

Preventing Babies' Deaths

what needs to be done



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Jude Thomas with her son Henry just before he died, 21 hours after he was born, on 26th February 2009



**17 babies are stillborn
or die before they
are one month old
every day in the UK**

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Peter Brady with his son Jude who was stillborn
on the 16th June 2006

Introduction

Sands' *Saving Babies Lives* report, launched in 2009, highlighted for the first time the unacceptable numbers of babies who are dying in the UK. It argued that many of the 17 deaths every day are avoidable and that more must be done to stop so many babies dying before and soon after their birth.

The Lancet's Stillbirth Series in 2011 pointed out the UK's poor mortality record relative to other high income countries, and argued that a reduction in stillbirth rates is entirely possible.

Public awareness of stillbirth and newborn baby death has begun to change and the call for action to reduce the levels of death is growing ever stronger. Around the UK, parents, clinicians and researchers are joining forces to look at what must be done now.

There have been important steps forward. The Scottish Government has acted quickly in tasking an expert group to identify and implement changes that will impact on mortality in Scotland. In England we welcome the inclusion of perinatal mortality as an outcome measure in the NHS framework for 2011/12.

Sands is currently working with the Department of Health to bring together the relevant professional bodies and key experts to focus on stillbirth prevention, starting with a national stillbirth workshop early in 2012.

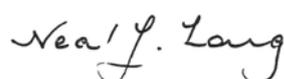
But the problem is complex and many different factors play a part. In this report we aim to highlight the areas where we believe action must be taken in

public health, research, data collection, resourcing, reviewing deaths and bereavement care. We want to see real national commitment to tackling these issues and preventing all avoidable baby deaths in the future.

As an organisation run by and for parents whose own babies have died, Sands is passionate about its cause: saving babies' lives. We know the devastating, heart-breaking impact when a baby dies and the pain and isolation of grief. Yet we also know there is real potential to prevent the loss of many hundreds of babies' lives every year.

We would like to thank all the many health professionals and researchers who have generously given us their time and support, and whose knowledge and experience has underpinned our messages for change.

We would especially like to thank the many parents, both featured and not included here, who have bravely shared the stories and pictures of their precious babies with us, inspiring, informing and illuminating not just this report but all the work we do.



*Neal Long, Chief Executive, Sands
January 2012*



*"We want to see real national commitment to tackling this ignored tragedy and preventing all avoidable baby deaths in the future."
Neal Long, Chief Executive, Sands*

What needs to be done

Over 6,500 babies die just before, during, or soon after their birth every year in the UK. More babies die during this period of their early lives than at any other stage of childhood.

The number of stillbirths has not changed in more than a decade. Yet many hundreds of babies' deaths could be avoided. We want action to save more lives and spare families the desperate heartbreak of losing their precious baby.

1 How many babies die and why?

Good data and audit are essential to advance understanding of why babies die and to improve care. But key health policy work for collecting national perinatal mortality data in the UK is currently suspended. Information on the 17 babies who die today may be irretrievably lost. This is unacceptable.

- **The Clinical Outcome Review Programme Maternal and Newborn Health must be resumed by April 2012 at the latest. The specification for this work must be thorough and the programme properly funded if it is genuinely to contribute to saving lives.**

2 A public health issue?

Without greater awareness of the risks of their baby dying how can prospective parents make informed choices about their health and pregnancy care? Awareness alone can help prevent deaths. Meanwhile despite government initiatives, inequalities in perinatal mortality persist.

- **A national forum should be established to share understanding of the public health aspects of perinatal death and develop public health and education messages.**

- **New research is needed to understand social inequalities in perinatal death.**

3 Research and new interventions

A third of stillborn babies are perfectly formed and born at gestations when they might safely be delivered. But routine antenatal care is failing to detect far too many babies who need help. New reliable, diagnostic tests are urgently needed. Stillbirth is where cot death was 30 years ago. There is still so much to be done.

- **Government research funding bodies must direct funds expressly into the causes and prevention of unexplained stillbirth.**

4 Review: the key to improving care

Sometimes babies die because of failures of care. Yet lessons about what went wrong are too often overlooked and opportunities to improve care are missed. Standardised review would help those who organise and deliver health care to learn from mistakes and make sure they implement best practice.

- **A national standard for reviewing perinatal deaths must be developed and followed in all Trusts. This needs to incorporate the parents' perspective.**

- **The quality and effectiveness of hospital level perinatal mortality review must be audited.**

- **The Clinical Outcome Review Programme must re-introduce a programme of national confidential enquiries into perinatal deaths.**

5 Staffing for quality and safety

Without adequate staffing and skills mix how can services be safe? Under-resourcing across the board in maternity and neonatal care has very real and tragic consequences. Yet calls to achieve even minimum staffing levels are still not being met.

- **Urgent action is needed to ensure minimum levels of staffing and the right skills mix in all areas of perinatal life and death - as outlined by the Royal College of Midwives, the Royal College of Obstetricians and Gynaecologists, the British Association of Perinatal Medicine and in consultation with the Royal College of Pathologists.**

- **Medical training for doctors and midwives must include a module on the risks and impact of perinatal death to improve awareness and understanding.**

“After Erin died, I got a letter from the hospital and it described all the scans I’d have if I got pregnant again. But it’s too little too late. I wanted Erin. She wasn’t a test run.”

Louise McGeechan

“For an otherwise healthy baby to die undelivered near term is, with hindsight, an easily avoidable event.

Research to make it avoidable in practice is a priority.” Professor Jim Thornton, Professor of Obstetrics and Gynaecology, University of Nottingham

6 Care after a death

The quality of the care that thousands of bereaved families receive every year when their baby dies has long-lasting effects. At a time of overwhelming distress parents need the right support from trained staff in making important choices about the precious and painfully short time they have with their baby.

- **Managers and service commissioners must fund and organise bereavement services in line with Sands’ *Guidelines for Professionals*, and to include high quality perinatal pathology services.**

- **There must be support for the development and implementation of a Bereavement Care Pathway, outlining minimum standards of care for bereaved families.**

- **Trusts should adopt the national perinatal post mortem consent form and improve training in consent taking in tandem with the form.**



**Stillbirth rates in the UK
are the same today
as they were in
the late 1990s**

Julie, Remy and Tia Sharp who was stillborn at 40 weeks plus 9 days
with no explanation, on 31st August 2010

How many babies die and why?

Every year in the UK over 6,500 babies die just before, during, or soon after their birth. More babies die during this period of their early lives than at any other stage of childhood and yet the numbers of baby deaths have changed little in more than a decade.

For most families the death comes as an unexpected and devastating shock.

“The next few hours are a blur. The ambulance, being rushed into a delivery room, the monitors, the doctors’ faces, giving birth to our baby, her lifeless body being placed on my chest and then being whisked away, being told she’d died. It was pure shock and inconsolable grief.”
Emma Johnston, mother of Daisy

In 2010, 4,110 babies were stillborn; 1,850 babies died in the first hours or days of their lives, and another 507 babies died between one and four weeks old¹.

