July 2025

sands

Lost in the system:

Bereaved parents experiences of mental health care following baby loss.

Saving babies' lives.
Supporting bereaved families.

Foreword

Thousands of parents in the UK experience the heartbreak of pregnancy loss or the death of a baby every year. Research shows that bereaved parents are at a significantly higher risk of developing mental health problems requiring specialist psychological support.

One of the biggest issues that bereaved parents tell us they want to campaign on is the lack of support available to them for their mental health following their experience, so we spent the first half of 2025 finding out about mental health care following pregnancy or baby loss. We were interested in understanding what services are available and how bereaved parents find them, what's working well and what needs to change.

We heard directly from bereaved parents about their experiences of accessing mental health support following their loss, and how helpful they found what they were able to access. We also spoke to professionals delivering these services and directly asked commissioners what they provide for bereaved parents in the geographical areas they are responsible for.

We would like to extend a huge thank you to everyone who took part in our research and particularly everyone with personal experience of pregnancy and baby loss who so openly shared their stories. Your voices are central to this report, and we will make sure that policymakers hear them.

There have been some big changes in this area in recent years. It has been encouraging to see some improvement, particularly in England, where Maternal Mental Health Services were introduced following the 2019 Baby Loss Awareness Week Alliance report, Out of Sight Out of Mind: Bereaved parents falling through the gaps in mental health care. While researching this report, bereaved parents told us that when they can access the therapy they need through the NHS for long enough, it's really helping them. But only a minority of bereaved parents are able to access the support they need.

The findings below show that it is a postcode lottery for bereaved parents looking for support for their mental health. There is huge variation across the UK and different NHS areas. Fathers and partners, those experiencing earlier pregnancy losses, and those from more marginalised communities are less likely to access the support they need.

We now need concerted action and a real commitment from governments across the UK to strengthen and expand mental health services which support bereaved parents.

This report sets out 21 recommendations for governments, commissioners, NHS bodies and NHS services to make sure all bereaved parents can access the mental health support they need, when they need it, for as long as they need it - no matter where they live or who they are. There is still a long way to go to achieve this. But we know that recent changes are already having a positive impact for some. We need this to be replicated everywhere.

Dr Clea Harmer
Chief Executive, Sands

Dr David Hall
Chair, Sands Board of Trustees

“

The support was good, the fact free support is available is amazing! Especially for those who don’t have a lot of income.

Woman who experienced multiple losses at 8 weeks gestation

sands

I wasn't offered any support at all after leaving the hospital without my child, he passed away at 17 days old after being born at 24 weeks. I have since seen GPs for help over the years to be told they will refer me and then get a text to say they are full and not even taking any details for waiting list patients as they don't have the staff.

Mother of a baby who died neonatally

Content warning

This report covers areas that can be difficult to read about, including suicidal thoughts.

If you are in urgent need of support, the Samaritans free helpline is open 24 hours a day, 7 days a week on **116 123**.

If you need bereavement support, the **Sands National Helpline** provides a safe, confidential place for anyone who has been affected by pregnancy loss or the death of a baby before, during or shortly after birth.

Whether your baby died long ago or recently, we are here for you.

The telephone helpline is free to call from landlines and mobiles on **0808 164 3332.**

You can also email the team at **helpline@sands.org.uk.**

Contents

Use of language and key terms

Definitions

Definitions of miscarriage, stillbirth and neonatal death are available on our website: sands.org.uk/support-all-types-baby-loss

When we talk about people

Bereaved parents and families

These terms are used throughout this report to describe participants, as we know they are acceptable to many of the people we support at Sands. However, we understand that not everyone who experiences pregnancy loss or the death of their baby wishes to be referred to as a parent. Where a preference for alternative language has been shared by a participant it is used when referring to their contributions.

Ethnicity

Is a form of collective social identity which encompasses elements of physical features (such as skin colour and hair texture), language, culture, shared history, and common ancestry. It is socially constructed and dynamic; identities and meanings are shaped by ethnic groups' own members and wider society. Data on ethnicity is based on self-declaration by adults and, for children under the age of 12, guidance from the child's parent, guardian or carer. The two-stage approach to categorising ethnic groups used in our survey is based on that used by the Office for National Statistics. We do not use collective terms such as Black, Asian and minority ethnic (BAME), which emphasise certain groups and exclude others, while also masking differences between groups. Where it is necessary to refer to broad categories to describe inequalities, we refer to 'minoritised ethnic groups' to recognise that individuals have been minoritised through social processes of power rather than existing in distinct statistical minorities.

Women and birthing people

Is used when discussing the whole birthing population, to include individuals who do not identify as women. When discussing our findings, we use gendered language as appropriate to reflect the identity of individual participants. However, when referencing research or policy documents and guidance, we will mirror the language used to avoid introducing inaccuracies.

When we talk about different types of support and services, care and level of need

Bereavement care

Refers to the care provided by healthcare professionals for a mother or birthing person, and their partner (should they have one), at the time of, and shortly after their pregnancy loss or the death of their baby. This care is usually provided within a healthcare setting. It is different and separate to bereavement support provided by Sands staff and volunteers to bereaved parents and families, and to mental health or psychological care provided by mental health staff.

Bereavement support
Refers to the different types of support that charities, such as Sands, provides to anyone touched by pregnancy and baby loss, which may include peer led support. It is different and separate to bereavement care provided by healthcare professionals to bereaved parents, partners and families. It is different and separate to mental health or psychological care provided by mental health staff.

Community Mental Health Services
Provide support for people living with mental health problems in the community, within a local area, rather than in a hospital.

Grief
Is a personal response to death. It refers to the emotional and physical effects of a bereavement.

Integrated Care Board (ICB)
NHS organisations with overall responsibility for planning and commissioning services in their local areas. Whilst the Integrated Care Board (ICB) are responsible for commissioning mental health services for their local populations, services themselves are delivered by a provider – for example NHS Trusts.

Maternal Mental Health Services (MMHSs)
Combine maternity, reproductive health and psychological therapy for women and birthing people experiencing moderate to severe or complex mental health difficulties directly arising from, or related to, their maternity experience in England. This may include those who experience post-traumatic stress disorder following birth trauma, perinatal loss or severe fear of childbirth (tokophobia) (1). These services have been introduced following recognition that perinatal mental health services were not providing support to bereaved parents.

Mild / Moderate / Severe and Complex
Throughout this report you may see references made to mild to moderate, or moderate to severe mental health needs. When first contacting mental health services, patients should be offered an assessment by a qualified healthcare professional, which will consider the severity of symptoms and the impact these are having on daily activities. This will help healthcare professionals to decide the most appropriate pathway and treatment.

Specialist Perinatal Mental Health Services
Provide care and treatment for women and birthing people with serious or complex mental health needs during and after pregnancy. They also offer women with mental health needs advice for planning a pregnancy (2). With the exception of women who are pregnant following loss, bereaved parents are usually not able to access support through these services.

Talking Therapies
Are psychological treatments for mental and emotional problems, for example stress, anxiety and depression, and are available through the NHS. This may include counselling or cognitive behavioural therapy (CBT). You can refer yourself to NHS talking therapies at any time.

Executive summary

What we know

In the UK, thousands of parents experience the heartbreak of pregnancy and baby loss every year. One in two of us is affected. Currently, 13 babies die shortly before, during or soon after birth every day, and at least 1 in 6 pregnancies end in miscarriage. Research shows that bereaved parents are at a significantly higher risk of developing mental health problems requiring specialist psychological support.

We wanted to understand what was happening with mental health support for bereaved parents across the UK. Are they getting the support they need, when they need it, and if not, what needs to be improved?

At the beginning of 2025, we started our research. We asked commissioners about the services they commission to support bereaved parents' mental health following their loss. We spoke to professionals about the services they deliver. Most importantly, we asked bereaved parents about their experiences of accessing the support they need for their mental health. We were particularly interested in finding out about changes in England since the roll out of Maternal Mental Health Services (MMHSs) in 2022.

What we found

86%
(36 out of 42)
of Integrated Care Boards (ICBs) in England told us they commission a MMHS,with the remaining 14% unable to answer this question.

No ICB told us they do not commission a MMHS. 74% (31) told us about the services they commission to support bereaved parents. Many don't commission anything for fathers and partners or those experiencing losses at an earlier gestation or the death of an older infant. The picture is mixed across the nations, with the least provision available in Wales.

A large majority of bereaved parents want support for their mental health. But half can't access any and, only a small minority are able to through the NHS.

81% of bereaved parents who completed our survey told us they wanted access to support for their mental health following their loss.

50% of those who wanted support told us they couldn't access any.

Only **17%** were able to access support through the NHS.

When bereaved parents can access support for their mental health, it is making a difference.

87% of those who told us they received support through the NHS reported that it was at least somewhat helpful.

Bereaved parents who accessed support for a longer period (over 12 weeks) found it more helpful than those who accessed it for shorter periods. What's available on the NHS is often not provided for long enough.

100% of parents who received support for more than 24 weeks found it helpful.

54% of parents who received support for less than 6 weeks found it helpful.

Bereaved parents found universal mental health services unsuited to their needs but are often referred into them. Some healthcare professionals are not aware of specialist services in their area.

66% of bereaved parents who received support from the NHS told us they were referred by a midwife or GP.

- We heard from a GP in England that Primary Care providers are not always aware of new services or provided with updates when services like a MMHS is set up in their area.

> **If there are services that specialise in this, we need to be informed via the Primary Care Networks so that we know the exact place to refer patients.**
>
> **GP in England**

Targets for waiting times are being missed in England for both assessment and referral to treatment.

Only **50%** of bereaved parents told us they are being seen within six weeks (the target is 75%) and 83% within 18 weeks (the target is 95%).

> **It felt as though we were in limbo - no longer with the NHS midwifery team and not yet in counselling. It felt very lonely during that time.**
>
> **Mother whose baby died at 19 weeks gestation**

> **My symptoms got worse. I started feeling suicidal.**
>
> **Mother of a baby who died at 38 weeks gestation**

There are inequalities in the support people received for their mental health.

- The support bereaved parents can access often depends on what's available where they live, not what they need.
- Psychological support from the NHS is far less accessible for bereaved fathers and partners than for mothers and birthing people.
- Black and South Asian parents were less likely to find mental health support helpful.
- 26% of bereaved parents responding to our survey told us they paid to access a mental health service privately. This option is obviously only available to those who can afford it.
- LGBTQIA+ families described a lack of understanding from healthcare professionals about negative or traumatic experiences during their journey into parenthood and in maternity care.

