

A collection of blogs from key healthcare professionals involved in the Maternity Bereavement Experience Measure (MBEM) initiative. More can be seen at: <http://www.wecomunities.org/blogs/2301>

MBEM BLOG – DONNA

Hello my name is Donna Ockenden; I am a midwife and nurse and for the last four years I have been Co Clinical Director of the London Maternity Clinical Network. Over the last six months it has been a tremendous privilege to have worked with Sands and NHS England on the creation of this Maternity Bereavement Experience Measure or MBEM. It is at times like this- as we launch this Measure across England that I reflect on how far we have come in improving maternity bereavement care and how far we still have to go in ensuring that consistently high quality and supportive maternity bereavement care is provided to women and families and that consistency of support, resources and training are provided to front line staff.

I recall two stories from thirty years of clinical practice which highlight the need to listen to parents and provide care according to their needs rather than care that we think they may need.

I remember a young student midwife, always being 'told off' for questioning senior staff (who said they knew better than her – because of their years of experience.) Thirty years ago a young mother had taken the heartbreaking decision to terminate her pregnancy because her baby had congenital abnormalities incompatible with life. The despair and grief she experienced was compounded by the senior midwives insistence that it was 'better' that she did not see her baby, because 'she really doesn't look very nice and you don't want to remember her like that....' The student midwife who crept into the sluice in her break on night shift to dress the tiny baby, cover the top of her missing head with a tiny bonnet and show her mummy her perfect hands got into the most terrible trouble for questioning authority...again! The student midwife and the mother never met again after this night. But, even after the passage of almost three decades the student midwife still has the card in which the mother wrote 'Thank you for sharing such a tender moment, I will always remember my baby's perfect little hands...'

Many years later that same student midwife, by now a Head of Midwifery and Divisional Clinical Director across a large Women and Children's Division was still passionate about providing the best quality and compassionate bereavement care to families and supporting her staff to deliver the very best care they could. Training in bereavement care was readily available for everyone from support staff to consultants, staff were given dedicated time to fulfill bereavement care roles and a new bereavement suite had been opened which reflected the needs, wishes and feedback of recent parents and the staff working within the facility. The joint roles of the Divisional Clinical Director and Head of Midwifery were so very different from that of the student midwife who had supported the mother almost thirty years earlier but in her heart the passion for providing the kindest and most supportive bereavement care possible to parents was still there as was the absolute commitment to supporting the multi professional teams she led.

One day there was an unannounced visitor requesting to meet the Head of Midwifery and Divisional Clinical Director. The visitor was a husband of a lady whose baby had died almost twenty years ago. He announced he was not leaving the hospital until he saw 'the person in charge' no matter how long he had to wait. Meetings for that afternoon were changed and the visitor was seen almost immediately.

He explained that at the time of the baby's death the family, of the (then) very young mother had agreed with the midwives that it was 'better' for the mother not to see the baby. It was thought it would be 'easier to get over' the death of the baby if the mother 'didn't get too attached to it.' The mother was advised that she 'could make a fresh start much more easily' if she didn't see the baby as to see it would 'upset her too much....' The young mother had come perilously close to losing her own life and had not been able to attend the baby's funeral service which was carried out by the hospital with the baby laid to rest in a location unknown to the mother and her family.

The mother had never 'got over it' and although she had subsequently had two lovely daughters who she adored and was very proud of she had never come to terms with the stillbirth of her baby son or indeed believed it had happened. For each of the twenty years since her baby had died (and in the hope that her baby would come back) the mother had bought Christmas and birthday presents and every year had gone out to buy school uniform in his size for the schools he would have attended had he lived. This had all been carefully stored in secret in the attic unknown to her family. 'Can you help me?' he asked. 'How can my wife grieve for a baby she never saw and never held?'

The original case notes were obtained and within them was found a sealed envelope written on the front 'For my Mummy when you come to find me, with love from your little baby xx' Inside were a number of old fashioned Kodak 'Instant' photos of a stillborn baby carefully dressed lying in a little crib. The accepted 'wisdom' at the time was that these photos lasted no longer than five years before fading. Despite the passage of time the photographs were as clear as the day they were taken. Even though it would have been known at the time that this mummy was not seeing her baby before burial someone had taken a great deal of care and time to dress this beautiful baby and to leave photos for his mum in her case notes.

With the additional information that had been carefully stored within this mother's notes we were able to identify exactly where the baby was buried. All of the staff who had cared for this mother some twenty years earlier were contacted and asked to share their memories of her care. This included writing to the then Registrar, now a Consultant working many hundreds of miles away who responded with a personal and beautifully written letter. With the help of the Trust chaplaincy team and support from a clinical psychologist the mother was able to arrange a memorial service at the graveside of her tiny son. After almost twenty years this mother was finally enabled to lay her little son to rest. The mother kept in touch for a number of years updating the Head of Midwifery and Divisional Clinical Director on the arrival of new grandchildren and other key family events. Visiting her baby's grave on birthdays and anniversaries remains important to her. Although the member of staff who carefully dressed the baby and took and kept safe the photos will never know how much that meant to this mother the time and effort taken then made a huge difference decades later.

