

Bereavement Care Report 2010



Survey of UK maternity units and the care they provide
to parents whose baby dies before, during or shortly after birth



"It's hard to put into words. It really is devastating. I wish my baby was here to hold, feed and look after. Instead I have empty arms and a box of ashes." Mother

"We didn't know you could feel pain like that. I think of our daughter every single day and will live with this aching loss for the rest of my life. I do not feel whole and my family is not whole. I have another daughter now and whenever she does anything new I wonder what our first daughter would have been like." Mother

Acknowledgements

We would like to thank everyone who took the time to complete this questionnaire, which covered the whole spectrum of care from antenatal care to care in a subsequent pregnancy.

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Front cover image – Jason Hyde with his stillborn son, Sherman

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1 Introduction

"I cannot really find the words to describe the deep impact that the death of my daughter has had on my family. Still, 18 years on, I am deeply affected emotionally and still grieve for my baby, albeit behind a mask of normality." Mother

Every day in the UK 17 babies are stillborn or die shortly after birth: almost 6,500 babies die every year. The care that these thousands of families receive around the time of their baby's death is extremely important. Good care cannot remove the pain of their loss, but care that is inadequate or poor makes things worse and affects both their short-term and long-term wellbeing.

This report provides a snapshot of the care currently provided to parents whose baby dies before, during or shortly after birth. It summarises the findings of an online survey that Sands distributed to UK maternity units in May 2009. Invitations to complete an online questionnaire were emailed to 312 maternity units in the United Kingdom. 77 units (25%) returned completed questionnaires. (Please note that this report does not cover bereavement care in neonatal units.)

Aims and findings

The aim of the survey was to find out the extent to which units are following the recommendations contained in the widely-acclaimed Sands 2007 publication *Pregnancy loss and the death of a baby: Guidelines for professionals*. These Guidelines, based on research evidence, discussions with professionals, and parents' experiences, provide standards for care for parents whose baby dies during pregnancy, labour or shortly after birth.

It is important to note that in most maternity units provision and the organisation of care for these parents have improved greatly over the last few decades. Most of the units that responded are able to provide and resource care in line with the standards set out in the Sands Guidelines. This indicates that these standards are realistic: there is no good reason why all units should not achieve them.

However, it is of great concern that in about 20% of the units that responded, care is still poorly resourced and organised, and in others it is patchy. In addition, the fact that care in most units is good, is of absolutely no help or comfort to those parents whose baby dies in a unit where care and resources are poor or inadequate.

Resources

"The support and help that bereaved parents get are influenced to a great extent by the number of staff available, their knowledge and education, and their ability to offer individualised care." Midwife

Much of the survey focused on the way that resources are allocated and care is organised. However hard individual midwives and other staff work, and however committed they are, they cannot provide high quality care for parents if the resources and systems they need are not in place. They are in an impossible and very stressful position.

It is also important to bear in mind that at a time when the birth rate is rising rapidly, midwifery budgets in many places are static or are even being cut. In a survey carried out in 2009 by the Royal College of Midwives, over two-thirds of Heads of Midwifery reported that they did not have enough midwives to cope with the workload in their unit, and well over two-thirds said they needed more midwives to bring their midwifery staffing levels up to an acceptable level (RCM 2009).

Looking forwards

Sands, through its Helpline and UK-wide parent support groups, knows only too well the impact that poor and inadequate resources and systems, and over stretched staff have on the care given to bereaved parents.

Few of the changes that are identified in this report can be made by the staff who actually deliver care to parents. Almost all must be initiated and implemented by managers or requested by service commissioners.

Bereaved parents need and deserve the highest levels of care and those looking after them should have the necessary resources to provide this care at all times. Sands hopes that this report will help Hospital Trusts, Health Boards, Primary Care Trusts and Maternity Services Liaison Committees to review their services and make any necessary improvements.

2 Summary of findings

Bereavement support midwives

“Disparity of care is evident across the country, sometimes within the same hospital Trust. Hospital managers and those who hold the purse strings need to invest in recruiting bereavement midwives with the training and purpose to deliver the care that parents deserve.” Midwife

Designated bereavement support midwives can be an invaluable source of help and support both for bereaved parents and for other health professionals. However:

- Fewer than half of all units – only 47% – have designated bereavement support midwives.
- Three-quarters of units have midwives or other staff who do part or all of the work of a bereavement support midwife, though without the official title or remuneration.
- Nevertheless, in more than half of all units there is no midwife whose main role includes overseeing the entire package of care that is offered to bereaved parents in the unit.

Training for staff

“Midwives need to be proactive in securing support from managers for training and recognition of the vital role they play, but in many places they are increasingly frustrated and disillusioned, battling against local restrictions imposed either by financial or other constraints.” Midwife

Providing good care for parents whose baby dies is very hard. It requires great sensitivity, thought and commitment. All staff – midwives, doctors, sonographers etc – who work with parents whose baby dies should receive specific training on this topic. At least some of this training should be multidisciplinary so that staff from different disciplines can work seamlessly together to provide good care. However:

- Specific training on caring for parents whose baby dies is only included in regular training for midwives in about half of all units.
- This topic is only included in regular training for doctors in about a third of all units. Doctors are therefore even less likely to have had training in this area than midwives, although they are most frequently brought in when problems occur during pregnancy, labour, birth or afterwards.

In the majority of units, therefore, most training in this area is optional. Given the heavy pressures on staff time, the cost of attending training, and the difficulty of the subject matter, it is very unlikely that most staff will attend optional training sessions on this topic.

- Multidisciplinary training on this topic is provided in fewer than a third of units.
- Four-fifths of units said they would like information about the training that Sands offers on pregnancy loss and the death of a baby. This demonstrates a clear awareness that staff need more training in this area.

Support and mentoring for staff

The quality of care that parents receive depends greatly on the staff who care for them. To enable them to offer consistently good care in this very difficult situation, all staff who care for parents whose baby dies should have support and regular supervision or mentoring. This is particularly important for student and junior staff and also in units with a high staff turnover, or where staff rotate frequently. However:

- In a quarter of units, student and newly-qualified midwives do not always have access to support and mentoring when a baby dies.
- In a third of units, experienced midwives do not always have access to support and mentoring.
- In nearly two-thirds of units, medical students and junior doctors do not always have access to support and mentoring.
- In nearly two-thirds of units, senior doctors do not always have access to support and mentoring.
- In a small number of units there is no support or mentoring at all for medical students, for junior doctors or for senior doctors.

Ultrasound scans and antenatal care

Almost all units provide written information to mothers before their first antenatal scan and their anomaly scan. Most units have at least one trained counsellor who can talk to parents if an anomaly is found. In almost all units continuity of care is provided when a mother decides to continue a pregnancy with a serious or lethal anomaly. However:

- In nearly a fifth of units, parents waiting to confirm an anomaly or an intra-uterine death (IUD) have to wait in a room with other parents who are having a routine scan in a healthy pregnancy.
- In nearly a fifth of units, there is nowhere quiet and private for counselling and discussion with parents when an anomaly or an IUD has been found.

Having to wait for a scan with parents whose pregnancies are progressing normally, and having to discuss devastating information about their baby in a noisy public area cause parents additional and unnecessary distress.

“We booked into reception and were asked if we had attended before. Nobody seemed to know or care that we had been referred from another hospital. We were told to wait in a large square room with 6 or 7 other women, some with partners and young children. Then we were led into a darkened room with a very large ultrasound machine by a doctor...he asked, ‘So what can I do for you today?’ I couldn’t believe that he had to ask. Surely everybody in the world knew that ours had come crashing down around us?” Mother

Communication within the NHS

When there is a problem with the pregnancy or the baby has died, good communication between staff within a unit, between different hospitals, and between hospital and community staff, is essential so that parents can be offered seamless care. In most units antenatal staff are informed when a woman has had an IUD, a stillbirth or a neonatal death. However:

- In one-third of hospitals the antenatal class leaders are not informed. It is likely that mothers whose baby has died will still receive invitations to antenatal classes, causing additional distress.
- In about one-fifth of units there is no designated person to ensure prompt communication between the hospitals and the primary care team when a problem is discovered during pregnancy or a baby dies.
- In about one-third of units the Bounty Pack organiser is not informed when a baby has died. Bounty Pack mailings are likely to be sent to bereaved parents after they go home causing unnecessary additional distress.

