

PATHWAY FOR MANAGEMENT

OF FATAL FETAL ANOMALIES AND/OR LIFE-LIMITING CONDITIONS DIAGNOSED DURING PREGNANCY

PERINATAL PALLIATIVE CARE

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Loss and Perinatal Death**

January 2019

PATHWAY FOR MANAGEMENT OF FATAL FETAL ABNORMALITIES AND / OR LIFE LIMITING CONDITIONS DIAGNOSED DURING PREGNANCY

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1. BACKGROUND

Around 2-3% of pregnancies are complicated by congenital abnormalities, around 15% of which are life-limiting or potentially life-limiting.

In the United Kingdom, MBRRACE-UK report the perinatal mortality rate as 5.92 per 1,000 births (2016); while in Ireland, the National Perinatal Reporting System (NPRS, 2016) reports a perinatal mortality rate of 6.2 per 1000 livebirths. The leading cause of early neonatal death in Ireland is reported as congenital malformations (37.4%) with immaturity contributing to 17.6% of total early neonatal deaths (NPEC, 2017). Major congenital anomaly was the primary cause of death in over one in four (n=79, 26.9%) of the 294 Stillbirths that occurred in Ireland in 2015 (NPEC, 2017).

Advances in antenatal diagnosis of fetal abnormalities, obstetric care, neonatal care and care at the margins of viability have all increased the need for decision making about end-of-life care for the fetus and neonate. These decisions present both clinicians and Parents with new and difficult challenges.

The British Association of Perinatal Medicine (BAPM; 2010) has suggested categories where palliative care is indicated, including three antenatal scenarios:-

- An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, or
- An antenatal or postnatal diagnosis which carries a high risk of significant morbidity or death,
- Babies born at the margins of viability, where intensive care has been deemed inappropriate

2. AIMS

The purpose of developing a pathway of care is:

- to enable clinical staff to deliver consistent, high quality ongoing care for families electing to continue or terminate pregnancy with a fetus with a life-limiting condition/fatal fetal abnormality or potential life limiting condition
- to develop and communicate advance care plans
- to help ensure uniform standards of care wherever families are cared for in Ireland.

This pathway deals with two circumstances:

- Prenatally diagnosed fatal fetal anomalies or life-limiting conditions.
- Imminent birth of a preterm pre-viable fetus.

This pathway does not refer to

- Newborn with postnatally diagnosed life-limiting condition.

3. ANTENATAL DIAGNOSIS OF FATAL FETAL ANOMALIES / LIFE-LIMITING CONDITIONS

Structural anomalies are usually suspected or diagnosed at routine ultrasound screening in the first or second trimester of pregnancy. They can also be seen at routine scans carried out as part of general antenatal care at any stage including late pregnancy. It is important to note that ultrasound scans will not identify all structural anomalies

The Obstetrician or the Midwife/Sonographer performing a routine booking/dating or anomaly ultrasound scan may be faced with the initial breaking of bad news to the pregnant woman and partner. A second opinion may be sought in such circumstances. Those performing the initial scan should respond to Parents' questions with whatever information is available at that time.

Prompt referral to a fetal medicine specialist ideally within 24 to 72 hours is the standard of care where a major fetal anomaly is suspected followed by provision of written information resources and support. While awaiting referral the Parents should be given contact details of a support person in the referring hospital.

There are different pathways around antenatal diagnosis/initial care:

- Antenatal diagnosis of a major structural abnormality may be made at the 11-13-week scan or second trimester anomaly scan and is ordinarily confirmed by either the local obstetrician and/or fetal medicine consultant in a tertiary centre (or by a fetal medicine specialist from the tertiary centre who has a sessional commitment in another unit).
- The majority of pregnant women in this situation will be referred to the tertiary hospital (or to the fetal medicine team in the tertiary centre) in their area for review and assessment by fetal medicine specialists. This may include additional investigations (e.g. invasive testing for genetic diagnosis or fetal MRI), and recourse to specialist fetal echocardiography for cardiac anomalies. These cases are subsequently discussed by the multi-disciplinary team (usually at the tertiary site) to reach a consensus about the diagnosis and prognosis and to consider any implications for maternal health where the pregnancy is on-going.
- Some fetal conditions for which there are simple definitive diagnostic tests and an unequivocal prognosis (e.g. T13, T18, anencephaly), may be diagnosed and managed entirely at local hospital level, especially where fetal medicine expertise exists. In other cases, invasive testing may occur at the tertiary unit, but results are communicated to local units and ongoing care is managed with the local obstetricians and neonatologists/paediatricians, supported as needed by the tertiary site.

Referral to fetal medicine services

What is a fetal medicine specialist?

A fetal medicine specialist is a medical practitioner who is actively practicing in the area of fetal medicine. The fetal medicine specialist has undergone specific further training either through an approved Maternal-Fetal Medicine (MFM) fellowship or a higher qualification in diagnostic ultrasound or has a long-term expertise in ultrasound/fetal medicine and trained at a time before these fellowships/qualifications were available.

