

A Guide to

Palliative Care Service Development:

A population based approach



PALLIATIVE
CARE
AUSTRALIA

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Front Cover Design: The conceptual design of the front cover represents the multilayered, unique and interwoven roles primary health care and specialist palliative care services have in providing high quality end of life care to all Australians.

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president's foreword

The Council of Palliative Care Australia is pleased to present a national policy document, *A Guide to Palliative Care Service Development: A population based approach*. This guide has been developed in consultation with members of the palliative care community. It suggests a plan for providing equitable access to palliative care in the context of efficient, effective and ethical use of resources. It also recognises the quality and extent of care currently provided by primary care providers and complemented by specialist palliative care services.

As outlined in the *National Palliative Care Strategy*¹, the development of appropriate networks between primary health care providers and specialist palliative services is crucial for the provision of palliative care to all Australians. In many areas, these networks are already delivering excellent, coordinated care. As palliative care services continue to develop throughout Australia, we anticipate this guide will provide one of the

cornerstones in developing new networks and strengthening those networks already in place.

This guide needs to be read in conjunction with the *Palliative Care Service Provision in Australia: A Planning Guide*² and the *Standards for Palliative Care Provision*³, the standards are currently being revised. In these three documents PCA has provided the framework for needs-based and equitable access to quality end-of-life care.

PCA is keen to further build towards the vision of quality care for all Australians at the end of life, and looks forward to continuing to work with the whole community in achieving the vision. I commend this document to you as an integral step in the development of palliative care and hope that it will provide you with a practical tool in your organisation's practice.



Professor David Currow

President

- 1 Commonwealth Department of Health and Aged Care – National Palliative Care Strategy: A National Framework for Palliative Care Service Development. Commonwealth Department of Health and Aged Care, Canberra, 2000.
- 2 Palliative Care Australia – Palliative Care Service Provision in Australia: A Planning Guide (2nd Edition). PCA, Canberra, 2003.
- 3 Palliative Care Australia – Standards for Palliative Care Provision (3rd Edition). PCA, Canberra, 1999.

definitions

A number of terms are used in this document, and their meaning is described below:

The term **life limiting illness** is used to describe illnesses that can be reasonably expected to cause the death of the patient within a foreseeable future. This definition is inclusive of both a malignant and non-malignant illness. Life limiting illnesses might be expected to shorten an individual's life. This differs from chronic illnesses where, even though there may be significant impact on the patient's abilities and quality of life, there is likely to be a less direct relationship between the illness and the person's death.

The word **patient** is used to describe recipients or potential recipients of palliative care. People with a 'life limiting illness' is also used in this document to describe the same group of people where the context and language flow allow for it.

The **primary carer** is generally in the close kin network of the patient, and is usually self identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, eg administration of medications. They provide the primary support role for the patient at all levels of need.

The **family** is defined as those closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets).⁴

⁴ Adapted from Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A model to Guide Hospice Palliative care. Canadian Hospice Palliative Care Association, Ottawa, ON, 2002, p 92.

The use of the term **primary care providers** in this context is inclusive of general practitioners, community nurses, staff of residential aged care facilities and multipurpose centres. It also includes other specialist services and staff, for example oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals and services. These staff, while specialists in their own areas, may undertake an ongoing role in the support of patients with a life limiting illness. In this context they are seen as the primary care service with specialist palliative care services involved on an ‘as required’ basis only. In general the substantive work of the primary care provider is not in palliative care.

Specialist palliative care service is used to denote a multi-disciplinary health care service whose substantive work is with patients who have a life limiting illness as defined above. Specialist palliative care professionals would be expected to have recognised qualifications or accreditation in palliative care. Specialist palliative care services provide consultative and ongoing care for patients with a life limiting illness and provide support for their primary carer and family during and after the patient’s illness. In general, specialist palliative care services would not be directly involved in the care of people who have uncomplicated needs associated with a life limiting illness.

introduction

Escalating community concern with the quality and cost of health care in Australia places health care services under increasing pressure to deliver high quality, cost effective services. Health care services are expected to be well coordinated with clearly defined roles, which are, as far as possible, not duplicated. Services must also recognise and respond to community need and expectation, including those of disadvantaged, marginalised or culturally and linguistically diverse groups. Palliative care services are not exempt from these pressures.

Facing the consequences of a progressive, life limiting illness can exhaust the physical and emotional resources of patients, primary carers and their families, and indeed can also deplete those of the health care professionals who care for them. It is important in a caring and compassionate society, that health and social support systems are developed to ensure that the needs of all these people can be appropriately supported.

The success of community and public health education about palliative care has meant that more people now expect to be able to access palliative care.

Palliative care services are under pressure to accept increasing numbers of patients as community awareness grows, and express concern about their capacity to meet projected demand over the coming decade. Changes in clinical practice and policy in other clinical specialities (aged care and oncology for example), have also influenced patterns of referral and impacted on palliative care service development over the past decades.

Palliative Care Australia (PCA), as the national peak body for palliative care, has previously developed *Palliative Care Service Provision in Australia: A Planning Guide* and the *Standards for Palliative Care Provision* to provide a framework for the ongoing development of palliative care policy within the health care system. The palliative care standards have been recently revised following a national consultation project funded by the Commonwealth Department of Health and Ageing. This document provides a context within which the revised standards and the resource guide can be interpreted and applied. Taken together, the three Palliative Care Australia documents represent a compendium of resources

which provide guidance for the development of palliative care at a national, state, regional and service level.

As we better understand the needs of people living with a life limiting illness, it has become clear that not all dying people need, or indeed desire, the same type of level of access to specialist palliative care during the course of their illness. Many patients' needs can be, and are currently, appropriately and adequately met through the existing and ongoing relationship with their primary care practitioner or service.⁵ Even when patient or family needs are such that specialist care is needed, it is likely to be episodic rather than sustained care that is required. It can be estimated that in Australia in 2002 of all the deaths that occurred (approximately 134,000) about half, or sixty four thousand, could

have been reasonably expected to be due to their diagnosed illness.⁶ Currently specialist palliative care services are involved in the care, on average, of approximately 37.5% of the total number of people who are expected to die each year.⁷

Not all patients for whom death is expected will need specialist care. From the data and information currently available, it is difficult to ascertain whether those patients whose needs are greatest are in fact those receiving care from specialist services. Similarly we do not clearly understand if the needs of people whose deaths might be expected and who are not seen by a specialist are appropriately or adequately addressed.

