Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

National Standards for

Bereavement Care Following Pregnancy Loss and Perinatal Death

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Part 1

The Four Standards

1. Bereavement Care

Bereavement Care is central to the mission of the hospital and is offered in accordance with the religious, secular, ethnic, social and cultural values of the parents who have experienced a pregnancy loss or perinatal death.

2. The Hospital

The hospital has systems in place to ensure that bereavement care and end-of-life care for babies is central to the mission of the hospital and is organised around the needs of babies and their families.

3. The Baby and Parents

Each baby/family receives high quality palliative and end-of-life care that is appropriate to his/her needs and to the wishes of his/her parents.

4. The Staff

All hospital staff have access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care in accordance with their roles and responsibilities.

Introduction

Dealing with the loss of a baby or pregnancy can be a difficult and devastating time for parents and families (Coleman, 2015; Murphy & Jones, 2014; Mulvihill & Walsh, 2013; Purandare et al., 2012; Malm et al., 2011). Parents and families may need a range of immediate and longer term supports to help them with their bereavement. The role of family, friends and 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 purpose of the Standards for Bereavement Care is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. These Standards cover all pregnancy loss situations that women and parents may experience, from early pregnancy loss to perinatal death, as well as situations where there is a diagnosis of fetal anomaly that will be life-limiting or may be fatal.

These Standards for Bereavement Care following Pregnancy Loss and Perinatal Death are a resource for both parents and professionals. The Standards 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. The Standards will 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. The Standards acknowledge the impact of perinatal loss on staff and the importance of having formal structures in place to support staff (Nuzum, 2014; Hill, 2012; McCready et al., 2009).

These Standards were developed in response to a recommendation in the HSE National Incident Management Team (NIMT) 50278 (2013) report which stated:

> *'ensure that the psychological impact of inevitable miscarriage is appropriately considered and that a member of staff is available to offer immediate support and information at diagnosis. Members of staff should also advise of the availability of counselling services for women and partners at diagnosis. Care given, including counselling and support, should be documented. The availability of counselling services for women, partners and families who have suffered any incident or bereavement in childbirth should be reviewed, considered and developed as appropriate at each maternity site'.*

These Standards can be used by parents, families, staff and support organisations to understand the range of hospital responses that the HSE are aiming to put in place. It is acknowledged that much improvement can and needs to be made in this area. These Standards will form an important focus in our improvement efforts into the future.

Context for the Standards

Providing bereavement care is an integral part of a maternity service. It is important that such bereavement care is integrated with the hospital's overall medical and clinical care response to parents. All families have bereavement care needs. These needs are viewed as ascending from basic to more complex needs. Bereavement Care is often described in terms of three levels and it is important that the maternity setting has staff who can assess needs at each of these levels, provide care and/or refer to the most appropriate support.

At the most basic level (level one) mothers and families need reliable, accurate information given in a sensitive and supportive manner. They need to be able to express their responses in a safe

environment. Level two bereavement care, also described as 'sensitive' care, is required by people potentially at risk of disenfranchised or complicated grief because of, for example, social isolation, demanding caring duties and reduced coping capacity. Level two care is provided by staff with a formal understanding of the grief process and who use the general skills of counselling including listening, affirming and clarifying. At level two, some people may benefit from an opportunity to talk to and receive more formal supports which are often provided by trained volunteers or convened by 'peers' who have had a similar bereavement experience. A minority of bereaved persons may experience significant or debilitating difficulties in their grieving, in which case they will be referred for professional and therapeutic support by the Bereavement Care Staff. This is considered Level 3 support.

In providing and integrating bereavement care, hospitals should be aware that there are a range of other professionals and services that may be involved with bereaved parents. The approach and skill of all professionals involved should be led by the principles and domains of competence as defined in the National Palliative Care Competency Framework. The framework will assist in providing an agreed and graded model for staff from different parts of the hospital and health system to understand the principles and types of skills required to be involved in a holistic and caring response to parents. As the role of the Bereavement Team and the role of the Paediatric Palliative Care Team are distinct, this document does not prescribe for the responsibilities of the Paediatric Palliative Care Team or for Outreach Nurses or other services such as physiotherapy, pharmacy, etc.

Within the context of perinatal palliative care approach the standards that follow are primarily concerned with the early neonatal period (within 7 completed days of birth). Maternity hospital staff (obstetric, midwifery, anaesthetic, paediatric, neonatology, nursing and bereavement team) are responsible for providing care that incorporates anticipatory bereavement care and perinatal palliative care for the unborn baby, and for the parents and baby during the first week of the baby's life. Thereafter palliative care, provided in accordance with the Palliative Care for Children with Life-limiting Conditions National Policy (http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf), is transferred to the Paediatric Palliative Care Team. Bereavement care for the family continues to be provided by the maternity hospital's bereavement team.

Bereavement Care Standards and Other Policies

These Standards are intended for use in conjunction with current clinical guidelines, professional codes of practice, government policy and relevant legislation. Clinical guidelines are under continuous review and reflect contemporary research and current best practice. There is general and specific legislation that directly effects the practice of all healthcare professionals. This includes those working in the area of bereavement care and all health professionals applying these Standards. It is important that professionals comprehend legislative and other requirements when dealing with parents and undertake all interactions/consultations in line with appropriate legislation. A list of relevant guidelines, policies and pertinent relevant legislation is available in Appendix 1.

The HSE's Corporate Plan for Health Services (2015 – 2017) sets out our values of care, compassion, trust and learning (http://www.hse.ie/eng/services/publications/corporate/corporateplan15-17.pdf). These Standards are a direct expression of these values and have been directly informed by them. These Standards contribute to the HSE's Goal (number 3) to foster a culture that is honest, compassionate, transparent and accountable.

The HSE is committed to providing an open, timely and consistent approach to communicating with service users and their families when things go wrong in healthcare. This is called Open Disclosure (http://www.hse.ie/opendisclosure/). It is important to recognise that openness and honesty when things have gone wrong form an important part of the bereavement and recovery process. This is not to suggest that openness and honesty are not integral to the bereavement process at all other times.

Pregnancy Loss and Perinatal Death

There were 500 perinatal deaths in Ireland in 2013 (National Perinatal Epidemiology Centre, 2015). These included 301 stillbirths, 162 early neonatal deaths (within 7 completed days of birth) and 37 late neonatal deaths (after the 7th and within 28 completed days of birth). Miscarriage occurs in approximately one fifth of clinical pregnancies equating to approximately 14,000 miscarriages per annum in Ireland (Poulose et al, 2006). There were 26 terminations of pregnancy in Ireland carried out under the Protection of Life during Pregnancy Act in 2014. The British Department of Health reported that 3,735 terminations were undertaken in England and Wales in 2014 for women with an address in the Irish Republic (https://www.gov.uk/government/statistical-data-sets/abortion-statistics-england-and-wales-2014).

There are also a range of other pregnancy losses for which limited or no information is currently available. For example, national information on ectopic and other forms of pregnancy loss is not currently available. The provision of bereavement care is based on the needs of parents and not on the type of loss.

It is important to note that the Standards apply to all parents who experience a pregnancy loss, diagnosis of fetal anomaly or perinatal death, irrespective of the source of that loss or the term used in these Standards. As a result all terms have been included in the glossary.

Use of Disputed Terminology in the Standards

During the Standards development process, a set of terms to describe parents with a baby who has a life-limiting condition; fatal/lethal fetal abnormality / fetal anomaly was the subject of discussion and consultation feedback. In writing these Standards, it is acknowledged that there is no clear or universal term that can be used or is acceptable to the majority of parents. Any terms used in this area are subject to conceptual and practical challenges inherent in defining such terms (Wilkinson et al. 2012). In respect of this, the Standards will use the term ‘life-limiting condition’, a term consistent with the National Policy on Palliative Care for Children with Life-Limiting Conditions (DOH, 2009). However, it is important to note that although the term ‘life-limiting condition’ is used, the aim of the Standards is to provide bereavement care to parents who would prefer to use other terms to describe their experience and who would not agree with the use of the term ‘life-limiting condition’. Preference for different terms from parents or health professionals should not in any way impact on the type or quality of bereavement care that is provided.

Glossary of Terms and Conditions

Anticipatory Grief

Anticipatory grief describes the normal grief response that occurs prior to death that includes sadness, sorrow, anger, crying and emotional preparation for death (Kehl, 2005). Anticipatory grief differs from conventional grief in so far as it is not infinitely prolonged since there is always an endpoint in death (Sweeting & Gilhooly, 1990). Anticipatory grief is frequently experienced by the patient and his/her family. Anticipatory bereavement care plays an important role in lessening the intensity of the post-death bereavement (Duke, 1998).

Bereavement

Bereavement describes the entire experience of family members and friends in the anticipation of death and subsequent adjustment to living following the death of a loved one (Christ et al., 2003). It takes account of the unique individual experience of the bereaved person (National Clinical Programme for Palliative Care Glossary of Terms, 2012). Bereavement also refers to the objective situation of having lost someone significant through death (Stroebe et al., 2008).

Bereavement Care and Support

It is accepted by bereavement specialists that there are three levels of bereavement care for the general population (Keegan, 2013; Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008).

- Level 1 care, also described as ‘universal’ care, involves good end-of-life care, sensitive communication, reliable information and guidance (Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008). Level 1 care provides people with information on how to access up-to-date and useful information about the practical, emotional and other challenges associated with loss.
- Level 2 care, also described as ‘sensitive’ care, is required by people potentially at risk of disenfranchised or complicated grief because of social isolation, demanding caring duties and reduced coping capacity. At level 2, some people may benefit from an opportunity to talk to and receive more formal supports which are often provided by trained volunteers or convened by ‘peers’ who have had a similar bereavement experience.
- Level 3 care, involves professional and therapeutic support and is required by only a minority of bereaved people and required by bereaved people who are experiencing significant or debilitating difficulties in their bereavement.

Bereavement care staff are trained to assess the bereavement care needs of individuals; to identify people in need of extra support and/or therapeutic care and will have in place care pathways for referring parents to therapeutic services if necessary. Staff acknowledge that this group of people may also incur greater physical and mental health difficulties (Stroebe et al., 2007).

Bereavement Committee

The Bereavement Committee is multidisciplinary and may be composed of; a senior hospital administrator, clinical midwife specialist in bereavement, bereavement coordinator, medical social worker with responsibility for bereavement care, chaplain, clinical leads, hospital managers, clinical midwife specialist in mental health, service user and nominated representatives from midwifery management, obstetrics, paediatrics, neonatology, ultrasonography, psychiatry, pathology, laboratory, mortuary staff, clerical and household staff. The committee convenes on a regular basis as determined locally.

Bereavement Coordinator

The Bereavement Coordinator is responsible for the development, implementation and evaluation of the hospital's bereavement program. He/she works closely with the CMS in bereavement, Chair of the Bereavement Committee, associated professionals and hospital management, and is responsible for ensuring the hospital has capacity and referral systems in place for providing each of the levels of bereavement care. The Bereavement Coordinator has overall responsibility for the educating, training and upskilling of all hospital staff in bereavement care.

Bereavement Specialist Team (BST)

The BST is composed of staff members who have undertaken specialist and extensive education in bereavement care. The team includes; a bereavement coordinator, clinical midwife specialist in bereavement, chaplain and senior medical social worker. The team is supported in its work by the hospital chief executive officer (CEO), director of midwifery, clinical leads, obstetricians, paediatricians, neonatologists, perinatal psychiatrist, midwives, nurses, neonatal care nurses, chaplains, ministers of religions, palliative care teams, bereavement committees, end-of-life care committees, administrative and auxiliary staff – all of whom have received training appropriate to their role in bereavement care.

Care Pathway

A care pathway is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period (Vanhaecht et al., 2007). A care pathway is defined and documented in the patient's Healthcare Record (HCR) and is explicit in its goal statement. The care pathway is based on best practice and is discussed and agreed, in the case of a baby, with his/her parents.

Chaplain

The role of the Healthcare Chaplain in the maternity service is to provide spiritual and pastoral care and support to babies, parents and their families in the midst of illness or bereavement. This support is available to all and respects the personal, spiritual, religious and cultural expressions (or none) of the individual and family and is provided in accordance with the Association for Clinical Pastoral Education (ACPE Ireland Ltd.) training and in accordance with Healthcare Chaplaincy Board (HCB)/ Chaplaincy Accreditation Board (CAB) requirements.

Children's Outreach Nurses for Life-limiting Conditions

The Children's Outreach Nurses for Life-limiting Conditions provide a bridge between hospitals, community, statutory and voluntary services and are involved in supporting children with life-limiting conditions and their families in their homes.

Children's Palliative Care

Palliative care for children is a highly specialised field of healthcare. Palliative care aims to maintain quality of life for the duration of the child's illness which may be days, but can be months, and sometimes years. Children's palliative care is holistic in nature where the child and their family are viewed as one unit. Most children with palliative care needs will have these needs met by their family who are supported by locally provided services. This may sometimes, but not always, require the support of a specialist palliative care team.

Support for children with palliative care needs starts at the time of diagnosis, and for many children with life-limiting conditions this can be at birth. Palliative care support can be given alongside active treatments aimed at cure or prolonging life and should, where possible, be provided in the location where the child and family choose to be. Families vary in how strongly they wish to pursue treatments aimed at cure or prolonging life. Decisions about moving away from active care are difficult for both

the family and staff and should only be made following full discussion. A care plan, once decided, should include details of what, if any, emergency treatment measures should be taken. The child's comfort should always be central to the decision-making process. Parents' wishes should be documented and care should be planned accordingly. Clear communication between parents and all healthcare professionals involved in the care of the child is essential. (DOH, 2009. Palliative Care for Children with life-limiting conditions in Ireland – A National Policy). Available at http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf].

Clinical Midwife Specialist (CMS) in Bereavement

The Clinical Midwife Specialist (CMS) in Bereavement is recognised by the Nursing and Midwifery Board of Ireland as a specialist post. He/she is an experienced midwife who has undertaken specific training and education at level 8 or above in the area of bereavement. The CMS's role is to support and facilitate the loss and bereavement process in all areas of pregnancy loss. The CMS provides anticipatory bereavement support to those families whose baby is diagnosed with a life-limiting condition, working with the Multidisciplinary Team (MDT) within the Perinatal Palliative Care framework. He/she is an identifiable resource to bereaved mothers, partners and siblings around the time of loss, following discharge home and in subsequent pregnancies.

The CMS works within the framework of the NICE (2004) guidelines, being involved in the direct provision of level one support, signposting to level two supports in the community and adequately trained to recognise, treat and/or appropriately refer to level three support in the event of a complicated grief diagnosis (Kristjanson et al., 2006). The CMS demonstrates expertise in the aetiology of pregnancy, pregnancy loss and perinatal death and works collaboratively with his/her clinical colleagues in the formal follow-up care of bereaved parents. He/she is an advocate for bereaved families, provides education and training to staff, as well as being involved in audit and research aimed at enhancing bereavement care.

Complicated / Pathological Grief

Bereaved parents have been recognised as a high-risk group for complicated grief (Ellis et al., 2016). Grief that is complicated involves the presentation of certain grief-related symptoms at a time beyond which is considered adaptive (Kristjanson et al., 2006). Complicated grief is characterized by intense grief that lasts longer than would be expected according to social norms and causes impairment in daily functioning. Complicated grief has a prevalence of approximately 10-20% following the death of a romantic partner and an even higher prevalence amongst parents following the death of a child (Meert et al., 2011).

Culture

Culture can be defined broadly as the web of meaning in which humans live (Browning & Solomon, 2005). It is expressed through the characteristics and knowledge of a particular group of people, through their language, religion, cuisine, social habits, music and arts. Culture influences social interactions, cognitive constructs and understanding that are learned by socialisation.

Disenfranchised Grief

Disenfranchised grief occurs when the impact of a death is not recognised. It occurs when grief is not openly acknowledged, socially validated or publicly mourned (Doka, 2002). Circumstances that expose an individual to the risk of experiencing disenfranchised grief include:

- non-traditional relationships
- society failing to recognise that a significant loss has occurred
- society failing to recognise that a person such as a child or a disabled person is capable of grieving
- misunderstanding of an individual's response to their loss

- a bereaved person denying him/her self the right to grieve
- social isolation, demanding caring duties and reduced coping capacity
- social and psycho-social disadvantage e.g. domestic abuse, lone parent

Disenfranchised grief inhibits mourners' capacity to overcome suffering and live meaningfully again. Bereaved persons who experience disenfranchised grief may require specialised therapies to overcome their grief (Stroebe et al., 2007).

End-of-life Care

For the purpose of these Standards the term end-of-life care is used to describe the perinatal palliative care of a baby during its first week of life (early neonatal period) when life expectancy is limited and death is imminent. It encompasses care of the baby from the time of diagnosis through to his/her death and care of the baby and parents following death.

Family

A family is defined as those closest to the patient in knowledge, care and affection and who are connected through their common biological, legal, cultural, and emotional history (National Clinical Programme for Palliative Care Glossary of Terms, 2012).

Fatal / Lethal Fetal Anomaly

There is no agreed definition of a fatal/lethal fetal anomaly (Wilkinson et al., 2012). Neither is there a legal definition for fetal anomaly that maybe fatal, or an agreed list of conditions associated with fatal fetal anomaly. Fatal fetal anomaly describes a medical condition suffered by a fetus that is not expected to survive beyond the new born period. An assessment of the seriousness of a fetal abnormality should be considered on a case-by-case basis, taking into account all available clinical information (RCOG, 2010).

Grief

Grief is the reaction to bereavement. It is a natural human response that is irrespective of culture and class and its expression varies considerably (Hooyman & Kramer, 2006; Gardner, 1999).

Health Care Record (HCR)

A Health Care Record in the maternity services is a record of the entire obstetrical, medical and social history of a woman and the care she has been receiving from a multidisciplinary team in the hospital and in the community.

Hospital

Hospital includes maternity hospitals and maternity units in general hospitals.

Intra Uterine Fetal Death

An intra uterine fetal death, also described as an intrauterine death (IUD), describes a baby who dies in the womb (RCPI & HSE Clinical Practice Guideline Number 4, 2011).

Levels of Palliative Care

- Level 1 care, also described as 'universal' care, involves good care from the point at which the potential for loss is identified; it can encompass end-of-life care and always includes sensitive communication, reliable information and guidance (Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008). Level 1 care provides people with information on how to access up-to-date and useful information about the practical, emotional and other challenges associated with loss. It is compassionate care and should be provided by all who come in contact with the family.

- Level 2 – At this level of practice, those providing palliative care will have additional training and expertise. This is viewed as an intermediate level of expertise, where engagement in palliative care is part of the health professional's caring role but does not define it.
- Level 3 – This level refers to those whose core activity is limited to the provision of palliative care. Caring for patients with complex and demanding palliative care needs requires a greater degree of training, staff and other resources.

(DOH, 2009. Palliative Care for Children with life-limiting conditions in Ireland – A National Policy). Available at http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf].

Life-limiting Condition

National Health Policy describes a life-limiting condition as any illness in a child where there is no reasonable hope of cure and from which the child or young adult will die (DOH, 2009: Palliative Care for Children with Life-Limiting Conditions). Children with these conditions are likely to have palliative care needs.

Live Birth

Birth of an infant which, after complete separation from his/her mother, shows sign of life. Evidence of life includes breathing movements, presence of a heartbeat, pulsation of the cord or definite movement of voluntary muscles (RCPI & HSE Clinical Practice Guideline Number 4, 2011).

Medical Social Worker Specialist in Bereavement

The Medical Social Worker Specialist in Bereavement in a maternity setting provides emotional and practical support at a time of loss to bereaved parents, children and extended family members. They are available to offer bereavement support to parents in the weeks and months following their discharge from hospital and throughout subsequent pregnancies. The bereavement social worker also provides advice on children and loss and is available to do direct work with children, if this support is needed. They are an advocate for bereaved parents and work as part of the bereavement team to ensure optimum care for bereaved families.