Fetal medicine consultation

A fetal medicine specialist should confirm the antenatal diagnosis of a structural anomaly and a suspected fatal fetal anomaly / life-limiting condition (FFA/LLC).

This will usually involve performing diagnostic ultrasound on an appropriate, functioning, up to date ultrasound machine. Further invasive investigations including amniocentesis, chorionic villus sampling, fetal blood sampling to establish the fetal genetic profile, in addition to maternal bloods and fetal MRI to confirm the diagnosis or to add further information may be necessary.

All fetal medicine units should have timely access to clinical genetics specialists who may advise further on the type of testing necessary, depending on the ultrasound presentation/family history and previous history. All fetal medicine units should have timely access to fetal MR Paediatric radiology specialists when clinically appropriate, for confirmation of diagnosis, or when additional information is warranted. A perinatal cardiologist using fetal specialist echocardiography should assess cardiac anomalies or cases where specific abnormalities are associated with cardiac anomalies. This should be carried out in the relevant tertiary centre, ideally within a short time frame.

Appropriate investigations may need to be agreed by a multidisciplinary team (MDT). This is not essential in fetal conditions for which there are simple definitive diagnostic tests and an agreed prognosis, e.g. anencephaly.

These investigations should be followed by a multidisciplinary team discussion to agree the diagnosis and prognosis and to consider any implications for maternal health and antenatal care. The diagnosis and prognosis is then explained and discussed with the Parents.

Principles of management

The option of continuing the pregnancy with planned perinatal palliative care for the baby or terminating the pregnancy should be discussed with the Parents. These discussions are usually held with the fetal medicine team and associated professionals. It can be helpful to involve neonatologists / paediatricians at this point.

There is a significant challenge in decision-making for Parents related to the degree of certainty of the antenatal diagnosis, expected prognosis, and the certainty of lethality, as well as the meaning of the diagnosis for the family.

For some, terminating a pregnancy is the right decision for them and their family, but it is rarely what we understand as a 'choice'. It is often traumatic. Others may benefit from an alternative approach and continue their pregnancy. A perinatal palliative care approach can provide support to families who make either of these decisions and hospital guidelines must be structured in a way to allow this.

Types of antenatal diagnosis

Fatal fetal anomalies/life-limiting conditions (FFA/LLC) have an almost certain diagnosis and prognosis, including a very high chance of death in utero or by 28 days of life (the neonatal period) despite medical treatment.

Potential Life-Limiting Conditions include diagnoses where there is a significant chance of death in utero, in the newborn period, or in early infancy, and are often associated with substantial burden of care for the family.

These diagnoses also include pregnancies complicated by second trimester pre-term pre-labour rupture of membranes (PPROM), where early neonatal mortality from pulmonary hypoplasia is the anticipated outcome irrespective of gestation at delivery.

Definitive diagnosis may follow early or mid-trimester ultrasound. However, prognosis may not always be clear at the time of diagnosis and may be influenced by a variety of factors including gestational age, fetal growth restriction, multiple pregnancy and rupture of membranes.

Neonatology input may be necessary to ascertain and/or agree on prognosis, and specialist colleagues (e.g. surgery, cardiology, neurology, radiology, and genetics) should be consulted as necessary. If there are differing opinions within the team, then additional formal multi-disciplinary team meetings may be necessary.

Where a diagnosis or prognosis is uncertain there is still a role for perinatal palliative care input. However, definitive plans about post-natal care may need to be deferred until after birth. If there are differing opinions within the team, then additional formal multi-disciplinary team meetings may be necessary.

It is important to note that lists of fetal diagnoses or conditions are not static over time. Any list of eligible diagnoses may become outdated in a number of years. Similarly, combinations of fetal abnormalities which by themselves may not be lethal, in combination with other abnormalities could lead to a prognosis that is extremely poor and the following list should not be considered to be exhaustive or complete.

Fatal fetal anomalies /life-limiting conditions include diagnoses that are highly likely to lead to death in utero or in infancy. For these conditions, the diagnosis and prognosis are unequivocal. Estimates of prevalence range from 1 in 1000 (anencephaly) to 1 in 10,000 (Triploidy; Trisomy 13, Renal agenesis).

FFA/LLC include: but are not limited to

- Bilateral Renal agenesis
- Severe skeletal dysplasia
- Anencephaly/acrania
- Thanatophoric dwarfism
- Trisomy 13 or 18
- Triploidy
- Hydranencephaly
- Severe osteogenesis imperfecta
- Multicystic/dysplastic kidneys with early onset anhydramnios
- Polycystic kidney disease with early onset anhydramnios
- Congenital severe hydrocephalus with absent or minimal brain growth
- Non-immune hydrops with major cardiac defect
- Inoperable conjoined twins

Potentially life-limiting conditions (PLLC): include diagnoses where there is a significant chance of death in utero, in the newborn period, or early infancy. Prognosis may not always be clear at the time of diagnosis, and it may not be clear until after birth whether or not active intervention is indicated.

