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The investment in research relating to palliative care for people living with a life-limiting illness is an issue of high importance to Palliative Care Australia (PCA). PCA is the national peak body for palliative care, and represents all those who work towards high quality palliative care for all Australians. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, with the primary goal of optimising quality of life. End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers are higher at this time and this phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This encompasses the terminal phase (when the patient is recognised as imminently dying), death and extends to bereavement care.

Historically, it was assumed that palliative care would commence only once all treatment aimed at 'curing' people had finished. Now, it is well-accepted that there is benefit in providing palliative care concurrently with disease-modifying therapies in response to changing needs of people living with a life-limiting illness. It is also recognised that many people with life-limiting illnesses are not 'cured', but continue to live with these illnesses for many years¹.

PCA have identified the following gaps in knowledge and capacity across the healthcare system and research pipeline that we consider need to be addressed in the 2018-2020 MRFF priorities, particularly given the impending release of the National Palliative Care Strategy and increasing recognition by governments of the need to address issues relating to palliative care in Australia.

Research into the impacts of early referral to palliative care for non-malignant life-limiting illnesses

There is substantial evidence that early referral to palliative care following a life-limiting illness diagnosis has substantial benefits for the patient, their families and the health system generally. The integration of palliative care early in the course of an illness trajectory can improve

¹ PCA (2018) Palliative Care Service Development Guidelines

symptoms and patient quality of life, reduce aggressive care at the end of life, increase patient-centred advance care planning, reduce hospital length of stay and hospitalisations overall, and improve caregiver quality of life².

The most recent data from the Palliative Care Outcomes Collaboration (PCOC) indicates that 75% of referrals to palliative care are for a cancer diagnosis with the remaining 25% for non-cancer (non-malignant) diagnoses³. However, of the 160,000 deaths in Australia each year only 30% are from cancer, due to earlier detection and improved treatment options. The leading cause of death in females is actually Dementia, and the leading cause of death in males is coronary heart disease⁴.

Non-malignant life-limiting conditions such as Chronic Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), Renal and Liver Disease, Dementia, Diabetes, Multiple Sclerosis, Motor Neurone Disease or HIV/AIDs are very amenable to palliative care interventions⁵. Despite this, while people with chronic life-limiting conditions have symptoms as severe and distressing as those of cancer patients, they often do not have equal access to palliative care. The majority of studies on the costs of palliative care have only included populations with an advanced cancer diagnosis and not individuals with non-malignant conditions⁵.

The cost-effectiveness of palliative care for patients with other chronic life-limiting conditions may differ and therefore should be investigated. Research is needed to:

- Develop best practice models of care, from the time of diagnosis, where a physician treating a non-malignant life-limiting condition incorporates palliative care into their treatment and/or works with specialist palliative care physicians to coordinate care.
- Establish an agreed set of criteria or processes for referral to palliative care which will be promoted across Australia.
- Monitor and record improvements or changes in quality of life, use of clinically non-beneficial treatments and ICU presentations, life expectancy and experiences of the patient and their carers working within different models of care and at different points in the illness trajectory.

Evidence for off label use of medicines in palliative care

'Off-label' prescribing occurs when a medicine is prescribed for an indication, a route of administration, or a patient group that is not included in the approved product information document for that medicine, and is common in specialised care settings⁶. One of the elements of palliative care is the treatment of pain and other symptoms. In order to do so many palliative care clinicians incorporate off-label use of medicines in their treatment of patients as it is the only viable option⁶. Examples include the use of morphine for dyspnoea (shortness of breath)

² PCA (2017) The Economic Value of Palliative Care and End-of-Life Care webpage

³ PCOC Palliative care services at a glance, 2017 data tables [last reviewed 9 July 2018]

⁴ Australian Institute of Health and Welfare 2018. Deaths in Australia. Cat. no. PHE 229. Canberra: AIHW.

⁵ PCA Economic Research Note 5, July 2017 'The Economic Benefits of Integrating Palliative Care and End-of-Life Care Into Chronic Disease Management'

⁶ Council of Australian Therapeutic Advisory Groups. Rethinking medicines decision-making in Australian Hospitals. Guiding principles for the quality use of off-label medicines. Council of Australian Therapeutic Advisory Groups; 2013.

and use of Haloperidol or Olanzapine for nausea, with shortness of breath and nausea two of the most highly distressing symptoms experienced by palliative care patients.

In palliative care units in the United Kingdom, approximately 25% of prescriptions are off-label⁷. Palliative care clinicians use their experience of off-label use of medicines to benefit patients but there is a lack of supporting research and evidence to guide clinicians within a regulated regime. Further research in this area is needed to increase the evidence supporting off-label medicine use and examine risk-benefit ratios. This could lead to the current off-label usage of medicines being recognised in the indications, dose, and route of administration or patient group set out in the TGA-approved Product Information (PI). This would have flow-on benefits to palliative care patients in relation to potentially accessing the Pharmaceutical Benefits Scheme (PBS) and other pharmacy reimbursement options.

Research into the health system benefits of grief and bereavement support

Support for those experiencing grief can be from many informal and professional sources. While many who experience grief will not require professional services, evidence suggests that approximately 7% will develop prolonged grief disorder⁸ and will benefit from targeted specialist services. This need remains constant regardless of socioeconomic status or geographic location.

PCA expect that all providers of palliative care (including general practitioners) have the capacity to assess where family members and carers sit along a continuum of need for bereavement support and refer accordingly. However, in practice referral for grief and bereavement support does depend on the provider, the locality and capacity to pay.

There are many gaps in knowledge regarding:

- What level of grief and bereavement support is needed in different situations and for what length of time.
- The impact that grief and bereavement services have on improving physical and mental health wellbeing and ability to maintain active engagement in the workforce, study and other community obligations.
- The specific needs of Indigenous Australians, people from culturally and linguistically diverse communities and people who have experienced trauma.
- The impact of death and dying within the workplace.

⁷ Australia and New Zealand College of Anesthetists. Faculty of Pain Medicine 'Use of "off label" or drugs beyond licence in pain medicine'

⁸ PCA and Australian Centre for Grief and Bereavement. 2018 'Policy Statement: Grief & Bereavement'