Miscarriage

A miscarriage is the loss of a baby before viability. A miscarriage may occur during the first trimester (early miscarriage) or during the second trimester (late miscarriage).

Multidisciplinary Team (MDT)

The MDT is a team of health and social care professionals working together to provide holistic care. The MDT in a maternity hospital includes sonographers, fetal medicine consultants, obstetricians, neonatologists, anaesthetists, midwives, nurses, neonatal nurses, allied health professionals, bereavement care specialists, palliative care staff, bereavement care staff including chaplains, medical social workers and clinical midwife specialists, laboratory and mortuary staff. All staff play a central role in supporting and giving information to parents who receive bad news.

Neonatal

Refers to the period after birth up until the fourth completed week of life (National Perinatal Epidemiology Centre, 2015).

Neonatal Death

Death of a baby occurring within 28 completed days of birth.

An early neonatal death describes a neonatal death occurring within 7 completed days of birth.

A late neonatal death describes a neonatal death occurring after the 7th and within 28 completed days of birth (National Perinatal Epidemiology Centre, 2015).

Next-of-Kin

The term next-of-kin has no legal definition in Ireland except for inheritance law (Succession Act 1965) where it is defined as the nearest blood relative to the deceased. For the purposes of this guideline, next-of-kin describes a spouse or nearest blood relative.

Parent

Parent is used to denote a mother, father or other parent.

Perinatal Bereavement Care

For the purpose of this guideline, perinatal bereavement care refers to the care provided by the multidisciplinary maternity hospital staff to parents who experience pregnancy loss; parents who receive a diagnosis during pregnancy of a life-limiting condition; parents whose baby is stillborn and parents whose baby dies during the early neonatal period. Perinatal bereavement care includes physical, psychological, emotional and spiritual care following loss and is extended to siblings and grandparents.

Perinatal Pathologist

The perinatal pathologist ensures that within the pathology department the post mortem practice is viewed as parent-centred and that the baby and its parents are treated with respect at all times. He/she is also responsible for ensuring;

- that post mortems are performed to a high standard, in keeping with national and international guidelines
- that members of the BST and others are educated about the post mortem process and placental pathology; what it involves and what is possible to learn from the examination
- that the limitations of the post mortem examination are understood

The pathologist is also responsible for integrating information obtained from the post mortem examination, placental examination, cytogenetics testing and other available investigations to formulate a cause of death (if possible) and to correlate the pathological findings identified with the clinical course leading up to the miscarriage, stillbirth or neonatal death. If a definitive cause of death is not identified, potential contributors or relevant negative findings can be documented. He/she communicates the results of post mortems and placental examinations to the clinical team caring for the parents. The perinatal mortality multidisciplinary team meeting is a vital forum for this communication as it ensures accurate understanding of all aspects of individual cases and thereby facilitates appropriate follow-up (e.g. specialist medical genetics referral). These meetings are also a valuable forum for learning for the wider disciplinary team and for students.

Perinatal Mortality

Perinatal mortality refers to the death of babies in the weeks before or four weeks after birth. Perinatal mortality includes stillbirths (babies born with no signs of life after 24 weeks of pregnancy or weighing at least 500 grammes) and the deaths of babies within 28 days of being born (National Perinatal Epidemiology Centre, 2013).

Post Natal Care

Post-natal care includes the physical and emotional care of a woman after birth.

Pregnancy Loss

Pregnancy loss is all types of loss, including spontaneous and medically supervised terminations that can occur during a pregnancy from the first to third trimester.

Recurrent Miscarriage

Recurrent miscarriage, defined as the loss of three or more consecutive pregnancies before 24 weeks gestation, affect 1% of couples (RCOG, 2011).

Staff

Staff describes all people who work in the maternity unit/hospital including all members of the multi-disciplinary team, reception staff, security staff, kitchen staff, midwifery and nursing students, nurse assistants, laboratory staff, mortuary staff, cleaning staff, porters and all other auxiliary staff in hospitals.

Stillbirth

A child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life (Stillbirths Registration Act, 1994). Available at http://www.irishstatutebook.ie/1994/en/act/pub/0001/print.html#sec1.

Stakeholders

Stakeholders denote parents, siblings, grandparents, aunts, uncles, extended family, guardians, community health care personnel and voluntary support groups as well as hospital staff.

Symbol

A symbol that is recognised by hospital staff and the public is used in maternity units to indicate when an end-of-life issue is happening for a family and/or to indicate that a bereavement has taken place. The symbol selected for use in each hospital is agreed locally by staff and management. Parental consent for use of the symbol is necessary.

Part 2

The Four Standards

1. Bereavement Care

Bereavement Care is central to the mission of the hospital and is offered in accordance with the religious, secular, ethnic, social and cultural values of the parents who have experienced a pregnancy loss or perinatal death.

2. The Hospital

The hospital has systems in place to ensure that bereavement care and end-of-life care for babies is central to the mission of the hospital and is organised around the needs of babies and their families.

3. The Baby and Parents

Each baby/family receives high quality palliative and end-of-life care that is appropriate to his/her needs and to the wishes of his/her parents.

4. The Staff

All hospital staff have access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care in accordance with their roles and responsibilities.

Standard 1: Bereavement Care

Bereavement Care is central to the mission of the hospital and is offered in accordance with the religious, secular, ethnic, social and cultural values of the parents who have experienced a pregnancy loss or perinatal death.

1.1 Bereavement Care at time of Diagnosis

Statement: All relevant hospital staff sensitively communicate bad news to parents in a quiet and private environment and with special consideration of individual needs and preparedness for the emotional and physical management of their diagnosis.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Guidelines are in place for identifying the needs of and for supporting a parent experiencing bereavement in the maternity services. All relevant staff are aware of and use these guidelines where appropriate. *Cacciatore and Bushfield (2007); SANDS (2007); ISANDS (2007); Hutti (2005); Cook et al. (2002); Catlin & Carter (2002).*	✓	✓	✓	✓	✓	✓
Parents who experience bereavement in the maternity services are cared for compassionately, with dignity and with respect. *Nuzum et al. (2014); RCPI/HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); Stratton and Lloyd (2008); SANDS (2007); ISANDS (2007); Callister (2006); Catlin & Carter (2002).*	✓	✓	✓	✓	✓	✓
There is an acknowledgement on the part of the hospital that all hospital staff (see glossary) have an important role to play in ensuring effective and sensitive communication with parents. Hospital staff play an important role in the bereavement care provided to bereaved parents. Bereavement care training appropriate to their role in the hospital, is provided to all staff when commencing employment and bereavement training refresher courses are provided every three years. This is a core value of the hospital and is reflected in the decision and actions of the hospital *Ellis et al. (2016); McQueen (2011); Gold (2007); SANDS (2007); Fauri (2000).*	✓	✓	✓	✓	✓	✓
It is recommended that, with a woman's permission, a symbol denoting that a pregnancy loss or perinatal death has taken place is sensitively placed in a woman's Healthcare Record (HCR). *RCPI/HSE Clinical Guideline No. 4 (2011); Gold (2007); SANDS (2007); ISANDS (2007).*	Optional	Optional	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
At commencement of employment, all hospital staff providing care to bereaved parents receive mandatory training, appropriate to their role in the hospital on how to communicate sensitively and how to break bad news. *Rådestad et al. (2014); Roehrs et al. (2008); Lalor et al. (2007); Yee and Ross (2006).*	✓	✓	✓	✓	✓	✓
Suitable rooms are available in the Admission Unit/Ultrasound Department to facilitate discussion and provide support to the mother/parents when bad news is broken. *Rådestad et al. (2014); SANDS (2007); Alkazeleh et al. (2004).*	✓	✓	✓	✓	✓	✓
If the mother is unaccompanied, staff always offer to contact her partner, a relative or a friend. Staff will strive to ensure that she does not leave the hospital alone. *RCPI/HSE Guideline No. 4 (2011); SANDS (2007); Alkazeleh et al. (2004); Forest (1989).*	✓	✓	✓	✓	✓	✓
Following the diagnosis of an ectopic pregnancy or first trimester miscarriage parents are given time to reflect on the diagnosis and discuss the woman's treatment options. *RCPI/HSE Clinical Guideline No. 29 (2014); Henley & Schott (2008).*	✓	✓	✗	✗	✗	✗
Special consideration is given to the bereavement needs of families where there is a death in utero of a baby in a multiple pregnancy, e.g. staff acknowledge the complexity of the family's bereavement. *Richards et al. (2015).*	✓	✓	✓	✓	✓	✗
Parents are offered timely bereavement support following the diagnosis of an anomaly that is life-limiting or may be fatal. Aspects of this support, information provided or consultations with parents may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act, 1995. *McNamara et al. (2013); Kobler & Limbo (2011); SANDS (2007); Lalor et al. (2007).*	✗	✗	✗	✓	✗	✓
Parents are offered access to the BST for support and guidance in relaying the loss to siblings. Involvement of the siblings is considered in accordance with the parents' wishes. *Machajewski & Kronk (2013); Avelin et al. (2012); Torbic (2011); Riley (2003).*	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
In the event that parents choose to terminate their pregnancy, they are provided with up to date information and contact details of the services available. Information provided or specific consultations with parents must be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act, 1995. Information on accessing bereavement care is provided to all women registered at a maternity hospital. *Protection of Life During Pregnancy Act 2013; Implementation of the Protection of Life During Pregnancy Act (2013).* *Regulation of Information (services outside the state for termination of pregnancies) Act, 1995.* *Irish Medical Council (7th ed., 2009) Guide to Professional Conduct and Ethics for Registered Medical Practitioner.* *Nursing and Midwifery Board of Ireland (2015). The Code of Professional Conduct for each Nurse and Midwife.* *Coleman (2015); McCoyd (2009); Kersting et al. (2009); Lalor et al (2007).*	✘	✘	✘	✓	✘	✘
Parents are given enough time after receiving a diagnosis of an intra-uterine death or the pre-natal diagnosis of a baby with an unanticipated life-limiting condition to reflect upon the information and to discuss their preferences, wishes and plans. Any fears the mother may be experiencing are addressed in a timely and sensitive way. Parents are encouraged to articulate their concerns with staff. Consultations with parents and information provided may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act, 1995. *Gibson et al. (2011); Malm et al. (2011); Henley & Schott (2008); RCOG (2008); Munson & Leuthner (2007); Mitchell (2004).*	✘	✘	✘	✓	✓	✓
Parents who receive a diagnosis that their baby will be born with a life-limiting condition are invited to meet a Consultant Neonatologist/Paediatrician and the appropriate medical, paediatric sub-specialist or palliative care team to discuss their baby's diagnosis. Consultations with parents and information provided may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995). *Williams et al. (2008); Munson & Leuthner (2007); SANDS (2007).*	✘	✘	✘	✓	✘	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Parents who receive a diagnosis that their baby will be born with a life-limiting condition are referred to appropriate hospital and community specialist service providers. *Coleman (2015); Munson & Leuthner (2007).*	✗	✗	✗	✓	✗	✓
If the baby is likely to be admitted to a Neonatal Intensive Care Unit, and where feasible, the parents are offered an opportunity to visit the unit before the baby is born. *SANDS (2007); Fowlie & McHaffie (2004).*	✗	✗	✗	✓	✗	✓
Following a diagnosis of pregnancy loss or anticipated stillbirth or birth of a baby with a life-limiting condition that may be fatal, parents are invited to meet with a member of the BST. *Sudia-Robinson (2011); Munson & Leuthner (2007); SANDS (2007).*	✓	✓	✓	✓	✓	✓
Parents are offered two types of information – written information specific to the diagnosis (to supplement the discussions they have had with their obstetrician, paediatrician/neonatologist and midwife) and written information about the local, community and hospital specialist services available which should include the details of a named health professional and a phone number that they can contact if required. When required, information is translated. *RCPI /HSE Clinical Guideline No. 24 (2011); SANDS (2007); Catlin & Carter (2002).*	✓	✓	✓	✓	✓	✓
Parents awaiting the spontaneous onset of labour or spontaneous miscarriage are given the details of a named health professional and a phone number that they can contact if required. A system of prompt admission to a ward such as the use of a direct admission card should be provided by hospitals and recognised by all staff. *RCOG (2010); SANDS (2007); Catlin (2005).*	✓	✓	✓	✓	✓	✗

1.2 Treatment Options

Statement: All parents receive continuity of care with due consideration to minimising the stress of attending hospital and are given ample opportunities to discuss treatment options available in the hospital and provided within the framework of current legislation.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
The medical and/or surgical treatment options available to the woman are clearly outlined with a full explanation of the advantages and disadvantages of each option. The woman is supported in making informed choices about her care and allowed time with her partner to consider her options. Appropriate explanations, supplemented with written information, are given to the parents. Staff should ensure sufficient time is made available to discuss any issues or concerns the parents may have during the course of the woman's care. Consultations with parents and information provided may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995. *Ellis et al. (2016); RCPI/HSE Clinical Guideline No. 33 (2014); Malm et al. (2011); Henley & Schott (2008); Lalor et al. (2007); SANDS (2007); Fallowfield & Jenkins (2004).*	✓	✓	✓	✓	✓	✓
When parents have chosen to continue their pregnancy, and as part of palliative care approach, they will meet with a member of the Bereavement Specialist Team (BST) for anticipatory care inclusive of; • placing emphasis on baby alive in utero • discussing memory making both of the pregnancy and following delivery • sibling involvement in accordance with parents' wishes and consent • counselling and support in managing the uncertainties of loss and life expectancy • preparation for birth inclusive of documented parental wishes/birth preferences as discussed with family and Palliative Healthcare Team (PHT) *Ellis et al. (2016); Coleman (2015); van der Gest et al. (2013); Machajewski & Kronk (2013); Avelin et al. (2012); Branchett & Stretton (2012); Torbic (2011); Catlin (2005).*	✗	✗	✗	✓	✓	✓
A woman known to have a pregnancy complicated by potential loss, who attends for scanning or other out-patient procedure, should not have to wait alongside other pregnant women. Where resources do not permit such accommodation, the woman's appointment should be scheduled so as she will be the first woman seen by her sonographer, obstetrician or midwife on that day. *Mulvihill & Walsh (2013); Branchett & Stretton (2012).*	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Multidisciplinary evidence-based pathways are utilized in providing care to parents. All relevant staff are aware of and use these care pathways and care plans where appropriate. There is a system in place to ensure that throughout her care a woman has continuity of care both as an out-patient and as an in-patient. The importance of continuity of care across health and social care services is paramount and is applied within the capacity of local resources. *Ellis et al. (2016); Gibson et al. (2011); Munson & Leuthner (2007); Gold (2007); Gold et al. (2007).*	✓	✓	✓	✓	✓	✓

1.3 Preparing for Birth

Statement: In preparation for birth, parents are sensitively advised verbally and in writing of what to expect before, during and immediately after birth and are invited to meet with a member of the BST. A care pathway that takes in to consideration the cultural, religious and secular preferences of the parents is designed with the parents.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Throughout a woman's care she and her partner are offered specific information in a sensitive manner, both verbally and in written format, regarding her diagnosis and treatment. Relevant information booklets/leaflets are provided for parents. *McCoyd (2009a); Yee & Ross (2006); Leuthner & Jones (2007); SANDS (2007).*	✓	✓	✓	✓	✓	✓
The mother is offered individualised preparation for labour that is tailored to her and her partner's needs. *Koopmans et al. (2013); RCPI /HSE Clinical Guideline No. 4 (2011); SANDS (2007); Sälfund & Wredling (2006); Catlin (2005).*	✓	✓	✓	✓	✓	✓
Staff ascertain parental preferences for care during delivery and, based on these preferences, parents are supported in drawing up a care pathway for their baby. *Kobler & Limbo (2011); Siddiqui & Kean (2009); Munson & Leuthner (2007); SANDS (2007).*	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Parents are often ill-prepared for the appearance of their baby, especially where death occurred several days before delivery. Staff, gently and sensitively, explain to the parents what their baby might look like after birth. *RCPI /HSE Clinical Guideline No. 4 (2011); Trulsson & Rådestad (2004).*	✘	✘	✓	✓	✓	✓
Following a diagnosis of a first-trimester and second-trimester miscarriage, the parents are sensitively informed that it may sometimes be difficult to determine the sex of their baby at birth. *RCPI /HSE Clinical Guideline No. 29 (2014).*	✘	✓	✓	✘	✘	✘
All health professionals are aware of the psychological sequelae associated with pregnancy loss and perinatal death. Parents are made aware of the availability of the services of the BST. *Nuzum et al. (2014b); Donovan et al. (2014); RCPI /HSE Clinical Guideline No. 4 (2011); Rowlands & Lee (2010); Badenhorst et al. (2006); Browne et al. (2005).*	✓	✓	✓	✓	✓	✓
A woman with a history of ectopic pregnancy, recurrent miscarriage, stillbirth or perinatal death who is booked into the hospital on a subsequent pregnancy is offered access to the BST. *Keegan (2013); Aoun et al. (2012); RCPI /HSE Clinical Guideline No. 4 (2011); Currier et al. (2008); Walsh et al. (2008); SANDS (2007); Catlin & Carter (2002).*	✓	✓	✓	✓	✓	✓
There is a system in place to cancel antenatal clinic appointments and all other antenatal-related appointments within one working day following the mother's diagnosis. *Branchett & Stretton (2012); Williams & Datta (2012); SANDS (2007); Kean (2006).*	✓	✓	✓	✓	✓	✘

