

Lost in the system:

Bereaved parents experiences of mental health care following baby loss. Scotland 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 Scotland:

In Scotland, access to specialist mental health support for bereaved parents can be delivered through Maternity and Neonatal Psychological Intervention Teams. The second of the Scottish Perinatal Mental Health Care Pathways, these teams provide interventions for women with common or mild to moderate mental health problems with mental health difficulties which arise from pregnancy, birth or neonatal complications, trauma or loss (current/past).

We received 120 responses from bereaved parents living in Scotland.¹

We found that:

Only

of bereaved parents told us that they resemble they wanted through the NHS. This was much lower than in of bereaved parents told us that they received the support England where 17% of bereaved parents reported being able to access the support they wanted through the NHS.

of bereaved parents received the support they wanted through charities or the voluntary sector with an additional 11% accessing support privately. These figures are higher than those receiving support through the NHS.

40% of bereaved parents told us they wanted support but either didn't get it or didn't know how to get it.

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



There needs to be support. My entire life felt like it had imploded. You need support to begin to rebuild your life. My son died at 41+4 weeks during labour there was no support from GP, I didn't get a 6 week review, and the bereavement midwife phoned me twice, the first time said 'oh, you had an emergency C-section, that makes things so much worse', as though there could be a 'worse'.

Bereaved mother whose baby died during labour from Scotland.

We sent Freedom of Information requests to Health Boards in Scotland, to better understand whether they were delivering psychological support for bereaved parents through MNPI teams and, if not, what support was available.

We found that 71% of Health Boards are delivering Maternity and Neonatal Psychological Intervention Teams.

However:

- We found considerable variations in the support available for bereaved parents even within services with an MNPI team, this included not all services supporting parents after miscarriage or sudden unexpected death in infancy.
- Some services told us that they only support bereaved parents during a pregnancy after loss.
- Some services reported waiting times of up to 9 months for bereaved parents to receive psychological support.

Variations in the support available

We found significant variation in the support bereaved parents could access through different MNPIs. This would exclude bereaved parents who are not currently pregnant.

We also found variations by type of pregnancy or baby loss particularly for those experiencing miscarriage or sudden unexpected death in infancy:

43% of services supported bereaved parents after Miscarriage

50% supported bereaved parents after Termination of Pregnancy for Fetal Anomaly or Stillbirth

57% supported beloated after Neonatal Death supported bereaved parents

29% supported bereaved parents after Sudden Unexpected Death in Infancy

Maternity and Neonatal Psychological Intervention teams must be able to support all bereaved parents, regardless of whether they are currently pregnant or the experience of pregnancy and baby loss.



Access to support services

All services who had an MNPI were able to provide information on their service wait times and service provision:

- We found the majority of services (50%) reported wait times of 1-3 months for an assessment.
- Whilst the majority of services reported either no wait (29%) or between 1-3 (29%) to begin therapy, a minority reported wait of between 4-6 months (7%) and 7-9 months (7%).
- MNPI services must be properly funded to ensure that they can meet capacity to provide support to all bereaved parents.

When asked about their referral criteria, we found that:

of services told us that bereaved parents could access the service up to 1 year after their experience of pregnancy or baby loss, with only 7% offering access indefinitely.

Being outright asked if you want it would help, it was mentioned briefly to me in the hospital when I had my son but with everything going on I didn't really take anything in, and was never really asked again.

Bereaved mother who experienced a TFMR from Scotland

Additionally, we found that when asked about how long bereaved parents could access therapy most services (57%) did not answer in a set time but answered with 'other' informing us this was patient centred, linked to babies first birthday or anniversary and longer if pregnant again.

Access to psychological support must be available to all bereaved parents, whenever they need it.

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.

The government in Scotland 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.



