

Parliamentary Briefing: Baby Loss debate on Thursday 13th October 2016

Aimee and Michaels' Story

Aimee and Michael Tulloch have had to endure the loss of three babies – Eli, Storm and Isaiah – who all had short lives before they sadly passed away in hospital. *Aimee told us:*

“After losing Eli the pain was unbearable, but becoming pregnant with the twins gave us some hope and happiness back. But once again we had to leave the hospital without our babies. With empty arms and two more pieces of our hearts missing. Now we were back in the unbearable pain.

“Every day it hurts, but some days it hurts so much it takes my breath away.”

About Tamba

Tamba is delighted that there is due to be a debate on baby loss during this important awareness week. We launched our [#2ExpectMore campaign](#) in 2015 supported by the NCT, RCOG, RCN, RCM, Bliss, Sands, MBF, Action Cerebral Palsy, Action against Medical Accidents, and the British Maternal Fetal Medicine Society to press for better care in multiple pregnancies and to raise awareness of the higher risk of stillbirth and neonatal death in these pregnancies.

Tamba, is the only UK-wide charity to support families of multiples, and has a network of 150 clubs and nearly 18,000 members. It sponsors [clinical research](#), has received funding from the Department of Health to deliver [a quality improvement programme to improve](#)

[outcomes in targeted maternity units](#) and has a number of [support services for bereaved families](#), including secure online communities, a peer to peer befriending service, and bereavement resources for families and professionals.

The HIDDEN Problem - The Higher Risk of Perinatal Death in Multiple Pregnancies

Twins, triplets and more make up 1.5% of pregnancies in UK (around 12,000 each year), 7% of stillbirths, and 14% of neonatal deaths.

The latest figures from ONS show that there were 281 multiple birth stillbirths and 292 multiple birth neonatal deaths in England in 2014, making an average perinatal death rate of 2.28% (the average perinatal death rate for singletons in 2014 was 0.64%). This means multiples are at over three and a half times greater risk of perinatal death than a singleton. In contrast to other stillbirths, which have been falling for years, those involving multiples increased by 13.6% between 2013 and 2014.

According to recent parliamentary questions, multiple pregnancies now account for around 10% of all stillbirth maternity litigation claims in England. Claims involving multiple births to date cost £74m between 2004 and 2014.

The risk of preterm birth is also considerably higher occurring in at least 50% of twin pregnancies with twins facing six times the risk of cerebral palsy.

Reducing still births and neonatal deaths, and health inequalities, are national policy objectives. Unfortunately a one size fits all approach has been adopted by a range of agencies, which hides the specific needs of high risk groups. Consequently, national audits have yet to focus on multiple pregnancies in any detail and targeted steps to reducing perinatal deaths among multiple pregnancies have been consistently absent from service reviews, commissioning documents, inspection frameworks and more recently the [still birth care bundle](#).

Given this group's problems have historically be hidden, it is welcome that this is starting to change. In recent months the specific needs of these families were explicitly recognised in the [Better Births; the national review of maternity care in England](#). And the Department of Health have confirmed that they will be reporting back on multiple pregnancies separately

as part of their ambition to halve stillbirths, neonatal deaths and brain injuries by 2030. Although a good start, there is far more than needs to be done if the national ambition is to be realised.

Evidence of how good practice reduces poor outcomes

There is good clinical guidance produced by NICE covering antenatal care in multiple pregnancies published in 2011. Best practice examples and published research shows where implemented stillbirths, late term neonatal admissions, C-section rates and patient safety incidents are reduced and maternal satisfaction appears to be higher.

Unfortunately, the guidance has only been fully implemented in 10-18% of units across the UK. According to [the latest report into maternity care in multiple pregnancies produced by the NCT and Tamba](#), average levels of compliance with NICE measures have increased by 10% from 58.8% in 2010/11, to 64.9% in 2013/14 and 69.1% in 2014/15. Among the best units, St George's has a compliance rate close to 90% and has noted a reduction in stillbirths from 10/1000 to 3/1000. At the current rate of progress it is estimated to take another 12 years to achieve full compliance. NICE recommend that compliance is achieved within three.

Furthermore, the recent NCT/Tamba report also reviewed the NHS Maternity Safety Thermometer, which shows that mothers having twins experience five commonly used adverse indicators almost twice as frequently as those having a singleton birth. Part of the problem may be that there is no standardised guidance for intrapartum care (timing and method of delivery) in multiple pregnancies, which may also reduce stillbirths, neonatal deaths and regional differences in neonatal admissions.

The Solutions:

To address these issues, the following agencies need to act.

1. As part of their ongoing review programmes, individual clinical teams, trusts, commissioners and networks need to see how care in multiple pregnancies across their local maternity pathways can be improved.

2. All the national audits including those looking at maternity care (led by the RCOG), neonatal care (led by the RCPCH) and perinatal deaths (MBRRACE) need to collect data and report back on multiple pregnancies separately to singleton pregnancies to provide a clearer understanding of the problems that arise.
 3. National bodies like NHS England need to ensure that the benefits of adherence to NICE guidelines and good intrapartum care in multiple pregnancies clearly feature in the stillbirth care bundle updates. They also need to ensure that these benefits are also explicitly outlined in the national commissioning frameworks and the costs of good care are fully covered in any updated maternity tariff or payment mechanism.
 4. NICE need to update their guideline for antenatal care in multiple pregnancies to include the intrapartum phase.
 5. Inspection bodies like CQC need to explicitly include care in multiple pregnancies in their inspection frameworks.
 6. Strategic Transformation Programmes, or service reconfigurations, need to demonstrate the minimum number of multiple pregnancies that need to be treated in their area or in individual's units to provide safe, satisfactory care and how this has been considered.
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Catherine's Story

After the joy of having identical twin boys, Catherine Oxborrow gave birth to identical twin girls Alys and Clara. Sadly, soon after their birth she was told that Alys did not survive. Catherine told us:

"We were completely torn – part of me wanted to sob my heart out and completely immerse myself in grief for Alys, but we had to be strong for Clara and the boys.

"It's awful so many babies die and we don't understand why. Before it happens to you or someone you know, you don't really think about it or appreciate what a difficult thing it is to experience."

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