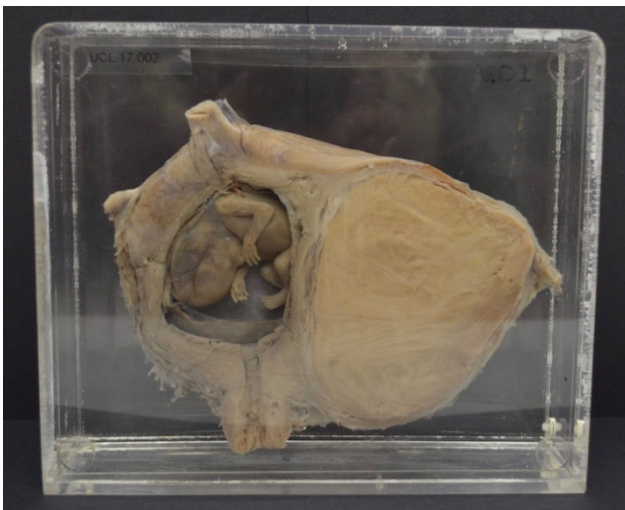


## **The Known Unwanted and Unknown Unborn: Unexpected Consequences of the Diagnosis and Treatment of a Uterine Fibroid Pre-ultrasound**

A visit to the UCL Pathology Museum at the Royal Free Hospital is a compelling but unsettling experience - not for the faint hearted - you are confronted with a vast collection, nearing 3000 specimens, of explicit human remains brought together from several hospitals in London. It includes one particularly fascinating, yet disturbing, specimen: the *pregnant uterus with large fibroid*. A uterus, also known as the womb, is a pear-shaped, hormone-responsive secondary sex organ of the female reproductive system, located between the bladder and rectum, in the lower abdomen, consisting of muscular, epithelial and connective tissue layers. Whilst, a fibroid, specifically identified as an intramural fibroid, is a non-cancerous growth of muscle and fibrous tissue that develops in the uterus of roughly 1 in 3 women around the reproductive age of 16-50<sup>1</sup>. Frozen in time between life and death, the specimen is suspended within a rectangular, coffin-like transparent box, filled with Kaiserling preservative, which is revitalising on the one hand, yet, dehumanising on the other. Labelled with the catalogue number UCL.17.002, the intended viewpoint is indicated, looking directly at an intricately curled up 12-14-week-old fetus (5-9cm long), appearing almost mummified, asleep in the womb. Although, the fetus, no larger than the palm of my hand is extremely premature, delicate bodily features are more than distinct. The enlarged head, subtly characterised with a dainty mouth, nose and closed eyes, bows downwards, tenderly cupped by its fingers and hands, attached to a set of extended arms oblique to the body and legs, that in themselves are arched to fit into the confined space. It reminds me of Ian McEwan's novel *Nutshell*, that retells Shakespeares play *Hamlet* from the perspective of an unborn child: 'My limbs are folded hard across my chest, my head is wedged into my only exit. I wear my mother like a tight-fitting cap'<sup>2</sup>. Covered in a network of veins and being slightly darker in colour compared to the surrounding tissue, the fetus is a focal point, immediately grabbing our attention, despite the adjacent larger, amorphous fibroid invading the uterus, pressing close to the once-pulsating new life. The fibroid to a non-medical eye becomes invisible, however the narrative begins with the fibroid, not the fetus.



*Figure 1: Front perspective of specimen UCL.17.002 (photograph taken by author)*



*Figure 2: Detailed closeup of the fetus inside specimen UCL.17.002 (photograph taken by author)*

<sup>1</sup> NHS, *Overview Fibroids*, 2018 <<https://www.nhs.uk/conditions/fibroids/>> (accessed 20 February 2019).

<sup>2</sup> Ian McEwan, *Nutshell*, (London: Jonathan Cape, 2016).

