Senate Standing Committees on Community Affairs

Inquiry into Palliative Care in Australia

Submission from Barwon Health

Contents

1. Introduction

Palliative care is a relatively new and evolving specialty discipline. It provides comprehensive assessment and holistic care for individuals and their families through a combination of medical, nursing, therapeutic and volunteer services.

Palliative care is a modern concept with a relatively short history. Beginning in the 1950s in the United Kingdom and led predominantly by Dame Cecily Saunders, who is widely regarded as the founder of the modern hospice movement, the modern hospice originated and gained momentum after the founding of St Christopher's Hospice in London in 1967. As a form of healthcare it is now active throughout the world, with Australia highly involved in its development.

It is widely recognised that the palliative approach to patient care provides many health benefits to patients and economic gains to health services. Yet for many, palliative care is a concept only associated with the final days prior to death, rather than providing the best quality of life throughout the illness trajectory.

Palliative care has been defined by the World Health Organization as;

"*The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.*"

While awareness of palliative care is growing and referrals for non-malignant patients are slowly increasing, there are many misconceptions about palliative care within aged care, certain medical disciplines and the general wider public. Culture change through a targeted communications campaign and Government policy is necessary to enable positive change within health services and to allow the general population to embrace and understand the real concept of palliative care.

Whilst we advocate for a specialised palliative care approach to end of life care, we also acknowledge that end of life care is not solely the domain of palliative care as many people with chronic illnesses die within other services and without referral to palliative care. Acute health systems have not been designed to care for people who are dying. Nor has there been appropriate communication skills training for clinicians to deal with the difficult conversations that occur prior to and following death. Therefore, we are also advocating for a whole of health and community service system focus on end of life care. Should the Commonwealth develop a whole of system approach to end of life care, similar to the United Kingdom's End of Life Strategy, this would enable health and community services to take a higher level of responsibility to care for people at the end of life.

Our major recommendation to the Senate Committee is;

For the Commonwealth to implement a whole of health and community system approach to end of life care, similar to the UK Department of Health's *End of Life Care Strategy* as implemented by the NHS End of Life Care Programme.

2. Barwon Health Palliative Care

Barwon Health Palliative Care is based in Geelong, which is 75 kilometres south-west of Melbourne and services a population of 263, 279, including the local government areas of Greater Geelong, Surf Coast, Golden Plains and Queenscliff regions.

Figure 1 – Distance between Melbourne and Geelong

The Barwon Health Palliative Care Program is a specialist interdisciplinary palliative care service, which is committed to providing an equitable, seamless, person-centred approach; strengthened by education, research and development to support our community.

The Palliative Care Program encompasses a Community Palliative Care program, a 16 bed Palliative Care Unit (both located at the McKellar Centre – a sub-acute site), and a Hospital Based Acute Consultancy Service located at the Geelong Hospital. It also holds outpatient clinics located at the McKellar Centre and at the Andrew Love Cancer Centre, Geelong Hospital. The Palliative Care Program also has a team of dedicated volunteers and a Supportive Care team comprising of a clinical psychologist, grief and bereavement counsellor, social worker and pastoral care worker.

In March 2010, Barwon Health became one of 15 national sites to be an accredited palliative care clinical trials site and our Palliative Care Program is currently participating in seven clinical trials studies from the Palliative Care Clinical Studies Collaboration (PaCCSC). The Palliative Care Program is also participating in two international clinical trials on cachexia in non-small cell lung cancer through Helsinn Medpace and has recently become the first site in Australia to recruit patients to the study.

Barwon Health was granted Commonwealth funding to build an integrated regional cancer centre at the Geelong Hospital site. Negotiations are still underway for the fourth stage of this project, which is to build a palliative care ward at the Geelong Hospital.

2.1 Supporting the Geelong sub-region

The Barwon Health Palliative Care Program also support other health services in the Geelong sub-region (see Figure 2), namely Colac Area Health and Bellarine Community Health by providing medical consultations, senior nursing clinical supervision, grief and bereavement and psychology services to their palliative care patients.