Care on the labour ward and after the birth

"When you bury your baby, you don't just bury their future, you bury with them your dreams, your own plans and your own future. You make as many memories in those few days as you can, as you know they will have to last your entire lifetime." Mother

"It can be very difficult when you feel under pressure at work to give the care and support you want to. Often I think the importance of the precious few hours the parents have with their baby is lost when the ward is so busy and short staffed. I need to have enough time to explain properly what the parents' choices are. I don't want to be rushed or to compromise the care I give. The memories I am helping to provide are priceless and have to last a lifetime. There will be no Christmases or birthdays or first day at school for these parents. All they have is now." Midwife

Many parents whose baby dies value opportunities to see and hold their baby, to collect mementoes, and to have or participate in a funeral for their baby. In almost all units staff offer parents these opportunities.

- In all units all or most staff offer the parents opportunities to see and hold their baby, to take photographs and hand and footprints, and to collect other mementoes.
- In all units staff support partners and encourage them to stay with the mother.

"Comfort food, as simple as tea and toast, being frequently offered, with care and concern. It significantly helped in those first few hours and days of intense grief. It represents the basic, but so fundamental part of caring." Father

- In almost all units staff support members of extended families.
- In almost all units all or most staff use the Sands form (or a modified version of the Sands form) to record discussions and parents' decisions about seeing and holding their baby. This helps to ensure that parents are offered genuine choices and are given time to reflect on what they want, and also that those who have declined previous offers are not asked repeatedly if they have changed their minds.
- In all units staff offer parents verbal information about funeral options. In most units they also offer them written information.

However, the place of care for parents in this situation is far less satisfactory:

- Nearly half of all units have no dedicated room on the labour ward for mothers whose baby has died, where they cannot hear other mothers and babies.
- A quarter of all units have no dedicated room away from the postnatal ward where bereaved parents can be cared for after the birth.

"I was taken back to the postnatal ward after my baby was stillborn. I was so upset because none of the staff seemed to know what had happened to me and they asked me where my baby was. I cried and cried and visitors came and went with balloons and flowers for the living babies on the ward." Mother

Although space in most hospitals is at a premium, the provision of dedicated rooms for these parents would make a fundamental difference to their experience. It should therefore be seen as a priority.

After the birth, those parents who wish should have easy access to their baby's body. This is best achieved by having a mortuary fridge in the maternity unit.

Some parents may want to take their baby's body out of the hospital and there is no legal reason why they should not. However:

- Fewer than half of all maternity units have a mortuary fridge.
- Most units do not offer parents the option of taking their baby's body out of the hospital.

Late miscarriage: care on the gynaecology ward and elsewhere

The cut-off point after which mothers who are miscarrying are always cared for on the labour ward varies in different units between 14 and 24 weeks. In most units it is 20 weeks.

In most units mothers who are miscarrying and who are not cared for on the labour ward are accommodated on a gynaecology ward.

However, on many gynaecology wards, provision for these mothers and their partners is not as good as that on the labour ward. Gynaecology nurses do not always have the necessary training to care for a mother in this situation, nor to deliver and handle the baby as sensitively and carefully as if he or she were alive.

"I was put in a gynae ward because I was only 20 weeks. I wanted my baby to be acknowledged and recognised as a baby, but I wasn't allowed into the labour ward. Everyone around me was having Ds and Cs and hysterectomies." Mother

In a small number of units, women having a miscarriage are cared for in areas that are clearly not suitable, for example, on a medical or general ward, or in an Accident and Emergency department.

Giving birth in these areas, with staff who do not have the necessary training, support or experience, adds to the trauma of the loss and to parents' distress. For the staff too, the knowledge that they are unable to give good care to these mothers is frightening and stressful. It is unfair to put them in this position.

Women who miscarry in the second half of the second trimester should normally be cared for on the labour ward. All staff who care for women who miscarry at any stage of pregnancy should have the necessary training, facilities and support. Poor or insensitive care at this traumatic time adds significantly to parents' distress. Good care should be universal and should not depend on where a mother happens to live or to be cared for.

Post mortem examinations

In most units care and communication surrounding post mortem examinations are good. However:

- In a fifth of units parents normally have to wait two weeks or more until their baby's body is returned to the hospital and they can hold their baby's funeral.
- In a very small number of units parents normally have to wait over six weeks.

Many parents feel that their lives are "on hold" until the funeral. Any prolonged or unnecessary wait adds to their distress.

Funerals and sensitive disposal

"We went to the funeral. We felt we just had to be there even though it was incredibly painful. It was a simple one, arranged by the hospital. I am so grateful they did that for us. I couldn't have possibly done it myself." Mother

All units make suitable arrangements for the sensitive disposal of the remains of babies born dead before 24 weeks. Almost all units offer to arrange funerals for stillborn babies, babies born dead in the second trimester, and for babies who died shortly after birth. Almost all units' contracts with local funeral directors, cemeteries and crematoria specify that all babies' funerals must be handled sensitively and respectfully. Most contracts cater for the needs of families of minority religions. However:

- In nearly a quarter of units no one checks the quality of contract funerals.

Over half of hospitals use shared (communal) graves for babies of some gestations. However, in most units:

- Staff do not warn parents if the cemetery does not allow memorials etc on shared graves.
- Staff do not warn parents that they cannot move their baby from a shared grave at a later date for reburial elsewhere.

Only a third of units use lockable grave covers on shared graves until the grave is filled and the ground is reconstituted. This poses the very real risk that a grave will be disturbed and the baby's body will be harmed. All shared graves should have lockable grave covers until they can be finally covered over and the ground reconstituted.

Information about financial benefits

Many families suffer a drop in income for months and even years following the death of their baby. Perinatal deaths also disproportionately affect parents in the poorer socio-economic groups. Bereaved parents need timely and accurate information about the financial benefits to which they are entitled, some of which must be claimed within four weeks of the birth. However:

- In more than half of all units bereaved parents do not get any written information about the benefits they are entitled to.

Another pregnancy

"I was fortunate in that the midwife who ran the baby loss support group I attended was with me throughout the pregnancy, the time in hospital and was there waiting in the delivery suite when I came out of theatre with my second son. She and another Mum who had lost a child were the only people who understood my fear of another loss. Others just got angry." Mother

Although it is never possible to predict how individual parents will feel during and after another pregnancy, many experience overwhelming anxiety and mental anguish. Parents' fears are likely to be strongest in the first pregnancy after the loss, but often recur in later pregnancies following the birth of one or more healthy babies. They need extra understanding and support in all subsequent pregnancies. However:

- Over a tenth of units do not offer extra support and monitoring to all mothers in a subsequent pregnancy.
- A quarter of units do not offer extra support after the birth of another baby.

Information materials for parents

Most units offer parents leaflets, certificates etc that are easy to understand, free of specific religious symbols, and attractively produced.

However, very few units meet the information needs of parents whose first language is not English or of those with disabilities:

- Fewer than half the units with significant numbers of non-English speakers in their area provide any leaflets in the main minority languages spoken locally.
- Fewer than a fifth of units have any information in formats suitable for parents with visual impairments.
- Very few units provide adequate access to signers for parents with hearing impairments.
- Even fewer units provide training for midwives or doctors in working with signers.
- Fewer than a fifth of units have any information in formats suitable for parents with learning disabilities.

Under Section 20 of the Race Relations Act 1976 (amended in 2000), it is illegal knowingly to provide an inferior quality of care to a particular racial minority group. The 2005 Disability Discrimination Act requires organisations to ensure that people with disabilities can benefit from their services.

Parents whose first language is not English

Even if people usually speak English well, distress and anxiety can drastically affect their ability to understand and express themselves. Government codes of practice and other documents stress the importance of using trained professional interpreters to interpret between parents and staff whenever valid consent is required and whenever important or difficult issues are discussed. Staff who work with interpreters also need training. However, when parents need an interpreter:

- In about one-third of units staff do not usually use a trained interpreter.
- In just under one-tenth of units staff never use a trained interpreter. (These figures exclude units with very few non-English speakers.)
- In fewer than a fifth of units staff usually use a telephone interpreter. In such a distressing situation, telephone interpreting is obviously far less suitable than a face-to-face interpreter. However, it is generally better than the alternatives.
- In two-fifths of units staff usually expect the father to interpret for the mother. This is likely to be extremely difficult for him, since he is also shocked and distressed: the mother may not get a full translation of what is said. Using the father also raises serious issues of confidentiality and of valid consent.
- A small number of units usually use children to interpret. This is completely unacceptable, is unlikely to achieve good communication, and may cause lasting damage to the child and to family relationships.
- In most units, midwives or doctors have had no training in communicating across language barriers or in working with interpreters. Doctors are even less likely than midwives to have had such training.

