



# Good Palliative Care Plan Western Australian Edition – Aged Care

## Information for Care Providers

The Good Palliative Care Plan is:

- a record of a treatment plan regarding the resuscitation of people who have entered the last phase of life
- designed to help ensure the involvement of the patient, their family, any Guardian/s or 'persons responsible' in creating the treatment plan
- designed to be included in patient notes, and, if necessary, follow the patient when transferred
- a clinician-initiated plan (such plans are 'more likely to be followed through' if the patient is admitted to a hospital<sup>1</sup>)
- particularly valuable when the patient does not have capacity to execute a statutory advance care directive.

Palliative Care WA Inc introduced a Western Australian version of the Good Palliative Care Plan in 2010 for the following reasons:

- a recognition that there was no widely available planning instrument suitable for adults who do not have the capacity to complete a statutory planning instrument (under the *WA Guardianship and Administration Act 1990*)
- anecdotal evidence that in many cases terminal care treatment plans were never documented in aged care services
- evidence that there was no standardised method or documentation, services using instead a wide variety of locally developed planning documents.

The Good Palliative Care Plan originated in South Australia in 1996 following the suggestion that it might prove more acceptable to health consumers and care providers than Do Not Resuscitate or Not For Resuscitation documents, and might overcome the use of ambiguous abbreviations and codes in patient notes (eg 'NFR' or 'DNR' etc).<sup>2</sup>

A survey of residential aged care facilities in South Australia during the early 2000s showed that 61% of facilities recommended the eventually-adopted Good Palliative Care Plan to their residents/families (statutory advance directives 69% and powers of medical attorney 67%).<sup>3</sup> The South Australian Good Palliative Care Plan is widely recognised and accepted.

## The Benefits of Advance Care Planning

Advance care planning is more than simply completing an advance care directive. Palliative Care Australia defines advance care planning as:

*the process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources...*<sup>4</sup>

Street and Ottman summarise the potential advantages of advance care planning, including:

*...improving quality of care, facilitating patient self-determination and reducing unwanted and unwarranted medical treatments and hospitalisations. By respecting every person's right to autonomy, dignity and fully informed consent, health professionals can assist individuals to reflect upon, choose and communicate their wishes regarding their current and future health care.*<sup>5</sup>

A recent randomised controlled trial involving Australian hospital patients who died<sup>6</sup> showed those who received advance care planning were more likely to be satisfied with care, have completed a plan, and had their end of life care wishes known and followed, while their family members had fewer symptoms of complicated grief and were more likely to be satisfied with the quality of the person's death.

## The Importance of Clear Communications

Improving care at the end of life requires good therapeutic communications.<sup>7</sup>

- establishing trust
- dealing with medical uncertainty
- paying attention to the feelings of those dealing with bad news or making difficult decisions
- helping people 'manage their hope and their resources in a realistic way'
- sharing information and coordinating care between providers.

*Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life-limiting illness, and their caregivers* were published by Australian researchers in 2007.<sup>8</sup> The Guidelines include recommendations on when (and when not) to discuss whether or not to offer or continue cardiopulmonary resuscitation.

<sup>4</sup> *Advance Care Planning Position Statement* – Palliative Care Australia – [www.palliativecare.org.au](http://www.palliativecare.org.au) (seen Feb 11)

<sup>5</sup> *State of the science review of advance care planning models* – Street & Ottman, LaTrobe Uni – 2006

<sup>6</sup> 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' – Detering – *British Medical Journal* – 2010 – vol 340

<sup>7</sup> 'Beyond advance directives: Importance of communications skills at the end of life' – Tulsky JA, *Journal American Medical Association* – 2005 – vol 294 # 3 pp 359-366

<sup>8</sup> Clayton et al – 2007 – *Medical Journal of Australia* – vol 186 #12 pp s78-s108

<sup>1</sup> 'Hospitalisation, care plans and not for resuscitation orders in older people in the last year of life' – Chan et al – *Age & Ageing* – 2003 – vol 32 # 4 pp 445-449

<sup>2</sup> "'Good Palliative Care' orders' – Maddocks – *Palliative Medicine* – 1993 – vol 7 pp 35-37

<sup>3</sup> 'Documenting end of life decisions in residential aged care facilities in South Australia' – Brown et al – *Australian & New Zealand Journal of Public Health* – 2005 – vol 29 # 1 p 88

### Advance Care Planning in Residential Aged Care

The 'Charter of Resident's Rights and Responsibilities', included in the *User Rights Principles 1997* (made under the *Aged Care Act 1997*) stipulates that an aged care resident has the right to 'maintain control over, and to continue making decisions about, the personal aspects of his or her daily life, financial affairs and possessions'. This is further supported by the *Code of Ethics and Guide to Ethical Conduct for Residential Aged Care*, which asserts 'the right of competent individuals to self determination' (Value 4), and that providers should 'develop ways of consulting with residents and their families or representatives on all aspects of the provision of care' (Value 5iii).