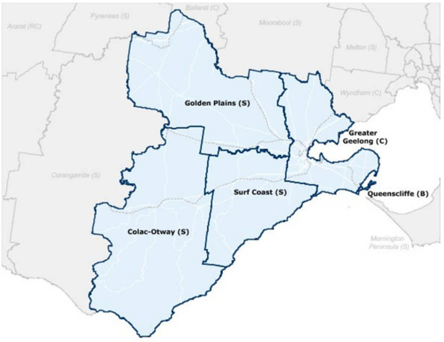

Figure 2 – Local Government Areas – Geelong Sub-Region

2.2 Population predictions

According to data in the *Community Health and Wellbeing profile* (2009), 30 per cent of deaths in the Geelong region alone are caused by cancer. It is estimated that this figure will rise with the growing ageing population and place an increasing demand on our palliative care services. As seen in Table 1, in the Borough of Queenscliff alone, it is expected that 45 per cent of the population will be over the age of 65 by 2021.

Local Government Group	Increase in people aged 65+ by 2021	Percentage of population - people aged 65+ by 2021
City of Greater Geelong	43.7%	17.9%
Surf Coast Shire	88.6%	15.1%
Borough of Queenscliff	50.5%	45%
Golden Plains Shire	113.1%	14.1%

Table 1 – Population aged above 65 in 2021. Source: G21 Alliance (www.g21.com.au)

Population and expected population growth

Local Government Area	Population 2009	Population 2026	Growth Rate % per annum	Area (km2)
City of Greater Geelong	216,330	269,653	+1.3%	1,245
Surf Coast Shire	25,458	34,781	+1.9%	1,553
Borough of Queenscliff	3,318	3,349	+0.1%	9
Golden Plains Shire	18,173	24,387	+1.8%	2,704
Total	**263, 279**	**332,171**	**+1.0%**	5,511
Victoria	5,443,228	6,711,190*	+1.3%	227,590

Table 2 – Population and expected population

Source: Australian Bureau of Statistics, 'Estimated Resident Population, June 2008'.
Department of Sustainability & Environment, 'Victoria in Future 2008'

3. Regional Leadership – the Barwon South West Region Palliative Care Consortium

Barwon Health is a member of the Barwon South West (BSW) Region Palliative Care Consortium in Victoria. The Barwon Health Manager Palliative Care is the Consortium Chair, as voted by the other BSW regional health services. The Consortium Manager is also located at the Barwon Health.

Figure 3: Location of the Barwon-South Western Region in Victoria.

The Consortium aims to ensure there is consistent access to specialist palliative care services and to enable continuity of care across the care continuum for people with a terminal illness and their carers and families across the BSW region. The consortium aims to enable a more efficient and cooperative use of resources while supporting an integrated approach to care for the patient.

The clinical leaders group (a sub-set of the Consortia) together with the Consortia have driven change in implementing a population needs based model of care and common standard assessment tools to standardise palliative care throughout the south west region. Funding from the Commonwealth was available to develop software to support this. After initial development and piloting at Barwon Health, PERM (Specialist Palliative Care Electronic Record Management system), was also rolled out to South West Healthcare, Portland District Health and Western District Health. It is expected that Colac Area Health will be using the software from February 2012 and Bellarine Community Health by 30 June 2012.

The other members of the Consortia include Bellarine Community Health, Colac Area Health, Portland and District Health, South West Health Care and the Western District Health Service.

