











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

# To be used from 24+0 weeks gestation

If less than this please see Second Trimester Pregnancy Loss Guideline and ICP

Version 3 March 2018



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

# **Document Control**

**Ownership** 

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### **Version control**

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# Contributors

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Thank you.



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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 thank the Neonatal Research Network for sharing their Butterfly Project resources.

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.

Shitale.

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# Contents

	Page
1. Introduction	5
2. Presentation, Diagnosis and Immediate Care	6
3. Psychological Support	8
4. Multiple Pregnancies	8
5. Delivery Management	10
6. Timing	10
7. Drug Information	11
8. Care of Baby	18
9. Further Management of Baby Including Transfer and Funeral Arrangem	ents 20
10. Follow Up Visit	22
11. Governance	23
12. Support Organisations and Groups	25
Appendices	26
Appendix 1 - Patient Information	26
Appendix 2 - Butterfly Project	26
Appendix 3 - Post Mortem Information, Consent Form for a Hospital Post Examination & Consent Guidance	
Appendix 4 - Placental Pathology	27
Appendix 5 - Cytogenetic Testing	27
Appendix 6 – ReCoDe Classification of Stillbirth	28
Appendix 7 – Palliative Care Hospice Information	29
Appendix 8 – Suggested Health Visitor letter	29
Appendix 9 – Example of auditable points and collection of data	29
Appendix 10 – Collecting feedback from families	30
References	31



# 1. Introduction

Stillbirth is a devastating event with enduring psychosocial consequences for parents, including anxiety and depression, guilt, complicated grief, social isolation, and relationship breakdown<sup>1</sup>.

In 2016, approximately 1 in 233 babies in England were stillborn, and although a reduction from the previous year<sup>2</sup>, the UK continues to have an above average rate of stillbirth when compared to other high income countries<sup>3</sup>. Approximately 33 to 40% of stillbirths are small for gestational age<sup>4</sup>. 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 pregnancies<sup>5</sup>. Commenting about mid-trimester 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."<sup>6</sup>

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 Stillbirth<sup>7</sup>. 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

#### **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.

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.



#### 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) fetocide is not a legal requirement<sup>12</sup>.

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 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 / Miscarriage Association (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.

#### Place of Care

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

#### **Pastoral Care**

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.

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

# 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.<sup>13 14</sup>

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 and can be improved. The resources can be viewed at the following link: <a href="http://www.neonatalresearch.net/butterfly-staff-resources.html">http://www.neonatalresearch.net/butterfly-staff-resources.html</a>

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 <u>patient information in Appendix 1.</u>

# 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 SCBU. 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 Neonatal Research Network <u>www.neonatalresearch.net/butterfly-project</u> has developed two concepts.

- 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**.



# 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 IUFD<sup>15</sup>.

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 weeks<sup>16</sup>.

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.

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 and 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 delivery<sup>17</sup>.

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.

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

#### **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.

#### **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 delivery suite with access to high dependency care 24 to 48 hours later, or sooner when there is an urgent need to deliver for obstetric indications. There is no evidence against earlier induction of labour following mifepristone – induction can occur anytime from 0 to 48 hours after administration.

#### **Induction**

#### 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 dose can be obtained by dividing a 200 microgram tablet into two halves using a pill cutter. Similarly 50 microgram can be obtained by dividing the  $\frac{1}{2}$  tablet into 2 (i.e.  $\frac{1}{2}$  tablet) – use pill cutter for accurate division.

With respect to route of administration there is a slower onset but more sustained effect if misoprostol is given vaginally (PV) or sublingually (SL) compared to the oral (PO) route. It is not recommended to give misoprostol vaginally if there is heavy vaginal bleeding. 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.



#### Women with an unscarred uterus

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

	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	>27+6 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

#### 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 section<sup>18</sup>. Discussion about safety and benefits of induction of labour should be undertaken by a Consultant Obstetrician.

# a. One previous lower segment caesarean section (LSCS) In women with an unfavourable cervix:

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 UK<sup>7</sup>. Alternatively a cervical ripening balloon may be considered<sup>19</sup>.

If the cervix is favourable then induction by amniotomy and oxytocin can be used – discuss with Consultant on call

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

If not effective after a course of 5 doses, discuss with Consultant consider repeat misoprostol at least 12 hours after the last dose.



#### b. 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<sup>20, 21</sup>. 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.

