Miscarriage Survey Results

The survey was targeted at women who had an early pregnancy loss (16 weeks or before) in the last 3 years and who had accessed services at Frimley Park Hospital or Wexham Park Hospital and was undertaken by the Frimley and Wexham MVP team in May 2021. This report will summarise the key findings from the survey. Whilst there was some negative feedback and a lot of suggestions, there were also some very positive and complementary comments about the services women encountered during their pregnancy loss which have been included in the appendix.

Section 1: Who answered the survey?

The survey was answered by 318 women, 54 women had not had a pregnancy loss in the last 3 years so did not meet our criteria, leaving 264 women in our final sample.

Table 1: Demographics of Survey Respondents

	N	%
Age group		
18-24	7	2.65
25-30	59	22.35
31-35	89	33.71
36-40	68	25.76
41-45	37	14.02
45+	3	1.14
Not answered	1	0.38
Ethnic Group		
White British	236	89.39
White other	11	4.17
Asian	8	3.03
Mixed/other	6	2.27
Not answered	3	1.14
English as first language		
Yes	254	96.21
No	9	3.41
Not answered	1	0.38
Education Level		
Degree level	161	60.98
Higher education below degree level	45	17.05
A-level or equivalent	36	13.64
GCSE or equivalent	16	6.06
No qualification	1	0.38
Not answered	5	1.89

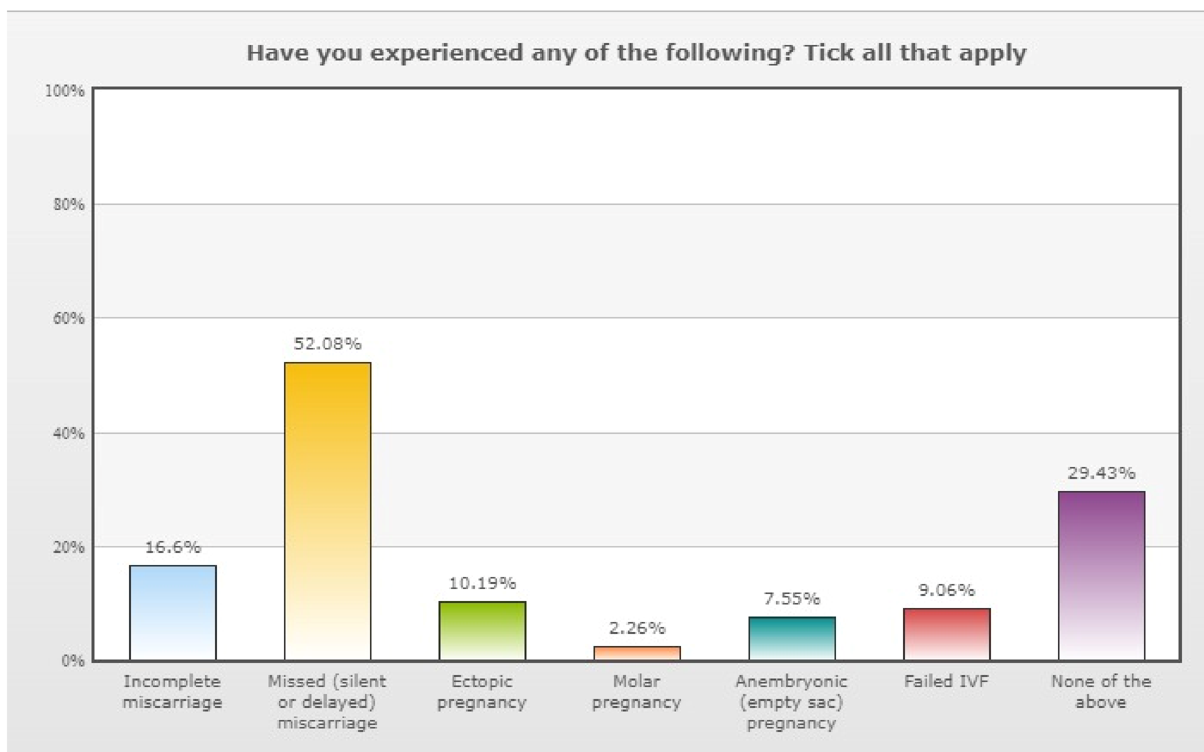
The vast majority of respondents are well educated (78% with a degree or other higher education qualification), older (75% are over 30 and 41% over 35) and white British (89%). This is a common demographic who are more likely to respond to surveys but also older

individuals (and the better educated are more likely to delay fertility (and be undergoing IVF) than the less educated) have a higher prevalence of miscarriage (de La Rochebrochard et al., 2002; Nybo Anderson et al., 2000).

