



# Pregnancy loss, mental health and the NHS

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A summary of relevant findings from research by the Miscarriage Association, conducted in August 2018

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## Introduction

The Miscarriage Association conducted some research to help us review and develop the support we offer around pregnancy loss and mental health.

Preliminary research published in 2016<sup>1</sup> showed that women who have miscarried are at higher risk of post-traumatic stress disorder (PTSD). And women with pre-existing mental health problems may be particularly vulnerable after pregnancy loss, as well as during pregnancy itself. A search for 'mental health' on the Miscarriage Association private Facebook group showed that this is something people are talking about but an initial search on existing mental health support websites does not reveal any specific information or support.

For more information about our research methods, please see Appendix 1.

The resources produced by the Miscarriage Association as a result of this research can be found here.

- Online resources
  - [Your mental health.](#)
  - [Looking after your mental health after pregnancy loss.](#)
  - [Counselling after a miscarriage.](#)
- A leaflet – '[Looking after your mental health during and after pregnancy loss](#)'.

We also conducted some research on the experience of women and their partners who are pregnant after a loss. Many people reported very high anxiety. We created a [leaflet](#) and [some online information](#) as well as some specific private online support spaces.

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<sup>1</sup> Farren J, Jalmbrant M, Ameye L, *et al*  
Post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy: a prospective cohort study  
*BMJ Open* 2016;**6**:e011864. doi: 10.1136/bmjopen-2016-011864

## Research findings

### NICE guidelines and quality standards

- Information in the NICE guidelines ([Antenatal and postnatal mental health: clinical management and service guidance \[CG192\]](#)) is more focused on traumatic birth and late pregnancy loss/stillbirth than miscarriage. They suggest offering advice and support to women who wish to talk about their experience and trauma focused CBT to those women who have PTSD as a result of the above. A follow up appointment in primary or secondary care is also recommended.
- NICE guidelines [Ectopic pregnancy and miscarriage: diagnosis and initial management \[CG154\]](#) contain no specific mention of mental health but do include information about support and guidance.
- NICE information for the public on treatment of miscarriage and ectopic pregnancy does not mention mental health although has a small section on '[Giving you support](#)'. This information only covers first trimester loss.
- Statement 7 in [Antenatal and postnatal mental health quality standard \[QS115\]](#) suggests that previous loss of a child may mean you have additional mental health support needs (pregnant after a previous loss).

### NHS review of support

[NHS review of support for loss in early and late pregnancy \(2014\)](#) focuses on the immediate aftermath and emotional and practical care needs rather than ongoing mental health support.

### National Bereavement Care Pathway

The [National Bereavement Care Pathway](#) for miscarriage, ectopic and molar pregnancy contains general recommendations for care that, if followed, may make some women's experiences less traumatic. There is specific mention of mental health on page 12. They discuss ongoing emotional support with a reference to knowing to whom to refer for mental health assessments and treatment. There is little info for the healthcare provider on when this referral might be appropriate.

Page 13 also contains a recommendation that women with a previous loss should be offered screening for mental health difficulties during a subsequent pregnancy. Their Useful Contacts page does not provide links to counselling services.

## Our survey

### Symptoms and experiences

We listed common symptoms of mental health problems as identified in Mind's information on depression, anxiety, PTSD and their [introduction to mental health problems](#) and asked people to tell us which of these they experienced.

*Feeling alone or isolated* (74%) is reported as highest, followed by *persistent low mood and tearful* (69%) and then *feeling numb and shut off from other people* (61%), *feeling tired all the time* (58%) and then *anxiety that feels strong, long lasting or difficult to control* (56%). Respondents could select more than one option.

In the written responses throughout the survey, many people also reported low self-esteem or ongoing negative self-talk.

See Appendix 2 for more detail.

### Seeking help

#### *Where and when?*

We asked respondents **where** they went for support and information. Over half of those who replied (51.33%) went to their GP and a quarter (25.88%) looked for NHS counselling. Slightly more (31.64%) looked for private counselling. Respondents could select more than one option.

