

I am making this submission on my own behalf as a bereaved mother. I have two living children and a child, Elliott, who was pronounced still born on October 28<sup>th</sup> 2016, born at 21 + 5 weeks gestation. He was healthy with no genetic abnormalities and was above his expected weight for his gestation. He was simply born too early after I had suffered PPROM, a preterm premature rupture of membranes (with no diagnosed reason for it happening) and died sometime during the labour to bring him into the world.

In this submission I will share my story of my hospital and post-natal experience and highlight the areas I discovered through my experiences that are lacking in both treatment received and services available (both medical and mental health/support) when parents are faced with the unthinkable of their baby dying. I will suggest ways in which I believe these areas can be addressed. I will highlight the need for broad education and awareness to create a cultural change to remove the taboos around baby loss in general and the need to include stillbirth education as part of standard pre-natal care. I will discuss the ways in which I believe government could help both medically and socially through increased research and education including the implementation of a nation-wide roll out of the current WA Pre-term Birth Initiative to prevent still birth caused by very premature birth and the need for better access to bereavement support for both parents and siblings after.

## **OUR STORY**

### HOW IT HAPPENED; HOSPITAL EXPERIENCE

On Monday the 24<sup>th</sup> of October 2016 I had a gush of fluid so I rang the hospital and was told to go up to be checked. I was scared but very positive. My husband and I went to the hospital and the nurses there did some tests and found no evidence of amniotic fluid. They were unsure what it was but could not confirm it was my waters. What a sigh of relief, I hoped that it was just my pelvic floor giving way being my third pregnancy. We searched the internet desperate for information and found so many positive stories so we felt comforted. I said to my husband everything should be ok, but in my heart, I knew something wasn't quite right and my instinct was telling me that we needed to prepare ourselves for a preemie baby, possibly with medical problems if he was born very early.

My obstetrician called me in for a scan the next day. The first of the terrifying news came our way. My fluid levels were lower than they were in my morphology scan done 3 weeks before but were still within a normal range. I was told it is possible that I could go on to have a healthy baby close to full term, BUT due to the fact the fluid levels had decreased and based on my accounts, it was also possible I did in fact have a tear in my membranes. I was told if the rupture was big enough, I could go into labour and at 21 weeks, the baby will not be viable. I was told there was nothing they could do to help with this except put me on antibiotics and to go home to rest and take it easy and watch for signs of infection such as fever. The leaks continued the next day then the cramping began that night. I rang the hospital and they said to come in to be checked again.

Whilst I was walking in to the hospital I received a phone call from a different obstetrician as mine was away and not back until Tuesday afternoon. I was told, "Your doctor has passed the information onto me with grave concerns, I hear you are still having loss, and I know your Doctor has advised you that your baby will not be viable. If you were before 20 weeks we could offer you a termination" I was confused and upset to why this was mentioned and stated that I was over 20 weeks. I was told "Yes I know, so you are in a grey area because your baby will still not survive". I was in shock and again confused stating "but they haven't been able to confirm it is a rupture yet". I was told "Yes but from what you are describing I'm sure it would be. So you need to make plans and might have to

admit into the hospital because your baby will probably be born over the next few days if not sooner”

I was examined again and still there was absolutely no evidence of amniotic fluid. Our baby’s heartbeat was still very strong as were his kicks. The midwives were very confused and they suggested it could be a range of other things that were not related to a rupture of membranes. I asked if the doctor would come and give me a scan or check, they said no so I went home, had to just be careful and see what happens. Within 30 minutes of being home I began to have cramps which I knew were initial stage contractions. I went back to the hospital, had yet another check which confirmed contractions and this time I also had an internal examination as the dip test to see if fluid is amniotic fluid was coming up negative again despite two different midwives doing them. On internal examination there was still no evidence of fluid pooling. They called the doctor and said I could have an irritable uterus caused by a UTI. I did a test and was advised to stay in hospital. The contractions got worse and started having more loss and I knew I was in the start of labour. I cried and was petrified but tried to remain positive knowing how strong this baby was, kicking like crazy, and I just needed to hold on for a couple of weeks until he would be classified as ‘viable’ where they would medically intervene once born. The midwife examined me late at night when the pains were getting stronger, she told me my cervix was budging and was so sad to say it was possible everything was going to happen that night. I asked over and over again if they were going to give me anything to try stop the labour and told me she’s so sorry she’s asked but he will not prescribe anything. I was so confused as to why they wouldn’t attempt to stop it when he said it may just be a UTI causing the contractions but also felt completely helpless. We made it through the night, the contractions slowed down and our baby was still strongly kicking.

