Department of Health, Social Services and Public Safety
www.dhsspsni.gov.uk

Regional Bereavement Guidance on evidence-based, holistic care of parents and their families after the experience of miscarriage, stillbirth or neonatal death

November 2014

Updated December 2015

HSC Health and Social Care

NIPEC

Acknowledgements

The Department of Health, Social Services and Public Safety (DHSSPS) and Northern Ireland Practice and Education Council (NIPEC) wish to acknowledge the valuable input of the Steering Group into the development of this regional guidance and corresponding pathways.

In addition, thanks are also extended to the women and professional staff who gave up their time to attend regional workshops and to provide comments on the guidance and pathways.

Contents

		Page
1.0	**Introduction and strategic context**	4
2.0	**Purpose of this guide**	5
3.0	**Women and family-centered choices**	5
4.0	**Spiritual, religious and cultural support**	6
5.0	**Psychological and emotional aspects of care**	7
6.0	**Continuity of care and communication**	7
7.0	**Record keeping**	9
8.0	**Role of Coroner**	14
9.0	**Role of *Northern Ireland Maternal and Child Health* (NIMACH)**	15
10.0	**Multidisciplinary team support and care**	16
11.0	**Use of Regional Bereavement Pathways**	18
12.0	**Pregnancy Loss up to 12 weeks**	18
13.0	**Pregnancy Loss from 12 weeks to 20 completed weeks**	20
14.0	**Pregnancy Loss from 20 weeks or later**	20
15.0	**Neonatal Loss**	24
16.0	**Useful contacts**	28

1.0 Introduction and strategic context

Sensitive, thoughtful care cannot take away the pain of a woman'[1] who loses a baby at any gestational age, but it may provide some comfort in the months and years to come. It is also recognised that a compassionate and sensitive approach throughout all the procedures and processes surrounding death can impact positively on the grieving process[2]. Establishing bereavement pathways should ensure continuity and consistency in approach, which are so important at a time when parents and in particular, women are very vulnerable. The interaction among all those involved in the care of parents and their families is dynamic, unique but sometimes unpredictable.

Research confirms that good care can affect parents' long-term wellbeing and may prevent the need for costly intervention later[3]. In addition, evidence shows that listening to parents about the care they receive around the time of their baby's death is extremely important[4].

The Northern Ireland Bereavement Strategy (2009) identifies six standards of care to assist Health and Social Care in the delivery of services at the end of life. The standards highlight the importance of promoting safe, effective care and support, to include effective communication to bereaved families and relatives.

In Northern Ireland, there is a stillbirth rate of approximately 4.5, perinatal mortality rate of 6.35 and neonatal mortality rate of 4.6 per 1,000 births.[5] Miscarriage occurs in 10–20% of clinical pregnancies and accounts for 50,000 inpatient admissions to hospitals in the UK annually (RCOG 2006). Every day in the UK, 17 babies are

[1]Woman - will refer to women, partners and their families throughout this document

[2] Department of Health, Social Services and Public Safety, (DHSSPS 2009).Northern Ireland Health and Social Care Services Strategy for Bereavement Care. Belfast, 2009.

[3]Stillbirth and Neonatal Death Society, (SANDS 2011). *The Sands Audit Tool for maternity services. Caring for parents whose baby has died*. London, 2011.

[4]Royal College of Obstetricians and Gynecologists, (RCOG 2006). *The Management of Early Pregnancy Loss*: Clinical Green Top Guideline No 25, London. http://www.rcog.org.uk/womens-health/clinical-guidance/management-earlypregnancy-loss-green-top-25 (assessed 15th Nov 2012).

[5]http://www.nisra.gov.uk/archive/demography/publications/births_deaths/deaths_2013.

stillborn or die shortly after birth, and there are almost 6,500 baby deaths every year. Over two-thirds of these stillbirths and deaths occur in maternity units.

2.0 Purpose of this guide

The aim is to aid professionals in providing support to women and their families throughout the time of the loss of their baby. This guide should be read in conjunction with the relevant regional care pathway (depending on gestation of pregnancy loss). The overarching aim is to:

- promote a sensitive and thoughtful parent and family-centered approach to care
- provide health professionals and others with the guiding principles of good evidence-based practice
- establish a regional standard of care throughout Northern Ireland by the implementation of the Regional Bereavement Pathways for Care
- provide guidance around the various legislations, for example, The Human Tissue Act 2004[6].

3.0 Women and family centered choices

Pregnancy loss can occur in many different circumstances, and parents and families being told that their baby has died before or around birth is devastating. The grief experienced by parents, close relatives and friends is extremely distressing. They will therefore require considerable support from all health and social care staff who care for, or come into contact with them during this time.

