

17 November 2011

Dr Simon Towler
Chief Medical Officer
WA Department of Health
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Dear Simon

Draft Chronic Health Conditions Framework 2011-16

Thank you for your invitation of October 2011 to provide feedback on the draft *Chronic Health Conditions Framework 2011-16*.

The provision of quality care and support at the end of life¹ for people living with complex chronic health conditions is recognised by Palliative Care WA Inc as one of the most critical policy matters confronting the health system in the next decade.

We support the Department's approach, in the Framework, of identifying reform and development opportunities which can benefit people coping with a range of chronic health conditions. The key objectives of any piece of work in this arena include:

- improving the lives of people living with – and dying from – chronic illnesses
- the reduction of harms often associated with dying, death and bereavement
- ensuring equitable access to primary² and specialist services for people at the end of life
- supporting health professionals and carers in the community
- developing safer services and more effective interventions
- ensuring the appropriate resource of limited health system and community resources.

Palliative Care WA Inc welcomes explicit acknowledgement, as part of the chronic illness continuum of care, of end of life and palliative care. Within this context, we offer the following brief observations (a more detailed discussion is provided at Appendix A) which should be borne in mind as the Framework is refined and implemented:

- the number of people whose death is attributable to the exacerbation of existing chronic illness is increasing and will continue to increase
- people with cancer are more likely than those with other chronic conditions to access specialist palliative care services in Western Australia
- people living with (and dying from) advanced complex chronic conditions may be less likely to be referred to specialist services because their existing clinicians are unable or reluctant to diagnose dying or negotiate new goals of care
- palliative care teams positively alter the end of life experiences of patients and their carers
- the majority of people want to die at home, and those who receive care from a specialist service are more likely to do so
- specialist palliative care services do not have the capacity to provide hands-on care to all Western Australians who die an expected death, nor does everybody need such care.

¹ throughout this paper, when the term 'end of life' is used, we mean that period of during which a person is living with increasing disability and impairment as a result of their health conditions, a period which may last months or years

² throughout this paper, when the term 'primary care' is used, we mean all those health care providers (this may include specialists) whose substantive work is NOT in palliative care

As a member of Palliative Care Australia, Palliative Care WA Inc endorses *A Guide to Palliative Care Service Development: A Population Based Approach*,³ which outlines a system of end of life and palliative care service provision which is designed to ensure equitable access to safe, needs-based care for all Australians. We believe this policy document furnishes the Department with valuable guidance on how to orientate services – primary and specialist – to meet the growing demand for end of life care.

Palliative Care WA Inc also subscribes to the *Standards for providing quality palliative care for all Australians*.⁴ The Standards include specific criteria for primary care. These criteria will be especially important as the Department proceeds to implement the Framework, which should empower and equip chronic illness care clinicians of all disciplines to provide quality end of life care to those of their patients/clients who are approaching the end of life (the strategy proposed in *A Guide to Palliative Care Service Development*).

We also recommend the National End of Life Framework Forum's report on *Health System Reform and End of Life Care: A Guidance Document*. This 2010 report summarises current issues and challenges in Australia and outlines a values-based framework for practical action in the context of far-reaching reform at different levels of the structure.

Specific Items in the Draft Framework

Dr Simon Towler's introduction to the Framework says while WA has a good range of services to help manage chronic conditions, 'these services are not always integrated and linked.'⁵ Palliative Care WA Inc agrees with Dr Towler's comment. The National End of Life Forum highlights dangers to people who are dying (and their carers and families) associated with this lack of integration.⁶

The Framework's guiding principles are:⁷

1. *integration and service coordination*
2. *interdisciplinary care planning and case management*
3. *evidence-based, consumer-centred care*
4. *health literacy and self-management for chronic health conditions.*

The *South Australian Palliative Care Services Plan 2009-16*⁸ acknowledges the importance of improving end of life and palliative care health literacy using health promoting methods. The main approaches employed in South Australia, which are consistent with Palliative Care Australia's recommendations,⁹ and national strategy¹⁰ are:

- promoting advance care planning
- increasing the capacity of specialist palliative care services to work within their communities to normalise dying, death and bereavement
- funding the stake peak body for palliative care to provide community education on palliative care.