#### **Termination of pregnancy**

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

#### **Scarred Uterus**

The safety of induction is unknown<sup>18</sup> 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.

#### 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. Birth choices remain as for any labouring woman. A Consultant Obstetrician should be made aware of the admission.

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 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.

Adequate analgesia should be provided. All usual modalities should be made available including regional analgesia and patient-controlled analgesia. If opiate analgesia is chosen then diamorphine should be used in preference to pethidine. Offer review with the obstetric anaesthetist. Assessment for disseminated intravascular coagulopathy (DIC) and sepsis should be undertaken before administering regional analgesia.



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.

#### Management of third stage

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

#### **Investigations**

Parents report three reasons why they have investigations<sup>22</sup>, 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 diagnosis<sup>23</sup>. 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.

Even with full investigation parents should be advised that a specific cause for death may not be found in approximately 15% of cases<sup>24</sup>.

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 analysis<sup>25</sup>.

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.

The following investigations should be offered to all patients unless cause known as in TOP for malformation:

#### 1. Kleihauer to identify fetomaternal haemorrhage

Ideally taken as early as possible after presentation.

#### 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. 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 <u>Deciding about a post-mortem</u><sup>26</sup>. 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**.

#### 4. 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. The following is a suggested schedule:

At delivery	ACL/Lupus ac
At least 6 weeks	Protein C, Protein S, Antithrombin, Factor V Leiden
postnatal	Prothrombin gene variants
12 weeks postnatal	Repeat ACL/Lupus Ac if positive previously

Thromboprophylaxis – assessment needs to be performed. Stillbirth increases the risk of venous thromboembolism 6 fold. <sup>15.</sup>

If DIC is present then discuss thromboprophylaxis with a haematologist.

#### 5. 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. If the placenta cannot be fixed in formalin, it should be refrigerated and sent to the laboratory at the earliest opportunity.

The placenta should be examined by an experienced paediatric/perinatal pathologist. See <a href="mailto:appendix4">appendix 4</a>



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

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 stillbirth<sup>27</sup> <sup>28</sup> <sup>29</sup> <sup>30</sup>. In cases where fetal malformation is noted a microarray assessment will be performed on the section of umbilical cord, if there is no malformation a PCR will be performed to assess for chromosome abnormalities of chromosomes 13, 18 and 21.

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 routinely, or for fetal sexing. See **Cytogenetic Testing** information in <u>appendix 5</u> 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.

#### 7. 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, herpes simplex and parvovirus B19

The following selective investigations should only be performed if 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 or suspected fetal growth restriction, placental abruption, placental insufficiency or pre-eclampsia

- (a) 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
  - At delivery
  - Lupus anticoagulant
  - Anticardiolipin antibodies

At 6 weeks postnatal (as Protein S usually low at delivery)

- Factor V leiden
- Protein C
- Protein S
- Antithrombin
- Prothrombin gene variants



If Anticardiolipin antibodies or lupus anticoagulant were positive at delivery these need repeating at 12 weeks postnatally.

If thrombophilia investigations are not taken at these timings results will need to be interpreted in line with changes that occur physiologically.

#### (b) If history suggests maternal substance abuse

Maternal urine for cocaine metabolites (need maternal consent)

#### 3. If hydrops fetalis is present

- · Red cell antibody screen
- Maternal anti-Ro and anti-La antibodies

#### **4.. If fetal intracranial haemorrhage** (on post mortem examination)

Maternal alloimmune antiplatelet antibodies.

#### 5. Parental chromosomes should be obtained only if

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

#### 6. If there is no obvious cause

- Bile salts
- HbA1c
- Thyroid function

#### 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 <a href="Appendix 6">Appendix 6</a>).

#### **Maternal Care**

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. Contraception should be discussed before discharge home.

## 8. Care of Baby

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



#### **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.

#### **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.

#### 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 <a href="http://www.remembermybaby.org.uk">http://www.remembermybaby.org.uk</a>, 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**

#### 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.

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.

#### 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 <u>appendix 7</u>). 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 <a href="http://www.neonatalnetwork.co.uk/hospice-care/file/Hospice%20Information%252Edocx">http://www.neonatalnetwork.co.uk/hospice-care/file/Hospice%20Information%252Edocx</a>



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 (disposal) 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 of disposal 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: <a href="https://www.hta.gov.uk/faqs/disposal-pregnancy-remains-faqs">https://www.hta.gov.uk/faqs/disposal-pregnancy-remains-faqs</a>.