Long-term emotional support is essential and extremely beneficial. General Practices and some of the charitable organisations offer support to anyone affected by the death of a baby before, during or shortly after birth.

[6] The Human Tissue Act 2004 accessed at http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/legislation/humantissueact.cfm

No matter how or when a pregnancy has ended a woman's individual needs must be carefully and sensitively addressed. Adequate time should be given to provide verbal and written information and support, as there are a number of different choices available in relation to bereavement care. Women and their families need time to reflect in order to make choices that are best suited to their needs.

It is recommended that Health and Social Care Trusts should ensure the services of a dedicated **Bereavement Midwife** who would have the capacity to provide continuity of care to women and their families.

4.0 Spiritual, religious and cultural support

Women and their families will have access to relevant cultural, religious and spiritual support. This can be either through hospital staff (Chaplains) or through their own personal contacts. There should be availability of a multi-faith room or quiet facility where parents and their families can spend time together.

Staff need to ensure that they are fully aware of the options available to women and their families in order to discuss these with them to make informed decisions. If possible, staff should ascertain the parents' wishes and requirements for any specific cultural or religious customs. These may include decisions regarding the parents' last wishes for remains, taking their baby home, funeral arrangements, reflecting on the impact of different faith and/or religious beliefs.

Parents should have the opportunity to make their own personal choices regarding memories. They should also be informed of memorial events, either those that are organised through the Trust, for example, *Book of Remembrance*/*Annual Memorial Services* or other memorial events. Staff should be mindful of the need for this opportunity for parents to create positive memories and physical mementoes to provide a focus for their grief. These reminders will prove to be invaluable for the women and their families during the grieving process and beyond.

5.0 Psychological and emotional aspects of care

Opportunities to allow for reflection by women and their families must be planned as part of the management of care. They may have lots of questions and seek answers as to why their baby has died. In particular, they may also have questions on what happens next and about the physical and emotional reactions they are likely to experience. Staff should inform parents of the availability and range of relevant support services and provide contact details if required.

All midwives and medical staff have responsibility in providing compassionate care and support. The role of a dedicated Bereavement Midwife is an important one as it will provide consistent advisory support to professionals and vital counselling services to women and their families. For a small number of women however, the services of an accredited counsellor should be offered.

6.0 Continuity of care and communication

It is important to work in partnership with parents and their families, keeping them informed about the plan of management of their care before, during and after the loss of their baby.

The importance of continuity of care and carer, the involvement of senior clinicians and effective communication in the co-ordination of care is paramount. Less experienced staff can be involved in the care with supervision and support. They should be present during any discussions with the parents so that they are fully conversant with the care plan and can gain valuable experience and develop their skills in bereavement care.

The holistic approach to care including good communication in relation to referrals and handover of care should improve co-ordination and avoid unnecessary repeated questioning, thereby impacting positively on the overall experience of the parents and families.

It is also important that professionals caring for these parents and families protect the dignity of the bereaved parents by showing respect and understanding of the distress they are experiencing[7][8]

> *'Never forget the tissue you hold in your hands isn't just a piece of tissue, it is a mum and dad's baby son or daughter, a baby they had hopes, dreams and aspirations for'*
> *Quote from Peter and Lynne Ross, bereaved parents of baby Ruth*

For this to become a reality Trusts and individual professionals need to acknowledge the impact perinatal loss and subsequent care can have on bereaved parents and recognise that efforts must be made to ensure that parents' grief and distress is not unnecessarily exacerbated[9].

Communication interfaces among all professionals involved including Community Midwife, Health Visitor and the woman's GP, is key to the ongoing, holistic approach to care. This includes the importance of when to share information in a timely manner with all professionals involved in providing care. Parents and their families should be notified of who will visit them and when in the days immediately after discharge.

6.1 Follow-up appointments

The follow-up care of bereaved parents is considered a very important component of care. Each appointment provides the opportunity for women and their families to be seen by the consultant in charge of their care and to receive the results of any investigations. Every effort should be made to be sensitive regarding location and settings for follow-up care and support arrangements. This should, where possible, be planned with the woman.

> For example, we have learnt of women, following loss, attending review clinics where babies could be heard crying

[7]Department of Health Social Services and Public Safety, (DHSSPS 2008).*Improving the Patient & Client Experience*DHSSPS, Belfast.
[8] Department of Health Social Services and Public Safety, (DHSSPS 2009).Northern Ireland Health and Social Care Services Strategy for Bereavement Care
[9]Hughes, K.H. (2013) *Perinatal bereavement care: Are we meeting families' needs?* British Journal of Midwifery April 2013 Vol 21, No 4. London

If the appointment for follow-up is arranged in a hospital setting, avoiding a maternity facility should be considered.