These strategies have been proven effective in Victoria¹¹ and should be added to the Framework as priorities or objectives.

The focus of the Framework is on 'slowing the progression of chronic conditions and enabling early intervention across the continuum of care – from the well population to end of life including palliation.'¹²

Both the World Health Organisation (in its definition of palliative care – see Appendix B) and the evidence¹³ demonstrate the critical importance of the early introduction of palliative care thinking (the so called 'palliative approach') for people living with long-term eventually fatal health conditions, and early referral to specialist services when needs begin to, or are likely to, exceed the capacities of primary health care providers and other specialists, even if this is some time before the person actually dies.

³ Palliative Care Australia, 2005

⁴ Palliative Care Australia, 2005

⁵ *Framework* p 2 – 'Foreword'

⁶ *ibid* National EOL Framework Forum, 2010: *Health System Reform...* – pp 37-38

⁷ *Framework* p 5 – 'Executive Summary'

⁸ SA Dept of Health, 2009: *South Australian Palliative Care Services Plan 2009-16* – p 20 & p 51

⁹ *ibid* PCA, 2005: *A Guide to Palliative Care Service Development* – p 10 **AND** *ibid* PCA, 2005: *Standards* – Standard 9 pp 34

¹⁰ Commonwealth of Australia, 2010: *National Palliative Care Strategy 2010* – p 11

¹¹ LaTrobe University Palliative Care Unit & Palliative Care Victoria, 2006: *Strengthening Palliative Care in Victoria Through Health Promotion: Final Report*

¹² *Framework* p 5 – 'Relationship to WA Health Networks chronic conditions Models of Care'

¹³ Haines I, 2011: 'Managing patients with advanced cancer: the benefits of early referral for palliative care' – *Medical Jnl Aust* vol 194 # 3 pp 107-8

An identified Priority Area in 'service coordination, case management and multidisciplinary care planning' is to:¹⁴

Create positions and recruit Complex Care Coordinators to facilitate care transition between hospital and community-based care providers.

Cognisant of the issues discussed in Appendix A, Palliative Care WA Inc suggests the Priority Area strategy should instead read: 'Create positions and recruit Complex Care Coordinators to facilitate transitions between settings and phases of care.'

In addition, we note the recent National Health and Medical Research Council publication *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions*¹⁵ which provides guidance for health care professionals as they navigate the transition between curative treatment and palliative care. This guidance should be widely available within the health system and Complex Care Coordinators should have a detailed knowledge of the ethical framework.

One of the Priority Areas identified is to:¹⁶

Promote and facilitate the use of Advance Health Directives in end of life planning for people with chronic conditions.

The evidence shows completion by health consumers of advance directives alone does not ensure those individuals receive the end of life care they want, or have much effect on minimising the incidence of those individuals receiving futile, burdensome and expensive care at the end of life.¹⁷ Integrated advance care planning programs demonstrate much greater effectiveness and efficiency.¹⁸

The WA government should invest in this area, and the Priority Area in the Framework, as a first step, should read: 'Develop and implement an integrated advance care planning framework across the WA health system to ensure quality end of life care planning and care outcomes.'

An identified Priority Area is to:¹⁹

Support the accreditation and monitoring of standards for health care organisations where appropriate.

Palliative Care WA Inc notes that specialist palliative care providers throughout WA have embraced participation in the National Standards Assessment Program, a continuous quality improvement initiative developed by Palliative Care Australia which supports services to assess their own performance against the *Standards for providing quality palliative care for all Australians*. This Program could serve as a model for organised improvement in a wide range of health delivery settings and service types.

The specific objective relating to palliative and end of life care on the Continuum of Care is to:²⁰

Ensure informed planning and decision making and safe and high quality palliative care.

This is (necessarily) a broad objective. It might be helpful to make clear some essential ideas within it, including:

- using health promotion of palliative care to foster an informed community
- negotiation of appropriate goals of care for people living with advanced illness
- appropriate early referral to specialist services for those whose needs exceed the capacity of their existing providers
- sustaining effective end of life care service provision in both the specialist and non-specialist sectors.

