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EACH EGG A WORLD ONLINE – GIVING A VOICE TO BEREAVED PARENTS AND BREAKING THE TABOO ON STILLBIRTH

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BACKGROUND

Globally there are now about 2 million stillbirths a year (Blencowe, Cousens et al. 2016, Lawn, Blencowe et al. 2016, United Nations Children's Fund (UNICEF) 2020). This makes stillbirth the fifth biggest cause of death (Blencowe, Cousens et al. 2016), yet it's rarely reported as such, as it affects infants before birth. Despite their frequency, stillbirths were not mentioned in Millennium and Strategic Development Goals. Critically, the distribution of stillbirths is not felt equally across the world, 98% of these deaths occur in low- and middle-income countries. Furthermore, of the cases occurring in high-income settings women who come from non-White populations (e.g. women who are Black or Asian in majority White populations) or women from socio-economically deprived groups experience rates that are much higher than the least economically-deprived White women (Flenady, Wojcieszek et al. 2016, Draper, Gallimore et al. 2021).

Stillbirth, simply describes the outcome that a baby has died before birth, it does not give information about the cause. There is insufficient data globally, as in many places, the number of stillbirths and consequently their timing and cause, are not recorded reliably. Globally, preterm birth is the most common cause of stillbirth (Norman, Morris et al. 2009) and fetal growth restriction (FGR) is the second most common cause, in all responsible for 30% of all stillborn babies (Nardozza, Caetano et al. 2017); FGR is thought to be the most common cause of stillbirth in high-income settings. FGR usually results from conditions that prevent the placenta (afterbirth) working effectively. There are no effective treatments for FGR after the condition has been diagnosed, but if it is detected before birth (usually using ultrasound scanning), it need not be a cause of death, as in many cases the birth of the can be safely planned to minimise risk to the baby (Gardosi, Madurasinghe et al. 2013). However, FGR, and especially late onset FGR is often not detected due to lack of appropriate screening in the last third of pregnancy.

Globally, many stillbirths could be prevented by instituting simple measures, such as good reproductive health care, folic acid supplementation adequate antenatal care, management of existing medical conditions (e.g. HIV infection) and pregnancy complications (e.g. pre-eclampsia) and access to basic and emergency obstetric care in labour (de Bernis, Kinney et al. 2016). Critically, these interventions would not only prevent stillbirths, but would prevent deaths of women in pregnancy and childbirth (termed maternal deaths) and babies in the first month of life (called neonatal deaths) (Heazell, Siassakos et al. 2016). The Every Newborn Action Plan ratified in 2014 set a target of 12 or fewer stillbirths per 1,000 total births in every country by 2030 (UNICEF and WHO 2014). However, more than 45 countries must more than double their current progress to meet this target (International Stillbirth Alliance Stillbirth Advocacy Working Group 2023). There are many barriers to achieving the proposed reduction in stillbirths, but a



lack of appreciation of the impact of stillbirth on mothers, their partners and wider families and society plays an important role.

The death of a baby from stillbirth is associated with significant psychological impacts which endure (Heazell, Siassakos et al. 2016). A systematic review of 144 quantitative, qualitative, and mixed-methods studies found the most common impact was negative psychological symptoms (77% of included studies) (Burden, Bradley et al. 2016). Critically, disenfranchised grief, where society does not recognise the grief or loss, was reported in 31% of studies. The most common negative psychological impact was symptoms of depression; a large-scale review of the psychological and social impact of stillbirth estimated that 4.2 million women a year globally suffer from depression following a stillbirth (Heazell, Siassakos et al. 2016). So given the magnitude of its impact it isn't clear why stillbirth isn't given more global and political attention. Seven years ago, the *Lancet* concluded after a large international study in 2016 that most stillbirths are preventable with healthcare system improvements (de Bernis, Kinney et al. 2016), yet in the last couple of years stillbirth figures have risen, not declined.

