An Interactive Workbook to Shape Bereavement Care for Midwives in Clinical Practice

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2012

FOREWORD

Midwives are often called upon to care for parents who have experienced a pregnancy loss or the death of an infant. In such circumstances, midwives are expected to interact with bereaved parents and their families in a supportive manner. Consequently, it is important that staff feel adequately prepared with strategies to deliver effective bereavement care.

The Stillbirth and Neonatal Death Society (SANDS) recommends that all community health practitioners who support bereaved parents should have access to basic, post basic and in-service training to equip them to offer adequate care to such families (SANDS, 2009). This has recently been endorsed by the Scottish Government's guidance "Shaping Bereavement Care" (2011), which called for improved training and support for all NHS staff working in this field. For many bereaved parents, the care that midwives provide has a crucial effect on their response to a loss or death (Engler & Lasker, 2000; Rowa-Dewar, 2002). Providing care to grieving parents can be demanding, difficult and stressful (Gensch & Midland, 2000; Sa¨flund et al., 2004), with some midwives feeling ill equipped to provide appropriate help (Robinson et al., 1999). In 2009, the National Maternity Support Foundation (NMSF) survey reported that the level of bereavement care delivered in a number of maternity units in the UK was inadequate:

> *"It is clear that there is a somewhat "patchy" approach to bereavement midwife care with an apparent lack of national strategy and clear up-to-date guidelines" (NMSF, 2009, p.12).*

In response to the results of the NMSF (2009), three experienced midwifery lecturers from three universities (*University of Salford*, *Glasgow Caledonian University* & *The University of the West of Scotland*) collaborated to design this interactive workbook called "*Shaping bereavement care for midwives in clinical practice".* This workbook has been designed to facilitate midwives and neonatal nurses with developing structured skills to deliver effective bereavement care. On completion of this workbook, the reader should be equipped with fundamental skills to support childbearing women, partners and families who have experienced childbirth related bereavement.

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SHAPING BEREAVEMENT CARE FOR MIDWIVES IN CLINICAL PRACTICE

INTRODUCTION

Grief is a multi-faceted response to the loss of someone or something to which a bond has been formed. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioural, social, spiritual and philosophical dimensions. While terms are often used interchangeably, bereavement refers to the state of loss and grief in reaction to loss of someone or something important. For example, someone important could mean a miscarriage or stillbirth and something important could be the social identity of potential motherhood lost when a baby is adopted. The term bereavement encompasses grief and mourning and denotes the emotions and behaviour of a childbearing woman who has suffered a loss. A childbearing woman who has experienced a loss may be said to go through a bereavement period, which is the time it takes to grieve and adjust to the loss. Every bereavement process is specific to each childbearing woman, partner and family dependent upon their attachment and beliefs surrounding their loss. Grief expressed signals the emotional responses invoked by the loss. Mourning refers to actions customarily associated with grief, such as styles of crying and lamenting the loss. Childbearing women and their families who have experienced a loss in varying degrees will experience grief. As such, midwives should be familiar with the various ways of supporting women and families when they are experiencing bereavement. Midwives and neonatal nurses do not care for bereaved parents in isolation. They are part of a collaborative team that may include doctors, chaplains, bereavement officers and counsellors, registrars, funeral directors, representatives of faith communities, voluntary support agencies and, of course, parents' families and friends.

Pregnancy loss is a form of 'disenfranchised grief' (Bartellas & Van Aerde, 2003), with many parents recognising that sometimes it is not socially acceptable to talk about the miscarriage or stillbirth they have experienced. As a consequence, they may feel isolated from and misunderstood by friends, family and colleagues (Kelly, 2007). The impact of loss and bereavement on an individual's spiritual well being can be profound. A person's sense of meaning and understanding of the world can be called into question. Existential questions such as 'why?, why me?', 'why now?', 'what have I done to deserve this?' or 'If there is a God, how can God allow this to happen?' are commonly expressed (Kelly, 2007). The bereaved are not looking for answers to these questions, but often a appreciate time and space provided by a non-judgemental other to express and explore these issues. Other symptoms of spiritual distress are a sense of hopelessness, helplessness, lack of

control, struggles with identity, purpose and role. Questions may be asked like, ‘if I am no longer a wife, mother or son, then who am I?

For most who experience bereavement, no professional support is required, whilst others may decide to seek supplementary support from appropriately trained professionals. Grief counseling, professional support groups, educational classes and peer-led support groups are resources available to the bereaved. Where grief has occurred in consequence to a childbearing event, the midwife is usually the first point of contact. It is therefore important that all midwives are equipped with appropriate knowledge about how to best support a woman, her partner and her family in this position.

Crying is a normal and natural part of grieving, as is talking about the loss experience. If forced or excessive, grief can become harmful. George Bonanno conducted a research study that focused on grief and trauma (Bonanno, 2009). Bonanno’s subjects experienced loss through war, terrorism, death of a child, premature death of a spouse, sexual abuse, childhood diagnoses of AIDS, and other devastating loss and trauma events. Bonanno (2009) found that people have an innate resilience in the event of grief and trauma events.

Kübler-Ross (1969, 2005) developed a theory that incorporates five discrete stages by which people deal with loss. These include denial, anger, bargaining, depression, and acceptance. The theory purports that the stages comprise a framework that facilitates people to learn to live without what they have lost. Midwives may use the Kübler-Ross model or a similar framework to help them identify and understand what a childbearing woman who has suffered a loss may be feeling. The incorporated stages are not discrete entities on a linear time line of grief, and not every bereaved childbearing woman will progress through all five stages in the prescribed sequence. The Kübler-Ross five stage model of grieving has been credited with bringing mainstream awareness to the sensitivities required for better treatment of people who are dealing with loss. More recently, researchers have developed several new models or theories to help professionals understand the processes of bereavement. These models serve to facilitate professionals who are involved in supporting the bereaved, by providing a knowledge base from which to practise. For example, Worden’s (1980) tasks of bereavement provide a framework to guide grief work, while the dual process model demonstrates the need to deal with both the primary loss and secondary stressors (Stroebe & Schut, 1999). No model of grieving is recommended above another, as all have mechanisms that may be helpful towards aiding understanding of the bereavement process and the processes involved in adaptation to loss.

A physical reaction to bereavement precedes any psychological symptoms (O'Connor et al., 2009). Functional Magnetic Resonance Imaging (fMRI) scans of women, who have experienced death of a mother or sister within five years, identified a local inflammation response through measuring salivary concentrations of pro-inflammatory cytokines. Production of these chemicals was correlated with activation in the anterior cingulate cortex and orbitofrontal cortex of the human brain. This activation also correlated with free recall of grief-related word stimuli. That is, talking about the bereavement experience stimulates feelings and its associated expression. This suggests that grief can cause stress and is linked with the emotional processing parts of the frontal lobe (O'Connor et al., 2009). Among those bereaved within the last three months, those who reported thoughts about their loss showed ventral amygdala and rostral anterior cingulate cortex hyperactivity. In the case of the amygdala, this links to sadness intensity. In those who avoid thoughts about their loss, there is a related opposite type of pattern in neurological responses (O'Connor et al., 2009).

The rationale underpinning why a midwife should complete this workbook, is because their role encompasses responsibility for delivering holistic evidence-based care to childbearing women. Consequently, it is important to recognise the physical, psychological and social components of bereavement, loss and grief and be equipped with appropriate skills to handle related adversity.

PURPOSE OF THIS INTERACTIVE WORKBOOK

This workbook will be a valuable resource for all midwives, especially those who provide bereavement support to childbearing women, and for midwifery lecturers who educate student midwives for their future role as clinicians. To view the Learning Objectives (LO) encompassed within this workbook see *Table 1*.

Table 1: Learning Objectives (LO) to shape bereavement care for midwives in clinical practice

(LO1) Classify areas of midwifery practice that incur bereavement.

(LO2) Discuss sensitive and supportive processes of delivering bad news to childbearing women, partners and families.

(LO3) Critically appraise the procedures categorised on a bereavement protocol.

(LO4) Critically appraise the models of grieving.

(LO5) Recognise instances where a childbearing woman's grief process has become dysfunctional and help is required from mental health experts.

(LO6) Outline processes involved in caring for and advising a bereaved woman / partner / family about how to access ongoing support on discharge from midwifery care.

(LO7) Recognise where a bereavement incident may affect a member of staff adversely.

(LO8) Assess individual women / partner / family's spiritual / religious beliefs and adapt bereavement care to accommodate.

Chapter One: Areas of midwifery practice that incur bereavement

Learning Objective addressed

On completion of *Chapter One* the midwife should be able to:

(1) Classify areas of midwifery practice that incur bereavement.

1.1. Areas of midwifery practice that incur bereavement

Death of a child can take the form of a loss in pregnancy, the perinatal period or infancy. For example:

- Early pregnancy loss such as ectopic pregnancy and miscarriage
- Stillbirth
- Perinatal death
- Neonatal death
- Sudden Infant Death Syndrome (SIDS)
- Death of an older child.
- Infertility

In the majority of cases parents experience excruciating grief. The death of a child could be considered to be one of the most intense forms of grief and one of the hardest to bear (Shane, 1992). For the majority, the death of a child is an event which evokes unbearable anguish and sorrow (Stack, 2003). A childbearing woman does not simply just get over her loss. Instead, she will need to adapt and learn to live with her loss. Interventions and support can make all the difference to the fortitude of a parent in this type of grief, with risk factors such as family breakup or suicide a potential outcome. Feelings of responsibility, whether legitimate or not, are omnipresent. Also, the nature of the parent / infant relationship may result in an assortment of problems, as women, partners and families seek to cope with their loss. Parents who suffer miscarriage or a regretful termination of pregnancy may experience resentment towards others who have accomplished successful pregnancies.

Other losses

Parents may grieve due to loss experienced through means other than death. For example:

- Having a child adopted or fostered.
- Termination of a pregnancy for medical or social reasons.
- Loss of a healthy child through prematurity, illness or abnormality.
- Legal termination of parental rights incited by the social work department.
- Having a history of child abuse, neglect or incompetent parenting.
- Loss of paternal identity due to separation from the childbearing woman.
- Loss of a romantic relationship (i.e., divorce or break up).
- A childbearing woman who strongly identifies with her occupation may feel a sense of grief if she has to discontinue or alter her work arrangement due to parenting responsibilities.
- Those who have experienced a loss of trust may also experience some form of grief.

Each society has its own particular cultural approaches to managing bereavement within the community. These include specific rituals, styles of dress and habits, as well as attitudes that the bereaved are expected to follow. Far East cultures continue their ties with the deceased through religious rituals. In contrast, amongst the Hopi people of Arizona the deceased are swiftly forgotten and life continues on. In essence, different cultures grieve in different ways and will be discussed in more detail in chapter seven. Also later on in this workbook you will be looking at some of the rituals that midwives in the UK undertake when dealing with loss of a baby in clinical practice.

1.2. Defining the terms loss, grief and bereavement

Consider what the following terms mean to you:

- Loss
- Grief
- Bereavement

Activity 1

Consider what the terms loss, grief and bereavement mean to you.

Loss……………………………………………………………………………………………..

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Grief……………………………………………………………………………………………

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Bereavement…………………………………………………………………………………

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Now let us consider formal definitions of loss, grief and bereavement and how midwives can better understand the feelings experienced by childbearing women, their partners and family members.

What is loss?

Loss is defined as the severing or breaking of an attachment to someone or something that results in a changed relationship. Two general categories of loss exist: (1) Physical loss, and (2) Psychological loss. A physical loss is the loss of something tangible. For example:

- A car that is stolen
- A house that burns down
- A precious belonging that has been mislaid

One might assume that the possessor may have emotions in response to that loss. In contrast, a psychological loss is a symbolic loss and features something intangible and psychosocial in nature. For example:

- Experiencing a divorce
- Retiring
- Developing an unremitting illness
- Having one's fantasy or dream wiped out

What is perinatal loss?

Perinatal loss is defined as a stillbirth beyond 20 weeks gestation or death of the infant within the first twenty eight days post delivery. In response to such an event it is common for the mother to experience emotions such as fear, anxiety and helplessness, which requires sensitive handling and appropriate discussion with the

midwife (Shane, 1992). During such an event, the care that midwives provide may have a crucial effect on the parent's response to their loss (Engler & Lasker, 2000). Caring for and supporting parents who have lost a baby can be extremely demanding, difficult and stressful (Billson & Tyrrell, 2003).

Much of the published literature includes references to perinatal loss and bereavement care in western societies (Caelli et al., 2002; Engler et al., 2004; Engler & Lasker, 2000; Gardner, 1999; Gensch & Midland, 2000; Lin & Lasker, 1996; Shane, 1992). Most of this research has focused on parental grief responses and interventions that facilitate parental adaptation to their loss (Blackburn & Copley, 1989; Brost & Kenney, 1992).

Just as no two deaths are alike, so it is with grief and bereavement. To the childbearing woman, partner, family and friends, bereavement causes great stress that can temporarily impair concentration, decision-making and performance. Without adequate support, grief and bereavement may affect a person’s health. But with sufficient support, the experience of grief and bereavement can enhance an individual’s personal growth and facilitate development of their understandings about the meaning of life.

However, as has been mentioned, perinatal loss does not only relate to a death. You may not consider that some events within midwifery practice are potential provoker’s of grief. Examples may include:

- Loss of a normal labour due to the childbearing woman requiring an emergency caesarean section.
- Loss of a healthy normal sized baby when the infant has been born extremely premature.
- Loss of one’s uterus due to essential removal to alleviate postpartum haemorrhage.

Activity 2

(a) Identify a loss that you have experienced and classify your reactions in terms of psychological, behavioural, social and physical response:

Psychological responses to grief……………………………………………………………

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Behavioural responses to grief………………………………………………………………

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Social responses to grief ………………………………………………………………...

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Physical responses to grief ……………………………………………………………….

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Spiritual responses to grief ……………………………………………………………….

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(b) Identify a loss that a childbearing woman in your care experienced and classify her reactions in terms of psychological, behavioural, social and physical response:

Psychological responses to grief……………………………………………………………

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Behavioural responses to grief………………………………………………………………

…………………………………………………………………………………………………

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Social responses to grief ………………………………………………………………...

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Physical responses to grief ……………………………………………………………….

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Spiritual responses to grief ……………………………………………………………….

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What is grief?

Grief refers to the process of experiencing psychological, behavioural, social and physical reactions to the perception of loss. Five important clinical implications derive from this definition:

(1) Grief is experienced in five major ways:

- psychologically
- behaviourally
- socially
- physically
- spiritually

(2) Grief is a systematic process that involves several emotional states. It is not motionless and stationary. In other words, it actively incorporates change over time.

(3) Grief is a normal expectable response to a loss. The absence of it could in some situations be considered abnormal or even pathological.

