

Bereavement care in South Yorkshire

A survey report on the lived experiences of bereaved parents accessing care after pregnancy or baby loss

"The midwife on shift at the time was very kind, empathetic and helped me through all the stages ensuring I fully understood." - Bereaved parent

"We were given an envelope with information in for support, that was the bereavement care. No care was shown throughout the process." - Bereaved parent

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Content warning

This report covers areas that can be difficult to read about, including pregnancy loss and the death of babies.

If you need support, the Sands National Helpline provides a safe, confidential place for anyone who has been affected by the death of a baby. Whether your baby died long ago or recently, we are here for you. The telephone helpline is free to call from landlines and mobiles on 0808 164 3332. You can also email the team at helpline@sands.org.uk or use Sands support chat via our website sands.org.uk.

If you feel you need specialist mental health services, please ask your bereavement midwife or your GP for a referral. If you are worried about your own or your baby's health, then please speak to your health professional.



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Project background

Context

In 2024, we heard reports of inconsistent bereavement care from people who experienced pregnancy or baby loss in South Yorkshire hospitals. Some people experienced very good care - others felt like they had a poorer experience.

What we wanted to learn

We wanted to hear directly from bereaved parents who accessed bereavement and mental health care in the South Yorkshire region. With this information, we aim to better understand the experiences of bereaved parents and make positive recommendations to improve services for both bereaved parents and frontline staff.

Survey methodology

In March and April 2025, we gathered the responses from 75 bereaved parents who received care in the South Yorkshire region via a survey. We obtained responses from every bereaved parent – regardless of when their loss was. However, we have highlighted losses in the last 10 years in our analysis.

This survey has been created, implemented, and analysed by a group of bereaved parents based across South Yorkshire, with the support of staff from Sands. All quotes used in this report are from bereaved parents that took part in the survey and agreed to share their responses anonymously.



Executive summary

Survey findings

Our survey of 75 bereaved parents across South Yorkshire highlighted the following key themes in local bereavement and mental health services.

• Bereavement care in South Yorkshire can be inconsistent.

"The bereavement midwifes were so wonderful to us."

"I did have a few doctors/health care people who were amazing however the care afterwards was just terrible with no empathy shown."

- o 34 of 75 bereaved parents felt their bereavement care in hospital was good or very good. However, 28 of 75 bereaved parents felt their care was poor or very poor.
- o This suggests that whilst many people may be receiving excellent care, a substantial group of bereaved parents may be experiencing poor care.
- o We want every bereaved parent to consistently receive the great care that we know can be provided.
- Care from bereavement specialists is generally very good.

"Excellent bereavement midwife who helped my children to hold my daughter."

- o When bereaved parents received care from a specialist bereavement midwife or nurse in hospital, their experience of care was usually good. Bereaved parents provided many examples of personalised and empathetic care with a few exceptions where improvements could be made.
- o Out of the 24 bereaved parents who received care from a bereavement midwife or nurse, 17 of 24 rated their experience as very good or good.
- However, most bereaved parents did not get to see a bereavement specialist which impacted the quality of their care.



"Most of the staff were lovely. But I had absolutely no contact with a bereavement nurse. Some nurses seemed confused as to why I was upset."

- o Only 24 of 75 bereaved parents received care from a bereavement midwife or nurse.
- o When bereaved parents did not receive care from a bereavement midwife or nurse, their experience of care in the hospital was more likely to be poor.
- o This suggests that bereavement care in the hospital can vary in quality depending on whether you receive care when a bereavement midwife or nurse is available. It also indicates that healthcare staff were sometimes not confident enough to provide personalised bereavement care.
- o We know that all healthcare staff want to provide compassionate and personalised bereavement care to every bereaved parent but we are concerned they do not have the resources, training, and support to do this 24/7, 7 days a week.
- o This suggests a need for further investment in bereavement staff to enable more bereaved parents to be supported by a bereavement midwife or nurse, and to allow the bereavement team to provide more comprehensive training to non-specialist staff.

• Experiences of follow-up care, following discharge from hospital, were generally poor.

"We were given VERY limited information. I didn't even know Sands existed."

- o Most bereaved parents received almost no follow-up support. 47 of 75 of bereaved parents were not contacted by anyone in the NHS to discuss support options after their loss.
- o 41 of 75 bereaved parents rated their experiences of follow-up care as very poor or poor. Many bereaved parents reported wanting more regular, longer-term communication and support from bereavement teams.
- o 17 of 75 bereaved parents rated their follow-up care as good or very good highlighting consistent communication and support from healthcare staff following discharge.
- o We know that all healthcare staff want to provide good follow-up care. However, we are concerned that staff may lack the necessary capacity and support to be able to provide this for every bereaved parent.



• Bereaved parents described an acute lack of specialist mental health services for people following pregnancy or baby loss.

"I did not receive any information around mental health support."

- o Most bereaved parents felt like they needed specialist mental health support from the NHS but the majority weren't offered any. 60 of 75 bereaved parents felt like they needed specialist mental health support from the NHS. Out of these 60, only 21 received it.
- o When people did receive support on the NHS, many bereaved parents found it not tailored to their needs, and too short to make an impact. This forced many people to seek support privately, or from the charity sector.

Summary of recommendations for change

Bereavement and mental health care for people following pregnancy or baby loss in South Yorkshire needs urgent investment and prioritisation from local health leaders and politicians.

We are calling on **every NHS Trust in South Yorkshire** to:

- 1. **Increase staff capacity in specialist bereavement teams.** Every trust should be staffed by a bereavement team in accordance with the National Bereavement Care Pathway standards, allowing them to provide a 24/7 bereavement care service inclusive of weekends, Bank Holidays, annual leave and sickness in any setting, at any time.
- 2. **Provide more comprehensive training to healthcare staff**. Every staff member who is involved in the care of parents during pregnancy, and after birth, should receive mandatory training in bereavement care upon induction and in annual refresher sessions.



- 3. **Review and improve follow-up care**. Current follow-up care processes should be reviewed and revised. All bereaved parents should have a parent-led bereavement care plan in place upon discharge to manage their transition between settings.
- 4. **Optimise existing facilities**. Every hospital unit that provides care to bereaved parents has a dedicated room or suite for the sole use of families experiencing the loss of a pregnancy or death of a baby. This should include gynaecology wards, early pregnancy units and A&E departments.
- 5. **Ensure memory making experiences are consistent.** Memory making experiences should be reviewed, ensuring that every bereaved parent is supported to make memories with their baby, with as much time and space as they need.
- 6. **Review and improve care upon arrival at hospital**. All staff that interact with bereaved parents upon arrival at hospital must have the training and resources they need to provide consistent, and personalised bereavement care.

We are calling on the **South Yorkshire Integrated Care Board** to:

- 1. Ensure NHS Trusts have the funding to provide a fully staffed, 24/7, 7 days a week bereavement service. Where needed this should including releasing new funds to hire additional bereavement midwives, nurses and support staff.
- 2. **Ensure every NHS Trust has the funding to optimise bereavement facilities.** This should include funding where needed to soundproof existing rooms, and build new rooms where needed.
- 3. **Invest in mental health services to ensure they support all bereaved parents.** All bereaved parents that need specialist psychological support should be able to access it, at a time and place that is right for them regardless of the gestation of their loss. This should include support for fathers and partners too.



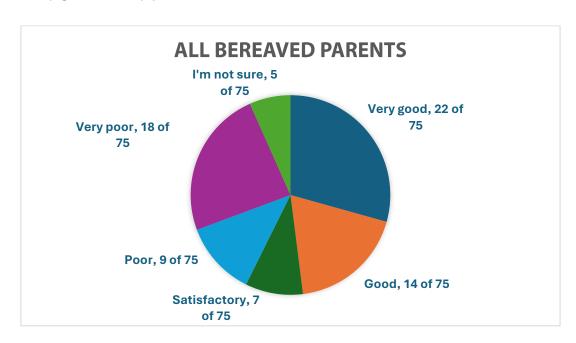
Section 1: care in the hospital

Overall rating of bereavement care

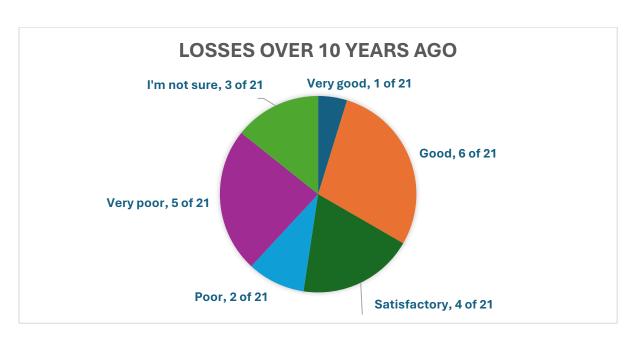
"Staff were amazing and everyone was very supportive, particularly the bereavement midwife and the midwife that cared for me during labour."

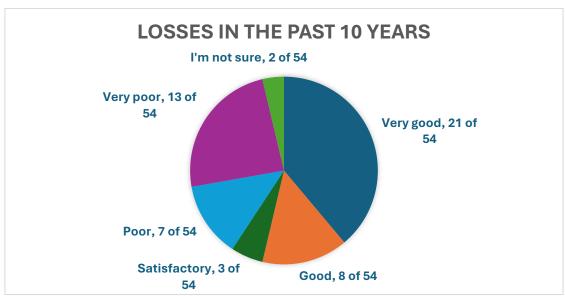
"There was no care or compassion. I never saw a midwife or a specialist nurse. I was put in a side room and left to it."