PLLC include but are not limited to:

- Severe multicystic dysplastic kidneys and oligohydramnios
- Severe hydrocephalus
- Life-limiting complex cardiac defects as agreed with the paediatric cardiology team
- Holoprosencephaly
- Hydrops fetalis

4. PREGNANCY OPTIONS AFTER DIAGNOSIS OF FFA/LLC OR PLLC

Following diagnosis of FFA/LLC or PLLC, Parents should be counselled about all available pregnancy options. This includes continuation of pregnancy with a perinatal palliative care plan, or (in some cases where the prognosis is uncertain or may change) continuation of pregnancy with a perinatal palliative care and a post-natal care plan.

Parents should also be counselled by their consultant obstetrician regarding their options to terminate the pregnancy, in accordance with the Health (Regulation of Termination of Pregnancy) Act, 2018.

Initial counselling is usually delivered by the fetal medicine consultant/obstetrician with fetal medicine training with input from a specialist midwife/ midwife sonographer. Additional counselling may be provided from a neonatologist/paediatrician. In cases of serious fetal anomaly, Parents should always receive counselling from a fetal medicine specialist. In some cases, it would be helpful if the fetal medicine specialist and Neonatologist/Paediatrician met the Parents together for a consultation.

It is good practice to ensure that fetal medicine multidisciplinary team (MDT) discussions should form an important component of the assessment of fetal anomalies, their prognosis and outcomes. A summary of the outcome of these clinical meetings should be documented in the clinical notes. These discussions would include management plans for the delivery of the care.

If either the Parents or members of staff are still uncertain about the diagnosis or prognosis, a second opinion, either internal or external, should be sought. The involved department should arrange this, although some Parents may want to choose another tertiary centre, and this should be facilitated in a timely fashion, ideally within 24-72 hours.

Healthcare professionals should be aware of their personal beliefs and consider the possible influence they may have on women's experiences, especially when caregivers and women's choices diverge.

Ideally, to develop expertise all staff should be mentored by senior colleagues before taking the lead in this sensitive area. It is particularly important to discuss openly Parents' priorities, hopes and fears, in order to facilitate shared decision-making that is respectful of Parents' values, and

to tailor support to their needs. Respect for the values and decisions of Parents is central to providing compassionate supportive care.

5. CARE AROUND TERMINATION OF PREGNANCY

Where a prenatal diagnosis of a serious fetal anomaly is made during pregnancy, management options include continuing or terminating the pregnancy.

Healthcare professionals should know what the law allows and be clear about the circumstances in Ireland for which termination of pregnancy for fatal fetal anomalies is legal in 2019 and beyond (Health (Regulation of Termination of Pregnancy) Act, 2018).

Women should have access to accurate and objective information and, if required, counselling and support. There should be local arrangements in place for providing value-neutral information to women about termination of pregnancy.

These decisions may be revisited over time by the family, and as clinical information about prognosis may change during the pregnancy.

For some Parents, termination of pregnancy in Ireland may not be an option, and this may be for complex reasons including legislative restrictions in Ireland for non-fatal fetal anomalies, the need to travel to another country for treatment, financial or social considerations, as well as the medical procedures involved.

During this time, and before termination of pregnancy, these Parents should be assisted with preparing for the birth and death of their baby. Opportunities for memory-making can be discussed and planned, as well as the logistics around making arrangements for the baby when the family are back in Ireland (and/or when/if baby's remains are returned).

Care following termination of pregnancy

For many, termination of pregnancy is seen as the only pathway to coping into the future, and these families need to be supported and given access to resources to help them through their grief. However, the care must be provided in a place away from busy maternity clinics and areas of routine clinical activity.

Parents need integrated and ongoing support through the end of the pregnancy, delivery and into the postnatal period, as well as bereavement care.

Parents must be offered bereavement support by the bereavement team in their local hospital (e.g. the Bereavement CMS/CNS, or the CMS in Prenatal Diagnosis). The bereavement team (a named HCP) should follow up with the Parents and offer them bereavement support, as with Parents who experience pregnancy loss/ fetal death within the hospital.

All women (and partners) should be offered a review appointment (or support visit as appropriate) in the weeks (2-4 weeks) following the procedure to assess the woman's wellbeing. These Parents must also have a follow-up postnatal appointment with the fetal medicine team and/or their local obstetrician, to assess wellbeing and review results of any post-mortem

investigations. This post-pregnancy visit should also discuss potential planning for future pregnancies (if appropriate) and relevant preconception care or early prenatal screening.

Refer to Pathway for Management of Fetal Anomalies/ Life-limiting Conditions diagnosed during Pregnancy – Termination of Pregnancy; Institute of Obstetricians and Gynaecologists, RCPI, January 2019

6. THE PRETERM PRE-VIABLE INFANT

What is a pre-viable preterm infant?

Though debate continues to exist, 22+6 weeks is the approximate agreed cut off for viability. From 23 weeks, survival rates of 19-30% have been reported in Ireland (NPEC, 2018).

Where should these babies be born?