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



- 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 14 Health Boards in Scotland asking about the psychological support services they provide to bereaved parents. We received responses from all 14 Health Boards. The results of the Fols are displayed below:

Question		Responses	%
Does your Health Board commission Maternity and Neonatal Psychological Interventions (MNPI) Teams?	Yes	10	71%
	No	4	29%
	Total	14	100%
	Both parents	6	43%
If you do commission MNPI teams, does this	Mother/Birthing person only	0	0%
service include access to specialist psychological support (1:1 therapies), for people with the	Told us they do not have an MNPI/Did not answer	0	0%
following experiences:	Other answer provided	4	29%
Miscarriage, ectopic pregnancy	Yes, mother/birthing person in subsequent pregnancy	1	7%
and molar pregnancy	Yes, both parents in subsequent pregnancy	2	14%
	No	1	7%
		14	100%
	Both parents	7	50%
	Mother/Birthing person only	0	0%
If you do commission MNPI teams, does this service include access to specialist psychological support (1:1	Told us they do not have an MNPI/Did not answer	4	29%
therapies), for people with the following experiences: Termination of Pregnancy for Fetal Anomaly (ToPFA)	Other answer provided	0	0%
	Yes, mother/ birthing person in subsequent pregnancy	2	14%
	Yes, both parents in subsequent pregnancy	1	7%
	No	0	0%
		14	100%

Question		Responses	%
If you do commission MNPI teams, does this service include access to specialist psychological support (1:1	Both parents	7	50%
	Mother/Birthing person only	1	7%
	Told us they do not have an MNPI/Did not answer	4	29%
therapies), for people with the following experiences:	Other answer provided	0	0%
Stillbirth	Yes, mother/birthing person in subsequent pregnancy	1	7%
	Yes, both parents in subsequent pregnancy	1	7%
	No	0	0%
		14	100%
	Both parents	8	57%
	Mother/Birthing person only	0	0%
If you do commission MNPI teams, does this service include access to specialist psychological support (1:1	Told us they do not have an MNPI/Did not answer	4	29%
therapies), for people with the following experiences:	Other answer provided	0	0%
Neonatal Death	Yes, mother/ birthing person in subsequent pregnancy	1	7%
	Yes, both parents in subsequent pregnancy	1	7%
	No	0	0%
		14	100%
	Both parents	4	29%
If you do commission MNPI teams, does this service include access to specialist psychological support (1:1 therapies), for people with the following experiences:	Mother/Birthing person only	0	0%
	Told us they do not have an MNPI/Did not answer	4	29%
	Other answer provided	1	7%
Sudden Unexpected Death in Infancy	Yes, mother/ birthing person in subsequent pregnancy	2	14%
	Yes, both parents in subsequent pregnancy	1	7%
	No	2	14%
		14	100%

Question			Responses	%
If you do commission MNPI, how long after the experience of pregnancy and baby loss are bereaved parents able to access the service?	Up to one year		7	50%
	Up to two years		0	0%
	Indefinitely		1	7%
	Other		2	14%
	Did not answer		4	29%
		No wait/<1 month	2	14.29%
		1-3 months	7	50%
		4-6 months	1	7%
		7-9 months	0	0%
		Over 9 months	0	0%
		Varied by postcode	0	0%
		Other	0	0%
If you do commission MNPI, what was the average		No response/Could not answer	4	29%
length of time bereaved parents waited to be seen			14	100%
by the service, following referral, in 2024 for:		No wait	4	29%
		1-3 months	4	29%
		4-6 months	1	7%
		7-9 months	1	7%
		Over 9 months	0	0%
		Varied by postcode	0	0%
		Other	0	0%
		No response/Could not answer	4	29%
			14	100%

Question		Responses	%
If you do commission MNPI, how long are	Up to 6 weeks	0	0%
	6-12 weeks	1	7%
	12-24 weeks	0	0%
parents able to access therapies from the MNPI services?	Indefinitely	1	7%
	Other	8	57%
	Did not answer	4	29%
		14	100%
	Both parents	4	28.57%
If you do commission MNPI teams, does this service include access to specialist psychological support (1:1	Mother/Birthing person only	1	7.14%
therapies), for people with the following experiences:	Father or partner only	0	0%
Neonatal Death	No	5	35.71%
	Unsure/Blank	4	28.57%
		14	100%
	Both parents	4	28.57%
Do you commission any other specialist	Mother/Birthing person only	1	7.14%
psychological therapy service,	Father or partner only	0	0%
TOPFA	No	5	35.71%
	Unsure/Blank	4	28.57%
		14	100%
	Both parents	4	28.57%
Do you commission any other specialist	Mother/Birthing person only	2	14.29%
psychological therapy service,	Father or partner only	0	0%
Stillbirth	No	4	28.57%
	Unsure/Blank	4	28.57%
		14	100%

