Joint Committee on the Eighth Amendment of the Constitution.

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Introduction: I am Master of the National Maternity Hospital (NMH) which is one of Europe's largest maternity hospitals, delivering approximately 9,000 infants annually and is a major Irish tertiary referral centre providing advanced obstetric, neonatal and gynaecological care. I am a Specialist in Maternal and Fetal medicine and one of a team of seven specialists in tertiary fetal medicine at NMH. I am an Honorary Clinical Professor with RCSI and a Fellow of the RCOG UK and the RCPI in Ireland. I am an Eisenhower Fellow and an Honorary Fellow of the American College of O&G. I have practiced as an obstetric consultant since 2008 and have been Master of NMH since 2012.

My submission today is based on my clinical experience as an obstetrician practising in the Republic of Ireland under the terms of the 2013 Protection of Life in Pregnancy Bill and Article 40.3.3 of the constitution commonly referred to as the Eighth amendment. These legal instruments currently govern the circumstances in which termination of pregnancy can be lawfully performed in Ireland.

Termination of pregnancy is defined as the "intentional procurement of miscarriage". In other words a pregnancy is interrupted prior to fetal viability and neonatal intensive care is not provided. At present 24 weeks completed weeks of gestation represents the threshold of viability, whereby the provision of sophisticated neonatal intensive care is associated with approximately a 50% chance of survival. This is not an absolute cut off and some babies will survive at 23 weeks gestation while others will not be viable at 25 weeks due to complications of extreme prematurity. When a baby is delivered in whom viability has been reached and intensive care provided, we refer to this as a delivery and not as a termination of pregnancy.

The subject of termination of pregnancy is a deeply complex one and not surprisingly, it provokes strong views and many differences of opinion. We know that approximately 3,000 women travel to the UK every year from this country to obtain termination of pregnancy in all kinds of circumstance. Our constitution protects women to travel abroad for termination of pregnancy in circumstance that would be a criminal offence in Ireland. In effect, this means that women in Ireland have similar access to termination of pregnancy as women in the UK with the exception of children and women who do not have the

means or ability to travel. It is impossible not to be affected by the personal testaments of individual women and their partners and while every case is unique, it is evident that in the present situation in Ireland, women will continue to travel to the UK or access unknown medications from potentially unregulated sources using the internet. With all the attendant clinical risk.

Somewhere in the midst of personal opinion is the need to ensure that women in Ireland have access to sound clinical care and I would like to address the following clinical issues.

In Ireland a woman qualifies for a termination of pregnancy if there is a real and substantial risk to her life that may be removed only by termination of pregnancy. The process which determines this qualification is cumbersome and complicated and despite the fact that it relies on clinical judgement delivered in good faith to save a woman's life, it is framed in a criminal context. An error in clinical judgement is potentially punishable by a custodial sentence of 14 years for both the mother and her clinician in the event that an identified risk is deemed not substantial enough. Equally, waiting for a woman to be sufficiently ill so that she is perceived to be at risk of dying is potentially dangerous. It relies on a range of presumptions. Firstly, it assumes that we can accurately predict the risk of dying. Haemorrhage, infection, heart disease, liver disease and a host of other disorders can make you very ill but they can also kill you. It is not always possible to predict clinical course with precision. In medicine we deal with probability informed by available clinical evidence and experience.

Doctors may rarely be certain that a pregnant woman will inevitably die as a result of her pregnancy. In women with underlying morbidity such as cystic fibrosis, portal hypertension, corrected congenital heart disease, renal disease and many other conditions, the additional physiological burden of pregnancy can create significant maternal risk. The critical question arises as to how a substantial risk of mortality is defined. Is it a 10 per cent risk of death or an 80 per cent risk of death or a requirement for intensive care support? This is medical roulette. A woman herself will have a view as to what constitutes a substantial risk to her life and her view deserves consideration. It must be recognised that it is clinically difficult, if not impossible at times, to distinguish with certainty the difference between risk to health and risk to life. This is real-life medicine. We frequently counsel patients about a range of risks and potential outcomes. We arrive at a decision with our patients input which we believe is in the best interest of our patient but I cannot think of any other circumstance where risks to life are balanced in the shadow of a custodial sentence for both the clinician and the woman.

In my experience, one of the most challenging conditions we experience clinically is the development of chorioamnionitis prior to fetal viability. We see a significant number of cases annually and perform termination in this context

three to five times per year. Chorioamnionitis is an infection in which the pregnancy itself becomes infected. It is often preceded by prolonged rupture of the membranes around a fetus and is treated by terminating the pregnancy, which itself has effectively become the source of infection. The diagnosis is initially made on clinical grounds of symptoms and signs, while the confirmatory blood culture results may take up to 48 hours to be processed. If, for example, a woman is 14 weeks' pregnant and the membranes surrounding the pregnancy rupture, there is very little chance that this fetus will survive, although fetal death is not inevitable. This mother, however, runs a significant risk of developing chorioamnionitis, although this is not inevitable. Therefore, in this case, a patient and her physician are required to monitor for the potential onset of chorioamnionitis and the resulting risk to life if such infection takes hold. We understand from experience that a young woman with severe infection can appear relatively well despite advanced infection – but she can decompensate suddenly and unpredictably. It is then to be hoped that modern medical therapies can successfully resuscitate her and treat her infection. Attempting then to terminate a pregnancy in a woman who is very ill and potentially at risk of dying confers additional risk but that is the current requirement of the law. And clinicians are tasked with getting it right in what can be a very narrow therapeutic window.

