Consumers
Health Forum
of Australia

Submission to the Senate Community Affairs Committee
Inquiry into Palliative Care in Australia

March 2012

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The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF welcomes the opportunity to provide a submission to the Senate Community Affairs Committee's *Inquiry into Palliative Care in Australia* (the Inquiry). CHF's work in this area has drawn on consultation with our membership, which includes organisations advocating for older consumers, disease specific groups and networks, state and territory peak consumer organisations and individual consumers.

Of particular interest to CHF are the Inquiry's terms of reference relating to:

- The factors influencing access to and choice of appropriate palliative care that meets the needs of the population
- The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities
- Advance care planning.

CHF's submission calls for the implementation of an Australian Primary Palliative Care Framework, improved palliative care services for consumers in acute settings, and implementation plans to accompany the *National Framework for Advance Care Directives* and the *National Palliative Care Strategy.* CHF also calls for the full implementation of the recommendations made by the final report of the Productivity Commission's *Inquiry into Caring for Older Australians,* aimed at reforming the provision of palliative care in aged care settings.

The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

Many consumers would welcome the opportunity to access palliative care services in the community or in the home. Much of the last year of a consumer's life is spent at home, and most healthcare is provided in the primary care sector. However, CHF appreciates that providing high quality care at the end-of-life is among the most complex challenges within primary care. Patient symptoms may be severe, disease trajectories difficult to predict, family issues complex and the clinician's own beliefs and fears about death and dying challenging.

There are also a number of structural and resource barriers, including lack of time and remuneration, lack of training, knowledge and resources, and limited experience in palliative approaches. Despite these barriers, there is evidence that the integration of palliative care into community and primary care settings enables more consumers to die at home and that this is the preference of consumers and their carers.

CHF therefore considers it imperative that clinicians in the primary care sector are well equipped to provide care to people as they approach the end of their life. On this basis, CHF supports calls made by the Australian General Practice Network (AGPN) and Palliative Care Australia (PCA) to implement a framework for the provision of palliative care in the primary care setting.

PCA has proposed that such a framework be modelled on the Gold Standards Framework (GSF) developed in the United Kingdom.[1] The GSF provides the fundamentals of quality care at the end-of-life through:

- education and promotion of quality end-of-life care delivery
- organisational and system changes to accommodate optimal delivery of end-of-life care
- discussion of advance care plans
- care planning in the final years of life
- providing care closer to home.

The GSF is consumer-led and focused on consumer needs, and is applied across all care settings including home, hospice, hospitals and others.

The proposed model would need to be adapted from the United Kingdom to the Australian health system to suit the Australian context. However, a framework of this kind could complement and build on existing models at state and territory level rather than duplicate them.

The establishment of Medicare Locals could provide the foundation for this, as they have already been charged with the task of developing and implementing coordinated, integrated primary health care services for the whole population, including older consumers. They are ideally placed to work with GPs and other primary health care providers in their local communities.

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[1] Palliative Care Australia (2011) *EoL – Towards quality care at the end-of-life*. Palliative Care Australia: Canberra.

CHF supports calls made by the AGPN and PCA proposing that the Government allocates $3.9 million over 3 years, 2012-13 to 2014-15, to move from development to implementation of the Australian Primary Palliative Care Framework to support the provision of appropriate end-of-life care to consumers in the primary healthcare setting.

Provision of Specialist Palliative Care Services

CHF notes the findings of a recent English study, which found that optimising resource allocation in end-of-life care is one of the most difficult issues to be addressed in health systems around the world:

> *How do we define the initiation of the process of 'dying,' and at what stage does the balance of care provision switch from curative to palliative intent? Clinicians may be reluctant to diagnose a patient as dying, as they may perceive this to be a recognition of their failure. However, such acknowledgment is essential in refocusing clinical effort from cure to care and ensuring that the quality of care provision is maintained during the crucial palliative phase of the patient's care pathway.*
>
> *Optimising the consumers' remaining quantity and quality of life requires clinical standards to be maintained or even enhanced, with clinical thresholds (e.g. initiating blood transfusions in response to low haemoglobin levels or providing antiemetics in response to nausea) being maintained unless it is in the patient's interest or in response to their expressed wishes to relax them.*[2]

These findings are supported by the experiences of many Australian consumers. In many acute care settings, consumers with palliative care needs are often not identified and not appropriately referred, or are referred for inappropriate treatment. There is limited discharge planning and coordination of subsequent care. As a result, consumers may not be provided with adequate care, may face unreliable and poorly coordinated transitions between services, and find it difficult to navigate the complexities of the healthcare system.

