Prologue

This is the tale of a boy, a girl, and the heart they share. It is a story that no one was meant to tell. In the impassioned world of transplant surgery, the families of organ donors almost never encounter the people into whom those organs are transplanted. For obvious reasons, transplant services go to great lengths to ensure that donor and recipient families are kept at a distance. The entire process of organ donation is fraught enough without creating additional emotional entanglements that could heap distress upon vulnerable individuals.

Exceptionally rarely, however, donor and recipient families do discover each other's identity. Invariably the catalyst is media attention. I first encountered the story of nine-year-old Max Johnson in the *Mirror*, in June 2017. In England at that time, people who wished to donate their organs after death had to proactively opt *in* to making their wishes known by signing up to the national organ donor register. Many medical and patient advocacy groups argued that more lives could be saved if the law was changed so that – as in a growing number of other countries – adults would be presumed to have consented to organ donation unless they opted *out*. The hope was that this

would address the scarcity of organs, enabling many more lives to be saved. The *Mirror*, a newspaper with a history of advocating on a wide range of social issues, chose to run a campaign on this one. Under the headline 'Change the Law for Max', the paper ran a front-page splash making a powerful appeal to the then UK Prime Minister, Theresa May, to introduce new legislation addressing the scarcity of organs available for transplant.[1] The editor hoped that public pressure would galvanise the government into making the drafting of the necessary legislation a priority.

Max had been a footballing, tree-climbing, play-fighting force of nature until a mysterious illness caused his heart to fail, leaving it so dangerously weak and unstable he was forced to spend nine months confined to a hospital bed. Ordinarily, nothing in the human body is quite as single-minded as the heart. Its four chambers, fibrous flesh, electrical waves and swing-door valves are designed with one aim and one alone: to beat. Through beating – or, more accurately, through contracting then relaxing – the muscle of the heart jolts blood into every last crevice of the human body, delivering oxygen, nutrients and hormones to tissues while whisking away the cellular by-products of life. Around 100,000 times a day – 3 billion times over an average lifetime – all four chambers squeeze as one, forcing blood to surge through our arteries. The adult heart pumps 260 litres of blood every hour, enough to fill a small swimming pool each day. One contraction is so powerful it can send blood spurting 3 metres straight up into the air if the aorta, the body's principal artery, is severed. The heart, in short, is a toiling, tireless, muscular miracle. Barely the size of a pair of clasped hands, its capacity for circulating blood is extraordinary.

Max's heart muscle had been fatally harmed, probably by a mild viral infection he had scarcely noticed. While Max was in the hospital, his parents acquired the new and terrible knowledge that up to one in five children in Britain and America might die while waiting on the transplant list. They were equally aware that the only thing that could give Max what he needed to live was the death, appallingly, of someone else's child. Max became the poster boy for the *Mirror*'s campaign. Young, sweet and immensely charismatic, he captivated the hearts of readers. After months of waiting for a replacement heart – and just when it started to seem that hope was lost – another child, Keira, had the terrible misfortune to suffer a catastrophic brain injury as a result of a road traffic collision. Keira's family, upon being told she was brain dead, immediately decided to gift her organs. They knew with absolute certainty that this was what their daughter would have wanted.

In September 2017, a photo of Max in his hospital bed dominated the front page of the *Mirror* once more.[2] The former wraith whose haunted stare had so moved readers was now pink-cheeked and beaming. His chest was bandaged, hiding a livid median sternotomy scar that extended all the way from the top of his sternum to the bottom of his ribs. Behind that scar, Keira's heart sat and squeezed, flooding his body with blood and life. In addition to Max, Keira's organs had saved the lives of another child and two adults. Overwhelmed with gratitude, Max's parents Emma and Paul Johnson shared the following letter with the UK's transplant service, NHS Blood and Transplant, who gave it in turn to the anonymous child's family:

To the donor family,

We are writing to you as you hold a very special place in our hearts. Our son, Max, is 9 and he had a heart transplant. He was very poorly and a heart transplant was his only chance of coming home and starting a new life.

We are so sorry that you lost your loved one, but we would like to thank you for the incredibly kind, courageous decision that you made to allow organs to be donated. We do not know the circumstances, but we can only imagine what a dreadful, harrowing time you have been through and are doubtless still going through, with the loss. Even in your grief, you have made a selfless decision to help others and we are indescribably grateful to you.

