

## **Joint Oireachtas Committee on the Eighth Amendment of the Constitution**

### **Opening Statement by Ms. Liz McDermott, One Day More**

Thank you Senator Noone and members of the Committee for inviting me here today.

I am a member of One Day More, a support group which came about because of the experiences of parents who received poor prenatal diagnoses for their babies - either that they would not survive til birth or long after birth, or that their babies had significant developmental defects or anomalies which would impact them for life.

When we received the poor prenatal diagnosis for our children, some of us were fortunate enough to speak to someone who had gone through a similar experience. We found this emotional and personal support of enormous help and in the end it's what prompted the setting up of One Day More.

I have brought along some additional information about One Day More and the stories and testimonies of women we have supported. I would request that these form part of the record of these proceedings.

Their experiences in maternity hospitals vary from very good indeed to very difficult and disappointing. One mother was told at her initial scan that her baby looked like a "Michelin Man" and was asked why she was persisting with a "futile pregnancy". She was asked at each appointment to consider abortion and had to keep refusing and eventually she was advised to pick a plot to bury her daughter in. This little girl celebrated her 3rd birthday last week.

Another mother who refused to abort her baby who had Down Syndrome was contacted after each hospital appointment to change her mind and have an abortion. She did not change her mind and gave birth to her daughter last summer.

Couples have contacted One Day More after they came home from England after an abortion and told us they had not known of One Day More and would have continued with the pregnancy if they'd been able to access the supports and peri-natal care available. This shows how necessary these supports and efforts are and that many couples would not choose abortion if peri-natal hospice care was talked about more than abortion.

Some medical experts try to reassure people that abortion would only be available to women who want it, not to those who do not; they and their babies would be given every care and support throughout pregnancy and birth. But we can see from the experiences of women who contact One Day More that they did not receive this kind of support. Instead, they were dealt with insensitively and felt like they were almost causing problems for the hospital they were attending for ante-natal care.

Some of our members' babies died before birth, some not long after birth. Thankfully, some children are still alive and many are thriving against all predictions and expectations.

There is a very important point to make about this, which is that medical prognoses can be wrong, and occasionally very wrong. Doctors can't always accurately predict outcomes and parents of sick babies can be amazed at how much better things turn out for their baby than was thought.

Hope is a vital human instinct and gives us strength and support at various difficult times all through life. Challenging pregnancies are no different and One Day More exists to offer support and hope to parents of very sick and disabled babies before during and after birth.

As well as providing direct support to parents, One Day More raises funds for better provision of perinatal hospice care; we also provide Care Boxes for families awaiting the arrival of their baby with a focus on making the time they have together as a family as precious as possible. When death is expected, the experience is bittersweet but it's incredibly uplifting to hear families describe the wonderful memories their time with their baby gave them and how much love they all felt towards each other and the baby. Even babies who don't live very long can bring with them tremendous gifts which can't be predicted or quantified but only felt by going through the experience.

### **My Personal Experience**

I became pregnant with John in early summer 2002. He was my second child. All was fine, as far as I thought and I felt ok, though very tired, having a very active 2 year old daughter. I had a routine scan at 24 weeks in mid-December 2002 and on that occasion the nurse said she saw something amiss as she saw "shortened limbs" and couldn't see hands, though this might be positional, she said. My husband and I had to come back the next day for an in-depth scan and you can imagine how we felt overnight.

The next day we went into the hospital and a consultant obstetrician carried out a scan which took a good while as he wanted to check everything out and take measurements. I remember just looking away from the scanning machine the whole time, facing the wall. I felt numb and very anxious. Afterwards he said these words which I'll never forget: "I'm afraid it's a very serious abnormality. The baby's limbs haven't grown, there are 2 very short arm buds and I can't even get a measurement on the legs." He then showed us the pictures and described in detail what he saw. I remember looking at the baby's face and thinking he looked like my husband especially round the eyes. He told us it was a little boy. The doctor finished by saying "He'll never do anything but lie on a bed. I am obliged to tell you that if you want to travel to England it won't be a problem."

I remember instinctively replying that, no I wouldn't be going to England. I'd just seen my baby's face and even though I had no idea how I was going to cope, I had no right to interfere with this child's life in any way. This certainty was instinctive protectiveness more than anything else at that time but I certainly did not relish the prospect of how life would have to change.

I recall feeling jealous of women whose babies were not going to survive as at least their story had a certain beginning, middle and end to it but mine was not going to end soon and the future looked very uncertain.

I had a number of friends who were expecting babies at the time and all of them had no problems and their babies duly arrived safe and sound and healthy. I did feel very sorry for myself and felt I was living on another planet to everyone else.

My bump attracted comments like "gosh, you're so neat" and "I'm sure you're all thrilled to be having another baby". I can identify with all of the harrowing experiences and feelings of isolation which all mothers with difficult pregnancies go through and we can all agree that much more needs to be done for such women and their families too, as the fathers are affected too and don't know how to process all their emotions.

I had support from family and friends and I pushed myself to stay connected to the world I lived in rather than go completely in on myself. When times are tough you just dig deep and are frequently surprised at what you can cope with.

