



Palliative Care Strategy 2005-2009



'Care in the Community'

From the 'Many Ways of Caring: The Central Australian Aboriginal Palliative Care Painting Story'.

Jukkurpa Artist ~ Rachel Napaljarri Jurra



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The Government
is committed to
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community services
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better health for
all Territorians

*Building Healthier Communities:
A Framework for Health & Community
Services 2004–2009, p12*

Minister's foreword

Not long ago, a traditional Aboriginal woman came to Darwin from her country for cancer treatment. On learning that she was dying, she said she wanted to die at home. The palliative care team stepped in. They helped with her essential care and discharge, coordinated her flight home and made arrangements for home care, thus enabling her to fulfil her wish.

Palliative care is a crucial part of the health system. It is a client, family and carer-focused service that relies heavily on strong partnerships between government and non-government organisations, general practitioners and a wide range of other primary care providers.

In my many years of living and working in the bush I have witnessed many people leave their community and never return. As our *Building Healthier Communities* framework articulates, addressing Aboriginal ill health and disadvantage and providing services close to home are two of the Northern Territory Government's highest health priorities. The Territory has a high incidence of palliative clients who are Aboriginal and Torres Strait Islander people and who are from rural and remote areas.

The challenge for Government is to build on the progress in palliative care provision to ensure an equitable, accessible and quality service that meets the needs of all Territorians, from the Northern Suburbs to the bush.

As promised, we are making further progress. We said we would build the Territory's first dedicated palliative care facility. A 12-bed hospice in Darwin will open soon. This is a monumental step forward and will provide specialised care in a supportive and peaceful environment to people with a life-limiting illness. In addition, through the priority areas of this Palliative Care Strategy, the Central Australian palliative care service will be further developed.

The Department of Health and Community Services has developed this Strategy in collaboration with stakeholders. I believe it will ensure the growth, development and improvement of palliative care services for the next five years. Its priority areas are first-rate, practical and provide a clear framework for meeting the challenges in this difficult area. Most of all, this Strategy will have a real impact on people with a life-limiting illness, their families and carers.

The Hon Dr Peter Toyne MLA
Minister for Health
April 2005

Chief Executive's foreword

Palliative care is an essential part of the Territory's health care system. We face many challenges in providing palliative care services, given our vast geographical area, high rate of chronic illness and cultural diversity. The Department of Health and Community Services' Palliative Care Strategy 2005–2009 tackles the major priority areas and will lead to the growth, development and improvement of palliative care services.

Several important steps have already been taken. The new Hospice –a first for the Territory–will provide dedicated care and support. We have recently employed the Director of Palliative Care Medicine, who will provide overarching leadership in this Territory-wide role and, with stakeholders, fashion future services.

Palliative care is the business of every health and community services professional. A disproportionate number of palliative clients are Aboriginal people, many of whom live outside of urban areas. Thus the new Hospice is just one element of care. The key is to ensure that the palliative approach is effectively utilised across the entire health continuum, and to address the needs of people living in rural and remote areas. Underpinning this Strategy is the recognition of strong partnerships, supported by coordinated systems and responses both within the government and non-government sectors.

To ensure that people with a life-limiting illness maintain their dignity and have the best possible quality of life, and to ensure that their families and carers receive the best support we can, we need to offer accessible, quality palliative care services. We must have an expert specialist and primary care workforce that is supported and nurtured to achieve these goals.

Effective community engagement is another focus of this Strategy, a document that is the end product of extensive consultation with a range of stakeholder groups.

It is also a testament to the dedication and wisdom of staff and to the individuals and groups who willingly participated in the consultation workshops and provided useful input that guided this Strategy. I appreciate your passion for and ongoing commitment to the realisation of our goals.

Robert Griew
Chief Executive Officer
NT Department of Health and Community Services
April 2005



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the business of
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community services
professional

The Department would like to gratefully acknowledge all the stakeholders who supported the development of this document



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The Palliative Care Strategy was made possible through extensive consultation across the Northern Territory. The Department of Health and Community Services would like to gratefully acknowledge all the stakeholders who supported the development of this document through their participation in consultation workshops, interviews and the provision of feedback on the public consultation draft Palliative Care Strategy. In particular, contributions from the following people are acknowledged:

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DHCS

Territory Palliative Care teams, particularly

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Non-DHCS

Professor David Currow	Professor of Palliative and Supportive Services, Flinders University, Director Southern Adelaide Palliative Services
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Palliative Care Northern Territory	
Ron Parker	Consultant, Acute Care Services

The palliative care service in the NT is a compassionate and professional service



Mission Statement

Our mission is to provide high quality palliative care through an integrated service, accessible across the Northern Territory.

We will achieve this through a client, their family and carer-centred approach which allows choice and is responsive to cultural and spiritual needs.

“The palliative care service in the Northern Territory is a compassionate and professional service for people with a life-limiting illness, their families and carers. I have had personal experience with the palliative care service in Central Australia. They provided immediate assistance, thorough compassionate care, and enabled my friend to pass away with dignity. We are so appreciative of this team who looked after us so graciously. Palliative care is a wonderful service available for all Territorians.”

*His Honour Mr Ted Egan AO, Administrator of the Northern Territory
Patron of Palliative Care Northern Territory*

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community services
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better health for *all*
Territorians

Building Healthier Communities, DHCS



About this document

Northern Territory Palliative Care Strategy aims

The Palliative Care Strategy provides the pathways and direction for the growth, development and improvement of palliative care in the Northern Territory (NT) for the next five years. The Palliative Care Strategy recognises that people with a life-limiting illness, their families and carers have a central role in their care. The policy aims to provide choice and access to quality services across an integrated palliative care service. This document identifies opportunities for improving care for people with a life-limiting illness, their families and carers. The document provides a framework for stakeholders and will inform future policy development for palliative care.

Northern Territory Palliative Care Strategy development

The Department of Health and Community Services (DHCS) has a strong commitment to developing and improving palliative care in the NT. DHCS identified the need for future direction and successfully gained funding from the Australian Government Department of Health and Ageing in mid-2003 to achieve these objectives.

The Palliative Care Strategy has been developed as the result of many initiatives. These have included extensive stakeholder input across the NT, recent and past service reviews, the NT Palliative Care Policy (1999), community advocacy, and local and national palliative care research.

The Palliative Care Strategy is informed by the *National Palliative Care Strategy* (Australian Government Department of Health and Aged Care, 2000), the *National Indigenous Palliative Care Needs Study* (Sullivan et al, 2003) and the *Indigenous Palliative Care Service Delivery—A Living Model* document (McGrath et al, 2004). The health promotion foundational

documents of the Ottawa Charter (World Health Organisation, 1986) and the Jakarta Declaration (World Health Organisation, 1997) as well as the *Health Promotion Framework for Action* (Keleher and Murphy, 2003) have also been incorporated into the Palliative Care Strategy. The Strategy nests within the DHCS *Building Healthier Communities* framework (2004) providing direction for Health and Community Services from 2004–2009.

Palliative Care Clinical Reference Group

The Palliative Care Clinical Reference Group has provided guidance and direction for the Palliative Care Strategy development. The group was convened in January 2004 to provide input, advice and direction for palliative care across the NT. It consists of NT representatives of palliative care clinicians, management, executive and non-government organisations including Aboriginal community-controlled health organisations.