Conclusion

Too many bereaved parents' mental health needs are still not being met. When bereaved parents can reach the NHS services they need for long enough, they find them helpful. But this is a minority of people. We found a postcode lottery in NHS mental health support available for bereaved parents with poor oversight from commissioners.

Bereaved parents are less likely to get the psychological support they need if they:

- Are fathers and partners.
- Live in the Nations (particularly Wales).
- Experience miscarriage or sudden unexpected death in infancy.
- Are from poorer backgrounds.
- Are from minoritised ethnic groups.
- Are from LGBTQIA+ groups.

Action is needed at both a national and local level to make sure all bereaved parents get the psychological support they need.

Recommendations

We are calling on governments across the UK to strengthen and expand specialist mental health services for bereaved parents so all who need it can access support.

Governments must:

- Review need across the population.
- Set national standards for mental health services for bereaved parents.
- Ensure that commissioners and local service providers have access to the resources and appropriately trained staff needed to:
  - deliver support to bereaved parents in line with national standards.
  - provide strong oversight of mental health services providing care for bereaved parents.

Commissioners must:

- Ensure enough specialist psychological support is commissioned for all bereaved parents who need it.
- Monitor delivery of mental health care for bereaved parents against nationally agreed standards.
- Ensure that healthcare professionals working with bereaved parents in both primary and secondary care are given information on specialist psychological services available in their area that they can refer them to.
- Integrate maternity, neonatal and mental health services to ensure bereaved parents do not fall through the gaps, with maternity and neonatal staff able to seamlessly pass care to the mental health team.

Introduction

In 2019, the Baby Loss Awareness Week Alliance's Out of Sight, Out of Mind report (3), found significant gaps in mental health care for bereaved parents. In the six years since, governments across the UK have introduced new services, some with specific pathways for loss. However, bereaved parents still tell us they usually can't access the specialist mental health support they need through the NHS, at a time and place that is right for them.

> **I was told over and over again that the lists were too long or there wasn't capacity for me to access this type of support. I was turned away from multiple organisations and all NHS options.**
>
> **Mother whose baby died at 27 weeks gestation**

New services are rolling out across the UK, aimed at improving access to mental health care in the perinatal period, including following loss. We wanted to find out what difference this is making to bereaved parents.

To do this, we:

- Carried out a survey of bereaved parents and received 1,960 responses from across the UK (See Appendix 1 for overview of survey findings).
- Ran four diverse focus groups and conducted six in-depth interviews with bereaved parents from diverse backgrounds.
- Interviewed health professionals from across the UK.
- Conducted an extensive literature review on the topic of mental health and baby loss.
- Sent Freedom of Information requests (FOI) to all commissioners of NHS mental health services in the UK to find out about the services they are commissioning to treat bereaved parents with psychological conditions arising from their bereavement. (See Appendix 2).
- This report provides a summary of our findings and explores the barriers bereaved parents face in accessing the right mental health care. It will outline our recommendations to ensure that all bereaved parents can access the psychological support they need.

Why do bereaved parents need mental health support?

Thousands of parents in the UK experience the heartbreak of pregnancy loss or the death of a baby every year. One in two of us is affected. Currently, 13 babies die shortly before, during or soon after birth every day, and at least 1 in 6 pregnancies end in miscarriage (4).

Every bereaved parent's grief is unique to them, and every grief journey is different. It is possible to grow around grief, but it never disappears.

Grief is a natural response to the loss of a baby, and some parents will find comfort in the support of their families and communities. However, the loss of a pregnancy or death of a baby can be a traumatic experience, and bereaved parents are at a significantly higher risk of developing mental health problems requiring specialist psychological support (5) (6).

As shown by research:

- Women and birthing people who have experienced stillbirth (7), miscarriage or ectopic pregnancy (8) are at higher risk of post-traumatic stress disorder (PTSD), anxiety and depression than those who haven't.
- **60-70%** of grieving mothers in high-income countries report grief-related depressive symptoms regarded as clinically significant (9).
- **35% of mothers and 13% of partners** who have experienced a stillbirth or neonatal death report four or more negative psychological symptoms nine months postpartum. (This is over three times higher than the rates for live births) (10).
- The risk of an attempted or completed suicide is higher for women who have experienced a stillbirth, miscarriage or termination (11).
- Women who have experienced any form of pregnancy loss or baby death are at a higher risk of common mental disorders later in life, highlighting the long-term impact of pregnancy and baby loss (12).
- Anxiety, depression and post-traumatic stress disorder (PTSD) from a loss and/or traumatic birth were prevalent among partners in the second and third trimester during a subsequent pregnancy. In some fathers and partners, these symptoms continued up to six weeks after pregnancy too (13).
- Minoritised ethnic women may face additional barriers to receiving adequate perinatal mental health support due to cultural expectations, ongoing stigma, culturally insensitive and fragmented health services and interactions with culturally incompetent and dismissive healthcare providers (14).
- LGBTQIA+ bereaved parents can also experience additional stressors because of queerphobic and heteronormative assumptions in care (15).

I have depression and PTSD. I haven't been able to return to work since. I cry every day. I have had suicidal thoughts. I've needed sleeping tablets. I do receive half pay. I no longer speak to my family.

Woman who experienced multiple miscarriages

Not being able to access the right support, at the right time, can have serious impacts on bereaved parents. For example, loss of employment or income, strain on relationships, stigma and social isolation, increased substance abuse, loss of self-esteem, and changes to sense of identity (9).

I can't work at the moment, as the meds they gave me make me so tired. I had to drop out of my studies. If I had received therapy, it all could have been different.

Bereaved mother who experienced a stillbirth and several miscarriages

Fathers and partners can often feel overlooked after loss, experiencing their own grief while also trying to support their partner. There can also be an expectation that their primary role is to support the mother, (16)(17) which not only ignores their status as a grieving parent in their own right, but it also adds extra burdens (18).

I felt that I was forgotten about, and everything was designed for my wife. I was just left to deal with my thoughts and feelings by myself which caused great stress in my life.

Bereaved father to a baby who died during birth

Psychological support for bereaved parents across the UK

Health is the responsibility of the different governments in each UK nation. Therefore, the care and support currently available for bereaved parents is different in each.

To be able to access specialist psychological support specific to baby loss, bereaved parents usually need to be assessed as having a moderate to severe mental health need. This can create a very high threshold for support which many bereaved parents experiencing mental health difficulties do not meet. Those with mild to moderate needs are usually referred into universal talking therapies, rather than specialist mental health services.

England

The 2019 NHS Long Term Plan (19) introduced a new service known as maternity outreach clinics. Launched as Maternal Mental Health Services (MMHSs), they support women experiencing moderate to severe mental health difficulties directly arising from, or related to, their maternity experience, including a perinatal loss pathway. Alongside this, they should offer all fathers and partners an evidence-based assessment for their mental health and signposting to support. The services were piloted between 2020 and 2022 and introduced across England between 2022-2024. Bereaved parents with mild to moderate mental health needs are expected to access support through NHS talking therapies (formerly IAPT - Improving Access to Psychological Therapies).

Scotland

In 2021, the Perinatal Mental Health Network Scotland published new Scottish Perinatal Mental Health Care pathways. On one of these pathways, Maternity and Neonatal Psychological Interventions teams (MNPIs) (20) provide help to women who have mental health problems related to pregnancy or giving birth. This may include support following pregnancy or postnatal loss. However, not all Health Boards have an MNPI service, and not all services provide support to bereaved parents who may be referred to other non-specialist services including perinatal mental health teams or primary care psychological therapy services.

Wales

In Wales, a pilot service based on the model of MMHSs in England has recently been introduced in Cardiff and Vale University Health Board. However, in the other Health Boards, bereavement care and support are largely provided by bereavement midwives and the third sector. Some psychological care may be provided by primary mental health services and perinatal mental health services. In these areas, there are no specific pathways designed to meet the mental health needs of bereaved parents. A new Mental Health and Wellbeing Strategy and Delivery Plan for Wales was published in April 2025 (22).

Northern Ireland

In 2021, funding was approved to develop specialist Community Perinatal Mental Health Services in all five Health and Social Care Trusts in Northern Ireland. As of 2023, these are now operating in all five Trusts (21). However, there do not appear to be universal pathways designed to meet the mental health needs of bereaved parents across Northern Ireland.

Summary of findings

1. Freedom of Information Requests - what did commissioners tell us?

Although there have been policy changes across the UK, we know that implementation can take time. Commissioners can face challenges adapting national policy for their local services. To understand this, in February 2025, we sent Freedom of Information (FOI) requests to all commissioners across the UK, asking them what services they commission and who can access them (See Appendix 2 for more details).

In England and Scotland, where we know specialist pathways are more embedded, commissioners reported a greater range of services available to a wider group of bereaved parents.

	Commissioners who told us there was a specialist service	Commissioners who told us there was no specialist service	Commissioners who did not answer or N/A
England	86%	0%	14%
Scotland	71%	29%	0%
Wales	*28.5%	28.5%	43%
Northern Ireland	40%	40%	20%

*These results include Cardiff and Vale University Health Board where we know that there is a pilot of a pregnancy and baby loss pathway for bereaved parents.

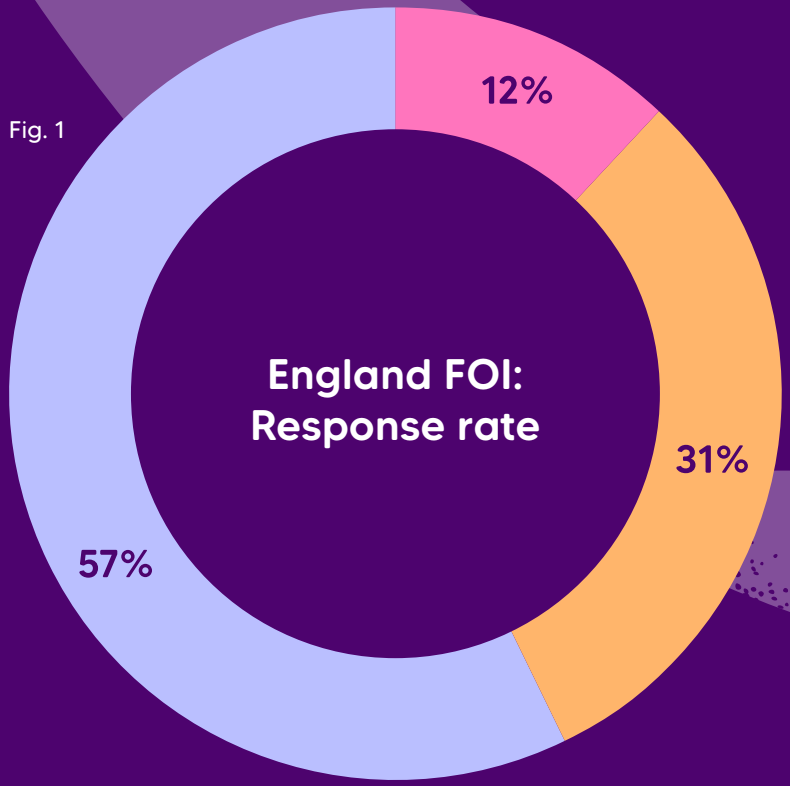
[1]Please note, no MMHS told us they do not commission a service. The additional 14% were commissioners who did not answer the question.

