THE ROLE OF THE CREATIVE ARTS IN BIOETHICAL DEBATES

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What is the role of the creative arts in the bioethics debate? Mary Shelley's 1871 novel *Frankenstein* captured the zeitgeist of the early 19th century, when scientific discovery gave rise to the fear that we play God with nature at our own peril. The themes embedded in *Frankenstein* still resonate. Can I own myself? Can I be bought, sold, traded or even created to serve someone else's purpose? Can I sell my organs or can they be forcibly taken from me? In grappling with these themes, writers take us deep into the messy complexity of what it is to be human.

What is the place of the creative arts in a conference about bioethics? What can a writer of fiction or a film maker have to say that is going to challenge or enlighten us much as the thoughts of a legal or medical expert?

At the Australasian Bioethics Association (ABA) and Australian & New Zealand Institute of Health, Law & Ethics (ANZIHLE) Conference at the Queensland University of Technology in July 2006, I was the only representative from the literary discipline presenting a paper. While there was a considerable amount of interest for a fiction writer such as myself in the papers being presented, at the start of the proceedings I wondered what role humanities had to play in the bioethics debate. A reasonable amount, it transpired. The title of the ABA/ANZIHLE conference: 'Life, death and human nature: bioethics and biolaw in the twenty-first century' is the life blood of fiction writers – for life, death and suffering are fundamental to human existence. And the humanities teach us what it means to be human in all its messy complexity.

My conference paper explored the changing attitude of body ownership through the narrative device of the monster in three gothic horror novels; Mary Shelley's *Frankenstein*,[1] Kazuo Ishiguro's *Never Let Me Go*,[2] and Jodi Picoult's *My Sister's Keeper*,[3] all of which concern issues of personal autonomy and the ownership and location of the soul.

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1 M Shelley, *Frankenstein, or the Modern Prometheus* (revised edition 2003, Penguin Books, 1818).

2 K Ishiguro, *Never Let Me Go* (Faber and Faber Limited, 2005).

3 J Picoult, *My Sister's Keeper* (Allen & Unwin, 2005).

Mary Shelley's 1871 novel *Frankenstein* or *The Modern Prometheus* established a new strand of the gothic horror genre. She captured the zeitgeist of the early 19th century, when scientific discovery gave rise to the fear that we tamper at playing God with nature at our own peril: a strong parallel with how society feels about the rapid progress of technology in the 21st century.

Mary Shelley wrote about a scientist who used the bodies of the dead and the power of electricity to create life. Her scientist Viktor Frankenstein claimed 'benevolent intentions, and thirsted for the moment when I should put them in practice.'

> It was on a dreary night in November, that I beheld the accomplishment of my toils. With an anxiety that almost amounted to agony, I collected the instruments of life around me, that I might infuse a spark of being into the lifeless thing that lay at my feet. It was already one in the morning; the rain pattered dismally against the panes, and my candle was nearly burnt out, when, by the glimmer of the half-extinguished light, I saw the dull yellow eye of the creature open; it breathed hard, and a convulsive motion agitated its limbs.[4]

But Dr Frankenstein rejected the creature he had birthed, who then turned his rage on a world that could not accept him. Even today it serves as a grim metaphor for scientists and their creations – no matter what good intentions they may begin with, who knows where pushing the boundaries of life and death may lead?

> The different accidents of life are not so changeable as the feelings of human nature. I had worked hard for nearly two years, for the sole purpose of infusing life into an inanimate body. For this I had deprived myself of rest and health. I had desired it with an ardour that far exceeded moderation; but now I had finished, the beauty of the dream had vanished, and breathless horror and disgust filled my heart. Unable to endure the aspect of the thing I had created, I rushed out of the room, and continued a long time traversing my bedchamber, unable to compose my mind to sleep.[5]

Shelley created this disturbing novel when she was just 18 years old - and grieving the loss of her baby. The novel was finally finished when she was pregnant with her third child. Through the monstrous form of the creature, the themes embedded in Shelley's visionary novel still resonate: can my creator kill me? Can I own myself? Can I be bought, sold, traded or even created to serve someone else's purpose? Can I sell my organs or can they be forcibly taken from me? Indeed, who owns my body after I die?

