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Dear Secretary

Submission to the Senate Inquiry on the Future of Australia's Aged Care Sector Workforce

Thank you for the opportunity to contribute to the inquiry into the future of Australia's aged care sector workforce. This is an issue of high importance to Palliative Care Australia (PCA), as increasingly it will be the aged care sector workforce that will be caring for Australians at the end of their lives. Three-quarters of people who died in Australia aged 65 and over used an aged care service in the 12 months before death (Use of Aged Care Services Before Death, AIHW 2015), and three-fifths were an aged care client at the time of their death. This places the aged care workforce as a key part in the network of people who need to work together to ensure people have maximised quality of life as they are approaching the end of their lives, and that they have as good a death as possible.

Attached is input from PCA to the inquiry. PCA predominantly calls for opportunities for training and continuing professional development for the aged care workforce in the area of end-of-life care and palliative care.

If you have any queries about the content of this submission please direct them to Philippa Kirkpatrick, National Policy Manager on philippa@palliativecare.org.au or phone 02 6232 4433.

Yours sincerely

A handwritten signature in black ink, appearing to read "Liz Callaghan", with a horizontal line extending to the right.

Liz Callaghan
Chief Executive Officer
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Submission



Introduction

This paper responds to the call for submissions by the Community Affairs Reference Committee to their Senate Inquiry on the Future of Australia's Aged Care Sector Workforce.

The paper addresses some of the template questions and targets the interface between aged care and end-of-life service provision, including palliative care. It is clear that there is some way to go before we can be confident in saying that people who are in receipt of aged care services receive adequate end of life care, delivered by the aged care workforce. Before this can occur the workforce will need to be provided with sufficient training and continuing professional development opportunities in the area of end-of-life care and the culture within services that provide aged care services needs to prioritise the delivery of end-of-life care and subsequently support their staff to deliver it according to benchmarked standards.

The role of the aged care workforce in end-of-life care, and implications for the future aged care workforce

70% of Australians state that they want to die at home, yet the national rate sits at 14%. Choice and flexibility in place of death is an option not available to most Australians, including Australians receiving aged care services. It is not possible for all these people to be cared for by a specialist palliative care service.

The proportion of the population aged 65 years and over is forecast to increase from 12% in 1996 to around 15% (or 3.6 million people) in 2016 (based on 2013 ABS figures). By 2031 the proportion of people over 65 years is forecast to be around 19% (or 5.7 million), and could be as high as 25% (between 9 and 12 million) by 2066 (according to the ABS, 2013). The vast majority of Australians who died in 2013 were people aged 65 years and older (119,000 people, or 81%). Therefore the number of people who die each year will increase over the next 50 years, and the workforce will need to be able to respond in providing care to them.

There is therefore a need for the aged care workforce to be able to support people as they are approaching the end of their lives, both in the home and in residential aged care.

People in receipt of aged care services increasingly have complex health care needs due to multiple chronic diseases; they will require long-term care including palliative care and end-of-life care. The complexity of their care needs is as high as people in acute hospitals and the trajectory of their care is long term and ultimately terminal. Yet, aged care services are often much less

equipped in terms of staffing, funding and skills to provide high quality holistic care to these people, who are among the most vulnerable in our community.

In 2008 the Aged Care Funding Instrument was revised and triggers were identified for increased support to those in residential aged care requiring palliative care. In 2012 a ten year reform program for aged care commenced and in 2013 packages and resident care levels were re-defined and home care packages commenced delivery on a consumer directed care basis in 2015. Services have changed over a long period of time from provider-led systems to funder-led systems and now transitioning to consumer-led systems. There has been policy rhetoric about the shift from care provided in residential settings to care delivered in the community in peoples own homes. What is known however is that the number of residential aged care beds is expected to grow from about 190,000 to 260,000 by 2022 (see inaugural *Report on the Funding and Financing of the Aged Care Sector*, Aged Care Financing Authority 2013). The aged care workforce is now caring for people with long-term sub-acute, complex chronic health conditions and ultimately conditions where palliative care would be beneficial to patients. . Within residential aged care at least it could be suggested that the staffing skill mix and numbers are no longer adequate to deliver high quality holistic care to these residents that allows dying in place of residence.