(4) Grief is a reaction to all types of loss. It is not just about fatality. Death of a baby in midwifery practise is only one example of loss.

(5) Grief is dependent upon the childbearing woman's unique perception of her loss. It is not necessary for this loss to be socially recognised or validated by others for her to grieve. It is however helpful for midwives to recognise the possibility that it may happen.

A childbearing woman's response to a significant loss will usually express one or all of the following four dimensions:

(1) Her feelings about the loss, e.g., sadness, despair, remorse.

(2) Her objection to the loss and wish to reverse the situation, e.g., anger, searching, fixation with what has happened.

(3) The effects on her as a direct result of the loss, e.g., disorganisation, bewilderment, horror, anxiety state and/or physical symptoms (loss of appetite, palpitations, nausea etc.).

(4) Her response behaviours to the loss, e.g., crying, social withdrawal, use of medication, drugs and/or alcohol.

(5) Existential questions about the loss may be asked. For example, wrestling with 'why' the loss might have happened. A search for 'why' questions may call into question the way the bereaved understood the world prior to their loss.

Grief is a natural response to loss and it incorporates a range of reactions. Associated emotions include:

- Sadness
- Anger
- Guilt
- Pain
- Longing for the lost person or thing.

A grief reaction may be experienced following:

- The end of a relationship
- Moving away from home
- Loss of a fantasy or dream

Grief is painful to experience and witness, with the majority of people innately equipped to adapt and survive their loss.

Activity 3

Consider your own situation or someone you know and how they responded to a significant loss.

The loss event...…………………………………………………………………………………

1. Associated feelings about the loss, e.g., sadness, despair, remorse…………………

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2. Objections to the loss and wish to reverse the situation, e.g., anger, searching, fixation with what has happened…………………………………………………………..

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3. Effects that directly resulted from the loss, e.g., disorganisation, bewilderment, horror, anxiety state and/or physical symptoms (loss of appetite, palpitations, nausea etc.) ……………………………………………………………………………...

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4. Individual response behaviours, e.g., crying, social withdrawal, use of medication/drugs/alcohol...

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5. Existentialist questions asked?...

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Grieving is about coming to terms with a loss. The length of time it takes for an individual to adjust is variable. Adaptation can depend on several factors:

- The significance of the loss to the person concerned.
- The character of the loss.
- Other events running simultaneously to the loss.
- Prior experience of loss.

Although there may be similarities in peoples' responses, there can also be marked differences; each person grieves and recovers in their personal way.

Activity 4

Identify a loss that caused you grief...

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What strategies did you use to help you cope?

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Which of these strategies were beneficial?

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Which of these strategies were detrimental?

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What is bereavement?

Bereavement is the total reaction to a loss and includes the process of healing and recovery from the loss. Bereavement results in a great longing for the lost person or object and requires a period of adjustment by the experiencer that may take years. All parts of the bereaved individual may be affected. This includes emotional, physical, spiritual and social aspects of that person. The overriding feeling is ordinarily one of intense pain, which is otherwise known as grief.

Chapter Two: *Breaking bad news*

Learning Objective addressed

On completion of *Chapter Two* the midwife should be able to:

(2) Discuss sensitive and supportive processes of delivering bad news to childbearing women, partners and families.

2.1 . Breaking bad news

Breaking bad news to women and their families is an inevitable part of a midwives role, especially when working with those who are experiencing a difficult pregnancy or loss. As such, it is imperative that midwives are aware of the importance of being a good communicator, and that they know how to impart difficult information in a sensitive manner. Cases that involve breaking bad news include fetal compromise, or demise, with the woman, partner and family unaware, or fully aware, of the situation and its implications. In such situations, it is the midwives duty to impart salient information and provide referral and support networks to those involved. In doing so, a fine balance requires to be achieved between the information imparted causing pain and distress, at the same time as providing essential knowledge. A sensitive and informative approach will initiate processes for those involved coming to terms with their loss.

When problems arise, childbearing women are often transferred to a hospital that has specialised neonatal facilities, where best possible care can be provided to the childbearing woman, partner and baby. Although the woman may be aware of complications, she may not have full cognition of the extent of the problem and its potential outcomes. Misinterpretations and misconstructions can make this a perplexing time for those at the centre of care provision. Once investigations have taken place to update and confirm the impediments involved, the midwife may be considered the right person to break the bad news to the family. It is imperative that midwives are prepared for such events and that they plan an appropriate time and venue to impart information to the childbearing woman, partner and family. For example, a side room with attractive and comfortable chairs, bathroom facilities,

which is absent of sounds of mothers with healthy crying babies and external telephone calls. Upon receiving difficult and perhaps complex details, the couple must be afforded time to absorb information in a safe environment. Such action will facilitate healthy commencement of the grieving process.

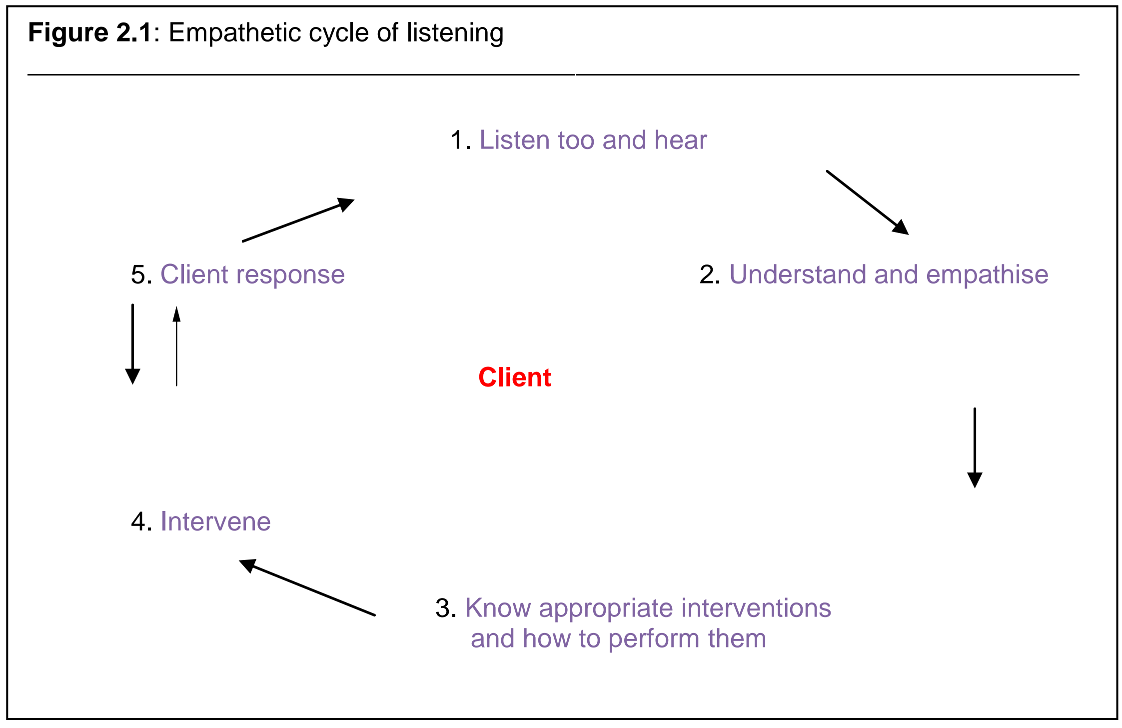
The woman may have been referred from home or an outlying clinic for ultrasound to confirm the suspected diagnosis. In order to be fully prepared for such events, the midwife should ensure that relevant background information is available; for example, a midwife or general practitioner referral letter and the childbearing woman's case records. Schedule in an appointed amount of time to ensure that appropriate attention is paid to the woman's needs. An unfitting time would be to deliver "bad news" in the middle of a busy clinic, where there is countless interruptions and distractions. Providing accommodation for a supportive significant other is paramount for the troubled and grieving woman's companionship needs. If the midwife is prepared in advance about the type of bad news to be broken, she/he can decide whether another professional person is required to provide additional professional information. For example, a specialist midwife, social worker, nurse or doctor. If the woman is oblivious to the gravity of the situation, she may have elected to attend the maternity unit unaccompanied. In this instance, it may be relevant to contact an individual of her choice to provide more intimate support.

Before breaking the bad news, the midwife must elucidate on the childbearing woman's precise understandings of her situation. This may be achieved through use of the following example probing open-ended questions. Examples follow:

(1) What have you been told so far?
(2) What has happened since your last appointment?
(3) How have things been for you?

Listening is a skill that midwives must use during the communication event. At all times the childbearing woman must be at the centre of the communication. The communicator must not trivialise the communication event with irrelevant conversation about mundane inconsequential events that do not relate to the issue in hand. This is particularly relevant when breaking bad news, with displays of empathy crucial to developing trust and showing that staff care. *Figure 8.1* depicts an empathetic cycle of listening.

Figure 2.1: Empathetic cycle of listening



The information given at the "breaking bad news" event is a snapshot that is likely to be replayed repeatedly in the childbearing woman's mind. This makes the communication event momentous, with irrevocable implications. In light of this possibility, it is essential that the midwife is professional, supportive and demonstrates sincere and genuine empathy.

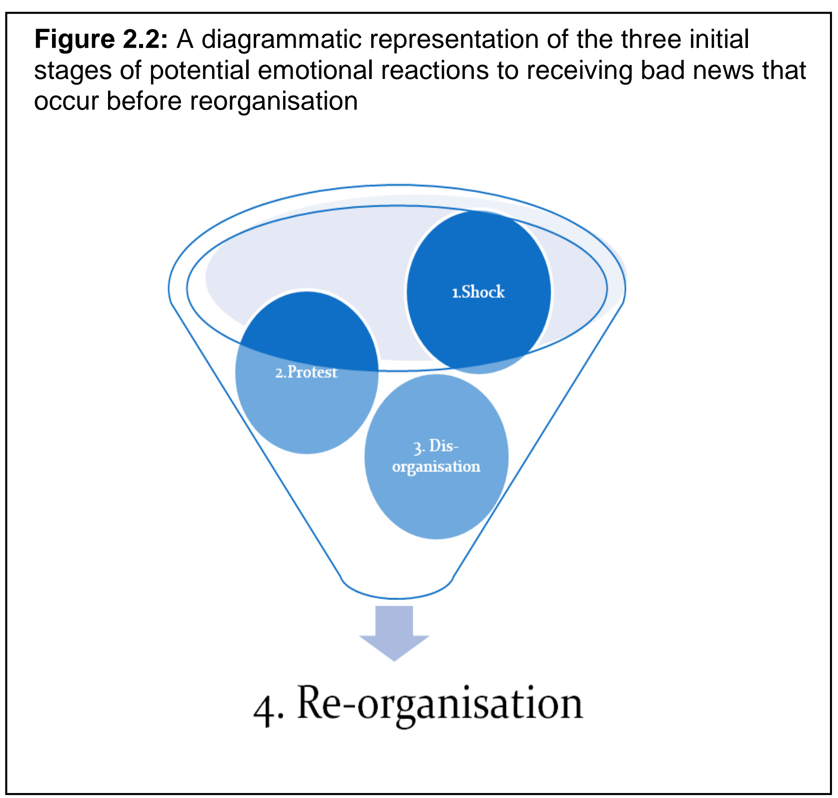
It is recommended that a fairly direct approach be taken when breaking bad news. The couple may have intuitively recognised that something is amiss and therefore one must not prevaricate and protract anguish. ARC (2012) proposes some example statements that will indicate the serious nature of the situation:

(1) I do have something to tell you.
(2) I am afraid it is more serious than we expected.
(3) I am very sorry to have to tell you.
(4) It is not very good news I am afraid.

Once "bad news" has been given, there is a range of potential emotional and behavioural responses that may be displayed between re-assimilation and regularity being resumed. The emotional process during the "breaking the bad news" event is the beginning of the grief process, which is customarily exhibited in different phases (see *Chapter 3*). More often the initial response is: (1) Shock, which may incorporate feelings of numbness, denial, disbelief, hysteria and inability to think cohesively. The second most common emotion exhibited is one of: (2) Protest, whereby an individual

may have strong, powerful feelings of anger, guilt, sadness, fear, yearning and searching for answers. As the reality and enormity of the situation is acknowledged: (3) Disorganisation of emotions may occur. During this phase, the woman may experience feelings of overwhelming bleakness, despair, apathy, anxiety and confusion. Having passed through the three preceding stages of: (1) *Shock*, (2) *Protest*, and (3) *Dis-organisation*, once *Re-organisation* of the facts have begun to be assimilated, there is a gradual return to more ordinary functioning. To view a diagrammatic representation of three initial stages of possible emotional reactions to receiving "bad news" that occur before *Reorganisation* (see *Figure 8.2*).

Figure 2.2: A diagrammatic representation of the three initial stages of potential emotional reactions to receiving bad news that occur before reorganisation



It is salient that the information issued is paced in small amounts of clearly stated and uncluttered facts. It is also important not to overload the woman with information in one bite, or confusion and cognitive overloading may occur. Allows time for the woman to go through her "potential emotional reaction set" before formulating questions she wants to ask during the shock and disbelief stage. It is best not to follow the initial "bad news" with an information avalanche that is unlikely to be absorbed. Until *Re-organisation* has occurred, stick to the significant points and answer questions that are repeated. Also, reiterate what is necessary as many times as is requested to help facilitate progression to the *Re-organisation* stage.

It is a difficult time for all, professionals included, with those involved requiring to overcome awkwardness that relates to the childbearing woman's grief. In

response, accommodate silences and do not feel compelled to fill gaps in the conversation. Show an empathic disposition and encourage the woman to talk when she is ready. Empathy may be expressed through verbal or physical signs. Listen and take a non judgemental approach. No pressure should be applied in attempts to compel the woman or family to talk. Have respect for individual reactions and coping strategies.

Initiating conversation

It can be really difficult to know where to start. Having the right words is not as important as having a caring presence and being willing to dance attendance upon the bereaved couple. What follows are some ideas that may help the midwife share this journey with the woman and which will optimise time spent together. There is no quick fix to grief and midwives cannot fast track pain. Midwives require to learn to accept that psychological processes are as they are designed to be. It may be helpful to give the woman a journal in which she can record her thoughts, feelings and memories. This can provide support to the woman as she writes. Also the record can be used to reflect back in years to come on the enduring memory of this grief experience. Some guidelines for a series of conversations follow.

Getting to know each other

As with all relationships, midwives require to earn the right for childbearing women to share their grief with us. Building trust is crucial. It may be helpful to share a little of yourself with the couple to initiate some connections.

Sharing memories

It can be helpful to ask the woman to share memories of special things about her pregnancy. These memories could be written in the journal for keepsake. If relevant, ask if the couple would like to peruse photograph's that have been taken of their baby and together create meaningful stories to tell. Never force this issue. As an alternative, the woman can take the photographs in a sealed envelope home with her. Memory jars are another way of creating a meaningful picture of the event and attempting to continue a bond that has been established while the baby was in utero.

