



# AIMS

## Stillbirth

Creating memories

Bereavement care – getting it right

Supporting parental decision making

[www.aims.org.uk](http://www.aims.org.uk)

# Diary

## AIMS meetings

Saturday 21 November 2015,  
York or Wakefield (to be confirmed)

All AIMS members are warmly invited to join us. For further details, to let us know you are attending or to send apologies please email [secretary@aims.org.uk](mailto:secretary@aims.org.uk)

## AIMS AGM

### and talk with Nicky Leap

Saturday 12 September 2015,  
Bristol

### AGM 10.30 for 11.00 start

AIMS members only

### Lunch 1.30 - 2.30

For AIMS members and those attending the talk  
Please bring food to share

### General Discussion 2.30 - 3.30

### AGM talk and workshop

Open to all

### Working with Pain in Labour with Nicky Leap

3.30 – 6.00pm

Close 7.00pm

(Tickets for talk must be purchased in advance)

For further information and tickets please email [talks@aims.org.uk](mailto:talks@aims.org.uk)

Please contact

[secretary@aims.org.uk](mailto:secretary@aims.org.uk) if you wish to attend the AGM or send your apologies.

Please always check our website or contact us to confirm details as sometimes these change.

## Time to Grow Midwifery Conference 2015

Wednesday 23 September 2015,  
William Harvey Hospital  
(Ashford)

Speakers include

Dr Michel Odent, Lesley Page CBE, Sheena Byrom OBE, Dianne Garland, Amanda Burleigh - BJM Midwife of the Year 2015 and Rebecca Schiller

[www.eventbrite.co.uk/e/time-to-grow-midwifery-conference-2015-tickets-16232820804](http://www.eventbrite.co.uk/e/time-to-grow-midwifery-conference-2015-tickets-16232820804)

## Association of Radical Midwives Oxytocin

31 October 2015

Nottingham, England

[www.midwifery.org.uk](http://www.midwifery.org.uk)

## Economic and Social Research Council

### Breastfeeding Seminars

November 2015 -

November 2016, Bristol

[www.esrc.ac.uk/news-and-events/events/33627/seminar-1-social-experiences-of-breastfeeding-building-bridges-between-research-and-policy.aspx](http://www.esrc.ac.uk/news-and-events/events/33627/seminar-1-social-experiences-of-breastfeeding-building-bridges-between-research-and-policy.aspx)

## Chichester Home Birth

### Home Birth: Inspiring Women

12 March 2016

contact Mandy 02392 462786

[www.chichesterhomebirth.org.uk](http://www.chichesterhomebirth.org.uk)

# AIMS

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in the Maternity Services  
Registered Charity Number 1157845

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AIMS Research Group

A group has been established to review research for the Journal. If you are interested in joining the team, please email [research@aims.org.uk](mailto:research@aims.org.uk)

Association for Improvements in the Maternity Services

founded in 1960

by

Sally Willington 1931 – 2008

# AIMS

campaigning for better maternity services for over 50 years

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**Cover Picture:**

Surrender: a quilt by artist and quiltmaker Maria Elkins. For more information see page 19.

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# Contents

<b>News</b>	4
<b>Editorial</b>	
Caring for parents	5
<i>Gill Boden, Debbie Chippington Derrick, Shane Ridley</i>	
<b>Articles</b>	
What happens next?	6
<i>Brenda van der Kooy</i>	
A stillbirth legacy	7
<i>Nicky Heppenstall</i>	
One chance to get it right	9
<i>Amanda Hunter</i>	
Stillbirth support resources	11
<i>Shane Ridley</i>	
<b>Report</b>	
Perinatal mortality	13
<i>Beverley Lawrence Beech</i>	
The Birth Project Paintings	14
<i>Shane Ridley</i>	
<b>Research</b>	
Counting the kicks	15
<i>Gemma McKenzie</i>	
Support for loss	17
<i>Nadia Higson</i>	
<b>Readers' forum</b>	
One-to-one care	20
<i>Lulu Stacey</i>	
My story	22
<i>Rose Wilsher</i>	
Memories of George	23
<i>Radka Elliott</i>	
After stillbirth	24
<i>Shane Ridley</i>	
<b>Reviews</b>	
When a baby dies	25
<i>Gill Boden</i>	
The children who sleep by the river	25
<i>Debbie Chippington Derrick</i>	
We were gonna have a baby but we had an angel instead; Goodbye baby; Lucy's baby brother	26
<i>Gill Boden</i>	
<b>Report</b>	
Women and midwives working together	27
<i>Olivia Lester</i>	

# News

## Maternity review

[www.england.nhs.uk/wp-content/uploads/2015/03/maternity-rev-tor.pdf](http://www.england.nhs.uk/wp-content/uploads/2015/03/maternity-rev-tor.pdf)

In the context of the highest birth-rate for 40 years with an increasing proportion of multiple births, preterm babies, older mothers and pregnant women with pre-existing medical problems, the government has set up a maternity review, the NHS Five Year Forward View, to recommend how to provide *'modern, high quality and sustainable maternity services across England'*. It is expected to report by the end of the year.

The review will consider outcomes for women and babies, looking particularly at the stillbirth rate across the UK and how it varies according to area. Noting the fact that most women want to give birth in a midwife-led setting and that NICE guidance makes clear the advantages of doing so, it will investigate the provision of midwife-led units, paying attention to the challenge of providing services in rural and sparsely populated areas.

If you want to be kept informed about the progress of the review, including receiving details of how you will be able to input, send your contact details to [england.maternityreview@nhs.net](mailto:england.maternityreview@nhs.net).

## Portlaoise Hospital and perinatal deaths: when 'investigations' and 'reviews' fall drastically short of the mark

A report called 'Fatal Failures' aired on Irish television's Primetime in January 2014. It revealed that between 2006 and 2012, the deaths of four babies in the maternity unit of Portlaoise Hospital, initially communicated to their parents as being unavoidable stillbirths and 'rare' occurrences, were in fact perinatal deaths sharing common factors of poor care, negligence, and subsequent cover-ups.

Roisin and Mark Molloy were shell-shocked by their baby boy's death and further traumatised by the appalling and insensitive treatment meted out to them. Roisin, unwell and with four young children to care for, *'became the crazy mother telling everybody that my child had died when he should not have died and highlighting safety concerns in regard to the maternity unit at Portlaoise hospital'*.<sup>1</sup> She and Mark relentlessly pursued all possible official channels over several years to find out why baby Mark had died. The unanswered correspondence, fruitless meetings and endless avoidance tactics reaped the whirlwind when the Primetime programme uncovered these deaths and then, in April 2014, a fifth death under similar circumstances with similar lies.

This provoked first a report by the Chief Officer of Health, and then one by HIQA, the health standards authority, both of which bore out the parents' accounts. The publication of the second report was delayed

because the overseeing agency of the health services, the HSE, threatened HIQA with a court injunction over misrepresentation of the facts. The current Minister for Health, jettisoning the oft-stated claim that Irish maternity services are the safest in the world, has confirmed that the families were *'lied to'* by HSE staff.<sup>2</sup>

We are currently awaiting an additional review of the Portlaoise baby deaths, to investigate the role played by syntocinon overuse as a factor in these perinatal deaths. We are also awaiting reviews of perinatal deaths in Cavan and Portlinculla hospitals.

*Jo Murphy-Lawless*

## References

1. Testimony by Roisin Molloy, Joint Oireachtas Health Committee, 19 May 2015. [oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/HEJ2015051900002?opendocument#C00100](http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/HEJ2015051900002?opendocument#C00100)
2. Flaherty R (2015) Varadkar: Parents of babies who died at Portlaoise hospital 'were lied to'. Irish Times, 17 May 2015. [www.irishtimes.com/news/politics/varadkar-parents-of-babies-who-died-at-portlaoise-hospital-were-lied-to-1.2215623](http://www.irishtimes.com/news/politics/varadkar-parents-of-babies-who-died-at-portlaoise-hospital-were-lied-to-1.2215623)

## Each Baby COUNTS

[www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/](http://www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/)

In January 2015 the Royal College of Obstetricians and Gynaecologists (RCOG) started to collect detailed data on intrapartum stillbirths (babies thought to be alive at the beginning of labour, or induction of labour), early neonatal death and severe brain injury diagnosed in the first seven days of life.

All UK trusts and health boards have been asked to nominate a lead reporter who will be responsible for reporting events when they occur. Cases should be reported by the hospital or unit in which the birth took place. If the mother was transferred in labour the location of the onset of care in labour will be recorded. All data submitted will be available for review and for changes to be made by the lead reporter.

By bringing this data together for the first time, RCOG hope to be able to identify common themes across the country which relate to these events and share the lessons learned to improve future care. Then it hopes to be able to advocate for national change, where appropriate, as well as local service improvements.

RCOG will not be recording personal details and recommends that lead reporters maintain a local log of Each Baby Counts IDs and the baby's NHS number and date of birth to assist with any queries that may arise and asks that all investigation reports should be anonymised prior to submission.

RCOG acknowledges the overlap with MBRRACE reporting and states that the primary aim of Each Baby Counts is to bring together the results and recommendations of local incident investigations because, as they say, this detailed information is not captured by MBRRACE or any other organisation at a national level. RCOG is working with MBRRACE to cross-check the data and ensure that all eligible cases are identified.

# Caring for parents

Gill Boden, Debbie Chippington Derrick and Shane Ridley talk about stillbirth

*'Imagine a love so strong that saying hello and goodbye at the same time is worth all the sorrow.'*

(author unknown)

**I**nstead of the joy of a new life, stillbirth means parents are faced with the loss of their baby. So, while routinely preparing women for stillbirth may not be appropriate, more openness might make it easier for those who find themselves in this extremely distressing situation. Lack of preparedness also means those who are supporting the parents through pregnancy and birth have a very important role to play.

Stillbirth is when a baby is born dead after 24 completed weeks of pregnancy; it includes babies who die before or during labour and those who show no signs of life when born. A baby born alive who then dies within seven days of birth is classified as a perinatal death, this overlaps with neonatal death where a baby dies in the first 28 days of life. When a baby dies in pregnancy before 24 weeks it is classified as a miscarriage. Although this Journal primarily focuses on stillbirth, the issues raised frequently apply just as much to miscarriage, perinatal or neonatal death.

The article by Amanda Hunter (page 9) details the support and training that Sands is able to provide, developed from years of experience of meeting the needs of parents. The report of the NPEU review of support available for loss in early and late pregnancy (page 17) provides details of successes in this area as well as issues that still need to be addressed, after miscarriage as well as stillbirth.

When a baby dies before birth parents need to make plans for the birth. Brenda van der Kooy (page 6) discusses how these may be different from their previous plans and how, to avoid later regrets, parents should be given time to make decisions that are right for them. AIMS' experience is that a more medicalised birth is assumed when a baby has died, planned homebirths are often abandoned unnecessarily, and certainly homebirth is not usually offered as an alternative.

Much of the improvement in services and support has come about through the efforts of those who have experienced stillbirth. For example, Nicky Heppenstall (page 7) explains why professional photographers volunteer their services for UK parents whose baby has died.

Following a stillbirth parents will need to be helped to do what is right for them, organise a funeral, a burial place or other memorial, and to cope through the days, weeks, months and years ahead.

Shane Ridley (page 24) looks back on the difference made by the support she and her husband received. If there are other children they will need support in grieving for their lost sibling. Gill Boden (page 26) reviews three books for young children exploring things they may experience following a stillbirth or miscarriage.

