









North West Management of Stillbirth

Guideline



To be used in association with the North West Management of Stillbirth Integrated Care Pathway V4

To be used from 24+0 weeks gestation

If less than this please see

Second Trimester Pregnancy Loss Guideline and ICP

Version 4 March 2021



In honour of all the babies who are delivered stillborn and the parents and families who experience the unimaginable

Document Control

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I would also like to acknowledge and thank the contributions from members of the GMEC SCN Maternity Stillbirth Special Interest Group and North West Neonatal Operational Delivery Network.

Once finally endorsed these guidelines are available to be adopted across the North West (and anywhere else that finds this useful) in order that parents and their families receive universal and high quality care if they experience this difficult event.

Please note that appendices are geographically orientated and may need editing or localisation.

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1. Introduction

Stillbirth is a devastating event with enduring psychosocial consequences for parents, including anxiety and depression, guilt, complicated grief, social isolation, and relationship breakdown¹.

In 2018, approximately 1 in 263 babies in England were stillborn (3.8 per 1000). Although a welcome reduction from the previous year^{2,3} the UK continues to have an above average rate of stillbirth when compared to other high income countries.

Approximately 33% to 40% of stillbirths are small for gestational age⁴. The 8th Annual Report of the Confidential Enquiries into Stillbirths and Deaths in Infancy (CESDI) identified suboptimal care as being evident in half of the pregnancies⁵. Commenting about midtrimester loss (but equally applicable to stillbirth) a Sands (Stillbirth and Neonatal Death Charity) report noted "Poor or insensitive care at this traumatic time adds significantly to parents' distress. Good care should be universal and should not depend on where a mother happens to live or to be cared for." 6

This guideline has been written by a multidisciplinary team of professionals working in units across the North West Strategic Clinical Networks. This draws largely on the Royal College of Obstetricians and Gynaecologists (RCOG) Green Top Guideline No.55 Late Intrauterine Fetal Death and Stillbirth⁷. This guidance was reviewed and the recommendations considered as to how to integrate into a clinical guideline which also is written to support an integrated care pathway tool to enable optimal care to be given from the point of diagnosis of fetal death.

Definition

The definition of "stillborn child" in England and Wales is contained in the Births and Deaths Registration Act 1953 section 41 as amended by the Stillbirth (Definition) Act 1992 section 1(1) and is as follows:

"a child which has issued forth from its mother after the 24th week of pregnancy and which did not at any time breathe or show any other signs of life".

2. Presentation, Diagnosis and Immediate Care

2.1 Diagnosis

When an intrauterine fetal death (IUFD) is suspected this **must** be confirmed by twodimensional ultrasound at the earliest opportunity. If the diagnosis is suspected in the community setting then the mother should be referred to hospital for confirmation.

The optimal method will be a scan performed by trained sonographers. However, out of normal working hours a practitioner with appropriate training may use a portable ultrasound machine. The fetal chest should be imaged in the transverse so that a 4 chamber view can be identified. This is not always identifiable in cases of intrauterine death and colour flow Doppler is useful to verify the absence of heart activity. This may be documented on either electronically archived imaging or thermal paper.

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It is advisable to obtain a second opinion from a suitably trained person whenever possible although it is recognised that this may not always be possible in emergency situations.

Following the diagnosis and confirmation of an IUFD the parents must be given time to absorb and accept this news. A clear, sensitive and honest explanation should be given as to what has happened by experienced staff. The language used should be clear. Below is an example statement:

"I'm terribly sorry, I can see your baby's heart properly and it is not beating. I am sorry this means your baby has died."

If the mother has attended on her own, unless it is an emergency, it may be prudent to delay detailed explanation before support has arrived. An immediate offer to contact her partner or a family member or friend must be made and support given.

Many parents are surprised and shocked that they will still have to go through labour. Also that they may go home whilst awaiting delivery and that there may be a delay in giving birth to their baby who has died. It is vital that they are fully informed. Questions should be welcomed and encouraged.

The parents should be included in discussions about management – some mothers will want to go home and see other family members before delivery, others will want the induction to commence as soon as possible.

A patient information leaflet should be offered such as "When your baby dies before birth information for you" or "When a baby dies before labour begins" from Sands (Appendix 1). Options for management should be discussed which could include induction or expectant management. If the mother goes home the possibility of passive movements should be discussed with her and contact numbers should be given.

2.2 Stillbirth Following Late Termination of Pregnancy (TOP)

Infrequently, stillbirth can occur following termination of pregnancy following a diagnosis of a severe congenital abnormality. Parents need sensitive, non-judgmental and empathetic care.

The RCOG recommends that "for all terminations at gestational age of more than 21 weeks + 6 days, the method chosen should ensure that the fetus is born dead" 11. TOP at this late gestation requires administration of intracardiac potassium chloride (KCI) to the fetus, prior to induction of labour.

In certain specific situations where the fetus would die in the immediate neonatal period from the abnormality (which are anencephaly, limb body wall complex, bilateral renal agenesis and lethal skeletal dysplasias) feticide is not a legal requirement¹².

This is a rare event and will be arranged in liaison with a tertiary centre (where the feticide will be performed). Clause E of the Abortion Act form will need to be completed by two doctors prior to performing this procedure.

The timing of medication will need to be agreed with the tertiary centre. In general mifepristone 200mg could be given 48 hours prior to the procedure, and the woman could then return to the local unit for induction after the procedure has been performed. However, if there is a high risk that labour will follow administration of mifepristone (e.g. if there is

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spontaneous rupture of the membranes, polyhydramnios or is near term / >34 weeks) then this should be given after the feticide.

The feticide procedure is performed under ultrasound control with 15% KCl solution injected into either the umbilical cord vein or heart. A further ultrasound scan is performed 30 minutes after the procedure to ensure fetal demise.

Ensure the woman has a 24 hour contact number, in case she starts to labour prior to her planned admission. Provide parent information booklets and literature i.e. ARC / Sands (see Support Organisations and Groups) as appropriate.