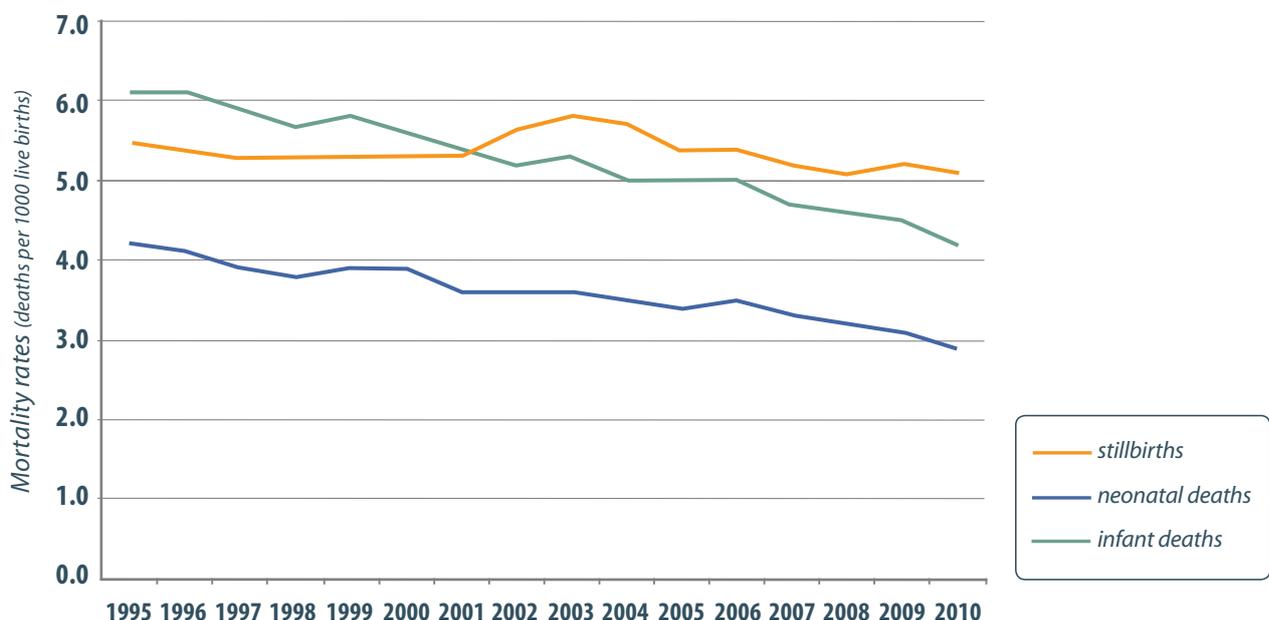
Contrary to common perception, stillbirth is not a rare event: one in every 200 babies is stillborn (a death after 24 weeks gestation).

In the last 20 years the decline in stillbirth rates which accompanied advances in maternity care has slowed and halted. UK rates of stillbirth today are the same as in the late 1990s (figure 1).

More than 30% of stillbirths happen at term (after 37 weeks gestation), the age when a baby is preparing to start life outside the womb⁸.

The number of babies who die in the neonatal period - within the first 28 days of birth - has fallen by 20% over the last decade (figure 1), largely due to progress in caring for premature infants. However, it still remains the case that one in 300 babies dies in the first four weeks of life and around a quarter of these babies are born at term⁸.

Figure 1: UK stillbirth, neonatal and infant mortality rates over time



Source: Office for National Statistics

The most common form of child mortality

There are as many stillbirths in the UK as there are deaths of children under the age of five. If we count all babies who are alive from 24 weeks of pregnancy onwards as children, about 75% of all child deaths occur in the womb or in the first week of life².

Infant mortality rates (deaths under one year of age) have fallen dramatically in the last decade to the lowest levels ever in the UK, but stillbirth rates have not changed³. Yet while there is proper focus and concern about preventing child deaths caused by, for example: meningitis (around 50 deaths per year⁴), road deaths (81 deaths in 2009⁵), or cot deaths (400 per year⁶), the 4,000 stillbirths each year are more or less ignored.

The taboo around a baby's death, something that is hard to talk about or acknowledge, keeps the issue of stillbirth hidden and unaddressed.

The international picture

Stillbirth rates in the UK compare poorly with other countries that have similar populations. A recent international analysis in *The Lancet* placed the UK's stillbirth rates 33rd out of 35 similar high income countries⁷.

Other countries have managed to reduce their stillbirth rates in recent decades: in Norway and the Netherlands stillbirths have fallen by 50% and 40% respectively in the last 20 years. *The Lancet* authors conclude that: "The variation in stillbirth rates clearly shows that further reduction in stillbirth is possible in high income countries".

Part of the difficulty is that there is not one single solution to the complex problems of perinatal mortality (the stillbirth or death of a baby within the first week of life).

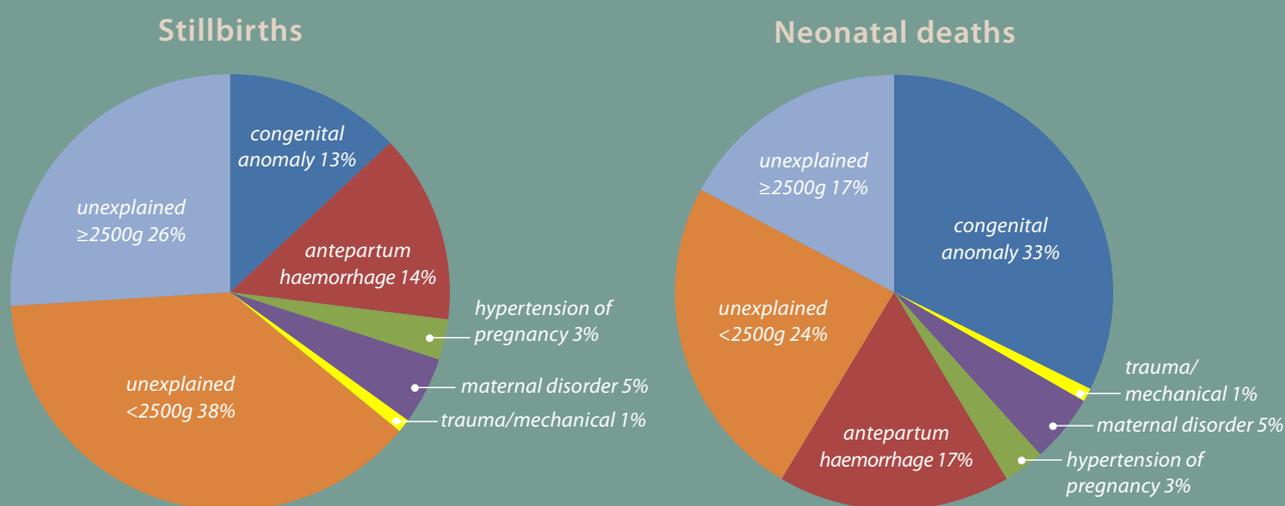
Why do babies die?