As science continues to advance into areas where we can prolong life, cheat death and create life in previously infertile couples, authors like Kazuo Ishiguro and Jodi Picoult use the gothic horror genre to allow readers to explore what it means to use one life to prolong another.

The gothic is frequently considered to be a genre that re-emerges with particular force during times of crisis and which serves to negotiate the anxieties of the age by working through them in a displaced form.[6]

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4 Shelley, above n 1, 58.
5 Ibid.
6 D Punter and G Byron, *The Gothic* (Blackwell Publishing, 2004) 39.

The power of gothic fiction stems from the way it helps us address and disguise some of our most important desires, quandaries, and sources of anxiety, from the internal and mental to the widely social and cultural. Extreme fictions such as gothic can seem to resolve or even confront deep fears and longings in western readers.[7]

While Mary Shelley's monster is a hideous freak cobbled together with the spare parts of dead bodies, Ishiguro and Picoult's 'monsters' are artificially created humans, with nothing to set them apart from anyone else. Except their very existence and purpose isolates them and causes loathing in others, as it reminds people of their own monstrous intentions. Each 'monster' faces problems with autonomy because they were created specifically for a purpose. They have no rights over their bodies and what is taken from them.

Ishiguro and Picoult, like Shelley before them, have used the gothic horror genre to wrestle with bioethical questions about the ownership of the body. Here the living organ donor – a young woman in Ishiguro's book and a teenage girl in Picoult's novel - embody the gothic horror tradition, where the body is the site of fear, power and control that forms the core of the gothic theory. Both protagonists in these novels are required to provide an endless series of ongoing donations to save other's lives. This is done at the expense of their own health and autonomy.

Frankenstein's monster was grafted from the parts of the dead, while Ishiguro and Picoult's "monsters" were created via modern in-vitro fertilisation and cloning technology. Regardless of how they were made, they are all commodities. I suggest the authors argue that if you are created for a purpose, then you cannot avoid your fate. Shelley, Ishiguro and Picoult's "monsters" all suffer from social exclusion and ultimately untimely deaths. But not before searching for the existence of their souls, as if to make sense of their "humanity".

Kazuo Ishiguro's *Never Let Me Go* is set perhaps now, perhaps in the not to distant future. Scientists have been able to clone people and use them as spare parts for organ donations. Asking what it is that makes us human, Ishiguro paints a grim picture of a possible future of slave-donors. If technology can create living donors cloned for the purpose of saving other's lives, then should science be given a free hand to do what it is capable of?

Ishiguro uses the device of a narrator called Kathy who looks back on her idyllic life as a school girl in a boarding house in England. But here amongst the green fields and hockey lessons the children learn of their role in society. They must look after their health – and have near weekly check ups – for they are living donors who once they reach adulthood will give their organs until they finally 'complete' after the fourth donation.

The donors are on the fringe of society, and even though they look like everyone else, people fear them and the donors must care for each other after their operations. But even though they passively accept their fate, the donors still fear the unknown.

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7 J E Hogle, *The Cambridge Companion to Gothic Fiction* (Cambridge University Press, 2002) 4.

> You know why it is, Kath, why everyone worries so much about the fourth? It's because they're not sure they'll really complete. If you knew for certain you'd complete, it would be easier. But they never tell us for sure.
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> You'll have heard the same talk. How maybe, after the fourth donation, even if you've technically completed, you're still conscious in some sort of way, how then you find there are more donations, plenty of them, on the other side of that line; how there are no more recovery centers, no carers, no friends; how there's nothing to do except watch your remaining donations until they switch you off.[8]

Ishiguro forces the reader to confront the reality of living organ donation by taking an idea to its extreme conclusion. Is it all right to buy a kidney from someone? Do you just stop at getting one organ per person? Or do you keep taking and taking? A scientist would say this is a ridiculous premise and that it would never happen, but a fiction writer asks *what if* it did happen.

Where do we draw the line between what is natural and what is not? In his public lecture on the opening session of the 2006 ABA/ANZIHLE Conference, Professor John Mattick, from the Institute for Molecular Bioscience at the University of Queensland said that in the debate about therapeutic cloning no one ever cuts to the chase on the debate – which is when does the soul come into the body? 'Does that cell in that Petri dish contain a soul?'