In pregnancy we deal with two lives inextricably linked by a complex physiology. This is dealt with in the Constitution by a balance of rights. The equal right to life of the mother and the fetus. From a medical perspective, this provision creates difficulty in its presumption that the implications of a range of complex medical disorders can be reduced to a matter of individual right. If the legal world explores the balance of rights, the medical world explores the balance of risk. In a pregnancy complicated by serious disease, clinically, it is not a question of right; it is a question of risk. Once fetal viability is achieved we have the option of delivering the baby and attempting to save both lives. We do this all the time in clinical practice and over 2% of babies in Ireland are born before term because of medical indication in the context of fetal or maternal disease.

However, prior to fetal viability, we do not have the option of delivering a fetus because the fetus cannot survive and if a pregnant mother dies, her baby dies too. Therefore, prior to fetal viability this constitutional provision makes no clinical sense. However, its presence facilitates a real possibility that clinical decision-making may be delayed or distorted as clinicians ponder the law rather than medicine.

Unfortunately, there is evidence of this. I will never forget the High Court case that dominated Christmas 2015 when somatic function was maintained in a dead woman so that her fetus could be incubated in what was described as a "macabre experiment". The woman in question was approximately 14 weeks gestation when she died. Weeks away from fetal viability. Her father had to apply to the high court in order to switch off the machines and let his daughter be laid to rest with dignity. The overwhelming clinical judgement in the High Court attested that this fetus would not survive. A "futile exercise" the High Court said but it

happened because of a medico legal interpretation of the Eighth Amendment and it could happen again.

In addition to being an obstetrician, I am a specialist in fetal and maternal medicine. A significant part of this role is diagnosing fetal anomaly including severe anomaly that may be associated with in utero fetal death, death of a baby soon after birth or severe and complex physical or mental challenge. Ireland has the second highest rate of infants born with congenital anomaly in Europe. (Eurocat 2014). The most common congenital anomalies we see include chromosomal and genetic disorders, cardiac anomalies, cerebral and neural tube disorders.

NMH is a large tertiary centre for fetal medicine. We are fortunate to have a large multidisciplinary team including neonatal, midwifery, bereavement, radiology, paediatric, obstetric, genetic, social work and pathology experts to provide guidance and expertise in the context of complex fetal anomaly. A care pathway has been developed that adopts a multidisciplinary specialist approach to provide individualised care to families. We see women from all over Ireland and we know it is very difficult for families who have to travel long distances for care in the context of fetal anomaly. In 2016 195 women with a fetal anomaly were referred to NMH from units around the country.

The specialty of fetal medicine is increasing in complexity and our ability to identify genetic and structural anomalies in the fetus in utero is increasing. New techniques include the ability to detect chromosomal abnormalities by testing free fetal DNA carried in a mother's bloodstream from as early as 10 weeks gestation. This is done using a simple but expensive maternal blood test. Over 1,000 women at NMH opted for this test in 2016 with a rapidly increasing trend in uptake.

Chromosomes are essentially the frames within our cells which carry genetic material. While we previously relied on determining karyotype (the number and shape of the 23 chromosomes in every cell), new microarray technology provides better resolution so that we can see the genetic material carried on chromosomes in a more detailed way. This has increased our ability to identify genetic fetal abnormality.

Fetal imaging has also improved including enhanced ultrasound imaging and more recently MRI imaging provided at NMH. A scan performed at 18 to 22 weeks gestation to detect fetal anomaly is a standard of care but is not yet provided in all maternity units in Ireland which is hard to justify in 2017. One third of units in Ireland do not provide routine anomaly scanning. NMH performs over 33,000 pregnancy scans per year including 11,000 fetal anomaly scans per year for our own hospital population and for patients referred from HSE hospitals who do not provide a comprehensive fetal anomaly scan service. In 2016 at NMH, we identified 400 significant structural anomalies and over 60 chromosomal anomalies.

The diagnosis of a major fetal anomaly and particularly a fetal anomaly in which survival is unlikely after birth is a really difficult part of my job. You know when giving such devastating news that you change a family's life irrevocably. Counselling is always non directive but includes the variety of options available in each individual case.