One factor contributing both to the lack of visibility and progress on stillbirth as well as disenfranchised grief is that of stigma and taboo. Studies from around the world, including high-burden settings such as Sub-Saharan Africa and South Asia highlight the stigma surrounding the stillbirth (Heazell, Siassakos et al. 2016). For example, a survey of health professionals in Laos described that mothers found limited support or opportunities to openly express their grief, due to stigma (Choummanivong, Karimi et al. 2020). This is also present in high-income countries, a survey of 3,503 parents, 2,020 care providers and 1,113 community members from 32 high-income countries described that parents experience consistently differed from that anticipated by care providers or community members. For example, in response to the statement "*In the community I live/work, people/my colleagues generally think that a stillborn baby is the same as the death of a child.*" 69.8% of care providers reported this was the case, 63.3% of community members, but only 40.2% of parents. In response to the statement "*In the community I live/work, people/my colleagues generally think that parents should not talk about their stillborn baby because it makes people feel uncomfortable.*" Only 3.2% of care providers perceived this to be the case, but 42.7% of parents reported this was their experience (Flenady, Wojcieszek et al. 2016). Thus, we conclude that not only is stillbirth stigmatized, but professionals and community members may greatly underestimate the stigma and taboo experienced by bereaved parents.

Because stillbirth is taboo, there is no open discussion about the possibility of stillbirth as a possible outcome of pregnancy; this makes it a dangerous taboo as it keeps women uninformed about their own risk of stillbirth and creates an alienating environment for people who have experienced a stillbirth. They often have suddenly very few people to turn to, as it is common for even close family members and



friends to act unpredictably in the face of stillbirth. Instead of offering support people on the outside often chose the route of silence (Downe, Schmidt et al. 2013). They tell themselves it's so as to not upset the grieving parent(s), but most mothers are much more afraid of their child being forgotten than they are of they are of talking about their baby.

Although stillbirth is recognized to be stigmatized and a taboo, efforts to reduce stillbirth and improve care after a baby dies have consistently recognized that the status quo must be challenged; in fact "reducing stigma" is the first goal of the principles of perinatal bereavement care (International Stillbirth Alliance Stillbirth Advocacy Working Group 2023). However, there have been no studies that have been able to investigate the impact of challenging the stigma and taboo on stillbirth rates or on bereaved parents' mental health and wellbeing. Pollock et al. set out to develop and validate a scale to quantify the stigma experienced by bereaved parents (Pollock, Pearson et al. 2021). Their work commenced with a survey of over 800 bereaved parents from Australia, the United States of America, UK, New Zealand, Canada and Ireland (Pollock, Pearson et al. 2020). In this sample over a third, 38.3% (n = 313), directly reported feeling stigmatized following their stillbirth and almost all bereaved parents endorsed the feeling that silence surrounding stillbirth existed, (96.1%). Respondents revealed a sense that the bereaved mother must have done something "wrong" and there was a feeling that stillbirth was "contagious". There was also a perceived loss of status and a sense of being discriminated. A further study also found that stigma was related to the degree of negative psychological symptoms experienced by mothers. However, the original study also noted that bereaved parents were "agents of change" and could act in advocacy roles to challenging stigma and taboo.

For the first time, the Global Advocacy and Implementation Guide produced by the International Stillbirth Alliance in 2023 has recommended that to raise awareness of stillbirths individuals and organizations should "develop strong, culturally relevant messages to fight stigma and deliver messages through inspiring champions" to target politicians or influencers, media, affected parents and community leaders (International Stillbirth Alliance Stillbirth Advocacy Working Group 2023). Such an approach requires a multidisciplinary approach that is routed in collaboration between bereaved parents, those with communication skills (e.g. artists) and those with specialist knowledge to ensure that the messages disseminated are accessible, relevant and evidence-based.

THE ARTIST'S EXPERIENCE

In a desire to address the stigma and taboo surrounding stillbirth, I set about creating *Each Egg a World Online*, currently live at: <https://www.stillbornproject.org.uk/eacheggaworld/>. This online participatory



artwork is based on the *Each Egg a World* painting I made in 2017, which was exhibited at the International Federation of Placenta Associations meeting in Manchester as part of its community outreach programme. This black and white ink drawing contains 44,061 dots that together create patterns of human female egg cells inside the larger shape of a bird's egg. Each dot in the painting represents a stillbirth and all that entails. The painting tries to humanize large numbers by bringing back the personal stories behind each of these deaths. The online version of the artwork went live in June in 2020 and allows people to select and name one of the dots in the artwork after their stillborn baby. The mother or the father of the baby or both parents together can then write a short statement on their experience of stillbirth and related emotions. A named dot will turn red once the statement has been reviewed and has been added to the online artwork.

When hovering over a named dot (or by clicking on it when using a phone or tablet), the user can see the statement that the parent(s) of this baby left behind. People from all over the world have participated in this artwork. To see how many people from which different countries have participated, visitors to the artwork can select the countries button on the top left of the interface; this colours in the egg shape by the percentage of the eleven most submitting countries, these countries are listed in the matching colour that's used for colouring in the egg. Participants can also search for contributions per country by selecting the country of their choice underneath the 'Select by country' section and then clicking 'Show all' to see all statements from the chosen country in one image. Clicking on the right arrow button allows the user to see one statement at a time.

