

Saving Babies' Lives Report 2009



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Sarah and Martin Speake
with their daughter Amélie
shortly before she died on
March 17th 2005

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Together we *can* make a difference.

Saving Babies' Lives Report 2009

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Peter Tan with his son Jeremy Tan
Ming Ken who was stillborn
February 12th 2005

Foreword

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.

Over the past 30 years Sands has supported many thousands of families whose babies have died, offering emotional support, comfort and practical help. Working in partnership with health professionals and service providers, we have transformed the culture and practice of bereavement care in the UK. Gone are the days when stillborn babies were delivered and then whisked away before their parents could see them, in what became known as 'the rugby pass'.

Our *Guidelines for Professionals* is the reference text for best practice when a baby dies. Increasingly Sands is recognised as an international leader in the bereavement field, and we have been invited to the Far East, Australia, Africa and Europe to share our model of working.

Every parent whose baby has died wants to know why it happened, and what can be done to stop other parents experiencing the same heartache. Over the years we have heard a growing number of stories from parents, and more and more information from health professionals, which strongly point to the fact that many perinatal deaths are avoidable.

Bereavement support is at the core of everything that Sands does. But we want to do more to ensure that there are fewer bereaved parents to support.

Over the last five years, we have invested substantially in developing our connections with leading individual researchers and organisations to facilitate a greater exchange of information to improve our understanding of stillbirth and neonatal death.

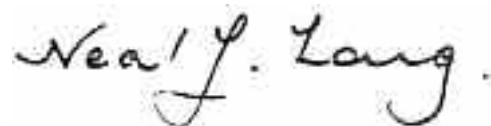
In 2008 we launched our **Why17?** campaign which asks a simple question. Why, in spite of medical advances, do 17 babies die every day in the UK?

In some cases we simply do not know enough yet to be able to say why a baby has died. Which is why Sands is raising £6 million through the campaign to fund the research that is needed.

But increasingly, Sands believes that many of those deaths are potentially avoidable.

Our report *Saving Babies' Lives* which we are presenting today, highlights why we believe that in many cases the devastating impact of the death of a baby on the parents, their families and friends could be prevented.

The overriding message from Sands and the thousands of parents who are supporting the **Why17?** campaign is that the deaths of 17 babies a day in the UK is totally unacceptable. What we want to see is a clear acknowledgement of the seriousness and extent of the problem and a real, collaborative commitment to address these individual tragedies as a matter of urgency and priority.



Neal Long
Chief Executive,
Sands

Summary of key messages

- 1 The death of a baby before or soon after birth has a devastating and long-lasting impact on the families left behind. A stillbirth or neonatal death should be recognised as being no less significant than any other death.
- 2 In the UK, one baby in every 200 is stillborn and one baby in every 300 dies within four weeks of birth. 6,500 babies died in 2006. This level of death is unacceptable.
- 3 Stillbirth rates have remained the same for the last ten years. Stillbirths are ten times more common than cot deaths.
- 4 We need to break the taboo surrounding the death of a baby and raise awareness of this ignored problem. With increased funding for research and real improvements in clinical care, a significant number of babies' deaths could be prevented.
- 5 In 50% of stillbirths the baby is normally formed and dies apparently for no reason; the majority of these deaths are in 'low-risk' pregnancies. We need antenatal screening which effectively identifies pregnancies at risk of stillbirth, so they can be given the extra care they need. Fetal growth restriction and reduced fetal movements are associated with stillbirth, and we need better methods to use these indicators to identify poor fetal wellbeing.
- 6 Suboptimal antenatal care plays a role in many stillbirths. Maternity services are under-resourced, leading to shortages of staff and equipment. The safety of babies is suffering as an overstretched service is failing to ensure all babies have the personalised and safe care they need during pregnancy and labour.
- 7 Sick and vulnerable babies are not getting the one-to-one care they deserve in neonatal units. Units are understaffed and overstretched. Strategic Health Authorities must ensure their Primary Care Trusts have the necessary resources to draw up action plans to tackle the drastic shortage in neonatal nurses.
- 8 A serious lack of direct funding for scientific research to understand and prevent stillbirths is holding back progress that could be made in reducing the numbers of deaths.
- 9 Data collection on pregnancies is limited in the UK, the exception being in Scotland. We need nationally collated, detailed and standardised data about all pregnancies and outcomes on which to base research.
- 10 Perinatal post mortems can provide valuable information for parents about why their baby died, and contribute to research. But the uptake of post mortems has fallen to 40%. Parental consent to post mortem is discouraged when there are long delays in getting results and babies have to be transported across the country, due to severe shortage of specialist pathologists. We need to double the number of perinatal pathologists if we are to meet even current low rates of post mortem uptake.
- 11 By working together, informed parents and well-trained health professionals can collaborate to identify the risks of stillbirth and neonatal deaths, reduce those risks, and act effectively to avoid harm. Parents are powerful advocates for change to save babies' lives.

Sands would like to see

- Prioritisation of stillbirth and neonatal deaths at a national level as a major health issue.
- Funding for stillbirth research - a minimum of £3 million to match the £3 million Sands will invest over five years.
- A national research strategy, bringing together all interested parties, to reduce the numbers of babies dying.
- Resources directed at improving antenatal care, with the safety of babies prioritised in plans to raise standards.
- Action to fill gaps in the knowledge and evidence needed to guide effective antenatal detection of babies at risk of stillbirth.
- Neonatal care commissioned in complete compliance with British Association of Perinatal Medicine 2001 standards.
- Standardised data collected on all pregnancies, including information about the mother, baby and care in pregnancy and labour.
- Comprehensive review of every stillbirth and neonatal death, which fully incorporates the parental perspective of care.
- High-standard perinatal pathology services across all regions, so that all parents have access to perinatal pathologists.
- Public health messaging about the risks of stillbirth so prospective parents can make informed choices about their own pregnancy.

When a baby dies

The personal perspective on the death of a baby

This report aims to focus attention for the first time on the hidden tragedy of babies' deaths in the UK. Every day 17 babies die before or shortly after their birth.

To anyone who has not experienced a baby's death it can be all too easy to underestimate the significance of this event. But the death of a baby, whether before their birth or in the days immediately afterwards, is no less a death than the death of any other child. A child who dies very early in their life is no less loved and cherished.

But while the grief and pain for the parents and family is no less intense and enduring, the death of a baby is different to any other bereavement. When a baby dies before he or she has lived for long, or at all, outside the womb, parents are left with a terrible sense of emptiness. There is no object for their love and care. It means the end of hopes and plans and the loss of a future. Couples whose first baby dies lose their identity as parents;

those with children lose a new family member. It is hard to overstate the levels of trauma and devastation bereaved families experience.