In some cases women wish to continue their pregnancy knowing what will be but they tell me that whether or not their baby survives for a minute, an hour, a day or a week - this time is of infinite importance. The fetal medicine team, multidisciplinary neonatal teams in conjunction with our bereavement team support parents in this context as best we can in each individual circumstance. There are now national standards of bereavement care which address anticipatory bereavement. Strategies include an individualised multidisciplinary approach, memory making, support and advice for family members, bereavement counselling.

For some women the decision to continue with a pregnancy can be associated with increased maternal risk. For example in a case of conjoined twins where separation is not possible because of organ sharing, there are significant technical difficulties in delivering the conjoined babies requiring high risk caesarean surgery.

Some women chose not to continue with their pregnancy and to me it is understandable that parents will navigate these tragic circumstances in different ways.

Sixty women attending our service travelled to the UK for Termination of pregnancy in the context of fetal anomaly in 2016 and to date this year 43 women have travelled in this context. The majority of women had pregnancies complicated by chromosomal or genetic anomaly, multiple anomalies, anencephaly and ventriculomegaly. UK data suggest that in 2015, 135 women travelled from Ireland to the UK in the context of fetal anomaly where they terminated their pregnancy under clause E-"substantial risk of physical or mental handicap as to be severely handicapped".

Women who chose this option must travel to a different jurisdiction to obtain termination of pregnancy. The constitution protects women who decide to travel but a termination in this country in this context would be a criminal offence. As an obstetrician I can only give limited practical support in this decision. This includes contact details of fetal medicine centres in the UK. We do not make direct referral for pregnancy termination or advocate for one management option over another. Parents must make their own appointments and make their own travel arrangements. Families must find this particularly cruel. Parents also bear the cost of treatment in the UK which can run to several thousand euro

including medical treatment, flights, accommodation, laboratory bills and the cost of bringing their baby's remains home.

In this context parents frequently report feeling abandoned and the tragedy of their loss is exacerbated by the practical difficulties of bringing fetal remains home, navigating a different city and jurisdiction, being separated from their families at such a difficult time and the shame and stigma associated with travelling to England for termination of pregnancy.
From a clinical perspective care between two different jurisdictions is inevitably disjoint and clinical risk is increased. Some families cannot afford post-mortem analysis which may be so important in informing risk for future pregnancy.

I am struck by the findings of the UN Human Rights Committee which on several occasions have found that the current criminalisation and restrictive abortion provision in Ireland today, violate women's human rights including the right to freedom from cruel, inhuman or degrading treatment, the right to privacy and the right to freedom from discrimination.

Conclusion:

I have raised a number of difficult issues which I have encountered in my medical career. No law will adequately address the reality of the ethical dilemmas generated by human reproduction but we must acknowledge the real risks that women face in clinically complicated pregnancies. I believe that there are two main domains that need to be addressed from a clinical perspective.

We must address the criminalisation of medical care in Ireland.

At present a woman must have a substantial risk of dying before she can qualify for termination of Pregnancy.
Failure to adhere to this is punishable by a 14 year custodial sentence for both the woman and her Doctor.
This has the capacity to create clinical risk by distorting clinical decision making.

In the context of severe fetal abnormality the constitution protects a woman to travel to the UK but a termination of pregnancy performed in this context in Ireland is a criminal offence, punishable by a 14 year custodial sentence for both the woman and her doctor.
The criminalisation of care in this context creates social stigma, makes it harder for parents to confide in family and friends and separates parents from their family and friends at a most difficult time in their lives leading to a sense of abandonment.

In September 2017, The Council of the Royal College of Obstetricians and Gynaecologists (RCOG) voted strongly in favour of supporting the removal of criminal sanctions associated with abortion in the UK.

"We believe that the procedure should be subject to regulatory and professional standards, in line with other medical procedures, rather than criminal sanctions.

Abortion services should be regulated; however, abortion - for women, doctors and other healthcare professionals - should be treated as a medical, rather than a criminal issue."

We must address access to clinical Care:

Women require access to safe health care and to sound clinical decision making in the context of pregnancy complicated by severe maternal disease. A woman herself must have an input in to her care management and both she and her doctor must have the flexibility to make sound clinical decisions in good faith. It should not be a requirement that she is dying prior to these decisions being made. Timely appropriate clinical decision making in pregnancies associated with significant maternal risk will make women safer.
Children require special consideration in relation to clinical risk.

In the context of severe fetal abnormality, women currently travel to jurisdictions outside of Ireland to access complex medical care. While doctors provide non directive counselling and can provide information on termination of pregnancy, doctors cannot make appropriate clinical referral. Care delivered between jurisdictions raises all kinds of risk including lack of continuity of care, inability to access timely care, incomplete evaluation and confirmation of prenatal diagnosis and incomplete analysis of implications for future pregnancies.
Parents would much prefer to have the option to access this care at home close to their families and friends.
The ability to deliver such care in one specialist centre with appropriate multidisciplinary input will undoubtedly improve clinical care available to parents in this tragic circumstance.

Finally, the presence of the Eighth Amendment in our constitution creates unacceptable clinical risk and should be removed.