Moral Theology: Dodo or Phoenix?

V
Death:
A Point of Definition for Christians in a New Century

A

I have argued that Christian Ethics and Moral Theology will arise, Phoenix like from the ashes, only if Christians learn to place our present moral vocabulary within a larger frame of reference. If you will, Christian Ethics will survive as Christian Ethics only if the present moral vocabulary of our culture is subordinated to a more basic, and distinctively Christian one. Care of the dying, euthanasia and assisted suicide are further issues that lend themselves to making this point.

Why is this the case? In numerous ways, I have located what I believe to be the central point of moral difference between Christians and the political and moral culture in which we live. The point of difference is defined by a view of moral agency that is unanchored in a larger set of beliefs about human nature and destiny. The floating nature of our dominant moral terms (individual, person, and self) produces a sort of bracket creep whereby these terms migrate into areas of human concern where they have no business. One can observe similar phenomena when these terms creep into our beliefs and practices in respect to death and dying. First, however, I must put before us another factor that colors our reactions when we are confronted with these and other similar issues. This is a factor that colors not the way we think but the way we feel.

In *Begotten not Made*, Oliver O'Donovan points out that our confidence in technology carries with it a certain attitude, namely; that human suffering can and ought to be eliminated. Consequently, we feel that the presence of suffering is something we ought to be able to escape. Suffering is not a normal part of the landscape of life; and, as a result, when suffering comes, we have a heightened sense of "compassion" for anyone so afflicted. We feel that things ought not to be this way, and that the conditions that produce the suffering either are or ought to be subject to elimination by whatever means are at hand. So prevalent is this reaction that it is safe to say that "compassion," rather than say endurance or perseverance, has become our chief social virtue.

"Compassion," like "person hood" is such a part of the intellectual and emotional

furniture of our daily lives that we hardly stop to reflect on its meaning and status. No one, myself included, wishes to speak against "compassion." It is a humane and admirable virtue. Nevertheless, it would be well to note with Prof. O'Donovan that "compassion" is not an *intellectual* virtue. It asks *sympathy* from us, but not *thought* and the critical distance thought can bring. As a result, our chief social virtue leads us to respond to the immediacy of other people's lives. It leads us to respond to their suffering, but it does not ask many questions about the means that might be employed to relieve that suffering. It simply wishes the suffering to be removed.

For our purposes, it is important to note that our primary notion of moral agency, "person hood," and our chief social virtue, "compassion," have combined to produce a unique form of public argument about moral matters. I call it the public exposure of private lives as a means of justifying a moral belief or practice. If you will, our chief *fora* for shaping moral opinion are television shows like Oprah. The format on this and other shows like it is always the same. Someone who has suffered gets up in public and tells their story. That story includes the account not only of their suffering but of their exercise of the freedom that "person hood" confers upon them. Their story of suffering and choice immediately evokes the "compassion" of the audience, and any serious discussion of the moral character of the means taken to relieve that suffering is short circuited or omitted altogether. The very format of the discussion means that all attention is focused on the happiness of an outcome.

B.

The problem, of course, is that what we feel does not tell us all we need to know about the morality of our actions. There are things to be *thought* and well as *felt* and, for Christians, some of those things place limits on the directions in which our feelings may rightly lead us. Belief may and indeed ought to limit our expressions of both moral agency and moral sentiment. As a first example of what I mean, let us look for just a moment at what is now becoming standard medical practice in the early stages of pregnancy. There are now batteries of tests to be given to determine the health of a fetus. Their names, though not exactly household words, are nonetheless well known. Any ObGyn can and does offer ultra sound, alpha-fetoprotein, amniocentesis, and chorionic villus sampling. None of these tests can guarantee a normal child, and some of them

carry distinct dangers, but they can detect some normal features like sex and a number of abnormalities like Down Syndrome, neural tube defects, and sickle cell anemia.

