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## **Title: Care Following Stillbirth: Latest evidence, guidelines and best practice points**

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## **Key Words**

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## **Abstract (140 words)**

Third trimester stillbirth affects approximately 2.6 million women worldwide each year<sup>1</sup>. The impact of stillbirth ranges from stigma to disenfranchised grief, broken relationships, clinical depression, chronic pain, substance use, increased use of health services, employment difficulties and debt<sup>4</sup>. A systematic review highlighted the need for future investment and research into both stillbirth prevention and aftercare to minimise its negative impact for parents and babies worldwide<sup>4</sup>. Appropriate bereavement care following a stillbirth is essential to minimise the negative socioeconomic impact on parents and their families. Most stillbirths (98%) occur in low and middle-income countries however much of the research on the impact of stillbirth and bereavement care has come from high-income countries<sup>1,4</sup>. This chapter will present the best practice points in stillbirth bereavement care using the latest published research, guidelines and best practice points from high-income countries and will highlight the gaps in the research which urgently need to be addressed.

# Care Following Stillbirth: Latest evidence, guidelines and best practice points

## Introduction

Third trimester stillbirth affects approximately 2.6 million women worldwide each year<sup>1</sup>. Globally stillbirth rates have declined more slowly than either maternal or child mortality<sup>1</sup>. In 2014, there were 3,254 stillbirths in the United Kingdom (UK) affecting 4.7 in every 1000 pregnancies<sup>2</sup>. There are twice as many stillbirths as deaths due to HIV/AIDs and it is 14 times more common than sudden infant death syndrome, yet stillbirth remains under-researched and unrecognised in the global health agenda<sup>3</sup>.

Stillbirth is associated with substantial psychosocial, economic and intangible costs to women, their partners and families, health-care providers, the government and wider society<sup>4</sup>. The impact ranges from stigma to disenfranchised grief, broken relationships, clinical depression, chronic pain, substance use, increased use of health services, employment difficulties and debt; and from staff despair to resignation<sup>4</sup>. Evidence has demonstrated that financial costs associated with stillbirth were 10-70% greater than that of a livebirth<sup>5</sup>. A recent systematic review found the most frequently reported experiences after stillbirth were negative psychological symptoms, including high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic, and phobias<sup>6</sup>. It highlighted the need for future investment and research into both stillbirth prevention and aftercare to minimise its negative impact for parents worldwide.

Appropriate bereavement care following a stillbirth is essential to minimise the negative socioeconomic impact on parents and their families. In the UK, a survey of over 2,000 healthcare professionals including midwives and obstetricians found that one third did not have satisfactory training to counsel parents after stillbirth<sup>7</sup>. Furthermore, a survey of 473 parents showed that fewer than half of the parents felt involved in the decision-making process after stillbirth<sup>8</sup>. A confidential enquiry of 133 term antepartum stillbirths showed wide variation in care, including inadequate communication between health professionals and parents<sup>9</sup>. Insensitive interactions have been reported, with partners ignored and little attention paid by healthcare professionals to their individual needs<sup>9,10</sup>. These poorly managed interactions can lead to a negative and lasting impact on bereaved parents<sup>11</sup>.

Most stillbirths (98%) occur in low and middle-income countries however much of the research on the impact of stillbirth and bereavement care has originated from high-income countries<sup>1,4</sup>. This chapter will present the best practice points in stillbirth bereavement care using the latest published research, guidelines and best practice points from high-income countries and will highlight the gaps in the research which urgently need to be addressed.

## What is bereavement care?

Bereavement is the condition of loss resulting from a death and grief is the natural psychological and emotional response to human loss<sup>12</sup>. The term "bereavement care" in the setting of stillbirth encompasses the formalised and informal care and support given to bereaved parents and their families to help the through the grieving process. This care begins in the period following the diagnosis of stillbirth and continues throughout the postnatal period within the hospital and community settings. There are no quality standards for bereavement care for stillbirth however the National Institute of Clinical Excellence's Guideline for End of Life Care suggests that people closely affected by a

death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences<sup>13</sup>.