A major area of concern for CHF is the increasing number of consumers with life-limiting chronic conditions such as heart disease, chronic obstructive pulmonary disease and dementia. To meet the growing needs of these consumers, many professional associations and consumer advocacy organisations have proposed that palliative care and curative care be offered at the same time, with the transition to palliative care increasing and curative care subsiding as the disease progresses. Such an approach would require more seamless integration and transition from curative to palliative care, transfer of information, mutual understanding of goals and possibilities of care, and liaison between multiple service providers working in diverse sites of care, wherever the consumer is at the time.

CHF notes that some specialist palliative care services do provide consultative and ongoing care for consumers with a life-limiting illness and provide support for their primary carer and family in a range of care settings, including the home, hospital, hospice and aged care settings. Although some of these services are funded on a limited basis by state and territory governments, this approach is not currently supported by current funding arrangements or in targets or models of service provision for palliative care.

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[2] Haycox, A. (2009) 'Optimizing Decision Making and Resource Allocation in Palliative Care', *Journal of Pain and Symptom Management,* 38(1):45-53.

The consulting service role of palliative medicine physicians and specialist palliative care services continues to expand, with increasing demands for:

- outpatient clinic based services
- services that are available twenty four hours a day, seven days a week
- management of palliative care needs from a referrals base which increasingly involves consumers with non-cancer life-limiting chronic diseases
- palliative care input to advance care planning in hospitals
- meeting the increasing need for palliative care in response to intensive care calls.

CHF believes that better resourcing of tertiary palliative care services, including home care, would:

- assist a greater number of consumers to clarify palliative care goals that might enable consumers to return home, who would otherwise remain in acute settings receiving unwanted or unnecessary treatments at the end-of-life
- reduce the expenditure on hospital beds
- improve liaison between tertiary and primary providers.

CHF recommends that the Committee supports the allocation of funding to enable acute care hospitals to better identify and provide appropriate care services for people with palliative care needs. This could be applied through increased resourcing for internal specialist palliative care consultancy within acute hospitals.

CHF believes that the adoption of this model would provide a real opportunity to implement cross-jurisdictional health program reform in palliative care. However, this reform should not be the sole mechanism for palliative care case funding. Both community and primary health care models also need development.

The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

CHF is concerned by the findings of the final report of the Productivity Commission's *Inquiry into Caring for Older Australians*, which found that entry to residential care is becoming increasingly limited to consumers with a higher level of frailty or cognitive conditions such as dementia.[3] The report predicted that this will lead to increased demand for palliative and end-of-life services to be delivered in both residential and home environments.

To address these issues, the Commission calls for a greater role for residential and community care providers in the delivery of palliative care. In Recommendation 9 of its report, the Commission argues that there is a strong case for a greater role for residential and community care providers and that this role should be supported:

> *The Australian Government should set scheduled fees for the delivery of certain subacute services that are delivered in a residential aged care facility. These fees should be cost reflective and, in general, lower than the scheduled fee for the equivalent service provided in a hospital.*[4]

Following on from this, Recommendation 10 states that:

> *The Medicare rebate for medical services provided by general practitioners visiting residential aged care facilities and people in their homes should be independently reviewed to ensure that it covers the cost of providing the service…*
>
> *The Australian Government should ensure that residential and community care providers receive appropriate payments for delivering palliative and end-of-life care. These payments should form part of the assessed entitlement determined by the Gateway assessment process. The appropriate payment for palliative and end-of-life care should be determined by the Government on the transparent advice of the Australian Aged Care Commission and in consultation with the National Hospital Pricing Authority.*[5]

Other suggested mechanisms to enhance service provision include:

- enhanced Medicare items for GP provision of palliative care services in the community, and in residential aged care
- enhanced Medicare items for specialists such as palliative medicine physicians and geriatricians to provide services in the community, and in residential aged care
- funding for aged care providers to contract service provision with GP group practices
- funding of care coordinators whose role is to liaise between clinicians, including GPs and palliative medicine physicians, aged care facilities and specialist palliative care services about consultation, appointment times and other administrative arrangements. Medicare Locals could be in a position to employ these care coordinators
- a specific Medicare item for clinicians to work with consumers on preparing advance care plans.