The only information about the specimen is a terse and rather ambiguous accompanying document provided by the UCL Pathology Museum that claims the fetus was ‘accidentally aborted’ when the fibroid was removed by a total hysterectomy, which traumatically suggests neither the patient nor doctor were aware of the pregnancy! It thus likely dates back to a time before ultrasound scanning, resulting in a terminus ante quem of 1956, first used for clinical reasons in Glasgow<sup>3</sup> and a terminus post quem of 1853, when the first successful abdominal hysterectomy was achieved<sup>4</sup>. These significant dates act as historical milestones in gynaecology, together with the invention in the late 1960s of the first home test kit for human chorionic gonadotropin hormone (hCG), a reliable marker of pregnancy that’s secreted after a fertilised egg is implanted<sup>5</sup>. Crucially the doctors failure to detect the pregnancy, highlights the difficulty of diagnosis for medical professionals prior to these revolutionary developments; especially when previous pregnancy tests were reliant on pseudoscience and false assumptions, dating as far back as the ancient Egyptians who mixed urine with various grains to prognosticate a pregnancy depending on whether the grains germinated or not. Even when, obstetric surgeon John Bland Sutton by 1913 established uterine fibroids as common tumours, having performed many hysterectomies, and made the observation that ‘a large sub-mucous fibroid produces similar changes in the uterus to those set up by the growth of the fetus’<sup>6</sup>, closely mimicking pregnancy, it was still extremely challenging, if not impossible, to determine between the two states with their almost indistinguishable symptoms. This further explains how such an unfortunate mistake may have been made in the past, with the extreme consequence of an abortion. Furthermore it emphasises the added challenges of diagnosis when an overriding condition may mask other complications or concerns. The specimen exists as a haunting memory of the moment of discovery, if indeed the doctor and patient did not know about the pregnancy. It also marks an era in medical history when the development of hysterectomy should be celebrated, but, at the same time, is overshadowed by the number of accidental abortions that may have potentially occurred.

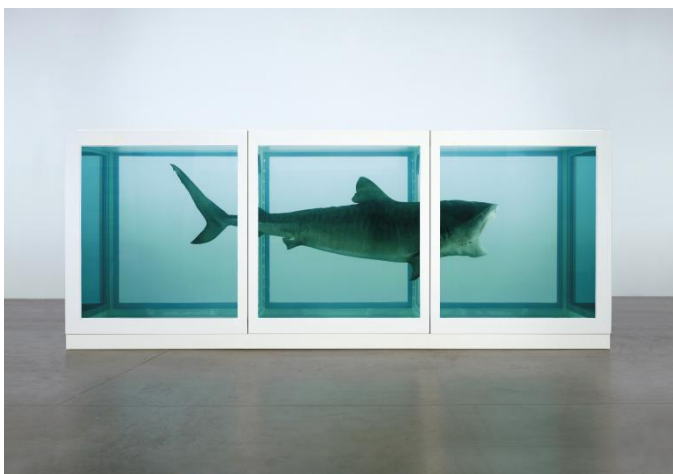


Figure 3: *The Physical Impossibility of Death in the Mind of Someone Living* (1991) by Damien Hirst (Photographed by Prudence Cumings Associates)<sup>7</sup>

The temptation is to focus on the fetus and its emotive impact. It evokes Damien Hirst’s iconic shark in formaldehyde art installation: ‘The Physical Impossibility of Death in the Mind of Someone Living’<sup>7</sup>. This is why I’m especially moved by the arresting image of a life cut short, evoking many questions. Would this baby have been the woman’s first child, therefore robbing her of the chance of future children? What sort of background did the woman come from and why did she not know she was pregnant? Herein lies the trick with this specimen to draw the viewer into its human and deeply relatable story, to solve its mystery and make up for a life un-lived, but this path, however inviting leads us into fiction, detracting from medical scrutiny and the primary

<sup>3</sup> John E. E. Fleming and Malcolm Nicolson, *Imaging and Imagining the Fetus: The Development of Obstetric Ultrasound* (Baltimore: The Johns Hopkins University Press, 2013).