1.4 Care Following Hospital Admission for Birth

Statement: Staff discuss with parents their options and choices for, during, and after their baby's birth and allow time for parents to reflect on their options and review their choices.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Following admission/re-admission and resources permitting, the woman is cared for in a dedicated room with an en suite toilet and shower. Each dedicated room has a double bed and/or a second single bed to facilitate the mother's partner or companion to stay overnight during her stay in hospital. *Ellis et al. (2016); Branchett & Stretton (2012); RCOG (2010); Siddiqui & Kean (2009); RCOG (2008); SANDS (2007).*	✗	✗	✓	✓	✓	✓
A woman admitted to hospital with a diagnosis of ectopic pregnancy or early miscarriage is accommodated in a Gynecological Ward or in an alternative non-obstetric ward. *RCPI /HSE Clinical Guideline No. 29 (2014); Mulvihill & Walsh (2013); Jones & Pearce (2009).*	✓	✓	✗	✗	✗	✗
A woman is advised of her choices in pain relief during treatment. Consideration is given to scheduling surgical procedures for ectopic pregnancy and miscarriage at the beginning of a surgical list. *Sagili & Divers (2007); Lozeau & Potter (2005).*	✓	✓	✓	✓	✓	✓
Parents who choose to see/hold their baby at the time of birth are facilitated in doing so in a caring environment. Those parents who choose not to do so at birth are offered other opportunities at a later interval. *Ellis et al. (2016); Kingdon et al. (2015); NICE, CG192 (2014); Williams et al. (2008); Gold (2007); Gold et al. (2007); SANDS (2007).*	✗	✗	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Guided by the parents' wishes and consent, the midwife/doctor gently enquires how they would like to meet and parent their baby, for example would they like to; • have their baby delivered into the mother's arms • cut their baby's umbilical cord • have skin to skin contact with their baby • hold, touch, sit or lie beside their baby • take photographs of their baby • have photographs taken of their baby by staff which can be held in the HCR • if available, parents are offered the option of having a professional photographer take photographs of their baby • spend time (alone) with their baby • create memories of their baby for a memory booklet or memory box • take a print of their baby's hand or foot • cut a lock of their baby's hair • keep their baby's ID bracelet and measuring tape • wash and dress their baby *Ellis et al. (2016); Kingdon et al. (2015); Branchett & Stretton (2012); Rådestad & Christeoffersen (2008); Williams et al. (2008); SANDS (2007).*	✘	✘	✓	✓	✓	✓
If parents have chosen a name, the baby is referred to by name at all times. *Henley & Schott (2008); SANDS (2007); ISANDS (2007).*	✓	✓	✓	✓	✓	✓
In the event that a baby is born with a life-limiting condition that was not diagnosed before birth, a referral is made to the appropriate hospital and community specialist service providers. *Balaguer et al. (2012); Sumner et al. (2006).*	✘	✘	✘	✘	✘	✓
Consideration is given to the needs of mothers whose babies have been transferred to another hospital. All efforts are made to safely locate the mother with her baby. A copy of the baby's HCR accompanies the baby at the time of transfer. If medically unfit to travel, frequent updates on baby's condition are communicated sensitively to the mother and based on information from the clinical team in the other hospital. In consultation and with the permission of the parents a nominated family member is facilitated to be with the baby and where possible the parents are offered photographs of their baby. *Marshall & Fanaroff (2013); Branchett & Stretton (2012).*	✘	✘	✘	✘	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
All parents are invited to meet with a member of the BST (Bereavement Coordinator, Clinical Midwife Specialist in Bereavement, Chaplain and Medical Social Worker Specialist in Bereavement). Parents are informed of the specific support services of each discipline and will decide what is most appropriate for them. *Burden et al (2016); Queensland Maternity & Neonatal Guideline MN11.29-V3-R16 (2015); Nuzum et al. (2014); RCPI/HSE Clinical Guideline No. 4 (2011); D'Almeida et al. (2006).*	✓	✓	✓	✓	✓	✓
All parents are offered both verbal and written information in relation to funeral options and arrangements and are supported in organising a service, burial or cremation for their baby. Funeral costs in relation to hospital and private burials are made clear. In accordance with their wishes parents are supported in the planning of their baby's funeral. It may be suggested and if parents wish they may; • lift their baby into the coffin • accompany their baby to the mortuary • write a goodbye note or place a toy, keepsake or drawing in the coffin if they so wish • do whatever is culturally appropriate for the family *Woodroffe (2013); Gibson et al. (2011); RCPI /HSE Clinical Guideline No. 4 (2011); Brown (2009); SANDS (2007); ISANDS (2007).*	✗	✗	✓	✓	✓	✓
Parents are offered mementoes from their time with their baby, such as a Certificate of Blessing or Certificate of Naming. *Roose & Blanford (2011); SANDS (2007); ISANDS (2007); Capitulo (2005); Busch & Kimble (2001).*	✗	✗	✓	✓	✓	✓
A symbol that is recognised by all staff is visible on the ward/department. The symbol used in each maternity hospital is referred to as an end-of-life care symbol and is used to denote anticipatory loss as well as to denote that a bereavement has occurred. On seeing the symbol, staff should create an atmosphere of quiet and be prepared to meet people who are grieving. *Ellis et al. (2016); RCPI /HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); SANDS (2007).*	✓	✓	✓	✗	✓	✓
If a baby (fetus) is identified following an early miscarriage, the parents are offered the opportunity to see their baby. *Mansell (2006).*	✗	✓	✗	✗	✗	✗

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
If a baby (fetus) is not identified following an ectopic pregnancy or early miscarriage; • this is clearly explained to the parents and recorded in the woman's HCR • the possibility of finding a fetus or fetal tissue in the histology specimens is discussed with the parents before discharge from hospital • there are clear procedures in place to inform parents if fetal tissue is found in histology specimens. Parents are provided with the opportunity to collect and bury the fetal tissue if they so wish. If parents do not wish to collect fetal tissue, and with their consent, it will be sensitively and ethically buried/cremated by the hospital in accordance with local practice and recorded in the mother's HCR. *HSE Standards and Recommended Practices for Post Mortem Examination Services (2012); Limbo et al. (2010); Mansell (2006).*	✓	✓	✗	✗	✗	✗
Policies and guidelines are in place in relation to the retention of organs and/or tissue samples for histological examination. All relevant staff are aware of and use the guidelines where appropriate. Discussions are held with the parents as to the interment of the temporarily retained organs at a time distant from the baby's funeral. Discussions with the parents are undertaken in a sensitive manner regarding their wishes for burial of organs/fetal tissue. The parent's wishes are documented in the mother's HCR. *RCPI /HSE Clinical Guideline No. 29 (2014); HSE Standards and Recommended Practices for Post Mortem Examination Services (2012); SANDS (2007); ISANDS (2007); Mansell (2006).*	✓	✓	✓	✓	✓	✓
Staff offer parents the option of taking their baby home before burial/cremation takes place. Parental choice is respected in how parents wish to take their baby home (e.g. in an infant carrier, coffin or in their arms). The midwife/nurse ensures that the baby is sensitively escorted from the ward and hospital in a dignified manner. *Limbo et al. (2010); Covington (2009); Kobler et al. (2007).*	✓	✓	✓	✓	✓	✓
All hospitals should have a Book of Remembrance available to parents and all parents should be invited to have the baby included in the Book of Remembrance if that is their wish. *Walsh et al. (2008); Platt (2004).*	✓	✓	✓	✓	✓	✓

1.5 Post Natal Care

Statement: In addition to bereavement care, a woman's physical and social care is offered in accordance with her needs.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
While emphasis is placed throughout these Standards on bereavement care to ensure the emotional and psychological recovery of the bereaved mother, it is important that her physical care, particularly lactation issues and her mental health are provided as for a non-bereaved post-natal woman. *McGuinness et al. (2014); RCPI /HSE Clinical Guideline No. 4 (2011); ISANDS (2007).*	✓	✓	✓	✓	✓	✓
Lactation can be a distressing as well as painful experience for a bereaved woman. It is the responsibility of midwives caring for a bereaved post-natal woman to inform her that lactation may be initiated spontaneously after delivery. Midwives instruct and provide literature on options for managing and suppressing lactation. *McGuinness et al. (2014); Gale & Brooks (2006).*	✗	✗	✓	✓	✓	✓
Management of expressed breast milk stores is sensitively discussed with the parents at an appropriate time. *Welborn (2012).*	✗	✗	✗	✗	✓	✓
In the event that a pregnancy has been terminated, post-natal clinical care is made available. *Kersting & Wagner (2012); Lalor et al. (2009); Kersting et al. (2009).*	✗	✗	✗	✓	✓	✗

1.6 Preparing for Discharge from Hospital

Statement: Parents are advised on community and hospital health resources; on birth and death registration processes and are provided with appointments for follow-up care. They are also informed about the hospital's annual non-denominational Remembrance Service.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
All staff are aware of the requirement for rapid communication with the woman's GP and appropriate community teams after discharge. A phone call to the relevant professional(s) is made on the day of the woman's discharge and followed up with written communication by post, fax or email within 1-2 working days. *Queensland Maternity & Neonatal Guideline MN11.29-V3-R16. (2015); Kripalani et al. (2007); SANDS (2007); ISANDS (2007); Gold (2007); Hummel & Cronin (2004).*	✓ Letter/Fax	✓ Letter/Fax	✓ Phone & Letter/Fax	✓ Phone & Letter/Fax	✓ Phone & Letter/Fax	✓ Phone & Letter/Fax
The discharge letter should include; • the diagnosis • follow-up plan • services offered • information about the condition • the hospital plans for follow up • a list of the support services that have been offered to the woman and how to contact them *Jones et al. (2007); Kripalani et al. (2007); SANDS (2007); Mansell (2006).*	✓	✓	✓	✓	✓	✓
If a baby is diagnosed as having a life-limiting condition or diagnosed in utero with a life-limiting condition, the mother's GP is informed by phone on the day of diagnosis or the next working day. The phone call is followed up by a more detailed letter with information about the follow-up care plan including a list of supports available within the hospital and how the woman can contact these supports should she wish. *Branchett & Stretton (2012); Kripalani et al. (2007); SANDS (2007); Jones et al. (2007).*	✗	✗	✗	✓	✗	✓
A woman who has experienced a loss is encouraged to attend her GP for review following discharge. If appropriate, a follow up out-patient appointment with a member of the BST is arranged. Prior to being discharged from a tertiary hospital, and if it is the wish of the family, a follow up appointment will be arranged for the family with the specialist bereavement service in the family's own local area hospital. *Branchett & Stretton (2012); RCPI/HSE Clinical Guideline No. 4 (2011); Limbo & Kobler (2010); Jones et al. (2007); SANDS (2007); ISANDS (2007).*	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
If early discharge is requested by the mother her GP, and when appropriate her Public Health Nurse, is notified on the day of the early discharge. All other members of the Community Health Care Team involved in on-going care of the mother are also contacted if necessary. *Donovan et al. (2014); Rowlands & Lee (2010); Kripalani et al. (2007); SANDS (2007).*	✓	✓	✓	✓	✓	✓
Parents are provided with verbal and written information about the birth and death registration as well as stillbirth registration. *Civil Registration (Certified Extract of Register of Deaths) Regulations (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); Stillbirths Registration Act (1994).*	✗	✗	✗	✓	✓	✓
Hospitals must schedule annual non-denominational Remembrance Services that are sensitive to the needs of parents of different religious faiths and none. All parents are welcome to attend. *Walsh et al. (2008); Platt (2004).*	✓	✓	✓	✓	✓	✓
Prior to discharge from hospital, the woman is reviewed by a senior obstetrician, registrar or consultant. She is provided with verbal and written information in relation to her post-natal care. *McGuinness et al. (2014); RCPI/HSE Clinical Guideline No. 4 (2011); SANDS (2007).*	✓	✓	✓	✓	✓	✓
Parents are provided with written details, as appropriate, of national and local sources of support and organisations and guided to relevant web sites. *Donovan et al. (2014); Rowlands & Lee (2010); SANDS (2007); ISANDS (2007).*	✓	✓	✓	✓	✓	✓
A follow-up medical appointment with a woman's obstetrician is recommended for all women who have experienced an ectopic pregnancy, second trimester miscarriage, termination of pregnancy, stillbirth or neonatal death. *RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Gold (2007); SANDS (2007).*	✓	✗	✓	✓	✓	✓
Healthcare professionals providing care for a woman with a history of recurrent miscarriage, ectopic pregnancy or who experienced complications during treatment will ensure that an appropriate follow-up appointment is arranged with a Consultant Obstetrician at a pregnancy loss clinic or gynaecological clinic. *RCPI/HSE Clinical Guideline No. 4 (2014); Stratton & Lloyd (2008); SANDS (2007); ISANDS (2007); Laing (2004).*	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
When a hospital post mortem has been carried out the parents are informed that they will receive an appointment, at approximately 3 months following discharge from hospital, to meet with their Consultant Obstetrician, Neonatologist/Paediatrician and CMS who the family has built a relationship with to discuss the findings of the post mortem. All available results are collated and are to hand before the appointment. *SANDS (2007); ISANDS (2007); Laing (2004).*	✗	✗	✓	✓	✓	✓
Parents are advised that results from the Coroner's post mortem will take an unpredictable length of time. The baby's death cannot be registered until these results are available from the Coroner. *RCPI/HSE Clinical Guideline No. 4 (2011); Coroners Post Mortems* http://www.coroners.ie/en/CS/Pages/Coroners%20Post%20Mortems Birth, Deaths and Marriages Registration Act, 1972 http://www.irishstatutebook.ie/1972/en/act/pub/0025/index.html Stillbirth Registration Act, 1994 http://www.irishstatutebook.ie/1994/en/act/pub/0001/print.html	✗	✗	✓	✓	✓	✓
Community-based medical, nursing and allied professionals e.g. Mental Health Care Team (MHCT) and social workers who are engaged in a woman's on-going medical or social care are, in certain circumstances, informed about the bereavement at the time of discharge. *RCPI /HSE Clinical Guideline No. 29 (2014); Donovan et al. (2014); Rowlands & Lee (2010); Kripalani et al. (2007); SANDS (2007); ISANDS (2007).*	✓	✓	✓	✓	✓	✓
Parents are offered information and support following their baby's death and following discharge from hospital that responds to their individual bereavement needs. BST staff are sensitive to the social, religious and cultural values of individual parents. *Donovan et al. (2014); RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Brier (2008); SANDS (2007); ISANDS (2007); Hutti (2005).*	✓	✓	✓	✓	✓	✓

1.7 Bereavement Care after Discharge

Statement: Parents are informed of the availability of hospital and community bereavement supports appropriate to their social, religious and cultural values.

	Ectopic Pregnancy	First-trimester Miscarriage	Second-trimester Miscarriage	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
A parent returning to the hospital for a follow-up consultation with an obstetrician, paediatrician and/or neonatologist, bereavement specialist, chaplain or other staff member will be reviewed, where feasible, in a suitable room separate from mothers and babies and conducive to discussion and counselling. *Flenady & Wilson (2008); SANDS (2007).*	✓	✓	✓	✓	✓	✓
Where possible and at parents' request, an opportunity is afforded to parents to meet the staff who cared for them and their baby when the baby died. *Branchett & Stretton (2012); SANDS (2007).*	✗	✗	✗	✓	✓	✓
Parents should be consulted regarding how they would like to receive sensitive documentation or personal belongings following their discharge from the maternity hospital. *SANDS (2007).*	✓	✓	✓	✓	✓	✓

Standard 2: The Hospital

The hospital has systems in place to ensure that bereavement care and end-of-life care for babies is central to the mission of the hospital and is organised around the needs of babies and their families.

2.1 A Culture of Compassionate Bereavement Care

Statement: The Hospital Service Plan includes bereavement care as a core component.

Criterion	Source
There is a clear and transparent hospital ethos of bereavement care in place.	*Donovan et al. (2014); SANDS (2007); ISANDS (2007); Catlin & Carter (2002).*
The hospital acknowledges and promotes that all staff play a valuable role in ensuring a culture of compassion. Recruitment and retention of appropriately trained staff in relevant roles within the specialist bereavement team is prioritised. This is formally acknowledged by senior hospital management as a core value of the hospital and is reflected in the decision and actions of the hospital.	*SANDS (2007); ISANDS (2007); Fauri (2000).*
A designated member of the Hospital Group Management Team is allocated responsibility for bereavement care quality improvement across the hospital group.	*SANDS Audit tool (2011); RCOG (2008).*
A named member of the hospital management team e.g. Director of Midwifery, Hospital Manager or Lead Clinician is allocated responsibility and is accountable for developing the structures and processes necessary to implement the bereavement components of the Hospital Service Plan.	*IHF Quality Standards (2010); SANDS Audit tool (2011).*
The hospital has a committee with multi-disciplinary representation, including midwifery staff, that is responsible for overseeing quality improvements in bereavement care and end-of-life care. This committee reports directly to the senior management team in the hospital/hospital group.	*Donovan et al. (2014); SANDS Audit tool (2011); IHF Quality Standards (2010); WHO (2006); Johnston et al. (2000).*
Each maternity unit should have a bereavement specialist team in place.	*IHF (2014).*

2.2 General Governance Policies, Guidelines and Care Pathways

Statement: Governance policies and guidelines for bereavement care and/or care pathways are in place in the hospital to ensure best practice and that care is provided within the framework of current legislation and professional codes of practice.

Criterion	Source
All staff who provide bereavement and end-of-life care do so in accordance with the mission, vision and values of the hospital.	*IHF Quality Standards (2010); SANDS (2007); Fauri (2000).*
Policy, standards and guidelines on bereavement care in the hospital are available to all hospital staff. The National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death should be easily available and widely disseminated to all grades and disciplines to ensure awareness and appropriate use.	*Catlin & Carter (2002); SANDS Audit tool (2011).*
In accordance with their roles, all staff are educated to use and implement these Standards for Bereavement Care following Pregnancy Loss and Perinatal Death.	*Blood & Cacciatore (2014); Walsh et al. (2013); Weissman & Meier (2008).*
There is a system in place for reviewing and updating all policies, guidelines and care pathways relating to bereavement care. Individual hospital policy incorporates relevant national policy and direction from external agencies. The member of the hospital management team allocated responsibility and accountability for developing the structures and processes necessary to implement the bereavement components of the Hospital Service Plan is also responsible for updating and reviewing the guidelines. Hospitals promote cross-agency communication.	*IHF (2014); Gold et al. (2007); SANDS (2007); Browne et al. (2005).*
Consideration is given to the provision of free or reduced-fee car parking for partners while a bereaved mother is admitted in the hospital.	*SANDS (2007); Browning & Solomon (2005); Catlin & Carter (2002).*

2.3 Effective Communication with Parents

Statement: There is timely, clear and sensitive communication with the baby's parents and their families on all matters relating to dying, death and bereavement care.

Criterion	Source
Hospital staff work to the principle that good communication is fundamental to providing good patient care and is essential when communicating bad news.	*Ellis et al. (2016); HSE Open Disclosure (2013); Harrison & Walling (2010); Rowlands & Lee (2010); Meyer et al. (2009); Lalor et al. (2007); ISANDS: Guidelines for Professionals (2007).*
All communication between hospital staff, parents and family members is governed by the expressed wishes of the parents.	*Koopmans et al. (2013); IHF Quality Standards (2010); Sälfund & Wredling (2006); Gold (2007).*
The hospital communications guideline is formulated according to evidence-based protocols for communicating prognostic information to parents of babies and is revised regularly to take account of parents' experiences.	*Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Rowlands and Lee (2010).*
The hospital communications policy includes bereavement and end-of-life care and includes the importance of communication between departments, hospital and community/GP in relation to bereavement.	*Donovan et al. (2014); Rowlands & Lee (2010); Jones et al. (2007); Kripalani et al. (2007); Säflund et al. (2004).*
Expressed care preferences are clearly recorded in the HCR.	*IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Hammes et al. (2005).*
There is an acknowledgement across the hospital that staff other than clinicians and midwives/nurses may have an important role to play in ensuring effective communication with parents and their families in respect of bereavement care.	*IHF Quality Standards (2010); Rowlands and Lee (2010); SANDS (2007); Fauri (2000).*
Where the hospital uses a bereavement symbol, this symbol along with its explanation, is displayed in a public area to inform staff, parents and visitors to the hospital of its significance.	*IHF Quality Standards (2010); Williams et al. (2008).*

2.4 The Healthcare Record (HCR)

Statement: The HCR supports and enhances governance and communication in respect of bereavement care.

Criterion	Source
In cases where a woman does not have hand-held notes, her current HCR is retrievable by all departments on a 24/7 basis. Historical HCRs may be stored off-site and may not be available for 24 hours.	*IHF Quality Standards (2010).*
The HCR provides an accurate chronology of events and records all significant consultations, assessments, observations, discussions, parent's preferences, decisions, interventions and outcomes.	*IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*
A copy of a woman's HCR travels with her at the time of transfer for treatment to another hospital.	*Irish Medical Council (2009).*
If available, staff must consult a woman's current HCR and become familiar with the woman's condition and medical history before seeing her.	*Irish Medical Council (2009).*
Members of the multidisciplinary team consult each other's notes within the HCR on a regular and systematic basis.	*IHF Quality Standards (2010).*

2.5 The Hospital Environment

Statement: The physical environment where end-of-life care and bereavement care is provided supports high quality care and facilitates privacy and dignity.

Criterion	Source
Where applicable the Irish Hospice Foundation/HSE Design and Dignity guidelines are followed for all capital projects, with specific adaptations relative to maternity settings including delivery rooms, waiting areas and movement through the hospital. The hospital service plan identifies and prioritises funding to improve areas of the hospital used for bereavement care.	*IHF (2014); Siddiqui & Kean (2009); Branchett & Stretton (2012); Brown & Taquino (2001).* www.designanddignity.ie
The hospital facilitates access to rooms and spaces where breaking bad news, end-of-life care and bereavement care can take place in a quiet, comfortable environment where privacy is ensured.	*Parker et al. (2014); IHF (2014); Gibson et al. (2011); SANDS (2007); ISANDS (2007).* *http://hospicefoundation.ie/education-training/staffdevelopment/dealing-with-bad-news/*
The hospital facilitates parents with overnight rest and refreshment facilities.	*Parker et al. (2014); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*

2.6 Monitoring and Evaluating Bereavement Care

Statement: Bereavement care in the hospital is continuously evaluated.

