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ADVANCE CARE PLANNING: A COMMUNITARIAN APPROACH?

#### Tracey Evans Chan\*

This article examines the evolution of advance care planning (ACP) in Singapore through the development of a less formal, communications based model – the Living Matters programme – and its experience with local cultural and community responses to the process and its outcomes. Living Matters is, in practice, arguably a communitarian approach to ACP. The article then examines the challenges Living Matters poses to the overarching legal framework for ACP, and suggests improvements to the proxy decision making framework under the *Mental Capacity Act*, offering more flexible legal tools for ACP, and more regulatory support for the means to implement ACP outcomes effectively.

Advance Care Planning, Family/Shared Decision Making, Best Interests

#### I. Introduction

The challenges that medical technology have brought to care for persons at the end of life ('EOL') are not new; in fact, they are continuing. An ageing population and an evolving healthcare system with diversifying professions further intensify these problems. Much of medical technology deployed at the end of life is expensive and often does not ultimately confer benefit on dying patients, but instead prolongs the dying process without compensating gains in quality of life.¹ Physicians and tertiary healthcare institutions are still geared towards preserving life even though the palliative care movement has made significant progress, and patients and their families are often ill prepared to understand and make decisions on the types of care and treatments available at the EOL.

On the legal front in Singapore, two important steps were taken to try and get patients, their families and healthcare professionals to better anticipate and address these challenges. In 1996, the *Advance Medical Directive Act*<sup>2</sup> ('AMDA') was passed to allow adult individuals to refuse extraordinary life sustaining medical treatment when they become terminally ill. Unfortunately, apart from the many conceptual and operational challenges associated with the Advance Medical Directive ('AMD'), the basic fact remains that uptake of AMDs in Singapore has been very low, and implementation of AMDs even rarer despite best efforts at promoting them.<sup>3</sup>

Then, in 2008, the *Mental Capacity Act*<sup>4</sup> ('MCA') was passed which, while addressing a much larger range of care related decisions for incapacitated adults, brought some clarity for proxy or surrogate decision making in healthcare. The instrument of the

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<sup>&</sup>lt;sup>1</sup> Ruth Horn & Ruud ter Meulen, 'The Use of Advance Directives in the Context of Limited Resources for Healthcare", in P Lack et al eds., *Advance Directives* (Dordrecht, Springer, 2014), c.12

<sup>&</sup>lt;sup>2</sup> Cap 4A, Rev Ed 1997

<sup>&</sup>lt;sup>3</sup> Sing Parl Debates, Official Reports (17 Nov 2008), Vol 85:5 Col 695-696: At that sitting of Parliament, 10,100 AMDs (0.4% of the resident population) were registered, 19 revoked and 6 put into effect since the AMDA came into force. This number had risen to 13,900 by 2011: Sing Parl Debates, Official Reports (14 Feb 2011) Vol 87:16 Col 2611 <sup>4</sup> Cap 177A, Rev Ed 2010 ('MCA')

lasting power of attorney ('LPA') was introduced, but its efficacy in healthcare was limited drastically to the extent that donees of an LPA could not really make a significant impact on EOL decision-making.<sup>5</sup> Next, a statutory 'best interests' test was introduced, which clarified that the determination was not to be solely based on a medical welfare assessment, but must consider the past wishes and feelings of the incapacitated patient in question, and the views of her caregivers, donees of a LPA or court deputies (if any existed).<sup>6</sup> Nonetheless, the statutory best interests test is still relatively sparse in content and does not provide sufficient guidance or elaboration on how disparate objective and subjective factors are to be taken into account in making a proxy decision at the EOL. The upshot was that the medical profession still wielded ultimate responsibility and authority in deciding the course of EOL medical care based on the protection conferred by the MCA's section 7 general defence for acts of care or treatment.

A third, non-legal effort emerged in 2009 with the Agency for Integrated Care ('AIC') and National Healthcare Group's advance care planning ('ACP') initiative. Pioneered in various forms in different states in the USA, the principal innovation in ACP is a move away from formal, transactional measures in planning for EOL care, to a more fluid and open communications model of decision making.<sup>7</sup> These models were adapted for the Singapore context in the 'Living Matters' programme promulgated by AIC,<sup>8</sup> and piloted in projects such as HOME and CARE.<sup>9</sup> ACP in these pilot programmes was supported by trained facilitators and standardised care plan templates to document preferences and anticipatory decisions at different stages of a patient's disease trajectory. This initiative has since moved to a national level, with the National ACP Steering Committee working with service providers and government agencies to systematically implement ACP in all public hospitals and other sectors in the healthcare system.<sup>10</sup>

While systematic empirical evaluations of the impact that Living Matters has had on the quality and accuracy of decision-making in EOL care have yet to emerge, 11 several basic questions relating to the legal infrastructure supporting ACP arise. This article seeks to consider whether better legal tools or processes are needed to encourage and support ACP, or if such a programme is best left alone to develop organically in accordance with evolving professional healthcare practices. The next section describes in further detail how the existing Living Matters ACP programme is envisaged to work, and how the existing legal framework bears on these processes and written instruments. The following three sections then consider specific issues that arise in implementing Living Matters ACP in Singapore.

<sup>&</sup>lt;sup>5</sup> See Part III.C below.

<sup>&</sup>lt;sup>6</sup> See Part III.A below.

 $<sup>^7</sup>$  C Sabatino, "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) Millbank Quarterly 211 at 218

<sup>&</sup>lt;sup>8</sup> Living Matters National Advance Care Planning Programme, https://livingmatters.sg/about-living-matters/
<sup>9</sup> AIC's 'Holistic Care for Medically Advanced Patients' and Tan Tock Seng Hospital's 'Care at the End of Life for Residents in Homes for the Elderly' respectively: Lien Centre for Palliative Care, *Report on the National Strategy for Palliative Care* (2011) at 22-24, https://www.duke-nus.edu.sg/sites/default/files/Report\_on\_National\_Strategy\_for\_Palliative\_Care%205Jan2012.pdf

 $<sup>^{10}</sup>$  I Chung  $\it et~al,$  "Implementing a National Advance Care Planning Programme in Singapore (2013) 3 BMJ Support & Palliative Care 256

<sup>&</sup>lt;sup>11</sup> See WSK Teo et al, "Economic impact analysis of an end-of-life programme for nursing home residents" (2014) 28(5) Palliative Medicine 430, for an initial study on the economic impact of Project CARE.

#### II. THE LIVING MATTERS ACP PROGRAMME IN SINGAPORE

### A. Unpacking the concept of ACP

The 'Living Matters' programme in Singapore was modelled on the 'Respecting Choices' system developed in the Gundersen Health System in La Crosse, Wisconsin. 12 Respecting Choices sought to facilitate reflection and deliberation on preferences concerning EOL by encouraging patients to anticipate these issues, discuss them with a trained non-physician facilitator, family members and carers, and finally document them in *standardised* care plans that are stored and easily accessible across the relevant health system.<sup>13</sup> This process is supported by structured conversations, evidence-based information and tool kits to support patient reflection on values and goals in end of life care. The emphasis is on a relational, patient centred process that is well supported, and seeks to move away from earlier legally focussed, document driven transactional processes. 14 ACP as envisaged by Respecting Choices and Living Matters must also therefore be an iterative process because patient goals and preferences can change over time based on different or evolving circumstances and experience. 15 The underlying goal of Respecting Choices (as its name implies) is the same as advance directive policy: to enable patients to retain control over their terminal care once they lose decisionmaking capacity by making advance treatment decisions. 16 Although the same philosophy promoting respect for patient autonomy underpins Living Matters, the reasons for promoting ACP in Singapore extend to pre-empting hasty and unwise medical decision making that invites aggressive and expensive healthcare, and supports better communication within the family and with the healthcare team.<sup>17</sup>

Measurements of success of ACP were historically based on the number of advance directives executed, although these encompass both written advance treatment decisions and durable powers of attorney. However, in a more recent consensus statement of ACP policy, the stated objective is to help ensure that people receive healthcare that is consistent with their values, goals and preferences during serious and chronic illness. This would also include choosing and preparing another trusted person(s) to make healthcare decisions for a person who becomes incapacitated. However, in a more recent consensus statement of ACP policy, the stated objective is to help ensure that people receive healthcare that is consistent with their values, goals and preferences during serious and chronic illness. This would also include choosing and preparing another trusted person(s) to make healthcare decisions for a person who becomes incapacitated.

This shift in emphasis stems from the well discussed short-comings of advance directive oriented policies, such as the procedural difficulties of executing an advance directive, the psycho-social difficulties of being asked to make an anticipatory decision without all

<sup>12</sup> Living Matters programme, n8

 $<sup>^{\</sup>rm 13}$  BJ Hammes & BL Rooney, "Death and End-of-Life Planning in One Midwestern Community" (1998) 158 Ann Int Med 383

<sup>&</sup>lt;sup>14</sup> TJ Prendergast, "Advance Care Planning: Pitfalls, progress, promise" (2001) 29(Supp 2) Crit Care Med N34 at N37-38; In relation to the Living Matters programme, see I Chung, "Advance Care Planning in an Asian country", in K Thomas *et al, Advance Care Planning in End of Life Care*, 2<sup>ed</sup> (OUP, 2018), c.23 at 326-327.

<sup>&</sup>lt;sup>15</sup> CL Auriemma et al, "Stability of End-of-Life Preferences: A Systematic Review of the Evidence" (2014) 174(17) JAMA Internal Medicine 1085 at 1090

<sup>&</sup>lt;sup>16</sup> S Hickman et al, "Hope for the Future: Achieving the Original Intent of Advance Directives" (2005) 35(6) Hastings Center Report S26 at S30; LL Emanuel et al, "Advance care planning" (2000) 9 Arch Fam Med 1181; MR Gillick, "Advance Care Planning" (2004) 350 New Eng J Med 7.

<sup>&</sup>lt;sup>17</sup> Chung, n14

<sup>18</sup> Hammes & Rooney, n13 at 386

<sup>&</sup>lt;sup>19</sup> R Sudore et al, "Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel" (2017) 53(5) Journal of Pain and Symptom Management 821 at 826.

the relevant facts,<sup>20</sup> and the scepticism about how effectively advance directives would be implemented by healthcare professionals at the relevant time.<sup>21</sup> Furthermore, empirical research questions whether a majority of people really want to control the specifics of their EOL care. Various studies reveal that most people would prefer to delegate complete authority over EOL care to their families, and do not expect their living wills to be strictly followed.<sup>22</sup> They have no wish to micro-manage their EOL medical treatment. Instead, they would rather articulate more general values and goals about such care, and discuss how much discretion their authorised surrogate should have in deciding on their behalf.<sup>23</sup>

While the overall emphasis of current ACP programmes such as Living Matters has been to downplay the completion of legal documents, experience from Oregon suggests that an additional systemic measure will be needed to bridge the gap between the general documentation of patient goals and preferences and the implementation of an actual plan of care that embodies these goals and preferences.<sup>24</sup> An important threshold protocol used to achieve this is the Physician Order for Life Sustaining Treatment ('POLST') developed in Oregon.<sup>25</sup> It is a system that has gained considerable traction across the US, although the terminology for the concept varies.<sup>26</sup>

At the core of POLST is a brightly coloured, simple form that documents patient preferences regarding a wide range of life sustaining medical treatments like cardio-pulmonary resuscitation, artificial feeding and hydration, and even the use of antibiotics. This is derived from a discussion between the attending physician and the patient, or his authorised proxy. The order carries the authority of a medical order as it must be executed by a physician or other authorised healthcare professional, and ideally follows the patient throughout his journey through the healthcare system, whether in physical or electronic form. POLSTs are to be followed seemingly without question by emergency and other healthcare staff in a medical crisis, to ensure that the patient is not resuscitated, intubated or otherwise treated contrary to his prior expressed wishes. The POLST is *not* just an advance directive, but should reflect the patient's current goals based on her current medical condition.<sup>27</sup> Various studies have

<sup>&</sup>lt;sup>20</sup> See PH Ditto et al, "Imagining the End of Life: On the Psychology of Advance Medical Decision Making" (2005) 29(4) Motivation and Emotion 481, for the various psychological limits and biases involved in making prospective decisions about preferences in a future state of poor health.