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[3] Productivity Commission (2011) *Caring for Older Australians: Final Inquiry Report. Report Number 53*. Productivity Commission: Melbourne.

[4] Ibid.

[5] Ibid.

CHF strongly supports the Commission’s findings, and considers this Inquiry to be an opportunity to advance these proposals. Not only is the provision of palliative care in aged care settings less expensive than services delivered in a hospital, but CHF believes it would deliver more appropriate care for consumers.

CHF urges the Committee to endorse Recommendations 9 and 10 of the final Productivity Commission report in full, and to seek their urgent funding and implementation by the Australian Government.

Advance care planning

Many consumers who have provided feedback to CHF on end-of-life care issues have referred to advance care planning. There has been a general consensus that both primary and specialist health care providers must be trained in strategies to conduct end-of-life discussions around advance care planning.

CHF favours PCA's definition of advance care planning as a process to help people formulate and communicate their preferences regarding care during future incapacity. It also encompasses the provision of care that accords with people's preferences, which is often hindered by a failure to discuss and implement advance care plans. This provides consumers with the opportunity to determine the likely scenarios when approaching the end-of-life, including the treatment they receive and the way they would like to be cared for.

Advanced care directives can be a key part of advance care planning. They include instructions outlining consent or refusal of treatments, and provide preferences for treatment and lifestyle options. Advance care planning and advanced care directives are an important means of preserving the autonomy of the consumer at the end of life.

Advance Care Planning in Aged Care Settings

Consumers have told CHF that awareness of the option of an advance care plan is dependent on their care location and care provider. In other words, it is dependent on 'luck'. The National Health and Hospitals Reform Commission (NHHRC) has recognised this issue, and has recommended that consumers, particularly those in residential aged care, should be given opportunities to explore the type of care they would like to receive at the end of their lives, with particular emphasis on consumers in aged care settings.[6] CHF agrees with this finding, and believes that consumers in aged care settings should be supported to seek access to resources and services in line with their care needs.

CHF recommends that the Committee supports implementation of the NHHRC recommendations to improve palliative care services in residential and community aged care settings. This would include funded programs to support advanced care planning and the provision of end-of-life care as a basic competency for aged care workers.

The importance of advance care planning has also been highlighted by the Productivity Commission, which advised:

> *Given that advance care planning can result in a win-win situation, there is a case for assisting care recipients, their families and health professionals and care workers to be better informed about advance care planning and the common law rights of people to make decisions about their medical treatment (including the right to decline treatment).*[7]

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[6] NHHRC (2009) *A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission*. Commonwealth of Australia: Canberra.
[7] Productivity Commission Op Cit.

The Commission added that:

> *The Commission suggests that funding should be made available for community awareness education (which could be linked to better informing Australians about the probability of needing care)... about the importance of talking about dying and advance care directives. Health professionals and aged care providers also need to be appropriately trained to talk to care recipients about end-of-life issues and assist them to put in place advance care directives.*[8]

Finally, the Commission concluded:

> *The effective communication of advance care plans between health care sectors (for example from hospital to residential aged care facilities and vice versa) is vital if patient's treatment preferences and end-of-life care wishes are to be known and respected.*[9]

The experiences of many consumers consulted by CHF support these findings. In practice, advance care plans can be disregarded in acute care and other hospital settings, particularly if they are not in a legally binding format and the consumer is transitioning from another care setting, or if advance care plans are not communicated, but also if the care plan does not accord with the service provider's care protocols. For the consumer, this can mean unwanted 'heroic' care interventions to extend life with little consideration of its quality. In some instances, it also results in unnecessary and unwanted hospitalisations.

CHF recommends that funding be made available for an education campaign to promote advance care planning and advance care directives, in line with the findings of the Productivity Commission.

CHF also recommends that the Committee explores training options for aged care providers around the discussion of end-of-life issues and assistance in advance care planning.