Telling the story

Telling the story is a crucial element of support the midwife can offer to the woman. It may be the only opportunity she ever has to tell her story to someone who is prepared to listen and fully understands the complexity of her circumstances. The midwife can commence the story by asking the woman what life was like before she

lost the pregnancy, or the baby died. It can be useful to ask her to write or draw her story.

Talking about difficult feelings

Being able to understand that difficult feelings are a normal part of the grieving process can be helpful for the childbearing woman. To know that she is not going mad and that pain, anger, guilt and relief are all acceptable ways to feel when one has lost a baby. This approach can create relief in itself. The midwife requires to recognize that the woman will display an array of behaviour changes, with her/his role to provide support absent of judgement. There may be displays of angry behaviour directed at hospital staff. Often this is an outward expression of the woman's inner turmoil. Just expressing understanding that anger is normal is sometimes all that is needed. There are helpful ways to explore difficult feelings. Again writing in a journal can be cathartic. It may also be helpful to identify what triggers anger and pushes buttons. Sometimes the smaller issues are key and it may be possible to remove them from the environment. Drawing an anger scale may also be useful (see *Figure 8.3*).

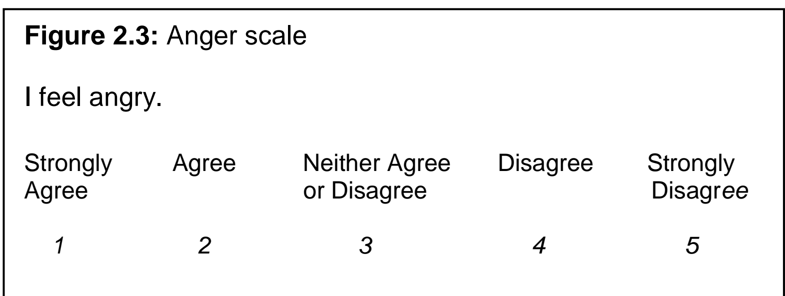


Figure 2.3: Anger scale

I feel angry.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1	*2*	*3*	*4*	*5*

There are many other activities for exploring feelings. For example, visual activities for working with anger and discussing difficult feelings can initiate great conversations.

Talking about what helps and discussing coping strategies

Ask the woman what helps her when she feels upset. She may choose to make a list. It may be helpful to listen to music, eat a favourite food, go for a walk, and/or to look at photographs and mementos. Each person has different coping strategies, and what helps one woman may hinder another. It may also be facilitative to encourage the woman to channel her energies into something positive. For example, exercise releases mood enhancing hormones.

Thinking about hope for the future

Women require encouragement to think positively about the future. Regardless of the fact that her baby has died, she can attempt to make the future as she would like it to be. It is important to help her appreciate that she does have some control over her providence. The past is behind and out of her control, but she can make her own life choices about the future. It may be helpful for her to write down some of her hopes for a future in the journal. This conversation can be a special time for reflection and can be commemorated by lighting a candle in remembrance of the baby who departed this life. In the future, again candles can be used as a reminders that the family light on special days. A balloon release can also be special. A helium balloon of a significant colour and a written message on paper attached before release can be most therapeutic. Special days, such as anniversaries and imagined birthdays, can be commemorated with such rituals.

Body language

It is important for midwives to consider their body language when communicating with the woman, partner and family. Body language is a form of mental and physical non-verbal communication. It consists of body posture, gestures, facial expressions, and eye movements. Humans send and interpret non-verbal signals almost entirely subconsciously. Human communication consists of 93% body language and paralinguistic cues, with only 7% consisting of actual words (Borg, 2010). Body language provides clues about the attitude and state of mind of the woman. Body language indicates aggression, attentiveness, boredom, relaxed state, pleasure and amusement. This is especially relevant in sensitive situations, such as breaking bad news, since the midwife wants her body language to match what is being communicated verbally. To some extent what constitutes helpful and unhelpful behaviour is in the eye of the beholder. However, there are certain behaviours that more often than not are considered helpful and therefore tend to engender favourable reactions from people. This applies whoever the person is; senior, junior, same level, clients, patients, friends or relatives. Some examples of helpful body language include (ARC, 2012):

- Being open
- Genuine
- Making eye contact
- Being relaxed and attentive
- Smiling where appropriate
- Facing the person being addressed

Unhelpful behaviours are those which hinder the midwife from achieving his/her objectives, or which run the risk of creating a bad impression. What is helpful and unhelpful depends upon circumstances. Nevertheless, there are certain behaviours that tend to engender unfavourable reactions in people the midwife is dealing with. Some examples of unhelpful body language include:

- Having a blank expression
- Leaning away, arms folded, legs crossed
- Using a desk as a barrier
- Fidgeting
- Hair twirling
- Placing hands in front of one's mouth
- Talking too loud or too low
- Looking bored

Whilst communicating, it is essential to check for understanding? Clarification may be sought through asking questions. Always respond to questions and consider what follow up would be appropriate and helpful. This is dependent upon the situation and individual needs of the woman, partner and family. Before closure, the midwife requires to make appropriate contact arrangements and provide details about her/himself, other relevant professionals and potential support persons. Trying to end the consultation can be difficult. What follows are suggestions about how to close a consultation:

(1) Agree further plans
(2) Provide time to gather thoughts
(3) Discuss transport home
(4) Ask if the woman wants a significant person contacted to keep her company
(5) Reinforce contacts
(6) Make some physical contact, e.g., shake hands or touch arm

Activity 5

Case Scenario

You are the midwife working on the antenatal ward and have just admitted Fiona, who is a primigravida at 28 weeks gestation. Fiona has been transferred into the midwifery unit from a rural hospital. From the referral information you are aware that there are concerns about fetal well-being and growth. She has been transferred to your unit for more in-depth screening. Fiona is alone and unaccompanied by her partner, and is keen to get in touch with him. She is unaware of the suspected clinical findings. As you conduct a routine CTG, Fiona starts to ask questions about her baby and the CTG findings. It is now mid evening and the doctor is not due to visit until tomorrow.

How will you initially manage this situation?

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What on-going care will you provide to Fiona?

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***Chapter Three**: Procedures categorised on a bereavement protocol*

<u>Learning Objective addressed</u>

On completion of *Chapter Three* the midwife should be able to:

(3) Critically appraise the procedures categorised on a bereavement protocol.

3.1. Protocols for caring for women who have experienced late fetal loss or stillbirth

A protocol should tackle seven essential aspects of bereavement care:

(1) The care given to parents should be responsive to their individual needs and feelings.
(2) Parents require information.
(3) Communication with parents should be clear, sensitive and honest.
(4) Parents should be treated with respect and dignity.
(5) Parental loss should be recognised and acknowledged. Their experience and feelings should be validated.
(6) Parents need time to adjust to their loss.
(7) All those involved in the care of bereaved parents should have access to support.

Activity 6

Midwives can address the essential aspects of bereavement care. For example:

- **The care given to parents should be responsive to their individual needs and feelings.**
- **A care plan could be developed that asks specific questions about the couples desires in relation to their management whilst in the maternity unit and post discharge.**

Generate six ideas about ways that midwives can deliver bereavement care in relation to the following principles:

(1) Parents require information:

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(2) Communication with parents should be clear, sensitive and honest:

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(3) Parents should be treated with respect and dignity:

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(4) Parents loss should be recognised and acknowledged. Their experience and feelings should be validated:

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(5) Parents need time to adjust to their loss:

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(6) All those involved in the care of bereaved parents should have access to support:

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The aims and objectives of a bereavement protocol

The aims and objectives of a bereavement protocol are as follows:

(1) Provide an environment suitable to meet individual needs of the woman and family following a stillbirth or late fetal loss.

(2) Support staff in providing individual family needs.

(3) Give essential information to the woman and family to enable them to make informed choices in relation to subsequent arrangements.

(4) Ensure that care provided is evidence-based.

(5) Ensure effective prompt communication exists between health care professionals and voluntary group members who are providing the bereavement care.

Activity 7

Midwives need to address the objectives of a bereavement protocol. Here is an example of a protocol and how directives can be achieved:

- **Provide an environment suitable to meet individual needs of the woman and family following a stillbirth or late fetal loss:**

- **An environment suitable for a grieving couple could consist of a private room with double bed, comfortable chairs, private bathroom, internet access, television, open visiting and privacy from childbearing women who have had successful outcomes and have healthy crying babies.**

Now generate four more ideas about ways in which midwives can address the objectives of a bereavement protocol:

(1) Support staff in providing individual family needs:

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(2) Give essential information to the woman and family to enable them to make informed choices in relation to subsequent arrangements:

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(3) Ensure that care provided is evidence based:

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(4) Ensure effective prompt communication exists between health care professionals and voluntary group members who are providing the bereavement care:

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The following are exemplars of protocols designed to guide midwives on management of women who have experienced loss (*Tables 3.2 -3.11*):

Table 3.2: *Protocol of how to manage a woman who has experienced a late fetal loss or stillbirth following delivery*

(1) Parents should be given time and confidence to see and hold their baby and take photographs if they wish.

(2) Photographs should be taken using the unit's digital camera and printed out. If parents do not wish to have copies of the photographs, they should be placed in a sealed envelope and securely stapled to the mother's case notes.

(3) A memory box should be offered to the parents. Hand / footprints and a lock of hair are obtained and placed in a memory card. The unit's remembrance book and a church service should be discussed with parents.

(4) Parents should be asked if they wish to have their baby bathed and if appropriate asked whether they want to be involved. This will depend on the condition of the baby and the extent of maceration. The bathing process should be carried out using cool water.

(5) The baby should be examined for abnormalities. If any are identified they should be documented.

(6) Appropriate skin, cardiac blood, placental swabs and samples should be collected in accordance with the checklist. In babies of a very young gestational age, it may be difficult to identify sex from genitalia alone. If this is the case, advise parents that further investigations will confirm sex.

(7) The baby should be weighed, measured and labelled with two name bands.

(8) The baby should ideally be dressed in personal clothing. Parents may wish to supply these. Where appropriate, parents may wish to dress or help dress their baby.

(9) Parents should be given the opportunity to have their baby blessed and/or named by a representative of their faith community or the hospital chaplain. Parents can create a personalised funeral for their baby whatever their beliefs or faith. This may be discussed prior to delivery.

(10) The opportunity to have a Post Mortem (PM) performed should be discussed with the parents. Consent must be obtained.

(11) Once parents are ready, the baby should be transferred to the mortuary with the following forms:

- Confirmation of death
- Removal to mortuary
- Consent to PM (if required)

. Parents should be advised that they can arrange to see their baby again if they wish.

(12) If the baby was stillborn (>24 weeks) a stillbirth certificate requires to be completed. This form is taken to the registrar who will record the death. If the baby was born alive, but then died, a neonatal death certificate needs to be completed (regardless of the baby's gestation). Both the birth and death certificates require to be registered.

(13) The Confidential Enquiry into Maternal and Child Health (CEMACH) form should be completed and forwarded to the designated co-ordinator.

(14) With maternal consent, a teardrop sticker should be applied to the main hospital notes.

Table 3.2 cont'd: *Protocol of how to manage a woman who has experienced a late fetal loss or stillbirth following delivery (continued)*

(15) If the mother is Rhesus Negative, administration of Anti-D should be arranged if required.

(16) Checklists should be completed. If the woman wishes to go home before checklists are completed, omissions need to be communicated to the community team and outstanding tasks documented clearly.

(17) The mother should be seen by her own consultant or the on-call consultant for labour ward prior to discharge.

(18) It is acceptable for the parents to request to take their baby home for twenty four hours after the PM.

(19) An appointment should be made with the appropriate office to discuss arrangements and for collection of the necessary documents and certificates.

(20) The mother should be allowed home as soon as her medical condition allows.

(21) An eight week follow up appointment with the named obstetrician and specialist midwife should be made. Test results should be available for discussion on this date.

(22) The woman should be given all the necessary contact telephone numbers prior to discharge.

(23) The mother / parents / family should be made aware of counselling services.

(24) Staff should be made aware of the employee's counselling service.

(25) Explain details of the unit's memorial service for bereaved parents. The chaplainry hold regular memorial services in collaboration with the maternity unit and/or local Stillbirth and Neonatal Death Society (SANDS). These services are tailored to meet the needs of both religious and non-religious bereaved parents.

These guidelines cannot anticipate all possible circumstances and exist only to provide general guidance on clinical management to midwives.

Checklist procedures

It is usual to have a bereavement pack that contains all protocols and checklists to keep the midwife on track when caring for a woman / her partner and family who have experienced a late fetal loss or stillbirth.

Table 3.3: *CHECKLIST ONE: Essential communication in bereavement care*

Woman informed of death by: ……………………………………..… Date …………..
Partner informed of death by: ……………………………………... Date…………..
On call consultant obstetrician informed by………………………. Date…………..
Woman's own consultant informed by…………………………….. Date…………..
Team midwife informed by phone by……………………………… Date…………..
GP informed by phone by……………………………………………. . Date…………..
Health visitors informed by phone by……………………………… Date…………..
Social worker informed (if applicable) by……………………………. Date………….
Antenatal clinic informed by phone by…………………………….. Date…………..

Table 3.4: *CHECKLIST TWO: Maternal investigations*

The following specimens should be obtained as soon as possible after fetal demise has been diagnosed and preferably before delivery of the baby:

(1) High Vaginal Swab (prior to delivery if possible)

(2) Mid Stream Specimen of Urine (white top bottle)

(3) Endocrine Screen (grey topped bottle – 2 mls of blood required)

- HbA1C
- Random Blood Sugar

(4) Thyroid Function Tests (yellow topped bottle – 3.5 mls of blood required)

- Liver Function
- Bile Acids

(5) Urea and Electrolytes (yellow topped bottle – 3.5 mls of blood required)

(6) Immunological Tests (red topped bottle – 10 mls of blood required)

- Anticardiolipin/lupus antibodies (8+ weeks post loss)

(7) Thrombophilia Screen (blue topped bottle – 3.5 mls of blood required)

- Lupus, Protein S & Protein C at 6 weeks postnatal

(8) Haematological tests

- FBC (purple topped bottle – 3 mls of blood required)
- Group & Save>
- Rhesus Antibodies> (pink topped bottle – 6 mls of blood required)
- Kleihauer>
- Clotting Studies (blue topped bottle – 3.5 mls)

(9) Genetics screen (Green topped bottle)

- Chromosomes

(10) Alpha-Feto Protein (red topped bottle – 10 mls of blood required)

(11) Infection Screen (red topped bottle - 6 mls of blood required)

- TORCH Screen
- Toxoplasmosis
- Rubella
- Cytomegalovirus
- Herpes Simplex
- Parvovirus
- Listeria
- VDRL

NOTE:

- *Anticardiolipin/lupus antibodies should not be performed until 8 weeks post pregnancy as doing this before then can affect the value.*
- *Infection screen is not always routinely performed. It is usually only carried out if there is a particular suspicion.*
- *Maternal & paternal not necessarily routine and only carried out if required. Often done at follow-up after three miscarriages.*
- *Blood bottles are not the same in every health board area. Remember to familiarise yourself with local requirements.*

Table 3.5: *CHECKLIST THREE: Fetal Investigations*

It is important that the following samples are taken from the deceased baby:

(1) Baby details:
- Weight…………………………………………………………………………
- Length…………………………………………………………………………
- Head circumference………………………………………………………………
- Sex of baby (Male / Female / Uncertain - confirm by PM and/or DNA)

(2) In suspected / confirmed cases of fetal abnormality only:
- Skin sample taken at post mortem (full depth 0.5 cms into a dry sterile pot and covered with saline)

(3) Cord (2-3 cm taken as near to fetal insertion point as possible (put into a dry sterile pot and cover with saline)

(4) Placenta / membrane / cord from as near to insertion point in the placenta as possible (put into a dry sterile pot and cover with saline)

(6) Placenta (if consent for PM, placenta is sent with baby in a pot with formalin)
In all cases a small piece of placenta is sent to microbiology in a dry pot.
If not for PM, remainder of placenta goes to histopathology in a pot with formalin.