In our survey, we asked bereaved parents to rate their bereavement care on a scale from very good to very poor.









The results show that just over half of people in the last 10 years had a very good, or good experience of bereavement care overall – which is positive to see. In the positive experiences, bereaved parents often mentioned:

- Empathetic, person-centred and kind care from staff.
- Information being explained carefully and well upon arrival at hospital and throughout their stay.
- Excellent facilities, such as bereavement suites.



• Positive opportunities to make memories.

There is a notable increase in the number of people that felt they experienced very good bereavement care in the past 10 years – suggesting good progress in providing positive care.

People's experiences of bereavement care were also much more likely to be positive if they were cared for by a specialist bereavement midwife or nurse.

However, experiences of bereavement care were also **inconsistent** – whilst most people experienced good care, a sizable group of people did not. The number of people who have experienced poor care has not significantly changed in the last 10 years – illustrating that several problems have not improved.

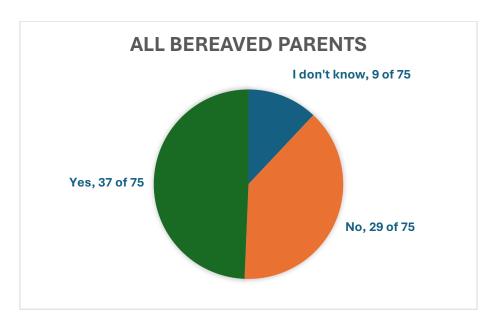
Examples of poor care were often linked to:

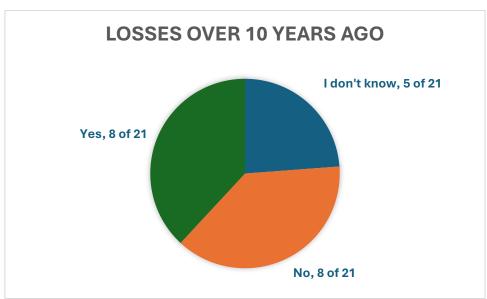
- Inadequate staffing, especially no specialist bereavement midwife or nurse being available.
- Care that sometimes-lacked empathy, with bereaved parents not feeling listened to.
- Evidence of wider healthcare staff being poorly trained and not being equipped to provide adequate care.
- Lack of access to appropriate facilities and rooms to give birth.
- Poor opportunities to make memories.

Arriving at hospital

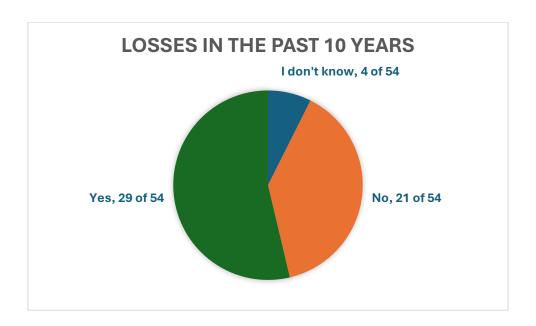
We asked bereaved parents, "when you arrived at hospital, do you feel like you were fully informed about what would happen during your stay?".











Most people felt that they were informed about what would happen during their stay – but a large group of people did not feel informed. When people did feel informed, they mentioned staff clearly explaining what would happen during their stay and empathising with their loss.

"The staff were really compassionate and sensitive to our situation"

"The labour ward staff were amazing with both me and my husband and explained everything to us."

"I was in shock when I arrived to the hospital and I remember been explained how the journey would go..."

"As our baby had already died, we were given a card to hand into reception so that we didn't have to explain."

In the poorer experiences, bereaved parents pointed towards a lack of information being given, or badly explained, as well as feeling ignored. Some parents felt like they were just 'in the way'.



"Minimal information about the induction process given. Were not told that we would be able to see our baby after he was born or that we could spend time with him and invite family to meet him."

"I was dismissed."

"I was just shown to my bed."

"I felt like I was in the way and nothing was explained."

"They did not believe I was in labour even though it was my 4th baby! They neglected me and I gave birth alone."

"I went in A&E and was left for hours wondering what was going on. No one even offered me a pad. It was horrific and extremely traumatic thinking back about it."

This suggests an inconsistency in care. Sometimes bereaved parents received clear explanations and empathetic care upon their arrival at hospital, but many felt like they had been pushed aside and forgotten.

We are calling on all NHS Trusts in South Yorkshire to review their processes and care plans for when bereaved parents arrive at hospital. They must ensure that all staff that interact with bereaved parents upon arrival at hospital have the training and resources they need to provide this care.

Facilities

After arriving at hospitals, many bereaved parents had mixed experiences of facilities. Many women and birthing people who were experiencing an earlier loss described being placed amongst other pregnant women and people.

"I was pushed into a ward with a lady who'd just given birth, and a lady who wanted an abortion - all whilst I was experiencing a missed-miscarriage. Staff were very dismissive."



"We were on G1 because of gestation where people were going for abortions there was no care."

"I was on a ward where women were also having abortions. Although I had my own room this didn't feel right at all."

"I was on a gynaecology ward and felt the staff didn't have the care and compassion to deal with the situation. They were very matter of fact and brushed off my concerns."

This suggests both a lack of suitable facilities for bereaved parents who are receiving care on a gynaecology ward, and sometimes a lack of training and expertise in providing bereavement care from staff on the ward.

We are calling on every NHS Trust to ensure that staff of gynaecology wards have the training, guidance, and resources they need to provide personalised bereavement care. This should include dedicated bereavement staff capacity on gynaecology wards, and specific bereavement rooms or areas for families that experience an earlier loss in these settings.

More positively, several bereaved parents provided good feedback on the setup of bereavement rooms and suites on labour wards.

"The bereavement suite at Jessops is amazing and gave us the chance to make memories with our baby girl."

"We were moved to the tulip room which was private and away from the noise of labour ward which we had been hearing throughout the labour process."

"I was away from sight and sound of the ANPN Ward. The private room was mine for the whole day as long as I needed."

However, not every bereaved parent was able to access a bereavement room when on labour ward, and several parents feedback indicated that the rooms were not always adequately soundproofed – creating a distressing experience:



"The only negative was the room was close to hearing the new babies crying. We were placed at the end of the hall in a beautiful room however some sound proofing would have helped."

"I'd say that we were on the main labour ward and you could hear other mothers giving birth and newborns crying which was very triggering for a loss parent."

"It was extremely difficult being in the same area as mothers who had their babies with them, and I could hear other babies crying at night which I found very difficult."

Guidance on the <u>National Bereavement Care Pathway</u> from Sands states that every bereavement room should be soundproofed if located where parents will be able to hear other babies and families. Rooms should also be accessible for bereaved families without requiring them to go past families with live babies.

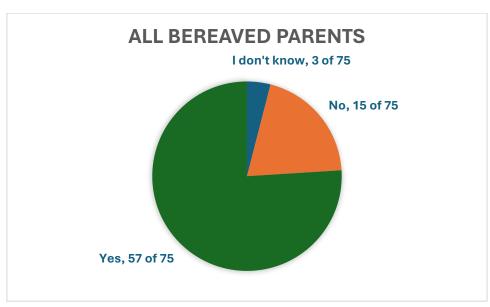
These experiences suggest that although several bereavement rooms are providing a good experience to bereaved families, there is a need to review whether they are sufficiently soundproofed.

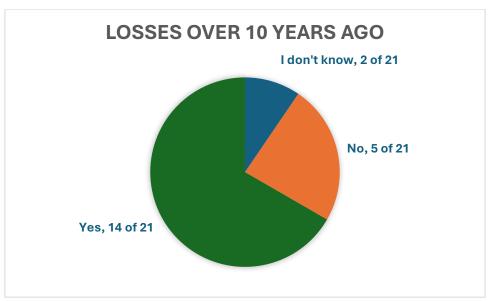
We are calling on NHS Trusts across South Yorkshire to ensure that every hospital unit that provides care to be reaved parents has a dedicated room or suite for the sole use of be reaved parents and families. This should include gynaecology wards and early pregnancy units.

Memory making

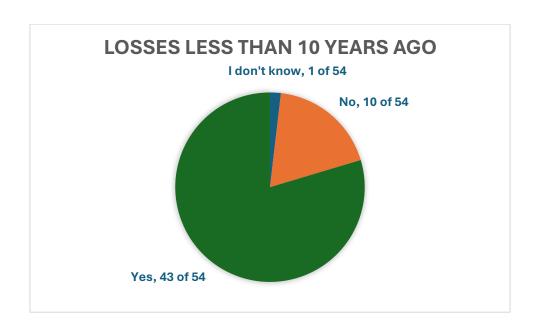
We asked bereaved parents "Were you given the opportunity to spend time with your baby, including the chance to make memories? For example, taking photos or making hand and footprints."











Most bereaved parents felt like they were given the opportunity to spend time and make memories with their babies – which is positive to see. In the positive experiences of memory making, parents mentioned being given plenty of time to spend with their baby and not feeling rushed.

"They brought my baby clean, in a little basket, wrapped in a beautiful blanket and they allowed me all the time I wanted to spend with him."

"Remember my baby came and took photos for us and I can't thank them enough for providing these special photos."