If you happen to be the client of a fertility clinic and seek to conceive using IVF there are even more amazing options open for perspective parents. By having an embryo sexed a couple that might pass on Duchenne muscular dystrophy can, for example, discard all male embryos and so insure that the disease will not appear in their child. As more and more genetic markers are detected in the Genome Project, tests will become available to identify these markers and so also the presence or possible presence of things like schizophrenia, manic depression, freckling, myopia and some learning disorders.

The possibilities for prenatal screening and diagnosis seem limitless. Speaking of pre-implantation screening of embryos produced by IVF one researcher said that pre-implantation screening that allows for the discard of genetically tainted embryos has the promise of becoming "the ultimate measles vaccine." One can simply be rid of genetic defects within a generation by extensive prenatal screening and the discard of defective embryos. Another IVF researcher even speculates that there may come a time in the 21st Century when "sex will be for pleasure only" and conception will take place always in a medical setting, namely, in a petri dish.

Enough of these speculations and scenarios from the Sci Fi channel! I want now to focus on the normal means of conception and the more normal forms of screening connected with the earlier stages of pregnancy. I am thinking of such tests as ultra sound, alpha-fetoprotein and amniocentesis. They are significant for our purposes because in these tests birth and death so clearly meet. The fact is that, in looking at life at its beginning by means of these tests, we are often looking in order to end what has just begun

In thinking about prenatal screening and diagnosis, the notion of "person hood" and the virtue of "compassion," though they leave us with more questions than they answer, once more play a large part in shaping public reaction. For some, "persons'' have "reproductive rights" and numbered among these "rights" is the "right" not only to have a child, but also the "right" to do all they can to see that they have a healthy child. For others, the notion of "personhood" and "rights" extends also to the embryo or child in the womb; and so the increasingly common practices of prenatal screening and diagnosis

seem to them to pit the "rights" of one "person" against those of another "person." In the case of prenatal screening and diagnosis, when abnormalities or likely abnormalities are detected, those who think in this way are apt to say that the "right" of the child to life trumps the "reproductive rights" of the parents. There then follows the stand off in respect to abortion with which we are all familiar.

Or again, the important place we give to "compassion" is apt to weigh in, and once more it is difficult to know where it will focus. Will "compassion" lead us to feel that it is not right to force parents to struggle for years, perhaps for the rest of their lives, with a deformed, retarded, pain wracked or dying child? Will "compassion" lead us to say of an afflicted child, it is better that it not be born? Or will "compassion" lead us to take the side of the child yet to be born whose life, short and painful as it may be, might be snuffed out at its very beginning by the genuine but misguided "compassion" of others?

For most of us, I suspect, "compassion," in circumstances where sufferings compete, leaves us simply in a dither. We feel so many conflicting things that we don't really know which way to turn. So what do we do about prenatal screening and diagnosis? There are a number of forces pushing toward making such testing routine. There are, however, a number of cautionary notes now being sounded about these recent developments in medical practice. Among the most alarming is a caution put forward by Barbara Katz Rothman in a Special Supplement to the *Hastings Center Report*. There she points out that her research indicates that prenatal screening has several questionable effects upon prospective mothers. The most serious of these is that these tests do not appear actually to enhance the freedom of prospective mothers in the way supporters claim. Rothman writes:

Yet (she says) it too (like pre-implantation biopsy) moves a sadness, grief, and loss from the realm of ascription, of things that just happen, to the realm of personal responsibility. A woman who chooses not to use the testing has in some sense come to be seen as having 'chosen' to have a child with a disability. In choosing the risk, she is understood to have chosen the condition."

She continues:

We are a culture that values information. Knowledge is power, we say. That can certainly be true. But knowledge can also be disempowering, as I learned from interviews with women who got bad news from amniocentesis. Faced not with a baby with specific, albeit serious problems and needs, but with the potential of such a baby, some felt powerless to cope. Although abortion was experienced, and expressed, (by the women interviewed) not in terms of abortion, but…of killing a baby, it was most often experienced as an 'only choice,' coming out of a sense not of empowerment, but of being trapped.