 $<sup>^{21}</sup>$  A Fagerlin & CE Schneider, "Enough: The Failure of the Living Will" (2004) 34(2) Hastings Center Report 30 at 36-37

<sup>&</sup>lt;sup>22</sup> Ditto et al, n20 at 498 and the literature cited there.

NA Hawkins et al, "Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making" (2005) 45(1) Gerontologist 107; RD McMahan et al, "Advance Care Planning Beyond Advance Directives: Perspectives from Patients and Surrogates" (2013) 46(3) Journal of Pain and Symptom Management 355
 See Sabatino, n7 at 228-229; Chung, n14 at 332

<sup>&</sup>lt;sup>25</sup> See e.g. National Quality Forum, A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report (December 2006) at 43-44, online:

 $http://www.qualityforum.org/Publications/2006/12/A\_National\_Framework\_and\_Preferred\_Practices\_for\_Palliative\_and\_Hospice\_Care\_Quality.aspx$ 

<sup>&</sup>lt;sup>26</sup> See T Pope & M Hexum, "Legal Briefing: POLST: Physician Orders for Life Sustaining Treatment" (2012) 23(4) Journal of Clinical Ethics 353-376; The 'Respecting Choices' programme in fact strongly advocates the complementary POLST paradigm in out-of-hospital settings: Hickman et al, *supra* n16 at S28.

<sup>&</sup>lt;sup>27</sup> Sabatino, n7 at 228-229; National POLST Paradigm, POLST Paradigm Fundamentals, <a href="http://polst.org/about-the-national-polst-paradigm/what-is-polst/">http://polst.org/about-the-national-polst-paradigm/what-is-polst/</a>

demonstrated the efficacy of the POLST system in ensuring that healthcare administered adheres to the prescriptions in a POLST form.<sup>28</sup> According to Sabatino:

POLST represents a sea-change in advance care planning policy by standardizing providers' communications to prescribe a plan of care in a highly visible, portable way, rather than focussing solely on standardizing patient communications.<sup>29</sup>

Thus, although the current conception of ACP is process and communication oriented, it still does require a supportive legal framework to facilitate and guide implementation of ACP for EOL care.

#### B. *ACP implementation in Singapore*

The push towards embracing and implementing the concept of ACP in Singapore was in part driven by the inadequacies of the prior AMDA framework. Whereas the AMD was completed under the veil of confidentiality – to the extent that healthcare workers could not generally even ask if a patient had executed one<sup>30</sup> – the current ACP framework envisages open communication between healthcare professionals, patients and their families.<sup>31</sup> In one exploratory study involving family caregivers of patients, family was cited as the point of access to the patient for ACP, and a key to successful implementation,<sup>32</sup> while in another, lack of family support was a factor in patient reluctance to engage in ACP discussion.<sup>33</sup>

The AMD was designed as a legal transaction, with appropriate safeguards to ensure individual patient voluntariness. This stringency even extended to criminalising any undue influence on the person executing an AMD.<sup>34</sup> These concerns, however, potentially run counter to the relational needs of patients who often require emotional and decision-making support to address the difficult questions that serious illness and corresponding EOL care raise. Therefore, the National Medical Ethics Committee's current recommendations regarding ACP downplay the objective of executing an AMD or LPA, but instead promote the outcome of a statement of wishes either in written or oral form that covers the patient's desired comfort level, views, values, goals and preferences. This statement, even though *not* legally binding, would be useful in determining that patient's best interests under the MCA framework when she loses capacity to make her own decisions.<sup>35</sup> Correspondingly, the AIC's policy is to steer away

 $<sup>^{28}</sup>$  Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington DC: National Academies Press, 2015), c.3 at 176-178

<sup>&</sup>lt;sup>29</sup> Sabatino, n7 at 230

<sup>&</sup>lt;sup>30</sup> AMDA, n2, s. 15

<sup>&</sup>lt;sup>31</sup> National Medical Ethics Committee, *Guide for Healthcare Professionals on the Ethical Handling of Communications in Advance Care Planning* (Sep 2010) at paras. 15, 19 and Annex B; Lien Centre for Palliative Care, *Report on the National Strategy for Palliative Care* (4 Oct 2011) at para 12.4

<sup>&</sup>lt;sup>32</sup> R Ng et al, "An exploratory study of the knowledge, attitudes and perceptions of advance care planning in family caregivers of patients with advanced illness in Singapore" (2013) 3 BMJ Supportive & Palliative Care 343

 $<sup>^{33}</sup>$  K Cheong et al, "Advance care planning in people with early cognitive impairment" (2015) 5 BMJ Supportive & Palliative Care 63

<sup>34</sup> AMDA, n2, s.14

 $<sup>^{\</sup>rm 35}$  NMEC, Guide for Communications in ACP, n31 at paras 14-18, 25

from legal intervention through the prescription of legal directives, and to rely on "common law governance of good practice".  $^{36}$ 

Third, the AMDA implemented a standalone registry that was not integrated into the care systems and pathways in the Singapore healthcare system. Unless doctors or families were aware of the AMD registry, and were minded to initiate a search for an AMD under the prescribed circumstances,<sup>37</sup> the directive would not be referred to or invoked at all. This in part explains the very low implementation rates for AMDs in Singapore,<sup>38</sup> even as the rate of completion of AMDs has risen appreciably in the last decade.<sup>39</sup>

Responding to these shortcomings, the Living Matters programme sought to take on board the fundamental features of the Respecting Choices programme. This included standardised ACP instruments tailored for different stages of healthcare encounters. and protocols for implementation to ensure that these documented views and choices were available to direct EOL medical decision-making using a locally adapted POLST form.<sup>40</sup> Apart from the training and deployment of a growing number of accredited ACP facilitators, who have protected time and better skills to facilitate discussions on ACP, the documentary tools used in the Living Matters ACP programme have also been modified for the local context.<sup>41</sup> These broadly map to the three stages of planning in the Respecting Choices programme, based on a person's particular state of health.<sup>42</sup> The National ACP Steering Committee and AIC have also rolled out an ACP information technology system that captures key decisions on care options, and catalogues conversation transcripts and other supporting documents into a single record. Since April 2017, this system has been integrated with the National Electronic Health Record, thus enhancing accessibility and availability across different institutional care settings.43

Notwithstanding the importance of documentation and the usefulness of having these templates and accompanying structured discussion guides, the Living Matters programme emphasises a less formal, more open communication process facilitated by trained persons that results in *non-binding* statements of wishes. While these may look

 $^{39}$  J Tai, "More people making living wills as awareness arises", Straits Times (5 Apr 2015): there was a five-fold increase in AMD executions between 2005 and 2015, although this was still a very small percentage of the resident population.

<sup>&</sup>lt;sup>36</sup> Chung, n14 at 333: This presumably refers to the *Bolam-Bolitho* professional standard of care that regulates healthcare practices, that would allow for flexibility in recognizing evolving clinical standards of care in ACP: see *Hii Chii Kok v London Lucien Ooi* [2017] 2 SLR 492 at [81]-[83]

<sup>37</sup> AMDA, n2, s.9

<sup>38</sup> See n3

 $<sup>^{40}</sup>$  Teo et al, supra n11 at 432, describing the various features of the pilot CARE programme which preceded Living Matters.

<sup>&</sup>lt;sup>41</sup> A basic ACP Workbook is used at a very early stage where ACP discussions are offered to the general community to middle aged persons and older: see https://livingmatters.sg/uploadedFiles/LivingMatters\_B5\_Booklet\_FA\_V3\_270815.pdf. Disease Specific Advance Care Plans, for which there is a general template and three others tailored for heart, lung and kidney disease patients, and the second type of ACP document. These plans relate to chronic disease patients where death is not imminently anticipated and the discussion points are tailored to the issues such patients are likely to face along the typical disease trajectory – for a sample, see Appendix 1. The final type of template is a Preferred Care Plan, which is meant to be used for patients where death within a year would not be a surprise, and very frail elderly patients (for a sample, see Appendix 2): National University Hospital Singapore, Advance Care Planning, https://www.nuh.com.sg/patients-and-visitors/specialties/advance-care-planning.html

 $<sup>^{\</sup>rm 43}$  See Chung, n14 at 327-8; NMEC  $\it Guide$  on  $\it Communications$  in ACP, n31 at para 16

very much like an advance directive, they are not legally binding on the surrogate decision maker or carer under the MCA.<sup>44</sup> Nevertheless, the NMEC Sub-Committee recognised that formal advance directives and lasting powers of attorney for medical decisions were also potential products of the ACP process, where patients formed specific, firm views on future treatment and care options.<sup>45</sup>

In summary, the Living Matters programme seeks ostensibly to move from the shadow of the deficient AMDA regime. The hope is that at the least, Living Matters ACP will lead to more conversations and therefore better preparation for patients and their families when acute or terminal illness occurs, and offer more effective means to record and communicate these deliberations to healthcare professionals who advise and formulate care and treatment recommendations.

#### C. Guiding ethical principles for ACP

The ethical principles governing the ACP process and its implementation in Singapore are equally important for they influence how ACP is conducted and implemented. The National Medical Ethics Committee ('NMEC'), in a report that sought to clarify the ethical basis on which ACP discussions should occur between healthcare professional and patients, identified individual autonomy as the primary principle guiding ACP in Singapore. ACP seeks to allow the individual to achieve some sense of control over his future care by ensuring that his wishes are respected.<sup>46</sup> Individual autonomy, however, encompasses relational concerns, and is not purely atomistic. ACP discussions are meant to be open communications involving not just a physician or accredited facilitator, but also family members, carers and other loved ones.<sup>47</sup> Long before ACP emerged in its current form, the NMEC had recommended in its earlier report on the AMD that the profession should avoid taking a "purely legalistic approach in the implementation of an advance directive..." and make every effort to obtain the family's support – recognising the need for a relational approach to implementing advance medical directives notwithstanding the overtly individualistic form that the AMD takes under the AMDA.<sup>48</sup> In this way, the patient is supported through the provision of information on relevant medical issues, the involvement of family members and healthcare professionals, and offering some means – the statement of wishes, an AMD or LPA – to implement her preferences in order to confer a measure of control over her EOL care.49

Notwithstanding these formal positions, it is argued that there is a nascent ethical tension in the understanding of ACP. One informed commentator asserts that Singaporean culture is largely Confucian at heart, despite its multiracial population, and the general population holds similar views and beliefs about the role of the family in EOL care. The understanding of autonomy is "very different from that of Western civilisation at large", and "the need for understanding and consensus building within the

<sup>&</sup>lt;sup>44</sup> See Part III.A below

 $<sup>^{\</sup>rm 45}$  NMEC Guide on Communications in ACP, n31 at para 17

 $<sup>^{\</sup>rm 46}$  NMEC, supra n31 at para 21

<sup>&</sup>lt;sup>47</sup> NMEC, *ibid* at para 22.B

<sup>&</sup>lt;sup>48</sup> National Medical Ethics Committee, *Advance medical directives: a report by the National Medical Ethics Committee.* Singapore (NMEC, 1995) at 21 para 4

<sup>&</sup>lt;sup>49</sup> NMEC, supra n31 at paras 15-20

family is paramount."<sup>50</sup> Thus cultural factors and the ensuing non-involvement of the patient accounted for the non-completion of more that 50% of ACP cases initiated in one local study.<sup>51</sup> This highlights a very different community appreciation and approach to the importance placed on the process and outcomes of ACP, with decision-making authority reposed in the family as a sub-unit of the community rather than the individual.

A thick conception of family autonomy would argue that it is entirely permissible to override the patient's previously expressed wishes concerning care, and there is no priority placed on appointing an appropriate surrogate decision maker in advance. The family unit would collectively resolve this based on the evolving patient circumstances and relevant competencies of able family members to act as a spokesperson. This arguably more 'authoritarian' communitarian conception of ACP would also generally eschew any strict compliance with the terms of a formal advance directive, viewing it as the patient's relevant prior input in the family coming to a current considered judgment of what is best for the patient. Indeed, the ethical argument in such quarters is that formal advance directives are irrelevant.