Criterion	Source
The hospital collects data on an ongoing basis that reflects the quality of provision of bereavement care. This information is recorded, reported and interpreted in order to direct changes where required.	*SANDS Audit tool (2011); Irish Medical Council (2009).*
Structures are put in place to encourage, collect and collate parents' feedback. This information is reported to the hospital's bereavement committee.	*Palliative Care Competence Framework (2014); SANDS Audit tool (2011).*
Complaints about bereavement care are recorded and are dealt with fully in a timely manner by the Hospital Risk Manager and in line with the Open Disclosure Policy.	*IHF (2014); Health Act 2004; HSE (2013) http://www.hse.ie/opendisclosure/*
Stillbirths, neonatal deaths and in some instances second trimester miscarriages, are discussed and reviewed at monthly perinatal mortality meetings. Input from a perinatal pathologist is central to the functioning of these meetings.	*RCPI/HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); SANDS Audit tool (2011); ISANDS (2007); Drife (2006).*
There is regular review of the bereavement care provided by the hospital.	*IHF (2014); Irish Medical Council, (2009); SANDS (2007).*

2.7 Assessing and Responding to Baby's End-of-Life Care Needs

Statement: All babies who require end-of-life care are identified and provision for their individual care is made accordingly.

Criterion	Source
End-of-life care for each baby is guided by the Lead Paediatric Clinician, Lead Neonatologist and Multidisciplinary Team, and the principle of anticipatory bereavement care is put in place and included as part of an individual care pathway.	*Coleman (2015); van der Gest et al. (2013); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Browning & Solomon (2006); Kehl (2005).*
Policy and guidelines are available for communicating with parents of babies requiring end-of-life care.	*Palliative Care Competence Framework (2014); IHF Quality Standards (2010).*
There are effective mechanisms in place to identify babies who may require end-of-life care. The needs of the baby who require end-of-life care are identified, assessed and documented and care pathways are developed accordingly. Early referral is made to the local specialist palliative care team and local Outreach Nurse for Children with a Life-limiting Condition.	*Branchett & Stretton (2012); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Catlin & Carter (2002).*

2.8 Clinical Responsibility and Multidisciplinary Working

Statement: All babies who require end-of-life care are supported by a named Lead Clinician working in consultation/partnership with the Multidisciplinary Team.

Criterion	Source
At birth the Paediatrician/Neonatologist responsible for the baby's care is identified, documented and communicated to the parents.	*Lisle-Porter et al (2009); Munson & Leuthnen (2007); Mack & Wolf (2006).*
Where care is being transferred within the hospital to another consultant, the consultant assuming care should be identified to the parents and clearly documented in the HCR. Similarly, when a baby moves to a different clinical environment within the hospital and the responsible Lead Clinician changes for a period, this change should be clearly communicated to parents and to staff.	*Branchett & Stretton (2012); Yee & Ross (2006).*
The clinical diagnosis that a baby's circumstances may require end-of-life care is communicated to the parents by the Paediatric Team. Verbal information may be supplemented with written information about what to expect and what supports are available. Consideration should be given to language and literacy difficulties.	*Armentrout & Cates (2011); Gale & Brooks (2006); Catlin (2005).*
Policy and guidelines should be in place for communication between disciplines, teams and service providers whether hospital based or community based in order to facilitate a planned approach to the baby's care and discharge/transfer out of hospital.	*Palliative Care Competence Framework (2014); Donovan et al. (2014); Branchett & Stretton (2012); Rowlands & Lee (2010); Kripalani et al. (2007); Säflund et al. (2004).*
The Neonatal Team responsible for discharge planning ensures that there is clear allocation and documentation of responsibility within and between clinical teams involved in the care of the parents and baby, particularly regarding discharge/transfer out of the hospital. The Neonatal Team is also responsible for equipping parents with the skills to care for their baby.	*Griffin & Abraham (2006).*
The Neonatal Team responsible for discharge planning communicates directly with the family's GP and PHN when a baby dies. Messages communicating the death of a baby should not be limited to messages being left on an answering machine but there should be follow-up verbal and written communication with the GP and the PHN in due course.	*Branchett & Stretton (2012); Henley & Shott (2008); Kriplanai et al. (2007); Jones et al. (2007).*
The Neonatal Nurse Discharge Planner or the Neonatal Nurse caring for the baby at her/his time of death is responsible for notifying the baby's death to the CMS in Bereavement, Chaplain, Medical Social Worker, National Centre for Inherited Metabolic Disorders, the Hospital's Accounts Department, the hospital from which the baby was referred, and the Neonatal Out-Patient Appointments System.	*Palliative Care Competence Framework (2014); Branchett & Stretton (2012); IHF Quality Standards (2010).*

2.9 Pain and Symptom Management

Statement: Effective pain and symptom management is provided as a key component of end-of-life care and staff education in the hospital.

Criterion	Source
A baby is referred to Palliative Care Services in a timely manner as soon as his/her needs and symptoms and other care factors indicate a need for such expertise.	*van der Geest (2014); Munson & Leuthner (2007); Gale & Brooks (2006); Sumner et al. (2006).*
There is a written hospital/departmental ethos regarding pain and symptom management that is evident through attitude, action and documentation.	*Caitlin & Carter (2002); Kean (2006).*
When assessing the extent of pain being experienced by a baby staff should employ the N-PASS or other pain assessment tool but must also take physiological symptoms into account.	*Spence et al. (2005); Duhn & Medves (2004).*

2.10 Clinical Ethics Support

Statement: Hospital management ensures that each staff member has access to clinical ethics support as appropriate to his/her role.

Criterion	Source
Hospital management promotes a climate within the organisation that promotes open discussion and provides a forum in which all employees feel comfortable raising and discussing ethical concerns.	*IHF Quality Standards (2010); SANDS (2007); Corley et al. (2005).*
The hospital actively promotes a climate where ethical concerns are routinely raised. Transparent processes and mechanisms for supporting ethical decision making are in place and may be used to resolve disagreements about the interpretation of policies or to address potentially difficult or contentious ethical issues that may arise in relation to bereavement care.	*Palliative Care Competence Framework (2014); SANDS (2007); Corley et al. (2005).*
Hospital staff consult with the parents to ensure that their wishes for their baby are respected.	*IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*

2.11 Care after Death

Statement: Policies and guidelines for care after death are respectful of the parents' wishes and beliefs.

Criterion	Source
Policy and guidelines are in place for care of the deceased baby. All relevant staff use, and are trained in the use of, these.	*RCPI/HSE Guideline No. 4 (2011); ISANDS (2007); Catlin & Carter (2002); Hughes et al. (2002).*
A recognisable symbol or alert system that is recognised by all staff and by the public as indicating that a death has occurred should be clearly visible in the ward/department.	*RCPI/HSE Guideline No. 4 (2011); IHF Quality Standards (2010); Gold (2007); SANDS (2007).*
Hospitals should also give consideration to the use of a symbol for the HCR and appointment cards to alert staff of previous bereavement e.g. on return to OPD.	*SANDS (2007).*
The hospital has clear written procedures for the examination of baby/fetus by senior Neonatologist/Paediatrician following delivery. This examination includes the option of a skeletal survey regardless of whether post mortem examination is being done or not.	*RCPI/HSE Clinical Guideline No. 4 (2011).*
The hospital has clear and written procedures for the formal notification of death to the authorities. Parents are advised that notification is delayed when hospital or Coroner's post mortems have taken place.	*SANDS (2007); RCPI (2011); Catlin & Carter (2002).*

2.12 Post Mortem Examinations

Statement: The hospital manages all aspects of post mortem examination in a transparent, timely and sensitive manner and in accordance with the HSE Standards and Recommended Practices for Post Mortem Examination Services (2012).

Criterion	Source
Parents are offered hospital/consented post mortems as appropriate. Where a death is reportable, the Coroner is notified and a post mortem is carried out with his/her authorisation where he/she deems appropriate.	*HSE (2012); RCPI/HSE Guideline No. 4 (2011).*
All staff are aware that post mortem policy is guided by statutory legislation and the *HSE Standards and Recommended Practices for Post Mortem Examination Services* and are familiar with how to access specific detailed information/expertise. The hospital policy is available in clinical areas and staff know how to access it.	*HSE (2012); Coroners Acts (1962 & 2005).*
Clarity in relation to Coroner's post mortem examination is achieved prior to discussing post mortem examinations with parents.	*HSE (2012); RCPI/HSE Guideline No. 4 (2011); Coroners Acts (1962 & 2005).*
In the event that a Coroner's post mortem is required the parents are informed of the reason for this requirement and the process is clearly explained. Parents' written consent is not required for a post mortem instigated by a Coroner. The post mortem process is explained to the parents and written information is always provided.	*Ellis et al. (2016); HSE (2012); RCPI/HSE Guideline No. 4 (2011); SANDS (2007); ISANDS (2007); Laing (2004).*
All maternity units should have access to perinatal pathology services. A time frame for the availability of a Pathologist to perform post mortem examination and a time frame for the availability of a standardised report should be established and explained to the parents.	*RCPI/HSE Guideline No. 4 (2011).*
As post mortem facilities are not available in all hospitals, transfer of the deceased may be required. Parents are sensitively informed of the necessity for transfer and kept informed of proceedings.	
A senior member of staff, neonatologist, pathologist or obstetrician known to the parents seeks informed consent for the non Coroner post mortem examination. At the time of consent parents are informed about the possibility of organs being temporarily retained for further examination and their wishes for the internment of these organs at a time distant from the funeral is sought and documented.	*Ellis et al. (2016); Breeze et al. (2012); RCPI/HSE Guideline No. 4 (2011); Irish Medical Council (2009); SANDS (2007); ISANDS (2007); Rankin et al. (2002); RCPI/Faculty of Pathology (2000).*

Criterion	Source
The loss being experienced by the parents is recognised and acknowledged. Staff are sensitive to avoiding the potential for further distress when communicating information about the post mortem examination.	*RCPI /HSE Clinical Guideline No. 29 (2014); Breeze et al. (2012); RCPI/HSE Guideline No. 4 (2011); SANDS (2007); ISANDS (2007).*
Staff are educated to understand what a post mortem entails and are able to answer parents' questions.	*Heazell et al. (2012); SANDS (2007); ISANDS (2007); Rankin et al. (2002).*
Families are provided with verbal and written information regarding hospital post mortem examination and Coroner post mortem examination.	*RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Guideline No. 4 (2011); SANDS (2007); ISANDS (2007); Rankin et al. (2002).*
In accordance with their religious or spiritual tradition and wishes, all parents are offered the option of a ceremony or prayer service by the chaplaincy team or their own spiritual advisor prior to leaving the hospital for burial or cremation. Staff accept that for some parents it is important to hold the funeral within 24 hours of death.	*Burden et al. (2016); IHF Quality Standards (2010); Chichester (2007); Gordijn et al. (2007); SANDS (2007); ISANDS (2007) ; Chichester (2007).*
The hospital has policies and guidelines for post mortem examinations which address; • requesting informed consent for in-house or non-Coroner's post mortem examination • the role of the Coroner • hospital post mortem examination • Coroner's post mortem examination	*IHF Quality Standards (2010); Putman (2007); SANDS (2007); ISANDS (2007).*
A senior clinician is available to speak with bereaved parents where a Coroner's post mortem examination is to be carried out.	*HSE (2012); IHF Quality Standards (2010); Coroners Acts 1962 and 2005; Laing (2004).*
Meetings between parents and bereavement specialist staff may continue while awaiting the results of the hospital or Coroner's post mortem.	*SANDS (2007); ISANDS (2007); Laing (2004).*

2.13 Bereavement Care

Statement: The hospital provides assistance and support to parents in dealing with the death of their baby during the period approaching and following the death.

Criterion	Source
Bereavement care is resourced and managed in a multidisciplinary manner to ensure that all needs can be responded to effectively.	*IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Hutti (2005).*
Parents' questions about their baby's condition are answered fully and promptly by a senior staff member from the appropriate discipline. This support continues following discharge with appropriate onward referral as clinically indicated e.g. to a Geneticist.	*Branchett & Stretton (2012); Henley & Schott (2008); SANDS (2007); ISANDS (2007).*
Where there is a clear indication that death may be imminent parents and family members are alerted as appropriate.	*IHF Quality Standards (2010); Henley & Schott (2008); SANDS (2007).*
Where parents have differences of opinion, these are acknowledged and addressed sensitively. Staff must be responsive to gender differences in grieving and supportive of parents ensuring they have the opportunity to express themselves.	*Meyer et al. (2009); Callister (2006).*
Parents who are experiencing a high level of distress are referred to the appropriate member of the Bereavement Specialist Team.	*Kobler & Limbo (2011); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); RCPI /HSE Clinical Guideline No. 4 (2011).*
If requested, the baby's parents can obtain further information or discuss concerns about the care and treatment of their baby with a member of the multidisciplinary team.	*RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Guideline No. 4 (2011); Hamilton et al. (2007); IHF Quality Standards (2010).*
Parents, siblings and extended family are offered timely and appropriate bereavement supports from within hospital and/or community resources. Written information leaflets should be used to supplement/reaffirm verbal information. Parents are informed of what support is available to them from the hospital and in the community before and after the birth/death of their baby and how to access this support.	*Avelin et al. (2012); Erlandsson et al. (2010); Redshaw & Hamilton (2010); Gold (2007).*
Parents are assured of confidentiality and privacy when using bereavement services.	*Roush et al. (2007); SANDS (2007).*

Criterion	Source
Staff have an understanding of the range of responses to bereavement.	*Machajewski & Kronk (2013); Kersting & Wagner (2012); Lang et al. (2011); Brier (2008); Dyer (2005).*
Parents are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion.	*Williams et al. (2008); Gold et al. (2007).*
Staff have an understanding of the types of risk factors that may result in complicated bereavement and refer parents to the appropriate services. Such factors may relate to the person (poor coping resources, mental ill-health, gender); to the circumstances of the death such as a twin in utero; termination of pregnancy or to their own particular circumstances (having other children, degree of emotional and social support available to the person). Consideration should be given to individual circumstances e.g. teen parents, psychosocial difficulties. Bereavement support should be provided in conjunction with support services already in place, e.g. Teen Parent Project, Mental Health Services.	*Kersting & Wagner (2012); Shear et al. (2011); Roehrs et al. (2008); Kristjanson et al. (2006); Friedrichs et al. (2000).*
Staff have information on and access to appropriate professional and peer support to address different types of risk factors and possible grief responses.	*McGrath (2011); IHF Quality Standards (2010); Kene et al. (2010); Roehrs et al. (2008).*
Bereavement support is offered by the hospital. It is offered with reference to professional and voluntary providers.	*RCPI/HSE Guideline No. 4 (2011); D'Agostino et al. (2008); Gold et al. (2007).*
Access to bereavement services is guided by the families' bereavement needs.	*IHF Quality Standards (2010); SANDS (2007); ISANDS (2007) ; Hutti (2005); Friedrichs et al. (2000).*
The Bereavement Support Team organise hospital-funded events that facilitate the grieving process such as Remembrance Services and Public Talks.	*Koopmans et al. (2013); Cacciatore (2007); Kavanaugh & Moro (2006).*

Standard 3: The Baby and Parents

Each baby/family receives high quality palliative and end-of-life care that is appropriate to his/her needs and to the wishes of his/her parents.

3.1 Communicating a Diagnosis of a Need for End-of-Life Care

Statement: There is timely, clear and sensitive communication with parents in respect of a diagnosis that their baby's circumstances may require end-of-life care.

Criterion	Source
The hospital has a policy and related guidelines to assist in communicating with the parents of a baby who requires end-of-life care. Staff use and are trained in accordance with their roles to use these guidelines.	*Palliative Care Competence Framework (2014); Henley & Schott (2008); IHF Quality Standards (2010); Gold (2007).*
The parents are facilitated to discuss the care of their baby with the Paediatrician/Neonatologist/Palliative Care Consultant and are involved in the decision making process of care.	*Gold et al. (2007); SANDS (2007); ISANDS (2007); Jones et al (2007).*
Staff are aware of parents' capacity for understanding and are aware of parents' specific religious, cultural and ethnic preferences.	*RCPI/HSE Guideline No. 4 (2011); Laing & Freer (2008); Chichester (2007).*
Confidentiality is always maintained in respect of any matters relating to diagnosis of a possible need for end-of-life care.	*IHF Quality Standards (2010); Catlin & Carter (2002).*
Opportunities are provided on an ongoing basis by the multidisciplinary team for the parents to clarify issues and concerns about their baby's well-being.	*Malm et al. (2011); IHF Quality Standards (2010); Munson et al (2008); Leuthner & Jones (2007).*

3.2 Clear and Accurate Information

Statement: Clear and accurate information is provided as appropriate to the baby's parents about their baby's condition, treatment options, prognosis and care pathways in a timely and culturally appropriate manner and in accordance with the parents' preferences and the baby's best interests.

Criterion	Source
As part of care, unexpected changes to the baby's condition or care plan are communicated to the parents in a timely manner.	*Lisle-Porter & Podruchny (2009); Gold (2007); Jones et al (2007).*
General information on end-of-life care and support services is provided to the parents both verbally and in written form.	*IHF Quality Standards (2010); Flenady& Wilson (2008); Moro et al. (2006); Catlin & Carter (2002).*

3.3 Parental Preferences

Statement: The parents are consulted to ensure their baby receives care in a manner and in a care setting of choice that is most appropriate for their baby

Criterion	Source
Family-centered care facilitates that the baby is placed at the center of care by supporting the parents as the primary representatives of the baby's best interest.	*Redshaw & Hamilton (2010); Lisle-Porter & Podruchny (2009); SANDS (2007); ISANDS (2007).*
The baby is cared for in a manner that protects his/her rights and best interests after discussion with the parents.	*IHF Quality Standards (2010); Redshaw & Hamilton (2010); Hammes et al. (2005).*
Decisions and choices that are important to the baby and parents are regularly assessed, optimised and reviewed by the multidisciplinary team.	*Gibson et al. (2011); Williams et al. (2008); Munson & Leuthner (2007); ISANDS (2007); Fowlie & McHaffie (2004).*
Anticipatory bereavement support is offered to all families upon diagnosis of a life-limiting condition or a fetal anomaly that may prove fatal. This includes support to parents on how to communicate the diagnosis to extended family members. Any support or information provided may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995.	*Coleman (2015); van der Gest et al. (2013); Machajewski & Kronk (2013); Avelin et al. (2012); Torbic (2011); Williams et al. (2008).*
Parents are offered age-appropriate advice in relaying the diagnosis to siblings.	*Avelin et al. (2012); O'Leary & Gaziano (2011); Erlandsson et al. (2010); SANDS (2007); ISANDS (2007); Stokes (2004); Riley (2003).*
Consent by the parents for the care of their baby is easily and clearly identifiable in the HCR.	*Woodroffe (2013); IHF Quality Standards (2010); SANDS (2007); Yee & Ross (2006).*
Should parents request a second opinion, this is facilitated in a timely manner.	*Romesberg (2007).*

3.4 Pain and Symptom Management

Statement: Pain and symptom management for each individual baby takes full account of the multifaceted nature of pain.

Criterion	Source
Comfort care measures such as skin to skin contact and non-nutritive sucking are employed with parental involvement as appropriate.	*Mancini et al. (2014); Liu et al. (2010).*
There is documentation within the HCR of regular monitoring of the baby's symptoms and the effectiveness of interventions.	*Branchett & Stretton (2012); SANDS (2007); ISANDS (2007).*

3.5 The Baby who is Dying

Statement: The particular needs of a baby whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.