Table 3.6: *CHECKLIST FOUR: Post Mortem (PM)*

Decision to have PM investigation discussed by: Yes / No

Signature………………………….……………….. Date……………

If baby having PM
PM leaflet given to parents
Obtain parents consent on consent form
Appropriate office informed
Inform mortuary of date and time of arrival
Inform parents results will be issued in approximately 8 weeks
Baby is sent to mortuary accompanied by:

- Consent to PM form
- Photocopy of case notes

Doctor decides if additional tests are required, e.g. genetic screening

Table 3.7: *CHECKLIST FIVE*
Provision of emotional and spiritual support

Emotional support provided by: Yes / No
Signed………………………………. Date…………....

Parents held baby	Yes /No
Photographs taken with polaroid camera	Yes /No
Photographs given to parents / stored in notes	Yes /No
Photographs taken with digital camera	Yes /No
Parents taken photographs with own camera	Yes /No
Mementoes given	Yes /No
Memory box given	Yes /No
Memory card given	Yes /No
Hand and footprints taken	Yes /No
Lock of hair taken	Yes /No
Permission given by parents	Yes /No
Name band given	Yes /No
Spiritual support	Yes /No
Baby named / blessed / baptised	Yes /No
Naming / blessing / baptism certificate given	Yes /No
Seen by chaplain	Yes /No
SANDS information leaflets provided	Yes /No

Table 3.8: *CHECKLIST SIX: Parents request to take the baby home*

Discuss parents request to take baby home with woman's consultant.

Parents can take the baby home if there is no PM being undertaken or after PM has been carried out (not before PM).

A stillbirth certificate must be completed prior to taking the baby home.

Parents should be advised:

- That in the event of a PM there may be leakage from the restoration suturing site.
- To keep their baby in a cool room.
- To exclude pets from the room.

The baby should be transported home in a crib.

A letter explaining the situation should be handed to the parents in case of police interest.

Baby should be returned to the hospital mortuary within twenty-four hours of departure.

Table 3.9: *CHECKLIST SEVEN: Funeral arrangements*

Funeral arrangements discussed by: Yes / No
Signature…………………………………………….. Date…………………….

Do family wish to have:

- A burial Yes / No
- A cremation Yes / No

Do family wish to have:

- A hospital burial Yes / No
- A private cremation Yes / No

Parents informed they can choose to attend / not attend hospital burial Yes / No
If family decide to attend hospital funeral, inform general office Yes / No
If specimens are to be returned to the baby, funeral may be delayed Yes / No
Parents offered contact details of hospital chaplain for further information about what cremation / funeral involves and experiences of other bereaved parents. Yes/No

Parents should be encouraged to take their time before making decisions about funeral arrangements. Choices should be outlined orally before discharge and also given on paper. Ask parents to make contact with the maternity unit when finalised. Provide contact numbers and addresses.

Telephone number…………………………………………………………….. Yes / No
Email address………………………………………………………………….Yes / No

Comments……………………………………………………………………………
………………………………………………………………………………………….

Table 3.10: *CHECKLIST EIGHT: Forms to be completed*

Forms completed by:
Signed……………………………………… Date………………

The following forms may be requisite for completion:

Confirmation of death form completed	Yes / No
If for PM, consent to PM form completed	Yes / No
Consent for removal of tissue samples (on the PM Form)	Yes / No
Removal to mortuary form completed	Yes / No
If born alive, then died, neonatal death certificate	Yes / No
Burial form completed	
• Hospital burial	Yes / No
• Private burial	Yes / No
Cremation form completed (if applicable)	Yes / No
Antenatal clinic notification form completed	Yes / No
Delivery details entered on computer	Yes / No
Clinical incident form completed	Yes / No
Suspected congenital anomaly form	Yes / No
Stillbirth certificate completed	Yes / No
Neonatal death certificate completed (if applicable)	Yes / No
Parents informed of registration procedure	Yes / No

Table 3.11: *CHECKLIST NINE: Discharge procedures*

Discharge procedures carried out by:
Signed…………………………………………… Date……………………………..

Baby	
Ensure two name bands fastened to baby prior to mortuary transfer	Yes / No
If parents did not want to see their baby, offer again before discharge	Yes / No
Shroud / sheet ticket completed and secured to baby	Yes / No
Wrap baby appropriately before transfer to mortuary	Yes / No
Copied forms completed and sent to mortuary with baby	Yes / No
Removal to mortuary form signed by transferring porter	Yes / No
Mother	
Mother's notes completed	Yes / No
Teardrop sticker applied to notes	Yes / No
Follow up appointment discussed	Yes / No
Drugs discussed, prescribed and discharge pack given	Yes / No
Seen by on call consultant before discharge	Yes / No
Remembrance book discussed with parents	Yes / No
Inform GP by phone of mother's discharge	Yes / No
Inform community midwife by phone of mother's discharge	Yes / No
Discuss physical care / emotional reactions	Yes / No
Give parents appropriate office contact number	Yes / No

3.2. Protocol discussion

It is psychologically traumatic to give birth to a stillborn child. The emotional changes experienced by parents are enormous. Several decades ago stillbirth was normally regarded as a non event (Bourne, 1968). Nowadays, the approach is the reverse. The contemporary view endorses that parents should be confronted with the reality, as this facilitates healthy mourning. This involves the midwife practising the routines outlined in the protocols. Such schedules have limitations, in that staff may inflexibly apply the prescribed steps, stipulating for example that all women should hold their stillborn child (Kennel & Traause, 1978). The risk is that checklists and behavioural protocols can produce chronic institutionalisation of bereavement (Leon, 1992).

With reference to parental decision-making following an in-utero death, Hughes at al. (2002) assert that mothers have no clear plan of how to manage their situation, quite simply because they are in shock. Therefore, they usually go along with what they perceive is expected of them, rather than actively making choices that meet their own particular needs. Parents should be given information that will aid their decision-making in both oral and written form. After a period of time has been given to peruse, consider and reflect, they should then be provided with ample opportunity to ask questions and clarify issues (Brown, 1993).

Radestad et al. (1996) in a nationwide Swedish population based epidemiological study concluded that it is advisable to induce delivery as soon as possible post diagnosis of death in utero. A calm environment for the woman to spend as much time as she wants with her stillborn infant is beneficial and tokens of remembrance should be collected. The results of a study by Radestad et al. (1996) contradicts the high figures for psychological morbidity previously reported (LaRoche et al., 1984; Nicol et al., 1986; Rowe et al., 1978; Toedter et al., 1988). Zeneah (1989) and Kirkley-Best and Kellner (1982) criticise these studies for their lack of standardised ways of measuring outcome, the lack of a control group and the low precision due to small numbers. Radestad et al. (1996) also noted a strong association between waiting more than twenty-four hours before commencing delivery after the diagnosis of death in utero and related anxiety symptoms. Thus, postponing delivery for a length of time can induce unnecessary negative psychological experiences that are difficult to cope with. The optimal interval from diagnosis in utero to induction of delivery remains uncertain, but more than twenty-four hours is typically too long. Radestad et al. (1996) also found that not offering the woman the opportunity to see the infant for as long as she wants, and a lack of tangible tokens of remembrance, increases the risks of anxiety and depression.

Minimising such incidents requires skill on the part of the midwife. The woman’s expressions of grief and shock may also be accompanied by feelings of

pride in her child; therefore the care offered should embrace a meeting and a parting of the infant simultaneously. Confronting mothers of stillborn babies with the reality of the death has been thought to facilitate healthy mourning (Radestad et al., 1996). Rather than enforcing mourning rituals, flexibility should be shown towards the mother's own needs. The notion that, while creating a tranquil atmosphere around the newborn baby post delivery, midwives should not force the mother to hold, caress or kiss the deceased child. Mothers wishing to engage in activities should be supported, whilst those that wish to abstain should be permitted to disengage.

It is psychologically traumatic to give birth to a stillborn child. A stillbirth is often unexpected and happens quickly, and the emotional changes experienced by the parents are enormous. Investigations have reported that 20-30% of women with perinatal loss of a child have appreciable psychiatric long term morbidity (Barr & Cacciatore, 2008; Kennel & Klaus, 1970; Kroth et al., 2004; Lasker & Toedter, 1991, 2000). Consequently, it is salient for midwives to understand processes of bereavement that enhance positive outcomes and diminish those that are negative.

Many parents will not know what a cremation or funeral involves. Consequently, they will require time to consider potential decisions after being given knowledge from which to make informed choices. For example, burial means that parents have a special place to visit and remember their baby. A hospital burial usually involves the deceased being laid to rest in an area of a cemetery exclusively for babies. Cremation of the baby may involve no ashes to disperse afterwards, unlike what happens with a deceased adult. This situation is dependant upon the type of cremator used and the question requires to be asked in advance of decision-making. It may be important for some parents to visit their intended crematorium or cemetery in advance of their decision. Often graves are elaborately marked, dependant upon local regulations, with parents requiring to consider what they would want for themselves before deciding to have their baby laid to rest there.

It is a good idea for the maternity unit to keep a folder with pictures of the local baby cemetery and graves held within. Parents may find this helpful whilst decision-making. Such viewing may also lessen fear of the unknown for parents on the day of the funeral or cremation. Significant numbers of parents change their mind about attending or not attending the funeral of their baby. As such, they require as much information as possible prior to making an informed choice about funeral arrangements (Kelly, 2007). Attendance or non attendance at the funeral is an area of personal preference, and parents should never be made to feel obliged to be present. However, once their baby has been buried or cremated, the style in which the ceremony was conducted cannot be reversed. Decisions made have the potential to influence the parents' subsequent grief process. Hence, stressing the importance

of giving parents time to think through their decisions about laying their baby to rest, the rituals that take place and marking of the grave are important.

Formal ritual marking, such as blessing, naming and having a funeral for the baby, may empower bereaved parents to feel they have parented their baby in some constructive way in the given set of circumstances (Kelly, 2007). If parents choose to be actively involved in co-creating or personalizing rituals, it can work towards them feeling they are retaining some control. Through choice provision, the parents are afforded a place to be creative in a situation which otherwise they may feel they have failed to create. Such involvement can enhance parental self-worth (Kelly, 2007). Rituals can enable parents to act out their relationship with their baby with some dignity and pride (McHaffie, 2001). Examples of rituals may include, carrying the coffin into the crematorium, or lowering the coffin into the ground. Doing so can create special memories and an association with their baby (Kelly, 2007), which may deepen 'continuing bonds'. (Klass et al.,1996). Of course, such actions may not be the choice of all parents. It is important not to make parents feel that they should ritualise the reality of their baby's death in this particular way. Nevertheless, active involvement in informed decision-making regarding the place and type of funeral and the form and content of ritual marking of their baby's short life and death can enable parents to create some meaning and purpose at this time of loss. Being involved in rituals can create constructive memories and give parents something to hold onto and reflect upon for the rest of their lives (Kelly, 2007).

Activity 8

A Stillbirth and Neonatal Death Society (SANDS) teardrop sticker may be used to distinguish the notes of a woman whose baby has died both in the time following the death and during subsequent pregnancies. This sticker alerts staff to a previous bereavement and ensures that everyone involved in the care of the woman, partner and family are aware of the loss and do not inadvertently say anything that could augment distress. Teardrop stickers can be used on the GP notes for the mother, the father, siblings and grandparents. Individuals must provide consent before their notes are marked with a teardrop sticker. The label should be placed in a prominent position on the outside cover.

Task

Be creative and design your own teardrop sticker in the space below:

Activity 9

Self Assessment Test

(Q1) Classify ten areas of midwifery practice that may incur bereavement:

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………..

(Q2) Differentiate between the meaning of the terms loss, grief and bereavement:

………..

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(Q3) Discuss the four dimensions of a childbearing woman's response to a significant loss:

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(Q4) What are the six essential aspects of bereavement care that a protocol should tackle?

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………..

(Q5) What are the aims and objectives of a bereavement protocol?

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(Q6) Critically discuss the role of checklists within bereavement care:

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***Chapter Four**: Models of grieving*

<u>Learning Objective addressed</u>

On completion of *Chapter Four* the midwife should be able to:

(4) Critically appraise the models of grieving.

In *Chapter One* some aspects of grieving in relation to midwifery practice are considered. In contrast, this chapter looks more closely at the stages of grieving and will provide you with more in depth perspectives on grief.

Grief and grieving theory have tenuous roots in Freud's psychoanalytical theory, but Lindeman (1944) is credited with the first attempt to explain the grieving process. The most well known work is the classic stages of the grieving process as defined by Kubler-Ross (1970). Kubler-Ross originally applied these stages to people facing death, but later recognised that these could pertain to any form of catastrophic personal loss (e.g., loss of job, income, or freedom). Kubler-Ross suggested that the identified stages of grieving could be recognised in many significant life events, such as death of a loved one, divorce, drug addiction, the onset of a disease or chronic illness, an infertility diagnosis, as well as many tragedies and disasters.

<u>Activity 10</u>

Reflect on an episode in your life which has resulted in a sense of loss. This may be due to the loss of a job, being jilted by a boyfriend or the loss of a grandparent.

Write down words that describe your feelings immediately and over time:

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Discuss these feelings with reference to the description of the grieving process that follows:

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The grieving process, as described by Kubler-Ross, moves through the following five stages:

Denial – Initially the person expresses disbelief that death has occurred. They may feel that the world is a meaningless place and be overwhelmed by events. They are likely to present in a state of shock, but as they begin to accept what has occurred enter the next stage.

