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## CONSIDERATIONS FOR THE USE OF ADVANCE DIRECTIVES AMONG OLDER PERSONS WITH DEMENTIA IN HONG KONG

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In recent years, the Hong Kong Probate Registry has witnessed remarkable increases in contested guardianships and wills, with a high prevalence of elder abuse and exploitation by family members, friends, caregivers and strangers etc.. A report and a consultation on the use of advance directive by the law commission and Food and Health Bureau was published in 2006 and 2009, respectively to urge for protective legislation including advance directive, but these were later dismissed because of a lack of understanding among the public on advance directive. With emphasis on the needs of persons with dementia, this paper provides a general overview of the use of advance directive in various countries, and scrutinises the necessity of advance directive in Hong Kong, as a crucial part of advance care planning to ensure persons' self-predetermination of medical treatments are respected.

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#### INTRODUCTION

Dementia has been identified by the World Health Organisation as one of the world's most burdensome conditions for older persons. In a study conducted by Harvard University School of Public Health and the Alzheimer's Europe consortium, it was identified that, the second leading health concern among adults, after cancer, is Dementia. Dementia.

As the Asia-Pacific population ages at an unprecedented pace, the prevalence of cognitive ageing, as commonly seen in dementia, has increased dramatically over the past decade. Issues surrounding assessments of older person's decision making capacity have received much attention since the twentieth century due to global prevalence of longevity, age associated effects of disability, and substantial transfers of wealth through inheritance of the baby boomer generation.

Today, one in eight of the Hong Kong population is an elder aged 65 and above.<sup>3</sup> The Hong Kong Government has recognized dementia<sup>4</sup> as a significant challenge associated with its fast growing ageing population.

<sup>&</sup>lt;sup>1</sup> World Health Organization and Alzheimer's Disease International, *Dementia: A Public Health Priority*, (2012). *Available at* 

http://www.who.int/mental\_health/publications/dementia\_report\_2012/en/ (last visited June 10, 2015).

<sup>&</sup>lt;sup>2</sup> Swaminathan N., *How to Save Your Brain*, 45 PSYCHOL TODAY 74-9 (2012).
<sup>3</sup> Census and Statistic Department, *Demographic Trends in Hong Kong 1981-2011*, (2012). *Available* 

at http://www.statistics.gov.hk/pub/B1120017032012XXXXB0100.pdf (last visited June 5, 2015). Dementia, previously known as senile dementia, is a condition commonly found amongst elderly which causes a loss of mental ability that interferes with daily living activities. After age 65, the likelihood of developing dementia generally doubles every five years. (See OLENDORF D., JERYAN C., BOYDEN K., & FYKE, M. K., THE GALE ENCYCLOPEDIA OF MEDICINE (Olendorf D., Jeryan C., Boyden K., & Fyke, M. K. eds., Michigan: Gale Research 1999).

There is currently an estimate of 36 million people living with dementia globally, which is projected to double in 2030 and triple by 2050.<sup>5</sup> A study (Yu, et al., 2010) conducted in 2010 shows that, 0.09 million Hong Kong residents above the age of 60 have dementia, of whom over 30% are aged 85 and above. It is projected that, by 2036, more than 0.28 million people in Hong Kong above the age of 60 will suffer from dementia or Alzheimer's disease, the most common form of dementia.<sup>6</sup>

Patients of dementia suffer from progressive deterioration of cognitive and physical competences are closely linked to daily functioning such as decision making skills. The loss of cognitive abilities leads to impairments in memory, reasoning, planning and behaviour, and as such causes one to lose the mental capacity to make sound choices and critical decisions concerning their wellbeing. The increase in the prevalence of dementia along with its "burdensome" condition does not only affect the patients, but also extends to their family members and medical practitioners. While the patients suffering from dementia have lost their capacity to make rational decisions, these aforementioned correspondences are often inadvertently challenged to face dilemmas in making critical decisions on behalf of the patients regarding types of medical treatment, care services and end-of-life choices in hope that the substitute decisions made would serve best for them. Such dilemmas often arise when family members' ideas of "patient's best interest" conflicts with the actual wishes of the patient.

To deal with such dilemmas, advance directives, or "living wills" provide the means for patients to predetermine and declare their desired treatments for health care and for end-of-life. This is an instruction given by the patient, well before his/her loss of sanity, to medical and health care institutions for care arrangements when the patient loses his/her capacity to make critical decision in his/her own interest. This is done with the witness of the medical and health care professional(s) responsible for the patient. Advance directives have been practiced as an integral part of health care internationally, including the United Kingdom, Australia, New Zealand and Singapore, for more than two decades.<sup>8</sup>

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<sup>&</sup>lt;sup>5</sup> World Health Organization and Alzheimer's Disease International, *Dementia: A Public Health Priority*, (2012). *Available at* 

http://www.who.int/mental\_health/publications/dementia\_report\_2012/en/ (last visited July 20, 2015). 
<sup>6</sup> Yu R., Chau P., McGhee S., Cheung W., Chan K., Cheung S., & Woo J., *Dementia Trends: Impact of the Ageing Population and Societal Implications for Hong Kong*, (Hong Kong: The Hong Kong Jockey Club 2010).

<sup>&</sup>lt;sup>7</sup> American Psychiatric Association, *The Diagnostic and Statistical Manual of Mental Disorders*, (5th ed. (DSM-5), Washington, DC: American Psychiatric Association 2013).

<sup>&</sup>lt;sup>8</sup> Simon A., *Historical Review of Advance Directives*, ADVANCE DIRECTIVES 3-16 (Lack P., Biller-Andorno N., & Brauer S. eds., Dordrecht: Springer 2014).

Apart from medical decision making capacity, financial capacity is another vital aspect for signifying an individual's autonomy in society. According to Marson (2001) and Marson, et al.(2011), "financial capacity comprises of a broad range of conceptual, pragmatic and judgments abilities that are critical to the independent functioning of adults in our society", 10. One of the critical aspects when determining a person's financial capacity is the ability to make critical decisions, which are consistent with one's own best interest. Depending on a person's socio-economic status, the impact of such financial decisions may vary greatly. Aspects of inheritance and financial disposition are generally safeguarded by the Wills Ordinance (1997) 11 and the Inheritance (Provision for Family and Dependants) Ordinance (1997) <sup>12</sup> in Hong Kong where every person has "free testamentary capacity". These inclusive legislations provide statutory protection for persons who wish to make advance decisions regarding the disposition of assets and the treatment of their remains after death. The legal requirements of such testate arrangements are similar to advance directives where the testator should be mentally competent and the decision made should be free from undue influence. For the purposes of this paper, we shall focus only on advance directives relating to wishes of persons with cognitive impairment (i.e., dementia patients) for healthcare arrangements, prior to death.