## **General principles**

The interactions between healthcare professionals can have a memorable impact on parents and careful considered communication is essential throughout<sup>14</sup>. A recent systematic review (2016) found that clear, easily understandable and structured information given sensitively at appropriate times helps parents through their experience. The review found that parents wished for acknowledgement of the stillbirth and prioritisation of their situation by healthcare staff<sup>14</sup>. Continuity of care is important to parents and consideration should be made to ensure they are under the care of a dedicated and consistent bereavement midwife and obstetrician<sup>14</sup>. An inclusive approach should be taken to ensure partners are involved in decision-making where appropriate<sup>14</sup>.

## **Signs and Symptoms of Stillbirth**

One of the most common symptoms women present with prior to the diagnosis of stillbirth is reduced fetal movements. Confidential enquiries and a number of studies have consistently described the relationship between poorly managed episodes of reduced fetal movements and stillbirth<sup>15-17</sup>. In the Listening to Parents Survey, two-thirds felt there was something wrong before their baby died and only 57% felt that their concerns were taken seriously<sup>8</sup>. Healthcare professionals should support parents to express their concerns, particularly when something is not feeling right and there is a perception of reduced fetal movements. Furthermore, antenatal notes should make women aware of reduced fetal movements and signpost them to further information<sup>18</sup>. The Saving Babies Lives Care Bundle was launched in the UK in 2016 with the aim to reduce halve the rate of stillbirths by 2030<sup>19</sup>. One of the elements is to raise awareness amongst pregnant women of the importance of detecting and reporting reduced fetal movements<sup>19</sup>. The Care Bundle also recommends that providers have protocols in place, based on best available evidence, to manage care for women who report reduced fetal movements<sup>19</sup>. The AFFIRM study is currently exploring the impact of increasing maternal awareness of the importance of reduced fetal movements, both on service demand and on stillbirth rates<sup>19</sup>.

Crucially, the Investigation into Stillbirth to Inform and Guide Healthcare Training (INSIGHT) study<sup>18</sup> showed that management of reduced fetal movements is inconsistent both before and after the diagnosis of stillbirth, with the degree of urgency and attention varying and often disappearing just after the bad news has been discussed with parents. It is urgent that every obstetric unit should have a protocol for primary care referral for suspected fetal death and an integrated care pathway once in hospital<sup>19</sup>.

## **Diagnosis and Breaking bad news**

The diagnosis of a stillbirth by a healthcare professional is something that parents who experience this loss are likely to remember. Therefore, it is important that this diagnosis is made in a timely manner by adequately trained healthcare professionals within a private environment<sup>14</sup>. National guidelines recommend that this diagnosis is made using real-time ultrasonography and confirmed by a second healthcare professional<sup>20</sup>. Mothers should be warned in advance of the possibility of passive fetal movements as they can be common<sup>21</sup>. Additionally, if the mother reports passive fetal movements after the scan, a repeat scan should be offered<sup>14,21</sup>. A recent study interviewed healthcare

professionals and found that this diagnosis is often difficult to confirm, particularly when senior staff are unavailable to make the diagnosis, for example during the night in the hospital<sup>18</sup>. Deferring diagnosis to the following day can lead to increased parental anxiety and therefore should be avoided<sup>18</sup>. The study recommended that every maternity unit should have a private room with at least one healthcare professional, experienced in confirming the diagnosis of stillbirth, available 24 hours a day and seven days a week<sup>18</sup>. Health professionals undertaking the scanning should be trained to communicate empathetically and clearly using appropriate verbal and non-verbal cues<sup>18</sup>. Furthermore, the professional undertaking the scan should communicate clearly to the parents about the process prior to conducting the scan. The clinician should explain to parents that there may be silence during scanning process until the diagnosis can be made with certainty<sup>18</sup>. There is an urgent need for further ultrasonography skills and communication training for all healthcare professionals likely to be diagnosing stillbirths in maternity units<sup>18</sup>.