The artwork is an interdisciplinary collaboration between myself, obstetrician and stillbirth researcher Alexander Heazell and programmer Toby Harris. To reach out to people who could participate, we contacted 50 different stillbirth support charities and organisations worldwide, as well as 16 different UK stillbirth support organisations, including one with 75 different local email contacts. The *still* born project website (<https://www.stillbornproject.org.uk/>) was also promoted via social media and shared by many stillbirth support organisations. At the time of writing this article 260 submissions had been received from people in 16 different countries. Most submissions are from UK-based people as this is where we have most contacts, but we hope that over time we may get more involvement from other parts of the world too. Although low and middle-income countries account for the largest part of the world's stillbirths, many of these countries have fewer stillbirth charities and support organisations than high-income countries and there is often even greater taboo on the death of a baby. There are also potential language barriers in terms of participating in this artwork. However, the artwork is going to be live until at least May 2026 so it is hoped that uptake will widen and continue in the remaining years.



We believe art can help bring awareness of the impact a stillbirth can have on families. It can create a place to explore the complicated grief that comes with a stillbirth. The participatory online artwork *Each Egg a World Online* creates such a safe space for people to share their experience of stillbirth and make this visually available for society at large. In doing so it hopes to help break down the stigma and taboo that rests on stillbirth, that can stop people from demanding better. Helping to break the stillbirth taboo could thus pave the way for a more empowered approach in lowering the stillbirth figures internationally.

Having myself experienced a stillbirth in 2010, I knew that something ought to be done about breaking the taboo around stillbirth. I reached out to Alexander shortly after my stillbirth when I found out about his research and what was then called the 'placenta clinic' (a special NHS clinic for women who have previously experienced a stillbirth, to receive antenatal care in an understanding environment). I was hoping we could work together on an interdisciplinary art project, but it took seven years to get the first bit of funding. Our first funding bid was rejected '*because the subject matter might upset people*'. Ten years later, *Each Egg a World Online* was made with our second arts council grant when I was pregnant with my third baby and Alexander was one of the doctors supervising the pregnancy. People's statements from all over the world kept coming in throughout the pregnancy. At times this heightened my fear of another bad outcome, especially when I received statements from people who experienced multiple stillbirths, but I also knew that I was doing an important thing. Any pregnancy after a stillbirth is ridden with fear and leaves little space for the happy anticipation a mother can feel who has been unscarred by ante-natal death. Having a doctor onboard who truly understood my mistrust of empty reassurance and was willing to explain everything in the minutest detail, so I could understand why a particular course of action was recommended, helped me to feel that I was doing the right thing at each step of the way.