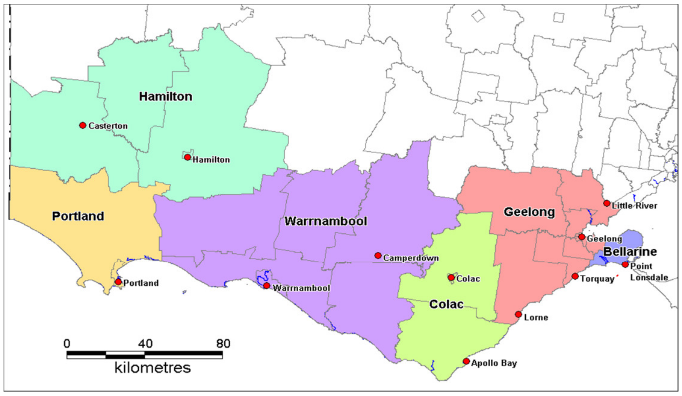

Figure 4: BSW region.

4. Access to Palliative Care

It is widely recognised that the demand for palliative care is rapidly growing. This is due to various factors including; the ageing population, an increase in the awareness of the benefits of palliative care and an increase in non-malignant referrals to palliative care.

Evident gaps in palliative care access and provision include the lack of day hospice facilities, unequal access to palliative care for patients with a non-malignant diagnosis and unequal access for rural and remote patients, particularly in after-hours care.

4.1 Rural disparity in Palliative Care services across the Barwon South West Region

Having the choice to die at home is not available to many patients in rural and remote settings. There is minimum access to specialist staff and community nursing in rural areas. Often, if you live approximately 30km from a regional or rural centre, patients are unable to receive nursing visits out of hours. However, the State Government has now funded out-of-hours telephone access to a specialist palliative care nurse for patients and carers in these areas.

The availability of suitably trained specialist physicians, nurses and GPs impacts on the choice to allow patients to die in their own homes in rural areas. The specific resources required are specialist physicians and chemists, with the drugs that are frequently used in palliative care readily available. In 2010/2011 at a small regional palliative care provider, out of 35 palliative patients who died, only three died in their own home. International evidence has found that 90 per cent of people with a life threatening illness would prefer to die at home, yet out of this figure only 26.5 per cent die at home (Victorian Government).

This is not an easy issue to tackle. More funding is one answer, but without GP culture change and training more funding may be ineffectual. Some possible resolutions include incentives to encourage GP palliative care specialty training for rural and regional areas. This would tie into a clinical governance hub-and-spoke model with the GPs linking into peer review programs to be monitored by palliative care specialists in regional centres.

Recommendations:

- **Increase the funding of specialist nursing palliative care staff in rural areas**
- **Provide incentives to train GPs in a post-graduate Palliative Care sub-speciality and MBS incentives to support people to die in the venue of their choice**
- **Create a clinical governance structure to enable two way communication/ training/ monitoring between rural and regional GPs and regional palliative care services**
- **Explore the use of telehealth for rural and regional areas.**

4.2 Unmet Palliative Care Demand for Patients with a Non-Malignant Disease

Patients with a non-malignant terminal disease have a similar symptom burden to cancer patients and would benefit from palliative care. However, these patients are often not being referred to palliative care and of those who are referred, the timing is too late. This is an area Barwon Health Palliative Care is trying to amend, yet it is facing many challenges due other medical disciplines' views on palliative care. Silos across the health services and within service providers are preventing equitable access to palliative care for these patients.

Equal access for patients with a non-malignant terminal illness across all health services is not occurring. According to Fitzsimons et al (2007), patients dying from chronic illness have many concerns and unmet clinical needs. He also states that,

> *'An earlier and more effective implementation of the palliative care approach is necessary if the needs of patients in the final stages of chronic illness are to be adequately addressed.'*

According to the Victorian Government, only 15 per cent of all referrals to palliative care in Victoria are for non-malignant patients. While the Victorian Government also acknowledges that these referrals are gradually increasing, it estimates that each year 7,500 people with chronic illnesses continue to miss out on palliative care.

