

Part I

Relocating the Dead-End

**Our Dead Are Never Dead To Us,
Until We Have Forgotten Them**

[*Adam Bede*, George Eliot, 1819–1880]

Introduction: A Consignment for the Cul-de-Sac of History?

At the heart of modern conceptions of biomedicine sits a core narrative of ‘progress’, one in which profound scientific breakthroughs from the nineteenth century onwards have cumulatively and fundamentally transformed the individual life course for many patients in the global community. Whilst there remain healthcare inequalities around the world, science has endeavoured to make medical breakthroughs for everybody. Thus for many commentators it has been vital to focus on the ends – the preservation or extension of life and the reduction of human suffering emerging out of new therapeutic regimes – and to accept that the accumulation of past practice cannot be judged against the yardstick of the most modern ethical values. Indeed, scientists, doctors and others in the medical field have consistently tried hard to follow ethical practices even when the law was loose or unfocussed and public opinion was supportive of an ends rather than means approach. Unsystematic instances of poor practice in research and clinical engagement thus had (and have) less contemporary meaning than larger systemic questions of social and political inequalities for the living, related abuses of power by states and corporate entities in the global economy, and the suffering wrought by cancer, degenerative conditions and antibiotic resistant diseases. Perhaps unsurprisingly given how many patients were healed, there has been a tendency in recent laboratory studies of the history of forensic science, pathology and transplant surgery, to clean up, smooth over and thus harmonise the medical past.¹ Yet, these processes of ‘progress’ have also often been punctuated by scandals (historical and current) about medical experimentation, failed drug therapies, rogue doctors and scientists and misuse of human research material.² In this broad context, while the living do have a place in the story of ‘progress’, it is the bodies of the dead which have had and always have a central role. They are a key component of medical training and anatomical teaching, provide the majority of resources for organ transplantation and (through the retention and analysis of organs and tissue) constitute one of the basic building blocks of modern medical research. For many in the medical sciences field, the dead could and should become bio-commons given the powerful impact of modern degenerative and other diseases, accelerating problems linked to lifestyle, and

4 Relocating the Dead-End

the threats of current and future pandemics. Yet, equally inside the medical research community there remain many neglected hidden histories of the dead that are less understood than they should be in global medicine, and for this reason they are central to this new book.

Such perspectives are important. On the one hand, they key into a wider sense that practice in medical science should not be subject to retrospective ethical reconstruction. On the other hand, it is possible to trace a range of modern challenges to the theme of ‘progress’, the ethics of medical research and practice, as well as the scope and limits of professional authority. This might include resistance to vaccination, scepticism about the precision of precision medicine, an increasing willingness to challenge medical decisions and mistakes in the legal system, accelerating public support for assisted dying, and a widening intolerance of the risks associated with new and established drugs. Nowhere is this challenge more acute than in what historians broadly define as ‘body ethics’. By way of recent example, notwithstanding the provisions of the Human Tissue Act (Eliz. 2 c. 30: 2004) (hereafter HTA2004), the BBC reported in 2018 that the NHS had a huge backlog of ‘clinical waste’ because its sub-contracted disposal systems had failed.³ Material labelled ‘anatomical waste’ and kept in secure refrigerated units contained organs awaiting incineration at home or abroad. By July 2019, the *Daily Telegraph* revealed how such human waste, including body parts and amputations from operative surgeries, was found in 100 shipping containers sent from Britain to Sri Lanka for clinical waste disposal.⁴ More widely, the global trade in organs for transplantation has come into increasingly sharp relief, while the supply of cadavers, tissue and organs for medical research remains contentious. Some pathologists and scientists, for instance, are convinced that HTA2004 stymied creative research opportunities.⁵ They point out that serendipity is necessary for major medical breakthroughs. Legislating against kismet may, they argue, have been counterproductive. Ethical questions around whose body is it anyway thus continue to attract a lot of media publicity and often involve the meaning of the dead for all our medical futures.