This familial conception of ACP also implicitly acknowledges the cultural and legal realities of the provision of intermediate and long term care and healthcare financing in Singapore. Various studies have documented the priority of family centred decision making processes in Singapore healthcare.<sup>55</sup> The overarching state social welfare system also has a distinctly familial ideology.<sup>56</sup> In relation to healthcare financing, individual contributions to the compulsory health savings account, Medisave, may be, and are very often, used to fund healthcare for close family members.<sup>57</sup> Correspondingly, the state endowment-based Medifund support<sup>58</sup> for indigent healthcare is disbursed on the basis of *household* need; if an individual's family is means tested to be able to afford treatment, the patient is not eligible for Medifund.<sup>59</sup> Ultimately, children of elderly patients in Singapore have a legal responsibility to provide maintenance for their parents, including medical costs.<sup>60</sup>

<sup>51</sup> K Mok et al, "Familial Influence on Healthcare Decision Making in an Asian Society" (2015) 5(S2) BMJ Supportive & Palliative Care A65. There is some evidence, however, that the situation is evolving in response to more staggered disclosures of diagnosis to the patient and therefore greater receptivity to ACP: K Tay et al, "Cultural Influences upon advance care planning in a family centric society" (2017) 15 Palliative and Supportive Care 665 at 672

<sup>52</sup> RP Fan, "Self-determination vs. Family-determination: Two Incommensurable Principles of Autonomy" (1997) 11

 $<sup>^{50}</sup>$  Chung, n14 at 332  $\,$ 

<sup>&</sup>lt;sup>52</sup> RP Fan, "Self-determination vs. Family-determination: Two Incommensurable Principles of Autonomy" (1997) 11 Bioethics 309 at 318

 $<sup>^{53}</sup>$  RP Fan, "The Confucian bioethics of surrogate decision making: Its communitarian roots" (2011) 32 Theoretical Medicine & Bioethics 301 at 305-306

<sup>54</sup> Ibid; see also HM Chan, n71 below.

<sup>&</sup>lt;sup>55</sup> See e.g. J Tan & J Chin, *What Doctors Say About Care of the Dying* (Singapore: Lien Foundation, 2011) at 12, <a href="http://www.lienfoundation.org/sites/default/files/What Doctors Say About Care of the Dying 0.pdf">http://www.lienfoundation.org/sites/default/files/What Doctors Say About Care of the Dying 0.pdf</a>; J Tan et al, "Cultural and Ethical Issues in the Treatment of Eating Disorders in Singapore" (2013) 5(1) Asian Bioethics Review 40 at 43-45

<sup>&</sup>lt;sup>56</sup> See generally YY Teo, "Support for Deserving Families: Inventing the Anti-welfare Familialist State in Singapore" (2013) 20(3) Social Politics 387-406

<sup>&</sup>lt;sup>57</sup> CPF (Medisave Account Withdrawals) Regulations, RG 17, 2007 Rev Ed Sing; Tan & Chin, n55 at 21-23

<sup>&</sup>lt;sup>58</sup> Established under the *Medical and Elderly Care Endowment Schemes Act* (Cap. 173A, 2001 Rev. Ed. Sing.), Part II <sup>59</sup> J Lim, "Sustainable Health Care Financing: The Singapore Experience" (2017) 8(S2) Global Policy 103 at 105; Tan & Chin, n55 at 24-25

<sup>60</sup> Maintenance of Parents Act, Cap 167B Rev Ed 1996, s.5(2)

Consequently, Living Matters' programmatic move away from completing formal instruments towards more open-ended, iterative communications between healthcare professionals, patients and families may give rise to greater medical decision-making uncertainty in the face of potentially conflicting values at play – in particular, whether individual or family autonomy holds sway in resolving differences of opinion on the best interests of the incapacitated patient. A much better ethical approach that candidly acknowledges the inherent tensions between the autonomy based and familial based perspectives of ACP is a responsive communitarianism. It offers a framework that promotes the policy of iterative communication and non-legal resolution of decision making conflicts. According to Etzioni, responsive communitarianism:

... seeks to balance autonomy with concern for the common good, without a priori privileging either of these two core values. And it seeks to rely on society (informal social controls, persuasion and education) to the greatest extent possible and minimise the role of the state (law enforcement) in promoting compliance with the norms that flow from these values.<sup>61</sup>

In a healthcare system that legally and professionally values respect for individual patient autonomy, yet concurrently places primary responsibility for the provision of care and healthcare financing on the family unit, ACP can be seen as an intervention that seeks to strike a fair balance between these competing ethical approaches. As Jox observes:

The dialogue – or, rather, trialogue – between the patient, his loved ones, and professionals forms the core community that drives the success of ACP. If this trialogue works well, medical-treatment decisions can reliably, responsibly, and consensually be made within this subsidiary core community without the need for court proceedings or other involvement of higher state institutions. ... In fostering an awareness of life's finitude, a reflective deliberation of life plans, and a critical stance towards medicine within communities and the society as a whole. ACP serves relevant interests of democratic societies. 62

What proceeds below evaluates the Living Matters programme and its supporting legal and ethical framework through the lens of responsive communitarianism, emphasising the trialogue necessary to promote both individual and family or public goods. Three specific issues that arise are considered in turn: first, is the legal best interests decision making framework truly supportive of values of ACP, if a family-based model of medical decision making is the usual norm? Secondly, does the legal framework adequately support patients with strong individual preferences or who lack adequate familial support in EOL care? Finally, assuming that ACP successfully prepares patients and their families for future medical decision making challenges, are there appropriate legal or regulatory mechanisms to ensure that resulting care plans are properly implemented across institutional boundaries in the Singapore healthcare system?

#### III. DIFFICULTIES WITH THE ACP LEGAL FRAMEWORK

<sup>&</sup>lt;sup>61</sup> A Etzioni, "Authoritarian verses responsive communitarian bioethics" (2011) 37 Journal of Medical Ethics 17-23 at 17 [emphasis added]

<sup>&</sup>lt;sup>62</sup> RJ Jox, "Preparing existential decisions in later life: Advance healthcare planning", in M Schweda et al, *Planning Later Life: Bioethics and Public Health in Ageing Societies* (Routledge, 2017), c.11 at 174.

#### A. Ambiguity in the end-of-life decision-making model

Where ACP has occurred to some meaningful extent, its less formal, non-binding outputs do plug into the 'best interests' surrogate decision-making framework under the MCA. At this stage, the trialogue becomes a dialogue once the patient loses decision making capacity. Section 6 of the MCA the requires that a proxy decision maker relying on a reasonable belief defence under section 7 ('general defence') take into consideration the patient's "past and present wishes and feelings (and in particular, any relevant written statement made by him when he had capacity)."63 In addition, the Living Matters ACP standard template care plans all record the appointment of primary and secondary healthcare spokespersons for the patient.<sup>64</sup> There is some legal recognition of such an 'appointment' in section 6(8) of the MCA, which states that a person determining the best interests of another must take into account the views of "anyone named by the person as someone to be consulted on the matter in question or matters of that kind... as to what would be in that person's best interests, or their relevant wishes, feelings, beliefs and values." The requirement is, however, only to consult. Such spokespersons do not have any decision-making authority or corresponding protection for their decisions under the MCA.

The MCA thus recognises the typical outcomes of the ACP process without the need for explicit recognition of the Living Matters care plans or the notion of an appointed healthcare spokesperson. To the extent that the programme enhances the accessibility of such care plans through the ACP IT system,<sup>65</sup> it provides a foundation for the goals of Living Matters by improving the quality of patient preference information available to healthcare providers and proxy decision makers in EOL care.

However, the persisting criticism of the best interests standard under the UK MCA 2005 and the Singapore MCA 2008 is that it does not actually elaborate on how the proxy decision maker(s) is to use or weigh the different factors in coming to a decision that reflects the patient's best interests. In particular, it is not clear what weight or influence the contents of care plans possess in relation to the views of family members. The evidence from the UK on implementation of the UK MCA 2005 demonstrates that there is common misunderstanding about what the statutory test requires, with many clinical teams and healthcare institutions mistakenly assuming it represents a clinical standard, or medical notion, of best interests, and input from the patient or her family members is often absent or untrusted.<sup>66</sup>

In Singapore, different concerns have been raised. While healthcare professionals often consult family members, they too readily give in to family wishes even if these run contrary to the patient's previously expressed wishes (whether through ACP or not).<sup>67</sup>

<sup>63</sup> MCA, n4, s.6(7)(a) [emphasis added]

<sup>64</sup> See Appendix 1 and 2 at p28 and 30 respectively

<sup>65</sup> See Chung, supra n14 at 327-328

<sup>&</sup>lt;sup>66</sup> House of Lords Select Committee Report on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-Legislative Scrutiny. Report of Session 2013-2014*, HL paper 139 (London: The Stationary Office, 2014) at paras 90-94; HJ Taylor, "What are 'Best Interests'? A Critical Evaluation of 'Best Interests' Decision-Making in Clinical Practice" (2016) 24(2) Med LR 176 at 193-195.

<sup>&</sup>lt;sup>67</sup> L Krishna et al, "Advancing a Welfare-Based Model in Medical Decision" (2015) 7(3) Asian Bioethics Review 306 at 312; Correspondingly, a recent study reveals that there is a misunderstanding amongst some family caregivers and patients that family members have the right to make decisions for patients even though this is strictly not the legal

In one study of oncology doctors and nurses, while a majority of respondents (55.4%) thought that the patient's views should prevail in relation to the making of a Do-Not-Resuscitate ('DNR') order, another 23.3% thought that it depended on the situation, and 18.5% felt that the family ought to be given precedence.<sup>68</sup> Other empirical studies reveal that in practice, patients are seldom actually consulted on matters such as a DNR,<sup>69</sup> while in another study, 59.9% of doctors were prepared to override the previously expressed wishes of the patient in favour of the family's.<sup>70</sup> Although professional motivations underlying such a stance are unclear, the dependence on family in social or cultural traditions for decision making, care provision and health finance, health professionals' discomfort with engaging family members in EOL discussions, avoidance of confrontation and fear of litigation are possible explanations. What is clear is the real potential for the patient to lose any influence over the course of future care once she loses capacity.

A more benign interpretation of this state of affairs is that the Living Matters programme would operate within a family model of decision making, where the 'voice' of the previously competent patient is better heard when articulated by appointed family representatives. This facilitates the ongoing family, rather than individual, dialogue with healthcare professionals on the patient's EOL care. In the words of HM Chan, this renders the patient's preferences and values encapsulated in ACP *merely a factor* to be weighed in reaching what is ultimately a communal, family decision on EOL care:

The [advance] directive is a means of helping them to know my voice and of facilitating the ongoing dialogue with them when I lapse into incompetency. My family members would then try to talk to me as if I were competent, but the whole point of the dialogue is not so much to figure out what I would have wanted for myself (my counterfactual choice) but to arrive at a family decision with my counterfactual participation. The prior directive only encodes my initial voice, and my voice, along with those belonging to my significant others, is likely to be transformed as the dialogue goes along. So, the final decision need not be dictated entirely by the literal meaning of my advance directive, however clear and specific it is, though it is nevertheless an important reference for my family in the decision making process. ... So in the familial model of decision making, it is not necessary to institutionalise the 'individualistic' expression of prior wishes strictly by laws and regulations <sup>71</sup>

position: S Menon et al, "Advance care planning in a multi-cultural family centric community: A qualitative study of healthcare professionals, patients' and caregivers' perspectives" (2018) 56(2) J Pain Symptom Management 213.  $^{68}$  GM Yang et al, "Should Patients and Family be Involved in "Do Not Resuscitate Decisions?" Views of Oncology and Palliative Care Doctors and Nurses" (2012) 18(1) Indian Journal of Palliative Care 52 at 54-55. A subsequent study of the same group of physician's patients indicated that less than 10% of those patients were consulted on their DNR orders: JA Ching et al, "Patient and Family Involvement in Decision Making for Management of Cancer Patients at a

Centre in Singapore" (2015) 5 BMJ Support Palliat Care 420.

