TERMINATIONS FOR MEDICAL REASONS:
THE WOMEN AND FAMILIES LEFT BEHIND BY REPEAL

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REPORT SUBMITTED BY TERMINATION FOR MEDICAL REASONS TO THE REVIEW OF HEALTH (REGULATION OF TERMINATION OF ABORTION) ACR 2018

ABOUT THIS SUBMISSION

TFMR Ireland is a group established in 2012 by six women who had experienced a diagnosis of a fatal fetal anomaly for their baby while pregnant. They were prevented by the Irish Constitution and legislation from accessing a termination of pregnancy in Ireland and had travelled to other jurisdictions to do so. TFMR is the advocacy arm of LMC Bereavement Support (LMC), a registered Irish Charity. LMC is the only non-directive, non-judgemental, choice-based Irish charity that supports parents facing a decision in their pregnancy following a fetal diagnosis, or who are bereaved through a termination for medical reasons.

LMC provides peer support, group support, online and email support to women and families before during and after their loss.

TFMR advocates and campaigns for legislative and constitutional changes to improve access to abortion for medical reasons in Ireland, for improved patient care for people accessing abortion, for inclusion of termination for medical reason into perinatal bereavement services, and for better standards of care in perinatal bereavement.

TFMR members and LMC service users are all women and families who have navigated the Irish health and legal systems after their baby is diagnosed with a fetal anomaly. First-person testimonies have been collected from those women and families, and their experience is at the centre of every recommendation made and we believe it should be at the centre of every decision made about the future of their care.

In preparing this report, TFMR was supported by Professor Fiona de Londras, Birmingham Law School, University of Birmingham

TERMINOLOGY NOTE

Throughout this submission we use the words ‘women’ ‘woman’ ‘pregnant woman’ ‘pregnant women’ ‘pregnant person(s)’ and ‘pregnant people’ interchangeably to include all persons who are or can be pregnant, regardless of gender identity.

EXECUTIVE SUMMARY

As a voluntary group that provides support to people who receive diagnoses of foetal anomalies, we have become painfully familiar with the shortcomings of the Health (Regulation of Termination of Pregnancy) Act 2018 ('the 2018 Act').

In this submission to the review of the 2018 Act, we bring together legal analysis, experiential knowledge from our work supporting women and families, and first-person narratives from people who have received diagnoses of foetal anomalies since the commencement of the 2018 Act. Combined, these sources and analyses show that **the 2018 Act is not fit for purpose from the perspective of persons who seek termination for medical reasons**.

The 2018 Act is (a) too narrowly drawn to meet the needs of people who receive diagnosis of foetal anomaly, (b) made narrower still in practice by the chilling effect of continued criminalisation and the burdensome processes prescribed in clinical guidance, (c) incompatible with international human rights law, and (d) being applied in a healthcare system that is under-resourced and inappropriately organised to deliver sensitive, woman-centred, rights-based care to women who seek termination for medical reasons.

Our submission includes a set of recommendations that we submit could improve the operation of the Act. In this Executive Summary we present these recommendations in order of priority, taking as our guiding principle that all women who seek termination for medical reasons should be able to access sensitive, compassionate, rights-based care at home in Ireland.

RECOMMENDATIONS

- Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).
- Amend s. 23 of the Health (Regulation of Termination of Pregnancy) Act 2018 to fully decriminalise abortion.
- Ensure the full and appropriate resourcing of the maternal health system.
- Amend clinical guidance to ensure that in all cases where a foetal anomaly is diagnosed, consideration be given to both s.s. 9 (risk to life or health) and s. 11 (condition likely to lead to death of the foetus) in assessing whether a termination of pregnancy may lawfully be provided.
- Revise clinical guidance on termination of pregnancy under s.s. 9 and 11 to be less burdensome for clinicians and pregnant people, to centre the pregnant women more fully in the assessment, and to ensure timely decision-making.
- Revise the clinical guidelines to make clear that multidisciplinary teams are not required to make a legally-significant determination under s. 11, although they may be appropriate to make clinical recommendations to the pregnant woman.
- Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to require notification of cases where s. 11 assessments concluded that a woman did not qualify for termination of pregnancy under the Act, indicating the relevant foetal diagnosis and allowing for on-going evidence-based assessment of the (in)adequacies of the Act.
- Amend s. 13 of the Health (Regulation of Termination of Pregnancy) Act 2018 to ensure that, in all cases, women receive a determination within 5 days of having sought the review.
- Amend s. 13 of the Health (Regulation of Termination of Pregnancy) Act 2018 to ensure that, where a foetal anomaly is diagnosed but it is determined that s. 11 is not satisfied, a review is (i) automatically initiated without the need for the woman to seek one, and (ii) completed within 3 days of its initiation.
- Train healthcare workers and design healthcare facilities to ensure that women who receive a diagnosis of foetal anomaly are treated with sensitivity, given full information about the diagnosis in language and forms they can understand, assured privacy and confidentiality, and provided with support and timely healthcare in all circumstances.
- Reform clinical care pathways to ensure that, where appropriate and chosen by the pregnant person, referrals are made promptly to healthcare facilities in England and Wales or another appropriate jurisdiction to enable the transfer of medical records and files and the provision of continuity of care before and after termination for medical reasons.
- Ensure that the costs of accessing termination for medical reasons in another jurisdiction are borne by the state through its usual arrangements for overseas healthcare provision.

1. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: RELEVANT PROVISIONS

When pregnant people in Ireland receive diagnoses of foetal anomaly their options relating to termination of pregnancy are governed by the 2018 Act. In particular, s.s. 8 (definitions), 9 (risk to health or life), 11 (condition likely to lead to death of the foetus), and 23 (offences) shape their experiences of care and the availability to them of termination of pregnancy in Ireland should they wish to receive it.

Section 8 of the Act defines, among other things, health ("'health' means physical or mental health"), and viability ("the point in a pregnancy at which, in the reasonable opinion of a medical practitioner, the foetus is capable of survival outside the uterus without extraordinary life-sustaining measures").

Section 9 makes provision for the termination of pregnancy where "2 medical practitioners, having examined the pregnancy woman, are of the reasonable opinion formed in good faith that...there is a risk to life, or of serious harm to the health, of the pregnant woman...the foetus has not reached viability, and... it is appropriate to carry out the termination of pregnancy in order to avert the risk" to life or health.

Section 11 makes provision for the termination of pregnancy where "2 medical practitioners, having examined the pregnancy woman, are of the reasonable opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth".

Section 23 provides that it is an offence "for an person, by any means whatsoever, to intentionally end the life of a foetus otherwise than in accordance with the provisions of the Act" (s. 23(1)), and that it is an offence "for any person to aid, abet, counsel or procure a pregnant woman to intentionally end, or attempt to end, the life of the foetus of that pregnant woman otherwise than in accordance with the provisions of this Act".

2. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: UNMET NEED FOR ACCESS TO ABORTION

In 2019 and 2020 combined, 197 people accessed abortion under s. 11 of the 2018 Act in Ireland (100 in 2019; 97 in 2020). Over the same period of time, 41 people accessed abortion under s. 9 of the Act (21 in 2019; 20 in 2020).[1]

Meanwhile, people in Ireland continued to access abortion care in England and Wales, albeit at a much-reduced rate than before the 2018 Act was introduced. In 2019, 375 people resident in Ireland accessed abortion in England Wales. Of these, 64 people accessed abortion under 'Ground E' of the Abortion Act 1967, i.e. where there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously disabled. 311 people resident in Ireland accessed abortion under Ground C in England Wales in 2019, i.e. where the pregnancy has not exceeded its 24th week and the continuation of the pregnancy would involve risk greater than if the pregnancy were terminated of injury to the physical or mental health of the pregnant woman.[2]

Similarly in 2020, and notwithstanding the challenges of the COVID-19 pandemic and restrictions on movement and travel, 194 people resident in Ireland received abortions in England Wales. Of these, 63 people received abortions under Ground E and 131 under Ground C.[3]

Grounds C and E of the Abortion Act 1967 are broader than s.s. 9 and 11 of the 2018 Act in significant ways.

Ground C allows for abortion where there is a risk to health up to 24 weeks (as opposed to viability in Ireland), and permits abortion where there is a risk to health of any severity that is greater if pregnancy is continued than if it is ended. In procedural terms, access to abortion on the health ground in England and Wales is subject to less burdensome procedures (certification by two doctors, usually done in a timely fashion) than in Ireland where clinical guidance lays out a burdensome and difficult process for access to abortion reminiscent of that which operated under the Protection of Life During Pregnancy Act 2013 and which is more demanding than is strictly required by the legislation.[4]

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[1] Department of Health, *Notifications in Accordance with Section 20 of the Health (Regulation of Termination of Pregnancy) Act 2018: Report 2019* (2021; Department of Health); Department of Health, *Notifications in Accordance with Section 20 of the Health (Regulation of Termination of Pregnancy) Act 2018: Report 2019* (2020; Department of Health).

[2] Department of Health and Social Care, *Abortion Statistics, England and Wales: 2019* (Department of Health and Social Care, 2020).

[3] Department of Health and Social Care, *Abortion Statistics, England and Wales: 2020* (Department of Health and Social Care, 2021).

[4] See both Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020); RCPI, *Interim Clinical Guidance on Risk to Life or Health of a Pregnancy Woman in relation in relation to Termination of Pregnancy* (May 2019).

Ground E allows for abortion in a far broader set of circumstances (where there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously disabled) than s. 11 in Ireland (2 medical practitioners, having examined the pregnant woman, are of the reasonable opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth"). Importantly, it is used where a pregnancy has exceeded 24 weeks and/or where people seek to have induced labour and to end their pregnancies in hospital settings with specialist expertise and support.

For some women who seek termination for medical reasons before 24 weeks, Ground C will be more appropriate (including, for some people, for reasons of cost). Women whom we have supported since January 2019 also indicate—expressly or by implication (e.g. by referring to needing to travel before they are 24 weeks gestation)—that they access abortion under Ground C. Thus, the amount of unmet need among women who need termination for medical reasons must be considered by reference to both Ground C and E in the United Kingdom, with at least some of the people who access abortion under Ground C doing so following receipt of a diagnosis of foetal anomaly.

2019	Ireland	England and Wales: Irish residents
Health ground	21 (+ 3 emergency) (s. 9, 2018 Act)	311 (Ground C, 1967 Act)
Foetal anomaly	100 (s. 11, 2018 Act)	64 (Ground E, 1967 Act)

2020	Ireland	England and Wales: Irish residents
Health ground	20 (+ 5 emergency) (s. 9, 2018 Act)	131 (Ground C, 1967 Act)
Foetal anomaly	97 (s. 11, 2018 Act)	63 (Ground E, 1967 Act)

Thus, the statistics on access to abortion under s.s. 9 and 11, and Ground C and E, in Ireland and England and Wales respectively are indicative of unmet need for women who require termination for medical reasons.

We note also that these statistics show that the limitations of the 2018 Act have a disproportionate impact on women who require termination for medical reasons. Even if we consider abortions for Irish residents under Ground E alone, in 2019 this constituted 17% of abortions for Irish residents in England and Wales,[5] and 32% of such abortions in 2020.[6]

Although it is clear that there is unmet abortion need in Ireland, we can only guess at the scale of that need and extrapolate from statistics published by the Department of Health and Social Care in England and Wales. In part this reflects the inadequate reporting requirements under the 2018 Act. Under s. 20 of that Act, all terminations must be notified to the Minister for Health, however there is no requirement to report situations where, following assessment under s. 11, it was concluded that the legal requirements for access to abortion were not met. As a result, we do not have any comprehensive record of how s. 11 is operating in practice, and what kind of diagnoses are falling out of the net and thus outside of the provision of care in Ireland.

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to require notification of cases where s. 11 assessments concluded that a woman did not qualify for termination of pregnancy under the Act, indicating the relevant foetal diagnosis and allowing for on-going evidence-based assessment of the (in)adequacies of the Act.

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[5] Department of Health and Social Care, *Abortion Statistics, England and Wales:* 2019 (Department of Health and Social Care, 2020), p. 16.

[6] Department of Health and Social Care, *Abortion Statistics, England and Wales:* 2020 (Department of Health and Social Care, 2021), section 4.17.

3. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: OVERLY-RESTRICTIVE DEFINITIONS

… this excludes a wide range of people from access to abortion in Ireland …

In part, we submit that the disproportionate impact of the limitations of the 2018 Act on women who seek termination for medical reasons is attributable to overly-restrictive definitions within the Act itself. In particular, s. 11 of the 2018 Act prescribes a very limited and limiting definition, restricting it to conditions "likely to lead to the death of the foetus either before, or within 28 days of, birth". In reality this excludes a wide range of people from access to abortion in Ireland, both because the foetal diagnosis does not meet this narrow definition (even though it relates to an extremely serious and life-limiting condition from which physicians can assure a woman the baby would not recover or with which life would be extremely short), *and* because s. 11 combined with the criminal offences in s. 23 operate to cause physicians to be extremely cautious about certifying that the requirements of s. 11 have been met, for fear of criminal liability (discussed further in Part 7 below).

The women and families we work with have experienced both of these phenomena as precluding their ability to access abortion under the 2018 Act.

"They weren't 100% sure that he would die within 28 days"

"His brain disability was moderate to severe. He would have daily seizures, would never walk, talk or even sit up. He'd need multiple operations because of the cleft and would have difficulty feeding. I was told as a single parent, I wouldn't be able to work again because I'd have to care for him, that was if he survived, of course. His ribs were very short so they were unsure if his lungs would develop enough for them to inflate for him to take his first breath. It was this uncertainty that placed me outside of the legislation. They weren't 100% sure that he would die within 28 days and now I had to make the decision whether I wanted to put my precious boy through daily excruciating pain just to survive to have a non-functioning life. A horrific decision no parent should ever have to make. The team were very clear that they would support me whatever my decision, but… I couldn't put anyone though that torture, I would terminate the pregnancy."

Author E

“… we can’t help you here … ”

“Our medical team in the hospital helped us process the news as much as they could but in the end the consensus was that our child would likely never survive birth and if he did, he would die soon after. However, to our utter and additional shock we were told by the head of fetal medicine ‘we can’t help you here because we can’t be sure he will die within 28 days although we are sure he will die soon after if not before birth’. We were told by our Consultant that we had two options: 1. Continue and let nature take its course or 2: travel to the U.K. for a termination for medical reasons.”

Author F

“It’s not possible to explain the extent of the heartache when you attend for a specialist prenatal appointment, pregnant with a much wanted baby, and hoping that they might have a clear, and fatal, diagnosis that is compatible with Irish legislation.”

“We did not initially understand the implications of what the fetal specialist midwife had told us in terms of termination in Ireland being entirely dependent on the baby having a clear diagnosis. However as the weekend progressed and we read more we understood that in situations where there are multiple foetal anomalies, anomalies which may be just as fatal as Trisomy 13 or 18, but where there is no diagnostic certainty, there is no possibility for termination in this country. It seemed and still seems completely bizarre that compassionate care is provided only on the basis of getting the ‘right’ awful diagnosis. This was even more unbelievable to us because we had both voted for the 8th Amendment to be repealed and our understanding was that this meant women would no longer need to travel for terminations for medical reasons.

It’s not possible to explain the extent of the heartache when you attend for a specialist prenatal appointment, pregnant with a much wanted baby, and hoping that they might have a clear, and fatal, diagnosis that is compatible with Irish legislation. Knowing that the options for termination here were so limited meant that we felt we were almost wishing the worst for our little girl when all we wanted was for her to be ok and to get the help we needed at home.”

Author B

“… despite the medical experts being very clear that my baby would be unlikey to survive.”

“This news was delivered sensitively and with great empathy. Both my husband and I felt listened to and respected. All our options were discussed but it was made clear to us, that my pregnancy was past the twelve week point at which I would be eligible for a termination on any grounds, and that the hospital could not facilitate a termination for medical reasons (TFMR) despite the medical experts being very clear that my baby would be unlikely to survive.”

Author A

“I thought that my vote to repeal the 8th had meant real change for the right to abortion care in Ireland. I was wrong.”

“That day, we got a call from our doctor to tell us that our very wanted unborn baby was high risk for Trisomy 21 (T21) or Down Syndrome. It was the worst phone call I have ever had to receive and our hearts were shattered. I don’t remember much from the actual call, just the doctors voice which will stay with me forever. I knew bad news was coming as I had been told the results would be back earlier than they came and I had already called the clinic 3 times that day to follow up on the results. Each time I was fobbed off and told the doctor would call me so I knew something was wrong. The one thing that did stick with me from that call was the doctor telling me we had plenty of time should we choose to terminate the pregnancy, and that we would need to travel to the UK for care. My husband and I were very shocked to hear this. We thought we had voted for change when we repealed the 8th and had no idea that we would have to travel to the UK for care. I thought that my vote to repeal the 8th had meant real change for the right to abortion care in Ireland. I was wrong.”

Author D

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).

4. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: INCOMPATIBILITY WITH INTERNATIONAL HUMAN RIGHTS LAW

Ireland is a party to multiple international human rights law treaties, including the International Covenant on Civil and Political Rights, and the International Covenant on Economic and Social Rights. In the cases of *Mellet v Ireland*[7] and *Whelan v Ireland*[8] the UN Human Rights Committee found that Ireland had violated the ICCPR by its failure to make abortion available in situations of fatal foetal anomaly. The 2018 Act does not remedy this incompatibility with international human rights because the narrowness of s. 11, combined with the continuing criminalisation of abortion (albeit not for women who avail of abortion themselves) produce a highly-restrictive approach to the determination of whether a woman 'qualifies' under the 2018 Act.

