Royal Commission into Aged Care Quality and Safety

PERTH HEARING: PALLIATIVE CARE

Common Ground Propositions

Palliative Care Generally

1. Death is a natural part of life and most people die an expected death at an older age due to complexities of frailty and other co-morbidities.

2. Australians pay little attention to death: to quote Dr Reymond, we tend to "focus on living rather than on dying" [71]. Where we do discuss death, many of us express a preference to be cared for or die at home, just as most of us want to receive aged care services at home.

3. The WHO definition of Palliative care is commonly and appropriately used in many policy documents in Australia: Reymond, [12(a)]. This is an approach to care that improves the quality of life of patients and their families, facing the problem associated with life threatening conditions through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual

4. Palliative care is most effective when considered early in the course of an illness which not only improves quality of life but also reduces unnecessary hospitalisations and use of health care services.

5. Palliative care is often misunderstood, focussed on dying. It is not the same thing as end of life care. Where end of life care proceeds from a prognosis base, palliative care proceeds from a person's needs basis and is not time constrained.

6. A tenet of quality palliative care is that it is that it is always adapted to the individual needs and identity of the person receiving care, i.e. that it is person-centred.

7. Palliative care extends the concept of person-centred care beyond the patient, as palliative care recognises a unit of care, usually composed of the person and their family/significant others.

8. Palliative care is care that is provided by all health and aged care professionals involved in supporting people living with life-limiting illness, their families and carers. It is often delivered via a multi-disciplinary team approach with a team which may consist of nursing and care staff, primary care staff primarily GPs, allied health professionals as required and may, depending on the circumstances, extend to aboriginal health workers, pastoral care workers, dieticians and others.

9. Ideally, all such health professionals, including care workers, should have as part of their base competencies and skills the ability to care for people living with a life-limiting illness.

10. Not everyone needs specialist palliative care. Specialist palliative care is for people with complex and persistent needs or intermediate and fluctuating need. Specialist palliative care is provided by a specialist palliative care team with specialist skills, competencies and training.

11. There is presently a disconnect between national and state/territory aged care policies and downstream clinical strategies and service provision. Aspirational statements are not matched by service resources.

12. Despite Australia's aging population meaning that we are dying with more co-morbidities and correspondingly higher palliative care needs, most of those needs can be catered for by generalist clinicians working in the community if they have the support when needed from specialist palliative care services.

13. However, there is a lack of specialist palliative care capacity due to underfunding which is exacerbated by an increasing number of deaths annually.

Palliative Care in the Aged Care Sector

14. Because 80% of people aged 65 or over who die in Australia have used at least one aged care program, aged care has a significant role to play in the delivery of palliative care.

15. Palliative care cannot and should not be considered an optional extra within the aged care system. It needs to be an integral part (core business) of any aged care service.

16. Good palliative care in aged care includes a collaborative decision-making approach that encompasses the life experiences and preferences of the individual, their family and the expertise of all clinicians and support providers involved, while recognising that agreed goals of care may change overtime.

17. The aged care system does not currently support optimal provision of palliative care. The focus within aged care policy and systems is generally limited to care provided in the last few days or week of life. This is driven in part by clinical care funding limitations under the Aged Care Funding Instrument (ACFI) which focusses on end of life care

18. These limitations mean that it is not possible to identify with precision the number of people receiving palliative care or who have access to specialist palliative care within residential care because the ACFI payments data do not reflect the number of residents who either need palliative care or receive palliative care.

19. A significant number of residents are transferred from aged care settings to hospitals or hospices for palliative care and / or end of life care. Transfers also occur from hospitals or hospices to aged care settings, for palliative care. The extent and appropriateness of such transfers is difficult to quantify because of the fragmented and incomplete palliative care data.

20. Early completion of advance care planning documents by a patient strongly contributes to delivery of patient-centred palliative care. This should not be confused with completing an Advance Care Directive, which only come into effect when someone loses capacity.

21. The following aspects are also important to delivery of palliative care in aged care:

(a) community awareness of death and dying and palliative care;
(b) access to different models of Specialist Palliative Clinical care;
(c) an aged care workforce trained in palliative care;
(d) the involvement, understanding and support of family and carers in palliative care; and
(e) grief and bereavement support for the aged care workforce, family and carers

22. Palliative care must be provided across all environments of care, including (though not limited to) hospitals, people's homes, correctional facilities and residential aged care environments.

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