69 J Phua et al, "End-of-Life Care in the General Wards of a Singaporean Hospital: An Asian Perspective" (2011) 14(2) Journal of Palliative Medicine 1296

 $<sup>^{70}</sup>$  WT Foo et al, "Factors Considered in End-of-Life Care Decision-Making by Healthcare Professionals" (2013) 30 Am J Hosp Palliat Care 354-358

<sup>&</sup>lt;sup>71</sup> HM Chan, "Sharing Death and Dying: Advance Directives, Autonomy and the Family" (2004) 18(2) Bioethics 87 at 96-97 [emphasis added]. A similar practice is observed in Taiwan, notwithstanding legislation that prioritises patient autonomy and nominates specific legal proxies: SC Lee, "Family Consent in Medical Decision-Making in Taiwan: The Implications of the New Revisions of the Hospice Palliative Care Act", in R Fan ed, *Family-Oriented Informed Consent* (Springer International Publishing, 2015) c.8 at 127-129.

In contrast, there is scepticism in professional quarters whether families should be given *de facto* decision-making authority to begin with. These commentators question the value of family inputs where the underlying relationships are bare, priority of interests may be skewed in favour of other extraneous interests, and the potential for coercion or abuse is real. A common observation in the literature is the local familial concern with the discharge of filial obligations in order to preserve honour and dignity as judged by the extended family and community, which often result in a preference for futile or burdensome treatments to avert suggestions of abandonment or neglect.<sup>72</sup> In addition, family-centric decision making ignores distinct individual aspects of personhood that cannot be fully captured by notions of relational or family interests in a family based decision making process, and are liable to be ignored or neglected if family based authority always holds sway.<sup>73</sup>

These professional concerns have prompted a call for an objective, welfare-based interdisciplinary clinical assessment of a patient's best interests. Originating in the palliative care setting, the interdisciplinary membership of the clinical team allows for more holistic assessment of the patient's interests beyond the clinical, with the aim of setting "clear limits to care determinations to ensure that basic care and best interests of the patient are not compromised."74 Under this 'welfare' model of decision making, the multidisciplinary team drawn from different healthcare disciplines is guided by prevailing "professional, clinical and legal guidelines" in order to "ensure a holistic and balanced picture of the patient and their (sic) needs".75 It would seem that local advocates of this 'welfare' model are prepared to override the previously expressed wishes of the patient, <sup>76</sup> and even her apparently autonomous preferences if the 'holistic' evaluation of a patient's best interests warrant it.<sup>77</sup> However, what comes out most clearly under this model is the lead role that the attending healthcare team takes in making decisions. It is they who undertake the inquiry, with inputs from the patient (where competent) or her ACP documentation, her family and other close relations, before coming to a decision on what represents her overall best interests. This stance on who wields decision making authority is also echoed by the Singapore Medical Council in its *Handbook of Medical Ethics*.<sup>78</sup>

It has previously been argued that the statutory best interests test under the MCA 2008 involves a balancing approach that seeks to maximally promote the welfare of the

<sup>72</sup> Tan & Chin, n55 at 22-23; Krishna et al, n67 at 313-314; K Tay et al, "Studying Cost as a factor in the Choice between Quality and Quantity of Life amongst Patients with Cancer and their Caregivers at a Cancer Centre in Singapore" (2016) 6(4) Journal of Palliative Care & Medicine 1000276 at 5

<sup>73</sup> J Blustein, "The family in medical decision making" (1993) 23(3) Hastings Center Report 6 at 10-11; L Krishna et al, n6767 at 311; SW Sim & L Krishna, "Respecting the Wishes of Incapacitated Patients at the End of Life" (2016) 31(1) Ethics & Medicine 15 at 21

<sup>&</sup>lt;sup>74</sup> L Krishna, D Watkinson & LB Ng, "Limits to relational autonomy – The Singaporean experience" (2015) 22(3) Nursing Ethics 331 at 337

<sup>&</sup>lt;sup>75</sup> B Chan, J Chin & L Krishna, "The welfare model: a paradigm shift in medical decision-making" (2015) 1(9) Clinical Case Reports and Reviews 185 at 186

<sup>&</sup>lt;sup>76</sup> Krishna et al, n74; JA Sy, M Tan & L Krishna, "A review of decision-making models in end-of-life care in Singapore" (2015) 1(8) Clinical Case Reports and Reviews 169 at 171

<sup>77</sup> B Chan et al, n75 at 187

<sup>&</sup>lt;sup>78</sup> SMC, Handbook of Medical Ethics (2016 Edition) at 30: "You should support patients by: Making decisions based on a consideration of overall benefits, risks and burdens for the patients which may not be limited to purely clinical considerations, and avoiding biases based on your own beliefs and sense of values";

http://www.healthprofessionals.gov.sg/docs/librariesprovider2/guidelines/2016-smc-handbook-on-medicalethics---(13sep16).pdf

incapacitated person.<sup>79</sup> The twist is that it incorporates considerations associated with the substituted judgment standard<sup>80</sup> as relevant in determining best interests – her past wishes, values and beliefs that would be likely to influence her decision if she had capacity, and any other factors she would likely consider if she were able to.<sup>81</sup> The value of authenticity, rather than autonomy, better captures these considerations. It directs the surrogate decision maker to respect the patient by deciding rationally in accordance with her values and beliefs, rather than a pretence based upon the idea of a counterfactual choice by the patient.<sup>82</sup> In the absence of clear indications as to what these preferences, values and beliefs are, the approach devolves into an objective welfare appraisal.

This approach resonates with recent observations made by the UK Supreme Court in *Aintree University Hospitals NHS Foundation Trust v. James.*<sup>83</sup> Baroness Hale makes clear that under the UK MCA 2005,<sup>84</sup> the best interests involves "looking at welfare in the widest sense, not just the medical but the social and psychological".<sup>85</sup> In doing so, these interests are to be determined from the perspective of the particular patient, and not objectively as a reasonable person would decide:

The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. ... insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.<sup>86</sup>

Baroness Hale's observations are also consistent with the contingency of an assessment of what is authentic to a person's preferences, values and personal system of beliefs.<sup>87</sup> Circumstances may demonstrate that the patient's prior preferences, such as a desire to die at home, cannot be reasonably realized with the resources available.

We are dealing with a hybrid standard of proxy decision making that does not give presumptive normative weight to either individual autonomy nor beneficence objectively conceived.<sup>88</sup> It is an inquiry meant to promote decisions that are as respectful and consistent with the patient's personhood and values as far as the circumstances and resources permit. An illustration of how this plays out is seen in the

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<sup>&</sup>lt;sup>79</sup> TE Chan, "The elderly patient and the Healthcare Decision Making Framework in Singapore", in WC Chan ed, Singapore's Ageing Population: Managing Health Care and End of Life Decisions (Routledge, 2011), c.8 at 123-125

<sup>80</sup> See A Buchannan and D Brock, "Deciding for Others" (1986) 64(2) Millbank Quarterly 17 at 56

<sup>81</sup> MCA, n4, s.6(7)

<sup>&</sup>lt;sup>82</sup> See D Brudney, "Choosing for Another: Beyond Autonomy and Best Interests" (2009) 39(2) Hastings Center Report 31

<sup>83 [2013]</sup> UKSC 67; [2014] 1 AC 591

<sup>&</sup>lt;sup>84</sup> This is in *pari materia* with the definition of best interests under the Singapore MCA, n4

<sup>85</sup> Aintree, n83 at para 39

<sup>86</sup> Aintree, n83 at para 45 [emphasis added]

<sup>87</sup> Brudney, n82 at 35-36

<sup>88</sup> Chan, n79 at 124

post-Aintree Court of Protection decision in Re Briggs (Incapacitated Person) (Medical Treatment: Best Interests Decision) (No 2).89 There, the court had to weigh the strong presumption in administering treatment to preserve life, against the great weight to be placed on whether the patient would have considered that life as being worthwhile in accordance with his values and beliefs.90 It is also significant that the judge eventually decided on the latter based on the consistent evidence of his family that he would not have agreed to such treatment in accordance with his individual beliefs and values.91

ACP in Singapore should therefore seek to enrich the medical decision-making process by enhancing the availability of evidence concerning the patient's values and preferences – particularly on the process by which future decisions should be made. This will better enable healthcare professional to specify the goals of care for the patient, and make treatment plans and recommendations accordingly. Indeed, some commentators argue that enhancing 'authenticity', rather than 'accuracy' with respect to autonomy, should be the proper goal of ACP. <sup>92</sup>

#### B. Shared decision making at the EOL

What remains to be worked out is the process of decision making and how the relevant parties should understand their roles and authority under the auspices of the statutory best interests standard. It might seem that the 'welfare' approach outlined above better fits with the legislative and judicial positions. However, it is submitted that this 'welfare' approach fails to give appropriate weight to the views and contributions of designated family members who are appointed to be the spokespersons for the patient under ACP. Empirical work has revealed that most patients are not minded to micro-manage their future care through decisions to request or refuse specific treatments and mandate that these advance decisions be followed. They instead prefer to make general personal statements concerning their values and goals of care, and to discuss how their surrogates should go about the task of deciding on their behalf.<sup>93</sup> However, there is some variability in patient preferences on the amount of discretion or flexibility the surrogate should have in interpreting the patient's best interests, and it is important to them to explain the reasons for doing so.<sup>94</sup> The insights on the psychological challenges of making advance treatment decisions in different states of existence mentioned above reinforce these findings.95

Therefore, in situations where ACP is successfully engaged and appropriate discussions and planning occurs, the effect would also be to prepare designated family and other

<sup>89 [2016]</sup> EWCOP 53; [2017] 4 WLR 37

<sup>90</sup> *Briggs*, ibid at para 128

<sup>91</sup> Briggs, n89 at paras 96-112

<sup>&</sup>lt;sup>92</sup> Y Schenker et al, "What Should Be the Goal of Advance Care Planning?" (2014) 174(7) JAMA Int Med 1093 at 1094 <sup>93</sup> Hawkins et al, n23 at 113-114; In a Hong Kong study, only a small minority of patients, family members and physicians thought that a patient's prior wishes expressed in an advance directive should be followed strictly. Rather, patient wishes in advance directives should be taken seriously: HM Chan et al, "End-of-Life Decision Making in Hong Kong: The Appeal of the Shared Decision Making Model" in RP Fan ed, *Family-Oriented Informed Consent* (Cham, Springer, 2015), c.10 at 159-161

<sup>94</sup> McMahan et al, n23 at 363

<sup>95</sup> See n20 and accompanying text

close intimates for in the moment decision making after the patient loses capacity. 96 This increases the value of their insights to the best interests determination, as compared to family members that have not been involved. Furthermore, meaningful ACP discussions would increase levels of trust between patient, chosen surrogates and healthcare professionals. This offers another reason why the judgment of such patient surrogates on a patient's best interests should be accorded greater moral weight – because they have been advisedly chosen by the patient to speak on their behalf. Nevertheless, potential conflict with other family members is not automatically avoided as the designated surrogate decision makers will still have to make decisions in the family context, where there may be a diversity of views about what represents the patients interests. 97

The difficulty under the MCA framework is that it effectively places the onus on healthcare professionals who perform acts of care and treatment to take responsibility for these decisions. 98 The SMC *Ethical Code and Ethical Guidelines* do not sufficiently recognise the role that family members who are appointed ACP surrogates play, and relegate them to the status of information providers.<sup>99</sup> Patient-centred ethical narratives accompanying the ACP process are complicated by the potential tensions between the interests of the patient and those of his family members. While the MCA may emphasise that decision making be patient focussed, the law also recognises the rights of family members based on their financial and other contributions to the care of the patient. The ethics of ACP also clearly recognise the need to involve family and close intimates in the formulation of care plans, but do not address how conflicting interests and interpretations of the patient's values and preferences are to be resolved, especially in their implementation.<sup>100</sup> Finally, close family members commonly do expect to have moral authority to make decisions for their loved ones, and may not accept that legal authority ultimately rests with the healthcare professional. 101 This is another source of interpersonal tension that may arise in the implementation of ACP.