This paper attempts to first explain what advance directives are with an intention to safeguard older persons' interest, and then to discuss considerations in preparing such directives, and finally to propose an initial model taking into all considerations for its application in Hong Kong.

#### I. ADVANCED DIRECTIVES

Advance directives are legal documents, usually in written form, which allow individuals to convey their informed decisions regarding end-of-life care and actions to be taken by a third party in advance of conditions or illnesses leading to death, or in the event of mental incapacity. <sup>13</sup> They provide a communicative mechanism for individuals to formally and clearly

<sup>&</sup>lt;sup>9</sup> Marson D., *Loss of Financial Capacity in Dementia: Conceptual and Empirical Approaches*, 8 AGING, NEUROPSYCHOLOGY AND COGNITION 164-81 (2001).

Marson D., Sawrie S., Snyder S., McInturff B., Stalvey T., Boothe A., Aldridge T., Chatterjee A., & Harrell L., Assessing Financial Capacity in Patients with Alzheimer Disease: A Conceptual Model and Prototype Instrument, 57(6) ARCHIVES OF NEUROLOGY 877-84 (2000).

<sup>&</sup>lt;sup>11</sup> Wills Ordinance, Cap 30 (HONG 1997).

<sup>&</sup>lt;sup>12</sup> Inheritance (Provision for Family and Dependants) Ordinance, Cap 481 (HONG 1995).

<sup>&</sup>lt;sup>13</sup> The Law Reform Commission of Hong Kong, Substitute Decision-Making and Advance Directives in Relation to Medical Treatment, (Hong Kong: The Law Reform Commission of Hong Kong 2006).

convey their wishes to family and friends well before the patient eventually loses his/her decision making ability. It also facilitates health care professionals in fulfilling their professional responsibility to patients upon extension or withdrawal of life-sustaining treatment, in their best interest. Advance decisions can bring reassurance to the elder patients by ensuring that, their wishes are taken into account. It can also serve as guidelines for family members or health professionals when confronted with choices regarding the optimal care or treatments for the elderly patients.

Under the Common Law legal framework in countries like UK, Australia, Canada and USA, the application of advance directives for refusing life-sustaining treatment is legally binding, however, Hong Kong has not yet accorded any legal status for the use of advance directives. A main concern for legality of advance directives stems from the lawfulness of the advanced expression or expressed preferences. In a situation where or if a patient had either specifically wished for euthanasia to be administered (a positive act), or specifically wished not to receive certain life-sustaining treatments (a passive act)<sup>14</sup>, the former request cannot be carried out as it involves the unlawful actions of a third party<sup>15</sup>, while the latter highly depends on the presence of advance directive or guardians—even so, the current lack of statue implies that, not only medical practitioners can lawfully carry out life-sustaining treatment without consent, it is also their duty to treat, based on the ground of necessity to save life<sup>16, 17</sup>.

Nonetheless, despite the lack of legislation of advance directives in Hong Kong, any person wishing to make advance expressions regarding medical treatment is free to do so. Such directives are generally recognised and validated upon the determination of the patient's mental capacity and their being free from undue influence. A good example of non-legislative means of advance directive can be found in the Hospital Authority's Guidelines on life-sustaining treatment in the terminally ill (2002) which expressively states that, "valid advance directive refusing life-sustaining

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<sup>&</sup>lt;sup>14</sup> Examples of life sustaining treatment include cardiopulmonary resuscitation (CPR) and tube feeding.

<sup>&</sup>lt;sup>15</sup> Acts of intentional killing, manslaughter, aiding, abetting, counselling or procuring the suicide of another or an attempt by another to commit suicide are outlawed in Hong Kong.

<sup>&</sup>lt;sup>16</sup> See Re F., Mental Patient: Sterilization, (1990), 2 AC 1, where the courts in England has expressed that permanent incapacity may empower medical practitioners with wider range of actions, which includes actions in the best interest of a patients on doctor's clinical judgements. This is likely to be one of the guiding decisions for Hong Kong.

<sup>&</sup>lt;sup>17</sup> Liu A., Consent to Medical Treatment by or for a Mentally Incapacitated Adult: The Interplay between the Hong Kong Common Law and Part IVC of the Mental Health Ordinance, LAW LECTURES FOR PRACTITIONERS (2005).

treatment should be respected". <sup>18</sup> In addition, Guardianship Board as established under Mental Health Ordinance Cap. 136 (1999) <sup>19</sup> has been given the authority to further safeguard the wishes of the patient as well as his family during critical decision making. It is a requirement under the Ordinance for guardian to take into account any prior wishes expressed by the patient before he/she becomes incapacitated—thus decision making ability at the time of making the instruction is key to the validity of the directives.

### II. CAPACITY FOR MAKING ADVANCED DIRECTIVES

When assessing a person's decision making ability, the first step should be to medically examine whether a person's cognitive ability has been compromised or impaired, thereafter determine if such impairment has affected the person's legal capacity in making informed decisions. According to the Law Reform Commission of Hong Kong (2006), the basic Common Law test of capacity specifies 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. It states further that, legal determination of capacity should not be determined by the judge alone, but also on the basis of evidence from the patient's doctors and others who know him.

On the basis of Common Law, every adult is presumed, prima facie, to have full mental capacity for exercising his/her right to making autonomous decisions, unless determined otherwise. Persons diagnosed with dementia do not necessarily invalidate their decision making competence, although the loss of cognitive capacity to understand, reason and appreciate the consequences of decision made may be a gradual process. The determination of the lack of capacity, whether permanent or provisional, must only be established upon a balance of probabilities and should be function specific. The most common types of function specific advance decisions or informed consent usually relate to matters of preferred treatment, finances and/or appointments of substitute decision makers in the

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<sup>&</sup>lt;sup>18</sup> Hospital Authority, *Hospital Authority Guidelines on Life-Sustaining Treatment in the Terminally Ill*, paras. 5.16-5.23., 4 (Hong Kong: Hospital Authority 2002).