Anger – They may feel confused and begin to find blame in everyone around. They may be angry with the midwives and obstetricians who let this happen, with partner and friends, with self and maybe also God.

Bargaining – They may bargain with self and others and hope that by fulfilling their side of the bargain they will wake up from this nightmare to find it was all a dream. They enter the stage of "if only" or "what if" and want to turn back the clock to do things better for a good outcome.

Depression – They may enter a period of time where they recognise how empty their lives are without the individual who has died. They may feel deeply depressed as they try to come to terms with life without that person.

Acceptance – Eventually the pain of their loss should diminish as they recognise that life must continue. A new pattern of normal life emerges. The person is never forgotten. Memories remain, but these become an accepted part of the new reality.

Although Kubler-Ross (1970) clearly defined these stages, it is essential to recognise that grieving is a very dynamic process that individuals experience to a greater or lesser degree. Not every individual experiences every stage. Reactions to illness, death, and loss are as unique as the person experiencing them. Those caring for the bereaved women must also recognise that individuals may go through the process at different paces, in a different order and may regress to an earlier stage before moving on. Evidence now points towards a more general pattern that fits most of the theories written about the process of grieving. What is important is that carers recognise that the process may manifest differently between individuals.

The immediate reaction to the unfolding event is a temporary defensive mechanism of delaying tactics which aid denial and inevitability of the death (Engel, 1961). This enables the individual to prepare emotionally for the reality of loss. Kubler-Ross (1970) identifies this phase as one of *denial*. This reaction has been explained by Jones (1989) in terms of shock, both physiologically and/or

psychologically. In the event that *denial* becomes extreme, it may be classified as a pathological reaction to loss and should be managed appropriately.

After a variable length of time, the individual enters a period of developing awareness of the inevitability of loss or death. During this phase, powerful emotions may be displayed, such as *anger* and expressions of guilt. Wrath may manifest towards any number of individuals who may or may not have been involved in the loss event. Feelings of guilt may relate to unfinished business, to activities carried out during pregnancy or to lack of input into care. Some people find that they are unable to let go of the lost individual, feeling his/her presence nearby or experience hallucinations such as hearing the baby cry (Mander, 2006). As this phase progresses, the individual may make silent bargains to a higher being, such as God, in an attempt to delay or even prevent the imminent loss. However, once it is clear that these tactics are going to be unsuccessful, the grieving individual may enter a period of apathy and despondency, which Bowlby (1961) terms disorganisation.

The next phase is one of full realisation of the loss. Many theorists identify this as a period of profound depression (Jones, 1989; Kubler-Ross, 1970). Depression brings with it very real symptoms of psychological distress, which may include sleeplessness, loss of appetite and the inability to concentrate on tasks for a given period of time. This phase can become very protracted in terms of time.

The final phase is one of resolution. Kubler-Ross (1970) calls this *acceptance* that life must go on. The lost individual becomes a valued, accepted and realistic part of future memories. There is an ongoing debate about whether this includes the severance of emotional bonds (Walter, 1999).

Whilst there are obvious differences between the ways women manifest their grief, in generic terms the underlying processes are the same. During the avenue of recovery, it is vitally important that the experiencer establishes a support network and shares events with others who are also deeply affected. During this time, shared activities can help strengthen bonds between family members and friends, and work towards creating constructive memories.

Additional models or theories of bereavement

In addition, researchers have developed several new models or theories to help professionals understand the processes of bereavement. These models serve to facilitate professionals who are involved in supporting the bereaved, by providing a knowledge base from which to practise. With this in mind, a further five bereavement models / theories have been selected to enhance sensitivity of professionals who work with the bereaved.

(1) *Bowlby's (1961, 1981) theory of attachment*

Bowlby (1961, 1981) provides an explanation for the common human tendency to develop strong affectionate bonds to the deceased individual. He views attachment as a reciprocal relationship that results from long-term interactions between an infant and his or her parents. Bowlby proposes that grief is an inherent response to separation and that the grieving process follows a predictable orderly pattern of response to the loss. The initial shock that results in numbness can last for days, especially when a death is sudden. This initial reaction normally proceeds to intense grief, which may be accompanied by physical symptoms, such as chest tightness, shortness of breath, loss of appetite and / or insomnia. Lack of concentration, restlessness, feelings of isolation, loneliness, anger, guilt and fear may also be in accompaniment. Anger expressed depends on the individual's circumstances, with guilt often associated with self recrimination for "things done" or "not done". When these feelings are suppressed, the bereaved woman may exhibit irritation. Fear may manifest as insecurity, a desire to escape from reality, or as anxiety. These responses become irregular when they induce panic attacks and / or normal living is disrupted.

(2) *Worden (1980) tasks for the bereaved*

Worden (1980) described grief as a process and not a state, with people requiring to work through their reactions in order to make a complete adjustment to their loss. Bereavement is considered to consist of four overlapping tasks that the bereaved person requires to work through whilst adjusting to changes in circumstances, roles, status and social identity. These tasks are completed when the bereaved person has integrated the loss into their life and let go of their emotional attachment to the deceased individual. Once the bereaved person has completed their tasks of mourning, they are free to invest in the present and the future.

(3) *Stroebe and Schut (1999) dual process model*

Stroebe and Schut (1999) suggest that avoiding grief may be both helpful and detrimental, depending upon circumstances. Whilst prior models centred on loss, the dual process model acknowledges that expressing and controlling feelings are important. The dual process model introduces the idea that the bereaved individual oscillates between focusing on the loss of the pregnancy and baby (loss orientation) and avoiding that focus (restoration orientation). *Loss orientation* encompasses grief work, whilst *restoration orientation* involves dealing with secondary losses that result from the death. For example, an older widow may have to deal with finances and house maintenance that her deceased husband previously dealt with. Both *loss*

orientation and the *restoration orientation* are necessary for future adjustments to be made.

(4) *Klass et al. (1996) continuing bonds theory*

Klass et al. (1996) challenged conventional thinking that the purpose of grieving was the reconstitution of an autonomous individual who could leave the deceased behind and form future attachments. This requires bonds to be broken with the deceased infant. Instead, Klass et al. (1996) proposes that the purpose of grieving is to maintain a bond with the deceased individual, which is compatible with other, new and continuing relationships.

(5) *Families making sense of death theory*

Most models of grief deal with individuals who have experienced loss. However, more often death affects the family as a whole, with the loss holding different meaning to each individual member. Families in which there are fragile relationships, secrets and members who hold differing belief systems may have greater difficulty adjusting to the loss, in contrast to those who have frequent contact, rituals and willingness for each member to share their feelings.

In summary, most models of grief suggest that the bereaved person requires to engage and work through their loss in order for life to be reordered and regain meaning. Most midwives and neonatal nurses are familiar with the stage theories that identify cognitive, social and emotional factors (e.g., Kubler Ross). In addition, Worden's (1980) tasks of bereavement provide a framework to guide grief work, while the dual process model demonstrates the need to deal with both the primary loss and secondary stressors (Stroebe & Schut, 1999). It is important to acknowledge that the bereaved childbearing woman and family do not need to forget and leave their deceased baby behind. Instead, they can integrate them into their future lives through continuing to bond with them through memories. It is also important to identify tensions between family members and assess how each person is influencing one another's adaptation process and what the loss individually means to each of them. It is also important to acknowledge that there are no rights or wrongs in relation to how to grieve. No model of grieving is recommended above another, as all have mechanisms that may be helpful towards aiding understanding of the bereavement process and the processes involved in adaptation to loss.

Chapter Five: *Difficulties with adjusting to the loss*

Learning Objective addressed

On completion of *Chapter Five* the midwife should be able to:

(5) Recognise instances where a childbearing woman's grief process has become dysfunctional and help is required from mental health experts.

In *Chapter Three* you learned about the normal grief process and the classic stages of grieving according to Kubler-Ross (1970) and other models or theories that aid understanding of grief (e.g., Bowlby, 1961, 1981; Klass et al., 1996; Stroebe & Schut, 1999; Worden, 1980). Grief is a normal response to loss and bereavement, and although generally the stages are the same for many people, the timing and responses may differ between individuals. For some, adjusting to the loss may become problematic, with the experiencer becoming trapped into a particular reaction which may not facilitate incorporation and adjustment to the new situation. This problematic grief may prevent the experiencer from adapting to the loss and learning to grow from the experience. Unusual responses may impact negatively on personal relationships and the ability to regain normal everyday interactions with the world. This chapter is designed to help you learn about grief that becomes challenging to the family and how to recognise instances where a childbearing woman's grief process has become maladaptive.

5.1. Bereavement and maternal mental health

Maintaining mental health is important for everyone's well-being, but for a new mother, this is particularly the focus of the midwife. Recently there has been a recorded rise in the number of women affected by mild to moderate mental health problems and in some instances psychosis during the perinatal period (Raynor & England, 2010). The impact of mental health problems experienced by childbearing women has been identified in the Confidential Enquiry into Maternal and Child Health (CEMACH) reports of 2004 and 2007 (Lewis 2004, 2007). Within these reports, maternal suicide was testimonied to be the biggest indirect cause of maternal death during the five year period of 2000 to 2005. This finding highlights the

importance of midwives being vigilant about maternal mental health and developing the ability to recognise, diagnose and treat families who experience loss. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000) makes particular reference to bereavement, in particular bereavement and its relationship to depression. It also emphasises that depression following childbirth related bereavement differs to similar diagnosis outside childbirth (Kendler et al., 2008). Despite this focused attention, the pain and impact of perinatal grief on women and their families is sometimes not acknowledged (Capitulo, 2005).

Bereavement in the perinatal period can originate from two main sources. The first source involves actual loss of a baby through miscarriage, prematurity, stillbirth or neonatal death. The second source involves loss of idealisation through events such as traumatic pregnancy or birth, producing a baby of the wrong gender, a baby that cries perpetually, having an unwell or abnormal baby, or through premature birth and loss of the cherubic infant. Enkin et al. (1995) and Mander (2006) discuss the colossal sense of grief that parents endure when they lose the baby they dreamed of, or their ability to engage normally in the childbearing process. Some situations can mentally traumatise the childbearing woman and leave her grieving for the experience she had fantasised and hoped for, even when the outcome is a healthy infant.

Miscarriage adversely affects the psychological wellbeing of 50% of experiencers, with symptoms persisting for up to a year post event (Lok & Neugebauer, 2007; Séjourné et al., 2010). In addition, the ordeal of pregnancy loss may result in Post Traumatic Stress Disorder and its associated unresolved grief issues (Engelhard et al., 2001). The loss of a baby due to prematurity, stillbirth or neonatal death can cause serious short and long term distress to both parents, which may adversely affect their relationship and sabotage any opportunity for progressing to acceptance, incorporation and adaptation (Badenhorst et al., 2006; Büchi et al., 2008). In light of this evidence, it is important for midwives to provide care that is empathic and meets the individualised needs of childbearing women and families who are experiencing loss (Caelli et al., 2002; Brier, 2008).

5.2. Signs and symptoms of difficulties with adjusting to the loss

A lack of a response to perinatal bereavement is considered abnormal (Capitulo, 2005), as is not adapting after a period of time to the new situation. Some responses may indicate that a woman has not progressed to accepting her new situation.

Denial

Although death or loss cannot be ignored indefinitely, women who remain in denial of the situation will present as coping well and do not cry in relation to their loss. Often they avoid discussions surrounding their loss and present as if life is normal. Such reactions may be due to an initial sense of shock or state of non-belief, which continues past one month post loss.

Anger

It is customary for the anger stage to peak at five months post loss, with displays of wrath beyond this point considered unusual. Displays manifest as frequent, inappropriate, unprovoked outbursts of temper directed at self and others. This is more often contained within families who disclose information to the midwife.

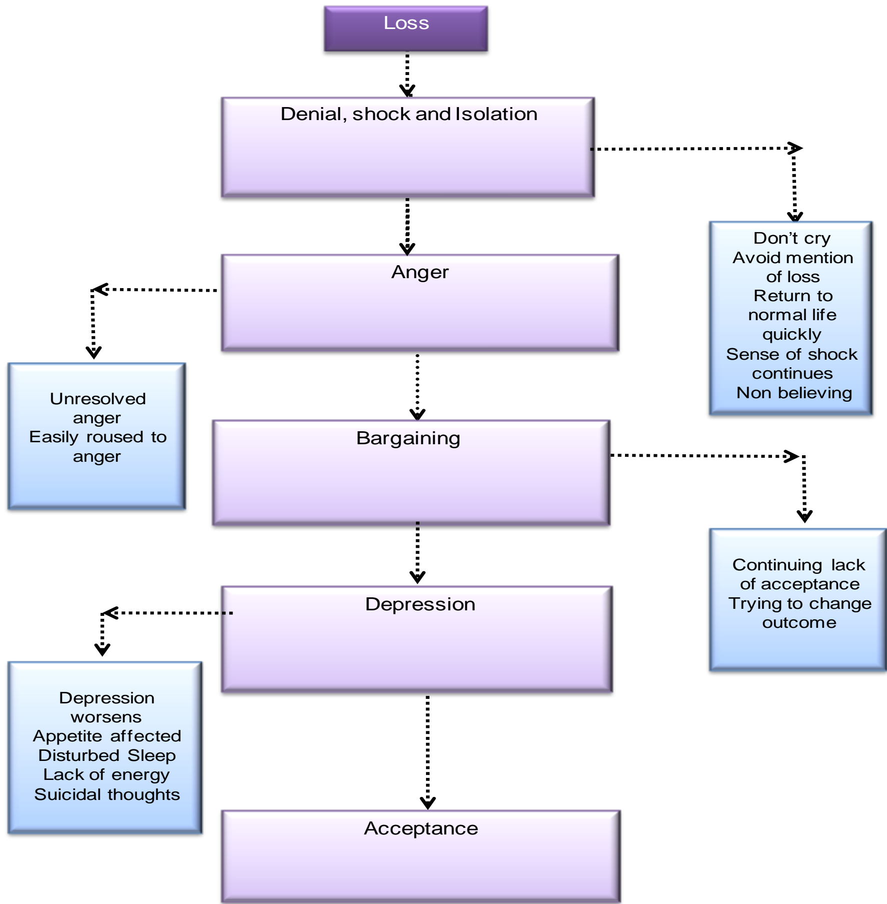
Bargaining

Women stuck at a bargaining stage of grief demonstrate continued lack of acceptance. They often look for unrealistic ways to negotiate a compromise or better outcome from the situation. An example of this would be for the woman to strike a deal with God, that if she were to stop smoking, the situation would be reversed or have a better outcome.