In its General Comment No. 36, the UN Human Rights Committee outlined the international human rights obligations of states under the ICCPR in comprehensive terms. Paragraph 8 of General Comment No. 36 provides:

"States parties must provide safe, legal and effective access to abortion where the life and health of the pregnant woman or girl is at risk, or where carrying a pregnancy to term would cause the pregnant woman or girl substantial pain or suffering, most notably where the pregnancy is the result of rape or incest or is not viable." [9]

s. 11 of the 2018 Act does not comply with these international human rights standards. In particular, and as clearly evidenced by the experiences of women and families whom we have supported since the Act came into effect, the overly narrow definition of condition likely to lead to the death of the foetus in s. 11 forces women either to continue with a pregnancy that causes them substantial pain or suffering, or to travel to access abortion in another jurisdiction. As was the case under the 8th Amendment, abortion travel imposes significant harms on women. These include pain, suffering, indignity, stigma and isolation (discussed further in Part 10 below). These experiences are strikingly similar to those of women who accessed abortion for medical reasons before the Act came into effect.

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[7] Human Rights Committee, *Mellet v Ireland* (17th November 2016) UN Doc. CPCPR/C/116/D/2324/2013.

[8] Human Rights Committee, *Whelan v Ireland* (12th June 2017) UN Doc. CCPR/C/11/D/2425/2014.

[9] HRC General Comment No 36 on article 6 of the International Covenant on Civil and Political Rights, on the right to life (30th October 2018), UN Doc. CCPR/C/GC/36, para 8.

“We didn’t get to bring our baby home with us and this will mean we never grie[ve] for our loss properly. This is something that haunts me daily and will do until the day I leave this world. I was asked by the nurse in the UK clinic what I wanted to do with the remains when I was taking the tablet that would start the termination. I was in no fit state to decide then and there what I wanted to do. My husband was in the waiting room so we couldn’t discuss it. I was told that the remains would have to go in check in luggage should we decide to keep them. I had no idea what we could do with the remains then when we got home. Do you call a funeral director? Can you have the remains cremated? None of this was discussed with us in Ireland before travelling to the UK. I panicked and our very loved baby now rests in Liverpool without us. I wish I had them here with me. I wish I had the compassion and support of our health service at this harrowing time so this wasn’t even something we had to worry about until later on.”

Author D

> “ I wish I had the compassion and support of our health service at this harrowing time.”

The pain, suffering and indignities experienced by women who are excluded from termination of pregnancy in Ireland are a direct consequence of the legislative design of the 2018 Act. Thus, not only is the 2018 Act incompatible with the ICCPR, but it produces effects that themselves constitute inhuman and degrading treatment and thus violate women’s rights under the ICCPR.

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).

5. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: FAILURE TO CONSIDER MULTIPLE GROUNDS FOR ACCESS

A further barrier to care experienced by people we have supported is that, once a foetal anomaly is diagnosed, the assessment of qualification for access to termination of pregnancy appears to focus exclusively on s. 11 of the 2018 Act. In our experience, there is no consideration of whether, as a separate matter, the pregnant woman is experiencing a risk of serious harm to her health, which would indicate legal qualification for abortion under s. 9.

The treatment of s.s. 9 and 11 as entirely different and, seemingly, exclusive pathways to accessing termination of pregnancy is not mandated by the legislation. Neither is it expressly mandated by the relevant clinical guidance, although there is no clinical guidance on how to undertake assessments of legal qualification under both of these grounds simultaneously. Such simultaneous assessment would allow for timely analysis of whether a termination of pregnancy can lawfully be provided, as well as recognising that receiving a termination of severe fatal anomaly can (a) indicate comorbidities on the part of the pregnant woman that should be considered under the s. 9 ground, and (b) may contribute to the development of a risk of serious harm to health under s. 9. Furthermore, in many cases foetal anomalies are diagnosed after 12 weeks LMP (i.e. after the cut-off for access to abortion without restriction as to reason) but before 'viability' as defined by the legislation. Therefore, complementary assessment under s. 9 is appropriate, even while s. 11 determination is taking place.

We reiterate that the 2018 Act defines health as both physical and mental health. We also note that s. 9 is satisfied where there is a risk of serious harm to health—there is no requirement in the legislation for the risk to grave, serious or significant. Nor is there a requirement that the materialisation of the risk would be imminent. Rather, the 2018 Act simply requires (a) that there be a risk, and (b) that the risk be one of serious harm to either physical or mental health. It is manifestly the case, and certainly the experience of some women that we have supported, that receipt of a diagnosis of foetal anomaly may be associated with risks of serious harm to health which should be assessed as a standalone consideration under s. 9.

Recommendation

Amend clinical guidance to ensure that in all cases where a foetal anomaly is diagnosed, consideration be given to both s.s. 9 (risk to life or health) and s. 11 (condition likely to lead to death of the foetus) in assessing whether a termination of pregnancy may lawfully be provided.

We appreciate that the clinical guidance for assessment under s. 9 is burdensome, however we stress that such a burdensome process is not mandated by the legislation. Indeed, the Guidance itself acknowledges this, stating that "While the legislation requires only two medical practitioners for certification under the legislation, this guidance document recommends discussion at an Obstetric Multidisciplinary Team meeting as a good practice point. We recommend that *Obstetric Multidisciplinary Team (MDT)* discussions take place for individual cases, which would form an important component of the assessment of the risk to the life of, or of serious harm to the health of, the pregnant woman".[10]

Recommendation

Revise clinical guidance on termination of pregnancy under s.s. 9 and 11 to be less burdensome for clinicians and pregnant people, to centre the pregnant women more fully in the assessment, and to ensure timely decision-making.

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[10] RCPI, *Interim Clinical Guidance on Risk to Life or Health of a Pregnancy Woman in relation to Termination of Pregnancy* (May 2019).

6. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: THE ILLUSORY NATURE OF REVIEW

Section 13 of the 2018 Act allows for a person to seek a review where, inter alia, an opinion is sought under s. 11 and either no opinion is given (s. 13(1)(a)) or the opinion is that the foetus has not been diagnosed with a condition likely to result in its death before or within 28 days of birth (s. 13(1)(b)). The Act requires that a woman be informed in writing of her right to seek such a review (s. 13(1)).

We are not aware of any person who has been told they do not qualify for termination under s. 11 ever making use of this review mechanism. This is partly because, in many cases, there has already been delay in receiving a decision under s. 11 and they seek to avoid further delay (including in order to access abortion under Ground C in England and Wales, i.e. before 24 weeks), partly because in some cases definitive diagnosis and s. 11 assessment in Ireland can take so long that people act to access abortion outside of Ireland before a formal opinion is communicated (thus there is, strictly speaking, no opinion to seek to review), and partly because the review mechanism is not fit for purpose. In some cases people are told that it is not worth their while using the review process.

It is important to stress that where a s. 11 opinion is sought a pregnant woman will usually already be in a state of distress, and perhaps disbelief, often focusing on trying to research the condition, get a firm diagnosis, and finding out about what her options are outside of Ireland. A woman is also often, although not always, at an advanced stage of pregnancy (20 weeks +) and, where she has decided not to continue with the pregnancy, will seek to access termination in as timely a fashion as possible.

As discussed in Part 9 below, s. 11 determinations in Ireland sometimes take quite a long time to be finalised, and the timelines laid down for completion of the review process (which, under s.s. 15 and 16, can take up to 10 days from the review being initiated) are simply not practical. Even if the review were to take place and to be successful (i.e. to determine that a woman may access termination of pregnancy under s. 11) the delays produced by the process would contribute significantly to her distress. Simply put, the review process laid down by the Act has not been designed with the realities, interests, and needs of pregnant women who seek termination for medical reasons in mind.

"It seems the decisions being made around whether you qualify for treatment here or will have to travel is very inconsistent..."

"Following on from all of this we have had meetings with fetal medicine consultants in our Dublin hospital and they were surprised at the information we were given around the appeals process. We were told that in our consultant's experience appealing it would be a waste of time and energy and it was unlikely to change anything for us. When we met with two other consultants in the same Irish hospital we had attended, they did not agree with this. It was very hard to hear that they thought our story may have gone differently if we had of appealed the decision before travelling. I am sure our consultant was not lying to us and had said she would support us if we wanted to appeal. It seems the decisions being made around whether you qualify for treatment here or will have to travel is very inconsistent and really depends on your hospital and that is wrong."

Author J

Recommendation

Amend s. 13 of the Health (Regulation of Termination of Pregnancy) Act 2018 to ensure that, in all cases, women receive a determination within 5 days of having sought the review.

Recommendation

Amend s. 13 of the Health (Regulation of Termination of Pregnancy) Act 2018 to ensure that, where a foetal anomaly is diagnosed but it is determined that s. 11 is not satisfied, a review is (i) automatically initiated without the need for the woman to seek one, and (ii) completed within 3 days of its initiation.

7. THE HEALTH (REGULATION OF TERMINATION OF PREGNANCY) ACT 2018: THE CHILLING EFFECT OF CONTINUED CRIMINALISATION

The continued criminalisation of abortion under s. 23 of the 2018 Act produces a chilling effect on medical decision making. As medical decision-making is central to—and in practice determinative of—legal qualification for access to abortion in situations of foetal anomaly, this has direct detrimental impacts for women who seek termination for medical reasons. International human rights bodies consistently recognise that criminalisation of abortion, including the criminalisation of health professionals who provide abortion outside of limited legislative provisions, has a chilling effect and produces caution and conservatism in decision-making.[11] Our experience is that this remains the case in Ireland.

In the experience of women and families we have helped, medical practitioners are reluctant to certify termination of pregnancy under s. 11 unless they reach a very high level of certainty that the foetus will die before or within 28 days of birth. In practice, this means that they are applying a higher standard of certainty than is required by the legislation, which requires that the two medical practitioners are "of the *reasonable opinion* formed *in good faith* that there is present a condition affecting the foetus that is *likely to lead to the death of the foetus* either before, or within 28 days of, birth" (emphasis added). This in-practice higher standard than is required by the legislation in turn further limits the availability of termination.

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[11] ECtHR, A, B & C v Ireland, App No 25579/05, 16th December 2010; Human Rights Committee, *Mellet v Ireland* (17th November 2016) UN Doc. CPCPR/C/116/D/2324/2013; Human Rights Committee, *Whelan v Ireland* (12th June 2017) UN Doc. CCPR/C/11/D/2425/2014.

"It appeared that in a country where medics can still be prosecuted around termination they are reluctant to, and ultimately will not, offer a medical opinion outside of having absolute diagnostic certainty."

"The appointment with the consultant foetal specialist confirmed the multiple anomalies on scan and the amniocentesis was performed. Our experience of talking to the two consultants we met (one at this appointment and another at the subsequent appointment for results) was very difficult. While they were professional and warm they refused to discuss the potential prognostic implications of the anomalies for our daughter. At our first appointment we were repeatedly told that we would have "a more thorough discussion" once the test results were back. However when the amnio failed to yield any diagnostic clarity the refrain we heard over and over was "we cannot tell you what life will be like for your little girl". I wanted to scream and cry hearing this. It left us completely alone in terms of trying to understand the meaning of these severe anomalies when what we needed was information from our medical team. As a healthcare professional myself I am familiar with prognostication and the limits of this so we were clear that we did not expect them to accurately predict what life would be like for our baby if she lived. Rather we wanted to discuss with them the international and epidemiological data that is published and which outlines what outcomes are like for babies with multiple anomalies such as those she had. While we cannot know the reasons for this behaviour on the part of our medical consultants, our perception was that they still feel like their hands are tied in terms of discussing the impact of such anomalies with parents, especially if the genetics tests do not provide a clear diagnosis. It appeared that in a country where medics can still be prosecuted around termination they are reluctant to, and ultimately will not, offer a medical opinion outside of having absolute diagnostic certainty. This is just not fair or realistic as many parents find themselves in situations such as ours."

Author B

The continued criminalisation of abortion outside of the circumstances provided for by the Act may contribute to the complexity of medical decision-making under the clinical guidelines applicable to s. 11 and s. 9. Even though the Act requires certification by two medical practitioners, in practice, and in accordance with clinical guidance,[12] determinations are made by a multidisciplinary team, which takes time to assemble and to review the files. While multidisciplinary decision-making is entirely appropriate from a clinical perspective, it introduces delays, uncertainties and in some cases further traumatising examinations and scans for pregnant women.

We consider that the guidelines mandating multidisciplinary decision-making in practice for s. 11 determinations go beyond what is required under s. 11 of the Act as a matter of law. We recognise that this is likely at least partly a result of the conflation within the Act of clinical and legal decision-making, exacerbated by the continuing criminalisation of abortion and associated apprehension of criminal liability in case of error (even though practitioners acting on *reasonable opinions formed in good faith* are not committing an offence under the Act).

Some hospitals and some practitioners are impacted more acutely by the chilling effect of s. 23 so that women who present with a particular diagnosis in one hospital may be provided with termination under s. 11, whereas the same diagnosis is not sufficient to access termination in another hospital or when considered by a different team of practitioners. This creates unevenness in provision across the country and can also produce the need for domestic abortion travel as women are referred into other hospital settings in Ireland where their diagnosis is known to be considered sufficient to satisfy s. 11.

The inchoate offences under s. 23 are extremely broad ("to aid, abet, counsel or procure a pregnant woman to intentionally end, or attempt to end, the life of the foetus of that pregnant woman otherwise than in accordance with the provisions of this Act") and unclear. As discussed further in Part 10 below, they may be operating to prevent referral for treatment outside of Ireland and thus create further burdens and isolation for women who do not qualify for termination under s. 11, and to undermine best medical practice for continuity of care.

Recommendation

Amend s. 23 of the Health (Regulation of Termination of Pregnancy) Act 2018 to fully decriminalise abortion.

Recommendation

Revise the clinical guidelines to make clear that multidisciplinary teams are not required to make a legally-significant determination under s. 11, although they may be appropriate to make clinical recommendations to the pregnant woman.

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[12] See both Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020); RCPI, *Interim Clinical Guidance on Risk to Life or Health of a Pregnancy Woman in relation to Termination of Pregnancy* (May 2019).

8. ACCESS TO TERMINATION OF PREGNANCY IN IRELAND: PRACTICAL IMPEDIMENTS

The women and families whom we have supported have reported significant practical impediments to accessing termination of pregnancy under s. 11 of the 2018 Act. In some cases, those impediments have been so significant that women have travelled to access care abroad to mitigate delays introduced by the shortage of specialised clinicians in Ireland, particularly given the clinical guidance requiring multidisciplinary team decision-making where a foetal anomaly is diagnosed. We recognise that the relevant clinical guidance provides that "All fetal medicine units should have timely access to clinical genetics specialists who may advise further on the type of testing necessary depending on the ultrasound presentation/family history and previous history",[13] however in practice this is not the case.

In many cases these impediments are manifestations of the under-resourcing of the health system and, in particular, the shortage of appropriate scanning and diagnostic equipment as well as specialist health care practitioners. Importantly, much of the resource that is currently used to underpin a decision about whether someone qualifies for abortion under s. 11 is required not because of clinical need, but because of the nature and form of the legislation, the continued criminalisation of abortion, and the associated processes laid down in the clinical guidance. In other words, much more health system resource is required to make a determination of foetal anomaly *as understood under s. 11* than is required to make a determination of foetal anomaly and associated prognosis *as a clinical matter*. Thus, the detriments experienced by women awaiting a s. 11 determination having already received a devastating diagnosis of foetal anomaly are not produced by clinical complexity but by the requirements of the legislation itself.

In its requirements and implementation the legislation does not take appropriate account of the realities of the Irish health system. Indeed, as well as creating burdens for pregnant women it also mandates the diversion of resources within the health system to making *legal* determinations under s. 11.

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[13] Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020), p. 4.

"Once the first consultant appointment was over we had a 10day wait for the results of the full microarray to be returned. In this time we spent hours liaising with hospitals and clinics in the UK trying to clarify our options. If we decided to pursue a termination we wanted to do this via a hospital in the UK so that we would have the support of a full maternity team, as well as access to genetic/post mortem facilities and a bereavement team. It was hugely important to us to pursue further genetic testing if the amniocentesis did not yield any clarity. We wanted to find answers and understand our little girl's life, both in terms of informing our future fertility but more importantly as a way of honouring her memory and understanding her story. The hospitals in the UK were responsive and kind. However they would not provide an opinion as to whether or not we were eligible for a termination under category E (after 24weeks due to severe/life limiting disability) until we had been reviewed by a geneticist in Ireland first. We did everything we could to see the geneticist in Dublin but the maternity hospital said that they only deal with one geneticist and that he would not see us until the full micro-array results of the Amniocentesis was back. We could understand the rationale for this however these results were not due back until I was 23wks pregnant so the window was too tight for us to take the chance to wait and so we booked in for a termination with a BPAS clinic at 23wks +4days. This booking was provisional but given the uncertainty inherent in the options here in Ireland we felt we had to plan both. It was like a race to get as many questions answered as possible in a couple of weeks and knowing that we just couldn't get all the information we needed was awful.

....