<sup>&</sup>lt;sup>19</sup> Mental Health Ordinance, Cap 136 (HONG 1999).

<sup>&</sup>lt;sup>20</sup> The Law Reform Commission of Hong Kong, *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment*, 4 (Hong Kong: The Law Reform Commission of Hong Kong 2006). <sup>21</sup> *Ibid*.

event they become incompetent to make informed decisions on their own.

# III. Underlying Controversy between Self-determination of Health and Medical Paternalism

The Universal Declaration of Human Rights (1948) recognizes that, all members of the human family are born free with equal entitlement in dignity and rights, who shall be entitled to equal protection against any discrimination.<sup>22</sup> Under this fundamental human rights instrument, everyone has an inherent right to life, health and liberty which should be respected at all times, just and moral. Such liberty includes an individual's freedom of expression, thought and belief. The European Court of Human Rights concurs with the general comment of the Committee on Economic. Social and Cultural Rights where one's right to health contains both freedoms and entitlements which include the right to control one's health and body, and the right to be free from interference (International Covenant on Economic, Social and Cultural Rights (ICESCR), 1976, Article 12)23,24. According to Article 1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1976)<sup>25</sup> and International Covenant on Civil and Political Rights (ICCPR) (1976)<sup>26</sup>, the right to self-determination of all persons should be encouraged and respected where the right to health should not be understood as simply a right to be healthy, but also right to control one's own health and body. Older persons with dementia should be equally entitled to the enjoyment and protection of the right of self-determination, as a basic human right. The key element in making any informed decision is the capacity of a person to understand the nature of the decision and the competence to evaluate the impacts and consequences of his/her decision. WHO furthers that, if a patient experiences difficulties in appreciating the implications of a decision (i.e., incompetent in making informed decisions), he/she should have the right to be assisted in the exercise of selfdetermination, and shall benefit from the assistance of a knowledgeable

<sup>&</sup>lt;sup>22</sup> United Nations, *Universal Declaration of Human Rights*, (1948). *Available at* http://www.un.org/en/documents/udhr/ (last visited June 10, 2015).

<sup>&</sup>lt;sup>23</sup> The right to be free from interference incorporates the right to be free from torture, non-consensual medical treatment and experimentation.

<sup>&</sup>lt;sup>24</sup> UN General Assembly, *International Covenant on Economic, Social and Cultural Rights*, (1976). Article 12. *Available at* http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (last visited June 15, 2015).
<sup>25</sup> *Ibid*.

<sup>&</sup>lt;sup>26</sup> UN General Assembly, *International Covenant on Civil and Political Rights*, (1976). *Available at* http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx (last visited July 19, 2015).

third party.<sup>27</sup>

There has been much controversy regarding the patient's fundamental liberty to refuse medical treatment and the patient's capacity in providing informed consent or refusal on kinds of treatment, against the professional judgments of health experts. Especially in cases of emergency, where a patient lacks capacity to make informed health decisions regarding his or her own wellbeing, the necessity of treatment such as life-prolonging treatment, are generally determined by competent medical professionals, who are under duty to act in the best interest of their patients. Nonetheless, in *Malette v. Shulman* (1990) <sup>28</sup> and *Cruzan v. Director, Missouri* Department of Health (1990)<sup>29</sup>, the United States Supreme Court ruled that, a patient's right to self-determination should not be lost simply because an individual is unable to sense a violation to his/her rights; and that even if an individual is incompetent, he/she should retain their essential right to refuse treatment. Further, the interest of Mrs. Malette, in her case, "to reject, or refuse to consent to, intrusions to her bodily integrity"<sup>30</sup> should righteously outweigh the state's interest in the sanctity of life and health, or the protection of the integrity of the medical profession.

Hence, to avoid falling into such a controversy, it is desirable to have an advance directive made among patients with terminal illnesses or those losing decision making abilities.

#### IV. OVERVIEW OF INTERNATIONAL PRINCIPLES AND REGIONAL PRACTICE

In recent years, the Hong Kong Probate Registry has witnessed striking increases in contested guardianships and wills, with a high prevalence of elder abuse and exploitation by family members and strangers, friends, caregivers etc.. The establishment of advance directive is especially valuable for those who are more susceptible to abuse or exploitation due to contested impairments in decision making capacity, such as those with symptoms of MCI, mild dementia or lucid mental competences. An average of more than four hundred cases of elder abuse have been reported between 2007 to 2011, with statistics indicating spouses (71%), children (13%) and domestic helpers (8%) as the highest rated abusers. Based on the Central

<sup>&</sup>lt;sup>27</sup> World Health Organization, *Mental Health Care Law: Ten Basic Principles*, (1996). *Available at* http://www.who.int/mental\_health/media/en/75.pdf (last visited July 8, 2015).

<sup>&</sup>lt;sup>28</sup> Malette v. Shulman, 72 OR (2d) 417 (1990).

<sup>&</sup>lt;sup>29</sup> Cruzan v. Director, Missouri Department of Health, 497 US 261 (1990).

<sup>&</sup>lt;sup>30</sup> Malette v. Shulman, 72 OR (2d) 417 (1990).

<sup>&</sup>lt;sup>31</sup> Social Welfare Department, *Application for a Guardianship Order under the Mental Health Ordinance (MHO)*, Cap 136 (Hong Kong: Social Welfare Department 2014).

Information System on Elder Abuse Cases<sup>32</sup>, the most common types of reported abuse cases between 2007 and 2011 were physical abuse (303). psychological abuse (81), financial abuse (51) and other reported abuse cases  $(29)^{33}$ .

It should be noted that, the dichotomy of statutory protection and prevention of abuse for older persons should not hinder the older person's role as an agent of self-determination. Rather, within a statutory protected environment, older persons' participation in decision making processes are encouraged, especially in matters affecting their own health and wellbeing. The World Health Organization recognizes that, having a legislation protecting vulnerable citizens (including people with mental disabilities, including dementia) reflects a society's respect and care for its people. The Madrid Plan of Action on Ageing (MIPAA)<sup>34</sup> together with The Convention on the Rights of People with Disabilities (CPRD)<sup>35</sup> was developed with the aim of ensuring that, all persons, including those with mental disabilities, can age with security and dignity, and allowing older persons to participate as active citizens with full rights as specified in international human rights law. A person's dignity and autonomy should not be discriminated on the basis of their disabilities. Under the universal recognition of dignity of all persons with disabilities, older persons with cognitive disabilities should continue to be viewed as "subjects" of natural rights who are capable of making sound decisions for affecting their individual life.