Commissioners do not have good oversight of what they are commissioning

One of the most striking findings from the FOI requests in England was the number of ICBs who could not answer questions about the service they commission. Only 40% could tell us average waiting times, and 38% could not tell us how long after an experience of pregnancy or baby loss bereaved parents could be referred. This demonstrates a lack of oversight and raises concerns about whether ICBs are aware of service gaps or vulnerabilities in the services they are responsible for commissioning.

Commissioners must have better oversight of the services they are commissioning, including clear monitoring and reporting on referral criteria, eligibility and waiting times. They also need the infrastructure and resources from central government to be able to adequately fulfil this role.

Fig. 1



Full response - we received a response from the ICB answering all questions

Partial response - the ICB responded and could answer some of the questions

The ICB responded to tell us that they do not hold any information and did not answer a single question

We received more complete responses from commissioners in Scotland, Wales and Northern Ireland. However, the lack of oversight is not unique to England. One Scottish mental health professional told us that their commissioners do not ask for any outcome data.

> **I write a regular report for commissioners voluntarily - they don't require it of me, and they don't really ask about our service. I think they value us but I'm not sure they fully understand what it is we do.**
>
> **Mental health professional working in the NHS**

Less specialist psychological support is commissioned for fathers and partners

In England, ICBs consistently told us they commission specialist services which support the mother or birthing person only. Only a small number of these confirmed that they signpost, assess or involve the father or partner in therapy. In Scotland, more services told us that the specialist pathways were available to both parents. However, we found some services only offered support to parents during subsequent pregnancies, excluding non-pregnant bereaved parents who continue to fall through gaps.

England FOI: If you do commission a MMHS, can parents with the following experiences access support?

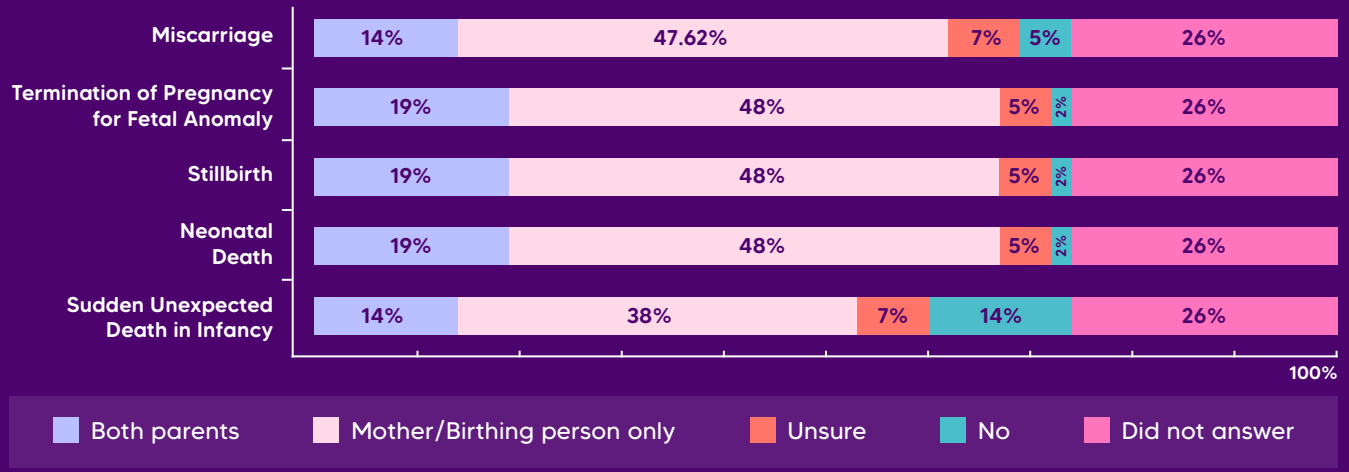


Fig. 2

Scotland FOI: If you do commission an MNPI, can parents with the following experiences access support?

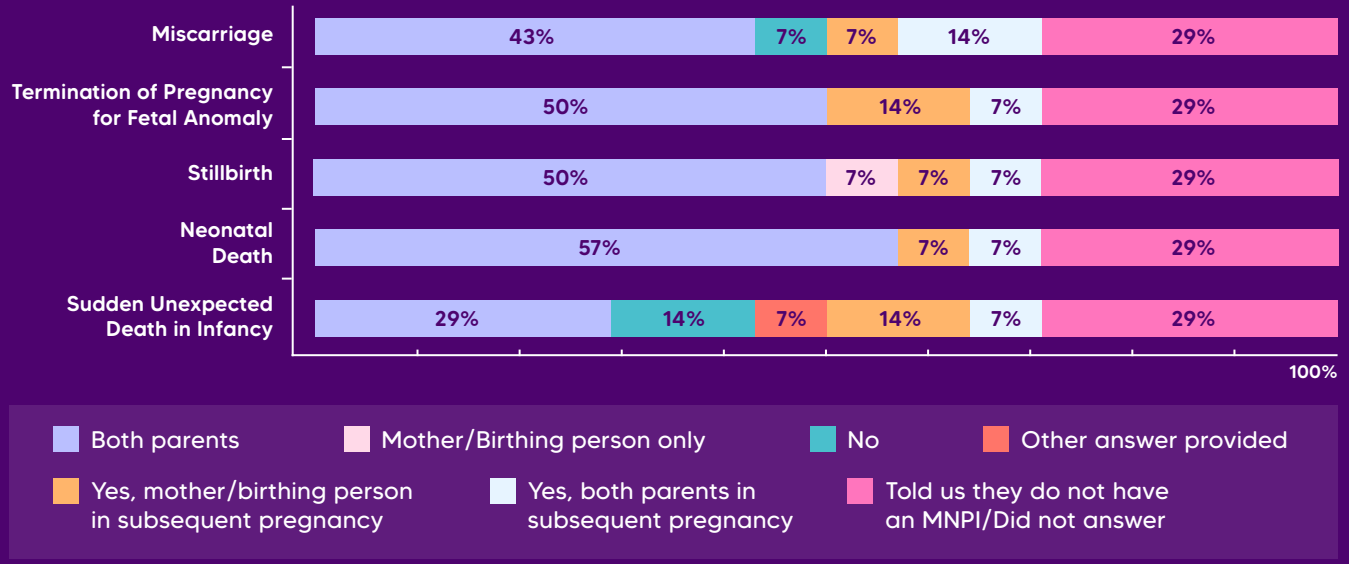


Fig. 3

The small number of specialist services in Northern Ireland and Wales meant quantitative data was not sufficient to draw meaningful conclusions. We did however speak to Welsh mental health professionals who highlighted that their service did not support fathers or partners. It is crucial that all nations increase the service provision and accessibility for fathers and partners, who are also at increased risk of mental health issues.

Less psychological support is commissioned for parents who have experienced miscarriage or sudden unexpected death in infancy.

In England and Scotland, we found that access to care was most variable for parents who had experienced a miscarriage or sudden unexpected death in infancy (SUDI), with a higher number of commissioners informing us that they do not support these groups (5% and 7% for miscarriage respectively in England and Scotland and 14% for SUDI in both nations).

Services who did support these groups reported varying criteria based on gestational or baby's age. For example, one ICB only supported women and birthing people after 20 weeks of pregnancy. Others only supported those who had experienced SUDI up to three months after birth. This could also be seen in the service in Cardiff and Vale (the only specialist pregnancy and baby loss pathway in Wales) who told us they only support parents after 17 weeks of pregnancy or whose baby had died up to 28 days of age.

Overall, the FOIs showed a large variation in the support available. There were large differences in the services available across the four nations and also between the services commissioned in each nation.

Recommendations

Governments must:

- Monitor mental health service provision for bereaved parents.
- Issue national guidance on the commissioning and oversight of specialist mental health services to support bereaved parents, including fathers and partners.
- Ensure that commissioners are given the funding and resource required to provide strong oversight of mental health services providing care for bereaved parents.

The government in Northern Ireland:

- Must expand perinatal mental health services to ensure that specialist psychological support pathways are available in all five Health Trusts.

The government in Wales:

- Must commit to evaluating the specialist psychological support pathway in Cardiff and Vale and expanding it to all Health Boards.

2. Survey of bereaved parents' experiences of mental health care

We wanted to understand bereaved parents' experiences of accessing mental health services, particularly since the introduction of MMHSs in England. To do this, we ran a survey between 17 February 2025 and 1 April 2025. It was completed by 1,960 bereaved parents from across the UK.

The survey was open to anyone who had experienced pregnancy or baby loss, no matter when their loss happened. However, about half of respondents had experienced a loss in the last five years.

We asked parents:

- About their mental health needs and whether they felt they needed or wanted psychological support.
- If they did feel they needed support, their experience of trying to access it.
- If they did access support.
- The impact of receiving or not receiving support.

We also asked parents about the type of loss they had experienced as well as demographic information (see Appendix 1 for more detail on the questions asked and overall results).

What bereaved parents told us

Access to specialist psychological support

More than

4 in 5 bereaved parents

told us they needed specialist psychological support, of those,

Half could not access any support and only

1 in 6 were able to access help via the NHS.

81% of bereaved parents told us they wanted access to support for their mental health, and 50% told us they couldn't access any.

Only 17% of bereaved parents told us they were able to access support through the NHS. 17% accessed support through a charity[2]. A further 15% accessed support privately.

[2]Charity care may be provided free of charge, or at a cost, by the charity. Additionally, some charities are a commissioned provider of NHS services.

