

Twins trust.

**Bereavement
Support Group**

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



BEREAVEMENT CARE

**BEFORE, DURING AND AFTER THE
DEATH OF A TWIN, TRIPLET OR MORE**

APRIL 2022



Introduction

Twins Trust has undertaken research in order to better understand bereavement care during and after the death of a twin, triplet or more. This analysis, undertaken by Twins Trust's bereavement team, examined the care provided by hospitals and health professionals, as well as how our own bereavement support is accessed and any improvements needed.

The research was conducted amongst 250 bereaved parents over the course of one month. The survey was undertaken by members of the Twins Trust Bereavement Support Group and others unaffiliated with the charity. The responses ranged from very recent losses to over 20 years ago.

Key findings

Our responses showed that whilst there are many shining examples throughout the UK of fantastic care – including bereavement care - for twins, triplets and more, often this is sadly not the case. Over 50% of respondents were not seen in a twins' clinic and over 1 in 3 felt that they received poor care during pregnancy. Additionally, only 60% received counselling after the loss whilst almost half of respondents felt that their aftercare was poor or could have been improved.

The findings highlight the fundamental impact that health professionals have at a devastating time for parents. The research found a huge gap between what parents wanted and expected in terms of aftercare and the support that was provided. Twins Trust offers a range of bereavement support services which the report found to be pivotal for many responders.

For bereaved families, there is wide-ranging support available and the research found an extraordinary breadth of responses to people's grief. At Twins Trust, we know that different people need different things at different times and there is support available – both within the charity and beyond – for people at each stage of grief.

Shauna Leven, CEO, Twins Trust

Although multiple pregnancies (twins, triplets or more) only make up 1.5% of all pregnancies in the UK, nearly two thirds are born prematurely compared to less than one percent of singleton pregnancies. Multiple pregnancies are twice as likely to be stillborn than singletons and are 4.3x more likely to result in neonatal death compared with singleton pregnancies¹. Sadly, there is also a higher risk of disability.

At Twins Trust, we believe that antenatal care for all women pregnant with twins, triplets or more should be provided by a core, multidisciplinary team of specialists within a dedicated multiple pregnancy clinic. This is in line with the MBRRACE Perinatal enquiry into twin deaths, published in 2021². It is clear from our research that this is not currently the case.

We also believe that there is a need to create a bereavement care pathway for multiples that recognises the unique needs of our families when a parent loses one or more of their babies from a multiple pregnancy.

All health professionals should be able to deliver at least the minimum level of care – including bereavement care - as outlined by the National Bereavement Care Pathway (NBCP)³: compassionate care; excellent communication; and trained and supported staff. Everyone experiencing a multiple pregnancy who has experienced bereavement – and everyone who has experienced the death of a baby or babies amongst twins, triplets or more – should have access to counselling, should they want it.

For Health Professionals, we would recommend them reading and understanding the tips provided by our bereavement specialist, Sharon Darke, at the end of this report.

¹ <https://www.npeu.ox.ac.uk/mbrance-uk/reports>

² https://www.npeu.ox.ac.uk/assets/downloads/mbrance-uk/reports/perinatal-report-2020-twins/MBRRACE-UK_Twin_Pregnancies_Confidential_Enquiry.pdf

³ <https://nbcpathway.org.uk/about-nbcpathway/bereavement-care-during-covid-19-outbreak>

Twins Trust Questionnaire

We had 252 responses over one month – from December 2021 – January 2022. The questionnaire was shared via Twins Trust’s private and public Facebook pages, Twitter, Instagram and in the newsletter.

The responses were received from parents with a range of experiences across all types of multiple pregnancies over a wide time period, from very recently to over 20 years ago.

QUESTION 1

Did one or more of your twins or triplets die?

