

Spotlight on Sands

Parliamentary Bulletin

Introduction

Welcome to issue two of *Spotlight on Sands*, our parliamentary bulletin, bringing you the latest news and updates on the charity's campaigns.

Since launching our *Why17?* campaign and the *Saving Babies' Lives Report* in March 2009, we have successfully put the issues surrounding stillbirths and neonatal deaths on the political agenda in Westminster and all three devolved governments.

However, with 6,500 babies stillborn or dying shortly after birth every year in the UK, we still have much work to do if we are to prevent further unnecessary loss of these young lives, and the devastating impact such losses have on their families.

We are pleased to welcome so many new MPs, and to congratulate all those MPs who were reappointed, following the General Election in May. We are looking forward to

working with many of you over the coming months to address some of our key concerns, particularly around bereavement care services and the process of review following the death of a baby. The impending changes to the health system will present many challenges to already-stretched maternity services, but we hope that there will also be opportunities to learn lessons from the past and make improvements for the future.

On behalf of all bereaved parents, and all future parents, Sands intends to play an instrumental role in ensuring that saving babies' lives is given the priority it truly deserves.

Neal Long, Chief Executive, Sands

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Latest campaign: improving bereavement care services.



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Campaigning news

Northern Ireland: *Every Baby Matters* and the Maternity Services Review

In March 2010, Sands joined forces with the charities TinyLife and Bliss, to raise awareness in the Northern Ireland Assembly of the issues.

The three charities produced a briefing, *Every Baby Matters*, to outline our specific concerns in Northern Ireland. Jim Wells MLA hosted an event on our behalf at Stormont, which was well-attended, and we also had a series of one-to-one briefing meetings with key MLAs and ministers.

Following the event, we wrote to the Chairperson of the Assembly's statutory committee for Health, Social Services and Public Safety, to ask them to ensure that the views of the parents we support are taken into account by the Health Minister in the Review of Maternity Services in Northern Ireland this autumn.

In July, Sands was contacted by the Patient and Client Council which has been commissioned to undertake pre-consultation with interested parties to inform the content of the full formal public consultation on regional maternity services.

Pre-consultation is being undertaken across Northern Ireland on a range of issues relating to maternity services. Of particular relevance to Sands is a focus on the views of parents whose experiences of birth were not straightforward.

This has been a great opportunity for Sands to advocate on behalf of bereaved parents and to feed into the formal policy-making process. Members from the Sands Northern Ireland group held a focus group with the Patient and Client Council to put forward our priorities for improving maternity services in Northern Ireland.

These included:

- ▶ bereavement training for health professionals
- ▶ improved information relating to post mortems
- ▶ prevention of inequality of treatment for young mothers in post-bereavement aftercare
- ▶ the need for support mechanisms for staff caring for bereaved parents

Over the coming months we'll be seeking to ensure that our views are properly incorporated in the review.



Sands parents Cathy Pidgeon and Claire Moffatt with Kieran McCarthy MLA at the Northern Ireland *Every Baby Matters* launch

Scotland: One year on from *Why17?* campaign launch

Since launching our *Why17?* campaign in Scotland last autumn, we are encouraged by progress made with the Scottish Government to date.

We tabled a petition urging the Scottish Government to (1) note and act upon the Sands *Saving Babies Lives Report 2009* in support of its *Why17?* campaign; (2) develop a strategy for reducing levels of stillbirths and neonatal deaths; (3) fund further research to improve understanding of why stillbirths and neonatal deaths happen; (4) develop gold standard antenatal care provision in all NHS boards; and (5) work with

Sands to improve public awareness of these issues.

As initial steps forwards, the Scottish Government has provided funding to Sands until 2011 to work with NHS boards to ensure the relevant staff receive appropriate education and training to support bereaved parents. The Scottish Government has also recently formed a Neonatal Services Expert Advisory Group which will include Sands representatives, to provide advice and guidance to the Regional Managed Clinical Networks for neonatal services which will consider the issues raised in the petition. In addition, the Scottish

Government has set up, and will chair, a short-life working group made up of Sands representatives and health professionals to consider how best to address the issues raised in the petition.

Whilst these are positive outcomes to our campaigning efforts, Scotland still has one of the highest perinatal mortality rates in Europe. We therefore continue to work closely at government level to ensure that our concerns are addressed on an on-going basis.

Perinatal post mortem: national programme needed

Sands has written to the Department of Health requesting a nationally driven programme to address issues surrounding perinatal post mortem.

