

Health and Social Care Committee

HSC(4)-19-12 paper 2

Inquiry into Stillbirths in Wales – Written Evidence from Sands

In Wales in 2010 there were 190 stillbirths: one baby in every 200 is stillborn. Across the UK 11 babies are stillborn every day, devastating the lives of over 4,000 families each year. While neonatal and infant mortality rates have improved significantly over the last decade, stillbirth rates have barely changed.

Despite how prevalent stillbirths are across Wales they are the deaths no-one wants to talk about – the final taboo. There is a tendency to see the death of a baby before birth as ‘just one of those things’, and stillbirths have historically attracted little national attention or action. Yet many of these deaths are potentially preventable.

“I’m not an expert but I know her death was avoidable, that if she’d been taken out sooner she’d have survived.

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 McGeehan

“So often as obstetricians we sit down with a couple who have lost their baby and make plans for how we can work together to carefully monitor and manage the next pregnancy for a better outcome. It’s time we all got it right first time round”

Bryan Beattie, Consultant in Fetal Medicine, University Hospital of Wales

A. BACKGROUND: 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, Sands has supported many thousands of families whose babies have died, offering emotional support, comfort and practical help.

Today Sands operates throughout the UK and focuses on three main areas:

- supporting bereaved families
- working in partnership with health professionals to promote awareness of perinatal mortality and provide professional training in bereavement care.
- raising awareness of the numbers and causes of babies' deaths and promoting prevention work, and funding research that could help to reduce the loss of babies' lives.

In Wales there are currently seven Sands voluntary groups offering support to parents across most regions, and co-ordinated through the Sands Welsh Network. The groups fundraise and have equipped four bereavement suites in maternity units in Wales, as well as a number of cold cots. Trained group members run training sessions for midwives and Supervisors based around Sands' internationally respected *Guidelines for Health Professionals*.

Sands parents in Wales lobby for more action to reduce the numbers of babies dying. In 2009 we presented our *Saving Babies Lives Report* to the Welsh Assembly and our petition calling on the Welsh government to develop a strategy for reducing stillbirths in Wales was signed by 816 people.

Our new *Preventing Babies Deaths: what needs to be done* report was launched in Westminster in March 2012.

B: OVERVIEW

1. The stillbirth rate in Wales is no worse or better than the UK generally, but that does not mean that stillbirths in Wales are something to be complacent about. Across the UK the levels of baby loss are unacceptably high.
2. When a baby is stillborn families are devastated by the loss of their precious baby. The impact is heart-breaking, profound and life-long.

“I left the house thinking I would come home with a car seat with my baby in. Instead I didn't bring my baby home until a few weeks later, and that was in a tiny box.”

A Welsh mum

3. There is real potential to prevent a significant proportion of stillbirths in Wales.
4. A devolved Wales with close communication between policy makers and those who deliver care has the opportunity to make a difference. But leadership and a clear commitment from government is needed to tackle this relatively ignored issue.
5. There have been some relevant steps forward in addressing stillbirths around the UK:
 - The Scottish Government established a Stillbirth Working Group in 2010 which is focussing on areas where real and tangible work can be done. Key themes include: failure to identify risk by health professionals and parents; and inequalities in practice in adhering to guidelines and in care after a baby dies.
 - The Department of Health in England and Sands held a Stillbirth Workshop in March 2012, including parents and experts from a wide range of key disciplines. Five working groups are being set up to focus on particular issues:
 - standards for perinatal death review;
 - determining dataset indicators that ought to be collected in order to improve detection of risk of stillbirth;
 - harmonising guidance and training for midwives and doctors;
 - identifying key public health messages for reducing the risk of stillbirth;
 - developing information needed to build stillbirth prevention into the commissioning of maternity services.
 - The Stillbirth Clinical Study Group, set up in 2011 within the National Reproductive Health Research Network and sponsored by Sands, aims to develop new research into stillbirth and to field prospective projects to improve their quality and access to funds.

- Sands is supporting a National Post Mortem Working Group which is aiming to design a more acceptable and workable national template for a post mortem consent form. Wales is represented in this group.
- The Wales Maternity Collaborative has very recently set up a new National Stillbirth Working Group as part of the 1000 Lives Plus programme. The group is starting to shape an action plan to tackle stillbirths in Wales. Sands is delighted to be contributing to this group.
- The Clinical Outcome Review Programme which will gather perinatal outcomes data across the UK is due to resume this year, though final confirmation of the programme's start is still pending.