A better approach that gives more even-handed weight to the contributions that family and healthcare professionals make in EOL decision making is shared decision making. This recognises that families can provide unique insights into a patient's values and beliefs, and how these might be realised in the overall care provided. Healthcare professionals of course come to the table with the wealth of medical knowledge and experience in dealing with the complexities of such care that the family would usually lack. In this respect, the Hong Kong Hospital Authority's *Guidelines on Life-sustaining Treatment in the Terminally Ill* ('HKHA Guidelines') provide a good starting conception of the process of shared decision making and negotiation between healthcare professionals and family:

<sup>&</sup>lt;sup>96</sup> See R Sudore & TR Fried, "Redefining 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making (2010) 153(4) Annals of Internal Medicine 256 at 259

<sup>97</sup> McMahan et al, n23 at 362

<sup>98</sup> MCA, n4, s.7

 $<sup>^{99}</sup>$  (2016 Edition) at 20, part A7, http://www.healthprofessionals.gov.sg/docs/librariesprovider2/guidelines/2016-smc-ethical-code-and-ethical-guidelines---(13sep16).pdf; SMC Handbook of Medical Ethics, n78

<sup>100</sup> NMEC, Guide on Communications in ACP, n31

<sup>&</sup>lt;sup>101</sup> See House of Lords Select Committee Report, n66 at para 95; Menon et al, n67

<sup>&</sup>lt;sup>102</sup> See e.g., LA Siminoff & MD Thomson, "Decision Making in the Family", in MA Diefenbach et al eds, *Handbook of Health Decision Science* (Springer Science+Business Media, 2016) 171 at 173

The decision-making process for balancing the burdens and benefits towards the patient should be a consensus-building process between the health care team and the patient and family... The health care team communicates to the patient and the family the realistic assessment of the patient's prognosis, i.e. the reversibility of the acute illness, the severity of underlying disease, and the expected quality of life... During such deliberations, the health care team also explores the values and wishes of the patient and the views of the family acting in the best interests of the patient. This fair process of deliberation and resolution, sometimes necessitating time-limited treatment trials, forms the basis for determining, and subsequently withholding or withdrawing futile care...<sup>103</sup>

As Tse and Tao observe, the emphasis is on an iterative, consensus building process to work out what the patient's best interests are. In the context of a patient who has undertaken ACP, there would be a clearer articulation of her values and goals of care, and this would constitute a firmer basis for negotiations between physicians and family over disagreements concerning the interpretation of those wishes in relation to the patient's current needs. The explicit contingency of a care plan also recognises that there cognitive and affective limits to what a patient can anticipate and desire in relation to future medical conditions, in proportion to, for e.g., how distant in time they are. The closer in time and experience a prevailing care plan is, the greater its moral authority in speaking to what the person's values and preferences are in relation to the current medical situation, and how much weight should be accorded to respecting the preferences embodied in a care plan or as articulated by the designated surrogates. Furthermore, patient requests for full treatment under a care plan would also call for further evaluation, negotiation and judgment in the face of changing medical conditions and prognosis.

Professional ethical guidelines also need to address how healthcare professionals should approach a situation where consensus is not possible. Family involvement entails greater complexity as healthcare teams must work out what the reasons are for the disagreement and determine if the motivations are legitimately oriented towards the interests of the patient or reveal other extraneous interests at work. In this respect, the HKHA Guidelines also place final decision-making authority with physicians:

The final decision 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*. <sup>106</sup>

The proviso first requires a high degree of certainty that the family's decision is indeed contrary to the patient's best interests. This deference reflects the arguments mentioned above for including family in decision making. Understanding autonomy relationally entails recognising that ACP involves individuals engaging with persons of

<sup>104</sup> Ditto et al, n20 at 495-496

 $<sup>^{103}</sup>$  Hong Kong Hospital Authority, *Guidelines on Life-sustaining Treatment in the Terminally Ill* (Version 2, 1 Dec 2015) at para. 4.3.3 [emphasis added; citations omitted]. See also paras 5.4.2 and 5.4.3

<sup>&</sup>lt;sup>105</sup> This is subject to the caveat that some individuals might want ACP statements to act as pre-commitments against unwanted influences that might affect future decisions: Ditto et al, n20 at 496-497; see Spranzi & Fournier, n127 below and accompanying text.

<sup>&</sup>lt;sup>106</sup> HKHA Guidelines, n103 at para. 5.4.1

relational significance in formulating their values and preferences in end of life care. In a vulnerable state of health, the patient will correspondingly be more dependent on significant relational others, and personal carers in particular, to realise these preferences. This subjects patients to the reality that their individual interests may be subject to compromise or negotiation in the process of ACP and the eventual implementation of EOL care. 107

Secondly, it recognizes that family surrogates may be subject to cognitive, emotional, cultural and financial constraints in impartially seeking the patient's best interests. The individual patient should not be sacrificed at the altar of familial or relational harmony and compromise. There should be limits or boundaries to when a patient's interests may be compromised or sacrificed to promote some other relational or familial interest. The HKHA Guidelines' proviso to consensus building therefore recognises the possibility of relational abuse, even if inadvertent. In a *de facto* shared model of decision-making under the MCA, the duty would fall on the healthcare professional to police this.

How should we determine when a family's views or requests are clearly contrary to the best interests of the patient? First, on the assumption of legitimacy of a relational approach to ACP and end of life care, the determination of abuse can be made on the basis of a breach of relational norms applicable to the situation. In the context of undue influence in contract, it has been argued that these norms are determined by social consensus, while giving a large margin of tolerance to various valid conceptions of the good. 108 Second, a process of deliberation in EOL care can be argued to step outside the bounds of relational norms when it neglects or fails to protect the patient's core or essential interests and instead, solely pursues other relational or familial interests such as the financial and emotional well-being of the family. 109 Third, we might begin to determine what a patient's core interests are by drawing a distinction between a patient's interests in basic aspects of health, well-being, functioning and the avoidance of pain and suffering, and her preferences in how these interests are to be maintained or supported. 110 If the family's deliberations on medical advice fail to protect the patient's core interests, sacrifice them without compensating gain in service of another core interest, or consistently ignore a patient's prior expressed wishes without good reason, it is submitted that this would cross the line into abuse.

In this respect, while the model shares decision-making authority based on the distinct expertise that family and healthcare professionals bring to the dialogue, it is still patient-centric in that it seek to ensure the protection of the patient's core interests. The approach is also responsively communitarian in that it works on the assumption that a patient's core interests are not entirely self-regarding, but include concern for the overall well-being of family members in various dimensions such as the psychological, emotional, financial and spiritual, and that there is a corresponding trust in their

<sup>&</sup>lt;sup>107</sup> In the words of Baroness Hale in *Aintree*, n86, "We cannot always have what we want."

<sup>&</sup>lt;sup>108</sup> M Chen-Wishart, "Undue Influence: Vindicating Relationships of Influence" (2006) 59(1) Current Legal Problems 231 at 247-249

<sup>&</sup>lt;sup>109</sup> I Hyun, "Conceptions of Family-Centred Medical Decisionmaking and Their Difficulties" (2003) 12 Cambridge Quarterly of Healthcare Ethics" 196 at 198-199, who describes these as overlapping interests within the family unit. <sup>110</sup> Adapted from C Levine & C Zuckerman, "Hands On/Hands Off: Why Health Care Professionals Depend on Families but Keep Them at Arm's Length (2000) 28 Journal of Law, Medicine & Ethics 5 at 14-15. See also factors considered in the HK Hospital Authority's Guidelines, n103 at para 5.4.2

judgment on such matters.<sup>111</sup> The objective of the ACP trialogue, which eventually devolves into a dialogue between family and healthcare professionals once the patient loses decision making capacity, involves a balancing between these interests when they are in tension or conflict by considering the relative adverse impact of a proposed course of action on the patient's core interests and her relational interests in the family's overall well-being. 112

To illustrate the dynamics of such a shared model, where a family insists on a curative goal notwithstanding the deteriorating condition of a cancer patient with increasing distress, health professionals in a Singapore cancer centre worked towards a compromise where it was possible to offer opioid pain relief while allowing the continued administration of a clinically unproven therapy. Although the dosage may not have completely relieved his distress, the family's wish to persist in seeking a cure was accommodated in the absence of the clear expression of the patient's goals of treatment.<sup>113</sup> Presumably, if the patient had indicated a preference for comfort care, this might have tilted the balance against any attempt at unproven therapy. In contrast, where the eldest son of another cancer patient insisted on discharge to access traditional Chinese medicinal therapy, this was refused as the TCM procedure posed a real risk of harm given the patient's condition. There was also no indication that this was in accordance with the patient's wishes, and was in fact opposed by the rest of the family.114

In summary, the statutory best interests standard needs to be supplemented with a shared decision making process that seeks to achieve consensus on EOL care with ACP appointed surrogate decision makers and other family intimates. This model is however circumscribed by the need to protect the core interests of the patient, responsibility for which falls principally on healthcare professionals. The latter need to steer carefully between the potentially conflicting values of patient welfare, patient autonomy and the reality of familial involvement, connectedness and possible over-reach. Such a shared decision making model should be explicitly incorporated into the relevant professional and EOL ethical guidelines, as is the case in Hong Kong, in order to encourage greater consistency in implementation.

#### C. Respecting patients with strong preferences, or without adequate family support

A changing demographic and social circumstances invert the issue just discussed. It was assumed that family members are easily identifiable, willing and available to provide support and inputs under a shared decision making model. A growing category of patients are better educated and have firmer preferences for EOL care, 115 who may correspondingly have weakening family and social bonds that may result in a lack of meaningful social support. 116 The proportion of single adults and married persons

<sup>111</sup> Blustein, n73 at 8-9; Etzioni, n61 at 20

<sup>&</sup>lt;sup>112</sup> Etzioni, n61 at 22

<sup>113</sup> M Ho et al, "Chinese Familal Tradition and Western Influence: A Case Study in Singapore on Decision Making at the End of Life" (2010) 40(6) Journal of Pain and Symptom Management 932

 $<sup>^{114}</sup>$  TZ Oo et al, "The role of the multidisciplinary team in decision making at the end of life" (2015) Advances in Medical Ethics 2:2; doi:10.12715/ame.2015.2.2 at 3-4

<sup>115</sup> See M Ho et al, "The physician-patient relationship in treatment decision making at the end of life: A pilot study of cancer patients in a Southeast Asian society" (2013) 11 Palliative & Supportive Care 13

 $<sup>^{116}</sup>$  This was a distinct sub-theme in a recent study on patient perspectives of ACP in Singapore: Cheong et al, n33 at 66

without children are steadily increasing. <sup>117</sup> The question is whether the Living Matters ACP process adequately addresses their needs in desiring to frame and control the decision making process after they have lost capacity. The loss of capacity itself imposes a dependency on such individuals, but should they have to be content with accepting the default model involving deliberations between health care professionals and distant family members, or amongst the healthcare team members alone? <sup>118</sup>

In addition, if individual autonomy is indeed the primary guiding principle in ACP, then the MCA framework gives little comfort to individuals who have specific and strong views on their medical treatment at the end of life. No matter how involved and detailed their advance care plans, they are not legally binding on healthcare providers within this framework. Unfortunately, such individuals have very few formal options apart from the AMDA or advance directive at common law in retaining greater control over their EOL care. The former is highly restrictive in scope and implementation, while the latter lacks the legal certainty of recognition, legal protection for healthcare professionals, and accessibility as there is no registry service apart from standard AMDs under the AMDA.

