

# Reproductive loss and disposal of pregnancy remains<sup>+</sup>

LOUISE AUSTIN\* AND SHEELAGH MCGUINNESS\*\*

*Centre for Health, Law, and Society, University of Bristol Law School*

## Abstract

*In this paper we examine the legal framework which governs the management of pregnancy remains in the context of reproductive loss; specifically pregnancies which reach an unwanted end prior to 24 weeks' gestation. It is important to consider the role for law as it is clear that law has the capacity to shape the nature of the care that people receive and their experience of bereavement at the time of reproductive loss. The unwanted end of a desired pregnancy can have profound consequences for those who experience it. How we respond to the needs of these individuals will have important consequences not just for their well-being, but it can also impact their future reproductive experiences. Furthermore, the original empirical research on which this paper is based demonstrates how healthcare practice in this area is problematic in its inconsistency, and in failures to account for the particular needs of the person who has suffered an unwanted end to pregnancy. Because appropriate healthcare is properly determined in this context by the perspective of the individual, we argue that healthcare professionals should, as a matter both of good practice and of law, follow the individual's lead when seeking to understand their needs. Accordingly, we advocate for the importance of all legal options for disposal of pregnancy remains being discussed when a person who has suffered reproductive loss wants that information and present practical measures that can be introduced to ensure this happens.*

**Keywords:** reproductive loss; miscarriage; human tissue; Human Tissue Authority; pregnancy remains; informed consent; *Montgomery*.

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\* Mrs Louise Austin, PhD Candidate in Law, Centre for Health, Law and Society and Centre for Ethics in Medicine, University of Bristol Law School, UK; louise.austin@bristol.ac.uk. I would like to acknowledge the support of ESRC through my 1+3 Scholarship (1653376).

\*\* Dr Sheelagh McGuinness, Centre for Health, Law, and Society, University of Bristol Law School UK; sheelagh.mcguinness@bristol.ac.uk. I would like to acknowledge the support of the ESRC, ES-N008359–1.

## 1 Introduction

The loss of a pregnancy, either through miscarriage or stillbirth, affects many people each year.<sup>1</sup> In addition to this, each year pregnant people will end a much-wanted pregnancy for many reasons, e.g. following a diagnosis of fetal abnormality.<sup>2</sup> The unwanted end of a desired pregnancy can have profound consequences for those who experience it. How we respond to the needs of these individuals will have important consequences not just for their well-being, but it can also impact their future reproductive experiences.<sup>3</sup> It is now accepted that appropriate care at the time of loss should be responsive not just to clinical but also emotional needs.<sup>4</sup> In particular, care that facilitates the ability to grieve, if necessary, can reduce the need for longer-term follow-up psychological care and improve future reproductive outcomes.<sup>5</sup> As such, the care and support provided to affected people and their families can help to mediate how they experience the loss and significantly impact their on-going health and well-being, including future reproductive decision-making.

In this paper we examine the legal framework which governs the management of pregnancy remains<sup>6</sup> in the context of reproductive loss; specifically pregnancies which reach an unwanted end prior to 24 weeks' gestation.<sup>7</sup> We do not focus on stillbirth because, as we will explain in more detail below, there is ambiguity about the status of pregnancy remains after miscarriage which does not exist in stillbirth, and often pregnant people are not aware of the legally permissible options for disposal of miscarried pregnancy remains. The medico-legal framework that governs miscarriage and stillbirth has not been the subject of sustained academic critique, notwithstanding the burgeoning

- 1 It is estimated 1 in 8 pregnancies end in miscarriage amongst those who know they are pregnant: NHS, *Overview: Miscarriage* <[www.nhs.uk/conditions/miscarriage/#how-common-are-miscarriages](http://www.nhs.uk/conditions/miscarriage/#how-common-are-miscarriages)>.
- 2 The most recent statistics show that 3314 abortions were performed under this ground: Department of Health and Social Care, *Abortion Statistics, England and Wales: 2017 Summary Information from the Abortion Notification Forms Returned to the Chief Medical Officers of England and Wales* (DHSC, 2018).
- 3 See, for example: Dimitrios Siassakos, 'All Bereaved Parents are Entitled to Good Care after Stillbirth: A Mixed-methods Multicentre Study (INSIGHT)' (2018) 125(2) BJOG: An International Journal of Obstetrics and Gynaecology 160–70; Sarah Cullen, Barbara Coughlan, Anne McMahon, Brenda Casey, Sheila Power and Mary Brosnan, 'Parents' Experiences of Clinical Care during Second Trimester Miscarriage' (2018) 26 British Journal of Midwifery <[www.magonlinelibrary.com/doi/abs/10.12968/bjom.2018.26.5.309](http://www.magonlinelibrary.com/doi/abs/10.12968/bjom.2018.26.5.309)>.
- 4 The emotional and psychological impacts of miscarriage have been identified as a priority area for future research: see Matthew Prior et al, 'Priorities for Research in Miscarriage: A Priority Setting Partnership between People Affected by Miscarriage and Professionals following the James Lind Alliance Methodology' (2017) 7(8) BMJ Open 1–8. There is evidence that miscarriage can have psychological and emotional impacts and that these are often under-recognised: see Ingrid Lok et al, 'Psychological Morbidity following Miscarriage' (2007) 21(2) Best Practice and Research Clinical Obstetrics and Gynaecology 229–47.
- 5 Siassakos (n 3); NHS North Bristol NHS Trust, *PARENTS Study* <[www.nbt.nhs.uk/www.nbt.nhs.uk/WCHResearchPARENTS](http://www.nbt.nhs.uk/www.nbt.nhs.uk/WCHResearchPARENTS)>; Aleena Wojcieszek, 'Care in Subsequent Pregnancies following Stillbirth: An International Survey of Parents' (2018) 125 BJOG 193–201.
- 6 Here we follow the language of the HTA guidance. The Authority explains its use of this term, and why it doesn't distinguish between fetal tissue and other products of conception as follows: 'Women define their pregnancy according to their own circumstances, values, understanding and beliefs. The HTA and professionals in the field consider that any attempt to categorise the pregnancy may result in health professionals viewing the pregnancy differently from the woman involved. Furthermore, if the mode of disposal were to be linked to types of pregnancy or pregnancy loss, some women may find themselves being denied certain choices. Acting in response to the needs and wishes of the women first and foremost helps avoid such problems.' <[www.hta.gov.uk/faqs/disposal-pregnancy-remains-faqs](http://www.hta.gov.uk/faqs/disposal-pregnancy-remains-faqs)>.
- 7 We adopt the categorisation of reproductive loss provided by Sarah Earle, Pam Foley, Carol Komaromy and Cathy Lloyd, 'Conceptualizing Reproductive Loss: A Social Sciences Perspective' (2008) 11(4) Human Fertility 259–62. However, we wish to emphasise that situations where an unwanted pregnancy is ended with the consent of the pregnant person can constitute a reproductive gain, for more on this see Erica Millar, *Happy Abortion: Our Bodies in an Era of Choice* (Zed Books 2017).

social science literature.<sup>8</sup> However, it is important to consider the role for law, as it is clear that law has the capacity to shape the nature of the care pregnant people receive and their experience of bereavement at the time of reproductive loss. Our analysis draws from the findings of the Death Before Birth (DBB) project – on which the first author provided research assistance and the second author was a co-investigator – in order to support the arguments that we make.<sup>9</sup>

DBB was a socio-legal, linguistic study of how people in England who have experienced miscarriage, termination and stillbirth reach decisions concerning the disposal of the remains of pregnancy, how their perceptions of the law impact their decision-making, and how they communicate their experiences and choices to those who support them.<sup>10</sup> The options for disposal are set out in key guidance documents: cremation (shared or individual); burial (shared or individual); sensitive incineration (incineration separate to other clinical waste); burial at home or at some other site subject to certain limitations.<sup>11</sup> The first stage of the DBB project involved an examination of hospital documentation to find out what options were being offered or discussed with those who experience reproductive loss. The next stage of the project involved semi-structured interviews with a range of stakeholders including bereavement care providers in hospitals within NHS England; professionals in the funerary industry; those who worked with relevant bereavement support organisations; and women who experienced stillbirth, miscarriage, or termination following a diagnosis of fetal anomaly. These interviews bore out a key finding of the DBB project: that those who experience miscarriage are offered information about some (usually cremation), but not all of the legally permissible options for disposal.<sup>12</sup> It was also clear that individuals who miscarried outside of the hospital setting were not always fully informed about what to expect or how to manage the pregnancy remains they passed.

