

THE LAW REFORM COMMISSION OF HONG KONG

REPORT

***SUBSTITUTE DECISION-MAKING AND ADVANCE
DIRECTIVES IN RELATION TO MEDICAL TREATMENT***

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Preface

Introduction

1. *"Making decisions is an important part of life. It empowers people by allowing them to express their individuality. It enables people to control their lives and gives them a sense of self-respect and dignity. However, for some decisions to be legally effective, it is necessary that the person making the decision has a certain level of understanding. The reason for this is very simple: it is to protect against abuse or exploitation of a person who may be made vulnerable by impaired decision-making capacity. It also helps other people who may be affected by a decision to know where they stand."*¹

2. When an individual has the level of understanding sufficient to make a legally binding decision he is said to have the "capacity" to make that decision. In certain circumstances, the individual's capacity to make decisions for himself may be impaired by his physical or mental condition. Decisions may still need to be made, however, particularly when they affect the individual's health and wellbeing. There is therefore a need for the law to provide a mechanism for decision-making where the individual's capacity is impaired.

3. This report is concerned with two specific circumstances, both relating to decision-making for persons who are unable to make those decisions at the time of execution of the associated action. The first relates to decisions made by a third party in respect of the medical treatment and the management of property and affairs of persons who are comatose or in a vegetative state. The second relates to advance decision-making by the individual himself as to the health care or medical treatment he wishes to receive at a later stage when he is no longer capable of making such decisions. The two aspects of the subject can perhaps best be distinguished or contrasted as being concerned with pre-incapacity decision-making (for persons in the second situation) and post-incapacity decision-making (for persons in the first situation).

Terms of reference

4. On 23 March 2002, the Secretary for Justice and the Chief Justice directed the Law Reform Commission:

¹ The Queensland Law Reform Commission Report No 49, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Vol 1(1996), Ch 1, para 3.

"To review the law relating to:

(a) decision-making for persons who are comatose or in a vegetative state, with particular reference to the management of their property and affairs and the giving or refusing of consent to medical treatment; and

(b) the giving of advance directives by persons when mentally competent as to the management of their affairs or the form of health care or medical treatment which they would like to receive at a future time when they are no longer competent,

and to consider and make recommendations for such reform as may be necessary."

The Sub-committee

5. The Sub-committee on Decision-making and Advance Directives was appointed in May 2002 to examine and to advise on the present state of the law and to make proposals for reform. The members of the Sub-committee are:

Hon Mrs Sophie Leung, SBS, JP (Chairman)	Legislative Councillor
Dr Lawrence Lai, JP (Deputy Chairman)	Cluster Chief Executive, Hong Kong West Hospital Authority
Mr Sunny Chan	Senior Government Counsel Law Drafting Division Department of Justice
Dr Ho Kin-sang	Consultant (Family Medicine) Elderly Health Services Department of Health
Dr Patrick Li, BBS	Chief of Service Department of Medicine Queen Elizabeth Hospital
Mr Herbert Tsoi, BBS, JP	Partner Herbert Tsoi & Partners, Solicitors
Mrs Annie Williams	Assistant Official Solicitor Official Solicitor's Office Legal Aid Department

Dr Agnes Yeung

Sociologist

Ms Judy Cheung
(Secretary)

Senior Government Counsel
Law Reform Commission

6. The Sub-committee considered the reference over the course of seventeen meetings between 31 May 2002 and 27 September 2005. On 13 July 2004, in order to seek views and comments from the community, the Sub-committee issued a Consultation Paper setting out its initial proposals on the reference. Over 60 written responses were received, many of these were substantive with practical comments on the issues addressed in the Consultation Paper. While some reservations were expressed about certain of the initial proposals for reform, the proposals were generally welcomed. We will, nevertheless, deal with the specific comments and observations on both the recommendations and the issues discussed in the Consultation Paper in the following chapters.

7. We wish to express our thanks to all those who responded to the Consultation Paper. We would also like to express our particular thanks to the following persons whose advice and assistance have proved invaluable:

Dr P S Shum (former Hospital Chief Executive of Kwai Chung Hospital)

Dr Hung Kin Cheung (Chief of Service, General Adult and Community Psychiatric Service, Castle Peak Hospital)

Professor Chin Hin Chew (former Chairman of the National Medical Ethics Committee, Singapore)

Chapter 1

The concept of capacity and decision-making

Concept of capacity

1.1 It is presumed at common law that an adult has full capacity unless it is shown that he or she does not. The present law offers a number of tests of capacity depending on the type of decision in issue. Case-law provides answers in some circumstances, and individual statutes contain provisions on capacity in others. However, it is important to distinguish between the *legal* concept of capacity or incapacity and the *medical* concept of capacity or incapacity. They may well coincide for certain people in certain contexts, but sometimes they do not.

1.2 A legal incapacity arises whenever the law provides that a particular person is incapable of taking a particular decision, undertaking a particular juristic act, or engaging in a particular activity. Incapacity can arise from a variety of conditions. Historically, these included being under the age of majority, or a married woman, or of unsound mind. Under current law, a great many different approaches have developed to the question of capacity based on mental state, and capacity is judged in relation to the particular decision or transaction involved. There is also a basic common law test of capacity, to the effect that the person concerned must at the relevant time understand in broad terms what he is doing and the likely effects of his action. Thus, in principle, legal capacity depends upon understanding rather than wisdom; the quality of the decision is irrelevant as long as the person understands what he is deciding. However, the basic test has been adapted *ad hoc* to meet specific situations and the precise test now employed by the common law or statute may differ according to the situation. The English Law Commission pointed out in its 1991 Consultation Paper on mentally incapacitated adults that the Mental Health Act 1983 itself contains different approaches, with that adopted for compulsory admission to hospital differing from that applied to guardianship and the management of property and affairs.¹ The Commission said:

"Statutory tests for other purposes may resemble the diagnostic categories set out in the Mental Health Act 1983 or may follow the common law principles or may not greatly resemble either. For certain purposes, such as compulsory admission to hospital, a test may include people who are quite capable of taking the decision, in the sense that they understand what it is and what it will mean, but are nevertheless suffering from such a degree of

¹ The English Law Commission Consultation Paper No.119, *Mentally Incapacitated Adults and Decision-Making: An Overview* (1991), at 19-20.

*mental disorder that it is thought appropriate to take the decision out of their hands, either in their own interests or for the protection of others. ... A lawyer might say that such people were legally incapacitated from deciding whether or not to remain in hospital. Others, however, might draw a distinction between those who are unable to take any decision at all and those whose particular delusional system, lack of insight or otherwise abnormal mental state leads them to take irrational or unwise decisions."*²

1.3 Turning to the capacity required under the Mental Health Act 1983 for the management of property and affairs, the English Law Commission observed:

*"The powers of the judge or Master of the Court of Protection are exercisable when the court is satisfied, after considering medical evidence, that 'a person is incapable, by reason of mental disorder, of managing and administering his property and affairs [Mental Health Act 1983, s.94(2)]'. The definition of mental disorder is the very broad one ... but the emphasis is on assessment of functional capacity rather than diagnostic categories. Specialist medical evidence is not statutorily required, although it may be necessary if the issue is disputed. Where conflicting medical evidence is presented, it is for the court to decide which to prefer."*³

1.4 Decision-making capacity is not a medical or psychological diagnostic category; it rests on a judgement of the type that an informed person might take.⁴ If the issue of capacity comes before a court because there is a dispute or because a legal determination of capacity is required for some purpose, the judge makes his determination not as a medical expert but as a lay person on the basis of evidence from the patient's doctors, others who know him, and possibly from personal observation.⁵

Causes of mental incapacity

1.5 Mental incapacity may arise from a number of different causes. It may be caused by:

- a congenital intellectual disability
- brain damage brought about by injury or illness
- dementia

² The English Law Commission Consultation Paper No.119, *Mentally Incapacitated Adults and Decision-Making: An Overview* (1991), at paras 2.10-2.11.

³ Above, at para 2.15.

⁴ U.S.A. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, *Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient – Practitioner Relationship*, Vol.I (1982), at 172.

⁵ *Making Health Care Decisions*, above, at 172.

- a psychiatric condition
- substance abuse

Dementia

1.6 Dr Mavis Evans, Consultant Psychiatrist in Old Age of Clatterbridge Hospital in the United Kingdom, in her article *Dementia*⁶ described dementia as "*a global impairment of intelligence, memory and personality, in clear consciousness*". Her view is that dementia can occur at any age but becomes more frequent with age, with a prevalence of 5% - 10% in persons over 65 and 20% in persons over 80. She has also listed various diseases which are associated with dementia. These include:

- Alzheimer's disease
- Lewy Body disease
- Multi infarct dementia (arteriosclerotic dementia)
- Alcoholic dementia
- AIDS related dementia
- Parkinson's disease
- Toxic or traumatic injury
- Malignant disease

Dr Evans adds that dementia is a descriptive name for the group of symptoms and signs seen in these conditions.

1.7 The 1999 report prepared by the Working Group on Dementia ("the 1999 report") set up by the Elderly Commission in Hong Kong has similar observations regarding the causes, signs and symptoms of dementia:

"[It] is a pathological state characterised by gradual decline in intellectual function that occurs in clear consciousness. It is not a process of normal ageing. It is a disease.

2. There are many causes for dementia. The commonest cause is Alzheimer's disease, an irreversible degenerative disorder of the brain, followed by vascular dementia. Commonest reversible causes are drugs, depression and metabolic causes like hypothyroidism. Risk factors for Alzheimer's disease include ageing, family history of dementia and Down's syndrome. Other possible risk factors include head injury.

⁶ Green (ed), *Psychiatry in General Practice* (Kluwer Academic Publishers, 1994) at <<http://www.priory.com/dem.htm>>.

3. *The typical clinical course in dementia is progressive decline in mental and physical functions, leading to total dependence on others and requiring multiple levels of services. The course is variable and can last up to 15 years. The average survival is 8-10 years.*"⁷

1.8 The 1999 report further outlined four stages of the clinical course of dementia:

- "(a) *Very early stage – mild memory impairment, subtle personality changes, diminished interest and skills, emotional distress*
- (b) *Early stage – more severe memory impairment (especially short-term memory for recent events), and deterioration in self control*
- (c) *Middle stage – common problems include wandering, language impairment, disturbing behaviour, delusions and incontinence*
- (d) *Late stage – loss of physical agility, becomes bed bound.*"⁸

1.9 The 1999 report also remarked that up to 70% of persons suffering from dementia, apart from suffering from gradual cognitive decline, also develop non-cognitive symptoms of dementia. Such non-cognitive symptoms include personality changes, delusions, hallucinations, depression and behavioural problems.

Elderly dementia in Hong Kong

1.10 In line with global trends, Hong Kong's population is rapidly aging. The 1999 report noted that the number of those aged 65 or above in 1981 was 334,000, and this elderly population had increased to 690,000 by 1998. This figure was said to represent 11% of the total population. The report further said that this rising trend was expected to continue. This projection was supported by the statistical data released by the Census and Statistics Department, which revealed that the number of those aged 65 or above at the end of 2004 was 829,300. This figure represented 12% of the total population.⁹ The 1999 report also projected that by 2016, the number of elderly persons in the population would reach 1,080,000, amounting to about 13% of the total population. Again, this is in line with the population projections¹⁰ released by the Census and Statistics Department, which show those aged 65 and above would rise to 26.8% of the total population by 2033.

⁷ *Report of the Working Group on Dementia* (July 1999), Chapter 1, paras 1-3.

⁸ *Report of the Working Group on Dementia* (July 1999), Chapter 1, para 3.

⁹ <http://www.info.gov.hk/censtatd/eng/hkstat/fas/pop/by_age_sex.htm>, (18 May 2005).

¹⁰ *Hong Kong Population Projections 2004-2033*, p.37.

1.11 The 1999 report referred to a 1997 study¹¹ which found that 25% of those aged 60 and above had some degree of cognitive impairment. The 1999 report further said that the findings of a survey at 57 care and attention homes conducted by the Hong Kong Council of Social Services in 1997 were that, out of the 6,116 residents, 2,261 (about 37%) had cognitive impairment. And another survey in 25 day care centres for the elderly conducted by the Hong Kong Council of Social Services in 1998 revealed that, out of the 1,111 clients, 251 (about 22.6%) had cognitive impairment. The 1999 report also indicated that the findings of these surveys of an overall prevalence of moderate to severe dementia in those aged 65 and above of 4% were similar to the rates found in other countries. The findings of these surveys, however, appear to be at odds with the analysis of the National Long Term Care Surveys (NLTCs)¹² in the USA, which revealed that dementia cases had decreased from 1.3 million (4.7%) in 1982 to 0.9 million (2.5%) in 1999, and that a million fewer cases were found in 1999 than had been predicted by the 1982 rate. The analysis concluded that more recent cohorts were less likely to suffer severe dementia in old age, despite their longer life expectancy.

1.12 Nevertheless, the rapidly aging population will mean that the needs of the elderly, in terms of welfare and health care, will become an increasingly important issue. The legal problems that stem from health care and medical treatment of the elderly will inevitably arise, particularly when they are, or are becoming, mentally incapacitated by reason of illness or physical injury.

1.13 In the light of the observations made in the 1999 report, the Elderly Commission's Working Group on Dementia¹³ recommended the promotion of enduring powers of attorney and guardianship. It also suggested that the concept of advance directives be studied in the longer term.

Coma

1.14 In relation to the term "coma", the Brain Injury Association of America provides this helpful explanation:

"Coma is defined as a prolonged state of unconsciousness. The person does not respond to external stimuli. There is no speech, the eyes are closed, and the person cannot obey commands.

When persons experience a brain injury, they can lose consciousness. When the unconscious state is prolonged, it is termed a 'coma'. A coma is a continued unconscious state that can occur as part of the natural recovery for a person who has

¹¹ *Community Survey of the Study of the Needs of Elderly People in Hong Kong for Residential Care and Community Support Services*, conducted by Deloitte and Touche Consulting Group.

¹² Elizabeth H. Corder and Kenneth G. Manton, *Change in the Prevalence of Severe Dementia among Older Americans: 1982 to 1999* (Duke University, Centre for Demographic Studies).

¹³ Comprising members of the Elderly Commission, medical and welfare professionals, academics and representatives from Government departments.

*experienced a severe brain injury. While in a coma, a person can continue to heal and progress through different states of consciousness. Persons who sustain a severe brain injury and experience coma can make significant improvements, but are often left with permanent physical, cognitive, or behavioural impairments. A coma can last days, weeks, months, or indefinitely. The length of a coma cannot be accurately predicted or known."*¹⁴

Vegetative state

1.15 In 1994, the House of Lords Select Committee on Medical Ethics recommended that the acronym "PVS" (used to denote both "persistent" and "permanent" vegetative state) should be defined and that a code of practice should be developed relating to its management.¹⁵ A working group was subsequently convened by the Royal College of Physicians and endorsed by the Conference of Medical Royal Colleges and their faculties of the United Kingdom. Richard S Harper, a District Judge of the Principal Registry of the Family Division, made a succinct summary of the Working Group's findings:

"The Working Group recognises that the commonly used acronym 'PVS' can denote either the 'persistent vegetative state' or the 'permanent vegetative state' and could thus lead to confusion. It is therefore recommended that the following terms and definitions should be used:

The vegetative state

A clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which may simulate sleep and waking. This may be a transient stage in the recovery from coma or it may persist until death.

The continuing vegetative state (CVS)

When the vegetative state continues for more than four weeks it becomes increasingly unlikely that the condition is part of a recovery phase from coma and the diagnosis of a continuing vegetative state can be made.

The permanent vegetative state (PVS)

A patient in a continuing vegetative state will enter a permanent vegetative state when the diagnosis of irreversibility can be established with a high degree of clinical certainty. It is a

¹⁴ <<http://www.biausa.org/Pages/Coma.html>> (4 April 2003), p1.

¹⁵ House of Lords, *Report of the Select Committee on Medical Ethics*, Session 1993-4, London: HMSO, 1994, (HL Paper 21-I).

*diagnosis which is not absolute but based on probabilities. Nevertheless, it may reasonably be made when a patient has been in a continuing vegetative state following head injury for more than 12 months or following other causes of brain damage for more than six months. The diagnosis can be made at birth only in infants with anencephaly or hydranencephaly. For children with other severe malformation or acquired brain damage, observation for at least six months is recommended until lack of awareness can be established."*¹⁶

1.16 Judge Harper also set out the preconditions for diagnosis of PVS:

*"There shall be an established cause for the condition. It may be due to acute cerebral injury, degenerative conditions, metabolic disorders or developmental malformations."*¹⁷

Problems of decision-making disability

1.17 The Queensland Law Reform Commission pointed out the problems which decision-making disability may present:

*"Where a person with a decision-making disability is unable to make a decision alone, he or she may be able to make that decision with an appropriate level of assistance However, some people have a decision-making disability which impairs their decision-making capacity to such a degree that they lack legal capacity to make some or all of their own decisions, either alone or with assistance It may mean that the person is unable to make legally effective decisions about matters such as personal welfare and health care, and financial and property management. Yet certain decisions may have to be made: the person concerned may need medical treatment, for example, or it may be necessary to sell the person's home to arrange alternative accommodation. The problem that arises is that no one has an automatic right to make decisions on behalf of another adult, no matter how closely the two are related [A] decision-maker for an adult with impaired decision-making capacity must be legally authorised to act on behalf of the other person before the decision-maker's decisions have any legal force."*¹⁸

¹⁶ *"Medical Treatment and the Law: The Protection of Adults and Minors in the Family Division"* [1999] Fam Law, p 133.

¹⁷ *"Medical Treatment and the Law: The Protection of Adults and Minors in the Family Division"* [1999] Fam Law, p 133.

¹⁸ The Queensland Law Reform Commission Report No 49, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Vol 1(1996), Ch 1, para 3.

1.18 The present law, which is examined in detail in Chapters 3 and 4, is unclear as to who has authority to authorise medical treatment in the case of comatose or vegetative persons, or to manage the property and affairs of the individual in the absence of an enduring power of attorney (which is considered further in Chapter 3 of this paper). In relation to advance directives given by persons when mentally competent as to the form of health care or medical treatment which they would like to receive at a future time when they are no longer competent, there is at present no legal framework to give force to such advance decision making.

Chapter 2

The concept of advance directives

Advance directives

2.1 The concept of advance directives has been explained as follows:

*"An advance directive for health care is a statement, usually in writing, in which a person indicates when mentally competent the form of health care he/she would like to have in a future time when he/she is no longer competent. The development of advance directives is largely derived from the principle of informed consent and the belief in a person's autonomy in health care decisions."*¹

2.2 The University of Michigan Health System provides the following elaboration of the concept of advance directives:

"Advance directives are written instructions about your future medical care. They do not go into effect until you are no longer able to make decisions. Advance directives have several functions:

- *They allow you to decide ahead of time what medical procedures you do or do not want. This usually involves decisions about breathing machines, CPR [cardiac pulmonary resuscitation], food, water, and medicines.*
- *They help your family make decisions.*
- *They make sure your wishes are followed if they are different from your family's wishes."*²

2.3 An advance directive about health care can also be explained as an "anticipatory decision" about health care which is intended to have effect even if a patient loses the capacity to make such a decision at some future time. Some commentators use the term "living will"³. The key issue arising

¹ Helen FK Chiu, SW Li, *Advance Directive: A Case for Hong Kong*, Journal of the Hong Kong Geriatrics Society, Vol 10, No. 2, July 2000, at 99.

² <http://www.med.umich.edu/1libr/aha/aha_medicald_sha.htm>, (18 May 2005).

³ In the course of the House of Lords debate on the Report of the Select Committee on Medical Ethics, Lord Allen of Abbeydale suggested that the description "living will" reflected an American gift for "phrases which defy intellectual analysis" (Hansard (HL) 9 May 1994, vol 554, col 1363). Lord McColl of Dulwich suggested that "declaration" should be used instead of "directive" which, meaning "an order, an issue of command", is technically incorrect. (As above, col 1372).

from this legal concept is the nature and legal effect of the views which have been expressed by the person concerned. It must be emphasised that there is a clear distinction between the legal effect of an advance expression of views and preferences on the one hand, and an advance decision on the other. If the patient has in fact made an advance decision then a further important distinction is to be drawn between the legal effect of a decision *in favour of* a particular (or all) treatment and a decision *against* such treatment.⁴

2.4 In his article in the British Medical Journal, George S Robertson (Consultant in the Department of Anaesthesia at Aberdeen Royal Infirmary) has the following comments:

*"It is now accepted that a patient who is adequately informed and mentally competent has the right to refuse any proposed medical treatment provided that the refusal does not create a hazard to the health of others."*⁵

And

*"[b]ecause elderly people are living longer the incidence of illnesses that cause dementia is increasing, and commentators have singled out dementia as being 'the most common condition for which an advance directive would be appropriate'. The greatest demand for advance directives will probably come from elderly people who are still competent."*⁶

2.5 Dr Robertson made the following observations at the conclusion of his article:

*"Decisions to limit treatment are an increasingly common feature in the clinical management of patients towards the end of life, and not necessarily only in hospitals with high technology facilities. Advance directives allow patients to influence these decisions by expressing a personal view of the balance between the quality and duration of life."*⁷

2.6 Advances in clinical treatment and in life-sustaining technologies have prompted debate as to whether the use of life-supporting machines is justified in medically "hopeless" cases, such as those who are terminally ill, or in a persistent vegetative state. The relatives of some of those patients and individual physicians may feel strongly that they should "do everything possible" to prolong life whatever the circumstances, as long as adequate technology is available.

⁴ English Law Commission, *Report on Mental Incapacity* (1995) Law Com No 231, at para 5.1.

⁵ *Making an advance directive*, British Medical Journal, 1995; 310:236-238, at <<http://bmj.com/cgi/content/full/310/6974/236>> (23 July 2003).

⁶ *Making an advance directive*, British Medical Journal, 1995; 310:236-238, at <<http://bmj.com/cgi/content/full/310/6974/236>> (23 July 2003).

⁷ *Making an advance directive*, British Medical Journal, 1995; 310:236-238, at <<http://bmj.com/cgi/content/full/310/6974/236>> (23 July 2003).

2.7 It is worth noting that in 1999 the Council of Europe adopted the following recommendation:

*"... The Assembly ... recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects ... by protecting the terminally ill or dying person's right to self-determination, while taking the necessary measures ... to ensure that a currently incapacitated terminally ill or dying person's advance directive or living will refusing specific medical treatments is observed."*⁸

2.8 The issues in the debate can be summarised as follows:

"No reasonable arguments have been made that medical professionals shall make final decisions about how long a patient shall live. But, then, who shall make those decisions? Should a professional culture, whether medical or legal, have the final word in making crucial decisions, and to what extent can the law ever have an effective steering function in areas of highly technical decision making and judgement?"

Traditional physician ethics of beneficence mandated that the beneficent expert combine ethics and expertise in the craft, making life-and-death decisions without burdening others, particularly the patient, with conflicts in decision making. Such a position made much sense in times when medical possibilities were limited and views of life and death were more or less uniform within the community. But in modern societies, rich with diverse values and wishes manifest in individual expressions and convictions, there is no longer a uniform, general answer to the question of when life-supporting medical interventions should cease. ...

All cultures and traditions accept that individuals should not be treated against their will, that is, without giving consent. Weaker and stronger concepts of 'informed consent' principles have made it into the textbooks of ethics and medicine and the paragraphs of law books and court decisions. But what about those who cannot give consent because of infirmity, anxiety, dementia, coma, or incompetence? Who shall decide for them, the physicians, the family, or procedural standards set up by providers or payees of medical services? Here is where advance health care planning and surrogates for health care decision making come in. The following question also arises: How much self-determination and power to direct care and treatment decisions can be entrusted to those who are no longer

⁸ Recommendation 1418: "Protection of the human rights and dignity of the terminally ill and the dying", <<http://assembly.coe.int/documents/adoptedtext/ta99/erec1418.htm>> (18 September 2003).

competent in the strict legal sense? ...

... in cultures where self-determination and individual autonomy and choice play a primary role in day-to-day life, competent and risk-aware adults will favour the execution of medical care directives in advance just as they write wills and employ other strategies, legal and nonlegal, to reduce future risk that their wishes will not be carried out."⁹

⁹ Hans-Martin Sass, Robert M Veatch and Rihito Kimura (eds), *Advance Directives and Surrogate Decision Making in Health Care* (The Johns Hopkins University Press,1998), Introduction.

Chapter 3

Mentally incapacitated persons: existing statutory provisions

Introduction

3.1 In this chapter, we examine the existing statutory provisions which aim to provide protection for mentally incapacitated persons in respect of their health care, their consent to medical treatment, and the management of their property. The shortcomings and other areas of concern in the law in this context will be considered later in this report.

3.2 We have seen in chapter 1 that mental incapacity may be caused by disease or physical injury. As pointed out earlier, Hong Kong's population is rapidly ageing and there is a significant incidence of moderate to severe dementia in those aged 65 and above. A survey conducted by Deloitte and Touche Consulting Group in 1997 found that in the elderly population, 25% of those aged 60 and above had some degree of cognitive impairment. These findings highlight the problem of decision-making for mentally incapacitated persons in respect of their health care, medical treatment, and the management of their property and affairs.

3.3 Obviously, the question of decision-making applies equally to persons who are comatose or in a vegetative state. The need for decisions to be made in relation to such persons' health care and medical treatment, as well as the management of their property and affairs, arises almost daily. The Queensland Law Reform Commission has pointed out:

*"The problem that arises is that no one has an automatic right to make decisions on behalf of another adult, no matter how closely the two are related. ... [A] decision-maker for an adult with impaired decision-making capacity must be legally authorised to act on behalf of the other person before the decision-maker's decisions have any legal force. ..."*¹

Mental Health Ordinance (Cap 136)

3.4 In Hong Kong, the statute law relating to mental incapacity is principally consolidated in the Mental Health Ordinance (Cap 136). The key parts of the Mental Health Ordinance for our purposes are:

¹ The Queensland Law Reform Commission Report No 49, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Vol 1 (1996), Ch 1, para 3.

- Part II, which deals with the management of property and affairs of mentally incapacitated persons;
- Part IVA, which provides for a Mental Health Review Tribunal;
- Part IVB, which provides for Guardianship; and
- Part IVC, which regulates consent to medical and dental treatment.

3.5 The Mental Health Ordinance contains a range of provisions that deal with the property and affairs, as well as medical and health care, of persons who are mentally incapacitated. As stated in its long title, the Ordinance provides for the following:

- (a) the care and supervision of mentally incapacitated persons;
- (b) the management of the property and affairs of mentally incapacitated persons;
- (c) the reception, detention and treatment of mentally incapacitated persons who are mentally disordered persons or patients;
- (d) the guardianship of mentally incapacitated persons who are mentally disordered persons or patients, and for mentally incapacitated persons generally;
- (e) the giving of consent for treatment or special treatment in respect of mentally incapacitated persons who have attained 18 years of age; and
- (f) the removal of objectionable terminology relating to mental incapacity in other statutory provisions and to provide for matters incidental or consequential thereto.

3.6 "Mental incapacity" is defined in section 2 to mean "mental disorder" or "mental handicap." Section 2 defines "mental disorder" as:

- "(a) *mental illness;*
- (b) *a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned;*
- (c) *psychopathic disorder; or*
- (d) *any other disorder or disability of mind which does not amount to mental handicap."*

"Mental handicap" means "*sub-average general intellectual functioning with deficiencies in adaptive behaviour*".² Also relevant to interpretation is the meaning of "patient" in section 2, which is defined as "*a person suffering or appearing to be suffering from mental disorder*".

Management of property and affairs of mentally incapacitated persons

Court's power

3.7 Part II of the Mental Health Ordinance generally empowers the court, on application, to make an order directing enquiry as to whether any person who is alleged to be mentally incapacitated is incapable, by reason of mental incapacity, of managing and administering his property and affairs.³

3.8 The other key provisions of Part II of the Mental Health Ordinance are:

- the application may be made by any relative of the person alleged to be mentally incapacitated, but if no such application is made by a relative, then it may be made by the Director of Social Welfare, the Official Solicitor, or any guardian of that person appointed under Part IVB,⁴
- the application must be accompanied by two medical certificates and evidence from the mentally incapacitated person's relatives or next-of-kin and such other evidence as may be required by the Court,⁵
- the Court may with respect to the property and affairs of a mentally incapacitated person, do or secure the doing of all such things as appear necessary or expedient for the maintenance or other benefit of that person, or otherwise for administering the mentally incapacitated person's property and affairs,⁶
- the Court has the power to make such orders and give such directions as it thinks fit for the control and management of any property of the mentally incapacitated person; the sale, acquisition, and settlement of any property of the mentally incapacitated person; the execution for the mentally incapacitated person of a will making any provision; and the conduct of legal proceedings in the name of the mentally incapacitated person or on that person's behalf,⁷

² See section 2.

³ Section 7(1).

⁴ Section 7(3).

⁵ See section 7(5).

⁶ Section 10A(1).

⁷ See section 10B(1).

- in cases of emergency, where the Court is of the opinion that it is necessary to make immediate provision for the person's property and affairs, the Court may do so pending the determination of the question as to whether that person is so incapable,⁸
- the Court may appoint a committee of the estate, and for this purpose, the Official Solicitor may be so appointed to do all such things in relation to the property and affairs of the mentally incapacitated person and may make such order as to the remuneration of the committee out of the person's estate, and as to the giving of security by the committee, as to the Court may seem fit,⁹
- the Registrar of the High Court may without an order of reference, receive any proposal and conduct any inquiry respecting the management of the estate of a mentally incapacitated person if such proposal relates to any matter which the committee of the estate has not been empowered by an order of the Court to dispose of,¹⁰
- if it appears to the Court that the mental incapacity of a mentally incapacitated person is of a temporary nature, the Court may direct that his property (or part of it) be applied to make temporary provision for his maintenance or the maintenance of his family, instead of appointing a committee of the estate,¹¹
- when after inquiry the Court finds any person to be mentally incapacitated and incapable, by reason of mental incapacity, of managing and administering his property and affairs, the Court may recommend the applicant under Part II to make an application for a guardianship order under Part IVB,¹²
- the Court may, on application, vary any powers of a committee of the estate or replace the committee. An application may be made by any relative of the person alleged to be mentally incapacitated, or if no application is made by a relative, by the Director of Social Welfare, or the Official Solicitor, or any guardian of that person appointed under Part IVB, or the relevant committee,¹³ and
- a review mechanism is also provided in Part II. Where, following inquiry, the Court finds that a mentally incapacitated person has become capable of managing his affairs, the medical

⁸ See section 10D.

⁹ See section 11.

¹⁰ Section 13(1).

¹¹ Section 25.

¹² Section 26A.

¹³ See section 26B.

superintendent of the mental hospital must refer the case to the Mental Health Review Tribunal.¹⁴

Guardianship Board's power

3.9 Part IVB of the Mental Health Ordinance deals with the guardianship of mentally incapacitated persons, and the establishment and role of the Guardianship Board. The Board is a body corporate,¹⁵ which considers and determines applications for the appointment of guardians of these persons who have attained the age of 18 years.¹⁶

3.10 A guardianship application may be made on the grounds that a mentally incapacitated person who has attained the age of 18 is suffering from mental disorder of a nature or degree which warrants his reception into guardianship, and that it is necessary in the interests of his welfare or for the protection of other persons.¹⁷ Such an application must be accompanied by, and founded on, the written reports of two registered medical practitioners.¹⁸

3.11 After conducting a hearing into any guardianship application, the Guardianship Board takes account of any representations by persons present at the hearing and considers the social enquiry report prepared by the Social Welfare Department.¹⁹

3.12 The Guardianship Board makes (and reviews) guardianship orders regarding the care and welfare of mentally incapacitated persons upon the application of the following persons:

- "(a) a relative of the mentally incapacitated person;*
- (b) a social worker;*
- (c) a registered medical practitioner; or*
- (d) a public officer in the Social Welfare Department, ..."²⁰*

3.13 The Guardianship Board gives directions to guardians as to the nature and extent of guardianship orders.²¹ In exercising its functions, the Board must ensure that the interests of the mentally incapacitated person are promoted, and that his views and wishes (so far as they can be ascertained) are respected, though these may be over-ridden where the Board considers that that is in the interests of the mentally incapacitated person.²²

¹⁴ See sections 27 and 28.

¹⁵ Section 59J.

¹⁶ Section 59K(1)(a).

¹⁷ See sections 59M(1) and (2).

¹⁸ Section 59M(3).

¹⁹ See section 59O.

²⁰ See section 59N(1).

²¹ See section 59K(1)(d).

²² Section 59K(2).

3.14 A guardianship order may confer on the guardian the power to hold, receive or pay such monthly sum for the maintenance or other benefit of the mentally incapacitated person as if the guardian were a trustee of that monthly sum.²³

3.15 In addition to this power, a guardianship order may also confer on the guardian the power to specify the place where the mentally incapacitated person must reside, and the power to specify, and consent to, medical and dental treatment for the mentally incapacitated person.²⁴ The powers which may be exercised under a guardianship order in respect of medical treatment are set out at section 59R(3)(c) to (e):

- "(c) the power to require the mentally incapacitated person to attend at places and times so specified by the guardian for the purpose of treatment or special treatment ...*
- (d) the power to consent to that treatment (other than special treatment) on behalf of the mentally incapacitated person but only to the extent that the mentally incapacitated person is incapable of understanding the general nature and effect of any such treatment; [and]*
- (e) the power to require access to the mentally incapacitated person to be given, at any place where the mentally incapacitated person is residing, to any registered medical practitioner, approved social worker, or other person (if any) specified in the order ..."*

Medical care and treatment

3.16 It should be noted that section 26 (under Part II) of the Mental Health Ordinance also empowers the court to make an order for a mentally incapacitated person to be sent to a mental hospital.²⁵ This would of course depend on his mental condition as revealed by the relevant medical certificates.

3.17 If a person appears to require treatment in a mental hospital and if he is desirous to receive such treatment, he may lodge an application with a medical superintendent who may admit him as a voluntary patient.²⁶

3.18 An application may be made to a District Judge or magistrate for an order for the detention of a patient for observation on the grounds that the patient is suffering from mental disorder of a nature or degree which warrants his detention in a mental hospital for observation and that he ought to be so detained in the interests of his own health or safety or with a view to the

²³ See section 59R(3)(f).

²⁴ See section 59R(3).

²⁵ See section 26.

²⁶ See section 30.

protection of others.²⁷ This application must be founded on the written opinion of a registered medical practitioner who has examined the patient within the previous 7 days.²⁸

3.19 A medical superintendent may detain in a mental hospital for observation, investigation and treatment any person who is the subject of such an order.²⁹ An elderly person who is considered to be mentally incapacitated under the Mental Health Ordinance may in such a case receive treatment for his mental condition in a mental hospital, if his condition also warrants such detention, observation and treatment.

Provisions governing consent

3.20 Sections 59ZB to 59ZK of Part IVC make provision for the giving of consent to the medical, dental or "special" treatment of a mentally incapacitated person who has attained the age of 18 years and is incapable of giving consent to that treatment. "*Special treatment*" is defined by section 59ZA as medical or dental treatment "*of an irreversible or controversial nature*" as specified by the Secretary for Health, Welfare and Food. Before specifying that a particular treatment is "*special treatment*", the Secretary for Health, Welfare and Food is required to consult the Hospital Authority and "*other appropriate bodies*", which include the Department of Health, the Hong Kong Medical Association and the Hong Kong Dental Association.³⁰

3.21 As was pointed out earlier, consent to the carrying out of treatment may be given by the guardian in respect of whom a guardianship order has conferred the power to consent. Consent may also be given by the Court under Part IVC.³¹

3.22 The Court or the guardian must apply certain principles when considering whether or not to give consent to the carrying out of treatment. They must:

- (a) ensure that the mentally incapacitated person is not deprived of the treatment merely because he lacks the capacity to consent to the carrying out of that treatment; and
- (b) ensure that any proposed treatment of the mentally incapacitated person is carried out in his best interests.³²

Section 59ZBA makes it clear that any consent given on behalf of a mentally incapacitated person does not extend to organ transplant.

²⁷ See section 31.

²⁸ As above.

²⁹ See section 31(4).

³⁰ Section 59ZC(1).

³¹ See section 59ZD. "Court" is defined in section 2 as meaning the Court of First Instance and any judge of the Court of First Instance.

³² Section 59ZB(3).

3.23 Under section 59ZE, any registered medical practitioner or registered dentist may request a guardian of a mentally incapacitated person to consent to the carrying out of treatment in respect of that person. Treatment may be carried out without the consent of the mentally incapacitated person or that person's guardian where the registered medical practitioner or registered dentist intending to carry out or supervise the treatment considers that as a matter of urgency that treatment is necessary and is in the best interests of the mentally incapacitated person.³³

3.24 Any person can apply to the Court for consent to the carrying out of treatment of a mentally incapacitated person where that person's guardian is, unable or unwilling to make a decision on consent; or where the guardian has failed properly to observe and apply the principles set out in section 59ZB(3) and refuses to give such consent.³⁴

3.25 If, after conducting a hearing into an application for consent, the Court is satisfied that it is in the best interests of the mentally incapacitated person that the treatment should be carried out, the Court may make an order giving its consent to the carrying out of that treatment. However, the Court is not required to consider an application if the Court is not satisfied that the applicant has a sufficient interest in the health and well-being of the mentally incapacitated person.³⁵

3.26 A particular restriction is imposed on the court by section 59ZJ in respect of consent to special treatment. That section provides that the Court shall not give consent unless the Court is satisfied that the special treatment is the only or most appropriate method of treating the mentally incapacitated person, or that the special treatment is in the best interests of that person.³⁶

3.27 A guardianship order made by the Guardianship Board may confer on the guardian the power to consent to treatment (other than special treatment) on behalf of the mentally incapacitated person to the extent that the person is incapable of understanding the general nature and effect of the treatment.³⁷

Enduring Powers of Attorney Ordinance (Cap 501)

3.28 The Enduring Powers of Attorney Ordinance (Cap 501) came into operation on 27 June 1997. The Ordinance provides a procedure whereby a power of attorney, if made in the prescribed form, executed in the prescribed manner and containing the prescribed explanatory information, can continue after the donor becomes mentally incapacitated.³⁸ An enduring power of attorney can only confer on the attorney authority to act in relation to the

³³ See section 59ZF.

³⁴ See section 59ZG.

³⁵ See section 59ZI.

³⁶ Section 59ZJ(1).

³⁷ Section 59R(3).

³⁸ Enduring Powers of Attorney Ordinance, sections 3(1) and 4(1).

property and financial affairs of the donor and must specify the particular matters, property or affairs in relation to which the attorney has authority to act.³⁹ An enduring power of attorney is of no avail in relation to consent to medical treatment. If the attorney has reason to believe that the donor is or is becoming mentally incapable he must apply to the Registrar of the High Court for registration of the instrument creating the power.⁴⁰ If the donor subsequently becomes mentally incapable, the attorney may not do anything until the power is registered.⁴¹

3.29 "Mentally incapable" is defined by reference to the definition of that term in section 1A of the Powers of Attorney Ordinance (Cap 31). That section provides that a person is mentally incapable if "*he is suffering from mental disorder or mental handicap*" and is unable to understand the effect of the power of attorney, or to make a decision to grant such a power. The terms "*mental disorder*" and "*mental handicap*" have the meaning given to them by the Mental Health Ordinance.⁴²

3.30 The court may, on the application of an interested party, require information about accounts and records, revoke or vary an enduring power, or remove the attorney.⁴³ The Enduring Powers of Attorney Ordinance follows to a large extent the UK Enduring Powers of Attorney Act 1985. The 1985 Act was designed to overcome the previously widespread problem of attorneys continuing to operate ordinary powers of attorney invalidly after the onset of the donor's incapacity.

³⁹ Above, section 8(1).

⁴⁰ Above, section 4(2).

⁴¹ Above, section 4(3).

⁴² See section 1A(2) of Cap 31

⁴³ Section 11(1) of Cap 501.

Chapter 4

Mentally incapacitated persons: the common law and consent to medical treatment

Introduction

4.1 It is a long established principle that every person's body is inviolate. A doctor cannot treat a patient who is competent without the patient's consent. To do so, without consent, would be unlawful.

Factors affecting medical and health-care decisions

Consent

4.2 Under common law, any touching of another person, however slight, is *prima facie* tortious if it occurs without his consent.¹ The cardinal principle, plain and incontestable, is that every person's body is inviolate. In *Airedale NHS Trust v Bland*, Lord Keith of Kinkel said that:

*"... it is unlawful, so as to constitute both a tort and the crime of battery, to administer medical treatment to an adult, who is conscious and of sound mind, without his consent Such a person is completely at liberty to decline to undergo treatment, even if the result of his doing so will be that he will die."*²

4.3 The solution which the common law now provides is that a doctor can lawfully operate on, or give other treatment to, an adult patient who is incapable, for one reason or another, of consenting to his doing so, provided that the operation or other treatment concerned is in the best interests of the patient and that the doctor's actions satisfy the principle of necessity. The operation or other treatment will be in the patient's best interests if, but only if, it is carried out in order either to save the patient's life, or to ensure improvement or prevent deterioration in the patient's physical or mental health.³

Informed consent or refusal

4.4 The case of *Re T (Adult: Refusal of Treatment)* concerned a patient's refusal of a blood transfusion which was considered necessary in

¹ *Collins v Willcock* [1984] 1 WLR 1172.

² [1993] 1 All ER 821, at 860.

³ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1, per Lord Brandon of Oakbrook at 55.

order to save the patient's life. Lord Donaldson of Lymington MR said that:

*"What is required is that the patient knew in broad terms the nature and effect of the procedure to which consent (or refusal) was given. There is indeed a duty on the part of doctors to give the patient appropriately full information as to the nature of the treatment proposed, the likely risks (including any special risks attaching to the treatment being administered by particular persons), but a failure to perform this duty sounds in negligence and does not, as such, vitiate a consent or refusal. On the other hand, misinforming a patient, whether or not innocently, and the withholding of information which is expressly or impliedly sought by the patient may well vitiate either a consent or a refusal."*⁴

Vitiating effect of outside influence on consent

4.5 Lord Donaldson further said:

*"When considering the effect of outside influence, two aspects can be of crucial importance. First, the strength of the will of the patient. One who is very tired, in pain or depressed will be much less able to resist having his will overborne than one who is rested, free from pain and cheerful. Second, the relationship of the 'persuader' to the patient may be of crucial importance In other words the patient may not mean what he says."*⁵

Best interests principle

4.6 Lord Brandon of Oakbrook in *Re F (Mental Patient: Sterilisation)*⁶ said that the giving of medical treatment to mentally disordered adult patients was, save as to treatment for their mental disorder under the UK Mental Health Act 1983, governed by the common law.⁷ In the same case, Lord Griffiths remarked that the Crown's *parens patriae* jurisdiction in respect of such persons no longer existed following the revocation of the Royal Warrant in 1960,⁸ and Lord Brandon pointed out that the UK Court of Protection's powers with regard to the "*affairs of patients*" under Part VII of the UK Act were, on their true construction, limited to legal transactions and other business matters.⁹ Lord Brandon also observed that at common law, the court had no jurisdiction to approve or disapprove the giving of medical treatment to such persons, and that the lawfulness of the action depended

⁴ [1992] 4 All ER 649, at 663.

⁵ [1992] 4 All ER 649, at 662.

⁶ [1990] 2 AC 1.

⁷ [1990] 2 AC 1, at 55 A-C.

⁸ [1990] 2 AC 1, at 71 E.

⁹ [1990] 2 AC 1, pp 58-59.

upon whether the treatment was in the best interests of the patient.¹⁰ It would, however, be open to the court under its inherent jurisdiction to make a declaration that a proposed operation was in a patient's best interests.¹¹ Lord Goff of Chieveley said that where the state of affairs was permanent or semi-permanent, as might be so in the case of a mentally disordered person, there was no point in waiting to obtain the patient's consent. The need to care for him was obvious, Lord Goff said, and the doctor must then act in the best interests of his patient, just as if he had received his patient's consent to do so. A doctor who had assumed responsibility for the care of a patient might not only be treated as having the patient's consent to act, but might also be under a duty to act.¹²

4.7 In *Re T*, Lord Donaldson explained that the decision on treatment had to be made according to the principle of best interests:

"If in a potentially life threatening situation or one in which irreparable damage to the patient's health is to be anticipated, doctors or hospital authorities are faced with a refusal by an adult patient to accept essential treatment and they have real doubts as to the validity of that refusal, they should in the public interest, not to mention that of their patient, at once seek a declaration from the courts as to whether the proposed treatment would or would not be lawful. This step should not be left to the patient's family, who will probably not know of the facility and may be inhibited by questions of expense. ... [W]hen [such cases] do arise, ... the courts can and will provide immediate assistance."¹³

4.8 This principle of "patient's best interests" was applied in a 2004 case, *R (on the application of Burke) v General Medical Council*, where the UK General Medical Council's guidance on withholding and withdrawing treatment was heavily criticised. Munby J, in his judgment, commented that *"the legal content of the guidance is nonetheless properly vulnerable to criticism in four respects"*¹⁴. He pointed out that the guidance *"fails sufficiently to acknowledge the heavy presumption in favour of life-prolonging treatment and to recognise that the touchstone of best interests is intolerability."* On this issue of "best interests and life-prolonging treatment", Munby J made the following comments:

" ... But what of best interests in the context of life-saving or life-prolonging treatment, specifically ANH [artificial nutrition and hydration]?"

If the patient is competent (or, although incompetent, has made an advance directive which is both valid and relevant to the

¹⁰ [1990] 2 AC 1, at 56 C-D.

¹¹ [1990] 2 AC 1, at 64 C-D.

¹² [1990] 2 AC 1, at 77.

¹³ [1992] 4 All ER 649, at 663.

¹⁴ [2004] 79 BMLR 126, para 218.

treatment in question), there is no difficulty in principle: the patient decides what is in his best interests and what treatment he should or should not have. But if the patient is incompetent and has not made such an advance directive, then the decision has to be taken by someone else. Either the doctor or the court has to decide what is in the patient's best interests. What is the proper approach if what is in issue is the withholding or withdrawing of life-prolonging treatment?

I agree entirely with Mr Francis when, referring to what Sir Thomas Bingham MR said in Airedale NHS Trust v Bland [1993] AC 789, ... he submits that the mere prolongation of life is not necessarily in a patient's best interests; that the purpose of treatment or care is to bring about recovery, to prevent or retard deterioration in the patient's condition and to alleviate pain and suffering in body and mind; and that treatment that does not achieve any of these may be regarded as futile. But the starting point, and it seems to me, must be the very strong presumption in favour of taking all steps which will prolong life. Save in exceptional circumstances, or where the patient is dying, the best interests of the patient will normally require such steps to be taken.