The *Guidelines for a Palliative Approach in Residential Aged Care* released in 2006, support advance care planning for the residents of aged care facilities; Guideline 8 reads:<sup>9</sup>

*Developing comprehensive advance care plans that include ongoing assessments responds to changes in the resident's health and increases the resident and his/her family's satisfaction with care.*

Many studies have demonstrated that formal, documented, advance care planning mechanisms are not widely taken up within the Australian community.<sup>10,11,12</sup> A NSW study about implementing advance care planning in residential aged care lists the following difficulties, as reported by facility staff:

- an unwillingness by residents and family to discuss the future
- a low level of understanding within the community
- reluctance of treating physicians to initiate advance care planning discussions
- uncertainty in people's minds about the legal status of directives made as part of advance care planning
- low levels of training about advance care planning for facility staff
- absence of integrated systems across care settings such as hospital and primary health care.<sup>13</sup>

Several programs designed to overcome some of the barriers to completing advance directives by taking a system-wide approach have been developed or implemented in Australia. The most notable in recent years is the Respecting Patient Choices Program, which was first trialled at the Austin Hospital in Melbourne and later extended to other settings.

<sup>9</sup> *Guidelines for a Palliative Approach in Residential Aged Care* - Department of Health and Ageing – May 2006 - p 60

<sup>10</sup> Brown et al, op cit – p 89

<sup>11</sup> 'Understanding how advance care planning is approached in the residential aged care setting: A continuum model of practice as an explanatory device' – Shanley et al, *Australasian Journal on Ageing* – December 2009 – vol 28 # 4 pp 211-215

<sup>12</sup> 'Implementation of best practice in advance care planning in an "ageing in place" aged care facility' – Fernandes – *Int Journal Evidence Based Healthcare* – 2008 – vol 6 # 2 p 275

<sup>13</sup> Shanley et al, op cit – p 212

Evaluation of the program found several 'facilitating factors' for successful implementation:<sup>14</sup>

- leadership from managers
- commitment from the organisation's governing body
- training of adequate numbers of appropriate staff in advance care planning skills
- provision of consultation and support to facilities
- comprehensive system changes to documentation processes
- provision of support to Respecting Patient Choices Program trained staff.

Other studies identified similar success factors.<sup>15</sup>

### Advance Care Planning for People Without Legal Decision-Making Capacity

An American study reports the views of health care providers, expressed in focus groups, that due to a lack of planning mechanisms for people who do not have capacity, 'many families never seriously consider their loved one's preferences for life-sustaining treatment until they are called upon to make a critical decision in the midst of a medical emergency,' that in these circumstances, 'it was difficult if not impossible to build a mutually trusting relationship' between families and doctors, and that 'patients without advance care plans often suffer needlessly.'<sup>16</sup>

The *Guidelines for a Palliative Approach* recommend involving the person's appointed representative, or if there is no legally appointed representative, the person's family members, in an advance care planning process for those residents who lack decision-making capacity.<sup>17</sup> The Guidelines also include examples of forms which can be used to record these discussions and decisions.<sup>18</sup>

The successful implementation of advance care plans for people without decision-making capacity often depends upon 'a shared dialogue and negotiation between the health care provider and the surrogate [decision-maker]... at each major decision point.'<sup>19</sup>

Palliative Care WA Inc notes the draft *Code for Ethical Practice for Advance Care Directives* published in the *National Framework for Advance Care Directives Consultation Draft* in 2010.<sup>20</sup>

<sup>14</sup> *Final evaluation of the community implementation of the Respecting Patient Choices Program* – Austin Health – January 2006 – p 4

<sup>15</sup> Detering et al, op cit – p 5 of 9

<sup>16</sup> 'Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity' – Volicer et al – *Journal American Geriatrics Soc* – 2002 – vol 50 pp 761-767