But all too often these feelings go unrecognised by the wider community. Despite better understanding of the significance of a baby's death among health professionals, it is still considered taboo in some way beyond the doors of the hospital – the death that no one likes to mention. Families often suffer in silence without understanding or adequate support.

If we undervalue the level of damage which follows a baby's death, we leave bereaved families isolated, with their grief unacknowledged. Worse, the problem remains hidden, with little incentive to act to prevent these deaths.

To paint a picture of just what it really means when a baby dies, this report starts with the powerful words of parents.

**Peter, Lynn and Travis Brady
with Jude who was stillborn on
June 16th 2006**



What parents say

"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."

"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."

"My life has changed completely. I am functioning, I'm not depressed, I work, I have a wonderful husband and lovely family, I am even happy again but I will never, ever, be the same person again. I miss my baby every second of every day and even though the pain will ease and the hurt will fade I will always, for the rest of my life, not have my baby."

"We have been devastated by losing our baby. It has caused us to have no faith in what we used to take for granted. We understand a pain so deep and raw and senseless now."

"It has devastated us. Our baby was an IVF baby, conceived after three attempts. I am tearful at all times, resentful and jealous of those with babies and children. I get hurt when people say things without thinking and I blame myself for my baby dying."

"My son, who was 4 at the time, still has nightmares nearly three years on."

"I cannot really find the words to describe the deep impact that the death of my daughter, Louise, 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."

"It affected everything from that day on. I changed my job as I couldn't face going back to the same job. We are lucky to have gone on to have two other children, who are an absolute blessing. The loss of Thomas will never leave us though and I am often caught out and reduced to tears by a memory, song, even smell, over six years on. The dawning realisation that the pain never goes away is hard to live with. The pain lessens but it is always there, lurking just below the surface."

"It's taken the smile out of us. My older son has missed out on so much love from me because I have been neck deep in fighting this for four years. It's changed my personality, it's rocked my faith. I cope with life now whereas before I lived it to the fullest."

"It has left a huge space in our lives that we cannot fill. It feels like an isolated and private grief, as it was only us that knew him and feels like it's only us that miss him. It feels like we can't talk about what happened, or him, or say his name as nobody wants us to."

Introduction

Mistaken beliefs

“Pregnancy has always been risky, babies have always died.”

Better maternity care has improved mortality rates for babies and mums. But, while all other mortality rates have dropped, the stillbirth rate hasn't changed significantly for ten years.

“A baby doesn't really count because you didn't get to know it.”

For the parents, their baby is every bit as real and loved as any other child. It is precisely the realisation of this love, and that parenting begins well before birth, that makes the death so hard to bear.

“Never mind. You can always have another one.”

A subsequent child brings joy of course, but does not replace or compensate for the child that is not there. For some couples, having another baby is not a possibility.

“It's just one of those things.”

No it isn't. Many babies die because their failure to thrive was not spotted, or the right action was not taken. With better care and more research, deaths could potentially be avoided.

“Nothing can be done.”

We hope this report will show that action can and must be taken to save babies' lives.

Numbers

Every year around 6,500 babies die before or shortly after their birth; that is one baby every hour and a half, or the equivalent of 16 jumbo jets crashing every year. 4,000 babies are stillborn and another 2,500 die within a month of their birth.

These are not rare events. One baby in every 200 is stillborn. One baby in every 300 dies in the first four weeks of life, the majority within the first few days.

Many people have experienced the devastating death of their baby. If we ask our immediate friends and colleagues, almost all of us discover we personally know someone who has had a stillbirth or whose baby has died shortly after they were born. But these individual tragedies are invariably hidden. The death of a baby is an uncomfortable subject which people prefer to avoid, but that doesn't mean it isn't a serious and urgent problem.

Compare the mortality figures to other causes of death: road traffic accidents kill around 3,000 each year, and we are horrified and want something done. Yet there are twice as many babies dying and the situation is unnoticed.

Preventable

Shockingly, a significant number of these deaths may be avoidable. The perception that stillbirths and early baby deaths are sad but inevitable events, that these babies were somehow 'meant to die', is far from the truth. Although there are certainly cases of stillbirth where nothing could have been done, there is an increasing body of evidence and opinion that many of those lives could be saved.

In the UK a combination of problems means we fail to identify many babies who are at risk, and to ensure their best possible chance of life:

- We lack knowledge, data and research into why babies die.
- We have no reliable way to predict which pregnancies are at risk of stillbirth or death early in life.
- There is little awareness of the extent of the problem or what the risks are.
- We don't have the resources in maternity care to ensure optimal care for every baby.

Above all there is no political will to make things change.

The costs

The death of a baby at birth is a tragedy. Parents are left devastated, their lives changed forever. The trauma of losing their baby damages physical and mental health, relationships, careers and incomes.

In our survey of parents, 81% said they suffered depression after the death of their baby. 39% said it affected their physical health, and 25% said they lost earnings because they had to change jobs or career⁽¹⁾.

The ripples of such damage have far-reaching consequences.

A stillbirth in the family has repercussions for siblings who suffer from the dented family dynamics and the difficulties their parents experience. Grandparents, wider family and friends are often profoundly affected too. 33% of our parents said their marriages or relationships suffered as a result of the death of their baby; 80% said it had an emotional impact on the wider family.

There is invariably an impact on doctors and midwives and any other service providers who have been involved. Some may feel they have failed in their professional role, or may simply be deeply distressed by being part of such a tragic event.

Meanwhile funding which could be going into research or resourcing better maternity care is being used to settle litigation claims.

Why are these deaths ignored?

It is hard to draw resources and attention to stillbirths and neonatal deaths if they are perceived to be 'just one of those things'. There is alarmingly poor awareness at all levels of the actual numbers, impact and costs of these deaths.

- **Society** - in our survey of the general public 75% of people were very surprised by the numbers of babies dying. They were more concerned about Down's Syndrome and cot deaths than stillbirths, which are much more common.
- **Prospective parents** – parents are not aware of risk factors and don't know what level of care they should expect, or when they should raise concerns.

- **Health care provision** – the risk of baby death is underplayed, with a lack of focus on strategies for prevention.
- **Funders** – there are many competing demands for health care resourcing and research funds. Stillbirth, which is politically unfashionable, is ignored as a priority.

A cohesive approach

There is no co-ordinated focus on reducing perinatal death.

All the relevant disciplines, including clinicians, researchers, service providers, funders, regulators and parents, have a stake in how to reduce the numbers of deaths, with their own professional and personal perspectives on where the problems lie and what the solutions are. But we need a co-ordinated approach to the issues where all the elements are drawn together into a cohesive strategy.

Action now

To the parents whose baby has died, the messages in this report could not be more important and more urgent. Behind the statistics are real, loved and desperately missed babies.