Implementation of National Policies and Frameworks

In recent months, CHF has expressed concerns about *A National Framework for Advance Care Directives* (the Framework) and the *National Palliative Care Strategy: Supporting Australians to Live Well at the End of Life* (the Strategy). These documents were recently released by the Australian Health Ministers' Advisory Council (AHMAC). CHF has written to the Minister for Mental Health and Ageing, the Hon Mark Butler MP, to outline our concerns.

Both the Framework and the Strategy are aimed at providing guidance to the state and territory governments' palliative care policy development and service delivery. It is therefore essential that they provide a positive, consumer-centred, measurable and effective framework that supports the goal of a healthy approach to end-of-life care.

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[8] Ibid.

[9] Ibid.

In our submission to the development of the Framework, we expressed disappointment that it did not adopt a consumer-centred approach to advance care directives and the provision of end-of-life care. CHF also raised concerns regarding the Framework's approach to informed consent.

Pages 7 and 31 of the Framework state that there is no requirement for professionals to inform consumers of their treatment options when preparing their directive. In providing guidance to state and territory jurisdictions, pages 31-32 further state that consumers:

> *…can write medical directions refusing future treatment with no requirement to be informed themselves about the potential consequences of their ACD being applied.*
>
> *Law and policy must not require that a competent adult completing an ACD be medically informed or seek or follow medical advice in order for the ACD to be considered valid.*[10]

CHF agrees that consumers should not be required to follow medical advice in their advance care directive, but believes that they must be *informed* of the consequences of not doing so. This Framework is intended to provide guidance over time, and its approach to informed consent therefore represents an opportunity to provide direction to states and territories and promote best practice. With this in mind, the Framework's definition of informed consent is regressive.

While CHF appreciates that the Framework has already been endorsed by Australian health ministers, we urge the Committee to consider consumer concerns around informed consent in end-of-life care in preparing its report. Consumers must be advised of all treatment options when preparing their advance care directive and should be provided with all relevant information pertaining to its application.

CHF recommends that the Committee's findings recognise the significance of informed consent in the provision of end-of-life care. Consumers must be advised of all treatment options when undertaking advance care planning or preparing an advance care directive. This principle should be reflected in all future government policies and strategies relating to end-of-life care.

CHF is also concerned that neither the Framework nor the Strategy contain any timelines or quantitative targets for implementing their goals. To increase the value of both documents, CHF recommends that they be accompanied by an implementation plans to guide and measure progress against priority areas. These plans could include:

- a commitment to putting consumers at the centre of end-of-life care
- a commitment to informing consumers about advance care directives and end-of-life care options
- tangible actions and targets to improve the uptake of advance care planning
- timeframes to measure progress against priority areas.

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[10] Clinical, Technical and Ethical Principal Committee (2011) *A National Framework for Advance Care Directives*. Australian Health Ministers' Advisory Council: Canberra.

An implementation plan could also contain statements outlining how both documents fit into broader health reform frameworks, as well as specific palliative care initiatives, such as the *Best Practice Standards for Advance Care Directives*.

CHF recommends that an implementation plan be developed to accompany the *National Framework* and the *National Palliative Care Strategy.* The implementation plan should include tangible actions and targets to improve the uptake of advance care planning and timeframes to measure progress.

Conclusion

CHF welcomes the opportunity to comment to the *Inquiry into Palliative Care in Australia*. Our submission addresses the Inquiry's terms of reference relating to the factors influencing access to and choice of services, the effectiveness of palliative care arrangements and advance care planning.

CHF's submission calls for the implementation of an Australian Primary Palliative Care Framework, improved palliative care services for consumers in acute settings and implementation plans to accompany the *National Framework for Advance Care Directives* and the *National Palliative Care Strategy*. CHF also calls for the full implementation of the recommendations made by the final report of the Productivity Commission's *Inquiry into Caring for Older Australians* relating to palliative care, and considers this Inquiry an opportunity to advance the Commission's proposed reforms to the provision of palliative care in aged care settings.

CHF looks forward to reviewing the Committee's report. We would welcome the opportunity to expand on our submission in a public hearing of the Committee.

Representing consumers on national health issues

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of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.
CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

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