While an updated position paper is awaited from the RCPI/RCOG, current practice would suggest transfer to a tertiary centre from 23 weeks for management if delivery is imminent. If gestation is uncertain or unknown, this should be discussed on a case-by-case basis.

In pregnancies up to 22 weeks and 6 days, intensive care would not be offered to the infant, therefore it is appropriate for the Mother to give birth in her booking (local) hospital.

Decisions about palliative care

Perinatal palliative care may be indicated where birth at the margins of viability is anticipated.

Discussion with the family should take place prior to the birth of the infant; where possible remote from the day of delivery, but there will always be emergent and unpredictable situations where these discussions are held shortly before birth. Because of gestation and/or other associated issues (e.g. congenital abnormalities, preterm rupture of membranes, multiple birth), a decision about non-intervention may be made prior to birth. For other infants, intensive care may be initiated at birth and later discontinued.

Parents should be informed of these possibilities prior to the birth of their infant and kept updated as events unfold.

7. PERINATAL PALLIATIVE CARE (PPC)

Definitions of perinatal palliative care

- Perinatal palliative care provides holistic multidisciplinary support for families facing the death or potential death of their newborn infant. It is an active or total approach to care, from the point of diagnosis or recognition through to the infant's death and beyond (Thames Valley Framework, 2017).

- The provision of ongoing support from the diagnosis of a life limiting condition in a fetus, and during pregnancy, delivery, post-natal care and bereavement care (NICE, 2016).
- Palliative care for the fetus, neonate or infant with life limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the neonate and support for the family. It includes the management of distressing symptoms and care through death and bereavement (Together for Short Lives, 2017)
- Perinatal palliative care is described as the holistic management of supportive and end of life care following multidisciplinary agreement on eligibility for a fetus, and their family (NHS, Scotland, 2013).

Guiding principles of perinatal palliative care

- To provide timely support tailored to the needs of families
- To provide multidisciplinary support for Parents' choices and values
- To facilitate delivery close to the family's home
- To provide specialist input and advice to support local hospitals to provide PPC to families delivering in their local hospital
- To provide training and support for staff locally and in regional units providing PPC
 - to enable confidence to care for the Mother in the antenatal period,
 - to care for the baby at birth,
 - to engage in parallel planning,
 - to assist in transitioning to the neonatal unit and/or home
 - to deliver a responsive end-of-life care plan.

Who is eligible for consideration of perinatal palliative care?

Women and families who have had an antenatal diagnosis of a confirmed or potentially life-limiting condition, and who are continuing their pregnancy are considered eligible for PPC.

While women and families who opt for termination of pregnancy may not be referred to all members of the multi-disciplinary team, their care can still have a perinatal palliative *approach*.

It is important to remember that if a woman decides to continue her pregnancy knowing that her baby has a condition that will cause significant disability impairing quality of life but is not life limiting, the baby is not necessarily eligible for palliative care.

Referral for perinatal palliative care

Referral can be made at any point from diagnosis to enable care planning for pregnancy and after birth. Perinatal palliative care input may be valuable at any point after diagnosis. How the referral is made and to whom will depend on a number of factors:- where the diagnosis of LLC/PLLC was made, and/or where ongoing care is planned, as well as the planned place of birth, and arrangements that may be specific to each hospital.

Fetal medicine consultants/ obstetricians and neonatologists/ paediatricians should be involved together in care planning; the Bereavement CMS/CNS may act as liaison antenatally.

Suggested Multidisciplinary Team Members for perinatal palliative care

Consultant Obstetrician / Fetal Medicine Specialist
Consultant Neonatologist / Paediatrician Consultant
Paediatric Palliative Care Consultant
Hospital Bereavement Clinical Midwife/ Nurse Specialist
Dedicated Prenatal Diagnosis / Fetal Medicine Midwife
Prenatal diagnosis Co-Ordinator/CMS
Delivery Suite Senior Midwife
Midwife sonographer
Maternity Social Worker
Neo-natal Unit Senior Midwife/ Nurse
Midwife on postnatal / pregnancy loss wards
Chaplaincy / spiritual care

Key components of palliative care planning

Bereavement support should be provided all along the care pathway and continue through the baby's death and beyond.

Place of birth

For babies with confirmed FFA/LLC, the aim is to facilitate delivery in their local hospital, in which they had originally booked their care.

Delivery in the tertiary centre may be appropriate (as would be the case for any pregnancy), where there are anticipated specialist obstetric or neonatal care needs that cannot be provided in local hospital. Where this is planned, the local hospital should remain updated concerning care planning, as some patients will present locally in emergency situations. The tertiary centre is responsible for communicating the care plans to the referring (local) hospital and GP.

Potential life-limiting conditions (and with an uncertain prognosis) would often require delivery in the tertiary centre. These decisions around appropriate place of birth should be made well in advance by the multidisciplinary team and communicated appropriately to all.

Advance care planning

This is appropriate for an ongoing pregnancy where the baby has an anticipated FFA/LLC.