We asked people **when** they looked for support. Many people sought online support straight away. They would seek additional NHS support such as counselling later – when they felt able to or when they recognised that they weren't coping. Many people said that initially they thought their feelings would change on their own.

*“When I need support I need it ASAP. It's hard to plan for when the grief hits and hard to secure support when you're in grief. My advice to people dealing with miscarriage or infertility or even first time pregnancy is get a therapist now when you don't think you need one so that's it's all taken care of when you do.”*

#### *What did you find helpful?*

- Some respondents found NHS counselling helpful. This seemed to be mainly when counsellors understood the impact of their loss – or explained in detail how the counselling might help.  
*“NHS counselling helped save my life and give me the tools and strength to not let fear put me off trying again.”*
- Some respondents found mental health medication helpful – but others were worried about starting medication if they were trying to conceive or pregnant. There is very little information about medication and

conception/pregnancy and as a result GPs and women seem to err on the side of caution and avoid medication - even if this isn't necessarily the right choice for the patient.

*"Medication helped me cope during recurrent miscarriage. It gave me a bit of breathing room to let time pass and kept me from quitting my job."*

- GPs taking patients' feelings seriously and signing them off work if needed. Offering options – e.g. counselling, medication, time off work and helping women to decide what is right for them. GPs providing follow up care and checking in also helped.

*"The GP was also brilliant giving me options of counselling, medication and signing me off from work."*

- Reading other experiences and seeking help online was usually considered very helpful in reducing isolation and normalising experiences – this could be something that health professionals signpost to more frequently.

### ***What was unhelpful or made things more difficult?***

- Responses suggested that the attitudes of health professionals (focusing purely on the physical aspects and, in many cases, diminishing the importance of the loss) contributed to a feeling that they 'should be able to manage'. This increased negative self-talk and prevented people from seeking help before things reached a crisis point.

*"Mental health was never discussed either by the GP or by the EPU team. Everything was dealing with the physical. Consequently, I felt weak and even more of a failure for the impact my ongoing experiences have on my mental health."*

- Many reported that counselling was too general. Respondents wanted to speak to a counsellor who understood the relationship between mental health problems and pregnancy loss. However, any good counsellor should be able to support people with the experiences that go around the loss – anxiety, depression, low self-esteem etc. For more comment see 'Insights' section.

*"I found the counsellor didn't really seem to have much understanding of pregnancy loss. I couldn't really talk to him. I only went to 4 sessions."*

- Long waiting lists – particularly difficult if women seek help at crisis point.

*"A very long waiting list for NHS counselling. Feeling like I was being brushed off by my midwife."*

- Support from GPs seems to be very inconsistent with many being dismissive and failing to follow up. For more comment see 'Insights' section.

*"At the time of MC, NHS sonographer and nurses were abrupt and rude making it difficult to ask questions or even fully understand what was happening. Later when I reached out to GP for emotional help she ignored it. Both of these made me feel stupid for feeling the way I did and pushed me toward bottling my feelings rather than dealing with them. Looking back, that was very damaging at the time."*

- Some women found having to self refer very difficult. Reported feelings of depression, anxiety, isolation and low self-esteem and stigma around both mental health and pregnancy loss may also make it harder to seek appropriate help.  
*“Having to contact them yourself...I couldn’t even get myself dressed let alone phone anyone.”*
- Some women who were pregnant after a previous loss felt that health professionals did not take their (often overwhelming) anxiety seriously during their pregnancy.  
*“Every time I fell pregnant again there wasn’t enough attention paid to my anxieties about being pregnant and it was overlooked.”*

### ***What would have helped/encouraged you to seek more support?***

Respondents listed four relevant issues.

