

**Hunter New England LHD Palliative Care Clinical Stream's response to the Parliament of Australia Senate Community Affairs Committees Inquiry into Palliative Care in Australia**

**Parliament of Australia Senate Community Affairs Committees**

**Palliative Care in Australia**

**Terms of Reference**

**The provision of palliative care in Australia, including:**

**(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:**

**(i) people living in rural and regional areas,**

- Lack of specialist palliative care services and beds in rural areas;
- Existing rural and remote palliative care services coordinated by Clinical Nurse Consultants who share the care with community nursing service – counting this activity and attributing it to the correct service is complex and time-consuming. It is therefore difficult for services to demonstrate the need for additional resources based on incomplete activity statistics.
- Extensive amounts of travel required to visit patients over sparsely populated areas;
- Overall low number of allied health staff employed in rural areas affects availability to palliative care patients;
- Pressure on specialist palliative care services in regional areas limits the number of patients that can be serviced;
- Ageing nursing population – lack of succession planning;
- Lack of policy framework for the management, supply and governance of medication after hours;
- Lack of endorsed policy for non-medical staff to certify extinction of life – which results in un-necessary distress for family and carers when a doctor is unable to attend and issue a death certificate and a crime scene is established;
- 24 hours / after hours service provision is not possible due to sole practitioners or small teams covering a large area or work safe issues;
- 24 hours / after hours advice hotline is not able to be safely established due to fragmented clinical information, paper based records, disparate information systems;
- Variable access to general practitioners – varied experience and expertise in the management of palliative patients;
- Access to services to support patients to stay at home e.g. specialist loan equipment; volunteer support; respite services;
- Travel and accommodation from home to facilities for treatment & consultation;

**(ii) Indigenous people,**

- Require culturally appropriateness of services to be offered;
- Late diagnosis of advanced disease may limit the opportunity for a referral to be made / acted upon prior to death – improvements in screening rates and earlier diagnosis would help increase referral rates;

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- Lack of specialist palliative care services in remote and rural areas, which have a significant indigenous population, limits the services that can be offered / provided locally to patients with complex burden of symptoms and complex care needs (especially in a non-admitted setting);

### **(iii) people from culturally and linguistically diverse backgrounds,**

- Access to interpreter services;
- Knowledge of different cultures attitudes to death and dying may be limited;
- May not be aware of potential services;

### **(iv) people with disabilities, and**

- Where possible, palliative care for people with disabilities is integrated within 'mainstream' services – clients needs are assessed and addressed;
- Consultations, education and support is provided to specialist residential facilities to ensure that staff are well supported in caring for disabled patients;
- Assessment and management of symptoms for clients with severe disabilities is most effectively done in partnership with the clients regular carers who have established effective communication;
- Provision of palliative care to patients with mental health issues, including dementia, may be limited;
- The issue of long term care and respite for patients who are young but who require full time nursing care, but who have a life limiting illness rather than a disability. Finding suitable long term accommodation for such patients (i.e. stable glioblastoma, patients with advanced HIV etc) is an area greatly overlooked. Such patients are required to seek care in Residential Aged Care Facilities either long term or for respite. This process has been dependant upon the ACCR delegate being prepared to facilitate such pathways without needing to undertake referrals via the adult disability pathway, first. Often placing such patients who have a foreseeable prognosis in such facilities can be distressing and might be deemed to be inappropriate for this client group.

### **(v) children and adolescents;**

- Specialist paediatric palliative care services provided in HNE are done so on a consultation liaison basis. It is difficult to count and report this activity and it is therefore hard to demonstrate the extent of the service provided;
- There is a lack of recognised standard assessment tools for use with paediatric palliative care patients;
- Paediatric palliative care is not classified in the Sub- and Non-Acute Patient (SNAP) classification and is not part of the Palliative Care Outcome Collaboration (PCOC) which hinders services ability to benchmark their services;
- Provision of specialist loan equipment to support paediatric patients is limited;

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- Transition between specialist city services and rural home locations poses challenges;