Whilst putting together this Journal we were struck by how often we encountered the issue of women requesting a caesarean. When a baby dies before birth mothers often want to end their pregnancy as quickly as possible and not have to birth a dead baby,

something a caesarean section would achieve. However, evidence-based practice is to encourage vaginal birth to avoid compromising the next pregnancy with a uterine scar. We had much discussion about whether the lack of emphasis on the risks of this common surgery is affecting women's reactions. We feel that there is an issue here that needs exploring further, as the risks of caesareans seem to be being made much clearer to women facing a stillbirth, while they are often minimised for a live baby.

Although in this journal we have not considered interventions to try to reduce the numbers of stillbirths, we are aware of the increasing pressure on women to have induction and ultrasound monitoring late in pregnancy. While these interventions can be life-saving, they also carry risks. We need good research to tell us if and when their use can improve outcomes, and when they may result in more harm than good.

Controversy has also been seen in relation to encouraging women to monitor fetal movement; Gemma McKenzie (page 15) looks at changes in practice, the research, what information women should be given and how their concern about their baby should be addressed. Some research into fetal movements has uncovered a failure to listen to women: our review of Kohner and Henley's book, *When a Baby Dies*, (page 25) highlights the importance of increased individual care and support.

Attempts to prevent stillbirth can involve promoting interventions that conflict with maintaining normality in pregnancy and birth. Yet continuity of carer offers the potential to improve outcomes and to maintain normality. There are links between stress and adverse outcomes such as IUGR (Intra-Uterine Growth Retardation), prematurity and low birth weight,<sup>1</sup> and there are also links between these problems and stillbirth and neonatal deaths.

The significantly lower stillbirth rate achieved by the Albany Midwifery Practice (thealbanymodel.com) suggests a link with excellent midwifery care and continuity of carer and it has been shown that continuity of midwifery carer reduces early fetal loss.<sup>2</sup>

We are concerned about the increasing medicalisation of pregnancy and birth in the name of reducing stillbirths and other adverse outcomes. Women are being exposed to more tests, ultrasound scans, inductions and other interventions which often have not been shown to improve outcomes and are not without consequences. We call for more research on the difference continuity of midwifery support can make, an intervention that women want and are campaigning for, and which has been shown to have the potential to improve many outcomes, psychological as well as physical, without doing harm.

*Gill Boden, Debbie Chippington Derrick and Shane Ridley*

## References

1. Gardosi J, Kady SM, McGeown I et al (2005) Classification of stillbirth by relevant condition at death (ReCoDe): population based cohort study. *BMJ*. doi: 10.1136/bmj.38629.587639.7C
2. Sandall J, Soltani H, Gates S et al (2013) Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD004667.pub3

# What happens next?

Brenda van der Kooy looks at the importance of giving parents time to decide

**L**earning that your baby has died before being born is a devastating shock which most parents have never before contemplated happening to them. Suddenly that wonderful excitement and anticipation of the future, dreams and joy are swept away. The pain of grieving is profound and there are no shortcuts in the emotional journey that must be travelled. However when a baby dies in the womb, the reality is that the baby still needs to be born.

For some parents an early reaction is to ask for a caesarean section in the hope that this will get it over quickly and prevent further distress for the mother. However, unless she has a specific medical condition, having a caesarean section would pose an increased risk for the mother in this pregnancy and importantly for future pregnancies. Therefore, having a vaginal birth is likely to be recommended as the safest option.

So if labour has not already begun, the options come down to inducing the labour or waiting for labour to start spontaneously. NICE Induction of Labour Guideline ([www.nice.org.uk/guidance/cg70](http://www.nice.org.uk/guidance/cg70)) recommends 'if the woman appears to be physically well, her membranes are intact and there is no evidence of infection or bleeding, she should be offered a choice of immediate induction of labour or expectant management.'

Both these options are equally valid and are a matter of the mother's personal choice. It is really important that parents are encouraged to take time to decide what is right for them given all the information about both options. During my midwifery career I have never met anyone who has regretted taking time to make a decision, but I have met families who wished they had. I have also learnt that parents' decisions can frequently change a number of times, even over just a few hours.

A general misconception is that the baby will begin to decompose in its mother's womb and therefore action must be taken straightaway. This is not true. The baby will gradually change in appearance but not decay. Some mothers have waited weeks, savouring the precious time together with their baby. For others, labour starts spontaneously within hours or days. Other parents have chosen to have labour induced. The decision to have an induction of labour can be made at any time. Some feel clear about having an induction after considering their choices overnight. Others prefer to take longer to see if labour will start on its own. The most important thing is that parents are supported to give themselves some time.

Another important choice to make is where they would like to have their baby. This may be where they originally planned – an obstetric unit, midwifery led-unit or at home – or they may wish to change.

Over the last couple of decades much has been learnt about how healthcare professionals can support parents

in ways that help them to come through the grieving experience. Hospitals will all have guidelines that should ensure parents are offered the full range of options and the care offered is truly parent centred and flexible.

However, due to the fragmented model of midwifery care in most NHS Trusts, few women will have a midwife they already know and trust to care for them through labour and the following weeks. As it is well recognised that this is not ideal, many hospitals have a specialist Bereavement Midwife who will become directly involved and/or support the midwives who are allocated to caring for the parents. The Bereavement Midwife is a great resource for any parents who find themselves in this situation and will have the confidence and experience to support parents' choices.

## The choices and decisions don't stop with the birth of the baby

The choices and decisions don't stop with the birth of the baby – how those precious early hours and days are spent can make a huge impact. If the baby is born in hospital there may be a quiet room with a double bed that parents can use and stay in for as long as they wish. Or parents may prefer to take their baby home with them for a period of time. All the options should be explained and parents should be empowered and supported to do what is right for them.

If there are other children in the family, parents will be anxious for them. Again much has been learnt in recent years on how to support children who are bereaved – regardless of their age. An excellent resource is the charity Child Bereavement UK. They support families and educate professionals when a baby or child dies or is dying, or when a child is facing bereavement, with specific information about stillbirth. As does another charity, Sands (Stillbirth and neonatal death charity). Both organisations' websites can also be extremely helpful for grandparents and the extended family and friends to gain information that can help them to support the family.

When a baby dies, time to be together in which to build memories has been snatched from parents. Therefore it is vital everyone supports parents to take time to make choices that are right for them at this life-changing point in their lives.

**Brenda van der Kooy**  
RGN, RM, PGCEA, MSc

# A stillbirth legacy

Nicky Heppenstall shares why she became a volunteer remembrance photographer

**T**he moment you're told your baby has died, that they're stillborn, you are shocked and numb, there are so many unanswered questions rushing through your mind, and the last thing you think about is photographs. But this is probably the most important photo opportunity ever: a lifetime's worth of chances to capture all those milestones is gone in the blink of an eye.

In April 2001, I lost a stillborn daughter, Kim. After three days I was able to take some photographs, but I was upset, still in shock; it was the best I could do: they're not great. But that was then.

In 2009, I came across an American website and was moved to tears as I watched a video of stunningly beautiful and sensitive images that bereaved parents could treasure forever, that could be framed and on display without fear of causing fright. The website belonged to a US based charity offering remembrance portraiture free of charge.

At that time I was a keen amateur photographer, tentatively exploring taking my passion further, but I knew immediately that I wanted and needed to be able to provide that service to bereaved parents. Discovering there was such a charity out there was a major catalyst in the decision to turn professional and so I became a Baby Remembrance Photographer.

## It is a privilege to be a part of this family's journey

The first family contacted me after their unborn baby was diagnosed with Trisomy 13 (Patau's Syndrome); unlikely to be born alive, or to live long if she survived her birth, her parents wanted me to photograph her. I had the chance to meet with this young mum in advance and talk at length about what was likely to happen, and about my own experience of loss. Baby Imogen was born on a Tuesday some months later, alive. I photographed her with her parents and brother on the Thursday at the hospice where they were being looked after for the few days that Imogen survived. She died in her mother's arms in the small hours of Sunday and I returned to the hospice on Sunday afternoon to photograph her without her oxygen tube, as if peacefully sleeping. Meeting a family in advance is not the norm, but does happen from time to time when a diagnosis means a loss is inevitable.



It is a privilege to be a part of this family's journey through grief, and to provide a tangible link to the precious few days that Imogen was with them.

I met Jonah's family a few days after he'd been stillborn, and photographed him with his parents and grandparents, an older sibling and his aunt. The midwife had made them aware of my own loss and they commented how this must be difficult for me to do, but I think it's because of my own loss that I am able to do this at all. I have travelled my journey, I am comfortable with my grief, and I have found that whilst I can feel empathy for their loss, I am able to softly and gently go about capturing images that will bring much greater comfort than any word or gesture of mine could possibly do.

Following on from my experience of volunteering for the US charity, myself and seven others with the same passion co-founded a dedicated UK Baby Remembrance Photography charity called 'Remember My Baby', which was formed on 18 August 2014.

Remember My Baby (RMB) coverage within the UK is steadily growing. It is our aim to have an official RMB Volunteer Photographer linked with all hospitals and birth centres across the UK, but how can we tell people about this amazing service at such a delicate and painful time? More importantly, how can we keep it from them?

There is such a small window of opportunity; there is only one chance, to capture images that will provide comfort for a lifetime. Every parent should have the choice. Midwives are the best-placed people to make parents aware of this service – as the frontline carers they are on hand as parents are losing their baby. If there is an official RMB Volunteer Photographer local enough to the unit, staff can check if they are available before showing parents a leaflet that explains exactly what we do. A phone call to check our availability, and a second one to request we attend if the family wish it, are all that's required; the rest is up to us.



© Nicky Heppenstall – Remember My Baby

Families receive a disc/USB which includes high-resolution images suitable for printing, low-resolution images for smart phones or sharing via email, and some volunteers also create slideshows of their images in formats suitable for smart phones and for viewing on a laptop or PC. This is all provided free of charge within four to six weeks.

All RMB volunteers are skilled photographers; applicants are assessed to ensure a high standard. They are fully insured and independent from the hospitals and birth centres they visit. We are truly grateful to those who help us to provide this service for bereaved parents. More and more Bereavement Midwives and managers are hearing about us and getting in touch to see how the service works and requesting that we set it up in their



© Nicky Heppenstall – Remember My Baby

## Our co-founders regularly meet with and present to Bereavement Teams and the feedback is incredibly positive

hospital. Our co-founders regularly meet with and present to Bereavement Teams and the feedback is incredibly positive.

Since August last year we have gained registered charity status with the Charity Commission in England and Wales, and also with the Scottish Charity Regulator; we have recruited over 90 volunteers and have carried out more than 60 sessions in more than two dozen hospitals; we have also appeared on BBC2's Jeremy Vine show, talking about stillbirth. In less than a year we have achieved a great deal. Being part of Remember My Baby is the silver lining in my stillbirth cloud, Kim's legacy.



© Jocelyn Conway – Remember My Baby

To find out more about RMB's Remembrance Photography Service please visit [www.remembermybaby.org.uk](http://www.remembermybaby.org.uk). The RMB Find a Photographer Directory appears on the left side of our website, simply type in your postcode to see your nearest Volunteer Photographer's contact details. In the event that we don't yet have a volunteer in your area, please email [info@remembermybaby.org.uk](mailto:info@remembermybaby.org.uk) or call 07837 739855 as we may have a volunteer willing to travel to your location – some of our volunteers literally go the extra mile.

**Nicky Heppenstall**

Nicky is a parent, a bereaved parent, a photographer, and co-founder and trustee of Remember My Baby. She has been volunteering as a Baby Remembrance Photographer since 2010 and believes the images she provides can make a real difference to the families who have lost a lifetime of capturing memories in photographs.



