



## **Cancer Council NSW and LifeCircle**

### **Response to Senate Inquiry into Palliative Care**

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**20 March 2012**

This response from Cancer Council NSW and LifeCircle has been developed from input from relevant staff from the two organisations, as well as consultations with organisations and individuals with expertise in palliative care. In our response, we have commented on the sections of the terms of reference that most relate to the knowledge and experience of the two organisations.

#### **Background of Cancer Council NSW and LifeCircle**

Both LifeCircle and Cancer Council NSW provide services for people with a terminal illness and their carers. While LifeCircle specifically focuses on end of life issues, the Cancer Council's mission is to defeat cancer, and therefore focuses more broadly on prevention, research, patient support and advocacy for the cancer cause. One of the strategic priorities of Cancer Council NSW is to ensure that no one faces a cancer diagnosis alone, including people with cancer who are terminally ill.

##### *LifeCircle*

LifeCircle's primary role is to support carers of people who are terminally ill and to more broadly support the family and community of people with terminal illness. Specific services include a mentoring program, telephone counselling, information events and an annual conference.

LifeCircle conducts a mentoring program, in which trained volunteer mentors who have been family carers themselves provide support exclusively to primary carers. LifeCircle has a dedicated staff of nine based in Melbourne, Sydney and Canberra, who work with over 100 volunteers supporting families caring for a loved one who chooses, in the majority of cases, to die at home. In NSW, for example, two part-time co-ordinators recruit, train and currently support about 32 mentors. Each mentor provides support to two to three carers at any one time, through the course of the terminal illness and one year of bereavement.

LifeCircle mentors are usually locally based and offer an enhancement to services provided by palliative care staff. LifeCircle relies on organisational and private donations/funding to conduct its programs and services, including its mentoring program. LifeCircle's ability to

expand this program is limited by the availability of funding for co-ordinators and for mentor training and support.

LifeCircle provides a nation-wide telephone counselling service from 9am-9pm for people affected by a serious or potentially terminal illness. It is staffed by trained volunteers, who have either been carers for someone with a terminal illness or who have been through a life-threatening illness themselves.

In addition, LifeCircle conducts “Life Matters” information sessions and expos that provide information about preparing for the future. The “Life Matters” program is directed to seniors living at home or in residential communities and their families. LifeCircle’s annual conference, “Live, Talk, Die” aims to promote conversations in the wider community about dying and death. LifeCircle has also developed “Help Sheets” which it distributes at its “Life Matters” events and through its website. These provide information about what to expect at end of life and how to address end of life issues.

#### *Cancer Council NSW*

Cancer Council NSW provides a wide range of services for people with cancer and their carers, including information, practical, financial, legal and emotional support. Support is provided via different mechanisms including: online and telephone; through support groups (online, telephone and face-to-face); and peer support.

In 2010-11, 8092 patients and carers accessed the Cancer Council NSW Helpline, and 223 telephone support group sessions were held. Through the Financial Assistance Scheme, Cancer Council NSW assisted 1573 cancer patients and carers with emergency financial support. Over 1000 cancer patients and carers were provided with pro bono legal or financial advice through the Legal Referral Service and the Financial Planning Referral Service.<sup>1</sup>

In some geographic locations in NSW, Cancer Council NSW is involved in fostering regional networks around palliative care, as well as joint practical support projects. Cancer Council NSW also undertakes advocacy around palliative care.

Other services specifically provided by Cancer Council NSW for people with more advanced cancers include telephone support groups. Publications and multi-media resources have been developed about cancers with high mortality rates.

## **Responses to Terms of Reference**

### **(a) The provision of palliative care in Australia, including the factors influencing access to and choice of appropriate palliative care that meets the needs of the population**

Access to palliative care is affected by the availability of specialist palliative care services, as well as referral to palliative care. The availability of services provided by general practitioners, community palliative care and Home and Community Care (HACC), as well as support for carers, impacts on the ability of people with a life-threatening or terminal illness to die at home and the ability of carers to care for them at home. Access to palliative care is affected by low levels of knowledge in the community about palliative care, as well as limited forums for discussion about death and dying.

#### *Late referral*

Early referral to palliative care has been demonstrated to significantly improve clients’ quality of life and mood and to improve their survival time.<sup>2</sup> A barrier to timely access to palliative

care services is late referral by general practitioners or specialists to these services. A number of factors may contribute to late referral including community members, specialists and general practitioners being unaware of the role of palliative care services in enhancing quality of life prior to the final stages of a terminal illness.<sup>3</sup> In some cases, people with a terminal illness and/or their health practitioners may experience denial about the severity of the illness and the need for specialised care.

Mechanisms to promote appropriate and timely referral to palliative care services are required. Palliative Care Australia has highlighted the need for establishing nationally agreed referral and discharge criteria to ensure responsive, evidence-based care that meets patients' needs. Further education of general practitioners and specialists about palliative care is also required. Cancer Council NSW and LifeCircle encourage the Australian Government to implement mechanisms which will promote appropriate and timely referral to palliative care services by specialists and general practitioners.

**Recommendation:**

1. That the Australian Government explores and implements mechanisms to promote appropriate and timely referral to palliative care services by specialists and general practitioners.

*Access to services to support people dying at home and in residential aged care facilities*

Appropriate services are required to support those who wish to die at home, regardless of their geographic location. This includes access to community palliative care services, general practitioners and support for carers.

