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### **About us**



#### **Healthwatch County Durham**

This report has been produced by Healthwatch County Durham. We are an independent organisation whose aim is to help people get the best out of their local health and social care services, whether it's improving them today or helping to shape them for tomorrow. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience.

As a statutory watchdog, our role is to ensure that local decision-makers put the experiences of people at the heart of their care so that those who buy (commissioners) and provide our services (NHS Trusts, local authorities, GPs, the voluntary sector, and independent providers) can benefit from what people tell us.

The Healthwatch network currently consists of 153 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London.

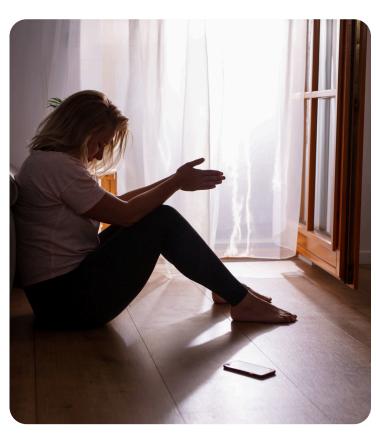
For more information about us please click on this link: <u>Healthwatch County</u> Durham Or scan this QR code



# Summary

Miscarriage is a common experience, yet many people go through it without the support they need. Despite affecting thousands of families each year, it is still often met with silence, stigma, and inconsistent care.

This report focuses on the experiences of people in County Durham who have faced miscarriage, drawing on survey responses and personal stories. Their voices highlight where care is compassionate and effective, but also where systems fall short.



#### **Key Findings**

- Emotional impact: Nearly all respondents reported long-term mental or physical effects, including grief, trauma, and anxiety about future pregnancies.
- Support gaps: Three-quarters did not feel adequately supported by healthcare professionals. Information was often unclear, and emotional needs were overlooked.
- Care environment: Many described distressing experiences, such as waiting alongside expectant parents while facing the loss of their baby.
- Communication and choices: Families were not always given clear explanations or time to make decisions about their care.
- Positive experiences: Where support felt meaningful, it came from individual staff members showing empathy, rather than from the wider system.

#### Conclusion

Every miscarriage is deeply personal and deserves care that is respectful, compassionate, and informed. While some families experienced kindness and support, too many were left feeling dismissed, isolated, or even traumatised. By listening to these voices and acting on their recommendations, services in County Durham can move closer to providing care that truly supports families through one of the most difficult experiences of their lives.

## Introduction

The nature of this content is particularly sensitive, and we want to acknowledge that it may evoke strong emotions. We have made every effort to approach it with care and respect. However, please be aware that some of the details discussed may be upsetting or distressing to some readers.

Miscarriage remains one of the most common yet often overlooked experiences in pregnancy, with approximately 120,000 miscarriages occurring annually across the UK (Sands & Tommy's). According to the NHS, around 1 in 5 pregnancies end in miscarriage, highlighting how widespread and impactful this issue is. Despite the frequency, miscarriage is often surrounded by silence and stigma, leaving many individuals and families without the emotional support or understanding they need.

This report explores the lived experiences of miscarriage from residents of County Durham. County Durham is served by the maternity department of the County Durham and Darlington NHS Foundation Trust (CDDFT), which plays a central role in providing care and support to women and families experiencing pregnancy loss. Understanding how services like these support—or fall short of supporting—patients is essential for identifying areas of improvement.

The motivation behind this research stemmed from a recognition that miscarriage is often experienced in isolation. By giving space to these stories, this report aims to shed light on the personal, social, and systemic factors shaping miscarriage experiences and to inform more compassionate, inclusive, and responsive support systems.

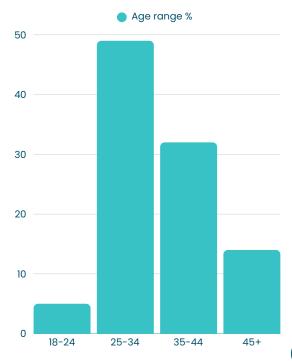
## **Method**

We designed a survey after consultation with County Durham and Darlington Maternity and Neonatal Voices Partnership (MNVP) and the Patient Experience Team at University Hospital of North Durham (UHND) to help us gain a full understanding of some of the issues families are facing. The survey was then shared with County Durham Family Hubs, Sands online support meetings, and MNVP. We promoted the survey on our website and ebulletin, across our social media networks, along with taking paper copies to our engagement events.

The survey was open to responses between May 2024 and April 2025, during which we received 71 responses. While the majority of our respondents identified as female, we also received valuable insights from partners who had experienced miscarriage. Ninety-five percent of respondents were white British.







# **Personal Experiences**

The report that follows includes the original words of people who kindly shared their stories with us.

#### Personal experience A

"I had a miscarriage on Saturday 27th August 2022. I spoke with the Midwife following spotting the previous Monday and received advice to monitor this given that I was prior to 16 weeks Pregnancy assessment would not see me which was acceptable advice at that time. However on the Saturday when the bleeding was heavier, I attended Darlington A&E, I was there alone given I have an older child in bed whom my husband stayed with and it was early hours of the morning. The Doctor at A&E was brilliant and kept checking in on me and offering comfort if needed, however I was then transferred to gynaecology ward for an assessment. This was where my experience went downhill. The on call gynaecologist showed no empathy in a time which I felt very vulnerable and scared. After completing a physical examination the words offered to me from this doctor was "Well there's nothing going on down there" and walked out of the room. I didn't get anything further other than the woman assisting advising I was okay now to leave the hospital. It was only when was one of the nurses on the ward stopped me and gave me a cuddle, I explained what was happened and she had been informed by the other woman who assisted the doctor, did the nurse then apologise on the doctors behalf. I was then offered some leaflets and sent on my way with nothing else."



#### **Summary personal experience A:**



#### **Emotional Vulnerability**

- Attended A&E alone in the early hours, feeling scared and vulnerable.
- Initial care from A&E doctor was compassionate and reassuring.



#### Lack of Empathy in Specialist Care

- Transferred to gynaecology ward where empathy was absent.
- On-call gynaecologist said: "Well there's nothing going on down there" deeply insensitive.
- No further explanation or emotional support provided.



#### **Compassion from Nursing Staff**

- A nurse stopped the patient from leaving, offered a cuddle and apology.
- Provided leaflets, but no further guidance or emotional care.



#### **Communication Breakdown**

- No clear information about what had happened or what to expect next.
- Patient left feeling dismissed and unsupported.