7.0 Recordkeeping (reporting and recording)

Good record keeping is an integral part of practice and is essential to the provision of safe and effective person-centred care. Discussions with women, and specific choices or requests made by them, should be clearly documented in the Regional Maternal Hand Held Record and in the specific bereavement pathway. Care should be based and documented on current evidence from NICE Clinical Guideline 154[10], RCOG Green Top 25[11], Green Top 55 Guideline[12] and MBRRACE –UK[13].

Guidance for nurses and midwives on record keeping is provided through the Nursing and Midwifery Council's *The Code*[14] (2015) and additional support may be accessed through the Northern Ireland Practice and Education Council[15].

Medical Staff guidance on record keeping practices is provided through the General Medical Council (GMC), *Good Medical Practice*[16] (2013).

7.1 Certification

Staff should be fully conversant with all procedures, forms and certificates explaining these to parents and what they have to do with them. For a baby born dead before 24 weeks, the law does not require or permit certification or

[10]National Institute Clinical Excellence, (NICE 2012). Ectopic pregnancy and miscarriage. Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage.Issued: December 2012**NICE Clinical Guideline 154** guidance.nice.org.uk/cg154Clinical Guideline 154

[11]Royal College Obstetricians and Gynecologists (RCOG 2006). ***Early Pregnancy Loss, Management (Green-top 25)***. London.

[12]Royal College Obstetricians and Gynecologists (RCOG 2011). ***Late Intrauterine Fetal Death and Stillbirth*** **(**Green Top 55).

[13] Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE – UK 2015). Perinatal Confidential Enquiry. Term, singleton, normally formed, antepatrum stillbirth. November 2015. https://www.npeu.ox.ac.uk/mbrrace-uk

[14] Nursing and Midwifery Council (2015) The Code. Professional Standards of practice and behaviour for nurses and midwives. Accessed at http://www.nmc.org.uk/standards/code/

[15]Northern Ireland Practice and Education Council (NIPEC 2010). *Evidencing Care - good record keeping practices*. Belfast www.nipec.hscni.net

[16]General Medical Council (2013). *Good Medical Practic. A*ccessed: www.gmc.uk.org/guidance/good_medical_practice.asp

registration but parents should be offered a **delivery certificate** from the hospital.

In the case of a stillborn baby (born dead after 24 weeks) a Certificate of Still-birth should be completed and given to the parents to register their stillborn baby.

For babies born alive, who subsequently die, a Medical Certificate of Cause of Death (MCCD) issued by a doctor enables the deceased's family to register the death.

All staff completing MCCD or stillbirth forms should ensure that they are competent by updating their knowledge and reflecting on their practice. Additional information can be obtained from:
https://www.dhsspsni.gov.uk/publications/guidance-death-stillbirth-and-cremation-certification

7.2 Registration

Stillbirth

There is no legal requirement to register a stillbirth unless the parents wish to bury or cremate their baby. Most parents however, see this as an opportunity to have a formal record of their child. A stillbirth may be registered within one year of the date of the birth. To enable the parents (or others) to register a stillbirth they should be given a Certificate of Still-birth signed by a registered medical practitioner or registered midwife who was present at the birth, or who has examined the body of the stillborn child.

Neonatal death

If a baby is born, then breathed or showed any signs of life irrespective of gestational age, there must be a Notification of Birth completed by the midwife, as well as the MCCD completed by the doctor. Parents should be advised of the need for registration of both birth and death in this instance.

7.3 Who can register a stillbirth?

If married, the mother or father can register their baby as a stillbirth. If the parents are not married to each other, the name of the father may only be recorded if he attends and signs the registration, or if a declaration of paternity is produced.

The following people may also register the stillbirth:

- the grandmother, grandfather, uncle or aunt of the stillborn child
- any person present at the stillbirth
- any person having charge of the stillborn child
- the occupier of the premises where the stillbirth took place

Details required to register a stillbirth

- full name of the stillborn child
- sex and date of the stillbirth
- district and place of stillbirth
- full names and dates of birth of the parents and full addresses and occupations of the parents
- Certificate of Still-birth (GRO33)

Once the registration is completed the Registrar will issue a Still-birth Certificate (GRO34) free of charge.

7.4 Certified copies of stillbirth certificates

Due to the sensitive nature of stillbirth registrations the procedure for ordering a certificate differs from that for other types of certificate.