Several studies have found that most Australians, when asked where they would prefer to die, nominated their home as their preference.<sup>4</sup> While many people express a preference for dying at home, only 16% die at home, with 20% dying in hospices, 10% in nursing homes and the remainder in hospitals.<sup>5</sup>

The demand for palliative care services within the home has increased due to reduced availability of hospital beds, a desire for less institutionalised care and an ageing population, where the morbidity and mortality associated with illnesses such as cardiovascular disease, cancer and respiratory disease increase with age.<sup>6</sup>

Services provided by general practitioners and community palliative care services are essential in supporting people dying at home and in residential aged care facilities. Community palliative care services in rural areas are particularly under-resourced. This is discussed further in section (a) (i) of this submission.

*General practitioners*

When diagnosed with a life-limiting illness most, but not all, patients will have an existing relationship with a general practitioner and a medical specialist. These health care services and professionals are considered 'primary' or 'first contact' services.

For most patients, their carers and families, the relationship with a general practitioner will continue until the death of the patient and beyond. The role of the primary care service, whether a general practitioner or another medical specialty, is fundamental to the provision of high quality care for people with life-limiting illness.<sup>7</sup>

However, general practitioner visits to residential care facilities and home visits are declining because they are time consuming, are relatively poorly remunerated and there are concerns

about personal safety.<sup>8</sup> The Australian Medical Association has also identified a range of other barriers to providing services in residential settings.<sup>8</sup> These include:

- a lack of access to registered nurses with whom to coordinate care
- an increasing use by residential aged care facilities of agency staff who are not familiar with residents, which compromises continuity of care
- poor access to properly equipped clinical treatment rooms, which limits the medical treatment that can be provided in that setting
- an absence of information technology infrastructure to facilitate access to electronic patient records and medication management, including software appropriate to the needs of GPs
- a growing tendency to build residential aged care facilities in the outer growth corridors or ‘urban fringe’ of metropolitan areas, which further adds to the time spent by doctors away from their surgeries.

The Productivity Commission report “Caring for Older Australians” has recently recommended 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.<sup>8</sup>

Cancer Council NSW and LifeCircle agree with this recommendation and encourage the Australian Government to identify and address other barriers to general practitioners visiting residential aged care facilities and people with a terminal illness in their homes.

#### Recommendations:

2. That the Australian Government identifies and addresses the range of barriers to general practitioners visiting residential aged care facilities and people in their homes, in order to provide increased access to palliative care services.
3. That the Australian Government commissions an independent review of the Medicare rebate for medical services provided by general practitioners visiting residential aged care facilities and people in their homes to ensure that it covers the cost of providing the service, in order to provide increased access to palliative care services.

#### *Access of carers to services*

Access to a range of services is required for carers, who have a critical role in enabling people with a terminal illness to die at home. Access to 24-hour support, HACC services, respite services and bereavement services should be improved.

Although only about one-third of all patients receiving palliative care services die at home, up to 90% of terminally ill patients spend the majority of their last year of life at home. Thus, home palliative care would be impossible for many people without the support of carers.<sup>6</sup> Having a live-in carer significantly improves the chances of a person with a life-threatening illness being able to die at home.<sup>2</sup>

Being the family carer to a patient nearing the end of their life can be a challenging, confronting and emotionally draining experience. The responsibilities of care may include complex physical and medical tasks, financial administration, patient advocacy, decision making, emotional support and coordination of care.<sup>9</sup>

Furthermore, studies show that caregiving can have negative consequences on the health of family carers including fatigue, sleep problems, depression, anxiety, burnout and an

increased risk of mortality. Family carers of palliative care patients not only face the demands associated with caregiving, but also the grief and loss associated with their relative's impending death.<sup>9</sup>

Caregiving is often associated with a negative impact on financial security and wellbeing. The primary caring role reduces a person's chances of being employed as caring commitments mean that some carers are unable to work, have to work fewer hours, or are employed in a lower-paid job. Limited employment opportunities for primary carers are reflected in their incomes, with over half reporting a government pension or allowance as their principal source of income.<sup>10</sup>

Studies have shown that carers of people with a terminal illness need: psychological support (emotional, social, bereavement and spiritual); information; help with personal, nursing and medical care for the patient; out-of-hours and night support; respite care; and financial support.<sup>11</sup>

A range of different service models have been developed which can assist carers of people with a terminal or life-threatening illness. These include: access to respite care; access to 24-hour palliative care telephone support (that includes medical advice); group and individual support (such as online or telephone support); peer support; and bereavement support. However the provision of support to carers, particularly those of people with life-limiting diseases, is patchy. Mapping service availability would assist in ensuring appropriate referrals and service planning.

Access to 24-hour support (including medical advice) is vital for carers.<sup>11</sup> Carers of patients with end stage disease are particularly vulnerable at night and at any time that normal healthcare services are not available. Strategies to deal with queries and forward planning may help to avoid crisis situations and unnecessary transfers to hospital emergency departments. This means that services should design mechanisms to provide support day and night, for example dedicated telephone helplines.<sup>12</sup> Some jurisdictions, such as Victoria, have plans to implement 24-hour support more widely within their jurisdiction.<sup>2</sup>

Access to residential and flexible at-home respite arrangements is also required to assist carers to sustain their role in caring for someone approaching the end of life.<sup>13</sup> Providing respite enables carers to have a break, and has been demonstrated to help carers undertake their role for longer periods.<sup>2</sup> Research undertaken by Palliative Care Australia suggests that many high intensity carers see respite care as the most important support service to promoting their health and wellbeing.<sup>10</sup>

Access to respite care varies across the nation.<sup>10</sup> Being able to gain access to in-patient respite care for palliative care patients in rural NSW is extremely difficult because of limited availability. There are no designated palliative care respite beds in most rural areas of NSW, so carers rely on patients being able to access generalist beds. In some regions of rural NSW, access to home-based respite care is also problematic.<sup>14</sup>