Depression

Women who are unable to progress to acceptance, incorporation and adaptation to their loss by six months post event may present with a symptomatic depression. During diagnosis, clinical features should not be confused with the normal feelings of sadness, regret and uncertainty that present in women who have started to accept the reality of their loss. Symptoms of depression include appetite disturbance, altered sleep patterns, lack of energy, suicidal thoughts, low mood and loss of enjoyment, anxiety, poor concentration, low self-esteem, low energy levels and loss of libido (NICE, 2007). *Figure 1* depicts potential manifestations of grief and possible maladaptive responses at suggested points in adjustment and adaptation to the loss.

Figure 1: **Examples of potential manifestations of grief and possible maladaptive responses at suggested points in adjustment and adaptation to loss**



Activity 11

Discuss examples where a woman does not appear to be adjusting, incorporating and adapting to her loss:

5.3. Role of the midwife in risk assessment

History taking

Good history taking has been recognised as a vital component of planning a woman's care (NICE, 2007). Of particular relevance is ensuring that care is provided by appropriate health professionals. Although it is more usual for midwives to care for women who are by and large well, it is also within their sphere of professional practice to make appropriate referrals and also participate in the care of those who are sick or compromised by medical conditions. A necessary part of this role is risk assessment, which is aimed at detecting and preventing problems (NMC, 2010). Risk assessment, in part, involves taking a thorough history which includes assessment of physical, emotional and social aspects of the woman's life. Midwives are more often the first professional to be in contact with women during the perinatal period. From the outset of preconception care to the end of the postnatal period, midwives are provided with the opportunity to develop an open and trusting therapeutic relationship with the woman (Price, 2007; Raynor & England, 2010).

Preconception visits should be arranged with women who are known to have experienced a previous loss. During the interim gap between pregnancies, ongoing support should be offered from specialist midwives who discuss issues surrounding the loss and facilitate the woman to prepare and plan any desired future pregnancy. Specialist advice such as genetic counselling may prove beneficial. In the early stages of pregnancy, a midwife may unearth prior pregnancy loss or emotional issues affixed to a traumatic pregnancy or birth. During their interactions with women, midwives are able to observe adaptive grief and identify where it becomes problematical. Appropriate responses from midwives are required if women are to be helped to untangle maladaptive aspects of grief.

Activity 12

Think about the different areas in which midwives practice and using the following headings, consider how you might assess a women for signs of difficulties with adjusting, incorporating and adapting to a previous loss. Write your answers below:

Preconception advice:

Antenatal visits

Postnatal visits

Current theoretical perspectives on parental grief emphasise the importance of parents maintaining a relationship and bond with their deceased baby. Also of importance, is establishing a therapeutic intervention to support parents, instead of facilitating them to minimally let go (Davies, 2004). The protocols that you looked at in *Chapter One* take into account this issue. For example, Surkan et al. (2008) support that allowing a mother to be with her stillborn baby for as long as she wishes may positively influence symptoms of depression at a later stage. This period of bonding with the infant may assist the woman to cope better and prevent prolongation of the *depression* stage of grieving. Midwives involved in counselling grieving couples are in a position to explain the benefits of physical contact with the deceased baby in reducing the likelihood of women becoming depressed. Midwives also require to understand that women who do not have a subsequent pregnancy are at higher risk of depression three years post loss, compared with women who became pregnant again within six months of their loss (Surkan et al., 2008).

Midwives require to be proactive at providing advice and offering support interventions designed to facilitate parents and families with creating meaning to their loss (Capitulo, 2008). One goal is to prevent deterioration in mental health and offset the need for referral to specialist mental health services. With this in mind, midwives should:

- Provide consistent and clear advice to parents.
- Be compassionate in their approach to parents.
- Involve parents in decision making.
- Provide appropriate physical and emotional support to parents.
- Provide relevant follow-up.
- Involve the multi-disciplinary team

(Williams et al., 2008).

5.4. Subsequent care

Unfortunately it is not always possible to prevent mental illness. When a woman has become severely unwell during her grieving process, it is necessary to seek advice and possibly refer her to the local mental health services. In Scotland there are currently two “mother and baby” facilities. One is located in Glasgow and the other in Lothian. These units cater for women who have pre-existing or have developed mental health problems during the perinatal period. Referral to these services can be made by the midwife, health visitor or family doctor. Knowledge of specialist services and the referral protocols are important when planning ongoing care beyond the timescale of the midwives remit. This matter will be discussed further in *Chapter Five*.

To develop your knowledge of specialist services available in your region complete *Activity 12*.

Activity 13

Find out what specialist services are available in your area for women in the perinatal period and who have been bereaved and who's grieving appears to have become problematic:

5.5. The multi-disciplinary team

Although midwives generally care for women in normal childbearing situations, they must recognise when the boundaries for normal processes change. As such, it is crucial for midwives to be proactive within a multi-disciplinary team in order to care holistically for women and cater for their varied needs (Midwifery, 2010). There is much evidence to support the assets of multi-disciplinary team working (NES, 2006; Reiger & Lane, 2009; Walsh & Gamble, 2005) and this is of particular relevance when providing bereavement care to women and their families. Psychiatry and in particular, perinatal psychiatry is an obvious choice for referral of women. However, other areas of clinical expertise that could be consulted in the care of women might include clinical psychologists, fetal medicine experts, physicians and haematologists, as they all see women and families during the pre-pregnancy period to counsel and plan for future pregnancies. It might also be helpful to consider family bereavement counselling, if required. To effectively meet the needs of bereaved women who are struggling with their mental health, midwives are required to know the differing roles and responsibilities of people within the multi-disciplinary team and how to access them accordingly. A coordinated approach to bereavement care between providers is a crucial part of ensuring that women and families receive appropriate and vital support (Scottish Government, 2011).

Activity 14

List the key professions involved in the care of bereaved women:

Discuss how you would access each profession:

5.6. When grief becomes problematic

At this point in the workbook, the reader should be able to identify causes and manifestations of problematic grief. Equipped with this information, read the scenarios in Activities 14, 15, and 16 and answer the questions asked. Respectively consider what actions of care planning each woman in the individual case study requires.

NOTE:
Remember to consider each woman and her situation as individual. Women respond to grief in many different ways.

Activity 15

Petra is 34 years old and has been trying for a baby for 5 years. She has just experienced her 6th miscarriage. You were the community midwife involved in Petra's pregnancy, but did not know her before this. When you visit Petra at home for a postnatal follow up, she tells you that she is returning to work the next day.

What issues might be affecting Petra at this time?

How would you recognise if Petra was adjusting to her loss?

What advice would you give to Petra and why?

What follow-up do you arrange for Petra and why?

Activity 16

Roseanne has four healthy boys. She is now 32 weeks gestation and in her fifth pregnancy. She attends for a routine antenatal check up and tells you that she has been having recurring dreams in which she sees that the baby is a boy. She admits to feeling distressed by this occurrence and states that her emotions and thoughts are affecting her mood and appetite.

Although this pregnancy is progressing well, what features indicate that Roseanne could be experiencing a grief reaction in this situation?

What advice would you give to Roseanne and why?

What follow up care plan would you discuss with Roseanne?

Activity 17

Saliha is a 30 year old woman who was 32 weeks gestation and in her third pregnancy when she had endured an antepartum haemorrhage. The cause of the haemorrhage was disruption of a type three placenta praevia. During preparation for an emergency caesarean section, it was discovered that there was an absent fetal heartbeat. Following the birth of her dead baby daughter, Saliha made a good physical recovery and displayed normal grieving symptoms. Six months later both Saliha and her husband attend a pre-pregnancy counselling session, because they desire to conceive another baby. At this meeting Saliha's husband mentions that she goes into the nursery every day to search for her baby and still talks in disbelief and shock that she is not there. Her husband affirms that he finds this circumstance a challenge to manage.

How would you respond to this situation?

What indicators make you think that Saliha's has not adjusted, incorporated or adapted to her loss?

What follow up care plan would you discuss with Saliha and her husband?

Chapter Six: *Ongoing support*

Learning Objective addressed

On completion of *Chapter Six* the midwife should be able to:

(6) Outline processes involved in caring for and advising a bereaved woman / partner / family about to access ongoing support on discharge from midwifery care.

Having previously discussed how to recognise when a woman's grief process has become problematical, it is important to be aware of referral pathways for women and their families. *Chapter Five* has been designed to inform you about the processes involved in caring for and advising a bereaved woman and her family about how to access ongoing support on discharge from midwifery care.

6.1. Role of the midwife in bereavement care

Grief following the loss of a child is recognised to be one of the most intense and difficult categories of loss to tackle. Associated bereavement impacts on the entire family and social structure and therefore poses a challenge to care providers. During the antenatal period parents psychologically prepare for a life incorporating the unborn child, which involves development of attachments that continue following birth (Condon, 2010). When the baby dies, loss of the potential relationship can create a discordant grieving cycle associated with a myriad of feelings, one of which is anxiety. In Rosemary Mander's (2006) book "Loss and bereavement in childbearing", she discusses how Bowlby (1990) viewed grief as an adult version of child separation anxiety which manifests with similar feelings.

Midwives are in an ideal position to support women during pregnancy, childbirth and the puerperium (Ó Lúanaigh & Carlson, 2005). As part of this role, midwives require to provide appropriate tailor made support and education to women experiencing perinatal bereavement (Williams et al., 2008). Midwives who provide compassionate personalised care to the woman are more effective at relieving grief and promoting a normal bereavement process. Within this role, in order to provide effective care, it is essential for the midwife to be aware of his/her own feelings about bereavement. A midwife who feels uncomfortable may act impersonally, assume a superior role and/or make decisions for the parents (Capitulo, 2008). Consequently, it

is important for you to reflect on your own feelings about handling bereavement and consider whether you can provide an open and empathic response during support provision to a bereaved woman and her family. More specifically, midwives can facilitate certain practical functions that promote a healing response for parents' grief. Some interventions that you require to provide include:

Good communication

Good communication includes allowing the parents to talk and tell their story of pregnancy, birth and loss, and provide some validity to their bereavement by using helpful expressions such as "*I understand your baby has died*" and "*I'm so sorry about that*". The use of the word died helps to convey the reality of the situation and should be used rather than saying "*passed away*". Also, statements such as "*you're young and can always have another baby*" should be avoided.

Support for loss

Although midwives work with women in the first 10-14 days after birth, this period can be extended in particular circumstances. To provide adaptable care, midwives need to have a clear understanding of the different types of loss that women and families can experience. The type of loss may be transparent, as occurs when a woman has a miscarriage, stillbirth or neonatal death. Conversely it may not be so obvious, as occurs when a woman's expectations are dashed by a traumatic birth, unwanted gender of baby or ill neonate. Once you have recognised a loss, it is necessary to action appropriate care. Type of support required by an individual woman is dependent upon how she frames her loss and the type of loss experienced. An inventory of types of support and services follows:

Early pregnancy loss / miscarriage

- Consent for investigation of fetus
- Obstetrician consultation
- Between pregnancy testing
- Pre pregnancy Counselling
- Genetics counselling
- Contraceptive advice
- Multidisciplinary notification
- Specialist appointments

Stillbirth / neonatal death

- Memory moments
- Cultural sensitivity

- Post mortem
- Undertaker
- Obstetrician / paediatrician consultation
- Bereavement counselling
- Multidisciplinary notification

Loss of expectations

- Pregnancy and birth debriefing
- Counselling services
- Pre-pregnancy counselling
- Multidisciplinary notification
- Pregnancy care plan

6.2. Support services

Support groups

Midwives can advise parents of additional help available from support groups. Although these might not be suitable for all women, the midwife can provide information about them and let the woman make her own judgements. Research suggests that support groups are particularly helpful to those parents who are able to create meaningful memories of their baby (Côté-Arsenault & Morrison-Beedy, 2001; Calhoun et al., 2003; Capitulo, 2005). Consequently, it is important for the midwife to promote positive memories. In addition, there are numerous voluntary organisations who offer specialised support to women who are experiencing bereavement. The midwife should provide women and their families with details about how to contact these organisations. Examples follow:

Cruse

www.crusebereavementcare.org.uk

Telephone: 0844 477 9400

Cruse is an organisation that attempts to facilitate the bereaved person to understand their grief and cope with their loss. As well as providing free care to all bereaved people, the charity also offers information, support and training services to those who are looking after bereaved persons. Cruse is a member of the British Association of Counsellors and Psychotherapists and follows the rigorous code of ethics set out by that organisation. The welfare services that Cruse provides, particularly via its telephone helpline, have also been awarded a Quality Mark by Community Legal Advice.

SANDS

www.uk-sands.org

Telephone: 020 74365881

The Stillbirth and Neonatal Death Society (SANDS) is an organisation which can offer support to the woman and her family when their baby dies during pregnancy or after birth. The death of a baby is a devastating experience and effects of grief can be overwhelming to parents, their families and friends who can be left feeling dazed, disorientated, isolated and exhausted. At SANDS, members of the organisation have often been through the experience and therefore can identify with what the woman is experiencing, and offer support and information where needed. For example, when a baby has been stillborn or has died during or soon after birth, or has spent some time in a Special Care Baby Unit (SCBU). It may be that the baby died at an earlier gestation or that a difficult decision to end the pregnancy was required. SANDS offer support to mothers, fathers, and other members of the family, inclusive of grandparents and other siblings.

Bliss

www.bliss.org.uk

Telephone: 0500 618140

Bliss exists to ensure that all babies born too soon, too small or too sick in the UK have the best possible chance of survival and of reaching their full potential. Members of Bliss support mothers and families of babies that are premature, making sure that the voices of babies and families are heard. By driving quality and innovation in the NHS, Bliss works to improve care provision for premature and sick babies, and their families.

The Miscarriage Association

www.miscarriageassociation.org.uk

Helpline: 01924 200799

Local Contact (Glasgow) Mana Hazlett Tel: 0141 942 8088

The Miscarriage Association acknowledges the distress associated with pregnancy loss and strives to make a positive difference to those it affects, including the father and other children. It aims to:

- Offer support and information to anyone affected by the loss of a baby in pregnancy.
- Raise awareness of miscarriage.
- Promote good practice in medical care.

Samaritans

www.samaritans.org

Telephone: 08457 909090

Samaritans provide a confidential emotional support service to residents of the United Kingdom and Ireland who are experiencing distress, despair or feel suicidal. Support is available 24 hours a day. The service is manned by volunteers who respond to phone calls, emails and letters. Alternatively members of the community can visit a branch of the Samaritans, where they can have a face-to-face meeting with an affiliate of the organisation.

The Family Bereavement Counselling Service

http://www.nhsggc.org.uk

Telephone: 0141 201 9257

The Family Bereavement Counselling Service at Yorkhill hospital offers bereavement and counselling support for users and staff of GG&C Health Board. Anyone affected by miscarriage, stillbirth or termination can be offered one to one support, telephone support and befriending services. A lending library is also available for use.