¹⁴ Framework p 13-14

¹⁵ National Health & Medical Research Council, 2011: An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal conditions

¹⁶ Framework p 14 – 'Priority Areas'

¹⁷ The SUPPORT Principal Investigators, 1995: 'A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)' – *Jrnl American Medical Assoc* vol 274, no 20, pp 1591-1598

¹⁸ Detering K et al, 2010 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' – *British Medical Jrnl* – 340:c1345

¹⁹ Framework p 14 – 'Priority Areas'

²⁰ Framework p 17 – 'Service components across the continuum of care'

The overall objective is further broken down into the following 'key service components':²¹

Right Care	<ul style="list-style-type: none"> ▪ evidence-based pathways and care plans for end of life and palliation are implemented eg Liverpool Care Pathway ▪ support for families and carers
Right Time	<ul style="list-style-type: none"> ▪ appropriate high quality and safe care is delivered in a timely manner
Right Team	<ul style="list-style-type: none"> ▪ consumers and carers actively participate in decision-making process ▪ promotion of Advanced Care Directives ▪ coordinated interdisciplinary Palliative Care Team
Right Place	<ul style="list-style-type: none"> ▪ where possible services will be delivered in the community or home environment ▪ unless clinically required end of life care and palliation will not be in tertiary settings

Right Care

Palliative Care WA Inc supports the strategic adoption of evidence-based system-wide reforms which incorporate quality improvement methods, such as the Liverpool Care Pathway.

Carers in the community are critical to the operation of the entire end of life care system.²² The involvement of carers is the most important predictor of whether a person is able to die at home²³ but carers suffer harms as a direct result of undertaking this role.²⁴ Easing the burden on informal carers, specifically resident carers and spouses, is necessary if more people are to be able to realise their personal goals of being cared for and dying at home.²⁵ The service component shown in the Framework should be expanded to show that the involvement and support of carers must extend to their consistent identification, needs assessment, training, information provision, respite and bereavement care. A self management approach may be worth exploring.

Right Time

The National End of Life Care Framework Forum argues that a fundamental barrier to achieving quality care at the end of life 'arises from the inability or unwillingness to recognise those who are dying and treat them appropriately' (see also the discussion in Appendix A). This barrier inhibits the provision of the 'right care at the right time' and has profound impacts upon patients, carers, families and the health system. The Forum asserts:²⁶

Reform is needed at a systems level to ensure that all health professionals understand the journey that most individuals will make to the end of their lives... First and foremost will be the ability to recognise when that phase has begun. Health systems and care processes must be designed to respond appropriately to that recognition.

Palliative Care WA Inc suggests that such reform would constitute **the most significant outcome** of the implementation of the proposed Framework, and that this should be given high priority. The systemic incorporation of assessment, review and referral triggers may be a way forward. Practical experience of this approach is accumulating in Britain,²⁷ while an Australian strategy is emerging.²⁸

Right Team

As mentioned above (in the section on Right Care), the contribution of carers in the community to end of life care is indispensable.

As mentioned above (in comments about the Priority Area on advance directives), Palliative Care WA Inc recommends the development and implementation of an integrated advance care planning program across the entire health system.

Right Place

Palliative Care WA Inc agrees with these goals.

²¹ Framework pp 17-19 – 'Service components across the continuum of care'

²² PCA, 2005: *A Guide to Palliative Care Service Development* – p 27

²³ Maida V, 2002: 'Factors that promote success in home palliative care: a study of a large suburban palliative care practice' – *Jrnl Palliative Care* – vol 18 pp 282-286 **AND** Viser et al, 2004: 'The end of life: informal care for dying older people and its relationship to place of death' – *Palliative Medicine* – vol 18 # 5 pp 468-477

²⁴ PCA, 2004: *The hardest thing we have ever done: Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People*

²⁵ Gott et al, 2004: 'Older people's views about home as a place of care at the end of life' – *Palliative Medicine* – vol 18 # 5 pp 460-467

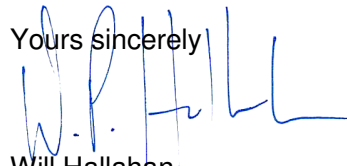
²⁶ National EOL Framework Forum, 2010: *Health System Reform* – pp 34-35