Carers may also experience difficulties in accessing other types of in-home support. It can be very difficult to access in-home support to assist the patient to stay at home, particularly in rural areas. In 2009, NSW Health's Statewide Centre for Improvement of Palliative Care undertook a survey to assess issues of timely access, eligibility and coordination in relation to HACC services for palliative care patients. The survey was distributed through members of the NSW Palliative Care Service Development Officer network in each Area Health Service between April and July 2009, with 37 respondents. The research found that:

- 70% of network members currently experienced problems with accessing HACC services. The top three problems experienced related to: domestic assistance (96%), personal care (92%) and respite care (65%) (*multiple responses were permitted*).
- Following publication of an article in the Department of Ageing, Disability and Home Care Newsletter outlining palliative care eligibility for HACC services (a key strategy to improve awareness of palliative patients' eligibility), 73% of respondents noticed no improvement in accessing HACC services.
- 90% of respondents experienced difficulties accessing HACC services due to full capacity.
- 65% of respondents indicated that 1-5 clients per month experienced problems accessing HACC services.
- On average, 27% of palliative care clients waited 2 weeks for HACC services assessment, and 22% waited 1-6 days. Once an assessment was completed, 24% waited 2 weeks and 24.3% waited 1-6 days.
- 70% of respondents indicated that accessed HACC services were 'good,' 24% rated them 'excellent' and 5% rated them 'poor.'<sup>15</sup>

Qualitative information from the survey revealed that: confusion exists about whether palliative care patients are eligible for HACC services; procedures to access the services can be complex; and there is a substantial shortage of services. Comments from several respondents are included below:

*There is a great complexity in the means by which services can be accessed (we actually have to attend a community information session in the hope of clarifying some of this). Also, there are simply not enough available services to meet the needs of an aging community with limited alternative options. We have a significant number of patients who are unable to die at home in accordance with their wishes due largely to this major gap in services.*

*Many patients apply for HACC services only to get a letter several weeks later saying that HACC cannot provide service, this is usually for home care...*

*It's a shame that palliative care clients are made to wait for access to services... some have actually died prior to HACC assessment has been completed.*

Cancer Council NSW and LifeCircle consider that people with a terminal illness should be able to access quickly and easily, services such as domestic assistance, personal hygiene, laundry, transport, shopping, respite care. The Australian Government is encouraged to enhance in-home service provision for people with a terminal illness.

#### Recommendations:

4. That the Australian Government reviews the provision of in-home support and respite care for people with a terminal illness and ensures it is provided in a timely manner.
5. That the Australian Government ensures there are clear, consistent and well-publicised guidelines for access to in-home support and respite care for people with a terminal illness.

Bereavement support for carers and families is a key component of providing best-practice

palliative care.<sup>2</sup> Although it is recommended that bereavement care is available to all individuals, the literature strongly supports offering more intensive support to those considered at risk of complicated bereavement reactions.<sup>16</sup>

An Australian survey of palliative care bereavement services, conducted in 2007, found that the most common obstacles to bereavement service delivery were lack of sufficient staff time (73%), funding pressures (44%), lack of personnel (35%), lack of organisational support of bereavement services (29%). The work of bereavement care was commonly co-ordinated by a nurse, often on top of his/her other duties and in some cases it was co-ordinated by a social worker. Most organisations surveyed reported that less than 5% of the palliative care budget was allocated to bereavement services.<sup>16</sup>

Bereavement services provided by rural palliative care services, if any, are not formalised services of adequate size to be able to provide a service to families. Generalist services, if any, often do not have the capacity to support these families.<sup>14</sup>

The National Palliative Care Strategy 2010 includes an action area relating to bereavement, which is to “Provide mechanisms to ensure palliative care providers across the continuum are aware of, and provide, culturally appropriate palliative care and end of life support including care preferences, spiritual requirements and bereavement expression.”<sup>17</sup> Cancer Council NSW and LifeCircle support this action and encourage the Australian Government to establish and fund appropriate levels of bereavement service provision to families and carers of people with a terminal illness.

Recommendation:

6. That the Australian Government works with states and territories and other key stakeholders to establish and fund minimum levels of bereavement service provision to families and carers of people with a terminal illness.

*Lack of knowledge about palliative care services*

Australians have limited knowledge of palliative care. A 2006 survey found that over eight in 10 Australians were aware of palliative care. However, of those aware, most have only limited knowledge, with only four in 10 reporting sufficient knowledge to be able to explain palliative care to someone else.<sup>18</sup>

A common myth is the belief that palliative care is only for people with a few months left to live. This affects the willingness of people to access services early for pain management and enhanced quality of life. Strategies to increase community understanding of palliative care are required.

There is also a substantial need for increased community education and forums for discussion about death and dying. Many people find it difficult to talk about dying and are reluctant to have these discussions.<sup>4</sup> Different cultural perspectives influence how death and dying are discussed.

A range of individual, communal and societal benefits can result from strengthening the community’s awareness and understanding of death, dying, loss and palliative care. Benefits include an increased capacity in the community to initiate or take part in conversations that relate to death and dying. This in turn raises the possibility of people in the community being able to support each other in a variety of ways and to consider timely access to palliative care services.<sup>2</sup>

In order for communities to better support people with a life-threatening illness, specific strategies to build the capacity of the community need to be implemented. Community capacity-building strategies have been demonstrated to lead to positive outcomes.<sup>2</sup> For example, Australian and international research has demonstrated that involving communities in the planning and provision of services improves clinical palliative care. In addition, a stronger understanding of what palliative care is, improves the timeliness of referrals to palliative care.<sup>2</sup>

Expanding programs conducted by organisations such as LifeCircle will assist in building the capacity of the community to deal with death and dying. LifeCircle actively promotes community discussion of death and dying. Its “Life Matters” information sessions provide information about preparing for the future to seniors living at home, in residential communities and with their families. These sessions frequently attract audiences of 50-125 people and provide information about a range of matters including advance care planning, guardianship, tissue and organ donation, palliative care, as well as lighter topics such as laughter therapy.

