

THE CHALLENGE OF BIOETHICS TO DECISION-MAKING IN THE UK

A lecture for the Von Hugel Institute series 'Ethics in Public Life'

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The context of the series of lectures of which this is one is ethics in public life, and I would like to start by taking some time to describe the creation and operation of Westminster Abbey Institute, and use it as a prism for our consideration of bioethics and decision making in the UK. I want to say a little bit about the sacred-secular divide which I do not see. Then the two thorny examples I will use in bioethics, when I come to them, will be embryology and assisted dying.

Establishing Westminster Abbey Institute

Westminster Abbey Institute was launched in November 2013 to revitalize moral and spiritual values in public life, working with the public service institutions around Parliament Square, and drawing on its Benedictine resources of spirituality and scholarship.

Westminster Abbey sits on the south side of Parliament Square, with the Judiciary in the form of the Supreme Court on the west side, the Executive in the form of Whitehall on the north side, and the Legislature in the form of the Houses of Parliament on the east side. The Institute is the Abbey's answer to the question: what is it bringing to public service and how can it support those in public office?

We knew, when we started, what we were not: a think tank, part of the commentariat, a campaigning organisation, nor a fawning courtier. Nor were we apologists for religion in the public square. The Abbey is already more integrated than that. There is no sense of a sacred-secular divide, and as I go about my work as Director I feel none between my work and that of the public service institutions around the Square. The similarity is that we are identifying at the heart of the Parliament Square endeavour a sincere wish to support the good, to serve society, to make things better in the world. And in that sincere wish I see spirit moving, hearts opening, minds analysing, bodies acting, as a holistic, responsive flow to the call of public service.

I am not naive: the motivation to serve the public and the vocation to public service are not pure. In amongst the good wheat of service are the tares of motives such as selfish ambition, personal gain, fame, and the needy weakness of human nature to be recognised and rewarded. I see those other motives, but I know them for my own also, so am in no position – the Abbey Institute is in no position, let's be clear – to judge or condemn them. Like the parable, we leave that till the harvest. And meanwhile, by supporting the good, believing in the motives that are for service, recognising and applauding the rightness in the work around the Square, the murky tares, if I may torture the analogy beyond its capability, melt away. We hope.

I see a wholeness, then, responding to a call to serve. The deeper the response the more effective and lasting it will be – and here is a place where our religion makes a specific contribution. The further back into God it reaches, the more effective and lasting and good the call to public service will be. I call it God. Spirit, depth, the swirling deep movement of creativity, the meditation of the soul, the rest before action. The further the archer draws back the bow, the further and truer the arrow will fly. It has been notable just how much of a longing for depth has shown itself in the people and institutions around the Square in the short time the Institute has been operating.

The Westminster Abbey Institute method

Our method is first to offer a Benedictine context. That is, we offer conversation that locates itself in stability, community and the conversion of manners. We will sit down with a group of, say, senior Civil Servants, or those tasked with offering professional development to MPs, or a group of Peers, and together we will devise a seminar for their department or group which will look at the good that the department or group is trying to do. What is significant and distinctive is that the psychological and philosophical location of the conversation is deep. That depth is also physically expressed by the Jerusalem Chamber where King Henry IV died and V became King, and the King James Version of the Bible was finalised, and so forth, where the seminars happen. Part of the Abbot's and then the Dean's lodging, a space where spiritual and worldly do not separate.

I was set a great example of how to do depth by Rowan Williams when he was the interlocutor for a series of four public conversations at St Paul's Cathedral, taking in turn global economy, ecology, governance and health, and asking the experts in those fields questions which immediately drew them into a consideration of the philosophical and even theological underlying currents of the subjects. The bishops did a similar thing with genetics experts when they spent a day learning about the subject. They were really good questions, and ones that practitioners, officials, public servants often don't have time to ask, but they are the most important questions because they lead us into our spiritual humanity.

A really lovely example emerged yesterday when we were sitting around the table in the Permanent Secretary's office of a Government Department, discussing a forthcoming seminar for the Department. One of the Civil Servants spoke about how too often officials in the Department will apply formulaic approaches, such as the benefit-cost ratio, in a way that masks or even undermines vital human qualities such as empathy and humility, and we will look at this in the seminar. Importantly, the words and the disposition came from the Civil Servant, not from the Abbey Institute. We are not functioning on the Square to tell others what the Good is. It emerges in the encounter.