She then concludes with this question: "Even if we eliminate all issues of abortion, is it empowering for parents to have this kind of information? If you know your child is twice as likely as most to develop a particular cancer, or to be mildly retarded, what exactly are you supposed to do?"

What indeed is one supposed to do? The social forces pushing for more elaborate prenatal testing are enormous and probably ineluctable. Nevertheless, there are more than the somewhat practical reasons I have just mentioned that ought to give Christians pause and lead them to resist, perhaps even to refuse to participate in, the trend. There are, I think, very strong theological factors that once more place brackets about the freedom of "persons" and raise questions about the power of "compassion" to tell us always what we ought to do. These theological factors, at a minimum, push against to easy an acceptance of current practice.

In the first instance, there is much in the direction of our present medical practice that seems to indicate an increasingly common view that deformed or disadvantaged lives are somehow not worth living. In its extreme form this view leads to the legal notion of a wrongful life. For the moment, let us prescind from discussing those diseases like Tay-Sachs, a genetic disease found among Saphardic Jews that involves the painful degeneration of the nervous system, dementia and death by the ages of 3-5, or Lesch-Nyhan syndrome whose even more dreadful symptoms I will discuss later. Because of the physical pain involved, diseases like these may constitute a special case that I will consider when we take a look at euthanasia. For the moment I want to look at our desire

to detect other, less painful but nonetheless limiting, debilitating and eventually fatal conditions like Down Syndrome, sickle cell, or even cystic fibrosis.

Given the Christian view that life both comes from and returns to God, it has, over the ages, proved impossible for Christians to brand any form of life as wrongful or bad. To do so appears to label God's creation bad. Thus, the saints of the church have tended to weep over the suffering that is present in many lives, but their typical reaction has been, not to condemn a suffering life as wrongful but to offer care and comfort in the midst of suffering as a sign not only of God's love but also of the presence of truth, beauty and goodness in the midst of unspeakable pain and suffering. Given these theological convictions and given this history, an elaborate system of screening that excludes injured life from the outset is bound to raise questions as to whether or not these practices are born of a contrary attitude. At worst the contrary attitude might be one that demands a perfect child.

This unwillingness to welcome those who are, as it were, lame from the beginning, indicates, perhaps, a practice that is ill suited to the primary Christian virtue of love. It is quite true that love is connected with sympathy for all forms of human suffering, but the virtue of love, as exhibited in Christ's life and handed over across the centuries in Christian teaching and practice, has always moved the saints, not simply toward general benevolence and compassion but toward both the care and the affirmation of the least advantaged among us. That is, love has found its prismatic expression in care for and affirmation of those from whom we derive no benefit and who are in obvious need, particularly our enemies and those who are weak--the poor, the widow, the orphan, children, the sick, the infirm, prisoners and captives.

C.

I am suggesting that Christian belief will serve in the years to come both to contain the autonomy of "persons," and perhaps redirect the actions prompted by the "compassion" they have for certain particularly significant forms of human suffering. This ability to contain autonomy and shape the expression of "compassion" meets its most sever test, however, in respect to questions concerning care of the dying or chronically ill; and it is to these questions that I wish now to turn.

None of the issues connected with chronic illness or dying are new, but they have

been made more urgent and more complex in recent years by advances in medical knowledge and technology. We can now sustain life far beyond any point we could have imagined 50 years ago. Nevertheless, what we value in one way we dread in another. We all have some fear of spending either the last of our days entubated and hooked up to machines that will not allow us to die even if we want to.