The doctor finally came to see us after breakfast and said he wasn’t sure what’s happening and seeing as we made it through the night finally decided to give us some medication to relax my uterus, which should slow down the cramps, and it might just be an irritable uterus after all. Within a few minutes of the medication being given my contractions stopped. We would have a scan later to check what was actually going on and waited until 5pm that night until that happened. That scan would confirm that there was in fact no amniotic fluids left except a pocket around his bum which is likely to be his urine. In that moment my world fell apart. I felt like my heart had literally been torn to shreds. We were told this meant that even if he made it past 24 weeks he would not survive because his lungs have not been able to inflate and practice breathing without the fluid there. We were told within a week 3 out of 4 women will go into labour naturally. I was told “you can let nature take its course” or medically intervene to help bring the labour on. We were given overnight to absorb it all and make a decision.

I could not wrap my head around this process feeling him still kick strongly. How do you deliver a healthy baby who is kicking when you know their birth will kill them? We were advised he may be born still or alive in which we would just have to hold him until he died as the doctors will not medically interfere at this gestation. I said to them my other children were all early (2-3 weeks) and did not have any troubles at all, I also said that our dates made him 22+5 not 21+5. None of that mattered. We were so very close to that line of being able to fight to have medical interference but just couldn’t touch it. The contractions continued and he started kicking more and more, and I knew he was in distress. We made the decision that if it didn’t happen overnight we’d help the labour along the next morning, for him as we didn’t want him suffering. The next morning I had two tablets inserted to soften my cervix and within 10 minutes my labour intensified.

I cannot describe how awful the labour was knowing he would be born still or die soon after, to be in the maternity suite listening to babies cry while knowing I would never hear that from our son. It

was like torture. 20 months later I still have flashbacks to this and can visualise, feel and hear myself laying there in pain in labour and hearing the sound of a cry. For a long time after I would go into a panic when I heard the sound of a newborn cry and it's something I still struggle with. It can bring back the trauma (possibly slight PTSD) and is like twisting a knife that is already in my heart.



At 12.30 pm on October 28<sup>th</sup> 2016, our perfect, beautiful baby boy measuring 28.5 cm long at 450 grams was born. The midwife declared he had no heartbeat meaning he had died sometime during the labour meaning he was stillborn.

We were so lucky that we got to spend 3 days with our son, thanks to a cuddle cot (a cooling device that is placed into the cot and keeps their body cool to preserve it from deteriorating) in the hospital. This is something I cannot stress enough of the importance of having available in all hospitals as I know many parents have not had access to them. Our whole family, including our other two children cherish these three special beautiful days

with all our heart. We are grateful for every second we were able to have and I believe this has helped our healing to be able to have memories we made with him to reflect on.

The care from the midwives while we were in hospital was amazing and I cannot commend them enough. We had special care from some particular midwives who clearly had professional experience with stillbirth and neonatal death and dealt with us perfectly in every way. Ensuring that the right midwives who are gentle, caring, knowledgeable and helpful with parents is vital at this time to make this time as least psychologically damaging as possible. They were calm and gentle, filled out paperwork for us so all we had to do was sign, they always told us how beautiful our son was (something that made a world of difference and comfort to us as all proud parents want to hear that from others) and made us feel comfortable asking any questions.

#### POST NATAL CARE

While we were in hospital we were given a beautiful and very helpful Bears of Hope care bag and some pamphlets. SANDS was mentioned as an organisation we could contact. Unfortunately, the only local service, Sids and Kids NT who provide bereavement support for families who have experienced the unexpected loss of a child of any gestation and age up to 18 years old was not mentioned. Luckily, I already knew they provided the services.