#### 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.

When such a request is received:

- 1. Obtain the parents' contact number.
- 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.
- Inform parents of the name of the person who will meet and accompany them.
   Check that the baby is lying peacefully in the Moses basket; (with/wearing any clothing or items that have been specified by the parents).

#### **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.

#### **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.

All cases of stillbirth should be formally reviewed in a local perinatal mortality meeting to ascertain the cause of death (by Relevant Condition at Death ReCoDe classification)

Appendix 6.

## 10. Follow Up Visit

Follow up of patients who had 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 smoking<sup>3</sup> as well as others that are apparent from the maternal history or investigations. Having had one stillbirth increases the chance of recurrence five-fold<sup>31</sup> 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<sup>32,33</sup>.

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.

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
- 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
- Who to contact when pregnant
- Book under Consultant Obstetrician
- Screen for gestational diabetes (if unexplained)
- Ultrasound scan schedule (if SGA)
- 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**.

## 11. Governance

A recent review identified 31 different classification systems that could be used for stillbirth<sup>34</sup> 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 use<sup>35</sup>. This system is referenced in appendix 6.

#### **Perinatal Mortality Review Tool**

The Department of Health has commissioned the Health Quality Improvement Partnership (HQIP) to develop 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 will be able to 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.

The new national standardised Perinatal Review Tool (PMRT) will be launched in 2018 and will be free for units to use. For more information go to: <a href="https://www.npeu.ox.ac.uk/pmrt">https://www.npeu.ox.ac.uk/pmrt</a> <a href="https://www.sands.org.uk/our-work/fewer-baby-deaths/learning-lessons/national-perinatal-mortality-review">https://www.sands.org.uk/our-work/fewer-baby-deaths/learning-lessons/national-perinatal-mortality-review</a>

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



# 12. Support Organisations and Groups

National	
ARC Antenatal Results & Choices	MIND
Support for parents whose baby is diagnosed with a fetal abnormality in pregnancy. Helpline: 0845 077 2290 or 0207 713 7486 <a href="http://www.arc-uk.org/">http://www.arc-uk.org/</a>	Promoting and supporting people with mental health problems. Freephone : 0161 272 8205 http://www.mind.org.uk/
Bliss for babies born sick or premature	Samaritans
Family support helpline offering guidance and support for premature and sick babies. Helpline: 0808 801 0322 http://www.bliss.org.uk/	Confidential emotional support in times of despair. Telephone: 116 123 http://www.samaritans.org/
Child Bereavement UK	Sands Stillbirth & Neonatal Death Charity
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  www.childbereavementuk.org	Support for families affected by the death of a baby before, during or shortly after birth.  Telephone: 0207 436 5881 <a href="http://www.uk-sands.org">http://www.uk-sands.org</a>
Child Death Helpline	Saneline
For all those affected by the death of a child. Freephone: 0800 282 986 0808 800 6019 http://childdeathhelpline.org.uk/	Emotional support and information for people with mental health problems Telephone: 0845 7678000 http://www.sane.org.uk/
Contact a Family	TAMBA (Twins & Multiple Birth Association)
Support and information about specific conditions. Telephone: 0808 808 3555	Bereavement and special needs support groups Telephone: 01252 332344
http://www.cafamily.org.uk/	http://www.tamba.org.uk/bereavement
Cruse Bereavement Care For adults and children who are grieving. Telephone: 0808 808 1677	The Miscarriage Association Support for parents who have experienced miscarriage Telephone: 01924 200 799
http://www.cruse.org.uk/bereavement-services/	http://www.miscarriageassociation.org.uk/
Daddies With Angels Advice and support to male family members following the loss of a child/children. Telephone: 007513 655134	The Compassionate Friends UK Offering support after the death of a child at any age. Helpline: 0845 123 2304 www.tcf.org.uk
http://www.daddyswithangels.org	T
Lullaby Trust Sudden infant death bereavement support: Telephone: 0808 802 6868 <a href="http://www.lullabytrust.org.uk">http://www.lullabytrust.org.uk</a>	Tommys Bereavement-trained midwives available Monday to Friday, 9am to 5pm Helpline: 0800 0147 800 tommys.org/stillbirth-information-and-support
Regional	
Children of Jannah Support for bereaved Muslim families in the UK, based in Manchester. Telephone: 0161 480 5156 www.childrenofjannah.com	Once Upon A Smile Provides emotional and practical support to bereaved families. Telephone: 0161 711 0339 http://www.samaritans.org/
Listening Ear Free self-referral counselling to help deal with anxiety, bereavement and depression. Telephone: 0151 487 9177 http://listening-ear.co.uk/	- TARREST WAS ARREST OF THE PARTY OF THE PAR