It is expected that the role of the aged care workforce will continue to expand, with an increasing demand for:

- *Provision of respite*: supporting people to live at home until the end of their lives relies on the commitment of *informal* carers. Provision of support to these carers, including through respite is important.
- *Recognition of dying*: by staff of when end-of-life care and palliative care is needed. This is dependent upon staff being provided training and professional development opportunities that skill the staff *and* provide them with a suite of skills they can enact when required. It is also highly dependent upon established relationships with General Practitioners caring for these residents.
- *Grief, loss and bereavement*: support by qualified staff needs to be given more attention / resources within aged care *services*.
- *Dementia care*: Over 50% of residential aged care facility (RACF) permanent residents have dementia (AIHW 2015). Provision of high quality palliative and end-of-life care to people with dementia is challenging. Given the very high proportion of the RACF population with dementia, it is important that aged care facilities have a workforce with expertise in dementia care. Where the person still has capacity to be involved in decision-making, it is important for *RACF* to provide early involvement of the person, where possible, and family, in the decision making and delivery of palliative and end-of-life care, and to document those decisions in an advance care plan so that the future treatment can continue to reflect the person's value and goals of care.

In addition to advance care planning for residents with dementia, there is a need for the aged care workforce to be skilled in the development of advance care plans more broadly, and in

making decisions that align with those plans when required. It should not be the aged care services responsibility to instigate advance care planning, but rather to check that existing plans (previously completed in the community or hospital setting) remain relevant and express the wishes of the person in their care, and where there is no plan or goals of care in place, to support the completion of one.

A review has identified that improved advance care planning and use of existing resources could reduce avoidable transfers to hospital (Dwyer et al. 2014). Studies have also found that while attitudes of RACF staff were positive with regard to advance care planning, they have relatively little experience in developing advance care plans with residents, and the quality of existing documentation is poor (Silvester et al. 2013).

In order to reduce avoidable hospital transfers, there is a range of initiatives that could be undertaken. Aged care workforce staff need to engage first and foremost with families in the decision making. Sometimes transfers are appropriate and indeed in alignment with resident wishes. Anecdotally, aged care staff report that there is often a great deal of pressure brought to bear on staff to transfer residents to acute hospitals. This is why it is important that resident's wishes are known and that family members are continually informed of changes to their loved ones and included as part of the decision making. All of this takes time, and under the current funding arrangements is not remunerated. Better financial support for case conferencing with resident, families and general practice would make a difference to avoidable hospital admissions. There is a need to provide time for staff to engage in these discussions, and also provide support to the RACF to implement the advance care plan and/or support the substitute decision maker. This may include increasing availability of medical practitioners to the RACF, and also to increase the risk appetite of facilities in managing the dying patient.

All of these services cannot be provided to recipients of aged care services when the need arises unless the aged care workforce are provided adequate opportunity for continuing professional development in end-of-life care, including palliative care. In addition the organisational culture within which services operate must recognise that end-of-life care and provision of palliative care is as much core business for aged care as is dementia care. Leadership and prioritisation of this area throughout organisations must be demonstrated in order to effect any change. Some aged care services are well recognised as taking this seriously and have invested in ensuring residents and clients are supported well at the end of life (see <http://www.hammond.com.au/services/palliative-care>, <http://www.bupaagedcare.com.au/choosing-a-home/types-of-care> and <https://www.silverchain.org.au/wa/our-services/palliative-care>)

Aged Care Workforce will require knowledge and skills in:

- **Advanced communication**
- **Advance care planning**
- **Palliative care delivery**
- **End-of-life care**

Aged Care Organisations will need to:

- **Provide opportunities for training and professional development for staff**
- **Institute a culture that prioritises care at the end-of-life**
- **Support their workforce through cultural change to actively engage with families, residents and clients in decision-making**

Expertise and training of the aged care workforce

Personal Care Assistants provide the mainstay of care in residential aged care. The level of education, training and supervision they receive need to be increased so they are better equipped to provide quality care and support under the direction of an interdisciplinary team of health care professionals. The level of professional health care staffing may not need to increase but should include nursing and the broad range of allied health disciplines so that the holistic physical, social, emotional, psychological, spiritual, and cultural needs of those receiving care are addressed. This includes developing communication skills, health literacy, cultural competence, capacity to deal with issues of dying, death, grief and loss. Access to this multidisciplinary approach to care is the hallmark of good palliative care, and mechanisms to access these funded services should be made available to aged care services, including bereavement support. The role of rehabilitation strategies to support quality of life and the achievement of personal goals should also be actively supported. Currently access to this type of multidisciplinary approach to care is variable and largely dependent upon leadership within each organisation.