Mattick maintained 'no one has a mortgage on the truth' and different religions have different views of when a soul comes into place in the body. But is this an argument that will only last as long as technology is in its infancy? Will health triumph over ethics?

In *Never Let Me Go*, society looks away from the donors so it isn't forced to confront the issue that they might very well be human and have feelings and desires and fears like the rest of us. At the end of the novel, Kathy and her friend Tommy track down Miss Emily, a teacher at their old boarding school, and ask her why she was obsessed with them doing creative projects such as art and poetry at school.

> Why train us, encourage us, make us produce all of that? If we're just going to give donations anyway, then die, why all those lessons? Why all those books and discussions? Why did we take your artwork? Why did we do that? You said an interesting thing earlier, Tommy. When you were discussing this with Marie-Claude. You said it was because your art would reveal what you were like. What you were like inside. That's what you said, wasn't it? Well, you weren't far wrong about that. We took away your art because we thought it would reveal your souls. Or to put it more finely, we did it to prove you had souls at all.
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> She paused, and Tommy and I exchanged glances for the first time in ages. Then I asked: Why did you have to prove such a thing like that, Miss Emily? Did someone think we didn't have souls? A thin smile appeared on her face. It's touching, Kathy, to see you so taken aback. It demonstrates, in a way, that we did our job well. As you say, why would someone doubt you had a soul? But I have to tell you, my dear, it wasn't something commonly held when we first set out all those years ago. And although we've come a long way since then, it's still not a notion universally held, even today.[9]

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8 Ishiguro, above n 3, 255-6.
9 Ibid, 237-8.

The first night of the Bioethics Conference, I went out to dinner and by chance sat next to a book group discussing Jodi Picoult's *My Sister's Keeper*, a novel that I would use in my conference paper.

Another coincidence – another conference paper took up the real-life topic of 'Savior Siblings', arguing that the legal distinction made in Victoria between the two types preimplantation genetic diagnosis - one to select embryos free of genetic disease, the other to select an embryo to be a tissue match for an existing sibling who requires a transplant – is inconsistent, both from an ethical and comparative policy perspective.[10]

Yet what is the social fall out of this argument? Does creating a child free of cystic fibrosis, for instance, really have the same outcome as creating a child born to be a savior for another?

In Picoult's *My Sister's Keeper*, the parents of a dying child decide to have another child through IVF to be a donor for her. First it is cord blood, but over the years other more invasive donations are required, until the mother demands a kidney is donated. The novel starts with the teenager's bid for medical emancipation from her parents.

Anna is only 13 – does she have a right to go against her mother's wishes and refuse to give a kidney to her dying sister? After all, she was created with the sole purpose of being a suitable organ donor, and her usefulness was established at the moment of her birth, when stem cells from her umbilical cord were harvested.

During the court scenes where Anna fights to avoid being forced to give her sister a kidney, her lawyer questions the doctor overseeing her dying sister's care.

> I stand up, my hands in my pockets. Can you tell the Court how the Fitzgeralds came to consult providence Hospital's preimplantation genetic diagnosis team to conceive Anna?
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> After their son was tested and found to be an unsuitable donor for Kate, I told the Fitzgeralds about another family I'd worked with. They'd tested all the patient's siblings, and none qualified, but then the mother got pregnant during the course of the treatment and their child happened to be a perfect match.
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> Did you tell the Fitzgeralds to conceive a genetically programmed child to serve as a donor for Kate? Absolutely not, Dr Chance says, affronted. I just explained that even if none of the existing children was a match, that didn't mean that a future child might not be. Did you explain to the Fitzgeralds that this child, as a perfectly genetically programmed match, would have to be available for all these treatments for Kate throughout her life? We were talking about a single cord blood treatment at the time, Dr Chance says. Subsequent donations came about because Kate didn't respond to the first one. And because they offered more promising results. So if tomorrow scientists were to come up with a procedure that would cure Kate's cancer if Anna only cut off her head and gave it to her sister, would you recommend it?[11]

There is a good reason *My Sister's Keeper* is a favorite of the book clubs – it is at once perversely realistic and suburban and yet as horrifying in the consequences of parent's

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[10] C Liu, 'Savior Siblings? The distinction between PGD with HLA tissue typing and preimplantation HLA tissue typing', in the *ABA/ANZHILE 2006 Conference program*, 68.

