Ad Hoc Interfaith Committee

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C/o Committee Secretary
Senate Standing Committees on Community Affairs
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Dear Senators,

Submission to provision of palliative care in Australia enquiry

Executive summary and recommendations

The Ad Hoc Interfaith Committee fully endorses the provision of palliative care for those who need it. We believe that palliative care provided in accordance with the WHO definition has the potential to address the needs of those experiencing a range of diseases which are not amenable to cure. We endorse the view that palliative care is best offered early in the disease process, rather than waiting until the patient is in the terminal phase. Optimal care includes support for families. We believe appropriately prepared and supervised volunteers can augment specialist palliative care services to provide this care for people in their own homes, in aged care homes or in in-patient hospice contexts.

We believe that advance care planning is pivotal to achieving the best outcomes for patients receiving palliative care, provided it is offered within a flexible framework suited to the patient's unique needs, is regularly reviewed and is not prescriptive. We therefore oppose the rigid directives suggested by the national framework, and which cannot represent informed consent.

We believe that palliative care, when accessible to a wider number of people than is currently the case, offers Australian citizens a realistic alternative to euthanasia or physician assisted suicide.

We acknowledge that specialist palliative care services urgently require more resources in order to provide for all those who need such care; particularly for residential aged care, additional support for families and increased training for health professionals. We make the following recommendations in respect of the terms of reference, for the reasons outlined above:

1. *We recommend that palliative care services give greater attention to the WHO definition when providing access for all those who need it, emphasising that*

palliative care is not limited to the last days or hours of life. One of its aims is to maintain the person's function and comfort, assisting the person to live as fully as possible throughout the disease process until the end of life. We note however our reservation about the WHO use of "quality of life" in this context which seems to be discriminatory implying a relative value of individuals rather than equal respect for the worth and inherent dignity and equal and inalienable rights of every member of the human family. Instead they should refer to "maintaining or improving function including lucidity, where that is possible, while still controlling uncomfortable symptoms".

2. *We recommend that specialist palliative care services be adequately resourced to provide support for older people in aged care homes, and their families.*

3. *We recommend that resources for specialist palliative care services be increased to provide early intervention, thereby facilitating care planning.*

4. *We recommend that the effectiveness of the 'Guidelines for a palliative approach in residential aged care' be examined in relation to contemporary research, in order to provide confidence and encouragement for aged care workers in best practice care.*

5. *We recommend that all aged care homes in Australia be encouraged to develop a working relationship with their regional palliative care service.*

6. *We recommend that the application of resources to palliative care take into account the need for increased perinatal palliative care to assist women and their partners who receive a life limiting diagnosis for the child during pregnancy.*

7. *We recommend urgent action on the workforce needs for aged care. Having identified the serious burden of older people with end stage chronic disease, it is of paramount importance that such patients receive care comparable to that given to people dying of cancer.*

8. *We recommend that GPs attending the care of older dying people in the community or aged care homes work closely with their palliative care colleagues, particularly in providing best practice pain management.*

9. *We recommend that funding for aged care address the discrepancy between aged care and specialist palliative care in the provision of multidisciplinary health professionals and volunteers.*

10. *We recommend that, when PCA's Standards are reviewed, consideration be given to*
    (a) strengthening their stance on euthanasia and physician assisted suicide
    (b) acknowledging the need for bereavement support in residential aged care
    (c) increasing the level of service offered by volunteers.

11. *We recommend that advance care planning should focus on continuous conversation and review, rather than be constrained by binding directives and*

that the law explicitly exclude the possibility of directives being interpreted in a way that binds health professionals, representatives and families.

12. *We recommend an urgent increase in research funding for palliative care in chronic disease (including dementia), comparable to that provided for cancer research.*

13. *We recommend research be undertaken to guide aged care health professionals in improving their communicating with families.*

14. *We recommend that the 'Guidelines for a palliative approach in residential aged care' be reviewed; to ensure aged care and palliative care health care practitioners have access to current best practice evidence based guidelines.*

15. *We recommend further research into the benefits of perinatal palliative care,(that is support for a woman who has received a diagnosis of a life limiting condition in her child), and exploring whether, as evidenced overseas, increasing women's opportunities for support influences their decision in relation to continuing a pregnancy in those circumstances.*

Introduction

The Ad Hoc Interfaith Committee was formed five years ago in Melbourne to provide an opportunity for people of different faiths to meet and to respond to the many social issues that are currently the subject of public policy formation. The membership of the Committee is by invitation to people who share similar ideas about being unafraid to give witness to faith and to seek respectfully to persuade others by that witness as well as by appeal to reason. We regard it as a civic responsibility to listen to what others are saying and to add our voices to the discussion on issues that shape the kind of community to which we belong.

The committee understands that palliative care is the provision of multidisciplinary services to relieve distressing or discomforting symptoms of illness or disease, and particularly to assist people who have a terminal illness to live as fully as possible with the dying process.

Palliative care should not be restricted to the dying, but should be available to anyone who suffers from discomforting or distressing symptoms of illness and disease. The committee is uncomfortable with the new Palliative Care Australia (PCA) definition which states:

> Palliative care is specialist care provided for all people living with, and dying from a terminal condition and for whom the primary goal is quality of life.[1]

Our concerns with the new PCA definition are:

- Palliative care should be available to all those in the community whose pain and distress warrants the application of the multidisciplinary expertise available in palliative care and should not be restricted to those who have a terminal prognosis;
- Palliative care delivered by home hospice services often depends on the assistance of trained volunteers operating under professional direction, but non-professional nonetheless. Much of the assistance needed extends beyond that offered by health specialists, such as volunteers sitting with patients to give family members respite, providing assistance with getting to medical and other appointments, shopping, cleaning, mowing, lawns.
- To make the primary goal “quality of life” places a focus on outcome. The latter is both difficult to measure and tends to be discriminatory against people with disabilities and against people who have chronic illnesses. The focus instead should be on the care options offered and the benefits to be attained, rather than on a potentially prejudicial judgement, especially a third party judgement about so-called “quality of life”.

For those reasons and though it still uses the prejudicial phrase “quality of life”: we would be more comfortable with the existing WHO definition:

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

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[1] http://www.palliativecare.org.au/Default.aspx?tabid=1940

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[2]

However we would still like acknowledgement of the need to involve volunteers and would prefer that the phrase "quality of life" were not used for the reasons given. In particular, it implies relative worth of lives that is not consistent with respect for inherent human dignity and equal and inalienable human rights. It would be better to say "maintains or improves functioning including lucidity where that is possible while still controlling uncomfortable symptoms".

