Solving the end-of-life care equation

1 July 2014 marks the implementation date of the *Advance Care Directives Act 2013* and the 7 Step Pathway. As **Dr Chris Moy** explains in the following article of four parts, they may represent the critical first two elements in the development of a coherent statewide strategy to change the landscape in end-of-life decision making and care for the better.

FOR all the admiration we garner as doctors in our ability to cure, there remains a nagging doubt in the minds of some patients about our ability to care for them at the end.

End-of-life care continues to be the subject of sustained negative media and a high proportion of health complaints. And it is likely that some of those advocating for euthanasia do so out of a lack of confidence in what they see in the current models of end-of-life care.

But why is this occurring when 50% of people die in hospital, the most controlled of environments, and when, in the US, an estimated 30% of Medicare expenditure is for patients in the last year of life – with up to 40% of this concentrated on a patient's last month of life?

Maybe, these are symptoms and signs of a community which perceives that the health system does not always listen to or respect their wishes, and sometimes abandons them at the end, allowing them to suffer as they die.

What cannot be fully understood, except by those given the responsibility, is that end-of-life decision making and care can be difficult. Decisions often have to be made in urgent and emotionally heightened situations with very little information about the wishes of a patient who may be unconscious or delirious. There is often confusion about legal and ethical responsibilities. The basis of decision making can be unclear to some: varying from being based on noble impulses to preserve life at all costs, to confusion about what the patient would have wanted ('substitute decision making') vs what is thought to be best for the patient ('best interests decision making'). The individual values of the doctor or relative can greatly affect decision making. And sometimes protocols or best practice rule decision making – sometimes even fear too – in decisions made with a legally defensive mindset, or in a reluctance to enter difficult discussions with the patient and the family about death and dying when it might be easier just to offer another round of treatment.

But, maybe, in the relief of coming to a decision, the small matter of ensuring that the patient does not suffer as they die, is sometimes forgotten.

So end of life has remained a terrible riddle in western healthcare systems, fodder for many high profile pundits, but ultimately with few reasoned solutions, for a subject dense with emotion.

Perhaps, in the emotion of this subject, we have forgotten to apply plain logic in trying to find a solution.

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It is with this in mind that South Australia has quietly embarked on a plan to develop a coherent strategy for end-of-life decision making and care, with its basis being common sense and logic rather than hyperbole.

So, if this problem was an equation, what is the answer that you would want? End-of-life care which respects patient wishes in a legal, ethical and compassionate way so that patients die in comfort and dignity – but which also reduces instances where treatment is provided which is of no benefit to dying patients, such as vain attempts at resuscitation or inappropriate intensive care admissions. Let's call this answer X.

And, logically, to get X, we need:

A. **A standardised way for patients to document their wishes, backed by good law** which is clear and emphasises patient self-determination, but is balanced with protections in line with good medical practice: ***The Advance Care Directives Act 2013* and Form**

B. **A way of converting these patient wishes into clinically useful instructions**, in line with the law and ethical principles, but which also ensures treatment to maintain the comfort and dignity of patients if they are not for resuscitation: **The 7 Step Pathway**

C. **A system of getting this information to the point of care when it is required**, especially in emergencies: Such as eHealth strategies: EPAS or PCEHR

D. **Access to a general and specialist workforce able to provide the comfort and palliative care** to patients who require it

So, **A + B + C + D = X**

Given that from 1 July 2014, the first two steps in this equation, A and B, will be implemented across South Australia, it would be appropriate to consider these at the outset. ▶

The Advance Care Directives Act 2013 and the Advance Care Directive form

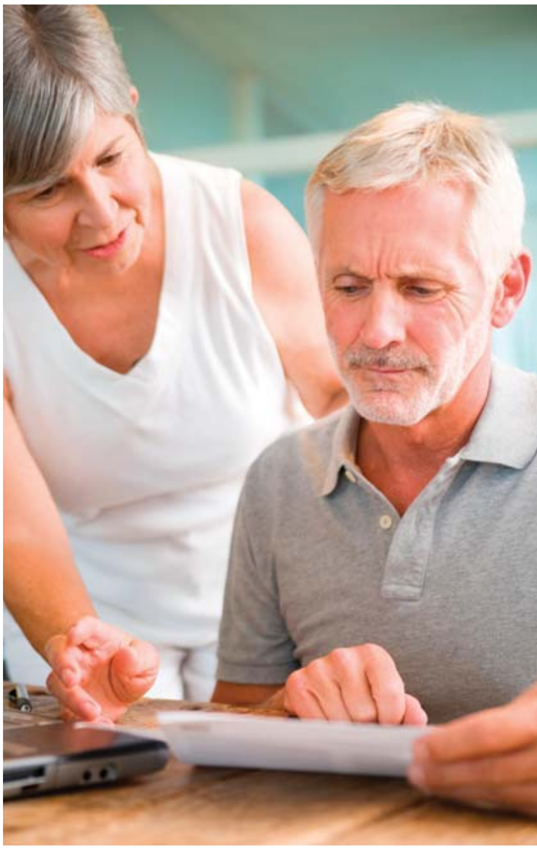
THE first thing to be clear about is that the effects of the *Advance Care Directives Act 2013* (and amendments to the *Consent Act*) apply to every situation where a patient has lost capacity and a decision needs to be made requiring consent. Not just at end-of-life, but also when patients suffer mental illness, dementia, delirium, or are under anaesthesia, for example. And not only in regard to medical decisions, but also decisions regarding personal or accommodation (but NOT financial) matters.

