

6 Missed Disputes

Brainstorming Neuroscience

Introduction

On 15 March 2017, the BBC reported the controversial case of John Culshaw deceased. Greater Manchester Police (hereafter GMP) had retained his organs for over twenty years.¹ An investigation found that there had been no official audit of his retained human material by the Home Office, despite HTA2004. The facts were that after Mr Culshaw was stabbed to death in Wigan on 23 October in 1993, Manchester Coronial Office appointed a senior forensic pathologist from Birmingham to his case. The bereaved family were not informed of the extent of the subsequent histopathology; effectively John Culshaw's 'stomach, liver and other organs and tissues had been retained after two post-mortem examinations' – one to establish the cause of death and the other to gather evidence for a criminal prosecution of homicide. Contemporaneous and subsequent harvesting meant that around 50 per cent of his entire body mass had been taken, much more than was required to satisfy legal evidence standards in court at the time. The victim's family meanwhile thought they had buried him mostly intact. The GMP thus told the press that they had 'agonised over a number of months' whether to tell the family or not that 'a significant amount of extra human material of John Culshaw' had been stored in a police laboratory ever since his death. On balance their ethics committee concluded that they had a moral duty to do so. The retentions had been before HTA2004 came into force, and were not therefore, strictly speaking, illegal. Nevertheless, GMP wanted to be transparent about the pathology error in keeping the body parts for so long without doing anything with them.

This chapter's central focus is therefore a third type of body dispute compared to those we have encountered in Part II of this book so far. In Chapter 4 we examined disputes that arose because consent was implied but never done properly with incomplete post-mortem paperwork inside the system of bequest or donation that supplied anatomical schools and medical research facilities. In Chapter 5 we examined two further types of explicit body dispute involving the Coronial Office: cases in which loved ones wanted to donate a dead relative's organs but were stopped by the coroner who owned the dead body in law if

there was an outstanding legal case to be decided as a result of an unnatural death such as a fatal road accident. And another type involving cases where someone carried a kidney donor card but then after they died their body was harvested for the heart, lungs, brain, and other associated human tissue too. Taking these extra donations resulted in explicit body disputes between grieving relatives, coroners, their pathologists and transplantation teams needing more human material to save lives. In this sixth chapter we now explore missed disputes. A typical missed dispute, as we shall see, arose because of delayed, missing or withheld information about the extent of the harvesting of human material and its long retention period that relatives of each dead person expected to be kept informed about, but were not. Instead, pathologists involved in checking on causes of death for coroners often took the opportunity to harvest brains to do further research. Although families knew that some human material had been retained for legal purposes to secure a court conviction in cases of dangerous driving, homicide and manslaughter charges, not everything about the extent of human harvesting was disclosed. The Culshaw case that opened this sixth chapter is emblematic of that commonplace situation.

Like, therefore, our longer Chapter 5, which contained human stories to illustrate common dilemmas, this chapter is likewise divided into two parts. Part I sets in context the liminal space of medical death and how biotechnology made calling the time of death much more complex in the modern era. It was not an exact science as the ability to monitor even the smallest traces of life-signs in the brain-stem became feasible, complicating the medical ethics of death's door. This discovery reflected the rise of neuroscience and its *brain banking* activities that became the new frontier of medical science in the late twentieth century. To appreciate how this new medical landscape gave rise to missed body disputes, Part II of the chapter investigates the controversial case of the Isaacs family, which created a national outcry in 2000 after it was found that Mr Isaac's brain had been retained with 23,900 other brain material deposits for ten years or more without fully informed consent (themes first introduced in Chapter 2). Families missed an opportunity to know what was happening to the brains of their loved ones because of a controversial and covert system of brain supply by pathologists. For whereas *brain banking* usually was done with the consent of families, generally what was described by pathologists as *brain accumulation* and *brain collection* was not. It was thought that after HTA2004 those missed body disputes had been resolved, but by the time GMP in 2017 got in contact with bereaved families about human material they had held in forensic pathology facilities around the UK for a decade or more, the time gap between the rhetoric and reality of informed consent was obvious for all to see. We return, therefore, briefly here to the story of John Culshaw deceased that opened this chapter and the reaction of his

grieving family to a missed body dispute since it is a historical prism of many of the themes and human situations which we will be exploring together in this sixth chapter.

Jenny Culshaw, mother of John Culshaw deceased, told the BBC that she was shocked to learn that so much of her dead son, who had been murdered in 1993, was still in closed storage in 2017, supposedly supervised by a senior Home Office pathologist for almost a quarter of a century. Had she known, she would have asked questions about what was happening and why. Instead, she now found herself involved in a missed body dispute. It was evident she had not been told the full material facts relating to her son's fatality and subsequent criminal investigation in 1993. Being kept in ignorance for twenty-four years had prevented her from asking the right sort of questions and querying the ongoing situation. She knew that some human material had been taken because it was very necessary for a court case (and thus this was not an implied process of consent that she was objecting to); instead, it was the extent of human harvesting she was querying and the length of time such information was withheld from her, which she would have objected to had she known. As she put it:

He's my son. And he's been left – half of him – If he'd have died and they'd asked me if they could use his parts to help somebody, then yes. But just to be sat in a lab for 23 years doing nothing, that's just horrendous – Somebody has made a big mistake. Not just me but a lot of other families are suffering as well – I don't want anyone else going through this. It's devastating.²

Further inquiries by a journalist working for the *Manchester Evening News* revealed that '180 dead victims of crime in Greater Manchester had been discovered during a recent audit of organ retentions' under the official jurisdiction of GMP.³ Again, Jenny Culshaw questioned the reason that her son's body had been harvested for so many organs that did not relate to how he had been murdered and could not therefore have informed the victims' court case in 1994:

I thought I had buried the son that I gave birth to. In fact I buried a shell. Why? He was stabbed through the heart. Why would they need to retain other parts? We don't know we've got everything back. That's what we are panicking about. Are they going to come back and say they have found some more? The officer who visited us apologised to us. But there are other people out there suffering like I am. We have been visiting him at the cemetery every two weeks. But he's not there. He's not at rest.⁴

Jenny Culshaw was not alone. An audit of all human tissue stored on behalf of police forces around the country, carried out in 2012: 'revealed 492 whole organs or *significant* body parts [like brains] were kept at police stations, labs and hospitals mortuaries on behalf of the police in murder or suspicious death cases'. These related to cases across England, Wales and Northern Ireland

(Scotland has a different legal system). When pressed by angry families about missed body disputes (and their human parts), the Home Office took the view that: 'this is an operational matter for the police'. In the case of GMP, its former Forensic Science Service came under the audit spotlight in 2014, leading to the rediscovery of John Culshaw's potential missed body dispute. The description of his human material in clinical terms ('one of 180 samples') is noteworthy given our discussion in previous chapters about the need for the human life to be put back front and centre to the body 'gift' process. In this case, GMP appointed a dedicated team of detectives familiar with the original case files. They worked methodically to identify the retained human remains of all of their 'police cases' and to contact their respective families. A spokesperson for the GMP review confirmed to the *Manchester Evening News*:

In this case we have been to visit John Culshaw's family twice and had several open and honest conversations with them. Every family we visited has reacted differently to this difficult conversation and in this case they were clearly upset by the news. As with all cases we have offered them specialist support and will continue to do so. We have now spoken to dozens of families and in many cases they have thanked us for the personal visit, but we accept that everyone reacts differently.⁵

In response, Jenny Culshaw told the press that there needed to be more human understanding of the impact that such delayed news would have on the majority of families. She refuted the accusation that her emotional response was either exceptional or excessive. Mrs Culshaw conceded that she was perhaps more outspoken than others about feeling pained, but all those she now knew in similar circumstances were equally shocked. Indeed, she and the other families resented the corporate-speak used to describe how the GMP press office was engaging with them in 'open and honest conversations'. Repeating that phrase several times made it feel like the opposite was happening and the GMP staff were out of touch. The Culshaw family's expectation was that HTA2004 had sorted out 'all' potential missed body and body parts disputes, not just in the NHS. Now they learned that John Culshaw's human material was located at a forensic science laboratory in Birmingham:

Honestly, this has put 10 years on my life. We've kept this quiet because the detective who visited us said 'don't say anything until the other people have been told'. And we have kept it quiet until now. But I can't cope with this all on my own. There's somebody else out there suffering like I am. Somebody should be standing up and saying they have done this. We were never ever told anything had been kept from John. In fact, after the Alder Hey scandal my daughter wrote to the authorities to find out if anything from his body had been kept and she was told no. She did that for me. I don't believe in cremation [Mrs Culshaw is a Roman Catholic]. We're now going to have another burial on Thursday and put those remains in his grave.⁶

The Culshaw family went back to the original grave plot at Westwood Cemetery, Ince, in Wigan and held a second burial service, some twenty-four years after they had interred John Culshaw.

This story is emotive because it has a history of emotions and oral history context. For that reason, it gets to the heart of many of the core themes of this book. First, it alerts us to the multilayered material pathways, networks and thresholds that dead bodies once broken up did not simply travel along – from supplier to medical research facility – but also occupied for some considerable period, often forgotten time, in cold storage. Second, because this pathology system had to be confidential to secure convictions in court, it could also be secretive about everything that was being done and retained out of interest by pathologists. Third, this meant that spaces were created in which time stood still as harvested human material was held in refrigerated suspension for far longer than the general public expected to happen, notwithstanding the legal imperative of a pending prosecution. Fourth, the personalised history of each body (organs, parts, tissues and brain) may have faded from public view, but the identity of each did not dissolve altogether. That which was dissected and disaggregated could be – with a great deal of detailed detective work by the police – reassembled and re-identified when public tastes changed. Fifth, that outcome shows that bio-commons could have been documented by post-mortem passports in the first instance; if it was possible to reactivate human identities, it was equally possible to keep track of them inside forensic pathology facilities. It was therefore not impossible (as historically many inside the system claimed) to monitor working methods and paperwork protocols. Sixth, this finding represented a major public relations challenge for pathologists trained clinically to conduct their expertise because the feelings of families were a human checking mechanism that had never been a direct part of their standard workload allocations. As a result, the challenge for a historian of the body when assessing what was done and why is to rebalance hidden histories of the dead in these clinical settings with experiential perspectives after public exposure. Our approach is therefore that introduced in the conclusion of Chapter 3, namely, to build on Paul Thompson's seminal book about the value of oral history, *The Voice of the Past* (2000).

Thompson argues that there needs to be a reconstruction of the written and spoken historical record because it 'can give back to the people who made and experienced history, through their own words, a central place'.⁷ To do so, we must keep in mind Julianne Nyhan and Andrew Flinn's important observation that it is essential to keep asking of oral histories whether or not they were or are 'fatally compromised by the biases and uncertainties introduced by the interview process'.⁸ In other words, what we are going to do in this chapter is to subject the evidence base that came to light since 2000 to a 'rigorous cross-checking with other sources, arguing for the general accuracy of memory and

its suitability as a source of historical evidence'. For as Alessandro Portelli reminds us, oral histories when combined with histories of emotion can provide new perspectives often hidden from public view. Indeed, he is praiseworthy of what he called 'the peculiarities of oral history' and their subjectivity precisely because they are 'not just about what people did, but [what] they wanted to do, what they believed they were doing, and what they now think they did'.⁹ This conceptual approach is pivotal to this chapter's method of listening to both sides – the clinical (by pathologists) and emotional (by the families) – to arrive at a consensus about what the balance of the evidence is telling us. For as William Reddy points out, the advantage of exploring the navigation of feelings is that historians of emotions can appraise the extent to which giving voice to a set of difficult experiences gives those involved a greater awareness of their fragility in trauma, or an ability to cope in a difficult personal crisis. Often it provides the chance to reconcile difficult circumstances which can produce a more philosophical outlook and thus a positive set of outcomes from something that was imposed but can be accommodated by the person or people involved.¹⁰ In other words, we can assess did people feel worse, about the same, or much better than they thought they might once hidden histories of the dead and their missed body disputes about brain harvesting were revealed for the first time. And what do those discoveries tell us about the changing shape of cultural attitudes to the body and its material afterlives in a Genome era? It is exactly this set of human scenarios that we will encounter as we appraise the Culshaw story with others like it, and encounter those spoken by pathologists at the time, too. For the Culshaws' position (as was inferred in the oral history evidence) was not unique.

