The Cancer Council NSW

There's no place like home: Challenges for palliative care

Issues Paper
October 2006

The Cancer Council
New South Wales

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Preface

The Cancer Council NSW (TCCN) is the leading cancer charity in New South Wales. Our mission is to defeat cancer. To achieve our mission we are working to build a cancer smart community by providing information and services, conducting research, and generating funds. The Cancer Council also aims to reduce the impact of cancer on communities by speaking up for the rights and interests of cancer patients and their carers and families.

TCCN provides emotional and practical support, facilitates access to services and provides publications and education resources for palliative care patients and their friends and relatives. Some examples of these are included overleaf.

Many stakeholders have told TCCN that people providing home-based palliative care for loved ones with a terminal illness need more practical support to undertake their day-to-day caring role. This Issues Paper has been released in response to those concerns. TCCNs interest in palliative care is primarily cancer-focused, however, we recognise that improved support regarding palliative care will also benefit those with other illnesses and their carers.

This Issues Paper has been informed by input from government agencies (NSW Department of Health; NSW Department of Ageing, Disability and Home Care; and Australian Government Department of Health and Ageing); palliative care and allied health professionals and volunteers from metropolitan and rural NSW; and other organisations including Carer Respite Centres, Palliative Care Australia and Cancer Voices NSW. We appreciate the time and information they have contributed. In addition, The Cancer Council NSW acknowledges Kylie Ruth, Joanna Quilty, Jenny Owen and Britt Granath for their combined effort in preparing this document.

This Issues Paper aims to generate discussion about improving practical support for home-based palliative carers and the results will inform TCCN policy and advocacy agenda as well as the direction of our support and information services. You are invited to comment on the issues and questions raised. We would especially welcome any input on the **action items** outlined, or on any other issues you feel are relevant to palliative care.

Please email any comments by **15 December** to the Senior Policy Analyst at **healthpolicy@nswcc.org.au** or mail to:

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The Cancer Council NSW palliative care activities.

Publications	• *Understanding Palliative Care* • *When Cancer Won't Go Away* • *A Guide for Women with Metastatic Breast Cancer*
TCCN Helpline	The **Helpline** is a confidential telephone information and support service whereby specialist cancer nurses answer questions about any aspect of cancer, including palliative care issues. In 2005, the Helpline nurses fielded 524 calls regarding palliative or hospice care. The majority of these calls (81%) were from family or friends of someone with cancer. The **Helpline database** has listings of 242 palliative/hospice services and 107 bereavement care services. This database is now publicly available as the **Cancer Services Directory,** the details of which are sent out in the TCCN *Support and Information Pack* to every person upon diagnosis of cancer.
Cancer Council Connect	**Cancer Council Connect** is a free, confidential support service that provides one-to-one peer support for people diagnosed with certain types of cancer in NSW. Support is provided by volunteers who have been recruited and specially trained by TCCN. Cancer Council Connect assists more than 2,500 people each year, and many feel that the support and encouragement they receive through the service is an important part of their overall care and recovery. Cancer Council Connect volunteers also have access to a one-day palliative care workshop as part of their training.
Telephone and on-line support groups	**Telephone Support Group** offers free, confidential emotional support and advice through talking with others who are going through a similar experience. These groups are guided by two trained facilitators. Telephone Support Group is an important option for people living in remote areas, for those who are isolated by their illness or simply prefer not to meet face to face. Support programs available via telephone or on-line include: • Advanced cancer telephone group • Carers telephone support group • On-line carers group – a 6 week on-line program for anyone who is supporting someone with cancer.
Caring Communities Project	This project aimed to increase the capacity of communities to support individuals with life threatening illnesses and their carers. The project consisted of providing two coordination volunteers as well as bereavement support in rural communities throughout the Central West.
Navigators	TCCN has established full-time "navigator" positions designed to assist people affected by cancer to access local support services and to report on unmet needs. These positions are being trialled in Newcastle and Orange.

The Cancer Council NSW palliative care activities continued…

Workshops	**The Living with Cancer Education Program** This series of workshops for cancer patients and their friends is held for one morning a week for 6 to 8 weeks. This free program provides information about cancer, treatments and side effects, nutrition during treatment, healthy eating and support services and offers an opportunity for patients and friends to share their experiences and learn from each other. Health professionals, who are experts in their field, are invited as guest presenters. The Living with Cancer Education Program is run in different community languages including Chinese, Italian, Greek, Arabic, Spanish and Vietnamese. **The Living with Cancer Education Program For People Experiencing An Advanced Cancer** This is a four-week free program that can be offered in any hospital, community health care centre, and palliative care facility. The program runs over 1½–2 hours per week and includes information about treatments, communication, relationships, looking ahead, self care and well-being. **Intimacy and Sexuality in Palliative Care Workshop** This is a one-day training workshop for palliative care health professionals. The aims of the workshop are to improve communication skills to meet the physical, social and emotional needs of people facing the end stage of their life.

1. Executive Summary

The Cancer Council NSW Issues Paper, ***There's no place like home: challenges for palliative care***, examines the adequacy of support services available for people providing home-based palliative care for loved ones with a terminal illness in NSW.

Palliative care is any form of treatment that focuses on reducing the severity of the symptoms of a disease and improving the quality of life of patients, rather than providing a cure. The carers of palliative patients who are treated at home undertake a daunting role - caring takes a toll on their well-being and health, and they face difficulties in obtaining necessary services and support. In addition, the wish of many patients and their carers is for those in the end-stage of disease to be able to die at home. However, most deaths in Australia still occur in hospital.

Approximately 64,000 people each year experience an expected death. Of these, under 40% are seen by palliative care services. The NSW Department of Health estimated that demand for palliative care services would increase by around 17.3% over an eight-year period. These factors, along with the ageing population, will place more pressure on already over-burdened health services and result in a growing number of terminally ill people being cared for at home. At the same time, the availability of carers is expected to diminish.

Although people with cancer constitute approximately 85% of adult palliative care patients, the issues outlined in this Paper will affect all palliative care users. The Cancer Council NSW welcomes comment and feedback on the matters raised. Three overarching issues of concern have been identified for home-based palliative carers:

1. Access to medical and allied health services
There are policy guidelines at both a national and state level for the provision of palliative care, including home-based palliative care and accompanying support services. Despite these frameworks, carers in NSW are not assured of receiving high quality, consistent medical and allied health services for their terminally-ill loved ones. There are differences in models of care, access to after-hours services, and availability of specialist and primary health providers. Problems also include insufficient resourcing of community-based palliative care services, the lack of a state-wide plan for service development, and few strategies to address barriers to involvement of general practitioners (GPs) in providing palliative care. People in rural areas rely on GPs and community nurses for most of their direct care and have very limited access to specialist palliative care services.

2. Assistance with household tasks and physical care
Home-based palliative carers in NSW are technically eligible for a range of household support programs and services provided by the Home Care Service of NSW and other Home and Community Care (HACC)-funded programs. In reality, carers have problems accessing these services because of confusion about eligibility, the lack of intensive support packages for those wishing to remain at home, limited availability of services, and variable approaches to coordination of palliative care volunteers by Area Health Services.