What maternity units most want to improve

To conclude the survey Sands asked respondents to list the things that they would most like to improve in their units. It is extremely encouraging and heartening to see that staff are aware of what would really make a difference to the parents they care for, and are highly motivated to improve the service that their unit offers. However, most of these improvements have resource implications and may therefore be problematic to achieve.

The most frequently mentioned improvements were:

- a separate, dedicated suite or facilities for parents both during labour and afterwards.
- one or more bereavement support midwives (or equivalent).
- bereavement support training for doctors, especially junior doctors. Also more multidisciplinary training.
- better written information for parents, including information in other languages.
- continuity of carer during labour and after the birth.
- better communication between the different staff involved in care, including better, more streamlined documentation.

3 Method

Invitations to complete an online questionnaire about bereavement care were emailed to 312 maternity units in the United Kingdom via the Local Supervising Authority Midwifery Officers for England, Wales, Scotland and Northern Ireland in May and June 2009.

Only 25% (77 in total) of maternity units contacted actually completed the Sands questionnaire. This appears to indicate that in many units care for these parents is not considered a resourcing priority. If this is so, it is seriously worrying for Sands and the thousands of parents it represents. Another possible factor in the low response rate may have been the length of the questionnaire, and the fact that respondents had to get information from colleagues in other departments. Where staff are already overstretched this may have been too much to ask.

Nevertheless, we believe that looking at the whole process of care from diagnosis onwards was a useful exercise. Indeed, several respondents emailed us to say that they had found the questionnaire valuable and thought-provoking: it had allowed them for the first time to look at their service for bereaved parents as a whole and to assess its strengths and weaknesses at each stage.

The 77 units that completed a questionnaire had a total of 267,208 births in 2008:

- 30% (23 units) had between 150 and 3,000 births
- 47% (36 units) had between 3,001 and 4,000 births
- 23% (18 units) had 4,001 births and over.

These 267,208 births included 1,393 stillbirths and 626 neonatal deaths.

4 Detailed findings

4.1 Bereavement support midwives

"Trusts, Health Boards and managers should appoint and train specialist bereavement support staff. They should be responsible for offering emotional support and practical guidance to parents and for training, updating, and supporting other members of staff who care for bereaved parents. They should also be involved in helping to ensure standards of bereavement care, and in establishing policies that ensure excellent co-ordination and communication between departments and with primary care staff." (Sands 2007: 224)

"Disparity of care is evident across the country, sometimes within the same hospital Trust. Hospital managers and those who hold the purse strings need to invest in recruiting bereavement midwives with the training and purpose to deliver the care that parents deserve." Midwife

- Only 47% of units have designated bereavement support midwives.
- 74% of units have midwives or other staff who do part or all of the work of a bereavement support midwife, though without the official title or remuneration.

Over one third of the survey respondents said that the main thing they would like to change in their unit is to have a bereavement midwife, or to increase the hours of the existing bereavement midwife.

4.2 Training and support for staff

Training

"...It is essential that staff involved in caring for...people who are bereaved are well informed so they feel confident about the care and support they give. They should have adequate opportunities to develop their knowledge, understanding, self-awareness and skills." (DoH 2005b: 8)

"Midwives need to be proactive in securing support from managers for training and recognition of the vital role they play, but in many places they are increasingly frustrated and disillusioned, battling against local restrictions imposed either by financial or other constraints." Midwife

Providing good care for parents whose baby dies is very hard. It requires great sensitivity, thought and commitment. All staff – midwives, doctors, sonographers etc – who work with parents whose baby dies should receive specific training on this topic.

The table below shows that midwives are more likely than doctors to have training provided by their units. However, in many units staff training on care for parents whose baby dies is only optional. Given the pressures on staff time, the cost of training, and the strong emotions aroused by the subject, it is very unlikely that most staff will attend optional training courses.

Many survey respondents commented that the thing they would most like to change in their unit is to have training for doctors in the care of parents experiencing perinatal loss, especially for junior doctors who are very often called in when a crisis occurs. Respondents also mentioned the need for training for gynaecology nurses and for nursing and midwifery support workers, and training for sonographers in giving bad news.

Multidisciplinary training enables different health professionals to understand each other's roles and responsibilities and to work together to provide seamless care for parents:

- In 26% of units all or most training is multidisciplinary.
- In another 26% of units no training is multidisciplinary. Several respondents commented that they would like more multidisciplinary training.
- 81% of units said they would like information about the training that Sands offers on pregnancy loss and the death of a baby. This demonstrates clear awareness that staff want more training in this area.

	For midwives	For doctors
This topic is included in regular training sessions	in 51% of units	in 32% of units
They have special training workshops or days on this topic	in 47% of units	in 26% of units
They can attend courses on this topic if they want	in 96% of units	in 94% of units

Support and mentoring for midwives and doctors

"Caring for parents around the time of a childbearing loss is stressful and demanding. Trusts, Health Boards and managers should ensure that there is provision for good staff support, and that the culture of the organisation recognises that it is both responsible and professional for staff to seek support when they need it." (Sands 2007: 229)

Support and regular supervision or mentoring are particularly important for student and junior staff and also in units with a high staff turnover, or where staff rotate frequently. The table below shows that mentoring and support are more likely to be provided to student and qualified midwives than to medical students or doctors.

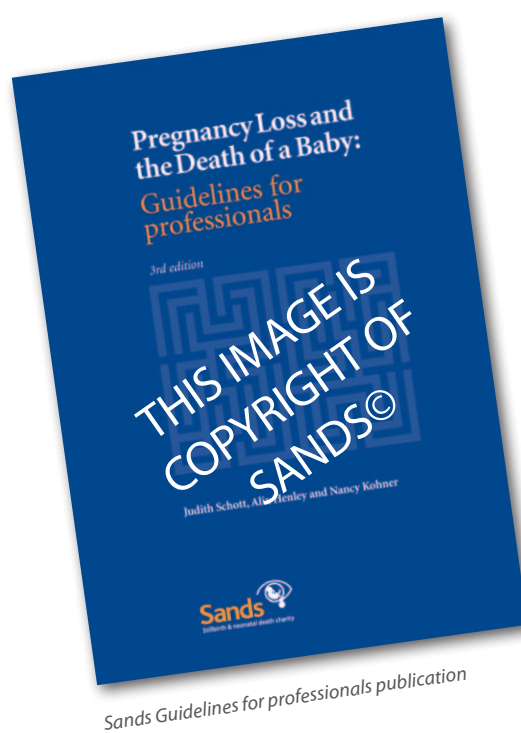
When a loss occurs, are support and mentoring available?	Always	Usually/Sometimes	Never
For student and newly qualified midwives	in 74% of units	in 26% of units	in no units
For experienced midwives	in 61% of units	in 36% of units	in 3% of units
For medical students and junior doctors	in 42% of units	in 54% of units	in 4% of units
For experienced doctors	in 42% of units	in 54% of units	in 4% of units

Are other forms of training offered?	Yes	No
To midwives	in 61% of units	in 39% of units
To doctors	in 29% of units	in 71% of units

The Sands Guidelines

In 70% of units copies of the Sands Guidelines, which are widely recognised as setting standards for good practice in relation to pregnancy loss and the death of a baby, are easily available to all midwives and doctors. However:

- In only 10% of units specific training on the Guidelines has been provided for doctors.
- In only 27% of units specific training on the Guidelines has been provided for midwives.
- In 70% of units there has been no training on the recommendations in the Sands Guidelines for either midwives or doctors.



4.3 Ultrasound scans and antenatal care

Information for parents

"Clear written advice should be given before ultrasound screening in pregnancy. The advice should indicate the nature and purpose of the examination, together with the detection rate for defined common conditions ... women should be given the opportunity to request further information and such a discussion should be clearly documented in the patient record." (RCOG 2008a: 4.3)

- 92% of units offer written information to all mothers before their first antenatal scan.
- 94% of units offer written information to all mothers before their anomaly scan (between 18 and 20 weeks of pregnancy).

Waiting for a scan

"Wherever a woman goes for further tests, the staff should be expecting her and should welcome her (and her partner). She should not have to wait with other pregnant women who are having scheduled scans or tests, but should be offered a private room." (Sands 2007: 83)

- In 19% of units mothers who are waiting to confirm an abnormality or IUD have to sit in a room with other parents who are having a routine scan in a healthy pregnancy.

Having to wait for a scan with parents whose pregnancies are progressing normally causes parents additional and unnecessary distress.