Improved access to training and continuing professional development as well as appropriate staffing mix and numbers is required to facilitate the delivery of palliative care and end-of-life care, along with access to consultancy advice from specialist palliative care and end-of-life care services. This should be aligned with existing palliative care workforce development initiatives funded by government. There needs to be a commitment to fund such projects on an ongoing basis. These include, but are not limited to:

- *The Decision Assist advisory line.* The phone advisory service is designed for use by health care workers for recipients of aged care services, either in a residential care facility or within the community. The phone line can be accessed by GPs, nurses, allied health professionals and personal care attendants. The phone advisory service provides information about advance care planning as well as access to specialist palliative care advice, to support services in their delivery of care.
- An ongoing program of *continuing education* that includes education for GPs. Current Decision Assist aged care workshops are focused around palliative care in the community and advance care planning and are designed for people working in aged care. General Practice education, under the Decision Assist project, has provided GPs with access to clinical audit tools as well as online applications (PalliAGED) regarding information about palliative care and symptom management.
- The *Program of Experience in the Palliative Approach (PEPA)*, funded under the National Palliative Care Funding program, provides free placements in palliative care services for practicing health professionals (2-5 days duration) and free palliative approach

workshops, and the opportunity for a specialist palliative care staff member to travel to residential aged care settings to facilitate palliative care learning.

- Other training and resources are available at Palliative Care Online (<http://www.palliativecareonline.com.au/>), which aim to help health professionals and others providing care to aged persons in the community to improve the quality of their practice.

Aged Care Workforce will require knowledge and skills in:

- **Working in multidisciplinary ways**
- **Death literacy**

Aged Care Organisations will need to:

- **Provide opportunities for staff to undertake PEPA and other palliative care specific training**
- **Foster relationships with primary health care providers and specialist palliative care services so that clients / residents receive all the support they need at the end-of-life**

Staffing skills

Care at the end of life can be complex, with the need to consider the increasing co-morbidities of people with chronic diseases as they age, as well as the psychosocial health of people as they and their families face difficult choices, and manage issues of grief and bereavement.

At present, there are no mandated requirements for RACF on staff to resident ratios or skill requirements of RACF staff. The benefit of not having ratios within RACFs allows organisations to staff appropriately and flexibly and aligns with consumer directed needs. For example if the care needs of residents is such that less staff or more staff are required, the systems for rostering in place should allow this flexibility to occur. The benefit of having ratios means predictability for staff in terms of rosters (regardless of workload) and there is a growing body of evidence that adequate nurse to patient ratios leads to better outcomes.

The outcome PCA seeks when discussing staff skill and mix is to ensure that a predictable standard of care is provided. Revised aged care standards should ensure that older Australians receiving care regardless of setting have their end-of-life wishes respected and have access to high quality palliative and end-of-life care. The relevant standards in place and adhered to will ensure the correct staffing levels are achieved.

PCA suggests that an approach similar to the Australian Atlas of Healthcare Variation (ref <http://www.safetyandquality.gov.au/atlas/>) could be undertaken with regard to aged care services and access to specialist palliative care advice. The outcomes of such a review may reveal areas where further support of the workforce in providing safe and high quality care is warranted.

Aged Care Workforce will need to:

- **Work flexibly in the future**
- **Broaden skill sets, eg providing grief and bereavement support**

Aged Care Organisations will need to:

- **Commit to delivering a predictable standard of palliative care / end-of-life care**
- **Identify how to access and integrate specialist palliative care support when needed**

Factors that impact the ability of the aged care workforce to provide high quality end-of-life care

Many factors impact the ability of the aged care workforce to provide high quality end-of-life care, including:

- Low pay, perceived low status and stressful workloads impact on staff recruitment and retention. There are high rates of turnover and reliance on a casual, part-time, culturally and linguistically diverse and predominantly female workforce. These circumstances in themselves do not lead to delivery of poor quality end of life care, but could be considered at times as contributing factors.

