



# Submission to the Special Oireachtas Committee on the 8th Amendment

TFMR Ireland

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## OPENING STATEMENT

We would like to thank Senator Noone and all the members of this Oireachtas Committee for extending us the invitation to speak with you today. It is a privilege to be able to address you and we hope that our presentation and our contributions during the questions and answers sessions will help you to arrive at an informed position as you prepare to make your own recommendations to the government.

We would like to remind you all that behind all the circumstances we describe to you and the stories we refer to, there are real, bereaved families. We would like to thank all those who were prepared to share their experiences with us so that we might best represent them here today. We trust that this committee will show due respect for these families in all that is said here today, even if you do not agree with the decisions that some of these families made, or believe that had you been in their positions you would have made a different choice.

## WHO WE ARE

We in TFMR Ireland are all parents who have had pregnancies affected by severe or fatal foetal anomalies. Most of us received this news while still pregnant. Many had to leave our country to obtain the healthcare we needed. Others chose to remain and let our pregnancies come to their end naturally. This was not because we wanted it, but because we could not afford to travel or were not prepared to go through with the loss of our babies in a foreign country away from the love, care and support of our families. Others did not realise that their babies could not survive until after they were born, and they had to make the heart-breaking decision to withdraw life support and cradle their babies as they died.

We are involved in destigmatising terminations of pregnancy in these circumstances by telling our stories. Those of us who choose to do so publicly know that we will be condemned by some, but we also know that by sharing our stories we have helped to inform public discussion and we have, we hope, helped others who have travelled similar journeys realise that they are not alone, even if they have been unable to talk to others about their experience.

## TERMINOLOGY

During our presentation we refer to women, girls and pregnant people interchangeably. In all cases these are intended to represent all people who can and do become pregnant, irrespective of age, relationship or marital status, sexual orientation or gender identity, and irrespective of the circumstances under which they became pregnant.

We refer to Fatal Foetal Anomalies. These are anomalies or combinations of anomalies which unfortunately mean that babies will most likely die before birth, during delivery or shortly afterwards.

We also refer to Severe Foetal Anomalies. This is where survival is likely but the impact of the anomalies on quality of life are severe.

We fully understand that some parents when presented with a diagnosis of a severe or fatal foetal anomaly prefer to use the term “life limiting condition” and we support their use of this terminology for their own families. We would never presume to dictate to other families what words or phrases they should use to describe their own situations. However, “Fatal Foetal Anomaly” and “Severe Foetal Anomaly” are expressions regularly used by doctors in discussions with their patients. Many women and families prefer to use this language. We believe that the language preferred by the individual patient should be reflected by the doctor in communications with them. We further believe that the attempts by some to prohibit phrases like “Fatal Foetal Anomaly” and “Incompatible With Life” are entirely inappropriate.

## DIAGNOSIS & PROGNOSIS

Most of us received our initial diagnosis at our anomaly scan. This scan is not provided to all patients in our maternity hospitals and units, but where it is provided, usually takes place between 19 and 22 weeks. The anomalies are usually identified by ultrasonographers who then involve obstetricians and foetal health specialists. In some cases, further tests are undertaken such as amniocentesis and chorionic villus sampling (CVS). Sometimes, abnormalities may be detected in earlier scans, or following tests conducted as a result of requests being made by the parents, tests which they usually have to pay for themselves.

It can also happen that the woman has never received a scan or any tests, or that these indicated a positive outcome, but at a later stage in the pregnancy she became concerned by a weakening of her baby's movements over time, or that changes to her own health prompted further investigation.

These tests, performed by suitably qualified and experienced medical professionals, give us a very significant level of confidence in the diagnosis, however much we do not want to believe it. The doctors discuss the conditions with us, the average and longest survival rates and in the individual circumstances of our own pregnancies, the most likely outcome.

Where the prognosis is lethal, the expected outcomes vary between death occurring before the pregnancy reaches full-term and death during or shortly after delivery.

Where the prognosis is not necessarily fatal, but the nature of the anomalies are likely to have a very serious impact on our babies' quality of life, we may need to schedule even more tests with specialist cardiologists, paediatricians and neurologists, to name but a few. All of this can take several weeks. There may even need to be observations taken over a period of time to assess whether or not the initial prognosis is improving or deteriorating. It can therefore be well into the third trimester of the pregnancy before a clear understanding of the likely outcome is available.

Although this news can be very difficult to give to expectant parents, it would be negligent of medical professionals to be anything other than honest with the families, as to raise false hope would be an additional cruelty.

In every circumstance where parents chose to travel, more tests were undertaken by the overseas hospital.

The tests, the expertise of the medical professionals conducting them and their prognosis of likely outcomes form the context in which we make our decisions about whether or not to continue with the pregnancy.

## THE DECISION

Receiving the news that your much loved and wanted baby is either not going to live or that their quality of life will be severely impacted is a significant life event for anyone, and one which is completely devastating.

Because of the different interpretations of the Regulation of Information Act 1995 the amount of information, if any, women and couples receive is a complete lottery depending on your hospital and consultant. The option of terminating the pregnancy, if it is discussed at all, is often couched in euphemisms and 'code', like "some people choose to travel" or "all we can do for you in this jurisdiction..."

Usually, we are left to our own devices and there is a clear implication that choosing to terminate a pregnancy is a bad option because it is illegal here. The stigma associated with this is considerable and leaves people very unsure about who it is safe to discuss their situation with. Many of us told only our closest family and friends and some not even that. We did not know what medical staff or counselling agencies we could safely speak to. In some cases, doctors and counsellors have refused help to women who have reached out, or in subsequent pregnancies because of their own anti-choice ethos. However, the refusal was not explained as a conscientious objection – it was made by way of judgement and disapproval.

The decision either to continue with or to terminate a much-wanted pregnancy in these circumstances is complex and painful for all parents and one which requires all factual information available and plenty of personal space and time, and is never arrived at lightly or rashly.

It is important that we point out at this stage that it is completely impractical to apply a gestational limit in any of these cases. We must also point out that there was no discussion on severe foetal anomalies during the Citizen's Assembly process, and it would appear that this omission has led to a recommendation for a completely unworkable 22-week limit. Ironically, imposing such a limit is likely to lead to *more* parents deciding to terminate out of fear that they will miss out on the opportunity because of an arbitrary ill-conceived limit, and this would inevitably lead to increased levels of regret. This is why parents need the

private space and enough time to collect all available information and make a decision which is best for them and their baby, no matter what that decision is.

## TO TRAVEL

Where we choose to have a termination of pregnancy we typically have to identify hospitals or clinics ourselves, make our own appointments, obtain our own medical records and fax them to the overseas facilities. If we don't have access to a fax machine we need to find someone who has, forcing us to involve other people in what is essentially our own personal business. In any other medical circumstance which requires treatment overseas, our doctor would make recommendations, referrals and appointment bookings on our behalf.

We also have to make our own travel arrangements. Do we fly or get the boat and drive? How do we get from the airport or ferry port to the hospital? Who will travel with us? If we have children at home who will look after them? How do we get time off work? Do we have to share this medical information with our employers to get approved time off at short notice? Do we have passports or other identification required by the airline or ferry company? If we are travelling to mainland Europe can we cope with the language barriers? Do we have the right to travel? People in direct provision or in the care of the HSE for example may be denied that right.

Due to the unpredictable nature of labour and delivery, and of our own recovery requirements following these procedures, we cannot be certain when we will be able to come home.

There is also the very considerable expense involved, and this alone could be a barrier to accessing services for many. Justice Horner stated in December 2015 that forcing women to travel to avail of services in these circumstances "**can have the consequence of imposing an intolerable financial and mental burden on those least able to bear it.**" He went on to state that "**The protection of morals should not contemplate a restriction that bites on the impoverished but not the wealthy. That smacks of one law for the rich and one law for the poor**".

When we travel, we find ourselves in another country having left Ireland in secret, feeling like medical refugees. We feel abandoned by Ireland - the state and its people, isolated from our families and friends, and separated from our trusted medical teams who had looked after us up to this point.

## THE TERMINATION

When we undergo our terminations, we experience all the grief, loss and pain that would normally be associated with any other still birth or loss of a baby, but we go through this alone.

Our termination of pregnancy may be a medical or surgical procedure. Most mothers prefer to have a compassionate induction of labour but this is not always an option for them. Mothers may be limited by money, as medical terminations, particularly at later gestational ages, take longer and are therefore more expensive. They may be limited by time, in that they are not able to stay away from home, kids or from work long enough to have an induced labour and delivery.

Depending on the gestational stage of pregnancy parents can be advised to use a medical intervention to stop the foetal heartbeat. Usually from 23 weeks onwards this is advised by medical teams to ensure that neither the labour nor birth will result in added distress or pain to our babies. The decision to avail of this procedure is a very difficult one.

Considering all of the distress and pain that labour, delivery and a live birth could cause to their baby, some mothers feel that letting this happen naturally is not looking after the best interests of their baby. They take the responsibility for choosing an intervention that will allow their baby to pass in a gentle, peaceful, dignified, respectful yet still achingly sad manner which will alleviate that pain and suffering.

In some circumstances, where foetal demise during delivery is a certainty, this procedure may not be required or recommended. In others, the mother may choose not to avail of it in the hope that she will get to spend some time with her baby before he or she passes away, no matter how short that time may be.

## RETURNING HOME

Before we return home, we need to find out whether or not we can bring our baby home, and if we can, how?

We can bring our babies home in their white coffins by car on the ferry. Our babies' coffins must be concealed however. For those who want to introduce our baby to their grandparents or to their young brothers or sisters we face the additional stress of preserving our babies' remains. This involves having to buy freezer packs in supermarkets and making regular stops of the homeward journey to open the coffin and change packs, to keep the bodies cold. Our babies must cross the Irish Sea on their own, in our cars, on the ferry car decks.

Couples who want to bring their baby home for a funeral but who do not have access to a car have faced the prospect of having to carry their coffin on public transport. They board busses and trains, within hours of giving birth, and travel to the ferry to come home, as a foot passenger. Others, travelling by plane, have been advised to place the coffin in a suitcase or holdall. This means checking our baby as luggage and collecting them from a carousel in the Irish airport, or carrying them through security and onto the plane with us.

Others among us chose to have our babies remains cremated and these can be collected by us and brought home on the plane (having to explain our little packages at airport security) or we can have them delivered to us by international couriers. Couples have recently been quoted more than STG£900 for the courier alone.

Some others have chosen to bury their babies overseas and now need to travel just to visit their graves.

If we bring our babies home for a funeral and burial, there are more logistics to deal with. For many families the ability to have a funeral service at home following the loss of their baby is so important, particularly where they already have other children who were excited about the prospect of meeting a baby brother or sister. They simply cannot return home empty handed. The funeral rites are necessary to help bring closure not just to the parents but to their other children and extended family too. For a lot of parents, receiving a blessing

and having a religious service are important too. The acceptance of their Church is an important part in their spiritual recovery. However, many find themselves afraid to approach their priests. They do not want to lie but they are also afraid of rejection and condemnation. That said, we have heard many encouraging stories of priests and other religious leaders in communities offering the love, empathy and compassion that these parents needed.

If we do not bring our babies home, we have the void of having neither a baby nor a grave. We do not get to have a funeral, a public recognition of our son or daughter and our loss of them. We do not get the support of friends, family and our wider communities and this serves to further compound the sense of isolation and abandonment we felt following our diagnosis. It renders it almost impossible for us to grieve normally and can lead to higher levels of complicated and disenfranchised grief than would be expected if we were properly supported throughout this process.

## TO STAY

Many women and couples who receive these diagnoses choose to continue with their pregnancies. This is of course a perfectly valid choice, and these women, their babies and their families should be fully supported in that choice and throughout the remainder of their pregnancy and with all their diverse needs afterwards.

It is important to recognise however that there is another category of woman who all too often is ignored in these discussions, and this is the woman who wishes to terminate her pregnancy but for a variety of reasons cannot or does not wish to travel. These women are essentially forced by Ireland to remain pregnant with a severely compromised pregnancy against their will.

There are numerous reasons why a woman may find herself in this position. There is the woman who cannot afford to travel, or the woman who does not have the legal status to travel. We are all aware of the lack of freedom to travel imposed upon the asylum seeker, but there is also the woman or child who is in the care or custody of the state. There are women who are advised not to travel because of their own health conditions. There are women who may be in abusive or controlling relationships with partners or parents. There

are also women who simply cannot face the stress of travelling and returning home with neither bump nor baby. The emotional toll of travelling is another important consideration. Grief has many more facets to it than just sadness. Anxiety, exhaustion, panic attacks and deep distrust are all symptoms of complicated grief that make the experience of travelling through airports, foreign cities and to a strange hospital or clinic far more traumatic than it may appear to an outsider.

Some of these find it particularly difficult to explain this outcome to family, friends or community who they fear will not support them, will forever judge them and will make them the subject of ongoing gossip. All that these women want in these circumstances is to be able to deliver their babies in their own hospitals at a time of their choosing, with their own medical teams and to have their funerals and continue their grieving in the normal manner. When they attend their hospital appointments they are often required to attend the same clinics as other excited expectant mothers. They are essentially forced to continue their pregnancies, maintaining a facade for the benefit of others or locking themselves into the privacy of their homes where they feel more and more isolated and depressed.

All these women should have the right to choose their own care path here in Ireland. Those women who then choose to continue with their pregnancies, and their families, should be offered first class maternal mental health care and perinatal emotional support, no matter where in Ireland they live and irrespective of whether they are public or private patients. However, there are no laws preventing them from making these choices in Ireland. Our Constitution upholds their rights and our laws do not criminalise them. The only impediment to them receiving such support is the lack of resources provided by this State.

## MATERNAL HEALTH

As you are undoubtedly aware we are approaching the 5th anniversary of the avoidable death of Savita Halappanavar in Galway. You have already heard from eminent medical professionals who have made their views clear that had Savita been granted a termination of pregnancy when she requested it she would still be alive today.

There are those who recognise the risk of this happening again persists to this day. There are also those who believe that the 8<sup>th</sup> had nothing to do with Savita's death, but it did.