The causes and associated risks of a baby dying perinatally are myriad. They include medical causes in the mother, baby and placenta (see figure 2 for a breakdown); issues of lifestyle and demographics, and the safety and effectiveness of the maternity or neonatal care that is being given.

It is often assumed that a baby who has died was born too soon or too sick to live. In fact only around 10% of stillbirths are caused by a fatal congenital abnormality. For the majority of deaths – over 60% – there is no clear cause. Half these 'unexplained' deaths are of growth restricted babies (weighing less than 2.5kg). Around a third of stillborn babies are normally sized and perfectly formed. Many of these deaths could be avoided.

The deaths of some babies soon after birth are also due to potentially avoidable causes that have originated in pregnancy and during labour. Around 500 babies die every year because of a trauma or event during birth that was not anticipated or well managed⁸. These deaths, when they occur at term, should never happen and almost always could be avoided with better care.

Figure 2: Causes of stillbirths and neonatal deaths



Source: Scottish Perinatal and Infant Mortality and Morbidity Report 2009. Information Services Division, NHS Scotland

Who is at risk?

There is an increased risk of stillbirth associated with certain medical conditions, with previous obstetric complications, in multiple pregnancies and in first pregnancies.

Stillbirths and neonatal deaths are also more common among some groups of mothers, principally women who smoke, who are obese (a body mass index, or BMI, over 30) and who are over 35 years old. Women from areas of social deprivation, and those from some minority ethnic groups are also at increased risk⁹.

However, because so little is still known about the underlying causes of stillbirth every baby is, to some degree, at risk. The only way to understand what is really happening is to carry out research and audits, and to learn whatever we can from babies who do die so that we can improve care. This work, however, is currently under threat.

Auditing deaths

If deaths are not counted, in official terms they as good as disappear. Yet the UK's national audit programme, the Clinical Outcome Review Programme (CORP) Maternal and Newborn Health, which is tasked with collecting perinatal mortality

data, has been suspended since April 2011. In other words the 17 babies who die today will not go into any kind of national audit to help understand why babies die and how to improve care.

Evidence shows that audit can save lives¹⁰. Without facts on where and why deaths are happening, or any review of maternity units' performances on perinatal mortality, the potential and impetus to do something about the problem fades. In a health care system driven by outcomes this situation is unacceptable.

The official panel who reviewed the CORP programme recommended that it recommence by April 2012, but that is not certain¹¹. Meanwhile, there is grave concern, and a sense of disbelief, that two or more years of vital perinatal mortality data have potentially been lost.

The Clinical Outcome Review Programme Maternal and Newborn Health must be resumed by April 2012 at the latest. The specification for this work must be thorough and the programme properly funded.



Simon and Chloe Baker with their baby Solomon who died during labour on 28th October 2010 at 33 weeks and 5 days



**Public health messages
about pregnancy are
never linked to the
possibility of the
baby actually dying**

A public health issue?

In August 2008 Lisa and Glen Cooper had given up virtually all hope of becoming pregnant after five years of trying for a baby. Then Lisa was diagnosed with epilepsy and had to change her job. She became depressed but in the midst of all this she also became pregnant.

Because of her health issues, Lisa's pregnancy was on a high-risk pathway until 36 weeks when her doctor said she was so confident about the baby's growth that Lisa could be transferred into community care. Now diagnosed as low-risk, when Lisa went to hospital, in labour, on the night of May 7th 2009, 12 days past her due date, she was sent home again because she was only 2cm dilated.

"They said not to come back 'til it got worse but Lisa was in incredible pain and I couldn't imagine it getting any worse," says Glen, who has three children from a previous marriage. When the Coopers finally went back to hospital

early the next morning after a long night, staff couldn't find Archie's heart beat: one midwife tried, then another and another until finally the consultant arrived and confirmed that Archie had died.

It wasn't just the fact that Archie, far from growing well, was in fact "severely growth restricted" that left the Coopers bewildered and angry about the care they'd received, it was also the discovery that Lisa - aside from being on medication for epilepsy and depression at the start of her pregnancy - also had two risk factors for stillbirth that she was unaware of: she was over 35, and she had a BMI of 40. Both Lisa and Glen wished they'd known more.

"As a pregnant woman, how can I contribute to the management of my own care if I don't know the risks?" argues Lisa.

"At least if it had been mentioned in our antenatal classes I would have felt better prepared for being hit by this particular express train," says Glen.



The Cooper's son Archie

Time and time again parents tell Sands of the devastation they experienced when their baby died and of their subsequent shock when they discovered how relatively common the death of a baby is, before and soon after birth.

Some bereaved parents had never even heard the term 'stillbirth'. When their lives are devastated by this tragedy many ask why they were never told it could happen.

It is not just parents who are surprised to hear 17 babies die every day in the UK. A medium sized maternity unit with 3,000 births may see around 15 deaths in a year; some midwives working in that unit will never have a pregnant woman in their care who has a stillbirth. There are nearly 40,000 General Practitioners in the NHS¹²; on average only one in ten will see a stillbirth in any one year. Many of these health professionals may perceive perinatal death as a rare event, but it is not rare nationally.

While stillbirths can happen to any woman, it is well established that some women are at increased risk: a third of stillbirths are associated with BMI, smoking and maternal age¹³.

In the UK a woman with a BMI over 30 has almost twice the risk of stillbirth as a woman with a BMI below 25, and risk increases with increasing obesity¹⁴.

A quarter of stillbirths and a third of neonatal deaths are associated with smoking during pregnancy¹⁵. Women who smoke more than ten a day double their risk of stillbirth¹⁶. Maternal age also has a bearing on risk, with the odds of a stillbirth increasing for women over 35, and doubling for mothers over 40¹⁷.

As the pregnancy population becomes increasingly complex, all these risks are increasingly relevant to public health messaging and service provision. The past decade has seen a 71% rise in births to women over 40¹⁸ and today one in five women is obese at the start of pregnancy¹⁹. But bereaved parents who come to Sands for support feel that these risks were simply not made clear. Public health messages are never linked to the possibility of the baby actually dying.

There are other risks that parents can do little to modify. Babies born into socially deprived families and from black or Asian minority ethnic groups are also at an increased risk of dying. Despite government initiatives to tackle inequalities in infant and maternal mortality, the reasons for the persistently higher prevalence of perinatal death in

these groups is still not well understood. We need more research to dig deeper and understand why.

