

OUT OF SIGHT, OUT OF MIND

Bereaved parents falling through
the gaps in mental health care

Baby Loss awareness week

2019 Campaign report



#BLAWOutOfSight

“

After my baby died, I felt I needed psychological support. I was referred and the support took place in the neonatal ward of the hospital where I gave birth to my dead baby. I had to sit in a waiting room each week while other people's babies were wheeled past me. The psychiatrist who saw me informed me that my thoughts/grief were unhelpful and wrong and if I just “thought differently I'd feel better.”¹

”

We are calling on Governments across the UK to take action

1. Summary

We are calling on Governments across the UK to take action to ensure that all parentsⁱ who experience pregnancy and baby loss and need specialist psychological support can access it, at a time and place that is right for them, free of charge, wherever they live.

Grief is a natural response to this particularly isolating bereavement. Some people carry this with them for the rest of their lives but do not develop a mental health problem. However, many bereaved parents will go on to experience psychiatric illnesses that require specialist support, triggered by intense grief and the trauma of their experience.

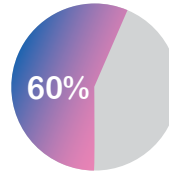
Information gathered by the Baby Loss Awareness Alliance shows that there is a clear need for specialist psychological support for this group. However, across the UK provision is too often unavailable, inaccessible or inappropriate. Too many people who experience a psychiatric illness after their loss do not receive the support they need.

Simply put, parents who have lost a baby are currently falling through the gaps between policy and funding, and are often overlooked altogether.

ⁱ We use 'parents' to refer to expectant and bereaved mothers, fathers and partners. This is used when referring to individuals who experience the loss of a pregnancy or baby at any stage. Many people will consider themselves parents from the time they discover they are, or were, pregnant, while others may not. By using this term, we attempt to cover those most closely affected by pregnancy and baby loss.

The Baby Loss Awareness Alliance

The Baby Loss Awareness Alliance is a group of charities committed to raising awareness of pregnancy and baby loss, providing support to anyone affected by pregnancy loss and the death of a baby, and working with health professionals, services and decision-makers to improve bereavement care and reduce preventable deaths. The organisations involved are listed at babyloss-awareness.org/organisations



A survey carried out in 2019 found that 60% of bereaved parents felt they needed specialist psychological support for their mental health, but were not able to access it on the NHS.²

With the current focus on improving mental health, and in particular perinatal mental healthⁱⁱ, it is imperative that Governments across the UK take the opportunity to come together and act now to solve this problem.

The negative impact individuals experience if they do not get the right support is vast. It affects all aspects of people's lives including future pregnancies, personal relationships, physical health and employment. The repercussions are felt across wider society, costing the NHS more in the long run.

There are pockets of good practice emerging across the UK, showing that bereaved parents can receive excellent specialist psychological support if the need is recognised and steps are taken to meet it. We must act to learn from this good practice and develop a shared understanding of what needs to be done, so that all bereaved parents requiring specialist psychological support get the help they need.

ⁱⁱ 'Perinatal' means the period of time covering pregnancy and up to around a year after giving birth.

“

I self-referred after our first loss and was diagnosed with PTSD. The counsellor told me that group bereavement counselling was not suitable as I'd not lost a loved one. After our second loss I chose not to look for help.³

”

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2. Introduction

Thousands of parents experience pregnancy or baby loss every year.

It is estimated that:

1 IN 4

1 in 4 pregnancies end in miscarriage ⁴

1 IN 80

1 in 80 are ectopic ⁵

**15 BABIES
A DAY**

15 babies are stillborn or die shortly after birth every day in the UK. ⁶

A loss during pregnancy or around the time of birth is complex and unique. ⁷

“ For parents, a **childbearing loss** may be the **loss of hopes, dreams and expectations for the future**, including the **loss of a person who would have been**.⁸ ”

Good care from professionals and support from family, friends and voluntary organisations are vital in helping bereaved parents to cope with their grief. But those who develop a psychiatric illness need more than this.

While there have been welcome improvements in the care directly provided to parents by the NHS following the death of their baby,ⁱⁱⁱ this now needs to extend to better support for parents' mental health in the weeks, months and years following this most tragic and traumatic of experiences.

