SIGNIFICANT BIOETHICAL ISSUES AT THE END OF LIFE

This article discusses the framework for living wills or advance medical directives. From the standpoint of a broad assessment of social cost, the author argues that there is a need to introduce means by which the currency of living wills could be ascertained. The adverse cost implications that could arise from ambiguity in the legal status of the tissue and body of a deceased person are also highlighted. Their disposal could also be made more complex by religious concerns. It is suggested that a legislative response may be the most expedient way forward.

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I. Introduction

1 Death is an inevitable outcome of life and dying is an integral part of the process of living. In many societies and communities, there are different perceptions of dying. These perceptions are shaped by various social, cultural and religious factors. Some of these are peculiar to specific societies and communities. Very often dying is associated with suffering. In other communities, dying is seen as positive as it is seen as bringing about freedom from suffering.

2 Given the inevitability of death and the process of dying, different societies and communities have adopted different modalities to deal with death as well as the process of dying. A major and common goal of such modalities is to provide comfort to the dying as well as his loved ones. A major modality for dealing with death and dying is reliance on religion. Belief that the soul is immortal and would continue despite the termination of earthly existence is a major source of comfort both for the dying as well as his loved ones during the process of dying, as well as after the person's death.

3 An example of a cultural modality to deal with death and the end of life is the traditional Chinese practice of personally preparing for his own death. It was a traditional practice for many Chinese to prepare for their own funerals and afterlife. This can include the purchase of a coffin as well as burial plots, and often burial clothes as well.

4 All the above notwithstanding, in today's world, discussion of death is generally avoided. This is especially so in Asian societies where there is an ingrained belief that discussion of one's own death can only result in "bad luck" and the hastening of the event. The resistance to discussions of death means that death, the end of life, is often ill-prepared for. Singapore is a microcosm of Asia where nearly all Asian societies and communities, including their social and cultural mores, can be found. There is little discussion in Singapore within families as to what is to occur upon the death of a loved one while that person is still living. This means that when the inevitable comes about, the person himself and his family are often unprepared for the many issues that they will be confronted with when that death comes about.

5 It is a truism that evolving technologies, better medical care, and changing social paradigms have resulted in longer life spans. This can only mean that the issues that arise as life approaches termination are now more pronounced. These issues would now have greater impact on the person himself, his loved ones, the society and the nation as a whole. Notwithstanding the lack of public discussions on end-of-life issues, a number of such issues have generated much attention and interest. Foremost are the concerns over the legality and ethics of euthanasia. There are also much concern in the medico-legal literature over palliative care for the terminally ill, particularly the issue of access which often is directly linked to the issue of who is to bear the cost. There have even been attempts to link this with human rights and thereby impose obligations on the State to bear fully or mainly the costs of such care at the end of life. There are considerable concerns over issues such as consent for palliative care and consent by persons who are in a permanently vegetative state. Media reports on difficult instances where such issues arose have also caused the public generally to be sensitive to these issues.

6 The focus of this article will not be on end-of-life issues that have engaged the public or have otherwise been broadly discussed in academic journals. Rather, the article considers issues that have not been generally discussed up to this time. The first relates to the vexed issue of medical and healthcare costs at the end of life, and what modalities are there in the law to mitigate these costs, while the other relates to the disposal of human tissues after death.

II. Costs

7 The process of dying imposes varying degrees of cost on the person, his family and society. These include not just monetary costs but also social and emotional costs. Recent advances in medical technology have brought about numerous benefits and the prolongation of human

life. But these come at a cost which in many instances can be substantial. The fact that these advances have resulted in prolongation of life means, conversely, that the process of dying is prolonged with all the attendant costs.

8 Other important factors that contribute to the increasing cost of healthcare are the expectations on what the healthcare industry can deliver in terms of addressing medical issues, as well as the growth and increasing influence of commercialised medicine. As with any industry, profits are driven largely by demand. Demand can be artificially generated through marketing. It is therefore only natural that the commercialised healthcare industry will seek to generate demand for healthcare services. This is another factor contributing to rising healthcare costs, and the increasing cost of the process of dying which consumes much of an individual's as well as the nation's healthcare costs.

9 The true cost of healthcare is, as with every other cost, the opportunity cost. Resources consumed by healthcare means diversion of these same resources from some other area of need. In the case of healthcare costs at the end of life, resources that are applied to the dying deprive the living of these same resources. Yet it is very difficult to speak about costs when human life is involved. The emotional factors as well as the social and religious mores surrounding human life make meaningful discussion about costs at the end of life not just difficult but perhaps even impossible. No one wants to be seen as deliberately not wanting to continue to attempt to save a human being from death in order to save a few dollars. Thus, there is little to restrain the continuing growth of the cost of healthcare at the end of life.