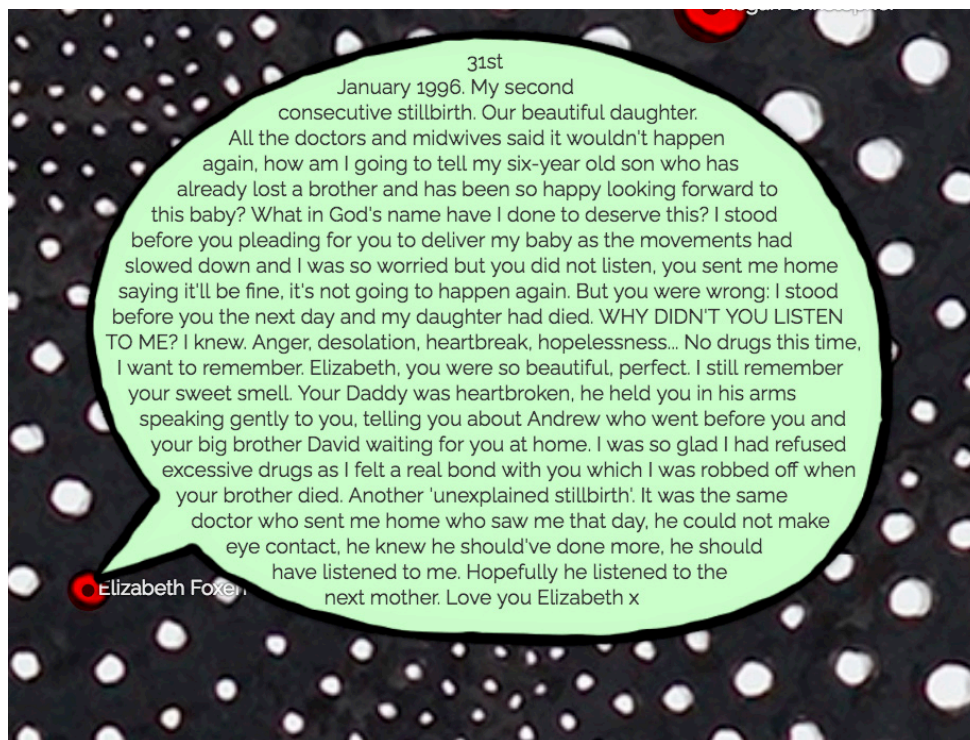


Figure 1, one example of a mother's statement on Each Egg a World Online (2020), available at: www.stillbornproject.org.uk/eacheggaworld/

The feedback we have received from participants to *Each Egg a World Online* has been very positive. Below some examples of feedback by participants to the artwork:

"Any way that we can share about stillbirth is worthwhile to get the conversation going to hopefully get more funding into research. I found this artwork comforting to hear other stories and I loved being able to share my baby boy's story in another way. Our greatest fear as bereaved parents is our baby being forgotten and this type of thing helps us to share about them and a piece of them will always exist through this."

"An artwork is another way in to the experience. Some people respond to words, pictures, etc. and this is another angle in the experience. So powerful, seeing and reading all the stories and babies. Thank you."

"To see others suffering eases your own in a way I will never understand."

"It is nice to feel part of a group and understand that we are not alone in this very bumpy journey."



"Fellow sufferers understand you better than anyone ever."

"Each comment, each like, each share gets bereaved parents talking. Our babies are all together on one perfect artwork."

"The number of babies remembered on this artwork gives a strong message that more must be done to prevent the tragedy of stillbirth for families."

"There are so many things people don't understand about baby loss unless they have been through it themselves and they are worried to ask in fear of upsetting the parents. I think most parents just want to talk about their baby, it recognizes their existence and that is invaluable. Just asking their name can mean the world but most people are too afraid to ask."

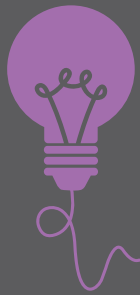
"It can be a lonely world after a stillbirth. I think this will help a lot of parents like us feel less alone. Knowing you're not alone helps and unfortunately we all know how it feels."

"Talking about my lost son helps me to let the world around me remember that I have three boys, not only the two who live with me. I will never forget, and sometimes I think people around me need a reminder of his existence as well."

"People are scared to talk about something which they have no experience of and something which is beyond comprehension for many. In order to get people talking, then a project such as this will go a long way to opening up a dialogue with people. I love to talk about our angel and we mention his name every day in our house so that my children know about their brother and so that our families and friends know that they too can mention his name."

As well as helping people who have experienced a stillbirth find a receptive audience for their words, the artwork has also been an eye opener to some people who have experienced the artwork as observers. Feedback on the artwork from those people includes the following statements:

"I was surprised at how common stillbirth is and reflected that it isn't seen or spoken about as part of many people's lives. It made me think about health inequalities and how women's health is more broadly still taboo."



"I once worked closely with three young women who were all expecting their first child at roughly the same time. Two gave birth to a healthy baby, a son and daughter respectively. The third suffered a stillbirth. It was very difficult to know what to say in the circumstances - the joy of two women and the devastation of the third. She left the company, moved away and eventually had a healthy child. Life moved on. The need to say anything seemed to have been overtaken by events. I think through this artwork and the testimonies of others I now understand what she was going through and have a better idea of what I could/should have said."

"It was very moving and made me realise the importance of breaking the taboo in order that people can share their experiences. I hope that Each Egg a World raises awareness and helps to bring support to those that have experienced this terrible loss."

"The artist should be proud to have provided a forum for such powerful human experiences, which still functions aesthetically. It will be intriguing to see the transformation in the work as statements accrue, with more and more detail at greater zoom levels. The art object here has true potential social impact."

"It's beautiful to read how much love people feel for their babies but so sad they had to lose them. It's also made me aware of how important it is to let people talk about their baby and to actively ask questions about them rather than ignore the issue."