That was said by all three judges in Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam 33, ... though all emphasised that the presumption is not irrebuttable. Thus, at 46 and 375 respectively, Lord Donaldson of Lynton MR said:

'There is without doubt a very strong presumption in favour of a course of action which will prolong life, ... but it is not irrebuttable. As this court recognized in Re B, account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself.'...

Taylor LJ, at 53 and 381 respectively, said that 'the court's high respect for the sanctity of human life imposes a strong presumption in favour of taking all steps capable of preserving it, save in exceptional circumstances.'

As Taylor LJ went on to observe, 'the problem is to define those circumstances'¹⁵.

4.9 Munby J elaborated on this issue of "exceptional circumstances" by referring to the view of Lord Goff of Chieveley in *Airedale NHS Trust v Bland*:

¹⁵ [2004] 79 BMLR 126, paras 98-101.

"Of course, in the great majority of cases, the best interests of the patient are likely to require treatment of this kind, if available, should be given to a patient. But this may not always be so. To take a simple example ... it cannot be right that a doctor, who has under his care a patient suffering painfully from terminal cancer, should be under an absolute obligation to perform upon him major surgery to abate another condition which, if unabated, would or might shorten his life still further. The doctor who is caring for such a patient cannot, in my opinion, be under an absolute obligation to prolong his life by any means available to him, regardless of the quality of the patient's life. Common humanity requires otherwise, as do medical ethics and good medical practice accepted in this country and overseas. As I see it, the doctor's decision whether or not to take any such step must (subject to the patient's ability to give or withhold his consent) be made in the best interests of the patient."¹⁶

4.10 He went on:

"I should add that in this as in other contexts where life is at stake (see paras [76]-[77] above), 'in case of doubt, that doubt falls to be resolved in favour of the preservation of life' and 'the evidence must be scrutinised with especial care. Clear and convincing proof is required'.

Some cases may be reasonably straightforward, at least in terms of legal analysis. The mere fact that the patient is physically or mentally disabled is not, of course, any reason for withholding life-prolonging treatment. ... But where the patient is dying, then the goal may properly be to ease suffering and, where appropriate, to 'ease the passing' than to achieve a short prolongation of life. ... It may also be permissible to withhold life-prolonging treatment where it is simply impracticable to administer it (for example, because the patient, although incompetent, strongly objects and is not prepared to submit to the relevant procedure) or where it would be futile (for example, in the case of a patient in PVS [persistent vegetative state])."¹⁷

4.11 Munby J discussed the more difficult situations:

"The much more difficult cases are those where the patient although gravely disabled is not dying. ...

The most illuminating analysis, as it seems to me, is to be found in Taylor LJ's judgment at 55 and 383 respectively:

'Despite the court's inability to compare a life afflicted by

¹⁶

Airedale NHS Trust v Bland [1993] AC 789, at 867.

¹⁷

R (on the application of Burke) v General Medical Council [2004] 79 BMLR 126, paras 103-104.

the most severe disability with death, the unknown, I am of the view that there must be extreme cases in which the court is entitled to say: "The life which this treatment would prolong would be so cruel as to be intolerable". If, for example, a child was so damaged as to have negligible use of its faculties and the only way of preserving its life was by the continuous administration of extremely painful treatment such that the child either would be in continuous agony or would have to be so sedated continuously as to have no conscious life at all, I cannot think Mr Munby's absolute test¹⁸ should apply to require the treatment to be given. In those circumstances, without there being any question of deliberately ending the life or shortening it, I consider the court is entitled in the best interests of the child to say that deliberate steps should not be taken artificially to prolong its miserable life span.

Once the absolute test is rejected, the proper criteria must be a matter of degree. At what point in the scale of disability and suffering ought the court to hold that the best interests of the child do not require further endurance to be imposed by positive treatment to prolong its life? Clearly, to justify withholding treatment, the circumstances would have to be extreme ... I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. I say "to that child" because the test should not be whether the life would be tolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable."¹⁹

4.12 Munby J, in summarizing his conclusions, made the following remarks in relation to the withdrawal of ANH (artificial nutrition and hydration):

"(a) Under the European Convention, as at common law, if the patient is competent (or, although incompetent, had made an advance directive which is both valid and relevant to the treatment in question) his refusal to accept ANH – his decision that ANH not be started or, if started, that it be stopped – is determinative.

¹⁸ The first, or absolutist submission of Mr James Munby, QC acting for the Official Solicitor in *Re J (A Minor) (Wardship: Medical Treatment)* was that a court was never justified in withholding consent to treatment which could enable a child to survive a life-threatening condition, whatever the pain or other side effects inherent in the treatment and whatever the quality of the life which it would experience thereafter.

¹⁹ *R (on the application of Burke) v General Medical Council* [2004] 79 BMLR 126, paras 105 & 107.

(b) *If the patient is competent (or, although incompetent, has made an advance directive which is both valid and relevant to the treatment in question) his decision to require the provision of ANH which he believes is necessary to protect him from what he sees as acute mental and physical suffering is likewise in principle determinative. There are two separate reasons why this is so. The first is based on the competent patient's rights under Art 8. The second is based on his rights, whether competent or incompetent, under Art 3.*²⁰

4.13 *R (on the application of Burke) v General Medical Council* was considered in *W Healthcare NHS Trust v H and others*, in which Brooke, LJ, hearing the appeal, said:

"... The Court cannot in effect sanction the death by starvation of a patient who is not in a PVS [persistent vegetative state] other than with their clear and informed consent or where their condition is so intolerable as to be beyond doubt. ...

The way that the judge [of first instance] came to the conclusion was that in KH's present state²¹ he was unable to say that life prolonging treatment would provide no benefit, and that death by, in effect, starvation would be even less dignified than the death which she will face in due course if kept artificially alive for more weeks or months or possibly years. ...

*The judge, having rightly put on one side the question whether there was a legally binding advance directive, looked, on the one hand, at the consequences of withdrawing nutrition and the effect this would have and, on the other hand, at the continuance of a life in which there is some feeling of pain, some sensation and some slight ability to answer questions. He came to the conclusion that it was in the best interests of the patient to accede to the unanimous wish of those who are responsible for her treatment [to re-insert a percutaneous gastrostomy tube (PEG) into KH in order to allow nutrition to continue on a permanent basis]."*²²

²⁰ *R (on the application of Burke) v General Medical Council* [2004] 79 BMLR 126, para 214(a) & (b).

²¹ The patient, KH, who was 59, suffered from multiple sclerosis and, for at least 20 years, had been incapable of taking informed decisions for herself. Most of her bodily functions had ceased to work. She was conscious but could not speak more than the odd word and she was disorientated in time and place and recognised nobody. For 5 years she had been fed through a percutaneous gastrostomy tube. In August 2004 that tube fell out and she was admitted to hospital. It was the unanimous view of those responsible for her care that the tube should be reinserted but the patient's family did not want that to happen since they believed that, in the circumstances, she would rather die.

²² *W Healthcare NHS Trust v H (CA)* [2005] 1 WLR 834, paras 22, 27 & 29.

Conflict between patient's and society's interests

4.14 There may be situations where the interests of the patient conflict with those of society:

"The patient's interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms." ²³

4.15 Society's (or the state's) interest was likewise considered in an American case: *Cruzan*²⁴. In this case, the guardians of a patient in a persistent vegetative state brought declaratory judgment action seeking judicial sanction of their wish to terminate artificial hydration and nutrition for the patient. The Supreme Court held that due process did not require the state to accept the substituted judgment of the patient's close family members in the absence of clear and convincing evidence that their views reflected those of the patient, because a state could legitimately seek to safeguard the personal element of the choice between life and death of an incompetent individual through the imposition of heightened evidentiary requirements. The state was entitled to guard against potential abuses in situations such as where family members either were unavailable to serve as surrogate decision-makers or would not act to protect a patient. The Court also held that the state was entitled to assert an unqualified interest in the preservation of human life, and that interest would be weighed against the constitutionally protected interests of the individual. The state could place a heavier evidentiary burden on those seeking to terminate an incompetent individual's life-sustaining treatment, since the interests at stake were more substantial, on both the individual and societal level, than those involved in a run-of-the-mill civil dispute. An erroneous decision not to terminate would result in the maintenance of the status quo, while an erroneous decision to withdraw life-sustaining treatment was not susceptible of correction.

4.16 Rehnquist, CJ, referred to a number of US cases²⁵ in the course of his judgment in *Cruzan*. He highlighted the state's interest in the preservation of human life in those cases and said:

"Reasoning that the right of self-determination should not be lost merely because an individual is unable to sense a violation of it, the court held that incompetent individuals retain a right to refuse treatment. It also held that such a right could be exercised by a

²³ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649, per Lord Donaldson of Lynton MR, at 661.

²⁴ 497 US 261.

²⁵ Cases referred to by the judge included *Quinlan*, 70 NJ 10; *Garger v New Jersey*, 429 US 922; *Superintendent of Belchertown State School v Saikewicz*, 373 Mass 728; *Re Storar*, 52 NY 2d 363; and *Re Conroy*, 98 NJ 321.

surrogate decision-maker using a 'subjective' standard when there was clear evidence that the incompetent person would have exercised it. Where such evidence was lacking, the court held that an individual's right could still be invoked in certain circumstances under objective 'best interests' standards. Thus, if some trust-worthy evidence existed that the individual would have wanted to terminate treatment, but not enough to clearly establish a person's wishes for purposes of the subjective standard, and the burden of a prolonged life from the experience of pain and suffering markedly out-weighed its satisfactions, treatment could be terminated under a 'limited-objective' standard. Where no trustworthy evidence existed, and a person's suffering would make the administration of life-sustaining treatment inhumane, a 'pure-objective' standard could be used to terminate treatment. If none of these conditions obtained, the court held it was best to err in favour of preserving life."²⁶

4.17 In *R (on the application of Burke) v General Medical Council*, Munby J expressed his view as follows:

"The personal autonomy protected by Art 8 [of the European Convention] means that in principle it is for the competent patient, and not his doctor, to decide what treatment should or should not be given in order to achieve what the patient believes conduces to his dignity and in order to avoid what the patient would find distressing. A competent patient's Art 8 rights – his rights to physical and psychological integrity, to autonomy and dignity – must prevail over any rights or obligations located in Arts 2 and 3. Any positive obligations of the State under Art 2 or 3 necessarily cease at the point at which they would otherwise come into conflict with or intrude into the competent patient's rights of autonomy and self-determination under Art 8. Art 3 does not entitle anyone to force life-prolonging treatment on a competent patient who refuses to accept it. Nor does Art 2. ..."²⁷

Treatment against refusal amounts to battery in tort

4.18 In *Malette v Shulman*, the physician who examined an unconscious patient who had been severely injured in a traffic accident was of the view that a blood transfusion was necessary to preserve her health and life. The physician personally administered transfusions to her, despite being shown a card which was carried by the patient indicating that she was a Jehovah's Witness and that she should not be given a blood transfusion under any circumstances. In the course of his judgment, Robins J.A. said:

²⁶ 497 US 261 at 273.

²⁷ [2004] 79 BMLR 126, para 213(n).

"A doctor who performs a medical procedure without having first furnished the patient with the information needed to obtain an informed consent will have infringed the patient's right to control the course of her medical care, and will be liable in battery even though the procedure was performed with high skill and actually benefited the patient A doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency. The law does not prohibit a patient from withholding consent to emergency medical treatment, nor does the law prohibit a doctor from following his patient's instructions. While the law may disregard the absence of consent in limited emergency circumstances, it otherwise supports the right of competent adults to make decisions concerning their own health care by imposing civil liability on those who perform medical treatment without consent The principles of self-determination and individual autonomy compel the conclusion that the patient may reject blood transfusions even if harmful consequences may result and even if the decision is generally regarded as foolhardy. Her decision in this instance would be operative after she lapsed into unconsciousness, and the doctor's conduct would be unauthorised."²⁸

4.19 He went on:

"In sum, it is my view that the principal interest asserted by Mrs. Malette in this case – the interest in the freedom to reject, or refuse to consent to, intrusions of her bodily integrity – outweighs the interest of the state in the preservation of life and health and the protection of the integrity of the medical profession. While the right to decline medical treatment is not absolute or unqualified, those state interests are not in themselves sufficiently compelling to justify forcing a patient to submit to non-consensual invasions of her person. The interest of the state in protecting innocent third parties and preventing suicide are, I might note, not applicable to the present circumstances."²⁹

Principle of necessity

4.20 The development of the common law in relation to anticipatory health care decisions in the United Kingdom is reflected in *Airedale NHS v Bland*,³⁰ and a number of other cases.

4.21 In *Airedale*, Lord Keith of Kinkel expressed his view as follows:

²⁸ (1990) 67 DLR (4th) 321 (Ont. CA) 321, pp 328-330.

²⁹ (1990) 67 DLR (4th) 321 (Ont. CA) 321, at 334.

³⁰ [1993] 1 All ER 821.

"The first point to make is that it is unlawful, so as to constitute both a tort and the crime of battery [emphasis added], to administer medical treatment to an adult, who is conscious and of sound mind, without his consent Such a person is completely at liberty to decline to undergo treatment [emphasis added], even if the result of his doing so will be that he will die. This extends to the situation where the person, in anticipation of his, through one cause or another, entering into a condition such as PVS [permanent vegetative state], gives clear instructions that in such event he is not to be given medical care, including artificial feeding, designed to keep him alive. The second point is that it very commonly occurs that a person, due to accident or some other cause, becomes unconscious and is thus not able to give or withhold consent to medical treatment. In that situation it is lawful, under the principle of necessity, for medical men to apply such treatment as in their informed opinion is in the best interests of the unconscious patient."³¹

4.22 Staughton L.J. expressed his view in *Re T* that:

*" ... when [an] adult is brought to hospital unconscious after an accident, and has had no opportunity to signify whether she consents to treatment or not ... treatment can only be justified by the principle of necessity ..."*³²

4.23 Regarding the principle of necessity, Lord Goff of Chieveley in *Re F (Mental Patient: Sterilisation)* said that:

"When a person is rendered incapable of communication either permanently or over a considerable period of time (through illness or accident or mental disorder), it would be an unusual use of language to describe the case as one of 'permanent emergency' – if indeed such a state of affairs can properly be said to exist. In truth, the relevance of an emergency is that it may give rise to a necessity to act in the interests of the assisted person, without his consent. Emergency is however not the criterion or even a pre-requisite; it is simply a frequent origin of the necessity which impels intervention. The principle is one of necessity, not of emergency."³³

4.24 He went on:

"... to fall within the principle, not only (1) must there be a necessity to act when it is not practicable to communicate with the assisted person, but also (2) the action taken must be such as a reasonable person would in all the circumstances take,

³¹ [1993] 1 All ER 821, at 860.

³² *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649, per Lord Donaldson of Lynton MR, at 668.

³³ [1990] 2 AC 1, at 75.

acting in the best interests of the assisted person. On this statement of principle, I wish to observe that officious intervention cannot be justified by the principle of necessity. So intervention cannot be justified when another more appropriate person is available and willing to act; nor can it be justified when it is contrary to the known wishes of the assisted person, to the extent that he is capable of rationally forming such a wish."³⁴

4.25 Lord Goff further said that the principle of necessity should also apply to a mentally disordered person. He had the following view:

*"I can see no good reason why the principle of necessity should not be applicable in this case [of a mentally handicapped person] as it is in the case of the victim of a stroke. Furthermore, in the case of a mentally disordered person, as in the case of a stroke victim, the permanent state of affairs calls for a wider range of care than may be requisite in an emergency which arises from accidental injury. When the state of affairs is permanent, or semi-permanent, action properly taken to preserve the life, health or well-being of the assisted person may well transcend such measures as surgical operation or substantial medical treatment and may extend to include such humdrum matters as routine medical or dental treatment, even simple care such as dressing and undressing and putting to bed."*³⁵

Principle of the sanctity of life

4.26 In *Airedale*, Lord Keith considered whether the principle of the sanctity of life should be adhered to, given that existence in a persistent vegetative state is not of benefit to the patient. He said:

*"The principle is not an absolute one [emphasis added]. It does not compel a medical practitioner on pain of criminal sanctions to treat a patient, who will die if he does not, contrary to the express wishes of the patient. It does not authorise forcible feeding of prisoners on hunger strike. It does not compel the temporary keeping alive of patients who are terminally ill where to do so would merely prolong their suffering. On the other hand it forbids the taking of active measures to cut short the life of a terminally ill patient."*³⁶

4.27 In the same case, Lord Goff of Chieveley had commented on this applicable principle of law. He said:

"Here, the fundamental principle is the principle of the sanctity of human life – a principle long recognised not only in our own

³⁴ [1990] 2 AC 1, pp 75-76.

³⁵ [1990] 2 AC 1, at 76.

³⁶ [1993] 1 All ER 821, at 861.

society but also in most, if not all, civilised societies throughout the modern world, as indeed evidenced by its recognition both in art 2 of the European Convention on Human Rights ... and in art 6 of the International Covenant on Civil and Political Rights. ... But this principle, fundamental though it is, is not absolute We are concerned with circumstances in which it may be lawful to withhold from a patient medical treatment or care by means of which his life may be prolonged. But here too there is no absolute rule [emphasis added] that the patient's life must be prolonged by such treatment or care, regardless of the circumstances." ³⁷

Principle of self determination

4.28 On the principle of self-determination, Lord Goff had the following view:

"First, it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that, if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. ... To this extent, the principle of the sanctity of human life must yield to the principle of self-determination On this basis, it has been held that a patient of sound mind may, if properly informed, require that life support should be discontinued Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it; though in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred (see eg Re T (adult: refusal of medical treatment))"³⁸

4.29 Lord Goff added that:

"... in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to do, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient's wishes."³⁹

³⁷ [1993] 1 All ER 821, pp 865-866.

³⁸ [1993] 1 All ER 821, at 866.

³⁹ [1993] 1 All ER 821, at 866.

Lord Goff further remarked that:

*"[I]n many cases not only may the patient be in no condition to be able to say whether or not he consents to the relevant treatment or care, but also he may have given no prior indication of his wishes with regard to it But the court cannot give its consent on behalf of an adult patient who is incapable of himself deciding whether or not to consent to treatment. I am of the opinion that there is nevertheless no absolute obligation upon the doctor who has the patient in his care to prolong his life, regardless of the circumstances. Indeed, it would be most startling, and could lead to the most adverse and cruel effects upon the patient, if any such absolute rule were held to exist."*⁴⁰

4.30 In the same case, Lord Keith also expressed his approval of the decisions taken in this area by the courts of other jurisdictions:

*"Although this case falls to be decided by the law of England, it is of some comfort to observe that in other common law jurisdictions, particularly in the United States where there are many cases on the subject, the courts have with near unanimity concluded that it is not unlawful to discontinue medical treatment and care, including artificial feeding, of PVS [persistent vegetative state] patients and others in similar conditions."*⁴¹

Human rights

4.31 The decision in *Airedale NHS v Bland* was applied in *NHS Trust A v M; NHS Trust B v H*⁴², in which human rights considerations were argued vigorously in relation to the withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state without hope of recovery. At the hearing, the court was asked to consider whether the discontinuance of the artificial nutrition and hydration would contravene the right to life in article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (as set out in Schedule 1 to the Human Rights Act 1997). In particular, it was asked to determine whether such discontinuance constituted an intentional deprivation of life within the meaning of article 2 and, if not, whether, in the circumstances, that article imposed a positive obligation to provide life-sustaining treatment. A further issue was whether the prohibition on inhuman or degrading treatment in article 3 of the Convention would be breached during the period between the withdrawal of treatment and the patients' deaths, or whether that article could be invoked to ensure protection of the right of a patient in a permanent vegetative state to die with dignity.

⁴⁰ As above.

⁴¹ As above, pp 861-862.

⁴² [2001] 1 All ER 801.

4.32 Dame Elizabeth Butler-Sloss (P), in the course of her judgment in *NHS Trust A v M; NHS Trust B v H*, examined article 2 of the European Convention, which states:

"1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary ..."

She went on to explain that:

*"Withdrawing treatment would not be ending the life of either patient by the act of another, nor by culpable omission if carried out within the guidelines laid down in [Airedale NHS Trust v Bland]. The cause of death would be the disease or injury that created their condition The question of discontinuing artificial nutrition and hydration to a patient in a permanent vegetative state has not yet arisen in the European Court of Human Rights, and guidance on the applicability of art 2 has to be gleaned from decisions of that court dealing with entirely different situations Article 2 clearly contains a negative obligation on the state to refrain from taking life intentionally. ... [T]here are limits to the extent of the negative obligation under art 2(1). The medical profession cannot treat patients who are competent without their consent. To do so, without consent would be unlawful. A competent adult would have the absolute right to refuse artificial nutrition and hydration even though such refusal would lead to his death. ... If a patient does not have the capacity to accept or refuse treatment it is the duty of the doctor, under the doctrine of necessity, to treat such a patient if it is in his best interests. ... If, however, it is no longer in the patient's best interests to have that treatment, it is not the duty of the medical team to continue it. ... Although lack of entitlement to treat an incompetent patient if it is not in his best interests was not specifically referred to in the other speeches in *Bland's* case, such treatment would violate the patient's personal autonomy which he retains despite being incompetent."⁴³*

4.33 Dame Elizabeth Butler-Sloss further remarked that:

"Although the intention in withdrawing artificial nutrition and hydration in PVS [permanent vegetative state] cases is to hasten death, in my judgment the phrase deprivation of life must import

⁴³ [2001] 1 All ER 801, pp 807-809, paras 18-28.

*a deliberate act, as opposed to an omission, by someone acting on behalf of the state, which results in death. A responsible decision by a medical team not to provide treatment at the initial stage could not amount to intentional deprivation of life by the state. Such a decision based on clinical judgment is an omission to act. The death of the patient is the result of the illness or injury from which he suffered and that cannot be described as a deprivation. It may be relevant to look at the reasons for the clinical decision in the light of the positive obligation of the state to safeguard life, but in my judgment, it cannot be regarded as falling within the negative obligation to refrain from taking life intentionally. I cannot see the difference between that situation and a decision to discontinue treatment which is no longer in the best interests of the patient and would therefore be a violation of his autonomy, even though that discontinuance will have the effect of shortening the life of the patient."*⁴⁴

4.34 Article 2 contained a positive obligation to take adequate and appropriate steps to safeguard life. Dame Elizabeth Butler-Sloss remarked however, that that positive obligation upon a state to protect life was not absolute. She had the following view:

*"In a case where a responsible clinical decision is made to withhold treatment, on the grounds that it is not in the patient's best interests, and that clinical decision is made in accordance with a respectable body of medical opinion, the state's positive obligation under art 2 is, in my view, discharged."*⁴⁵

4.35 It is worth noting that the reasoning in the *NHS Trust A v M*⁴⁶ decision is entirely in accord with the principles laid down in *Airedale NHS Trust v Bland*, where Lord Goff said:

*"... for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition."*⁴⁷

4.36 The discontinuance of artificial nutrition and hydration in PVS cases was considered compatible with the values of democratic societies. Dame Elizabeth Butler-Sloss said:

"It is also of significance, in my judgment, that discontinuance of artificial nutrition and hydration in PVS cases is accepted in many parts of the world both in common law and civil

⁴⁴ [2001] 1 All ER 801, pp 809-810, para 30.

⁴⁵ [2001] 1 All ER 801, at 811, para 35.

⁴⁶ [2001] 1 All ER 801.

⁴⁷ *Airedale NHS v Bland* [1993] 1 All ER 821 at 870.

jurisdictions. In some countries there are constitutional guarantees such as a Bill of Rights in New Zealand, legislation in Denmark, the Civil Code in France. A parens patriae jurisdiction is applied in parts of the United States and in Ireland. The jurisdictional basis varies and thought processes differ but the conclusions that there is no continuing obligation to maintain life in the circumstances of PVS patients and that it is compatible with the right to life to withdraw artificial nutrition and hydration in such cases are the same. ... The existing practice in the United Kingdom is accordingly compatible with the values of democratic societies."⁴⁸

4.37 Regarding article 3 of the European Convention for the Protection of Human Rights and Fundamental Freedoms which states that "no one shall be subjected to torture or to inhuman or degrading treatment or punishment", Dame Elizabeth Butler-Sloss referred to *Ireland v UK*, a European Court of Human Rights case which ruled that degrading treatment, in the context of interrogation tactics in Northern Ireland, meant "ill-treatment designed to arouse in victims feelings of fear, anguish and inferiority, capable of humiliating and debasing them and possibly breaking their physical or moral resistance."⁴⁹ She said:

*"On the assumption that art 3 requires to be considered, I am satisfied that the proposed withdrawal of treatment from these two patients has been thoroughly and anxiously considered by a number of experts in the field of PVS patients and is in accordance with the practice of a responsible body of medical opinion. The withdrawal is for a benign purpose in accordance with the best interests of the patients not to continue life-saving treatment. It is legitimate and appropriate that the residual treatment be continued until death. I am, moreover, satisfied that art 3 requires the victim to be aware of the inhuman and degrading treatment which he or she is experiencing or at least to be in a state of physical or mental suffering. An insensate patient suffering from permanent vegetative state has no feelings and no comprehension of the treatment accorded to him or her. Article 3 does not in my judgment apply to these two cases."*⁵⁰

4.38 In *R (on the application of Burke) v General Medical Council*⁵¹, Munby J expressed his view on the inter-relationship of autonomy, dignity and the European Convention as follows:

"It is important to note that personal autonomy and dignity are both aspects of the 'private life' respect for which is guaranteed by Art 8 of the European Convention. As the Strasbourg court

⁴⁸ [2001] 1 All ER 801, at 812, para 39.

⁴⁹ *Ireland v UK* (1978) 2 EHRR 25.

⁵⁰ *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801, at 814, para 49.

⁵¹ [2004] 79 BMLR 126.

said in *Pretty v United Kingdom* (2003) 35 EHRR 1, [2002] 2 FLR 45 at para 61:

'... the concept of 'private life' is a broad term not susceptible to exhaustive definition. It covers the physical and psychological integrity of a person. It can sometimes embrace aspects of an individual's physical and social identity ...'

And at para 65 it added:

'The very essence of the Convention is respect for human dignity and human freedom.'

It is also important to note what the court said in *Pretty v United Kingdom* ... at paras 63-66:

*'While it might be pointed out that death was not the intended consequence of the applicant's conduct in the above situations, the court does not consider that this can be a decisive factor. In the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Art 8(1) of the Convention. As recognised in domestic case-law, a person may claim to exercise a choice to die by declining to consent to treatment which might have the effect of prolonging his life.'*⁵²

4.39 In summarising his conclusions, Munby J pointed out:

"(g) Personal autonomy – the right of self-determination – and dignity are fundamental rights, recognised by the common law and protected by Arts 3 and 8 of the European Convention.

(h) The personal autonomy which is protected by Art 8 embraces such matters as how one chooses to pass the closing days and moments of one's life and how one manages one's death.

(i) The dignity interests protected by the European Convention include, under Art 8, the preservation of mental stability and, under Art 3, the right to die with dignity and the right to be protected from treatment, or from a lack of treatment, which will result in one dying in avoidably distressing circumstances.

⁵²

[2004] 79 BMLR 126, paras 59 & 62.

(j) *An enhanced degree of protection is called for under Arts 3 and 8 in the case of the vulnerable.*⁵³

Capacity to make an advance refusal

4.40 Lord Donaldson of Lymington MR made a useful summary of his judgment in *Re T (Adult: Refusal of Treatment)*:

"1. Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent. This is so notwithstanding the very strong public interest in preserving life and health of all citizens. However, the presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable.

2. An adult patient may be deprived of his capacity to decide either by long term mental incapacity or retarded development or by temporary factors such as unconsciousness or confusion or the effects of fatigue, shock, pain or drugs.

3. If an adult patient did not have the capacity to decide at the time of the purported refusal and still does not have that capacity, it is the duty of the doctors to treat him in whatever way they consider, in the exercise of their clinical judgment, to be in his best interests.

4. Doctors faced with a refusal of consent have to give very careful and detailed consideration to what was the patient's capacity to decide at the time when the decision was made. It may be a case of capacity or no capacity. It may be a case of reduced capacity. What matters is whether at that time the patient's capacity was reduced below the level needed in the case of a refusal of that importance, for refusals can vary in importance. Some may involve a risk to life or of irreparable damage to health. Others may not.

5. In some cases doctors will not only have to consider the capacity of the patient to refuse treatment, but also whether the refusal has been vitiated because it resulted not from the patient's will, but from the will of others. It matters not that those others sought, however strongly, to persuade the patient to refuse, so long as in the end the refusal represented the patient's independent decision. If, however, his will was

⁵³

[2004] 79 BMLR 126, para 213.

overborne, the refusal will not have represented a true decision. In this context the relationship of the persuader to the patient – for example, spouse, parents or religious adviser – will be important, because some relationships more readily lend themselves to overbearing the patient's independent will than do others.

6. In all cases doctors will need to consider what is the true scope and basis of the refusal. Was it intended to apply in circumstances which have arisen? Was it based upon assumptions which in the event have not been realised? A refusal is only effective within its true scope and is vitiated if it is based upon false assumptions.

7. Forms of refusal should be designed to bring the consequences of a refusal forcibly to the attention of patients.

8. In cases of doubt as to the effect of a purported refusal of treatment, where failure to treat threatens the patient's life or threatens irreparable damage to his health, doctors and health authorities should not hesitate to apply to the courts for assistance.⁵⁴

4.41 An individual's right of self-determination is embodied in his capacity to give advance instructions as to his medical treatment, including a refusal of such treatment. This is interwoven with the fundamental principle of consent and is reflected in English case law. Sir Thomas Bingham MR made the following comments in his judgment in *Airedale NHS Trust v Bland*:

"There are certain important principles relevant to this issue [the issue of whether artificial feeding and antibiotic drugs may lawfully be withheld from an insensate patient with no hope of recovery when it is known that if that is done the patient will shortly thereafter die] which both parties accept. (1) A profound respect for the sanctity of human life is embedded in our law and our moral philosophy, as it is in that of most civilised societies in the East and the West. ... (2) It is a civil wrong, and may be a crime, to impose medical treatment on a conscious adult of sound mind without his or her consent: see *F v West Berkshire Health Authority (Mental Health Act Commission intervening)* [1989] 2 All ER, 545, (3) A medical practitioner must comply with clear instructions given by an adult of sound mind as to the treatment to be given or not given in certain circumstances, whether those instructions are rational or irrational. ... This principle applies even if, by the time the specified circumstances obtain, the patient is unconscious or no longer of sound mind."⁵⁵

⁵⁴ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649, at 664.
⁵⁵ [1993] 1 All ER 821, at 835-836.

4.42 In *Re C (Adult: Refusal of Treatment)*⁵⁶ a patient who was diagnosed as a chronic paranoid schizophrenic was advised by his surgeon to have his leg amputated from below the knee in order to save his life because his foot was gangrenous. He refused to consent to amputation, but agreed to conservative treatment, as a result of which his condition improved. The patient applied for an injunction to prevent the amputation of his leg without his written consent. The court granted the injunction. Thorpe J was able to say that the legal principles applicable to the case were "*readily ascertained*" from certain propositions set out by the Court of Appeal in *Re T*⁵⁷. He said:

"Those propositions are common ground. It is also common ground that a refusal can take the form of a declaration of intention never to consent in the future or never to consent in some future circumstances."⁵⁸

4.43 Dame Elizabeth Butler-Sloss (P), in *Re B (adult: refusal of medical treatment)* reiterated some basic principles underlying the issue of capacity and set out additional guidelines for dealing with situations similar to those in *Re B*⁵⁹:

"(i) *There is a presumption that a patient has the mental capacity to make decisions whether to consent to or refuse medical or surgical treatment offered to him/her.*

(ii) *If mental capacity is not in issue and the patient, having been given the relevant information and offered the available options, chooses to refuse the treatment, that decision has to be respected by the doctors. Considerations that the best interests of the patient would indicate that the decision should be to consent to treatment are irrelevant.*

(iii) *If there is concern or doubt about the mental capacity of the patient, that doubt should be resolved as soon as possible, by doctors within the hospital or NHS trust or by other normal medical procedures.*

(iv) *In the meantime, while the question of capacity is being resolved, the patient must, of course, be cared for in accordance with the judgment of the doctors as to the patient's best interests.*

(v) *If there are difficulties in deciding whether the patient has sufficient mental capacity, particularly if the refusal may have grave consequences for the patient, it is most important that those considering the issue should not confuse the question of mental capacity with the nature of the decision made by the patient, however grave the consequences. The view of the*

⁵⁶ [1994] 1 WLR 290.

⁵⁷ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649.

⁵⁸ *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, at 294.

⁵⁹ A tetraplegic patient being kept alive by ventilator, but wishing to have ventilator turned off.

patient may reflect a difference in values rather than an absence of competence and the assessment of capacity should be approached with this firmly in mind. The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgment in answering the primary question whether the patient has the mental capacity to make the decision.

(vi) In the rare case where disagreement still exists about competence, it is of the utmost importance that the patient is fully informed of the steps being taken and made a part of the process. If the option of enlisting independent outside expertise is being considered, the doctor should discuss this with the patient so that any referral to a doctor outside the hospital would be, if possible, on a joint basis with the aim of helping both sides to resolve the disagreement. It may be crucial to the prospects of a good outcome that the patient is involved before the referral is made and feels equally engaged in the process.

(vii) if the hospital is faced with a dilemma which the doctors do not know how to resolve, it must be recognised and further steps taken as a matter of priority. Those in charge must not allow a situation of deadlock or drift to occur.

(viii) If there is no disagreement about competence but the doctors are for any reason unable to carry out the wishes of the patient, their duty is to find other doctors who will do so.

(ix) If all appropriate steps to seek independent assistance from medical experts outside the hospital have failed, the NHS hospital trust should not hesitate to make an application to the High Court or seek the advice of the Official Solicitor.

(x) The treating clinicians and the hospital should always have in mind that a seriously physically-disabled patient who is mentally competent has the same right to personal autonomy and to make decisions as any other person with mental capacity."⁶⁰

Pregnant women

4.44 The case of *Re S*⁶¹ involved a refusal by a pregnant woman to consent to a Caesarian section. The health authority applied for a declaration to authorise the surgeons and staff to carry out an emergency Caesarean operation to save the woman's life and the life of her unborn baby. Sir Stephen Brown granted the declaration as sought. This case appears to be

⁶⁰ *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449 at 474.

⁶¹ *Re S (adult: refusal of medical treatment)* [1992] 4 All ER 671.

at odds with the later decision in *Re C*⁶² described above, or its *ratio* may be limited to cases where the life of an unborn viable foetus is in danger.

Withholding life-sustaining treatment

4.45 The question of withholding life-sustaining treatment has also been considered by the courts. As pointed out earlier in this chapter, Lord Goff of Chieveley commented in *Airedale* that a patient of sound mind may, if properly informed, require that life support should be discontinued. He also said that the principle of self determination should also apply where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it. He made the following remarks:

*"... in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to do so, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient's wishes."*⁶³

4.46 Sir Thomas Bingham, MR also made the following remarks:

*"In the United States the issue has been much litigated. Despite variations of practice and strong expressions of dissent, the courts have in the great majority of cases sanctioned the discontinuance of artificial feeding of PVS patients. They have reached this result in deference to the express wishes of the patient where there were such and, where there were not, on the basis either that the court could judge what the patient's wishes would have been if expressed or that such discontinuance was in all the circumstances of the patient's best interests. The courts have consistently rejected the suggestion that such discontinuance amounts to suicide or criminal homicide."*⁶⁴

4.47 Dame Elizabeth Butler-Sloss, in delivering her judgment in *NHS Trust A v M; NHS Trust B v H*⁶⁵, had examined article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950, concerning the state's negative obligation to refrain from taking life intentionally. She said that there were limits to the extent of the negative obligation. The medical profession could not treat patients who were competent without their consent. A competent adult would have the absolute right to refuse artificial nutrition and hydration, even though such refusal would lead to his death. She also noted that the discontinuance of artificial nutrition

⁶² [1994] 1 WLR 290.

⁶³ [1993] 1 All ER 821, at 866.

⁶⁴ [1993] 1 All ER 821, at 837.

⁶⁵ [2001] 1 All ER 801.

and hydration in persistent vegetative cases was accepted in many parts of the world, both in common law and civil jurisdictions, and that that was compatible with the values of a democratic society.⁶⁶

4.48 It should be noted, however, that the highly publicised US case of *Schindler v Schiavo* concerning the withholding of artificial nutrition and hydration from a vegetative patient, was not a straightforward one. Theresa Schiavo suffered a cardiac arrest in 1990 and lapsed into a persistent vegetative state. Schiavo's husband was appointed guardian in 1998 and he applied to court to have her feeding tube removed. Schiavo's parents strongly opposed the husband's application. Schiavo had not drawn up an advance directive as to her medical treatment. A series of bitter legal battles ensued, involving interventions by the Florida legislature and governor, the US House of Representatives, the US Senate and the US President. The matters were finally resolved in March 2005 when the US Supreme Court refused for the sixth time to intervene, hours after a US federal appeals court rejected a petition by the parents to have the feeding tube reinserted. Schiavo died on 31 March 2005, 13 days after her feeding tube was last removed.

Summary

4.49 The provision of medical treatment to an individual is governed at common law by the following considerations:

- The principle of consent which requires it to be an informed one.⁶⁷
- Consent should be free from the vitiating effect of outside influence. The patient has to mean what he says.⁶⁸
- The principle of sanctity of life. Society's interest is in upholding the concept that all human life is sacred and it should be preserved if at all possible. In case of doubt, that doubt falls to be resolved in favour of the preservation of life, for if the individual is to override the public interest, he must do so in clear terms.⁶⁹
- The principle of self determination⁷⁰. Respect must be given to the wishes of the patient, if the patient's wishes can be ascertained. If the patient's wishes cannot be ascertained, treatment should be given in accordance with the principle of the best interests of the patient. It should be noted that if an adult patient of sound mind refuses, however unreasonably, to consent

⁶⁶ [2001] 1 All ER 801, at 812, para 39.

⁶⁷ *Re T* [1992] 4 All ER 649.

⁶⁸ *Re T* [1992] 4 All ER 649, at 662.

⁶⁹ *Re T* [1992] 4 All ER 649, at 661.

⁷⁰ *Airedale NHS v Bland* [1993] 1 All ER 821, at 866.

to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. To this extent, the principle of the sanctity of human life must yield to the principle of self-determination.

- Patient's best interests principle.⁷¹ The evaluation of a patient's best interests involves a welfare appraisal in the widest sense, taking into account where appropriate a wide range of ethical, social, moral, emotional and welfare considerations.⁷² The obligation to preserve life is not absolute. Important as the sanctity of life is, it may have to take second place to human dignity. In the context of life-prolonging treatment, the touchstone of best interests is intolerability. So if life-prolonging treatment is providing some benefit it should be provided unless the patient's life, if thus prolonged, would from the patient's point of view be intolerable.⁷³
- The principle of necessity. When for example an adult is brought to hospital unconscious after an accident, and has had no opportunity to signify whether he consents to treatment or not, treatment can only be justified by the principle of necessity.⁷⁴
- On the basis of the principle of self determination, a patient of sound mind, if properly informed, may require that life support should be discontinued and he should not be treated as having committed suicide, nor should the doctor be treated as having aided or abetted the patient to commit suicide.
- In the United States, the majority of cases have sanctioned the discontinuance of artificial feeding of PVS patients who had made no express wishes in relation to the discontinuance, if such discontinuance was in all the circumstances in the patient's best interests. The courts have consistently rejected the suggestion that such discontinuance amounts to suicide or criminal homicide.⁷⁵ However, because of the gravity of the decision and the likely possible variation in the facts of individual cases, the court considered that the approval of the court should be sought in cases of a similar nature.⁷⁶

⁷¹ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1; *Re T* [1992] 4 All ER 649, at 663; *R (Burke) v General Medical Council* [2004] 79 BMLR 126, paras 105 & 107.

⁷² *R (Burke) v General Medical Council* [2004] 79 BMLR 126, para 213(d).

⁷³ *R (Burke) v General Medical Council* [2004] 79 BMLR 126, para 213(o).

⁷⁴ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649, at 668.

⁷⁵ *Airedale NHS Trust v Bland* [1993] 1 All ER 821, at 837.

⁷⁶ *Airedale NHS Trust v Bland* [1993] 1 All ER 821, at 833.

Chapter 5

Practice in the medical profession relating to medical treatment and the assessment of mental capacity

Introduction

5.1 This chapter takes a brief look at the medical profession's existing practice in relation to the medical treatment of comatose, vegetative or other mentally incapable patients, including the Hospital Authority's *Guidelines on Life-sustaining Treatment in the Terminally Ill*. This chapter also considers the guidelines provided by the British Medical Association. Further assistance is provided by the *Frequently Asked Questions and Answers in the Application of the Mental Health Ordinance* prepared by Dr H K Cheung of Castle Peak Hospital.

Hospital Authority's Guidelines on In-Hospital Resuscitation Decisions¹

5.2 The Hospital Authority requires its *Guidelines on In-Hospital Resuscitation Decisions* ("the resuscitation guidelines") to be read by "all staff who are required to manage seriously ill patients in whom cardiorespiratory arrest is anticipated".

5.3 The summary of the resuscitation guidelines sets out the following key points, which are in line with the common law position:

"1. The purpose of the [resuscitation] guidelines [is] to enable clinicians to arrive at a professionally and ethically sound resuscitation decision which will safeguard the best interests of the patient and clinician. ...

3. Before arriving at an in-hospital resuscitation decision, clinicians need to consider a number of ethical principles including:

- the principle of beneficence (meaning to preserve life, to restore health, to relieve suffering, and to limit disability),
- the principle of nonmaleficence (meaning above all, do no harm),

¹ Issued by the Hospital Authority Head Office in July, 1998.

- *the principle of patient autonomy,²*
- *the principle of medical futility,³ [and]*
- *the principle of non-abandonment.⁴*

4. *Treatment decisions about potential resuscitation interventions should be based on:*

- *the patient's medical condition,*
- *the overall treatment plan,*
- *the likelihood of the patient benefiting from the resuscitation intervention,[and],*
- *the patient's expressed wishes.*

The issue of in-hospital resuscitation decision should be raised for all seriously ill patients in whom cardiorespiratory arrest is anticipated. In-hospital resuscitation decisions should be properly communicated with the patient/family where appropriate.

5. *In arriving at a resuscitation decision, the process should be initiated by the doctor-in-charge in conjunction with his/her team members. The decision should be documented and reviewed at regular intervals or when there is a significant unexpected change in the patient's condition."*

5.4 The purposes of the resuscitation guidelines are said to be:

- To share with health care professionals the ethical principles involved in administering or withholding resuscitation.
- To safeguard the rights of patients.

² The principle of patient autonomy is explained as "to respect the right of the competent individual, to make an informed choice to consent to or to refuse any clinically indicated medical treatment, including life-saving or life-sustaining treatment. In order to help the competent adult make an informed decision, the doctor has the responsibility to fully and honestly inform him/her of the nature of the disease, its prognosis, and the risks, benefits and likely outcomes of various treatment options."

³ The principle of medical futility is explained in the resuscitation guidelines which say "doctors are not obligated to provide medically futile therapy when asked to do so by the patient or patient's family. However, the term 'medical futility' in performing cardiopulmonary resuscitation in the strictest senses refers to a lack of reasonable hope in restoring or sustaining cardiorespiratory functions. Clinical decision on resuscitation for this category of patients is normally made by the doctor-in-charge based on his/her clinical judgment. In other clinical situations, cardiopulmonary resuscitation can also be considered medically futile if there is no hope of restoring the patient to a quality of life which can be valued by the patient. As such 'quality of life' involves varying degrees of interpretative subjectivity on the parts of the patient, the family, and the doctor. The clinical decision on resuscitation in such situations should be supported by the patient and the family."

⁴ The principle of non-abandonment explains that "doctors are obligated to provide a continuous caring partnership with the patient, which may begin in health or in sickness, last through potential recovery or adjustment to chronic illness, and often continue to the patient's death."

- To establish a code of professional conduct in the practice of resuscitation.
- To facilitate communication on the issue of resuscitation among caregivers, and between caregivers and the patient/family.

5.5 The resuscitation guidelines also set out some guiding principles for communicating with patients or their families on resuscitation decisions. These guiding principles cover the following aspects:

- Good health care requires open communication and discussion among caregivers, patients and their family members.
- The principle of patient autonomy should be respected if the patient is mentally competent.
- Determination of mental competence is made by the attending doctor in consultation with other caregivers. A competent adult is defined as one with decision-making capacity, which consists of the elements of (i) the ability to understand the medical information presented; (ii) the ability to reason and consider this information in relation to his own personal values and goals; and (iii) the ability to communicate meaningfully.
- In cases where a mentally incompetent patient's wishes are not known, treatment decisions must be based on the patient's best interests, taking account of (i) the patient's disease diagnosis and prognosis; (ii) the patient's known values, preferences, culture and religion which may influence the treatment decision; and (iii) information received from those who are significant in the patient's life and who could help in determining his or her best interests.
- The contents of communication should include, but not be limited to, (i) the patient's condition in terms of diagnosis, extent of disease, prognosis, treatment options, chance of recovery, quality of life, and the chance of going into cardiorespiratory arrest; (ii) the patient and family's expectations, values, and preferences; (iii) what cardiopulmonary resuscitation is, and the goals and limitations of cardiopulmonary resuscitation; and (iv) the likelihood of the patient benefiting from cardiopulmonary resuscitation.
- Communication should preferably be made in the presence of another member of the medical or nursing staff.

5.6 The resuscitation guidelines also set out how a resuscitation decision should be reached:

"1. The process should be initiated by the doctor-in-charge in conjunction with his/her team members.

2. Decision considerations should be taken for individual patients in accordance with the [ethical and other] principles.

3. Be the patient's advocate: all considerations must be made in the best interests of the patient.

4. Document the decision, the communication process, and the patient's and/or family's wishes in the medical records to ensure that all health care providers involved in the care of the patient are aware of the decision and will respect the decision.

5. Review the resuscitation decision at regular intervals or when there is a significant unexpected change in the patient's condition.

6. A doctor's recommendation should be supported by another doctor, where appropriate."⁵

5.7 In relation to other care and treatment, a decision not to initiate cardiopulmonary resuscitation does not imply the withholding or withdrawing of any other treatment or intervention. A patient who will not receive cardiopulmonary resuscitation should receive all other appropriate treatments, including other life-saving treatment and palliative care.

