

Senate Standing Committees on Community Affairs Inquiry into Palliative Care in Australia

Submission from the Respecting Patient Choices Program

This submission to the Senate Inquiry into Palliative Care in Australia has been made by the Respecting Patient Choices® (RPC) Program. This advance care planning program, based at Austin Health, has been funded from 2003 to present, by the Commonwealth Department of Health and Ageing and by the Victorian Department of Health. This submission is restricted to the section of the inquiry pertaining to the role of advance care planning in palliative care.

“Since the 1990s there has been an increasing awareness of the inadequacy of end of life care and of the poor knowledge of patients’ wishes about their medical treatment at a time when they lose the capacity to make decisions, resulting in patients being cared for in a way they would not have chosen. This has continued to the present day. Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning.” (From Detering K & Silvester W, BMJ 2010;340:c1345)

1. What is advance care planning?

Advance care planning (ACP) is a process whereby people can voluntarily plan for, and record, their future healthcare preferences in preparation for a time when they are not able to express their wishes, particularly regarding, but not limited to, 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 the authors of 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 a 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.

2. 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. Therefore most people will benefit from the opportunity to consider the care that they would want during that chronic illness, particularly near the end of life.
2. Many Australians (up to 50%) will not be in a position to make their own decisions when they are near death. Therefore the opportunity to guide their doctors and family regarding their treatment preferences will be lost if preferences have not been expressed and recorded earlier.
3. Families have a significant chance of not knowing their loved one's views on how they want their end of life to be. Therefore the families are at risk of making a wrong substitute decision and feeling burdened by it.
4. In the absence of a clear statement of a patient's wishes, doctors usually initiate aggressive treatment that 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. It is now widely acknowledged that the application of ACP is an important component of personalised end-of-life care, and that recognition and accommodation of preferences expressed in ACP documents allows individuals to have control over the level of health care they receive at the end of life.¹⁻⁵ Studies conducted in a range of healthcare settings suggest that ACP can improve patient and family satisfaction with care,⁶⁻⁷ reduce nursing home to hospital transfers,⁸⁻¹⁰ limit the application of burdensome treatments at the end of life in line with patient preferences,^{7,11-12} and reduce indicators of stress, anxiety and depression in surviving relatives.⁶⁻⁷
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 a reason for delaying such implementation.

Advance Care Planning is not euthanasia

It is important to emphasise that ACP 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 ACP 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.

3. Advance Care Planning and Community Palliative Care

Patient surveys reveal that they support five factors as important for a good death: managing symptoms, avoiding prolongation of dying, achieving a sense of control, relieving burdens placed on the family, and the strengthening of relationships.^{13,14} Most of these are facilitated by ACP. Respecting Patient Choices, Austin Health, introduced ACP to two community specialist Palliative Care Services (PCS) during 2003-2005. While evaluation provided evidence of ACP in the community based PCSs, particular challenges to implementing the RPC model, and also collecting this evidence were encountered. These challenges included the way in which community based PCSs share health care delivery between services, lack of co-ordinated documentation systems within and between services (e.g. electronic and paper) and the requirement that clients kept their Advance Care Plans in their own homes. Further barriers to implementation included the appropriateness of the RPC Consultant training for Palliative Care staff.

As a result of these findings, in conjunction with La Trobe University, Department of Nursing and Midwifery, we identified a model of Advance Care Planning for community based PCS. A number of recommendations for future implementation in community based Palliative Care Services arose from this work and the need for further research around the model specifically used by PCS. The Australian Government Department of Health and Ageing funded a further three year research project (2007-2010) to determine if the implementation of the RPC – Community Specialist Palliative Care Model in community specialist palliative care services led to improvements in the safety and quality of care for patients at their end-of-life, and to evaluate the systems and processes implemented in the model. The study¹⁵

demonstrated indirect evidence, of increased ACP activity in the participant Community Palliative Care Services, although significant change in direct evidence was more difficult to obtain. This was largely a result of absence of suitable mechanisms to record the process of ACP which is not a single event but occurs over time and needs to be re-assessed regularly as situations change rapidly near end-of-life. However, interviews conducted with PCS clients and the experience of PCS staff, indicated that ACP had significant impacts on client and family outcomes.

