

## Chapter 1

# ‘YOU DON’T HAVE A CHOICE, YOU HAVE TO DO IT’

## DIAGNOSIS OF THE FOETAL BODY AND THE DETERMINATION OF HEALTHCARE TRAJECTORIES FOR PREGNANT WOMEN

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One of my early encounters in this research was with Paula, a business owner in her 40s, and mother of four living children. Paula had extensive experience and knowledge of pregnancy and birth, from six pregnancies over a twelve-year period. Her first two pregnancies were straightforward and ended in uncomplicated vaginal births. The third pregnancy ended in a miscarriage late in the first trimester, which was resolved surgically. After the fourth pregnancy, which had resulted in the birth of a third child, she and her husband started worrying about the middle child being left out, and decided to try for a fourth child to even out the family. Nineteen weeks into this pregnancy, after diagnostic blood tests had come back normal, an ultrasound scan detected anomalies in the foetus. Paula and her husband were asked to decide whether they wanted to continue the pregnancy. After consultation with friends and their parents, they eventually decided to end the pregnancy and returned to the hospital to discuss this with medical staff:

Initially I said to them, ‘Are you just going to take it away?’ Because I’d had a D&C<sup>1</sup> before. I said to them, ‘are you just going to take it away?’ and they were like, ‘Oh, no, no, you’ve got to have a, you’ve got to come in and give birth.’

*Was that a shock to you?*

Yeah . . . I’d probably say that that was the biggest shock. The

realisation that I would have to go through childbirth. I'd have to deliver. And it just hadn't crossed my mind. I just thought that they would put me to sleep, deal with it, and then I would wake up and it would be all gone, sort of thing.

Instead of the anticipated disappearance of the pregnancy and foetus, Paula endured a slow and painful induction of labour, involving an epidural for manual removal of the placenta. This removal of the placenta was incomplete, and a week later she woke in the night haemorrhaging and had to return to hospital for surgical removal of retained placenta under general anaesthetic. Despite Paula's previous pregnancies, she had had no idea that a termination for foetal anomaly in the second trimester normally involves a labour and vaginal delivery. This was the case for almost all the women who talked to me about their pregnancy loss. There was no prior knowledge that foetal death or termination for foetal anomaly would be managed by vaginal delivery, and that an established spontaneous labour before viability would be allowed to run its course. The processes by which pregnancies come to an end in the second trimester are invisible in wider English society, and there is little knowledge that these pregnancy endings can be protracted, painful and may involve serious complications. In this chapter, I explain how biomedical diagnosis of the foetal body as being in the second trimester of pregnancy produces specific trajectories of care (Allen 2019, Corbin and Strauss 1988, Allen, Griffiths and Lyne 2004) for the pregnant woman in the English NHS in which her choices and autonomy are limited.<sup>2</sup>

### **Classification, Categorisation and Diagnosis**

Mechanisms of classification and categorisation are ways that social worlds create structure and meaning (Durkheim and Mauss [1903] 2010, Bowker and Star 2000). Classification sets boundaries between things which might otherwise be understood as on a spectrum (such as trimesters in pregnancy). It then puts those things alongside others in order to convey complex meaning, to produce knowledge, or to make things happen (Bowker and Star 2000). As I will show below, the temporal classification of pregnancies as being in the second trimester, through diagnosis of the foetal body, does bureaucratic work within healthcare in terms of setting pregnant women onto different trajectories of care within

the English NHS. However, classifications are contingent and value-laden, rather than absolute and neutral. Referring to earlier work on boundary objects (Star and Griesemer 1989), Bowker and Star (2000) think of classifications as abstract boundary objects: things with enough of a constant identity to be used by different communities of practice but which are plastic enough to adapt to different local meanings. Classifications are thus part of the production of ontologies, as understandings of what is there, in reality, and of epistemologies, relating to how that reality can be accessed or described. Classificatory systems, as with any boundary objects, are embedded in systems of meaning, knowledge and power, and are not politically neutral (Huvila 2011, Foucault 1998). They may involve processes of standardisation which have a variety of origins including simply confirming how things are already done (Timmermans and Epstein 2010).

The process of applying classificatory categories in medicine is the process of diagnosis (Blaxter 1978), which results in the labelling of medical conditions (Jutel and Nettleton 2011), particularly in relation to deviation from a norm (Brown 1995). In England, the power to designate a foetus as being in the second trimester, and to then divert the pregnant woman in whose body it has developed into a particular path of medical care, lies with the medical profession within the institution of the National Health Service. This is consistent with classic sociological work on the balance of power between medicine and lay society or patients (Zola 1972, Conrad 1992, Foucault [1963] 2003), and specifically the medicalisation and medical control of pregnancy, childbirth and abortion (Arney 1982, Oakley 1984, Sheldon 1997). Sociologists of diagnosis have described how diagnosis defines access to different treatment or resources (Brown 1995, 1990, Jutel 2011a). Diagnosis, or classification in medicine, therefore exists as a 'site of contest and compromise' (Jutel 2011a: 5) through which power relations can be perceived and produced. The identification of diagnostic categories is not an objective, scientific exercise defining some external reality, but a social one into which different facets of life can be drawn. In New Zealand, Jutel has shown how medical classification of foetuses as viable and non-viable<sup>3</sup> is rooted in 'the values and concerns of the society in which the diagnosticians practice' (Jutel 2011b: 51) in conjunction with available resources, such as neonatal care for very early neonates.