Priority Action Areas

The NT Palliative Care Strategy proposes initiatives in six priority areas. These are:

1. Territorians have improved access to palliative care services on the basis of identified care needs and informed choices.
2. People with a life-limiting illness, their families and carers access a flexible service model to ensure a holistic continuum of care.
3. The needs of people in rural and remote areas are reflected in palliative care and support services.
4. A skilled and competent workforce that is committed to palliative care is developed and nurtured.
5. Territorians have an improved awareness and understanding of palliative care through a health promoting framework that incorporates education, advice and support.
6. A sound data, continuous evaluation and evidence base is developed to inform service delivery and development.

A plan for the future

The Implementation Plan will follow, describing how the priority action areas will be achieved, the time frames for the actions and the areas or persons responsible. Reporting, monitoring and evaluation mechanisms are being built into the Implementation Plan to support quality procedural systems. The Palliative Care Clinical Reference Group will subsequently oversee and monitor the implementation of the Palliative Care Strategy.

The focus of the Palliative Care Strategy is on providing an accessible and quality service through a flexible service model for all Territorians. Particular attention is paid to the needs of those in rural and remote areas and the nurturing and development of a skilled and supported palliative care workforce.

Our vision is to ensure that all Territorians have long and healthy lives, and have a health and community services system that is responsive, accountable and effective



Building Healthier Communities

Our vision

Ensuring that all Territorians have long and healthy lives, and have a health and community services system that is responsive, accountable and effective.

The Palliative Care Strategy links with and supports the Department of Health and Community Services (DHCS) *Building Healthier Communities* framework providing direction for Health and Community Services from 2004–2009. The *Building Healthier Communities* framework “lays the foundations to meet the challenges and to make a real difference to the health and wellbeing of all Territorians” (DHCS, 2004).

The *Building Healthier Communities* framework focuses on:

- Giving kids a good start in life
- Strengthening families and communities
- Getting serious about Aboriginal health
- Creating better pathways to health services
- Filling service gaps
- Tackling substance abuse.

The Palliative Care Strategy directly addresses these foci. Actions within the Palliative Care Strategy include measures to support and strengthen families, and build capacity in communities in the area of palliative care. The Strategy has a strong focus on improving palliative care in rural and remote areas, and addressing the culturally appropriate palliative care needs for Aboriginal and Torres Strait Islander people.

Better pathways to palliative care have been identified and actions determined to enable improved care, closer to home. Strategic changes addressing gaps within the palliative care service will ensure a holistic continuum of care.

Building a Better System focuses on:

- Building quality health and community services
- Creating better pathways of working together
- Valuing and supporting our workforce
- Creating a health information network.

The Palliative Care Strategy recognises that sustainable improvements are dependent on robust systems ensuring quality services, development of information technology to improve client care and effectively manage data, and effective monitoring, evaluating and reporting mechanisms. The Strategy aims to strengthen partnerships with palliative care stakeholders across the continuum of care. Actions are described to nurture and support staff working in palliative care and to meet the challenges of providing effective palliative care across the Territory.

The Palliative Care Strategy will help to achieve the goals of the *Building Healthier Communities* framework for the NT and help develop and improve palliative care services for all Territorians.

You matter
because you
are you.
You matter to the
last moment of
your life, and we
will do all we can
to help you die
peacefully,
but also to live
until you die

Dame Cicely Saunders, 1976



The nature of palliative care

What is palliative care?

“Palliative care is an approach that improves the quality of life of people facing a life-limiting illness, their families and carers, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems.” (WHO, 2005).

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2005).

Palliative care principles

1. The focus of care is the person with a life-limiting illness, their families and carers who have a key role in care planning decisions
2. Sensitivity to cultural, religious and spiritual values is essential in the delivery of effective palliative care
3. Quality of life is enhanced by provision of access to physical, psychological, emotional, social and spiritual support in a culturally appropriate manner
4. Palliative care services are delivered by a collaborative interdisciplinary team providing care, education, advice and support
5. Bereavement support is recognised as a core component of palliative care
6. Palliative care is an integral part of the total health service
7. Access to palliative care is available throughout the Northern Territory.

(Northern Territory Palliative Care Strategy Workshops, 2004).

Palliative approach

The palliative approach aims to improve the quality of life of people with a life-limiting illness, their families and carers, by preventing and relieving suffering through early identification, assessment and treatment of pain, physical, psychosocial and spiritual needs (World Health Organisation, August 2004). This definition implies that people with a progressive fatal illness, including illnesses other than cancer, may benefit from the palliative approach. Furthermore, the approach is not confined to the end stages of an illness (Kristjanson et al, 2003).

Underlying the philosophy of a palliative approach is a positive and open attitude toward death and dying. This approach facilitates identification of the wishes of clients, their families and carers about care throughout a period of declining health and during end-of-life care (Australian Government Department of Health and Ageing, 2004).

Health promoting palliative care

Territory Palliative Care operates within a health promoting framework. A high priority for Territory Palliative Care is the provision of education and information regarding death and dying, the provision of personal and community social supports, and to encourage inter-personal problem solving where appropriate. Furthermore, palliative care services aim to build public policies that support health for people with a life-limiting illness by encouraging the reorientation of palliative care services and by combating death-denying health policies and attitudes in the wider society (Kellehear, 1999).

It's great to know that we have a service which is both professional and personal. You should all be very proud of the excellent care you provide for people who are terminally ill

Family member of a palliative care client



Profile of Northern Territory Palliative Care Services

Northern Territory Palliative Care Services

A wide range of health care workers and organisations provide palliative care services across the NT. Strong links between the specialist team at Territory Palliative Care and primary care providers help to ensure a smooth continuum of care for people with a life-limiting illness, their families and carers.

The specialist palliative care team

Territory Palliative Care commenced in 1995 as a new service model across the Northern Territory. The specialist service was developed partially in response to the 1995 *Rights of the Terminally Ill Act* and to better meet the growth in demand of clients seeking palliative care. In July 1997, Territory Palliative Care became two separate specialist operational units, one based in Darwin for the Top End and one in Alice Springs for Central Australia. The service has been guided by the Palliative Care Policy endorsed by Territory Health Services in 1999.

The specialist, interdisciplinary consultancy team of Territory Palliative Care provides professional expert support, advice and education to a wide range of people. These include clients, their families and carers, primary care providers in urban and remote areas, and to the community. The service also provides assessment and care for clients, their families and carers whose needs exceed the capability of primary care providers. The team provides advocacy and mediation and is accessible for consultation 24 hours per day for clients, their families and carers, and service providers. Bereavement and pastoral care services are available in the Top End and a limited bereavement follow-up is provided in Central Australia.

The primary care providers

People with a life-limiting illness receive high quality care from primary care providers. For those clients with relatively uncomplicated journeys, most, if not all, of their needs may be met by primary care providers. The specialist palliative care team supports the primary care providers to ensure their continuing development of skills and quality care. The primary care providers include:

- General practitioners, District Medical Officers, Medical Specialists
- Allied health staff
- Pastoral carers
- Community health nurses, remote health clinic staff
- Residential aged care facility staff
- Red Cross, Anglicare, Lifeline
- Aboriginal-controlled community health organisations
- Palliative care volunteers
- Complementary therapies
- Aboriginal Health Workers, Aboriginal Liaison Officers
- Home Care Services, Community Care Services, NT Carers, Carer Respite
- Acute care hospital and hospice staff
- Chelsea's, Golden Glow, HACC
- Somerville, Crisis Line, Centacare.