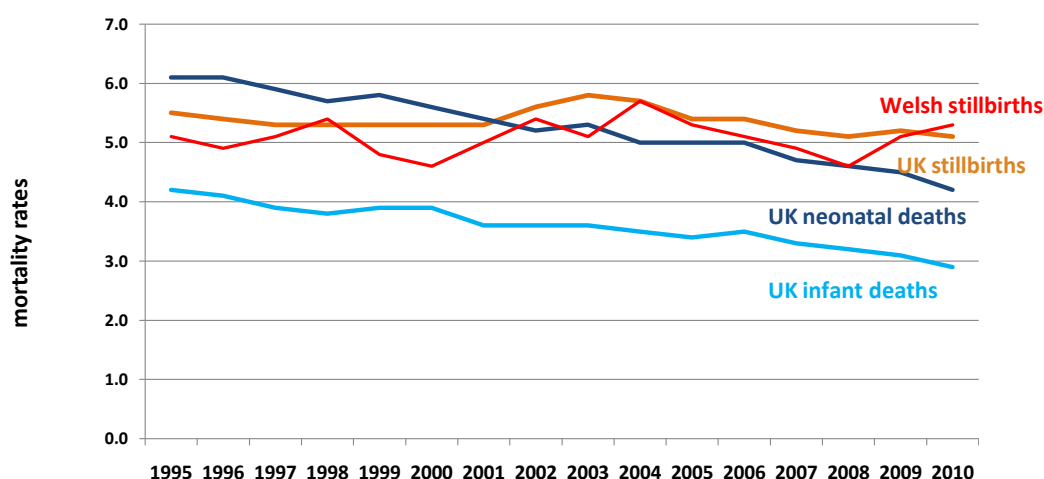
SUMMARY OF SANDS RECOMMENDATIONS:

- 1. Key public health messages need to be developed so that parents and the pre-pregnant population in Wales are aware of the risks of stillbirth and can make informed choices about their health and pregnancy.**
- 2. Stillbirth and associated risks must be more prominently featured in Welsh midwifery and obstetric training curricula.**
- 3. Standards of practice in detecting and managing at-risk babies must be raised across Wales: best practice guidance must be shared and implemented as standard, and audited, so that all mothers and babies receive the best antenatal care.**
- 4. Funds for research into the causes and prevention of stillbirth must be prioritised.**
- 5. Action is needed to ensure minimum staffing levels and the right skills mix in all areas of maternity care in Wales, as outlined by the relevant professional bodies.**
- 6. A national standard for reviewing perinatal deaths must be developed and followed across Wales. The quality and effectiveness of hospital level review must be audited.**
- 7. At least one more full -time Perinatal Pathologists should be appointed in Wales. Training for consent takers needs to be improved in tandem with improved information for parents.**
- 8. Bereavement services across Wales should be organised and resourced in line with standards set out in Sands' *Pregnancy Loss and the death of a Baby: Guidelines for Professionals*.**

C: STILLBIRTHS IN WALES – THE FACTS

1. In Wales in 2010, 190 babies were stillborn. The rate of stillbirth has remained at the around the same level for over a decade¹. This lack of change in stillbirth rates reflects the situation for the UK².

Comparative mortality rates 2010: stillbirth, infant deaths and neonatal deaths



Sources: Welsh Statistics Office; Office of National Statistics; General Register Office for Scotland; Northern Ireland Statistics and Research Agency.

2. Unlike stillbirths, neonatal mortality and infant mortality have fallen significantly in the same time. Stillbirth is in fact the most common form of child mortality³.
3. As a cause of death for children, stillbirths are 10 times more common than cot death⁴; 40 times more common than child road deaths⁵; 80 times more common than childhood meningitis⁶. While rightly there are strenuous efforts to reduce these deaths, stillbirths, which are far more common, remain relatively ignored.
4. Similar high-income countries have lower stillbirth rates: the UK ranks 33rd out of 35 similar nations in a recent Lancet analysis⁷. What is more worrying still, while other countries are reducing their stillbirth rates, the same is not true in both Wales and England where rates have not changed for more than a decade.
5. 90% of stillborn babies have a no lethal congenital anomaly or any significant fetal condition⁸, challenging the perception that these babies are somehow 'meant to die'. The majority of stillbirths are unexplained, in other words the baby was perfectly formed and no maternal condition or problem was found.