In order to remedy the gap in information disclosure, we argue that the test for informed consent as laid out in *Montgomery v Lanarkshire Health Board* provides a legal basis for requiring that pregnant people be given information on all legally permissible options for disposal.<sup>13</sup> Legally, pregnancy remains prior to 24 weeks' gestation are regarded as the person's tissue. Ensuring that the person has a choice in what is done with those remains once they cease to be physically connected to them forms part of their interest in their own physical integrity which the law of informed consent seeks to protect. In addition, options for disposal may have important implications for the acceptability of different

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8 See, for example, Linda Layne, *Motherhood Lost: A Feminist Account of Pregnancy Loss in America* (Routledge 2003); Sarah Earle, Carol Komaromy and Linda Layne (eds), *Understanding Reproductive Loss: Perspectives on Life, Death, and Fertility* (Routledge 2016); Roseanne Cecil, *The Anthropology of Pregnancy Loss: Comparative Studies in Miscarriage, Stillbirth, and Neonatal Death* (Berg 1996).

9 Death Before Birth: Understanding, Informing and Supporting Choices made by People who have Experienced Miscarriage, Termination and Stillbirth <<https://deathbeforebirthproject.org>> (ESRC, ES-N008359-1).

10 Death Before Birth, 'About the Project' <<https://deathbeforebirthproject.org/about>>.

11 See: HTA, *Guidance on the Disposal of Pregnancy Remains following Pregnancy Loss or Termination* (HTA 2015); Royal College of Nursing, *Managing the Disposal of Pregnancy Remains* (RCN 2015); Institute of Cemetery and Crematorium Management, *The Sensitive Disposal of Fetal Remains: Policy and Guidance for Burial and Cremation Authorities and Companies* (ICCM 2015); Sands Stillbirth and Neonatal Death Charity, 'Chapter 20. Funerals and Sensitive Disposal', *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* (4th edn, Tantamount 2016) 323–53.

12 For a detailed summary of the key findings, see: Sheelagh McGuinness and Karolina Kuberska, *Report to the Human Tissue Authority on Disposal of Pregnancy Remains (less than 24 weeks' gestational stage)* (2017) <<https://deathbeforebirthproject.org/research/htareport2017>>.

13 *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 [108].

treatment options to the pregnant person. As such, disposal of pregnancy remains should be discussed as part of the care and management of miscarriage.

The legal question in *Montgomery* related to risk disclosure when seeking informed consent to medical treatment, and whether a doctor had breached her duty of disclosure by failing to warn a pregnant patient of the risk of shoulder dystocia occurring during vaginal delivery, and the alternative option of delivering the baby by way of a caesarean section instead. The Supreme Court concluded that the doctor's duty was:

... to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would attach significance to it.<sup>14</sup>

Thus, information disclosure in healthcare goes beyond information about risk to include variant or alternative treatments, and should be tailored to individuals.<sup>15</sup> In adopting this approach, the court endorsed the approach to consent set out in General Medical Council (GMC) guidance which also focuses on the need to tailor information to individual patients.<sup>16</sup> In keeping with this, we argue in section 3 of this paper that in accordance with Human Tissue Authority (HTA) guidance, healthcare staff should advise pregnant people of all disposal options, including those not available through the hospital, and details of whom to approach if the person's preferred method of disposal is not offered by the hospital.<sup>17</sup>

Prior to that legal argument, in section 2 we provide an overview of the conceptual framework that grounds our arguments. We endorse a feminist person-centred approach to understanding pregnancy loss. The strength of this approach is that it acknowledges the range of views that different people may have with regard to pregnancy remains. The remainder of the section details the practical implications which management of pregnancy remains has for treatment for miscarriage. As we detail below, alternative approaches to the management of miscarriage will have consequences for the physical experience of miscarriage and may also impact the options for disposal available to the pregnant person. As indicated, in section 3 we detail the legal basis for ensuring that pregnant people are provided with appropriate information on disposal options. We argue that disposal of pregnancy remains should be discussed as part of the explanation of different options for the management of miscarriage. Disposal options are part of the information necessary to ensuring that a pregnant person knows what to expect from treatment and the relationship between treatment and disposal may influence the acceptability of different approaches to management of miscarriage. The final part of our paper makes some specific recommendations about the possibility of using standardised policies, consent forms and information leaflets to promote consistency in

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14 Ibid [87].

15 Ibid [87] and [90].

16 Ibid [93]. GMC, 'Consent: Patients and Doctors making Decisions Together' (GMC 2008) [4] <[www.gmc-uk.org/-/media/documents/consent---english-0617\\_pdf-48903482.pdf](http://www.gmc-uk.org/-/media/documents/consent---english-0617_pdf-48903482.pdf)>. This guidance is in the process of being revised post-*Montgomery*, but the current draft revised guidance still focuses on the need to tailor information disclosure to the individual patient: GMC, 'The Main Principles of this Guidance', *Decision Making and Consent: Supporting Patient Choices about Health and Care: Draft Guidance for Consultation* (GMC, 2018) 6 <[www.gmc-uk.org/-/media/ethical-guidance/related-pdf-items/consent-draft-guidance/consent-draft-guidance.pdf](http://www.gmc-uk.org/-/media/ethical-guidance/related-pdf-items/consent-draft-guidance/consent-draft-guidance.pdf)>.

17 HTA (n 11) [9].

information provision and thus facilitate better care in this area. Clearly defined information provision pathways will be extremely important. It is our intention in this paper to identify practical solutions, with a clear foundation in law, which can improve healthcare in this area.

## 2 Reproductive loss and remains of pregnancy

### 2.1. UNDERSTANDING PREGNANCY LOSS

Earle et al describe how ‘reproductive loss may not be experienced and understood in the same way by different groups of people’.<sup>18</sup> The DBB Project findings echo this and evidence heterogeneous attitudes towards the end of a pregnancy, towards the remains, and towards options for treatment and disposal. In order to accommodate this diverse range of views, we advocate a person-centred approach to understanding pregnancy and reproductive loss.<sup>19</sup> In particular we highlight the embodied nature of reproductive experience and detail the implications of this for how we understand the relationship between the pregnant person and the pregnancy remains and for the care and management of miscarriage. In the opening to *Mass Hysteria: Medicine, Culture, and Mothers’ Bodies*, Rebecca Kukla states:

the fetus and with it the pregnant woman are not objects that come with ready-made stable boundaries . . . the maternal body incarnates one human being at the beginning of pregnancy and two at the end of it, and it is by no means clear how to tell a coherent story about this passage.<sup>20</sup>

For those who experience reproductive loss, particularly prior to 24 weeks, this lack of coherence continues, or indeed can be exacerbated, as once the pregnancy ends there are not two. One of the DBB project participants describes the situation as follows:

There’s only me that knew that I was ever pregnant. You know. There’s only me that knows I ever had a baby well obviously my family knows but um there is nothing to say that she existed okay she never made it into this world but she existed.<sup>21</sup>

As such the fetus and subsequently the remains occupy a liminal category. Some parents will perceive this material as their child and want it to be afforded all the respect, dignity and ceremonial disposal as that of a formerly living person.<sup>22</sup> Others, perhaps most obviously those ending an unwanted pregnancy, may not view the tissue in this way and would not want ceremonial disposal.<sup>23</sup>

Isabel Karpin has influentially argued for the importance of reconceptualising the maternal–fetal relationship to counter-narratives that frame the pregnant person in

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18 Earle et al (n 7) 260

19 Layne (n 8); For an excellent recent contribution to this call, see Abigail McNiven, ‘(Re)collections: Engaging Feminist Geography with Embodied and Relational Experiences of Pregnancy Losses’ (PhD thesis, Durham University 2014) <<http://etheses.dur.ac.uk/10786>>.

20 Rebecca Kukla, *Mass Hysteria: Medicine, Culture, and Mothers’ Bodies* (Rowman & Littlefield 2005) 4.

21 This was someone who had themselves experienced reproductive loss and now supported others in this situation. WP3–05/2017. Some of the quotations in this paper have been edited to ensure they are intelligible to the reader. These edits have been minimal and have not impacted the substance of the quotations.

22 Here we use ceremonial disposal to describe cremation or burial as often these are accompanied by a ceremony with features similar to a truncated funeral. See further, Karolina Kuberska, ‘Unwitnessed Ceremonies: Funeral Services for Pre-24-week Pregnancy Losses in England’ in S Kilshaw and K Borg (eds), *Negotiating Miscarriage: A Social, Medical and Conceptual Problem* (Berghahn Books forthcoming).

