

# AMARANTH FOUNDATION

## SUBMISSION TO THE SENATE INQUIRY INTO PALLIATIVE CARE

“How People *Live* Matters”

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## **Introduction:**

*“To understand how we die – or better said how we live the last part of our lives – is to understand not only how we have lived but also to understand the social context in which our lives are pursued and the end of our lives occur.*

*Our attitudes towards life (and therefore, our attitude towards death), our hopes and aspirations and expectations are moulded and shaped by the kind of life we lived and continue to live.*

*The end of life is not separate or separable. All our life takes place in and is a response to a particular culture and its social conditions.” (Loewy 2000)*

Palliative care embraces the whole person, in the context of their family, community and culture. The practice of palliative care, then, has to take into account all aspects of that person, their family, their culture, their attitudes, values, preferences, their spirituality and their relationships. It is a complex area of care in that it is not just about the patient and their illness. Because palliative care concerns that part of life when a person living with dying, then all that relates to how they find meaning in the experience, how they conceptualise and understand the multiple losses in their lives, and how they learn to live in a different way with their loved ones impacts on their health care.

*How people live matters and how people die matters.*

*How care is provided before dying impacts the lives of the bereaved after death.*

*This is then a critically important part of health and community care.*

**Amaranth Foundation** has developed a system of care that builds on and enhances previous Commonwealth funded projects into Mental Health and Palliative Care. These grants, Round 2,3,5,and 6, under the Local Palliative Care grants rounds have seen the development of a rigorous and sustainable model of care that can be transferable across the primary health care sector, and we believe that it can also be implemented into acute and rehabilitative care as well as residential and community aged care sectors.

This model of care addressed the under recognition and under diagnosis of psychological and psychosocial issues in people who are living with dying, their families and care givers. This model supports the person where they live, and in the community that supports and cares for them. This model extends the practice of allied health clinicians, especially social workers, so that they are better able to identify, respond to and evaluate the effectiveness of a variety of best practice supportive care and therapeutic interventions for this cohort.

Amaranth Foundation employs accredited Mental Health Social Workers as key clinicians, who are accredited with Medicare and DVA in the provision of a variety of evidence based therapeutic interventions appropriate for people living with advanced chronic and terminal illnesses, their families and care givers. Working under the Commonwealth funded Medicare system, utilising the Chronic Disease and Better Access to Mental Health initiatives, Amaranth Social Workers are able to work collaboratively with the person’s general practitioner, their local multidisciplinary health care team, community care services and a host of other community and

rehabilitative services. We bulk bill for all our services, if a referral has been received from the person's general practitioner or specialist.

Based on the Commonwealth funded Round 6 Local Palliative Care project – Your Mind Does Matter, which looked at the Mental Health and Palliative Care interface, working with this cohort requires specialist and advanced skills across a range of therapeutic interventions that support people with advanced chronic diseases. These interventions include - coping with the effects of living with a terminal illness, adaptation to change, cognitive affects related to the meaning illness and dying has on their lives, family and care givers concerns, issues regarding 'burden of care', and because of the relationship between spirituality and palliative care, issues relating to hope, meaning and existentialism. In the provision of quality palliative care and care at the end of life, the reason for the care has to be central – and that is the facilitation of a respectful and dignified dying, and care for the bereaved. This care has to be person centred, and family focussed.

Evidence has shown repeatedly that a generic response to psychological and psychosocial needs and concerns does not meet the needs of this cohort. Implicit in the needs of people living with dying are the needs of their family and care givers, as a Unit of Care. Understanding this and being able to respond effectively to this Unit of Care is critical to understanding the complexity of working with these people.

Dying is a private and a public affair. It is not just about the person, their symptomology and their illness trajectory, but the impacts of this disease and its trajectory and the multiple losses on the people close to that person, and the person's broader community.

### **Role of Social Work**

In health, social work is concerned with the individual as well as the wider context of illness and care. The following definition is taken from the Australian Association of Social Work (AASW) Practice Standards for Social Work, 2003 and the AASW Education and Accreditation Standards 2010.