3. Psychological Support

The death of a baby can be associated with short term and chronic anxiety and depression not only in the mothers but also fathers and other family members. It is important to ensure that the family are well supported throughout the hospital stay and beyond, with as much continuity of care as possible. Every woman who has an IUFD is at risk of depression, but those with a previous psychiatric disease or of a vulnerable social group are at particular risk.

3.1 Place of Care

Whilst in hospital the parents should be cared for in a suitably furnished bereavement suite, both throughout the intrapartum course and the postnatal stay with close access to continuous midwifery/obstetric care. The partner/family may remain with the mother as long as she wishes.

3.2 Pastoral Care

Health care professionals caring for grieving families should ask if there are any religious customs which are important to the family.

Parents may want the opportunity to see their own religious leader or a member of Pastoral Care Chaplaincy Services. This should be facilitated by the maternity unit staff.

For more information on religious customs see https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/06/NWNODN-Religious-Practices-.pdf

Some Trusts hold an annual Remembrance Service, which parents should be informed about and may wish to attend.

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4. Multiple Pregnancies

Multiples make up approximately 3% of pregnancies in the UK with numbers rising significantly over the past 20 years due to the increasing use of assisted conception techniques such as IVF. Clinicians should be aware that intrauterine fetal death occurs more frequently in multiple pregnancies than singleton pregnancies. At gestations greater than 20 weeks there will be IUFD of one or more babies in approximately 6% cases.^{13 14}

Clinicians should appreciate the complexity and mixed emotions of couples who experience miscarriage, termination or selective reduction of one fetus with a surviving twin or higher order multiple. They will require the same support through delivery and bereavement care. Parents want to talk about the baby that has died and to acknowledge that they were twins. Some parents may wish to take photographs of the babies together so this should be discussed and offered.

The Butterfly Project has produced materials to educate staff so that the experience of families who have single fetal demise in a multiple pregnancy can be improved. The resources can be viewed at the following link: http://www.neonatalresearch.net/butterfly-staff-resources.html

The timing and mode of delivery for multiple pregnancies in the case of single fetal demise will depend on chorionicity, gestation, the position of the fetuses and the wellbeing of the surviving baby/babies. Specialist advice should be sought in complex cases (e.g. local multiple pregnancy lead). The following websites may give assistance in these circumstances: See patient information in **Appendix 1**.

4.1 The Butterfly Project: Supporting parents who have lost a baby from a multiple pregnancy

Parents who have suffered a bereavement from a twin pregnancy (or higher order multiple) face the difficult challenge of dealing with the bereavement, while often simultaneously feeling anxious about the prognosis for surviving multiples. They differ from parents who have lost a singleton in many ways, but one important difference is that parents who have lost a twin delivered prematurely often remain in hospital for weeks or months while the surviving twin is cared for on the neonatal unit. Staff attitudes, behaviours and actions have a huge impact on parents both in the short and longer term. Generally parents appreciate it when staff acknowledge that a surviving baby is a twin, and value the importance of knowing about the circumstance of the loss (e.g. when did it occur) as well as the name of the baby who died.

The two concepts developed by the Neonatal Research Network are:

- A small sticker of a butterfly that can be put on the front of the mother's notes, including hand held notes, where the loss happens before birth. Where the loss happens after delivery the butterfly could be placed on the medical notes of the surviving twin. However, check with your hospital that this is allowed.
- A butterfly symbol that is placed inside of, or next to the incubator or cot of any surviving babies. We have found that most parents like to write the name of the baby who died on the card. Remember to individualise care some parents may not wish for this.

For further reading see Appendix 2

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5. Delivery Management

This section is designed to assist midwives and obstetricians in the management of labour and birth in cases of IUFD and should be implemented once a robust diagnosis has been confirmed.

Over 90% of women in this situation will spontaneously deliver within 3 weeks of the IUFD¹⁵.

Problems related to delayed delivery are intrauterine infection if the membranes are ruptured or disseminated intravascular coagulopathy (DIC) if the fetus is dead for more than 4 weeks¹⁶.

In certain clinical situations the maternal medical condition will necessitate expediting the delivery.

6. Timing

Urgent delivery is required if there is sepsis, abruption/antepartum haemorrhage (APH), severe pre-eclampsia.

In these conditions it may be more appropriate for the woman to be cared for on the Labour Ward to monitor closely for any signs of ongoing bleeding or elevated early warning score and ensure the woman remains stable throughout her stay.

The method of delivery and/or induction of labour under these circumstances should be customised to the presenting condition and other patient factors including past obstetric and past medical history.

If the above have been excluded then timing and the process can be discussed with the mother by a senior clinician. The mother should be offered a choice of induction of labour or expectant management. If she chooses the latter option, then arrangements for review will need to be made. In the majority of cases of singleton IUFD parents opt to induce labour to expedite delivery.

On presentation, check full blood count (FBC), clotting screen and Kleihauer (irrespective of maternal blood group as this is to assess for fetomaternal haemorrhage). As there may have been fetomaternal haemorrhage, if the mother is Rhesus D negative an appropriate dose of Anti-D should be administered now. A further dose will need to be administered after delivery¹⁷.

If delivery is delayed >48 hours repeat FBC and clotting screen twice weekly.

Also advise that if expectant management is performed then:

- The value of some information from post mortem may be reduced
- The appearance of the baby may deteriorate

All mothers should be given a 24 hour contact number if they are managed as an outpatient for any time between diagnosis and delivery.

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Recommendations about labour and birth should take into account the mother's preferences as well as her medical condition and previous intrapartum history. Vaginal birth is the recommended mode of delivery for most women as this decreases morbidity and will have fewer implications for future delivery than a caesarean section. However a caesarean birth may be required due to past obstetric or medical history as well as emotional and psychological factors. Given this complexity the decision regarding mode of delivery should be made by the parents in consultation with a consultant obstetrician.

The timing and mode of delivery for multiple pregnancy will depend on chorionicity, gestation and the position of the fetuses. Specialist advice should be sought (e.g. local multiple-pregnancy lead).

Consent

Written or verbal consent should be obtained in line with Trust guidance prior to commencing the induction process.