Case study - A local Care Manager (Canberra) was inducting new care workers to her RACFs. One staff member commented that she had originally tried to get work at McDonald's as the pay rates were similar, but because her English language was not good enough she decided on aged care instead.

- To deliver high quality end-of-life care often requires, though not at all times, levels of training and skill that are not recognised in the funding / remuneration of workers compared to other similarly paid roles.
- Structure and staff mix is heavily weighted in the lower paid unregulated staff (PCAs) with inadequate levels of qualified health care staff especially outside standard business hours. This again is dependent upon setting and location. Some providers do provide adequate access to registered nurses 24 hours a day, others do not. Therefore it can be suggested that care delivered can be variable in nature.
- Levels of literacy, health literacy and death literacy need to be addressed through education strategies focused on building capacity among the workforce to provide high quality person-centred care.
 - The general population has low levels of death literacy, and it is likely that levels of death literacy within the aged care workforce may be higher, but not significantly so. Death literacy is defined as a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options.

- The increasingly culturally and linguistically diverse care attendant workforce that delivers aged care services may require specific education about issues of death and dying and death literacy in general. In some cultures death and dying remain taboo subjects, and there are anecdotal stories of care attendants having not been supported in their roles to care for the dying and facing difficulty when faced with the care of a dying person.
- Workplaces should be encouraged to provide workplace English language and literacy programs (see Southern Cross Care Victoria <http://www.sccv.org.au/> who have also initiated a multicultural women’s health education program to support staff from diverse backgrounds) not only to support culturally and linguistically diverse staff but also to support the delivery of care to Australia’s diverse population. The contribution that bi-lingual staff can make to delivery of end-of-life care to communicating with residents and clients is largely underestimated.
- Insufficient systems in place to ensure aged care staff in all systems access training and ongoing professional development opportunities to ensure access and equality of treatment for older Aboriginal and Torres Strait Islander people. Because these systems are not in place Aboriginal and Torres Strait Islanders do not receive patient-centred care that recognises the centrality of culture (including family and country) to health and wellbeing, and therefore they are missing out on quality care at the end of life. (Please note: PCA supports recommendations in the joint submission to the Australian Senate Standing Committee on Community Affairs inquiry into the future of Australia’s aged care sector workforce, put forward by Australian Indigenous Doctors Association; Congress of Aboriginal and Torres Strait Islander Nurses and Midwives; National Aboriginal and Torres Strait Islander Health Worker Association and Indigenous Allied Health Australia)
- Insufficient training and education opportunities at entry level, VET level, graduate and post-graduate levels in learning about palliative care, palliative approach, communication skills, advance care planning and death and dying. Palliative care, communication skills, discussion of care goals and advance care planning and experience in these areas need to be given much more time and attention in the education curricula. This is also true of the General Practice workforce who are part of the aged care workforce team.

The role of government in providing a coordinated strategic approach for the sector

The Commonwealth is a critical player in the primary care and aged care sector, and leadership from the Commonwealth is critical in implementing a systems approach to improvements for older Australians. Currently there is fragmentation in funding arrangements in the delivery of end-of-life care for older Australians, and this can lead to cost-shifting. Palliative Care Australia’s pre-budget submission called for the establishment of a *National Cooperative for Palliative and End-of- Life Care* to be implemented as part of the national reform agenda. The cooperative would engage all governments in policy co-design for provision of end-of-life care and would provide for sharing of risks between governments to achieve the best possible service provision within currently available resources.

PCA recommends that the Australian Government agree to invest in greater palliative care support in aged care facilities in order to reduce emergency presentations, providing a saving for the states and territories through reduced hospital costs. In return the states and territories may agree to invest savings realised from potential reduced emergency presentations and bed days into supporting transitions to community care, and providing education and professional support to community care organisations, realising a benefit to the Australian Government.

Leadership from the Commonwealth is also required to facilitate alignment at the interface between policies. This includes at the interfaces between health and aged care, as well as with disability services. Such leadership may include supporting equal pay and conditions for nurses and other staff between these sectors. Commonwealth leadership is also required in the development and implementation of interfaced IT systems, to support sharing of information between different organisations responsible for the care at the end of a person's life, and also to support delivery of such care, including through telehealth systems.