Criterion	Source
Where the parents wish their baby to die at home, or in another community setting, this is facilitated as far as possible. Information on logistical and financial issues; palliative care and community services are discussed with the Medical Social Worker and Palliative Care Team and the necessary arrangements are put in place prior to discharge.	*Palliative Care Competence Framework (2014); Craig & Mancini (2013); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*
Parents are advised as a matter of urgency when death may be imminent and are facilitated to be present with their baby.	*Armentrout & Cates (2011); SANDS (2007); ISANDS (2007).*
The needs of the dying baby are assessed and prioritised to ensure that, as far as possible, the best possible level of comfort is provided and the baby's parents' wishes are respected.	*Mancini et al (2014); De Rooy et al. (2012); Hellmann (2012); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*
Staff allocation is structured so as to ensure that the nursing care and support of the baby/parents is in accordance with their needs. If the baby's parents are not present when the baby is dying, a staff member is allocated to ensure that the baby is always accompanied at this time.	*Reid et al. (2011); IHF Quality Standards (2010); Flenady & Wilson (2008).*
The dying baby is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested by his/her parents. If death is to take place in an open plan ward activity is kept to the minimum and noise levels controlled as far as possible.	*Laing & Freer (2008); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007).*

3.6 Discharge Home/Out of Hospital

Statement: The parents are actively involved in discussions and decisions regarding admission, discharge home or transfer to another setting for end-of-life care for their baby.

Criterion	Source
Prior to discharge from hospital, the parents are given opportunities to discuss their baby's care plan with the Paediatrician/Neonatologist and the Multidisciplinary Team involved in their baby's care.	*Parker et al. (2014); Kripalani et al. (2007); SANDS (2007); ISANDS (2007); Hummel & Cronin (2004); Craig & Goldman (2003).*
Parents are provided with information and advice both verbally and in writing on various aspects of caring for their baby at home.	*SANDS (2007); ISANDS (2007); Griffin & Abraham (2006); Hummel & Cronin (2004); Craig & Goldman (2003).*
Discharge home is facilitated as efficiently as possible. The hospital has a process of proactive admission and discharge planning that addresses the baby's and the parents' individual needs.	*Parker et al. (2014); ISANDS (2007); Hummel & Cronin (2004).*
The Neonatal Team communicates directly by telephone with the baby's GP, PHN, Outreach Nurse for Children with a Life-limiting Condition and Specialist Palliative Care Services to clearly outline the baby's care plan. Verbal communication is followed up on the same day with written communication.	*DOH (2009); Henley & Schoot (2008); Kriplianai et al. (2007).*
Written information provided to the GP and/or other service providers is formulated so that essential relevant information is shared. This should include: - relevant clinical information - the parents' awareness of prognosis - the parents' wishes regarding preferred place of death - any other non-clinical information that is important.	*DOH (2009); Craig & Goldman (2003); Hummel & Cronin (2004); SANDS (2007); ISANDS (2007).*
If a baby dies at home the GP should notify the baby's hospital team.	*DOH (2009).*
The Community Pharmacist is notified prior to discharge of all medication requirements and medical supplies.	*IHF Quality Standards (2010); Kripalani et al. (2007); Levine et al. (2001).*
The Medical Social Worker will expedite the processing of a Long Term Illness or Medical Card.	*http://health.gov.ie/future-health/reforming-primary-care-2/medical-cards/*

Criterion	Source
Parents are provided with names and contact details of members of the healthcare professionals involved in the ongoing care of their baby.	*SANDS (2007); ISANDS (2007); Hummel & Cronin (2004).*
The content of conversations between staff and the parents of a baby discharged home to continue end-of-life care are documented within the HCR.	*DOH (2009); Hummel & Cronin (2004); Heller & Solomon (2005).*
Parents are provided with support and advice on supporting their other children/siblings during the baby's time at home.	*Avelin et al. (2012); O'Leary & Gaziano (2011); Torbic (2011); Erlandsson et al. (2010); SANDS (2007); ISANDS (2007).*

3.7 Communication with the Parents in the Event of a Baby's Sudden/Unexpected Death or Sudden Decline in Health Leading to Death

Statement: In cases involving a sudden change in the baby's condition likely to lead to death and or in cases of sudden/unexpected death of a baby, the baby's parents are provided with prompt and clear information as appropriate.

Criterion	Source
The clinical decision that a baby may no longer be responding to treatment and may be dying is communicated clearly, sensitively and timely to the parents and documented in the HCR.	*Woodroffe (2013); Henley & Schott (2008); SANDS (2007); ISANDS (2007); Widger & Wilkins (2003).*
In the event of a redirection of care being provided, the parents are consulted and any decisions required are made jointly with them.	*Fowlie & McHaffie (2004); Roy et al. (2004).*
The hospital has guidelines on consulting parents to ascertain the parents' known wishes in respect of resuscitation and organ donation.	*Roush et al. (2007); Catlin & Carter (2002).*

Standard 4: The Staff

All hospital staff have access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care in accordance with their roles and responsibilities.

4.1 Cultivating a Culture of Compassionate Bereavement Care Among Staff

Statement: Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in bereavement care.

Criterion	Source
Each staff member ensures that he/she is familiar with and guided by the professional ethical code of conduct appropriate to his/her role.	*Rådestad et al. (2014); McQueen et al (2011); IHF Quality Standards (2010); Catlin & Carter (2002).*
The hospital ensures that there are education, training and staff programmes in bereavement care for hospital staff in accordance with the size, complexity and specialties of the hospital.	*IHF Quality Standards (2010); Fenwick et al. (2007); SANDS (2007); Browning & Solomon (2005); Engler et al. (2004).*
It is the responsibility of hospital management to outline the responsibilities of each member of the Bereavement Team and to ensure that all staff are adequately trained and educated at the point of recruitment (or within 3-4 weeks of commencing employment) and throughout their time as an employee. It is therefore the responsibility of hospital management to ensure that the education and training needs of staff are assessed, addressed and resourced to implement and sustain the Standards. Assessment should include local factors, but also ensure that contemporary developments are incorporated (e.g. competencies, findings from research).	*Ellis et al. (2016); Rådestad et al. (2014); Blood & Cacciatore, (2014); Mancini et al. (2013); Walsh et al. (2013); Branchett & Stretton (2012); Roehrs et al. (2008); Yee & Ross (2006).*
Hospital staff are competent to deliver high quality bereavement care in accordance with the HSE's Palliative Care Competence Framework (2014).	*Palliative Care Competence Framework (2014); Mancini et al. (2013); Ferguson et al. (2012); IHF Quality Standards (2010); SANDS (2007).*
Staff are educated to compassionately and sensitively communicate bad news to parents and to regularly update parents on their baby's health. This includes communicating changes in care such as the commencement of end-of-life care.	*Palliative Care Competence Framework (2014); DOH (2009); Henley & Schott (2008); SANDS (2007); ISANDS (2007).*

4.2 Staff Induction

Statement: All newly recruited staff are inducted on the general principles and components of bereavement care in the hospital. It is important that all staff are aware of the culture of compassion of the hospital. It is critical that staff involved in direct patient care, and who are more likely to be involved in bereavement care, receive a more significant induction and training programme.

Criterion	Source
The hospital's general induction programme includes a component on bereavement care.	*Donovan et al. (2014); Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Fenwick et al. (2007).*
Hospitals should ensure that the organisation and availability of Chaplaincy Services within the hospital are presented during the staff induction process. For key staff that are more likely to be involved in bereavement care, the induction process related to Chaplaincy Services should be more extensive.	*Burden et al. (2016); Rosenbaum et al. (2011); Barletta and Thomsen (2001).*
Bereavement Care Pathways form an essential part of the induction of new staff. Staff are informed and briefed on all new and revised care pathways and are easily accessible by all staff.	*Donovan et al. (2014); Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Gold (2007); Gold et al. (2007).*

4.3 Staff Education and Development Needs

Statement: The development needs of staff are assessed relative to their roles in bereavement care and underpinned by continual learning and according to emerging national consensus on competencies and standards.

Criterion	Source
A core group of hospital staff with the required expertise in bereavement care (Bereavement Team) are facilitated and supported to deliver bereavement care education and training to hospital staff (see glossary).	*Mancini et al. (2013); Ferguson et al. (2012); Branchett & Stretton (2012); SANDS (2007).*
Staff members who would benefit from specialised education in bereavement care are identified and their participation in standard and accredited education programmes on an ongoing basis is facilitated by the hospital.	*McCool et al. (2009); Lalor et al. (2007); Engler et al. (2004).*
The hospital provides and maintains resources and facilities for education, training and continuous professional development in coordination with the regional education and training services, including access to computers, libraries and the internet.	*Mancini et al. (2013); Browning & Solomon (2005); SANDS (2007); ISANDS (2007).*

4.4 Education and Training Programmes for staff

Statement: Education and training programmes for all staff have defined objectives that reflect evidence-based best practice and legislation. These programmes must be delivered at an appropriate level for all staff relevant to the position they hold within their organisation.

Criterion	Source
The design of staff education and training programmes involves stakeholders (state organisations, voluntary bodies, educational institutions and bereaved parents), with relevant experience and knowledge and includes both adult and children's bereavement care needs. The design of education and training programmes is provided at an appropriate national standard and relative to defined competencies and allows for new competencies.	*Palliative Care Competence Framework (2014); Mancini et al. (2013); Heazell et al. (2012); IHF Quality Standards (2010); SANDS (2007).*
Staff education and training programmes are mandatory and should cover the key elements of these national standards specifically addressing how to support parents' or families' preferences and values.	*Mancini et al. (2013); Mancini (2011); Flenady & Wilson (2008); Aycock & Boyle (2006).*
Competency statements are developed by heads of departments for different categories of staff in accordance with their individual roles. Performance management systems are used to measure this aspect of care within their role.	*Blood & Cacciatore (2014); Walsh et al. (2013); Catlin & Carter (2002); SANDS (2007).*
Education and development programmes relating to bereavement care are revised annually. The impact of training is evaluated regularly.	*Walsh et al. (2013); IHF Quality Standards (2010); Browning & Solomon (2005).*
Staff are knowledgeable about and practice in accordance with current legislation for termination of pregnancy. Staff are also aware of relevant aspects of their codes of professional conduct in this area.	*Protection of Life During Pregnancy Act 2013; Guide to Professional Conduct and Ethics for Registered Medical Practitioner (7th ed., 2009); Mansell (2006); The Code of Professional Conduct for each Nurse and Midwife (2000); Regulation of Information (services outside the state for termination of pregnancies) Act 1995.*

4.5: Staff Support

Statement: Staff support services relating to Bereavement Care reflect the need for peer support and professional support systems.

Criterion	Source
A formal policy on staff support for those working in maternity settings is devised and resourced. This policy defines and addresses the efficacy of a range of support options (supervision, individual debriefing, time-out, peer group support, the services of a professional counsellor).	*Larcher et al (2015); McCready & Russell (2009); Catlin & Carter (2002).*
Reliable information is provided to each staff member so that staff are also encouraged to take individual responsibility for well-being and self-care.	*Mancini et al. (2013); IHF Quality Standards (2010); Mancini (2011); Aycock & Boyle (2009).*
Hospital Management recognises the importance of providing debriefing for staff involved with trauma or sudden deaths and puts in place formal and informal systems to support staff who have been involved, directly or indirectly, in such events.	*Larcher et al (2015); Hughes & Goodall (2013); Kene et al. (2010); Aycock & Boyle (2009); McCready & Russell (2009).*
Senior Management observe for signs of stress and difficulty in staff members and recognise the importance of support for staff involved in caring for bereaved parents.	*Walsh et al. (2013); Keene et al. (2010); Catlin & Carter (2002).*
Staff are accommodated to provide informal support to each other. Regular team meetings are important for peer support.	*Nuzum et al. (2014); McNamara et al. (2013).*
Each staff member takes personal responsibility for her/his self-care and knows how to access structured debriefing services. She/he has access to the Employee Assistance Programme provided by Hospital Management.	*Mancini et al. (2013); Mancini (2011); McGrath (2011).*
Staff concerned with ethical issues should have a resource to which they can seek support for ethical decision making.	*IHF Quality Standards (2010); SANDS (2007); Corley et al. (2005).*
Issues and challenges for staff arising from the delivery of bereavement care form part of team discussions and are addressed in reviews of bereavement care.	*Hughes & Goodall (2013); Aycock & Boyle (2009); Rogers et al. (2008).*
Staff who use support services to address issues that may arise during provision of bereavement care are facilitated to provide feedback on their appropriateness and value. These can be achieved through both formal and informal evaluations.	*SANDS Audit tool (2011); Aycock & Boyle (2009); McCreight (2005).*
Private space is available to enable staff to discuss and address issues that may arise when providing bereavement care and dealing with death.	*McCreight (2005); IHF Quality Standards (2010); SANDS (2007).*

Appendix 1: National Guidelines, Policy and Legislation

- Department of Health (DOH) (2014). *National Clinical Guideline No. 5: Communication (Clinical Handover) in Maternity Services.* Available at http://health.gov.ie/national-clinical-guideline-no-5-communication-clinical-handover-in-maternity-services/
- Department of Health (DOH) (2009). *Palliative Care for Children with Life-limiting Conditions: A National Policy.* Available at (http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf)
- Health Information and Quality Authority (HIQA) (2012). *National Standards for Safer Better Health Care.* Available at www.hiqa.ie/system/files/Safer-Better-Healthcare-Standards.pdf
- Health Service Executive (HSE) (2012). *Standards and Recommended Practices for Post Mortem Examination Services.* Available at http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Standards/hseStandardsandguidance/PME_services/PM_services_docs/QPSDD0071.pdf
- Health Service Executive (HSE). *Palliative Care Competence Framework.* Available at http://lenus.ie/hse/bitstream/10147/322310/1/CompetenceFrameworkFinalVersion.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2014). *Clinical Practice Guideline 1: Ultrasound Diagnosis of Early Pregnancy Miscarriage.* Available at https://www.rcpi.ie/wp-content/uploads/2016/05/1.-Ultrasound-Diagnosis-of-Early-Pregnancy-Loss.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2011). *Clinical Practice Guideline 4: Investigation and Management of Late Fetal Intrauterine Death and Stillbirth.* Available at https://www.rcpi.ie/wp-content/uploads/2016/05/4.-Investigation-and-Management-of-Late-Fetal-Intrauterine-Death-and-Stillbirth.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2012). *Clinical Practice Guideline 10: Management of Early Pregnancy Miscarriage.* Available at https://www.rcpi.ie/wp-content/uploads/2016/05/9.-Management-of-Early-Pregnancy-Miscarriage.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2012). *Clinical Practice Guideline 14: Management of Multiple Pregnancy.* Available at https://www.rcpi.ie/wp-content/uploads/2016/05/11.-Management-of-Multiple-Pregnancy.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2014). *Clinical Practice Guideline 29: Management of Second Trimester Miscarriage.* Available at https://www.rcpi.ie/wp-content/uploads/2016/05/24.-Management-of-Second-Trimester-Miscarriage.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2014). *Clinical Practice Guideline 33: Diagnosis and Management of Ectopic Pregnancy*. Available at https://www.rcpi.ie/wp-content/uploads/2016/05/28.-Diagnosis-and-Management-of-Ectopic-Pregnancy.pdf
- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care (2006). *The Future of Maternity and Gynaecology Services in Ireland 2006-2016.* Available at https://www.rcpi.ie/news/publications/topic/obstetrics-gynaecology/

- Irish Hospice Foundation (2010). *Quality Standards for End-of-Life Care in Hospitals.* Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf
- Irish Hospice Foundation (2015). *Handy-to-have quick guides to different aspects of end-of-life care.* Available at http://hospicefoundation.ie/education-training/staffdevelopment/prompts-for-good-practice
- Irish Medical Council (7th ed., 2009) *Guide to Professional Conduct and Ethics for Registered Medical Practitioners.* Available at http://www.medicalcouncil.ie/News-and-Publications/Publications/Information-for-Doctors/Guide-to-Professional-Conduct-and-Ethics-for-Registered-Medical-Practitioners
- Nursing and Midwifery Board of Ireland (2015). *Scope of Nursing and Midwifery Practice Framework.* Available at http://www.nmbi.ie/nmbi/media/NMBI/Publications/Scope-of-Nursing-Midwifery-Practice-Framework.pdf?ext=.pdf
- Nursing and Midwifery Board of Ireland (2014). *The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives.* Available at http://www.nmbi.ie/nmbi/media/NMBI/Publications/Code-of-professional-Conduct-and-Ethics.pdf?ext=.pdf
- Nursing and Midwifery Board of Ireland (2000). *Guidance for Nurses and Midwives on the Development of Policies, Guidelines and Protocols*. Available at http://www.lenus.ie/hse/handle/10147/45056
- Social Workers Registration Board (2011). Code of Professional Conduct and Ethics for Social Workers. Available at http://coru.ie/uploads/documents/typeset_Social_Worker_Code_Feb_2010.pdf.

Legislation

- Children and Family Relationships Act (2015). Available at http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html
- Civil Registration Act (2004). Available at http://www.irishstatutebook.ie/2004/en/act/pub/0003/.
- Civil Registration (Certified Extract of Register of Deaths) Regulations (2014). Available at http://www.irishstatutebook.ie/pdf/2014/en.si.2014.0371.pdf
- Coroners Act (1962). Available at http://www.irishstatutebook.ie/1962/en/act/pub/0009/index.html
- Coroners (Amendment) Act (2005). Available at http://www.irishstatutebook.ie/2005/en/act/pub/0033/index.html
- European Convention on Human Rights Act (2003). Available at http://www.irishstatutebook.ie/2003/en/act/pub/0020/
- Health Act 2004 (Complaints) Regulation 2006 (2007). Available at http://www.irishstatutebook.ie/eli/2006/si/652/made/en/print
- Medical Practitioners Act (2007). Available at http://www.irishstatutebook.ie/pdf/2007/en.act.2007.0025.pdf
- Nurses and Midwives Act (2011). Available at http://www.irishstatutebook.ie/pdf/2011/en.act.2011.0041.pdf
- Protection of Life During Pregnancy Act (2013). Available at http://www.irishstatutebook.ie/pdf/2013/en.act.2013.0035.pdf
- Regulation of Information (services outside the state for termination of pregnancies) Act (1995). Available at http://www.irishstatutebook.ie/eli/1995/act/5/enacted/en/html
- Stillbirths Registration Act (1994). Available at http://www.irishstatutebook.ie/1994/en/act/pub/0001/print.html

Appendix 2: Project Methodology

Under the direction of the National Implementation Steering Group - HSE/HIQA Maternity Services Investigations, the Bereavement Care Sub-group was established in February 2014. The Sub-group sits within the RCPI Clinical Programme for Obstetrics and Gynaecology and the National Quality Assurance Programme of the HSE. Its membership reflects the multidisciplinary nature of bereavement care and its members are drawn from the fields of obstetrics, fetal medicine, paediatrics, perinatal psychology, ultrasonography, chaplaincy, medical social work, midwifery, neonatal nursing, palliative care and specialist bereavement care. The Sub-group's remit was to develop Standards for bereavement care following pregnancy loss and perinatal death for implementation throughout the maternity services. The two main categories of loss occurring in maternity units are the demise of a fetus/baby and the demise of a mother. The sub-group identified that the standards for bereavement care in the maternity services would be developed in two phases.

