

Lost in the system:

Bereaved parents experiences of mental health care following baby loss.
Northern Ireland briefing.

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







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

Summary of our findings across the UK

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.

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.

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.

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.



Summary of our findings in Northern Ireland:

In Northern Ireland, there are no national pathways supporting bereaved parents with psychological support after pregnancy and baby loss. However, perinatal mental health services are now available in all 5 Trusts. These are still relatively new services, with the potential to be expanded to support bereaved parents as well as those with a living baby.

In Northern Ireland we received 68 responses from bereaved parents.¹

We found:

of bereaved parents received the support and, through the NHS. This was the second highest in the UK. of bereaved parents received the support they wanted

However

of bereaved parents reported they wanted support 28% or pereaved parents reported and but didn't receive it with another 21% needing report but not knowing how to get it.

So grateful my husband and I both got psychology sessions-I dread to think what our lives would look like without it.

Bereaved Mother whose baby died before birth from Northern Ireland.

This suggests that despite Northern Ireland not having a specific pregnancy and baby loss pathway, bereaved parents were able to access some psychological support. To understand what support was available, we sent Freedom of Information requests to Trusts about the services they commission:

40% of Trusts told us they do not offer talking therapies for people following pregnancy/birth with staff trained in bereavement and grief counselling. 20% offered this to both parents and another 20% offered support to the mother or birthing person only.

However, it became clear through free text responses that one of these services was a telephone listening service not a counselling service, whilst the other was able to provide psychological support to parents on the neonatal unit when their baby was a patient and to offer 1:1 sessions with a bereavement midwife. Although the Trust was answering yes to this question, it is important to distinguish between psychological support and bereavement care.



Not being offered mental health support led to me having a breakdown when it all got too much. I feel this could have been avoided if I had been given the right supports at the time.

Woman who experienced recurrent miscarriage and ectopic pregnancy from Northern Ireland

^{*}Please note that for a full breakdown of survey questions and responses please see the main report.

- We asked if the Trusts offer a specialist psychological support pathway through the NHS for people who have had experiences of pregnancy and baby loss with moderate to severe mental health illness, no Trusts told us this was available to both parents, with 40% reporting that this available to the mother or birthing person.
- However, it is important to recognise that again in free text answers, both Trusts who told us that this was available to the mother or birthing person also highlighted that this was for women and birthing people who were already under the care of the perinatal mental health team. One Trust explicitly told us that that baby loss was not a referral criteria to the service.



We did, however, hear from one Trust who told us:



Maternity services within the [Redacted] trust recognise the emotional and psychological needs of bereaved parents who have experienced pregnancy-related loss.

Whilst not every bereaved parent will wish for or warrant specialist psychological support, the maternity psychological service offers psychological input to bereaved parents with additional vulnerability due to factors such as a history of mental health problems, fertility problems, previous losses or when trauma symptoms impact alongside their grief. The maternity psychological service works closely with our childbirth and loss midwives to enable a stepped care approach to bereavement care for parents. When referrals for bereaved parents are accepted, they are offered individual or couples based sessions depending on the clinical need.

The maternity psychology service is integrated within the [Redacted] and is currently funded for 2.4wte clinical psychology provision. There is a longstanding high demand for psychological input into maternity services coupled with limited resources within the maternity psychological services contributes to lengthy waiting times for bereaved parents. The service is actively exploring opportunities to improve access for psychological interventions and reduce waiting times for bereaved parents.

Therefore, whilst there may be some examples of good practice in an individual Trust, we saw no evidence that there were any specialist pregnancy and baby loss pathways being provided nationally as part of perinatal mental services. We would, therefore, recommend that in Northern Ireland the government expands perinatal mental health services to ensure that specialist psychological support pathways are available in all 5 Health Trusts for bereaved parents.

Recommendations

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.**

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.



For a list of the full recommendations please see our main report: sands.org.uk/lostinthesystem





- 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.



We sent Freedom of Information requests to the 5 Health Trusts in Northern Ireland asking about the psychological support services they provide to bereaved parents. We received responses from all 5 Health Trusts. The results of the Fols are displayed below:

Question			Responses	%
	Both parents	Yes	1	20%
		No	3	
		Did not answer	1	20%
Do you offer talking therapies for people	For mother/birthing person only	Yes	1	20%
following pregnancy/birth with staff trained		No	2	40%
in bereavement and grief counselling		Did not answer	2	
		Yes	0	
	For father/partner only	No	3	
		Did not answer	2	
	Both parents		1	20%
Are people who have had the following experiences able to access these services?	For mother/birthing person only		1	20%
	For father/partner only			
Miscarriage, ectopic pregnancy and molar pregnancy	No		2	40%
	Did not answer		1	20%
	Both parents		1	20%
Are people who have had the following	For mother/birthing person only		1	20%
experiences able to access these services?	For father/partner only			
Termination of Pregnancy for Foetal Anomaly	No		2	40%
	Did not answer		1	20%

Question		Res	sponses	%
Are people who have had the following	Both parents		1	20%
	For mother/birthing person only		1	20%
experiences able to access these services?	For father/partner only			
Stillbirth	No		2	40%
	Did not answer		1	20%
	Both parents		1	20%
Are people who have had the following	For mother/birthing person only		1	20%
experiences able to access these services?	For father/partner only			
Neonatal Death	No		2	40%
	Did not answer		1	20%
	Both parents		1	20%
Are people who have had the following	For mother/birthing person only			
experiences able to access these services?	For father/partner only			
Sudden Unexpected Death in Infancy	No		3	60%
	Did not answer		1	20%
Do you offer a specialist clinical psychological	Both parents			
support pathway through the NHS for people	For mother/birthing person only		2	40%
who have had the following experiences, with moderate to severe mental health illness?	For father/partner only			
Miscarriage, ectopic pregnancy	No		2	40%
and molar pregnancy	Did not answer		1	20%

