

**Australian Government Productivity  
Commission Draft Report on Caring for  
Older Australians**

**Submission by the Respecting Patient  
Choices "Making Health Choices"  
Steering Committee**

## **Introduction**

The members of the Respecting Patient Choices (RPC) 'Making Health Choices' Steering Committee welcome the opportunity to provide input to the Productivity Commission Public Inquiry into Caring for Older Australians.

The RPC 'Making Health Choices' project is a pilot implementation and evaluation of advance care planning in Residential Aged Care Facilities (RACF) in Victoria, funded by the Department of Health and Aging. As such we are currently implementing a tailored, sustainability based model of advance care planning in 19 RACFs across the state.

The RPC Program at Austin Health aims to provide best practice in advance care planning to all Australians and has been working at the forefront of this field for the past 9 years. The RPC Program was funded in 2002 by the National Institute of Clinical Studies and, from 2003 to present, by the Commonwealth Department of Health and Ageing and the Victorian Department of Health. We have made previous submissions, including to the 2008 National Health and Hospital Reform Commission, and the 2007 Parliamentary Inquiry into Older People and the Law.

The focus of this submission is the extent to which advance care planning should be addressed in the Productivity Commission Draft Report.

We fully endorse the Commission's recognition of the need for improved palliative care provision in the aged care sector. Advance care planning is a key component of effective palliative care. In addition, we support the draft recommendation that legislation and documentation around advance care planning is made nationally consistent (12.9). It is vital that the process of advance care planning is clear and effective regardless of state of residence. Standardised documents and legislation will help to ensure that treatment preferences are known and respected. The process of standardisation needs to be prioritised and achieved in a timely manner.

The draft report clearly highlights the need for improved patient centred care and consumer choice. We were therefore surprised that advance care planning was not included more extensively in the draft recommendations. We would suggest that advance care planning is a key component of consumer choice and patient centred care, and that its inclusion in the reform of the aged care system will help to improve the provision of high quality care and provide protection for this vulnerable population. We believe that the draft report reflects a lack of awareness that the provision of quality advance care planning is a holistic, systematised process that is significantly more complex than ensuring consistent legislation and documentation.

In this submission we provide further information regarding the process of advance care planning, including evidence demonstrating the positive impact of quality ACP on the aged care sector. We have made suggestions for more comprehensive and accurate coverage of advance care planning in the recommendations to be put forward by the Productivity Commission.

### **What is advance care planning?**

Advance care planning (ACP) is a process whereby Australians can voluntarily plan for, and record, their future healthcare preferences in preparation for a time when they are not able to express their wishes regarding end-of-life decisions.

ACP is based on the ethical principle of autonomy, particularly the right to informed consent, and the principle of respect for human dignity, particularly the prevention of suffering.

ACP involves health professionals discussing with patients and their families, the likely progression of, and treatment options for, their respective illnesses. Patients

can then consider and make choices about their future health preferences, based on an understanding of likely outcomes.

ACP usually involves a person appointing a substitute decision-maker to convey their healthcare preferences at a time when they might not be able to do so. In the experience of most joint signatories to this submission, the vast majority of patients approached about advance care planning wish to appoint a family member or a close friend as a substitute decision-maker. They invariably indicate that this is because they trust that person to make the right decision in the future, based on what is in their best interests and respectful of their previously expressed wishes.

ACP also enables the patient to record preferences regarding specific treatments or to document their view regarding unacceptable outcomes. Completed Advance Care Plans enable health care providers and substitute decision-makers to consider these recorded views when making treatment decisions, at a time when the patient is no longer competent to do so. Specifically, awareness of the patient's views enables loved ones and health professionals to make an informed decision as to whether the patient would regard a treatment as being acceptable or overly burdensome.

### *Advance care planning in action: a case study*

A 93 year old man, Mr F, was admitted to an RACF with dementia, heart disease, arthritis, bilateral knee replacements, deafness, incontinence, insomnia and increasing frailty. He had previously managed at home with the care of his aging, frail wife, community services and daughters.