#### **Patient Recommendations**

- Empathy training for all clinical staff, especially in gynaecology.
- Clear communication and emotional support during miscarriage care.
- Follow-up resources should include emotional guidance, not just leaflets.

#### Personal experience B

"My first miscarriage - I was told that my baby was only measuring 7 weeks at my 12 week scan. I was told that something was very wrong and I was most likely going to miscarry. I was told I could abort the pregnancy but it would be recorded that I had terminated the pregnancy! I was then sent home just before Christmas and left for 2 weeks to miscarry at home. I did not miscarry and ended up at UHND hospital for another scan to confirm my baby had died. I sat in a waiting room with other parents who were talking about their babies as they came out with their 12 week scan photos beaming at each other. It was confirmed I'd had a missed miscarriage and I was admitted and gave drugs to make me miscarry. It was the worst experience of my life. My second miscarriage - told at the 12 week scan I had another missed miscarriage (at approx the 8wk stage). Back to UHND for another procedure to make me miscarry. It didn't go well and I became very poorly during the process with a fever and pain. I think at all scans, this should be done away from the baby unit. Parents should go into the room from a waiting area and exit from another door which does not put you back into that waiting room."



#### Summary personal experience B:



#### **Emotional Impact**

- "The worst experience of my life."
- Deep trauma from two missed miscarriages.
- Emotional distress from being around expectant parents.



#### **Communication Sensitivity**

- Language used felt judgemental ("terminated pregnancy").
- Need for more compassionate, supportive dialogue.



#### **Environment & Privacy**

- Shared waiting areas caused emotional harm.
- Recommendation: separate entrances/exits for miscarriagerelated scans.



#### **Care Experience**

- Sent home to miscarry naturally over Christmas prolonged distress
- Second procedure led to severe pain and fever.



#### **Patient Recommendations**

- Scans for miscarriage should be away from baby units.
- Patients should exit via a different door to avoid re-entering shared waiting areas.

#### Personal experience C

I had an unusually medically complex missed miscarriage: -

- 1 urgent care visit for unexpected bleeding at 12 weeks -
- 1 follow up at maternity assessment for a scan which found no heartbeat present, advice given about options but direction towards letting nature take its course

Nature clearly didn't feel in any hurry to take its course, not much clarity or advice about how long to wait or what to do, heavy bleeding began suddenly then worsened massively, blue light ambulance to hospital for management of bleeding and medical intervention to remove ERPC (evacuation of retained products of conception)- lost a lot of blood but not quite at threshold for transfusion. 6-8 weeks recovery feeling physically dreadful and traumatised by haemorrhage (NOT the pregnancy loss which was sad but not felt by me as a bereavement) abdominal pain and bleeding began again, back to assessment for a scan. Needed ERPC. - Op scheduled. It was awful. I was satisfied by the care at various points and clearly quite unlucky. I also know the NICE guidelines were followed in terms of options put to me when missed miscarriage was diagnosed. HOWEVER, I was in shock when this was discovered the USS (ultrasound technician) actually cried and while I cognitively understood the options, was in no position whatsoever to make a decision about medical or surgical management and so went with the default recommendation to let nature take its course. I appreciate this is the NICE guideline but it deviates entirely from international practice and is a piece of \*\*\*\* as far as I'm concerned. Women need to have options and make choices but in a traumatic situation directing them to a scenario where there is a risk of haemorrhage (however low) and seeing the embryo/foetus when miscarrying etc takes no account of the psychological impact of the experience and potential for this to be harmful. Not clear that the NICE guidelines consider this psychological aspect (they are generally poor on psychological topics).

I would have surgical management 10,000 times over waiting for nature to take its course and the idea that a miscarriage is like a "heavy period" is the single most nonsensical comparison I've heard. Not if you're over 6-8 weeks it isn't. Ban the phrase and let women know what they're in for. I understood that my experience was unusual and asked everyone I knew who had had a miscarriage and every single woman agreed and had been freaked out and terrified by the amount of bleeding. It is barbaric not to offer surgical management as the default with the other options available if preferred. It is the most let down I've ever felt by the health service, all the more so when I discovered in other comparable countries there is no question of hanging around waiting for the miscarriage to happen naturally...

#### Cont....

I was sad and shocked when the USS diagnosed the missed miscarriage and was treated with kindness. It's not ideal that the USS tech cried, but I can't fault her for being a human being. Equally, I was then in the position of trying to make her feel better and this might have gone down a lot worse with somebody else. She was very apologetic and I really didn't mind greatly, but I [job role in the health sector\*] and obviously recognise this is not really what is supposed to happen. I also want to be really clear that this miscarriage was not a significant bereavement to me. I was sad and shocked but miscarriages are extremely common and I knew that, even at the 12 week point. It's not nice to be with other heavily pregnant women when miscarrying but for me the issue was not that this was a grief and loss situation but that it was a hideous physical experience. I know some women feel a lot of grief even for very early pregnancy loss but loads of us don't and that's fine too. What I didn't feel well supported in was the "like a heavy period", "let nature take its course" default.

I wasn't at the threshold for a transfusion, but just on the edge of it. I had lost a lot of blood and was very anaemic – had to sit down to rest climbing a flight of stairs in the first couple of weeks. This was also not helpful since I had a two year old. I got iron tablets on discharge but no clear info in terms of managing my expectations about the impact of anaemia on physical fatigue and cognitive function, which was not a great combination. I also suffered an acute stress reaction following the haemorrhage which I diagnosed myself and treated while in hospital using [a therapy\*], because I happen to be a [job role\*]. Chances are this could have progressed to PTSD if I hadn't known what I was doing. Not one single enquiry about psychological symptoms of acute stress reaction despite a really significant haemorrhage: blood was dripping through a child's nappy I had used to try to absorb it and trailing along the A&E floor while the trolley was getting me in off the ambulance. Some kind of acute stress reaction check, normalisation, self-help info should be standard in such a situation.

\*Words in italic and [] indicate text has been changed to protect the identity of the individual

#### Summary personal experience C:



#### **Physical Trauma**

- Sudden, massive bleeding led to emergency ambulance and medical intervention.
- Two ERPC procedures required.
- Severe anaemia post-miscarriage, impacting daily life and parenting.



#### **Psychological Impact**

- Acute stress reaction following haemorrhage.
- No psychological screening or support offered.
- Patient self-managed symptoms using techniques known through job role.



#### **Communication & Decision-Making**

- Diagnosed during scan; ultrasound technician cried; compassionate but emotionally complex.
- Patient felt unable to make informed decisions due to shock.
- Criticism of "let nature take its course" as default recommendation.