Activity 18

Above are a few of the recognised organisations which provide support to grieving parents and families. Identify what additional support is available in your local community and list these below:

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Provide the contact details of these additional organisations:

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***Chapter Seven**: Staff support*

Learning Objective addressed

On completion of *Chapter Seven* the midwife should be able to:

(7) Recognise where a bereavement incident may affect a member of staff adversely.

For the most part, there are positive outcomes from the work a midwife carries out within her/his sphere of practice. However, there are limited opportunities for caring for women and families who are experiencing bereavement. As a consequence, it is often an experienced midwife who is ascribed the role of caring for women in this situation, which makes it problematical for the inexperienced midwife to gain familiarity in dealing with this complex situation.

Activity 19

Contemplate how you now feel about providing care to a bereaved woman, partner and family. Consider:

- **What you would say to the bereaved woman, partner and family?**
- **What constitutes a suitable environment for a bereaved woman and family within the hospital setting?**
- **How you personally may be affected by a childbearing woman's loss?**

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Mander (2006) reports that, for three main reasons, midwives and Allied Health Professional's encounter difficulties in coping with perinatal death:

(1) Western societies, due to sophisticated technology, more often find death of a baby unexpected and therefore shocking. We find it easier to accept death of an older person.

(2) Midwives may feel that they have let the mother and her family down. In other words, that the profession has not succeeded to help a mother give birth to a healthy baby. Since childbirth is considered a routine part of life, when a mother herself has died, the midwife may feel she has failed to accomplish the usual anticipated successful outcome.

(3) Some midwives have little experience of caring for people who have encountered bereavement. Also, they may have had minimal encounters of death in their personal lives. As a result, they may feel ill equipped to provide appropriate emotional support.

These three factors may, for some, make dealing with a bereaved woman and family a particularly stressful aspect of work. It is therefore essential that midwives recognise colleagues who require additional support in handling a bereaved woman and family. It is also the responsibility of each midwife to recognise her/his own limitations. Midwives should learn to recognise when they are out of their depth and seek support of an experienced colleague in situations they find difficult to manage. For example, it is important to recognise when self or others have had a difficult personal experience, such as a ruptured ectopic pregnancy or traumatic birth, which may make care provision more challenging for that midwife to deal with. It is important that midwives work as a team to recognise and discuss each others limitations and aptitudes when allocating workload.

A wealth of research has been carried out, which in particular examines stress experience of staff during the processes of delivering bereavement care. Peer support has been found to be one variable that affects the midwives experience of delivering bereavement care (Kirkham, 1999; Mander, 1999; Stapleton et al., 1998). So how does a midwife recognise when a member of the multidisciplinary team has been affected adversely by a traumatic event or the death of a baby or mother? Stress may initially manifest itself in the form of an increase in sickness absence, or through a rise in errors in the workplace. If stress continues, a syndrome named "burnout" may develop (Hillhouse & Adler, 1997). Such responses make recognition of stress in consequence to a death or adverse event an important concept.

Midwives must be vigilant to recognise when a member of staff is not coping well with a bereavement situation.

Within the midwifery profession there are two key players who should be mindful when a colleague is struggling with coping with a woman and family who have experienced bereavement. Firstly, the senior midwife on duty at the time of the bereavement incident, and secondly, the relevant supervisor of midwives. Specifically when a midwife has voluntarily withdrawn from care provision, or has been removed through recognition of stress symptoms by peers. At all times, the intention should be to provide support and debriefing to that midwife and recognise training and educational needs. The goal must never to be punitive.

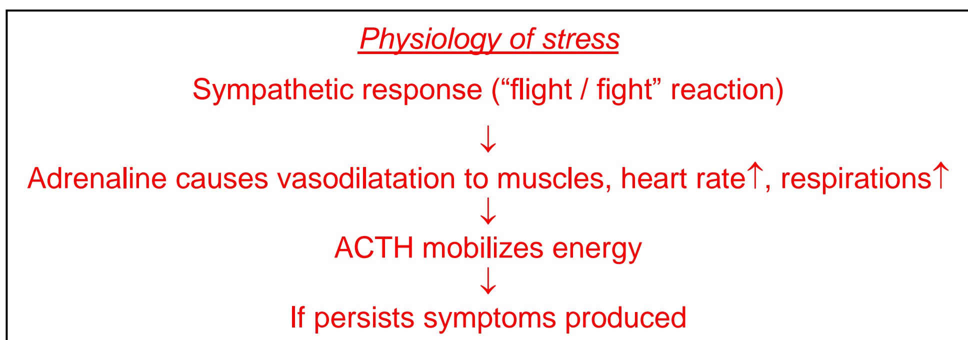
7.1. Recognising stress

Activity 20

Define the term "stress":

What is Stress?

Stress is a *physical*, *cognitive* and *behavioural* response to a real or imagined situation that is perceived to be threatening to our personal well-being.



Both physical exercise and stress are associated with sympathetic activation. In the case of exercise, free fatty acids are utilised as an energy source and are thus cleared from the circulation. If free fatty acids are not removed, as occurs when a driver is stressed by being stuck in city traffic, they can after chemical conversion,

deposit plaques of fatty material on the walls of the arteries to form atherosclerosis (Toates, 1992).

Cognitive effects of stress

Negative thoughts

Inability to make decisions

Hypersensitivity to criticism

Decreased concentration

Forgetfulness

Activity 21

Write down an episode where you felt really stressed. Recall some of the thoughts you had:

Physical effects of stress

Palpitations

Sweating

Redness

Nausea

Urgency to go to the bathroom

Goosebumps

Activity 22

In the episode you recalled in *Activity 20*, recall some of the physical symptoms you experienced:

Behavioural effects of stress

Trembling

Accident prone

Emotional outbursts

Over/under eating

Drinking

Smoking

Impulsive behaviour

Impaired speech

Nervous laughter

Restlessness

Activity 23

In the episode you recalled in *Activity 20*, recall some effects on your behaviour:

Bereavement as a cause of stress

Causes of stress or stressors fall into two categories labelled:

(1) External stressors.

(2) Internal stressors.

External stressors

External stressors consist of physical stimuli within the person's environment, e.g., uncomfortable hot or cold temperatures. Alternatively, the external stimuli may be an abusive colleague or being given too much work to cope with within a given time period.

Internal stressors

Internal stressors consist of stimuli contained within the person's body, e.g., infection, inflammation, lack of sleep, hunger or thirst. Alternatively, the internal stimuli may be psychological in origin, e.g., experiencing worrying thoughts, unpleasant dreams or anxiety.

Stressors are also described as short-term (acute) or long-term (chronic):

> *Short-term "acute" stress* is a reaction to an immediate threat. This is also known as the *fight* or *flight* response. When stress results from a stimulus, the primitive part of the brain produces chemicals that prepare the body to deal with potentially harmful stressors. The purpose is to prepare the person to run away (*flight*) or defend themselves (*fight*) from, e.g., noise, over-crowding, danger, bullying or harassment, or even an imagined or recalled threatening experience. When the threat subsides the body returns to normality, which is called the *relaxation response*. The relaxation response varies among people, with different individuals recovering from acute stress at different rates.
>
> *Long-term "chronic" stressors* are pressures that are continuous, which result in the urge to *fight* or *flight* being suppressed. Chronic stress has effects on health and performance. It has been proven beyond doubt to make people ill, and evidence is increasing as to the number of ailments and diseases caused by stress. Stress is now known to contribute to heart disease, to cause hypertension and to impair the immune system. Stress is also linked to strokes, IBS (Irritable Bowel Syndrome), ulcers, diabetes, muscle and joint pain, miscarriage during pregnancy, allergies, alopecia and even premature tooth loss. Stress significantly reduces brain functions, such as memory, concentration, and learning, all of which are central to effective performance at work. Examples of chronic stressors include ongoing pressurised work, ongoing relationship problems, isolation, and persistent financial worries.

The working environment is capable of producing both acute and chronic stressors. A childbearing woman experiencing bereavement can be one stimulus that produces a stress reaction in the midwife.

Other typical causes of stress at work:

- Bullying or harassment, by anyone, not necessarily a person's manager.
- Feeling powerless and uninvolved in determining one's own responsibilities.
- Continuous unreasonable performance demands.
- Lack of effective communication and conflict resolution.
- Lack of job security.
- Long working hours.
- Excessive time away from home and family.
- Office politics and conflict among staff.
- A feeling that one's reward is not commensurate with one's responsibility.

Influencing the effects of stress and stress susceptibility

A person's susceptibility to stress can be affected by any or all of the above factors in combination. Also, everyone has different tolerance levels in relation to individual stressors. Consequently, stress susceptibility is not fixed, with each person's stress tolerance changing across time. Several factors can influence a person's stress susceptibility. These include:

- Childhood experiences, e.g., child abuse or domestic violence.
- Personality, with some personalities more stress-prone than others.
- Genetics, with some people having an inherited relaxation response. This is connected with serotonin levels. Serotonin is the brain's well-being chemical.
- Immunity abnormality, which results in the person having diseases such as arthritis or eczema.
- Lifestyle issues, such as eating a poor diet, lack of exercise and/or sleep.
- Duration and intensity of stressors.

How can we measure stress?

Crises such as death, divorce or bankruptcy can disrupt even the best stress management regime. Different life crises have different impacts. In many cases, however, it may be possible to anticipate crises and prepare for them. It may also be useful to recognise the impact of crises that have occurred so one can take account of them appropriately.

Some very interesting work in this area has been done by Holmes and Rahe using the *Social Readjustment Scale*, which allocates a number of "Life Crisis Units" (LCU's) to different events, so that people can evaluate them, and take action accordingly. While this approach is an over simplification of complex situations, using LCU's can provide overall useful information. The aim is to total the number of LCU's that have occurred to a person in the prior two years.

LCU's and probability of illness

Score of	300	80%+
Score of	200-299	50%
Score of	150-199	33%

Event	*LCU scores*
Death of spouse	100
Divorce	73
Separation	65
Jail term	63
Death of close family member	63

Personal illness or injury	53
Marriage	50
Fired at work	47
Marital reconciliation	45
Retirement	45
Change in health of family member	44
Pregnancy	40
Sex difficulties	39
Gain of new family member	39
Business readjustment	38
Change in financial state	38
Death of close friend	37
Change to a different line of work	36
Change in number of arguments with spouse	35
A large mortgage or loan	30
Foreclosure of mortgage or loan	30
Change in responsibilities at work	29
Son or daughter leaving home	29
Trouble with in-laws	29
Outstanding personal achievement	28
Spouse begins or stops work	26
Begin or end of school or college	26
Change in living conditions	25
Change in personal habits	24
Trouble with boss	23
Change in work hours or conditions	20
Change in residence	20
Change in school or college	20
Change in recreation	19
Change in church activities	19
Change in social activities	18
A moderate loan or mortgage	17
Change in sleeping habits	16
Change in number of family get-togethers	15
Change in eating habits	15
Holiday	13
Christmas	12
Minor violations of law	11

When one recognises in self or others the danger of suffering the ill effects of life crises, they should attempt to minimise disturbance to their life. If, for example, they have experienced bereavement try to avoid additional stressors.

Signs of stress: stress test

At a clinical level, stress in individuals can be assessed scientifically by measuring the levels of two hormones produced by the adrenal glands - cortisol and DHEA (De Hydro Epi Androsterone). However, ordinarily midwives and managers do not have ready access to such methods. They must therefore rely on other signs to identify when a person is stressed. Some of these are not exclusively due to stress, nor are they certain proof of stress. They are merely indicators to prompt investigation as to whether stress is present. You can use this list of ten key stress indicators as a simple initial stress test: tick the factors applicable.

- Sleep difficulties
- Loss of appetite
- Poor concentration or poor memory retention
- Performance dip
- Uncharacteristic errors or missed deadlines
- Anger or tantrums
- Violent or anti-social behaviour
- Emotional outbursts
- Alcohol or drug abuse
- Nervous habits

Activity 24

How did you do?

LCU's and probability of illness scale

Signs of stress: stress test

Sleep deprivation and stress

Healthy tiredness - There is a satisfying tiredness which follows a hard day's mental activity, i.e., a hard day decorating, a strenuous round of golf or jogging in the park. Healthy tiredness is removed through sleep and relaxation.

Unhealthy tiredness –This does not result from hard work and is present in spite of a good nights sleep. It manifests itself as mental apathy, lack of physical energy, emotional flatness and absence of highs and laughter. Unhealthy tiredness will not ease with sleep.

Methods of stress management and relief

When a midwife recognises signs of stress in self or a staff member, in this case in relation to managing a woman and bereaved family, she/he must not ignore it. It is her/his duty to do something about it. As a midwife if you do not feel capable of dealing with the situation, you must not ignore it. You must instead refer the situation to someone who is equipped to deal with it. In addition, the midwife must also look for signs of non work related stressors or factors that may increase a colleague's susceptibility to stress, because these will make that person more vulnerable to not coping with tricky situations in the workplace.

Stress relief methods are many and various. There is no single remedy that applies to every person suffering from stress, and most solutions involve a combination of remedies. Successful stress management frequently relies on reducing stress susceptibility and removing the stressors. Here are some simple pointers for reducing stress susceptibility and stress itself, for both yourself and others:

Stress relief pointers

(1) Think seriously about and talk with others to identify the cause of the stress. Knowing what you are dealing with is essential when developing appropriate stress management approaches.
(2) Remove the stressed person from the situation.
(3) Eat a healthy diet. Group B vitamins and magnesium are important.
(4) Reduce toxin intake. Tobacco and excessive alcohol intake especially, because they work against homeostasis of the body and contribute to stress susceptibility. Therefore they increase stress itself.
(5) Take exercise. It burns up adrenaline and produces endorphins which create positive feelings.
(6) Share worries. Talk to colleagues. Discussion will help colleagues understand.
(7) Consider relaxation therapy e.g., yoga, meditation, self-hypnosis or massage.

Acceptance, cognisance and commitment on the part of the stressed person are essential. No-one can begin to manage their stress when they are still feeling acutely stressed, as they continuously are in *fight* or *flight* mode. The identified stressful situation must be handled by someone who will not perpetuate the stressful

influence, by for example bullying the person concerned. Removing the stressor(s) or the person from the stressful situation is only part of the solution. It is also important to look at factors which affect the person's stress susceptibility. Where possible try to improve factors that could possibly contribute to stress vulnerability. For example, improve diet and increase levels of exercise.

Anger management and stress

The term "anger management" is widely used now as if the subject stands alone. However, anger management is simply an aspect of managing stress, since anger in the workplace is a symptom of stress. Anger is often stress in denial, and as such is best approached via one-to-one counselling. Training courses can convey anger management and stress reduction theory and ideas, with counselling necessary to turn theory into practice. Management of anger and the stress that causes it can only be improved if the person wants to change. This involves acceptance, cognisance and commitment. Consequently, awareness is the first requirement. Some angry people take pride in their anger and do not want to change. Others fail to appreciate the effects on self and others. Without a commitment to change there is not a lot that a manager or employer can do to help. Anger management is only possible when the angry person accepts and commits to the need for change.