Specialist palliative care services have an important role in supporting discussions in the community about death and dying, to help create a culture that is more accepting of the need for palliative care services and more able to support people with a life-threatening illness and their families and carers.<sup>2</sup>

At a local level, palliative care services, especially in rural areas, currently have little capacity to undertake community education about palliative care services and death and dying. There is a need to enhance the capacity of palliative care services to undertake this role, possibly through the resourcing of community development/health promotion positions within local health district palliative care services. These positions could have a role in promoting communication between services, community and service provider education, volunteer support, as well as assisting in the adoption of a health promoting approach to palliative care.

One of the action areas of the National Palliative Care Strategy 2010 is to “Develop a comprehensive, evidence-based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote the services and options available for people nearing the end of life.”<sup>17</sup> Both local and broad-based strategies are required to inform and empower communities to deal with end of life matters.

Cancer Council NSW and LifeCircle consider that it is vital to bring about national public awareness of palliative care services and to promote dying as a normal part of living and encourage the Australian Government to provide funding for community events which include a focus on advance care planning, palliative care and death and dying as a normal part of life.

#### Recommendations:

7. That the Australian Government funds a comprehensive national public awareness strategy, with the input of key stakeholders, to promote death and dying as a normal part of living and to promote the services and options available for people nearing the end of life.
8. That the Australian Government funds relevant and appropriate bodies to conduct community events about death and dying that include a focus on advance care planning, as a part of a national public awareness strategy.
9. That the Australian Government provides funding to allow specialised palliative care services to undertake community education about palliative care and death and dying.



**(a)(i) The provision of palliative care in Australia, including the factors influencing access to and choice of appropriate palliative care that meets the needs of the people living in rural and regional areas**

*Specialist palliative care services*

Specialist rural palliative care services in NSW are under-staffed and there are very few palliative care specialists located in rural NSW. In addition, few regional centres are currently serviced by fly-in/fly-out medical specialists. This has an impact on the level of service provided to patients and their carers.

There is evidence to suggest that people who live in remote or rural areas have unmet palliative care needs.<sup>2</sup> However, most rural palliative care services have extremely limited staffing. People in some parts of NSW do not have any access to specialised palliative care services<sup>19</sup> – for example in the Riverina area of NSW, there are 87,000 people without any access to palliative care.<sup>20</sup>

Services closer to the Sydney metropolitan area are also under-resourced. For example, in the Central Coast area there are no specialised hospital palliative care beds. Cancer Council NSW staff on the Central Coast report that the shortage of resources for palliative care has resulted in people being referred to palliative care services at a later stage of their illness. While there are now 5-6 specialised palliative care nurses for the Central Coast, some of these positions have only recently been established and there is still insufficient capacity.

Palliative care nurses working in rural areas in NSW are over-extended. For example, palliative care nurses are seldom relieved when taking leave. During this time palliative care nurses from neighbouring services may provide services across two geographic areas, however they are only able to provide limited coverage by telephone.<sup>21</sup> Many palliative care nurses are operating at advanced practice level<sup>22</sup> because of the lack of availability of medical specialists.

The limited availability of specialist palliative care services and primary health care has resulted in palliative care staff in some regions no longer being able to promote early referral to palliative care. In some cases patients with non-complex needs being looked after by primary health care providers are developing complications that could have been avoided with specialised input earlier on.<sup>14</sup>

There are major shortages of palliative care specialists. Australia has about half the palliative care specialists it needs under current referral patterns, with unmet need being by far the greatest outside of metropolitan areas.<sup>23</sup> As at June 2011, outside of the Sydney, Newcastle and Wollongong regions of NSW there was only one palliative care specialist.<sup>19</sup> The lack of availability of specialists has significant implications in relation to the ability to develop flexible models such as shared care or hub and spoke models in non metropolitan areas, as they rely on specialist medical care to be proximate within a geographical service region.<sup>23</sup>

A range of initiatives could be undertaken to improve access to specialist palliative care services. This includes access to 24 hour support, enhanced funding to develop regional palliative care services to agreed minimum standards and enhanced provision of palliative care specialists to rural areas through the Medical Specialist Outreach Assistance Program (MSOAP).

Access to 24-hour support and medical advice (for example through telephone support) for people with a terminal illness and their carers can assist in allaying fears and concerns of people dying at home and their carers, and can help to reduce unnecessary admissions to emergency departments and intensive care units.<sup>24;25</sup> Most rural services are only funded to

provide a service during business hours, with very limited or no access to specialist palliative care nursing support after 5 pm, over the weekend and during the Christmas/New Year period.<sup>21</sup> It is essential that 24-hour advice/support is available in all rural areas, as well as in urban areas.

