



Special Oireachtas Committee TFMR Ireland Oral Presentation on The 8th Amendment

TFMR Ireland

25th October 2017

TABLE OF CONTENTS

Introduction	2
Diagnosis and Prognosis	3
The Decision.....	4
To Travel.....	4
Returning Home.....	5
To Stay.....	7
Maternal Health.....	8
Safe Access to Services	8
Conclusion.....	9

INTRODUCTION

We would like to thank Senator Noone and this Committee for extending an invitation to us to present to you today.

We are a group of parents, Mums and Dads, who have all been affected by pregnancies where there was a diagnosis of a severe or fatal foetal anomaly. We were all denied access to the care that we needed as a direct result of the 8th Amendment.

Many of us had to travel to another country to access the care we needed, while others among us were forced to continue our pregnancies in Ireland against our will. All of us were forced to endure suffering above and beyond the loss of our babies because of the constraints this amendment placed upon us and our caregivers.

We have also been providing emotional support to other women and families who have faced into similar tragedies and journeys for many years now, and we are privileged to have had some of them entrust their stories to us so that we can share them today with you all.

We would like to remind you that behind all of the circumstances we describe to you, and the stories we refer to, are bereaved families, and we trust that you will all afford them the respect and dignity that they deserve.

We hope that our submission document and the contribution we make here will help each of you to arrive at a fully informed position as you make your own recommendations to Government at the end of this process.

DIAGNOSIS AND PROGNOSIS

We think it would be appropriate for us to start off by looking at the events which lead up to us having to make what is without doubt the most difficult of our lives. This decision is a deeply intimate and personal one.

Most of us received our first indication that there was a problem with our baby's development at our anomaly scan. This typically takes place between 19 and 22 weeks. Others who may have a history of foetal anomaly or are at increased risk may have discovered this sooner at earlier scans or tests. Of course, it should be noted that not all women have access to these tests, only about half of pregnant women in Ireland are offered anomaly scans.

I'm sure you don't need us to tell you how much of a shock it is to be so excited about your pregnancy in one moment, only to have your doctor tell you that there may be a serious problem in the next.

In some cases, further tests may need to be performed to get a confirmed diagnosis. There may also be a need to refer to other specialties like cardiologists, paediatricians and neurologists to name but a few.

It can take several weeks to schedule all of these tests and to get results back. In some cases, we may need to have tests or observations performed over a period of time to see whether or not the prognosis for our baby is improving or deteriorating.

Eventually, our doctors will sit down with us and explain what they believe is the most likely outcome for our pregnancy. Our babies are going to die, or have a seriously compromised quality of life. This will be based upon the results of our tests, what they have learned through their professional experience, and the specific manner in which these anomalies have affected our babies.

It is devastating to hear. Our hearts are broken and our worlds stop. But it is so important that our doctors are frank and honest when they deliver the prognosis to us. It is important

that they do not sugar-coat the news with euphemisms, because we must have a clear understanding of what our baby faces, and indeed what we face, so that we can accept reality, and make an informed decision on how best to proceed.

THE DECISION

Receiving the news that our much loved and wanted baby is going to die, or that their quality of life will be severely impacted is completely devastating. I can't begin to describe the pain in that moment to someone who hasn't experienced it.

The decision to either continue with or terminate a pregnancy in these circumstances is an extremely difficult one for most people. To make this decision we need to have all of the best information available to us, we need to be able to discuss all options with our medicals teams, and most importantly we need enough personal time and space to arrive at the decision which we believe to be best for our baby, for us and our families.

It is important that we point out here that it is impossible to require families to get this information and process it, and to arrive at a decision within a 22-week gestation limit. This limit is one area that we feel must be reconsidered by this committee.

Nobody should be judged for coming to the point where hope ends.

TO TRAVEL

Those of us who chose to terminate our pregnancies and were forced to travel to lose our babies, were basically left to our own devices.

Because our doctors can't do this for us, we have to find and contact overseas hospitals. We have to make our own appointments, get copies of our medical records and find fax machines. Who these days even has a fax machine?

We have to make our own travel arrangements. Do we go by plane, by car or boat? 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 a passport? Can we afford it?

It is also worth pointing out that when we go for an induced labour and delivery we have no way of knowing how long it will take and when we will be coming home. This adds to the stress and cost.

I think it is worth reflecting here on the words of Justice Horner when he said that forcing women to travel 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 say **“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.”**

At a time when we are experiencing the most intense grief of our lives, we find ourselves in another country having left Ireland in secret, feeling like medical refugees. We are abandoned by Ireland - the state and its people - isolated from our families and friends, and separated from the trusted medical team who looked after us up to this point.

RETURNING HOME

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

If we have our car we can bring our baby home on the boat. This journey involves us having to go to a supermarket to buy freezer packs, and then we have to stop at regular intervals to open the coffin and change them so that we can keep our baby cold. We also have to leave

our baby in a coffin in our car, covered by a blanket or in the boot, while we cross the Irish sea.

If we are coming home by ferry but don't have a car, we have to carry the coffin on public transport – buses or trains – and carry our baby onto the ferry as a foot passenger.

If we are flying home, we may be able to bring our baby's remains on the plane. We have to check in advance with the airlines and deal with their special assistance staff. We may need to place the coffin in a holdall or suitcase and check it in as luggage. This will mean our baby will be put in the hold by baggage handlers and we will have to collect them from a luggage carousel in Dublin, Cork, Shannon, Galway or Knock. Alternatively, we could take the coffin onto the plane as hand luggage.