It would be wrong to think, however, that stillbirths only happen to women in these higher risk groups. More than 70% of mothers of stillborn babies have no significant medical condition; around 60% have not had any previous pregnancy complications; 90% went for antenatal care before 20 weeks; 66% have never smoked; and 48% are in their first pregnancy²⁰. In other words, stillbirth can happen to anyone, including a supposedly 'low-risk' mother with a healthy-sized baby in the very final stages of a problem-free pregnancy.

If women and health professionals perceive stillbirth to be a thing of the past, there is a danger that health professionals will miss warning signs or under-estimate potential risk and prospective parents will find out too late that pregnancies can go wrong.

"You can't make informed decisions if you're not informed," says Glen. "We asked the Head of Midwifery to review the information they give parents but she said, 'We don't want to scaremonger parents'."

Is it scaremongering to tell prospective parents of the risks, however relatively small, of their baby dying before or soon after birth (after all women are expected to assess information about Down's syndrome and cot death) or is it giving them the power to make truly informed choices about their own health and pregnancy care?

A national forum should be established to share understanding on the public health aspects of perinatal death and develop public health and education messages.

New research is needed to understand social inequalities in perinatal death.





**A third of stillbirths
happen at or near term
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Research and new interventions

Louise McGeechan was 21 years old, and 12 days overdue when she went into hospital early on the 31st August 2010 to be induced. Her pregnancy scan at 20 weeks had shown no problems and since then her pregnancy had only been monitored with a tape measure.

But on the day she went into hospital, Louise was already anxious; her baby hadn't moved much the night before and when she woke up that morning the baby still wasn't moving. She told herself to hang on, that she'd be having the baby soon anyway. When she reached the hospital and the midwife couldn't find a heartbeat, Louise started to cry.

"The midwife said, 'Why are you crying?' But I already knew."

Louise went through a ten hour labour before Erin was stillborn.

"I just remember thinking I don't want to get to the end of this

because that'll be it. My baby will leave my body and I'll have to get on with my life and I don't know how I'm going to do it."

Erin was a perfect 8lb 1oz baby, but she died of oxygen starvation. After a post mortem, Louise's consultant told her that they believed her placenta had started to fail at 41 weeks and that there was cord compression.

"There should be more checks and scans in pregnancy, especially if you're overdue. I'm not an expert but I know her death was avoidable, that if she'd been taken out sooner she'd have survived."

Louise is now pregnant again. She has been told that she will have a scan every four weeks up to 28 weeks and then every two weeks until 38 weeks when she'll be induced.

"But it's too little too late. I wanted Erin. She wasn't a test run."



Craig and Louise McGeechan with Erin after she died

It is a common misconception that all stillbirths are unavoidable tragedies where something is irreversibly wrong with the baby.

In fact over 90% of babies who are stillborn have no congenital abnormality; around a third of stillbirths are unexplained (in other words perfectly formed, normal-sized babies); and a further third are also perfectly formed but growth restricted.

As with Erin, a third of stillbirths happen at or near term when babies could survive if they were delivered²¹. Why are these babies dying? And how can more of them be saved?

Most unexplained stillbirths happen in so called low-risk pregnancies. Routine antenatal care is clearly failing to spot too many of the babies who need help.

The National Institute for Clinical Excellence (NICE) guidance for assessing fetal wellbeing after 24 weeks is simply “Symphysis–fundal height should be measured and recorded at each antenatal appointment”²²; in other words use a tape measure. Screening methods today are not dissimilar to those in use 40 years ago.

They rely largely on the instincts of health professionals, their sense that ‘this doesn’t seem right’. This places a huge and unreasonable burden on their intuition and judgement. Current antenatal care only picks up on 30% of babies who are growth restricted and who would therefore need further monitoring²³.

More sophisticated assessment tools such as ultrasound scans are not routinely offered after 24 weeks of pregnancy because there is no evidence of how they can be used to reduce mortality.

Cardiotocographs (CTGs) are not recommended routinely and fetal movement monitoring, even when carried out according to improved national guidelines²⁴, can indicate a possible problem rather than strongly predict a death. Routine antenatal care with its focus on low intervention has few tools for assessing fetal wellbeing in the third trimester and babies continue to slip through the net and die.

Tragically, many bereaved parents themselves suspected something was wrong. But because there were no clear and objectively measurable warning signs to enable staff to distinguish between normal pregnancy anxieties and valid maternal fears, no action was taken. It is common for parents to tell Sands that they reported a reduction in their baby’s movements, were reassured and sent home, only for their baby to die hours later.

Improving risk assessment has been crucial in reducing neonatal deaths. Today it is rare to lose a baby in a high-risk pregnancy. But when it comes to stillbirth the so-called ‘low-risk’ women who in fact have high-risk babies are being missed.

“The midwife called mine a textbook pregnancy. Daisy’s growth was always between the two lines, she never dropped off. So there were no alarm bells that something was wrong.” Emma Johnston

High-tech care for rare conditions in pregnancy is improving all the time. The national screening programme for Down’s syndrome is properly funded in order to identify pregnancies that parents may want to terminate, and yet a screening test to prevent the most common death in infancy – stillbirth – is still undeveloped.

It is time there was an effective screening regime for stillbirth which is fit for 21st century health care.



Emma and Nick Johnston with Daisy who was stillborn on 21st February 2011, at 41 weeks and 5 days

“A common scenario that leads to stillbirth is a woman who lacks risk factors but has a poorly functioning placenta. If we had tests that could identify babies at risk of death in late pregnancy, induction of labour would have a very high chance of preventing stillbirth. A test providing reassurance of normality could also help avoid ‘medicalising’ the pregnancies of women who may have risk factors, but who are not clinically at risk.” Professor Gordon Smith, Head of Department of Obstetrics and Gynaecology, University of Cambridge

Sands has recently supported the setting up of an expert group to identify the research that is needed. But without much more funding for work with a primary focus on stillbirth their recommendations cannot be acted on.

Sands parents and supporters are passionate in their commitment to fundraise for research. A petition in 2011 in leading women’s magazine *Grazia* attracted over 22,000 signatures demanding “more research to prevent the stillbirth scandal”²⁵. But the funds generously donated to Sands for research are still small compared to the huge task involved.



Samir Patel who has raised over £1,300 for Sands in memory of his daughter Amaari



Around £10 million has been spent on cot death research in the past 30 years. As a result the numbers of babies who die unexpectedly in the first year of life has fallen by 70%²⁶. We believe the same can be done for perinatal deaths. But if this is to happen, the generosity of parents and the public must be matched by a commitment from government.

Government research funding bodies must direct funds expressly into the causes and prevention of stillbirth.