A big factor in persuading someone of the need to commit to change is to look objectively and sensitively with that person at the consequences for self and others of their anger. Often angry people are in denial, with removing this denial essential. Helping angry people realise that their behaviour is destructive and negative is an important first step. If the problem is a temporary tendency then short-term acute stress may be the direct cause. One-to-one counselling may help discover the causes, followed by agreeing a plan of action to deal with the colleague. Where anger is persistent, frequent and ongoing, long-term chronic stress is more likely to be the cause. Again, counselling is required to get to the root cause. Exposing these issues can be very difficult, so great sensitivity is required. The counsellor may need several sessions in order to build sufficient trust and rapport.

Where a deep and persistent upset has been caused through dealing with a childbearing woman's loss, the midwife may be willing to be referred to a suitably qualified counsellor who can help unravel their personal situation. Identifying the cause is sufficient for most people to make changes and improve. The will to change, combined with awareness of cause, often leads to resolution.

The solutions are more complex than blaming people for not being able to cope with a situation. Existing staff and new people in stress-prone roles are also likely to benefit from relaxation techniques, stress relief strategies, meditation, peace

of mind and well-being workshops, all of which work towards increasing personal reserves necessary to deal with stressful situations. This approach, in turn, may work towards reducing absenteeism and staff loss.

Preventing stress specifically from dealing with a woman's bereavement

Prevention of undue stress can be achieved by meeting the training needs of staff involved in the care of women where there is potential for an adverse outcome. During student midwife training, mentors commonly protect the student midwife from facing situations where mortality is likely. It is a mistaken belief that the student midwife should be cosseted from this kind of situation, since she can only become experienced through exposure. Once qualified, this midwife will lack the experience required to minimise stress during such situations. Ideally the student should be exposed to bereavement situations during midwifery education, with encounters handled in a supportive way. The student should be provided with opportunities to reflect and discuss appropriate management. To promote thinking about how a bereavement incident may cause a midwife stress, consider the following activity:

Activity 25

Your colleague Rebecca has just returned to work after having a miscarriage and she tells you that although she feels physically well, she is still upset at losing her baby. Due to staff shortage, Rebecca has been requested to help out in the early pregnancy assessment unit.

- **How do you react to this request and why?**

Midwifery managers, lecturers and supervisors of midwives should take responsibility for continuing to provide support to midwives while they gain experience in all areas of midwifery practice. Reducing stress can be helped by ensuring that there are adequate staffing numbers. This will allow the midwife to encounter bereavement situations, firstly, as an observer and subsequently taking more responsibility over time.

Encouraging continuing professional development through becoming actively involved in support groups will also provide opportunity to observe parents over a

long period of time. Such opportunities facilitate staff and parents to explore ways in which difficult situations can be managed.

Chapter Eight: Assessment and care of a bereaved woman and family's spiritual and religious needs.

Learning Objective addressed

On completion of *Chapter Eight* the midwife should be able to:

(8) Assess individual woman / partner / family's spiritual / religious beliefs and adapt bereavement care to accommodate.

Bereavement will ripple in effect to many people outside the immediate family. Extended family and friends are also likely to grieve for what has been lost. Family dynamics vary. Not all family members are close knit, whilst others may communicate daily. Strong religious and cultural beliefs may also influence the extent and way in which each family grieves. Within each unit, friends and family will react in their own special and individual way. Consequently, midwives who come into contact with a grieving woman must adapt their support behaviour accordingly to meet each families spiritual and religious needs.

Researchers have identified gender differences in the application of the process of grieving. Parkes (1996) and Stroebe and Schut (1995) identify hesitation and oscillation between stages as a component of gender differences, with a feminine passive style of grieving compared to a more active masculine style. Care must be taken by health professionals to be aware of these gender differences, but not to stereotype, since styles may differ between individuals. Recent thoughts have interpreted these styles as a logical interpretation between two distinctive coping styles (Mander, 2006).

Activity 26

Reflect for a moment on members of the extended family who may have an essential role to play in a woman coming to terms with bereavement. Jot down some thoughts about what role these individuals may play in supporting the childbearing woman during her bereavement process:

Partner:

Brother:

Sister:

Grandfather:

Grandmother:

Aunt:

Uncle:

Friend:

8.1. Effects of family bereavement on children

Children develop their attitudes and behaviours by observing those around them. Many families feel that it is better for children not to be too involved in the more distressing aspects of life, with the intention of protecting them from the anxieties and later inevitabilities of a death in the family. As such, these children may become puzzled by what is going on when bereavement actually occurs in the family. The child may recognise that their mother is deeply distressed, but feel incapable of comforting her. Lack of experience may lead the child to being ill equipped to deal with grief in their subsequent adult lives.

Activity 27

Reflect for a moment on your own beliefs about discussing death with children. At what age do you think:

1. **Children should be told about a person's death?**
2. **Children understand the irreversible truth about death?**

Explore the underpinning of your thoughts on this matter:

It is rare for a child not to be faced with the reality of loss and change during their childhood. Children will usually face bereavement through the loss of a relative or even a friend. When someone close dies, adults are commonly so wound up in their own grief that they may fail to notice that their children are also grieving. A child's grief must be handled sensitively and truthfully, and will depend on their understanding of the concept of death.

Brown (2009) proposes that children progress in their understanding of death in the subsequent manner, with understandings dependent upon the extent to which the family includes the child in discussions and upon the cultural and emotional reactions they are exposed to.

Children of 7 years of age and under do not understand the permanence of death. They may react adversely to the absence of a close relation who was previously involved in their day to day routine, but fundamentally believe that being dead means being away or asleep.

Children of 8 -11 years of age are beginning to realise that death is permanent and that it can happen to anyone. They usually expect it only to occur in older members of the family. How the child grieves will differ incalculably from overt sadness to an apparent acceptance of the event. However, the child may deny their own feelings.

Children of 12 years of age and above usually fully understand the finality of death. They generally wish to be involved in the arrangements for the funeral, but may turn to friends outside the family to talk about their emotions and to explore the concept of bereavement.

Telling children about a death, especially when they are toddlers, can be very difficult. The midwife's role in supporting women who ask how to "break the news" to other children can be challenging, as she/he may not be fully cognisant of their own attitude to life and death. The person closest to the child is usually the best person to explain the situation, even though they themselves may be in the throes of grief. The midwife can suggest that the parents relate the news in a peaceful and familiar environment. The midwife may also point out that it is important for the child to develop an understanding of what has happened in order to develop their skills for life. Using simple truthful terminology to explain what has happened will allow the family to acknowledge the shared loss and facilitate grieving together. If the midwife is asked to be a part of this discussion, she should be open and honest and not relate the death to a non factual circumstance. For example, she should not explain that the dead person is "asleep" since this portrays that the death is reversible.

8.2. Religious and cultural beliefs

Beliefs are formed in childhood and adopted from parents and guardians who influence the child. Attitudes are a way of being set towards or against particular pattern of beliefs. Allport (1935) states that attitude is a mental and neural state of readiness. This attitude is organized through experience that exerts a directive or dynamic influence upon the individual's response to all objects and situations with which it is related. In this instance we are talking about bereavement. Allport emphasises four basic aspects of attitudes:

(1) Attitudes are internal (within neural networks).

(2) Attitudes are learned (organized through experience).

(3) Attitudes are response related (a stimuli triggers the neural network).

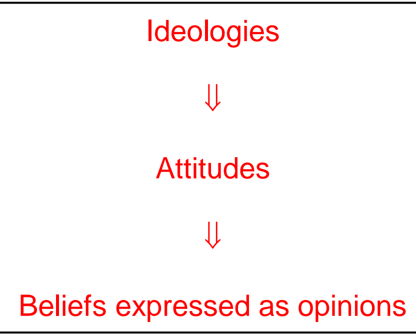
(4) Object orientated (towards a stimuli, e.g., religious practice and belief).

As stated in point (1) attitudes are internal, i.e., stored in neural networks within the brain. These neural networks have been (2) reorganized through past experience in relation to the object of concern. In this case a past bereavement and its associated rituals are seen to be appropriate responses. Attitudes stances in relation to how to react to a loss are learned through socialization. We acquire most beliefs about a particular topic quite directly. We hear or read a fact or opinion, or other people reinforce our statements by expressing a particular attitude (Carlson, 1993).

For example a family member may say to a child, “pull yourself together and stop crying”. Conversely parents may applaud their child’s tears in relation to the bereavement. Children in particular form attitudes through imitating or modelling the behaviour of people who play an important role in their lives. Children usually repeat opinions expressed by their parents. The tendency to identify with the family unit, and later with peer groups, provides a strong incentive to adopt group attitudes (Carlson, 1993).

Scobie (1978) explains that once an attitude has been established it develops some resistance to change. This has profound implications for the midwife who is supporting a grieving woman and her family, as they may not accept some of the behaviours that are suggested may help. For example, the concept of touching their dead infant post delivery may not be acceptable to them.

Attitudes are underpinned by ideologies and expressed as opinions. Ideologies underpin attitudes and orientate characteristic ways of thinking about the bereavement and how to behave. In other words ideologies provide an underlying template which directs thoughts:



Aspects of personality also influence how a person responds to the situation. For example, an individual with the underlying ideological dimension of conservatism may manifest with personality characteristics, such as stimulus aversion and risk avoidance. These characteristic ways of thinking will be revealed through opinions expressed in conversation. Opinions are often withheld if social pressure is exerted. This may make it difficult for the midwife to ascertain the woman's true opinion about what it is that has been suggested.

Midwives should provide choice and control to women in their care. This means that midwives must respect a woman's ideologies, attitudes and opinions (beliefs). Ascertaining women's views requires successful communication and the empowerment of women to have the confidence to be honest about expressing their opinions. Robertson (1997) provided eight key points that facilitate empowerment of women to make decisions and express views:

(1) Ensure accurate information is provided.
(2) The specific points where choice is available are detailed and defined.
(3) The advantages and disadvantages of the various options are outlined.
(4) Enough time is given for consideration of the physical and psychological implications of each choice.
(5) There is information included about potential risks, flowing from specific decisions, presented in a sensitive non-threatening manner.
(6) Crisis decisions are delegated to the health care professionals.
(7) Emotional support is available, regardless of the decision made.
(8) Evaluation is made to ensure that information is understood.

Katbamna (2000) identifies that there is wide variation in the ways different cultures display grief and the mourning rituals that accompany bereavement. Veneration of the dead is based on the belief that the deceased have continued existence and possess the ability to influence the fortune of the living. Many communities venerate their ancestors. For example, the Catholic Church venerates the dead through saints, as intercessors with God. In contrast, within some eastern cultures the goal of veneration is to ensure the ancestors' continued wellbeing and positive disposition towards the living, which often involves asking for special favours or assistance. The purpose of veneration is underpinned by belief in an afterlife and survival of the deceased's personal identity beyond death. Cross culturally, these beliefs are far from uniform. In some cultures people believe that their ancestors need to be provided for by their descendants. Others do not believe that the ancestors are even aware of what their descendants do for them. Instead, an expression of filial piety is what is important. The act of veneration is a way to respect

honour and care for ancestors in their afterlives, and seek guidance for their living descendants. For example, this may be by maintaining the graves of parents or other ancestors and leaving flowers to honour and remember them. In addition, midwives may be familiar with the wailing and stark displays of grief shown by some ethnic groups, with some finding it difficult to relate to these demonstrations of raw emotions. Within cultural groups, however, there can also be wide variations in emotions displayed between individuals in relation to death.

Activity 28

Ancestor veneration is practiced by the Chinese and other Buddhist and Confucian-influenced societies. Take a look on the internet and identify some of the cultural practices that help members of these societies cope with their bereavement.

Examples

(1) ....

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(2) ....

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(3) ....

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Schott and Henley (1996) observe that some people with strong religious faith gain strength and comfort from their spiritual and religious belief systems. Others find it difficult to retain their faith and blame God for allowing this shocking loss to happen to them.

The amount of support gained through religious and cultural beliefs may vary greatly. What is found to be acceptable may be profoundly influenced by the attitude of community members and religious leaders. For example, the characteristics of the ceremony carried out to mourn the death of the infant. Whatever processes are involved, the midwife must allow the family to express grief as they see appropriate.

It would be useful for caring professionals to have some understanding of different religious and cultural beliefs about death and bereavement. Mander (2006) states that sometimes midwives encounter difficulties accepting differing attitudes to loss by women from cultures other than their own. Mander goes on to question

whether midwives are able to work through these feelings in order to support women during the grieving process. Midwives must work to overcome their intolerances. Providing support and time to listen are essential components of the midwife's role.

Activity 29

Reflect on the different cultural groups that you have encountered during your clinical practice as a midwife.

What have you observed about some women's particular belief systems and their reactions to particular events?

8.3. The role of rituals

Rituals are an important way of expressing grief and it is appropriate that parents be encouraged to plan the funeral and burial within their own cultural and belief system. Midwives must be respectful of individual cultural backgrounds and ensure that parental wishes are facilitated. Families must be asked about their needs and every effort made to embrace their requested cultural and religious rituals. In order to facilitate another's grief process effectively, midwives require to be at ease with the concept of their own death. This requires that they consider what they would like to happen to them when they die.

Activity 30

Consider other structured belief systems. Find out what rituals are common practices at funerals in the following three religions:

Judaism

Buddhism

Muslim

8.4. Encouraging memories

As mentioned in *Chapter Two*, protocols can help shape the bereavement care that midwives provide. An important part of following a protocol is to be flexible and accommodate parents' cultural and spiritual beliefs. As part of these protocols, midwives are required to help parents gather meaningful memories of their infant, which is designed to help them appropriately grieve and adapt to their loss. For example collecting the following memory items:

- Gathering photographs, hand or foot prints, ultrasound photograph, baby's name card.
- Taking a lock of hair.
- Facilitate parents with spending time with their deceased baby.
- Supporting parents when viewing and holding their deceased baby.
- Using appropriate grief symbols, such as angels, candles and flowers.

These treasured items and symbols can help parents construct the infant's social identity and promote creation of constructive and concrete memories.

WORKBOOK CONCLUSION

Well done for completing this work book. What has been learned will expectantly make the reader better equipped to cope with women and families who have experienced loss or death within the childbearing remit. Palliative care is composed of three components: pain and comfort management, assistance with end-of-life decision-making, and bereavement support. Within this delivery, midwives must acknowledge their own grief for the death of an infant in their care and work to support the bereaved before, during, and after this devastating experience. Grief is a journey, and by travelling the road with the woman and her family, midwives can help validate the meaning of life. It is the midwives charge to remain open so that she/he may give without breaking. During process, it is important that midwives recognise the philosophical significance of each childbearing woman's journey.

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