A large sub-set of this group are patients with ischaemic heart disease. According to the Victorian Government, in 2001 ischaemic heart disease was the highest cause of mortality for both males and females. The *NHS End of life care in heart failure: A framework for implementation* notes that,

> *'Despite a growing recognition of the requirement to provide supportive and palliative care for this clinical cohort [heart failure patients], the recent National Heart Failure Audit demonstrated continuing significant unmet needs: only 6% of those dying with heart failure were referred to palliative care.'*

Unfortunately, our data at Barwon Health presents similar findings. It demonstrates that in 2010 there were a total of 697 admissions to the Geelong Hospital for patients with heart failure. Out of these 697 admissions (this includes multiple patient admissions); only 58 patients were referred to palliative care. Out of these 58 referred patients, 19 died during the same hospital admission; several prior to assessment by the palliative care team.

The implications of not referring the appropriate patients with a non-malignant disease are wide ranging, for both health services and patients. This may result in unnecessary interventions and admissions; an inefficient use of health resources and funding; a worse quality of life for the patient; and no psycho-social and bereavement support for the patients and their families.

This view is supported by the *NHS End of life care programme*. According to the *NHS End of life care in heart failure*, heart failure 'consumes a major and increasing proportion of clinical and public health resources due to multiple hospital admissions.'

Patients who have multiple hospital admissions for chronic heart failure within one year have a worse prognosis then most lung cancer patients. There is a strong possibility of death within twelve months (Heart Foundation 2006). Evidence suggests best practice for patients with recurrent hospitalisation for heart failure or if their heart failure is classified at New York Heart Association (NYHA) Stage III or Stage IV, is to be referred to palliative care (Heart Foundation 2010, Gold Standards Framework).

While the evidence suggests what is best practice, in reality this is not occurring. In 2010, 79 patients were admitted to The Geelong Hospital twice with heart failure; totalling 158 admissions and resulting in only **six** referrals to palliative care. Also in the same year, 29 patients had three admissions with heart failure; totalling 87 admissions. Only **seven** of these patients were referred to palliative care. This data demonstrates the severity of the unmet demand for this particular chronic illness group. Considering that patients with chronic heart failure have a similar symptom burden as cancer patients, it is difficult to comprehend that such a large number of patients are not being referred.

Prognosis and when to refer to palliative care is difficult to determine in many chronic illnesses, yet specialist palliative care is often considered (if at all) too late. Specialist palliative care can assist with symptom management earlier in the patient's illness trajectory and also avoid the trauma of unnecessary admissions and interventions for patients. As well as benefitting patients on a physical and emotional level, this also makes economic sense.

Recommendations:

- **To include palliative care in the National Chronic Disease Management Strategy.**
- **For a national coordination of End of Life Care Pathways in Chronic Illnesses, similar to those initiated by the NHS National End of Life Care Programme.**
- **Identify triggers for referral to palliative care based on literature review**
- **Explore methods of greater integration particularly for end-stage heart failure, similar to end-stage renal failure.**

4.3 Health promotion in Palliative Care – Public Health Palliative Care

According to CareSearch (www.caresearch.com.au), 'Public Health Palliative Care, previously titled Health Promoting Palliative Care, is considered a new concept that has emerged over the past decade. It is based on the public health concept of a population approach linking to the World Health Promotion Guidelines, The Ottawa Charter.

The goals of Public Health Palliative Care are;

- Building public policies that support death, dying, loss and grief
- Creating supportive environments (in particular social supports)
- Strengthening community action
- Developing personal skills in these areas
- Re-orientating the health system (Kellehear, 1999)'

Although well supported by evidence based projects and research as a means to build resilience and skill in local communities around death, dying, loss and grief, this aspect of palliative care is seriously underfunded and under-utilised in the majority of palliative care services across the country.

Palliative care practitioners are interested and willing to promote public palliative care, however due to limited resources and personnel, this is often seen as an "extra" and is not funded into programs as an essential element of care.

Providing innovative, creative, effective, and well planned public palliative care impacts on clinical need in the community, e.g. if resilience is built in a community around managing grief, then the clinical load for professional bereavement services will be lessened, freeing up resources to be used where most needed. Health promotion is about up-skilling and building stronger communities. Providing strategic development in health promoting palliative care is essential. Greater co-ordinated funding and project development at state and national levels would benefit everyone, both professionals and the general public.

