Baby Loss Awareness Week

This pack has been prepared ahead of the general debate to be held in the Commons Chamber on Tuesday 9 October 2018. The subject for the debate has been selected by the Backbench Business Committee.

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1. Baby Loss Awareness Week

A general debate on Baby Loss Awareness Week will take place in the Commons Chamber on 9 October 2018. The subject of the debate was decided by the Backbench Business Committee, and the debate will be led by Antoinette Sandbach MP.

Baby Loss Awareness Week 2018 is on 9-15 October. This is an opportunity for those affected by baby loss to remember and commemorate their babies’ lives, and to raise awareness of this issue. The Baby Loss Awareness Week website provides more information about the aims of the week:

Baby Loss Awareness Week is an opportunity:

- for bereaved parents, and their families and friends, to unite with others across the world to commemorate their babies’ lives.
- to raise awareness about the issues surrounding pregnancy and baby loss in the UK, and push for tangible improvements in bereavement care and support.
- to let the public and key stakeholders know what charities and other supportive organisations are doing on bereavement care and support around pregnancy and baby loss.

The charities leading Baby Loss Awareness Week are committed to raising awareness of pregnancy and baby loss, providing support to anyone affected by pregnancy loss and the death of a baby, working with health professionals and services to improve bereavement care, and reducing preventable deaths.¹

Baby Loss Awareness week is coordinated and supported by over 60 UK charities including Sands, the Miscarriage Association and Antenatal Results and Choices (ARC). In Baby Loss Awareness Week 2018, these charities are calling for improvements and increased consistency in the provision of bereavement care in UK hospitals:

We believe that everyone who has experienced pregnancy loss or the death of their baby should be offered high quality bereavement care and support, wherever they live in the UK, when they need it, for as long as they need it.

The care that bereaved families receive from health and other professionals can have long-lasting effects.

Good care cannot remove parents’ pain and grief, but it can help them through this devastating time. In contrast, poor care can significantly add to their distress.

However, the standard of care in the UK varies between regions, and even within settings depending on at what stage a loss occurs – from early pregnancy through to infancy.

As a result many parents do not receive the good quality bereavement support they so desperately need after pregnancy or baby loss.

¹ Baby Loss Awareness Week website
Bereavement care training is mandatory in less than half of NHS Trusts and Health Boards. At the last count, one in three Trusts and Health Boards did not have a dedicated bereavement room in each maternity unit they cover.

Source: Sands Bereavement Care Audit Report 2016

Bereavement care must get better and we will be announcing during Baby Loss Awareness Week how we believe this can happen.2

The term baby loss can describe a number of different types of bereavement including, miscarriage, ectopic pregnancy, stillbirth, neonatal and infant death, and termination of pregnancy. It is not possible to provide a comprehensive briefing on these in this debate pack. However, this briefing will highlight key recent policy announcements and parliamentary activity in this area.

A number of Commons library and POST publications may provide useful information in preparation for the debate on baby loss awareness week:

- Commons Library briefing paper, The investigation of stillbirth, October 2018
- Commons Library briefing paper, Registration of stillbirth, October 2018
- Commons Library briefing paper, Infant cremation, October 2018
- POSTnote, Infant Mortality and Stillbirth in the UK, May 2016
- POST Briefing, Bereavement Care after the Loss of a Baby in the UK, July 2016

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2 Baby Loss Awareness Week website: About Baby Loss Awareness Week
2. Stillbirth and neonatal deaths in the UK

The most recent review of stillbirths and neonatal deaths in the UK reports that out of 780,043 births in 2016, 3,065 of these were stillbirth and 1,377 were neonatal deaths. The stillbirth rate for the UK in 2016 was at 3.93 per 1,000 total births and the neonatal death rate was 1.72 per 1,000 live births.3 Whilst noting a reduction in stillbirths since 2013, the report highlighted that UK stillbirth rates still remain high compared with similar European countries.

An article in the Lancet journal (part of a series on stillbirth) in 2016, Stillbirths: recall to action in high-income countries, noted that inequality exists both between, and within, high income countries in stillbirth rates.4 The authors state that “if all high-income countries achieved stillbirth rates equal to the best performing countries, 19,439 late gestation (28 weeks or more) stillbirths could have been avoided in 2015.” The UK was ranked 24th of 49 high income countries in the Lancet study.

Whilst perinatal mortality has decreased in the last few decades, there are concerns that the rate of this decrease has slowed over recent years. Another concern is that whilst numbers overall are improving, there remains a geographical and socio-economic inequality in rates. In 2016, NHS England reported that there was around a 25% variation in stillbirth rates just across England.5

Another 2016 Stillbirth series study reported that parents, family, health services, society and Government may all be affected by wide ranging and substantial impacts of stillbirth.6 These include “medical care and investigations at the time of stillbirth and in subsequent pregnancies; funeral costs; grief and negative psychological effects; reduced social functioning; family and relationship disruption and breakdown; and negative effects on employment.” These impacts are often enduring and long lasting.

The UK Government have taken action to address maternity care and stillbirth rates. A number of programmes have stemmed from an announcement made by the then Secretary of State for Health, Jeremy Hunt in November 2015- a national ambition to halve the rates of stillbirths, neonatal and maternal deaths in England by 2030.7

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3 MBRRACE-UK, Perinatal Mortality Surveillance Report – UK Perinatal Deaths for Births from January to December 2016, June 2018

4 Stillbirths: recall to action in high-income countries, Flenady, Vicki et al. The Lancet, Volume 387, Issue 10019, 691 - 702


6 Stillbirths: economic and psychosocial consequences, Heazell, Alexander E P et al.

7 Department of Health, New ambition to halve rate of stillbirths and infant deaths, November 2015
In November 2017, the Department of Health published *Safer Maternity Care: The National Maternity Safety Strategy* which set out some additional measures to prevent serious incidents in maternity services, and updated its ambitions, including bringing the target date forward from 2030 to 2025.

Medical professional organisations, such as the Royal College of Obstetricians and Gynaecologists, and charities such as Sands also play an important role in developing programmes and reviewing and improving the care provided to both expectant and bereaved parents.

### 2.1 Surveillance and statistics

The MBRRACE-UK team at the National Perinatal Epidemiology Unit (NPEU) conducts UK wide surveillance of perinatal mortality, which includes all stillbirth and neonatal deaths, and maternal deaths.

As part of this programme, MBRRACE-UK publishes an annual perinatal mortality surveillance report, which identifies risk factors, causes and trends, and makes recommendations on how stillbirth and neonatal mortality rates can be reduced.

The most recent report was published in June 2018 and provides information about rates of stillbirth and neonatal deaths in 2016, including comparing rates between different organisations delivering healthcare across the UK.

The report notes that there was little change in the rate of extended perinatal mortality in the UK in 2016: 5.64 per 1,000 total births for babies born at 24 weeks gestational age or later compared with 5.61 in 2015. However, this does represent an overall fall from 6.04 deaths per 1,000 total births in 2013.

The stillbirth rate for the UK in 2016 also remained fairly static at 3.93 per 1,000 total births. This follows a period of year on year reduction from 2013 to 2015: from 4.20 to 3.87 stillbirths per 1,000 total births.

Over the same period, the rate of neonatal mortality in the UK has shown a slow but steady decline: from 1.84 deaths per 1,000 live births in 2013 to 1.75 per 1,000 in 2016.