It soon came to light in the national press that: 'the Police Service of Northern Ireland kept the most samples with 71 items, West Midlands kept 30, Metropolitan Police 39, Merseyside 37, Cambridgeshire 35 and West Yorkshire 31'.¹¹ These had been located after an investigation was ordered following the discovery that 'many criminal investigations failed to record accurately why human material had been kept'. In response to the public furore in the media about this finding in 2017, all the families involved stated they would have wanted to have been kept informed about material retentions, whether in the past, present or future. The majority spoke to journalists about the emotional 'bolt out of the blue', 'the shock of not knowing', and 'the knock at the door telling us we did not know what had really happened' after so many years.¹² Those who learned their dead child was part of the 'sample size' were understandably very upset indeed. In the cases of body parts retained from '90 children' often involving their brains, it was being misinformed that bereaved parents objected to the most. Hannah Cheevers was one bereaved parent. She told BBC Radio 4's *Today Programme* how after her baby son died of heart failure, she and her husband assumed they had buried him. Then one day

a police officer came and told them: ‘totally out of the blue. . . . We had his funeral, we got on with our lives as you have to and 13 years later we have a knock on the door from the Dorset police to inform us that his brain has been retained at Southampton hospital.’¹³ There were no suspicious circumstances surrounding their child’s death and therefore his brain retention had no legal justification or the family’s consent for over thirteen years. Hannah, like Jenny Culshaw, was not against donation. It was the lack of consultation which was objectionable. Now she too was involved in a missed dispute. She felt this outcome was very sad, since: ‘We had absolutely no idea that they had kept his brain.’ Indeed, the Cheevers family, despite the controversy, ‘decided to donate his brain to hospital research, rather than have it destroyed or reburied after another funeral’. Hannah told BBC News that the family decided they ‘did not want to disturb his human remains again’, even though they were very heart-broken by the hidden history of what had happened.

These symbolic but not unrepresentative cases attest both to the emotive nature of not being informed and to the almost universal feelings of revulsion felt by most people when missed disputes were exposed to public enquiry. Since these missed disputes often involved brain retentions, we need to engage with two practical factors before we encounter more human stories and engage with their historical lessons in hidden histories of the dead. First, why was medical death so confusing after WWII, and how did that context shaped *brain banking* and *brain collecting* that led to so many missed disputes? Part I now outlines that pivotal medical landscape, before Part II takes up their human stories again.

Part I

Medical Death’s Dead-End?

Contrary to perception, death is not a specific moment but a potentially reversible process that occurs after any severe illness or accident causes the heart, lungs and brain to cease functioning. If attempts are made to reverse this process, it is referred to as ‘cardiac arrest’; however, if these attempts do not succeed it is called ‘death’ [Sam Parnia, Professor of Critical Care Medicine and Director of Resuscitation Research at the State University of New York at Stony Brook, USA, 2014].¹⁴

In April 2016, *National Geographic* opened with a lead article that posed a thought-provoking medical question: ‘Is Science Redefining the Boundaries of Life and Death?’¹⁵ The answer was a resounding yes, thanks to new, sophisticated technology. An investigative journalist explained that once society accepted that death was a physical set of processes (based on a growing body of empirical evidence in emergency room medicine), the boundaries of

when that occurred in medico-scientific parlance were always going to shift. This new status quo had prompted a Harvard University panel of experts in 1968 to look at the two ways death had been defined since the eighteenth century: 'the traditional way, by cardiopulmonary criteria, and a new way, by neurological ones'.¹⁶ Their conclusions led to a new recognition that death in the brain mattered just as much as death in the heart and lungs. Evidence showed how, unaided and without extra oxygen, the brain could still survive for about three minutes even after the heart had stopped and the lungs had ceased to inflate. Consequently, 'brain death' in medico-legal circles now had 'three cardinal benchmarks'. These included: 'coma or unresponsiveness, apnea or the inability to breath without a ventilator, and the absence of brainstem reflexes'; these have tended to be 'measured by bedside exams such as flushing the ears with cold water to see if the eyes move, poking the nail bed to see if the face grimaces, or swabbing the throat and suctioning the bronchia to try to stimulate a cough'. Therefore, death acts like a dimmer switch in the body; it can be turned down in trauma, but that does not mean that the light of life has expired in the brain or vital organs. Quoting Dr Sam Parnia (who opened this section), the article observed:

Death is 'a process, not a moment', writes critical-care physician Sam Parnia in his book *Erasing Death*. It's a whole-body stroke, in which the heart stops beating but the organs don't die immediately. In fact, he writes, they might hang on intact for quite a while, which means that 'for a significant period of time after death, death is in fact fully reversible'. . . . He says 'CPR works better than people realize and that under proper conditions – when the body temperature is lowered, chest compression is regulated for depth and tempo, and oxygen is reintroduced slowly to avoid injuring tissue – some patients can be brought back from the dead after hours without a heartbeat, often with no long-term consequences'. Now he's investigating one of the most mysterious aspects of crossing over: why so many people in cardiac arrest report out-of-body or near-death experiences, and what those sensations might reveal about the nature of this limbo zone and about death itself.¹⁷

Yet, the interesting thing about this storyline was the reaction to the online newsfeed by regular readers of *National Geographic*. Some subscribers blogged that they thought the evidence presented of a number of cases in which patients had been brought back from the dead many hours after they seemed to expire in the emergency room was disturbing. Others dismissed the notion of a Near-Death Experience (hereafter NDE) calling it pseudo-science. Many more believed that this NDE grey zone proved life after death existed in some form and thus validated how many people had a spiritual faith in the global community. Few, however, expressed an opinion about the reporting of the history of resuscitation and whether 'the facts' as presented in the article were reliable or not. Although the reportage did not intend to mislead, it did not cover just what a long and disruptive issue medical death has been in the history

of anatomy: an important context for this chapter's central focus on the role that medical death and brain research would play in creating missed disputes by the turn of the twenty-first century.

Recently, historical scholarship has established that English penal surgeons had been very troubled by when to call medical death since at least the mid-eighteenth century. As this author has argued extensively elsewhere, those medical men who were given the task of dissecting criminals convicted and hanged for murder on the gallows under the Murder Act (25 Geo. 2. c. 37: 1752) found that in the winter, cold corpses that should have been dead could be revived when cut down from the hangman's rope.¹⁸ Hypothermia in the body protected the brain, heart and lungs from expiring, and when warmed up the deceased began to wake up in the dissection theatre. Since they were socially dead (having committed homicide), legally dead (being condemned in court and hanged in public) but not medically dead (still having life signs in the body), the only solution was to transport the convict for life to the Americas or Australia. Somewhere today there are the ancestors of condemned criminals who are living proof that the boundaries of life and death have always been fluid. This unforeseen outcome seldom features in standard historical accounts, so it is perhaps unsurprising that such findings have not informed modern debates concerning when death really occurs. In other words, from the eighteenth to the twentieth century medicine behind closed doors knew about the complexities of 'calling the time of death'. Indeed, one physical factor that eighteenth-century surgeons encountered regularly, which twenty-first-century consultants in emergency medicine know to be a physical fact, is that to keep the brain-stem alive, effective oxygenation of the bloodstream must be sustained in trauma. It is best to start oxygenating the blood at the point of injury, even before ambulance transfer. This is because biomedicine really does work best when it is as easy as breathing. That discovery has complicated today when exactly to call the time of death. For traditionally doctors used to call the time of death at twenty minutes in emergency rooms around the world. That was when they accepted the flatline of the heart as proof of medical death. There seemed little point in continuing to do compressions or jolt the heart with an electrical stimulus beyond the twenty-minute marker if the brain was beyond repair. The person in trauma would be in a vegetative state, functioning on a heart-lung machine but not capable of an independent quality of life. This customary practice, however, started to run counter to the new capabilities of medical technology. From the 1980s, it was feasible to monitor even the very faintest traces of life in the brain-stem. Sophisticated equipment began therefore to elongate the timing of medical death. In resuscitation medicine, the twenty-minute marker looked outdated. Thus, in the recent past, saving a life involved oxygenating the brain-stem and reviving patients thought dead. This discovery has redrawn the fine line we all will cross one day into our individual deadlines.

In other words, by the 1960s research facilities around the world reliant on brain material to advance neuroscience now faced new practicalities, and medical ethics had to respond in kind.

In 1968 (as we have seen) invited scientists, anaesthesiologists and experts working at the forefront of emergency medicine, as well as leading ethicists and a medical historian, convened at Harvard University. They styled themselves the Ad-Hoc Committee on Brain Death (hereafter AHCBD) and assembled at Harvard Medical School. Their remit was to review and make new policy recommendations concerning the changing ethics of ‘irreversible coma’ and shifting medico-legal definitions in a biotech world.¹⁹ The AHCBD concluded that in a non-functioning brain, permanent death needed a clinical description of ‘brain death’, re-defined in three diagnostic ways:

1. *Unreceptivity and unresponsivity* – patient shows total unawareness to external stimuli and unresponsiveness to painful stimuli
2. *No movements or breathing* – all spontaneous muscular movement, spontaneous respiration and response to stimuli are absent
3. *No reflexes* – fixed, dilated pupils; lack of eye movement even when hit or turned, or ice water is placed in the ear; lack of response to noxious stimuli; unelicitable tendon reflexes²⁰

However, because there was also a considerable weight of medical evidence that some bodies in hypothermia or after drug intoxication could sometimes be revived in the brain-stem and still had a beating heart, a fourth checking mechanism was required, too. Each patient had to have an electroencephalogram (EEG) and two experts in resuscitation medicine to check the reading. They had to agree that the person was deceased and could potentially be part of an organ donation scheme, provided, that is, they met the new medico-legal protocol steps 1–3 plus EEG. A patient was only then essentially ‘brain dead’ and this diagnosis defined their end of life, rather than a non-beating heart. The hope was that this new diagnostic tool would separate out ‘brain dead’ patients from those in a ‘persistent vegetative state’: the latter can still physically experience cycles of sleep and wakefulness despite being in a deep unconscious state.²¹ A priority was to protect transplant surgeons against accusations of killing patients during technical procedures when the heart had to be stopped to be transferred to a donor or a kidney was taken from a so-called ‘living cadaver’ on life support until the transplant was complete. In medico-legal circles ever since, the AHCBD meeting became renowned as a landmark ethical event.²² It also stimulated considerable controversy.²³

From the outset, critics observed the close links between the AHCBD report and organ donation schemes in Intensive Care Units (hereafter ICUs). Collected evidence from around the medical world seemed to indicate that the majority of ‘brain dead’ patients became ‘solid organ’ donors (heart, lungs, kidneys and liver). Harvesting of on average four donations per dead donor

soon became the norm. Other ‘donors’ became ‘tissue transplants’ (eyes, bone grafts and general human material). Sceptics questioned therefore the degree to which ‘the dead donor rule’ was ethical. Did it effectively drive up donation rates? It looked like those involved in transplantation actor networks could have been motivated to improve biotechnology, rather than promoting medical altruism (in that order of priority). For this reason, the AHCBD report, whilst influential, did not create a global medical consensus about an agreed precise timing of ‘brain death’. Consequently, the US government convened a President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research in 1981. The aim was to look again at patients who seemed to be ‘beyond coma’. This diagnostic emphasis stressed that it was ethical to explore when the ‘whole of life’ appeared to have ended in a patient in deep trauma. As Margaret Hayden, bioethicist, explains: ‘The report’s other reason for this new definition was equally pragmatic, stating that patients in irreversible comas (with beating hearts but irreversible brain damage) could place an undue burden on families and hospitals.’²⁴ The review group hence concluded that the holistic essence of life is in the brain. Hayden elaborates that in 1981 the President’s Commission drew ‘on both biological and philosophical premises’ concluding that:

death is the moment at which the body’s physiological system ceases to constitute an integrated whole. Even if life continues in individual cells or organs, life of the organism as a whole requires complex integration, and without the latter, a person cannot properly be regarded as alive.²⁵

In other words, brain research and advances in emergency medicine were dealing with a new reality – death’s door stayed open for longer than many skilled medics cared to admit in public – and on its threshold were the living-dead which required new protocols. Soon, the 1981 President’s Commission findings were being enacted across America.