3. Information and education for carers

Primary health professionals play a key role in educating carers about how to access support services and provide medical care for their loved one including controlling pain and other symptoms. Volunteers can also be effective providers of information. Problems regarding information provision include the lack of ongoing professional development for health care workers regarding palliative care, the potential for duplication or inconsistencies in education resources, and the variable support and coordination of volunteers as information providers.

A call for action. TCCN seeks your comments on the appropriateness, relevance and feasibility of the following directions for improving services and support for home-based palliative carers:

1. Strategies to improve access to primary care in home-based palliative care situations, including enabling home visits and out-of-hours availability of GPs and other health professionals.
2. The recommendation that NSW Health develop and implement a state-wide palliative care services plan. This plan should consider various models for service provision in metropolitan, rural and remote areas and implement a policy of monitoring of service delivery and standards. The plan should also attempt to map and address areas of unmet need in palliative care service delivery.
3. Raising awareness of the eligibility of home-based palliative patients and their carers for the Home Care Service and other Home and Community Care-funded programs, and an assurance that they will receive equitable and timely access to these services. Increased funding to the Home Care Service in order to address unacceptably high levels of unmet need is required immediately.
4. Extending availability of the Community Aged Care Packages and Extended Aged Care at Home packages to palliative care patients.
5. Ensuring the continuation of Commonwealth funding programs for respite services targeted at palliative care clients
6. Ensuring the adequacy of practical support services, such as domestic care and live-in housekeeper services, as part of a continuum of support for home-based palliative carers available through non-government organisations. The potential to establish these services state-wide and targeting those most in need should be examined.
7. Establishing properly coordinated and resourced palliative care volunteer programs, which are linked to palliative care teams in every Area Health Service, and which have assistance from non-government organisations.
8. Developing ongoing professional development initiatives for primary health professionals and palliative care specialists in effective, culturally-appropriate communication and education techniques so that they can adequately prepare home-based palliative carers for their caring role.
9. Establishing a clearing-house for all information and education materials aimed at home-based palliative carers, so that duplication of effort and resources are minimised and content is standardised.

Taking action on these matters should result in a greater proportion of those with a terminal illness being able to obtain medical treatment in comfort at home, increase their quality of life and reduce the number of hospitalisations. In addition, this will allow those with end-stage disease to die at home if they so wish.

2. Introduction

What is palliative care?

Palliative care is any form of treatment that concentrates on reducing the severity of the symptoms of a disease or slowing its progress, rather than providing a cure.[1] Palliative care aims to improve the quality of life of patients, their families and carers by addressing the problems associated with terminal illness. This may be through the prevention and relief of suffering by means of early identification, or by the assessment and treatment of pain and physical, psychosocial and spiritual problems.

The Cancer Council NSW (TCCN) Issues Paper, ***There's no place like home: Challenges for palliative care***, was drafted in response to stakeholder input, which highlighted the difficulties carers face in obtaining necessary services and support when caring for a terminally ill person in the home. The Issues Paper aims to examine the adequacy of available services and generate comment on the practical support needs of palliative carers in NSW by exploring:

- The policy context within which home-based palliative care is provided
- Key findings from the literature
- Current arrangements for providing carers with practical support
- Issues impacting adversely on carers
- Action that may achieve better outcomes for carers.

Although people with cancer constitute approximately 85% of adult palliative care patients, the issues outlined in this Paper will affect all palliative care users.

Home-based palliative care

In Australia, palliative care has emerged as a specialised field in the health care system, and there has been significant growth in the number and type of palliative care services available.[2] Most palliative care services are community-based, with the assumption that the needs of most palliative care patients can be met through the primary health care system, which includes general practitioners and community health nurses.[3] It is also assumed that the majority of recipients will need episodic rather than ongoing specialist palliative care services.

A growing emphasis on enabling the terminally ill person to stay at home as long as possible has meant that there is increasing reliance on the availability of family and friends to provide the majority of care.[4] Other factors which contribute to the growth in home-based palliative care are meeting the wishes of patients, continuing pressure on the acute care system, early discharge policies and, in some areas, a lack of inpatient facilities or beds. In addition, there may be areas within the health care system where palliative care services are difficult to access or are in very limited supply, such as in rural or remote areas.[2]

> "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"[3]

In this Paper, a **carer** or **palliative carer** is defined as a family member, parent, partner, significant other, friend or neighbour who provides substantial home-based care on an unpaid basis to a loved one with a terminal illness. The daunting role of the carer, as well as the toll it takes on their well-being and health, have been extensively documented elsewhere. Studies such as the *Inquiry into the Social Impact of Caring for Terminally Ill People in Australia*[5] portray the scale of problems encountered in caring for a person with terminal illness at home.

Dying at home

This Issues Paper focuses on the needs of a subset of those requiring palliative care - those in the end-stage of disease who express a desire to die at home, rather than in a hospital setting. Various studies indicate that dying at home is now the preference of most terminally ill people and this choice is supported by their carers.[6] Home death is seen as promoting normality, choice, comfort and dignity.[7] However, despite the desires of most terminally ill people, the majority of deaths in Australia still occur in hospital.[8]

3. Background Data

This section summarises the limited data available regarding contemporary palliative care service provision in Australia.

3.1. Carers

Data from the 2003 survey conducted by the Australian Bureau of Statistics, *Disability, Ageing and Carers,*[9] provides useful information on unpaid caring in general, although palliative carers were not specifically identified as a subgroup. Across Australia, nearly 2.6 million people considered themselves to be carers (see Box 1).

Similarly to the ABS study, a study of 106 family caregivers involved in metropolitan home-based palliative care found that approximately one quarter had stopped work and another quarter had reduced paid work in order to care for the patient.[10] Thus, unsupported carers may represent a significant loss of productivity to the economy.

A decline in the number of family carers is predicted for the future, due to more marriage breakdowns, smaller families, childlessness, and the increased participation of women in the workforce. The provision of home-based caring will depend more and more on people's ability to combine work and family responsibilities.[11]

Box 1. Snapshot of Carers in Australia[9]
2.577 million people (13% of the population) were carers who provided some assistance to those who needed help because of disability or age.
About one in five carers (**474,600**) were identified as primary carers.
Most primary carers cared for a person living in the same household.
Overall, the majority of primary caregivers were female (**71%**). The difference between the sexes was less pronounced for carers aged 65 years, with over **58%** being women.
Primary carers had a lower labour force participation rate (**39%**) than people who were not carers (**68%**).

3.2. Hospital-based palliative care

The Australian Institute of Health and Welfare report *Admitted Patient Palliative Care in Australia 1999/00*[12] provided a picture of palliative care delivered in Australian hospitals over one year. The report noted its limitations including that some episodes of hospital care may not have been recorded as "palliative," reporting methods between States and Territories were inconsistent, and data about community-based palliative care were not captured in the report. However, given that most deaths still occur in hospital, the data does provide some insights into palliative care provision in Australia (see Box 2). Although palliative care separations[a] represent a small proportion of the total separations, the length of stay in hospital is longer than non-palliative episodes. Interestingly, most of these separations occurred in the public system.

[a]Separation from a healthcare facility is a term used to denote when a patient leaves because of death, discharge or transfer (that is, they are 'separated' from the hospital). Separations, rather than admissions, are used because hospitals gather data regarding inpatient care at the time of discharge. The number of separations is the most commonly used measure of the utilisation of hospital services.