There are some too who claim that the 8<sup>th</sup> Amendment saves women's lives. It doesn't. The 8<sup>th</sup> does nothing to protect women lives or health, it's the 13<sup>th</sup> that does that. Women now are more aware of the risks to their own health that infection, or sepsis, can cause and they choose to exercise their right to travel for a termination of pregnancy before they get too sick to travel but not sick enough for medical intervention.

There is something particularly shameful about the fact that in Ireland, simply not dying is considered an acceptable benchmark for pregnant people, whereas in every other area of life the duty of care we are owed is so much higher, whether using our roads, working or shopping. Why is it that we seem to set this duty of care aside when a woman becomes pregnant? And why only for the duration of the pregnancy? Is she worth so little to us? Is her physical, emotional and mental wellbeing worth so little to us all?

We don't ask anyone else to trade their health away, and there is no reason for us to ask the same of pregnant women.

## CRUEL, INHUMAN AND DEGRADING

We have always maintained that the manner in which we have been treated by Ireland was barbaric. Our own country has fought strenuously over the years to defend the way it has treated and continues to treat us and so many other women on a daily basis.

It took the bravery and determination of two women, Amanda Mellett and Siobhan Whelan, to take complaints against this country to the United Nations Human Rights Committee. These two women selflessly waived their rights to anonymity so that they could shine a light on Ireland's shameful behaviour, in the hope that this would lead to other women in the future not being subjected to the same treatment.

The UNHRC found unanimously in both cases that Ireland had treated these women in a cruel, inhuman and degrading manner, in contravention of our requirements under the International Covenant on Civil and Political Rights. It further ruled that Ireland breached their rights to privacy and discriminated against them based on their gender.

We believe that there are who voted for the insertion of the Eighth Amendment in 1983 who did not envisage the reality of the pain and suffering that Constitutional provision has

caused, people who have seen what the impact of their votes has been on their own family members, neighbours and friends.

However, whatever about what we may or may not have known or envisaged 34 years ago, we now know what we know.

We trust that this committee, through its deliberations, will come to the conclusion that we as a nation and as a society must look after all of the women in Ireland, here in Ireland, whatever their medical needs. If, by design, we continue to rely on other nations to do this for us we can hardly continue to describe ourselves as “Independent”.

## OUR RECOMMENDATIONS

### CITIZEN’S ASSEMBLY RECOMMENDATIONS

It is our considered view that this Committee should recommend to Government that a referendum be held to Repeal Article 40.3.3, and that there should be no replacement clause. Our Constitution does not address other areas of healthcare and it should not be charged with addressing reproductive healthcare either.

### SEVERE FOETAL ANOMALIES

We call upon you to remove the 22-week term limit in respect of severe foetal anomalies. It is entirely inappropriate that gestational limits be applied in respect of either foetal or maternal health.

### DECRIMINALISATION

We further recommend that abortion be decriminalised. Healthcare can never be a black-market commodity, and nobody should ever be afraid to seek medical assistance for fear of criminal prosecution.

### CONSCIENTIOUS OBJECTION

In relation to conscientious objection, we feel that it is only those medical staff directly involved in the termination of pregnancy that have the right to object because of their

conscience. These objections need to be handled in line with current medical guidelines and can never amount to a denial of or frustration of access to service. Furthermore, medical facilities cannot have a conscience. We ask you to recommend that all maternity hospitals and units in Ireland be required to provide these services irrespective of ownership or religious ethos, and these facilities should also be required to employ sufficient numbers of staff who are not conscientious objectors, to prevent this clause being misused to deny access.

## SAFE ACCESS

We also feel it is necessary to include safe access zones around all medical facilities where terminations of pregnancy are performed, dispensed or discussed. While people have a right to protest, the right of patients, visitors and staff to privacy and security must be paramount. Protestors can still protest, but they can do so away from these facilities.

## CONCLUSION

We would again like to thank you for the invitation to make this presentation to you and we hope that it has shed some light on the practical and emotional impacts of the current constitutional, legislative and medical restrictions on ordinary families in Ireland. We wish you the best of luck as you continue with these hearings and when you decide on your own recommendations.

## PERSONAL STORIES

### NICOLA CAVANANGH, DONEGAL – CONTINUED PREGNANCY

**Nicola describes what could have been if Ireland was compassionate in cases of severe or fatal foetal anomaly. She then goes on to describe the reality of being forced to continue her pregnancy against her wishes and in spite of the fact that she wished to determine what was best for her and for baby Sam.**

It was the 1st of November 2009 when I heard the news that my much wanted second child had fatal foetal abnormalities and would not survive. I was 19 weeks pregnant and this was my first scan. I had been waking up crying for about a month before I was told the news by anyone medical. I just had a feeling that something was wrong. I was told that basically my baby was going to die. It might live and go full term and die after birth, or it could die tomorrow! The only certainty was that my baby was going to die.

I was calm when I received the news. I was calm and strong while myself and my two year old son waited for my husband to arrive at the hospital. He had to work that day so I had gone alone to the scan along with my little son. I was calm when my husband arrived and the sonographer came into the room to talk to us. She told us our baby was very very sick. I simply said "Ok so, what next? If my wee baby is so sick, when will I be induced?"

*That was the Tuesday and I was told that they would bring me in on the Thursday. I went home and cried. I grieved. I hugged my son Jack and my husband and we all grieved together. I organised for my mum and dad to come up on the Thursday to mind Jack while I went into hospital. I felt so much sadness but I also felt calm and ready as my little family had had the couple of days to prepare. When we arrived at the hospital the staff were fantastic and so considerate of myself and my husband's feelings. It was all very calm and respectful. My baby boy Sam was born at 2am on Friday the 10th of December 2009. He was beautiful and very like his big brother. We got to hold our son. It was the hardest thing I've ever had to do but I got home the next day and had loads of support from family, friends and the medical team from the hospital. It would take time but we could start to move forward again.*

Unfortunately, I would love if the above was true. However, I live in Ireland so let me tell you what really happened.

-00o-

"Ok so, what next? If my wee baby is so sick, when will I be induced?" The sonographer's response was, "I'm very sorry Nicola, we can't do that, not in Ireland."

"What? Then what will happen? When will my baby be born? I can't wait another 20 weeks knowing my baby is so sick. Oh my God, oh my God. You have to induce me. Why can't you?" To which I got the response, "That is classed as an abortion in Ireland, we can't perform an induction while your baby is alive, it can only be done after your baby has died." It was at this stage I stopped being calm. I lost control. I couldn't comprehend this.

After the doctors had confirmed my baby's diagnosis, they left the room. One of the female doctors gave me the name of a crisis pregnancy counsellor in town before she left. It was then left up to the sonographer to deal with me. I have to say she was amazing. She explained to me that some of her other parents in the same situation had travelled to the UK to avail of a termination. I couldn't believe what I was hearing. I couldn't fault her. She was so kind. She told me I could call up to her at any time for a scan to check on my baby.

The next morning, I travelled to Holles Street from Donegal. The consultant there just confirmed what I already knew. We asked what we should do. He told us that we would have to continue with the pregnancy unless we travelled overseas for a termination. He said that if I lived in the UK or Europe I would be offered a termination.

On the Thursday, I visited the crisis counsellor. She was very good and helped me ring around the UK hospitals to find out a bit more about travelling for the procedure. What we found out was that because I was 19 weeks pregnant the procedure would probably be around £1600. Factor into that the travel and accommodation costs and we were taking well over £2000. Also, if I didn't have the procedure before I was 21 weeks pregnant the cost would rise considerably again. I felt under such pressure to make a quick decision as I could barely afford the fee as it was. Let me now add that both myself and my husband were looking for work after moving home to Donegal. The recession was just beginning. My

husband was getting a few days with a friend but had nothing steady. We had spent our little bit of savings on our house. We could not afford this type of money.

This was the beginning of what was to be the most stressful few days of my life. Close friends were offering us money as a gift. Anyone who knew what we were going through wanted to help. I really wanted to travel so that we could start to get on with our lives again. However, the thought of leaving my two-year-old son behind nearly broke me. Also, the whole ordeal of travelling overseas and also putting my little family into debt nearly drove me insane. Couple that with feeling my little baby's movements every few hours and you can only start to imagine how I felt. I eventually felt I had no option but to stay in Ireland and wait for my little Sam to die.

And so began an agonising journey. I was functioning just for the sake of my husband and Jack. It was like a dream. I could feel Sam's little movements. They were more like a flutter than a kick. He was obviously very weak. I'd never had sleep problems before but now I used to wake up to the feeling of his slight movements and I would lie awake wondering was he suffering as much as his mum.

Once I let the sonographer know my decision, I agreed that I would visit her for a scan every Monday morning to see how Sam was getting on. My son Jack came with us to the scans. I remember one day arriving and the sonographer told me sympathetically that she could hardly see Sam today. She said he was all curled up and seemed very unwell today. Can you imagine how that feels? To think of your wee sick baby all curled up inside you? Wondering was he in pain? There were times after I heard this that I literally couldn't stand up with grief. I couldn't get that picture out of my head. I never will. I feel like curling up as I write this.

I stopped going out very much as I didn't want people to ask me how far gone I was and when I was due. Two of my best friends were pregnant with their first babies and were due within weeks of me. I still tried to be upbeat and happy for them. I knew when I spoke to them that their hearts were breaking for me. I felt like I was tainting their first pregnancy with my awful situation. On one of the few occasions that I went anywhere, my friends brought me for a spa treatment. The therapist asked me all upbeat about my pregnancy. I simply said "my baby is dying, please don't ask me about it". I'll always remember the poor girl's face.

I woke at 5am. I had broken out in a cold sweat. I felt sharp pains in my stomach. I knew he was gone. I waited for my next scan which was 3 days later. I spent the weekend coming to terms with the fact he was gone and at peace. I was 24 weeks pregnant. Before the sonographer turned on the ultrasound I told her he was gone. She confirmed it straight away.

Now let me tell you, I had not seen a doctor since they broke the news to me that Sam was dying. Once they had broken the news to me they had walked out of the room. Now the sonographer had to get a doctor to confirm that there was indeed no heartbeat. The doctor came and confirmed it. He then said, "We can take you in this evening to deliver your baby". What? Just like that? It was as if they had washed their hands of me until my baby had died. Now it was all hands on deck. What about the 5 weeks I was after going through? If it hadn't of been for the sonographer I would have had no contact with the hospital at all. I told the doctor, no, I would not be in that evening. I had a two-year-old and I had to make arrangements for his care.

I came into hospital on Thursday 9th December and Sam was indeed born at 2.40am on the 10th. He was beautiful. Myself and my husband held him. I felt very peaceful. I got out the next day. We had a wee service for Sam the following Thursday. I wasn't feeling well and ended up back in hospital that evening. In fact, I ended up spending two weeks in hospital after his birth. I had to have two D&Cs and two blood transfusions, due to an infection from part of the placenta being left behind. I got out for Christmas Day but ended up back in on St Stephen's Day. For the final week I was there I was in a ward in the gynaecological department. Every night several new women would be admitted to the ward with miscarriages, and I would have to lie there listening to them crying on their phones to family members or their mums. It was horrific. I didn't get a chance to grieve for my Sam. When I had to have my final blood transfusion two of the nurses had to hold me down to insert the needle, as I was so distraught. I got out on New Year's Eve. My husband had to take me to our local NowDoc who prescribed Valium. I was convinced I'd have to go back into hospital and was having panic attacks. My poor son didn't know what was happening to his mum.

And so I started on the road to recovery. What could have been such a short ordeal turned into a 4-month ordeal. We had to wait until March 2010 to receive the results of genetic testing that was carried out on Sam. We were told to hold off trying for another baby until we received these results as we needed to make sure Sam's condition wasn't passed on through us.

As I slowly started to recover, I started becoming more and more angry. Throughout my whole ordeal I had felt an overwhelming sense of abandonment. We were very much alone. Our friends and family were brilliant but I felt like we had been let down by our medical system and by the government. I am at peace now with my son's illness and his death.

However, I am not at peace with the fact that in our time of need this country turned its back on us. You can only imagine how I felt when it started coming to light that so many other women had gone through what I did. When I started hearing about the women who had travelled abroad and the ordeal they had to also go through, the anger and feeling of abandonment grew. I was only starting to recover from depression at the time and constant stories on the TV and radio made it impossible for me to move forward. Making the decision to travel, or making the decision to stay because you feel you have no choice, it doesn't matter. Either way you are alone and the country you call home abandons you during what can only be described as the hardest and most heart breaking time of your life.

SHAME on you Ireland!

Repeal the 8th amendment now.

## LAOISE'S MUM – SUBMISSION TO THE OIREACHTAS REGARDING SEVERE FOETAL ANOMALY

**Laoise's mother tells us how, out of love, she and her husband chose to give her daughter peace and dignity, rather than life and suffering, for their very much wanted daughter Laoise. Her story gives us a rare glimpse into the care paths available in France in cases of severe foetal anomaly. She also highlights the additional complications which arise when forced to travel for an unknown period of time to an unfamiliar country, away from family, friends and trusted medical professionals, with the added stresses of language barriers. She eloquently articulates why gestational limits are completely unworkable in cases of severe foetal anomaly, and indeed may even lead to higher incidence of termination of pregnancy because of the pressure of some arbitrary deadline.**

### INTRODUCTION:

Following the recommendations of the Citizen's Assembly in relation to provision of abortion in the case of severe foetal abnormalities, and following the recent Oireachtas Committee debates, I wish to communicate to the Oireachtas Committee my own personal experience of a late term abortion due to my baby being diagnosed with severe foetal abnormalities. I hope that by sharing my own experience the committee members may gain insight into these aspects of abortion, at least from my own family's perspective.<sup>1</sup>

### DECISION TO HAVE AN ABORTION:

My baby was very, very much wanted and my pregnancy was a very joyful and exciting time for my husband, my two children, and I. I had an anomaly scan at 22 weeks in which no anomalies were detected and I welcomed this reassurance. However, at a later 32 week scan serious anomalies were detected that ultimately led to a diagnosis of such severe abnormalities that my husband and I felt that it would have been cruel to allow our baby to live. We did not reach this conclusion because of any lack of strength to witness her suffering but rather because we felt she had a right not to suffer the possible life envisaged for her. My husband and I chose peace and dignity for our daughter, rather than life, as we felt this to be the kindest, most loving choice we could make in our circumstances. We

<sup>1</sup> I have previously written of my experience in the Irish Times, <https://www.irishtimes.com/life-and-style/people/severe-foetal-abnormality-her-short-life-was-a-burst-of-sunshine-1.2113963>, through participation in Amnesty International's *She is Not a Criminal* campaign <https://www.amnesty.org/en/documents/eur29/1597/2015/en/> and in a submission to the Citizens' Assembly.

made this choice despite desperately wanting to have brought her into this world alive, to have met her and to have continuously cared for her.