I had a follow up appointment with my Obstetrician when he was back to answer any questions and check I was ok physically. I can't fault this Obstetrician, down to the fact he opened his arms to hug me and said "this is so sad, such a sad thing to happen, I am sorry and I'm sorry I wasn't there" A few words that made a world of difference. To finally have the acknowledgement of how awful this really is and to hear the words "I'm so sorry" by a doctor. It showed that to him, our baby mattered. He also mentioned the charities we could talk to. After that I did not have any home visits from a nurse or follow up with a checklist for PND as you would when a baby is born alive. We were not referred to a social worker or Sids and Kids NT. I don't believe this is a fault with the doctor but of the system.

5 days after our son was born I received a cheery phone call from the hospital saying that they have noticed we were discharged but we didn't do the newborn hearing check and they are checking when can we book that in. This was just another stab, and I had to tell this person our baby died so no we won't be needing a hearing test.

A week after I had to be readmitted into hospital for a Dilation and Curette procedure for retained placenta. The nurse placed me in the birthing suite to wait to be checked instead of an observation room or normal room. It was the worst possible place to be, sitting in a delivery suite looking at the resuscitation/check table, birthing ball, change table etc only a week after delivering my still baby adding extra trauma I would later have to recover from. I was admitted into hospital to stay the night to have a scan and then the procedure the next morning. I asked if I could have my sister come and stay in my room with me while my husband went home to organise our other children and if they could quickly come up and see me. She bluntly told me “you are fine, you don’t need anyone here, it’s only a minor thing”. It wasn’t a minor thing at all, I was in the maternity suite, trigger central, less than a week after our baby died, verging on a panic attack and breakdown, terrified and full of anxiety as I no longer trusted ‘statistics’ and thought that I would somehow die from complications of the procedure. Our 4-year-old son was also in a complete panic saying “mummy isn’t going to come home”, just like Elliott didn’t. My obstetrician said he was sorry that I was there, acknowledged how hard it must be, and made sure I was able to be out as soon as possible. The doctor (not my obstetrician) who was called in to put my IV line in kept asking questions about “what procedure are you having?”, something that again was extremely traumatic to have to deal with on top of things.

I discovered how isolating the road can be after baby loss. There is a social expectation to ‘move on’, ‘get over it’ and a taboo about talking or sharing stories or photos of your child. Parents are forced behind closed groups of other bereaved parents, all discussing their isolation and lack of understanding and awareness people have. 20 months later our whole family hurt and suffer a great deal, including our 2 other children now 6 and 9, despite all the early interventions, research, strategies we have had implemented and had available to us. The impacts of the loss of Elliott is beyond words to describe how devastating it is. These impacts will last and be felt forever, just as our love will.

## TERMS OF REFERENCE

### **a. Consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;**

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### **b. Coordination between Australian and international researchers;**

I began researching PPROM after Elliott’s death as we were given no reason as to why or how it happened. I believe education to every medical staff member and hospital of the most current medical research and recommended practice and implantation on the best level of care is vitally important.


I found the UK organisation Little Heartbeats (<http://www.little-heartbeats.org.uk/>) who are not researchers but focus on education on PPROM. Their Aims and Missions (To give parents as much information as possible to help make more informed decisions; Educating and empowering women to understand this condition and the choices available to them should they suffer PPROM; To offer support to those women throughout their PPROM journeys; To contribute in the development of professional policies on the improvement of communication skills and bedside manner specifically when dealing with PPROM patients; To provide hospitals with RCOG literature outlining treatment and choices; Invest in Specialist Midwives who are trained in PPROM management and related conditions to support women regardless of outcome.) are things that would be very beneficial to have in an Australian organisation. There is currently no organisation specifically for PPROM

patients. Coordination with international organisations enables the sharing of research and practice to better improve our health care.

Little Heartbeats state “where there’s a heartbeat there is hope”, a medical outlook which would be amazing to be adopted within Australia.