#### Guidelines & Systemic Issues

- NICE guidelines followed, but felt outdated and psychologically harmful.
- Compared to international practice, UK approach felt barbaric and unsupported.
- Strong rejection of the phrase "like a heavy period" misleading and minimising.



#### **Patient Recommendations**

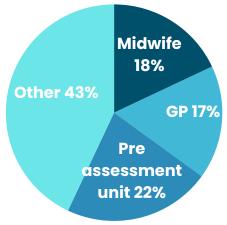
- No single option should be presented as the default. The priority must be on offering genuine choice and delivering personcentred care
- Ban misleading language and provide realistic expectations.
- Psychological checks and support should be standard after traumatic miscarriage experiences.
- Clearer guidance on recovery, anaemia, and physical fatigue.

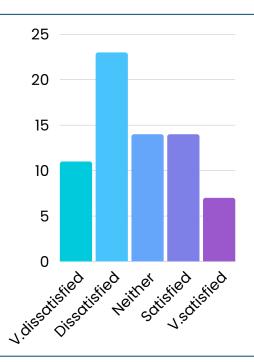
# **Survey Responses...**

The following charts and data have been produced from the survey responses we received and provide further insight into the experiences of

those who contributed.

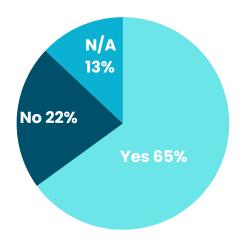
Which service did you contact/speak with?



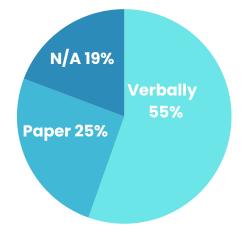


How satisfied were you with the advice you were given?

Did you know what your options were?



How did you receive the information about your options?

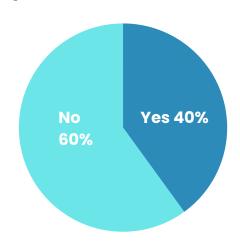


# **Survey Responses...**





If you went into hospital were you placed where you could hear babies?



80% were placed alongside pregnant women whilst waiting for an ultrasound scan to confirm miscarriage

# Did you feel supported following your loss by health professionals?

We asked individuals if they felt supported by health processionals following their loss. We found the majority of people (74%) didn't feel they got the support they needed during and after their miscarriage. Please find below some of the feedback we received about support.

"There was no support, I was just told there was no baby and sent on my way and didn't hear anything from them after"

"No support given. One GP said I could talk to someone if I wanted, but every other time there was no support. No one even asked whether I was trying for a baby or wanted to look into why I miscarried so often. I was never offered a scan or follow up."

# 74% of people **didn't** feel supported by health professionals

"They were compassionate, but the care and support was minimal."

"Partly. I felt supported by the nurses after my scan but not by the people who dealt with me before."

"The only professionals who I felt supported me were on the pregnancy assessment unit when I knew I had miscarried. All others were terrible."

"Handed a load of leaflets and sent on my way. No contact from any departments with any offer of help."

"I was told at my 12 week scan I had missed miscarried, handed some leaflets and told to go home and think about what I wanted to do, no help or advice on what to do. How are you supposed to think when you have just been told the worst news possible. All you need is some verbal advice on the best option to take, not leaflets! Was told I would be contacted, 2 weeks later, still waiting for a phone call!"

"Overall everyone was supportive. But we repeatedly had to sit amongst pregnant women for long periods of time in the waiting rooms. When I actually had the surgery for medical removal of miscarriage, the team there were very matter of fact and there was less compassion for the reasons I was in hospital to have surgery."

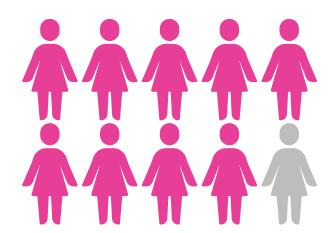
## How did people feel about their care experience?

	Dissatisfied	Neutral	Satisfied
Care received	49%	17%	35%
Dignity being respected	35%	26%	39%
Length of time to make a decision	32%	43%	25%
Length of time to wait for a scan	33%	28%	39%
Information about next steps	48%	18%	34%

# 80% were allowed to have a partner stay with them

# Has your miscarriage experience impacted you mentally or physically?

Miscarriage had significant and enduring mental health impacts on nearly all participants, often exacerbated by negative healthcare interactions and insufficient support. The physical repercussions varied, including severe pain, untreated anemia, and even permanent infertility. Partners were affected as well, but their experiences often went unnoticed. The lack of grieving practices, such as burial or cremation, left many feeling unresolved guilt. Positive experiences primarily stemmed from the empathy of frontline staff, like midwives and sonographers. However, many emphasised the urgent need for systematic mental health screenings, improved communication, and compassionate care following a miscarriage. Below are some of the comments people shared with us.



#### Nine out of ten

people told us they
had been impacted by
their miscarriage
experience

"Extreme impact mentally, it still affects me every day... I'm scared to get pregnant again. I am stuck in the most awful limbo."

"Required counselling 6 months after due to lack of support at the time. Following pregnancy was horrific as I was hyper anxious constantly. I now have had 2 healthy pregnancies but still feel the impact of the first one."

"I underestimated the physical effects - pain and cramping for many days, all the loss of pregnancy symptoms, the blood loss. I stupidly hadn't expected to feel so physically uncomfortable. The mental anguish is very difficult to process. Immense sadness. Anger at myself for having got excited by a potential baby and change to my life. Embarrassment that I have to tell people I lost the baby."

"I don't want to leave the house, I feel afraid about trying for another baby if this may happen again. I feel lost with myself and I feel like I've lost a part of me due to the miscarriage."

The following summary outlines the key themes shared with us by families and individuals who have experienced miscarriage. These insights highlight the emotional, psychological and social impacts they told us about.

#### **Mental Health Impacts**

#### • Extreme grief, sadness, and guilt

- o Many respondents feel responsible or ashamed.
- Long-term guilt about how the loss was handled and lack of memorial (no burial/cremation site).

#### Anxiety and fear

- Fear of future pregnancies ("I am scared to get pregnant again").
- o Heightened anxiety in subsequent pregnancies, even when successful.

#### • Depression and withdrawal

- Reports of becoming withdrawn, weight changes (both weight gain and eating disorders/weight loss).
- o Ongoing struggles with sleep, avoidance, and loss of confidence.

#### • Trauma & PTSD-like symptoms

- Traumatic medical experiences (painful procedures, haemorrhage, dismissal by clinicians).
- o Flashbacks, acute stress reaction, and risk of PTSD.

