

July 2025



Lost in the system:

Bereaved parents
experiences of mental
health care following
baby loss. Wales 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



**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





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.

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.



Summary of our findings in Wales:

Across the UK, bereaved parents in Wales reported the highest rates of wanting support but not being to access it through the NHS, they also reported the lowest rate of parents being able to access support through the NHS.

In Wales we received 66 responses from bereaved parents.¹

We found:

Only **5%** of bereaved parents in Wales told us that they could access the support they wanted through the NHS, with 9% receiving support through a charity or voluntary organisation. These were the lowest figures for both across the UK.

36% of bereaved parents told us they wanted support but couldn't access it. With a further 9% telling us they wanted support but didn't know how to access it.

27% of bereaved parents didn't know if they needed that kind of support. This was significantly higher than other parts of the UK.



Bounced back and fourth between gp and mental health care and no one actually has done anything.

Bereaved mothers whose baby died at 8 months from Wales.

Although concerning, these stats are not necessarily surprising as we know that there are no psychological support pathways for pregnancy and baby loss in 6/7 of the Health Boards in Wales. To better understand what services were available in each of the Health Boards we sent freedom of information requests. As Cardiff and Vale have a pilot pathway, we specifically asked them about this service. We asked the other Health Boards more general questions about whether they had psychological support available for bereaved parents.

We found that:

- Whilst Cardiff and Vale University Hospital are currently piloting a pregnancy and baby loss psychological support service, support is only available to bereaved parents who lose a baby after 17 weeks pregnancy and the service can only be accessed up to one year after pregnancy or baby loss.

86% of the other Health Boards, do not commission talking therapies for people following pregnancy/birth with staff trained in bereavement and grief counselling.

Only **17%** of the other Health Boards told us they 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, with 33% answering no, and 50% not answering.

¹Please note that for a full breakdown of survey questions and responses please see the main report.



It was quite challenging accessing support and if anything this added to my distress at the time. Coming from a mental health background I was shocked at the lack of support available.

Bereaved mother who experienced a TFMR from Wales.

In Cardiff and Vale, we are pleased to see the pilot of a pregnancy and baby loss pathway the service reports some restrictive eligibility criteria including:

- Only supporting bereaved parents over 17 weeks of pregnancy
- Only supporting bereaved parents up to one year after their experience of pregnancy or baby loss

However, we also found that:

- Support was available to bereaved parents after referral indefinitely.

We would recommend that any permanent service rolled out across Wales is open to all bereaved parents, no matter their gestation, and indefinitely after their experience of loss.

As the other Health Boards do not have specific pregnancy and baby loss support pathways, it is unsurprising that such a large percentage reported having no services and were, therefore, unable to answer questions. This was similarly reflected in the experiences of bereaved parents.

We saw a greater response of free text responses from Health Boards in Wales; these suggested a reliance on maternity bereavement staff and the third/ voluntary sector to provide bereavement care and support. This showed a clack of distinction between psychological support services and bereavement support services:



[Name of hospital] has a pregnancy loss specialist nurse who provides support to families that have suffered a miscarriage. Unfortunately, this service is not Health Board wide.



[Name of Health Board] provides specialist support via our bereavement midwife and Care After Death team. If a bereaved family require specialist bereavement support services we utilise third sector companies and charities.

Whilst unsurprising, given the lack of specialist pathways these show the inequity in support available across the different Health Boards and demonstrates the need for a national pathway to be rolled out across Wales.



Recommendations

The government in Wales must commit to evaluating the specialist psychological support pathway in Cardiff and Vale expanding it to all Health Boards.

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/lostinthetystem

Across the UK 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.

We sent Freedom of Information requests to the 6 Health Boards in Wales who do not have a pregnancy and baby loss pathway. We received responses from all 6 Health Boards. We sent a separate request to Cardiff and Vale, asking about their pregnancy and baby loss services. The results of the Fols are displayed below.

Question			Responses	%
Do you offer talking therapies for people following pregnancy/birth with staff trained in bereavement and grief counselling	Both parents	Yes	1	17%
		No	5	83%
		Did not answer		
	For mother/birthing person only	Yes		
		No	5	
		Did not answer	1	
	For father/partner only	Yes		
		No	5	
		Did not answer	1	
	Total		6	100%
Are people who have had the following experiences able to access these services? Miscarriage, ectopic pregnancy and molar pregnancy	Both parents		2	33%
	For mother/birthing person only			
	For father/partner only			
	No		1	17%
	Did not answer		3	50%
			6	100%
Are people who have had the following experiences able to access these services? Termination of Pregnancy for Foetal Anomaly	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		4	66%
	Did not answer		1	17%
			6	100%

Question			Responses	%
<p>Are people who have had the following experiences able to access these services?</p> <p>Stillbirth</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		4	66%
	Did not answer		1	17%
			6	100%
<p>Are people who have had the following experiences able to access these services?</p> <p>Neonatal Death</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		4	66%
	Did not answer		1	17%
			6	100%
<p>Are people who have had the following experiences able to access these services?</p> <p>Sudden Unexpected Death in Infancy</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		4	66%
	Did not answer		1	17%
			6	100%
<p>Do you offer a specialist clinical psychological support pathway through the NHS for people who have had the following experiences, with moderate to severe mental health illness?</p> <p>Miscarriage, ectopic pregnancy and molar pregnancy</p>	Both parents		1	
	For mother/birthing person only			
	For father/partner only			
	No		2	
	Did not answer		3	
			6	100%