## **Labour and birth**

Mode of birth should be discussed in detail by an obstetrician with the parents. Vaginal birth is the recommended mode of delivery but caesarean birth may need to be considered for some parents. The INSIGHT Study interviewed parents to explore the maternity bereavement care they had experienced and reasons why bereaved families often ask for a caesarean birth over a vaginal birth<sup>18</sup>. Mothers felt that by giving them the option to choose the timing and mode of birth they could restore a sense of control, they could shorten the variably long process from diagnosis to discharge and they could avoid labour pain by having a caesarean section<sup>18</sup>. Some parents believed that a quick caesarean section followed by resuscitation might save the baby. Whilst others felt that the baby might still feel pain and that a caesarean birth is a less traumatic option for the baby<sup>18</sup>. Overall, it is crucial for healthcare professionals to understand the several different reasons<sup>18</sup> why parents may request a caesarean birth over a vaginal birth, so that they can counsel women effectively about the risks and benefits and help them make informed decisions regarding the birth of their baby. Joint decision-making is vital and support from healthcare professionals may help parents who feel emotionally unprepared for the birth<sup>14</sup>.

Parents understandably find the birth experience challenging. Importance should be given to this experience taking place on a dedicated bereavement suite away from the standard maternity unit where mothers and babies might be heard<sup>14,20</sup>. It is vital that women and their partners feel supported throughout this experience and do not feel abandoned once the diagnosis of stillbirth has been made<sup>14</sup>. Recommendations about labour and birth should incorporate the mother's preferences as well as her medical condition and previous intrapartum history<sup>14,20</sup>. Women should be strongly advised to take immediate steps towards delivery if there is sepsis, preeclampsia, placental abruption or membrane rupture; but a more flexible approach can be discussed if these factors are not present<sup>20</sup>. However, for some parents prolonging the birth may increase anxiety and stress in the short and long-term<sup>18</sup>.

Pain relief options should be fully discussed with parents<sup>14,20</sup>. In addition, regional anaesthesia should be available and women should have the opportunity to meet with an obstetric anaesthetist<sup>20</sup>.

## **Suppression of lactation**

In the Listening to Parents Study and the MBRRACE confidential enquiry (2014) over one third of women were not offered lactation suppression<sup>8,16</sup>. It is important to explain to women that following the birth of their baby they will begin to lactate and many women find this distressing if they are unprepared for this. Women should be advised that

almost one-third of those that choose non-pharmacological measures are troubled by excessive discomfort<sup>20</sup>. Non-pharmacological measures may include support brasseries, ice packs and analgesics<sup>20</sup>. Dopamine agonists successfully suppress lactation in a high proportion of women (over 90%) and are well tolerated; cabergoline has been found superior to bromocriptine<sup>20</sup>. However, dopamine agonists should not be given to women with hypertension or pre-eclampsia as they have been associated with intracerebral haemorrhage<sup>22</sup>.

## **Memory making**

A recently published systematic review (2016) which investigated how to improve care after stillbirth, suggested that memory making should be an option for parents and should be offered more than once during their hospital admission<sup>14</sup>. Memory making can take many different forms including activities such as seeing and holding the baby, photographs, taking hand and foot prints and creating memory boxes. Currently there is a mixed body of evidence surrounding seeing and holding the baby after birth. In 2013, a Cochrane review concluded that the evidence of the potential detrimental effect of seeing and holding the baby remains inconclusive<sup>23</sup>. A subsequent systematic review (2014) found that the impact of parents holding the baby on mental health and wellbeing is sparse and poor quality<sup>24</sup>. The studies included within the systematic review were too heterogeneous in their outcome measurements and the authors were unable to quantitatively synthesise the results to form a meaningful conclusion<sup>24</sup>. A recent secondary analysis of data (2016) from a postal survey of 468 women who had experienced a stillbirth, found that women had higher self-reported anxiety levels and relationship difficulties<sup>25</sup>. However, there should be caution in interpreting this data, as the survey had a low response rate (30.2%) and used self-reported outcome measures. Conversely, another systematic review published in 2014 suggested that parents seeing and holding their baby could be beneficial to their future well-being. It also suggested that there is a strong body of evidence for parents to be given the option to see or hold their baby and many women are satisfied with their decision<sup>26,27</sup>. In summary, due to the mixed body of research, parents should continue to be offered, but not forced, to hold their stillborn baby; unless more substantial evidence emerges. There is a need for high-quality prospective research with standardised outcomes and outcome measurement tools with attention to confounders, to guide practitioners' and parents' decision-making and to ascertain the life-long impact of this decision process on parents.