Forty-five US states adopted a definition of ‘total brain failure’ under new legislation known as the Uniform Determination of Death Act (1981) (hereafter UDDA). Again, however, critics like Hayden point out: ‘Much of the clinical guidance is designed to mitigate and mask the ambiguity between what a brain dead individual looks like (well-perfused, warm skin, with a beating heart) and how we expect a dead body to appear (grey, “lifeless,” with no heartbeat or pulse).’²⁶ Often ICU staff reported on families feeling upset and confused about being informed their relative was ‘technically alive’ and not knowing what exactly this meant clinically. Thus, the UDDA had provided a useful working-protocol, but families trusted their instincts too and this led to a cultural stand-off, sometimes culminating in body disputes. What further complicated the separation of life from death by the Millennium were new clinical findings highlighted by Dr Caroline M. Quill, the lead author of

a disquieting study into ICU practices across the USA. These were coordinated by the Pearlman School of Medicine at the University of Pennsylvania. As *NBC News* explained in May 2013: 'If you land in an intensive care unit sick enough for doctors to consider withdrawing life support, be warned – Whether and when to pull the plug may depend in large part on the practices and culture of the ICU itself . . .'

Quill and her team analysed records of more than 269,000 patients treated in 153 ICUs in the United States between 2001 and 2009. Overall, nearly 12 percent of patients had a decision made to go from a 'full code' – an all-out effort to save lives – to some kind of limit on care. That could have included: a DNR or do-not-resuscitate order; an order to withhold CPR or cardio-pulmonary resuscitation plus removing mechanical ventilation; dialysis or other life-saving treatments; or simply an order to provide only comfort measures or hospice care. About 59 percent of the patients died in the ICU and another 41 percent survived to discharge, the study found. Particular patient characteristics accounted for most of the variability in decisions to withdraw life support, Quill acknowledged. But even after age, illness, functional status and other factors were analysed the variation among ICUs to authorize a DFLST – decision to forgo life-sustaining therapy – was striking.²⁷

Dr Douglas White, an Associate Professor of Critical Care Medicine and Director of the Ethics of Critical Illness at the University of Pittsburgh, likewise pointed out that often 'decisions about whether and when to withdraw support are not scientific ones'. Hence, patients should be encouraged to talk much more openly about what they would want to happen in a critical situation at the end of life and leave a legal will stating their healthcare wishes. Yet, many in the recent past felt unable to do so; others put off the inevitable, or hoped their families would take over, often with mixed results, as an anonymous nurse working in ICU explained to *NBC News*:

Speaking as a registered nurse in a hospital myself, the choice to withdraw life support is one of the hardest decisions to make during the crisis. Often times what I see is not so much that the person in crisis isn't ready to go, it's usually the family isn't ready to let go. I once had a patient wheeled up to floor who looked me in the eye and said: 'I want to die'. He had stage 4 cancer with no chance of treatment, his body was starting to shut down little by little, he was confused but not THAT [*sic*] confused. So, because of the 'confusion' he had to depend on his family to withdraw life support. They didn't want to. So, instead of letting the man go with some dignity, he ended up tied to a bed for trying to pull his lines out, he ended up with an infection as his body had stopped fighting off invaders, his kidneys had stopped working properly so he gained water weight from all the IV antibiotics we gave him. A few days later he did eventually pass. I just remember thinking, instead of being able to die peacefully in his right mind, he had to beg every day to die, live through the torture of feeling his body shut down piece by piece, and what was accomplished? Nothing. People deserve to die with dignity and honour, and sometimes life support is a curse.²⁸

Even so, a further complicating factor was advances in emergency medicine during the same period.

In April 2013, Sam Parnia expanded on his hands-on experiences of medical death. In *The Lazarus Effect*, he wrote about how after training in resuscitation medicine at Guy's and St. Thomas' hospitals in London and then becoming head of ICU at Stony Brook University Hospital in New York, he observed that:

The one thing that is certain about all of our lives . . . is that we will all eventually experience a cardiac arrest. All our hearts will stop beating. What happens in the minutes and hours after that will potentially be the most significant moments of our biography. At present, the likelihood is, however, that in those crucial moments we will find ourselves in the medical environment of the 1960s or 1970s. The kind of CPR (cardiopulmonary resuscitation) that we are familiar with from medical dramas – the frenzied pumping of the chest – remains rooted . . . in its serendipitous discovery in 1960. It remains a haphazard kind of procedure, often performed more in hope than anticipation. Partly, this is a question of personnel. Most doctors will do CPR for 20 minutes and then stop. . . . The decision to stop is completely arbitrary but it is based on an instinct that after that time brain damage is very likely and you don't want to bring people back into a persistent vegetative state. But if you understand all the things that are going on in the brain in those minutes – as we now can – then you can minimise that possibility. There are numerous studies that show that if you implement all the various resuscitation steps together you not only get a doubling of your survival rates but the people who come back are not brain damaged.²⁹

In other words, the culture of ICU functioned with an out-of-date historical concept of life and death: as Parnia explained at the start of this chapter's Part I. Such basic findings reflect how much medicine has been about looking forward, not back: criticisms which echo those of George Steiner discussed in the Introduction. He highlighted that science's methodologies have a fundamental flaw. Discarding 'old knowledge' happens routinely with each new medical breakthrough. By contrast, the medical humanities seldom casts off accumulated human experiences or their arts forms, recognising instead that the potential remains for the revival of old ways of thinking in a future context.³⁰ Kwame Anthony Appiah (philosopher, cultural theorist and novelist) said the same thing during the recent Reith Lectures for the BBC. He observed once more: 'Although our ancestors are powerful in shaping our attitudes to the past' and we need to always be mindful of this, we equally 'should always be in active dialogue with the past' to stay engaged with what we have done and why.³¹ In many respects, mapping hidden histories of the body is an important way to reveal the flaws in medico-scientific methodologies, as this book and others by this author have done for the first time.³² They reiterate that an eighteenth-century surgeon and his twenty-first-century equivalent in ICU face the same ethical dilemmas. It is not therefore the case that ICU has been too respectful of historical concepts of life/death, as many claim today in

resuscitation medicine and standard historical studies.³³ What has really happened is that ICU never engaged with its own past practices. They thus lost sight of the working protocols of their surgical predecessors dissecting in the Georgian period. Eighteenth-century criminal surgeons first discovered the extraordinary capacity for resuscitation in the brain, even after it sounded like the heart had stopped beating in the chest cavity of a hanged criminal. Sam Parnia has therefore returned to old medical questions with renewed biomedical capabilities. In so doing, he alerts us to two important factors on missed body disputes of the modern period – that the brain was the frontier of medical research and that we know less than we should have done of its harvesting networks. To appreciate the importance of this context for our human stories later, it is important to reflect briefly on the dominance of neuroscience in our biomedical world.

Brainstorming Neuroscience

We have a brain, and people without brains don't have thoughts. So the brain must do it. It's a huge problem to discover how it does it, but that will come. There's no alternative.³⁴ [Professor Colin Blakemore, Chair in Neuroscience, University of Oxford, quoted in 'Brain research's golden age', *BBC News Magazine*, 22 June 2011]

Few scientists would disagree with Professor Colin Blakemore that brain research has become *the* medical frontier in a biomedical age across the global community, and a timely one. As the Brain Research Trust highlighted in 2016, 'over 12.5 million are affected by neurological conditions in the UK (that's one in five)'.³⁵ The medical charity's online promotional video explains that: 'the brain is the most complex organ in our body – it weighs just 3 pounds – yet it controls our emotions, senses, and actions – it's how we process the world around us – so when it breaks down, we break down'. In a similar refrain, Carl Zimmer explained how in 2014 he surveyed the most innovative brain research for *National Geographic* across America:

Some neuroscientists are zooming in on the fine structure of individual nerve cells, or neurons. Others are charting the biochemistry of the brain, surveying how our billions of neurons produce and employ thousands of different kinds of proteins. Still others . . . are creating in unprecedented detail representations of the brain's wiring: the network of some 100,000 miles of nerve fibres, called white matter that connects the various components of the mind, giving rise to everything we think, feel, and perceive. The U.S. government is throwing its weight behind this research through the Brain Research Advancing Innovative Neuro-technologies (BRAIN) Initiative. In an announcement last spring, President Barack Obama said that the large-scale project aimed to speed up the mapping of our neural circuitry, 'giving scientists the tools they need to get a dynamic picture of the brain in action.'³⁶

In many respects, new digital technology entrepreneurs and their personal computer revolution have also been leading the way globally, too. One such is the late Paul G. Allen, co-founder of Microsoft with Bill Gates. He created the Allen Institute for Brain Research in 2003 with a philanthropic donation of \$100 million. Subsequently, Allen donated another \$400 million to ensure that brain research remains an 'Open Science'. His window-on-the-world legacy is a data portal known as the Allen Brain Atlas – 'part of a 10-year plan launched in March 2012 to understand the neural code—how activity in the brain's cortex leads to perception, decision making, and ultimately action'. His foundation thus promises: 'We will be focusing our understanding through simultaneous study of the brain's components, computation and cognition.'³⁷ Allen, before his untimely death (he died of septic shock related to a terminal cancer diagnosis), was the personification of an *Idea Man* (the fitting title of his 2012 memoir), for he has taken up the anatomical legacy of the past and pushed it forward into a neurological future he often described in his public speeches as '*What if*'. It is a motto penal surgeons working on the dark science of the brain were once very familiar with in the past, too. They punished the 'dangerous dead' in popular culture and found that around 25 per cent of criminals hanged came back to life on the dissection table across England between 1752 and 1832.³⁸ Continually, the boundaries of life and death shifted in the anatomy theatre. They proved to be more fluid than conventional European science traditionally thought over the next two centuries. So much so, that with the advent of biotechnology and the rise of neuroscience, the boundaries of life and death came into even sharper clinical and research focus, revealing differential power relations depending on claims of scientific expertise. And even though this remarkable work on the brain looked like it was robust, this was not necessarily the case. One example stands in for many at the time, and it explains why the general public started to become more sceptical about missed body disputes involving brain retentions once they came to public attention in modern Britain.