The Impact of ACP on Community Palliative Care Services Clients

Providing Choice and Hope

With the introduction of the ACP model clients found they could express their preferences for future care.

with a lot of people they go along with whatever medically you are told you are doing and so it is the concept of 'Oh, I can actually make a decision, how do I actually make the right decision?'

Many patients living with a long standing chronic illness had not previously been offered an opportunity to make decisions about their future care. Some found it unusual and refused. As the following case demonstrates, events revealed benefits of ACP to some families, not only to them, but to the staff as well, as this story shows,

One morning [a client's] daughter rang the office and said to me I am just letting you know dad has collapsed and he can't breathe and we have rung an ambulance. I said that is fine but I have a feeling your dad might have made an advance care plan and she said yes I think he did too...so it was great because I was able to look up on our computer and see that yes there was an advance care plan, I went and got it out of the history, read it, he wanted no heroics and I rang her back

After discussion between the daughter and the staff, it was agreed that the family wanted the terminal phase of their father to be managed in hospital. The nurse contacted the emergency department and indicated that the client had an advance care plan in their hospital record:

They admitted him to a medical bed and he died two days later very comfortable and with no heroics and the family rang me back and were very grateful that everything went to smoothly so because I have that example of it working so well I am more committed to it.

For other clients they needed time to think about it. For a client who had previously been discharged from the service:

[she] rang me up and said she wanted to do her advance care plan, this is some eighteen months after we admitted her, amazing, and she has just sent it to me in the mail. We had a good talk about it, she needed to know all the shades of grey aspects and she and her daughter came in we tossed it around and then she went home to write it. That is the first I have had like that.

Such experiences reinforce the value of an ACP procedure one service developed, in which all case managers must report the ACP status when they discharge a client, at the client review and ensure it is documented. If there is no evidence of ACP discussion they need to reaffirm that clients have been given the RPC ACP planning guide for future use. For one primary carer, it was important to know what her sister wanted in the terminal phase of her illness to reduce the potential for family conflict:

What was important that I was going to provide care for her ongoing and that I needed to know what she wanted because ...I was anxious about how she was going die ...and I needed to be clear about what level of intervention she wanted and how she wanted to die...[and] ...if I had her wishes in a formal way it meant that I could fulfil that role for her ...and I knew that family would be doing everything to keep her alive and would have trouble not providing intervention unless that was in a legal way.

The Impact of ACP on Community Palliative Care Services Clients

The paradigm case

A regional palliative care nurse consultant was asked by the rural community nurse to visit a client who had asked about euthanasia. He lived alone after nursing his wife through her terminal illness and had now been diagnosed with a terminal illness himself. A 'lady friend', who had been prepared to move to the town to care for him died suddenly:

[H]e was pretty devastated and he felt that there was no meaning at all in his life....He was going to kill himself. He said he would do it before he got too bad because he didn't want to be lonely and he didn't want to burden his children. He didn't want to be in the nursing home. He didn't want to be stuck in hospital and not able to get out and be in his home. They were the openings...

The client was assessed as depressed and referred to the GP and psychologist. The nurse also said:

we talked about an advanced care plan, went through a little bit about what the process was. He said that yes he'd really like to have a look at that. So we got a couple [advance care plan documents] for the community nurses. I just went through the process with the community nurses on how you filled it out and things to raise with him. They took it out and they said it was a really lovely experience filling it out with him because it was almost like a bereavement visit as well because he was remembering things that had happened to his wife and talking. Basically he filled it out and said he just felt so much better and distributed the copies.

Although the client did visit the GP, he chose not to commence the prescribed anti-depressants and only visited the psychologist once:

...after that the nurses said that when they went around there he's never home. It seemed to pick him up....I think it was certainly filling out the advance care plan and being able to say what he wanted. But again I think it was the discussion as well. The day that I visited him, we were there for an hour and a half. We really did spend quite a bit of time. And then the community nurses went back a couple of times.

Although the conversation with the nurse was relatively short, the investment resulted in long term gain and improved quality of life for the client. The health services also had clear guidance about his preferences for his future care.

4. Advance care planning in other healthcare settings

The provision of palliative care within Australia extends beyond specialist palliative care services to other health care settings including acute hospitals and residential aged care.

Demonstrated positive impact in the aged care sector

The implementation of the RPC Program in 17 residential aged care facilities (RACFs) during 2004-2005 demonstrated a successful model of ACP in these settings.¹⁶ 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.