6. There is an increased risk of stillbirth associated with certain maternal medical conditions such as hypertension and diabetes, with previous obstetric complications, in multiple pregnancies and in first pregnancies⁹. However most stillbirths happen in pregnancies that were considered 'low risk', until the baby died.
7. A quarter of stillbirths are associated with smoking in pregnancy. Women who smoke more than 10 cigarettes a day double their risk of stillbirth¹⁰. In Wales 16% of mothers continue to smoke through pregnancy¹¹.
8. Stillbirth rates are higher amongst mothers who have a BMI over 30, with almost twice the risk of stillbirth than a mother with a BMI under 25. The risk increases with increasing obesity¹².
9. The odds of having a stillbirth increase steadily with age in mothers over the age of 35, doubling for mothers over 40¹³.

D: RECOMMENDATIONS FOR IMPROVEMENT

1. Public health and informed choice

Time and again parents tell Sands of the devastation they experienced when their baby died, and the subsequent shock when they discovered how relatively common stillbirths are. Many ask why they were never told this could happen. Cot death and Down's syndrome are openly discussed, yet stillbirths which account for many more deaths are rarely mentioned.

Welsh mothers are not informed of the risk factors for stillbirth. The messages about the dangers of smoking and obesity in pregnancy do not mention that stillbirth is also a risk, yet these are factors which mothers can potentially modify. An older mother might want to know her risk of stillbirth is increased, when she makes decisions about her birth plan.

"You can't make informed decisions if you're not informed"
Bereaved dad

Is it scaremongering to tell prospective parents of the risks, however small, of their baby dying or is it giving them the power to make truly informed choices?

Key public health messages need to be developed so that parents and the pre-pregnant population in Wales are aware of the risks of stillbirth and can make informed choices about their health and pregnancy.

2. Training for health professionals

It is not just parents who are surprised to hear that 1 in 200 babies is stillborn. An individual health professional in Wales may never, in their professional career, care for a woman who has a stillbirth; many perceive stillbirth as an uncommon event, but it is not rare nationally.

Lack of awareness means too often that women who do exhibit risk factors are not actually picked up. Many trainee midwives tell Sands that they graduated without having learned about stillbirth and the risks; many say they do not feel confident about caring for bereaved parents.

If Welsh health professionals perceive stillbirth to be a rare event there is a danger they will miss warning signs or underestimate the potential risks.

Stillbirth and associated risks must be more prominently featured in Welsh midwifery and obstetric training curricula.

3. Picking up risk

Routine antenatal care in Wales is failing to spot too many babies who need help. NICE Guidelines for routine assessment of fetal wellbeing after the 24th week is simply, "Symphysis-fundal height should be measured and recorded at each antenatal appointment"¹⁴, in other words, use a tape measure. Screening methods today are not dissimilar to those in use 40 years ago.

Today it is rare to lose a baby in a pregnancy where a risk has been identified. But most stillbirths are in pregnancies where the risk was not spotted: the 'low risk' women who in fact have high risk babies are being missed.

Growth restriction in the baby is strongly associated with stillbirth, yet current antenatal care only picks up 30% of babies in the womb who are growing too slowly¹⁵. Growth monitoring varies in practice and quality from unit to unit, and is not audited. Too many babies who are failing to thrive and who should be having high risk care are not picked up until it is too late.

A decrease in fetal movements can indicate that a baby is in trouble yet it is common for parents to tell Sands they reported a decrease in their baby's movements but were reassured and sent home, only for their baby to day hours or days later. Parents in Wales are not equipped with good advice about fetal movements, but neither are many health professionals fully aware of the latest guidance from the Royal College of Obstetricians and Gynaecologists (RCOG) on managing decreased fetal movements¹⁶. In Norway a focus on improving fetal movement advice was accompanied by a significant fall in the numbers of stillbirths¹⁷.

"I had been telling the midwives for weeks that my bump wasn't moving as he used to but was told that it was normal as there is less space in the womb.

I went into labour in morning and the midwife made an appointment for me at the antenatal day clinic for the afternoon, a good six hours away. During the morning my little bump was moving, but on the way to the hospital I knew something wasn't right. I told them when I arrived but felt that they didn't take me seriously and I was made to wait.

Now for me looking back those six hours were a long time to wait and if I could have gone in during the morning things could well have been different." A Welsh mum

A third of stillbirths are term babies, in other words babies who might otherwise be ready to start their lives outside the womb. It is well known that stillbirth risk increases near the end of pregnancy, particularly for women who already have some other risk factor such as advanced age, yet practice about when to induce delivery in prolonged pregnancies varies greatly.