So the conversation is located in a Benedictine place (in a way, for a short while, that Permanent Secretary's office became a Benedictine space). First, it is stable, it is safe here, and here is not going to go away, it's an historical place where we can feel our own passing, gain a perspective on our place in history. Second, it is a place of community, which means

that we are gathered in goodwill together, seeking the good together, united in our efforts and made companions in our purpose, not by any means agreeing with each other but feeling safe with each other. As a community of goodwill we feel it is safe to get things wrong, to take time to form conscience, to work things out. And of course we operate to the Chatham House rule. Third, we are about the conversion of manners. We expect transformation to take place though we don't necessarily know what it will be. Broadly, though, borrowing from Philip Shepherd, we will be looking for moves:

From self-consciousness to mutual awareness
From doing to being
From self-achieved independence to self-achieved submission
From enclosure to receptivity
From knowing to feeling
From self-conflict to grace
From Idea to Energy
From regulatory systems to responsiveness
From coarseness to subtlety
From rules to principles¹

And I don't mind admitting that this transformation is probably only realised after the talking is over and everyone has gone to evensong and then wandered around the Abbey in the semi-dark and silence of the close of the day – and had a glass of wine back in the Jerusalem Chamber!

In agreeing that we are a community of goodwill seeking to articulate the good I have offered an analogy from sailing that works well. A Government Department can be imagined as a sailing boat. At the helm stands the Permanent Secretary, who, like all good helmsmen, seeks never to steer the boat more than five degrees either side of the compass direction upon which the boat is set. Civil Servants in the Department form the crew, from the navigator who must know the course and ensure the helmsman anticipates obstacles, to the scrubber of decks who ensures no one slips up. All play their part in ensuring the boat remains shipshape and able to withstand the waves and the winds in travelling its appointed course.

The waves are the events of the nation and the world. They may be relatively calm or they may rise into steep and stormy mountains of water, threatening the stability of the boat.

The winds are public opinion, which can fill the sails of the boat and send it scudding on its chosen course. They can gust and buffet, interrupting the boat's smooth journey. Or they can blow adversely, threatening to push the boat off course altogether.

Hence, the helmsman cannot simply hold the tiller fixedly. He or she must constantly respond and adjust to the wind and the waves, aiming to keep within five degrees either side of the compass direction or risk increasingly over-compensatory swings away from the course of travel.

The compass point towards which the boat is sailing is The Good. As such, it is not a destination; the journey is the thing, the direction of travel the concern, not the arrival.

By whom is The Good defined? It is true that the Government Minister is granted that responsibility and privilege by virtue of having been elected by universal franchise. But in defining The Good, Ministers have to have their Party's support. And of course the strength of the prevailing wind, public opinion, may be such as to determine a change of compass direction altogether. For the politician, public opinion will set parameters on what he or she can achieve. The great political leader will have a vision of the Good that transcends narrow-minded concerns but retains Party support, and respects the parameters set by the prevailing wind of public opinion. The visionary and skilled politician will learn, quite possibly from his or her Civil Servants, about the art of tacking.

Because of course it is the helmsman and the crew who execute the tack, and any other sailing manoeuvres required. The Civil Service crew, having gathered the evidence – sniffed the wind, watched the waves – will need to be able to tell Ministers when their proposed direction of travel will not work: when, whatever the Ministers might want to think, their proposed direction is possibly not towards The Good. Thus the Good is sought by all.

And in passing, if one imagines Whitehall as a fleet of boats, those, too, will need to be taken into account by the helmsman. But – and it is a wonderful sight – sailing boats, journeying as a fleet in the same direction across the waves, subject to the same wind, stay uniform distances apart.

Having established a common concern with identifying the Good, seated in our Benedictine space, we then spend time as moral philosophers, looking at the specifics of the policy drivers for a given Government Department. Our analysis is rigorous, using the method I developed in the Centre of Medical Law and Ethics at King's College, London, under Ian Kennedy, in the 1990s.

We use the three broad approaches that moral philosophers have taken over the centuries as they have sought to determine what is good. These we have called goal-based, duty-based and right-based, following Dworkinⁱⁱ, Botrosⁱⁱⁱ and Foster^{iv}. Very briefly and broadly, a goal-based thinker will see the good of an action in its consequences rather than in the content of the action itself; a duty-based thinker will look at the action and judge it according to pre-existing moral rules; and a right-based thinker will judge the action according to the views of those most affected by it. The *goal-based* approach is valid insofar as it is the case that we rarely act without some end in view and it is right to consider whether that end is a good one. The goal-based approach is limited in that even very desirable goals should not justify actions which in themselves are intrinsically nasty. The ends are important moral considerations but they don't justify the means. Morality is not a mathematical exercise. The *duty-based* approach is valid in that it makes us think hard about what we are doing rather than merely why we are doing it, recalibrating the needle of our moral compass, making us morally

sensitive rather than mathematically certain. The duty-based approach is limited because it can blind us to important consequences (Kant would have us truthfully respond to a murderer seeking her prey); and it is limited because it can make us arrogant: concerned only with our own place in heaven earned by doing the right thing, regardless of its effect or the views of others (the poor soul who will be murdered because Kant refused to tell a lie, or the patient who wants his life support switched off and we refuse to take a life). The *right-based* approach is valid because it requires us to listen to others, it makes us community-minded instead of purist. It is limited because on its own it would make someone's request, for example, to take their life, right with no other consideration except that it is their wish.