23 Amanda J Myers, Patricia A Lohr and Naomi Pfeffer, ‘Disposal of Fetal Tissue following Elective Abortion: What Women Think’ (2014) *Journal of Family Planning and Reproductive Health Care* 84–9.

opposition to the fetal subject.<sup>24</sup> Using the frame of ‘not one but not two’, she suggests we recuperate the maternal–fetal connection:

... to place the woman in control of her body/self and the fetus and not, as she was constructed in the pre-technological era, as subject to her body nor, as she might otherwise be constructed in the age of technology, as subject to the fetus.<sup>25</sup>

We suggest that a similar recuperation of the interest a person might have in their pregnancy remains is important to meeting the needs of those who have experienced reproductive loss. Peel and Cain note:

It is hard to locate pregnancy loss in the lexicon of feminism: Feminists have been well taught to mistrust the concept of the ‘pre-born’ child, the now ubiquitous foetal image which threatens to take over the mother’s subjectivity and agency.<sup>26</sup>

The lack of opportunity to acknowledge the status of the remains poses a challenge to the pregnant person’s agency and subjectivity different to that traditionally identified in the abortion debate; in this case the ‘strangeness’ that the remains are not recognised as ‘a child’. Linda Layne argues that:

It is time for feminists to move pregnancy loss from ‘a private space of shame’ to a ‘public space of solidarity’ . . . Feminists must frankly acknowledge the frequency and import of such events in women’s lives and create a woman-centred discourse of pregnancy loss.<sup>27</sup>

We agree and argue that such an approach provides a nuanced framework for how we might understand the relationship between the person and the remains. Such an approach is driven by the needs and interests of the pregnant person rather than fear or suspicion of fetal personification. By placing the person in control of defining the boundaries of their interests in pregnancy remains it is possible to accommodate a range of views and experiences from those who view the material as their future child, to those who attach no significance to it at all.

In her study of reproductive loss amongst white middle-class American women, Layne highlights the way in which those who experience pregnancy loss often find themselves caught between two contradictory cultural forces. First, is the power of medical and reproductive technologies which (i) make the fetus increasingly visible and public and (ii) increase expectation of a ‘successful’ reproductive outcome. Home use tests facilitate people finding out they are pregnant before they have even missed a period. In addition to this, medical and reproductive technologies have increasingly facilitated the entry of the fetus into ‘public life’ and mean that pregnant people get to ‘see’ their child at earlier

24 See Isabel Karpin, ‘Legislating the Female Body: Reproductive Technology and the Reconstructed Woman’ (1992) 3(1) *Columbia Journal of Gender and Law* 325–49.

25 *Ibid* 330.

26 Elizabeth Peel and Ruth Cain, ‘Chapter 6. “Silent” Miscarriage and Deafening Heteronormativity: A British Experiential and Critical Feminist Account’ in Earle et al (eds) (n 8) 87 drawing on the work of Petchesky. For a discussion of the relationship between the pregnancy loss movement and anti-abortion politics, see Layne (n 8).

27 Layne (n 8) 239.

gestational stages.<sup>28</sup> Van der Sijpt describes the dominant linearity of reproductive narratives:

Current thinking and theorizing about pregnancy and childbirth often take a linear time frame as a starting point. Dominant biomedical embryological notions trace the development of a fertilized ovum into an embryo and eventually, a foetus that is believed to be viable at a specific gestational age. Consequently, pregnancies are conceptualised as a gradual process evolving over time and expressible in days, weeks, months and trimesters.<sup>29</sup>

Furthermore, there is the perception that a pregnancy, particularly one which is medically managed, will progress along a trajectory that gives rise to a living child. Layne argues that this combination of 'earlier and more intensive social construction of fetal personhood' and increasingly unrealistic expectations about the possibilities of biomedicine can exacerbate experiences of reproductive loss.<sup>30</sup> The Royal College of Obstetricians and Gynaecologists (RCOG) Green-top Guideline No 17 defines miscarriage 'as the spontaneous loss of a pregnancy before the fetus reaches viability', taken to be 24 weeks' gestation.<sup>31</sup> They provide the following statistics on occurrence of miscarriage:

If this happens in the first 3 months of pregnancy, it is known as an early miscarriage. Unfortunately, early miscarriages are common, with 10–20 in 100 (10–20%) pregnancies ending this way. Late miscarriages, after 3 months of pregnancy but before 24 weeks, are less common: 1–2 in 100 (1–2%) pregnancies end in a late miscarriage.<sup>32</sup>

Miscarriage, particularly early miscarriage, is therefore a relatively common experience. Notwithstanding this, it is usually unplanned and unexpected. Discourses of pregnancy commonly focus on positive birth outcomes and future living children, often overlooking potential negative experiences.<sup>33</sup> As Peel and Cain summarise:

Pregnancy loss is an example of the cultural silence around reproductive 'malfunction': statistically common it remains shrouded in secrecy.<sup>34</sup>

28 The role of ultrasound in pregnancy has been subject to sustained and varied critique, see for example, Rosalind Petchesky, 'Fetal Images: The Power of Visual Culture in the Politics of Reproduction' (1987) 13(2) *Feminist Studies* 263–92; Janelle Taylor, *The Public Life of the Fetal Sonogram: Technology, Consumption, and the Politics of Reproduction* (Rutgers University Press 2008). For a succinct overview of these arguments and a fascinating account of the role of ultrasound in the context of termination of pregnancy, see Sian Beynon-Jones, 'Revisioning Ultrasound through Women's Accounts of Pre-abortion Care in England' (2015) 29 *Gender and Society* 694–715.

29 Erica Van der Sijpt, 'Chapter 8. Focusing on Force and Forms in Cameroon: Reproductive Loss Reconsidered' in Earle et al (eds) (n 8) 79. See also Erica van der Sijpt and Catrien Notermans, 'Perils to Pregnancies: On Social Sorrows and Strategies Surrounding Pregnancy Loss in Cameroon' (2010) 24(3) *Medical Anthropology Quarterly* 381–98.

30 Layne (n 8) 29.

31 Royal College of Obstetricians and Gynaecologists, *The Investigation and Treatment of Couples with Recurrent First-trimester and Second-trimester Miscarriage* (Green Top Guideline No 17) (RCOG, 2011) <[www.rcog.org.uk/globalassets/documents/guidelines/gtg\\_17.pdf](http://www.rcog.org.uk/globalassets/documents/guidelines/gtg_17.pdf)>.

32 Royal College of Obstetricians and Gynaecologists, *Information for You: Recurrent and Late Miscarriage: Tests and Treatments of Couples* (RCOG 2012) <[www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-recurrent-and-late-miscarriage--tests-and-treatment-of-couples.pdf](http://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-recurrent-and-late-miscarriage--tests-and-treatment-of-couples.pdf)>.

33 For example, pregnancy support books rarely include information about reproductive loss, and if they do it is minimal and tends to focus on the risks of early miscarriage. This is indicative of a broader glossing over of positive negative outcomes to pregnancy: see, for example, in relation to pre-natal testing, Pam Lowe et al, "'Making it All Normal": The Role of the Internet in Problematic Pregnancy' (2009) 19(10) *Qualitative Health Research* 1476–84.

34 Peel and Cain (n 26) 79.

This taboo leads to the second cultural force Layne identifies. The experience of reproductive loss is often met with silence or by attempts to minimise the significance of the experience.<sup>35</sup> Samantha Murphy states ‘by creating this foetus, this unborn child as a social being, we turn this woman into “its mother” – defining her in terms of the foetus’.<sup>36</sup> Yet, in situations of reproductive loss where there is no living child existing in the world:

[T]he very people who have encouraged the mother-in-the-making to take on this role and may have participated with her in the social construction of her ‘baby’ often withdraw their support for these interrelated projects and act as if nothing of any significance took place.<sup>37</sup>

When reproductive loss is mediated through the cultural taboo surrounding it, the experience can be made worse through lack of recognition or acknowledgment of what the person has been through. For example, some of the DBB project participants pointed to lack of acknowledgment of reproductive loss from colleagues once they returned to work.<sup>38</sup>

In addressing the cultural taboo surrounding reproductive loss we need to acknowledge the complexity of the relationship that people may have with their pregnancy remains, as is clear from the following account from one of the DBB project participants:

Obviously mine was, um, so mine stopped growing at six weeks but I was twelve to thirteen weeks pregnant cause my body hadn’t realised that nothing was happening. Um so so he said your only options are a cremation and that has to be on site erm and it’s up to it whether you want to be there or not and then if you want but the remains to remain on site. And I was like right okay that makes no sense bothering to uh. I just thought oh why wouldn’t it just go in with general like clinical waste if it’s – if they’re not deeming it as a thing? So it sort of made no sense I was like is it a thing? Cause one minute it is a thing and the next it’s not a thing?<sup>39</sup>

This quotation emphasises the importance of information provision being context-specific and sensitive to the needs of the individual. For this woman, the fetus did not constitute a baby at this point, but rather, ‘a thing’. The offer of a cremation diverges with this perception and elevates the status of the remains in a way which does not accord with her perception. We are thus sensitive to the fact that the way in which options for disposal are offered can have implicit meaning for the status of pregnancy remains: by placing a particular value on the remains, we may be transforming the pregnant person into a role or a relationship they do not yet identify with.<sup>40</sup> As this quote emphasises, we must also be careful of imposing narratives or scripts on grieving individuals by assuming that a

35 Alice Lovell, ‘Some Questions of Identity: Late Miscarriage, Stillbirth and Perinatal Loss’ (1983) 17(11) *Social Science and Medicine* 755–61; Claudia Malacrida, ‘Complicating Mourning: The Social Economy of Perinatal Death’ (1999) 9 (4) *Qualitative Health Research* 504–19.