On arrival at the RACF his daughter and wife were introduced to the concept of **advance care planning** by the admitting nurse and were given the Respecting Patient Choices Information booklet. The following week a meeting occurred with the Nurse Manager, Mr F, his wife and two daughters.

Mr F was restless but was able to express that he did not wish to be transferred to hospital if he became sicker. His family confirmed that his previous wish was that he “never die in a hospital”.

His family members were able to complete an informal advance care plan on his behalf, based on his previously stated wishes:

- \* He did not want CPR or life prolonging treatments
- \* He only wanted to be transferred to hospital for an acute episode that couldn't be managed at the facility, \* (eg. fractured femur) and then return to facility at the earliest possible time after this
- \* He wanted the family to be contacted and to be with him when he was dying
- \* The family and doctor will discuss any alternative treatment at the time
- \* We request the normal palliative care process to be commenced.

His condition declined over a two year period. Mr F suffered a stroke and so a meeting was held with his family, his GP and the Nurse Manager of the facility. A decision was made, in keeping with his Advance Care Plan, that Mr F would stay at the facility and receive palliative care (this included fresh flowers in his room daily, soft music playing, and aromatherapy). The GP visited daily, to ensure that Mr F had adequate pain control.

The family kept a bedside vigil and Mr F died peacefully at the facility three days later.

### **Learnings from this case study:**

1. That ACP can still occur successfully with patients who are no longer competent
2. That ACP does not require formal documentation. It is the discussion and reflection that is important, not the paperwork.
3. That, although complying with the law, ACP does not require constant or, often, any engagement with “legalities”

If a patient's preferences are known, understood and accepted, the patient, family and carers can be reassured that health professionals will respectfully consider the patient's wishes.

### **The case for advance care planning**

Advance care planning is important to all Australians, particularly those aged 65 and over, for the following reasons:

1. Most people (approximately 85%) will die after chronic illness, not a sudden event.
2. Many Australians (up to 50%) will not be in a position to make their own decisions when they are near death.
3. Families have a significant chance of not knowing their loved one's views on how they want their end of life to be.
4. In the absence of a clear statement of a patient's wishes, doctors usually initiate aggressive treatment which the patient may not want.
5. At present, many Australians are kept alive under circumstances that are not dignified and this causes unnecessary suffering. . .
6. Our experience shows that if doctors inform patients about possible future treatments and listen to their wishes, better end of life care is the result. Unwanted investigations and interventions are avoided and, therefore, inappropriate use of resources. Examples of such treatments include: undergoing surgery then being transferred to intensive care and dying whilst on a ventilator; having a feeding tube inserted into the stomach because of poor oral intake due to advanced dementia with no improvement in life expectancy; or having suffered a severe stroke with major disability, from which the patient has no hope of recovery
7. A study at the Austin Hospital, published in the *British Medical Journal*<sup>1</sup> in March last year, demonstrated that *Respecting Patient Choices*<sup>®</sup> significantly reduced the incidence of anxiety, depression and PTSD- post traumatic stress disorder- symptoms in the surviving relatives of patients who died.
8. The vast majority of ACP throughout Australia is conducted in compliance with, and support from, common law, not statutory law. RPC has been successfully introduced into every Australian state and territory irrespective of the prevailing legislation. This is possible because the focus and the power of the ACP process is that it catalyses reflection and discussion amongst patients, family members and health professionals and leads to the completion of advance care plans that are recognised documents under common law and is NOT reliant on documents defined by legislation. Therefore, although it would be ideal to have similar legislation and uniform terminology in each state and territory, such changes are not crucial for ACP and a delay in such changes should not stand in the way of implementing ACP for the aged or be used as an excuse for delaying such implementation.

### **Advance Care Planning is not euthanasia**

It is important to emphasise that advance care planning does not support or facilitate euthanasia, which is the deliberate taking of life. On the contrary, our experience has shown that, after completing and documenting their end of life health care wishes, many patients feel that they have regained control. "I now feel that I have some control over what will happen to me in the future and have turned my mind away from contemplating euthanasia," is a typical response. Furthermore, the advance care planning process has also ensured that patients, often elderly, have requested, and received, treatments that their doctor and family had wrongly assumed they would not want.