It is very clear that both of these families and so many others have rich insight and feedback on their bereavement care experience. The care that is provided at a time of pregnancy loss and baby death can clearly have very long term implications for both physical and mental health. Much feedback is

simply never heard by professionals because consistent processes haven't existed until now to seek them out.

Women and their families know what really matters to them and how we can best support them and meet their needs. It is very clear that how women and their families experience care and the after effects of that care is sometimes different to how we as professionals believe it is. When the death of a baby occurs during a pregnancy we now know that the care women and families receive stays with them for a lifetime. It's the 'little things' such as in the stories above that have a huge impact. Key to delivering these 'little things' on a sustainable basis is ensuring that staff are supported to support parents. This support needs to be multifaceted but must include training to ensure staff have the skills to care for bereaved mothers and families and crucially appropriate time and infrastructure to deliver the compassionate care families deserve.

As that student midwife thirty years ago I believed that bereaved families had the right to be heard, cared for and supported in a compassionate and sensitive manner at all times. My passion and drive to achieve this has not dimmed with the passage of time. Staff have the right to be supported to provide the very best care they can. The challenge facing Maternity services now is that excellent bereavement care is found in 'pockets' rather than spread widely. Sustainability of high quality bereavement care and services seems often to depend on the passion and focus of a leadership team which can change over time. The focus on excellence in bereavement care can then subsequently reduce as the focus of service leaders change. My aspiration is that the Maternity Bereavement Experience Measure ensures that excellence in Maternity bereavement care becomes an 'Always Event' across all maternity services in England with well supported staff enabled to deliver compassion, kindness and care that matters to bereaved parents at all times.

Please do follow #LossExp #MatExp #BetterBirths to tweet into the event on 22/6/17. We'll be posting the live link on the 22/6/17 to download the resource then too.

You can also join @wemidwives for a twitter chat on the 29/6/17 where together how we can explore using this questionnaire and resource to keep improving the quality of care in maternity.

I'm working to improve the experiences of maternity bereavement care- please join me!

Donna Ockenden

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MBEM BLOG – KATH

Hello my name is Kath Evans; I work at NHS England and lead on improving experiences of maternity care with women, families and practitioners.

Having stood in a churchyard with friends and watched 39 balloons drift into the sky recognising 39 weeks of pregnancy prior to a beautiful sleeping baby boy entering the world, sat with a friend hearing how he valued the time he held his niece who had been also been born sleeping and heard the frustration of a mother who was excluded from general maternity survey processes when her son had died following birth, it very clear all of these families and so many others have rich insights on their care experience that are never heard by professionals because consistent processes haven't existed to seek them out. We have an opportunity to change this.

I believe we have two jobs in health care, the job of delivery of care and also the job of improvement. Health care professionals strive to offer optimum care to women receiving maternity. Yet as receivers of care, women and their families know what really matters to them and how we can best meet their needs. How women and their families see and experience care is different to how we as professionals perceive care to be. It's only by professionals asking, 'how was for you?' that we can glimpse the reality of these lived experiences and what it feels like to use services, these insights can and should, truly inform the focus for our improvement work.

There are some areas however where seeking out experiences are perceived to be very difficult or challenging due to sensitivities. When the death of a baby or babies occurs during a pregnancy we know that the care women and families receive stays with them for a lifetime. It's the 'little things' that have a huge impact and Sands (the Stillbirth and neonatal death charity) from their work with families encourage us to do better in this area of care delivery. As professionals the very last thing we want to do is cause further distress to a family when they have already gone through so much by asking about these experiences, yet families have told us they want to be asked sensitively about what made a difference and they also want to share ideas for improvement where they may be needed too.

Until now a tool to seek out these experiences had not been developed. The 2014 National Perinatal Epidemiology Unit (NPEU), 'Listening to Parents after Stillbirth or the Death of their Baby' study highlighted that we need to listen to this group of parents and to monitor their needs and experiences of care and to act upon that feedback. The Maternity Bereavement Experience Measure (MBEM) questionnaire will be launched later this week and to address this gap.

The Maternity Bereavement Experience Measure (MBEM) questionnaire has been informed and developed with bereaved families; it's been tested nationally and will be available for local use. It provides a more standardised approach to seeking out experiences of pregnancy loss and addresses themes identified by families that really matter to them in a sensitive manner. The questionnaire can be used face to face, on paper, online, in whatever way suits the family best. Trusts will be able to add their logo and personalise the supporting letter included in the resource. The resource also provides information to health care professionals, providers and commissioners on how to gather feedback when bereavement has occurred during or shortly after pregnancy and importantly suggests how the feedback gathered can be used to drive improvement.

