

Introduction

In 2024, ARC conducted an online survey on experiences of care for termination for medical reasons (TFMR) in the UK within the last 4 years. The survey was designed to get an up-to-date overview of experiences of care when people decide to end a wanted pregnancy after a diagnosis, with questions covering diagnosis, choice of and views on method of termination, and care and support during and after termination.

Our survey had 399 completed responses from across England, Wales, Scotland and Northern Ireland. This report covers some of the main findings of the survey; including that the majority of parents reported good experiences of care. We describe what parents said they valued in their care during TFMR. We also cover the need for improvements to ongoing care and support after TFMR, as well as choice of method.

A note on language: We use the terms parents and baby in this report because this is the language most people use when ending a wanted pregnancy. We recognise that some people would prefer to use other language such as 'people' or 'fetus'. We also use the acronym TFMR as it has become the preferred wording for many parents. We always recommend following bereaved parents' lead and using the language they choose.

Most parents had good care

Overall, the majority of survey respondents (84%) rate their care as excellent (42%), very good (29%), or good (13%). Parents who experience good care are grateful to staff, and emphasise the importance of receiving such good care during a potentially traumatic time. While any TFMR is a difficult experience for parents, good care can help parents cope during and after the procedure.

"I feel lucky to have received such good care. To have had poor care would have significantly increased my trauma."

"Despite this being a particularly unpleasant and traumatic experience, I can reflect positively on the amazing care I received at my hospital. It has given me hope and comfort for the future should I manage to get pregnant again."

"The midwives were so understanding ... They really made the most awful situation as nice and calm as it could be. I'm forever grateful to them."

Only 9% of survey respondents say their care was poor (4%), or very poor (5%). However, any level of poor care is concerning.

What parents value

We asked survey respondents to share the most helpful and positive aspects of the care they received. We found eight main themes in the responses: 1. Compassionate care; 2. Adequate pain relief; 3. Offer of memory making; 4. Privacy with partner support; 5. Continuity and contact details; 6. Clear information; 7. Time to ask questions and make decisions; 8. Short waits for appointments, with choice of timing.

Compassionate care

The importance of kindness to parents going through TFMR was an overwhelming theme in the survey responses. Being treated with kindness and compassion can support parents in their grief for

the loss of a wanted baby. It also helps alleviate parents' fear of judgment for making the decision to end their pregnancy.

"Midwives, nurses and consultants were all kind and compassionate. They did not pass judgement on us and knew it was a very painful decision."

"All the staff introduced themselves, including in the operating theatre, which made it feel safe. They all knew why we were there and were very compassionate and caring. They made it clear they understood how terrible this was for us."

Adequate pain relief

Parents value being given information about the full range of pain relief available to them, and timely access to appropriate pain relief in labour.

"The midwives were supportive and sympathetic. I was offered plenty of pain management options"

"Our midwife was absolutely amazing and asked us ... what pain management we want and was very supportive throughout the birth process."

Women should be prepared with information on pain when choosing method of termination and staff should be trained to support women's informed choices on pain relief.

"The midwives had real misconceptions on the length of labour to expect (I was led to believe it would be very quick and easy when in fact it was a very difficult and excruciating 12 hour labour). ... a junior anaesthetist wrongly refused an epidural saying they "don't give that to women in [my] situation."

Offer of memory making

Receiving information about options for memory making is important to parents. Parents prefer having information in advance to give them time to make decisions and help them prepare. Supportive, trained staff can help parents who may be unsure about how they will feel and act on the day.

"They took a scan photo for us ... The nurse at BPAS put it in an envelope and sealed it for us to open when we felt we could. That was one of the kindest things anyone has ever done. The BPAS nurses also provided us with options in relation to taking hand and footprints as well as the offer of cremation, which we chose."

"Midwives informed us of professional photography service by remember my baby, and this was just so precious to have done. Hospital also provided a cuddle cot so our baby could come home with us, which allowed us five very cherished days at home with our baby before we said our final goodbyes."

Respect for whatever decisions women and partners make is also crucial. Different people will choose to memorialise their baby in different ways, or not at all. Those who choose not to memorialise or mark the loss of the pregnancy should feel equally supported.

"The midwives were incredible. They were so friendly, supportive and professional. They respected my wishes not to see the baby"

Privacy with partner support

Parents value having access to a private space and for a partner or support person to be with them during their TFMR care, wherever possible.

