For many people, growing older can be a challenging time in life. It is a time when people have to deal with loss – be it the loss of health, mobility, social connections, friends or their spouse, and the changes that happen as a result of those losses.

As a large state-wide aged care organisation, Southern Cross Care (Vic) is committed to assisting older people to live the best possible life, regardless of their life circumstances, background, care needs, health or socio-economic status. We believe that like all of us, older people need to continue to live their life until their death, contributing to their families and the community, albeit with the support they need to do so. This is the philosophy that underpins all that we do as an aged care provider, and sees us ‘valuing every person’ and treating everyone with the same respect and compassion.

Looking at the submissions already received (up to 2\textsuperscript{nd} July) the vast majority are from people who have experienced a close family member dying with a chronic illness and the experience has been a poor one. This situation lives out the quote from Cicely Saunders (best known in UK and internationally as the founder of palliative care), “How people die remains in the memories of those who live on”. It seems from among the submissions, there are very few voices so far that provide a solution along the lines of quality of life and person centred care. The solutions posed are almost exclusively pro euthanasia and seemingly with little understanding of the benefits of end of life care planning, palliative care and recognition of changing treatments over the course of a chronic illness. Providing one solution does not provide choice for the dying person.

Choice is not whether to live or to die with terminal illness. Having a choice is not one thing or another. It is much more complex than that. As with many aspects of the human condition exercising choice can be along a continuum of experience and changing life situations. The choice may not be about death, it may be more about how a person wants to live, now and until the end. Real choice about end of life care cannot be made unless there is sufficient information for health practitioners, caregivers and the dying person and only if the wishes of the dying person are known and respected. Prior experience, beliefs and knowledge all play important parts in the exercise of choice and empowerment to make decisions.

So in order to exercise choice at the end of life we as a community member, or as a dying person, or as a health professional, or as a family member or caregiver, or as a combination of all these, need:
• Public conversations about End of Life care with contributions from experts, consumer groups, ethicists and religious communities, and dying people and their families
• Access to Advance Care Plans, End of Life Care Plans, advanced care directives, or medical powers of attorney while people are well and able to make informed decisions
• Improved education about palliative care to give health professionals skills and confidence to raise the issues about end of life
• Improved knowledge, better understanding of treatments and what they mean
• Improved access to palliative care services, where a person lives
• Knowledge about what a hospital admission at the end of life might mean
• Acknowledgement of changing treatments for diseases at the end of life
• Improved quality of life and preparation for death for all people
• Acknowledgment of spiritual life
• Choice for health professionals
• Leadership from health professionals.

When should choice start? Often the discussion about how, when, where, and what care come late in the progress of the chronic disease, even though death is the expected outcome. Much effort is made in the treatment and cure phase of the disease to the exclusion of planning for future demise. So when is there a choice? When should palliative care start?

There is a compelling body of academic literature that deals with the topic of dying in Australia. Some pertinent areas of research, that contribute to the discussion on choice, follow.

**Place of death:** Most people in Australia do not die where they want. Although 70% say they would like to die at home but only about 14% do. Most people die in hospital or residential aged care. ¹

**The dying trajectory:** End of life has become very medicalised and technical, often extending the dying period, but without discernible improvements in the experience. Efforts need to be put into co-ordinating care with communication between family members, the dying person and health professionals. Education about death and dying would also improve the experience of dying for the dying person and give health professionals skills and confidence to recommend change of treatments as necessary. ², ³, ⁴

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Use of health services: The apparent overuse of Emergency Departments in acute hospitals by people whose deaths are expected occurs where there is poor planning, lack of professional support, anxiety about death, uncertainty of what to do and symptoms of disease causing distress. Better use of emergency departments and proactive seeking of alternatives to hospital care, improved planning of palliative and end of life care are called for. Emergency department staff need to be educated about end of life care and be provided with the knowledge, skills and confidence to implement palliative and other care as appropriate. Where there are advance care plans or similar documents or wishes in place; they need to be followed, thereby reducing the number of people presenting at emergency departments. Education in the acute sector needs to be multidisciplinary, ongoing, evaluated and supported by management.5 6 7 8 9

Residential Aged Care: The Aged Care sector is a common site for end of life care to be given and there is considerable variability in care provision across the sector. Where advance care plans are in place and followed, there should be fewer emergency admissions to hospitals and residents can die at home (in residential care). Education to provide staff with skills and confidence are again essential. This requires leadership and commitment by management to the principles of palliative care and ensuring that good care at the end of life and resident choices are respected.10 11 12 13

Critical issues for clinicians: The support people receive towards their end of life is being increasingly recognised as an important component of high quality health and social care. This support includes attending to emotional and spiritual wellbeing and sustaining function while ensuring choice and control over treatments by the dying person supported by appropriate information.

5 Rosenwax, LK; McNamara, BA; Murray, K; McCabe, RJ; Aoun, SM; Currow, DC. (2011). Hospital ad emergency use in the last year of life: a baseline for future modifications to end-of-life care. MJA, Vol 194 No 11, 2011.
11 Sharp, T; Moran, E; Kuhn, I; Barclay, S. (2013). Do the elderly have a voice? Advance Care Planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. Br J Gen Pract 2013; doi: 10.3399/bjgp13X673667
12 Silvester, W; Fullam, RS; Parslow, RA; Lewis, VJ; et al. (2013) Quality of advance care planning policy and practice in residential aged care facilities in Australia. BMJ Supportive & Palliative Care 2013;3:349-357
Advances in palliative medicine have produced effective means for treatments at the end of life; in particular pain control. Inadequate pain control is now ranked as the least common reason for requesting assistance with death in the US state of Oregon where a Dying with Dignity Act has been in place since 1997. Most request assistance because of loss of autonomy and dignity and the inability to engage in meaningful life activities. (N Engl J Med July 2012).