The key findings of this report are summarised overleaf in the infographic reproduced from the report.
Baby deaths in the UK
The national picture for 2016

780,043 births of babies delivered live at any time during pregnancy, excluding terminations of pregnancy

3,065 stillbirths
1,337 neonatal deaths

Overall reduced mortality rates between 2013 and 2016

8.14 to 5.64
This represents approx. 300 fewer baby deaths

Stillbirths
4.20 to 3.93
This represents approx. 200 fewer stillbirths

Neonatal deaths
1.84 to 1.72
This represents approx. 100 fewer neonatal deaths

Improved survival for twins
The stillbirth rate in twins has reduced by almost half since 2014
Neonatal deaths in twins have reduced by almost a third during the same period

Regional variation still evident in England

Crude neonatal mortality rates

Wide variation in the timing of reporting of deaths to MBRRACE-UK

Post-mortem examination continues to vary between stillbirths and neonatal deaths

Almost all parents of stillborn babies were offered a post-mortem

8 out of 10 parents of babies who died neonatally were offered a post-mortem

Of these parents, 1 in 2 consented to a post-mortem
Of these parents, 1 in 3 consented to a post-mortem

Placental histology was carried out for:

9 out of 10 stillbirths but for only 7 out of 10 neonatal deaths which occurred on day 1, or were related to problems during delivery

Full report available from: https://www.patients.ac.uk/mbrrace-uk/reports. Couple by Jon Taiming and Microscope by Maxim Kuflik from the Noun Project.
© 2018 The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester.
Each Baby Counts
The Royal College of Obstetricians and Gynaecologists’, Each baby Counts initiative is a national quality improvement programme launched in October 2014. The investigation team conducts a detailed analysis of all stillbirths, neonatal deaths and brain injuries that occurred during childbirth. A large 2017 report, based on 2015 data, concluded that three quarters of the babies reviewed might have had a different outcome with different care:

The reviewers concluded that three quarters of these babies - 76% - might have had a different outcome with different care. This finding was based on 727 babies where the local investigation provided sufficient information to draw conclusions about the quality of care. A quarter of the local investigations were not thorough enough to allow full assessment.

Co-principal investigator, Professor Zarko Alfirevic, consultant obstetrician at Liverpool Women’s Hospital, said: “Problems with accurate assessment of fetal wellbeing during labour and consistent issues with staff understanding and processing of complex situations, including interpreting fetal heartrate patterns, have been cited as factors in many of the cases we have investigated.

“This is the first time the Each Baby Counts team has been in a position to identify and share the lessons learned across the whole UK maternity service. However, until every incident is thoroughly investigated and important lessons identified locally, our understanding of the national picture will remain incomplete. The focus of a local investigation should be on finding system-wide solutions for improving the quality of care, rather than actions focusing only on individuals.”

A July 2018 Each Baby Counts report focused specifically on anaesthetic care given to women in labour and makes a number of recommendations on improving care in this area.

The wider findings and recommendations from the Each Baby Counts programme are due to be published in autumn 2018.

2.2 Government policy and programmes

National Maternity Review
In March 2015, Simon Stevens, Chief Executive of NHS England, announced an independent review of maternity services as part of the NHS Five Year Forward View.

In February 2016, the report of the National Maternity Review, ‘Better Births’, was published. The review found that whilst there had been

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8 RCOG, Teamwork in maternity units key to reducing baby deaths and brain injuries during childbirth, 21 June 2017
9 RCOG, Recommendations made into anaesthetic care to reduce perinatal deaths and brain injuries during childbirth, July 2018
significant improvements in maternity care over the last decade, geographical variations remained and there were opportunities to improve services further. The report highlighted seven key improvements for maternity care. These included that women should be able to have care focused on their personal needs and choices, that women should have a named midwife, who is known to them and based in the community, and that there should be improvements in the provision of perinatal and postnatal mental healthcare.10

The Maternity Transformation Programme Board is leading the implementation of the Maternity Review, including work to reduce the rate of stillbirths, neonatal and maternal deaths in England.

Government target to reduce stillbirths, neonatal and maternal deaths

On 13 November 2015, the then Health Secretary, Jeremy Hunt, announced a new Government ambition to “reduce the rate of stillbirths, neonatal and maternal deaths in England by 50% by 2030.” He further promised that the Government would target the number of brain injuries occurring during or soon after birth.11

In doing so, maternity services were tasked to develop “initiatives that can be more widely adopted across the country as part of a national approach”, such as appointing maternity safety champions to report at board level, or ensuring that all staff have the right training to be able to identify risks and symptoms associated with perinatal mental illness. Trusts were provided with a share of over £4 million of Government funding “to buy high-tech digital equipment and to provide training for staff already working to improve outcomes for mums and babies”.

Over £1 million was allocated to funding the rollout of training packages developed with the Royal College of Midwives and the Royal College of Obstetricians and Gynaecologists. In addition, £500,000 was allocated to “developing a new system for staff to review and learn from every stillbirth and neonatal death”.12

In October 2016, the Department of Health published Safer Maternity Care: Next steps towards the national maternity ambition, which was intended as guidance as to the actions required to be taken by trusts to “make improvements to the services they provide for women and their newborns”.13 It included a “Maternity Safety Training Fund” of £8 million, designed to support trusts in providing training, a share of which was available from October 2016 upon application to Health Education England.14 It also included a new £250,000 Maternity Safety Innovation Fund, available from the Department of Health, which

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11 “New ambition to halve rate of stillbirths and infant deaths”, Department of Health press release, 13 November 2015
12 Ibid.
13 Department of Health, Safer Maternity Care: Next steps towards the national maternity ambition, October 2016, p8
14 Ibid., p20
invited open applications “for pioneering proposals for new ways to drive improvements in maternity safety”.\textsuperscript{15}

The guidance stated that, in order to ensure that progress was being made, it expected to see a reduction of 20% in the rate of stillbirths, neonatal and maternal deaths by 2020.\textsuperscript{16}

This plan also included an action for NHS England to publish a final \textit{Saving Babies’ Lives care bundle} for use of maternity commissioners and providers. This is comprised of the following interventions:

- Reducing smoking in pregnancy
- Risk assessment and surveillance for fetal growth restrictions
- Raising awareness of reduced fetal movement; and
- Effective fetal monitoring during labour.\textsuperscript{17}

On 30 July 2018, NHS England \textit{claimed} that an \textit{evaluation} had demonstrated that an estimated 600 stillbirths could be prevented annually if maternity units adopted this care bundle.\textsuperscript{19}

In November 2017, the Department of Health published \textit{Safer Maternity Care: The National Maternity Safety Strategy} which set out some additional measures to prevention serious incidents in maternity services, and updated its ambitions, including bringing the target date forward from 2030 to 2025:

- Around 55,000 babies are born pre-term (i.e. 24 - 36 weeks gestation) each year. This represents a national pre-term birth rate of 7.9% in England and Wales. We need to focus efforts on reducing the pre-term birth rate if we are going to achieve the national Maternity Safety Ambition.

  \textbf{To encourage this additional focus, the Department of Health is setting an additional ambition to reduce the national rate of pre-term births from 8% to 6% by 2025.}

- We are currently on track to meet our ambition to reduce stillbirths, neonatal and maternal deaths by 20% by 2020. The range of additional funding and support should enable maternity and neonatal services to go farther and faster.

  \textbf{We have, therefore, decided to re-set the national Maternity Safety Ambition to halve the rates of stillbirths, neonatal and maternal deaths and brain injuries occurring during or soon after birth to 2025.}\textsuperscript{20}

In January 2018, Jackie Doyle-Price provided the following update on Government attempts to reduce stillbirths in answer to a \textit{PQ}:

\begin{itemize}
  \item \textsuperscript{15} \textit{Ibid.}, p22
  \item \textsuperscript{16} \textit{Ibid.}, p12
  \item \textsuperscript{17} NHS England, \textit{Saving Babies’ Lives: A Care Bundle for Reducing Stillbirth}, March 2016
  \item \textsuperscript{18} “NHS action plan can prevent over 600 still births a year says NHS England”, NHS England press release, 30 July 2018
  \item \textsuperscript{19} Saving Babies’ Lives Project Impact and Results Evaluation (SPIRE), \textit{Evaluation of the implementation of the Saving Babies’ Lives Care Bundle in early adopter NHS Trusts in England}, July 2018
  \item \textsuperscript{20} Department of Health, \textit{Safer Maternity Care: The National Maternity Safety Strategy – Progress and Next Steps}, November 2017, p9
\end{itemize}
Since the Maternity Safety Action Plan was launched in 2016, more than 90% of trusts have appointed a named board-level maternity safety champion; 136 National Health Service trusts have received a share of an £8.1 million maternity safety training fund and, as of June 2017, more than 12,000 additional staff have received training. The maternal and neonatal health safety collaborative was launched on 28 February 2017 and 44 wave 1 trusts have attended intensive training on quality improvement science and are working on implementing local quality improvement projects with regular visits from a dedicated quality improvement manager; and 25 trusts were successful in their bids for a share of the £250,000 maternity safety innovation fund and have been progressing with their projects to drive improvements in safety.

The majority of maternity care providers are now implementing all four elements of the Saving Babies’ Lives Care Bundle, which recommends four key elements of evidence-based care and practice: reducing smoking in pregnancy, risk assessment and surveillance for fetal growth restriction, raising awareness of reduced fetal movement and effective fetal monitoring during labour. The Department has also funded the National Perinatal Epidemiology Unit at the University of Oxford to develop a national standardised Perinatal Mortality Review Tool to support local perinatal death reviews.