We hope that it brings you some comfort to know that Max's post-transplant recovery has been smooth and without complication. His new heart has been described as a happy heart and a brilliant heart. Max is very thankful and he is looking after his new heart. He says 'Good Morning' to his new heart every day and sends it lots of love, while it adjusts to the new environment.

He is eating healthily and exercising when he feels able, so that his heart will stay fit and strong. Max is getting used to all the medication, but he is full of energy and enthusiasm, as a result of the new lease of life that has been gifted by your family. He is relishing every moment back at home, without sickness, tubes, wires, machines, procedures etc. It was a very upsetting time, waiting so long for the call, but when we did get the call, we prayed for you and your family.

We continue to pray for you and think about you. We wanted you to know that your sacrifice was not in vain and you

have given an incredible legacy of love and good will to others. We thank you so much for making a decision that has saved our son and given him the prospect of a future ahead of him. As he grows older, we will encourage him to cherish his heart in memory of you.

With our eternal gratitude,
Emma and Paul

When Keira's parents received this letter, they realised that the Max to whom it referred was very likely to be the same Max whose plight they had read about in the *Mirror.* It took no time at all for Keira's mother, Loanna, to locate Emma Johnson on Facebook. After much deliberation, Loanna decided to write a letter of her own, introducing herself via a private message to the mother of the boy whose life her daughter had almost certainly saved. What happened next would change the history of transplant surgery in the UK.

Organ transplantation is both a marvel of modern medicine and one of the purest expressions of human altruism. In 2022 alone, the lives of 42,887 people in the US were saved by the generosity of 21,369 people donating their organs after death.[3] Collectively, over a million life-saving transplants have been successfully performed in the US since records began. In the UK, the numbers are smaller but still remarkable. In 2022–23, organs donated by 1,429 people after their death saved the lives of 3,575 people.[4] Right now, there are currently over 60,000 people alive in Britain – planning their child's birthday party, setting off on a bike ride, enjoying an ice cream, savouring the summer sun – thanks to the gift of another person's heart,

liver, kidney or lungs.[5] Without this radical generosity, the vast majority of those individuals would be dead. None of them would be alive without the doggedness, toil and creative genius of a remarkable cast of doctors and scientists whose obsession and brilliance in the twentieth century led to the series of medical breakthroughs that enabled the death-defying act of removing an organ from one human body and successfully reimplanting it in another.

Transplant surgery today is conducted with such skill and rigour that almost no part of the anatomy is too challenging to replace. Bones, tendons, heart valves, veins, voice boxes, uteruses, penises, nerves and entire limbs have all successfully been transplanted. In 2008, a thirty-eight-year-old woman in the UK gave birth to the world's first baby from a transplanted ovary.[6] Two years later, the first total face transplant – comprising skin, muscles, eyelids, nose, lips, upper and lower jaw, teeth, palate and cheekbones – was performed on a man in Spain who had been severely disfigured in a shooting accident.[7] Since then, bilateral arm and leg transplants have occurred, unmanned drones have delivered donor kidneys to patients in remote hospitals, and life-long illnesses such as sickle cell disease and Type 1 diabetes have been cured by transplants of bone marrow and insulin-producing pancreatic islet cells respectively.[8,9]

The hidden logistics required to ensure no viable organ goes to waste are immense. Most moderate- and high-income countries have a national organ register and transplantation service that coordinates the retrieval, distribution and transplantation of organs according to fairness and need.

The UK's National Organ Retrieval Service comprises sixteen teams of exceptionally skilled surgeons, anaesthetists and

theatre operatives. At any given moment, day or night, 365 days a year, up to eleven of these teams can plunge into action, retrieving precious organs from hospitals anywhere in the country. The allocation of organs is determined by the national NHS Organ Donation Register, established after a lengthy campaign by two bereaved parents, John and Rosemary Cox, who fought for their twenty-four-year-old son Peter to become a donor after he died of a brain tumour in 1989.[10] In the midst of their grief, the Coxes were dismayed to discover that no national register existed of people who wanted to donate their organs after their death. They wrote hundreds of letters, gave multiple newspaper and television interviews and tirelessly lobbied the government until, in 1994, the register was finally set up. Today, more than 30 million people are registered, representing 42 per cent of the UK population.[11]

Underpinning both the positioning of patients on the waiting lists for organs and the logistics of organ procurement is rigorous science. Every human organ is delicately embedded in a cat's-cradle of veins, arteries, nerves and tissues that sustain and control its function. Less than a century ago, the idea of surgically excising a human organ, transporting it on ice, and successfully implanting into another living person's body was the stuff of science fiction. Children in end-stage organ failure today stand a chance at life thanks to decades of laborious effort and flashes of inspiration from immunologists, vascular surgeons, physiologists, pharmacologists, anaesthetists, engineers and many other doctors and scientists. An entirely new medical specialty – intensive care – had to be invented before transplantation could occur successfully, not to mention the small matter of redefining the very concept of death itself.