Box 2. Inpatient Palliative Care Separations in 1999-2000[12]	
Australia	
Number of palliative care separations (PCS) from public and private hospitals	21,341
Proportion of PCS of all hospital separations	0.4%
Proportion of PCS in public hospitals	78.4%
Proportion over 65 years of age requiring PCS	Men: 61.3% Women: 53.2%
Average length of stay PCS vs. non-PCS	12.3 vs. 3.8 days
New South Wales	
Number of PCS from public and private hospitals	7,867
Number (%) of palliative patients who died in hospital	3,988 (50.7%)
Number of PCS patients who returned to normal place of residence upon discharge	2961 (37.6%)
Number of PCS patients who were discharged to other health care /residential /aged care facilities	918 (11.7%)

3.3. Community and home-based palliative care

A study of over 300 organisations involved in palliative care across Australia found that they catered to over **12,000** community-based patients over the study year (this included patients at home and in aged care and supported care facilities).[13] An average of approximately 7,000 hours of community-based care was provided each week by these organisations.

The study found that although the number of patients per year is less than that of inpatient facilities, the average length of treatment for community-based patients was 91 days**.** This was more than **seven times** that of inpatient services. The study concluded that community-based services are a vital component of palliative care in Australia.

3.4. Dying at home

It is estimated that, of the 80% of Australians whose preference is to die at home, at best only one in three will be able to do so.[8] A recent study of 26,882 people who died in Western Australia over a 30-month period found that only 20% died in their private residence.[14]

Also, the majority of the 806 Indigenous WA residents who died during the study period died in hospital. The study found that having access to community-based palliative care services increased the chance of dying at home by seven times.

Box 3. Factors associated with dying at home	
Having cancer or HIV/AIDS[15]	Not living alone[15]
Higher socio-economic status[15]	Having less symptom severity or depression[15]
Avoiding extreme fatigue in carers[15]	Expressing a preference for dying at home[15]
Having a healthy full-time primary caregiver or more than one caregiver[15]	Acceptance by the patient and family of impending death[15]
Being female[14]	Access to palliative care services[14]
Being of Australian descent[16]	Being married[16]
Having private health insurance[16]	

As well as access to services, other factors have been associated with dying at home, compared to dying whilst in inpatient care (see Box 3).[15,16] Views about the best place for death which change over time, crisis situations, carer exhaustion or a wish to ease the carer's burden, may lead to a hospital admission shortly before death.[7] Increasingly complex care needs may mean that the carer is no longer able to provide what is required.[17] There is also evidence that a proportion of hospital admissions at the end of life may be due to poorly coordinated and inadequate palliative care and related support services.[17] All of these factors can mitigate against the likelihood of dying at home.

3.5. Demand for palliative care services

The NSW Department of Health projected that a 17.3% increase in demand for all palliative care services would occur between 1998 and 2006, compared to an overall population growth of 7%.[18] Given that the estimate was derived from data relating to in-patient and sub acute settings only, these figures were probably underestimated.

According to Palliative Care Australia, approximately 64,000 people each year experience an expected death. Of these, only 37.5% are seen by palliative care services.[3] People with cancer constitute the majority of adult palliative care patients, representing over 85% of referrals to palliative care services.[18] Approximately 40% of people diagnosed with cancer are expected to die of their disease.[19] An expected 25% increase in the incidence of cancer in NSW over the next six years[20] along with the ageing population, will place more pressure on already over-burdened health services and lead to further increases in the number of people with advanced illness being cared for at home.

4. Palliative Care Policy

There are policy guidelines and documents at both a national and state level for the provision of palliative care, which encompass home-based palliative care and accompanying support services. In addition, non-government organisations (NGOs) have released guidelines and standards to guide palliative care services. A brief overview of relevant government policy is below.

4.1. The National Palliative Care Strategy

The Commonwealth's *National Palliative Care Strategy,*[21] which was released in 2000, guides the development and implementation of consistent, accessible palliative care policies, strategies and services across Australia. Its three main goals are to:

- Improve community and professional awareness of the role of palliative care
- Support continuous improvement in palliative care service delivery
- Promote and support partnerships in the provision of care.

The *Strategy* recognises the need for choice in the setting and type of palliative care provided. It identifies general practitioners and community nurses as providing the bulk of care, with consultancy and support from specialist services for complex needs, and acknowledges the important role of families and their need for practical and emotional support, information and skills development. Commonwealth funding to support the national strategy is provided under the **National Palliative Care Program**, which commenced in 2002. In NSW, additional funding is provided to palliative care through the State Budget.

Activity Implementation Report

Since the endorsement of the national strategy, the Palliative Care Inter-governmental Forum (PCIF) has released the *Activity Implementation Report*[22] which outlines the activities progressed under the framework of the National Strategy.

Indigenous Palliative Care Issues

The Department of Health and Ageing (DoHA) commissioned a study into the provision of palliative care services to Indigenous Australians.[23] The study found that, in most regions, Indigenous clients are either not referred to palliative care services or are referred at a very late stage of their illness. Being able to be treated at home whilst ill was the preferred option of most respondents to the study.

Subsequently, DoHA released a resource kit[24] aimed at providing strategies and training material to support mainstream health services in the provision of culturally appropriate palliative care to Indigenous Australians.

4.2. The NSW Palliative Care Framework

NSW Health's *NSW Palliative Care Framework*[18] is the basis for palliative care service delivery in NSW and promotes access, continuity and standard levels of care, regardless of location. It recognises that care is best provided within the patient's local environment or community, that the patient and carers are the focus of care and that there should be access to a range of specialised disciplines. An interdisciplinary team approach and an enhanced role for volunteers are essential elements of the *Framework*.

The *Framework* also identifies specialist and generalist health providers as well as support services which assist with daily living tasks for those requiring palliative care. Its focus is primarily on specialist palliative care services and it does not specify roles and responsibilities *vis a vis* generalist providers, nor indicate desired models and levels of service provision for different populations. The *Framework* also indicates that:

- Numerous models and levels of service exist in NSW
- Palliative Care Australia standards apply
- Each Area Health Service (AHS) must develop a three-year palliative care plan outlining its service delivery model, how standards will be complied with, and service and funding reconfigurations to meet identified and projected need
- The AHS plan must ensure 24-hour access to trained staff, and partnerships between specialist services and GPs
- Each AHS determines its palliative care budget

A review of AHS service plans led to the establishment of the NSW Palliative Care Advisory Group (PCAG) in 2003, which was designed to provide expert advice to NSW Health on issues relating to palliative care. The review included AHS service plans as submitted and did not investigate actual areas of unmet need.

NSW Health: Role Delineation Framework

A role delineation framework is in the process of validation by the NSW Department of Health to classify palliative care services.[25] The framework includes two tiers:

- The **Working Together Framework** (WTF) describes the relationship between specialist and primary palliative care services. The WTF is based on the assumption that for most patients and their carers, the relationship with their GP will be ongoing and is central to an integrated approach to caring for a patient with a terminal illness. The WTF is based on the premise that the majority of people with a terminal illness will experience a relatively uncomplicated trajectory from the point of diagnosis and will be able to receive most of their care from primary care providers. A smaller subset of people with complex needs will require direct care from the specialist palliative care service.

- The **Resource and Capability Framework** (RCF) defines levels of specialist palliative care services. The RCF outlines the staffing profile, support services and other requirements appropriate for different levels of service to meet patient need at an individual and population level.