Our heads are filled with newspaper accounts of people so circumstanced and they trouble us greatly. When we read of these cases, what do we tend to think and feel? My observation is that most people my age and older want to remain independent both to preserve our freedom and dignity and to escape becoming a burden to our families and friends. At this point, I want to suggest only that Christian belief raises a number of hard questions about our present ideas, attitudes and practices in respect to chronic illness, dying and death. In the first place, it is difficult for Christians to elevate autonomy in the way it now is, namely, as a human attribute that is so central to our identity that life without it is not worth living. *In respect to our creation*, Christian belief holds that our autonomy, though real, is limited both because we belong to God as his creatures; and because, as human creatures, we, by nature, are dependent both upon God and upon social life with others. This dependence and interdependence, furthermore, are thought to be good. Thus, to claim the autonomy of "person hood" in all dimensions of life, particularly in the hour of death, in fact constitutes, for Christians, a Faustian denial of and reaching out beyond our nature as dependent creatures. It is the case that we come into the world naked and we leave the world naked, and this dependence and interdependence are from God. Dependence and interdependence are just as much a part of the good life God intends for us, as are "person hood" and autonomy.

In the second place, *in respect to our redemption*, Christian belief holds that death is in the world by divine will both as the defining mark of our finitude and as limitation of and judgment upon human pretension. Death is our final and great enemy, but that enemy has been put in the world by divine intent. However, Christian belief holds also that, because Christ has passed through death in utter dependence upon God, death no longer has dominion over life. Christian belief centers in the conviction that in Christ's death and resurrection our bondage to this great enemy has been overcome. Consequently, just as we are to struggle to maintain life because it is good, so also we are

free to relinquish it when it comes to its end.

In the third place, *in respect to reconciliation and our ongoing life in Christ*, Christian belief holds that fellow believers are bound one to another, in Christ, in a way that is so close that it is best described as being "one body." The members of that body owe one another appropriate care in all dimensions of life. After all, as Paul insists, if one suffers, all suffer. To grasp at autonomy in the face of weakness and death is therefore also a refusal to participate in the defining feature of life in Christ, namely, the mutual give and take of love.

Looked at in these ways our attempts to manage our decline and death and to preserve our autonomy through it all do not appear in an unambiguously altruistic light. The encompassing beliefs I have mentioned do not demand, but they do suggest, that, in making arrangements for our last days, we would do better to think of simple advanced directives and medical powers of attorney that place us in the hands of those appointed to care for us than of overly defined wills and pre-arranged funeral arrangements that seek to extend our autonomy even beyond death itself.

Looked at in this way, advanced directives and medical powers of attorney are less expressions of our autonomy and more provisions that allow those who care for us to give up attempts to cure and/or preserve life when such attempts are medically futile or overly burdensome to the patient. They are instruments that allow those in whose hands we lie when we are no longer fully autonomous to refuse to prolong our dying in the name of prolonging our lives. Looked at in this way, advanced directives and medical powers of attorney are expressions of love rather than autonomy—expressions of love that allow those who love us to see that proper care is given us in the time of dying; namely care that provides company in the face of death and seeks to make one comfortable in that hour.

D.

The question, of course, is what if our condition seems to be so bad that it either seems to nullify any reasonable ascription of goodness to the life we have or appears to place us beyond the reach of those who would care for us. At the beginning of life I am thinking of a fetus in whom we might detect Lesch-Nyhan syndrome, or anencephaly. In the first case we know that the child born will live but a short time and during that time

will be subject to terrible forms of self-mutilation. In the case of anencephaly, the child will normally live only for a brief period and will never have powers of reason. At the end of life I think of people who have fallen into a permanently vegetative state or who suffer form intractable pain as *might* be the case with some forms of bone cancer or rheumatoid arthritis. What constitutes appropriate care in circumstances such as these? Might such circumstances warrant ending the life of some one so afflicted?

Before mentioning some of the factors that must be taken into account by Christians when addressing this very topical issue, I must point out and warn against the way in which it is being argued out in the public area. The typical strategy of public advocates of euthanasia and assisted suicide fits well the Oprah model I mentioned earlier. In his recent book on the Dutch experiment with euthanasia and assisted suicide, Herbert Hendin, an opponent of the Dutch practice, points out that in the public battle over euthanasia and assisted suicide picked cases which present goulish and nightmare images are put forward by the advocates of a change in our practice and then represented as typical. There then comes in behind them, as it were under the cover of darkness, a more generalized warrant for euthanasia and assisted suicide—one that includes these actions as legitimate means to deal with chronic illness or with a death thought to be contrary to one's understanding of the integrity of their own life.