Survey: If bereaved parents wanted support, did they get it, and if so, where from?

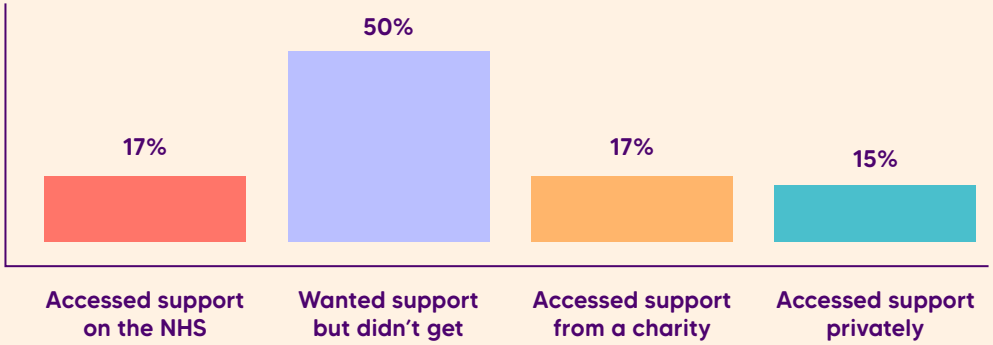


Fig. 4

In England

In England, we compared responses before and after 2022, when MMHSs and specialist pathways for baby loss were rolled out.

The introduction of MMHSs appears to have improved access to specialist mental health services for bereaved parents. When bereaved parents could access support on the NHS, the majority told us they were very satisfied and grateful for the help they received. 87% of people receiving help from the NHS since 2022 found the support helpful.

Free text answers in our survey linked dissatisfaction with NHS provision to support that was too short, generic, or not suitable.

Survey: England Post-22 - How helpful was the support you received from the NHS?

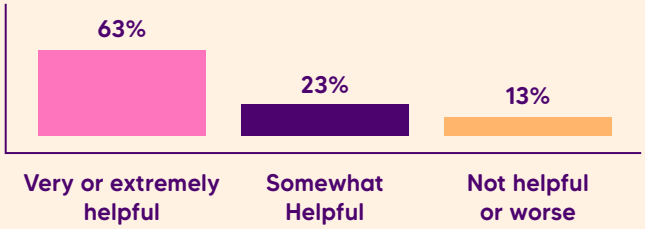


Fig. 5

> **The support was good, the fact free support is available is amazing! Especially for those who don't have a lot of income. It probably could have been a bit longer but definitely gave me the tools to cope with the loss.**
>
> Woman who experienced multiple losses at 8 weeks gestation

> **It saved my life and was invaluable. I will never forget my clinical psychologist and will be eternally grateful.**
>
> Bereaved mother who experienced multiple miscarriages and a stillbirth

Across all types of losses, there was a notable difference in access to services leading up to the launch of MMHSs (2018 and 2022) and after their launch (2022 onwards). We found that whilst only 11% of respondents received support through the NHS between 2018 and 2022, this increased to 17% after 2022.

The biggest improvement between the two time periods was among those who experienced losses after 23 weeks gestation. For this group, access to NHS support rose from 16% to 26%, and those who reported wanting support but not being able to access it fell from 25% to 10%. The extent of this improvement did not apply to earlier losses.

Survey: Difference in access to support - 2018-2022 vs Post-2022

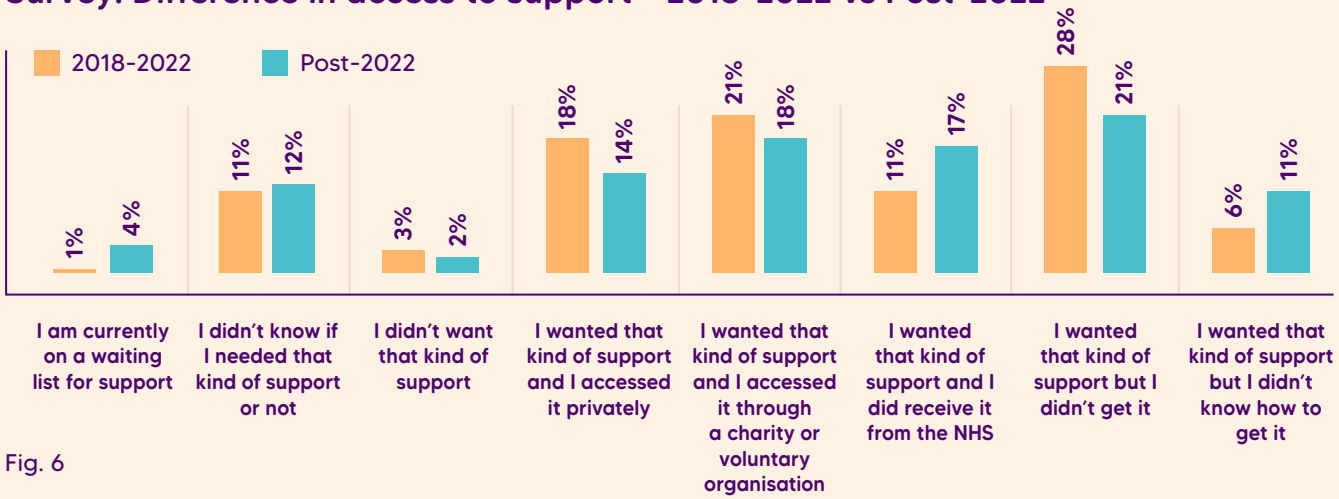


Fig. 6

Similarly to how the FOIs found variable access to psychological support after miscarriage, this provides further evidence that bereaved parents who lose a baby before 23 weeks may still face additional barriers to accessing NHS psychological support. Whilst the percentage of people who experienced a loss before 23 weeks accessing NHS support increased from 2% to 8%, these numbers remain very low.

This suggests that there remain significant barriers to accessing support for this group.

Sadly, even after 2022, we found that the percentage of people unable to access support (32%) was still twice as high as those who accessed it through the NHS (17%).

When bereaved parents were able to access support 20% were still waiting five months or more for support.

This suggests that whilst the services are now in place to better support bereaved parents there are still significant barriers to accessing them.

Survey: Access to specialist mental health services across the nations

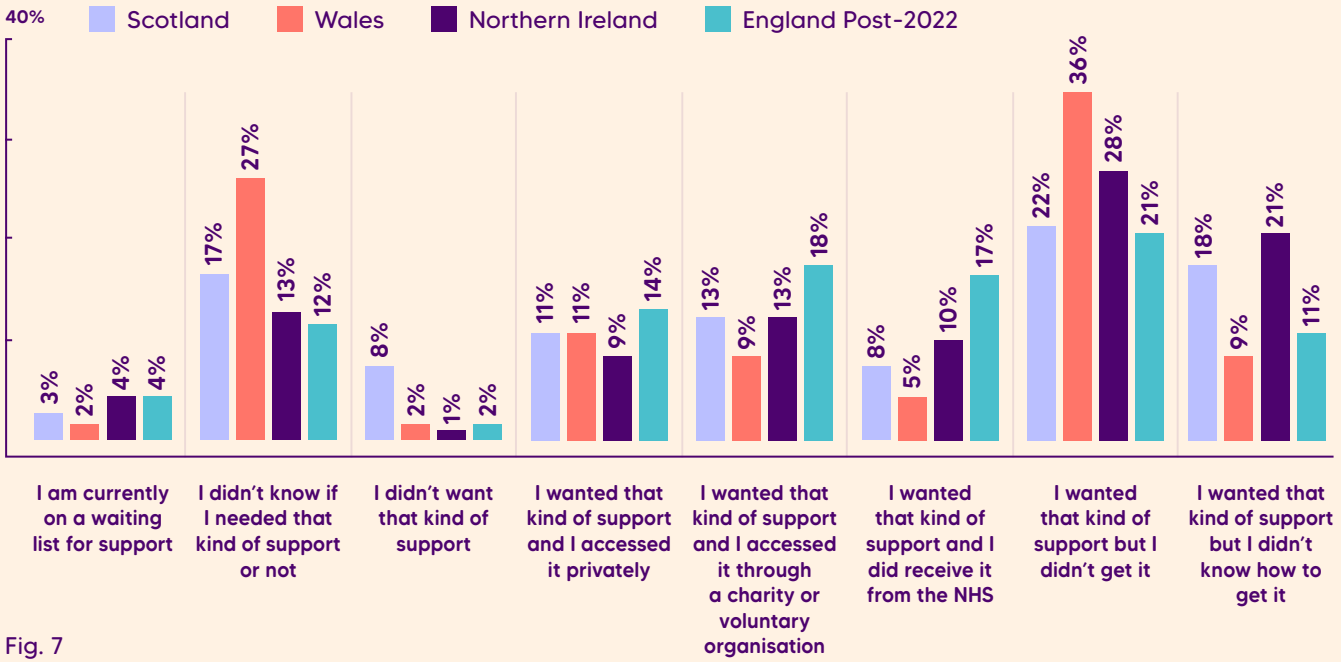


Fig. 7

When comparing the experiences of parents across the nations, England (after 2022) has the highest percentage of bereaved parents receiving support from the NHS (17%) and the smallest percentage reporting that they wanted support but couldn't access it (21%).

Conversely, bereaved parents living in Wales reported the highest levels of wanting support and not receiving it (36%) whilst also having the lowest levels of parents who were able to access NHS support (5%). This is unsurprising given the small number of commissioners telling us they commission a specialist service.

Scotland and Northern Ireland show mixed results. The percentage of bereaved parents who received support through the NHS was higher than in Wales, but lower than England (10% in Northern Ireland and 8% in Scotland). The number of parents who told us they wanted support but couldn't get it was higher than in England but lower than Wales (28% in Northern Ireland and 22% in Scotland).

Our findings suggest that the implementation of specific pregnancy and baby loss pathways and MMHSs are having a positive impact on access in England. Parents in Wales, who do not have specific pathways embedded into national services, are the least likely to receive the NHS support they want.

Length of support

Bereaved parents who accessed support for longer told us they found it more helpful than those who accessed it for shorter periods.