7. Drug Information

Mifepristone is an anti-progestogenic steroid used as pre-treatment. It facilitates uterine response to subsequent administration of a prostaglandin and takes time to work so is usually given before prostaglandin.

This drug must only be administered in a maternity unit and patients should be observed when taking this medication.

Contraindications include – uncontrolled or severe asthma, chronic adrenal failure and acute porphyria.

Cautions – asthma, risk factors for cardiovascular disease, prosthetic heart valves or endocarditis and haemorrhagic disorders.

Misoprostol (prostaglandin E1) is usually used for induction of labour in late IUFD.

Cautions – inflammatory bowel disease, conditions that are exacerbated by hypotension (e.g. cerebrovascular or cardiovascular disease).

Side effects include fever, nausea, vomiting, abdominal cramping and diarrhoea. **These are less common if the tablets are given vaginally**.

Serious complications, including uterine rupture, major haemorrhage and cervical tear are rare.

7.1 Pre-induction

A single dose 200 milligram oral mifepristone is given and the mother should be allowed home wherever possible (unless she has a scarred uterus – see below). The interval between administration of mifepristone and misoprostol can be between 0 and 48 hours.

Arrangements should be made for admission to a labour ward with access to high dependency care 24 to 48 hours later, or sooner when there is an urgent need to deliver for

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obstetric indications. There is no evidence against earlier induction of labour following mifepristone – induction can occur anytime from 0 to 48 hours after administration.

7.2 Induction

(see section 7.3 for Termination of Pregnancy)

Unscarred uterus: No history of lower segment caesarean section

In women with a favourable cervix or in early labour, amniotomy followed by oxytocin infusion could be considered for induction or augmentation of labour.

In women with an unfavourable cervix misoprostol should be administered.

Vaginal assessment should be performed prior to commencing oral or vaginal misoprostol.

The dosage of misoprostol to be administered will depend on the gestation at which the IUFD occurred (see table below).

Misoprostol is typically available as a 200 microgram scored tablet

100 microgram doses can be obtained by dividing a 200 microgram tablet into two halves using a pill cutter. Similarly, 50 micrograms can be obtained by dividing the ½ tablet into 2 (i.e. ¼ tablet) – use pill cutter for accurate division.

For the sublingual route the tablet should be held under the tongue or between the teeth and cheek for 30 minutes with the remnants swallowed after this time. FIGO recommend vaginal/sublingual or buccal.

Women with an unscarred uterus

Mifepristone 200 milligram single dose followed by misoprostol 0 to 48 hours later.

Unscarred u	Unscarred uterus				
	Gestation	Misoprostol	Dose	Comments	
Unscarred uterus	24+0 to 26+6 weeks	200 micrograms	PV/SL/PO 6 hourly (5 doses)	If not effective, discuss with Consultant - consider repeat misoprostol at least 12 hours after the last dose	
Unscarred uterus	27+0 to 27+6 weeks	100 micrograms	PV/SL/PO 6 hourly (5 doses)	If not effective, discuss with Consultant - consider repeat misoprostol at least 12 hours after the last dose	
Unscarred uterus	28+0 to 42 weeks	50 micrograms	PV/SL/PO 6 hourly (5 doses)	If not effective, discuss with Consultant - consider repeat misoprostol at least 12 hours after the last dose	

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Women with a scarred uterus: History of caesarean section or atypical uterine scars

There is an increase (between 3% and 12%) in risk of uterine rupture in women with IUFD who have had a previous caesarean section¹⁸. Discussion about safety and benefits of induction of labour should be undertaken by a Consultant Obstetrician.

 One previous lower segment caesarean section (LSCS). If the cervix is favourable then induction by amniotomy and oxytocin can be used – discuss with Consultant on call.

In women with an unfavourable cervix:

- Mifepristone 600 milligrams should be given on 2 consecutive days, 24 hours apart.
 The woman should be advised to remain in hospital during this time.
- On day 3 a cervical ripening balloon should be offered.¹⁹
- Misoprostol may be considered for induction of labour in women with a single previous LSCS and an IUFD but with doses not yet marketed in the UK⁷.
- If not effective after a course of 5 doses, discuss with Consultant consider repeat misoprostol at least 12 hours after the last dose.

Scarred uterus				
Day 1	Mifepristone	600 milligrams	РО	
Day 2	Mifepristone	600 milligrams	PO	
Day 3	Cervical Ripening Balloon OR Misoprostol	50 micrograms	PV/SL/PO 6 hourly (5 doses)	

Women with 2 or more lower segment caesarean sections or atypical scars

Women with two previous LSCS should be advised that the safety is unknown regarding the risk of induction of labour with prostaglandin, therefore a cervical ripening balloon (CRB) may be associated with lower risk and should be considered^{20, 21}. This is associated with a lower hyper stimulation rate and higher maternal satisfaction and the uterine rupture rate is similar to that which occurs with spontaneous labour.

The regime above may be used. It is unknown what the absolute risk of uterine rupture is, however it can be stated to be higher than if only 1 LSCS. Thus, mode of delivery should be discussed with a Consultant Obstetrician on an individual basis.

7.3 Termination of pregnancy

Unscarred Uterus			
24 to 27+6 weeks	Misoprostol	200 micrograms	PV/SL/PO 4 hourly
28 to 42 weeks	Misoprostol	100 micrograms	PV/SL/PO 6 hourly

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Scarred Uterus

The safety of induction is unknown¹⁸ as frequently this is excluded from case series and therefore it is recommended to use the same method for induction as if the patient presented with an IUFD – see above.

7.4 Care in Labour

Women with IUFD should be admitted to a delivery room where their emotional and practical needs can be taken into account without compromising their safety.

Care in labour should be given by an experienced midwife. Ideally one to one care should be facilitated at least for the first 24 hours to support the mother and the family and undertake necessary paperwork, though this is aspirational and may not always be possible during times of high activity in the maternity unit. A Consultant Obstetrician should be made aware of the admission. Birth choices remain as for all women in labour and the woman's birth plan should be reviewed with her.

Blood tests including full blood count (FBC), clotting screen, and group and save should be performed.

