

My reading for Baby Loss Awareness Week
St Mary's Service 14th October 6pm

For those of you who don't know who I am, along with 2 other volunteers, I help to run Oxfordshire Sands- the Stillbirth and Neonatal Death Charity. I have been involved with the charity since losing my first daughter Kayleigh, 11 years ago- and am very passionate about supporting others and raising awareness.

Apologies this is rather long- this is the edited cut-down version. But I hope you can either relate to what I am going to say and therefore it will bring you some comfort and strength ... or that it helps bring some understanding to you, to enable you to support those around you.

I have a different life, the life of a grieving mother.

Do not judge the bereaved mother.

She comes in many forms.

She is breathing, but she is dying.

She may look young, but inside she has become ancient.

She smiles, but her heart sobs.

She walks, she talks, she cleans, she works, she IS, but she IS NOT, all at once.

She is here, but part of her is elsewhere for eternity.

For it really is the darkest time in life .. saying goodbye before having a chance to say hello... walking away from the hospital and having to leave your baby there... just having memories in a box ... and a funeral to plan in place of a christening... a visit to the registry office to obtain legal proof that they were here - they were real... Birth and death shared the same paper... the only document they will ever have.

I watched the recently aired George Shelley- Learning to grieve- and he used this analogy which I am sure everyone here can relate to , in some context - "Grief is like glitter. No matter how much you try to tidy it up, you're never gonna get rid of it all. You're always gonna find bits of it somewhere. The challenge is to accept that those flecks of sadness will always be there"

I also read this short piece about grief recently and thought it so apt to share today:

When do the days of raw grief from child loss end? That's something every parent asks a million times over. The truth is it's different for every person. How much we wish we could attach a timetable to our grief, but that's impossible to do. The raw grief of those first few months seems to wane after two years or less, but then it reappears again when we hit the reality of our loss. It's like starting all over again with fresh grief. Many parents get alarmed about this, but that's how the grief works. The "reality of our loss" is when we know with full certainty that our child is no longer here, and our hearts have that daily throbbing ache that will not go away. For most parents of child loss, that's where we remain. This is a grief that remains with us forever. Child loss is unlike any other kind of loss. This isn't like having a leg or arm severed, then learning to use a prosthetic leg or arm. There is no replacement for a child! We must now learn to live with a huge hole -- a void -- that is right in the centre of our heart. Every day, we walk this journey of loss with pain. Every day we think of our child thousands of times a day. Every day we wish this had never happened. Every day our hearts struggle to beat to the rhythm of child loss.

And so my piece that I have written to share with you today is entitled **As the years go by**

The time of concern is over, few people ask how we are doing these days. The name of our child is rarely mentioned. A curtain has descended.

Those close and compassionate people in our lives- they are the lamps in the darkness that we hold onto. For most - the drama is over.

But for us, the effect is timeless and the greatest events in our lives should not be tiptoed around- love does not simply die.

I know I speak for all bereaved parents when I say that the names of our babies are written on our lives.

You say they WERE our children.
We say they ARE our children.

So please say their names to us and say their names again.

You worry that you will upset us by reminding us that our baby has died - but how little you understand that we cannot ever forget and we wouldn't ever want to.

It may well be uncomfortable to talk to bereaved parents about their baby who died ... but the thing is - if you think you should stay away because family and friends will be there.... The truth is, everyone thinks the same thing .. and sometimes parents are left with no-one. There is much truth in the saying that friends often become strangers and strangers become friends.

To those people who accept me for who I am - who understand that Kayleigh's loss changed me- I thank you

To those people who have stayed away from me as the years have passed by- because it is too difficult for you to talk about Kayleigh or because you worry about upsetting me- you should remember that your upset is temporary - mine is permanent And actually if you took the time to get to know me ... maybe you'd still like me.

I know my daughter's death was hard on you... it was hard on me too. I'm sorry it makes you uncomfortable when I say her name- to be honest it makes me uncomfortable that you won't say it.