The need for psychological support following pregnancy loss and stillbirth is recognised in NICE guidance⁹ and there is currently a political focus on improving mental health care, with large amounts of new funding going into perinatal and community mental health

ⁱⁱⁱ Bereavement care is provided by health and social care professionals from the time a parent experiences a loss, or when it is expected the baby will die. It includes all communications with the parent, the care environment, resources and facilities.

services. But the evidence we have gathered shows that there are significant gaps in the availability and quality of support for this group of people.

The majority of bereaved parents who need help cannot access it in an appropriate place and at an appropriate time.



Perinatal mental health services are focused on women who are pregnant or have a living baby, resulting in mothers whose baby has died often not meeting the inclusion criteria to access support. On the rare occasions that they are able

to access perinatal mental health services, they do not find them appropriate. For example, being invited to attend clinics surrounded by families with living babies.

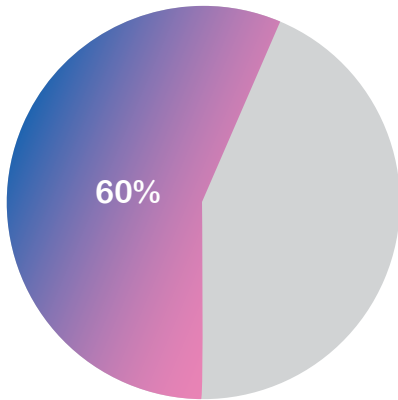


While commissioners have informed us that community mental health services should be available to parents who have experienced pregnancy or baby loss, this has not been reflected in parents' experiences. They tell us that waiting lists are too long and that these services lack the specialist skills and knowledge to support them.

Partners' needs are also often overlooked.

“ Expressing your emotions as a father who has lost a child is difficult - the emphasis at all stages is on the mum which I fully understand is important, however I feel further support could be provided.¹⁰ ”

This is clearly unfair and inequitable - an unintentional oversight in the reorganisation of maternity and perinatal mental health care. More consideration is needed to stop bereaved parents falling through the gap between policy and funding, to ensure high quality specialist psychological support services are adequately funded and delivered.



3. Why do bereaved parents need additional psychological support?

Pregnancy and baby loss have a significant impact on the emotional and mental wellbeing of parents and families. Grief is a natural response to this most devastating and isolating bereavement. Parents may seek emotional support, but not develop a mental health problem.

However, many bereaved parents do go on to experience psychiatric illnesses, which can include post-traumatic stress or PTSD, prolonged and complicated grief, clinical depression and anxiety disorders. These people need to be identified as early as possible and provided with high quality, easily accessible psychological support services when they need them.

60% of parents who experienced pregnancy or baby loss told us they would have liked specialist psychological support for their mental health, but were not able to access it on the NHS.¹¹

What the research tells us

PTSD



Women who have experienced stillbirth¹², miscarriage or ectopic pregnancy¹³ are at higher risk of post-traumatic stress disorder (PTSD), anxiety and depression than those who haven't.

A significant proportion of women suffer from symptoms of PTSD after losing a pregnancy.¹⁴

60-70% of grieving mothers in high income counties reported grief-related depressive symptoms that they regarded as clinically significant.¹⁵

One in three women showed a clinically significant level of post-traumatic stress symptoms 5–18 years after stillbirth.¹⁶



Sudden or unexpected deaths are more likely to result in prolonged grief reactions.¹⁷



39% of women, 3 months after suffering an early pregnancy loss meet the criteria for probable moderate-to-severe PTSD. No people in the control group did.¹⁸

There may be an association between surgically-treated ectopic pregnancies and suicide.¹⁹



68% of mothers and 44% of partners reported four or more negative psychological symptoms^{iv} at 10 days. 9 months later the figures were still significant with 35% of mothers and 13% of partners experiencing problems.²⁰



Much of the available research and current political focus is on mothers and women, but we know that fathers and partners also experience mental health problems following pregnancy or baby loss. In one study, fathers report feeling unacknowledged as a legitimately grieving parent. The burden of keeping these feelings to themselves increased the risk of chronic grief.²¹ In June 2019, 62% of men reported feeling suicidal following their experience of pregnancy or baby loss.²²

^{iv} including depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic and phobias

4. What needs to change?

4.1 Awareness, assessment and referral pathways

LACK OF AWARENESS

“ I suffered from PTSD as a result of my daughter’s birth. It took me 4 years to get a diagnosis as everyone kept saying I was grieving and needed counselling. No one fully addressed or listened to how severe my symptoms were.”²³ ”



If healthcare professionals, such as GPs, do not have a proper understanding of the range and severity of psychiatric illness that bereaved parents are at risk of experiencing, they are less likely to identify those needing help and refer them on for the necessary care.

