Issues At The Borders of Life

edited by Bernadette Richards and Vic Pfitzner



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Introduction: On the Borders

Drew Carter and Annette Braunack-Mayer

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All of these essays have at their core nothing less than, to quote Greg Pike, 'different conceptions of human life itself and of our place in the natural order'. Most are written, often explicitly, in response to a philosophical and broader cultural development in which the sanctity or value of all human life has been openly challenged. In recent decades such value has sometimes been acknowledged only in those possessing certain qualities such as self-awareness or the capacity to choose and then follow a direction in life. These qualities can come most under pressure at the borders of life.

Medical advances have sharpened all of the ethical 'issues at the beginning of life' that the first four essays address. In turn, they examine ethical dimensions of abortion, contraception, the use and manipulation of embryos in reproductive technology and medical research, and the legal and other debates surrounding unintended births and the arguably culpable negligence that contributed to them.

The collection ends with four essays that examine ethical dimensions of palliative care and speak to renewed pushes to legalise euthanasia and physician-assisted suicide (with the exception of Gerald Gleeson, who instead asks an underlying question).

Gareth Jones resists the conventional polarisation of the abortion debate: views can be far more nuanced and equivocal than the diametri-

cal opposition of pro-life with pro-choice can allow. Jones diagnoses as intractable the conflict between rigid 'foetal-based' and 'mother-based' 'systems of thought': each tends to trivialise the claims of the entity that the other asserts as centrally valuable. Consequently, each system tends not to register the depth of the 'awful dilemma' (to abort or not to abort). Each resolves the dilemma one-sidedly – unhesitantly, unremittingly and universally (at least in theory). Furthermore, each system is all the weaker for being one, in the sense that what is centrally important in making decisions about abortion is not any cascade of *logic*. Logic can accord a twocelled embryo the same value as an adult human being or, conversely, lead from abortion to questioning the value of other 'non-persons' as diverse as infants, the comatose, and the severely handicapped. In both cases logic increasingly runs counter to our everyday moral experience. Rather, what is most important in making decisions about abortion is the value actually bestowed upon human life, as glimpsed in all manner of instructive circumstances, both pre- and postnatal.

Jones offers 'an alternative' to the polarised systems of pro-life and prochoice. It is one guided by his interpretation of 'the Christian ethos', which carries a 'bias' against abortion by 'sensitising' us 'towards all forms of human life'. He argues against the idea that, ethically, the foetus is *completely* inviolable: this idea is not implicit in the Bible, nor is it supported by appeal to a special innocence belonging to the foetus. Foetuses are only as innocent as infants and others who participate in an imperfect world and whose claims we must balance in sometimes terrible circumstances. Jones does warn, however, against interpreting high rates of natural pregnancy loss as implicit commentary on the lesser value of foetuses. (Greg Pike echoes this warning later in the collection.) The foetus is protectable, not inviolable. Its claim to protection is grounded in its potential to realise its humanity (or personhood - Jones intentionally, if implicitly, collapses this distinction, as does Pike). The claim to protection is made when potential first arises - at fertilisation. Moreover, it grows in line with the foetus itself, as it develops biologically. Jones points to our usual moral responses and gives them normative weight: 'under most circumstances, the loss of a child that almost made it is felt much more acutely than that of a child that had hardly begun to develop'. He concludes with a series of 'propositions' that articulate his position:

Foetal protection should be as stringent as possible, and yet it cannot be absolute . . . There are occasions . . . when the welfare of the foetus may

come into conflict with the welfare of other parties, and induced abortion is justified.

Jones offers the examples of a thirteen-year-old rape victim and of a foetus with dangerous biological abnormalities.

Ea Mulligan and Margie Ripper present a work not in Christian bioethics but in feminist and public health ethics. While Jones observes the 'appalling excesses of liberal abortion practices', Mulligan and Ripper accent the importance of equitable and confidential access to safe and legal contraception and abortion in empowering women to manage their own health and lives. This is important for both intrinsic and extrinsic reasons. It respects women's 'autonomy', which is intrinsically valuable. Furthermore it results in positive consequences population-wide, improving the health and social well-being of women and the children they rear. Contraception and abortion are public health measures that minimise harm, in particular the harm resulting from unsafe abortion practices: 'The harm that restrictive abortion laws cause to women's health and morbidity are well documented and world trends are towards liberalising access to abortion'. Mulligan and Ripper cite work mapping the incidence of unsafe abortion practices and consider women abused or otherwise oppressed, for whom fertility control may be especially critical in gaining health and independence. They conclude that contraception and abortion are ethical whenever they result from informed, voluntary decisions. Their arguments recognisably draw on utilitarianism and principalism, where the acquisition of informed consent is critical to respect for a patient's autonomy.