Clearly palliative care and support should be available to patients and their families in such a way that ensures that they have access to an appropriate level

- 5 The use of the term primary care providers in this context is inclusive of general practitioners, community nurses, staff of residential aged care facilities and multipurpose centres. It also includes other acute care hospitals and services. These staff, while specialists in their own areas, may undertake an ongoing role in the support of patients with a life limiting illness. In this context they are seen as the primary care service with specialist palliative care services involved on an 'as required' basis only. In general the substantive work of the primary care provider is not in palliative care.
- 6 Aust Institute Health & Welfare – Latest Mortality Data 2002 (sourced November 2004) available at www.aihw.gov.au/mortality/data/current_data.html. The number of 'expected' deaths has been extrapolated from cancer and IHD mortality figures. Prognostic reliability is greatest for patients with cancer with less clinical reliability for non-malignant diseases. However to provide a rough estimate of the size of the target population for palliative care services a proxy measure that only includes all cancer and all IHD deaths has been used. Significant work is currently being undertaken to improve prognostication in heart disease and IHD disease has been incorporated in the 'expected death' group on that basis.
- 7 Projection based on number of palliative care patients shown in Palliative Care Australia – State of the Nation 1998 – Report of National Census of Palliative Care Services. November 1998.

of care when, and where it is required. Service networks need to be able to respond to a diverse range of needs, from the simple and uncomplicated to those that threaten to consume the resources of specialist, interdisciplinary teams. In addition, there is a need to build capacity within our social and public health systems to reduce the future burden on patients, primary carers and families and to work collaboratively with local communities and groups to foster community self-sufficiency.

Community education and other public health approaches require strengthening to enable communities, patients, primary carers and families to better understand and cope with dying and death as a natural part of life. Establishing and maintaining genuine partnerships between communities and health service providers at all levels is pivotal to this.

Anecdotal evidence suggests that the greater majority of patients will have reasonably uncomplicated needs for most of the time following their diagnosis and therefore may not require ongoing care provided by a specialist service. For these patients care provided

by their usual general practitioner or primary care provider will be adequate and appropriate to their needs most of the time. There will always be a smaller proportion of people within this group who will experience severe or complex problems associated with their advancing illness. These problems can and do often include and affect the primary carer and family, and in some cases extend out to include the whole community. These patients, primary carers, families and extended communities require access to specialist palliative care services to provide episodic or ongoing care in partnership with their primary care providers to meet those needs.

This policy document has been developed to be used alongside the *Palliative Care Service Provision in Australia: A Planning Guide* and the revised *Standards for Providing Quality Palliative Care to all Australians*.⁸ These guides have been developed to support policy makers, funding bodies, and services as they continue to build a world class palliative care service in Australia - where every person receives high quality, compassionate care equal to their needs.

8 Palliative Care Australia – Standards for Providing Quality Palliative Care for all Australians (4th Edition). PCA, Canberra, 2005. Currently being developed.

defining the palliative care population – a needs based model

The terms ‘population’ or ‘population based’ have increasingly been used in health care to describe a range of specific approaches to service planning and delivery. Populations for the purposes of health service planning are usually defined on the basis of geography, for example all people resident in nominated areas, regions or jurisdictions, by medical conditions (cancer, non-cancer, HIV) or by other clinical needs. **A population based service planning approach seeks to understand and plan for the health needs of the target population as a whole, and to implement and evaluate interventions to improve the health or well being of that population.**

In population based approaches to care delivery, individual patient care is provided within the context of the culture, health status and health needs of the entire population of which that patient is a member. **When planning care for a population, as distinct from caring for an individual member of that population, health services are accountable for measuring outcomes for all members of the targeted population, including those who may not, for a variety of reasons, access services.**

This is largely what differentiates population based planning models from traditional, individual patient-centred service plans and/or models.

Population based approaches have been used to plan and deliver services for people with a wide range of health conditions and diseases, including tobacco dependence, breast cancer, diabetes, asthma and chronic heart failure.⁹ By thinking in terms of whole populations at the planning stage, services have collaborated to provide the means and resources to implement systems and processes of care that have lead to improved outcomes for whole populations of patients, as well as for individual members of those populations.

9 For examples visit www.health.gov.au/campaigns.htm or www.thecommunityguide.org.

The core target population for palliative care delivery services is made up of those people who have a progressive and advanced life limiting illness,¹⁰ their primary carer and family. For public health initiatives and health promotion activities the entire community becomes the target group. For the purposes of population based service planning it is proposed that all people with a life limiting illness (including their carer(s), family and community) be conceptualised as falling within three broad sub-groups, based on the complexity of their needs (see figure 1).

Currently, based on the best available estimates, the total size of the population represented in Figure 1 is approximately 64,000 people per annum whose death can be expected. Just over 37.5% of these patients are currently seen by palliative care services. These patients are distributed between sub-groups B (those patients requiring consultation care) and C (those requiring ongoing specialist care). It is unclear how they are proportionally distributed between sub-group B and C.

¹⁰ For the purposes of this document the term life limiting illness has been used to describe those patients who may require palliative care. Access to specialist palliative care services and/or resources should be based on the secondary criteria of level of assessed need.

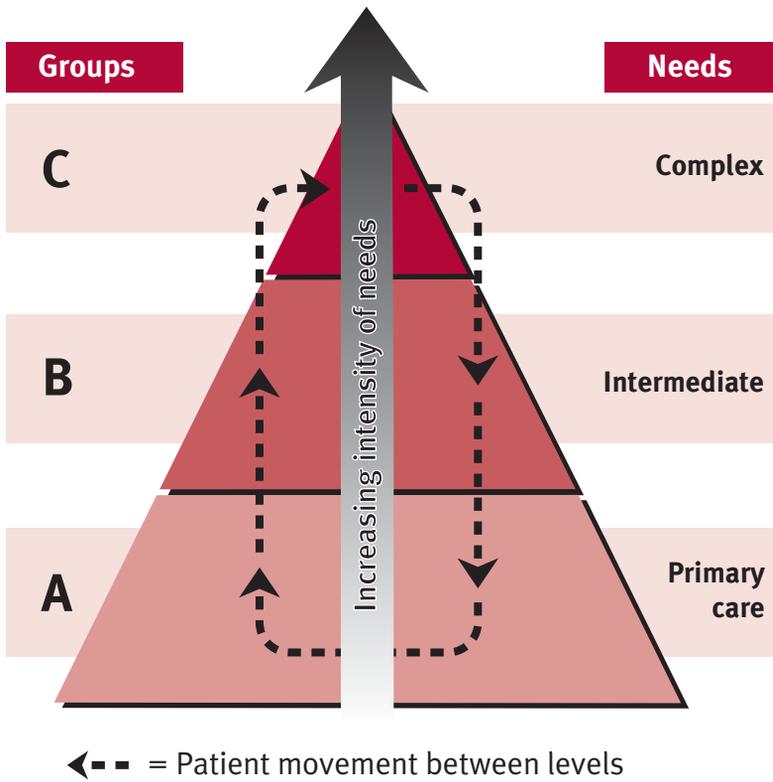


Figure 1: Conceptual model of level of need within the population of patients with a life limiting illness.

describing the sub-groups

Sub-Group A

The largest sub-group (A) is those patients who do not require access to specialist care to meet their needs which are met either through their own resources or with the support of primary care providers, (for example generalist medical and nursing services as well as other specialist staff – oncologists, cardiac services, geriatricians and so on). Currently, almost two-thirds of all people whose death is expected, fall within sub-group A and are not seen by a specialist palliative care service prior to their death. The majority of these patients would be expected to have a diagnosis of a non-malignant disease as the proportion of cancer patients who are seen by a palliative care services tends to be much higher. It is anticipated, when the entire population of patients is taken into account, that this group would represent the largest of the three identified subgroups in the target patient population.