# One chance to get it right

Amanda Hunter talks about providing bereavement care after stillbirth or the death of a baby

**T**he Listening to Parents report examined parents' experiences of bereavement care when their baby is stillborn or dies after birth.<sup>1</sup> Many of the 720 women who participated in the research felt that they had been treated with kindness, respect and sensitivity around the time when their baby died.<sup>1</sup> It is important to recognise, however, that 30% of these women *'did not feel listened to or felt listened to only "to some extent" at this point, that their concerns were not always taken seriously or did not feel wholly informed about what was happening.'*<sup>1</sup>

That 30% of women were not fully satisfied with their bereavement care is significant as several pieces of research looking at bereaved parents' experiences of stillbirth highlight the importance of the communication between healthcare staff and parents following perinatal death.<sup>2,3,4,5</sup> These studies have found that the support received by bereaved parents from healthcare professionals has potential long-term implications for parents' emotional and mental health.<sup>2,3,4,5</sup> For example, one study showed that parents' perceptions of the support they receive from professionals have been associated with the parents' risk of developing post traumatic stress disorder (PTSD) or depression after the stillbirth of their baby.<sup>3</sup>

The impact of parents' experiences of bereavement care is also seen in quotes from parents commenting on their care during the stillbirth of their baby.

*'I was so worried about having to walk in there [delivery area] and say who I was. I didn't have to. I walked through the door and she [her midwife] looked at me and she knew it was me... She was so friendly and so honest. She holds a special place in our lives.'*<sup>2</sup>

*'The delivery was just awful from beginning to end. They almost treated me like "The Woman With The Dead Baby"[mother's emphasis]. There was no sympathy. When I asked to see a doctor, this particular doctor came in and said "we're very busy." And his exact words, I'll never forget them "Well, with all due respect, your baby's dead already." Which was just the most awful thing you could say.'*<sup>2</sup>

Furthermore, Downe et al. highlight that: *'Professionals in hospitals and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial well-being of parents who have experienced stillbirth. By ensuring that parents receive care that is clinically skilled, emotionally intelligent, consistent and authentically caring, there is the best chance that, even in the midst of a difficult situation, they will have the healthiest experience possible, as well as the best chance of achieving optimum well-being in the longer term.'*<sup>2</sup>

To ensure that bereaved parents receive the best care possible, it is important that measures intended to improve bereavement care such as training, skill-sharing and support are available for healthcare staff.<sup>2</sup> The

recently completed InSight study investigated bereavement care practices and found that many staff wanted more maternity bereavement care training while highlighting the significant emotional effects of providing stillbirth care on staff and their need for support.<sup>6</sup> Support for staff is important as personal and professional grief and loss may be experienced or triggered when providing bereavement care following a stillbirth.<sup>7</sup>

Sands (Stillbirth and neonatal death charity) offers support to professionals including bereavement care training and other resources. Sands' bereavement care training provides healthcare professionals with the insight, understanding and skills needed to deliver supportive, empathetic and sensitive care for parents after the death of their baby. The Sands helpline is available to support anyone who is affected by the death of a baby, including healthcare professionals.

## Ideally, all maternity unit staff should have access to support from a specially trained bereavement midwife

Ideally, all maternity unit staff should have access to support from a specially trained bereavement midwife.<sup>8</sup> A bereavement midwife would also have the responsibilities of organising staff training and monitoring policies and procedures to ensure that bereaved parents receive good quality care. Despite this recommendation, any member of staff could organise or attend bereavement care training or assess their practice using a tool such as Sands' Audit Tool for Maternity Services.

Parents should also have access to a dedicated bereavement room where they can be cared for during and after labour when their baby has died.<sup>8</sup> This room would ideally be away from other expectant parents and the sounds of crying babies. When it is not possible for parents to access a dedicated bereavement room, staff can prepare parents for what they might see or hear while in the room or on their way to the room that is available. For example, it may be helpful for staff to acknowledge that parents may find it distressing if they pass expectant parents or hear the sounds of babies crying.

### Bereavement care best practice points:

- Communicate with bereaved parents sensitively and empathetically.
- Support bereaved parents to make informed choices.
- Care for bereaved parents in a dedicated bereavement room or suite.
- Provide written information and support literature for bereaved parents (including a list of local resources).
- Ensure staff have access to a bereavement midwife, adequate support and training in bereavement care.

Bereavement care literature such as Sands' Support booklets should also be available for parents and healthcare professionals.<sup>8</sup> Written support information for parents and a copy of Sands' Pregnancy Loss and the Death of a Baby: Guidelines for professionals should be available on every maternity unit. In addition to receiving written information, all parents should be offered the opportunity to discuss a post mortem examination.<sup>8</sup> This discussion should take place with a senior doctor or midwife who is properly trained in taking consent for a post mortem. Consent for a post mortem should also be taken using a form that is based on Sands' post mortem consent form. This form has been designed to support the needs of bereaved parents.

While Sands promotes best practice in bereavement care following the death of a baby, we recognise that these recommended resources are not always available to healthcare professionals. Despite this, good care needs to be available to parents in any setting and many healthcare professionals provide good bereavement care to parents in conditions that are not optimal.<sup>9</sup> Even when resources are limited, healthcare professionals are able to provide parents with empathy and respect. Parents must also be supported to make informed choices about their care following the death of their baby. Healthcare professionals can support bereaved parents to make informed choices by providing them with information about their options and sufficient time to make a decision about their care or options for creating memories with their baby.<sup>9</sup> Additionally, it is important that midwives are able to listen actively and attentively to bereaved parents' stories in order to support parents as they narrate their experiences.<sup>7</sup>

It is good practice for staff to compile a list of local resources that are available to bereaved parents. This list should be kept on every maternity unit and a designated member of staff should be responsible for updating this list regularly (at least every six months). This list should also include information about local post mortem and

mortuary practices and how parents obtain certificates and register their baby's stillbirth, birth and/or death. Every parent should be offered this list.

In order to provide good bereavement care, healthcare professionals and their employers have a responsibility to ensure that they are as prepared as possible to support the needs of bereaved parents and staff. This may be difficult given the time and resource constraints faced by healthcare services. However, the significance of the quality of bereavement care for parents' well-being should not be underestimated and many of our suggestions can be implemented without great pressure being placed on local budgets and staff time.

It is important to remember that there is only one chance to get it right.

*Amanda Hunter*

Improving Bereavement Care Co-ordinator  
Sands, the Stillbirth and neonatal death charity

### More information about Sands Bereavement Care Training is available at:

[www.uk-sands.org/professional-training](http://www.uk-sands.org/professional-training).

For support, Sands can be contacted on 0207 436 5881 or [helpline@uk-sands.org](mailto:helpline@uk-sands.org)

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# Stillbirth support resources

Shane Ridley highlights good support organisations and their websites

## Groups supporting parents

There are many sources of support listed on the Internet and I have picked out a number which are relevant and current. I found others but chose not to add them to this list – many, for instance, I found to be not kept up-to-date. My apologies if I have missed any good ones.

## UK based

### Sands

[www.uk-sands.org](http://www.uk-sands.org)

The 'go to' site for up-to-date resources for parents and health workers, and listed are details of current and completed research projects and campaigns. There is a very detailed list of links and organisations on this page: [www.uk-sands.org/resources/useful-links-and-organisations](http://www.uk-sands.org/resources/useful-links-and-organisations)

### Child Bereavement UK

[www.childbereavementuk.org](http://www.childbereavementuk.org)

A charity that provides resources and support when a baby or child dies, including after miscarriage or stillbirth. Support includes a helpline, groups, information sheets and training packages for health workers.

### The Baby Centre

[www.babycentre.co.uk/a1014800/when-a-baby-is-stillborn](http://www.babycentre.co.uk/a1014800/when-a-baby-is-stillborn)

This is extremely well written and full of information. It is the very best piece I found on the explanation of stillbirth and what it means for the parents. It was last reviewed in March 2015 and I felt confident reading it.

### Tommy's

[www.tommys.org](http://www.tommys.org)

Tommy's fund research into stillbirth, premature birth and miscarriage as well as providing information for parents. The summaries of on-going research are well worth reading. Tommy's has set up the UK's first placenta clinic to focus on the placenta to improve monitoring of women whose pregnancies are affected by fetal growth restriction. There are many write-ups to read, which shows how much work is going on to reduce the stillbirth rate.

### Miscarriage Association

[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)

There is a wealth of information including counselling services after loss. In particular there is another list of remembrance services and details of Baby Loss Awareness Week held in October every year.

### Remember My Baby

[www.remembermybaby.org.uk](http://www.remembermybaby.org.uk)

Nicky Heppenstall explains more about this organisation in her article on page 7. The volunteers aim to promote baby remembrance photography across the UK.

### SiMBA

[www.simbacharity.org.uk](http://www.simbacharity.org.uk)

Simpson's Memory Box Appeal is a Scottish charity and its main aim is to provide memories for parents who have suffered baby loss, not only in Scotland but across the UK. It has lovely ideas including memory boxes and trees of tranquillity, as well as promoting family rooms in hospitals, providing gifts of cuddle cots, beds and cameras to labour wards and setting up support groups.

### Count the Kicks

[www.countthekicks.org.uk](http://www.countthekicks.org.uk)

This is a charity that aims to help mums-to-be to understand their baby's movements. The resources are available to dads-to-be too. It has free leaflets, posters and antenatal note stickers.

### Child Death Helpline

[childdeathhelpline.org.uk](http://childdeathhelpline.org.uk)

Bereaved parent volunteers, who are supported by a professional team, staff the helpline.

### The Lily Mae Foundation

[www.lilymaefoundation.org](http://www.lilymaefoundation.org)

The Lily Mae Foundations works closely with Sands, mainly in the West Midlands area.

## International

I could only do my search in English, so have not found the information for non-English speaking countries. If our overseas readers know of any other sites, please let us know.

### The International Stillbirth Alliance

[www.stillbirthalliance.org/](http://www.stillbirthalliance.org/)

They have held conferences in 2013 and 2014 – the abstracts are available online and contain data on research results. Unfortunately, though, the newsletter is not kept up-to-date, the last one being October 2011.

## Stillbirth in Ireland

### Féileacáin

[www.feileacain.ie](http://www.feileacain.ie)

Butterflies or Féileacáin are said to be the spirits of the departed who return to visit their favourite place and their loved ones to reassure them that they are alright. This is one of the sites I thought was most impressive, it's fairly new and is gentle but upbeat. There are some lovely ideas for remembering babies and the supporters of this charity are certainly providing a positive and thoughtful website and services.

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## Article

### Stillbirth in Australia and New Zealand

#### The Stillbirth Foundation

[www.stillbirthfoundation.org.au](http://www.stillbirthfoundation.org.au)

This is similar to Sands, including information about a potential mobile phone App called 'My Baby's Movements', similar to the Count the Kicks campaign in the UK. They also have information about research into 'maternal sleep health'.

### Stillbirth in the USA

#### The Star Legacy Foundation

[starlegacyfoundation.org](http://starlegacyfoundation.org)

A very useful website, again similar to Sands, in particular there is an extensive list of worldwide published research updated to 2013 as of now. It also has a campaign on See Me, Feel Me – based on counting the kicks the baby makes. It highlights a list of potential considerations that may be linked with poor pregnancy outcomes. For example high and low blood pressure, snoring or having trouble breathing at night; along with potential changes in behaviour or practice such as

sleeping on the left side which enhances blood flow to the baby and avoiding invasive vaginal examinations and membrane stripping which can increase the risk of infection. It also has a campaign called ASAP – Action for Stillbirth Awareness and Prevention.

This is a very comprehensive website and well worth reading. It includes a blog called Stillbirth Matters.

#### Ist Breath

[www.Istbreath.org/](http://www.Istbreath.org/)

An organisation similar to Sands. It has an interesting App for women pregnant after previously experiencing a stillbirth (unfortunately named) SPROUT Pregnancy Essentials. It also promotes a device called Kick Trak which automates a kick chart – for more information on counting kicks see page 15.