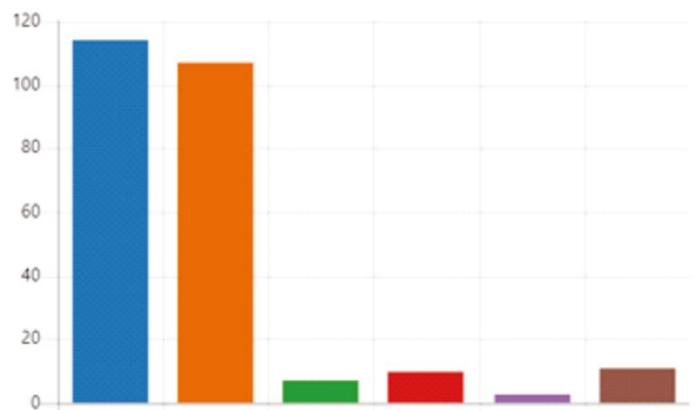
| | |
|------------------------------------|-----|
| ● One twin | 145 |
| ● Both Twins | 86 |
| ● One triplet | 12 |
| ● Two or all triplets | 8 |
| ● A higher order multiple pregn... | 1 |



QUESTION 2

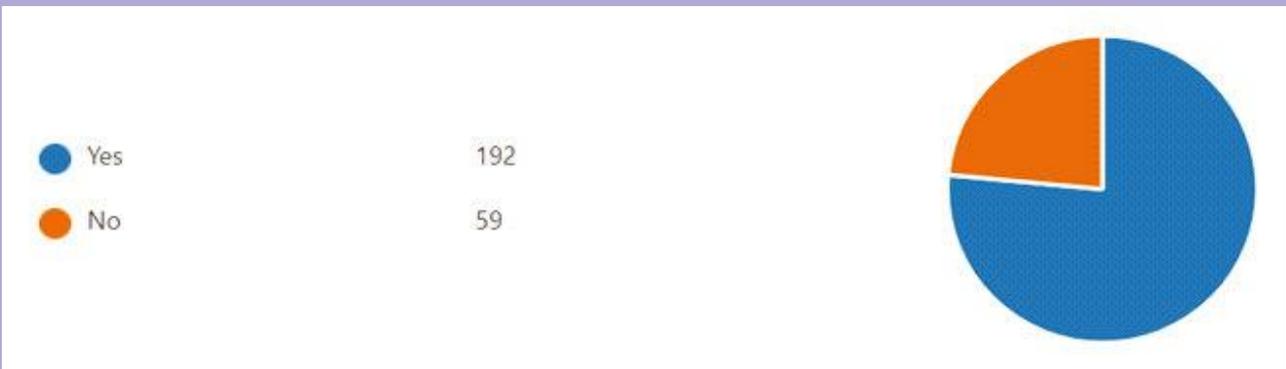
Did you have identical or non-identical twins or triplets?

| | |
|---------------------------------------|-----|
| ● Identical twins | 114 |
| ● Non identical twins | 107 |
| ● Identical triplets | 7 |
| ● A set of identical twins within ... | 10 |
| ● Non identical triplets | 3 |
| ● Don't know | 11 |



QUESTION 3

Were you told that your pregnancy was a high risk pregnancy?



QUESTION 4

Were you seen in a twins clinic?



5. Do you feel like you experienced good care during your pregnancy? - please specify

57% of responders thought that some aspects of their care during pregnancy was good.

34% thought that some of their care was poor.

6% did not fit either category. For example they thought that their care was reasonable, or that the care was partially ok. A few commented on the lack of specialist knowledge.

(Some responders experienced both good and poor care)

'Our consultant and the team were excellent.'

'Yes, but I didn't have any warmth from my consultant and felt awkward asking questions.'

'The twin consultant was excellent, we were scanned every week.'



I had to push for scans every 2 weeks after 16 weeks as per NICE guidelines. It was only because I had bleeding that they allowed me to have them, even though I knew the policy and had advocated for myself.

'We were seen every two weeks, but there was never any real continuity of care. We saw two different consultants and there was a twin midwife but she was never there as she was split between different hospitals in the trust.'



The care that I received was no different to my singleton pregnancy.

'Horrendous experience with fetal medicine due to attending alone because of Covid restrictions in place at the time.'

'The midwives knew nothing about MCDA twin risks. I wasn't put on the correct twin pathway initially until I challenged my care. I then began getting scanned every two weeks'