Sub-Group B

Some patients with a life limiting illness will have sporadic exacerbations of pain or other symptoms or may experience social or emotional distress. These patients may have a temporary increase in their level of need and may require access to specialist palliative care services for consultation and advice. They will continue to receive care from their primary care provider.

Sub-Group C

Palliative care patients who have the greatest needs are often those with complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. These patients represent a variable but minor proportion of all those people who are living with a life limiting illness. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers. This sub-group (C) is likely to be the smallest of the three sub-groups of the population.

Population based approaches in palliative care employ needs-based referral thresholds to guide decision-making about access to specialist care. The goal is to achieve high quality and cost effective care appropriate for each sub-population and for each of the individual patients within that group.

the need for palliative care

Patient, primary carer and family needs, balanced with an assessment of their individual and collective strengths and limitations, are the criteria used to determine access to appropriate levels of care for patients with a life limiting illness.

All people diagnosed with a life limiting illness, as an absolute minimum, require access to primary care providers that have knowledge and skills in the care of people with a life limiting illness. These skills, attributes and knowledge applied within the context of a primary care relationship are sometimes referred to as a 'palliative approach'. A palliative approach is based on the basic principles of palliative care, adapted to recognise and reflect the different expertise, experience and resources of primary care providers working with patients who have been diagnosed with a life limiting illness.

Specialist palliative care services may be required to assist the person with a life limiting illness at times when they experience problems of increased complexity or acuity beyond the capabilities of the primary care provider or service. For most people this is likely to be episodic need for specialist care, provided in partnership with their primary care team. A patient may expect to access specialist services on a number of occasions while receiving ongoing in care from their primary care providers.

Figure 2 demonstrates a number of possible scenarios for a person with a life limiting illness based on their needs, and their individual strengths and limitations or those of their primary carer and family. In order for this kind of access to services to be positive, care needs to be well coordinated, with a clear understanding of the roles of the various service levels, and effective communication between service providers.

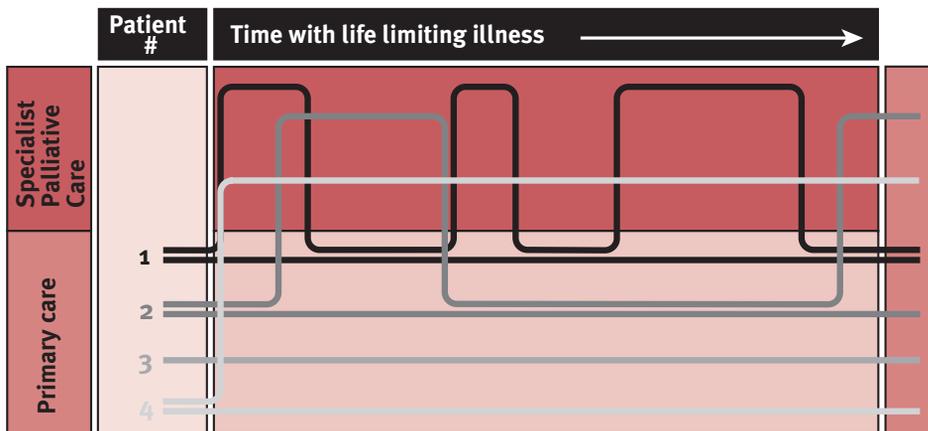


Figure 2: Episode of care scenarios to meet palliative care needs.

A number of access pathways need to be in place for patients, primary carers and families requiring palliative care support. Many patients receiving primary care will already have an established and ongoing relationship with their primary care provider. For these patients, a palliative approach will be introduced as part of the ongoing and comprehensive care they are already receiving. Access to primary care providers will generally utilise existing referral and relationship mechanisms.

Access to specialist palliative care will ideally be based on referral from a primary care provider, however palliative care services need to have mechanisms in place to respond to self or family/carer referral. Access to specialist palliative care should be based on complexity or intensity of need and these services should have established assessment and referral protocols in place.

a palliative care service planning framework for australia

For some time palliative care practitioners and other service providers have been aware of the need for a clear, consistent and nationally endorsed framework for the provision of palliative care to guide service planning and provision at all levels of health care.

Limited guidance as to effective service models or organisational frameworks is currently available to support service planners and/or providers who have the responsibility for establishing or developing palliative care services. Consequently, considerable diversity exists around the country in the ways that health services have sought to provide access to palliative care for the communities they serve.

This document describes a service planning framework that has been developed to provide assistance to health service planners, funding bodies and care providers to ensure that health care services are designed to meet the needs of the population, so that:

- all people who have a life limiting illness are able to access timely, high quality care appropriate to their needs¹¹
- all care offered and received is consistent with the person's level of need
- all needs, not only physical needs, are considered in determining access to specialist care
- resources are appropriately distributed across the health care system and utilised based on level of need, and
- all health professionals have an understanding of the public health, primary and specialist domains of palliative care and how they interact with each other.

¹¹ Needs: requirement for professional support where demands placed on the patient, primary carer and family exceed their available capacity for self care.

This framework for palliative care service planning incorporates generalist and specialist health care providers and specifically seeks to:¹²

- ensure that palliative care is provided based on assessment of needs
 - encourage primary and specialist providers to see themselves as a part of a single continuum/system delivering palliative care to the entire community
 - provide a framework that will support the development of systems and processes for information sharing and decision making
 - ensure the delivery of care accords with evidence-based protocols
- improve communication between primary and specialist palliative care providers
 - better understand the utilisation of palliative care services and use this to predict future need
 - effectively and appropriately manage demand for specialist palliative care services, and
 - identify cost efficient and effective ways to increase service capacity to meet identified needs.