**AIMS will be keeping this information on the website, so if any reader would like to add to it, that would be most helpful and very welcome.**

*Shane Ridley*



© Nicky Heppenstall – Remember My Baby

# Perinatal mortality

Beverley Beech comments on the MBRRACE Perinatal Surveillance Report

**T**his is the first UK perinatal surveillance report produced by MBRRACE-UK (Mothers and Babies Reducing Risk through Audits and Confidential Enquiries), a collaboration led by the National Perinatal Epidemiology Unit (NPEU) in Oxford together with members from leading universities, a retired GP from Oxford and representatives from Sands (Stillbirth and neonatal death charity).

The report focused on surveillance of all late fetal losses (between 22+0 and 23+6 weeks' gestation), stillbirths and neonatal deaths<sup>1</sup> and was launched at a packed day-long conference at the Royal College of Obstetricians and Gynaecologists. The new statistics now include all late fetal losses – it has been particularly difficult to ascertain these statistics because there are such wide variations in definition and subsequent registration and reporting across the UK. 1 in 1000 babies are born at 22 or 23 weeks and, as few survive, these deaths make up a high proportion (a fifth) of all babies dying in the first month of life.

Jenny Kurinczuk, the Director of the NPEU, introduced Janet Scott from Sands who gave the opening address, pointing out that *'By understanding why babies die today the data can be used to help prevent deaths in the future'* and that while there has been a fall in mortality rates over the last ten years there are unacceptable variations in mortality around the UK. She was followed by Christian Cook, whose baby Talia was stillborn. He performed his very moving poem about that experience, highlighting the fact that every one of these baby deaths is a personal human tragedy for the families. (Christian can be viewed performing his poem at: [www.youtube.com/watch?v=O3155YPltk0](http://www.youtube.com/watch?v=O3155YPltk0)).

We were reminded that CMACE (Centre for Maternal and Child Enquiries) last produced a report in 2011 relating to deaths in 2009. The 2010 data revealed large amounts of under-reporting from England, some from Wales and no Scottish data. Over a third did not match Office for National Statistics (ONS) data and the returns for 2011 and 2012 had possibly 30–40% missing. Because the data for these years was incomplete and unreliable the collaborators decided to focus on 2013 onwards. They hope to introduce the ReCoDe system ([www.ncbi.nlm.nih.gov/pmc/articles/PMC1283273/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1283273/)) to improve classifications and allow international comparisons.

English, Welsh and Scottish reports can be found at: [www.hqip.org.uk/assets/Downloads/Report-on-2010-2011-2012-perinatal-mortality-data-FINAL.pdf](http://www.hqip.org.uk/assets/Downloads/Report-on-2010-2011-2012-perinatal-mortality-data-FINAL.pdf)  
[www.medicine.cf.ac.uk/awps/awps\\_reports/](http://www.medicine.cf.ac.uk/awps/awps_reports/)  
[www.healthcareimprovementscotland.org/default.aspx?page=14046](http://www.healthcareimprovementscotland.org/default.aspx?page=14046)  
[www.healthcareimprovementscotland.org/our\\_work/reproductive,\\_maternal\\_child/programme\\_resources/spimmr\\_2011.aspx](http://www.healthcareimprovementscotland.org/our_work/reproductive,_maternal_child/programme_resources/spimmr_2011.aspx)

Pauline Hyman-Taylor explained how the data was collected and by whom, with over 250 units in the UK participating with a Lead Reporter in each Trust and Health Board. There are 450 reporters across the UK – the majority are midwives. There is now an established MBRRACE-UK reporting structure to be further refined, meaning that the main cause of death for over 1,500 babies, currently classified as unknown, will be completed with more accurate information. There are YouTube downloads which show the details of the collection of data. Note that the 'standard of care' is now a collectable piece of data.

The report reveals that while the rate and number of stillbirths and neonatal deaths fell in the UK, there were, nonetheless, over 5,700 babies who died either before, during or shortly after birth in 2013 – equivalent to 15 babies dying every day.

There is a map of the UK showing the organisations responsible for local health care, with dots representing the number of babies born in hospitals run by that organisation; the mortality rates have taken into account the number of high-risk pregnancies that are cared for by each organisation. There are a few red dots indicating mortality is 10% higher than the UK average and only two areas of green dots (Dorset and Barnet) indicating 10% lower than the UK average. Yellow and orange dots make up the rest, none achieving the lowest mortality rates in Europe.

The report recommends that national aspirational targets should be set for the UK for reducing the number of babies who die, aiming for a rate closer to that achieved in the best-performing European countries; and that those Care Commissioning Groups in the red dot areas are required to have specific local reviews. The report found that local mortality rates varied across the UK from 5.4 to 7.1 per 1,000. The variation is not explained by differences in poverty, ethnicity or the age of the mother. However, women living in poverty experience 57% more stillbirths or neonatal deaths. Perinatal mortality was 50% higher for Black, Black British, Asian and Asian British babies, whilst the rate for teenage mothers and mothers over 40 is 39% higher.

The report recognised that while being born too early is a risk, one in three babies who died in 2013 had reached term (37 weeks' gestation or more) and speculated that *'in some cases, issues to do with care may play a role'*: 1 in 12 babies died either during or after birth because of a complication in labour.

The RCOG 'Each Baby Counts' (see page 4) is pushing for local investigations into these deaths so that meaningful data can be collected to prevent deaths in the future.

## Report

As well as the local reviews mentioned above, the report recommends that post-mortems should be offered in all cases of stillbirth, neonatal death and extended perinatal death in order to improve future pregnancy counselling of parents.

All of those who have been involved with gathering and analysing the data and preparing this report deserve our most heartfelt thanks for a superb document. It is crammed with valuable information detailing the wide variation around the UK in the numbers and rates of babies who die and gives pointers to future action.

One hopes that this information will enable professionals to understand better the issues in their area and work collectively to reduce the incidence of these sad deaths. We look forward to future reports exploring

trends and characteristics as the data improves, for example, better understanding of the effects of increased BMI, previous obstetric history and addictions. This work, however, is only one side of the coin: while NHS staff work to save babies, little effort is being made by our Government to act effectively to address the huge levels of social deprivation, poor housing, poverty and other inequalities.

A copy of the Report can be downloaded from [www.npeu.ox.ac.uk/mbrace-uk/reports](http://www.npeu.ox.ac.uk/mbrace-uk/reports)

Beverley A Lawrence Beech

### Note

1. Neonatal death – a live born baby (born at 20+0 weeks' gestation or later, or with a birthweight of 400g or more where an accurate estimate of gestation is not available) who died before 28 completed days after birth.

# The Birth Project Paintings

**T**his painting is of Ruth, the title is *The glow that she left in me is forever ignited* and the original is 47x56 inches.

Ruth contacted Amanda two months after Lucy was born; Amanda painted from a photo that Ruth's son Luke took of his mother days after the news that Lucy had anencephaly – he painted her belly with sunflowers because they knew they would name her Lucy Sunflower. Ruth would welcome an opportunity to connect with anyone on the topic of anencephaly through her blog [SweetBabyLucy](http://SweetBabyLucy.com).

Ruth wrote to her unborn child *'I will only get to see you for a minute, an hour or hopefully a day or two...but you have to know my dear, that every moment you are inside my womb, every vibrant movement you make, every hiccup you take...I cherish...and I love you and always will. I wish you could be with us always, but even though you won't be with us long... you will always be there, our little light, our little Sunflower.'*

Amanda says on her website *'I hope that we are able to love and support each other, to hold each other up and to reach out through pain and loss. Life includes hurt, and I hope that we can share our stories of loss, and listen to other's stories. Many mothers also grieve, let's allow those voices to speak and let's talk about their little ones.'*

Amanda Greavette started the Birth Project Paintings in 2008 after the birth of her second child. The paintings portray pregnancy, birth and motherhood in life-sized oil paintings. Each painting is inspired by documentation of a real birth. The Birth Project as a body of work (along with other feminist and birth art) validates the maternal experience and supports empowerment of childbearing women and their families, filling a visual gap in birth culture.

Amanda exhibits the Birth Project in many contexts so that the paintings can be seen in real life, allowing their size, vibrancy and detail to be appreciated. For most of us, sadly, the only way to view is on line at [www.amandagreavette.com](http://www.amandagreavette.com).

Amanda lives and works in Ontario, Canada. She is busy raising five beautiful children, painting and being active in her community. Amanda is a La Leche League leader and a founding member of a midwifery advocacy consumer group in Ontario.

Amanda loves to attend births for family and friends.

### AIMS Comment

I came across Amanda's paintings on a blog and immediately connected; they tell the story of pregnancy and birth, happiness and joy and sometimes loss. Each painting has a story but the viewer can use their imagination; each one can invoke a personal response. For those bereaved, there are many ways to heal using the arts – reading other people's words in prose or poetry, listening to music, watching films that make you happy or sad, and paintings and photographs.

I see a strong woman with a sense of fun in the painting of Ruth, but she is hurting. I think she was extremely brave to capture and keep this image – I know it will always stay with me.

Shane Ridley



# Counting the kicks

Gemma McKenzie asks, what's the evidence behind it?

**T**here has been growing interest in the charity 'Count the Kicks' and its campaign to empower women with the knowledge to recognise when a decrease in their baby's movements may indicate potential problems. The charity has enjoyed celebrity support with the likes of Alesha Dixon and Holly Willoughby promoting its work.

But what is meant by 'counting the kicks'? And what is the research behind it?

It has long been accepted that fetal movement is a reassuring sign, whereas a reduction in movement is a potential cause for alarm.<sup>1</sup> Pregnancies affected by reduced fetal movement (RFM) are at increased risk of an adverse outcome such as fetal growth restriction, premature birth and stillbirth.<sup>2</sup> But how much movement is normal? How few kicks are needed to indicate a reduction significant enough to warrant medical intervention? In the past, these questions were frequently asked, and by the mid-1980s various kick charts had been developed. Although there were many different types, they broadly fell into two main schools of thought: the daily fetal movement count and the 'count to ten' or Cardiff method.<sup>1</sup>

## The daily fetal movement count

This required the mother to count the kicks for a set period of time. Initially, this was 12 hours, but it was soon moderated to between 30 minutes and 2 hours. One problem with this was to find a time frame long enough to count enough kicks so that a reduction could be noted, whilst also ensuring that the duration of time was short enough for women to be able to comply with it.

## The Cardiff method

This method required the mother to time how long it took to feel 10 kicks. This was to be done at the same time of day, with a view that it is normal to feel 10 kicks within two hours.

## The problems with formal counting

Although all pregnant women, regardless of health issues or previous problems, were encouraged to formally count their baby's kicks, it was never an ideal situation. Some of the problems included:

- The difficulty in finding an evidence based consensus from researchers as to what number of kicks was 'normal.'
- The time and effort required by mothers to adhere to the counting routine.
- The issue that if there is a minimum number of kicks a woman must experience before she is taken seriously by a health care professional, there is a risk that a woman with a very active baby will wait too long before contacting her midwife.
- The risk of too many false positives. In other words, too many women would note a reduction in their baby's movements and attend hospital even though their baby is healthy. It has been argued that this would

waste considerable resources and expense.<sup>3</sup>

- Asking women to formally count their baby's kicks can result in maternal anxiety.

## What changed?

Even with these issues, during the 1980s pregnant women were regularly recommended to formally count their baby's kicks. Then in 1989 a study appeared in *The Lancet* which put an end to routine formal kick counting.<sup>3</sup>

## The Grant study

This large randomised controlled trial put 68,000 women from the UK, USA, Belgium, Ireland and Sweden, who were between 28 and 32 weeks pregnant, into two groups. The first group was told to formally count the kicks of their baby using the 'Cardiff method.' The second group of women was asked to informally monitor their baby's movements and to report any changes to their midwife. The researchers then analysed the outcome of all of the pregnancies, and in particular those that resulted in stillbirth.

