after they are born. The parents should also be told about support organisations such as Twins Trust and ARC, who can help with support at the time of the TFMR and afterwards.



We named Thomas before we named our survivor Grace. It felt important to give him an identity especially for the doctors and it was also a way of us building a bond with him during the pregnancy."

Stillbirth



Women expecting multiples are 2.25 times more likely to experience stillbirth than singletons according to the MBRRACE 2020 report.

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died. Some parents may not feel able to grieve until after their babies are born when they are able to say goodbye to the baby or babies who have died. They may also have been concerned that their grief would affect any surviving babies before the birth. Parents should be offered sensitive bereavement support if one baby has died, and another baby is still being cared for. Charities such as Twins Trust and Sands offer support and their details and/ or literature should be shared where possible. However, some parents may find that they are not ready to access this support, particularly if they are focusing on the surviving baby or babies.

Staff should acknowledge the baby who has died as well as any surviving babies as it can be difficult for parents if the focus is only on the surviving babies. Staff should also offer parents opportunities before, during and after the labour and birth to discuss how they are

feeling. It is important that staff should offer to gently describe to parents how the baby or babies may look after they are born. Many parents appreciate the chance to see their baby or babies even if their appearance has deteriorated or they have a visible anomaly. If parents want to see the baby or babies who have died, it may be helpful to see and perhaps hold the living and the dead babies together if this is possible, as well as to take family photos of all of the babies together.

Later on in their grief, the parents may value the memory of being with all their babies together. It is important to ensure that other ward staff are aware that the surviving baby or babies are part of a multiple birth. Health professionals should use all of the babies' names where

possible, including the baby that has died.

The Skye High Foundation provide butterfly stickers which can be placed on the surviving baby's/ babies' cots to indicate they are the sibling of one who died. Please see the section below for more details.

Special consideration is needed for the parents of twins or multiple babies. It is important that staff acknowledge the importance of the baby (or babies) who have died and avoid focusing only on the baby or babies that are alive.

As with all stillbirths, if both babies are stillborn, it will be a devastating time for the parents. They may still have been getting used to the fact that they were having twins



After losing Rayna there was a purple butterfly on my maternity notes. It meant a lot for the medical team to mention her name whilst caring for her surviving twin Hakeem."

or triplets, and this has suddenly happened. It may be difficult for the parents to take everything in, and they may need to take some time to digest the information and make

any decisions about the birth. It is important to refer to the memory making section of this guidance as these memories will be so very special.

Neonatal Death



Multiples are 3.5 times more likely to experience neonatal death than singletons (MBRRACE 2020) and are much more likely to be born prematurely, so healthcare professionals should consider this when communicating with parents of multiples.

In the case of a multiple birth, parents may feel torn between their babies and feel even more pressure if they have other children. Parents should be encouraged to spend time with their healthy babies, as well as with babies that are sick or unlikely to live. Many hospitals will also try to keep babies together. If parents have two or more babies in the unit, they should be placed near to each other if possible. The babies' incubators should be visually distinguishable from each other, and individual care plans should be devised for the babies. For many parents it is very important to see, hold and/or photograph all of their babies together and with the family. This may be their only chance to do so if one of the babies is critically ill, and this opportunity should be offered to parents.

Parents must be given opportunities to parent both of their twins where possible, especially

if it is known that one or more of the babies will die. Gentle encouragement and support may make parents feel more comfortable.



Consistent reference to our survivor as Twin 2 in paperwork, ward rounds etc. in the early days after Oscars passing was so upsetting and triggering."

If one of the babies dies the parents may also want to place a photo of the baby or babies who died with or near the surviving baby or babies. Some trusts also use a Purple Butterfly sticker to put on a cot to indicate that this baby is a surviving twin or

triplet. Please see the section below on butterfly cot cards.

If one baby has already died, it is important that the staff caring for the surviving baby or babies in the neonatal unit recognise the importance of all the babies to the parents and listen when the parents want to talk about the baby who has died.

Support from staff will be crucial for parents' well-being. It is helpful if one member of staff can be allocated as the main contact for the family so as not to overwhelm them. Many parents appreciate it if staff bring up the subject of the baby who has died, as this gives them an opportunity to express their feelings.

Parents should be offered considerate bereavement support if one baby has died,

““

It felt important to me to still spend time with my twin that had died while the other twin was still alive. We tried to spend equal time with them both.”

and another baby is still being cared for on the neonatal ward. However, some parents may find that they are not ready to access this support, particularly if they are focusing on the surviving baby or babies. It may be distressing for some parents if surviving babies are located near other multiples on the unit. It can be particularly difficult after one baby has died, to see a new baby in the same incubator/cot and staff should be sensitive to this. Parents should be told about the support that Twins Trust bereavement group can offer them at any point after the death of one or more of their twins, triplets, or higher order multiples. Staff should also be aware of the position of the cot or incubator of the surviving baby or babies.

““

My husband broke down when we walked into the room and another baby was in the incubator that Charlie had been in.”

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour

and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died.