10 But the resources of any person, family and the nation as a whole are never infinite. The true cost of dying must be balanced with the need to provide for other human (and communal) needs. This requires a meaningful and open discussion among all those who will be impacted by the end-of-life issues. These are not just individuals, all of whom will at some point face the end of life, his family and loved ones, but also the State. Such discussions can result in policies and actions that seek to mitigate the impact of the emotional, social and religious factors that influence the decisions that have to be taken near and at the end of a person's life.

III. Advance Medical Directives

11 One vehicle that can address costs at the end of life is the Advance Medical Directive ("AMD") or Advance Directive. This is often referred to as a "living will". It is a written direction made by a person as

to when further medical treatment should cease to be provided to him. Such an advance direction is crucial where a person is in a state where he is no longer able to speak for himself, such as where he is at the end of his life. Given the principle that all medical treatment requires consent of the patient, where treatment has commenced and the patient has arrived at a state where he can no longer express his will, there is uncertainty whether treatment should or should not continue. Commercial considerations would militate towards continuation of the treatment, notwithstanding its futility. At the same time, those who could otherwise speak for the patient, such as his family members, may be constrained by many emotional and religious factors from taking any decision that may end his life. This can result in high medical and other healthcare costs being needlessly incurred by the person and especially by his family.

12 The AMD provides a means for an individual to speak for himself at a time when he can no longer do so. It thus is a means of empowering a person when he is powerless. It underscores the principle of patient autonomy. It is also a means of ensuring that medical and other healthcare costs which must be borne by his loved ones are not allowed to balloon unjustifiably.

13 In order to be legally effectively and protect the healthcare providers who act on its terms, an AMD must be provided by law. In Singapore, this is set out in the Advance Medical Directives Act.[1] The effect of this legislation is to protect from liability a doctor or a hospital when they give effect to the intention of the maker of the AMD not to continue his medical treatment. However, the effectiveness of an AMD in Singapore is limited by the provision that an AMD can be revoked at any time, but there is no mechanism for determining with certainty and in an expeditious manner whether or not that AMD has been revoked. While an AMD is required to be registered with the Ministry of Health, there is no requirement that a revocation of an AMD must be similarly registered. Thus, at the time when an AMD has to be given effect, which is when the maker can no longer speak for himself, the persons responsible for giving effect to that AMD would not be able to satisfy themselves that there has been no revocation of that AMD. Given that if the AMD has been revoked, they would have to bear any liability that may arise from failing to continue with the medical treatment of the maker of that AMD, a prudent legal adviser will certainly advise that the AMD not be relied on. This is because there is no way to ascertain with certainty whether or not that AMD has been revoked.[2]

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[1] Cap 4A, 1997 Rev Ed.

[2] The Mental Capacity Act (Cap 177A, 2010 Rev Ed) empowers a person to appoint an attorney to make decisions about his personal welfare and matters affecting his

(*cont'd on the next page*)

14 The principle that in the same way that a person can make an AMD at any time, he should also be able to revoke any AMD made by him at any time is attractive. But given the purposes for which an AMD is made, which includes the principle of patient autonomy but also to reduce the burden of medical costs on the maker and his loved ones, and the circumstances when an AMD has to be applied, the failure to provide a mechanism to determine with certainty whether or not that AMD is or is not still valid compromises the very purpose of an AMD. This issue thus requires review.

15 While it is uncharitable to regard the provision in our laws for the making of AMDs as one means to reduce healthcare costs, it is plain that this would be one of its effects. It is one means to mitigate medical and other healthcare costs at the end of life without the need for governmental intervention. But it is difficult to envisage other means of mitigating the growing costs of healthcare and other medical costs at the end of life without some form of governmental intervention. Given the emotional and social factors that attach to human life, and which apply particularly towards the end of life, it is unrealistic that costs can be mitigated by the operation of market principles. In fact, more likely than not, given the rising expectations of the ability of medical technologies to address all ailments, and the pressures of commercialised healthcare, the likelihood is that the application of market principles would result in an explosion, rather than a mitigation, of healthcare costs at the end of life.

16 There appears little option, other than governmental intervention, if healthcare costs at the end of life are to be mitigated. This is especially since ultimately the cost of providing healthcare at the end of life is borne by the State through not just socialised medicine, where provided, but also through the diversion of national resources from other areas of national need.

17 The simplest option open to governments is to introduce measures which effectively ration healthcare with a fixed allocation only for the care of persons at the end of their lives. This conceivably is possible only in countries with socialised healthcare, as other than in such countries, the extent of personal consumption of healthcare is dependent on personal choice and not a matter for state determination. The rationing of healthcare through executive *fiat* would be an extreme measure and plainly will be politically unsustainable except possibly in the most brutal of societies. It will not be acceptable in a society such as

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property and affairs when he no longer has the capacity to make such decisions. This does not affect decisions concerning Advance Medical Directives ("AMD") as s 26(*j*) of the Act expressly excludes AMDs from its operation.