The Miscarriage Association found that the majority of people who sought mental health support following a pregnancy loss went to their GP. Many reported that attitudes of health professionals and a focus on their physical health contributed to a feeling that they ‘should be able to manage’ and prevented people from seeking help before things reached a crisis point.²⁴

“ Mental health was never discussed either by the GP or by the EPU [Early Pregnancy Unit] team. Everything was dealing with the physical. Consequently, I felt weak and even more of a failure for the impact my ongoing experiences have on my mental health.”²⁵ ”

LACK OF NEEDS ASSESSMENT AND REFERRAL PATHWAYS

The lack of a standard needs assessment for parents following pregnancy or baby loss means that those requiring specialist psychological support are not identified.

Having to self-refer is also very difficult. Feelings of depression, anxiety, isolation, low self-esteem as well as stigma around both mental health and pregnancy loss make it even harder to seek help.

“ Having to contact them yourself...I couldn't even get myself dressed let alone phone anyone.”²⁶ “

Over 60% of parents who responded to the 2019 Finding Your Way survey reported keeping their feelings of isolation, depression and suicidal thoughts to themselves.²⁷



**support professionals
with resources**



**high quality risk
assessment**



**national guidance
on specialist
psychological services**

AWARENESS, ASSESSMENT AND REFERRAL PATHWAYS – WHAT NEEDS TO CHANGE?

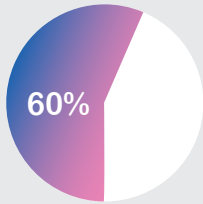
Healthcare professionals need to understand the risk that bereaved parents have of developing a psychiatric illness and be supported with resources to help them undertake a high-quality needs assessment.

National guidance should exist to help those planning, funding and delivering services to set up appropriate referral pathways so bereaved parents can access specialist psychological services.

4.2 Availability of services

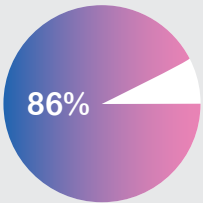
LACK OF ENTITLEMENT AND ACCESS

“ I walked out of hospital and no one ever contacted me! Only a letter from the GP with congratulations and dates to bring my deceased baby for jabs and check-ups. I called for some counselling but was told I’d have to wait 6 months. I got no support.”²⁸



60% of bereaved parents told us they could not access the specialist psychological support they needed through the NHS.²⁹ Which is unsurprising, given that those needing support are not being identified. If they aren’t identified, how will commissioners know that this is a gap that needs to be addressed?

In July 2019, we sent Freedom of Information Act requests to health commissioners across the UK to help us understand whether psychological support is provided to parents whose baby has died or who have lost a pregnancy.



The responses we received paint a patchy picture of support, with commissioners in over 86% of areas across the UK telling us they do not commission specialist therapies to support this group (see Appendix 1). In areas where a more general service was available for parents post-birth, less than 40% said this was accessible for both parents when they had experienced pregnancy or baby loss.

Many commissioners in England told us that this group can access IAPTs (Improving Access to Psychological Therapies). However, this service is often limited to generic support for anxiety

and depression and does not cover the range of psychiatric illness experienced by bereaved parents. Lack of NHS services leads some parents to seek private care, which not everyone can afford.

“ I have got to the point where I need proper psychological support and I am about to access it privately; it’s making me anxious as I can’t really afford it, especially as I’m currently on maternity pay.³⁰ ”

Only 16% of respondents to the Sands Survey of Maternity and Neonatal Care reported being able to access the psychological support they needed on the NHS.³¹

LACK OF TIMELY ACCESS (TOO SOON OR TOO LATE)



It is important that people who need it are able to access appropriate support at the right time, but our research shows that is not happening for many people. Many parents reported that they felt they had to wait too long for support, particularly when referred by their GP.

In some cases parents do receive a very short, time-limited offer of support, of a certain number of sessions, available for a number of weeks, but this is also inadequate as many people are not ready to seek help immediately.