CRPD obliges its State Parties to ensure the social protection and promotion of independent living for disabled and vulnerable persons through the development of supportive policies, laws and administrative measures which are in line with the aims and objectives of the Convention. They are to safeguard access to justice on an equal basis with others (Article 13)<sup>36</sup>, and ensure that, persons with mental disabilities enjoy the right to liberty, security and non-discrimination, and not be deprived of their liberty

<sup>&</sup>lt;sup>33</sup> Other reported abuse cases include multiple abuses, neglect, abandonment and sexual abuse. <sup>34</sup> United Nations, Department of Economic and Social Affairs, Social Policy and Development Division, Political Declaration and the Madrid International Plan of Action on Ageing, (2002). Available at http://undesadspd.org/Portals/0/ageing/documents/Fulltext-E.pdf (last visited June 7,

<sup>35</sup> United Nations, Committee on the Rights of Persons with Disabilities, Convention on the Rights of Persons with Disabilities. Final Report of the Ad Hoc Committee on a Comprehensive and INTEGRAL INTERNATIONAL CONVENTION ON THE PROTECTION AND PROMOTION OF THE RIGHTS AND DIGNITY OF PERSONS WITH DISABILITIES 5-29 (2006). Available at http://daccess-ddsny.un.org/doc/UNDOC/LTD/N06/645/30/PDF/N0664530.pdf?OpenElement (last visited August 10, 2015).

<sup>&</sup>lt;sup>36</sup> *Ibid.* at 13.

unlawfully or arbitrarily (Article 14)<sup>37</sup>. The Convention also reinforces respect for mental integrity of disabled and vulnerable persons (Article 17)<sup>38</sup>.

The Mental Capacity Act (2005) of Hong Kong is one of the most important legislations for empowering and protecting adults who are mentally incapacitated in making informed decisions due to mental illness or cognitive disability. Unlike Hong Kong, advance directives under this UK legislation are legally binding. 39 Any ill treatment and neglect of mentally incapacitated persons will be charged as a criminal offense under this Act. Apart from the rights enshrined under MIPAA and CRPD, the Mental Capacity Act (2005) further provides a checklist of instructional and proxy factors for all decision makers to consider when determining the best interests of the incapacitated person. The Act furthers that, all alternatives must be considered and the option chosen should be the least restrictive to the person's basic rights and freedoms, and when such alternative is carried out, its effects should not be detrimental to the person concerned. 40 The Act also established the Lasting Powers of the Attorney (LPA) and the Independent Mental Capacity Advocate (IMCA) as a proxy for the mentally incapacitated person to manage their personal, legal and financial affairs. 41

Australia had instituted a similar legislative framework for Advancing Health Directives under the Powers of the Attorney Act (1998), the Mental Health Act (2000), Guardianship and Administration Act (2000) and its subsidiary tribunal. In promoting individual autonomy and minimizing public intrusion, the Australian system places various restrictions on the powers of an attorney or guardian especially in matters relating to life sustaining measures and special health matters. The Powers of the Attorney Act recognizes the preferred role of primary carers or appropriate family members to act as proxy decision makers above statutory appointed attorneys as they are most likely to have the patients' best interests at heart and are more familiar with the patient's wishes and values. 42 The Mental Health Act further emphasizes on the importance of taking into account a person's age, gender, religion, culture and other special needs such as language of communication, when deciding matters on an individual's behalf. It stipulates that, direction given in any advance health directive will have priority over the general powers of the attorney or health provider,

<sup>37</sup> *Ibid.* at 13.

<sup>&</sup>lt;sup>38</sup> *Ibid*. at 14

<sup>&</sup>lt;sup>39</sup> For an advance decision to be legally binding, it must be made in writing, signed by the person making it and witnessed.

<sup>&</sup>lt;sup>40</sup> Mental Capacity Act§ 4, sub-§ 1-6 (HONG 2005).

<sup>41</sup> Ibid

<sup>&</sup>lt;sup>42</sup> Powers of the Attorney Act (AU 1998).

unless in cases of violation of good medical practice or in matters relating to urgent health care where there is an imminent risk to the person's health or life. <sup>43</sup> Conducting any unauthorized health care treatment on mentally impaired persons is to be criminally sanctioned.

Unlike most countries where advance directives can include the nomination of a person for making decisions on one's behalf, New Zealand regulates proxy appointments through the Enduring Power of Attorney under the Protection of Personal Property Rights Act (1988). The New Zealand Code of Health and Disability Services Consumers' Rights (2009)<sup>44</sup> allows older consumers to use advance directives in accordance with the Common Law. The Code recognizes Section 11 of the New Zealand Bill of Rights Act (1990) where everyone has the right to refuse to undergo any medical treatment, therefore enables consumers to use advance directives to refuse medical treatment in the event that the consumer becomes incompetent or unconscious. Any unreasonable interference with the consumer's valid advance refusal of treatment will be a breach of the Code.<sup>45</sup>

In 1996, with full consideration of the merits for formalizing "advance directives" and "living wills" legislation, Singapore enacted the Advance Medical Directives Act (AMD) (1996) with subsequent implementation of its provisions a year later. Singapore declared that, the need for AMD legislation was based upon the intention to enable its citizens to live with dignity, till the end of their life. Nonetheless, it stipulates that, no one shall be coerced into executing any directives against their will, and further specifies that, AMDs should not be used to condone euthanasia in any circumstance, as the use of "mercy killings" continues to be a criminal offence in Singapore. 46

### V. ADVANCE DIRECTIVES IN HONG KONG

The basis of Common Law helps form various guidelines of the Hong Kong Hospital Authorities regulating all staff on resuscitation decisions, consent to or refusal of treatment, and life-sustaining treatment for the terminally ill. The onset of these guidelines follows the customary doctrine of best interest of the patient, with emphasis on a proper consensus building process through effective communication when arriving at any professional

<sup>&</sup>lt;sup>43</sup> Mental Health Act (AU 2000).