I also discovered the WA Preterm Birth Prevention Initiative, funded by the Women’s and Infants Research Foundation. This initiative is based on the following principles (image from their website)-

## The seven interventions for the prevention of preterm birth



1. No pregnancy to be ended until at least 38-plus weeks unless there is obstetric or medical justification.
2. Measurement of the length of the cervix at all mid-pregnancy scans.
3. Use of natural vaginal progesterone (200mg each evening) if the length of cervix is less than 25mm.
4. If the length of the cervix is less than 10mm, consider cerclage or progesterone.
5. Use of vaginal progesterone if you have a prior history of spontaneous preterm birth.
6. Women who smoke should be identified and offered Quitline support.
7. The establishment of a new Preterm Birth Prevention Clinic at King Edward Memorial Hospital.

The Initiative has resulted in an 8% reduction (196 pre term births prevented) in the rate of preterm birth across the state in its first year of implementation in WA. The Still Birth Foundation lists in their report on the economic impacts of still birth (<http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf>) that 190 babies are still born due to spontaneous pre term birth (11.7% of total still births). While the statistics of overall prevention of preterm death cannot be simply translated to the prevention of still births, if 8% of these deaths could be prevented simply by preventing 8% of all pre term births, 15 babies every year would be here (and 15 families every year would be prevented from the excruciating reality that follows). This doesn’t include the babies who are born with a heart beat and die in the hours, days or weeks after. If we could save 15 road accident deaths by implementing certain safety rules for example we would, so shouldn’t we also be trying to also prevent these babies from dying? Rolling out the WA intervention Australia wide in all hospitals could potentially save hundreds of babies being still born, and thousands dying within the first 5 years from complications arising from preterm birth, so it is imperative that there is an Australian wide collaboration of such research and implementation of practice

I live with the trauma of the questions that start with “what if”, wondering if there is a possibility my baby could have been saved. These are the questions that haunt and damage you. What if we had

been given a more timely or different medical response, and perhaps the steps outlined in the WA initiative? Would there be a different outcome? If I knew everything was done in line with the top research as quick as possible I believe these questions would not have so much weight for us.

Current collaborations between international and Australian researchers are making ground breaking advances. One such important advance has come from a collaboration from researchers again from the Women and Infants Research Foundation, the University of Western Australia, and Tohoku University Hospital, Japan, to develop an artificial womb which is hoped to be an effective treatment strategy for extremely preterm infants born at the border of viability (22-23 weeks). ( <https://www.scimex.org/newsfeed/artificial-womb-keeps-lambs-alive,-raising-hopes-for-preemies> )

In the case that all other things fail in preventing pre term birth, this technology could potentially save hundreds of babies from still or neonatal death, babies like my own. These collaborations should be encouraged and funded not only being able to save lives but would provide an economic benefit of export of machinery and licences. An article in the Australian ( <https://www.theaustralian.com.au/higher-education/opinion/medical-research-a-major-export-earner/news-story/74157227cefa198b7f570e060326405c> ) states

“Financial modelling of return-on-investment in medical research further supports the economic benefits. Various reports, including from Rand in Britain and Deloitte Access Economics in Australia, have used different methodologies to show the net health gains, including improved quality of life, and the return on investment to the economy as a result of investment in medical research.

The results show that for every \$1 spent on research, at least \$2 was generated in additional economic output, with this figure much higher in several studies. There are, of course, limitations with this data, particularly with regards to when the returns will be made, but there is general agreement that spending on science generates jobs and economic growth.”

### **c. Partnerships with the corporate sector, including use of innovative new technology;**

See the above article and information on the artificial womb being developed. This could be an opportunity for the corporate sector to partner with researchers to develop this and other new technology.

The Australian Government should encourage more corporate sponsorship in regards to charity donations and funding of equipment and technology. A cuddle cot for example only costs \$6000 and yet there is a shortage in hospitals over Australia. While it cannot save a life, it can create priceless memories for a family, something I cannot personally state the importance. I have talked to mothers who did not have this option given to them and they have been devastated to not have that opportunity. Encouraging the corporate sector to invest in such things will relieve the burden of charities, individuals and the government to provide funds, and the benefits roll on throughout the community through decreased economic costs associated.