"All our family were able to come and visit the boys and we took photos and handprints etc."

"I'm glad I got the time to see my baby and didn't feel rushed."

However, the quality of these experiences was again inconsistent. When bereaved parents were given the opportunity to make memories, these weren't always positive experiences – with many parents feeling like the process was rushed, incomplete, or the importance of it poorly communicated.



Some bereaved parents said they would have appreciated more information and encouragement. As a result, sadly some parents felt like they were not able to make the most of the opportunity.

"...I wish someone would have sat with me and talked to me about holding my boy.
I would have had more time with him."

"Not long enough and at the time they didn't tell me to make the most of the time to take photos etc. they gave me a card with her handprint and footprint only."

"We had time to do footprints but we were rushed."

"I was offered to see my baby, but I wasn't told that they would clean baby up etc. I said no to seeing the baby when they were delivered but didn't realize that they would wash them and then I could see them."

"After we were able to spend time with the baby (this was 15 minutes max, and the nurse came to say she was taking her)."

Unfortunately, there were a few examples of memory making which were generally negative experiences for bereaved parents:

"We could spend time however no notice was put on the door and cleaners were coming in people asking if we wanted cups of tea and window cleaners it wasn't private and was an awful experience."

"...however hospital made a mistake letting the wrong person into our room to take photos, sending the remember me photographer away, this meant our photos were taken the next day after we had already said goodbye/changed her out of her clothing etc. this added to the trauma."

"Got to spend time with my baby but they lost the hand and footprints."

"Didn't feel like a could take proper photos at he was placed in a cardboard sick bowl. And wasn't dress or cover appropriately. I didn't even get his length and weight."



"Photos were taken 2 weeks after my daughter's death so are not what we'd hoped. No handprints or footprints arrived."

Some bereaved parents also felt rushed or forced into deciding around funerals and burials, before they had time to fully consider their options.

"When we were deciding whether to have a private funeral or the NHS Service we were told by the nurse we were 'overthinking it'."

"We were asked whether we wanted to cremate or bury our son within 30 minutes of him dying."

Sadly, there were also examples of people not having access to memory making opportunities at all.

"None whatsoever. I never got to hold him."

"No one helped me to do any hand and footprints, I wasn't even asked."

Overall, although most parents were given the opportunity to make memories, too many of these experiences did not meet their needs.

Standard three of the National Bereavement Care Pathway states that "All bereaved parents and families are offered opportunities to make memories." This should include as much time and space with their baby as parents need.

We are calling on all NHS Trusts to review their memory making processes and ensure that every bereaved parent is supported to make memories with their baby, with as much time and space as they need.

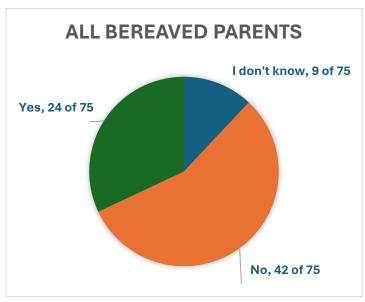
Staff should be provided with the right guidance and training to facilitate memory making and empower bereaved parents to make the decisions most appropriate for them.

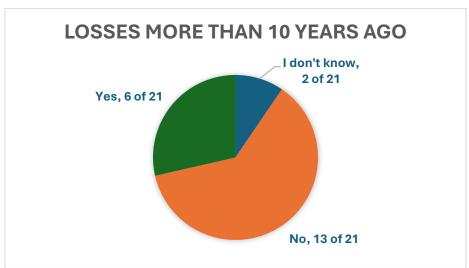


Staffing and care

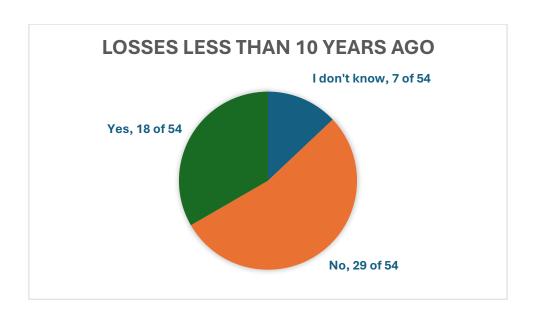
Care from specialist bereavement staff

When you were in hospital, were you cared for by a bereavement midwife or bereavement nurse?









Most people were not cared for by a specialist bereavement midwife or nurse. At Sheffield Hospital in the last 10 years this was even more pronounced - with only 6 out of 35 people certain they received care from a bereavement midwife or nurse.

When people did receive care from a bereavement midwife, they often highlighted the kind and empathetic care that they provided.

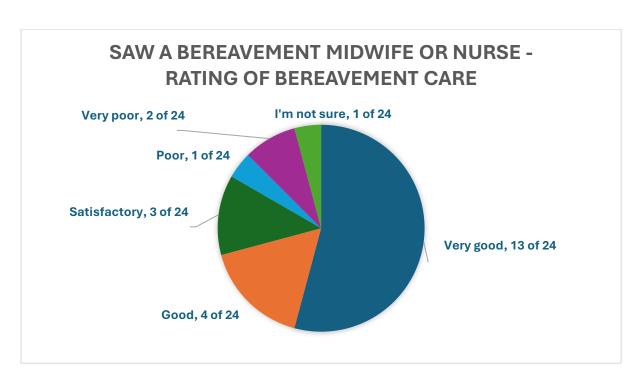
"Staff were amazing and everyone was very supportive. Particularly the bereavement midwife and the midwife that cared for me during labour. There was also a side room which was for our circumstances, this felt private and away from everyone else."

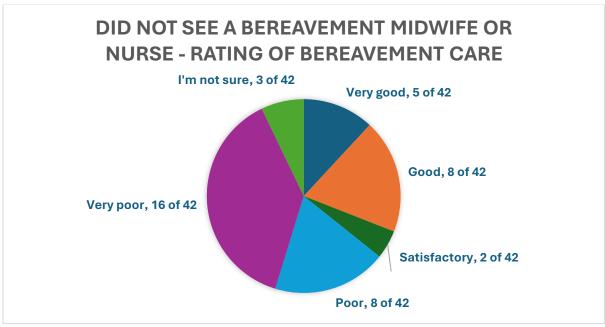
"I had two amazing bereavement midwives."

"My bereavement midwife was brilliant and was even on the scene for 2 subsequent pregnancies, the first which ended in another loss and the second which resulted in my rainbow baby. She arranged for me to be in private rooms and not on the ward etc...."

The below charts show the experiences of care when people were seen by a bereavement midwife or nurse – compared to when they did not see one.







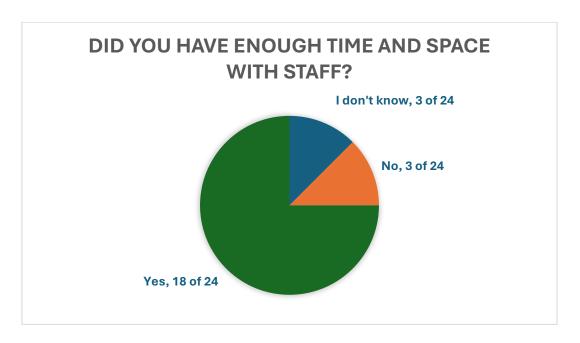
Overall, when people were given care by a bereavement midwife or nurse, they usually had a more positive experience of care. When they were not seen by a bereavement midwife or nurse, and instead received care from a different healthcare professional, their care was more likely to be poor.



This data suggests an urgent need for increased investment in the number of bereavement midwives and nurses across South Yorkshire – as well as the need for additional training and support for other healthcare professionals.

More capacity in bereavement teams would allow more bereaved parents to be seen directly by bereavement midwives and nurses. It would also give bereavement teams more time to provide more regular, comprehensive training and resources on bereavement care for all other staff involved in the care of bereaved parents and families.

When bereaved parents said that they did see a bereavement midwife, we asked them if they felt like they had enough time and space with staff:



The overwhelming majority of people did feel like they had enough time with their bereavement midwife or nurse – highlighting the high standard of care they are usually able to provide to bereaved parents.

There were only a few very limited examples of poor care being given by bereavement midwives and nurses.

"Bereavement midwife came in to see us a few times to explain the next steps after our baby died however it felt like she was reading from a script/just assessing mental state rather than being there to care and advocate for us."



"I felt the bereavement midwife didn't have much time but was lovely."

These comments show a potential need for additional training support for some bereavement staff to equip them with the confidence and skills they need to speak with and care for bereaved families

The National Bereavement Care Pathway states that healthcare staff should "be effectively supported to care for bereaved parents and families" and "receive the training and resources they need to provide high-quality bereavement care." All Bereavement Leads should receive "specialist bereavement care service delivery training".

We are calling on all NHS Trusts in South Yorkshire to ensure all bereavement staff have access to be eavement care training to equip them with the essential skills they need to care for be eaved families.

Other healthcare staff

Many bereaved parents were not able to be seen by a specialist bereavement midwife or nurse. As shown, this was often linked to parents having a much poorer experience of care.

Many parents stated that there was no bereavement midwife or nurse on shift when they were in hospital. Other parents told us that they weren't sure whether they had contact with a named bereavement midwife following the loss of their baby.

"Staff member from the bereavement suite came and talked to us about planning the funeral etc. but no specialist bereavement nurse/midwife."