Obstetric staff should be vigilant to clinical features that may suggest uterine scar dehiscence/rupture: Maternal tachycardia, atypical pain, vaginal bleeding, haematuria and maternal collapse.

A partogram should be used so that trends that may indicate this complication are apparent. Please see pregnancy loss partogram in the ICP (pages 5 and 6).

Ensure the woman has adequate analgesia for delivery of the baby.

Offer the opportunity to speak to the obstetric anaesthetist to discuss analgesic options.

All usual modalities should be made available, including regional analgesia and patient-controlled analgesia, taking into account any specific contraindications for each woman. Assessment for disseminated intravascular coagulopathy (DIC) and sepsis should be undertaken before administering regional analgesia.

If patient-controlled analgesia is chosen, fentanyl may be more appropriate than remifentanil. If intramuscular opiate analgesia is chosen, then diamorphine should be used in preference to pethidine.

Women with sepsis should be treated with intravenous broad-spectrum antibiotics as per Trust guidelines, including cover for chlamydia (if clinically high risk) after sepsis screening investigations have been performed.

Women with IUFD and Group B Streptococcal (GBS) colonisation of the vagina do not require antibiotic prophylaxis in labour.

7.5 Management of third stage

The third stage should be managed in accordance with local delivery guidance.

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7.6 Investigations

Parents report three reasons why they have investigations²², firstly, to find out why their baby died and to allow their grief to progress, secondly to find out useful information for subsequent pregnancies and finally for research to prevent stillbirths in the future.

Making a diagnosis allows more accurate prognostic information for future pregnancies. This is essential as women who experience one stillbirth are at a two to ten-fold increased risk of stillbirth in subsequent pregnancies so clinicians need information to develop management plans to prevent recurrence. Under-investigation impedes efforts at gaining an accurate diagnosis²³. Unfocused investigation could yield results which were not contributory to the death, thus clinicians should consider the clinico-pathological correlation between abnormal investigation results and the clinical condition.

Where there is a fetal malformation and the cause known investigation should be advised by the Consultant managing the case. In some circumstances no further investigations are necessary.

Even with full investigation parents should be advised that a specific cause for death may not be found in approximately 15% of cases²⁴.

Birthweight should be entered into the GROW database in order to generate the birthweight centile to identify if the baby was small for gestational age or of normal weight.

The three investigations most likely to give useful information are:

- 1. post-mortem
- 2. placental histology
- 3. fetal chromosomal analysis²⁵.

Postmortem provides useful information in 24.7% to 84.5% of cases, placental histology 69.5% to 95.7% and chromosomal analysis in 11.7% to 29.0%.

See the GMEC SCNs Integrated Care Pathway for Stillbirth for details of samples needed and timing of taking samples.

Before taking any investigations, a history and examination should be taken to appreciate the clinical presentation to guide investigations.

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The following investigations should be offered to <u>all</u> women unless cause known as in TOP for fetal anomalies:

1. Kleihauer to identify fetomaternal haemorrhage

Ideally taken as early as possible after presentation for all women, not only women who are rhesus negative.

2. External examination of the baby

This should be performed by the midwife and in cases of difficulty or suspected abnormality should be confirmed by a paediatrician, neonatologist or geneticist, see page 8 in the Integrated Care Pathway for verbal consent.

3. Screen for fetal infections

- Obtain a swab from the baby's axilla
- Placental swabs from the maternal aspect only
- Maternal serology for toxoplasma, rubella, Cytomegalovirus and parvovirus B19

4. Post-mortem examination

This requires informed written consent from an appropriately trained individual. It can be full, when all organs are examined or limited to specific locations e.g. head, chest or abdomen. The parents should be provided with a post-mortem patient information leaflet – examples of which can be found at Deciding about a post-mortem²⁶. Offer the parents the opportunity to discuss their options. If a post-mortem is accepted, consent is to be taken by an appropriately trained individual. Consent forms can be printed at Appendix 3.

5. Thrombophilia screen

Pregnancy suppresses the protein S and protein C levels and therefore results for analysis of these two factors will not be reliable if taken around delivery. Also, lupus anticoagulant and anticardiolipin antibodies should only be considered significant if two analyses show positive results 3 months apart. Any antiphospholipid screen (APS) screen should include anti B2GP1 antibodies with lupus anticoagulant and anticardiolipin antibodies as per the Sapporo International consensus statement on an update of the classification criteria for definite antiphospholipid syndrome (APS)²⁷.

The following is a suggested schedule:

Thrombophilia screen (all investigations)		
At delivery	Anticardiolipin antibodies/lupus anticoagulant Anti-beta2 glyco protein1 antibodies Factor V Leiden, Prothrombin gene variants	
At least 6 weeks postnatal	Protein C, Protein S, Antithrombin	
12 weeks postnatal	Repeat anticardiolipin antibodies/lupus anticoagulant if positive previously	

6. Placental examination

Placental pathology should be performed and is recommended even if post-mortem examination is declined. Swabs and cord samples should be taken prior to placing the placenta in formalin or other preservative as per local policy. If the placenta cannot be fixed in formalin, it should be refrigerated and sent to the laboratory at the earliest opportunity.

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The placenta should be examined by an experienced paediatric/perinatal pathologist. See appendix 4.

Report all infectious agents to the pathologist (for example coronavirus, hepatitis, HIV).

7. Fetal chromosome analysis (PCR or Microarray – see below)

Babies that are stillborn with known physical abnormalities on ultrasound scan or abnormalities noted at birth may benefit from genetic testing. This would be determined by the clinical geneticist.

Take 3cm of umbilical cord and place in saline for transport. In the absence of a fetal malformation there is unlikely to be a chromosomal cause for the stillbirth²⁸ ²⁹ ³⁰ ³¹.

In cases where fetal malformation is noted a microarray assessment will be performed on the section of umbilical cord. It is not necessary to send a maternal blood sample with the umbilical cord segment for microarray following a stillbirth. Microarray samples are processed at the Manchester Centre for Genomic Medicine.

If there is no malformation a PCR will be performed to assess for chromosome abnormalities of chromosomes 13, 18 and 21. PCR analysis is performed at the Liverpool Centre for Genomic Medicine.