#### • Counselling and unmet needs

- Some accessed counselling (helpful but often too short).
- Many highlight lack of mental health screening or support, both immediately after and long-term.
- Some self-treated due to professional knowledge (therapists, midwives).

#### **Physical Impacts**

#### • Severe pain & medical neglect

- Reports of extreme pain during procedures.
- o Prolonged untreated pain at home on GP advice.

#### Complications

- o Anaemia and physical weakness post-haemorrhage.
- o Infections and blocked fallopian tubes due to delays in hospital treatment
- o Infertility.
- o Strong physical symptoms underestimated by patients themselves

#### • Recovery without guidance

Lack of information on physical recovery, what to expect (e.g. anaemia, fatigue).

#### **Impact on Partners**

- Husbands/partners also affected, but no support offered.
- Feelings of neglect of the couple's shared grief experience.

#### **Experience with Healthcare Professionals**

#### • Insensitive or dismissive comments

- o "It's just your age."
- o "It's population control."
- o "It wasn't a baby, just a sac."

#### • Positive examples

- o Some scan teams and midwives praised for compassion.
- o National research study (Tommy's) offered hope and eventually led to a birth.

#### • Neglect in follow-up care

- No standard psychological checks after traumatic miscarriage events.
- o Inadequate information on cremation/burial options.

#### Long-term impact

- **Lingering grief** The loss is described as something that never truly goes away. Even years later, the feelings resurface, leaving many feeling as though they are carrying a permanent wound.
- **Stuck in limbo** Instead of closure, many feel trapped in a cycle of grief, guilt, and unanswered questions. The absence of burial or cremation sites adds to this sense of being unable to move forward.
- **Pregnancy after loss** Subsequent pregnancies were often filled with fear and anxiety rather than joy, with the shadow of the miscarriage shaping how mothers experienced new life.
- **Identity and motherhood** Feelings of inadequacy, guilt, and failure remain deeply embedded, creating a sense of being "frozen" in the moment of loss.

## Conclusion

This report highlights the deeply complex, emotional, and often traumatic experiences faced by individuals and their families following pregnancy loss.

While statistics may suggest that miscarriage is a common occurrence, this does not reflect the profound impact it has on those affected. Every pregnancy is significant and most are deeply valued by the parents, and should never be reduced to a number or a routine event. It is essential that services and staff approach each family's experience with empathy, respect, and sensitivity. This is an exceptionally vulnerable time, and compassionate care and support are critical.

Unfortunately, existing systems often contributed to prolonged distress. Many respondents reported a lack of clear information about what to expect during and after pregnancy loss, compounded by the difficulty of processing information while in an emotionally overwhelmed state.

One of the most frequently raised concerns was the environment in which care was delivered. Several individuals described the heartbreak of waiting in areas alongside expectant parents receiving positive scan results, while they themselves were coming to terms with the loss of their baby.

Where positive experiences were reported, they were typically attributed to individual staff members who demonstrated genuine care and attentiveness—rather than the systems or processes in place. This underscores the importance of person-centred care and the need for improvements to better support families during such a critical time.



# Recommendations

- Clear communication of options when miscarrying must be provided. This should include medical management, surgical intervention and expectations management ("letting nature take its course"). No single approach should be presented as a default option.
- Provide sufficient time and space to process the situation and the options available, with recognition this will vary for each family. Rushed decisions can lead to trauma; therefore, care pathways should allow for flexibility and emotional readiness.
- Acknowledge that miscarriage can have lasting psychological and emotional
  effects. It is essential that healthcare providers recognise the potential for trauma
  and offer appropriate mental health support. This includes identifying grief
  responses and validating the significance of the loss.
- Support should be consistent, regardless of the department or staff member involved. A uniform approach across all areas of care — from emergency services to maternity units — ensures that individuals receive consistent, compassionate treatment throughout their experience.
- All staff should receive comprehensive training in pregnancy loss care, with a strong focus on empathy and trauma-informed practice. To enhance the quality and relevance of this training, it is recommended it is co-produced with individuals who have lived experience of miscarriage. Their unique perspectives and insights are invaluable in shaping training content and delivery, ensuring it is both authentic and sensitive to the needs of those affected.
- Following the news of a miscarriage, individuals should not be required to wait or receive care in spaces shared with those experiencing healthy pregnancies. Scans to confirm pregnancy loss should take place in private, neutral settings, separate from areas designed to celebrate pregnancy milestones.
- Support must extend beyond the moment of diagnosis. This includes:
  - Clear aftercare plans, outlining physical recovery, emotional support options, and follow-up appointments.
  - Named support contacts, such as bereavement midwives or counsellors, who can guide individuals through the aftermath of loss.
  - Access to a miscarriage-dedicated support worker, who can provide continuity of care and act as a liaison between departments.

# Thank you

We would like to sincerely thank everyone who took the time to complete the survey and share their personal experiences of miscarriage with us. Your openness and honesty have been invaluable in helping us understand what truly matters in care and support during such a difficult time.

We recognise that revisiting these experiences may have been emotionally challenging, and we are deeply grateful for your contribution. This report would not have been possible without you, and we hope it leads to meaningful change in how care is delivered.

# Appendix a

#### Copy of the survey questions asked

o in paper form/leaflet o not applicable

1. Are you completing this survey o as a person who has miscarried o as a partner of someone who has miscarried o a family member o anyone else – please state who
<ul><li>2. What year did you have a miscarriage?</li><li>o 2020 or before</li><li>o 2021</li><li>o 2022</li><li>o 2023</li><li>o 2024</li></ul>
3. Did you/the person who miscarried know that they were pregnant when they miscarried? o yes o no
4. How many weeks do you think you were when you miscarried? o 4-6 weeks o 7-10 weeks o 11-14 weeks o 15-20 weeks o 21-23 weeks o 23 + weeks
5. Did you contact/speak to any of the following services/departments? Please tick all that apply.  o Midwife o GP o pre assessment unit within the maternity ward o Maternity ward o Accident and Emergency Department o Urgent Care Centre o NHS 111 o another health professional at the hospital o none o anyone else – please state
6. How satisfied were you with the advice you received o very dissatisfied o dissatisfied o neither satisfied nor dissatisfied o satisfied o very satisfied Any other comments
7. Did you know what options you had for miscarriage ie waiting for nature to take its course, medication or surgical procedure at this point? o yes o no o not applicable
8. How did you receive this information? o verbally