4.3. Other policy documents

In view of the large proportion of cancer patients who require palliative care, the *NSW Cancer Plan,*[26] released by the Cancer Institute NSW, describes several collaborative initiatives which aim to raise the profile of palliative care services among health professionals and ensure early referral of cancer patients.

Other documents relevant to palliative care have been released by non-government organisations. Palliative Care Australia (PCA), the peak representative body for palliative care, has released three documents which aim to provide guidance for the development of services at a national, state and local level. Following a collaborative project with the Commonwealth Government, the revised *Standards for Providing Quality Palliative Care for all Australians*[27] applies to primary care providers and specialist services and recognises that the majority of care is likely to be provided in the community. Adoption of these standards is voluntary.

PCA has also released a planning guide for service provision[28] which recommends levels of specialist staff required per 100,000 population across a range of different settings including community-based services, acute hospital services and palliative care services within the acute care setting (see Box 4, adapted from PCA, 2003). Elements of this service-planning guide have been incorporated into the NSW Department of Health's role delineation framework.[25] The third resource in the series, *A Guide to Palliative Care Service Development,*[3] aims to provide a resource allocation model which will guide equitable access to palliative care services.

Box 4. Palliative care service provision[28]

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.

Palliative Care Outcomes Collaboration

DoHA have provided funding for three years to establish the Australian Palliative Care Outcomes Collaboration (PCOC) project. A collaboration between four Australian university research centres is in the process of inviting specialist palliative care service providers to collect data items relating to service delivery. The collaboration will compare and measure the services provided by palliative care organisations in order to ensure quality improvement in the long-term. The ultimate aim of the project is to develop a national benchmarking system to improve clinical palliative care outcomes in both the public and private sectors.

Although PCOC is investigating specialist palliative care service providers, and does not specifically target generalist primary health care providers, the project should provide a map of service provision across Australia. The PCOC project supports the goal of continuous improvement in the quality and effectiveness of all palliative care service delivery as outlined in the National Palliative Care Strategy.

5. Providing Practical Support to Carers

Case study

Brother and sister John and Christine, both in their sixties, had shared a home for many years in a regional centre not far from Sydney. When Christine was diagnosed with a terminal brain tumour, it was their wish that she be cared for, and die, at home.

An assessment by the palliative care team was initially very positive, indicating that a specialised bed, lifting equipment and community nursing could be provided to support John in his caring role. However a follow-up visit revealed two problems: the bed could not be supplied because of the long waiting list for such equipment; and Christine's needs would require two nurses for lifting/bathing purposes and these could not be supplied because of staff shortages.

This meant that John and Christine were left to persevere at home with assistance from family and friends only. Eventually Christine's needs increased to the point where it became impossible for John to continue caring for her at home without specialised support and equipment.

Christine was initially admitted to the regional hospital, but the family felt that staff were not experienced in palliative care and appeared to lack specialised training, so they decided to transfer Christine to the local hospital, closer to home. As the end drew near, Christine was transferred to the local nursing home.

Throughout all three placements, it took great effort on the part of the family to ensure that Christine's pain management and other needs were appropriately addressed, including co-ordinating communication between hospitals, so that she could die in peace surrounded by her loved ones, as eventually happened.

Had the services identified at the first assessment been provided, along with follow-up assessments and other support services as necessary, Christine's wish to die at home would most likely have been fulfilled.

The case study illustrates how families often have to 'battle the system' to ensure an adequate standard of care for their loved one. It also highlights how the absence of practical support for palliative carers can mean that a dying person's wish to remain at home is not fulfilled.

The following sections of the Issues Paper look at how practical support is provided in NSW to assist palliative carers. **Practical support** is defined as basic services and resources that carers need to provide an adequate standard of care in the home to ensure the comfort and well-being of their loved one. The issues below will be discussed separately in the next chapters:

- Access to medical and allied health services
- Assistance with household tasks and physical care
- Information and education for carers.

6. Access to Medical and Allied Health Services

6.1. Key findings from the literature

Issues identified from the literature reviewed for this Paper highlight that:

- The success of home-based palliative care depends on access to appropriate medical and allied health services.[29]
- Specialised palliative care services in Australia have developed in an *ad hoc* manner and there has been little in the way of population-based planning.[30]
- Accessing appropriate medical and allied health services can be problematic – infrequent home visits, poor control of distressing symptoms, and poor communication contribute to patient and carer distress.[31]
- Some patients struggle needlessly with symptoms which could have been treated had appropriate medical advice been sought.[32]
- A family-centred approach in which health professionals see the patient and the carer as the unit of care is often lacking.[33,34]
- Poorly coordinated services hinder the development of trusting relationships and continuity of care.[4,7,34,35]
- Carer distress is reduced when intervention is by nurses with specialized palliative care training.[29]
- The input of specialist teams improves referral processes, coordination of care and patient/family satisfaction.[36]
- Specialist inpatient care to supplement home-based care, on an 'as needed' basis, is important, with the availability of hospice beds for short stays permitting more confident perseverance at home.[37]
- In both metropolitan and rural areas, palliative care services are generally provided by mainstream service providers, which often do not have formal networks with Indigenous health services. Mainstream and Indigenous service providers tend to work in parallel and may be unaware of services each organisation provides.[23]
- Home visits by health professionals and 24-hour access for advice and support are critical supports for home-based palliative care arrangements. [31,38]
- In rural areas where the population is thinly spread over large areas and there are few specialists, primary health care professionals (such as GPs and community nurses) play a critical role in palliative care service delivery.[39]

6.2. Current arrangements in NSW

In NSW, medical and allied health services for community-based palliative patients vary, depending on geographic location, population size and characteristics, available resources and historical factors. The principal model appears to rely on general practitioners and community nurses providing the primary care, supported by specialist palliative care teams attached to hospital palliative care units on a consultative or advisory basis.

Area Health Services make decisions about the level of resources available to palliative care teams, and these decisions appear to be influenced by historical factors, budgetary constraints and the availability of appropriately skilled professionals.

Adoption of the *Standards for Providing Quality Palliative Care for all Australians*[27] by Area Health Services plus the release of policy frameworks that are currently under consideration by the NSW Department of Health have the potential to improve medical and allied health services with respect to palliative care.

Models of palliative care

Input to this Paper has identified the following general models of palliative care services in NSW:

In metropolitan and regional areas

Specialist dedicated palliative care teams are often available and generally include palliative care medical specialists, nurses with palliative care training and allied health staff such as physiotherapists, social workers and bereavement counsellors. However, there appears to be considerable variation as to the resourcing levels across these disciplines.

The palliative care team consultative role can involve initial assessment, liaison with primary health care providers on care needs, symptom review, and follow-up as required. In some instances, specialist teams play a direct care role which is not necessarily just for patients with more complex needs. The type of service patients receive appears to be determined by how the original referral was made (i.e. to the palliative care team or to the community health centre). Specialist medical and allied health staff may also provide services to inpatients as well as to those in the community. Patients who have been admitted to hospital are more likely to receive services from the specialist team after discharge.

In rural and remote areas

When available, the specialist team usually consists of palliative care nurses who provide advice and support to primary health nurses and GPs. Specialist medical services and advice may be 'brought in' from the nearest regional centre or metropolitan areas.