[11] Picoult, above n 4, 334.

desperate actions as Mary Shelley's *Frankenstein*. Yet the fiction writer is presenting only an exaggerated situation now happening in the realm of science rather than science fiction. In 2006, the Cystic Fibrosis NSW on-line magazine Connections reported that "clinical history was made at The Mercy Hospital in Werribee…when baby Aiden Brundell donated his cord blood in the hope that his precious stem cells could one day rejuvenate sister Mikaela's lungs, which are failing from CF and save her life."[12] Although a newborn baby can not give informed consent to a donation, Professor Bob Williamson, spokesman for CF Victoria, explains: "Everyone agrees that the use of cells from cord blood poses no ethical problems."[13]

But imagine if, as in Picoult's novel, more is wanted of baby Aiden than his umbilical cord blood? What if his bone marrow is needed, and then his kidney? Is this still acceptable? What are the social consequences of baby Aiden being created for a purpose? What if he fails in his task? What does this do to his concept of self worth and identity? Would he feel like Picoult's fictional saviour sibling Anna?

> I was born for a very specific purpose. I wasn't the result of a cheap bottle of wine or a full moon or the heat of the moment. I was born because a scientist managed to hook up my mother's eggs and my father's sperm to create a specific combination of precious genetic material…It made me wonder, though, what would have happened if Kate had been healthy. Chances are, I'd still be floating up in Heaven or wherever, waiting to be attached to a body to spend some time on earth. Certainly I would not be part of this family. See, unlike the rest of the free world, I didn't get here by accident. And if your parents have you for a reason, then that reason better exist. Because once it's gone, so are you.[14]

These are not questions debated by scientists, but that is what fiction writers do: they step out of the now, the probable, the literal, the factual and explore the unthinkable, the unimaginable. Fiction writers are not constrained by facts, law or current reality, they ask "what if"? and then take us down that path. And therein lies their power in bioethical debates.

Scientists, bioethicists, doctors and lawyers all have their specialized input into the bioethics debate, but should questions such as post-mortem sperm harvesting, the collation of human genetic research databases and legalization of the sale of organs and tissues be left solely to them?

A writer takes a debate about disability rights in end of life decisions and makes it flesh and blood through imaginary characters and their plight. Writers make us feel and care as well as educate and entertain.

I spent many years as a journalist on the mass circulation newspaper the Herald Sun, but even in the opinion pages – of a broadsheet or tabloid paper - I doubt there is lasting resonance in these debates. A knee jerk reaction is always required because of the immediacy the media demands. The adage ‘yesterday's news’ applies to newspapers, radio, television, magazines and YouTube. But literature and the creative arts endure.

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[12] "First Cycstic Fibrosis Cord Blood Collection", June 2006, Connections, Cystic Fibrosis New South Wales, page 9, sited: www.cysticbibrosis.org.au on April 27, 2007.
[13] Ibid.
[14] Picoult, op.cit, 7-8.

People turn to them to make sense of the rapid changes science and technology have made to their lives, and they look for answers as well.

During the Bioethics Conference, a young doctor told me that she would unhesitatingly donate all her organs if she died, but added, 'Not my eyes, I do not want someone else using my eyes. Now why do you think that is?' Where do we turn for an answer like that? Certainly not to science, for there was no medical or scientific reason for her gut reaction, which she was well aware. In the ancient world the eye was believed to be the window to the soul, and it is no surprise that celebrities favor sunglasses to shield themselves from the media's intrusions. We beseech people to 'look me in the eye' and tell the truth, imagining we will see a lie in the way their eyes respond. We talk of eagle eyes, being starry eyed and green eyed with envy.