## **Post-mortem discussion**

A post-mortem (autopsy) examination should be offered to parents to help explain the cause of the stillbirth and may guide the management of any future pregnancy<sup>14,20</sup>. Attempts to persuade parents to choose a post-mortem should be avoided, to respect individual, cultural and religious beliefs that might make a post-mortem unacceptable to parents<sup>14,20</sup>. An adequately trained health practitioner should obtain written consent for any invasive procedure on the baby including tissues taken for genetic analysis<sup>20</sup>. Further consent should be sought when tissues are retained for clinical investigation, research and teaching<sup>20</sup>. A recent study interviewed parents and found that the health professionals taking consent are not always clear in their approach and that health professionals should consider discussing post-mortem early on to allow time for the parents to think about their wishes<sup>18</sup>. Further evidence suggests that parents believe staff should receive improved training, to better facilitate tailored discussions and that the provision of well-written information would help them make informed decisions about post-mortem<sup>14</sup>. Healthcare professionals should be able to communicate the purpose of the post-mortem in a respectful way and to explain local

processes and timescales effectively<sup>18</sup>. It should also be explained that not all post-mortem investigations will find the cause of the stillbirth and that not finding a reason in itself is useful and can be framed in positive terms as often important diagnoses can be excluded<sup>18</sup>.

Evidence suggests that parents may regret certain decisions they have made around post-mortem and this may be due to inadequate information or poor communication<sup>14</sup>. A survey of 473 parents found only two-thirds of parents were given written information about the post-mortem and only half agreed to a full post-mortem examination<sup>8</sup>. Parents' reasons for not agreeing to a post-mortem were mainly that they perceived that they already knew the cause of death<sup>8</sup>. The process for obtaining consent is naturally difficult for parents and health professionals and so interventions may be required to support this decision-making process. A Cochrane Review published in 2013 found no randomised controlled trials investigating interventions to support decision-making on autopsy or associated investigations<sup>28</sup>. The authors concluded there are challenges in conducting randomised controlled trials and that meta-analyses will be necessary to resolve uncertainty in this area<sup>28</sup>. Standardised outcomes and measurements will again need to be used to synthesise the results of multi-centre trials. Moreover, future research should focus on implementing and evaluating interventions to support decision making around post-mortem discussions<sup>28</sup>.

### **Perinatal mortality review process**

In 2012, The Department of Health (DoH) in the UK established a Perinatal Mortality Task and Finish Group to improve the review process that takes place in each hospital following the death of a baby either before or shortly after birth. The DoH task group recommended a comprehensive and robust review of all losses from 22 weeks gestation until 28 days after birth, which fits into three of the five domains of the NHS Outcomes Framework 2013-2014<sup>29</sup>. Furthermore, the DoH task group and the recent Morecambe Bay Report have recommended that there should be scope for parental input into the process from the beginning<sup>30</sup>. This is in line with the Francis inquiry which recommends the need for a consistent culture of openness and candour in the NHS, so that errors can be addressed and lessons learnt<sup>31</sup>. Additionally, the MBRRACE-UK Confidential Enquiry (published in November 2014) recommended that parents' perspectives of their care should be included in the standardised multidisciplinary review of their perinatal death and the results of the review shared with parents<sup>16</sup>.

Evidence from a large focus group undertaken with bereaved parents (PARENTS 1 Study), which investigated their knowledge of the Perinatal Mortality Review process, showed that parents were largely unaware that a review of their child's death took place, and found it distressing that they were not involved or kept informed<sup>32</sup>. Parents were unanimously in favour of an optional opportunity to contribute information, and would welcome a flexible system that could provide them with feedback, outcomes and lessons learnt following the review<sup>32</sup>. Further work to evaluate a perinatal mortality review process with parental involvement is currently under way (PARENTS 2 Study).