### **Advance care planning in action: a case study**

*Mrs. P. is 82 years old, with severe end-stage lung disease. She is on home oxygen 24 hours a day. She has coronary heart disease with angina and has sustained several rib fractures and a fractured humerus (upper arm). Due to severely decreased exercise tolerance and fear of falls she is housebound. She is cared for 24 hours a day by her 48-year-old son.*

*Through a process of advance care planning, Mrs. P. expresses her wish not to be admitted to hospital again or even be assessed by ambulance officers. It is her choice to be seen by her General Practitioner for all medical issues. She nominates her son as her substitute decision-maker.*

*The patient's son is now better equipped to manage his mother's severe health issues. Her Advance Care Plan in regard to end-of-life wishes allows him to legally refuse treatment. The GP has made a commitment to fulfil this choice if possible.*

*The patient is very happy with the advance care planning process and knows she has left her son with clear guidance about her end-of-life wishes.*

## **Advance Care Planning- improves quality of care to the elderly and their family**

There has been an increasing awareness of the inadequacy of end-of-life care and of the poor knowledge of patient wishes regarding their medical treatment at a time when they lose the capacity to make decisions, resulting in patients being cared for in a way that they would not have chosen. Apart from progress in palliative care, the main focus to address these needs has been the development of ACP.

Patients consider that a "good death" requires five important factors: symptom management, avoiding prolongation of dying, achieving a sense of control, relieving burdens placed on family and the strengthening of relationships. Furthermore, although traditional understanding of the benefits of ACP are respect for autonomy, preparation for possible future incapacity and completion of formal advance directives, patients see that the benefits of ACP include preparation for end-of-life care and death, avoiding prolongation of dying, strengthening of personal relationships, relieving burdens placed on family and the informal communication of future wishes.

In a recent randomised controlled trial, published in the British Medical Journal in March 2010<sup>1</sup>, we delivered advance care planning to people over the age of 80 who were admitted to a tertiary referral hospital for medical treatment. We demonstrated that properly conducted ACP by trained non-physician staff improves end-of-life care by enabling patients' wishes to be determined, documented, and then respected at end-of-life. In this study in 95% of cases where patients' wishes were known, they were respected.

Patients welcome ACP and expect health professionals to initiate discussions. Our findings dispel the common myth that patients are distressed by this discussion. Intervention patients were significantly more likely to be very satisfied with overall care in the hospital, information provided, being listened to and being involved in decision-making.

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<sup>1</sup>The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. Detering KM, Hancock AD, Reade MC, Silvester W. BMJ 2010;340:c1345

A very important outcome of this study was that emotional trauma was reduced in the family members of patients who underwent ACP and subsequently died. Our program involved surrogate decision makers throughout ACP, thereby increasing their knowledge and understanding of the patient's wishes, thus reducing the burden of making difficult end-of-life decisions on behalf of the patient. ACP significantly reduced symptoms of post-traumatic stress, anxiety and depression in family members.

### **Advance Care Planning – the demonstrated positive impact in the aged care sector**

The implementation of the RPC Program in 17 RACFs during 2004-2005 demonstrated a successful model of advance care planning (ACP) in these settings. The vast majority of older Australians welcomed discussions about their future health care decisions. Indeed, only 2.3% of residents approached about ACP wanted no further discussion<sup>2</sup>.

Secondly, families welcomed the opportunity to discuss and make decisions regarding these sensitive and deeply personal issues involving frail elderly relatives (Commonwealth of Australia, 2006). Residents, their families and health professionals achieve peace of mind in knowing that an individual's preferences have been discussed and recorded prior to them losing ability to "have a say about what happens to them".

The discussion and documentation of these future decisions greatly diminishes any uncertainty for doctors about what to do regarding end-of-life care.

All (100%) residents who completed an RPC initiated advance care plan, and who died during the evaluation period, had their medical treatment wishes respected at their end-of-life.

Almost 90% of the residents who had completed advance care planning died in their facilities receiving palliative care, whereas approximately half of those residents who had not had an advance care planning discussion died in hospital (  $p < 0.05$ ).

RPC in the 17 RACFs significantly reduced the likelihood of hospital admission prior to death and the length of stay in hospital<sup>2</sup>.