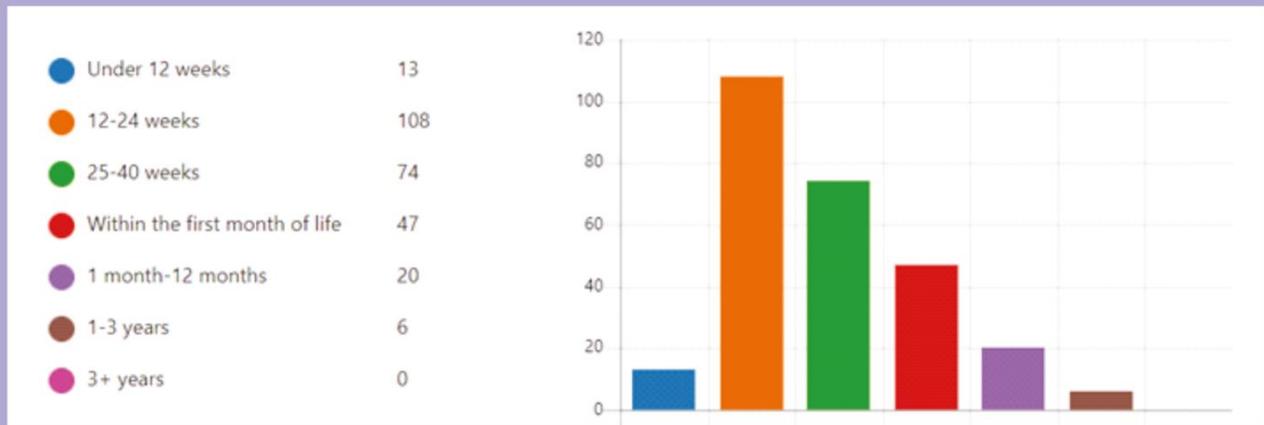
'We experienced first class care all the way, no exceptions'



My NHS midwife care was wonderful.

QUESTION 6

At what gestation/age did your baby or babies die?



7. Did you experience good bereavement care after your baby or babies died? - please specify

45% of respondents felt like they experienced good bereavement aftercare.

44% felt that their aftercare was poor or could have been improved. 8% thought that their care afterwards was mixed or reasonable.

'Yes, in the form of a photographer and memory boxes. No with regards to counselling etc. I had to pay to see someone.'

'Yes excellent care from the bereavement midwife and local charity.'

'Yes, I was visited at home by a bereavement midwife.'

'Mostly - there were some amazing midwives, unfortunately with a surviving twin some Health Care Professionals didn't really know how to talk to me or support me, there were some careless comments by Paediatricians and Consultants.'

'We were never offered a bereavement nurse, or bereavement counselling from the hospital or anyone else, we were just given a sands leaflet.'



I received two phone calls, and was given materials, but no follow up support. I am now seeking more follow up support in groups on my own.



We were supported in the NICU with a special room where we stayed for a couple of days and given a bereavement/memory box for each twin. We were supported after by the in-house psychologist at the hospital who was amazing. We continued to be supported by her during our subsequent pregnancies. We also had a follow-up appointment with our consultant.

'Once I was discharged I had no follow up. I went home with a premature baby and a dead baby and the GP wouldn't see me for 10 weeks and the Health Visitor only saw me for maximum of 10 mins because of Covid restrictions.'

'I was just given a bereavement folder of information.'

'I was offered bereavement care but turned it down. In hindsight it was offered too soon after the death of a child and perhaps should offered again a few times within the first year.'

'We have still not managed to see the bereavement team 10 weeks on. There was no bereavement midwife. I was referred to counselling but the appointments were very infrequent.'

Twins Trust Bereavement Support Group Questionnaire, December 21

"We had good bereavement aftercare. I had the opportunity to meet with the bereavement midwife afterwards."



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Twins Trust Bereavement Support Group Questionnaire, December 21

"The neonatologist tried so hard, was incredibly patient and explained all decisions to us. The whole NICU team were great. We were able to spend time with her after she died by using the cold cot. We were allowed as much time as we needed. We took hand and footprints and photos."