Integral Stakeholders

The peak bodies and agency organisations involved in palliative care include:

- Cancer Council of the NT
- Council of Remote Area Nurses of Australia
- Palliative Care NT
- Australian Government Department of Health and Ageing
- Aboriginal Medical Services Alliance NT
- NT Aboriginal Health Forum
- Top End Division of General Practice
- NT Council of Churches
- Australian Medical Association
- Australian Nursing Federation
- Central Australian Division of Primary Health Care
- General Practice and Primary Health Care Northern Territory
- Department of Veterans' Affairs
- Council on the Ageing
- Drake, Skilled Engineering.

Palliative care services are very limited and variable in some areas of the NT. The provision of equitable access to services is challenging given the remoteness of the NT, the geographical challenges, the cultural diversity and the limited workforce in rural and remote areas.

I have encountered people who are highly committed and highly motivated to ensure excellent care at the end of life for the people they served. The continuing commitment of each (specialist) team member and of each member of the (primary care) health service reflects the energy that continues to be put into providing care for people with life limiting illnesses

Professor David Currow, regarding the NT Palliative Care Service (2004) President, Palliative Care Australia

Palliative care service model

The NT palliative care service model aims to address the inherent challenges for service delivery in the NT. An integrated service delivery model has been developed to meet the palliative care needs of Territorians. The service operates within a client, their family and carer-focused model and provides culturally appropriate palliative care services.

Integrated service delivery model

The integrated service delivery model meets the needs of Territorians, accounting for the demographics, geographical setting, cultural differences, broad number of service providers and future directions both locally and nationally for palliative care (see Figure 1). The service model was developed in 2004 following stakeholder consultation. The model is similar to the current model of care however will result in clearer role delineation, strengthened partnerships, ongoing review of the service by all service providers, and will help the NT palliative care service grow and develop into the future.

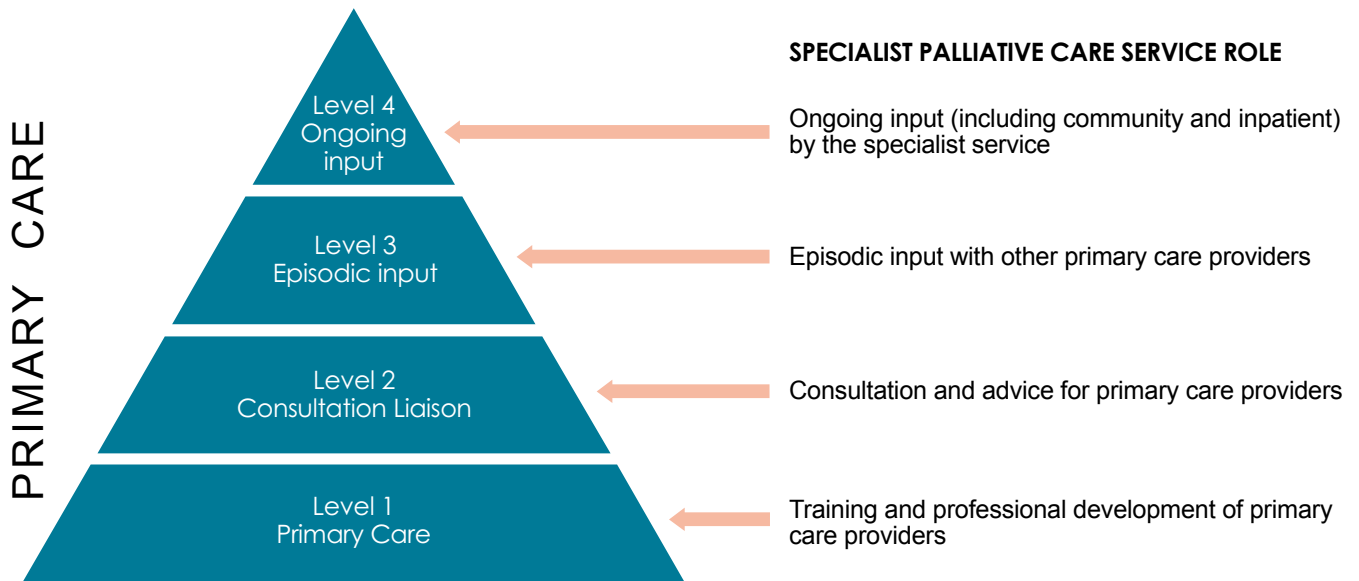
Many aspects of this model have been developed from the Palliative Care Australia Policy *A Guide to Palliative Care Service Development: A population based approach* (2005) and the review of the Tasmanian Palliative Care Service *Palliative Care in Tasmania: current situation and future directions* (Eager et al, 2004). The model helps to achieve several of the main priorities of the *Building Healthier Communities* framework (DHCS, 2004) by creating better pathways to health services and better ways of working together.

The integrated service delivery model is based on clients receiving different levels and types of service depending on their needs. Four levels of care are proposed and clients may move between different levels of care over time if their needs change. The primary care providers are integral players in this model. Every client has an identified primary medical carer and those providers are involved with the clients' care throughout their entire palliative journey.

A fundamental prerequisite for this model is that the skills and expertise of mainstream primary care providers are strengthened to allow them to deliver quality palliative care services. This will require strengthening of the role of the specialist palliative care service in education, professional development and consultancy services. Furthermore, a strong health promotion role is essential to provide education and support to community groups, families and carers.

This model is based on formalised clinical partnerships and role delineation between specialist and primary care services across the NT. The formation or continuation of regional palliative care networks will assist in the implementation of the integrated model.