[...] From April 2018, every case of a stillbirth, neonatal death, suspected brain injury or maternal death that is notified to the Royal College of Obstetricians and Gynaecologists’ (RCOG) ‘Each Baby Counts’ programme, about 1,000 incidents annually, will be investigated independently, with a thorough, learning-focused investigation conducted by the Healthcare Safety Investigation Branch. The new independent maternity safety investigations will involve families from the outset, and they will have an explicit remit not just to get to the bottom of what happened in an individual instance, but to spread knowledge around the system so that mistakes are not repeated.

In addition, the Department has provided funding for the RCOG to launch ‘Each Baby Counts Learn and Support’ - a programme of work to enable greater collaboration between the Royal Colleges and the NHS via the Maternal and Neonatal Health Safety Collaborative - the aim is to align quality and safety improvement, multi-professional learning and clinical leadership into a consistent and sustainable safety strategy across the system. The Department is also providing new funding to train health practitioners, such as maternity support workers, to deliver evidence-based smoking cessation according to appropriate national standards.21

In March 2018, the then Health Secretary Jeremy Hunt announced plans to roll out the ‘continuity of carer’ model, where women have a consistent midwife and/or obstetrician throughout the antenatal, intrapartum and postnatal periods, to all women by 2021. It is intended that 20% of women will be covered by the model by March 2019. In announcing this target, the Secretary of State argued that:

21 PQ 122321 [Perinatal Mortality], 17 January 2018
Women who have continuity of carer are 19% less likely to miscarry, 16% less likely to lose their baby and 24% less likely to have a premature baby.\textsuperscript{22}

2.3 National Bereavement Care Pathway

The National Bereavement Care Pathway is a project which was started in 2017 by an alliance of charities and professional bodies, with support from the All Party Parliamentary Group on Baby Loss, and with funding from the Department of Health & Social Care.\textsuperscript{23} Its objective is to create a care pathway for England which ensures that all bereaved parents are offered equal, high quality, individualised, safe and sensitive care in any experience of pregnancy or baby loss, be that miscarriage, Termination of Pregnancy for Fetal Anomaly, Stillbirth, Neonatal death, or Sudden Unexpected Death in Infancy up to 12 months.\textsuperscript{24}

To achieve this, it has undertaken pilots in 32 sites across England and developed pathway guidance for professionals, as well as a toolkit containing various training materials.\textsuperscript{25}

During Prime Minister’s Questions in \textit{on 11 October 2017}, the Prime Minister said that the Government expects this pathway to be implemented nationally from October 2018.\textsuperscript{26}

In addition, in March 2017 NHS England produced guidance for Local Maternity Systems (LMSs) to implement the recommendations from the report, Better Births, which had been published a year earlier in February 2016 and which had been one result of the of the National Maternity Review.\textsuperscript{27} This guidance stipulates that LMSs should “pay particular attention to the provision of bereavement support to women and their families when a baby dies during pregnancy or whilst receiving specialist support through neonatal intensive care units”.\textsuperscript{28}

In June 2017, NHS England published Gathering feedback from families following the death of their baby. This is a resource being used across England to improve bereavement care by supporting Local Maternity Systems to seek feedback from families when bereavement occurs and to use the insight to commission bereavement services that are fit for purpose.\textsuperscript{29}

\textsuperscript{22} HC Written Statement: Improving Maternity Safety – Continuity of Carer and the Midwifery Workforce, 27 March 2018
\textsuperscript{23} PQ 110207 [Bereavement Counselling], 2 November 2017
\textsuperscript{24} “National Bereavement Care Pathway”, Sands stillbirth & neonatal death charity website.
\textsuperscript{25} Ibid.
\textsuperscript{26} HC Deb 11 October 2017 c332
\textsuperscript{27} National Maternity Review, Better Births: Improving outcomes of maternity services in England, February 2016
\textsuperscript{29} NHS England, Gathering feedback from families following the death of their baby: A resource to support professionals in maternity care, June 2017
2.4 Parental Bereavement (Leave and Pay) Act 2018

The *Parental Bereavement (Leave and Pay) Act 2018* received Royal Assent on 13 September 2018. The Act will create a statutory entitlement to parental bereavement leave and pay by amending the *Employment Rights Act 1996* and social security legislation. It will require implementing regulations, which are yet to be laid before Parliament. Once brought into force, bereaved parents will be entitled to at least two week’s leave, paid at the same flat rate used for other parental rights, such as maternity pay (currently £145.18 per week).

2.5 Scotland

Review of maternity and neonatal services in Scotland was announced on 25 February 2015. The review looked at the quality and safety of maternity and neonatal services, and choice within those services. The report of the review, *The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland*, was published in January 2017. The key recommendations were:

- **Continuity of Carer**: all women will have continuity of carer from a primary midwife, and midwives and obstetric teams will be aligned with a caseload of women and co-located for the provision of community and hospital based services.

- **Mother and baby at the centre of care**: Maternity and Neonatal care should be co-designed with women and families from the outset, and put mother and baby together at the centre of service planning and delivery as one entity.

- **Multi-professional working**: Improved and seamless multi-professional working.

- **Safe, high quality, accessible care**: including local delivery of services, availability of choice, high quality postnatal care, colocation of specialist maternity and neonatal care, services for vulnerable women and perinatal mental health services.

- **Neonatal Services**: proposes a move to a new model of neonatal intensive care services in Scotland in the short and long term.

- **Supporting the service changes**: recommendations about transport services, remote and rural care, telehealth and telemedicine, workforce, education and training, quality improvement and data and IT.\(^{30}\)

In a [February 2017 statement to the Scottish Parliament](http://www.parliament.scot), the Minister of Public health and Sport, Aileen Campbell, said that the Government were committed to implementing the recommendations, and that an implementation group was being established.

2.6 Wales

In Wales, a National Stillbirth Working Group was set up within the 1000 Lives Plus programme of work in April 2012 and included representation of important stakeholders in maternity care. The National

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Assembly for Wales published an Inquiry into stillbirths in Wales in 2013, which identified a number of actions to improve the stillbirth rate in Wales.

In March 2017, the Safer Pregnancy Wales campaign was launched. It is an initiative developed by the Wales Maternity Network in collaboration with 1000 Lives Improvement.

2.7 Northern Ireland

In December 2013 a new Northern Ireland Maternal and Infant Loss (NIMI) steering group was established to focus on policy to reduce the number of stillbirths and neonatal deaths. Chaired by Northern Ireland’s Chief Medical Officer, Dr Michael McBride, the Northern Ireland group’s remit covers all infant deaths in Northern Ireland, from miscarriage to one year. The group consists of healthcare professionals, officials and charities. Further information on this is available on the Sands website.

The Department of Health launched a Maternity strategy, A strategy for maternity care in Northern Ireland 2012 - 2018 in 2012.
3. News items

Guardian

Huge numbers of stillborn babies ‘may have been missed’
27 September 2018

https://www.theguardian.com/lifeandstyle/2018/sep/27/huge-numbers-of-stillborn-babies-may-have-been-missed

Telegraph

Parents of stillborn babies given legal right to paid bereavement leave for first time
15 September 2018


Independent

Maternity units could prevent 600 stillbirths a year if new national guidance is adopted, says NHS England
30 July 2018


Independent

Health Secretary Jeremy Hunt orders review of parents' registering rights after miscarriage
1 February 2018

4. Press releases

Bliss

A quarter of extremely premature babies are born in the wrong hospital, report warns

October 02, 2018

Bliss has warned that more needs to be done to ensure that extremely premature babies are born at a hospital which is best equipped to properly care for them.

Bliss’ comments come in response to the latest National Neonatal Audit Programme (NNAP) 2018 report which found that one in four babies born at less than 27 weeks gestation was born at a hospital without an on-site neonatal intensive care unit (NICU). Further to this, only two of 15 neonatal networks are meeting their target of ensuring that 85 per cent of babies born before 27 weeks are delivered in centres with a NICU.