On 6 July 2016, *Forbes* magazine asked its readers to think the unthinkable – 'Could Brain Research from the Past 15 years Really Be Wrong?' The lead article, penned by Bruce Lee (Assistant Professor of International Health at Johns Hopkins University Bloomberg School of Public Health) highlighted how three researchers from Linköping University in Sweden had published a startling neurological study in the *Journal of the Proceedings of the National Academy of Sciences of the United States of America*.³⁹ It explored the use of Functional Magnetic Resonance Imaging (fMRI) in brain research. This was a twenty-five-year old piece of technology and surprisingly few researchers have ever asked: Does it actually work properly, and have its research results been reliable? Essentially, the Swedish research team found a flaw in the

operation of software used to detect brain activity, tracked under fMRI scans. As Lee explained:

Anders Eklund, Thomas E. Nichols and Hans Knutsson examined fMRI data from 499 healthy patients and found that the software (i.e., SPM, FSL and AFNI) used to generate the fMRI images often showed parts of the brain lighting up when it shouldn't have, in some cases up to 70% of the time (i.e., a false positive rate of up to 70%). These software packages had bugs or glitches in them that were leading to faulty images and may have existed for 15 years until they were recently found and corrected. This means that up to around 40,000 fMRI studies published in the scientific literature over this period could have shown incorrect results.⁴⁰

Soon Lee's article made medical news around the world because as he asked: 'Why wasn't this software glitch caught earlier?' There were 'Several Reasons', he explained –

First, there is not enough research being done on the software used for medical research and how to improve or develop new software. Secondly, scientific journals often will not publish studies that try to recreate already-published studies. At the same time, funders may not support research that tries to recreate other people's research. This means that once a study is published, others may have no incentive to check or re-do the study. Instead, we need to change the system to encourage people to test and re-test scientific hypotheses and findings. Like a new fashion, scientific ideas are sexiest when they are first demonstrated, and then the scientific community quickly loses interest afterwards. But the first person to find or study something is not always right.⁴¹

In other words, in brain studies leading researchers had taken their own working histories for granted. *Science Alert* likewise highlighted that although scientists thought they were measuring brain function using fMRI, what they had really been doing was interpreting data produced by a machine, not the actual human brain. In other words, 'Software, rather than humans . . . scans the voxels looking for clusters [of brain activity]. . . .When you see a claim that "*Scientists know when you're about to move an arm: these images prove it,*" they're interpreting what they're told by the statistical software' – an important data distinction.⁴²

The particular computer software bug that the Swedish study identified was located and repaired in May 2015. Even so, it had skewed the results in some 40,000 published papers since the 1970s. As the Swedish team explained: 'One of the biggest obstacles has been the astronomical cost of using these [fMRI] machines – around US\$600 per hour'. Thus, 'studies have been limited to very small sample sizes of up to 30 or so participants, and very few organisations have the funds to run repeat experiments to see if they can replicate the results.'⁴³ An added problem had been 'that because software is the thing that's actually interpreting the data from the fMRI scans, your results are only as good as your computer, and programs used to validate the results

have been prohibitively slow'. Debates and disputes should have been happening on a more regular basis inside the medical research community about the status of the science involved in brain work, and what this might have meant for public relations in terms of brain bequests. But this was not the case. To appreciate that context, and why it would later give rise to missed disputes, it is necessary to focus on the advent of *brain banking* because this provided the backdrop for future NHS scandals over retentions.

Cambridge University in the 1970s was the centre of new directions in neurosciences. In particular, it started to attract talented researchers interested in neurodegenerative disorders such as Huntington's disease. By 1975, a consortium of these researchers had come together to form what became known as the Cambridge Brain Bank. Not only was this one of the first research facilities in the UK, but one of only four in the world at that time. Its nearest geographic rival was an early brain collection set up by Professor John (Nick) Corsellis (1915–1994) at Runwell Hospital in Essex during the 1950s which contained over 6,000 specimens from patients suffering from psychiatric illnesses, as well as neuro-degenerative diseases. However, although Corsellis shared brains with other leading researchers from time to time, his main research focus was *brain collecting* for his own use, rather than *brain banking* (in the latter, brain tissue is shared routinely for distribution amongst the research community). What made *brain banking* a new trend at Cambridge, and elsewhere, from the 1970s was the discovery that enzymes in brain tissue could be studied chemically post-mortem. So, for instance, in the case of dementia it was feasible after death to still study the enzymes active in brain tissue and reach meaningful results to potentially make better drug treatments. At a recent Witness Seminar run by the Wellcome Trust in London, Professor Gavin Reynolds described what it was like to be a young researcher and to acquire brain material at Cambridge in the 1970s:

... we were often seen, I think, as sort of eccentric scavengers. In Cambridge I, or my technician, used to go downstairs to the mortuary and negotiate over brains. This was, of course, in the days when this sort of thing was rather more possible. We could discuss the opportunity that we might be able to provide some pathological feedback in exchange for having these brains that we could then bank and formally provide for those who in the future wished to withdraw. But it was very much a sort of negotiated process, wasn't it?⁴⁴

Likewise, Professor David Mann elaborated on how a *brain bank* was set up in Manchester too and for what research reasons. Although lengthy, his explanation is worthwhile quoting in full, as it sets the scene for the *Isaacs Report* that we will be encountering later in this chapter. This was the typical sort of research pathway and actor network in pathology and new neuroscience that we have been rediscovering throughout this book:

We wanted really to follow this up in a large number of cases, and getting cell biopsies and the right amount of material from cell biopsy was really not easy to achieve. So we looked and said: 'How can we use post mortem material to answer that question?' In Manchester we set up a system whereby we obtained pre-mortem consent to brain recovery with the relatives fully involved when the whole situation was explained to them. They gave their agreement that we could obtain the brain tissues as soon as the patient died, so we weren't hidebound by this 'green form' paraphernalia that so besets us nowadays. And the net effect of that was that I would make journeys across Manchester at 2 o'clock in the morning to Prestwich Hospital, a big psychiatric hospital at the time, where many of the patients were resident. There, I would meet the local mortician and we would extract the contents of the head from these individuals who had kindly agreed to donate the tissues for research, and I would hot foot, literally, across Manchester back to the University of Manchester laboratories, where we would dissect the brain and put it into these wonderful containers that David and Paul had devised, which contained preservative fluids. The next day the brain would find its way, courtesy of British Rail, down to Queen Square, and Paul will love to tell the tale that I would ring him up at some unearthly time in the day or night and say in my best Yorkshire voice: 'Hello Paul. There's a brain on a train for you.' [Laughter] And really, as Paul says, it was the chemistry that drove the need not only to collect brains, but to collect brains of better quality than those you could simply get hold of from pathological archives, where everything had just been stuck willy-nilly into preservative. It was a rather surreal experience carrying really warm brains across a city at 2 o'clock in the morning.⁴⁵

Mann was pressed for his views on what he believed the general public thought about this sort of brain research at the time. He replied: 'I think actually it was not in the public perception until the Alder Hey story broke and then the stuff really did hit the fan at that time. That really did impact upon brain collections and brain donations.' It was his perspective as a young researcher that: 'I think, by and large, people had an understanding of why it was necessary to collect brains and were happy to participate in that process, but with the Alder Hey scandal, the whole notion of pathologists became people who kept things in cellars and dark rooms. We were tarnished badly by the whole business.'⁴⁶

Other participants at the same oral history event spoke up for the first time concerning their personal feelings about Alder Hey. As Professor Margaret Esiri explained: 'I felt very, very undermined by it. I felt the media portrayed it in the wrong way.'⁴⁷ She elaborated that:

I felt we were the victims of a system that involved particularly coroners' post mortems, which had nothing to do with the hospital system, where we had what we called medical interest post mortems and that often contributed to the brain banking as well. That was completely different to the coroner system where the problem was, I think, that the coroners never really explicitly said what you should do with an organ after you'd examined it for their purposes, which was to find the cause of death.⁴⁸

These ethical issues were exacerbated, she explained, by a lack of communication. There were too many overlapping agencies involved. As a consequence,

missed disputes occurred routinely in what was a fundamentally flawed coroner/pathologists' set of procedures: 'So [hospital] departments ended up with a lot of organs that they'd taken from coroners' cases, and they didn't know what to do with those organs afterwards.' This was the complex cultural context that the Culshaw family experienced, too, in this chapter's opening story. In order, however, to assess the historical value of these oral histories taken from a pathology perspective, and engage with the navigation of their feelings too, to balance the evidence of clinical and family lived experiences, it is necessary to understand a little bit more about the history of brain banking. In particular, we are going to focus in on the detailed activities of the Cambridge Brain Bank because it was pivotal to the actor networks of pathologists across the country and set new research standards that came in for significant public criticism involving many potential missed disputes after WWII.

Brain Banking

In 2003, the Department of Health (DofH) decided to investigate the controversial issue of brain retention in the post-war era. The research focus soon fell on the Cambridge Brain Bank because it was of national importance. Civil servants examined its paperwork processes and pathology records. The results of their findings are summarised in Table 6.1. In total, '2,547 . . . whole brains' were banked for research purposes between 1980 and 2001, something that can be confirmed by cross-matching to Addenbrooke's Hospital pathology records. The DofH report concluded that: 'The Cambridge brain bank evolved from research undertaken by Dr. Bird in the Neurochemical Pharmacology Unit in the early 1970s. The first research was into Huntington's Chorea (now referred to as Huntington's disease).' Having explained that context briefly, the report went on to state its broad findings from the DofH audit in 2003 (Tables 6.1 and 6.2). There were several important observations that would create a growing climate of mistrust in medical research, culminating in HTA2004. The first was that pathologists did not maintain proper post-mortem records. The DofH had a great deal of difficulty locating the incomplete paperwork trail. This meant that the figures they were able to ascertain were probably very conservative about the extent of unauthorised retentions. Anatomists, as we saw in Chapter 5, faced the same audit trail problem. They had been understaffed, had not done their paperwork efficiently in the 1980s and 1990s and thus had failed to get all their cremation work signed off officially by the DHSS once they had completed their teaching and research work on the dead. They looked guilty of holding on to human material for much longer than they actually did. In the case of pathologists, there was so little paperwork that it was difficult to assess for audit purposes whether the system was at fault because of similar low staffing issues or whether everyone preferred to operate

Table 6.1 *Cambridge Brain Bank: an analysis of the brains collected, c.1980 to c. 2001*

Category	Number of brains received	Earliest date	Most recent date
Prader-Willi syndrome (B)	3	21.01.1997	24.02.2001
Normal control (C)	557	05.01.1980	08.10.2001
Dementia: long PM delay (D)	172	10.01.1980	02.03.1993
Epilepsy (E)	39	10.05.1983	28.12.1988
Dementia: short PM delay (FD)	272	21.11.1985	23.04.2001
CC75C (L)	206	22.06.1989	29.11.2001
Huntington's disease (H)	707	17.02.1980	10.12.2001
Fronto-temporal dementia (JH)	102	20.01.1992	16.01.2002
Down's syndrome (M)	16	04.03.1981	19.10.1998
Multiple sclerosis (MS)	2	12.03.1995	22.05.1997
Parkinson's disease (P)	62	01.02.1980	02.09.1992
CFAS (RH)	86	14.05.1993	21.12.2001
Schizophrenia (S)	182	04.01.1980	22.09.1994
Spinal cord (SC)	2	Unknown	Unknown
Progressive supranuclear palsy (SR)	1	07.09.1979	-
Depression (X)	66	01.02.1983	23.12.1992
Suicide (Y)	43	18.02.1983	13.03.1989
Tissue held for Oxford CFAS	29	In one batch, sometime mid 90s	
TOTALS	2547		

Source: TNA, *Isaacs Report*, 'The Cambridge Brain Bank', section 4, chapter 26, 'Recent analysis of brains collected by the bank', archived on behalf of the Department of Health, accessed 1/6/2017 at: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/browsable/DH_4889626

with a lack of efficiency and transparency. One outcome, though, was certain. The DoH report concluded that a significant amount of paperwork involving the Cambridge Brain Bank was destroyed, misfiled or never created in the first place from the 1970s onwards.