FIGURE 1. THE INTEGRATED SERVICE DELIVERY MODEL

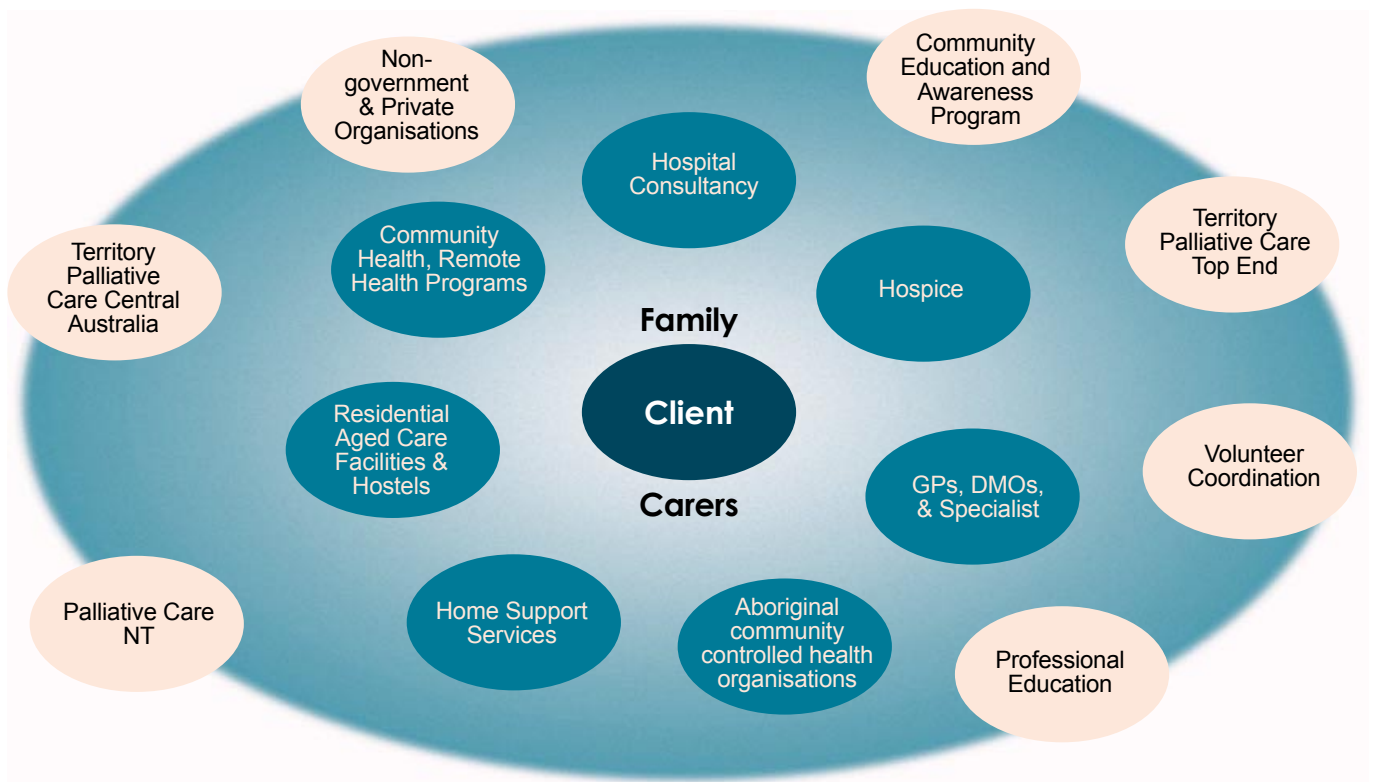


Adapted from *Palliative Care in Tasmania: current situation and future directions* (Eager et al, 2004), reproduced with permission of the Tasmanian Palliative Care Service.

A client, their family and carer focused model

The client, their family and carers remain the focus of care in the integrated service delivery model. The following diagram demonstrates the organisations available for clients, their families and carers.

FIGURE 2. A CLIENT, THEIR FAMILY AND CARER FOCUSED MODEL



Adapted from the *Palliative Care Policy* (THS, 1999).

The way palliative care is presented to Aboriginal people will determine their quality of life and also their bereavement management

Beverley Derschow, Aboriginal Health Worker, Territory Palliative Care

Culturally appropriate palliative care

The palliative care service operates under the Cultural Respect Framework (Australian Health Ministers' Advisory Council, 2004). The *Living Model—The Model in Action* is recognised for palliative care service delivery for Aboriginal and Torres Strait Island people in the NT (Derschow, cited by McGrath et al, 2004) (see Appendix, page 44). This model is a culturally appropriate model for Aboriginal and Torres Strait Islander people and aspects of this model may be readily transferable to all cultural groups.

Demand for palliative care services

People with a life-limiting illness, their families and carers present to Territory Palliative Care diagnosed with a wide spectrum of conditions. Malignancy is the main cause of death for clients managed by Territory Palliative Care (64% in Central Australia and 87% in the Top End for 2003/04). Central Australia has a higher incidence of clients with non-malignant conditions (36%). There has been a noticeable trend of an increasing number of clients referred to Territory Palliative Care with non-malignant conditions. The high rate of chronic disease in the NT, particularly in the Aboriginal and Torres Strait Islander population, has led to increased referrals to Territory Palliative Care. This increased demand on the palliative care teams has implications for funding.

A high proportion of the clients referred to Territory Palliative Care are Aboriginal and Torres Strait Islander people and from rural and remote communities. In Central Australia, 45% of the clients are Aboriginal and Torres Strait Islander people and in the Top End, 42% are Aboriginal and Torres Strait Islander people (2004). In Central Australia, 33% of clients are from remote regions and in the Top End, 42% are from remote regions (Territory Palliative Care, 2004).

The palliative care service offers support, as far as is practical, for anyone who wishes to die at home. In the Top End, 33% of clients died at home in Darwin, 18% died at home in remote areas, 6% died in Darwin residential aged care facilities, 36% died in Darwin hospitals, 4% in regional hospitals and 3% interstate. In Central Australia, 6% of clients died at home in Alice Springs, 9% died at home in remote communities, 17% died in Alice Springs residential aged care facilities, 59% died in Alice Springs Hospital, 5% in Tennant Creek Hospital and 3% interstate (Territory Palliative Care, 2004).

A bereavement service is offered in the Top End, and is predominantly accessed by non-Aboriginal and Torres Strait Islander clients (92%). Although Central Australia does not have a specific bereavement service, Territory Palliative Care is able to refer clients to several organisations for bereavement care.

The most common age range of clients in Central Australia is the 70–79 year old group (23%) followed by the 50–59 year old age group (18%). In the Top End the 50–59 year old age group is the most common age range of clients (23.5%) followed by the 60–69 year old age range at 23% (Territory Palliative Care, 2004).

Given the high mortality and morbidity rate of Aboriginal and Torres Strait Islander people, and the high proportion of Aboriginal and Torres Strait Islander and remote clients, an increased focus on palliative care services to remote areas is required.

There are many ways of caring for a sick person. Everyone is special and different. People might belong to different cultures or countries or they might speak different languages. So it's really important to look after them properly their way

Many Ways of Caring – the Aboriginal Palliative Care Paintings Project, Central Australia



Challenges for palliative care in the Territory

Demographics

The NT has a relatively small population of approximately 200,000 people, dispersed over one-sixth of the Australian land mass. Much of this land is not accessible during the wet season. The population includes a diversity of cultures and languages.

The NT has a high Aboriginal and Torres Strait Islander population (29%) compared to the rest of Australia (2%) (ABS, Cat 1362.7, accessed August 2004). Some 71% of these Aboriginal and Torres Strait Islander people live in rural and remote areas of the NT. Generally, this population component is highly mobile with regular intra-Territory and inter-state movement across neighbouring borders to maintain connections to kin and country. By contrast, 83% of non-Aboriginal and Torres Strait Islander people live in the urban areas of Alice Springs and Darwin (ABS, Catalogue 1306.7, accessed September 2004). These figures highlight the difficulties in providing equitable access to health care services in remote areas.

The NT has a younger age structure than the rest of Australia, however, the average rate of increase in the aged population is higher. In the 12 months to June 2002, the number of persons aged 65 and over increased by 4.9% compared to 2.2% nationally. People aged 65 years and over are projected to increase to 12% of the NT population in 2051 compared with 4% in 2002 (ABS, Catalogue 4102.0, accessed August 2004). Although the mean age is younger in the NT, the increasing ageing population will significantly affect palliative care services in the future.

Territory Palliative Care faces many challenges in providing equitable services across the NT. The population is culturally diverse, dispersed across a wide area and has an increasing ageing population. These population characteristics impact significantly on the delivery of palliative care services in the NT.

Health status

Vast differences in health status are apparent between Aboriginal and Torres Strait Islander people and non-Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander people have a higher morbidity rate, a higher incidence of chronic disease and an average life expectancy 15 to 20 years lower than that of non-Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare, 2004). Aboriginal and Torres Strait Islander people have a lower socio-economic status, lower education levels, higher levels of unemployment and higher levels of substance misuse.

By contrast, the non-Aboriginal and Torres Strait Islander population of the NT has a similar health status to that of other Australians and significantly better than Aboriginal and Torres Strait Islander people. “Getting serious about Aboriginal health” is a key priority for DHCS (*Building Healthier Communities*, DHCS, 2004).

Health Workforce

High levels of transience characterise the NT workforce. Despite a fairly stable specialist palliative care workforce, the primary care services in urban and remote areas have a relatively high staff turnover. Furthermore, difficulties are experienced with staff recruitment to the NT and subsequent retention of staff, resulting in challenges to develop programs, offer regular training and maintain a consistent knowledge base in palliative care, particularly amongst primary carers. To address the challenges of a transient workforce, Territory Palliative Care has made education of service providers and families an essential part of its work and has developed a variety of means to deliver palliative care education.