Written consent should be obtained. Please use Section 6 of the **Post mortem Consent Form** in **appendix 3**, then complete statement box on referral form

"It is the referring clinician's responsibility to ensure that the patient/carer knows the purpose of the test and that the sample may be stored for future diagnostic tests".

Do not send cord samples for fetal sexing. See **Cytogenetic Testing** information in **appendix 5** for full referral criteria.

If in doubt contact the cytogenetics service. For Greater Manchester, this is St Mary's Hospital on 0161 276 6553. For Cheshire and Merseyside this is Liverpool Women's Hospital 0151 702 4229.

The following selective investigations should only be performed <u>if</u> there is a clinical indication:

1. Infection screening

If mother at presentation has had fever, flu-like symptoms, abnormal liquor (purulent or offensive) or prolonged ruptured membranes assess for maternal bacterial infection including listeria monocytogenes and chlamydia species:

- Maternal blood cultures
- Midstream specimen of urine (MSU)
- High vaginal and endocervical swabs

2. If birthweight < 10th centile on customised chart, placental abruption, placental insufficiency or pre-eclampsia

Thrombophilia screen - below is a suggested timing. It may be more relevant to take all these at delivery if failure to attend appointments is a risk.

Pregnancy suppresses the protein S and protein C levels and therefore results for analysis of these two factors will not be reliable if taken around delivery. Also, lupus anticoagulant and anticardiolipin antibodies should only be considered significant if two analyses show positive results 3 months apart. Any antiphospholipid screen (APS) screen should include anti B2GP1 antibodies with lupus anticoagulant and anticardiolipin antibodies as per the

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Sapporo International consensus statement on an update of the classification criteria for definite antiphospholipid syndrome (APS)³².

The following is a suggested schedule:

Thrombophilia screen (selective investigations)		
At delivery	Anticardiolipin antibodies/lupus anticoagulant Anti-beta2 glyco protein1 antibodies Factor V Leiden, Prothrombin gene variants	
At least 6 weeks postnatal	Protein C, Protein S, Antithrombin	
12 weeks postnatal	Repeat anticardiolipin antibodies/lupus anticoagulant if positive previously	

3. If history suggests maternal substance abuse

Maternal urine for cocaine metabolites (maternal consent required)

4. If hydrops fetalis is present

- Red cell antibody screen
- Maternal anti-Ro and anti-La antibodies
- Clinical genetic examination (even if post mortem declined)
- Skeletal survey (even if post mortem declined)
- Post mortem
- Placental histology (even if post mortem declined)

5. If fetal intracranial haemorrhage (on post mortem examination)

Maternal alloimmune antiplatelet antibodies

6. Parental chromosomes should be obtained only if

- Initial chromosomal analysis shows an unbalanced translocation
- If fetal chromosomal analysis fails with a high-risk history (e.g. abnormality on USS or PM, previous unexplained stillbirth or recurrent miscarriage)

7. If there is no obvious cause

- Bile acids
- HbA1c
- Thyroid function
- Thrombophilia screen (see above)

7.7 Certification

Legally, a medical certificate of stillbirth should be issued in all cases of stillbirth from 24+0 weeks gestation by a doctor or midwife who has either delivered the baby or thoroughly examined the baby afterwards. If there is any uncertainty of cause of death, clarity should be sought from a senior clinician. The direct cause, antecedent causes and other significant conditions that are recorded on the stillbirth certificate should be recorded in the mother's notes. Reference to the ReCoDe classification (Relevant Condition at Death) is a useful guide to ensuring that accurate information is recorded here (see Appendix 6).

Give stillbirth certificate to parents if required (see local policy as stillbirth certificate may be required to be emailed to the registry office or Trust bereavement office).

In extenuating circumstances (such as maternal death), the responsibility for registration may be delegated to the hospital after discussion with the Registrar.

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7.8 Maternal Care

Thromboprophylaxis – a risk assessment needs to be performed. Stillbirth increases the risk of venous thromboembolism 6-fold.^{15.}

If DIC is present then discuss thromboprophylaxis with a haematologist.

Suppression of lactation should be discussed and cabergoline 1 milligram **may** be administered orally, unless there is maternal hypertension/pre-eclampsia or puerperal psychosis. For rarer contraindications see the ICP page 19.

Some mothers choose to continue to express milk following the loss of their baby. While this option does not suit everyone, some families find comfort in continuing to express and donate. Healthcare professionals should discuss the option of milk donation with bereaved families to help make a decision that feels right for them. Further information can be found at https://www.milkbankatchester.org.uk/donate/donationafterloss, the North West human milk bank.

Parents should be informed that there is a strict screening process. Sometimes the bank may be unable to accept milk if the mother has taken certain medication. Some medication may be safe when breastfeeding however may not be acceptable for donation purposes. Parents should also be informed that the milk bank is unable to accept milk if anyone in their household smokes. If a bereaved mother expresses a wish to donate, the first step is to contact the milk bank. They will talk the family through the donor recruitment process and answer any questions. Alternatively, parents can fill in the online screening form using the above link.

Contraception should be discussed before discharge home.

8. Care of Baby

Each family's individual and cultural needs should be identified and accommodated. Assistance should be given to facilitate the grieving process including empathetic care, appropriate literature and contact telephone numbers.

8.1 Contact with baby

Seeing and spending time with their baby is valuable. It may be necessary to prepare parents about their baby's appearance if death occurred some time before the birth. Some parents may wish to see and hold their baby immediately after birth, others may prefer to wait; their decision should be respected. Parents are free to change their minds and can ask for their baby to be brought to them whenever they feel ready. Parents may wish other family members to be given opportunity to see/hold baby.

Parents should be offered the use of the cooling cot (if available) to maintain baby's skin condition. The use of the cooling cot can improve the quality of bereavement care as it allows parents to spend more time with their baby and enhances their lasting memories.

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8.2 Mementos

Mementos should be offered and obtained once the parent's verbal consent has been given. These may include a lock of hair or hand and foot prints, cord clamp, tape measure used to measure baby, cot card, and identity band. Most parents welcome these tokens and they can be presented in memory boxes.

