

Féileacáin

Stillbirth and Neonatal Death Support Ireland



Joint Committee on Health

OPENING STATEMENT

Issues relating to the National Maternity Strategy 2016-2026

(including progress in its implementation)

By Mairie Cregan

and

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Good morning Cathaoirleach and members of the Committee, thank you for the invitation to meet with the Committee today.

My name is Mairie Cregan, the co-founder of Féileacáin. I am a bereaved parent, mother to Liliana who died the day before she was due, and James who died in the midtrimester of pregnancy. I am also a bereaved grandparent: grandmother to baby Darragh who died at 3 days old, following a ‘perfect’ pregnancy. Today I am joined by my colleague Anne-Marie Farrell whose son Ruairi was stillborn unexpectedly on his due date, again after a seemingly healthy pregnancy. I also wish to acknowledge the PLRG¹, whose research Feileacain supports through funding and also active participation. In addition, we salute the Irish Nurses and Midwives Organisation knowing full well the crucial role their members play in providing frontline care comfort and support to all families, and also acknowledge the role played by NWIHP in working to improve care and involving the bereaved parents in these initiatives.

Féileacáin is a not-for-profit organisation providing support to anyone affected by the death of a baby around the time of birth. The loss of a baby during this period is widely recognised as one of the most traumatic experiences a family can endure. A key aim of Féileacáin is to ensure that every bereaved parent and family member in Ireland will have the opportunity to create precious memories with their baby at the time of loss and access appropriate support services afterwards. Through our direct, personal engagement with bereaved parents, Féileacáin is uniquely positioned to advocate on their behalf. We aim to promote improvements in bereavement care and also to end preventable baby deaths.

Let us start with a statistic that is stark and largely unknown: in Ireland, more babies are stillborn (which means that they die in utero on or after 23 weeks of pregnancy) or they die within the first 28 days of life their life (neonatal death) than people tragically die on our roads annually [1] [2]. While we have all seen the powerful road safety campaigns by the RSA, baby deaths remain heartbreakingly in the shadows, thereby missing opportunities to improve bereavement care and end preventable baby deaths.

It is a common myth that baby deaths (perinatal deaths) are just “one of those things”. However, many of these deaths are preventable and unfortunately, every pregnancy is at risk. An analysis of 12-years of singleton stillbirths in Ireland of babies with a major congenital anomaly [3] revealed:

- A minority of mothers had a BMI greater than 30 or smoked
- The average age of mother was only 31.7 years
- 40% were first time mothers

¹ [Pregnancy Loss Research Group | University College Cork](#)

Over a third of these stillbirths were at term (37 weeks or later), when babies are considered to be fully developed and ready for delivery. The babies appeared healthy with 70% a normal weight. These families had not only imagined taking their baby home; they were lovingly prepared with newborn clothes, a pram and car seat - that their baby would never use.

While we know that twins account for approximately 10% of all baby deaths (despite representing only 3-4% of total births) [4], we continue to see twin deaths of babies with major congenital anomalies, or birth before 28 weeks gestation, occurring in hospitals without the appropriate neonatal care expertise [4].

While the maternity strategy focuses on supporting vulnerable groups, regrettable inequalities persist - baby deaths disproportionately affect families from our Black, Irish Traveler, and Asian communities [5].

I will share some specific concerns regarding Health & Wellbeing, Safety and Quality²³ and Bereavement Standards⁴.

Health and Wellbeing & Safety and Quality

We acknowledge the Maternity Strategy's focus on empowering women to make informed decisions about their care. However, significant gaps remain in antenatal education and adherence to clinical guidelines. We continue to hear of tragic cases where medical assessments for reduced fetal movements (sometimes the only warning sign that a baby is unwell) were delayed, missing the vital window for intervention. To be clear, this delay is not a mother's fault. Patient information leaflets, part of the clinical guidelines, are not provided to mothers so that they are aware of the issue. Myths about fetal movements like "drink something sugary to get the baby moving" are worryingly widespread – and believed. Recent discussions with politicians revealed that they were surprised to learn that this is a myth. Another concern is the amount of pregnant women who use the internet for health information [6], and where information about pregnancy is of variable quality [7], [8], [9], and where half of the relevant Google search results have been found to contain misinformation, including websites of Irish hospitals [10]. This specific example illustrates the issue, but it is just one of many instances where there is failure in the implementation of the strategy.