¹² Adapted from UK NHS' Key change principles for improving cancer care. Cancer Services Collaborative 2001, cited in National Cancer Control Initiative Optimising Cancer Care in Australia, February 2003, p 101-102.

Working together to improve care

In order for the patient, primary carer and family to receive and/or have access to required social and health care support and comforts, various individuals and services must be available and be well coordinated.

The palliative care service planning framework provides a collaborative inclusive model that incorporates care provided by primary and specialist providers. It describes the relationships and coordination of care between the multiple providers and service levels on a population basis. The model is driven by the hierarchy of patient, primary carer and family needs, and attempts to align services to most appropriately, effectively and efficiently meet those needs. The palliative care service planning model is illustrated in figure 3.

Within this model, formalised links between generalist and specialist health care providers will ensure all people with a life limiting illness have a right of access to services appropriate to their particular needs. It is also expected that, ultimately, better use of resources, improved quality of care and improved demonstrable outcomes will be achieved as a consequence of the implementation of the framework. In addition, it is anticipated that improved coordination of care, better relationships between care providers and clearer role delineation will result from implementation. Figure 3 describes the relationship between the primary care provider, specialist services and patient needs.

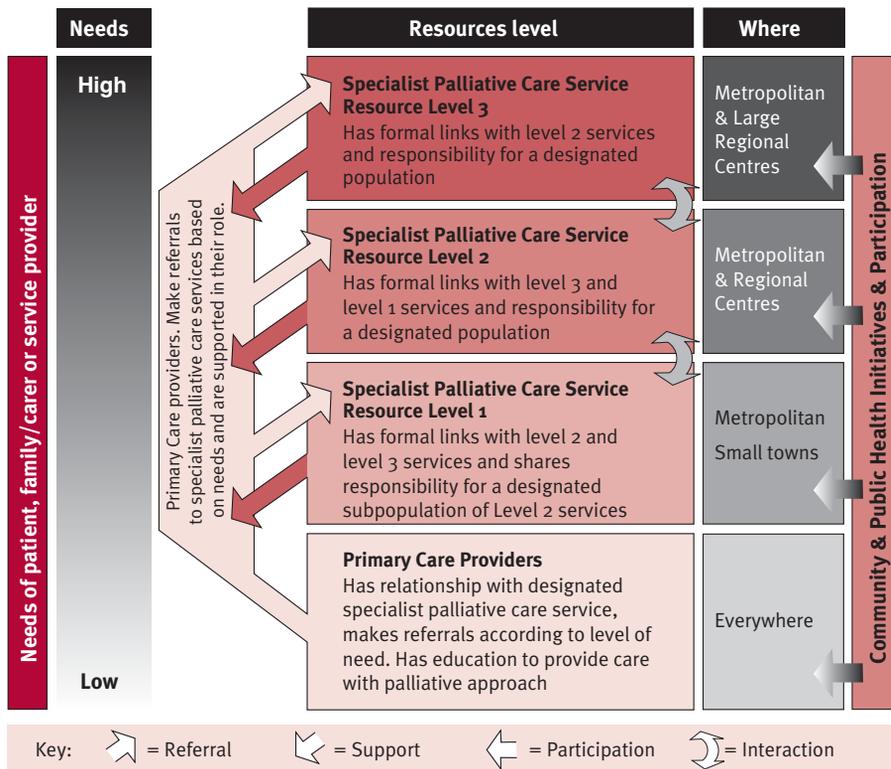


Figure 3: Framework for palliative care service planning

Benefits of the Model

There are a number of identifiable benefits anticipated from the implementation of the framework, in summary:

- the model is driven by the level and intensity of patient, primary carer and family needs as well as their strengths and limitations, rather than by organisational and service structure or objectives, or by traditional patterns of service delivery
- the model operates across all clinical settings and incorporates care provided by primary and specialist providers
- the role and importance of primary care providers in the care and management of dying patients, primary carers and families is fully recognised and supported
- the resource requirements of dying patients cared for outside of specialist palliative care services can be measured and included in resource and funding plans
- the model recognises and respects the relationship between primary care providers and patients, primary carers and families
- the skills of primary care providers are enhanced through increased and formalised opportunities for collaboration, education and experience presented in the model
- relationships between services involved in providing care to dying patients are clearly articulated, improving coordination and integration of these services.

The palliative care service planning framework involves the role of the patient's primary carer, family, community and public health initiatives, primary and specialist palliative care. These are discussed in the next sections.

The framework articulated in this model incorporates a number of levels at which care is provided and organised. These include the broad community and public health initiatives in palliative care, and incorporate discussions around determining need. The role of the patient's family, friends and local networks has always been a cornerstone of palliative care and the contribution they make must be recognised and included in all service planning activities.

Likewise primary care providers play a central and critical cornerstone role in the care of people living with a life limiting illness. They are, and will continue to be, full and effective partners in the provision of supportive end of life care to the majority of people who die of an expected illness.

Specialist palliative care services play an important role in a population based framework for service delivery and community care. This role in general provides additional support to both patients and their primary care providers when needs exceed the resources available to them. Specialist palliative care services support the population through the provision of education, research as well as through the provision of expert consultative and ongoing care.

A discussion of the role of each care provider is given in the following section.

community and public health initiatives in palliative care

Where death, dying, loss and grief are concerned, there is potential for everyone in the community to be affected.

Palliative care and health promotion providers may work with workplaces, schools, clubs, trade unions and local government to design joint programs that increase public awareness of topics of importance to dying people, their primary carers and families. Topics might include: stigma and social rejections; lack of long term support for grief; the importance of support in the workplace for cycles of treatment or tiredness; or the need to support carers of someone who is dying. There are also important educational needs that community and public health initiatives can address, for example: accessing and understanding the role of local palliative, bereavement or community health services; positive grieving; positive aging; maintaining a healthy lifestyle while living with a life limiting illness ; HIV/AIDS and cancer sex education; or hope and health promoting social activities with religious groups, recreational clubs, day hospices and nursing homes.

Community and public health initiatives bring about changes to social settings and attitudes. They are designed to be implemented in creative and supportive environments outside direct services. Public health initiatives also build or enhance a community's capacity to share the responsibility for dying, loss and palliative care in partnership with formal, professional care.

Although death is inevitable, many of the social, psychological and spiritual issues that can accompany it are not. Community and public health initiatives in palliative care are joint programs developed by palliative care services in partnership with their local communities to reduce these possible harms.

The great majority of people who live with a life limiting illness spend most of their time – not in treatment centres or in the cradle of direct service provision – but at home with their primary carer, friends, co-workers or family.¹³

Some spend their time in nursing home facilities or in remote indigenous communities, while others are itinerant. Public health initiatives send targeted messages to the widest number of settings to reach those who live with a life limiting illness, dying, loss or grief in settings outside conventional family homes and acute care settings.