"Their excuse was because it was New Years Eve that I would not receive any of the usual care provided to those who experienced stillbirth on other days of the year (bereavement midwife / a professional in to take photos etc)"

"Induction happened over a weekend so no bereavement staff present."

"I never saw or heard from the bereavement midwives."

"I never saw a midwife or a specialist nurse."

"It was after I'd given birth that I was cared for by the bereavement midwife. She came to visit me once I was home."



When bereaved parents did not receive care from a bereavement midwife or nurse, they instead were seen by other healthcare staff. These experiences were often mixed. Some healthcare staff lacked the skills and confidence to provide effective bereavement care, creating an inconsistency in care for bereaved parents depending on who was on shift.

Some bereaved parents did note that non-specialist midwives, doctors and other healthcare professionals were confident in providing good bereavement care.

"...all nurses were simply fantastic and full of compassion and professionalism..."

"Midwife who cared for was fantastic I could not have wished for a more supportive and caring person to help and care for me."

"I felt that we were lucky that the midwives we had were kind and compassionate."

"Incredible care from senior midwife and neonatal nurse as well as our consultant"

"All the midwives during my labour were extremely kind and supportive."

In some instances, bereaved parents noted that some staff were confident in providing bereavement care, and some were not - creating variations in the standard of care they received

"Some were bereavement trained and some weren't."

"...nurses were great... found the Dr's and scan staff and language used uncaring."

"They were lovely, but they just had no idea what to do with it. It's like they'd never seen someone distraught due to their baby dying before. No one said sorry, no one offered me any emotional support."

One bereaved parent went into detail, explaining how they didn't even receive the basics of good bereavement care:



"I'd gone in for a scan and they'd told me there was no heartbeat. I sobbed uncontrollably for what seemed like a lifetime. Nobody hugged me or spoke to me for minutes and minutes. then a member of staff came through with a leaflet... It absolutely broke my heart...I think even the basics would've have gone a long way, a little pre info... can I jot down a name or number if we need to contact anyone on your behalf....Yes it instils a little worry but I'd much have preferred that over the treatment I received..."

Other parents felt similarly and described receiving almost no care in the absence of a bereavement midwife or nurse:

"There was absolutely no bereavement care offered."

"As soon as our baby died, we felt like we was in way and didn't matter. And was asked to leave hospital straight away."

"Delivered my son on my own. No one was around."

"It was terrible. Staff were rude and harsh. They did not explain I would have contractions and have to push... it felt very traumatic"

When a specialist bereavement midwife or nurse is not available to provide care, it's important that other healthcare staff are confident to provide bereavement care to parents.

However, these experiences clearly suggest that many healthcare staff are not confident enough to provide personalised bereavement care in the absence of a bereavement midwife or nurse.

Sands guidance on the National Bereavement Care Pathway states that a 24/7 bereavement care service must be in place in every NHS Trust – inclusive of weekends, Bank Holidays, annual leave and sickness. Bereaved parents and families must be able to access a high-quality bereavement care service in any setting, at any time – regardless of who is on shift.

However, the experiences of bereaved parents in South Yorkshire suggest that many hospitals are not providing this 24/7 service.



Instead, the quality-of-care bereaved parents receive can fluctuate depending on whether a bereavement midwife or nurse is on shift.

This suggests a need for more rigorous and comprehensive training on bereavement care for all healthcare staff that interact with bereaved parents – equipping them the skills, knowledge, resources and confidence they need to provide consistent, compassionate and personalised bereavement care.

It's important that this additional training comes alongside further capacity in bereavement teams. This will allow more bereaved parents to receive care directly from a bereavement midwife or nurse, and give bereavement teams more time to provide comprehensive, regular bereavement care training to other healthcare professionals.

We are calling on every NHS Trust in South Yorkshire to ensure they are appropriately staffed by a bereavement team in accordance with the National Bereavement Care Pathway standards. The South Yorkshire Integrated Care Board must ensure that NHS Trusts have the funding to provide these staffing levels.

We are calling on all NHS Trusts to ensure that every staff member who is involved in the care of bereaved parents who experience a loss at any stage of pregnancy to receive mandatory, comprehensive training in bereavement care – upon induction and in regular refresher sessions. Time must be provided to attend this training in work hours.

In conclusion - care in the hospital

The experiences of bereaved parents suggest that bereavement care across South Yorkshire is inconsistent.

We've seen many examples of healthcare staff providing kind and empathetic care to bereaved parents that undoubtedly improved their experience in hospital. This is encouraging to see and shows that good bereavement care is being provided across the region.

We have also seen that people's experience of bereavement care can improve drastically when they are seen by a specialist bereavement midwife or nurse.

This shows that bereavement midwives and nurses are providing great care and highlights how important these specialist roles are.



However, we've also seen many experiences of poor care. These instances of poor care often happen when specialist bereavement staff are unavailable, and bereaved parents instead receive care from staff that do not have the necessary training, confidence and skills to deliver high quality bereavement care to families.

We know hospital staff want to provide excellent, personalised bereavement care for every bereaved parent – but it's evident that many of them do not have the resources, training, staff capacity and support to do so consistently.

Senior NHS leaders and politicians in South Yorkshire must act to prioritise bereavement care, ensuring that staff have the capacity, training and resources to provide effective bereavement care 24/7, 7 days a week.



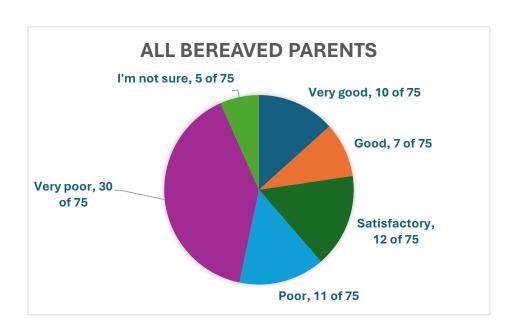
Section 2: follow-up care and mental health support

"I wasn't offered any support after my daughter passing at all. As in nothing. No support at all."

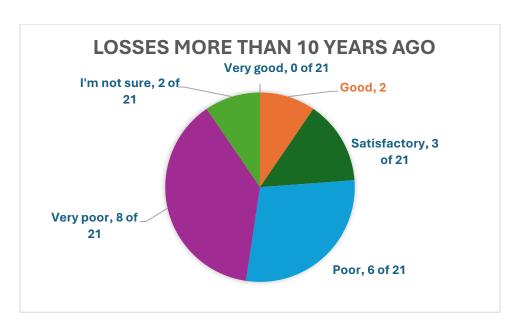
Overall rating of care after leaving hospital

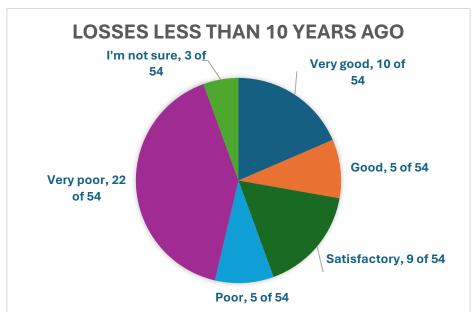
We asked bereaved parents "overall, how would you rate the follow-up care you received in the weeks and months after you were discharged from hospital?"

We defined follow-up care as any care bereaved parents received after their discharge from hospital. This could include communications from NHS staff, follow-up appointments and meetings, signposting to other support services, and access to specialist mental health services like counselling or therapies.









Sadly, most people rated their follow-up care as very poor. Many bereaved parents reported simply receiving no contact or follow-up care at all after their discharge from hospital. When people did receive some form of follow-up care, many found it insufficient to meet their needs. Key themes from the responses were:

• Sometimes an absence of any contact from healthcare staff after discharge.



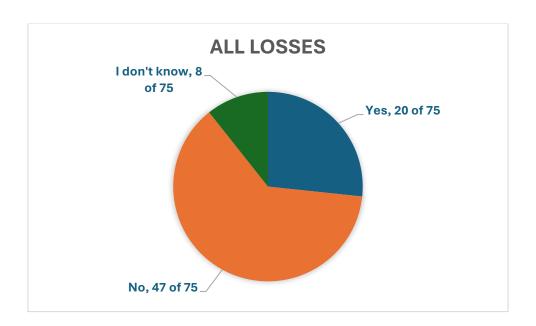
- Bereaved parents requiring more time, and regular communication, with bereavement teams.
- Having to fight and self-advocate to receive support.
- A lack of signposting to other support services, or incorrect information.
- Long waiting lists for NHS therapies with most people never receiving mental health support.
- When available, mental health services being inappropriate and not tailored to their needs as bereaved parents.
- A reliance on charity and private sector support.

There were a smaller group of people that rated their follow-up care as good or very good. This seems to have increased in the past 10 years, showing some signs of improvement.

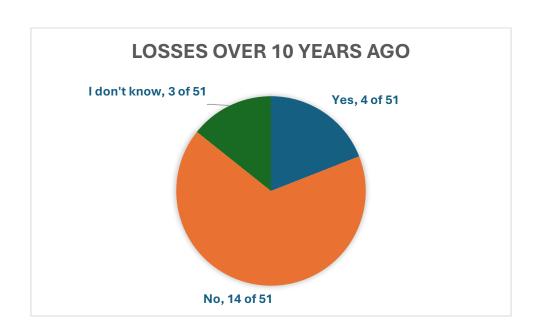
The positive experiences of follow-up care usually involved **empathetic and long-term care from bereavement midwifes** – showing the impact bereavement professionals can have if they have the time and capacity to provide the level of care bereaved parents need.