The mother or father (if named on the certificate) can apply for a certified copy of the certificate (GRO34).

The cost of a certificate is £15.00, or if two or more copies of the same certificate are applied for at the same time, the first copy will be charged at £15.00 and any additional copies at £8.00 each.

If the parents are deceased or unable to make an application another family member can apply, providing their reason for doing so. The application will be considered and a decision made on a case-by-case basis.

To perform a search of the registers the fee is £7.00 for each five-year period or part of it. The results of the search will be sent to the applicant in a letter. A certificate can be issued when an additional £8.00 fee is paid.

For further details contact: http://www.nidirect.gov.uk/index/information-and-services/government-citizens-and-rights/births-and-registration/registering-a-stillbirth.htm

Or call - General Register Office, Telephone - 0300 200 7890 (028 9151 3101 if calling from outside Northern Ireland)

Address - Oxford House
49-55 Chichester Street
Belfast

7.5 Consent

Consent is a person's agreement for a health professional to provide care, treatment or perform investigations. For the consent to be valid the person must:

- be competent to take the particular decision
- have received sufficient information to take it

- not be acting under duress[17].

All healthcare staff seeking consent for histopathology, examinations and/or hospital post mortem must be appropriately trained.

7.6 A post-mortem examination on a baby may be

- Full - external and internal examination of the body after death. It is also called an autopsy. This is carried out by a paediatric pathologist - a doctor specialising in the diagnosis of disease in babies and identification of the cause of death
- Limited - combines an external examination with a partial internal examination. The internal examination will be limited to whatever parents are willing to consent to, for example, a single organ such as heart or brain, a body system such as the respiratory system, or one area of the body such as the chest or abdomen. Tissue blocks and tissue slides will be made in the same way as for a full PM examination
- External option - the baby's body will be visually examined and measurements taken. The body will not be opened or organs removed. Photographs and x-rays may be taken. Other tests, including analysis of chromosomes, can be carried out with parents' consent. This examination will provide limited information. Staff explaining this procedure will need to discuss the limitations and implications with the parents.

The length of time required to obtain results may vary and parents should be informed that this will take at least three months. It is important to let them know that they will be informed when the results are available. Copies will be sent to the woman's obstetrician and GP. There will be a follow-up appointment with their obstetrician to discuss the PM results

[17] Department of Health, Social Services Public Service (2003). **Good practice in consent:** Implementation guide for health care professionals. Belfast, DHSSPS.

For further guidance, see RCOG and DHSSPS **HSC Consent for Hospital Post-Mortem Examination Regional Policy Jan 2011, and information for parents leaflet: http://www.dhsspsni.gov.uk/booklet-parents-baby.pdf.**

Other information can be obtained in Sands (2013) *Guide for consent takers*; Seeking consent/authorisation for the post mortem examination of a baby

7.7 Cremation/burial of babies by Trust

Parents may wish to make their plans to bury or cremate their own babies. It is therefore important to note that each HSC Trust will have its own policy and local arrangements on cremation or burial.

Staff need to ensure that they are familiar with these arrangements so that a clear and full explanation of the choices available to parents can be given.

If a Trust does arrange cremations, these will take place at Roselawn Crematorium and cannot be attended by the families. When the baby's body is to be cremated, the appropriate cremation forms must be completed. The ashes are scattered in the 'Garden of Remembrance' at Roselawn. If however, the baby was 12 weeks gestational size or over, and it is the parents' wish, the ashes can be retained with prior agreement at Roselawn for collection - more detail obtained in the appropriate pathway. There is no fee attached to the cremation of a baby and a certificate of cremation will be issued. Contact:

Roselawn Cemetery and Crematorium
127 Ballygowan Road
Crossnacreevy
Belfast
BT5 7UD
Telephone 028 9044 8288

8.0 Role of Coroner

The Coroners Service for Northern Ireland (CSNI) has a remit for all of Northern Ireland and is headed by a High Court Judge. Coroners in Northern Ireland are either barristers or solicitors and are appointed by the Lord Chancellor. They inquire into deaths that:

- Have a cause other than natural illness or disease
- Are unexpected or unexplained
- Occur as a result of violence
- Occur as a result of an accident
- Occur as a result of negligence
- Are from any circumstances that may require investigation.

In accordance with the recent CMO letter HSS(MD)38/2014 which outlines the conditions whereby deaths of “a fetus in utero then capable of being born alive”, these need to be reported to the coroner. Medical practitioners must, based on current survival rates, consider babies born from 23 weeks onwards as well as stillbirths. If **at the point of demise** this fetus was capable of being born alive then the case needs to be reported to the coroner.