In the case of pregnancy loss in England, diagnosis is concerned with biomedical classification, but it also draws in legal positions

on the status of the foetus before viability. Social values cannot be separated from biomedical diagnosis in the context of the English foetus. Furthermore, the social values in this particular context are actually positions in ontological politics concerning the control of fundamental realities of human personhood and kinship. When biomedical diagnoses are made concerning the foetal body which locate a pregnancy in the second trimester, doctors are not producing a disease classification, but a legal and ontological category of foetal person / non-person. When a pregnancy ends without the production of a person, that classificatory decision is linked to other decisions about what a pregnancy ontologically is, for example that it is necessarily productive, that the end result (a live baby) teleologically determines the nature of the process. The end result also determines the actors in the process, and the component parts, such as a pregnancy, a labour, a birth, an abortion, a foetus, an embryo, some parents (for other examples of similar teleological thinking, see Thompson 2005, Beynon-Jones 2012, Franklin 1991, Pfeffer 2009). In relation to the medical management of second trimester pregnancy loss, I will show in the next chapter that these ontological positions expressing understandings of an underlying reality underpin the care of pregnant women experiencing second trimester loss.

Diagnosis in pregnancy loss is also complicated by the fact that the site of diagnosis is the foetal body – its vitality, its normativity, its developmental stage – but the actions which are taken as a result of this diagnosis are also on the pregnant body. Medical classification of the foetal body as gestationally between 14 and 24 weeks of pregnancy, i.e. in the English pre-viability second trimester, takes place in the context of medicalised pregnancy (Rothman 1993, Duden 1993). This is an understanding of pregnancy in which the foetal body has become the subject of medical scrutiny and observation (Williams 2005, Williams, Alderson and Farsides 2001, Weir 2006, Casper 1998, Petchesky 1987, Lee and Jackson 2002), often using standardised time in the obstetric management of pregnancy and birth (Simonds 2002). The proven existence of an embryonic or foetal body within her own body defines the pregnant woman in the dominant model of pregnancy in England today. Legally, for example, in the context of assisted reproduction the 1990 Human Fertilisation and Embryology Act defined a woman as ‘carrying a child’ from the point of implantation of the embryo. This is a biomedical model of pregnancy (Clarke et al. 2003) in which it is necessary to have proof or evidence, derived from biomedical

surveillance technology, of the existence of a foetal body. In the NHS, this evidence of the foetal body is determined through routine ultrasound, offered at roughly 12 and 20 weeks of pregnancy (NHS 2019a). At these appointments, besides being assessed for possible anomaly, the foetal body is measured to estimate the standardised gestational duration of a pregnancy (Loughna et al. 2009), within a margin of error (Beynon-Jones 2012). Gestational time is therefore determined by the foetal body as observed by medical technology, rather than the pregnant woman's account of her menstrual cycle or sexual activity, or medical assessment of the pregnant body, such as pelvic examination of women, which is no longer recommended because it does not 'accurately assess gestational age' (National Institute for Health and Care Excellence 2008).

Biomedical examinations in pregnancy are standardising disciplinary apparatuses which are acting on the body of the foetus in the defined, enclosed space of a woman's body. They are forms of hierarchical observation of the foetus which 'see without being seen' (Foucault 1991: 171) and which judge and value the foetal body in relation to norms of measurement and norms of morphology, in relation to a temporal elaboration of standardised foetal development. This measurement and normalisation results in medical judgements or diagnoses being made about the gestational age of the foetal body which have profound consequences for the medical management and care of the pregnant woman's body in the second trimester, as noted in late abortion provision in Scotland (Beynon-Jones 2012). This is because as the gestational age of the foetus increases during pregnancy, so does the likelihood of women having to labour and give birth to the body of the foetus, whether it is already dead because of spontaneous foetal death or feticide in a termination, or will die during or after premature labour. The examined and normalised foetal body thus determines the existence of pregnancy as an ontological category, and the possibilities of medical care available to the pregnant woman's body.

### **Invisible Labour in the Second Trimester**

When women in a wanted or accepted pregnancy receive a diagnosis of foetal death, irreversible premature labour, or serious foetal anomaly for which they have decided to terminate the pregnancy, there are two levels of shock, as Paula's story illustrated. One is that their anticipated baby has died or will die. The other shock is that

they will be required to labour and give birth to remove the foetal body from their own. This shock is recognised in the medical literature, for example on termination for foetal anomaly (Royal College of Obstetricians and Gynaecologists 2010b). In my research, the only participant who was aware of the requirement to give birth in advance of being told it in relation to her own pregnancy worked in a clinical capacity with pregnant women. All of the other women received the news with incredulity, whether they had had previous pregnancies or not. They had knowledge of the process of early miscarriage (eleven women had experienced first trimester miscarriage), and they were aware of the spectre of late term stillbirth, but they had not given any thought to the possibility of second trimester loss and how it could occur. It is a feature of the invisibility of second trimester loss in society that experienced women have no knowledge of it until it happens to them. Eva, already a mother of two, was told at an ultrasound scan 18 weeks into the pregnancy that her son had died in the womb. Like Paula, she was not expecting the news:

*Did you know what that would mean for you, what you would have to do?*

No, not at all. I hadn't considered it at all. I hadn't really realised that you'd have to go through sort of full labour. I just assumed that's what happened when you were, you know, 30 weeks pregnant or whatever. I just thought they could do a quick operation.