Recommendation:

- **To implement a whole of system End of Life Care Strategy across health and community services, including health promotion and entailing a national and state communications campaign raising awareness and addressing the common misconceptions about palliative care.**

4.4 Day hospice

Day hospices for palliative care patients provide many benefits for both patients and health services. These benefits include;

- Good symptom management. This enables patients together with medical staff to manage their symptoms if/when there are changes and empowers the patient to be able to return to their homes. As a consequence, there would be fewer presentations to the emergency department for palliative patients as their symptoms have been controlled, avoiding unnecessary emergency admissions.
- Respite for carers and families. This gives carers a legitimate break. It is currently difficult for carers to obtain respite.
- Social contact with other palliative patients is beneficial to the emotional health of patients
- Access to medical, nursing and psycho-social supports for patients on one site without the need for overnight care.
- Cost effective and enables patients to return home at night to be with their families and friends.

The vision is that day hospices would be a Centre for Palliative Care (similar to the 'Wellness Centre' for cancer patients) with the potential to create positive connotations to the wider public. The Centre would provide a structured program mostly in a non-acute setting encompassing medical, nursing, supportive and spiritual care, therapies (e.g. art and massage) and palliative chemotherapy/radiation treatments in an appropriate environment.

A day hospice has been trialled in the Bendigo area with positive results.

Recommendation:

- **That the Commonwealth and State Governments consider funding day hospice centres as a cost effective means of delivering services and providing respite for patients and carers.**

5. Efficient funding for Palliative Care

The current funding arrangements are about to be reformed. The activity based funding which the Commonwealth will soon introduce for acute, sub-acute and outpatients (and eventually for community services) will require accountability and are based on many clinical indicators. This transparent approach to funding is welcomed by Barwon Health Palliative Care.

The drivers of an efficient use of resources are good governance – integrated care provided through one governance structure, clinical excellence, performance incentives related to funding (for bed-based services) and palliative care beds located on an acute site.

Barwon Health is unique in Victoria as it operates community palliative care, hospital based acute palliative care consultancy team, palliative care unit, community nursing, outpatient medical and outpatient nursing review clinics. It would be beneficial to see this model emulated in other health services to minimise the barriers between service providers and patient information sharing, provide timely coordination across services and improve the patient journey.

As noted previously, the palliative approach reduces unnecessary hospital admissions and interventions. Consequently, this places less strain on health resources and funding. According to the Victorian Government, supporting people's wish to die at home makes economic sense. The Victorian Government's 2009 review found that "it is about five times less expensive to care for a person with a life-threatening illness at home than it is to care for them in hospital" and stated that this finding is also supported by overseas studies. The review also found that patients who are enrolled in a palliative care program are also less likely to present to emergency or be admitted to a hospital via the emergency department, consequently placing less strain on emergency departments and health resource funding for overnight admissions in acute settings.

Recommendation:

- **Ensure that activity based funding provides incentives for patient choice in site of care and death.**

5.1 Barriers to the efficient use of resources

The palliative approach has economic benefits which are currently not realised due to barriers blocking the efficient use of resources. This in turn impacts palliative care as a speciality, its referrals, health promotion, workforce and engagement with other services and disciplines.

5.1.1 Location of acute and sub-acute services

The delivery of care across acute and sub-acute sites is a challenge both for patient care and for the efficient use of resources. Currently 75 per cent of referrals to palliative care are for patients with a malignant disease. To provide efficient and seamless patient care, these patients need to have access to diagnostics, chemotherapy, radiation therapy, spinal analgesia and access to other specialty teams, such as the pain team. Currently, our palliative care beds are located at a sub-acute site. Should a patient require any of the aforementioned services, they must be transferred to the acute site via ambulance. This is disruptive to patient care and can cause significant stress. It is also an obvious waste in funding and resources. In larger metropolitan and regional hospitals, palliative care beds need to be on an acute site so patients have access to the appropriate treatments and teams.