I have no idea how to communicate the pain and trauma involved in everything I described in the paragraph above. As our little baby started to kick and move in my tummy we spent 10days making phone calls to termination clinics and hospitals. As her Mum I had to make all of the calls myself as that is the policy of the clinics. I had to liaise directly with the hospitals in the UK and get together all of the information they needed only to be blocked each time because we had not seen a geneticist. My heart broke every time I had to make a call and tell our story and the story of our little girl.

During all of this time we were still hoping against hope that the amnio results would tell us she had a very manageable condition but because of the restrictions of the legislation here we had to go down this parallel road of planning a termination we didn't ever want, in a country we don't live in. The specialist fetal midwives in Dublin were very helpful and answered all calls and queries but they couldn't

> "...these results were not due back until I was 23 weeks pregnant so the window was too tight for us to take the chance to wait..."

get us what we needed which was prompt access to a geneticist. They informed us that since the introduction of the new legislation around the 8th amendment they don't have any increase in Consultant geneticist posts so the wrap-around services that families like us need are not there."

Author B

This can be effectively addressed by broadening the understanding of foetal anomaly for the purposes of access to lawful abortion under s. 11, the associated revision of the clinical guidance, and the commitment of further and better resources to support appropriate clinical care within the maternal health system.

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).

Recommendation

Revise the clinical guidelines to make clear that interdisciplinary teams are not required to make a legally-significant determination under s. 11, although they may be appropriate to make clinical recommendations to the pregnant woman.

Recommendation

Ensure the full and appropriate resourcing of the maternal health system.

9. ACCESS TO TERMINATION OF PREGNANCY IN IRELAND: LIVED EXPERIENCE

The 2018 Act is not merely a piece of legislation; it is a framework that helps to shape and determine intimate, distressing, and often isolating experiences for women who receive foetal anomaly diagnoses in Ireland. For many of us, that experience is not substantially different to what was experienced under the 8th Amendment, including being required to travel to seek abortion (see Part 10 below). However, the women we have supported report a range of experiences that point to difficulties beyond the Act.

Delay

The women and families we have supported have often reported significant delay in getting second opinions or confirmation of diagnosis, and in some cases it has been clear that these delays are a direct product of the requirements of the legislation:

> "After almost two weeks I was contacted… I needed to get another scan."

"I was informed that I had a molar pregnancy which never results in a viable pregnancy. I was distraught. I was told that I should not continue with my pregnancy for medical reasons.

…

After almost two weeks I was contacted by a lady from the hospital and she informed me that I needed to get another scan. I asked why and she said as you are choosing to terminate your pregnancy it is hospital protocol to have two scans by two different people and that a MDT team would meet to discuss my case in line with the new abortion laws in Ireland."

Author G

In other cases, delays that are endemic within the health system are experienced by women who have received fatal diagnoses and who may hear nothing further from their consultant or hospital for many days after the initial scan. While these delays might be routine within the healthcare system, for women in this situation time is of the essence, especially if they need to make decisions around accessing abortion care in England and Wales given the 24-week cut-off under Ground C. We note that the clinical guidance mandates "Prompt referral to a fetal medicine specialist ideally within 24 to 72 hours is the standard of care where a major fetal anomaly is suspected, followed by provision of written information resources and support",[14] however in reality women do not always receive follow-up appointments within this time frame.

“For the three days following I called each day with no return call.”

“The day after our news, I called the hospital to speak to my doctor about our decision, only to get an answering machine. For the three days following I called each day with no return call. I eventually called the Early Pregnancy Unit and spoke to the lovely ladies there, who booked me in for a follow up scan for Thursday the 25th for a second opinion. The same outcome came from this scan on the 25th of March. On the 26th of March (Friday), my partner and I left our home in the southeast at 3pm and drove to Belfast for our ferry at 21:30 pm.”

Author H

It is vital that the care pathways in Ireland are designed with the temporalities of abortion law in mind, i.e. bearing in mind (a) the traumatic nature of the receipt of such a diagnosis and the experience of prolonged uncertainty and lack of communication in such circumstances, (b) the need for certainty to enable timely decision-making if termination is sought in another jurisdiction where gestational limits for access to abortion apply, and (c) the centrality of timely, sensitive communication and information provision to good quality maternal healthcare provision.

Insensitivity in Communication

Women and families whom we have supported have generally been treated with sensitivity and kindness including in communications with healthcare professionals. However, this is not always the case. While health care workers are working under stressful conditions, there are occasions when their communication is insensitive and/or practitioners seem not to realise the likely impact of their words and conversations on the pregnant woman who is usually experiencing uncertainty, panic, and high levels of anxiety. In addition, and even though the clinical guidance recommends that “[i]nformation around termination of pregnancy should be provided in simple, clear and concise English with avoidance of medical terminology”,[15] this is not always the case in practice.

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[14] Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020), p. 4.

[15] Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020), p. 5.

"The test came back inconclusive a few days later so I was booked in again for another CVS. I went in on my own the second time as I knew what to expect and my husband had to work. There were 2 consultants this time and they were talking among themselves looking at the scan. The midwife turned the screen off that I could see as she saw me getting upset and closing my eyes. The consultant turned to me and said it's still tricky with the bowel there but it's doable. I really didn't want to hear that as I was terrified as it was. I said "is there any chance I can have the test trans vaginally again" and the consultant said I had been very lucky to be in the position that the other consultant was here there to do the procedure. I didn't feel very lucky! After the test the other consultant was asking me questions and I just didn't want to be there. I felt very intimidated."

Author C

"I felt very intimidated."

Insensitivity in Facilities

The nature and organisation of the physical infrastructure of many healthcare facilities in Ireland is such that women who have received a diagnosis of foetal anomaly find themselves waiting for further care and consultation with other pregnant women. They lack privacy or any facility where they can try to process the information they are receiving.

"…it would have been extremely useful to have an area or little room where I could have gone to compose myself…"

"The second radiographer came in and …[said] 'it's the fluid on his brain that we're worried about" Wait what? A hundred questions instantly came into my mind. What fluid? Where did that come from? What does that mean? Is it hydroencephalus? The radiographers looked very uncomfortable all of a sudden and it became clear that they just wanted me out of the room. They told me the consultant would answer my questions and thankfully I had an appointment that afternoon. The radiographers knew I was on my own and that I had to wait 2 hours until my appointment but just shuffled me out of the room on my merry way. I was in shock, what had just happened? At this point it would have been extremely useful to have an area or little room where I could have gone to compose myself before getting in my car and driving away."

Author E

"I had to sit in a waiting room with many other pregnant women…"

"On Tuesday 4th August we attended a larger hospital for further testing and scans in the foetal medicine department. I had to sit in a waiting room with many other pregnant women, alone, waiting to be called in."

Author D

"I rang my husband while I was waiting and I just said I know they are going to offer termination. I just felt something was really wrong.

I naively thought I'd be seen straight away so I still hadn't gone to the toilet since the first scan. I was so afraid I would be called and miss the consultant that I sat outside the door for about an hour still and trying not to have a panic attack. The heat from wearing a mask didn't help either. After an hour I went to the toilet.

I was there in the corridor for 2.5 hours watching heavily pregnant women pass. Then I was sitting beside a heavily pregnant women talking on the phone about Christmas presents. There was another girl there that the same sonographer who brought me up brought her up too and we kept on looking at each other."

Author C

"I was there in the corridor for 2.5 hours watching heavily pregnant women pass."

The lack of appropriate facilities causes significant pain and suffering, and has been exacerbated in the COVID-19 pandemic when women have generally been alone when receiving initial diagnoses or when waiting for further consultations due to facility-level restrictions on partners or support persons attending with them. Where partners have been given permission to attend, this has often not been communicated to security or reception so that people have had to explain they are attending with a diagnosis of foetal anomaly in order to secure admission, which is extremely upsetting for people and results in them having to sacrifice their privacy.

"The next day...I was called to go for the chromosomal test. My partner was given permission to attend the appointment. I had no written letter as I was just told over the phone so to get my partner past the reception desk / COVID security I had to explain what we were going through and he was let in."

Author G

"...I had to explain what we were going through..."

"My husband outside the hospital waiting and worried..."

"At my 12 week scan, at which I was alone due to covid 19, a potential anomaly was identified... Multiple weeks passed with trips to the fetal medicine scan unit at the hospital with countless scans and invasive fetal testing over a period of 3 awful weeks...I was alone for all of these scans and testing. My husband outside the hospital waiting and worried...At the final scan my husband was sitting on the curb at a back entrance to the hospital waiting again for me to text him to hear how bad it was. In my worst days I was on my own without the support of my husband beside me. I was asked to sit outside in the waiting room whilst the team of doctors discussed what they could see. There were 5 heavily pregnant expectant mothers around me. I couldn't bear to sit among them. At 15 weeks pregnant and in utter shock I went outside and sat on the curb outside the hospital with my husband. Both of us inconsolable waiting to be seen by the head of fetal medicine."

Author F

In some cases, women have also suffered from the lack of communication between health care workers, finding themselves having to explain to their consultant that the scans indicated a foetal anomaly.

"…she had no idea of any scan results from the morning…"

"Back to the hospital where I waited an hour in the waiting room full of pregnant people to see my consultant. When I eventually saw her, she had no idea of any scan results from the morning so I had to explain there was an issue. She read the scan after she had eventually located it and said I would have to go to Dublin for an amniocentesis. I made a face and she said 'Well that's only if you want to continue with the pregnancy' Again I was floored, was that what we were talking about, a fatal fetal abnormality? She then explained the extent of his issues, his brain hadn't developed properly and the structure joining the hemispheres wasn't present along with fluid and enlarged areas. His bones were very short, he had a cleft lip and probably palate and there could be problems with his kidneys. How was none of this seen at the 20 week scan, surely it was obvious that something had been missed. Well it's not an exact science I was told."

Author E

Lack of Information

Women and families we have supported have often reported that they received no information about support groups when they received a diagnosis of a foetal anomaly. This is the case even though the clinical guidance recommends that "[w]omen should have access to accurate and objective information and, if required, counselling and support. There should be local arrangements in place for providing value-neutral information to women about termination of pregnancy".[16] The women we have supported are generally told to return for further medical tests and diagnostic procedures, but do not have the condition clearly explained and, critically, do not generally receive written information or referrals to formal or informal support structures, leaving women alone and isolated in this time of great uncertainty.

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[16] Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020), p. 5.

"He said as I was just over the 12 weeks by their dates he needs to prove the condition is fatal. If I wasn't over 12 weeks I could take tablets there and then and go home and that would be the end of it. Then he said 'Or I could tell him I wanted to continue with the pregnancy and see how it goes'. He sent me on my way and said I need to come back in for a CVS test in the coming days to determine the diagnosis. I left the hospital in total shock and panic and no information on support groups or anyone to talk to after getting this news. it's not as if he said there might be a fatal condition, he said there is one and the CVS will tell us which one.

Thankfully no one close to me has had to go through this but I felt so alone. After hours of internet searching I found Leanbh Mo Chroi who were very understanding and supportive and gave me the bereavement midwife details etc. I just think women should be given a number at least to call if they are panicking and anxious."

Author C

"I left the hospital in total shock and panic and no information on support groups..."

Being a Burden

In some cases where women we have supported have been provided with a termination in Ireland, they have felt like they are a burden on the system, taking up a bed within a maternity unit that could be used by someone else. They are also, usually, provided with terminations within maternity care facilities and thus often have their grief exacerbated by sharing facilities with or being near people who are pregnant or who have just had their babies.

"I saw my consultant that morning and he told me my blood levels were worse but I could go home if I hadn't fainted. I called my partner to collect me.

I felt like as I was just waiting to go home I should offer up my bed to someone else. I was told I could stay. I don't think I fully realised how weak I was.

I walked out carrying my bag and past by a family who were heading home with a baby from hospital."

Author G

Recommendation

Train health care workers and design healthcare facilities to ensure that women who receive a diagnosis of foetal anomaly are treated with sensitivity, given full information about the diagnosis in language and forms they can understand, assured privacy and confidentiality, and provided with support and timely healthcare in all circumstances.

10. THE POST-REPEAL REALITY: CONTINUED ISOLATION AND TRAVEL FOR TERMINATION FOR MEDICAL REASONS

The reality for many of the women and families whom we support is that the Health (Regulation of Termination of Pregnancy) Act 2018 is not sufficient to meet their needs: either they do not qualify for abortion under the hyper-restrictive terms of s. 11 or the process of making such a determination is so time-consuming that they cannot wait for it to be completed and must instead travel to access termination. For these women, the repeal of the 8th Amendment has not brought about the changes that they need to ensure that they receive woman-centered, rights-based, respectful, and sensitive abortion care at home in Ireland. Instead, they continue to travel to access abortion in England and Wales. In this part of our submission, we focus on those women who continue to travel to access abortion, and the impediments that they face in doing so.

Access to Information

In cases where women do not qualify for abortion in Ireland, they are not usually provided with information on access to abortion in England and Wales. Instead they are told that they can 'travel' or 'go to England' but they are largely left to identify possible locations for care and navigate the health system there alone. While the clinical guidance anticipates situations where people may need to travel for termination, it does not clearly mandate the provision of information or facilitation of travel, but instead focuses on the provision of bereavement support which, while vital, is not sufficient. The clinical guidance provides:

"For some Parents, termination of pregnancy in Ireland may still not be an option, and this may be for complex reasons including legislative restrictions in Ireland for non-fatal but major fetal anomalies, the need to travel to another country for treatment, financial or social considerations, as well as to access specific medical procedures. During this time, and before termination of pregnancy, these Parents should be assisted with preparing for the birth and death of their baby. Opportunities for memory-making can be discussed and planned, as well as the logistics around making arrangements for the baby when the Parents are back in Ireland." [17]

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[17] Institute of Obstetricians and Gynaecologists, *Interim Clinical Guidance: Pathway for Management of Fatal Fetal Anomalies and/or Life-Limiting Conditions Diagnosed During Pregnancy: Termination of Pregnancy* (version 1.0; Published 2019; revised January 2020), p. 16.

Recommendation

Where relevant, women should always be provided with a list of abortion providers in England and Wales, details of information and support groups, and an opportunity to talk through options for clinical care with their health care providers.

Recommendation

Reform clinical care pathways to ensure that, where appropriate and chosen by the pregnant person, referrals are made promptly to healthcare facilities in England and Wales or another appropriate jurisdiction to enable the transfer of medical records and files and the provision of continuity of care before and after termination for medical reasons.

Recommendation

Ensure that the costs of accessing termination for medical reasons in another jurisdiction are borne by the state through its usual arrangements for overseas healthcare provision.

When we are contacted, TFMR attempts to provide women with information about centres of excellence, and other voluntary mutual aid organisations such as the Abortion Support Network provide information and, where necessary, funds to help support women to access care.

"I left the hospital in total shock and panic and no information on support groups or anyone to talk to after getting this news...After hours of internet searching I found Leanbh Mo Chroi who were very understanding and supportive and gave me the bereavement midwife details etc. I just think women should be given a number at least to call if they are panicking and anxious."

Author C

Lack of Referral

In all cases of which we are aware where women received diagnosis of a foetal anomaly that was determined not to satisfy s. 11, no referral to a healthcare facility in another jurisdiction was made. Instead, women who decide to end their pregnancies must arrange their care abroad alone. In some cases, this is impeded by the lack of access to their medical files and of timely access to scans and diagnostic tests which may be required by facilities in England and Wales to determine their ability to provide care.

As a group, we have long sought to ensure that the care pathways in Ireland for foetal anomaly diagnosis included referral to facilities abroad.[18] To date this has not been done. It is possible, as considered in Part 7 above, that health care providers and institutions consider that referral for an abortion that would not be lawful in Ireland is an offence under s. 23 (inchoate offences). If this is the case, this points to the extremely wide and disproportionate nature of the criminalisation provision, and even if this is not an accurate reading of the legislation it indicates how continuing criminalisation impacts on appropriate healthcare provision.

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[18] Leanbh Mo Chroí sent a letter detailing proposed care pathways following meetings with the HSE in July 2018 (ref: letter of 19 July 2018 (on file)). The proposed fully-developed care pathway for referral abroad where necessary is contained as Annex 3 of this report.

Travel, Trauma and Isolation

Since the introduction of the 2018 Act, the experiences of women who have travelled to access termination for medical reasons bear an eerie similarity to those who travelled before repeal of the 8th Amendment. Women experience fear, confusion, and indignity in travel. They incur considerable cost. They are alone. They experience great difficulty in handling remains. They feel isolated, excluded, and betrayed by their country. They experience acute pain, exacerbated by the content and operation of Irish law.

"I hear the gruff impatient voice reply as I try to cope with the physical aftermath of my termination in a portaloo toilet in a carpark. We are the very last car on the harbour boarding area, and the ferry is about to leave.

Meanwhile, I look down and see a continuous flow of blood fall into the toilet below me. I begin to panic. A rush of frenzied thoughts cross my mind in just a few moments. I don't know if this is normal, I don't know if something has gone wrong, I don't know if I am about to die in a portaloo in Holyhead. I reason with myself that everything will be fine, and I pray that I am not haemorrhaging. I take a deep breath, fix myself up and run back to the car. I find myself apologising to the staff member for "holding him up". We board the ferry back to Ireland, with irritated port staff watching us dismissively as we board.

When I considered writing this letter it was this image that replayed over and over in my mind. Perhaps those who govern us and who debate our legislation, consider the terminations but do they really consider everything that surrounds them? The Before, the After. My country has traumatised me not only by forcing me to undergo this procedure abroad, but also by forcing me into a situation in which I prayed for my health in circumstances I never thought I could find myself in. As I considered writing this letter, I thought to myself that the women of Ireland deserve better! I deserved better."