Hospital Authority's Guidelines on Consent to or Refusal of Treatment and/or Blood Transfusion by Patients

5.8 The *Guidelines on Consent to or Refusal of Treatment and/or Blood Transfusion by Patients*⁶ ("the transfusion guidelines") state that, other than in emergency situations, a doctor cannot treat a patient or give a blood transfusion to him against his wishes. Even if the patient would die without treatment or a blood transfusion, treatment or a blood transfusion should nevertheless not be given in the face of the patient's refusal.

5.9 The transfusion guidelines also state that, in an ordinary situation, the requirement that a patient should be of sound mind applies to all patients, including those who may be suspected of mental illness and mental retardation. Whether the patient is of sound mind should be judged by the attending doctor. In case of doubt, a second doctor should assess the patient's understanding and intelligence to confirm the attending doctor's assessment.

5.10 If the patient refuses treatment or a blood transfusion, the doctor should consider if there are other alternatives available, and, if so, the

⁵ *Guidelines on In-Hospital Resuscitation Decision*, (1998), Section IX.

⁶ Issued by the Hospital Authority on 18 January 1995.

transfusion guidelines say that the doctors should proceed with these alternatives with the patient's consent.

5.11 If there are no other alternatives available, then the doctor should, in the presence of a witness, counsel the patient carefully and explain to him the consequences, which may include death, of a refusal to receive treatment or blood transfusion.

5.12 In an emergency situation, where the patient is admitted to hospital unconscious, and where the person who accompanies the patient advises the doctor that the patient would object to treatment or a blood transfusion, then, if time permits, an effort should be made to ascertain whether the patient has previously clearly expressed a refusal to receive treatment or blood transfusion.

5.13 In considering whether the patient has previously clearly expressed a refusal to receive treatment or a blood transfusion and whether such refusal still applies to the current circumstances, the doctor should take into account all relevant circumstances, including information provided by relatives and a document or card which the patient may carry with him on which such refusal is stated.

5.14 If the doctor having the care of the patient has absolutely no doubt that such a refusal has clearly been expressed by the patient previously and that the patient knew the consequences, including death, of such a refusal, then the doctor cannot treat the patient or give him a blood transfusion and must record all details in the medical notes.

5.15 If time does not permit, or if the doctor is not sure that a refusal has clearly been expressed by the patient previously, the doctor should carry out such treatment (including blood transfusion) as is necessary. In considering whether it is necessary, the doctor in charge may have to decide whether the patient will die or suffer very serious consequences if nothing at all is done. If the answer to this question is in the affirmative, the doctor may volunteer his efforts.

Hospital Authority's Guidelines on Life-sustaining Treatment in the Terminally Ill

5.16 The Working Group on Clinical Ethics of the Hospital Authority's Clinical Ethics Committee issued the *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* ("the Guidelines") in April 2002. The purpose of the Guidelines is set out in the first paragraph of its Executive Summary, as follows:

"[T]his document delineates the ethical principles and communication pathways in making decisions on withholding or withdrawing life-sustaining treatment, emphasises the importance of a proper consensus-building process and

recommends approaches to handle disagreement. The ethical principles and approaches in this document apply also to other seriously ill patients who do not fall into the strict definition of the terminally ill."⁷

5.17 The ethical principles, in common with the guiding principles of the Hospital Authority's *Guidelines on In-Hospital Resuscitation Decisions*, include the principle of beneficence, the principle of non-maleficence and the principle of patient autonomy. In addition, the *Guidelines on Life-sustaining Treatment in the Terminally Ill* also emphasise the principle of justice, which is to treat all persons according to what is fair or due to them. An individual should not be unfairly treated on the basis of disability, age, social status, etc. On the other hand, an individual cannot claim an unlimited right to treatment (for example, to be treated at all costs), without regard to the impact on other persons or to scarcity of resources.

5.18 The Guidelines also emphasise that the ethical principles should be interpreted in the local cultural context:

*"In the Chinese culture, the concept of self may be different from the Western concept and is more of a relational one The role of the family in decision-making may also be more important than that of Western societies This document [the Guidelines] therefore acknowledges the importance of involvement of the family in the decision-making process, though the views of the family cannot override that of the mentally competent patient."*⁸

5.19 The Guidelines define the terminally ill as patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months. The goal of care in terminally ill patients is aimed to provide appropriate palliative care to the patients and provide support to their families, and that care and support would be continued even if inappropriate life-sustaining treatment is withheld or withdrawn. The Guidelines also observe that it is ethical to withhold or withdraw life-sustaining treatment when a mentally competent and properly informed patient refuses the life-sustaining treatment or when the treatment is futile.

5.20 The Guidelines also set out the major principles for decision making for adults:

- Refusal of treatment by a mentally competent and properly

⁷ It should be noted that "life-sustaining treatments" is defined by the British Medical Association in section 3 of its 1993 Guidelines as:

"all treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration".

⁸ Para 1.3.2 of the Guidelines.

informed patient must be respected, and the medical team must ensure that the patient is adequately informed and has the mental capacity to refuse the treatment.

- When the patient has lost the capacity to decide, a valid advance directive refusing life-sustaining treatment should be respected.
- A guardian who is vested with the power to consent to treatment of a mentally incapacitated adult patient incapable of giving consent is legally entitled to give consent for treatment considered to be in the best interests of the patient, and by implication to withhold consent for treatment which is futile to the patient. The health care team should provide accurate information to the guardian, and together arrive at a consensus if possible.
- For a mentally incapacitated patient with neither an advance directive nor a guardian, the final decision to withhold or withdraw life-sustaining treatment should be a medical decision, based on the best interests of the patient. However, the health care team should work towards a consensus with the family if possible, unless the view of the family is clearly contrary to the patient's best interests. To balance the burdens and benefits to the patient, the factors to consider would include the effectiveness of the treatment, the likelihood of pain or suffering, the likelihood of irreversible loss of consciousness, the likelihood and extent of recovery, and the invasiveness of the treatment. The prior wishes and values of the patient should be ascertained if possible. These factors should be communicated to the family to seek their views about what the patient is likely to see as beneficial, for the purpose of aiding consensus building. If possible, the decision should be taken at a pace comfortable to those involved.
- The health care team has no obligation to provide physiologically futile treatment requested by the patient or the family. If they are uncertain about the futility in the broad sense, they should communicate further with the patient and the family to arrive at a consensus. When faced with requests to continue all technically possible treatment without real hope of recovery, doctors are not obliged to comply with requests that make inequitable demands on resources available to them.
- When the futility of life-sustaining treatment is considered likely but not firmly established, the health care team may consider a time-limited trial of life-sustaining treatment by working out a well-defined set of therapeutic goals and end points with the patient, family or guardian. If, at the end of this trial period, no progress is made towards the agreed therapeutic goals, then futility is established, and resolution can then be jointly reached

to withdraw the treatment.

5.21 The Guidelines also set out the following steps to tackle disagreement:

- If there is a serious disagreement between the health care team and the patient and his family which cannot be resolved despite repeated communication, the advice of and facilitation by the respective hospital or cluster clinical ethics committee may be sought. For a mentally incapacitated adult patient without a legally appointed guardian, one possible option is to apply to the Guardianship Board to appoint a guardian. For disputes which cannot be resolved, advice may be sought from the Hospital Chief Executive to consider whether to apply to the Court.
- If consensus cannot be reached among members of the health care team, a second opinion may be sought. Further, advice of the hospital or cluster clinical ethics committee may be sought. If after thorough discussion, a member of the care team has a conscientious objection (other than on medical grounds) to the withholding or withdrawing of life-sustaining treatment, he or she may, wherever possible, be permitted to hand over care of the patient to a colleague.

5.22 With regard to artificial nutrition and hydration, the Guidelines set out the following:

"Artificial nutrition and hydration are classified as medical treatment. These are different from the offer of oral food and fluid, which is part of basic care and should not be withheld or withdrawn. However, additional safeguards are necessary in consideration of withholding or withdrawing artificial nutrition and hydration, except when:

- (a) *death is imminent and inevitable, or*
- (b) *it is the wish of a mentally competent patient."*⁹

5.23 The Guidelines also require that the basis for the decision in withholding or withdrawing treatment should be carefully documented in the medical notes and the decision must be reviewed before and after implementation, as appropriate, to take into account changes in circumstances.¹⁰

⁹ Executive Summary, *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* (2002), at 5.

¹⁰ Executive Summary, *HA Guidelines on Life-sustaining Treatment in the Terminally Ill* (2002), at 6.

British Medical Association's Guidelines on Withholding and Withdrawing Life-prolonging Medical Treatment

5.24 The British Medical Association has set out the criteria for doctors to properly assess a patient's mental capacity in refusing treatment.¹¹ These guidelines emphasise that the individual should be able to:

- understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
- understand its principal benefits, risks and alternatives;
- understand in broad terms what will be the consequences of not receiving the proposed treatment;
- retain the information for long enough to make an effective decision;
- use the information and weigh it in the balance as part of the decision-making process; and
- make a free choice (that is, free from pressure).

5.25 Section 10 of the 1999 edition of the British Medical Association's Guidelines offers guidance for the consideration of advance directives made by patients:

"10.1 Where a patient has lost the capacity to make a decision but has a valid advance directive refusing life-sustaining treatment, this must be respected. ...

10.2 In order for an advance refusal of treatment to be valid the patient must have been competent when the directive was made, must be acting free from pressure and must have been offered sufficient, accurate information to make an informed decision. The patient must also have envisaged the type of situation which has subsequently arisen and for which the advance directive is being invoked. ...

10.3 A valid advance refusal of treatment has the same legal authority as a contemporaneous refusal and legal action could be taken against a doctor who provides treatment in the face of a valid refusal. ..."

5.26 It should be noted that the British Medical Association's Guidelines define "life-sustaining treatments" as:

"all treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors,

¹¹ *British Medical Association Guidelines on Withholding and Withdrawing Life-prolonging Medical Treatment* (1999), Section 13.2.

specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration."¹²

UK General Medical Council's Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making

5.27 The General Medical Council in the UK published *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* in August 2002. Paragraph 81 states:

"Where patients have capacity to decide for themselves, they may consent to, or refuse, any proposed intervention of this kind. In cases where patients lack capacity to decide for themselves and their wishes cannot be determined, you should take account of the following considerations:

... Where death is imminent, in judging the benefits, burdens or risks, it usually would not be appropriate to start either artificial hydration or nutrition, although artificial hydration provided by less invasive measures may be appropriate where it is considered that this would be likely to provide symptoms relief.

Where death is imminent and artificial hydration and/or nutrition are already in use, it may be appropriate to withdraw them if it is considered that the burdens outweigh the possible benefits to the patient. ...

Where significant conflicts arise about whether artificial nutrition or hydration should be provided, either between you and other members of the health care team or between the team and those close to the patient, and the disagreement cannot be resolved after informal or independent review, you should seek legal advice on whether it is necessary to apply to the court for a ruling."¹³

¹²

At section 3 of the Guidelines.

¹³

In *Burke v GMC* [2004] 79 BMLR 126, paragraph 81 of the guidance issued by the General Medical Council entitled *Withholding and Withdrawing Life-prolonging Treatment: Good Practice in Decision-making* was ruled by Mr Justice Munby as unlawful in that "(1) it fails to recognise that the decision of a competent patient that artificial nutrition and hydration should be provided is determinative of the best interests of the patient, (2) it fails to acknowledge the heavy presumption in favour of life-prolonging treatment and that such treatment will be in the best interests of a patient unless the life of the patient, viewed from that patient's perspective, would be intolerable, and (3) provides that it is sufficient to withdraw artificial nutrition and hydration from a patient who is not dying because it may cause suffering or be too burdensome in relation to the possible benefits." The General Medical Council launched an appeal which was allowed by the Court of Appeal, and the declarations made by Munby J set aside, on 28 July 2005. The Court of Appeal also ruled that those sections of the General Medical Council's guidance on withholding and withdrawing life-prolonging treatment challenged by the claimant were lawful and their application did not infringe articles 2, 3 or 8 of the Human Rights Convention.

Hong Kong Medical Council's Professional Code and Conduct for the Guidance of Registered Medical Practitioners

5.28 Section 26 of the Hong Kong Medical Council's *Professional Code and Conduct for the Guidance of Registered Medical Practitioners* deals with care for the terminally ill:

"26.3 The withholding or withdrawing of artificial life support procedures for a terminally ill patient is not euthanasia. Withholding/withdrawing life sustaining treatment taking into account the patient's benefits, wish of the patient and family, when based upon the principle of the futility of treatment for a terminal patient, is legally acceptable and appropriate.

26.5 Doctors should exercise careful clinical judgement and whenever there is disagreement between doctor and patient or between doctor and relatives, the matter should be referred to the ethics committee of the hospital concerned or relevant authority for advice. In case of further doubt, direction from the court may be sought, as necessary.

26.6 Doctors may seek further reference from the Hospital Authority, the Hong Kong Medical Association and the relevant colleges of the Hong Kong Academy of Medicine."

5.29 It should be noted that Section 26.2 of the Hong Kong Medical Council's Guidance¹⁴ defines euthanasia as a "*direct intentional killing of a person as part of the medical care being offered*". The Medical Council of Hong Kong makes clear in the Guidance that it does not support the practice of euthanasia, which is illegal and unethical.

Dr H K Cheung's Frequently Asked Questions and Answers in the Application of the Mental Health Ordinance

5.30 In March 2001, Dr H K Cheung, the Chief of Service of the General Adult and Community Psychiatric Service at Castle Peak Hospital, issued a selection of questions and answers which were frequently raised by medical practitioners in relation to the application of Part IVC of the Mental Health Ordinance (Cap 136).¹⁵ Dr Cheung noted that Part IVC of Cap 136 referred to "mentally incapacitated persons" (MIP). That term was defined in section 2(1) as:

"(a) for the purposes of Part II of the Ordinance, a person who is incapable, by reason of mental incapacity, of managing

¹⁴ *Professional Code and Conduct for the Guidance of Registered Medical Practitioners* (revised in November 2000).

¹⁵ Internal guidelines prepared in March 2001 by Dr H K Cheung, Chief of Service of the General Adult and Community Psychiatric Service at Castle Peak Hospital.

and administering his property and affairs; or

- (b) *for all other purposes, a patient [ie a person suffering or appearing to be suffering from mental disorder] or a mentally handicapped person, as the case may be."*

5.31 For the purposes of Part IVC, an MIP (although suffering from a mental disorder or mental handicap) might not necessarily lack mental capacity to perform a particular function. Whether or not he did lack capacity would depend:

"... firstly on the severity of the mental incapacity (which in some instances may vary from time to time), and secondly on the complexity of the task in question."

5.32 Dr Cheung suggested that the use of the confusing term "mentally incapacitated person" could only be understood in the light of the legislation's history:

"In the old MHO [Mental Health Ordinance], the umbrella-term was Mental Disorder, which embraced, among other things, the present category of Mental Handicap. With the amendment of the MHO in 1997 upon the request of certain pressure-groups, the category of Mental Handicap was partly taken away from the original province of Mental Disorder, so as not to stigmatise the 'mentally handicapped' as 'mentally ill'. However, since there are many situations in which we still need an umbrella-term to cover both Mental Disorder and Mental Handicap, the term Mental Incapacity was coined for this purpose Regrettably this is an unsatisfactory term, because it conveys the meaning of loss of mental capacity, which is not necessarily true. ..."

5.33 Dr Cheung advised physicians to apply the following three tests:

- "(a) Is the patient a Mentally Incapacitated Person?
(b) Is the patient incapable of Giving Consent?
(c) Is the treatment in the patient's Best Interests?"¹⁶*

5.34 As to what constituted valid consent, Dr Cheung said that "adequate information" plus "mental competency" [capacity] plus "genuine voluntariness" amounted to "valid consent". He explained:

"In other words, if the patient is mentally competent, the other 2 components (ie Information and Voluntariness) should be carefully considered. On the other hand, if the patient is mentally incompetent, we would have to proceed with Part IVC."

¹⁶

Answer 8 of FAQ.

5.35 With regard to the determination of a person's "*Mental Competency*" in performing a specific task, Dr Cheung's view was that the person should know in broad terms, *what* the task was, *how* to do the task, the *consequences* of doing the task or not doing it, and *why* he should or should not do it. He added the following comments:

"Please note that there is no global mental competency for a person, and the consultation question 'Is the patient competent?' requires immediate clarification by asking, 'Competent for what?' The specific task may vary from making a will, to signing a contract, standing a trial in court, getting divorced, managing an estate, consenting a medical treatment, and so on. In all situations, the same 4 key-words [what, how, consequences and why] can be applied, although of course the specific contents vary."¹⁷

5.36 Section 59ZB(2) of Cap 136 stipulates that an MIP is incapable of giving consent to treatment or special treatment if that person "*is incapable of understanding the general nature and effect of the treatment or special treatment.*" To assist medical practitioners to determine whether an MIP would be considered incapable of giving consent, Dr Cheung suggested applying the four key words as follows:

- "(a) What: Does he know in broad terms the general nature of his illness and the specific treatment suggested?*
- (b) How: Does he know how to express and communicate his consent or refusal in an understandable manner?*
- (c) Consequences: Does he realise the possible consequences of consenting to that treatment (both therapeutic and adverse outcomes), and of refusing that treatment (in which case he realises the effect of alternative therapies or non-therapy)?*
- (d) Why: Can he weigh the pros and cons to arrive at a reasonable decision? Sometimes the reasons which the person offers may not necessarily appear entirely rational to the doctor, but at least they should be compatible with the cultural, religious and educational background of the person. Sometimes the patient may not be giving any explicit reason for his decision, or just says he would accept any treatment the doctor gives him ('waive' of autonomy), but his decision may still be considered valid so long as his cognitive, emotional and behavioural manifestations appear otherwise reasonable. On the other hand, if the decision is obviously a distorted one under the influence of psychotic symptoms such as delusions, his mental competency is in question."¹⁸*

¹⁷ Answer 10 of FAQ.

¹⁸ Answer 11 of FAQ.

5.37 As regards the tricky question of whether doctors used different criteria for assessing consent and refusal, Dr Cheung commented that doctors might have double standards because they sometimes considered an MIP as capable of giving consent if he consented to the treatment, but would regard the same person as incapable of giving consent if he refused. As he explained:

"... the standard for Mental Competency is not in reality a black and white categorization (although the Court always demands an answer in such terms), but in fact a continuum of grey. If '0' is absolutely no awareness and understanding, and '100' is total knowledge and understanding (ie the patient knows and understands as fully as the doctor himself), any MIP can understand 50%, 60%, 70% and so on. How much understanding is regarded by the doctor as adequate is indeed 'adjustable', according to the benefits and risks of that treatment. If the MIP's decision is of high benefit (ethical principle of Beneficence) or low risk (ethical principle of Non-maleficence), that decision is generally upheld (ethical principal of Autonomy). On the other hand, if that decision is of low benefit or high risk, the principles of Beneficence and Non-maleficence take priority over the principle of Autonomy, and the doctor may tend to regard the MIP as incompetent."¹⁹

5.38 In Dr Cheung's view it would be advisable to postpone treatment until the MIP recovered his capacity to give consent if to do so would not result in undue adverse consequences. An example of such a case would be the excision of a benign tumour which was not causing any immediate harm.²⁰ This would only be applicable:

"...if the patient's mental capacity is able to recover within a reasonable period of time, such as acute alcoholic intoxication, a depressive episode, or a schizophrenic illness which would respond to medications, rather than irreversible conditions like mental handicap."

5.39 Section 59ZB(3) of Cap 136 requires the Court, when considering whether or not to give consent to the carrying out of treatment to the MIP, to ensure that the treatment "*is carried out in the best interests of that person.*" Dr Cheung suggests in Question 14 of the FAQs that it is nevertheless still good clinical and ethical practice to consider the views and wishes of the patient:

"Unfortunately, there are not many occasions when we can know the incompetent MIP's genuine desire for sure:

¹⁹ Answer 12 of FAQ.
²⁰ Question 13 of FAQ.

Example 1: Cultural-religious considerations (such as Jehovah's Witness's objection to blood transfusion)

Example 2: Previous refusal or consent to the same treatment when in a mentally competent state (However, the previous refusal or consent is still valid only if all the clinical circumstances have remained unchanged from those when the previous refusal or consent was made.)

Example 3: Advance directive (This means that an individual can decide in advance, when he is still mentally competent, whether he will accept or refuse a specific medical treatment by the time he has become incompetent in future. An example is a 'living will' such as a do-not-resuscitate order, but an advance directive cannot legalise euthanasia which involves active killing of the incompetent person. However, in order to produce a valid advance directive, it is not sufficient for the individual simply to understand what an advance directive is, he must be able also to imagine and understand future possible situations. The doctor must decide whether those situations referred to in the advance directive indeed apply to the present clinical situation of the now incompetent person.) ... "

5.40 On the question of whether the assessment of the mental capacity of an MIP for the purposes of Part IVC should be done by a psychiatrist, a clinical psychologist or an "approved doctor" as defined by section 2(2) of Cap 136, Dr Cheung had the following view:

"Part IVC does not specify who should do this, and hence any medical practitioner of the general hospitals is legally empowered to do this, although consultation of a psychiatrist or clinical psychologist may be made in cases of doubt. This means that if everything is so obvious (eg a comatose patient or a severe-grade mental handicap), it is not really necessary to routinely refer the case to the psychiatrist or psychologist for mental assessment.

As for the list of doctors approved by the Hospital Authority under section 2(2) of MHO as having special experience in mental disorder or mental handicap, one such medical opinion is required for the application of Guardianship under MHO, but would not really be necessary if we are applying Part IVC without the involvement of such guardian."²¹

5.41 As regards the types of medical or dental treatment that would be covered by Part IVC, section 59ZA provides that these include any medical, surgical or dental procedure, operation or examination carried out by, or under the supervision of, a registered dentist or medical practitioner, and any care

²¹

Answer 17 of FAQ.

associated therewith. Section 59ZBA(1) makes it clear that this does not include the removal of an organ from the MIP for the purpose of transplanting it into another person. This exclusion was added by the Mental Health (Amendment) Ordinance (No 19 of 2000). Dr Cheung observed that as a result of this amendment:

"... even the Guardianship Board or the Court of First Instance has no power to consent to an organ donation from an incompetent MIP to another person. On the other hand, it does not forbid an incompetent MIP from receiving an organ donation."²²

5.42 Section 59ZA of the Mental Health Ordinance defines "special treatment" as medical or dental treatment *"of an irreversible or controversial nature as specified by the Secretary for Health, Welfare and Food under section 59ZC"*. Dr Cheung notes that, as at March 2001, the only treatment so specified as "special treatment" was *"sterilization operations except for operations that are intended primarily to treat other diseases of the reproductive system but having the effect of sterilization."* Such treatment cannot be given to any incompetent MIP unless approval is obtained from the Court of First Instance.

5.43 The FAQs also consider the position of other controversial treatments like psychosurgery.²³ Dr Cheung's view was that any treatment other than organ donation and sterilization would be ordinary treatment. He thought therefore that any controversial treatment could be carried out subject to the "best interests" principle. He had reservations, however, as to whether a truly controversial treatment could ever be said to satisfy that test. He noted:

"In the specific example of Psychosurgery, the position is rather different in UK and Hong Kong. According to the Mental Health Act of UK, Psychosurgery can be done only with the patient's explicit consent plus a specified second medical opinion, and hence can never be done at all if the MIP is incapable of giving consent In Hong Kong ... theoretically [it] can still be performed under the 'best interests' principle. In reality, this possibility remains theoretical only, because Psychosurgery has not been performed in Hong Kong since the early 1980s."

5.44 In Question 21 of the FAQs, Dr Cheung considers whether urgent treatment is dealt with differently from non-urgent treatment:

"There is no real difference in the underlying principles, viz if the patient is capable of consent, the patient's consent is required; but if not capable, treatment can be given only if necessary and in the patient's best interests."

²² Answer 18 of FAQ.

²³ Question 20 of FAQ.

*The only legal difference is that, in the case of an Urgent Treatment, there is no requirement to obtain consent from the Guardian of the MIP even if there is one. Whether the guardian's opinion, or if no guardian, the relative or carer's opinion is sought would depend on whether it is accessible quickly enough. A 2nd doctor's opinion may be obtained before the treatment if such opinion is immediately available, but otherwise a very urgent treatment may have to be given first and the 2nd medical opinion obtained only later."*²⁴

5.45 In determining whether a particular treatment is "in the best interests" of the MIP, Dr Cheung considered that the medical practitioner should balance the risks and benefits of carrying out that treatment, taking into consideration whether the treatment would:

- save the life of the MIP;
- prevent damage or deterioration to the physical or mental health and well-being of that person; or
- bring about an improvement in the physical or mental health and well-being of that person.

He added that these considerations could be summarised as the risk:benefit ratio (RBR): *"the lower the RBR, the more likely it would be in the best interests of the patient."*²⁵

5.46 The FAQs also considered whether a clinical trial could be carried out on an MIP who cannot consent to treatment.²⁶ In Dr Cheung's view, this could fall within the definition of "medical" or "dental" treatment under section 59ZA of the Mental Health Ordinance and therefore could be governed by Part IVC of that Ordinance. He explained:

"The RBR formula for the decision on the 'best interests' of the patient is the same, but in this case the 'Benefit' part would be much more uncertain since the ultimate benefit of the research on the person undergoing research may or may not occur, and then usually occur, if at all, only some time in the remote future... . A procedure which should in clinical practice be of low RBR would thus become moderate RBR if it is merely a 'trial', and one of moderate RBR would become high RBR. In effect, a clinical trial should not be performed on an adult incapable of giving consent, unless the risk entailed is very minimal. In practice, the relative's consent and the Ethics Committee would play further safeguards. Of course if there is a Guardian

²⁴ Answer 21 of FAQ.

²⁵ Answer 22 of FAQ.

²⁶ Question 24 of FAQ.

appointed under the MHO, he can give consent on behalf of an incompetent adult MIP.¹²⁷

5.47 Whether artificial life support procedures could be withheld or withdrawn from a terminally ill patient, and whether a "Do Not Resuscitate" order could be executed on an MIP in the "best interests" of the patient were also discussed in the FAQs. In Dr Cheung's view:

"... a deliberate 'non-action' is in fact an 'action'. You may say 'not providing the treatment' is in the patient's best interests. Alternatively, you may say 'providing the treatment' is not in the patient's best interests. Either way, the result is the same, viz you do not provide the treatment.

Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are probably no legal or moral differences between the 2 actions.

The ethical principles involved include the following:

*The principle of beneficence
The principle of non-maleficence
The principle of patient autonomy
The principle of medical futility
The principle of non-abandonment.*

The patient's right of self-determination is always given the first priority if the patient is mentally competent. A valid advance refusal of treatment has also the same legal authority as a contemporaneous refusal.

However, if the patient is no longer capable of giving a competent consent, and he has not made any valid advance directive either, then the principle of futility of treatment becomes important. An American task force, for instance, concluded that a persistent vegetable state can be judged to be permanent 12 months after a traumatic injury and 3 months after a non-traumatic insult. Although an occasional verified recovery has been reported after these times, such recovery is virtually always associated with severe disability. Thus, in the Risk:Benefit formula, the 'Benefit' part would be continuously dropping as time moves on...

According to the guidelines of British Medical Association, 'it is not an appropriate goal of medicine to prolong life at all costs, with no regard to its quality or the burdens of treatment'."

²⁷

Answer 24 of FAQ.

5.48 Dr Cheung then quoted from that part of the November 2000 version of the Hong Kong Medical Council's *Professional Code and Conduct for the Guidance of Registered Medical Practitioners* dealing with care for the terminally ill discussed above and concluded that:

"... the principle of Non-Abandonment means that even if the doctor has decided not to provide the treatment, he is not abandoning the patient because this is a decision made after careful consideration of what is actually in the best interests of the patient."

5.49 Dr Cheung considered it good practice to seek the views and consent of the MIP's relative or carer before giving treatment, even though this was not strictly necessary at law unless the relative or carer had been appointed as a guardian:

"However, in good clinical practice the doctor would usually seek the views of the relatives or carers and ask them to sign on a consent form, because firstly their views should usually (though not always) be in the 'best interests' of the patient, and secondly they are the people who may make complaints or take legal actions should anything go wrong as a result of the treatment given."²⁸

5.50 Dr Cheung understood the term "carer" to cover any person who had a substantial interest in the patient's welfare:

"This may cover, for instance, the person in charge or social worker of an old aged home or hostel for mentally handicapped, but probably should not extend to someone who merely transports or accompanies the patient to hospital."

Since this is not actually a legal requirement, we don't really need to be too meticulous about who is a 'carer' and who is not. The spirit behind it is that we would like to look at the patient's welfare from multiple angles as expressed in the viewpoints of the patient's various 'significant others'.

As a matter of fact, some 'carers' would not necessarily like to be involved in shouldering this responsibility of deciding on whether 'to treat' or 'not to treat'. They may like to stay 'indifferent' It doesn't really matter, and their views should be respected."²⁹

²⁸ Answer 28 of FAQ.
²⁹ Answer 29 of FAQ.

Chapter 6

Problems with the existing law

Introduction

6.1 We outlined in chapters 3 and 4 the existing law in Hong Kong relating to mentally incapacitated persons. One difficulty is that it is unclear whether persons who are "vegetative" or in a state of coma, or who suffer from other forms of incompetence such as dementia, may be regarded as "mentally incapacitated" for the purposes of the Mental Health Ordinance (Cap 136). A second difficulty is that the common law provides uncertain guidance as to the lawfulness of treatment given to a mentally disordered patient. This chapter examines these issues in turn.

Deficiencies in the Mental Health Ordinance (Cap 136)

The definition of "mental incapacity"

6.2 As noted in chapter 4, the statute law relating to mental incapacity is principally consolidated in Cap 136, and "mental incapacity" is defined in section 2 to mean "mental disorder" or "mental handicap". "Mental disorder" is defined as:

- "(a) mental illness;*
- (b) a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned;*
- (c) psychopathic disorder; or*
- (d) any other disorder or disability of mind which does not amount to mental handicap."*

6.3 "Psychopathic disorder" is defined in section 2 as:

"a persistent disorder or disability of personality (whether or not including significant impairment of intelligence) which results in abnormally aggressive or seriously irresponsible conduct on the part of the person concerned."

Cap 136 therefore provides an explanation of categories (b) and (c) of its definition of "mental disorder", but does not clarify what falls within categories (a) and (d) of that definition.

6.4 The term "mental illness," which is used in category (a) of Cap 136's definition of "mental disorder", is not defined in the Ordinance and the determination of the mental competence or incompetence of a patient therefore depends on the particular doctor's diagnosis. In the absence of statutory definition, assistance must be sought from guidelines such as those issued by the United Kingdom Department of Health, which describe "mental illness" as having one or more of the following characteristics:

- "(i) more than temporary impairment of intellectual functions shown by a failure of memory, orientation, comprehension or learning capacity;*
- (ii) more than temporary alteration of mood of such degree as to give rise to the patient having a delusional appraisal of his situation, his past or his future, or that of others or to the lack of any appraisal;*
- (iii) delusional beliefs, persecutory, jealous or grandiose;*
- (iv) abnormal perceptions associated with delusional misinterpretation of events;*
- (v) thinking so disordered as to prevent the patient making a reasonable appraisal of his situation or having reasonable communication with others."*

The absence of a precise legal definition in Cap 136 of "mental illness" places a significant burden on the individual medical practitioner in deciding his patient's mental competence.

6.5 Category (b) of the definition of "mental disorder" refers to "*a significant impairment (emphasis added) of intelligence and social functioning (emphasis added) which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*" Some members of the medical profession consider the term "*impairment*" in section 2 to mean any loss or abnormality of psychological, physiological or anatomical structure or function, and they interpret the phrase "*social functioning ... of the person concerned*" to cover all aspects of that person's social behaviour. As regards the phrase "*abnormally aggressive or seriously irresponsible conduct ... of a person*", their view is that this depends to a certain extent upon the cultural context within which the behaviour occurs. The terminology used in category (b) of the definition leaves scope for considerable latitude for doctors in determining a person's mental capacity and adds to the difficulties for the medical profession.

6.6 Clearly, a person in a coma or "vegetative state" does not fall within category (b) or (c) of the Cap 136 definition of "mental disorder" as he obviously cannot exhibit "*aggressive or seriously irresponsible conduct.*" It is also doubtful that he would fall within category (a) of the definition as the exact

meaning of the term "mental illness" is far from clear and it is not defined in the Ordinance. This term was nevertheless discussed in an English case, *W v L (mental health patient)* in 1973, concerning a psychopathic patient, where arguments had ensued as to whether psychopathic disorder could be regarded as a kind of mental illness. Lawton LJ had the following observations:

*"Lord Denning MR and Orr LJ have pointed out that there is no definition of 'mental illness'. The words ['mental illness'] are ordinary words of the English language. They have no particular medical significance. They have no particular legal significance. How should the court construe them? The answer in my judgment is to be found in the advice which Lord Reid recently gave in Brutus v Cozens, namely, that ordinary words of the English language should be construed in the way that ordinary sensible people would construe them. ... [A]lthough the [present] case may fall within the definition of 'psychopathic disorder'... it also falls within the classification of 'mental illness' It is that application of the sensible person's assessment of the condition, plus the medical indication, which in my judgment brought the case within the classification of mental illness ..."*¹

However, Lord Denning MR in the same case criticised the lack of definition of the term "mental illness" in the UK Mental Health Act 1959. Lord Denning commented:

*" ... strangely enough, 'mental illness' is not defined. [The Act] defines everything else, but it does not define 'mental illness'. It is presumably something worse than psychopathic disorder But what is it? It is apparent that this problem – which is a mixed legal and medical problem – perplexed all those concerned in this case."*²

6.7 Whether a "vegetative" patient or a person in coma would fall within category (d) ("*any other disorder or disability of mind which does not amount to mental handicap*") is again unclear. There are no illustrations or explanations given in the Ordinance to explain the phrase "disorder or disability of **mind**" (emphasis added).

6.8 Coma is "*a deep prolonged unconsciousness where the patient cannot be aroused. This is usually as the result of a head injury, neurological disease, acute hydrocephaly, intoxication or metabolic derangement.*"³ The *British Medical Journal* offered the following comments on vegetative state:

¹ *W v L* [1974] 3 All ER 884 at 890.

² *W v L* [1974] 3 All ER 884 at 888.

³ Defined in *Online Medical Dictionary* at <http://cancerweb.ncl.ac.uk/cgi-bin/omd?query=coma&action=Search+OMD> (11 Aug 2003).

*"The vegetative state usually develops after a variable period of coma; it may be partially or totally reversible or may progress to a persistent or permanent vegetative state or death. ... Vegetative state may be caused by acute cerebral injuries, degenerative and metabolic disorders, and developmental malformations. Injuries form the largest and most important group of causes and can be subdivided into traumatic (resulting from road traffic accidents, for example, or direct cerebral injury) and non-traumatic (including hypoxic-ischaemic encephalopathy, a stroke, infection of the nervous system, a tumour, or a toxic insult)."*⁴

6.9 There is a subtle difference between "brain" and "mind". Dr Silvia Helena Cardoso made the following observations in the magazine *Brain and Mind*:

*"The brain, although being the most complex structure existing on Earth – and perhaps in the Universe – is a well defined object: it is a material entity located inside the skull, which may be visualized, touched and handled. It is composed of chemical substances, enzymes and hormones which may be measured and analysed. ... But ... what about the mind? It is amazing to verify that even after centuries of ... hard dedication to brain research and remarkable advances in the field of neuroscience, the concept of mind still remains obscure, controversial and impossible to define within the limits of our language. One strongly held view is that the mind is an entity distinct from the brain; this speculation has its historical roots: the early theories, termed dualistic hypotheses of the brain function, which stated that the material brain can be viewed mechanistically but that mind is some entity with different and undefined physical character."*⁵

6.10 Returning to the legal consideration of the term "any other disorder or disability of mind", it may be worth noting that Cap 136 broadly follows the UK Mental Health Act 1983. The Mental Health (Amendment) Act 1982 introduced definitions of new expressions in section 1 of the Mental Health Act and:

"... substituted references to mental impairment or severe mental impairment for references in the Mental Health Act 1959 to subnormality or severe subnormality and introduced definitions of the new expressions which are now reproduced in sub-s (2) The concept of 'mental impairment' seeks to overcome the confusion that arises between two separate

⁴ Editorials, *The persistent vegetative state*, *British Medical Journal*, *BMJ* 1995;310:341-342 (11 February), at <http://bmj.com/cgi/content/full/310/6976/341?maxtoshow=&HITS=10&hits=10&RESULTF...> > (11 Aug 2003).

⁵ *What is Mind?* Editorial, *Brain & Mind*, at http://www.epub.org.br/cm/n04/editori4_i.htm > (11 Aug, 2003).

*conditions, that of mental handicap, an unalterable condition usually acquired before birth, and mental illness, a treatable condition which may be acquired at any age. Such confusion resulted in cases of mentally handicapped people inappropriately being made the subject of compulsory detention or guardianship under the Mental Health Act 1959, ...*⁶

There was no apparent discussion of whether persons in a coma or "vegetative state" would fall within the term "mental illness".

6.11 The purpose of the Mental Health Ordinance when it was first enacted in 1960 was stated in its preamble as being:

"... to amend and consolidate the law relating to mental disorder and its treatment and to make provision for the reception, detention and treatment of persons of unsound mind."

6.12 In moving the First Reading of the Mental Health Bill in 1960, Dr Teng Pin Hui drew the attention of members of the Legislative Council to the Bill's *Objects and Reasons*, which explained the purpose of each part. The first paragraph of the *Objects and Reasons* stated:

*"The object of this Bill is to replace the Mental Hospitals Ordinance, Cap.136, with a comprehensive Ordinance dealing with all aspects of the detention, custody, care and treatment of mentally disordered persons and the management of their property."*⁷

6.13 The term "mentally disordered person" in the Ordinance enacted in 1960 was defined as follows:

*"a person who is so far disabled in mind or who is so mentally ill or subnormal due to arrested or incomplete development of mind as to render it either necessary or expedient that he, either for his own sake or in the public interest, should be placed and kept under control."*⁸

"Any other disorder or disability of mind" was not included in the definition provision.

6.14 The definition of "mental disorder" in the Ordinance remained the same until 1988. The phrase "*any other disorder or disability of mind*" was first included in the definition provision of the term "mental disorder" in the Mental Health (Amendment) Bill 1987. "Mental disorder" was first defined in this Bill as:

⁶ General Note, *Halsbury's Statutes of England and Wales*, 4th ed, Vol 28, (2001), at 835.

⁷ *Hong Kong Hansard*, Session 1960, 278 (10 Aug 1960).

⁸ Section 2, Mental Health Ordinance 1960.

"'Mental disorder' means mental illness, arrested or incomplete development of mind (including mental impairment), psychopathic disorder or any other disorder or disability of mind."

6.15 After some debate in the Legislative Council, the definition of "mental disorder" was adjusted to become: *"mental illness, arrested or incomplete development of mind, psychopathic disorder or any other disorder or disability of mind"*. In the debate, Mrs Rosanna Tam said:

"The first major controversial area concerns the definition of 'mental disorder'. Whilst agreeing with the broad definition provided in the Bill, the group (the Legislative Council ad hoc group which was set up to examine the Bill) was concerned that the inclusion of 'mental impairment', as a state of mind which was associated with aggressive or irresponsible conduct might give rise to unnecessary misunderstanding. It was also felt that mentally handicapped persons without aggressive or irresponsible conduct should not be liable to detention in a mental hospital. ... [T]he Administration has agreed to remove any unfortunate labelling effect which this Bill may have on the mentally handicapped. Amendments will be moved in Committee."⁹

6.16 The comments made in the Second Reading debate by Dr Ho Kam-fai explain the background to the amendment in the definition. He said:

"Mental disorder is defined in clause 2 of the Bill, among other things, as arrested or incomplete development of mind, including impairment. Representatives of organisations working with the mentally handicapped have argued that only a small proportion of the mentally handicapped population is afflicted with mental impairment which is associated with aggressive or irresponsible conduct. ... Therefore, they suggested that the mentally handicapped without aggressive or irresponsible conduct should not be subject to compulsory detention and treatment in a mental hospital. After consultation, the Administration has agreed to delete the phrase under section 2 'including mental impairment' and to amend the relevant section to the effect that persons suffering only from arrested or incomplete development of mind should not be subject to detention."¹⁰

6.17 Mr Hilton Cheong-Leen's observations in the Second Reading debate further clarified the background:

"... the Bill will now be amended to give protection to the mentally handicapped. A person suffering only from arrested or incomplete development of mind will not be compulsorily

⁹ Hong Kong Hansard, Session 87/88, Vol II ,1665 (22 June 1988).

¹⁰ Hong Kong Hansard, Session 87/88, Vol II ,1667 (22 June 1988).

detained in a mental hospital, unless the patient is certified by two medical practitioners, as defined, to be abnormally aggressive or that his conduct is seriously irresponsible. ... The general public, especially at the district level, do not always find it easy to draw a distinction between the mentally handicapped who are not abnormally aggressive or whose conduct is not seriously irresponsible, from others who are suffering from psychopathic disorders or any other disability of mind which may require treatment in a mental hospital.

The Ordinance, which was first enacted about 30 years ago, has now been revised to improve the manner in which mental patients are to be handled. Those suffering from psychopathic disorders, or any other disorder or disability of mind, associated with abnormally aggressive or seriously irresponsible conduct, can be detained and given medical treatment in a mental hospital in accordance with prescribed procedures and having regard to adequate safeguards for the liberty of the individual."¹¹

6.18 It therefore seems clear that the legislative intent when the term "mental disorder" was re-defined in 1987 was to divide the affected persons into two groups, one of which (including those with "any other disorder or disability of the mind") might be subject to detention or treatment in a mental hospital, and the other being the mentally handicapped who should not be subject to detention or treatment in a mental hospital unless their state of mind was associated with abnormally aggressive or seriously irresponsible conduct.

6.19 The term "mental disorder" was re-defined again in 1997, and has remained unchanged since then. The term now means:

- "(a) mental illness;*
- (b) a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned;*
- (c) psychopathic disorder; or*
- (d) any other disorder or disability of mind which does not amount to mental handicap."¹²*

6.20 The then Secretary for Health and Welfare explained that the objective of the 1997 Amendment Bill was:

"to strengthen the provision[s] [of the Mental Health Ordinance], with a view to providing better legal safeguards for mentally disordered and mentally handicapped persons as well as people caring for them. The Bill aims to remove the misconception that mental disorder and mental handicap are the same by redefining

¹¹ *Hong Kong Hansard*, Session 87/88, Vol II, 1670-1671 (22 June 1988).
¹² Section 2, Mental Health Ordinance (Cap. 136).

the existing definition of mental disorder and introducing a new definition for mental handicap in the Mental Health Ordinance."¹³

There was no discussion about comatose or "vegetative" patients during the debate on the Bill.

6.21 It would appear from the extracts from the debate on the 1987 Bill which have been referred to above that the thinking behind the definition of "mental disorder" (including "*any other disorder or disability of mind*") was that it was associated in some way with "*abnormally aggressive or seriously irresponsible conduct.*" Such a definition would obviously exclude comatose or vegetative patients from its ambit. The current wording in the Ordinance, however, gives no indication that "*any other disorder or disability of mind*" is intended to be restricted to cases involving aggressive or irresponsible conduct, and nothing said in the debate on the 1997 amendment suggests that that was the intention. There is therefore some uncertainty as to whether or not comatose or vegetative patients can be said to fall within the bounds of "*any other disorder or disability of mind*" in category (d) of the current definition of "mental disorder".¹⁴

Exception to definition of "mental disorder"

6.22 Further uncertainty arises in respect of section 2(5) of Cap 136, which provides that:

"Nothing in subsection (1) shall be construed as implying that a person may be dealt with under this Ordinance as suffering from mental disorder, or from any form of mental disorder described in that subsection, by reason only of promiscuity or other immoral conduct, sexual deviancy or dependence on alcohol or drugs."

Although these forms of behaviour are excluded from the scope of mental disorder within the terms of Cap 136, doctors nevertheless consider some specific conditions arising from alcohol/drug intoxication, alcohol/drug psychosis, and alcoholic dementia may constitute mental disorder.

Progressive/fluctuating mental incapacity

6.23 A further difficulty in determining whether or not a particular patient is mentally incapacitated is that the patient's mental condition does not necessarily remain constant and his mental capacity may fluctuate, or it may be only partial. Such circumstances can arise, for instance, in cases of dementia.

¹³ *Hong Kong Hansard*, Session 96/97, 192 (17 June 1997).

¹⁴ The uncertainty in the interpretation of the phrase "any other disorder or disability of mind" can be readily observed: the former Chairperson of the Guardianship Board considered that category (d) *did* include coma patients, while the then Health and Welfare Bureau took the opposite view and considered it did not.

6.24 The World Health Organisation, in its tenth revision of the International Classification of Disease ('ICD-10'), has grouped dementia under the classification of "Mental and Behavioural Disorders". It describes dementia as follows:

*"Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain. In assessing the presence or absence of dementia, special care should be taken to avoid false-positive identification: motivational or emotional factors, particularly depression, in addition to motor slowness and general physical frailty, rather than loss of intellectual capacity, may account for failure to perform."*¹⁵

6.25 In reply to an enquiry as to whether "dementia" should be classified as a "mental" or "behavioural" disorder, the World Health Organisation made the following comments:

*"While it is clear from this description that dementia is a mental disorder due to brain disease, there is no attempt within the ICD-10 chapter of mental and behavioural disorders to make a taxonomic distinction between these two types of disorders."*¹⁶

6.26 Even if the illness is classified medically as a form of mental disorder under the Ordinance, the fluctuating or progressive nature of dementia means that it may be difficult to identify the exact moment when the illness proceeds to a stage where the Mental Health Ordinance would begin to apply to those patients.

6.27 The rate of progression of impairment of mental capacity varies: it is usually more rapid with coma or mental confusion, but more gradual with dementia. The extent of mental incapacity may fluctuate over time, and some elderly patients may have repeated episodes of confusion associated with incidental illnesses. Reversibility may depend on the nature of the underlying cause and the severity of damage done to the nervous system. Some chemical stimulant may enable a patient who has taken an overdose of sedative drugs to carry out near-normal cognitive functions, and he may be

¹⁵ "The ICD-10 Classification of Mental and Behavioural Disorders", World Health Organisation, Geneva, 1992, at <<http://www.mentalhealth.com/icd/p22-or05.html>> (10 July 2003).