Our request comes as a result of research Sands has funded with the University of Manchester into perinatal post mortem services and care for bereaved parents.

Research, undertaken by Dr Alex Heazell, clinical lecturer in Obstetrics at Manchester, was presented at a one-day workshop with leading specialist pathologists, as well as obstetricians, midwives and Sands parents, in April. The aim of the workshop was to understand how to improve care for bereaved parents in helping them decide whether to

have a post mortem performed on their baby.

The uptake of perinatal post mortem in the UK has not recovered since the Alder Hey organ retention scandal a decade ago. Presently only 45% of bereaved parents agree to have a post mortem performed on their baby. Reasons for this include lack of adequate training for health professionals to provide them with the skills required to obtain consent from parents for a post mortem (many knowing very little about the value or process of post mortem); the language of the present consent form is brutal and complex, making it difficult for distressed and grieving parents to consent; and perinatal pathology services are badly

stretched meaning some parents wait months to receive results of post mortem. Sands hears from parents who have endured long and painful delays, often stretching into many weeks or several months, for the return of their baby's body from post mortem.

We will be raising these issues during National Pathology week from November 1st to 7th 2010.



Attendees at the post mortem workshop, April 2010

Public health minister supports Sands Awareness Month

We were delighted when Public Health Minister, Anne Milton MP, visited St Thomas' Hospital's maternity unit and the Evelina Children's Hospital's neonatal unit on Thursday 10th June to mark Sands Awareness Month.

During her time at the hospital, Mrs Milton met with staff and families, and visited the maternity unit, the neonatal unit and the Sands suite, available to parents whose baby is stillborn or dies shortly after birth.

Commenting on her visit, Anne Milton said, "It is so impressive to see the complete dedication of the midwives, nurses, doctors and other staff who care for very sick and premature babies and their parents at St Thomas'. These babies really are the most vulnerable members of our society.

Thanks to the hard work of neonatal professionals, both here and across the country, increasing numbers of babies are alive today who only ten or twenty years ago would not have survived.

The death of a baby is a devastating experience which can be overwhelming for parents, their families and friends. For more than thirty years Sands has provided invaluable support to those affected by stillbirth or the death of a baby.

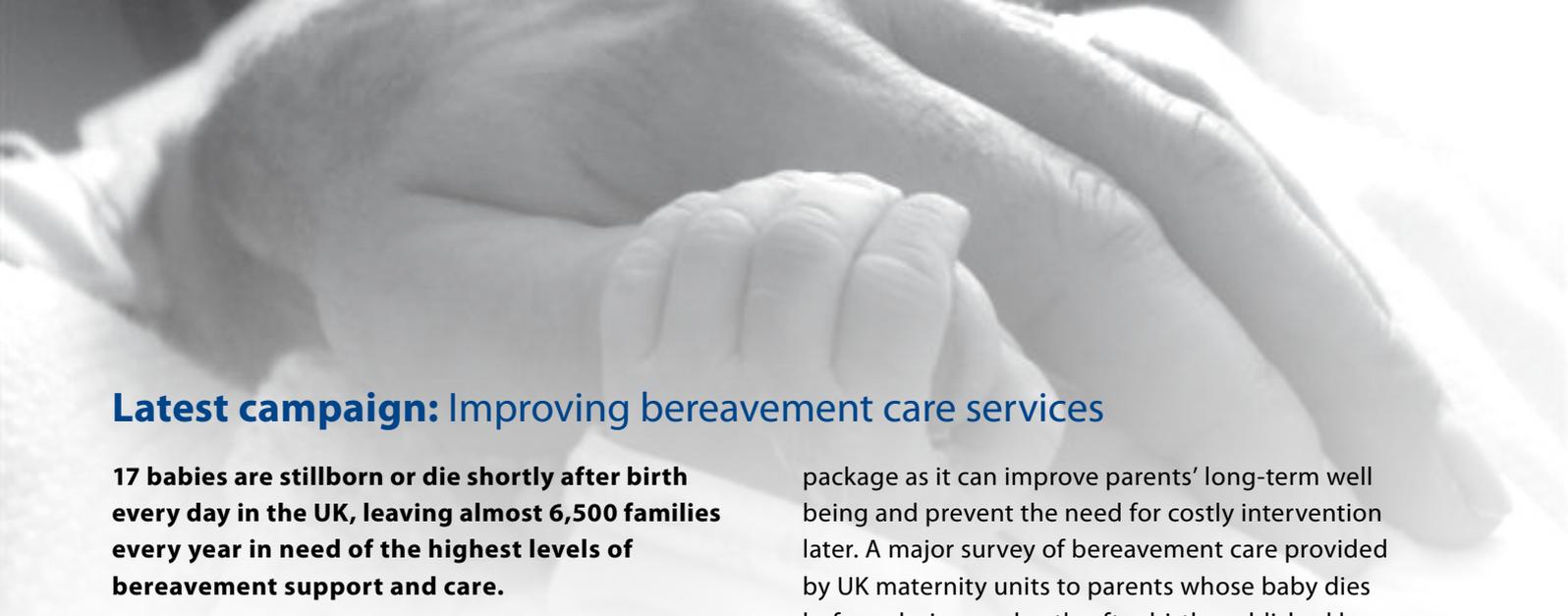
I am very supportive of the charity and pleased to have this opportunity to thank them for the important work they do."