We believe it is unacceptable to be complacent about each of these babies. We are calling for the political will to prioritise the lives of babies as an urgent health issue.

We believe it is unacceptable to be complacent about each of these babies.

Stillbirths

In the UK one baby in every 200 is stillborn. That makes a stillbirth ten times more likely than a cot death. Stillbirth rates have remained unchanged for the last ten years, even rising between 2002-2005. In contrast, infant mortality has improved and rates of cot death have dropped dramatically over the last two decades.

Despite reports from as far back as the mid 90s that these deaths in pregnancy could potentially be reduced, stillbirths have remained comparatively neglected.

Causes

In the UK by far the largest proportion of stillbirths - 50% to 60% - are classified as 'unexplained' where no cause of death is found. After this the most common causes of stillbirth are: placental problems, congenital abnormalities, intrapartum causes, maternal disorders, pre-eclampsia, and infection⁽²⁾.

Who is at risk?

The average risk of stillbirth is 1:200. But the risk in an individual pregnancy is increased when the mother belongs to a group at higher risk of

stillbirth. Any combination of a number of risk factors multiplies the risk even further. For example, a mother who is over 40 years old, experiencing her first pregnancy, where the baby is over 37 weeks gestation has a risk of stillbirth closer to 1:120⁽³⁾.

Compare this to risks of Down's Syndrome. In the Department of Health's *Pregnancy Book*, a Down's Syndrome risk of 1:250 is described as 'high-risk'⁽⁴⁾. We would like stillbirth to receive at least the same attention as Down's and cot deaths.

Risk factors such as obesity, age, ethnicity, obstetric history and maternal disorders must be taken into account when deciding what kind of antenatal care each pregnant woman should have. This has to be continually assessed and adapted, if it needs to be, throughout the pregnancy. At Sands we hear many tragic personal stories from parents where this continues not to happen.

Health professionals caring for pregnant women need to be more aware that stillbirth is a real risk, and they should all know what factors increase that risk for an individual mother. Safety and risk awareness should be a more important part of professional training for all obstetric staff.

Mother's age:

- Advanced maternal age increases the risk of stillbirth. Women over 40 are around twice as likely to have a stillborn baby, and are more likely to have a stillbirth than a baby with Down's Syndrome.
- Teenage mums are also at an increased risk of stillbirth.

Mother's health:

- Obesity: a quarter of mothers whose babies are stillborn have BMIs over 30.
- Some medical disorders are associated with a greatly increased risk of stillbirth. These include diabetes, hypertensive disorders, lupus, thyroid problems, infections and renal disorders.
- Smoking is a significant risk factor for stillbirth, with rates around double those for non-smokers.

Ethnicity:

- Stillbirth rates amongst women from black or Asian ethnic groups in the UK are higher than amongst white women.

Social factors:

- Stillbirths increase in areas of social deprivation; rates are 1.7 times higher in lower social groups.

Pregnancy:

- Nulliparity: 40% of stillbirths happen in a first pregnancy.
- Multiplicity: the risk of stillbirth is approximately 3 times higher for multiple pregnancies compared to singleton pregnancies.
- A previous stillbirth, previous growth restricted infant and previous obstetric complication are all associated with increased risk of a subsequent stillbirth.
- Small baby: growth restriction is associated with adverse outcome, at any gestation.
- Post term: risks of stillbirth are higher after 41 weeks of pregnancy.



Carolyn and Grev Bray with their daughter Rebecca who was stillborn on June 4th 2002

Detection of at-risk babies

Most pregnancies are straightforward and antenatal care strives to de-medicalise a natural process. While this approach may be right for pregnancies in which all goes well, pregnancies at risk of stillbirth are still being missed because the current system often fails to detect and manage problems.

National Institute of Clinical Excellence (NICE) antenatal care guidelines⁽⁵⁾ highlight conditions in pregnancy that require extra clinical care. When a high-risk pregnancy is flagged the likelihood of a baby dying in pregnancy is low. In fact the risk of stillbirth is higher in low-risk pregnancies: low-risk has become the new high-risk.

With 4,000 stillbirths a year, we need to build into routine antenatal care a much greater awareness that stillbirths can be reduced if at-risk pregnancies are recognised early on and given the right care.

*"I have seen huge strides in the care of **high-risk mums with high-risk babies**, and **high-risk mums with low-risk babies** are easy to care for. And **low-risk mums with low-risk babies** are VERY easy to care for. But the real problem is **low-risk mums with HIGH-risk babies** that are not being identified before their demise."*

Professor Jim Dornan, Head of Fetal Medicine Department, Queens University, Belfast

Unexplained stillbirths

An 'unexplained stillbirth' is when an apparently healthy, normally formed baby dies for no clear reason. You might call it 'a cot death in the womb'. Half of stillbirths in the UK are classified as unexplained, suggesting that these deaths are a mystery. But unexplained does not mean these deaths are inevitable.

The Confidential Enquiry into Stillbirth and Deaths in Infancy (CESDI) reports during the 90s found that the largest area for improving perinatal mortality was unexplained antepartum stillbirth⁽⁶⁾⁽⁷⁾. If these otherwise healthy babies can be identified before they die, there is potential to save their lives.

But the majority of unexplained stillbirths occur in low-risk pregnancies, suggesting that routine antenatal monitoring is failing to pick up these babies who are in fact at risk.

At present the only intervention for an unborn baby who is not thriving is early delivery. For clinicians making decisions about a pregnancy, this means having to balance the risk of stillbirth and the risks of prematurity for the baby. However, many unexplained stillbirths occur at gestations when the risks of early delivery are lowest.

“The risk is that ‘unexplained’ may be regarded as synonymous with ‘unavoidable’, which could lead to the complacent conclusion that little can be done about them.”

Professor Jason Gardosi, Director of the Perinatal Institute, British Medical Journal, October 2005

Screening for at-risk pregnancies

At present there is no effective screening test for pregnancies at risk of unexplained stillbirth. It is possible that biochemical indicators of placental function early in pregnancy might lead to a simple blood test for stillbirth, similar to screening tests for Down’s Syndrome⁽⁸⁾. If at-risk pregnancies could be accurately identified early in pregnancy, care could be better targeted at those who really need it. Babies at risk of term stillbirth could be scheduled for routine early delivery, while minimising the number of interventions in pregnancies which are not at risk.

Growth restriction

A baby is considered small for their gestational age if they are below the 10th centile of growth. Stillbirth is associated with poor growth in the baby in around half of all deaths, and in two-thirds of unexplained stillbirths⁽²⁾. The Perinatal Institute in Birmingham estimates that a baby who is smaller than he or she should be is 5 to 11 times more likely to die⁽⁹⁾.