With **Greg Pike** we return from 'mother-based' to 'foetal-based' discussion. His piece is a twelve-megaton blast to the complacent and the illiterate when it comes to embryo science and the history of embryo research and use. His chronicle is comprehensive, rich in detail and insight and, all the while, considerate of the reader. He catalogues a history of proliferating experimentation and research in which embryos are created then destroyed in the pursuit of knowledge. He identifies two distinct drivers behind this activity: the 'praiseworthy goal of improving health' and the less easily assessed goal of improving the species as a whole. The reader is given the sense that this research continues to varying degrees unhinged from the full communion that for the meantime Pike only implies. He reviews current embryo manipulation and use and offers provocative speculation as to likely future directions. He also discusses the uses and misuses of empirical study in evaluating the embryo's moral status.

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After examining early embryo development, Pike emphasises that at fertilisation there comes into existence an entity that is new and individual, genetically distinct from its parents. Furthermore, it contains all of the genetic information necessary to organise itself and mature. In short, it is a 'self-integrating whole organism'. On this basis Pike argues that 'the embryo is a whole individual member of the human species [merely] at an immature stage of development'. He opposes the 'gradualist' view (akin to Jones's), in which the human being and corresponding moral status emerge progressively over time. Pike imputes this view to Peter Singer. Embryos may lack *personality*, but they do not thereby lack personhood. Nor, like so many other members of the human species, do they immediately express their potential, but they no less brim with it. Pike accuses Singer of confusions on these scores that lead him to distinguish persons from members of the human species. For Pike, the distinction is nefarious: embryos are fully members of the species and therein fully valuable. The moral fellowship we share with embryos is total because the genetic fellowship we share is total: 'What adults, children and infants have that makes them valued is the very same something which makes foetuses and embryos likewise valued'. For Pike that 'something' is membership of the species.

Pike concludes that human embryos are completely inviolable: they ought no more be destroyed or risked harm to than any other member of the species. In a surprising twist, he thereby precludes the vast tracts of medical research and application that he earlier rehearses (including current *in vitro* fertilisation practices), explicitly refuting utilitarian arguments in their favour.

Bernadette Richards examines well-publicised court cases in which claims of 'wrongful life' and 'wrongful birth' have failed to win financial compensation for the negligence (usually medical) that has been found to obtain. She explains that a wrongful life action is brought by a child (or its advocate) against someone for having failed to prevent them from being born, while a wrongful birth action is brought by the parents of an unintended child against those without whose negligence the child would not have been born.

Richards diagnoses the labels of wrongful birth and wrongful life as fundamentally distracting and the cause of much muddled thinking. She redirects the focus of the courts and commentators alike away from the 'diverting' and ultimately 'derailing' broader question of whether life can ever be considered worse than the alternative (death or never having been born) and towards the 'true issue' before them, namely the detriment (financial or otherwise) suffered by one person due to the wrongful (because negligent) actions of another.

Courts have denied damages out of 'a concern that life itself will be challenged or cheapened'. But it is possible that in each case an appeal simply for financial assistance or 'relief' is misheard, strategically miscast or misdirected as a condemnation of life. Richards suggests that cases for the defence may wrongly accomplish and profit by

a legal sleight of hand: direct the attention towards the 'abhorrent' job of placing an economic value on life and the true issue of responsibility for a harm suffered at the hands of another is put to one side.

Richards uses her knowledge of court cases in Australia and overseas in order to systematically rehearse, and then dismantle, legal arguments against any awarding of damages. She concludes that

The true loss can be found in the removal of choice, or the denial of choice . . . The life of the child is not at issue. What ought to be at issue is the autonomy of the parents.

It is that which negligence has fundamentally compromised and in the light of which damages should be awarded.

Ian Maddocks' contribution serves as a fitting and eloquent introduction to the collection's second half. It is full of observation, as its title suggests. It shows a poetic quality that is arguably a requisite for any good meditation on the 'borderland' between life and death that an individual enters when diagnosed with a potentially fatal illness:

Like the border marches of old, where warlords engaged in repeated conflict, it is a fringe region that can be dangerous, bewildering, and scary. Its unfamiliar territory is filled with new relationships with doctors and hospitals, bringing new vocabularies of diagnosis and therapy, and – often – new discomforts.