Pregnancy Loss Experience and Services Accessed

53% of respondents have had one miscarriage, 20% two, 15% three and 11% 4 or more. 79% of respondents have had a successful pregnancy. 61% had suffered a pregnancy loss at 6-9 weeks and 44% at 10-12 weeks, with before 6 weeks (24%) and after 13-16 weeks (9%) less commonly reported. The risk of pregnancy loss decreases as the pregnancy progresses, but some women experiencing a miscarriage prior to 6 weeks may not know they are pregnant. The most common indication that they were experiencing a loss, was bleeding (59%) followed by severe pain 27% and the most commonly reported experience, as shown in figure 1 was a missed miscarriage (52%), followed by an incomplete miscarriage (16.6%), with 29% reporting other.

Figure 1: Type of Loss Experienced



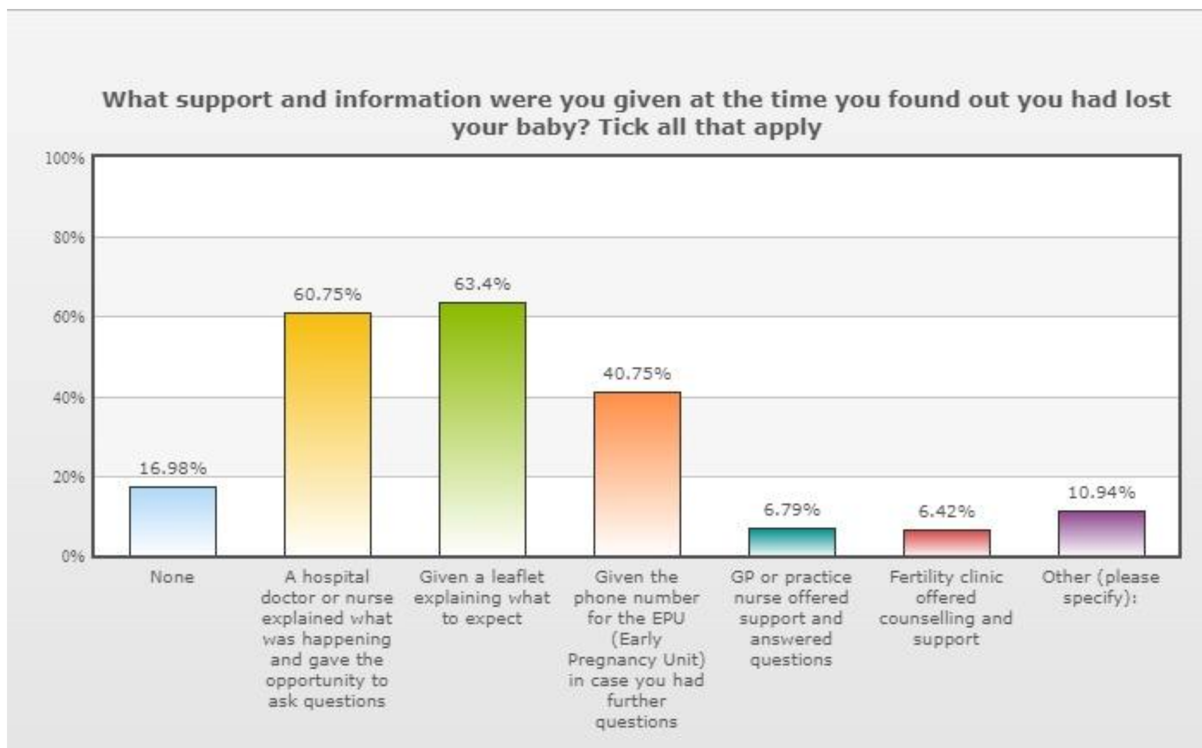
52% had expectant treatment (letting the miscarriage happen naturally), 48% surgery and 28% medical management. 89% of respondents had accessed the early pregnancy unit, 39% accident and emergency and 35% their GP.