### **d. Sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;**

Lack of government funding causes a great deal of pressure on all charities and researchers to find public and corporate funding often making it unsustainable. This includes bereavement charities that assist after such an event of still birth. There is only 1 organisation in NT to support bereaved parents, and it relies on donations and volunteers making a lot of the effort go on fundraising to keep them afloat instead of being able to dedicate that money and time on services to aid grieving and struggling families after loss. Unfortunately the corporate sector is small in the NT compared to the states therefore government funding is vital as we are unable to rely or secure other forms of large donations to keep charities running. The NT has the highest rate of still birth per capita in Australia, but very few services available.

The research funded should include in-utero death along with other factors than can also cause still birth such as preterm birth. The WA initiative discussed is currently limited to WA only, but this will prevent many still births Australia wide with the prevention of pre term births.

There was no diagnosable reason to why my membranes ruptured and no further tests done to see if I have an incompetent cervix which is one of the leading causes of PPROM. It is often not until the death of more than one baby that investigations are done to diagnose this. No option to undertake any surveys to pin point factors that may have caused my PPROM was given. Funding restraints cause lack of available research. If we can find out more about PPROM, many still births could potentially be prevented. I was told "this is just an unfortunate thing that happened". Not knowing the cause doesn't mean there was none.

I believe a mix of corporate and government support will enable the sustainable funds to continue research long term and distribute education of the findings to stop preventable still birth. We need to remove the taboos around still birth first so corporate bodies are happy to put their money behind as primary sponsors for fundraising events and research facilities. Having known public ambassadors stand behind the cause will help this occur raising profile and acceptance of the subject matter, similar to what we have seen with the current bowel cancer campaigns. Having government backing for research and initiatives will also help not just financially but culturally with a top down approach to support, sending the message that this matters.

**e. Research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education;**

together with

**f. Communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;**

As stated previously, in regards to preventing still birth due to premature birth the WA pre term birth prevention initiative should be a priority to roll out Australia wide, including private obstetricians and hospitals. It is a current initiative with proven success and a developed model. Co-ordinating this through other hospitals, even without other specialised clinics would provide substantial difference to reducing pre term births and still births associated with pre term birth.

The focus in pre-natal care I was given in all three pregnancies (which have spanned a decade) was around safe eating with statistics and information given around first trimester miscarriage. I was never given information on still birth, the risks/statistics/possibility or other information in regards to the safe pregnancy practices Still Aware promote such as kick counting and sleeping on your side. In fact I had never heard of Still Aware before.

I have spoken to two friends after we lost Elliott who have had reduced foetal movements. I only knew from the experiences of bereaved mothers I have connected with and their stories, and the advice I found from Still Aware AFTER Elliott was born that this could be of concern. I was the only person to tell them they should go to the hospital without delay to be checked. The old wives tale of “a baby will slow down further along” was mentioned to them on Facebook comments regarding their reduced movements. No one wants to be the person to say “get checked” which may “worry the mother”. Just like “don’t sleep a baby on their tummy” is normal now knowledge, so should “get checked immediately with a change in movements”.

Ensuring the practices Still Aware promote for empowered and safe pregnancy are widely endorsed through national campaigns similar to the SIDs campaigns on safe sleeping and by all medical practitioners including obstetricians and midwives during antenatal appointments is a priority in order to reduce the unacceptable levels of still birth.

Education will prevent still birth, just as it has with reducing the levels of SIDs deaths. Red Nose states on their website “Programs introduced in 1990 to educate parents about safely sleeping babies – especially the advice to avoid tummy sleeping – are believed to have been a significant reason for the reduction in sudden and unexpected child deaths – in 1989 there were 485 deaths under one year of age; in 2015 there were just 113. The estimated lives saved in that time is 9,450.” The same type of public campaigns should be implemented with still birth prevention. A national broad approach will remove the need for individual bereaved parents or single organisations to try to educate people. It is difficult to have people listen as its just not something anyone wants to hear. Repetitive fact based and statistic driven government backed education is a way to do this, otherwise people feel you are just paranoid.