Another mother may have chosen to have given her a chance to live and may have believed that to be the kindest choice. Neither choice can be determined the right or wrong choice. All mothers should have the right to choose what they believe is best for their own baby.

I travelled to France (my husband being French) to access the care of a foetal diagnostic centre and team of excellence and renown<sup>2</sup>. We travelled with the awareness that this was co-located with a renowned paediatric hospital should my daughter have been born unexpectedly during the period in which her health was being assessed.

From the outset, the medical team in France set about providing the best foetal medicine care to our baby, and her wellbeing was undoubtedly their priority. I had ongoing consultations and multiple scans, MRI and x-ray which confirmed that our daughter had very severe and complex heart defects, a significant brain defect, multiple sensory deficits and other abnormalities. At 35 weeks gestation we let our daughter go. In France I was entrusted with this decision. French legislation facilitates a process whereby a termination may be authorised in certain circumstances following, firstly, comprehensive foetal assessment diagnosing severe foetal abnormality and, subsequently, an evaluation of the individual case by a multidisciplinary medical team. The mother is able to consider all of the medical information available to her in the context of her own circumstances. The mother is never influenced or directed to make a particular choice – either choice is facilitated by the legislation and the care structure of the health system.

#### **THE PROCEDURE OF INTERRUPTION OF PREGNANCY FOR MEDICAL REASONS:**

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The French term for the choice we made translates as an interruption of pregnancy for medical reasons. My daughter's death was gentle, peaceful, dignified, respectful and achingly sad. She died when a drug was injected into the umbilical cord causing her heart to cease beating. She felt no pain. After she was born the midwife cradled her in her arms and chatted warmly to her, as she would have to any newborn, before she placed her in my husband's arms.

#### **COMPLEXITIES OF SEVERE FOETAL ABNORMALITY DIAGNOSIS:**

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<sup>2</sup> In tandem with repealing the 8<sup>th</sup> amendment we must improve access to foetal diagnostics and to foetal medical care in Ireland.

The severity of a condition may sometimes only be determined on a case by case basis. There cannot be a list of severe conditions. My daughter's genetic defect resulted in multiple, very severe abnormalities, some of which are very rare, and much rarer than the occurrence of the genetic defect itself. The same genetic defect may have much less severe and less numerous manifestations in other cases.

The impact of a severe diagnosis and a family's ability to cope may also vary depending on other circumstances, including socio economic. In our case we were very mindful of the risk of neglect our other children could have faced if we devoted all our energies and time to the care of a very unwell child.

In France there are no time restrictions for an interruption of a pregnancy for medical reasons and indeed it is suggested that where gestational limits exist this may lead to an increased number of abortions. This is because when a severe abnormality is diagnosed it is not always possible to assess prognosis during the 1st or 2nd trimesters - assessment of prognosis may require observation of the foetus as it grows and its condition evolves.

#### **HOW THE 8<sup>TH</sup> AMENDMENT COMPOUNDED MY FAMILY'S HEARTACHE:**

Our heartache was compounded in many ways as a direct result of having to travel. If I had been able to access the same level of diagnostic care in Ireland and if I had been able to have an abortion in Ireland, I wouldn't have had to frantically arrange child care for my then 4 and 6 year old children while reeling from the shock and grief of learning of my baby's severe and possibly fatal abnormalities. I wouldn't have had to negotiate with officials to obtain an emergency replacement for an expired passport despite hardly being able to speak through my tears.

I wouldn't have had to pack my children's clothes and teddies and send them off for their first sleepover without us while desperately trying to stay clear headed and strong for them and our baby. I wouldn't have had to say goodbye to them without even being able to tell them when I would see them again. I wouldn't have had to reply to their anxious questioning on skype each evening and tell them on skype that baby was very sick and prepare them for the fact that she might die. I would have been able to hug them. They wouldn't have been as scared or worried. They would have later seen their stillborn baby sister and they could have held her. My son wouldn't have had the anger and regret that he felt because he didn't see his baby sister.

My husband and I wouldn't have had the irony and horror of staying in a beautiful city, sharing that space with happy tourists, while utterly heartbroken ourselves. We wouldn't have had to navigate a strange city alone to find an undertaker (listed on a spreadsheet) to manage our baby's funeral while I was still pregnant.

I wouldn't have been alone in a hotel room when I was in the early stages of my labour. I wouldn't have constantly struggled to communicate with hospital staff in a foreign language. We could have accessed anticipatory grief counselling. We could have been told simple things that may have comforted us in the long term – such as being told that it's ok to take photos of our stillborn baby.

We would not have been away from our children and family and friends for two and a half weeks.

My daughter's name could have been on the still birth register in Ireland, our home country, rather than in France.

My husband and I wouldn't have felt ashamed and stigmatised on our return home. This initial sense of shame contributed to my decision to forfeit most of my maternity leave and return to work before I was ready.

After our baby was born we couldn't bear the thought of our baby's body being alone in a mortuary for a prolonged length of time. Nor could we contemplate her body being carried in the hold of a plane back to Ireland. So we chose not to repatriate her body and we had her cremated in France. Now we feel emotionally compelled to travel to the city where we held her funeral as often as finances will allow – I feel that our daughter's remains are there and it is the place where she was shown compassion and care.

However, we were able to travel and we were therefore able to make choices for our baby. We are poignantly aware that there are others who may wish to have an abortion but who cannot travel due to income, disability, lack of travel documentation, or other reasons.

## **CONCLUSION:**

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We will never forget or stop loving our baby and we will always cherish the memory of when she was in my tummy and the intense happiness that she brought to our family at that time. We are comforted that our baby received expert foetal medical care in France and that we were allowed to let our baby die gently and with dignity and that she is at peace.

The additional grief caused to us by having to travel has now been replaced by a seething anger at the abhorrent injustice that this choice is only available to those of us who are able to travel.

## AOIFE, DUBLIN – TIMELINE OF A THREAT TO MATERNAL HEALTH

**When the Citizen's Assembly started its deliberations in 2016, Aoife was excitedly looking forward to the birth of her second baby. However, she soon found herself in a position to submit a first-hand account of her experience to the Assembly as things took a sharp turn for the worse for her. She wrote this heartbreakin account of her experience at 3am two days after ending her pregnancy in November 2016. How many near Savitas do we need? Aoife told me this week that when she made her decision, her main concern was her own mental health. However, she was shocked to hear Dr Rhona Mahony describing her exact circumstances to the Special Oireachtas Committee on 11 October 2017, and she sees that her life was at far more risk than she realised.**

I am not an activist, or at least I wasn't, but my life has been turned upside down over the last couple of weeks, and while I do not revel in the idea of my life being in the public eye, I also feel it needs to be known. And I guess I'm just pissed off. Pissed off at being in a country that makes me feel ashamed while making the hardest decision of my life.

Last Wednesday I travelled to Liverpool to terminate my 14 week pregnancy. This was not a baby I didn't want; he was very much wanted. I had already imagined him and Oscar being best buddies, and excited to see how they got on, and what Oscar made of this new little person.

But a couple of weeks ago, just as I had started to tell people, confident, almost at 12 weeks, that I was out of the danger zone, things took a turn for the worse. I got sick. I had a fever and was passing blood clots. After several times in and out to the maternity hospital, they admitted me. Four days after initial symptoms, I was told I had a bacterial infection - haemophilus influenza - in my blood. With this, most pregnant women suffer a miscarriage, but the fact that the baby was still there with a good strong heartbeat was promising - however I should be prepared for a very early delivery. Paul and I cried - it was a lot to take in.

Five days after being admitted to the hospital I was discharged on IV antibiotics and told to come back in for a scan three days later to check on the baby. My consultant met me at the scan, and pointed out the baby's heartbeat (relief!) and then asked had I had any gushes since being in the hospital. I said yes, but I'd been bleeding so much that I didn't think anything of it. The membrane around the baby had ruptured and I had lost the fluid

supporting the baby. My heart fell to the floor. I had been on such a high after seeing the heartbeat and had convinced myself since being discharged that I was going to be one of those lucky people that beat all the odds, and that this little boy and Oscar were going to be best of buds. The consultants face said it all. He was really great - I have to say that - he delivered the news, with compassion but was upfront and direct. Without the fluid around the baby, the lungs couldn't develop and wouldn't have the elasticity to expand and take in air. There was a considerable risk of infection to us both as the baby was now exposed. As the baby grew there would be more pressure on him and muscles wouldn't develop properly and there was the possibility of organ damage. Basically, the baby would not develop in the current environment. But the baby was still attached by cord so his heart was still beating away.

I was told that one of three things could happen:

1. The baby's heart would stop and they could induce labour.
2. I would get sick with a fever, or show some sign of infection, and they could intervene and carry out a termination.<sup>3</sup>
3. I could go to England.

I had been at a Repeal the 8th march a few weeks before, but never thought it'd affect me! Now here I was, with an awful decision to make having just been told that our son wasn't going to make it. Our baby was perfect, but everything around him wasn't; he needed support systems and my infection had corroded those. It wasn't fair! What did I do wrong? How did this happen?

I was admitted into hospital again, a week after the first time. A maternity hospital is a very hard place to be after news like that. And it was all very different. Same nurses, same ward, but more solemn. I was still on the antibiotics and then the next morning I went for a scan and the baby's heart was beating. I broke down. It's something you should never have to want - your baby's heart to stop beating, and yet, here I was... I didn't want to go to England... So what could I do but hope he'd pass away quickly. The next day, the same thing, down to the scan, and baby's heart still beating. Nope, I couldn't do this. I couldn't wait in a hospital for my baby to die. It could have been weeks. After a chat with the consultant on

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<sup>3</sup> *Aoife didn't fully understand at the time the parallels between her circumstances and those of Savita Halappanavar. She didn't realise that being sick was not enough – her life would need to be under threat before there could be an intervention.*

duty, we agreed I could go home. She advised us of an agency in England to contact if that was the decision we made.

And off we went. I made Paul ring the agency because I just couldn't. They were very kind, took our details and said someone would be in touch in 48 hours, and average waiting time was 2-3 weeks. I really didn't want to have to wait that long. I wasn't sleeping, I just wanted this to be over. I was physically and emotionally exhausted. I got an appointment for 9 days later.

I had two scans in those 9 days. I had more scheduled, but I cancelled them, I just couldn't do it. The second one was on the Monday before the England trip. I was really hoping not to have to travel. I talked everything through with my consultant, just to reaffirm to myself that there was no possibility for this baby. I didn't want make a selfish decision.

The trip to Liverpool was exhausting in every way. I kept wondering if people could tell if we were going over for a termination. On the plane I said to Paul, I hope the taxi driver is ok about it. I had visions of being yelled at and being told to get out of the taxi. After the procedure we went for something to eat as I hadn't eaten in almost 20 hours, and I kept wondering, was the waiter just surly or did he know where we came from by the plaster on my hand and disapprove. I worried the taxi man on the way back to the airport would figure it out and judge me. I wondered if the group of girls that were on our flight that had gone on a day shopping trip, recognised us from that morning and figured it out. I felt like I had just done something wrong. I wanted to shout from the roof tops, he wasn't going to live, you don't understand!!

I hate that my country has made me feel like a criminal for ending a pregnancy early that was not going to produce a baby that could survive outside the womb. If I had to wait until the baby's heart stopped my mental health would have suffered hugely. I couldn't have done it. I was already a mess.

Over the past few weeks, I have received the most amazing support. But I have also realised that people don't think of people in my situation when they consider whether or not to repeal the 8th amendment. I wish for the 8th amendment to be repealed so that abortion can be legislated in a way that considers the person carrying the child, and what they are going through.

I know that deciding to have an abortion was the hardest thing I've ever done in my life, and I haven't even started to process and grieve yet. But right now, I'm angry that I had to travel to a foreign country, away from my family, friends and home to get the treatment I should be able to get here. I'm angry that I'm made to feel shame at a time when I really don't need that added to the sadness I already feel.

## MAGGIE, MAYO - THE SOUND OF SILENCE – FATAL FOETAL ANOMALY

**Maggie's story highlights the fear of being judged, the insidious nature of secrecy, the uncertainty about who she could trust with the truth – all while she was navigating the most traumatic events of her life. Her story illustrates how the Irish system imposes up to three trips on devastated Irish families – one for the termination of pregnancy, one for the service and cremation and one to collect the baby's remains. Many of us return for remembrance services each year too.**

We can all live our lives in a bubble and be oblivious to issues that affect the people around us. It is not until you are faced with a real life trauma that will challenge your core beliefs, tear your world apart and turn it upside down that can change a much wanted future and a great love lost. For me this was the moment I heard that our precious bundle of joy would not survive, her condition was incompatible with life.

We were told in a Dublin hospital that our baby girl had Edwards Syndrome, a fatal foetal abnormality, which means that baby is incompatible with life and cannot survive outside of the womb and may not even survive to full term. An Amniocentesis would have to be done but with all the presenting problems our girl was very sick. Our consultant drew a picture of everything that was wrong with our little girl. He knew I could not comprehend what he was telling us. It is a picture that will remain vivid in my memory, etched there for a life time. A drawing that showed that all our baby girls organs were in the wrong place, all squashed into a space they should not be. She also presented with cysts on her brain. If she survived and the medical team could struggle to keep her alive with all manner of interventions she would have no standard of life and would remain on life support. This however would only be an option if she did make it to term.