<sup>&</sup>lt;sup>44</sup> Right 7 (5) of the Code of Health and Disability Services Consumers' Rights (2009): *Right to Make an Informed Choice and Give Informed Consent*.

<sup>&</sup>lt;sup>45</sup> New Zealand Bill of Rights Act, § 11 (NEZ 1990).

<sup>&</sup>lt;sup>46</sup> Advance Medical Directives Act (SIN 1996).

and ethically sound decisions. It is a common practice for attending physicians in hospitals to seek for consents for "not to resuscitate" from patients and their close relatives, mostly in written forms, when the patient's condition is diagnosed to be terminal and has been suffering from pain for some time.

There is currently a lack of legislative framework in Hong Kong to legally bind advance decisions made by mentally competent persons for matters affecting their health or wellbeing in the event they become mentally incompetent. Advance directives are generally accepted to be valid based on moral arguments for the patient's right to self-determination. The Code of Professional Conduct for Registered Medical Practitioners (The Medical Council of Hong Kong, 2009) requires doctors to respect the wishes of patients by following advance instructions expressed with regards to medical treatment. However, as advance directives in Hong Kong are not legally binding, any conflict arising from the patient's wishes may be contended in court and advance directives are generally superseded by existing statutory provisions in such cases. However, cases of such kind have not yet been contended in courts of Hong Kong.

One of the most important legislations concerning decision making of mentally incapacitated adults in Hong Kong is the Mental Health Ordinance Cap. 136 (1999), which governs the care and supervision of mentally incapacitated persons. Its overarching provisions include the management of property and affairs, the medical and health care of mentally incapacitated persons, and the provision of guardianship for the giving of consent for treatment or special treatment (excluding organ transplantation) in respect of mentally incapacitated adults. The establishment and appointment of the Guardianship Board (2015) under this Ordinance serve the purpose of appointing guardians as substitute decision-makers for adults who are unable to make decisions about their personal, medical or financial affairs due to an established lack of mental capacity. It also gives directions to guardians as to the nature and extent of guardianship orders. The primary function of the Guardianship Board is to promote and respect the views and wishes of mentally incapacitated persons, however, such views may be overridden when they are considered not serving the best interests of affected persons. While the Enduring Power Of Attorney is appointed as a custodial alternative for elderly persons who wish an attorney to represent

<sup>47</sup> Chu L., *One Step Forward for Advance Directives in Hong Kong*, 18(3) Hong Kong Medical Journal 176-77 (2012).

<sup>&</sup>lt;sup>48</sup> The Medical Council of Hong Kong, *Code of Professional Conduct for Registered Medical Practitioners*, (2009). *Available at* http://www.mchk.org.hk/code.htm (last visited July 10, 2015).

his/her interests, the authority conferred to the attorney is restricted to make decision only on the management of property and financial affairs but not medical treatment.

In situations where no advance instructions has been provided by dementia patients, the High Court normally adopts the doctrine of *parens patriae* in its power to make orders, and gives directions as it thinks fit for the control and management of any property of the mentally incapacitated person (as would have been the case for the Guardianship Board). The matters of medical treatment are more complicated as Common Law does not recognize proxy consent for medical treatments even in the event of emergency.

In Re, F. (Mental Patient: Sterilization) (1990), the House of Lords held that, a doctor may lawfully treat an incapacitated person without consent provided that, it is in the best interest of the patient. 49 This decision is problematic in application as there is currently no universal definition of "best interest", and the topic of who should be the most appropriate person to decide in another person's best interest is still much contended. Under Common Law, courts have no jurisdiction to approve or disapprove the giving of medical treatment to mentally incapacitated persons based on subjective interpretations of "best interest", but merely decide upon the lawfulness of proposed treatments. The necessity and appropriateness of treatment in such cases are normally decided upon judgments of medical professionals and are carried out in accordance to the code of professional conduct. Nevertheless, judicial approval would serve to reassure public confidence in the undertakings of the medical profession in such emergency situations. In sum, authority rests with medical professionals in Hong Kong seems to overrule advance directives made by patients who are now incapable of sustaining their original wishes.

## VI. CHALLENGES IN THE APPLICATION OF ADVANCE DIRECTIVES FOR DEMENTIA PATIENTS

## A. Problematic Application of the Mental Health Ordinance

There are various similarities of the Hong Kong practice to that of the Australian system in safeguarding persons with dementia via advance decisions. One of the most recognizable similarities is the wide application of the Mental Health Ordinance (1999) for regulating matters relating to persons with dementia. Although the Mental Health Ordinance is an

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<sup>&</sup>lt;sup>49</sup> Re F., Mental Patient: Sterilization, (1990) 2 AC 1.

inclusive instrument for governing affairs of the mentally incapacitated person, one should be cautioned not to equate the concept of mental illness to age associated effects of dementia. Under Section 2 of the Ordinance, direct correlations are made between "mental incapacity" with "mental illness and mental handicap" when determining mental competence by medical practitioners. The Ordinance provides a description for the behaviour of mentally handicapped persons who are to have "significant impairment of intelligence and social functioning ... which is associated with abnormally aggressive or seriously irresponsible conduct" (Mental Health Ordinance s2(1)). While it is discerning and confusing to assume that, aggressive behaviour may be pertinent to all older persons with dementia, the increase prevalence of dementia patients associated with our ageing population certainly has no direct link to any increase in irresponsible or reckless behaviours. It is likewise questionable whether the fault of irresponsibility should be claimed for someone who is mentally incapable of understanding or appreciating the nature and consequences of their actions or decisions.

A person suffering from mental disorder or has a mental handicap usually possesses an Intelligence Quotient (IQ) of 70 or below according to the Wechsler Intelligence Scales for Children. There is, however, no scientific evidence to show the direct correlation between one's IQ scores which denotes the medical condition of dementia or Alzheimer's disease. Although researchers have shown that, those with relatively higher IQs and have more active lifestyles during their youth might lower the risk of developing dementia when entering their old age, one should be caution not to assume the low level of intelligence for all dementia patients. <sup>51</sup>

Moreover, the Mental Health Ordinance (1999) seems to be insufficient in its scope to safeguard those who might undergo lucid intervals of cognitive reliability, a common case in dementia. The fluctuating or progressive nature of dementia makes it difficult to identify the exact moment for when the patient would be protected under the scope of the Ordinance. There is also no provision for the delaying of medical or surgical treatment until the reasonable restoration of the patient's mental competence. The common practice of attaining the consent of close relatives prior to special or emergency medical treatment is a misconception of Common Law legal practice, where relatives actually have no legal right to either consent to or refuse a treatment on the patient's behalf. This practice

<sup>&</sup>lt;sup>50</sup> Mental Health Ordinance, Cap 136 (HONG 1999).