²⁷ Boyd & Murray, 2010: 'Recognising & managing key transitions in EOLC' – *Brit Med Jrnl* – vol 341 c48 **AND** the Gold Standards Framework's 2008 *Prognostic Indicator Guidance Paper V8*

²⁸ Waller A et al, 2008 'Development of a palliative care needs assessment tool (PC-NAT) for use by multidisciplinary health professionals' – *Palliative Medicine* – vol 22 pp 956-64

The President of Palliative Care WA Inc, Mr Andrew Allsop, and I would be very pleased to meet with you and other members of your team to further discuss the development of better end of life care for people living with chronic health conditions in Western Australia, simply contact me at this office or call direct on 0412 412 532 to arrange an appointment.

Yours sincerely



Will Hallahan
Executive Officer

Enclosures:

- *Health system reform and care at the end of life: A guidance document*
- *Standards for providing quality palliative care for all Australians*
- *A guide to palliative care service development: A population based approach*

Appendix A

Palliative and end of life care for people with complex chronic health conditions

Need

There were 12,752 deaths in Western Australia in 2008.²⁹ Based on causes of death data in Australia, we estimate that up to 70% (>8,900) of these deaths were 'expected'. This means the person had (perhaps well in advance) a clear diagnosis of the condition that led directly to their death.³⁰

Specialist palliative care services support approximately 5,000 people each year in Western Australia: less than a third are admitted to a specialist palliative care inpatient facility, where the average length of stay is less than ten days.³¹

Review evidence suggests palliative care positively effects the end of life experiences of patients and carers, is more cost effective than standard care and improves family satisfaction with care.³² A recent American study found that people with metastatic non-small lung cancer receiving palliative care were likely to live significantly longer than those who did not.³³

There is a clear consensus amongst palliative care clinicians, and increasing numbers of those who care for people with non-cancer chronic illness that a palliative approach and, if needed, specialist palliative care services, are appropriate for people with non-malignant terminal conditions.³⁴ People approaching death in this population report:³⁵

- deteriorating health status
- decreased independence
- social isolation for patients and carers
- increasing family burden
- limited availability of resources
- poor access to community services (including GPs)
- varying degrees of acceptance of their survival prospects
- depression, anxieties and concerns for their future health and care options
- spiritual distress.

Issues

Crucially, people with terminal non-cancer conditions may have longer and less predictable trajectories compared to those who are living with terminal cancer.³⁶ Clinicians caring for people dying from non-cancer illnesses may have a 'reluctance and/or inability to define palliative status and predict time to death.'³⁷

Murtagh et al summarise the problem:³⁸

In those diseases with an 'entry-re-entry' pattern such as heart failure and chronic lung disease, decisions about when palliative care is appropriate are particularly difficult. Professionals, patient and family can all become accustomed to periods of severe illness, with

²⁹ Australian Bureau of Statistics, 2008: *33020DO001_2008 Deaths, Australia, 2008*

³⁰ Australian Bureau of Statistics, 2009: *3303.0 - Causes of Death, Australia, 2009*

³¹ Palliative Care Outcomes Collaborative, 2011: *Report 10: Western Australia July to December 2010*

³² Higginson I et al, 2003: 'Is there evidence that palliative care teams alter the end-of-life experiences of patients and their caregivers?' – *Jrnl Pain & Symptom Mngmnt* – vol 25 # 2 pp 150 **OR** Higginson I & Evans C, 2010: 'What Is the Evidence That Palliative Care Teams Improve Outcomes for Cancer Patients and Their Families?' – *The Cancer Jrnl* – vol 16 # 5 pp 423 **OR** Zimmerman et al, 2008: 'Effectiveness of specialized palliative care' – *Jrnl American Medical Assoc* – vol 299 # 14 p 1698

³³ Temel J et al, 2010: 'Early palliative care for patients with metastatic non-small-cell lung cancer' – *New England Jrnl Medicine* – # 363 pp 733-42

³⁴ Mitchell G et al, 2010: 'Palliative care beyond that for cancer in Australia' – *Medical Jrnl Aust* – vol 193 # 2 pp 124-126