Section 2: Support

This section explores where did they get support, what support was helpful, what would they have liked more support/better support.

Most respondents (61% and 63% respectively) had a doctor/nurse explain what was happening with an opportunity to ask questions and were given a leaflet. Only 41% were given the EPU number which might explain several comments relating to feeling they were left "alone" to "get on with it".

Figure 2: Support and Information provided during Pregnancy Loss

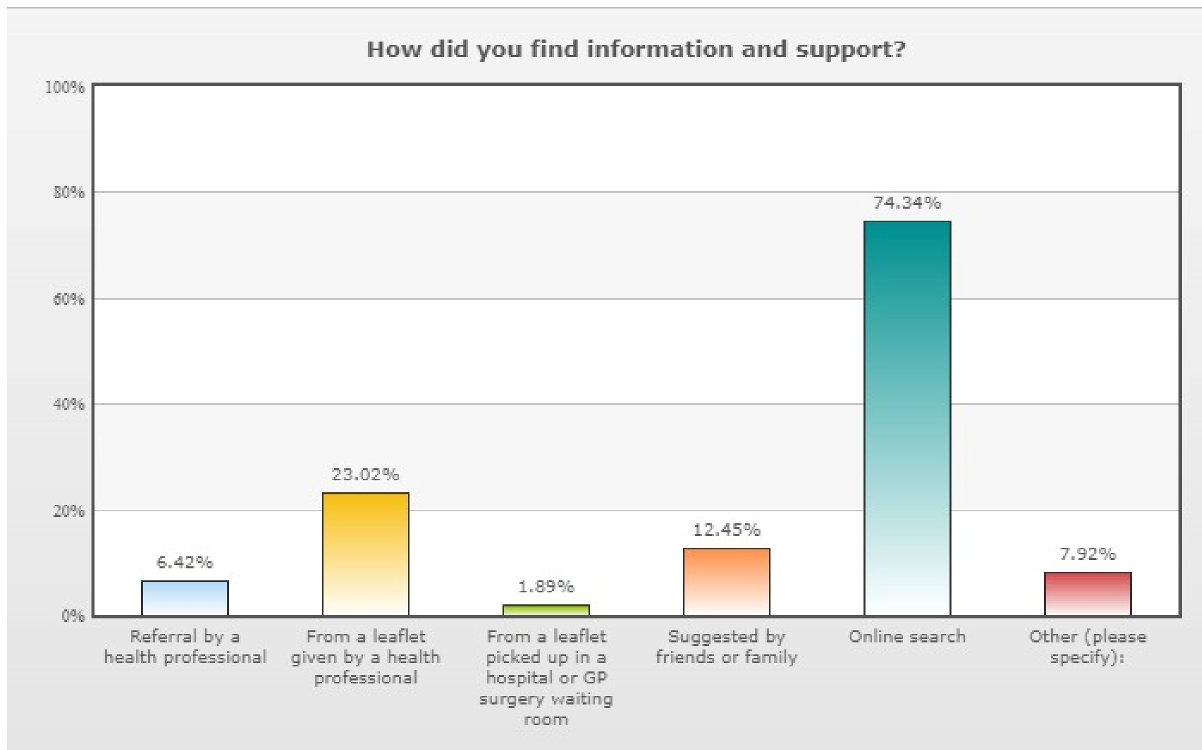


However, despite most women receiving information (figure 2) this was inadequate as only 23% stated they found information from a leaflet and 75% had searched for information online (figure 3). The comments in the free text boxes suggested that women felt they lacked information about the physical experience and what a what a miscarriage would be like and, secondly, felt they received little to no information about mental health or what to expect emotionally. Women felt unprepared for the physical side such as not knowing they would pass the foetus/sac, that they would have contractions and no indication of how long they would bleed for and what was considered 'normal'. They felt the information provided "lacked reality" e.g., they were told they would experience period like cramps but in reality the physical pain was far worse. Several women also commented that it was hard to take in information after receiving bad news.