The auditors concluded that although they lacked accurate figures for the 1970s–1980s period, the surviving but scattered figures they had located for the 1990s probably reflected general working protocols. The DoH auditor thus explained that:

The post mortem reports sent to the Coroner listed any tissue samples or other investigations made by the pathologist that could have a bearing on the cause of death. The reports did not mention that brains had been retained for the brain bank. All the post mortem reports on the 43 suicide victims whose brains had

Table 6.2 *Cambridge Brain Bank: audit report (2003–2004)*

I.	The Huntington's disease study had the active support of relatives and of COMBAT (the voluntary organization formed to support families of those with Huntington's disease). Consent was obtained for brain removal in these cases.
II.	Further programmes developed and in 1985 the MRC received a proposal to support the brain bank as a service facility to support research teams undertaking neurochemical and other investigations that required brain tissue.
III.	'Control' brains from 'normal' subjects were collected. Consent from the relatives was not sought or obtained.
IV.	The Department of Pathology of the University provided diseased brains and 'control' brains.
V.	No distinction was made between hospital and Coroners' cases when brains were obtained.
VI.	There is no record that the collection of 'control' brains was ever considered by an Ethical Committee before 1985.
VII.	The 1985 application to the MRC was ambiguous on the question of consent. One section, referring to collection of index cases, underlined the need for consent by the relatives. Elsewhere the requirement for 'control' brains is set out with no linkage to consent of the relatives.
VIII.	During the 1980s the brain bank technician would review the list of post mortems scheduled each day and identify brains that would be of interest to the brain bank.
IX.	In 1987 the funding basis of the bank changed. From that date it was to focus on individual projects rather than provide a 'banking' facility.
X.	In 1988 the bank became involved in a multi-centre prospective epidemiological study of dementing diseases of the elderly (the CFAS programme). This study received Ethical Committee approval.
XI.	For the CFAS programme, full consent for brain retention had been routinely obtained from the relatives.
XII.	Collection of brains from Coroners' cases as 'controls' and for the suicides study continued in parallel with the large prospective dementia study.
XIII.	The post mortem reports to the Coroners failed to record when brains were retained for use by the brain bank.
XIV.	In 1991 Mr Smith, the Coroner for Cambridge City, discovered that brains were being removed from Coroners' cases. He ordered that no brains or other organs from Coroners' cases were to be retained for research without the consent of the relatives. Organ retention was permitted only for diagnostic purposes.
XV.	The brain bank continues to collect brains, with consent, from hospital cases.
XVI.	As earlier chapters have indicated, the Cambridge brain bank was regarded as a model for other brain research routes to follow, and the methods of obtaining 'controls' from Coroners' cases appear to have been copied.

Source: TNA, *Isaacs Report*, 'The Cambridge Brain Bank', section 4, chapter 26, 'Recent analysis of brains collected by the bank', archived on behalf of the Department of Health, accessed 1/6/2017 at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/browsable/DH_4889626

been obtained for the bank were examined. The records of the brain bank confirm that these brains were retained but none of the post mortem reports mentions brain retention. These reports were made to the Coroners for Cambridge City, South Cambridgeshire and Huntingdon Districts. A number of post mortem reports on cases where the brain had been retained as a control were also cross checked against the brain bank records. Again, the post mortem reports were silent about brain retention for the bank. In this respect these post mortem reports were deficient as they did not alert the Coroners to what was going on.⁴⁹

There was therefore a sustained culture of a lack of informed consent for families. In other words, although the figures available were incomplete, it was reasonable to conclude that there had been many different sorts of missed disputes generated inside the brain research community. Leading brain researchers did not necessarily know everything on the supply side about the activities of coroners and their pathologists or morticians. However, they also did not choose to look in any greater detail. As a result, it is only the recent oral histories (introduced above and elaborated below) which confirm that there was a lack of persistent questioning, notably from the pathologists on duty. The system was peopled by caring staff, but it was equally careless in its working practices, and this was the chief cause of different sorts of missed disputes by the late 1990s. It seemed thus that many people felt tarnished by a lack of others' transparency. To better understand that wider context, we need now to turn our attention to the controversial *Isaacs Report* (2003), first introduced briefly in Chapter 2. It is a historical prism of what was happening on a regular basis inside hidden histories of the brain dead and outlines how paperwork was disguised, and crucial information withheld, to create missed disputes. Part II of this chapter is thus all about engaging with the human stories that people medical death and its neuroscience context.

Part II

The Isaacs Controversy

In April 2000, Mrs Elaine Isaacs discovered the retention of the brain of her deceased husband for post-mortem and further research purposes in Manchester.⁵⁰ She was very upset by this because the revelation came 13 years into widowhood under traumatic circumstances. On 26 February 1987, Mr Cyril Isaacs committed suicide. Aged 54 years, he had been suffering from episodes of mental ill health and had tried to take his own life on several occasions. His detailed medical case notes explain that during 1986–1987: 'In

the five months before his untimely death, Mr Isaacs had experienced depressive mental illness and had been under the care of both private and NHS doctors.' In this state of mind: 'He had taken three overdoses, two of these in the same weekend within one month of his death.' Subsequently, it also reported that: 'Mr Isaacs had received in-patient psychiatric care as a voluntary patient. He had been prescribed medication at the time of his death and was due to see his general practitioner Dr Rosenburg' on the day he took his own life. In the evening, Mrs Isaacs and a relative named Mr Clive Lingard discovered Mr Isaacs dead at home. They made an emergency call to the police on Thursday evening, 26 February 1987. Mr Isaacs had hanged himself from a hatch in the loft. A duty police surgeon attended the suicide scene and pronounced death at 7.50 p.m. As the circumstances surrounding the unnatural death were unclear, it was essential to involve the coroner. This was when Mrs Isaacs lost control of the material fate of her dead husband, as Chapter 2 introduced, and a missed body dispute occurred that will be elaborated in detail here.

The Isaacs family were devout Jews. Their traditional faith required them to bury Mr Isaacs's body within twenty-four hours of death. It must be 'whole': according to religious rites, it must not be cut extensively, and the organs must not be removed. They argued that as the cause of death was obvious, there were witnesses to verify its sad circumstances, and medical notes would confirm a recent case-history of depression, no post-mortem should take place. The coroner had the option to do just an autopsy. In this way, the family could adhere to their deeply felt culture of laying out the body at home, saying prayers for the dead over it and burying it according to orthodox Jewish rites. It was therefore very distressing for Mrs Isaacs and her son to discover that Mr Isaacs's body was taken from the family home in preparation for a full post-mortem scheduled for Monday, 2 March 1987. An undertaker transported the body by arrangement with the local police. They issued instructions to deliver it to the mortuary at Prestwich Hospital, where the local coroner according to standard practice commissioned a full pathology report. The dead body arrived at 20.45 p.m. on 26 February 1987, just 55 minutes after the police surgeon on duty pronounced death. In material terms, it was a very fresh cadaver. The body, refrigerated overnight, would be in a good condition for pathology. It was also potentially ready for further medical research.

There were, according to the official records, two people present at the subsequent post-mortem – Dr R J Farrand (pathologist) and Mr Dennis Walkden (mortician) – both were acting for the coroner. They did bring forward the date of the post-mortem in recognition of the Jewish family's burial rites. A written record confirms the removal of Mr Isaacs's brain at 11.15 a.m. on Friday, 27 February 1987 by the conclusion of the post-mortem. In accordance with standard practice, those on duty telephoned the coroner, confirming that

the cause of death was suicide. There was no evidence of foul play. The North Manchester's Coronial Office released the body for burial to the family's Jewish undertakers. Nobody informed them of the brain retention. Nor did it form part of the evidence presented at a reconvened Inquest conducted by Mr Bryan North, coroner for the area in which Mr Isaacs had died. As the verdict of suicide was unopposed, the coroner had the official capacity to declare it a 'paper inquest' (like the 'non-jury' cases of the past). This meant that various written documents (police report, GP statement, post-mortem evidence and so on) were enough to pass a verdict and establish there were no suspicious circumstances. Crime scene photographs were taken, but it was never officially explained why they did not form part of the Inquest evidence reviewed by the coroner (forensic teams in the event of an unexplained suicide take digital images as a matter of course). Mrs Isaacs did have an opportunity to attend the Inquest. She was supported by a solicitor and barrister arranged by the elders in the Jewish community. What upset the family the most was the final verdict of '*Suicide . . . Hanging . . . Cyril Mark Isaacs died of the aforesaid at his home. He was found hanging from the loft by an electric flex*' [sic].⁵¹ In the Jewish community, the taking of life is taboo and there had been no official reference to Mr Isaacs's accumulated history of mental ill health at the Inquest. The family felt that as it stood, the verdict could bring them cultural shame in their community since the exonerating circumstances did not form part of the official reporting.

Mrs Isaacs remained very troubled about her husband's death and the removal of his body from their home for a post-mortem without her consent. She wrote many letters to the coroner, Mr Brian North, between 1987 and 1991 to query the verdict because it seemed to her to reflect a lack of cultural and human understanding. Each time, the coroner informed her that it was his duty to base his verdict on the written evidence presented by the police, witnesses and pathologist assigned to the case; their medico-legal verdict was prescribed in regulations and could not be adjusted retrospectively. Eventually, Mrs Isaacs managed to get official access to Mr Isaacs's medical records still held by his general practitioner in April 2000. She was anxious to read these to see if they would exonerate in any way the stark verdict of suicide. What she found amongst her dead husband's medical papers was surprising and upsetting. A letter to Mr Isaacs's general practitioner, Dr Rosenburg, explained that the Department of Psychiatry at Manchester University 'had collected samples from Mr Isaacs' brain' and the research team were anxious to frame their research study by reference to his history of mental ill-health and medication for depression administered prior to death. The coroner permitted this hidden history to be used for research purposes, but he did not reconsider the humanity of the suicide verdict. A dead husband's brain was fresh, a research opportunity, and thus formed part of

a large mental ill-health project. At the time of death, Mrs Isaacs had explained her religious convictions to the police, a coroner and her husband's general practitioner. It was self-evident she had been ignored. There was a clear breach of medical ethics, resulting in a missed body parts dispute. Mrs Isaacs's son thus wrote to the Secretary for Health, Hon. Alan Milburn MP, demanding a full investigation into the original circumstances surrounding the death, post-mortem, retention and disposal of Mr Cyril Isaacs's brain. Events revealed a pathology and medical research cover-up.

On 29 July 2001, Her Majesties Inspector of Anatomy, Mr Jeremy Metters, conducted a formal investigation on behalf of the government into the controversial *Isaacs Case*. Over the next two years, his enquiries were extensive and exhaustive. He found that there was a 'joint research team' involved in brain study comprising members of the physiology and psychiatry departments at Manchester University. Their main research focus was neuropathology and in particular mental ill-health conditions (broadly defined). North Manchester Coronial service from 1985 to 1997 had routinely permitted the retention of brains for further research purposes at Manchester University without the knowledge of the families involved: a common practice amongst many pathologists employed by coroners across the country. In addition, GMP were criticised for their officious conduct in relation to Mrs Elaine Isaacs (a theme we will be returning to later in this chapter since such criticisms have re-emerged with renewed force recently, as we saw in our opening story of the Culshaws in this chapter). Essentially, the *Isaacs Report* (2003) highlighted:

7. The report shows, among other things, that relatives were not aware that:

- Organs would be removed as part of a coroner's post mortem examination;
- Organs removed might not be returned to the body after the post mortem examination;
- Organs could be retained legally by the coroner without their permission in connection with establishing the cause of death; and
- Organs might be retained for other purposes, such as research, without their consent and thus without legal authority.

8. Relatives were not given:

- Information about the coroners' post mortem process;
- Information about the options for the ultimate disposal of any organs removed;
- Support, advice or counselling; or
- Suitable consideration of religious or cultural beliefs.⁵²

Jeremy Metters provided a national census of all brain material held in research repositories across England and Wales (see Table 6.3). Mr Cyril

Table 6.3 *Nature of retentions in pathology stores, which had been accumulated since 1970, and were present at the National Census Point, c. 2001–2003*

Organ	Number of organs	Percentage of total retentions
Brains	23 900	44%
Hearts	9 400	17%
Lungs	6 900	13%
Other Organs	6 100	11%
Body Parts	3 700	7%
Stillbirths/Fetuses	2 900	5%
Not Specified	1 400	3%
Total(s)	54 300	100%

Source: *Isaacs Report Response*, written by the Department of Health, Home Office and Department for Education and Skills (London: HMSO, 2003), p. 25 [ISBN 011322611X] – see also, www.doh.gov.uk/cmo/isaacsreport/response

Isaacs's brain was one of 23,900 deposits that had been stored since the 1970s for further research purposes. Pathologists generated these on behalf of coroners across the UK. In Manchester, several morticians co-operated at Prestwich Hospital with this 'supply mechanism of donation' for a reported fee of '£10 per brain'. Although one particular coroner denied he knew the specifics of what was taking place, Metters concluded that this was 'hardly credible' under the circumstances. It appeared that 'brain collections' rather than 'brain banking' had constituted the majority of 'retentions-without-consent'; it was difficult to retrace the individual research thresholds inside the supply system because the paperwork trail was either never created in the first place, had been destroyed subsequently or was ambiguous at best. The media and patients' groups who took this as confirmation of a culture of duplicity queried the extent to which the official figures were a true picture of pathologists' covert working practices and their corporate culture of denial.