Responding to the Terms of Reference

The following are our responses to each term of reference for the inquiry into the provision of palliative care in Australia, including:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

(i) people living in rural and regional areas,
(ii) Indigenous people,
(iii) people from culturally and linguistically diverse backgrounds,
(iv) people with disabilities, and
(v) children and adolescents;

Our major concerns are that, in our collective experience, in many jurisdictions, too little is done to make adequate palliative care available to those who need it:

- Current entry requirements for palliative care usually exclude people with chronic pain and are often limited to people who are in the last stage of cancer[3] with an expectation that they will die soon. Anecdotally it is said that admission requires a prognosis of less than eight weeks; this does not fit the WHO definition.
- Government pharmaceutical subsidies, where they exist, for the more effective forms of pain relief are often restricted to cancer patients;

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[2] http://www.who.int/cancer/palliative/definition/en

[3] There are efforts to broaden the diagnostic criteria to include the terminal phase of other illnesses, and some services already admit non-cancer patients.

- People living outside major cities often have little access to palliative care services, this particularly affects people who are aboriginal or Torres Strait Islander, but also all other people living remotely. Palliative care is largely a phenomenon of the major cities.
- The latter is compounded by the fact that few doctors are adequately trained to provide palliative care, despite recent funding efforts to support professional development and palliative care training placements for GPs.
- Such palliative care services as exist outside major centres are chronically underfunded and struggle to provide the complex range of services that are needed to assist a person to live with pain and disability.
- Most pain clinics are over subscribed and have long waiting lists. For people who are left suffering, such waiting is unconscionable.
- Limited resources prevent many people being cared for at home until death, when this is their preferred option, and this need can better be met by the development of home hospice services that deliver professional and trained volunteer support to the home.

We recommend that palliative care services give greater attention to the WHO definition when providing access for all those who need it, emphasising that palliative care is not limited to the last days or hours of life. One of its aims is to maintain the person's function and comfort, assisting the person to live as fully as possible throughout the disease process until the end of life.

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

This issue is more a matter for those who have responsibility for funding sub-acute areas of care. One such area is the care provided in aged care homes where it can be difficult to obtain adequate palliative care for someone who is technically not terminally ill in terms of having a definite limited prognosis, but would still meet the WHO definition (see above), but not the PCA definition. Often people we see in aged care have multiple ailments and the likely cause of death may be variable and the prognosis quite uncertain. They may not meet the descriptor of a limited prognosis that anecdotally still seems to be applied, but the funding for palliative care should still ensure that provision is made for palliative care if they are suffering pain or discomfort, whether physical, psychological, emotional or spiritual.

We recommend that specialist palliative care services be adequately resourced to provide support for older people in aged care homes, and their families.

(c) the efficient use of palliative, health and aged care resources;

Often older people being cared for in their own home or an aged care home may struggle to obtain a palliative care consultation in situ and must be moved to an acute care facility to have a chance of accessing adequate palliative care. That means an over use of acute care resources when better planning of palliative care funding and a less restrictive criterion for access to include those who may not be imminently dying but nonetheless need multidisciplinary efforts to relieve their discomfort and distress, including linking into volunteer supports available through home hospice services.

This approach fits with the WHO definition of palliative care support being available 'early in the disease process'.

We recommend that resources for specialist palliative care services be increased to provide early intervention, thereby facilitating care planning.

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

Home hospice services that support the training and engagement of volunteers need better encouragement and funding of specialist resources to train the volunteers and provide support to them and to the primary carers and families outside of the specialist palliative care facilities so that people can receive the supports that they need whether they are at home or in aged care. In the latter context many older people have no family support, and would benefit from appropriately skilled volunteers to support them throughout their illness, and particularly when they are approaching death.

The *Guidelines for a palliative approach in residential aged care* [4], an important initiative of the Commonwealth Government in 2002, are the only guidelines in the world to combine palliative care and aged care. The guidelines were formulated to provide aged care workers with evidence on which to base their care; and encouragement to work in partnership with specialist palliative care services where needed (for complex symptom management, for example). The guidelines acknowledge that most people entering residential aged care will have at least one (and in many instances four or more) life-threatening diseases which are not amenable to cure and for which a palliative approach is therefore appropriate. The rationale for a palliative approach 'should not be based on the individual's clinical stage or diagnosis; rather, it should be offered according to the needs of the individual.' [5]It is regrettable that the uptake of these guidelines is generally poor, and as noted in Terms of Reference (h) below, the guidelines are now in urgent need of review.

We recommend that the effectiveness of the 'Guidelines for a palliative approach in residential aged care' be examined in relation to contemporary research, in order to provide confidence and encouragement for aged care workers in best practice care.

Many specialist palliative care services provide a comprehensive range of support services to their regional aged care homes. However, there are many staff in aged care homes who have no knowledge of these services, to the detriment of the older people who would benefit from them.

We recommend that all aged care homes in Australia be encouraged to develop a working relationship with their regional palliative care service.

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[4] Commonwealth of Australia (2006). *Guidelines for a Palliative Approach in Residential Aged Care: enhanced version* May 2006. Canberra, Australian Government Department of Health and Ageing. Note also the guidelines for a palliative approach in community aged care are pending.

[5] *Ibid,* p.39.

At the beginning of life, palliative care also has an important role to play in *peri natal palliative care*. Recent research suggests that parents who have received a diagnosis of a life limiting condition in their child would benefit greatly from palliative care and support at that time. There is a lack of Australian research into the needs of women in these circumstances. The studies available are very small scale and the samples not representative of either the health professionals involved or of women experiencing a diagnosis of a life limiting condition in their foetus /unborn child. The Murdoch Institute is pursuing some grants for research into this area.

Overseas research indicates that how the needs for support through the process of screening, diagnostic testing, considering options and managing pregnancy are met may significantly affect the choices made and the outcomes.

In a recent UK study[6] women and their partner were offered perinatal palliative care, following a diagnosis of lethal fetal abnormality, as an alternative to termination of pregnancy. The article shows that perinatal palliative care is a significant alternative because 40% opted for perinatal palliative care compared to the usual 90% who opt for abortion. The study included 20 pregnancies and of the eight parents who chose to continue the pregnancy and pursue perinatal palliative care, six of these eight babies were live born and lived for between 1 hour and 3 weeks.

The numbers are too small and the sampling not reliable enough to make it possible to draw general conclusions. But it does seem significant that 40%, when offered an option of perinatal palliative care, chose not to terminate compared to the 10% who would normally be expected not to do so. There is a need for more research into whether offering perinatal palliative care would broaden the range of women's choices and what the comparative outcomes would be for those women and their families who chose to continue to birth and those who chose to terminate.

This study would seem to indicate how important it is for women to be well informed and given genuine options to continue with their pregnancies. Perinatal palliative care would seem to be insufficiently developed in Australia and much needs to be done to make genetic counselling routinely available prior to women entering into the screening and diagnosis pathway so that they have the time and space to make well informed decisions in accordance with their own beliefs.