*The social work profession is committed to the pursuit of social justice, the enhancement of the quality of life and the development of the full potential of each individual, group and community in society. Social Workers work at the interface between people and their environments, utilising theories of human development and social systems.*

*Social Work practice is informed by professional education based on an analysis and understanding of human behaviour and complex social systems. It accepts a commitment to working within a stated value position and code of ethics*

The practice of social work invites us to work across multiples layers of the community – the micro level ( concerns of the individuals) the mezzo level ( concerns of the local and broader community and groups) and macro level ( socio-political concerns). It is this unique nature of the profession that is its strength. Social Work brings the psychological and the physical into connection. Social Work and Social

Care are the oldest of the caring practices and professions, with traditions dating back centuries. Modern Social Work, with its focus on the person and their 'fit' in their environment, rather than the person and their problem, needs to find its place within the thinking of health and policy planners, as an essential health care professional working collaboratively within and across health care settings, in all domains of care.

### **What we are doing**

The Foundation is involved in developing competency standards for social workers in end of life and palliative care, in conjunction with Charles Sturt University in Wagga Wagga, NSW, the Australian Association of Social Workers (AASW), Palliative Care Australia (PCA), and Oncology Social Work Australia (OSWA) as well as providing input into the primary health responses to a National approach to end of life care.

The Foundation has developed a partnership with the Respecting Patient Choices® program developed by the Austin Hospital in providing resources to patients, their families and care givers in Advanced Care Planning (ACP). As a part of this program all staff, including Social Work students and administrative staff are qualified ACP facilitators. This work compliments the narrative approaches to care and contexts of hope and meaning.

The Foundation Social Workers are working collaboratively with other regional and national organizations providing individualized support for people with a range of other chronic and complex health conditions, such as Motor Neurone Disease, Multiple Sclerosis, end stage organ failure, and Alzheimers disease and other dementias.

We are receiving referrals from individuals, families, GP's, other facility based social workers, community care workers in small rural communities, and we currently provide outreach services across the rural and regional communities of the Riverina, NSW. We are further developing a model that will allow social work practitioners in private practice, and those working with primary health care teams in other regions and states to practice utilising our model of care.

### **Evidence for the Model**

A comprehensive literature review was conducted to provide the evidence base to underpin this new model. Over 6 years this model was trialled in 32 rural communities, reaching over 700 clients ( 350 patients, and over 400 families and care givers) , and provided a range of services such as specialist social work case management; common intake, assessment and consent processes that incorporated the patient, the family and care giver/s as the unit of care, flexible and individualised brokerage of equipment and services, resources to support carers, and the provision of targeted therapeutic interventions for patients, family members and carers. A rigorous evaluation of the trial indicated that the model provided significant benefits

for patients, their family members, care giver/s, service providers and the broader primary and acute health care system.

Essential to this new model is the incorporation of key elements of the Enhanced Primary Health Care initiatives delivered through Medicare into the holistic psychological and psychosocial assessment and support components.

The model broadly uses elements of the following national and international policy and service delivery documents:

- WHO report (2008) Primary Health Care – now more than ever
- Draft of Australia's National Primary Health Care Strategy (2009)
- Case Management Service Model developed by the Case Management Society of Australia (CMSA),
- Case Management and Community Care – a discussion document ( 2006) CMSA
- Social Work Competency Standards for Hospice Palliative Care developed by the Canadian Social Work Association
- the flexible 'packages' approach to community care as practiced in Australian community care packages such as COPs, CAPs and EACH Packages
- Standards for providing quality Palliative Care for all Australians
- Identifying the carer project : Final report and recommendations for the Commonwealth of Aust.
- Clinical Practice Guidelines for the psychosocial care of people with cancer

Key elements of this model of Primary Health End of Life and Palliative Care include:

