



Enhancing bereavement care for people who experience a pregnancy loss or perinatal death

The Challenge

The loss of a baby or pregnancy can be a difficult and devastating time for parents and families. Parents and families may need a range of immediate and longer term supports to help them with their bereavement. The role of family, friends & community is crucial in helping parents come to terms with their loss. There are a range of health and other support services that can play a positive and helpful role for parents during this time.

The [National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death](#) (the Standards) were developed in response to recommendations in the Health Service Executive (HSE)'s investigation report into the death of Savita Halappanavar (2013).

The purpose of the Standards is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. These Standards cover all types of pregnancy loss that women and parents may experience, from early pregnancy loss to perinatal death, including the end of a pregnancy as well as situations where there is a diagnosis of fetal anomaly that will be life-limiting or may be fatal.

The Standards:

- Are a resource for both parents and professionals
- Intend to promote multidisciplinary staff involvement in preparing and delivering a comprehensive range of bereavement care services that address the immediate and long-term needs of parents bereaved while under the care of the maternity services
- Guide and direct bereavement care staff on how to lead, develop and improve a hospital response to parents who experience the loss of a pregnancy or a baby and will assist staff to develop care pathways that will facilitate the hospital's response to the grief experienced by parents and their families
- Acknowledge the impact of perinatal loss on staff and the importance of having formal structures in place to support staff.

The Work



Members of the Pregnancy Loss Research Group (PLRG) have played, and continue to play, a key role in informing the development and implementation of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.

Development phase

The HSE in conjunction with the Clinical Programme in Obstetrics and Gynaecology tasked a multidisciplinary group of 21 perinatal bereavement care experts to develop the Standards. Professor Keelin O'Donoghue and Dr Daniel Nuzum were members of this Development Group. Research from the PLRG informed the content of the Standards.

Following a two-year development and review process, chaired by Dr Ciaran Browne, the Standards were launched in August 2016.

Mr Simon Harris, Minister for Health, launched the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death in Farmleigh House. The launch of the Standards, attended by healthcare professionals from all 19 maternity units and parent representatives, was welcomed by both healthcare professionals and parents who have experienced pregnancy loss.

At the launch, Professor O'Donoghue was announced as National Implementation Lead for the Standards.





Standards Launch, Farmleigh House Dublin, August 2016. Mr Tony O'Brien, Minister Simon Harris, Professor Keelin O'Donoghue



Standards Development Group, Standards Launch, Farmleigh House Dublin, August 2016. Back row (l-r): Ms Marie Finn, Ms Brid Shine, Ms Aileen Mulvihill, Dr Mary Moran, Ms Fiona Mulligan, Ms Kathryn Woods, Rev Dr Daniel Nuzum, Dr Barbara Coughlan, Ms Grace O'Sullivan, Ms Anne Mc Keown. Front row (l-r): Ms Marie Hunt, Dr Anne Bergin, Mr Tony O' Brien, Minister Simon Harris, Dr Ciaran Browne, Professor Keelin O'Donoghue.

Implementation phase

The two-year Implementation Programme for the Standards commenced in March 2017, with Professor O'Donoghue as Implementation Lead. Ms Ríona Cotter was appointed as Programme Manager.

The implementation was facilitated by a National Implementation Group of 14 healthcare professionals all involved in various aspects of bereavement care in Irish Maternity Units. Membership included several members of the PLRG: Dr Brendan Fitzgerald, Ms Orla Jennings (2018-2019), Dr Daniel Nuzum, Ms Stacey Power, Ms Anna Maria Verling.

The National Implementation Group carried out its work through six work streams:

- Quality and Service Improvement, chaired by Professor Keelin O'Donoghue
- Policies and Procedures, chaired by Ms Ríona Cotter
- Information technology, co-chaired by Professor O'Donoghue and Ms Cotter
- Referrals and Integration, chaired by Dr Daniel Nuzum
- Perinatal Palliative Care/Termination of Pregnancy for Fetal Anomalies, co-chaired by Professor O'Donoghue and Dr Mary Devins
- Education, training and staff support, chaired by Professor Mary Higgins (2017-2018), Professor O'Donoghue (2018-2019).

Development and Oversight Group

After the two-year Implementation Programme came to an end in 2019, an Oversight Group was convened to manage the continued implementation and ongoing development of the Standards in the 19 maternity units/hospitals in Ireland.