³⁵ Fitzsimmons D et al, 2007: 'The challenges of patients' unmet palliative care needs in the final stages of chronic illness' – *Palliative Medicine* – vol 21 # 4 pp 313-322 **AND** Murray S et al, 2007: 'Patterns of social, psychological and spiritual decline toward the end of life in lung cancer and heart failure' – *Jrnl Pain & Symptom Mngmnt* – vol 34 # 4 pp 393-402

³⁶ Lynn J, 2005: 'Living Long in Fragile Health: The New Demographics Shape End of Life Care' – *Improving End of Life Care: Why Has It Been So Difficult* – Hastings Centre Report 35 – # 6 pp 14-18 **AND** Coventry et al, 2005: 'Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review' – *Age & Ageing* – vol 34 pp 218-227

³⁷ *ibid* Fitzsimmons D et al 2007

³⁸ Murtagh F et al 2004: 'Patterns of dying: palliative care for non-malignant disease' – *Clinical Medicine* – vol 4 # 1 – p 41

subsequent dramatic improvement, which may bring a false perspective and detract from awareness of the overall decline... Recognition of dying is especially difficult. Which deterioration will be the one from which there is no recovery?

There are several consequences of this reluctance to discuss the issues:

1. advance care planning is not widely broached with patients with non-cancer life-threatening conditions and their families, or taken up³⁹ despite evidence that 'elderly, chronically ill patients are more satisfied with their primary care physicians and the care they deliver when advance directives are discussed'⁴⁰
2. as detailed below, Rosenwax and McNamara's Western Australian research⁴¹ shows people with non-cancer diagnoses do not access specialist palliative care services at the same rate as those with cancer, and as a result are more likely to die in a hospital or other inpatient setting
3. people with non-cancer terminal conditions may be 'more likely to die with aggressive, technological care directed at preservation of life' and receive end of life care of poorer quality than the care received by people dying with cancer.⁴²

The McNamara and Rosenwax study showed that 92% of people who died in Western Australia during the study period from 'selected non-cancer conditions' (including MND, heart, liver or renal failure, COAD, Alzheimer's HIV/AIDS and Huntington's) did not access any form of specialised palliative care service. These people were likely to suffer with various intense physical, emotional, social and spiritual problems amenable to palliative care. By comparison 68% of people in the McNamara and Rosenwax study who died from cancer received palliative care services. Lack of access to palliative care services predisposes people to die in hospitals or other institutions.

³⁹ Knauff E et al 2005: 'Barriers and facilitators to end of life communication for patients with COPD' – *Chest* – vol 127 – pp 2188-89

⁴⁰ Tierny W et al 2001: 'The effect of discussions about advance directives on patients' satisfaction with primary care' – *Jrnl General Internal Medicine* – # 16 pp 32-40

⁴¹ McNamara & Rosenwax 2006: 'Who receives specialist palliative care in WA – and who misses out' – *Palliative Medicine* – vol 20 # 4 pp 439-445

⁴² *ibid* Murtagh et al 2004

Appendix B

World Health Organisation Definition of Palliative Care⁴³

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

- 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.

About Palliative Care WA Inc

The aims of the Palliative Care WA Inc are to:

1. be a representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life
2. promote the principles and practices of palliative care with the intention of enhancing the broader community's capacity to provide care and support at the end of life
3. advocate for appropriate services and benefits for Western Australians confronting issues and problems commonly associated with the end of life
4. advocate for appropriate palliative care education and training for all who provide care and support to people at the end of life
5. promote the aims of the Association through cooperation and collaboration with stakeholders in palliative and end of life care
6. act as a coordinating body and information resource for organisations and service agencies which provide care at the end of life and which promote the principles and practices of palliative care
7. establish and maintain committees which are active in areas including, but not limited to, clinical services, standards and quality, education and community capacity building.

Palliative Care WA Inc is a not-for-profit association incorporated under the Western Australian *Associations Incorporation Act 1987*. We support and are subject to the *WA Carers Charter*.

Palliative Care WA Inc is a founding member of Palliative Care Australia and a member of the WA Seniors Alliance.

⁴³ accessed Nov 11 at <http://www.who.int/cancer/palliative/definition/en/>