Cultural diversity

One of the greatest challenges for palliative care is to provide a service that is culturally appropriate to all Territorians.

Aboriginal and Torres Strait Islander people

Vast cultural differences are evident between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander societies. Territory Palliative Care is a national leader in the provision of culturally appropriate palliative care for Aboriginal and Torres Strait Islander people. The focus of the service is on the family and understanding the importance of relationships.

We as Aboriginal people are constantly going to funerals – we plan all our life around funerals

Dr Puggy Hunter (cited by Couzos and Murray, 2003)

Territory Palliative Care has an Aboriginal Health Worker available for Aboriginal and Torres Strait Islander families in the Top End. Since the appointment of this health worker, an increasing number of Aboriginal and Torres Strait Islander people have accessed the Top End service. Aboriginal and Torres Strait Islander people are sharing their cultural understanding with the team and are demonstrating stronger trust through the positive experiences provided by the team (Derschow, cited by McGrath et al, 2004). Good communication, combined with cross-cultural awareness, has been shown to be the key to a successful palliative care service.

Many Aboriginal and Torres Strait Islander people do not speak English with 70% of Aboriginal and Torres Strait Islander Territorians speaking another language at home (Northern Territory Office of Aboriginal Development, cited by Lowell, 2001). Poor communication can occur due to a limited number of interpreters or cultural brokers available in the NT, which can lead to misunderstandings and reduced uptake of services by Aboriginal and Torres Strait Islander people (Sullivan et al, 2003). Wherever possible interpreters, Aboriginal Liaison Officers and Aboriginal Health Workers are utilised to improve communication and provide advocacy and cultural brokerage for clients and their families.

Multi-cultural

The NT is a multi-cultural society with a large number of people from non-English speaking backgrounds. Territory Palliative Care ensures that practising culturally appropriate care is the cornerstone of its practice. Interpreters are utilised whenever possible and information is provided in other languages to ensure good communication and relationships are achieved. Furthermore, the service practices cultural safety and respects the client's worldview and experience.

Remote services

The provision of services to people living in remote areas provides a great challenge that requires innovative approaches. Potential barriers include the difficulty in accessing clients due to their isolation, inaccessibility during the wet season, unreliable telecommunications, few respite services and difficulties in transport and maintenance of equipment to remote areas. In addition, difficulties arise for remote clients and their families when services are required in the larger centres, including accommodation and transport costs.

Only a small number of specialist palliative care staff provide consultative services to remote areas of the Northern Territory. Allied health services to remote areas is limited and sporadic. As the rural and remote clientele make up almost half of the service, the Territory Palliative Care team has developed innovative strategies to address these issues.

These include the use of tele-conferencing, up-skilling health workers, clinic staff and carers in communities, building relationships, utilising the dedicated palliative care beds in regional hospitals for clients and their families, and assisting with end-of-life care in the community by the Territory Palliative Care team.

Continuum of care

Breakdowns in the continuum of client care occasionally occur, given the number of stakeholders involved in the provision of palliative care. The NT suffers a large general practitioner workforce shortage, resulting in difficulties with after hours medical care for palliative clients. Furthermore, clients and their families are often unaware of the available social supports, resulting in a strong advocacy role by the Territory Palliative Care team.

Family

The high incidence of single person families in the NT also provides challenges in palliative care service delivery. The lack of social and family supports, respite and frequent geographic isolation results in complex care requirements for such clients. A flexible service model and strong partnerships between services are required to ensure appropriate palliative care. The strengthening of families and communities is a key priority in the *Building Healthier Communities* framework for NT Health and Community Services (DHCS, 2004).

There are many challenges in providing an integrated, holistic, culturally sensitive palliative care service in the NT. Territory Palliative Care has addressed these challenges by providing innovative approaches and a flexible palliative care service.

Many achievements in palliative care have been gained since the commencement of the service



Where we are now

The palliative care service is a well-respected and highly valued service in the NT. Many achievements in palliative care have been gained since the commencement of the service.

What has been done

- Employed a Director of Palliative Medicine to provide clinical and strategic leadership for palliative care services across the NT
- Implemented a coordination and advisory structure through the establishment of the Palliative Care Clinical Reference Group who will oversee palliative care in the NT
- Commenced construction of a 12 bed Hospice on Royal Darwin Hospital campus
- Commenced and completed projects to improve palliative care in the NT as part of the National Palliative Care Program, in collaboration with the Australian Government Department of Health and Ageing including:
 - The *Indigenous Palliative Care Practice Principles* to contribute to improving the end of life care for Aboriginal and Torres Strait Islander Territorians
 - The *Program of Experience in the Palliative Approach (PEPA)* established to provide primary health care practitioners with an opportunity to develop skills in the palliative approach
 - The *Growth, Development and Improvement of Palliative Care Project*:
 1. Developed an NT Palliative Care Strategy to guide palliative care into the future
 2. Developed an integrated palliative care service delivery model
 3. Identified an appropriate information system to best meet the needs of the palliative care service

- Participated as lead researchers into Aboriginal and Torres Strait Islander palliative care through the development of the *“Indigenous Palliative Care Service Delivery–A Living Model”* project (McGrath et al, 2004)
- Enhanced profile of palliative care in the community
- Improved access to palliative care services across the Territory
- Incorporated Territory Palliative Care into the hospital accreditation process
- Commenced the integration of the hospice and palliative care services
- Assisted Palliative Care NT in the Australian Government-funded *National Palliative Care Equipment Program* with the procurement of palliative care equipment to assist palliative clients to die at home.

Where we are going

The following developments in palliative care have been commenced and will link in with the Palliative Care Strategy.

- Implement the NT Palliative Care Strategy
- Employ a volunteer coordinator in the Territory Palliative Care Top End team to train volunteers
- Implement the Integrated Service Delivery Model for NT Palliative Care Services
- Engage and strengthen relationships with all primary care providers in palliative care
- Increase Territory Palliative Care staff through the employment of two Aboriginal Health Workers
- Increase staffing corresponding with the increase in the ageing population
- Link to an interstate Centre of Excellence in palliative care
- Evaluation of palliative care services in three years
- Consumer participation in the Palliative Care Clinical Reference Group
- Annual consumer consultation regarding palliative care services
- Planning program every two years with participation from staff from the Centre of Excellence, palliative care service providers, consumers, families, carers and volunteers
- Enhance staff training
- Encourage volunteers and consumers in the involvement in palliative care
- Enhance the information system for the palliative care specialist team
- Provide education for general practitioners and other primary care providers in palliative care
- Continue to build linkages with Palliative Care NT and the Australian Government Department of Health and Ageing
- Strengthen partnerships with peak bodies associated with palliative care.

It takes special
people to do
what you do
and people even
more special to
do it so well

Family member of a palliative care client



Priority action areas

The following pages outline the strategies in each of the six key priority areas identified under the NT Palliative Care Strategy. The initiatives from these priority areas provide clear strategic direction for palliative care services to advance into 2005–2009.

- 1** Territorians have improved access to palliative care services on the basis of identified care needs and informed choices
- 2** People with a life-limiting illness, their families and carers access a flexible service model to ensure a holistic continuum of care
- 3** The needs of people in rural and remote areas are reflected in palliative care and support services
- 4** A skilled and competent workforce who are committed to the palliative approach is developed and nurtured

5 Territorians have an improved awareness and understanding of palliative care through a health promoting framework that incorporates education, advice and support

6 A sound data, continuous evaluation and evidence base is developed to inform service delivery and development.

Under each priority action area, strategies are identified, along with examples of what has been done and what the next steps should be.