We recommend that the application of resources to palliative care take into account the need for increased perinatal palliative care to assist women and their partners who receive a life limiting diagnosis for the child during pregnancy.

(e) the composition of the palliative care workforce, including:

(i) its ability to meet the needs of the ageing population,

Palliative care has moved from its initial (1970s) focus on patients dying with cancer and a specified prognosis of less than six months. Quite properly, this (earlier) focus attracted clinicians with expertise in cancer care. Now that many cancers are considered curable, and many of the 'killer' diseases such as heart attacks and strokes

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[6] A C G Breeze, C C Lees, A Kumar, H H Missfelder-Lobos, E M Murdoch
"Palliative care for prenatally diagnosed lethal fetal abnormality" *Arch Dis Child Fetal Neonatal Ed* 2007;92:F56–F58.

can be treated effectively, older people are dying of chronic, incurable diseases in which the 'end stage' is considered two to three years. [7] One of the main contributors to this increasing phenomenon is dementia, which has reached epidemic proportions worldwide. [8] The implications for palliative care include the evidence that people dying from dementia have symptoms and health care needs comparable to those dying from cancer, except they occur for longer. [9] The 'impeccable symptom management' recommended by the WHO definition of palliative care has specific application for older people, particularly those with cognitive impairment who cannot articulate their pain and other distressing symptoms. Therefore, a different set of skills is needed to address the needs of older people, not only when death is imminent, but 'early in the disease process'.

A recent survey by Alzheimer's Australia found that four out of five Australians do not recognise dementia as a serious, life-threatening disease of the brain, which ends in death. [10] Palliative care emphasises the need to talk openly about death and dying; yet the stigma and ignorance surrounding dementia compromises the acceptance of the palliative approach recommended in the 'guidelines'.

As noted in (d) above, the effectiveness of palliative care services would be strengthened by a mutual recognition of skills on the part of palliative care specialists and aged care specialists, particularly where the latter may have more skills and experience in dementia care.

We recommend urgent action on the workforce needs for aged care. Having identified the serious burden of older people with end stage chronic disease, it is of paramount importance that such patients receive care comparable to that given to people dying of cancer.

(ii) the adequacy of workforce education and training arrangements;

The major lacks are for the training of qualified health care professionals to meet the needs of the ageing population (refer (d) above) and secondly, in the training, organisation and resourcing of volunteers, who for very little expenditure on them can make all the difference in a person being able to stay at or return to home.

One of the most successful programs conducted mostly by volunteers is what is called the "Narrative/Biography Therapy" project run by *Melbourne's Eastern Palliative Care Service*. The project trains people to sit with a person who is expected to die and records questions about their life for the purposes of preparing a typed and bound record of the life to which the person or family members may have added images. The effect of the project is to create interest in the past life for the person and for their

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[7] Lynn, J (2008) Reliable comfort and meaningfulness. *BMJ* 336:958-959 (26 April 2008). http://www.bmj.com/cgi/content/full/bmj.39535.656319.94

[8] Access Economics Pty Limited (2009). Making choices: future dementia care: projections, problems and preferences. Canberra.

[9] Commonwealth of Australia (2006). Guidelines for a Palliative Approach in Residential Aged Care: enhanced version May 2006. Canberra, Australian Government Department of Health and Ageing, p.62. Refer also Volicer, L. (2008). End-of-life care for people with dementia in long-term care settings. *Alzheimer's Care Today* (April-June 2008), 84-102.

[10] Alzheimer's Australia. Dementia Health Report, Issue #45, /p.3.

family. It is not the family's story, just that of the dying person as he or she recalls it. Often though present memory may be affected, past memories are rich with recollections, often recollections of which family members have been unaware. The effect is often to enhance the sense of worth and dignity for the person because who he or she is and has been is made dominates over the present frailties and disabilities. Such work by trained volunteers adds immeasurably to the experience of illness and dying and can change quite dramatically the overall impact of symptoms. There needs to be strong support for work of that kind and effort made to ensure that palliative care services are funded and planned to include training and support for the work of volunteers.

Palliative care emphasises the need to support families as well as patients. However, there is no routine training for health care professionals to acquire skills in communication with families and until recently, no guidelines for the conduct of family meetings.[11] The stress arising from family conflict, lack of mutually agreed goals of care, unrealistic expectations and lack of information provided for families, impacts on the care of the dying person.

Residents in aged care homes have the right to choose their own GP (general practitioner). However, many GPs have not had access to the palliative approach recommended in the guidelines cited above; nor have they necessarily received undergraduate preparation in gerontology, palliative care or dementia care. Skills and confidence in prescribing opioids, to cite one very common example, are not necessarily the province of medical 'generalists'. 'Dying patients, in Australia and around the world, are being denied opioids to treat their pain because some medical and aged care professionals have not received the necessary education or training required to tackle their fear of prescribing the drugs.' [12] There is therefore an urgent need for GPs to be trained in the 'impeccable assessment' of dying patients, and in particular, appropriate pain management.

Another hallmark of palliative care is teamwork and team decision-making. This is often not appreciated in aged care where one person (usually the GP) makes the decision which is not always in accordance with contemporary palliative care symptom management. Lack of expertise in dementia often results in the doctor's judgement 'She doesn't look like she's in pain', with the regrettable outcome of a disagreement with the aged care worker's judgement (which should be based on comprehensive assessment using a tool designed for those with cognitive impairment). Other serious issues arise when the doctor makes the judgement 'he'd be better off in hospital' without exploring the options of palliative care on site.

We recommend that GPs attending the care of older dying people in the community or aged care homes work closely with their palliative care colleagues, particularly in providing best practice pain management.

Analysis of the literature pertaining to spiritual care is beyond the scope of this submission. However, it is evident that although the quadrilateral of palliative care

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[11] Hudson, P, Quinn, K, O'Hanlon, B, Aranda, S (2008) 'Family meetings in palliative care: Multidisciplinary clinical practice guidelines'. http://www.biomedcentral.com/1472-684X/7/12.

[12] Noone, Y. 'There's no need to suffer in silence.' *Australian Ageing Agenda*, February, 2012. http://www.australianageinagenda.com.au/2012/02/03/article/Theres-no-need-to-suffer-in. . . .

(physical, spiritual, emotional, psychological) is widely acknowledged for its emphasis on ‘holistic’ care; few health care professionals have access to education and training in spiritual care. The outcome of this gap in workforce training and education is that the dying person’s spiritual care is reduced to the ticking of a box identifying their religious denomination. Or, otherwise, it is regarded solely as the chaplain’s domain; whereas the palliative care literature emphasises all care is the responsibility of the whole (multidisciplinary) team.