Anne is one of our Sands Parliamentary Voices – find out more about this group on page 6.



Sands staff visit St Thomas's with Anne Milton MP. **L to R:** Marie McDonald, Clinical Director, Women's Services; Zahra Familli, Bereavement Midwife; Anne Milton MP; Katie Duff, Communications Manager; Erica Stewart, Bereavement Support Manager; Lynne Pacanowski, Director of Midwifery.

As part of our improving bereavement care services campaign this autumn (see page 3), we are encouraging all MPs to tour their local maternity units and meet with their local Sands groups. **Contact Tara MacDowel to find out more information: tara.macdowel@uk-sands.org or call 020 8973 3691.**



Latest campaign: Improving bereavement care services

17 babies are stillborn or die shortly after birth every day in the UK, leaving almost 6,500 families every year in need of the highest levels of bereavement support and care.

Good bereavement support is essential and should form an integral part of every bereaved woman's care

package as it can improve parents' long-term well being and prevent the need for costly intervention later. A major survey of bereavement care provided by UK maternity units to parents whose baby dies before, during or shortly after birth, published by Sands in June 2010, however reveals worrying disparities in care for bereaved parents.

What are the problems?

Whilst the provision and organisation of care for bereaved parents has improved over the last few decades, in around 20% of maternity units care is still poorly resourced and poorly organised, and in others it is patchy.

The key problems that our report identifies are:

- ▶ Disparity of care across the country resulting in a postcode lottery for parents
 - ▶ Lack of bereavement support midwives, who should play a vital role in delivering care to bereaved parents
 - ▶ Inadequate training provision, on caring for parents whose baby
- dies, for midwives and other health professionals
 - ▶ Lack of privacy for parents, with many units not having designated rooms for parents on the labour ward or postnatal ward
 - ▶ Poor information provision to minority ethnic and disabled groups, and lack of translated information and trained interpreters

What needs to happen?

Above all, we are calling on those commissioning and managing maternity services to ensure the resourcing and funding for good bereavement care is in place.

Good support can improve the long-term well being of parents and prevent the need for costly intervention later.

Our specific calls are for all maternity units to:

- ▶ Employ at least one (preferably more for larger units) bereavement support midwife
 - ▶ Ensure the unit is set up to allow for a separate, dedicated suite or facilities for parents both during labour and afterwards
 - ▶ Provide bereavement support training for all midwives and multi-disciplinary training for trainee obstetricians and gynaecologists
- ▶ Offer high-quality, written support information to all bereaved parents, including information in other languages and in a fully accessible format
 - ▶ Plan staffing levels to ensure that a continuity of carer can be offered to parents during labour and after the birth of their baby
 - ▶ Improve communication between the different staff involved in care, establishing consistent processes and producing streamlined documentation and recording of events

Support our campaign

We need parliamentarians to support our campaign this autumn to improve bereavement care services. To find out more and to get involved, or to arrange a personal briefing from a local constituent, **please contact Tara MacDowel at Sands: tara.macdowel@uk-sands.org or call 020 8973 3691.** The full *Bereavement Care Report 2010* can be downloaded at www.uk-sands.org.

Other News

The preventable deaths of 100 babies a year

A new study in the British Medical Journal has found that babies are at higher risk of dying soon after delivery if they are born outside normal working hours.

The lives of 100 babies every year in the UK might be saved if those babies had been born in office hours, when staffing in maternity units is better than it is at night and weekends.