“ I didn't want counselling whilst in hospital as it was too soon and I was struggling to process what had happened, I was only in 4 days after the twins had passed away. I asked for it a few weeks after I was discharged to be told it was too late?! I find that shocking.³² ”

AVAILABILITY – WHAT NEEDS TO CHANGE?

Every parent who has experienced pregnancy or baby loss who needs psychological support must be entitled to receive it free of charge on the NHS, at the right time for them.



**timely access
on the nhs**

4.3 Quality

LACK OF SPECIALIST HIGH QUALITY SERVICES IN AN APPROPRIATE LOCATION

“ I self-referred after our first loss and was diagnosed with PTSD, the counsellor told me that group bereavement counselling was not suitable as I'd not lost a loved one. After our second loss I chose not to look for help ³³ ”

All too often parents who are able to access services have a bad experience, with care provided by people who lack specialist knowledge of pregnancy and baby loss, or offered in unsuitable surroundings. This can put people off seeking support in the future and delay their recovery from psychiatric illness.

A good quality service for bereaved parents experiencing psychiatric illness needs to be delivered at the right time by professionals with specialist knowledge about pregnancy and baby loss, in a suitable location.

“ I had the mental health team come round daily. Basically telling me to get over it. They had no clue about child loss. Called me selfish. ³⁴ ”

“ Was offered counselling by the hospital but didn’t find it useful. The counsellor was very one dimensional and unable to adapt to the unique circumstances. The session didn’t help at all and I found her patronising and unhelpful.”³⁵ ”

The Miscarriage Association found that counselling was too general. Respondents to their survey wanted to speak to a counsellor who understood the relationship between mental health problems and pregnancy loss.

“ I found the counsellor didn’t really seem to have much understanding of pregnancy loss. I couldn’t really talk to him. I only went to 4 sessions.”³⁶ ”

Some parents also found the location of the support they were offered unsuitable, because it was difficult to get to, or situated in a maternity setting alongside families with living babies, in an early pregnancy unit near waiting rooms filled with pregnant women, by a labour ward, or even in the same unit where their loss had occurred.

QUALITY – WHAT NEEDS TO CHANGE?

Those providing specialist support must have the skills and knowledge to understand pregnancy and baby loss.

Bereaved parents who are experiencing mental health problems should not be expected to attend clinics for care in the same ward where their baby was born or where they lost their pregnancy, where other families are with their living babies or waiting to be seen in an early pregnancy unit, or by the labour ward.



skills
and
knowledge

5. Examples of good practice

“

I received EXCELLENT care from free counselling attached to the neonatal ward. Exceptional, and carried on for as long as we wanted (several months)³⁷

”

Our Freedom of Information request responses identified some examples of good practice. For example, some practitioners delivering Improving Access to Psychological Therapy services receive specialist training from perinatal mental health services in parental bereavement and how to provide support to both parents. A small number of areas had specific pathways within perinatal mental health services for mothers whose baby had died.

Included below are some case studies highlighting areas of good practice that we are aware of. This is not an exhaustive list and much more needs to be done to understand what is working well across the UK.

Case study

PETALS

Petals is a specialist trauma-based counselling service which currently runs out of 7 hospitals across London and the South East of England.

The charity offers 6 free-of-charge sessions to women and couples who experience baby loss, and a further 6 sessions for bereaved parents who have a subsequent pregnancy. Working in close partnership with each hospital, a fast-track referral is possible immediately after the death of a baby meaning counsellors are able to see parents for the first time within 15 days of their loss.

Referrals are passed to Petals via the local bereavement midwife. Petals staff assess initial eligibility for the service prior to a psychological assessment by a Petals counsellor. Patient self-referral is also possible by directly contacting the charity. In 6 years, Petals has supported over 2000 women or couples.

Counsellors are all Petals-approved, which means that they are specialists in the types of grief and trauma that are unique to baby loss, as well as being professionally registered. 95% of patients who access support from Petals report an improvement in their health and wellbeing.

Funding sources from each hospital vary, but in some areas there is formal NHS CCG commissioning of the service to ensure a sustainable funding stream, combined with a variety of charitable funding sources.

www.petalscharity.org

Case study

MAKING MIRACLES

Making Miracles is a trauma and bereavement care charity set up in 2014 after its founder struggled to access appropriate psychological support following a traumatic high-risk pregnancy and the near loss of life of her daughter. It is entirely funded through charitable grants and donations.

