

## **Submission to Senate Enquiry**

### **Senate Inquiry into 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,
- (ii) Indigenous people,
- (iii) people from culturally and linguistically diverse backgrounds,
- (iv) people with disabilities, and
- (v) children and adolescents;

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

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

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

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

- (i) its ability to meet the needs of the ageing population, and
- (ii) the adequacy of workforce education and training arrangements;

(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;

(g) advance care planning, including:

- (i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,
- (ii) national consistency in law and policy supporting advance care plans, and
- (iii) scope for including advance care plans in personal electronic health records; and

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

### **Submission**

The South Australian Cancer Clinical Network would like to comment particularly on Terms of Reference item a) the system of access to palliative care. Our interest is in relation to access for cancer patients in both the public and private health systems in South Australia. Close to 50% of patients with cancer are on a journey which is, or has become non-curative and 80% of patients cared for by palliative care have cancer. The interface therefore between cancer and palliative care services is therefore vital.

The Cancer Clinical Network commends the palliative care service providers in South Australia for the excellent work they generally do in

1. helping the patient understand what support services there are for patients with a life-threatening malignancy both at diagnosis or at the stage when prognosis is poor because of poor response to treatment.
2. dealing with end-of-life support issues particularly in providing home help and/or transiting to hospice.

They are also generally very good at reminding clinicians that for patients approaching end-of-life, quality of life and simplifying care are more important than quantity when considering continuing treatment with high toxicity potential.

The main challenges in SA in the management of patients with non-curative cancer are:

1. How to achieve an effective shared care model with oncologists and haematologists in the period between diagnosis with a poor prognosis/poor treatment response and end of life. . This is particularly relevant in haematological malignancies where the disease trajectory could be quite different from that in solid tumours, ie, patient may be attempting more aggressive treatment when the disease is not responding to or relapsing after initial treatments, eg, transplantation after initial induction chemotherapy for leukaemia and lymphoma, or when a number of new agents in clinical trials are available to patients with poor prognosis myeloma. For instance, the patient may be continuing to receive active treatment particularly via clinical trials yet their life-expectancy would be short so palliative care teams are called in. While the aim is to prepare the patient for possible failure and end-of-life, there is not necessarily an intention to stop acute care. The consequence is that patients may become confused by apparently conflicting pictures from the haemato-oncologists and from the palliative care team.

Concerns also include the failure of some hospice services to develop documented and effective care plans for hospice patients when they transition back to the community setting. The result is that the patient may end up unnecessarily back in the acute care facility.

2. Access to Palliative Care medical specialists in SA is subject to gate-keeping. Even referrals for patients with urgent, specialist, end-of-life palliative care needs are not guaranteed acceptance although early referral is frequently and strongly urged. It is clear that there is not a sufficient palliative care workforce to deal with early referral of all patients, and it is difficult to have a situation where patients with acute, pre-terminal needs are “competing” for resources with patients earlier in their disease.
3. Informal evidence indicates that very few palliative care practitioners, with the possible exception of those trained in Victoria and NSW, have experience with haematological malignancies compared with their familiarity with malignancies which involve medical oncology and/or radiation oncology interventions. Training requirements may therefore need to be reviewed. At the same time, haematologists often contribute to the problem by referring too late. More proactive discussions between palliative care specialists and haematologists would be highly desirable to achieve better patient outcomes.
4. A further issues is how best to look after patients requiring in-patient care after active treatment ceases and yet before they reach hospice phase. At present these patients end up in acute hospital wards which is a sub-optimal outcome. This arises because even when acute hospitals do have palliative care in-patient beds, further gate-keeping is undertaken to manage workload. This exposes the mismatch between (falsely raised) expectations and delivery.
5. There is significant variation in service quality and accessibility across the state. In some parts of South Australia there is frustration with the incapacity of palliative care services to deliver what is promised and would in fact be ideal. Where there are resourcing restrictions the Cancer Clinical Network

believes it is important to be honest about the impact of these so that better alternatives than presentation to emergency departments can be set up.

In some local health regions there has been limited engagement to date between the community care and palliative care sectors and the acute sector towards resolving these problems. Efforts continue.

The Network notes that an evaluation is near completion of a pilot alternate model of service delivery in SA for the management of overnight emergencies involving palliative patients via a paramedic intervention program. The outcomes of this model of care should be taken into consideration in future service planning.