Phase 1

- conduct a literature review of the impact of ectopic pregnancy, miscarriage, a diagnosis of fetal anomaly, stillbirth and early neonatal death
- evaluate current bereavement resources and services through hospital staff questionnaires
- consult with maternity service users and voluntary support groups on their experience of bereavement care in the maternity services
- evaluate the strengths and weaknesses in current bereavement care service
- develop standards for bereavement care for parents bereaved by ectopic pregnancy, miscarriage, a diagnosis of fetal anomaly, stillbirth and early neonatal death using the framework on which the Hospice Friendly Hospital's *Quality Standards for End-of-Life Care in Hospital* are built (http://hospicefoundation.ie/wp-content/uploads/2013/04/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf)
- submit monthly reports to the Chair of the National Implementation Group – HSE/HIQA Maternity Services Investigations
- hold a national forum on early pregnancy loss (December 2014)
- complete Phase 1 of the project in June 2015

Phase 2

- distribute draft *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to statutory and voluntary stakeholders for public consultation (July 2015)
- engage with stakeholders remotely through a web based questionnaire and directly through focus groups and interviews (July-September 2015)
- consult with international experts to review the draft *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (August 2015)
- finalise the *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (January 2016)
- submit the *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to the National Implementation Group – HSE/HIQA Maternity Services Investigations and the HSE National Directorate for endorsement (January 2016)

Related Bereavement Project:

In recognition of the need for providing comprehensive and holistic bereavement care to families following a maternal death, the Bereavement Care Sub-group, in parallel with developing *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death*, is engaged in developing a *National Guideline for Bereavement Care Following Maternal Death within a Hospital Setting.* It is anticipated that the guideline will be launched in September 2016.

Appendix 3: References

Peer-reviewed Journal Articles

Aho AL, Tarkka MT, Åstedt-Kurki P, et al. (2011). Evaluating a bereavement follow-up intervention for grieving fathers and their experiences of support after the death of a child - a pilot study. *Death Studies, 35:879–904.*

Alderman L, Chisholm J, Denmark F and Salbod, S (1998). Bereavement and stress of a miscarriage: as it affects the couple. *Omega*, 37(4):317-327.

Alkazaleh F, Thomas M, Grebenyuk J, Glaude L, Savage D, Johannesen J, Caetano M and Windrim R (2004). What women want: women's preferences of caregiver behaviour when prenatal sonography findings are abnormal. *Ultrasound in Obstetrics and Gynaecology*, 3(1):56-62.

Aoun SM, Breen LJ et al. (2012). A public health approach to bereavement support services in palliative care. *Australia and New Zealand Journal of Public Health*, 36(1):14-6.

Armentrout D and Cates L (2011). Informing parents about the actual or impending death of their infant in a Newborn Intensive Care Unit. *Journal of Perinatal & Neonatal Nursing*, 25(3):1-7.

Auman MJ (2007). Bereavement support for children. *Journal of School Nursing*, 23(1):34-39.

Avelin P, Erlandsson K, Hildingsson I, Bremborg AD and Rådestad I (2012). Make the stillborn baby and the loss real for siblings: parents' advice on how the siblings of a stillborn baby can be supported. *The Journal of Perinatal Education,* 21(2):90-98.

Aycock N and Bolye D (2009). Interventions to manage compassion fatigue in oncology nursing. *Clinical Journal of Oncology Nursing,* 13(2):183-191.

Bacik I (2013). The Irish Constitution and gender politics: developments in the law on abortion. *Irish Political Studies*, 28(3):380-398.

Badenhorst W, Riches S, Turton P and Hughes P (2006). The psychological effects of stillbirth and neonatal death on fathers: systematic review. *Journal of Psychosomatic Obstetrics and Gynaecology,* 27(2):245-256.

Balaguer A, Martín-Ancel A, Ortigoza-Escobar D, Escibaro J and Argeni J (2012). The model of palliative care in the perinatal setting: a review of the literature. *Journal of BMC Paediatrics*, 12(25). Available at http://www.biomedcentral.com/1471-2431/12/25

Blood C and Cacciatore J (2014). Best practice in bereavement photography after perinatal death: qualitative analysis with 104 parents. *BMC Psychology*, 2:15. Available at http://bmcpsychology.biomedcentral.com/articles/10.1186/2050-7283-2-15.

Branchett K and Stretton J (2012). Neonatal palliative and end of life care: What parents want from professionals. *Journal of Neonatal Nursing*, 18(2):40-44.

Breeze A, Statham H, Hackett G, Jessop F and Lees C (2012). Perinatal postmortem: what is important to parents and how do they decide? *Birth*, 39(1):57–64.

Brier N (2008). Grief following miscarriage: a comprehensive review of literature. *Journal of Women's Health*, 17(3):451-464.

Brin DJ (2004). The use of rituals in grieving for a miscarriage or stillbirth. *Women and Therapy,* 27(3-4):123-132.

Broen AN, Moum T, Bödtker AS and Ekeberg Ö (2004). Psychological impact on women of miscarriage versus induced abortion: a 2-year follow-up study. *Psychosomatic Medicine*, 66(2):265-271.

Browning D and Solomon M (2005). The initiative for paediatric palliative care: an interdisciplinary educational approach for healthcare professionals. *Paediatric Nursing*, 20(5):326-334.

Burden C, Bradley S, Storey C, Ellis A, Heazell A, Downe S, Cacciatore J and Siassakos D (2016). From grief, guilt pain and stigma to hope and pride – a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BioMed Central Pregnancy and Childbirth*, 16(9). Available at http://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-016-0800-8.

Busch T and Kimble CS (2001). Grieving children: are we meeting the challenge? *Pediatric Nursing,* 27(4):414-418.

Cacciatore J (2010). Stillbirth: patient-centred psychosocial care. *Clinical Obstetrics and Gynecology,* 53(3):691-699.

Cacciatore J (2010). The unique experiences of women and their families after the death of a baby. *Midwifery,* 49:134-148.

Cacciatore J (2007). Effects of support groups on post-traumatic stress responses in women experiencing stillbirth. *OMEGA: Journal of Death and Dying*, 55(1):71-90.

Callister LC (2006). Perinatal loss: A family perspective. *The Journal of Perinatal and Neonatal Nursing,* 20(3):227-234.

Capitulo KL (2005). Evidence for healing interventions with perinatal bereavement. *American Journal of Maternal Child Nursing,* 30(6):389-96.

Catlin A (2005). Thinking outside the box: prenatal care and the call for a prenatal advance directive. *The Journal of Perinatal and Neonatal Nursing,* 19(2):169-176.

Catlin A and Carter B (2002). Creation of a neonatal end-of-life palliative care protocol. *Neonatal Network: The Journal of Perinatology,* 22(3):184-195.

Chichester M (2007). Requesting perinatal autopsy: multicultural considerations. MCN: *The American Journal of Maternal/Child Nursing,* 32(2):81-86.

Coleman PK (2015). Diagnosis of fetal anomaly and the increased maternal psychological toll associated with pregnancy termination. *Issues of Law and Medicine*, 30(1):3-23.

Cook P, White D and Ross-Russell (2002). Bereavement support following sudden and unexpected death: guidelines for care. *Archives of Disease in Childhood*, 87:36-38.

Contro N and Sourkes BM (2012). Opportunities for quality improvement in bereavement care at a children's hospital: assessment of interdisciplinary staff perspectives. *Journal Palliative Care,* 28(1):28-35.

Corbet-Owen C and Kruger LM (2001). The health system and emotional care: validating the many meanings of spontaneous pregnancy loss. *Families, Systems and Health,* 19(4):411-427.

Corley MC, Minick P, Elswick R and Jacobs M (2005). Nurse moral distress and ethical work environment. *Nursing Ethics,* 12:381-390.

Cote-Arsenault D and Donato K (2011). Emotional cushioning in pregnancy after perinatal loss. *Journal of Reproductive and Infant Psychology,* 29(1):81-92.

Covington SN (2009). Pregnancy Loss: A protocol to help patients cope. *Postgraduate Obstetrics and Gynecology,* 29(9):1-7.

Craig F and Goldman A (2003). Home management of the dying NICU patient. *Seminars in neonatology*, 8(2):177-183.

Craig F and Mancini A (2013). Can we truly offer a choice of place of death in neonatal palliative care? *Seminars in Fetal and Neonatal Medicine,* 18(2):93-98.

Currier J, Neimeyer B and Berman JS (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: a comprehensive quantitative review. *Psychological Bulletin,* 134(5):648-61.

D'Agostino NM, Berlin-Romalis D, Jovcevska V and Barrera M (2008). Bereaved parents' perspectives on their needs. *Palliative and Supportive Care*, 6(1):33-41.

D'Almeida M, Hume R, Lathrop A, Njoku A and Calhoun BC (2006). Perinatal hospice: family-centered care of the fetus with a lethal condition. *Journal of American Physicians and Surgeons*, 11(2):52-55.

Daly SF, Harte L, O'Beirne E, McGee, H and Turner MJ (1996). Does miscarriage affect the father? *Journal of Obstetrics and Gynaecology,* 16 (4):260-261.

de Rooy L, Aladangady N and Aldoo E (2012). Palliative care for the newborn in the United Kingdom. *Early Human Development,* 88(2):73-77.

Donoghue S and Claire-Michelle S (2013). Abortion for foetal abnormalities in Ireland; the limited scope of the Irish Government's response to the A, B and C judgment. *European Journal of Health Law,* 20(2):117-143.

Donovan LA, Wakefield CE, Russell V and Cohn RJ (2014). Hospital-based bereavement services following the death of a child: a mixed study review. *Palliative Medicine*, published online 13 Nov 2014. Available at http://pmj.sagepub.com/content/early/2014/11/12/0269216314556851. [Accessed 12 Dec 2014].

Dowling M, Kiernan G and Guerin S (2007). Responding to the needs of children who have been bereaved: A focus on services in Ireland. *The Irish Psychologist,* 33(10):259-62.

Drife JO (2006). Perinatal audit in low-and high-income countries (2006). *Seminars in Fetal and Neonatal Medicine,* 11(1):29-36.

Duhn L and Medves J (2004). A systematic integrative review of infant pain assessment tools. *Advances in Neonatal Care*, 4(3):126-140.

Dyer KA (2005). Identifying, understanding, and working with grieving parents in the NICU, Part I: Identifying and understanding loss and the grief response. *Neonatal Network: The Journal of Neonatal Nursing*, 24(3):35-46.

Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, Heazell A and Siassakos D (2016). Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BioMed Central Pregnancy and Childbirth,* 16(16).

Engler AJ, Cusson RM, Brockett RT, Cannon-Heinrich C, Goldberg MA, West MG and Petow W (2004). Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *American Journal of Critical Care,* 13(6):489-498.

Epstein EG (2008). End-of-life experiences of nurses and physicians in the newborn intensive care unit. *Journal of Perinatology*, 28(11):771-778.

Erlandsson K, Avelin P, Säflund K, Wredling R and Rodestad I (2010). Siblings' farewell to a stillborn sister or brother and parents' support to their older children: a questionnaire study from the parents' perspective. *Journal of Child Health Care,* 14(2):151-16.

Fallowfield L and Jenkins V (2004). Communicating sad, bad, and difficult news in medicine. *The Lancet*, 363(9405):312-319.

Fauri BE, Kovacs PJ and Ettner B (2000). Bereavement services in acute care settings. *Death studies,* 24(1):51-64.

Fenwick J, Jennings B, Downie J, Butt J and Okanga M (2007). Providing perinatal loss care: satisfying and dissatisfying aspects for midwives. *Women and Birth,* 20(4):153-160.

Fleanady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, Neilson J, Ezzati M, Koopmans L and Ellwood D (2011). Stillbirths: the way forward in high-income countries. *The Lancet,* 377(9778):1703-1717.

Flenady V and Wilson T (2008). Support for mothers, fathers and families after perinatal death. Cochrane Database Syst Rev, 1. doi: 10.1002/14651858.CD000452.pub2. [Accessed 04 June 2016].

Fowlie PW and McHaffie H (2004). Supporting parents in the neonatal unit. *British Medical Journal,* 329(7478):1336-1338.

Friedrichs J, Daly MI and Kavanaugh K (2000). Follow-up of parents who experience a perinatal loss: Facilitating grief and assessing for grief complicated by depression. *Illness,Crisis and Loss,* 8(3):296-309.

Gale G and Brooks A (2006). Implementing a palliative care program in a newborn intensive care unit. *Advances in Neonatal Care*, 6(1):37-53e2.

Gallagher K, Cass H, Black R and Norridge M (2012). A training needs analysis of neonatal and paediatric health-care staff in a tertiary children's hospital. *International Journal of Palliative Nursing,* 18(4):197-201.

Gardner JM (1999). Perinatal death: uncovering the needs of midwives and nurses and exploring helpful interventions in the United States, England, and Japan. *Journal Transcultural Nursing*, 10(2):120-30.

Gibbons, MB (1992). A child dies, a child survives: the impact of sibling loss. *Journal Pediatric Health Care,* 6(2):65-72.

Gibson J, Finney S and Boilanger M (2011). Developing a bereavement program in the Newborn Intensive Care Unit. *Journal Perinatal Neonatal Nursing*, 25(4):331–341.

Gilmartin M and White A (2011). Interrogating medical tourism: Ireland, abortion, and mobility rights. *Signs*, 36(2):275-280.

Gilrane-McGarry U and O'Grady T (2011). Forgotten grievers: an exploration of the grief experiences of bereaved grandparents Part 1. *International Journal of Palliative Nursing,* 17(4):170-176.

Govindarajan MJ and Rajan R (2008). Heterotopic pregnancy in natural conception. *Journal of Human Reproduction Science,* 1(1):37–38.

Gold KJ, Dalton VK and Schwenk TL (2007). Hospital care for parents after perinatal death. *Obstetrics and Gynecology,* 109(5):1156-1166.

Gold KJ, Sen A and Hayward RA (2010). Marriage and cohabitation outcomes after pregnancy loss. *Pediatrics,* 125(5), e1202-e1207.

Gold K J, Kuznia AL and Hayward RA (2008). How physicians cope with stillbirth or neonatal death: a national survey of obstetricians. *Obstetrics & Gynecology,* 112(1):29-34.

Gold K J (2007). Navigating care after a baby dies: a systematic review of parent experiences with health providers. *Journal of Perinatology,* 27(4):230-237.

Goopy S, St John A and Cooke M (2006). Shrouds of silence: three women's stories of prenatal loss. *The Australian Journal of Advanced Nursing,* 23(3):8-12.

Gordjin SJ, Erwich JJH and Khong TY (2007). The perinatal autopsy: pertinent issues in multicultural Western Europe. *European Journal of Obstetrics and Gynecology and Reproductive Biology*, 32(1):3-7.

Griffin T and Abraham M (2006). Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process. *The Journal of Perinatal and Neonatal Nursing,* 20(3):243-249.

Gardino CM and Schetter CD (2014). Understanding pregnancy anxiety: concepts, correlates and consequences. *Zero to Three*, 34(4):12-21.

Hamilton KES, Redshaw ME and Tarnow-Mordi W (2007). Nurse staffing in relation to risk-adjusted mortality in neonatal care. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, 94(1):99-103.

Hammes BJ, Klevan J, Kempf M and Williams MS (2005). Pediatric advance care planning. *Journal of Palliative Medicine,* 8(4):766-773.

Harrison ME and Walling A (2010). What do we know about giving bad news? A review. *Clinical Pediatrics,* 49:619-626.

Heazell A, McLaughlin M, Schmidt E, Cox P, Flenady V, Khong T and Downe S (2012). A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth. *BJOG: An International Journal of Obstetrics and Gynaecology,* 119(8):987–997.

Heller KS and Solomon MZ (2005). Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing*, 20(5):335-346.

Hellmann J, Williams C, Ives-Baine L and Shah PS (2012). Withdrawal of artificial nutrition and hydration in the Neonatal Intensive Care Unit: parental perspectives. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, 98(1):F21-5.

Henley A and Schott J (2008). The death of a baby before, during or shortly after birth: good practice from the parents' perspective. *Seminars in Fetal and Neonatal Medicine*, 13(5):325-328.

Himelstein BP, Hilden JM, Boldt AM and Weissman D (2004). Pediatric palliative care. *New England Journal of Medicine,* 350(17):1752-1762.

Hughes P, Turton P, Hopper E and Evans C (2002). Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *The Lancet,* 360(9327):114-118.

Hughes KH and Goodall UA (2013). Perinatal bereavement care: are we meeting families' needs? *British Journal of Midwifery;* 21(4)248-253.

Huisman TA (2004). Magnetic resonance imaging: an alternative to autopsy in neonatal death? *Seminars in Neonatology,* 9(4):347-353.

Hummel P and Cronin J (2004). Home care of the high-risk infant. *Advances in Neonatal Care,* 4(6):354-364.

Hutti MH (2005). Social and professional support needs of families after perinatal loss. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 34(5):630-638.

Johnston G, Crombie IK, Davies HTO, Alder EM and Millard A (2000). Reviewing audit: barriers and facilitating factors for effective clinical audit. *Quality in Health Care,* 9(1)23-36. doi: 10.1136/qhc.9.1.23 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1743496/ [19 January 2016].

Jonas-Simpson C, Steele R, Leeat G, Davies B and O'Leary J (2015). Always with me: Understanding experiences of bereaved children whose baby sibling died. *Death Studies,* DOI: 10.1080/07481187.2014.991954. Available at www.ncbi.nlm.nih.gov/pubmed/25551421 [13 January 2015].

Jones K and Pearce C (2009). Organising an acute gynaecology service: equipment, setup and a brief review of the likely conditions that are managed in the unit. *Best Practice and Research Clinical Obstetrics and Gynaecology,* 23(4): 427-438.

Jones L, Woodhouse D and Rowe J (2007). Effective nurse parent communication: a study of parents' perceptions in the NICU environment. *Patient Education and Counseling,* 69(1-3):206-212.

Kavanaugh K and Moro T (2006). Supporting parents after stillbirth or newborn death: There is much that nurses can do. *The American Journal of Nursing,* 106(9):74-79.

Kavanaugh K and Paton JB (2001). Communicating with parents who experience a perinatal loss. *Illness, Crisis, and Loss,* 9:369-380.

Kain VJ (2006). Palliative care delivery in the NICU: What barriers do neonatal nurses face? *Neonatal Network: The Journal of Neonatal Nursing,* 25(6):387-392.

Kehl K (2005). Recognition and support in anticipatory mourning. *Journal of Hospice and Palliative Nursing*, 7(4):206-211.

Kean L (2006). Intrauterine fetal death. *Obstetrics and Gynaecology and Reproductive Medicine*, 16(4):199-205.

Kene EA, Hutton N, Hall B, Rushton C (2010). Bereavement debriefing sessions: an intervention to support health care professionals in managing their grief. *Paediatric Nursing,* 36(4):185-189.

Kersting A and Wagner B (2012). Complicated grief after perinatal loss. *Dialogues Clinical Neuroscience*, 14(2):187-194.

Kersting A, Kroker K, Steinhard J, Hoernig-Franz I et al. (2009). Psychological impact on women after second and third trimester termination of pregnancy due to fetal anomalies versus women after preterm birth: a 14 month follow-up study. *Archives of Women's Mental Health,* 12(4):193-201.

Kersting A, Kroker K, Steinhard J, Lüdorff K et al. (2007). Complicated grief after traumatic loss. *European Archives of Psychiatry and Clinical Neuroscience*, 257(8):437-443.

Khan RA, Drudy L, Sheehan J, Harrison RF and Geary M (2004). Early pregnancy loss: how do men feel? *Irish Medical Journal,* 97(7):217-8.

Kingdon C, Givens JL, O'Donnell E and Turner M (2015). Seeing and holding baby: systematic review of clinical management and parental outcomes after stillbirth. *Birth,* 42(3):206-18.

Kripalani S, LeFevre F, Phillips C, Williams M, Basaviah P and Baker D (2007). Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. *Journal of Hospital Medicine,* 2(5):314-23.

Kobler K and Limbo R (2011). Making a case: creating a perinatal palliative care service using a perinatal bereavement program model. *The Journal of Perinatal and Neonatal Nursing,* 25(1):32-41.