The service is open to all family members who may be affected by the death of a baby, including parents, grandparents and siblings in the Kent and Medway area. The organisation delivers a specialised counselling service for baby trauma and loss in order to improve emotional wellbeing and reduce mental illness. This service is free and usually lasts for 6 weeks. Referrals are made by medical staff, other charities and by individuals. The average waiting time for support is around 1 week.

All clients are asked to score their wellbeing before starting counselling and at the end. The initial average wellbeing score is 3.6 out of 10 at the beginning, rising to 8.6 out of 10 at the end.

“ We refer our patients to Making Miracles and have had nothing but amazing feedback. The families using the counselling service are in great need and the fact we can help refer them following their baby loss journey after leaving the hospital is fantastic.
Professor Ranjit Akolekar-
Medway Maritime Hospital

www.makingmiracles.org.uk

It is worth noting that while good practice does exist, it is only in a few areas and is often entirely or partly dependent on charitable grants and donations. Without stable funding and commissioning, access to provision remains patchy, and services fragile.

6. National developments

Across the UK, Governments and the NHS are working hard to reduce the rate of perinatal deaths and to improve mental health services.



In **England** the 'Better Births' report, Maternity Transformation Programme, and NHS Long Term Plan all highlight plans to improve perinatal mental health care, with funding attached. The NHS Long Term Plan also commits to increasing access to evidence-based care for women experiencing moderate/complex–severe mental health problems. New Maternity Outreach Clinics including access to psychological therapy will be introduced, which we believe should,

include provision of specialist services for bereaved parents affected by pregnancy and baby loss. NHS England has also commissioned best practice guidance on supporting mental health care in maternity and neonatal settings. This project, led by the University of Liverpool³⁸, will consider care for those who have suffered a loss within these settings and therefore could help to set out clear referral processes.



Work has begun in **Wales** to map bereavement support for parents who have experienced pregnancy and baby loss across the country, with

a review identifying areas needing extra resourcing expected late in 2019.



In **Scotland**, new investment in perinatal mental health has been announced following the ‘Delivering Effective Services: Needs Assessment and Service Recommendations for Specialist and Universal Perinatal Mental Health Services’ report published in March 2019. This endorses recommendations in The Best Start (Scottish

Government, 2017) on ensuring support for bereaved parents prior to discharge and appropriate signposting to third sector services which provide bereavement and other mental health support.



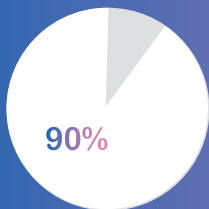
In **Northern Ireland**, in 2018 an NSPCC report highlighted challenges for health professionals in responding to perinatal mental illness. Since then support for new mothers at risk of mental illness has been announced, including funding to train healthcare professionals.

Action now needs to be taken to ensure that improvements to maternity, perinatal and mental health services do not exclude those parents who have experienced pregnancy and baby loss and need access to good quality psychological support on the NHS. This vulnerable group must be given specific consideration so that the services they needed can be funded and delivered.

7. Conclusion and recommendations



This report shows a long-standing and demonstrable need for **better psychological support for parents** who have experienced pregnancy or baby loss. These individuals are falling through the gaps between policy and funding, and are often overlooked altogether. This is not acceptable, and the public agree.



When asked, nearly **90% support NHS funding** for free psychological support for those affected by the death of a baby, if they need it.³⁹

Although these parents form a small group, it is critical that their needs are addressed. We believe Governments and the NHS can achieve this, if they give specific attention to those who have experienced pregnancy or baby loss when planning, funding and delivering psychological support services.

There are pockets of good practice across the country that show what is achievable, but further work is needed to develop and evidence the solutions. The Baby Loss Awareness Alliance are committed to working alongside decision makers to tackle this issue. We now need to bring people together to embed new initiatives and share promising practice.