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

- Specialist paediatric palliative care services provided in HNE are done so on a consultation liaison basis. It is difficult to count and report this activity and it is therefore hard to demonstrate the extent of the service provided;
- Paediatric palliative care is not classified in the Sub- and Non-Acute Patient classification;
- Existing rural and remote palliative care services coordinated by Clinical Nurse Consultants who share the care with community nursing service – counting this activity and attributing it to the correct service is complex and time-consuming. It is therefore difficult for services to demonstrate the need for additional resources based on incomplete activity statistics;
- Reporting palliative care activity across inpatient / outpatient / consultative services is time consuming and is fragmented resulting in an unclear picture of the total amount of care provided for patients;

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

- Specialist palliative care services are best used to provide input in the management of the more complex patients. The bulk of palliative care is currently, and will need to continue to be, provided by non-specialist services with the support of specialist palliative care if required;
- Non-specialist services need to be adequately trained and supported to provide non-specialist palliative care;
- Adopting a structured approach to assessing a patient's needs supports the ability for services to identify and address the most pressing issues regardless of the setting.

**(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;**

- Care needs to be available in the setting of choice, where practical and safe. This includes low and high level care aged care facilities. Low care RACF are not currently staffed adequately to provide this level of care;
- Palliative care patients living alone, or with an elderly spouse, in the community require significant support to be able to die at home. At least 2 other people need to be able to provide support 24 hours per day during the terminal phase;
- There is a lack of palliative care provided by the private sector.

**(e) the composition of the palliative care workforce, including:**

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**(i) its ability to meet the needs of the ageing population, and**

- Specialist palliative care services alone will not be able to address the shortfall of services for an ageing population. Whilst they will be able to contribute to a strategy to address what is required, a plan needs to be developed that defines what services can be provided, in what settings and identifies who will be best be able to provide the different levels of palliative care required.

**(ii) the adequacy of workforce education and training arrangements;**

- Succession planning and an attractive career path need to be defined to ensure that a career in palliative care is considered by new graduates;
- Adequate resources, education and support are required to ensure that staff are equipped to deal with complex needs of palliative care patients.

**(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians;**

- Demonstrated compliance with the standards across all care settings will highlight any gaps that can be addressed;
- Participation in programs such as NSAP and PCOC enables services to benchmark their services and to undertake quality improvement measures.

**(g) advance care planning, including:**

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

- Improved communication between patients, their carers and clinicians underpins the success of advance care plans;

**(ii) national consistency in law and policy supporting advance care plans, and**

- A national approach to advance care planning is needed to avoid confusion in regard to language and local interpretations;

**(iii) scope for including advance care plans in personal electronic health records; and**

- Strategies are needed to ensure that advance care plans are dynamic documents which reflect the current needs and wishes of patients;
- Tamper proof electronic signatures and robust audit trails would be needed to ensure non-repudiation of the contents.

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### **(h) the availability and funding of research, information and data about palliative care needs in Australia.**

- In order to understand the gaps in care, resources to routinely collect information at the point of care must be in place. Such information allows not only an individual patient's needs to be identified and tracked, and this information to be used clinically to inform treatment, but also allows population level data to be considered. Such data allows research to be more easily conducted;
- It is of note that in terms of physical symptom control, support from the Federal Government has allowed establishment of a robust research group who are now attracting funding competitively at local, state and national levels. In order to advance palliative care research in other areas of care, a similar program driven by population needs would be of benefit.

### **Other comments**

- It would be worthwhile to examine if those cohorts under represented in Specialist Palliative Care Services are being offered a referral to palliative care and, if so, why these referrals are being declined.
- It may also be useful to ensure that people from culturally and linguistically diverse backgrounds are identified as such in patient administration systems.
- There is dilution of funding and duplication of effort through various not-for-profit organisations providing support for palliative care patients and their carers. This has resulted in organisations 'competing' to assist some patients with 'popular' conditions (such as breast cancer) whilst others struggle to find any assistance. It is also sometimes very difficult for patients and their carers to obtain simple practical support or appropriate loan equipment that would enable them to die at home with comfort and dignity.
- There are a number of non-PBS-listed drugs currently in use to ease the burden of symptoms experienced by dying palliative care patients. However, the (often high) costs associated with the use of these drugs must be either borne by the patient or by the prescribing service.