

“A planning guide”: developing a consensus document for palliative care service provision

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IN JUNE 2003, Palliative Care Australia (PCA) released an outline (“a planning guide”)¹ of the population-based resources necessary to provide palliative care services in Australia. In this world first, PCA, through evidence and consultation, has created a blueprint to guide service planning over the next decade. Resources outlined in the planning guide are independent of budget-holders and local models of care. The guide aims to ensure that a network of health professionals with skills in supporting people with life-limiting illnesses is available to patients who need it.

Why was the planning guide necessary?

Although palliative care is often perceived to be relevant only to elderly people who are dying of cancer, this is too narrow a view of the current and potential benefits of palliative care. As it is a recently developed area of specialised clinical care, attracting adequate resources for the development and evolution of palliative care is a challenge.

In Australia, the palliative care team generally comprises the patient, caregivers (family and friends) and primary health professionals (general practitioner, community nurse and allied health practitioners). The number of palliative patients seen by most GPs is small.² For patients with complex needs, the involvement of an interdisciplinary specialised palliative care service, working alongside primary clinical carers, is likely to be of benefit.³

Although the federal government has now developed a national palliative care strategy for planning palliative care services,⁴ there are still wide variations in equitable access to services. There are differences in funding at state and territory level, and there is no agreement among funding agencies on the health disciplines necessary for delivering quality palliative care. PCA’s planning guide¹ was developed to encourage a more consistent approach to workforce planning, service planning and bed needs, and to improve patient and carer outcomes. The guide should be a useful working document for service providers, health planners, and funding and professional bodies.

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ABSTRACT

- Over the past 30 years, palliative care services have developed in an ad-hoc way in Australia and around the world.
- Community expectations for palliative care have grown in recent years.
- As palliative care has evolved, the World Health Organization definition of palliative care has changed substantially. The changes challenge those who are involved in planning, funding and provision of services to meet new expectations.
- Many services have not attracted adequate nursing, medical and allied health resources to provide interdisciplinary palliative care.
- A national consensus document (“a planning guide”) has been developed in consultation with key stakeholders and organisations. It outlines the minimum needs for service provision, independent of fundholders and models of service delivery.

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Service development

Although palliative care services have been evolving in Australia over the past 25 years,⁵ most of the development has been *ad hoc*. In the 1970s, services were offered for a small number of people who chose to refuse aggressive treatment in the terminal stage of their lives. Today, many people with life-limiting illnesses benefit from the involvement of specialised palliative care teams, and patients need not have exhausted all disease modifying treatments before accepting referral for palliative care.⁶ The proportion of dying patients who access palliative care services continues to rise.⁷

Service evolution

Palliative care is a young specialty and continues to evolve internationally. Significant advances that have occurred in the understanding of palliative care in recent years are reflected in the differences between the 1990 and 2002 World Health Organization definitions of palliative care.^{8,9} The latest WHO definition does not mention diagnosis or prognosis, but focuses only on the needs of the patient, caregivers and professional carers.¹⁰ A report by the National Cancer Control Initiative, *Optimising cancer care in Australia*, acknowledges the need for timely involvement of palliative care services in the management of many people with cancer.¹¹ Palliative care is now also offered to people with AIDS, end-stage organ failure and neurodegenerative diseases.

Estimated minimum staffing levels for professional support of interdisciplinary palliative care in the community, acute-care settings and palliative care units by discipline, expressed as full-time equivalent staff

Discipline/staff category	Community-based services*	Acute-care hospital consultative service [†]	Designated palliative care beds [‡]
Palliative care specialist [§]	←	1.5	→
Registrar [§]	←	1.0	→
Resident medical officer	0	0	0.25
Liaison psychiatry	←	0.25	→
Clinical nurse consultant [§]	1.0	0.75	0
Registered and enrolled nurses [§]	0	0	6.5 hours per patient per day
Discharge liaison	0	0.25	0
Psychology	0.25	0.1	0.1
Social work	0.5	0.25	0.25
Bereavement support	0.25	0.1	0.1
Pastoral care	0.25	0.25	0.25
Speech pathology	0.2	0.2	0.2
Dietitian	←	0.2	→
Physiotherapy	0.4	0.2	0.2
Occupational therapy	0.4	0.2	0.2
Pharmacist	0	0.25	0.1
Other therapies [¶]	0.5	0	0.25

* Full-time equivalent staff per 100 000 population served.

† Full-time equivalent staff per 125 hospital beds.

‡ Full-time equivalent staff per 6.7 beds, whether in an acute-care setting or in a freestanding palliative care unit or hospice (6.7 palliative care beds per 100 000 population would be needed).

§ Assumes that these roles in the community are consultative, with well resourced primary clinical care (general practitioners and community nurses).