However, it is reported that some rural AHS do not have any access to specialist medical staff. There is therefore a much greater reliance on primary health providers. Allied health staff attached to hospitals and community health centres are generally relied upon to provide services to rural palliative patients being cared for at home. Again, some rural AHS reportedly have no access to allied health staff for either inpatients or those in the community.

Inpatient facilities

Inpatient facilities are often used alongside community care for dealing with acute episodes or for end-stage care or even to provide respite. Hospices and hospitals with designated palliative care units tend to be based in cities and larger regional centres. Hospitals without a palliative care unit may still have designated palliative care beds or accept palliative care patients. In many rural and remote parts of NSW, palliative care patients would need to travel to access an inpatient bed.

Case conferencing

The Council of Australian Governments (COAG)[40] recently announced a funding initiative, which supports **case conferencing** for cancer specialists through the Commonwealth Medicare Benefits Schedule. This funding should become available from November 2006. The COAG initiative has also promised to provide incentive funds to improve the integration of medical services, public community health services, allied health services and non-governmental organisations, but it has not specified how this money will be directed .

Case coordination

Approaches to case coordination vary. In some areas, the primary health nurse is formally recognised as the case manager, with care plans and weekly meetings ensuring regular communication and joint planning between relevant staff. The case manager is generally responsible for coordinating necessary support services. Palliative care nurses can often play a key part in this aspect of care as well.

In other areas, case coordination is less structured. The health professional who has the most contact with the family, usually the primary health nurse or palliative care nurse, may informally assume the role of case manager. Communication between relevant professionals also occurs on a more informal level. Some nurses will assume responsibility for coordinating access to available support services while others will not see this as part of their core role.

Input to this Paper emphasised that a less structured approach to case coordination is appropriate in rural and regional areas where primary health professionals such as community nurses may only see a small number of palliative care patients each year.

After-hours care

Palliative care teams in both metropolitan and rural settings usually provide after-hours services and support. In some areas it includes telephone advice and an on-call roster for home visiting; in other areas it is phone advice only. Available information suggests that some rural areas do not provide any after-hours services.

The Commonwealth Government's *Round-the-Clock* Medicare policy has increased Medicare rebates on after-hours GP services by $10 and provides some investment to both existing and new after-hours GP infrastructure. However, barriers to greater general practitioner participation in home-based palliative care still include the undersupply and uneven distribution of GPs in some areas and personal safety fears surrounding home visits.

The National Rural Palliative Care Program

The Australian Division of General Practice is piloting a multidisciplinary model of palliative care in eight areas across Australia, including two in NSW, to address the problems encountered in accessing palliative care services in rural and remote areas. The model is based on another successful pilot project, known as the **Griffith Area Palliative Care Service** (GAPS).[41] The GAPS project was undertaken in 2001 to improve coordination of local palliative care services. GAPS used a case-management model with an integrated team of primary health care professionals, including GPs and community nurses.

The National Rural Palliative Care Program incorporates features from the GAPS model:

- Weekly one-hour case conference meetings which include GPs, with the costs currently being met through the Enhanced Primary Care items under the Medical Benefits Schedule
- A "1800 number" and on-call roster to provide 24-hour access to advice and services
- Creation of a patient-held record
- Common referral criteria, procedures and service protocols

GAPS was evaluated as having had a positive impact on the quality of care provided, and many of its initiatives did not require additional funding (for example patient-centred records, guidelines and manuals). The University of Wollongong is currently evaluating the National Rural Palliative Care Program and is due to report its findings in December 2006.

Alternative models for providing palliative care to Australians living in rural and remote areas are also worth consideration. The 'pop-up model'[42] for palliative care provision recognises that individuals in rural and remote areas do not always have access to health care services and provides a framework and resource kit for such situations. This model and its resources have been trialled in Emmaville in a remote area of NSW - the evaluation is currently underway.

6.3. Issues of concern

Home-based palliative care recipients in NSW are not assured of receiving high quality, consistent medical and allied health services. The key issues are outlined below.

No state-wide plan

While each AHS in NSW must provide a plan for palliative care service provision, there is no overarching state-wide plan identifying current and future need, resource requirements, standards and targets to be met, and strategies for ensuring continuous improvement and addressing deficiencies.

Unmet need

Anecdotal evidence suggests that certain groups in the community, such as Indigenous peoples, do not access palliative care services when needed. Little is known about their needs and characteristics and any barriers to access. Lack of resources for community-based palliative care would, in any event, make it difficult to meet any additional needs.

AHS palliative care plans appear to be required to identify 'resource reconfigurations' only, for the purposes of meeting current and future needs. The use of population data and other indicators of need would enable a more systematic and rigorous approach to assessing current and future resource requirements. This would seem to be a fundamental component of any state-wide plan.

Different models of care

There are different models of community-based palliative care service even within metropolitan Sydney. It is unclear whether they represent the most effective use of resources and provide for equitable access to services. Available information suggests that the type of service provided is not determined by need, but by factors such as where patients live, how they are referred, the model of service provision that has evolved over time and the availability of resources.

Inadequate specialist resources

Resource levels have not kept pace with the growth in referrals to community-based palliative care services. There does not appear to be any systematic planning process in place to quantify, prioritise and address resource deficiencies. Those consulted for this Paper particularly noted a lack of palliative care and allied health staff.[b] Where such resources are shared with inpatient services, inpatients tend to get priority. In rural areas, there can be a complete lack of access to any specialist medical and allied health staff.

[b]For instance, one metropolitan palliative care service assessed its resources for both inpatient and community-based services as significantly deficient, when measured against the PCA recommended staffing levels. The service highlighted the need for an additional: 7.63 palliative care specialists, 4.4 registrars, 12 clinical nurse consultants, 6 social workers, 6.2 speech pathologists, 7 physiotherapists and 2 volunteer coordinators.

Variable GP involvement

Input to TCCN from palliative care staff in both metropolitan and rural areas mentioned that lack of, or minimal, GP involvement in home-based palliative care can be a significant problem. In metropolitan areas in particular, GPs tend to be available during business hours only and rarely do home visits. Problems are also experienced in obtaining certification of death when a patient dies at home on a weekend, at night, or when their GP is away. The comment was made a number of times that current payment arrangements for GPs under Medicare may not be sufficient to encourage home-based palliative care service provision which can be time consuming and involve out-of-hours care. While standards that apply to primary health providers have now been developed by PCA, it remains unclear how they will be applied and monitored.

Variation in case coordination

Primary health nurses vary in their ability to provide case coordination and assistance to families to access support services. There have been suggestions that palliative care nurses sometimes have to assume a 'social work' role, for example, in order to assist disadvantaged families get food and clothing and deal with Centrelink, as primary health nurses often do not have the time to attend to such matters and social workers are not available. It is also difficult getting GPs involved in case coordination activities, with the time factor seen as a significant impediment.

The introduction of the Medicare Benefits Schedule item may help to facilitate GP involvement in case conferencing and coordination activities in rural and metropolitan areas for cancer care. However it will not extend to other terminal illnesses, which may require multidisciplinary input.

Rural issues

Indications are that rural areas are particularly affected by a lack of specialist resources and rely more on GPs and other primary health workers as key providers of home-based palliative care. Where specialist palliative care nurses are available, their limited numbers mean that their role can only be advisory. Consequently any barriers to increasing the involvement of GPs and community nurses in palliative care, has greater impact in rural areas.