All three approaches are needed. They conflict, they make us think, they require sensitive responses, honest appraisal, self-awareness because we will temperamentally favour one approach over the others, but taken together they form a three-legged stool that stands firm, if the legs are all of the same length, even on rocky ground.

Bioethical decisionmaking

And then comes the real challenge of bioethics. The Department of Health wants us all 'to live better for longer'. But when does life begin and when does it end? I want in this third and final part of my lecture to explore the contemporary challenge of these questions by looking at two issues – embryology and assisted dying – that have been working their way around Parliament Square, with cases in the Supreme Court, policy development in Whitehall, and legislation or attempts at legislation in the Houses of Parliament.

Embryo Research

Human fertilisation and embryology are scientifically complex and they are also, at every stage, morally sensitive. The challenge to Government and Parliament has been whether and how to draw these extraordinary scientific developments within a regulatory framework in a way that respects the science and does not ride roughshod over the sensitive moral questions, or ban the research and practice altogether. Having chosen the former course of action, what principles needed to underlie the regulatory framework?

Let us take a step back in time and thought. Let us bring the issue into our safe Benedictine space. Here we are allowed to think out aloud. We do not have to have a pre-determined position, but if we do, we won't be shouted down or assumed to be on the side of the devil. None need feel defensive. In this Benedictine space we are seeking the Good, aware that many have tried before us and God willing there will be many afterwards, all calibrating their moral compass and seeking to steer the boat no more than five degrees either side of the compass point, but having to allow, because of the wind of public opinion and the waves of ever changing events, that much leeway either side. We know we will not find perfect answers.

And now for the three-legged framework. From a goal-based perspective, we ask what embryology is for, and why it matters. Embryology is important as a cure for infertility, as a therapeutic response to currently incurable diseases using cell transplantation and, very

recently proposed, eliminating mitochondrial disease altogether. Its goals, then, are for life: new life, and curing diseased life. No one, really, could argue with the goals of embryology. We would want the research and practice to be done excellently, so as to ensure these good goals were reached, but from a goal-based perspective, taken on its own, there can be no quarrel with it.

From a duty-based perspective, what does embryology involve? Here the moral questions start to bite. The first question must be about the status of the embryo itself. Because if the embryo has the same status as a human life, no matter how wonderful the goals are, no one would countenance destroying a human life to reach them, and embryology (which always involves destroying embryos) would fall at this moral fence.

The reasons you might regard the embryo as a human life are as follows: the embryo is formed from the fertilisation of an egg by a sperm forming a unique genome – no one (if it is a person) was ever like it before, and no one will be ever again. We, each of us diverse people, were all embryos once. If we are to choose a point when life begins, the formation of the fertilised egg is certainly a definite stage one could choose.

The reasons you might not regard the embryo as human life are: the place of fertilisation is not the womb or the field in which the embryo is implanted, but at the base of the fallopian tubes. The embryo still has a journey to make to reach the womb and implant. (Some Shia teaching on this argues that life cannot be said to have begun until the seed, egg and field are all in place, ie at implantation.) During that journey, in the normal course of events, 70% of embryos do not reach the womb. It is during that journey that the all-important stem cells start to proliferate, hence the interest in the early, pre-implanted embryo, not the fetus in the womb. During that journey, the embryo may divide and become more than one fetus, hence genetically identical twins. These reasons may persuade you that it would be acceptable to see the early embryo not as human life but as potential life, and that its use therapeutically is acceptable. You may feel the goal-based tug: the status of the early embryo is in question, and the use of them therapeutically is so full of promise... Should the duty-based consideration, that the embryo has independent moral status like that of a human being, give way?

What is important to recognise is that we do not say that the embryo has no status. The legislation has recognised its moral importance by regulating its use. But the law has accepted that the embryo is not the same as a human life.

From a right-based perspective, you cannot really make a judgement. The embryo cannot speak for itself. Is it fanciful to conduct a thought-and-feeling experiment predicated on the fact that we were all embryos once. Would we be happy to have been destroyed even before reaching the womb, to save another life or lives, or to create a new life? ??