Furthermore, if the coroner wishes to perform a post-mortem consent from the parents is not requirement.

In addition, funeral arrangements cannot be confirmed until the Coroner has authorised the release of the body. Families should be informed that a death cannot be registered until the Coroner's investigation has been completed. The DHSSPS will be revising their advice to the HSC on this issue.

9.0 Role of NIMACH (Northern Ireland Maternal and Child Health)

NIMACH (Northern Ireland Maternal and Child Health) facilitates HSC Trusts in N.I to submit data to the national Maternal, Infant, Newborn and Child Health Clinical

Outcome Review Programmes (also known as confidential enquiries). The National programme is run by the MBRRACE-UK consortium -:
Mothers and Babies: Reducing Risk through Audit and Confidential Enquiry. [https://www.npeu.ox.ac.uk/mbrrace-uk]

Contact details for NIMACH:	**NIMACH Regional Office, Public Health Agency Eastern Office (floor 2), 12-22 Linenhall Street, Belfast BT2 8BS**
Telephone: 028 9055 3611	

10.0 Multidisciplinary team support and care

All staff should receive training in the principles of bereavement care and sensitive communication with parents. This should be included within their induction and continuous professional development, which should include 'breaking bad news'. Training for ancillary and administrative staff is equally important, especially when communicating with parents and families at this sensitive time.

Good practice would indicate that the team providing the care to bereaved women and their families would benefit from a supportive culture within the organisation, for example:

- *de-briefing meetings* - should be arranged soon after an unexpected pregnancy loss for all professionals – for example, intrapartum stillbirths, unexpected neonatal deaths. These meetings should be facilitated by a senior member of staff or external facilitator. Although attendance is voluntary, all the professionals who have provided care/support and treatment before, during and after loss of a baby should be encouraged to attend. Further support should be provided by the Trust for staff if they require it, and additional support for midwives may be obtained from their Supervisor of Midwives (SoM)
- *case review meeting*- recommended for all stillbirths, intrapartum and neonatal deaths. This should involve a small multidisciplinary internal team,

an external review may be considered on occasions. NPSA proformas are a useful resource and recommended for use[18]. These case review meetings will enable transparency with those who have suffered a pregnancy loss and allow reflective learning for individuals involved; lessons should be learnt and shared with the entire team, if appropriate

- *perinatal meetings* - should occur on a regular basis, with multidisciplinary attendance, to continually review any interesting case and contribute to lifelong learning and professional development
- Regional learning from child deaths classified as Serious Adverse Incidents (SAI).

The above meetings are specifically designed to provide an open, transparent environment to review and support reflective learning on the practice, care and collaborative working of the team involved.

[18]DHSSPS (2011) Letter from Jim Livingston - **CMACE – The Centre for Maternal and Child Enquiries Report "Perinatal Mortality 2008"**
http://www.nrls.npsa.nhs.uk/resources/type/toolkits/?entryid45=66360

11.0 Use of Regional Bereavement Pathways

Regional Bereavement Pathways have been agreed for use and should be implemented in all HSC Trusts. They provide a detailed flow of the management of care to guide and support professionals and aid the delivery of high quality, evidence-based care, whilst providing women with the information they need to make their choices.

There is a suite of care pathways to cover miscarriage, intrauterine deaths and neonatal deaths. These are as follows:

No	Pathway
1	Pregnancy loss up to 12 weeks - (standalone)
2	Pregnancy loss pathway for intrauterine death (Miscarriage) between 12-20 weeks
3	Core Care Pathway for all babies after 20 weeks
3A	Baby born 20-24 weeks without signs of life - (Late fetal loss)
3B	Baby born greater than 24 weeks without signs of life (Stillbirth)
3C	Baby born at any gestation with signs of life, who then dies
4	Neonatal Death of a baby of any gestation, in the first 28 days of life or in a Neonatal Unit

12. 0 Pregnancy Loss up to 12 weeks

12.1 Introduction

This section of the guidance should be read in conjunction with Pathway no.1 in relation to the care and management of pregnancy loss in first trimester. This will include ‘missed’ and ‘incomplete miscarriage’, ‘early fetal demise’, ‘ectopic’ and ‘molar pregnancy’.

12.2 Definition

Pregnancy loss before 12 weeks (11wks + 6 days) gestation or fetus < 12 weeks size on ultrasound scan.

12.3 Women/family-centered care

HSC Trusts should provide a dedicated early pregnancy assessment service seven days a week. This service must be appropriately staffed by trained healthcare professionals competent to diagnose and care for women with pain and/or bleeding in early pregnancy. Ultrasound, including trans-vaginal and serum beta HCG assessment, must also be available.