If an anomaly is found during a scan

"Every department undertaking screening scans should have at least one individual trained in counselling in the area of prenatal diagnosis and screening... A quiet room should be available for the use of the trained counsellor to talk to women who need to receive and understand bad or troublesome news about their baby." (RCOG 2000: 43.1, 4.3.3)

- 19% of units have no member of staff who is trained and able to counsel parents if an anomaly is found.
- 14% of units do not offer mothers written information if an anomaly is found.
- 18% of units have no quiet room in the ultrasound department for counselling and discussion with parents when an anomaly has been found or a baby has died.

Several survey respondents commented on the difficulties caused by the lack of a separate area in the ultrasound unit where anxious parents could wait, and of a quiet private space for discussion with parents when a problem had been found.

"Discussion of the implications of a suspicious scan should occur with an obstetrician within 24 hours (or one working day). If indicated, referral to a tertiary centre with maternal fetal medicine specialists and other relevant practitioners should be possible within 72 hours (or two working days). If referral to a tertiary centre is not possible within this time limit then at least an explanation about the need for referral should be given." (RCOG 2000: 4.3.4)

The table below shows that most units are able to meet these standards most of the time.

	All mothers	Most/Some mothers	No mothers
Offered a discussion with an obstetrician within 24 hours	in 71% of units	in 26% of units	in 3% of units
Offered referral to a tertiary centre within 72 hours	in 66% of units*	in 34% of units	in no units

* This figure includes units that also have a specialist fetal medicine unit.

4.4 Mothers who continue the pregnancy following the diagnosis of a serious or lethal anomaly

Continuity of carer

"To avoid creating additional stress and anxiety for parents who are already under enormous pressure, it is very important that their care is well co-ordinated. In addition to the obstetric consultant, the mother should be cared for during pregnancy by a small number of staff whom she can get to know and trust. She should not, for example, see a different midwife or junior doctor at every antenatal visit." (Sands 2007: 91)

- In 94% of units these mothers always or usually get continuity of carer at their antenatal appointments.
- However, in 6% of units they never get continuity of carer.

Preparation for labour and birth

"Parents in this situation are unlikely to feel able to attend a standard antenatal class. If possible, they should be offered individual preparation sessions with an antenatal teacher who can empathise with them, understand their distress and help them to prepare for a birth that is likely to end in tragedy." (Sands 2007: 94)

- In 88% of units, these mothers are always or usually offered individual preparation for labour tailored to their needs.
- However, in 12% of units this is never offered.

4.5 Communication within the NHS

"We booked into reception and were asked if we had attended before. Nobody seemed to know or care that we had been referred from another hospital. We were told to wait in a large square room with 6 or 7 other women, some with partners and young children. Then we were led into a darkened room with a very large ultrasound machine by a doctor...he asked, 'So what can I do for you today?' I couldn't believe that he had to ask. Surely everybody in the world knew that ours had come crashing down around us?" Mother

When a baby has died, communication between staff within a unit, and between hospital and community staff, is essential so that the parents can be offered seamless care.

Communication between staff in the unit

"The designated member of staff should also make sure that all outstanding antenatal and scan appointments are cancelled, and the antenatal class co-ordinator is informed. She should also cancel the Bounty Pack." (Sands 2007: 138)

"When I went back to the hospital for my follow-up appointment the doctor said cheerfully, 'Who's watching your baby?'" Mother

- In 96% of units, antenatal staff are informed when a woman has had an IUD, a stillbirth or a neonatal death.
- In 66% of units, antenatal class leaders are informed.

Several respondents commented that they would like to see better communication between the different staff involved in caring for parents whose baby dies, and better, more streamlined documentation.

- In 69% of units the Bounty Pack organiser is informed and/or a Bounty Mailing Suppression form is completed. This ensures that the mother will not receive mailings from or through Bounty (UK) Limited. (She may however continue to receive mailings from other companies to which she signed up while she was pregnant.)
- In 31% of units the Bounty Pack organiser is not informed and parents are therefore likely to continue to receive mailings from Bounty. (See Baby Mailing Preference Service on P26.)

"The Sands teardrop sticker can be used to identify the notes of a mother whose baby has died, both in the time following the death and in any subsequent pregnancies. It can be used on hospital and GP records, antenatal notes and appointment cards to ensure that everyone who comes into contact with a bereaved mother is aware of her loss and does not inadvertently say things that will add to her distress." (Sands 2007: 124)

- In 65% of units labour ward staff always ask the mother if they can mark her notes with a sticker.
- In 42% of other wards (mainly gynaecology) staff always ask the mother if they can mark her notes with a sticker.

Communication between the hospital and the primary care team

"Local guidelines must include clear communication pathways between secondary care and the primary care team with both the woman's GP and community midwife informed of any death within one working day."
(RCOG 2008b: 20.4)

There is a designated person who ensures prompt communication between the hospital and GPs and community midwives:

- In 81% or more of units following a stillbirth or a neonatal death.

- In 79% of units following a late miscarriage.
- In 78% of units following the discovery of a serious problem or fetal abnormality during pregnancy.
- However, in about one-fifth of units there is no designated person to make sure that GPs and the primary care team are informed promptly.

4.6 Care on the labour ward and after the birth

Training for staff

- In 93% of units all or most staff on the labour ward have the necessary training and support to give good care to women and their partners during labour and at the birth.
- In 96% of units, all or most staff on the labour ward have the necessary training and support to deliver and handle the baby sensitively.

These figures conflict with the figures on training for midwives and doctors in section 4.2 above. It is therefore difficult to assess the actual situation.

Pressures on staff

Respondents in over a quarter of units commented that they would like to provide greater continuity of care for parents experiencing perinatal loss. They would also like to have more time for these parents and to be able to provide individualised care. Several mentioned how difficult it is for a midwife on the labour wards to move between mothers having healthy babies and a mother whose baby is dying or has died, and to give appropriate sensitive care to each. All this requires higher staffing levels as well as understanding from managers about the time and emotional commitment required to give good care to bereaved parents.

"It can be very difficult when you feel under pressure at work to give the care and support you want to. Often I think the importance of the precious few hours the parents have with their baby is lost when the ward is so busy and short staffed. I need to have enough time to explain properly what the parents' choices are. I don't want to be rushed or to compromise the care I give. The memories I am helping to provide are priceless and have to last a lifetime. There will be no Christmases or birthdays or first day at school for these parents. All they have is now." Midwife

Offering informed choices after the birth

"When you bury your baby, you don't just bury their future, you bury with them your dreams, your own plans and your own future. You make as many memories in those few days as you can, as you know they will have to last your entire lifetime." Mother

Many parents whose baby dies value opportunities to see and hold their baby, to collect mementoes, and to have or participate in a funeral for their baby. Staff should always offer parents these choices. In almost all units care for mothers and their partners on the labour ward is very good:

- In 100% of units, all or most staff on the labour ward offer the parents opportunities to see and hold their baby.
- In 100% of units, all or most staff on the labour ward offer the parents opportunities to take photographs and hand and footprints and to collect other mementoes.

These figures are excellent news. They show that staff understand the significance of the death of a baby for parents and the importance of enabling parents to make decisions about what happens when their baby dies.

- In 91% of units, all or most staff on the labour ward use the Sands form (or a modified version of the Sands form) to record discussions and parents' decisions about seeing and holding their baby.

These forms are designed to ensure that parents are offered genuine choices and are given time to reflect on what they want, and also that parents who have declined previous offers are not asked repeatedly if they have changed their minds. (See P27 for details of the form.)

Place of care during labour and the birth

"Trusts and Health Boards should ensure that each labour ward has – depending on the size of the unit and the number of deliveries per annum – one or more specially equipped rooms in which women who have had an intra-uterine death, and women having a mid-trimester loss, can labour. These rooms should be a short distance from the main labour rooms. Every effort should be made to ensure that women can remain in them for labour and for delivery, and that, after the birth, they are also cared for in rooms especially designed for bereaved parents." (Sands 2007: 227)

- 55% of units have one or more dedicated room(s) on the labour ward where mothers whose baby has died cannot hear other mothers and babies.
- However, 45% of units have no suitable room in which mothers whose baby has already died or is expected to die at birth can labour.

Sands receives many reports from parents whose baby has died about being confronted by the sight and sounds of women and families with healthy babies, and of the additional anguish and distress this causes.

Over half the respondents to this survey commented that the thing they would most like to change in their unit is to provide one or more dedicated rooms for parents experiencing pregnancy loss.