Poor growth can indicate that something may be wrong, but current standard antenatal tests are identifying as few as 15% to 30% of babies who are small⁽⁹⁾.

Work in the Perinatal Institute, Birmingham, suggests that changes in antenatal care could prevent more than half of stillbirths with growth-restricted babies. Their protocols for measuring growth and referring babies for further investigation have been adopted by hospitals in the West Midlands, with hopeful signs of a reduction in perinatal mortality.

Routine antenatal screening for growth using fundal height measurements and ultrasound varies in different maternity units around the country. There is still insufficient evidence on which to base national guidelines for monitoring growth, or protocols for referring babies to extra care. We need more research to maximise the effectiveness of these screening tools in identifying small babies.

The latest NICE antenatal guidelines call for further research saying: *“Poor fetal growth is undoubtedly a cause of serious perinatal mortality... Unfortunately, the methods by which the condition can be identified antenatally are poorly developed or not tested by rigorous methodology. However, existing evidence suggests that there may be ways in which babies at-risk can be identified and appropriately managed to improve outcome, and this should form the basis of the study.”*⁽⁵⁾

“The eighth CESDI report found that 45% of all stillbirths were associated with suboptimal care, including failure to recognise the ‘high-risk’ woman at booking, and the report recommended better screening for intra-uterine growth restriction (IUGR)...Despite this, screening for IUGR has not changed.”

Professor James Drife, Expert Reviews, Obstetrics and Gynaecology, 2008

Fetal movement

A decrease in fetal movement is associated with poor growth and with antepartum stillbirth. But because of a lack of evidence, current guidelines advise against routine counting of fetal movement, or ‘kick counting’.

Recent studies are trying to change this view. Large numbers of bereaved parents report that they were concerned about their baby’s movements prior to their baby’s death but they waited 24 hours before contacting their midwife, not realising it might indicate something was seriously wrong⁽¹⁰⁾⁽¹¹⁾. Mothers can be very ‘tuned-into’ their baby’s patterns of behaviour (75% of our surveyed mothers said they felt their baby’s movements slow down or change hours or days before they died) and this opportunity for monitoring should not be ignored.

There are no national guidelines for responding to reported decreased fetal movement, with every maternity unit drawing up their own protocols. Monitoring with cardiotocographs (CTGs, or heart monitors) as a response may actually give dangerous false reassurance.

More research is urgently needed to develop effective tools to manage reported reductions in fetal movement.

Quality of care

The serious problems of safety in maternity care in the UK are well documented, with a series of recent reports highlighting the poor standards of care which result from staff shortages and poor management^{(12) (13) (14)}. Stillbirth is often a low priority in discussions of maternity standards, or not mentioned at all. But suboptimal care, driven by poor resourcing, is estimated to contribute to adverse outcome in around 40% of unexplained stillbirths⁽⁷⁾.

- Understaffed midwifery units means continuity of antenatal care – which is known to improve pregnancy outcome – is often not possible. 42% of parents in our survey said they had not had time to develop a positive relationship with their midwives, and 44% felt their midwife was not familiar with their notes.
- Parents feel rushed through antenatal appointments where they feel unable to raise issues of concern. 64% of our parents had this experience.
- There are shortages of trained ultrasound staff and ultrasound equipment, which means some high-risk pregnancies are not being properly screened.
- Inappropriate grades of staff are involved in care. Sands parents report being looked after by student midwives without the experience to give the necessary care.
- There is a shortage of consultants available to give expert care when required.
- Communication failures between staff and between different departments, lead to loss of vital information and delays in responding to high-risk situations.
- Overstretched units cannot release staff or cannot afford to fund training for midwives to update their knowledge and skills.

Standards of care and resourcing vary around the country. But all parents should feel they can rely on their local services to offer the safest care for their baby. We need the right resources, in the right place, at the right time. When a service is under pressure, errors happen, and babies die as a result. This is unacceptable.

Listening to mothers

In our survey parents repeatedly emphasised that the mother's views and instincts about her baby's welfare should be listened to. 45% of parents who had an antepartum stillbirth felt something was wrong prior to any medical diagnosis of a problem. Too many women reported being told that their fears for their pregnancy were

unfounded and were sent home, only for their baby to die soon afterwards. When asked what they would like to see change in the way pregnancies are managed, many parents said they'd like to see a change in the whole culture of antenatal care, to be more collaborative.

"Treat every woman as an individual and not as if we are on a conveyor belt. Take time to listen and hear the concerns that women have and not to dismiss us. We were told that if we had been monitored more closely our son would be with us. I think this says it all."

"Take pregnant mothers more seriously rather than telling them they worry too much."

"I would like them to concentrate less on normal procedure and more on individual care."

"Listen to parents, really take into account that each woman knows her own body and is not trying to question anyone's judgement but needs her concerns heard. I was completely powerless and even begging (for early delivery) did not work. It is that lack of voice and right to be heard that makes a preventable loss so filled with extraordinary anger as well as sadness."

Monday, 17 babies

JUDE BRADY
DANIELLE GUY
REBECCA BRAY
LESLEY KATHRYN CURRIE
JON ALEXANDER CURRIE
THOMAS DUFF
MATTHEW HALE
BABY SHANE
EMILY NICHOLLS
JENNIFER NICHOLLS
JULIA NICHOLLS
HEULWEN GITTOES
ELLIOT AUSTIN WILDSMITH
AMY LYNAGH
ALISON HANNAH MCMAHON
ROBERT SCOTT
ALICE MAY LELLIOTT

Intrapartum-related deaths

Intrapartum deaths include stillbirths and neonatal deaths that are directly related to events occurring from the onset of labour until birth.

In 2006 there were 434 intrapartum-related stillbirths and neonatal deaths. These were all labours which started with a live and apparently healthy baby, but ended with that baby dying. The risk of intrapartum-related deaths is virtually unchanged since 2000⁽²⁾.

Half of all intrapartum-related deaths are unexplained. This is devastating for parents who can see no reason for their baby's death. Research is urgently needed to identify the cause of these unexplained deaths and to understand how they may be avoided. The proportion of babies who are small for their gestational age is higher in both intrapartum stillbirths and neonatal deaths that are related to labour and we need to understand what part this plays.

"We lost our baby because I was in active labour with a premature baby for two hours with no care or checks made. The hospital admitted it was a mistake."

Events during delivery

Of intrapartum deaths for which a cause is identified, most are related to catastrophic events during delivery. These include placental abruption, cord accidents, malpresentation and ruptured uterus and maternal infection.

Labour is a critical time. The need to improve safety in childbirth is discussed in a number of recent reports^{(15) (16)}. For parents who have lost their baby the perspective is clear; safety of baby and mother should override all other considerations.

"I can't describe the shock and pain. I'd gone to hospital in labour and it never occurred to me I might not be able to take my son home. It was a nightmare, and still is."