Parents should be seen within 24 hrs of referral. A second ultrasound scan, a minimum of seven days after the first scan, should be provided before confirming a diagnosis and deciding ongoing management

Information both verbal and written should be provided for parents when there are uncertainties after an ultrasound scan, or if the pregnancy is of unknown location. They should also be given a 24hr contact number (NICE 154)

Patient choices – all women should have choices available to them such as: expectant medical management as an outpatient or inpatient; manual vacuum aspiration; or surgical management. These should be discussed with them and they should be given sufficient time to make their decisions. Throughout a woman's care, supporting information leaflets should be provided and explained to them if required. There may also be a need to signpost them to additional appropriate information that can be retrieved online

All women should be treated with dignity and respect. The importance of care and compassion when communicating information is extremely important for example, although professionals may describe this as fetal loss, to the woman and her family the loss is that of a baby, regardless of gestation.

When examining tissue passed by the woman an identifiable fetus may not always be present but if a fetus is seen, then the mother may wish to see the fetus to have the opportunity to create memories. The presence of a fetus

should be recorded in the pathway with a description, measurement and if possible a photograph.

Staff need to ensure careful recording of the parents' choice regarding their last wishes for the remains

All existing antenatal appointments, classes and scan appointments should be cancelled, including the Bounty service

All professionals involved in care should be notified of stillbirth.

13.0 Guidance - Pregnancy Loss from 12 weeks to 20 completed weeks

13.1 Introduction

This section of the guidance is for care of parents of babies delivered between 12 and before 20 weeks and includes those born with no signs of life and those born alive on the threshold of viability. It should be read in conjunction with Pathway 2.

13.2 Definition

A baby born with no signs of life is legally defined as a late miscarriage.If signs of life are seen at birth, then this is defined as a live birth and therefore needs to be registered as such. If the baby subsequently dies soon after birth, it will be defined as a neonatal death. Each unit should have a policy on the care of babies born alive, after 20 weeks gestation (Pathway 3 and 3C).

The NMC[19] in their circular, quoting the Who Health Organisation (WHO) explain:

'a live birth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or any definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached'.

[19] http://www.nmc-uk.org/Documents/Circulars/2007circulars/NMCcircular03_2007.pdf

13.3 Women/family-centered choices and care

- Care pathways need to be adapted according to gestation and whether the fetal heart is present
- If delivery is after 12 weeks, induction of labour will need to be discussed
- If a late miscarriage is diagnosed, discussion should include the management choices being either conservative, or medical inpatient
- The choices for bereavement care and support should be the same as for third trimester losses.

All existing antenatal appointments, antenatal classes and scan appointments should be cancelled and the Bounty service cancelled. All professionals involved in care should be notified of stillbirth.

14.0 Guidance - Pregnancy Loss from 20 weeks or later

14.1 Introduction

This section of the guidance should be read in conjunction with Pathways numbered 3, 3A, 3B and relates to the care and arrangements where a baby is born at 20 completed weeks' gestation or above without signs of life.

The circumstances may vary to include those where it is known that the baby will not be born alive, and those where the death of the baby is unexpected and occurs during labour or birth. In all circumstances parents will be in need of continuous sensitive support time and space to make decisions when they feel ready.

14.2 Definitions

Late Fetal Loss (Miscarriage): Up to 23 completed weeks with no signs of life.

***Stillbirth**:* Refers to a baby born with no signs of life, known to have died after 24 completed weeks of pregnancy (NIMACH).

***Intrauterine fetal death**:* Refers to a baby with no signs of life in utero.

14.3 Women/family centred choices and care

If a woman is unaccompanied, an immediate offer should be made to call someone to support her. Partners should also be supported and encouraged to stay with the woman. Each family will have unique needs which must be recognised and addressed.

- Breaking bad news proforma should be implemented
- It is important that diagnosis and ongoing care should be explained to the woman by a member of senior medical staff
- All findings should be conveyed to the woman and accompanying person sensitively, in a private area. Staff should be aware of the impact of the initial shock and grieving process affecting their ability to understand the news they have been given
- The woman should be given clear, concise information regarding her options for ongoing management
- Time should be allowed, according to individual needs, for questions to be asked and answered and a plan of care devised
- If a woman is going home prior to hospital admission, contact numbers and appropriate advice should be given in the event of any concerns
- Arrangements for time and date of admission should be made, unless the woman wishes to have an immediate induction of labour
- A suitable side room (preferably a dedicated bereavement suite) should be available for the woman and her partner with facilities for them to stay overnight

- Written information on choices and care may be given to the woman at the appropriate time
- Parents should be given the opportunity to speak with an experienced obstetrician before discharge
- The process of induction including care in labour, the use of a partogram and analgesia options should be discussed with the woman and her partner/relative
- Information regarding available investigations, including discussion regarding post mortem of the baby, should occur if considered appropriate at this stage
- Women's choices in care should be documented in the hand held maternity record, to include:

    - Wishes on who will be at the birth
    - Seeing and holding the baby
    - Cultural requests
    - Options for spiritual support should be discussed and spiritual advisors contacted as per woman's request
    - Options for burial and cremation
    - If a woman wishes her partner to stay overnight, this should be facilitated.