The other right-based question relates to those who might benefit from stem cell or mitochondrial therapy: if they think of the embryo as having human status they may not want

to benefit from such treatment. Healthcare practitioners may seek to be conscientious objectors.

The challenge to UK decision-making of embryology has been profound and I think, myself, that we have not done badly at it. Prior to this last development on mitochondrial DNA, the debates have been long and thoughtful, no speedy legislation was drawn up (except to prevent cloning), and the regulation is careful. In the UK, embryo research can take place but it is all regulated. (In the US, embryo research may not take place if it is federally funded; if you can pay for it yourself, you can do what you like!)

However, courts continue to be referred to as no legislation could possibly anticipate the science. It has turned out that the most fruitful source of embryonic stem cells has not come from embryos but from de-differentiated adult cells. Since however these de-differentiated cells, if placed in a womb, could theoretically grow into a clone of the person whose cell it was, this has had to be specifically outlawed and, much more recently, and potentially worryingly, a court has ruled that: ‘The mere fact that a parthenogenetically activated human ovum commences a process of development is not sufficient for it to be regarded as a ‘human embryo’’. This judgement opens the way to patenting the process of creating stem cells. It is potentially worrying since it arguably robs the embryo of its moral status. However, what is the status of a de-differentiated cell, which could originate from any one of the bodies in this room just by scraping our skin?

Is the very recent decision of the Commons to allow the process that removes diseased mitochondrial DNA from the offspring of mothers with the disease a case of slipping down a slippery slope into unethical waters? Is it the first step towards eugenics, since it eliminates the disease from the germ line permanently? Or is it an intelligent use of skills and techniques we have developed through carefully regulated embryo research, that will allow the cure of a vile disease?

Assisted Dying

Assisted dying, unlike embryo research, has not been made legal and given a set of regulations by which to abide. Despite its repeated return to Parliament and the apparent public support for a change in the law, none has happened, as yet. In practice, cases have been decided by the Courts and the number of cases coming to the Courts is only increasing. It is something of a sore point for the judges: they cannot turn cases away. All the time, as they see it, Parliament refuses to take the bull by the horn and create legislation, they are obliged to give judgements on a case by case basis that creepingly changes the law, and it is changed by lawyers not by democratically elected representatives of the public debating in public.

Before reflecting on the challenge to law and policy-makers that assisted dying has posed, let us once again step back into our Benedictine space, and we should pause here for a moment and recollect that the primary quality of that space is listening...

And now conduct our analysis. Assisted dying is the act of making available to a person, who has expressly and competently asked for it, the means to take his or her life by their own hand.

From a goal-based perspective, one goal of assisted dying is to alleviate suffering. Another is to respect the autonomy of individuals. Another may be put more boldly: to end life deliberately.

From a duty-based perspective, principles of the sanctity of life and of respecting autonomy both raise their concerns, and conflict. How are they resolved?

From a right-based perspective, the principle of respect for autonomy trumps any duty of other individuals to save, sustain or end life. It is, simply, up to the individual. When polls are taken on the subject of assisted dying and euthanasia the vast majority of responses are in favour of it, on the grounds, though, that it is my life to do with as I please and who is any doctor to prevent me. But a law that permitted a solely right-based approach that the request should be granted simply because it had been made would be impossible to apply. It would be impossible to know if the person had actually asked for death, because they would be dead. Additional safeguards have to be included in any legislation, and these require that certain relevant professionals are satisfied that the conditions allowing assisted dying are met. This is not, then, a purely rights-based activity any more. Similar difficulties arise in seeking abortion - it is not, in the legislations, simply up to the mother whether or not the abortion takes place. She has to satisfy two doctors that she fulfils the criteria set by the law. The fact that doctors will very often sign the forms without questioning the mother, because they take a right-based approach in profoundly believing in her right to choose, is symptomatic of the challenge of lawmaking in areas of bioethics.

If the dying in question is assisted only, ie the person has to take the lethal substance themselves, this right-based problem is allayed. That is to say, we may be fairly sure that if the 'pink drink' given by organisations such as Dignitas is drunk without assistance once it is put in the hands of the one seeking assisted dying, then he or she most definitely did want to die.

We cannot know what passes in their hearts however, and Mary Warnock has been worryingly at ease with the idea that it would be perfectly all right to seek euthanasia on the grounds that one felt a burden to one's family and friends. The wishes and needs of the community of that individual: family, loved ones, society are all included in the right-based approach, and what of these? Chaplains ministering to those receiving euthanasia in Holland speak of the devastation of families, resonant of the desolation of the families of suicides.