Finally, the Commonwealth has a critical role in providing a strategic approach for the sector by setting minimum accreditation standards for aged care service providers. There is a need to ensure that Standards for aged care align with the relevant National Safety and Quality Health Service Standards and other national standards for the provision of care, where appropriate. This alignment is particularly important in relation to the new actions relating to end-of-life care. PCA also supports the submissions in the Let's Talk Quality Report (<https://www.aacqa.gov.au/providers/promoting-quality/lets-talk-about-quality-report-1>), which is to ensure that the Standards have a broader focus than just accreditation, and support quality improvement in a broader sense including providing support for carers and family members.

All levels of government must make end-of-life care in residential and community settings a joint priority

Government policies which have a significant impact on the aged care workforce

There are many government policies that impact the delivery of aged care services, and therefore impact the aged care workforce. Many of the primary drivers link back to the availability of funding. For example, there are funding provisions in place to support delivery of palliative care services to people both in hospitals and in the community. These include various programs implemented by state/territory governments as well as provisions in the Medicare Benefits Schedule for providing home visits and case conferencing to people living in the community that require access to palliative care. No such funding is available for residential care, and it is unclear whether clients currently receiving Home Care Packages have the opportunity to access these services either. This may lead to inequity of access to services for older people.

A primary driver in funding of residential aged care is the Aged Care Funding Instrument (ACFI). At present, there is very little evidence to assess this, particularly as it relates to residential aged

care facilities. Some organisations have expressed concern to PCA about the current funding arrangements for provision of palliative care in aged care facilities. However, there is insufficient data to assess whether these concerns are leading to poor quality end-of-life care, or whether service providers are able to work within the funding that is available. Such concerns include:

- A lack of clarity on the activities to be scored under the palliative care item in the Aged Care Funding Instrument (ACFI)
- A lack of alignment of the ACFI with contemporary approaches to palliative care
- No additional funding is available for provision of a palliative care program to residents where a score of 10 has already been reached
- There is no funding mechanism in the ACFI for facilitating advance care planning and case conferencing.

PCA recommend the conduct an audit of the quality of deaths in aged care facilities. The audit would identify the services that are provided under the current ACFI and the family experience with the death of their family member. Data analysis would include consideration of whether specialist palliative care support was provided, and if not, whether the aged care facility thought it would have been beneficial, the number of emergency department presentations and hospital admissions, and whether an end-of-life care pathway was commenced. The study would provide benchmarks to assess the impact of future changes to the way palliative care is provided, while also identifying areas for improvement to guide future policy and program development.

The recent Let's Talk About Quality Report (Australian Aged Care Quality Agency 2015) recognises the need to incentivise what matters – that is while minimum standards of quality care are important, there is a need to recognise psychological and spiritual wellbeing as quality factors. This aligns with PCA's call to provide time for staff to engage in conversations with residents and their families about their goals of care and to confirm an existing advance care plan or document an advance care plan if one is not already in place. At present, the ACFI does not provide a funding mechanism for the important work of aged care staff in facilitating advance care planning (ACP) and case conferencing, and supporting the workforce to undertake this important work will be crucial to increasing the quality of deaths in RACFs.

Government policies relating to MBS items also affect the provision of aged care in Australia. Providing MBS funding for provision of medical services by GPs and palliative care specialists in aged care, and by improving discharge arrangements from hospitals to aged care facilities, all assists in preventing avoidable readmissions.

The Commonwealth government must:

- **commit to conducting an audit of the quality of deaths in aged care facilities**
- **better resource end-of-life specific activities such as case-conferencing, psychological and spiritual wellbeing, and grief and bereavement support**

Challenges of creating a culturally competent and inclusive aged care workforce

Aged care staff (Registered Nurses, Personal Care Attendant and other staff) must be offered training and ongoing professional development opportunities in cross cultural awareness training to enable them to have respectful conversations with residents from CALD backgrounds and their families and to understand the cultural and spiritual needs appropriate for their residents or clients. These conversations take additional time and they may require the use of interpreters who should be briefed about the content of the conversation prior to the meetings occurring.