The concept of a multidisciplinary team in residential aged care is more myth than reality. [13] Whereas many specialist palliative care services have appropriate access to allied health professionals, chaplains and volunteers, there is no funding provision for such a team in aged care. The literature attests to the benefits of physiotherapy, occupational therapy, music therapy, art therapy, reminiscence therapy, life story therapy, and spiritual care for older people with chronic disease burden, including depression and dementia. While ‘impeccable symptom management’ often requires judicious prescribing of relevant medicines, the benefits of non-pharmacological approaches has proven efficacy.

We recommend that funding for aged care address the discrepancy between aged care and specialist palliative care in the provision of multidisciplinary health professionals and volunteers.

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians;
Standard 7 states: ‘The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.’ [14] PCA recently declared a position of ‘studied neutrality’ on euthanasia. We are heartened by the fact that the statement has been withdrawn from the website. However we would urge PCA to strengthen their professional and philosophical stand on euthanasia and physician assisted suicide. Rather than promoting a culture of ‘studied neutrality’ we argue that killing is never compassionate; with adequate palliative care resources Australian citizens of any age should be confident of access to the highest quality of care when it is most needed. Some would argue that euthanasia or physician assisted suicide fits within the goals of palliative care. We argue strongly against that stance. Making euthanasia available would substantially change the trust of patients and to have palliative care professionals mentioning the option as available, as they would be required to do, would encourage patients to consider themselves to be a burden to themselves and others. Patients look to their health professionals for encouragement to cope with the illness. Having them offer euthanasia, would be like a coach of a sports team declaring that he or she expected a loss.

Standard 8 refers to bereavement care. [15] The lack of appropriate bereavement support for residents and their families in aged care homes represents a significant gap in

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[13] Hudson, R & O’Connor, M. (2007) *Palliative care and aged care: a guide to practice.* Ausmed Publications: Melbourne, Australia, pp.37-8.

[14] Palliative Care Australia (2005). *Standards for providing quality palliative care for all Australians.* Canberra, Australia, p.6.

[15] Palliative Care Australia (2005). *Standards for providing quality palliative care for all Australians.* Canberra, Australia, p.6.

service provision. While patients of specialist palliative care services have access to this support, formal bereavement services are not routinely available to people in aged care homes. For example, many older people experience profound grief when a spouse dies after several decades of marriage; not to mention grief attached to losses through other relationships, independence, pets, garden and many other factors.

Standard 12 pertains to staff and volunteers who are 'appropriately qualified for the level of service offered. . .' [16]. We are very concerned that training, direction and support of volunteers should recognise the complexity of coping with pain and suffering and the extent to which the circumstances in which a person feels loved, supported and wanted are beyond medical control and depend on the assistance that may be given by non-professional people.

We recommend that, when PCA's Standards are reviewed, consideration be given to
(a) strengthening their stance on euthanasia and physician assisted suicide
(b) acknowledging the need for bereavement support in residential aged care
(c) increasing the level of service offered by volunteers

(g) advance care planning, including:

> ***(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,***
> ***(ii) national consistency in law and policy supporting advance care plans, and***
> ***(iii) scope for including advance care plans in personal electronic health records;***

The Ad Hoc committee thinks that this is perhaps the most significant of the terms of reference because we are on the brink of potentially doing a great deal of harm as an Australian community if we do not manage the development of advance care planning well. There are great advantages to be attained but also significant risks. We hope that the Senate can produce a balanced report on this aspect of the report.

The committee is deeply concerned about the National Framework for Advance Care Planning and its apparent support for advance care directives or "living wills". These unfortunately have been given statutory status in Queensland and to a limited extent in ACT and South Australia. The basic problem with such statutorily enforced directives is that they are unlikely to represent informed consent because issued before the experience of the later illness or its exacerbation, and may bind health professionals and families without regard to the actual circumstances that have developed and the effects of the treatment options available. Advance care directives are not consistent with seeking to respect the dignity and autonomy of the patient. They are likely to reflect some earlier understanding and not the present reality. The experience of illness is a developing process about which understanding also develops in the interactions between the patient, health professionals and family and care givers. Often a person will come to accept eventualities that earlier might have seemed unsatisfactory, unreasonable or even hideous. A person, for instance, who is confronted by the likelihood of a fulminating cancer of a limb may well completely

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[16] *Ibid,* p.7.

refuse amputation initially. However later the patient may come to accept life without the limb when the condition develops, the need becomes more apparent and also the assistance available to life family life as an amputee and the effect on the family and on himself become clearer. The problem with a directive is that it is a snap shot of a stage of a process of communication and discussion when there is still so much to develop between the health professionals and the patient about the illness and its treatment.

(h) Options for Planning Future Care[17]

Advanced directives are often promoted as a way of ensuring that when people cannot make their own decisions, appropriate decisions are still made. A major problem with such directives is that health professionals may lack information about what the patient meant, what their state of mind was, and what they understood of the options at the time

Because illness is seldom predictable, a directive is not likely to be adequately informed. Before a health professional could act on a directive he or she would need to ask:

- Do the present circumstances correspond to the circumstances envisaged at the time when the person recorded his or her wishes?
- Do the treatment and care options available correspond to those about which the patient made his or her statement?
- Do the effects of implementing the patient’s wishes correspond to the effects that the patient understood would be their consequence?
- Are there new or changed factors in the present circumstances which the patient may not have taken into account but would have wanted to be considered in the present circumstances?

A better option than issuing a directive is for a patient to appoint someone he or she trusts to make decisions for them, and explain to that person the values and priorities that the patient would want to be applied. They can then respond to the circumstances as they arise.

Many people prefer to trust in the health professionals, and their family and friends, rather than trying to direct events beforehand. However, in our increasingly secular culture, there may be less and less reason for people with a religious perspective to have that confidence. Further, making end of life decisions can be very difficult for loved ones, and providing them with some indication of the patient’s wishes may relieve them of a difficult burden. For those reasons people may well prefer to appoint someone to represent them in discussions with their health professionals, for a time when they cannot speak for themselves, and have discussions with the representative and even document the values they wish to guide their future care, Future care planning differs from advanced directives in that the latter are intended to be binding whereas future care planning is intended only to guide.

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[17] This and the following sub-sections have been adapted from materials co-authored by Nicholas Tonti-Filippini with Bishop Anthony Fisher OP, Rev Dr Gerald Gleeson and Dr Bernadette Tobin, published as *A Guide to Future Care Planning* by Catholic Health Australia approved by the Australian Bishops and available as a free download from http://www.cha.org.au/site.php?id=223

(ii) Accepting Death and Dying

The reality of our own mortality requires human beings to engage with the reality of the human condition and to take responsibility for our lives until death comes. While they are still able to do so, there is a realistic need for people to accept the inevitability of their own illness and death, and consider the implications for themselves and others.