9. How long did you have to wait for an ultrasound to diagnose your miscarriage? o less than 3 days o more than 4 days o miscarriage diagnosed at routine scan o not applicable
10. If you had an ultrasound were you placed alongside pregnant women waiting for a scan? o yes o no o not applicable
II. Did you feel supported following your loss by health professionals? o yes o no Please feel free to provide more information
12. During this time, on a scale of 1 to 5 how would you rate the following  1-not at all satisfied 2-dissatisfied 3-neither satisfied nor dissatisfied 4-satisfied 5- very satisfied The care you received Your dignity being respected The length of time you had to make a decision on your next steps The length of time you had to wait for a scan (if applicable) The information that you received about your next steps
13. While you were in hospital
Was your partner allowed to stay with you?
Were you placed where you could hear babies crying?
Were you left for long periods of time alone?
Was your care well organised?
14. Has your miscarriage experience impacted you mentally or physically? o no o yes
15. Were you offered any support or counselling? o yes o no
16. Were you offered a memorial for your baby? ie included in a book of remembrance, memory box? o yes o no
17. Any other information about your experience or anything else that could have been done better that you feel comfortable sharing?

# Appendix b

We felt it was important all the experiences we were told should be in the report. Therefore please find below the details of all the quotes shared with Healthwatch County Durham via the survey. Please note these are the original words (except any identifiable information) of those who contributed to the survey and contain details of a sensitive nature which may be upsetting.

#### How satisfied were you with the advice you received?

I miscarried in Feb 21 and Jan 22.
The way I was informed was poor
The attitude of hospital staff was poor

When I went in for support in miscarrying (as the baby had died but my body wasnt miscarrying by itself) they put me in a room that was like a cupboard as loads of stuff stored in there to wait for a proper room for the meds to deliver and all the while midwives were in and out of the cupboard I was in for things for mothers / babies. It was quite insensitive and upsetting. If I had been a bit older I would have complained.

The first miscarriage I was 12 weeks, my midwife told me to call the hospital, she didn't even bother to call me back to see how I'd got on. I had to have an emergency removal as I was bleeding so heavy, the hospital had left me in a side ward and didn't check on me for 4 hours where I was getting much worse and they also brought part of the fetous they'd tried to remove vaginally in a jar and placed it next to my bed

As my miscarriage was during COVID I was advised that I "wasn't bleeding enough" to warrant being seen in person and to just "watch and wait" and it could just be implantation bleeding. Knowing my body, I knew I was miscarrying and I continued to ring and tell them the bleeding wasn't stopping but they wouldn't see me. I ended up paying to see a private sonographer who did me a "reassurance scan", and told me I was likely miscarrying. I called the hospital and told them this and they still would not see me to confirm/deny, and sent me an envelope in the post containing three pregnancy tests and a leaflet titled "what is a miscarriage". They told me to take pregnancy tests three weeks after and if I was still "pregnant" to contact them again. I received no support in terms of the actual miscarriage, what to do when I actually passed the baby, how to grieve, I felt the most alone I think I've ever felt in my entire life and still to this day I struggle with worrying if I did something wrong

I was initially misdiagnosed at scan with having an empty sac, told to go home and expect to miscarry. 5 days later I required emergency life saving surgery as I had a ruptured ectopic pregnancy

I've had 6 miscarriages and different experiences although I have always felt supported. My first was in 2012 and I had access to a grief counsellor which was so very helpful.

No one seemed to care or be concerned that I had bleeding. Was told I would have to wait 5 days for an nhs scan. Paid privately so found out I had miscarried that way but then had to spend 3 further days before i could receive any treatment. Left 9 phone messages for my midwife who didn't get back in touch with me for over a week.

The staff treated me with enormous compassion and kindness and they kept me away from other women who were having scans and with their children

Although very upset

Excellent support from my community midwife who check I'm with me to support. 111 and urgent care dismissive of my feelings.

I was left in total limbo unexplained miscarriage.

Satisfied with the support from the EPEC unit at North tees, dissatisfied with the A&E department at North Tees hospital

I had a miscarriage on Saturday 27th August 2022. I spoke with the Midwife following spotting the previous Monday and received advice to monitor this given that I was prior to 16 weeks Pregnancy assessment would not see me which was acceptable advice at that time. However on the Saturday when the bleeding was heavier, I attended Darlington A&E, I was there alone given I have an older child in bed whom my husband stayed with and it was early hours of the morning. The Doctor at A&E was brilliant and kept checking in on me and offering comfort if needed, however I was then transferred to gynaecology ward for an assessment. This was where my experience went downhill. The on call gynaecologist showed no empathy in a time which I felt very vulnerable and scared. After completing a physical examination the words offered to me from this doctor was "Well there's nothing going on down there" and walked out of the room. I didn't get anything further other than the woman assisting advising I was okay now to leave the hospital. It was only when was one of the nurses on the ward stopped me and gave me a cuddle, I explained what was happened and she had been informed by the other woman who assisted the doctor did the nurse the apologise on the doctors behalf. I was then offered some leaflets and sent on my way with nothing else.

There was no real advice or guidance other than to let my body do what it needed too. No explanation of what to expect or signposting to further support and certainly no follow up care physically or emotionally. The staff I met were empathetic at times but no real care.

Lack of compassion. No offer of further support despite history of severe mental health difficulties

I had to attend a scan at the early pregnancy unit in Durham hospital. I had to sit in a waiting room full of pregnant people while I waited for my scan, this is very upsetting

My first miscarriage - I was told that my baby was only measuring 7wks at my 12 WK scan. I was told that something was very wrong and I was most likely going to miscarry. I was told I could abort the pregnancy but it would be recorded that I had terminated the pregnancy! I was then sent home just before Christmas and left for 2 weeks to miscarry at home.

I did not miscarry and ended up at UHND hospital for another scan to confirm my baby had died. I sat in a waiting room with other parents who were talking about their babies as they came out with their 12 week scan photos beaming at each other.

It was confirmed I'd had a missed miscarriage and I was admitted and gave drugs to make me miscarry.

It was the worst experience of my life.

My second miscarriage - told at the 12wk scan I had another missed miscarriage (at approx the 8wk stage). Back to UHND for another procedure to make me miscarry. It didn't go well and I became very poorly during the process with a fever and pain.

I have had about 13 miscarriages (ranging from 4 weeks to 14 weeks). GP advice is to 'ride it out'. The 14 week one led to me miscarrying twins at work in the staff loo...

