Barwon Health Response to Parliamentary Inquiry into End of Life Choices
July 2015

THEMES, ISSUES AND CHALLENGES

This submission is provided by the Barwon Health Palliative Care Program in response to item 1 of the Inquiry into End of Life Choices - 'How current medical practices and palliative care can assist a person manage their end of life'.

1. Palliative Care Program Limitations:

1.1 Respite

Limitation of, and access to, at-home and urgent or elective inpatient / residential respite:

- Activity Based Funding (ABF) would result in less revenue for respite care.
- Families often take on more intense caring roles if they are offered booked regular respite. Knowing there are periods of respite available helps them with the knowledge and confidence that they will cope with the responsibilities. Without respite care being available, carers/families are often torn between Residential Aged Care Facilities (RACFs), which in itself is a stressful process or placing their family member in a palliative care unit for longer periods. This raises uncertainty and causes distress about how families/carers will manage. It may also have significant financial impacts on carers who have limited access to carer leave.
- When palliative bedded services are at capacity then a carer crisis, such as inter-current illness, often results in utilisation of ED attendance and temporary acute inpatient care until a palliative care bed becomes available. This can occur frequently. Possible further loss of patient function may result, which complicates discharge planning and can cause delays. Delays in discharge creates difficulty in access for other patients.
- The availability of a range of respite services for carers/families to use has been shown to increase the likelihood of a home death, or if the person is an inpatient, death in a palliative care unit rather than acute bed. Having patients in a bed appropriate for their condition contributes significantly to health services' ability to manage access and flow for all patients.

1.2 Preferred Place of Death

Respecting people's wishes, as far as reasonably practicable, is a critical part of providing exceptional quality end of life care. Place of death is an important part of this, however, there are many factors that limit achieving preference for death at home if that is the patient's wish. Barwon Health data for 2013-14 revealed that 52 per cent of people did not die in their venue of their preference. Reasons for this include:

- Service constraints, particularly during the terminal phase, when significant physical care may be required for short periods, or during a period related to an unstable symptom such as delirium.
- Carer capacity: this is particularly true for elderly frail carers with no other social support and those patients who live alone.

- Medication management can be a particular issue for carers with visual or cognitive impairment or in RACFs when ‘as needed’ medications such as analgesia are needed but cannot be dispensed by facility staff.

1.3 Palliative Care Unit Capacity issues

- If preference for death is a palliative care unit, when beds are not available, then there is considerable risk (and reality) of palliative patients dying in an acute hospital bed or the Emergency Department.
- Barwon Health data from 2005 has shown that 2500 bed days were occupied with people waiting for a palliative care bed following palliative care specialist assessment.
- Numerous patients, often with acute sudden events such as stroke, die in acute facilities despite an overt wish to take a palliative approach. This is frequently due to the lack of rapid access to palliative care beds. If available palliative care beds are at another location medical staff face dilemmas about the appropriateness of transporting patients. The exceptions are those organisations with acute palliative care beds on site at the main campus.
- Significant numbers of patients state their preference for care to be in a specialist palliative care unit. However as there are insufficient beds in this type of unit, many remain in an acute facility, which is not optimal to their care, nor consistent with their preferences.
- The inability to “fast-track” palliative care patients to a designated palliative care bed has resulted in a high number, 58% of patients known to community palliative care services, attending the ED during the last 90 days of life. This resulted in 358 presentations to the ED during last 90 days. They spent a total of 2566 hours in the ED before being transferred to another care venue. This can have a major impact for the patient, and their family, particularly if they are close to death. In addition it has resource implications for an ED which may already be at capacity. This was despite a 24/7 specialist on call service being available to the ED.
- Patients known to palliative care frequently are admitted for acute care. For Barwon Health during 2013/14, approximately 60% of community palliative care patients had an acute inpatient admission in the last 90 days of life. This amounted to approximately 600 admissions. Of note:
  - 22.8% had 3 or more acute episodes in that time
  - the highest number of admissions by an individual patient was 18 episodes
  - the time occupied in acute beds following these admissions (2300 bed days) may have been better for the patient by being in a designated palliative care bed.
    - This is a large cohort of patients in oncology wards who may be better off in a palliative care ward. They often remain there to get access to “acute” services such as pain interventions, palliative procedures requiring operating theatre time, radiotherapy, diagnostic imaging or other specialist medical consultations.

2. Patient Cohorts with Limited Access to Palliative Care

A small, but significant number of people require complex palliation in an appropriate environment for medium term periods:

- This may apply, in particular, to patients who have a progressive neurological condition, such as MND, spinal cord compression (high disability with relatively long prognosis), and primary brain tumours (particularly Glioblastoma Multiforme {GBM} & Gliomas).
- They can often be of a younger age group, with dependent children, complex financial stressors, and have high physical and complex cognitive and psycho-social care needs.
- Such patient cohorts may require medium term stays, which can sometimes be of many months duration. A Palliative Care Unit is not the most appropriate place for these patients, and there is no recognised public funding stream to accommodate it. In addition, residential aged care may not be appropriate as it may not have the correct skill mix, timely access to key professional disciplines or have staff who are confident about the rapidly changing care needs for the patient and carers.
- Many family members and carers are concerned about, and become distressed at the prospect of a transfer to a 'standard' RACF despite the ability of Palliative Care experts to provide regular support to the staff, which is necessary due to the complex nature of their loved one's illness.