There is the same lack of consistency in detecting and managing maternal conditions associated with stillbirth such as infections, hypertension and diabetes.

Standards of practice in detecting and managing at-risk babies must be raised across Wales: best practice guidance must be shared and implemented as standard, and audited, so that all mothers and babies receive the best antenatal care.

4. New research

Even if we standardise care, and improve detection of at risk babies with the tools we already have, there is still so much we do not know. Research into stillbirth is where cot death research was 20 or 30 years ago: at the very beginning of its journey. The Lancet's 2011 Stillbirth Series recommends that, *"Further research is needed on underlying mechanisms to aid early detection and effective management of women at increased risk."*¹⁸

We have made huge advances in other difficult areas such as prematurity but virtually no progress in understanding why a seemingly perfectly healthy baby dies at term. Placental problems underlie most unexplained stillbirths but research into what is going wrong is lacking and there is no accurate way of predicting a failing 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."

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

Sands parents and other parent charities are passionate in their commitment to fundraise for the research that is so desperately needed. The numbers of babies dying from cot death has fallen by 70% as a direct result of research, and we believe the same could be done for stillbirth. But for this to happen the generosity of parents must be matched by a commitment from government.

Funds for research into the causes and prevention of stillbirth must be prioritised.

5. Resourcing for quality and safety

Safety and quality of care are threatened by understaffing throughout maternity care in Wales.

High quality antenatal care depends on continuity of midwifery care. Routine antenatal monitoring relies on the instincts of health professionals, their sense that 'this doesn't seem right'. When a mother is seen by a different midwife at every antenatal appointment, and has a relationship with none, is it surprising that warning signs are missed?

Births are rising in number at the same time as becoming increasingly complex. The Royal College of Midwives is calling for 136 more midwives in Wales to meet rising demands¹⁹, and the Royal College

of Obstetricians and Gynaecologists has expressed concern about the continuing lack of obstetric cover on labour wards^{20, 21}.

The death in labour of a term baby is a tragedy that should never happen. Yet the numbers of avoidable intrapartum death rates remain stubbornly unchanged, the same failures being repeated.

Under-resourcing and under-staffing can have tragic consequences. This was confirmed in recent research which found the chance of a baby dying from labour related causes increased by 45% at nights and at weekends, when staffing levels were lower²². Although 70% of babies are born at night maternity services are not run as a 24/7 service.

High quality maternity care requires that we have the right numbers of staff with the right skills mix in the right place, at the right time. There are too many maternity units with inadequate numbers of midwives and doctors, putting pressure on team working, communication and risk allocation.

Action is needed to ensure minimum staffing levels and the right skills mix in all areas of maternity care in Wales, as outlined by the relevant professional bodies.

6. Learning lessons through perinatal review

When their baby dies, most parents want to know why. Especially if the death was 'unexplained', it is often presented to them as a rare and regrettable, but unavoidable, tragedy. Yet we know that substandard care plays a role in many stillbirths.

Confidential enquiries into stillbirths have consistently found that sub-optimal care factors contributed to the baby's death in at least 45% of cases^{23, 24}. These enquiries also find that lessons are too often lost because deaths are not adequately investigated and recommendations for change are not implemented.

When a case of sub-standard care is so extreme that parents sue for negligence it costs the NHS dearly: in Wales obstetrics is the largest single contributor to clinical negligence costs. Claims over £1million in 2010/2011 in obstetrics amounted to £9.5 million out of total costs of £17.2million: well over 50% of payments²⁵.

Experts agree that rigorous and independent perinatal review is vital if sub-optimal care is to be identified²⁶. But the quality of review in Wales varies widely: each unit conducts reviews differently and it is unclear who attends the meetings or what the outcomes are. We believe the process requires scrutiny and analysis to establish minimum standards of review with minimum time frames.

Parents need honest answers about why their baby died. They also need their own perspective of their care to be acknowledged and included in the review when appropriate. A review process which is rigorous, fair and open will answer questions for parents. It is not to apportion blame for blame's sake, but to gain some measure of 'truth and reconciliation', to learn lessons and improve quality and safety of care for the future.

A national standard for reviewing perinatal deaths must be developed and followed across Wales. The quality and effectiveness of hospital level review must be audited.

7. Perinatal Post mortem

Perinatal post mortem rates are low. The most recent data shows only 45% of parents consent to a post mortem in Wales²⁷.