The researchers envisioned that the counting policy would only have an impact on certain types of fetal death. The types they were looking at were the following:

- A Unexplained death.
- B Death influenced by isoimmunisation, maternal disease and infection, and pre-eclampsia.
- C Death caused by malformation, antepartum haemorrhage and mechanical problems [mechanical problems were not defined in the published study].

The researchers considered that deaths in category A would be most affected by the counting policy, whereas those in B would only be marginally affected. They also envisioned that deaths caused by C would not be influenced at all by the suggested counting policies.

## Results of the Grant study

The researchers concluded that formal fetal movement counting had no advantageous effect on the stillbirth rates. They stated that there was no significant evidence that a policy of routinely recommending formal fetal movement counting leads to a lower risk of antepartum late fetal death. The results suggested that formal counting does not result in a better outcome for the baby, any more than relying on women to informally take note of any changes in their baby's movements.

The study highlighted that introducing a policy that all pregnant women were to formally count their baby's kicks would use considerable extra resources. They estimated that over a year this would lead to '140,000 midwifery hours, 90 million hours of pregnant women's time, 13,000 extra cardiotocographs, and 5,000 more admissions.'<sup>3</sup> The researchers also noted that it would take at least 1,250 women with a singleton pregnancy to formally count their baby's movements in order to prevent one unexplained antepartum death.<sup>3</sup>

## Research

### Additional issues raised by the Grant study

Two further points can be taken from this study. An article by Frøen in 2004<sup>1</sup> highlighted that the death rate during the Grant study was 2.8%, which was much lower than Grant et al's 4% estimate. [The 2013 rate for England and Wales is currently 4.7 stillbirths per 1000 births.<sup>4</sup>] As the study was so large and it involved different medical staff in various countries, Frøen suggests that the increased vigilance and awareness of reduced fetal movement had a positive effect on the stillbirth rate, highlighting the value of supporting pregnant women to be aware of their baby's movements and to feel confident to contact their midwives should they notice any decrease or change.

A second major point that was raised by both Grant and Frøen was that the response by health care professionals to a woman's concerns of RFM was crucial to whether the pregnancy resulted in a stillbirth. Grant stated that:

*'In none of the 17 cases [of unexplained stillbirth] where the fetus was alive on reaching formal medical care was emergency delivery attempted after reduced movements had been recognized. This reflected false reassurance from diagnostic testing, especially cardiotocography, and clinical error.'*<sup>3</sup>

Although this statement does reflect the maternity care in 1989 – which it would be hoped has vastly improved since then – it does highlight that an appropriate response from health care professionals is a major factor in the outcome of a woman's concerns of RFM.

### What is the appropriate medical response to a woman's concerns of RFM?

Although a woman experiencing RFM should always be able to see a midwife promptly, it can be reassuring to know that the amount a baby moves in the womb and a mother's ability to perceive those movements can be influenced by many factors, such as:

- The position the mother is in (such as lying down or standing)<sup>5</sup>
- Activity and exercise<sup>6</sup>
- Anxiety<sup>7</sup>
- Stress<sup>8</sup>
- Blood sugar<sup>9</sup>
- Smoking<sup>10</sup>
- The position of the placenta<sup>11</sup>
- The mother being overweight<sup>12</sup>

The Royal College of Obstetricians and Gynaecologists provides very detailed information on the management of RFM. Its Green-top Guideline No.57<sup>13</sup> outlines all of the relevant research in the area and creates recommendations based on this evidence. This is useful to women who are experiencing RFM, as they can use the guidelines to understand the minimum response they should expect from health care professionals. Some of the notable points include:

- Women who are concerned about RFM should not wait until the next day for an assessment of their baby's well-being.
- An ultrasound scan should be carried out if:
  - a woman is over 28 weeks pregnant and the RFM persists despite a normal CTG (monitoring of the baby's heart);

- a woman is over 28 weeks pregnant and there are additional risk factors for fetal growth restriction or stillbirth;
  - a woman experiences recurrent RFM.<sup>13</sup>
- For women who are between 24 and 28 weeks pregnant, their baby's heart beat should be checked with a Doppler and an ultrasound carried out if the clinician suspects fetal growth restriction.

There are no studies looking at the management of women who present with RFM before 24 weeks of pregnancy. In this case, the guidelines suggest a full antenatal assessment, including the use of a Doppler to listen in to the baby's heartbeat.

### Conclusion

The research shows that a pregnant woman is best placed to know when her baby's movements have reduced. As one study recently concluded, *'There is no evidence that formal FMC [fetal movement counting] with their fixed alarm limits are superior to maternal common sense...'*<sup>2</sup> Formal kick counting has, therefore, been discredited, but a woman's general awareness of the times and frequency of her baby's movements is still a powerful tool in being able to set in motion an appropriate response from health care professionals.

Gemma McKenzie

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# Support for loss

Nadia Higson reviews bereavement support in early and late pregnancy

**W**omen's experiences of the care they receive following bereavement have not been included in any previous national surveys. A report<sup>1</sup> by NHS Improving Quality was therefore commissioned at the end of 2013 to review the support that exists both within and outside the NHS for women and families experiencing the loss of a baby through miscarriage or stillbirth.

The report aimed to highlight to stakeholders, such as commissioning groups, the needs of women experiencing the loss of a baby in early or late pregnancy; to identify gaps in the care available and opportunities to work in partnership; and to acknowledge good practice and encourage others to reflect on it. The authors say 'Our aim is not to apportion blame but to begin open and honest discussions in order to ensure that all women receive excellent care.'

The report looked at support for bereavement at different stages of pregnancy: early loss (defined as up to 13 weeks), late loss (13-24 weeks) and stillbirth (after 24 weeks).

The authors sought input from the 12 Strategic Clinical Networks for Maternity, Newborn, Children and Young People in England, plus numerous local and national charities, and the Royal Colleges, but perhaps the most helpful feature is the inclusion of personal stories from bereaved parents (many drawn from Patient Opinion Portal [www.patientopinion.org.uk](http://www.patientopinion.org.uk)) which help to illustrate the importance of timely and sensitive support. Mothers and their families will have different needs depending on their individual circumstances, but the attitudes of the staff providing care, and the surroundings in which it is given, can make a huge difference to the experience. It should hardly come as a surprise that many women in this situation 'find it distressing to be around newborns or to be with other pregnant women' and yet all too often they are being cared for in such settings, and by staff without specialist training.

Much of the information in the report draws on the work done by national charities or other bodies outside the NHS, which highlights the lack of comprehensive national data on the availability and quality of services for women undergoing the trauma of miscarriage.

However, although support is clearly patchy and can be hard for women to locate, there are many examples of good practice and collaborative working which the authors hope will be taken forward to improve care in the future.

## Attitudes to miscarriage can be dismissive – charities are a lifeline

Even among family members, the impact of miscarriage, especially if it occurs in early pregnancy, may not be

appreciated. Women who have not yet shared the news of their pregnancy may find it particularly hard to then talk about their miscarriage.

It isn't known for sure how many women suffer an early miscarriage (before 13 weeks) as often they are cared for in the primary sector, but it seems that many are left to cope with little or no support. According to the Miscarriage Association website ([www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)) nearly half did not feel well informed about what was happening to them and only 29% felt well cared for emotionally. As one mother quoted in the report said, 'No-one handed out leaflets/contacts to support groups. It felt that there was little for early miscarriages.'

It appears that national and local charities are often filling the gap left by the NHS in providing both information and emotional support to women and their families after a miscarriage. According to the report, 'It appears that very few areas are not covered in some way by local charities. The size, number and what support is provided, however, varies across the country ... the authors have been impressed with the speed of response and what is available with limited funding.' The national charities such as the Miscarriage Association often have their own local groups, and smaller local charities draw on information provided by the national charities. Having often been founded and run by parents who have experienced the loss of a baby, local groups can 'offer a level of enthusiasm, depth of understanding and support that is commendable.'

## Parents may want to remember their baby, however early the loss is

Parents may want to remember their baby, however early the loss is. A number of local charities provide opportunities to do this, for example providing memory boxes, spaces for quiet contemplation or memorial services, but this is not available everywhere.

Increasingly people seek support via the internet and social media, but internet search engines are not always good at identifying local groups. The authors note that NHS Choices highlights national charities, but suggest it could do more by providing a postcode search for local support.

## Research

### Lack of specialist resources is a challenge to delivering good care

Ideally, women experiencing pain or bleeding in early pregnancy would be seen promptly at an Early Pregnancy Unit (EPU) for diagnosis and care. There are over 200 EPUs in England but fewer than 20 appear to offer the seven-day service recommended by NICE.<sup>2</sup> Many do have extended opening hours, but some are only open for a few hours a day. Larger hospitals may offer an Emergency Gynaecological Unit which can provide assessments when the EPU is closed. These may be open 24/7, but as they deal with a range of gynaecological problems the staff will not necessarily have the specialised skills to support women who are miscarrying.

Worryingly the report says that *'In the absence of provision of the specialist areas women often find themselves in Accident and Emergency units, gynaecology wards and sometimes even general surgical beds where the staff may not have the time or the skills to offer the level of compassionate support and advice needed.'*

Similarly, mothers going for a scan to check for a suspected miscarriage may find themselves waiting alongside other expectant parents: *'Laura felt that the hardest thing was watching the others. She couldn't stop crying and felt that it wasn't good for the other people there either.'*

NICE guidelines for care of women suffering a late miscarriage (between 13 and 24 weeks) are due in 2016, but many hospitals have developed their own. Sometimes a separate bereavement suite is available for mothers experiencing a late miscarriage as well as for stillbirths; however, according to Sands,<sup>3</sup> the gestation at which women will be admitted to these or to the maternity ward varies from 14 to 24 weeks. This means that some women find themselves having to give birth – sometimes even to a baby who is showing signs of life – in a gynaecological ward – causing great distress to the mothers, their families and the staff.

Those admitted to the main maternity ward may find themselves distressed by the presence of other babies: *'...due to shortage of beds I was moved to the maternity department where I was put in a side room and forgotten*

*about. All through the night I lay awake and crying to myself as the newborn, very newborn baby next door cried all through the night as if it was in my own room.'*

Clearly what is needed is a dedicated area away from the main maternity ward, but all too often this is not available to women having a late miscarriage.

### Staff need training, and support too

Staff report struggling to provide good emotional support in the face of their own workload and competing priorities. One positive move is the growing number of specialist Bereavement Midwives; however in smaller hospitals the staff can lack the necessary experience and training. This is also the case for newly-qualified midwives who may have had limited exposure during their training to mothers and families dealing with a loss.

Midwives and other healthcare professionals may be given training, and be able to seek support from their colleagues when faced with emotionally challenging situations – but who looks after agency or support staff? *'Whilst many Trusts will offer general bereavement training as part of their training programmes it is very likely that they will be targeted at the professional groups, but consideration should also be given to the ancillary and support staff who are often on the side lines but still can be impacted.'* Some hospitals have already introduced training for all staff who may come into contact with bereaved parents.

### Building on best practice through collaboration

A key theme of the report is the value of working in collaboration, both within the NHS and between the NHS and the charitable sector. There are good examples of this, but often hospitals and especially primary care staff seem to be working in isolation.

Both the Miscarriage Association and Sands have been working with the Royal Colleges for many years, as well as producing their own surveys, guidelines and training offers. The Miscarriage Association is currently investigating the needs of partners of women who miscarry, and wants to look at the needs of young people and those with limited English or communication difficulties.