Even assuming the availability of a more general, wide ranging advance directive, the cognitive and affective limits of individuals to make anticipatory decisions on healthcare, particularly fraught ones at the end of life, are well demonstrated. Many patients also doubt whether they would remain the same person under changed medical circumstances, and therefore doubt the wisdom of tying their different selves to an advance directive. Recognising this uncertainty as to future medical scenarios and continuity of self, many patients prefer to leave decision making to future dialogues between their carers and doctors when the moment for decision arises. In addition, US studies reveal that advance directives often do not affect the quality of EOL care or improve clinician and surrogate knowledge of patient preferences. 125

<sup>117</sup> National Talent and Population Division, Prime Minister's Office, "Population in Brief 2015" (September 2015), <a href="https://www.strategygroup.gov.sg/docs/default-source/Population/population-in-brief-2015.pdf?sfvrsn=0">https://www.strategygroup.gov.sg/docs/default-source/Population/population-in-brief-2015.pdf?sfvrsn=0</a>: The proportion of single males/females in the 45-49 age group stood at 14% (up 0.6% from 2004) and 15.2% (up 2.2% from 2004) for men and women respectively in 2014; the proportion of ever married resident females who are childless between 40-49 years rose from 7.1 to 11.2% between 2004 and 2014. The MCA was recently amended to allow for professional donees of a LPA to address the needs of a growing population of singles and elderly persons living alone: CJ Tan, Opening Speech at the Second Reading of the Mental Capacity (Amendment) Bill 2016 (14 March 2016), <a href="https://www.msf.gov.sg/media-room/Pages/Opening-Speech-by-Mr-Tan-Chuan-Jin-at-the-Second-Reading-of-the-Mental-Capacity-(Amendment)-Bill-2016-in-Parliament-14-Mar.aspx.">https://www.msf.gov.sg/media-room/Pages/Opening-Speech-by-Mr-Tan-Chuan-Jin-at-the-Second-Reading-of-the-Mental-Capacity-(Amendment)-Bill-2016-in-Parliament-14-Mar.aspx.

 $<sup>^{118}\,\</sup>mbox{For}$  an example of the latter process, see Tan & Chin, n55 at 40-41

<sup>&</sup>lt;sup>119</sup> See supra n63 and accompanying paragraph.

 $<sup>^{120}</sup>$  The AMD only applies to 'extra-ordinary life sustaining treatment', and this explicitly excludes palliative care, nutrition and hydration. It also only applies to terminal illness, which is clinically difficult to predict, and would also by definition not apply to patients in a persistent vegetative state: supra n2, s.3 read with s.2 and s.9

<sup>&</sup>lt;sup>121</sup> Healthcare professionals and institutions may not ask a patient if she has executed an AMD, and can only make a search of the AMD registry if the patient is certified terminally ill by the attending physician: AMDA, n2, ss 15 and 9 respectively.

<sup>&</sup>lt;sup>122</sup> At common law, the onus of proof is on the clinician relying on it, and where the withholding or withdrawal of life sustaining treatment is involved, clear and convincing proof is required of the patient's prior wish: *HE v A Hospital NHS Trust* [2003] 2 FLR 408 (High Court).

<sup>123</sup> AMDA, n2, s.6

<sup>&</sup>lt;sup>124</sup> M Spranzi & V Fournier, "The near-failure of advance directives: why they should not be abandoned altogether, but their role radically reconsidered" (2016) 19(4) Med Health Care and Philos 563 <sup>125</sup> Sudore & Fried, n96 at fn 9-13.

This raises the question whether it might be necessary at all to revise the existing AMDA framework, if informal ACPs will just as well serve these features of advance directives for those minded to complete them. It is argued that this turns on how inclusive we want the ACP framework to be. There is little direct evidence from Singapore, but elsewhere, qualitative studies reveal that there is a distinct but stable minority of patients who want to retain control over their end of life care. This is consistent with their personality, their distrust of leaving matters entirely in the hands of unknown doctors or distant family members, and the clarity of their convictions on particular clinical interventions and their goals of care. 126 Spranzi and Fournier point out that while a majority of patients have difficulties and reluctance in committing care preferences to paper, there is a distinct minority of persons with firm views who would like to be able to exercise control in EOL care. For such individuals, there is a need for authoritative processes from which they can draw confidence that decisions will be taken in accordance with their preferences. 127 A minority notwithstanding, the legal framework should offer a facility for patients who desire greater assurance that their goals and preferences will be recognised and implemented, with suitable legal protection for healthcare professionals who act on these advance directives. 128 This embrace of facilitating diverse patient approaches to EOL care is consistent with the recognition of individual patient autonomy in ACP communications. The ACP framework should not generalise or insist on a one-size fits all solution. 129 Commentators arguing along these lines also note that such recognition and implementation of more flexible advance directives are equally consistent with the default framework under the MCA, given its overarching principled emphasis on respecting and engaging the individual patient's autonomy. 130

In the light of the problems associated with completing and enforcing advance directives, the policy recommendations in the US in relation to legal instruments have also shifted to durable powers of attorney that empower the individual patient to authorise a trusted relation or loved one to make decisions on their behalf.<sup>131</sup> In the context of advance care planning, this appointment of a legally recognised healthcare proxy has greater significance for two reasons. First, despite criticisms that healthcare proxies often do not predict the choices of their appointers well, <sup>132</sup> this may well be

<sup>&</sup>lt;sup>126</sup> Spranzi & Fournier, n124 at 566: "Others envisaged writing them because they wanted their own voice to silence others': very often, they were people who either lived alone, were in situations of potential conflict with family members and other loved ones, or were deeply mistrustful of medicine. One of them told us: "The ultimate decisions should not belong to doctors, they are strangers. That is the reason why I wrote ADs; and I did so because I am alone, there is nobody around anymore"".

<sup>&</sup>lt;sup>127</sup> Spranzi & Fournier, n124 at 565: About 15% in their study cohort valued control over their future, and were willing to accept the constraints that advance directives place on their future selves. Correspondingly, a systematic review of studies on patient preferences revealed that patients who complete advance directives have more stable preferences that those who do not: Auriemma et al, n15 at 1091.

<sup>&</sup>lt;sup>128</sup> See LS Castillo et al, "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care" (2011) 154(2) Annals of Internal Medicine 121 at 124-125

<sup>&</sup>lt;sup>129</sup> JJ Rhee et al, "Uptake and Implementation of Advance Care Planning in Australia: findings of key informant interviews" (2012) 36 Australian Health Review 98 at 102; BS Koh, "Living with the End in Mind: A Study of How to Increase the Quality of Death in Singapore" (Lien Foundation, Singapore, 2011), c. 3 at 20-22, http://www.lienfoundation.org/sites/default/files/ living\_with\_the\_end\_in\_mind.pdf

<sup>&</sup>lt;sup>130</sup> Chan, n79 at 122

<sup>131</sup> Sabatino, n7 at 225

<sup>&</sup>lt;sup>132</sup> See e.g. A Foo et al, "Discrepancies in End-of-Life Decisions Between Elderly Patients and Their Named Surrogates (2012) 41(4) Annals Of the Academy of Medicine Singapore 141; DI Shalowitz et al, "The accuracy of surrogate decision makers: a systematic review" (2006) 166 Arch Intern Med 493

beside the point in many cases.<sup>133</sup> Hawkins et al observed in their study that many patients are in fact more interested in meta preferences relating to process of decision making – to what extent they want to be involved, how much leeway they want to confer on surrogates, and who else they would want to include in the discussions on EOL care.<sup>134</sup> Participation by the appointed proxy in ACP prepares the appointee for the role by developing better understanding and commitment to the patient's values and preferences in a reflective dialogical process.<sup>135</sup> Finally, written lasting powers of attorney are useful when there is disagreement within the family, between family and the health care team, and when patients appoint a non-traditional intimate as a proxy decision maker.<sup>136</sup>

Unfortunately, the instrument of the LPA under the MCA in Singapore deprives them of this alternative facility because the powers of a donee of a LPA do not extend to (a) life sustaining treatment or (b) any other treatment necessary to prevent a serious deterioration in the patient's condition. This effectively eschews the notion of a healthcare proxy in Singapore. It might be argued that this can still be achieved practically because the MCA requires anyone named as a so-called healthcare spokesperson should be consulted for that purpose. But the consulted spokesperson has no legal authority to make and take responsibility for the decision, however qualified she might be for that role. In situations where family and other loved ones take different positions on what constitutes the best interests, then the relationship and understanding developed by the healthcare spokesperson during ACP acquires no particular legal significance under the present regime.

In a system where health financing is significantly personal or family reliant, conflicts can arise over the course of care between family members. It would not be surprising if incapacitated patients had prior specific preferences on who should undertake responsibility for proxy decision making. There is at present no clear legal resolution of who amongst disagreeing family members has the decision making authority to help direct the course of medical care; in effect, the attending physician is left to resolve this conflict. This may still arise notwithstanding the best efforts at ACP involving family members because disagreements may arise with persons not involved earlier in ACP discussions. Legal recognition of the appointment of a health proxy under the ACP process, if so appointed, would put this uncertainty to rest even if it cannot forestall disagreement and conflict.

<sup>&</sup>lt;sup>133</sup> See S Kim, "Improving Medical Decisions for Incapacitated Persons: Does Focusing on "Accurate Predictions" Lead to an Inaccurate Picture?" (2014) 39(2) Journal of Medicine & Philosophy 187

<sup>134</sup> Hawkins et al, n23; See also McMahan et al, n23

<sup>&</sup>lt;sup>135</sup> MG Kuczewski, "Narrative Views of Personal Identity and Substituted Judgment in Surrogate Decision Making" (1999) 27 Journal of Law Medicine & Ethics 32 at 34-35; JJ Fins et al, "Contracts Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of the Patient and Proxy" (2005) 29(1) Journal of Pain and Symptom Management 55 at 64

<sup>&</sup>lt;sup>136</sup> JA Tulsky, "Beyond Advance Directives: Importance of Communication Skills at the End of Life" (2005) 294(3) JAMA 359 at 361

<sup>137</sup> MCA, n4, s.13(8)

<sup>&</sup>lt;sup>138</sup> On this point, there also appears to be a critical misconception amongst some local healthcare professionals in the "value of a formal ACP being medically binding and legally legitimate, in the form of a lasting power of attorney...": Cheong *et al*, n33 at 67. As explained in the main text, there is nothing in legislation or common law that gives effect to this patient intent in the standardised ACP documented care plans.

<sup>139</sup> MCA, n4, s.6(8)(a)

 $<sup>^{140}</sup>$  See Tan & Chin, n55 at 15.

The obvious solution seems to be to do away with the restrictions on the powers of a donee of a LPA under the MCA. Concerns about opening the door to abuse are perhaps overblown because care can only be delivered in conjunction with the opinions of healthcare professionals in a shared deliberative model outlined above. Furthermore, the powers of a donee are still subject to the best interests test, which requires consideration of the prior views wishes and preferences of the incapacitated patient. If a donee makes decisions in disregard of these matters and consensus not possible, other actors in the healthcare system may respond to protect the best interests of the patient by referring the matter to the hospital ethics committee<sup>141</sup> or, ultimately, seeking directions from a court with jurisdiction.<sup>142</sup>

The drawback of the LPA is that its procedural requirements and cost may be barriers that inhibit uptake during ACP. The standard form 1 of the LPA provides only for the power to make medical treatment decisions, without any directions for the donee of the LPA on how she should go about deciding. 143 Any specially tailored provisions in the LPA will require the services of a lawyer. It may be worth considering legally recognising a healthcare spokesperson appointed under the Living Matters ACP process in the respective standardised care plans. This would allow patients the convenience of producing a specially tailored LPA for the purposes of healthcare as a product of the ACP process without having the engage a separate process for the LPA, which covers a much wider range of personal and property matters. Such a spokesperson could be conferred decision making powers only in respect of healthcare decisions, and not any other decisions relating, for example, to the disposition of property. The process of ACP already provides precautionary measures like the witnessing by the ACP facilitator and the attending physician, and would not require additional oversight machinery as compared to the LPA registry under the MCA. An appointed healthcare proxy for this purpose should be required to participate in the discussions and deliberations leading to the formulation and revision of the ACP plan, in order that this appointee have the requisite understanding and preparation to act as a healthcare proxy. On the whole, a specialised healthcare proxy would assist patients in strengthening the basic legal outcomes of ACP in ensuring that a proxy who is most knowledgeable of the patient's values and preferences, and best prepared to undertake the responsibilities of the position, is legally recognised.