The process of advance care planning involves discussions with Parents about the goals and desired direction of their baby's management, particularly with regard to end of life care. This typically covers Parents' concerns and wishes about care, including what should be done, where, how, when and by whom.

Importantly, advance care plans also consider what should not be done. An effective care plan allows care to be delivered according to the wishes of the family allowing them to retain autonomy, to influence how they are looked after and what is done to their baby.

For Parents who have received a definitive diagnosis the focus needs to be on supporting Parents to build a relationship antenatally with their baby and on individualised memory-making, preparing them for the birth and death of their baby. Family-centered care, including psychological, spiritual and social support should be available throughout.

For Parents where the diagnosis is uncertain and/or prognosis is unclear until after birth, the antenatal period is also a time where their obstetrician may sensitively bring up the option of post-mortem investigations and examination.

Planning obstetric and neonatal management around birth is important to ensure that the care reflects the wishes of Parents and the best interests of the baby. Formal care plans should be communicated to all involved in the pregnancy. Communication between tertiary and local centres needs to be clear and timely

Parallel planning

For conditions with uncertain prognosis, or where longer-term survival is possible, planning needs to encompass a range of possible outcomes, and can involve elements of active medical management and palliative care.

Parallel planning includes:-

- consideration of end of life care and early death
- ongoing care needs in the event of survival
- transition from routine care to neonatal palliative care, (or vice versa)

While there are many conditions where there is reasonable certainty of death during fetal and neonatal life, there are babies who survive longer than expected during supportive and end-of-life care. It is vital that all care planning is continuously reviewed in the best interests of the baby. There should be parallel planning for transition periods into and out of active, supportive and end-of-life care. The care plan may need to be altered to allow for changes in the place of care, the condition of the Mother or the baby and the Parents' views and wishes

Training and support of staff and multidisciplinary teams

Successful implementation of a PPC pathway will require appropriate training and support for staff to enable confidence to care for the baby at birth and to deliver the supportive and end-of-life care plan. For deliveries where the baby is anticipated to die soon after birth, consideration should be given to supporting and (formally and informally) debriefing staff caring for the family; these needs should be assessed in each circumstance. This is the responsibility of local hospital management.

8. OVERVIEW OF DELIVERY OF PERINATAL PALLIATIVE CARE

Maternal health and wellbeing during pregnancy, birth and the postnatal period remain components of maternity care, including when there is a perinatal palliative approach to the care of the baby.

Joint consultation with obstetrics/neonatology or paediatrics/palliative care/midwife specialists potentially serves to ensure efficient review within the shortest time, reducing unnecessary overlap in counselling, and improve communication between teams.

Antenatal care

It is important to get an accurate antenatal diagnosis for the baby to ensure that consistent clinical care and management are provided to the Parents.

In most cases, the Mother would continue to receive antenatal care with individualised support from the multidisciplinary team. There is a focus on supporting Parents to build bonds with their baby in the antenatal period, as well as on memory-making and antenatal counselling/anticipatory grief counselling.

If the fetal diagnosis increases the risk to maternal health, additional appropriate antenatal care should be arranged (e.g. fetal hydrops or polyhydramnios). Care can be revised and agreed by the Multi-Disciplinary Team and the Parents as the pregnancy progresses and circumstances change.

Parents might request more frequent or less frequent visits to the antenatal clinic, depending on the circumstances and personal feelings. However, if there is any risk to maternal health, appropriate and timely antenatal care should always be arranged. Fetal medicine assessment should continue alongside antenatal care.

Ideally, Parents should not be asked to sit in the waiting room with women with healthy pregnancies, and on arrival to the antenatal clinic should be met by a dedicated antenatal clinic midwife who is familiar with the family's circumstances.

The staff whom the Parents meet at the clinic should also be informed of the situation beforehand and a dedicated antenatal clinic midwife should be present for the consultation, whenever possible. This will help with continuity of care and avoid unintentionally saying things that could cause additional distress to the couple.

Mothers should be encouraged to discuss their wishes for labour and birth before preparing a birth plan. An explicit care plan should be developed in conjunction with the Mother, which should include the question of fetal monitoring (normally not recommended if there is certainty around the diagnosis of FFA/LLC), the action to be taken in the event of abnormal fetal monitoring, the conduct of the delivery, and how the baby will be handled and cared for at and after the birth. An anaesthetic review may also be organised to discuss analgesia at the time of delivery.

In general, timing of delivery should have been discussed by 34 weeks' gestation, and a plan documented in medical notes.

Where a preterm birth is anticipated or imminent, discussion with the family should also take place prior to the birth of the infant, and plans documented. Because of gestation and/or other associated issues (e.g. congenital abnormalities, preterm rupture of membranes, multiple birth), a decision about non-intervention may be made prior to birth. For other infants, intensive care may be initiated at birth and later discontinued.

Options around neonatal organ transplantation may be discussed with the Parents during the pregnancy and plans can be put in place for this, as appropriate, after birth.

The Mothers medical chart must be updated throughout the pregnancy. The antenatal diagnosis and care plan must be clearly documented in the notes.