Suggestions: Information

- Further information about the physical side of miscarriage and what is normal
- Separate leaflets for the physical and mental health side
- A chance to receive information and ask questions via email
- "An easily accessible person I could call to ask questions to put my mind at rest."
- Suggestions on where to receive longer term support to cope with grief and anxiety e.g., details of who to contact for advice or support (e.g., Tommy's, The Miscarriage Association etc)

Figure 3: How they found information and support



As reported in figure 4 the most common organisations respondents sought information and support from were: the Miscarriage Association and Tommy's (in particular respondents reporting using their online forums and Facebook groups). Other organisations which people sought information and support included:

Facebook groups, Instagram and online forums such as Mumsnet, BabyCentre; Worst Girl Gang Ever (on Instagram and a Podcast); Sands; Aching Arms; SIMBA; Little Hearts Matter; CRISIS team; Kicks count; Zoe Adele - saying goodbye charity; Mariposa Trust/Saying Goodbye; Amari Pregnancy Choices; NHS website; Blogs; Samaritans; Health Unlocked

Figure 4: Organisations Sought Information and Support From

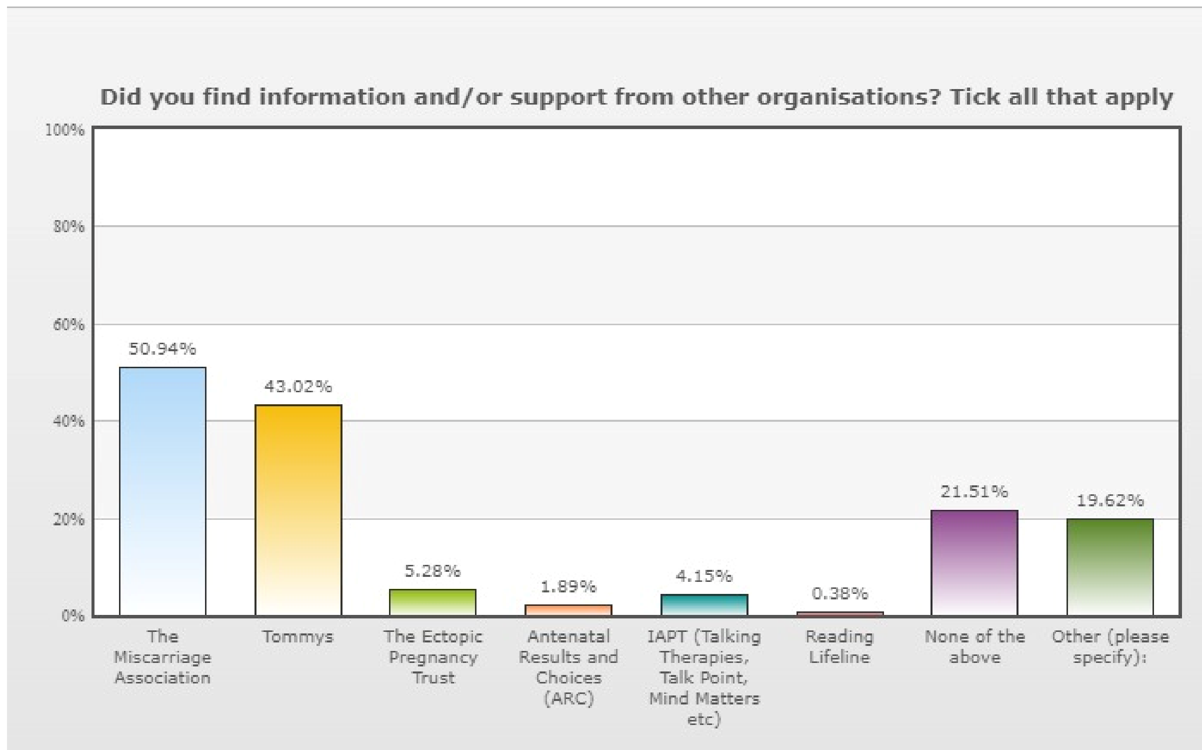


Table 2 reports whether respondents found the sources and information about pregnancy loss they used useful. Table 2 reports the % who find each source excellent/good and poor/terrible. One should be cautious about the last three sources (faith and community leaders, and other) given these have small sample sizes. Respondents tended to find the online information and other organisations excellent/good whilst those sources that were rated as poor/terrible tended to be health professionals which corresponds with the idea that women then go and seek further information from other sources after conversations with health care professionals and being given leaflets.