<sup>4</sup> endofibroid.com, *History of Myomectomy*, 1999 <<https://www.endofibroid.com/fibroid-articles/history-of-the-myomectomy>> (accessed 22 February 2019).

<sup>5</sup> early-pregnancy-tests.com, *The History of the Pregnancy Test from Rabbit Tests to Websites*, 2017 <<https://www.early-pregnancy-tests.com/history>> (accessed 21 February 2019).

<sup>6</sup> John Bland-Sutton, ‘The Visceral Complications Met With Hysterectomy for Fibroids and the Best Methods for Dealing With Them’, *British Medical Journal*, 2, no. 2757 (1913), pp. 1130-1132.

<sup>7</sup> damienhirst.com, *The Physical Impossibility of Death in the Mind of Someone Living 1991*, 2012 <<http://www.damienhirst.com/the-physical-impossibility-of->> (accessed 22 February 2019)

reason for the specimens existence resulting from the removal of the fibroid. Yet, we appreciate from their co-existence the intriguing narrative about the problems of diagnosis, providing a glimpse into the history of gynaecology and female health. I was also tempted to challenge the claim that it was an ‘accidental abortion’, that would lead our narrative down other routes... possibly a case of medical maltreatment or even murder... perhaps the mother was unfit physically, mentally or financially to have a baby so the abortion was actually a well-informed, life-changing decision... But these suppositions only progress the investigation when backed up by what we do know. Therefore, we cannot ignore the fact an entire hysterectomy was carried out and the procedures poor history of misdiagnosis and masking of pregnancy, leads us to concur with the UCL notation that this was indeed an accident. Furthermore, although, the majority of fibroids are asymptomatic, others can cause harm to your health, even interfering with gestation, especially if large like the one shown here, thus justifying the doctor’s actions. Ironically these queries mirror the ambiguity associated with the specimen, also diagnostic problems, highlighting the importance of a holistic or whole health approach, promoted as best practice within contemporary medicine.



*Figure 4: Alternative, rear perspective of specimen UCL.17.002 to help gain a better idea of size (photograph taken by author)*

*Figure 5: Detailed closeup of the fibroid inside specimen UCL.17.002 (photograph taken by author)*

It wasn’t until the end of the twentieth century that ultrasound scanning became a routine check in maternity clinics, further transforming the process of hysterectomy, also the diagnosis of uterine fibroids. Today, there are alternative less pervasive options for the treatment of fibroids that can be carried out before pregnancy to preserve fertility, such as Myolysis (coagulation of blood supply to the fibroid using laser surgery) and Uterine Artery Embolisation (embolic agents injected into the arteries supplying the uterus, cutting off blood flow to the fibroid) or even during pregnancy, such as Myomectomy (surgery using instruments inserted through the vagina and cervix into the uterus). Thus, it’s unlikely a doctor and patient would find themselves in a similar situation of misdiagnosis to the one proposed by the specimen. Conversely, despite the common nature of fibroids, cases today can remain undiagnosed for years and doctors have misdiagnosed pregnancy over the presence of a severe fibroid before being checked via ultrasound. A surprisingly large amount of personal stories are posted on the British Fibroid Trust website where women are complaining about poor diagnosis and treatment, with titles such as, ‘Slow to act, no good info’, ‘Always dismissed’ and ‘confusing decision’<sup>8</sup>.

Much progress has been made, from the first successful treatments of fibroids just over 200 years ago, often involving horrific and painful interventions leading onto the first hysterectomy operations towards the beginning of the Victorian era, which in themselves often resulted in high mortality rates due to sepsis or haemorrhage<sup>9</sup>. This era was generally characterised by poor female reproductive health and a significant divide between male and female rights. Case studies further highlight the lack of concern and surgical trial and error that was prominent, providing a worrying glimpse into the way women were treated. One wonders how doctors might

<sup>8</sup> British Fibroid Trust, *Story List*, 2000 [http://www.britishfibroidtrust.org.uk/story\\_list.php](http://www.britishfibroidtrust.org.uk/story_list.php) (accessed 24 February 2019).