Intrapartum care

In general, unless there is a specific maternal health issue, the aim would be to wait for spontaneous labour. Caesarean section would be considered if labour would increase risk for the Mother.

The plan for management of labour and delivery needs to be clearly documented and communicated to the hospital staff who will be involved in the family's care. It should be discussed and specified who should or should not be present at the delivery (e.g. paediatricians, chaplaincy, and family members).

There needs to be a focus on the emotional support given to the Parents during labour and delivery. The Parents' personal wishes around the care of their baby, including comfort care, bonding, cultural & religious preferences, need to be facilitated.

Non-resuscitation or limitations to resuscitation should be discussed and regularly reviewed with the neonatal/paediatric team. The suitability of the care plan should be confirmed after birth by a senior paediatrician or neonatologist.

If a decision of non-intervention has been made prior to delivery, it is appropriate that the woman be managed by her healthcare team (midwife and obstetrician) during labour and delivery. The Paediatric/Neonatal team should be available for support and reassurance. A pre-viable preterm infant may breathe and have a heartbeat after being born. The family should be counselled about this prior to birth. Healthcare teams may also need to be supported.

The baby should remain with the family as much as they wish. The baby should be weighed, measured and examined for signs of congenital abnormalities when appropriate and at a time when the family are comfortable with this.

In the case that there is a failure to resuscitate the infant (e.g. in the preterm pre-viable infant) or intensive care is commenced and then discontinued, the baby should be returned to the care of the family as soon as possible.

Comfort measures and pain relief may be provided to the baby as per Paediatric Palliative Care Guidelines.

The different scenarios that may arise during labour / after birth should be discussed and where possible anticipated with the Parents:-

- Intrapartum death (death during labour resulting in Stillbirth)
- Neonatal death on the delivery suite (minutes or hours)
- Leaving the delivery suite / admission to wards for ongoing palliative care (days)
- Admission to the neonatal unit for care / investigation
- Discharge from the neonatal unit to be with the Parents for end of life
- Transition to neonatal palliative care in the neonatal unit and /or home /or location chosen by the Parents

Parents may wish to handle their baby immediately after birth. Some Parents may prefer not to see the baby until he/she is dressed.

In the event of baby's death, staff should explain to Parents the physical changes that are likely to occur as their baby dies and should discuss with them whether they want to see and hold their baby while dying / or after death. It is important to make it clear to the Parents that they can change their minds at any time.

A symbol that is recognised by hospital staff and the public should be 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 and may vary on the circumstances of bereavement (e.g. for multiple pregnancy, miscarriage or stillbirth). Parental consent for use of the symbol is necessary.

Postpartum care

After delivery care for the Mother should be as per usual local pathways following vaginal birth or caesarean birth.

It is important that women receive, as a minimum, normal postnatal care and emotional support from the midwives looking after her in delivery suite and on postnatal wards.

Parents/family bonding and holding the baby, providing comfort care and the making of mementoes should be facilitated (and encouraged), and in accordance with Parents' wishes.

In the case of fetal demise/infant death the local care pathways for same should be followed.

Bereavement support should be provided by members of the MDT caring for the Parents in conjunction with the bereavement CMS/CNS.

A senior member of staff (Obstetrics / Neonatology/ Paediatrics) should sensitively discuss consent to post-mortem (PM) investigations and examination to help clarify the diagnosis and management of subsequent pregnancies.

It is important for the family's GP and PHN to be informed as soon as possible of the outcome of the pregnancy.