Even with medical and experiential knowledge, most women could not opt for surgical resolution of the pregnancy loss. Kerry was a nurse with a substantial experience of pregnancy, including two full-term births, several early miscarriages managed surgically and two surgical abortions under Ground C of the Abortion Act, one of which was somewhere between 14 and 16 weeks. In her last, wanted pregnancy, she started bleeding at 18 weeks. An attempt to stop her going into premature labour with a cervical stitch<sup>4</sup> failed, and the amniotic fluid started leaking, exposing the foetus and her to infection. Labour was therefore induced at 20 weeks and her son was born alive, living for 45 minutes before he died. I asked her if she was given a surgical option when it became clear the baby would not survive: 'They just said, "we've got to take the stitches out and you've got to give birth", that's what they said.' Kerry had experienced surgical removal of previous foetuses which she does not mourn. She deeply mourns the son who died in the second trimester, who was anticipated as the only child of a new relationship, who lived for a short time, and who looked in the

posthumous photos she shared with me like a small, skinny baby. I will discuss the relational aspects of labour, birth and encounters with the foetal body in later chapters. Here I consider the mandating of labour and birth in the medical management of second trimester pregnancy loss in the English NHS.

*The Foetus as Too Big: Labour and Birth because of Foetal Size*

The most salient factor in the mandating of non-surgical removal of the foetal body from the pregnant one is foetal gestation. A pregnancy which has reached the second trimester will usually be one with a substantially sized foetus (Kiserud et al. 2017). In the English NHS, those women experiencing loss in the second trimester who do not go into spontaneous labour are not offered surgical removal of the foetal body. This includes women who have had foetal death confirmed by ultrasound, or who are undergoing termination for foetal anomaly, or those in spontaneous labour where the labour has not progressed. In the first trimester, smaller foetal bodies can be removed via the cervix and vagina using surgical methods or vacuum aspiration (National Institute for Health and Care Excellence 2019a) and in the third trimester sometimes Caesarean section may be possible. However, in the second trimester whilst surgical removal is possible there are very few surgeons who are capable of undertaking surgical removal of the foetal body, or who are willing to do so. The larger foetal body requires more expertise to remove, and it is likely it will not be able to be removed in one piece. Doctors are allowed under the Abortion Act 1967 to refuse to undertake abortions on conscience grounds and there is a consequent skill shortage (Speedie, Lyus and Robson 2014). For example, Tamsin, carrying twins who were discovered at 17 weeks to have no heartbeats, was told that they were too big for her to have surgical removal at her local hospital because of the lack of a surgeon capable of carrying out the procedure. The twins were smaller than would have been expected of a singleton foetus at this gestation, where this would be less likely to be considered. This is similar to findings in Scotland where surgical management of abortion is not available after 18–20 weeks (Purcell et al. 2017, Purcell et al. 2014). The alternative offered to women whose foetuses exceed the required size for surgical management is induced labour and birth.

In my research, foetal size was a factor for those women who were on the lower threshold of the second trimester, and gestational time affected their access to surgical management for this reason. In

her third pregnancy, after a miscarriage and an older child from a previous relationship, Joelle was told at the routine 12-week ultrasound scan that there was the possibility of a chromosome disorder. This was then confirmed by chorionic villus sampling (CVS),<sup>5</sup> the results of which came through about a week later:

They basically phoned me back the next day, and by that point I was almost 14 weeks. They said, 'if you, if you want the surgical termination, you need to do it this Friday.' and she was like, 'you need to let me know this afternoon because I need to get you booked in.' [This made Joelle cry.]

So. They didn't give me much time to decide. I said, 'I'm not, not really ready to make that decision.' So by that point I had to go for the induction.

This lack of availability of surgical removal of the foetus in the second trimester is supported by literature on second trimester abortion provision which states that surgical removal using D&E (dilation and evacuation) is not widely available in the NHS because there are few gynaecologists with the necessary skills (Royal College of Obstetricians and Gynaecologists 2010b, Speedie, Lyus and Robson 2014, Rowlands 2019). The method of surgical removal of the foetus used in the first trimester, vacuum aspiration through a cannula inserted through the cervix, is not thought suitable for after 16 weeks, again because of the size of the foetal body (Lohr and Lyus 2014), though it can take place between 14–16 weeks (Royal College of Obstetricians and Gynaecologists 2015).