Author A

"…I don't know if I am about to die in a portaloo in Holyhead."

"We were unable to return to the UK to collect her remains if cremated and so we found ourselves bringing our much loved little girl home with us in a portable fridge that we could plug into our car. As I type that I feel so very sad I cannot even tell you. That was my little girl. I loved her more than anything. I wanted to cradle her in my arms and make everything better but I couldn't do that so instead we spent our final days with her alive trying to negotiate the practicalities of bringing her remains home. I'll never forget sitting on the Stena ferry with her remains in a portable fridge beside us as families

"I'll never forget sitting on the Stena ferry with her remains in a portable fridge…"

all around us chatted and played cards. I couldn't breathe with the grief and trauma."

Author B

"I left at 4:30pm, emotionally exhausted, bleeding heavily, and empty."

"On the 26th of March (Friday), my partner and I left our home in the southeast at 3pm and drove to Belfast for our ferry at 21:30 pm. We slept on the ferry in our private cabin until 05:30am, we docked in Liverpool and drove to another UK city for my appointment with NUPAS. We arrived at the clinic at 8am. I left at 16:30pm, emotionally exhausted, bleeding heavily, and empty. We then travelled back to the ferry in Liverpool for 7pm, and arrived back in Belfast at 6am, then drove back down to Waterford for 11am. I cried for two days straight. It was the most traumatic experience one could have."

Author H

"TFMR is a devastating type of loss, further stigmatised within the loss community."

"They do the absolute best they can under current legislation. But nothing can change the fact that I will forever feel cast aside by my country, in my time of need when I needed support the most.

My baby was wanted, was conceived, loved, dreamed of, cared for, adored, cherished, was hoped for, longed for, had a name planned, was thought about, had a heartbeat, shared my body, had a future planned, had a due date, had a life mapped out, had adoring parents, had a family to love them. Existed. We have taken the pain for them so he or she never had to experience it. We live with that every single day. TFMR is a devastating type of loss, further stigmatised within the loss community. Why do we keep terrorising and punishing TFMR families? Our loss is already great enough. Our pain and suffering held forever.

Current legislation needs to change. We need to be supported here, in Ireland. We need the freedom to choose what is best for our families."

Author D

Recommendation

Amend the Health (Regulation of Termination of Pregnancy) Act 2018 to permit abortion under s. 11 in situations of serious foetal anomaly (including but going beyond conditions likely to lead to death before or shortly after birth).

“It is barbaric and cruel, and it must stop.”

Author A

CONCLUSION

Prior to repeal of the 8th Amendment and the introduction of the 2018 Act, we made submissions to *inter alia* the Citizens’ Assembly and the Oireachtas Joint Committee on the 8th Amendment to communicate the ways in which the law as it then was punished, isolated, and failed to meet the needs of women and families who needed termination for medical reasons. In submissions to the Citizens’ Assembly, we sought to capture the realities for people who sought termination for medical reasons thus:

“… 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’ – ‘some people choose to travel’ or ‘all we can do for you in this jurisdiction’…”

“We typically have to identify hospitals or clinics ourselves, make our own appointments and obtain our medical records and send or bring them to these facilities ourselves….”

“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.” [19]

Almost four years after repeal of the 8th Amendment, and as outlined in this submission, women and families continue to have these same experiences. When it comes to termination for medical reasons, the 2018 Act is not fit for purpose.

On 26 May 2018, the then Minister for Health Simon Harris reacted to the vote to repeal the 8th Amendment by saying “Under the Eighth Amendment, women in crisis pregnancy have been told take the plane, take the boat, today we tell them; take our hand”. The reality, however, is that healthcare professionals continue to be precluded from offering them their hands and ensuring that they receive appropriate healthcare at home in Ireland, surrounded by their loved ones and treated with dignity and respect.

The women and families we support continue to take the plane and take the boat. The law continues to let them down.

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[19] TFMR, Submission to the Citizens Assembly (2016).

ANNEX 1: METHODOLOGY

TFMR was committed to ensuring that the personal experiences of women and pregnant people who sought termination for medical reasons under the Health (Regulation of Termination of Pregnancy) Act 2018 would be centered in this report. The report accordingly reflects (a) desk research, (b) insights gleaned from experience of the TFMR core team, and (c) evidence from first-hand accounts of seeking termination under the 2018 Act.

At the start of this research, TFMR approached people to whom they had provided support since the introduction of the Act to invite them to share their personal narratives. At the time, TFMR had provided direct support to approximately 30 people. Ten personal narratives were received. These narratives were submitted free form by those who wished to participate and are all included in full as ANNEX 2 of this report. Narratives were sent by email to one member of the research team who anonymised them, assigned them each a letter (A-J) and then sent the narrative to the lead author of the report (Fiona de Londras). Only the team member who received the reports directly ever had access to the non-anonymised narratives.

All participants were provided with an information sheet and consent form, and their narratives were used only once this was completed. All participants had the opportunity to ask questions about the research and could withdraw at any time. One participant (Author I) provided a narrative without the accompanying consent form. This narrative is accordingly not included in the report. All participants have been provided with this report in advance of its publication. Ethical approval for this work was provided by the University of Birmingham (Ref: ERN_21-0521).

ANNEX 2: PERSONAL NARRATIVES

Author A

From a small portacabin window above me, I hear my husband shout from the car to a ferry-port worker in a British port:

“Sorry, my wife is just in the toilet!”
“Could she not have waited ’til she boarded?”

I hear the gruff impatient voice reply as I try to cope with the physical aftermath of my termination in a portaloo toilet in a carpark. We are the very last car on the harbour boarding area, and the ferry is about to leave.

Meanwhile, I look down and see a continuous flow of blood fall into the toilet below me. I begin to panic. A rush of frenzied thoughts cross my mind in just a few moments. I don’t know if this is normal, I don’t know if something has gone wrong, I don’t know if I am about to die in a portaloo in Holyhead. I reason with myself that everything will be fine, and I pray that I am not haemorrhaging. I take a deep breath, fix myself up and run back to the car. I find myself apologising to the staff member for “holding him up”. We board the ferry back to Ireland, with irritated port staff watching us dismissively as we board.

When I considered writing this letter it was this image that replayed over and over in my mind. Perhaps those who govern us and who debate our legislation, consider the terminations but do they really consider everything that surrounds them? The Before, the After. My country has traumatised me not only by forcing me to undergo this procedure abroad, but also by forcing me into a situation in which I prayed for my health in circumstances I never thought I could find myself in. As I considered writing this letter, I thought to myself that the women of Ireland deserve better! I deserved better.

This happened to me in January 2021 at the height of the Covid-19 pandemic, and this is my story.

Our nightmare started with a phone call from a consultant, followed by a scan at 13 weeks in the Hospital. Unfortunately, like many couples, we were given the devastating news that it was highly unlikely my baby would survive until full term. This news was delivered sensitively and with great empathy. Both my husband and I felt listened to and respected. All our options were discussed but it was made clear to us, that my pregnancy was past the twelve week point at which I would be eligible for a termination on any grounds, and that the hospital could not facilitate a termination for medical reasons (TFMR) despite the medical experts being very clear that my baby would be unlikely to survive.

Looking back, it is now clear to me that it was after being told that we would not be treated at home, that this devastatingly sad diagnosis became a living hell. Like many people in my situation, I did not fit into the extremely narrow criteria of: “a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth”.

The sad reality is that it is very few who fit the above criteria. It feels like women in my situation have “fallen between the cracks” of the Repeal the eight legislation. I wholeheartedly agree that the Law needs to be reviewed and amended to facilitate women like me in our own country and to stop punishing tragedy.

When listening to a TFMR discussion, I heard a bereaved mother saying that she could accept that her baby would not live, even though she was heartbroken. What she could not accept was the way in which her country had treated her. This really resonated with me. I have been pregnant five times (three miscarriages and one TFMR) but I only have one son. I can accept this. I can accept life does not always work out and that unfortunate things sometimes happen. What I cannot accept is that at my most vulnerable, devastated, stressed and sick time in my life, I was forced to:

1. Leave my own country
2. Navigate the English health system
3. Book ferries
4. Find over two thousand euros to cover all costs
5. Sort out childcare for our three year old son

On top of this, our journey took place right at the height of the Covid-19 pandemic which meant:

- My husband could not enter the clinic with me
- We had a deadline of 12 midnight to return to Ireland or we would be faced with sourcing Covid testing and having to remain in the UK for days, due to banned travel
- Self-isolating from our families for 10 days upon returning to Ireland
- Putting my high risk husband who is a Type 1 Diabetic in peril by having to travel in the midst of the pandemic.

All this stress was on top of coming to terms with the fact that our much-wanted baby girl would not survive this trip. All because my

country continues to export me as a problem that someone else can deal with, no matter what the consequences are for me.
A human right is defined as “a right which is believed to belong to every person”. I believe it was my human right to be taken care of in my country, with dignity and respect. So, if I had been in my own country, what would the real differences have been? If my hospital had been allowed to care for me:

- I might have had a bed and a privacy curtain. This would have afforded me the dignity to cry in peace. My reality was a chair in a clinic waiting room for a full 8 hours, trying to hold back my emotions until it became impossible and my tears flowed freely whilst sat among a room of strangers in another country.
- I would have felt safe in the knowledge that in a few hours I would be recovering at home in bed, with my husband and son to hug and comfort me. My reality was a 48hr sleepless round trip, and due to delays a 14hr period with no food.
- I believe my stress levels would have been greatly reduced. My reality was the clinic informing me that they were facing long delays and that a patient’s partner was threatening to throw a brick through the window if he was not allowed enter the premises, due to the Covid restrictions.
- I would have felt safe in the knowledge that my mum could support me during those awful sad days following my TFMR. My reality was self-isolating for 10 days purely as a result of having to leave the country.

If I had been treated in my own country, most of this could have been avoided. I could have focused solely on what was important; me, my husband and the awful decision we were facing. I passionately believe my healing could have started much sooner if things had been different.

I find all this extremely difficult to put into words, part of me feels embarrassed or dramatic to share these hugely private events. However, I know in my gut that all I was asking for was to be treated with dignity. This is not shame on me, but shame on the current legislation and government for not changing it.

I have a loving, supportive husband and luckily, the financial means to just about cover the costs that were involved, but this whole experience has left me physically and emotionally exhausted, and my spirit crushed. I find myself thinking of the women who may have to deal with a diagnosis on their own. I think of the women who have no means of financial support or are having to take this journey totally alone. This fills me with anger and sadness. It is barbaric and cruel, and it must stop.

I have always considered myself to be a proud Irish woman. This whole experience has shaken me to my core. How can a country I love treat its women like this? Making them feel that not only does their country not care but by not facilitating them, it is impossible to escape an underlying feeling of judgement and shame. Have we learned nothing from the mistakes of our past? Why are we continuing with piecemeal solutions which do not adequately address the issue we claim to be committed to? I have always had great faith in humanity and perhaps naively, I always tried to see the best in people and situations. I told myself that bad situations arise out of ignorance. I believed if people knew better, they did better. I know stories like mine have been told many times before. Ignorance is not an excuse, this country knows what it does. We continue telling our stories, determined to ensure that the next generation of women will not have to face what we have had to experience.

My hope for 2021 is that as a country we do better, and that this is the last year any woman/couples are forced into making this awful trip to receive a TFMR. I call on those with the power to effect change to recognise that there are many complex medical reasons why a pregnancy cannot, or should not, continue. Such complexity cannot be simply quantified through a small list of 'eligible' diagnoses. Our lives are not a 'tick the box' exercise of bureaucracy.

My hope for the future is that no other woman feels the indignity I felt. My hope is that in the not-too-distant future, I can feel proud to be an Irish woman again.

Author B

Our little girl was longed for well before she ever existed. We had difficulty conceiving so there was a long road and ultimately she was conceived via IVF. My husband and I were beside ourselves with joy. Because of the IVF we had early scans which were all routine so we went to the 21week anomaly scan as excited parents-to-be. Within seconds we found out that our little girl was indeed a girl and then learned that she had multiple anomalies. The fetal medicine specialist midwife who joined us gave us clear information about her physical anomalies and booked us in for an appointment with the consultant and an amniocentesis the following Monday. She also gave us the facts with regards to our options which boiled down to: if there is a diagnosis of trisomy 13 or 18 you would be eligible for a termination in Ireland. If not we would have to travel to the UK before 24weeks to obtain a termination unless we are classed as eligible for their 'severe and life limiting' category (Category E) which does not have a time restriction.

This awful balancing of diagnostic certainty/uncertainty and timing completely shaped the rest of our experience with our daughter. The following days were spent reading everything we could find about the outcomes for babies with multiple anomalies such as those our baby had. The more we read the more we understood that she was unlikely to survive and that if she did her life would be heavily medicalised. We also began to understand that while many babies with multiple anomalies have an identifiable genetic diagnosis others do not. We did not initially understand the implications of what the fetal specialist midwife had told us in terms of termination in Ireland being entirely dependent on the baby having a clear diagnosis. However as the weekend progressed and we read more we understood that in situations where there are multiple foetal anomalies, anomalies which may be just as fatal as Trisomy 13 or 18, but where there is no diagnostic certainty, there is no possibility for termination in this country. It seemed and still seems completely bizarre that compassionate care is provided only on the basis of getting the 'right' awful diagnosis. This was even more unbelievable to us because we had both voted for the 8th Amendment to be repealed and our understanding was that this meant women would no longer need to travel for terminations for medical reasons.

Which is why when we returned to the hospital the following Monday we were hoping more than anything for diagnostic clarity. Our main hope was that the amniocentesis would identify the cause of the anomalies and that these would not be severely life limiting. We wanted the results to indicate that our little girl would be ok. But in the absence of this option we were left in a position where we were hoping for a diagnosis of Trisomy 13 or 18 because without this we knew that the implications of our daughter's anomalies were no less severe but the help available to us at home would be next to nothing. It's not possible to explain the extent of the heartache when you attend for a specialist prenatal appointment, pregnant with a much wanted baby, and hoping that they might have a clear, and fatal, diagnosis that is compatible with Irish legislation. Knowing that the options for termination here were so limited meant that we felt we were almost wishing the worst for our little girl when all we wanted was for her to be ok and to get the help we needed at home.

The appointment with the consultant foetal specialist confirmed the multiple anomalies on scan and the amniocentesis was performed. Our experience of talking to the two consultants we met (one at this appointment and another at the subsequent appointment for results) was very difficult. While they were professional and warm they refused to discuss the potential prognostic implications of the anomalies for our daughter. At our first appointment we were repeatedly told that we would have "a more thorough discussion" once the test results were back. However when the amnio failed to yield any diagnostic clarity the refrain we heard over and over was “we cannot tell you what life will be like for your little girl”. I wanted to scream and cry hearing this. It left us completely alone in terms of trying to understand the meaning of these severe anomalies when what we needed was information from our medical team. As a healthcare professional myself I am familiar with prognostication and the limits of this so we were clear that we did not expect them to accurately predict what life would be like for our baby if she lived. Rather we wanted to discuss with them the international and epidemiological data that is published and which outlines what outcomes are like for babies with multiple anomalies such as those she had. While we cannot know the reasons for this behaviour on the part of our medical consultants, our perception was that they still feel like their hands are tied in terms of discussing the impact of such anomalies with parents, especially if the genetics tests do not provide a clear diagnosis. It appeared that in a country where medics can still be prosecuted around termination they are reluctant to, and ultimately will not, offer a medical opinion outside of having absolute diagnostic certainty. This is just not fair or realistic as many parents find themselves in situations such as ours.

The result of this lack of open communication was that we felt completely alone in terms of accessing and understanding information that could support us with our decision. Worse still, it felt as if we were the people bringing up the ‘worst case outcomes’ only to be shushed; a pattern of interaction that left us feeling as if we were somehow betraying our little girl by trying to realistically appraise the situation rather than clinging to hope. The consultants were clear that there was potential for further anomalies, particularly neurologically, to emerge in utero or present at birth but would not discuss the potential impact of the multiple anomalies on our little girl’s life expectancy or functioning. Because of my job I have access to all of the appropriate journals and ability to read and understand the research but my husband and I were very distressed that no-one would talk this information through with us. We were, and still are, also concerned that others in our position wouldn’t even have access to the information we had. Informed decisions can only be made with accurate information and we were not provided with adequate information regarding the impact of multiple anomalies on our daughter’s longevity and functioning.

Once the first consultant appointment was over we had a 10 day wait for the results of the full microarray to be returned. In this time we spent hours liaising with hospitals and clinics in the UK trying to clarify our options. If we decided to pursue a termination we wanted to do this via a hospital in the UK so that we would have the support of a full maternity team, as well as access to genetic/post mortem facilities and a bereavement team. It was hugely important to us to pursue further genetic testing if the amniocentesis did not yield any clarity. We wanted to find answers and understand our little girl's life, both in terms of informing our future fertility but more importantly as a way of honouring her memory and understanding her story. The hospitals in the UK were responsive and kind. However they would not provide an opinion as to whether or not we were eligible for a termination under category E (after 24weeks due to severe/life limiting disability) until we had been reviewed by a geneticist in Ireland first. We did everything we could to see the geneticist in Dublin but the maternity hospital said that they only deal with one geneticist and that he would not see us until the full micro-array results of the Amniocentesis was back. We could understand the rationale for this however these results were not due back until I was 23wks pregnant so the window was too tight for us to take the chance to wait and so we booked in for a termination with a BPAS clinic at 23wks +4days. This booking was provisional but given the uncertainty inherent in the options here in Ireland we felt we had to plan both. It was like a race to get as many questions answered as possible in a couple of weeks and knowing that we just couldn't get all the information we needed was awful.