In the CESDI report in the 90s into intrapartum deaths⁽¹⁷⁾, avoidable factors were found in three quarters of cases. The report pointed out failures in identifying problems, in intervening, and in communication. But suboptimal care continues to contribute to deaths ten years on.

As with care throughout pregnancy, there is huge variation in standards of care.

Issues of concern include:

- Inadequate staffing levels on labour wards during busy periods and at night.
- Delays in responding to problems, or inappropriate action.
- Failures to adequately supervise junior or inexperienced staff.
- Lack of consultant cover for high-risk cases on labour wards, particularly during the night.
- Need for more training of staff for high-risk situations.
- Need for improved teamworking and communication between staff.
- Failure to consider stillbirth and neonatal deaths as triggers for reporting a serious incident.
- Need for audit. The deaths of babies in labour should be investigated as maternal deaths are, and lessons learned.

It is intolerable that babies may be dying whose lives might be saved with better standards of care.

"Only through relentless focus on standards and continuing research and investigation into cases of fetal loss can women continue to enter childbirth, knowing that it is truly as safe as it can be."

**Chief Medical Officer's Annual Report 2006,
500 Missed Opportunities**

"They were under so much pressure that they had to concentrate on day to day issues with little spare time to attend training courses, risk meetings or clinical audit meetings....there has been pressure on bed occupancy, with some midwives worried that mothers and babies were being sent home too early to make way for the next delivery."

Healthcare Commission, reviewing maternity care in Milton Keynes General Hospital⁽¹⁸⁾

"My baby's distress was not picked up until it was too late to save him. I did not have a midwife with me during my labour and did not feel supported when I was having problems. This, I feel, was due to there not being enough experienced and caring midwives on duty to look after everyone on the ward that day."

"I had 42 weeks of a reasonably normal pregnancy then a labour which stopped and then nothing. Our beautiful daughter lost to us forever. I feel guilt (as the fault was in my body), anger (at the substandard care), pain, tears. This will stay with us forever."

"A failure to sustain minimal midwifery staffing levels..prevented support and guidance being available for junior and inexperienced midwives, and when complicated cases were managed by inexperienced and unsupported staff, especially during heavy workloads, it resulted in accidents waiting to happen."

**Brenda Ashcroft, Lecturer of Midwifery,
University of Salford**



Tuesday, another 17 babies

**ALAN RICHARD STURGEON
HARRY ELSTON
MATT PROUDFOOT
LAURA MCCAFFREY
JENNI CLARKE
NOAH LAMERTON
THEA LEWIS-WOODHEAD
ANNABELLE LUCY KELLY
GEORGE BEANSE
CHARLIE CLIFFORD SMART
LENNI SHAFFER
FREYA GELDART
AMÉLIE SPEAKE
OLIVIA PAIGE FROST
SOPHIE MCKELVEY MCINALLY
MALACHI DUNCAN
FREYA CHAPMAN**

Neonatal deaths

In 2007 around 82,000 babies in the UK needed specialist hospital care when they were born. Eleven percent of **all** babies born require some level of neonatal care and the neonatal period has one of the highest rates of mortality of any period of life with 70% of infant mortality occurring in the first 28 days of life.

Medical techniques for caring for sick and premature babies have made enormous advances in the past twenty years. This means that greater numbers of very small babies are being born alive and surviving. However, around 2,500 babies die each year in the neonatal period and the services that care for them both before and after they are born are still far from optimal.

Antenatal care

In some cases, suboptimal care before the baby is born plays a role in a baby's neonatal death. Babies whose wellbeing is not properly monitored either before or during labour, who lack oxygen and are delivered too late, may be too sick by the time they are delivered to survive, and die within hours or days of being born.

"Tomorrow is my eldest son William's fourth birthday. Arriving at Intensive Care with him as a very sick baby was terrifying. Leaving without him after he died was devastating. As we think about his all too short life, the NICU staff who cared for him form a large part of our memories and will always hold a special place in our hearts."

One-to-one care

The British Association of Perinatal Medicine (BAPM) states⁽¹⁹⁾ that sick and premature babies in intensive care need one-to-one nursing as a minimum. But only 14 out of 50 intensive care units in the UK say they are able to provide this⁽²⁰⁾. The Royal College of Nursing and other key stakeholders⁽²¹⁾ are calling for babies to receive the same level of care adults receive in intensive care.

National shortage of neonatal nurses

In order to meet minimum standards of care, as set out by BAPM, a further 1,700 neonatal nursing posts need to be filled.



Clare and Wayne Roberts with their children and daughter Tilly who died February 22nd 2008

Cot capacity

The BAPM report states that services should be planned for average occupancy of 70%. According to Bliss' survey of the UK's neonatal units almost a third of all units worked at 100% capacity or more.

Closure of units

Bliss' report shows that many units often close due to lack of specialist nursing staff, with only 4% of units achieving recommended staffing levels⁽²²⁾. While medical and technological advances, over the past 20 years, have resulted in improved rates of survival for premature and low birth weight babies, funding for staff and training has not kept pace with demand⁽²³⁾.

Transfers

These are a necessary part of neonatal care and the introduction of neonatal networks has improved the way transport is co-ordinated. Babies sometimes need to be moved so they can get the specialised care they need, or moved back to a unit closer to home. However, Bliss' research has identified that on average three babies every day are transferred between hospitals because of a lack of capacity or staff shortages. This means that families may be split up and have to travel long distances. The emotional and financial costs can be severe and this should not be happening.

Training

The Royal College of Nursing and other stakeholders are currently working on a UK-wide framework for the education and training of neonatal nurses. But this framework must be adopted in order to be effective.

"Babies are entitled to the same level of nursing care as adults and children in intensive care. Anything less than one-to-one nursing for babies in intensive care is unacceptable...The care of our most vulnerable babies continues to be compromised by a lack of qualified neonatal staff and the recruitment and training of more nurses must be a top priority for every Trust and Health Board."

**Andy Cole,
Chief Executive, Bliss**

Wednesday, another 17 babies

LAUREN BAKER
GRACE JACKSON-FARRELL
MARLEY BURRELL
SOPHIA PENN
HOPE WILLIAMS
DANIEL GOULD
ELEANOR CHILDS
KIRSTY SPIERS
EMMA LOUISE WHITTINGTON
ADAM STEPHEN HOWITT
ISABELLA BOEM
CHARLEY CORDEN
AMALIA NICOLE DEVINE
CHARLIE JACK SMITH
JESSICA MORRIS
TREVOR JUNIOR
ZACK MILLINGTON



Erin Bowditch born August 5th 2008,
died aged 34 days

Research

Research in the area of stillbirth and early infant death has attracted low levels of funding from statutory and other funders. Scientists and clinicians who work in this field passionately believe that perinatal mortality can be significantly reduced if the research work is funded and the outcomes incorporated into clinical practice.