## **Appendices**

## **Appendix 1 - Patient Information**



Sands\_WABDBLB\_20 13.pdf



RCOG\_When-your-b aby-dies-before-birth



Tamba Bereavement.pdf

## **Appendix 2 - Butterfly Project**

# Appendix 3 - Post Mortem Information, Consent Form for a Hospital Post Mortem Examination & Consent Guidance





# Appendix 4 - Placental Pathology

Greater Manchester and Eastern Cheshire	Lancashire, South Cumbria, Cheshire and Merseyside		
POF POF	If below 16 weeks	If more than 16 weeks	
Placenta instructions Placenta Request ver4 200716.pdf form ver4 200716.pd	Whiston Hospital, St Helens & Knowsley Trust  Histology cytology form Whiston.pdf	Alder Hey Children's Hospital  Examination of placenta form_recd 1	

# Appendix 5 - Cytogenetic Testing

Greater Manchester and Eastern Cheshire	Lancashire, South Cumbria, Cheshire and Merseyside
Cytogenetic Analysis Referral Criteria_CMF Cytogenetic Test Req	Cytogenetics LWH Clinical form_LWH recd 10.1(Genetics_Referral_Fc



# Appendix 6 - ReCoDe Classification of Stillbirth

Α	Fetus	<ol> <li>Lethal congenital anomaly</li> <li>Infection         <ol> <li>1.1 Chronic – e.g. TORCH</li> <li>2.2 Acute</li> </ol> </li> <li>Non-immune hydrops</li> <li>Iso-immunisation</li> <li>Fetomaternal haemorrhage</li> <li>Twin-twin transfusion</li> <li>Fetal growth restriction</li> <li>Other</li> </ol>	Usually fetal direct (a). Consider fetal indirect (b) and other contributory (e)
В	Umbilical cord	Prolapse     Constricting loop or knot	Usually fetal direct (a)
	Coru	3. Velamentous insertion	Usually fetal indirect (b)
		4. Other	May be fetal direct (a) or indirect (b)
С	Placenta	1. Abruptio	Usually fetal direct (a)
	2. Praevia     3. Vasa praevia     4. Placental insufficiency/infarction		May be fetal direct (a) or indirect (b)
		5. Other	Usually fetal direct (a)
D.	Amniotic fluid	<ol> <li>Chorioamnionitis</li> <li>Oligohydramnios</li> <li>Polyhydramnios</li> <li>Other</li> </ol>	May be fetal direct (a) or indirect (b)
E.	Uterus	1. Rupture 2. Other	Often maternal direct (c)
F.	Mother	<ol> <li>Diabetes</li> <li>Thyroid disease</li> <li>Essential hypertension</li> <li>Hypertensive disease in pregnancy</li> <li>Lupus/antiphospholipid syndrome</li> <li>Cholestasis</li> <li>Drug abuse</li> <li>Other</li> </ol>	May be maternal direct (c) Consider maternal indirect (d) and other contributory (e)
G.	Intrapartum	1. Asphyxia 2. Birth trauma	Usually fetal direct (a)
H.	Trauma	External     Introgenic (e.g. MTOP in case of lethal congenital anomaly)	Usually fetal direct (a). Consider maternal direct (c) or indirect (d)
l.	Unclassified	No relevant condition identified     No information available	Usually fetal direct



# **Appendix 7 – Palliative Care Hospice Information**



# Appendix 8 - Suggested 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:





Parent feedback questionnaire letter J Bereavement Experie

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## **Greater Manchester and Eastern Cheshire Strategic Clinical Networks**

Greater Manchester Health & Social Care Partnership
4th Floor | 3 Piccadilly Place | Manchester | M1 3BN
http://www.gmecscn.nhs.uk/
www.gmhsc.org.uk

#### **North West Coast Strategic Clinical Networks**

Vanguard House | Sci-Tech Daresbury | Keckwick Lane | Daresbury | Halton WA4 4AB

https://www.nwcscnsenate.nhs.uk/