<sup>&</sup>lt;sup>51</sup> Social Welfare Department, *Application for a Guardianship Order under the Mental Health Ordinance (MHO)*, Cap 136 (Hong Kong: Social Welfare Department 2014).

has often been criticized where hypothetical judgments are made by family members on behalf of the patient, whom if mentally competent, might have made in their own best interest. It should be acknowledged that, proxy decisions made by family members often encounter conflicts of interest when family members equate their respective opinions "for" best interests, to be the best interests "of" the patient. There is also a lack of appeal systems in Hong Kong for patients who had undergone involuntary treatment in circumstances of proxy consent.

### B. Undue Spousal or Relational Influence

Much attention has been paid to the determination of mental capacity to equate the making of a valid and applicable directive as seen in the provisions of the Mental Capacity Act (2005) (MCA), yet little consideration is made to the process facilitation to ensure the making of informed and effective decisions. Section 4(6) of the MCA (2005) provides a checklist of factors for guiding medical professionals in making decisions which are "as far as is reasonably ascertainable"<sup>52</sup> for the best interests of their patients. However, should all advance decisions made be interpreted conclusively as valid and applicable? The notions of undue spousal or relational influence have often been noted by medical professionals where family members play an active role in affecting the preparation of advance directives or living wills by their elderly loved ones. Vulnerable patients tend to regard the opinions of their family members to be in better authority than their own, especially in situations where such patients are already overwhelmed by their own medical conditions, and feel insecure in making "best" decisions regarding their own health and wellbeing. complications in differentiating loving encouragements from deceptive and coerced actions of a relative or friend can leave vacuum for manipulation and exploitation of the clouded judgments of the elderly.

The Law Reform Commission (LRC) of Hong Kong attempts to eliminate the complicities of undue spousal influence by specifying that, an advance directive is effective "unless challenged on the grounds of, for instance, incapacity or undue influence" when making an decision.<sup>53</sup> It does not, however, offer any formal procedure for making, altering and/or revoking advance directives if the older person later decides that, the previous decision made is no longer in his/her current best interest. Yet, it

<sup>&</sup>lt;sup>52</sup> Mental Capacity Act§ 4, sub-§ 1-6 (HONG 2005).

<sup>&</sup>lt;sup>53</sup> Law Reform Commission of Hong Kong, *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment*, 161 (Hong Kong: Law Reform Commission of Hong Kong 2006).

provides the rationale that hospitals and relevant institutions should be accorded the freedom to draft their own procedures for making, altering and revoking advance directives to best suit their respective institutional mission, values, and operational needs. The Hospital Authorities' Guidelines on In-Hospital Resuscitation Decisions (1998)<sup>54</sup>, Guidelines on Life-sustaining Treatment in the Terminally III (2002)<sup>55</sup>, "Guidance for HA clinicians on Advance Directives in Adults" (2010)<sup>56</sup> and "Consultative Paper on Guidelines for DNACPR in HA" (2013)<sup>57</sup> specify that, the principle of patient autonomy should be respected and that advance decisions should be made free from pressure. However, it omits the provision of a clear definition for undue influence while the conditions for determining the directive's validity remain non-specific. The discourse of Hospital Authority's Guidelines has often been criticized for being overly complicated for understanding, and the practicality of doctors' application is still questionable.

Over reliance on public authorities such as High Court in making proxy decisions can also be cumbersome, time-consuming and costly. Even with the appointment of Guardians and Enduring Powers of the Attorney, there is no specific procedural obligation or monitoring mechanism available to ensure the wishes and instructions of the mentally incapacitated person are followed in such arrangements. There are further concerns of the suitability of appointed attorneys or decision makers. Understandably, not all attorneys are professionally specialized in either healthcare or finance to make appropriate proxy decisions in such matters. Likewise, appointed decision makers under the Guardianship Board are usually someone entirely unrelated and unfamiliar to the dementia patient so they may not be able to make proxy decisions in the best interest of the affected persons.

### C. Influences of Chinese Culture

The values of making advance directives are obvious for those with foreseeable medical conditions, such as mental deterioration associated with Alzheimer's disease. Nonetheless, not all events are predictable where

<sup>&</sup>lt;sup>54</sup> Hospital Authority, *Hospital Guidelines on in-Hospital Resuscitation Decisions*, (Hong Kong: Hospital Authority 1998).

<sup>&</sup>lt;sup>55</sup> Hospital Authority, *Hospital Authority Guidelines on Life-Sustaining Treatment in the Terminally Ill*, paras. 5.16-5.23 (Hong Kong: Hospital Authority 2002).

<sup>&</sup>lt;sup>56</sup> Hospital Authority, *Guidance for HA Clinicians on Advance Directives in Adults*, (Hong Kong: Hospital Authority 2010).

<sup>&</sup>lt;sup>57</sup> Hospital Authority, *Consultative Paper on Guidelines for DNACPR in HA*, (Hong Kong: Hospital Authority 2013).

advance decisions can be made in the expectation of what "may" come later. Furthermore, the concept of preparing one's own "living will", or "death will" is also a topic tabooed by the Asian culture where any matter associated with "death" or "sickness" is considered inauspicious. When deciding on end-of-life treatments, research (Tang, Chiu and Lam, 2007) has shown that, while most Chinese patients with dementia preferred to avoid causing any burden to their families and had expressed strong wishes to shorten suffering, filial piety has often caused conscientious objections from their children who wish to prolong the life of their parents. 58 The significance of Chinese culture where the endorsement of family members are highly valued as a sign of solidarity, often plays a critical role in influencing the decision making process of patients. In situations where high medical costs are financed by children or relatives, there are usually undue pressure on the elderly patients to make decisions regarding their medical treatment which may deem more preferable by their financial sponsors. In such circumstances, the decision making processes are normally affected by the elder patients' wish to reduce financial stress on their children or relatives rather than by their own health and wellbeing.