We hope that maternity teams, Maternity Voices Partnerships, patient experience teams, Patient Advice and Liaison Services (PALS), organisations such as Healthwatch; along with Local Maternity Systems, Maternity Voices Partnerships and local charities will also find the resource and questionnaire useful.

I believe that parents and families have the right to be heard in a compassionate and sensitive manner and then have the right to see the changes in services they have told us are needed when this is required.

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I'm working to improve Experiences of Care, will you join me?

Kath Evans @kathevens2

Experience of Care Lead, Maternity, Infants, Children & Young People,

NHS England

MBEM BLOG – CHERYL

Hello, my name is Cheryl. I am the Improving Bereavement Care Manager at Sands, the Stillbirth & neonatal death charity. My focus is to support health and social care professionals to feel able and confident in providing best quality bereavement care for families when a baby dies.

I am delighted that Sands has been involved in creating this Maternity Bereavement Experience Measure (MBEM) for maternity staff. It follows on from the new chapter in the [Sands Guidelines](#) for professionals around receiving and responding to feedback from bereaved parents. This MBEM resource provides the questionnaire to help you capture the parent voice, but also offers some practical guidance on how to implement the MBEM in your unit.

Sands has worked with NHS England for some time on this project to make sure there is a suitable way of capturing parents' feedback. Importantly, bereaved parents have been engaged with and have informed this project from the outset.

From a Sands survey we know that the majority of bereaved parents want to give feedback and feel it is appropriate for them to be sensitively asked about their experience of bereavement care. It can feel challenging to obtain feedback from bereaved parents. However, this resource highlights the importance of hearing the parents' voice and supports maternity staff in doing this.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to. Receiving feedback from parents in a structured and supported way gives room for reflection and learning and promotes the sharing of best practice.

It may feel difficult to listen to parents who didn't receive optimal care, and it is important that you are supported to do this so you are able to listen to parents in these circumstances.

This resource will support you to sensitively capture vital feedback from parents in a way that feels comfortable for you and in a way that can be used to promote best care. This MBEM will most likely feature in the upcoming [National Bereavement Care Pathway](#) (#NBCP).

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You can also join @wemidwives for a twitter chat on the 29/6/17 where together we can explore using this questionnaire and resource to keep improving the quality of bereavement care in maternity.

MBEM BLOG – JANE

Hello my name is Jane; I'm the Senior Bereavement Midwife at Imperial College NHS Healthcare Trust. I coordinate the maternity bereavement services at St. Mary's Hospital in Paddington and Queen Charlotte's Hospital in Hammersmith.

We have approximately 9,000 deliveries per year with an average of 160 being a combination of stillbirths, neonatal deaths, late miscarriages or medical terminations for abnormalities, all are over 20 weeks' gestation.

Very early on in my career as a labour ward midwife (a few too many moons ago)! I noticed that there were unacceptable voids in service for bereaved families and along with the Labour Ward manager I pushed for my post to be created.

In 2013 the funding was approved and I was literally given a blank sheet! I had lots of ideas! I am proud of how the service has developed across sites since then, but I felt that I needed to find out what other units were doing and compare the quality of care that was being offered across England. The bereavement midwives I contacted didn't need much coaxing to share their work and we met at St. Mary's Hospital for the first Bereavement Midwife Forum at the end of 2015. There was an overriding feeling amongst us that the role of the Bereavement midwife would be strengthened with accredited training and standardised job descriptions and this is ongoing work. The passion of all the midwives in the room was palpable and we were all on the same page regarding our goals to improve maternity bereavement care for the families at our hospitals.

The Bereavement Midwife forum meets every 3 months and we now have over 30 members. Sands (the Stillbirth and Neonatal Death charity) and the Royal College of Midwives (RCM) actively support the forum. We swap best practice tips, resolve queries, share experiences and support each other emotionally. The forum was delighted to input their ideas and suggestions into the resource that's been developed to hear the experiences from families who have experienced in pregnancy.

This is the resource I have had the pleasure of working with a team including Kath Evans and Donna Ockenden over the past 8 months, together with Sands and families we've developed a questionnaire to gather the thoughts of bereaved parents about the care they received during their time in hospital. The work also includes a guide for healthcare professionals on how to use the feedback tool at a local level. Please do download the Maternity Bereavement Experience Measure questionnaire and resource and consider how you can use it in your practice.

I am really excited and optimistic about the future care for the families that are dealt one of life's most catastrophic blows. The introduction of Petals, a trauma and bereavement counselling service at Imperial College has been without a doubt one of the best additions to the care we provide. I've also just started tweeting, so all followers appreciated! You can follow me at @JBereavementUK