The Association of Early Pregnancy Units (AEPU) is encouraging units to collaborate and share resources, and offers education and networking with the aim of raising standards of care. It also provides information for women, including details of their local unit. AEPU has been working with the Miscarriage Association on e-learning resources for staff.

### Developing specialist services

There are a number of examples of good practice in the hospital sector, with awards from the Royal College of Midwives and others to encourage and share these ideas.

An increasing number of Trusts are seeing the value in appointing one or more Bereavement Midwives who can provide training and also directly support other staff in *'difficult conversations'*, as well as supporting parents and signposting them to other helpful services or groups.

## Early Pregnancy Unit

A special unit within a hospital staffed to deal with common early pregnancy issues and worries.

From chickenpox to bleeding,  
nausea to pregnancy loss,  
cravings and diet to exercise.

There are 200 units in the UK involving doctors,  
midwives, ultrasonographers, nurses and support staff.

For more information visit:  
[www.earlypregnancy.org.uk/](http://www.earlypregnancy.org.uk/)

Some hospitals have developed a Bereavement Service for women who lose a baby at any gestation. As well as specialist support from a Bereavement Midwife while in hospital such services may include assessment of the woman's emotional well-being once home; telephone support at home; one or more face-to-face follow-up meetings with the Bereavement Midwife, often including one with a consultant after a few weeks; referral to other services such as counselling or support groups; and help with practical issues such as funeral arrangements.

## The report identifies a number of areas where the NHS could work in partnership

### Recommendations

The authors note that the Strategic Clinical Networks are in the process of setting out their priorities. None has so far identified support for loss as a focus, but many have included maternal mental health, which should provide an opening for exploring ways to reduce the emotional impact of a loss on women's long-term mental well-being.

The report identifies a number of areas where the NHS could work in partnership with the charitable sector and the Royal Colleges, including:

- *'Set up or utilise existing mechanisms to actively encourage the sharing and/or spread of best practice.'*

- *'Bring together a national stakeholder event promoting best practice. Delegates and presenters should be from all areas – primary care, A&E, and acute care and charities.'*
- *'Work in partnership with the Royal Colleges and charities to follow up on the uptake of NICE guidelines and toolkits such as the Sands audit tool.'*
- *'Work in partnership with the Miscarriage Association to take forward their work on the needs of young people and fathers.'*
- *'Consider working with NHS Choices to improve the access to local charities through the search facility on their website.'*
- *'Undertake an in-depth audit of training in terms of provision access and uptake across all staff who may come into contact with women who undergo loss in pregnancy and their families, to ensure that patient experience is everyone's business.'*
- *'Review ways of engaging with bereaved parents to seek feedback on experience of care across the pathways.'*
- *'Widen the scope of work to include support for termination of pregnancy and neonatal death.'*

We can only hope that these recommendations will be picked up and acted upon, because, in the words of one Bereavement Midwife, *'If there's ever a time to get right care it's during this time.'*

*Nadia Higson*

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## The quilt on the cover

The beautiful quilt featured on the cover of this Journal is called *Surrender* and is 24" square – it is the picture of unconditional love in the face of inevitable loss.

Bethany Conkel is the owner of the quilt and it was made by her mother, Maria Elkins. Bethany's son Amalya Nathaniel had anencephaly and died an hour and twenty minutes after his birth. After the loss of her son, she became a birth and bereavement doula and started a non-profit organisation in the States called Purposeful Gift that works with expectant families who have received a terminal diagnosis by

giving information on neonatal organ, eye, tissue and whole body donation ([purposefulgift.com](http://purposefulgift.com)). Bethany and Eric also have a short documentary about their son [agency.thehumanstory.com/projects/amalya/](http://agency.thehumanstory.com/projects/amalya/).

As far as AIMS knows, there is not an organisation like this in the UK as the rules for neonatal organ transplant are different. The Royal College of Paediatrics and Child Health has reviewed the guidance and the latest criteria can be found at [www.rcpch.ac.uk/news/criteria-diagnosing-death-infants-less-2-months-age-published](http://www.rcpch.ac.uk/news/criteria-diagnosing-death-infants-less-2-months-age-published)

# One-to-one care

Lulu Stacey shares her experience of supportive midwifery in a case-loading practice

**This personal reflection draws on my experience of caseholding as a student midwife providing a woman with midwifery continuity of care.**

There is strong evidence that the intertwined concepts of midwifery continuity of care and woman-centred care should be established for all women.<sup>1,2,3</sup> Woman-centred care is defined by Nicky Leap<sup>4</sup> as focused on the woman's individual, unique needs, expectations and aspirations, encompassing the needs of her baby, family and community, and holistically addresses the woman's social, emotional, physical, psychological, spiritual and cultural needs and expectations.

Working closely with my community midwifery mentor, we approached Anna (I've changed names in accordance with guidance from the Nursing and Midwifery Council).<sup>5</sup> Anna was a mother of three, pregnant with twins; sadly she miscarried, at 12 weeks' gestation, on Boxing Day 2013, but on becoming pregnant again with triplets (monochorionic twins and a singleton) she enquired whether I was still available for caseholding. Unfortunately, the twins showed signs of acute twin-to-twin transfusion syndrome and died in utero at 18 weeks' gestation. Anna's pregnancy continued without further physical complication, but inevitably with uncertainty and emotional discord: the remaining 20 weeks of her pregnancy and the postnatal period were extremely challenging to both Anna and her husband Nick as they grieved the loss of their much-wanted twins at the same time as celebrating the healthy development of the surviving triplet.

Anna was booked to have an elective caesarean section at 38 weeks following three previous sections. This had been an issue in previous pregnancies as Anna desperately wanted to experience a vaginal birth and was disappointed not to do so, however, she was accepting that this baby would be born by caesarean section. The anticipation of the birth was difficult on many levels: Anna did not believe she would reach full term and set milestones to reach 24, 28 and 36 weeks, each time adjusting her mental preparation for the baby she was to birth.

Anna found it difficult to look forward to the birth of her daughter, as she knew she had to say goodbye to her twins at the same time; furthermore, it was difficult to anticipate what would remain of the twins at the time of birth. Anna's consultant had indicated that twins at 18 weeks' gestation would be very small and may have been reabsorbed. Anna and Nick discussed whether they would like to see the babies, or hold them, without knowing whether there would be anything to see or hold. Their personal preferences differed, with Nick feeling he didn't want to see them but rather hold a memory of them from their scan images, whilst Anna was unsure and unable to make a decision until the time came.

The fetal-maternal medicine consultant and midwife, their community midwife and specialist bereavement midwife all gave the family considerable support. I observed the highest-quality parent-led care in which both parents were given time and freedom in which to discuss their options and preferences with healthcare professionals. Their now trusted consultant provided continuity of care, performing the caesarean section, providing postnatal care and support, and significantly enhancing the birth experience.

## A trusting relationship had developed with their consultant through continuity of care

Anna and Nick were concerned that the day of delivery must be focused on the celebration of their daughter's birth and made arrangements to say goodbye to their twins the following day. The antenatal input of the bereavement midwife was invaluable for helping Anna and Nick prepare for the imminent birth, validating their mixed emotions, and eliminating as much formality as possible. Consent forms for histological investigations, and post-mortem examination and funeral arrangements were discussed without fully knowing what remains would be available for investigation. We discussed and prepared memory boxes for which Anna's mother knitted blankets: two boxes were prepared in advance with two teddies in each and the blankets, one kept at home and one taken to hospital ready to receive the twin babies. I collected the necessary documentation for Anna's notes, which was left in the baby room on labour suite where I would lay the babies to rest in their box until they were ready to be taken to the mortuary.

As the lead midwife under supervision, I liaised with Anna's consultant and introduced myself to the theatre team when signing in. Anna and Nick, understandably anxious on the morning of the operation, disclosed to us how calming it was to have us leading their care. As Huber and Sandall<sup>6</sup> have demonstrated, women and their birth partners aspire to a calm childbearing experience, linked to the establishment of relational continuity, and this relationship built up over time instilled confidence and mutual understanding between Anna and Nick, their

consultant obstetrician and myself as their midwife. We were able to form a picture of the couple, which helped us to advocate for them, as Huber and Sandall<sup>6</sup> and McCourt<sup>7</sup> have shown. For example, I informed the theatre staff that, encouraged by Anna's consultant, we were planning skin-to-skin contact so I would stand next to Anna to help her position her baby at the breast instead of receiving and taking the baby to the resuscitaire as is normally done.

I found that the enhanced relationship and mutual respect resulting from collaborative working provide team members with enriched social relationships and greater reward at work.<sup>8</sup> It also helps midwives to share knowledge and expertise with obstetric colleagues, presenting alternative methods of realising positive outcomes for vulnerable women. Together midwives and obstetricians can be innovative, combining their skills to think laterally and provide flexible, responsive continuity of care to women with increased social, emotional or physical need. Anna reported afterwards that holding her baby in a skin-to-skin embrace while the placentas and her twins were being delivered made all the difference to her ability to cope with the situation emotionally. All Anna and Nick's attention was on their new baby; the focus was on Anna's needs, not the clinical situation.

## the focus was on Anna's needs

Anna and Nick did not wish to see the twins on the day of birth and some comfort was offered by knowing they were wrapped in a blanket made by their grandmother, which had been in the family home until that day. We did not discuss further what remained of them until the following day, as arranged. I kept the healthy placenta of the surviving singleton safely on labour suite too as I knew that Anna might wish to see this when she was ready. From recovery I accompanied Anna and her newborn to the postnatal ward and remained with them providing their post-operative care. I returned to the postnatal ward the following day and worked the full shift as Anna's caseholding midwife.

Providing continuous, sensitive care demands knowledgeable practice and commitment from the midwife, ensuring appropriate and timely interventions responding to women's individual needs.<sup>9</sup> Before a special service of blessing for the twins carried out by the Chaplain from the family's church, Anna was moved into a side room overnight in order to have the necessary privacy. I brought the remains of her babies to the ward for her before Nick arrived, as he did not wish to see them. It is a prerequisite of the midwifery profession to assess women's needs and provide advocacy on an individual basis.<sup>5</sup> Caseloading provides an excellent level

of service for those with complex needs where the midwife's advocacy helps the woman to access the best available care and increases satisfaction for both midwives and women.

I was extremely fortunate to have the opportunity to care for Anna and her family through this emotional childbearing experience that was most likely to be her last. I felt privileged to be able to focus my attention entirely on the needs of Anna and her family without being torn away by the usual pressures of mounting workload.

Anna benefited from having a known and trusted caseloading midwife. In the emotional tension that had reached a climax on the day of birth, Anna and Nick knew that the consultant obstetrician and I would make sure that the day would start as we had discussed and planned. I was aware of their hopes and fears and was able to advocate, intervene or avert deviation from the intended plan of care. Equally they knew they could say anything to me to change the plan at any time if they wished to. They didn't need to explain to anyone that their daughter's birthday was to be a day of celebration and that their demised twins were to be kept safe until the following day when they would bless them, see them if they wished to and say goodbye, because I was there to discreetly explain their preferences.

Lulu Stacey

**AIMS note: we will continue to campaign for caseloading so that this kind of care can be provided for all women.**

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# My story

Heather talks about creating memories of her son Raymond

**B**eing a mother is all I have ever wanted to do, but the fates seem to conspire against me. My son was conceived after years of infertility and IVF.

Having finally achieved a pregnancy I felt in some ways I had a head start; I had subscribed to the Mother magazine since 2006 and been reading books and articles and on online sites; I already knew pregnancy and birth could be beautiful; I already knew my rights; I didn't have years of negative images and conditioning to undo. I often felt my pregnancy worked in reverse, starting out high tech and full of scans and needles and going to low tech as I employed an independent midwife to support me for my homebirth.