Metters concluded that his figures were the best indication of the scale of brain retentions, and he distributed them into three research categories: *Brain Accumulation* (generally created by coroners' cases via hospital mortuaries and commissioning pathology reports for post-mortem purposes); *Brain Collection* (held by pathology departments initially for diagnosis, but also for further teaching and research use); and *Brain Banking* (linked to pathology departments and university research centres), often working with relatives who have given consent to further specialised research into specific conditions like Creutzfeldt–Jakob Disease (hereafter CJD), Huntington's or Alzheimer's

neuro-degenerative diseases. Metter decided that it was *Brain Accumulations* and *Brain Collections* that were ethically questionable. Pathologists had been working their way around the law to facilitate brain research.⁵³ Effectively, they colluded in a system of supply that ignored codes of practice on informed consent. In turn, these should have been defined properly under HTA1961 and Coroners Rules (see Chapters 2 and 5), but were not. The paternalism of the past had been exposed to public scrutiny and found wanting in a biomedical era. It was this culture of concealment which would result in HTA2004. Yet, like all new legislation, it would take time for ingrained attitudes to change. In other words, the medical research community that had relied on hidden histories of the dead for so long neglected to appreciate the range of disputes they had generated for the future. They did operate within the legal requirements of their time, but this also meant that medical ethics remain fixed in an era when biotechnology was fast changing. As a result, only by blending the numerous historical and hidden ethical issues created can we begin to appreciate their cultural ramifications, including, importantly, notions of trust and expertise, the problem of piecemeal legislation and the ambiguities of consent, which went undetected from the 1960s to 2000. This proved to be a public relations mistake, exposing differential power relations in an era of full democratic representation when everyone had a taxpayer stake in the NHS. There were many gains from the new era of medical research for the general public in this historical process, but equally the bereaved expressed how excluded they felt in terms of the role of memory, the changing boundaries of life and death and the scale of the Information State's lack of accountability in their medical lives. To better appreciate how pathologists defended their position in response, we need to trace a representative sample of oral histories that document typical reactions to the public outcry for HTA2004 because of the scale of the missed disputes being rediscovered.

Once HTA2004 became law, many pathologists in the UK resented the position they were placed in. Most felt hounded by the media, made a scapegoat for the degree to which the Coronial service relied on their expertise. The Pathological Society of Great Britain and Ireland hence took the decision in 2008 to commission a new book by Sue Armstrong called *A Matter of Life and Death: Conversations with Pathologists*,⁵⁴ based on extensive interviews with practicing pathologists. An important theme of the oral histories assembled was the Alder Hey scandal in the NHS and its aftermath. There was uniform agreement amongst participants that it was 'a dark hour for pathology' across the British Isles and Ireland. As Professor James Ironside – an expert on the neuropathology of CJD and member of the new Human Tissue Authority set up in 2005 – explained:

What happened in Alder Hey was terrible. It opened up the whole question of autopsies – retention of tissues and organs, how much relatives knew, how much relatives had been consulted – and had some terrible messages for all concerned. It was a dark hour for pathology, no doubt about it. Not helped, I must say, by the media. You were made to feel that not only had you examined a baby that had died from cot death or something, you'd actually gone out and killed it beforehand. Just terrible! And also I think that we were not best supported by the Minister of Health at the time, Alan Milburn. He just opted to go 'belly up' and do anything to satisfy the various pressure groups that had emerged from the media, and I think a more measured response would have been better. Some of the first attempts at the legislation were just completely unworkable. And through pressure from a whole range of groups, the legislation was changed in the UK. It's still not perfect, but it's better than it was.⁵⁵

Professor David Levison (now retired), former Chair in Pathology at Dundee University, reflected with a slightly different emphasis:

I don't think that Alder Hey and Bristol were scandals. They're only scandals because the media say they were scandals. . . . I know of quite a few people who have given up being paediatric pathologists because of this – because they couldn't stand the kind of pressures they were being put under, the phone calls, and the abuse they were getting as they walked home, and this sort of thing. It has done a lot of harm to some people, and I mean it has really kicked paediatric pathology in the teeth. . . . I know of studies that have not been done because it's just not worth the effort of going through the ethical hoops. . . . It really does slow things up.⁵⁶

Others such as Professor Sebastian Lucas, Chair in Clinical Histopathology at Guy's, King's and St Thomas' hospitals, pointed out that from a pathology point of view in 2008:

In a way things haven't got all that much better [since Alder Hey]. They've got more bureaucratic, but there's still a huge grey area in tissue retention across the consented to coronial autopsy spectrum, and it's not very clear. Or it's very clear what to do if you want to stay absolutely within the letter of the law, be squeaky clean. You do nothing! But the point is, to be good and to be useful for public health you need to do a bit more than that, and that's where the grey areas come in.⁵⁷

Most argued that it was poor communication that was at the heart of recent biomedical debates and the public exposure of pathology's inner working practices. Irene Scheimberg, Consultant Paediatric and Perinatal Pathologist at the London Hospital, thus took the view that:

At one point during the Alder Hey crisis I said, 'I am going to go and talk to the Liverpool parents so that they realise that not all pathologists have horns and are horrible'. At the beginning they were all very confrontational – there were lots of them – and I said, 'I do understand what it is to lose people, to experience the untimely death of people' [as someone from the Jewish community who needed political asylum, she lost many friends and family to war and conflict]. And I told them my story –

because they were so immersed in their grief that they didn't realise other people might have had a traumatic history as well. They were surprised because I was crying. One of them came up and hugged me afterwards, and said: 'I never thought I'd ever hug a pathologist.'⁵⁸

Scheimberg suggested that it was better for people when grieving to keep looking forward, an attitude of mind she had learned from the long history of being political refugees in her Jewish family of Russian extraction. Her personal motto was: 'Memory is very wise – you don't remember what you cannot live with.' She did respect the fact that learning later that information had been withheld about human harvesting could be shocking for families. Consequently she explained how:

In coroners' cases I write a personal letter to the families. I use the name of the child, and I explain to families why I'm asking them if we can keep blocks and slides. In the first place because it's important for their sakes in case there is a problem or something later. Then, so that we can use them for teaching and training. Because someone has to carry on with the work when I'm no longer here; the knowledge has to be passed on. And then I explain why we need them for research, and what type of research we're talking about – because it's important for them to know that it's research that will benefit them personally, but we can't do it unless we have specific consent.⁵⁹

In this selection of oral history material we have therefore an important opportunity to elaborate on the conceptual approach of Alessandro Portelli, who reminded us at the start of this chapter about the importance of 'the peculiarities of oral history' and their subjectivity precisely because they are 'not just about what people did, but [what] they wanted to do, what they believed they were doing, and what they now think they did'.⁶⁰ Thus, it is apparent that some pathologists operated on a need-to-know basis because they felt it was better to keep pressing ahead with their research agendas, and unkind to tell the general public everything about brain research when they were grieving. Others did not accept that the organ donation and pathology retentions in the NHS around 2000 were a scandal but a media-generated medical outrage designed to sell newspapers. Most had been as open and engaging in their working-lives as they could be under difficult circumstances, committed to communicating the importance of their work and legacy of human material retentions. Pathologists were thus complex actors, shaped by social, cultural, political, economic and administrative circumstances. Like all human beings, they could fail, and some did so in terms of public relations; for there was a general recognition by HTA2004 that pathology's paternalism and patriarchy were past their clinical sell-by-date. Its actor network had to leave behind the ethics of conviction of the past and embrace the ethics of responsibility for tomorrow. Against this backdrop, the Royal College of Pathologists (hereafter RCP) have been working extensively to try to resolve these experiential issues,

and they recognise the need for consensual medical ethics: a trend that has increased in the past ten years or so. There has been an official recognition that pathologists had taken a 'proprietary' view of the body rather than a 'custodial' one: a theme that has run throughout all the chapters of this book.⁶¹ At the same time, in the intervening years since HTA2004, common themes have emerged in conversations with pathologists: as we saw above and touch on below, too.⁶² Ingrained attitudes have been of long duration, and some pathologists have refused to make the clinical adjustments, retiring early. There has continued to be ambivalence felt by many RCP members about the extent of public accountability required by new statutes, mushrooming bureaucracy and the media.

Today the RCP publishes widely its latest research and innovations, engaging the public with stories of how pathology into common cancers, for instance, saves lives every day in the NHS. It has also been keen to promote new solutions for old pathology problems. One innovation it has been eager to publicise is digital autopsies in cases where the probable causes of death are known in Coronial cases in England and Wales. RCP now recognises that CT scanning techniques could provide a cultural and practical solution for families like the Isaacs who would not consent to the cutting of the body and the removal of human material on religious grounds but would be amenable to a CT scan instead because it is non-invasive, replacing a post-mortem. The way it works is that the deceased can undergo a CT scan to confirm 'unnatural death' with a minimal amount of interference with the dead body. A new study published in the *Lancet*, co-ordinated by Professors Guy Ruttly and Bruno Morgan at the University of Leicester, thus showed recently that in a sample size of 241 cases in which an adult had died of unexpected outcomes that were not necessarily suspicious, some 92 per cent of these coroners' cases (where n=222) could be established from digital CT solutions.⁶³ Currently, the cost is £500 per case, paid for by the family in question, raising ethical issues about fair access to the technology for everyone, especially in communities of high-density ethnicity and poverty patterns. Nevertheless, as the RCP press office told the *Guardian* newspaper in May 2017: 'The College fully supports further research in this area while reinforcing the need for thorough and robust governance in this emerging field.'⁶⁴ Evidently, the *Isaacs Report* was an important catalyst for cultural change in medical research around the Millennium in Britain. It has resulted in an emphasis on informed consent in brain research and finding new solutions to complex human dilemmas over the ownership and use of bodies and body parts. Even so, in interviews given off the record for this book, many pathologists have made it clear why they left the profession in the past five years or so. Most felt their job description 'was now too restrictive', 'there's just too much bureaucracy' and 'it's taken away my sense of

professional standing . . . I mean who wants to deal with all the hassle'.⁶⁵ So rather than reform from within, what has tended to happen since HTA2004 is that the numbers of qualified RCP members have thinned out. There is unquestionably a lot less hands-on experience than there once was inside the Coronial system. To balance this sense of a loss of professional expertise, the final section of this chapter thus returns to the human impact of pathologists' workload, particularly involving those who have just retired or resigned from office. In this way, we can engage with a wider cross section of lived experiences of missed disputes, similar to the storyline of the Culshaw family which opened this chapter. For the events described test public trust in pathology work since HTA2004, which was supposed to have been changed fundamentally the national conversation about harvesting brains and human tissue retentions.

*'Hospital Stored Dead Children's Brains in Jars': Southampton Hospital under Public Scrutiny*⁶⁶

In 2012, the Association of Chief Police Officers (hereafter ACPO) faced an ethical dilemma. They had to inform the Human Tissue Authority that a large number of organ and tissue retentions had gone unnoticed at the time of HTA2004. This was because the police had special powers concerning human material retention up until 2006. They were exempt under Section 39 of the HTA2004, as follows:

Section 39 of Human Tissue Act

- (1) Subject to subsection (2), nothing in section 14(1) or 16(2) applies to anything done for purposes related to—
 - (a) the prevention or detection of crime, or
 - (b) the conduct of a prosecution.
- (2) Subsection (1) does not except from section 14(1) or 16(2) the carrying-out of a post-mortem examination for purposes of functions of a coroner.