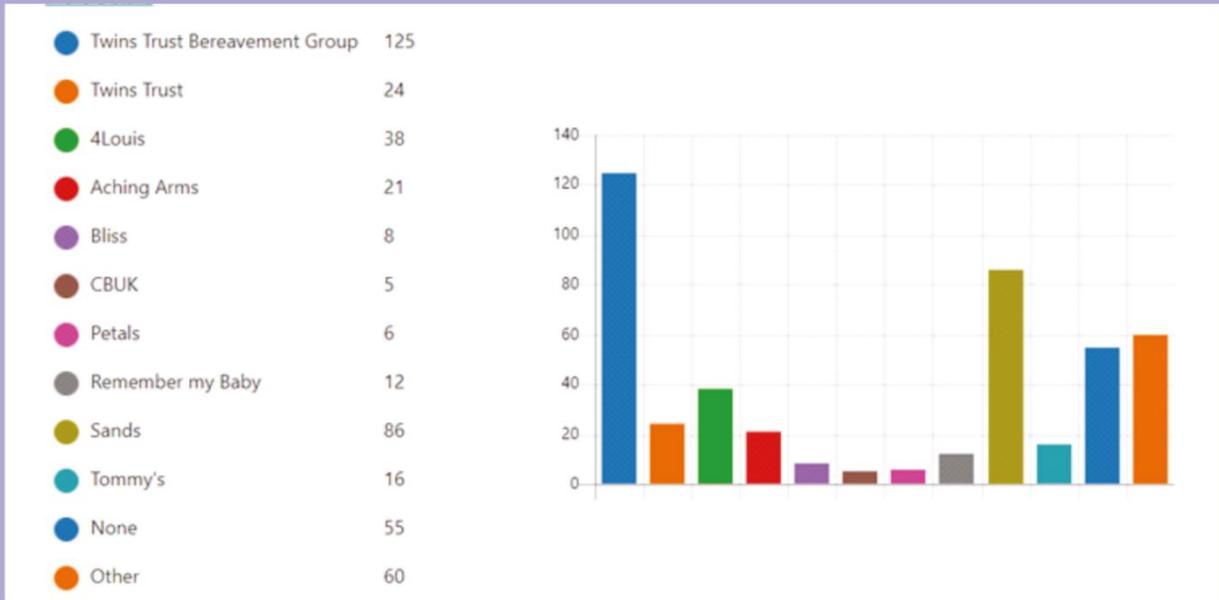


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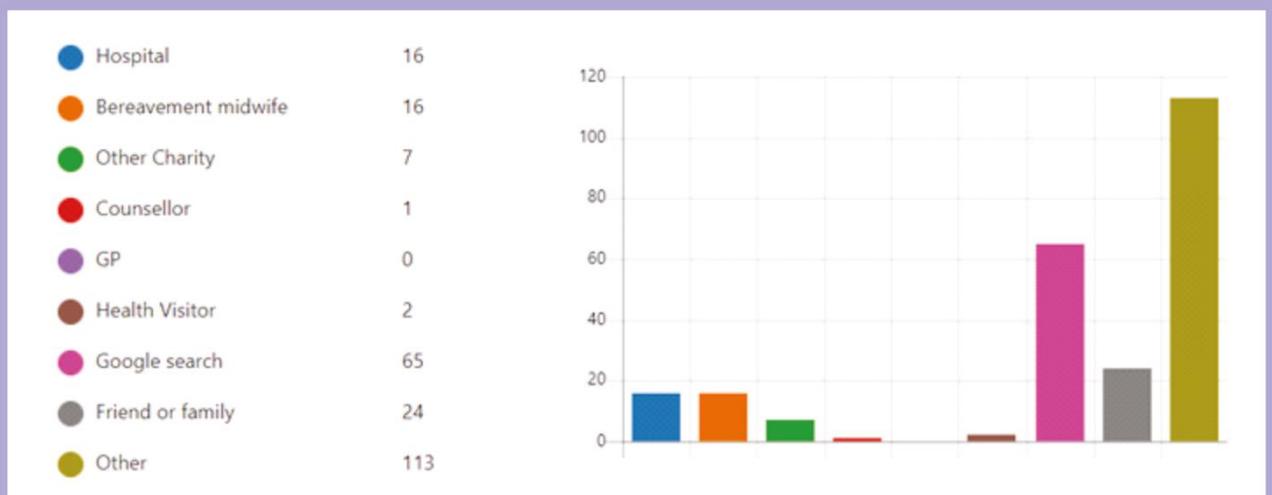
QUESTION 8

**Which charities did you get help/support from following the death of your baby or babies?
- Please select all that apply**