36 Samantha Murphy, ‘Chapter 9. Bereaved Parents: A Contradiction in Terms?’ in Earle et al (eds) (n 8) 118.

37 Layne (n 8) 17.

38 This may be because people are unsure what to say. See Jeannette Littlemore et al, ‘Pregnancy Loss: How to Find the Right Words to Talk about it’ (*The Conversation*, 25 August 15 2018) <<https://theconversation.com/pregnancy-loss-how-to-find-the-right-words-to-talk-about-it-100915>>.

39 WP4–10/2017.

40 For a similar, but sharper, account of dissatisfaction in a similar situation see Leslie J Reagan, ‘From Hazard to Blessing to Tragedy: Representations of Miscarriage in Twentieth-Century America’ (2003) 29(2) *Feminist Studies* 356–78.



much-wanted pregnancy means an automatic preference for ceremonial disposal.<sup>41</sup> Nor should we assume that because someone has elected to have a termination they have no interest in the remains.<sup>42</sup> Instead, we argue that healthcare professionals should take the lead from pregnant people about their needs.

*Montgomery*, whose application to this area is explained below, endorsed a patient-centred approach to information disclosure in healthcare.<sup>43</sup> Consistent with that, our critical reasoning here, and the findings from the DBB Project, we advocate for the imperative of a person-centred approach to care in the area of disposal of pregnancy remains; one that acknowledges the heterogeneity of views that individuals might have about their pregnancy remains and the range of feelings they may have about the status of those remains. In order to ensure that someone is prepared for what to expect from the experience of miscarriage, and also to allow them to make an informed choice about different treatment options. We argue for the importance of all options for disposal being discussed unless, in response to the healthcare professional advising there are different options available, the pregnant person indicates they do not want that information. We will now detail the legal framework that sets the contours for the permissibility for the management of fetal remains.

## 2.2 MISCARRIAGE AND STILLBIRTH – DEFINITIONS, REGISTRATION AND DISPOSAL

Legally, pregnancy losses that occur prior to 24 weeks' gestation are treated differently from those that occur after this time. A pregnancy that ends before 24 weeks' gestation is a miscarriage; after this time it will be defined as a stillbirth and subject to different rules regarding registration and burial.<sup>44</sup> In England and Wales, the Births and Deaths Registration Act 1953, s 41 (as amended by the Stillbirth (Definition) Act 1992, s 1(1)) defines stillbirth as 'a child which has issued forth from its mother after the 24th week of pregnancy and which did not at any time after being expelled from its mother breathe or show any other signs of life'. A stillbirth must be registered and, upon registration, the parents will be issued with a certificate which permits burial or cremation.<sup>45</sup> There is no legal requirement to register a miscarriage and, while a very clear set of legal rules surrounds the disposal of the body of a baby born dead after 24 weeks, the law governing the disposal of remains prior to this gestational age is much less clear.<sup>46</sup>

As mentioned in the introduction to this paper, prior to 24 weeks' gestation the remains are treated as the person's tissue, or, in the language of the Human Tissue Act 2004, 'relevant material'.<sup>47</sup> The HTA Code of Practice summarises the situation as follows:

The law does not distinguish between fetal tissue and other tissue from the living; fetal tissue of less than 24 weeks gestation is considered to be the mother's tissue, as are non-fetal products of conception (i.e. placenta, membranes, umbilical cord, amniotic fluid). Consequently, fetal tissue and non-fetal products of

41 For a critical reflection on the transforming meanings of miscarriage and the growth of grief narratives, see Reagan (n 40).

42 See, for example, the diversity of views identified by Myers et al (n 23).

43 *Montgomery* (n 13) [87].

44 NHS, 'What Happens if your Unborn Baby Dies: Stillbirth' <[www.nhs.uk/conditions/stillbirth/what-happens](http://www.nhs.uk/conditions/stillbirth/what-happens)>.

45 Births and Deaths Registration Act 1953, s 11(2) or (3); Births and Registrations Act 1926, s 5.

46 For a discussion of this, see 'Management of Miscarriage: Your Options' <[www.miscarriageassociation.org.uk/wp-content/uploads/2016/10/Management-of-miscarriage-2016.pdf](http://www.miscarriageassociation.org.uk/wp-content/uploads/2016/10/Management-of-miscarriage-2016.pdf)>.

47 Human Tissue Act 2004, s 53.

conception are subject to the same consent requirements under the HT Act as all other tissue from the living (see section on tissue from the living, paragraphs 108–112). However, because of the sensitivity surrounding pregnancy loss, consent should always be sought, even where it might not be lawfully required.<sup>48</sup>

Alluded to in this quotation is the fact that disposal of relevant material does not normally fall within the remit of the HTA; rather the Authority has a statutory function to regulate removal, storage, or use of human tissue through a system of licensing and inspection. Thus, when an individual miscarries, the pregnancy remains are regarded as their tissue. If that tissue is to be stored or used for the purposes of a histological or post mortem examination to ascertain the cause of the miscarriage, ‘appropriate consent’ must be sought.<sup>49</sup> Disposal of human material is not subject to the same statutory rules as removal, storage and use; most importantly for our purposes, specific consent is not required for disposal. It is not our purpose in this paper to provide an argument for specific consent to disposal. Instead we argue that in order to give fully informed consent to management of the miscarriage, pregnant people need to be informed about what to expect during the experience of miscarriage and how to manage the remains subsequently, as part of the discussion of different management options.

As already noted, while the law makes no distinction between pregnancy remains and other tissue, the HTA recognises that pregnancy remains are different as their nature is ‘particularly sensitive’.<sup>50</sup> The Authority has therefore sought to address this sensitivity by issuing specific guidance entitled ‘Guidance on the Disposal of Pregnancy Remains following Pregnancy Loss or Termination’.<sup>51</sup> This sets out the disposal options which should be offered, and requires that all those options be discussed.<sup>52</sup> The guidance was developed between 2014 and 2015 following a request from the Chief Medical Officer. Caroline Brown, then Head of Regulation at the HTA, summarises the background to the guidance as follows:

During 2014, miscarriage and the disposal of fetal remains had been the subject of increased levels of media controversy and public scrutiny: there had been scandals regarding the disposal of fetal ashes by crematoria in Scotland and the disposal of fetal remains by hospitals across the UK, followed by a call for a change in the legal status of fetal remains.

It was the Channel 4 Dispatches programme aired in March 2014 that exposed the poor practices of some hospitals, which were routinely disposing of fetal remains by incineration without any reference to the wishes of the parents. A ministerial statement stating that incineration was not an acceptable method of disposal prompted the Chief Medical Officer to ask the Human Tissue Authority (HTA) to develop new national guidance and to consider how compliance with it might be monitored.<sup>53</sup>

The problematic practice that Brown mentions was the use of incineration as a method of disposal of pregnancy remains in the absence of parental consent. The documentary led to headlines such as ‘Thousands of Unborn Foetuses Incinerated to Heat UK

48 HTA, *A: Guiding Principles and the Fundamental Principle of Consent: Code of Practice* (HTA 2017) [141] <[www.hta.gov.uk/sites/default/files/files/HTA%20Code%20A.pdf](http://www.hta.gov.uk/sites/default/files/files/HTA%20Code%20A.pdf)>.

49 Human Tissue Act 2004, s 1(1).

50 HTA guidance (n 11) [4].

51 Ibid.

52 Ibid [5], [8].

53 Caroline Brown, ‘Foreword’ in McGuinness and Kuberska (n 12).

Hospitals'.<sup>54</sup> In the subsequent fallout there was confusion between normal incineration practices and the practice of 'sensitive incineration'; that is, incineration separate to other clinical waste. Sensitive incineration was recommended at the time in the HTA Code of Practice and in guidance issued by the Royal College of Nurses.<sup>55</sup> Brown states that one of the key debates was whether sensitive incineration should continue to be considered an appropriate disposal option.<sup>56</sup> Guidance issued in Scotland in 2012 had indicated that incineration was no longer appropriate in that jurisdiction.<sup>57</sup> Ultimately the HTA decided that sensitive incineration would continue to be an acceptable disposal option. We suggest that sensitive incineration does form an important choice for some people. Amanda Myers et al undertook research with people who elected to have a termination and their findings show that many in this situation, i.e. ending an unwanted pregnancy, would not find ceremonial disposal acceptable.<sup>58</sup> The DBB Project findings highlight that such an option may also be important for those experiencing the loss of a wanted pregnancy, as illustrated in the quote above.

Despite the guidance from the HTA emphasising that 'the wishes of the woman, and her understanding of the disposal options open to her, are of paramount importance',<sup>59</sup> the DBB project found that many pregnant people are not given full information about the disposal options available to them. In the same way that the HTA has turned to the common law to address the validity of what is 'appropriate consent' for the storage and use of pregnancy remains,<sup>60</sup> we will argue in section 3 that consent and the test in *Montgomery* can be used to provide a legal basis to ensure that people are given information about all disposal options, in accordance with the HTA guidance. In order to make this case we suggest that information about disposal and management of pregnancy remains is a necessary aspect of information disclosure as part of the informed consent to treatment process. We will now explain the relationship between disposal and management of pregnancy remains and variant treatments that form part of miscarriage care.