Maddocks maps this borderland on the back of twenty years of medical work in palliative care, a specialty that concentrates on 'care rather than cure, relief of discomfort rather than reversal of pathology'. Maddocks does this narratively, delineating the routes most often taken (and which we usually expend energy putting out of mind). Here even a simple, factual outline stimulates the sympathetic imagination. Maddocks's tone is humble and direct; he touches the daily reality of death 'tentatively, with a sense of awe and agnosticism'. The effect is quite moving, and as a guide he earns our trust.

His routes include a gateway (diagnosis), resistance to entry (a resolve to fight), journeying (receiving palliative care), and the question of hastening that journey (euthanasia):

Many patients will ask about how it might be possible to hasten the inevitable... Usually, in my experience, this is not an ideological statement building from long-standing advocacy for euthanasia, but a response to a feeling of powerlessness, and of being a nuisance and an expense to family and society.

Maddocks registers the conflict that arises for him as a doctor: he seeks to act beneficently and to respect the patient's autonomy but also to do no harm (more formally, to obey the ethical principle of non-maleficence). In this articulation he draws on the principlist approach used also by Mulligan and Ripper. Maddocks touches on 'many complexities' and ultimately advocates 'a cautious approach', encouraging 'further consideration and debate' before any legislative change. He invites advocates of change to recognise the complexities and to be 'respectful of the wonder of life and the mystery of death' (which, we might observe, an accent on autonomy alone cannot register).

Rosalie Hudson examines palliative care within the context of endstage dementia. She seeks to significantly reorient it, critiquing the 'traditional bio-medical paradigm' and offering in its place a ('countercultural') vision of care that is arguably more worthy of the name. The traditional bio-medical paradigm mistakes aging for 'a scientific problem ripe for a technical solution': end-stage dementia foremost calls for a certain *doing* in response. Hudson disagrees. She distinguishes questions of what we are to *do* from those of how we are to *relate* (and of what things might *mean*), not reducing ethics to the former. Hudson mines both words and relationships for their meaning. To 'palliate' originally meant to 'cloak', to protectively cover distressing symptoms. The first 'hospice' was so called by virtue of the 'true hospitality' that carers showed their charges. Hudson observes that the world of dementia . . . lends itself . . . to imagination and creativity, and the risky business of appearing foolish and 'non-professional' in an attempt to understand the other person's situation.

In this fragment alone we can find Hudson's emphasis. It falls less on patient management than on the *meaning* of patients' lives, of the lives that mingle with theirs, and of the relationships that develop. As human beings we exist and find meaning 'in mutuality and reciprocity—in the *interdependence* of our relationships', and this is imaged in the Holy Trinity. This anthropology contrasts with Pike's, whereby human beings are centrally defined not by their relationships but by their shared genetics. It serves the same end, however: 'When persons are seen in their communal relationships, no person can be regarded as more, or less, worthy of care than any other person'. Like Pike, Hudson opposes Singer. She considers his conception of the person to be an absurdity that threatens to kill both frail older people and (what is less commonly observed) the spirit of our relationships with them.

How are we to relate to people with end-stage dementia? Hudson answers that we should recognise our own dependency (on one another and on God) and thereby with humility care for the 'whole person', not merely what presents as the sum of their symptoms. We are equals together 'in Christ'. Even when we forget ourselves God remembers us—this is Hudson's cause for hope. God calls us to remember one another, and even *for* one another: in ministering spiritually to those with dementia, we might remember God for them. Such a vision contrasts radically with Hudson's target, which casts the dementia patient foremost as devoid of 'rationality' and 'autonomy'.

Hudson adds to her anthropology some consequentialist reinforcement: 'the therapeutic value of human-to-human encounter is incalculable'. She concludes with practical recommendations for change in both carer practice and education, and emphasises the importance of establishing comprehensive care plans with patients and their families early on.

To the question posed by his chapter title, **Gerald Gleeson** answers 'yes'. He argues that life is the most fundamental thing that is good *for* a person. It enables every other thing good for a person and, indeed, is presupposed in any (usually consequentialist) attempt at weighing goods and ills in a life. Life has (in Kant's sense) a transcendental character—Gleeson interpolates 'value'—defying reduction to but one good among many.