QUESTION 9

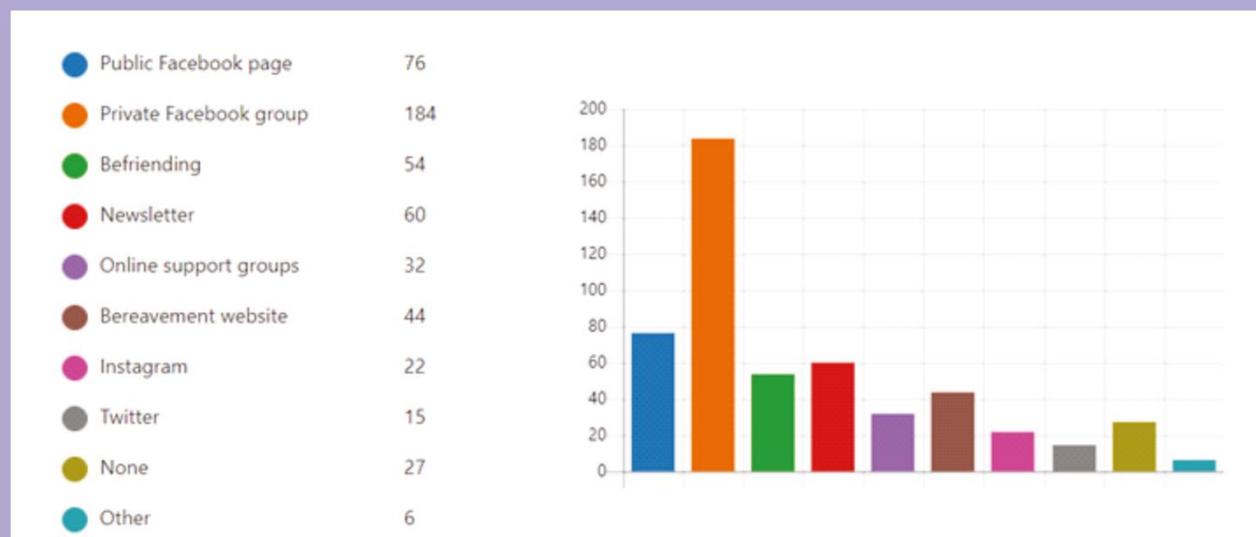
How did you hear about the Twins Trust Bereavement Support Group?



NB: 'Other' includes social media such as Instagram, Facebook and Twitter as well as from Twins Trust as a result of cancelled courses or membership after the baby/ babies have died.

QUESTION 10

What Twins Trust bereavement support services have you used?



11. What have you found most helpful with your grief? Please specify

The most significant response was having shared experiences and feeling understood which was mentioned in 76 responses. 58 people said that talking about their baby/ babies is helpful. 34 responses specifically mentioned the Twins Trust private Facebook group and 29 people have found counselling the most helpful. There were many other things that were mentioned such as our online support groups, time, support from family and friends, other charities, other children, keeping the baby/ babies' memory alive, and some people have not found anything helpful yet.

'I loved hearing my little girls name bring read out at the wave of light. Thank you.'

'Allowing myself to identify as a twin mum, a title I feel isn't visible to others but is so meaningful to me.'

'Being acknowledged as a mother of twins. Having my twins acknowledged as people not "a pregnancy loss.'

'Monthly support group network.'

'Befriending and being able to continue talking about my triplets.'

'The Twins Trust Bereavement Support Group feels like a safe space with people who care.'

'My befriender is amazing and I can talk about anything with her.'

'Having a befriender to talk to really helped me - someone who truly understood my grief / loss.'



Being able to post how I feel, without being judged and not necessarily looking for comments. Also, a safe place to post pictures where others will understand and not be put off by the sometimes sensitive content.

'We bought a rose for our garden named after our son.'

'It has been so helpful talking to and being around other bereaved families who actually know what you're going through and totally understand.'

'Speaking with others who've been through the same has really helped, especially in the online meetings'

12. What do you think could be improved with bereavement care? Please specify

Some of the ideas for improving bereavement care include-

Quicker access to counselling and it being more consistent, support for dads, consistent care across the country, funeral support/ information, a more proactive outreach and follow-up care, and access to all support available. Better signposting to charities and other support organisations. Understanding health professionals who can take the lead in memory-making.

'I didn't understand why people were telling me to take photos of my boys it felt weird but now they are the most precious thing to me. I wish someone had explained it better.'

'If hospital stay is required, avoid being placed in NICU next to twins/triplets as I found it difficult to sit with my survivor looking at sets of twins.'

'Local, face to face service to be able to meet with other families who have lost a twin or multiple; there is support for the loss of a baby but I don't think that my hospital knew of support for twin or multiple loss; I think I had to search myself online; perhaps doctors/hospitals should have better information?'

'I would have loved to have been offered any type of support.'