“Unexplained stillbirth receives far less research investment than it deserves, perhaps because of the inappropriate assumption that ‘unexplained’ means ‘unavoidable’. Until researchers investigate the aetiology of - rather than associations to - stillbirth at term, I fear that this will remain a prevalent, heart-breaking tragedy for prospective parents.” Professor Basky Thilaganathan, Director, Fetal Medicine Unit, St George’s Healthcare Trust



**In the past five years the
NHS Litigation Authority
has spent over £1 billion
settling negligence claims
in obstetrics**

James, Emily and Hoa Titcombe, pregnant with Joshua the summer before he was born and died

Review - the key to improving care

Joshua Titcombe's hospital birth on 27th October 2008 appeared to be problem free. Thirty minutes after he was born, however, his mother Hoa collapsed and fell unconscious. Although she recovered and was given antibiotics, the Titcombes were concerned Joshua might also be ill.

Despite voicing repeated concerns over their new son's temperature, his wheezing and bubbling at the mouth, James and Hoa Titcombe were told a paediatrician did not need to see him.

They took photographs of their eldest daughter Emily holding her new baby brother. But by the next morning Joshua had collapsed. He was air lifted to two subsequent hospitals with higher-level neonatal care, but Joshua eventually bled to death from a pneumonia infection resulting from his mother's illness.

While the hospital where Joshua was born admitted some failures of care and accepted liability for his death, James and Hoa felt that many of their questions remained unanswered.

The clinical records relating to Joshua's care at the hospital where he was born had gone missing. When James asked to see statements made by staff in the Trust's investigation into Joshua's care, he was initially rebuffed. When he was eventually provided with a copy of those statements, it was clear that his and his wife's accounts of events differed widely from those of the hospital staff, and he became determined to seek the truth.

After pursuing several avenues of independent investigation over two years, James finally persuaded the coroner to open an inquest. That inquest found that his son had died a needless and "horrible" death over nine days following ten different failings by staff: failure to recognise a common infection, failure to listen to the parents' concerns, inaccuracies in records, and a "strained and dysfunctional" relationship

between midwives and paediatricians. With the medical notes still missing, the coroner accused the hospital of a "cover up".

"We want Joshua's legacy to be a safer maternity unit so no other family has to go through this experience. It has been unspeakably hard," says James.



Emily holding her baby brother shortly after he was born

Joshua's avoidable death - the true causes of which would never have come to light without the courageous persistence of his father - not only highlights extreme failures of care, it also emphasises the unwillingness of some Trusts to learn in an open and honest way from those mistakes, thereby risking repeating these failures in the future.

The Titcombes' case is an extreme example of poor care but it is also just the tip of the iceberg. Most bereaved parents do not have the leverage - particularly if their baby was an 'unexplained' stillbirth - to pursue answers as to whether the quality of the care they received contributed to their baby's death. The death is generally presented to them as a rare and regrettable, but unavoidable, tragedy. Yet we know that substandard care plays a role in many perinatal deaths.

In a national confidential enquiry into stillbirth in 2000, sub-optimal factors were found to have contributed to the death in three quarters of cases with failures in identifying problems (especially poor growth), in intervening and in communication²⁷. In more recent regional confidential enquiries into the deaths (before or shortly after birth) of 65 normally formed babies, carried out in 2008/9 by the West Midlands Perinatal Institute, it was concluded that 54% could have been avoided with better care²⁸.

When a case of substandard care is so extreme that parents sue for negligence it costs the NHS dearly. In 2010/11, the NHSLA spent £328,626,806 in costs relating to clinical negligence claims in obstetrics, which annually represent 60% of NHSLA payouts. In the past five years over £1billion has been spent settling these claims²⁹.

Despite the massive costs of failures, clinical standards for high quality maternity care as defined by the professional bodies and NICE are known to be inconsistently applied across the country³⁰. There is good thinking about how these variations can be addressed in the future, namely through Women's Health Networks³¹, which we hope will help establish much needed minimum standards of care across all regions and promote best practice.

Standardisation is also missing from perinatal mortality review. Although it is normal practice to hold regular perinatal mortality meetings where deaths are discussed, the quality and

rigour of the process is highly variable. There is no independent scrutiny of, for example: who attends meetings; what information is incorporated (for example post mortems) in the discussion; nor indeed whether practice changes or mortality rates fall as a result. Parents, who have the biggest stake in understanding the death of their baby, are not informed of the content of these meetings or the actions resulting from them.

Experts agree that rigorous and independent perinatal mortality review, which include the results of all relevant investigations, is vital if sub-optimal care is to be identified. In its 2011 *Stillbirth Series* *The Lancet* describes what good perinatal audit should look like and models of effective audit already exist in some regions of the UK^{32 33}. But good practice needs to be adopted nationally.

Simply counting deaths is not enough. Thorough and independent local reviews must also feed into the information about perinatal data collected and audited nationally, once the Clinical Outcome Review Programme is running again. National confidential enquiries into perinatal deaths, which have not been undertaken since the 90s, must return to the heart of the CORP's work if avoidable deaths are to be identified.

As Joshua's story tells so vividly, parents need honest answers and maternity units need to learn lessons so that potentially avoidable events do not lead to the same tragic outcomes next week or next month.

"Perinatal death is an ongoing tragedy that requires greater prominence and investigation. Simple counting of the deaths is of little value without the education that independent review committees provide." Professor James Walker, Senior Vice President (International), Royal College of Obstetricians and Gynaecologists



© Sands

A national standard for reviewing perinatal deaths must be developed and followed in all Trusts. This needs to incorporate the parents' perspective.

The quality and effectiveness of hospital level perinatal mortality review must be audited.

The Clinical Outcome Review Programme must re-introduce a programme of national confidential enquiries into perinatal deaths.



**The risk of death
increases by 45%**
for babies born
out of hours

Michelle Hemmington three weeks
before Louie was born and died

Staffing for quality and safety

Between her arrival at the hospital, just after 9am on May 17th 2011, and the birth of her baby Louie, just after 11pm that day, Michelle Hemmington was under the care of eight different midwives but developed a relationship with none of them.

Michelle was offered a warm bath to cope with the pain and then moved to triage because there were no beds free on the labour ward. During that time – nearly five hours – no one came in to monitor mother or baby. Michelle's sister tried to call for more gas and air because it had run out. When a midwife did arrive 45 minutes later Michelle was 8cm dilated.

Michelle was moved to the labour ward where Louie's heart began to decelerate. The midwife asked for assistance but the obstetric registrar was in theatre. The consultant wasn't called, and there was no 'fresh eyes' protocol for the CTG. By now Louie's heart rate was deteriorating further.

"I kept saying, 'I can't get him out'. I asked several times for an emergency section but they told me I was too far gone."

The paediatric registrar arrived, stayed in the room for only three minutes, and left without giving any instruction, leaving the midwives bewildered.

Within minutes Louie was born and put on Michelle's chest but then swiftly taken away. *"There was lots of commotion suddenly and I heard them shouting for a new resuscitaire"*.

Nearly half an hour later Michelle and her partner Paul were told Louie had died. The post mortem indicated Louie had been starved of oxygen and had signs of a pneumonia infection.