¶ Includes combinations of music, art, complementary, narrative and diversional therapies.

In the deliberation process, it was accepted that the GP and community nurse are the primary clinical carers, and that if a person does not speak English they should have access to healthcare interpreters.

Having collected the data, a small national interdisciplinary team drafted a consensus document that was circulated to state and territory palliative care organisations for comment. Incorporating changes, the document was circulated to more than 30 national consumer, professional and community organisations for comment, modification and endorsement. A final consensus document was then produced.

Main messages of the planning guide

The planning guide acknowledges that there are patients with a life-limiting illness who do not need to see specialised palliative care services and whose GP and community nurse can provide comprehensive support. Current utilisation rates and best estimates suggest a model in which 90% of people dying of cancer will need an assessment by a specialised interdisciplinary palliative care service and that 70% of people dying of cancer will benefit from ongoing contact with the team. For people with a non-cancer life-limiting illness, the estimates are 50% and 30%, respectively. A small proportion of people would need to be cared for in an inpatient setting by specialists.

An estimate of the minimum human resources required to provide adequate palliative care services in Australia is presented in the Box. For medical staff, there is a need for adequate training positions while services are developing. The number of senior staff (registrars and consultants) is similar to the number required in many other areas of internal medicine, but the ratio at the moment is weighted towards registrars. In the field of nursing, adequate nursing hours per patient per day for inpatients continues to be a major issue. Clinical and educational support for primary care nurses in the community and hospitals is very labour-intensive.

Allied health practitioners are under-represented in Australian palliative care services. Given that the aim of palliation is to optimise levels of comfort and function, and in view of the emotional, social, existential and physical challenges for many people with life-limiting illnesses, the input of psychologists, bereavement support staff, occupational therapists, physiotherapists, speech pathologists, dietitians and specialist pharmacists is crucial. Complementary and diversional therapies, including art, music and narrative therapy, also have a role.

Given the reliance on volunteers in palliative care services, paid coordinators with skills in people management, debriefing, support and reflective practice are needed. The planning guide acknowledges that the level of support needed by volunteers will vary depending on the type of patient contact they have.

The planning guide suggests that all staff should have professional support in the work they do.¹⁷ Staff whose work is predominantly in palliative care are encouraged to gain postgraduate qualifications in palliative care or related areas.

How the planning guide was developed

In gathering data for the planning guide, a number of approaches were taken:

- Studies and systematic reviews from peer-reviewed literature confirmed the disciplines necessary for a comprehensive palliative care service.¹²

- Services that had models of care or an area of clinical excellence nationally were consulted about staffing and other resource levels. Services that had been designed as comprehensive regional palliative care services were also contacted.

- Data from the 1998 *National census of palliative care services*¹³ and PCA's *Standards for palliative care provision*¹⁴ were taken into account.

- Data from current/projected deaths and comorbidities among the ageing population were included. Populations with special needs, including children, Indigenous people and people with culturally and linguistically diverse backgrounds, were also considered.¹³⁻¹⁶

Every clinician working in palliative care must be able to identify *all* members of the appropriate palliative care team, including people not employed by the same organisation or health service. Professionals for each of the core disciplines should be identified, and details of how to contact and interact with them should be available. In rural and remote areas of Australia, the palliative care team is more likely to be a “virtual” team, interacting with one another by telephone or video-conferencing.

The planning guide as a “living” document

Through continuing consultation with stakeholders and the community more broadly, the planning guide can evolve as a “living” document. Changes in the past decade in palliative care have been enormous, and there are likely to be similar changes in the next decade. The guide will need to be updated to reflect evidence-based advances in service delivery and any changes to levels or models of service provision in primary healthcare. It will need to be revised as each discipline better defines its contributions to palliative care. Services and health systems may use the guide as a benchmark to refine the original estimates. More broadly, the continued evolution of society’s attitudes to death and dying will influence demand for palliative care.

As the palliative care workforce stabilises, the ratio of registrar positions to consultants will decrease. As national palliative care curricula for all health science courses are adopted in Australia, we will, in years to come, see a workforce better prepared for the complexities of palliative clinical practice.

National scoping studies in palliative care provision, paediatric and Indigenous palliative care, and competency based guidelines for providing palliative care in residential aged-care facilities are all nearing completion. The findings of these studies will inform future editions of the planning guide.

The guide can provide the basis for a needs-based model of service provision that can be used nationally and linked with outcome measures for patients, caregivers and professionals. Documents dealing with these specific issues are currently being developed. Ultimately, the guide should improve the access of patients and caregivers to palliative care services and lead to improved quality of care.

The planning guide engages, in a single document, all groups who need to be represented in the planning process. It is essential that all disciplines involved be given a voice before negotiation for resources begins. The successful handling of such a process may provide a template for the development of other services.

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Competing interests

None identified.

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