<sup>17</sup> *Guidelines for a Palliative Approach* – op cit – p 57 & p 58

<sup>18</sup> *ibid* – pp 250-251

<sup>19</sup> 'Role of written advance directives in decision making: Insights from the qualitative and quantitative data' – Teno et al – *Journal General Internal Medicine* – 1998 – vol 13 p 445

<sup>20</sup> *A Nat'l Framework for Advance Care Directives: Consultation Draft 2010* – Aust Health Ministers' Advisory Council – at [www.hwlebsworth.com.au/acdframework](http://www.hwlebsworth.com.au/acdframework) (seen Feb 11)

## Relationship Between Good Palliative Care Plan and Western Australian Legislation

Palliative Care WA Inc notes that although the Western Australian *Guardianship and Administration Act 1990*, as amended in early 2010, permits people with legal decision-making capacity to complete Advance Health Directives<sup>21</sup>, there is currently no analogous routinely available mechanism to record plans for end of life care for people who do not have decision-making capacity.

We propose the Good Palliative Care Plan as a suitable advance care planning instrument for people without legal decision-making capacity who live in residential aged care facilities. People who retain legal decision-making capacity should be encouraged to complete either an Enduring Power of Guardianship<sup>22</sup>, an Advance Health Directive, or both.

Helpfully, for any cases where there is no other formal advance care plan in already place, and where the patient is unable to make reasonable judgements about proposed treatments, the *Guardianship and Administration Act 1990* lays out those people who can act as 'persons responsible' and make decisions on the patient's behalf. A 'person responsible' has the following characteristics under the legislation:

- of full legal capacity and over 18 years of age
- reasonably available
- willing to make a treatment decision in respect of treatment
- the spouse or de-facto partner of the patient and is living with the patient; or the patient's nearest relative who maintains a close personal relationship with the patient; or the primary provider of care and support (including emotional support) who is not paid for that care and support.<sup>23</sup>

The 'persons responsible' should be consulted in completing the Good Palliative Care Plan when:

1. the patient lacks the capacity to make a reasonable decision about their future treatment, AND
2. there is no guardian<sup>24</sup> or enduring guardian or relevant Advance Health Directive or common law directive<sup>25</sup> (all of which take precedence over any Good Palliative Care Plan).

It may be helpful to complete a Good Palliative Care Plan even if some other advance care planning mechanism is in place because, for example, an existing Advance Health Directive may not be exactly relevant to the patient's clinical situation, or in order to specifically operationalise broader preferences articulated in another planning document or by the resident's guardian/s or 'person/s responsible'.

<sup>21</sup> WA *Guardianship and Administration Act 1990* – Part 9B

<sup>22</sup> *ibid* – Part 9A

<sup>23</sup> *ibid* – Part 9C

<sup>24</sup> *ibid* – Part 5

<sup>25</sup> *ibid* – Clause 110ZB

The Good Palliative Care Plan is (like a Do Not Resuscitate or Not For Resuscitation order) not a statutory document, nor is it a consent document. Instead it records a clinical decision and treatment plan.

It is not compulsory to complete a Good Palliative Care Plan or any other advance care directive.

## Medicare Item Numbers

Palliative Care WA Inc notes that the Case Conferencing process, through which General Practitioners may claim against several items in the Medicare Benefits Schedule (Enhanced Primary Care Items 775, 778 and 779) to participate in meetings to plan multidisciplinary management of residents with complex care needs, has the potential to be an ideal way to discuss and complete the Good Palliative Care Plan. Medicare item number 731 (Chronic Disease Management), which General Practitioners can claim against in order to contribute to the development and review of a resident's care plan, may also be useful.<sup>26</sup>

## Research and Continuous Improvement

Palliative Care WA Inc warmly encourages researchers to investigate the effectiveness and efficiency of the Good Palliative Care Plan. We also invite all users of the Plan to provide ongoing feedback about its use in clinical practice so that we can improve the quality of the document.

## Additional Information

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>27</sup>

Palliative Care WA Inc is the representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life.

Copies of the Good Palliative Care Plan and information about its use can be obtained from:

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<sup>26</sup> *Medical care of older persons in residential aged care facilities* 4<sup>th</sup> Ed 2005 – Royal Aust College of GPs Silver Book Nat'l Taskforce - [www.racgp.org.au/silverbookonline/3-1.asp](http://www.racgp.org.au/silverbookonline/3-1.asp) (seen Feb 11)

<sup>27</sup> *Definition of Palliative Care* – World Health Organisation – 2002 – [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/) (seen Feb 11)