In the science fiction film *Blade Runner*, a detective must kill human 'replicants' who are so convincing that proof their 'humanness' can only be assessed using a specially devised test that looks into their eyes to access reactions to ethical questions.[15]

The reason someone is attached to their eye but not another body part can be found in myths, superstitions and folklore rather than science. Writers tap into these fears and uncertainties as dramatic conflict is the life blood of engaging fiction. But rather than trivializing important issues, I argue that the creative arts bring them to the masses where they can be debated. It's hard to think of a bioethical issue that hasn't be touched by an author's pen, whether in a novel or screenplay.

Genetic engineering and stem cell research provided the bioethical quagmire for the movie *Gattaca*,[16] where in the not to distant future, society analyzes your DNA and determines where you belong in life. Science fiction? It raised so many ethical questions about whether humanity can be defined or limited by our DNA that it was studied as a Year 12 text in Victoria.

The film *Code 46*,[17] gave form to society's growing fears about sperm donation and IVF. How are we going to know if we are genetically related to each other in generations to come? In *Code 46* you have to undergo DNA testing before you can mate with someone.

As far fetched as these fictional scenarios may sometimes seem, they all concern issues of body ownership that have touched most people in western countries. It is no coincidence that these stories proliferate in an age of stem cell research, cloning and human surrogacy. As increasing numbers of would be parents turn to IVF, the idea of scientists creating life outside the human body has long ceased to be the realm of science fiction.

As a genre Science Fiction has taken readers on a wild ride through ideas conceived in the Petri dish of imagination and sprinkled with the tiniest grains of fact. But it is the gothic horror genre that delves into the blackest shadows of our souls. As far fetched as these movies are, they all concern issues of body ownership that have touched most people in western countries.

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15 Motion Picture, Warner Bros, 'Blade Runner', 1982, director Ridley Scot, starring Harrison Ford.

16 Motion Picture, Sony Pictures, 'Gattaca', 1997, director Andrew Niccol, starring Ethan Hawke.

17 Studio MGM, 'Code 46', 2003, director Michael Winterbottom, starring Tim Robbins.

In Shelley's day, the resurrectionists and anatomists had to do their secret work on the dead under the cover of darkness to learn what lies beneath. In the 18th century there was such a desperate shortage of specimens in London and Edinburgh, where private anatomy tuition was beginning to thrive as a lucrative business. Corpses became a profitable commodity.[18] These Resurrection men inspired Robert Louis Stevenson's short story *The Bodysnatcher*,[19] and Australian author James Bradley's 2006 novel *The Resurrectionist*,[20] whose central character flees to Australia from Edinburgh after falling in with the body snatchers. While Bradley's protagonist tries to put his past behind him, he is forever tormented by what he has done; killing people for dissection.

The contemporary work of controversial anatomist Dr Gunther von Hagens, the inventor of Plastination,[21] can be seen as inspiration for the German gothic horror films *Anatomie*,[22] and *Anatomie 2*,[23] where doctors perform grisly autopsies on human subjects – while they are still alive. The doctors are presented as brilliant but ruthless, bent on developing the first synthetic body parts at all costs. These screenplays and novels tap into a deep anxiety the public has about scientific progress and medical advances that rely on human experimentation – the world's first face transplant, for instance, raises profound questions about identity. While these are contemporary examples, the creative arts role in medical ethics has a long tradition. This was illustrated in UK Medical Historian Ruth Richardson's brilliant plenary paper at the 2006 ABA Conference, entitled Medical ethics and the arts: a Georgian controversy. Richardson spoke at length on a satirical print by Thomas Rowlandson about the transplantation of human teeth in the eighteenth century.

Why is it, Richardson asked in her talk, that the modern discipline of medical ethics seems to have become sequestered to philosophers? She pointed out that those who raised ethical concerns about the commercial exploitation of the poor and its human impact, were not philosophers but creative artists and 'doctors of conscience'.[24]

The trade in body parts continues today with Pakistan earning the dubious title of 'kidney bazaar' where an economic system enmeshes farmers in chronic debt, forcing them to sell their kidneys. While donors need constant follow up checks to keep their blood pressure and sugar under control and protect the remaining kidney, it is rare for this to happen.[25]

I am intrigued by the portrayal of organ donation in the media and how the complex bioethical debates surrounding this issue are rarely brought to public attention. Since the

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18 S Simblet, *Anatomy for the Artist* (Dorling Kindersley, 2001) 18.