This means that in the second trimester an induced labour and vaginal delivery, known as medical management or medical termination of pregnancy, is the usual means of management in the NHS of terminations for foetal anomaly (Royal College of Obstetricians and Gynaecologists 2010b, Speedie, Lyus and Robson 2014) and for foetal death or irreversible premature labour which is not progressing. Medical induction of labour in these circumstances is through the use of a dose of oral mifepristone and then after 36–48 hours up to 4 doses of misoprostol given vaginally every 3 hours (Speedie, Lyus and Robson 2014, Royal College of Obstetricians and Gynaecologists 2010a). This was the treatment experienced by the women in my study who did not spontaneously go into labour, such as Eva, and also those women whose spontaneous labour stopped after membrane rupture and partial opening of the cervix, such as Kerry. This management occurs despite there being an increased risk of complications for pregnant women, including

retained placenta, in medical management compared to surgical management (Lohr, Hayes and Gemzell-Danielsson 2008, Whitley et al. 2011, Grossman, Blanchard and Blumenthal 2008, Grimes 2008, Comendant et al. 2014), and also as gestational time increases (Royal College of Obstetricians and Gynaecologists 2010b), though NICE considers risk differentials to be unclear (National Institute for Health and Care Excellence 2019a).<sup>6</sup> These studies have been done with reference to cases of medical termination, but it is reasonable to assume the same consequences apply for induction for foetal death carried out using the same medication, and may also apply in cases of spontaneous labour in the second trimester. This suggestion is supported by a workshop hosted by the Royal College of Obstetricians and Gynaecologists which grouped together all forms of second trimester pregnancy loss to claim that surgical management is the safest method of uterine evacuation (Royal College of Obstetricians and Gynaecologists (RCOG) 2019). In other medical systems, such as in the USA, suction evacuation methods are used in second trimester termination (Ludlow 2008). And in cases of termination in England in the second trimester which are not for reasons of foetal anomaly (for example under Ground C of the 1967 Abortion Act), surgical management may be available through outsourcing to the British Pregnancy Advisory Service or Marie Stopes (personal communication with anonymous NHS abortion provision staff, 23 September 2019). However, this option is not available to women in the English NHS experiencing termination for foetal anomaly or any other foetal loss in the second trimester.

Joelle's daughter, the baby diagnosed with a chromosomal disorder, was eventually born at 16 weeks after medical induction of labour. I asked Joelle if she thought it would have been easier if she had had surgical management of the termination:

Um, I don't know. I, I do appreciate the time that we got to spend with her. And originally we didn't even plan to see her or anything. And then, when it all happened, I had really bad haemorrhaging and really traumatic. I don't think they really tell you all the risks of things that can go wrong? Because I had a lot of retained placenta, I was really unwell for about six weeks afterwards.

The substantial physical consequences of medical management of second trimester loss which were faced by Joelle and are mentioned in the literature related to medical termination were common in my research. Many of the women endured long and painful labours. Eva for example, who had hoped for a quick operation to remove

the foetal body, spent five days in hospital waiting for labour to progress. Although a few women reported that they had not felt much pain, most experienced painful contractions and were sometimes given oral morphine and gas and air to combat the pain.<sup>7</sup> Women with other children were able to compare the second trimester loss with full-term birth experiences. I asked Lucy how the birth of her second child at 21 weeks during a termination for foetal anomaly compared to the vaginal births of her two other children:

The pain was as bad. The only thing that wasn't as uncomfortable was the actual crowning,<sup>8</sup> because obviously the size is completely different. You know, he came out literally with no, I didn't really feel, sounds awful doesn't it, but he almost fell out. Whereas with my other two that actual crowning feeling was like [strained tone] oh God! Painful! But the rest of it was exactly the same, it was just as painful contraction wise.

Not only was the actual physical experience exhausting and painful for women, the postnatal consequences could be serious too. For example, at least ten other women besides Paula and Joelle had retained placentas, requiring surgery to remove the remains of the pregnancy. Several developed infections and others lost large amounts of blood, with one needing an iron infusion and three needing blood transfusions as a consequence.

Assessments of the gestational age of the foetal body, as determined by normalised measurements on ultrasound scans, therefore have consequences for the medical treatment of the pregnant woman facing second trimester loss in relation to NHS resources and capacity. However, this is either not explained to women, or other reasons are given to them for mandating labour and birth. Fiona's first baby died in utero, and the discovery was made in a private ultrasound scan at 16 weeks at which she had hoped to discover the baby's sex. She was then told by NHS doctors that they needed to induce delivery:

I remember speaking to my sister, and her saying to me 'I think you should have a – is it called D&C? – I think you should have that. I think you shouldn't be doing this.' And I was like, 'why?' and she said 'I think it will be awful, it will be too traumatic, you need to find a private doctor and have a D&C . . .

And I remember thinking, maybe I should, maybe that's better? I rang a private doctor and he said – I spoke to his secretary – long story short, eventually they phoned me back and said not at sixteen weeks when I'd never had another baby, I needed to follow [NHS

hospital]'s advice. Which then I thought, ok, I accept that. I understood the reasons why. Because your cervix has never opened.

