

Position Statement of the MISS Foundation

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Whatever is unnamed, undepicted in images, whatever is omitted from biography, censored in collections of letters, whatever is misnamed as something else, made difficult-to-come-by, whatever is buried in the memory by the collapse of meaning under an inadequate or lying language – this will become, not merely unspoken, but unspeakable.

-Adrienne Rich

Definitions for purposes of this document:

Stillbirth: The intrauterine death of a baby after twenty completed gestational weeks until birth. Stillbirth is always a naturally occurring event ***and often occurs at or near full term for no apparent reason.***

Miscarriage: The intrauterine end of a pregnancy anytime from conception to twenty completed gestational weeks. Miscarriages are also spontaneous, naturally occurring and unpreventable events.

Qui tacet consentit:

In response to the promulgation of the term “Pregnancy and Infant Loss” used in Awareness Campaigns:

The MISS Foundation has been asked its position on the Pregnancy and Infant Loss Awareness Campaigns. Several years ago, after careful consideration with the bereaved parents advisory board, the MISS Foundation made an executive decision for our organization not to utilize the term “*pregnancy and infant loss,*” but rather recognize October as *Infant & Child Death Awareness Month*. We use this language to describe all the awareness campaigning we do for the month of October and on the day of October 15th .

The key reason relates to the use of the vernacular “*pregnancy loss*” when addressing the issue of a sudden, intrauterine death of a child. Language chosen to describe social issues is very powerful. Historically, euphemisms are used to sanitize social problems. Yet, if we do not call it what it is, in the case of stillbirth, the birth of a dead baby, society will never pause to pay attention and the 'cause' will take longer to establish firm roots.

For most of our members, the use of the phrase “pregnancy loss” was not an acceptable description of their personal, traumatic losses. Rather, the language, for them, felt dismissive. In dissecting the phrase, there is an inference that a child, in fact, did not die. Rather that a pregnancy was “lost.” For many women, the phrase decries and derogates their very personal tragedies.

We also found that some women who have experienced the loss of a child to miscarriage also reported feeling offended by the term “*pregnancy loss*.” Author and artist Kara LC Jones says, “I did not lose my children or my state of pregnancy in a crowd. With my stillborn son, I had a c-section. With my miscarried son, I was in full, natural labor for two days before he was born. When I chose to raise awareness about the life, death, grief experiences, I wanted to use a term that gave full gravity to what happened. Infant & Child Death Awareness expresses my experience, because so much more happened here that is deserving of honest language.”

Scientists illuminate some important factors to consider when addressing the issue of perinatal death:

1. Loss is complex. The responses to loss are even more complex. Bowlby’s theory posits a continuum of responses seen in parents who lose children to death more closely associated with the degree of attachment than "time" spent with a child. In other words, quality of the attachment not quantity of the attachment informs the psychological responses of the bereaved. Ambiguous losses tend to cause "complicated mourning" and these are often the most difficult to resolve. There isn't 'more love or attachment,' rather, mixed or ambiguous emotions, either from internal or external sources (meaning that often society assigns taboos and stigma to some losses), that discombobulate the parent's response (they know they feel overwhelmed, bereaved, and desperate but may not feel their feelings or loss are acknowledged and they struggle for validation from the 'social group' which they often do not receive). These are often disenfranchised losses such the death of a "less than perfect child," AIDS deaths, deaths by suicide, stillbirths, and even some highly conflicted relationships that end in death.
2. Stillbirth has been demonstrated to evoke strong and enduring psychological distress and emotional responses in women, similar to any child's death. In addition, there is a physiological paradox stemming from the many physiological responses that occur during the final trimester of pregnancy and in the postpartum period to prepare the woman's body to give birth and to facilitate the many changes that occur, including pain receptor preparation. These nuances coupled with the final outcome, a dead baby, at the end of the birth process, seems to incite an impasse for many women. Her body knows she gave birth and responds accordingly however there is no baby.
3. Miscarriages evoke a variety of responses in scientific data. The continuum ranges from grief responses similar to any child's death to little or no grief responses. There are many hypotheses in the scientific world about this phenomenon. One posits that women who conceive easily and are younger handle early miscarriages "better." Thus, older mothers or the women who endured years of infertility might respond differently. Some studies demonstrate that women with unplanned pregnancies who miscarry report feeling "relieved". Other women who were not particularly trying to conceive but who were happy with the pregnancy appear to be somewhere in the middle of the continuum. Another hypothesis has to do with spiritual beliefs about when life begins. For women who believe enthusiastically that life begins at the moment of conception, the

miscarriage, at any stage, is the death of their child. For another woman who may not hold the same spiritual values, or who may not "attach" early in the pregnancy, the miscarriage may be viewed as a "pregnancy loss" and not the death of a child. Yet, even in these studies, there are diverse responses.

Because love and loss nuanced and complicated, and because language is so powerful, the MISS Foundation chooses to channel its energy into campaigns that align with our philosophies about supporting women, men, and children after the death of a child at any age and from any cause. Indeed, love – and sometimes predictive grief- are not always measurable in a scientific test.

There is never a good age or a good time to lose a child to death. Whether at birth, one year, ten years, thirty years, or sixty years, it is simply out of life's natural order. Children should not die before their parents. This is the cornerstone principle of the MISS Foundation.

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