Lately these ethical issues have also been the focus of high-profile discussion in the global medical community, especially amongst those countries participating at the International Federation of Associations of Anatomists (hereafter FAA). It convened in Beijing, China, in 2014, where a new proposal promised ‘to create an international network on body donation’ with the explicit aim of providing practical ‘assistance to those countries with difficulties setting up donation programmes’.⁶ The initiative was developed by the Trans-European Pedagogic Anatomical Research Group (TEPARC), following HTA2004 in Britain that had increased global attention on best practice in body donation. Under the TEPARC reporting umbrella, Beat Riederer remarked in 2015: ‘From an ethical point of view, countries that depend upon unclaimed bodies

of dubious provenance are [now] encouraged to use these reports and adopt strategies for developing successful donation programmes.⁷ Britain can with some justification claim to be a global leader in moving away from a reliance on ‘unclaimed’ corpses for anatomical teaching and research to embracing a system of body bequests based on informed consent. Similar ethical frameworks have begun to gain a foothold in Europe and East Asia, and are starting to have more purchase on the African⁸ and North and South American subcontinents too.⁹ Nonetheless, there is a long way to travel. As Gareth Jones explains, although ‘their use is far less in North America’ it is undeniable that ‘unclaimed corpses continue to constitute ... around 20 per cent of medical schools’ anatomical programmes’ in the USA and Canada.¹⁰ Thus, the *New York Times* reported in 2016 that a new City of New York state law aimed to stop the use of ‘unclaimed’ corpses for dissection.¹¹ The report came about because of a public exposé that the newspaper ran about the burial of a million bodies on Hart Island in an area of mass graves called Potter’s Field. Since 1980, the Hart Island Research project has found 65,801 ‘unclaimed’ bodies, dissected and buried anonymously.¹² In a new digital hidden history project called the ‘Passing Cloud Museum’, their stories are being collected for posterity.¹³ And with some contemporary relevance, for during the Covid-19 pandemic the Hart Island pauper graveyard was re-opened by the New York public health authorities. Today, it once more contains contaminated bodies with untold stories to be told about the part people played in medical ‘progress’. For the current reality is that ‘in some states of the US, unclaimed bodies are passed to state anatomy boards’. Jones thus points out that:

When the scalpel descends on these corpses, no-one has given informed consent for them to be cut up. ... Human bodies are more than mere scientific material. They are integral to our humanity, and the manner in which this material is obtained and used reflects our lives together as human beings. The scientific exploration of human bodies is of immense importance, but it must only be carried out in ways that will enhance anatomy’s standing in the human community.¹⁴

In a global medical marketplace, then, the legal ownership of human material and the ethical conduct of the healthcare and medical sciences can twist and turn. But with the increasing reach of medical research and intervention, questions of trust, communication, authority, ownership and professional boundaries become powerfully insistent. As the ethicist Heather Douglas reminds us: ‘The question is what we should expect of scientists *qua* in their behaviour, in their decisions as scientists, engaged in their professional life. As the importance of science in our society has grown over the past half-century, so has the urgency of this question.’ She helpfully elaborates:

The standard answer to this question, arising from the *Freedom of Science* movement in the early 1940s, has been that scientists are not burdened with the same moral

6 Relocating the Dead-End

responsibilities as the rest of us, that is, that scientists enjoy ‘a morally unencumbered freedom from permanent pressure to moral self-reflection’. . . . Because of the awesome power of science, to change both, our world, our lives, and our conception of ourselves, the actual implementation of scientists’ general responsibilities will fall heavily on them. With full awareness of science’s efficacy and power, scientists must think carefully about the possible impacts and potential implications of their work. . . . The ability to do harm (and good) is much greater for a scientist, and the terrain almost always unfamiliar. The level of reflection such responsibility requires may slow down science, but such is the price we all pay for responsible behavior.¹⁵

Whether increasing public scepticism of experts and medical science will require a deeper and longer process of reflection and regulation is an important and interesting question. There is also, however, a deep need for historical explorations of these broad questions, and particularly historical perspectives on the ownership and use of, authority over and ethical framing of the dead body. As George Santayana reminds us, we must guard against either neglecting a hidden scientific past or embellishing it since each generic storyline is unlikely to provide a reliable future guide –

Progress, far from consisting in change, depends on retentiveness. When change is absolute there remains no being to improve and no direction is set for possible improvement: and when experience is not retained . . . infancy is perpetual. Those who cannot remember the past are condemned to repeat it.¹⁶