The importance of education of health professionals, both as undergraduates and practitioners, about palliative and end of life care continues to be a critical issue; whatever the nature of clinical practice or specialty. End of life care is everyone's business.

Another issue for clinicians, especially doctors, is the conflict between preservation of life and perceived duty of care to patients, and conflict between the principles of patient autonomy and medical paternalism. Ethical and professional guidelines sometimes do not provide clarity for action and the legal system is also unclear across state boundaries.  

**Advance Care Plans:** There are many forms of Advance Care Plans available, and most hospitals and other health services, including the aged care sector, recognise the value of some formalised discussion or conversation with patients and families about end of life. Advance care directive, advance care plan, living will, medical Power of Attorney are all terms used to denote a personalised plan developed or written by an individual, in conjunction with professional caregivers and family members, which specifies the way that person would like to be treated at the end of life and the care he or she wants, or does not want. It can be a highly formulated legal document, an informal note or conversation the person has had to assist carers in making decisions, especially when the individual is no longer able to make decisions for him or herself.

A good death requires preparation, time for discussion with family members and health professionals, adequate information about what is possible, futile and necessary. Advance care plans at any point in life will assist in ensuring a good death and will enable patients to have a voice when they can no longer express themselves directly. Plans are often completed with the help of a health professional, but not necessarily so. Some GPs and other health professionals are unwilling or lack the expertise to be able to assist in this. Education remains a key to a good death.

It is clear that advance care planning enhances end of life and gives people choice and control. The literature also supports the implementation of systematised and universal end of life care that is embedded in the health

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17 Palliative Care Australia (2011), National Palliative Care Consensus Statement, www.palliativecare.org.au
system, is evidence based, quality controlled, provided by all staff and communicated to patients whose opinions are sought and wishes are taken into account when designing treatments and programs of care.\textsuperscript{18,19,20,21,22}

**Demography of dying:** People are more likely to die in old age and of a chronic disease, meaning that death is predictable and occurs over a long period of time. Seventy percent of deaths in Australia are expected and about two thirds of deaths occur between the ages of 75-95. With an ageing population, the number of deaths occurring will almost double in the next twenty-five years.\textsuperscript{1,23}

**Risks**

Too much legislation can lead to institutional dying – not only within a hospital or health service, but also within the legal system.

Access inequality will lead to unequal experiences and suboptimal choice at the end of life. Aspects that contribute to reduced access are:

- Socioeconomic status, ethnicity, gender and age
- Geographic region: urban, regional, rural, remote
- Hierarchy of medical conditions that impact on available services and choice; and
- Transport.

The clarity about what contributes to a good death can be clouded by concerns about euthanasia and assisted dying or suicide and debates about legalising euthanasia prevent clear discussions about treatment at the end of life. It is true that some medical treatments or the change of treatments at the end of life will not only alleviate pain and other symptoms but will also hasten death. This is not euthanasia. Many patients will have treatments withheld or withdrawn when the treatments are considered useless and death is imminent. These decisions are made with the patient or the family member, and if in existence, in line with an advance care plan.

Public education needs to be conducted about palliative care and end of life, with a focus on dispelling the current negative perception around death and dying, so that a culture of cure, in the face of futility, is changed to a person centred model of care, where choice and control of the dying person are supported. This education can also focus on ensuring that advocacy groups for “dying with dignity” and consumer groups are well versed in the evidence

\textsuperscript{18} Palliative Care Australia. Advance Care Planning Position Statement, www.palliativecare.org.au
\textsuperscript{19} ANZSPM Submission to National Health and Hospital Reform Commission, Caring for People at the End of Life.
for current palliative care practice and end of life care. The public conversation is necessary and the healthcare sector must be part of this. Where advance care plans are in existence, it has been shown that there is a better death.\textsuperscript{14,24}

It is also true to say that the most media attention is given to poor deaths and then this leads to numerous horror stories, with little regard to facts and truth, being produced in social media or indeed social media is likely to drive the mainstream media and turn the tide of public opinion.

Conclusions

SCCV endorses choice for people at the end of their lives in the presence of evidence and information. It undertakes to do this by ensuring all its residents and clients have the opportunity to complete advance care plans or similar and that these are appropriately acknowledged. SCCV also undertakes to do this in providing an impeccable example of this in its organisation wide model of care for residents and clients and their families.

SCCV supports improvements in and access to palliative care to optimise choice. These will require more funding, better education of health professionals and the community, and active promotion of good medical, health, social, spiritual and psychological care of older people at the end of life. SCCV also acknowledges the role of family and caregivers and puts the resident and client at the centre of the care.

SCCV does not support the notions of euthanasia or physician assisted suicide because:

- these are contrary to Christian teachings and beliefs
- they are based on the underlying assumption that a person’s life may not be worth living
- universal criteria cannot and/or should not be developed to judge whether a person’s life is not worth living; and
- these suppose that human life can or should be ended by doctors or others.

\textsuperscript{24}Detering, K; Hancock, AD; Reade, MC; Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. \textit{British Medical Journal} 2010; 340:c1345.