Forensic PM examinations

If a person dies in circumstances considered to be 'suspicious' or where homicide is suspected, HM Coroner after consultation with the police can authorise a Home Office Registered Forensic Pathologist to perform a forensic PM examination to—

- Ascertain the identity of the deceased
- The cause/surrounding circumstances of death
- To allow collection of evidence from the body⁶⁷

The Human Tissue Authority also issued a public statement clarifying that there were three statutes that authorised the police to hold human material. These were: the Coroners and Criminal Justice Act (Eliz. 2 c. 25: 2009), the Police and Criminal Evidence Act (Eliz. 2 c. 60: 1984, especially sections 19 &

22) and the Criminal Procedure and Investigation Act (Eliz. 2 c. 25: 1996). Together they permitted an investigating officer to be present at a post-mortem, which they had authorised by virtue of asking forensic scientists and Home Office pathologists to lawfully enter premises and seize whatever material evidence was necessary to bring a criminal act to justice. They also had extra powers under English Common Law of seizure for physical items or human material found elsewhere that were not on the premises of a specific crime in the locality where it was committed. Since these procedures had overlapping regulations, there was not a coherent national policy in the police force of how to seize, record, evaluate evidence, present in court and return human material after a conviction or court hearing. The Murder Manual (2006, especially Section 11) did try to give clear pathology guidelines, but this too resulted in disparity amongst actual police forces in England and Wales, with individual senior officers taking a pragmatic view of their particular medico-legal position. The ACPO thus conceded in 2012 that many police forces did not actually know what their responsibilities were in respect of human material retentions. Most thought this problem of a lack of uniformity was delegated to coroners and their pathologists to monitor and resolve, given the former's historic powers of discretionary justice (a theme we encountered in Chapter 5).

In 2012 a central government commissioned ACPO audit grew out of the National Gold Group established alongside the National Police Improvement Agency (later to be renamed the Home Office Pathology Unit). These policing bodies were granted permission to take proper legal advice from suitably qualified barristers during the national audit process, which was concerned with three categories of material infringement:

Category 1 – Material taken at PM examination which would not generally be considered part of the body e.g. scrapings, fingernails, hair, stomach contents

Category 2 – Samples of human tissue which are not a significant part of the body e.g. small tissue samples, blocks, slides & so on

Category 3 – Samples of human tissue that incorporate a significant part of the body e.g. organs, limbs & so on⁶⁸

Category 3 formed the central focus of the ACPO audit, in liaison with the Human Tissue Authority. Together they found that '492 organs' or what was described as '*significant [sic] body parts [brains] were held on police premises or other establishments. These related to historical cases going back to the 1960s.*' To try to reassure the public that this did not repeat Alder Hey, the Human Tissue Authority issued a press release confirming that 'between 1960 and 2010 there had been 6.2 million PM [post-mortem] examinations' conducted in England and Wales. Of these 6.2 million, just 2.45 per cent, or 151,900, resulted in the need for a forensic examination in which the police became involved. Of the 151,900 cases, only 0.33 per cent, or 50,633, related to

potential organ retentions or *significant* body parts kept by the police and their Home Office pathologists.⁶⁹ Yet, this statistical statement still did not provide enough reassurance to the families involved, because even a basic calculation underscored that in a 50-year period, on average there were not less than 1,000 cases a year that could potentially have resulted in missed body disputes. It was (again) media testimony of those who were misled that would prove to be a powerful reminder of the need to remain vigilant in a biomedical era.

At first, ACPO tried to counter any negative publicity by stressing the expertise of those that retained the human material and the important legal reasons for doing so. Thus, it was explained that under police powers, a selection of NHS hospital premises were designated as regional autopsy units. Here coroners and their pathologists on behalf of the Home Office had stored human material pending a court case. The Home Office expressed regret that human material had been kept without informing families, but the police tried to reassure the media that it was done in the best interests of criminal justice. One such location was Southampton Hospital in Dorset, a regional autopsy unit for the West Country. The families involved were told on a case-by-case basis that their loved one's remains were still in cold storage. It did not help that as this slow process was just getting under way, a civil servant at the Home Office was despatched to tell the press that: 'It is down to individual forces to decide . . . whether the material is needed or not. In some cases the retention period may have been longer than necessary.' This was a classic case of official understatement, as events subsequently proved in the press.

On 14 August 2012, the *Sun* newspaper led with a headline – 'They took brains from our boys too . . . WHY?' Their investigative journalist, John Coles, spoke to Hannah Cheevers, whose baby son had died of a heart defect aged 2 days old in 1998, and Melanie Galton, whose infant son died aged 1 of sudden infant death syndrome in 1997. Each was told that there would be a post-mortem, but neither was informed that their offspring's brain had been retained and kept for 15 years by pathologists on behalf of the police. Melanie explained:

They turned up just before Christmas and told me, 'We've found Ricky's brain at the hospital'. I was stunned, I couldn't believe what I was hearing. . . . I asked them 'Why have you kept it so long?' and all they could say was something like it had 'got lost in the system' and they were now chasing everything up. . . . They gave me a letter and leaflet explaining the situation – but instead of 'son' the letter refers to him in one place as 'mother' and 'father' in another. . . . I'm disgusted and angry as well as upset. I'm not going to let this drop. . . . They had a post mortem which found the cause of death as sudden infant death syndrome, so why did they need to keep his brain? I imagine it's been forgotten about on the back of a shelf somewhere. I want to have another funeral – it will probably be just me by

his grave – because I want it returned to his body where it should be. I don't want it to go *missing* [author's emphasis] for another 15 years.⁷⁰

In a similar refrain, Hannah Cheevers and her partner, Martin Lovell, from Wimborne Dorset were shocked to be in an equivalent missed body part dispute. Hannah recounted:

They told us tissues from Rhys had been retained – I thought they meant a sliver of tissue on a slide. Then they said it was his whole brain. I was shocked. I was never told about this and if they'd asked my permission I would have said 'no'. They wouldn't tell me why it had been kept and they said that nothing had been done to it. It was dreadful – I had a new baby in my arms and it brought it all back. . . . If they'd kept Rhys's heart I might have understood, but there was no reason to keep his brain. When he died they offered us a post mortem to find out what had happened and we agreed because we wanted to know. So he was taken from Poole Hospital to Southampton Hospital, but we had no idea they would keep his brain. It's absolutely disgusting what has happened. I remember the Alder Hey scandal, and I said to my mum at the time that I was glad it wasn't Southampton. There really needs to be an inquiry into this.⁷¹

Each mother recalled having to go through a harrowing series of police enquiries at the time of their child's death to make sure that it was not suspicious – it felt as though old and very painful memories were being reopened again. Indeed, one of the most poignant press stories to appear was that of Ryan Franklin who 'was killed by his dad, aged two in 2002'. A case of manslaughter was secured in court based on medical evidence that the child had been battered to death. His mother then explained what happened a decade later. She was told by Southampton Hospital that her dead baby's brain, eyes and spinal cord had been retained. Like the other mothers affected, she had known it was necessary to have a post-mortem but she claimed that she had said 'no to donating his organs', telling doctors in 2002: 'He came into this world full and I want him to go out full – don't touch him.'⁷² Around the time of the Alder Hey scandal, she began to suspect that she may have been misinformed. This uneasy sense of a missed dispute re-emerged in 2012: 'When I heard about this review police are carrying out I hoped they would have got in touch with me. I would like someone to come forward and tell me what's happened to his organs so I can have closure.' Catherine Franklin 'discovered that some of Ryan's organs had been taken. His eyes went to a hospital in Sheffield for research – but no one knew what happened to the rest.' The newspaper reporter explained how she had gone on to have 'another son, Benjamin, eight'. Nonetheless Catherine stressed: 'Every time I try to find out what happened I hit a brick wall. I hope now police are doing their audit I'll finally get the truth' about what really happened. In fact, it soon emerged that there were forty cases in Southampton all relating to young dead children whose brains had been removed and stored.⁷³ In the majority of cases, it appeared that any fears of

suspicious deaths were cleared up quickly and no physical evidence for the criminal court was necessary to secure a conviction. Each was a tragic tale of child bereavement. The mothers, according to their own testimony, all found the pain of loss almost unbearable to experience again after ten years had elapsed.

Personal spoken and reported histories like these representative cases provide thought-provoking testimony concerning the conduct of the medical research community in a biomedical era. Their discourse reiterates Alessandro Portelli's inciteful comments (encountered earlier in this chapter's introduction) about the value of the 'the peculiarities of oral history' in the medical humanities. Their subjectivity again reveals 'not just about what people did, but [what] they wanted to do, what they believed they were doing, and what they now think they did'.⁷⁴ To many pathologists, it had seemed that the press has been responsible for stirring up emotive stories and putting the spin of scandal on the editorial byline to sell more newspapers about the recent ACPO audit findings. Yet, it is undeniable that the same sorts of experiential histories were often repeated, and verbatim by those families involved. Indeed, as Philip Cheung has recently pointed out, it is impossible to deny how much the twice-bereaved have needed each other for support when missed body parts disputes recur, exemplified by the number of support groups that have been set up and continue to flourish today. There is:

NACOR (The National Committee Relating to Organ Donation), and PITY II (Parents who have Interred their Young Twice) ... Respect for Leicester, Stolen Hearts in Birmingham, Bristol Heart Children's Action Group, Cambridge Area Support Network, Derbyshire Organ Retention Support Group, South Yorkshire/North Derbyshire Support Group for Post-Mortems Retention Parents and Relatives, NERO North East Organ Retentions Group), Storm in Manchester, Our Children, REGAIN groups in Nottingham, Legacy Faborio, PORSH in Plymouth, and so on.⁷⁵

Cheung points out that there is 'a danger that' such support groups will 'be seen by scientists and medical researchers as anti-science and anti-research'.⁷⁶ Many scientists do not believe in an afterlife or appreciate that the physical remains can have a powerful meaning in the grieving process of the bereaved, even though there is ample evidence that the GMP failed not only the Isaacs family in 2002, but the Culshaws and others more recently. Too often, points out Cheung, such families who express strong natural emotions are 'perceived in the same light as animal research campaigners'. He thus argues that the medical research community need to accept 'the challenge of shaping ideas and attitudes' to their work and its importance by meeting those bereaved with genuine humanity to bridge the recent past to a better biomedical future for everybody. It is therefore informative and important how the journal *Science*

reported on 7 April 2017 that: 'the Rules of Memory are being *beautifully rewritten*'.⁷⁷ Because such perspectives have the potential to reshape how historians evaluate oral histories on the sensitive topic of missed disputes too.

It is often said in the global media that the British have a character trait that is admired around the world. They are renowned for being stoic, exemplifying the stiff upper lip in times of adversity. It was a national trait that was said to have brought the country through two world wars, associated food rationing and many millions of deaths. As, however, public tastes changed during the 1960s with the liberalisation of British society, the old values of a wartime generation were refashioned. It became culturally less acceptable to button-up emotions, and instead many more people began to speak about issues of mental health and well-being. Today, it is a popular topic of national conversation in Britain. At the same time as this process of promoting more compassion and understanding of mental and physical well-being was happening, neuroscience was also contributing to debates about the relationship between the brain and emotions. Recently, evidence has come to light that the way we thought the brain absorbed and accommodated trauma has been misleading. In the past, a medical assumption was made that the best way to help people to get over a very traumatic episode in their life was never to talk about it again – the stoic approach. Then this changed from the 1960s with qualified therapists encouraging those suffering from mental ill-health to come to terms with a dramatic experience by talking it through – the compartmentalising approach. Each medical intervention was about reviewing negative experiences and helping the patient to move on in a more positive direction. However, new scientific studies in Japan and the USA have challenged the neuroscience of this type of trauma management, and the results of these recent scientific findings are very important for assessing the emotional reactions of families to the missed disputes of the ACPO audit in 2017. The key to understanding what the bereaved were going through has been to better appreciate that the way we thought we handled and remembered trauma has been scientifically incorrect.

