ADVANCE CARE PLANNING – AHEAD OF OUR TIME OR NEVER TOO LATE

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Throughout known history, mankind has constantly sought to navigate the courses of nature and secure some certainty amidst its unpredictability. Where circumvention is unattainable, mitigation is desired. Intense devising and planning to lessen the influence of uncertainties in human existence permeate everything from financial markets and property prices to bus schedules and weather forecast. Strangely enough, however, where the one aspect of life – mortality – is most certain and oftentimes predictable, many do not plan ahead at all.

Dying is not necessarily a quick process of succumbing to contagion or trauma, and many endure the travail of a protracted loss of mental and physical integrity before death. It is not too dogmatic to proposition planning ahead for one's eventual demise.

Understanding Advance Care Planning

Indeed, advance care planning (ACP) has an indisputable role in health and social care today. ACP is based on the premise that one ought to have the ability and space to make conscious and informed decisions regarding care and treatment options at the end of one's life, even if one should lapse into a state wherein active decision making is rendered impossible. But the idea of starting a conversation on planning for the end of life, although logically resonant with many, might not be accepted readily. There appears to be a pervasive myth that such conversations distress the person in question and reticence can often be encountered among care providers who also hold concerns over legal and accountability issues.

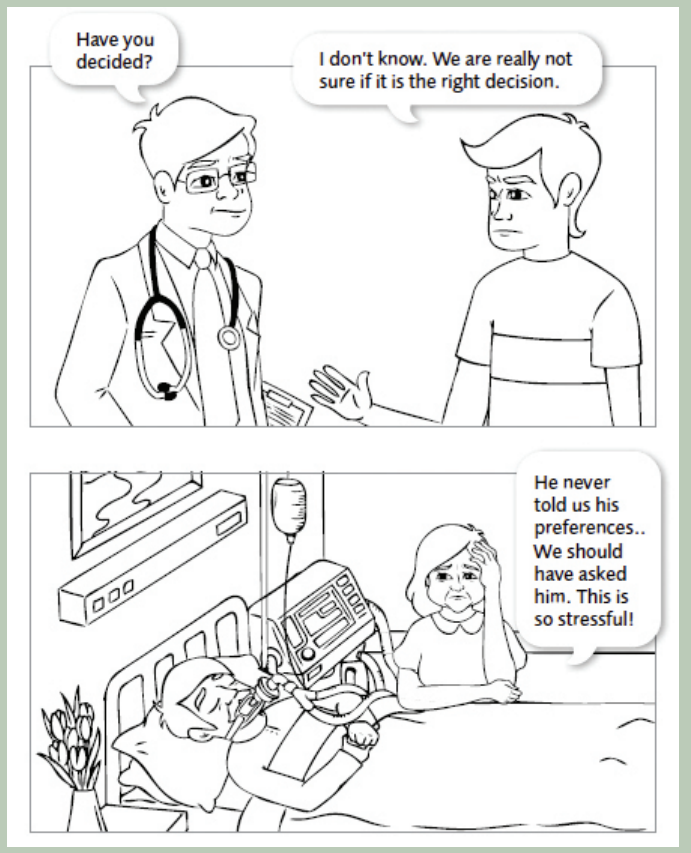
However, it is not unseemly to opine that ACP is more an art than a science, and we really cannot whitewash the challenges faced in applying ACP as a standard of care in our healthcare systems. Experiences from across the developed world, notably the United Kingdom, Canada, Australia and the United States suggest that institution, practitioner and community acceptance, both emotional and rational, are essential in ensuring that ACP resonates with good care. Interestingly, the public in general has been found to recognise and accept the benefits of ACP, especially the incorporeal such as having choices honoured, pre-empting conflicts in decision-making, reducing stress on proxy decision makers and opening the channels of communication among various stakeholders. Nonetheless, they all do need a fair bit of persuasion to talk about death and dying per se.