Question		R	Responses	%
Do you offer a specialist clinical psychological support pathway through the NHS for people	Both parents			
	For mother/birthing person only		2	40%
who have had the following experiences, with moderate to severe mental health illness?	For father/partner only			
	No		2	40%
ToPFA	Did not answer		1	20%
	Both parents			
Do you offer a specialist clinical psychological support pathway through the NHS for people	For mother/birthing person only		2	40%
who have had the following experiences, with moderate to severe mental health illness?	For father/partner only			
	No		2	40%
Stillbirth	Did not answer		1	20%
	Doth powents			
Do you offer a specialist clinical psychological	Both parents			4.00/
support pathway through the NHS for people who have had the following experiences, with	For mother/birthing person only		2	40%
moderate to severe mental health illness?	For father/partner only			
Neonatal Death	No		2	40%
Noonata Douth	Did not answer		1	20%
	Both parents			
Do you offer a specialist clinical psychological support pathway through the NHS for people	For mother/birthing person only		2	40%
who have had the following experiences, with moderate to severe mental health illness?	For father/partner only			
	No		2	40%
SUDI	Did not answer		1	20%

If yes, what service do you offer?	Women who have experience the above and who are under the care of the perinatal mental health team will psychological support offered until stabilised then signposted to either charity groups e.g. Sands or referral to Adult psychological services if applicable. The perinatal community health team supports birthing persons with a diagnosis of severe and enduring mental health issues. It has 0.3 wte consultant clinical psychologist, a 1 wte specialist clinical psychologist (vacant) of 0.3 wte parent infant practictioner (vacant). In addition there is a 0.6 wte clinical psychologist who supports specialist access for perinatal parents (specifically birthing person) within the psychological therapies service. Whilst the psychologists providing these services have specialist training in perinatal loss, they do not specific provide services within the context of mental health. The non-birthing person or co-parent is only invited to sessions as a support and are not seen in their own right unless referred on the basis on their own complex mental health condition. For PNCMHT baby loss is not a referral criteria, however a referral for perinatal mental health issues can be made up to 12m following birth. A referral prior to birth can be made at any point during the pregnancy.			
Question			Responses	%
	Up to one year		1	20%
If you do commission a specialist therapy	Up to two years			
service, how long after the experience of pregnancy and baby loss are bereaved	Indefinitely			
parents able to access the service?	Did not answer		2	40%
	Other		2	40%
	Assessment	No wait/<1 month	2	40%
		1-3 months	1	20%
If you do commission a specialist therapy service, what was the average length of time bereaved		4-6 months		
parents waited to be seen by the service, following referral, in 2024 for:		Other		
Tollowing referral, in 2024 for.		Did not answer	2	40%
	Therapy	Did not answer	5	100%

Question			Responses	%
If you do commission a specialist therapy service, how long after the experience of	Up to 6 weeks			
	6-12 weeks			
	12-24 weeks			
pregnancy and baby loss are bereaved parents able to access the service?	Indefinitely			
parents able to access the service:	Did not answer		2	40%
	Other		3	
Additional questions 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?	1) Maternity servicews within the [Redacted] trust recogparents who have experienced pregnancy-related loss. specialist psychological support, the maternity psycholowith additional vulnerability due to factors such as a his losses or when trauma symptoms impact alongside thei with our childbirth and loss midwives to enable a stepper referrals for bereaved parents are accepted, they are of the clinical need. The maternity psychology service is integrated within the psychology provision. There is a longstanding high demiwith limited resources within the maternity psychological parents. The service is actively exploring opportunities the reduce waiting times for bereaved parents. 2) Parents can be signposted to Sands/ Bliss/ Tinylife 3) No, the Trust does not currently hold any more inform experienced pregnancy or baby loss. 4) The [Redacted] Trust do not offer formal psychological support for charitable organisations and we can offer scharities. 5) Parents are given general information on admission of leaflets from Sands and RCOG. The bereavement midwinformation on additional support services. Parents are services available in the [Redacted]/ [Redacted] and [Redacted] formation outlining support services available in the [Redacted]/ [Redacted] and [Redacted] and [Redacted] information outlining support services available in the [Redacted]/ [Redacted] and [Redacted] information outlining support services available in the [Redacted]/ [Redacted] and [Redacted]/ [Redacte	Whilst not every bereaved paragical service offers pychological service offers pychological service offers pychological service offers pychological service of mental health problem of grief. The maternity psychological care approach to bereaven offered individual or couples be completed individual or couples be completed in the couples of the couple	rent will wish for cal input to bere s, fertility proble gical service wo nent care for parsed sessions defunded for 2.4w o maternity service work of the for parents what for parents what for parents what for parents who sers are sign poices available the nag their stay and ossible and proble 2 weeks, detail	r or warranteaved paresems, previous closely irrents. When the clinical vices coupes for bereations and the clinical vices coupes for bereations and the clinical vices coupes for bereations and the clinical vices coupe clinical vices clinical



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