Make sure that people take control of their illness however they want to. We have to allow people to make their own choices regarding care in the last stages of life. Make sure that people get the right story

Participant, Palliative Care Strategy development workshop

1

Territorians have improved access to palliative care services on the basis of identified care needs and informed choices

The NT Palliative Care Strategy recognises that people with a life-limiting illness, their families and carers require information regarding options for their future care and desire to be actively involved in making care planning decisions in the way that they wish. For this to be achieved, strategies such as advanced care planning, improving access to palliative care services, supporting the family and carers, and ensuring culturally appropriate care must be addressed.

Strategies

- Provide people with a life-limiting illness, their families and carers, with the opportunity to make an informed choice regarding their future palliative care
- Provide people with a life-limiting illness, their families and carers, with the opportunity to make informed choices regarding location of palliative care
- Improve access to palliative care services across the NT
- Support families and carers of people with a life-limiting illness
- Provide access to culturally appropriate palliative care services across the NT.

What we have done

- Applied for funding to the Australian Government for the Respecting Patient Choices Program to assist with advanced care planning for end-of-life care
- Engaged an independent consultant to develop options for future radiation oncology services in the NT
- Conducted an independent review of the Palliative Care Service.

Where we are going

- Ensure clients, their families and carers, are provided with the opportunity to make informed choices for future care
- Ensure clients, their families and carers, are actively involved in early advanced care planning across the care continuum to determine needs, culturally appropriate responsibilities and location of care
- Actively support flexible palliative care options for clients, their families and carers, in the desired location of care
- Increase palliative care outreach services to remote and rural areas of the NT
- Investigate and improve transport options for palliative clients and their families, including options to return to country where possible
- Increase access to and utilisation of tele-health facilities to enhance client management
- Provide access to the specialist palliative care service for consultation across the NT on a 24 hour basis
- Review after hours palliative care service in Darwin and Alice Springs
- Work toward improving respite care services in the NT
- Provide access, where possible, to support services such as pastoral, spiritual, home and personal care and social support services
- Provide access to bereavement care that is culturally appropriate for clients, their families and carers
- Provide cultural brokerage for clients, their families and carers, including increasing the number of Aboriginal Health Worker staff in the specialist palliative care teams
- Integrate cultural security policy in the cultural respect framework for palliative care services
- Ensure cultural awareness training for health staff includes a component regarding Aboriginal and Torres Strait Islander cultural practices surrounding death and dying.

By working with all areas of Government, and with the community and its organisations, we will build healthier and stronger communities

Building Healthier Communities, DHCS

2

People with a life-limiting illness, their families and carers, access a flexible service model to ensure a holistic continuum of care

A flexible service model is required to meet the palliative care needs of Territorians. The provision of equitable palliative care services across the NT is difficult given the inherent challenges for service delivery in the NT. These include the remoteness of parts of the NT, its geographical challenges, cultural diversity and limited workforce in rural and remote areas. Strong partnerships between primary care providers and the specialist palliative care team must be forged to ensure a seamless continuum of care for people with a life-limiting illness, their families and carers.

Strategies

- Strengthen partnerships between specialist and primary care providers to ensure clear coordination of care
- Implement the Integrated Service Delivery Model for palliative care in the NT
- Review and formalise pathways of care for people with a life-limiting illness, their families and carers, regarding inpatient service delivery
- Enhance palliative care support services.

What we have done

- Formed the Palliative Care Clinical Reference Group to provide a coordination and advisory structure from a range of stakeholders for palliative care across the NT
- Reviewed the service model for palliative care and recommended the Integrated Service Delivery Model
- Commenced the integration of the hospice and palliative care services in the Top End.

Where we are going

- Commence a project to implement the Integrated Service Delivery Model and strengthen partnerships between specialist and primary care providers of palliative care
- Develop networks of palliative care service providers in each region to assist in formalising clinical partnerships, role delineation and implementation of the Integrated Model
- Continue to support the palliative care networks to provide input into palliative care service provision across the NT
- In collaboration with specialist and primary care providers, develop and communicate common standards, protocols and pathways for access to palliative care services, including after hours care
- Develop policies and formalised partnerships, links and networks with the Divisions of General Practice and the NT State Based Organisation to optimise the Integrated Service Delivery Model
- Develop and implement mechanisms to assist care co-ordination with primary care providers including Community Health, allied health, Aboriginal community controlled health organisations, residential aged care facilities, non-government organisations, volunteers, pastoral carers and carer organisations
- Develop protocols and communication between the hospice in Darwin, the NT Hospital Network and palliative care service providers
- Review discharge planning processes, including interstate hospital transfers, to manage care across the system
- Support and establish outpatient clinics for ambulant patients to encourage access to palliative care services
- Review medical officer admitting rights at Royal Darwin Hospital, Alice Springs Hospital and Darwin Private Hospital
- Promote a comprehensive pastoral care service for people with a life-limiting illness, their families and carers
- Facilitate access to complementary therapies in the care of people with a life-limiting illness, their families and carers
- Actively support the volunteer programs within the palliative care service
- Explore and provide bereavement care options in Central Australia
- Advocate for appropriately resourced allied health services for the care of people with a life-limiting illness, their families and carers

Territory Palliative Care is a great service and clients always sing their praises regarding the care provided. We have strong links between our organisation and the palliative care teams. This is evidenced by our Advanced Cancer Peer Support Group in Darwin which is co-facilitated by the organisations and leads to enhanced care for clients

Helen Smith, Cancer Council NT CEO

3

The needs of people in rural and remote areas are reflected in palliative care and support services

It is very important for many people on remote communities to go home to die. We need to do everything possible to ensure that this can happen

Participant Palliative Care Strategy development

Delivering high quality palliative care services to people in rural and remote areas of the NT requires collaboration and negotiation with many stakeholders. Providing services close to home is a priority for the NT Palliative Care Strategy.

Strategies

- Improve palliative care services in rural and remote areas
- Improve services in regional centres for rural and remote palliative care clients, their families and carers
- Provide timely access to equipment required for palliative care in rural and remote areas
- Provide a palliative care service to each community that is sensitive to Aboriginal and Torres Strait Islander cultural practices
- Improve access to respite services in rural and remote areas of the NT.

What we have done

- Formed a remote specialist palliative care team for the Top End including an Aboriginal Health Worker and a clinical nurse consultant
- Obtained funding from the Australian Government for the Implementation of the *Indigenous Palliative Care Practice Principles* to assist primary care providers in delivering culturally appropriate palliative care services to Aboriginal and Torres Strait Islander people and communities through the development of practical, useful resources
- Obtained funding from the Australian Government for the *Program of Experience in the Palliative Approach (PEPA)* to provide primary health care practitioners with an opportunity to develop skills in the palliative approach by undertaking a short, flexible, planned workforce placement with a palliative care specialist service
- Territory Palliative Care Staff members participated as lead researchers in the *Indigenous Palliative Care Service Delivery—A Living Model* project (McGrath et al, 2004), which developed an innovative model for Aboriginal and Torres Strait Islander palliative care.