The various religious traditions tend to accept that life is a gift, not a possession. As responsible stewards of this gift, religious people are inclined to seek assistance when sick and generally to look after our health and well-being. However one regards life, whether as gift or possession, it is prudent to make known our own preferences for medical treatment, in case we are ever incapacitated and unable to communicate, and it is often a good idea to ensure that there are people appointed who have the authority to make decisions in the event of sickness or disability preventing us from making or implementing our own decisions.

For many people, the days leading up to death can acquire a positive, life-giving meaning. Believers accept the unpredictability of the human condition, and strive to place their trust in God’s will. Realistically all people need to face the likely unavoidable disability and dependence of our later years, and not expect fully to control the dying process. To some extent, patients ought to leave those entrusted with their care free to respond to the course of illness as it unfolds in the mystery of the patient’s life, rather than attempt to tie their hands with instructions, issued without direct knowledge of those future events.

(iii) Desirability of Future Care Planning

No-one should be compelled to issue instructions about future care. Nevertheless, it is desirable that patients give some guidance about their medical treatment to those who have authority to make such decisions. The best way to do this is by means of someone who is able to speak for the patient when he or she is unable to do so.

People often need time and assistance to reflect on the place of death in their lives, to face and resolve interpersonal differences within families, and to avoid future conflict between family members.

There are different ways in which people can guide their future medical treatment; it is not necessary to leave written instructions. Many people can simply trust their families and their healthcare professionals to know and do what is best for them. In some cultures and ethnic groups, this is the normal way in which healthcare decisions are made.

In all cases, communication between a person, and his or her family, friends and healthcare professionals is invaluable. It is recommended that patients seek out a personal doctor or nurse practitioner with whom they can develop a good continuing relationship. With the development of trust and understanding, good communication of one’s fears, hopes, and desires becomes possible.

Patients need their healthcare professionals to explain the likely course of an illness, the various treatment options available, and their benefits and side-effects.

Health professionals need to hear from their patients about their hopes and goals in life, their relationships with their families and communities, their tolerance of treatment side-effects, their religious commitments, and what will be important to the person as death approaches.

It is best for this communication to occur by means of many conversations over the months and years with one's family and friends, and with one's doctors and other health care professionals. If conversations about these matters are gradually and gently introduced, then it will be easier to discuss specific and immediate questions when they arise in relation to terminal illness. Fresh opportunities for conversation may occur when there is a change to living circumstances caused by illness or disability.

(iv) How is a representative appointed?

Illness and disability may change a person's status and role in life. How each person endures, and the relationships that form through illness and dependency, are an important part of the journey that continues until death. Those relationships continue even when the person's own ability to contribute actively diminishes. For religious people and many others, in becoming more dependent on others, one still has important witness to give to who one is essentially. How we face illness, suffering and death often has a profound effect on how others see us and our convictions, strength and courage may greatly influence the lives of those around us. A young person seeing the responses of an older person at that time may gain a great deal from that experience. In illness, frailty and dying we are nonetheless human and a witness to our own beliefs and values.

If a person becomes unable to make decisions for his or her own medical treatment, there are three ways in which someone may be or become that person's representative:

a) The person has appointed someone previously;
b) A court or tribunal appoints someone after the person becomes incompetent;
c) The spouse, carer, other next of kin, or close friend, according to law, may have that authority automatically. The senior available next of kin has that authority in Australian jurisdictions, if no-one else has been appointed by the person or by a court or tribunal.

The representative should be made aware that he or she is likely to have that responsibility, and should be given some guidance about how the role is to be exercised. If a person does not have confidence in those who would automatically have the role of representative, then that person needs to appoint someone of his or her own choosing. In most jurisdictions there are legal processes for doing that.

The advantage of appointing such a person is that he or she is able to respond, on one's behalf, to the changing circumstances in which treatment decisions are needed. While the representative's formal role is to make medical treatment decisions on the patient's behalf, he or she might also have a less formal role in coordinating discussion among the family members, where practicable, and communicating with the treatment team.

A person chosen as a representative should:

- a) be able to make good judgements in what may be difficult and painful circumstances;
- b) know the person who is represented, and his or her values and wishes;
- c) appreciate the person's sense of stewardship in relation to health and life;
- d) be likely to be available to fulfil that role should it be needed in the future.

The patient may trust that health care professionals can assist them to make decisions that are in their best interests' and, with respect to 'capacity', just because a patient may have lost capacity does not mean that he or she should not be involved in decision-making. Those appointed to make decisions should still consult the patient and his or her family in deciding what is in the patient's best interests.[18]

(v) What to Record?

A person appointing a representative may wish to give some guidance as to how decisions should be made. Some people will simply be happy to discuss what may happen with them, while others may also want to provide their guidance in writing.

There are several ways in which a person's wishes may be recorded:

- a) The doctor or nurse may (and normally should) keep his or her own notes of what the person has said, and review them regularly, as they will change as circumstances change.
- b) The person may prepare a statement of general principles about what he or she would like done in the future.
- c) The person may prepare a specific plan for care in the immediate circumstances of a degenerative illness about which he or she has been well informed. In preparing such a plan, communication with one's doctor is essential because normally only a medical practitioner has the expertise and experience to inform patients of their prognosis and of the treatment options. Guidance from other healthcare professionals, pastoral carers, ministers of religion or community elders may also be helpful.

As mentioned in some jurisdictions, but not in Victoria or New South Wales, advanced directives or advanced care plans have been given a statutory status. However the common law is uncertain about how they might be applied in State that have not given a statutory status. The problem is often that they are issued without adequate information so that when seeking to apply the doctor does not know what the patient knew at the time and whether the situation of applying the document is what the patient wanted.

Advanced directives are unsatisfactory, because they are likely to be inflexible, and their legal status may prevent doctors and nurses from changing care to suit changes in the circumstances. They may also suggest wording that would refuse care that should be provided or insist on treatment that should not be. It would be better not to use documents that attempt to be *directive*. Rather, one's written wishes should *guide*

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[18] Ibid. p. 6

what happens, while being flexible enough to allow your representative to adjust to new situations on the advice of the doctors and nurses.

(vi) Why Guide the Representative?

A representative will have the role of evaluating medical treatment decisions, if the person represented becomes unable to do so. He or she will need to assess what a particular treatment may achieve and what difficulties it may cause.

By giving guidance to others about future treatment and care, the person represented may relieve the anxiety and burden of decision-making for the representative. Such guidance should respect the representative's responsibility to value and care for the person until death intervenes. A representative takes on the same obligation that each of us has to protect and sustain our own life.

