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on baby
loss



Beyond Awareness to Action: Tackling baby loss in the UK

All-Party Parliamentary Group on Baby Loss
October 2016

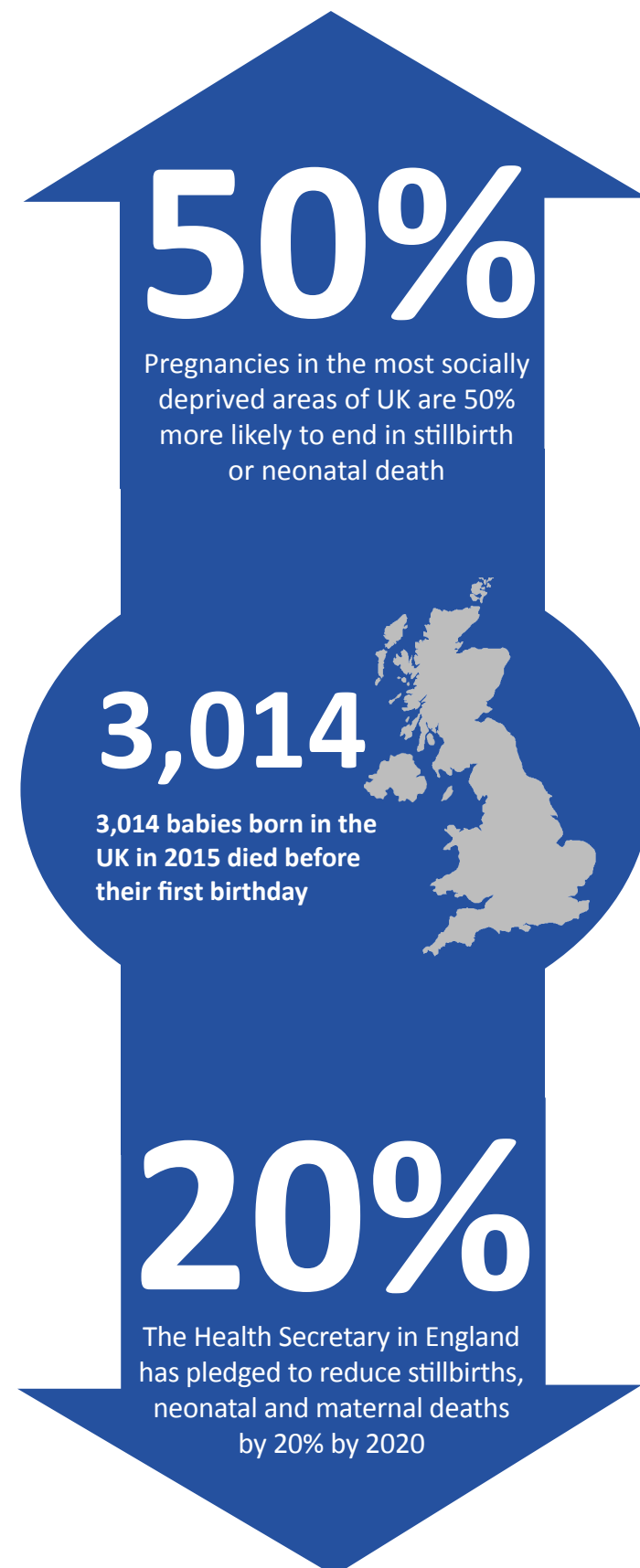
1. Introduction to the APPG

The death of a baby is one of the most devastating experiences any parent will face, and many families will struggle. Baby loss takes many forms, including miscarriage and ectopic pregnancy; termination of pregnancy due to foetal anomaly; stillbirth; loss following pre-term birth; neonatal death; and post-neonatal death, which ranges from sudden infant death syndrome (SIDS) to toddlers who die suddenly and unexpectedly for no apparent reason. Regrettably, for the foreseeable future there will continue to be instances of baby loss in the UK.

We care deeply about this issue. We work tirelessly to have fewer baby deaths and address the impact of pregnancy and baby loss in the UK. To that end, we founded the All-Party Parliamentary Group (APPG) on Baby Loss in February 2016.ⁱ The APPG officers are Antoinette Sandbach MP & Will Quince MP (Co-Chairs), and Victoria Prentis MP & Sharon Hodgson MP (Vice Chairs). We all have our own experiences of baby loss, so this is both a personal and professional interest for us.

The APPG develops policy to support families who experience the death of a baby. To that end, we work with charities, healthcare professionals and families directly affected by baby loss to best engage with national government, local authorities and national public health bodies across the UK nations. We will collaborate with our parliamentary colleagues in Westminster as well as the devolved administrations in Scotland, Wales and Northern Ireland to help prevent and reduce baby deaths, as well as improve the care that parents and families receive when a baby dies.

We are delighted to support Baby Loss Awareness Week 2016, and present *Beyond Awareness to Action: Tackling baby loss in the UK* as a starting point for the work ahead.



“The reason why Storm and Isaiah didn’t survive? There isn’t one. This we find so hard to deal with. They should both be with us now, causing us sleepless nights. But there’s only silence.”