Information packs given out at hospital. A booklet with FAQ the day my son died would have helped.

'Consistency in well-trained considerate care.'

'More awareness of losing a multiple and having to continue a pregnancy.'

'Everyone should be offered the same level of support. Some people seem to get it and others miss out.'

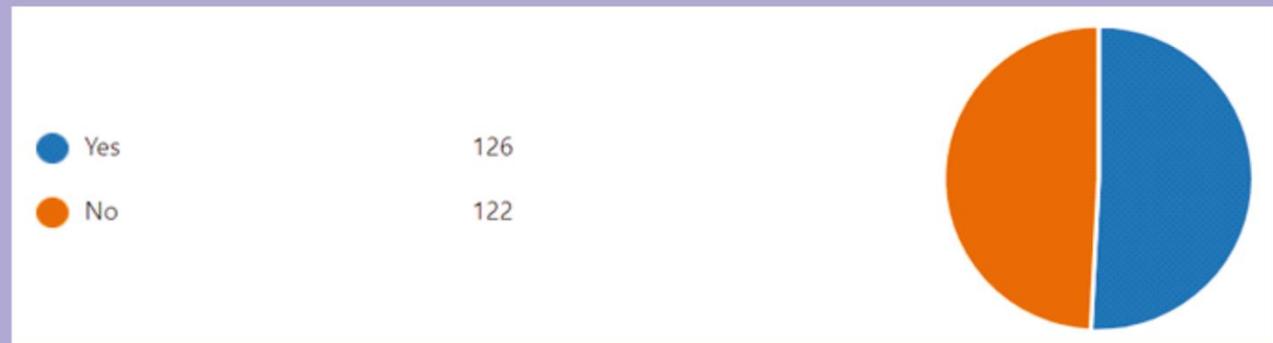
'Support with how to plan a funeral- we did not have one for our sons. We were so deep in grief we couldn't begin to think of how to even plan such an event. We had a small memorial a year later but I always wished we had a real funeral for them.'



Explaining to the parents that they should spend as much time with their babies as they can, and do things like putting nappies on them, putting them in clothes etc.

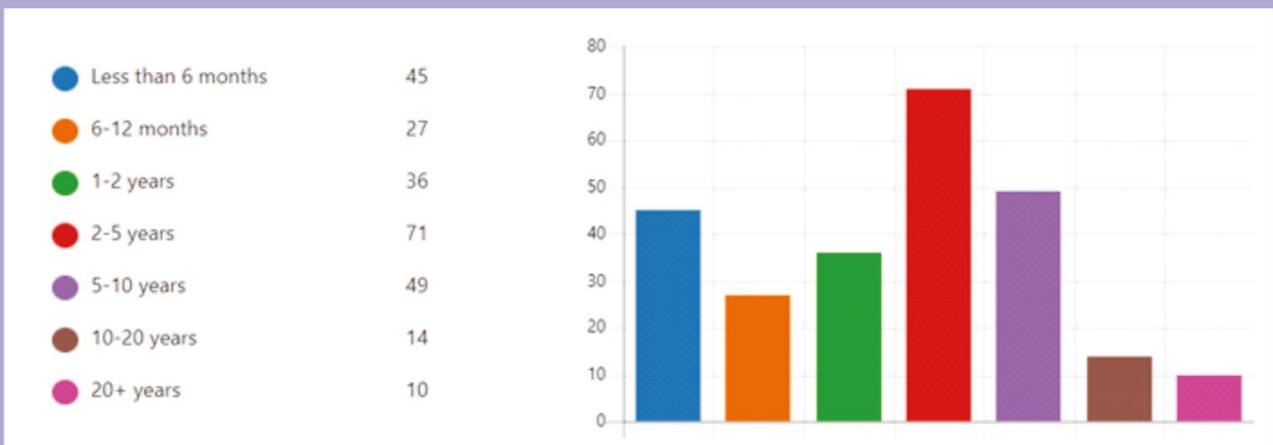
QUESTION 13

Have you fundraised following the death of your baby or babies?



QUESTION 14

How long ago did your twins, triplets or more die?



QUESTION 15

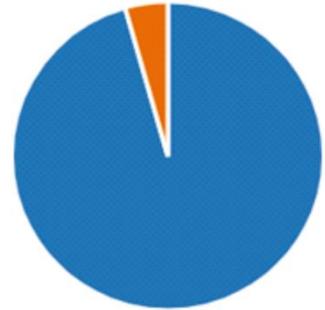
Did you have counselling?