Very little compassion for the situation from consultant about needing a c n d. waited for surgery then got sent home without it. Had to return to then get a c n d. very distressing. No

I was sent home 4 times in the 2 days before I miscarried and was told I was fine and nothing was wrong and the bleeding was normal. I knew something was wrong which I told them each time because of the pain and each time I was told not to worry. Then I miscarried at 12 weeks. I was heartbroken. However when I was in the hospital when I miscarried there was a nurse who was amazing in making sure I was okay and was very caring

I started the miscarriage when I was at work, had to get the bus home, Dr. visited my home and left me lying in bed for a week!

The ladies that helped me in A&E were fantastic helped me really quickly I was bleeding a lot. Then was left on the ward for 2hrs before being seen to by a doctor

The care and empathy I received was shocking, both me and my partner were left feeling very upset with Durham Hospital. I was given/offered no support even though they knew this was my third miscarriage & the longest I'd managed. I was made to feel stupid, inadequate and lonely. It has put my and my partner off wanting to try further as I've practically begged for fertility support and we are a year on and are yet to receive that.

The advice we were given was appropriate to the gestation of our pregnancies

I was not signposted to any support during this time I felt a and e didn't want to know.

When going to the maternity unit, the sonographer lacked sympathy for my situation.

However, the nurse after my scan was so thoughtful, kind, caring and helpful. She was very reassuring and made me feel hopeful for the future.

I had an unusually medically complex missed miscarriage:

- 1 urgent care visit for unexpected bleeding at 12 weeks
- 1 follow up at maternity assessment for a scan which found no heartbeat present, advice given about options but direction towards letting nature take its course
- nature clearly didn't feel in any hurry to take its course, not much clarity or advice about how long to wait or what to do, heavy bleeding began suddenly then worsened massively, blue light ambulance to hospital for management of bleeding and medical intervention to remove ERPC
- lost a lot of blood but not quite at threshold for transfusion, 6-8 weeks recovery feeling physically dreadful and traumatised by haemorrhage (NOT the pregnancy loss which was sad but not felt by me as a bereavement)
- abdominal pain and bleeding began again, back to assessment for a scan. Needed ERPC.
- Op scheduled.

It was awful. I was satisfied by the care at various points and clearly quite unlucky. I also know the NICE guidelines were followed in terms of options put to me when missed miscarriage was diagnosed. HOWEVER, I was in shock when this was discovered (the USS tech actually cried) and while I cognitively understood the options, was in no position whatsoever to make a decision about medical or surgical management and so went with the default recommendation to let nature take its course. I appreciate this is the NICE guideline but it deviates entirely from international practice and is a piece of \*\*\*\* as far as I'm concerned. Women need to have options and make choices but in a traumatic situation directing them to a scenario where there is a risk of haemorrhage (however low) and seeing the embryo/foetus when miscarrying etc takes no account of the psychological impact of the experience and potential for this to be harmful. Not clear that the NICE guidelines consider this psych aspect (they are generally poor on psych topics). I would have surgical management 10,000 times over waiting for nature to take its course and the idea that a miscarriage is like a "heavy period" is the single most nonsensical comparison I've heard. Not if you're over 6-8 weeks it isn't. Ban the phrase and let women know what they're in for. I understood that my experience was unusual and asked everyone I knew who had had a miscarriage and every single woman agreed and had been freaked out and terrified by the amount of bleeding. It is barbaric not to offer surgical management as the default with the other options available if preferred. It is the most let down I've ever felt by the health service, all the more so when I discovered in other comparable countries there is no question of hanging around waiting for the miscarriage to happen naturally.

# Did you know what options you had for miscarriage, ie waiting for nature to take its course, medication, or surgical procedure at this point?

In the second miscarriage I was given the option, in the first this was not explained

We went to urgent care when I started bleeding and they explained

**Needed surgery** 

At initial scan I was given a leaflet with options in

Miscarriage was confirmed as complete.

Had to look into these myself at first due to delay to access services.

I knew this due to prior research

Wasn't given options just told nature would take its course.

Advice was always to just let nature take its course and take a paracetamol for the pain.

I was booked in for a procedure however nature took its course over the weekend

I was made aware of these options once we had been scanned within the Gynae department

As per previous example. Options were put at a point when it was emotionally challenging to process them and I was directed towards letting nature take its course. I subsequently checked the NICE guidelines and everything had been done by the book, but as I've explained "letting nature take its course" is a recommendation I strongly disagree with.

Sudden onset of bleeding. No options required

#### Did you feel supported following your loss by health professionals?

There is no aftercare

No one checked on me, no one followed up what had happened, there was no offer of mental health support. I had 5 miscarriages, after my experience with the first I decided to avoid medical intervention where possible thereafter.

Not after misscariage but during and before i was.

As mentioned

Wasn't offered any support

It was at a time when you were just sent home with no understanding of what happen as focus in the ward was for those who were pregnant

Was sent away from hospital and never contacted again, nor signposted to any services of support.

I was told at my 12 week scan I had missed miscarried, handed some leaflets and told to go home and think about what I wanted to do, no help or advice on what to do. How are you suppose to think when you have just been told the worst news possible. All you need is some verbal advice on the best option to take, not leaflets! Was told I would be contacted, 2 weeks later, still waiting for a phone call!

After gyne discharged me I had to fight to get the results of the genetic testing, a referral onto recurrent miscarriage who also then failed to do all tests they promised.

I felt the staff who looked after me in hospital were amazing but there was not much aftercare. I was given leaflets on counselling and informed I could write in book or remembrance. I felt as though mt partner wasn't really acknowledge in having losses a baby. I wasn't told what happened to my baby after, as in was my baby cremated, was it an option for me to take the cremation. A dried had a miscarriage a year later and she was given a remembrance box and was told the baby was cremated.

#### Partly

I felt supported by the nurses after my scan but not by the people who dealt with me before.

Handed a load of leaflets and sent on my way. No contact from any departments with any offer of help.

I didn't inform them at the time. When mentioned afterwards it was not considered important

Miscarriages under 6 weeks do not require any further medical treatment or attention. This felt like my loss was not as significant and wasn't checked as thoroughly.

The only professionals who I felt supported me were on the pregnancy assessment unit when I knew I had miscarried. All others were terrible.

The staff at Darlington Memorial Hospital were incredibly supportive and I felt very cared for at a horrific time

The department was very busy and we had to leave quickly.

I had no support from health care and didn't receive any information on support groups etc

They were compassionate, but the care and support was minimal.

I was given a leaflet and sent home.

No support given. One gp said I could talk to someone if I wanted, but every other time there was no support. No one even asked whether I was trying for a baby or wanted to look into why I miscarried so often. I was never offered a scan or follow up.