Table 2: How helpful did you find the following sources for information about pregnancy loss?

	Reported/Used by	Excellent/good (%)	Poor/terrible (%)
Hospital doctor or nurse	251	35.9	**35.5**
GP or practice nurse	167	27.6	**46.1**
Friends and family	243	45.7	19.3
Online information	226	**65.5**	3.1
Other organisations	98	**63.3**	6.1
Printed information	155	31.0	18.7
Faith leaders/groups	16	**56.3**	18.8
Community leaders/groups	13	**61.5**	38.5
Other	20	75.0	10.0

Respondents were then asked about how helpful the health professionals, organisations and other individuals/organisations they encountered during their pregnancy were at providing emotional/mental health support. Table 3 also reports the percentage who reported each category as excellent/good and poor/terrible. Respondents tended to rate charitable and private organisations favourably, and were less favourable towards health professionals, particularly doctors and GP/GP practice nurse.

Table 3: How helpful were the following at providing emotional / mental health support regarding your loss?

	Reported/Used by	Excellent/good	Poor/terrible
Hospital doctor (at the time of the miscarriage)	221	16.74	**51.13**
Hospital nurse (at the time of the miscarriage)	226	37.17	33.18
Midwife	110	27.28	49.1
NHS counsellor / mental health specialist	31	29.03	**64.51**
GP	134	23.88	**55.23**
GP practice nurse	35	14.29	**74.28**
Health Visitor	16	37.5	**50**
Friends/Family	238	49.58	13.02
IAPT (Talking Therapies, Mind Matters etc)	31	51.62	25.8
Charitable organisations	60	**76.67**	6.67
Private organisations	26	**61.54**	23.08
Private counsellor	28	**78.57**	14.28
Faith leader/group	11	**90.91**	9.09
Community leader/group	7	**85.72**	14.29

In the free text boxes, there were several themes relating to respondents' experience of the services they accessed that may shed some light on why respondents felt they lacked information and support from the health professionals they encountered during their pregnancy loss.

There were some common themes relating to an insensitive service that negatively impacted respondents' mental health:

- Some respondents commented that treatment was clinical, staff were unsympathetic and unhelpful, and they were "treated as a number rather than a person who has gone through a terrible loss".
- There were several comments relating to being in a waiting room with other pregnant women, having to pass the labour ward, and hearing cries of newborns; all reported to have a negative impact on a women's mental well-being
- There were several comments about that women found it distressing being told bad news and then discussing options in same place they had the scan and/or being left crying in a side room waiting for someone to explain next steps
- There was a perceived lack of care in A & E: some women reported being left to bleed in the waiting room, told to stop crying and that they felt they were an "inconvenience"

- Several comments related to the handling of the remains: for example one woman reported the placenta was thrown in the bin in front of them (in a & e); one woman who miscarried at home would have liked to have the option to bring the remains to the hospital to be dealt with humanely (rather than flushed away); one woman reported being asked what they wanted to do with the remains minutes before going into surgery which they found very distressing
- Some women felt pressured into surgery/medical management
- Having to pay for photos in advance is distressing if they have no photo to take away, also means women are scared to pay for a photo in subsequent pregnancies

There were also several comments related to language use which added to women's distress:

- "My own loss came as an abrupt shock and the news was not broken in a caring or compassionate way by the sonographer, which made it worse.",
- "Was told just to stop worrying and to just keep trying"
- "just 'one of those things'"
- "I was told I'm young and can try again, I already have a child so I'm lucky"
- Women do not want to be quoted statistics: "Every time was told: very common, 1 in 4. Was little consolation when I was heartbroken"
- "I found I was quoted a lot of statistics about having a baby in the future rather than focusing on the loss we were experiencing"
- "Not being told oh now you have footprints on your heart you're so lucky, are the NHS serious"
- "The wording and terminology used can be scary and daunting for people who are not familiar with miscarriage"
- Women don't want to hear their pregnancy described as "cells" "product of conception", "pregnancy not viable" "termination" "spontaneous abortion"

Some women said they would have liked some positive information:

- "Paperwork promoting positivity would be very useful as I found myself constantly looking at information about it all going wrong. And this was reinforced in the information the hospital provided about miscarriage."
- "At my scan they never gave me any pictures even though I could see baby. It would have given me some comfort having a picture"
- Positive stories, "Statistics for reassurance"

There were also several comments relating to having to go scans alone without partners and the impact this had on emotional and mental health, summed up by this comment:

> "Dealing with all that without my husband was by far the hardest part of the whole thing, and I probably would have had a more manageable experience if he'd been there to listen properly to what was being said""

Suggestions: For a more sensitive service

- Reconsider the layout to reduce women who are miscarrying encountering other pregnant women or hearing new-borns
- A space away from the EPU/antenatal unit to wait in.
- Have a separate less clinical room to discuss options, and to be given information, away from scanning area
- Have a more private area in A & E where women miscarrying can wait
- Have a policy to assure that the issue of what to do with remains are dealt with more sensitively
- Allow for payments of photos afterwards
- Training in appropriate language use and phrases to avoid, and staff to receive regular training on how to break difficult news
- A specific team trained fully in dealing with loss
- More positive information
- Option to have a scan photo

There were several comments relating to a lack of communication between services

- Women received calls after their loss from their midwives for booking appointments and to check on pregnancy
- "The midwife who saw me after my son was born saw in my notes this was my second pregnancy and asked where my other child was, not realising I had lost them."
- "Every single time I come back for a scan I see a different doctor and I have to go through all the dates and all the details - I don't get why it's not on the system and
- why I am expected to remember all the exact dates of my now numerous scans. It means that every time I come in I am re-living my miscarriages".

A recurring theme was several women who reported long waits for scans and/or surgery (reports of up to 2.5 weeks), with no support over the weekend or outside of working hours (as EPU is closed): "miscarriage is not a 9-5 problem". These delays led to a feeling of being "left in limbo", prolonged women's distress and left women without support, with some feeling forced into going private. These problems were exacerbated by many having to be referred to the EPU through their GP, with GP surgeries also closed on weekends and outside of normal hours, and sometimes hard to get through to.

Suggestions: Communication Between Services

- Being reassured that future midwife appointment/scans etc. will be cancelled
- Better communication with midwives so they are informed of miscarriages
- More information in patient records and on the system and shared with different departments
- Mental health history on maternity notes
- Whether self-referral to EPU could be possible
- Clearer information on how to gain access to services.

Section 3: Mental Health

78% said they found it hard to come to terms with their loss(es) and would have benefited from mental health support. Similarly, 76% said they were not offered mental health support but would have liked some with only 11% said they would not have liked some. 13% were offered some mental health support (of which 45% took up the offer). 69% suffered from grief, 58% anxiety and 34% depression. 87% suffered from fear about pregnancies. Past studies have found incidence of anxiety is higher among women who miscarry than depression, although the figures in this survey (which are self-reported) are higher than found in other studies (typically a quarter to a third of women exhibit anxiety symptoms after an early miscarriage, and around 10% depression symptoms (Cumming *et al.*, 2007; Farren *et al.*, 2016), using established anxiety and depression scales. 41% also struggled getting back into normal life.