We received most contributions in the first year of existence of the artwork when we were directly reaching out to stillbirth charities. This was also at the height of the Covid pandemic when the face-to-face meetings that stillbirth charities would usually support weren't possible and this online artwork offered an alternative way for parents to share in their loss. It must be said that without sustained marketing efforts, participation in the artwork has subsided in the last year(s). Breaking a taboo requires a mass shift in thinking, which can only occur if enough people are aware of the issues. Therefore, a renewed marketing push would be needed to make a bigger or continued difference with an artwork such as this, which is ultimately about reaching enough people. This remains challenging in the current climate where arts funding bodies still have little appetite for the subject of stillbirth and where there is no funding stream from government or medical science bodies to address the importance of breaking this particularly persistent taboo.

It's important to remember that this artwork is more than a community building exercise for people who have lost a baby. It is also a database that gives an insight, for anyone who wants to look at it, in some of the overriding sentiments that people stay behind with after a stillbirth. The first is an overwhelming



feeling of love that often finds little outlet, and the second is a desire to remember and honour this life that was lost without purpose. Can we call this a civilised world if the life of the unborn baby is not held as valid as the lives of those who have walked this planet for many years? Only a short while ago we all gave up a few years of freedom to protect the vulnerable elderly part of the population. What can we do now to help pregnant women and the desired lives they carry inside? Can we not at least promise them a world where preventable deaths are indeed prevented, also in the womb?*

THE HEALTH CARE PROFESSIONAL'S EXPERIENCE

One of the first studies I undertook was describing parent's experiences of stillbirth in the UK; since then further studies have been published which have continued to expand the evidence-base. Some common themes amongst studies include the unexpected nature of the death of a baby and isolation of parents from well-intentioned friends and family members. Ongoing efforts to improve the perinatal bereavement service within the maternity unit where I practice have focused on identifying parents' needs and determining whether these have been met. Responses from the survey identified that parents valued sensitive care during labour and birth and support to see and hold their baby; however, it is important that care provided is adapted to each woman and families' situations (Aiyelaagbe, Scott et al. 2017). To this end, it can be difficult for care professionals to train and gain sufficient experience in caring for bereaved parents. Parent's experiences are a key component of this, and I have worked with several different media to develop an archive of parents' stories (<http://stillbirthstories.org/>). Whilst access to these stories improved professionals understanding of some of the issues bereaved parents experience, professionals found it difficult to have sufficient time to access and reflect upon the content (Beck, Gibson et al. 2019).

I have always been interested in the possibility of using art to reach beyond the traditional boundaries of medicine. The opportunity to work with an artist with personal insight into perinatal bereavement provided me with a chance to see whether using this media can reduce the stigma associated with stillbirth. We have experienced the taboo surrounding stillbirth as several of our applications for funding were initially rejected due to the challenging nature of the topic. At times, this felt like a vicious circle, that we were unable to secure funding to produce art to reduce stigma and taboo due to the persistence of these issues affecting funding agencies. In contrast to the difficult journey to secure funding to support

* I don't mean to sound like a pro-life supporter here, as I do believe that it should be the woman's choice as to whether a pregnancy is supported or ended by termination.



the artwork, it has been encouraging that feedback directly from staff and patients who experienced the *Each Egg a World Online* artwork when it was exhibited in our clinical area, was predominantly positive.

In addition to *Each Egg a World Online*, our team at Tommy's led by Dr Michelle Desforges, has specifically used art to reach out to the Jewish community in Manchester, as part of a wider community outreach programme, to address issues around perinatal bereavement. Previously, healthcare professionals had found it difficult to address the topic of perinatal bereavement with this community due to uncertainty about religious and societal practices surrounding the death of a baby. The Still Life project ran from 2019 to 2020 (<https://sites.manchester.ac.uk/maternal-and-fetal-health/still-life-gallery/>) and involved presentations and discussions with the Jewish community. The challenge to stereotypes and confidence from discussing baby loss led to the development of new clinical guidelines to assist professionals. In this way, the creation of art facilitated discussion and created an environment in which parents and professionals could work together to address the stigma and taboo surrounding stillbirth.

As our collaboration with van 't Klooster continues, we are currently reaching out again to the people who participated in *Each Egg a World Online*, hoping they will participate in an online survey that asks them about their experience of stigma related to stillbirth. Using Danielle Pollock's Stillbirth Stigma Scale described above we hope to be able to demonstrate that participating in the artwork has helped people feel less stigmatised about stillbirth. We hope that moving forward this provides a basis for our and other art and media projects that aim to address stigma and taboo surrounding stillbirth and other forms of baby loss. It is anticipated that by addressing stigma and taboo we may ultimately have a positive effect upon parents' mental health after the death of a baby.

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