### **Follow up**

Follow up should be offered to parents as debriefing can help resolve uncertainty<sup>14,20</sup>. Prior to hospital discharge parents should be supplied with information about what to expect post-natally on their return to the community setting and this should include a single point of contact in the follow up period<sup>14</sup>. There is no evidence to support home visits over clinic follow-up or the optimum timing and frequency of such appointments<sup>14</sup>. Six to ten weeks is common practice for the interval between discharge from hospital and the appointment. The consultation should be led by



someone experienced in bereavement<sup>14,20</sup>. This should ideally be with a senior obstetrician the parents have met before. A personalised approach should be taken, using the baby's name within the consultation unless the parents prefer not to<sup>14</sup>. It is important that all results, including post mortem investigations, are made available for this appointment since long delays and inconclusive results can cause distress to parents<sup>14</sup>. It is recognised that many parents find it distressing to return to the unit where their baby was born and therefore consideration should be made to the environment where the consultation takes place. It is important that the follow up is comprehensive in nature yet tailored to the parents' needs. Evidence suggests that parents appreciate a system where emotional support is made available following birth and discharge from hospital<sup>14</sup>. The cause of stillbirth should be discussed and there should be acknowledgements if there were mistakes. The primary focus of the consultation should be around the stillborn baby and the parents<sup>20</sup>. However, the possibility of future pregnancy and the level of antenatal care the parents are likely to receive should also be discussed within the consultation<sup>20</sup>. Further investigations may need to be organised and advice or treatment may be required to improve maternal health for subsequent pregnancies. The consultation may include assessments for complex grief with appropriate referral mechanisms, should bereavement counselling or further psychological assessment be required<sup>18</sup>.

Clear pathways are required at the interface of primary and secondary care<sup>14</sup>. Therefore, good communication to the primary health care team (including General Practitioners, Community Midwives and Health Visitors) is required regarding the outcome of this consultation to ensure continuity of care. The INSIGHT Study found that parents and healthcare professionals agreed that the period between hospital discharge and follow-up consultation is characterised by delay and lack of information for parents and varied support<sup>18</sup>. There was the assumption follow-up with the primary health care team will automatically be arranged, which contrasted with what bereaved parents experienced<sup>18</sup>. Streamlined, standardised and collaborative care is urgently needed between hospital and community settings.

### **Interventions that might aid psychological recovery**

Interventions are required to reduce the negative impact of stillbirth on parents and families. However, an individualised, flexible approach should be taken to adapt to individual and cultural responses to death. The Royal College of Obstetricians and Gynaecologists (RCOG) Intrauterine and Fetal Death Guideline recommends that counselling and support groups should be offered to all women and their partners and that other members of the family such children and grandparents should also be considered<sup>20</sup>. However, there is a paucity of evidence to support this intervention<sup>4</sup>. A mixed-methods narrative systematic review assessed the current available evidence (from 1894 to 2014) on interventions to reduce the negative impact of stillbirth for bereaved parents and families who experience stillbirth<sup>4</sup>. Forty-three studies provided evidence on what works to reduce the negative effects of stillbirths, of which no randomised controlled trials were found<sup>4</sup>. The types of support described by the literature included emotional support, informational support, esteem and network support and tangible support<sup>4</sup>. Tangible support was subdivided into seeing and holding the baby, making memories through photographs, rituals to help saying goodbye including funeral arrangements, post-mortem discussions, and formal counselling input<sup>4</sup>. Within this systematic review only four studies assessing the outcomes of parents who had received counselling support were found worldwide<sup>4</sup>. The numbers within each study were too small to draw definitive conclusions<sup>4</sup>. Furthermore, the review found a minority of interventional studies included fathers and the wider family<sup>4</sup>. It is important to note not all parents may need psychological input as grief can be a "normal" part of the bereavement process. Therefore, future comparative

research should focus on how to support those parents and the wider family following stillbirth who might benefit from psychological input.