¹⁶ Reply of 5 November 2001 from the Technical Officer (Classification, Assessment, Surveys and Terminology, Evidence for Health Policy (GPE)) of the World Health Organisation to an enquiry made by the Secretary of the Law Reform Commission of Hong Kong.

able to make a decision relating to his medical treatment. Whether the Ordinance would apply to patients suffering from those medical conditions is unclear, particularly when their level of mental functioning may be unstable in different sets of circumstances.

Decision-making capacity not considered

6.28 As in the UK, many patients detained in hospital under the Mental Health Ordinance in Hong Kong may lack decision-making capacity, at least temporarily and in relation to some matters, but the doctors or District Judge/magistrate who arrange their admission are not concerned with this question of capacity. The test is instead whether it is necessary "*in the interests of his own health or safety or with a view to the protection of other persons*" that the patient should be detained for observation and treatment.¹⁷ It was held in *B v Croydon District Health Authority* that the patient did have the capacity to refuse the treatment being offered to her, and was refusing it, but that she could nevertheless lawfully be given that treatment by virtue of section 3 of the UK Mental Health Act 1983 because it was "for" her mental disorder within the meaning of that section.¹⁸

Uncertainty of the common law regime

Decision-making as to health care or medical treatment

6.29 It was held in *Re F (Mental Patient: Sterilisation)*¹⁹ that, at common law, the court had no jurisdiction to approve or disapprove the giving of medical treatment to mentally disordered persons. The lawfulness of the action depended upon whether the treatment was in the best interests of the patient. It may not be desirable that the "best interests" of the patient should be a matter of "clinical judgement". It has been suggested that *Re F* :

*"... can be viewed with disquiet as yet another example of the House of Lords' willingness to hand over to the doctors an inappropriate degree of unsupervised power over the patient on the basis of 'doctors know best'".*²⁰

6.30 The courts have expressed differing views on the "best interests" criterion. In *Re F*, Lord Brandon said that "*[t]he operation or other treatment will be in [a patient's] best interests if, but only if, it is carried out in order to save [his life], or to ensure improvement or prevent deterioration in his physical or mental health*".²¹ Lord Brandon went on to say that:

¹⁷ Section 31(1)(b), Mental Health Ordinance (Cap 136).

¹⁸ *B v Croydon District Health Authority*, (1994) BMLR 13.

¹⁹ [1990] 2 AC 1.

²⁰ C. Lewis, "Medical treatment in the absence of consent", (1989) 30 L.S. Gaz. 32, p 33.

²¹ [1990] 2 A.C. 1, at 55.

*"[d]ifferent views have been put forward with regard to the principle which makes it lawful for a doctor to operate on or give other treatment to adult patients without their consent The Court of Appeal in the present case regarded the matter as depending on the public interest. I would not disagree with that as a broad proposition, but I think that it is helpful to consider the principle in accordance with which the public interest leads to this result. In my opinion, the principle is that, when persons lack the capacity, for whatever reason, to take decisions about the performance of operations on them, or the giving of other medical treatment to them, it is necessary that some other person or persons, with the appropriate qualifications, should take such decisions for them. Otherwise they would be deprived of medical care which they need and to which they are entitled."*²²

6.31 In the same case, however, Lord Goff spoke of cases which involve *"more than a purely medical opinion"*²³, and Lord Keith in *Airedale NHS Trust v Bland*²⁴ has explained that the grounds for the decision of the House of Lords in *Re F* was that the operation would be in the patient's best interests *"because her life would be fuller and more agreeable"*.

6.32 The concerns of clinicians regarding medical treatment of the mentally incapacitated have been reflected in an article written by Julie Stone, a lecturer in medical law and ethics at the University of Birmingham Medical School. She said:

"Whilst the judiciary have struggled to adjudicate on the merits of individual cases, judges have had their hands tied by the House of Lords' authority in Re F that such clinical decisions will be assumed to be in the patient's best interests provided the doctor is non-negligent as judged by the Bolam²⁵ test. Cases involving pregnant women needing caesareans have even relied on the Mental Health Act 1983 for want of appropriate provisions. ... Our increasingly ageing, incapacitated population, together with technological advances which result in more brain injured people being kept alive, mean that there are more mentally incapacitated people than ever before. Cases which have considered the withdrawal of treatment from patients in PVS [permanent vegetative state] and near-vegetative states reveal how unrealistic it can be to apply the concept of 'best interests'. Similarly, research is vital if drugs for conditions such as Alzheimer's are to be developed, but no-one can pretend that

²² [1990] 2 A.C. 1, at 55.

²³ [1990] 2 A.C. 1, at 78.

²⁴ [1993] 2 W.L.R. 316, at 361.

²⁵ *Bolam v Friern Hospital Management Committee* [1957] 1 W.L.R. 582. It was held that a doctor who had acted in accordance with a practice accepted at the time as proper by a responsible body of medical opinion skilled in the particular form of treatment in question was not guilty of negligence merely because there was a body of competent professional opinion which might adopt a different technique.

*research on affected patient groups could be said to be in their 'best interests'. Notwithstanding the absence of a theoretical framework, practical decisions like these must be taken every day, and clinicians struggle to arrive at the best solutions for incapacitated patients, usually in consultation with the patient's family. They do so, however, against a legal backdrop in which their ministrations could be viewed as a potential assault, or their failure to act could be construed as negligence."*²⁶

6.33 Recent developments in medicine and technology and the changing nature of contemporary society have highlighted the need for an adequate substitute decision-making mechanism for the mentally incapacitated. In the case of *Nancy Cruzan*, Chief Justice Rehnquist of the United States Supreme Court referred to a series of cases and said:

*"At common law, even the touching of one person by another without consent and without legal justification was a battery. ... More recently, with the advance of medical technology capable of sustaining life well past the point where natural forces would have brought certain death in earlier times, cases involving the right to refuse life-sustaining treatment have burgeoned. ... In re Quinlan, ... [r]ecognizing that this right was not absolute, however, the court balanced it against asserted state interests. Noting that the State's interest 'weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims,' the court concluded that the state interests had to give way in that case."*²⁷

6.34 The balancing of the state's interest in preserving the life or health of a patient with the patient's right to self-determination was considered in the Canadian case of *Malette v Shulman*, where Robins JA of the Ontario Court of Appeal said:

*"The state's interest in preserving the life or health of a competent patient must generally give way to the patient's stronger interest in directing the course of her own life. ... [T]here is no law prohibiting a patient from declining necessary treatment or prohibiting a doctor from honouring the patient's decision. To the extent that the law reflects the state's interest, it supports the right of individuals to make their own decisions. By imposing civil liability on those who perform medical treatment without consent even though the treatment may be beneficial, the law serves to maximize individual freedom of choice."*²⁸

²⁶ Julie Stone, "Mental incapacity: reform at last?", *Solicitors Journal*, 20 March 1998, at 259.

²⁷ *Cruzan v Director of Missouri Department of Health*, 497 U.S. 261, at 269-271.

²⁸ 67 DLR (4th) 321, at 333-334.

6.35 Although it has been held at common law that the court has no jurisdiction to approve or disapprove the giving of medical treatment to a mentally disordered patient and that the lawfulness of the action depends upon whether the treatment is in the best interests of the patient, the court retains its power of inherent jurisdiction to make a declaration. In *Re F*, Lord Donaldson of Lynton MR made the following comments:

*"For my part, I do not think that is an appropriate procedure. A declaration changes nothing. All that the court is being asked to do is to declare that, had a course of action been taken without resort to the court, it would have been lawful anyway. In the context of the most sensitive and potentially controversial forms of treatment the public interest requires that the courts should give express approval before the treatment is carried out and thereby provide an independent and broad based 'third opinion'. ... In the case of adults who are themselves incompetent to consent, the law will impose an equally heavy burden of justification if those who carry out the treatment do not first seek a determination of the lawfulness of the proposed treatment by enabling the court to approve or disapprove. ... As this problem has only recently arisen, there is no specific procedure laid down for obtaining the court's approval. ... Fortunately the court has inherent jurisdiction to regulate its own proceedings where the rules make no provision ..."*²⁹

6.36 Lord Brandon in *Re F* concurred and said:

*"[T]he substantive law is that a proposed operation is lawful if it is in the best interests of the patient, and unlawful if it is not. What is required from the court, therefore, is not an order giving approval to the operation, so as to make lawful that which would otherwise be unlawful. What is required from the court is rather an order which establishes by judicial process (the 'third opinion' so aptly referred to by Lord Donaldson of Lynton MR) whether the proposed operation is in the best interests of the patient and therefore lawful, or not in the patient's best interests and therefore unlawful."*³⁰

6.37 However, these cases do not provide complete or clear guidance for health care professionals in dealing with patients who, through advanced age or serious illness, have lost the capacity to make or communicate health care decisions.

6.38 Doctors place much emphasis on respect for their patients' rights of informed consent to, or refusal of, treatment. They are particularly cautious about the vulnerability of decisions made by themselves or patients' relatives on behalf of patients who may possess intermittent mental competence. We also note the concerns expressed by doctors as to whether

²⁹ [1990] 2 A.C. 1, at 20-21.

³⁰ [1990] 2 A.C. 1, at 64.

substitute decisions can be made for stroke patients on, for example, cardiopulmonary resuscitation.

6.39 The problem of proxy decisions is present almost daily and with an aging population its incidence can be expected to increase. It may therefore be necessary to put in place a mechanism which facilitates the decision-making process and to ensure that this mechanism articulates the rights and duties of those affected.

Lack of autonomy of patient

6.40 It is important that any legislation recognises that persons with a decision-making disability, whether through mental incapacity or some other cause, enjoy the same fundamental human rights as any other members of the community. Persons with a decision-making disability should be afforded as much autonomy as possible and given appropriate decision-making assistance whenever it is required. Their rights should not be taken away from them by virtue of the fact that they have become mentally incapacitated.

6.41 The United Nations High Commissioner for Human Rights' ("the UNHCHR") "*Declaration on the Rights of Disabled Persons*"³¹ ("the Declaration") emphasises:

"... that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged".

Such an emphasis can be seen from Article 3 of the Declaration, which states:

"Disabled persons have the inherent right to respect for their human dignity. Disabled persons³², whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible."

6.42 It may be worth noting at this point that the other relevant Articles of the Declaration provide:

"Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible." (Article 5)

³¹ Proclaimed by General Assembly resolution 3447(XXX) of 9 December 1975, at <<http://www.unhchr.ch/html/menu3/b/72.htm>> (10 July 2003).

³² Article 1 explains the term "disabled person" to mean "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and /or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities."

"Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account." (Article 11)

6.43 The UNHCHR has also formulated the "*Principles for the protection of persons with mental illness and the improvement of mental health care*"³³ which were adopted by General Assembly resolution 46/119 of 17 December 1991. Principle 1 states, *inter alia*, that all persons with a mental illness have the right to be treated with humanity and respect for the inherent dignity of the human person, and to exercise all civil, political, economic, social and cultural rights recognised by the United Nations. Any decision that, because of mental illness, a person lacks legal capacity to make and for which he needs another person appointed to act on his or her behalf, should be made only after a fair hearing by an independent and impartial tribunal. Such decisions should be reviewed at reasonable intervals and be subject to the right of appeal to a higher legal authority, and where a person with a mental illness is unable to manage his or her affairs, his or her interests should be protected by such measures as are necessary and appropriate.

Issues for consideration

6.44 As discussed above, a number of defects and anomalies may be identified with respect to the law in this area. The deficiencies of the existing law are aggravated by a number of factors, such as the evident demographic change in recent years. Similar to many developed countries, Hong Kong has an aging population. The result is a greater need to provide a satisfactory mechanism for decisions to be made as to the health care, personal care and finances of the elderly. That demographic change is coupled with advances in medical science resulting in an enhanced life expectancy, and the survival of many who might previously have died from trauma or disease. Some may survive with impaired mental capacity, or even in a "persistent vegetative state" where they can express no decision about what should happen to them in future.

6.45 The "*Guidelines on Life-Sustaining Treatment in the Terminally Ill*" issued by the Hospital Authority Clinical Ethics Committee attempts to provide some guidance for doctors in their consideration of whether to withhold or withdraw life-sustaining treatment from terminally ill patients. However, whether doctors would find the guidelines practical or overly complicated to follow remains to be seen. It has been pointed out that in medical practice, treatment decisions may not be too difficult to deal with, because medical professionals may refer difficult cases to the Ethics Committee for guidance or decision. We note, however, that some doctors consider it unusual or even rare for medical professionals to go against the wishes of the mentally

³³ At <<http://www.unhchr.ch/html/menu3/b/68.htm>> (10 July 2003).

incompetent persons' relatives and bring treatment decisions to the court, and that greater difficulties arise in relation to property management.

6.46 The existing legal mechanisms are complicated, inflexible and piecemeal. The establishment of the Guardianship Board under the Mental Health Ordinance has made some improvements to the Ordinance in promoting the welfare and care of the mentally incapacitated, but there are still gaps and deficiencies in relation to the certainty of advance instructions that may be given by an individual regarding his medical treatment or care. It is recognised that there are situations in which it may be more appropriate for a decision to be made by an independent third party. However, there are also many situations where such outside intervention is unnecessary. Insufficient attention has been paid to the need to facilitate the making of fully informed and effective decisions about the person's well-being. At the same time, there are also inadequate safeguards associated with ascertaining the prior wishes or instructions of the mentally incapacitated person.

6.47 The Enduring Powers of Attorney Ordinance (Cap 501) can only confer on the attorney authority to act in relation to the property of the donor.³⁴ It provides no solution to those who wish to make effective long-term arrangements about their health care or medical treatment.

6.48 Order 80 of the Rules of the High Court (Cap 4) governs the participation in legal proceedings of people under a disability. It does not provide arrangements for health care or medical treatment of the mentally incapacitated. These rules, in practice, can prove cumbersome, restrictive, and may be too costly for most applicants.

³⁴ Enduring Powers of Attorney Ordinance, section 8(1).

Chapter 7

The law and proposals for reform in other jurisdictions

Introduction

7.1 We examine in this chapter the position in Australia, Canada, England and Wales, Scotland, Singapore, and the United States. It can be seen that all the major common law jurisdictions have introduced the concept of advance directives in respect of elderly people or the mentally incapacitated, and that each of these jurisdictions has proposed reforms of varying degrees and scope.

Australia: Queensland

7.2 All states and territories of Australia have comprehensive legislative schemes providing for assisted or substituted decision-making for people with a decision-making disability. The last one of the states to have such legislation is Queensland. In September 1990 the Attorney-General of Queensland requested the Queensland Law Reform Commission to review the existing Queensland laws concerning people with disabilities. The Commission focused its attention on the laws relating to decision-making by and for adults whose capacity to make their own decisions was impaired.¹ Impaired decision-making capacity may arise from a number of causes. It may result from a congenital intellectual disability, or be the consequence of brain damage brought about by injury or illness. It may be the effect of dementia, of a psychiatric condition, or of substance abuse.²

7.3 The Commission affirmed that "*people with a mental or intellectual disability are entitled to respect for their human dignity and to assistance to become as self-reliant as possible.*"³ A discussion paper on the issue of whether and to what extent people with a mental or intellectual disability require assistance to make decisions, balanced against their right to the greatest possible degree of autonomy, was published by the Queensland Law Reform Commission in July 1992. The discussion paper analysed the existing law of Queensland, emphasising that people should be encouraged to be self-reliant in matters relating to their personal, domestic and financial affairs, and cited the Disability Services and Guardianship Act 1987 of New

¹ Queensland Law Reform Commission Report No 49, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Vol 1, at 1.

² Queensland Law Reform Commission Report No 49, Vol 1, at 1.

³ Queensland Law Reform Commission Discussion Paper No 38, *Assisted and Substituted Decisions: Decision-making for people who need assistance because of mental or intellectual disability: A New Approach*, at 1.

South Wales as a suitable model.⁴

7.4 The Commission recommended that a person should have "decision-making capacity" for a decision if the person is capable, whether with or without assistance, of understanding the nature and foreseeing the effects of the decision and communicating the decision in some way.⁵ On the other hand, a person has "impaired decision-making capacity" for a decision if the person does not satisfy those criteria.⁶ Under these definitions, a person who is incapable of understanding the nature of a decision because, for example, he is in a coma or suffering from senile dementia is included as a person with impaired decision-making capacity.

7.5 Reforms to this area of the law were the subject of a lengthy examination by the Queensland Law Reform Commission over a period of some five years. The Healthy Ageing Research Unit of the University of Queensland's Department of Social and Preventive Medicine also undertook research over a two to three-year period within the community, and examined future health care planning with medical practitioners and other health-care professionals.⁷

7.6 The legislation relevant to decision-making for a person with a decision-making disability which was reviewed by the Queensland Law Reform Commission was:

- the Mental Health Act 1974 (repealed by the Mental Health Act 2000);
- the Public Trustee Act 1978; and
- the Intellectually Disabled Citizens Act 1985 (repealed by the Guardianship and Administration Act 2000).

Mental Health Act 1974

7.7 The Fifth Schedule to the Mental Health Act 1974 (which was entirely replaced by the Mental Health Act 2000) provided for decisions to be made on behalf of a "patient". A "patient" was defined in the Act as a person for whom a protection order under the Public Trustee Act 1978 had not been made and who was "mentally ill" and incapable of managing his or her property and affairs. The Mental Health Act did not define "mental illness". It did, however, state that its provisions applied to "drug dependence and intellectual handicap" as if each of those conditions were a mental illness.⁸

⁴ Queensland Law Reform Commission Discussion Paper No 38, at 3.

⁵ Queensland Law Reform Commission Report No 49, Vol 1, *Draft Assisted and Substituted Decisions Bill* (the "Bill"), Sch 1, Pt 1, para 2.

⁶ Queensland Law Reform Commission Report No 49, Vol 1, the Bill, Sch 1 Pt 1, para 3.

⁷ *Queensland Parliament Hansard*, 8 October, 1997, at 3685.

⁸ Queensland Law Reform Commission Report No 49, Vol 1, at 6.

- 7.8 There were two ways for a person to become a "patient":⁹
- by notification to the Public Trustee, which may be given by certain medical practitioners;¹⁰ or
 - by order of the Supreme Court,¹¹ on the application of the Public Trustee or a relative or carer for the appointment of a committee of the person's estate.

Public Trustee Act 1978

7.9 Under this Act, the Public Trustee, or any other person who appears to the Court to have a proper interest, may apply to the Supreme Court for a protection order appointing the Public Trustee to manage all or part of the money and property of the person to whom the application relates.¹²

7.10 The Court may make an order if it is satisfied that, as a result of age, disease, illness, physical or mental infirmity or substance abuse, the person concerned is continuously or intermittently:

- unable to manage his or her own affairs; or
- subject to undue influence in relation to the person's money and property, or to the disposition of the person's money or property;

or if the person is in a position which in the opinion of the Court renders it necessary in the interest of that person or of the person's dependants that the person's property be protected.¹³

Intellectually Disabled Citizens Act 1985

7.11 The Intellectually Disabled Citizens Act, which was repealed by the Guardianship and Administration Act 2000, provided for intellectually disabled citizens to receive special assistance under the Act. "Intellectually disabled citizen" was explained in the Queensland Law Reform Commission's Report to mean:

"... a Queensland resident, aged eighteen years or over, who is limited in his or her functional competence because of an intellectual impairment of congenital or early childhood origin or resulting from illness, injury or organic deterioration. 'Functional competence' relates to the person's competence to

⁹ Queensland Law Reform Commission Report No 49, Vol 1, at 6-7.

¹⁰ Mental Health Act 1974, section 55, Fifth Schedule, cl 1.

¹¹ Mental Health Act 1974, Fifth Schedule, cl 1.

¹² Queensland Law Reform Commission Report No 49, Vol 1, at 9.

¹³ Queensland Law Reform Commission Report No 49, Vol 1, at 10.

carry out the usual functions of daily living, including the person's ability to take care of himself or herself and to look after his or her home, to perform civic duties, to enter into contracts and to make informed personal decisions."¹⁴

7.12 An application for assistance could be made by, amongst others, the intellectually disabled citizen, an adult relative of the citizen, a police officer, a "legal friend", or any other adult who had a proper interest in the well-being of the citizen.¹⁵

7.13 A "legal friend" was defined as a barrister or solicitor appointed to perform certain functions under the Act.¹⁶ The functions of the legal friend include instructing a solicitor to act for the assisted citizen, and to obtain for the citizen information regarding the citizen's legal rights and legal procedures and specialised services available to the citizen. The legal friend could be authorised by the Intellectually Disabled Citizens Council to consent, on behalf of an assisted citizen, to any medical, dental, surgical or other professional treatment or care being carried out on or provided to the citizen for the citizen's benefit.¹⁷

7.14 The Queensland Law Reform Commission's Report set out the steps that the legal friend must take before deciding whether or not to consent to treatment for an assisted citizen. He must:¹⁸

"consult with relatives of the assisted citizen who are providing ongoing care for the citizen and give due consideration to any views expressed by the relatives; and

be as fully informed as possible on matters requiring consent and on available options by consulting with appropriate professional persons, with persons providing ongoing care to the assisted person and with relatives of the assisted citizen or other persons who appear to the Legal Friend to have a proper interest in the well-being of the assisted citizen.

The Legal Friend must also ensure that the assisted citizen is as fully informed as possible, consistently with the citizen's ability to understand the information, on matters requiring consent and on available options.¹⁹ In giving consent, the Legal Friend must ensure that, as far as possible, the consent is for the least restrictive option available, after taking into account the health, well-being and expressed wishes of the assisted citizen.²⁰"

¹⁴ Queensland Law Reform Commission Report No 49, Vol 1, at 13.

¹⁵ Queensland Law Reform Commission Report No 49, Vol 1, at 13-14.

¹⁶ Intellectually Disabled Citizens Act 1985, section 4.

¹⁷ Intellectually Disabled Citizens Act 1985, section 26(3).

¹⁸ Queensland Law Reform Commission Report No 49, Vol 1, at 20.

¹⁹ Intellectually Disabled Citizens Act 1985, section 26(5)(c).

²⁰ Intellectually Disabled Citizens Act 1985, section 26(5A).

Inherent jurisdiction of the Court

7.15 In addition to the statutory mechanisms for determining whether a substitute decision-maker should be appointed for a person with a decision-making disability, the Supreme Court has a power, known as the *parens patriae* jurisdiction, as part of the Court's wider inherent jurisdiction, to appoint decision-makers for people made vulnerable by decision-making disability.²¹

Criticisms of the old law

7.16 The Queensland Law Reform Commission made a number of criticisms of the old law:

"The Mental Health Act [1974] and the Public Trustee Act [1978] reflect an outdated, paternalistic approach to people with a decision-making disability and give little recognition to their right to participate to the greatest possible extent in the decisions which affect their lives. Even the Intellectually Disabled Citizens Act, which at the time of its enactment in 1985 contained a number of innovative features, has been overtaken by legislative developments in other Australian jurisdictions and overseas. ... [T]he existing legislative framework is gravely inadequate, and cannot be satisfactorily remedied by piece-meal amendments to the present laws. An entirely new approach is required. The overwhelming majority of the submissions received by the Commission ... call for the mechanisms set up under the Mental Health Act, the Public Trustee Act and the Intellectually Disabled Citizens Act to be replaced by a comprehensive model."²²

7.17 Some of the principal problems the Queensland Law Reform Commission had identified were:

- Lack of principle
- Complexity
- Limited choice of decision-maker
- Lack of flexibility of decision-making powers
- Unsuitability of existing procedures²³

Lack of principle

7.18 The Queensland Law Reform Commission criticised the fact

²¹ Queensland Law Reform Commission Report No. 49, Vo 1, at 21.

²² Queensland Law Reform Commission Report No 49, Vol 1, at 23.

²³ Queensland Law Reform Commission Report No 49, Vol 1, at 24-26.

that many of the provisions of the three Acts failed to meet internationally recognised standards, and in some situations a decision-maker might be appointed without the safeguard of an impartial hearing by an independent body. It further commented that review mechanisms were either non-existent or inadequate, and that there was insufficient provision for substitute decision-makers to be required to respect the rights of people with a decision-making disability.²⁴

Complexity

7.19 The fragmented approach of the legislation meant that people were treated differently depending on the reason for their decision-making disability, even though they suffered from the same fundamental problem of lacking capacity to make decisions. It also meant that because the provisions of the three Acts overlapped, people with the same kind of decision-making disability might be treated differently according to which law was used. Uncertainty, inconsistency and injustice may result and may cause unnecessary delay, expense and anxiety.²⁵

7.20 The Commission also made the following observations:

"The categorisation in the existing legislation causes problems for people who have dual or multiple disabilities. There are also some people with a decision-making disability who have difficulty in obtaining the assistance that they require. Queensland is the only State or Territory in Australia which does not have a comprehensive legislative scheme to provide decision-making assistance for all people with a decision-making disability, regardless of the cause of the disability."²⁶

Limited choice of decision-maker

7.21 The Commission noted:²⁷

"Most of the present rules concentrate power to make decisions for a person with a decision-making disability who lacks the capacity to make those decisions on his or her own behalf in the hands of a public officer.²⁸ The Commission acknowledges that there are situations in which it may be more appropriate for a decision to be made by an independent third party. However, there are many situations where such outside intervention is unnecessary."

²⁴ Queensland Law Reform Commission Report No 49, Vol 1, at 25.

²⁵ Queensland Law Reform Commission Report No 49, Vol 1, at 25.

²⁶ Queensland Law Reform Commission Report No 49, Vol 1, at 25.

²⁷ Queensland Law Reform Commission Report No 49, Vol 1, at 26.

²⁸ Quoting the example of *public trustee* and *legal friend*.

Lack of flexibility of decision-making powers

7.22 The Commission commented that the three Acts offered little scope as to the extent of the powers which might be given to a decision-maker, and that the emphasis was largely on protecting the property of a person with a decision-making disability. Insufficient attention had been paid to the need to facilitate the making of legally effective decisions about the person's well-being.²⁹

Unsuitability of existing procedures

7.23 Many of the procedures required an application to be made to the Supreme Court. The expense of making a Supreme Court application is often financially beyond the means of a person with a decision-making disability and his or her family or close friends. In addition, people may feel alienated and intimidated by the traditional courtroom atmosphere, with its associated legal culture of adversarial proceedings, and the judge may have little expertise, experience or understanding of the needs of a person with a decision-making disability.³⁰

The Commission's recommendations and reform

7.24 The Queensland Law Reform Commission's report advocates the adoption of a comprehensive legislative scheme to apply to all people who, because of a decision-making disability, need assistance to make their own decisions or a substitute decision-maker to make decisions on their behalf.³¹

7.25 Central to the Commission's recommendations was the establishment of an independent tribunal to provide an accessible, affordable and simple, but sufficiently flexible, way of establishing whether a person has decision-making capacity, and of determining issues surrounding the appointment and powers of decision-makers where it is necessary for another person to have legal authority to make decisions for a person whose decision-making capacity is impaired.³²

7.26 A consultation draft of the Powers of Attorney Bill, together with an explanatory memorandum and draft forms, was released for public consultation on 2 June 1997. Specific consultation took place with key community organisations representing people with various decision-making disabilities, professional and commercial bodies and the public,³³ and a two phase approach was adopted to address the issues.

7.27 D E Beanland, Queensland Attorney-General and Minister for Justice, in moving the second reading of the Powers of Attorney Bill on 23 April

²⁹ Queensland Law Reform Commission Report No 49, Vol 1, at 26.

³⁰ Queensland Law Reform Commission Report No 49, Vol 1, at 26.

³¹ Queensland Law Reform Commission Report No 49, Vol 1, at 27.

³² Queensland Law Reform Commission Report No 49, Vol 1, at 27.

³³ See Explanatory Notes to the Powers of Attorney Bill 1997, at <<http://www.legislation.qld.gov.au/Bills/48PDF/1997/PowersofAttorneyB97E.pdf>> (1 Aug 2003).

1998 made the following points:

"[A]lthough the Queensland Law Reform Commission had produced a draft Bill, it was acknowledged within its report that further drafting would be required. Enduring powers of attorney were treated within that report primarily as a disability issue when in fact they were closely related to general powers of attorney. The Government decided to introduce the process in two stages for very good reasons. ... By first establishing a regime to facilitate greater levels of individual autonomy it is expected that there will be less need for intrusion into the family situation by a guardianship and administration regime, as occurs in other States. Furthermore, those cases necessitating guardianship and/or administration orders will be able to be dealt with more efficiently ...

The Queensland Law Reform Commission scheme meant that the law in relation to powers of attorney and enduring powers of attorney would be covered by two quite distinct pieces of legislation rather than being contained in a comprehensive framework. The focus of the Queensland Law Reform Commission's recommendations in relation to enduring powers of attorney were concerned with their use for substitute decision making for a person with a decision-making disability. The Guardianship and Administration Bill was released for public consultation The Powers of Attorney Bill does not cover cases about financial decision making. The appointment of a family member to make financial decisions is part of the draft Guardianship and Administration Bill.³⁴

Powers of Attorney Act 1998

7.28 The Powers of Attorney Act 1998 consolidated, amended and reformed the law governing general powers of attorney and enduring powers of attorney. It also made provision for "advance health directives", and contains the following salient features:³⁵

- Chapter 1 provides an overview of the types of authorisations and directions which a person may give. These include general powers of attorney, enduring powers of attorney, advance health directives and powers of attorney under the common law. It further provides that this Act has to be read in conjunction with the Guardianship and Administration Act 2000, which provides a scheme for the establishment of a tribunal. It should be noted that the tribunal may consent to the withholding

³⁴ See *Queensland Parliament Hansard*, second reading of Powers of Attorney Bill, 23 April 1998, at 909-911.

³⁵ See explanatory notes to the Powers of Attorney Bill 1997, at <<http://www.legislation.qld.gov.au/Bills/48PDF/1997/PowersofAttorneyB97E.pdf>> (18 July 2003).

or withdrawal of a life-sustaining measure and to particular special health care.³⁶

- Chapter 2 retains the statutory form of general power of attorney. It also gives statutory recognition to the common law principles relating to the revocation of a power of attorney.
- Chapter 3 deals with enduring powers of attorney and "advance health directives" which continue in force after the principal has lost decision-making capacity. In particular, clause 35 enables an adult to give directions about health matters and special health matters and to give information about that direction. The adult may give directions consenting to particular future health care despite objections; requiring, in specified circumstances, that particular life-sustaining measures be withheld or withdrawn; and authorising an attorney to physically restrain, move or manage the principal for the purpose of health care despite objection. It should be noted that "*an attorney or guardian may not be given power for a special health matter. However, a principal may give a direction about a special health matter in an advance health directive. Alternatively, in particular circumstances the tribunal may consent to special health care.*"³⁷ Special health care is defined in the Act to include sterilisation of the principal, termination of a pregnancy of the principal, and participation by the principal in special medical research or experimental health care, electro-convulsive therapy or psychosurgery for the principal, and prescribed special health care of the principal.³⁸ Prescribed special health care is defined as health care prescribed under the Guardianship and Administration Act 2000.³⁹ A direction in an advance health directive to withhold or withdraw a life-sustaining measure is ineffective (other than a direction to withhold or withdraw artificial nutrition or artificial hydration) unless the commencement or continuation of the measure would be inconsistent with good medical practice.⁴⁰ "Life-sustaining measures" are defined to include cardiopulmonary resuscitation, assisted ventilation, artificial nutrition and hydration, but do not include a blood transfusion.⁴¹ "Good medical practice" is defined as "*good medical practice for the medical profession ... having regard to the recognised medical standards, practices and procedures of the medical profession ... and the recognised ethical standards of the medical profession ...*"⁴² The Act specifically provides that a direction in an advance health directive has priority over a

³⁶ See Powers of Attorney Act 1998, section 6A(1)(c).

³⁷ See footnote to section 6 of Schedule 2, Powers of Attorney Act 1998.

³⁸ See Powers of Attorney Act 1998, Schedule 2, section 7.

³⁹ See Powers of Attorney Act 1998, Schedule 2, section 17.

⁴⁰ See Powers of Attorney Act 1998, section 36.

⁴¹ See Powers of Attorney Act 1998, Schedule 2, section 5A.

⁴² See Powers of Attorney Act 1998, Schedule 2, section 5B.

general or specific power in relation to health matters given to an attorney, and that an advance health directive is not revoked by the principal becoming a person with impaired capacity. The Act also specifies the formal requirements for the making and revocation of an enduring power of attorney. Section 37 provides that nothing in the Act authorises, justifies or excuses killing a person, or affects the Criminal Code, section 284 or chapter 28.⁴³ It is therefore clear that the Act does not in any way authorise euthanasia or assisted suicide.⁴⁴ To avoid conflict of interest or abuse, if the attorney becomes the service provider for a residential service where the principal is a resident, the enduring document is revoked to the extent that it gives power to the attorney.⁴⁵

- Chapter 4 contains provisions that authorise a "statutory health attorney" to make health care decisions, drawn from a list of persons who are readily available and culturally appropriate. The list includes "an adult who has the care of the adult."⁴⁶ *"This recognises the role of a primary carer as being the appropriate member of the family to make decisions in health matters on behalf of a person with a decision-making disability."*⁴⁷ If no one listed is available, then the adult guardian is the statutory health attorney. It should be noted that a statutory health attorney's power to make any decision in respect of an adult's health matters does not include a "special health matter". A special health matter, for a principal, is a matter relating to the special health care of the principal.⁴⁸

- Chapter 5 contains provisions that protect an attorney who, without knowing a power is invalid, purports to exercise that

⁴³

Quoting:

Criminal Code –

'Consent to death immaterial

284. Consent by a person to the causing of the person's own death does not affect the criminal responsibility of any person by whom such death is caused.'

Chapter 28 (Homicide-suicide-concealment of birth), including -

'Acceleration of death

296. A person who does any act or makes any omission which hastens the death of another person who, when the act is done or the omission is made, is labouring under some disorder or disease arising from another cause, is deemed to have killed that other person.'

'Aiding suicide

311. Any person who –

(a) procures another to kill himself or herself; or

(b) counsels another to kill himself or herself and thereby induces the other person to do so; or

(c) aids another in killing himself or herself;

is guilty of a crime, and is liable to imprisonment for life.'

⁴⁴

See *Queensland Parliament Hansard*, second reading of Powers of Attorney Bill, 8 October, 1997, at 3687.

⁴⁵

Powers of Attorney Act 1998, section 59AA.

⁴⁶

Powers of Attorney Act 1998, section 63(1)(b).

⁴⁷

See *Queensland Parliament Hansard*, second reading of Power of Attorney Bill, 8 October, 1997, at 3688.

⁴⁸

See Powers of Attorney Act 1998, Schedule 2, section 6.

power. The attorney will not incur any liability, either to the principal or anyone else, because of the invalidity.⁴⁹ Chapter 5 also provides that a person, other than an attorney, who, without knowing that an advance health directive or a power in relation to a health matter under an enduring document is invalid, acts in reliance on the directive or purported exercise of the power, does not incur any liability, either to the adult or anyone else, because of the invalidity.⁵⁰ A health provider is not affected by an adult's advance health directive to the extent that the health provider does not know the adult has an advance health directive.⁵¹

- Chapter 6 ensures that the Supreme Court's powers have application to all powers of attorney and are not limited to documents made under the Act. It preserves the inherent *parens patriae* jurisdiction of the Supreme Court in relation to people with a disability.⁵² It also provides that the Guardianship and Administration Tribunal would be given the same jurisdiction and powers for enduring documents as the Supreme Court.⁵³
- Chapter 7 of the Act (on adult guardians) is repealed by the Guardianship and Administration Act 2000.⁵⁴
- Schedule 1 of the Act contains the general principles. An adult is presumed to have capacity for a matter.⁵⁵ It provides that the power to exercise decisions in respect of a health matter for an adult should be exercised by an attorney in the way least restrictive of the adult's rights, and that the exercise of the power should be appropriate to promote and maintain the adult's health and well-being.⁵⁶ In deciding whether the exercise of a power is appropriate, the attorney must, to the greatest extent practicable, ascertain the adult's views and wishes and take them into account, and take the information given by the adult's health provider into account.⁵⁷ The adult's views and wishes may be expressed orally, in writing (for example, in an advance health directive) or in any other way, including, for example, by conduct.⁵⁸ The health care principle does not affect any right an adult has to refuse health care.⁵⁹

49 See Powers of Attorney Act 1998, section 98(2).

50 See Powers of Attorney Act 1998, section 100.

51 See Powers of Attorney Act 1998, section 102.

52 See Powers of Attorney Act 1998, section 109.

53 See Powers of Attorney Act 1998, section 109A.

54 Guardianship and Administration Act 2000 No. 8, section 263, Schedule 3, section 29.

55 See Powers of attorney Act 1998, Schedule 1, section 1.

56 Powers of Attorney Act 1998, Schedule 1, section 12(1).

57 Schedule 1, section 12(2).

58 Schedule 1, section 12(3).

59 Schedule 1, section 12(4).

Guardianship and Administration Act 2000

7.29 As stated in its preamble, the purpose of the Guardianship and Administration Act 2000 is to:

"consolidate, amend and reform the law relating to the appointment of guardians and administrators to manage the personal and financial affairs of adults with impaired capacity, to establish a Guardianship and Administration Tribunal, to continue the office of adult guardian, to create an office of Public Advocate, and for other purposes."

7.30 The 2000 Act seeks to strike an appropriate balance between the right of an adult with impaired capacity to the greatest possible degree of autonomy in decision-making, and the adult's right to adequate and appropriate support for decision-making.⁶⁰

7.31 The 2000 Act should be read in conjunction with the Powers of Attorney Act 1998. If there is an inconsistency between the Powers of Attorney Act 1998 and the Guardianship and Administration Act 2000, the latter Act prevails.⁶¹

7.32 A guardian appointed under the 2000 Act may only be appointed for personal matters.⁶² A personal matter is defined in schedule 2 of the Act to mean a matter, other than a special personal matter or special health matter, relating to the adult's care, including the adult's health care, or welfare, including:

- where the adult lives,
- day-to-day issues, including, for example, diet and dress,
- health care of the adult,
- a legal matter not relating to the adult's financial or property matters, and
- whether to consent to a forensic examination of the adult.

7.33 A person or other entity who performs a function or exercises a power under the 2000 Act in respect of a matter relating to an adult with impaired capacity must apply the general principles stated in schedule 1 (and, for a health matter, the health care principle).⁶³

7.34 The Guardianship and Administration Tribunal may by order appoint a guardian for a personal matter if the tribunal is satisfied that the adult has impaired capacity. It may make the order on its own initiative or on

⁶⁰ Guardianship and Administration Act 2000, section 6.

⁶¹ Guardianship and Administration Act 2000, section 8(2).

⁶² See section 9.

⁶³ See section 11.

the application of the adult, the adult guardian or an interested person.⁶⁴ An interested person means a person who has sufficient and continuing interest in the person of impaired capacity. The tribunal may decide whether a person is an interested person under this Act or the Powers of Attorney Act 1998.⁶⁵

7.35 Subject to section 74⁶⁶, section 14 provides that no one may be appointed as a guardian for a special personal matter or special health matter. The appointment order may include a declaration, order, direction, recommendation, or advice about how the power given is to be used.⁶⁷

7.36 Section 62 sets out the scope of Division 1 of Part 2 of Chapter 5, when health care other than special health care may be carried out without consent.

7.37 Section 63 provides for the provision of urgent health care, other than special health care, without consent. This section covers two situations. Firstly, if a health provider considers that an adult has impaired capacity in respect of the health matter, and the health care needs to be carried out urgently to meet an imminent risk to the adult's life or health, the health care can be carried out unless the health provider knows that the adult has given a direction in an advance directive objecting to such health care. Secondly, if the health provider considers that the adult has impaired capacity in respect of the health matter, and the health care has to be carried out urgently to prevent significant pain or distress to the adult, and it is not reasonably practicable to obtain consent from a person who may give it under the Act or the Powers of Attorney Act 1998, the health care can be carried out.⁶⁸

7.38 Section 63A specifically deals with life-sustaining measures in an acute emergency. A life-sustaining measure may be withheld or withdrawn for an adult without consent if the adult's health provider considers the adult has impaired capacity for the health matter concerned; and the commencement or continuation of the measure for the adult would be inconsistent with good medical practice; and, consistent with good medical practice, the decision to withhold or withdraw the measure must be taken immediately. It should be noted that the measure may not be withheld or withdrawn without consent if the health provider knows the adult objects to the withholding or withdrawal.⁶⁹

7.39 A consent to the withholding or withdrawal of a life-sustaining measure for the adult cannot operate unless the adult's health provider

⁶⁴ See section 12.

⁶⁵ Section 126.

⁶⁶ Section 74 provides that the tribunal may appoint one or more persons who are eligible for appointment as a guardian or guardians for the adult and give the guardian or guardians power to consent for the adult to continuation of the special health care, or the carrying out on the adult of similar special health care.

⁶⁷ See Guardianship and Administration Act 2000, section 74(2).

⁶⁸ See Explanatory Notes to Guardianship and Administration Bill 1999, Chapter 5, Part 2, Division 1.

⁶⁹ Guardianship and Administration Act 2000, section 63A (2).

considers the commencement or continuation of the measure for the adult would be inconsistent with good medical practice.⁷⁰

7.40 Section 64 of the Act allows minor and uncontroversial health care to be carried out without consent for an adult with impaired capacity where the health provider considers the health care is necessary to promote the adult's health and well-being, if it is of a type that will best promote the adult's health and well-being and is minor and uncontroversial. In addition, the adult must not object to the health care and the health provider should not know (or cannot be reasonably expected to know) of a decision about the health care made by a person who is able to make the decision under the Act or the Powers of Attorney Act 1998, or any dispute among persons with a sufficient and continuing interest in the adult about the carrying out of the health care or the capacity of the adult in respect of the health matter. The health provider must certify the details of this health care in the adult's clinical records.⁷¹

7.41 Division 2 of Part 2 of Chapter 5 deals with health care and special care with consent:⁷²

- Section 65 provides a hierarchy for dealing with special health matters. Firstly, if an adult has made an advance health directive giving directions about a special health matter, the matter can only be dealt with under that direction. If there is no advance health directive but another entity is authorised to deal with the matter, the matter may only be dealt with by that entity. Finally, if there is no advance health directive or authorised entity, and the tribunal has made an order about the matter, the matter may only be dealt with under that order.
- Section 66 provides a hierarchy for dealing with health matters for an adult with impaired capacity. If the adult has made an advance health directive giving a direction about a health matter, the matter can only be dealt with under that direction. If there is no advance health directive and the tribunal has appointed one or more guardians in relation to the matter, or made an order about the matter, the matter can only be dealt with by the guardian or guardians or under the order. If there is no advance health directive, tribunal-appointed guardian or tribunal order but the adult has granted an enduring power of attorney in respect of the matter, the matter can only be dealt with by the attorney or attorneys so appointed. If there is no advance health directive, tribunal-appointed guardian or tribunal order, or attorney appointed under an enduring power of attorney, the matter can only be dealt with by the statutory health attorney.

⁷⁰ See Guardianship and Administration Act 2000, section 66A(2).

⁷¹ See Guardianship and Administration Act 2000, section 64(3).

⁷² See Explanatory Notes to Guardianship and Administration Bill 1999, Chapter 5, Part 2, Division 2.

- Section 67 provides that consent given on behalf of an adult with impaired capacity in respect of a health matter is generally ineffective if the adult objects to the particular health care. That objection can be overridden, however, if the adult has minimal or no understanding of what the health care involves and/or why the health care is required and any distress likely to be caused is outweighed by the benefit to the adult of the proposed health care. This power to override the objection does not, however, apply to objections to tissue donation, participation in special medical research or experimental health care or approved clinical research, or the withholding or withdrawal of life sustaining measures.

7.42
care:⁷³

Part 3 of Chapter 5 of the Act governs consent to special health

- Section 68 empowers the tribunal to consent on behalf of an adult to special care, other than electro-convulsive therapy or psychosurgery. "Special health care" is defined in Schedule 2. Section 68 also provides that if another entity is authorised by the Act to make a decision about prescribed special health care (that is, further special health care to be prescribed by regulation) the tribunal does not have the power to make the decision.
- Section 69 allows the tribunal to consent to the removal of tissue from an adult with impaired capacity for donating to another person only if the tribunal is satisfied of the matters specified. The tribunal cannot consent if the adult objects to the health care. Where the tribunal does consent to the removal of tissue for donation, the tribunal order must specify the proposed recipient.
- Sections 70 and 71 respectively govern consent by the tribunal to sterilisation, or termination of pregnancy, of an adult with impaired capacity.
- Section 72 provides that the tribunal may consent to participation by an adult with impaired capacity in special medical research or experimental health care, either relating to a condition the adult has or to which the adult has a significant risk of being exposed, or to gain knowledge that can be used in the diagnosis and treatment of a condition affecting the adult. The tribunal can only consent to the adult's participation in special medical research or experimental health care to diagnose or treat the adult if it is satisfied of the matters specified in this section. The tribunal cannot consent if the adult objects to the research or health care, or if in an enduring

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See Explanatory Notes to Guardianship and Administration Bill 1999, Chapter 5, Part 3.

document the adult has indicated unwillingness to participate in the research or health care.

- Section 73 provides that if another entity has not been authorised to consent to any prescribed special health care, the tribunal is empowered to do so. That consent is subject to any matters which may be prescribed by regulations.
- Section 74 provides that where the tribunal has consented to particular special health care, it may appoint one or more persons who are eligible for appointment as a guardian for the adult and give them the power to consent to the continuation of the special health care or the carrying out on the adult of similar special health care. In exercising a consent power under this section, a guardian must apply the general and health care principles set out in Schedule 1.

7.43 There is a protective provision for the health provider in Part 4 of Chapter 5:

*"To the extent a health provider giving health care to an adult complies with a purported exercise of power for a health matter or special health matter by a person who represented to the health provider that the person had the right to exercise the power, the health provider is taken to have the adult's consent to the exercise of power."*⁷⁴

7.44 A criminal sanction is provided under section 79, which makes it an offence to carry out health care of an adult with impaired capacity unless authorised.

7.45 A person carrying out authorised health care of an adult is not liable for an act or omission to any greater extent than if the act or omission happened with the adult's consent and the adult had capacity to consent.⁷⁵

7.46 Sections 81 to 114 deal with the establishment, functions and powers of the Guardianship and Administration Tribunal.

7.47 Part 1 of Chapter 8 provides for the establishment, functions and powers of an adult guardian:⁷⁶

- Section 173 provides that there must be an adult guardian.
- Section 174 sets out the role of the guardian as protecting the rights and interests of adults who have impaired capacity. The adult guardian's statutory functions include protecting adults who have impaired capacity from neglect, exploitation, or abuse,

⁷⁴ Section 77.