Where we are going

- Investigate, develop and implement palliative care training and education opportunities for remote health clinics and visiting remote allied health and outreach service providers
- Collaborate with Aboriginal and Torres Strait Islander communities to investigate, develop and provide palliative care education, support and mentoring opportunities for Aboriginal and Torres Strait Islander people and staff involved in palliative care in rural and remote areas, and enhance two-way learning
- Collaborate with primary care providers to support patient choices regarding care and location of care
- Increase access to specialist palliative care services in remote areas
- Enhance the capacity of the Central Australian specialist palliative care team to increase rural and remote services in Central Australia and the Barkly region
- Improve access to transport for remote palliative clients requiring transfer to and from home and regional centres
- Co-ordinate and support palliative care networks in regional centres to raise awareness of services, determine equipment and resource requirements, determine and utilise existing services and monitor future directions for palliative care in the region
- Investigate options regarding improvements in palliative care services in the regional centres of Katherine, Tennant Creek and Gove
- Address short-term accommodation issues in regional centres for clients, their families and carers visiting for medical treatment from remote areas, including collaboration with housing agencies
- Ensure Territory Palliative Care is adequately resourced and equipment is readily available and maintained
- Review the hospital discharge planning process for palliative care clients to ensure adequate time for transport of equipment and medication for return to communities
- Provide comprehensive education to clients, families and carers about palliative care equipment prior to return to remote areas
- Endorse, support and implement the Indigenous *Palliative Care Practice Principles* Project to educate palliative care service providers about culturally appropriate practices
- Include a palliative care component to the cultural awareness programs for health care staff, including culturally appropriate palliative care
- Endorse the use of traditional healers, where appropriate, in the care of palliative clients and their families
- Investigate and work towards increasing respite options in Alice Springs, Tennant Creek and Katherine to prioritise palliative care clients for respite care
- Provide input into the Multi-purpose Service in Gove to ensure respite beds for palliative clients in East Arnhem
- Explore and advocate for increasing respite options for people in Aboriginal communities.

4

A skilled and competent workforce that is committed to palliative care is developed and nurtured

The importance of excellent palliative care was as strong a theme outside the (specialist) team as it was within

*Professor David Currow, regarding the NT Palliative Care Service (2004)
President, Palliative Care Australia
Professor of Palliative and Supportive Services, Flinders University*

People with a life-limiting illness, their families and carers, must have access to quality services and skilled staff to meet their needs. This priority action area recognises that all staff and volunteers involved in the care of people with a life-limiting illness, their families and carers, practise the palliative approach. Furthermore, care is provided by suitably qualified service providers who are supported in their educational needs. The Strategy also recognises the need for further Aboriginal and Torres Strait Islander peoples to be employed in palliative care service provision.

Strategies

- Ensure all palliative care service providers practise within the palliative approach
- Enhance the skills and provide support for primary health practitioners in providing care for people with a life-limiting illness, their families and carers
- Support the educational needs and enhance support mechanisms of the specialist palliative care workforce
- Increase participation of Aboriginal and Torres Strait Islander people in palliative care
- Ensure palliative care staff training and services meet current best practice.

What we have done

- Implemented the Australian Government funded *Program of Experience in the Palliative Approach (PEPA)* to provide primary health care practitioners with an opportunity to develop skills in the palliative approach
- Presented a submission to the Australian Government for PEPA 2, a program to include Medical Officers and Palliative Care Clinical Specialists in the PEPA program
- Implemented the Australian Government funded *Indigenous Palliative Care Practice Principles* to assist palliative care professionals in providing culturally appropriate services to Aboriginal and Torres Strait Islander people and communities.

- Employed an NT Director of Palliative Medicine
- Provided education for nursing students at Charles Darwin University and the Centre for Remote Health
- The Territory Palliative Care team assisted in the development of the Flinders University post-graduate subject “Palliative Care for Indigenous Populations: Health, Culture and Society”.

Where we are going

- Support the educational needs of the specialist palliative care workforce to meet consultancy and client complex care needs
- Enable and fund regular professional development opportunities to improve skills and encourage retention of staff
- Enhance primary health practitioners’ knowledge and skills in palliative care including education and participation in the Program of Experience in the Palliative Approach (PEPA) program to enable primary care providers to gain professional exposure to, and experience in, palliative care in providing care for people with a life-limiting illness, their families and carers
- Provide education across a broad range of health care providers to endorse palliative care as an integral part of the health care system, with all health care providers responsive to the clinical and social needs of people with a life-limiting illness, their families and carers
- Provide education to the client, their family and carers to promote the palliative approach
- Support and enhance the skills of the specialist team and the primary care practitioners in working collaboratively across professional boundaries
- Work with academic institutions to identify opportunities to influence education to promote palliative care
- Establish effective, sustainable mechanisms for debriefing and ongoing clinical support
- Strengthen Territory Palliative Care teams by improving links between the Top End and Central Australian branches
- Develop formal links with a related interstate palliative care Centre of Excellence
- Develop information-sharing networks for palliative care services such as forums, newsletters and workshops
- Increase levels of Aboriginal and Torres Strait Islander people employed and trained in palliative care to reflect the palliative care client demographic
- Explore the options into including Aboriginal and Torres Strait Islander palliative care volunteers
- Ensure staff compliance with their relevant organisations’ professional standards, including continuing education
- Enable regular performance development opportunities to improve skill and encourage retention of staff.

PEPA participants have gained insight and confidence in using the palliative approach for their clients with a life-limiting illness, their families and carers. As a result of the program offering a workplace placement for primary care providers with the NT palliative care specialist staff, the palliative care network of health professionals in the NT has been strengthened

*Julie Barnes, PEPA NT
Program Manager*

An essential part of our work is educating service providers and families in the community about effective ways of caring for Indigenous people with a serious illness

Beverley Derschow, Aboriginal Health Worker, Territory Palliative Care

5

Territorians have an improved awareness and understanding of palliative care through a health promoting framework that incorporates education, advice and support

The access to, and delivery of, quality palliative care is dependent on the awareness, knowledge and understanding of palliative care at a community and professional level. The community needs a general awareness of palliative care, how to access services and how to cope with the emotional and practical demands of care. Furthermore, an informed health sector, committed to the benefits of palliative care, will ensure effective palliative care service delivery.

Strategies

- Improve the knowledge and skills of families, carers and community groups regarding palliative care so they can better support people with a life-limiting illness
- Improve awareness and understanding of palliative care for people from multi-cultural backgrounds, ensuring culturally sensitive communication
- Improve the knowledge and understanding of the palliative approach for palliative care service providers
- Improve the knowledge and understanding of Aboriginal and Torres Strait Islander cultural practices relating to death and dying for palliative care service providers
- Build systematic awareness and recognition, at the health policy and decision-making level, that quality care for people with a life-limiting illness, their families and carers is an integral part of a health system.

What we have done

- Participated annually in National Palliative Care Week activities in conjunction with Palliative Care NT, including Memorial Services, Palliative Care Breakfasts and education sessions
- Developed Territory Palliative Care brochures to inform the public about palliative care, services available and the objectives of the service
- Increased awareness and understanding of palliative care across the NT through the development of the NT Palliative Care Strategy by conducting workshops, maintaining clear communication and development of the website.