A number of key principles underpin all public health initiatives in palliative care. These principles are linked to the *PCA Standards for Providing Quality Palliative Care to all Australians* and *Palliative Care Service Provision in Australia: A Planning Guide* and express the minimum expectations for any community and public health service development in palliative care:

1. Evidence of a community development or community capacity building strategy in palliative care services. These may take the form of simple activities such as a school education program about death, dying, loss or grief; or perhaps a poster campaign designed with a large employer group. Much community capacity building results from direct experience with a primary carer, close friend, partner or family member with a life limiting illness.
2. Social activities developed by a service in partnership with their local community to demonstrate that such activities can promote prevention or harm-minimisation. These should be early intervention activities that aim to prevent the social harms that may be derived from either living with a life limiting illness, experiencing loss or grief. Where such harms cannot be prevented, the social activity should as a minimum demonstrate that they reduce the negative impact.

¹³ Rhodes P & Shaw S. – Informal care and terminal illness – Health Soc.Care Community, 1999; 7: p 39-50. Cited in Hudson P. – Home-based support for palliative care family/carers: challenges and recommendations. Medical Journal of Australia, 2003, 179 (6), p S35-S37.

3. Social activities developed by a service demonstrate that such activities are genuinely the result of a partnership with key community organisations (eg workplaces, unions, schools, councils, clubs etc) and not simply a service driven educational drive.
4. All such activities need to be able to demonstrate how a setting or environment has been altered to improve or better care for people living with a life limiting illness, loss or grief.
5. All such activities need to display sustainability. Programs should not be dependent on ongoing support from services but display community ownership and maintenance after their initiation.

The efforts described above will make it possible for all people diagnosed with a life limiting illness, and those who care for them, to have access to a seamless level of support from their communities and their service providers when facing death, dying and loss and during all phases of their primary and/or specialist professional care.

Scenario – Public health care

Michael is a 12 year old boy whose mother is receiving palliative care. His school teachers have been told about Michael's circumstances and offer him class-time flexibility and pastoral support to allow him to tailor his attendance around cycles of his family's needs. Several family members also host Michael for some weekends to support his parents' need for some occasional time alone. When Michael's mother dies the school offers to send a small group of staff and students to the funeral as a gesture of further support – a gesture gratefully accepted by the family in his case. A year later Michael and his family join a school memorial service in memory of all significant losses from the school's history. Michael is aware of all these patterns of support because his school had a policy developed by staff and students in partnership with the local palliative care service about caring for each other in times of serious illness, death and loss.

the role of the patient's primary carer

Living and dying at home has been widely acknowledged as a desirable alternative to inpatient care for many people during the terminal phase of an illness, providing both quality of life from the patient's perspective and efficient use of resources from the perspective of the health care system. All community based palliative care services in Australia (along with many other community based area health services) are established on the basis of reliance upon care provided by a member of the patient's family, friends or community. Indeed the single most useful predictor of home death for those who would prefer this is the presence of a carer at home.¹⁴ This care may be provided on a full or part time basis, but often involves a live-in relationship with the patient.¹⁵ The absence of a carer means that the chances of being cared for at home until death may be limited.^{16 17}

In the development of a framework for service delivery and planning it is necessary to clearly define the contributions of primary carers, to ensure that they contribute in a way that does not place an inequitable and overwhelming burden upon them. It has been found that up to three quarters of primary carers for terminally ill patients have chronic health problem themselves.¹⁸ There is also a tension in the relationship between the palliative care service and the patient's primary carer. The primary carer is at once an individual with their own needs, emotional and spiritual responses and a care provider, part of the team involved in supporting and caring for the patient. Recognition and acknowledgement of these dual roles will ensure that primary carers are both enabled in their caring role and cared for themselves.

14 Maida V – Factors that promote success in home palliative care: a study of a large suburban palliative care practice – *Journal of Palliative Care*, 2002 18: p 282-286. Cited in *Palliative Care Australia The Hardest Thing We Have Ever Done: The Social Impact of Caring for Terminally Ill People in Australia*, 2004, p 12.

15 Australian Bureau Statistics – Disability, ageing and carers: summary of findings (ABS Catalogue No 4430.0) – 1999 and Hudson P – Demographic and health status profile of family caregivers of palliative care cancer patients (poster presentation) – 28th Annual Scientific Meeting Clinical Oncological Society Australia Congress, Brisbane, November 2001.

16 Maida V – *ibid* 2002.

17 Grande G E, Addington-Hall J M & Todd C T – Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med*, 1998, 47 (5), p 565-79.

18 Briggs H & Fisher D – Warning – Caring is a health hazard. Carers Association of Australia, 1999.

Systems that rely heavily on primary carers without adequately supporting them, or which have little regard for the potential negative impact on their health and well being, will in the end, be counter productive and inefficient both at an individual and ultimately population level. Examples of strategies to support primary carers in their role include provision of:

- information about relevant services and entitlements
- education about self care and manual handling
- access to appropriate respite
- coordination of services
- information about various symptoms and their management, and
- information and bereavement support.

primary care providers

It is important to understand what the differences are (in terms of type or level of care) between primary care providers and specialist palliative care services so that constructive and continuous care partnerships can be established in the care of patients with a life limiting illness. Primary care providers include general practitioners, community and hospital based doctors, nurses and allied health staff, and staff of residential aged care facilities whose substantive work is not in palliative care. Primary care providers, in the context of palliative care, can also be other specialist service providers, for example oncologists, general physicians, geriatricians and so on.

One of the principles underpinning this policy is the need to match service response to the identified needs of patients, their primary carers and families. For those patients who have relatively uncomplicated journeys, most, if not all, of their needs may be met by their primary care providers.

Primary care providers will need to have established and supportive relationships with specialist palliative care services to ensure their continuing development of their skills and to ensure quality of care¹⁹ so that patient, primary carer and family needs can be met.

Care of patients with a life limiting illness at the primary care level is provided by non specialist health care providers who incorporate a palliative approach into their care of the patient. In some instances patients may either not have a primary care provider, or may have a primary care provider who is unable to provide support or care using a palliative approach. In these instances it is imperative that the patient is referred to a primary care provider who is able to provide the required support.

¹⁹ Mt Olivet Community Service Ltd – Research study into the educational, training and support needs of general practitioners in palliative care – Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra, 2003, p 132-135.

Patients with a life limiting illness, their primary carers and families who are receiving care from primary care providers would be expected to have either:

- uncomplicated symptoms responsive to standard protocols of care
- carer availability
- a social support network in place adequate to meet the needs of the patient, primary carer and family
- low identified level of risk for complicated bereavement.