⁷⁵ Guardianship and Administration Act 2000, section 80.

⁷⁶ See Explanatory Notes to Guardianship and Administration Bill 1999, Chapter 8, Part 1.

and investigating complaints and allegations about actions by any person acting or purporting to act under a power of attorney, advance health directive or order of the tribunal made under the Act.

- Section 175 provides that the adult guardian may do all things necessary or convenient to be done to perform the adult guardian's functions.

7.48 Part 2 of Chapter 8 provides for the investigative powers of the adult guardian. Section 180 provides that the adult guardian may investigate a complaint or allegation that an adult with impaired capacity :

- (a) is being or has been neglected, exploited or abused; or
- (b) has inappropriate or inadequate decision-making arrangements.

7.49 Part 3 of Chapter 8 provides for the protective powers of the adult guardian. Section 197 provides that where the adult guardian considers there are reasonable grounds for suspecting there is an immediate risk of harm, because of neglect (including self-neglect), exploitation or abuse, to an adult with impaired capacity, the adult guardian may apply to the tribunal for a warrant to enter a place and remove the adult.

7.50 Chapter 9 of the Act provides for the establishment, functions and powers of the public advocate. Section 209 sets out the functions of the public advocate, which include promoting and protecting the rights of adults with impaired capacity, promoting the protection of the adults from neglect, exploitation or abuse, and encouraging the development of programs to help those adults to reach the greatest practicable degree of autonomy.

7.51 Part 2 of Chapter 11 of the Act sets out the relationship with the Court's existing jurisdiction. Section 239 provides that the Act does not affect the Rules of Court of the Supreme Court, District Court or Magistrates' Court in respect of a litigation guardian for a person under a legal incapacity. Section 240 provides that the inherent jurisdiction of the Supreme Court, including its *parens patriae* jurisdiction, is not affected by the Act. Section 241 provides that the Supreme Court may, if it considers it appropriate, transfer a proceeding within the tribunal's jurisdiction to the tribunal, and that the tribunal may, if it considers it appropriate, transfer a proceeding within the Supreme Court's jurisdiction to the Supreme Court. The transfer may be ordered on the Court's or tribunal's initiative or on the application of an active party to the proceeding.

7.52 Section 247 provides for "whistleblowers" protection. A person is not liable civilly, criminally or under an administrative process for disclosing to an official information about a person's conduct that breaches either the Guardianship and Administration Act 2000 or the Powers of Attorney Act 1998. Without limiting that wide protection, the section provides that in a proceeding for defamation the discloser has a defence of

absolute privilege for publishing the disclosed information.

Mental Health Act 2000

7.53 The purpose of this Act (which repealed the Mental Health Act 1974) is to provide for the involuntary assessment and treatment of persons who have mental illnesses, while at the same time safeguarding their rights.⁷⁷ It entirely replaced the Mental Health Act 1974.

7.54 The legislation is "*necessary to provide for treatment of mental illness when the person is unable to consent or is unreasonably objecting to treatment*"⁷⁸. However, there is nothing in the legislation that prevents a person from being admitted as a voluntary patient.⁷⁹

7.55 Section 8 of the Act lays down the general principles for the administration of the Act in relation to a person who has a mental illness. These include:

- the right of all persons to the same basic human rights must be recognised and taken into account;
- a person is to be encouraged to take part in making decisions affecting his life, especially decisions about treatment;
- in making a decision about a person, the person's views and the effect on his family or carers are to be taken into account;
- a person is presumed to have capacity to make decisions about his assessment and treatment;
- a person is to be helped to achieve maximum physical, social, psychological and emotional potential and quality of life and self-reliance;
- a person's age-related, gender-related, religious, cultural, language, communication and other special needs must be taken into account; and
- treatment provided under the Act must be administered to a person who has a mental illness only if it is appropriate to promote and maintain the person's mental health and well-being.

7.56 "Mental Illness" is defined in the Act as "*a condition*

⁷⁷ Mental Health Act 2000, section 4.

⁷⁸ See Explanatory Notes to Mental Health Bill 2000, p 4.

⁷⁹ Section 6 of the Mental Health Act 2000 provides that "[t]his Act does not prevent a person who has a mental illness being admitted to, or receiving assessment or treatment at, an authorised mental health service other than as an involuntary patient".

characterised by a clinically significant disturbance of thought, mood, perception or memory."⁸⁰ However, section 12(2) provides exclusions to this definition:

"a person must not be considered to have a mental illness merely because of any 1 or more of the following-

- (a) the person holds or refuses to hold a particular religious, cultural, philosophical or political belief or opinion;*
- (b) the person is a member of a particular racial group;*
- (c) the person has a particular economic or social status;*
- (d) the person has a particular sexual preference or sexual orientation;*
- (e) the person engages in sexual promiscuity;*
- (f) the person engages in immoral or indecent conduct;*
- (g) the person takes drugs or alcohol;*
- (h) the person has an intellectual disability;*
- (i) the person engages in antisocial behaviour or illegal behaviour;*
- (j) the person is or has been involved in family conflict;*
- (k) the person has previously been treated for mental illness or been subject to involuntary assessment or treatment.*

(3) Subsection (2) does not prevent a person mentioned in the subsection having a mental illness."

Canada: Alberta

Law reform proposals

7.57 The law in the area of advance directives and substitute decision-making in personal health care was examined by the Alberta Law Reform Institute, which published a "report for discussion" in November 1991.⁸¹ A final report followed in 1993, jointly issued by the Alberta Law Reform Institute and the Health Law Institute. That report summarised the law in Alberta as follows:

"1. If an adult (other than an involuntary psychiatric patient) is mentally incapable of consenting to medical treatment, the only person who has legal authority to consent on the adult's

⁸⁰ Mental Health Act 2000, section 12.

⁸¹ Report for Discussion No.11, *Advance Directives and Substitute Decision-Making in Personal Health Care*.

behalf is a guardian appointed under the Dependent Adults Act.

2. *Treatment can be given to a mentally incompetent person without anyone's consent if (a) the treatment is immediately necessary to preserve the life or health of that person, or (b) the person has no guardian and two physicians issue a written certificate⁸² stating that he or she is in need of the treatment and is incapable of consenting to it.*

3. *It is generally assumed that an advance healthcare directive (often referred to as a 'living will') has no legal force in the absence of legislation, but recent case-law from Ontario⁸³ casts significant doubt on this assumption. The position under Alberta law remains uncertain.*

4. *The appointment of an attorney with authority to make healthcare decisions on behalf of the principal in the event of the latter's mental incapacity is probably ineffective under the current Alberta law.⁸⁴*

7.58 The report commented that the existing law was unsatisfactory, primarily for two reasons:⁸⁵

"First, it places healthcare professionals in an untenable position. On the one hand the law requires that consent be obtained before treatment is administered, but on the other hand the law fails to provide a practicable mechanism for obtaining consent where the patient is mentally incapable of providing it. This may well interfere with patient's receiving timely and proper treatment. It is also unacceptable that healthcare professionals should be faced with uncertainty in the law with respect to such vital issues as the legal effect of living wills and other advance directives for healthcare.

The other deficiency in the present law is that it fails to provide individuals with a mechanism of planning for their own incapacity with respect to healthcare decisions."

7.59 The Federation of Law Reform Agencies of Canada has prepared a compendium of law reform activity which summarises the comments and recommendations for reform made in the Alberta Law Reform Institute's report:⁸⁶

⁸² Pursuant to the Dependent Adults Act, section 29.

⁸³ Quoting *Malette v Shulman* (1990) 72 OR (2d) 417 (CA)

⁸⁴ Alberta Law Reform Institute, Report No 64 (a joint report of the Alberta Law Reform Institute and the Health Law Institute), *Advance Directives and Substitute Decision-Making in Personal Healthcare* (1993), at 4.

⁸⁵ Alberta Law Reform Institute, Report No 64 (a joint report of the Alberta Law Reform Institute and the Health Law Institute), *Advance Directives and Substitute Decision-Making in Personal Healthcare* (1993), at 4-5.

⁸⁶ *Canadian Law Reform 1992/93*, Report No.64, at <http://www.bcli.org/pages/links/folra/clr92-93.htm> (07/12/2001).

"The report suggests that legislation be introduced to give legal force to healthcare directives. A directive could appoint an agent to make the healthcare decisions in the event of the incapacity of the maker of the healthcare directive; it could identify anyone whom the individual does not wish to act as a healthcare proxy; finally it could give specific instructions as to what is to happen in certain specified circumstances.

The second major recommendation is the creation of a back up system of substitute decision-making for those patients who have not appointed a healthcare agent. This is done by a statutory list of proxy decision-makers whose order of priority roughly corresponds to the closeness of the relationship to the individual.

Either the healthcare agent or the healthcare proxy uses three stages to determine what healthcare decision is correct. First the agent or proxy looks to the relevant and unambiguous instructions given by the individual; second, the agent or proxy looks for the decision which it is believed the patient would have decided if competent. Finally, as a last resort, the agent or proxy will make a decision which is in the best interests of the patient.

The intention of the proposed scheme is to create advance directives which provide clear and unambiguous instruction to the healthcare decision-maker and will settle issues without resort to delaying litigation. To encourage the use of advance directives, the formalities for creation of such a document are relatively simple and straightforward. They demand only that serious thought be given to the instructions and that the document be signed and witnessed."

Personal Directives Act 1996

7.60 A Personal Directives Act was enacted in 1996 after public consultation. The key principles of this legislation can be readily ascertained from the statement made by Ms Carol Haley, Member of the Legislative Assembly in Alberta, in moving the second reading of the Bill.⁸⁷

"The key principles of this legislation are that it has a broad scope so that all personal matters that are non-financial - for example, health care, place of residence, participation in social, recreational, and education activities, as well as legal affairs - can be included in a personal directive. We want to ensure that making a personal directive is simple and does not require the

⁸⁷

<http://199.213.89.9:8080/ISYSquery/frame/IHT3699.c> at 46, (7 December 2001).

involvement of a lawyer. We [have] included in this legislation that making a personal directive is strictly voluntary. We are expressly prohibiting any illegal instructions from being included in a personal directive. An agent, when making decisions on behalf of an individual, must follow any clear instructions in a directive that are relevant to the decisions to be made. If no instruction exists, then the agent must try and make the decision that the individual would have made based on that person's wishes, beliefs, and values. If the individual's wishes, beliefs, and values are not known, then the agent must make the decision which appears to be in the best interest of the individual, and finally, [this legislation recognises] the court as having final authority to settle a dispute that may arise about the validity of a personal directive or the decision made by the agent, ...

Under the proposed Bill, any Albertan who is at least 18 years old who understands the nature and consequences of a personal directive would be able to make one. To be valid, a personal directive would need to be in writing, dated, and signed by an individual and signed by one witness. A personal directive could contain any information or instructions regarding personal matters, including an appointment of one agent or more than one agent, identifying the authority of the agent, providing instructions about specific decisions, naming a person to assess the individual's capacity for purposes of bringing a personal directive into effect, or outlining how an agent should go about making decisions.

A personal directive would only come into effect when the individual lacks the capacity to make a decision about a personal matter. A directive would be brought into effect on a determination by a person named in the directive, after consulting with a physician or a psychologist, that the individual lacks capacity, or, if a person is not named, on a determination that the individual lacks capacity by two service providers, one of whom must be a physician or a psychologist. The court would have the ultimate authority to settle disputes on such matters as the validity of a personal directive, the capacity of an individual or an agent, or specific decisions made by an agent. ...

[It] would include all personal matters that are non-financial in nature. It would not be limited to health care decisions. ... The concept of decision-making by a relative selected from a list of nearest relatives would be dropped. Instructions that could be provided in a directive would be expanded to allow an individual to name a person to assess his or her capacity in order to bring a directive into effect."

7.61 "Service provider" is defined in the Act to mean a person who carries on a business or profession that provides, or who is employed to

provide, a personal service to an individual and when providing the service requires a personal decision from the individual before providing the service.⁸⁸ "Personal service" means a service provided with respect to a personal matter.⁸⁹

7.62 A protective provision is made in section 28(3) of the Act that:

"No action lies against an agent or service provider for anything done or omitted to be done in good faith in reliance on a personal directive if the maker of a personal directive has:

- (a) changed or revoked the personal directive, or*
- (b) revoked the authority of the agent*

*without the knowledge of the agent or service provider, as the case may be.*⁹⁰

Canada: Manitoba

7.63 The Law Reform Commission of Manitoba also dealt with the issues in this area and issued reports in 1991⁹¹ and 2003,⁹² the first of which led to the enactment of the Health Care Directives Act 1992.

The Health Care Directives Act

7.64 The key principles of this legislation are as follows:

- A personal health care directive or living will instructs family members and medical practitioners on the nature and extent of medical or other treatment if, at some future time, the adult is incompetent or unable to communicate his or her wishes.
- The adult can set limits on medical treatment and appoint a person to make such decisions on the adult's behalf.
- It provides some legal assurance that living wills will be respected by families and the medical profession.

7.65 The health care directive tends to have greatest impact in serious circumstances, such as where extreme measures of resuscitation are applied or where the individual is maintained for extended periods of time on

⁸⁸ See Personal Directives Act, section 1(n).

⁸⁹ Personal Directives Act, section 1(m).

⁹⁰ Reproduced with the permission of the Alberta Queen's Printer.

⁹¹ *Self-Determination in Health Care (Living Wills and Health Care Proxies)*, (Report No 74, 1991).

⁹² Manitoba Law Reform Commission, *Withholding or withdrawing life sustaining medical treatment* (Report No 109, 2003)

life support apparatus. However, should the health directive include the adult's desire for euthanasia in the event of contracting a painful and fatal disease, the directive would not be followed as it would be against the law to do so.⁹³

7.66 A person who is 16 years of age or more has the capacity to make health decisions under the Act.⁹⁴

7.67 Section 5 provides that "*a directive may express the maker's health care decisions or may appoint a proxy⁹⁵ to make health care decisions on the maker's behalf, or both.*"

7.68 The formal requirements of a directive are that:⁹⁶

- it has to be in writing and dated, and
- it has to be signed by the maker, or by some other person at the direction and in the presence of the maker, in which case the person signing shall not be a proxy appointed in the directive or a proxy's spouse, and the maker would have to acknowledge the signature in the presence of a witness, who should not be a proxy appointed in the directive or a proxy's spouse, and the witness shall sign the directive as witness in the maker's presence.

7.69 It is worth noting that section 9(2) provides that the appointment of a spouse as a proxy is automatically revoked where the marriage is terminated by divorce.

7.70 Similar to the legislative provisions in other jurisdictions, a proxy must act in accordance with certain principles. In particular, if the proxy knows of relevant wishes expressed by the maker when the maker had capacity, and believes the maker would still act on them if capable, and if those wishes are more recent than the decisions expressed in a directive, the wishes must be followed.⁹⁷

7.71 There are also limitations on the extent of the proxy's power to consent. For example, a proxy cannot consent to sterilisation, the removal of tissue from the maker's body or medical treatment for the primary purpose of research.⁹⁸

⁹³ Manitoba Law Reform Commission, *Adult Protection and Elder Abuse*, (Report No 103, 1999), at 22.

⁹⁴ "Health care decision" is defined to mean a consent, refusal to consent or withdrawal of consent to treatment.

⁹⁵ "Proxy" means a person appointed in a directive to make health care decisions on behalf of the maker of the directive.

⁹⁶ The Health Care Directives Act, section 8.

⁹⁷ The Health Care Directives Act, section 13(3).

⁹⁸ The Health Care Directives Act, section 14.

7.72 There are provisions which protect the proxy from liability where he has acted in good faith,⁹⁹ and a presumption of validity of the directive.¹⁰⁰

7.73 The existing rights under the common law are expressly preserved by section 25 of the Act.

Manitoba Law Reform Commission report on Withholding or Withdrawing Life Sustaining Treatment

7.74 In December 2003, the Manitoba Law Reform Commission issued a report on withholding or withdrawing life sustaining medical treatment¹⁰¹, following the release of a discussion paper in June 2002. The Executive Summary of the report summarised the issues examined in the report:

"It explores a range of issues relating to end of life medical decision-making including: the power of modern technology to prolong life beyond its natural end; the propriety of providing life sustaining medical treatment which offers no therapeutic benefit and may threaten additional harm; the competing interests of patients, physicians and other stakeholders; the allocation of ultimate authority for making decisions to withhold or withdraw life sustaining medical treatment; and the principles and procedures that should guide the decision making process."¹⁰²

7.75 The report outlines the policies and procedures that should guide end-of-life decision-making and makes recommendations as to implementation. The Commission considered that certain fundamental principles and policies should be reflected in the rules or framework controlling the withholding or withdrawal of life-sustaining medical treatment. Some of the principles and procedures are set out below:

- There must be a uniform approach and process to withholding or withdrawing life-sustaining medical treatment in all health care institutions.
- The decision-making process must be clear and transparent and must be communicated clearly not only to the patient and his or her family but also to the public in order to facilitate a broad understanding of how these decisions are made.
- Emphasis must be placed on the process for decision-making rather than the formulation of specific rules which would purport to dictate the decision. The process must be designed to

⁹⁹ The Health Care Directives Act, section 19.

¹⁰⁰ The Health Care Directives Act, section 23.

¹⁰¹ Manitoba Law Reform Commission, Report No. 109.

¹⁰² Manitoba Law Reform Commission, *Report on withholding or withdrawing life sustaining medical treatment*, at 106.

facilitate an agreement between the physician and the patient or his or her substitute decision-maker.

- Where there is disagreement between the physician and the patient or substitute decision-maker on the appropriate course of action, the patient must be given an opportunity to secure an independent second opinion from a physician who is not a member of the patient's health care team and/or request that his or her care be transferred to another willing physician.
- The Commission did not favour a right to indefinite life-sustaining medical treatment. The appeal of autonomous decision-making and personal control of all end-of-life medical decision making is initially attractive, but an unfettered right to life-sustaining treatment may result in unreasonable demands being made for indefinite inappropriate medical treatment.
- Final resort to the courts will remain available where the procedures designed to achieve consensus have irretrievably broken down.

7.76 The Manitoba Law Reform Commission did not propose that the principles outlined in the report should be implemented by legislation. The Executive Summary of the report summarised the Commission's view regarding implementation as follows:

"The Commission does not favour a legislative implementation of these principles. Its preference is to see them embodied in a statement or by-law of the College of Physicians and Surgeons of Manitoba. ... We also recommend that other health care institutions, agencies, associations and bodies involved in delivering health care in Manitoba should adopt the Policy of the College once amended to reflect our advice. We urge them to use the Policy as a template for their own protocols and procedures.

We envisage a cohesive and integrated approach to maximise consensus decision making without imposing an obligation on physicians to provide inappropriate medical care. Such an approach, coupled with an extensive program of public education and awareness of the end of life decision making process, will serve the citizens of Manitoba well."¹⁰³

¹⁰³

Manitoba Law Reform Commission, *Report on withholding or withdrawing life sustaining medical treatment*, at 108.

England and Wales

Existing law

7.77 In England, the governing statute relating to mental incapacity is the Mental Health Act 1983 ("the Act"). The provisions of the Act are broadly similar to those of the Mental Health Ordinance (Cap 136) ("the Ordinance"), before the enactment of the Mental Health (Amendment) Ordinance 1997.

7.78 Part I of the Act provides for its application to "mentally disordered" patients. The definition of "mental disorder" in the Act is similar to that in the Ordinance. The Mental Health (Amendment) Ordinance has made the application of the Ordinance wider by including "mentally handicapped" persons.

7.79 Part II of the Act provides for civil procedures for compulsory admission to hospital and for the guardianship of patients suffering from mental disorder. The person named as guardian in a guardianship application may be either a local social services authority or any other person.¹⁰⁴

7.80 A local social services authority for the area may, with the approval of the Secretary of State, make arrangements as regards patients suffering from mental disorder who are received into guardianship.

7.81 A guardianship application, subject to regulations made by the Secretary of State, confers on the guardian the following powers:¹⁰⁵

- "(a) the power to require the patient to reside at a place specified by the authority or person named as guardian;*
- (b) the power to require the patient to attend at places and times so specified for the purpose of medical treatment, occupation, education or training;*
- (c) the power to require access to the patient to be given, at any place where the patient is residing, to any registered medical practitioner, approved social worker or other person so specified."*

7.82 Sections 25A to 25J provide for the supervision of the after-care services of a patient after he leaves hospital.

7.83 Part III deals with patients concerned in criminal proceedings or under sentence. A hospital order or interim hospital order may be made by the court on the written or oral evidence of two registered medical practitioners in respect of a person who is convicted before the Crown Court

¹⁰⁴ See section 7(5) of the Mental Health Act 1983.

¹⁰⁵ See section 8 of the Mental Health Act 1983.

or the magistrates' court of an offence punishable with imprisonment, if the court finds him to be suffering from a mental disorder which warrants such an order being made.¹⁰⁶ Alternatively, a guardianship order may be made by the court in respect of such a person, in which case he would be placed under the guardianship of a local social services authority or of another person approved by a local social services authority.¹⁰⁷

7.84 Part IV regulates consent to medical treatment for mental disorder.

7.85 A review mechanism is provided in Part V through the establishment of Mental Health Review Tribunals to deal with applications and references relating to patients suffering from mental disorder. Applications may be made in respect of such matters as admission for assessment, admission for treatment, guardianship application, transfer from guardianship to hospital, and discharge from hospital, etc.¹⁰⁸

7.86 Part VI deals with the removal and return of patients within the United Kingdom.

7.87 Part VII (repealed by the Mental Capacity Act 2005) dealt with the management of the property and affairs of patients suffering from mental disorder. The functions conferred by Part VII of the Act on the judge might be exercised by the Lord Chancellor, the judges nominated by the Supreme Court, the Master of the Court of Protection appointed by the Lord Chancellor ("the nominated judges") and other officers of the Court of Protection ("nominated officers").¹⁰⁹ The judge must have regard to the interests of creditors and also to the desirability of making provision for the obligations of the patient in administering a patient's affairs.¹¹⁰

Deficiencies of the existing law

7.88 The major issue associated with this area of the law was succinctly described by the English Law Commission ("the Law Commission") in its 1995 *Report on Mental Incapacity*. That report, the Law Commission said, "*seeks to provide a new set of coherent answers to a single question. The question, put simply, is 'who decides?'*"¹¹¹

Issues

7.89 Although many patients detained in hospital under the 1983 Act may lack decision-making capacity, at least temporarily and in relation to

¹⁰⁶ See sections 37 and 38 of the Mental Health Act 1983.

¹⁰⁷ See section 37 of the Mental Health Act 1983.

¹⁰⁸ See section 66 of the Mental Health Act 1983.

¹⁰⁹ See section 94 of the Mental Health Act 1983, which was repealed by the Mental Capacity Act 2005.

¹¹⁰ See section 95 of the Mental Health Act 1983, which was repealed by the Mental Capacity Act 2005.

¹¹¹ Law Commission, *Report on Mental Incapacity* (1995) Law Com No 231, at para 2.1.

some matters, the doctors and social workers who arrange their admission are not concerned with this question of capacity. The 1983 Act asks instead whether it is "*necessary for the health or safety of the patient or for the protection of other persons that he should receive treatment.*"¹¹² As noted in chapter 6, it was held in *B v Croydon District Health Authority* that the patient did have a capacity to refuse treatment being offered to her, and was refusing it, but that she could nevertheless lawfully be given it by virtue of section 3 of the UK Mental Health Act 1983 because it was "for" her mental disorder within the meaning of that section.¹¹³ The law relating to mental incapacity and decision-making must address quite different legal issues and social purposes from the law relating to detention and treatment for mental disorder.¹¹⁴

7.90 The "guardianship" scheme set out in the 1983 Act can be applied to mentally disordered persons who are living outside hospital and it does address matters other than treatment for mental disorder. However, questions of mental capacity have little relevance to these provisions. Guardianship enables a social worker (or a family member) to acquire essential powers in respect of personal welfare decisions, health care decisions and financial decisions. It cannot, however, be applied to the majority of people with a mental disability.¹¹⁵

7.91 The principle of "supervised care" in the community addresses the need to control the decisions which some people might make. This is entirely different from providing for what should happen when people are unable to make their own legally effective decisions. Neither guardianship nor supervised discharge addresses the need for substitute decision-making.

The Court of Protection

7.92 The Court of Protection is an office of the Supreme Court. Its jurisdiction is restricted to questions of "property and affairs". The Law Commission pointed out that the Court of Protection's jurisdiction is limited to decisions of a financial or business nature, and is premised on an assumption that capacity is an all-or-nothing status. No provision is made for a partial intervention in a person's affairs, limited in scope or in duration because the person concerned has partial or fluctuating capacity.

7.93 In essence, the jurisdiction of the Court of Protection is both too limited, in that it can only address financial and business issues, and too wide, in that it does not cater for partial and limited interventions.

Enduring powers of attorney

7.94 The Enduring Powers of Attorney Act 1985 ("the 1985 Act"), (which was repealed by the Mental Capacity Act 2005) allowed a person with

¹¹² Mental Health Act 1983, section 3(2)(c).

¹¹³ *B v Croydon District Health Authority*, (1994) BMLR 13.

¹¹⁴ See Law Com No 231, para 2.2.

¹¹⁵ See Law Com No 231, para 2.3.

capacity to appoint an "attorney" to manage his or her finances even after the person who has made the appointment loses mental capacity. This scheme, like the jurisdiction of the Court of Protection, was limited to property and business matters and provided no solution to those who wished to make effective long-term arrangements about health care matters or, for example, where to live.

Personal welfare and health care decisions

7.95 There is no statutory scheme for the making of a non-financial decision on behalf of a person who cannot decide for himself, or for the appointment of a substitute decision-maker with continuing powers. The Court of Protection has jurisdiction to make all necessary provision regarding the financial interests of a person without capacity, including the appointment of a "receiver" to deal with matters for the patient. In contrast, the only form of guardianship to protect "personal well-being" which is currently available in England and Wales is guardianship under the 1983 Act. The Law Commission suggested in its Report that the guardianship scheme contained in the Mental Health Act was not principally designed to provide a disabled person with a proxy decision-maker but to enable a mentally ill person to live safely in the community.¹¹⁶

7.96 A guardian under the 1983 Act now has the power "to require" the patient to comply in two areas: to reside at a specified place and to attend at specified places for medical treatment, occupation, education or training. In addition, the guardian has power "to require" access to the patient to be given to doctors, social workers or other specified persons. Mental Health Act guardianship is there to allow others to take over from the patient's family. In conformity with the philosophy behind this part of the legislation, there is no assumption that the patient is unable to take any of these decisions for himself, but rather that, left alone, the decision made would be inconsistent with his own "welfare" or the protection of other persons.¹¹⁷

The declaratory jurisdiction

7.97 The High Court has both an inherent and a statutory jurisdiction to make a declaration as to whether an act is lawful or not. In *Re F*¹¹⁸ it was held by the House of Lords that, since English law has no procedure whereby a substitute or proxy can be appointed to take medical decisions for an incompetent patient, the declaratory jurisdiction should be used to fill the gap.¹¹⁹

7.98 A declaration by the High Court does not determine what is best for the patient, but only whether a particular course is or is not legal. Furthermore, a declaration does not provide the applicant or anybody else with the authority to take decisions in the future. In spite of the fact that the

¹¹⁶ See Law Com No 231 para 2.18.

¹¹⁷ See Law Com No 231, para 2.22.

¹¹⁸ [1990] 2 AC 1.

¹¹⁹ See Law Com No 231, para 2.24.

declaration cannot change anything, the court has expressed the view that certain serious procedures should always be referred to it for a declaration in advance. Conversely, the court has sought to restrict the availability of declarations in some cases and has told applicants on occasion that no declaration is needed. It is clear that the declaratory jurisdiction is of only limited value, except in so far as it provides a necessary stop-gap while more permanent measures are devised.

Protective powers

7.99 Statutory provisions already exist to give public officials powers to take protective measures in order to help vulnerable people. However, the Law Commission had no confidence that these powers strike the appropriate balance between the principles of protection and autonomy.¹²⁰ Two of the powers are to be found in the 1983 Act: a power to enter and inspect premises in which a mentally disordered person is living, and a power to apply for a warrant to enter premises and remove a patient to a place of safety. There is no need to show that the persons are lacking in capacity, or even that they are mentally disordered. The power may therefore be invoked against those who choose, in the exercise of their own free will, to live in situations which others find "insanitary", or to enjoy care and attention which others find less than "proper". The Law Commission argued that a new set of modern and acceptable emergency protective powers should be introduced. The exercise of these powers would serve where necessary as a preliminary to invoking the new decision-making jurisdiction, if it should transpire that the person who appears to be in need of protection in fact lacks decision-making capacity.¹²¹

Factors emphasising the need for change

7.100 The shortcomings of the existing law are, in the Law Commission's view, exacerbated by a number of social changes which have taken place in recent years. Firstly, in common with many other developed countries, the United Kingdom has an aging population. An increasing proportion of elderly people means an increasing need to provide the means to make decisions about their health care, personal care and finances.

7.101 An increasing emphasis on the rights of the individual has also exposed the defects of the UK's existing law. The 1971 United Nations Declaration on the Rights of Mentally Retarded Persons¹²² provides a benchmark for the way in which those who have mental disabilities (and especially mental illness) should be dealt with. Since then, civil rights arguments have been instrumental in bringing about a number of legislative changes. The National Health Service and Community Care Act 1990 and

¹²⁰ See Law Com No 231, para 2.28.

¹²¹ See Law Com No 231, paras 2.24-2.26.

¹²² In 1975 the UN made a further Declaration on the Rights of Disabled Persons, while in 1991 the General Assembly adopted *Principles for the protection of persons with mental illness and the improvement of mental health care* (Resolution 46/119 of 17 December 1991).

the Government's policy guidance on that Act both make it clear that those who are charged with arranging community care services must consult with those who will use or benefit from them.¹²³

7.102 A further factor driving reform has been increasing concern at the abuse and neglect of older people. It is said in the Law Commission Report that the phrase "elder abuse" has gained considerable currency on the social policy agenda.

7.103 It may be worth noting at this point the observations made by the Law Commission in its 1995 report:

"The social context now makes the reform of the unsatisfactory state of the law an urgent necessity. Those who responded to our first consultation paper almost four years ago recognised that the need for reform would become increasingly pressing in the face of community care policies, demographic changes, medical advances and an increasing awareness of the rights agenda. Developments over the past three years, in particular the perceived need for a decision-making jurisdiction which is being illuminated by case-law, the growth in interest in 'living wills' and the increasing concern about abuse of the elderly and disabled, have only strengthened the case for rationalisation and reform."¹²⁴

The Law Commission's reform proposals

7.104 Between 1991 and 1995, the Law Commission issued a series of four consultation papers on aspects of the law relating to mentally incapacitated adults,¹²⁵ and published its final report on *Mental Incapacity* in February 1995.¹²⁶ The Law Commission's report recommended the introduction of a single piece of legislation, and the repeal of the Enduring Powers of Attorney Act 1985 and Part VII of the Mental Health Act 1983 regarding the management of property and affairs of patients. The draft Mental Incapacity Bill annexed to the report was intended to create a statutory scheme to which recourse could be had when any decision (whether personal, medical or financial in nature) needed to be made on behalf of a person aged 16 or over who lacks capacity. The essential provisions of the Commission's draft Bill did the following:

¹²³ 1990 Act, s 46(2). *Community Care in the Next Decade and Beyond*, Policy Guidance (1990) paras 2.7-2.10.

¹²⁴ See Law Com No 231, para 2.45.

¹²⁵ The four consultation papers are: *Mentally Incapacitated Adults and Decision-Making: An Overview* (No 119) ("the First Consultation Paper"); *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (No 128) ("the Second Consultation Paper"); *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (No 129) ("the Third Consultation Paper"), and *Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection* (No 130) ("the Fourth Consultation Paper").

¹²⁶ Law Com No 231.

- *defined lack of capacity*
- *established a single criterion for the taking of decisions on behalf of people who lack capacity*
- *clarified the law where action is taken without formal procedures or judicial intervention*
- *extended and improved the law for powers of attorney which outlast capacity*
- *provided for a decision to be made, or a decision-maker appointed by, a court.*

7.105 It was intended that the provisions of the legislation should in general apply to those aged 16 and over.

Two fundamental concepts: lack of capacity and best interests

7.106 The Law Commission recommended that there should be a presumption against lack of capacity, and any question as to whether a person lacks capacity should be decided on the balance of probabilities.

7.107 The expression "mental disability" in the new legislation should mean any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning.

7.108 The Law Commission recommended that a person should be defined as without capacity if at the material time he is:

- (a) unable by reason of mental disability to make a decision on the matter in question; or
- (b) unable to communicate a decision on that matter because he or she is unconscious or for any other reason.

7.109 A person should be regarded as unable to make a decision by reason of mental disability if the disability is such that, at the time when the decision needs to be made, he or she is unable to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.

7.110 The mere fact that a person makes a decision "*which would not be made by a person of ordinary prudence*" would not mean that he should be considered as unable to make a decision by reason of mental disability.

7.111 The Law Commission recommended that anything done for, and any decision made on behalf of, a person without capacity should be done or made in his best interests. In deciding what is in a person's best interests,

regard should be had to his ascertainable past and present wishes and feelings, and the factors that he would consider if able to do so.

General authority to act reasonably

7.112 The Law Commission recommended that a person should be lawfully entitled to do anything for the personal welfare or health care of someone who is, or is reasonably believed to be, without capacity in relation to the matter in question if it is in all the circumstances reasonable for the action to be done by the person who does it.

7.113 Where reasonable actions for the personal welfare or health care of the person lacking capacity involve expenditure, it should be lawful for the person who is taking the action (1) to pledge the other's credit for that purpose or (2) to apply money in the possession of the person concerned to meet the expenditure.

7.114 The general authority should not authorise the doing of anything which is contrary to the directions of, or inconsistent with a decision made by, an attorney or manager acting within the scope of his authority. However, this restriction will not apply to actions necessary to prevent the death, or a serious deterioration in the condition, of the person concerned while an order is being sought from the court.

Independent supervision of medical and research procedures

7.115 The "general authority" should not authorise certain listed treatments or procedures, which the Law Commission recommended should require authorisation by the court or the consent of an attorney or manager.

7.116 The Law Commission proposed the establishment of a statutory committee, to be known as the Mental Incapacity Research Committee. This committee would approve proposed research if satisfied that it is desirable to provide knowledge of the causes or treatment of, or of the care of people affected by, the incapacitating condition with which any participant is or may be affected, and that the object of the research cannot be effectively achieved without the participation of persons who are or may be without capacity to consent.

7.117 In addition to the approval of the Mental Incapacity Research Committee, non-therapeutic research in relation to a person without capacity should require either:

- (1) court approval,
- (2) the consent of an attorney or manager,
- (3) a certificate from a doctor not involved in the research that the participation of the person is appropriate, or

- (4) designation of the research as not involving direct contact.

Continuing Powers of Attorney

7.118 The Law Commission proposed the introduction of a new form of power of attorney, to be called a "continuing power of attorney" ("CPA"). The donee of a CPA should have authority to make and implement decisions on behalf of the donor which the donor is without capacity to make.

7.119 A CPA could cover matters relating to a donor's personal welfare, health care and property and affairs (including the conduct of legal proceedings), and may be subject to conditions or restrictions.

7.120 An attorney acting under a CPA should act in the best interests of the donor, having regard to the statutory factors. No attorney may consent to or refuse any treatment unless the donor is, or is reasonably believed by the attorney to be, without capacity to give or refuse personal consent to that treatment.

7.121 Unless expressly authorised to do so, no attorney may consent to any treatment refused by the donor by an advance refusal of treatment, or refuse consent to any treatment necessary to sustain life.

7.122 There should be an express provision that nothing in the legislation should preclude the donor of a CPA from revoking it at any time when he or she has the capacity to do so.

7.123 Subject to any contrary intention expressed in the document, the court should have power to appoint a donee in substitution for, or in addition to, the donee mentioned in a CPA, or to modify or extend the donee's power to act. The court may act where the donor is without capacity to act and the court thinks it desirable to do so.

7.124 Once the new CPA was introduced, the Law Commission proposed that it should no longer be possible to create enduring powers of attorney.

Decision-making by the court

7.125 The court should have power to make a declaration in relation to: (1) the capacity of a person; and (2) the validity or applicability of an advance refusal of treatment.

7.126 The court may:

- (1) make any decision on behalf of a person who lacks capacity to make that decision, or
- (2) appoint a person to be responsible for making a decision on behalf of a person who lacks capacity to make it.

The decision in question may extend to any matter relating to the personal welfare, health care, property or affairs of the person concerned, including the conduct of proceedings.

7.127 The court's power in relation to health care matters should cover (1) the approval or refusal of particular forms of health care, (2) the appointment of a manager to consent or refuse consent to particular forms of health care, and (3) the requirement that a different person be allowed to take over responsibility for the health care of the individual concerned.

7.128 The court may not approve, nor a manager consent to, the withholding of basic care, or any treatment refused by an advance refusal of treatment.

7.129 The court should have power to order the admission to hospital for assessment or treatment for mental disorder of a person without capacity, if satisfied on the evidence of two doctors as to his condition and that it is appropriate, having regard to his "best interests", that he should be admitted to hospital.

Public law protection for vulnerable people at risk

7.130 The Law Commission defined a "vulnerable person" as any person over 16 who (1) is or may be in need of community care services by reason of mental or other disability, age or illness, and (2) is or may be unable to take care of himself, or unable to protect himself against significant harm or serious exploitation.

7.131 "Harm" should be defined to mean ill-treatment (including sexual abuse and forms of ill-treatment that are not physical); the impairment of, or an avoidable deterioration in, physical or mental health; and the impairment of physical, intellectual, emotional, social or behavioural development.

The judicial forum

7.132 The Law Commission recommended the creation of a new superior court of record called the Court of Protection. At the same time, the office of the Supreme Court known as the Court of Protection should be abolished.

7.133 Magistrates' courts and single justices of the peace should have jurisdiction to deal with applications under Part II of the draft Bill only, which should be treated as "family proceedings".

7.134 Leave should be required before an application to the Court of Protection can be made. In granting leave the court should have regard to:

- (1) the applicant's connection with the person concerned,

- (2) the reasons for the application,
- (3) the benefit to the person concerned of any proposed order,
- (4) whether that benefit can be achieved in any other way.

7.135 No leave should be required for any application to the court by:

- (1) a person who is, or is alleged to be without capacity, or, in respect of such a person who is under 18 years old, any person with parental responsibility for that person,
- (2) a donee of a CPA granted by the person without capacity or a court appointed manager,
- (3) any person mentioned in an existing order of the court.

7.136 The Court of Protection should have power to make an order or give directions on a matter, pending a decision on whether the person concerned is without capacity in relation to that matter.

7.137 Where the person concerned is neither present nor represented, the court should (unless it considers it unnecessary) obtain a report on his or her wishes.

Advance statements about health care

7.138 The Law Commission thought that the fundamental question which had to be considered was the nature and legal effect of the views which had been expressed by the person concerned. The Law Commission said:

*"Our approach to this topic will emphasise that there is a clear distinction to be drawn between the legal effect of an advance expression of views and preferences on the one hand, and an advance decision on the other. If the patient has in fact made an advance decision then a further important distinction is to be drawn between the legal effect of a decision in favour of a particular (or all) treatment and a decision against such treatment."*¹²⁷

The Law Commission's recommendations on advance statements about health care

7.139 The Law Commission's recommendations are summarised as follows:¹²⁸

- An advance refusal of treatment should be defined as a refusal made by a person aged 18 or over with the necessary capacity of

¹²⁷ Law Com No 231, para 5.1.

¹²⁸ Law Com No 231, paras 5.1-5.38.

any medical, surgical or dental treatment or other procedure and intended to have effect at any subsequent time when he or she may be without capacity to give or refuse consent.

- The general authority should not authorise any treatment or procedure if an advance refusal of treatment by the person concerned applies to that treatment or procedure in the circumstances of the case.
- In the absence of any indication to the contrary it shall be presumed that an advance refusal of treatment does not apply in circumstances where those having the care of the person who made it consider that the refusal (a) endangers that person's life or (b), if that person is a woman who is pregnant, the life of the foetus.
- No person should incur liability (1) for the consequences of withholding any treatment or procedure if he or she has reasonable grounds for believing that an advance refusal of treatment applies; or (2) for carrying out any treatment or procedure to which an advance refusal applies unless he or she knows or has reasonable grounds for believing that an advance refusal applies.
- In the absence of any indication to the contrary it should be presumed that an advance refusal was validly made if it is in writing, signed and witnessed.
- An advance refusal of treatment may at any time be withdrawn or altered by the person who made it, if he or she has capacity to do so.
- An advance refusal of treatment should not preclude the provision of "basic care", namely, care to maintain bodily cleanliness and to alleviate severe pain, as well as the provision of direct oral nutrition and hydration.
- An advance refusal should not preclude the taking of any action necessary to prevent the death of the maker or a serious deterioration in his or her condition pending a decision of the court on the validity or applicability of an advance refusal or on the question whether it has been withdrawn or altered.
- It should be an offence punishable with a maximum of two years imprisonment to conceal or destroy a written advance refusal of treatment with intent to deceive.

The UK Government's response to the Law Commission's proposals

7.140 In December 1997, the Lord Chancellor's Department issued a Consultation Paper entitled "*Who Decides?*" ("1997 Consultation Paper"), seeking views on a possible framework for protection for mentally incapacitated adults and for those who look after them, "*and for providing an organised framework of law to manage the welfare and affairs of mentally incapacitated adults.*"¹²⁹

7.141 The 1997 Consultation Paper stated that:

*"[I]n a number of areas the Government is minded to accept the principles underlying the Law Commission's recommendations. Those areas include the report's proposals on: the definition of incapacity; more extensive powers for the Court of Protection so that decisions can be made regarding a person's health care, personal welfare and finance within the same jurisdiction; and powers of attorney for the care of the person."*¹³⁰

7.142 The 1997 Consultation paper went on:

*"Consultation in these areas is aimed at ensuring that the detailed recommendations made by the Law Commission are considered appropriate and practical. On a number of issues, the Government wishes to ensure there are sufficient safeguards in place for the protection not only of the patients, but also those charged with their care."*¹³¹

7.143 The Lord Chancellor's Department added that there were aspects of the Law Commission's final report "*which raised issues of particular moral and ethical sensitivity,*" and on which the Government recognised that there were strong personal views.¹³² Those areas included advance statements about health care and non-therapeutic research, such as the termination of life support and research procedures which were of benefit to others.

7.144 Following consultation, the Lord Chancellor's Department set out the Government's conclusions in a Policy Statement in the form of a report in October 1999. While deciding to take forward a number of the issues raised in the consultation paper (subject to the availability of Parliamentary time), the report said:

"The Government has decided, in the light of the responses to the consultation, that a number of issues raised in [the 1997 Consultation Paper] should not be taken forward at this time. These issues are:

¹²⁹ 1997 Consultation Paper, para 1.1.

¹³⁰ 1997 Consultation Paper, para 1.4.

¹³¹ 1997 Consultation Paper, para 1.5.

¹³² 1997 Consultation Paper, para 1.6

- *Advance statements about Healthcare*
- *Independent Supervision of Medical and Research Procedures*
- *Public Law Protection for People at Risk.*¹³³

7.145 The Department for Constitutional Affairs, created in June 2003, has taken up the responsibilities of the former Lord Chancellor's Department. In publishing a new draft Mental Incapacity Bill, the Department for Constitutional Affairs quoted the then Lord Chancellor's announcement to the House of Lords on 10 December 1997:

*"The law is confusing and fragmented. Many carers in particular are expected to make decisions on behalf of incapacitated adults without a clear idea as to the legal authority for those decisions. Everybody will know of a friend or relative whose lives are affected by the current state of the law."*¹³⁴

7.146 The Department for Constitutional Affairs also expressed its other concerns:

*"The current law is not as helpful to carers and professionals as it could be. ... On a daily basis professionals come into contact with adults who lack capacity and they need to know how to go about the decision making process. We want to improve the lives of all these people and introduce a comprehensive decision making framework for all people who may lack capacity. The Mental Incapacity Bill aims to provide a clear, simple, informal system that will ensure people can maintain a maximum level of autonomy. People would be able to choose someone who can make decisions for them when they cannot do so themselves. And there would be clear rules on how decisions should be taken, making sure that vulnerable people were not left open to abuse."*¹³⁵

7.147 The Department for Constitutional Affairs explained that the 1999 Policy Statement formed the foundations of the draft Mental Incapacity Bill, and set out the key principles of the draft Bill as follows:

"Lack of capacity relates to each decision to be taken

The Bill lays out a single definition of capacity that requires capacity to be assessed according to each decision that needs to be taken. This means that individuals will not be labelled 'incapable'; rather they would only be regarded as lacking capacity for certain decisions at the time that that decision needed to be taken. ...

¹³³ (Cm 4465), October 1999, Introduction, para 12.

¹³⁴ <<http://www.lcd.gov.uk/menincap/intro.htm>> (6 AUG 2003).

¹³⁵ Overview of the Mental Incapacity Bill issued by the Department for Constitutional Affairs on June 2003, at <<http://www.lcd.gov.uk/menincap/overview.htm>> at 2, (6 Aug 2003).

The starting point is always that the person has capacity and the Bill states that 'all practicable steps' must be taken to help the person make the decision before they can be regarded as lacking the capacity to make that decision.

Best interests

...The Bill includes a checklist of factors that decision makers must work their way through when considering what is in the best interests of the person concerned. It will provide a common standard around which all interested parties should discuss and agree how to make a decision for the person who lacks capacity.

The best interests checklist requires the decision maker to consider matters such as whether the person is likely to regain capacity in the future and the need to include the person as far as possible in decision making. Account must be taken of the past and present wishes of the person concerned and the views of other people concerned with the person who lacks capacity.

Informal decision making

At the moment, the law provides for actions and decisions to be taken on behalf of adults who lack capacity under the common law principle of necessity. However, this is not especially well understood. ... The Bill will clarify this by setting out a general authority. The general authority makes it lawful to act for someone who lacks capacity where it is reasonable for the person taking the action to do so and the act is in the person's best interests. No formal powers are necessary. ... Where financial matters are concerned the general authority makes it lawful to act where reasonable and in the best interests of the person concerned. ...

Formal decision making powers

... The Bill sets out a number of ways in which formal decision-making powers can be acquired or granted. These powers represent an extension to the current ways in which financial decisions can be taken on behalf of others, allowing decisions to be taken on welfare (including healthcare) matters as well.