It is positive to note that more pilot projects are underway to improve palliative care service provision to rural areas, following the success of the GAPS project at Griffith. However they focus on only three sites in NSW. These projects are due for completion in 2006.

7. Assistance With Household Tasks and Physical Care

7.1. Key findings from the literature

Issues identified from the literature reviewed for this Paper highlight that:

- Having to assume responsibility for all household chores on top of caring responsibilities can negatively impact on the carer's health and well-being and present significant coping challenges.[33,43]
- Both mainstream and Indigenous carers say they need more access to services such as Home Care and respite care, and to information about the practicalities of caring.[23,27]
- A survey of 107 families with a child diagnosed with a terminal illness identified that less than half had close family members available to provide support with 'frequent and time consuming tasks' and that, for most, a trained volunteer would be able to provide the help they needed.[44]
- Lack of practical support for carers in the home can result in palliative care patients being admitted to hospital.[45]
- Home-based caregivers may be reluctant to leave their loved one and feel ambivalent about accessing services such as respite.[46,47]
- People who access both respite and support services (such as those supplied by the Home and Community Care Program or Community Aged Care Packages) are more likely to avoid being admitted to a permanent aged care facility. Around 65% of those who use respite plus support services remain at home, compared to 55% of those who only access respite. [48]
- Provision of special equipment (hoists, commodes and hospital-style beds) can facilitate the care of the dying person at home.[41]
- Evaluation of a 'sitting service', which provided practical and emotional help to cancer patients and families, found that 86% of respondents felt able to go out and leave the sitter and 70% found the service to be important to them.[46]
- Evaluation of a night-respite community palliative care pilot project found the majority of clients who received the service whilst in the final stages of illness were able to die at home. Overwhelming support for the service was also reported from carers; and the costs appeared lower than in-patient admission for end-stage care.[45]

7.2. Current arrangements in NSW

Community Care Programs

A range of Commonwealth and State Government community care programs provide practical assistance with, and respite from, the caring role. Some AHS and non-government organisations also coordinate volunteers to provide practical assistance in the home. Following a major review of community care services, as detailed in the report *A New Strategy for Community Care – the Way Forward*[49] the Commonwealth Government intends developing an overarching framework within which all community care programs will operate to achieve consistency and common arrangements regarding access, eligibility and accountability.

The framework will also seek to establish an appropriate balance of Home and Community Care (HACC) funding across care needs, and review HACC eligibility criteria. The changed arrangements will be reflected in new HACC agreements between the Commonwealth and States. The Commonwealth also intends exploring the potential for aligning the functions and infrastructure of Carer Respite Centres and Carelink Centres.

In addition, a Commonwealth/State government funding initiative[40] has promised that by December 2007, governments will simplify entry points and improve eligibility and assessment processes for the HACC program. However, the eligibility of palliative care patients and their carers has not as yet been specifically addressed under this initiative. The major community care programs relating to palliative care are outlined below.

Home Care Service and other HACC services

The Home and Community Care (HACC) Program is a joint Commonwealth/ State initiative aimed at enhancing the independence of frail aged people and younger people with a disability and their carers, to avoid premature admission to long term residential care.[50] There are around 700 HACC service providers in NSW, of which the **Home Care Service of NSW (HCS)** is the largest. The HCS, part of the NSW Department of Ageing, Disability and Home Care (DADHC), provides domestic assistance, personal care and respite care to clients who meet the HACC target group. Other HACC services are largely provided by community organisations and local government and include transport services, home maintenance, meals and other food services, nursing care and linen services.

According to DADHC, a terminally ill person being cared for at home who is assessed as having difficulties performing the tasks of daily living meets the HACC eligibility criteria. However, due to the high level of demand, eligibility does not guarantee that a service will be provided. As well, if other than basic maintenance services are required (i.e. nursing care) the request is deemed outside the scope of HCS service provision.

Input to this Paper indicates that there is confusion and inconsistency around the eligibility of palliative care patients and their carers for services from HCS:

- Unless the person with the terminal illness or their carer is aged or has a disability, it is difficult to get services
- Staff undertaking HCS assessments may automatically assume that the condition of a palliative care patient is 'unstable' and their needs are outside the scope of HCS
- Even where the patient or carer are deemed eligible, waiting times of six to eight weeks mean that services cannot be accessed
- Public information about HCS and other HACC services does not make it sufficiently clear that people with a functional disability, at risk of admission to residential care, are eligible for services

Although carers are also classed as meeting the HACC target group criteria, they rarely access HACC services. In 2003/04, of nearly 200,000 HACC clients in NSW, the care recipient (patient) was classed as the client in 98.3% of cases, with the carer the client in only 1.7% of cases.[51]

Home Care Service Performance Audit

The NSW Auditor General undertook a performance audit of the HCS in 2004.[52] It found that at least 50% of eligible applicants were unable to receive a service and that two major factors contributed to this:

- A focus on applicants with more complex needs requiring more hours of personal care
- A low turnover of clients with only 3.1% exiting the service over four years

Because HCS does not routinely review and refer existing clients to other programs that may provide more appropriate care, the Auditor-General suggested that the service "may be masking demand for other care programs by retaining clients indefinitely." The audit recommended that clearer eligibility criteria and an exit policy be developed to ensure fairer access to services and appropriate client turnover.

Intensive Care Packages

The Commonwealth Government-funded intensive care packages are designed to assist aged people with more complex care needs, so that they can remain living independently in the community. Services such as assistance with bathing and personal hygiene, transport, laundry and meal preparation can be provided under **Community Aged Care Packages** (CACP). More intensive **Extended Aged Care at Home** (EACH) packages provide support to people eligible for high level residential care who are able to stay at home. The EACH package is designed as an alternative to high level residential care for frail older people with higher level needs than those eligible for CACP.

Input to this Paper suggests that such packages should also be available for those terminally ill people (and their carers) who wish to be cared for at home but whose needs are more complex. It was pointed out that providing such a care package would be less costly than admission to an in-patient facility.

National Respite for Carers Program

The National Respite for Carers Program supports and assists relatives and friends caring at home for people who are unable to care for themselves because of chronic illness, disability or frailty. It funds 455 community-based services to provide respite for carers. A stocktake of services is underway to identify providers and develop a profile of service delivery, carer access and usage.

It is unclear how the target group for this program differs from the target group for HACC respite services. The eligibility of home-based palliative carers is also unclear although the need to establish a separate pool of palliative care respite funding (see below) suggests that there are problems with palliative carers accessing services funded under this program.

Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres (CRCs) are a key component of the National Respite for Carers Program. There are 18 CRCs in NSW, which provide information and advice on support options and help with organising respite, including assistance with the cost of respite if required. CRCs have a broad role in helping carers to access respite services, which includes a specific focus on home-based palliative carers.

The Federal Government allocated $207.6 million over four years (2005 – 2008) across Australia to help in providing respite for carers. This includes $61 million for the CRCs to purchase 55,000 nights of care for 2,000 carers. Budget initiatives have also allowed access to extra day respite centres for employed carers.