It is impossible to ignore the fact that, not unsurprisingly, similar methods of public discussion are at work in ecclesiastical circles. That is, we are apt to jump from a discussion of very hard cases to a more general discussion of a right to end one's life if facing a long illness or an illness that may be thought to rob one of dignity. There then creep into the conversation such notions as a wrongful life, or a life not worth living, or an inability to die with dignity, or a desire to spare one's family the expense and strain of a long illness. I want to suggest that one of the mandates of Christian belief is that our discussions follow a different pattern. That is, we are called upon to address first the more normal circumstances in which we die, and only then move to hard cases. In moral theology, reasoning from hard cases to more usual ones makes for bad morals just as in the law reasoning from hard cases to more normal ones makes for bad law.

Having laid out this way of developing the argument, there are two more things that must be said by way of introduction. The first is that among Christians, and indeed

more generally in the history of Western juris prudence, there is a long tradition that allows one to refuse treatment for oneself even in death dealing situations. Treatments deemed either futile or overly burdensome have never, from either a moral or legal perspective, been required. The second thing to be said, however, is that when we turn to consider the care of people *other than ourselves*, once more our notions about "persons" and "person hood" are likely, at least initially, to dominate our conversation. We will ask if a child with no brain is or ever will become a "person." We wonder if someone in a permanent vegetative state still is a "person," and we judge forms of death involving entubation, artificial nutrition, and hydration along with constant bed care affronts to the dignity of "persons." It is also the case that, when confronted with these cases and others like them, our moral sentiments are directed in no small measure by the virtue of "compassion." When we contemplate the anguish of a person falling into a state of total dementia because of Alzheimer's, or the pain of a child afflicted with Lesch-Nyhan syndrome, or the likely end of a person dying from AIDs, we recoil and wonder if it might not be right simply to end their lives.

There are, of course, a number of practical worries about euthanasia and assisted suicide that are being voiced by people who hold a variety of beliefs. There are many concerns that Christians and others must take into account in the public debate that now rages, but there are theological constraints specific to Christians when these matters are considered. In the first place, they will be suspicious of any attempt to say that because someone either will never or will soon or has now lost their ability to reason they may have their lives ended because they are not or soon will not be "persons." "Personhood" is but one way to describe human beings and for Christians it is not a quality necessary to qualify one for the sanctity God bestows on human life. At the end of their lives, a person with Alzheimer's or a person in a permanently vegetative state isn't much of a "person" any more, but they are people with names and a history who are precious to God and so deserving of our care. At the beginning of life, an anecephaletic child is not in the technical sense a "person" and never will be, but they nonetheless are one of our neediest neighbors—perhaps even a neighbor who experiences more than we know.

I also believe that Christian belief will serve to constrain and direct the expression of "compassion." Even in extreme cases, "compassion" will not lead Christians to the

conclusion that a child with even Lesch-Nyhan syndrome is the possessor of what we now call a wrongful life. To reach this conclusion is to reach the conclusion also that this life is not good to God and I do not see how a Christian can reach this conclusion and yet remain a Christian. Furthermore, Christian belief will constrain those forms of "compassion" that, in the first instance, lead people to seek to end a life that is ending painfully. Belief that the life in question belongs neither to the afflicted person nor to those responsible for their care will press Christians to make every effort, not to end life but to see that adequate palliative care is available for those whose end is painful. An early attempt to prevent or alleviate suffering by doing away with the sufferer will appear as a form of "compassion" to be sure, but as a form of "compassion" that is insufficiently aware of God's dominion over human life, its sanctity, its goodness, of Christ's victory over suffering and death, and of the bonds of love that in imitation of Christ lead us to go with both God and our fellow sufferers into the valley of the shadow of death and there keep company with those of our number who are dying.