As there are no beds on the acute site, this also leads to a duplication of services when patients already registered the palliative care program are admitted to an acute setting. These patients are admitted under another team (oncology, renal, etc.) and are managed by the admitting team. This creates communication and governance issues as to who is responsible for care of the patient and a duplication of servicing patients. The palliative care consult team still provides a consultancy service but the day-to-day management of the patient (who is deemed a palliative care patient) is performed by the admitting team.

5.1.2 The clinical and resource challenges of mixing palliative care beds with other traditionally sub-acute specialties

Combining palliative care beds with GEM or another speciality is another key barrier to effectively using our resources and a major barrier in providing specialist palliative care. It compromises the care of the patient and the quality of the service provided.

The ideal model for the provision of palliative care in an acute and/or sub-acute environment is an exclusive palliative care ward staffed with a specialist palliative care nursing, medical and supportive care team members. In reality, this model is difficult to implement unless you have a critical mass of twenty plus funded beds to enable efficient operations.

Currently, Barwon Health has 16 palliative care beds (15 funded and one flexible). These beds are combined in a ward with 16 Geriatric Evaluation Management (GEM) beds. GEM patients are most often in the process of rehabilitation – a goal clearly at odds with palliative care. These differences can inhibit the provision of specialist palliative care. It is not adequate to have staff that are specialised in other fields, but not skilled in palliative care, to be working in a specialist palliative care setting. The differences between the goals of care, the provision of care, and the needs of patients and their families, indicate a need to separate the delivery of care.

Recommendation:

- **As far as possible set funding guidelines to facilitate the adequate funding for more palliative care beds and to ensure that palliative care beds are not mixed with other beds at the appropriate health services (a minimum of 20 beds to be viable).**
- **Ensure that metropolitan and regional centres are funded for stand-alone palliative care beds at acute sites.**

5.2 Funding for overnight nursing

Funding is required for home overnight nursing. This is currently not funded by either the State or Commonwealth. This would enable some patients' wish to die at home to be fulfilled, particularly in rural areas. Currently, Barwon Health Palliative Care can access very limited funding from *Geelong Hospice*, a charity organisation, to allow nursing or personal care for a limited number of nights for care of patients who wish to die at home. If the Government considered funding overnight nursing, this would increase the number patients who wish to die at home to be able to fulfil their wish. This would also provide a night of respite or more for carers who have been continually caring for patients at home. Respite is an important element of palliative care, as it provides carers with an opportunity to ‘recharge’. However, it is quite difficult to obtain a respite admission as patients with a higher level of need due to unstable symptoms or a terminal phase receive priority for admission.

Recommendation:

- **Consider flexible funding for overnight home nursing.**

6. Palliative Care Workforce Training and Education

It is well recognised that having sufficient supply of an appropriately trained and skilled workforce is a current and future issue. As such the Commonwealth agency, Health Workforce Australia, is undertaking significant work to address this workforce issue.

Similar to other areas within the health workforce, the average age of the palliative care workforce is 45 for nursing and higher for medical staff. Soon staff will be retiring and there is not enough specialist staff to replace them, let alone increase the number of staff required due to the ageing population and the increase in demand for palliative care.

There are several barriers to the attraction and retention of palliative care specialist staff. These are;

- Insufficient scope for development of career pathways
- Insufficient funding available to cover staff to allow palliative care nursing staff to further develop skills
- Insufficient post-graduate modules for other specialities (i.e. social work, psychology, allied health, spiritual care).

At Barwon Health, palliative care is not funded to have a nurse educator and clinical facilitators. This depreciates palliative care as a specialist discipline. The introduction of nurse educators and clinical facilitators would provide career structure and provide the support for career growth. Consequently, this could increase the retention of nursing staff. Currently in palliative care, there are limited career pathways for nurses on the wards, especially on the wards with mixed beds.