The hospital initiated a Serious Incident investigation and concluded among failures in communication, team work and training, that the lack of continuity of care and the 12-hour work shift of the labour

ward co-ordinator, during "a high-activity day", had affected her ability to allocate risk.

There had been several warning signs to escalate Michelle's care, but they were all missed by every speciality.



Paul Buckley holding his son Louie

The current mantra in maternity care delivery is choice but every woman's first choice is to have a healthy baby. Michelle chose a hospital birth because she thought it would be safer than being at home:

"But I felt totally left alone. It's not just one person who failed us, it's the whole system."

Safety and quality are currently threatened by under-staffing in every area of perinatal care, from midwives to specialist pathologists.

The Royal College of Midwives (RCM) is petitioning the government for 5,000 more midwives across England and warns that current shortages are affecting both quality and safety:

*"Births are also becoming increasingly complex needing more of midwives' time. The combination of this and the rising birth rate is a dangerous cocktail threatening the safety and quality of maternity care. It means that too many maternity units across England are under-staffed and under-resourced to meet the demands made of them."*³⁴ Cathy Warwick, General Secretary, RCM

At the same time, Cathy Warwick warns, *"the midwifery workforce is ageing dramatically, and student training numbers into the future are not guaranteed"*³⁵.

Safe, high-quality maternity care also requires the right skills mix so that staff can respond to problems when they arise³⁶. In its latest report *High Quality Women's Health Care: A proposal for change*, the Royal College of Obstetricians and Gynaecologists (RCOG) states its concern about the continuing lack of 24-hour obstetric cover on wards³⁷:

"Despite the expansion in (consultant) numbers, consultant presence on the labour ward still falls woefully short of the recommendations made in multi-professional standards."

The potentially tragic consequences of under-resourcing are borne out by research into the risk of perinatal deaths during the normal working week versus at night and weekends. A recently published analysis concluded that the risk of neonatal death increased by 45% for babies born out of hours. Although 70% of babies are born at night, maternity units are not a 24/7 service³⁸.

In 2010 Bliss, the special care baby charity, reported a desperate shortage of 1,150 neonatal nurses³⁹. However, in July 2011 Bliss' survey of neonatal units found that one in three hospital units caring for premature and sick babies: *"have or will be making cuts to their nursing workforce over the past year or in the coming 12 months"*.

*"Already more than half of units do not meet the Department of Health and NHS's Toolkit for high quality neonatal services standard"⁴⁰ ... Cuts will have an impact on the survival rates and long-term health of children in neonatal care."*⁴¹

Resource pressures extend through to the provision for families after a death. The Royal College of Pathologists estimate that a 20% increase in the numbers of perinatal pathologists is needed to deal with even the current low rates of post mortem uptake. A recent survey reported 30% of the perinatal pathology workforce will retire between 2013 and 2018⁴². It is not clear what strategies there are to replace them.

The resourcing of perinatal pathology services varies widely between regions meaning that babies often have to travel long distances for a post mortem and that post mortem reports are often unacceptably slow in reaching parents.

"The wait for the results was absolute torment. The actual post mortem was done about five days after he was born but the report wasn't written for two and a half months." Parent response to Sands 2009 Parent Survey

Staff training is a further concern. Stillbirths barely feature in undergraduate or on-the-job training for doctors and midwives. It is left to Sands to provide this information through our multi-disciplinary training days in bereavement care. During these sessions clinicians routinely admit their lack of awareness of both how common stillbirths are and how profound the impact a baby's death is.

As the NHS undergoes the upheaval of re-organisation and financial constraints against the backdrop of a changing population with greater health needs, the care of babies must not be even further demoted. Women and their families expect and deserve safe care, delivered by the right people at the right time, and co-ordinated across all specialities.



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Urgent action is needed to ensure minimum levels of staffing and the right skills mix in all areas of perinatal life and death - as outlined by the relevant professional bodies.

Medical training for doctors and midwives must include a module on the risks and impact of perinatal death to improve awareness and understanding.



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52% of maternity units
have no dedicated
bereavement support
midwife

Care after a death

On 18th August 2011, Dharmistha Patel gave birth to her stillborn daughter Amaari on a busy labour ward. Although the pain of hearing other mothers welcome their new babies into the world when Dharmistha knew her own was dead was unbearable, she was also moved by the dedication of her midwives.

“One of the midwives didn’t leave my side for 13 hours. She went out to get things for my care but didn’t stop for lunch. I’m indebted to her. I’ve spoken to other people who had terrible experiences and I think it makes it ten times harder to deal with.”

The Patels were told they could have a memory box for Amaari, if they wanted. Initially they said no but then changed their minds, taking hand and foot prints, a lock of her hair and photographs and dressing their daughter. The hospital helped arrange Amaari’s funeral and a bereavement midwife remained in touch when

the Patels had questions later. The Patels consented to a full post mortem which revealed Dharmistha had blood clots in her placenta, information that will impact the management of a subsequent pregnancy.

Compare the Patels’ experience with that of Anna and Andrew Milloy, just 100 miles away. Like the Patels, their baby girl died with no warning during labour at home. It was New Year’s Eve 2008 and Anna was transferred by ambulance to hospital where Philomena was finally delivered. After a sleepless night, Anna, tired and devastated, asked to

take Philomena home but was told by hospital staff that her request was “very strange” and would create more paperwork for the hospital.

“I wanted to go home but I just couldn’t leave her at the hospital. I just couldn’t be separated from her.”

Anna’s wishes were eventually met but she and Andrew did not have a post mortem.

“I just assumed that by wanting to take Philomena home I’d effectively turned down the opportunity of having a post mortem,” says Anna.



Family and friends gathered at Anna and Andrew’s house to meet and say goodbye to Philomena. *“We realised that we could take prints of her hands and feet, so I had the chance to get her little hands and feet covered in paint and then the one-off chance to wash her ‘stickywicks’ clean.”* Philomena’s grandmother Rosemary.

The care that thousands of bereaved families receive every year around the time of their baby’s death is extremely important. Good care cannot remove the pain of loss, but care that is inadequate or poor makes things worse and affects a family’s wellbeing both in the short and long term.

Based on research evidence, discussions with professionals and parents' experiences, *Sands' Pregnancy loss and the death of a baby: Guidelines for professionals* sets out standards of care for parents whose baby dies during pregnancy, labour and shortly after birth. Widely-acclaimed, the Guidelines are now in their 3rd edition.

In 2009, Sands ran an online survey of maternity units in the UK with the aim of finding out how far units were following recommendations set out in the Guidelines. While there have been improvements in care in the past few decades, it was clear from the results that not all units feel bereavement care is a priority. In around 20% of the units that responded care is still poorly resourced and organised. In other units care is patchy⁴³.

The survey found, for instance, that 52% of units have no designated bereavement support midwife.