There are pockets of excellent research work around the UK and internationally, but much higher levels of funding are needed. A nationally co-ordinated and funded research strategy will go a long way to reducing stillbirths and premature births.

Stillbirths

Understanding the causes of stillbirths

The causes of stillbirths, particularly unexplained stillbirths which account for half of all stillbirths, are poorly understood. Placental function is thought to play a big part in many unexplained deaths, as well as in other causes of stillbirth, including pre-eclampsia and abruptions. But there is little detailed understanding of how these mechanisms work. Scientific research could lead to a clearer understanding of the underlying biophysical processes and is desperately needed if tests and preventative interventions are to be developed.

Screening for stillbirth

An effective population-based screening test which accurately predicts which pregnancies have a high risk of ending in stillbirth could have a huge impact on stillbirth numbers. There is potential to develop such a test, but if work like this is to succeed, funding for further research and large scale trials are now urgently needed.

Underpinning guidelines for clinical care

We can only adapt antenatal care to help prevent deaths if we have a full evidence base. Many risk factors for stillbirth have been identified, but we need further work to improve understanding of how risk should determine clinical care. As yet not enough is known about how best to use existing tests of fetal wellbeing, including Doppler and ultrasound, to identify when a baby is at risk. More research is needed to determine how these screening tools can most effectively be used to detect at-risk pregnancies in the general population.

In-utero treatment

At present there are limited options for intervening to prevent stillbirth other than delivering the baby. But therapies which can improve fetal wellbeing in-utero could clearly be of great benefit, particularly at gestations when early delivery is more risky. We need to support research into treatments which could have a huge impact on preventing deaths.



Prematurity

47% of neonatal deaths are related to prematurity, and the incidence of premature births has changed little in recent years⁽²⁾. Strategies for preventing deaths are hampered by a lack of knowledge and research needs to be targeted at:

- Understanding the biological processes causing premature births.
- Improving understanding of who is at risk of prematurity.
- Improving diagnosis of premature labour and developing new treatments to delay labour.
- Developing treatments to prevent premature labour.

Data

Research needs data, but historically only limited pregnancy-related data has been collected in England, Wales and Northern Ireland. This isn't the case for Scotland where detailed information about pregnancies and outcomes is available. If we are going to help inform research, we need detailed, standardised data to be gathered on all pregnancies, across the UK, and collated centrally where it can be made available to researchers.

We need a nationally co-ordinated and funded research strategy to reduce stillbirths and premature births.

“Stillbirth is a major problem which is relatively ignored. Key priorities are to develop methods which identify women at high risk of stillbirth, followed by trials of interventions to determine how the risk can be reduced.”

Professor Gordon Smith, Department of Obstetrics and Gynaecology, Cambridge University

“When I first came to Sands I had a lot of questions that needed answering and I wanted to know what research was being done. For many of us, part of the bereavement journey is this desperate need to know that something is being done, that research is underway, that we are not being ignored. It is amazing to see Sands now pushing the research agenda forward. Who else is going to do it?”

Thursday, another 17 babies

ETHAN FOX
ADAM ROTHERY
AMY CLARE BIRLEY
BRUCE LESLIE
LUCAS CRAVEN
SAMUEL TUDOR
DIANE STANDRING
WILLIAM JOHN
HANS PETER BUDD THIEMANN
LILY BLAND
MITCHELL STAMMERS
OLIVER TWEDDELL
BENJAMIN HOGAN
LEO JAMES DILLON
PIP WELBURN
THOMAS HARWOOD
HELEN COYNE

Learning lessons

When their baby dies parents want to know that the cause of their baby's death has been fully investigated and that any lessons learned are used to improve the safety of babies' lives in the future.

But the level of investigation and review varies around the country. Some parents feel that too little attention was paid to their baby's death that it was 'brushed aside', that failures were not openly examined and nothing changed as a result. In our parent survey 20% were dissatisfied with the effort that was made to explain as fully as possible what had happened.

Many parents simply do not have the energy to pursue answers; others are driven to initiate complaints procedures in an effort to highlight mistakes and ensure other parents do not have to go through the same tragedy. But it should never be left to grieving parents to force hospitals to look at what has gone wrong.

We are calling for every stillbirth or early neonatal death to be reviewed with the same rigour as any other child death.

Every death should be examined with a view to understanding fully the circumstances which led to the death so that any avoidable factors can be identified. There has to be agreement on standards for review used in all hospitals, with resourcing to support the process.

Confidential enquiries

A confidential enquiry seeks answers rather than laying blame. In the 90s CESDI carried out confidential enquiries into antepartum and intrapartum stillbirths^{(6) (7) (17)}, and identified key areas for improving practice. But these enquiries have stopped since the formation of the Confidential Enquiries into Maternal and Child Health (CEMACH) which has less funding to cover a far wider remit of work. We would like to see resources to enable a return to enquiries into all stillbirths, in particular those which are unexplained.

Implementing lessons

When failures are identified, changes in practice must be implemented as a result. This does not always happen. The CESDI reports were written in the 90s but the same suboptimal care issues exist ten years later. We need to take the reports off the shelves and make sure the lessons are used.

"We've just had the third anniversary of my baby boy's death and have issued proceedings in the High Court against the Trust. Our original complaint was ignored and eventually the Healthcare Commission - the healthcare watchdog - had to step in and force them to investigate what went on. Litigating is not the easy option but it was the only way to get accountability. All we wanted was for the Trust to say sorry, to tell us that they value our son, to make sure that this would never happen again."

Litigation cases

The vast majority of parents who go to litigation are seeking an admission that something went badly wrong and an assurance that it won't happen again. Very few are motivated by financial payouts.

Litigation can highlight failures in care and lead to change. A recent report from Foot Anstey Solicitors⁽²⁴⁾ analysed 20 negligence cases and found common areas of negligent care: errors in monitoring high-risk pregnancies, often during periods when staffing shortages affected quality of care.

But litigation cases are just the tip of the iceberg, representing the extreme end of the spectrum of failures of care. There are lessons to be learned from all deaths, whether serious mistakes were made or not.

When a service is under pressure, errors happen, and babies die as a result. This is unacceptable.

Post mortem

Post mortems can provide important information about a baby's death and make a significant contribution to research. In up to 40% of cases the post mortem identifies important new information, including the cause of death when it was not known. The results can inform families of the risks of a recurrence in a future pregnancy and guide the management of future pregnancies, potentially preventing another death.

But in the UK uptake of post mortem examinations has fallen to less than 40% of deaths⁽²⁾. In the West Midlands, which has the highest rates of perinatal mortality in the UK, the rate is 30%.