In writing this I am trying to give a clear account of the steps we went through during this process. But I have no idea how to communicate the pain and trauma involved in everything I described in the paragraph above. As our little baby started to kick and move in my tummy we spent 10days making phone calls to termination clinics and hospitals. As her Mum I had to make all of the calls myself as that is the policy of the clinics. I had to liaise directly with the hospitals in the UK and get together all of the information they needed only to be blocked each time because we had not seen a geneticist. My heart broke every time I had to make a call and tell our story and the story of our little girl. During all of this time we were still hoping against hope that the amnio results would tell us she had a very manageable condition but because of the restrictions of the legislation here we had to go down this parallel road of planning a termination we didn't ever want, in a country we don't live in. The specialist fetal midwives in Dublin were very helpful and answered all calls and queries but they couldn't get us what we needed which was prompt access to a geneticist. They informed us that since the introduction of the new legislation around the 8th amendment they don't have any increase in Consultant geneticist posts so the wrap-around services that families like us need are not there.

When we returned to the maternity hospital for the results of our amniocentesis I was 23weeks pregnant. Unfortunately neither the chromosomal test or microarray provided any clarity as to why our baby had several anomalies. So we were in the position we most feared. We knew things were looking extremely bad for our little girl but we had no clarity as to why. We thought that we would immediately see the geneticist at this point so that we could discuss things further. However we were told at the appointment that he had gone on leave that very day and would not return for 3weeks. I don't begrudge anyone their leave but the reality where there are parents such as ourselves making the most difficult decisions of our lives under extremely time sensitive circumstances and there was no one who could provide cover was just horrendous. Any hope that we could attend a hospital in the UK as opposed to a clinic was shattered in that moment. This meant that we would not have the option of delivering our little girl and holding her for whatever brief moments we might have had. We would not have the support of the professional services offered in a hospital. We could not avail of post mortem facilities or further genetic testing in the UK. And we would have to attend a termination clinic which, for all their care and kindness, is just not the same as being able to deliver your child in a maternity environment.

All of this contributed to us feeling that the problem was with us, or certainly as Mum that was how I felt. That somehow we were bad parents for considering termination as an option. Rationally we knew that it was out of love that we were doing this. We knew and still do that we would not wish for our daughter to suffer and that being a parent means that sometimes you have to make the most awful decisions, decisions where there is no right answer and where no one can tell you what to do. However the fact that none of the adequate supports were in place, that our doctors would not discuss the potential outcomes for our daughter, and the extent of the restrictions in the Irish legislation in terms of needing to get a specific diagnosis to qualify for care, meant that the implicit message we picked up was somehow we were at fault. The one exception to this was our specialist fetal midwife nurse who at all times made us feel understood and cared about. Without her, and our wonderful families and friends I'm not sure we would have survived emotionally.

Ultimately we travelled to a BPAS clinic in the UK at 23wks+3 and our little girl died by feticide the following day. The clinic were compassionate and kind but we had to stay at a hotel, travel alone and try to figure out how to bring the remains of our little girl home. We were unable to return to the UK to collect her remains if cremated and so we found ourselves bringing our much loved little girl home with us in a portable fridge that we could plug into our car. As I type that I feel so very sad I cannot even tell you. That was my little girl.

I loved her more than anything. I wanted to cradle her in my arms and make everything better but I couldn't do that so instead we spent our final days with her alive trying to negotiate the practicalities of bringing her remains home. I'll never forget sitting on the Stena ferry with her remains in a portable fridge beside us as families all around us chatted and played cards. I couldn't breathe with the grief and trauma. Awfully, at the time and now, we were so aware of how 'lucky' we were that we could even afford to make this journey. In addition to the emotional cost, the journey to the UK, the procedure itself and burial arrangements for her remains were a significant financial cost that we know many families could not afford. The fact that access to this healthcare should exclude those who cannot afford it is simply not ok.

No one should ever have to go through what we went through. We should not have had to be in that position. I do not believe that all of those of us who voted to repeal the 8th ever intended to create a situation where families like ours would be left in this awful in-between place where access to humane care is reduced to ticking the right diagnostic box.

I hope that sometime in the future we will be able to remember our little girl and connect only with the love we felt for her. For now those memories and feelings of love still come with so much sadness, hurt and trauma. Some of that I can accept. It is the grief that is inevitable when someone we love dies. But the trauma and even shame that I still have to work so hard to let go of I cannot accept. Those feelings are the result of systems that are not fit for purpose. A legislative system that is not adequate enough to take into account the complex reality of life as it pertains to life limiting prenatal presentations and a medical system that is not adequately resourced to provide timely and complete care. Writing this account of our experience is incredibly painful but our hope is that it will provide even a little insight into the reality of these systemic failures for families like ours.

There are no 'right' or easy answers when you find out your longed-for child has multiple severe anomalies. There are only difficult decisions, unknowables and what ifs. This time of our lives was always going to be devastating but it did not have to be so traumatic, devoid of compassion and lonely.

Author C

We were trying to conceive for 4 months on our second child. We found out early September that I was pregnant. My son was 2 at the time. We were over the moon that we would welcome a sibling for our son at the end of May 2021. I actually would have probably had our little girl by now but it just wasn't in the stars.

From very early I felt this pregnancy was different from my previous one. I had spotting at 7 weeks and again at 10 weeks so decided to go for a private scan just to make sure all was okay. The sonographer said baby was measuring 8 and this can happen, and it is normal. I didn't feel reassured at all leaving that scan and just felt something was not right.

Another 2 weeks passed and spotting started up again so I went into the hospital emergency this time. I was 12 weeks by my dates and the doctor on call did a scan and he said baby was measuring 8 to 9. As my dating scan was the following Thursday, he said to wait the few days to see what they said.

I went in on the Thursday and the sonographer said baby was measuring 10 weeks although my dates were 12 weeks 5 days.

I asked if all was okay and she said yes, this happens all the time and to come back in 2 weeks so she can see things properly.

I went back in on the 26th of November and after a few minutes she told me there was something wrong with the baby's brain. I was there on my own due to Covid restrictions and I didn't know what to do. I could feel myself starting to panic and I just said will this cause me to miscarry. She said she will bring me up to a consultant who will explain everything.

I rang my husband while I was waiting and I just said I know they are going to offer termination. I just felt something was really wrong.

I naively thought I'd be seen straight away so I still hadn't gone to the toilet since the first scan. I was so afraid I would be called and miss the consultant that I sat outside the door for about an hour still and trying not to have a panic attack. The heat from wearing a mask didn't help either. After an hour I went to the toilet.

I was there in the corridor for 2.5 hours watching heavily pregnant women pass. Then I was sitting beside a heavily pregnant women talking on the phone about Christmas presents. There was another girl there that the same sonographer who brought me up brought her up too and we kept on looking at each other.

I finally got called and the consultant asked me could he scan my stomach. He was quite for about 20 minutes. I was trying not to cry but my stomach kept bouncing while I was silently crying. He finally asked me to sit up and take a seat. He said it wasn't good news. That he thought my baby had a condition called Patau syndrome or Triploidy. He started drawing chromosomes on a sheet of paper and how these conditions can happen. I just zoned out and kept on looking at his polka dot socks!

He said as I was just over the 12 weeks by their dates he needs to prove the condition is fatal. If I wasn't over 12 weeks I could take tablets there and then and go home and that would be the end of it. Then he said 'Or I could tell him I wanted to continue with the pregnancy and see how it goes'. He sent me on my way and said I need to come back in for a CVS test in the coming days to determine the diagnosis. I left the hospital in total shock and panic and no information on support groups or anyone to talk to after getting this news. it's not as if he said there might be a fatal condition, he said there is one and the CVS will tell us which one.

Thankfully no one close to me has had to go through this but I felt so alone. After hours of internet searching I found Leanbh Mo Chroi who were very understanding and supportive and gave me the bereavement midwife details etc. I just think women should be given a number at least to call if they are panicking and anxious.

I received a call from the consultant the next day and he asked me to come back in the following Monday.

My husband was able to come with me on the Monday for the CVS. It was a bit of a struggle to get him into the hospital with the restrictions at the reception area. After hours of researching different conditions I made up my mind that I will have a termination if the results are bad but that I would rather be put to sleep and have a surgical procedure. I felt this would be easier for me mentally. I had loads of questions for the consultant and I was given straight answers. I remember trying to get the words out about the surgical option but my husband had to talk for me. I felt like if I took the tablets, I would be killing the baby, as opposed to being put asleep and the procedure happening.

The consultant replied by saying it was not a baby it's a foetus. I was taken aback and I just stopped talking and could feel my eyes welling up. He saw how upset I was and his attitude changed a bit. I think he knew what he said had hurt me as she was a baby to me. He said he can try and give me a surgical termination, but I might be too far gone.

They could not do the CVS test trans abdominally as my bowel was in the way so they called another consultant up and he was able to do it trans vaginally. I was glad of this as I suffer with my bowel and my aunt was dying in hospital with a perforated bowel due to a procedure, she had had so I was very anxious. The test came back inconclusive a few days later so I was booked in again for another CVS. I went in on my own the second time as I knew what to expect and my husband had to work. There were 2 consultants this time and they were talking among themselves looking at the scan. The midwife turned the screen off that I could see as she saw me getting upset and closing my eyes. The consultant turned to me and said it's still tricky with the bowel there but it's doable. I really didn't want to hear that as I was terrified as it was. I said "is there any chance I can have the test trans vaginally again" and the consultant said I had been very lucky to be in the position that the other consultant was here there to do the procedure. I didn't feel very lucky! After the test the other consultant was asking me questions and I just didn't want to be there. I felt very intimidated. I did however voice my opinion on giving women some sort of support numbers and contacts when they are initially given the bad news.

The results came back about 4 days later and it was confirmed over the phone that the condition was Triploidy . They were not sure if it was part molar or not so I would have to wait until January to find out that it was not part molar.

I was booked in for the termination 4 days later on the 19th of December. I had to go into the hospital on the Thursday to take the first does of tablets. Then go into the hospital to deliver on the Saturday. My husband was allowed come with me and we packed a bag to prepare to stay for the night. My mother-in-law took our little boy for us for the night.

Trying to get into the hospital together was a struggle and the girls were not letting my husband in. I was so upset I just walked off and he explained why we were there.

We were brought up to the ward and given the best treatment. Our midwife was so nice. The room was so cold and plain, and I felt chills when I walked in, but we soon made it better with our few bits we brought. I started taking the tablets at 10am and the pains started getting worse gradually. The consultant who I was dealing with was on call that weekend, so he came to check on me.

I was able to manage the pains with just the initial pain killers I was given and breathing techniques. I delivered our daughter in the bathroom in a bed pan at 5.10. At the time I wasn't sure if I had delivered or if it was tissue I was passing. She felt so small, then I passed another bit that felt the exact same size about 2 minutes later. I said a prayer and massaged my stomach, but I didn't look as we have chosen not to as she was going to be so small. I went back out to my husband and I said I think it just happened but I'm not sure. I said maybe we should wheel the bed pan out, so the baby isn't in there on their own. While I was in the bathroom the pains started to ease off, so I knew it was over. It happened very peacefully and relatively pain free and I was only [].

We called our midwife in and she confirmed. She wheeled the bed pan out. It was very emotional, and we just held each other and cried. The midwife came back with a Feileacain box which was so nice and such a thoughtful thing to do. At the time we still did not want to know the gender, so we were calling the baby Angel baby. I was 18 weeks by my dates and 15 by the hospital dates. The consultant came and scanned me and said it looks like everything was okay. He said she was much smaller than they had expected but it was just because of her condition. They said my dates could have been correct but who knows. All I know it I was 18 weeks when I delivered.

The Chaplain came in also to have a chat and talk about the remains. We had decided to have them buried out with the other angels in Glasnevin. We wanted to be there for the burial, so we were told we had to collect the coffin and bring the remains out ourselves. We did that the day before Christmas Eve. Just the 3 of us. Our son was a great distraction.

A few weeks passed and I was anxious to get the results of the part molar. Everything was delayed due to Covid so we got the results near the end of January. The consultant rang me while I was in work and said it was not part molar and was explaining in scientific language how they knew it was not molar. This went over my head. I was just relieved it was not part molar.

We went back into the hospital for overall results 6 weeks later and the consultant let slip our baby was a girl. He said they knew it was not part molar because there were 3 X chromosomes so it came from me. If it was part molar it would have been from my husband. I nearly died. I just turned to my husband and said I knew she was a girl. I said to the consultant we still did not want to know, and he said he would have explained on the phone in January but I obviously did not realise then. I've been struggling with this news since we found out. I wanted to know when I was a bit stronger to deal with it but I suppose these things happen.

Thank you for listening to our story. I hope this helps change things and that women who are in the position I was in do not have to travel for help.

Author D

This is our story our very wanted and planned second pregnancy. We were very lucky to get pregnant the second month of trying in May 2020 and were so happy at the prospect of welcoming another baby and expanding our family of 3. We have a son who was born in 2018.

The pregnancy was a tough one from the start. I was quite sick, something I never experienced first time around with my living son. I was lucky to be working from home though and the sickness was manageable. My sister was helping out with creches closed so she was the only one we told in the early weeks as she could see how sick I was. We wanted to wait until we had our first scan before telling anyone else. Looking back now, that was so naive of us! We had booked in for the Harmony test (NIPT test) at 10 weeks. We had also done this test on our first pregnancy so I guess we saw it as a formality and nothing to worry about. I went in for the test and the scan on 20th July 2020, alone under COVID restrictions. When I saw the heartbeat on the screen, I was overjoyed. Everything looked well and the blood sample was taken for the test. That very day we started to tell our families the good news that baby number 2 was on the way and due in February 2021.

On 31st July 2020, our lives changed forever. I was nearly 12 weeks pregnant. That day, we got a call from our doctor to tell us that our very wanted unborn baby was high risk for Trisomy 21 (T21) or Down Syndrome. It was the worst phone call I have ever had to receive and our hearts were shattered. I don't remember much from the actual call, just the doctors voice which will stay with me forever. I knew bad news was coming as I had been told the results would be back earlier than they came and I had already called the clinic 3 times that day to follow up on the results. Each time I was fobbed off and told the doctor would call me so I knew something was wrong. The one thing that did stick with me from that call was the doctor telling me we had plenty of time should we choose to terminate the pregnancy, and that we would need to travel to the UK for care. My husband and I were very shocked to hear this. We thought we had voted for change when we repealed the 8th and had no idea that we would have to travel to the UK for care. I thought that my vote to repeal the 8th had meant real change for the right to abortion care in Ireland. I was wrong.

On Tuesday 4th August we attended a larger hospital for further testing and scans in the foetal medicine department. I had to sit in a waiting room with many other pregnant women, alone, waiting to be called in. As soon as I was brought through though, the doctor called down to allow my husband up to be with me. I was scanned and the scan confirmed the initial NIPT screen as a structural abnormality consistent with T21 was seen, megacystis. I still think daily that this news would have been given to me alone during my first routine scan, had we not decided to pay for an early scan and NIPT testing. I would have been alone during that first routine 12week scan when they found that megacystis and my husband would have been sitting in the car, waiting for me. I would have received that harrowing news alone.

CVS samples were taken to confirm the diagnosis. We were again told during this appointment that we would need to travel to the UK if we decided we didn't want to continue with the pregnancy. The nurses in the foetal medicine department in the hospital are living angels. They have carried me through the pain of our loss and did everything they could for us. Ultimately though, all they can do is give advice and documentation for both sides, if we wanted to continue with the pregnancy or end it. All of the organisation for a TFMR falls on you after that, the paperwork I was given included a number to call to book into a UK clinic.

I called the clinic in the UK that day to book in for the termination, knowing we had very little time to organise everything. Neither me or my husband were in a fit state to have to plan travel to the UK for a termination after receiving the most harrowing news that our very wanted baby had a chromosomal abnormality. We had very little time to just sit with the diagnosis. I was terrified that COVID restrictions would change and we would have no options available to us. I was terrified that all flights would be cancelled.

We didn't get the choice between a medical or surgical termination, surgical was all that was offered.

We received the confirmation from the CVS sample that our beautiful baby had Down Syndrome (T21) on 11th August 2020. On Friday 14th August just after 1pm, we terminated the pregnancy in Liverpool, UK. I was 14 weeks pregnant. My husband and I had to leave our 2-year-old at home, take unwanted risks in a COVID world to travel to Liverpool at a very significant cost to avail of a basic human right. This decision was not taken lightly and we had to make the heart-breaking decision to end a much-wanted pregnancy. This decision will stay with us for the rest of our lives and there is not a day that goes by that we don't think about our baby and what could have been. We will live with the pain and the guilt of our decision forever.