The brain is clever. It seeks to protect us in trauma. To do this, it does not ask us to be exclusively stoic or to compartmentalise what is happening when confronted by extreme stress. Instead, new scientific studies in Japan and the USA have found ground-breaking evidence that all painful memories are absorbed in two ways. First, the brain will store short-term recollections when we are in shock. Then, at the same time, it begins a neurological process of transferring the memories of that initial trauma from the hippocampus of the brain. Slowly, the brain has a neurological mechanism that converts short-term experiences into long-term memories in the cerebral cortex where they are 'banked' for life. In this way, the brain 'doubles up' its memory system. It creates two simultaneous memories that mirror each other every time we experience something out of the ordinary as human beings.⁷⁸ This neurological

balancing act is unconscious in the mind. The function of this doubling up is to help us as human beings to live with what has happened. We cope by assimilating together physical reactions (short-term shock, hippocampus) and their emotional impact (long-term feelings, cerebral cortex) of trauma. This works well neurologically, provided that the balancing mechanism is not disturbed. If, many years after a shocking event, it revived in an unexpected manner, then that would have the effect of unbalancing the brain's trauma survival mechanism. So, we can be stoic and we can compartmentalise, precisely because of the amazing balancing mechanism in our brains, and this is what scientists mean when they say that 'the Rules of Memory are being *beautifully rewritten*'.⁷⁹ In 2017, the families involved in the findings of the ACPO audit experienced what happens when this newly discovered neurological balancing system was disturbed by reviving painful memories.

When we encounter oral histories and the navigation of their feelings in a history of emotions, it is important in the medical humanities not simply to dismiss their testimony of trauma as too subjective. In fact, what people recount is telling us that we need to fully consider the latest neurological perspectives of what is happening in the brains of the bereaved. The ACPO families experienced what it was like to go through a missed dispute about withheld information. This destabilised the short-term and long-term neurological centres of memory formation and unbalanced the maintenance of their well-being. Those involved thus found it mentally very hard to cope, and this is verifiable by the neuroscience of memory formation and maintenance. Effectively, some experienced a neurological U-turn that triggered a very stressful episode in the mind's emotional centres. Importantly, the implications for this book's study into missed disputes and how people emotionally react (hippocampus, short-term shock) and learn to live with the unpalatable facts (cortex assimilation, very painful emotions) are profound. If medically correct, Mrs Jean Culshaw and others like her were not being duplicitous or exaggerating when they said they were 'suffering' mental upheaval in March 2017. In neurological terms, their minds were, literally, disturbed, as they had to again go through very painful memories from 1993. Thus, in a history of emotions, scholars, such as William Reddy, are correct to emphasise how talking about feelings is essentially the only way that a person can then rebalance if forced to revisit something so painful.⁸⁰ Ironically, science, which has long stressed its dispassionate and secular purpose (laudable aims), has itself discovered that the brain has a '*beautiful*' medical function that is all about re-balancing the rational and the instinctive when missed disputes occur. It works with human nature holistically, and this is a significant finding for the medical humanities, echoing what George Steiner the moral philosopher suggested in this book's Part I. The brain does not discard 'old' information for 'new' memories – instead, it runs these lived experiences 'in parallel' because life is like that, and this is what

keeps us creative as human beings. In other words, those involved in missed disputes could cope well, provided communication was very good and trust existed between all those involved in the network of actors when a crisis point involving the death of a loved one had to be revisited. To illustrate that there could be more positive outcomes in this more transparent process for pathologists too, we end with the sort of brain story that seldom features in oral histories or the press on this sensitive topic.

In 2000, Sean and Sarah Luff became new parents. Tragically, soon after birth, their 3-day-old baby died because of medical negligence in Southampton Hospital. Mistakenly, staff on duty gave him a morphine overdose – ‘100 times the proper dose of painkillers’ – in an attempt to save his young life.⁸¹ At a subsequent Inquest, the medical evidence established that their son would have died in any case, such were the fatal complications in this sad case. This did not excuse the medical errors, but the hope was that the forensic findings would alleviate the Luffs’ concerns that their baby was not in pain when he died. However, the family was shocked when Dorset police informed them in 2012 that Southampton Hospital had retained their baby son’s brain in a jar without their consent in 2000. Sean Luff asked: ‘How many times can one family, and one little baby, be betrayed by the authorities?’ He questioned in the press: ‘How much more heartache can they inflict on us?’ There was, even so, to be a twist to this news story, and one that exemplifies the Janus-like nature of pathology expertise today. In February 2012, Sean Luff received a diagnosis of myeloid leukaemia. This happened just several months after Dorset police informed him about his dead son’s brain retention. Sean became very ill and had to endure ‘three gruelling sessions of chemotherapy and a bone marrow transplant’.⁸² Unfortunately, this series of life-saving treatments compromised his immune system, and he caught pneumonia just before the Christmas holidays in 2013. Because Sean was unable to fight the serious infection in his lungs, doctors judged it best to place him in a medically induced coma. It would take eight months of intensive care before Sean was stabilised and able to go home. Yet, the medical team that had saved his life three times in those eight months was based at Southampton Hospital, where his baby son had died under exceptionally stressful and medically culpable circumstances, twelve years earlier. Even so, the Luff extended family were grateful for Sean’s recent medical interventions. They hence decided to raise money for more medical research at Southampton Hospital in August 2013. The Luffs were happy to publicise the good work of medical staff in the local press. There was self-evidently a pathology paradox in this case, and a poignant one. Sean Ruff was kept alive by the same expertise that had once retained his baby son’s brain without his consent. The latter’s successful outcome did not justify the lack of medical ethics in the former case-history. Yet, it did make for a thought-provoking parallel in what have too often been hidden histories of the brain.

For it left open the unanswered question: How much more could have been achieved if brain research and retentions had been a more open and engaging research partnership with the bereaved across Britain after WWII?

Conclusion

In 2010, a consortium of scholars convened at the University of Manchester to explore 'forensic cultures' in contemporary society prompted by the fact that coroners, pathologists and DNA specialists 'now have an unprecedented level of visibility' across the UK, not least because of 'true crime' drama on television.⁸³ The conference concluded that 'forensics is best understood as a historically-shifting material and social entity but also as mediated through a cultural grid of forms, languages and resources, through which credibility is built up, negotiated and contested'. Simon Cole, one thoughtful contributor, 'questioned the idealised image of a scientific culture as a unified entity governed by a clear and stable set of rules which produce and guarantee a single form of knowledge'. This was essentially the case in many types of missed disputes in brain research, too, of the modern era. Recently, Paul Roberts has hence helpfully pointed out that histories of forensic science and pathology cannot simply be pieced together to produce a harmonious picture that does not reflect local realities or public sensibilities. Indeed, he has been critical of a strong confirmation bias in histories of science covering laboratory studies that elevate the positive and ignore the negative aspects of secretive working cultures (themes the Introduction and Chapter 1 highlighted). Thus, the Manchester conference concluded that there is more

value of attending to the complex interrelationships, cultural specificities, and diverse and shifting identities of forensic practitioners, the institutions within which they work, the techniques they deploy to produce and display forensic truths, and how these truths are transformed in public as forensic cultures engage the worlds in and for which they act.⁸⁴

One of the main difficulties with researching the nature of pathology and neuroscience in the modern era has been the culture of the closed door. Not only was recording of brain retentions insubstantial but those records that survive in archive collections are often sealed under the 100-year rule. General statistics are obtainable under special written request according to the provisions of the Freedom of Information Act (Eliz. 2 c. 26: 2000) in the UK. Even so, there are many legal barriers erected to complicate better open and transparent research in the medical humanities. In protecting the past, pathology has often looked guilty of maintaining a culture of denial and subterfuge, and this has unquestionably damaged its reputation. When, moreover, new evidence emerges of past failings, like the GMP revelations recently after the ACPO audit, those

conducting the conversations with relatives came across as insincere. Occasionally, named pathologists were revealed, but most remained hidden behind an anonymous title or official jurisdiction disclosed in the most general terms to families left confused and upset – angry about the faceless mandarins of a Home Office firewall. The corporate-speak which was often repeated by the police force about holding ‘open and honest conversations’ with relatives informed of brain retentions, sounded more like a publicity campaign for the press than a genuine attempt to engage with how the twice-bereaved felt. Jenny Culshaw and others felt understandably that their emotional well-being was being devalued and undermined. Indeed, it is noteworthy just how many shocked parents in the same situation repeated their shared understandings, using the same phrases and words to describe common predicaments and feelings of distress. In tragic circumstances, they had to re-open painful memories to gain concrete information. That neuroscience itself has discovered the ‘Rules of Memory are being *beautifully rewritten*’ in order to explain the double memory and its careful balancing mechanism we all create in the brain to deal with traumatic events in our lives is informative.⁸⁵ The Culshaw and Isaacs families were not, it turns out, being excessive, overdramatic or unreasonable in their reactions, but rather their neurological response was functioning in a normal manner. In a history of emotions, it has always been essential to talk about such feelings to rebalance traumatic experiences reopened by time delays, misinformation, and half-truths.⁸⁶ As all good historians know, careful attention should, likewise, be paid to what is not said, just as much as to what is. For the history of these missed disputes is like a dry-stone wall – in its research gaps are the future human solutions to consensual medical ethics. First we have to locate them, and then we must look that past honestly in the face to ensure we provide better access for professional researchers to evaluate those gaps in a measured manner.

In an ageing population around the world, brain research has a powerful role to play wherever we live in our community settings. With approximately one in five people in Britain now suffering from neuro-degenerative disorders, healthcare practitioners need the co-operation and co-creation of the public to make new medical breakthroughs. This cannot, though, be achieved in cultural isolation – the consent of the silent majority being taken for granted is no longer the *modus operandi* of pathologists, post–Alder Hey. Most recognise this and are working together to promote the sort of expertise in histopathology that we all need. Others resent the levels of bureaucracy and have retired or resigned from the profession, bruised by the public criticisms, which they still believe is excessive. That this will be a lost research opportunity in some respect, curtailing individual career paths in the short term, is undeniable. Yet, it is equally irrefutable that such a status quo had been created by closing ranks and not engaging with the public

enough in the recent past. The responsibility, therefore, first and foremost, for this cultural stand-off, rests with pathologists and not society as a whole. The history of missed body disputes and disputed body ethics brought together in this chapter shows clearly that some pathologists acted as though they owned the human body, its parts, organs and tissue. In the 1950s, those entering the medical profession spoke of a vocation, a calling, a sense of purpose that this was the job they were meant to do. Some were arrogant about their expertise; others genuinely thought that they were working hard for the greater good. Medical science too has become an endeavour concerned with career progression, enhancing one's scientific reputation and making headlines promoting the latest drug therapy. Those with a vocation did and do still people the system, yet the consensual and custodial only very slowly – too slowly, in many cases of missed disputes – gained ascendancy over proprietorial approaches to bodies and body ethics. Thus, missed disputes in brain research are a function of, and embody, slow and partial processes of cultural change in the post-war era. Yet even as medicine and the medical sciences have learned to talk *with*, rather than *at*, their patients, the expanding frontiers of the possible in terms of the cure and the extension of life made possible through precision medicine introduce a new potential for body disputes and a much more complex landscape of body ethics. It is to this matter that we turn, finally, in Chapter 7, the conclusion to this book, when we reflect on the question of scientific eternities of material afterlives in a Genome era.

Notes

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