Against this backdrop, in his totemic book *The Work of the Dead*, Thomas Laqueur reminds us how: ‘the dead body still matters – for individuals, for communities, for nations’.¹⁷ This is because there has been ‘an indelible relationship between the dead body and the civilisation of the living’.¹⁸ Cultural historians thus criticise those in medico-scientific circles who are often trained to ignore or moderate the ‘work of the dead for the living’ in their working lives. Few appreciate the extent to which power relations, political and cultural imperatives and bureaucratic procedures have shaped, controlled and regulated the taking of dead bodies and body parts for medical research, transplantation and teaching over the *longue durée*. Yet our complex historical relationships with the dead (whether in culture, legislation, memory, medicine or science) has significant consequences for the understanding of current ethical dilemmas. Again, as George Santayana observed: ‘Our dignity is not in what we do, but in what we understand’ about our recent past and its imperfect historical record.¹⁹ It is to this issue that we now turn.

History and Practice

To offer a critique of the means and not the ends of medical research, practice and teaching through the lens of bodies and body parts is potentially contentious. Critics of the record of medical science are often labelled as neo-liberals,

interpreting past decisions from the standpoint of the more complete information afforded by hindsight and judging people and processes according to yardsticks which were not in force or enforced at the time. Historical mistakes, practical and ethical, are regrettable but they are also explicable in this view. Such views underplay, however, two factors that are important for this book. First, there exists substantial archival evidence of the scale of questionable practice in medical teaching, research and body ethics in the past, but it has often been overlooked or ignored. Second, there has been an increasing realisation that the general public and other stakeholders in the past were aware of and contested control, ownership and use of bodies and body parts. While much weight has been given to the impact of very recent medical scandals on public trust, looking further back suggests that ordinary people had a clear sense that they were either marginalised in, or had been misinformed about, the major part their bodies played in medical ‘progress’. In see-saw debates about what medicine did right and what it did wrong, intensive historical research continues to be an important counterweight to the success story of biomedicine.

Evidence to substantiate this view is employed in subsequent chapters, but an initial insight is important for framing purposes. Thus, in terms of ownership and control of the dead body, it is now well established that much anatomy teaching and anatomical or biomedical research in the Victorian and Edwardian periods was dependent upon medical schools and researchers obtaining the ‘unclaimed bodies’ of the very poor.²⁰ This past is a distant country, but under the NHS (and notwithstanding that some body-stock was generated through donation schemes promoted from the 1950s) the majority of cadavers were still delivered to medical schools from the poorest and most vulnerable sectors of British society until the 1990s. The extraordinary gift that we all owe in modern society to these friendless and nameless people has until recently been one of the biggest untold stories in medical science. More than this, however, the process of obtaining bodies and then using them for research and teaching purposes raised and raises important questions of power, control and ethics. Organ retention scandals, notably at Liverpool Children’s Hospital at Alder Hey, highlighted the fact that bodies and body parts had been seen as a research resource on a considerable scale. Human material had been taken and kept over many decades, largely without the consent or knowledge of patients and relatives, and the scandals highlighted deep-seated public beliefs in the need to protect the integrity of the body at death. As Laqueur argues: ‘The work of the dead – dead bodies – is possible only because they remain so deeply and complexly present’ in our collective actions and sense of public trust at a time of globalisation in healthcare.²¹ It is essentially for this reason that a new system of informed consent, with an opt-in clause, in which body donation has to be a positive choice written down by the bereaved and/or witnessed by a person making a living will, was enshrined into HTA2004. Even under the

terms of that act, however, it is unclear whether those donating bodies or allowing use of tissue and other samples understand all the ways in which that material might be recycled over time or converted into body ‘data’. Questions of ownership, control and power in modern medicine must thus be understood across a much longer continuum than is currently the case.