### 2.3 TREATMENT FOR MISCARRIAGE

Guidance from the National Institute for Health and Care Excellence (NICE) notes that with regard to variant treatment for miscarriage:

[T]here is a lack of research into the effects of these different approaches from the woman's perspective, in particular their psychological and emotional impact. Miscarriage is distressing for most women, and the type of management itself might affect women's need for counselling, with a resulting cost to the NHS.<sup>61</sup>

54 Adam Withnall, 'Thousands of Unborn Foetuses Incinerated to Heat UK Hospitals' *The Independent* (London, 24 March 2014) <[www.independent.co.uk/life-style/health-and-families/health-news/thousands-of-unborn-foetuses-incinerated-to-heat-uk-hospitals-9212863.html](http://www.independent.co.uk/life-style/health-and-families/health-news/thousands-of-unborn-foetuses-incinerated-to-heat-uk-hospitals-9212863.html)>. This is a headline which re-emerges from time to time in relation to broader anti-abortion editorial agendas, see, for example: Sarah Knapton, 'Aborted Babies Incinerated to Heat UK Hospitals' *The Telegraph* (London, 24 March 2014) <[www.telegraph.co.uk/science/2016/03/15/aborted-babies-incinerated-to-heat-uk-hospitals/](http://www.telegraph.co.uk/science/2016/03/15/aborted-babies-incinerated-to-heat-uk-hospitals/)>.

55 Royal College of Nursing, *Managing the Disposal of Pregnancy Remains* (RCN 2007).

56 Browne, 'Foreword' in McGuinness and Kuberska (n 12).

57 'Disposal of Pregnancy Loss up to and Including 23 Weeks and 6 Days Gestation' (Scottish Government 2015) <[www.sehd.scot.nhs.uk/cmo/CMO\(2015\)07.pdf](http://www.sehd.scot.nhs.uk/cmo/CMO(2015)07.pdf)>

58 Myers et al (n 23).

59 HTA guidance (n 11) [4].

60 See (n 48) [19] and [20].

61 NICE, '2. Research Recommendations. 2.4. Management of Miscarriage', *Ectopic Pregnancy and Miscarriage: Diagnosis and Initial Management* (Clinical Guideline [CG154], NICE 2012) <[www.nice.org.uk/guidance/cg154/chapter/2-Research-recommendations](http://www.nice.org.uk/guidance/cg154/chapter/2-Research-recommendations)>.

Interviews conducted as part of the DBB Project suggest the lack of information and variation in practice does have an impact on people's experience of pregnancy loss.<sup>62</sup> This lack of clarity and choice can have long-term impacts on the grieving process as noted by one participant:

[The lack of choice] can complicate people's grief if they found afterwards, you know, 'I would have liked to have done this thing that someone else has done but I never had that choice.'<sup>63</sup>

When a miscarriage does occur, there are three main treatment options: natural or expectant management; medical management; or surgical management. Natural or expectant management does not involve medical intervention, instead letting 'nature take its course'.<sup>64</sup> Medical management of miscarriage involves administering misoprostol to soften the cervix and thus speed up the process.<sup>65</sup> Surgical management involves removal of the fetal and pregnancy-related tissue, either by manual vacuum aspiration under local anaesthetic or in the operating theatre under general anaesthetic.<sup>66</sup>

NICE guidance recommends expectant management as the first-line management strategy for 7–14 days from confirmation of diagnosis of miscarriage with some exceptions, such as previous negative reproductive outcomes, or where there is a risk of haemorrhage, or evidence of infection.<sup>67</sup> Medical management is recommended if expectant management is not successful or where expectant management is *not acceptable* to the pregnant person.<sup>68</sup> Finally, it is recommended that surgical management should be offered where clinically indicated, although there is no elaboration on what the clinical indications might be.<sup>69</sup> The RCOG information for patients states: '[t]he risk of infection is the same if you choose medical or surgical treatment'.<sup>70</sup> Given this explicit preference for expectant management, it is clear that the majority of people will experience the physical process of miscarriage outside of a clinical setting.

The NICE guidance does not consider disposal of pregnancy remains as part of the treatment process. However, it does state that pregnant people should be appropriately informed about what to expect during treatment, including expectant management.<sup>71</sup> We argue that if it is important that people are informed about 'what to expect' this should include being provided with information about what to expect with regard to pregnancy remains and options for management of these remains.

Research undertaken by Abigail McNiven also evidences how the variation in physical experiences can impact on a person's perception of the acceptability of different forms of management of miscarriage.<sup>72</sup> McNiven details how '[u]ncertainty regarding the distinction between "normal" and "worrying" experiences within miscarriage, including

62 McGuinness and Kuberska (n 12).

63 WP3–06/2017.

64 Royal College of Obstetricians and Gynaecologists, *Information for You: Early Miscarriage* (RCOG 2016) 3 <[www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-early-miscarriage.pdf](http://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-early-miscarriage.pdf)>.

65 NICE, 'Recommendations. 1.5. Management of Miscarriage' (n 61).

66 Ibid.

67 Ibid.

68 Ibid emphasis added.

69 Ibid.

70 Royal College of Obstetricians and Gynaecologists (n 64) 3.

71 NICE, 'Recommendations. 1.5. Management of Miscarriage' (n 61).

72 McNiven (n 19) 63.

both bleeding and pain, emerged in a number of participants' narratives'.<sup>73</sup> Within the DBB Project, we found similar evidence of uncertainty, including uncertainty about what to do with the remains, as detailed in this account from one of the support workers whom we interviewed:

I get quite a few calls about that: 'how much blood should I be losing?', 'these pains that I'm having, is that normal?', 'I've been getting these pains' and I'll be saying to them, 'well, the pains you are getting are labour pains because your body has got to go into labour for the cervix to open and for the baby to go away.' So the pains that you are experiencing can be really quite severe and they didn't realise they were gonna have these pains. They're told it's like a period pain . . . – it's nothing like a period pain.<sup>74</sup>

Lack of information was a common theme in these interviews, as was guilt or dissatisfaction on the part of the woman with the decisions she made in the absence of full information or preparedness. The lack of information about the physical experience of miscarriage can be exacerbated by confusion as to what to do with the remains once passed. The following quote from one of the DBB Project participants starkly illustrates this:

And I didn't know what to do. I didn't know how to cope with what was happening. I was in pain. So it sounds awful but the baby ended up falling into the toilet. And I couldn't I couldn't stay in the bathroom so I I went back into the bedroom and my husband who who was in the bathroom with me the whole time and helping me to pass the baby he he had a look at the baby and tried to get it out of the toilet so that we could do something with the body. Um, but he came back in the bedroom a couple of minutes later and just said the the baby had sort've disintegrated. The body'd split apart and um there was nothing much he could do about getting it out of the toilet.

[A]nd then we, we had a terribly awful practical talk about what did we do next so we ended up flushing the toilet.<sup>75</sup>

This participant was deeply upset by the experience and deeply regretted that she was not better prepared about what to expect, and also about the steps that would have preserved her options for what to do with the remains. Clear and comprehensive information provision about what the physical experience of miscarriage entails, what to expect with regard to the remains, and information on the legally permissible options for disposal are therefore vital for '[i]mprovement in the diagnosis and management of early pregnancy loss . . . in order to reduce the incidence of the associated psychological morbidity'.<sup>76</sup>

Similar findings are reflected in the work of Myers et al who interviewed people undergoing termination of pregnancy about the options they would want for disposal of pregnancy remains.<sup>77</sup> The authors note managing the process at home, where disposal by professionals was not an option, caused feelings of anxiety for some people, whilst not being problematic for others. Some of the Trust documentation, examined as part of the DBB project, did not address options for those who miscarry at home. And for those that did, the advice varied from being told to bring the remains to hospital for disposal to

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73 Ibid 118.

74 WP3–05/2017.

75 WP4–11/2017.

76 NICE, 'Recommendations. 1.5. Management of Miscarriage' (n 61).

77 Myers et al (n 23) 86.

being advised to flush the remains down the toilet.<sup>78</sup> One interviewee, a volunteer with a support organisation, describes how the lack of information and understanding about the physicality of the remains, and permissible disposal options, can lead to confusion and feelings of guilt about choices made:

Some mums will come and say oh I collected it in a in a Tupperware box or whatever and then others will be really against like I didn't think I just flushed the toilet I didn't think there'd be anything and then they've got that guilt as well you know that they just flushed it while somebody else has buried it and made made a memorial you know and because they didn't know 'cause they were never told that there would be something and also some people get a phone call after an ARPC and are told we've got the remains what do you want us to do with them and they never knew there would be remains.<sup>79</sup>

In this section we have argued that the pregnant person has an interest in their pregnancy remains, including an interest in how the remains are disposed of. In addition, we have discussed the heterogeneity of views that different people hold following loss of pregnancy. Finally, we provided an overview of the proximate relationship between different treatment options for miscarriage and the embodied experience of loss both in terms of pain and also in terms of the management of disposal of pregnancy remains. The acceptability of different treatment options may be influenced by the physical experience that attaches to each option, including what it means for the management of pregnancy remains. In the next section we will explain how the law on informed consent grounds the obligation to take seriously the person's interests in disposal of their pregnancy remains, as part of the process of care and management of miscarriage.