- Utilisation of the Enhanced Primary Care Medicare initiative, incorporating Chronic Disease Management Plans, Team Care Arrangements and Mental Health Treatment Plans and their review processes.
- Specialist Social Work case management and intervention
- Single point of contact and common intake, assessment and consent processes
- Use of quality evidence based assessment and screening tools, including the PCOC data tools (Kanofsky Scale, Stages of Illness, RUG Score), the Hospital Anxiety and Depression Scale (HADS) and the Distress Thermometer.
- Prognostication based on the 'no surprise question' – (I wouldn't be surprised if this person were to die in the next twelve months).
- Person centred, strengths based approach recognising the patient, the family and care givers as the 'unit of care'.
- Psychosocial assessment, support and counselling for the patient, family and care giver/s, including grief and loss / bereavement counselling

- Flexible brokerage of equipment and services that is timely, affordable, flexible and appropriate to the level of care requirements depending on the individual disease trajectory and prognosis
- Development of partnerships between key service providers and stakeholders in each community
- Multidisciplinary care planning across and within care settings
- Continuity of care and seamless referral processes
- Home Notes and patient centred Home Diary
- Carer support and information - available 24 hours, seven days a week through the Commonwealth Career Respite and CareLink Service
- Access to the P1 Protocol of the NSW Ambulance Service for Palliative patients
- Professional support, education and supervision to Social Workers and other health professions working in and across this field of care.

### **Understanding Mental Illness and End of Life Care**

Whilst mental illness does not threaten life or decrease life expectancy of itself, it can have a severe impact on a person's health and wellbeing<sup>1</sup>. Many people carry mental illness into their final years of life.

Having a terminal illness and a coexisting mental illness is a very complex situation and requires a specialised knowledge and skill base, both in the diagnosis and treatment of mental illness and in end of life and palliative care. Applying a generic mental health response and strategy to this population group will not attend to their over arching and immediate issues relating to their terminal or life threatening illness.

Mental illness in the terminally ill is under diagnosed and undertreated. People generally underreport their distress and there is an expectation by health care professionals and the community at large that dying people will and should experience depression, anxiety and sadness.

Whilst existential and psychological care are considered crucial to the provision of quality end of life care, people continually report that theirs, their families and care givers needs in this domain are not addressed.

There have been many advances in end of life and palliative care, with medical and nursing clinical specialities making great improvements in patient care and symptom management. The training and skill base of mental health clinicians and other allied health professionals have not kept up with this change.

Research has shown that GP's and other medical and nursing clinicians face significant challenges in discussing death with their patients and families, exploring the patients emotional responses to terminal illness and also specific outcomes for

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<sup>1</sup> DoHA (2010) Draft National Palliative Care Strategy : *Supporting Australians to live well at the end of life.*

the patient and family. This has been shown repeatedly in research conducted by the psycho-oncology group and medical practitioners themselves.

Some issues identified from the literature in the treatment of people with a mental illness and who have an advanced progressive disease and are terminally ill:

- The utility of psychotherapy to this population group needs specialised training and may not work quickly enough to be of primary therapeutic value for patients with limited life expectancy<sup>2</sup>
- Clinicians report that they are uncomfortable in probing too deeply into the psychological experiences of their patients<sup>3,4</sup>
- Clinicians score reasonably well in identifying people who do not have depression, but they miss those that are depressed unless they present with particularly obvious signs and symptoms<sup>5</sup>.
- The consequences of failing to treat depression successfully can lead to greater difficulty in managing the patients physical symptoms and helping to resolve social and existential concerns. For many this leads to an earlier admission to an acute or aged care facility<sup>6</sup>.
- Previous research suggests that terminally ill cancer patients who wish to accelerate their death were more likely to report dissatisfaction with emotional support and communication with their health care providers<sup>7</sup>.
- Chochinov et al (2009) stated that many patients have occasional transient periods of distress or demoralisation during their course of their advanced illness. Although they are usually not considered to be experiencing a mental disorder during these periods, some may qualify for a diagnosis of adjustment disorder. Even if not formally diagnosed with a mental illness or disorder, many people with significant distress may value the opportunity to receive supportive care addressing the source of that distress<sup>8</sup>.
- A life threatening illness is clearly a major stressor that may precipitate an episode of depression in individuals who are particularly vulnerable<sup>9</sup>
- The sense that a person is a burden on one's family members is a common experience among the terminally ill and is consistently associated with depression and suicide ideation.
- Screening for depression does not necessarily lead to better outcomes. The issues related to depression and palliative care are complex when patients may not be screened until too late to introduce an optimal intervention<sup>10</sup>.