Sustaining the science of transplantation is something equally wondrous: the human instincts that underpin every donation. There is no purer act of giving. The impulse to donate your organs after death, or those of your child, arises from the desire – as profound as it is simple – to help a fellow human being, irrespective of who they are or where they come from. Grieving relatives will often derive immense comfort from the knowledge that the person they once loved so dearly has, through their death, enabled others to live, but this does not diminish a donor or a donor family's fundamental altruism.

As with all medical advances, however, the new technologies of transplantation expose uncomfortable truths and ethical dilemmas. Organs are inherently scarce. Therefore, as moral philosopher Janet Radcliffe Richards says in her elegant book on the subject, *The Ethics of Transplants*:

> To put the matter objectively and starkly, there is a perpetual competition between the people who need organs and the rest of us who have them. We are all now potential sources of spare parts for people whose own organs have failed, and whose hope lies in getting one of ours.[12]

At its ugliest, this conflict is played out in horror stories from around the world about black market organ trafficking. In Afghanistan, for example, after the Taliban returned to power in 2021, crushing poverty and famine forced displaced, starving people to sell both their children and their body parts. At the time, the going rate for a kidney was around 150,000 afghanis or just over £1,000 (a daughter could be sold for less than half this price).[13] In China, despite official denials, evidence exists

of systematic, state-sanctioned, involuntary harvesting of kidneys and portions of livers from prisoners while they are still living, plus the macabre phenomenon of 'execution by organ procurement' in the case of those incarcerated on death row, whose organs are harvested prior to, not after, their slaughter.[14] It is tempting to recoil from the amorality of this trade in stolen body parts. Kazuo Ishiguro, in his devastating novel *Never Let Me Go*, chooses instead to confront and interrogate the psychology of a world in which children are cloned and bred for the sole purpose of harvesting their organs once they reach adulthood.[15] His fictional dystopia forces us to consider how fiercely we yearn to extend our own lease on life, and – perhaps even more uncompromisingly – the lifespan of those we love.

Several thousand people die in the UK and the US every year while hoping and waiting for a donor organ, the clock inexorably ticking down. The donors from whom organs are euphemistically 'sourced' or 'made available' are, of course, human beings themselves, with all the ethical consequences that entails. Radcliffe Richards makes the assumption that:

> The people on the waiting lists for transplants from deceased donors are, in effect, hoping that one of the rest of us will die so that they can have our organs. And, furthermore, their hopes are not for the incidental scraps left behind by those of us who have reached the inevitable end of a long life, because if we die from wearing out our body parts they will not be of much use to anyone else. What the patients hoping for transplants need, ideally, is the sudden death of a young and healthy person, whose organs are still in good condition.[16]

Yet for those waiting for organs and their families there is a subtle but incredibly important distinction. Far from 'wishing' that someone else's child will die, their only hope is that – should another family find themselves in the unthinkable situation of losing a child – then they might find it within themselves to say yes to organ donation going ahead.

Moreover, these moral complexities ensure that organ donation is rightly one of the most tightly regulated areas of modern medicine. It is crucial that the instinctive altruism underpinning a person's decision to donate their own organs after their death, or those of a deceased family member, is not in any way tainted by the suggestion that doctors are seeking to retrieve organs through opportunistic or self-serving means. The medical teams who treat patients and diagnose death are deliberately kept entirely separate from the teams responsible for organ donation. Nobody in the UK or US is paid for their organs. Nor do clinicians or managers profit from arranging an organ retrieval. These are not transactions of power or of wealth. They are exchanges whose driving force is compassion. They reflect the startling capacity of death's proximity to strip away life's trivial details. If we allow ourselves to consider, for a moment, our final days, could anything befit them more than helping to save – through death – the life of another human being? How could we resist such radical kindness?

I am not a surgeon but a physician who specialises in palliative care, the branch of medicine in which matters of life and death are more intricately entwined than any other. I became captivated by the wonder of transplant surgery during my paediatrics rotation at medical school. I had just returned to my