Survey: Number of weeks bereaved parents received mental health support from the NHS

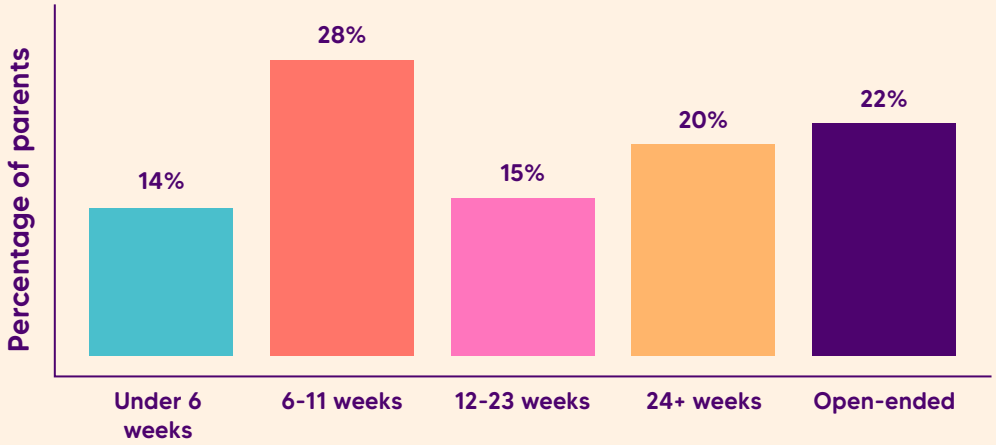


Fig. 8

We found that 42% of bereaved parents who were able to access support through the NHS received less than 12 weeks of support.

Although most bereaved parents who accessed psychological support through the NHS told us it was at least "somewhat helpful" (87%), the perceived helpfulness of the support varied with the length of support. While 100% of parents who received support for more than 24 weeks found it helpful, this figure was only 54% for those who received support for less than six weeks (see Fig.9 opposite). This means that almost half of parents who received support for less than six weeks from the NHS did not find it helpful.

Helpfulness of support based on duration - NHS

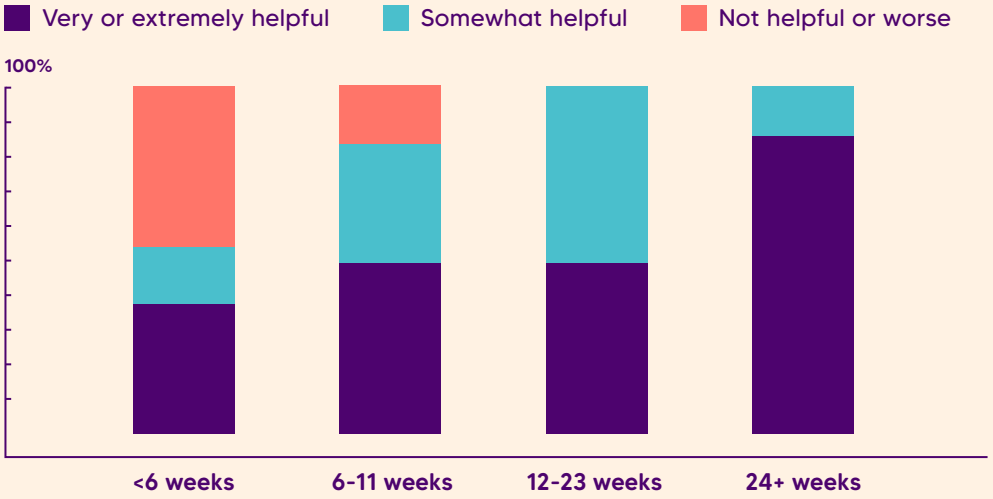


Fig. 9[3]

We also found that over half of bereaved parents who received less than 12 weeks of therapy told us they felt this was too short.

[3]"Helpfulness of support based on duration – NHS" - The four bars show different durations of support, with the proportion of respondents who found the support helpful shown in each bar.

Survey: Level of satisfaction with service based on length of time

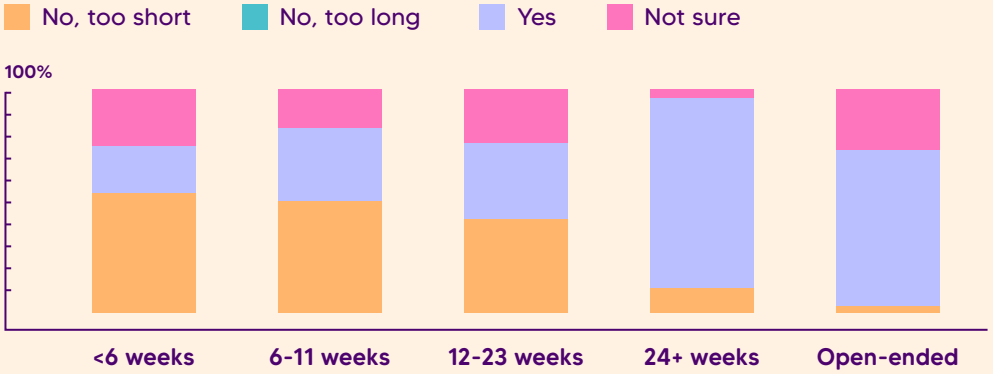


Fig. 10

Some bereaved parents who received fewer sessions than they would have liked reported staff saying this was because of a lack of funding:

> **The psychologist made it clear that our sessions would end after six weeks because there isn't much funding.**
>
> **Bereaved mother whose baby died at 39 weeks gestation**

By listening to the experiences of bereaved parents, we have learnt that current specialist NHS mental health services for bereaved parents are helpful when they are provided for long enough, which, bereaved parents responding to our survey told us, is for 12 or more weeks. We also know that they are difficult to access and are struggling with under-funding and resource pressures. Most parents told us the support they received through the NHS was helpful, but many elaborated that support was often too short, and wished they could have accessed it for longer.

Accessing the right support

Bereaved parents found universal mental health services unsuited to their needs.

Some bereaved parents who completed our survey reported being referred to general Cognitive Behaviour Therapy (CBT) that they did not feel was tailored to or suitable for their needs. Healthcare professionals also told us that they felt there was a tendency to overprescribe CBT, and that decisions to set time-limited treatment were most often based on funding and resource limitations, rather than what is best for bereaved parents.

> **Initially I was referred for CBT which I found very unhelpful, and I felt the therapist really didn't have experience of supporting people through baby loss. I was then changed to talking therapy which was much more helpful.**
>
> **Bereaved mother whose baby was stillborn at 41 weeks gestation**

Recommendations

Commissioners must:

- Ensure enough specialist psychological support is commissioned for all bereaved parents who meet the criteria of demonstrating moderate to severe mental health needs.
- Ensure access to therapy for longer than six weeks and ideally over 12 weeks is available for bereaved parents who would benefit.
- Ensure all professionals who deliver universal services to bereaved parents are trained in understanding pregnancy and baby loss.
- Monitor delivery of mental health care for bereaved parents against nationally agreed standards.

Governments must:

- Review need across the population.
- Set national standards for mental health services for bereaved parents.
- Ensure that commissioners and local service providers have access to the resources and appropriately trained staff needed to deliver support to bereaved parents in line with national standards.

Information about, and referral to, psychological support following pregnancy and baby loss

We found that in some areas where specialist services exist, professionals responsible for referring bereaved parents to them hadn't been given any information, so are unaware that they are there. In some areas, there are no specialist services to refer parents to. This can lead to referrals to inappropriate services and leaves bereaved parents unsupported to search for what they need.

Who referred you to your mental health support? (NHS only)

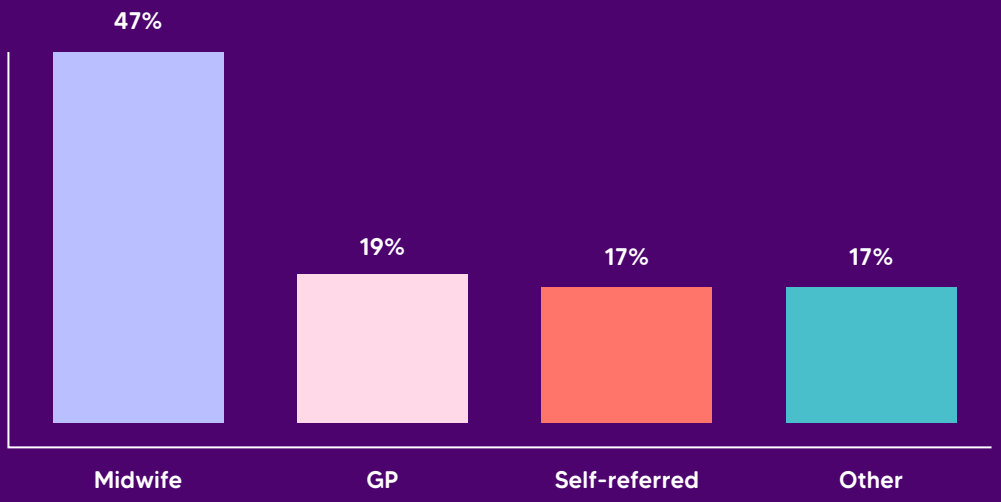


Fig. 11

66% of bereaved parents who received support from the NHS told us they were referred by a midwife or GP.

We heard from a GP in England that Primary Care providers are not always aware of new services or provided with updates when services like a MMHS are set up in their area.

> **If there are services that specialise in this, we need to be informed via the Primary Care Networks so that we know the exact place to refer patients.**
>
> GP in England

This is despite NICE guidance clearly stating that, "Managers and senior healthcare professionals responsible for perinatal mental health services (including those working in maternity and primary care services) should ensure that there are clearly specified care pathways so that all primary and secondary healthcare professionals involved in the care of women during pregnancy and the postnatal period know how to access assessment and treatment. (23)"

If GPs are not aware of the specialist pathways available, they will not refer bereaved parents on to them and are more likely to refer parents to the universal mental health services they are aware of, which do not specialise in supporting people following baby loss.

When health care professionals are unaware of the services available the responsibility is placed on bereaved parents to know about them and to advocate for a referral.

30% of bereaved parents told us they either didn't know what kind of support they needed, or wanted support but didn't know how to get it. Many bereaved parents said they felt "abandoned" by the system following their discharge from hospital.

> **Hospital support following my loss was terrible. No aftercare whatsoever. I felt abandoned. My mental health spiralled due to lack of support and not knowing where to get help and support. I left that hospital with a broken heart.**
>
> Bereaved mother whose baby died at 37 weeks gestation

The FOI requests showed that there are differences in referral criteria across ICBs. This adds an extra layer of difficulty for midwives who work in hospitals covering multiple ICB areas. They will have to be aware of the different referral criteria for families based on their postcode and may be faced with situations where different families they are supporting with the same psychological support needs are not eligible for the same care because of where they live.