We had our first scan at 9 weeks 6 days gestation in our regional hospital. We arrived very excited and with a little apprehension to see our baby for the first time. Apprehension because you can never be sure that everything is alright, apprehension because I was 41 years old. I knew at this appointment that something was not right. I knew this from the reaction of the sonographer. She halted, she stalled while doing the scan and she became awkward. She asked if I had considered having any genetic tests, because of my age she said they referred people to Dublin. I was apprehensive about this, I had said that I didn't want any invasive tests and if there were any disabilities we would deal with it. She said it was a more in-depth scan that they had better equipment. I agreed to this. There was a mix up in correspondence and they didn't book me in for a scan at this point. She wanted to see me in 2 weeks' time when I would be 12 weeks pregnant as this was a better time to do

scan. I had 2 more ultra sound scans in the regional hospital. At the last ultra sound scan at 17 weeks sonographer told me that everything looked normal. She took me down to the consultant. The consultant said he was told about the mix up with appointments and that he would see me after the appointment in Dublin. I asked him if it was necessary as the sonographer said everything was normal was it necessary to go but the appointment had been made so best to attend. I rang my partner; I rang my mother to relieve her fears as well.

I got an appointment for the big scan the following day. We were to go up the following Monday. The scan went on forever. She told us it was a girl as there were no dangle bits. We joked that baby girls' clothes were nicer than baby boys' clothes as I was convinced previous to this that I was having a boy. She went to get the consultant and then he dropped the bomb. He offered us an amniocentesis test which was to be sent to Scotland to confirm his diagnosis. We would have the results the following week. He wanted my phone number to ring with the results. I gave him my partners number as it was a phone call that I knew I could not take. We were taken to a private room for us to cry and pull ourselves together before they let us out on the street. I am rhesus negative so I was asked to come back in 4 hrs to be given an injection to stop my body rejection this pregnancy or any future pregnancies. It would only take a few minutes and I would be treated in a separate room to ease any discomfort of seeing healthy pregnant women. This was not the case, I returned only to have to sit in the waiting room with all pregnant women. How my partner kept me from running out I do not know. Every second felt like an hour, every minute an eternity. Adding insult to injury.

So what now? What do we do? I lost the ability to think, my mind went into overdrive, I was in a panic. We went back and booked into the hotel, to hide so no one could see our grief, so no one could see our tears. It would have been impossible for either of us to drive back home at this point. I had to hide my bump so no one could see I was pregnant for fear they would ask me how far along I was and how was it all going. I cannot describe the anguish we felt at this time. We were so heartbroken. I was so angry with our sonographer in the regional hospital as she said everything was normal, which led me to a false belief that everything was ok, setting me up for the biggest fall of my life.

I am lucky to be blessed with great friends. My friend organised an appointment in the family planning centre for me for the following day. She was an angel to weak for this world. I knew that I needed to let her go. Go to a place where she would be safe were she would not feel pain where she would be free. Somewhere over the rainbow.

That night I did not sleep, I cried all night, my heart was broken for everything i was going to lose. I was so afraid for the future and what it held for me and my family. My partner was great, he held me together somehow keeping himself together too. The following morning, I went to the family planning centre. We talked for 2 hrs, discussing all options, discussing feelings. We came to the conclusion that to travel was the best option for our baby and for us. I asked about supports to help us and was told none were available once we chose to travel. I was told about the honeysuckle team in England. They were to become our main supports and carers. I was also given information for the group Termination for Medical Reasons (TFMR) and Feileacain, a support for stillborn and babies born too soon. Both organisations became our support throughout the whole experience. Otherwise I don't know how I would have coped - lifesavers in a time of trauma. They offered practical support and information at a time when I was going crazy with grief, when our country could not provide anything to help.

We got the phone call from our consultant to confirm that our baby had Edwards Syndrome. He apologised for having to tell us this and that he has to do this all too often. He asked if we had thought about what we were going to do. My partner remained silent as again we did not know with our laws who could do what. He said that some parents in our situation choose to travel. My partner said yes it was an option we had discussed. On hearing that the consultant faxed over our file to his colleagues in the UK. We got an appointment for the hospital the following week. It was a week I imagine was like being in hell having to remain silent as to what was going on, to continue with work in a child care setting. To walk to a different room when the pain of what was happening became too much, when the grief became too much and the tears refused to stop.

During that week so much had to be organised - hospital appointments, flights, hotels - all the while in silence for fear people would find out the route we had chosen to take. We were full of fear of being judged by people who had not had to face this situation, silence so our nearest and dearest would not be affected by our decision, because it is impossible to understand what is going on if you have not faced a situation like this. It was a week I liken to living in hell because there are no other words to describe this time. It was a time of knowing that our daughter was struggling to survive, that she was never going to be in our arms, that I was never going to read her stories or run on the beach. It was a time during which we had to tell people that our daughter had health issues and that we had to go back to Dublin for another scan – a time during which we feared that we would be told that our daughter had passed away because she was so weak - a lie to protect others, only adding to the loneliness and the building of the silent wall.

Our flight was due to leave from Dublin on the Monday, and we were to check into the hospital at 9am that morning. So we did not sleep, nervous about what was ahead of us and having to travel the length of the country to get a flight. We were hoping people would not know us for fear they would ask us where we were going - fugitives going under the cover of darkness.

We were met in the hospital by a team of people who took over our care. They were colleagues of our own consultant who had handed us over to their care. The procedure was explained, the finance team came to discuss payment and the honeysuckle team came for a chat too - to support us and help us through this horrendously traumatic time. The labour was terrible, very painful and long. I was exhausted. I was filled with grief. I was in hell. I wanted it to stop. I wanted to hold our baby - I wanted her to be healthy. I longed for her to be safe in my arms. The nurses and doctors were brilliant, apologising for what we had to go through in a strange country away from our family and friends - always kind, with many hugs and words of encouragement - empathy that was lacking in our own country. I felt so let down by Ireland. So alone. So lost.

Our baby girl was born sleeping in April of this year. An angel who was now sitting with God. A chaplain came and blessed our angel and offered us his sympathy. We spoke about the cremation and our options. He made us feel at peace despite our anguish, despite the feeling of guilt that was laid on us by our country.

Leaving the hospital and leaving our baby there to be looked after by the honeysuckle team until her cremation was the hardest thing I have ever done. It put a scar on my heart that will not be mended. I had to leave the hospital only hours after giving birth, in excruciating pain, exhaustion and shock - we had to catch flights home. Adding to trauma of everything that I had already gone through, having to leave the country and leave her behind was an experience I would not wish on anyone.

We returned home. I was filled with grief. It knew no end, all the while silently protecting others from our grief. The loss of a baby does not only affect the parents involved, it affects your nearest and dearest; friends who would want to support you if only they knew how; grandparents that want to hold a funeral to acknowledge a life lost. We had to explain that this would not happen, as the baby's remains were being minded by another team of carers

in a different country. I went into lockdown, hiding from the world, from people, alone in grief. Broken and with no sign of an end to the pain.

We returned three weeks later to attend the cremation. It was a lovely service performed by the deacon who blessed our little lady. We were looked after by the undertakers, again showing so much empathy and saying how sorry they were that we had to go through this in a strange country, away from all support.

We returned again to collect her ashes from the Honeysuckle team. They were amazing people, an amazing team. They gave us a letter for us to show going through the airport in case we were stopped. They had all angles covered. The Honeysuckle team are still in contact - a support we still use.

The experience of having to travel to a foreign country, the exhaustion of all the travel, the whole traumatic experience was made harder by the isolation of doing it alone without our families and friends by our side. My doctor here in Mayo diagnosed me with post-traumatic stress disorder and prescribed medicine to help alleviate this. The start of my healing began when I attended a support meeting in Dublin held by Leanbh Mo Chroi. I met other families suffering and struggling through the grief. They are my new friends. They are here through the break downs/breakthroughs on the long road to recovery. They share the silent grief, a grief that, unless you have experienced the loss, you cannot understand or know the depth of feeling. People are great - they can offer empathy but because there is no funeral, there is no coffin to grieve over - it still remains a silent grief.

Our daughter's ashes sit in our kitchen. We still light candles and place flowers beside her. I still picture what she would look like now. I still grieve, I still cry and I still wish things could have been different. I do not regret the choices we made. I no longer feel the guilt laid on me by our country. I sincerely wish that our country would look at the unnecessary trauma that is caused to people when you have to travel for a service, a medical intervention that could be performed here. We need to untie the hands of the consultants who do not want to see their patients referred to their colleagues in England for continued care. Parents who are grieving should be surrounded by their family and friends that they could provide the care and support that is needed during the time when they grieve the loss of a much wanted and treasured pregnancy. I do not want to think of anyone having to go through this last year that we have had. Stop adding trauma to tragedy.

End the silence of Fatal Foetal Abnormality.

## HANNAH – CORK –ADDED TRAUMA OF REPATRIATION OF REMAINS

**Hannah sadly lost her first two babies to early miscarriage, and so was delighted when everything seemed to be progressing without incident in her third pregnancy. Discovering the seriousness of daughter Rose's condition was like peeling layers off an onion. Then the gut-wrenching decision to end the pregnancy necessitated huge expense and three separate trips to the UK. Please, members of the Special Oireachtas Committee, this cruelty needs to end.**

Our daughter passed away in Liverpool Women's Hospital on the 23rd July 2016.

We were married in March 2015 and decided to try for a baby after our honeymoon. We got pregnant and had a miscarriage at 6 weeks, we again got pregnant but miscarried this baby at 7 weeks.

We got pregnant a third time in February 2016 and were delighted when we got to 12 weeks without any problems.

We went for a scan with our consultant on the 19th May 2016. I was 13 weeks. She said everything looked good bar one thing, which she hoped would rectify itself in a couple of weeks- our baby's bladder was slightly enlarged. She said she'd send us for a second opinion at the CUMH and we got this scan on the 3rd June. Unfortunately, the bladder was still enlarged and had not rectified itself. This consultant organised an amniocentesis and we had this on the 10th June 2016.

We got the main results from this back a week later and the chromosomes were fine, but at this stage the bladder was even more enlarged.

We met our own consultant on the 21st June and there was only a tiny amount of amniotic fluid left around the baby and we were told there was only a 5 percent chance our baby would be born healthy. We now knew our baby's bladder was completely blocked and it was therefore only a matter of time before all the amniotic fluid surrounding our baby would be gone.

We returned a week later for another scan and this time there was no fluid left and we were told our baby would not survive as her lungs would not develop and her kidneys could not function. This opinion was confirmed by a 2nd specialist consultant in the CUMH. They were definite and certain that our baby if she survived the pregnancy, would not live for 5 minutes if she was born alive.

It took us another few weeks to decide what to do. This was an extremely difficult decision as this baby was very much wanted. We wanted to be looked after in the CUMH with our consultant who wanted to help us. Having to travel to the UK made us feel like criminals. We were going through an awful time - deciding to travel to the UK added severely to our heartache. Our own country would not help us in 2016! This is happening - ignoring it does not solve the problem.

We flew to Liverpool on the 21st July and had the procedure Friday morning, the 22nd July 2016. I delivered Rose on Sat. afternoon 23rd July 2016. She was 22 weeks. Prior to this procedure the consultant in Liverpool conducted a detailed scan and agreed with the two Irish consultants that our baby would not survive, if she even reached full term. We were told this consultant would not go through with anything unless he agreed with our consultants one hundred percent. We now had three professionals telling us exactly the same thing.

The hospital cost was €2,500 including Rose's funeral service and cremation.

I stayed in the hospital for one night. We booked and paid for the hotel in advance - 3 nights, this cost €320 (we were unsure of how long we'd be in Liverpool and booked 3 nights to be on the safe side as it was over a weekend in Liverpool and accommodation was scarce).

Our flights were dear as we flew from Cork. Our 3 flights cost a total of €950. Between 21st July and 28th Sept. we flew to Liverpool three times, for the procedure, for the cremation and the final time to collect Rose's ashes. (The courier costs to Ireland at £800stg were too expensive.)

For the cremation and collection of ashes we stayed in a hotel again for a night each time at a cost of €100.00 per night as the flight times from Cork are not frequent.

We are in the fortunate position of being able to afford this, but with a total cost well in excess of €4,000 (when other costs such as taxis, airport parking etc. are included), this might be beyond a lot of people.

No one bar our immediate family knew I was pregnant until after we had Rose, as I stayed in and hid my pregnancy for five and a half months.

This has been extremely hard for us as a couple but also for the family members we confided in. To not have our parents at our daughter's birth and funeral was awful and by having to travel to the UK for this procedure when it should be available in Ireland added to

the pressure and stress of it. Our parents should have been at their granddaughter's birth and funeral but were denied this and we were also denied having our daughter at home with us in a cuddle cot prior to her funeral.

We are still coming to terms with all that has happened but by having to travel has made it so much harder.

Having said that, we are very grateful to Liverpool Women's Hospital who were extremely caring and professional and treated us with respect for the entire time and who did not turn their back on us.

All we wanted was our baby girl but unfortunately she was too ill.

Thank you for taking the time to read this.

Hannah

## AMY WALSH – REVISING DECISIONS AS CIRCUMSTANCES CHANGE

**Amy was Voice 4 in the personal testimonies that were presented to The Citizen's Assembly. She wanted to give baby Rose every possible chance at life, but it gradually became evident that continuing the pregnancy posed a threat to Amy's mental and physical health with no corresponding benefit to either herself or Rose.**

My story is not unique or different. While the exact particulars of my story are distinct to my husband, my daughter and I, my story is in a sense universal to the people of Ireland. Thousands of women, couples and families share my story. Every day ten women travel from Ireland to England for medical care that they cannot access at home. Some women travel alone, others travel with their partner, husband, sister, friend, mother, father or brother. Others leave their children and loved ones behind traveling in secret. The circumstances in which each woman had to leave Ireland are unique to her. However, all these women were forced to leave their home, loved ones and their support network to receive the medical care that they needed because of the eight amendment.