Kobler K, Limbo R and Kavanaugh K (2007). Meaningful moments: The use of ritual in perinatal and pediatric death. *MCN: The American Journal of Maternal/Child Nursing*, 32(5):288-295.

Koopmans L, Wilson T, Cacciatore J, Flenady V (2013). Support for mothers, fathers and families after perinatal death (Review). *Cochrance Database System Review. The Cochrane Library,* Issue 6. Available at http://www.academia.edu/3779002/Support_for_mothers_fathers_and_families_after_perinatal_death_Cochrane_review. [10 September 2014].

Kripalani S, Lefevre F, Phillips CO, Williams MV, Basaviah P and Baker DW (2007). Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. *Journal of American Medical Association*, 297(8):831-841.

Laing IA (2004). Clinical aspects of neonatal death and autopsy. *Seminars in Neonatology*, 9(4):247-254.

Laing IA and Freer Y (2008). Reorientation of care in the NICU. *Seminars in Fetal and Neonatal Medicine*, 14(6):396-400.

Lalor J, Begley CM and Galavan E (2009). Recasting Hope: a process of adaptation following fetal anomaly diagnosis. *Social Science and Medicine,* 68(3):462-472.

Lalor J, Devane D and Begley CM (2007). Unexpected diagnosis of fetal abnormality: women's encounters with caregivers. *Birth*, 34(1):80-88.

Lang A, Fleiser AR, Duhamel F, Sword W, Gilbert KR and Corsini-Munt S (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *Journal of Death and Dying,* 63(2):183-196.

Larcher V, Craig F, Bhogal K, Wilkinson D and Brierley J on behalf of the Royal College of Paediatrics and Childhealth (2015). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *British Medical Journal,* 100(suppl 2):s1-s23. Doi:10.1136/archdischild-2014-306666.

Leuthner S and Jones EL (2007). Fetal concerns program: a model for perinatal palliative care. MCN: *The American Journal of Maternal/Child Nursing*, 32(5):272-278.

Levine SR, Cohen M, Blanchard N, Federico F, Magelli M, Lomax C, Greiner G, Poole R, Lee C and Lesko A (2001). Guidelines for preventing medication errors in pediatrics. *Journal of Pediatric Pharmacology and Therapeutics*, 6 (5):426-442.

Limbo R, Kobler K and Levang E (2010). Respectful disposition in early pregnancy loss. *MCN: The American Journal of Maternal/Child Nursing,* 35(5):271-277.

Limbo R and Kobler K (2010). The tie that binds: Relationships in perinatal bereavement. *MCN: The American Journal of Maternal/Child Nursing,* 35(6): 316.

Lisle-Porter MD, and Podruchny AM (2009). The dying neonate: family-centered end-of-life care. *Neonatal Network: The Journal of Neonatal Nursing,* 28:75-83.

Liu MF, Lin KC, Chou YH and LeeTY (2010). Using non-nutritive sucking and oral glucose solution with neonates to relieve pain: a randomised controlled trial. *Journal of Clinical Nursing*, 19(11-12):1604-1611.

Lozeau AM and Potter B (2005). Diagnosis and management of ectopic pregnancy. *American Family Physician,* 72(9):1707–1714.

Lok, IH and Neugebauer R (2007). Psychological morbidity following miscarriage. *Best Practice and Research Clinical Obstetrics and Gynaecology,* 21(2):229-247.

Lynch CM and Malone FD (2007). Prenatal screening and diagnosis. *Irish Medical Journal,* 100(3):405-406.

Machajewski V and Kronk R (2013). Childhood grief related to the death of a sibling. *Journal for Nurse Practitioners,* 9(7):443-448.

Mancini A (2011). Developing a neonatal palliative care education programme within the North West London Perinatal Network. *Journal of Neonatal Nursing,* 17(4):146-149.

Mancini A, Kelly P and Bluebond-Langner M (2013). Training neonatal staff for the future in neonatal palliative care. *Seminars in Fetal and Neonatal Medicine*, 18(2):111-115.

Malm MC, Rådestad I, Erlandsson K and Lindgren H (2011). Waiting in no-man's-land: mothers' experiences before induction of labour after their baby has died in utero. *Sexual and Reproductive Healthcare*, 2(2):51-55.

Mansell A (2006). Early Pregnancy Loss. *Emergency Loss*, 14(8):26-28.

McCool W, Guidera M, Stenson M and Dauphinee L (2009). The pain that binds us: midwives' experiences of loss and adverse outcomes around the world. *Health Care for Women Internatonal,* 30:1003-1013.

McCoyd JLM (2009a). What do women want? Experiences and reflections of women after prenatal diagnosis and termination for anomaly. *Health Care for Women International,* 30(6):507-535.

McCoyd JLM (2009b). Discrepant feeling rules and unscripted emotion work: Women terminating desired pregnancies due to fetal anomaly. *American Journal of Orthopsychiatry,* 79(4):441-451. http://dx.doi.org/10.1037/a0010483.

McCready S and Russell R (2009). A national survey of support and counselling after maternal death. *Anaesthesia,* 64(11):1211-1217.

McCreight BS (2005). Perinatal grief and emotional labour: a study of nurses' experiences in gynae wards. *International Journal of Nursing Studies,* 42(2005):439-448.

McGee H and Turner M (1991). The experience and psychological impact of early miscarriage. *The Irish Journal of Psychology,* 12(2):108-120.

McGrath JM (2011). Neonatal nurses: what about their grief and loss? *The Journal of Perinatal and Neonatal Nursing*, 25(1):8-9.

McGuinness D, Coughlan B and Power S (2014). Empty Arms: Supporting bereaved mothers during the immediate postnatal period. *British Journal of Midwifery,* 22(4):246-252.

McNamara K, O'Donoghue K, O'Connell O and Greene RA (2013). Antenatal and intrapartum care of pregnancy complicated by lethal fetal anomaly. *Obstetrician and Gynaecologist,* 15(3):189-194.

McQueen A (2011). Ectopic pregnancy: risk factors, diagnostic procedures and treatment. *Nursing Standard,* 25(37):49-56.

Meaney S, Gallagher S, Lutomski JE and O'Donoghue K (2014). Parental decision making around perinatal autopsy: a qualitative investigation. *Health Expectations.* Available at http://www.ncbi.nlm.nih.gov/pubmed/25376775. [06 Jan 2015].

Meert K, Shear K, Newth C, et al. (2011). Follow-up study of complicated grief among parents eighteen months after a child's death in the paediatric intensive care unit. *Journal Palliative Medicine*, 14(2):207-214.

Meyer EC, Ritholz MD, Burns JP and Truog RD (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*, 117(3):649-657.

Meyer EC, Sellers DE, Browning DM, McGuffie K, Solomon MZ and Trupg RD (2009). Difficult conversations: Improving communication skills and relational abilities in health care. *Pediatric Critical Care Medicine,* 10(3):352-359.

Mitchell LM (2004). Women's experiences of unexpected ultrasound findings. *Journal of Midwifery and Women's Health,* 49(3):228-234.

Moro T, Kavanaugh K, Okuno-Jones S and Vankleef JA (2006). Neonatal end-of-life care: a review of the research literature. *The Journal of Perinatal and Neonatal Nursing,* 20(3):262-273.

Moules NJ, Rhinsk LM and Bell JM (2008). A Christmas without memories: beliefs about grief and mothering – a clinical case analysis. *Journal of Family Nursing,* 12(4):426-41.

Moules NJ, Simonon K, Fleizer AR, Prins M and Glasgow Rev B (2007). The soul of sorrow: grief and therapeutic interventions with families. *Journal of Family Nursing*, 13(1):117-141.

Mulvihill A and Walsh T (2014). Pregnancy loss in rural Ireland: an experience of disenfranchised grief. *British Journal of Social Work*, 44 (8):2290-2306.

Munson D and Leuthner SR (2007). Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatric Clinics of North America*, 54(5):787-798.

Murphy S and Jones KS (2014). By the way knowledge: grandparents, stillbirth and neonatal death. *Human Fertility,* 17(3):210-213.

Murphy S, Shevlin M and Elklit A (2014). Psychological consequences of pregnancy loss and infant death in a sample of bereaved parents. *Journal of Loss and Trauma*, 19(1):56-69.

Nuzum D, Meaney S and O'Donoghue K (2014a). The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. *BJOG: An International Journal of Obstetrics & Gynaecology*, 121(8):1020-1028. Published online 3 March, 2014. DOI:10.1111/1471-0528.12695.

Nuzum D, Meaney S and O'Donoghue K (2014b). The provision of spiritual and pastoral care following stillbirth in Ireland: a mixed methods study. *BMJ Supportive and Palliative Care,* bmjspcare-2013-000533.

O'Leary JM and Gaziano C (2011). Sibling grief after perinatal loss. *Journal of Prenatal and Perinatal Psychology and Health,* 25(3):173-193.

Parker H, Farrell M, Ryder A, Ferney K, Cox C, Farasat H and Hewitt-Taylor J (2014). Family-focused children's end-of-life care in hospital and at home. *Nursing Children and Young People*, 26(6):35-39.

Platt J (2004). The planning, organising and delivery of a memorial service in critical care. *Nursing in critical care,* 9(5):222-229.

Putman MA (2007). Perinatal perimortem and postmortem examination: obligations and considerations for perinatal, neonatal, and pediatric clinicians. *Advances in Neonatal Care*, 7(6):281-288.

Purandare N, Ryan G, Ciprike V, Trevisan J, Sheehan J and Geary M (2012). Grieving after early pregnancy loss - a common reality. *Irish Medical Journal*, 105(10):326-8.

Prigerson HG, Horowitz MJ, Jacobs SC, Parkes CM, Aslan M and Goodkin K et al. (2009). Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11. DOI: 10.1371/journal.pmed.1000121. http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000121#pmed-1000121-g004.

Rådestad I, Malm MC, Lindgren H, Pettersson K and Larsson LL (2014). Being alone in silence - mothers' experiences upon confirmation of their baby's death in utero. *Midwifery*, 30(3): e91-5. doi: 10.1016/j.midw.2013.10.021. Epub 2013 Oct 30.

Rådestad I, Westerberg A, Ekholm A, Davidsson A and Erlandsson K (2011). Evaluation of care after stillbirth in Sweden based on mothers' gratitude. *British Journal of Midwifery,* 19(10):46-52.

Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelöv E and Dickman PW (2009). Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery,* 25(4):422-429.

Rådestad I and Christoffersen L (2008). Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery,* 16(9):588-591.

Rankin J, Wright C and Lind T (2002). Cross sectional survey of parents' experience and views of the post mortem examination. *British Medical Journal,* 324(7341):816-818.

Redshaw M and Hamilton KS (2010). Family centred care? Facilities, information and support for parents in UK neonatal units. *Archives of Disease in Childhood-Fetal and Neonatal Edition,* 95(5): F365-F368.

Reid S, Bredemeyer S, van den Berg C, Cresp T, Martin T and Miara N (2011). Palliative care in the neonatal nursery: Guidelines for neonatal nurses in Australia. *Neonatal, Paediatric & Child Health Nursing,* 14(2):2-8.

Resta R, Biesecker BB, Bennett RL, Blum S, Hahn SE, Strecker MN and Williams JL (2006). A new definition of genetic counselling: National Society of Genetic Counsellors' Task Force Report. *Journal of Genetic Counsellors,* 15(2):77-83.

Riley M (2003). Facilitating Children's Grief. *Journal of School Nursing*, 19(4):212-21.

Robertson MJ, Aldridge A and Curley AE (2011). Provision of bereavement care in neonatal units in the United Kingdom. *Pediatric Critical Care Medicine,* 12(3):e111-e115. doi: 10.1097/PCC.0b013e3181e911e3.

Roehrs C, Masterson A, Alles R, Witt C and Rutt P (2008). Caring for families coping with perinatal loss. *Journal of Obstetric, Gynecologic and Neonatal Nursing,* 37(6):631-639.

Rogers S, Babgi A and Gomez C (2008). Educational interventions in end-of-life care: Part I: An educational intervention responding to the moral distress of NICU nurses provided by an ethics consultation team. *Advances in Neonatal Care*, 8(1):56-65.

Romesberg TL (2007). Building a case for neonatal palliative care. *Neonatal Network: The Journal of Neonatal Nursing,* 26(2):111-115.

Roose RE and Blanford CR (2011). Perinatal grief and support spans the generations: parents' and grandparents' evaluations of an intergenerational perinatal bereavement program. *Journal of Perinatal Neonatal Nursing,* 25(1):77–85.

Rosenbaum JL, Smith JR and Zollfrank R (2011). Neonatal end-of-life spiritual support care. *The Journal of Perinatal and Neonatal Nursing,* 25(1):61-69.

Roush A, Sullivan P, Cooper R and McBride JW (2007). Perinatal hospice. *Newborn and Infant Nursing Reviews*, 7(4):216-221.

Rowlands IJ and Lee C (2010). The silence was deafening: social and health service support after miscarriage. *Journal of Reproductive and Infant Psychology,* 28(3):274-286.

Rubertsson C and Cross M (2014). Anxiety in early pregnancy: prevalence and contributing factors. *Archives of Women's Mental Health*, 17(3):221-8.

Säflund K, Sjögren B and Wredling R (2004). The role of caregivers after a stillbirth: views and experiences of parents. *Birth: Issues in Perinatal Care,* 31(2):132-137.

Säflund K and Wredling R (2006). Differences within couples' experience of their hospital care and well-being three months after experiencing a stillbirth. *Acta Obstetricia et Gynecologica Scandinavica*, 85(10):1193-1199.

Sagili H and Divers M (2007). Modern management of miscarriage. *The Obstetrician and Gynaecologist,* 9(2):102-108.

Schut H and Stroebe M (2005). Interventions to enhance adaptation to bereavement. *Journal of Palliative Medicine*, 8 (suppl 1):S140–S147.

Shear K, Frank E, Houck PR and Reynolds C (2005). Treatment of complicated grief: a randomised controlled trial. *Journal of American Medical Association*, 293(21):2601-2608.

Shear MK, Simon N, Wall M et al. (2011). Complicated grief and related bereavement issues for DSM-5. Published online 28 February 2011. doi: 10.1002/da.20780. Available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3075805/

Siddiqui F and Kean L (2009). Intrauterine fetal death. *Obstetrics, Gynaecology and Reproductive Medicine,* 19(1):1-6.

Simpson R and Bor R (2001). 'I'm not picking up a heart-beat': experiences of sonographers giving bad news to women during ultrasound scans. *British Journal of Medical Psychology,* 74(Part 2):255-272.

Smuelsson M, Rådestad I and Segesten K (2001). A waste of life: fathers' experience of losing a child before birth. *Birth,* 28(2):124-130.

Stratham NH, Solomou H, Solomou W and Greene JM (2003). Communication of prenatal screening and diagnosis results to primary-care health professionals. *Public Health*, 117(5):348-357.

Stratton K and Lloyd L (2008). Hospital-based interventions at and following miscarriage: literature to inform a research-practice initiative. *Australian and New Zealand Journal of Obstetrics and Gynaecology,* 48(1):5-11.

Stroebe MS, Folkman S, Hansson RO and Schut H (2006). The prediction of bereavement outcome: development of an integrative risk factor framework. *Social Science and Medicine* 63(9):2440-51.

Stroebe M, Schut, H and Stroebe W (2007). Health outcomes of bereavement. *The Lancet,* 370(9603):1960-1973.

Sudia-Robinson T (2011). Ethical implications of newborn screening, life-limiting conditions, and palliative care. *MCN: The American Journal of Maternal/Child Nursing,* 36(3):188-196.

Summer L, Kavanaugh K and Moro T (2006). Extending palliative care in to pregnancy and the immediate new born period: state of the practice of perinatal palliative care. *Journal of Perinatal and Neonatal Nursing*, 20(1):113-116.

Sweeting H and Gilhooly M (1990). Anticipatory Grief: a review. *Social Science and Medicine,* 30(10):1073-1080.

Thorstensen KA (2000). Midwifery management of first trimester bleeding and early pregnancy loss. *Journal of Midwifery and Women's Health,* 45(6):481-497.

Torbic H (2011). Children and grief: but what about the children? *Home HealthC Nurse*, 29(2):67-79.

Tucker EB, Fager C, Srinivas S and Lorch S (2011). Racial and ethnic differences in use of intubation for periviable neonates. *Pediatrics*, 127(5): e1120-e1127. doi:10.1542/peds.2010-2608. Epub 2011 Apr 18. e1120-e1127.

Trulsson O and Rådestad I (2004). The silent child - mothers' experiences before, during, and after stillbirth. *Birth,* 31(3):189-195.

van der Geest IM, Darlington AS, Streng IC, Michiels EM, Pieters R and van den Heuvel-Eibrink MM (2014). Parents' experiences of paediatric palliative care and the impact on long-term parental grief. *Journal of Pain Symptom Management,* 47(6):1043-53.

Wakefield JC and First MB (2012). Validity of the bereavement exclusion to major depression: does the empirical evidence support the proposal to eliminate the exclusion in DSM-5? *World Psychiatry,* 11(1):3-10.

Wakefield JC (2012). Should prolonged grief be reclassified as a mental disorder in DSM-5?: reconsidering the empirical and conceptual arguments for complicated grief disorder. *Journal of Nervous and Mental Disease.* 200(6):499-511.

Walsh T, Foreman M, Curry P, O'Driscoll S and McCormack M (2008). Bereavement support in an acute hospital: an Irish model. *Death Studies*, 32(8):768-86.

Walsh T, Breslin G, Curry P, Fireman M and McCormack M (2013). A whole-hospital approach? Some staff views of a hospital bereavement care service. *Death Studies,* 37(6):552-568.

Weissman DE and Meier DE (2008). Operational features for hospital palliative care programmes: consensus recommendations. *Journal of Palliative Medicine*, 11(9):1189-1194.

Welborn JM (2012). The experience of expressing and donating breast milk following a perinatal loss. *Journal of Human Lactation,* 28(4):506-510.

Wenzel J, Shaha M, Klimmek R and Krumm S (2011). Working through grief and loss: oncology nurses perspectives on professional bereavement. *Oncology Nursing Forum,* 38:4, E272-82. doi: 10.1188/11.ONF.E272-E282.

Widger KA and Wilkins K (2003). What are the key components of quality perinatal and pediatric end-of-life care? A literature review. *Journal of Palliative Care*, 20(2):105-112.

Wilkinson DJC, Thiele P, Watkins A and De Crespignyb L (2012). Fatally flawed? A review and ethical analysis of lethal congenital malformations. *British Journal of Obstetrics and Gynaecology*, 119(11):1302–1308.

Williams C, Munson D, Zupancic J and Kirpalani H (2008). Supporting bereaved parents: practical steps in providing compassionate perinatal and neonatal end-of-life-care: a North American perspective. *Seminars in Fetal and Neonatal Medicine*, 13(5):335-340. doi: 10.1016/ j.siny.2008. 03.005.

Woodroffe I (2013). Supporting bereaved families through neonatal death and beyond. *Seminars in Fetal and Neonatal Medicine,* 18(2):99-104.

Woods-Giscombé CL, Lobel M and Crandell JL (2010). The impact of miscarriage and parity on patterns of maternal distress in pregnancy. *Research in Nursing and Health,* 33(4):316-328.

Wool C (2013). State of the science on perinatal palliative care. *Journal of Obstetric, Gynecologic and Neonatal Nursing,* 42(3):372-382.

Yee W and Ross S (2006). Communicating with parents of high-risk infants in neonatal intensive care. *Paediatrics and Child Health,* 11(5):291-295.

Books

Christ GH, Bonnano G, Malkinson R and Rubin S (2003). 'Bereavement Experiences after the death of a child' in Field MJ and Berrman RE (eds.), *When Children Die: improving palliative and end of life care for children and their families.* Washington DC: National Academy Press.

