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**HCCA Submission:
Supporting Australians to live
well at the end of Life.**

May 2010

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HCCA Submission to Department of Health and Aging on:
Supporting Australians to Live Well at the End of Life
Draft Palliative Care Strategy 2010

The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

Consumer-Centred Care

We recognised that our health system is under pressure and cannot cope if policies and planning continue to focus on diseases rather than consumers. The key to changing our health system lies in involving individual consumers, to empower us to understand our conditions, treatments and options. It is through understanding that we adhere to treatments, make behavioural changes and self-manage. HCCA considers that consumer-centred health care is the most cost-effective way to improve health outcomes for our community.

The essence of consumer-centred health care is that the health care system is designed and delivered to address the health care needs and preferences of consumers so that health care is appropriate and cost-effective. By promoting greater consumer responsibility and optimal usage, consumer-centred health care leads to improved health outcomes, quality of life and optimal value for health care investment.

We support the common priorities that the International Association of Patient Organisations have identified as critical to achieve consumer-centred health care at every level in every community.

To achieve consumer-centred health care we believe that health care must be based on the following Five Principles:

1. **Respect**
2. **Choice and empowerment**
3. **Consumer involvement in health policy**
4. **Access and support**
5. **Information**

We call on the Department of Health and Aging to review this strategy to ensure that consumer-centred care is paramount in all aspects of the strategy.

All health strategies should as a bare minimum have the Australian Charter of Healthcare Rights as their first point of reference.

These rights are

- I have a right to health care
- I have a right to receive safe and high quality care
- I have a right to be receive safe and high quality care
- I have a right to be shown respect, dignity and consideration

- I have a right to be informed about services, treatment options and costs in a clear and open way.
- I have a right to be included in decisions and choices about my care
- I have a right to privacy and confidentiality of my personal information
- I have a right to comment on my care and to have my concerns addressed.

General Comments

While this draft strategy is designed to drive change and improve outcomes for people at the end of their lives HCCA feels that it fails to place their rights at the centre of the strategy. Instead it reads as a document which is primarily from a service providers point of view. The document needs to be revoiced to put the consumer and their rights as the primary focus of the strategy.

We strongly support the inclusion of outcomes, indicators and measures of success along with action areas in the strategy. We have some suggestions on how to improve these (details below). HCCA also feels that it is important to tighten the measures for reporting in this area.

We noted that ten consultations with stakeholders and consumers were held to inform the strategy. However, we cannot see where the information gathered from these consultations has influenced the strategy. What did consumers have to say about palliative care and how has it shaped this document? This needs to be explicitly stated.

We are very concerned that this document, as it stands, is designed to address the needs of the palliative care workforce rather than the consumers of palliative care services. For instance it talks about training, getting their message out to the public and while it mentions the reform package which says that care should be patient centred this document fails to reflect this. While HCCA is strongly supportive of policies to improve the skills and resourcing of the workforce (a skilled and supported workforce is critical to good health care), nevertheless, a Strategy in line with health reform also needs to provide a patient/consumer focus.

It is interesting to note that the diagram which appears on p.7 entitled *Scope of Palliative Care Service System* places the family, carers and volunteers at the centre of the diagram. The consumer (patient) is entirely absent. Health consumers have the “right to be included in decisions and choices” about their care and most palliative care patients are and should be involved in these decisions. This diagram also fails to acknowledge that the majority of people live on their own towards the end of their life and that it is not unusual for consumers to be living alone when seeking palliative care. Consumers need to be in the centre of the strategy.

The other “elephant in the room” is euthanasia. While the Australian community has a great deal to say on this subject it is not mentioned in this strategy. Nor is the current medical practice of increasing pain medication as a palliative care measure. This increased medication often leads to an earlier

death. This practice is not discussed at all in this strategy. Why has this along with end of life directives been ignored by this strategy? Also missing from this strategy is any discussion of the importance of hospices in the provision of end-of-life care.

We feel strongly that the strategy should include a vision for palliative care in Australia. The World health Organization definition quoted in the report was written nearly twenty years ago and does not fully reflect current community thinking on end-of-life care. This vision should be consumer centred, mindful of the current reform agenda and the charter of Healthcare Rights. The ACT Palliative Care Strategy 2007 – 2011 states its vision as:

ACT Health will deliver palliative care as appropriate to people of all ages, recognizing their choices and needs ensuring care is provided in accordance with the standards developed by Palliative Care Australia.

This could be a starting point for developing a national vision for palliative care.

HCCA feels that the referencing and bibliography for the strategy is inadequate. For instance it is not clear where the actions come from. More transparency is needed.

Specific Feedback

The Strategy

In the last paragraph of page eight it states that in the last ten years “much has happened”. Indeed much has happened and the writing of this strategy is an opportunity to address some of the big issues around end-of-life care. In a recent article entitled Diagnosis of Dying published in the Health Advocate, Professor Ken Hilman from the University of NSW points out that death has become medicalised in much the same way that pregnancy and childbirth became medicalised in the 1950’s and that:

...management of end-of-life in acute hospitals is often inappropriate and cruel. Nevertheless, there are pressures to place people at the natural end of their life on a conveyor belt from their home to their hospital and from there into an ICU to spend their last days connected to machines when there is no hope of recovery.

HCCA does not feel that this strategy forcefully address this “often inappropriate and cruel” end-of-life care in hospitals?

Goals

HCCA feels that another goal to put the consumer at the centre of the strategy needs to be articulated. We suggest the following goal:

To provide patient centred palliative care that is appropriate to the health consumers cultural approach to life and dying.

The strategy states:

Action will be undertaken to support the national roll out of advanced care planning including any barriers to uptake.

This should be rewritten to include.

Action will be undertaken to address any barriers to the roll out of advanced care planning to provide palliative care services with direction from the consumer's wishes for end-of-life care.

In the measures of success for this goal we would like add a more concrete measure. Namely:

The percentage of consumers coming to palliative care services with advanced care planning orders.

Page 13 Appropriateness and Effectiveness

In the Action areas section of this goal under the second dot point we suggest that the strategy acknowledge the need to respect individual rights and choices and add the following action to the top of the list:

Evolution of models conducive to clients who do not want to have their life extended and wish to die with dignity.

Page 14 Appropriateness and Effectiveness

In the measures of success for this goal HCCA is concerned that they are not specific enough. For instance: *outcome data and trends form relevant data collections* is very vague and could really mean anything. This should be made more specific and read something like:

Outcome data and trends from relevant data collections including the percentage of people who have died in acute settings or intensive care units.

We would also suggest the following be included in the measures of success

Effective pain and nausea care.

Page 15 Leadership and Governance

In the action areas for this goal the strategy should include:

Ensure that all palliative care services operate in a patient centred manner in line with the Charter of Healthcare Rights.

Feedback from consumers should also be included in the measures of success.

Conclusion

HCCA broadly supports the measures outlined in this strategy. However the focus of the document needs to shift from the palliative care workforce to the palliative care recipient and all goals, actions and measures of success need to reflect this.

Compiled by Julie Derrett
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