The cervix not having previously opened would not be a reason to prevent a woman having a surgical procedure for abortion on grounds other than for foetal anomaly in the second trimester, but it was used as a reason to persuade Fiona in a case of foetal death to accept medical management. Generally, women were not told about the possibility of any other forms of management of the situation besides labour and birth, nor given any comparison of the potential risks of medical management in relation to surgical management. They were presented with a trajectory of care which had no alternative. They did sign consent forms for any medication they were given, and also if they had surgical removal of retained placentas after delivery, but I do not know the details of these. And as I will describe in the next chapter, the potential medical seriousness of labour and birth in the second trimester was routinely minimised in their healthcare experiences.

It is clear, therefore, that medical assessments and classification of the foetal body have consequences for the medical treatment of the pregnant woman in the second trimester of pregnancy in the English NHS, resulting in medical management of the removal of the foetal body in cases of foetal death and termination for foetal anomaly. Furthermore, this provision of treatment is at least partly based on lack of NHS resources rather than selection of the treatment option with fewest complications for the pregnant woman.

#### *The Foetus as Too Young: Labour and Birth because of Non-Viability*

The other factor in deciding on the medical management of second trimester loss is the stage of development of the foetal body in terms of its viability as a separate physical being outside the body of the pregnant woman. The foetal body which has gestated for less than 24 completed weeks is considered non-viable, as defined by English law. This classification as non-viable before 24 weeks means that in many hospitals, excluding those with advanced neonatal care mostly located in cities, there will be no attempt to preserve the life of the foetus after premature labour if it is born before 24 weeks. Similar viability threshold related decisions about treatment have been described in medical settings in the USA (Christoffersen-Deb 2012) and neonatal intensive care in the UK (Flessas and Jackson 2019). Furthermore, in cases of foetal death, or termination for medical reasons, there is no need to factor in the consequences of

birth for the foetal body – it either is already dead or is intended to be dead. This means that there is no clinical reason to carry out a Caesarean section to save the life of the baby, with its attendant risk to the pregnant woman. Amber, facing the termination of her pregnancy after diagnosis of a congenital syndrome, had only experienced birth by Caesarean section previously:

With [older daughter], I got to seven centimetres [dilation of the cervix] before my emergency C section, but I never pushed, I'd never given birth to a baby. So I didn't know. What it would be like. And not that you can, you don't have a choice, you *have* to do it, they don't offer you a C section. Cos [husband] said, 'you can't do it any other way?'

Caesarean was not an option open to Amber in this birth process, despite her husband asking for alternatives. Induced labour and vaginal birth is how foetal deaths or terminations for foetal anomaly are managed if the pregnant woman is considered physically able to go through labour.

Assessment of the gestational age and developmental stage of the foetus, this time as not having reached sufficient maturity to survive, has consequences for the treatment of the pregnant woman in circumstances where the foetus may be understood to be healthy. This is well illustrated by the story of one woman who had the misfortune of being able to compare her experiences of two spontaneous premature labours, either side of the 24-week foetal viability categorisation. Charlie, aged 30 when I spoke to her, had become unexpectedly pregnant at the age of 22 and went into spontaneous premature labour at 23 weeks and 5 days' gestation. She described how being two days short of viability affected her and her unborn daughter's care in the non-specialist local hospital as she faced the possibility of lack of intervention if the baby was born alive:

They tried to play with my dates, as far as they could, and they were like, 'there's no way we can get this pregnancy, like, above 24 weeks. You *are* 23 and 5.' Like, 'it is what it is, we can't get this pregnancy above, however we try, like growth scans, dates, she is just 23 and 5.'

*In terms of intervening when she was born, was that?*

Yeah. So they said – so this is when they said, and I remember this conversation like, like, it's probably the most graphic in my head. More than anything else. [Charlie cried here.]

She said: 'when this baby is born, you're going to have to hold her until she, sorry, until she passes.' [pause]

And I remember my mum just looked at her and was like, 'you're

not intervening? If this baby's born and this baby's like, breathing and crying, you won't intervene?' And they said 'no, cos she's not 24 weeks. We don't have the care here to care for her.'

After hours of painful labour, Charlie requested a Caesarean: 'At this point I was like "give me a section, like, I don't even care!" But they don't like doing it for babies that have passed because they don't want the scar to remind you, [midwife] was saying they don't want the scar to remind you?' Like with Fiona, staff appear to have come up with an excuse to stop Charlie requesting a different form of treatment, which she accepted as a valid reason. Eventually after a long and difficult labour the baby girl was delivered with forceps but had died during the labour:

They took me down to theatre, gave me an epidural . . . And then they delivered her with forceps, and they were like 'oh, she's here.' But then the whole room goes quiet. And in my naivety, I was thinking I was going to hear a baby cry. But obviously, I didn't. And then they came over and said that she'd already passed.