### D. Beyond Legal and Practical Aspects

Additional inferences are triggered from advance decisions which specify the discontinuation of life support of the elderly or the refusal of treatment which deem critical for the sustainment of the patient's life. The legal consequences of suicidal commitments and its financial effects on indemnity coverage such as life insurance are still widely contested. It should be made clear that, even with the completion of advance directives, such documents are insufficient to ensure that, all decisions regarding end-of-life care can be made in accordance to their wishes. The Hong Kong Bar Association criticizes the LRC in its omission to address issues relating to the confirmation of advance directives through indication of the maker's full understanding and communication to his/her family members, friends or medical doctors. <sup>59</sup> Acknowledgements by the elder patient's family members or medical professionals of the advance decisions are crucial for ensuring such wishes and decisions for health care, personal care and finances. Without a formal registry system for recording and monitoring

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 <sup>&</sup>lt;sup>58</sup> Tang C., Chiu H., & Lam L., Attitudes to End-of-Life Decisions: A Survey of Elderly Chinese with Dementia and Their Carers, 2(3) ASIAN JOURNAL OF GERONTOLOGY AND GERIATRICS 119-25 (2007).
 <sup>59</sup> Hong Kong Bar Association, Comments of the Hong Kong Bar Association on the Consultation Paper Concerning the Introduction of the Concept of Advance Directives in Hong Kong, (Hong Kong: Hong Kong Bar Association 2010).

advance directives, proper documentation or communication mechanism, any advance decisions made will be the sole responsibility of the maker and acknowledged only by the maker. There may be further implications when the proof of a written instruction is required in litigations against medical institutions or professionals concerned. The Hong Kong government's hesitation in advocating or encouraging the public to make advance directives rests precisely on the recognition that, advance directives can affect a wide range of issues beyond its legal and practical aspects, and should be warranted careful consideration and deliberation.

# VII. TENTATIVE SOLUTIONS: PRAGMATIC APPROACH TO INSTITUTION OF ADVANCED DIRECTIVES

While the Hong Kong SAR Government continues to waver between the formal institution of advance directives and the application of non-legislative means for the promotion of advance directives, medical professionals and families continue to face the conundrum of proxy decisions on a daily basis. The rising incidences of proxy, value or instructional directives are becoming more widespread with our ever-increasing ageing population. And although the challenges of resolving all associated consequences of the institution of advance directives may be extensive and demanding, a person's right to health, right to participation and decision in matters affecting one's wellbeing, and right to not being discriminated on the ground of their health status or old age should demand the government's urgent attention.

The concept of advance directives is still new to most members of the public community. Within Asian cultures, "living wills" are perceived no differently from death planning, and family conversations relating to end-of-life treatments or disposition of assets for their elderly parents or relatives are still avoided as far as possible. Even health care professionals in Hong Kong feel uncomfortable to mention death and dying issues to their patients, while most of them are not sufficiently equipped with the necessary skills to support patients and families in advance care planning. Recognizing the profound effects of Chinese culture in the application of advance directives, the Law Reforms Commission (2006) stated that, "it would be premature to attempt to formulate a statutory frame work and to embark on any legislative process for advance directives, without greater public awareness of the issues involved".

<sup>60</sup> The Law Reform Commission of Hong Kong, Substitute Decision-Making and Advance Directives in Relation to Medical Treatment, 161 (Hong Kong: The Law Reform Commission of Hong Kong 2006).

To date, there is scarce availability of public information or education initiatives for enhancing the public understanding of advance directives. Apart from the lack of confidence to properly guide patients through advance care planning, medical professionals are unable to spare extra time out of their busy schedules to properly communicate with individual patients and the patient's family members in order to explain the benefits and processes of formulating advance directives. The formulation process is one that requires much sensitivity to the patient's personal values by taking full considerations of their physical, psychological, socio-economic, religious and cultural influences. Care and medical staff should receive specialized training in supporting their elder patients, making informed decisions at the onset of dementia, and properly recording these decisions as advance directives. This could be done by integrating multi-disciplinary gerontology components into academic facilities to allow understandings of contemporary ageing issues, followed by specialized training on supporting patients and their families in making advance decisions from a life review perspective (i.e., reviewing the life of the patient from what the patient needed to what the patient will need). To alleviate the work stress of professionals, the general public should also get more familiar with ageing matters via accessing to public information or community workshops so as to better facilitate older persons, at home or at work, in making decisions that best suit their diverse needs.

The stigmatization of advance directives and stereotypes of elderly incompetence could be transformed into open dialogues among the elderly patients, their families and close friends as well as doctors or nurses. Stimulated conversations regarding advance planning for old age can help relieve the burden of future proxy decision making where the elderly, while still mentally capable, can actively inform and participate in the decision making process for all matters relating to their future wellbeing. This interchange not only supports Chinese tradition of filial piety where the children can respect the wishes of their elderly, but also encourages more frequent dialogues between family members and the older patients about their needs, which in turn enhances relational and family bonding.

MIPAA's recommended actions for older persons and development specified that, the full and equal participation of older persons in all levels of decision-making processes should be encouraged so as to secure the needs and concerns of older persons (MIPAA 2002). Representative organizations of older persons should also be consulted in decision making process for legally enforcing advanced directives. MIPAA also reinforces WHO's definition of health as a multidimensional state of wellbeing, and

who else knows best the actual needs of older person than the elderly themselves? It must be noted that, the legal enforcement of advance directives does not mean that, it should be rigid in application, nor be the respect for the patient's autonomy, nor be the professional judgment of best treatment exclusive concepts. <sup>61</sup> Clear guidelines should be provided to demonstrate how professional judgments can supplement and guide patients in making better informed choices. If special treatment must be provided to a mentally incapacitated patient, circumstances of such exceptional cases should be provided and recorded in writing; an official monitoring system should also be in place to ensure professionalism.

In an era where medical advances have radically increased the possibility of prolonging life, the right to self-determination is a vital principle in determining the types of treatment one wishes to receive or refuse. The World Medical Association's Declaration of Lisbon on the Rights of the Patient (2005) states that, "if the patient is unconscious or cannot communicate and if a legally entitled representative is not available but a medical intervention is urgently needed, consent of the patient may be presumed, unless it is obvious and beyond any reasonable doubt on the basis of the patient's previous firm expression or conviction that he/she would refuse consent to the intervention in that situation".62. Hence, prior to the application of the existing Guardianship or Enduring Powers of the Attorney arrangements in Hong Kong, the first and foremost consideration must be the explicit expression of the patient for the determination of treatment. In order to ensure the binding status of the patient's expressed wishes, formal institution of advance directives must be enforced within a supportive statutory framework.