#### D. *Implementing ACPs – the last hurdle*

Finally, there is also a concern that there may be an implementation gap between the documentation of the patient's statement of wishes or care plan, and its actual implementation by healthcare workers across the different settings in the healthcare system. Evidence in the US demonstrates that apart from lack of availability and specificity of advance directives, the lack of or integration into medical orders was another shortcoming that led to the design of the POLST form. <sup>144</sup> In Singapore, do-not-resuscitate orders are not legally regulated, but occur frequently in hospital based

<sup>&</sup>lt;sup>141</sup> See Ministry of Health, *Licensing Terms and Conditions on Hospital Ethics Committees* (7 Dec 2012), online: https://elis.moh.gov.sg/elis/info.do?task=guidelines&section=GuidePHMCTnC

<sup>&</sup>lt;sup>142</sup> MCA, n4, ss. 19 and 20

<sup>142</sup> MCA, n4, ss. 19 and 20

 <sup>143</sup> Office of the Public Guardian, Resources: https://www.publicguardian.gov.sg/opg/pages/Forms.aspx
 144 C Sabatino & N Karp, "Improving Advanced Illness Care: The Evolution of State POLST Programs" (Washington DC, AARP Policy Institute Report, 2011) at 2-3;

general and intensive unit care.<sup>145</sup> The criteria for placing such orders are often unclear and vary between institutions and decision-making is done in situ.<sup>146</sup> Decisions on DNRs have also generally been observed not to involve patient input.<sup>147</sup> In contrast, medical orders concerning other types of life sustaining treatment were infrequent, although some hospitals have since instituted standardised order forms which detail the limits of care for each patient.<sup>148</sup>

At the national level, the Living Matters programme appears to address this issue by modelling its Preferred Care Plan ('PCP') on the US POLST paradigm described above. 149 The PCP however differs from POLST in a couple of ways. First, it is not clear from the PCP that it is in fact a medical order that seeks to implement patient preferences, whether communicated directly or via a healthcare proxy, into actionable medical orders for treatment in the relevant healthcare setting. The US POLST template indicates clearly that it is a physician order sheet, and instructs healthcare workers "to first implement these orders, then contact (the) physician". <sup>150</sup> In contrast, the PCP is described as "a document that captures the patient's wishes regarding future medical care." It then qualifies that with the observation that the doctor "will always act in the patient's best interests", which must refer to the statutory best interests standard that only requires the consideration of these wishes without necessarily indicating a particular treatment outcome. 151 Further, the notes to the PCP makes clear that it is only meant to guide and not 'dictate' treatment. 152 However, the substance of the plan's listed options is couched in directive terms: when the patient is in cardiopulmonary arrest, either proceed with CPR, or "DO NOT attempt CPR. ... When not in cardiopulmonary arrest, follow orders in B, C and D."153

There is also a lack of legal, regulatory, or professional clarity as to the standing of the PCP in determining the treatments administered to an eligible patient with advanced illness. There is, thus far, no express mention of Living Matters care plans in any of the applicable legislation in Singapore, while the regulations promulgated under the *Private Hospitals and Medical Clinics Act* only require that a patient's advance care plan be including in her institutional medical records. The only relevant professional standards or ethical guidance relates to ACP communications, rather than professional clinical standards of implementing ACPs. Thus, there are concerns that the ambiguity of the PCP and the lack of legal, regulatory or professional recognition would impede its implementation across different care settings, particularly when patients with advanced illness are referred to emergency medical services or acute hospitals from their own homes or a nursing home in a medical emergency. Consistent with these observations,

<sup>&</sup>lt;sup>145</sup> See e.g. JA Low et al, "Care of Elderly Patients with DNR Orders in Singapore – A Descriptive Study" (1998) 39(10) Singapore Med J 456; IYO Leong & DYH Tai, "The Practice of Foregoing Life Support in the Critically Ill "Old Old": A Singapore Perspective" (2001) 30(3) Ann Acad Med Singapore 260; Phua et al, supra n69

<sup>&</sup>lt;sup>146</sup> S Sahadevan & WS Pang, "Do-Not-Resuscitate Orders: Towards a Policy in Singapore" (1995) 36 Singapore Medical Journal 267

<sup>&</sup>lt;sup>147</sup> Phua et al, n69 at 1298

<sup>&</sup>lt;sup>148</sup> Phua et al, n69 at 1299

<sup>&</sup>lt;sup>149</sup> See Appendix 2 below

<sup>150</sup> Hickman et al, n16 at S29

<sup>151</sup> Appendix 2, p29

<sup>152</sup> Appendix 2, p30

<sup>153</sup> Appendix 2, p29, Section A

<sup>&</sup>lt;sup>154</sup> Ministry of Health, *Licensing Terms and Conditions on Medical Records for Healthcare Institutions* (6 Aug 2015) at paras 4.2(j) and 5.2(i)

<sup>155</sup> NMEC, Guide on Communication in ACP, n31

the local press has reported incidents where emergency workers proceeded to administer cardio-pulmonary resuscitation in accordance with standing treatment protocols notwithstanding the refusal of such treatment in several patients' ACP care plans. 156 Similar advance directive implementation issues were experienced in Taiwan with the Hospice Palliative Care Act. 157 There has to date only been one study published on the use of a modified POLST in Singapore which demonstrated that ACP and the use of a modified POLST form reduced healthcare costs for patients in nursing homes within a regional health service helmed by palliative care staff from Tan Tock Seng Hospital. However, it cannot be readily inferred from the study whether these cost savings also correspond with a respect for and implementation of specific PCP directives into the actual care received. The study did however find that there were on the whole reduced hospital admissions and shortened inpatient lengths of stay. 158 Furthermore, the study was done in the context of a specific regional health system and it is unclear whether these findings could be extrapolated to the entire healthcare system, and to care across different regional clusters. The impact on recourse to emergency services on the outcomes is also unclear.

#### E. Developing clinical protocols for POLST implementation

The implementation of ACP outcomes is perhaps the clearest juncture at which the law can provide authoritative support. An Australian survey by Rhee et al identified the clarification of legal status of ACP and standardisation important for implementation, as professional fear of liability and expressed need for indemnity in carrying out an ACP was identified as a significant barrier.<sup>159</sup> The US literature documents three broad strategies to implement and incentivise the use of POLST in various states: (a) explicit legislation; (b) regulatory means targeting the relevant healthcare actors; and (c) establishing clinical consensus.<sup>160</sup> Often, these strategies will be preceded by pilot studies to develop an evidence base for wider implementation.<sup>161</sup>

The question therefore becomes whether further development and use of an explicit POLST type order is called for in the Singapore context. First, there needs to be some clarity on the difference between an advance directive or care plan and a POLST. The latter is an "actionable medical order dealing with the here-and-now needs of the patient". This order should only be completed after discussion with a seriously ill patient or her proxy of their medical options in the context of the patient's current condition. The POLST reflects the interpretation and implementation of the patient's or proxy's goals of care into medical orders that are standardised and actionable within and without the institution. Such legal or regulatory stipulations would cover the content of the order, the required signatories for validity (e.g. whether patients or their proxies should sign, in addition to a treating physician or other designated healthcare professional), and the appropriate clinical or medical situations when POLST should be offered. Thus, legal or regulatory standardisation that promotes clarity of objectives and

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<sup>&</sup>lt;sup>156</sup> J Chew, "Honouring Last Wishes", Straits Times (10 Jul 2014)

<sup>&</sup>lt;sup>157</sup> TY Chiu, "End of Life Decision Making in Taiwan" in RH Blank & JC Merrick eds, *End-of Life Decision Making: A Cross-National Study* (1996) at 176-177

<sup>&</sup>lt;sup>158</sup> Teo et al, n11 at 434.

<sup>&</sup>lt;sup>159</sup> Rhee et al, n129 at 100-101.

<sup>&</sup>lt;sup>160</sup> Pope & Hexum, n26 at 356-360; Sabatino & Karp, n144 at 10, 13

<sup>&</sup>lt;sup>161</sup> Pope & Hexum, n26 at 359-360

<sup>162</sup> Sabatino & Karp, n144 at v

portability are critical to serving these functions. Finally, regulations should correspondingly provide healthcare workers with legal protection when complying with the terms of a POLST. There is a substantial body of evidence from the US and other nations that POLSTs increase the conformity of care delivered with preferences indicated in a duly completed POLST. 164

However, criticisms of POLST remain. The principal issue raised is that there is very little evidence establishing that processes leading to the execution of a POLST accurately reflect a patient or surrogate's current preferences. The second concern is that unusual combinations of orders in a POLST form, such as a DNR order coupled with full treatment, leads to confusion about how the POLST should be implemented. Thirdly, others point out that POLST forms have been offered inappropriately to patients who are not suitable – e.g. nursing home residents who are not seriously ill and whose preferences about EOL treatments may therefore be less stable. In such situations, POLST usage would detract from patient-centred decision-making in the moment, especially in the absence of a mechanism to ensure that regular reviews of POLST are done when clinical status changes.

The challenges in adopting a POLST type system reveals a tension between increasing certainty of implementation and recognising the uncertainty or instability of patient and proxy preferences. In a healthcare system like Singapore's, there is increasing emphasis on the correct siting of care, and therefore greater transferability of patients between healthcare institutions, intermediate and long term care facilities, hospices and homes. This increases the need for better systemic coordination of care through tools like POLST. In addition, standardisation and appropriate legal protections for implementation by the spectrum of healthcare workers delivering routine or emergency care will facilitate adherence to POLST stipulations.

However, POLST usage may detract from better quality, patient-centred care if they are rigidly implemented without proper review mechanisms to ensure that they are sufficient updated especially when there is a material change in the patient's health condition and care goals. This also depends on the development of best practices on when to offer POLST to patients, how to consistently interpret various permutations of POLST orders, and determine under what criteria of temporal currency POLSTs are validly actionable. These features suggest that a regulatory route to implementation is

<sup>&</sup>lt;sup>163</sup> JE Jesus et al, "Physician Orders for Life-Sustaining Treatment and Emergency Medicine: Ethical Considerations, Legal Issues and Emerging Trends" (2014) 64(2) Annals of Emergency Medicine 140 at 142-143

<sup>&</sup>lt;sup>164</sup> SE Hickman et al, "Use of POLST Program in Clinical Settings: A Systematic Review of the Literature" (2015) 63 Journal of the American Geriatrics Society 341

 $<sup>^{165}</sup>$  Hickman et al, n164 at 348; A more recent preliminary study involving 28 participants revealed discordance in a minority of cases, the least being orders relating to CPR and the most in relation to decisions about antibiotics, although in more than half of those instances, participants were not inclined to further discuss the discrepancy: SE Hickman et al, "The Quality of Physician Orders for Life-sustaining Treatment Decisions: A Pilot Study" (2017 ) 20(2) Journal of Palliative Medicine 155 at 159-160 .

<sup>&</sup>lt;sup>166</sup> TA Schmidt et al, "Physician Orders for Life Sustaining Treatment (POLST):lessons learned from the analysis of the Oregon POLST Registry" (2014) 85 Resuscitation 480

<sup>&</sup>lt;sup>167</sup> California Advocates for Nursing Home Reform, *Physician Orders for Life Sustaining Treatment: Problems and Recommendations* (CANHR, San Francisco, 2010) at 5;

 $http://www.canhr.org/newsroom/newdev\_archive/2010/POLSTWhitePaper.html\\$ 

<sup>&</sup>lt;sup>168</sup> KA Moore et al, "The Problems with Physician Orders for Life-Sustaining Treatment" (2016) 315(3) JAMA 259

preferable to legislative or professional approaches. <sup>169</sup> Coordination by a regulatory agency for healthcare services, such as the AIC, would allow for more responsive adaptations of the system and its documentation in the light of a developing evidence base, and ensure greater authoritativeness of the POLST for implementation across different sectors in the healthcare system.