In providing guidance, one can help by considering the possible course of one's illness and indicating one's priorities. Believers may well recognise that we are obliged to use those means of preserving our lives that are effective, not overly burdensome and reasonably available. (Such means are referred to in the Catholic tradition as "ordinary" or "proportionate.") Each person has a moral right to refuse any treatment that is futile, or that he or she judges to be overly burdensome or morally unacceptable, and such refusals must be respected. (Such means are referred to in the Catholic tradition as "extraordinary" or "disproportionate.")

A person who has a degenerative disease with a predictable course (e.g. renal failure, advanced ischaemic cardiac disease, metastatic cancer, advanced multiple sclerosis) would normally be informed of the likely progress of the disease, and of the likely benefits and burdens of treatment options, especially in the latter stages. It may help others if the person represented were to think about the circumstances in which he or she would regard some intrusive life-sustaining interventions, such as cardio-pulmonary resuscitation, renal dialysis, or mechanical ventilation, as overly burdensome.

Those without a degenerative illness may nevertheless wish to guide their treatment and care in the foreseeable circumstances of a life-threatening situation (e.g. stroke, heart failure, accident). In such a case, one can give only general guidance about the treatments wanted and the kind of benefits and burdens of treatment that one would judge to be reasonable. A frail, elderly person, for example, might judge that, in the circumstances of an arrest, intubation, cardiac massage and defibrillation (the usual elements of resuscitation) would be overly burdensome. But he or she might want ordinary care to continue in the meantime, including, for instance, antibiotics for infection or assistance with feeding.

The person represented may wish to clarify the burdens on others that he or she would find acceptable, for example, by requesting only the kind of treatment or care that can be provided where he or she lives, without the need for prolonged hospital care.

In other words, there is an important place for providing non-binding advice "future care planning" or "advance care planning" but not to do so in a way that may prevent discretion in the actual circumstance by being directive.

(vii) More about the Problem of Advanced Directives

There are thus good reasons for people to appoint someone with an enduring power of attorney for medical treatment (or the equivalent in other jurisdictions) to make decisions in the future, as the Victorian *Medical Treatment Act* provides, and to discuss future health care planning with them.

For instance, the Australian Catholic Bishops' Conference has supported documents issued by Catholic Health Australia by which people can indicate their wishes, but has not supported issuing binding advanced directives. In a recent submission to the Victorian Law Reform Commission, the Church strongly opposed the issuing of binding instructions (advanced directives or living wills) for several reasons:

a) The Church supports the notion of informed consent and it is unlikely that a directive for future events can be adequately informed. The evidence[19] suggests that because health practitioners have to make a decision at that future time about what the person understood at the time of making the decision, and to interpret what their wishes mean in that new circumstance, advance directives in practice have little effect on decisions. People are better off appointing someone and discussing with them their values and preferences.
b) It is immoral to seek to bind someone else to acting in ways which they may find to be against their conscience. Advance directives are such that they risk violating the right to freedom of conscience, thought and belief.
c) Some of the proposals for advance directives are in effect suicidal, refusing everything, including food and water, that would keep the person alive.

Advanced directives, or living wills, are not appropriate for medical treatment decisions because of their binding nature in circumstances of a lack of relevant information, and because they provide no opportunity for discussion especially when carrying them out may involve ethical difficulties.

In passing the Victorian *Medical Treatment Act* 1988, the Victorian Parliament rejected the notion of advanced directives. The Act provides for a person to refuse a medical treatment option, but not as an advance directive. The refusal is limited to a current condition only[20]. The purpose of so doing was to prevent the certificates being used as an advanced directive.

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[19] Angela Fagerlin and Carl E. Schneider "Enough:The Failure of the Living Will" *The Hasting Centre Report Vole 34* No 2 March-April 2004; Arnold R. Eiser and Matthew D. Weiss The Underachieving Advance Directive: Recommendations for Increasing Advance Directive Completion *The American Journal of Bioethics* :: Volume 1 Number 4 2001 p. 1-5

[20] ***Medical Treatment Act* 1988 Section 5, Refusal of Treatment Certificate**
(1) If a registered medical practitioner and another person are each satisfied—
(a)that a patient has clearly expressed or indicated a decision—
(i)to refuse medical treatment generally; or
(ii)to refuse medical treatment of a particular kind—
for a current condition; and
(b)that the patient's decision is made voluntarily and without inducement or compulsion; and

Currently, in many jurisdictions the law allows people to provide instructions or wishes when appointing an enduring guardian or an enduring attorney (financial) or its legal equivalent. There are different titles used for the documenting of the power. However in most jurisdictions, there would appear to be little provided in the practical circumstances for them to enforce such a request. This is not just a local factor. The evidence internationally[21], such as those US states that have legislated to enforce advanced directives, indicates that where they exist they play little role in the decisions made. They may get invoked to validate a decision in accordance with them, but otherwise they appear to be largely ignored.

There is a problem with trying to direct future events because of the lack of knowledge about what the future may hold. The reason for appointing someone is to trust in their judgment about what is in your best interests. This is particularly significant if there are matters of health and life at stake, but seemingly not so personally significant otherwise, though of course financial matters may affect health matters. Where one lives may also determine what care is available, and where one lives may be determined by financial decisions.

Suggestions have been made by the Victorian Law Reform Commission[22] that new offences be created for people failing to comply with instructional directives. The issue is one of trust. The purpose of giving a power of attorney is to entrust matters to that person. If there were offences associated with holding a power of attorney, then it would be foolish to be prepared to accept the role, and their function would be undermined and be likely to fall into disuse. The Ad Hoc Committee suggests that the power not be enforceable, but that it be definitely reviewable if there is concern that decisions were being made not in the person's best interests.

Health professionals who encounter a representative who is making decisions not in the patient's best interests, which often happens, should seek review of the representation in the interests of the represented person.

In aged care it sometimes happens that the life of the family member who has the authority for a resident with dementia has moved on from the relationship, in the sense that they may have formed a new relationship or want to travel, and they may feel that they and the household assets are tied down by the continued survival of the aged care resident. It is not uncommon in those circumstances that the representative may refuse any treatment, including non-burdensome effective treatments, such as influenza vaccine or antibiotics, not in the resident's best interests, but because they do not want them to survive.

(c)that the patient has been informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) for that condition and that the patient has appeared to understand that information; and
(d)that the patient is of sound mind and has attained the age of 18 years—
the registered medical practitioner and the other person may together witness a refusal of treatment certificate.

[21] See for instance: Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42.

[22] Victorian Law Reform Commission Op. Cit.

The committee is concerned about any weakening of the capacity for representation to be reviewed if any of those concerned fear that the representation is not in the represented person's best interests.