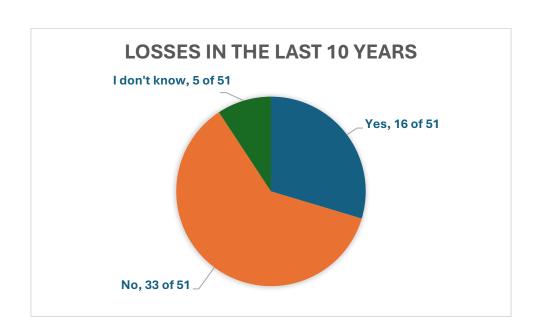
Immediate follow-up care

We asked bereaved parents 'following your loss, were you contacted by an NHS professional to discuss the different types of support that were available to you?'.









Unfortunately, most people were not contacted by an NHS professional to discuss the types of support available to them following their loss. There was no notable progress in the past 10 years. Many bereaved parents reporting feeling like they had no access to support after leaving hospital.



"There was none. My baby didn't exist to them."

"There was no follow up"

"I wasn't offered any support after my daughter passing at all. As in nothing. No support at all."

"No follow up care received."

One bereaved parent described feeling abandoned by healthcare staff and feeling unsure where to turn to for support. Sadly, they were also given incorrect information about the local Sands bereaved parent support group – being told it was inactive, which it was not.

"Follow up contact with the bereavement midwife would have been wanted, it made me felt like my loss was not the same as it was a TFMR. I felt abandoned by everyone including the bereavement team and was not able to ask for help as I did not know what I needed. I was told that SANDS was not active in Sheffield by the psychological wellbeing midwife and I would have to travel to Chesterfield if I wanted to join a group."

Other bereaved parents felt similarly that the information they received about other types of support available felt insufficient.

"I received no contact from my local GP regarding a follow up appointment, I was given no information around mental health support I ended up googling support available."

"I had to ask lots of time to be put in touch with a counsellor. I never saw or heard from the bereavement midwives. I'm worried that this is because I had a TFMR and this has really effected the guilt that I feel. I was also handed a leaflet entitled abortion on my entry to the ward. I wasn't having an abortion, I was delivering my baby."



Other bereaved parents shared that they did receive some physical leaflets and materials – but these were often not explained thoroughly enough or contained inappropriate information.

"We was just given a brown envelope which was full of age concern stuff, nothing to do with losing a baby."

"We were given leaflets and not explained anything."

"We were given an envelope with information in for support, that was the bereavement care. No care was shown throughout the process."

The above examples highlight the importance of staff taking the time to explain the contents of bereavement resources and packs, at an appropriate pace and in enough detail that works for bereaved parents. Another bereaved parent described feeling rushed to make decisions and process information, very shortly after their son dying.

"We were asked whether we wanted to cremate or bury our son within 30 minutes of him dying. We had been staying in a overnight family room at Jessops and was asked if we were leaving now or whether we wanted to stay the night, again within 30 minutes of our son's death."

When people did receive contact from healthcare staff after discharge, many parents felt like it was very limited.

"I had 1 post-natal appointment but nothing else."

"The bereavement Midwife did check in via text."

"Very bare minimum. A mental health midwife - who did not specialise in baby loss."

"...we had one meeting and that was it."

"Only follow up care was one 5 minute visit from a bereavement midwife."



One bereaved parent described the brief contact they received, and how they felt the signposting to other support was not explained in enough detail.

"One text from the bereavement midwife after one week asking how we were. After replying that I was not in a good place I received a phone call from the psychological wellbeing midwife who said that it was still early and my feelings were normal. After a further phone call a few weeks later which was similar there was no further contact and no signposting to other resources apart from a printout of charities we were given when we left hospital."

These examples highlight how many bereaved parents wanted more follow-up care, including more time and frequency of contact from bereavement teams, as well as more detailed information about the different types of support available to them – such as local Sands support groups.

Several bereaved parents described feeling listened to when they did speak to staff – but what they really needed was mental health support like therapy. We will explore the absence of specialist mental health support in the next section.

"Bereavement midwife. Great concept but all she did was listen and tell me it's ok to be sad etc, not offer any therapies."

"She did not offer counselling or therapy. Just listened to me which was not very helpful."

This highlights the importance of follow-up care from bereavement teams being accompanied with clear referrals to specialist mental health support.

Sadly, one bereaved parent felt like their experience of follow-up care felt almost adversarial, and not supportive.

"I had an appointment with a bereavement midwife, this appointment felt like I was being questioned by the police. The midwife was never available when I tried to contact for support and on the day I had my appointment with consultant to discuss my situation and what happened to my baby causing the stillbirth the bereavement midwife said she would be at the appointment to help me understand



everything properly and she never turned up to the appointment. She said she forgot."

However, we know good follow-up care is possible and is happening across South Yorkshire. Several bereaved parents shared several examples of detailed and empathetic follow-up care.

"My midwife who had cared for me throughout my pregnancy (in Barnsley where I lived) was amazing. She visited me daily after the birth. She introduced me to a bereavement midwife from Barnsley hospital who was also amazing and spent lots of time with me. I also spoke to my health visitor who was also amazing, she visited me regularly."

"Follow up call from the bereavement midwife and she went through the counselling and referred us in."

"Bereavement midwife would not usually be involved in care for gestation less than 20weeks. We were lucky we had this support. I think everyone should get bereavement support."

"My bereavement midwife stayed in touch regularly. The counselling didn't happen until 3 months after the loss but that was on when the course was recommended in terms of you not being ready for it immediately after. I also attended an art/craft group for baby loss organised by the bereavement midwife which I think was monthly but then stopped due to covid."

These examples emphasise the importance of follow-up care being regular, past just one meeting or communication, for a period that works for bereaved parents. They also suggest that when bereavement staff have the capacity to provide long-term follow-up care, it can make a real difference to be eaved parents.

We know bereavement midwives in some trusts in South Yorkshire provide follow-up care to bereaved parents for as long as they need, up to 12 months. This should be the standard across the region.



In conclusion – immediate follow-up care

These experiences suggest that follow-up care for bereaved parents across South Yorkshire needs to be reviewed.

We know that healthcare staff want to provide comprehensive follow-up care to be reaved parents and families – but we are concerned that they do not have the capacity to contact every be reaved parent, for as long as each individual needs.

Too many bereaved parents are not receiving any contact at all after discharge – highlighting a need to review how bereavement teams are checking whether they've contacted each bereaved parent. Many bereaved parents also wanted much more long-term, regular contact from bereavement teams, past simply one meeting, phone call or text.

The pockets of positive follow-up care were encouraging to see and must become the standard.

We are calling on NHS Trusts throughout South Yorkshire to review their follow-up bereavement care, and ensure every bereaved parent and family receives a parent-led bereavement care plan following discharge from hospital – for as long as they need it.

The South Yorkshire Integrated Care Board must ensure that bereavement teams have the capacity and resources to provide this follow-up care consistently to every bereaved parent that needs it.

Long-term mental health support

We initially asked bereaved parents whether they felt like they needed specialist mental health support – "following your loss, do you feel like you needed specialist mental health support from the NHS - such as counselling or therapy?"



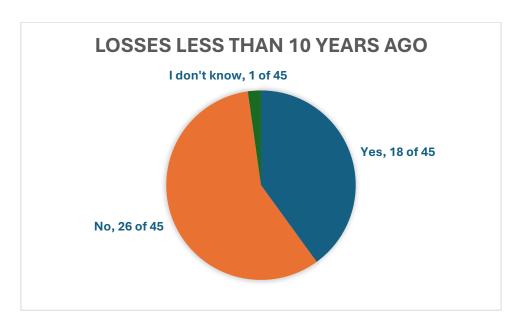


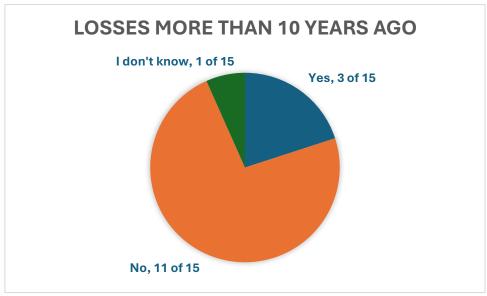
Most bereaved parents felt like they needed mental health support from the NHS following their loss – highlighting the emotional and psychological impact pregnancy and baby loss has.

We then asked people who said 'yes' to needing mental health support from the NHS the following question – "were you offered any specialist mental health support from the NHS following your loss? For example, counselling or therapy."









Most people that needed mental health support from the NHS were not offered any.

21 people were offered mental health support, but it was often unable to meet their needs. The above data does suggest that there has been an improvement in the proportion of bereaved parents being offered mental health support in the past 10 years, which is promising to see.



Sadly, many bereaved parents told us that they desperately needed support – but received nothing.

"There was none and I needed it"

"Absolutely diabolical. So bad. Felt like no one cared at all."

"We desperately needed mental health support and weren't able to access this via the NHS."

"No counselling was offered or support."

Some bereaved parents said they didn't receive this support because of their location.

"Feel like I needed more support than was offered, partly due to covid pandemic and lack of NHS resource in Barnsley."