Our children live on in spirit within us you see -
They are of our past -
But they are part of our lives now and they are alive in us.

And so the truth is - that just because you never saw my baby- it doesn't mean that she doesn't deserve your acknowledgement.

Some people think that if they mention the baby's name at the time of loss... that is enough .. but we bereaved parents need to talk about our babies as time goes by - and by continuing to talk about our babies - it shows people haven't forgotten and that they do care and understand.

As the years go by - too many people think that they shouldn't mention my child for fear of stirring up the dust that has seemingly settled. The truth is - the idea that my child will one day be forgotten is something that terrifies me the most.

The greatest gift you can give to a family is the gift of remembrance ... it costs nothing and requires very little.. yet hearing the names of our children is more precious than gold. It is the greatest reminder that our children are not forgotten.

I know the fact that my baby died is scary for many people... I was scared too. I still feel scared at times, scared that the suffocating grief that grabs me still now- will smother me and drag me down ...such is the intensity of my love for my child.

So many people judge bereaved parents- because they are not acting the way that is expected of them

I hear some people say that they have never dealt with this before- well neither had I- this is the first time my child died- I'm still trying to figure it out too, after all these years.

The truth is that grief is a very personal thing and we are all different people who deal with things differently. There are good days, which don't mean we are 'over it' and there are bad days, which don't mean we are being unreasonable. There is a no normal way to act. And as we get used to carrying the pain, loss and love around with us - it becomes a little easier to bear the weight ... but that doesn't mean that within days, weeks, months or even years, that we will never ever get over it.

I mentioned that there is no normal way to act - how can there be - because when your baby dies- nothing is normal. Giving birth to a baby who isn't breathing. When your milk comes in without a baby to feed. Walking back into a house that your child will never enter. Planning your child' funeral. Deciding what to do with your baby's lifeless body. Having to tell people that your child died. The feeling of panic when asked 'How many children do you have?' It is my norm- but it is not normal.

As the years go by, I will never finish telling my story- just as I will never finish missing my baby. After all - a mother's love never dies.

I know now - years on- that people's intentions have been heartfelt- even if their words and actions have left me heartbroken.

Those close and compassionate people I am lucky to have- who recognise sad times - are the only reason I make it through Kayleigh's birthday...Mother's Day, Christmas and other celebration times.

And what about Father's Day ... what about the dads who are expected to be strong... who feel they have to fix everything and make it right ... who watch their partner grieving whilst totally helpless... because a mother - during the process of getting physical care - gets emotional care throughout .. but this risks men feeling sidelined and powerless to help. People ask the dad how the mum is doing -but how many people ask the dad how THEY are doing?

After we were told those few words that took away so much 'there's no heartbeat, I'm so sorry'...I remember being in labour with Kayleigh- it was a long and traumatic labour- and we knew I had to give birth to our dead child and my husband had to watch me ... and could do nothing to take away the physical , mental or emotional pain

I read recently something that Gary Barlow had said - that there is nothing worse than seeing a mother holding her dead child..... My husband had to watch me as I held my baby tight and although I could barely speak, I was screaming inside.. unable to comprehend what was happening, in the deafening silence of the room.

Then he had to watch me physically heal from birthing our first child offered to clear the nursery if that was what I wanted (it wasn't) ... and then after 2 weeks of paternity leave, he returned to work to face everyone - knowing that he was leaving me at home alone, totally lost - not who I was - not who I was meant to be and no idea of the way forward ... isolated and lonely...I didn't have a job to go back to - my class had been given to another teacher to cover my maternity leave ... and who am I kidding - I couldn't even write in those early days... the physical effects of grief were absolutely terrifying.

Days become years and as they say- life goes on -I still don't like that phrase- but my heart and mind, is sometimes back in that moment when I held Kayleigh tight.. in that silent room, as if it were yesterday.

I still feel it is so wrong- being so connected and yet not being together.... My baby is always there in the undercurrent of my thoughts... The way we are fused can only be explained by mothering a child you cannot hold.