Secondly, families welcomed the opportunity to discuss and make decisions regarding these sensitive and deeply personal issues involving frail elderly relatives.¹⁷ 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 ACP 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 (from 46% to 18%, $p < 0.05$) and the length of stay in hospital for those who were admitted. It was estimated that, if ACP was made available to residents in RACFs across Australia, this implementation alone would lead to an annual saving in national hospital expenditure of at least \$250 million.¹⁴

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

Demonstrated impact in the acute care sector

The RPC Program was implemented nationally to one lead site in each State/Territory during 2004-06, and, since 2003, has been expanded to nine health services across Victoria. Each expansion has used the train-the-trainer model, thereby encouraging local ownership and further expansion. Evaluation of the national roll-out of the RPC model showed that RPC had a significant impact on the level to which consumers were involved in choices regarding their future care, and on the skill, confidence and involvement of health service providers in facilitating the advance care planning process.¹⁸ Data showed that if a person's end-of-life wishes are discussed in a sensitive and supported manner, and documented clearly and consistently within and between service sectors, then people receive healthcare in their place of choice and avoid receiving unwanted and, often, burdensome treatments.

The perception of the patients, their families and the health professionals is that the process of advance care planning improves quality of care and increases awareness of, and respect for, patient autonomy and human dignity.

Randomised controlled trial in elderly medical patients

The latest research conducted by the Austin RPC team was a randomised controlled trial of advance care planning in elderly inpatients.⁶ The results of the study were published in the British Medical Journal in March 2010.

Over a six-month period, between 2007 and 2008, all patients aged 80 or over who were admitted to the Austin hospital under general medicine, cardiology or respiratory medicine were screened for entry into the study (English speaking, mentally competent, significant illness). Suitable patients who gave informed consent were randomised to standard care (control) or standard care plus ACP (intervention).

The primary outcome measure was compliance with a patient's wishes during end-of-life care. This required a patient's wishes to be both known and respected for the primary outcome to be met. The secondary outcome measures included the completion of advance care planning documentation, the patient's perception of quality of care, the family's

perception of quality of care, the level of psycho-emotional trauma for the families of patients who had died.

Between August 07 and March 08, 877 patients were screened to achieve 309 patients providing informed consent. The single biggest exclusion criterion was non-competence amongst these elderly patients. 154 of the 309 patients were randomised to advance care planning, 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%; $P < 0.001$). In the intervention group, surviving family members of patients who died had significantly less stress ($P < 0.001$), anxiety ($P = 0.02$), and depression ($P = 0.002$) than those of the control patients. This was because, through their participation in the ACP discussions, the family knew their loved one's wishes and were, therefore, not stressed about making the end of life decisions when required. Patient and family satisfaction with care was higher in the intervention group.

5. Avenues for individuals and carers to communicate with health care professionals about end of life care

Respecting Patient Choices®

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 by the Victorian Department of Health.

The Australian RPC advance care planning program was based on the Respecting Choices™ model from the Gundersen Lutheran Medical Foundation, La Crosse, Wisconsin, USA. The Australian RPC Program has been completely adapted to the Australian health sector. The key elements of the RPC model are:

1. Providing training to doctors, nurses and allied health workers to be able to discuss advance care planning (ACP) with patients and their families.
2. Providing a comprehensive system for documenting and communicating patient choices.
3. Providing information materials to explain advance care planning to patients, and
4. Ensuring executive and organisational support for advance care planning.
5. Enabling the organisational system changes required to implement advance care planning effectively.

The guiding principle of the RPC Program is:

'If your choices for future health care are known, they can be respected.'

RPC supports the right of patients to have a say in their health care, now and for the future.

The five aims of RPC are to:

1. initiate conversations with adults regarding their views about future medical care
2. assist those individuals with advance care planning
3. ensure that their plans are clear

4. ensure that their plans are available when required
5. ensure that their plans are followed appropriately when decisions are required.