Question			Responses	%
<p>Do you offer a specialist clinical psychological support pathway through the NHS for people who have had the following experiences, with moderate to severe mental health illness?</p> <p>ToPFA</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		2	33%
	Did not answer		3	50%
			6	100%
<p>Do you offer a specialist clinical psychological support pathway through the NHS for people who have had the following experiences, with moderate to severe mental health illness?</p> <p>Stillbirth</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		2	33%
	Did not answer		3	50%
			6	100%
<p>Do you offer a specialist clinical psychological support pathway through the NHS for people who have had the following experiences, with moderate to severe mental health illness?</p> <p>Neonatal Death</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		2	33%
	Did not answer		3	50%
			6	100%
<p>Do you offer a specialist clinical psychological support pathway through the NHS for people who have had the following experiences, with moderate to severe mental health illness?</p> <p>SUDI</p>	Both parents		1	17%
	For mother/birthing person only			
	For father/partner only			
	No		2	33%
	Did not answer		3	50%
			6	100%

<p>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?</p>	<p>The [Redacted] confirms that in [Redacted], it has a pregnancy loss specialist nurse who provides support to families that have suffered a miscarriage. Unfortunately, this service is not Health Board wide.</p> <p>Signposted us to the baby loss support page on website.</p> <p>Our Sam provides support and a QR code to local and national baby loss charities including Andy's Man Club & The Stillbirth and Neonatal Death Charity (SANDS).</p> <p>[Redacted] Board provides specialist support via our bereavement midwife and Care After Death team. If a bereaved family require specialist bereavement support services we utilise third sector companies and charities such as Sands, Sandy Bear, 2wish and Aching Arms. There is also the [Redacted] Loss Support group we signpost families to which is peer led.</p>
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Question		Responses
Does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Miscarriage, ectopic pregnancy and molar pregnancy	Both parents	Yes, if after 17 weeks
	Mother/Birthing person only	Both parents
	Did not answer	
	Unsure	
	No	
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)	Both parents	Yes, if after 17 weeks
	Mother/Birthing person only	Both parents
	Did not answer	
	Unsure	
	No	
Does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences: Stillbirth	Both parents	Only 28 days post birth
	Mother/Birthing person only	Both parents
	Did not answer	
	Unsure	
	No	

Question		Responses
What is the current composition of the clinical team:	Consultant clinical psychologist 8c	
	Clinical/counselling psychologist 8b	0.2
	Project manager	
	Clinical/counselling psychologist	8a 0.4
	Art therapist	
	Specialist mental health practitioner	
	Mental health nurse	
	Specialist midwife	
	Peer support worker	
	Assistant Psychologist	
	Project officer	
	Administrator	
	Other	
	Blank	
How long after the experience of pregnancy and baby loss are bereaved parents able to access the service?	Answered	
	Up to one year	Yes
	Up to two years	
	Indefinitely	
	Other	
	Did not answer	

Question		Responses
What was the average length of time bereaved parents waited to be seen by the service, following referral, in 2024 for:?	Assessment: Answered	
	No wait/<1 month	4 weeks
	1-3 months	
	4-6 months	
	7-9 months	
	Over 9 months	
	Varied by postcode	
	Other	
	No response/could not answer	
	Therapy: Answered	
	No wait	Currently no wait but will change with caseload.
	1-3 months	
	4-6 months	
	7-9 months	
	Over 9 months	
	Other	
	No response/could not answer	
How long are parents able to access therapies from the maternal mental health service?	Answered	
	Up to 6 weeks	
	6-12 weeks	
	12-24 weeks	
	Indefinitely	Yes
	Other	
	No response	

Question		Responses
Do you commission any other specialist psychological therapy service Miscarriage, ectopic pregnancy and molar pregnancy	Answered	
	Both	
	Mother	
	Father or partner only	
	Unsure	
	No to all	Yes
	No response	
	Other - freetext response	
Do you commission any other specialist psychological therapy service, TOPFA	Answered	
	Both	
	Mother	
	Father or partner only	
	Unsure	
	No to all	Yes
	No response	
	Other	
Do you commission any other specialist psychological therapy service, Stillbirth	Answered	
	Both	
	Mother	
	Father or partner only	
	Unsure	
	No to all	Yes
	No response	
	Other - free text response	

Question		Responses
Do you commission any other specialist psychological therapy service, Neonatal Death	Answered	
	Both	
	Mother	
	Father or partner only	
	Unsure	
	No to all	Yes
	No response	
	Other - freetext response	
Do you commission any other specialist psychological therapy service, SUDI	Answered	
	Both	
	Mother	
	Father or partner only	
	Unsure	
	No to all	Yes
	No response	
	Other	
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?	Third sector charities - 2wish if baby was born alive and passes away in NICU. The Junction also offers counselling for parents who have experienced loss.



sands.org.uk/lostintheshystem

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