The most tangible effect of the new Act is the introduction of a new legal form, called the Advance Care Directive (ACD), on which patients can appoint Substitute Decision Makers (SDMs) and/or document their values or wishes for a time in the future when they might lose capacity to decide. This form replaces the previously confusing and poorly utilised array of legal instruments comprising Anticipatory Direction, Medical Power of Attorney, and Enduring Guardianship – with the completion of the new ACD form for a patient revoking all such instruments previously completed by that patient.

The less tangible, but more important effect of the Act for clinicians is in better law which emphasises patient autonomy, but is balanced with protections that align with good medical practice.

The more straightforward aspects of this for doctors include the introduction of the concepts of Binding Refusals – that is, a clearly documented refusal of treatment (eg, CPR) must be complied with if relevant to the situation – and Non-Binding Requests, which are only advisory but which should be complied with if possible.

Then there are new protections in that doctors are protected if they act in good faith even if they misinterpret an ACD; a doctor cannot be made to provide treatment which breaches professional code/standards; a doctor can conscientiously object (but should hand over care in line with the professional code); and an ACD cannot be used to demand treatment which is illegal, aid in euthanasia, assisted suicide, or a refusal of mandatory treatment (eg, under the *Mental Health Act 2009*).



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And, there is a simplified course of action in resolving disputes that may arise – initially via the Public Advocate, and then the Guardianship Board.

But the heart of this legislation, and where it brings a fine legal balance between patient autonomy and protections for doctors, is in four main points to which the Act gives clarity:

Firstly, it makes it absolutely clear what patient autonomy (self-determination) is. The overriding principle inherent in the Act is for all parties – Substitute Decision Makers (SDMs), Persons Responsible and doctors – to 'act as if they are in the patient's shoes' and to do what the patient would have done – that is, 'substitute decision making'. This especially applies to binding refusals. So, in making decisions for a patient who has lost capacity, all individuals acting for the patient must discard their own values, what they themselves may want for the patient, or even what they think might be 'best' for the patient (ie, 'best interest decision making'). In this way, any confusion about the basis on which to decide for a patient is minimised.

Secondly, in applying this patient autonomy, there is a much clearer legal hierarchy or 'pathway' that must be kept to in obtaining consent for treatment for a patient without capacity. Doctors, in the first instance, must consult an SDM if one is appointed by the patient on the ACD form – they in effect 'become' the patient. If a patient has wishes and values documented on an ACD form, but with no SDM appointed, these wishes and values should then become the basis of decision making. If a patient has not completed an ACD, consent should be via the Person Responsible – a group of individuals including relatives and carers codified in a legal hierarchy under the new Act. So the legal order is an SDM – followed by wishes and values documented in an ACD – followed by Persons Responsible. And, of course, all parties should act as if they are 'in the patient's shoes'.

This consent hierarchy has the advantage of clarity, but there will also be less room for the loose thinking that has been allowed to occur in the confusion between the current Acts – and this may entail some risks in that it will be much more obvious when people are 'off the legal pathway'.

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The third main change comprises a protection for health practitioners when acting in uncertain and urgent situations (emergencies). A doctor now has a defence if they provide treatment which appears to be against a documented binding refusal, if it is an urgent situation (where an SDM is not present), and where they may have doubt about whether the refusal was meant to apply in that situation. This is a new security which has never existed before.

The final change is that doctors will no longer be required to provide, and they will be able to withdraw, treatment which they do not think to be of benefit to the patient (contentiously given the name 'futile' treatment by some). In end-of-life situations, this may fundamentally change the basis of decision making – and may shift decision making from the current bias toward default resuscitation and treatment based on legally defensive medicine – to making more appropriate decisions about whether to resuscitate or offer treatment based on whether it will actually benefit the patient. This brings the law into line with professional standards. The Medical Board of Australia, Good Medical Practice, March 2014 states that doctors: 3.12.3 *should understand the limits of medicine in prolonging life and recognise when efforts to prolong life may not benefit the patient, and, 3.12.4 Understand that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.*

So, the new Act represents a major change affecting consenting when patients lose capacity – including at end of life, but not because it is complex, rather because it alters and clarifies the fundamental tenets on which doctors will make clinical decisions from 1 July 2014.

The 7-Step Pathway

WHILE the focus in many states has been on improving end of life care by improving the way that patients can express their wishes in advance of losing capacity – either by Advance Care Directives (ACDs – legal documents backed by specific legislation) or Advance Care Plans (ACPs – informal documents working only within common law) – there has been a glaring lack of insight into the fact that the clinician side of the equation, and the ability of doctors to convert these wishes into clinically useful instructions, has not been addressed.