Caroline Lee-Davey, Chief Executive at Bliss said:

It is extremely disappointing that opportunities for transfer before birth in complicated pregnancies are being missed. Evidence shows that extremely premature babies born at hospitals with a NICU have the best possible chance of survival thanks to the specialist staff and equipment in place at these units. While it is not always possible for mothers in spontaneous labour to be transferred safely to a hospital with a NICU on-site, there is wide and unacceptable variation across the UK in how often this happens.

Bliss echoes the recommendations of the report and calls upon neonatal and maternity services to work together as a matter of urgency to address this variation in practice, so that as many extremely premature babies as possible are born in a hospital which is fully equipped to care for them safely.

The NNAP report also found that some babies admitted into neonatal care might be separated from their parents for longer than necessary. Term babies receiving a low level of specialist care spent an average of 3.2 days in the neonatal unit when separation from their mother was not necessary.

The report recommends that neonatal units with above average numbers of separation days for term, or late preterm babies should consider a revision of their admission or discharge criteria.

Caroline Lee-Davey said:

Babies have the best start in life when they are able to have their parents with them - for term or late preterm babies who need a little bit of extra help after birth, this means being cared for alongside their mother in a post-natal or transitional care ward, rather than being admitted into neonatal care and separated from their parents.
Research has shown that parental involvement in a baby’s care supports brain development and cognition.\[i\] Other benefits for parents staying with their babies in hospital playing a hands-on role in their care include improved breastfeeding rates, earlier discharge from hospital, and reduced re-admission rates.\[ii\] \[iii\] It is therefore essential that avoidable separation of babies from their parents is closely scrutinised and that processes of admission into and discharge from neonatal care are reviewed.


\[ii\] Flacking et al. (2012) ‘Closeness and Separation’


**Royal College of Midwives**

**RCM response to the publication of the AFFIRM trial in the Lancet**

**28 September, 2018**

The Royal College of Midwives welcomes the publication of this important cluster randomised trial today in the Lancet. The AFFIRM trial has aimed to explore how we can reduce the number of stillbirths. Reducing stillbirths is a vital goal that the RCM fully supports – any stillbirth is an absolute tragedy for any family.

The AFFIRM trial used an innovative and robust design to test the impact of a package of care to reduce stillbirths and perinatal mortality. The study sought to test whether, by raising awareness about the importance of fetal movements among pregnant women and health professionals and introducing a consistent package of care when women present with a history of reduced fetal movements, that stillbirth rates could be reduced. The study was large, including outcomes from more than 409,000 pregnancies in 37 maternity units across the UK.

The results of the study are clear: the package of care did not lead to a statistically significant reduction in the number of stillbirths and led to a significant increase in medical interventions including induction of labour and caesarean section. Induction of labour rose from 35.9% in the control period to 40.7% of births in the intervention period. Caesarean sections rose from 25.5% to 28.4% in the intervention period.

The RCM fully supports research and quality improvement initiatives to reduce stillbirths and neonatal death. The AFFIRM trial suggests that a reliance on reduced fetal movements alone will not lead to the reduction that we all wish to see in the number of stillbirths and neonatal deaths. The AFFIRM trial, with its negative result, has made an important contribution to our current knowledge. Further research
into this important topic is always needed. Current quality improvements initiatives underway in the UK, including ‘MCQIC (Maternity and Child Quality improvement collaborative) in Scotland and the ‘Saving babies lives’ care bundle in England, take a multi-faceted approach to reducing risks, including supporting women to give up smoking, improving risk assessment and surveillance of fetal growth, effective monitoring in labour, developing a safety culture with positive multi-disciplinary team working and implementing continuity of carer, alongside increasing awareness about fetal movements.

The results of this study should not lead to a situation where a woman’s concerns about her baby’s movements are not taken seriously. We would still encourage all pregnant women to become familiar with their baby’s usual movements and to contact their midwife or maternity unit if they notice a change or reduction. We would also still encourage all midwives, GPs and obstetricians to respond when women describe a reduction in their baby’s movements, taking a careful history and monitoring the baby’s growth, heart rate and activity in a face to face assessment.

The risks posed by increased interventions need to be balanced by their potential benefits. This study did not demonstrate that the interventions tested provide the benefits sought in relation to reducing stillbirth or perinatal mortality. There was also an increase in the number of admissions of babies to special care baby units for more than 48 hours after the intervention compared to before.

The RCM supports ongoing research and quality improvement work alongside our colleagues in the multi-disciplinary maternity team. We hope that the findings of the AFFIRM trial will be considered carefully and will support health professionals in providing women with evidence based information to make informed decisions about their care.

Tommy’s
28-week definition of stillbirth leaves 50% of babies uncounted
28 September 2018

The number of stillbirths in Europe is being vastly underestimated according to new research looking at the definition of a stillbirth.

At what point is a stillbirth not a miscarriage? Many babies who die in the womb in late pregnancy are not counted in international estimates on stillbirths, because of the differences in the gestational age at which a death is recorded as a stillbirth instead of a miscarriage, new research published in The Lancet shows.

According to the study of 2.5 million babies in 19 European countries the rate of stillbirth has been underestimated by at least a third, because of recommendations to report only stillbirths occurring after 28 weeks gestation.

The UK counts a death as a stillbirth when it happens at 24 weeks onwards. Before that, losses are recorded as miscarriages.
Figures in 2015 estimated 2.6 million babies a year worldwide were stillborn but only data from babies dying at 28 weeks or more is used for international comparisons and estimates. This is because the World Health Organisation recommends countries collect stillbirth data from 28 weeks of pregnancy onwards.

**This impacts on funding for stillbirth research**

This threshold means a huge number of stillbirths that occur earlier in pregnancy are not being recognised, with data from this research revealing international estimates could be around 50% higher, at least for high-income countries, if stillbirths from 22 weeks are included.

“This work was to emphasise how many parents’ losses are not being acknowledged by the standard rates and also to look at stillbirths at those early in gestation,” said Dr Lucy Smith, first author of the research from the University of Leicester. “If we don’t have data on them, we can’t look at how we can design interventions to reduce those early gestation stillbirths – and they may have different causes of death, or different patterns.”

Stillbirth rates varied from country to country – particularly before 24 weeks – and a handful of countries included late terminations in their data.

Three countries, including the UK, did not have data for stillbirths before 24 weeks.

Tommy’s chief executive Jane Brewin said;

> Losing a baby at 22 weeks or indeed at any time during pregnancy is as much a heartbreak to the families as it is at 28 weeks. To the families labelling the first a ‘miscarriage’ can seem an inaccurate reflection of their loss. It also has big implications in terms of the emotional and clinical care they get after the death of their baby, with much more support available for parents who have suffered a 28 week stillbirth.

> From a research point of view, we know that the underlying causes of a 22 week loss are very likely to be similar to the causes of a 28 week loss so having accurate figures is hugely important to help us make the case and get funding to investigate these causes and find ways of prevention.

The findings reveal that in 2015 alone more than 3,000 stillbirths occurred in Europe between 22 and 28 weeks of pregnancy, accounting, overall, for 32% of all stillbirths at or after 22 weeks.

The authors say gestational age used for international comparisons and estimates should be lowered to 24 weeks, and that countries should do better at collecting data from 22 weeks to allow researchers to better probe trends.

Professor Joy Lawn, of the London School of Hygiene and Tropical Medicine, who co-authored an accompanying commentary, said global figures for stillbirths could be 30-50% higher than current estimates if stillbirths from 22 weeks gestation are included.

> If we don’t count them and don’t look at the trends, people don’t invest in changing them.
Rates of stillbirth are falling – but not fast enough.

Tommy’s is the largest UK charity funding research to prevent stillbirth. We carry out vital research to find out why stillbirths happen, and how we can prevent them. Rates of stillbirth are falling – but not fast enough. Our research is helping us understand the causes of stillbirth, so we can find the babies at risk in time to help them.

Our research aims to reduce stillbirth rates by finding the missing links between stillbirth, the placenta, and the baby’s growth. Most of our stillbirth research takes place in our Manchester Research Centre, where we have made great progress in our Rainbow and Placenta Clinics. Research focuses on three main areas:

1. Understanding the causes
2. Treatment and prevention
3. Improving care for women at risk of, and following, a stillbirth

We are already making strides towards our goals.

Recent achievements

- In St. Mary’s Hospital, we lowered the average number of stillbirths by 19% from 2012 to 2017. This is equivalent to 12 fewer babies dying every year.
- In Edinburgh, obese women attending our antenatal clinic were 8 times less likely to have a stillbirth than women receiving standard care.
- We have developed a new way of looking at the placenta using Magnetic Resonance Imaging (MRI). This will help doctors tell which women have healthy pregnancies and which babies may be struggling.