The same observation might be made of related issues of public trust and the nature of communication. There is little doubt that public trust was fundamentally shaken by the NHS organ retention scandals of the early twenty-first century, but one of the contributions of this book is to trace a much longer history of flashpoints between a broadly conceived ‘public’ and different segments of the medical profession. Thus, when a *Daily Mail* editorial asked in 1968 – ‘THE CHOICE: Do we save the living ... or do we protect the dead?’ – it was crystallising the question of how far society should prioritise and trust the motives of doctors and others involved in medical research and practice.²² There was (as we will see in subsequent chapters) good reason not to, something rooted in a very long history of fractured and incomprehensible communication between practitioners or researchers and their patients and donors. Thus, a largely unspoken aspect of anatomical teaching and research is that some bodies, organs and tissue samples – identified by age, class, disability, ethnicity, gender, sexuality and epidemiology – have always been more valuable than others.²³ Equally, when human harvesting saves lives, questions of the quality of life afterwards are often downplayed. The refinement of organ transplantation has saved many lives, and yet there is little public commentary on the impact of rejection drugs and the link between those drugs and a range of other life-reducing conditions. It was informative, therefore, in the summer of 2016 that the BBC reported on how although many patients are living longer after a cancer diagnosis, the standard treatments they undergo have (and always have had) significant long-term side effects even in remission.²⁴ These are physical – a runny nose, loss of bowel control, and hearing loss – as well as mental. Low self-esteem is common for many cancer sufferers. A 2016 study by Macmillan Cancer Support, and highlighted in the same BBC report, found that of the ‘625,000 patients in remission’, the majority ‘are suffering with depression after cancer treatment’. We often think that security issues are about protecting personal banking on the Internet, preventing terrorism incidents and stopping human trafficking, but there are also ongoing biosecurity issues in the medical sciences concerning (once more) whose body and mind is it anyway?²⁵

Other communication issues are easily identifiable. How many people, for instance, really understand that coroners, medical researchers and pathologists have relied on the dead body to demarcate their professional standing and still do?²⁶ In the past, to raise the status of the Coronial office (by way of example) there was a concerted campaign to get those coroners that were by tradition

legally qualified to become medically qualified. But to achieve that professional outcome, they needed better access and authority over the dead. And how many people – both those giving consent for use of bodies and body parts and those with a vaguer past and present understanding of the processes of research and cause of death evaluation – truly comprehend the journey on which such human material might embark? In the Victorian and Edwardian periods, people might be dissected to their extremities, with organs, bodies and samples retained or circulated for use and re-use. Alder Hey reminded the public that this was also the normative journey in the twentieth century too. Even today, Coronial Inquests create material that is passed on, and time limits on the retention of research material slip and are meant to slip, as we shall see in Part II. The declaration of death by a hospital doctor was (and is) often not the dead-end. As the poet Bill Coyle recently wrote:

The dead, we say, are departed. They
 pass on, they pass away, they leave behind
 family, friends, the whole of humankind –
 They have gone on before. Or so we say.²⁷

But, he asks, ‘could it be the opposite is true?’ To be alive is to experience a future tense ‘through space and time’. To be dead is all about the deceased becoming fixed in time – ‘while you stay where you are’, as the poet reminds us. Yet, this temporal dichotomy – the living in perpetual motion, the dead stock-still – has been and remains deceptive. Medical science and training rely, has always relied, on the constant movement of bodies, body parts and tissue samples. Tracing the history of this movement is a key part in addressing current ethical questions about where the limits of that process of movement should stand, and thus is central to the novel contribution being made in this book.

A final sense of the importance of historical perspective in understanding current questions about body ethics can be gained by asking the question: When is a body dead? One of the difficulties in arriving at a concise definition of a person’s dead-end is that the concept of death itself has been a very fluid one in European society.²⁸ In early modern times, when the heart stopped the person was declared dead. By the late-Georgian era, the heart and lungs had to cease functioning together before the person became officially deceased. Then by the early nineteenth century, surgeons started to appreciate that brain death was a scientific mystery and that the brain was capable of surviving deep physical trauma. The notion of coma, hypothermia, oxygen starvation, resuscitation and its neurology entered the medical canon. Across the British Empire, meantime, cultures of death and their medical basis in countries like India and on the African subcontinent remained closely associated with indigenous spiritual concepts of the worship of a deity.²⁹ Thus, the global challenge of

'calling the time of death' started to be the subject of lively debates from the 1960s as intersecting mechanisms – growing world population levels, the huge costs of state-subsidised healthcare, the rise of do not resuscitate protocols in emergency medicine, and a biotechnological revolution that made it feasible to recycle human material in ways unimaginable fifty years before – gave rise to questions such as when to prolong a whole life and when to accept that the parts of a person are more valuable to others. These now had more focus and meaning. Simultaneously, however, the reach of medical technology in the twentieth century has complicated the answers to such questions. As the ability to monitor even the faintest traces of human life – chemically in cells – biologically in the organs – and neurologically in the brain – became more feasible in emergency rooms and Intensive Care Units, hospital staff began to witness the wonders of the human body within. It turned out to have survival mechanisms seldom seen or understood.