### 3 *Montgomery*: closing the information gap

*Montgomery* is now the leading case on the standard of disclosure when seeking informed consent to medical treatment.<sup>80</sup> This paper does not explore the history of the law relating to informed consent leading up to this decision as that has been written about extensively elsewhere.<sup>81</sup> Instead, we focus on the ruling in *Montgomery* and how that can be utilised to close the legislative gap around information provision on disposal options for people experiencing miscarriage prior to 24 weeks.

As has been stated above, by the time of the Supreme Court hearing in *Montgomery*, the key question for the court concerned risk disclosure and the correct test for determining whether or not a particular risk should have been disclosed to the patient.<sup>82</sup> Mrs Montgomery had been under the care of the defendant Health Board during her pregnancy. Due to her small stature and diabetes, she was more likely to have a large baby, which was associated with an increased risk of shoulder dystocia occurring during vaginal delivery. Shoulder dystocia involves the baby's shoulders becoming stuck behind the

78 The possibility of passing remains in the toilet arose in several of our interviews. While for some there was concern about this possibility, and they took steps to avoid this taking place, for others this was deemed an acceptable or desirable outcome. A key theme in these accounts was lack of preparedness and lack of information and understanding about what to do.

79 WP3-06/2017.

80 *Montgomery* (n 13).

81 See, for example, Margaret Brazier, 'Patient Autonomy and Consent to Treatment: The Role of Law?' (1987) 7(2) *Legal Studies* 169; Michael A Jones, 'Informed Consent and Other Fairy Stories' (1999) 7(2) *Medical Law Review* 103; José Miola, 'On the Materiality of Risk: Paper Tigers and Panaceas' (2009) 17(1) *Medical Law Review* 76.

82 The initial claim included a claim for negligent management of the labour. This was unsuccessful at first instance and was not pursued on appeal: *Montgomery* (n 13) [2]-[4].

pelvis during delivery. The medical evidence in *Montgomery* suggested that 70 per cent of such cases are resolved without further complications but, where that is not the case, there can be high perinatal mortality and morbidity and an increased risk of maternal morbidity.<sup>83</sup> Despite Mrs Montgomery expressing concerns during her pregnancy about her ability to deliver the baby vaginally, her treating doctor did not disclose the risk of shoulder dystocia to her, or discuss the alternative option of delivering the baby by way of caesarean section.<sup>84</sup> Unfortunately for Mrs Montgomery and her child, shoulder dystocia did occur during vaginal delivery causing the baby to suffer cerebral palsy affecting all four limbs and a brachial plexy injury resulting in paralysis of one arm.<sup>85</sup> Mrs Montgomery asserted that she should have been told of the risk of shoulder dystocia and the alternative method of delivery by way of caesarean section and, had this occurred, she would have elected to undergo a caesarean section and her child would have been born unharmed.<sup>86</sup>

At first instance and on appeal, the courts concluded that, applying *Sidaway v Board of Governors of the Bethlem Royal Hospital*<sup>87</sup> which had taken the *Bolam* standard<sup>88</sup> as the starting point for determining the adequacy of disclosure, there was no obligation for the risk of shoulder dystocia and alternative method of delivery by way of caesarean section to be discussed as other doctors would not have done so.<sup>89</sup> The Supreme Court overturned those decisions, rejecting the application of *Bolam* as the standard for determining whether information about medical treatment should be disclosed.<sup>90</sup> Instead, the court held:

An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken. The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.<sup>91</sup>

The court also held that there were exceptions where doctors would not be held to this standard. These were: (1) when information was withheld from a patient on the grounds that the doctor reasonably believed its disclosure would be seriously detrimental to the

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83 *Montgomery* (n 13) [9]–[10].

84 *Ibid* [17], [29].

85 *Ibid* [22].

86 *Ibid* [13], [18] and [22].

87 [1985] AC 871.

88 *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582, 587, per McNair J: A doctor 'is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art'.

89 *Montgomery* (n 13) [3].

90 *Ibid* [86].

91 *Ibid* [87].

patient's health (termed the 'therapeutic exception');<sup>92</sup> (2) where treatment was necessary (for example, treatment was required urgently and the patient was unconscious and so unable to consent); and (3) if the patient did not wish to be informed of attendant risks and alternative or variant treatments.<sup>93</sup>

The court went on to find that applying the correct standard, Mrs Montgomery should have been advised of the risk of shoulder dystocia occurring and the alternative method of delivery by way of caesarean section and, had she been given that information, she would have elected to undergo a caesarean section and her child would have been born uninjured.<sup>94</sup>

### 3.1 PROTECTING BODILY INTEGRITY: INTERESTS IN FETAL TISSUE

In *Montgomery*, Baroness Hale stated that the interest informed consent seeks to protect 'is a person's interest in their own physical and psychiatric integrity, an important feature of which is their autonomy, their freedom to decide what shall and shall not be done with their body'.<sup>95</sup> As has been noted above, the HTA guidance regards pregnancy remains that result from a miscarriage as the person's tissue.<sup>96</sup> It is, therefore, part of their body, such that ensuring they have a choice in what is done with those remains once they cease to be physically connected to them forms part of their interest in their physical integrity, which, as stated by Baroness Hale, the law of informed consent seeks to protect. It is also important to ensure that a pregnant person is fully informed about what to expect from the experience of miscarriage and to minimise confusion and upset regarding what can be done with the pregnancy remains. As we have detailed, people respond to pregnancy loss differently and thus healthcare professionals, when considering what information to offer about disposal, should take their lead from the person experiencing the miscarriage. This requires healthcare professionals to advise that there are different methods of disposal available and then asking if the person would like information about these. This is consistent with the emphasis in *Montgomery* on patients having a right not to know, as well as the right to have information if they want it. It is also consistent with *Montgomery's* focus on tailoring information provision to the needs of the individual patient in order to ensure the right to decide what is done to your own body is protected.<sup>97</sup>

### 3.2 TAILORING INFORMATION TO THE INDIVIDUAL

Whilst *Montgomery* was primarily concerned with the question of risk disclosure, it also addressed the wider question of what information patients should be given and the extent to which that should be driven by the needs of the individual patient. That information should be tailored to the individual is suggested not only by the reference to risks the particular patient would be likely to attach significance to in the test for materiality, but also by the reference to the need to discuss the individual patient's condition and the

92 We return to the application of the therapeutic exception later in this section, but the scope and need for the therapeutic exception has been called into question, see Rob Heywood and Jose Miola, 'The Changing Face of Pre-operative Medical Disclosure: Placing the Patient at the Heart of the Matter' (2017) 133 *Law Quarterly Review* 296; Emma Cave, 'The Ill-informed: Consent to Medical Treatment and the Therapeutic Exception' (2017) 46(2) *Common Law World Review* 140. It is notable that, despite *Montgomery's* approval of the therapeutic privilege, in the GMC's proposed revised consent guidance (n 16), the therapeutic privilege has been referenced in a footnote only on the basis it is not seen as necessary in medical practice.

93 *Montgomery* (n 13) [85], [88], [91].

94 *Ibid* [94] and [104].

95 *Ibid* [108].

96 HTA (n 48) [141].

97 *Montgomery* (n 13) [85], [87].



alternative treatments available in light of that.<sup>98</sup> It is given further support by the court noting that in endorsing this standard, it was reflecting ‘a broadly similar approach’<sup>99</sup> to that taken in the guidance issued by the GMC. The guidance in question sets out the standards expected of doctors in the context of seeking informed consent to medical treatment and had long required doctors to ‘tailor’ information provision according to the patient’s ‘individual circumstances’.<sup>100</sup> We have explained the importance of tailoring discussions around the management of miscarriage and options for disposal to the individual patient in keeping with the HTA guidance.

The court also said that the obligation to disclose information is not dependent upon the patient asking questions. If it is information a patient could be expected to need to know, it should be disclosed whether they have asked for it or not, unless one of the exceptions identified above applies, such as the person indicating they do not want information about a particular disposal option.<sup>101</sup> Therefore, those Trusts identified in the DBB project which make disclosure contingent upon women asking questions about particular disposal options<sup>102</sup> are in breach of *Montgomery*’s explicit rejection of this requirement.