Lasting powers of attorney (LPAs)

The Bill proposes a new system of Lasting Powers of Attorney (LPA) which allow people to appoint an attorney to act on their behalf if they should lose capacity in the future. A Lasting

Power of Attorney will be able to apply to welfare (including healthcare) matters as well as financial matters. Thus LPAs are a wider form of the current Enduring Power of Attorney system. ...

Court appointed deputies

The Bill also creates a system of court-appointed deputies to replace and extend the current system of receiverships in the Court of Protection. As with LPAs, deputies will be able to take decisions on welfare (including healthcare) decisions as well as financial matters. A deputy could be appointed by the Court where someone has not made, or has never been able to make, a LPA. ...

The court will have to consider whether the person has capacity to make their own decisions and will only appoint a deputy for those matters where the person lacks capacity. The deputy will have to act according to the court order and if the person regains capacity for particular decisions, the deputy will lose his authority to make those decisions. The principle of considering the best interests of the person concerned will govern both the court appointment of the deputy and the on-going role of deputy.

Single orders of the court

...There may ... be times when people cannot agree best interests and they have been through informal ways of seeking to agree this but as a last resort the dispute will require a court hearing to resolve.

In these cases it will be possible to apply for permission to go to the court for a single order enabling the particular decision in question to be resolved. To gain permission it will be necessary to demonstrate that the order from the court will benefit the person who lacks capacity and that it is not possible to resolve the matter without going to court.

Advance decisions to refuse treatment

... In the interests of clarifying the status of advance decisions to refuse treatment, the Bill now includes them within the comprehensive decision making framework. They are one of the decision making mechanisms that may be chosen by people who wish to plan for a future loss of capacity and who wish to make clear what treatments they would wish not to receive.

The Bill seeks to codify the current common law position on advance decisions to refuse treatment whilst at the same time

increasing the safeguards attached to them. The Bill sets out that an advance decision must be made whilst the person has capacity, it must not have been withdrawn or altered and it must be shown to be both 'valid' at the time when the decision needs to be taken and 'applicable' to the actual situation. To be valid the person must not have acted in a way since the advance decision was made that clearly demonstrates that his views are now inconsistent with that of that advance decision. To be applicable there must be no circumstances at the time the decision is to be applied that would have caused the person to make a different advance decision if he had been able to foresee those circumstances. ...

The new Court of Protection

The current Court of Protection has jurisdiction in respect of financial decision-making on behalf of adults who lack mental capacity. Other decisions relating to adults who lack capacity, mostly serious healthcare cases, are dealt with under the inherent jurisdiction of the High Court.

The draft Bill proposes both to merge and to extend these two current jurisdictions. It will create a new dedicated Court of Protection that will have authority over all areas of decision-making for adults who lack capacity. ... The new Court will have a regional presence, which will be served by a centralised administration office and registry.

The new jurisdiction will be responsible for clarifying all issues covered by the draft Bill. It will be a superior court of record able to establish precedent and it will have the power to remove attorneys and deputies who have acted improperly. It will also be the option of last resort in cases of dispute, for example if there is disagreement between relevant parties as to the best interests of a person lacking capacity which cannot be resolved in any other way.

The new Public Guardian

The new statutory framework will be supported by a Public Guardian who will have a number of functions. The Public Guardian will be the registering authority for Lasting Powers of Attorney and deputies, he or she will supervise attorneys and deputies, and will provide information to help the Court in its decisions. ...

Criminal offences

The draft Bill proposes the creation of a new criminal offence where an attorney or deputy, or someone who has care of a

person who lacks capacity, ill-treats or wilfully neglects that person who lacks capacity. ...

*There will also be an offence of concealing or destroying an advance decision to refuse treatment. ...*¹³⁶

Mental Capacity Act 2005

7.148 The Mental Capacity Act 2005 received Royal Assent on 7 April 2005, and makes new provision relating to persons who lack capacity. It establishes a superior court of record called the Court of Protection in place of the office of the Supreme Court, also known as the Court of Protection. It also makes provision in connection with the Convention on the International Protection of Adults signed at the Hague on 13 January 2000.

7.149 The Explanatory Notes to the Mental Capacity Act prepared by the Department for Constitutional Affairs and the Department of Health set out the purpose of the Act:

*"The Act aims to clarify a number of legal uncertainties and to reform and update the current law where decisions need to be made on behalf of others. The Act will govern decision-making on behalf of adults, both where they lose mental capacity at some point in their lives, for example as a result of dementia or brain injury, and where the incapacitating condition has been present since birth. It covers a wide range of decisions, on personal welfare as well as financial matters and substitute decision-making by attorneys or court-appointed 'deputies', and clarifies the position where no such formal process has been adopted. The Act includes new rules to govern research involving people who lack capacity and provides for new independent mental capacity advocates to represent and provide support to such people in relation to certain decisions. The Act provides recourse, where necessary, and at the appropriate level, to a court with power to deal with all personal welfare (including health care) and financial decisions on behalf of adults lacking capacity."*¹³⁷

7.150 The Mental Capacity Act replaces Part 7 of the Mental Health Act 1983 and the whole of the Enduring Powers of Attorney Act 1985.

7.151 The Department for Constitutional Affairs pointed out that there are five key principles underpinning the Act:

"➤ *A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to*

¹³⁶ Overview of the Mental Incapacity Bill issued by the Department for Constitutional Affairs on June 2003, at <<http://www.lcd.gov.uk/menincap/overview.htm>> at 3-7, (6 Aug 2003).

¹³⁷ Explanatory Notes to Mental Capacity Act, *Summary and Background*, para 4.

have capacity to do so unless it is proved otherwise;

- *The right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions;*
- *That individuals must retain the right to make what might be seen as eccentric or unwise decisions;*
- *Best interests – anything done for or on behalf of people without capacity must be in their best interests; and*
- *Least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.*¹³⁸

7.152 Regarding the assessment of a person's capacity and best interests, the Department for Constitutional Affairs explained as follows:

- *Assessing lack of capacity – The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is a 'decision-specific' test. No one can be labelled 'incapable' as a result of a particular medical condition or diagnosis. Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person's age, appearance, or any condition or aspect of a person's behaviour which might lead others to make unjustified assumptions about capacity.*
- *Best Interests – Everything that is done for or on behalf of a person who lacks capacity must be in that person's best interests. The Act provides a checklist of factors that decision-makers must work through in deciding what is in a person's best interests. A person can put his/her wishes and feelings into a written statement if they so wish, which the person making the determination must consider. Also, carers and family members gain a right to be consulted.*
- *Acts in connection with care or treatment – Section 5 clarifies that, where a person is providing care or treatment for someone who lacks capacity, then the person can provide the care without incurring legal liability. The key will be proper assessment of capacity and best interests. This will cover actions that would otherwise result in a civil wrong or crime if someone has to interfere*

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<http://www.dca.gov.uk/menincap/bill-summary.htm>> (29 July 2005).

with the person's body or property in the ordinary course of caring. For example, by giving an injection or by using the person's money to buy items for them.

- *Restraint/deprivation of liberty – Section 6 of the Act defines restraint as the use or threat of force where an incapacitated person resists, and any restriction of liberty or movement whether or not the person resists. Restraint is only permitted if the person using it reasonably believes it is necessary to prevent harm to the incapacitated person, and if the restraint used is proportionate to the likelihood and seriousness of the harm. ...*¹³⁹

7.153 The Act deals with two situations where a designated decision-maker can act on behalf of someone who lacks capacity:

- "➤ *Lasting powers of attorney (LPAs) – The Act allows a person to appoint an attorney to act on their behalf if they should lose capacity in the future. This is like the current Enduring Power of Attorney (EPA), but the Act also allows people to let an attorney make health and welfare decisions.*
- *Court appointed deputies – The Act provides for a system of court appointed deputies to replace the current system of receivership in the Court of Protection. Deputies will be able to take decisions on welfare, healthcare and financial matters as authorised by the Court but will not be able to refuse consent to life-sustaining treatment. They will only be appointed if the Court cannot make a one-off decision to resolve the issues.*¹⁴⁰

7.154 The Act creates two new public bodies to support the statutory framework, both of which will be designed around the needs of those who lack capacity:

"A new Court of Protection – The new Court will have jurisdiction relating to the whole Act and will be the final arbiter for capacity matters. It will have its own procedures and nominated judges.

A new Public Guardian – The Public Guardian and his/her staff will be the registering authority for LPAs and deputies. They will supervise deputies appointed by the Court and provide information to help the Court make decisions. They will also work together with other agencies, such as the police and social services, to respond to any concerns raised about the way in which an attorney or deputy is operating. A Public Guardian

¹³⁹ <<http://www.dca.gov.uk/menincap/bill-summary.htm>> (29 July 2005).

¹⁴⁰ <<http://www.dca.gov.uk/menincap/bill-summary.htm>> (29 July 2005).

Board will be appointed to scrutinise and review the way in which the Public Guardian discharges his/her functions. The Public Guardian will be required to produce an Annual Report about the discharge of his/her functions."¹⁴¹

7.155 There are three further key provisions to protect vulnerable persons:

"Independent Mental Capacity Advocate (IMCA) – An IMCA is someone appointed to support a person who lacks capacity but has no one to speak for them. The IMCA makes representations about the person's wishes, feelings, beliefs and values, at the same time as bringing to the attention of the decision-maker all factors that are relevant to the decision. The IMCA can challenge the decision-maker on behalf of the person lacking capacity if necessary.

Advance decisions to refuse treatment – Statutory rules with clear safeguards confirm that people may make a decision in advance to refuse treatment if they should lose capacity in the future. It is made clear in the Act that an advance decision will have no application to any treatment which a doctor considers necessary to sustain life unless strict formalities have been complied with. These formalities are that the decision must be in writing, signed and witnessed. In addition, there must be an express statement that the decision stands 'even if life is at risk'.

A criminal offence – The Bill introduces a new criminal offence of ill treatment or neglect of a person who lacks capacity. A person found guilty of such an offence may be liable to imprisonment for a term of up to five years."¹⁴²

Scotland

Scottish Law Commission reports

7.156 In 1995, the Scottish Law Commission published its *Report on Incapable Adults* ("the 1995 Report").¹⁴³ This report followed the publication of the Commission's earlier discussion paper, *Mentally Disabled Adults: Legal Arrangements for Managing their Welfare and Finances*, in 1991.

7.157 The 1995 Report contains a study of the social phenomena in Scotland leading to the reform of the law in this area:¹⁴⁴

¹⁴¹ <<http://www.dca.gov.uk/menincap/bill-summary.htm>> (29 July 2005).

¹⁴² <<http://www.dca.gov.uk/menincap/bill-summary.htm>> (29 July 2005).

¹⁴³ Scot Law Com No 151 (1995).

¹⁴⁴ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), paras 1.2-1.4.

"In 1988 the Scottish Health Service Planning Council published a report on [the] Scottish Health Authorities Review of Priorities for the Eighties and Nineties which placed services for old people with dementia in the highest category followed by community care for the mentally ill and the mentally handicapped. ... The greater awareness of the needs of the mentally disabled is in part due to the increasing number of elderly people suffering from dementia and similar mentally disabling conditions. The incidence of dementia increases with age. It has been estimated that dementia affects some 3% of the population aged between 65 and 69 years old, but around 20% of those aged 80 or over. ... The number of people aged 80 or over has risen considerably over the last 15 years The number is expected to rise still further over the next few years due to demograhic trends and advances in medicine. ...

Another factor is the changing attitude of society and those professionally caring for the mentally disabled. The policy of care in secure institutions has over the years been replaced by one of providing appropriate support and care so that the mentally disabled can so far as possible live in the community. ...

There is also a greater awareness of the rights of the mentally disabled. The philosophy that lies behind the new approach is one of minimum intervention in their lives, consistent with providing proper care and protection and maximum help to enable individuals to realise their full potential and make the best use of the abilities they have."

7.158 The 1995 Report summarised the previously existing law as follows:¹⁴⁵

"Scottish law has a number of methods which enable decisions to be made or action taken on behalf of adults who are incapable of deciding or acting themselves. In the personal welfare field guardians under the 1984 Act (the Mental Health (Scotland) Act 1984), tutors-dative and tutors-at-law may be appointed by the courts and doctors and other health-care professionals have authority to give incapable patients treatment which [it] is in their best interests to receive. ...

Mental health guardians

A guardian under the Mental Health (Scotland) Act 1984 (a 'mental health guardian') may be appointed to an adult by the sheriff on application by a mental health officer (or occasionally a relative of the adult) of the local authority in whose area the

¹⁴⁵ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), paras 1.7-1.12.

adult lives. The application is supported by two medical reports specifying the form of mental disorder the adult is suffering from and stating that the disorder is such as to warrant guardianship, and a recommendation from the mental health officer that guardianship is necessary in the interests of the welfare of the adult ... The powers of a mental health guardian are statutory ... [including] power to require the adult to reside at a specified place, power to require the adult to attend for treatment or training, ...

Tutors-dative and tutors-at-law

Tutors-dative have been recently revived in order to provide a more personal type of guardianship. They are appointed by the Court of Session after consideration of two medical certificates of incapacity. In modern practice tutors-dative are granted personal welfare powers only. ... A tutor-at-law has full power over the personal welfare and financial affairs of the adult. The tutor-at-law can only be the nearest male relative. He is entitled to be appointed by virtue of his relationship unless his unsuitability is established. A tutor-at-law supersedes any tutor-dative or curator bonis who has previously been appointed.

Medical treatment

Patients who are unconscious or otherwise temporarily incapable of giving consent may, on the basis of necessity, be given treatment which is necessary and which cannot reasonably be postponed until capacity is recovered. The 1984 Act also contains special provisions on urgent treatment for patients who are detained under that Act. ...

Curators bonis

A curator bonis may be appointed to a person who is of unsound mind and incapable of managing his or her affairs or giving instructions for their management. The application for a curator is by way of petition to the Court of Session or the sheriff court. Usually one or more of the incapable adult's relatives will petition, but anyone with an interest may do so. The local authority must, and the Mental Welfare Commission may, petition if no-one else is doing so and a curator is necessary. The petition is supported by two medical certificates to the effect that the grounds for appointment are established. ...

Attorneys

An attorney is a person appointed by another (the granter) under a contract of mandate or agency to deal with some or all aspects of the granter's property and financial affairs. ..."

Criticisms of the previously existing law

7.159 The Scottish Law Commission criticised the law then existing as "*suffer[ing] from various defects and ... in need of reform.*" The Commission added that "*[t]here are however more general criticisms, that the present law is fragmented, archaic and fails to provide an adequate remedy in many common situations.*"¹⁴⁶

7.160 Other shortcomings identified by the Scottish Law Commission were:¹⁴⁷

- The powers of a mental health guardian were fixed by statute and could not be added to or varied to suit the needs and capabilities of the adult under guardianship.
- Because the tutor dative was a recently revived post of considerable antiquity, the powers and duties had to be gathered from centuries-old cases. It was not clear how far those judgments remained authoritative today in a society with a different outlook, values and procedures.
- Tutors-at-law were another recently revived type of guardian whose functions were therefore somewhat uncertain. The fact that the post could be held only by the nearest male relative was incompatible with modern notions of sexual equality. Furthermore, relationship should only be one of a number of factors that should be considered in selecting a suitable person to deal with the personal welfare and financial affairs of an incapable adult.
- A curator bonis takes over the management of the adult's whole estate. The curator's powers are not tailored to the needs and abilities of the adult.
- The main defect of attorneys is that they are unsupervised. Once the granter becomes incapable there may be no one with sufficient interest to monitor and, if necessary, challenge the attorney's actions.

7.161 The Scottish Law Commission further criticised the then existing law as follows:¹⁴⁸

"The existing Scottish law is fragmented. With the sole exception of a tutor-at-law all the other methods of dealing with incapacitated adults relate either solely to personal welfare or

¹⁴⁶ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), para 1.15.

¹⁴⁷ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), paras 1.16-1.20.

¹⁴⁸ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), paras 1.23-1.26.

solely to property and financial affairs. Thus curators have no functions in the personal welfare field while mental health guardians are prohibited by statute from intromitting with the funds of the adults under guardianship. In current practice tutors-dative are restricted to personal welfare matters while attorneys have only financial functions. However, most adults' welfare and finances are inextricably connected and decisions in one area may well have repercussions in the other. ...

Many of the existing methods are inflexible or limited. The law does not allow the remedies to be tailored to the adult's needs. ... There is no recognition of the concept of least restrictive action or minimum necessary intervention.

Much of the law is archaic. ...

The final general criticism is that Scottish law fails to deal with, or provide adequate remedies in, many common situations. It is not clear whether it is competent to appoint an attorney to make personal welfare decisions on behalf of the granter when he or she becomes incapable. ..."

7.162 The Scottish Law Commission went on to point out that as far as the authority to give medical treatment to incapable adults was concerned, the law in Scotland was uncertain. There was no Scottish authority dealing with advance statements made by patients while capable as to how they wished to be treated when incapable, and the legality of carrying out medical research on those who were incapable of giving consent was far from clear.¹⁴⁹

7.163 In their 1995 Report, the Scottish Law Commission made recommendations on the following aspects of the law:¹⁵⁰

- The general jurisdiction of the sheriff courts in relation to incapable adults and a proposed regulatory and supervisory framework of public officials and organisations.
- Measures that adults can take to ensure that their personal welfare and financial affairs will be looked after should they become incapable at some future date.
- Continuing powers of attorney which are confined to financial affairs. This power is operable before incapacity and continues to be effective after incapacity. The Commission also recommended the introduction of welfare powers of attorney, with the person appointed to be termed a "welfare

¹⁴⁹ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), para 1.26.

¹⁵⁰ Scottish Law Commission, *Report on Incapable Adults*, (Scot Law Com No 151, 1995), para 1.31.

attorney". A welfare attorney should not be entitled to exercise a welfare power contained in the document conferring the power of attorney unless the granter is incapable of making a decision regarding the welfare matter in question, or the attorney reasonably believes the granter to be incapable.

- Various schemes that would enable those caring for incapable adults to assist them without having to apply to the courts.
- Doctors and other health-care professionals should have a general statutory authority to treat incapable adults. Any decision about treatment would be governed by certain general principles.
- Certain treatments, however, would require prior authorisation from the courts or a second opinion from an independent specialist. Advance statements about future medical treatment are also considered and recommendations are made to put them on a firm legal basis.
- The introduction of a system of strict controls on medical research on incapable adults.
- The courts would be empowered to make various orders in the personal welfare and financial fields, including the appointment of a guardian where the incapable adult's circumstances make a long-term appointment necessary.
- A scheme for financial management of small estates by the Public Guardian is put forward to ease the burden on modest estates.

Adults with Incapacity (Scotland) Act 2000

7.164 The Scottish Executive subsequently accepted most of the Scottish Law Commission's recommendations, and presented their conclusions in a policy statement entitled *Making the Right Moves*.¹⁵¹ The Bill which followed was entitled the Adults with Incapacity (Scotland) Bill (rather than the Incapable Adults (Scotland) Bill, which was the title used by the Scottish Law Commission in the 1995 Report) to "*reflect the fact that incapacity is not an all-or nothing concept*"¹⁵². The Adults with Incapacity (Scotland) Act was passed by the Scottish Parliament on 29 March 2000 and received Royal Assent on 9 May 2000. The Act was implemented in stages between April 2001 and April 2002. The purpose of the Act is to provide for decisions to be made on behalf of adults who lack the legal capacity to do so themselves because of mental disorder or inability to communicate. The

¹⁵¹ Scottish Executive, "*Making the Right Moves*", <<http://www.scotland.gov.uk/rightmoves/docs/mrmm-02.htm>>(18 July 2003).

¹⁵² Adults with Incapacity (Scotland) Bill, *Policy Memorandum*, para 10.

decisions may concern the adult's property or financial affairs or personal welfare, including medical treatment.¹⁵³

7.165 According to the Summary¹⁵⁴ issued by the Scottish Executive at the time of publication of *Making the Right Moves*, the new legislation is intended to help adults with incapacity, including:

- People who have never had capacity to make decisions about their own affairs, such as those with learning disabilities;
- People who lose capacity temporarily or permanently through accident or illness, for example those who suffer from Alzheimer's disease, certain mental or physical illnesses, head injuries or stroke; and
- People who are unable to communicate decisions.

7.166 The Act is divided into seven parts:

- Part 1 gives a definition of incapacity and sets out general principles that are to apply to any intervention in the affairs of an adult under the legislation. It defines the role of the authorities that will act under the legislation: the sheriff, the Mental Welfare Commission and local authorities. It creates the new office of Public Guardian within the Court Service. It also provides for codes of practice containing further guidance to those acting under the legislation.
- Part 2 clarifies the position of attorneys with financial and welfare powers who act when the granter of the power loses capacity. It provides for the registration, monitoring and supervision of such attorneys.
- Part 3 sets up a new statutory scheme providing access to funds held on behalf of an adult with incapacity, with appropriate safeguards.
- Part 4 provides for hospital and care home managers to manage the finances of patients or residents with incapacity, subject to appropriate safeguards.
- Part 5 confers a statutory authority on medical practitioners and those acting under their instructions to give treatment to adults with incapacity and undertake research in certain circumstances.

¹⁵³ Adults with Incapacity: Adults with Incapacity (Scotland) Act 2000, *Explanatory Notes*, para 3, at < <http://www.scotland-legislation.hms.gov.uk/legislation/scotland/en/2000en04.htm> > (1 Aug 2003).

¹⁵⁴ Scottish Executive, "*Making the Right Moves: Rights and protection for adults with incapacity*", *Summary*, at <<http://www.scotland.gov.uk/rightmoves/docs/mrms-00.htm>> (18 July 2003).

- Part 6 creates a new system of welfare and financial intervention orders and guardianship.
- Part 7 includes various other miscellaneous provisions.

7.167 The general principles are that anything done under the new law for an adult with incapacity will have to:

- benefit the adult;
- take account of the adult's wishes and those of the nearest relative, primary carer and guardian or attorney, if appointed; and
- be the least restrictive of the adult's freedom while still achieving the desired purposes;

and any one authorised or appointed to intervene in the adult's affairs will have to encourage the adult to use their existing skills and acquire new skills where possible.¹⁵⁵

7.168 The Act sets out a number of principles to be followed, rather than a general test of what is in the best interests of the adult.

7.169 The Summary stated that the proposals (which have now become the provisions of the Act) would mean in practice:

*"(a) **Individuals** will be able to make plans for their future by granting a power of attorney to a person of their choice, while they are able to understand fully what they are doing. The attorney will also be able to deal with whatever welfare, medical treatment or financial matters the person granting the power has specified, in the event of their incapacity to make their own decisions. There will be a range of safeguards to protect people who grant a power of attorney."¹⁵⁶*

*(b) **Those holding the funds** of adults with incapacity, including banks and building societies, may be legally authorised to release funds from the account of an adult who loses the capacity to operate it, so that the money can be used to meet the adult's daily living expenses. Organisations will also be able to allow one holder of a joint account to continue to operate the account if the other holder loses capacity to do so."¹⁵⁷*

¹⁵⁵ See Adults with Incapacity (Scotland) Act 2000, section 1.

¹⁵⁶ Above, section 16.

¹⁵⁷ Above, section 32.

- (c) **Hospital and care home managers** will be allowed to manage the funds of patients and residents who lack capacity to do so. But they will only be able to do this if no suitable alternative is available and if the amount involved is fairly small. There will be stringent monitoring.¹⁵⁸
- (d) **Doctors and other healthcare professionals** will have a general authority to treat adult patients who are unable to give their consent and to conduct research relevant to that treatment. Relatives will have to be consulted. There will be safeguards. Certain treatments will not be covered by the doctor's general authority to treat and will require further approval by a second medical opinion or by the court.¹⁵⁹
- (e) **The sheriff court** will be able to make one-off orders, on the application of relatives or other interested parties, to deal with specific decisions faced by adults with incapacity such as selling a house or signing an important document. The court will also be able to appoint a longer-term guardian to deal with any combination of welfare, medical treatment and financial matters. The new kind of guardian will replace curators bonis, tutors and Mental Health Act guardians, all of whom are currently appointed to take decisions on behalf of adults with incapacity. The courts will be able to intervene in how guardians and attorneys use their powers where things go wrong.¹⁶⁰
- (f) **The Public Guardian** will be a new office within the court system. The Public Guardian's functions will include keeping public registers of attorneys, intervention orders and guardians and supervising those with financial powers.¹⁶¹
- (g) **Local authorities** will supervise attorneys and guardians with welfare powers.¹⁶²
- (h) **Registration and Inspection teams** in local authorities and health boards will authorise managers of residential and nursing homes to look after funds belonging to their residents who cannot manage their own financial affairs, where there is no alternative. Registration and Inspection teams will inspect accounts.

¹⁵⁸ See Adults with Incapacity (Scotland) Act 2000, sections 39, 41.

¹⁵⁹ Above, section 50.

¹⁶⁰ Above, section 53.

¹⁶¹ Above, sections 6, 7.

¹⁶² Above, section 10.

- (i) ***The Mental Welfare Commission will monitor attorneys and guardians with welfare powers and carry out investigations where something appears to be wrong.***¹⁶³

7.170 The Scottish Executive did not take forward the issue of advance directives in the Act and offered the following explanation:¹⁶⁴

"We have examined carefully a number of other proposals made by the Scottish Law Commission, by the Alliance for the Promotion of the Incapable Adults Bill and by others. Such proposals have included legislation to give clear legal force to Advance Statements ("living Wills") and to provide for the withholding or withdrawal of treatment from patients who may be in a persistent vegetative state (PVS). Although such proposals have the sincere support of particular interest groups, we do not consider that they command general support. Attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases."

Singapore

Mental Disorders and Treatment Act (Cap 178)

7.171 In Singapore, the governing statute relating to "mental disorder" and treatment is the Mental Disorders and Treatment Act (Cap 178). This Act regulates proceedings in cases of mental disorder, and provides for the reception and detention of persons of unsound mind in approved hospitals.

7.172 The term "mentally disordered person" is defined in the Act to mean *"any person found by due course of law to be of unsound mind and incapable of managing himself or his affairs"*.¹⁶⁵ "Treatment" in the Act includes *"observation, inpatient treatment, outpatient treatment and rehabilitation"*.¹⁶⁶

7.173 The Act is divided into three parts. Part I regulates proceedings in inquiries into mental disorders. It enables the High Court and the judges of the High Court, on application, to make an order directing an inquiry whether any person who is alleged to be mentally disordered is or is not of unsound mind and incapable of managing himself and his affairs.¹⁶⁷

7.174 The Court may appoint a committee of the person and estate of

¹⁶³ Above, section 9.

¹⁶⁴ Scottish Executive, "Making the Right Moves" policy statement, para 6.14, at <<http://www.scotland.gov.uk/rightmoves/docs/mrmm-07.htm>> (18 July 2003).

¹⁶⁵ Section 2, Mental Disorders and Treatment Act.

¹⁶⁶ Section 2, Mental Disorders and Treatment Act.

¹⁶⁷ Section 3(1), Mental Disorders and Treatment Act.

the mentally disordered person, and grant the person to whom the charge of the estate is committed the power to manage the estate, having regard to the nature of the property of which the estate consists.¹⁶⁸

7.175 Section 13 of the Act provides that the court may determine which of the relatives or next-of-kin should attend before the Registrar of the Supreme Court in any proceedings connected with the management of the estate. The court may also order any property to be sold, charged by way of mortgage or otherwise disposed of for the purpose of raising money to be applied for any of the following purposes:

"(a) the payment of [the mentally disordered person's] debts, including any debt incurred for his maintenance or otherwise for his benefit;

(b) the discharge of any incumbrance on his estate;

(c) the payment of or provision for the expenses of his future maintenance and the maintenance of his family, including the expenses of his removal to his country of origin or elsewhere, when he shall be so removed, and all expenses incidental thereto;

(d) the payment of the costs of any proceeding under this Act and of any costs incurred by order or under the authority of the court."¹⁶⁹

7.176 The court is also empowered to order maintenance for the mentally disordered person or his family without appointing a committee of the estate.¹⁷⁰

7.177 If it appears to the court that the unsoundness of mind of a mentally disordered person is of a temporary nature, the court may direct his property (or a sufficient part of it) to be applied to make temporary provision for his maintenance or the maintenance of his family.¹⁷¹

7.178 Part II of the Act deals with the admission and detention of persons of unsound mind in mental hospitals where these persons can receive treatment.

Advance Medical Directive Act (Cap 4A)

7.179 A National Medical Ethics Committee ("the Committee") was set up in January 1994 by the Ministry of Health to assist the medical profession in addressing ethical issues in medical practice. The Committee has no

¹⁶⁸ Section 10, Mental Disorders and Treatment Act.

¹⁶⁹ Section 15, Mental Disorders and Treatment Act.

¹⁷⁰ Section 23, Mental Disorders and Treatment Act.

¹⁷¹ Section 24, Mental Disorders and Treatment Act.

statutory powers. It serves as the national authority which provides advice to the Ministry of Health of Singapore and other agencies on prevailing ethical issues. One of the major issues the Committee studied during its first two years (1994-1995) was advance medical directives.

7.180 The Committee reviewed the position of advance medical directives or "living wills" practised in other jurisdictions and considered the merits of legislation for advance directives. Following the review, the Committee released a position paper in August 1994, proposing that legislation for advance directives be introduced in Singapore. The Committee invited feedback from the general public and a number of professional and religious groups.

7.181 In May 1995, the Committee presented its findings and recommendations in a report entitled *Advance Medical Directives* to the Minister for Health. The report's recommendations included the following:¹⁷²

"(a) The definition and the use of AMD (advance medical directives) be limited to instructions on medical treatment. Based on the principle of patient autonomy, AMD would provide the legal means for patients to continue to exercise autonomy over their medical treatment even when they were incompetent and in their final stages of illness.

(b) The need for legislation on AMD in Singapore to provide the necessary substantive and procedural safeguards for AMD. This legislation should be an enabling one, ie anyone who did not wish to execute an AMD should not be compelled or pressured to do so.

(c) The emphasis that appropriate palliative care must always be provided to the patient even after the AMD had been effected. The distinction between AMD and euthanasia was also made. Euthanasia was wrong and the Committee did not condone it under any circumstances."

7.182 The Minister for Health accepted the recommendations made in the report. The Advance Medical Directive Act was enacted in May 1996 and its provisions implemented in July 1997.

7.183 Dr Chew Chin Hin, Chairman of the Committee summarised the salient points of the report in a paper delivered at the *Joint Scientific Meeting, Medicine: East Meets West*.¹⁷³ He outlined the principles and framework of the Advance Medical Directive Act as follows:

"1) Scope

Firstly, the scope of legislation was limited to instructions on

¹⁷² At<http://www.gov.sg/moh/newmoh/pdf/pub/NMEC94_97.pdf > p.4, (01 Aug, 2003).
¹⁷³ On 15 October 2000 in Hong Kong.

medical treatment: to be more specific to the withdrawal or withholding of extraordinary life-sustaining treatment from a terminally ill patient with little or no hope of recovery and where death is imminent, thereby permitting natural death to occur.

'Terminal illness' is defined as an 'incurable condition caused by injury, diseases or illness, from which there is no reasonable prospect of a recovery, which regardless of the application of life-sustaining procedures, would within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serves only to postpone the moment of death of the patient'. (Adapted from the South Australia Natural Death Act and the California Natural Death Act).

2) AMD versus Euthanasia

The committee also was opposed to euthanasia or mercy killing. Euthanasia continues to be a criminal offense in Singapore. Euthanasia is the deliberate act by a doctor with the express intention of terminating the life of a patient. In contrast, a doctor who carries out a patient's AMD within the limits of our definition is only permitting death to occur naturally. Thus, the Committee made a clear distinction between AMD and euthanasia.

3) The Need for Legislation

The intention of legislation for AMD is to enable every individual the opportunity to decide not to prolong the inevitable end but to die with dignity. Thus, it is an enabling legislation. The making of an AMD must be entirely voluntary. Compelling or coercing a person to execute such directives must be penalised by law.

4) Palliative Care

The Committee also stressed that an AMD should not deprive a terminally ill person of palliative care. Palliative care must continue and will include the relief of pain, suffering and discomfort and the reasonable provision of food and water.

5) Time of AMD

When should AMDs be made? They are best done when patients are in good health. Doctors especially family physicians, should routinely raise the issue of advance planning and discuss with sensitivity and in depth the implications involved. All this will have the effect of strengthening the doctor-patient relationship. This is the reason why it is so important to have a doctor, preferably the patient's family

physician as one of the two witnesses in the making of the directive. It is also desirable that the immediate family is consulted before making the AMD.

In Singapore, we stress the importance of the family as the foundation of our society. Thus the making of an AMD should not be kept a secret from immediate family members. The patient's doctor would be the best person to explain the Advance Directive to the family members and to allay any fears that they may have.

6) The Law

In May 1995, the NMEC presented its Report and recommendations to the Minister of Health. These were accepted. The AMD Bill was tabled in Parliament, discussed in great depth and by its Select Committee and passed as the Advance Medical Directive Act on 2 May 1996.

i) Anyone who is 21 year old or above and mentally sound can make an AMD.

ii) The AMD is made on prescribed forms which are available free from hospitals, private clinics and polyclinics. The form must be signed in the presence of two witnesses, one of whom must be a doctor. Both must not stand to gain or benefit upon the death of the person who makes the AMD. The form is then returned to the Registry of AMD where it is kept confidential. I cannot over-emphasise the importance of confidentiality. Access to the register is strictly controlled. This is to ensure that the existence of an AMD must never be allowed to influence medical treatment and management decisions before the patient is certified to be terminally ill. Indeed it will be an offence for any person to require or prohibit the making of an AMD as a condition for receiving medical services or for being health insured.

iii) The AMD can be revoked any time by writing, orally or any other way which can be communicated to the Registry in the presence of one witness. This is deliberately made easy so that if there is any doubt, we err on the side of prolonging life.

iv) The AMD is only effected when the doctor-in-charge of the case and two other specialist doctors agree unanimously that the person is terminally ill. If an agreement could not be reached, a panel of three specialists appointed by the Director of Medical Services will be consulted.

The decision of this panel is final. If there is no consensus, the AMD cannot take effect. The AMD also provides for doctors

and those who work for them who are conscientious objectors of the AMD to register their objections. They will also be excluded from participating as witnesses to the making of AMDs and from certification of terminal illnesses."¹⁷⁴

United States of America

Advance directives

7.184 Professor Alan Meisel, JD, of the University of Pittsburg School of Law wrote:

"Twenty years ago the term advance directive did not exist. The term living will was not a household word, and a durable power of attorney was used to avoid guardianship proceedings for the management of financial affairs. Today, every state has recognized the validity of advance directives through statute, case law, or both. All States but three (Massachusetts, Michigan, New York) have adopted living will legislation, and all have enacted durable health care power of attorney legislation. Close to three-quarters have enacted statutes intended to clarify the status of family members as surrogate decision makers, and the number of these statutes is growing so quickly that it is difficult to get an accurate count (much as it was with living will and health care power of attorney statutes in the late 1980s and early 1990s)."¹⁷⁵

7.185 In their joint publication "*Shape Your Health Care Future With Health Care Advance Directives*", the American Association of Retired Persons, the American Bar Association Commission on Legal Problems of the Elderly and the American Medical Association explain the nature of a health care advance directive under US law as follows:

"A health care advance directive is a document in which you give instructions about your health care if, in the future, you cannot speak for yourself. You can give someone you name (your 'agent' or 'proxy') the power to make health decisions for you. You also can give instructions about the kind of health care you do or do not want.

*In a traditional living will, you state your wishes about life-sustaining medical treatments if you are terminally ill*¹⁷⁶. In a

¹⁷⁴ C H Chew, "*The Singapore Advance Medical Directive*", *Hong Kong College of Physicians Synapse*, December 2000, at <<http://www.hkcp.org/synapse.htm>> (19/12/2001).

¹⁷⁵ Alan Meisel, "Legal Issues in Decision Making for Incompetent Patients – Advance Directives and Surrogate Decision Making" in Hans-Martin Sass, Robert M. Veatch, and Rihito Kimura (eds), *Advance Directives and Surrogate Decision Making in Health Care – United States, Germany, and Japan* (The Johns Hopkins University Press, 1998), 34.

¹⁷⁶ Alan D. Lieberson, M.D., J.D. has commented that "[b]ecause statutory living wills are presently limited to patients close to death (or permanently unconscious), there is little need to

health care power of attorney, you appoint someone else to make medical treatment decisions for you if you cannot make them for yourself."¹⁷⁷

7.186 This joint publication offers the following explanation of the term "surrogates" under the heading of "What happens if I do not have an advance directive":

"If you do not have an advance directive and you cannot make health care decisions, some state laws give decision-making power to default decision-makers or 'surrogates'. These surrogates, who are usually family members in order of kinship, can make some or all health care decisions. Some states authorise a 'close friend' to make decisions, but usually only when family members are unavailable."¹⁷⁸

7.187 The law governing advance medical directives in the US consists principally of legislation governing living wills and durable powers of attorney for health care. Alan D Lieberson commented thus on the California Natural Death Act of 1976, which codified the law on living wills in California:

"Fear of malpractice forced legislators to prematurely codify LW (living will) law without time for the judicial system to define appropriate limits. California passed the first statute granting immunity to health care providers when honoring living wills in 1976. This premature emphasis on statutory LWs is unfortunate, the common law being more suited to defining individual rights which may be opposed by large constituents of voters.

Even now, the common law remains the best chance for developing clinically significant LW declarations, but this is seldom appreciated. In those forty plus jurisdictions with LW statutes, most physicians and attorneys, as well as the public, believe the narrowly worded statutes contain all the individual's rights to refuse medical care. This is not so.

Because the original California Natural Death Act [of 1976] was hastily drafted without common law precedents, its provisions created many difficulties which existed until the 1991 revision. In spite of these weaknesses, it was copied by other states, thus slowing the evolution of statutory right-to-life legislation."¹⁷⁹

differentiate these therapeutic modalities. As statutory living wills are expanded to include non-terminal clinical situations, the differentiation of modalities will become increasingly important." *Advance Medical Directives* (Clark Boardman Callaghan, 1992), at 72.

¹⁷⁷ At <<http://www.ama-assn.org/public/booklets/livgwill.htm>> at 1(1 Aug 2003).

¹⁷⁸ At <<http://www.ama-assn.org/public/booklets/livgwill.htm>> at 5.

¹⁷⁹ Alan D Lieberson, *Advance Medical Directives* (Clark Boardman Callaghan, 1992), at 43-44.

The Uniform Rights of the Terminally Ill Act

7.188 On the evolution of living will legislation, Alan Lieberman wrote:

"Other states passing LW (living will) statutes in the 1970s, Arkansas (1977), Kansas (1979), New Mexico (1977), North Carolina (1977), Texas (1977) and Washington (1979) tended to follow California's lead. Arkansas, New Mexico, North Carolina and Texas have subsequently been extensively revised.

In the early 1980s, LW acts were also passed in Alabama (1981), Arizona (1984), Delaware (1983), ... Mississippi (1984), ... but it was after the Catholic Church dropped its opposition to LWs in 1984 that the majority of states followed with 19 states passing LW acts between 1985 and 1987.

The major additional influence on these statutes was the Uniform Rights of the Terminally Ill Act, as formulated in 1985."¹⁸⁰

7.189 The Uniform Rights of the Terminally Ill Act was adopted by the National Conference of Commissioners on Uniform State Laws in 1985.

"[T]he Commissioners specifically desired to simplify the process of making an LW in the hope of encouraging people interested in participating in their medical decisions in the event of a terminal condition to execute such a document."¹⁸¹

7.190 The Uniform Rights of the Terminally Ill Act was revised in 1989 providing for the appointment of an agent for decision making, but Alan Lieberman commented that:

"[I]t fails to identify their duties, the basis on which decisions should be made, their relationship to other fiduciaries, or their role in interpreting the declarant's directives. It does not specifically delegate the broad scope of powers normally included in a [durable power of attorney for health care].

The official 'Comments' of the Commissioners states '[i]t is specifically anticipated ... that some people may choose to appoint their physician to make such decisions and, absent any ethical restrictions on such an appointment, Section 2 anticipates that the physician may act in the appointed capacity."¹⁸²

7.191 In reviewing the provisions of the living will statutes, Alan Lieberman made the following observations:

¹⁸⁰ *Advance Medical Directives*, at 53.

¹⁸¹ *Advance Medical Directives*, at 53-54.

¹⁸² *Advance Medical Directives*, at 57-58.

"Most states require a patient to be officially certified as a 'qualified patient'... To be qualified, some states follow [the] Uniform Rights of the Terminally Ill Act and require that the patient have prepared an advance directive, others require that the patient be simultaneously certified as incompetent, but still others expand the potential for surrogate decision making by following California and allowing such certification based solely on the terminal nature of the clinical situation."¹⁸³

7.192 Alan Lieberson expressed his view of the definition of "incompetency" and on the "certification of incompetency":

"Many states follow California and [the] Uniform Rights of the Terminally Ill Act leaving the determination of the patient's competency to make medical decisions to the discretion of the physician without a definition. ... Certification of incompetency, however, may not be controlling. A patient is assumed to be competent unless incompetency is overwhelming, and both statutory and common law dictate that even an incompetent patient can request continuation of therapy which would have been forsaken under the terms of an advance medical directive. Similarly, directives from a surrogate will not take precedence over the previously expressed desires of a competent patient who later becomes incompetent in most jurisdictions.

Most importantly, even when a patient has been certified to be incompetent, a directive to forsake non-comfort care is not likely to be honoured if the physician believes the patient is likely to regain competency. Although the directive is likely to be written without differentiating between temporary and permanent incapacity, directives are assumed to only apply when the incapacity is irreversible. This interpretation has received support under the common law."¹⁸⁴

7.193 New Jersey and Hawaii passed legislation in 1991 extending statutory advance directive coverage to include those persons who suffer from irreversible mental deterioration. Alan Lieberson commented that:

"[T]here are close to five million Americans with varying degrees of irreversible dementia, many of whom would elect to forsake care if able and most of whom would fall under the new statutory coverage. The present necessity to continue treatment of all these patients, even if they would wish otherwise, is a major problem in health care delivery which can only be relieved by obtaining written documentation of each individual's desires prior to the development of dementia."¹⁸⁵

¹⁸³ *Advance Medical Directives*, at 73.

¹⁸⁴ *Advance Medical Directives*, at 73-75.

¹⁸⁵ *Advance Medical Directives*, at 107.

7.194 He went on to say that:

"[A]t least 27 jurisdictions specifically enable durable powers of attorney for health care which permit the health care agent to direct the withholding or withdrawing of life support systems, and many others provide for health care decision-making by agents empowered by standard durable powers of attorney. These instruments are independent of living wills. ...

In contrast, other states allow designation of an agent, a 'DA (designated agent),' as part of the living will itself. ... Some [states] permit the designation of an alternate designated agent, but others do not."¹⁸⁶

7.195 Alan Lieberman referred to some commentaries favouring durable powers of attorney for health care, and said:¹⁸⁷

"Most commentators have been highly supportive of durable powers of attorney for health care, pointing out that an agent can enforce the patient's treatment preferences and ensure that they are not disregarded or forgotten by family members or physicians. 'Physicians relying on health care directives of an incompetent patient's personally designated and legally recognised agent in all probability will be less vulnerable to legal reprisals or professional censure than if they rely on the informal consent of a relative. The durable power of attorney for health care resolves uncertainty about who is authorised to consent for the incapacitated patient. It also resolves the problem of determining what should be done when relatives are in disagreement or when the family disagrees with the physicians. ... An agent, unlike a living will, gives doctors ... someone who is empowered to make decisions, surmounting the problem of interpreting by guesswork the often vague terms of a living will. ... A final advantage ... is that it solves substituted judgment problems for physicians meeting an acutely ill incompetent patient for the first time."¹⁸⁸

7.196 He further elaborated:¹⁸⁹

"Durable powers of attorney for health care have important advantages over living wills. While living wills are often limited to treatments in the setting of a terminal illness where death is imminent, durable powers of attorney for health care can generally be used to delegate authority for health care decisions

¹⁸⁶ *Advance Medical Directives*, at 115.

¹⁸⁷ *Advance Medical Directives*, at 282-283.

¹⁸⁸ Quoting Peters, *Advance Medical Directives: The Case for the Durable Power of Attorney for Health Care*, 8 J of Legal Med 437, 451, 452 (1987).

¹⁸⁹ *Advance Medical Directives*, at 283.

*in all cases of patient incompetence. ... [T]he agent is able to resolve ambiguities or inconsistencies in the patient's prior written and oral statements when deciding what the patient would want under the circumstances. ...*¹⁹⁰

7.197 Alan Lieberson also noted the advantages of the durable power of attorney for health care over guardianship proceedings:¹⁹¹

*"[T]he durable power of attorney has four important advantages over the guardianship proceedings as a means of arranging for future health choices. First, ... procedures for execution and approval of a durable power are generally less cumbersome than those for institution of a guardianship. Second, guardianship proceedings are sometimes perceived as embarrassing to the ward who is adjudicated an incapacitated person; the durable power, by contrast, is free of the stigma of a legal determination of incapacity. Third, an individual can designate a medical decision-maker through a power of attorney; but the individual's preference may be rebuffed in a ... court's choice of guardian. Finally, the individual can instruct the designated decision-maker in the exercise of the powers delegated in a power of attorney; but no reliable means of respecting the ward's personal autonomy exists in the guardianship framework."*¹⁹²

The Uniform Health-Care Decisions Act

7.198 In August 1993, the National Conference of Commissioners on Uniform State Laws approved a revision of the two previous Uniform Rights of the Terminally Ill Acts and the previous Model Health-Care Consent Act, to be called the Uniform Health-Care Decisions Act.¹⁹³

7.199 The prefatory note to the Uniform Health-Care Decisions Act describes the rapid changes in state law and the resulting conflicts:

"Since the Supreme Court's decision in Cruzan v Commissioner, Missouri Department of Health, 497 US. 261 (1990), significant change has occurred in state legislation on health-care decision making. Every state now has legislation authorising the use of some sort of advance health-care directive. All but a few states authorise what is typically known as a living will. Nearly all states have statutes authorising the use of powers of attorney for health care. In addition, a majority of states have statutes allowing family members, and in some cases close friends, to

¹⁹⁰ Quoting Office of the General Counsel of the American Medical Association: *Advance Medical Directives*, 263:17 JAMA 2365, 2366 (1990).

¹⁹¹ *Advance Medical Directives*, at 283-284.

¹⁹² Quoting Leflar, *Liberty and Death: Advance Health Care Directives and the Law of Arkansas*, 39 Arkansas Law Rev 375, 438,439.