In our survey, the reasons parents gave for declining a post mortem included: worries about what would happen to their baby's body; a belief that no further useful information would be found; and a feeling that they would have to wait too long to have their baby's body returned to them. 30% of parents who didn't have a post mortem said they would have done so, if they had thought a post mortem would provide some answers.

Despite evidence to the contrary many parents, it seems, do not realise that post mortems can be helpful. But without information from post mortem examinations of the baby and the placenta, important information is lost to individuals and research into causes of death is hampered.

In our *Guidelines for Professionals* Sands makes recommendations about how to communicate the necessary details about post mortems to parents after a death. We hope this will help parents make the difficult decision as to whether to consent to post mortem or not.

But even if uptake of post mortems improves, there is a severe shortage of specialist pathologists to do the work. To cope with even the current low rates of consent we need to double the number of perinatal pathologists. This means there are delays in getting results and babies' bodies are transferred across the country, making it even less likely parents will consent to

a post mortem. In some cases perinatal post mortems are carried out by general pathologists, or worse still post mortems not even offered to parents because services are so stretched.

As a matter of urgency efforts should be made to ensure perinatal pathology services are available in all areas of the country, so that post mortem examinations of babies and placentas can be performed quickly, and to a high standard, after a baby's death.

"Of course the consultants are not evenly spread so some areas have no or minimal access to perinatal pathologists, such as the South West and parts of Yorkshire, whilst others are better off... This means either post mortems are not done or they are done by general pathologists with little understanding of what they are looking for."

**Dr Phillip Cox, Perinatal Pathologist,
Birmingham Women's Hospital**

Friday, another 17 babies

**EVIE SACKS
LEE DALY
SAMUEL RICHARD OSBORNE
MAX DAKERS
SHONA LENNON
WILLIAM LEONARD CROSSLEY
JAMIE RUSHTON
DAISY LOVE
JASMINE JACKSON
ASAHI JAMES BIRD
LISA RUSKIN
BABY COYLE
DARREN KELLY
KATHERINE ANNE HOOLE
PHOEBE CHURCHILL
EWAN CAMPBELL
THOMAS DAVID FORDYCE**

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...little just beyond our eye
our baby plays with angel
tears that money cannot buy
who are as to wish you back
into this world of strife?
No Thomas, play on baby
You have eternal life

At night she sits in aisle
And you for as eyes
As you lie by our side
Your little hands caress us
Do tenderly and sweet
We'll whisper a prayer and close our eyes
And embrace you in our sleep.
In Loving memory of our precious baby boy
Born still
01/01/04
8:31am

"The loss is immense. You are all prepared for a new baby coming into your life and to leave the hospital with a box of handprints is heartbreaking."

Resourcing improvements in care

Lack of resourcing is repeatedly blamed for low standards in maternity care. The government has recently increased funding for maternity services. But it seems that this funding is not necessarily reaching maternity units and that resourcing 'on the ground' has not benefited services in all Trusts⁽²⁵⁾.

Commissioning

Newly implemented commissioning structures between the Primary Care Trusts (PCTs) and hospital trusts have been evolving to meet new government structures.

While this brings more focus to what is required from maternity services in each hospital, contracts may omit any proactive remit to reduce perinatal deaths. An issue that is not highlighted in a contract for funds is less likely to attract specific focus or resources.

As the contracts come into place hospitals can negotiate additional funds for posts or for focus as they see fit. However, many hospitals see contract negotiations as being driven by the PCTs and only a few have seen the opportunities provided by being able to focus on local issues.

Tariffs

It is unclear what is or is not included in the tariffs paid to trusts for obstetric services, with a great deal of room for interpretation on whether or not tariffs have been adjusted to allow for the funding of quality improvements. For neonatal care there is no nationally mandated funding system and health economies are left to make their own local arrangements which leads to an inevitable variability in the level of care provided.

Litigation costs

In the year 2006 to 2007 the NHS Litigation Authority paid out £579.3 million in connection with clinical negligence claims⁽²⁶⁾. In 2010 that figure is set to rise to £700 million. More than half of these sums are for maternity-related claims. This money comes directly from the Trusts, whose premiums to the Clinical Negligence Scheme for Trusts substantially increased last year⁽²⁷⁾. This will affect resources put aside for desperately needed improvements in maternity units. If a fraction of this money was spent on improving services, babies' lives might be saved and the emotional and financial costs of litigation avoided.

"The Authority is very concerned that maternity claims continue to be such a major issue. The emotional and financial cost to families is clearly enormous but there is also a cost to taxpayers and to the NHS as a whole. It is essential that all the organisations involved in this field work together to learn from experience and to reduce the incidence of negligence, loss of life and harm to babies."

**Dame Joan Higgins,
Chair of the NHS Litigation Authority**

Saturday, another 17 babies

HONEY ADAMS
AMELIE SAMANTHA NEWMAN
LENI LAYCOCK
SEREN MORGAN DAVIES
CHARLOTTE SEARS
DANIEL MCDERMOTT
OLIVER ROBERT WILLISHER
BENJAMIN NEWBOLD
EMILY GRACE
ETHAN NATHANIEL MURPHY LUCAS
BETH CARRUTHERS
WILLOW BEGGS
STEVEN KAY
JONATHAN CLACK
KITTY CHISNALL
LOUISE KNIGHT
ROSS IGGLESDEN

Working collaboratively

Parents have the greatest stake of all in the wellbeing of their baby but we think we are keeping them from harm by keeping them in the dark. We are not.

At Sands, parents tell us over and over again that they had no idea stillbirth was even a possibility; that they did not know there were factors which could increase their personal risk; and that because they were unaware of the risks they were not alert to signs that their baby was in trouble.

Among parents in our survey who had high blood pressure, half were not told that this presented any risk. Among those who were obese 76% were not told of any associated risk, while 46% of parents who had diabetes were not informed the condition posed a risk.

Good, clear balanced information about the risks to pregnancy is not scaremongering. Already, as part of routine antenatal care, parents make serious decisions about the risks and consequences of Down's Syndrome. It is the responsibility of health care professionals to be honest and open with parents, so that they can make decisions about their own babies.

"Had I known that having a small baby meant that I was five times more likely to have a stillbirth, I would have reacted much more decisively. Instead I stayed at home and took pain killers even though I could barely walk, because that's what I'd been told to do. I didn't want to bother anyone."



Chris and Nichola Wildsmith with their son Elliot who was stillborn on July 18th 2007

Parents need to be part of the drive to improve care and safety. Parents are the best source of information when it comes to knowing what is going on in their pregnancy. Parents can contribute their intimate knowledge of their own baby, 24 hour surveillance of their pregnancy and a parent's passion and commitment to ensure their baby's welfare.