We didn't get to bring our baby home with us and this will mean we never grieve for our loss properly. This is something that haunts me daily and will do until the day I leave this world. I was asked by the nurse in the UK clinic what I wanted to do with the remains when I was taking the tablet that would start the termination. I was in no fit state to decide then and there what I wanted to do. My husband was in the waiting room so we couldn't discuss it. I was told that the remains would have to go in check in luggage should we decide to keep them. I had no idea what we could do with the remains then when we got home. Do you call a funeral director? Can you have the remains cremated? None of this was discussed with us in Ireland before travelling to the UK. I panicked and our very loved baby now rests in Liverpool without us. I wish I had them here with me. I wish I had the compassion and support of our health service at this harrowing time so this wasn't even something we had to worry about until later on.

Having to travel abroad and knowing that what we were doing is still illegal in Ireland made it feel like we were doing something wrong. What was already the most traumatic and horrific event in our lives was made even worse by the fact that we could not safely and freely access abortion at home. We felt very much alone and cast aside by our health system and country. And we were lucky. We had the money to be able to make the decision that we felt was best for our family; we could freely travel to the UK. Many do not have the same choice; it is taken from them by their inability to obtain a UK visa or afford the travel and treatment. I wanted to include the breakdown of the costs incurred to us due the fact that we had to travel to the UK for this treatment in order for you to understand the financial burden that this places on people in our situation. Please keep in mind that the below costs do not include the costs incurred to us to organise childcare for our 2 year old while we were away and are also most likely reduced costs due to COVID.

Hotel Cost	€250	this was most likely a reduced rate due to COVID
Flight Cost	€200	for 2 adults (this was likely a reduced fare due to COVID)
Car Rental Cost	€100	
Food Cost	€100	
Termination Cost	€450	
TOTAL COST	€1,100	

No monetary value can explain the detrimental effect all of this has had on my mental health. I am fortunate to be seeing a counsellor since our return from the UK and this support was organised for me by the midwives in the foetal medicine department. She is amazing, as are the midwives that supported us in the Foetal Medicine Department. I was offered a scan before we got on the plane to the UK to confirm the heartbeat was still there, I was offered a follow up scan after the procedure to make sure there was no placental remains. They do the absolute best they can under current legislation. But nothing can change the fact that I will forever feel cast aside by my country, in my time of need when I needed support the most. Making the decision we did was the worst thing that has happened to us as a family and right when we needed to be held, our health system and country pushed our problem onto the UK. Yet, the mental health cost of what we had to endure is now borne by the HSE. I am 100% sure that had I been legally able to avail of the services I needed here in Ireland, the trauma of the event would have been reduced and the aftereffects would be easier to deal with.

Patient's rights need to come first. The right to choose needs to come first. No-one should be able to make a life changing decision like this, other than the family involved. A government should not be able to decide the fate of a family. They should have the choice to do what is right for them and their circumstances. Each and every situation is unique to that family experiencing it. Complications with much wanted pregnancies, like ours, are often not seen or diagnosed until after 12 weeks at which time it is too late to avail of abortion services in Ireland. Abortion needs to be readily available, not just for pregnancies up to 12 weeks. Abortion needs to be fully decriminalised in Ireland. It needs to be clear cut and not subjective. Abortion is a human right and people should NOT have to travel in a pandemic to access healthcare!

On 26th May 2018, Leo Varadkar said it was 'a day we say no more'. 'No more to doctors telling their patients that there's no more can be done for them in their own country, no more lonely journeys across the Irish sea, no more stigma as the veil of secrecy is lifted and no more isolation as the burden of shame is gone.'

So, why was I told there was nothing more that could be done for me in my own country? Why did we still have to make the lonely, heart-breaking journey across the Irish sea during COVID? Why do I feel so isolated? Why do I feel so much shame and guilt? Why is my beautiful baby still in Liverpool when I am here? Why?

My baby was wanted, was conceived, loved, dreamed of, cared for, adored, cherished, was hoped for, longed for, had a name planned, was thought about, had a heartbeat, shared my body, had a future planned, had a due date, had a life mapped out, had adoring parents, had a family to love them. Existed. We have taken the pain for them so he or she never had to experience it. We live with that every single day. TFMR is a devastating type of loss, further stigmatised within the loss community. Why do we keep terrorising and punishing TFMR families? Our loss is already great enough. Our pain and suffering held forever.

Current legislation needs to change. We need to be supported here, in Ireland. We need the freedom to choose what is best for our families.

Author E

I was overjoyed to get a positive pregnancy test in February 2019. It was my first fertility cycle and I couldn't believe how lucky I was that it worked first time. I had an amazing pregnancy too, very little nausea, no extra tiredness just happiness. I attended all my scans and did the NIPT at ten weeks where I was relieved that the results were low risk for chromosomal issues. My 20 week scan was perfect so I figured it was all plain sailing for me until the bombshell dropped at 25 weeks.

Lying on the ultrasound table where we just had to get a picture of his face as he was shy the last time and had his hands in front of it. The big milestone anomaly scan had passed so this was just a quick one before I saw the consultant. My daydream about where I was going to go for lunch was shattered by the words 'I think he does have a cleft lip, I'm just going to get my colleague'. A tear rolled down my face and I told myself not to be so silly, it wasn't the end of the world, just a cosmetic thing, it would be fine. The second radiographer came in and I asked her if this was the case and she replied 'yes but it's the fluid on his brain that we're worried about' Wait what? A hundred questions instantly came into my mind. 'What fluid? Where did that come from? What does that mean? Is it hydroencephalus? The radiographers looked very uncomfortable all of a sudden and it became clear that they just wanted me out of the room. They told me the consultant would answer my questions and thankfully I had an appointment that afternoon. The radiographers knew I was on my own and that I had to wait 2 hours until my appointment but just shuffled me out of the room on my merry way. I was in shock, what had just happened? At this point it would have been extremely useful to have an area or little room where I could have gone to compose myself before getting in my car and driving away.

During my 2 hours, I went to a café and unashamedly cried into my cappuccino. I had my laptop and Googled which surprisingly put my mind at ease. They could probably just put a shunt in, it would be alright. Back to the hospital where I waited an hour in the waiting room full of pregnant people to see my consultant. When I eventually saw her, she had no idea of any scan results from the morning so I had to explain there was an issue. She read the scan after she had eventually located it and said I would have to go to Dublin for an amniocentesis. I made a face and she said 'Well that's only if you want to continue with the pregnancy' Again I was floored, was that what we were talking about, a fatal fetal abnormality? She then explained the extent of his issues, his brain hadn't developed properly and the structure joining the hemispheres wasn't present along with fluid and enlarged areas. His bones were very short, he had a cleft lip and probably palate and there could be problems with his kidneys. How was none of this seen at the 20 week scan, surely it was obvious that something had been missed. Well it's not an exact science I was told. Not a very satisfactory answer and again there was this uncomfortableness now that there was a problem with the baby.

I was referred to a large Dublin hospital, who in fairness got back to me quickly but I had to wait a week for an appointment. A nail biting, horrendous week where every possibility went through my head. The scan there confirmed the previous findings, and they performed an amnio to see if there were any chromosomal or genetic reasons for his conditions. More anxious waiting for ten days and nothing showed up so no closer to having any answers. Then a fetal MRI was performed to see the extent of the damage to the brain. A bank holiday weekend so five days until I got the results of that, more waiting without knowing. They got the consultant neurosurgeon in to explain the results for which I was very grateful, I needed to know all the information. His brain disability was moderate to severe. He would have daily seizures, would never walk, talk or even sit up. He'd need multiple operations because of the cleft and would have difficulty feeding. I was told as a single parent, I wouldn't be able to work again because I'd have to care for him, that was if he survived, of course. His ribs were very short so they were unsure if his lungs would develop enough for them to inflate for him to take his first breath. It was this uncertainty that placed me outside of the legislation. They weren't 100% sure that he would die within 28 days and now I had to make the decision whether I wanted to put my precious boy through daily excruciating pain just to survive to have a non-functioning life. A horrific decision no parent should ever have to make. The team were very clear that they would support me whatever my decision, but I had four weeks to think about it and debate with myself at what threshold would be severe enough for a baby and me to endure.

I couldn't put anyone though that torture, I would terminate the pregnancy.

My files were sent to Liverpool who rang me with an appointment in 10 days. I spent those days trying to create a lifetime of memories with my boy. But I was also stuck to google worried about travel to Liverpool, how I'd get to the hospital from the airport, currency exchange, taxi timetables and also the cost of it. €3,500 for a termination and post-mortem, I was lucky that my family lent it to me. Things I really, really didn't need to be thinking about at this time. However, from the moment I got there both myself and my baby were treated with dignity and respect. I was there for 4 days as my labour couldn't be induced, I guess I wanted to hold onto him but I did get to spend a precious 24 hours with his body. I couldn't stay there forever though and a day after I gave birth, I had to take a taxi, a train, a flight and drive 2 hours to get home something that my poor battered body should not have had to go through. My son was sent off for post-mortem and I got to go back 2 weeks later for the cremation. I was lucky to be able to do this, a lot of parents aren't. My family never got to meet him, they were in another county anxiously awaiting texts from me to find out what was going on. I went away pregnant and came back not, it made it not seem real to everyone but me. The contrast in the care I received in Liverpool and my local hospital was stark. In the local hospital, the staff were ill prepared to break bad news and deal with the situation. There were no protocols in place and they were so uncomfortable. Liverpool were amazing with a designated room for my labour so everyone who entered the room knew to handle me with sensitivity. A beautiful nursery where I got to create memories with my son and follow up bereavement support groups. At no stage before now was I offered bereavement support or even a list of organisations who could help me through this difficult time.

Tragically my situation is not uncommon. Women fall through the legislation all the time and it's a gap that needs to be addressed. Getting a fatal or life limiting diagnosis is traumatic but the attitudes and treatment of the staff can make a tragic situation either worse or more bearable. 2 days after my birth, I attended my GP who told me she was Catholic but would endeavour to deal with me professionally. She didn't so much as take my blood pressure or ask me how I was either physically or emotionally, not very professional in my opinion. Having to travel takes away your support system at home and robbed my family of meeting my son, they have pictures instead. There's the physical and financial burden as well which all take their toll. The only positive to the situation is the compassion and care that I received when I was in Liverpool, I very much doubt that I would have received the same excellence of care had I delivered [baby's name] in Ireland.

Author F

"I am a heartbroken mother of one non-living child born
22 September 2020 in the UK"

My husband and I are both Irish we own a home in Ireland where we both live and work and contribute to the community.

Having had a miscarriage on my first pregnancy we were delighted to find out I was pregnant in June 2020 - 6 months later. I had two early scans to ease my mind. All was well. At my 12 week scan, at which I was alone due to covid 19, a potential anomaly was identified.

The doctor mentioned "oh the guts don't look to have gone back in". I was shocked and didn't know what this meant. My husband was outside in the car waiting for an update. I paid a €1000 booking fee for private patient care and left absolutely petrified.

I Googled. Multiple weeks passed with trips to the fetal medicine scan unit at the hospital with countless scans and invasive fetal testing over a period of 3 awful weeks. Our consultant finally diagnosed our beautiful son with a very rare condition- cloacal extrophy/OEIS Complex. I was alone for all of these scans and testing. My husband outside the hospital waiting and worried.

At the final scan my husband was sitting on the curb at a back entrance to the hospital waiting again for me to text him to hear how bad it was. In my worst days I was on my own without the support of my husband beside me. I was asked to sit outside in the waiting room whilst the team of doctors discussed what they could see. There were 5 heavily pregnant expectant mothers around me. I couldn't bear to sit among them. At 15 weeks pregnant and in utter shock I went outside and sat on the curb outside the hospital with my husband. Both of us inconsolable waiting to be seen by the head of fetal medicine.

I don't expect many to have heard of Cloacal Extrophy. Nor had we. This means our baby had a giant omphalocele containing all of his abdominal organs (stomach, spleen, intestines and liver) in a sac outside of his body. His bladder was split in two, it was also outside his body. He had no anus. His colon was connected to his bladder. He had no fallus/penis and his other reproductive organs were also outside his body uncovered by skin or muscle. His spine was split in two. We were told he would never live a comfortable life, if he even lived at all. Our medical team in the hospital helped us process the news as much as they could but in the end the consensus was that our child would likely never survive birth and if he did, he would die soon after. However, to our utter and additional shock we were told by the head of fetal medicine "we can't help you here because we can't be sure he will die within 28 days although we are sure he will die soon after if not before birth". We were told by our Consultant that we had two options: 1. Continue and let nature take its course or 2: travel to the U.K. for a termination for medical reasons.

The consultants knew what we needed to do and although they "guided" us they could only say so much without putting them on the wrong side of the law. When we told them that the choice was made for us by this diagnosis, they agreed that it was best for the sake of our child and his dignity.

The empathy from the doctors and the entire fetal medicine team was there in spades. They knew that this was such a case that warranted help within the Irish maternity system, but they told us their "hands were tied" by the legislation but that we have "options in the U.K.". The parting words were that they "hated to see us go in such tragic circumstances" when they themselves believed that "our case warranted help in Ireland".

We frantically sought an opinion from Great Ormond Street Children's Hospital in London just in case who could only tell us that "the right decision was being made". That decision was to terminate our baby purely out of love, compassion and mercy for a life that he would never get to enjoy.

A terrible decision for any parents to make compacted by my husband and I having to leave our family, our friends, our home and our dog. Everything good in our lives. Afraid and suffering physically, emotionally and mentally we would have to leave Ireland and go to an English city to do the final act of love for our son.

In the lead up to and after the official diagnosis I couldn't physically or mentally do anything in the days following the diagnosis, but I was advised by a consultant in the hospital that BPAS in the U.K. could help. I had to call them in convulsions of tears and in disbelief and unimaginable sorrow and find out if they would take me for a surgical termination. That call was absolutely brutal on my mind. The nurse was lovely, but it didn't help. I couldn't even comprehend what I was discussing with her. I told her I would call her back- I never did.

Meanwhile we contacted a centre of excellence specialist women and children's hospital in the U.K. and they considered our case. After a review they agreed that I could labour and deliver our baby there. I desperately wanted to meet my son, so a surgical termination was not an option for us personally so going to an NHS hospital was the only option. It was and still feels completely traumatic to me that I had to email a hospital in the U.K. and arrange times and dates for urgent medical help for myself.

My wonderful husband had to look up flights and book them and a hotel for us to stay in.

I will never board a flight again for good or bad without being reminded of this horrific time in our lives. I can't explain the feeling of getting on a flight, collecting bags in the airport, getting in a taxi, booking into a hotel and being forced to walk around an unfamiliar city trying to find a place to eat for my husband (as I just couldn't) knowing what was about to happen the next day. I feel sick to my stomach when I think about it which is daily. We needed our families watching out for us, feeding us, checking in on us but instead we were the most alone we have ever felt in a hotel room.

After a 7 hour intense and highly emotional labour our gorgeous boy was born at 3.55pm. That day changed our lives for the worst. Our son was born sleeping and none of our family could see him, no one was able to be there to support us because we had to travel.

The extent of his issues was clear to see. We didn't need further consultants to tell us that he was gravely ill. However, a consultant in fetal medicine in the hospital came to see us just before he arrived. She discussed the prognosis for our son on the basis of our scans which I had sent to her for review to see if they would accept our case.

She was horrified that we were there and not at home with the support we so desperately needed. She worked in the Irish maternity system as a doctor for 12 years before taking up a consultant position at this hospital. She advised us that the scans were so shocking to her and her colleagues that it was incomprehensible that we had to travel before proclaiming that the attitude to fetal medicine in Ireland remains barbaric for women/people like us. She's absolutely right I may as well have been a dying animal they way I was treated in this Country with the treatment so badly needed being denied to us.

That consultant also explained that she was "certain that the expertise was not available in Ireland to deal with the severity" of our baby's issues and that in the unlikely event that he be born full term the doctors would have had no option but "to leave him to die". She then left the room. I was frantic hearing this and so saddened.

The abortion legislation has forgotten the women and men like us whose babies are in that terrible grey area where they may or may not die within the prescribed time frame.

A few hours later out son was born. We held him and cried and longed for him before he was placed in a cold room overnight. My placenta broke during labour and without pain relief a doctor came in to try and manually remove it.

We held our baby again the following day and had him baptised by the hospital chaplain before we let him go back to the cold room. He was the only baby there the nurse told us. We were then sent on our way. He remained at the hospital so a post-mortem could take place.

I was physically sick at this point and due to leave our much loved and desperately wanted baby, completely numb the next day (2 days after giving birth). My legs barely move one in front of the other since that day.

It is vitally important to note that whilst back at home in Ireland, 9 days after giving birth, I suffered a massive haemorrhage. I was rushed to theatre for emergency surgery as parts of my placenta had still remained. I lost 2 litres of blood within 2 minutes and needed blood transfusions whilst I was in theatre. I am lucky I was at home in Ireland but if I wasn't I don't know what would have happened let alone if it had happened on the flight home.

Our baby was cremated 4 weeks after he was born. This was my saddest day just my husband and I and a priest who we didn't know saying his funeral mass. My husband and I had flown back for the cremation, another flight distraught. As this was all out of pocket expense we could not remain there until his ashes were released. They were couriered back to us and delivered by our local postman as if they were a pair of shoes ordered online 3 weeks later.

I will personally never be the same again but the added stress and vilification of having to travel for the TFMR has left me unable to live life like I used too.

My mental health has deteriorated severely, and I have had to attend trauma counselling as a result. In addition, as I had to travel, I didn't fall within the hospital system here in Ireland or in the UK on my return. Having travelled we fell between two stools. We were alone and left to find external support to help us grieve and process what had happened to us and our much-wanted baby.