That ominous silence was to return in a different manner when Charlie became pregnant with her second daughter two years later, this time after IVF with her new husband. Again, after vaginal bleeding in the second trimester, it became clear the pregnancy was under threat, and a cervical stitch to try to preserve it was carried out. Days later Charlie was discovered to have an infection and it was decided that the baby would need to be born, but this time at 24 weeks and 3 days, beyond the second trimester and the viability boundary. This time she insisted on being treated at a specialist hospital, where the consultant gave her steroids to attempt to mature the baby's lungs, magnesium sulphate to attempt to reduce any brain damage, and then decided to deliver the baby by Caesarean section with a paediatric team ready in the room for resuscitation. On Charlie's sitting room wall there is a photo of this little baby daughter being lifted alive from her body in the operating theatre, her thin arms and legs stretched in the startle reflex.

Did the section, [baby girl] was born. She cried. So we were like, 'she's crying, everything's going to be ok, she's crying!' And then they'd explained that I wouldn't get to hold her because she's so tiny, she straight away needed, like, warming up and stuff. And that was fine, like, she'd cried, so I felt. They were like 'congratulations, it's a beautiful baby girl, what do you want to call her?' And like, all the people were coming over and congratulating you, and like 'aww.'

And it was just so nice. And then. Like, she stopped crying. The cries stopped . . . And then all of a sudden the whole room went silent. Like, eerily silent.

Charlie's second daughter had lived for 45 minutes before dying from infection. This short life meant she was registered on the Births and Deaths register, in contrast to Charlie's first daughter, who was officially categorised as a miscarriage. For Charlie, the few days separating her daughters' gestations had enormous consequences for the medical treatment offered to her and to them. Such decisions about medical care of the foetus or born baby, made on the basis of assessments of the foetal body in relation to viability and resources available in medical contexts, are similar to those noted elsewhere (Christoffersen-Deb 2012). However, in this research, the impact is felt not only in relation to intervention on the foetal body, but also on the choice of treatment and birth process available to the pregnant woman.

### **Limiting Choice around Feticide in the Second Trimester: The Risky Foetal Body**

The position on live birth personhood in United Kingdom law means that the biomedical judgements on the state of the foetal body are instrumental in determining the use of another medical procedure, that of feticide.<sup>9</sup> This is also a procedure carried out on two bodies, that of a pregnant woman facing a second trimester loss in the case of termination for foetal anomaly towards the end of the trimester, and the foetal body. Feticide is carried out by the injection of potassium chloride into the foetal circulation through the pregnant woman's abdomen (Oloto 2014, Royal College of Obstetricians and Gynaecologists 2010b), whilst she lies still, using an ultrasound image to guide the needle into the foetal heart. This was the experience of the four women in my research who had experienced feticide in any of their pregnancies, who therefore witnessed the timing of the death of the foetal being.

Since the 1990 Human Fertilisation and Embryology Act extended the possibility of termination of pregnancy for severe foetal anomaly beyond the 24-week viability cut off, and since ever-evolving prenatal diagnosis techniques have increased the possibilities of prenatal surveillance and assessment, the possibility of later terminations for foetal anomaly has increased, as have the survival rates

of pre-24-week babies in neonatal units (Graham, Robson and Rankin 2008). This has led to anxiety about the possibility of live birth where one is not desired, and therefore to the development of feticide in late terminations for medical reasons (Graham, Robson and Rankin 2008). This is therefore a procedure sometimes faced by women who are seeking to terminate the pregnancy of a foetus in the second trimester which would not be offered to women in the first trimester, and which would be likely to be mandated in a third trimester termination. Guidance from the Royal College of Obstetricians and Gynaecologists states: 'The RCOG currently recommends feticide for terminations over 21+6 weeks. The only exception to this rule is when the fetal abnormality itself is so severe as to make early neonatal death inevitable irrespective of the gestation at delivery' (Royal College of Obstetricians and Gynaecologists 2010b: 29). As Graham et al. (2008) have noted, medical guidelines do not place feticide in any social context and present it as a neutral term.<sup>10</sup> They show that the use of feticide, and the term itself, both conceals and reveals the political positioning of the procedure in different settings. The ambiguity of the vocabulary in the RCOG guidance notes is interesting in this context, in terms of whether the guideline is a 'recommendation', or a 'rule'. And if it is a 'recommendation', who is deciding whether it is to be carried out? Graham et al. discuss the role of 'professional discretion' (Graham, Robson and Rankin 2008: 298), and Speedie et al. (2014) note that statistics show that feticide is sometimes not carried out at this gestation, which they suggest may be due to women declining it

In my research, there was variation in both who was offered feticide, and who was given no option to either choose or reject it. Out of 10 women who had terminations for foetal anomaly, three underwent the procedure, with a fourth having undergone it without being given a choice for a previous post-viability termination. Of the three who had a feticide in the second trimester, one woman at 21 weeks' gestation was presented with it as a choice which she accepted, and the other two, at 23 weeks' foetal gestation were not given the option to refuse, with both finding the procedure traumatic. Gemma's middle daughter was diagnosed in pregnancy with a congenital anomaly, and she and her husband decided to terminate the pregnancy:

*Did they give you an option about the injection [to stop the foetal heart]?*

No. They just said that that's what they did once the baby got to that gestation, because otherwise there was a chance she could be

born and still alive initially. And then that, kind of, whether then there would be a decision as to whether they would try to keep her alive or not, or, so. Yeah, it was just kind of, that's what they did really. I was probably in shock at the time and I just kind of went with what they said.