Support after a stillbirth

Stillbirth is one of the most devastating experiences any family can go through. We are here to support families who are going through this very difficult time. We have worked with women who have experienced stillbirth, their families and professionals who have supported them to develop supportive information below to help parents who have suffered a stillbirth.

See here for more stillbirth information and support.

Department for Business, Energy & Industrial Strategy

UK first: Parents who lose a child entitled to bereavement leave

A new workplace right to paid leave for bereaved parents has been officially enshrined in law today.

13 September 2018
A new workplace right to paid leave for bereaved parents has been officially enshrined in law today (Thursday 13 September) as the Parental Leave and Pay Bill achieves Royal Assent.

The first law of its kind in the UK will support those affected by the tragedy of childhood mortality and is expected to come into force in 2020.

The new Parental Bereavement Leave and Pay Act will give all employed parents a day-one right to 2 weeks' leave if they lose a child under the age of 18, or suffer a stillbirth from 24 weeks of pregnancy. Employed parents will also be able to claim pay for this period, subject to meeting eligibility criteria.

This new law honours the manifesto commitment to introduce a new entitlement to parental bereavement leave.

Business Minister Kelly Tolhurst, said:

This law makes Parental Bereavement Leave a legal right for the first time in the UK’s history.

Losing a child is an unimaginable trauma. I am delighted we have reached this important milestone which so many have campaigned for.

I’d like to thank all the people who have helped make this law a reality, including the brave parent campaigners who have spoken out about their own experiences.

Lucy Herd from Jack’s Rainbow said:

When I started the campaign 8 years ago after the death of my son Jack, I always hoped that a change would happen in his memory.

Knowing that 8 years of campaigning has helped create legislation to ensure bereaved parents are protected in the future is such a wonderful feeling and I am so grateful to all those involved.

The government-backed bill was introduced to parliament in July 2017 as a private member’s bill by Kevin Hollinrake, MP for Thirsk and Malton.

Kevin Hollinrake MP, Bill sponsor, said:

Losing a child is the most dreadful and unimaginable experience that any parent could suffer and it is right that grieving parents will now be given time to start to come to terms with their loss.

I am grateful to Will Quince MP, who first brought this issue to the fore in a ‘Ten-Minute Rule Motion’ on statutory entitlement during the previous parliamentary session. I am also grateful to Lord Knight and fellow MPs, on both sides of the House, some of whom have shared their own personal stories of losing a beloved
Will Quince MP said:

There can be few worse life experiences than the loss of a child and while most employers treat their staff with dignity and compassion when this tragedy occurs, all too often we have heard stories of grieving parents being forced back to work too early.

I am delighted that parents in this awful situation will now have the protection of paid leave enshrined in law, and we should be very proud that the UK now has one of the best worker’s rights in this area in the world.

Francine Bates, Chief Executive of The Lullaby Trust said:

At The Lullaby Trust we know how devastating the sudden and unexpected death of a baby or a child is for parents.

This new law is a big step forward in recognising the needs of bereaved families in our society and will help to ensure that parents are not unduly pressurised to return to work immediately following the death of their child.

Steven Wibberley, Chief Executive of Cruse Bereavement Care said:

We are delighted that this bill has been approved as it will make a huge difference to bereaved parents whose lives have been shattered by the death of a child.

It is important that parents are given time to grieve in the aftermath of a child’s death and this new law recognises this.

Lullaby Trust

The Lullaby Trust calls for urgent action as rates of sudden infant death syndrome rise for first time in 3 years

20 August 2018

The Lullaby Trust has expressed deep concern as rates of sudden infant death syndrome (SIDS) increase for the first time in 3 years, according to figures released today by the Office for National Statistics (ONS). The rate fell in 2014 and 2015 following an increase in 2013, which was the first since 2008.

The figures show the number of deaths increased from 195 in 2015 (a rate of 0.28 deaths per 1,000 live births) to 219 in 2016 (a rate of 0.31). The 2016 figures show an 11% increase in the rate of deaths from last year.

The ONS are unsure what has caused the increase but cites possible risk factors as maternal smoking and overheating. They point out that SIDS rates have declined overall over the last 10 years and attribute this to advice and guidance provided by The Lullaby Trust, NHS and Welsh Government.

The Lullaby Trust, the UK’s leading SIDS charity believes the increase may have occurred as a result of recent cuts to Public Health and local parental support services along with widening inequality. The UK already has one of the highest overall infant mortality rates in Western
Europe and this year overall infant mortality rates increased for the second year running in England and Wales breaking a decade long pattern of decline.

Francine Bates, CEO of The Lullaby Trust says:

> We are deeply concerned by the increased SIDS rate in England and Wales. The previous downward trend in SIDS deaths has been largely attributed to increased awareness of safer sleep advice so it is essential that this remains a top priority for local authorities and all professionals working with families. SIDS rates are highest in the most deprived areas and we worry that pressures on local authorities’ public health budgets and the increasing number of families being pushed into poverty will lead to slower progress or even further increases in the number of deaths. We urge local authorities to ensure there is adequate funding for health visitors and early years staff who provide crucial safer sleep advice to families with new babies.

The ONS figures also show an increase in unexplained infant deaths to mothers aged under 20 years in 2016, with an increase of 24% in SIDS rates being seen for this age group. The rate of SIDS is highest in the West Midlands, Yorkshire and the Humber and the North West each with 0.45 deaths per 1,000 live births. The highest increase was in the West Midlands with the SIDS rate rising 22% from 2015.

Advice on safer sleep can be found here

To read the full report click here

**NHS England**

**NHS action plan can prevent over 600 still births a year says NHS England**

30 July 2018

*Evaluation shows clinical improvements across 19 sites led to maternity staff helping to save more than 160 babies’ lives.*

An estimated 600 stillbirths annually could be prevented if maternity units adopt national best practice says NHS England.

Clinical improvements such as better monitoring of a baby’s growth and movement in pregnancy, as well as better monitoring in labour, means that maternity staff have helped save more than 160 babies’ lives across 19 maternity units, according to an independent evaluation due to be published on Monday (30 July).

The detailed report shows that stillbirths fell by a fifth at the maternity units where national guidance, known as the Saving Babies Lives Care Bundle, had been implemented. The best practice guidance is now being introduced across the country and has the potential if these findings were replicated, to prevent an estimated 600 stillbirths.

The Saving Babies Lives Care Bundle is part of ambitious plans by NHS England to make maternity care safer and more personal.
Dr Matthew Jolly, National Clinical Director for Maternity and Women’s Health at NHS England, said:

These findings show significant progress in the reduction of stillbirth rates. This is thanks to the dedicated maternity staff who have developed and implemented the clinical measures we recommend as national best practice. We know more can be done to avoid the tragedy of stillbirth and as we develop the 10 year plan for the NHS, we want to build on the progress we’ve made to make maternity services in England among the safest in the world.

Secretary of State for Health and Social Care, Matt Hancock said:

There is nothing more devastating than losing a child so this improvement is welcome and testament to the incredible NHS maternity staff who do everything they can to improve care; saving many babies’ lives as a result.

We still have more to do but these results demonstrate really positive progress towards our ambition to halve the rates of stillbirth, neonatal death and maternal death by 2025.

Prof Alexander Heazell, Professor of Obstetrics, University of Manchester, said:

This large scale evaluation of the NHS England Saving Babies Lives Care Bundle shows that the interventions to reduce cigarette smoking, detect small for gestational age babies, inform women about reduced fetal movements and improve monitoring of babies during labour, have been increasingly implemented in the early adopter maternity units. Over the same time period stillbirths have fallen by 20 per cent, meaning 161 fewer stillbirths in the participating units.

This is an encouraging step towards achieving the UK government’s ambition of halving stillbirths by 2025. Importantly, this project has also highlighted areas which need further work – to reduce preterm birth and ensure that intervention is focussed on women and babies who require it. This project shows the importance of continually developing and evaluating the care we give to women and babies.

Jane Brewin, CEO at Tommy’s Centre for Stillbirth Research, said:

Tommy’s is proud to have been involved in devising the programme which has been implemented in 19 NHS Maternity Units and has resulted in a significant reduction in stillbirth. When all Maternity Units adopt this programme, fewer families will have to experience the tragedy of stillbirth which destroys so many family’s hopes and dreams. We are finally making progress towards making this country the safest place to give birth in the world and that’s something really worth striving for.