My story begins on the 1<sup>st</sup> of September 2014 when I found out that I was expecting my first baby. My husband and I were over the moon. I could not believe that we were so lucky. When we had decided to start trying for a family I was very aware that not every couple is lucky enough to get pregnant easily. We however seemed to be one of the lucky couples that managed to start a family without any trouble. My early pregnancy was like any normal pregnancy; I was tired and nauseous but I was very excited. I bought all the pregnancy books and downloaded the apps which tracked my pregnancy and the development of my baby. I changed my diet to ensure I got all the recommended vitamins and minerals advised for pregnant women. I followed all the food safety guidelines as outlined and I had located my prenatal yoga classes which I could attend once my first trimester was over. I found it very difficult to keep the news of our pregnancy to myself and I had started telling friends and family members our good news.

My husband and I had spent a long time considering what the best maternity option for us would be. We were very aware of the cases and inquests into the deaths of the babies in Portlaoise Hospital and of Savita Halappanavar's death in Galway. We wanted to ensure as best we could that both our baby and I would be looked after. We decided to attend the National Maternity Hospital in Holles Street as a semi private patient. We chose this hospital for many reasons. My mother, my sister and I had worked in the hospital so we were

familiar with it and we knew a number of the staff who worked there. My mother had also attended this hospital as a patient when she was pregnant and my sister and I were born there. I felt safe in my choice of maternity care. This hospital looked after my mother and me before and it would look after my daughter and me this time.

During a scan when I was twelve weeks pregnant I learned that my baby was not well. The midwife was concerned that our baby was inactive and measuring small for its gestational dates. I also received some blood results that re-enforced the concerns that the midwife had. Two weeks later during another scan I was given the heart breaking news that I was going to lose my baby. The midwife told me that my baby had stopped growing and that her lungs and heart were so small comparatively to the rest of her body that she could never be born alive. I was told that I would most likely have an imminent miscarriage. Over the weeks that followed, I attended the hospital for weekly scans to check if my baby was developing and if her heart was still beating (as I had not miscarried yet) I also underwent a series of medical tests to determine what exactly was wrong with my baby. When I was eighteen weeks pregnant we received the results of the medical tests. My worst nightmare was confirmed. My baby had a Fatal Foetal Anomaly called Triploidy. The variant and severity of the specific form of Triploidy that she had meant that she had sixty-nine chromosomes instead of forty-six and would never be born alive. A team of medical experts made up of consultant obstetricians, specialist non consultant doctors in training and expert diagnostic midwives were charged with our care, they all unanimously agreed that our baby's condition was fatal and that she would pass away in my womb at some point during my pregnancy. Not wanting to believe the news that we had been given we sent over all our medical information including every scan and test result to the Foetal Medicine unit in Liverpool's Women's Hospital for a second opinion and they confirmed the diagnosis that the Irish hospital had given us. Through a family connection a professor of Foetal Medicine in Melbourne also confirmed that our baby could never be born alive.

When we were given the diagnosis we were told that, due to Irish law, the only care option available to us was to continue with our pregnancy if we wanted to have our baby at home in Ireland, at the hospital that we were attending. At our request we were also given contact information of two hospitals in England, one in London and one in Liverpool that we could attend if we wished to terminate our pregnancy. I was distraught. I wanted to be a mother, I wanted to have my daughter (the test results told us that we were also expecting a baby girl) at home. I had been hoping that all the doctors and midwives were wrong and the test results would give us some sliver of hope, but the results of our tests confirmed that she was never going to live. Due to the prolonged nature of our situation, it had taken six weeks for us to get our test results after initially learning that our baby was very ill and then being told that she was going to pass away. In our weekly scans I could see that she remained

static, unchanging. Her heart was beating, but she was not growing. She was not moving. I understood that we would never be bringing our daughter home alive.

While the grief of learning that you are going to lose your loved and wanted baby is overwhelming, the situation that I found myself in because of the eighth amendment made my grief and trauma much worse. I did not want to travel to England to some unknown hospital where I had never been before. I had so many questions, and no one could answer them. The regulation of information act meant that the medical team in Ireland could not speak freely or openly with me about travelling to England. The only health care treatment that they could advise was for me to 'let it happen naturally' and to stay with them and have my daughter at home. I did not know, if they actually thought this was the best option for me or if it was the only option that they were legally permitted to advise. I tried to discuss my pregnancy and options with one of the midwives in the Liverpool Women's Hospital over the phone, but I was so upset she could not hear me through the sound of my crying. If I went to England how would I know if the hospital would look after me and my baby? I did not know anything about these unfamiliar hospitals whose numbers I had been given on a piece of paper. I did not know anyone who had been a patient at one of these hospitals. I did not know what their care standards and practices were like. Would I be safe? Would they look after me like my Irish hospital? How would we get there? Where would we stay? Would I go into labour? What would happen after I had my baby? Could I bring my baby home? How long would it take? I did not know if my family and friends would accept my decision if I decided to end my pregnancy and travel to England. I did not know what I would say to people. At that point in my pregnancy, I could not face the added stress and stigma that I felt I would undergo if I travelled to England to end my pregnancy so I opted to continue with my pregnancy and to wait for my baby to pass away naturally at some point during my pregnancy.

In the weeks that passed I returned to the hospital every Friday for a scan and I watched my baby get sicker and sicker. Fluid started to collect on her brain and she developed a blockage in her colon. All of these were signs of her very slow demise. I was beyond heart broken. I was distraught. I was pregnant with my longed for and wanted baby, yet I was never going to get to meet her. I could not work; I could not sleep. I could not get out of bed. I cried all day, every day. I was on sick leave from work and I was not coping with the situation that I had found myself in. I was isolated and I had nowhere to go. I was afraid to leave the house because I did not know what I would say if I met someone and they asked me about my baby or my pregnancy (I was noticeably pregnant). There was also nowhere for me to go as there was no support system in place for women with pregnancies like mine. I could not go to any ante natal education classes as they are all for women with healthy

pregnancies and I could not go to any ante natal exercise classes because again they all catered for women with healthy pregnancies.

As my pregnancy progressed past twenty-four weeks I was told that I was no longer going to have what is medically classified as a miscarriage, that I would have a still birth. They explained to me that when my baby's heart stopped beating that the hospital would induce me, I would go into labour and deliver my baby. I did not know how to prepare for this mentally or physically. I was pregnant and I was going to give birth to a dead baby. The pain I felt is indescribable. I felt like I was being tortured having to return to the hospital every week, seeing other pregnant women and families leaving with healthy babies knowing that my baby would be leaving the hospital in a coffin. As my baby was so small I could not ascertain with a hundred percent certainty if she had moved or was moving inside me and because of this I never knew if she was alive or if she had passed away until I had my scan and was shown her heart beat on the sonographer's monitor.

It was around this time that my blood pressure also started to rise and I began to show signs of early preeclampsia. I was told that I would more than likely develop preeclampsia if my pregnancy continued into the third trimester. It had been over ten weeks since I learned my daughter would not live and now it appeared that continuing with my pregnancy would also pose a serious risk to my health and also affect my ability to have a healthy pregnancy in the future. I could not understand how I could be left in this situation with an unviable pregnancy that could potentially pose such a huge risk to my health. It was as if my daughter's life was pit against mine. In treating her life as equal to mine, my physical and mental well-being was put in danger. We could not protect her life as she could not live but we needed to protect my life and that started with protecting my physical and mental health. That is when we made the decision to travel to Liverpool.

Leaving Ireland to deliver my baby was the hardest, saddest decision that I have ever made and hope that I will never have to make again. In making the decision to travel we were not only looking after me but we believe that we were also looking after our daughter. The medical team in Liverpool Women's Hospital had explained to me that if we remained pregnant and my daughter's heart was still beating when I went into labour that it would be the stress of the labour that would cause her heart to stop beating. They explained how in their medical opinion that they did not think it would be fair to put our baby through a natural labour when they knew that she could not survive it. They believed that it would be kinder to my daughter to put her to sleep with an injection into my umbilical cord, insuring that she did not feel any pain and then to induce my labour. In following their advice, I

believe that I was looking after my daughter as best I could; making sure that she felt no pain when she passed. My daughter Rose was still born in Liverpool when I was twenty-seven weeks and four days pregnant. Liverpool looked after both of us when Ireland would not. While no medical team could give me what I wished and save my daughter, the team in Liverpool made sure my daughter felt no pain and gave me the medical care that I needed to survive.

While our story was never going to have a happy ending we could have been spared the extra trauma of either having to remain pregnant with an unviable pregnancy or been forced to leave our home and our support network and travel to another country at a time when we were most in need. Ireland let me down and my daughter down. The 8<sup>th</sup> amendment compounded the grief and trauma that we were already experiencing. It is my opinion that the eight amendment needs to be repealed and Ireland needs to look after its pregnant women and their families instead of sending them away.

## JESSICA'S BIRTH STORY – SHE COULD NEVER TAKE A BREATH

**Jennifer tells of having to choose between leaving her precious daughter in another country for a post-mortem or taking her home for a funeral, surrounded by family and friends. She touchingly describes how she swapped blankets at the last moment so that she could keep the blanket Jessica was wrapped in, and Jessica could take the blanket that Jennifer and her husband slept with.**

We found out we were expecting our second child in June 2012. My husband and I were thrilled. We booked an early scan for later that week. They said I was seven weeks pregnant. We were delighted when we found out our baby was due on our anniversary, it felt that it was meant to be.

I had some nausea and tiredness with the pregnancy, but otherwise I felt good. I had a couple of medical check-ups and all was looking well. I wasn't really showing but wasn't concerned as I had been the same during my first pregnancy.

That October, my husband and I went to hospital for our anomaly scan. I was 22 weeks pregnant. We had decided to ask the sex as we had already put a deposit on a pram and I was very eager to get shopping! We were so excited to see our baby on the screen.

At the appointment, the sonographer was finding it hard to get a good view of the baby. After a few moments she went quiet. She continued scanning for a while and eventually said that she needed to speak to a doctor. At this point I had a feeling that all wasn't as it should be, but I certainly was not expecting what was to come.

We saw the doctor next, who asked us to go for a cup of tea and come back to see the doctor in half an hour. After what seemed like a lifetime the doctor called us in. She scanned me for over half an hour in silence. The first words she said were "It's bad news, guys". She explained that there was no fluid surrounding our baby so it was very hard to see exactly what was wrong, but from what she could see, it didn't look good. Our baby had no fluid because she had no kidneys, our baby's lungs would never develop or function. They would not be able to intubate or give steroids to help her lungs as there was "no point" She also had a very severe form of spina bifida – so severe that even if everything else was working correctly it would still kill her. Our baby was sadly incompatible with life.

The consultant told us that we had two options: we could continue with the pregnancy and receive weekly scans to check for a heartbeat until it stopped, or we could travel to England

for a termination. Even though our baby had no chance of surviving, I could not ask for a termination of pregnancy at the hospital where I'd been getting checks and scans. We live in Ireland, where abortion is illegal – even in cases like ours.

My husband and I were told to come back the next morning for further tests. We drove home completely heartbroken, afraid and upset. Our world as we knew it had ended and we were in complete limbo.

The following day we went back to the hospital with my mother for support. I was rescanned by the consultant and a foetal medicine midwife. Again they told us the prognosis was the same: our baby was never going to survive – her condition was 100% fatal.

That evening we told our six-year-old daughter the bad news. It was so heart-breaking to have to tell her that her much longed-for sibling would die. She asked a lot of questions and we answered them as honestly as possible, in a child-friendly way. We had been given an information sheet on how to tell children news like this. That night we all slept in the same bed as none of us wanted to be without each other.

We chose a name for our baby and looked into local graveyards. We should have been looking at cots and buggies but instead we were looking at graveyards.

Over the weekend we discussed our options. Due to the severity of our baby's condition she was not protected in my womb and was slowly being crushed by my organs, which was a very distressing thought for me and would be very distressing experience for our baby. If our baby survived the remainder of the pregnancy she would either die in distress during labour or in the moments after she was born. She would never take a breath and there would be a pain specialist on standby to administer medication as soon as she was born. We had to terminate this pregnancy – for her and for me.

After a difficult weekend, we went to meet the consultant. She rescanned me and asked me if we had made any decisions. We told her we had decided to travel to England. As I was already 23 weeks pregnant and the cut off for medical terminations in England is 24 weeks we didn't have much time.

We were given the phone number for Liverpool's women's hospital and told to send them the scans, results and reports from our hospital. I arranged an appointment for the following Monday, by which time I would be 24 weeks pregnant. We spoke with the bereavement service in the hospital there who organised a coffin and said she would

arrange the forms needed for us to bring our daughter home.

We went out and bought our daughter a blanket to wrap her in. We also bought matching teddies – 12 in total, all little animals, so she would have six and we would keep the other six. We thought this was the fairest way because we knew we wouldn't be able to share just one teddy between the three of us!

It was less than a fortnight since my 22-week scan. So much had changed.

We tried to get a couple of hours' sleep before heading to get the 2.30am ferry to Holyhead. My husband drove from Holyhead to Liverpool through the night to the hospital.

At the hospital, a consultant rescanned me. We asked if there was any change or improvement – we were still wishing and hoping with all our hearts that something would change, but the consultant sadly said that there was no change, the condition was worse than the previous scans revealed and we were doing what was best for our daughter.

They were unsure whether she would have a cleft lip or if her spine would be covered by skin due to the lack of fluid which made scanning very difficult and we spoke briefly about that and other possible abnormalities that might be present and what she may look like. They brought us in forms to sign and tablets to soften my uterus and cervix to get it ready for induction. They asked us did we want to have a post mortem done but because we would have to leave her in Liverpool for a week we chose not to, we already knew enough about her condition to know that it wasn't genetic and it was "just one of those things". We felt she had been through enough already and we didn't want to receive a list of things wrong with our daughter.

It was early evening when they brought me in to be induced. It only took a couple of minutes before I was taken up to the labour ward.

Around midnight on Monday my labour started. At 9.08am on Tuesday morning my beautiful daughter Jessica was born. The room was silent. She was 28cm long and weighed 1lb 6oz. She was perfect to us. She didn't have a cleft lip but her spine wasn't fully covered by skin and we could see evidence of her abnormalities in her legs. We asked the nurses to dress her for us as she looked so delicate. They took her away and took hand and

foot prints and lovely photos for us and brought her back dressed in a beautiful hat and gown that had been donated by a charity.

