Charity position on the introduction of birth certification pre-24-weeks gestation & changes to gestation terminology due to viability.

Over recent weeks there have been many articles, discussions and petitions circulating social media and in the press about changing birth certification and terminology for babies lost before 24-weeks gestation. This statement sets out the position of the Mariposa Trust (incorporating Saying Goodbye and its other divisions) on this important issue.

Do we think babies lost before 24-weeks should be given birth/death certificates?
The idea of the legal recognition of baby loss (i.e. the issuing of a birth certificate) naturally represents an important and meaningful step for all parents who have lost a child before 24-weeks. However, due to the current legislation and how it relates to abortion law (which is NOT a topic being discussed or raised here) this is unlikely to happen in the near future. In light of this the Mariposa Trust think a positive move forward is for pregnancy loss (at any stage) to be better understood and accepted as a significant bereavement.

1. We would like greater acknowledgement of the emotional and physical implications of pregnancy loss in health policy (the UK has some of the highest rates of still birth in the developed world)\(^1\) and employment policy (parents who have suffered an early or ‘late’ miscarriage must negotiate for compassionate leave which they may or may not be granted)\(^2\)\(^3\).
2. We would like to see a wider cultural understanding of pregnancy loss - the reality of miscarriage, stillbirth, molar pregnancies and ectopic pregnancies is still very much misunderstood, to the detriment of families who experience this significant bereavement.
3. We would like to see the introduction across the NHS and Private Practice of a new national certificate, available to all parents of babies lost before 24-weeks gestation, who are ineligible for a formal birth certificate or death certificate. This new certificate would be nationally recognised, nationally registered and would help the hundreds of thousands of individuals, couples and families who suffer early or late miscarriage each year in the UK, to receive the recognition of their child’s life that so many are desperately wanting.

Should there be a change to gestation terminology?
Currently baby loss is segmented into stages of loss as follows:

- Loss from conception to pre-24-weeks gestation is termed ‘miscarriage’, with a loss in the first 12-weeks (1\(^{st}\) trimester of pregnancy) being termed ‘early miscarriage’ and from 12-24-weeks (2\(^{nd}\) trimester of pregnancy) being termed ‘late miscarriage’
- Loss from 24-weeks up until birth is termed ‘stillbirth’ and within the first 28-days of life is termed ‘neonatal’.

The 24-week mark between miscarriage and stillbirth originates from medical evidence relating to the viability of a baby and is protected in UK legislation\(^4\). Until recently it was rare for a baby born prior to 24-weeks to survive, but technological and medical advancements have led to an increasing number of babies born before 24 weeks to survive, throwing into question this distinction.

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\(^1\) [https://www.theguardian.com/lifeandstyle/2016/feb/07/rate-of-stillbirths-in-uk-higher-than-poland-croatia-and-estonia](https://www.theguardian.com/lifeandstyle/2016/feb/07/rate-of-stillbirths-in-uk-higher-than-poland-croatia-and-estonia)
\(^2\) [https://www.moneyadvice.service.org.uk/en/articles/if-you-have-had-a-late-miscarriage](https://www.moneyadvice.service.org.uk/en/articles/if-you-have-had-a-late-miscarriage)
\(^4\) See (Section 41 of the Births and Deaths Registration Act 1953, as amended by the Stillbirth Definition Act 1992), Scotland (Section 56(1) of the Registration of Births, Deaths and Marriages (Scotland) Act 1965, as amended by the Stillbirth Definition Act 1992) and Northern Ireland (Births and Deaths Registration (Northern Ireland) Order 1976, as amended by the Stillbirth Definition Northern Ireland Order 1992) Act.
As such, there have been a number of calls on the Department of Health to amend this terminology. Some have suggested that babies born at 20-weeks should be classified as ‘stillbirth’ instead.

To all who have spoken up on this subject over the past couple of weeks we applaud you. It takes courage to share ones story, and as soon as you do share it, you open yourself up to public comment, which can be a difficult experience. Our hope as an organisation is that by us all respecting one another’s stories and responding from a place of compassion we can heal pain, rather than causing further distress. It has always been and will always be the unequivocal position of the charity that every single baby lost deserves to be honoured and recognised, and we stand with all parents to make this a reality.

As a charity we ask those calling for change and writing posts and articles to be careful around the language they use. The Mariposa Trust (Saying Goodbye), has ardently sought for all babies lost to be equally recognised, but implicit and explicit in some of the commentary we have seen is the idea that the term ‘miscarriage’ is demeaning to families who have experienced a late miscarriage; early miscarriage has been relegated as something of less consequence and effect. We challenge this opinion: miscarriage is not an easy or unremarkable process physically or emotionally at any stage.

A common misunderstanding is that early miscarriage is akin to a ‘heavy period’; this is not accurate for the majority of people. Miscarriage can be frightening, it might include painful contractions, be prolonged, highly complex and in the case of ectopic, molar pregnancies and some miscarriage it might put the mother’s health and fertility at risk. Moreover, these physical aspects of miscarriage do not take into account the substantial trauma of losing a child. Tens of thousands of parents have spoken to us about long-term emotional distress and damaged mental health. Unfortunately, due to the lack of understanding about miscarriage, the reality and mechanics of it are not widely appreciated.

As a charity, our hope is that there will be universal agreement that ‘every lost baby matters’ and whatever label or terminology is used, everyone remembers, a baby has died and parents have been left behind broken-hearted and bereaved.

The Mariposa Trust since being launched in 2012 has become a leading support charity working within baby loss, with a comprehensive support portfolio that reaches over 50,000 people each week. It has pioneered the use of social media as being an effective platform for people to find support, and has utilised Facebook (over 50,000 followers), Twitter (11,000 followers), Pinterest (33,000), as well as website content (over 650,000 hits per month) to provide effective resources and support for anyone going through baby loss, whether the loss be recent or historic. More information can be found at www.sayinggoodbye.org. Media questions or interview requests should be emailed to press@sayinggoodbye.org

Petition:

A petition https://www.change.org/p/department-of-health-uk-allow-registered-birth-certificates-for-children-born-from-20-weeks has been launched by Sarah Henderson, who is passionate about getting every baby recognised. Whilst what she is asking for in the petition is unlikely to change in the near future due to complex legislation, The Mariposa Trust understand every parents desire to have their child formally recognised, and if a change did come about in the future we would welcome it like most charities would.

So why are we supporting this petition?

The awareness that is being created by the petition is fantastic as it is making people reflect on how devastated parents are after losing a baby and the bereavement they experience. What we don’t support are comments surrounding the petition (which are common elsewhere too) which have belittled early loss or minimised the trauma of miscarriage/ ectopic/ molar pregnancies compared to later loss and stillbirth.