The overarching stipulations of the Mental Health Ordinance and the Guardianship Board is simply too ambiguous and non-specific in its application to safeguard older persons in the decision making process or legal effectiveness of advanced directives. A clear distinction must be made between mentally ill patients or those suffering from psychopathic disorders, and older persons suffering from cognitive deterioration due to dementia. In fact, the Ordinance in all its provisions has not made any specific references to older persons suffering from such deteriorative condition, or how it can

<sup>61</sup> World Health Organization, WHO Resource Book on Mental Health, Human Rights and Legislation, (2005). Available at

http://www.who.int/mental\_health/policy/who\_rb\_mnh\_hr\_leg\_FINAL\_11\_07\_05.pdf (last visited July 17, 2015).

<sup>&</sup>lt;sup>62</sup> World Medical Association, World Medical Association Declaration of Lisbon on the Rights of the Patient, 3 (2005). Available at http://dl.med.or.jp/dl-med/wma/lisbon2005e.pdf (last visited July 9, 2015).

be applied to dementia patients. The Guardianship Board, although having specified its application to dementia patients, is limited in its powers which only extend to providing consent for medical or dental treatment but not the ensuring of actions being carried out in the presumed interest of the person concerned. The doctor's objective judgment for the best interest of the person concerned will in almost all cases override the opinions of the Guardian or the Board. The Guardianship order will not be applicable if the doctor agrees to provide treatment without the consent from the patient or with a consent form signed by the family member. There is no statutory precaution to determining how far the patient's wishes and interest are taken into consideration in such circumstances.

While the Enduring Powers of Attorney Ordinance provides no explanation for the term "best interest", the Guardianship Board only briefly defines "best interest" as "mental and/or physical wellbeing" 63. The isolated appointments of the Enduring Powers of the Attorney for property and financial matters and the Guardianship Order for medical treatments, also thwart the objective of making proxy decisions for the inclusive best interests of the patient concerned. The best interest principle should be established as the ultimate standard for all proxy decisions where nonexclusive considerations for physical, mental, socio-economical, religious or cultural status of the person affected must be taken into account. For if a guardian were to make reliable proxies for types of treatment best suited for his/her patient, they should undertake holistic considerations for the patient's socio-economic status to determine the affordability of treatment services. Likewise, the appointed attorney should not dispose of any property which might be sentimental to the patient, where losing ownership or connections to such possessions may lead to psychological detriment, or adversely affect the patient's health or quality of life. Appointments of specialized advance directive agents should fuse these separate roles for ensuring the patient's holistic status, at the time at which advance directives were created. With improvements in medical science and variations of treatment available, advance directive agents should also guide patients in reviewing and updating their advance directives so they reflect their most updated status, needs and desires. In doing so, they should develop longitudinal relationships with their donors so as to become better acquainted with their needs. This might be particularly valuable for lone elders who often lack channels for conveying their needs and wishes.

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<sup>&</sup>lt;sup>63</sup> Guardianship Board, *Guide to Doctors/Dentists: Consent to Medical and Dental Treatment of Mentally Incapacitated Person in the Context of Part IVB &Part IVC, Mental Health Ordinance (Cap. 136)*, (Hong Kong: Guardianship Board 2012).

#### CONCLUSION

Regardless of the gradual degeneration of cognitive abilities associated with dementia, older persons should be encouraged to actively participate in all aspects of life through the support of progressive legislation. States such as the Americas, the Nederland's, Denmark, Singapore and United Kingdom have all established formal legislations to provide legal enforcements for healthcare or medical advance directives. Other countries like Italy, Switzerland, Australia and New Zealand, lacking specific living wills legislation have adopted mental health ordinances and guardianship orders in dealing with end-of-life treatment decisions and related matters.

Misconceptions and cultural taboos of advance care planning should be rectified through public education initiatives. Once health carers, family members and the community are equipped with the relevant knowledge and skills to support elders in making advance directives, it can greatly reduce the cost and inconvenience of formal court adjudications. Of course, the role of the judiciary is not eliminated, but is transformed into gatekeepers maintaining the balance between rights as exercised by both agents and donors through the monitoring of professional conduct and lawfulness of directives.

The effective implementation of advance directives will necessitate the support of all stakeholders, including that of central authorities and the health and social care industry. Substantial commitments of manpower and financial resources will be required for evaluating the impact and value of advance directives, drafting of legislation and public education. Deficiencies of the current legislations in Hong Kong concerning the decision making of mentally incapacitated adults must be reviewed. Non-discriminatory discourse should be employed to avoid endorsement of ageism. The fluctuating or progressive nature of dementia should be taken into account when drafting living wills legislations, and the binding effects of decisions made during lucid intervals of the patient's cognitive reliability should be assessed. Clear guidelines in supporting the decision-making process or revocation of advance resuscitation decisions, prior informed consent to or refusal of treatment, and preferences in life-sustaining treatment must be provided not only to medical professionals within the Hospital Authority, but extend also to all relevant staff within the health and social care workforce, including those within public and private care homes, NGOs and relevant government bureaus. Public dissemination of information on advance directives should also be made available for family carers at home and any interested persons within the community.

Increased understanding of the benefits of advance directives is not only of the value in itself but is also of the provision of necessary means which enable the active living of older persons through participation in deciding on all matters for affecting their wellbeing. Although there are many complexities beyond the practical aspects of advance directives to be resolved, the value and need of legally enforcing advance directives or living wills in our fast ageing society is significant and thus their implementation should not be suspended any further. The institution of advance directives should be driven by the legal obligation of the Hong Kong Government to recognize and respect the civil, political, economic, social and cultural rights of everyone, which are essential for the improvement of the quality of living all persons in Hong Kong. Every adult should be recognized to hold capacity for making informed decisions regardless of the quality of the decisions made. No one should be discriminated on the ground of his or her illness, and older persons suffering from dementia should be not be perceived as lacking mental competence. The judiciary should not be the sole determinant of a person's legal capacity but should also consult medical professionals in obtaining evidence to prove one's lack of decision-making ability.