Frail and elderly patients with several co-morbidities:

- The role of specialist palliative care for this broader cohort remains unclear and the funding model could act as a negative incentive to providing complex one off secondary consultations to this cohort at home or in RACF.
- Linkage with aged care services and shared models of care should be further explored and developed, particularly in light of the ageing population.

3. External Partnerships and Factors

There is a need to consider the relationship between palliative care and primary care, particularly with regard to response to secondary consultation in the changing face of primary care with more 'corporate' GP services and a decreasing proportion of GPs doing home visits and out of hour's on-call:

- Facilitating partnership models fostering collaboration between primary and palliative care will enable more people to access a wider range of services and secure a more seamless approach to provision of care.

Variability of access to palliative care input into the private healthcare sector:

- This is improving but remains constrained by the variability of referral patterns and investment by the private sector.

Variability in palliative care and the palliative approach in Residential Aged Care Facilities (RACF):

- In-reach provision is variable though when available can have a dramatic and positive impact on residents' ability to stay in their residence when that is their choice.
- There is a large variation regarding systems and processes to assist non Barwon Health facility staff to make appropriate decisions at time of clinical deterioration. Often,

particularly out of hours, locum medical cover have a low threshold to send a deteriorating patient to the Emergency Department
- Variable access and referral to specialist palliative care to augment care provision for people with complex palliative needs.

There has been significant growth in the prevalence of concurrent disease modifying treatment including maintenance and targeted treatment:

- More disease modifying treatment may contribute to later referrals to palliative care. This results in the program being reactive rather than proactive.

Data Source: Barwon Health Data Warehouse Reports

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This submission is provided by a Barwon Health Volunteer/Consumer Representative/Carer in response to item 1 of the Inquiry into End of Life Choices - 'How current medical practices and palliative care can assist a person manage their end of life'.

I believe current practices in palliative care can assist a patient to come to a sense of completion in all aspects of life before their death. This may affirm death as a normal process.

Dying well (where possible) is a humanitarian right. Good palliative care focuses on a holistic approach to dying. These current practices include not only pain management and other distressing symptoms of dying but also the support of spiritual, psychological, social, legal and cultural needs. This supports the person dying and also their care giver and family members.

This has been evident to me as a volunteer on the palliative care ward for the last 9 years. Part of my support service is massaging and listening to peoples expressing their deepest feelings.

What I believe makes effective palliative care is when resources are made available to educate and train clinicians in communicating with the dying.

Every dying person (and their family) has the right to make choices and be treated with dignity and honesty in a non-judgemental way.

When Advanced Care Planning and My Values have been completed these documents are a starting point for choice. The benefits of written choices not only help clinicians in medical choices but are beneficial for the dying person and after the death for the bereaved family knowing that their loved ones wishes have been respected.

Christine Corby
Barwon Health Volunteer/Consumer Representative/Carer

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This submission is provided by the Respecting Patient Choices Program in response to item 3 of the Inquiry into End of Life Choices – 'Potential changes to our legislative framework".

From an ACP perspective and in respect for a person's self-determination and autonomy, our recommendation is:

- Consideration to amend the Medical Treatment Act 1988 regarding "Refusal of Treatment Certificate (RoTC)" (Schedule 1: Competent & Schedule 3: Non-competent), to remove the limitation re "current condition".

Through our Advance Care Planning program, we have been providing assistance for our health service consumers and wider Barwon community for some 10 years.

Based on this extensive experience, we believe the Medical Treatment Act is remiss in that it does not acknowledge that the frail and elderly may wish to exercise their autonomy and refuse treatments, in all circumstances, and in particular in the absence of a "current condition".

In addition, where a person refuses treatment, for example Cardio-Pulmonary Resuscitation (CPR) in the setting of heart disease (current condition), they may receive CPR as a treatment for another presenting condition which is likely against their wishes. This is due to the fact that under the current legislation, it is the "current condition" that the person is refusing treatment for. Should the person present with a different diagnosis, the existing RoTC does not pertain to this 'new' condition as is not listed on the previous RoTC. A new RoTC must be completed.

It would be ideal to provide greater legal weight and acknowledgment to individual's preferences, other than that of a RoTC, such as a 'common law' document in the form of a letter or formal 'Statement of Choices' so that there is a clear process of the obligations of treating Doctor's in respecting a person's autonomy.

There is confusion around the legalities and obligations regarding the common law document which can lead to distress for all parties concerned, including treating medical officers, care staff, families and consumers of our service. There can be devastating and lasting effects when the consumer's preferences are not followed or indeed ignored.

The following is feedback via client "experience" cards (feedback):

"I think the refusal of treatment (certificate) should always be offered to those with very strong views on not wanting intervention."

"As the Ambos are often first on the scene they must access our ACP's & wishes before attending. I have heard of attempting CPR on those who have stated to wives & husbands of not wanting CPR but they have not even asked the partner in the home & commenced same. And God help us who live alone. This must be addressed, it terrifies me."

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