Education on the risks and possibility of still birth is also important to change the culture of taboo and stigma around it. No one thinks it is going to happen to them, 1.6% seems next to nothing but when you label it as 1 in every 160 pregnancies, you realise how common that actually is. When it does happen, many people are still removed from it, not being able to empathise with it. Once it becomes a real acknowledgeable risk I believe the level of devastating isolation that often ensues after you have a still born baby will reduce.

As I have stated before, there was no known cause found to why my membranes ruptured. All I could be told was ‘these things happen’. But WHY do they happen? And HOW can they be prevented? Without these answers I have been unable to make the decision to try for another baby. If these things should happen but did, and no known cause can be given, all the same factors could be in place to cause them to happen again.

In the NT we have more rates of still birth per capita than any other place in Australia (ABS for no apparent reason) Surely this should/could be investigated which could potentially bring breakthroughs in the prevention of still birth.

### **g. Quantifying the impact of stillbirths on the Australian economy;**

The Still Birth Foundation has released the following report <http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf> which I can personally support.

These are our personal economic impacts-

**Immediate direct economic costs for us included the following-**

Hospital stay of 3 days

Financial costs of blood tests and genetic screening (over \$500)

Funeral cost of a few thousand

Readmission and D&C procedure due to retained placenta, very increased risk for pre term birth compared to full term.

(<https://www.sciencedirect.com/science/article/pii/S0002937890910760>)

#### **Indirect costs for us-**

The death of our baby impacted every area of our life including that of my ability to work. After our son was born I was unable to return to work as I was full of anxiety and bordering on panic attacks of facing people and walking into my business which due to being a baby boutique was four walls of triggers. As I was unable to return I increased staff members to cover my absence. If I had a different job I would have had to take extended leave. While I was working from home with behind the scenes things, it took 5 months to be able to begin working within my store and face customers. The impact of my absence and inability to do the job I normally do and increased staff members needed to cover on the store front placed a burden on us financially.

Difficulties sleeping impacted my ability to function with work as effective as I used to, with a clear loss of productivity. This year I closed my business after 8 years of trading as I was unable to continue to maintain the levels of stress on my physical and mental health it was putting on me after the loss of our baby. The still birth of our baby directly caused the shutdown of our business and with it the economic costs (Gross turnover, GST paid, staff wages paid, Superannuation paid to staff members, expenses now ceased, income ceased) associated with its closure.

My husband took four weeks leave which exhausted all his sick leave and annual leave. He has also had both paid and unpaid leave for mental healthcare and to be able to commemorate milestones like our son's birthday.

With the level of stress my husband and I have been under has brought physical ailments such as acid induced reflux and eye sight deterioration. Over the last 20 months my husband and I have never been as frequently sick. This has meant many doctor visits, time off work and lack of productivity.

We have sought counselling services for our children to help them with their grief, and this be up to \$240 a session. They have missed weeks of school over the last 2 years due to mental health care needed for them.

#### **Indirect costs for family members-**

2 grandparents took 10 days leave, 1 was paid bereavement leave from Govt job, 1 was unpaid leave.

1 Grandparent took a couple of 3 days paid leave off.

My sister quit her permanent Government job to help with my business.

### **h. Any related matters**

#### **1. CHANGE IN CULTURE AROUND BABY LOSS**

There is a massive taboo around baby loss, something I never realised existed. The death of a baby is often treated very differently to the death of an older child or adult. I now know that there's a culture of silence around such a topic, and that there can be an opinion to get over it and go back to normal, as quickly as possible. So many parents feel isolated and alone, left to grieve in silence or in closed groups of other bereaved parents not because they want to, but because they feel they have to, or because they are worried of judgement or hurtful or dismissive opinions from anyone outside of those who actually understand. The same themes are told time over, world over, of how they just want people to show them their baby matters and be accepted as a real person with a real life. The lack of awareness and understanding creates isolation fuelling a whole magnitude of mental health concerns.

There is an accepted notion that there is a set timeframe that you should grieve or that there are neat stages of grief that you go through. The reality is there is no "getting over" the death of your child, no matter how little or how much time you've had with them. The pain doesn't finish at the death of your baby, it continues as you live every day without them. There's no just moving on or forgetting about it. There is instead getting up and moving forward with life, learning how to live with it and finding a new normal which may be similar or wildly different to the old normal. There are stages but they don't happen in order, they don't happen just the once, they can occur all mixed up over and over again forever.