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<sup>2</sup> Chochinov et al (2009)

<sup>3</sup> Chochinov et al (2009). pp40

<sup>4</sup> Kelly.B et al (2008) *General practitioners' experiences of the psychological aspects in the care of a dying patient*. Palliative and Supportive care. 125-131

<sup>5</sup> Chochinov et al (2009)

<sup>6</sup> Et al

<sup>7</sup> Kelly.B et al (2008) *General practitioners' experiences of the psychological aspects in the care of a dying patient*. Palliative and Supportive care. 125-131

<sup>8</sup> Chochoniv et al (2009) pp 50

<sup>9</sup> Chochinov et al (2009) pp51

- It is important to accurately diagnose anxiety disorders because they have the potential not only to cause extreme distress but also to interfere with appropriate medical management.
- Depressed people were particularly at high risk of suicide ideation and are four times more likely to report a high desire for hastened death than those who were not diagnosed with major depression
- Hopelessness is significantly related to suicide ideation and stronger predictor than severity of depression
- Pre existing psychiatric disturbance increases the risk for the desire for hastened death and suicide ideation.

The data regarding mental illness in Australia is equally relevant to the population living with a life limiting illness as with other members of the community. Having a life limiting illness does not preclude the possibility of also having a pre-existing mental illness or one developing as a result of the psychological impact and trauma of the diagnosis or prognosis. Many people experience symptoms of Post Traumatic Stress Disorder as a result of the diagnosis of serious complex medical condition.

The 2007 National Survey of Mental Health and Wellbeing found that:

- Almost half the total population (45.5%) experience a mental health disorder at some point in the lifetime.
- One if five, or 20% of the Australian population aged 16-85 years, experienced mental disorders in the previous 12 months [of their survey]. This is equivalent to 3.2 million Australians.
- One in 16 (6.2%) had affective (mood) disorders; one in seven (14.4%) had anxiety disorders; and one in 20 (5.1%) had substance use disorders.
- Based on these prevalence rates, it is estimated that nearly 1 million Australians have affective disorders; over 2.3 million had anxiety disorders and over 800,000 had substance use disorders in the previous 12 months.
- The prevalence of mental disorders declines with age: from 1 in 4 young people (16-24) to 1 in 20 (75-85 years)
- Only one third of people (34.9%) with a mental health disorder used health services for their mental health problem – and two thirds of people with a mental health disorder did not report using services for their mental health disorder.

Delivering the right care at the right time and in the right place is a challenge the health system needs to meet. There is an emerging understanding of the need to improve the experiences of people as they approach the end of life<sup>11</sup>. Ensuring appropriate, timely and acceptable care is provided to all Australians at the end of life is not just the responsibility of the palliative care community, but rather everyone's business. `

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<sup>10</sup> Chochinov et al (2009) pp55

<sup>11</sup> PCA (2010). *EOL Towards Quality at End of Life*. Vol 2.No1.



Harvey Chochoniv in his work : “Innovations in End of Life Care”( 2002)<sup>12</sup> stated that there is a need for a broader and more inclusive model of end of life care’. He states that this is a stance which is supported by the observations that symptoms relating to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms amongst those people with life limiting illnesses.

The domains for quality supportive care have been reported as being: overall quality of life, physical well being and functioning, psychosocial well being and functioning, spiritual well being, patient perception of care, family well being and functioning<sup>13</sup>.

Kissane and colleagues<sup>14</sup> describe a new diagnostic entity for inclusion in the palliative and end of life language, of “demoralisation syndrome”. The core features include hopelessness, loss of meaning, and existential distress. They suggest that this syndrome can be differentiated from depression and is associated with chronic medical illness, disability, bodily disfigurement, fear of loss of dignity, social isolation, feelings of dependence, and the perception of being a burden. This syndrome has a propensity, due to the presence of hopelessness, and a sense of impotence, for hastened death or suicide or desire to die statements from patients and family members.