"Two and a half years after a traumatic episode is not ideal for trauma therapy and as a result was not effective in our case. We needed a bereavement midwife or nurse but was denied it because we lived outside the Sheffield area."

Some parents were told about available mental health support – but then received nothing. This points to a failure in mental health referral pathways, with many bereaved parents feeling like their expectations had been poorly managed.

"I was offered it but never got the actual help."

"Was offered counselling but never received it."

"I was informed I was on the wait list for counselling but nothing ever materialized."

When bereaved parents did manage to get referred to mental health support, they often encountered lengthy waiting lists.

"I didn't end up using it as the waiting list was 18 months."

"The NHS therapy has a very long wait, unfortunately I'm still waiting for this 8 months on."



"I had to contact Sheffield talking therapies and the wait was 5 months for counselling."

"There was a huge wait for support via Sheffield talking therapies."

Many bereaved parents described having to fight to get support and being put onto waiting lists – highlighting once again the lack of proactive referrals being made.

"I did receive counselling BUT I had to push for it. I was told a referral had been put in, then it hadn't, then it had. It was 12wk after my loss that I was contacted for an initial assessment for counselling."

"Given the impression that there wasn't any NHS support. I had to research where to find counselling myself, via a charity."

"I didn't receive any contact apart from the things that I initiated."

When bereaved parents did manage to get access to some form of mental health support on the NHS, they often reported the care being limited and not tailored to the complexities of pregnancy and baby loss. This suggests a training need in the specifics of baby loss for NHS counsellors and therapists providing talking therapies.¹

"But very bare minimum. A mental health midwife - who did not specialise in baby loss."

"This was very limited, and she discharged us after 1 session."

"We had a couple follow up appointments with grief counsellor which just cried at us, saying how terrible it was. No other follow up care. Was referred for trauma therapy from my gp and had to wait 2 1/2 years before I saw anyone and she was really unhelpful."

¹ Sands offers training for mental health services and professionals – including training specifically for counsellors and therapists. Find out more at https://training.sands.org.uk/



"After repeated miscarriages, I asked for more support. I met with a Mental Health Nurse who advised me to read a good book!"

"Yes but it was generic grief counselling."

Sadly, no bereaved parent provided an example of receiving effective mental health support from the NHS.

Faced with a lack of support, many bereaved parents were instead forced to seek help privately, or from the charity sector.

"Managed to access some paid counselling through a baby loss counselling charity in Huddersfield. No NHS support available."

"None - petals provided 6 counselling sessions (we were outside of there area but they helped)."

"Have to rely on charity support."

"I ultimately paid privately for counselling as I did not know how I was going to be able to continue in a world without my son."

Thankfully, one bereaved parent shared a positive experience of accessing mental health support via a charity – being provided with as many sessions as they needed and preparing them for subsequent pregnancies.

"The counselling was through a charity, not the NHS, and it was specific to pregnancy/baby loss. It was a 10-step program but could take as many sessions as required. I had more than 10 sessions and also I had extra ones with my counsellor to prepare me for IVF and how to deal with what would happen if it wasn't successful."

If bereaved parents were able to access timely mental health support after their loss, it would help prevent mental health problems escalating and reduce future pressures and costs on services. One bereaved parent summarised this well:



"I don't think I'd have needed much. Maybe a couple of sessions with a counsellor. I've held it all in for years and am now in therapy but still can't bring myself to talk about it. I think if I'd have been offered the support earlier it would have helped me accept and grieve."

Freedom of information request

As part of a wider project evaluating the provision of mental health services for bereaved parents across the UK, Sands sent Freedom of Information (FOI) requests to every Integrated Care Board in February 2025. The FOIs asked each Integrated Care Board:

- Whether they commission a maternal mental health service.
- Whether this service includes specialist psychological support (1:1 therapies) for bereaved parents.
- The length of time after an experience of pregnancy or baby loss, bereaved parents can be referred into services
- How long bereaved parents are waiting to access the service.
- How long bereaved parents can access the service for.

The response from the South Yorkshire Integrated Care Board stated that:

- Specialist psychological support is available for the mother or birthing person for losses 20-week gestation and above (except for losses defined as Sudden Unexpected Death in Infancy (SUDI)).
- There is currently a pilot in Sheffield for support for losses at 0 to 20 weeks gestation.
- Bereaved parents can refer themselves to this support indefinitely, any time after their loss, with an average waiting time of 6 months.
- Once they accessed this support, they could have therapy for as long as was needed usually between 12 and 24 weeks.

These results show that, on paper, specialist psychological support for bereaved parents is being commissioned in South Yorkshire.

However – the lived experience of bereaved parents shows that many people are simply not able to access these services.



This suggests that these mental health services may lack the capacity, funding and resources to effectively provide care consistently to be reaved parents. It's also possible that be reaved parents may not be being made aware of the service and are not being referred in.

This indicates a lack of knowledge of the service or concerns about the capacity of the service from healthcare professionals.

In conclusion - longer term mental health support

"I feel my daughter was supported brilliant in hospital but since she's hardly had any support."

Bereaved parents in South Yorkshire are consistently unable to access the specialist mental health support they need on the NHS.

Most people are not told about any mental health support options, and when they are they face long waiting lists. When people manage to access support on the NHS, it is usually too short and not tailored to their needs. Many people are not aware that services even exist.

As a result, the private and charity sectors are being left to fill the gap in NHS provision.

It's unclear whether charity sector provision is sufficient to meet the needs of bereaved parents. Undoubtedly, some bereaved parents won't be able to access charity services or afford private support. This also creates an inequality by income – with sometimes only people that can afford it able to access mental health support.

We are calling on the South Yorkshire Integrated Care Board to invest in mental health support for people who experience pregnancy or baby loss. All parents who experience pregnancy and baby loss and need specialist psychological support must be able to access it at a time and place that is right for them. This should be free of charge, wherever they live across South Yorkshire.



Section 3: recommendations for change

Conclusion

"It was a case of go home and get on with it. I was never ever offered any support of any kind."

"Amazing care we received. So thoughtful and caring towards us. They couldn't have provided more."

Everyone who experiences pregnancy or baby loss deserves access to timely, personalised bereavement and mental health care. The testimonies from bereaved families in South Yorkshire suggest that, for many people, they are not getting this care consistently.

We know that bereavement staff are working incredibly hard and want to provide the best possible care to every bereaved parent.

However, it's clear they don't have the support from senior health leader to provide this consistently to every bereaved parent that enters hospital.

The <u>Ockenden Review</u> into maternity services states that every bereaved parent should have access to compassionate, individualised and high-quality bereavement care 7 days a week. Guidance on the National Bereavement Care Pathway from Sands highlights that every trust should have a 24/7 bereavement care service.

Every NHS Trust in South Yorkshire is signed up the <u>National Bereavement Care</u> <u>Pathway Standards</u> – and should be implementing them.

However, these standards are clearly not being consistently met due to a lack of investment, support and capacity for healthcare staff.

At the same time, we've seen many examples of exemplary bereavement care happening every week in the region. There are examples of bereavement midwives providing



empathetic, personalised care, spending as much time as possible with families and creating invaluable memories with their babies. We know that seeing a bereavement specialist has a huge positive impact on a bereaved parent's experience of care.

However, it's evident that bereavement teams are simply not staffed well enough to ensure every bereaved parent can access this level of care 24/7, 7 days a week – in every setting, regardless of their gestation.

Many healthcare staff are not confident enough to provide personalised bereavement care in the absence of a bereavement midwife or nurse. As a result, the quality-of-care bereaved parents receive fluctuates depending on whether a bereavement midwife or nurse is available.

There also appears to be an acute absence of specialised mental health support for people that experience pregnancy or baby loss in South Yorkshire. This gap in service provision is leaving bereaved parents less able to process their experiences and grieve. Although these services are apparently being commissioned on paper, the reality on the ground is that bereaved parents are not receiving the support they need. This must change.

We know that the South Yorkshire Integrated Care Board has ringfenced funding to implement a 7 day a week bereavement service, and mental health support, for people who experience pregnancy or baby loss. This funding comes from the NHS England Three Year Delivery Plan for Maternity and Neonatal Services. However, it is not clear how this money is being used to improve bereavement care.

Our campaign is calling on local health leaders and politicians in South Yorkshire to invest in bereavement and mental health care for people that experience pregnancy or baby loss.

This is an issue that affects so many people. According to <u>polling</u> from the Baby Loss Awareness Week Alliance, half of UK adults said that they, or someone they know, had experienced at least one form of pregnancy or baby loss.

To be a kinder, fairer, more compassionate society, we must do better for bereaved parents and the frontline NHS staff who are working so hard to support them.



Short-term recommendations for change

Some improvements and changes can be made to be reavement care provision quickly, without the need to wait for increased investment.

1. Review and improve follow-up care

"I never got a how you doing phone call. No follow ups or anything."

Standard one of the National Bereavement Care Pathway states that "a parent-led bereavement care plan should be in place for all parents and families."

Standard five of the pathway states that "'A system should be in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement."

Follow-up care should:

- **Provide continuity between settings** and ensure high-quality bereavement care in any subsequent pregnancies. This should include clear communication between hospitals and GP surgeries. GP surgeries should have a consistent method of following up with patients following pregnancy or baby loss.
- Ensure bereaved parents and families are offered **informed choices** about decisions relating to their care and the care of their babies, and that care is tailored to the preferences of bereaved parents and families considering diversity of needs and experiences.
- **Include clear referral pathways** for accessing specialist mental health support are offered to be reaved parents and families. Professionals should also be also aware of local support organisations.