Imagine, all of this is happening within hours of giving birth in the most tragic of circumstances. How do you think this makes people who live here feel? Would any of you be comfortable with your own family members or neighbours having to go through this ordeal?

We may not be able to bring our baby home with us, in which case we return empty handed. Perhaps we need a post-mortem to provide us with specific information that we need to protect future pregnancies. Something we may have to pay £900 for. We may not feel able to cope with the stress of bringing the remains home with us, in which case we may arrange for a cremation. We may not be able to be present at our child's cremation, and we still need to arrange the return of the ashes. Specialist courier services are now costing between £800 and £900 Sterling. Our only option may be to fly back and collect the ashes, and this still presents us with difficulties when we go through airport security – having to explain what our packet of ashes, or powder, is.

Even when we bring our babies home, there are more logistics to overcome. How do we arrange a funeral? Can we get a priest to officiate? Some of us are afraid to tell the truth in case we are judged yet don't want to lie.

Not being able to bring our baby home and not being able to have a normal funeral service, with the support of our family, friends and community, further compounds the sense of

isolation and abandonment that we feel. This is a process which is important not just for the parents to get closure, but for the grandparents, siblings and other family members too. It makes it almost impossible for us to grieve normally and leads to more traumatic, complicated and disenfranchised grief than would be expected if we were properly supported throughout this entire process.

TO STAY

There are also those of us who wish to avail of a termination of pregnancy but who do not travel. Many families and women in Ireland continue a pregnancy, not because it is the right thing for them, but because the ordeal involved in ending a pregnancy under the current regime is too arduous. We might not be able to afford it - flights (up to three round trips), accommodation, cost of the procedure itself, post mortem, cremation and transport home of foetal remains costs each couple as much as €4,000. This is an enormous sum of money for most families and prohibitive in many cases.

We might not be able to travel. We might simply not be able to face the stress of travelling and returning home without a bump or a baby. The emotional toll of travelling really cannot be underestimated. Grief has many more facets to it than just sadness. Anxiety, exhaustion, panic attacks and deep mistrust are all symptoms of complicated grief that make travelling through airports, foreign cities and to a strange hospital or clinic even more traumatic than it may appear to an outsider.

The stigma associated with travel is enormous and many of us fear the gossip and judgement from family, friends or community, and this is more than we can bear.

These are just some of the limitless reasons why travelling to end a pregnancy is not an option for everyone, even when they know that a termination is the right thing for them, for their baby and their family.

So we're trapped. We're in the nightmare situation of looking like we're expecting a baby, while we're preparing for an enormous loss. Being asked questions about our growing bump can be just too much to bear. To avoid this, we isolate ourselves. We hide from the world, not wanting anyone to see our pregnancy or ask us questions, and we suffer the anxiety, the

nightmares, the constant knowledge that we will be losing our baby. While we wait. We can't participate in our normal lives, we can't go to work, we struggle to take care of other children, all our relationships suffer. And according to the 8th amendment none of this matters because we're alive, and that is considered enough.

MATERNAL HEALTH

Pregnancy can affect our physical and mental health. Even in previously healthy pregnancies where there are no foetal complications. However, when something goes wrong, be it an impending miscarriage, ruptured membranes or a foetal anomaly, these risks are increased. Why is it that while we are pregnant only our *lives* matter? Why is it ok to completely ignore our physical and mental wellbeing? Do we really not matter when we're pregnant? Whatever else we do with our laws, we really need to ensure that the normal duty of care to us as living breathing women is never set aside.

SAFE ACCESS TO SERVICES

When considering proposed changes to our laws we feel it is important that you also consider how women in Ireland will be protected, in terms of provision of information, safety, privacy, and real access to services.

If abortion is legalised it should be incorporated into current maternity care. It is important that lawful services are available to all pregnant women in Ireland, irrespective of their location or financial status. This means that every maternity hospital, irrespective of its ethos, must be in a position to provide these services at all times. Healthcare should never be a black-market product, and no woman should ever be afraid to seek medical assistance for fear of prosecution.

We respect and understand that some medical practitioners may object to carrying out abortions of any type because of their own sincere beliefs. We do not, however, believe that this should ever be allowed to prevent a person from accessing the medical care they need. The responsibility must be on every medical facility, regardless of ownership or ethos, to

ensure that they can, and will, provide procedures that are legal in this country. Conscientious objection should not be used in a manipulative manner to avoid taking care of some patients.

We also need to ensure that protests, harassment of patients or barring access to medical facilities are not tolerated under any circumstances. Legally enforceable safe zones around medical facilities, as part of any legislation that provides for legal abortion is crucial for the privacy and safety of staff, patients and visitors.

CONCLUSION

We really hope that we have been able to open a window into the unnecessary suffering that the 8th Amendment inflicts on us. And at a time when we are at our most vulnerable, at a time when the diagnosis we receive for our babies *should* be the worst thing that can happen to us.

We have gone into a lot more detail in our main submission and we really recommend to you that you take the time to read the personal stories that have been made available to you. None of us should have to reveal these intimate details in order to drive change, we are grateful to those who do.

We hope also that we have been able to shine a light on how unworkable any gestational limit will be when addressing issues of foetal and maternal health.

We are sure that by listening to our lived experiences and reading about how Ireland and its current laws added to our trauma, you will be in a much better-informed position to consider the very mature and compassionate recommendations that the volunteer citizens made to you.

We trust that you will take all of the expert evidence and lived experiences that have been presented to you and that you will recommend a solution to Government that recognises that we all make decisions around pregnancy and parenting in a mature and responsible manner, and that will support us all in those decisions, whatever they may be.