Nearly half of all units (45%) have no dedicated room on the labour ward for mothers whose baby has died to give birth, and a quarter of all units have no room away from the postnatal ward where bereaved parents can be cared for after the birth without hearing the sounds of other mothers and their live babies.

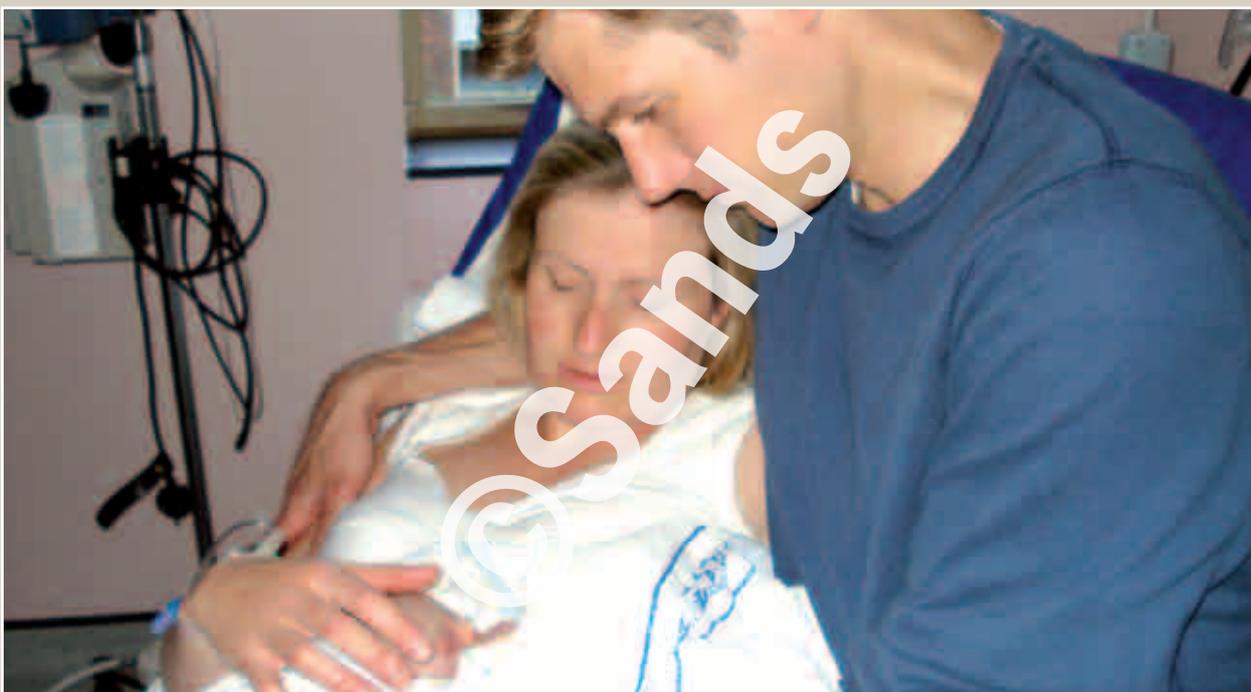
Like Anna, some parents want to take their baby's body home or to a place that has significance for them. There are no legal reasons to stop parents from doing this, but 31% of units did not offer parents the option.

We know that many parents suffer a significant drop in income following the death of their baby⁴⁴ and that perinatal deaths disproportionately affect parents in poorer socio-economic groups. Yet in 56% of units parents are given no information about their entitlements to time off work, benefits and payments.

When a baby dies almost every parent will want to know why.

But a parent's need to know what happened is often in conflict with a feeling that post mortem investigation is invasive and their child has 'already been through enough'⁴⁵.

Coupled with this, the organ retention scandal of a decade ago generated a good deal of negative publicity for pathology services, and post mortem uptake rates fell from 55% in 2000 to 45% in 2009 for stillbirths and from 29% to 18% for neonatal deaths⁴⁶. Meanwhile confidence in the value of post mortem has fallen, not just among the public but among professionals too.



Katie and Tim Johnston with Emily Rose who was stillborn on 10th May 2011

Research recently funded by Sands, and undertaken by the University of Manchester, aimed to gauge how confident and well-trained doctors and midwives are in taking consent for post mortem by asking professionals as well as parents about the experience⁴⁷.

The survey found that 36% of midwives who have had training in taking consent were dissatisfied with it. While 50% of obstetricians have actually seen a post mortem, as recommended by the Human Tissue Authority, only 4% of midwives have seen one. As many as 32% of midwives and 36% of obstetricians underestimate the value of a post mortem⁴⁸.

There is huge variation in post mortem consent forms around the country; many are long, complicated and distressing to read. At least half of the parents surveyed by Manchester University weren't satisfied with the information they received when asked for consent⁴⁹.

Sands and the University of Manchester are developing a national post mortem consent form in consultation with stakeholders as well as the Department of Health and the Human Tissue Authority.

But if it is to have any impact the new form must go hand in hand not just with training but also with improvements to the resourcing of perinatal pathology services. Sands' vision is for a Bereavement Care Pathway which sets out minimum standards for every aspect of care from bereavement to post mortem and support in another pregnancy.

Managers and service commissioners must fund and organise bereavement services in line with Sands' Guidelines for Professionals, and to include high quality perinatal pathology services.

There must be support for the development and implementation of a Bereavement Care Pathway, outlining minimum standards of care for bereaved families.

Trusts should adopt the national perinatal post mortem consent form and improve training in consent taking in tandem with the form.



Earlier this year *Grazia* magazine and Sands launched the *Stop the stillbirth scandal* campaign. We petitioned the government to fund research to discover new ways of screening pregnancies to find out which babies are at risk of stillbirth. 22,652 people signed the petition which was presented at Downing Street in September 2011.



Neal Long, Sands Chief Executive, Anne Milton, Parliamentary Under Secretary of State for Public Health, Tara MacDowel, Sands Public Affairs and Campaigns Officer, and Katie Duff, parent and Sands Communications Manager

Models for change

Sands aims to collaborate with all stakeholders – from other parents and charity organisations, to policy makers, health professionals and scientists – in order to focus on what can be done to prevent babies' deaths. We hope that by communicating how profound the death of a baby is, we can bring together the community of people who care about these deaths, in positive action for change. These are some of the initiatives we are involved in.

Royal College of Obstetricians and Gynaecologists Stillbirth Seminar

It is increasingly recognised by health professionals that a significant proportion of stillbirths are potentially avoidable. To present the latest thinking about stillbirth prevention, the RCOG hosted, in conjunction with Sands, its first Stillbirth Seminar in December 2011. The seminar aimed to educate all medical professionals involved in maternity issues by addressing the clinical issues surrounding stillbirth and enhancing sensitive management after a death. Speakers included leading experts and researchers in the field of stillbirth prevention as well as bereaved parents, and featured an exhibition of artwork by bereaved mother, Cordelia Spalding. To find out more about the seminar please go to www.rcog.org.uk.