In the USA, Professor Sam Parnia's recent work has highlighted how calling death at twenty minutes in emergency room medicine has tended to be done for customary reasons rather than sound medical ones.³⁰ He points out, 'My basic message is this: The death we commonly perceive today . . . is a death that can be reversed' and resuscitation figures tell their own story: 'The average resuscitation rate for cardiac arrest patients is 18 per cent in US hospitals and 16 per cent in Britain. But at this hospital [in New York] it is 33 per cent – and the rate peaked at 38 per cent earlier this year.'³¹ Today more doctors now recognise that there is a fine line between *peri-mortem* – at or near the point of death – and *post-mortem* – being in death. And, it would be a brave medic indeed who claimed that they always know the definitive difference because it really depends on how much the patient's blood can be oxygenated to protect the brain from anoxic insults in trauma. Ironically, however, the success story of medical technology has started to reintroduce medical dilemmas with strong historical roots. An eighteenth-century surgeon with limited medical equipment in his doctor's bag knew that declaring the precise time of death was always a game of medical chance. Their counterpart, the twenty-first-century hospital consultant, is now equipped with an array of technology, but calling time still remains a calculated risk. Centuries apart, the historical irony is that in this grey zone, 'the past may be dead', but sometimes 'it is very difficult to make it lie down'.³²

In so many ways, then, history matters in a book about disputed bodies and body disputes. Commenting in the press on controversial NHS organ donation scandals in 1999, Lord Winston, a leading pioneer of infertility and IVF treatments, said:

The headlines may shock everyone, but believe me, the research is crucial. . . . Organs and parts of organs are removed and subjected to various tests – They are weighed and

measured, pieces removed and placed under the microscope and biochemically tested. While attempts can be made to restore the external appearance of the body at the conclusion of a post-mortem, it is inevitable some parts may be occasionally missing.³³

Winston admitted that someone of Jewish descent (as he was) would be upset to learn that a loved one's body was harvested for medical research without consent and that what was taken might not be returned. As a scientist, he urged people to continue to be generous in the face of a public scandal. He was, like many leading figures in the medical profession, essentially asking the public to act in a more enlightened manner than the profession had itself done for centuries. The sanctions embodied in HTA2004 – the Human Tissue Authority public information website explains for instance that: 'It is unlawful to have human tissue with the intention of its DNA being analyzed, without the consent of the person from whom the tissue came' – are a measure of the threat to public trust that Winston was prefiguring.³⁴ But this was not a new threat. As one leading educationalist pointed out in a feature article for the BBC *Listener* magazine in March 1961: 'Besides, there are very few cultural or historical situations that are inert' – the priority, he pointed out, should be dismembering medicine's body of ethics – comparable, he thought, to 'corpses patiently awaiting dissection'.³⁵ By the early twenty-first century it was evident that medical ethics had come to a crucial crossroads and the choice was clear-cut. Medicine had to choose, either 'proprietary' or 'custodial' property rights over the dead body, and to concede that the former had been its default position for too long.³⁶ Phrases like 'public trust' could no longer simply be about paying lip service to public sensibilities, and there had been some recognition that the medical sciences needed to make a cultural transition in the public imagination from an ethics of conviction to an ethics of responsibility.³⁷ Yet this transition is by no means complete. New legislation crossed a legal threshold on informed consent, but changing ingrained opinions takes a lot longer. And wider questions for both the public and scientists remain: Is the body ever a 'dead-end' in modern medical research? At what end-of-life stage should no more use be made of human material in a clinical or laboratory setting? Have the dead the moral right to limit future medical breakthroughs for the living in a Genome era? Would you want your body material to live on after you are dead? And if you did, would you expect that contribution to be cited in a transcript at an award ceremony for a Nobel Prize for science? Are you happy for that *gift* to be anonymous, for medical law to describe your dead body as *abandoned* to posterity? Or perhaps you agree with the former Archbishop of Canterbury, Dr. Rowan Williams, Master of Magdalen College Cambridge, who believes that 'the dead must be named' or else we lose our sense of shared humanity in the present?³⁸

In this journey from proprietary to custodial rights, from the ethics of conviction to an ethics of responsibility, and to provide a framework for