



Tamba Parliamentary Briefing for MPs for the backbench debate on Tuesday 9th October 2018

#BLAW2018 #Babyloss Awareness Week

a vital time to remember...

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.”

For many like Aimee, it’s important to have the chance to remember but also for others to try to understand what they have been through.

...and an opportunity to prevent it happening to others

Summary

1. Twins, triplets and more are at higher risk than other groups of experiencing stillbirth, neonatal death and sudden infant death. Our bereaved families face unique challenges and we have a specialist support group to help them. Our service and the importance of tailored support is recognised in the National Bereavement Care Pathway (NBCP). It is an excellent step forward in improving the support and care for all families.
2. The record-breaking drop in twin stillbirths and neonatal deaths between 2014-16 has led to a significant drop in families needing our specialist bereavement support. The reasons behind this record fall are [here](#). We continue to offer the essential specialist support multiple birth families need and strive to reduce the health inequalities that make this group so vulnerable. But as we are seeing fewer people, it does mean we can offer even better care to those that need it.
3. In a world first, our quality improvement programme, supported by the Department of Health, has proved how we can continue cutting stillbirths, neonatal deaths and reduce neonatal admissions. This would also save the NHS £millions every year. We have written to the Minister asking for support in rolling out this programme, so we can continue to save babies’ lives and the NHS money. [Read the report here](#).

Significant reduction in families using Tamba's bereavement service

The Tamba Bereavement Support Group exists to support all parents and carers of multiples who have experienced loss whether it was during pregnancy, at birth or at any point afterwards. The group offers parent to parent support via our trained befriending service, a secure online community, and a range of unique resources. Every parent referred who wishes to will receive a personal call from our specialist bereavement team staff who listen to their experience and needs and works up a bespoke package of support going forward. Bereaved families can make use of the service for as long as they need. Commonly parents make contact shortly after their loss, but some make contact many years later.

Although the needs of our families and the service is noted in the new National Bereavement Care Pathway, and we have conducted more engagement with bereavement support professionals than ever before, last year saw a 12% year on year fall in referrals for our services. We have also seen a 36% fall in peer support – befriender requests. It appears this is part of a longer-term trend. On a practical basis it means we can provide more intensive support for those who need it and continue to improve the quality and range of services available.

The fall in referrals could be because NHS bereavement services are improving but is more likely to be as a consequence of the trend noted below.

Tamba's Bereavement Support Co-ordinator Sharon Darke says: "I find it such a privilege that people want to tell me about their precious babies and share their experiences with me. Tamba's Bereavement Support helps so many families and we have successfully campaigned to engage more with health professionals. It also helps that this important issue is being debated in parliament and in the National Bereavement Care Pathway."

Historic drop in twin stillbirths and neonatal deaths

The latest MBRRACE-UK Perinatal Mortality Surveillance Report noted that between 2014-2016 twin stillbirths reduced by almost 50% and neonatal deaths fell by 30%. These falls are statistically significant and the largest fall among any population since records began. This is 305 babies' lives saved and our [insights paper](#) explains how we have built a movement of organisations, families and professionals to press for improvements in care. These efforts include using the awareness created and contents of previous Parliamentary debates to engage with hospital trusts. They have certainly opened doors and made teams sit up and listen.

Although we have seen significant improvements, twins are still over one and a half times more likely to end in a stillbirth and over three times more likely to end with a neonatal death. Independent reports highlight that they are also six times more likely to result in a brain injury and contribute towards 10% of clinical negligence claims.

Nevertheless, NICE's maternity insights report ([view here](#)) and our own national audits show the slow and steady uptake of good practice in the care of mothers expecting multiples. Yet, good practice as set out in the NICE guidance – antenatal care in twin and triplet pregnancies (CG129) has only been fully implemented in 15% of units across the UK. According to the latest report produced

by the NCT and [ourselves](#), 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 across the UK NICE recommend that compliance is achieved within three years

As noted, there is still a long way to go with implementing good practice. The speed of improvement is likely to be slowed by workforce shortages, which have been highlighted in official figures and via the royal colleges, compounded in the maternity space by the high number of quality improvement requirements and programmes currently underway. This is making it even more difficult for units to make changes even when they are proven to work and we will return to this at the end of this briefing.