I didn't get my home water birth with candles and music. I had a hospital bed, epidural and purple pushing. But I'm still so glad I had nine months of looking forward to something lovely rather than fear.

My son Raymond was stillborn for reasons unknown. He had a good heart beat in the morning and was dead by the afternoon. I'm no expert in stillbirth. I'm still struggling to deal with it. But if anyone is interested I can share what I feel is most important for others to know from my experience.

Make pregnancy beautiful. I would say this is the most important thing that stillbirth teaches us. You might not go home with a baby, so don't wait for that reward. Enjoy the pregnancy. I don't know how I would have got through without being able to look back and treasure the memories of a lovely pregnancy. I had an independent midwife and it really helped to have lovely care that focused on the positive that wasn't aimed at scaring me, telling me what to do or making me feel guilty. I did so much to celebrate my pregnancy: yoga, belly casts, blessing way, baby shower, aqua aerobics, alternative therapies, NCT classes, and hypnotherapy. I wish everyone could have this kind of experience. No extra worry would have kept Raymond alive. I wish so much maternity care wasn't focused on getting mothers to worry.

Gather support. I am so pleased to have been part of the Positive Birth Movement. It has given me such a great connection to women who have really worked hard to support me. My birth partner was truly amazing. I have no idea how she did it, supporting me the whole time, never missing a beat during such an unexpected and distressing time. I wish I could order such a birth partner for every woman.

There are always ways to make birth more positive and it is always worth doing them. As soon as we got onto the delivery suite my midwife and birth partner took down the hospital curtains. I hated those curtains from staring at them during my husband's cancer treatment and death, it helped enormously to have them removed and

also to feel that I had some control in an uncontrollable situation, that I had birth partners who would challenge the protocol to give me what I needed. Every little thing counted and makes me proud. We had my wedding photos and altar items where I could see them during labour. I insisted on not having drips in both hands so I didn't feel too trussed up; I told the doctors not to discuss politics during my birth; I wore a pretty sundress to labour in. The epidural wore off enough to feel him coming out, and I saw his sex for myself; I had skin to skin and time to hold him and I carried him to the Teardrop room in my sling. These things matter.

## the attitude of the staff was brilliant

The staff and facilities at my hospital were also amazing. We had access to a special suite with double bed, kitchenette and more home-like facilities as well as a cold cot to keep Raymond with me; my parents could stay with me; my friends visited; we had Wi-Fi so I could communicate with friends, but most of all the attitude of the staff was brilliant. I was never once made to feel that even a small request, like paper to write on or a cup of tea, was less important than other work they could be doing with living babies whose outcomes could be changed. I had as much time as I needed with Raymond and had no pressure to leave him before I was ready. I can't imagine how much more difficult this time would have been without this.

Mementoes are good but aren't memories. I almost hesitate to write this part, as I fear I may feel differently from other parents. I am enormously grateful for the photos, prints, memory boxes etc. I have, but to me these aren't memories. Memories are the time I had with my living son. This is a record to his body. At times I felt almost rushed, being given the memory box even before Raymond was born, time alone with Raymond was very important. But I am glad for the beautiful photos I have – a lovely way to share my son with the world.

Finally, don't assume a woman knows about after-care. I'm fairly sure people talked to me in the hospital – I have no idea what they said. I was given Sands leaflets and these were really helpful as they let me access the information when I could cope, but really I needed people to get in touch later and talk about counselling and other support when I could listen.

Heather

# Memories of George

*Radka Elliott* wrote this piece only two days after George's birth

**I would like to share our story, which is very fresh and raw...**

My husband and I are hurting very much. Just last Thursday, on 23 April 2015, at 40wk+5, during a routine check, ready for an induction, we found out that our baby's heart had stopped beating. Our angel son George was stillborn on Sunday, 26 April, at 7:51am, weighing 3lb 13oz (1.8kg) and 48cm long.

My pregnancy had been a textbook one; I was blooming and loved being pregnant. We didn't know the sex of the baby, we wanted a surprise. I had no morning sickness, was looking after myself, ate the right diet, and was swimming, walking and practising yoga regularly. Check-ups with the midwife were quick, simply because there were no problems. I kept active to prepare me for the birth, which I feared greatly, yet I was so excited about the wee one coming that I simply suppressed my fear. My sweet hubby was ecstatic about the prospect of becoming a Daddy: we kept feeling the kicks on a regular basis, especially at night, that was like a ritual. We thought our wee one is a night owl ... just like his Mummy.

I was given a membrane sweep around my due date and was hoping for the labour to start, but nothing really happened. My next check-up with the midwife was Thursday 23 April. When she was listening for the wee one's heartbeat, there was none! Alarmed, she got another midwife and then we were sent to the hospital to get a thorough check. As soon as we arrived, they took us for a scan and broke the horrible news to us that our baby's heart was definitely not beating. A complete out of body experience thereafter, my hubby and I could not believe this was happening. We were taken to a different room where a very supportive midwife tried to console us and clarify things.

The next massive hit was being told that I had to give birth to the wee one! I mean WHAT? I am to give birth to a dead baby? Can they not do a C-section? No, the best way forward was to give birth vaginally – we felt this was so inhumane and heartless – did we not have enough to come to terms with already? I was given a pill to start the labour and we were told to come back to the labour ward on Saturday at 4pm to give birth. We were numb, it all felt so surreal when we told our parents and then our closest friends – I kept stroking my belly and talking to our baby hoping for a miracle to happen. Thankfully, my lovely in-laws came to stay and went to the hospital with us; I felt my husband needed his parents' support in order to be strong for me, and so on Saturday afternoon we made our way to the hospital, and I felt like I was going for an execution.

We were given a room at the very end of the labour ward, it was surprisingly therapeutic to both of us to hear a baby's cry: the birth of a healthy baby is a happy event after all, and a very compassionate and lovely midwife was looking after us from then on. The midwife was

perplexed that she could not feel any waters (and they had definitely not broken beforehand). She confirmed the baby was not alive, which was like a lightning strike to me, no hope for a miracle. At this point I was determined to be strong and give birth to my baby with as much dignity and love as I could muster, and this would be my gift to the wee soul.

I had a straightforward labour but a birth complicated by shoulder dystocia. I am very proud of myself and feel at peace for I delivered our angel with the help of TENS machine, gas and air, and only a small episiotomy (I suppose my grief was greater than the physical pain).

## I got timeless cuddles with my boy all Sunday before I had to say goodbye

After George was born his condition indicated that he may have been an angel for more than a few days, his placenta was very small, and he was also very light, they took him away (with our consent) and brought him back later all wrapped up and clean and sleeping. I got timeless cuddles with my boy all Sunday before I had to say goodbye the following day (just yesterday), and this helped me greatly with my grieving process. I took some pictures on my phone, and we got the SiMBA memory box too (see page 11 for further details).

My darling husband has not looked at or cuddled George, and that is totally fine by me. He said with time he may be brave enough to look at our son but, for now, he does not want to spoil the image he has.

The hospital staff were amazing, my in-laws were able to use the family room while we stayed overnight, everybody doing their utmost to make this horrible situation as bearable as possible. More importantly, they were treating our angel son with great dignity, respect and compassion, and for that we are very grateful.

Now at home and seeing all the baby stuff around us makes our hearts bleed, but we are strong, we love and support each other, and we shall come out of this even stronger. Our angel son will guide us through; after all he got us even closer together. We have become parents of a beautiful son, who we'll never see smile or grow up. In George's memory we have set up on a regular basis a donation to SiMBA, the amount is £26.04 (George's birthday) and it will come out of our account every 18th of the month (George's due date).

*Radka Elliott*

# After stillbirth

Shane Ridley reflects on her very positive experience of receiving support

**L**ooking back nearly 20 years to the stillbirth of our daughter Katie Eva, what do I see with the value of hindsight? The most important aspect was the people who made a difference; I've listed them here in no particular order.

On arrival at the hospital in labour, we learnt fairly quickly that our baby had died – I remember screaming 'get it out, get it out' and the voice of the registrar saying 'no, it's much better for you and for your next pregnancy if you can birth naturally – caesareans can mean your next pregnancy will be difficult.' 'I'm too old for another baby,' I screamed – with lots of calm and gentle advice, screams turned to crying and John and I followed her advice. I had lots of morphine but did birth her, albeit they used forceps in the end. I shall never forget the kindness shown to us that day.

A dear friend and colleague who had been going to support us as our birth partner – she came in the middle of the night to help us.

My consultant who visited us on the day and offered his condolences and his apology that he could not have done more. The new consultant who gave us the most superb support throughout the next pregnancy and birth.



The labour ward clerk helped us arrange to revisit the hospital to see Katie and helped with all the paperwork and kept in touch with us for years afterwards. The hospital chaplain who christened Katie and arranged for her name to be put in the Remembrance Book in the hospital chapel. We visited the chapel every year until we left the area.

The Chaplain from the hospital where I worked organised a beautiful funeral – a celebration of a life not lived. Katie has a grave and my friend's young daughter tended it for us when we moved away.

The lady from CRUISE who helped us with our grief. Our community midwives who came to Katie's funeral and helped us through the next pregnancy. The members of our local NCT branch who supported us and came to the funeral. Work colleagues who wrote to us.

Our friends and neighbours who were there to listen and who did our shopping for us in the first week or so. I remember being petrified that if John went out without me he wouldn't come back. I remember being frightened that the police or social workers would question me because I had done something wrong.

A friend and work colleague who was pregnant at the same time as my next pregnancy – remarkably she spent lots of time with me and talked me through it – I don't know what I would have done without her; it was her second pregnancy too, and she must have been so scared too.

Our homeopath who gave us the most wonderful effective remedy for grief and then continued to support us as she always had done.

John's mother was there at Patrick's birth – she supported John and John supported me...

During what was the worst time of our lives, we were loved and cared for and our marriage has stood the test of time. We've counted our blessings many times over the years. Katie is in a safe place in our family; we chose to believe that had she been born she would probably have died anyway. I didn't used to know what people meant when they said 'in our hearts' but I do now – Katie is in our hearts – we don't have to talk about her much, or have reminders about the place – she is just always there, quietly loved.

But you have to know this story has a happy ending. Our son, Patrick, was born 13 months after Katie was stillborn. He has grown into a gorgeous, happy, well-adjusted and strong-willed young man (I'm his mum, I'm allowed to say that!)

We wouldn't have missed having him, for all the world.

Shane Ridley



# Reviews

## *When a Baby Dies: the experience of late miscarriage, stillbirth and neonatal death*

By Nancy Kohner and Alix Henley  
Pandora Press  
ISBN 0 04 440566 9



When a Baby Dies is still probably the most useful book available for those who lose a baby, and in the UK that will be 8,000 families every year. It was produced first in 1991, last reprinted in 2001, in conjunction with Sands (the Stillbirth and neonatal death charity) and includes letters from and interviews with many bereaved parents. There is information about what is known about why babies die; issues such as hospital practice, professional attitudes, the nature of bereavement, the process of grieving, sources of support and future pregnancies but the most important aspect of this book is that it is told through the voices of those who have experienced this 'loss of a person'. The testimonies have been collected over many years: they are all different but with common themes, and the shared experience in these pages illustrates an intensely personal experience in a way that could, and I'm sure has, provided much comfort.

If this book were to be written today then some of the language might be different – using the word 'birth' more often rather than 'delivery', for instance – and some of the information will have changed, but fundamentally the experience of loss as told by those experiencing it will not have changed.

One section I particularly liked is, while discussing funeral and other ceremonies, the authors make the suggestion that it is never too late to mark a baby's death. They relate how parents overwhelmed at the time of the birth may decide, sometimes many years later, to mark the death. One such mother several years later, having had a subsequent miscarriage and a live baby, went back to the hospital for a debriefing and 'to her surprise' found herself agreeing to a memorial service.