(ix) Respecting Patent Choices

There is a national Respecting Patient Choices (RPC) program run from the Austin Hospital and funded under the *National Palliative Care Program* and supported by the Australian Government Department of Health and Ageing. The Respecting Patient Choices Advance Care Planning Program is also supported by the Victorian Department of Health. The program is available in many hospitals, palliative care services and aged care services.

The program encourages people to fill in a declaration of their wishes to "inform your agent, your family and your doctors of your medical treatment wishes in order to assist them in making decisions if you can no longer do so for yourself". The program also encourages an agent to fill in a similar form for an incompetent person.

As mentioned, there is some uncertainty under the Common Law as to how binding these documents are. The may be applied like living wills or they may simply be advisory. The program has different forms for each State because in some States advance directives had statutory force.

The Committee has some difficulties with the wording of the forms and their implications.

For instance, under the heading "**Respecting Patient Choices", the document refers to Life Prolonging Treatments and includes as examples, a** breathing machine (ventilator), kidney machine (dialysis), feeding tube, or surgery. It then gives three options:

> **I would like** life prolonging treatment in order to prolong my life as long as possible.
> **OR**
>
> **I would like** life prolonging treatments only if the doctors expect a reasonable outcome. To me, a reasonable outcome means:
> **OR**
>
> **I do NOT** want life prolonging treatments at all. If life prolonging treatment has been commenced I request that it be discontinued and that I receive palliative care.

The focus on outcome is problematic. Suppose, as a young person might, the person says that being unable to speak after a stroke, or losing her short-term memory through dementia, are completely unacceptable outcomes for her. What does that mean in terms of her care decisions? Does it mean that all forms of life prolonging care are to cease? If she has a feeding tube, is it to cease immediately? Is she not to receive any more dialysis? Would it be wrong for them to give her antibiotics to treat a lung infection?

If that is what is meant, then saying that those conditions are unacceptable is basically a death warrant. The patient or aged care resident is not being kept alive. That would be incredibly difficult for the staff and the family. Basically the patient is to be neglected to death.

The more nuanced decision that people would be more likely to want made is a distinction between difficult or burdensome treatment which may no longer be justified by benefits, and the care that would ordinarily be provided, such as feeding, washing, turning, watching TV or some other such entertainment, seeing relatives and friends, perhaps playing bingo or wheel chair carpet bowling, etc. The emphasis in giving advice for future care should be on what things the patient, doctors, nurses, family and carers think may be overly burdensome.

For instance, a man with dementia and on dialysis found it incredibly difficult because he no longer understood why he had to be tied to a chair and a machine for several hours on end. Dialysis was very distressing for him. Another patient with dementia happily watched TV throughout the sessions and chatted to the staff and other patients. In giving advice for her future, a patient on dialysis might say that if she suffers from dementia ***and the dialysis causes great distress***, then it can be withdrawn because it would be overly burdensome, but if she can cope then it should continue.

The focus needs to be more on what the treatment can do and how burdensome or difficult it is, rather than simply saying ahead of time that the patient does not want to be in that state.

In another part of the planning document the patient is asked to state:

> **The things that I most value in my life are: (eg. independence, enjoyable activities, talking to family and friends):**
>
> **Future situations that I would find unacceptable in relation to my health:**
>
> **Specific treatments that I would NOT want considered for me :**
>
> **Other things that I would like known, which may help with making decisions about my future medical treatment:**

The statement about “future situations that I would find unacceptable” raises the question, if the patient does end up in such a situation, what are the health care team, representative or the family to do? Might they end my life or end all those treatments that might keep her alive, such as quite ordinary things like feeding her or treating infection? How are the staff and family to interpret the statement that her situation is unacceptable? Again, a nuanced approach would keep non-burdensome, ordinary care going, but not see a justification for more burdensome things.

Similarly, the list of some treatments, that the patient would not want considered, would depend on how burdensome she found them at the time and what benefits they produced. For instance if her daughter or granddaughter is about to be married, she might have chosen to have even burdensome life prolonging treatments, rather than miss the wedding or die at a time that would spoil the big day. We need someone who knows us to make those judgements at the time rather than attempt to tie their hands with less well-informed predictions.

What may happen in the future is so unpredictable. We should not declare an outcome or a treatment to be off limits without knowing the circumstances.

Focussing on outcomes is problematic for those reasons. We would be better giving more general advice about what we consider to be overly burdensome and about benefits, so that the person making the decisions knows our priorities. A patient might, for instance, be concerned about the costs of prolonged intensive care at around 24 times the average wage. The patient might want to say that unless there are other strong reasons for keeping on going, she would like to limit the costs of ICU to a week and then to withdraw, but it would be important to allow the flexibility in case something depends on it that had not occurred to her, but would be important to her or to those she loves. It is better not to be too directive and better to focus on treatment alternatives and not on rejecting outcomes.

A problem with the RPC documents is that they direct patients and aged care residents to declare against certain outcomes, rather than focussing on the values and beliefs about the likely treatment options. Declarations of the RPC kind also have the meaning of a suicidal directive – do not let me live with that condition. They seem to be a statement implying euthanasia in the event of an unsatisfactory outcome.

An alternative approach is spelled out on the Catholic Health Australia website. It also contains a form that patients can download and modify. *A Guide to Future Care Planning* by Catholic Health Australia was approved by the Australian Bishops and is available as a free download from http://www.cha.org.au/site.php?id=223

The RPC program has undertaken research[23] into patient and family attitudes in relation to the intervention indicating significant satisfaction compared to controls who did not experience the intervention. The research, however, does not compare patients who simply had an opportunity to discuss their future care with their family, representative, and health care team, with those who were also asked to complete directive documentation of the kind prescribed by the RPC program. The research results also do not indicate the proportion that had the RPC intervention but declined to complete the directive documentation. Anecdotally it is reported that few people complete the directions. Finally, there seems to be an absence of research into what effects the completed directives had on outcomes. Did doctors comply and what does compliance mean if a patient develops a condition that he or she declared to be unsatisfactory or unreasonable? In Detering *et al's* research the main outcome measures were whether the patient's end of life wishes were known and respected; and levels of distress, anxiety, and depression in relatives of patients who had died. Of the former, 86% 'success' was recorded and of the latter family members in the intervention group had 'significantly less stress, anxiety and depression. [24]

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[23] Karen M Detering, Andrew D Hancock, Michael C Reade, and William Silvester, "The impact of advance care planning on end of life care in elderly patients: randomised controlled trial"
BMJ. 2010; 340: c1345

[24] Ibid

One of the problems with the RPC type of intervention is that if the directions are completed it records what the patient's view was at that time. Most doctors and nurses dealing with patients with a terminal illness speak of a process of ongoing consultation in which the patient and the team walk together as the disease develops, discussing and adapting as the disease changes. There are usually many attitude changes during that process. To have an attitude documented at one time and potentially binding (at least in Common Law and in statute law in those jurisdictions that have living will statutes) is unlikely to reflect what a patient may want at a later time when the disease process is more advanced and there is greater knowledge, acceptance and understanding of the condition.