I was very unwell from all the medications I had taken during labour. After an hour or so the catholic priest came in for a blessing and naming ceremony. They gave us a lovely blessing certificate with her name and time and date of arrival to keep. These are the only things we have our daughter's name on.

At 7pm that day I was discharged. We brought our daughter out in her coffin the hospital had organised for us and we headed off for the boat in Holyhead. We had contacted the ferry company before travelling and they had no problems with us bringing our daughter on board but we just couldn't have her coffin in sight in the car. We arrived home at 2.30am – just 48 hours after we had left for that ferry in the middle of the night.

The following day our six-year-old came home from school to meet her sister. Both sets of parents, brothers, sisters, nieces and nephews came to see her. We had another blessing with a local priest in our home and the following day we held her funeral and buried her in the local graveyard.

The priest did an amazing job and had even gone to the trouble of printing out booklets for the blessing and funeral for us. We consider ourselves lucky that we could do this as not everyone who travels has this opportunity to do this.

On the morning of the funeral we swapped blankets with her so we have the one she had been wrapped up in and we gave her the blanket we had been sleeping with. We placed six of the teddies with her and wrapped her in my husband's christening cardigan. Our daughter, nieces and nephews drew her pictures and wrote letters to her which we also put in. I gave her a piece of jewellery which I had since childhood and we said our final goodbyes.

We had three days with our daughter and it was nowhere near enough but it was the best we could have had and we are so grateful that we had that time together with her. We did what we believe was right for our daughter – she didn't suffer any pain or distress and just drifted off to sleep. We have a photo album full of photos of her with us, her blanket,

matching teddies and little mementos from the hospital. Her whole lifetime fits into a box but it is something we cherish and will forever.

We talk about Jessica daily; she is included into everything we do. She is the missing piece in our family which will never be replaced and she is forever in our hearts.

## SARAH - THE STORY OF THE 8<sup>TH</sup> AMENDMENT & ME

**Imagine being in a UK hospital, sedated and prepared for theatre. Imagine the pandemonium which breaks out when your consultant in your home hospital denies knowing that you are even there. Imagine being told that you will not be admitted to your hospital on your return with a dead baby inside you, because 'if the staff know what you did they can refuse to treat you on moral grounds.' Imagine the terror of being a woman in Ireland after Savita's death, and having pregnancy related sepsis. Article 40.3.3 of the Irish Constitution subjects countless women to cruel, inhuman and degrading treatment.**

I am a loving mother to two beautiful daughters and privileged to be in a relationship with a wonderful man who would do anything for me. When I found out I was pregnant in January 2015 we were over the moon. Another affectionately nicknamed little 'Bean' was going to become part of our family. Having been pregnant before I was aware of the 12 week 'wait' period before telling family and friends our good news but we couldn't contain ourselves. Everything had been plain sailing previously, how would this time be any different. We began to look to the future; what equipment we would need now with an infant and a toddler. There was a mother and baby event in MotherCare - we must go and have a look.

On the 10<sup>th</sup> March 2015 my booking scan was going to introduce us to our precious baby and we gushed with love and anticipation at getting our first glimpse of him. When the sonographer could not get a clear view we did not take any notice. When she shuffled in her chair and explained she would have to do a more invasive scan due to a poor view, we did not detect the change in her once jovial demeanour. Even when she excused herself to ask a more experienced sonographer to join us, we did not realise those were the last moments of naïve bliss. The more 'experienced' sonographer knew she was looking at a severe case of chromosomal abnormality in our baby and swiftly delivered the news that our baby was presenting with numerous anomalies consistent with a trisomy abnormality. She had been in this position before; muttered the same devastating words to other couples. The local sonographer had not, the pain on her face was so visible I felt sorry for her. Crying, disbelief, futile questions: it was clear that the outlook for my baby was bleak and my visions of my family's future were being dashed in front of my eyes.

I was referred to a Dublin hospital which was equipped in dealing with such cases. I realise now my rural, regional hospital was not. I would have to travel hours to get answers as to what the future held for my baby. That appointment was as swift as the Irish system could deliver, 12 days. 12 torturous days of internet searches for information on 'what is a

trisomy', 'statistics on children born with a trisomy', 'options for treatment during a chromosomal anomaly pregnancy'. Many of those searches came back with no answers. I do feel the unknown is a form of hell. The Dublin hospital were clinical in their approach and confirmed what was suspected. I was counselled as to my options which were continue with the pregnancy, which was not spoken of as a realistic option, or travel to the UK for a termination at the earliest possible convenience. The magnitude of the lack of options still had not sunk in and I was privately hoping that all the medical staff were wrong. Being given the details to book the procedure myself and the number to speak to the ward directly was wasted on me at that moment. 'I don't need them, they are wrong'. I did not comprehend that as a vulnerable and traumatised couple, it was our responsibility to arrange all the particulars with no help from the Irish establishment. That day was the first day that I as a female citizen of Ireland was made aware of the abortion laws in Ireland and how deeply rooted they are in our health system.

The specific tests carried out at our Dublin appointment had to be sent to Scotland as the facilities to diagnose chromosomal conditions are not available in Ireland. Another two weeks of the unknown; back in the depths of hell. I became cut off from my partner, my family and reality ceased. It was too painful to live in the moment. Another reality of the situation came to light during this time; with the heart-breaking diagnosis in my regional hospital, they failed to complete my booking for pregnancy services. Therefore I was not deemed a pregnant woman who was to receive any antenatal care. Why would I as I had been told of the impending outcome and how to 'deal with it'? I had been given the information to book the procedure that needed to be carried out. Though lost on me through my sobbing over my troubled pregnancy, the sonographers words 'don't worry you can go on to have normal pregnancies after this' meant in their eyes I was not going to be returning there during this pregnancy. Fear engulfed me as I realised I was on my own. No hospital appointments, no follow up checks, no nothing. The Irish medical system had essentially thrown me and my baby out on the street.

Thankfully my consultant from my previous pregnancy arranged to see me out of hours on an abandoned ward where I had a scan to see if my baby was still alive. That day the results arrived from Scotland and the consultant discussed the implications of the diagnosis; my precious baby boy had a severe case of Trisomy 18. The implications were probable risk to maternal health, the two risk factors being haemorrhage and sepsis. It was at this moment that my partner and I realised the enormity of the situation. I could die if I continue with this pregnancy. I asked for clarification over and over as to what was the probable outcome of carrying my son to full term, hoping the consultant would say something different just once. However the same words echoed in the empty, dark room: in the extremely unlikely event my son was to survive to full term, if he was to survive labour which was even more unlikely,

then it would be morphine based palliative care and assisted feeding. The problem with that was he had non-functioning intestines so he would starve to death. An animal would never be allowed to reach that level of suffering. Of course this was all dependent on if I survived the ordeal. I would leave my girls without a mother and my partner to raise them as a single father. It was too risky to adopt the mentality of the Irish healthcare system of a ‘wait and see’ approach. Action had to be swift.

We decided to travel to the UK for the first part of the procedure where they would oversee the cessation of the heartbeat and I could travel home to deliver my son in familiar surroundings, comforted by my loved ones. I was warned that the hospital staff could not be aware of this as they may refuse to treat me on moral grounds so in the best interest of the situation I should pretend to have had a late miscarriage. Again I was reminded of the ‘catholic ethos’ within our 21<sup>st</sup> century, 1<sup>st</sup> world, culturally diverse healthcare system, however, nothing shocked me anymore.

In May 2015, at 21 weeks pregnant and 9 weeks since our world was turned upside down at that first appointment, we travelled to England. All was arranged for me to travel back after the procedure, but something went very wrong. Having been already sedated and prepared for theatre, we were informed that my consultant in my regional hospital firstly denied having knowledge of me being in the UK, secondly that I would not be treated in my hospital upon my return. My partner argued with the UK hospital staff, I cried inconsolably whilst trying to speak in a slurred stupor, the UK consultant cursed Irish Laws; it was sheer pandemonium. We spent an hour ringing every number we had to talk to an Irish gynaecologist but oddly nobody was available. The chokehold of fear that is the 8<sup>th</sup> Amendment overshadows the 13<sup>th</sup> amendment which allows doctors to treat a woman after she returns from her right to travel. Another reminder of good old Catholic Ireland. We returned to Dublin airport broken. How could we have been let down so badly?

There followed another 3 weeks with no contact with an obstetric professional. Back in that unknown hell, my health was noticeably diminishing. The sum total of my ante natal care was my ill equipped GP and visits to a private scan clinic to determine if my son was still alive or not. I can’t begin to describe the guilt I would feel at each appointment, hoping that he had passed away peacefully himself, unaware of the suffering that I was undergoing; the guilt I would feel when I would hear his weakened heartbeat and the despair in my heart as I looked through tears at my elevated blood pressure levels and inflamed, swollen body. Something had to give. I had no choice but to have the full procedure and delivery in the UK. I was being criminalised for trying to do the right thing for my health, my family and my son.

I have never felt as lonely as I did boarding that late night ferry to the UK, knowing what lay ahead of us. The hospital were fantastic and so supportive - everything I had wished that my local hospital had been. Or any Irish hospital for that matter. I delivered my son at 24 weeks and 1 day. I felt an ease of conscience as I cradled him, realising by looking at his fragile and distorted body that I had saved him from any further agony. For a few short-lived hours we were afforded the luxury of being grieving parents. We had time to just be heartbroken before the preparations for returning with our infant son's body on an overnight ferry, knowing that we had a further four hour journey by car. My partner went to buy picnic coolers in a local supermarket to keep our sons body cool for our journey home, I filled out paperwork, the bereavement team organised the death certificate, travel documentation and his tiny coffin. It was so inconceivably sad, no words can quantify the emotions felt that afternoon.

Upon return to Ireland we had a small wake in the house with our family and close friends followed by an intimate service. Not long after my son's burial, I became extremely ill and had to go to hospital. In a fever induced delirium I begged my GP to send me to a different regional hospital as my original consultants words rang in my head 'if the staff know what you did they can refuse to treat you on moral grounds'. I was so ill, I was an emotional wreck, my body screamed in pain that I could not face the possibility of being treated like a criminal on top of everything else.

Over an hour from my home I was immediately treated for what turned out to be sepsis. The hospitals response was quick and I received two blood transfusions. My GP's dogged determination and help from an A&E doctor friend ensured the gynaecology ward, not the maternity ward, were ready for me. Ultimately they were receiving a patient that was less than 72 hours post-delivery with no baby and no hospital notes. I could feel them thinking 'How is this lady not in the system?'. My recovery was slow but I began to respond to treatment. During my second blood transfusion, the television reported that The United Nations Human Rights Committee had found Ireland's abortion laws amountd to cruel, inhuman and degrading treatment. I never felt as relevant and irrelevant in equal measures. The realisation of my situation hurt to the core, with comfort that the world could see the devastation the 8<sup>th</sup> amendment had caused to me and my family, yet it would never be recognised within this country.

I recovered physically over time but my mental health suffered considerably. I would like to point out that this was because of the complete lack of care in Ireland, not as a result of my son's termination. I had lost complete autonomy of my body and my mortality had been

seriously tested. It is mentally draining to hear how I was mere hours from becoming the 2<sup>nd</sup> Savita Halappanavar. My mind played tricks on me, leading me to thinking at times what a lucky escape it would have been from this torture. I had not been there for my living children throughout my ordeal, their needs were neglected and I felt deep shame for that. My state of mind deteriorated rapidly and I was institutionalised for 21 weeks, adding further to my complete lack of self-worth as a person, as a partner and a mother.

It is now two and half years since I began my nightmare and I wish I could say it is over. I have had ongoing fertility problems and numerous hospital admissions for gynaecological issues. Contrary to what the sonographer from March 2015 said, as it turns out, NO I cannot go on to have normal pregnancies. In November 2016 during surgery, I had retained tissue removed which had been there 18 months since my son's delivery. Had I delivered in an Irish hospital, I would have been observed correctly post-partum with necessary after care. How I am here to tell you my story is a miracle in itself. The first pregnancy after this find in February this year was one of joy but real fear. A fear that was well founded and the pregnancy was not to be. All I wished for was dignity and to be treated to the best of my attending hospital's ability during my miscarriage. Another different hospital I may add. However Catholic Ireland reared her ugly head again in matters pertaining to my reproductive health. My consultant was denied permission and theatre facilities to perform a much needed surgical procedure due to the hospital's 'very Catholic ethos'. I shiver every time I hear such words as I know exactly what that means now- my life is measured by medical directors who discuss me in terms of hospital accountability. The reason for the hospitals curtailment of treatment was absurd- I was miscarrying, and had been for over a week, there had never been a foetal heartbeat yet the hospital was afraid that it may be misconstrued as a termination as I had pregnancy symptoms. My new consultant furnished the hospital board with all medical history and my record of sepsis to which the reply was 'discharge her'. Thankfully my consultant believes in treating the patient and would not be bullied, even when pestered by numerous calls from board members to reverse the decision to treat me, and I eventually was brought to theatre three days later. I am ashamed to be a woman in this country, a country so lacking in compassion or empathy. A country that plays roulette with women's lives without any regard for the consequences. I am currently under long term treatment after another failed pregnancy and I am running out of hospitals to attend, my faith in our maternity services destroyed. My oldest daughter is terrified every time I go to hospital that I will not return. We cannot live with this constant fear for my safety and the future safety of my daughters, which is why we have looked at emigrating to a country which offers women reproductive autonomy.

Ireland, your 8<sup>th</sup> Amendment did not love both of us: in your eyes I am an incubating vessel and my unborn children political and statistical pawns. To hell with my living children, to hell with my partner, to hell with me. Well Ireland you win: to hell we have been.

## CARA'S MUM – SEVERE FOETAL ANOMALY & REPATRIATION

**Cara's mum takes us through test after test before a prognosis is arrived at. Then there is the agony of wishing the decision would be taken out of her hands, but having to make a decision in Cara's best interests. Even after terminating a much wanted and loved pregnancy, repatriation can be a long and involved process. So much of the additional trauma would be alleviated if we could have continuity of care here at home in Ireland.**

Our little girl should be here now. She was going to be the third smiling face in the back seat of the car.