We did not receive much in the way of support from the hospital we attended; with one exception, the scan doctor as we called him, all other medical staff appeared unconcerned about us and our baby. We just did what we had to do and I wanted to get the birth out of the way. I asked my consultant what would happen when John was born and he said nothing different would happen as there was no reason to think he could not be treated normally. On the day John was born, I went into hospital around 10am and my waters were broken and labour progressed. My husband and I were in a room with a student midwife only and a neonatologist came in and spoke about our baby to someone on the phone, saying, "weird case, no limbs". This is typical of the treatment we received but I was so focused on blocking them all out and getting on with having my baby that I said nothing and restrained my husband from objecting.

John was born after 2pm that day. My own consultant told me he was leaving the hospital to go and see other patients in his consulting rooms, if that was okay. At that point I didn't care who was there or not but I did feel he was choosing not to be present rather than having to leave for some urgent matter. He did not return that day, I recall.

Right after John was born, a number of doctors descended upon us, standing at the foot of the bed, all in white coats. One of them announced the baby was going to be taken to the Special Care Baby Unit (SCBU) for tests. John wasn't sick and didn't need medical intervention at all and I was heartbroken that he couldn't be with me as I wanted to breastfeed him. But at that moment I was so vulnerable and tired and these total strangers, who looked rather serious and expressionless, were in charge so I didn't challenge it.

John spent 2 days in the SCBU and I was in a room on another floor. This was a horrendous time because no provision was made for me and John in terms of comfort and privacy. I had to sit on a waiting room type chair in the middle of the SCBU, feeling in the way with very sick and premature babies all around, who needed the nurses' full attention. The feeding didn't go at all well and I was

very stressed. I so wanted to give my son this experience of closeness because he could not even use hands and feet to move and comfort himself at all.

After 2 days, John was brought down to me and finally we had some privacy and comfort and I was at last able to breastfeed him in peace. It was awkward changing his nappies in the communal changing room. I tried it a few times as it was awkward in the room but silence always fell when I lifted John onto a changing mat so from then on, I just did it in my room. I couldn't wait to get out of that hospital. No one was nice to us except one doctor.

### **The Vision for Future pre-and peri-natal care**

One Day More, Every Life Counts and places like Hugh's House represent concrete examples of reaching out to women with very poor prenatal prognosis. But these are a drop in the ocean compared to what could be achieved in the way of supports if our government would undertake research and investment in these areas. Women who've gone through this know what it's like and what would help other women; they are a tremendous resource to tap into, if there is the will on the part of government to really look to give women really meaningful support.

It is so disappointing to see that all through this process and the Citizens Assembly, and back the last 5 years or so, the only focus of political effort has been towards introducing abortion.

Looking back, I can honestly say the experience of having my son John in 2003 has had a hugely positive impact on me, my family and beyond. I could not have foreseen this at the time I was carrying him of course and that is the nature of life, we can't predict the future - how things will go, how we will feel and what help we might be able to get down the line. It's a mistake to try and plan these things out because we risk painting a bleaker picture than actually happens, that's a human tendency and doctors of course feel duty bound to give us the worst case scenario, to avoid unrealistic expectations.

Deeming people like my son as unworthy of legal protection before birth - is that to become our new definition of progress?

It's certainly what repealing or amending the 8<sup>th</sup> Amendment would amount to.

My story is far from an isolated one. Every day, new stories about women and families feeling pressure to abort emerge.

Some people I'm sure find it hard to believe stories the stories I mentioned earlier about pressure from medics to abort babies with special needs. But sadly they are all too real.

When we try to explain away this pressure, we shouldn't be surprised when the horror of what I just outlined starts to happen more often.

It's the kind of denial that led to the present situation in England where 90% of babies diagnosed with Down syndrome are now aborted.

Last month, the Care Quality Commission in England issued a damning report on abortion providers Marie Stopes. It revealed that staff were being paid bonuses to encourage women to go through with abortions. The inspectors found evidence of a policy in all 70 Marie Stopes clinics in the country directing staff to contact women who had decided not to go through with an abortion, offering them a new appointment.

This is just one of several recent scandals involving the abortion industry in England and elsewhere. I find it extraordinary that we're talking about having a referendum in Ireland to introduce abortion and no committee is even looking at what abortion has led to in other countries.

Speaking from my own personal experience, I agree with those who say legalised abortion is part of the old order. In the 50 years since it was legalised in England, it has led to millions of babies having their right to life taken from them in a most brutal way and caused a deep, hidden pain for countless women who were betrayed by the sloganeering about "choice" that pretends abortion is without any adverse after effects.

The 8th Amendment on the other hand acknowledges the right to life. It doesn't claim to be its author - merely its protector.

Those campaigning for repeal of the 8th Amendment clearly do not regard the right to life as inalienable. Instead they see it as something conferred or withheld by the State based on who the law at any given time deems worthy or unworthy of being protected.

If we vote to dismantle the 8<sup>th</sup> Amendment, we will be saying that we deem certain unborn babies unworthy of legal protection.

If we vote to keep the 8<sup>th</sup> Amendment, we will be recommitting to the goal of making a world that is worthy of the most vulnerable and defenceless members of the human family.