Stillbirth Clinical Studies Group

Scientific progress in understanding causes and developing new interventions for preventing stillbirths has been limited. To stimulate work in this relatively ignored area, Sands and the RCOG have established a Clinical Studies Group focussing on stillbirth. The aim of the CSG is to develop new research, and field prospective projects to improve their quality and access to funds.

The group consists of specialists who have extensive experience of conducting clinical research, with expertise in many aspects of modern research programmes, including biostatistics, public health research and molecular biology. The CSG, funded by Sands and begun in 2011, is chaired by Professor Gordon Smith, Head of Department of Obstetrics and Gynaecology, University of Cambridge:

"I envisage a partnership of bereaved families and the research community working towards a common, ultimate goal: a reduction in the unacceptably high rates of loss of babies through stillbirth. The success of the CSG will, however, depend on funding for research being available."

Scottish Stillbirth sub group

In 2009 Sands presented a report and petition to the Scottish Government, highlighting the level of perinatal deaths in Scotland. Recognising this as a priority issue, the Scottish Government established an expert working group (which includes Sands representatives) tasked with examining what can be done. The Chair is Dr Catherine Calderwood, Senior Medical Officer for Women and Children's Health:

"The group consists of experts who are determined to tackle the daily tragedy of stillbirth in Scotland. We immediately focussed on areas where real and tangible work could be done. Key themes include: failure to identify risks both by healthcare professionals and parents; inequalities in practice both in adherence to guidelines and in care and communication with parents following bereavement."

"We are developing parent information leaflets advising about fetal movements, and national guidance for Scotland for the detection and management of growth restriction. We also hope to standardise perinatal mortality reviews with the aim that lessons learned should not be lost. The group is taking forward the development of specific online learning modules on stillbirth which will be available to all maternity services staff."

Sands, Bliss and the Royal College of Midwives

Now in its third year, Sands, Bliss and the RCM have combined forces to run an annual conference entitled *Uncertainty and Loss in Maternity and Neonatal Care*. The aim of the day is to improve the knowledge base of health professionals, who are often faced with critical illness, loss and bereavement in the delivery of maternity and neonatal care.

Recognising the need for additional support for such professionals - both in and out of the workplace – the host organisations also initiated an online Bereavement Care Network in 2009 to facilitate information exchange and to provide a platform for peer support. This network now reaches almost 1,000 professionals including midwives and neonatal nurses. To join the network, please go to <http://bereavement-network.rcm.org.uk/login/>.

Sands Audit Tool



Sands recently published its Audit Tool for maternity services: *Caring for parents whose baby has died*. It has been developed to help those responsible for commissioning and providing maternity services to assess the quality of care they provide to bereaved parents, and identify any improvements that are needed.

Accredited by the RCM, the Audit Tool is based on standards set out by Sands in its widely acclaimed *Guidelines for Professionals* and by a range of professional organisations.

The Audit Tool has been sent to all Heads of Midwifery, Trusts, and Health Boards. Sands hopes that maternity units will also involve their local Sands support groups in providing feedback on the care parents

have received. To download a free copy of the Audit Tool please go to the Sands website at www.uk-sands.org, and click through to Improving Care.

International Stillbirth Alliance

The International Stillbirth Alliance (ISA) is a non-profit coalition of parents, researchers and healthcare professionals from all over the world who are dedicated to understanding the causes and prevention of stillbirth. ISA's mission is to raise awareness of stillbirth and to promote global collaboration in the prevention of stillbirth and provision of appropriate care for bereaved parents. Sands' active involvement in ISA has brought valuable global learning to the task of addressing stillbirths in the UK.

Members of ISA were the lead authors on *The Lancet's Stillbirth Series*, published in April 2011. The Series, for which Sands wrote a contributing chapter *Stillbirth: breaking the silence of a hidden grief*, consolidated research about the global burden of 3 million stillbirths every year.

"ISA brings together the knowledge of healthcare professionals and the passion of families, with the single purpose of advancing stillbirth research, medical care, and bereavement services. ISA now has 50 member organisations across 14 countries. The Lancet's Stillbirth Series represents ISA's raison d'être and ISA's members, such as Sands, have embraced this opportunity to push for the change that is urgently needed to address the global problem of stillbirth."
Vicky Flenady, lead author for *The Lancet Stillbirth Series* and ISA Chair.

National Post Mortem Working Group

In aiming to ensure parents are fully informed in their decision making, the perinatal post mortem consent forms used in different Trusts have become long and complex. Surveys carried out in 2010 by Dr Alex Heazell from Manchester University found that the forms are a barrier to consenting for both grieving parents and the staff caring for them^{47 49}.

As a result Dr Heazell and Sands brought together an expert working group of perinatal pathologists, midwives, obstetricians, parents and the regulatory bodies to design a more acceptable and workable national template for a post mortem consent form

for a baby. The new template will form the basis for further work on a Bereavement Care Pathway which incorporates best practice in seeking post mortem consent.

"The new national consent form template for post mortem is the end-product of research designed to improve care for parents. It is a salient example of how care after stillbirth can be improved by undertaking research and implementing the findings." Dr Alex Heazell, Obstetrician, University of Manchester

The voices of parents

Thousands of Sands parents, their families and friends are actively making a difference, raising awareness of the devastation of baby death and demanding change. They not only raise vital funds for Sands, they are also politically active, lobbying their local MPs for improved maternity services. There are over 90 Sands groups and at least half are involved with their local maternity units. Some parents sit on Maternity Liaison Committees and others feed into Child Death Review Panels, as well as providing bereavement care training to local hospitals. Sands parents are making their collective voice heard and demanding action now to prevent babies' deaths.



From left: Jerry Stimpson, David Johnston, Nick Hayes, Andrew Malm and Brian Ball climbing Ben Nevis in memory of Andrew's son Rudy Olaf who died shortly after he was born at 36 weeks on 14th September 2010. The Malms have raised over £9,000 for Sands

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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 bereavement 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 11 babies are stillborn and six 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 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
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Preventing Babies' Deaths: what needs to be done was written by Janet Scott and Charlotte Bevan.

The report was designed by Hotrod and printed by Mutual-Media (UK) Ltd.

Todd Hochberg has provided bereavement photography support to families experiencing the tragedy of perinatal loss in the US since 1997. We would like to thank the families pictured in this report for generously allowing us to use their images: Nathan and Stacey Schmidt and their baby daughter Alaina (page 12); Lynda Cafasso and Stephen Conroy and their baby son Joshua (page 20); Holly and Tom Lipostad and their baby daughter Cecilia, sister to Grace (page 24); Sandrika Davidson and her baby son Jeremiah (page 28).

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17 babies are stillborn or die before they are one month old every day in the UK

*"We want to see real national commitment
to tackling this ignored tragedy and preventing
all avoidable baby deaths in the future."*

Neal Long, Chief Executive, Sands

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