Key principles for primary care providers

A number of **key principles** need to underpin care provided to patients with a life limiting illness by primary care providers. These principles are linked to the *Standards for Providing Quality Palliative Care to all Australians* and express the minimum expectations of care provided by a primary care provider:

- patients, primary carers and families are provided with information to allow them to make informed choices and decisions
- patients, primary carers and families are encouraged to participate in the development of their care plan initially and on an ongoing basis
- all health care providers practice in accordance with the *Standards for Palliative Care Provision*.
- patients are referred to specialist services when needs are, or will become complex.
- primary care providers participate in learning and professional development relevant to meeting the needs of patients with a life limiting illness.

Scenario – Primary Care

Ken, a 68 year old man with a cancer diagnosis, recently died at home. Ken's wife and his two daughters were pleased that they were able to manage his care with the help of daily visits from the local district nurse. Ken's general practitioner had a long term relationship with the family and felt confident to manage Ken's medical care. He visited Ken regularly at home and was willing to allow Ken's wife to ring him after hours. Ken had few problems with symptoms, apart from some pain that responded well to regular opioid analgesics. Ken's family was well prepared for his death which happened peacefully in his own home. They were supported by their community through their bereavement.

specialist palliative care

Within a population based framework **specialist palliative care services** provide care to those patients whose needs exceed the capacity and resources of the primary care provider. Referral to a specialist palliative care service will in most cases be through the primary care provider. Specialist palliative care can be provided through consultation and support of primary care providers or through the provision of ongoing care to patients, primary carers and families with complex needs.

The availability of specialist palliative care services provides benefits to the wider health care system even though specialist services may not provide care directly to all of the people who make up the target population. Dedicated specialist palliative care services meet the needs of patients with complex or resource intensive needs that are beyond the expertise or exceed the capacity of primary care providers. Specialist palliative care is generally described as being provided through either individual patient based consultation or co-case-management with primary care providers.

Specialist services attract a critical mass of both patients with complex problems and highly skilled practitioners. In addition to the consultation and direct care roles of specialist services, which enable them to build and maintain skills, this critical mass supports the building of research capability and contributes to the better understanding of the needs of dying patients, primary carers and families wherever they may be cared for. In this way specialist services contribute to improvements in care across the entire health care system. Specialist palliative care services also provide indirect support for primary care providers through initiatives such as the development of standard protocols or guidelines for the management of commonly occurring problems, and for the development and delivery of ongoing education.²⁰

²⁰ Glare P, Auret K, Aggarwal G, Clark K, Pickstock S, Lickiss N – The interface between palliative medicine and specialists in acute-care hospitals: boundaries, bridges and challenges – Medical Journal of Australia, 2003, 179 (6), p S29-S31.

Specialist palliative care is provided in two main ways. Firstly, specialist services can provide consultation-based advice and support to primary care providers. In this situation specialist providers undertake a direct assessment of the patient and establish a plan of care with the patient, primary carer and family, and the primary care provider. The primary care provider, using criteria established by the specialist service, would undertake ongoing care and reassessment of the patient. Secondly, and much less commonly, specialist services may be involved for a longer period of ongoing care. In general all care provided by a specialist palliative care service will be provided in partnership with a primary care provider.

Patients requiring a specialist palliative care consultancy would typically experience:

- an exacerbation of a previously stable symptom, and/or
- identified needs (physical, social, emotional or spiritual) that exceed the capacity (knowledge, resources, facilities) of the primary care providers.

It would be expected that the patient would remain in the care of the primary care provider, and that ongoing care, monitoring and assessment would be undertaken by them.

Patients receiving care from a specialist palliative care service on an ongoing basis will generally have one or more of the following:

- complex pain or symptoms not responsive to established management protocols that has not stabilised following consultation
- complex psychological and/or social needs
- increased risk of complicated bereavement for the primary carer and family.

In general a specialist palliative care service should:

- develop and use evidence-based guidelines for practice for both primary and specialist levels of care
- accept referrals to assess and/or take on coordination and/or management of care for patients with complex needs
- continue to involve primary care providers in decisions related to the care of the patient
- provide opportunities for learning and professional development for primary care practitioners, including secondments, visits, formal and informal education sessions (eg PEPA program)
- undertake advanced preparation to ensure that they meet the standards for specialist care of dying patients with complex problems/needs
- in collaboration with relevant academic units, undertake and disseminate research to support the development of better practice.

The role of specialist palliative care services also includes a number of integrating leadership functions or roles, for example:

1. Development of protocols to guide the provision of care for patients, primary carers and families affected by a life limiting illness, by primary care providers

A key component of the proposed service model is the collaborative development of protocols guiding a palliative approach for use by primary care providers. These protocols need to establish referral and assessment criteria and provide specific clinical, patient management advice/strategies built around expert understanding of natural disease and end of life trajectories. The use of standard assessment criteria and the adoption of common protocols of care will establish minimum standards for quality of care. The development of palliative care protocols to cover commonly occurring symptoms and problems will ensure patients have access to responsive evidence based care wherever they receive it. These protocols could be developed at a local, state or regional level to reflect service and population needs and issues.

2. Development and provision of learning opportunities for both primary care and specialist palliative care providers

The development, dissemination and adoption of common protocols of care will ensure that a national standard of care exists for palliative care patients. The protocols need to be accompanied by a comprehensive education and training package developed for all health disciplines. An important role for specialist palliative care services will be the ongoing provision of education for both specialist palliative care and primary care providers to ensure that the standard is reached. These learning opportunities are required to be flexible, work-based and funded, and include opportunities for clinical experience.

3. Conduct of quality evaluation and research that will enhance primary care and specialist palliative care provision

Specialist palliative care services will also be responsible for the development of programs of research (in collaboration with academic centres and primary care providers) that will support and inform the network as an integrated service framework. Specialist palliative care services and staff need to be engaged in the development and implementation of research programs that are designed to improve continuity of care, clinical management and quality. The flow-on effect of research work, particularly clinical research, to primary care providers will ensure that all patients benefit from the work undertaken and coordinated by specialist providers.

Scenario – Consultation

Jan, 50 years, diagnosed with metastatic breast cancer, was admitted to a general ward in the local teaching hospital with an exacerbation of her pain. Her condition was deteriorating and her pain had escalated. Jan described severe pain that was no longer controlled by the analgesia prescribed by her general practitioner. The medical team caring for her tried various analgesic combinations over 24 hours with little effect. Jan remained distressed and her young family became agitated demanding that more be done to help her. The medical team referred on to the hospital palliative care consultancy team. The palliative care team assessed Jan and her family. They gave advice to Jan's medical team about more appropriate analgesia and provided social support for the family. An ongoing palliative care plan was developed in conjunction with the caring team. The palliative care team visited Jan for the next two days until her pain was controlled and her family were more settled. Jan continued to be cared for in the general ward until her family felt confident to take her home one week later.