There are currently around 665,000 babies born in England each year, but despite falling to its lowest rate in 20 years, there are around 3,000 stillbirths, with one in every 200 babies stillborn.

Key successes identified in the report include:

- Increase in the detection of small babies – there was a 59 per cent increase detection attributed to better monitoring and scanning in pregnancy
• Better awareness of a baby’s movement in pregnancy – with a high number of women attending hospital due to reduced movement.

• Carbon monoxide testing for smoking in pregnancy was almost universal – Smoking is strongly associated with stillbirth. A 1 per cent increase in smoking rates increases the chances of stillbirth by 1.7 per cent. Alongside carbon monoxide monitoring there has been a decline in the number of women smoking, at time of booking.

Sands
Sands urges the government to reduce smoking in pregnancy
10 July 2018

In a new report, Sands and the ‘Smoking in Pregnancy Challenge Group’ has called for the government to take action to tackle the number of women who smoke during pregnancy.

Such action has the potential to prevent harm to hundreds of babies every year.

The report comes in the wake of new government data on smoking in pregnancy [1].

It calls for action by the government to reduce the rates of women who smoke during pregnancy, as they are failing to meet their target. Meeting that target, would mean preventing over 2,000 premature or low-weight babies in the next 4 years.

Overall smoking rates for 2017 are at all-time low of 14.9%, down from 19.3% just five years ago. This brings the estimated number of smokers in England in 2017 to 6.1 million, 1.6 million fewer than in 2011 [1]

But smoking rates among pregnant women in the UK have remained the same over the past 3 years, at 11%.

Sands’ Chief Executive, Dr Clea Harmer, attended a Parliamentary Launch of the Group’s new report [2] at Westminster, said: “Action is urgently needed to address the fact that smoking rates among pregnant women are not improving.

“Smoking increases the likelihood of a baby being born prematurely, so he or she will have health and development problems in childhood and later life, so it’s of utmost importance that the government takes action now to do everything they can to help and support pregnant women to quit smoking.”

The lack of progress in reducing smoking rates among pregnant women is alarming, as is the growing gap in smoking rates between rich and poor.

The Challenge Group’s report [3] has set out its recommendations for ensuring that the government target is met, of reducing smoking in pregnancy to 6% or less by 2022.
To enable this to happen the right support should be integrated into NHS care which is something all smokers would benefit from.

The new analysis [4] estimates the positive impact of achieving the government’s ambition. It estimates that in 2022 this would mean that around 30,000 fewer women would be smoking in pregnancy. This would lead to:

- 45-73 fewer babies stillborn
- 11-25 fewer neonatal deaths
- 7-11 fewer sudden infant deaths
- 482-796 fewer preterm babies and
- 1,455-2,407 fewer babies born at a low birth weight

It will only be possible to avoid these tragic and unacceptable outcomes if the numbers of women who smoke during pregnancy are reduced.

The Challenge Group has made a number of recommendations including:

- National action to ensure that all areas have services and processes in place to identify, refer and support pregnant women who smoke to quit

- Increase support for women from disadvantaged backgrounds where smoking in pregnancy rates are highest. This should include greater use of incentive schemes, supporting women between pregnancies and providing support to fathers and other members of the household.

- Increase the use of alternative sources of nicotine to support pregnant women in their quit attempts. Health professionals and women often hold misconceptions about using Nicotine Replacement Therapy and e-cigarettes as part of attempts to quit

- Address gaps in training for midwives, obstetricians and health visitors. Stopping smoking is part of ensuring a safe pregnancy and should be a basic part of training.

The Group was established in 2012 in response to a challenge from the then public health minister, to produce recommendations on how the smoking in pregnancy ambition contained in the government’s tobacco strategy could be realised.

The Group which is led by The Lullaby Trust with funding from Sands, Tommy’s, Tamba and ASH has published resources to support the training of midwives and other health professionals to address smoking in pregnancy which can be found [here](#).

References

[1] Annual Smoking at Time of Delivery data has been published by NHS Digital. It provides an annual figure for the rate of smoking in pregnancy for 2017/18. Data to Q3 for 2017/18 has already been published [here](#).


[4] The Lullaby Trust has undertaken this analysis on behalf of the Challenge Group with funding from Sands, Tommy’s, Tamba and ASH. The full analysis and methodology is [here](#).

**Nuffield Department of Population Health**

**Sudden Infant Death Syndrome (SIDS) and other unexplained infant death: nearly 5-fold variation in risk between different ethnic groups in England and Wales**

9 July 2018

There is evidence of large differences between ethnic groups in the risk of unexplained death in infancy, including Sudden Infant Death Syndrome (SIDS).

Mary Kroll, Maria Quigley, Jenny Kurinczuk, Yangmei Li and Jennifer Hollowell at the NPEU, University of Oxford, and Nirupa Dattani at City, University of London, looked at newly-available data for 4.6 million babies born in England and Wales. They found the lowest risk of unexplained death in infancy in Indian, Bangladeshi, Pakistani, White Non-British and Black African babies; intermediate risk in White British babies; and highest risk in Mixed Black-African-White, Mixed Black-Caribbean-White, and Black Caribbean babies.

The disparity of risk did not seem to be explained by patterns of preterm birth, mother’s age, or socio-economic position, and may reflect cultural differences in infant care.

Read the full results in the [Journal of Epidemiology and Community Health](#).

**MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK**

**MBRRACE-UK release “Perinatal Mortality Surveillance for Births in 2016”**

15 June 2018

The Perinatal Mortality Surveillance Report for Births in 2016 is published today (15th June 2018). Whilst the overall perinatal mortality rate is essentially unchanged since last year, compared with 2013, when MBRRACE-UK started reporting, the rate has decreased overall. Importantly the stillbirth rate for twins has nearly halved since 2014 and although the decrease in neonatal deaths in twins is smaller at 30% both represent a statistically significant change which indicates these reductions are unlikely to be due to chance.
Variations in rates between Trusts and Health Boards remain, although the variation in the stillbirth rate between Trusts and Health Boards delivering similar levels of care is now less marked than in the past. Nevertheless, there is still room for improvement as our average rate of stillbirths and neonatal deaths is still higher than in many other similar European countries. This fact, together with the findings from recent MBRRACE-UK confidential enquiries, suggest that with further improvements to the organisation and systems of care provided to mothers and their babies, a continuing reduction mortality rates is indeed possible.

To read more you can download the full report, executive summary and the infographic on the reports page.

Bliss

Bliss responds to MBRRACE report on Perinatal Mortality

June 15, 2018

A new report by MBRRACE was released today showing that neonatal and perinatal mortality rates remain stagnant. Read our response here.

A report published by MBRRACE has found that there has been very little change in the rate of neonatal deaths over a four year period.

MBRRACE found that the rate of neonatal mortality in the UK declined slightly over the period 2013 to 2016 from 1.84 to 1.72 deaths per 1000 live births.

The report also highlights the need for a greater focus on reducing preterm mortality, as about 70 per cent of all extended perinatal deaths occur before term, and nearly 40 per cent occur extremely preterm (at less than 28 weeks’ gestation).

In order for the Government to reach its ambition of reducing stillbirths and neonatal mortality rates, the report outlines the following recommendations:

- A national forum should be established by NHS England, the Scottish government, NHS Wales and the Northern Ireland Department of Health in conjunction with professional bodies and national healthcare advisors to agree an appropriate benchmark against which stillbirth and neonatal mortality rates should be monitored across the UK.

- The development of public health initiatives to reduce the impact of known risk factors for perinatal mortality such as smoking and obesity.

- Counselling should be provided to bereaved parents in order to help them to make informed decisions about post-mortems.

Caroline Lee-Davey, Chief Executive of Bliss said:

It is striking how much more there is still to do to reduce the number of babies who die. This latest report shows that there has
been little change in the extended perinatal mortality rate in 2016 compared to the year before.

The MBRRACE report adds to the multitude of evidence that the Government needs to make urgent investment into perinatal and neonatal care in order to give every baby the best possible chances of survival and quality of life.

Miscarriage Association

Registration of pregnancy loss before 24 weeks’ gestation

4 May 2018

Back in February, we sought your views on the possibility of registering pregnancy losses that happen before 24 weeks’ gestation. We share the results here.