2. Key facts: baby loss in the UK

(a) Baby loss has significantly decreased in the UK over the last 100 years, but progress has slowed in the last two decades.ⁱⁱ

- Given that miscarriage is not always reported, specific figures are difficult to obtain, but around one in four pregnancies is thought to end in miscarriageⁱⁱⁱ
- In the UK, around 1 in every 80-90 pregnancies is ectopic, which is around 12,000 pregnancies per year^{iv}
- 3,213 terminations for foetal anomaly were carried out in England and Wales in 2015^v
- The latest available figures for stillbirth are 4.7 per 1,000 births (live and still) in England in Wales^{vi}, 2.9 in Scotland^{vii} and 3.3 in Northern Ireland^{viii}
- In 2014, 3,014 babies born in the UK died before their first birthday, with around 70% in the first 28 days of life^{ix}
- The number of unexplained deaths in children aged over one is not easy to identify for the whole UK, but in 2013 there were a total of 18 deaths in England and Wales in children aged between one and two years where cause of death could not be established^x

(b) The UK lags behind its international peers on baby loss prevention^{xi}

The UK has higher rates of stillbirth and infant mortality than many European countries, including Germany and Sweden.^{xii} Partly in response to this

disparity, the Health Secretary in England Jeremy Hunt MP has pledged to reduce stillbirths, neonatal and maternal deaths by 20% by 2020^{xiii} and 50% by 2030^{xiv} in England. We continue to work with the Department of Health on this goal, as well as supporting baby loss prevention in the rest of the UK.

(c) The extent of baby loss varies greatly within the UK^{xv}

Pregnancies “in areas with the highest levels of social deprivation in the UK are over 50% more likely to end in stillbirth or neonatal death compared to...the least deprived areas.”^{xvi}

One reason for this variety is the complex and interacting risk factors for baby loss, including wide socioeconomic inequalities, multiple pregnancies and varying rates of smoking and obesity in different areas.^{xvii} Another explanation is that while excellent services are available in some places, in others the quality of information and care received across pregnancy, during labour and in early infancy is inadequate.

As such, not only is the UK behind many of its European neighbours when it comes to reducing baby loss, but the likelihood of your baby dying depends on where you live in the UK. We can do better to prevent baby loss, and improve the availability and quality of support available when a baby dies.

While the vast majority of healthcare professionals who work with bereaved parents are dedicated, skilled professionals, our charity and health professional partners report a range of issues:

- a lack of bereavement suites in or near early pregnancy, maternity and neonatal care settings
- overworked or undertrained staff, including a lack of bereavement midwives
- poor care quality; existing pregnancy and maternity care guidelines are not being followed consistently^{xviii}
- medical focus eclipsing the need for bereavement support; following (sometimes life-saving) treatment for the mother, the loss of a pregnancy can be overlooked with the focus being on the treatment itself. In this context, the need for bereavement care is often neglected

- poor or insensitive communication around all forms of baby loss (indeed, bereavement care training is not obligatory for many healthcare professionals involved)

(d) The psychological impact of baby loss can be lasting and profound

It is unsurprising that some bereaved parents report depression, anxiety, post-traumatic stress, suicidal tendencies and panic.^{xix} Given the impact the death of a baby can have, it is imperative that we ensure appropriate care and support is available to all affected parents. The aftercare received is vital to families’ wellbeing^{xx}, and early intervention support can reduce the long-term psychological impact.^{xxi}

“The bleeding changed. I was no longer just spotting. I was miscarrying. I knew in an instant, and it was devastating. The heavy bleeding, passing of tissue and mild contractions lasted for about two hours. It was so quick. And we were back in the shock and devastation of realising that another baby wasn’t coming home. “

3. Our vision

Our vision is a UK where we have excellent prevention, commissioning, clinical care, and support around baby loss:

Goal 1: Prevention - research, information and support are developed to promote a healthy pregnancy and reduce the risk of baby loss

Goal 2: Commissioning - appropriate bereavement services are commissioned to meet the needs of local populations

Goal 3: Clinical care - excellent clinical bereavement and prevention care and appropriate bereavement facilities are provided across all regions

Goal 4: Support - all bereaved families have access to high quality free bereavement support and advisory resources.

We would propose these goals are best encapsulated within comprehensive infant mortality strategies for each of the UK nations. Below, we have outlined five key approaches to include.

Delivery of public information and health promotion campaigns

Helps to deliver Goal 1: Prevention

National governments and local public health commissioners across the UK should consider how they can develop public information and health promotion campaigns to reduce the number of preventable baby deaths, based on research and existing evidence of what works. These could include a concerted drive to reduce smoking in pregnancy rates and advice on safe sleeping practices for infants that works with or adds to existing initiatives.^{xxii}

That said, more research is also needed to better understand the causes of baby loss and reduce the rate of infant mortality in the UK. Studies into SIDS and the subsequent “Back to Sleep” advice has dramatically reduced the number of sudden infant deaths in the UK and other countries.^{xxiii} We believe that research is key to preventing or reducing all forms of baby loss in the future.