Although space in most hospitals is at a premium, the provision of dedicated labour rooms for these parents out of sight and hearing of other parents and babies makes a fundamental difference to their experience and to their memories of what happened. It should therefore be seen as a priority.

4.7 Postnatal care

- 75% of units have one or more dedicated room(s) where parents whose baby has died can be cared for until they go home. In some units women can stay in the same room or suite before, during and after the birth.
- However, this means that a quarter of all units have no dedicated room for parents after the birth.

Of those units with dedicated rooms:

- 64% have rooms that are situated where the parents cannot hear other babies.

Partners and other family members during and after the birth

"If a woman is being cared for in hospital after the birth, she should be offered a designated side ward, unless she prefers to be on a ward with others. The room should have a double bed or an additional single bed so that her partner or another supporter can stay with her through the night if she wishes... Partners – or other supporters – should be made to feel welcome, and their need for empathy and support should be acknowledged and met." (Sands 2007: 135)

"Comfort food, as simple as tea and toast, being frequently offered, with care and concern. It significantly helped in those first few hours and days of intense grief. It represents the basic, but so fundamental part of caring." Father

- In all units labour ward staff are expected to offer partners both practical and emotional support in their own right.
- In all units partners are encouraged to stay with mothers overnight on the labour ward.
- In all units there is a bed or a reclining chair (or equivalent) for the partner to sleep in.
- In 91% of units, there are washing and toilet facilities for men near the labour ward, and in 70% of units there are washing and toilet facilities for men near the postnatal ward.
- In 99% of units, hot drinks are available near the labour ward during the day, and in 97% of units hot drinks are available at night.
- In 99% of units, food is available near the labour ward during the day, and in 80% of units food is available near the labour ward at night.
- In 95% of units, all or most postnatal ward staff are aware of the possible needs of extended family members when a baby has died.

These figures show that facilities for partners, and understanding of the needs of partners and other family members have improved in most units.

- However, in 36% of units the dedicated room(s) are within sight and sound of women and families with healthy babies.

"I was taken back to the postnatal ward after my baby was stillborn. I was so upset because none of the staff seemed to know what had happened to me and they asked me where my baby was. I cried and cried and visitors came and went with balloons and flowers for the living babies on the ward." Mother

As mentioned above, this causes great distress to many parents. The provision of dedicated rooms for these parents should be seen as a priority.

4.8 Policies on place of care for a late miscarriage

Although the loss of a baby in the second half of the second trimester of pregnancy is legally a late miscarriage, the physical and emotional impact on the parents is much the same as when a baby is stillborn.

"Each Trust and Health Board should have a policy that sets out the place of care for women experiencing pregnancy losses. The policy should cover the different types of loss and the gestations at which they occur. Its starting point should be that the place in which a woman is cared for should not add unnecessarily to her distress, or limit her choices. A woman with a later mid-trimester loss should, wherever possible, be offered an informed choice about whether she is cared for on a gynaecology ward or on a labour ward. The policy should also ensure that staff in the different areas have the necessary skills, competencies and facilities to provide optimal care for women and their partners." (Sands 2007: 226)

Unit policies vary a good deal on the place of care for mothers having a late miscarriage.

- The most frequent cut-off point is 20 weeks.
- In 12% of units, the cut-off point after which women are cared for on the labour ward is 14 weeks.
- In 6% of units, the cut-off point is 24 weeks.

Late miscarriages: place of care outside the labour ward

- In 70% of units, mothers who are miscarrying in the second trimester may be cared for outside the labour ward.
- In 45% of these units, they are always cared for on a gynaecology ward. (For more on care on gynaecology wards see P17.)
- In 9% of these units, they are cared for on either a gynaecology ward or the labour ward, depending on beds and staffing.
- In 16% of these units, they are offered a choice between the labour ward and a gynaecology ward.
- In one unit women miscarrying before 15 weeks are cared for on an emergency ward by gynaecology nurses.

Several respondents commented that they would like to be able to care for all mothers having a late miscarriage on the labour wards where the facilities are more suitable and staff have the necessary training to give good care.

Care in areas other than gynaecology wards

In 25% of units mothers having a late miscarriage may also be cared for in a special area such as a dedicated bereavement suite, a Sands suite, a pregnancy loss ward, a private room next to the labour ward, an early pregnancy unit or a family room on the antenatal ward. In all these places women and families are likely to receive excellent care and support.

However, a few responses gave serious cause for concern:

- In two units women miscarrying before the 18th and 22nd week respectively are always cared for on a general ward.
- In one unit women miscarrying before 20 weeks are always cared for on a women's surgical ward.
- In one unit where there is no gynaecology ward, women miscarrying before 20 weeks are always cared for on a medical ward.
- In one unit women miscarrying before 16 weeks are cared for in the Accident and Emergency department.

Although the number of units in which mothers labour and give birth in an unsuitable area is very small, it is still worrying. No woman should labour and give birth in an area that is not designed for this purpose. No woman should ever give birth in an Accident and Emergency department unless there is no time to move her to a suitable ward.

For staff, the knowledge that they have not had the training to give expert and sensitive care to a mother who is giving birth to a baby in the second trimester is extremely frightening and stressful. They are also very unlikely to have the time to care for the mother properly. It is unfair to put staff in this position.

Poor or insensitive care at this traumatic time adds significantly to parents' distress. Good care should be universal and should not depend on where a mother happens to live or to be cared for.

4.9 Care on gynaecology wards

"I was put in a gynae ward because I was only 20 weeks. I wanted my baby to be acknowledged and recognised as a baby, but I wasn't allowed into the labour ward. Everyone around me was having Ds and Cs and hysterectomies." Mother

Care and support for a mother having a late miscarriage should be the same, whether she is cared for on a labour ward or a gynaecology ward. Although most gynaecology wards provide good care and support for these mothers and their families, some do not.



Sands 'Always Loved Never Forgotten' memory box

The table below compares standards of care between gynaecology wards, labour and postnatal wards.

	On gynaecology wards	On labour/postnatal wards
Staff training and support		
All or most staff have the necessary training and support to provide good care to mothers during labour and at the birth	in 74% of units	in 93% of units
All or most staff have the necessary training and support to deliver and handle the baby sensitively	in 77% of units	in 86% of units
Choices and information after the birth		
All or most staff offer the parents opportunities to see and hold their baby	in 83% of units	in 100% of units
All or most staff use the Sands form (or a modified version) to record discussions and parents' decisions about seeing and holding the baby	in 55% of units	in 81% of units
All or most staff offer the parents opportunities to take photographs and footprints and to create other memories	in 79% of units	in 100% of units
Funeral arrangements		
All or most mothers are given verbal information about possible funeral arrangements	in 96% of units	in 100% of units
All or most mothers are given written information about possible funeral arrangements	in 85% of units	in 90% of units
Care and support for partners and other family members		
Staff are expected to offer partners practical and emotional support in their own right	in 94% of units	in 100% of units
Staff encourage partners to stay with mothers overnight after a loss	in 94% of units	in 100% of units
Staff are aware of the possible needs of extended family members	in 82% of units	in 95% of units
Partners are given a bed or reclining chair	in 77% of units	in 100% of units
Partners can get food nearby	in 92% of units	in 100% of units

4.10 Access to the baby's body

"In order to facilitate easy access for parents to the bodies of their babies following a childbearing loss, Trusts, Health Boards and managers should ensure that there is a suitable mortuary fridge in the maternity unit." (Sands 2007: 227)

- 58% of maternity units have no mortuary fridge where a baby's body can be stored while the mother is in the unit.

Where mothers are cared for on a gynaecological ward or elsewhere, it is very unlikely that there will be a mortuary fridge nearby. However, this question was not asked.

Taking the baby's body out of the hospital

"There are no legal reasons to prevent parents from taking their baby's body home or to a place that has special significance for them. Staff should offer parents the option of doing this, and sensitive and efficient procedures should be in place to support them." (Sands 2007: 142)

- In only 24% of units, all or most parents are offered the option of taking their baby's body out of the unit.
- In 31% of units no parents are offered this option.

- Only 55% of unit policies state that there is no legal reason why parents should not take the baby's body out of the unit, and that no other authority or agency needs to be informed.
- In only 57% of units, all or most staff who advise parents understand that there is no legal reason why parents should not take the baby's body out of the unit.

"For the protection of parents who want to take their baby's body home, and to prevent misunderstandings, Trusts and Health Boards should issue a form to accompany the body." (Sands 2007: 227) (See P27 for details of the form.)