- Normalising the emotions experienced and emphasising the need for mental as well as physical care.  
*“Guidance/information from the hospital - I had felt discharged with a clean bill of health, and no one even mentioned a low mood. This made me feel like what I was experiencing was normal and therefore felt that my feelings would pass. I didn’t want to be a burden.”*
- More support and guidance from health professionals immediately after the loss.  
*“More information at the hospital so they could sign post me to the right services, more mental health guidance at the hospital too so I knew what I was feeling was ‘normal’!”*
- Counselling to be available sooner, rather than waiting lists of up to a year – by which time their circumstances may have changed.  
*“Counselling being available quicker through the NHS. They are fast to offer medication, but in my case I believed that only covered the problem and didn’t resolve it in the same way counselling did.”*
- More follow up support and advice after leaving hospital and from GPs on subsequent visits.  
*“Being told that what I was feeling was a sign of poor mental health that needed to be addressed. Follow up from health professionals subsequent to my losses which specifically addressed mental health.”*

## Insights and recommendations

The range of experiences of pregnancy loss, mental health problems (and the way they interact) is huge and complex. There is also a massive range of responses and ways of dealing with and managing these experiences.

Those who responded to the survey self defined as having experienced a mental health problem as a result of their loss or losses. Different people respond to difficult life events and define their experiences in very different ways. Only a few respondents said that, while they did experience difficult emotions, they felt they were understandable in the circumstances and therefore did not consider themselves to have experienced mental health problems.

People who experience grief may understand this as a mental health problem. Multiple losses or childlessness may become an ongoing bereavement with a constant need to manage emotions and avoid difficult situations.

In addition, it is clear that some people responded to the survey with their loss rather than their mental health at the forefront of their minds. This is completely understandable. Mental health and mental health problems are experienced within and exacerbated by events and reactions to the world we find ourselves in.

This has implications for how people talk about their needs and how health professionals understand these needs. It's possible that support sometimes gets lost in the gap between how people explain their experiences and how health professionals understand them. Women and their partners are likely to present with information on the loss and their grief rather than with specific symptoms. As a result they may be denied the additional mental health support they could benefit from.

*"My encounter with a doctor only a few weeks after the event that made me feel like I was over reacting and that I just needed time. I knew there wasn't something right but they made me feel like I was being silly."*

We may also see a similar issue when it comes to counselling. It may be helpful if counsellors spent more time helping people understand how more general counselling support could still help them to deal with their experience.

Respondents reported a range of experiences with medication – usually antidepressants. Not everyone wanted to take it, especially during pregnancy or trying to conceive, despite often feeling low or anxious enough to warrant them. [Mind suggest that SSRIs are associated with a slight increase in risk of miscarriage](#) but references provided are not clear and we were told they intend to soften this statement in the next update.

*"I was pretty adamant I didn't want antidepressants as we were trying for another pregnancy and I worried they could affect this."*

## Possible recommendations

Not all of these recommendations are expensive or difficult to implement. Health professionals have the opportunity to make a huge difference just by how they respond to grieving women and their partners. Our [films and good practice guides](#) have more information on caring for women and their partners experiencing pregnancy loss. Although they do not have a mental health focus, sensitive and considerate care at this early stage can help people feel supported and more able to approach the NHS for future support.

- Improve the relevant NICE Guidelines and quality standards to ensure they emphasise the need for mental health support.
- Encourage health professionals to [normalise the range of emotions](#) women and their partners may experience – and to help people look out for and identify a need for additional support before they reach crisis point. Information on emotional and mental health consistently given at the time of the loss would also be helpful (for example, the Miscarriage Association leaflet '[Looking after your mental health during and after pregnancy loss](#)').
- Additional training for health professionals on both supporting people with pregnancy loss and also on the possible implications for their mental health and how they might support women with this (e.g. offering follow up appointments, referring to counselling, discussing medication, considering a break from work, signposting to additional support).
- Consistent additional mental health support for women who are [pregnant after a previous loss](#).
- Prioritise women who have experienced pregnancy loss or who are pregnant after a previous loss on counselling waiting lists (as pregnant women and parents of children under 5 often are).
- Provide more information for GPs on how to have an informed discussion of the relevant risks and benefits of treatment options in order to support women in making decisions around taking medication. The issue of talking to health professionals about the impact of SSRI medication during conception and pregnancy loss is [explored in more detail here](#).