Question			Responses	%
Do you commission any other specialist psychological therapy service,	Both parents		4	28.57%
	Mother/Birthing person only		2	14.29%
	Father or partner only		0	0%
Neonatal Death	No		4	28.57%
	Unsure/Blank		4	28.57%
			14	100%
	Both parents		2	14.29%
Do you commission any other specialist	Mother/Birthing person only		1	7.14%
psychological therapy service,	Father or partner only		0	0%
SUDI	No		6	42.86%
	Unsure/Blank		5	35.71%
			14	100%
Additional Questions	If yes, what service do you commission	8 x health boards completed this box. One told us they utilise networks, existing services and the third sector. 2 x third sector (1 x held in our hearts). 1 x bereavement midwife. 1 x Child Bereavement UK. 1 x CMPHT and CMH 1 x Maternity and Neonatal Loss Team carry out four telephone calls to monitor wellbeing and referral to MNI if needed. 1 x bereavement counsellors.		d sector. 2 avement T and CMHT. out four
	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?	13/14 health boards responded NHS [redacted] does not have psychological support for being psychological services are awareferral via a GP or health to working in the community mean half days a week who offer expertise. NHS [Redacted] significantly Hearts, Nurture the Borders of We hope to develop this but Referral to GP, referral to thir bereavement nurse specialists.	e any specific so reaved parents, vailable in the [ro team. There is a ental health tear is a specialist pe gnpost to SIMBA is well as Nation link closely with d sector organis	ervices for however, edacted] with psychologist n one and erinatal . Held in our al Networks.

Third party sector colleagues SANDS also provide monthly baby loss groups in [Redacted] Hospital and peer support/ befriending services.

The Miscarriage Association provides online support for early loss.

MNPI bereavement pathway encourages a stepped care approach with the recognition that parents can receive support from the bereavement midwives, specialist bereavement support services and obstetric debrief before accessing specialist psychological therapy from MNPI. A clinical psychologist meets with the bereavement midwives on a regular basis and any parents who are identified as having additional or on-going need for specialist psychological therapy can be considered and referred to MNPI.

[Redacted] has bereavement care pathways for different experiences of pregnancy and baby loss. CB-UK service available to all bereaved parents and can also offer service to the extended family. CB-UK is offered to all families (an opt-out service) whose baby or child has breathed and then died. Families who have experienced pregnancy loss, including miscarriage, ectopic and molar pregnancy, ToPFA, and stillbirth can be referred-in to the service. Close links now also exist between the [Redacted] neonatal service and CHAS (Children's Hospices Across Scotland) with parents able to access support from CHAS bereavement counsellors if CHAS is involved with the family.

We signpost to a range of third party psychological support for parents who have experienced pregnancy or baby loss and have listed those organisations below:

SANDS who offer online services and information. SANDS Support chat, access to trained bereavement counsellors, Local befriending sessions.

ARC - on diagnosis support, Decision making support, Bereavement support, Parent forums, support for friends/ family, Parent meetings.

Miscarriage Association - online support and information, Helpline, Live chat, Support groups and,

Child Bereavement UK - Help line, Online support and information, bereavement support, Child/Sibling support. We work closely alongside third sector colleagues, in particular Held in our Hearts, and the NHS have recently invested support in their extended Hospital to Home

service to provide input to families who have experienced loss. This service allows both parents to access emotional and practical support in the weeks following their loss as well as linking them in with peer support and/or counselling following that initial period.

NHS [Redacted] are currently embedding the National Bereavement Care Pathway (NBCP) within our Board. This pathway ensures women are well supported throughout the whole process of bereavement, antenatally, intrapartum and postnatally. We also have a local SANDs group which provides on-going support for families.

People have access to Sands and are provided with this information on discharge. We also liaise closely with colleagues in primary care including GPs and Community Mental Health Services.

NHS [Redacted] has close links with third sector services and families are signposted to these routinely.

We provide a psychological support service provided by our bereavement support midwife. Parents can access her for 1:1 sessions at place of their choice, group discussions and very much led by the parents. Attendance at the groups sessions 1:1 in anyway and accessible almost immediately. This is psychological support more than therapies. In regards to SUDI we do not currently have pathways for psychological and specialised support. However, there is a newly appointed SUDI lead and this will be looked at as part of their role.



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