63% of those with a partner (254) said their partner found it hard to come to terms with the miscarriage and would have benefitted from mental health support. 45% said their partner would have liked mental health support, although they were not offered any. Past studies suggest 9-12% (4-5%) of men suffer anxiety (depression) post miscarriage (Cumming et al., 2007; Farren et al; 2021)

Respondents were asked in an ideal world what support they would have liked post miscarriage and what support their partner would have benefited from. 86% said they would have liked "Access to a specialist miscarriage service to provide support and answer questions" and 59% (with a partner) said their partner would also benefit from this. 58% said they would like access to counselling, with 27% saying their partner would have benefitted from counselling. 70% said they would have liked " a GP appointment to provide reassurance and discuss future options" but far less (33%) said this for their partner. Only 30% said they would like more written information but 44% said their partner would have benefited from this, suggesting a greater need for more information for the partner. 28% (23%) said they (their partner) would have liked (benefited from) peer support.

One key theme that came through the comments was that women felt they were left to go through the experience on their own, especially the emotional side with little follow up. Another theme was mental health support may not be needed straight away with several comments that emotionally they had a delayed reaction or were still struggling months later. Several mentioned they had existing mental health problems, but this was not taken into account, and they would have liked mental health support. Several respondents reported their mental health was negatively impacted by the fact they need at least three losses to receive medical help and are not helped to understand why the loss happened, these women found it hard to move on with an understanding of what had gone wrong.

Several further suggestions were made on how women (and their partners) could have been better supported; some suggestions related to support during the pregnancy loss, but the majority related to follow up support.

Suggestions: for support/follow up support

- Provide follow ups during and after the miscarriage process, to check on women and provide reassurance
- Someone who they can contact who can provide reassurance, answer questions, and someone to give a "medical 'once over'"
- "Treat everyone as an individual and offer a tailored support plan"
- Peer support e.g., "Weekly zoom groups for pregnancy after loss or TTC after loss"
- A recognition that some may have a delayed emotional response so may need to access information and services at a later date
- A recognition that those with existing mental health conditions may require more support after a miscarriage
- An individual based in the IAPT service specifically trained in pregnancy loss

Suggestions: Partner Support

- An acknowledgment that partners matter
- Some form of check up to check how they are coping
- More information about the physical process and how to support the mother and their own well-being
- Peer support

Section 4: Subsequent Pregnancies

Questions about their experience in subsequent pregnancies were asked to those who went on to have a successful pregnancy. 58% reported they had gone onto to have a successful pregnancy after miscarrying. 95% said they felt anxious on falling pregnant again, 86% nervous, 79% scared and 60% unable to acknowledge pregnancy in case of another miscarriage. Relatively few had positive emotions (20% excited, 17% relieved, 7% optimistic). It seemed these negative emotions lasted for the whole pregnancy (40% said they could not relax until the baby was in their arms) or a large part of the pregnancy (only 21% said they could relax after the 12-week scan). 64% felt they needed extra mental health support during their pregnancy (with 23% not sure), with 72% saying they had no extra support during their pregnancy (of those who did: 19% had early scans, 9% were referred to the perinatal mental health team, Crystal, Orchid or Emerald team; 8% received extra support from their community midwife). Although the sample sizes are small (due to the fact few received mental health support) it was clear that the more specialised services (perinatal team, crystal/emerald/orchid team) and the community midwife were more likely to be reported as excellent/good. It seems the obstetrician, GP and health visitor are less equipped to offer mental health support as less than half rated them as excellent or good.

Table 4: How good were the following people at supporting your mental health during pregnancy?

	Reported/Used by	Excellent/good	Poor/terrible
Community midwife	43	62.79	9.31
Obstetrician	28	46.43	14.28
Crystal Team/Emerald Team/ Orchid Team	7	71.43	14.29
GP	22	40.91	18.19
Health Visitor	15	46.67	20
Perinatal Mental Health Team	8	87.5	12.5

The free text comments added further insight to the support women would like during subsequent pregnancies. There were several comments relating to reassurance. For example, wanting earlier (including a scan at the same stage as the previous loss) and more scans/monitoring (e.g., more regular listening of the heartbeat), extra midwife appointments and requiring more mental health support in the early weeks of future pregnancies, and wanting a specially trained midwife.