With regard to the provision of aged care to Aboriginal and Torres Strait Islanders, the current National Aboriginal and Torres Strait Islander Flexible Aged Care Program Quality Standards requires each service user to have a documented care plan that addresses their identified care needs and preferences, including a cultural support plan which describes how assessed needs and service user preferences will be met in a culturally safe way. While this Standard appropriately reflects the approach to care that is needed, there is a paucity of publicly available data to demonstrate performance against this Standard. Data that is available does show a difference in demographics between people in RACFs who identify as Aboriginal, compared with non-Indigenous residents. Aboriginal and Torres Strait Islanders were overall under-represented on the basis of use per population in residential aged care, but over-represented in all aged groups under 75, with the highest number of Indigenous aged care residents being under 65. (AIHW n.d.) Providing appropriate care that is based on cultural safety and cultural respect has a basis in international human rights (see Articles 21, 23, 24, and 29 in the United Nations Declaration on the Rights of Indigenous Peoples). The *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* (NATSIHP) commits the Australian government to ensuring that the Australian aged care workforce, now and into the future, is positioned, capable and supported in meeting the unique health and wellbeing needs of older Aboriginal and Torres Strait Islander Australians. Action on this vision should see an improvement to the quality of end-of-life care for Aboriginal and Torres Strait Islanders.

A similar standard and approach also needs to be adopted for other vulnerable and/or minority groups, including the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) population. Provision of aged care to LGBTI people can be complicated by the discrimination that older LGBTI Australians may have experienced as they were growing up. Implementation of the action areas identified in the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy will be important to continue to realise improvements in this space.

Aged Care Workforce will need to:

- **Receive cross cultural awareness training**
- **Develop an understanding of cultural respect**
- **Develop skills in identifying the unique needs of Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds and people who identify as LGBTI**

Aged Care Organisations will need to:

- **Ensure their workforce is equipped to meet the unique health needs of Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds and people who identify as LGBTI**

Aged care workforce challenges in regional towns and remote communities

There are specific sets of challenges facing the rural and remote aged care workforce. Delivery of aged care services, including palliative care and end-of-life care, in rural and remote settings must, like metropolitan and regional areas, be inclusive of greater choice and equity. The challenge is how to achieve these things close to where people live, ensuring culturally appropriate aged care. In considering the aged care workforce requirements in rural and remote settings consideration of the flexible use of workforce requirements in Multi-Purpose Services ought to be made as well.

Remote aged care services rely on specialised programs to deliver services to remote settings. The Royal Flying Doctors Service for example provides primary health care across Australia through its telehealth and GP and nurse clinics. This specific remote workforce must be provided opportunities for training and professional development in the area of delivery of end of life care and palliative care in a remote setting.

A significant challenge in providing high quality end-of-life care in regional, rural and remote communities is the reduced access to specialist palliative care services. Specialist palliative care services as currently funded do not have sufficient capacity to provide direct service across all areas or provide the level of consultancy services needed. In regional centres there are specialist palliative care services available, but these are not spread equitably across the nation.

Case Study - A family member made a request of an aged care facility about their loved one who was a resident there, about accessing palliative care. They were advised that specialist palliative care provided a consultancy role only in respect of aged care residents and that they are not able to be involved in the person's day-to-day care. The family member indicated that this would not be adequate as the aged care staff at the facility are too stretched to provide adequate palliative care on a day-to-day basis. The family requested information about access to a private palliative care service so that the family could arrange for the care provided by the aged care facility to be augmented. (Location, Victoria. Date, 8 February 2016)

It is important to have ready and timely access to specialist palliative care advice, equipment and practical suggestions to support local provision of end-of-life care. The possible lack of services to support the aged care service in the delivery of end-of-life care increases the importance of ensuring the aged care staff are well-trained in providing end-of-life care. Providers in rural and remote areas should be supported to access specialist palliative care advice if and when required. A means to do this is through the existing Decision Assist national phone advisory service.

Aged Care Organisations in regional towns and remote communities must:

- **Provide opportunities for training and professional development in the areas of end-of-life care and palliative care**
- **Provide mechanisms and support for staff to access specialist palliative care advice when needed**