People don't realise that because my Kayleigh didn't take a breath in this world - that doesn't mean that it doesn't still hurt - that I don't still ache for her- as much now as I did then. She died at full term, shortly before I gave birth to her- she was a proper baby- a person... she just never took a breath and never opened her eyes. She wasn't just blood and tissue or a foetus- my baby had life for 9 months.. she had a soul, a heart and a body... she was a real person - she was alive.

Death didn't change the fact that it was the first time we met our baby... we were so full of love for our much-wanted child... but how devastating to hold everything you have been waiting for and dreamed of.. but knowing you have to give her back... the future- our future- erased in front of our very eyes.

Here's to more people understanding that motherhood is an all-consuming job - moreso true for the mother who doesn't have her child here with her... because her child's life consumes her in the most painful of ways..

Because the days creep by so slowly - with the days filled with nothing but longing and grief... nothing matters any more... the days are so long because even though the sun might shine - there is only darkness.... And emptiness.... Where even though a mother's breath hasn't stopped - her life has- and there is nothing to propel her forwards and in her stillness she is alone and misunderstood... though there is no reason to live- the mother knows she must. .. No sacrifices to be made for her child - just suffering... because she has missed out on a lifetime of memories with the one she loves most... because where there were 2 heartbeats... there is now just one...

When people still now - nearly 11 years on, would rather stay away from me, it still does hurt... losing my baby doesn't mean I am contagious- by staying away from parents who have lost their baby - you just make them feel isolated, confused and that it is their fault.

And even though Kayleigh didn't see this world- she has changed it by the action inspired in me, her mother.. there are many like me ... but also many who choose to hold their memories privately- who mourn behind closed doors... isolated in their grief.

This is why we must break the silence - break down the taboo and talk about baby loss... it is bad enough to bury your child ... without further repercussions as the ripples of grief spread

I have met so many bereaved parents who lost their baby 30.... 40.. 50 .. and even 60 years ago ... who have no tangible memories whatsoever and yet grieve so deeply for their baby every single day of their life still... suffering alone. It isn't right- nobody should suffer alone.

Most people know I am pretty passionate about raising awareness- and whilst this obviously goes for bereaved mothers, it also encompasses bereaved fathers, grandparents and those long ago bereaved too.

I was so moved to have been able to help a bereaved parent who got in touch with me recently- asking if I could help trace her baby's resting place- as it was approaching her baby's 30th birthday and she felt she really needed to know where he is. I was delighted to have been able to do this for her and I know that it has been quite lifechanging for her to receive the news all these years later. It is never too late to seek support.

Over these years - after being stripped back to my soul, I have learned that I am richer than ever before ... I have learned that true strength and courage arise when you experience traumatic loss and cannot imagine carrying on. I have learned that deepest joy is known to those who also have experienced deepest pain. And I have learned that I will always grieve because my love is unending.

I strive to live my life for both of us To find hope through the heartache, to find joy through the sadness, to find strength through the weakness, to live bravely- even when scared, to make the most of my days - in a way that would make my Kayleigh proud.

Just before I finish, I would like to mention that although Victoria Prentis wanted to be here with us, as she was last year, especially to remember her own baby, Boris - she has been unable to join us. However, she very kindly invited me to Parliament on Thursday for the Parliamentary launch of Baby Loss Awareness Week - and in the remembrance service that followed the reception, together we lit special candles for all our Oxfordshire babies.

As you leave the service today - please take with you a candle to light in the comfort of your own home tomorrow night at 7pm, to join in with the global Wave of Light.

Please also take one of the specially handknitted baby loss awareness ribbons from the tree as a gift from us at Oxfordshire Sands.

Finally, if you are nearby tomorrow evening - with the support of Banbury Town Council- the Town Hall will be lit up pink and blue to coincide with the Wave of Light, as part of the Baby Loss Awareness campaign to light up the country pink and blue.

Thank you for listening.