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Life is no mere 'instrument': it ought not to be intentionally consumed in the service of a higher goal, though it may be lost as an unintended side-effect, as in martyrdom or heroism. (In this clause we can glimpse the principle of double effect that Helen McCabe soon explores.) 'Being alive is not the highest personal good'. That good resides instead in expressing and fulfilling one's nature as a being self-directed but no less responsible to 'objective parameters'. Gleeson cites Aquinas: the realisation of its nature stands as the fundamental good of the person (with goods for the person following accordingly). But so centrally necessary to fulfilling our nature is being alive that we cannot intentionally take our own lives, just as we cannot sell ourselves into slavery. (Gleeson cites Mill here.) We cannot relinquish liberty for liberty's sake, nor willingly extinguish our own wills (or opportunities for their future expression): we would undercut the very thing we hope to affirm, contradicting ourselves. Far from suicide ever crowning autonomy, it undercuts it at the root. Life cannot be forfeited in the name of autonomy, for without life there can be no (further) autonomy. Life lies at the heart, not the margins, of the good of the person: 'the most fundamental way of respecting a person, myself or others, is by respecting their life' (not necessarily their wishes).

Gleeson also implies, we think, that intentionally to 'take, control and end' life, thereby determining its final meaning, is hubristic or fat on the notion of being one's own. It denies the 'objective parameters' of human nature that make of choices good and bad ones. An act is not good simply because it is freely chosen. Gleeson cites Charles Taylor in arguing that choices presuppose 'horizons of intelligibility and value' that make them meaningful. These horizons derive from the nature of reality, Gleeson proposes.

Helen McCabe concludes the collection in defence of the principle of double effect (PDE) as applied in end-of-life decisions. She defends the distinction between intending and (merely) foreseeing, arguing against critics who see none and who accordingly wish to legalise euthanasia with the view that it already occurs in practice. She does this first by expanding on the 'ethical tradition' (recognisably Christian) in which the PDE 'finds its philosophical home', then by attempting to demonstrate its superior realism with respect to moral psychology. McCabe's tradition recognises as morally significant the intrinsic nature of an act, its intention, its motive (or animating spirit, we might suggest), and its consequences for the 'the kind of person we become'. By contrast, the 'post-traditionalists', whom McCabe trains into her sights, exalt only autonomy and (broadly practical or material) consequences. (On this front McCabe allies with Hudson and opposes Mulligan and Ripper.) McCabe sees as two inadequacies of the post-traditionalist account its equations of medical negligence with outright murder and of withholding or withdrawing life support with killing (as otherwise distinct from 'letting die'). These equations are enabled by all disregard for intention as 'morally and psychologically distinct' from the ability to foresee.

McCabe concedes that not all end-of-life decisions can be 'guided coherently' by the PDE. A resource even older to McCabe's tradition may be needed, namely the distinction between ordinary and extraordinary measures of care. If a treatment represents something too extraordinary to ask of a patient, too painful, inaccessible, denigrating, repugnant, or morally or spiritually violative a recourse, then the patient may morally forego it.

McCabe concludes with some reflection on human dignity and on multiple threats to it posed by post-traditionalists. In particular she considers frightening any reduction of doctors to mere technicians in the service of our (ever vulnerable and variable) wills.

What are we to conclude from these rich and complex accounts of beginnings and ends in life? As noted at the outset, all of these accounts are concerned to enrich how we conceptualise human life. And yet, despite this, they both cut past and illuminate each other. There is a disconnectedness about these essays, a sense in which some of their writers seem to live and work in countries that are far removed from and foreign to one another. They just 'do things differently'.¹ This is most obvious if one compares the epistemology, ontology and sometimes theology that can be glimpsed (or guessed at) in various accounts. Differences on these counts can (but do not always) correspond to how central autonomy is taken to be in defining both morality and our very humanity (or personhood). Mulligan and Ripper and Richards would seem to assign autonomy a fundamental importance that Hudson, Gleeson and McCabe openly contest. Jones, Pike and Maddocks are perhaps border watchers or riders here, negotiating the concept in ways that traverse or avoid divides. Could any be bridged by more work toward a theological conception of autonomy, or of what that concept hopes to preserve and promote?

While these essays challenge our capacity to successfully integrate their ideas, they simultaneously enhance our understanding of them. Reading the essays as a collection rather than as individual rhetorical pieces, one

^{1.} Leslie P Hartley, The Go-Between, 1953.

can see how questions on some points are clarified by insights on others. For example, there exists a common thread of concern for human dignity, whether that be expressed through a desire to protect the vulnerable or to respect autonomous choices. Perhaps an adequate account of human dignity must unite both of these strands. There is also room for readers to align with that tradition which best expresses their own values while simultaneously being challenged to explore the limits of those values. The title of the collection thus bears on both the borders of human life and our own ethical borders, and these essays succeed in examining both.