While they may represent a patient's wishes, ACDs and ACPs often only provide vague statements such as 'I do not want to suffer' which are of limited value to health care workers in a medical emergency. They are also often completed a long time before a medical crisis and may not be relevant to the prevailing clinical situation. And worse, the ▸

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majority of patients still don't have ACDs or ACPs.

So relying solely upon ACDs and ACPs is a common, but fundamentally flawed strategy in regards to end-of-life decision making, because irrespective of how well a patient may have documented their wishes in an ACD or ACP, this may all be for nought if the doctor does not then turn this into clinically useful instructions about resuscitation and actions in regard to care.

Whilst it is important to know what the patient wants, via ACDs and ACPs, it was recognised in South Australia that we also needed a parallel approach in developing a way for the patient's doctor to convert these wishes into usable clinical instructions about resuscitation or end-of-life care, taking into account the patient's wishes, but also in line with appropriate medical practice (which the new Act now supports).

What became clear was the need for the development of Clinical/Resuscitation Plans (and planning) to replace the legally questionable ad hoc practice of writing Not for Resuscitation (NFR) orders in medical notes.

And the breakthrough was in understanding the distinction that ACDs and ACPs are the patient's form, and they represent what the patient wants, and that Clinical/Resuscitation Plans are by the doctor responsible for the patient, to assist other health practitioners who may later manage the patient.

> "If the patient is not for resuscitation, what are you going to do instead to maintain the patient's comfort and dignity?"

ACDs and ACPs represent the patient, Clinical/Resuscitation Plans are for the doctors.

And in South Australia, we have taken this one step further. We came up with the idea of turning Clinical/Resuscitation Planning into a simple pathway of

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logical and common sense steps for doctors to work through to get the right answers about resuscitation and end of life care.

Hence the development of the 7 Step Pathway Resuscitation Plan.

While it is a form, the 7 Step Pathway, unlike any other of its type, intuitively walks a doctor through the correct clinical, legal and ethical steps in end-of-life decision making, in the correct order. The doctor is asked to communicate with those they should (the form incorporates the changes in legal hierarchy brought about by the ACD Act 2013), it helps the doctor make the correct decisions about what is and what is not appropriate resuscitation or treatment and, most critically, it ensures that the patient and family are cared for until they die, with the doctor being asked the question: "If the patient is not for resuscitation, what are you going to do instead (to maintain the patient's comfort and dignity)?"

The process, rather than the form itself, ultimately protects both the patient and the doctor in regard to the decisions made, and the 7 Steps, in many ways, will support the practical application of the new *Advance Care Directives Act 2013*, with its balance between respect for patient wishes and protections for doctors in line with good medical practice.

And most importantly, it evolves the thinking about end of life from the current tortured emphasis on whether to resuscitate a patient or not, to one about ensuring their comfort and dignity until the end.

The final pieces of the equation

WITH the concurrent implementation of the *Advance Care Directives Act 2013* and the 7 Step Pathway, we have a mechanism for interweaving the patient's wishes, legal requirements and good medical practice into better end-of-life decision making.

But to finally solve this equation, we need two other things – C and D in the equation.

Firstly, we need systems to get the patient's practical instructions about resuscitation and end-of-life care to the point of care when it is required, so that doctors, nurses and ambulance officers, who may not be familiar with the patient, can respond correctly in emergency situations. For this to happen, the instructions from the 7 Step Pathway (or a patient's ACD if they have one) must be available at any time the patient deteriorates and wherever they happen to be. This requires systems to be developed to share this information across health care sectors – hospital, nursing home and home – which may be a paper-based system, or better still, electronic, via the state EPAS or national PCEHR ehealth record systems. These are ongoing pieces of work.

Finally, we need adequate training and resourcing of not only specialist Palliative Care, but all health care workers, in the provision of comfort and palliative care for our patients when they require it. In this regard, the Palliative Care service is steadily evolving its model of care to be more responsive and reliable to the needs of both the patients and their referrers. ▸

The recent development of a Statewide Palliative Care Referral Form is symbolic of the move to create a more cohesive service which will work hand in hand with both acute and primary care to better serve the palliative care needs of the community.

> … the 7 Step Pathway must be available at any time the patient deteriorates and wherever they happen to be.

So, in considering this problem with some logic, and putting the pieces together in a common sense way, there is now a chance to implement the first coherent statewide approach to end-of-life decision making and care. The AMA(SA) has worked constructively with the Minister and SA Health over many years in this endeavour.

Written into South Australia's Health Care Plan 2007-2016 document is a subtle implication which is generally unrecognised: that our job in health is not to cure until the end, but to care until the end. One hopes that, with the implementation of a more coherent strategy for end-of-life decision making and care, doctors will be able to work with more confidence and consistency with patients and their families to fulfil this mandate. And while dealing with the issues of death and dying may bring to us the discomfort of a recognition of our own mortality, it might also bring us more in touch with our own humanity.

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