If photographs are taken, these should be stored as per Trust guidelines. If mementos and/or photographs are requested but not taken home by parents these can be stored in the hospital records should the parents wish to access them at a later date.

Parents may wish to keep the linen from delivery or linen from incubator or cot and clothes baby was wearing.

8.3 Photographs of baby

Photographs of the baby are valuable and can be taken with the parents' own camera or with the hospital digital camera. If there is a multiple birth, photographs of the babies may be taken together and/or separately. If parents' own film/disposable camera is used, it is advisable that parents inform film developers that the film is of a sensitive nature.

Suggest different photos including family groups, photos of hands and feet and with baby dressed and undressed.

Taking photographs with the hospital digital camera requires parental verbal consent. Similarly, verbal or written consent may be required for photographs to be taken by medical photography (consult local Trust policy). Identification of the start and end of a series of photographs must be performed.

An additional option is http://www.remembermybaby.org.uk, a charity that has volunteer professional photographers who photograph babies for parents losing their baby before, during or shortly after birth.

9. Further Management of Baby Including Transfer and Funeral

Arrangements

9.1 Transfer of baby to the mortuary

Prior to transferring the baby to the mortuary, provide parents with the opportunity to spend special time with their baby.

Ensure that the baby has been properly identified. Recommendations for this include applying two completed name bands e.g. "Baby of (Mother's Name), Mother's Identity Number, date and time of delivery as well as hospital delivered at". Some Trusts use body labels as well, if this is the case, the card should read 'baby of (Mother's Name) and not as if it is the mother who has died.

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If the parents have given their baby personal items (teddy etc.) they should remain with the baby, (unless the parents change their mind), these can be labelled using identification bands.

Prior to transfer to the mortuary some Trusts wrap the baby in a sheet or place in infant body bag, ensuring that all body parts including the face are covered.

Attach second cot card or insert into the transport window of the infant body bag (if used).

Arrange transfer and if parents wish to accompany their baby, notify the anatomical pathology technician (APT) first. A member of maternity staff must accompany the family.

9.2 Taking baby home

Occasionally the family may wish to take their baby home. This is not always ideal as the baby may deteriorate rapidly and parents should be informed of this, especially if they wish to have a post-mortem. The parents' wishes should be supported. There is no legal reason why they cannot take their baby home or directly to the funeral directors of choice. The baby must be taken home in an appropriate casket or Moses basket. The transport home must be appropriate i.e. private not public transport. The mortuary must be informed if the parents are taking their baby home.

Some hospices offer the use of a cold room facility (see appendix 7). This allows the family to stay with the baby and say goodbye in a supportive environment. This is a place where babies can lay at rest after their death until the day of their funeral. For further reading see https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/
https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2021/02/Hospice-Information.pdf

If the parents would like the hospital to help them with the funeral arrangements, refer to local hospital policy. Document what arrangements are likely to be carried out. Complete a certificate for burial or cremation (stillbirth) and send to the dedicated individuals in your trust i.e. mortuary or bereavement centre. If the family are arranging their own funeral the certificate for burial or cremation (stillbirth) should be sent with the family who should be advised to give it to their funeral director.

If a hospital cremation is chosen ask the parents what they wish to do with the ashes. If they wish to collect them advise when and where this will occur. However, if they do not, or if the Trust policy is to scatter ashes in a designated place e.g. baby garden, ask the parents if they wish to know when this will occur. At very early gestations, or if the hospital offers shared cremation only then the parents should be informed that there will not be any individual ashes to collect.

Further advice and information on sensitive disposal of fetal remains can be found in the frequently asked questions section of the Human Tissue Authority website: https://www.hta.gov.uk/fags/disposal-pregnancy-remains-fags.

9.3 After discharge

After the parents have returned home, they can arrange to return to hospital to see their baby. Advise the parents how to make these arrangements should they wish.

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When such a request is received:

- 1. Obtain the parents' contact number.
- 2. Check whether the baby is still on hospital premises. This is particularly important if the baby was transferred out for post-mortem.

 Viewings are arranged on an individual basis only at the referring hospitals.
- 3. Inform parents of the name of the person who will meet and accompany them.
- 4. Check that the baby is lying peacefully in the Moses basket; (with/wearing any clothing or items that have been specified by the parents).

9.4 Ongoing psychological support

All women and their partners should be offered bereavement support; this could be from a bereavement support midwife or counsellor who can provide bereavement support from diagnosis of the stillbirth until well into the postnatal period. They may be able to offer continuity and psychological support in subsequent pregnancies. Information about support groups should be offered (if the woman has ongoing psychological or a known psychiatric disease, the GP and health visitor should be made aware of this).

Discuss with the mother when and where the postnatal debrief should take place; the appropriate appointment with the consultant obstetrician should be made. If the parents do not wish to return to see the consultant obstetrician, a letter should be sent to the family and the mother's GP.

If the parents have given the baby a name, health care professionals should use the baby's name in all discussions with the family thereafter.

9.5 Other postnatal care

All outstanding appointments with midwifery or medical staff should be cancelled to avoid potential upset. A letter should be sent to the mother's GP to explain that she has had a stillbirth.

If the woman booked at another Trust, please inform their bereavement midwife of the pregnancy loss.

All cases of stillbirth should be formally reviewed locally using the Perinatal Mortality Review Tool to ascertain the cause of death (by Relevant Condition at Death ReCoDe classification)

Appendix 6.

Parents should be informed about the Perinatal Mortality Review Tool (PMRT) process, given the local or national information leaflet and should be asked if they have any questions which they would like to be answered as part of the review. Inform parents that they can submit questions up to 28 days following their stillbirth (see PMRT Parent Engagement Flow Chart).

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10. Follow Up Visit

Follow up of parents who experience a stillbirth is a key element of care, with an opportunity to assess maternal recovery from the event, both physical and psychologically, as well as to convey information about investigations performed. It is also a chance to put in place a management plan for future pregnancies if that may be considered in the future. Risk factors can be reviewed and addressed including the common risk factors for stillbirth such as maternal obesity, advanced maternal age, and smoking³ as well as others that are apparent from the maternal history or investigations. Having had one stillbirth increases the chance of recurrence five-fold³³ however this is likely to be related to pre-existing maternal medical conditions or placental insufficiency, with recurrence following an unexplained stillbirth similar to background rates^{34,35}.