QUESTION 16

Is it important to you to be recognised as twin or triplet parents?

| | |
|-------|-----|
| ● Yes | 238 |
| ● No | 11 |



QUESTION 17

Do you talk about your baby or babies that have died?

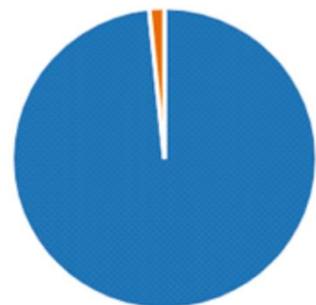
| | |
|--------------------------------------|-----|
| ● No | 8 |
| ● Yes with immediate family | 15 |
| ● Yes with family and close frien... | 108 |
| ● Yes with everyone | 119 |



QUESTION 18

Do you feel that it is important to keep your babies' memory alive?

| | |
|-------|-----|
| ● Yes | 248 |
| ● No | 4 |



19. If so, please specify how you do this?

We had lots of responses about how people keep their babies' memories alive. Many people had similar ideas such as talking about the baby/ babies and including them in everyday family life, visiting special places such as cemeteries and memorial gardens, fundraising in their memory, lighting candles, having symbols such as butterflies or stars which represent them, celebrating birthdays and anniversaries, special jewellery or volunteering for charities. Almost everyone who answered the question mentions talking about or to their baby.



Involve him in all we do, talking about him all the time with everyone and including him in special events throughout the year.

'We talk about her and how she might be with her twin sister, visit the baby garden occasionally, have a little candle and butterflies to remember her and I wear a necklace with her scan photo.'

'We have photos in the house, talk about them, draw stars in cards, Christmas decorations, special family day on their birthday etc.'

'I do this subtly in many things we do. In photos, I include something blue, in cards I add an extra kiss etc. I have fundraised in his memory and talk about him when it feels right, I feel it's important that our loss makes a difference particularly around TFMR and that's his legacy.'

'Including them in family traditions, memorial walks and events, fundraising, talking about them with their younger sister, keeping a memorial area in our home.'

'I struggle with this. They were only 20 weeks gestation when they died. They feel very real to me, and I miss them terribly every single day, but I don't know how to talk about it with people outside of my husband and closest friends.'

A message from Sharon Darke, Twins Trust's Bereavement Support Coordinator

For bereaved families and their friends and family

We all want and need different support after experiencing the death of a twin, triplet or more. It is important to understand that there are many ways to offer and receive help whilst you are grieving but that there is not one correct way. We encourage you to talk about what is helpful and not helpful with your family and friends and do what works for you. Have a look at the support that we offer at Twins Trust and from the many other wonderful charities and see what you find helpful at that time. Many people do find it helpful to keep their babies' memory alive although this can be difficult especially early on. If you would like to hear more about the support that we offer, please let us know.

Tips for health professionals when dealing with bereavement

Be informed It is so important that parents can access information easily when facing the death of one or more of their babies.

Language It is essential to consider how to deliver information to parents. Use clear, concise and caring language at all times, whether it is 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 has died if they're still pregnant with a surviving twin or triplets. Our families usually want the twin or triplet who has died acknowledged.

Memory Making Parents will often need you to take the lead in making memories with their baby/ 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.

Signposting Many people who find us at Twins Trust do not know about our bereavement group. They often find us later. Please help us by ensuring that anyone who experiences the death of a twin, triplet or more knows all about our support.

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

Counselling Many respondents experienced long waits for counselling or it simply wasn't offered. Almost everyone who has received counselling has found it helpful. If it is at all possible to keep in touch with the family during that first year, through the bereavement midwife or hospital counsellors, it is encouraged.

From the responses we received it clearly shows the impact that health professionals have at the most devastating time in the parents' lives. It is so important to acknowledge that kind, caring, personal care can make such a difference with the family's grief journey.

Please email us if you would like to connect with Sharon Darke, our Bereavement Support Co-ordinator bereavementsupport@twinstrust.org or you can add yourself to our mailing list to keep up to date with our group <https://twinstrust.org/bereavement/support/newsletter.html>

For more information and resources for bereaved families and healthcare professionals, please visit: www.twinstrust.org/bereavement