19 R L Stevenson, *The Bodysnatcher* (1884) eBooks@Adelaide <http://etext.library.adelaide.edu.au/s/stevenson/robert_louis/s848bs/> at 13 November 2006.

20 J Bradley, *The Resurrectionist* (Picador by Pan Macmillan Australia, 2006).

21 Firefly Film and Television Productions Ltd, 'Anatomy for Beginners', 2005, director David Coleman, starring Dr Gunther von Hagens.

22 Deutsche Columbia Pictures, 'Anatomie' 2001, directed by Stefan Ruzowitzky, starring Franka Potente.

23 Deutsche Columbia Pictures Filmproduktion, 'Anatomie 2', 2003, directed by Stephan Ruzowitzky, starring Barnaby Metschurat & Franka Potente.

24 R Richardson, 'Medical Ethics and the Arts: a Georgian Controversy' in the *ABA/ANZHILE 2006 Conference program*, 39.

25 'Poor Pakistanis sell their organs for transplant', *The Age* (Melbourne), 13 November 2006, 12.

first heart transplant took place in 1967, the media coverage has generally been of positive 'feel good' stories. The 'Gift of Life' is the standard cliché used. Yet with technological advances come inevitable human rights violations. In 1999 at the University of California, Berkeley, the Bellagio Task Force was established as a human rights oriented documentation centre to investigate allegations of organ stealing, organ trafficking, corruption of transplant waiting lists, violations of the human and medical rights of the nearly dead and mutilation of bodies of pauperized dead and violations of national regulations and international codes on removing and allocating organs for transplantation.[26]

Yet these are topics explored in many commercial fiction novels. Robin Cook's novel *Coma,*[27] deals with the illegal trade in human organs, as does Leonard S. Goldberg's *Deadly Harvest.* [28] Likewise, many movies released in the last eight years reflect these deep fears and uncertainties about body ownership when it comes to organ donation, such as Pedro Almodovar's *All About My Mother,*[29] the British black comedy romance *Heart,* [30] and Hollywood romantic comedy *Return To Me.*[31]

Dirty Pretty Things[32], a disturbing UK film about the underground human body trade, where passports and cash are swapped for kidneys, delved into harsher realities beyond the 'Gift of Life' promotion of organ donation, while the science fiction movie *The Island,*[33] follows a man (Ewan McGregor) on the run after he discovers that he is actually a 'harvested being' and is being kept along with others in a utopian fantasy.

Fiction also tackles 'cellular memory' in organ donation, with author Gayle Lynd's mystery-thriller *Mesmerized* weaving a tale of a transplant recipient receiving tastes, memories and characteristics from her donor.[34] The medical profession may dispute the existence of cellular memory and put any behavioral changes down to the effects of improved health and immunosuppressant drugs, but does fiction do us a disservice by exploring the unease so many feel about the issue of identity and body ownership in organ donation? For although organ donation is promoted by the Australian Government, the community and medical profession as desirable, we have a lower rate of organ donation than many comparable OECD countries.[35]

To counter this, the Australian Government ran a promotion which closed on August 11 2006 called 'The Flame of Life competition', to raise awareness among young people about the importance of organ and tissue donation in Australia. The Flame of Life, we

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26 Organs Watch, *Social Justice Human Rights and Organ Transplantation* (1999) University of California <http://sunsite.berkeley.edu/biotech/organswatch/pages/about2.html> at 13 November 2006.

27 R Cook, *Coma* (Little Brown and Company, 1977).

28 L S Goldberg, *Deadly Harvest* (Signet, 1997).

29 Dendy Films, 'All About My Mother', 1999, directed by Pedro Almodovar, starring Cecelia Roth & Marisa Paredes.

30 Granada Film Productions, 'Heart', 1999, director Charles McDougall, starring Christopher Eccleston.

31 MCM Pictures, 'Return To Me', 2000, director Bonnie Hunt, starring David Duchovny.

32 Buena Vista, 'Dirty Pretty Things, 2002', director Stephen Frears, starring Audrey Tautou.

33 Dreamworks, 'The Island', 2005, director Michael Bay, starring Ewan McGregor.

34 G Lynds, *Mesmerized*, (Atira, 2001).

35 Australian Government, Medicare Australia, *Australian Organ Donor Register: Frequently Asked Questions* (2006) <http://www.medicareaustralia.gov.au/yourhealth/our_services/aodr/faqs.htm> at 13 November 2006.

are told in the website, symbolizes the life-giving relationship between donation and transplant. Yet I wonder if this competition will have much impact. For society's fears about their body parts being taken away goes deep.