Continuity of care should be provided where possible and a 'teardrop sticker' should be placed on front cover of the mother's record and an explanation of the symbol given to parents.

14.4 Information

Information relating to stillbirth and neonatal death should be provided in written format at time and place appropriate to the family's needs.

Information should be given to parents regarding stillbirth certificate, and advice and assistance given, if requested, in relation to the use of a funeral director and regarding funeral arrangements.

14.5 Follow-up care

Explanations should be given regarding follow-up arrangements and the role of key professionals following discharge. This will be adapted according to local arrangements but will include:

- Review visit with Consultant Obstetrician to discuss investigations
- community midwifery service
- General Practitioner
- may include social workers and
- dedicated bereavement midwife.

Contact details of local voluntary and community support groups and resources should be provided. Explanations should be given to parents regarding local arrangements for books of remembrance and memorial services or events.

If it has not been appropriate to discuss any of the topics prior to discharge home, the community midwife should be informed of what has been discussed.

All existing antenatal appointments, antenatal classes and scan appointments should be cancelled and the Bounty service cancelled. All professionals involved in care should be notified of the baby's death.

15.0 Guidance - Neonatal Loss

15.1 Introduction

This section of the guidance relates to the care and arrangements where a baby is born at any gestation with signs of life, but subsequently dies in the first 28 days of life or in Neonatal Unit. This should be read in conjunction with Pathway 4.

The circumstances of a neonatal death can vary greatly from situations where the parents are aware that the baby has a serious abnormality incompatible with life, to those where death occurs unexpectedly shortly after birth or at some time in the first 28 days of life. In all circumstances parents will require ongoing, sensitive support and care. Each family will have unique needs which must be recognised and addressed.

15.2 Definition

Neonatal death – 'death of a live born baby (born at 20 weeks gestation of pregnancy or later, or 400g where an accurate estimate of gestation is not available) occurring before 28 completed days after birth'. (MBRRACE, 2013)

15.3 Women/family-centred choice and care - (please refer to point 14.3)

A fetal abnormality incompatible with a baby's survival may be diagnosed on ultrasound in the antenatal period. In this situation time should be taken in the preparation of the parents. This should include involvement of paediatric staff as appropriate. Good written communication among all staff is essential, especially between obstetric and neonatal staff.

All findings should be conveyed to the woman and partner or family member in a private, sensitive area.

The woman should be given clear, concise information as to what her options are for ongoing management and the support available during and after her pregnancy. Time should be allowed, according to individual needs, for

questions to be asked and answered, and a plan of care devised. Other professionals involved in care should be informed with parents' permission.

15.4 Care and support on admission for delivery

A suitable side room should be available for the mother and her partner. Information regarding care in labour and analgesia options should be discussed with the woman and the partner/relative.

Discussions regarding available investigations, including discussion regarding post mortem of the baby, take place if considered appropriate at this stage. There should be opportunity for discussion regarding immediate care at birth and what measures will be taken to ensure the comfort of the baby as far as possible.

Ample time should be allowed to answer questions and the discussion should be documented in the maternal hand held record, along with the woman's wishes for care including:

- Wishes on who will be at the birth
- Seeing and holding the baby
- Cultural requests
- Spiritual support
- Post-mortem, disposal of remains

Privacy and continuity of care should be ensured as far as possible.

15.5 After a neonatal death

When a baby dies, parents need clear and sensitive confirmation that their baby has died. Emphasis should be on individual needs, with available options explained clearly and fully, and adequate time given to consider choices. Options for spiritual support should be discussed, and spiritual advisors contacted as per parents' request.

If the woman is in a hospital facility, there should be consideration for her partner to stay overnight if she wishes. Other carers involved in the woman's postnatal care should be informed promptly of the baby's death e.g. Community Midwife / Health Visitor / GP.

'Teardrop sticker' should be placed on front cover of the woman and a record documented about the Consent for PM has having been discussed.