Guidance on referring bereaved parents on to specialist psychological support

30% of bereaved parents

told us they either didn't know what kind of support they needed, or wanted support but didn't know how to get it.

Healthcare professionals must be able to signpost and refer parents for psychological support.

Ensuring bereaved parents receive information about, and referral for, mental health support is one of the nine National Bereavement Care Pathway standards of care (24), which are currently being implemented across England and Scotland and developed in Northern Ireland and Wales. Additionally, all women and birthing people in England should receive an invite for a six-to-eight-week postnatal check to assess their emotional wellbeing (25). These present opportunities for healthcare professionals to provide information to and referral for bereaved parents.

These findings and experiences highlight the need for a clear and consistent approach across the UK. Healthcare professionals in contact with bereaved parents should be able to provide clear information on the services available and be ready to make a referral when bereaved parents feel they need support.

> **I called 111 after my loss because I was distraught. The lady was clueless and not very helpful. She didn't even signpost me to any charities that could help. My GP was helpful but again, no further counselling offered. I think because it was a first trimester loss, they didn't deem it necessary.**
>
> Woman who experienced a first trimester loss

Case study:
An integrated mental health service

> **The fact we're embedded in hospital means that bereaved parents don't wait to get support and end up getting referred by the GP. If they did that then they would end up being referred later to adult psychology therapies where there's waiting lists and they're not specialists in parental bereavement.**
>
> **Healthcare professional**

The service, based in the neonatal ward of the hospital, offers trauma-focused counselling and talking therapies specially tailored to bereaved parents who experience losses from 14 weeks gestation onwards. Parents can be referred to the service any time after their loss. Support is open-ended, meaning that parents receive support for as long as they wish – most families received support for eight weeks, with many continuing on longer-term.

Due to its integration with the neonatal ward, the service provides immediate access to bereaved parents when needed. Parents who do not want immediate support are offered to schedule a call for six weeks later to see if they want further help. For those parents who do not want to return to the hospital following their loss, home visits are routinely organised for support. When bereaved parents exhibit symptoms that are deemed more severe, they are referred to perinatal mental health services.

The use of the National Bereavement Care Pathway, which advises that health professionals should care for the partner as well as the birth parent, mean that both parents receive brief assessments for their mental health at the time of their loss, decreasing the chance that people will slip through the gaps and ensures that fathers and partners are not missed. The extra efforts to reach out to partners and fathers was reflected in the gender balance of service users, which is more balanced than many services we spoke to. 50% of service users are mothers, 25% couples, 25% fathers.

Recommendations

Commissioners must:

- Ensure that healthcare professionals working with bereaved parents in both primary and secondary care are given information on specialist psychological services available in their area that they can refer them to.
- Integrate maternity, neonatal and mental health services to ensure bereaved parents do not fall through the gaps, with maternity and neonatal staff able to seamlessly pass care to the mental health team.

Governments must:

- Mandate the nine bereavement care standards within the National Bereavement Care Pathway[4], to ensure that all bereaved parents receive the information, signposting and referral for mental health support they need.

NHS bodies across the UK must:

- Issue clear guidance to GPs on providing six-to-eight-week postnatal check-ups, whilst ensuring they have information about referral pathways for bereaved parents.

As per NICE guidance, CG192, paragraph 1.10.2: Managers and senior healthcare professionals responsible for perinatal mental health services must:

- Ensure that there are clearly specified care pathways so that all primary and secondary healthcare professionals involved in the care of women and birthing people during pregnancy and the postnatal period know how to access assessment and treatment in line with existing NICE guidelines (including those working in maternity and primary care services) (23).

[4]The NBCP standards are already mandatory in Scotland.

Specialist psychological support for bereaved partners

Psychological support from the NHS is far less accessible for bereaved fathers and partners than for mothers and birthing people.

Fathers and partners can often feel overlooked after loss, experiencing their own grief while also trying to support their partner. It is often assumed that the mother or birthing person is the primary griever when a couple experience the death of a baby. Fathers and partners are habitually expected to assume a supportive role without adequate recognition of their own loss. We consistently heard from fathers and partners who found they were not eligible for support as they were not the birth mother.

> **I felt so helpless in wanting to do everything for my wife, she was going through the mental and physical trauma and so I pushed my feelings aside to be there for her, which after a period of time left me in a dark place personally. I eventually found help after a breakdown, but it should never have come to that. We were not made aware of any help, not only mental health but also any help for recurrent miscarriages and had to 'fend for ourselves' to find the help we needed.**
>
> **Partner of a woman who experienced multiple losses**

In England, whilst MMHSs should offer signposting and referral for fathers and partners, not all ICBs told us they did this. These findings were in line with research carried out by the Maternal Mental Health Alliance in 2024, which found that only 29% of services provided a basic assessment and 17% provided the opportunity to join some therapy sessions with the mother or birthing person for fathers and partners (26).

Even when assessments are completed for fathers and partners, too often this does not lead to the treatment needed.

> **I was assessed and was recommended Trauma Focused psychological interventions … and a referral to an eating disorder clinic. The actual care plan I was given was a leaflet to a local self-help group. My wife was referred to the Birth Trauma mental health team, but they don't take referrals from men.**
>
> **Bereaved father whose baby died during birth**

We specifically asked commissioners in England if their MMHS included access to specialist psychological support for both parents. Only 19% told us this was available to both parents after a stillbirth, termination of pregnancy for foetal anomaly or neonatal death. This number reduced to 14% for bereaved parents who had experienced a miscarriage or sudden unexpected death in infancy.

This demonstrates that whilst MMHSs may be improving access to specialist pathways for bereaved mothers and birthing people, not all fathers and partners are benefitting from their introduction. To ensure that the whole family can be better supported after pregnancy and baby loss, it is essential that pathways for bereaved fathers and partners are developed.

Six ICBs also told us that whilst they only offered access to specialist psychological support for the mother or birthing person, this included an assessment, signposting or access to some sessions of counselling for fathers and partners with them. However, linking support for fathers and partners to a mother or birthing person's referral does not recognise the differing psychological needs of both bereaved parents who may need different support, at different times, as individuals.

> **I was invited to join my wife's bereavement counselling, but it felt more like an afterthought. After a couple of sessions, I felt like we were grieving differently and I didn't want to take up her space, so I stopped going. But there was no help for me as a bereaved father.**
>
> **Father whose baby died neonatally**

> **They need to be available equally for birthing and non-birthing partners, and all medical professionals, from midwives to GPs need to be more aware of what is available and actively direct people to that support. The onus should not be placed on the family to seek help, medical professionals should be being proactive, as this is a deeply traumatic time and using energy to find support services is just another burden.**
>
> **LGBTQIA+ bereaved mother who experienced multiple miscarriages**

Bereaved fathers and partners must be able to access their own assessment, and have their own care plan, irrespective of whether the mother or birthing person needs or is accessing support. Research shows that fathers and partners have different bereavement experiences and are more likely to suppress emotions whist their own mental health suffers following a loss. It is therefore crucial that services are able to offer tailored support to meet these specific needs.

Recommendations

Governments must:

- Governments must issue national guidance on mental health pathways for bereaved fathers and partners, recognising that they are individuals in need of their own support.

When support is available

Bereaved parents must be able to access support at the right time for them.

England FOI response: How long after an experience of pregnancy loss or death of a baby can parents access services?

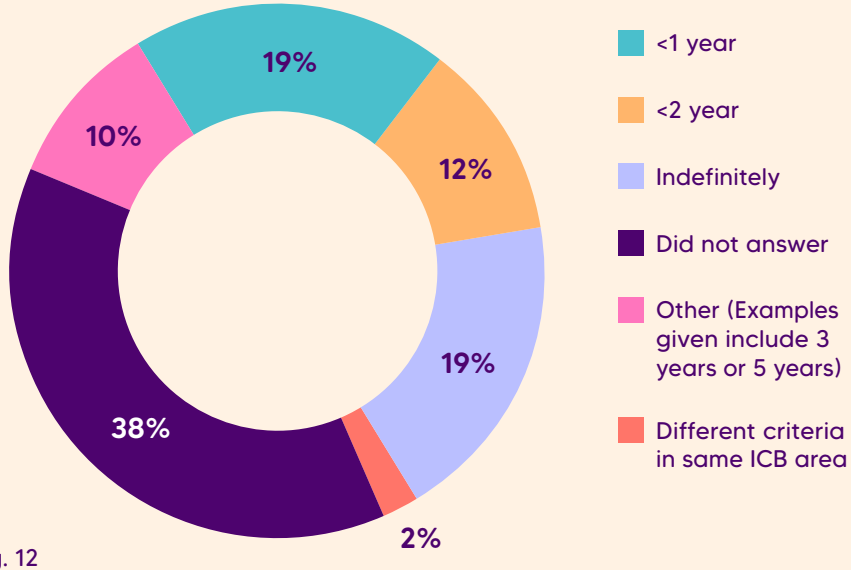


Fig. 12

In England, responses from commissioners showed variations in access criteria for services, with parents only able to be referred into services up to one, two, three, or five years after their loss.

One ICB area told us they commission different providers depending on where bereaved parents live. One will accept bereaved parents up to one year after their loss, whilst the other up to two years.

19% of ICBs told us that the services they commission are available indefinitely for bereaved parents to access. We believe that this needs to be equitable across England, with all ICBs commissioning services which are available to bereaved parents no matter how long ago their loss. **It's essential that all bereaved parents can access the support they need, when they need it.**

> **I wasn't offered any support at all after leaving the hospital without my child, he passed away at 17 days old after being born at 24 weeks. I have since seen GPs for help over the years to be told they will refer me and then to get a text to say they are full and not even taking any details for waiting list patients as they don't have the staff.**
>
> Mother of a baby who died neonatally

> **Only years after the loss when I had a mental breakdown did it all come out.**
>
> Bereaved mother who experienced baby loss

Targets for waiting times are being missed in England

In England, NICE Clinical Guidance on antenatal and postnatal mental health states that, "When a woman with a known or suspected mental health problem is referred in pregnancy or the postnatal period [1 year], assess for treatment within 2 weeks of referral and provide psychological interventions within 1 month of initial assessment (23)."

Additionally, NHS Service Standards set the following targets for Talking Therapies (27):

75% of patients should have a first appointment within six weeks of referral.

95% should have a first appointment within 18 weeks of referral.