<sup>9</sup> History-of-obgyn.com, *History of Midwifery, Obstetrics, Gynecology*, 2015 <<http://history-of-obgyn.com/fibroids1.html>> (accessed 21 February 2019).

have dealt with accidental abortions and this makes me sympathise with the plight of the patient who produced our specimen. Today, we can hope she would receive counselling and support. Furthermore, although abortion was considered a crime by the English Statute Law as early as 1803, this was only the case if carried out after 18-20 weeks of pregnancy and by the 1920's a get-out clause was introduced meaning abortion was not a crime if 'done in good faith for the purpose only of preserving the life of the mother'<sup>10</sup>. Thus, it is most likely the doctor would not have been punished, considering the age of the fetus and the arguably life-threatening size of the fibroid removed.

The fact that the specimen has been preserved, with no known damage, and is now in the UCL Pathology Museum collection, indicates the value of its existence. Perhaps it was the first accidental abortion via a hysterectomy to be recorded from its place of origin? Certainly it was and still is extremely useful for medical students and researchers to help understand the development of a fetus and fibroid construction. This is a very realistic proposal, considering the birth of modern embryology was only stimulated by Von Baer in 1827<sup>11</sup> and the accurate developmental chronology of the human fetus was not available until the invention of ultrasound scanning. There are no supporting documents regarding ownership rights or permissions and prior to the 2004 Human Tissue Act, the removal, storage and use of human tissue lacked regulation. Consent is the legislations fundamental principal, making DNA 'theft a new offence and ensuring steps are taken concerning the wishes of the deceased'<sup>12</sup>. This raises awareness about the ethical and social context about how human tissue, as with our specimen, might have been used in the past.

Specimen UCL.17.002 encapsulates the paradox of medical knowledge at any given time where here the fibroid was successfully treated but the pregnancy was missed. The advances in medical science strive to prolong and preserve life, but rely on successful diagnosis. The tragedy is that with today's advanced diagnostic tools, particularly ultrasound and pregnancy testing, the baby would have been saved. So we return to the ongoing conundrum thrown up by the multi-layered narratives conveyed by the specimen, that no matter how hard we focus on the fibroid we are ultimately drawn back to the life that never was, the delicate and most evocative fetus which could represent anyone of us.

(Word count: 1997)

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<sup>10</sup> BBC, *Historical attitudes to abortion*, 2006 <[http://www.bbc.co.uk/ethics/abortion/legal/history\\_1.shtml](http://www.bbc.co.uk/ethics/abortion/legal/history_1.shtml)> (accessed 23 February 2019).