The most recent case that came to the Supreme Court was that of Nicklinson, Lamb and the Director of Public Prosecution^v. Nicklinson and Lamb were both almost entirely paralysed; Nicklinson from a stroke which left him able to blink only and Lamb from an accident that meant he could only move his right hand. Hence neither would be able to take the 'pink

drink' unaided, so both wished to be assisted to die without fear of prosecution of those who helped. The Director of Public Prosecution sought the freedom to decide on the matter of assisting suicide on a case by case basis.

In the Supreme Court, all the Law Lords agreed that Article 8 of the Human Rights Act (which is the right to a private life, to be overridden only in the case of threats to public safety or criminal acts) is relevant to the issue of assisting someone to die if it is their express wish. That is to say, domestic rulings can be made by way of interpretation of the Article in relation to assisted suicide. But while some Law Lords believed that it was a right for a person to be assisted to die if it was their express wish, according to Article 8, others did not. It was recognised that there was a fundamental incompatibility between the sanctity of life and autonomy. Several Law Lords argued strongly that the debate should be held in Parliament as the representative body of society, not judged upon by appointed Justices. And indeed there is yet another bill to allow assisted dying making its way through the House of Lords now. It has reached the stage where the Lords are working through more than 100 amendments, some of which are clearly intended to wreck the bill, whilst others provide clarification and strengthening of safeguards. And arguably the intellectual purity of the moral reasoning of the judges is a better place to turn to than the mess of Parliamentary debate. What a strange way for law on such a sensitive and controversial issue as the management of the dying process to be written: by the tug of war of differing factions and the compromise that will inevitably be reached if the bill is to succeed.

And yet, how are we to decide these matters that affect us all? I should like to finish, provocatively, with a lengthy quotation from a recent lecture delivered by one of the Justices of the Supreme Court, Lord Sumption.

It is true that the political process is often characterised by opacity, fudge, or irrationality, and who is going to defend those? Well, at the risk of sounding paradoxical, I am going to defend them. They are tools of compromise, enabling divergent views and interests to be accommodated. The result may be intellectually impure, but it is frequently in the public interest. Unfortunately, few people recognise this. They expect their politicians to be not just useful but attractive. They demand principle, transparency and consistency from them. And when they do not get these things, they are inclined to turn to courts of law instead. The attraction of judge-made law is that it appears to have many of the virtues which the political process inevitably lacks. It is transparent. It is public. Above all, it is animated by a combination of abstract reasoning and moral value-judgment, which at first sight appears to embody a higher model of decision-making than the messy compromises required to build a political consensus in a Parliamentary system. There is, however, a price to be paid for these virtues. The judicial resolution of major policy issues undermines our ability to live together in harmony by depriving us of a method of mediating compromises among ourselves. Politics is a method of mediating compromises in which we can all participate, albeit indirectly, and which we are therefore more likely to recognise as legitimate.

The essential function of politics in a democracy is to reconcile inconsistent interests and opinions, by producing a result which it may be that few people would have chosen as their preferred option, but which the majority can live with^{vi}.

Concluding thoughts

To sum up, then. We have considered challenging and complex bioethical issues using the ‘Westminster Abbey Institute approach’ of first, creating a Benedictine space of safety and stability, second, subjecting the matter to rigorous moral analysis and third, coming to a decision, which decisionmaking is the responsibility of the lawmakers and the policymakers. What I have not done is to offer absolute rules or principles which trump every other consideration. It is far better to be morally sensitive than to be morally certain. And so I am agreeing with Lord Sumption that, however fallible it may be, Parliament is the place to fashion legislation on these matters. We do well to attend to whom we put there.

ⁱ Philip Shepherd, *New Self, New World: recovering our senses in the twenty-first century*, (Berkeley: North Atlantic Books), 2010 (p 282)

ⁱⁱ Ronald Dworkin, *Taking Rights Seriously*, 1977 (Harvard: Harvard University Press)

ⁱⁱⁱ Sophie Botros and Claire Foster, ‘The moral responsibilities of research ethics committees’, in *Dispatches*, **3**:3, Summer 1993

^{iv} Claire Foster, *The Ethics of Medical Research on Humans*, (Cambridge: Cambridge University Press) 2001

^v R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent); R (on the application of AM) (AP) (Respondent) v The Director of Public Prosecutions (Appellant); R (on the application of AM) (AP) (Respondent) v The Director of Public Prosecutions (Appellant) 25 June 2014

^{vi} Lord Sumption, ‘The Limits of Law’, 27th Sultan Azlan Shah Lecture, Kuala Lumpur, 20 November 2013