Keith Reed, CEO of Tamba, says: *"We have used the content of debates in Parliament, and the Government's ambition, to help us engage and open doors with trust management and their clinical teams. It's been incredibly enabling. Please don't stop – these efforts are helping to save babies lives."*

World first programme proves how to cut multiples stillbirths, neonatal deaths and neonatal admissions

Implementing this good practice is central to reducing poor outcomes in twin and higher order pregnancies and sustaining the momentum in delivering the Government's ambition to cut stillbirths, neonatal deaths, maternal deaths, and brain injuries by 50% and neonatal admissions from 8 to 6% by 2025. For the first time in the world, our Quality Improvement (QI) programme, which is supported by the Department of Health and Social Care has statistically proven that implementing the NICE guidance reduces twin stillbirths, neonatal deaths and neonatal admissions. The programme sets out how improvements in care can be achieved, and obstacles to delivering good care can be overcome, in units of varying size across the country.

An interim report outlining the programme and its findings to date can be accessed [here](#). In summary, if the learning from this programme can be embedded in units who are not currently involved then researchers estimate that:

- 63 baby deaths could be prevented every year if all maternity units in England followed NICE guidelines on twin, triplet and more pregnancies.
- Reducing the number of babies from a multiple pregnancy needing neonatal care could save the NHS in England more than £4million a year.

These are likely to be low estimations as the NICE guidance the QI programme is currently modelled around is in the process of being updated to become even more impactful. This will be achieved by extending it to cover the intrapartum phase, where there are significant difficulties which are not addressed in the current guidance.

From our successful experience, widespread uptake of good practice in maternity care greatly benefits from having an external third party providing targeted engagement and support to enable change to happen at pace. And whilst we have built up a team to enable this to happen, the funding for this work runs out in March 2019.

We estimate that we need to raise £800,000 to reach out and drive change in a further 120 Obstetric Units across England over the next six years. When compared to other national initiatives, at an

estimated cost of just over £12,500 per baby's life saved, this provides an excellent return on investment. Especially as the costs will be completely eclipsed by the savings made by fewer neonatal admissions.

"It is amazing how engaged units are and what has been achieved in such a short space of time. 94% of units have improved their alignment with NICE QS46 in only one year. We've seen multiple antenatal clinics established, specialist midwives introduced and antenatal care pathways specific to multiple being used," says Jane Gorringe, manager of Tamba's Maternity Unit Engagement Programme. *"Units recognise that having an independent third party really helps get buy in, effects change quicker, especially as there isn't a drain on already tight resources."*

Third sector stands ready to help deliver this ambition – it can't be done without us

As noted above, workforce shortages and the wide range of maternity improvement programmes currently underway in the NHS, alongside driving the reorganisation and improvements set out in Better Births means many teams lack capacity to implement even proven QI programmes. We and other baby charities stand ready to help support and deliver these improvements as we have the knowledge to successfully deliver and the capacity to scale up our work. In order to achieve this the Government needs to put in place a means of accessing the funds to make it happen. We already invest significantly in funding clinical research and delivering resources to parents and professionals alike. However, the amount of resource required to deliver these programmes is beyond the means of most charities.

"We have started engagement with another 25 units who are not part of Department of Health funded programme. Because we don't have the resources to help them directly we have offered them a self-audit version of our programme. Sadly, their capacity to carry out the audits is already proving to be a huge barrier as only two have managed to undertake this and have yet to introduce any of the improvement package. Without further funding we are unable to provide the support of a specialist midwife, essential to embedding a change in practice," says Helen Turier, head of support services at Tamba.

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."

For more information, please contact Keith Reed CEO or Alyson Chorley at Tamba on 01252 332344 or email alysonchorley@tamba.org.uk