Independent research by Latrobe University demonstrated that the RPC model of ACP in RACFs increased the level of satisfaction about the care being provided in RACFs, from the perspective of the residents, their family, the RACF staff and the GPs

### **Potential financial impact of the RPC Program in RACFs**

The impact of the RPC Program on the likelihood of a resident from an RACF being admitted to hospital prior to death, and the length of stay whilst in hospital is statistically significant and presents considerable resource implications for the Australian health care setting. These implications are independent of, and in addition to, the primary aim of the Program which is to improve quality and safety of care and to respect patient autonomy and dignity.

RACF residents that are not introduced to RPC have a 46% likelihood of admission to hospital with a mean length of stay of 15.3 days prior to death whereas deceased RACF residents who are introduced to RPC have an 18% likelihood of admission to hospital with a mean length of stay of 6.9 days (see above).

Therefore, for every 100 deceased residents who were not introduced to the RPC Program, they would incur a total of 703.8 hospital bed days whereas those introduced to the RPC Program would incur a total of 124.2 hospital bed days. Thus

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<sup>2</sup> Final evaluation of the Community Implementation of the Respecting Patient Choices Program : Report to Commonwealth Government Department of Health & Ageing Jan 2006

the implementation of the RPC Program has the potential to save 580<sup>3</sup> hospital bed days per 100 deceased residents or 5.80 hospital bed days per RACF death.

Given that there are approximately 41,000 deaths per year of permanent residents in RACFs in Australia (AIHW), there is a potential saving of 237,800 hospital bed days per annum. The average cost of one bed day, for example at the Austin Hospital, is \$1058, therefore there may be a potential annual saving of over \$251 million per year by introducing the RPC Program to all RACFs across Australia.

This analysis does not include the resource implications of providing hospital based treatment to residents who may not have wanted such interventions and who then returned to their RACF for continued care in a potentially worse state of health.

The potential savings, by acute health services, in excess of \$250 million per annum needs to be considered in the context of a shift in the utilisation of resources and provision of palliative care to individuals in their residential aged care setting. Guidelines such as the Guidelines for a Palliative Approach in Residential Aged Care should be utilised.

### **Potential impact of advance care planning on mental health in aged care.**

Australian studies suggest that there are high rates of depression and anxiety in residents of RACFs. For example, McSweeney and O'Conner<sup>4</sup> reported that 24.5% of newly admitted residents met the criteria for major depression, whilst Cheek et al reported that 11% of aged care residents exhibited generalised anxiety disorder. There are a number of risk factors associated with depression in the elderly including neurological disorders, however, environmental and intrapersonal factors are also considered important.<sup>5</sup> In line with this, pain, loneliness, visual impairment and stroke were found to be associated with depression on admission to aged care facilities.<sup>6</sup> In addition, it has been suggested that depression underpinned by feelings of disempowerment and loss may be more common in this population.<sup>5</sup>

We expect that effective ACP on admission to an RACF may reduce feelings of disempowerment by allowing the resident to gain a sense of control. In addition, an in-depth discussion between the resident, family and healthcare providers around their history, values, beliefs and wishes may help to reduce feelings of loneliness. Feedback from participants in the 'Making Health Choices' project debrief sessions indicates that the advance care planning process allows RACF staff to gain a more in-depth understanding of residents, improves therapeutic alliance, and engenders a feeling of relief and awareness of choice and control in residents.

There is an established interaction between symptoms of mental illness and physical illness.<sup>5,7</sup> Cole<sup>8</sup> suggests that effective treatment of pain in patients with co-occurring terminal illness and depression may improve symptoms of depression, whilst better treatment of depression in these individuals may reduce pain ratings and pain related functional impairment. This bi-directional relationship between physical and mental health lends support to the argument that the provision of ACP in combination with effective palliative care to RACF's may have significant positive impacts on all aspects of the end-of-life experience for residents.

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<sup>3</sup> 704 - 124 = 580

<sup>4</sup> McSweeney K, O'Connor DW. (2008). Depression amongst newly admitted Australian nursing home residents. *International Psychogeriatrics*, 20: 724-737.