Doka K (2002). *Disenfranchised Grief: new directions, challenges and strategies for practice*. US: Research Press.

Doka K (1989). *Disenfranchised Grief*. Lexington, M.A: Lexington Books.

Doka KJ (1995). *Children mourning, mourning children.* Washington, DC: Hospice Foundation of America.

Ferguson L, Fowler-Kerry S and Hain R (2012). 'Education' in Goldman A, Hain R and Liben S (eds.). *Oxford textbook of paediatric palliative care*. Oxford: OUP.

Forest G (1989). 'Care of the bereaved after perinatal death' in Chalmer I, Enkin MW and Keirse MJNC (eds.). *Effective care in pregnancy and childbirth,* Volume 2. Oxford Medical Publications.

Hooyman NR and Kramer BJ (2006). *Living through loss: Interventions across the lifespan.* Columbia University Press.

Mander R (2006). *Loss and bereavement in childbearing* (Routledge, 2nd ed.).

Marshall HK, Kennell JH and Farnhoff JM (2013). *Care of the high-risk neonate* (Elsevier, 6th ed.).

Stroebe MS, Hansson R, Schut H and Stroebe W (2008). *Handbook of bereavement research and practice: advances in theory and intervention.* Washington DC: National Academy Press.

Williams B and Datta S (2012). Previous fetal death in Karoshi M, Newbold S, B-Lynch C and Keith L (eds). *A textbook of preconceptional medicine*. Sapiens Publishing.

Reports

Bates U, Jordan N, Malone K, Monahan E, O'Connor S, and Tiernan E (2008). *Review of general bereavement support and specific services available following suicide bereavement.* Petrus Consulting, Dublin: NOSP.

British Association of Perinatal Medicine Working Group Report (2010). *Palliative Care (supportive and end-of-life care): a framework for clinical practice in perinatal medicine.*

Browne M, O'Mahony A and MacEochaidh G (2005). *Dying and death in an acute hospital: exploring the views and experiences of hospital staff.* Irish Hospice Foundation/Health Service Executive.

Department of Health / Irish Hospice Foundation (2005). *A palliative care needs assessment for children.* Available at http://hospicefoundation.ie/wp-content/uploads/2012/04/Palliative-care-needs-assessment-for-children-2005.pdf

Department of Health (UK) (2015). Abortion Statistics, England and Wales 2014. Available at https://www.gov.uk/government/statistical-data-sets/abortion-statistics-england-and-wales-2014

ESRI. (2013) *Perinatal statistics report 2012.* Dublin: ESRI Health Research and Information Division.

Health Information and Equality Authority (HIQA) (2013). *Investigation into the safety, quality and standards of services provided by the Health Service Executive to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway, and as reflected in the care and treatment provided to Savita Halappanavar.*

Health Service Executive (HSE) (2013). *Investigation of Incident 50278 from time of patient's self-referral to hospital on the 21st of October 2012 to the patient's death on the 28th of October, 2012.*

Institute of Obstetricians and Gynaecologists RCPI (2006). *The Future of Maternity & Gynaecology Services in Ireland 2006-2016*. Available at http://www.rcpi.ie/content/docs/000001/372_5_media.pdf

Irish Hospice Foundation (2012). *The Irish Childhood Bereavement Network: Supporting those working with grieving children and young people.* Available at http://hospicefoundation.ie/wp-content/uploads/2012/04/Irish-Childhood-Bereavement-Network-supporting-those-working-with-grieving-children-and-young-people.pdf

Irish Hospice Foundation (IHF) (2014). *The Hospice Friendly Hospitals Programme: Overview 2007-2013*. Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/The-Hospice-Friendly-Hospitals-Programme.-Overview-2007-2013.pdf.

Irish Stillbirth and Neonatal Death Society (ISANDS) (2007). *Guidelines for professionals.*

Keegan, O (2013). *Submission to the Oireachtas Committee on health and children: Public hearing on end-of-life care.* Available at http://hospicefoundation.ie/wp-content/uploads/2013/12/Bereavement-Oireachtas-submission-November-4thi-OKeegan.pdf.

Kristjanson L, Lobb E, Aoun S and Monterosso L for the Department of Health and Ageing, Australia (2006). *A systematic review of the literature on complicated grief.*

National Perinatal Epidemiology Centre (2015). *Perinatal Mortality in Ireland: Annual Report, 2013*.

Redshaw M, Rowe R and Henderson J (2014). *Listening to parents after stillbirth or the death of their baby after birth.* National Perinatal and Epidemiology Unit, Oxford.

Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M (2014). *Palliative Care Competence Framework*. Dublin: Health Service Executive.

International Clinical Guidance and Diagnostic Criteria

Association for Children's Palliative Care [ACT] (2009). *A neonatal pathway for babies with palliative care needs.* Available at www.londonneonatalnetwork.org.uk/.../ACTNeonatal_Pathway_for_Bab.

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders:* Fifth edition.

American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders*: Fourth edition (Text Revision).

American Psychiatric Association (1996). *Diagnostic and Statistical Manual of Mental Disorders:* Third edition.

British Association of Perinatal Medicine (2010). *Palliative Care (supportive and end-of-life care): A framework for clinical practice in Perinatal Medicine.* Available at http://bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_%20Aug10.pdf

Brown C (2009). Working with grieving children and families in Thompson, RA (Ed.). *The handbook of child life: a guide for Paediatric Psychosocial Care*. Springfield IL: Charles C. Thomas Publication Ltd.

Mancini A, Uthaya S, Beardsley C, Wood D and Modi N (2014). *Practical guidance for the management of palliative care on neonatal units.*

National Institute for Clinical Excellence (NICE) (2004). *Guidance on cancer services: Improving supportive and palliative care for adults with cancer (The Manual)*. London: National Institute for Clinical Excellence. http://www.nice.org.uk/guidance/csgsp.

National Institute for Care Excellence (NICE) (2005). Guideline Number 26. *The management of PTSD in adults and children in primary and secondary care.* Available at https://www.nice.org.uk/guidance/cg26/evidence/full-guideline-including-appendices-113-193442221

National Institute for Care Excellence (NICE) (2013). Guideline Number 13. *Quality Standard for end-of-life care for adults*. Available at https://www.nice.org.uk/guidance/qs13/resources/guidance-end-of-life-care-for-adults-pdf.

National Institute for Care Excellence (NICE) (2014). Guideline Number 192. *Antenatal and postnatal mental health: clinical management and service guidance*. Available at https://www.nice.org.uk/guidance/cg192/chapter/1-recommendations

Queensland Government (2015). *Queensland Maternity and Neonatal Clinical Guideline: Early Pregnancy Loss* MN11.29-V3-R16. Available at https://www.health.qld.gov.au/qcg/documents/g-epl.pdf

Royal College of Obstetricians and Gynaecologists (2011). Green-top Guideline No. 17. *The investigation and treatment of couples with recurrent first-trimester and second-trimester miscarriage.* Available at https://www.rcog.org.uk/globalassets/documents/guidelines/gtg_17.pdf

Royal College of Obstetricians and Gynaecologists (2010). *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales.* Available at http://docplayer.net/9207863-Royal-college-of-obstetricians-and-gynaecologists-termination-of-pregnancy-for-fetal-abnormality-in-england-scotland-and-wales.html

Stillbirth and Neonatal Death Charity (SANDS) (2007). *Pregnancy loss and the death of a baby: guidelines for professionals*.

Stillbirth and Neonatal Death Charity (SANDS) (2011). *The Sands Audit Tool for maternity services: Caring for parents whose baby has died*.

Stokes J (2004). *Then, now and always: Supporting children as they journey through grief: A guide for practitioners.* Gloucester: Winston's Wish.

Theses

Carroll, B (2010). Survey of Childhood Bereavement Services in Ireland. MSc Bereavement Studies. IHF/RCSI. Ireland.

Vanhaecht K, De Witte K and Sermeus W (2007). The impact of clinical pathways on the organisation of care processes. PhD dissertation, Belgium: KU Leuven.

Editorials, Opinion and Journalistic Reports

Irish Medical News (2014) 113 abortions on medical grounds carried out in UK. Retrieved from: http://www.imn.ie/index.php?option=com_content&view=article&id=5654:113-abortions-on-medical-grounds-carried-out-in-uk&catid=61:news&Itemid=28.

Editorial (2012). Lancet, 379(9816):589. DOI: http://dx.doi.org/10.1016/S0140-6736(12)60248-7.

Appendix 4: Implementation, Revision and Audit

Implementation of Guideline

An Implementation Group has been set up to identify the resources required and the processes necessary for the successful implementation in all hospitals of the Standards for Bereavement Care following Pregnancy Loss and Perinatal Death. The group is tasked with;

- the dissemination of the guideline to all hospital and community health service providers
- the development of teaching methodologies and teaching aids
- train the trainer workshops
- the design and dissemination of national literature covering pregnancy loss, perinatal death, congenital fetal anomaly and maternal death
- the development of audit tools including a confidential service user feedback process
- the development of debriefing programmes for hospital employees
- site visits
- bereavement care summit

Revision and Audit

The Bereavement Service will be audited through the tools under development by the Implementation Group. The audits, in conjunction with documented findings from the Multidisciplinary Perinatal Morbidity and Mortality meetings and with the confidential service user feedback, will be used to measure the quality of the bereavement service. Multidisciplinary bereavement care pathways will be reviewed and revised as indicated through the audits and in keeping with national clinical guidelines and research based up-to-date best clinical practice.

Appendix 5: Support and Advocacy Groups

Association	Services	Contact
A Little Lifetime Foundation (was Irish Stillbirth and Neonatal Death Society [ISANDS])	• provides telephone, email, forum and Facebook support for parents and families whose baby has died or is expected to die • regular parent support meetings in Dublin, Cork, Limerick, Tralee, Athlone, Cavan, Drogheda, Wexford, Waterford and Kilkenny • baby clothes to hospitals • information leaflets • a Little Lifetime Foundation Memories Collection • inter-denominational services of remembrance • representation to groups of professionals such as doctors, nurses, midwives, clergy and other interested groups • provide training for support team volunteers • heighten awareness about perinatal death • provide bereavement counselling by counsellor with special interest in bereavement • creative workshops • publishes bi-annual newsletter	www.alittlelifetime.ie Telephone: 01 882 9030
Ectopic Pregnancy Ireland	• raise awareness on ectopic pregnancy amongst the general public and health professionals • provide information and support to those who have been affected by an ectopic pregnancy • offer support rather than counselling. • advocate for the long term needs of couples following ectopic pregnancy	Telephone: 089 436 5742 (8-10pm) http://ectopicireland.ie/ Email: info@ectopicireland.ie
Fèileacàin (Stillbirth and Neonatal Death Association of Ireland)	• offer regular support meetings • provide a befriending service and support helpline • provide a safe and confidential setting, in which those bereaved through stillbirth or neonatal death can share their experiences • promote research into the causes of stillbirth, neonatal death and the effects of grief on the family • work in co-operation with support services and other support organisations • organise remembrance services and family events • provide hospitals with memory boxes for bereaved families	www.feileacain.ie Telephone: 085 249 6464

Association	Services	Contact
Every Life Counts	• offers a support network for parents who have received a diagnosis that their child may not live for very long after birth. Every Life Counts provides an outreach for parents to share their memories, their stories, their love and their pain. Every Life Counts seeks to secure support, information and services for families through the establishment of perinatal hospice care across Ireland.	Dominick Court, 41 Dominick Street Lower, Dublin 1 http://www.everylifecounts.ie Telephone: 01 879 2382 office@everylifecounts.ie
First Light (previously Irish Sudden Infant Death Association)	• offers bereavement group therapy for newly bereaved parents and children • befriending service • annual memorial service • book of remembrance • SIDS Model of Care and information hotline for professionals • regional information meetings • speakers for professionals and community groups • national Sudden Infant Death Register	First Light, Carmichael House, 4 North Brunswick Street, Dublin 7 Telephone: 01-8732711 24 Hour Helpline: 087 242 3777 Fax: 01-8726056 www://firstlight.ie
HSE Crisis Pregnancy Programme (previously Crisis Pregnancy Agency)	• provides training, education, information, research, communications and support • funds 34 agencies to provide sexual health projects, crisis pregnancy counselling, medical services, parenting support • provide post abortion counselling through 15 voluntary and statutory organisations	89-94 Capel Street, Dublin 1. Telephone: 01 8146292 www.crisispregnancy.ie
Leanbh mo Chroí	• provides telephone, text and group support to families after a diagnosis of a fatal fetal anomaly	http://lmcsupport.ie/
Miscarriage Association of Ireland.	• organises and facilitates monthly support group meetings in Dublin • telephone support, email support, Internet forum • regional support groups • newsletters • leaflets for hospitals and elsewhere • annual remembrance service • book of remembrance • memorial stone • support not counselling • make representation to groups of professionals such as doctors, nurses, clergy, midwifery students and other interested groups • public awareness campaigning	www.miscarriage.ie Telephone: 01 873 5702 (Carmichael House) Tel: Volunteers available by phone two hours morning and evening (10am-12md and 8pm-10pm) Monday to Friday (see website for mobile numbers)

Association	Services	Contact
NILMDTS (Now I Lay Me Down To Sleep)	• trains, educates, and mobilizes professional quality photographers to provide beautiful heirloom portraits to families facing the untimely death of an infant	www.feileacain.ie/now-i-lay-me-down-to-sleep-photographers/ Telephone: 083 377 4777 (open between 9 am – 9 pm)
NISIG - National Infertility and Support & Information Group	• provides information about infertility • offer support • organise support meetings	Telephone: 1890 647 444 (Lo-call) Telephone line open up to 9pm. P.O. Box 131, Togher, Cork. Email: nisig@eircom.net www.infertilityireland.ie
One Day More	• provides a support group made up of parents who received poor pre-natal prognoses for their babies • offers support to any parent who has just received a difficult pre-natal prognosis for their baby	One Day More 6-9 Trinity St,Dublin 2 Telephone: 086 0220362 www.onedaymore.ie SOFT Ireland Contact Co-ordinator
SOFT Ireland Support Organisation for Trisomy 13/18 (Patau's / Edward's Syndrome)	• offers support for families with newly diagnosed babies • support for families caring for babies and children with these disorders • support for families experiencing bereavement • information on Trisomy 13/18 • fund bereavement counselling • fund respite assistance • publish the SOFT booklet Why Our Baby and a newsletter • organise conferences • fund raising • links with S.O.F.T. organisations worldwide	Telephone: 1800 213 218 Email: soft.contactme@gmail.com https://www.facebook.com/pages/Soft-Ireland/193603640656322
TFMRI Ireland – Termination for Medical Reasons Ireland	• campaign group promoting the interests of couples who receive a diagnosis of lethal fetal anomaly	http://www.terminationformedicalreasons.com/

Additional Support Groups

Additional Support Group	Services	Contact
Anam Cara	• support for parents and siblings following the death of a child • information • on-line forums for parents, siblings and volunteers • support group • guest speakers • counselling	HCL House, Second Avenue,Cookstown Industrial Estate, Tallaght, Dublin 24 http://www.anamcara.ie/ Telephone: +353 (0)1 4045 378 Email: info@anamcara.ie
Bethany Bereavement Support	• voluntary support groups located in most counties and organised within parishes. • many Bethany members have themselves been bereaved and are trained to listen with understanding	www.bethany.ie See website for local contacts
Barnardos	• provides national bereavement counselling service specifically for children • provides information and advice through its helpline and counselling for bereaved children	Dublin Christchurch Square Dublin 8 Tel: 01 453 0355 Email: http://www.barnardos.ie/what-we-do/our-services/specialist-services/bereavement-counselling.html
Barretstown Camp	• offers bereavement weekends to support families when their child (aged infant to 17) dies from a serious illness • provides a sensitive and caring environment in which families can meet others who have suffered a similar loss, share their experiences and find ways to look to the journey ahead	Barretstown Castle, Ballymore Eustace Co. Kildare Telephone: 045 864 115 Web: www.barretstown.org
Compassionate Friends Ireland	• non-profit charitable organisation established in 2008 to provide consolation and support during the grieving process to families in which a child dies.	http://www.compassionatefriendsireland.ie/ Email: compassionatefriendsireland@gmail.com Telephone: Mary 086 382 2624. Nick 087 254 0355
CrosscareTeen Counselling	• provides counselling service for 12 – 18 year olds • offers bereavement counselling to young people and their families	Crosscare, The Red House, Clonliffe Road, Dublin 3 Telephone: 01 836 0011 Web: www.crosscare.ie/teencounselling Email: info@crosscare.ie

Additional Support Group	Services	Contact
Irish Childhood Bereavement Network	• founded in 2012 to act as a hub for those working with bereaved children, young people and their families. • provides information about age appropriate literature for children *	Telephone: 01 679 3188 http://www.childhoodbereavement.ie/
Irish Hospice Foundation	• a national charity dedicated to all matters relating to dying, death and bereavement in Ireland.	Telephone: 01 679 3188 www.hospicefoundation.ie
Irish Patients' Association	Advocates for the needs of patients while working in partnership with health care providers and addresses various committees, working groups and public bodies on behalf of patients	Tel: 087 6594183 http://irishpatients.ie/
Patient Focus	• point of contact and other supports to patients who have been damaged by the Healthcare system • assists people to try and resolve difficulties as early as possible after they arise • seeks to ensure the preservation and enhancement of patient rights in all healthcare settings	Telephone: (01) 885 1611; 885 1617; 885 1633; 885 1658 http://www.patientfocus.ie/site/index.php
Patients for Patients' Safety	Patients for Patients Safety Ireland (PFPSI) is a World Health Organisation (WHO) initiative aimed at improving safety in healthcare. PFPSI is supported by the HSE Quality Improvement Division. The WHO believes that safety will only be improved if patients are placed at the centre of care and included as full partners. This initiative brings together patients, providers, policy-makers and those affected by harm who are dedicated to improving health-care safety through advocacy, collaboration and partnership. Members regularly speak at patient safety events, work with health care teams to promote and encourage improvements in patient safety and highlight areas of unsafe practice focused by their own experiences.	http://www.hse.ie/eng/about/Who/qualityandpatientsafety/nau/patientsafety/

*A list of age appropriate literature is available at http://www.childhoodbereavement.ie/top-10-childrens-books-on-death-and-bereavement-the-guardian/#.VOxhIfmsV28

Additional Support Group	Services	Contact
TUSLA (Child and Family Agency)	• child protection and welfare services • education welfare services • psychological services • alternative care • family and locally-based community supports • early years services • domestic, sexual and gender-based violence services	St. Stephens Green House, Earlsfort Terrace, Dublin 2. Telephone: (01) 611 4100 Email: info@fsa.ie www.fsa.ie

Appendix 6: Abbreviations

AIMS	Association for Improvements in the Maternity Services Ireland
BST	Bereavement Specialist Team
CMS	Clinical Midwife Specialist
DOH	Department of Health
HCR	Healthcare Record
HFH	Hospice Friendly Hospitals
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHF	Irish Hospice Foundation
IUFD	Intrauterine Fetal Death
MDT	Multidisciplinary Team
MHCT	Mental Healthcare Team
NCEC	National Clinical Effectiveness Committee
NICE	National Institute for Health and Care Excellence
NILMDTS	Now I Lay Me Down to Sleep
NISIG	National Infertility Support and Information Group
NND	Neonatal Death
NPEC	National Perinatal Epidemiology Centre
OPD	Out Patients Department
PHT	Palliative Healthcare Team
RCOG	Royal College of Obstetrics and Gynecology (UK)
RCPI	Royal College of Physicians in Ireland
SANDS	Stillbirth and Neonatal Death Society
SB	Stillbirth
SOFT Ireland	Support Organisation for Trisomy 13/18 (Patau's/Edward's Syndrome)
TFMRI Ireland	Termination for Medical Reasons Ireland