Of those units where parents are offered the option of taking their baby's body out of the hospital:

- In 64% of units, all or most parents who take their baby's body out are given a form confirming their right to do so, in case anyone raises concerns.
- However, in 28% of units parents who take their baby's body out are not given a form or any documentation.

4.11 Post mortem examinations

"To ensure that all the relevant information is gained from a post mortem on a baby, and that the results are accurate and precise, post mortem examinations on fetuses and babies should be carried out by specialists in fetal and perinatal pathology. This may require the body to be transferred to another hospital or unit." (Sands 2007: 168)

- In 94% of units, perinatal post mortems on babies are always or usually carried out by a specialist fetal and perinatal pathologist.
- In 84% of units, there is provision for urgent or partial post mortems if, for religious reasons, parents need to hold the baby's funeral as soon as possible.

Time until the body is returned

A long delay until the baby's body is returned is distressing to many parents who feel that their lives are "on hold" until the funeral has taken place. It seems likely that delays are due to a national shortage of fetal and perinatal pathologists rather than to the length of the procedures.

- In 87% of units, all or some babies' bodies are transferred to another unit for a post mortem.

The following figures refer only to those units that transfer the bodies of babies for post mortem examination:

- In 26% of units the body is normally returned within three days.

- In 64% of units the body is normally returned within seven days.

However:

- In 36% of units the average delay is more than a week.
- In 29% of units the average delay is two weeks or more.
- In 6% of units the average delay is four weeks.
- In 3% of units the average delay is six weeks.
- In one unit the average delay is eight weeks.

Consent and communication

The Human Tissue Authority Codes of Practice state that the person who requests consent should be experienced and well informed and should have had specialist training on the essential requirements for and the implications of asking for consent. (HTA 2009: Codes 1 and 3)

- In 91% of units, consent is always requested by a senior member of staff who has had training in discussing post mortems and requesting consent from parents.
- In 97% of units, all parents are given back-up information about post mortems that is suitable for a perinatal loss.
- In 89% of units, there is good communication between the staff who request consent to a post mortem and the pathologists who carry it out.

However, in only 54% of units, pathologists are available to speak (face-to-face or on the phone) to parents who have questions or specific requests about the post mortem.

4.12 Funerals and the sensitive disposal of fetal remains

"Trust and Health Board policies on funerals and sensitive disposal should cover losses at all gestations, as well as stillbirths and neonatal deaths. The basis for all these policies must be that babies' bodies and remains are handled with respect. The policies should be carefully worked out in close consultation with representatives from all the departments that will have to implement them, as well as representatives of bereaved parents (for example, ARC, the Miscarriage Association, Sands and the Multiple Births Foundation). They should be communicated to all the staff concerned, and reviewed and updated regularly." (Sands 2007: 228)

Babies born dead before 24 weeks gestation

"Parents should be given the same choice on the disposal of fetal remains as for a stillborn child. They should be clearly and sensitively informed of the options available to them, both verbally and in writing, by trained health professionals." (RCN 2002: p. 4)

- All units ensure sensitive disposal for all fetal remains.
- 87% of units have good quality written information about the disposal of fetal remains for parents who request it.

Funerals

"We went to the funeral. We felt we just had to be there even though it was incredibly painful. It was a simple one, arranged by the hospital. I am so grateful they did that for us. I couldn't have possibly done it myself." Mother

- 92% of units offer to organise funerals.

Note: In Northern Ireland it is customary for parents to organise their own funerals, and hospitals are not generally involved.

Of those units that offer to organise funerals:

- All units offer to organise them for babies who were born dead in the second trimester, stillborn babies, and babies who died shortly after birth.
- 89% offer burial as an option to all parents.
- Another 7% offer burial only to parents for whom cremation is unacceptable on religious grounds.



Lockable grave cover

Information for parents about funeral options

"All parents should be offered written information relevant to the stage at which the pregnancy ended or the baby died, outlining (as appropriate): what arrangements will normally be made; what choices they have if they want the hospital to make the arrangements; what choices they have, and what they need to do, if they want to make their own arrangements; what, if any, costs are involved, and what to do if they might be eligible for a Social Fund Funeral Expenses Payment." (Sands 2007: 182)

- In 100% of units all or most mothers in the maternity unit are given verbal information about possible funeral arrangements.
- In 90% of units all or most mothers in the maternity unit are given written information about possible funeral arrangements.
- However, in 10% of units no mothers in the maternity unit are given written information about possible funeral arrangements.

Shared graves

"If their baby will be buried in a shared grave, parents should be told this in advance. They should also be told about any restrictions as to how the grave may be marked, and that it is usually impossible to move a baby from a shared grave for re-burial elsewhere later on. Lockable grave covers should be used to ensure that shared graves are not disturbed until the grave is filled and the ground re-constituted." (Sands 2007: 185, 189)

- 56% of those units that offer burial use shared graves for babies of some gestations.
- In 55% of these units, staff inform parents verbally about any restrictions that the burial ground imposes for shared graves. In 38% of these units staff give parents written information.
- In 30% of these units, staff inform parents verbally that moving a body from a shared grave is very unlikely to be possible. In 13% of these units staff give parents written information.
- Only 35% of the units that use shared graves use lockable grave covers.

Failure to use lockable grave covers poses the very real risk that a grave will be disturbed and a baby's body will be harmed. A recent case, in which a baby's body was removed from a partially-filled and unlocked shared grave, caused immense distress to the parents and generated a great deal of adverse publicity. It is therefore essential that hospital contracts with cemeteries stipulate that all shared graves should have lockable grave covers until they can be finally covered over and the ground reconstituted.

Funerals arranged by the hospital

Note: The rest of this section relates only to those units (92% of respondents) that offer funerals.

"The contract with a funeral director should ensure arrangements that parents will find acceptable, whether or not they choose to attend the funeral. Contracts should not be awarded on the grounds of price alone. The standard of a contract funeral should be at least as good as that of a simple private funeral, and parents who ask the hospital to make all the arrangements should not feel that they are choosing a "cheap" and therefore inferior service. A member of staff should attend contract funerals regularly to monitor the standard of provision and ensure that it is acceptable." (Sands 2007: 187)

- In all but one unit contracts with local funeral directors, cemeteries and crematoria specify that all babies' funerals must be handled sensitively and respectfully.
- In 48% of units, someone checks the quality of funerals at least twice a year, and in 17% of units someone checks once a year.
- However, in 23% of units the quality of funerals is never checked.
- In 90% of units, the funeral arrangements meet the needs of families of minority religions.

"Trust and Health Board policies should ensure that parents are informed about arrangements for funerals and sensitive disposal, and are enabled to express their own wishes about what happens to their baby's body or the products of conception. If parents want to, they should be able to participate in the arrangements made by the hospital or to make their own funeral arrangements. These policies should be communicated to all relevant staff, and should be regularly reviewed and updated." (Sands 2007: 228)

- In 86% of units, all or most staff are well informed about the different funeral options, including the option for the parents to arrange the funeral themselves.
- In 83% of units, all or most staff can explain these different options sensitively to parents.
- In 75% of units, there is good written information for parents on the different options.

If a family chooses a hospital-arranged funeral they are informed:

- In all units, that they can attend the funeral.
- In 97% of units, that they can participate in the service.
- In 86% of units, that they can help to plan the funeral.

4.13 Information for parents about financial benefits

Many families suffer a drop in income following the death of their baby (Sands 2009). In addition, perinatal deaths disproportionately affect parents in the poorer socio-economic groups (CEMACH/CEMACE 2007: 35)

"Trusts, Health Boards and managers should ensure that advice is offered to parents who have lost a baby, especially those on low incomes, about benefits and payments to which they may be entitled. Procedures should be in place to cancel the Bounty Pack for bereaved parents, but to ensure that parents of babies who die neonatally receive a Child Benefit claim form." (Sands 2007: 224)

- In only 35% of units, all or most parents are given written information about their entitlement to time off work, benefits and payments.
- In 56% of units no parents are given this information.

Parents of babies who die at any time after birth are entitled to claim eight weeks Child Benefit.

- However, 69% of units do not give a Child Benefit Claim form to these parents. Most parents whose baby dies after birth are therefore extremely unlikely to know that they are entitled to Child Benefit or to claim it.