Singapore's. There may also be other options but there are none that would be fully acceptable by all sectors of the citizenry of any nation. Any attempt by a government to introduce measures that seek to limit access to healthcare to any sector of a nation's citizenry will certainly be politically unacceptable. Particularly in democracies, this would be a most difficult policy direction for any government of the day to adopt.

18 However, without firm action by governments to address healthcare costs at the end of life, States and human society as a whole face the possibility that the quality of life and the well being of the majority of its people will be severely diminished because of the diversion of national as well as personal resources towards prolonging the process of dying for those who are at the end of their lives.

IV. Disposal of tissues after death

19 The basic principle in the law of many countries, including Singapore, is that there is no property right in human tissue. This can be seen as stemming from the principle that it is morally reprehensible for one human being to own another. If a person should not be able to own another person, he also should not be able to own parts of another person. This proposition is probably startling for many as most people assume that they own their own bodies. However, the law has moved from its original position during the time when slavery was legal and property rights in humans, which included the right to transfer that property, was recognised.

20 To some extent this principle has been moderated by developments in the law which recognised that property rights can arise in human tissue. In the case of *R v Kelly*,[3] where the defendant stole body parts from the Royal College of Surgeons in London, the English Court of Appeal concluded that this amounted to theft of property since the body parts had been transformed "by virtue of application of skill". The application of skill to these body parts had transformed them into objects that can give rise to property rights. In a sense, the principle that a person cannot own another person was not compromised since the property right in this case attached to the changed human tissue, not the original tissue which was worked on.

21 In recent times, because of the advance of commercialisation, substantial inroads have been made into this principle that there can be no property right in human tissue. In the main, these have been in the area of intellectual property law. One example would be the case of

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[3] [1999] QB 621.

Moore v Regents of the University of California,[4] where the University of California patented a cell line developed from cells extracted from a patient at its hospital without the consent of the patient. An attempt by that patient to obtain remuneration from the University for the profits it obtained from using his cells was dismissed by the court. There are numerous other instances where human tissue had been patented and thus owned by some other person or business. Given the increasing commercialisation of society and the relentless pursuit of profits, it is likely that this trend will continue. There will certainly be more attempts to create inroads into the principle that a person's body is not susceptible to claims for property rights which carries with it the right to profit from and to transfer the ownership of that human tissue. This has created considerable uncertainty as to the instances when property rights can arise in human tissue or parts of a human body.

22 The largest piece of human tissue is the human body taken as a whole. The question whether there can be property rights in a human body can arise acutely after a person's death. The clear rule in law as at this time is that there can be no property right in a human body. However, whoever has possession of the body has an obligation in law to dispose of that body. This rule was introduced obviously for reasons of public health. In the usual case, possession of a deceased person's body at the time of his death would be with the institution where he dies, such as a hospital or hospice, or with his loved ones. As there can be no property in a human body, no one can assert that they have a right to the body for whatever reason and thus have a right to obtain that body for disposal. Since there is no right for such an assertion, the law has not developed any rules for resolving disputes over assertions of rights to a human body.

23 The legal position here reflects not just logic but also social necessity. Death of a loved one can be a very trying time for any family. They deserve support and sympathy, and not be burdened with threats of litigation and the possibility of the remains of their loved one being taken away from them for whatever purpose. But there have been reports of instances in certain countries where religious authorities have successfully asserted that they, and not the deceased's loved ones, have a right to the deceased's body in order to dispose of the body in accordance with their religion. The reports state that this right was asserted because it was alleged that the deceased was a member of that religion, even though his immediate family and loved ones declared that they knew nothing of this fact. In one instance, it was reported that the allegation was that the deceased converted to that religion while he was in a comatose state.

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[4] 51 Cal 3d 120 (1990).

24 Successful claim to a deceased's remains in such circumstances can have drastic consequences for his immediate family. In certain religions, only believers can inherit the property of a deceased person. This is notwithstanding that the deceased has made a will. The fact that a deceased was dealt with in accordance with the rites of that religion provides strong grounds for those who assert that he was at the time of his death a member of that religion. This means that his loved ones can be totally dispossessed from the deceased's estate, notwithstanding the terms of the deceased's will. An extreme situation which can result is that they can be dispossessed of the family home that they have lived in all their lives. This is unless they agree to convert to that religion.

25 While no such reports have arisen about similar instances in Singapore, there is always the possibility that this may come about. This can give rise to considerable uncertainty and concern as to what would be the outcome should such a situation arise.