There is a need to enhance access to specialists in rural areas. Currently specialist support is provided to some rural centres on a fly-in/fly-out basis. Information from NSW Health, a NSW fund-holder for MSOAP, indicates that through this program palliative care specialists are visiting Wagga Wagga on a fly-in/fly-out basis (12 times per annum), Port Macquarie (12 times per annum) and Dubbo (11 times per annum).<sup>26</sup> The NSW Rural Doctors Network, the other NSW fund-holder for MSOAP, advises that MSOAP service agreements have been made to provide services to Moruya and Broken Hill.<sup>27</sup>

The benefits of a fly-in/fly-out service have been described in an evaluation of the Wagga Wagga service. However, this evaluation pointed to the need for a greater level of service provision, to meet expected demand as the service becomes more widely known and to meet recommended levels of specialist palliative care service provision per head of population.<sup>28</sup> The ratio of 1.0 FTE palliative medicine specialists per 100,000 population represents the minimum number of specialists for a reasonable provision of service.<sup>29</sup> As at June 2006, the population of Wagga Wagga was estimated to be 56,100 and the population of the Murrumbidgee statistical sub-division was estimated to be 149,200,<sup>30</sup> pointing to the need for a palliative care specialist to be located at Wagga Wagga.

While access to palliative medicine specialists through MSOAP is a good interim measure, there is a need to develop and fully fund palliative care centres in major regional centres to provide services to an agreed level for their regions. Appropriate service models should be implemented. Currently, a typical rural palliative care service in NSW only consists of a team of nurses covering vast distances, fly-in/fly-out doctors funded under MSOAP and no in-patient palliative care facilities.<sup>31</sup>

In rural centres, a “hub and spoke” approach could be utilised, where specialist teams provide support to generalist teams in the community. The NSW Health Subacute Care Reform Implementation Plan includes a funded strategy to provide palliative care services via specialist hubs to generalist spokes, in the Greater Southern Area Health Service and the Hunter New England Area Health Service of NSW.<sup>32</sup> The Plan also indicates that “Establishing networked Cancer Care and Palliative Care Clinical Services using a hub and spoke service model is also proposed in rural NSW.”

Agreed minimum standards of specialist palliative care service provision should be developed, taking into account factors such as population, remote/rural/urban location, Aboriginal population, and availability of other relevant services (e.g. general practitioners, community nurses, HACC services).

Palliative Care Australia has developed a consensus statement describing the minimum professional staffing needs required to ensure that palliative care is provided to those people with life-limiting illnesses who need it.<sup>33</sup> The consensus statement could help inform the development of agreed minimum standards for service provision across Australia involving the Australian Government, states and territories and key stakeholders.

It is critical that specialist palliative care services are adequately resourced given the shortage of allied health staff, community health staff and general practitioners in many rural areas. In many rural regions there are insufficient numbers of community nurses to provide adequate palliative care for even non-complex patients.<sup>21</sup> It should be noted that in developing the “hub and spoke” approach, sufficient primary health care service provision for the “spokes” is required.<sup>34</sup>

People living in outer regional centres have access to about a half as many allied health professionals as people in metropolitan centres.<sup>35</sup> This has an impact on palliative care service provision. For example, the lack of availability of social workers to provide services to palliative care patients has resulted in clinical nurse consultants in some areas undertaking social worker roles such as organising referral to services.<sup>36</sup>

The availability of general practitioners is also a generic problem with about half the number being available to regional, rural and remote areas compared to metropolitan areas.<sup>23</sup> These shortages are further exacerbated by logistical challenges of servicing highly dispersed populations.<sup>35</sup> This has an impact on service provision. For example, in some areas general practitioners have closed their books and are not accepting new patients.<sup>37</sup>

LifeCircle and Cancer Council NSW consider that regional, rural and remote areas should have far greater access to palliative care services and encourage the Australian Government to provide funding to rectify the disparity between metropolitan and rural/regional service provision.

Recommendations:

10. That the Australian Government should fund and enter into agreements with state and territory governments to ensure that the size and composition of specialist palliative services meets agreed minimum standards that account for factors such as population, remote/rural/urban location, Aboriginal population, availability of relevant services. The minimum standards should be developed in consultation with key stakeholders.
11. That the Australian Government should identify regional centres across Australia that currently do not have access to a palliative care specialist and increase funding to MSOAP to provide fly-in/fly-out palliative care medical specialist services to these regional centres.

**(a) (ii) The provision of palliative care in Australia, including the factors influencing access to and choice of appropriate palliative care that meets the needs of Indigenous people.**

A number of factors influence access of Aboriginal and Torres Strait Islander people to palliative care. Aboriginal and Torres Strait Islander people present late to health care facilities in general and few are being referred to palliative care services.

*Delayed access to medical services in general*

Aboriginal and Torres Strait Islander people use health care services reluctantly, and palliative and end-of-life care services rarely, due to a range of factors.<sup>38</sup> A major factor contributing to this reluctance is historical and contemporary experiences of institutionalised racism. This includes distrust stemming from fairly recent experiences of segregation in hospitals.

Within the hospital system Aboriginal people have experienced negative stereotyping by staff, racism from patients, as well as failure on the part of health care providers to assess and accurately diagnose symptoms in a timely and systematic manner.