It's not hard to find dozens of Facebook pages and websites dedicated to trying to expose the true reality of grief and loss, to change the taboo, to change the culture of silence we have and promote and spread education and awareness on how to ACTUALLY support those who have lost a baby or someone else they love. The problem isn't the lack of available resources to spread awareness and understanding of baby loss and living after, it's the inability for people to accept it into their lives. Those pages are left for those who are in the situation and often when we share posts or pages to try help those around us understand, heads are turned away because it's just too awful for others to think about, or care about.

Men/fathers have a particular barrier to awareness and understanding on the effects of grief and impacts on them when their baby dies. There is a further taboo added to men who are often called the silent grievers, not recognised as having the same loss as the mother. A prime example is a phone call my husband received from work while we are still in hospital. They were completely aware that I was in and out of hospital with dire potentials. The phone call took place on the Saturday by a woman in HR asking about Adams absence which was already communicated. He stated he was in hospital right now and his baby had died yesterday. The women simply asked "when will you be back at work" to which he replied "I don't know, all I know is my baby's funeral is Monday" She said "ok I'll call you Tuesday then" and did. He had just buried his baby the day before which they knew and had a phone call asking when he thinks he'll be back, with the pressure to go back straight away and a lack of understanding that this was impacting him too. Very few people ever asked how he was, family did not message him, and those who reached out often asked him how I was but not how he was. It made him feel like they did not recognise him as a father to our baby, or like he did not love him as much as I did.

Having government care will make a great deal of difference in this change. It will help bereaved parents feel cared for, supported, and show our babies matter. It will also normalise the conversation and provide a great deal of legitimacy to it, so we are not seen as having a problem that we need to get over. We need to take a broad national approach to change the culture and taboo around baby loss and the way we view grief, just as we have with depression and other

mental health with the Black Dog or are you OK campaigns, and well known supported organisations such as Beyond Blue, life line etc.

### **Simple ways government can do this include**

- support October Pregnancy and Infant Loss Awareness month, specifically October 15 and the international wave of light. With broader awareness will also come more business and corporate support for funding and sponsorship.
- Funding the distribution of educational materials for stillbirth prevention to the public.
- a public campaign to spread awareness and education on what grief really is like and what is actually helpful to those dealing with the loss of a baby (or other loved person)
- publicly backing initiatives, and being vocal about providing the funding for it
- funding public memorial gardens or projects
- more funding to bereavement services (SIDs and Kids NT, SANDs, Bears of Hope) who can help reduce the isolation parents feel and they in turn can spread awareness of baby loss and create more education on how to help support bereaved parents and children.
- Supporting business to include education and awareness on grief and the impacts on men as well as women when they hold sessions on mental health
- Increasing support for bereavement services including specific services for men.

## **2. POST CARE/BEREVEMENT SERVICES**

As stated in our story we were not given a social worker or referred to Sids and Kids NT, the NT's only bereavement service. The responsibility is put on a bereaved parent to access those service themselves, which is no easy thing to do emotionally to reach out. I feel like I did not need a social worker but what if I did? The fact that there was no after care after this made me feel like the health care system didn't care about us or our baby. There is so much education and effort into checking at 6 weeks if a mother is at risk for post-natal depression, ensuring she is supported and early intervention is met. I don't understand why this isn't done routinely with a check-up when a baby dies. We were cast out and left to ourselves to deal with it all as if it never happened. You go home without a baby and are expected to just return to life as normal. You feel isolated and alone with increased levels of anxiety and indications of PTSD.

Feel the Magic Organisation states "Grieving children who have experienced the death of someone they love can feel isolated and alone. They require ongoing support in developing strategies to cope with and move forward with their lives following a significant loss."