26 Given the uncertainty and the possibly drastic and tragic outcomes over assertions of rights in human tissue, including the entire human body of a deceased person, the question that arises is whether the law should prescribe who has the right to a person's body after his death? However, for the law to make such a prescription can be seen as embarking on a slippery slope towards creating property rights in human tissues, and the biggest piece of tissue, the human body. This can be regarded as a retrograde step taking human society back to the time when one human being could legally own another, *ie*, during the time when slavery was legal and was the norm.

27 Given the uncertainty in the law as to whether there can be property rights in human bodies and the extent of such rights in human tissues, the issue that requires consideration is whether the law should seek to define in a certain manner what rights can be asserted over a human body, the extent of property rights in human tissues, and the persons who can claim such rights. This would provide certainty on this issue and also mitigate the burden on persons who may be faced with unexpected competing claims over the remains of their loved ones. To achieve this, legislation would be necessary.

28 To a certain extent, the law in Singapore has already recognised that there can be property rights in human tissue and, by extension, to the human body as a whole. The Human Organ Transplant Act[5] provides for the harvesting of certain organs of deceased persons. This is unless that person has opted out of the provisions of this statute. The fact that a statutory power is required in order to harvest the organs of a

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[5] Cap 131A, 2005 Rev Ed.

person after his death, and that the subject can opt out of the application of this power, is an implicit recognition that that person has rights over his own tissues, and by extension, his entire body, after his death.[6]

29 The issue then is whether this recognition should be made explicit with clear rules as to whether there are property rights in human tissue, the extent of these rights, and who are entitled to assert these rights. While the social benefits of such clarity should be clear, the likelihood of such a law being enacted is not. Any proposal to enact such a law would very likely result in pressure being placed on legislators by vested interests, particularly commercial interests, for the rules to be coloured to enable greater commercial exploitation of human tissues. There will also be likely to be pressure from more principled interests for severe restrictions to ensure that society does not regress to the situation in the past when it was normal and legal for one human being to own another and deal with that other person as chattel. Over and above these competing interests, in a society such as Singapore, there may also be calls from certain religious quarters for their authorities to be able to exercise rights over the body of a deceased alleged to be a member of their religion, and for their rights to enjoy primacy over the rights of the deceased's loved ones.

30 The interests that would be aroused by any proposal to legislate on the issue of rights in human tissue and the human body would reflect very strongly held views. These views will surely be advanced with considerable force. Given the political process, legislators must be sensitive to the many competing interests and must consider how these can be reconciled. It may well be that the eventual assessment is that these competing interests cannot be reconciled. This is particularly when views are held and advanced forcefully on religious grounds. In such a case, the feasibility of such a law being promulgated is questionable. But the difficulties in enacting such a law notwithstanding, perhaps the most important consideration for legislators must be whether society can continue with the present uncertainty over the nature of legal rights, if any, in human tissue and the human body generally, after

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[6] Singapore has few legislative provisions regarding the disposal of human tissue after death. The most significant is the Medical (Therapy, Education and Research) Act (Cap 175, 1985 Rev Ed). This Act enables a person and specified relatives to donate all or any part of his body, the gift to take effect upon his death. But the Act does not deal with rights over parts of the body that were not subject to the donation. It merely provides in s 11(2) that after removal of the donated parts, custody of the remainder of the body vests in the surviving spouse, next of kin or other person under obligation to dispose of the body. It does not answer the question who the person under an obligation to dispose of the body is and what rights this person has in that body or parts of that body.

life has ended. This is one important consideration that legislators must not put aside.

V. Conclusion

31 The end of life is a trying time for any person and his loved ones. It gives rise to numerous bioethical as well as legal issues that impact not just that person but his family, his community and the nation as a whole. Many of these issues are defined by societal as well as religious imperatives. The crass commercialisation of the modern age and the expectations generated by advances in medical technologies are certainly major factors that contribute to high medical costs and the prolongation of the process of dying. These costs must be borne by the living. It also means the diversion of resources from other areas of need. Society must determine where the balance of providing for those at the end of life and allocation of resources to other areas of need must be struck.

32 Over and above these, the issue how human tissues, including the body of a person whose life has ended, is to be dealt with is, at this time, uncertain. This can be an added burden to the loved ones of a deceased person at the end of his life. This can be resolved through legislation, but given the strong emotions that any such legislation will generate, it is not likely that this will come about. This means that any dispute over such matters will have to be resolved through litigation. Litigation is an added burden to those who are already bereaved on account of the end of a life. It is also costly and the results are uncertain. Where such disputes involve religion, it can be politically divisive.

33 There appears to be no easy resolution to the many bioethical as well as legal issues that can arise at the end of life.