Scenario – Consultation /Advice

Kay, 38 years, divorced, with a sixteen year old daughter and twelve year son is a palliative care patient in a small rural town. The local community has banded together to support Kay and her children. There is a core group of community staff trained in palliative care. They have managed Kay's physical symptoms well but are finding the emotional burden of caring for Kay very stressful. In particular they feel they do not have the skills to support Kay's children. The community team requests a consultation with the metropolitan palliative care service to discuss the case and learn some strategies so they can better support the family. A video conference is set up for the nursing team in the country to link with the palliative care counsellor. The case is discussed and strategies to support the children are developed. The team arranges two further follow-up sessions to link with the counsellor via video conference.

Scenario – Ongoing care

Jack, 45 years, was married with three primary school age children. Following a short history of abdominal pain Jack was admitted to a teaching hospital for urgent surgery, which revealed an extensive inoperable tumour spreading throughout his peritoneum and liver. Further investigations revealed extensive lung metastases. Post operatively Jack had numerous complications including a wound which was broken down and infected, as well as ongoing pain. Jack's condition deteriorated quickly.

Jack's surgeon involved the hospital palliative care team who arranged to transfer Jack to the local hospice so that he could receive adequate care and support to help him to come to terms with his poor prognosis. The hospice staff assessed Jack's needs and developed a plan of care to address management of symptoms and wound care, as well as ongoing social, emotional and spiritual support for Jack and his children.

As the hospice staff got to know Jack they found that his real wish was to be cared for at home. The hospice staff liaised with Jack's general practitioner, the community palliative care service, his primary carer (his wife, Val) and a family, and a meeting was organized to discuss and plan his discharge home. The community palliative care service provided equipment and other resources, as well as regular specialist nursing and medical care to manage Jack's ongoing complex needs. Pastoral care and counselling were also made available to support and guide the primary carer and family through Jack's rapid illness. Jack died peacefully at home eight weeks following his diagnosis.

linking care providers – defining roles and creating networks

The key to ensuring equity of access for patients based on level of need, is to ensure that formalised links exist between palliative care services at all levels, allowing for seamless referral between service levels as patient condition or circumstances change.

Both primary and specialist services are necessary sub-elements of the framework to ensure that there is a capacity to meet both uncomplicated and complex needs within resource considerations. It is also important that agreed processes exist for moving patients between the various services as the patient's needs may change. Therefore the service model also incorporates a structure for accessing advice and/or care from specialist services and a responsibility to ensure the efficient use of specialist services.

The following table (Table 1) describes the various levels of service that are required to meet the needs of the entire population of people with a life limiting illness who require care. The table sets out a role delineation matrix that delineates the expected capabilities of primary care provider and variously resourced specialist services. One of the challenges in the provision of services

in regional and remote areas has been associated with cost of maintaining full multidisciplinary services in areas with small populations. Establishing role delineation frameworks will enable the creation of networks of services that include not only primary care and specialist services, but that also contain the potential to construct networks between specialist services with different resource and therefore capability profiles. The resource and role delineation matrix provided here provides a broad framework against which local state, based role delineation models, and therefore specialist networks, can be established

For service-level planning and resource requirements please refer to *Palliative Care Service Provision in Australia: A Planning Guide* 2nd Edition 2003.

Table 1: Capability and Resource Matrix

Level	Capability	Typical resource profile
Primary care	<p>Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care.</p> <p>Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.</p>	<p>General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff.</p> <p>Specialist health care providers in other disciplines would be included at this level.</p>
Specialist Palliative Care Level 1	<p>Provide palliative care for patients, primary carers and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers.</p> <p>Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients, carers and families with complex problems. Has quality and audit programme.</p>	<p>Multi – disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available, coordinates a volunteer service.</p>
Specialist Palliative Care Level 2	<p>As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community.</p> <p>Has formal links with primary care providers and level 3 specialist palliative care services for patients, primary carers and families with complex needs.</p>	<p>Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.</p>
Specialist Palliative Care Level 3	<p>Provides comprehensive care for the needs of patients, primary carers and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has a comprehensive research and teaching role.</p> <p>Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.</p>	<p>Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.</p>

Typically a **level 1 specialist palliative care service** would exist in smaller population centres where higher levels of resources are not warranted on an ongoing basis. However, it would be expected that large regional centres and metropolitan regions would have **level 2 specialist services** available as a minimum level of resources.

Level 3 specialist services would be readily available as part of the whole system but will be fewer in number and exist to cover their local areas, with additional responsibilities for a large region including regional and rural areas, through formal links with level 1 and 2 services. It is expected that level 3 services will also have responsibility for a designated local population in addition to the supportive and specialist consultation roles.

Volunteer services have been established in a large number of specialist palliative care services to increase the capacity of those services to provide for the care needs of patients, primary carers and families. Clear protocols should exist within specialist palliative care services about the utilisation and management of volunteer services, including access to volunteer services by primary care providers without the ongoing need for specialist palliative care support.

implications for primary care providers & specialist palliative care services

As the planning principles described in this document become accepted as an appropriate model for palliative care service provision in Australia, current specialist and primary care providers will be required to review, and perhaps modify, their strategic direction and related operational plans. Specialist palliative care services are unlikely to grow further by simply demanding an increase in funding without providing evidence as to how the total population's needs will be met (as opposed to their registered patients only) .

The emphasis on the development or refinement of the role of both primary and specialist palliative care services will ensure that a sustainable and comprehensive health care response is available to meet the needs of people who are faced with a life limiting diagnosis. Developing useful frameworks for incorporating the primary and specialist service contributions to meeting the needs of the community will be achieved through collaboration and partnership building. Resource and Capability matrixes, formal service agreements and collaborative sectoral or state wide

planning will all assist in the development of an integrated plan to deliver quality end of life care.

Central to this is the development of well defined and transparent referral and admission protocols and procedures, combined with a commitment on behalf of all health care providers to work collaboratively to ensure that the needs of those most vulnerable are met. Increasing demand for palliative care support, especially from patients with non-malignant diseases, will continue to put pressure on existing services. Distribution of these patients based on an assessment of their need for care, rather than on criteria such as diagnosis alone, may result in a redistribution of patients, and potentially an increase in acuity for patients currently seen by specialist palliative care services, with less complex patients being cared for by primary care providers.

There are a number of issues that will require further consideration and consultation during the period of implementation of this model. These issues relate to either specific responsibilities of either specialist palliative care providers or primary care providers, or both. A very brief discussion of some of these issues is provided below.