4.14 The place of care for postnatal check-ups

"Many parents find it very distressing to come back to the unit where their baby died for their postnatal check-up. Their distress is made worse if they have to share a waiting room with other mothers with healthy babies. Alternative arrangements are essential to avoid causing these parents unnecessary additional distress." (Sands 2007: 208)

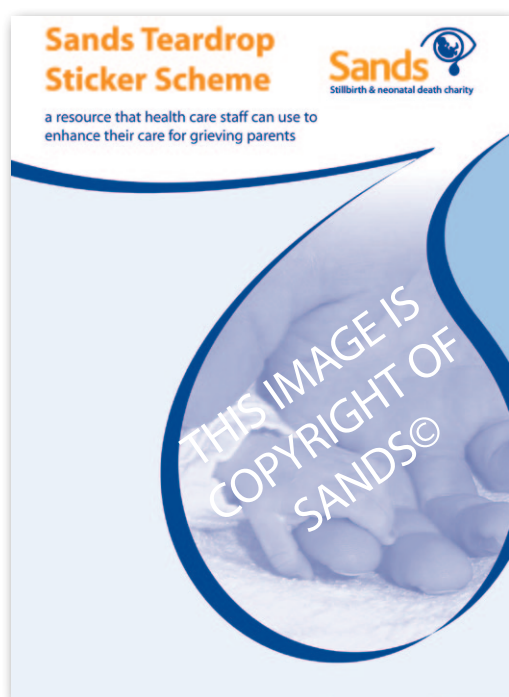
- 71% of mothers come back to the same maternity unit for their postnatal check-ups.
- Of these mothers, 15% have to wait in a room with other mothers and their babies.

4.15 Subsequent pregnancies

"Every pregnancy after the death of a baby is likely to be highly stressful. Most parents welcome extra support, additional check-ups, and frequent opportunities to talk to empathetic health care staff. It is important that staff understand parents' fears and avoid making them feel that they are over-reacting." (Sands 2007: 213)

"I was fortunate in that the midwife who ran the baby loss support group I attended was with me throughout the pregnancy, the time in hospital and was there waiting in the delivery suite when I came out of theatre with my second son. She and another Mum who had lost a child were the only people who understood my fear of another loss. Others just got angry." Mother

- In 87% of units staff offer all mothers extra support and monitoring in a subsequent pregnancy.
- In 13% of units, extra support and monitoring are not offered in a subsequent pregnancy.
- In 65% of units staff ask mothers for consent to mark their notes in a subsequent pregnancy with a Sands teardrop sticker (or equivalent). (See P27 for more details.)
- In 73% of units staff offer all mothers extra support and monitoring after the birth of another baby.
- In 27% of units, extra support and monitoring are not offered after the birth of another baby.



Sands Teardrop Sticker Scheme leaflet



Example of Sands Teardrop sticker

4.16 Communication and language support

Leaflets, certificates and written materials

"The leaflets, certificates and other written materials that bereaved parents receive should be easy to understand, free of specific religious symbols and attractively produced. They should also be produced in the main languages spoken locally." (Sands 2007: 48)

Bereaved parents receive a number of leaflets, certificates etc:

- In 97% of units, all or most of these are easy to understand.
- In 90% of units, they are all free of specific religious symbols.
- In 91% of units, they are attractively produced.

However, respondents in over a quarter of units commented that they would like to provide better written information for bereaved parents.

"Information should be available in different languages with particular cultural beliefs or sensitivities appropriately reflected." (RCOG 2008b: 20.3)

When asked about leaflets in minority languages, 23% of units said that there are very few non-English speakers in their area.

In the remaining units:

- In 41% of units, all or most leaflets, certificates etc that may be given to parents are in the main minority languages spoken locally.
- However, in 41% of units, no leaflets, certificates etc are in these languages.

Several respondents commented that they needed written information in other languages.

Communication across language barriers

Black and minority ethnic women in most communities have higher rates of stillbirth and neonatal death than white women. Social deprivation also increases the risk of perinatal mortality (CEMACH/CEMACE 2007: 33-36). Mothers who speak little or no English – who generally fall into both these groups – are therefore at increased risk of late miscarriage, stillbirth and neonatal death.

Interpreters

"All Trusts and Health Boards should employ trained, professional interpreters to translate for the main groups in their area whose mother tongue is not English. For other minority language speakers, they should organise access to interpreters through outside agencies, or use telephone interpreting services if the discussion is fairly straightforward." (Sands 2007: 52)

"Proficiency in English should not be a requirement for access to maternity care." Midwife

When parents speak little or no English, units use trained interpreters:

Usually	67% of units
Sometimes	19% of units
Never	14% of units

Note: These figures exclude the 10% of units that reported very few non-English speakers in their area.

Telephone interpreting services

"Telephone interpreters can be useful for emergency and out-of-hours interpreting, if there is no trained interpreter available. But communicating via an interpreter over a three-way telephone line is unlikely to be suitable for communicating with parents whose baby has died." (Sands 2007: 60)

When parents speak little or no English, telephone interpreters are used:

	Units with significant numbers of non-English speakers	Units with very few non-English speakers
Usually	in 14% of units	in 44% of units
Only in emergencies	in 22% of units	in 34% of units
Only out of hours and in emergencies	in 15% of units	in 11% of units
Never	in 49% of units	in 11% of units

Using fathers and other relatives to interpret

"When a father speaks better English than his partner, staff often use him to interpret. However, he is likely to find it extremely difficult to interpret properly while coping with the distress and shock of his own loss. He may also want to protect the baby's mother from distressing information and decisions. Using the father to interpret also raises serious issues of confidentiality and of valid consent. Couples should always be offered the help of a trained interpreter, even if one parent speaks English." (Sands 2007: 60)

	Use fathers to interpret	Use other relatives to interpret
Usually	in 38% of units	in 19% of units
Only in emergencies	in 48% of units	in 49% of units
Never	in 4% of units	in 13% of units

Using children to interpret

"Except in extreme emergencies, it is never acceptable to use a child or a teenager to interpret for parents who are experiencing a perinatal loss. The long-term consequences of doing so, for both the young person and the family, can be extremely damaging." (Sands 2007: 61)

- 60% of units never use children to interpret.
- 27% only use children in emergencies.
- 5% of units usually use children to interpret. This is completely unacceptable.

	All or most	Some	None	Don't know
Have doctors had training in communicating with people who speak little or no English?	in 19% of units	in 22% of units	in 14% of units	in 44% of units
Have doctors had training in working with interpreters?	in 7% of units	in 19% of units	in 12% of units	in 47% of units

Training for midwives in working across language barriers

"Trusts, Health Boards and managers should ensure that all staff who communicate with parents and families who speak little or no English have training in how to communicate better across a language barrier, and in how to work with interpreters." (Sands 2007: 225)

- In 31% of units, all or most midwives have had training in communicating with people who speak little or no English.
- However, in 35% of units no midwives have had any such training.
- In 43% of units, all or most midwives have had training in working with interpreters.
- However, in 32% of units no midwives have had any such training.

Training for doctors in working across language barriers

We believe that most if not all of the questionnaires were completed by midwives: just under half the respondents answered 'Don't know' to the next two questions about training for doctors. (See table below)

Parents with disabilities

Parents with hearing impairments

"The provision of...signers for people who are deaf or hard of hearing, is an essential part of safe and effective care. Although it is not possible to ensure that...signers for the deaf are always available, Trusts, Health Boards and managers should provide the best and most comprehensive service possible." (Sands 2007: 225)

- 24% of units have access in normal working hours and out of hours.
- However, 38% of units only have access to signers in normal working hours.
- 38% of units do not have any access to signers.

Signers are only useful if staff know how to contact them and how to work with them. Of those units that have access to signers:

- In 65% of units, all or most staff know how to contact signers.
- However, in 8% of units no staff know how to contact them.
- In 6% of units, all or most midwives have had training in working with signers.
- However, in 48% of units, no midwives have had this training.
- In 19% of units, some doctors have had training in working with signers.
- However, in 8% of units no doctors have had this training. (73% of units answered 'Don't know' to the question about doctors.)