The decision to terminate for medical reasons must be placed into the hands of patient and the fetal medical teams. Those who know the case. I have absolutely no doubt that I would have been treated in the hospital in Ireland if my consultant was not afraid of reprisal under the legislation."

Author G

I was very excited when I first found out that I was pregnant. My pregnancy was very much a planned pregnancy and was looking forward to becoming a mother for the first time at the age of 37.

I paid for a private consultant in a large maternity hospital. At my first scan (which I attended alone) everything looked good, and the consultant told me that my pregnancy was going well. I couldn't wait to share the news with my partner who was waiting anxiously in the car park.

I booked to have a harmony test (Non-invasive Prenatal Test) at 12 weeks. I just wanted to make sure that my pregnancy was going to plan before I shared my exciting news. Again my partner waited in the car park while I sat waiting for the test.

I chatted with a nurse who reassured that the odds of having an abnormal pregnancy were really low and not to worry.

I was excited and looking forward to the scan. I went in for the scan and as the scan progressed, I was asked was I sure of my dates and then told that everything was not going well even though there was still a heartbeat. I was shown what the concerns were, my little baby had fluid on the brain, around the placenta, the placenta was extra-large and I had cysts on my ovaries. I was in shock and alone. I was great full for the kindness shown but wished my partner could have been there.

I texted my partner "it's not ok" or something similar. A chromosomal test was recommended. I was very upset and distraught. I cried in the bathroom and tried to hold it together until I could tell my partner the news. I told him in the car park and I bawled crying as he tried to console me.

The next day (during my Easter holidays) I was called to go for the chromosomal test. My partner was given permission to attend the appointment. I had no written letter as I was just told over the phone so to get my partner past the reception desk / COVID security I had to explain what we were going through and he was let in.

We both were shown the concerns again on the scan. I had the test while my partner was waiting outside the door.

I was told that the results might take longer as it was the Easter holidays, given a leaflet to call if I experienced bleeding and told to rest.

All I could do was wait. The results came back and I was informed that I had a molar pregnancy which never results in a viable pregnancy. I was distraught. I was told that I should not continue with my pregnancy for medical reasons.

I was obviously so upset and felt a huge amount of guilt as I knew my baby still had a heartbeat. I was told that I would be contacted by the hospital as they would arrange a D&C.

After almost two weeks I was contacted by a lady from the hospital and she informed me that I needed to get another scan. I asked why and she said as you are choosing to terminate your pregnancy it is hospital protocol to have two scans by two different people and that a MDT team would meet to discuss my case in line with the new abortion laws in Ireland.

I was very upset and hurt by her words. I was not choosing to end my pregnancy, this wasn't my choice. My choice would have been to have a healthy baby.

I went up for my final scan. My partner waiting in the car. I waited along with 6/7 other pregnant ladies. I felt alone and vulnerable.

I went into the room and asked if my partner could attend this scan and I was told he could. I expressed my concerns for him getting past the reception desk. She rang reception and told them to let him through.

At this scan we were both bold the sad news that my baby had no heartbeat. Another lady came in to confirm this too. We found out the gender of our baby, a little girl.

I felt so upset but relieved that she had passed away herself. In a way I left like I had lost my little baby twice.

This made things easier I suppose as I no longer needed a MDT team to meet.

I went for a COVID test and then was told to come back with a hospital bag just incase the next day at 2pm. We arrived at 1:15 to get parking. My partner said goodbye to me as I headed in alone for the procedure.

I checked in and was told where to go. One of the nurses told me to sit on a chair while she found a bed for me. She was very formal but I felt no compassion.

I was just asked a series of questions and left to wait. I was brought down to have the procedure at around 6 o'clock. My partner waiting in the car until then.

The team of people In the theatre showed compassion. They performed the D&C.

During the procedure I lost 1.8 L of blood. I woke up and my legs were shaking. A nurse told me that the procedure went well and that she would ring my partner to tell him.

She said "the procedure went well and she is fine and that we are keeping her in overnight for observation". This was news to me. I didn't know this was happening and I wasn't sure was I fine if my leg was shaking.

I was brought back up to the ward. I was given offered some food and put on a drip. The consultant told me that everything went well but I had lost 1.8l of blood and that they had done there best to remove everything. He told me that with the molar pregnancy even though I was 14 weeks I was like someone who was 20 weeks.

The nurse who was on the later shift after my procedure asked me if I had a nightdress and I only had an extra large T-shirt as I hadn't been shopping because of COVID and I had avoided buying many pregnancy clothes until I was sure that everything went well. She didn't seem to impressed by me and by the fact that I didn't have slippers. In my stress I had forgotten them. I just felt really embarrassed so I just said I would sleep in the gown.

Then later that night the nurse came around and told me that I hadn't been to the toilet and that I had to go now.

Now I hadn't been to the toilet as I was on a drip, in shock and extremely weak because of the blood loss. She escorted me to the bathroom and I was told if I felt faint to pull on the red cord.

I managed to go to the toilet without fainting and the toilet and then I asked the nurse to help me into my the large T-shirt that I felt uncomfortable.

I think what I would have liked from the nurse would have been a simple I am sorry for your loss and maybe a little bit more compassion.

I managed to sleep with the help of sleeping tablets that my consultant had prescribed for me.

I saw my consultant that morning and he told me my blood levels were worse but I could go home if I hadn't fainted. I called my partner to collect me.

I felt like as I was just waiting to go home I should offer up my bed to someone else. I was told I could stay. I don't think I fully realised how weak I was.

I walked out carrying my bag and past by a family who were heading home with a baby from hospital.

I was as white as a ghost and just about able to walk and carry my bag. I don't know how I made it out to the car.

I told my partner to stop at a pharmacy to get iron tablets as my consultant had recommended them. He had also recommended b12 injections.

I spent the next couple of days in bed just getting up to go to the bathroom. My partner dropped me up food and drinks.

When I got the energy I rang my doctor. I spoke to the secretary and I told her what had happened. She told me that the doctor might ring me. She didn't. I booked in for a blood test so that the doctor would know how much vitamin b12 I would need.

I arrived to get my blood test and got very upset as I had presumed that the doctor would see me but I was told that she was too busy that I had only booked a blood test. My blood was taken and I felt feeling really embarrassed. My partner reminded me that my hormones were coming down and I was obviously not myself.

I booked an appointment to see the doctor the next day. She met me and apologised for not being able to see me and for putting the wrong date of birth on my bloods and told me that I would have to get a second blood test.

As my pregnancy was a molar pregnancy the consultant told me that I needed to get weekly blood tests in the hospital to check my hormone levels as they needed to be tracked to zero. A week after my D&C I arrived back up to the hospital to start my first of weekly blood tests.

I found this extremely hard as I was surrounded by pregnant women. A reminder of what I had lost.

I am getting used to my weekly blood tests but it's not easy being back in the same waiting area.

I understand that there is a global pandemic and that hospitals are under huge pressure but I left the hospital after the D&C upset for what I had to go through but also upset for all the other woman who may have to experience what I went through.

That's why I wanted to share my story. I was offered no counselling or no type of additional support in relation to my grief from the hospital.

I google miscarriage Ireland and spoke to a lovely lady Deidre on the phone. I spoke to another lovely lady called Amanda from Leanbh mo Chroi and joined a WhatsApp group.

I am a primary school teacher and I was working from home while I was pregnant. Then I was on sick leave after my miscarriage and D&C. Now I am back to school and finding it hard as many of the children that I taught are asking me why was I out and that they had heard that I was having a baby.

I hope sharing my experience helps.

Author H

My Story started the 15th of March 2021. It was the day after mother's day, when I received my first mother's day card and was feeling hopeful after having 6 scans in the previous 8 weeks as I was high risk after a missed miscarriage 3 years ago. When I entered the room, I was nervous scared, and not hopeful. I had learned at that point to never be too hopeful after having a missed miscarriage already. What I was so nervous to find out was if there was a heartbeat or not. I didn't even realise there could be potentially something worse ahead.

Once my appointment started, the sonographer immediately told me she has seen the heartbeat. After about 2-3 minutes there was complete silence, and once I asked if everything was ok, the dreaded words was spoken ''I'm so sorry". There was a Nuchal Translucency measurement of 7mm fluid at the back of my baby head which means there was a very high chance of my baby had a syndrome, and with a Measurement of 7mm, it was not looking good. Once I was told this information, I remember a cold feeling running through my body. I was quiet and took in the information the sonographer was telling me. After 5 minutes I was led out of the room into a private area and was told I could call my partner to come into the hospital to me, which I was very grateful for. Once he had arrived, we went into the doctor and spoke more about what was found.

I was given less than 10% chance of my baby being healthy.

I was told I will more than likely miscarry myself / have a still birth or my baby will pass away within a few hours after birth due to the amount of fluid found. I was given examples of Edwards syndrome, Down Syndrome, heart defect etc. we had been advised that our options were to get a harmony blood test to determine if there is a syndrome there and/or NIPT Test in Dublin. After our doctor gave us these options, she advised Ireland does not terminate Trisomy 21 in Ireland.

Once we left the hospital and went home to discuss this, we opted for no testing as by this stage I was 12 weeks pregnant, and the time frame for both tests would leave me to be 15 weeks by the time our results would be back. The reason why we decided against testing is because we felt I couldn't carry for a further three weeks, and then decide to terminate which would take another 1-2 weeks to organise and travel due to COVID. My partner and I just felt that was not something we could do to our baby. It was already devasting enough, never mind waiting until our baby could potentially be 17 weeks.

On the 16th of march, we booked our termination in the UK for the 27th of March. I would be 13 weeks and 6 days pregnant. This was the earliest appointment we could get as it was near next to impossible to get over to the UK due to COVID. There were zero available flights over to the UK. We booked our ferry and dealt with the hours upon hours of travel from South of Ireland over to the UK in the middle of a Global pandemic. The cost of this travel was another worry on top of everything we were already going through.

The day after our news, I called the hospital to speak to my doctor about our decision, only to get an answering machine. For the three days following I called each day with no return call. I eventually called the Early Pregnancy Unit and spoke to the lovely ladies there, who booked me in for a follow up scan for Thursday the 25th for a second opinion. The same outcome came from this scan on the 25th of March.

On the 26th of March (Friday), my partner and I left our home in the southeast at 3pm and drove to Belfast for our ferry at 21:30 pm. We slept on the ferry in our private cabin until 05:30am, we docked in Liverpool and drove to another UK city for my appointment with NUPAS. We arrived at the clinic at 8am. I left at 16:30pm, emotionally exhausted, bleeding heavily, and empty. We then travelled back to the ferry in Liverpool for 7pm, and arrived back in Belfast at 6am, then drove back down to Waterford for 11am.

I cried for two days straight. It was the most traumatic experience one could have. All I wanted was to be with my family – but we could not. We had to travel to another country to seek medical help – if I could not get over to the UK Due to COVID – we would have been forced to live with the fact I was going to lose my baby in one week, 2 months, or 3 hours after birth. There are many things that need to change within the Irish medical system. Nobody should be forced to carry a pregnancy under any circumstances. If we found the fluid 3 days earlier – we could have terminated in Ireland, in the comfort of our own country with our families.

3 days earlier.

Author I

[withdrawn]

Author J

On the 18th of November 2020, I attended my 20-week anomaly scan alone due to Covid-19 which I do not agree with but did not realize how big a deal it would be when I went on to receive bad news. The sonographer completed the scan and then informed me that she could see fluid on the baby's brain, initially she said she would go get a doctor and would be back. When she returned to the room, she said that I was to go home and come back with my husband in the morning to be seen. I broke down and told her I couldn't go home without knowing what was going on. I told her I would wait as long as it took to see someone that day. She left the room again and came back to advise me I was a "very, very lucky girl" that the doctor would see me that afternoon. I felt so, so far from "very, very lucky", sitting crying in a room where I was told there was an issue with my child's brain.

When I asked her if we should prepare ourselves for bad news, she ran out of the room! It is something I will never forget, I felt so, so alone. She could not look me in the eye. I know it is not an easy job to have to tell someone there is a concern but if you are in that job, it should be done with the compassionate and empathy that the situation deserved.

Thankfully, we got to see a consultant from fetal medicine and midwives that afternoon. However, my husband had to stand out on the street and wait for one hour while I sat in the waiting room with all the other pregnant women until they could see us. Again, this is so wrong, we should be together for this time, it was the scariest time of our lives. They performed another scan and confirmed what the sonographer had said however they previously made it seem like it was fixable. Our consultant explained with the compassion and understanding it deserved that the situation we were facing was pretty bad. We had an amniocentesis & blood tests taken and were to return on the 23rd of November for an MRI and then we went on to meet a neurologist on the 24th to discuss the findings.

In the room there was neurologist, a female with him who never spoke, unclear why she was there, a midwife and doctor from the hospital. It was in this meeting we found out our baby had Alobar holoprosencephaly, the worst form of this condition. The neurologist was very open with how severe our baby's condition was and explained to us that it would be unlikely they would make it to full term, if they did, they would struggle to get through childbirth and in the unlikely event that they made it they would be with us probably for a matter of hours. He said that our baby's brain wasn't developed in the way it should be and that they would remain in a very newborn state for the duration of their life no matter how long it was, they would struggle to do the basic things like breathing and eating, and they would never recognise us as their parents. The neurologist advised us they would support us no matter what, if we continued the pregnancy, they would do anything to help however there was no changing this condition and it would literally be palliative care or we could terminate the pregnancy.

We explained that we did not want our baby to suffer so we would like to terminate the pregnancy and lay them to rest, he told us that this is what the majority of couples decided to do in our situation and it was one he supported. The doctor from the hospital then said to us "just to inform you, we will not be able to facilitate that here".

So here we are having received the worst news possible, we never would have been able to imagine this situation happening. We were both first time parents, and our baby was very much planned and loved, and we were so so excited for their arrival and our own country wouldn't support us. We were told we would have to travel to the UK. We both went from floods of tears to pure anger. What was the referendum for if it did not protect women and couples and babies like us 3?

After the initial contact with London hospital the fetal medicine team in Dublin were able to deal with them on our behalf. They sent all our medical notes etc over to them. The UK Hospital came back to say the nearest date they could fit us in was the 14th of December. That was over 3 and a half weeks away. At this point I was over 21 weeks pregnant; I was completely showing and had no choice but continue to feel my son kick away inside me until we could get over to London. 3 and a half weeks of sitting in our apartment too afraid to move outside the door for fear of seeing anyone and having to have a conversation about our baby.

As if we didn't have enough to contend with, we had to travel at a time that London was in the strictest lockdown they have been in. All hotels were closed, we had to stay in an Air BnB for the first two nights before I was admitted to hospital which were among the hardest nights of the whole journey. Staying in a bare Air BnB just the two of us, no family or friends around us, no comfort, no familiarity. We had to face up to issues around organising a private funeral so we could cremate our baby and bring him home to Ireland with us and not have to leave him in a foreign country like many other parents had to. Once we got into the hospital we couldn't [have] asked for better care, we were blessed with the most amazing midwives and doctors, all who were shocked and angry as us that we had to be there to have our baby. One senior foetal medicine consultant actually said to us that it would have been cruel for us to bring our baby into the world knowing the severity of his condition. He told us our baby had very little brain tissue and he would be surprised if he made it to full term. The umbilical cord was acting almost as a life support machine at this point for the baby.

I had a compassionate induction of labour and after 25 hours in labour I gave birth to a beautiful boy. Our son at 24 weeks and 5 days on the 17th of December at 00:16. He was so so perfect. Myself and my husband were together every step of the way, there was no standing outside for my husband, he was given a bed to stay with me for the duration of my time in the hospital and they did everything they could to ensure we got time with our baby and made memories too.

Nearly exactly a week to the minute after having Our son while at home I started to haemorrhage and my husband called me an ambulance, I spent the next 2 nights in hospital and needed surgery due to retained product. I had to go through this alone due to the fact my husband had been in the UK with me for us to have our son. This was not explained to us before we went, that if we were to come into health difficulties afterwards, it would be harder for us to have the support we needed. We spent Christmas Eve and Christmas Day away from one another a week after losing our son.

At the time I felt like everything possible was done for us however since coming home after having Our son I am not so sure. Babies with the condition Holoprosencephaly have a 3% chance of making it to full term with the majority of them not expected to make it to 6 months old. We were told in London that our baby's diagnosis was fatal. Following on from all of this we have had meetings with fetal medicine consultants in our Dublin hospital and they were surprised at the information we were given around the appeals process. We were told that in our consultant's experience appealing it would be a waste of time and energy and it was unlikely to change anything for us. When we met with two other consultants in the same Irish hospital we had attended, they did not agree with this. It was very hard to hear that they thought our story may have gone differently if we had of appealed the decision before travelling. I am sure our consultant was not lying to us and had said she would support us if we wanted to appeal. It seems the decisions being made around whether you qualify for treatment here or will have to travel is very inconsistent and really depends on your hospital and that is wrong.

Having to travel to London robbed us of so many things as well as all the trauma we endured. None of our families ever got to meet our baby nor were they able to care for us at a time when we needed them the most. It robbed us of precious time with our baby. We had Our son at 00:16 on the 17th of December and his funeral was at 09:30am on the 18th of December. This was because otherwise we would have to wait until the 23rd of December and with London in lockdown we would have nowhere to go. We were robbed of bringing Our son home to the room we had prepared for him to grow up in. We were robbed of having anyone attend his funeral with us and had to go it alone. It robbed us of the option to have a post-mortem as we felt our duty as our son's parents were to ensure he was laid to rest and couldn't have even imagined leaving in him a hospital morgue alone in a foreign country as we flew home. Sitting on a flight back from London to Dublin on the evening of the 18th of December with our baby boy's ashes in our hands surrounded by people excited for Christmas and returning to see their families is a memory I would love to forget.

