

Sands' response to the Pregnancy Loss Review

Currently if a baby is born dead before 24 completed weeks of pregnancy, the birth cannot be formally registered, while a baby born dead after 24 completed weeks of pregnancy is registered as a stillbirth. Sands welcomes the Pregnancy Loss Review looking into whether the loss of a baby born dead before 24 weeks could be recognised differently – either by allowing registration (so it's the parents' choice) or mandating it (so it's legally required).



Sands believes all bereaved parents must be offered equal, high quality, individualised, safe and sensitive care. Parents who have experienced the death of a baby are at the heart of everything we do and it is vital that we reflect their needs and views in our work. In March 2018 we ran a survey seeking parents' views and received an overwhelming response. We shared the link with other leading baby loss charities who also promoted it.

Headline Findings

- 4,106 people responded
- 48% experienced having a baby born dead before 24 weeks, 10% experienced having a baby born dead after 24 weeks, 7% experienced a baby dying after birth, 35% were not a bereaved parent
- 63% of respondents are from England, 23% from Scotland, 6% from Wales and 5% from Northern Ireland

The majority (93%) of people support a change to the current system to enable registration of a loss before 24 completed weeks of gestation, with 87% of those saying this should be optional. Only 13% believe registration should be mandatory. This finding reflects a recognition that while many parents desperately wish to have this option, others would find the registration process very distressing. There is no consensus as to when optional registration should be offered, but responses clearly indicate that grief and the desire for formal recognition is not dependant on gestational age.

Respondents also told us that ensuring charities and other agencies are able to properly and fully support parents through a loss is equally important to changes in registration. Access to information, counselling and other support would be welcomed yet is often not available for miscarriages. Other areas touched upon include the unpleasant nature of the current registration process, the often upsetting language used by healthcare professionals, and the potential knock on effects of any changes on other areas of legislation – for example those relating to maternity leave, resuscitation and abortion laws. Many respondents also asked for any changes to be backdated, so it's important that the review considers if this is within its scope.

Better Bereavement Care

Parents' experiences are aligned with a recent survey of healthcare professionals also carried out by Sands. The research found that more than a third of health professionals agreed that their NHS Trust needs to do far more to improve bereavement care for parents. Care for parents experiencing early miscarriage and those in gynaecology wards was particularly highlighted as in need of improvement. Sands is working with a healthcare professionals, baby loss charities and Royal Colleges to deliver a National Bereavement Care Pathway for pregnancy and baby loss that seeks to address this variation in care.

Our Position

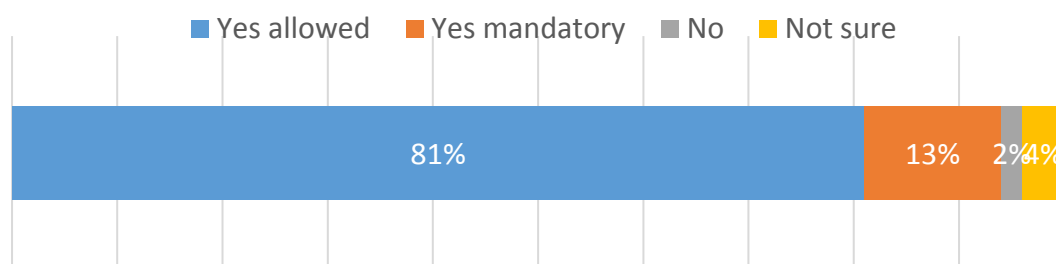
This issue is clearly important to bereaved parents, and Sands welcomes the formation of the review and the opportunity to take part. It is clear from our research that parents who have experienced a loss before 24 weeks completed gestation must receive better bereavement care. Parents need improved support, choice and the option of official recognition of their loss. Any changes must increase choice for all parents, and must prevent unintended consequences or undue distress such as for those parents who may find mandatory registration very upsetting.

While the review is ongoing, Sands will continue to support the provision of a Certificate of Birth to parents of all babies who are born dead before 24 weeks as an important keepsake of their baby. These certificates are a way for hospitals to provide recognition of the death for bereaved parents.