Parents and health professionals working collaboratively can reduce potential risk, identify risks where possible and act effectively to avoid harm where possible.

In the 21st century we have come to view pregnancy and childbirth as events where the outcome is expected to be good. Health services are focused on the quality of the birth experience and giving parents as much choice as possible.

While parental choice is undoubtedly a good thing, what every parent wants above all else is a live, healthy baby.

We believe parents have the right to know:

- **that sometimes babies do die in pregnancy**
- **if they personally are at an increased risk of stillbirth**
- **that there are certain things they can do to minimise those risks.**
- **that the quality of their antenatal care could make a difference to the outcome of their pregnancy**
- **what standards of care they should expect**
- **that their care is personalised and that risk management is incorporated into their care plan**
- **that the care they are receiving is of the highest standard**
- **the service is funded at a level that allows high standards to be maintained**

Sands parents have already shown that in the terrible circumstances of a baby's death they can make a real contribution to understanding what went wrong and what can be done to improve safety in the future. Several have worked tirelessly with their PCTs to change practice, even though such action will not bring back their own babies. It's time to give all parents a voice.

"If, after Elliot had died, I had walked away, nothing would have changed. I don't want to be seen just as a bereaved parent. I want to be seen as an advocate for change."

**Chris Wildsmith, Elliot's Dad,
who has worked closely with his PCT in Milton
Keynes to improve services**

Sunday, another 17 babies

EVAN THOMAS WHITTAKER
CHLOE MEDLEY
DANIEL STEWART
MARIA WOOLLEY
SOPHIE GALE
DANNY HARRINGTON
HIMAT SINGH LALI
LEWIS DENT
BERTIE WHALE
HARRY PEART
PHOEBE MCGUIRK
ELLA HURST
EVELYN MAUD PORTER
CIANÁN BOON
OLIVER JOHNSON
KELLY LENNOX-GORDON
EWAN STOCKTON

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Baby sculpture created by John Roberts for the Sands Garden located at National Memorial Arboretum, Alrewas, Lichfield, Staffordshire

Definitions and statistics

Stillbirths

A stillborn baby is a baby delivered with no signs of life after 24 completed weeks of pregnancy.

In the UK in 2006 3,987 babies were stillborn. The stillbirth rate was 5.3/1000 live and still births.

Improvements in maternity care led to a steady decline in the stillbirth rate from the 1950s to the mid 1990s. In 1994 the stillbirth definition was changed from 28 weeks to the current 24 weeks gestation limit, with an accompanying change in the stillbirth rate.

In 1997 the stillbirth rate was 5.3 and in 2000 it was 5.4. In 2002 the stillbirth rate went up to 5.7, staying at that level until 2006 when it returned to 5.3.

Neonatal deaths

A neonatal death is the death of a live baby occurring before 28 days from time of birth. Early neonatal deaths are deaths in the first seven days of life.

In the UK in 2006 there were 2,607 neonatal deaths. The majority of these deaths occurred in the early neonatal period - 1,956. The neonatal death rate was 3.5/1,000 live births.

Like the stillbirth rate, the neonatal mortality rate fell in the second half of the last century. In the early part of this decade the neonatal mortality rate continued to decline – from 3.9 to 3.4, but since 2005 has remained unchanged, at 3.5.

Perinatal deaths

Perinatal mortality includes stillbirths and early neonatal deaths, that is deaths in the first seven days after birth.

Causes

Stillbirth

Stillbirths are classified by cause of death in the death notification forms collected by Confidential Enquires into Maternal and Child Health (CEMACH) for England, Wales and Northern Ireland. Causes of death have been classified using the Wigglesworth classification system. From 2007 CEMACH has adapted this classification system to address its widely recognised limitations, particularly in gathering information about conditions associated with a death.

Unexplained antepartum fetal death 50%
Congenital malformation 15.8%
Antepartum haemorrhage 8.8%
Death from intrapartum causes 7.6%
Maternal disorder 5.6%
Pre-eclampsia 2.8%
Infection 2.7%
Unclassifiable 0.6%
Accident or non intrapartum causes 0.1%
Other specific causes 5.9%

Of the unexplained antepartum deaths, two-thirds of the babies were born weighing less than 2,500g.

Neonatal death

Neonatal death notifications are also collected by CEMACH. Deaths are classified according to the Aberdeen Obstetric classification system. Causes of neonatal deaths for 2006 are given as:

Congenital malformation 23.3%
Immaturity 47.1%
Infection 10.1%
Other specific causes 8.0%
Death from intrapartum causes 7.7%
Sudden infant death 2.4%
Accident or non-intrapartum causes 0.3%
Unclassifiable 1.1%

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CEMACH⁽²⁾.

What else Sands does

Improving care when a baby dies

Sands has worked tirelessly with health professionals to transform the care bereaved families receive in hospital. Seminal publications such as *The Loss of your Baby*, (1979) and *Sands Guidelines for Professionals* (1991, 1995, 2007), have resulted in midwives across the UK being properly trained in how to care for bereaved parents. Our guidelines are respected and used internationally.

Sands lobbied to change the definition of stillbirth to 'a baby born after 24 weeks completed gestation' (previously it had been 28 weeks) now incorporated in the Stillbirth (Definition) Act 1992.

Support for all

Sands offers support to anyone whose baby has died, whether their baby was stillborn or died during or after birth. A baby might have spent some time in a special care baby unit, or may have died at an early gestation, or parents may have had to make the difficult decision to end their pregnancy. Some parents contact us years or decades after their baby's death.

As well as supporting mothers and fathers, we help other family members, especially grandparents and other children. Many people can be touched by a baby's death, including friends and health professionals. Our support is open to everyone who wants it.

"At times you feel that you could drown in your grief, and that nobody understands the hurt inside, but reading other people's experiences shows that you are not alone and lets you know that your thoughts and feelings are perfectly normal."

Helpline : 020 7436 5881

Our experienced helpline team receive over 4,000 calls a year.

UK-wide support

Our 100 local support groups are run by and for bereaved parents.

Online support

Our support forum has over 1,800 regular users.

www.sandsforum.org

Sands website has information and support.

www.uk-sands.org

Support publications

Leaflets and books for a range of experiences.

"My need to speak to someone who had 'been there' was overpowering. I found myself on the phone to a woman whose baby, like mine, had died. 'Tell me about your baby,' she said and I found myself pouring my heart out to a perfect stranger with whom I felt an instant connection."

Fundraising for research

Sands growing fundraising arm is at the forefront of raising money to fund the research that is desperately needed to understand why babies die and what can be done to save lives.

Our fundraising also means we can expand our role in training and informing better practice in bereavement care, and continue to offer high quality support around the UK.



**Today, another 17 babies will die.
How much longer must this go on?**

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