However, only

50% of bereaved parents told us they were seen within six weeks and 83% within 18 weeks.

This is further supported by information from commissioners (Fig. 13). Almost half of those who did respond (19% of all commissioners) told us they were assessing bereaved parents within one month.

12% of ICBs reported waits of between four to six months for therapy. One ICB reported waits of up to six to nine months for EMDR (Eye Movement Desensitization and Reprocessing), a treatment for PTSD and anxiety.

> **I found that [the waiting] very tough. I knew I needed help and didn't know what to do in the meantime.**
>
> Bereaved mother whose baby died at 30 weeks gestation

> **It felt as though we were in limbo - no longer with the NHS midwifery team and not yet in counselling. It felt very lonely during that time.**
>
> Bereaved mother whose baby died at 19 weeks gestation

> **My symptoms got worse. I started feeling suicidal.**
>
> Bereaved mother of a baby who died at 38 weeks gestation

England FOI: Average waiting times from referral

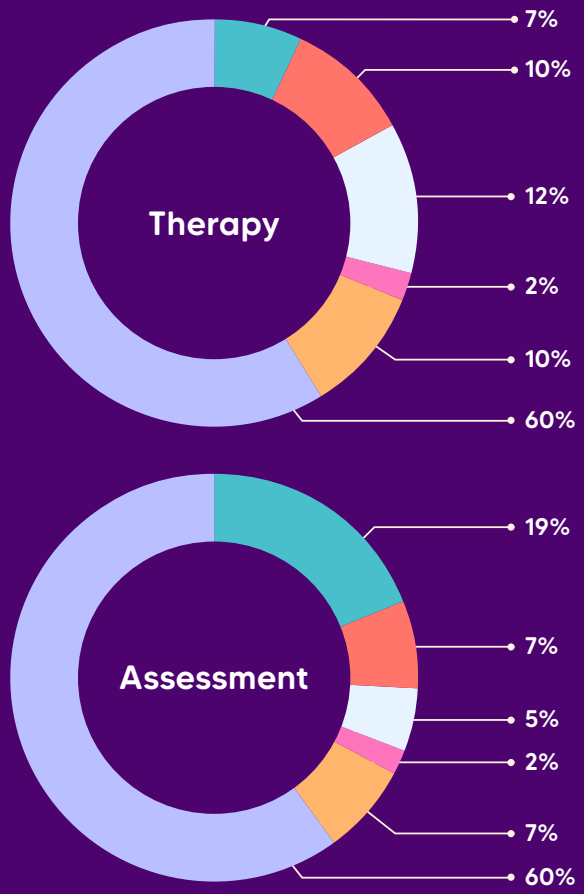


Fig. 13

In Wales, one professional told us that the service was only able to manage their caseload because of lack of knowledge about it, fearing that the waiting list would become unmanageable as word spread. Cardiff and Vale acknowledged in their response that there is "currently no wait [for therapy] but [this] will change with increasing caseload".

Despite the small number of bereaved parents who needed support telling us they were able to access it through the NHS, the waiting times reported by bereaved parents and commissioners suggest that existing services are not coping. Our interviews with mental health professionals also revealed concerns that if services were being accessed by everyone who needed them, waiting times would be even longer, with the service unable to meet demand. A psychologist at a MMHS in England told us:

> **We are aware that there are a lot of people who still don't know we exist. And we want people to know about us. But we don't want to then get overwhelmed with referrals and then the waitlist gets even longer.**
>
> **Psychologist working in a MMHS**

Recommendations

Governments must:

- Issue national guidance to commissioners, to ensure that specialist services are not arbitrarily timebound so bereaved parents can access the care and support they need, at a time that is right for them.
- Commit to services (such as Maternal Mental Health Services in England) which support bereaved parents with mental health needs at national and local levels. All services must be expanded to meet levels of need. (This echoes the recommendations made by the Maternal Mental Health Alliance in their report on MMHSs in October 2024 (26)).
- Monitor all perinatal mental health waiting times against national standards to ensure bereaved mothers and birthing people are being seen in line with antenatal and postnatal mental health guidance.

Inequalities in access to specialist psychological support

Services are not always culturally sensitive and access to translation and interpretation services varies.

We have already seen throughout this report that bereaved parents face many barriers to accessing the psychological support they need. However, we also heard about how inequalities in access and insensitive care can create additional barriers for certain groups of bereaved parents.

> **Counsellors are not faith based and didn't understand how I felt - baby loss needs specialist help.**
>
> **Bereaved South Asian mother whose baby died neonatally**

> **I wanted counselling and was looking for A black organisation but couldn't find anything.**
>
> **Bereaved Black mother whose baby died during labour**

Whilst bereaved parents told us that accessing support helped them, responses to the survey suggested that Black and South Asian parents were less likely to find mental health support helpful[4].

We heard how racist stereotyping of Black or mixed white and Black women or birthing people as "angry" can make advocating for care harder. There are additional barriers for bereaved parents who do not speak English as a first language.

During our interviews with Black and South Asian parents, we heard that factors affecting their experiences included racism, being referred for an inadequate therapy such as general CBT, and loss of trust in NHS services following poor care received at the time of their baby's death

Services often do not recognise that LGBTQIA+ parents face additional barriers to starting a family.

We heard from LGBTQIA+ bereaved parents who highlighted the importance of services recognising that there are additional complexities in LGBTQIA+ journeys to parenthood. They may have experienced negative and traumatic experiences within both maternity care and mental healthcare.

> **We need health professionals to understand that by the time we've experienced a loss, many of us have probably experienced misgendering or homophobic comments, and experienced other traumas around our identities and conception - and these have been part of our journeys into parenthood.**
>
> **LGBTQIA+ mother of a baby who died neonatally**

[4]As Black and South Asian respondents made up only 6% of total respondents and even small number received support – the numbers here may be too small to draw conclusions from. More research is needed.

It is important for healthcare professionals to recognise that LGBTQIA+ families face additional journeys to parenthood and are usually required to self-fund fertility treatments before receiving NHS support. This recognition is essential in being able to provide compassionate and patient-centred psychological support to LGBTQIA+ families.

Too many bereaved parents are having to pay for private treatment, creating unequal access to services.

> **My GP told me I wasn't depressed enough and to go private.**
>
> **Bereaved mother who experienced multiple miscarriages, ectopic pregnancies and whose baby was stillborn**

26% of bereaved parents responding to our survey told us they paid to access a mental health service privately.

Families from deprived areas are at a higher risk of baby loss, and babies born to mothers living the most deprived areas of the UK are twice as likely to die in the first month as babies born to mothers in the least deprived (28). These families are among the least likely to be able to afford private therapy, driving inequalities between those who can and cannot afford private treatment.

Whilst some bereaved parents may begin private treatment, there is always a risk that this becomes unsustainable. We know that bereaved parents are also at an increased risk of loss of employment and earnings. The Office for National Statistics have found that both earnings and probability of employment are significantly impacted by pregnancy and baby loss (29).

As one bereaved mother told us, her experience of loss:

> **Affected every part of my life. I lost friendships, I had to leave my job, family relationships continue to be strained, I am now unable to afford the private therapy.**
>
> **Bereaved mother whose baby died at 37 weeks gestation**

Recommendations

NHS services must:

- Ensure bereaved parents can access translation and interpretation services, both in hospital and community settings.
- Ensure all healthcare professionals supporting bereaved parents undertake cultural competency training so they can deliver culturally sensitive care.
- Ensure services for bereaved parents are patient-centred and ensure staff are trained to understand the needs of different demographics to eliminate instances of queerphobia and racism in mental health care.
- Ensure services are co-designed with the involvement of those with lived experience from minoritised ethnic groups and the LGBTQIA+ community.

Conclusion and recommendations

Our findings have shown that while bereaved parents are still too far away from being able to access the mental health support they need when they need it, the situation has improved in recent years, particularly in England since MMHSs were introduced.

When bereaved parents can access the psychological support they need for long enough through the NHS, they find it extremely helpful. But this is too small a minority of people at the moment, often the support is not available for long enough and it is a postcode lottery with poor oversight from commissioners.

Fathers and partners, bereaved parents in the nations (particularly Wales), those experiencing miscarriage or sudden unexplained death in infancy, those from poorer backgrounds and minoritised ethnic and LGBTQIA+ communities are less likely to be getting the psychological support they need.

Action is needed at both a national and local level to ensure all bereaved parents get the psychological support they need.

Summary of recommendations

We are calling on governments across the UK to strengthen and expand specialist mental health services for bereaved parents so all who need it can access support.

On commissioning

Governments must:

1. Monitor mental health service provision for bereaved parents.
2. Issue national guidance on the commissioning and oversight of specialist mental health services to support bereaved parents, including fathers and partners.
3. Ensure that commissioners are given the funding and resource required to provide strong oversight of mental health services providing care for bereaved parents.
4. The government in Northern Ireland must expand perinatal mental health services to ensure that specialist psychological support pathways are available in all five Health Trusts.
5. The government in Wales must commit to evaluating the specialist psychological support pathway in Cardiff and Vale to all Health Boards and expanding it to all Health Boards.

On support

Commissioners must:

6. Ensure enough specialist psychological support is commissioned for all bereaved parents who meet the criteria of demonstrating moderate to severe mental health needs.
7. Ensure access to therapy for longer than six weeks and ideally over 12 weeks is available for bereaved parents who would benefit.
8. Ensure all professionals who deliver universal services to bereaved parents are trained in understanding pregnancy and baby loss.
9. Monitor delivery of mental health care for bereaved parents against nationally agreed standards.

Governments must:

10. Review need across the population.
11. Set national standards for mental health services for bereaved parents
12. Ensure that commissioners and local service providers have access to the resources and appropriately trained staff needed to deliver support to bereaved parents in line with national standards.

On information and referral

Comissioners must:

13. Ensure that healthcare professionals working with bereaved parents in both primary and secondary care are given information on specialist psychological services available in their area that they can refer them to.
14. Integrate maternity, neonatal and mental health services to ensure bereaved parents do not fall through the gaps, with maternity and neonatal staff able to seamlessly pass care to the mental health team.

Governments must:

15. Mandate the nine bereavement care standards within the National Bereavement Care Pathway, to ensure that all bereaved parents receive the information, signposting and referral for mental health support they need.

NHS bodies across the UK must:

16. Issue clear guidance to GPs on providing six to eight week postnatal check-ups, whilst ensuring they have information about referral pathways for bereaved parents.