Care after discharge from hospital

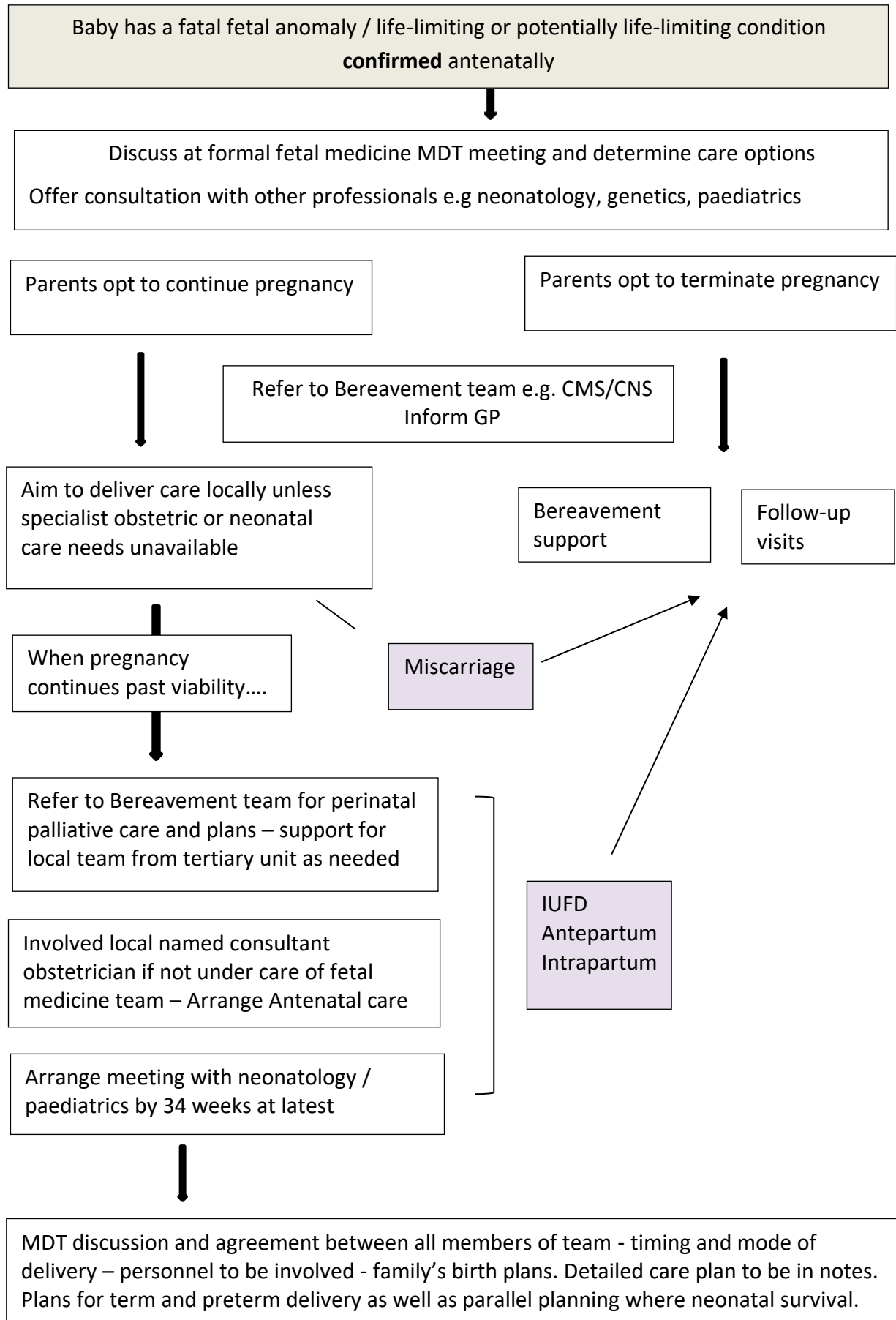
Liaison with the Bereavement support team and the family is important to ensure that the family receive appropriate support and bereavement support when the infant dies.

An obstetric (and sometimes additionally a neonatal/paediatric) review and debrief should be arranged a few months following the delivery. The discussion will be largely centered on the diagnosis and management. Investigation results and future pregnancies will be discussed.

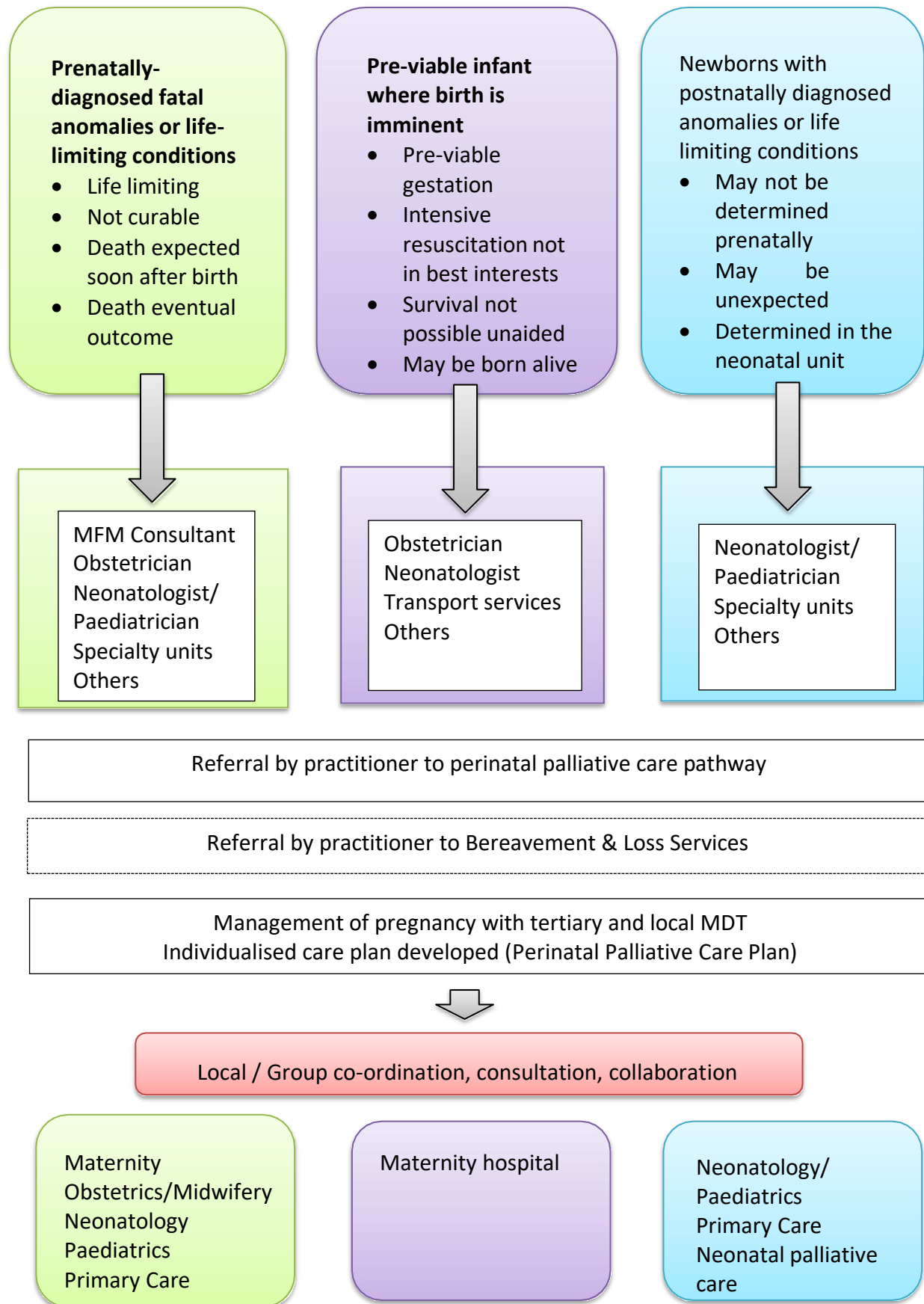
Where a PM examination has taken place, results should be shared with the Parents at the postnatal meeting. These reports should not be mailed directly to the Parents' home address either by the hospital or the local Coroner's office.