Input to this Paper from palliative care professionals rates the capacity of CRCs to purchase respite (usually from private nursing agencies) for palliative carers as an extremely valuable resource. It is often the only available means of providing respite for a palliative carer, other than the carers paying a private nursing agency themselves. CRCs also advised that where carers' requests for respite could not be fulfilled, it was because the cost exceeded budget, or the type of respite required was not available for purchase. Palliative care professionals also report that in some areas palliative care respite budgets are expended before the year is out due to the high level of demand.

The CRCs also received $11 million over 4 years (2002 – 2006) to provide respite specifically for carers of people with a life-limiting illness. The CRCs' role with palliative care respite has been reviewed and the preliminary findings released.[53] The evaluation will inform future planning to assist carers of people with a terminal illness. However, it is unclear whether CRC funding which is earmarked for palliative care respite will be continued.

Volunteer and housekeeper programs

Volunteers can play an important role in the care of people with a terminal illness. To maximise the role of volunteers, some AHS incorporate a volunteers' program as part of their palliative care support service. These volunteers can provide support ranging from pastoral care to assistance with transport, medical appointments, errands, housekeeping, 'patient sitting' and bereavement support. In addition, there are a number of local, non-government volunteer-based support programs for palliative patients.

Not all AHS volunteer programs are adequately coordinated. For example, one rural AHS has a long-established volunteer program that 'runs itself' as there is no funded position of coordinator. A metropolitan AHS has approximately 40 active volunteers with only a half-time Volunteer Coordinator position, although a full-time position is needed. Input from palliative care professionals emphasised the need for proper coordination and support of volunteers to maximize their usefulness in providing practical support to carers at home. Issues about the use of volunteers in rural communities included privacy concerns and difficulties in recruiting volunteers.

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The Cancer Council NSW and the Mid Western Area Health Service collaborated on a Caring Communities Program initiative, which aimed to increase the capacity of communities to support individuals with life threatening illnesses. The project consisted of two complementary initiatives; volunteer activity coordination, and bereavement support. The information gathered from this initiative will guide the development of a model of coordinated volunteer activities and bereavement support suitable for the diverse range of rural communities throughout the Central West

Access to equipment in NSW

A number of public programs provide appliances and equipment to people with disabilities or health conditions, including people with advanced terminal conditions. However, these programs are either not ongoing, or have insufficient coverage to meet the needs of palliative patients wishing to remain at home.

Local Palliative Care Grants Program

This program provides $23.1 million over four years (2005 – 2009) and is designed to help health related services support people requiring palliative care, and their families.

Amongst other things, this program provides grants for equipment and the fit-out of premises for palliative patients, including in-patient and home settings.

Palliative Care Equipment Program

Since March 2003, $3.8million has been made available under the Commonwealth's Palliative Care Equipment Program. Registered palliative care agencies are eligible to apply and funds are specified for the purchase of equipment only.

PCA manages the program and distributes the money to its state member organisations according to a population-based formula; those organisations then determine the allocation of funding. The program means that equipment which can ease the physical burden of caring and ensure patient comfort can be provided without causing further financial stress. This program has not received further funding, and appears to have been replaced by the Local Palliative Care Grants Program.

Program of Appliances for Disabled People

The Program of Appliances for Disabled People (PADP) is administered by AHS and provides equipment for some home-based palliative care situations. However, there are a number of limitations and eligibility exclusions.

7.3. Issues of concern

Lack of access to basic in-home support services
Home-based palliative carers would benefit from the provision of services, which provide assistance with domestic tasks and the physical aspects of caring for a terminally ill loved one. As the majority of people with a terminal illness will have a relatively uncomplicated trajectory from the point of diagnosis, their needs and those of their carers should be compatible with services provided through HACC, such as the Home Care Service. However, despite being eligible (in theory) for such services, access seems severely restricted.

The current review of HACC and HCS eligibility criteria is an opportunity to clearly affirm the entitlement of palliative carers and patients for these services. If recommendations made by the Auditor General for client reviews and service exit policies are implemented, HCS services could potentially be freed up for terminally ill and other shorter-term clients. Even once the issue of eligibility and under-funding for HCS services is resolved, there may also be a need for housekeeping services that are able to provide a higher intensity, live-in service.

Insufficient intensive at-home support
Palliative patients with generally uncomplicated needs may occasionally experience periods of increased distress, while a smaller subset of patients will experience ongoing problems of high intensity or complexity. Similarly, carers can experience periods where, due to their own or other family members' needs, more assistance is required. At the moment the only option for these patients and their carers tends to be inpatient admission.

Consideration should be given to providing more intensive packages of care for home-based palliative care situations where the needs of the patient or carer are such that a higher level of assistance is required to maintain home-based care. While such packages would be more expensive than the provision of basic maintenance services under HACC, they would be less expensive than inpatient care.

Difficulties concerning respite services
Input to this Paper suggests that despite the provision of respite services under HACC and the National Respite for Carers Program, home-based palliative carers encounter barriers in accessing respite. It is not clear whether such barriers are due to ineligibility, lack of priority or long waiting times. In this regard, Commonwealth funding to CRCs specifically for the purchase of respite for palliative carers has filled a much needed service gap, even given reports of some inconsistencies across CRCs as to how the funding is used. It is concerning that funding to CRCs for palliative carer respite may not continue beyond 2006, when the strong indications are that the program should remain and be strengthened. Certainly, barriers to palliative carers accessing other respite services should be addressed. The recent review of the palliative care funding component of CRCs should assist in this regard.

Use of volunteers
AHS should be encouraged and resourced to establish and support volunteer programs to provide practical assistance to home-based palliative carers. As a starting point, existing AHS and NGO volunteer programs should be evaluated to determine what they achieve, how useful they are to carers and patients, and the resources required to administer and support them.

8. Information And Education For Carers

8.1. Key findings from the literature

Issues identified from the literature reviewed for this Paper highlight that:

- Families who do not receive adequate information and support in the early stages of a patient's illness have greater needs, less trust and confidence in the health care system and cope more poorly.[35]
- An evaluation of a Carers NSW support and education project found that many carers either did not realise the care recipient was a palliative patient, or did not want to acknowledge them as such.[54]
- A survey of Indigenous people found that in general there is a poor understanding of palliative care, and people often understand it to mean going to a nursing home, hospital or hospice to die.[23]
- Carers can find it difficult to attend formal education programs. For this reason, health professionals should be the main facilitators of educating carers.[7]
- Many GPs identified that their undergraduate and post-graduate training programs in palliative care were deficient.[55]
- Educating families about pain relief is important as families may unintentionally contribute to poor pain management because of anxiety about administering opoids.[35]
- Carers need information about the patient's illness, how to care for them, signs of impending death and 24-hour access to advice and support. If such information is not available, carers will rely on secondary sources such as the internet or friends which can contribute to anxiety, confusion and uncertainty.[35]
- The provision of information has been found to be particularly important for home-based palliative carers living in rural areas. Without it, they felt out of control, not empowered to make decisions and not able to cope on a day-to-day basis.[56]
- Carers themselves have identified that a publication containing practical information, such as which equipment to purchase, would assist in preparing them for the caring role.[5]

8.2.Current arrangements in NSW

Providers of information to carers

As carers find it difficult to attend formal education programs, education and information specific to home-based palliative care is generally provided informally, rather than through structured programs or strategies. As well as the GP, primary health nurses and sometimes specialist palliative care nurses play a key role in educating carers about medical issues relevant to the care of their loved one. These topics may include bowel management, mouth care, administering medications, pain relief and ensuring patient comfort. Educational materials for palliative carers such as brochures and pamphlets on specific topics are developed by each AHS.