“There was a fantastic separate suite for us, away from other maternity wards, my husband was able to stay with me throughout and we were encouraged to spend as much time as we wanted with our son. Little things like checking the lift / corridors were clear before we left made such a difference so we didn’t have to leave with another couple and their healthy baby.”

“We were able to have our own room so we could be together in privacy. We felt respected and they knew how much we wanted and loved our baby.”

Parents having their care in NHS hospitals generally want to be in a separate space apart from general antenatal waiting areas and people on maternity wards having healthy, living babies.

“When we first arrived at the hospital we were made to wait in area surrounded by new mothers and pregnant women with baby monitors on. Hearing healthy babies, and strong heartbeats was incredibly difficult at that point.”

Parents having their care in the independent sector generally prefer to have separate waiting areas to those having terminations for unwanted pregnancies. They should also be prepared for the possibility of seeing protesters near clinics.

Wherever they are, most parents want it acknowledged that they are experiencing a bereavement. When preferences for privacy and partner support cannot be accommodated, it is important to prepare people for this before their TFMR. Not being allowed a partner or support person present during TFMR can be very distressing, particularly if parents have not been prepared in advance.

“I was not allowed to have someone with me before or after my operation. I had to wait for over 5 hours in a room on my own and I didn’t understand why my friend couldn’t be with me. That was very painful and I was not prepared for that.”

Continuity and contact details

Parents appreciate continuity of care where possible. Parents understand this may not always be feasible but are grateful when they are cared for by staff who are aware of their circumstances, and when they receive sensitive follow-up care. Parents also value having a point of contact with healthcare professionals if they have questions or need support between appointments or after TFMR.

“We had an amazing fetal medicine midwife and consultant who were both very caring and supportive and followed up during and after the termination. Our consultant came to see us while I was in labour.”

“I’ve had a bereavement midwife throughout the process so I had a continuity of care. She answers all my questions and showed me where I could go for support. ... She has been someone who ... knows and supported my whole story so I’ve not had to repeat myself and is there to check in with or she checks in with me.”

When continuity of care cannot be provided, it’s very important that staff are prepared and the circumstances of the TFMR are communicated in notes and staff handover.

“One midwife left me alone overnight without checking on me and forgot to inform other staff that my baby was not alive, this resulted in very emotional and embarrassing situations.”

Clear information

Receiving as clear information as possible at every stage is very important to parents. Knowing what to expect during the TFMR procedure is very important to women; for example, being prepared for possible complications can help if complications do occur.

“The midwives explained every aspect of what to expect including the possibility of retained placenta which then helped when this actually happened”

“Information was clear, I didn’t feel mollycoddled. Felt supported no matter which route we went down”

Time to ask questions and make decisions

Receiving a diagnosis and ending a pregnancy are highly distressing and stressful experiences. Even with staff doing their best to provide clear information, parents may struggle to take in information at these times and appreciate staff giving them time to ask questions and make decisions.

“We never felt rushed, everything was in our own time. They were informative and took time to answer all questions we had.”

Short waits for appointments

Finally, parents value being offered follow-up appointments quickly, and having choice of timing for their termination. While most parents are grateful to be offered a termination appointment as soon as possible, others may choose to delay the TFMR to a later date for individual reasons such as giving themselves time to prepare or reaching the qualifying date for maternity leave.

“I think it was best that everything moved so quickly once we had decided to end the pregnancy there was no reason to prolong the heartache”

“Very grateful that this was organised quickly and that they were able to do the operation in my local hospital.”

Improving aftercare

While most parents report receiving good care during their TFMR, support afterwards was rated much less highly, with many parents raising it as an area of care in need of improvement

71% of parents did say their care after TFMR was excellent, very good or good. Parents who did have supportive aftercare are very grateful and talk about how it helps them cope with their grief after TFMR. Many parents value having ongoing support from a bereavement midwife.

“I truly felt supported during and after and I don’t think I would have survived without the care of the bereavement midwife”

“the after care was more than we would have expected. We are sure this will make a big difference in our recovery journey”

However, other parents note that more proactive aftercare should be offered as standard, and beyond the support of a bereavement midwife. Parents suggest a pre-booked appointment to

discuss physical and emotional recovery and referral to specialist maternal/perinatal mental health services where appropriate.

“I was referred for low cost counselling a few months after my loss for anxiety and also had CBT on the NHS. This was very useful but I think some kind of support should be offered as standard and quicker - beyond the bereavement midwife.”