*'He began a simple service and as I heard the familiar prayers, the 23rd Psalm, my weeping subsided. He mentioned Luke and the little girl over and over again and talked of their value despite their brief existence. Profound gratitude swept over me to know they were being acknowledged at last.'*

There are accounts where parents are able to support each other throughout, others when the loss of a baby drives them apart – difficulties with sexual relationships afterwards are sometimes apparent – but a recurrent theme is that the process of grieving for a loss is not over quickly.

Care and support from professionals is enormously varied, from insensitive and seemingly uncaring to situations where midwives and doctors freely show their own feelings of sorrow: in one case a health visitor visited a bereaved mother for one hour every week for months until she felt able to cope. As well as help from family and friends, the attitude and behaviour of professionals is obviously crucially important. A study in Norway<sup>1,2</sup> looked at a sample of women who had a history of three or more consecutive miscarriages: it was found that among those women who had no specific abnormality, increased individual care and support, with no extra 'medical' care, from the professionals looking after them seemed to double the success rate in their next pregnancy. This is a really remarkable finding, and the authors suggest that we take this need for care very seriously. There are many useful messages in this book, but I would suggest that this is the key one for all of us, professional and lay, whatever our own histories, to take onboard ourselves.

Gill Boden

### References

1. Stray-Pedersen B and Stray-Pedersen S (1984) Etiologic factors and subsequent reproductive performance in 195 couples with a prior history of habitual abortion. *American Journal of Obstetrics and Gynecology* Vol. 148, No. 2. January 1984.
2. Stray-Pedersen B and Stray-Pedersen S (1988) Recurrent abortion: the role of psychotherapy. In Beard RW and Sharp F (Eds) *Early Pregnancy Loss: Mechanisms and Treatment*. Springer-Verlag.

## *The Children Who Sleep by the River*

By Debbie Taylor  
Interlink Books  
ISBN-10: 0940793962  
ISBN-13: 978-0940793965

This book draws you into the lives of several generations of women in rural Zimbabwe. It is the story of a young woman, her mother, aunt, sisters and cousins and the ghost of her grandmother. It shows their struggles to survive, but particularly focuses on pregnancy, birth and the healthcare of their children.

The mother is a traditional midwife and nganga; but she is also being trained to attend birth by the medical services. She struggles to reconcile the knowledge that had been passed on to her and that she has developed over many years, with the medical view that is being dogmatically drilled into the group she has joined.



## Reviews

The contrast is very illuminating, showing aspects of traditional midwifery in conflict with medical models. Some are commonly recognisable as conflicts within a UK setting. However, other aspects come over as 'primitive', highlighting the difficulty in identifying the best practices for any practitioner.

The death of babies is important to the story; the struggle to know whether deaths could have been avoided and how these uncommon events drive actions that may or may not help: something that is a huge issue in the drive to medicalise birth everywhere around the world.

I was so drawn in by the imagery of this book that I had an extremely abrupt arrival at Waterloo one morning. I

had been totally engrossed in the lives of these people when the tannoy announcement jolted me back from their world, leaving me totally disorientated for a moment or so.

It says that the book was written with the help and encouragement of the World Health Organization and was first published as an Emerging Voices publication.

I only happened upon this book on Amazon in the 'others who bought this' section and as it was published back in 1992, I am disappointed that I had not heard of it before, and will be off to see what else the author has written. This book was not only thought provoking, but a really good read too.

*Debbie Chippington Derrick*

## A selection of books for children who lose a baby brother or sister

Reviewed by Gill Boden



### *We were gonna have a baby but we had an angel instead*

By Pat Schweibert

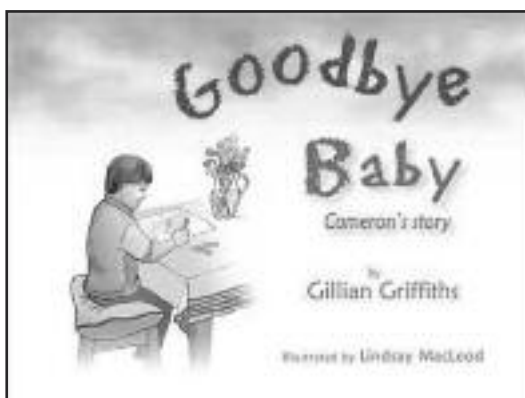
Illustrated by Taylor Bills

Grief Watch, Portland, Oregon

Publisher's recommended price £5.99

ISBN-13: 978-0-9724241-1-0

A rather schmaltzy title but nice illustrations of a little boy looking forward to his baby's birth, commenting on how sad his parents and grandparents are and candidly admitting that they are 'sadder than him' but reflecting that having a baby could have been fun. Recommended for children 2 and up.



### *Goodbye Baby: Cameron's story*

By Gillian Griffiths

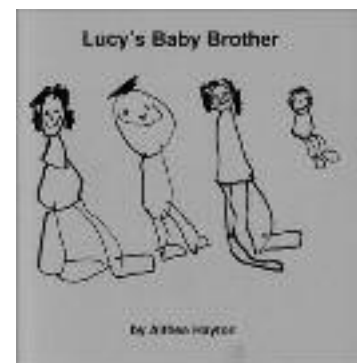
Illustrated by Lindsay MacLeod

Saint Andrew Press, Edinburgh, 2010

Publisher's recommended price £7.99

ISBN 978-0-7152-0940-0.

Gillian Griffiths wrote this after she'd had a miscarriage when her son Cameron was almost three to help her to explain and come to terms with his feelings. What is nice about the book is its practical detail and the fact that the older child has some negative feelings as well as sorrow. Some of the proceeds will go to the Miscarriage Association.



### *Lucy's baby brother*

By Althea Hayton

Drawings by John Farrell

Eddington Press, St Albans, 1995

Publisher's recommended price £3.99

ISBN 1-872067-05-0

This book has a front cover designed by a 4-year-old, and the illustrations inside are line drawings that could be coloured in. It seems to me a sensitive and child-centred book, told from Lucy's point of view. She goes to the hospital after her little brother's death and is able to hold him; her teacher at school talks to her about what has happened, encourages her to tell the other children in her own words and comforts her too. I found this a very positive story of how a child can be helped through a sad event by her family and the wider community.

# Women and midwives working together

**A**IMS members, midwives and doulas attended the AIMS talk in Sheffield at the Showroom Cinema on Friday 24 April, and our speaker Mavis Kirkham, Professor of Midwifery at the University of the West of Scotland, opened with a quote from Margaret Mead:

*'Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.'*

Good maternity care, good birth and successful breastfeeding have a positive long-term impact on families, lasting at least a generation; continuity of care reduces small-for-dates babies and premature birth, and a reduction in both of these leads to less cardio-vascular disease in later life for the infant; breastfeeding also has a lifetime effect for both mother and baby; and we know that postnatal depression negatively affects educational achievements. Nurturing mothers and babies therefore has a massive value for future generations.

In talking about the primary aim of maternity care, which is providing care that makes a mother feel safe and valued, Mavis pointed out that mother and baby are a unit and if nurtured as a unit they flourish. In all her years of practice as a midwife, Mavis has yet to meet a mother who is not deeply committed to the welfare of her baby. It should be our aim, unless in the most extreme circumstances, to treat mother and baby as a pair and not *'cast them asunder'* when it is no longer an intrauterine affair.

Given that the use of technology in birth can cause a negative hormonal cascade, we need to provide a space where mothers feel valued and safe and can achieve physiological birth, which cannot be bettered. This centres on relationships, and there is much research on the benefits of continuity of care; we have created a model of care for maternity that does not promote relationships, and has led to criticisms of staff for lacking compassion.

The dichotomies of expert and patient, hierarchy and control, surveillance and risk assessment, and the notion of 'right course of action' all characterise the medical model of healthcare provision, rooted in our societal values. They all combine to emulate an industrial model, characterised by a focus on efficient throughput, fragmented care, centralisation, economies of scale, standardisation and consumer choice within a culture that generates fear. These models reveal contradictions in relation to birth. The medical and industrial models produce fear and guilt, generate performance anxiety, generalise instead of focusing on the individual; they depend on a right course of action in place of flexibility

and tolerance of uncertainty. Where, in contrast, optimal conditions for birth require confidence, love and generosity. Medical and industrial models focus on the short term, whereas optimal conditions for birth have a multitude of long-term positive impacts.

In discussion with Mavis, we wondered about the impact of these contradictions and how it seems that rather than being in awe of birth, often the atmosphere in the birth arena seems to be in fear of death. She suggests that mothers and midwives can create a midwife-led place of safety for birth and for practice; with continuity of care, as in New Zealand, contributing to the reinvigoration of midwives: a refuge where 'small is beautiful', a community owned and managed hub where relationships are prioritised. There would be an emphasis on continuity, respect and equality, and non-violent communication, dialogue, 'peace and power'. We need to learn to be still and calm and to exude safety and nurturing, while acknowledging that if we set up such a place of safety we will need to maintain it. Medical definitions of safety don't fit these criteria; authoritarian medical models make women powerless; birth centres come and go, winning awards for excellence and then closing.

Mavis's vision is for a strategic nationwide plan and action for a network of Centres for Birth, along the lines of a hospice where the quality of care is paramount and there is an independence from medical treatment. This would first necessitate the difficult task of wresting control over birth away from the medical model. Secondly, since hospices require large amounts of charitable money, and new parents are unlikely to make bequests or fundraise, it would require non-NHS money and a good business plan to put to commissioners. But the big obstacle would be insurance: insurance companies have an immense impact worldwide on maternity care, partly because of the huge sums of money at stake. 'No-fault compensation' may be one way to proceed, as in New Zealand where in the event of a baby being born with severe disability lifetime care for that baby is assured. Women and midwives can create awareness about insurance control, and a more just situation.

At the end of the evening, as I was leaving, I met the community midwife who had enabled me to birth my second baby at home, 18 years to the exact hour: I was able to express my sincere gratitude and appreciation for her wonderful nurturing and care. As I return to teaching a small active birth class, I am struck by how much fear has been instilled into the women who arrive at my door and I am saddened to see that there is no longer any continuity of care available for these women such as there was for me.

*Olivia Lester*

# How you can help AIMS

AIMS has just become a Charity. It still has no paid staff – our committee and volunteers give their time freely. All monies raised go towards providing women with support and information.

All AIMS members are invited to the

## AIMS AGM

Saturday 12 September 2015

Bristol

10.30 for 11.00 start

Please contact [secretary@aims.org.uk](mailto:secretary@aims.org.uk) if you wish to attend or send your apologies.

Followed by

**Lunch**

For AIMS members attending the AGM and those attending the talk

Please bring food to share

1.30 - 2.30

and

**Interactive talk with Nicky Leap**

**Working with Pain in Labour**

3.30 - 6.00pm

Presentation followed by workshop

Tickets for talk must be purchased in advance, available online at [www.aims.org.uk/?NickyLeapTalk.htm](http://www.aims.org.uk/?NickyLeapTalk.htm)

For more information please email [talks@aims.org.uk](mailto:talks@aims.org.uk)

### **If you are not already a Member, you could join**

As a Member, your benefits include four AIMS Journals a year and access to the AIMS Members Yahoo Group. You will be able to stay in touch and have more of a say in what AIMS is doing. You will receive updates from committee meetings and early notice of events such as AIMS talks, as well as being able to contribute to discussions of current issues.

Visit [www.aims.org.uk](http://www.aims.org.uk)

If all our Members just encouraged one other person to join, we would double our membership and income!

A really easy way for everyone to help AIMS is to order cards and notelets from our website [www.aims.org.uk](http://www.aims.org.uk) and consider giving the new canvas bag or mugs for presents.

**A big thank you,  
whatever you can do!**