In tailoring discussions to the individual, the court in *Montgomery* said that doctors should engage in dialogue with patients in order to ensure they understand what treatment is proposed and alternatives.<sup>103</sup> Thus, disclosure of disposal options should not be a ‘tick-box process’ but a two-way discussion between the patient and the healthcare professional aimed at identifying what information the pregnant person wants and ensuring that, where they do want information about disposal options, they are informed of all options, including those not available at the hospital but available elsewhere. Otherwise, disclosure of disposal options may negatively impact a person’s experience, as is illustrated by the following quote from one of the participants in the Myers et al study:

From an emotional side, I wouldn’t like to hear the options, because it would make things really difficult . . .<sup>104</sup>

The information should also be provided in a sensitive way that is responsive to the needs of the person at the time. One of the DBB Project participants highlighted how, although patient was provided with information, it was not in a manner which was helpful at that time:

*Interviewer:* Can I ask if you got any leaflets?

*Interviewee:* Errm. We did in the EPU. Errm Just about what missed missed miscarriage is. She did start saying about what happens with the remains. And I ran out and threw up in the toilet because it was just it was so clinical the way she talked about it. And what happens. They asked what what happens afterwards once they’ve done the DNC. Do we want to keep them or what they do with them? It made me feel physically sick and I ran out and I threw up in the toilet.<sup>105</sup>

It could be argued that these quotes give rise to the possibility of non-disclosure as part of the therapeutic exception, i.e. healthcare professionals may consider disclosure of

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98 Ibid [87] and [90].

99 Ibid [93].

100 GMC (2008) (n 14)

101 *Montgomery* (n 13) [58]–[59].

102 McGuinness and Kuberska (n 12).

103 *Montgomery* (n 13) [90].

104 Myers et al (n 19) 88.

105 WP4–09/2017.

disposal options would cause significant harm.<sup>106</sup> However, although the exact threshold for significant harm has not been explicitly defined, it is accepted that it must go beyond anxiety or distress; specifically, in *Montgomery* the court said it must not be used to ‘prevent the patient from making an informed choice’.<sup>107</sup> The quotation above illustrates distress as a response to the *way* in which information provision was provided, and had the healthcare professionals established what the woman wanted to know and addressed matters sensitively, those reactions may not have occurred.

Tailoring information to individuals not only acts to protect a person’s interest in their bodily integrity, it is also reflective of good healthcare practice in the management of miscarriage. Baroness Hale was clear in *Montgomery* that the law protects both physical and psychiatric integrity.<sup>108</sup> Whilst *Montgomery* concerned the appropriate standard of disclosure in cases involving informed consent to medical treatment, it also has a wider application to healthcare.

### 3.3 MONTGOMERY AND ITS WIDER APPLICATION TO HEALTHCARE

In *Montgomery*, the court noted that, whilst the judgment was primarily concerned with doctors, as ‘a wider range of healthcare professionals now provide treatment and advice . . . it is also relevant, *mutatis mutandis*, to other healthcare providers’.<sup>109</sup> We suggest that the reference to the need to protect physical and psychiatric integrity, as well as its broader application to healthcare providers, supports the notion that the need for information provision is not confined to the provision of medical treatment but extends to all of a patient’s healthcare needs where those needs have the potential to impact their physical and psychiatric integrity. As spelled out above, the NICE guidance requires all options for the management of miscarriage to be discussed with the pregnant person in order for them to decide how to proceed. NICE does not include discussion of the disposal of pregnancy remains within that and, on the face of it then, disposal of pregnancy remains is not part of the medical treatment of miscarriage. What amounts to ‘medical treatment’ is contested and can vary between contexts.<sup>110</sup> These debates are outside the scope of this paper,<sup>111</sup> but we argued in section 2 that disposal of pregnancy remains should be considered as part of the discussion of different treatment options. The choice of approach to management of miscarriage can impact the disposal options available with consequential effects on the person’s psychological health. Therefore, disposal of pregnancy remains forms part of the person’s wider healthcare needs in the management of miscarriage.

Furthermore, case law post-*Montgomery* lends support to the argument that the requirement of informed consent to medical treatment set out in *Montgomery* encompasses events which, even if not regarded as part of the treatment itself, arise as a consequence of that treatment. In *Spencer v Hillingdon Hospital NHS Trust*,<sup>112</sup> nursing staff failed to

106 See Cave (n 92) who highlights information arguments about the scope and need for the therapeutic exception.

107 *Montgomery* (n 13) [91].

108 *Ibid* [108].

109 *Ibid* [75].

110 John Coggon, ‘Comments and Reflections on “Proper Medical Treatment”: A Case for Coherent Inconsistency’ in Sara Fovargue and Alexandra Mullock (eds), *The Legitimacy of Medical Treatment: What Role for the Medical Exception?* (Routledge 2016) 229. Fovargue and Mullock’s collection illustrates the range of interpretations that can exist as to what amounts to ‘proper medical treatment’.

111 For an example of these debates and discussions, see Fovargue and Mullock (110).

112 [2015] EWHC 1058 (QB).

advise a patient on discharge of the risk of developing post-operative deep vein thrombosis or pulmonary embolism. Collender HHJ found in favour of the patient, concluding that the need to disclose this information fell within the scope of *Montgomery* and commenting 'that the basic principles – and resulting duty of care – defined in *Montgomery* are likely to be applied to all aspects of the provision of advice given to patients by medical and nursing staff'.<sup>113</sup> Therefore, in addition to our argument that disposal of pregnancy remains forms part of healthcare in the management of miscarriage, its proximity to such treatment justifies our conclusion that the need to disclose information about disposal options falls within the scope of the test for informed consent as clarified in *Montgomery*.

### 3.4 THE BENEFIT OF APPLYING *MONTGOMERY*

When setting out the correct standard of disclosure that applied in the context of informed consent, the court in *Montgomery* noted this reflected the standard set out in medical professional guidance but felt imposition of the standard at law was necessary to ensure compliance.<sup>114</sup> The DBB project findings illustrate that, despite the HTA guidance being explicit that all disposal options should be discussed with people who miscarry, the extent to which this occurs in practice varies.<sup>115</sup> However, with regard to 'storage and use' of pregnancy remains for the purposes of further clinical examination, e.g. histology, findings suggest that people were provided with very detailed information, not just on how slides would be prepared for the purpose of examination but also about how they would be disposed of subsequently.<sup>116</sup> As such it is clear that this is an area where legal obligations can help achieve consistency in practice between healthcare settings and professionals.

That the HTA guidance should be the starting point for determining what the common law requires is supported by *O'Hare v Coutts*.<sup>117</sup> In this case, when considering the application of *Montgomery* in the context of financial advice, Kerr J said that a professional regulatory regime should be treated as strong evidence of what the common law requires.<sup>118</sup> The HTA guidance then is evidence that the common law should require disclosure of all disposal options in order to protect the patient's physical and psychiatric integrity as part of good healthcare, and *Montgomery* provides the legal basis for this. The following section explores how the argument we make in this paper can be translated into practice.

## 4 Facilitating better care in the context of reproductive loss

### 4.1 AN INTEGRATED CARE PATHWAY

If, as we have argued, consent and the test laid out in *Montgomery* provide a legal basis for the need to disclose information about all options for the disposal of pregnancy remains following miscarriage, then standardised policies, forms and information could be encompassed within a miscarriage care pathway. Pregnancy loss can occur within different departments, for example, A&E, Gynaecology, Early Pregnancy Assessment Units etc. In order to ensure comprehensive care, we argue for one policy to cover

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113 *Spencer*, *ibid* [32].

114 *Montgomery* (n 13) [93].

115 McGuinness and Kuberska (n 12).

116 *Ibid* 13.

117 [2016] EWHC 2224 (QB).

118 *O'Hare*, *ibid* [207].

disposal of pregnancy remains across hospital departments as part of an integrated care pathway.<sup>119</sup> The need for such a pathway is stark, given the inconsistent nature of provision of treatment for miscarriage, which is summarised as follows:

[T]he care of those experiencing miscarriage has developed in the UK in a much more patchy manner, despite the development of national guidelines; this type of reproductive loss has no obvious specialty to call home within the current National Health Service (NHS) structures, and can be housed in a range of organizational locations. Even limiting consideration to secondary care, people experiencing miscarriage might be cared for within a dedicated early pregnancy unit, a maternity or gynaecology ward.<sup>120</sup>

This patchiness, borne out in the DBB Project findings, shows different experiences of care depending on the clinical environment where the miscarriage took place. The use of standardised forms could help to overcome this patchiness by providing reliable resources that are easily accessible to health practitioners in a number of contexts. These resources will need to be supported by appropriate training. A standardised document on disposal options could be integrated into a miscarriage care pathway and could encompass those experiencing pregnancy loss at home, as well as those experiencing pregnancy loss within a hospital setting.

Sands (the Stillbirth and Neonatal Death charity) has led a coalition of organisations to develop a National Bereavement Care Pathway with a view to ensuring bereaved parents are all offered 'equal, high quality, individualized, safe and sensitive care'.<sup>121</sup> This was developed in conjunction with the Department of Health and several other baby loss charities and medical professional bodies.<sup>122</sup> Miscarriage care forms part of this national pathway and if comprehensively adopted will hopefully lead to improved care for all those who experience reproductive loss.