¹⁹³ Alan D. Lieberson, M.D., J.D., *Advance Medical Directives* (Clark Boardman Callaghan, Cumulative Supplement issued in August 2001), at 17.

make health-care decisions for adult individuals who lack capacity.

This state legislation, however, has developed in fits and starts, resulting in an often fragmented, incomplete, and sometimes inconsistent set of rules. Statutes enacted within a state often conflict and conflicts between statutes of different states are common. In an increasingly mobile society where an advance health-care directive given in one state must frequently be implemented in another, there is a need for greater uniformity.

The Health-Care Decisions Act was drafted with this confused situation in mind."

7.200 The following concepts are cited as building blocks for the proposed new Act:

"The Act is built around the following concepts. First, the Act acknowledges the right of a competent individual to decide all aspects of his or her own health care in all circumstances, including the right to decline health care or to direct that health care be discontinued, even if death ensues. An individual's instructions may extend to any and all health-care decisions that might arise and, unless limited by the principal, an agent has authority to make all health-care decisions which the individual could have made. The Act recognises and validates an individual's authority to define the scope of an instruction or agency as broadly or as narrowly as the individual chooses.

Second, the Act is comprehensive and will enable an enacting jurisdiction to replace its existing legislation on the subject with a single statute. The Act authorises health-care decisions to be made by an agent who is designated to decide when an individual cannot or does not wish to; by a designated surrogate, family member, or close friend when an individual is unable to act and no guardian or agent has been appointed or is reasonably available; or by a court having jurisdiction as decision maker of last resort.

Third, the Act is designed to simplify and facilitate the making of advance health-care directives. An instruction may be either written or oral. A power of attorney for health care, while it must be in writing, need not be witnessed or acknowledged. In addition, an optional form for the making of a directive is provided.

Fourth, the Act seeks to ensure to the extent possible that decisions about an individual's health care will be governed by the individual's own desires concerning the issues to be resolved. The Act requires an agent or surrogate authorised to make

health-care decisions for an individual to make those decisions in accordance with the instructions and other wishes of the individual to the extent known. Otherwise, the agent or surrogate must make those decisions in accordance with the best interest of the individual but in light of the individual's personal values known to the agent or surrogate. Furthermore, the Act requires a guardian to comply with a ward's previously given instructions and prohibits a guardian from revoking the ward's advance health-care directive without express court approval.

Fifth, the Act addresses compliance by health-care providers and institutions. A health-care provider or institution must comply with an instruction of the patient and with a reasonable interpretation of that instruction or other health-care decision made by a person then authorised to make health-care decisions for the patient. The obligation to comply is not absolute, however. A health-care provider or institution may decline to honour an instruction or decision for reasons of conscience or if the instruction or decision requires the provision of medically ineffective care or care contrary to applicable health-care standards.

Sixth, the Act provides a procedure for the resolution of disputes. While the Act is in general to be effectuated without litigation, situations will arise where resort to the courts may be necessary. For that reason, the Act authorises the court to enjoin or direct a health-care decision or order other equitable relief and specifies who is entitled to bring a petition."

7.201 The prefatory note, in its final paragraph, states the effect of the Health-Care Decisions Act:

"[t]he Health-Care Decisions Act supersedes the Commissioners' Model Health-Care Consent Act (1982), the Uniform Rights of the Terminally Ill Act (1985), and the Uniform Rights of the Terminally Ill Act (1989). A state enacting the Health-Care Decisions Act which has one of these other acts in force should repeal it upon enactment."

Chapter 8

Proposed options for reform

Introduction

8.1 As explained in the Preface, this report is concerned with two specific circumstances, both relating to decision-making for persons who are unable to make those decisions at the time of execution of the associated action. The first relates to decisions made by a third party in respect of the medical treatment and the management of property and affairs of persons who are comatose or in a vegetative state. The second relates to advance decision-making by the individual himself as to the health care or medical treatment he wishes to receive at a later stage when he is no longer capable of making such decisions. In this Chapter, we review the relevant findings of our consultation exercise and set out our recommendations for reform.

8.2 The Sub-committee received over 60 written responses to the consultation paper from both individuals and religious, professional, social welfare and educational organisations. All the feedback received has been given careful consideration and many of the suggestions have been incorporated in the formulation of this report. A list of the persons, associations and institutions that made submissions to us can be found in Annex 8 at the end of this report.

8.3 This report is concerned with decision-making as to health care for persons who do not have the capacity to make those decisions at the time the health care is to be carried out. The relevant distinction to be drawn is between those situations in which the individual has given an advance indication of his wishes before the onset of incapacity (as in the case of living wills or advance directives) and those in which he has not (as in the case of comatose or vegetative patients). We will consider the former category first.

Part 1: Advance directives

Options

8.4 In our Consultation Paper we identified five possible options for reform to resolve the problems which have been raised in earlier Chapters of this report:

- (a) Extend the existing scope of enduring powers of attorney;
- (b) Create welfare or continuing powers of attorney;

- (c) Expand the functions of the Guardianship Board;
- (d) Provide a legislative basis for advance directives; or
- (e) Retain the existing law and promote the concept of advance directives by non-legislative means.

(a) *Extend the existing scope of enduring powers of attorney*

8.5 In the Consultation Paper, we considered the option of extending the existing scope of enduring powers of attorney to incorporate within it the concept of a living will or advance directive. Provisions could be expressly made to permit competent adults to choose a proxy or attorney to make healthcare decisions or life-sustaining treatment decisions for them if they become critically ill or mentally incompetent. This could be done as well as, or instead of, executing a living will or an advance directive.

8.6 This option was favoured by a very small minority of the respondents, who highlighted the advantages we had acknowledged in the Consultation Paper. These included the following:

- This option would be relatively simple to implement.
- This mechanism is flexible as it would not be necessary to anticipate all future medical needs before the onset of illness.
- The attorney would be able to resolve ambiguities or inconsistencies in the patient's prior written and oral statements when deciding what the patient would want under the circumstances.
- The attorney provides doctors with the assurance that they have the authority to take particular actions, making doctors less vulnerable to legal reprisals or professional censure than if they rely on the informal consent of a relative.

8.7 We have duly considered these points, but, in common with the majority of respondents, consider that the possible problems associated with this option which we set out in the Consultation Paper outweigh any advantages:

- The decision-making process would be largely unregulated and may be open to exploitation and abuse.
- Attorneys are unsupervised. Once the donor becomes incapable, there may be no one with sufficient interest to monitor and, if necessary, challenge the attorney's decisions.

- The existing legislation has no provision to resolve the problem of determining the exact time of the onset of incapacity, which can be particularly difficult to establish in cases of senile dementia, where use of the enduring power is likely to be most frequently encountered. Although one respondent suggested that psychiatrists could help to determine the time of the onset of incapacity, fluctuation of mental incapacity in some cases still presents a problem.
- Not only may it be impossible for practical reasons to establish with precision the time at which incapacity occurs, but as soon as the attorney has reason to suspect that the donor has become, or is becoming, mentally incapable and the need to register with the Registrar of the High Court arises, the power lapses for most purposes until the registration procedure and other necessary formalities have been completed.
- There may be a lack of procedural safeguards to impose any positive duties on an attorney to act: *"An attorney is not a trustee and there are no sanctions available against one who through inertia or uncertainty sits back and simply does nothing."*¹
- It is possible that an attorney appointed to manage an individual's financial affairs may not necessarily be the most appropriate person to make healthcare or medical decisions.

8.8 On balance, we do not consider extending the existing scope of enduring powers of attorney would be desirable and we therefore do not recommend this option.

(b) Create welfare or continuing powers of attorney

8.9 We discussed in our Consultation Paper the option of permitting attorneys to take welfare and healthcare decisions on behalf of granters after the granters' incapacity. The distinction between this and extending the existing scope of enduring powers of attorney is that the powers of a person appointed under a welfare or continuing power of attorney would be restricted to welfare or healthcare and would not extend to the donor's financial or property affairs as they would under an enduring power of attorney. In contrast to a conventional power of attorney, a welfare or continuing power of attorney would only take effect after the donor's incapacity.

8.10 The arguments in favour of continuing powers of attorney are broadly similar to the arguments for extending the scope of the existing enduring powers of attorney scheme. Such powers would offer flexibility in

¹ The English Law Commission Consultation Paper No 119, *Mentally Incapacitated Adults and Decision-Making: An Overview* (1991), para 6.16, p 149.

meeting future medical needs; they would provide a mechanism to ensure the donor's wishes are reflected after his incapacity; and they would assist medical practitioners in their decision-making in relation to an incompetent patient.

8.11 The arguments against this option are also similar to those against the option of extending the existing enduring powers of attorney. The disadvantages of this scheme include:

- The decision-making process may be largely unregulated and may be open to exploitation and abuse.
- A continuing power of attorney may only be of value if the granter is properly advised and the need is perceived in time.
- Determining the exact time of the onset of incapacity still presents a problem.
- There may be a lack of procedural safeguards to impose any positive duties on an attorney to act.

8.12 This option did not find much support in the consultation exercise. In particular, concern was expressed about the possibility of exploitation and abuse of persons executing continuing powers of attorney. Again, after considering the arguments for and against this option, we have concluded that this option should be rejected.

(c) *Expand the functions of the Guardianship Board*

8.13 The Consultation Paper also discussed the option of expanding the functions of the Guardianship Board. Under the existing law, the Guardianship Board makes (and reviews) guardianship orders in relation to mentally incapacitated persons' care and welfare, taking account of their individual needs,² and grants consent to medical treatment of such persons.

8.14 The Guardianship Board gives directions to guardians as to the nature and extent of guardianship orders.³ In exercising its functions, the Board must ensure that the interests of the mentally incapacitated person are promoted, and that his views and wishes (so far as they can be ascertained) are respected, though these may be over-ridden where the Board considers that that is in the interests of the mentally incapacitated person.⁴

8.15 The Consultation Paper suggested that consideration could be given to expanding the scope and powers now conferred on the Guardianship Board to enable it to take account of advance directives given by mentally incapacitated persons. However, there might be a need for specific legislative provision to enable the Guardianship Board to recognise and to

² Mental Health Ordinance (Cap 136), section 59K(1)(b).

³ Mental Health Ordinance (Cap 136), section 59K(1)(d).

⁴ Mental Health Ordinance (Cap 136), section 59K(2).

adhere strictly to any advance directives made by an individual prior to his becoming mentally incapacitated.

8.16 This option has the benefit of balancing a "paternalistic" approach with some support for patients in their decision-making. It also ensures positive action in respect of the patient, in contrast to the previous option which imposes no duty to act on an attorney.

8.17 The disadvantages of this option are similar to those which apply to the other options discussed above. Advance directives are only of value if a patient is properly advised before the onset of his mental incapacity and he perceives the need in time. Other arguments against this option include the following:

- The Guardianship Board may not have full regard to the autonomy of the patient, and the patient's views and wishes could be overridden if the Board considers that it is in the interests of the patient to do so.
- The Guardianship Board can only give effect to advance directives if they are able to ascertain their existence. However, there may be difficulties in ascertaining the existence of advance directives in some situations.
- There is a limited choice of decision-maker under the framework of the Guardianship Board. In some cases, the decision-maker may be totally unrelated to the patient, or could be someone whom the patient regards as unreliable, or whom he does not favour.
- There would inevitably be some degree of inflexibility in giving effect to the advance directives, even if the advance directives could be ascertained by the Guardianship Board.
- Procedures for the institution of a guardianship application are more cumbersome than those for the execution of some form of power of attorney.
- Guardianship proceedings are sometimes perceived as embarrassing to the patients who are adjudicated as "mentally incapacitated." This could be viewed as a stigma by the patients and their families.

8.18 There was little support for this option among those who responded to the Consultation Paper. It was noted that the concept of guardianship did not chime with the underlying rationale of advance directives, which was to respect the wishes and autonomy of the individual. We do not therefore recommend an expansion of the functions of the Guardianship Board. We also consider the existing powers of the Guardianship Board are adequate

to protect the interests of incapacitated persons and do not recommend their expansion.

(d) Provide a legislative basis for advance directives

8.19 This option covers a range of possibilities, from a comprehensive statutory regime covering all aspects of substitute decision-making on behalf of mentally incapacitated adults, to a more modest provision which merely provides a statutory form of advance directive. There are a number of jurisdictions which have proposed or adopted a comprehensive legislative framework in this area.

Canada

8.20 In Canada, Manitoba enacted the Health Care Directives Act in 1992, while Alberta enacted the Personal Directives Act in 1996. It is worth pointing out that the Health Care Directives Act contains an express provision to preserve the existing rights under the common law; and the Personal Directives Act was enacted to provide legal force to healthcare directives.

England and Wales

8.21 The English Law Commission's 1995 *Report on Mental Incapacity* was concerned:

"... with the ways in which decisions may lawfully be made on behalf of those who are unable to make decisions for themselves. It covers issues of both substantive law and of procedure, and the decisions under consideration may relate to personal, financial or medical affairs."⁵

8.22 The Law Commission recommended a "unified approach" to reform of the law in this area and suggested that that would involve the repeal of Part VII of the Mental Health Act 1983 (which governs the management of property and affairs of patients) and the repeal of the Enduring Powers of Attorney Act in its entirety⁶. They further explained in their Report that:

"The draft Bill which we have prepared creates a coherent statutory scheme to which recourse can be had when any decision (whether personal, medical or financial in nature) needs to be made for a person aged 16 or over who lacks capacity. ..."

8.23 The Law Commission also recommended that:

"... the Secretary of State should prepare and from time to time revise a code or codes of practice to give guidance in connection

⁵ Law Commission, *Report on Mental Incapacity* (1995), Law Com No 231, para 1.1.

⁶ Part VII of the Mental Health Act 1983 and the Enduring Powers of Attorney Act were repealed by the Mental Capacity Act 2005.

*with the legislation. There should be consultation before any code is prepared or revised, and preparation of any part of any code may be delegated.*⁷

8.24 In the light of the responses to a consultation paper issued by the Lord Chancellor's Department in 1997, however, the UK Government decided not to take forward the issue of advance statements.⁸

8.25 As pointed out in our Consultation Paper, the advantages of a comprehensive scheme of reform are that it would be coherent and could more easily accommodate new ideas and models which might not fit easily into existing law or procedures.

8.26 We also note that there are limitations of advance directives however, as was pointed out by the Law Commission in their 1991 consultation paper:

*"Some people will never have sufficient capacity to use them. Many of those who do will retreat from the idea until too late. Few people face up readily to the prospect of advancing mental deterioration. The use of advance delegation mechanisms requires forethought and the obtaining of proper advice. Decisions also need to be taken about when advance directives should come into effect. If incapacity is taken as the 'triggering' event, the intractable problem of establishing the exact time of onset will continue to cause problems. No matter how carefully advance planning is undertaken, contingencies will inevitably occur which could not be foreseen, and for which no arrangements have been made."*⁹

8.27 The Law Commission considered the separate concept of a "living will" (the refusal of life sustaining treatment) might also present problems of implementation. The Law Commission made the following observations in their 1991 Consultation Paper:

"A number of problems have emerged with the implementation of living wills. Various questions may remain unresolved in the legislation. For example, does a doctor's failure to comply with the terms of a living will constitute professional misconduct? Can the refusal of life sustaining treatment constitute suicide, and what are the insurance implications of this? There are fears about undue pressure to sign a living will being placed upon people diagnosed as having a terminal illness, particularly in a country where medical care is largely privately funded.

⁷ Law Commission, *Report on Mental Incapacity* (1995), Law Com No 231, para 2.53.

⁸ (Cm 4465), October 1999, Introduction, para 12.

⁹ The English Law Commission Consultation Paper No 119, *Mentally Incapacitated Adults and Decision-Making: An Overview* (1991), para 6.3.

*There are many versions of living wills, and the clarity with which they give instructions varies widely. Very detailed living wills risk failing to foresee a particular turn of events, whereas those written in general terms may be ambiguous in their application to particular circumstances and require considerable interpretation by medical practitioners. Either may result in an outcome which the patient might not have wished. ..."*¹⁰

8.28 As noted in the previous chapter, following the *Report on Mental Incapacity* published by the Law Commission in 1995, the Lord Chancellor's Department issued a Consultation Paper in 1997 entitled "*Who Decides?*" This sought views on a possible framework for protection for mentally incapacitated adults and for those who look after them, "*and for providing an organised framework of law to manage the welfare and affairs of mentally incapacitated adults*"¹¹. As a result of the consultation exercise, the Lord Chancellor's Department expressed reluctance to take forward the issue of advance directives. In their 1999 Report on the subject, the department made the following remarks:

*"Given the division of opinion which exists on this complex subject and given the flexibility inherent in developing case law, the Government believes that it would not be appropriate to legislate at the present time, and thus fix the statutory position once and for all. The Government is satisfied that the guidance contained in case law, together with the Code of Practice 'Advance Statements about Medical Treatment' published by the British Medical Association, provides sufficient clarity and flexibility to enable the validity and applicability of advance statements to be decided on a case by case basis. However, the Government intends to continue to keep the subject under consideration in the light of future medical and legal developments."*¹²

Singapore

8.29 In Singapore, the Advance Medical Directive Act was enacted in May 1996, with its provisions implemented in July 1997. The Act implemented the recommendations contained in a review conducted by the National Medical Ethics Committee in 1994, which had emphasised the need for legislation in order to provide the necessary substantive and procedural safeguards for advance medical directives. The legislation made clear that anyone who did not wish to execute an advance medical directive should not be compelled or pressured to do so. It also emphasised that appropriate palliative care (including the relief of pain, suffering and discomfort and the reasonable provision of food or water) must always be provided to the patient even after an advance medical directive had been executed.

¹⁰ The English Law Commission Consultation Paper No 119, *Mentally Incapacitated Adults and Decision-making: An Overview* (1991), paras 6.6-6.7.

¹¹ Lord Chancellor's Department, Consultation Paper: *Who Decides?* (1997), para 1.1.

¹² (Cm 4465), October 1999, Introduction, para 20.

8.30 We pointed out in our Consultation Paper that a narrow approach similar to that taken by Singapore would give legal force to the concept of advance directives and would provide the legislative basis for the necessary substantive and procedural safeguards. Under this approach, both the format and the manner of execution of advance directives would be prescribed by law. The advantage is that this would provide greater certainty for doctors, and reduce the likelihood of disputes between doctors and patients' families. This option would also enhance the principle of patients' autonomy. Some respondents who favoured this option argued that disputes between doctors and patients' families, or among relatives themselves, would not be resolved unless the patients' advance directives had a statutory basis. In addition, they considered that a legislative framework for advanced directives would offer greater certainty and was necessary in order to offer sufficient protection to medical staff or health-carers. They expressed concern that the fear of potential litigation might hold doctors back from implementing non-statutory directives. In response to this last point, we would point out that the common law already recognises the validity of an advance directive and medical staff are entitled to act upon it until its validity is challenged.

8.31 On the more general issue of whether or not to introduce a legislative scheme, it would in our view be premature to attempt to legislate on advance directives when the concept is still new to the community and it is one of which most people have little knowledge. In addition, legislation may deter, rather than encourage, the use of advance directives. An advance directive which is statutory in nature would be less flexible, with an accompanying risk that its validity might be challenged on the basis of a minor technical error in its execution. We are also concerned that the process of revocation of a statutory advance directive may be seen as more daunting. We do not therefore favour at this stage either a comprehensive legislative scheme, or the more limited step of adopting a statutory form of advance directive.

(e) Retain the existing law and promote the concept of advance directives by non-legislative means

8.32 In our Consultation Paper, we proposed that the existing law should be retained and that the concept of advance directives should be promoted by non-legislative means, including the wide dissemination of a model form of advance directive.

8.33 Under the existing common law, an individual may, while capable, give directions as to his future health care once he no longer has the capacity to make such decisions. Those directions will be recognised as valid unless challenged on the grounds of, for instance, incapacity or undue influence. An advance directive made by a competent individual in respect of his consent to, or refusal of, medical treatment has the same effect as a contemporaneous oral instruction. Where a dispute arises over the patient's

prior instructions or wishes as to his medical treatment, application may be made to the court for a decision. If recourse is had to the court, the court will take into account the particular facts and circumstances of the case in reaching its decision. There is accordingly a degree of flexibility in the existing common law approach which would be lacking in a statutory regime.

8.34 The majority of respondents to our Consultation Paper agreed that the existing law should be retained and that the concept of advance directives should be promoted by non-legislative means. A significant number of those in favour of this approach, however, saw it as an interim measure and believed that legislation should be considered once the community had become familiar with the concept of advance directives. Those respondents considered that a legislative framework would provide greater certainty in the long run, and noted that the outcome of court proceedings was open to doubt and therefore offered insufficient protection to medical practitioners when implementing advance directives.

8.35 We have considered these points carefully. We acknowledge that the provision of a statutory form of advance directive would offer a greater degree of certainty than the existing unstructured position, where front-line medical staff must make decisions on the validity of advance directives, unassisted by any prescription as to what amounts to an acceptable form for such documents. While the court's assistance may still be necessary from time to time in relation to advance directives made under a statutory scheme, it is fair to assume that the scope for uncertainty and dispute would be less than under the present common law regime. Nevertheless, we maintain our earlier view that the way forward, at least initially, should be by non-legislative means. Those means should include the preparation, publication and wide dissemination of a model form of advance directive. This model form would provide a simple and convenient way of executing an advance directive which the individual could be confident is clear and unambiguous. We note that our conclusion is also in line with the view of the Manitoba Law Reform Commission in its report on withholding or withdrawing life sustaining medical treatment discussed in Chapter 7. The Manitoba Law Reform Commission, likewise, did not propose that principles outlined in the report should be implemented by legislation. Instead, they recommended that "*other health care institutions, ... involved in delivering health care in Manitoba should adopt the Policy of the College [of Physicians and Surgeons of Manitoba] once amended to reflect our advice.*"¹³

8.36 In reaching this conclusion, we have been persuaded by a number of considerations.

- Firstly, the concept of advance directives is not one with which the community is generally familiar. We believe that it would be premature to attempt to formulate a statutory framework, and to embark on the legislative process, without greater public awareness of the issues involved.

¹³ Manitoba Law Reform Commission, *Report on withholding or withdrawing life sustaining medical treatment*, at 108.

- Secondly, in such a socially sensitive matter as this, there is much to be said for proceeding by cautious increments. The law currently recognises the validity of advance directives but there is no guidance given as to what form such a directive should take to ensure it is sufficiently clear to provide medical staff with assurance that they may safely act upon it. The provision of a statutory form would fill that gap, but a half-way house (and a step on the road to legislation at a later stage) would be to offer guidance to the public in the shape of a model advance directive, without the backing of legislation.
- Thirdly, the publication and dissemination of a model form of advance directive can be achieved quickly and cost-effectively. It would offer immediate assistance to patients, their families and medical practitioners, without the delays inherent in the legislative process, by making widely available the means for individuals to make a clear and unambiguous statement of their wishes.

8.37 There are undoubtedly advantages in promoting the wider use of advance directives, both in enhancing patient autonomy and in providing greater certainty for medical staff. Equally, however, any proposals for reform in relation to such a socially sensitive matter must take account of the community's values and mores. We note in this regard that the Hospital Authority's *Guidelines on Life-sustaining Treatment in the Terminally Ill* has pointed out the significance in Chinese culture of the involvement of the family in the decision-making process:

"In the Chinese culture, the concept of self may be different from the Western concept and is more of a relational one The role of the family in decision-making may also be more important than that of Western societies This document [the Guidelines] therefore acknowledges the importance of involvement of the family in the decision-making process, though the views of the family cannot override that of the mentally competent patient."¹⁴

As we explain later, our proposals reflect similar thinking to that of the Hospital Authority's Guidelines, by encouraging the involvement of the family in the decision-making process while recognising the pre-eminence of an unambiguous advance directive.

Concerns of doctors and other health-carers

8.38 We understand the concern of some respondents that a non-legislative approach might not provide sufficient protection to doctors or other health-carers in implementing a patient's advance directives, particularly

¹⁴ Para 1.3.2 of the Guidelines.

when the directives are at odds with the wishes of the patient's family. The existing common law, however, already offers adequate protection to doctors as long as they have acted in the best interests of the patient, or the provision or otherwise of medical treatment is in accordance with the patient's instructions previously made. Some respondents also expressed concern as to possible liability in circumstances where the medical staff were unable to obtain details of an advance directive. Again, the existing common law permits doctors to treat their patients as long as the treatment is in the patients' best interests.

8.39 One respondent suggested that advance directives should not be binding upon doctors if new factors arise. We do not agree with this suggestion as this would be tantamount to disregarding the patient's wishes or autonomy.

8.40 We have duly considered the view of the majority of respondents that the promotion of the concept of advance directives by non-legislative means should be an interim measure. We agree with this approach and suggest that the position should be reviewed by the Government in due course once the community is more generally familiar with the concept of advance directives. We consider that any such review would need to take into consideration three factors, namely, how widely the use of advance directives had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of advance directive. In the meantime, however, for the reasons set out in the previous paragraphs, we confirm the view put forward in our consultation paper (and supported by the majority of respondents) that it would be premature at this stage to introduce a statutory scheme for advance directives. We therefore recommend that the concept of advance directives should be promoted initially by non-legislative means.

Recommendation 1

We recommend that the concept of advance directives should be promoted initially by non-legislative means. We recommend that the Government should review the position in due course once the community has become more widely familiar with the concept and should consider the appropriateness of legislation at that stage. That review should take into consideration three factors, namely, how widely the use of advance directives had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of advance directive.

A model advance directive form

8.41 It is inevitable that doubts as to the validity of an advance directive may arise in some cases, or that disputes may arise between medical staff and a patient's family as to the patient's wishes. In such cases, recourse may be had to the court to resolve such issues, but that is not ideal. Court proceedings are costly and beyond the financial means of many in the community. In addition, the traditional courtroom atmosphere and the legal culture of adversarial proceedings may alienate and intimidate applicants. We believe that it is in the best interests of patients, their families and medical staff to endeavour to reduce the areas for dispute which may arise in relation to an advance directive. One way to achieve this would be to devise and disseminate a model form of advance directive which, if completed fully, would offer a clear and unambiguous statement of the patient's wishes. If the form includes scope for consultation and communication with the patient's family, this would provide a means for including the patient's family in the decision-making process. An agreed form would greatly assist medical practitioners and healthcare professionals in their consideration of consent to medical treatment and make it easier for them to be confident as to the patient's prior wishes or instructions.

8.42 We believe the provision of a model form of advance directive would do much to answer the problems currently encountered by patients, their families and the medical profession. We have already explained that we prefer to avoid the rigidity of a statutory form, where any deviation from the form may affect the validity of the instructions from the outset. Instead, what we propose is that wide publicity should be given to a non-statutory form, which individuals could use if they chose. The advantage of the model form would be that, if correctly completed, the individual could be reasonably assured that his wishes would be executed. We must emphasise that there is no element of compulsion in our proposal and it would remain a matter for the individual to decide whether or not he wished to execute an advance directive in the form proposed, or to choose some other form. An advance directive executed in a different form would, as now, be enforceable so long as its instructions are clear, and it is freely made by a competent person.

8.43 We have accordingly prepared a model advance directive form, and this can be found at Annex 1 of this report. In drawing up the form, we have considered and referred to the respective sample advance directive forms produced by the British Medical Journal (at Annex 2), the District of Columbia Hospital Association of the United States of America (at Annex 3), and an "Advance Medical Directive" form produced by the Singapore Ministry of Health (at Annex 4).

8.44 The model form at Annex 1 reflects the responses received to our consultation paper and differs from the draft proposed in our consultation paper in a number of respects. Some respondents suggested that the model form should not contain positive instructions regarding the type of medical treatment a patient wishes to receive. This view, we note, is in line with the

decision of *Re Burke*¹⁵, a recent Court of Appeal case in England. We agree with this suggestion, and have amended the draft form accordingly.

8.45 Some respondents suggested that the object of drawing up advance directives should be spelt out in the form and that a statement should be added to the effect that euthanasia would not be performed under any circumstances, even if expressly requested. We agree, and have amended the model form to incorporate these suggestions. In this regard, we have referred to the advance directive form prepared by the British Medical Journal and consider its object clause very useful. We have therefore incorporated a similar clause in our model form, with some modifications concerning the medical conditions that trigger the application of advance directives, as follows:

"The object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf."

Recommendation 2

We recommend the publication and wide dissemination of the model form of advance directive we propose, and that the use of the model form should be encouraged.

8.46 We note the suggestion of one respondent that it is desirable that consideration should be given to the question of making an advance directive ahead of time and long before the individual is confronted with a life-threatening illness so that a properly considered view can be taken of the preferred options for end-of-life care. We agree with this suggestion, and have added a new recommendation to reflect this.

Recommendation 3

We recommend that appropriate publicity should be given to encourage individuals to consider and complete advance directives in advance of any life-threatening illness.

¹⁵ [2005] EWCA Civ 1003. The judgment was delivered on 28 July 2005.

Launching of publicity programmes

8.47 In our view, there is a need to promote greater public awareness and understanding of the concept of advance directives. The Government has a key role to play in any such campaign, and we think that general information on the making of advance directives and copies of the model directive we propose should be made available at all District Offices. We would also encourage family doctors and hospitals to participate in a campaign to raise public awareness and understanding, and to be ready to assist patients if they wish to make advance directives. We believe that the Medical Council, the various medical associations, the Hong Kong Academy of Medicine and Constituent Colleges, the Bar Association, the Law Society, medical and health care professionals and religious and community groups could usefully play a part in such a campaign. In response to the suggestion of one respondent, we also believe that the Government should encourage, support and facilitate care-providers in the non-governmental sector, such as those running residential homes and social centres for the elderly, to educate their clients and members about the concept of advance directives. The standing which these organisations have with their clients would, we believe, be particularly helpful in this educational role.

Recommendation 4

We recommend that the Government should launch publicity programmes to promote public awareness and understanding of the concept of advance directives. The Department of Health and all District Offices should have available for public reference material which provides general guidance to the public on the making and consequences of an advance directive and should provide copies of the model form of advance directive for public use.

Recommendation 5

The Government should endeavour to enlist the support of the Medical Council, medical associations, the Bar Association, the Law Society, the Hospital Authority, all hospitals and medical clinics, non-governmental organisations involved in care for the elderly, and religious and community groups in this information campaign about the use and effect of advance directives.

Application of advance directives

8.48 We proposed in our Consultation Paper that the instructions contained in an advance directive should apply when a patient is in one of three major medical conditions: irreversible coma, persistent vegetative state, or terminally ill. One respondent suggested that the proposed triggering conditions for activating advance directives were too narrow and might render advance directives redundant. This respondent submitted that life-sustaining treatment would be withheld under current medical practice in any event when patients became "terminally ill". We disagree, for although it might be in the best interests of the patient to withhold life-sustaining treatment in most situations when he becomes "terminally ill", difficulties may arise for medical staff where the patient's family objects to the withholding of life-sustaining treatment. In such situations, an advance directive would help solve disputes arising between the doctors and the patient's family. It is also important to point out that the concept of advance directives is in reality a fortification of the patients' best interests principle.

8.49 Some respondents suggested that "severe dementia" should be included as one of the triggering medical conditions. However, most responses were against this suggestion for fear of the high risk of abuse. We agree with the majority view and do not consider it appropriate to include "severe dementia" as one of the triggering medical conditions as the range of disability in the case of dementia is too wide. We maintain our view on this issue that the instructions contained in an advance directive should apply only where a patient is in one of the three medical conditions we have identified. We would point out that doctors do not need to wait until a patient has reached the very terminal phase before activation of any advance directives, provided the patient's medical condition falls within one of the three categories described above. We stress again that advance refusal of treatment is already acknowledged by both the medical profession and the common law.

Certification of medical conditions

8.50 In our Consultation Paper, we suggested that the three medical conditions that would activate advance directives, namely, irreversible coma, persistent vegetative state, or terminally ill should be confirmed and certified by at least two doctors before any advance directive was activated. Some respondents suggested that one of the doctors certifying the conditions should be a clinician experienced in the condition suffered by the patient. We fully appreciate the intent behind this suggestion, but are conscious that such a requirement would raise practical problems of the availability of resources and expertise. Noting this difficulty, we stand by our original position and maintain our view that such medical conditions should be confirmed and certified by at least two doctors before any advance directive applicable in those conditions can take effect.

8.51 Some respondents expressed concerns about the precision or the lack of definition of the medical conditions "persistent vegetative state" and "irreversible coma" referred to in the model advance directive form. We do

not consider it necessary to provide definitions of these medical conditions, as accepted medical practice and guidelines satisfactorily establish the diagnosis of these conditions.

Palliative and basic care

8.52 We take the view that palliative and basic care which is necessary to maintain the patient's comfort, dignity, or for the relief of pain, should always be provided. In the consultation exercise, we received diverse views as to what might constitute basic or palliative care. In our opinion, the matter should best be left to the medical profession to decide in accordance with the medical practice prevailing at the time when a person's advance directive is to be activated. However, we consider that non-artificial nutrition and hydration should form part of basic care, at least for the purposes of the advance directive form. We have therefore amended the wording regarding the instructions on the provision of basic or palliative care in the model advance directive form to:

"Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care."

Definitions of "terminally ill" and "life-sustaining treatment"

8.53 With respect to our proposed definition of "terminally ill" in our model advance directive form, some respondents commented that the condition of "*death being imminent*" might cause problems as the intervention of life-sustaining treatment might significantly prolong a patient's survival. These respondents also felt that the phrase "*only prolong the process of dying*" used to explain "*life-sustaining treatment*" was difficult to define. They suggested that reference should be made to the Hospital Authority's *Guidelines on Life-sustaining Treatment of the Terminally Ill* and that the definition of "life-sustaining treatment" provided by the British Medical Association in the Association's 1999 Guidelines, which is also adopted by the Hospital Authority, should be adopted to avoid confusion. We agree, as this would improve consistency in medical terminology.

Recommendation 6

We recommend that, for the purpose of making an advance directive, the terms "terminally ill" and "life-sustaining treatment" should be defined as follows:

- (a) the "terminally ill" are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few**

months.

- (b) "life sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. Artificial nutrition and hydration means the feeding of food and water to a person through a tube.

Witnesses

8.54 As we have already explained, the model form we put forward in this paper is precisely that: a model which those choosing to make an advance directive may choose to adopt if they wish. The model form has no element of compulsion or exclusivity, and persons making an advance directive may opt instead to use their own form of directive, though we believe that the use of the model form will greatly reduce the scope for uncertainty and dispute. Since our form is only a suggested model, it follows that the elements it contains may be adopted or omitted as the user chooses. One element of the model form is the witness requirement.

8.55 We suggested in our Consultation Paper that the model form should be completed in the presence of two witnesses, one of whom should be a medical practitioner. We also discussed alternative approaches which could be adopted in respect of witness requirements, each with their own potential disadvantages and advantages.

8.56 We highlighted in our Consultation Paper that in the six years following the enactment of the Enduring Powers of Attorney Ordinance (Cap 501) in 1997 only three enduring powers of attorney had been registered. It has been suggested that one reason for this low number is the fact that the document must be witnessed simultaneously by both a medical practitioner and a solicitor. We asked specifically in our Consultation Paper for views on our proposed requirement of two witnesses, one of whom must be a medical practitioner, as we were concerned that such a requirement might dissuade the public from executing advance directives. The majority of respondents, however, favoured the requirement of two witnesses and agreed with the requirement that one should be a medical witness.

8.57 The inclusion of a medical practitioner as one of the witnesses to the advance directive would serve a number of purposes. Firstly, the doctor acting as a witness would be in a position to explain to the maker the nature and implications of an advance directive. The witnessing doctor would be

able to advise the maker of the advance directive of the possibility that future medical or technological advances may affect decisions reflected in the advance directive, and that the advance directive should contain no unlawful instructions as to the maker's medical treatment, nor instruct doctors to withhold basic medical care. Secondly, a medical practitioner would be well able to assess whether the individual understands the nature and implications of an advance directive at the time of making the advance directive. Thirdly, the witnessing doctor would be able to explain to the second witness the nature of the document he is to witness. We consider that consistency of practice by witnessing doctors could best be achieved by the Medical Council or other relevant professional body issuing guidelines for doctors who witness the making of advance directives. One respondent to our consultation paper suggested that the expertise of a psychiatrist, rather than a general practitioner, might be required to assess whether an individual was of sound mind when he made the advance directive. We do not agree, and believe that a general practitioner is well able to assess whether an individual is able to understand the nature and implications of an advance directive at the time of making the advance directive. We have in this regard, also removed the statement by the maker in the proposed model form of advance directive that he is of sound mind as a person is presumed to have mental capacity unless otherwise established.

8.58 The responses to our question as to whether the witnessing doctor should be a doctor other than one who is treating, or has treated, the individual making the advance directive were mixed. Some respondents argued that an individual might prefer to involve his family doctor in the sensitive matter of making an advance directive and might feel inhibited in discussing this with a doctor with whom he was not familiar. Others, however, suggested that requiring the involvement of another doctor would prompt more careful consideration by the individual before completing an advance directive. On balance, we are of the view that the choice should be best left to the maker of the advance directive. We have amended the model form so that it now indicates whether or not the witnessing doctor is one who is treating or has treated the maker of the advanced directive.

8.59 A variety of other suggestions were made by respondents in relation to the witness requirements appropriate for an advance directive. Some argued that the requirements should be more demanding, with, for example, one witness having specialist expertise in assessing cognitive function, or that a multi-disciplinary team of doctors, social workers, spiritual care workers, etc, should participate in the process. Others argued that at least one member of the patient's family should act as a witness, and that beneficiaries of the patient's estate should not be precluded from acting as witnesses. It is important in our view that any witness requirements are not unduly burdensome on the maker of an advance directive, that they recognise the maker's autonomy in his choice of witness, and that they offer some assurance against the risk of abuse or undue influence. We have already explained that any proposal we make in respect of the witnesses we consider appropriate to the completion of the model form of advance directive is not binding, and a failure to follow our recommendations in this regard will not of

itself invalidate an advance directive. However, adopting the form of the model advance directive in all its aspects, including as to witnesses, will in our view reduce the scope for subsequent uncertainty and dispute. Taking all this into account, we confirm the proposal in our consultation paper that the model form of advance directive requires that it be witnessed by two witnesses, one of whom must be a medical practitioner. We also consider that guidelines should be issued by the Hospital Authority, the Medical Council, the Hong Kong Medical Association and other relevant professional bodies to provide guidance for the medical profession (a) as to the effect of an advance directive and (b) in assessing the validity of an advance directive. However, if in circumstances an individual may not be able to make a written advance directive, we suggest that he makes his oral advance directive before a doctor, lawyer or other independent person who must not have an interest in the estate of the person making the advance directive.

Recommendation 7

- (a) The model form of advance directive requires that it be witnessed by two witnesses, one of whom must be a medical practitioner, neither witness having an interest in the estate of the person making the advance directive.**
- (b) The Government should encourage bodies such as the Hospital Authority, the Medical Council, the Hong Kong Medical Association and other relevant professional bodies to consider issuing guidelines for doctors witnessing the making of advance directives to ensure consistency of medical practice in this area. The guidelines should also provide guidance for the medical profession (a) as to the effect of advance directives and (b) in assessing the validity of an advance directive.**
- (c) If in circumstances an individual may not be able to make a written advance directive, the oral advance directive should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the advance directive.**

Revocation of advance directives

8.60 The model form of advance directive we put forward in this report is intended to reduce uncertainty and to provide a convenient way in which an individual can make his wishes as to terminal health care known in advance.

We believe an individual who chooses to use the model form can be confident that his wishes will have been made clear and unambiguous. There is, however, no compulsion on anyone to use the model form if instead they prefer to adopt their own formulation, and an advance directive made in a different manner can be equally valid. As it is with the model form of advance directive, so it is with the recommendations we make in respect of revocation: we believe that by following our proposed method of revocation, the individual's wishes will be made clear, but we do not for a moment suggest that an individual may not validly revoke his advance directive in a different manner if he so chooses. Provided the revocation is clear and unambiguous, it will be effective. With those preliminary comments, we now set out our preferred methods of revocation.

8.61 In our Consultation Paper, we took the provisional view that where an advance directive was made in writing, the revocation should also be in writing, while an oral advance directive might be revoked either orally or in writing. In the light of the comments we have received, we have revisited this issue and revised our conclusion. In doing so, we have sought to balance the interests of patient autonomy and the need to ensure that his wishes (whether as to revocation or execution of the advance directive) are respected with the doctor's imperative to err on the side of preserving life in cases of doubt. We have also borne in mind the need to protect the patient from abuse and undue influence, while not making the procedure for revocation unduly burdensome.

8.62 Clearly, a revocation which is made in writing offers the greatest degree of certainty and clarity for all concerned. We therefore consider that for the sake of certainty and the avoidance of doubt, those wishing to revoke an advance directive (regardless of whether the advance directive is written or oral) should always be encouraged to do so in writing. We have set out at Annex 5 a sample form for revocation of an advance directive. There are circumstances, however, where the maker of the advance directive may not be able to make a written revocation. He may, for instance, have made an oral revocation in the presence of others, but is subsequently admitted to hospital in a condition where he is no longer competent to confirm that oral revocation, either orally or in writing. One option would be to allow the doctor to rely on oral confirmation of that earlier revocation from a third party. The difficulty with such an approach, however, is that it may raise concerns among those making advance directives that, for instance, their wishes might subsequently be frustrated purely on the basis of the oral say-so of a family member. We have therefore concluded that an oral revocation of an advance directive should be made before a doctor, lawyer or other independent witness who does not have an interest in the estate of the person making the revocation. Where practicable, we think it desirable that a written record of the oral revocation should be made by the witness, and we have included at Annex 6 an appropriate model form for this purpose.

8.63 We recommended in our Consultation Paper that the person who witnesses a written revocation need not be an independent witness. Again, in the light of views expressed on consultation, we have revised our view. On reflection, taking account of the need to protect the patient from undue

influence, we have come to the conclusion that the person who witnesses a written revocation should (as in the case of an oral revocation) be an independent person who has no interest in the estate of the person making the revocation. One respondent suggested that a medical practitioner should witness the revocation of an advance directive, but we consider this would be too restrictive.

8.64 Some of those commenting on our Consultation Paper suggested that if a member of the medical staff becomes aware of a patient's revocation, that information should be properly documented in the patient's medical records. We agree with this suggestion, and have reflected this in Recommendation 8 accordingly.

8.65 Finally, we should make it clear that an advance directive will only be implemented at the point where the patient lapses into an irreversible coma or persistent vegetative state. So long as the coma is acute, rather than irreversible, life-sustaining treatment will continue to be given. We consider that doctors should err on the side of caution in cases where the diagnosis of irreversible coma or persistent vegetative state is not clear-cut.

Recommendation 8

We recommend that :

- (a) for the sake of certainty and the avoidance of doubt, those wishing to revoke an advance directive should be encouraged to do so in writing;**
- (b) if an advance directive is revoked in writing, it should be witnessed by an independent witness who should not have an interest in the estate of the person making the revocation;**
- (c) if an advance directive is revoked orally, the revocation should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the revocation, and where practicable that witness should make a written record of the oral revocation; and**
- (d) if medical staff learn that an individual has revoked his advance directive, that information should be properly documented in the individual's medical records.**

Central registry

8.66 Most respondents agreed that a central registry for the safe-keeping of advance directives should be established. Some respondents however, expressed concerns about the possible manpower problems which would be caused by our original proposal that the registry be accessible 24 hours a day. Concerns were also raised in relation to possible operational and administrative difficulties, with one respondent suggesting that the process of filing might deter individuals from making advance directives. On reflection, we have decided not to recommend the establishment of a central registry. Although a central registry would offer a convenient way in which medical staff could ascertain the existence and terms of a patient's advance directive, the essence of our proposals is that they are non-mandatory. Just as the model form of advance directive is put forward as one which the individual may or may not choose to adopt, as he sees fit, so the filing of an advance directive in the proposed registry would be entirely voluntary, with each individual deciding whether or not he wished to make use of that facility. The result of voluntary filing means that the records kept by the proposed registry would not be complete, and any search of those records by medical staff would not be conclusive.

Conscientious objection

8.67 In the consultation exercise, some respondents suggested that administrative or statutory provisions should be considered to protect those healthcare workers who have a conscientious objection to the administering or withdrawal of therapy according to the instructions given in an advance directive. We do not consider this necessary, as any healthcare worker who finds himself unable to carry out the patient's instructions should make arrangements for some one else to act in his place.

Consideration of legal advice and consultation with family

8.68 In our Consultation Paper, we considered the question of legal advice in relation to the making of an advance directive. We thought that the completion of an advance directive was a matter of such importance that it should require legal advice and a lawyer to witness its completion, but we realised that this was unlikely to be within the financial means of the majority of the population. We therefore recommended that those wishing to issue an advance directive should be encouraged to seek legal advice, but that this should not be mandatory. Our view was supported on consultation that it should be possible for individuals to make an advance directive without incurring the costs of a lawyer to advise on, or witness, the document, although we encourage them to do so.

8.69 We also consider that individuals should be encouraged, before making any advance directives, to discuss the matter with their family members. Members of the family should also be encouraged to accompany the individual when he makes the advance directive. This would ensure that both the individual and his family understand the nature of the directive, and

should help to reduce disputes about medical decisions which may arise later between physicians and the individual's family.

Recommendation 9

We recommend that the Government should, as part of its public awareness campaign about advance directives, encourage those who wish to make an advance directive to seek legal advice and to discuss the matter first with their family members. Family members should also be encouraged to accompany the individual when he makes the advance directive.

Part 2: Decision-making for persons in a coma or vegetative state

8.70 Having presented our recommendations in respect of those who are in a position to give an advance directive as to the nature of their health care, we turn now to those who are unable to do so because they are comatose or "vegetative". The Mental Health Ordinance (Cap 136) ("the MHO") provides a mechanism¹⁶ for decisions to be made as to the management of a person's property and affairs, or the giving or refusing of consent to medical treatment for him, where he is a "*mentally incapacitated person*" within the meaning of section 2(1) of the MHO. We discussed in Chapter 6 of this report that "*mental incapacity*" is defined in section 2(1) as "*mental disorder or mental handicap*". "*Mental disorder*" is itself broken down into four categories, of which the fourth is "*any other disorder or disability of mind which does not amount to mental handicap*". We have already examined this issue in our Consultation Paper and in Chapter 6 of this report. We maintain our view that there is some uncertainty as to whether a comatose or vegetative person can be said to be suffering from "*any other disorder or disability of mind*," which would bring him within the scope of the definition of "*mentally incapacitated person*" in the MHO.