Nevertheless, there may be scope for legislative intervention of some sort if legal protection is thought necessary to promote usage and implementation. Various US states have enacted such protections. <sup>170</sup> In Singapore, the AMDA protection under s.9 of the Act are too specific to extend to non-statutory instruments such as POSLT or even advance care plans. However, the section 7 general defence under the MCA could potentially serve this function if it is based on clearer professional EOL guidelines on the status and suitability of POLST. In this scenario, a healthcare emergency staff or professional would be acting reasonably in inferring that a validly completed POLST would reasonably reflect an incapacitated patient's best interests, within the meaning of s.6 of the MCA. The pre-condition for section 7 is that the patient must lack decision making capacity; patients who still possess capacity can override what a POLST says. Section 7 would then confer the same protection or defence as if the patient's consent were given for implementing the terms of a POLST. Should s.7 not provide sufficient comfort to emergency workers and healthcare professionals, then a more specific legislative protection would be needed.

#### IV. **CONCLUSION**

Advance care planning offers the promise of more patient-centred care that appropriately respects their values and beliefs, as determined in the context of close relationships with family members, other intimates and healthcare providers. The thrust of the Living Matters programme is to open up communication channels, encourage individual and familial reflection on relevant values and beliefs in relation to healthcare needs and recording of these deliberations in order to facilitate access by subsequent healthcare professionals. The move away from formal binding advance decisions is rooted in better understanding of the challenges and burdens that such decisions raise, in favour of preparing patients and their appointed surrogates for inthe-moment decision making. The legal and professional ethical framework for Living Matters ACP needs to clarify the decision making standard and model for deliberation when ACP has been engaged. It is argued that a best interests standard that seeks authentic decisions that best reflect the values and preferences of the patient. determined through a shared decision making process where both professional and familial agents have standing and authority to work towards mutually agreed outcomes, would best resolve the potentially conflicting interests and perspectives at stake. There needs, however, to be a backstop protection for the core interests of a vulnerable patient whose family proxies are not adequately weighing or engaging such interests. Secondly, for the ACP framework to be more inclusive of the plurality of individual patient contexts, perspectives and values, more robust legal tools – more flexible advance directives and healthcare related lasting powers of attorney – need to be

<sup>169</sup> See in the US context: KL Cerminara & S Bogin, "A Paper About a Piece of Paper: Regulatory Action as the Most Effective Way to Promote Use of Physician Orders for Life-Sustaining Treatment" (2008) 29 Journal of Legal Medicine

<sup>170</sup> Sabatino & Karp, n144 at 11

introduced to cater to patients that do not fit within the ideal shared decision making model of ACP deliberations and implementation. Lastly, the POLST mechanisms, which are distinct from ACP documentation, need legal and regulatory intervention for effective co-ordination in execution. This will better translate upstream efforts by the affected parties into tangible care, treatment and palliative outcomes that are right for the patient as a relational individual.

**Disease Specific Advance Care Plan (General)** Appendix 1 **Patient's Particulars** This Advance Care Plan (ACP) captures and reflects, as far as Name: possible, the patient's wishes regarding future healthcare if the patient lacks mental capacity to make his/her own healthcare NRIC / ID No: decisions. The doctor will always act in the patient's best interests and everyone shall be treated with dignity and respect. Gender: The Disease Specific (DS) ACP discussion is held for patients Date of Birth: with progressive chronic illness by a certified ACP facilitator. Institution/ **Programme Name:** Place of **Documentation:** Date of Session: This plan is based on discussions with (May select more than one option) Patient Primary Nominated Healthcare Spokesperson □ Secondary Nominated Healthcare Spokesperson Serious Complication with Low Chance of Survival: If I have a serious complication from my illness, so that I was facing a prolonged hospital stay, requiring ongoing medical Α interventions AND my chance of living through this complication is low (for example, only 5 out of 100 patients will live), I would choose the following (in both situations, I want treatment to keep me as comfortable as possible): ☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long I live ☐ I am not sure what I would choose if this happens Serious Complication with Loss of Ability to Move Around or Communicate: If I have a serious complication from my illness and have a good chance of living through this complication, but it was В expected that I would never be able to either walk or talk (or both) and I would require 24 hour nursing care, I would choose the following (in both situations, I want treatment to keep me as comfortable as possible): ☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long ☐ I am not sure what I would choose if this happens **Serious Complication with Mental Incapacity:** If I have a serious complication from my illness and have a good chance of living through this complication, but it was C expected that I would never know who I am or who I am with and I would require 24 hour nursing care, I would choose the following (in both situations, I want treatment to keep me as comfortable as possible): ☐ I want all treatment I need to live as long as I can. Staying alive matters more than anything else Stop all efforts to keep me alive, allow natural death to happen. How I live my live means more to me than how long ☐ I am not sure what I would choose if this happens Cardiopulmonary Resuscitation (CPR): D If I have a sudden event that causes my heart and breathing to stop, I would choose the following: Attempt resuscitation Do not attempt resuscitation (No cardiopulmonary resuscitation, No CPR) under any circumstance, allow natural death to occur Do not attempt resuscitation if the treating physician believes the chance of surviving the attempt is low. Severe Breathlessness (Discuss if appropriate) Ε If I have an episode where I am unable to breathe on my own, I would choose the following: Attempt to use any appropriate non-invasive method, such as BIPAP, to assist my breathing AND ☐ Use mechanical ventilation if non-invasive methods fail Do not use mechanical ventilation if non-invasive methods fail

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	Do not attempt to assist my breathing by non-invasive methods, such as BIPAP, or mechanical ventilation							
F	If I have chosen to continue appropriate treatments to help me live as long as I can in <u>ANY</u> of the above situations, I would want treatment to stop for the following outcomes I find unacceptable (these could include length of time, more complications, discomfort, or burden on family). They include:							
G	Other Important Notes:							
0	Other important notes.							
Patient's Pa								
Name:	ticulars.	Primary Nominated Healthcare Spokesperson:		Secondary Nominated Healthcare Spokesperson:				
NRIC No:		Name:		Name:				
		Relationship:		Relationship:				
Signature:		Contact No:		Contact No:				
Date:		Signature & Date:		Signature & Date:				
Facilitator:			Physician-in-charge:					
Name:			Name:					
Last 4 digits of NRIC:			MCR No:					
Signature & Date:			Signature & Date:					
Personal Data Protection Act (PDPA) – Client Consent								
I understand that the information contained in this ACP document will be stored in hard copy and/or soft copy by this/my organisation using								
reasonable security measures to ensure that my information is only accessed for legitimate reasons by this/my organisation staff members and transmitted to external healthcare providers caring for me.								
н	Other Instructions:							
I have discussed my wishes for my future healthcare plan with the above substitute decision makers and the facilitator. When I am unable to communicate for myself or unable to understand what the care providers are saying to me, I would want the person I have chosen to:								
<ul> <li>Strictly follow my wishes.</li> <li>Do what he/she thinks is best at the time, considering my wishes.</li> </ul>								

#### **Directions For Healthcare Professionals**

When completing the "Disease Specific ACP Form (General)" document:

- Any incomplete section of the Disease Specific ACP Form (General) will require physician's discretion, as indicated.
- Photocopies and faxes of signed Disease Specific ACP Form (General) are valid.
- Place this document at the front of the patient's case notes during each hospitalization.
- This document serves to guide and not dictate medical treatment.
- The patient may verbally change his/her preferences.
- Contact the facilitator or physician-in-charge for any queries.

#### **Review Of This Disease Specific ACP Form (General)**

Disease Specific ACP Form (General) should be reviewed if:

- The patient is transferred from one care setting or care level to another, or
- There is substantial change in the patient's health status, or
- The patient's treatment preferences change.

#### PHOTOCOPIES OF THIS FORM ARE TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE

rete	erred Plan of Care (PPC)	Appendix 2				
		Patient's Particulars				
pos	s Advance Care Plan (ACP) captures and reflects, as far as sible, the patient's wishes regarding future healthcare if the ent lacks mental capacity to make his/her own healthcare	Name:				
deci	sions. The doctor will always act in the patient's best interests everyone shall be treated with dignity and respect.	NRIC / ID No:				
_		Gender:				
The PPC discussion is held for patients with advanced illness by a <u>certified ACP Facilitator.</u>		Date of Birth:				
		Institution/ Programme Name:				
		Place of Documentation:				
		Date of Session:				
This plan is based on discussion(s) with (Select all appropriate options)  Patient Primary Nominated Healthcare Spokesperson Secondary Nominated Healthcare Spokesperson  This discussion was held with the patient's Nominated Healthcare Spokesperson(s) because the patient lacks mental capacity to make his/her own healthcare decisions due to  (please state reason, e.g brain tumour, advanced dementia)						
Α	Cardiopulmonary Resuscitation (CPR):  (When the patient is in cardiopulmonary arrest and is not breathing or has no pulse)					
	☐ To proceed with CPR / attempt resuscitation. ☐ DO NOT attempt CPR (allow natural death).  When not in cardiopulmonary arrest, follow orders in B, C and D.					
В	Medical Intervention Guidelines: (When the patient has a pulse and is breathing)					
	☐ COMFORT MEASURES ONLY					
	Patient is to be treated with dignity and respect. Reasonable measures are made to offer food and fluids. Medications, oxygen and other measures may be used as needed for comfort. Do not intubate. These measures may be used where the patient resides. Consider transfer only if comfort needs cannot be met in current location.					
	☐ LIMITED ADDITIONAL INTERVENTION					
	Includes care described above. To initiate limited trial of treatment. May include oral/intravenous medications. Continue with comfort measures if there is no clinical improvement. Do not use endotracheal intubation or long-term life support measures. May consider non-invasive ventilation support. Transfer to hospital if indicated. Avoid transfer to intensive care unit.					
Ī	☐ FULL TREATMENT					
	Includes care described above. May consider intubation, mechanical ventilation, and cardioversion. Management may include transfer to intensive care if indicated. These measures are subject to the assessment and decisions of the hospital care team.					

	Additional Care Preferences (e.g. dialysis, artificially administered nutrition, use of antibiotics, blood transfusions etc):							
С	Preferred place of medical treatment and care in event of deterioration							
	Remain in my own home / nursing home / hospice / hospital (please select one) Trial of treatment in own home / nursing home / hospice before considering transfer to hospital (please select one) Transfer to hospital Others (transfer to hospice, etc) No Preference							
D	Preferred Place of Death in event of deterioration							
	_	☐ Acute Hospital ☐ No Preference ☐ Inpatient Hospice						
E	Other important notes (for e.g what is	living well means to	the patient)					
Patient's Particulars: Name: NRIC No: Signature & Date:		Primary Nominated Healthcare Spokesperson:		Secondary Nominated Healthcare Spokesperson:				
		Name:		Name:				
		Relationship: Contact No:		Relationship:				
				Contact No:				
		Signature & Date	:	Signature & Date:				
Facilitator:			Physician-in-charge					
Name:			Name:					
Last 4 digits of NRIC:			MCR No:					
Signature & Date:			Signature & Date:					
Personal Data Protection Act (PDPA)								
The information contained in this ACP document will be stored in hard copy and/or soft copy by this organisation using reasonable security measures to ensure that the information is only accessed for legitimate reasons by this organisation's staff members and transmitted to external healthcare providers caring for this patient.								

#### **Directions For Healthcare Professionals**

When completing the "Preferred Plan of Care" document:

- Any incomplete section of the Preferred Plan of Care form will require physician's discretion, as indicated.
- Photocopies and faxes of signed Preferred Plan of Care are valid.
- Place this document at the front of the patient's case notes during each hospitalization.
- This document serves to guide and not dictate medical treatment.
- The patient may verbally change his/her preferences.
- Contact the facilitator or physician-in-charge for any queries.

#### **Review of the Preferred Plan of Care**

Preferred Plan of Care should be reviewed if:

- The patient is transferred from one care setting or care level to another, or
- There is substantial change in the patient's health status, or

The patient's treatment preferences change.

PHOTOCOPIES OF THIS FORM ARE TO ACCOMPANY THE PATIENT UPON TRANSFER OR DISCHARGE