The advance care planning process includes:

- making sure that the patient is fully informed regarding their illness and treatment options
- giving the patient the opportunity to reflect upon, and discuss with their loved ones, their goals and values in life
- assisting the patient to identify their views regarding an acceptable outcome if their condition should deteriorate
- supporting the patient to record their views and to appoint a trusted substitute decision-maker

The two critical success factors of the RPC model, which distinguish it from other ACP models:

1. The RPC training course equips health professionals with the skills, knowledge and confidence to facilitate ACP discussions and the ACP process. The training has been further developed in 2007 into an e-learning module (including the role of the relevant legislation) and a one day communication skills workshop.
2. The attention to the organisational systems changes required for success and sustainability. Implementation of the RPC Model is facilitated by Implementation Guidelines which assist each health care setting to develop policy and protocols to ensure success.

6. National consistency in law and policy supporting advance care plans

A lack of national consistency in law and policy supporting advance care plans has been highlighted consistently in the medical literature,^{19,20} and this issue has been reviewed extensively in the National Framework for Advance Care Planning.²¹ Key issues include variation in terminology, a lack of consistency in legislated documents, limitations to the operation of advance directives, and accessibility issues.

Our experience from implementing the RPC model of ACP in eight different jurisdictions across Australia, each with different laws covering guardianship, advance directives and end-of-life care, has been instructive in understanding how the legislation can impact adversely on frail or elderly people in planning for their future healthcare. Some of the lessons learnt include:

- ❑ **Queensland.** The 24-page Advance Health Directive can be difficult to complete for some patients, who have preferred the simpler RPC “Statement of Choices” form. The document also needs to be witnessed by a lawyer, which can be difficult and costly for a frail or elderly person to arrange.
- ❑ **NSW.** The need for a lawyer or Registrar of the Court to witness the legislated enduring guardianship document significantly impedes the ability of the sick and elderly to see a lawyer or court registrar to have these documents witnessed. It is also suggested that lawyers are better than doctors in being able to assess whether a patient understands their health and future treatment decisions.
- ❑ **Northern Territory.** No legislation exists to allow the appointment of a substitute decision-maker for future medical decisions (this legislation is currently under review). Furthermore, the legislated form to limit unwanted treatment is only relevant to a terminal

illness, thereby preventing those with a chronic, but not imminently terminal illness, from completing the form.

- ❑ **Victoria.** Of the many hundreds of Advance Care Plans completed in Victoria, almost none used the statutory law document - the Refusal of Treatment Certificate – for two reasons. Firstly, the word “Refusal” leaves patients feeling uncomfortable and vulnerable to offending their doctor. Secondly, these Certificates are only valid for a current illness, which is not relevant for many of the elderly who do not have one specific illness but are still very clear about what they do, or do not, want in the future.
- ❑ **Variation in names.** There is confusing diversity between different jurisdictions about the names of enduring powers of attorney. In Victoria, the legislated term is Enduring Power of Attorney for Medical Treatment, in SA it is Medical Power of Attorney, in NSW it is Enduring Guardian, in QLD it is Enduring Power of Attorney for Personal/Health Matters, in Tasmania it is Enduring Guardian and in the ACT it is Enduring Power of Attorney. This variation increases the difficulty of educating doctors and nurses to understand and respect these appointments and, of course, of educating the public.
- ❑ **Interstate compliance.** The elderly often question RPC staff as to whether their requests or documents would be complied with if they traveled interstate. It would appear that the legislated documents are valid interstate, but only under common law and are, therefore, more easily contested.
- ❑ **Doctor ignorance regarding the law.** We have experienced numerous examples where a doctor is aware of a patient’s undocumented wishes not to have further life-prolonging treatment, but when the patient becomes incompetent, the doctor is pressured by the family to treat aggressively, and to provide a treatment that the doctor believes is either futile or not in the patient’s best interests. In these instances, the patient may be burdened by treatment that provides little, if any, benefit simply because the doctor is concerned about being taken to court.
- ❑ **Communication of documents.** The absence of jurisdictional policies regarding the communication and transfer of Advance Care Plans and legal documents means that general practitioners, hospital staff, RACF staff, even ambulance officers, are frequently unaware that a patient has completed important documents elsewhere, believing in good faith, that the document will be available when end-of-life care decisions need to be made.

7. Scope for including advance care plans in personal electronic health records

Advance care planning becomes entirely ineffective if patient preferences for treatment are not translated or communicated when a patient changes their location of care. RPC have been working with the National E-Health Transition Authority in order address the inclusion of advance care plans within future person controlled electronic health record (PCEHR) systems. The ideal PCEHR enables the patient to record their future medical treatment preferences so that their wishes are accessible to health professionals throughout Australia if and when required.

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