Better knowledge collection and usage

Helps to deliver Goal 2: Commissioning; Goal 3: Clinical Care; Goal 4: Support

We must address the service quality variations and knowledge gaps across the UK. There are examples of best practice resources out there; for instance, Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks have developed a stillbirth-specific integrated care pathway.^{xxiv} Doncaster and Bassetlaw Hospitals NHS Trust has introduced a system of butterfly signs on maternity room doors to alert support staff when a mother has lost their baby and to act with appropriate sensitivity.^{xxv}

1 in 4
UK pregnancies is thought to end in miscarriage

250

seemingly healthy babies
and toddlers die suddenly
and unexpectedly each
year in the UK^{xxvi}

Many charities, local and national, do provide services, training and resources to the NHS; for example, the charity Abigail's Footsteps offers equipment such as cold cots to hospitals.^{xxvii} However, without better knowledge acquisition and sharing within the NHS, too many services and professionals work without the benefit of this good practice.

Options we would suggest are regular national audits of bereavement care services offered by NHS Trusts and Boards, as well as promoting best practice sharing.^{xxviii} The charity Sands is due to deliver a full bereavement care audit report on NHS maternity services across the UK this Autumn following a similar report in 2010, and will undertake a comparable report on neonatal services next year. We welcome this work and support it being repeated regularly.

Commissioners for both primary and secondary care also need to assess the numbers of stillbirths, neonatal deaths, and infant deaths for their area. Services appropriate to the local population can then be provided to support bereaved parents, working in partnership with local charities and voluntary groups. We would expect local and specialised commissioning to consider:

- provision of sufficient specialist staff including bereavement midwives, and maintenance of safe staffing ratios
- development of bereavement suites, which should be available to all bereaved parents, including in neonatal care settings
- the offer of community bereavement counselling for all forms of baby loss

We recognise that pressures on public budgets present a considerable challenge. However, we and our partners will work with national and local government and the health service to explore resourcing options where shortfalls exist.

Development of a bereavement care pathway

Helps to deliver Goal 3: Clinical Care; Goal 4: Support

We need to ensure all relevant staff have a clear framework through which to offer skilled clinical care as well as sensitive support. Currently, there are no UK-wide bereavement pathways which cover all forms of baby loss, contributing to the variable quality of care and knowledge. To this end, we are pleased to report that following efforts of the APPG and our partners, the Department of Health in England has backed the charity Sands to develop a comprehensive bereavement care pathway, in partnership with other charities and healthcare experts. This project will seek to ensure parents can be appropriately supported not only in hospital, but in primary care as well if required, and highlight professionals' role in bereavement support with all forms of baby loss. As this is developed in England, we will work with colleagues in Scotland and Wales to apply the pathway (Northern Ireland has an established pathway).

Development of a national bereavement service

Helps to deliver Goal 4: Support

Parents need to know where they can find support when a baby dies. While there is a range of free services across the UK for parents experiencing all forms of pregnancy and baby loss, details can be difficult to find.

The development of a national bereavement service would be invaluable for both parents and healthcare professionals seeking support. This might include a joint helpline or online portal for bereaved parents,

“Alexander’s death is very poignant for us. At each and every milestone we have a constant reminder of the achievements he would have made had he still been with us.”

as well as a directory of the relevant support available in all areas. This service would help national and local charities and other providers to collaborate and offer targeted support for parents' specific needs. The APPG's charity partners - including Bliss, Sands and the Lullaby Trust - continue to explore opportunities to build their partnership work in order to improve baby loss bereavement services for parents.

Ongoing staff education and training

Helps to deliver Goal 1: Prevention; Goal 3: Clinical Care; Goal 4: Support

All professionals coming into contact with bereaved parents require and deserve continuous professional development on this subject. Amongst other delivery methods, training should help:

- provide quality clinical care in line with relevant guidance and frameworks
- build confidence in communicating sensitively with parents when a problem is diagnosed and when a baby dies
- promote reflective practice, enabling staff to be mindful of parents' needs and deliver personalised care
- understand what support is available to families (including siblings)
- work as an effective team around instances of baby loss

Effective staff development requires both funding as well as protected time for staff to learn and train. We will support work with local service providers and national public training bodies to help staff build the necessary skills and confidence.

4. Join us

We sincerely believe that this is the right vision for reducing baby loss and its impact in the UK, which can work in conjunction with existing government and charity initiatives to address and support these issues.

We can achieve our vision with the dedication and efforts of our parliamentary, health professional and

charity colleagues, as well as the tireless devotion of parents who have known the grief of baby loss. We call on our MP and Peer colleagues to support these efforts. Thank you in advance for your support, and for helping us prevent baby loss and lessen its impact.



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Learn more about the APPG and see the full list of references for this vision:
www.lullabytrust.org.uk/all-party-parliamentary-group-on-baby-loss

All quotes in this report come from parents who have experienced baby loss.

This document has been researched and funded by the Lullaby Trust on behalf of the APPG on Baby Loss, and is endorsed by:



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