In the normal run of things those holding Christian beliefs will be inclined toward doing all they can to provide appropriate care rather than toward eliminating the individual who makes such care necessary. This stance of care in the face of death and human loss goes all the way back to the Jewish roots of Christian belief. Indeed, there is a Jewish teaching that holds "that only disinterested parties may, by even so innocuous a method as prayer, take any action which may lead to premature termination of life. Husband, children, family and those charged with the care of the patient may not (even) pray for death."

But surely, you are thinking, there must be exceptions. There well may be exceptions; but if there are they are rare, and they ought not to be put forward as a general justification for legalizing or giving moral warrant to euthanasia and assisted suicide. They ought not to be justified on the grounds that they end a wrongful life, or that they preserve the dignity of persons who will lose their dignity because of a protracted illness.

If there are exceptions, my own view is that they involve a death so painful and so terrible that they effectively lie beyond our care. If there are exceptions they involve what Michael Walzer has called a "supreme emergency" where in there appears no way

to remedy or ameliorate a simply intolerable situation other than by the performance of an act one normally considers wrong. In the case of Lesch-Nyhan syndrome, one may face such an "extreme emergency" in that the life with which one is presented already lies beyond the reach of human compassion and care. Perhaps in this "supreme emergency" the taking of life is the only way to meet the emergency; perhaps the last and most unexpected way of showing care.

If there is such a case, Lesch-Nyhan syndrome is the most likely candidate I can think of. Lesch-Nyhan is a genetic disease passed on to male children. Children who have it cannot sit up or walk and they suffer uncontrollable spasms. When their teeth appear they will gnaw through their lips, gnaw their hands and shoulders. They often bite off fingers and mutilate any part of their body they can reach.

It may be that such a life indeed constitutes a "supreme emergency." Facing such a circumstance, it may be that we ought to pray for the courage to end the life in question, or for that matter any life that can be regarded as relevantly similar. Notice, I did not say the courage to end a life so terrible and painful that it can no longer be called good. All life is good to God and no contingency upon earth can change that. Christians cannot give up such a belief. Nor can we say with certainty that the pain involved is unendurable. We cannot know what can and cannot be endured any more than we can know that a person in a coma is utterly beyond our care. Notice I did not say either that in ending such a life we ought to feel as if we are taking part in a great humanitarian effort. I said only that we might hope for the courage to do such a deed in what would appear to almost any one a "supreme emergency."

It remains for us to think long and hard about the cases (if any) that might constitute a "supreme emergency" and I believe that we ought to remain vigilant lest we expand this category too easily and too broadly. A discussion of this sort will prove both long and painful, but, whatever its outcome, we cannot, *as Christians*, reason from these hard cases to a general justification of euthanasia and assisted suicide. In the normal course of things, we assume that those at the beginning of life, those at the end of life and those in the shadows of life are to be the particular focus of our care; and that the "compassion" that accompanies our care is limited in its expression by a range of beliefs that concern God's creation and the grace he has shown in our redemption and

reconciliation both with God and with one another. These beliefs will constrain us and lead us to believe that the care we owe the sick, weak and dying among us is the provision of as much comfort and as much company as are possible until life is ended. In the normal course of things we are not called upon to be respecters of "persons" *only*. Nor are we called up to spill our "compassion" randomly. We are rather called upon to see that it is both directed and constrained in its expression by the blessing God has given this good life in creation, by the love he has shown for it and by his victory over its worst enemy, death.

And finally, our beliefs will lead us to see that we cannot decide these very difficult matters on our own. We belong to a people whose calling is in part to plumb the depths of the mystery of God's will, and that exercise we can only do together as members of Christ's body. We cannot do it adequately as independent "persons" with freedom and reason and so rights. We can only do it as members one of another and so guardians of and witnesses to a common way of life—one that imitates in our faltering way the life of the Lord of the church.