Regarding Safety and Quality, we commend the NWIHP on publishing over 20 clinical guidelines related to pregnancy since 2021⁵. However, the work is incomplete, with 7 guidelines due for update and 18 commissioned, and there is no reporting on implementation. For the

² [National Maternity Strategy – Creating a Better Future Together 2016-2026](#)

³ [National Maternity Strategy Revised Implementation Plan 2021-2026](#)

⁴ [National Bereavement Standards | University College Cork](#)

⁵ [Royal College of Physicians of Ireland Website > Faculties & Institutes > Institute of Obstetricians and Gynaecologists > National Clinical Guidelines in Obstetrics and Gynaecology](#)

successful delivery of the strategy, we ask for dedicated resources to complete and implement all guidelines.

Coroner/Inquest

The distress caused to bereaved families by the coronial process cannot be overstated. Delays, lack of transparency, lack of support add to the already unbearable grief of bereaved parents following the loss of their child and we know of some areas without a perinatal pathology service at the moment. This needs to be addressed as a matter of urgency.

Bereavement Standards

Moving to bereavement care, we welcome the updated publication of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death and we are grateful for the incredible work and dedication provided by bereavement midwives to our families. However, we continue to hear of wide variations in the standards of bereavement care throughout the country.

So many of our families are supported in making precious memories with their baby in the short time available to them, such as bathing their infant, taking photographs, dressing the child, creating precious imprints, and bringing their son or daughter home. There is only one chance for bereaved families to make these precious memories, and concerningly, we hear from other families who did not receive the same care or support. Sometimes, it's as simple as no one in the hospital calling us so we can come in and take precious imprints. Other times, the bereavement midwife only works Monday to Friday, 9 to 5 or the post is unfilled. Babies don't always die during office hours, and the same care and support needs to be available to you whatever time your baby dies. We also hear from families about the anguish of being in a space where they could hear crying babies while their baby remained deafeningly silent, and some families who receive no follow-up from the hospital. We ask for all staff to be trained to support bereaved families, as well as the fulfilment of posts, and full implementation of the Bereavement Standards. Organisations like ourselves play a crucial part in research and also the support and education of those involved with bereaved families and pledge our support to future initiatives.

Looking ahead, we are optimistic about the development of the successor to the National Maternity Strategy. It is crucial that the next strategy incorporates the positive learnings and addresses the shortcomings of the current plan. Furthermore, it must be informed by the changes in the demographics and characteristics of women since the first strategy was published. We welcome the opportunity to return to the Committee to share the Ending Preventable Baby Deaths Action Plan, which we believe will be a valuable input into the next strategy.

Cathaoirleach, we thank you for your attention, and for listening to us. While we acknowledge the Maternity Strategy's progress, we must confront a silent truth: More babies are stillborn or die in their first 28 days than people die who are lost on our roads, and implementation of the strategy, guidelines and Bereavement Standards is required. Our hope is that fewer families will

walk our path, and that for every baby who dies, families will receive the dignified, compassionate care necessary to make those precious memories, honour their baby and support to negotiate the journey of healing ahead.

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Supporting Material

Background to Féileacáin

Féileacáin (Stillbirth and Neonatal Death Support) (Appendix 1) was established in 2009 and officially registered as a charity in 2010 (CHY 19635, CRA 20077235).

Féileacáin is a not-for-profit organisation providing support to anyone affected by the death of a baby around the time of birth. The loss of a baby during this period is widely recognised as one of the most traumatic experiences a family can endure. Yet, the societal impact of perinatal death remains largely unacknowledged, and the grief experienced is often misunderstood and disenfranchised.

A key aim of Féileacáin is to ensure that every bereaved parent and family member in Ireland will have the opportunity to create precious memories with their baby at the time of loss and access appropriate support services afterwards. We also work to raise public awareness and understanding of perinatal death, ensuring its impact is recognised within the community and reflected in legislation.

Féileacáin provides compassionate support to anyone affected by the death of a baby. This includes personal, emotional, and practical assistance at any time families wish to access it. Services include memory-making, counselling, social work advice, befriending, play therapy, support meetings, and remembrance services. Féileacáin also supports professionals caring for bereaved parents and the wider community affected by perinatal loss.

All Féileacáin services are offered free of charge to families experiencing perinatal bereavement. The organisation receives no central government funding and relies on community support, particularly from families who have used our services and wish to help others in similar situations.

Through our direct, personal engagement with bereaved parents, Féileacáin is uniquely positioned to advocate on their behalf. One of our core aims is to promote improvements in bereavement care and influence legislation to better support families experiencing perinatal loss.

Additional items:

1. <https://feileacain.ie/>
2. [Féileacáin Podcast](#)
3. [How do you get bereaved fathers to talk? Bring a football](#)
4. [IrelandAM](#) interview with Nina, Liam and Grace's mam, along with a bereavement midwife sharing the positive impact compassionate bereavement care has on families.