<sup>5</sup> Snowdon J. (2010). Depression in nursing homes. *International Psychogeriatrics*, 22(7):1143-8.

<sup>6</sup> Smalbrugge, M. S., et al (2006). Incidence and outcome of depressive symptoms in nursing home patients in the Netherlands. *American Journal of Geriatric Psychiatry*, 14, 1069-1076.

<sup>7</sup> American Psychological Association. *Psychology and aging: addressing the mental health needs of older adults*.

<sup>8</sup> Cole BE. The psychiatric management of end-of-life pain and associated psychiatric comorbidity. *Curr Pain Headache Rep*. 2003 Apr; 7 (2) : 89-97

## **Recommendations on how to effectively integrate quality Advance Care Planning into the Aged Care System.**

We believe these recommendations would fit within the broad sections 'Care and Support' and 'Catering for Diversity, Caring for Special Needs Groups', Delivering Care for the Aged – Workforce Issues.

1. Implementation of best practice advance care planning across residential and community aged care services.

The 2009 National Health and Hospitals Reform Commission (NHHRC) Report made a recommendation for the national implementation of ACP across all RACFs followed by an extension to other relevant groups in the population (recommendation 57)<sup>9</sup>. This recommendation needs to be reflected in the present productivity commission report.

The RPC Program in collaboration with Palliative Care Australia is currently conducting the 'Making Health Choices' project to develop, implement and evaluate a best practice model of advance care planning specifically for RACFs.

It is vital that this work is extended to community aged care services in order to support efforts to provide quality, patient centred, in-home care to the elderly. We would suggest that provision of advance care planning for individuals in the community could be achieved at first point of contact with the aged care services through the Australian Seniors' Gateway Agency.

2. Improved training and education of the aged care workforce for the provision of advance care planning

The NHHRC recommended that all aged care staff receive training in the provision of ACP (recommendation 51)<sup>10</sup>. This recommendation needs to be reflected in the present productivity commission report.

To ensure the sustainable and quality provision of ACP, workforce education needs to be an ongoing process to for the purposes of skill maintenance and to account for staff-turnover.

3. Recognition that advance care planning and quality palliative care are inherently linked in the aged care sector.

We would suggest that it is disingenuous to offer advance care planning in the aged care sector without ensuring the provision of quality palliative care in residential aged care facilities.

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<sup>9</sup> NHHRC recommendation 57. We recommend that advance care planning be funded and implemented nationally, commencing with all residential aged care services, and then being extended to other relevant groups in the population. This will require a national approach to education and training of health professionals including greater awareness and education among health professionals of the common law right of people to make decisions on their medical treatment, and their right to decline treatment. We note that, in some states and territories, this is complemented by supporting legislation that relates more specifically to end of life and advance care planning decisions.

<sup>10</sup> NHHRC recommendation 51. We recommend that all aged care providers (community and residential) should be required to have staff trained in supporting care recipients to complete advance care plans for those who wish to do so.



4. Improved funding to support the involvement of General Practitioners in the advance care planning process.

In line with the submission by the Australian General Practice Network we support the argument that an effective advance care planning process can only be achieved were GPs are fully involved in the advance care planning discussion and formulation of an advance care plan. Evidence from debrief sessions conducted as part of the RPC 'Making Health Choices' project suggests that currently, due to lack of funding to support the provision of GP services for RACFs, there is great variation in the involvement of GPs in advance care planning within our pilot facilities.

5. Improvements in the interface between aged care and the general health system around advance care planning.

The effective communication of advance care plans between health care sectors (e.g. from hospital to RACF and vice versa) is vital if patient's treatment preferences and end of life care wishes are to be known and respected.

The new National Health and Hospitals Network (NHHN), which will comprise Medicare Local primary health care organisations and Local Hospital Networks, will rely on close collaboration between the two. It will offer a good platform for greater communication of advance care plans between RACFs, Medicare Locals and Local Hospital Networks. Coordination will be assisted by the government announcement that Medicare Locals will have a key role in coordinating aged care in their regional communities.

**This submission has been endorsed by all members of the RPC 'Making Health Choices' Project Steering Committee**

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