The questions

We carried out an online survey of members, supporters and social media followers over 12 days, seeking views on the proposals in Tim Loughton MP’s Private Members’ Bill* on changing how pregnancy losses may be registered by law.

In it, we asked those with personal experience of miscarriage, ectopic pregnancy or molar pregnancy for their views on whether the law ought to be changed either to allow the registration of pre-24 week pregnancy losses or to require it.

Key findings

- There were 2,586 respondents and 93% of them said that they had experienced pregnancy loss themselves.

- The overwhelming majority, 74%, were in favour of allowing registration of pre-24 week loss (miscarriage, ectopic or molar pregnancy) at any gestation.

- 23% felt this should be an option only from a certain gestation. Those cut-off points varied widely, from 4 to 23 weeks’ gestation, but just under half of this group of people, 11% of all respondents, suggested 12 weeks.

- In summary, amongst our respondents there was overwhelming majority support for allowing registration for pre-24 week pregnancy losses.

It should also be noted that

- a significant minority, 44%, of all respondents were in favour of requiring registration of all pregnancy losses (these clearly included many who also supported allowing registration)

- 27% supported the requirement to register only from a certain gestation. Again those cut-off points varied from 4 to 23 weeks’ gestation, but just under half of this group of people, 12% of all respondents, suggested 12 weeks.
In summary, amongst our respondents there was **not majority support for requiring registration of all pregnancy losses pre-24 weeks**.

**Qualitative comments**

We had 908 responses that gave us more information. The most common of these related to registration as a means of acknowledging their baby's life, for example:

- I have had multiple miscarriages and an ectopic pregnancy. To register anything like this is to show that it happened and it did matter.

- I think you should have to register as it gives your baby a footprint on earth. It lets them be recorded and be an official part of their family. It will give families more confidence to speak freely of their loss.

A similar number stressed the importance of this being a personal choice, recognising that what was right for one person wouldn’t be right for another, for example:

- I would like it to be personal choice. It would help some people to register but may be harder for others.

- Don’t force women to legally enshrine one of the most painful moments of their lives. Give them the option but don’t make it a requirement.

Several people commented that while they supported allowing registration of miscarriage, ectopic or molar pregnancy, they wouldn’t want it themselves.

**Our position**

The Miscarriage Association broadly supports changing the law to give the option of registering losses that occur before 24 weeks’ gestation, under several conditions.

Please read our full position statement for the key details.
5. Parliamentary material

Bill proceedings

**Parental Bereavement (Leave and Pay) Bill** – Second Reading debate
HC Deb 20 October 2017 | Vol 629 c1158-

**Parental Bereavement (Leave and Pay) Bill** – Third Reading debate
HC Deb 11 May 2018 | Vol 640 cc1069-

**Civil Partnerships, Marriages and Deaths (Registration Etc.) Bill** – Commons Second Reading debate
HC Deb 02 February 2018 | Vol 635 cc1105-7

**Fetal Dopplers (Regulation)** – Ten-minute Rule Bill
HC Deb 11 October 2017 | Vol 629 cc345-7

Debates

Commons Adjournment Debate - **National Bereavement Care Pathway**
HC Deb 24 April 2018 | Vol 639 c850-

Commons debate **Baby Loss Awareness Week**
HC Deb 10 October 2017 | Vol 629 cc964-300

Statements

**Commons Written Statement Improving Maternity Safety – Continuity of Carer and the Midwifery Workforce**

The Secretary of State for Health (Mr Jeremy Hunt): I am today announcing steps towards ensuring that the majority of women will receive care from the same small team of midwives throughout their pregnancy, labour and birth by 2021, starting with 20% of women benefitting from a ‘continuity of carer’ model by March 2019.

Women who have continuity of carer are 19% less likely to miscarry, 16% less likely to lose their baby and 24% less likely to have a premature baby.
To support this, the Department of Health and Social Care is planning the largest ever increase in NHS midwives and maternity support staff, 650 new training places for midwives in 2019 – a 25% increase. We will continue to work with universities and the NHS to create even more training places in subsequent years to fill the gap of 3,000 midwives.

Other key parts of the announcement include:

- Professionalising the Maternity Support Worker role by developing a nationally defined role and national competency frameworks for Maternity Support Workers together with a voluntary accreditation register.
- Working with our key partners including the Royal College of Midwives, to identify better and clearer pathways for staff to progress and to develop new training routes to become a registered midwife.

Written statement - HCWS588  27 March 2018

Commons Statement followed by Questions Maternity Safety Strategy

HC Deb 28 November 2017 | Vol 632 c178-

The Secretary of State for Health (Mr Jeremy Hunt): With permission, I will make a statement about the Government’s new strategy to improve safety in NHS maternity services.

Giving birth is the most common reason for admission to hospital in England. Thanks to the dedication and skill of NHS maternity teams, the vast majority of the roughly 700,000 babies born each year are delivered safely, with high levels of satisfaction from parents. However, there is still too much avoidable harm and death. Every child lost is a heart-rending tragedy for families that will stay with them for the rest of their lives. It is also deeply traumatic for the NHS staff involved. Stillbirth rates are falling but still lag behind those in many developed countries in Europe. When it comes to injury, brain damage sustained at birth can often last a lifetime, with about two multi-million pound claims settled against the NHS every single week. The Royal College of Obstetricians and Gynaecologists said this year that 76% of the 1,000 cases of birth-related deaths or serious brain injuries that occurred in 2015 might have had a different outcome with different care. So, in 2015, I announced a plan to halve the rate of maternal deaths, neonatal deaths, brain injuries and stillbirths, and last October I set out a detailed strategy to support that ambition.

Since then, local maternity systems have formed across England to work with the users of NHS maternity services to make them safer and more personal; more than 80% of trusts now have a named board-level maternity champion; 136 NHS trusts have received a share of an £8.1 million training fund; we are six months into a year-long training programme and, as of June, more than 12,000 additional staff have been trained; the maternal and neonatal health safety collaborative was launched on 28 February; 44 wave 1 trusts have attended intensive training on quality improvement science and are working on implementing local quality improvement projects with regular visits from
a dedicated quality improvement manager; and 25 trusts were successful in their bids for a share of the £250,000 maternity safety innovation fund and have been progressing with their projects to drive improvements in safety.

However, the Government’s ambition is for the health service to give the safest, highest-quality care available anywhere in the world, so there is much more work that needs to be done. Today, I am therefore announcing a series of additional measures. First, we are still not good enough at sharing best practice. When someone flies to New York, their friends do not tell them to make sure that they get a good pilot. But if someone gets cancer, that is exactly what friends say about their doctor. We need to standardise best practice so that every NHS patient can be confident that they are getting the highest standards of care.

When it comes to maternity safety, we are going to try a completely different approach. From next year, every case of a stillbirth, neonatal death, suspected brain injury or maternal death that is notified to the Royal College of Obstetricians and Gynaecologists’ “Each Baby Counts” programme—that is about 1,000 incidents annually—will be investigated not by the trust at which the incident happened, but independently, with a thorough, learning-focused investigation conducted by the healthcare safety investigation branch. That new body started up this year, drawing on the approach taken to investigations in the airline industry, and it has successfully reduced fatalities with thorough, independent investigations, the lessons of which are rapidly disseminated around the whole system.

The new independent maternity safety investigations will involve families from the outset, and they will have an explicit remit not just to get to the bottom of what happened in an individual instance, but to spread knowledge around the system so that mistakes are not repeated. The first investigations will happen in April next year and they will be rolled out nationally throughout the year, meaning that we will have complied with recommendation 23 of the Kirkup report into Morecambe Bay.

Secondly, following concerns that some neonatal deaths are being wrongly classified as stillbirths, which means that a coroner’s inquest cannot take place, I will work with the Ministry of Justice to look closely into enabling, for the first time, full-term stillbirths to be covered by coronial law, giving due consideration to the impact on the devolved Administration in Wales. I would like to thank my hon. Friend the Member for East Worthing and Shoreham (Tim Loughton) for his campaigning on this issue.

Next, we will do more to improve the training of maternity staff in best practice. Today, we are launching the Atain e-learning programme for healthcare professionals involved in the care of newborns to improve care for babies, mothers and families. The Atain programme works to reduce avoidable causes of harm that can lead to infants born at term being admitted to a neonatal unit. We will also increase training for
consultants on the care of pregnant women with significant health conditions such as cardiovascular disease.