(<https://www.feelthemagic.org.au/who-are-we/>) No information was given to us on sibling grief and after we were left very unexpectedly with two children with immense grief and huge behavioural changes that presented from it. We had to search for information and help. We were given some pamphlets from Sids and Kids after we went to them outlining common traits for age groups after the loss of a baby with helpful advice, all information that we needed much early, from day 1 and not weeks after. We discovered that services for grieving children is very difficult to access. They are extremely expensive and many do not have a good understanding of the children's grief, let alone the specific grief that a sibling has of a baby. The cost can range from \$180 for an hour to \$240 for a half an hour, which is not something many parents can't afford no matter how much they want to be able to. We were unable to access any government subsidy for this unless our

children were diagnosed with a mental illness, depression or anxiety. Grief was not something that is listed as being able to access a mental health care plan for them. Very few people understand how our children 20 months on still grieve deeply for their brother. One of our children has developed extremely challenging behaviours, separation anxiety and a lack of security/helplessness. Our other child has large mood swings and depressive states. When I have talked to many other parents in similar situations with children of similar ages, they are all presenting with similar reactions and behaviours. You are left helpless and often struggle to help them with their grief, giving you further heartbreak. You need to put your own grief away to continue parenting to the best of your ability with no help or assistance.

#### **Ways to address this-**

Increased funding for bereavement services and parent support services and more access to the information

Protocol to refer every family to a social worker or bereavement service, not just for the first week or month but later on when reality hits and the support from others begins to fade.

Funding to services who focus on siblings after loss such as <http://www.seedsforsiblings.com/> and grieving children such as Feel the Magic.

Grants for creating resources to help grieving children (there is hardly any available)

Investment into research on childhood grief and the impacts on them, which will help provide better education for trained professionals.

Listing grief and loss as a part of availability to access a mental health care plan for children (non income tested).

More Medicare funding towards counselling services for moth adults and children so they are accessible and affordable.

Education within schools to teachers on the effects that grief can have of children is needed to ensure they are able to deal with, respond to and understand behaviours and reactions they may have after loss.

More accessibility for resources need to be made and included for parents with living children within hospital and after.

#### **3.PROTOCOLS**

Simple protocols should be in place to prevent unnecessary added trauma. Your file should be clearly marked as having suffered a loss so appropriate language is used and appropriate questions are asked, as well as appropriate treatment and best available options are given on any subsequent visits to hospitals. A mother after loss should not have to wait in a delivery suite when there are standard rooms or other examination rooms available.

The record of still birth should be filed in a specific area to prevent it being transferred to the wrong areas. This will stop phone calls for a baby who clearly can't have his hearing tested as we experienced.

#### **4. EDUCATION ON BEREVEMENT CARE**

I cannot stress the importance on educating all medical staff on correct ways to care for bereaved parents whether they are giving the devastating news to understanding of the difficulties and triggers involved in going into a hospital after loss.

A parent should never be told over the phone when there is an option to see them face to face that their child will die.

Every parent should be treated with gentleness and care when told the most devastating news. They should always start with "I'm so sorry". Every parent should feel like their doctor and hospital did absolutely everything in their power to save their baby, and this often comes down to the words in which are used over the actual medical practice. In our case simply saying "I am so sorry, I wish there was something I could do but there is just nothing available to change this" would make a world of difference. References like "let nature take its course" should never be used understanding this is someone's loved child and not a sick stray dog. Words can hold a huge amount of weight with lasting impacts, and education around this is important to reduce these impacts on patients.

Bereavement care education should be part of professional development and skills maintenance to ensure all staff are adequately trained on being able to provide the right care using the right words and actions. The interactions with staff can have a lasting and possibly severely detrimental effects on parents.

## 5. FACILITIES FOR STILLBIRTH

I would love to see every hospital with specific bereavement rooms that are separate enough from the maternity ward that you cannot hear or have to interact with newborns crying. I understand the logistics of needing to be in the same ward, but surely something different can be done, for example sound proofing a particular room to prevent added trauma. It is an incredibly traumatising thing to endure that can cause PTSD. All midwives who are responsible for the care of parents delivering or have had delivered a stillborn baby should be specifically trained in bereavement care.

Thank you for hearing my story and my submission.

Stephanie Vowles, Elliott's mummy