The RPC advance care planning form for use in aged care [25] (as distinct from the form used in hospital) is under revision in 2012. However, the principles accompanying the form state clearly that the process assumes an ongoing dialogue, and that the older person's documented preferences can be changed at any time. The form for aged care includes the option: 'I wish to receive palliative care that includes treatments to keep me comfortable, pain relief, and be offered food and drink of my choice.' It is also instructive to note the revised Standards for residential aged care, currently in draft form, include a specific, new Standard requiring ACP to be offered to all residents and families.

While PCA's 'Advance Care Planning' position statement [26] refers in most instances to 'advance care planning', the need for 'ongoing conversation' and the promotion of substitute decision makers, the statement also holds that: 'Formalised *advance care directives* can form an integral part of the advance care planning process . . .'. PCA acknowledges that the goals of advance care planning are broader than formalised advance care 'directives', and the legislative inconsistencies across Australian jurisdictions creates confusion. However, we urge the Senate to consider the arguments outlined above in relation to the proposed national framework.[27]

By contrast, our concern is that the States that have not legislated to make advanced care directives enforceable should not do so and that those who have should revise the legislation. The need is to support the consultations processes and encourage people to appoint someone to represent them, but to ensure that any advice that they give be advice only and not enforceable because it would be unlikely to correspond to informed consent and could cut short the consultation process by which patients often come to accept their illness, the disease process and the treatments available, despite initial negativity they may feel at the outset or when contemplating illness and disability at an earlier time.

Finally, on the issue of advance care planning, if Australian citizens, and particularly older Australians, could have confidence that their end-of-life wishes would be honoured through the appointment of someone to represent them, and that they would have access to relief of distressing symptoms through evidence based palliative care, perhaps fewer would be opting for euthanasia or physician assisted suicide.

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[25] http://www.respectingpatientchoices.org.au/

[26] Palliative Care Australia. *Advance Care Planning Position Statement* (undated). http://www.palliativecare.org.au.

[27] A national framework for advance care directives. September 2011. http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

We recommend that advance care planning should focus on continuous conversation and review, rather than be constrained by binding directives and that the law explicitly exclude the possibility of directives being interpreted in a way which binds health professionals, representatives and families.

(i) the availability and funding of research, information and data about palliative care needs in Australia.

Before anything is done to legislate to give binding force to advance care plans/directives, it is important that there be much better information available than we now possess about the desirability and the effects of issuing directives. A model in which people appoint a representative and embark on an ongoing process of discussion with the representative, the family and the health care team needs to be contrasted with models such as RPC that encourage people to issue directions, particularly directions based on outcomes. We need that research to be undertaken.

In Melbourne, for instance, the Northern Hospital and the Peter MacCallum Cancer Institute have not adopted the RPC intervention and documentation, but have instead favoured a process of ongoing consultation about future care planning which avoids a focus on outcomes and instead focuses on what care and assistance is available as the disease process advances. Those centres consciously rejected the documentation of directives and the language of the pro formas in the RPC program, while adopting what they considered to be the advantageous elements of the RPC format.

Other priorities for research include the benefits of applying a palliative approach to older people in advanced stages of dementia; and the value of routine family meetings both in specialist palliative care contexts and residential aged care contexts. While the literature is clear that patients/residents with end stage dementia experience distressing symptoms similar to those experienced by patients dying of cancer, there is a dearth of evidence to support best (palliative care) practice in aged care. [28]

We recommend an urgent increase in research funding for palliative care in chronic disease (including dementia), comparable to that provided for cancer research.

One of the hallmarks of palliative care is that the family and patient are treated as one unit. As aged care is increasingly adopting principles of palliative care for residents with chronic, incurable illness, there is little to guide aged care workers in accepting the family as ‘partners’ in care. On the contrary, the family is often perceived ‘in an adversarial light. . . to be accepted and tolerated’. [29] While research is progressing in

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[28] Van der Steen, JT. ‘Dying with dementia; what do we know after more than a decade of research. *Journal of Alzheimer’s Disease* 22 (2010): 37-55. Refer also Oxford University’s Baroness Susan Greenfield who states: ‘In Australia, dementia research receives approximately $20 million – a little more than four per cent of the total amount spent on research for all chronic diseases – despite the fact that it is already the third leading cause of death in this country. In comparison cancer research receives $144 million annually. . . Yet by 2060, spending on dementia is set to outstrip that of any other health condition in Australia.’ *The memory matters newsletter of Alzheimer’s Australia Vic,* Issue 102 Spring, 2011.

[29] Haesler E, Bauer M, Nay R (2006). Factors associated with constructive staff-family relationships in the care of older adults in the institutional setting. *International journal of Evidence Based Healthcare,* **4**: 288-336.

the specialist palliative care context, [30] and guidelines are available for conducting family meetings, [31] there is urgent need for these to be adopted in aged care.

We recommend research be undertaken to guide aged care health professionals in improving their communicating with families.

Another area overdue for research is a review of the *Guidelines for a palliative approach in residential aged care,* cited several times throughout this submission. The Guidelines were endorsed by the NHMRC in 2006, but they are now due for review.

We recommend that the 'Guidelines for a palliative approach in residential aged care' be reviewed; to ensure aged care and palliative care health care practitioners have access to current best practice evidence based guidelines.

Reference is made in (d) above to the emerging need for research in perinatal palliative care.

We recommend further research into the benefits of perinatal palliative care, exploring whether increasing women's choices influences their decision in relation to giving birth to a baby whose survival beyond birth is seriously compromised.

Conclusion

The Ad Hoc Interfaith Committee is grateful for the opportunity to make this submission to the enquiry. We wish the enquiry well with its deliberations. We would welcome the opportunity to be represented at the hearings if the Senators would like clarification of our submission and the opportunity to respond to matters that will have been raised by others.

Regards,

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On behalf of the following:

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[30] Hudson P, Zordan R, Trauer T. (2011). Research priorities associated with family caregivers in palliative care: international perspectives. *Journal of Palliative Medicine,* Volume 14, Number 4, 397-401.

[31] Hudson P, Quinn K, O'Hanlon B, Aranda S. (2008). Family meetings in palliative care: multidisciplinary clinical practice guidelines. *BMC Palliative Care.* **7:** 12. Available at http://www.ncbi.nlm.nih.gov/pubmed/18710576]

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