8.71 In order to remove the uncertainty, we proposed in our Consultation Paper that the term "mentally incapacitated person" should be given a new definition for the purposes of Parts II, IVB and IVC of the MHO, so that these Parts will apply to a comatose or vegetative person when the need arises, with regard to the management of his property and affairs and the giving or refusing of consent to medical treatment. However, we considered that the existing definition of "mental incapacity" given in the MHO should continue to apply to Part III (Reception, Detention and Treatment of Patients), Part IIIA (Guardianship of Persons Concerned in Criminal Proceedings), Part

¹⁶ See Part II (Management of property and affairs of mentally incapacitated persons), Part IVB (Guardianship) and Part IVC (Medical and dental treatment).

IIIB (Supervision and Treatment Orders Relating to Persons Concerned in Criminal Proceedings), Part IV (Admission of Mentally Disordered Persons Concerned in Criminal Proceedings, Transfer of Mentally Disordered Persons under Sentence and Remand of Mentally incapacitated Persons) and Part IVA (Mental Health Review Tribunal) of the MHO. These Parts deal specifically with the confinement and medical treatment of persons suffering from mental disorder and would not be expected to apply to a comatose or vegetative person. Accordingly, a reference to a "mentally incapacitated person" in these Parts will continue to mean a person suffering from mental disorder or mental handicap as currently defined. We maintain our position in this regard.

8.72 We noted in our Consultation Paper the approach taken by the English Law Commission in its draft Mental Incapacity Bill (now enacted as the Mental Capacity Act 2005) where two categories of person fall within the definition of "mentally incapacitated person". The first category comprises those who are unable to make decisions for themselves on the matters in question due to "*mental disability*". The second category comprises persons who are unable to communicate their decisions because they are unconscious or for any other reason. This second category would therefore include persons in a comatose or vegetative condition and clarifies the scope of the term "*mentally incapacitated person*".

8.73 We proposed in our Consultation Paper that a similar but slightly modified approach should be reflected in the new definition of "*mentally incapacitated person*" for the purposes of Parts II, IVB and IVC of the MHO. On further consideration and for the reasons discussed later in this chapter, we now recommend that two categories of person should be included within the definition of "*mentally incapacitated person*" for the purposes of Parts II and IVC (but **not** Part IVB) of the MHO. The first category should comprise those who are unable to make decisions for themselves due to:

- (a) mental illness;
- (b) a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct;
- (c) psychopathic disorder;
- (d) mental handicap; or
- (e) any other disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning.

8.74 As we discussed in our Consultation Paper, this formulation incorporates within a single definition the separate elements of mental disorder and mental handicap which currently constitute the definition of "mentally incapacitated person" in the MHO. The conditions described in paragraphs (a), (b) and (c) above are the same as the first three categories of "mental

disorder" as currently defined in the MHO, while paragraph (d) refers to mental handicap. Paragraph (e) is intended to provide greater clarity than the existing paragraph (d) of the definition of "mental disorder" in the MHO. Firstly, it states clearly that it would cover both permanent or temporary disability or disorder. Secondly, it is more comprehensive and will include patients whose mental disability is caused other than by psychiatric illnesses.

8.75 The second category of persons included in the proposed definition of "mentally incapacitated person" are those who are unable to communicate their decisions. This category would cover a comatose or vegetative person and certain stroke patients.

8.76 We also considered whether a person's mental disability needs to be permanent or persistent for that person to fall within the ambit of our proposed definition for the purposes of Parts II and IVC of the MHO, and for these two Parts accordingly to apply. We noted that there might be difficulties in establishing the permanency or persistency of a patient's mental disability. If such a requirement were to be stipulated, it would greatly restrict the application of the substituted decision-making mechanism provided under the MHO for the management of the property and affairs, and the consent to or refusal of medical treatment, of comatose or vegetative persons. As discussed in our Consultation Paper, we note that the English Law Commission's draft Bill (now the Mental Capacity Act 2005) includes no requirement that the person's mental disability is permanent or persistent.

8.77 Most respondents agreed that for the purposes of Parts II, IVB and IVC of the MHO, the current definition of "mentally incapacitated person" should be revised to clarify any doubt that might exist. Some respondents suggested that a new definition of "mental incapacitated person" for those Parts should refer only to persons within certain diagnostic categories, such as "suffering from dementia, stroke or mental handicap". We do not agree with this approach as it is impracticable to draw up an exhaustive list of medical conditions which would have the effect of rendering individuals incapable of making decisions. An alternative suggested by other respondents was to revise the existing definition so that it was solely based on an individual's functional capabilities, such as the ability to understand or retain information. We do not consider this approach desirable either, as the tests of a person's functional capabilities relating to decision-making are not easy to define or to apply and to rely solely on such tests may result in uncertainty. Our recommendation combines elements of both the "status approach" and the "functional approach": it refers, for instance, to a person who has a psychopathic disorder **and** is unable to make a decision for himself.

8.78 With reference to the proposed definition in Recommendation 9 of our Consultation Paper, some respondents suggested that "advance dementia" should also be included as a category within "mental disability" but we do not agree with this suggestion. As we have pointed out earlier in this chapter, the range of disability covered by dementia is too wide, and it would be difficult to provide a sufficiently precise definition as to when a person is

suffering from "advance dementia".

8.79 In Recommendation 9 of our Consultation paper, a "mentally incapacitated person" basically means a person who is unable by reason of mental disability to make a decision or unable to communicate his decision because of unconsciousness or any other reason. Some respondents expressed the concern that the proposed definition will vary the categories of persons who may be received into guardianship under Part IVB of the MHO. While it is our objective to ensure that the scope of application of Part IVB covers persons who are in a coma or vegetative state, there is no intention to exclude any person who may be received into guardianship under the existing law from the application of that Part if the proposed definition in Recommendation 9 of our Consultation Paper is adopted.

8.80 We therefore have examined again the question of who may be received into guardianship under the existing law. Under section 59M (2) of the MHO, a guardianship application may be made in respect of a mentally incapacitated person (currently defined as a mentally disordered person or a mentally handicapped person in Part IVB of the MHO) on the grounds that:

- (a) the mentally incapacitated person is suffering from mental disorder or mental handicap (as the case may be) of a nature or degree which warrants his reception into guardianship; and
- (b) it is necessary in the interests of the welfare of the mentally incapacitated person **or** for the protection of other persons that the mentally incapacitated person should be so received.

8.81 Unlike the proposed definition in Recommendation 9 of our Consultation Paper, section 59M does not require that a mentally incapacitated person who is the subject of a guardianship application must be one who is **unable** to make a decision for himself or to communicate a decision. But then what is the nature or degree of mental disorder or mental handicap which warrants reception into guardianship? The MHO does not give a clear answer. However, the MHO does prescribe the basis on which a guardianship order may be made. Section 59O (3) provides as follows:

"(3) In considering the merits of a guardianship application to determine whether or not to make a guardianship order under subsection (1) in respect of a mentally incapacitated person, the Guardianship Board shall observe and apply the matters or principles referred to in section 59K(2) and, in addition, shall apply the following criteria, namely that it is satisfied -

- (a) (i) that a mentally incapacitated person who is mentally disordered, is suffering from mental disorder of a nature or degree which warrants his reception into guardianship; or*

- (ii) *that a mentally incapacitated person who is mentally handicapped, has a mental handicap of a nature or degree which warrants his reception into guardianship;*
- (b) *that the mental disorder or mental handicap, as the case may be, limits the mentally incapacitated person in making reasonable decisions in respect of all or a substantial proportion of the matters which relate to his personal circumstances;*
- (c) *that the particular needs of the mentally incapacitated person may only be met or attended to by his being received into guardianship under this Part and that no other less restrictive or intrusive means are available in the circumstances; and*
- (d) *that in the interests of the welfare of the mentally incapacitated person or for the protection of other persons that the mentally incapacitated person should be received into guardianship under this Part."*

8.82 It then appears that it is possible that the basis for granting a guardianship order may not, arguably, be **equivalent** to the criteria for classifying a person as a mentally incapacitated person under the proposed definition in Recommendation 9 of our Consultation Paper. In particular, section 59O(3)(b) stipulates that the Board should be satisfied that the mental disorder or mental handicap **limits** the mentally incapacitated person in making reasonable decisions in respect of all or a substantial proportion of the matters which relate to his personal circumstances. This criterion relates to the reasonableness of a decision. If the Board thinks, among other things, that the mentally incapacitated person cannot make a reasonable decision in relation to certain matters, a guardianship order may be made. This criterion is, again, apparently different from the condition under the proposed definition in Recommendation 9 of our Consultation Paper that a mentally incapacitated person cannot make or communicate a decision.

8.83 Section 59K(2)(a) of the MHO provides that the Guardianship Board shall observe or apply the following matters or principles in the performance of its functions or the exercise of its powers:

- (a) that the interests of the mentally incapacitated person are promoted, including overriding the views and wishes of that person where the Board considers such action is in the interests of that person;

- (b) despite paragraph (a), that the views and wishes of the mentally incapacitated person are, in so far as they may be ascertained, respected.

8.84 This section further suggests that it is not merely the ability to make a decision that is relevant to the making of a guardianship order. It is possible that the Board may make such order contrary to the views and wishes of a mentally incapacitated person if the Board considers that the order would promote his interests.

8.85 The proposed definition in Recommendation 9 of our Consultation Paper, if adopted for the purposes of Part IVB of the MHO, will make it clear that the scope of application of that Part covers a person who is in a coma or vegetative state. On the other hand, if a mentally incapacitated person suffers from mental disorder or mental handicap of a degree which does not satisfy the condition of inability to make or communicate a decision, there is a risk that he may be excluded from the jurisdiction of the Guardianship Board, as he may not fall within the definition of "mentally incapacitated person". This result is not intended by us.

8.86 We therefore consider that Recommendation 9 of the Consultation Paper (now renumbered as Recommendation 10 in this report) should be amended by excluding Part IVB of the MHO from the application of the proposed definition of "mentally incapacitated person" (ie the proposed definition should apply only to Parts II and IVC of the MHO), so that the existing scope of Part IVB will not be restricted unnecessarily.

Recommendation 10

We recommend that the definition of "mentally incapacitated person" for the purposes of the application of Parts II and IVC of the Mental Health Ordinance (Cap. 136) should be amended along the following lines:

- (1) For the purposes of Parts II and IVC, a mentally incapacitated person is a person who is at the material time –**
 - (a) unable by reason of mental disability to make a decision for himself on the matter in question;**
 - or**
 - (b) unable to communicate his decision on that matter because he is unconscious or for any other reason.**
- (2) For the purposes of subsection (1), a person is at the material time unable by reason of mental disability to**

make a decision if, at the time when the decision needs to be made, he is –

(a) unable to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision; or

(b) unable to make a decision based on that information.

(3) In subsection (1), "mental disability" means –

(a) mental illness;

(b) a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned;

(c) psychopathic disorder;

(d) mental handicap; or

(e) any other disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning.

(4) A person shall not be regarded as unable to understand the information referred to in subsection (2)(a) if he is able to understand an explanation of that information in broad terms and in simple language.

(5) A person shall not be regarded as unable by reason of mental disability to make a decision only because he makes a decision which would not have been made by a person of ordinary prudence.

(6) A person shall not be regarded as unable to communicate his decision unless all practicable steps to enable him to do so have been taken without success.

8.87 One of the objectives of the Sub-committee is to remove any uncertainty as to whether the whole mechanism of guardianship provided for under Part IVB of the MHO is available to a vegetative or comatose person.

If the existing definition of "mentally incapacitated person" is to continue to apply to that Part, the uncertainty will remain. It is therefore necessary for us to deal with the definition of "mentally incapacitated person" specifically for the purposes of Part IVB of the MHO.

8.88 The existing definition of "mentally incapacitated person" under the MHO for the purposes of Part IVB is "*a patient¹⁷ or a mentally handicapped person¹⁸, as the case may be*". To make it clear that a vegetative or comatose person is included in the definition of "mentally incapacitated person" for the purposes of that Part, certain thinking behind our proposed definition of "mentally incapacitated person" for the application of Parts II and IVC of MHO may have to be applied. In the proposed definition, the second limb comprises persons who are unable to communicate their decisions because they are unconscious or for any other reason and this second category would clearly include persons in a comatose or vegetative condition and clarifies the scope of the term "mentally incapacitated person".

8.89 Applying the same concept behind the proposed definition in Recommendation 10 regarding vegetative and comatose persons, we seek to provide a new definition of "mentally incapacitated person" for the purposes of Part IVB of the MHO. We have examined earlier the grounds for application for a guardianship order under section 59M(2) of the MHO. Those grounds cover two categories of persons, namely, mentally incapacitated persons suffering from mental disorder and mentally incapacitated persons who are mentally handicapped. In the new definition proposed for the purposes of Part IVB of the MHO, those two categories of persons will be included without modification so as not to affect the scope of that Part. However, we recommend adding a further category, namely, persons who are unable to communicate their views and wishes.¹⁹

Recommendation 11

We recommend that the definition of "mentally incapacitated person" for the purposes of the application of Part IVB of

¹⁷ "Patient" is defined to mean "a person suffering or appearing to be suffering from mental disorder".

¹⁸ "Mentally handicapped person" is defined to mean "a person who is or appears to be mentally handicapped". And "mental handicap" is defined to mean "sub-average general intellectual functioning with deficiencies in adaptive behaviour".

¹⁹ It should be noted that a similar approach has been adopted in the Guardianship and Administration Act 1993 of South Australia. Under that Act, "mental incapacity" is defined as – "the inability of a person to look after his or her own health, safety or welfare or to manage his or her own affairs, as a result of –

- (a) any damage to, or illness, disorder, imperfect or delayed development, impairment or deterioration, of the brain or mind; or
- (b) any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever."

In our definition to be proposed for purposes of Part IVB of the MHO, the expression "views and wishes" is adopted instead of "intentions or wishes" because the former is used in sections 59K, 59P and 59S of the MHO. The adoption of "views and wishes" will ensure consistency in terminology throughout the MHO.

the Mental Health Ordinance (Cap. 136) should be amended along the following lines:

(1) For the purposes of Part IVB, a mentally incapacitated person is –

- (a) a person suffering from mental disorder;**
- (b) a person who is mentally handicapped; or**
- (c) a person who is unable to communicate his views and wishes because he is unconscious or for any other reason.**

(2) A person shall not be regarded as unable to communicate his views and wishes unless all practicable steps to enable him to do so have been taken without success.

8.90 In Recommendation 11, the persons described in subsection (1)(a) and (b) are the same as the two categories of persons in respect of whom guardianship orders may be applied for under Part IVB of the MHO. Paragraph (c) includes persons who are unable to communicate their views and wishes, such as a comatose or vegetative person. This definition would therefore not restrict the scope of Part IVB of the MHO and would clarify the scope of the term "mentally incapacitated person" for the purposes of that Part in that a vegetative or comatose person is clearly regarded as a "mentally incapacitated person" under that Part.

8.91 We consider that the effect of the new definitions proposed in Recommendations 10 and 11 will be to bring comatose and vegetative persons within the protection of the existing legal framework. We note that the Guardianship Board is enabled with various powers to issue orders dealing with the healthcare, medical treatment, property and affairs of a "mentally incapacitated person". We take the view that the existing powers conferred on the Guardianship Board are adequate for the protection of these persons. We also observe that sufficient safeguards are found in sections 7, 8 and 9 of the MHO, which provide a power of inquiry and a power to examine a person alleged to be "mentally incapacitated" when an application is made by a third person to deal with the property of the "mentally incapacitated person". Some respondents raised the concern that comatose or vegetative patients might be stigmatized by being associated with persons suffering from mental illness currently governed by the MHO. We are of the view that this concern is not justified in modern times.

8.92 Reflecting the inclusion of a reference to an inability to communicate in the proposed definition, we proposed in our Consultation Paper that the medical profession should establish guidelines for doctors to

follow in assessing a patient's ability to communicate. We note that our proposal was well received and we maintain our recommendation in this regard.

8.93 We are aware of the Hospital Authority's *Guideline on In-Hospital Resuscitation Decisions, Guidelines on Consent to or Refusal of Treatment and/or Blood Transfusion by Patients, and Guidelines on Life-sustaining Treatment in the Terminally Ill*. We are also aware of the British Medical Association's *Guidelines on Withholding and Withdrawing Life-prolonging Medical Treatment* which may be referred to by medical practitioners in giving or withholding treatment in some situations. As suggested in our Consultation Paper, however, we would encourage the Medical Council or other relevant professional body to review the existing practice in the light of our proposals on advance directives and to issue guidelines in this area to enhance consistency of medical practice.

Recommendation 12

The Government should encourage the Medical Council or other relevant professional body to issue guidelines or a code of conduct to enhance consistency of medical practice in relation to:

- (a) the assessment of a person's ability to communicate;**
- (b) the treatment of persons in a vegetative or comatose state;**
- (c) the criteria for basic care;**
- (d) the assessment of the validity of an advance directive; and**
- (e) the implementation of advance directives.**

8.94 As discussed in our Consultation Paper, certain other amendments to the MHO will also be necessary. These amendments, which may be classified into three groups, are described in the following paragraphs.

8.95 The first group relate to the three Parts (Parts II, IVB, IVC) of the MHO for the purposes of which the new definitions contained in Recommendations 10 and 11 are to be adopted, and are concerned primarily with the combined operation of the existing provisions and the new definitions. This will involve incorporating the new definitions into Parts II, IVB and IVC of the MHO and linking it up with the existing provisions. For example, the existing section 7(1) of the MHO (in Part II) provides that:

"The Court may, on application under this section, make an order directing an inquiry whether any person subject to the jurisdiction

of the Court who is alleged to be mentally incapacitated is incapable, by reason of mental incapacity, of managing and administering his property and affairs."

8.96 The new definition in relation to Part II defines a mentally incapacitated person as one who is unable to make or communicate a decision for himself on "*the matter in question*". It will therefore be necessary to amend section 7(1) to the effect that the Court may direct an inquiry whether a mentally incapacitated person (as newly defined) is able to make or communicate a decision on the management and administering of his property and affairs. Likewise, section 59ZB of the MHO (regarding the principles in giving treatment²⁰ and special treatment²¹ to a mentally incapacitated person in Part IVC) will have to be amended to the effect that Part IVC will apply to certain medical or dental treatment of a mentally incapacitated person who has attained the age of 18 years and is unable to make or communicate a decision on the carrying out of that treatment.

8.97 The second group of amendments give effect to the intention that the new definitions will have no application in Parts III, IIIA, IIIB, IV and IVA. This can be achieved by amending the existing definition of "mentally incapacitated person" in section 2(1) of the MHO to the effect that for the purposes of Parts III, IIIA, IIIB, IV and IVA, the term means a "patient" or a "mentally handicapped person" as currently defined.

8.98 The third group of amendments are consequential in nature. We have examined the references to "mentally incapacitated person" in Part V of the MHO to determine whether they should be appropriately amended to make it clear to which category of persons those references actually refer. That review involved an attempt to identify the legislative intention behind the particular reference. We have also reviewed Annex 6 of the Consultation Paper (now renumbered as Annex 7 of this report) and have made amendments to it in view of our proposed changes to Recommendation 9 of the Consultation Paper (now renumbered as Recommendation 10 of this report). We have removed those illustrations which do not refer directly to the term "mentally incapacitated person" from the Annex. This Annex sets out our views as to the definitions which should be adopted in each case. We consider that a similar exercise should be conducted in respect of all subsidiary legislation made under the MHO once the new definitions are enacted.

8.99 We have considered the enduring powers granted under the Enduring Powers of Attorney Ordinance (Cap 501) in the previous paragraphs and think that these powers should remain limited to the management of property and should not be extended to cover healthcare decisions because of the risks of exploitation and abuse.

²⁰ Section 59ZA defines "treatment" to mean "medical treatment, dental treatment or both, and includes proposed treatment but does not include special treatment."

²¹ "Special treatment" means medical treatment or dental treatment or both of an irreversible or controversial nature as specified under section 59ZC and includes proposed special treatment.

8.100 Our recommended new definition of the term "mentally incapacitated person" given in Recommendation 10 is intended to apply only for the purposes of Parts II and IVC of the MHO, and that given in Recommendation 11 is intended to apply only to Part IVB of the MHO, so that it is possible for a comatose or vegetative person to resort to the protection provided for in those Parts. The existing definition will continue to apply for all other purposes of the MHO, and it is that definition which will continue to apply to other Ordinances where "mentally incapacitated person" is defined by reference to the MHO. We make no recommendation that either of the proposed definitions should apply to provisions in other Ordinances concerning mental incapacity, having regard to the fact that each enactment has its own objectives.

8.101 However, the expressions "mentally incapacitated person", "mentally incapable" and "mental disorder" appear in a number of other Ordinances²² in the context of mental incapacity and are sometimes defined by reference to the MHO. Amendment to those Ordinances may be necessary to ensure the continued application of the existing MHO definition. This can be achieved either by incorporating the MHO definition for the term, or by making a specific reference to the definition "in section 2(1) of the MHO".

8.102 One respondent expressed concerns about orders which had been made in the past in respect of comatose and vegetative patients, and suggested that provisions should be made in the amending legislation that any amendment to the definition of "mentally incapacitated person" should not nullify or invalidate orders that had been made prior to the amendments. In our view, the revision to the definition should not in any way affect orders already made as amendments to legislation generally do not have retrospective effect. We would however, leave this issue to be considered and dealt with in due course by the Law Draftsman.

²² For example, the term "mentally incapacitated person" also appears in Cap. 200, 221, 238, 465 and Order 80 of the Rules of the High Court and Order 80 of the Rules of the District Court.

Chapter 9

Summary of recommendations

(The recommendations in this paper are to be found in Chapter 8, at the paragraphs marked.)

Recommendation 1 *(following paragraph 8.40)*

We recommend that the concept of advance directives should be promoted initially by non-legislative means. We recommend that the Government should review the position in due course once the community has become more widely familiar with the concept and should consider the appropriateness of legislation at that stage. That review should take into consideration three factors, namely, how widely the use of advance directives had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of advance directive.

Recommendation 2 *(following paragraph 8.45)*

We recommend the publication and wide dissemination of the model form of advance directive we propose, and that the use of the model form should be encouraged.

Recommendation 3 *(following paragraph 8.46)*

We recommend that appropriate publicity should be given to encourage individuals to consider and complete advance directives in advance of any life-threatening illness.

Recommendation 4 *(following paragraph 8.47)*

We recommend that the Government should launch publicity programmes to promote public awareness and understanding of the concept of advance directives. The Department of Health and all District Offices should have available for public reference material which provides general guidance to the public on the making and consequences of an advance directive and should provide copies of the model form of advance directive for public use.

Recommendation 5 *(following Recommendation 4)*

The Government should endeavour to enlist the support of the Medical Council, medical associations, the Bar Association, the Law Society, the Hospital Authority, all hospitals and medical clinics, non-governmental organisations involved in care for the elderly, and religious and community groups in this information campaign about the use and effect of advance directives.

Recommendation 6 *(following paragraph 8.53)*

We recommend that, for the purpose of making an advance directive, the terms "terminally ill" and "life-sustaining treatment" should be defined as follows:

(a) the "terminally ill" are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.

(b) "life sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialized treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. Artificial nutrition and hydration means the feeding of food and water to a person through a tube.

Recommendation 7 *(following paragraph 8.59)*

(a) The model form of advance directive requires that it be witnessed by two witnesses, one of whom must be a medical practitioner, neither witness having an interest in the estate of the person making the advance directive.

(b) The Government should encourage bodies such as the Hospital Authority, the Medical Council, the Hong Kong Medical Association and other relevant professional bodies to consider issuing guidelines for doctors witnessing the making of advance directives to ensure consistency of medical practice in this area. The guidelines should also provide guidance for the medical profession (a) as to the effect of advance directives and (b) in assessing the validity of an advance directive.

(c) If in circumstances an individual may not be able to make a written advance directive, the oral advance directive should be made before a doctor, lawyer or other independent person who should not have an

interest in the estate of the person making the advance directive.

Recommendation 8 *(following paragraph 8.65)*

We recommend that :

- (a) for the sake of certainty and the avoidance of doubt, those wishing to revoke an advance directive should be encouraged to do so in writing;
- (b) if an advance directive is revoked in writing, it should be witnessed by an independent witness who should not have an interest in the estate of the person making the revocation;
- (c) if an advance directive is revoked orally, the revocation should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the revocation, and where practicable that witness should make a written record of the oral revocation; and
- (d) if medical staff learn that an individual has revoked his advance directive, that information should be properly documented in the individual's medical records.

Recommendation 9 *(following paragraph 8.69)*

We recommend that the Government should, as part of its public awareness campaign about advance directives, encourage those who wish to make an advance directive to seek legal advice and to discuss the matter first with their family members. Family members should also be encouraged to accompany the individual when he makes the advance directive.

Recommendation 10 *(following paragraph 8.86)*

We recommend that the definition of "mentally incapacitated person" for the purposes of the application of Parts II and IVC of the Mental Health Ordinance (Cap. 136) should be amended along the following lines:

- (1) For the purposes of Parts II and IVC, a mentally incapacitated person is a person who is at the material time -
 - (a) unable by reason of mental disability to make a decision for himself on the matter in question; or
 - (b) unable to communicate his decision on that matter because he is unconscious or for any other reason.

(2) For the purposes of subsection (1), a person is at the material time unable by reason of mental disability to make a decision if, at the time when the decision needs to be made, he is –

- (a) unable to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision; or**
- (b) unable to make a decision based on that information.**

(3) In subsection (1), "mental disability" means –

- (a) mental illness;**
- (b) a state of arrested or incomplete development of mind which amounts to a significant impairment of intelligence and social functioning which is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned;**
- (c) psychopathic disorder;**
- (d) mental handicap; or**
- (e) any other disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning.**

(4) A person shall not be regarded as unable to understand the information referred to in subsection (2)(a) if he is able to understand an explanation of that information in broad terms and in simple language.

(5) A person shall not be regarded as unable by reason of mental disability to make a decision only because he makes a decision which would not have been made by a person of ordinary prudence.

(6) A person shall not be regarded as unable to communicate his decision unless all practicable steps to enable him to do so have been taken without success.

Recommendation 11 (following paragraph 8.89)

We recommend that the definition of "mentally incapacitated person" for the purposes of the application of Part IVB of the Mental Health Ordinance (Cap. 136) should be amended along the following lines:

(1) For the purposes of Part IVB, a mentally incapacitated person is –

- (a) a person suffering from mental disorder;**
- (b) a person who is mentally handicapped; or**
- (c) a person who is unable to communicate his views and wishes because he is unconscious or for any other reason.**

(2) A person shall not be regarded as unable to communicate his views and wishes unless all practicable steps to enable him to do so have been taken without success.

Recommendation 12 *(following paragraph 8.93)*

The Government should encourage the Medical Council or other relevant professional body to issue guidelines or a code of conduct to enhance consistency of medical practice in relation to:

- (a) the assessment of a person's ability to communicate;
- (b) the treatment of persons in a vegetative or comatose state;
- (c) the criteria for basic care;
- (d) the assessment of the validity of an advance directive; and
- (e) the implementation of advance directives.

Proposed model form of advance directive

ADVANCE DIRECTIVE

Section I : Personal details of the maker of this advance directive

Name : *(Note: Please use capital letters)*

Identity document No.:

Sex : Male / Female

Date of birth : _____ / _____ / _____
 (Day) (Month) (Year)

Home Address :

Home Telephone No. :

Office Telephone No. :

Mobile Telephone No. :

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.

3. I, _____ (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.
4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my wishes in relation to my medical care and treatment are as follows :

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

(A) Case 1 – Terminally ill

(Note: In this instruction -

"terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.)

- Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

I do not want to be given the following treatment:

-
-

(B) Case 2 – Persistent vegetative state or a state of irreversible coma

(Note: In this instruction -

"life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.)

- Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

I do not want to be given the following treatment:

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under :

- (i) my will; or
- (ii) any policy of insurance held by me; or
- (iii) any other instrument made by me or on my behalf.

**Signature of the maker of
this advance directive**

Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –

- (i) the will of the maker of this advance directive; or*
- (ii) any policy of insurance held by the maker of this advance directive;
or*
- (iii) any other instrument made by or on behalf of the maker of this advance directive.*

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

- (1) I, _____ (please print name) sign below as witness.
 - (a) as far as I know, the maker of this directive has made the directive voluntarily; and
 - (b) I have explained to the maker of this directive the nature and implications of making this directive.

- (2) I declare that this directive is made and signed in my presence together with the second witness named below.

(Signature of 1st witness)

(Date)

Name :

Identity document No. / Medical Council Registration No.

Office address :

Office Tel. No. :

Second witness

(Note: This witness must be at least 18 years of age)

- (1) I, _____ *(please print name)* sign below as a witness.

- (2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

(Signature of 2nd witness)

(Date)

Name :

Identity document No. :

Home address / Contact address :

Home Tel. No. / Contact No. :

**Form of advance directive prepared by
the British Medical Journal**

Advance directive for health care

Name:

Address:

Hospital unit number:

It is my express wish that if I should develop:

- (a) senile, severe degenerative brain disease (due to Alzheimer's disease, arterial disease, AIDS, or other agency, or
- (b) serious brain damage resulting from accidental or other injury or illness, or
- (c) advanced or terminal malignant disease, or
- (d) severely incapacitating and progressive degenerative disease of the nerves or muscles

and have become mentally incompetent to express my opinion about accepting or declining life sustaining treatment, and if two independent physicians conclude that, to the best of current medical knowledge, my condition is irreversible then the following points should be taken into consideration:

* In the event of a cardiac arrest, regardless of the cause, I should not be given cardiopulmonary resuscitation.

* Any separate illness — for example, pneumonia or a heart or kidney condition — that may threaten my life should not be given active treatment unless it appears to be causing me undue physical suffering.

* During such an advanced illness, if I should become unable to swallow food, fluid, or medication then these should not be given by any artificial means except to relieve obvious suffering.

* During such an illness, if my condition deteriorates without reversible cause, and as a result my behaviour becomes violent, noisy, or in other ways degrading, or if I appear to be suffering severe pain, then any such symptoms should be controlled with suitable drug treatment, regardless of the consequences on my physical health and my survival, within the extent of the law.

* Other requests:

The object of this directive is to minimise distress or indignity which I may suffer or create during an incurable illness, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

Signed:

Date:

Witness 1:

Witness 2:

Statement by one witness: I declare that in my opinion the above person is of sound mind.

Signed:

Date:

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**Form of advance directive prepared by
the District of Columbia Hospital Association, USA**

ADVANCE DIRECTIVE

Your Durable Power of Attorney for Health Care, Living Will & Other Wishes

INSTRUCTIONS AND DEFINITIONS

Introduction:

This form is a combined Durable Power of Attorney for Health Care and Living Will for use in the District of Columbia, Maryland and Virginia.

With this form, you can:

- Appoint someone to make medical decisions for you if you in the future are unable to make those decisions for yourself;
and/or
- Indicate what medical treatment you do or do not want if in the future you are unable to make your wishes known.

Directions:

- Read each section carefully.
- Talk to the person you plan to appoint to make sure that he/she understands your wishes, and is willing to take the responsibility.
- Place the initials of your name in the blank before those choices you want to make.
- Fill in only those choices that you want under Parts 1, 2 and 3. Your advance directive should be valid for whatever part(s) you fill in, as long as it is properly signed.
- Add any special instructions in the blank spaces provided. You can write additional comments on a separate sheet of paper, but should indicate on the form that there are additional pages to your advance directive.
- Sign the form and have it witnessed.
- Give your doctor, nurse, the person you appoint to make your medical decisions for you, your family, and anyone else who might be involved in your care, a copy of your advance directive and discuss it with them.
- Understand that you may change or cancel this document at any time.

Words You Need to Know:

Advance Directive: A written document that tells what a person wants or does not want if he/she in the future cannot make his/her wishes known about medical treatment.

Artificial Nutrition and Hydration: When food and water are fed to a person through a tube.

Autopsy: An examination done on a dead body to find the cause of death.

Comfort Care: Care that helps to keep a person comfortable but does not make him/her better. Bathing, turning, keeping a person's lips moist are types of comfort care.

CPR (Cardiopulmonary Resuscitation): Treatment to try and restart a person's breathing or heartbeat. CPR may be done by pushing on the chest, by putting a tube down the throat, and/or by other treatment.

Durable Power of Attorney for Health Care: An advance directive that appoints someone to make medical decisions for a person if in the future he/she cannot make his/her own medical decisions.

End-Stage Condition: Any chronic, irreversible condition caused by injury or illness that has caused serious, permanent damage to the body. A person in an end-stage condition requires others to provide most of his/her care.

Life-Sustaining Treatment: Any medical treatment that is used to keep a person from dying. A breathing machine, CPR, artificial nutrition and hydration are examples of life-sustaining treatment.

Living Will: An advance directive that tells what medical treatment a person does or does not want if he/she is not able to make his/her wishes known.

Organ and Tissue Donation: When a person permits his/her organs (such as eyes or kidneys) and other parts of the body (such as skin) to be removed after death to be transplanted for use by another person or to be used for experimental purposes.

Persistent Vegetative State: When a person is unconscious with no hope of regaining consciousness even with medical treatment. The body may move and eyes may be open, but as far as anyone can tell, the person cannot think or respond.

Terminal Condition: An on-going condition caused by injury or illness that has no cure and from which doctors expect the person to die, even with medical treatment. Life-sustaining treatments will not improve the person's condition and only prolong a person's dying.

District of Columbia, Maryland and Virginia

ADVANCE DIRECTIVE

My Durable Power of Attorney for Health Care, Living Will and Other Wishes

I _____, write this document as a directive regarding my medical care.

Put the initials of your name by the choices you want:

PART 1. MY DURABLE POWER OF ATTORNEY FOR HEALTH CARE

As long as I can make my wishes known, my doctors will talk to me and I will make my own health care decisions.

___ I appoint this person to make decisions about my medical care if there ever comes a time when I cannot make those decisions myself:

name:

home phone:

work phone:

address:

___ If the person above cannot or will not make decisions for me, I appoint this person:

name:

home phone:

work phone:

address:

___ I have not appointed anyone to make health care decisions for me in this or any other document. I understand that if I do not appoint a Durable Power of Attorney for Health Care, someone may be designated to make my health care decisions by law or by a court.

I want the person I have appointed, my doctors, my family, and others to be guided by the decisions I have made below:

PART 2. MY LIVING WILL

These are my wishes for my future medical care if there ever comes a time when I cannot make these decisions for myself.

A. In general, these are the goals I have for my care if I am ever seriously ill or have a serious injury (*state in your own words what you believe is most important to you*):

Put in the initials of your name next to important values for you if you are ever seriously ill or have a serious injury:

- ___ Medicines needed to keep me pain-free
- ___ Ability to recognize my family/friends
- ___ Other:

B. These are my wishes if I have a terminal condition:

Life-Sustaining Treatments

- ___ I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.
- ___ I want life-sustaining treatments (including CPR) started on a temporary basis; if I do not show signs of recovery, then I want them stopped.
- ___ I want life-sustaining treatments continued that my doctors think are best for me.
- ___ Other wishes:

Artificial Nutrition and Hydration

- ___ I do not want artificial nutrition and hydration started if it would be the main treatment keeping me alive. If artificial nutrition and hydration is started, I want it stopped.
- ___ I want artificial nutrition and hydration even if it is the main treatment keeping me alive.
- ___ Other wishes:

C. These are my wishes if I am ever in a persistent vegetative state:

Life-Sustaining Treatments

- I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.
- I want life-sustaining treatments (including CPR) started on a temporary basis; if I do not show signs of recovery, then I want them stopped.
- I want life-sustaining treatments continued that my doctors think are best for me.
- Other wishes:

Artificial Nutrition and Hydration

- I do not want artificial nutrition and hydration started if it would be the main treatment keeping me alive. If artificial nutrition and hydration is started, I want it stopped.
- I want artificial nutrition and hydration, even if it is the main treatment keeping me alive.
- Other wishes:

D. These are my wishes if I ever have an End-Stage Condition (including Alzheimer's or other dementia):

Life-Sustaining Treatments

- I do not want life-sustaining treatments (including CPR) started. If life-sustaining treatments are started, I want them stopped.
- I want life-sustaining treatments (including CPR) started on a temporary basis; if I do not show signs of recovery, then I want them stopped.
- I want life-sustaining treatments continued that my doctors think are best for me.
- Other wishes:

Artificial Nutrition and Hydration:

- I do not want artificial nutrition and hydration started if it would be the main treatment keeping me alive. If artificial nutrition and hydration is started, I want it stopped.
- I want artificial nutrition and hydration, even if it is the main treatment keeping me alive.
- Other wishes:

E. Other Directions

You have the right to be involved in all decisions about your medical care, even those not dealing with terminal conditions, persistent vegetative states or end-stage conditions. If you have wishes not covered in other parts of this document, please indicate them here:

PART 3. OTHER WISHES

A. Organ Donation

- I do not wish to donate any of my organs or tissues.
- I want to donate all of my organs and tissues.
- I only want to donate these organs and/or tissues:

B. Autopsy

- I do not want an autopsy.
- I agree to an autopsy if my doctors wish it.
- Other wishes:

PART 4. SIGNATURES

You and two witnesses must sign this document in order for it to be legal.

A. Your Signature

By my signature below, I show that I understand the purpose and the effect of this document.

Signature:

Date:

Address:

B. Your Witnesses' Signatures

I believe the person who has signed this advance directive to be of sound mind, that he/she signed or acknowledged this advance directive in my presence, and that he/she appears not to be acting under pressure, duress, fraud, or undue influence. I am not related to the person making this advance directive by blood, marriage or adoption, nor, to the best of my knowledge, am I named in his/her will. I am not the person appointed in this advance directive. I am not a health care provider or an employee of a health care provider who is now, or has been in the past, responsible for the care of the person making this advance directive.

Witness #1

Signature:

Date

Address:

Witness #2

Signature:

Date:

Address:

[Used with permission of the District of Columbia Hospital Association.]

- b. the application of extraordinary life-sustaining treatment would only serve to postpone the moment of death.
3. I understand that "extraordinary life-sustaining treatment" in the Advance Medical Directive Act 1996 means any medical procedure or measure which, when administered to a terminally ill patient, will only prolong the process of dying when death is imminent, but excludes palliative care.
4. This directive shall not affect any right, power or duty which a medical practitioner or any other person has in giving me palliative care, including the provision of reasonable medical procedures to relieve pain, suffering or discomfort, and the reasonable provision of food and water.
5. I make this directive in the presence of the two witnesses named on page 2.

Signature / Thumb Print

Date

INSTRUCTIONS ON THE REGISTRATION OF ADVANCE MEDICAL DIRECTIVE

1. The person making the advance medical directive should complete this form and send it in a sealed envelope by mail or by hand to the Registrar of Advance Medical Directives at the address given below. Faxed copies will not be accepted.
2. The advance medical directive is only valid when it is registered with the Registrar of Advance Medical Directives. The Registrar will send the maker of the directive an acknowledgement when the directive has been registered.

**The Registry of Advance Medical Directives
Ministry of Health
College of Medicine Building
16 College Road
Singapore 169854**

Tel: 3259136

Fax: 3259212

(Please direct all enquiries to this address)

Note:

As a *guide* for the purposes of determining whether the maker of the directive is of sound mind, the medical practitioner should ascertain whether the maker -

- understands the nature and implications of the directive;
- is oriented to time and space; and
- is able to name himself and his immediate family members.

SECOND Witness (This witness must be of at least 21 years of age)

Name:

NRIC No.: - -

Home Address:

Singapore

Home Telephone:

Office Telephone:

I declare that this directive is made and signed in my presence together with the witness named above.

Signature

Date

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Proposed form of revocation of advance directive

REVOCATION OF ADVANCE DIRECTIVE

Section I : Personal details of maker of this revocation

Name : _____ *(Note: Please use capital letters)*

Identity document No.: _____

Sex : Male / Female

Date of birth : _____ / _____ / _____
(Day) (Month) (Year)

Home Address : _____

Home Telephone No. : _____

Office Telephone No. : _____

Mobile Telephone No. : _____

Section II : Revocation

(1) I, _____ *(please print name)* being over the age of 18 years, revoke any advance directive relating to my medical care and treatment made by me before the date of this revocation.

(2) I make this revocation in the presence of the witness named in Section III of this revocation, who is not beneficiary under:

- (i) my will; or
- (ii) any policy of insurance held by me; or
- (iii) any other instrument made by me or on my behalf.

Signature
of the maker of this revocation

Date

Section III : Witness

Statement of Witness

(Note: This witness must be at least 18 years of age)

(1) I, _____ *(please print name)* sign below as witness.

(2) I declare that this document is made and signed in my presence.

(Signature of witness)

(Date)

Name :

Identity document No. :

Home address / Contact address :

Home Tel. No. / Contact No. :

**Proposed form to
record an oral revocation of an advance directive**

RECORD OF ORAL REVOCATION OF ADVANCE DIRECTIVE

Section I : Personal details of the maker of oral revocation

Name : _____ *(Note: Please use capital letters)*

Identity document No.: _____

Sex : Male / Female

Date of birth : _____ / _____ / _____
(Day) (Month) (Year)

Home Address : _____

Home Telephone No. : _____

Office Telephone No. : _____

Mobile Telephone No. : _____

Section II : Witness

Statement of Witness

(Note: This witness must be at least 18 years of age)

(1) I, _____ *(please print name)* sign below as a witness.

(2) I confirm that _____ *(please print name)* has, on _____ *(date of revocation)* at _____ am/pm, in my presence, orally revoked all previous advance directives relating to his/her medical care and treatment.

(3) I am not related to _____ (*please print name*)
by blood, marriage or adoption, nor to the best of my knowledge, am I a
beneficiary under his/her will or any policy of insurance held by him/her
or any other instrument made by him/her or on his/her behalf.

(Signature of witness)

(Date)

Name :

Occupation :

Identity document No. / Medical Council Registration No. :

Home address / Contact address :

Home Tel. No. / Contact No. :

Proposals for consequential amendments to Part V of the Mental Health Ordinance (Cap 136)

Section 60 - "mentally incapacitated person"

It is sufficiently clear that the reference refers to a "mentally incapacitated person" within the meaning of Part II. Definition in Recommendation 10 applies.

Section 62 - "mentally incapacitated person"

This section is not concerned with the person's ability to make decisions. Existing definition applies.

Section 64 - "mentally incapacitated person"

This section should cover the widest group. Both existing and new definitions should apply.

Section 71A - "mentally incapacitated person"

Subsection (1) is concerned with *"any person who is authorized under this Ordinance to take a mentally incapacitated person to any place, or to take into custody or retake a mentally incapacitated person who is liable under this Ordinance to be so taken or retaken"*. It is more concerned with powers under Parts III, IIIA, IIIB, IV or IVA. Existing definition applies.

Subsection (2) is concerned with a person whom an approved social worker believes to be a mentally incapacitated person. Decision making is not the key issue. Existing definition applies.

Section 72 - "mentally incapacitated person"

Subsection (1)(g) clearly refers to a mentally incapacitated person within the meaning of Part IIIA or IVB respectively. Existing definition applies in relation to Part IIIA and new definition in Recommendation 11 applies in relation to Part IVB.

Subsection (1)(h) should cover the widest group. Both existing and new definitions should apply.

Subsection (1)(ja) clearly refers to a mentally incapacitated person within the meaning of Part IVC. New definition in Recommendation 10 applies.

**List of organisations/individuals who responded
to the consultation paper**

1. Derrick K S Au
2. Caritas Medical Centre :
Caritas Medical Centre Service Development Subcommittee
Dr L C Ho (COS (O&G)), Caritas Medical Centre)
Dr K K Tse (COS (Ophthalmology), Caritas Medical Centre)
3. Chan Kin Hung
4. Louis Chan
5. Dr Cheung Hung Kin
6. Professor Iris Chi
7. Chinese Muslim Cultural & Fraternal Association
8. Mr Charles Chiu
9. College of Dental Surgeons of Hong Kong
10. Department of Health
11. Diocesan Commission for Hospital Pastoral Care
12. Federation of Medical Societies of Hong Kong
13. The Guild of St. Luke, St. Comas & St. Damian, Hong Kong
(Catholic Doctors' Association)
14. Health, Welfare and Food Bureau
15. Hong Kong Academy of Medicine
16. Hong Kong Alzheimer's Disease Association, Senior Citizen Home
Safety Association and Community Rehabilitation Network
17. Hong Kong Bar Association
18. Hong Kong Christian Council Justice and Social Concern
Committee
19. Hong Kong Christian Service
20. Hong Kong College of Emergency Medicine
21. Hong Kong College of Family Physicians
22. Hong Kong College of Paediatricians
23. Hong Kong College of Pathologists

24. Hong Kong College of Physicians
25. Hong Kong Council of Social Service
26. Hong Kong Dental Association
27. Hong Kong Doctors Union
28. Hong Kong Geriatrics Society
29. HK Jockey Club Centre for Suicide Research & Prevention,
University of Hong Kong
30. Hong Kong Medical Association
31. Hong Kong Neurosurgical Society and the Clinical Co-ordinating
Committee (COC) in Neurosurgery (Hospital Authority)
32. Hong Kong Polytechnic University, Faculty of Health and Social
Sciences
33. Hong Kong Psychogeriatric Association Ltd
34. Hong Kong Public Doctors Association
35. Hong Kong Sanatorium & Hospital, Ltd
36. Hong Kong Society of Community Medicine
37. Hong Kong Society of Palliative Medicine Ltd
38. Hong Kong St. John Ambulance
39. Hong Kong Tuberculosis, Chest and Heart Diseases Association
40. Hospital Authority
41. Professor Edwin C Hui
42. Judiciary
43. Peter Lally
44. Law Society of Hong Kong
45. Dr Grantham K H Lee
46. Dr Anthony K Y Lee
47. Legal Aid Department
48. Dr Athena Liu
49. Hon Mak Kwok-fung (Legislative Council Member 2000-2004)
50. Medical Council of Hong Kong
51. Mental Health Review Tribunal
52. North District Hospital
53. Pamela Youde Nethersole Eastern Hospital

54. Prince of Wales Hospital
55. Queen Elizabeth Hospital
56. Society for Community Organisation Patients' Rights Association
57. Society for the Promotion of Hospice Care (SPHC)
58. Social Welfare Department
59. St. Paul's Hospital
60. Dr C Y Tse
61. TWGHS Fung Yiu King Hospital and Macle hose Medical Rehabilitation Centre
62. Women's Commission
63. Wong Chuk Hang Hospital
64. Yeung Mei-chung
65. Yeung Wing-ching
66. Lena Young
67. Sister Marya Zaborowski