Recent research findings suggest that Aboriginal Australians with cancer have multiple reasons for their reluctance to attend cancer services.<sup>39</sup> Some of these reasons include discrimination and lack of respect and understanding of Aboriginal culture shown by health

care providers. Many Aboriginal patients find hospitals alienating and frightening with inflexible and discriminatory methods of care.<sup>39</sup>

Because of past and present experiences of institutionalised racism, many Aboriginal people do not seek help until it is really necessary – when they are desperate, they will seek assistance from a local general practitioner.<sup>38</sup>

It is imperative that non-Indigenous health professionals develop culturally safe practice through education or training and appropriate engagement with local Indigenous communities.<sup>38</sup>

*Delayed access to palliative care services*

Another major issue affecting the access of Aboriginal and Torres Strait Islander people to palliative care services is the failure of medical practitioners, both in the mainstream and Aboriginal health care systems, to refer Indigenous clients to palliative care. It appears that many Aboriginal and Torres Strait Islander people are not being referred to palliative care services or, if referrals occur, they occur very late.<sup>38</sup>

Given the burden of illness and high mortality rate in Aboriginal and Torres Strait Islander communities, an over-representation of Aboriginal and Torres Strait Islander people accessing palliative care would be expected. Statistics from palliative care services and research within Aboriginal and Torres Strait Islander communities indicate that very few Aboriginal and Torres Strait Islander people are accessing palliative care support.<sup>40</sup> More recent data collected from organisations participating in the Palliative Care Outcomes Collaboration (PCOC) in 2010 suggests that only small numbers of Aboriginal and Torres Strait Islanders are accessing palliative care support in Australia (see Table 1).<sup>41</sup>

**Table 1: Palliative Care Outcomes Collaboration 2010 - Indigenous Status - all patients**

Indigenous Status	Numbers accessing palliative care support
Aboriginal but not Torres Strait Islander origin	141
Torres Strait Islander but not Aboriginal origin	25
Both Aboriginal and Torres Strait Islander origin	17
Neither Aboriginal nor Torres Strait Islander origin	12,982
Not stated/inadequately described	720
Total	13,885

A number of structural and cultural barriers prevent Aboriginal and Torres Strait Islander people from using palliative care services,<sup>38</sup> including factors relating to limited services in rural and remote areas, which are discussed in section (a)(i) of this submission. These include limited access to allied health services, insufficient funding for community awareness (including Aboriginal and Torres Strait Islander community awareness), shortage of community nurses to undertake home visits, and a shortage of respite services.<sup>38</sup>

In addition, a lack of Aboriginal and Torres Strait Islander “faces” in health services is problematic. There is a need for mainstream palliative care services to employ Aboriginal and Torres Strait Islander health workers who have received training in palliative care or to be able to contract in services from Indigenous health services.<sup>38</sup>

Aboriginal and Torres Strait Islander Home and Community Care (HACC) Workers and Aboriginal Health Workers play a key role in providing appropriate community based care and in liaising with other health care professionals involved in planning and delivering end-of-life services. There is a great need for more Aboriginal and Torres Strait Islander people to be employed in these settings.<sup>42</sup>

The profile and skills of Aboriginal and Torres Strait Islander Health Workers in supporting palliative care as part of community controlled or mainstream health care services should be raised.<sup>23</sup> The Program of Experience in the Palliative Approach (PEPA) provides a tailored program for Aboriginal and Torres Strait Islander Health Workers, however there is a need for further Aboriginal and Torres Strait Islander health workers in NSW to receive training.

Many Aboriginal people express a preference for dying at home rather than within institutions. Well-resourced and culturally appropriate community palliative care services are an important mechanism to support this desire, as well as the provision of services through organisations such as LifeCircle. The National Indigenous Palliative Care Needs Study found that for home based care, the model that best accorded with Indigenous informants was to act as a coach and a mentor to support and train the family so they can undertake home based care.<sup>38</sup>

Innovative programs have been developed to increase access of Indigenous people to palliative care services. For example, the positively evaluated Victorian Aboriginal Palliative Care Project 2007–2010 developed resources, networks and strengthened awareness of Aboriginal palliative care needs.<sup>43</sup> The project worked closely with PEPA. During the life of the project the number of Aboriginal people who accessed palliative care increased significantly from 33 in 2006/7 to 165 in 2008-09.<sup>43</sup>

Indigenous Australians also generally have poorer access to services including medical care, domiciliary nursing care, allied health care, bereavement support and home care support, than do non-Indigenous Australians. This is a particular issue for people living in remote areas.<sup>6</sup>

The Australian Government funded MSOAP Indigenous Chronic Disease program focuses on service delivery to Indigenous residents in rural and remote outreach locations. The program enables multidisciplinary teams, comprising specialists, general practitioners and allied health professionals to better manage complex and chronic conditions in rural and remote Indigenous communities. There is potential for further expansion of this program in NSW.

LifeCircle and Cancer Council NSW consider Aboriginal and Torres Strait Islander access to palliative care to be a high priority and encourage the Australian Government to prioritise initiatives to increase access of Aboriginal and Torres Strait Islanders to culturally appropriate palliative care services.

#### Recommendations:

12. That the Australian Government's Program of Experience in a Palliative Approach (PEPA) continues to enhance its focus on Aboriginal and Torres Strait Islander palliative care, incorporating Aboriginal and Torres Strait Islander cultural awareness for specialist palliative care providers and generalist health workers involved in palliative care.
13. That the Australian Government funds and evaluates innovative Indigenous palliative care projects aiming to increase the number of Aboriginal and Torres Strait Islander people accessing palliative care.

14. That the Australian government provides funding for additional Aboriginal and Torres Strait Islander Health Workers and liaison officers who can connect health professionals and services with the necessary skills, experience and knowledge in the local community. This includes employing Aboriginal and Torres Strait Islander staff in palliative care services.
15. That the Australian government provides funding for additional Aboriginal and Torres Strait Islander HACC workers.
16. That Australian and State governments commit to education and training that builds the cultural competence and cultural awareness of Australia's health care workforce through undergraduate, postgraduate, vocational and continuing professional education, including:
  - i. appropriate training and education about cultural perspectives relating to palliative and end-of-life care issues, in core curricula for all health workers and health professionals providing services to Aboriginal and Torres Strait Islander people
  - ii. inclusion of palliative and end-of-life related topics in the core curricula for Aboriginal health worker Certificate III and IV.
17. That Aboriginal cross-cultural awareness is included as part of continuing professional education for hospital, primary and community health staff.
18. That the Australian Government funds positions within relevant and appropriate bodies to develop programs to provide emotional support to carers of Aboriginal and Torres Strait Islanders with a terminal or life threatening illness.
19. That state and territory governments collect and make publicly available system-wide data on Indigenous use of palliative care services.