Sadly, 17% of parents say their care after TFMR was poor (8%) or very poor (9%). Many describe trying to reach out for support after their TFMR and staff not responding, or staff being unaware of what support is available to parents after TFMR.

“After the termination I was told I would have a visit from a community midwife. I didn’t. I never heard from them, until 2 months later when they called me to ask why I’d missed my antenatal appointments. The bereavement midwife called me once and I asked for a petals referral, which she did. I’ve emailed her a couple of times since regarding some concerns I had and have never had a response.”

“The after care was very poor. Things were not explained to me and I was given no real guidance. I ended up back in hospital as I experienced excessive blood loss. I was also referred for counselling but the referral was lost in the system. When it finally went through it was for CBT and was not appropriate. The waiting time was also nine months.”

Parents also emphasise that aftercare and support should include partners.

“I would like to see more psychological support not just for women but also for their partners as well who may also be struggling with the decision but trying to stay strong to support the mother.”

Choice of method

Finally, the survey also asked whether people were offered a choice of method (medical or surgical termination), which method people chose and whether they felt that method was the right option for them.

We found that less than half of respondents (48%), excluding pregnancies over 23 weeks +6 days, were offered a choice of method of termination. Of those respondents, 29% had a surgical termination; some of these parents describe having to research and arrange their own surgical termination.

“I was upset at nhs information delivered by midwife that said only medical was covered by nhs. And surgical would have to be sorted by myself.”

“It was difficult to arrange the surgical procedure and there were additional layers of trauma that came from having to do this”

Others say they would have preferred a surgical termination but couldn’t face longer waiting times or travelling to access this care and decided to proceed with medical termination that could be arranged sooner and closer to home.

“I had wanted a surgical termination but I could not have waited weeks for the appointment.”

“The hospital didn't do surgical, we would have to travel far to London. It was hard enough and we had a living child to think of.”

“Only local option available - surgical through the independent clinics was too far away and logistically difficult”

There are also significant disparities between countries when it comes to choice of method. Only 7% of Scottish respondents say they were offered a choice of method and 100% of them went on to have a medical termination.

When asked about the choice of method of termination, many respondents express ambivalence around both methods of termination. With both methods, people describe having ‘what ifs’.

“Part of me wanted to see my baby but on balance I think it was better for my mental health not to go through the birth”

“I think either option would bring with it its own flavour of trauma. There are things I wish I’d known or had access to. But I also realise that the grass might not be greener on the other side.”

Some respondents who had a medical termination described the process of their TFMR as traumatic.

“I’m glad I got to meet my son and spend time with him, but giving birth to him and having to say hello and goodbye was the worst experience of my life. If I were to be put in the position again where I had to choose, I’m not sure I could put myself through that again.”

“I got to see and spend time with my little one after he was born although the process was traumatic”

Some respondents who had a surgical termination described feeling guilt and pain.

“I think it was right, and I accept it is what I needed at the time. But I have lived with and still live with a lot of guilt that I didn’t see the baby/name it/bury it the way that others do.”

“I feel guilt and pain since, that we didn’t get to meet our son ... But we made the right choice in the time we had to decide”

Importantly, overall, both methods were rated similarly. We asked ‘what extent do you feel the type of procedure you had was the right one for you?’, with a sliding rating scale numbered 1-100. Among those who had medical, the average rating was 80 and among those who had surgical, the average rating was 82. Interestingly, among Scottish respondents, who were mostly not offered a choice of method, the average rating was 70.

Despite ambivalence around both methods of termination, parents stress the importance of being given information about both methods. While for most parents no option will feel completely ‘right’ in the circumstances, parents often have strong feelings about which method is the ‘least worst’ for them. Parents should be supported in making an informed choice and accessing their preferred method.

“I remain incredibly grateful that surgical termination was available to me and that I was not required to go through delivery. I can understand that delivery feels like part of the process/closure for some mums-to-be (and tragically some have no option). I found my closure in other ways and felt huge relief that surgery was an option.”

“I wish I had fully known what each option would entail, and I wish I’d known that I could have met my daughter, or had her hand and foot prints.”

“I would have liked all the options to be provided. One consultant subsequently explained that we were so overwhelmed with the “decision” that they didn’t want to give us more to think about - it’s very important that women have autonomy over their bodies during such procedures and labour.”