Parents are asked, in the disorienting hours after they find out their baby is dead, to fill in a long and complex consent form with distressing details and choices about having a post mortem. It is essential that the staff caring for them have the information and skills to support them through this painful process. Yet recent research²⁸ has found that the health professionals who most often carry out this task often feel ill equipped or trained and voice their lack of confidence to do so.

Resourcing of perinatal pathology services in the Wales is inadequate: the whole country is serviced only by the equivalent of a 1.2 whole time perinatal pathologist. This situation has not improved over several years and parents continue to have to wait too long for post mortem reports.

Add to that the prospect of their baby being transported across the country to a specialist perinatal pathologist, it is little wonder so many parents opt to avoid post mortem altogether.

At least one more full -time Perinatal Pathologists should be appointed in Wales. Training for consent takers needs to be improved in tandem with improved information for parents.

8. Care after a death

The care that bereaved families receive 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.

Sands parents in Wales have experienced very variable standards of care after their baby died, with examples of truly excellent care alongside stories of desperately insensitive treatment and inadequate facilities.

A Sands survey of UK maternity units in 2009²⁹ found bereavement care is patchy. Basic facilities, such as a room away from the labour and postnatal wards where bereaved parents can be cared for without hearing the sounds of other mothers and their live babies, is still not standard in all units. Similarly, many units have no designated bereavement midwife.

Bereavement services across Wales should be organised and resourced in line with standards set out in Sands' *Pregnancy Loss and the death of a Baby: Guidelines for Professionals*.

BABY K

Baby K was stillborn on 8th November 2008 at 39 weeks and 4 days, weighing only 5lbs. At 34 weeks tests undertaken in response to abdominal pain and bleeding showed his mother had high blood pressure and traces of protein in her urine. A series of subsequent tests continued to show the same problems for hypertension.

At 38 weeks a community midwife was due to visit her at home to check her blood pressure but didn't show up. Baby K's mother had to call the hospital to have the visit re-arranged. She still had high blood pressure and the midwife attending this visit recommended a 'plan for delivery' but none was made. The midwife said she would be returning in a few days. She didn't and six days later the mother called to get an appointment. A community midwife eventually arrived and with a hand held monitor confirmed that Baby K had died.

Subsequent to Baby K's stillbirth, his mother found that no record of his growth had been charted in her notes for the last five weeks of her pregnancy, during which time she was seen 9 times in an emergency assessment unit. His post mortem indicated he was growth restricted and had died from lack of oxygen.

"My partner and I were totally devastated by our son's death. Some people say 'it's a shame but you're still young, you will have more children'. What do they know? Losing a baby is one of the worst things that can happen and we will never be the same."

Baby's K's mother always felt that she was labelled during the pregnancy as an anxious young mother. Two of her own siblings had died; one a stillbirth (seven years previously) and another a cot death (13 years previously). She was 21 year old when pregnant with Baby K and in her notes one of the many consultants she saw had recorded her as being "identified anxious, no risk factors".

"One of the most important things we would like to see changed is the communication between the team at the hospital and in the community. Communication is poor, the left hand doesn't know what the right hand is doing. We saw different midwives and consultants every time and they were often not familiar with my notes so we would have to remind them what my symptoms were. We truly believe our son was one of the babies that could have been saved if jobs were done properly. We now have no faith whatsoever in the NHS maternity services. Words can't really express how let down we are by them, to them we were just a number."

Baby K's parents are now involved in litigation with the hospital where she had her antenatal care.

BABY X

Baby X was stillborn on June 14th 2010 at 36 weeks. But the pregnancy had not been a normal pregnancy.

It was instead characterised by repeated water infections, the identification of Group B Strep and growth restriction – issues which Baby X’s mother believed she had had to continually fight to be taken seriously. At one point staff caring for her were unaware that the mother had tested positive for Group B Strep and no protocol for what might happen in labour was planned for, either in her notes or explained to her in person. Instead she was encouraged by midwives to go ahead with a planned water birth.

In her final week of pregnancy, Baby X’s mother complained daily of abdominal pain, leaking water and reduced fetal movements. She had no further scans but was checked on a day assessment unit with a heart monitor, a device that arguably only indicates a baby is alive at the time when you use it, but does not indicate anything more in depth about its wellbeing.

It was as if staff were simply watching Baby X gradually deteriorate, taking no action except to listen to her heart beat to assure themselves that she wasn’t yet dead.