These follow-up bereavement care plans should include:

- Information on local and national support organisations, available both physically and digitally. This should include up to date information on local Sands groups and be talked through with bereaved parents.
- Informing bereaved parents and families about, and where needed referring to,
 emotional and specialist psychological support. Bereaved parents should be



- informed about any waiting lists for mental health services and signposted to charity sector support where necessary.
- Bereavement teams providing **follow-up communications and check-ins** with bereaved parents through communication channels that work for them. This could be via a combination of texts, emails, phone calls, or in-person appointments, for as long as each bereaved parent needs them.

These care plans should be in place for as long as bereaved parents feel they need them. We've heard of pockets of good support where bereavement teams are offering parents follow-up care for up to a year in South Yorkshire – this type of long-term support should become the standard.

We are calling on NHS Trusts throughout South Yorkshire to review their followup bereavement care, and ensure every bereaved parent and family receives a parent-led bereavement care plan following discharge from hospital – for as long as they need it.

We are calling on the **South Yorkshire Integrated Care Board** to ensure that bereavement teams have the capacity and resources to provide this follow-up care consistently.

2. Optimise existing facilities

"The staff weren't sure which room I was in to have my baby so they put me back in the waiting room surrounded by pregnant women."

Standard two of the National Bereavement Care Pathway states that "all bereaved parents and families have the opportunity to use an appropriate, available and accessible bereavement room."

Sands guidance on this standard states that "All hospital units need to provide a dedicated bereavement room or suite for the sole use of bereaved parents and families, where parents have privacy from other families and babies." These rooms must be:

- Accessible for bereaved families without requiring them to go past families with live babies.
- Soundproofed if located where parents will be able to hear other babies and families.



- If in maternity and neonatal units, be equipped for use by parents who may be staying overnight.
- Co-designed with bereaved parents and families, with their needs are sought and considered.
- Available for the sole use of bereaved families and parents and not used for other purposes.
- 'On maternity units, facilities need to be equipped and suitable for care during labour, birth and the postnatal period.'

Existing bereavement rooms should be checked to ensure that they are sufficiently soundproofed so that bereaved parents cannot hear other babies and families.

Standard three of the National Bereavement Care Pathway states that "Cold cots should be available for use by bereaved parents and families."

• Staff should be knowledgeable and confident in supporting parents and families to use cold cots, including taking them out of the hospital – and about local protocols for use.

We are calling on NHS Trusts across South Yorkshire to ensure that every hospital unit that provides care to be eaved parents has a dedicated room or suite for the sole use of bereaved parents and families. This should include gynaecology wards and early pregnancy units. Cold cots must also be available for use by be eaved parents and families.

We are calling on the South Yorkshire Integrated Care Board to ensure that every NHS Trust has the necessary funding to build these rooms where needed – and to renovate existing facilities.

3. Review and improve care upon arrival at hospital

"I was in so much pain and no one seemed bothered."



As described above, standard one of the National Bereavement Care Pathway states that all bereaved parents and families should be provided with **personalised care** in all health care settings.

A parent-led bereavement care plan should be in place for all parents and families upon arrival at hospital. This care must be parent-centred, tailored to the preferences of bereaved parents and families, with parents offered informed choices about decisions relating to their care.

We are calling on all NHS Trusts across South Yorkshire to review their processes and care plans for when bereaved parents arrive at hospital. They must ensure that all staff that interact with bereaved parents upon arrival at hospital have the training and resources they need to provide this care.

4. Ensure memory making experiences are consistent

"They did hand and footprints for me both times, spent as long as we needed and was not rushed."

"We were not told that we would be able to see our baby after he was born or that we could spend time with him and invite family to meet him."

Standard three of the National Bereavement Care Pathway states that "All bereaved parents and families are offered opportunities to make memories."

All families should be given the opportunity to make memories, regardless of what gestation their loss is, or in what setting it has occurred.

This should include:

- Sufficient time and space to allow parents and families to make memories with their babies.
- Protocols and resources for taking babies outside of the hospital being in place, and staff being confident and knowledgeable about supporting parents and families to do so.

Every memory making experience must, where possible, include opportunities to:

• See and hold their baby.



- Wash or dress their baby.
- Take photographs.
- Collect keepsakes, such as hand and footprints and records of the baby's weight and measurements.

Detailed guidance on all aspects of the National Bereavement Care Pathway, including memory making, is available on the <u>NBCP website</u>.

We are calling on all **NHS Trusts across South Yorkshire** to review their memory making processes and ensure that every bereaved parent is supported to make memories with their baby, with as much time and space as they need.

Long-term recommendations for change

In the long-term, bereavement and mental health care provision will need sustainable, increased investment to ensure every bereaved parent can receive excellent care, 24/7, 7 days a week

1. Increase staff capacity in specialist bereavement teams.

"Both the bereavement midwives were off work during the time I had my baby."

Standard seven of the National Bereavement Care Pathway states that "bereaved parents should receive their care from an appropriately staffed team."

Sands guidance on these standard states that every Trust must have:

- A minimum full-time equivalent Band 7 Bereavement Lead in post to lead on bereavement care.
- A minimum full-time equivalent Band 7 Bereavement Midwife for every 2,500 deliveries.



• A minimum full-time equivalent Band 7 Neonatal, Palliative & Bereavement Care Nurse in each Level 3 Neonatal Unit and in all Level 2/Level 1 Neonatal Units.²

Within these teams:

- The Bereavement Lead should be responsible for ensuring systems, policies and protocols for bereavement care are embedded across all hospital settings where a bereavement may occur including across early pregnancy, gynaecology, maternity and neonatal units.
- The Bereavement Lead should also have dedicated time to support the service to meet the nine bereavement care standards including ensuring non-specialist healthcare staff receive training in providing bereavement care.
- Due to the amount of time it takes to be the strategic lead for the service, it's important that the **Bereavement Lead is supported by other Bereavement Midwives** who focus on providing patient centred care.
- The **Bereavement Lead should be supported by a team**, which may include maternity support workers, and necessary administrative support.
- The **Neonatal, Palliative & Bereavement Care Nurse** should be supported by a team, which may include healthcare support workers, and necessary administrative support.

As a result, a 24/7 bereavement care service must be in place in every trust. There should be sufficient staffing to deliver a 24/7 bereavement care service inclusive of weekends, Bank Holidays, annual leave and sickness.

As a result, bereaved parents and families must be able to access the same high-quality standard of bereavement care in any setting or unit, at any time – regardless of what gestation their loss is.

This should include ensuring:

 All staff who interact with bereaved parents are equipped with the skills, knowledge, resources and confidence they need to provide consistent, compassionate and personalised bereavement care.

² These calculations are based on work from the National Bereavement Midwives' Forum and Neonatal Palliative & Bereavement Care Nurses' Network.



• Bereavement midwives are supported by maternity support workers and necessary administrative support where needed.

We are calling on every NHS Trust in South Yorkshire to ensure they are staffed by a bereavement team in accordance with the National Bereavement Care Pathway standards, allowing them to provide a 24/7 bereavement care service inclusive of weekends, Bank Holidays, annual leave and sickness.

We are calling on the **South Yorkshire Integrated Care Board** to ensure that NHS Trusts have the funding to provide these staffing levels, and where needed release new funds to hire additional bereavement midwives, nurses and support staff.

At Sheffield Hospital, which has over 5,500 births, and a level 3 Neonatal Intensive Care Unit, there is a particular need for additional investment.

The current capacity of part-time staff is not sufficient to meet National Bereavement Care Pathway guidance on staffing levels. This limits the number of bereaved parents that can be seen by bereavement midwives or nurses, as well as the amount of training and support that bereavement midwives can give to other healthcare staff.

The experiences we've heard from bereaved parents also indicate a need for specific bereavement care capacity for early losses in the gynaecology unit.

We are calling on Sheffield Teaching Hospitals NHS Foundation Trust to ensure the bereavement team has the additional staff capacity to the equivalent of:

- 2 full-time Band 7 Bereavement Midwives
- 1 full-time Neonatal Bereavement Nurse
- 1 full-time Early Loss Bereavement Midwife or Nurse to support bereaved parents within the gynaecology unit.

This is in addition to the necessary administrative and coordination support capacity within the bereavement team.



2. Provide more comprehensive training to healthcare staff

"As soon as our baby died, we felt like we were in the way and didn't matter."

Standard eight of the National Bereavement Care Pathway states that "all staff involved in the care of bereaved parents and families receive the training and resources they need to provide high-quality bereavement care."

This should include:

- Staff receiving training on induction and annual refresher training. Staff should be able to access this training in working hours.
- The training covering the four elements of the Perinatal Loss Proficiency framework: Clinical Skills, Emotional and Spiritual support, Communication, and Paperwork.
- Specialist bereavement care service delivery training provided for all Bereavement Leads.
- All staff having access to up-to-date and relevant bereavement care resources.
- Staff in all hospital settings that provide care to be reaved parents including gynaecology wards, early pregnancy units, and in A&E.
- Staff in all community settings that may provide care to bereaved parents including GPs.

We know many bereavement teams are too stretched and low on capacity to provide this training comprehensively, and regularly.