The case coordinator or health professional having most contact with a family will usually provide information on available support services and how to access them. Palliative care nurses interviewed for this Paper commented that this role sometimes falls to them because primary health nurses are too busy and social workers are not available.

Input to this Paper indicated that volunteers can also play a critical role in information-giving and education of carers. Carers often feel more comfortable seeking information or discussing problems with volunteers, and can be hesitant to raise issues or concerns with nurses whom they perceive to be too busy. The volunteer can act as a liaison-point with the nurse to ensure that the matter is clarified and sufficient information provided. Carers can also access information regarding services through Commonwealth Government Carelink Centres, which aim to provide a single point of access to information about services to support independent living in the community. The Carelink on-line service directory[a] contains information on palliative care and services available to support in-home palliative care arrangements.

Education and training of the primary care workforce

Teaching resources have been developed to enable palliative care techniques to be incorporated into medical, nursing and allied health undergraduate curricula. These resources are currently being piloted at tertiary institutions, including the University of Newcastle and the University of New South Wales.[b] Postgraduate training courses in palliative care are also available. A national Program of Experience in the Palliative Approach (PEPA) provides workplace training opportunities to the primary health and allied workforce. This training requires undertaking a workplace placement with a palliative care specialist service within a metropolitan or large regional centre.

Information provided by non-government organisations

Palliative Care Australia and the NSW Palliative Care Association provide general information on palliative care and caring. Carers NSW, the peak body for carers, produces fact sheets on matters such as financial and legal issues and oversees the NSW Carers Resource Centre.[c] The resource centre is a federally-funded telephone support service providing information and referral, emotional support, and counselling programs designed specifically for carers.

The Cancer Council NSW has distributed over 40,000 *Support and Information Packs,* which contain booklets and information for people recently diagnosed with cancer. The pack includes information about access to a comprehensive on-line Cancer Services Directory, which contains 107 listings for bereavement care services and 242 listings for palliative care and hospice services. TCCN publications relevant to palliative care include *Understanding Palliative Care* and *When Cancer Won't Go Away*. The Cancer Council NSW also provides telephone and online support groups for advanced cancer patients and their carers, which includes a peer-support program. In addition, TCCN Helpline responded to 524 telephone calls regarding palliative or hospice care in 2005; the majority of these calls (81%) were from family and friends.

[a] Available from the Carelink website: www.commcarelink.health.gov.au
[b] More information on this project can be found at: www.pcc4u.org.
[c] Carers Resource Centre information available from: www.carersnsw.asn.au

8.3. Issues of concern

Training regarding informing carers about palliative care
Primary health providers receive varying degrees of training in relation to palliative care; however they are generally not formally trained in how best to inform or educate carers about the practicalities of providing palliative care in the home. The home-based palliative care environment can be stressful and emotional, carers may be fatigued, nurses are often pressed for time, and the information they need to impart can be technical or complex. These factors suggest that the primary care workforce needs ongoing professional development about how to impart information to carers and the services available to them.

Need for centralised access to written information
Input to this Paper stressed that most of the information that home-based carers need is communicated verbally and through hands-on demonstrations by nurses. However, providing carers with written information on particular issues can serve to reinforce the message and be a useful reference point. Because there is no central repository for such material and each AHS produces its own information, there is the risk of duplication of effort, and inconsistent information being provided.

Support and training for volunteers
Volunteers can play an important role in providing information to carers, but it is vital that they are adequately coordinated, supervised and supported, for example by AHS, in order to ensure appropriate information and support is provided.

Inadequate information on services to support palliative carers
The Carelink on-line service directory defines palliative care as 'the provision of health treatment, supervision and support in a residential facility'. Such a definition is at odds with the fact that much palliative care provided in Australia is home-based.

The directory does list a service sub-group of 'in-home palliative care'; although a search of the directory using this descriptor indicates that, for the 12 listed NSW regions, five regions list no services, and three regions list only one service. In total, only 169 palliative care services are listed plus there are no listings for community support services available to home-based patients and carers. This limits the usefulness of the directory as a resource for palliative carers in NSW.

9. A Call For Action

Home-based palliative care services are facing increasing challenges due to an ageing population and a preference for the terminally ill to be cared for at home. As a consequence, home-based palliative carers in NSW are not assured of receiving high quality, consistent health services and practical support for their terminally ill loved ones. Addressing the issues of concern identified in this Paper is difficult but important and will involve many stakeholders. Some of these issues may involve direct action from TCCN.

TCCN seeks your comments on the appropriateness, relevance and feasibility of the following directions for improving services and support for home-based palliative carers:

1. Strategies to improve access to primary care in home-based palliative care situations, including enabling home visits and out-of-hours availability of GPs and other health professionals.
2. The recommendation that NSW Health develop and implement a state-wide palliative care services plan. This plan should consider various models for service provision in metropolitan, rural and remote areas and implement a policy of monitoring of service delivery and standards. The plan should also attempt to map and address areas of unmet need in palliative care service delivery.
3. Raising awareness of the eligibility of home-based palliative patients and their carers for the Home Care Service and other Home and Community Care-funded programs, and an assurance that they will receive equitable and timely access to these services. Increased funding to the Home Care Service in order to address unacceptably high levels of unmet need is required immediately.
4. Extending availability of the Community Aged Care Packages and Extended Aged Care at Home packages to palliative care patients.
5. Ensuring the continuation of Commonwealth funding programs for respite services targeted at palliative care clients.
6. Ensuring the adequacy of practical support services, such as domestic care and live-in housekeeper services, as part of a continuum of support for home-based palliative carers available through non-government organisations. The potential to establish these services state-wide and targeting those most in need should be examined.
7. Establishing properly coordinated and resourced palliative care volunteer programs, which are linked to palliative care teams in every Area Health Service, and which have assistance from non-government organisations.
8. Developing ongoing professional development initiatives for primary health professionals and palliative care specialists in effective, culturally-appropriate communication and education techniques so that they can adequately prepare home-based palliative carers for their caring role.
9. Establishing a clearing-house for all information and education materials aimed at home-based palliative carers, so that duplication of effort and resources are minimised and content is standardised.

Taking action on these matters should result in a greater proportion of those with a terminal illness being able to obtain medical treatment in comfort at home, increase their quality of life and reduce the number of hospitalisations. In addition, this will allow those with end-stage disease to die at home if they so wish.

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AHS	Area Health Service(s)
CACP	Community Aged Care Package
CRC	(Commonwealth) Carer Respite Centre
DADHC	Department of Ageing, Disability and Home Care
EACH	Extended Aged Care at Home
GAPS	Griffith Area Palliative Care Service
GP	General practitioner
HACC	Home and Community Care (Program)
HCS	Home Care Service
NGO	Non-government organisation
PADP	Program of Appliances for Disabled People
PCIF	Palliative Care Inter-governmental Forum
PCAG	NSW Palliative Care Advisory Group
PCA	Palliative Care Australia
RCF	Resource and Capability Framework
TCCN	The Cancer Council NSW
WTF	Working Together Framework

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