RECOMMENDATIONS

- 1. **Governments and the NHS must ensure that any parent who has suffered pregnancy or baby loss and needs high-quality specialist psychological support can access it free of charge, at a time and place that is right for them, wherever they live in the UK.**

In order to achieve this Governments must:

- 2. undertake a review of current provision including an evaluation of models of best practice, involving parents and professionals
- 3. develop quality standards and national guidance to support those planning, funding and delivering specialist psychological support services for bereaved parents
- 4. ensure that relevant professionals across health services receive mandatory training in the identification of psychiatric illness in parents who have experienced pregnancy and baby loss
- 5. provide guidance to support local services to effectively assess the psychological support needs of bereaved parents, and develop referral pathways to meet those needs.



Commissioners must:

- 6. allocate sufficient resources for the provision of specialist psychological support for bereaved families based on an assessment of their needs
- 7. ensure that high-quality, specialist services are in place for bereaved parents when they need them
- 8. incentivise local services to show how they are meeting the specific needs of this small, but vulnerable group through their inclusion in local data sets and performance measures
- 9. provide clear referral pathways to high-quality, effective and evidence-based specialist psychological support.

8. Appendix 1

In July 2019, the Baby Loss Awareness Alliance sent out Freedom of Information Act requests on psychological support available for parents who have experienced pregnancy or baby loss to all Clinical Commissioning Groups in England, Health Boards in Scotland and Wales, and Health and Social Care Trusts in Northern Ireland.

By 2 September 2019 we had received 191 responses from 217 organisations - an 88% response rate.

Information was requested on talking therapies for all people following pregnancy/birth and also specialist services for parents who had experienced any of the following: miscarriage, ectopic pregnancy and molar pregnancy, termination of pregnancy for foetal anomaly, stillbirth, neonatal death and sudden and unexpected death in infancy.

SUMMARY OF RESPONSES

Question	Options	Response Yes	Percentage
Do you specifically commission talking therapies for people following pregnancy/birth?	Both	74	34.1
	Mother	50	23.0
	Father	30	13.8
	Did not answer question	16	7.4
Are people who have had miscarriage, ectopic pregnancy and molar pregnancy able to access these services?	Both	84	38.7
	Mother	49	22.6
	Father	41	18.9
	Did not answer question	23	10.6

Question

Are people who have experienced termination of pregnancy for foetal anomaly able to access these services?

Are people who have experienced stillbirth able to access these services?

Are people who have experienced neonatal death able to access these services?

Are people who have experienced sudden and unexpected death in infancy able to access these services?

Do you commission a specialist therapy service for people who have experienced miscarriage, ectopic pregnancy and molar pregnancy?

Do you commission a specialist therapy service for people who have experienced termination of pregnancy for foetal anomaly?

Options	Response Yes	Percentage
Both	82	37.8
Mother	47	21.7
Father	37	17.1
Did not answer question	24	11.1

Both	85	39.2
Mother	49	22.6
Father	41	18.9
Did not answer question	25	11.5

Both	86	39.6
Mother	50	23.0
Father	43	19.8
Did not answer question	25	11.5

Both	81	37.3
Mother	45	20.7
Father	38	17.5
Did not answer question	25	11.5

Both	27	12.4
Mother	27	12.4
Father	13	6.0
Did not answer question	26	12.0

Both	26	12.0
Mother	25	11.5
Father	11	5.1
Did not answer question	25	11.5

Question

Do you commission a specialist therapy service for people who have experienced stillbirth?

Do you commission a specialist therapy service for people who have experienced neonatal death?

Do you commission a specialist therapy service for people who have experienced sudden and unexpected death in infancy able to access these services?

Options	Response Yes	Percentage
Both	30	13.8
Mother	29	13.4
Father	15	6.9
Did not answer question	24	11.1
Both	31	14.3
Mother	29	13.4
Father	15	6.9
Did not answer question	24	11.1
Both	29	13.4
Mother	29	13.4
Father	15	6.9
Did not answer question	22	10.1

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34. Sands, Survey of Maternity and Neonatal care, May 2019
35. Sands, Survey of Maternity and Neonatal care, May 2019
36. Sands, Survey of Maternity and Neonatal care, May 2019
37. Miscarriage Association, 2019
38. Sands, Survey of Maternity and Neonatal care, May 2019
39. Research led by Pauline Slade at the Institute of Human and Life Sciences, University of Liverpool
40. Survey Conducted by YouGov On behalf of Sands, 23-24 August 2019, population representative sample size of 2,012

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Email: babyloss@sands.org.uk
www.babyloss-awareness.org



**Baby Loss
Awareness Week**
9-15 October
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