What parents told us

1. Parents want to have a choice

Do you support a change to registration practice?



"I had my baby's birth date tattooed on my hand so she had a mark, I need her to exist permanently in the world. A certified birth would have given me that."

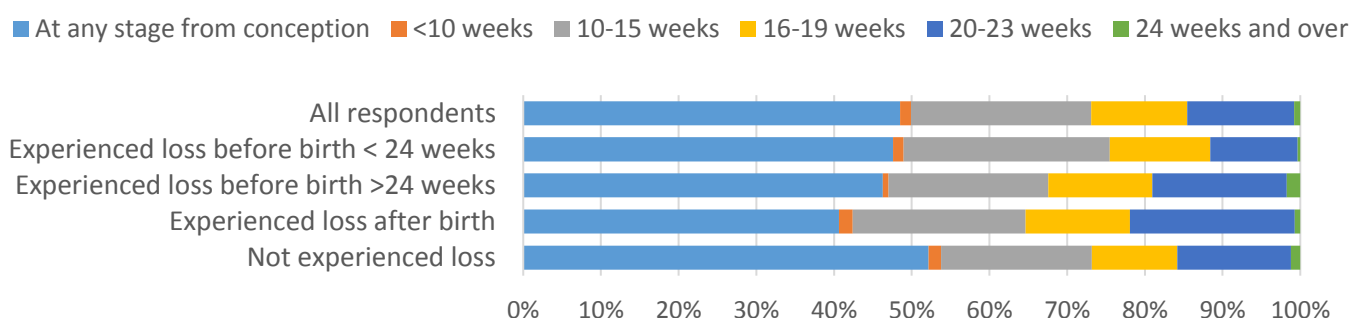
"Not every parent wants to go through this process and I think they should have the right to deal with a personal loss as they see fit - mandatory registration seems cruel even at 24 week, and perhaps an optional registration/certification could be offered until a later gestation."

"The idea of having to go and register my baby as being born and then dead, filled me with dread. It should not be mandatory but a parent's choice to be able to do it if they wish."

2. There are a range of views on when registration should become an option

At what stage should registration be provided from?

By respondent's experience of loss



"All babies matter from the moment that positive pregnancy test is in your hands you become a mother."

"I still gave birth to a baby with 10 fingers and 10 toes, yet I have no official proof of his existence except for medical records which will not state his name. I really hope this changes, for my baby and for all the other babies lost too soon."

"I personally feel if you physically have to go through the birth i.e. labour of your child you should get a birth certificate for your child. We have a cremation form and his ashes but nothing to say he was born. I really hope this changes for people in the future."

3. Better bereavement care is key

If you experienced pregnancy loss before 24 weeks, were you offered a Certificate of Birth?



"It would be better to have your lost baby described as a baby and NOT "Products of Conception". To me having a miscarriage was devastating, but having it in my notes as a "Spontaneous Abortion" was horrific, my baby WASN'T aborted, he died!!!!!!!!!!!!!!"

“Counselling should be offered for all forms of pregnancy loss, at any gestation, rather than individuals having to seek out charities or private counselling.”

“You should have a safe way to exit the scan room if you have been given bad news not just made to sit with other pregnant woman who are waiting on scans. Staff also need to be more consoling and not just shrug it off and push us out the room as there's others waiting.”

"My babies were both cremated without me knowing, this just added to the deep grief I was suffering!!!"

"I believe that maternity rights should also be considered as a birth is not registered my friend had to have sick pay which could be seen negatively when seeking new employment or promotion and may also be financially inferior to maternity pay causing women to make a decision to either leave work or return before they are ready."

4. Some parents want the review to go further

“Any parent whose baby was stillborn after 24 weeks should be allowed to register the birth - for me registering as stillborn not as birth was extremely painful.”

"My twin girls were born at 20+6 weeks in 2012. It would be amazing if these certificates can be back dated. It breaks my heart there will be no knowledge of my little girls even though I gave birth to them."

"I believe that it would be beneficial to allow backdated registration, for parents who have already gone through this awful tragedy to have their children registered and recognised."

Sands would like to thank all those who took part in our survey and shared their thoughts.