The sonographer at my second scan (to confirm whether this was a miscarriage or not) wasnt sympathetic at all which made a very difficult and upsetting situation much worse. After the appointment I was happy letting nature take its course, then after bleeding very heavily I ended up having emergency surgery. I was offered no follow up appointment and the doctors were pretty matter of fact about things; they were a bit thrown by the question about when we might be able to try again for a baby – a standard question in my mind but they were a bit confused. I realise now that they may have thought I was a patient who had either taken a morning after pill which had had complications or I was in for an abortion – both of which I strongly morally oppose to. This definitely had an impact on my care and the attitude staff had to me (another instance was needing the toilet after the surgery and I could barely sit upright and the nurse just telling me I should just get up and walk there).

Not enough after care was sent home from a&e with little to no information and wasn't allowed an early scan or to speak with midwife

Overall everyone was supportive. But we repeatedly had to sit amongst pregnant women for long periods of time in the waiting rooms.

When I actually had the surgery for medical removal of miscarriage, the team there were very matter of fact and there was less compassion for the reasons I was in hospital to have surgery.

No support....just went back to work!

In the weeks following I spoke with my GP. Her only advice was to not do pregnancy tests as it will make me feel sad if I have another early loss. Not entirely supportive. Could have had better training

I was sad and shocked but miscarriages are extremely common and I knew that, even at the 12 week point. It's not nice to be with other heavily pregnant women when miscarrying but for me the issue was not that this was a grief and loss situation but that it was a hideous physical experience. I know some women feel a lot of grief even for very early pregnancy loss but loads of us don't and that's fine too. What I didn't feel well supported in was the "like a heavy period", "let nature take its course" default.

Very off-hand. No further support

There was no support, I was just told there was no baby and sent on my way and didn't hear anything from them after

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Initially yes, however after the miscarriage had passed I've had no support since by professionals just by family and friends

We felt supported when we arrived at Hospital for medical management. The Nursing staff were very supportive, caring and compassionate. We were however scanned in the Antenatal Clinic with other pregnant women also awaiting an appointment. This is utterly soul destroying. In addition the Gynae ward we were admitted too, the only entrance is via Maternity. Surely this can be moved to a designated women's health area aware from other Mothers and babies. This is completely un forgiving. On our 2nd Miscarriage we were scanned in the EPAU within Gyane (please make sure through the survey you correct which Department women are referred too – early loss in Durham is always seen by Gynae services and I do hope it is there staff, the NURSES and not MIDWIVES, who receive feedback), and this was a much better experience. The Gynae ward was still next to Maternity that made it difficult to enter the area, but it was much better that we were in a private room being scanned and not in an Antenatal Clinic area (which too should have their signage changed to "women's health area" as there are not just pregnant people using it.)

#### Has your miscarriage experience impacted you mentally or physically?

The first doctor I saw tried badly to make me feel better by telling me that it's a way of making sure the world isn't over populated he said imagine if everyone who was ill lived and everyone created lived there'd be no room for everyone. Not at all helpful. He also tried to pull the fetous out through my cervix, I was in so much pain I was screaming, begging him to stop and I thought I was going to pass out.

#### Mental health and anxiety

Extreme impact mentally, it still affects me every day. I worry that I was the most horrific person ever because I didn't know I could have the baby's remains cremated etc and I had no idea what to do so I just flushed the toilet and still now I feel like the most terrible human being because what sort of mother does that to their child, now I see people having somewhere to go to grieve, a scatter site, a burial site, I don't have that. I'll never have that. I'm scared to get pregnant again. I am stuck in the most awful limbo

I can't remember a lot of details as it was a number of years ago. I had two miscarriages followed by an ectopic pregnancy. I didn't feel at the time that I received much support for this. It had a negative impact on my mental health.

It also effected my husband and there no support for him

#### Still don't feel like it has sunk in!

It has been 13 months and I am still having difficulties sleeping. I reached out for counselling when it first happened but ended this agtwr 2 sessions as I felt I was still processing it all.

When you have recurrent miscarriages people think you are used to the process. Scan teams and midwife were amazing. Clinicians following up on recurrent miscarriages were less than compassionate with a Newcastle Consultant saying it was 'just my age'. Due to my background and a GP referral to Coventry and Tommy's I took part in a national research study and now have a child as a result of that trial. Clinicians need to be more aware of what can be done to investigate recurrent miscarriage.

I feel my loss acutely. The feelings of loss come and go but will never go away.

I am a midwife myself so didn't seek support, especially as it was a very early miscarriage. I have been ttc for 18 months so it was devastating.

Required counselling 6 months after due to lack of support at the time. Following pregnancy was horrific as I was hyper anxious constantly. I now have had 2 healthy pregnancies but still feel the impact of the first one.

I underestimated the physical effects - pain and cramping for many days, all the loss of pregnancy symptoms, the blood loss. I stupidly hadn't expected to feel so physically uncomfortable.

The mental anguish is very difficult to process. Immense sadness. Anger at myself for having got excited by a potential baby and change to my life. Embarrassment that I have to tell people I lost the baby.

Fell pregnant quickly after miscarriage so have baby boy now who keeps my thoughts on track. Horrible loss though.

They told me I had not had a baby just a sac. I don't understand.

My mental health suffered alot after this experience, I gained lots of weight and withdrew from life

I have since had two babies and the anxiety throughout pregnancy was immense (especially as I had regular breakthrough bleeding).

After my miscarriage I became extremely depressed and developed an earring disorder (and consequently lost a lot of weight to the point of being underweight). I eventually went to the GP about getting some counselling which I got through the NHS for 6 weeks.

Has mentally affected my second pregnancy which I went to full term

Due to the fact that the Dr. recommended I lie in bed for a week in excruciating pain and not sending me to the hospital straightaway. After 7 days I was still in pain and the Dr. sent me to hospital where I received a D&C also was told that I was rhesus negative O and was lucky the blood from the baby did not mix with mine...they gave me a rogan injection. Due to the long wait of me not getting to hospital all my fallopian tubes were blocked and infected and I was never able to conceive again...so remained childless

it did at the time but I was lucky enough to fall pregnant again within a few months so this helped my mental health

I don't want to leave the house, I feel afraid about trying for another baby if this may happen again. I feel lost with myself and I feel like I've lost a part of me due to the miscarriage.