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

Through a COAG agreement as part of National Health Reform, NSW has received \$165 million in funding for subacute care.<sup>32</sup> \$33 million has been allocated to palliative care within NSW.<sup>32</sup> Funding was provided in 2008-09 for the state and territories to expand service provision levels by 5% annually over the period 2009-10 to 2012-13 in each state or territory, and better address regional availability.<sup>44</sup>

Part of the COAG agreement with the states and territories included the collection and public reporting of service levels and outcomes in the subacute care.<sup>44</sup> States and territories have made available their subacute care reform implementation plans which include varying levels of detail.<sup>45</sup> The NSW Ministry of Health has published reports on progress in implementing its agreement about subacute care.<sup>46</sup> There is a need to make stakeholders more aware of this progress.

It is concerning that there are a range of issues in relation to the provision of palliative care services, particularly in rural NSW, with only 12 months remaining of the funding period for the National Health Reform program.

Anecdotal reports have suggested that there has been little real additional money evident “on the ground” for palliative care services in NSW over many years and there are concerns that funding has been used elsewhere in the NSW health system, rather than for palliative care. According to the NSW Ministry of Health, there is no reliable information on NSW palliative care expenditure or service utilisation data.<sup>47</sup>

Recommendations:

20. That in 2012, state and territory governments publicly report on the roll-out of the subacute care reform implementation plans, comparing achievements against actions, as well as growth in service provision compared to the reform targets. Data should be provided for each type of sub-acute care.
21. That the Australian Government quarantines any additional funding made to the states for the provision of specialist palliative care services.
22. That the Australian government puts in place mechanisms to ensure state and territory expenditure on palliative care services is transparent and information about current and planned expenditure is publicly available.
23. That the Australian government puts in place mechanisms to ensure state and territory data on palliative care service utilisation is collected and made publicly available, including data about Indigenous service use.

*National Palliative Care Strategy*

The National Palliative Care Strategy 2010 contains action areas which relate to the issues and recommendations raised in this submission. This includes action areas about: bereavement; advance care planning; improvements in public awareness of palliative care, as well as death and dying; the evolution of innovative models of palliative care service provision; enhanced co-ordinated support for carers, volunteers, communities of carers; and carer respite.

While COAG funding for subacute care has been made available to states and territories, funding has not been allocated specifically for the implementation of the National Palliative Care Strategy 2010. As the actions in the strategy are over-arching, not detailed, a more detailed implementation plan should be developed. The implementation plan should include a substantial emphasis on Aboriginal and Torres Strait Islanders, which should address the issues and action areas identified in the National Indigenous Palliative Care Needs Study: Final Report.<sup>38</sup>

Recommendations:

24. That in 2012-13, the Australian Government publishes a more detailed implementation plan for the National Palliative Care Strategy 2010. This implementation plan should include a substantial focus on Aboriginal and Torres Strait Islanders.
25. That the Australian Government makes publicly available an interim and final report on progress in implementing National Palliative Care Strategy 2010 and the more detailed implementation plan.
26. That the Australian Government allocates funding to facilitate the implementation of the National Palliative Care Strategy 2010.

### *Statewide Palliative Care Strategies.*

Many Australian states and territories have jurisdictional palliative care strategies. In January 2010, the Palliative Care Strategic Framework 2010-2013 was released in NSW.<sup>48</sup> Compared to some state plans such as that of Victoria, the plan contains little detail about evidence-based strategic direction, existing and proposed service levels or models to be implemented in NSW. The NSW implementation plan, Palliative Care Development Planning Framework 2011-2014 provides more detail of the types of actions to be implemented.<sup>49</sup>

There is a need for the NSW Palliative Care Strategy/implementation plan to be updated to include: a mapping of existing service levels/types, service utilisation data, a greater focus on evidence-based strategic direction; areas of unmet need (both current and projected); strategies to address areas of unmet need. Details of planned enhancements through the National Health Reform Process, as well as existing and planned service enhancements at a health district level should be provided. The document should be publicly available and publicly reported against annually. It is noted that the NSW Ministry of Health is in the process of collecting some of this data through implementing the Palliative Care Development Planning Framework 2011-2014.

#### Recommendation:

27. That state and territory governments should make publicly available detailed jurisdiction-wide palliative care strategies/implementation plans that include, as a minimum, a mapping of existing service levels and service utilisation, areas of unmet need, evidence-based strategic direction and planned service enhancements. These should be publicly reported against annually.

### **(c) the efficient use of palliative, health and aged care resources.**

#### *Specialised palliative care services*

There is evidence of the effectiveness of community palliative care services. International studies have demonstrated that palliative care consultancy services can identify previously undiagnosed problems, significantly improve management of clients' physical and psychological symptoms, reduce admissions to intensive care units, lower the costs of care and improve documentation of clients' goals.<sup>50</sup> For example, Hearn and Higginson demonstrated improved patient and carer satisfaction when specialist palliative care teams are involved. They identified that more patient and family needs are identified and dealt with, time in acute hospitals is reduced and costs of overall care are reduced.<sup>51</sup>

An action area in the National Palliative Care Strategy 2010 is to "undertake further research and further monitoring of the relative cost of care and cost effectiveness of care models in the last year of life, particularly savings to be gained through appropriate hospital avoidance for clients approaching the end of their life."<sup>52</sup>

Cancer Council NSW and LifeCircle strongly support the development of research into relevant service models including potential cost savings to the Australian health system by using models of service such as community palliative care.