Other specialist services within Barwon Health have a dedicated clinical facilitator without a patient load specifically to enable mentoring, education and professional development. This is lacking in our palliative care service.

Palliative care as a discipline needs to be on the curriculum at an undergraduate level. This would provide undergraduates with exposure to palliative care and possibly encourage nurses into the field of palliative care.

As mentioned above, GPs can have a major role in shared palliative care particularly in rural areas. It is vital to the provision of palliative care that these GPs are trained in a palliative care sub-specialty and in clinical communication skills to manage difficult end of life discussions.

Recommendations:

- **To fund clinical facilitator and nurse educator positions within palliative care.**
- **To include placements for undergraduate nursing students in inpatient and community palliative care.**
- **To ensure that specialist palliative care services are adequately funded to provide training to primary care, aged care, sub-acute and acute nursing staff.**
- **Consider funding higher qualifications particularly for allied health and nursing through scholarships together from philanthropy and not-for-profit.**
- **To fund additional aged care-palliative care link nurses.**

7. End of Life Care Pathways and Planning

'The formal implementation of end of life pathways provides a way of supporting generalist staff to provide palliative care to non-complex patients' (Victorian Government).

Pathways are increasingly used in a growing number of health services across Victoria. There is substantial evidence to support the use of these pathways as it has led to improvements in the quality of care for those who are dying, particularly in patients with a non-malignant disease who are not referred to specialist palliative care. End of life care pathways can also be used in conjunction with advance care planning.

7.1 Clinical Communication Skills Training

However, a problem facing the implementation of End of Life Care Pathways and Advance Care Planning is a reluctance for many specialists and primary care clinicians to broach the issue of end of life care and to re-establish goals for their patients in this setting. This may be due to clinicians fearing that they will upset their patient or the perception that death may equal professional failure as a clinician.

Recommendations:

- **For clinical communication skills training to be included in the curriculum in all medical undergraduate degrees**
- **To encourage and fund clinical communication skills training in difficult conversations in all health services (medical, nursing and allied health).**
- **To encourage and fund education and training on palliative care and end-of-life issues in health services for all clinicians.**

7.2 Advance Care Planning

Advance care planning (ACP) ideally needs to be done earlier, before a patient reaches palliative care. There is less benefit to the patient, their family and carer in the later stages. Early planning provides time, a mapped journey and empowers the patient. Although it is a time-consuming process, it is useful in identifying the wishes of the patient. However, there seems to be a large resistance to advance care planning by many GPs.

Barwon Health provides an Advance Care Planning service across all sectors of Barwon Health and the region of Geelong through;

- ACP Clinic – provides rooms outside the hospital environment
- ACP program staff provides home visits if necessary
- ACP Clinic – in 10 of the regions General Practice clinics (project 12 months)
- ACP has been implemented into aged care facilities, engagement through Residential In-Reach program
- Hospital Admission Risk Program – providing awareness of and facilitation of ACP for patients with chronic illness prior to palliative stage
- Community Palliative Care nurses – core competency – to attend training and up-skill in ACP

The development of the National Framework for Advance Care Directives is a step in the right direction. Achieving national consistency is a goal to aspire to.

Currently advance care plans at Barwon Health are scanned into the patient’s Barwon Health electronic records and distributed to all involved in patient’s care (e.g. GPs, private hospitals, specialists). It is also built into the Palliative Care IT software system.

Recommendations:

- **To establish a national register for Advance Care Plans**
- **To implement a system to make discussion regarding an Advance Care Plan routine**
- **To implement a system to assist individuals to more effectively consider their values and treatment wishes.**

8. Palliative Care Standards

The National Standards Assessment Program (NSAP) is a useful way of assessing our own performance, maintaining quality and identifying areas that need to be improved.

However, there needs to be transparent standards that clearly denote to the general community what constitutes a palliative care provider or hospice. There are providers that do not have any specialist palliative care nursing or medical staff, yet advertise that they provide hospice or palliative care services. This is misleading and can put patients at risk.