As per NICE guidance, CG192, paragraph 1.10.2: Managers and senior healthcare professionals responsible for perinatal mental health services must:

17. Ensure that there are clearly specified care pathways so that all primary and secondary healthcare professionals involved in the care of women during pregnancy and the postnatal period know how to access assessment and treatment In line with existing NICE guidelines (including those working in maternity and primary care services) (23).

On accessing support

NHS services must:

18. Ensure bereaved parents can access translation and interpretation services, both in the hospital and community settings.
19. Ensure all healthcare professionals supporting bereaved parents undertake cultural competency training so they can deliver culturally sensitive care.
20. Ensure services for bereaved parents are patient-centred and ensure staff are trained to understand the needs of different demographics to eliminate instances of queerphobia and racism in mental health care.
21. Ensure services are co-designed with the involvement of those with lived experience from minoritised ethnic groups and the LGBTQIA+ community.

Appendix 1 - Survey results

Key survey questions

Q. Following your experience of loss, would you have liked specialist NHS psychological / mental health support? This means support such as counselling or psychotherapy and is different from support groups or peer support.

Type of support	Total	
I am currently on a waiting list for support	57	3%
I didn't know if I needed that kind of support or not	312	16%
I didn't want that kind of support	68	3%
I wanted that kind of support and I accessed it privately	231	12%
I wanted that kind of support and I accessed it through a charity or voluntary organisation	261	13%
I wanted that kind of support and I did receive it from the NHS	263	13%
I wanted that kind of support but I didn't get it	483	25%
I wanted that kind of support but I didn't know how to get it	283	14%
Total	1960	

Q. Who referred you?

Charity Worker	10	1%
GP	64	9%
Healthcare Assistant	4	1%
Midwife	176	24%
Nurse	13	2%
Obstretrician	12	2%
Other	112	15%
Self-referred	353	47%
Social Worker	3	0%
Total	747	

Q. How long did you have to wait for that support? Please state number of weeks

Under 4 weeks	236	39%
4-7 weeks	155	26%
8-11 weeks	58	10%
12+ weeks	157	26%
Total	606	

Q. Did you have to pay for the support?

Did you pay?		
No	439	74%
Yes	152	26%
Total	591	

Q. How long did you receive support for? Please state in number of weeks. Or if the support is open-ended, please write "open-ended".

How long did you wait?		
Under 6 weeks	70	12%
6-11 weeks	167	30%
12-23 weeks	80	14%
24+ weeks	86	15%
Open-ended	161	29%
Total	564	

Q: Was the length of time of support right for you?

	No, too short	No, too short (%)	No, too long	No, too long (%)	Yes	Yes (%)	Not sure	Not sure (%)	Total
Under 6 weeks	37	55%	0	0%	16	24%	14	21%	67
6-11 weeks	62	39%	1	1%	56	35%	41	26%	160
12-23 weeks	25	32%	0	0%	36	47%	16	21%	77
24+ weeks	10	12%	0	0%	68	81%	6	7%	84
Open-ended	11	7%	1	1%	102	67%	38	25%	152

Q: Overall did you find the support helpful?

Extremely helpful	221	39%
Very helpful	156	28%
Somewhat helpful	145	26%
Not so helpful	28	5%
Worse	7	1%
Much worse	9	2%
Total	566	

Demographic information

Ethnicity	Number	% of respondents who answered question
Black (including mixed ethnicity)	39	3%
South Asian (including mixed ethnicity)	43	3%
White	1224	90%
Other ethnicities	50	4%
Total respondents to questions	1356	

Gender	Number	% of respondents who answered question
Man	90	7%
Woman	1234	93%
Non-binary	3	0.2%
Total	1327	

For more information on the survey and the questions we asked, please contact campaigns@sands.org.uk

Nation	Number	% of respondents who answered question
Scotland	116	9%
Northern Ireland	68	5%
Wales	66	5%
England	1063	81%
Total	1313	

Sexuality	Number	% of respondents who answered question
LGBTQ+	53	4%
Non-LGBTQ+	1251	96%
Total	1304	

Appendix 2 – Freedom of Information (FOI) requests sent to Integrated Care Boards (ICBs) in England

	Response		ICBS who responded	%
How many responses did we receive?	Response received and answered all questions		13	30.95%
	Response received and answered some questions		24	57%
	Response received – ICB does not hold this information		5	12%
	No response received		0	
			42	100%
Question 1: **Does your ICS commission a maternal mental health service?**	Yes		36	86%
	No		0	0%
	No response/did not answer		6	14%
			42	100%
Question 2 (a) **If yes to Question 1, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Miscarriage, ectopic pregnancy and molar pregnancy**	Total number who answered		31	
	Both parents		6	14%
	Mother/Birthing person only		20	47.62%
	Did not answer		11	26%
	Unsure		3	7%
	No		2	5%
			42	100%

	Response		ICBS who responded	%
Question 2 (b) **If yes to Question 1, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Termination of Pregnancy for Fetal Anomaly (ToPFA)**	Total number who answered		31	
	Both parents		8	19&
	Mother/Birthing person only		20	48%
	Did not answer		11	26%
	Unsure		2	5%
	No		1	2%
			42	100%
Question 2 (c) **If yes to Question 1, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Stillbirth**	Total number who answered		31	
	Both parents		8	19%
	Mother/Birthing person only		20	48%
	Did not answer		11	26%
	Unsure		2	5%
	No		1	2%
			42	100%
Question 2 (d) **If yes to Question 1, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Neonatal Death**	Total number who answered		31	
	Both parents		8	19%
	Mother/Birthing person only		20	48%
	Did not answer		11	26%
	Unsure		2	5%
	No		1	2%
			42	100%

	Response		ICBS who responded	%
Question 2 (e) **If yes to Question 1, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: SUDI**	Total number who answered		31	
	Both parents		6	14&
	Mother/Birthing person only		16	38%
	Did not answer		11	26%
	Unsure		3	7%
	No		6	14%
			42	100%
Question 3 **If yes to Question 1, what is the current composition of the clinical team:**	Consultant clinical psychologist 8c		7	
	Clinical/counselling psychologist 8b		9	
	Project manager		3	
	Clinical/counselling psychologist		14	
	Art therapist		0	
	Specialist mental health practitioner		5	
	Mental health nurse		1	
	Spcialist midwife		13	
	Peer support worker		5	
	Assistant psychologist		10	
	Project officer		1	
	Administrator		13	
	Other		1	
	Blank		26	

	Response		ICBS who responded	%
Question 4 **If yes to Question 1, how long after the experience of pregnancy and baby loss are bereaved parents able to access the service?**	Total number who answered		26	
	Up to one year		8	19%
	Up to two years		5	12%
	Indefinitely		8	19%
	Other		4	10%
	Different criteria in same ICB (based on experience of loss or postcode)		1	2%
	Did not answer		16	38%
			42	100%
Question 5 **If yes to Question 1, what was the average length of time bereaved parents waited to be seen by the service, following referral, in 2024 for:?**	Assessment	Total number who answered	17	
		No wait/<1 month	8	19%
		1-3 months	3	7%
		4-6 months	2	5%
		7-9 months	0	0%
		Over 9 months	0	0%
		Varied by postcode	1	2%
		Other	3	7%
		No response/could not answer	25	60%
			42	100%

	Response		ICBS who responded	%
Question 5 **If yes to Question 1, what was the average length of time bereaved parents waited to be seen by the service, following referral, in 2024 for:?**	Therapy	Total number who answered	17	
		No wait/<1 month	3	7%
		1-3 months	4	10%
		4-6 months	5	12%
		7-9 months	0	0%
		Over 9 months	0	0%
		Varied by postcode	1	2%
		Other	4	10%
		No response/could not answer	25	60%
			42	100%
Question 6 **If yes to Question 1, how long are parents able to access therapies from the maternal mental health service?**	Total number who answered		23	
	Up to 6 weeks		0	0
	6-12 weeks		1	2%
	12-24 weeks		4	10%
	Indefinitely		9	21%
	Other		9	21%
	No response		19	45%
			42	100%

	Response		ICBS who responded	%
Question 7 (a) **Do you commission any other specialist psychological therapy service, Miscarriage, ectopic pregnancy and molar pregnancy**	Total number who answered		26	
	Both		6	14.29%
	Mother/Birthing person only		1	2.38%
	Father or partner only		0	0%
	Unsure		2	4.76%
	No to all		17	40.48%
	No response		16	38.10%
	Other-freetext response			
			42	100%
Question 7 (b) **Do you commission any other specialist psychological therapy service, TOPFA**	Total number who answered		26	
	Both		7	16.67%
	Mother/Birthing person only		0	0%
	Father or partner only		0	0%
	Unsure		2	4.76%
	No to all		17	40.48%
	No response		16	38.10%
	Other-freetext response			
			42	100%

	Response		ICBS who responded	%
Question 7 (c) **Do you commission any other specialist psychological therapy service, Stillbirth**	Total number who answered		26	
	Both		7	16.67%
	Mother/Birthing person only		0	0%
	Father or partner only		0	0%
	Unsure		2	4.76%
	No to all		17	40.48%
	No response		16	38.10%
	Other-freetext response			
			42	100%
Question 7 (d) **Do you commission any other specialist psychological therapy service, Neonatal Death**	Total number who answered		26	
	Both		7	16.67%
	Mother/Birthing person only		0	0%
	Father or partner only		0	0%
	Unsure		2	4.76%
	No to all		17	40.48%
	No response		16	38.10%
	Other-freetext response			
			42	100%

	Response		ICBS who responded	%
Question 7 (e) **Do you commission any other specialist psychological therapy service, SUDI**	Total number who answered		26	
	Both		7	16.67%
	Mother/Birthing person only		0	0%
	Father or partner only		0	0%
	Unsure		2	4.76%
	No to all		17	40.48%
	No response		16	38.10%
	Other-freetext response			
			42	100%
Question 8 **If yes to Question 7, what service(s) do you commission**	16 ICBs responded with additional information. Two commissioned Petals. Six made reference to talking therapies. Four referenced bereavement support services.			
Question 9 **Do you hold any more information on psychological support for parents who have experienced pregnancy or baby loss that maybe useful in helping us to understand the services they can access in your area?**	21 ICBS responded with additional information. These pointed to other services including petals, perinatal mental health, talking therapies. This section also included information about third sector services.			

For a breakdown of the results received in Wales, Scotland and Northern Ireland, please see the individual briefings **sands.org.uk/lostinthesystem**

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