Return to the Maternity unit can be difficult and it is best done in another location, inform parents in advance where the follow up debrief visit will occur.

Preparation is essential for any such consultation, for patients who have been through the experience of having a stillborn baby should not have the trauma of an unprepared consultation added onto that experience. It should be noted what the wishes are of the parents for follow up appointments.

Prior to consultation ensure that:

- 1. All results are available.
- 2. Notes of any case review are available.
- 3. The PMRT report is available.

At postnatal follow up the psychological well-being of both parents should be asked about and additional help offered if needed.

Particular care should be taken with women with a history of psychiatric disorder and other vulnerable groups of women. A high standard of communication across all health professionals such as psychiatrist, GPs and health visitors is required.

At the consultation possible areas for discussion include the following; however this needs to be done sensitively to the woman's needs:

- Results of investigations for stillbirth
- Likely cause of stillbirth
- Share PMRT report
- Pre-pregnancy plan for next pregnancy
- Smoking/alcohol status
- Folic acid advice
- Consider low dose aspirin
- BMI optimisation
- Any psychological issues
- Medications
- Optimisation of other medical conditions
- Pregnancy plan for next pregnancy consider referral to Rainbow Clinic, Fetal Medicine Unit or Preterm Birth Clinic
- Who to contact when pregnant

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- Book under Consultant Obstetrician
- Screen for gestational diabetes (if unexplained)
- Ultrasound scan schedule
- Place of delivery
 - Obstetric unit if unexplained
 - Choice of units dependent upon other risk factors if isolated cause
- Timing of delivery
- Consider extra precautions for post-natal depression

Write a letter to the parents as well as communicating with their General Practitioner.

A template letter that will need to be edited for local purposes for the health visiting teams can be found in appendix 8.

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11. Governance

A recent review identified 31 different classification systems that could be used for stillbirth³⁶ some of which cover all perinatal deaths with six designed for stillbirths. This guideline advocates use of the ReCoDe (Relevant Condition at Death) as this is a system that was devised for stillbirth, has no relevant condition identified and is easy to use³⁷. This system is referenced in appendix 6.

11.1 Perinatal Mortality Review Tool

The Department of Health has commissioned the Health Quality Improvement Partnership (HQIP) and has developed a web based tool in collaboration led by MBRRACE-UK (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries across the UK), Sands, the PARENTS1 and 2 studies, the British Association of Perinatal Medicine, the Royal College of Obstetricians and Gynaecologists and the Royal College of Midwives to support good quality hospital reviews. Maternity and neonatal units now use a standardised review process to understand events leading up to the death of a baby.

Sands aim is to ensure that Duty of Candour is upheld and that parents can share their experience as part of the review process, as well as receive feedback about the results of the review.

All pregnancy losses over 22 weeks (excluding terminations of pregnancy) with a birthweight of more than 500g, all stillbirths, early neonatal deaths up to 28 days after birth and all neonatal deaths that occur whilst the baby is an inpatient on the neonatal unit are eligible for a PMRT review. The PMRT report should then be shared with the family.

For more information go to: https://www.npeu.ox.ac.uk/pmrt
https://www.sands.org.uk/our-work/fewer-baby-deaths/learning-lessons/national-perinatal-mortality-review

The other audit standards are taken from the RCOG guideline section 11.57 and more detail is available on recommendations within the RCOG guideline.

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12. Support Organisations and Groups

National

ARC Antenatal Results & Choices

Support for parents whose baby is diagnosed with a

fetal abnormality in pregnancy.

Helpline: 0207 713 7356 (available Tuesday &

Thursday evenings 8pm to 10pm).

Email: info@arc-uk.org

Website: www.arc-uk.org/

Bliss for babies born sick or premature

Family support helpline offering guidance and

support for premature and sick babies.

Email <u>hello@bliss.org.uk</u> (response within 3–

5 working days)
Website: www.bliss.org.uk/

Child Bereavement UK

Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Helpline: 0800 028 8840

Website www.childbereavementuk.org

Child Death Helpline

For all those affected by the death of a child. **Helpline:** 0800 282 986 or 0808 800 6019 **Website:** http://childdeathhelpline.org.uk/

Cruse Bereavement Care

For adults and children who are grieving.

Helpline: 0808 808 1677

Website: https://www.cruse.org.uk/get-help

Daddies with Angels

Advice and support to male family members

following the loss of a child/children.

Website: https://www.daddyswithangels.org/

Jewish Bereavement Counselling Service:

Supporting Jewish individuals through loss and

bereavement

 Helpline:
 020 8951 3881

 Email:
 enquiries@jbcs.org.uk

 Website:
 www.jbcs.org.uk

Lullaby Trust

Bereavement support to anyone affected by the sudden and unexpected death of a baby.

Helpline: 0808 802 6868

Email: support@lullabytrust.org.uk
Website: http://www.lullabytrust.org.uk

MIND

Supporting people with mental health problems.

Infoline: 0300 123 3393

Website: http://www.mind.org.uk/
Petals Baby Loss Counselling Charity

Free counselling service to support women, men and couples through the devastation of baby loss.

Helpline: 0300 688 0068
Website: www.petalscharity.org

Samaritans

Confidential emotional support in times of despair.

Telephone: 116 123

Website: www.samaritans.org

Sands Stillbirth & Neonatal Death Charity

Support for families affected by the death of a baby

before, during or shortly after birth.

Helpline: 0808 164 332

Email: helpline@sands.org.uk
Website: http://www.uk-sands.org

Saneline

Emotional support and information for people with

mental health problems **Phone:** 0845 7678000

Website: http://www.sane.org.uk/

Twins Trust

Bereavement and special needs support groups

Email: enquiries@twinstrust.org

Website: www.twinstrust.org/bereavement

The Miscarriage Association

Support for parents who have experienced

miscarriage

Helpline: 01924 200799 (9am to 4pm)
Email:info@miscarriageassociation.org.uk
Website: www.miscarriageassociation.org.uk/

The Compassionate Friends UK

Offering support to bereaved parents and their

families

 Helpline:
 0845 123 2304

 Email:
 info@tcf.org.uk

 Website:
 www.tcf.org.uk

Tommy's

Information and support for parents on coping with

grief after having a stillborn baby.