#### 4.2 STANDARDISED FORMS

In Scotland, guidance issued by the Chief Medical Officer and Chief Nursing Officer on disposal of pregnancy remains of less than 24 weeks' gestation incorporates advice on information to be included in drafting patient information leaflets, and sample wording for a consent form.<sup>123</sup> Although we disagree with the Scottish rejection of sensitive incineration as an acceptable disposal option, we suggest that a similar approach to standardisation of information provision could be taken in England. We are aware that advocating for the use of a standardised information document could be criticised as

119 McGuinness and Kuberska (n 12) 21.

120 Ruth Graham et al, 'Experiences of Reproductive Loss: The Importance of Professional Discretion in Caring for a Patient Group with Diverse Views' in Earle et al (eds) (n 8) 210–11 (references omitted).

121 Sands, *Projects to Improve Bereavement Care* <<https://sands.org.uk/professionals/projects-improve-bereavement-care/national-bereavement-care-pathway>>.

122 Charities: ARC (Antenatal Results and Choices), Bliss, Lullaby Trust, Miscarriage Association; Professional Bodies: Institute of Health Visiting, NHS England, Neonatal Nurses Association, Royal College of Midwives, Royal College of Nurses, Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners: Sands, 'National Bereavement Care Pathway' <[www.sands.org.uk/professionals/projects-improve-bereavement-care/national-bereavement-care-pathway](http://www.sands.org.uk/professionals/projects-improve-bereavement-care/national-bereavement-care-pathway)>.

123 Chief Medical Officer and Chief Nursing Officer (Scotland), *Revised Guidance on the Disposal of Pregnancy Losses up to and Including 23 Weeks and 6 Days Gestation* (April 2015) <[www.sehd.scot.nhs.uk/cmo/CMO\(2015\)07.pdf](http://www.sehd.scot.nhs.uk/cmo/CMO(2015)07.pdf)>.

risking de-individualising care.<sup>124</sup> For example, some research indicates that patients who are asked to sign consent forms see such forms as protecting the hospital from litigation, rather than making their particular wishes known.<sup>125</sup> Similarly, use of standardised forms is often criticised for failing to take account of persons with poor literacy skills, or who do not read or write English.<sup>126</sup> *Montgomery* emphasises that the duty of information disclosure is not fulfilled by ‘bombarding the patient with technical information’.<sup>127</sup> Instead, the healthcare professional’s ‘advisory role involves dialogue’.<sup>128</sup> We argue here for the use of standardised forms to *support* active verbal discussion of options for management and disposal of pregnancy remains, not as a substitute for such dialogue. Recent research on consent conducted on behalf of the GMC suggests healthcare professionals find standardised information useful to ensure that everything that should be addressed is covered when seeking a patient’s consent.<sup>129</sup> One interviewee in the DBB Project, a volunteer with a support organisation, summarised how absence of information can lead to confusion about what options are available, or a feeling that there is a lack of choice as to what they can do:

I’ve heard people say well what seems to be on offer is this kind of group cremation. They’ve said ‘I don’t know if we’ve got the choice to do anything different and maybe we’ll want to do something different.’ People don’t always seem very clear on their options.<sup>130</sup>

Thus, standardised forms should not simply be distributed to those experiencing pregnancy loss in fulfilment of the obligation to discuss options for disposal of the pregnancy remains. Instead, they should be used to frame the dialogue between the pregnant person and the healthcare professional, to ensure the person’s choices are accurately recorded, and that they can leave the hospital with the information that they require. Standardised forms can provide a reliable resource that is easily accessible to health practitioners in a number of contexts. In accordance with HTA guidance, such forms should inform healthcare staff of the need to advise patients of *all* disposal options, including those not available through the hospital, and details of whom to approach if the person’s preferred method of disposal is not offered by the hospital.<sup>131</sup>

The DBB project found that people’s perceptions of time are sometimes skewed by the experience of miscarriage and that people needed to take time to reflect on their decisions, rather than being rushed through the decision-making process.<sup>132</sup> Therefore people experiencing miscarriage should be given time to reflect upon their options for disposal and discussion should happen in a quiet place, with the opportunity to ask

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124 Community Research, *Doctors’ Attitudes to Consent and Shared Decision-Making: Full Research Report for the GMC* (June 2017) 32 <[www.gmc-uk.org/Doctors\\_attitudes\\_to\\_consent\\_and\\_shared\\_decision\\_making\\_FINAL\\_research\\_report.pdf\\_72137875.pdf](http://www.gmc-uk.org/Doctors_attitudes_to_consent_and_shared_decision_making_FINAL_research_report.pdf_72137875.pdf)>.

125 Andrea Akkad, Clare Jackson, Sara Kenyon, Mary Dixon-Woods, Nick Taub and Marwan Habiba, ‘Patients’ Perceptions of Written Consent: Questionnaire Study’ *BMJ* (31 July 2006) 2 <[www.bmj.com/content/bmj/333/7567/528.full.pdf](http://www.bmj.com/content/bmj/333/7567/528.full.pdf)>; Peter Neary, Ronan A Cahill, W O Kirwan, E Kiely and H P Redmond, ‘What a Signature Adds to the Consent Process’ (2008) 22 *Surgical Endoscopy* 2698, 2699.

126 *Ibid* 3.

127 *Montgomery* (n 13) [90] per Lord Kerr and Lord Reed.

128 *Ibid*.

129 Community Research (n 125) 31–2.

130 WP3–06/2017.

131 HTA (n 11) [9].

132 Sarah Turner and Jeannette Littlemore et al, ‘The Production of Time-related Metaphors by People who have Experienced Pregnancy Loss’ in A Gargett and J Barnden (eds), *The Production of Metaphor* (John Benjamins forthcoming).

questions, and to read the patient information leaflets.<sup>133</sup> There may be practical issues with provision of such facilities; for example, finding a quiet place in a busy A&E department. This could be explored through a pilot study of the use of such forms. People should also be made aware of what will happen in the event of no decision being made. Adopting this approach to standardised forms as part of an integrated bereavement care pathway can facilitate person-centred care in the context of reproductive loss, utilising consent and the test laid out in *Montgomery* as the legal basis for such an approach acts to respect physical and psychiatric integrity in the management of miscarriage.

## 5 Conclusion

Reproductive loss is a relatively common experience and yet a cultural silence exists around it, despite the recognition that such loss can have a profound impact on a person's psychological and physical well-being and future reproductive experiences. Appropriate care at the time of loss which responds to the person's emotional and clinical needs, and facilitates grieving, can reduce the need for long-term psychological care and improve future reproductive outcomes.<sup>134</sup> This paper provides a legal argument for the importance of ensuring that information about different options for disposal of pregnancy remains should be discussed as part of this care. NICE recognises that all options for management of miscarriage should be discussed. We argue that details of the options for disposal should form part of this discussion as part of the information disclosure necessary to ensure informed consent to treatment.

The empirical research on which this paper is based demonstrates how healthcare practice in this area is problematic in its inconsistency and fails to account for the particular needs of the person who has suffered an unwanted end to pregnancy. Despite the existence of HTA guidance aimed at overcoming the legislative ambiguity around the need to discuss disposal options with individuals who miscarry prior to 24 weeks, the DBB project revealed that this guidance is not being consistently followed.

We recognise that people will view the pregnancy remains from miscarriage in different ways according to their experience, attitudes and beliefs. Some may want ceremonial disposal, whilst others will not. In recognition of this, we have advocated for a person-centred approach which recuperates the maternal–fetal relationship. Healthcare professionals should follow the pregnant person's lead in the management of miscarriage by providing information about all disposal options where they want this information. By placing the pregnant person at the centre of care, and facilitating their control over these remains, healthcare professionals should, as a matter both of good practice and of law, be responsive to needs of the individual.

We have advocated for the importance of all legal options for disposal of pregnancy remains being discussed. Adopting the approach outlined in *Montgomery*, we have suggested that a person's bodily interest in their tissue should be protected by disclosure and discussion of all information options, unless they have explicitly stated they do not want such information. Such discussions should be tailored to individuals in accordance with *Montgomery's* patient-centred approach and our person-centred approach, which acknowledges that people have different embodied experiences of, and attitudes towards, miscarriage.

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<sup>133</sup> McGuinness and Kuberska (n 12) 22–3.

<sup>134</sup> See (n 3), (n 4) and (n 5).

Reproductive loss will usually be unexpected and unplanned for, and people in this situation will need clear and accessible information about the options available to them. The medico-legal framework that governs miscarriage and stillbirth has important consequences for the care received by persons experiencing reproductive loss. As such, it is important that this framework is subject to scrutiny and critique; and it is extremely important that this critique acknowledges the embodied nature of pregnancy. To date, reproductive loss and disposal of pregnancy remains has been an underexplored area of legal scholarship, yet it is an area which is profoundly significant. *Montgomery's* requirement of patient-centred care in the context of informed consent to medical treatment should be echoed in the management of miscarriage and disposal of pregnancy remains, ensuring a person-centred approach to the care and management of miscarriage.