In a recent study on psychological support and interventions following a cancer diagnosis found that all patients diagnosed with cancer had some level of mood alteration, and one in five people had serious symptoms that progressed to a clinical depression<sup>15</sup>

### **The role of Social Work and End of Life Care**

In palliative and end of life care, the unit of care encompasses the patient, the family and care giver. Dying is a very public and community event and has to be understood in the context of the person’s environment. Because of this, the social work profession is ideally placed to provide effective assessment and support for people with terminal illnesses, inclusive of the needs of the person’s family and care givers.

Social work practice occurs at the interface between the individual and the environment. Social work activity begins with the individual and extends to the context of the family, social networks, community and the broader community. ( The micro, macro and mezzo levels of intervention). In the journal “Progress in Palliative Care (2010) the authors state that ‘both palliative care and social work reflect

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<sup>12</sup> Chochoniv HM (2002) *Thinking outside the box: Depression, hope and meaning at the end of life*. Innovations in End of Life care. Vol 4(6) accessed via the web at: <http://www2.edc.org/lastacts/archives/archivesNov02/editorial.asp>

<sup>13</sup> Institute of medicine(1997) *Approaching Death Improving Care at the end of life*. Washington DC

<sup>14</sup> Kissane DW, Clarke. DM, Street.AF,(2001) *Demoralisation Syndrome – a relevant psychiatric diagnosis for palliative care*. Journal of Palliative care 17:12-21

<sup>15</sup> *The Australian* 30/06/10 pg 7 Support: *Depression, cancer's forgotten side effect*

philosophies of caring that consider individuals in the full context of their lives". Social work, according to Powazki et al, sits at the interface of the patient, family system and the wider community or society and is concerned with the wider context of illness and care<sup>16</sup>.

### **Social Work, Psychological Distress and End of Life Care**

Understanding mental illness in palliative care requires an understanding of the person's social environment and the way this background colours and impacts on the person's experiences of the terminal illness and nature of the disease.

A diagnosis of mental illness in the terminally ill cannot be treated separately from the nature and impact of the person's illness and the reactions of the family and care givers to the realisation of impending death and bereavement.

Psychological distress in patients with serious medical illnesses is best understood as existing along a continuum; while many individuals will experience responses, such as fear, sadness and grief at varying times in response to their disease, others may progress to develop more clinically significant conditions<sup>17</sup>. Psychological morbidity, such as depression, anxiety, and adjustment disorders, are common in cancer patients, with between 35 and 50% of patients experiencing these psychological problems<sup>18</sup>.

Within non cancer populations, depression has been identified in 19- 23% of stroke survivors,<sup>9</sup> 50% of those with Parkinson's disease,<sup>10</sup> and 20\_30% amongst those with dementia disorders.

Despite its ubiquitous nature, the literature consistently indicates that psychological distress in palliative patients tends to be under-diagnosed and under-treated. Given its effect on patient well-being, social functioning, perceptions of symptom distress and length of hospital stay, research suggests that the importance of proper recognition and treatment of psychological distress cannot be overstated<sup>19</sup>.

Amaranth Foundation therefore believes that quality end of life and palliative care requires that both at a clinical and service development level that people living with a life limiting or terminal illness, their families and care givers deserve care that places them at the centre of that care, and that care is provided in a manner that responds to their individual and collective needs across the care continuum.

Current literature and quality systems must drive service improvement to ensure that end of life and palliative care upholds the WHO definition of Palliative care, and that the Australian standards for quality palliative care form the bedrock of this care.

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<sup>16</sup> Powazki. R; et al (2010) *The art and science of social work*. Progress in Palliative Care Vol 18. No 4.