*That must have been distressing?*

That was almost the hardest bit really. Obviously the labour and stuff was horrible, but you're kind of in a lot of pain and everything as well, and there was things going on at that point. Whereas the injection you just lie there while they do it. Which I found really, really difficult. And then, yeah. You sit in a little room . . . because they have to check you after half an hour and make sure the heart-beat has definitely stopped. You have to kind of sit in this little room drinking tea. And trying to – I don't know what we were talking about – trying to have a normal conversation, almost? Because you don't know what else to do. And then, go back and have another scan. So. That was, yeah, I found that day really hard.

In other termination cases, the RCOG guidelines appear to have been flexibly interpreted. One woman was not offered feticide at all at 23 weeks in a termination after diagnosis of chromosomal anomaly, perhaps because the diagnosis of anencephaly was so serious that survival of any sort after birth was impossible (Royal College of Obstetricians and Gynaecologists 2010b). In other cases, women were offered feticide around 20 and 21 weeks but declined. And in the case of Lucy, whose son was diagnosed prenatally with a congenital anomaly, doctors offered feticide at 21 weeks but suggested she might prefer a live birth:

I was really concerned about him feeling any discomfort or pain. And I had a conversation, once we'd made the decision that we weren't going to carry on, and that we were going to deliver him early, um, I remember having a conversation with one of the consultants about whether to have the injection.

And they said, 'well, we wouldn't normally offer it at your gestation, because he probably wouldn't survive, but if you wanted us to, we could do it.' And then the other consultant said, 'just think about it, because I know some mums in the past have really valued that time that they've had with their baby whilst they've been alive? So, just have a think about it. You can have it if you want to, but just think about it, especially with the likelihood being that he's not going to be alive very long, if at all.'

So we didn't have – they call it feticide – we didn't have the feticide, and I'm so glad that that consultant gave us that advice, to think about, because [baby boy] actually ended up living for 4 hours. So

you can see [showing me his birth and death dates on the lid of his specially made memorial box] he crossed a day, he was born at 11 and he died at 2 the next morning. And, you know, those 4 hours.

Feticide in the second trimester is both a recommendation in some cases, and a rule in others. Previous research has described some of the reasons for performing feticide, which include avoiding a resuscitation dilemma for the pregnant woman and medical staff, avoiding the consequences of an unintended live birth that survives, and avoiding the possibility of a coronial inquiry into the death of a neonate (Oloto 2014, Statham, Solomou and Green 2006). However, none of the ten women in my study who went into spontaneous premature labour, rather than terminations for foetal anomaly, were offered feticide to prevent a live birth. In fact, four of those women did experience live birth in the second trimester, in different hospitals. Furthermore, of those women with pre-viability potential live births, only one, Rachel, was offered resuscitation of her 23-week gestation daughter after her placental abruption. When the baby was born, resuscitation was initiated but then Rachel quickly gave permission to stop to prevent her daughter from suffering and allow her to die, and in fact live birth was never medically diagnosed. There is an inconsistency here which points the way towards the purpose of feticide. It cannot be mainly carried out to prevent parents being distressed by witnessing postnatal death, or the neonatal resuscitation dilemma, or the possibility of an early term survival, because it does not always apply in terminations for foetal anomaly, nor does it apply in other second trimester cases where a live birth could occur. Furthermore, in my research the distress of the feticide itself was enduring for some women who underwent it, whereas the distress of a live birth and subsequent death was balanced by some acceptance or even satisfaction at having witnessed the living baby in all the other cases in my research. This contrasts with other research which emphasised the acceptability of feticide to some parents, but which seems to have taken place in a context where they were given options to select or refuse it (Graham et al. 2009), which was not always the case for my participants.

Feticide, therefore, may often be routinely carried out because it is understood to be a procedural requirement, something in the guidelines, in a field in which bureaucracy can exempt doctors from prosecution for illegal abortion. Oloto (2014), in giving reasons for feticide, does not mention the bureaucratic consequences

for doctors of a termination which has not been successful, such as being required to inform the Care Quality Commission (CQC) of the death of a person during the provision of a regulated activity such as termination, and the requirement to report deaths of babies born alive after 20 weeks, including after termination, to the perinatal surveillance tool MBRRACE.<sup>11</sup> Nor does he mention the legal requirement to register a live-born baby and to produce a death certificate when it dies. Nor does he mention the potential expense to the state or private sector in terms of the costs of maternity leave and so on which can be claimed after a live birth in the second trimester. The burden is on doctors to carry out these state governance requirements in an environment where abortion is a criminal act from which they are merely exempted from prosecution under certain circumstances by the 1967 Abortion Act. It is likely more straightforward for caregivers to conduct a termination for foetal anomaly which does not end in live birth. And feticide also exists in the context of the illegality of euthanasia in the United Kingdom, where the distinction of birth between a foetus and a baby prevents the active taking of a born child's life – as Costeloe (2007) says, the procedure of feticide carried out moments after birth would be murder. The distinction between euthanasia and the withdrawal of life support is one of immense legal uncertainty for doctors in relation to withholding treatment from a born child, who has a right to care under the NHS. In cases where parents do not consent to the withdrawal of treatment for living children, the situation could become even more complicated for doctors, as has occurred in recent legal cases involving babies Charlie Gard (Wyatt and Siddique 2017) and Alfie Evans (Collins 2018), where lengthy court cases pitted parents against doctors.