We know that smoking during pregnancy is closely correlated with neonatal harm. Our tobacco control plan commits the Government to reducing the prevalence of smoking in pregnancy from 10.7% to 6% or less by 2022. Today, we will provide new funding to train health practitioners, such as maternity support workers, to deliver evidence-based smoking cessation according to appropriate national standards.

The 1,000 new investigations into “Each Baby Counts” cases will help us to transform what can be a blame culture into the learning culture that is required, but one of the current barriers to learning is litigation. Earlier this year, I consulted on the rapid resolution and redress scheme, which offers families with brain-damaged children better access to support and compensation as an alternative to the court system. My intention is that in incidents of possibly avoidable serious brain injury at birth, successfully establishing the new independent HSIB investigations will be an important step on the road to introducing a full rapid resolution and redress scheme in order to reduce delays in delivering support and compensation for families. Today, I am publishing a summary of responses to the consultation, which reflect strong support for the key aims of the scheme: to improve safety, to improve patients’ experience, and to improve cost-effectiveness. I will look to launch the scheme, ideally, from 2019.

Finally, a word about the costs involved. NHS Resolution spent almost £500 million settling obstetric claims in 2016-17. For every £1 the NHS spends on delivering a baby, another 60p is spent by another part of the NHS on settling claims related to previous births. Trusts that improve their maternity safety are also saving the NHS money, allowing more funding to be made available for frontline care. In order to create a strong financial incentive to improve maternity safety, we will increase by 10% the maternity premium paid by every trust under the clinical negligence scheme for trusts, but we will refund the increase, possibly with an even greater discount, if a trust can demonstrate compliance with 10 criteria identified as best practice on maternity safety.

Taken together, these measures give me confidence that we can bring forward the date by which we achieve a halving of neonatal deaths, maternal deaths, injuries and stillbirths from 2030—the original planned date—to 2025. I am today setting that as the new target date for the “halve it” ambition. Our commitment to reduce the rate by 20% by 2020 remains and, following powerful representations made by voluntary sector organisations, I will also include in that ambition a reduction in the national rate of pre-term births from 8% to 6%. In particular, we need to build on the good evidence that women who have “continuity of carer” throughout their pregnancy are less likely to experience a pre-term delivery, with safer outcomes for themselves and their babies.

I would not be standing here today making this statement were it not for the campaigning of numerous parents who have been through the
agony of losing a treasured child. Instead of moving on and trying to draw a line under their tragedy, they have chosen to relive it over and over again. I have often mentioned members of the public such as James Titcombe and Carl Hendrickson, to whom I again pay tribute. But I also want to mention members of this House who have bravely spoken out about their own experiences, including my hon. Friends the Members for Colchester (Will Quince), for Eddisbury (Antoinette Sandbach) and for Banbury (Victoria Prentis), as well as the hon. Members for Lewisham, Deptford (Vicky Foxcroft), for Washington and Sunderland West (Mrs Hodgson) and for North Ayrshire and Arran (Patricia Gibson). Their passionate hope—and ours, as we stand shoulder to shoulder with them—is that drawing attention to what may have gone wrong in their own case will help to ensure that mistakes are not repeated and others are spared the terrible heartache that they and their families endured. We owe it to each and every one of them to make this new strategy work. I commend this statement to the House.

PQs

**Babies: Death**

**Asked by: Mike Amesbury**

To ask the Secretary of State for Health and Social Care, whether hospitals are compelled to accept and act on Health Service Investigation Branch recommendations that result from the investigation of avoidable baby deaths.

**Answered by: Caroline Dineage**

In November 2017, my Rt. hon. Friend the Secretary of State announced that, from April 2018, the Health Service Investigation Branch (HSIB) would investigate each case of early neonatal death, term intrapartum stillbirth and severe brain injury in babies, as well as each case of maternal death in England. This remit and the definition of qualifying maternity cases was set out in the Secretary of State’s directions, NHS Trust Development Authority (HSIB Maternity Investigations) Directions 2018, published on 26 April 2018.

The new investigative approach began in a single region in April 2018 and will roll out to all areas of England during 2018/19. Rollout will be complete by the end of March 2019. It is estimated that there are approximately 1,000 cases of birth-related deaths or serious brain injuries in babies in England every year. The expectation is that the learning from investigations will spur system improvements leading to fewer deaths and injuries in the future.

The HSIB has been allocated £8 million of additional funding to implement the new maternity investigation programme in 2018/19.

The HSIB will produce an investigation report for each maternity investigation it undertakes and will make recommendations to the relevant National Health Service trust or foundation trust.
It will be for individual trusts to put into place actions to address the recommendations of individual reports and ensure that the learning from HSIB investigations is put into practice so that avoidable harms are reduced. The Care Quality Commission, which monitors, inspects and regulates NHS providers does, in carrying out its functions, take into account a variety of data and intelligence sources. The HSIB maternity investigation recommendations and the actions NHS trusts and foundation trusts have taken in response could form part of these data sources and be taken into account where relevant.

**WPQ 144996 21 May 2018**

**Perinatal Mortality**

**Asked by: Maria Caulfield**

To ask the Secretary of State for Health and Social Care, how many Health Service Investigation Branch investigations into late-term stillbirths were (a) undertaken and (b) completed in 2017.

**Answered by: Caroline Dinenage**

The Healthcare Safety Investigation Branch (HSIB) began work in April 2017 to conduct high-level investigations of serious patient safety incidents in the National Health Service in England with a specific focus on system-wide learning and improvement.

In November 2017, my Rt. hon. Friend the Secretary of State announced that, from April 2018, HSIB would investigate all cases of early neonatal deaths, term intrapartum stillbirths and cases of severe brain injury in babies, as well as all cases of maternal death in England. HSIB did not conduct investigations in these areas in 2017.

The new investigative approach will begin in a single region from April 2018 and rollout to all areas of England will be completed by the end of March 2019. It is estimated that there are approximately 1,000 cases of birth-related deaths or serious brain injuries in babies in England every year. The expectation is that the learning from investigations will spur system improvements leading to fewer deaths and injuries in the future.

The Secretary of State has been clear that the HSIB maternity investigations will involve patients and families in investigations. In carrying out the maternity investigations, the HSIB will consult and seek evidence or information from the patient, family members and staff involved in the care. In addition, the HSIB will share draft reports with family members, inviting comment, and provide family members with the final report.

**WPQ 137134 1 May 2018**

**Infant Mortality**

**Asked by: Tulip Siddiq**
To ask the Secretary of State for Health and Social Care, what plans his Department has to tackle the increase in infant mortality identified by the Office for National Statistics from 2.6 neonatal deaths per 1,000 births in 2015 to 2.7 neonatal deaths per 1,000 births in 2016.

Answered by: Jackie Doyle-Price

MBRRACE-UK is currently undergoing detailed analysis of the recent neonatal death statistics; this includes mortality adjusted in relation to important risk factors e.g. premature birth, congenital anomaly. NHS England will await the results of MBRRACE-UK’s analysis prior to making any new strategic plans relating specifically to the 0.1% increase in neonatal deaths in 2016.

The Department remains committed to our ambition to halve the rates of neonatal and maternal deaths, stillbirths and brain injuries that occur during or soon after birth by 2025. Further information about the measures in place to achieve the ambition can be found here in the National Maternity Safety Strategy:


WPQ 133209 27 March 2018
6. Useful links and Further reading

Baby Loss Awareness Week website
https://babyloss-awareness.org/

All-Party Parliamentary Group on Baby Loss
https://www.lullabytrust.org.uk/about-us/who-we-are/appg/

All-Party Parliamentary Group on Baby Loss, Beyond Awareness to Action: Tackling Baby Loss in the UK vision paper October 2016


SANDS Stillbirth and Neonatal Death Charity Three year strategy August 2017

MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
https://www.npeu.ox.ac.uk/mbrrace-uk

Department of Health Safer Maternity Care Action Plan October 2016

Bliss: for babies born premature or sick
https://www.bliss.org.uk/

Child Bereavement UK
https://childbereavementuk.org/

Tommy’s
https://www.tommys.org/

The Lullaby Trust
https://www.bliss.org.uk/

The Miscarriage Association
https://www/miscarriageassociation.org.uk/

The Lancet, Stillbirths: ending preventable deaths by 2030, February 2016
https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)00954-X/fulltext?code=lancet-site
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