Suggestions: Support in Subsequent Pregnancies

- A helpline or specialised midwife to talk to about emotional health/mental health
- More scans and monitoring
- An acknowledgement of anxiety following previous miscarriage by health professionals, especially at routine scans and by midwives. And where possible reassurance such as sonographers saying straight away if there is a heartbeat
- More patience and "Concerns being listened to and acknowledged."
- A standardised way to describe pregnancies (e.g., is it first baby/pregnancy) that is consistent for patients and health professionals
- A 'notification service' so that midwives are aware of miscarriage histories
- "I've seen a charity doing sheets for inside maternity notes where the parents can fill in details about the lost baby/babies so that the midwife/nursing staff can refer to them by their name."

References

Cumming, G. P. *et al.* (2007) 'The emotional burden of miscarriage for women and their partners: Trajectories of anxiety and depression over 13 months', *BJOG: An International Journal of Obstetrics and Gynaecology*, 114(9), pp. 1138–1145. doi: 10.1111/j.1471-0528.2007.01452.x.

de La Rochebrochard E, Thonneau P. (2002) Paternal age and maternal age are risk factors for miscarriage; results of a multicentre European study. *Human Reproduction*, 2002;17, 1649-56. doi:10.1093/humrep/17.6.1649

Farren, J. *et al.* (2016) 'Post-traumatic stress anxiety and depression following miscarriage or ectopic pregnancy: A prospective cohort study', *BMJ Open*, 6(11). doi: 10.1136/bmjopen-

2016-011864..

Farren, J. *et al.* (2021) ‘Differences in post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy between women and their partners: multicenter prospective cohort study’, *Ultrasound in Obstetrics and Gynecology*, 57(1), pp. 141–148. doi: 10.1002/uog.23147.

Nybo Andersen AM, Wohlfahrt J, Christens P, Olsen J and Melbye M. (2000) Maternal age and fetal loss: population based register linkage study. *BMJ*, 320, 1708-12. doi:10.1136/bmj.320.7251.170

Appendix: Positive Feedback

Positive Support

“Given a little charity produced memory box from Wexham park.”

“Midwives supportive”

“The EPU were excellent”

“The hospital nurses were brilliant. Knowledgeable about next steps and so caring.”

“The EPU nurses were amazing. I found anybody who was too sympathetic patronising, but the EPU nurse was matter of fact (but very caring) and gave me the time and advice I needed at the time of the miscarriage and I really appreciated that”

“The team at the EPU were extremely empathetic and I couldn’t fault them.”

“There is a nurse called Emma in the EPU at Frimley who was brilliant…..She is a great asset to your team and I'd love to tell her I am now a proud mum of baby Oliver who was in my belly that day!”

“ Can honestly say that I have found the care on both sides (healthy pregnancy and baby/ectopic pregnancy) to be everything I would want and more. Everyone has been warm and personable, knowledgeable and brilliant at sharing it.”

Positive support in future pregnancies

“I also want to shout out to the sonographer (male but did not tell us his name) who did our 12-week scan, who after knowing about my miscarriages was very reassuring and helped me relax enough to have the scan done! Only a small thing but had a positive effect on my mental health.”

“Midwives were lovely and reassuring”

“Being under consultant care, the consultant was really caring”

“That the perinatal team were there whenever I need them”

“My community midwife and consultant have been invaluable with their support and reassuring me that everything I was feeling was completely understandable, even if I felt like I was worrying too much. Having a very high-risk pregnancy meant that I wasn’t able to fully relax and enjoy being pregnant, and this was heightened by my previous miscarriages but they fully understood and provided support where needed.”

“Orchid team midwife (Paige S) has been amazing. Totally understand the fear and anxiety. Paige made sure I knew she was just at the end of the phone if I ever needed her and if she wasn’t working then another member of the team would be there for me”

“My midwife was amazing”

“The extra scans were really helpful”

“My midwife was amazing Lisa, she went above and beyond every time I felt anxious she would squeeze me in so I could listen to the heartbeat. I never felt like it was too much trouble. When your pregnant after loss you constantly feel like something awful is just about to happen. I felt like I was holding my breath for 9 months. Only when he was in my arms did I exhale”

“My midwife was very caring during appointments. I really appreciated the extra scans and my consultant (Frank Garcia) was really caring at these too, as were the other midwives I dealt with during this time. They made me feel that what I'd gone through had mattered and didn't brush it or my feelings aside.”