It is simpler for doctors to perform feticide and avoid these issues. However, the consequences of this legal framework are that the women in whose bodies the foetuses live often have little choice over whether to undergo the process during terminations for foetal anomaly towards the end of the second trimester. It is significant that Lucy, who was advised by doctors that she had the option to reject feticide in favour of a potential live birth at 21 weeks, was employed in the hospital in a clinical capacity and was personally known to the doctors involved. She may have therefore been less of a risky parent for doctors, who knew she would not insist on intervention to try to prolong her baby's life. In other cases, women facing a possible live birth after going into premature labour were not offered the procedure. The decision about feticide or live birth

is thus not usually made by the pregnant woman, but by clinical staff. In this research, there was little or no choice for the women about feticide, a medical procedure aimed at the foetal body, but also taking place on their own pregnant body.

### **Conclusion: The Foetal Body and the Production of Trajectories of Care for the Pregnant Body**

When facing pregnancy loss through foetal death, termination for foetal anomaly and premature labour, the biomedical assessment of the foetal body in relation to gestational time, and its diagnostic classification as being in the second trimester, structures the type of healthcare procedures available to the pregnant woman. Access to surgical removal of the foetal body, available in the first trimester of pregnancy through the cervix and vagina, and sometimes in the third trimester through Caesarean section, is usually not available to women in the second trimester, who must labour and give birth. A lack of doctors in the NHS with the relevant surgical skills means women cannot select this treatment even though it is medically less consequential for their bodies. This was not the reasoning offered to women, however, who if they did ask questions were given a variety of reasons for the requirement to labour and birth. Gestational time classifications also affect whether women must undergo feticide in terminations for foetal anomaly. However, in spontaneous premature labour feticide is not offered, and the focus is more on what neonatal treatment will or will not be offered to the resulting baby if it is born alive. This means that women may have no choice but to witness their newborn baby's death.

These restrictions on women's care, combined with a lack of clear information for women about alternative procedures and the comparative risks of different ways of managing second trimester loss, mean that pregnant women have their healthcare options restricted within obstetric and gynaecological care in the NHS in England. Furthermore, resource availability means the NHS is potentially not offering the safest care to women when surgical management is not available. These choices, or non-choices, are being made because of classifications of the foetal body, when that body is not alive or will not live. They are played out on the body of the pregnant woman, who is frequently required to suffer pain, postnatal complications and emotional distress without being able to weigh up for herself the benefits and disadvantages of labour,

birth and feticide. Stratified trajectories of care are produced in the English NHS in relation to pregnancy, in which different levels of agency are being accorded to pregnant women. Furthermore, access to these different trajectories of care is determined by biomedical classification of the foetal body rather than the agential choice of the pregnant woman, depending on the possible outcome of the pregnancy in terms of producing a living baby. This raises issues of consent, bodily autonomy, power and agency which have been a priority for feminist scholars of reproduction for several decades, in a field of reproductive politics to which this research contributes (see, for example, Sheldon 1997, Rothman 1993, Oakley 1984, Duden 1993, Bordo 2003, Colen 1995).

The next chapter will further illustrate the impact of biomedical classification of the foetal body on the care of the pregnant woman experiencing second trimester pregnancy loss by showing how women's experiences are minimised and marginalised in their day-to-day healthcare experiences.

## Notes

1. Dilatation and Curettage is an obsolete form of surgical abortion where a curette is used to empty the uterus. 'D&C' has become a lay term in England referring to any surgical evacuation of the uterus.
2. A version of this chapter has been published in the journal *Sociology of Health and Illness* (Middlemiss 2022).
3. In New Zealand, the legal foetal viability threshold is set at 20 weeks' gestation rather than 24 weeks as in England (Jutel 2011b).
4. Also known as cerclage, a cervical stitch is a suturing procedure used to try to prevent the cervix from opening.
5. Chorionic villus sampling is a procedure in which cells from the placenta are removed and tested during pregnancy to check for genetic and chromosome disorders in the foetus.
6. It might be assumed that a known potential for increased complications, such as retained placenta, would lead to increased postnatal care for women with second trimester losses. However, as Chapter 2 explains, this is not the case.
7. The availability of pain relief in second trimester loss is inconsistent and is discussed in Chapter 2.
8. Crowning is the point of passage of the foetal head through the vagina in vaginal birth.
9. Feticide is also spelt 'foeticide' but I have retained the more common biomedical spelling here.

10. The repercussions of a feticide in terms of lack of access to birth registration and maternity and paternity benefits are considered in Chapter 3.
11. Whilst neonatal deaths beyond 20 weeks' gestation, including after termination of pregnancy, are reportable to the perinatal death surveillance system MBRRACE-UK, terminations are not included in the different neonatal mortality rates produced by this surveillance.