I parked my car in work at 7am, and jumped in a taxi to rush for my 22 week scan. Not even fazed. I would be back to work by 9am. My husband waited for our child minder to arrive. Life was busy.

Then all of a sudden the world stopped.

Being a healthcare worker myself, I could read the sonographer's body language. I knew something was wrong. Finally she told me that the measurements of my baby's brain were a little wider than they would like them to be. Right then, I wanted to just take my baby out and hold it tight in my arms. I looked at the sonographer and said, "Please just tell me the truth. Is this something that can resolve or is it really bad?" I can't remember what she replied, but her honesty was compassionate.

I texted my husband, told him I was still waiting to be scanned, and asked him to drop in on his way to work. I waited in a room for the Fetal Medicine Consultant. Shivering is all I remember. When John arrived, he had no idea. I just hugged him and said "I'm sorry". I was sorry for squabbling over financial burdens, bills, dishwashers, little things.

All 6ft of him looked like a little boy whose world had just fallen apart. Exactly how I felt. Since that moment I have never felt closer to my husband. Our hearts felt the same pain, and still do.

The Consultant recommended that we have an amniocentesis performed. This would tell us if our baby had a genetic condition. Ultimately, this test would tell us if our baby had a “life limiting” condition, which would mean that he or she would die in the womb, at birth or shortly after. The word “travel” was also mentioned by the doctor, but passively dismissed by me. That was not something I would ever be able to do.

As we left to go towards the procedure room, I noticed a familiar purple “end of life” symbol hanging on the door. It felt strange to be on the other side of it.

I went into a total state of shock. After being convinced by our Consultant that I was not fit to go in to work, I picked up my car and we drove straight to my Daddy. He was the man who could fix everything.

He read the scan report with a hidden glaze of tears across his eyes. I knew they were tears for his little girl, but they never fell. My heart breaks for how strong he had to be for me that day. We all knew that our baby had severe brain malformation. It was catastrophic.

It was a Friday, we had to go home to our young children and get through the weekend. We went straight to the ice cream parlour.

Over the weekend, my pregnancy symptoms disappeared. I felt no movement and my bump almost deflated overnight. I felt like my baby had died. We took the children to see a movie. I drank Fanta and ate jellies, waiting to feel a kick but there was nothing.

I realised then, and admitted to my husband, that I wanted my child’s tragedy to end in my womb. Where it had begun. He was praying for the same thing. I expect nobody in this world to comprehend the feeling of wanting your unborn child to die, unless they have been in this dark and painful place.

Monday morning came and we both went to work as normal. My baby’s due date was almost four months away, so it was way too early to be taking sick days. Together John and

I hoped for the same answer in our amniocentesis results. Of course, the results were delayed until the next day, and the agony continued. Thank God for shock. I think that is what got us through this period of waiting.

That evening, our youngest child handed me a Valentine's card she had made in school. It was a drawing of a heart and it read "I love you to pieces". It had tiny bits of pink and red felt paper, carefully glued inside the heart shape. I knew our little family would hold my shattered heart together. I squeezed her so tight.

The results were not what we had prayed for. The amniocentesis revealed that our baby did not have Trisomy 13 or 18. These were the conditions that would have been life limiting. At 23 weeks gestation, our baby showed a probability of surviving. Again, we forgot to ask the sex of the baby. We decided that we now wanted to know, even though we were both certain it was a little boy.

There had also been signs of a cardiac defect at our 22 week scan, but this had almost paled into insignificance with the gravity of the brain abnormality. A cardiology review revealed that it was a minor defect and could be fixed with surgery. More importantly, it indicated that coupled with the brain abnormality, there may be a genetic syndrome which could involve other organs and systems.

A foetal brain MRI was performed the same day. We had no idea how conclusive it would be. But we had another weekend to get through, waiting for results.

We took the children to the circus. Everything was so real – the trusting acrobats holding hands, the palomino ponies' deep sparkly eyes, the cold.

The MRI report was unimaginable. Some structures of the brain were completely absent. Cruelly, the only part of our baby's brain that would function was that which would keep her alive. She would be able to breathe with difficulty, but nothing else. It was hard to believe that she could actually survive.

They told us it was a little girl. What a surprise, in the midst of all this devastation. I felt an overwhelming relief. It was a girl. She would understand.

Our decision was made. I didn't want to play God, I wanted to play Mother. I knew what was best for my child, just like her Father did. I did not want her to live this existence. I would not want to live this existence myself. She was my little girl. We were one. I had the privilege of carrying her. I had the comfort of knowing I was her voice.

Love was our solitary motivation to stop her little heart beating. This is a love that fortunately, not everybody can understand. It is heart wrenching. If you have never felt the ache of this love, please do not judge it.

Despite the legal restrictions in this country, we were left in no doubt by any medical professional who cared for us in Ireland. It was indirect but clear, not one of them wanted our girl to suffer the fate of living to be her own life support machine. We took comfort in this unanimity. Their genuine support was unspoken, but their hugs were defiant.

Now we were like one of those couples that you read about in the papers. I could not believe that we were in this position. We were going to Liverpool Women's Hospital. I wished the flights were more expensive - €16.99 each way. I felt sick.

This was just the beginning of the secrecy. We were sneaking around in order to carry out the most painful act of love we would ever have the misfortune of knowing. This was the only part that felt wrong. Our grief was disenfranchised.

Waiting for us in Liverpool was a full team of bereavement specialists. Their compassion was overwhelming. They knew that we didn't want to be there. We had waited two weeks for the earliest appointment, and I was now 26 weeks.

Our daughter's condition had significantly deteriorated by the time we reached Liverpool. It was a destructive pathology, worsening each day. We were reassured that it is only in the most severe cases of foetal abnormality that a pregnancy can be terminated at a late term gestation of 26 weeks.

The doctors were fully supportive of our decision and helped us understand that our daughter could have no quality of life whatsoever. We gave them permission to stop her heart beating. We named our daughter Cara.

Thirty hours later I delivered my little Angel. She was so peaceful. She would never cry a tear. She would never feel pain or suffer. That was for us to do. She was already in heaven.

We stayed in a spacious room with a bed for John, and a nursery for Cara with a cooling cot. We held her and loved her. I kissed her, and told her I was sorry. I knew that, had things been different, and she had grown up with our values and beliefs, she would have made the same heart breaking choice for her baby. The chaplain then arrived to bless our little girl. He prayed with us and for us.

The midwives were truly remarkable. This was all ok. We weren't bad people; we were bereaved parents. Through the night, Emma put together a memory box for us which included a print of Cara's hand and foot prints. She helped me dress her in beautiful pink robe, kindly knitted and donated by a local Liverpool women's organisation. We had a choice of a pink or a white hat. I held off on putting her hat on and wrapped her warmly in her big sister's pink blanket that we had brought.

Our plan had been to fly home the following day after a prayer service for Cara. She would then have a post-mortem followed by a cremation ceremony. We had been advised back home that a post-mortem would give us answers, and may provide important genetic findings.

The bereavement midwife had reassured us that a member of the team would attend Cara's cremation if we could not attend. It would be a couple of weeks, and many Irish families are unable to return. We wanted to be there for the service and to collect her ashes.

Then there was a change of plan. Cara had been examined by a paediatrician overnight, and showed no signs of having a genetic syndrome. A beautiful young doctor arrived with the

consent forms to be signed for post mortem. She was trying hard not to cry. I was grand. Now I know that is what was making her cry.

She explained that a post-mortem examination would be unlikely to add any value to the information already gleaned in our antenatal investigations. It was all there in black and white in Cara's MRI report that had been performed in Dublin. It was a primary brain abnormality.

The decision was made for us - Cara would not have a post-mortem. This changed everything. Her having a post mortem was the only reason we had decided on a cremation. Now we could just take her home as she was, and lay her to rest

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But we weren't at home, we were in a foreign country. We frantically called through a list of UK car rental companies to see if we could drive from Liverpool to Holyhead and take the ferry across to Dublin port. This was not possible.

John suggested we fly home as planned and he would drive straight back on the next ferry out of Dublin. He hadn't slept for a month. Our children were unsettled and waiting for us to get home. This is where the Honeysuckle bereavement team stepped in and tried to act as our rational minds. It was suggested to us that we could organise Cara's remains to be flown home to Ireland after us.

All this was unfolding for us in Liverpool while volumes of people were orchestrating campaigns across Ireland calling for a Repeal of the Eight Amendment.

The honeysuckle team assured us that Cara would be kept in their care until everything was in place for her transfer to Ireland. They sat by her cot as we walked away.

We landed in Dublin. I just wanted to lie down and grieve, but there were too many lies to be told. We immediately began making the calls to tell our loved ones that our baby had been still born. Many of them had no idea there was the slightest complication with our pregnancy.

Two days passed and we still had no confirmation of when Cara's body would come home. The phone calls were coming in – What happened to our baby? Would there be a funeral? Where was she now? What was taking so long? All our lies felt so wrong, yet each of their questions felt harshly intrusive. So many people cared, but we couldn't let them.

Each morning I woke up and said, today is the day. Friday came, 5pm came, and I knew we were facing another long weekend. I didn't like weekends anymore.

My sister arrived to see us on Saturday. I couldn't get out of bed. I sobbed so hard, I thought I might stop breathing. We decided that day, we were going back to Liverpool to take Cara home ourselves.

We sailed to Holyhead and drove through the night to Liverpool. The honeysuckle team would be waiting to meet us at 8am, we would do a quick U turn, get back on the ferry and be at our local cemetery that afternoon.

They knew we were under pressure and we were assured us that all the paperwork we needed would be ready, no delays. I imagined that Cara's coffin would be handed over to us, and we could get going. We were taken down honeysuckle lane, the section of the morgue reserved for still born babies, and led into a room.

The light was dim, and there were little lanterns and butterflies. Then I saw the Moses basket in the corner of the room. It was Cara. It was like a beautiful dream. "Can I kiss her?" I asked. I was kindly reminded, "She's yours".

Still cuddled in her sister's blanket, she was exactly as I had left her, with all her little things. Her Nana's Padre Pio beads, her teddy bear, her pink hat and her white hat.

Holding Cara one more time, and kissing her, I cannot describe. Being in that room felt like somebody had physically opened up my chest and put that piece of my heart back.

I kissed her one last time, placed her in her little white coffin, and closed it. I was the last one to touch her. “You needed to do that”, whispered a beautiful Liverpudlian voice.

Cara’s Daddy carried her coffin up honeysuckle lane. She wasn’t heavy, but he was so strong. He strapped the little white box in with the seatbelt where the third child car seat should have been.

As we drove out of Liverpool Women’s Hospital, our midwife from the Honeysuckle team stood and waved us off until our car was out of sight. It was almost like something you would see in Ireland.

It still wasn’t time to breathe out. We had to get through rush hour traffic in Liverpool and drive through Wales yet. We were pulled over by customs as we approached the boat in Holyhead.

A man in a high-vis coat asked John to open the boot. He had a look, just one bag. I reached for my handbag to show our official documents from the hospital. He asked “Is it just yourselves travelling?” looking at the blanket on the back seat.

John told him that we were taking our infant daughter’s remains home for burial. The man said, “Oh, I’m sorry Mate. On you go”. It was almost time to breathe out.

We drove past the children’s school, and on to the cemetery. Our little girl was laid to rest.

Our beloved Cara feels no pain. The certainty in our hearts of her peace is the only solace to our sorrow.

## SIOBHAN'S STORY – SIX YEARS ON

**Siobhan tells us of the dignity and compassion she and baby T.J. experienced from the staff in Liverpool Women's Hospital – not only the medical staff but the hospital chaplain who is a lovely Catholic priest, spoken of warmly by so many of the families who turn to TFMR Ireland for support.**

October 1st was my third child's sixth birthday. An important and significant milestone. However, it was a day of mixed emotions as it was also the sixth anniversary of his death.

T. J. had severe anencephaly. The top half of his head never formed. There was nothing above his eyes: no brain, no skull, no scalp. We found this out at his twenty week anomaly scan. I will never forget the words of the sonographer. "I'm a little concerned" she said. "I can't see the top of the baby's skull".

In that moment everything changed. I am a G. P. so I knew what she meant. "Do you mean like anencephaly?" I heard myself say.

"Oh you've heard of it" she said with relief.

She didn't need to explain that most babies with anencephaly will either be stillborn or die soon after birth. It did not take long for this to sink in and I was faced with a further twenty weeks of pregnancy knowing that my baby was going to die. I could foresee daily conversations with patients, friends and at my children's crèche. The usual seemingly banal questions every pregnant women gets asked: When are you due? Do you know if it's a boy or a girl? What I would say? Would I play along and answer as if nothing was wrong or would I tell them that my baby was going to die but thanks for asking? I'd be in bits. They'd be in bits. Day to day living would become intolerable. To me it seemed a cruel form of torture that would very quickly affect my mental health as well as the welfare of those closest to me. So I made the decision to end the pregnancy. I never dreamed I would choose to have an abortion but here I was faced with two horrible options with no good outcome. For me and my family an abortion was the least worst option.

My husband and I boarded an early morning flight to Liverpool along with business men, hen parties and couples enjoying a romantic break. I remember thinking how surreal it was. How could life just carry on as usual when we were faced with such tragedy?

The light in the darkness was Liverpool. When we arrived at Liverpool's Women's Hospital we were wrapped in a blanket of care and compassion. Everyone we met treated us with kindness and told us how sorry they were that we had to be there. They gently guided us through the next few days. After a scan to confirm the diagnosis I was given the first dose of medication to start the process. We then had 48 hours at our hotel before returning to the hospital to start the induction. I had never been to Liverpool before. I had a picture in my head of a grey industrial city but I was pleasantly surprised. It was a bright vibrant beautiful place that took care of us that weekend as we counted down the hours.

And so on October 1st, I was admitted for induction of labour. That's all it was: there was no drama, no blood and guts. I went through labour more or less as I had done on my previous pregnancies and late that night our little mite was delivered and as expected did not live. But we still got to hold him and named him and I felt a sense of peace for the first time since we learned that he would die.