I wasn't at the threshold for a transfusion, but just on the edge of it. I had lost a lot of blood and was very anaemic – had to sit down to rest climbing a flight of stairs in the first couple of weeks. This was also not helpful since I had a two year old. I got iron tablets on discharge but no clear info in terms of managing my expectations about the impact of anaemia on physical fatigue and cognitive function, which was not a great combination. I also suffered an acute stress reaction following the haemorrhage which I diagnosed myself and treated while in hospital using [therapeutic method], because I happen to be a [job title]. Chances are this could have progressed to PTSD if I hadn't known what I was doing. Not one single enquiry about psychological symptoms of acute stress reaction despite a really significant haemorrhage: blood was dripping through a child's nappy I had used to try to absorb it and trailing along the A&E floor while the trolley was getting me in off the ambulance. Some kind of acute stress reaction check, normalisation, self-help info should be standard in such a situation.

#### Mental health issues

# Any other information about your experience or anything else that could have been done better that you feel comfortable sharing?

I was in a lot of pain and had to ask for a nurse to help, they werent proactively checking how I was managing the pain. A lack of care really.

Bearing in mind I was in pain bleeding excessively I was given a sanitary pad and put in a room with two doubly incontinent ladies. I felt I had no privacy to grieve and there was no empathy from the staff generally

Not to of been on the labour ward whilst going through the process of my misscariage. But the staff on the maternity ward were brilliant and very supportive. They allowed me to come back in and visit my baby however this was again on the labour ward which was i feel was not the right place.

I sought help myself from two charities: Aching Arms and SiMBA. They did more for me/my mental health than the hospital or NHS in general ever did. They are incredible charities, but I had to do the legwork and seek them out. I was not taken to them.

I went to urgent care for my first miscarriage because it was my first time experiencing it and I didn't know what to do. I felt that staff were dismissive, blunt and unsympathetic. I understand that they were probably dealing with lots of other more serious and urgent medical priorities at the time but for me it was a huge, terrifying and distressing event which I didn't feel supported with. I knew more what to expect the second time it happened although it was a different physical experience as the second one was much more painful. I don't think people are given enough information about miscarriage and ectopic pregnancy when they become pregnant. To me it was such a shock and I didn't know what to do or what to expect.

It was pretty 2020 and hopefully things have improved

I wasn't cared for at all. By the time I started to miscarry my HCG levels had plummeted. The blood test was the only thing that was looked at and I was told by a consultant that 'I wasn't having a miscarriage, just a heavy period, and I needed to go home and have a paracetamol' I had 5 different positive pregnancy tests on various days from the previous week, and I passed a yolk sack and a large clot later that day.

This was my second miscarriage that year (2018)

My baby lost its heartbeat at 8weeks 6days. I didn't find out until my 12 week scan, no signs of miscarrying. My first midwife 'booking' appointment, my baby had already passed. I feel like you are not supported in the first stages of pregnancy! The statics of 1-5 women have a 'missed' 'silent' miscarriage is just astounding! Why is there not more support in early pregnancy and more scans on the nhs! If I was scanned at my first midwife appointment, I wouldn't have walked around for 12 weeks excited and planning because I was pregnant! Miscarriage is horrendous in itself, but missed miscarriage is just next level of heartbreaking! Not only is more support needed for women who miscarry, More support/scans are needed in early pregnancy!

On the day of being told I had an empty sac and to expect a miscarriage, the lady who delivered the news was lovely but just felt as though, here's the leaflets go and get on with it. This was my first experience of a miscarriage. I think more understanding, time to process the information, not to feel as though its just a normal thing to get on with. Having thw discussion of what happens to your baby after and being offered the remembrance box and book. I came away with nothing, lost my baby, my tube and nearly my life.

I was looked after well after my scan. I can't thank the nurse enough to sitting with me and my partner and going through everything. She gave us hope, care and empathy. I had a follow up phone call detailing my blood results and was sent bereavement information through the

However, during my visit to an and e and to the maternity unit for my scan, I did not have a good experience. I understand the staff in an and e are stretched but when I went in and I was miscarrying, it was the worst experience of my life. I then had to wait more than a week for my scan to confirm my miscarriage. Also, the sonographer I saw lacked empathy for my situation and her approach was very clinical. She did not know why I was there, she did not explain what she was doing and even when I was in tears, she just carried on. I was also made to sit in the emergency section of the maternity assessment ward alongside heavily pregnant ladies. This was highly traumatising. I wanted to fill in this survey so other mummy's will never feel 36 what I felt.

Information at booking in appointment on how common miscarriages are, symptoms etc. it never occurred to me that this would happen as it is not spoken about.

I should not have to wait so long to know if I am pregnant.

No

I think at all scans, this should be done away from the baby unit. Parents should go into the room from a waiting area and exit from another door which does not put you back into that waiting room.

I have had only awful experiences with regards the support offered when miscarrying. I stopped telling the gp as they didn't care. The lack of care affected me more than the miscarriages in some ways. I felt like I was pathetic.

I would like to have been offered tests after the first few miscarriages to see why they happen so frequently to me. I know it was bad luck in terms of care as others I know have had fantastic support after just one.

There needs to be an offer of a follow up appointment, this should be to check both physical and mental wellbeing. Especially when in the situation I was in, the medical staff should be informed about how the person feels about what's happening (eg. This is a miscarriage and the woman is very upset about it).

Had a second miscarriage at 6 weeks. Dismissed by healthcare professionals 'how did you even know you were pregnant?' I had been trying for a while. Very little sensitivity. Same hospital. Placed with pregnant women again.

All hospitals should be required to have a completely separate seating area for patients going through miscarriage or potentially receiving bad news.

I did not like the fact that my miscarriage was labelled as abortion on my medical records. I just had to get on with life and make the best of it, in my day it was hard to adopt so my life turned to loving animals. Later in life my husband of many years had an affair and she got pregnant....which hurt me very badly and brought back sad memories.

I had a silent miscarriage which i was Informed at my first routine scan. I was given information in leaflets about next steps and told I had to come back in a week and go through it all over again despite the fact they could confirm there was no heartbeat. I had to wait with all other pregnant women coming with their scans with happy news. I opted for the manual mva after waiting a week for the 2nd scan. Again in the same waiting room as all the other pregnant women whilst I was about to have mine removed. Then had to go back and forth to the same unit for a number of weeks for blood tests as the procedure had not been completed properly and then had to go back into hospital for the surgical MVA. I think finding a way to have miscarriages and procedures related in a different area to pregnant women would have made this experience slightly better.

I was looked after by QE hospital in Gateshead and they were amazing

Didn't want a memorial, did want psychologically-informed care and realistic information about what a miscarriage actually entails physically. It is not like a heavy period.

Even just reading about other people's experiences would have helped...

Being told on the phone and not asked anything about how you are is rubbish...

People took for granted that I understood, when I didn't - missed miscarriage / risk of ectopic pregnancy...

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