Additional training for all healthcare staff must therefore be accompanied by increased investment in the capacity of bereavement teams so they can provide this more regular training. Funding could also be provided to pay for external training and facilitators.

We are calling on all NHS Trusts in South Yorkshire to:

- Ensure that every staff member who is involved in the care of a baby receives mandatory training in bereavement care upon induction and in regular refresher sessions.
- Provide time in work hours to attend this training.
- Ensure all bereavement team members have access to specialist bereavement care service delivery training to improve their practise.



3. Invest in mental health services to ensure they support all bereaved parents.

"Asked my GP & they informed me of 18 month waiting list."

As set out in the <u>NHS Long Term Plan (2019)</u>, every Integrated Care Board in England should be commissioning a maternal mental health service that provides psychological support to be eaved mothers and birthing people.

These services should also offer an assessment and signposting for bereaved fathers and partners.

However, for most bereaved parents in South Yorkshire, they are simply not getting this support.

Although the early baby loss pilot in Sheffield is a promising development, it's wrong that this tailored support is only available to losses pre-20 weeks – leaving later losses unable to access support. The existing Birth in Mind Service in Sheffield is clearly not providing sufficient support to parents who experience later losses baby loss.

We know there are pockets of mental health support available in other areas in South Yorkshire, but many bereaved parents do not live close to where this support is available – creating a postcode lottery in access to mental health services.

We know that funding is available for specific baby loss mental health support in the NHS England Three-Year Delivery Plan for Maternity and Neonatal Services. However, bereaved parents are clearly not receiving this support.



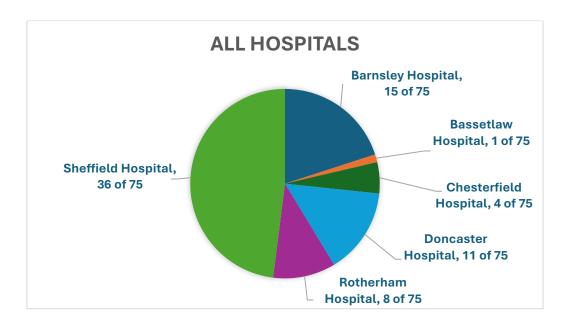
We are calling on the South Yorkshire Integrated Care Board to provide ringfenced funding to mental health services for the provision of a perinatal loss pathway for people who experience pregnancy or baby loss.

- This should ensure that all parents who experience pregnancy and baby loss and need specialist psychological support can access it, at a time and place that is right for them.
- This should be free of charge, wherever they live across South Yorkshire.
- This service should be available for bereaved parents who experience a loss at any gestation, have provision for fathers and partners, and be available at any time after their loss.



Appendix 1: results by hospital and time of loss

We looked at the experiences of bereaved parents across 5 hospitals: Sheffield, Barnsley, Chesterfield, Bassetlaw, and Doncaster.



We wanted to gather the experiences of every bereaved parent, regardless of when their loss was. However, we are also aware that there have been developments in the quality of bereavement and mental health care in recent years.

To take account of this, throughout this report we have separated the answers to survey questions by 1) all losses, 2) losses in the past 10 years, and 3) losses over 10 years ago.







Appendix 2: results by gestation of loss

We asked every respondent to our survey how many weeks pregnant they were before they gave birth. We also asked if their baby died before, or after birth.

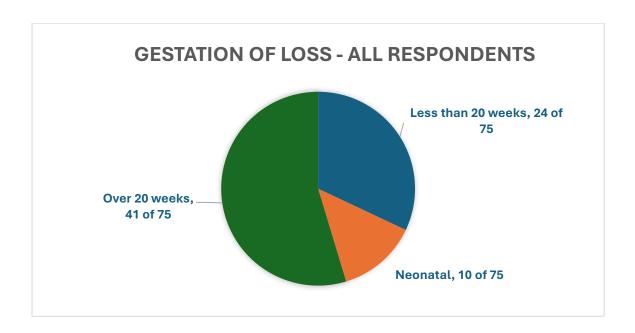
We know that hospital trusts across South Yorkshire have different criteria for whether bereaved parents receive care on a gynaecology, early pregnancy, maternity, or neonatal unit.

Bereaved parents at Sheffield Hospital receive care on the maternity unit if their baby is at least 20 weeks gestation. Since most of our respondents received care in Sheffield Hospital, we have split the data below by:

- Losses less than 20 weeks gestation indicating that they may have received care on a gynaecology or early pregnancy unit.
- Losses more than 20 weeks gestation indicating that they may have received care on a maternity unit.
- If their baby died after being born indicating that they may have received care on a neonatal unit.

From this we can infer some general trends in the quality-of-care bereaved parents received based on the gestation of their loss.





Rating of care in the hospital

The key themes in our report were present in responses from bereaved parents regardless of when their loss was.

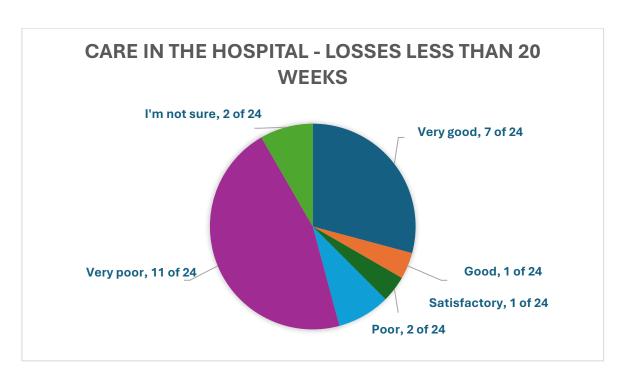
This includes inconsistency in the quality of care, lack of available specialist staff, training needs for wider staff, access to suitable bereavement facilities, and the need for more consistent memory making experiences. There were also exemplary, positive examples of care across every type of loss.

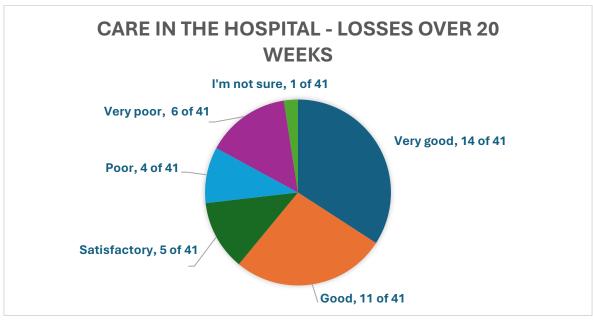
This suggests a need to support staff, and improve bereavement care, in all units that care for bereaved parents in hospitals across South Yorkshire.

However, bereaved parents were more likely to have a poorer experience of care if their loss was at less than 20 weeks gestation – suggesting an additional need for investment in bereavement staff, as well as training and support, in gynaecology and early pregnancy units.

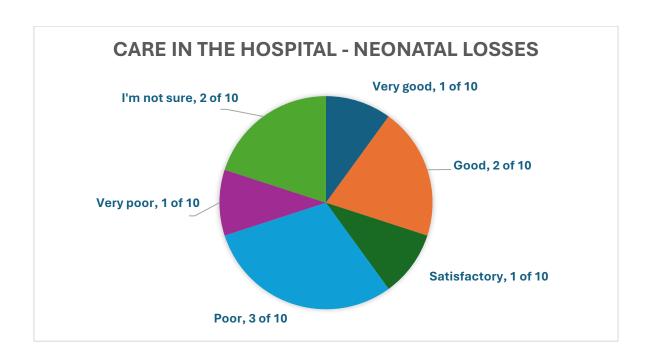
However, there were still stark examples of poor care in losses after 20 weeks, and from bereaved parents that experienced a neonatal death.











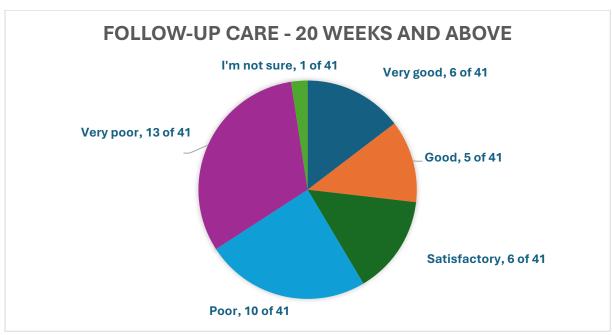
Rating of follow-up care

Similarly, bereaved parents highlighted a lack of suitable follow-up care regardless of what type of loss they experienced.

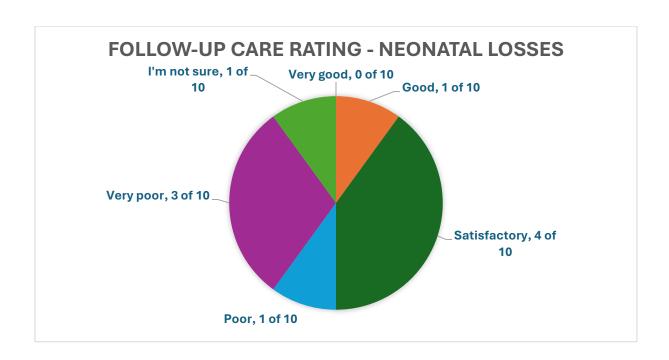
The results here are more consistent across different types of loss, indicating a strong need for investment in follow-up bereavement and mental health care for all bereaved parents and families.











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