Recommendations:

- **To strengthen the implementation of standards and be rigorous in the use of the term 'palliative care provider' and 'hospice'.**

9. Research in Palliative Care

Research in Palliative Care currently comes predominantly from universities. At times this research does not seem to translate at a local health service level. Funding for clinician led research would provide a balance to the current research environment.

There is a perception in the field that education on topics that palliative care staff want and need is difficult to access in rural and remote areas.

Recommendation:

- **Targeted seed funding for palliative care research**
- **To increase the capacity across disciplines for research**
- **To increase the funding to clinician-led research**

10. Summary of Recommendations

Many of these recommendations fit beneath our major recommendation to implement a whole of system End of Life Care approach and nationally driven strategy across health and community services. Other recommendations fall into the categories of efficient funding for palliative care and recommendations to improve the palliative care workforce, training and training.

Recommendations encompassing an End of Life Care Strategy

- For the Commonwealth to implement a whole of system approach to end of life care, similar to the UK Department of Health's *End of Life Care Strategy* as implemented by the NHS End of Life Care Programme.
- For a national coordination of End of Life Care Pathways in Chronic Illnesses, similar to those initiated by the NHS National End of Life Care Programme.
- To include palliative care in the National Chronic Disease Management Strategy.
- To implement a whole of system End of Life Care Strategy across health and community services, including health promotion and entailing a national and state communications campaign raising awareness and addressing the common misconceptions about palliative care.
- Identify triggers for referral to palliative care based on literature review.
- Explore methods of greater integration particularly for end-stage heart failure, similar to end-stage renal failure.
- Provide incentives to train GPs in a post-graduate Palliative Care sub-speciality and MBS incentives to support people to die in the venue of their choice
- Create a clinical governance structure to enable two way communication/ training/ monitoring between rural and regional GPs and regional palliative care services.
- To fund additional aged care-palliative care link nurses.
- For clinical communication skills training to be included in the curriculum in all medical undergraduate degrees.
- To encourage and fund clinical communication skills training in difficult conversations in all health services (medical, nursing and allied health).
- To encourage and fund education and training on palliative care and end-of-life issues in health services for all clinicians.
- To establish a national register for Advance Care Plans.
- To implement a system to make discussion regarding an Advance Care Plan routine.
- To implement a system to assist individuals to more effectively consider their values and treatment wishes.

- To ensure that specialist palliative care services are adequately funded to provide training to primary care, aged care, sub-acute and acute nursing staff.
- To strengthen the implementation of standards and be rigorous in the use of the term ‘palliative care provider’ and ‘hospice’.

Recommendations for efficient funding for palliative care

- Increase the funding of specialist nursing palliative care staff in rural areas.
- Explore the use of telehealth for rural and regional areas.
- That the Commonwealth and State Governments consider funding day hospice centres as a cost effective means of delivering services and providing respite for patients and carers.
- Ensure that activity based funding provides incentives for patient choice in site of care and death.
- As far as possible set funding guidelines to facilitate the adequate funding for more palliative care beds and to ensure that palliative care beds are not mixed with other beds at the appropriate health services (a minimum of 20 beds to be viable).
- Ensure that metropolitan and regional centres are funded for stand-alone palliative care beds at acute sites.
- Consider flexible funding for overnight home nursing.

Recommendations to the improve palliative care workforce, training and research

- To fund clinical facilitator and nurse educator positions within palliative care.
- To include placements for undergraduate nursing students in inpatient and community palliative care.
- Consider funding higher qualifications particularly for allied health and nursing through scholarships together from philanthropy and not-for-profit.
- Targeted seed funding for palliative care research.
- To increase the capacity across disciplines for research
- To increase the funding to clinician-led research.

If you require any further information regarding this submission, please contact Lise Pittman, Manager Palliative Care on 03) 5279 2800 or via email on lisepi@barwonhealth.org.au.

11. References

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