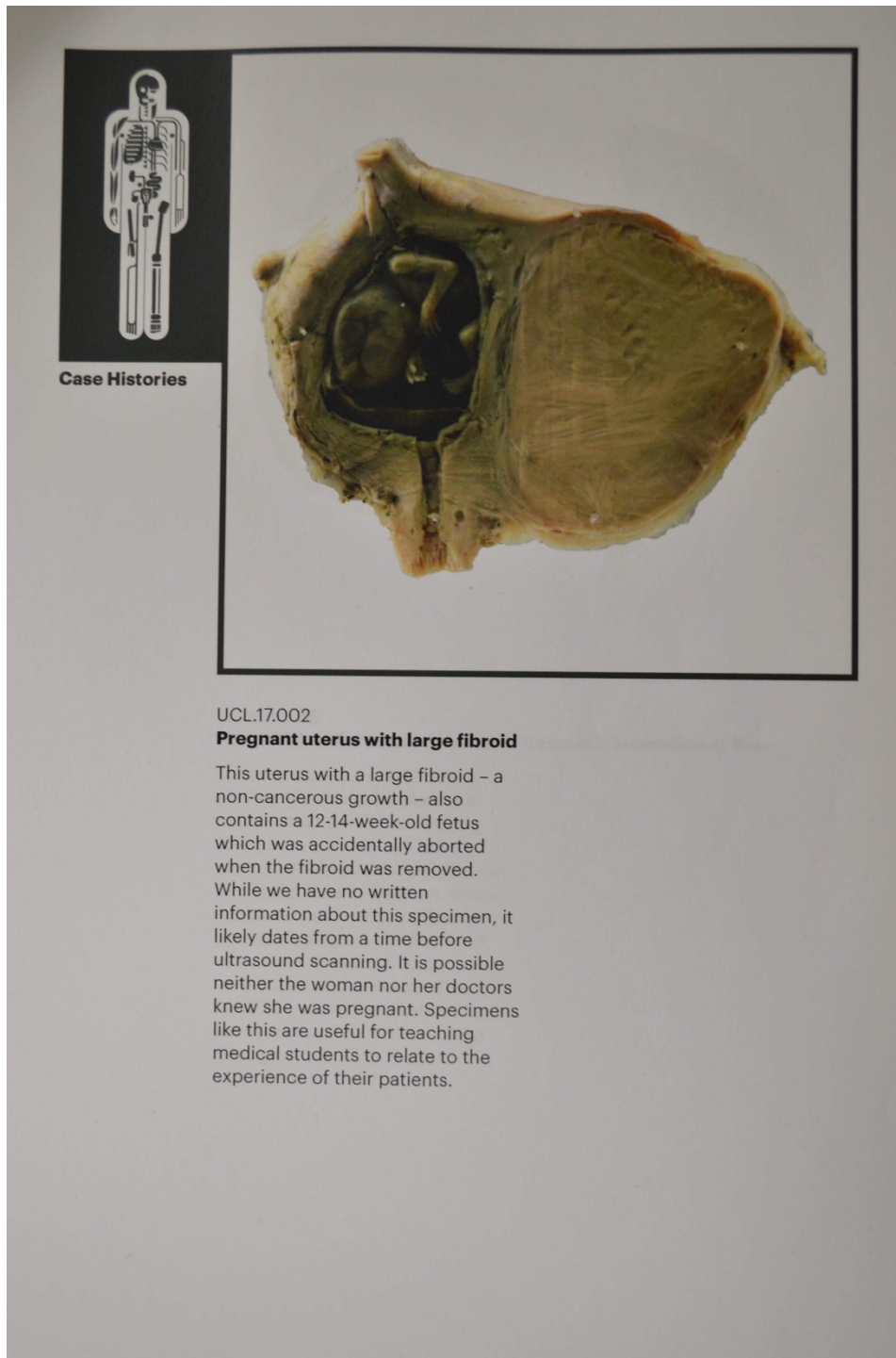
<sup>11</sup> Scott F. Gilbert (ed), *Developmental Biology, A Comprehensive Synthesis, Volume 7, A Conceptual History of Modern Embryology*, (New York: Plenum Press, 1991).

<sup>12</sup> Human Tissue Authority, *Human Tissue Act 2004*, 2016 <<https://www.hta.gov.uk/policies/human-tissue-act-2004>> (accessed 24 February 2019).



## Appendix

Figure 1: UCL Pathology Museum official record of specimen *UCL.17.002* (photograph taken by author)



### Further Recommended Reading:

BBC, *Historical attitudes to abortion*, 2006 <[http://www.bbc.co.uk/ethics/abortion/legal/history\\_1.shtml](http://www.bbc.co.uk/ethics/abortion/legal/history_1.shtml)> (accessed 23 February 2019).

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John Bland-Sutton, 'The Visceral Complications Met With Hysterectomy for Fibroids and the Best Methods for Dealing With Them', *British Medical Journal*, 2, no. 2757 (1913), pp. 1130-1132.

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V&A Museum, *Health and Medicine in the 19<sup>th</sup> century* <<http://www.vam.ac.uk/content/articles/h/health-and-medicine-in-the-19th-century/>> (accessed 21 February 2019).