The midwife dressed him for us taking his hand and foot prints as well as photos which they gave us in a memorial booklet. The hospital chaplain came and blessed T. J. for us. His kind words and compassion have stayed with me as the years have passed. They all treated him with respect and dignity.

And then we had to leave our baby boy behind and come home to our family. We had to go through the stresses of getting through airport security and queues while at the same time come to terms with the death of our baby. All because of the 8th amendment.

We chose to have T. J. cremated and his ashes were sent, by courier a couple of weeks later. I remember the day the courier van pulled up outside my home and the delivery man handed over the package. I knew it was my baby's ashes but I don't think he did. But it seems the courier companies now do know what they're delivering.

Nowadays parents in my situation often choose to fly back to the UK to collect their babies' ashes themselves as the couriers are now charging in the region of £900 to deliver the ashes. And all because of the 8th Amendment.

Since my experience I have met many parents who have been in similar circumstances to mine. I have met parents who have travelled for termination and those who were unable to do so and I have felt the persisting sadness that hangs over all these people because the 8th Amendment affected what they could or could not do. It is like the cruel twist of the knife at the lowest time in your life. The hardest part of this process should be dealing with the news that your baby is going to die but it isn't. The hardest and cruelest part is realising that your own country would force you to carry your baby to term regardless of what you wish to do having received such tragic news. And it's that feeling and haunts you and stays with you as time goes on.

It's time Ireland started looking after parents in these horrific and difficult circumstances. It's time for compassion. It's time to trust women in their reproductive choices. It's time to repeal the 8th.

## TWITTER - HEARTBROKEN & PUNISHED - @ITSTIMETOREPEAL

**On 5th November 2016 a Dad who was about to travel to the UK with his wife to terminate their pregnancy following a diagnosis of a Fatal Foetal Anomaly opened a twitter account @ItsTimeToRepeal under the name "Heartbroken & Punished". He outlined his reason for travelling and for wanting to share their experience as it happened. It was picked up by news outlets all over the world. Here's their journey.**

This Thursday the 10th of November we will travel to the UK from Ireland to have a termination. This is not by choice. Three months ago after many attempts we were overjoyed at the discovery we were successful. Our first child was born with a genetic condition that meant we spent many months in hospital and will continue to do so for the foreseeable future. Although there is a risk any future children may carry the same condition we decided it was a risk worth taking.

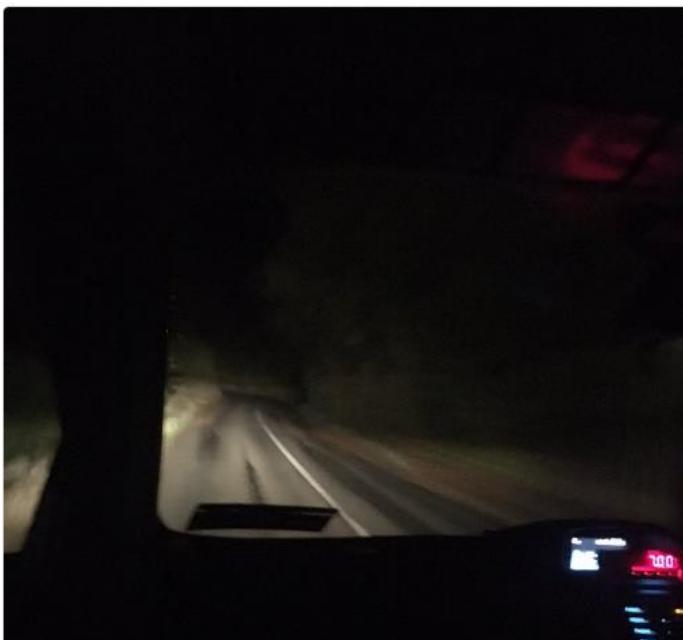
At our first prenatal appointment we were offered a genetic screening test. Although it does not screen for the condition that affects our first child, it will for others that may inhibit the baby's chance of survival. Of course we agreed to a simple blood test, after all the heart beat now visible was strong and all markers pointed to a healthy pregnancy. Then we got the call that nothing can prepare you for.

A fatal foetal abnormality was discovered. We had never heard of Edwards syndrome before but we were told that even if carried to full term the period of life would be counted in the minutes and hours after birth. It is a crushing sentence for any person to hear let alone for my wife who has had to give up her career to become a full time carer for our little boy. We went back for more tests and got confirmation. We should be telling our friends and relatives about our joyous news at just over twelve weeks instead we are now past the point of being able to go to a hospital in the UK so we had to make arrangements to visit a clinic.

Traumatic in its own right we also have to get someone to mind our child who requires constant monitoring throughout the day or his condition can cause him to slip into a coma and his brain can basically shut down. A lot of responsibility for us, even more putting it on someone else's shoulders. What should be a simple procedure that could be carried out 20 mins from home in a risk free environment we are being forced to travel to the UK, leaving

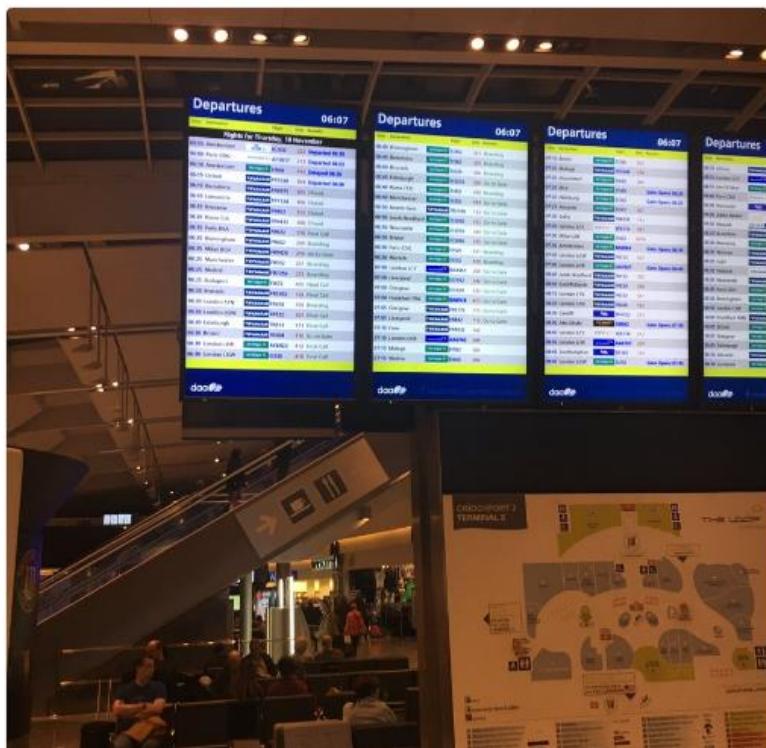
our child behind and the risks that involves to do the most humane thing possible to a baby that will never survive.

That's why we are going to document our experience from start to finish on Thursday. We hope that this may enlighten those who do not want to listen or even allow the people of this country to decide for themselves. Our government has continually kicked the can down the road and we the people must decide if we can allow this to happen. We hope that by documenting our experience may help those that may have been through something similar or may be unfortunate enough to do so in the future. Please share and check back on Thursday morning for updates throughout the day.

Tweets	Timestamp
<p> Heartbroken&amp;Punished @itstimetorepeal</p> <p>In less than 12 hours we will begin our journey. We don't know what to expect but we do know we won't be alone. #itstimetorepeal</p> <p>RETWEETS 122 LIKES 296</p> <p>7:16 PM - 9 Nov 2016</p> <p>30 122 296 ...</p>	<p>07:16PM 09th November 2016</p>
<p> Heartbroken&amp;Punished @itstimetorepeal · Nov 10 Stage one almost complete. Do we tell him we're going to Liverpool ? What for ? Because our country doesn't care. #itstimetorepeal</p> 	<p>06:42 AM 10th November 2016</p>



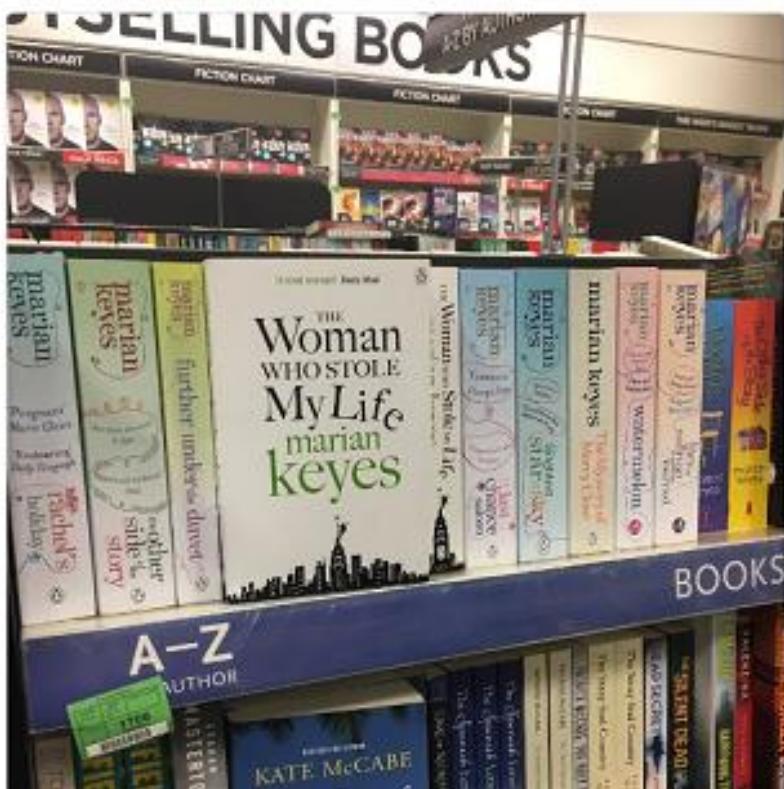
Heartbroken&Punished @itstimetorepeal - Nov 10  
Just in time.. #itstimetorepeal



06:42 AM  
10th November 2016



Heartbroken&Punished @itstimetorepeal - Nov 10  
Always buy a book for every journey, that way you will always  
remember.. #itstimetorepeal



07:34 AM  
10th November 2016



Heartbroken&Punished @itstimetorepeal · Nov 10

It's hard for us, imagine making this journey on your own like the thousands of women that made it before us & others that will have to..

— You, Roisin Ingle, Women Can't Wait Lmk and RepealEight



Heartbroken&Punished @itstimetorepeal · Nov 10

Goodbye Dublin.. #ItsTimeToRepeal



07:56 AM

10th November 2016

08:11 AM

10th November 2016



Heartbroken&Punished @itstimetorepeal - Nov 10  
Suitably miserably day in Liverpool.. #ItsTimeToRepeal



09:14 AM  
10th November 2016



Heartbroken&Punished @itstimetorepeal - Nov 10  
Planes, trains and automobiles.. how can our government sit idly by  
and let its people go through this.. #itstimetorepeal



10:05 AM  
10th November 2016



Heartbroken&Punished  
@itstimetorepeal



Following

10:23 AM  
10th November 2016

We have arrived. Forms filled in and shown to the waiting room that's almost full. Deathly quiet only broken by some very familiar accents..

RETWEETS LIKES  
247 454



10:23 AM - 10 Nov 2016

30 247 454 ...



Heartbroken&Punished  
@itstimetorepeal



Following

10:57 AM  
10th November 2016

Just discovered we should have been sent to a different room, one for women with FFA's butts there's no space for us.. #itstimetorepeal

RETWEETS LIKES  
95 156



10:57 AM - 10 Nov 2016

6 95 156 ...



Heartbroken&Punished @itstimetorepeal · Nov 10

Just got moved. Not sure if it's any better to be in here. Imagine sitting in here on your own.. #itstimetorepeal



31 113 213 ...

11:05 AM  
10th November 2016



Heartbroken&Punished  
@itstimetorepeal



Following

02:25 PM  
10th November 2016

Thank you all for your incredibly kind words.  
The support from home and other countries far  
and wide has blown us away.. ❤  
#itstimetorepeal

RETWEETS 54 LIKES 467



2:25 PM - 10 Nov 2016



Heartbroken&Punished  
@itstimetorepeal



Following

03:09 PM  
10th November 2016

Thank you @SimonHarrisTD perhaps you  
could share that information with your fellow  
TD's and act on it finally.. #itstimetorepeal

Today FM News @TodayFMNews

Health Minister @SimonHarrisTD says it 'saddens and frustrates' him that women  
can't access abortion in the case of fatal foetal abnormality

RETWEETS 174 LIKES 348



3:09 PM - 10 Nov 2016 from Liverpool, England



Heartbroken&Punished  
@itstimetorepeal



Following

03:12 PM  
10th November 2016

Finally got the call, heading up in 5 mins,  
thank you all again for your love and support  
❤ #itstimetorepeal

RETWEETS 86 LIKES 553



3:12 PM - 10 Nov 2016



86

553





Heartbroken&Punished  
@itstimetorepeal



Following

05:34 PM  
10th November 2016

All went fine and in recovery.. #itstimetorepeal



Heartbroken&Punished  
@itstimetorepeal



Following

07:36 PM  
10th November 2016

Our journey is almost over, our angel is coming home with us & will be laid to rest where we can watch over them forever.. #itstimetorepeal

RETWEETS    LIKES  
**187**        **768**



7:36 PM - 10 Nov 2016



107



187



768

...

We are finally home. Thank you for joining us on our journey, we will be reading your messages for the next few days at least.

On days like today it's heartening to know there are so many good people in this world. Many will wonder why we did this, we just wanted to tell our story, we are not trying to campaign only to help the countless others that have been through this before and for those that may have the misfortune of a Fatal Foetal Abnormality in the future.

To those who doubt our story is true, have fun in crazy town. We hope you will never have to go through the pain and anguish we had in making this impossible decision. To the trolls of which there were a few, get a life, your nasty comments only prove why we wanted to stay anonymous in the first place.

Take care everybody x

12:16 AM  
11th November 2016



Heartbroken&Punished @itstimetorepeal · Nov 11



46

176

570

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