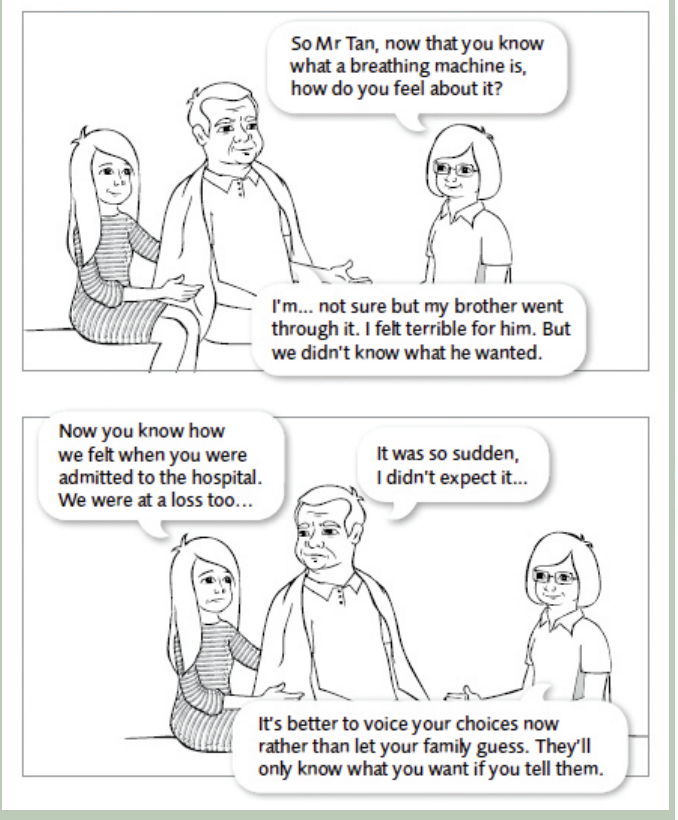
Changing Societal Mind-sets

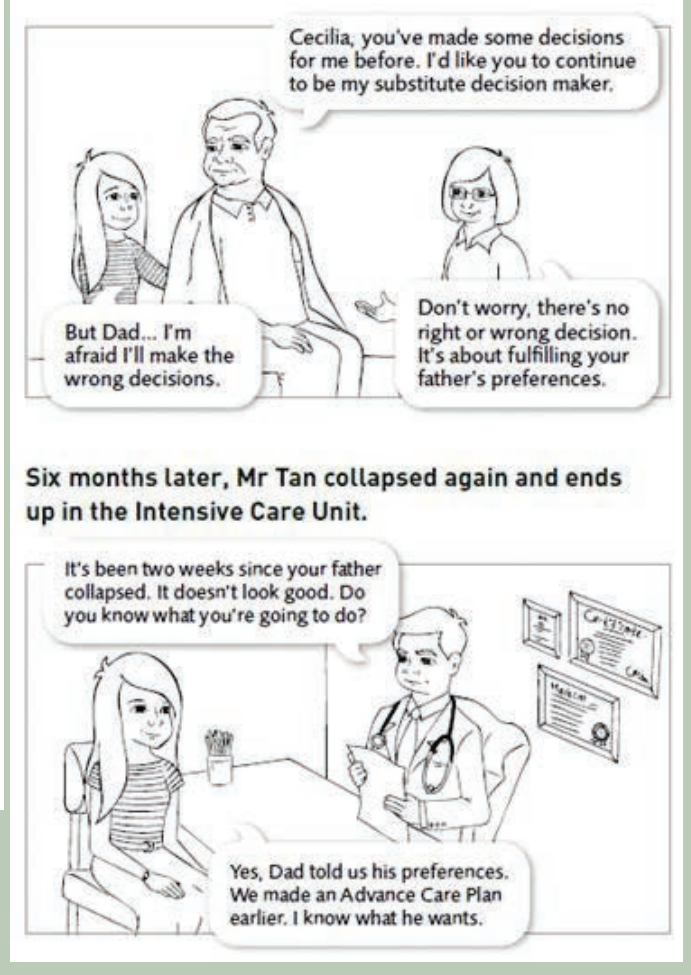
And translating ideals into practice is not without particular challenges. Besides dealing with the discomfort of talking about death and dying, concern over a covert agenda for euthanasia among faith-based advocates and apprehension towards a possibly unspoken intent to keep healthcare costs in check cannot be undermined. Here in Singapore (and likely in other Asian settings), Confucian thought and ethics exhort an almost heroic extreme of filial piety that tends towards doing whatever is physically possible to preserve longevity. This risks misjudgement of that which is truly needful and desired, and individuals' needs and wants are more often than not buried in the overzealous intentions of their loved ones. These prevailing sentiments potentially create a minefield of difficulties in propositioning ACP.