“Devastated and life shattering doesn't begin to cover how I felt. When they confirmed that she was dead, I screamed telling staff how I'd told them all week things weren't right and they refused to listen.”

Baby’s Xs mother had in fact been leaking amniotic fluid during the final week of Baby X’s life. An investigation of the placenta indicated that that she had a rare clotting disorder which had caused the placenta to slowly fail. Baby X also tested positive for Group B Strep; had she been born alive, there is a strong possibility she would have died neonatally.

The mother was told by staff at the hospital that a post mortem was ‘pointless’ and she didn’t therefore consent to one, a decision she now regrets.

Baby X’s mother went onto have another daughter and experienced the same symptoms (a drop in movements and abdominal pain) in that pregnancy. A scan revealed that this baby had also stopped growing and she was induced at 35 weeks. She now has a healthy little girl.

The story of Baby X reflects what Sands sees time and time again which is the experience of a mother who has to have a baby die in order to receive adequate care in a subsequent pregnancy.

“If I was able to receive immediate attention with my second daughter and an adequate level of care why didn't I get that with my first daughter? You should never ever have to lose a child to gain one.”

The family feel Baby X’s death could have been avoided with better care, and having been rebuffed by the trust they are now seeking legal redress.

“I believe strongly my daughter’s death could have been avoided had I received appropriate care and attention. I hope to get justice for her.”

BABY G

Baby G was stillborn on his due date on 30th January 2010. His mother had reported reduced fetal movements from 38 weeks to midwives. She attended a day assessment unit four times, when midwives checked the baby's heart beat.

She was advised to keep drinking cold water and be aware of her baby's movements although reduced movements were 'normal because there was less space in the womb'.

When she went into labour on 29th January Baby G's mother called into the hospital and was given an appointment to be admitted six hours later. While the baby had moved in the morning, on the way to hospital she knew something was wrong because he hadn't moved for several hours. After two scans it was confirmed that Baby G had died. He was 8lbs when born.

Baby G's mother was put in a private room on the labour ward and her family told to go home. The next morning she could hear a woman laboring in the next door room. Despite putting on the television and radio, as well as wearing I-pod headphones, she could still hear the cries of a new baby.

"I sat in the corner going out of my mind. Thankfully my partner came in at the point when I was just about to walk out. They wanted me to stay but I refused saying this isn't the right environment."

The family were given Sands information but offered no counseling and given no information from the hospital about holding a funeral for their son. They had to look the information up on the internet.

When they went to register their son's death, there was confusion over his stillbirth certificate. The registrar had never recorded a stillbirth before and despite having an allocated slot, the process took a long time, with the cries of babies in the waiting room audible throughout.

A post mortem found no explanation for Baby G's death.

"When I fell pregnant with second pregnancy I was naturally worried. Throughout the pregnancy I felt like I was on my own. I tried to talk about my anxiety and feelings to my midwife but got the feeling that she just didn't know what to say. I wish there was a specialist midwife that I and others in my situation could talk to with the feeling of being listen to and being supported."

BABY H

Baby H was stillborn at 42+ weeks on 14th January 2001. Her mother went into hospital three days before Baby H was born, complaining of acute abdominal pain. She was monitored overnight but not seen by a doctor despite staff saying she would be before she was sent home.

She went home only to return to hospital the following day with strong contractions. But labour was slow to progress and when the baby's heart rate dropped, her waters were broken to speed up delivery.

Staff found meconium in her waters and she was sent for an emergency C-section. When she woke from the general anaesthetic, she was told her baby had died.

"The only way I can describe it is to say it was like an out of body experience. I could hear this howling and I didn't realise it was me."

Baby H was 10lbs 1oz and while a post mortem was inconclusive and the hospital did not send her placenta for post mortem, doctors delivering her say the placenta was very degraded.

The story of Baby H reflects what Sands hears time and time again. A low-risk mother in a supposedly low-risk pregnancy, whose pregnancy goes well beyond term, only for her baby to die.

Baby H's mother has gone on to have two healthy boys, both delivered at 38 weeks by elective C-section.

IN CONCLUSION:

We believe there is real potential to tackle unacceptably high stillbirth rates in Wales. Other countries have shown that this can be done. A clear commitment from the Welsh Government to prioritise this issue and to lead a national prevention strategy, could lead to many babies' lives being saved.

We would welcome working with the Welsh Government and contributing to achieving this.

A handwritten signature in black ink that reads "Neal Long". The signature is written in a cursive, flowing style.

25th May 2012

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