Education for health care professionals

In order for palliative care to be provided for all people who need it, education that develops primary skills in the care of people with a life limiting illness up to and following on from death has to be included in the undergraduate preparation of all health care professionals. In addition, palliative care education at a post graduate, specialist level should be included in programs in clinical specialties where a proportion of the anticipated patient population may have palliative care needs, for example oncology, renal disease, rehabilitation and aged care.

The development of specialist training programs, especially for medical specialists, will be required to meet the

future workforce needs of specialist palliative care services. Specialist post graduate programs in palliative care should provide a focus on research, education and health promotion skills consistent with the role of specialist services set out in this framework.

Current levels of palliative care knowledge and skills

The education of health care professionals at undergraduate and postgraduate level is a medium to long-term strategy, and current levels of knowledge amongst qualified health care providers (at both primary care and specialist level) are inadequate in some instances to provide high quality, safe and effective palliative care to the target population. Sufficient resources and effective strategies will be required to implement a population based model for palliative care provision in Australia. This includes the education of all health care providers at primary care level, and, as relevant, those practicing at specialist level in other disciplines.

Development and dissemination of practice guidelines

Ensuring that patient care is not compromised by the service environment is an important consideration in the development of an effective and efficient model of care or service delivery. In the proposed model most palliative care patients will be cared for by primary care providers. These patients need to be assured that they will receive care of equivalent quality to that received by patients cared for by specialist services, based on their level of need. Standard protocols or clinical guidelines need to be developed in collaboration with primary care providers to assist them to establish and maintain minimum acceptable outcomes of care. These guidelines need to be based around acceptable and agreed boundaries of care for primary and specialist palliative care providers. The guidelines would provide specific information on common presentations and standard approaches to care and would also provide criteria for referral for advice or specialist management.

Development of resource materials to support primary care providers

Comprehensive resource material will need to be developed to support primary care providers. This might include for example, resource packages for generalist nursing services, general practitioners, primary allied health care providers, acute care hospitals including the emergency department and residential aged care facilities.

A Commonwealth funded project, Guidelines for a Palliative Approach in Residential Aged Care, has recently been completed. This project provides comprehensive guidance for residential aged care services providing care to people who have a life limiting illness.²¹

²¹ Australian Government Department of Health and Ageing. Guidelines for a Palliative Approach in Residential Aged Care. Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra, 2004.

Tracking patients receiving palliative care

The need to track patient movement will be of increasing importance to service providers, planners and researchers. The ability to follow patients through the different episodes and levels of care they require during the course of their illness will have multiple benefits, including better care coordination, improved estimates of resource demand, utilisation and cost, and more accurate estimates of the population size and characteristics. The current inability to follow patients through multiple, linked episodes of care is a problem when attempting to determine the true costs of care and creates communication and access difficulties for patients, and difficulty for funding bodies.

After hours access to palliative care services

Specialist palliative care services routinely provide after hours access to advice and support for patients, primary carers and families as well as other health care professionals. In a model of care that is based on ongoing care provided by the patient's primary care providers with episodic access to specialist palliative care, the ongoing needs of patients requiring access to 24 hour support and guidance will need to be addressed. For example, it is not reasonable for a specialist palliative care service to maintain contact with patients on a regular basis just in case they might be needed on an urgent basis. Primary care providers need to provide patients, their primary carers and families with clear instructions as to how to access advice and guidance on an urgent basis. However, specialist palliative care advice for health professionals should be available on a 24 hour 7 day basis, and this might be arranged on a regional or state wide level.

The use of ambulance services on occasions when there is an exacerbation of symptoms needs to be clarified with the patient, primary carer and family as part of their care plan. Inappropriate use of emergency departments as after hours admission pathways for known palliative care patients with expected (versus unexpected) clinical changes results in distress and discomfort for the patient, primary carer and family and additional pressure on an already overstretched health care service. Communications protocols between palliative care services, emergency departments and ambulance control need to be in place to ensure palliative care teams are advised of emergency admissions.

Access to practical resources

Existing palliative care services have built up considerable resources to assist patients, including equipment to maintain independence or comfort at home, for example, special mattresses, chairs, written resource materials. This has either been through equipment grants from government, but mostly through the local fund raising efforts of

services or by donation from primary carers and families as a way of showing their appreciation for care given. Access to these significant resources may be all that the patient, primary carer and family require from a specialist palliative care service in order to have their needs met. Equity of access to and maintenance of resources of this type will need to be assured in a model of care where access to specialist palliative care will be episodic rather than ongoing.

In addition, specialist palliative care services often have access to priority home assessment and modification services to ensure that the wishes of the patient, primary carer and family for care at home can be met. Mechanisms for ensuring that patients cared for by specialist and primary care providers have equitable access to supports such as equipment and after hours support will need to be incorporated into the service planning process.

the way forward

Palliative Care Australia has identified the requirement for a model of palliative care service provision that recognises the needs and specific characteristics of the various sub-groups within the overall target population. This policy *A Guide to Palliative Care Service Development: A population based approach* will help ensure a mechanism for providing equitable access in the context of efficient, effective and ethical use of resources. The policy recognises and incorporates the care currently provided by primary care providers and practitioners as well as that provided by specialist palliative care services.

However, it is important to realise that this policy is not intended to be a cost shifting exercise between specialist and primary care providers. Adequate resources will be required at all levels of care to ensure that the needs of the community are met. It is anticipated that full implementation of this model of palliative care provision would provide access to an appropriate level of care

for all Australians who have palliative care needs. Current perceived gaps in access to resources indicate that further investment will be required to achieve the goals of this policy.

It will take some time, perhaps a whole generation, for the primary care and palliative care systems to be configured to the intent put forward in this document. The role delineation model provides a broad framework for the development of more specific policies that suit the various health jurisdictions in Australia. Consideration of the principles and implementation where possible when service planning opportunities arise, will mean slow and steady progress towards the ultimate outcome: all Australians will have access to the quality of palliative care they need when they need it.

PCA is keen to further build on its policy work through projects that map the current level of population access to palliative care using the role delineation model and in the identification of triggers that will indicate the need for specialist care/additional resources.

With this policy document, PCA has provided recommendations on ways in which the resources suggested by the *Planning Guide* would be deployed and the *Standards for Palliative Care Provision* applied. The three documents complement each other. Decision makers at all levels (national, state/territory, regional, local) now have, in these three closely-related policies, a set of broadly applicable key service planning principles founded on improving access, quality, effectiveness, efficiency and sustainability in palliative care in Australia. PCA and its member associations seek to form partnerships with relevant authorities so that these principles can be implemented.

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