The Ancient Egyptians perfected elaborate mummification techniques and stored organs in jars around the body, because the body needed to be intact to be resurrected again in the next life. There is the Ancient Egyptian myth of Isis, who reassembles the fragments of her murdered lover, and for the first time in history performs the rights of embalmment which restores the murdered god to eternal life.[36]

In literary theorist Kelley Hurley's extensive analysis of Richard Marsh's 1897 gothic horror novel *The Beetle*, she retells the story of strange creature from Egypt who travels to London and transmogrifies into a priest of Isis and wages destruction. Hurley says the corporeal body in the novel is 'both a thing of terror, and a thing of sickness and fear'. Indeed, in while Mary Shelley's monster is horrific and hideous, made from the spare parts of dead bodies, Kazuo Ishiguro's clones in *Never Let Me Go* look seemingly 'normal' with nothing to set them apart from anyone else. But just like the creature in *Frankenstein*, the clones are cast out from society and fear they will die alone. The monster's body – no matter how seemingly 'normal' evokes fear and disgust.[37]

It is fair to say that when great fiction talks, the world sits up and listens. Society turns to storytellers to navigate its way to land whenever the rough seas of uncertainty confront. *Frankenstein* endures because of the issues Shelley forces us to confront – that of human accountability and the nature of life itself. Shelley showed science opening a Pandora's Box when it created artificial life, then running away from its creation. Ever since the nuclear bombs dropped over Hiroshima, the world has forced scientists to take responsibility for their creations. It expects no less from them when it comes to medical technology. But the public's sense of unease at science's will to be held accountable for their actions, seen most recently in the debates on stem cell research and therapeutic cloning, is palpable.

The concern is that scientists won't be able to keep their hands out of the cookie jar, that like Dr Frankenstein, the desire to see just how far they can go in pushing nature's boundaries will mean, to paraphrase Mary Shelley, they will see the beauty of the dream vanish and with breathless horror and disgust look at what they have created.

Animal-human hybrids? Cloned living organ donors? This is speculation now, but this is the role the creative arts play in bioethics. Using their skills, writers draw readers in with beguiling tales that force them to confront the darkness that lies next to the light of scientific and medical progress. They can use the structure of the gothic horror genre to expose society's deepest fears and worst excesses.

In the intervening 130 years between Mary Shelley's novel and the early 21st century, when Ishiguro and Picoult produced their gothic horror novels, the blame for the anguish and destruction caused *by* and *to* their protagonists has moved from science in to society. For Shelley, *science* was the monster, and at its most evil when it played

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36 I Shaw and P Nicholson, *The British Museum Directory of Ancient Egypt* (The British Museum Press, 1995).

37 K Hurley, *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siecle* (Cambridge University Press, 1996) 120-30).

God. For Ishiguro, it is faceless 'society' that has seen the cloning of humans as spare parts repositories, while Picoult points a finger at parents willing to do anything to save a dying child. The creator, rather than the creation, has become the monster. So the books and movies that 'popularize' or dramatize bioethical issues are vital – they need to open the eyes of the consumers of medical technology, as well as the practitioners.

This shift has occurred as scientific advances in areas such as IVF, organ donation and stem cell research have pushed the boundaries of life and death, body ownership and identity. It has made us all players and begs the question – who now sets the agenda? If people can get the immediate gratification of what they want – a longer life, a perfect baby – then who cares about the consequences? As Professor John Mattick asked, will health triumph over ethics?

The role of the creative arts in the bioethics debate is nothing less than a klaxon call to humanity. And that siren says: proceed with caution, we are only human. For now.