## Appendix 1 – Our research methods

We wanted to make sure that we understood the existing need in order to develop the right kind of support.

- **Existing content on the Miscarriage Association website was reviewed.** Survey participants were also asked to give their opinions.
- **NICE guidelines, National Bereavement Care Pathways** for miscarriage, ectopic and molar pregnancies and **existing research** were identified.
- **Existing support** elsewhere online was also reviewed.
- We ran a **survey through Survey Monkey in August 2018**. This was advertised through our Facebook page and groups, on our forum and news section of the website, through Linked in, Instagram and Twitter and through external forums Mumsnet and Netmums. In order to reach a wider audience, we asked members of our Facebook page and groups to share our survey with their own groups (if they felt it was appropriate). This enabled us to reach more local parents groups as well as our existing audience.
  - The survey was open for one week and we received 1,716 responses. This highlights how many people are in need of support and a place to talk about their feelings and experiences. Most (1652) survey respondents self-defined as having poor mental health as a result of their loss.
  - We asked respondents to tell us whether they lived in the UK. Of the 1288 people who answered this question, 89.21% (1,149) live in the UK.
  - 95.57% (1617) of people who were happy to tell us about themselves (1692 respondents) had experienced a loss or losses themselves. 4.2% (71) had experienced a loss or losses as a partner. 0.24% (4) had experienced both.
  - For the purpose of this summary report, answers to key questions were filtered by search terms – NHS, GP, doctor, hospital and medication.
  - The online nature of the survey does mean we inevitably excluded some groups and individuals who do not have access to or use the Internet or the MA website. This means we may have missed some perspectives and needs. In addition, those coming forward tend to be

those who may be keen to share their experiences rather than keep them private.

## Appendix 2 - Symptoms and experiences

1,487 respondents answered this question. We also provided a space for people to tell us about any other symptoms. The final percentages are listed in the table below (respondents could tick all that applied). They are rounded to the nearest percentage. The italicised entries are additional experiences added in the 'other' column.

Symptom/experience	Percentage of survey respondents (% of question respondents in brackets)	Number
Feeling alone or isolated	74% (85%)	1263
Persistent low mood, tearful or unable to find pleasure in things you used to enjoy	69% (80%)	1185
Feeling numb or shut off from other people	61% (70%)	1043
Feeling tired all the time	58% (66%)	988
Anxiety that feels strong, long lasting, out of proportion or hard to control	56% (64%)	953
Problems sleeping	54% (62%)	925
Flashbacks	52% (60%)	894
Avoiding feelings or memories by shutting them out	36% (42%)	625
Intrusive thoughts or images	31% (36%)	530
Panic attacks	27% (31%)	464
Nightmares	26% (30%)	452
Anger that felt uncontrollable or harmful to people around you	25% (29%)	436
Suicidal feelings	21% (24%)	360
<i>Struggle to cope with other people who are pregnant*</i>	<i>(3%)**</i>	45
<i>Feeling useless/negative self talk/guilt*</i>	<i>(3%)</i>	45
<i>Self harm</i>	<i>(0.5%)</i>	8

<i>Diagnosed PTSD</i>	<i>(0.5%)</i>	<i>8</i>
<i>Eating too much or too little</i>	<i>(0.4%)</i>	<i>6</i>
<i>Difficulties with memory/concentration</i>	<i>(0.3%)</i>	<i>5</i>
<i>Irritable</i>	<i>(0.1%)</i>	<i>2</i>
<i>Obsessive thoughts</i>	<i>(0.1%)</i>	<i>2</i>
<i>Low self confidence/unable to trust self</i>	<i>(0.1%)</i>	<i>2</i>
<i>Mania</i>	<i>(0.07)</i>	<i>1</i>
<i>Resentment</i>	<i>(0.07)</i>	<i>1</i>
<i>Alcohol/drug abuse</i>	<i>(0.07)</i>	<i>1</i>

\*This issue also came up in other questions. Many people who experienced this chose to write about it in our question about how their poor mental health affected their life.

\*\* From this point numbers are so small that rounded figures are the same.