15.6 Information

Information relating to neonatal death should be provided in written format at time and place appropriate to the family's needs. Information should be given to parents regarding Medical Certificate of Cause of Death (MCCD) and the need to register the birth, as well as the death. Advice and assistance should be given, if requested, in relation to the use of a funeral director and regarding funeral arrangements.

15.7 Follow-up care

Explanations should be given regarding follow-up arrangements and the role of key professionals following discharge. This will be adapted according to local arrangements but include community midwifery service, General Practitioner, and review by consultant neonatologist and or obstetrician, and may include social workers and dedicated Bereavement Midwife. Contact details of local voluntary and community support groups and resources should be provided. Explanations should be given to parents regarding local arrangements for books of remembrance and memorial services or events. If it has not been appropriate to discuss any of the topics prior to discharge home, the community midwife should be informed of what has been discussed. Care should be taken to ensure that all existing antenatal appointments, antenatal classes and scan appointments should be cancelled, and the Bounty service cancelled. All professionals involved in care should be notified of the stillbirth.

16.0 Useful contacts

NAME OF ORGANISATION	ADDRESS AND TELEPHONE NUMBER
Sands **Stillbirth and Neonatal Death charity**	http://sandsni.org/ Helpline: 0774 099 3450
Tiny Life	33 Ballynahinch Road Carryduff BT8 8EH Tel: 028 9081 5050 Fax: 028 9081 5850 Email: info@tinylife.org.uk
Life after Loss	http://www.lifeafterloss.org.uk/site/
Miscarriage Association	Tel: 01924200799 Email:info@miscarriageassociation.org.uk http://www.miscarriageassociation.org.uk/
NIDirect	http://www.nidirect.gov.uk/index.htm
Patient and Client Council	Tel: 0800 917 0222 Email: info.pcc@hscni.net
Remember Our Child	Piney Ridge, Knockbracken Healthcare Park, Saintfield Road, Belfast, BT8 8BH. Tel - 028 9079 7975
Cruse Bereavement Care	http://www.cruse.org.uk/ Tel: 0844 477 9400
Twins and Multiple Births Association TAMBA	58 Howard Street, Belfast, BT1 6PJ Tel/Fax. (028) 9023 9050 Email: nioffice@tamba.org.uk

HSC TRUST 'S ADDITIONAL CONTACTS

NAME OF ORGANISATION	ADDRESS AND TELEPHONE NUMBER

Pathways available as stock order items:

WPH000888	Pathway 1	Pregnancy loss up to 12 weeks
WPH000889	Pathway 2	Pregnancy loss pathway for Intrauterine death (miscarriage) between 12-20 weeks
WPH000890	Pathway 3	Core care pathway for all babies after 20 weeks
WPH000891	Pathway 3a	Baby born 20-24 weeks without signs of life (late fetal loss)
WPH000892	Pathway 3b	Baby born greater than 24 weeks without signs of life (Stillborn)
WPH000893	Pathway 3c	Baby born at any gestation with signs of life, who then dies
WPH000894	Pathway 4	Neonatal Death of a baby of any gestation, in the first 28 days of life or in a neonatal unit

Regional Bereavement Guidance and Integrated Care Pathways

Steering Group

Name	Designation	Organisation	Contact Details
Zoe Boreland – (Chair)	Midwifery Officer	DHSSPS	zoe.boreland@dhsspsni.gov.uk
Dr Heather Livingston	Medical Officer	DHSSPS	heather.livingston@dhsspsni.gov.uk
Hilary Patterson	Bereavement Midwife	SEHSCT	hilary.patterson@setrust.hscni.net
Gwyneth Peden	Trust Bereavement Coordinator	NHSCT	gwyneth.peden@northerntrust.hscni.net
Stephen Guy	Sands	Voluntary Organisation	stephen.guy@uk-sands.org
Rev Jack Moore	Chaplain	NHSCT	MethodistCpln.AAH@northerntrust.hscni.net
Dr Ann Hamilton	Consultant Obstetrician	SEHSCT	ann.hamilton@setrust.hscni.net
Brenda Devine (Project Lead)	Senior Professional Officer	NIPEC	brenda.devine@nipec.hscni.net

Department of Health, Social Services and Public Safety
Castle Buildings
Stormont
BELFAST
BT4 3SJ
Telephone: 028 90520500
Email: webmaster@dhsspsni.gov.uk

NIPEC
Centre House
79 Chichester Street
BELFAST, BT1 4JE
March 2012
Tel: 028 9023 8152
Fax: 028 9033 3298
Website: www.nipec.hscni.net

November 2014
Updated December 2015