This is generally arranged in the hospital where the Baby is born, although may also involve the local Obstetrician, where the baby is born in a tertiary hospital.

9. PATHWAY



10 ENTRY INTO PERINATAL PALLIATIVE CARE (after WA Perinatal Palliative Model of Care, 2015)



11 CONTACTS AND SUPPORT SERVICES (Ireland)

A Little Lifetime Foundation (previously Irish Stillbirth and Neonatal Death Society)
www.alittlelifetime.ie

Anam Cara
<http://www.anamcara.ie/>

Every Life Counts
<http://www.everylifecounts.ie/>

Fèileacàin (Stillbirth and Neonatal Death Association of Ireland)
www.feileacain.ie

First Light (previously Irish Sudden Infant Death Association)
<https://firstlight.ie/>

Irish Childhood Bereavement Network
<http://www.childhoodbereavement.ie/>

Irish Hospice Foundation
<https://hospicefoundation.ie/bereavement-2-2/>

Irish Multiple Births Association
<http://www.imba.ie/>

Leanbh Mo Chroi
<https://lmcsupport.ie/>

Now I Lay Me Down To Sleep
<https://www.nowilaymedowntosleep.org/articles/nilmtdtsinireland/>

One Day More
www.onedaymore.ie

SOFT Ireland
<http://www.softireland.com/>

12 ABBREVIATIONS AND DEFINITIONS

ANTICIPATORY GRIEF	The normal grief response that occurs prior to death that includes sadness, sorrow, anger, crying and emotional preparation for death
CMS/CNS	Clinical Midwife Specialist/ Clinical Nurse Specialist
EARLY NEONATAL DEATH	Death of a live-born Baby within the first seven days of life
END OF LIFE CARE	Describes the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less. It is care of the baby before death, during death, after death and bereavement care.
EXTREME PRETERM	Preterm is defined as babies born alive before 37 weeks of pregnancy are completed. There are sub-categories of preterm birth, based on gestational age: extremely preterm (<28 weeks' gestation), very preterm (28-32 weeks' gestation)
FETUS	The developing baby in utero after 8 weeks of pregnancy
FFA	Fatal Fetal Anomaly/Anomalies
GRIEF	The reaction to loss and bereavement
HOSPICE	A philosophy of care with a focus on the physical, emotional and spiritual support of a person at end of life.
INTRA-UTERINE FETAL DEATH/IUFD	Describes the death of a baby in the womb.
LLC	Life-limiting condition
NEONATAL	Refers to the period after birth up until the fourth completed week of life
NICU	Neonatal Intensive Care Unit
PALLIATIVE CARE	Care of the patient with a life-limiting / life-threatening condition and their families- a philosophy of care.
PERINATAL PALLIATIVE CARE	Describes the perinatal palliative care of a baby when life expectancy is limited and death is imminent. It encompasses care of the baby from the time of diagnosis through to death, and care of the baby and Parents following death.
PERINATAL PERIOD	The period from 24 weeks gestation to 7 days following birth
PLLC	Potential life-limiting condition
PPC	Perinatal palliative care

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14 ACKNOWLEDGEMENTS

Permissions:

For permission to use detail from the Thames Valley Network Perinatal Palliative Care Framework Document:-

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