It is also important to consider that if both twins or all babies in a triplet pregnancy die, that it can be very difficult for the parents to be going through it for a second and third time. Some parents may want things to be similar to how it was with the first baby that died, whilst others may not be able to comprehend that it is happening again. Give parents time to make any decisions, if at all possible and explain what is likely to happen using kind and considerate language. It is also important for the staff to continue to have a presence with the family even after the babies have died. The time spent memory making is often something that will always be remembered alongside the staff who helped make those memories. Please see the memory making section below.

““

I will always remember the kind and caring Neonatal staff that looked after our twins and gave us such precious memories, both when they were alive, and after they had died.”

Sudden Unexpected Death in Infancy (SUDI)



If the baby that died was a twin, triplet or higher order multiple, the health professional will need to be aware that the family will be grieving for the baby that has died, but will also need to continue caring for their surviving twin or triplet/s. This could bring many challenges. Please refer to Twins Trust who will be able to support the family with their bereavement and offer the family support. It is likely that their anxiety around

the surviving twins or triplets will be heightened. It can be particularly challenging to suddenly be caring for one baby and thinking about the sometimes-identical twin that has died. Emotional support is available from befrienders at Twins Trust and other charities such as Lullaby Trust. Please see the memory making section below for ideas.



My youngest twin, Jonah, passed at 5 weeks and 6 days on Boxing Day from SUDI. My husband and I struggle to sleep as we are so afraid for Xander, our surviving twin. I already had anxiety but now it's worse than ever. I'm plagued with nightmares, have developed PTSD and have flashbacks of my husband holding Jonah when he found him and of doing CPR. The anxiety is beyond measurement, but the breathing monitor has made sleeping possible again. We definitely worry more than ever now."

Palliative care

for when a baby dies after birth but not in NICU and not a Sudden Unexpected Death in Infancy (SUDI).

Some parents do experience the death of a twin or triplet outside of these categories that are covered by the five main pathways. Some babies will have an anomaly picked up during pregnancy and a TFMR will not be an option for them. Some of these babies will receive palliative care at

home or in a hospice for a number of days, weeks or months. It is important to ensure that these parents feel supported and that they know where to access help. Please see the Neonatal Pathway, P16/17 for further information on providing palliative care.

Some Universal Topics which are also in greater detail within the specific individual pathways – the information below relates specifically to twins, triplets and more.

Memory Making



Parents will often need staff to take the lead in making memories with their baby or babies. Offer as much as you can, such as photos, holding the baby, bathing and dressing the baby, hand and footprints, locks of hair, other family members meeting the baby etc. Where there is a loss in a multiple pregnancy, it is important to offer photographs of all of the babies together and with the parents. It is important to have a discussion with the parents about naming their babies.

A name may also be important for existing and future siblings, especially in a multiple birth where one or more babies survive. Staff should always use the baby's name when they have been given one by the parents unless they request otherwise. Some families may decide not to name their babies. If



We were with our surviving twin as he passed away and we were also encouraged to have photos taken and to be a part of the photography shoot. This was very gently done but I am grateful for it."



We opted to only have our hands photographed and this was both encouraged and respected."

parents have some time while their babies are alive it is important to encourage memory making such as changing nappies, skin to skin contact, feeding etc.

It is essential to offer choice with memory making after the baby or babies have died. Some parents may need to be led while others may know what they want to do. Some of the things that can be offered for the memory box are hand and footprints, the cot card, identification bracelets, scan pictures, lock of hair and blankets that they have been wrapped in. Do consider that with twins and triplets that many families will want the memory making to be the same for each baby but not always. It is important to give the family options with memory making but to respect their decisions and wishes.

Seeing the Baby



If one or more of the babies have died in utero, staff will need to have a conversation about what the dead baby or babies might look like.

At Twins Trust we often hear of parents who regret not seeing their baby but rarely hear of people who do regret seeing them.

They may need some gentle encouragement to see and hold their baby. It could be suggested that the baby is wrapped up if the parents are frightened. If they do not want to see the baby or babies the staff could take some photographs with the parents' permission that they can look at later on if they want to.

It is ok for the staff to be open and honest with parents about their experience with bereavement, if it is not something they have a lot of confidence in, it's ok to get some

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My biggest concern for the birth was whether we'd get to meet Thomas or not and what condition he'd be in. I'm very glad the hospital staff when I went in for my section were all very aware of this (briefed by my bereavement midwife) and my hospital experience was very validating and very much helped me process and accept what had happened.”

advice from a colleague. Don't not do things because of feeling afraid or out of their depth.

Funerals



There is a section about funerals in the **Twins Trust Bereavement booklet** which gives some greater details about the choices that parents can make.

It is important that parents are made aware that they are able to bury their twins or triplets in the same coffin if they wish to and that they can decide on the type of funeral ceremony that they would like.

Some parents may feel pressured to make funeral arrangements quickly for the baby or babies who have died, particularly if they feel that they need to focus on the surviving baby or babies in NICU. Staff should offer parents informed choices about their options

for a funeral. Parents may also choose to delay the funeral for the baby who has died while any other surviving babies remain in the hospital depending on their individual circumstances.