<sup>17</sup> Ryan et al ((2005) *How to recognise and manage psychological distress in cancer patients*. Eur J of Cancer Care. 14. 7-15

<sup>18</sup> Wilson.K; Chochinov H. (2000) *Diagnosis and management of depression in palliative care*. Handbook of psychiatry in palliative medicine. Oxford University Press. 25-49

<sup>19</sup> Kelly.B; McClement. S; Chochinov.H.(2006) *Measurement of psychological distress in palliative care*. Palliative Medicine. Vol 20. 779-789

Applying a one size fits all approach to the provision of end of life and palliative care will only further alienate many rural and remote communities and their people. The model that needs to be developed has to be mindful of the larger client capture areas in rural areas, smaller populations, paucity of public transport, geographic isolation and larger distances to access health care services, poorer reported health, lower life expectancy, fewer specialist and primary health care professionals and a very complex community care system. Rural and remote populations have many other factors that influence prosperity and economic stability such as drought, natural disasters, availability of resources and subsequent population migration and population changes. These conditions can affect demand for infrastructure and services and employment, as seen in many mining and irrigation communities<sup>20</sup>.

Ensuring that palliative patients and their families receive holistic care is a fundamental tenet of palliative care. As such, palliative care incorporates a wide range of healthcare providers from varying medical and non-medical disciplines which can make coordination of services difficult. Often there is little communication between various healthcare providers, including the general practitioner<sup>21</sup> resulting in isolated and fragmented care. Communication is particularly important at the primary health care level as currently 90 per cent of care at the last year of life occurs in the home<sup>22</sup>. A recent APHCRI study (2006)<sup>23</sup> on the integration, coordination and multidisciplinary approaches in primary care, examined literature related to primary health care for a variety of health care issues, including end of life, has shown that when caring for a patient with a life-limiting illness, multi-professional teams seem to be able to provide better care than the general practitioner or nurse working alone<sup>24</sup>.

Developing a model of person centeredness within primary health care will at times cause stresses at various points along the health care continuum for service providers, and may cause confusion for some patients and their families as they navigate new health care systems. Finding the right mix of both private and publicly funded services to provide quality end of life and palliative care services to all people in the primary health care interface is going to take some shifting in thinking about the way health care is managed. One of the observations of the APHCRI study was that it appeared that the more disciplines involved the greater the improvement in outcomes for the patient. They suggested that a greater number of disciplines brought different methods of inquiry, expertise and responsibility, identified more potential needs and delivered a more comprehensive response to those needs<sup>25</sup>.

The dilemma for the Australian palliative care sector, is the manner in which the specialist palliative care service provision, which has a predominately clinical focus, will interface effectively with the primary health care sector, both private and public, in order to deliver holistic, seamless and coordinated multidisciplinary care for the patient, their family and care givers. Different professional groups will offer different

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<sup>20</sup> AIHW (2007)<sup>2nd</sup> Ed. Regional, Rural and Remote Health: a study on mortality.

<sup>21</sup> Street A, Blackford J (2001) . Communication issues for the interdisciplinary community palliative care team. J Clin Nurs. Sep;10(5):643-50.

<sup>22</sup> Vic DHS (2005). Promoting partnerships in palliative care services project. Final report. In: Dept. Human Services V, ed.: PPR Consulting Pty. Ltd. p.:110 .

<sup>23</sup> APHCRI (2006) Integration, coordination and multidisciplinary approaches in primary care: a systematic investigation of the literature

<sup>24</sup> Goodwin DM, et al.(2002) An evaluation of systematic reviews of palliative care services. Journal of Palliative Care.18(2):77-83.

<sup>25</sup> APHCRI (2006) Integration, coordination and multidisciplinary approaches in primary care: a systematic investigation of the literature

perspectives on aspects of the identification, assessment and delivery of timely, effective and individualised interventions for the patient, their family and their care givers. Professional boundaries may in many instances be blurred depending on the individual need, and a spirit of team work and professional respect developed across different teams and communities is required so that quality care can be delivered in a truly multidisciplinary manner.

Patient centeredness in palliative and end of life care reminds us that care is delivered around the patient and their individual need, and that of the family and care givers. Ensuring that systems, management structures, funding sources, and the right mix of both publicly and privately provided specialist and primary health care services are delivered to meet that individual need, is going to be the challenge for communities and health care providers into the future.