PLRG members are part of this Group: Dr Brendan Fitzgerald, Dr Anne Helps (2021-), Marita Hennessy PhD (2021-), Dr Daniel Nuzum, Dr Stacey Power, Ms Rachel Rice, Ms Anna Maria Verling.

A number of projects have been carried out as part of the implementation and development programmes, and which have been underpinned by PLRG research. These include: [an update of the Standards document](#) (published in 2022), development and rollout of an annual national maternity



bereavement care audit in all 19 maternity hospitals (2015, 2017, 2020); development of, and support for, staff education programmes in all 19 maternity hospitals (including TEARDROP); the development, and continued management of the national pregnancy loss website – a directory of support services and knowledge for bereaved parents and health professionals (pregnancyandinfantloss.ie); support for the introduction of Schwartz rounds or other such staff support programmes in all 19 maternity hospitals.



National Website Launch, April 2019. Ms Rióna Cotter, Professor Keelin O'Donoghue



Pictured at the Bereavement Forum, Croke Park Dublin, 2018, L-R: Dr Mary Devins, Dr Anne Doolan, Stacey Power, Ms Marie Hunt, Professor Keelin O'Donoghue, Ms Rióna Cotter, Minister Simon Harris TD, Dr Daniel Nuzum, Dr Seosamh O'Coigligh, Ms Anna Maria Verling, Dr Brendan Fitzgerald, Ms Marie Lynch.

Two **Bereavement Forums** were held, in 2018 and 2019. On 26 April 2018, Minister Simon Harris opened the one-year progress meeting of the Implementation Programme for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in Croke Park. The day-long Forum brought together national and international experts along with healthcare professionals representing all 19 maternity hospitals to discuss the work of the implementation programme to date.

The second National Forum for the Implementation of Standards was hosted at University College Cork on 02 March 2019 and featured a range of international and national speakers. Professor O'Donoghue and Ms Rióna Cotter provided an overview of the Two Year Implementation Programme, while Dr Margaret Murphy co-presented the development of Perinatal Bereavement Education Standards. Ms Stacey Power provided an overview of the development of an education programme for support groups and Ms Anna Maria Verling presented the development and evaluation of a parental experience feedback tool.



Pictured at the Bereavement Forum, UCC, 2019, L-R: Ms Anna Maria Verling, Ms Stacey Power, Professor Keelin O'Donoghue, Dr Seosamh O'Coigligh, Ms Orla Jennings, Dr Brendan Fitzgerald, Ms Rióna Cotter, Dr Daniel Nuzum, Ms Marie Hunt.





The Impact

PLRG research informed the development of the original [National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death](#), and the revised Standards published in 2022, as well as the implementation of both.

This includes the following:

- Communication skills and stillbirth: Dr Daniel Nuzum and Ms Orla O'Connell
- Staff support: Dr Karen McNamara and Dr Daniel Nuzum
- Pregnancy after loss: Dr Margaret Murphy
- Termination of pregnancy for fetal anomaly: Dr Stacey Power Walsh.

In addition, Dr Stacey Power Walsh's PhD around experiences of pregnancy with major fetal anomalies was funded within the Implementation Programme for the Standards from 2017-2020 – supervised by Professor O'Donoghue and Dr Sarah Meaney. This funding was due both to the recognition of the lack of research in the Irish context on parents/families needs after diagnosis of major fetal anomaly in pregnancy and as termination of pregnancy legislation was anticipated.

This PhD led to the publication of several papers that contribute to the knowledge around the: incidence of fatal fetal anomalies associated with perinatal mortality; general public's knowledge of fatal fetal anomalies, perinatal palliative care and termination of pregnancy; influence of media commentary on fetal fetal anomalies; education needs of voluntary support groups who provide support to parents following a pregnancy loss and perinatal death; experiences of volunteers and fetal medicine specialists providing care and support following a fatal fetal anomaly diagnosis, during the implementation of a new service of termination of pregnancy for fatal fetal anomalies.



Since the launch of the Standards in 2016 there have been, and continue to be, improvements in bereavement care following pregnancy loss and perinatal death within maternity services in Ireland. Research conducted by the Pregnancy Loss Research Group, and the expertise of its members, has been pivotal in informing the development and implementation of the Standards.



Professor Keelin O'Donoghue, National Implementation Lead-National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, National Women and Infants Health Programme, and Lead, Pregnancy Loss Research Group