Gordon Smith, professor of Obstetrics and Gynaecology, and colleagues from the University of Cambridge gathered information on one million births over the past 20 years. They analysed 539 neonatal deaths (babies who die in the first four weeks of life)

excluding babies who had died of a congenital abnormality.

The research team found that one in four babies, who had reached term but who had died neonatally as a result of oxygen starvation during labour, might not have died if they had been born in office hours rather than at night or at the weekend.

A baby who is lacking oxygen during labour needs to be responded to rapidly in order to prevent lasting brain damage or death. Yet it's well known that labour wards are not as well staffed at weekends or at night as they are during the weekday, even though 70% of births happen

at night. It is shocking to calculate that as many as 100 babies' deaths a year across the UK could be the result of the poor quality of care those babies received because they were born outside of working hours.

The paper ***Time of birth and risk of neonatal death at term: retrospective cohort study***, 15 July 2010, Dharmintra Pasupathy, Angela M Wood, Jill P Pell, Michael Fleming, and Gordon C S Smith, is available to view free online at www.bmj.com.

New CMACE report: stillbirth rate barely changed

The neonatal death rate in the UK is continuing to improve, but the stillbirth rate has changed very little, according to a new report.

The Centre for Maternal and Child Enquiries' (CMACE) latest report on perinatal deaths in 2008 found that nearly 20% fewer babies died in the first four weeks of life compared to 2000. The stillbirth rate did fall very slightly between 2006 and 2008 (from 5.2 to 5.1 stillbirths per 1000 live births) but looking over a ten year period the change is insignificant.

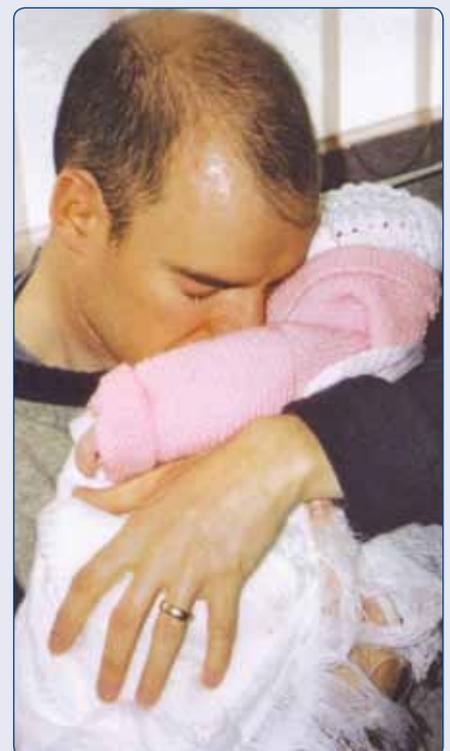
The number of babies who start labour apparently healthy and then die (intrapartum related deaths) is also unchanged with around 500 babies dying each year. Some of these deaths stem from poor care during delivery. Each of these tragic

deaths must be fully investigated and lessons learnt for the future.

The UK birth rate is rising and so are the risk factors for stillbirth and premature births. Obesity, smoking, social deprivation, teenage pregnancies and older mothers are all on the increase. This means pressure on maternity services is growing at a time when front-line services are already being hit in some areas regardless of government assurances that they will not be.

It's more important than ever to ensure the deaths of babies are not sidelined but treated with the same priority as any other death.

To download the full CMACE report, go to www.cmace.org.uk



Martin Lynagh's final moments with his daughter, Amy, stillborn at 39 weeks gestation

Support us as a Sands Parliamentarian

The Sands Parliamentarians Group is an informal group of MPs, MSPs, AMs, MLAs and Peers who are committed to supporting the issues that are of concern to Sands, because they are the issues that matter to the bereaved families we represent.

The group will help us to raise the profile of our *Why17? campaign* at a national policy level, to stimulate debate and encourage collaboration to create a national strategy to reduce the number of stillbirths and neonatal deaths.

For more information on becoming a Sands Parliamentarian, or how to support our *Why17? campaign* contact:

Tara MacDowel, Campaigns and Policy, Sands
tara.macdowel@uk-sands.org 0208 973 3691

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

Sands is a national charity, with nearly 100 support groups across the UK, focusing on three main areas of work:

- ▶ We support anyone affected by the death of a baby
- ▶ We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care
- ▶ We promote and fund research that could help to reduce the loss of babies' lives

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