Bereavement-trained midwives available Monday to

Friday, 9am to 5pm

Helpline: 0800 0147 800

Website: tommys.org/stillbirth-information-and-

support

Regional

Children of Jannah

Support for bereaved Muslim families in the UK,

based in Manchester. **Helpline:** 0161 480 5156

Email: info@childrenofjannah.com www.childrenofjannah.com

Listening Ear

Free self-referral counselling to help deal with anxiety, bereavement and depression.

Helpline: 0151 488 6648

Email: enquiries@listening-ear.co.uk
Website: http://listening-ear.co.uk/

North West Forget me not's & Rainbows

Support any member of the family who has been affected by the loss of a baby, during pregnancy, at

birth or afterwards.

Facebook: nwforgetmenotsandrainbows

Once Upon A Smile

Children's bereavement support **Phone:** 0161 711 0339

Website: www.onceuponasmile.org.uk

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Appendix 1 - Patient Information

Patient information

- https://www.sands.org.uk/sands-bereavement-support-book
- https://www.sands.org.uk/sites/default/files/Sands%20Bereavement%20Support%20 Book%20-%20web%20version.pdf
- https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-when-your-baby-dies-before-birth.pdf
- https://twinstrust.org/bereavement/booklet.html

Appendix 2 - The Butterfly Project

https://www.neonatalbutterflyproject.org/

Appendix 3 – Hospital Post Mortem Examination Consent Form

Patient information

https://www.sands.org.uk/support-you/understanding-why-your-baby-died/post-mortem-examination

Greater Manchester and Eastern Cheshire

- MFT Post mortem consent form
- MFT Post mortem help sheet for consent form
- Requesting a post mortem examination

Lancashire, South Cumbria, Cheshire and Merseyside

Patient information

- https://www.liverpoolwomens.nhs.uk/media/3505/post-mortem-examination-hst-information-leaflet.pdf
- Alder Hey Post mortem consent form
- Alder Hey Examination of fetus request form

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Appendix 4 – Placental Pathology

Greater Manchester and Eastern Cheshire

- MFT Placental histology information sheet
- Request Form for Histopathological Examination of Placenta

Lancashire, South Cumbria, Cheshire and Merseyside

Below 16 weeks

Saint Helens and Knowsley Cytology request form

More than 16 weeks

• Alder Hey Examination of Fetus request form

Appendix 5 - Cytogenetic Testing

Greater Manchester and Eastern Cheshire

Current forms can be printed from www.ManGen.org.uk/useful-forms

Cytogenetics referral form

Lancashire, South Cumbria, Cheshire and Merseyside

Current forms can be printed from <u>Genetic Laboratory Services - Liverpool Womens NHS Foundation Trust</u> or <u>genetics-referral-form-feb-2020.pdf (liverpoolwomens.nhs.uk)</u>

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Appendix 6 – ReCoDe Classification of Stillbirth

Α	Fetus	 Lethal congenital anomaly Infection Infection Chronic – e.g. TORCH Acute Non-immune hydrops Iso-immunisation Fetomaternal haemorrhage Twin-twin transfusion Fetal growth restriction Other 	Usually fetal direct (a). Consider fetal indirect (b) and other contributory (e)	
В	Umbilical cord	Prolapse Constricting loop or knot	Usually fetal direct (a)	
	55 1 G	3. Velamentous insertion	Usually fetal indirect (b)	
		4. Other	May be fetal direct (a) or indirect (b)	
С	Placenta	1. Abruptio 2. Praevia	Usually fetal direct (a)	
		Vasa praevia Placental insufficiency/infarction	May be fetal direct (a) or indirect (b)	
		5. Other	Usually fetal direct (a)	
D.	Amniotic fluid	 Chorioamnionitis Oligohydramnios Polyhydramnios Other 	May be fetal direct (a) or indirect (b)	
E.	Uterus	1. Rupture 2. Other	Often maternal direct (c)	
F.	Mother	1. Diabetes 2. Thyroid disease 3. Essential hypertension 4. Hypertensive disease in pregnancy 5. Lupus/antiphospholipid syndrome 6. Cholestasis 7. Drug abuse 8. Other	May be maternal direct (c) Consider maternal indirect (d) and other contributory (e)	
G.	Intrapartum	1. Asphyxia 2. Birth trauma	Usually fetal direct (a)	
Н.	Trauma	External Iatrogenic (e.g. MTOP in case of lethal congenital anomaly)	Usually fetal direct (a). Consider maternal direct (c) or indirect (d)	
I.	Unclassified	No relevant condition identified No information available	Usually fetal direct (a)	

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Appendix 7 – Palliative Care Hospice Information

https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/

Appendix 8 – Example Health Visitor letter

Example Health Visitor letter

Appendix 9 - Example of auditable points and collection of data

Below are examples of auditable points that units may wish to consider for collection and analysis of their own local data.

- Proportion of stillbirths reported as a clinical incident
- Completion of investigations for the cause of late IUFD.
- Proportion of parents offered postmortem examination.
- Proportion of parents declining full postmortem who were offered alternative tests.
- Proportion of parents who have postmortem consent undertaken by an appropriately trained obstetrician or midwife.
- Proportion of women offered suppression of lactation.
- Proportion of women given fertility and contraceptive advice.
- Proportion of parents offered follow-up with a senior obstetrician.
- Proportion of women and families offered counselling follow-up.

Appendix 10 – Collecting feedback from families

Some units may wish to collect feedback from parents.

The feedback from women and families gathered from the questionnaire will identify aspects of care that should always happen and improvements in maternity bereavement services can be influenced through the feedback gathered from the responses.

Below is an example of one that can be used:

- Example letter to parent
- Maternity Bereavement Experience Measure (MBEM)

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