Purple Butterfly



Parents should be offered a **purple butterfly cot card** which can be placed in the surviving twin or triplets' incubators or cots, and the name of the baby that has died can be written on the card. The poster should also be displayed nearby to avoid repetition of explaining about the butterflies.

You can request a purple butterfly cot card or find out more details from The **Skye High Foundation**.

A training session from **The Butterfly project – Newcastle Neonatal Team**, also provides further information.



The Purple butterfly became so important to us during our 12 week NICU stay with our surviving twin (we lost Oscar 36 hours after birth) and the hospital allowed us to take it and keep it in Charlie's memory box when we came home. There was clear signage on the ward as to what the butterfly meant which usually stopped people putting their foot in it and even gave some a gateway to having a conversation with us about our experience which was usually surprisingly nice to talk about. What I will say is that it did mean that we let our guard down on that front, expecting everyone to always know and understand what it meant so that the odd time that someone did put their foot in it, it really floored us."

Communication and Language

It is essential to consider how to deliver information to parents. Use clear, concise and caring language at all times, whether it's at the time of delivering bad or unexpected news, during the birth, while making memories with the family or afterwards at follow-up appointments. Your words can make such a difference. Consider how you refer to the twin who's died if they're still pregnant with a surviving twin or triplets. Families who have multiples usually

want the twin or triplet who has died acknowledged. Communication should always be empathetic, sensitive, non-judgemental and parent led.

Please look at Twins Trust **Bereavement Resources at the Tips for Health Professionals leaflet** which includes a section on things not to say.

Registration and Certificates



Twins Trust offer **Certificates of Birth for twins, triplets and more** that you can download from their website. It can be particularly difficult and distressing for families where one twin or triplet gets a legal birth certificate but the other/s do not, or when none of the babies get one.

Registration – There may be times when one baby will need to be registered and the other will not which can be distressing for the parents. For example, if the babies are born at 23 weeks and one is alive and the other is not.

Post-Mortem

Most of the Post-Mortem information can be found within the specific care pathways. Do consider that the parents may want it the same as with the

first twin or triplet that has died, so may want a Post-Mortem on all of the babies or on none of them unless they are ordered by the Coroner to have

Aftercare and Follow-up appointments



Some parents may be leaving with one baby and some with none. It may be a frightening and painful time for the parents. Some will want to leave quickly, and others will want to spend as much time as possible with their babies that have died. Parents should be informed of what will happen after leaving the hospital, should they expect to be contacted by the bereavement midwife for example as well as follow up appointments to discuss Post-Mortem results. If there is a surviving baby it may be difficult to return to where the other baby died so this should be considered when deciding the venue for follow up appointments.

An assessment should be made by the Health Care Professionals before the parents leave

the hospital which can be used to inform relevant referrals. Please refer to the relevant Care Pathway to find out more information about discharge and aftercare.

Follow up care - At the time of losing a baby, it is difficult to take everything in and so sometimes even if families are told about support, they won't remember or be in a place to follow it up. A check-in at some point later can be so valuable and a chance to remind families of the support available.

Counselling – It can be very helpful to families who have experienced the death of a multiple to participate in some counselling sessions. Consider signposting families to any local counselling services.

Another Pregnancy



The next pregnancy can be a very anxious time following the death of twins or triplets. There can be lots of apprehension, especially regarding if it might be twins or triplets again. If at all possible, it is helpful for the parents to have an early scan to see how many babies that they are having and to make a care plan for the new pregnancy. If this is not available, the parents may wish to book a private scan. This pregnancy will need to be monitored carefully so that the parents are as reassured as possible.

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I wanted to know as early as possible that my next pregnancy was not another twin pregnancy. I would have loved twins again, but a singleton pregnancy felt more hopeful.”

Ongoing Support



Twins Trust Bereavement Service offers support to you at any time following the death of a twin, triplet or more both during and after pregnancy.

Please help with signposting to Twins Trust Bereavement Service. Many people don't

know about Twins Trust's bereavement group and often find them later. Please help by ensuring that anyone who experiences the death of a twin, triplet or more knows all about the support.

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I wish I had known about Twins Trust when I lost my identical twin girls at 16 weeks. I wasn't offered much support before or after my loss and I would have really appreciated the chance to have spoken to someone who could have understood the pain I was going through emotionally.”

National Bereavement Care Pathway



The NBCP is based around nine bereavement care standards (below), which Trusts and Boards commit to reaching each time a baby dies or a pregnancy is lost. More information on the NBCP is available on their website.



A free e-learning module outlining the different types of loss, and explaining the NBCP in more depth, is available online [here](#).

The NBCP is led by Sands in conjunction with Royal Colleges and baby loss charities: Antenatal Results and Choices (ARC), Bliss, Lullaby Trust and Miscarriage Association.

[Sands website](#)

[ARC website](#)

[Bliss website](#)

[Lullaby Trust website](#)

[Miscarriage Association website](#)

For the National Bereavement Care Pathway in Scotland please visit their [website](#).

www.twintrust.org/bereavement

Twins trust.
**Bereavement
Service**

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

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Registered Charity Numbers: 1076478 and SC041055.
Registered Company Number: 3688825.