We can make peace knowing the "decision" and I use that word loosely as we feel we did not have a choice in all of this, was the best one for our baby. He knew no pain, only the warmth and love of inside my tummy. He knew nothing of his condition, and he never struggled to breathe like he would have done earthside. What we will never be able to make peace with is the fact we had to travel to a foreign country in order to do this. It makes it seem like we have done something wrong. The trauma of which will live with us for the rest of our days. We were let down by our country and our government.

ANNEX 3: PROPOSED CARE PATHWAY SUBMITTED TO HSE

Leanbh Mo Chroi (LMC) and Termination for Medical Reasons Ireland (TFMR)

Guidance and Care Pathway Recommendations

This document contains our recommendations and rationale for care pathways based on the direct experiences of the women who we have supported in LMC and TFMR. The recommendations are further informed by a survey of women who we supported in the past.

1. Almost 60% of the women who we support did not receive their diagnosis until they had their 20 weeks scan. For these reasons it is not only essential that all women are offered 12 and 20 week scans as standard but that they should also be offered a Nuchal Translucency Test at 12 weeks (as is standard within the NHS) and/or non-invasive blood tests such as the Harmony test or the Panorama test

2. Many of the women who we support felt that they did not get unbiased information from their care team and many felt 'judged' and 'stigmatised' by staff when asking for information about their 'choices'. For these reasons Doctors within the Irish Maternity Hospital system need to clearly indicate on the HSE website and the Hospital website as to whether they are a conscientious objector or detail what level of abortion healthcare they are willing to provide.

3. Many felt that they were not given sufficient information at diagnosis. As outlined in the National Standards for Bereavement Care when a potential anomaly is detected we feel that all patients in the Irish Maternity Hospital System should be given a special **information booklet detailing**:

  - a) Upcoming appointment with Foetal Medicine Team (FMT) in centre of excellence
  - b) Contact details of FMT and clinic
  - c) List of possible diagnostic tests and scans with rationale and procedure explained
  - d) List of support and advocacy groups for bereavement and possible life limiting conditions, medical conditions and counselling services

4. These recommendations are in-line with baseline 'Level 1 care' (Bereavement Care Following Pregnancy Loss and Perinatal Death, p.9) providing information, communication and guidance to all patients.70% of the women who travelled for treatment had to contact the hospital abroad themselves with many having to contact more than six hospitals or clinics before they could get an appointment. It is essential that a referral is made by the consultant / FMT and transfer of care to an equivalent centre of excellence if care cannot be provided in the Irish Hospital setting. Possible links with excellent standard of care

   - a) Liverpool Womens Hospital
   - b) Kings College (Harris Birthright Centre)
   - c) Guys Hospital London
   - d) St Georges Hospital London
   - e) St Mary's Lindo Wing London
   - f) Paddington Hospital London
   - g) Newcastle Upon Tyne NHS Foundation Trust

5. Established links are essential as wait times for current NHS patients within the NHS service is experiencing major delays (Abortion Support Network). Care needs to be guaranteed.

6. 40% of women did not receive any counselling. All centres of excellence need to have a Consultant Perinatal Psychiatrist and all patients with a diagnosis of severe or fatal anomaly should be offered a referral to this service when they have been given their diagnosis

7. All patients need to be offered a private ante class with the ante natal midwife and a tour of delivery suite

8. Only 17% surveyed said that they received information from their Irish Hospital Team pertaining to Termination of Pregnancy (TOP). On diagnosis of severe or fatal anomaly each patient should be given one of the following

a) **Fatal Information Pack** containing

- I. Information pertaining to TOP and ante natal information regarding labour and birth
- II. Bereavement support group information
- III. Chaplaincy Information, counselling information
- iv. Details regarding cremation, burial and funeral options
- v. Memory box and clothes
- vi. Information about how to talk to children, family and friends about this loss
- vii. Photography information and memory making supports
- viii. Link to Public Health Services and GP services

b) **Severe Anomaly Information Pack** containing

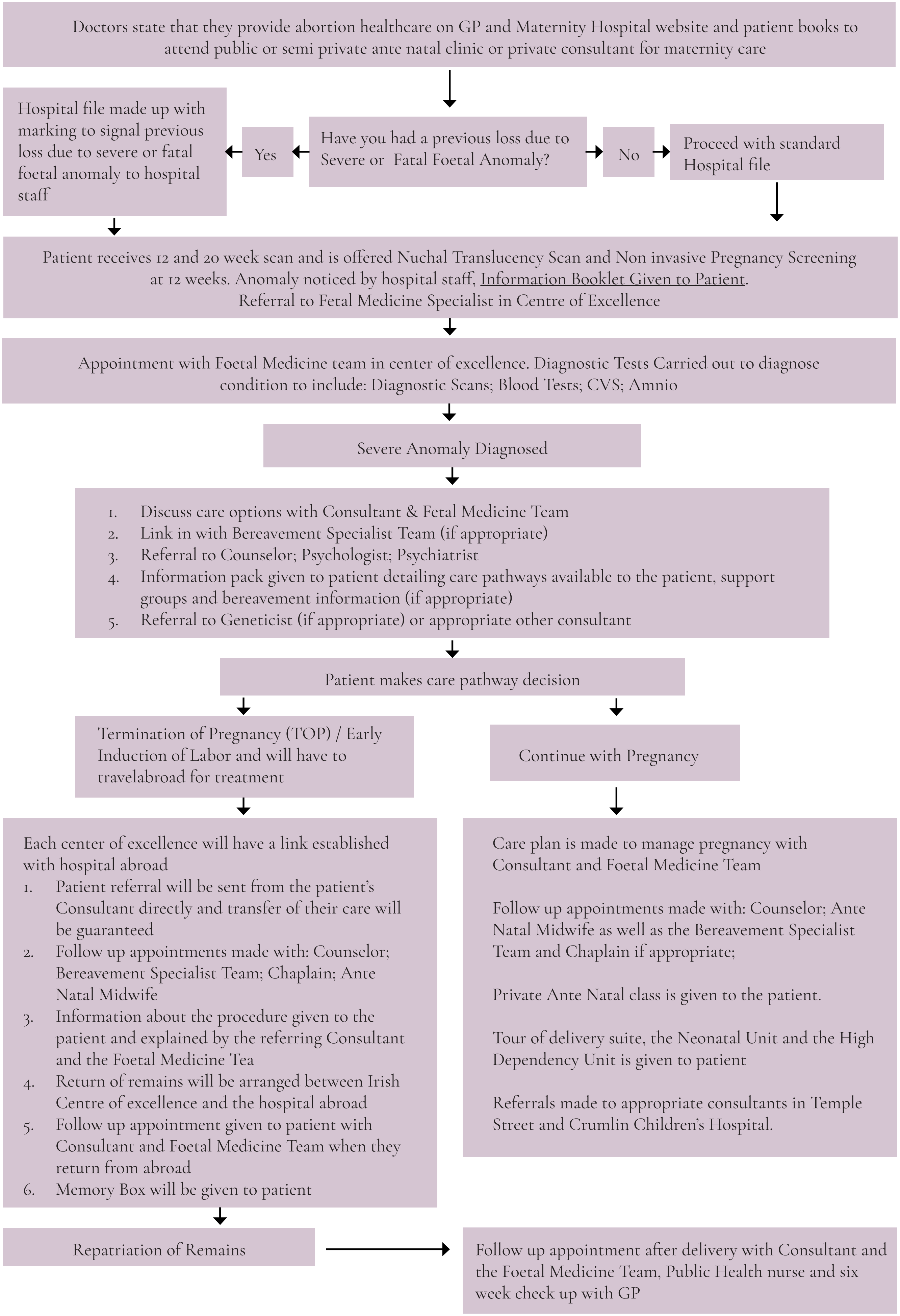
- I. Same as Fatal pack where appropriate
- ii. Support groups and contact information for specific chromosomal, physical and genetic conditions
- iii. Details of Children's Hospitals and appointment made for a tour of the High Dependency Unit and the Neo Natal Unit as appropriate
- iv. Referral to a genetic consultant and or team who will be looking after baby if appropriate

If patient decides to travel for TOP pack needs to contain information regarding

- v. Information detailing Hospital they are being referred to
- vi. Procedure that they are being refereed for
  1. Vacuum aspiration, Dilation and Evacuation, Medical Induction, Feticide
  2. Recovering Times and other medical information
  3. Repatriation of remains

9. We have made a flow chart of possible care pathways.

PREGNANCY CARE PATHWAY IN THE IRISH MATERNITY HOSPITAL SYSTEM FOR PATIENT WITH A DIAGNOSIS OF SEVERE ANOMALY



Doctors state that they provide abortion healthcare on GP and Maternity Hospital website and patient books to attend public or semi private ante natal clinic or private consultant for maternity care

Have you had a previous loss due to Severe or Fatal Foetal Anomaly?

Yes

Hospital file made up with marking to signal previous loss due to severe or fatal foetal anomaly to hospital staff

No

Proceed with standard Hospital file

Patient receives 12 and 20 week scan and is offered Nuchal Translucency Scan and Non invasive Pregnancy Screening at 12 weeks. Anomaly noticed by hospital staff, Information Booklet Given to Patient.
Referral to Fetal Medicine Specialist in Centre of Excellence

Appointment with Foetal Medicine team in center of excellence. Diagnostic Tests Carried out to diagnose condition to include: Diagnostic Scans; Blood Tests; CVS; Amnio

Severe Anomaly Diagnosed

1. Discuss care options with Consultant & Fetal Medicine Team
2. Link in with Bereavement Specialist Team (if appropriate)
3. Referral to Counselor; Psychologist; Psychiatrist
4. Information pack given to patient detailing care pathways available to the patient, support groups and bereavement information (if appropriate)
5. Referral to Geneticist (if appropriate) or appropriate other consultant

Patient makes care pathway decision

Termination of Pregnancy (TOP) / Early Induction of Labor and will have to travelabroad for treatment

Each center of excellence will have a link established with hospital abroad

1. Patient referral will be sent from the patient's Consultant directly and transfer of their care will be guaranteed
2. Follow up appointments made with: Counselor; Bereavement Specialist Team; Chaplain; Ante Natal Midwife
3. Information about the procedure given to the patient and explained by the referring Consultant and the Foetal Medicine Tea
4. Return of remains will be arranged between Irish Centre of excellence and the hospital abroad
5. Follow up appointment given to patient with Consultant and Foetal Medicine Team when they return from abroad
6. Memory Box will be given to patient

Repatriation of Remains

Continue with Pregnancy

Care plan is made to manage pregnancy with Consultant and Foetal Medicine Team

Follow up appointments made with: Counselor; Ante Natal Midwife as well as the Bereavement Specialist Team and Chaplain if appropriate;

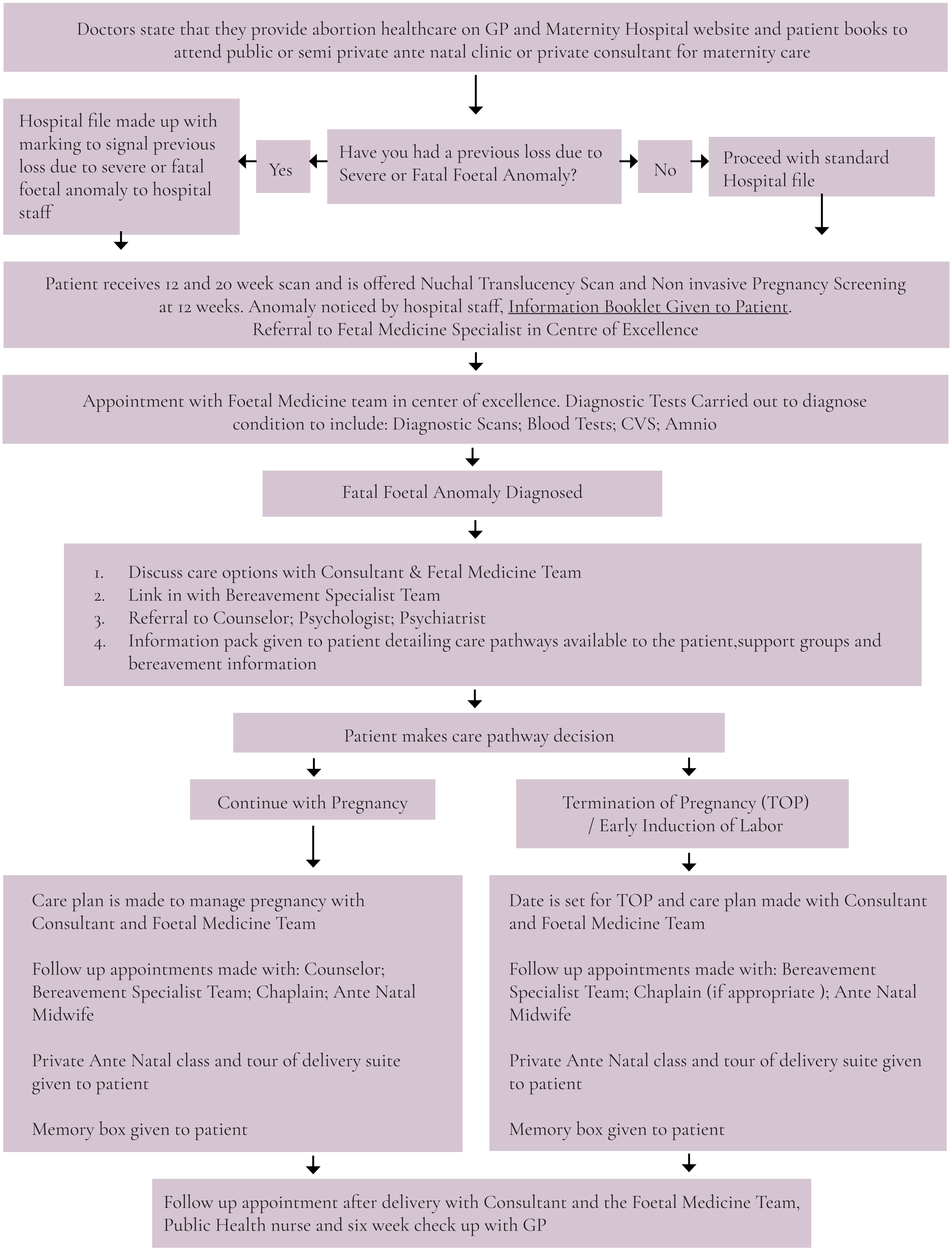
Private Ante Natal class is given to the patient.

Tour of delivery suite, the Neonatal Unit and the High Dependency Unit is given to patient

Referrals made to appropriate consultants in Temple Street and Crumlin Children's Hospital.

Follow up appointment after delivery with Consultant and the Foetal Medicine Team, Public Health nurse and six week check up with GP

PREGNANCY CARE PATHWAY IN THE IRISH MATERNITY HOSPITAL SYSTEM FOR PATIENT WITH A DIAGNOSIS OF FATAL ANOMALY



Doctors state that they provide abortion healthcare on GP and Maternity Hospital website and patient books to attend public or semi private ante natal clinic or private consultant for maternity care

Have you had a previous loss due to Severe or Fatal Foetal Anomaly?

Yes

Hospital file made up with marking to signal previous loss due to severe or fatal foetal anomaly to hospital staff

No

Proceed with standard Hospital file

Patient receives 12 and 20 week scan and is offered Nuchal Translucency Scan and Non invasive Pregnancy Screening at 12 weeks. Anomaly noticed by hospital staff, Information Booklet Given to Patient. Referral to Fetal Medicine Specialist in Centre of Excellence

Appointment with Foetal Medicine team in center of excellence. Diagnostic Tests Carried out to diagnose condition to include: Diagnostic Scans; Blood Tests; CVS; Amnio

Fatal Foetal Anomaly Diagnosed

1. Discuss care options with Consultant & Fetal Medicine Team
2. Link in with Bereavement Specialist Team
3. Referral to Counselor; Psychologist; Psychiatrist
4. Information pack given to patient detailing care pathways available to the patient,support groups and bereavement information

Patient makes care pathway decision

Continue with Pregnancy

Care plan is made to manage pregnancy with Consultant and Foetal Medicine Team

Follow up appointments made with: Counselor; Bereavement Specialist Team; Chaplain; Ante Natal Midwife

Private Ante Natal class and tour of delivery suite given to patient

Memory box given to patient

Termination of Pregnancy (TOP) / Early Induction of Labor

Date is set for TOP and care plan made with Consultant and Foetal Medicine Team

Follow up appointments made with: Bereavement Specialist Team; Chaplain (if appropriate); Ante Natal Midwife

Private Ante Natal class and tour of delivery suite given to patient

Memory box given to patient

Follow up appointment after delivery with Consultant and the Foetal Medicine Team, Public Health nurse and six week check up with GP

“TERMINATIONS FOR MEDICAL REASONS: THE WOMEN AND FAMILIES LEFT BEHIND BY REPEAL”

REPORT SUBMITTED BY TERMINATION FOR MEDICAL REASONS TO THE REVIEW OF HEALTH (REGULATION OF TERMINATION OF ABORTION) ACR 2018

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