#### Recommendation:



28. That the Australian Government progress the development of further research into service models, including community palliative care, which can appropriately reduce avoidable hospital admissions.

**(e) (ii) the composition of the palliative care workforce, including the adequacy of workforce education and training arrangements.**

*Health and Aged Care Staff*

The need for education and training in the health and aged care sectors in relation to palliative care is well-documented.<sup>53;54</sup> Cancer Council NSW and LifeCircle support the recommendations in domain ten of Palliative Care Australia's publication "Health system reform and care at the end of life: a guidance document"<sup>13</sup> relating to core competencies and training for health care and aged care workforces. This includes recommendations relating training about advance care planning, inclusion of cross-cultural content in palliative care training, as well as core competencies for palliative care in continuing professional education,

**Recommendation:**

29. That the Australian Government facilitates the implementation of recommendation ten of Palliative Care Australia's publication "Health system reform and care at the end of life: a guidance document"<sup>13</sup> relating to core competencies and training for health care and aged care workforces.

*Volunteers*

Some palliative care teams within local health districts also involve volunteers in a range of activities to support their clients, providing services such as transport, respite and emotional support.<sup>55</sup> Appropriate staff time and local health district volunteer policies are required to support these volunteers. Volunteer policies within local health districts have usually been developed to cover hospital-based volunteering, not volunteering within the community, which can include a much wider range of roles.

Volunteers are vital, core members of the interdisciplinary palliative care team, yet very little palliative care volunteer workforce development has been undertaken in Australia. Education and training is limited and little data collection is available to measure this workforce.<sup>56</sup>

Volunteers can bring unique skills to a situation. For example, the LifeCircle telephone counselling service for people affected by a serious or potentially terminal illness is staffed by trained volunteers who have either been carers for someone with a terminal illness or who have been through a life-threatening illness themselves.

Based on the experience of Cancer Council NSW and LifeCircle, appropriate volunteer support and matching of volunteers to roles is essential. For those involved in offering emotional/practical support to people who are terminally ill or their carers, this includes regular debriefing and training.

One of the action areas of the National Palliative Care Strategy 2010 is to provide enhanced, coordinated support for carers, volunteers, communities of carers and carer respite.<sup>17</sup> The development of a National Palliative Care Volunteer Strategy could form part of the implementation of the National Strategy Palliative Care Strategy 2010.

Key components could include, but would not be limited to:

- development and implementation of a National Managers of Volunteers Network;
- national volunteer service data collection to assist with building an evidence base;
- development of National Palliative Care Volunteer Standards and their incorporation into the National Standards for Palliative Care and the palliative care National Standards Assessment Program; and
- development and implementation of a nationally consistent competency based education and training framework for palliative care volunteers.<sup>56</sup>
- development and strengthening of initiatives that support the engagement of volunteers to assist people through life threatening illness and at end of life.

Cancer Council NSW and LifeCircle support the development of a National Palliative Care Volunteer Strategy for volunteers in palliative care services and recommend that the training and development opportunities be made available to volunteers in non-government organisations that assist people with a life threatening or terminal illness and their carers.

**Recommendation:**

30. That the Australian Government allocates funding to support the development of a National Palliative Care Volunteering Strategy.

**(g) (i) advance care planning, including avenues for individuals and carers to communicate with health care professionals about end-of-life care.**

Advance care planning has been demonstrated to assist people to receive care in the place of their choice and minimise the chance of them receiving unnecessary treatment. Clients, carers and health professionals have indicated that undertaking a process of advance care planning improves quality of care, increases respect for client autonomy and minimises distress, anxiety and depression for families by avoiding the need for them to make urgent decisions at a time of crisis.<sup>2</sup>

Cancer Council NSW Legal Referral Service has noted that confusion exists amongst community members and hospital staff about key components of advance care planning, enduring guardianship and advance care directives. For example, hospital staff may not know how to deal with advance care directives due to uncertainty about the legal status of these documents. The number of pro-forma documents available for advance care directives adds to this confusion.

Initiatives have been undertaken at a local level to address confusion associated with advance care planning. For example, on the Central Coast of NSW, the carer support unit attached to the regional hospital has provided education to hospital staff about advance care planning. In addition, “Life Matters Workshops” conducted by LifeCircle in partnership with Cancer Council NSW and the Carer Support Unit, Gosford Hospital, have been held over the last eighteen months in the region, with 50-100 participants attending at a time. These workshops have provided information about advance care planning and have been promoted through nursing homes, general practitioners, pharmacists and other appropriate networks. The “Life Matters” series supported by the Cancer Council NSW recently won an Australia Day Award from Pittwater Council (northern beaches of Sydney) NSW, acknowledging its benefit to the community.

The “National Palliative Care Strategy 2010” commits to the roll-out of advance care directives across all sectors, including addressing any barriers to uptake.<sup>17</sup> A multi-strategic approach such as that implemented on the Central Coast involving both hospital staff and

community members will assist in reducing confusion about advance care planning. LifeCircle and Cancer Council NSW consider that there is a critical need for a co-ordinated approach to the roll-out of advanced care directives and encourage the Australian Government to implement this approach.

Recommendation:

31. That the Australian Government resources and facilitates a co-ordinated approach by each state and territory to the roll-out of advanced care directives.

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