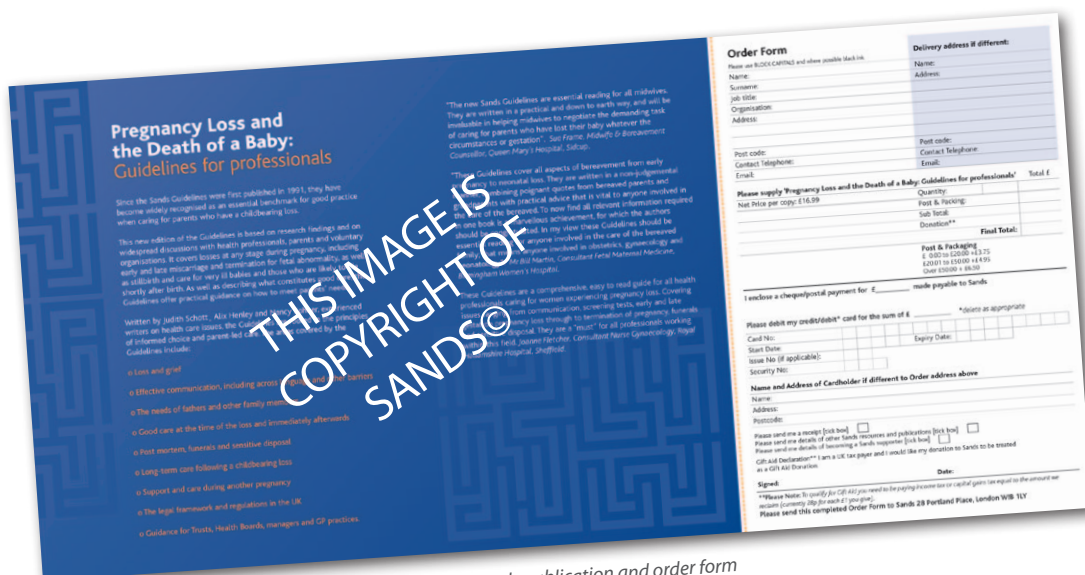
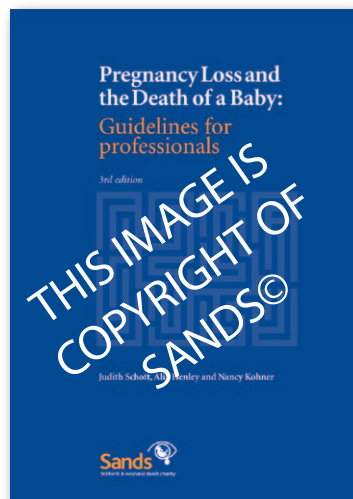
Parents who have a visual impairment

"The Disability Discrimination Act (1995 amended 2005) gives people with disabilities the right to equal access to all areas of life. Organisations that provide goods, facilities and services to the public, such as health care providers, have "a duty to make reasonable adjustments" to ensure that people with disabilities can benefit from services in the same way as those who are able-bodied." (Sands 2007: 62)

- 82% of units have no information in formats suitable for parents with a visual impairment.
- 92% of units do not provide any audio-material for these parents.

Parents with learning disabilities

86% of units have no information in formats suitable for parents with learning disabilities.



Sands Guidelines for professionals publication and order form

4.17 Sands and other parent support groups

“Central to the whole process of designing and implementing policies, and of reviewing current practice, should be the people for whom the services exist. Trusts, Health Boards and managers should find out the views and experiences of bereaved parents via organisations such as Sands, ARC, the Miscarriage Association, the Multiple Births Foundation and the TAMBA Bereavement Support Group, as well as through discussions with individual parents. They should also make special efforts to access the views of bereaved parents of minority cultures and faith groups, because these may not be represented by local voluntary groups.” (Sands 2007: 223)

65% of units that responded have one or more Sands groups in their catchment area.

Of those units with one or more Sands groups in their catchment area:

- In 76% of units, at least one staff member has regular contact with local Sands group(s) to find out how care for bereaved parents can be improved.
- When a baby dies, parents in all units receive written and/or verbal information about the Sands telephone Helpline.
- When a baby dies, parents in all but two units receive written and/or verbal information about other national groups as appropriate.

4.18 What maternity units most want to improve

To conclude the survey Sands asked respondents to list the things that they would most like to improve in their units.

It is extremely encouraging and heartening to see that staff are aware of what would really make a difference to the parents they care for, and are highly motivated to improve the service that their unit offers.

However most of these improvements have resource implications. They cannot be made by the staff who actually deliver care but must be implemented by managers or requested by service commissioners.

The most frequently mentioned improvements were:

- A separate, dedicated suite or facilities for parents both during labour and afterwards.
- One or more bereavement support midwives (or equivalent).
- Bereavement support training for doctors, especially junior doctors. Also more multidisciplinary training.
- Better written information for parents, including information in other languages.
- Continuity of carer during labour and after the birth.
- Better communication between the different staff involved in care, including better, more streamlined documentation.



References

Baby Mailing Preference Service

www.mpsonline.org.uk email babymyps@dma.org.uk
DMA House 70 Margaret St London W1W 8SS

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Schott J, Henley A and Kohner N (2007) *Pregnancy Loss and the Death of a Baby: Guidelines for professionals* Sands, London

To order: www.uk-sands.org/Shop/Shop-Home/Health-Professional-resources.html

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Available from Helen Sheldon at helen.sheldon@pickereurope.ac.uk

Resources available from Sands

Resources mentioned in the report that are available from Sands

The sample forms mentioned in this report can be downloaded from the Sands website: Go to www.uk-sands.org > **Improving Care** > **Resources for health professionals** > **Forms and certificates**

Form 1: To give to parents who take their baby's body out of the hospital

Form 7: Creating Memories - Offering Choices: for recording discussions with parents and decisions

Teardrop stickers Sheets of stickers are available from the Sands online shop. Go to www.uk-sands.org > **Shop** > **Health professional resources**

Always Loved Never Forgotten Memory Boxes are available from the Sands online shop. Go to www.uk-sands.org > **Shop** > **Health professional resources**

Sands publishes a series of support leaflets. These can be ordered by post, phone or from the Sands online shop. Go to www.uk-sands.org > **Shop** > **Support leaflets & literature**

- About the other children
- Another pregnancy – for parents whose baby has died
- Arranging a funeral for your baby
- For family and friends: how you can help
- Information for employers
- Long ago bereaved
- Mainly for fathers
- Returning to work after the death of your baby
- Saying goodbye to your baby
- Sexual relationships after the death of a baby
- Support for you
- The loss of your grandchild
- When a baby dies before labour begins

Sands website – information for professionals

The Sands website includes pages for health professionals. These contain updates and information and resources to download. Go to www.uk-sands.org > **Improving Care**

Sands training for professionals

Sands offers two training formats for health professionals:

- A half-day presentation that can be given to any size audience. This format is extremely popular as it can reach a large audience and does not take staff away from their workplace for too long. Topics covered include: the main principles of the Sands Guidelines, including care in hospital, ongoing care and the support needs of staff; the work of Sands at a national and local level; and an insight into a bereaved parent's personal experience.
- A full-day workshop that is fully experiential. This is suitable for a group of between 12 and 24 health professionals. Participants have opportunities to: extend their awareness of the range of childbearing losses; reflect on ways of managing stressful situations; develop their communication skills; enhance their awareness of parents' needs; and increase their ability to respond flexibly to the needs of individual parents.

For more information about Sands training for professionals please contact **Sue Hale**, call **0845 6520 443** or email sue.hale@uk-sands.org

Sands and the Bereavement Care Network

Sands, the Royal College of Midwives, Bliss and the National Maternity Support Foundation have set up an online network for staff involved in perinatal bereavement care. The network offers members an opportunity to share good practice and procedures, exchange ideas and provide informal support. It is also a way for the RCM, Sands and Bliss to keep network members informed about relevant information, developments and resources. It will not be used for any other purpose.

To apply, please go to:
<http://bereavement-network.rcm.org.uk/login/>

About Sands



Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Since that time we have supported many thousands of families whose babies have died, offering emotional support, comfort and practical help.

Sands today operates throughout the UK and focuses on three main areas of work:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- Helpline for parents, families, carers and health professionals
- UK-wide network of support Groups with trained befrienders
- Online forum and message boards enabling bereaved families to connect with others
- Website and a wide range of leaflets, books and other resources.

We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care

We undertake a comprehensive programme of training, workshops and talks for health professionals based on the Sands Guidelines which give practical guidance on how to meet parents' needs and provide good care.

We promote and fund research that could help to reduce the loss of babies' lives

In spite of medical advances, the shocking reality is that each day in the UK there are ten babies who are stillborn and seven who die within the first 28 days of life. Through our Why17? campaign, we are raising vital funds for research, while challenging the Government to address these individual tragedies as a matter of urgency and priority.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

If you would like any further information or support please contact us or visit our website.

Support: **020 7436 5881** **helpline@uk-sands.org**

Enquiries: **020 7436 7940** **info@uk-sands.org**

Website: **www.uk-sands.org** **www.why17.org**

Write to us: **Sands, 28 Portland Place, London W1B 1LY**