Entrenching ACP and end of life care into care services for those suffering long term debilitation and potentially life-threatening disease, therefore, necessitates a multi-dimensional approach. On the one hand, public education needs to focus on encouraging and normalising conversations over end of life issues and the need to make informed choices for care; on the other hand, care provider engagement needs to be pitched from a quality care standpoint, which tends to stir the interest and passion of committed professionals. To top it off, the use of information technology will bring about accessibility, universality and portability for ACP.

In spite of these challenges, the evidence for ACP is gaining ground. In the study of ACP programmes around the world, there is overwhelming consensus that ACP makes a palpable difference to the way people receive care at the end of life. In the United Kingdom, the Gold Standards Framework empowers and supports GPs in identifying, engaging and planning ahead for their patients who are likely to be in their final year of life; this puts in place multifaceted endeavours to ensure that the patients receive timely access to various forms of care and remain well supported throughout their disease trajectory. The efforts of the Tzu Chi Foundation in Taiwan are also a notable example. Leveraging on its Buddhist (and oftentimes universal) principles delivered through cross-cultural and multi-sector service contact points, it has managed to de-stigmatise end-of-life conversations through the use of community advocacy,







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comprehensive and targeted media outreach and the support of religious and civic leadership. This translates into better family appreciation and acceptance of treatment limits and builds a healthy respect for death and dying as a phase of life that need not be approached with trepidation, thereby reducing the stress of confronting death for the individual, the family and the care provider alike.

Making ACP Part of Standard Care

Particularly in care for the elderly, who are so vulnerable to the trauma of poor coordination, over-processing and inadequate handoffs in health and social services, having detailed and systematic care objectives in place that are readily available across the care spectrum can do much in avoiding the transitional pitfalls inherently present in many of our care systems. This is the reason why Singapore has taken its first steps in designing a national advance care planning system that can cut across institutional lines and be extended into the community care sector. Branded as Living Matters©, this system of ACP conversation and documentation has been adapted from the Respecting Choices© programme from Wisconsin, USA. The Agency for Integrated Care has been tasked with its phased implementation across the health and social care continuum beginning in 2011.

Living Matters© is comprehensively structured to approach the topic of ACP according to the needs of the person in question, and so its various components of deliberation are suitably pitched according to one's state of health. Its language is as far as possible non-technical and concise, yet specific enough to help the layman understand health and healthcare concepts. The formal process is facilitated by suitably trained and certified persons who are not necessarily clinical professionals. To date, more than a thousand facilitators have been trained. There are also plans to employ the use of community advocates in public outreach and education over the next few years.

Designing a universal information technology system to support the documentation of ACP has been established since the very beginning of its strategic deliberations. This will undoubtedly go a long way in enabling standardisation, supporting decisions and ensuring information portability and accessibility to care providers across the health and social continuum. With the added advantage of future interface with our ambitious National Electronic Health Record system, ACP will literally be at the fingertip of providers across care settings. In the years ahead, when health literacy and personal health management are better inculcated in the public, ACP will no doubt lend invaluable support to patient autonomy and critical healthcare decision making.

Conclusion

Yet, ACP implementation in Singapore remains fraught with potential hurdles. It is certainly not a straightforward "sell" to both consumers and providers. It takes as much effort in the realm of the heart as it does of the head. But we dare push ahead in this endeavour, because we believe it is intrinsically a good thing. To quote the late Mr Steve Jobs – [We're gambling on our vision, and we would rather do that than make "me, too" products. Let some other companies do that. For us, it's always the next dream]. First – the vision.

For more information on Living Matters©, one may refer to the website **www.livingmatters.sg**

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