### **Care in subsequent pregnancies**

Most parents conceive within one year of experiencing a stillbirth<sup>33</sup>. It is known that risk of stillbirth and other pregnancy complications is increased for parents who have had a previous stillbirth<sup>34</sup>. There is little evidence to guide management of subsequent pregnancies following stillbirth<sup>35</sup>. A recently published survey of 2716 parents from 40 high- and middle-income countries found that there was a wide variation of antenatal care provided across different geographic regions<sup>33</sup>. Additional antenatal appointment and ultrasound scans were provided, however access to psychological care was less frequently provided<sup>33</sup>. Furthermore, the survey found parents whose stillbirth occurred at more than 30 weeks' gestation were more likely to receive additional care such as the option for early delivery. The RCOG guidelines recommend that decisions for and early delivery following unexplained stillbirth should consider the gestational age of the previous stillbirth, previous intrapartum history, and the safety of induction of labour<sup>20</sup>. A metasynthesis of qualitative literature also highlighted the value of emotional and psychological support from healthcare providers in improving care in pregnancy after stillbirth<sup>36</sup>. Further research should explore the roles of specialist services, formal training for staff and the development of clinical guidelines providing care in pregnancies after stillbirth<sup>33</sup>. It might also be useful to consider dedicated follow-up clinics for parents who experience stillbirth or perinatal death, with involvement of the multidisciplinary team including a bereavement midwife, and/or neonatologist for deaths occurring after birth.

### **Healthcare professional training**

There is an urgent need for evidence-based training in care after stillbirth using a parent-centred integrated pathway<sup>18</sup> to improve the experience of bereaved parents. Training should include evidence-based principles of care and management in the context of bereavement care, including common challenges and how to address them, psychological theories and good communication principles. Communication skills training should focus on techniques for dealing with grief reactions, communicating the diagnosis of stillbirth, respectfully discussing the post-mortem consent process and the processes after discharge from hospital<sup>18</sup>. A multi-disciplinary approach should be taken to encompass doctors, midwives, paediatricians, ultrasonographers, allied health professionals and general practitioners, with improved links between primary and secondary care<sup>18</sup>. Lastly, there is a training need for all out-of-hours staff to be trained in ultrasound scanning to be able to diagnose intrauterine death competently and confidently<sup>18</sup>.

### **Best practice points**

- Support should be available for parents who express concerns regarding their pregnancy
- Healthcare professionals should be trained in confirming the diagnosis of stillbirth available 24 hours a day and seven days a week
- Sensitive and empathetic communication should be adopted by healthcare professionals in contact with parents who experience stillbirth
- An individualised patient-centred approach should be adopted
- Continuity of care should be adopted by maternity units with dedicated obstetricians and midwives experienced in bereavement care

- A flexible approach should be taken regarding discussion around mode of delivery and healthcare professionals should explore why parents might choose a caesarean birth
- Pain relief should be available and discussed with all parents
- Lactation suppression should be offered to all women
- Memory making, including seeing and holding the baby should be offered to parents
- Post-mortem should be offered to all parents by a healthcare professional trained in post-mortem consent
- Parents' perspectives of their care should be included in the standardised multidisciplinary review of their stillbirth
- A consultant follow-up appointment should be offered encompassing clinical and emotional aspects of care
- Counselling and support groups should be offered to those who need psychological input
- Care in subsequent pregnancies should be individualised

### **Research Direction**

- Evidence-based training in care after stillbirth using a parent-centred integrated pathway to improve the experience of parents experiencing stillbirth
- Improvement of the primary and secondary care interface
- Exploring the role of counselling and peer support in bereavement care
- Improvement in evidence for interventions after stillbirth
- Development of standardised outcomes and outcome measurement tools applicable to stillbirth to measure the effectiveness of interventions
- Exploring the role of the parental involvement in the perinatal mortality review process
- Exploring the role of specialist services delivering care in subsequent pregnancies after stillbirth
- Further research and better understanding of the needs of bereaved parents in low and middle-income countries as well as ethnic minority groups in high-income countries.

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