Where we are going

- Develop and conduct health promotion programs and materials including education, training and information strategies for local community groups to enable their informed participation in the support of people with a life-limiting illness, their families and carers
- Develop and promote programs that provide practical support, care information, skills development and counselling for family members and carers, to support them in caring for people with a life-limiting illness
- Develop programs of community education about the availability and benefits of palliative care in meeting the needs of people with a life-limiting illness, their families and carers
- Foster and promote open discussion and acceptance of death, dying and related issues as integral parts of the lifecycle
- Develop and support the implementation of education and information regarding the palliative approach for all primary care providers and organisations providing services utilised by palliative care clients
- Improve links with social support services to ensure people with a life-limiting illness, their families and carers are informed of their entitlements surrounding palliative care
- Promote open, honest and culturally appropriate communication regarding palliative care for people from multi-cultural backgrounds, including the use of interpreters and culturally appropriate resources
- Collaborate with people from remote communities and their organisations to engage advocates for palliative care and explore options to support, train and fund palliative care Aboriginal Health Workers, carers and volunteers
- Identify cultural practices relating to death and dying in Aboriginal and Torres Strait Islander communities and endorse practices into mainstream services
- Provide cultural awareness training for palliative care service providers relating to Aboriginal and Torres Strait Islander practices surrounding death and dying
- Strengthen collaboration between palliative care providers and multi-cultural communities to ensure two-way learning
- Recognise and respect customs, values and spiritual beliefs for all people from all backgrounds
- Ensure that policy makers have an increased awareness of deficiencies in the current systems to address the relevant issues
- Encourage and support the adoption and implementation of the Palliative Care Strategy by key stakeholders
- Develop and support mechanisms for consumer involvement and input in the development of palliative care policy.

The Government will build effective, innovative and sustainable health and community services, and will enforce high standards of accountability and quality

Building Healthier Communities, DHCS

6

A sound data, continuous evaluation, and evidence base is developed to inform service delivery and development

Essential elements underpinning an effective, quality palliative care service are sound data and a strong evidence base. The enhancement of a co-ordinated data monitoring and evaluation system, combined with a comprehensive information system will result in improved outcomes for monitoring, assessing and planning of palliative care services. Continuous quality improvement, research and implementation of the NT Palliative Care Strategy will aid in the future development of the palliative care service.

Strategies

- Coordinate, develop and extend existing data sets to establish a palliative care data management function
- Tailor the palliative care information system to accurately achieve the palliative care teams' data and reporting requirements
- Foster a culture of continuous quality improvement that enhances best practice and improves quality of care and services provided
- Develop appropriate performance indicators, monitoring and evaluation mechanisms to ensure achievement of the Palliative Care Strategy
- Participate in national initiatives to improve quality palliative care
- Promote, support and initiate research in palliative care to achieve best practice and develop the NT service as a leader in palliative care.

What we have done

- Completed a project to identify an appropriate information system for the specialist palliative care team
- Recommended a further project and commenced plans to tailor the information system function and reporting needs for the palliative care service
- Achieved accreditation in both the Top End and Central Australian Palliative Care teams
- Participated in the development of the National Performance Indicators and National Standards co-ordinated by the Australian Government Department of Health and Ageing.

Where we are going

- Develop a palliative care information system management group which is on-going to address issues relating to data sets, reporting and the palliative care information system
- Revise the palliative care information system to address gaps, implement changes and ensure a user-friendly, comprehensive system is utilised to provide accurate and useful data for monitoring, assessing and planning for future palliative care
- Participate in projects to integrate information systems across the health sector
- Establish monitoring, reporting and evaluation cycles for palliative care data across the care continuum to plan for current and future service delivery and resource allocation
- Engage staff in relevant quality activities and ensure clinical practice is evidence based
- Develop a feedback mechanism from all key stakeholders and consumers to improve quality performance
- Support the Palliative Care Clinical Reference Group through the provision of sound data and evaluation to provide advice, direction and best allocation for resources for NT palliative care
- Negotiate and develop agreements with relevant stakeholders regarding the priority areas of the Palliative Care Strategy, including action officers, timeframes, performance indicators and reporting mechanisms
- Collect current baseline data for the priority areas of the Palliative Care Strategy to enable clear identification of achievement of Strategy
- Continue to develop and implement programs arising from the National Palliative Care Strategy
- Work with the Australian Government Department of Health and Ageing in implementing the recommendations from the *National Indigenous Palliative Care Needs Study* (Sullivan et al, 2003) and the *Indigenous Palliative Care Service Delivery—A Living Model Project* (McGrath et al, 2004)
- Actively participate in recording of national palliative care performance indicators under the Australian Health Care Agreement
- Provide accurate data for national evaluation of palliative care services
- Provide opportunities to participate in national and Territory research, workshops, and conferences to further develop palliative care services in the NT
- Develop links to a palliative care Centre of Excellence to foster support, sharing of knowledge and research activities
- Continue to achieve the *Standards for Provision of Palliative Care for all Australians* (PCA, 2005) and gain accreditation.

Territory Palliative Care is a great service and clients always sing their praises regarding the care provided. We have strong links between our organisation and the palliative care teams. This is evidenced by our Advanced Cancer Peer Support Group in Darwin which is co-facilitated by the organisations and leads to enhanced care for clients

Helen Smith, Cancer Council NT CEO



Glossary

Advance care plans

Advance care plans are written documents that explain to health care staff what a client has decided regarding how they want to face their own death and are co-ordinated in advance. Ideally the plan involves ongoing discussion with the client, their family, carers and doctor to ensure that the client's and/or family's wishes are up to date (Australian Government Department of Health and Ageing, 2004).

Bereavement

Bereavement is the total reaction to a loss and includes the process of "recovery" or healing from the loss (Australian Government Department of Health and Ageing, 2004).

Carers

Carers are usually family members and sometimes friends. Their work is based on a pre-existing relationship and is often unpaid and often unrecognised. Carers provide informal assistance including mobility, self-care and communication (Australian Government Department of Health and Ageing, 2004).

Community

A specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social structure according to relationships which the community has developed over a period of time. Members of a community gain their personal and social identity by sharing common beliefs, values and norms that have been developed by the community in the past and may be modified in the future. They exhibit some awareness of their identity as a group, and share common needs and a commitment to meeting them.

In many societies, particularly those in developed countries, individuals do not belong to a single, distinct community, but rather maintain membership of a range of communities based on variables such as geography, occupation, social and leisure interests (World Health Organisation, 1998).

Cultural broker

A person who facilitates the border crossing of another person or group of people from one culture to another culture. The role covers more than being a language interpreter, some would suggest that cultural brokers are “interpreting” the culture (Michie, 2004).

Cultural respect

Cultural respect is the recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander peoples (AHMAC, 2004).

Framework for health promotion action

The framework incorporates downstream and upstream interventions including disease prevention, communication strategies, health education and empowerment, community and health development and infrastructure and systems change. These action areas incorporate primary care approaches, lifestyle/behaviourist approaches and socio-ecological approaches. (Murphy and Keleher, 2003).

Generalist palliative care model

Palliative care provided by community based health care professionals such as General Practitioners, community based registered nurses, community allied health staff, pastoral care.

Health care providers are not necessarily trained in palliative care. Care is provided to clients, their family and carers in a community setting eg outpatient, outreach and/or home-based setting. Service may meet client's identified needs without requiring specialist services (Palliative Care Australia Draft Policy, 2004).

General Practitioner (GP)

A general practitioner is a registered medical practitioner who is qualified and competent for general practice in Australia. A general practitioner:

- Has the skills and experience to provide whole person, comprehensive, coordinated and continuing medical care; and
- Maintains professional competence for general practice.

(Royal Australian College of General Practitioners, accessed September 2004).

Health promotion

Health promotion is the process of enabling people to increase control over, and to improve their health (World Health Organisation, 1986).

Interdisciplinary team

A functioning unit, composed of individuals with varied and specialised training, who co-ordinate their activities to provide services (Ducanis and Golin, 1979).

Jakarta Declaration

For health promotion in the 21st century the Jakarta Declaration identified five priorities:

- Promote social responsibility for health
- Increase investments for health development
- Expand partnerships for health promotion
- Increase community capacity and empower the individual
- Secure an infrastructure for health promotion.

The Jakarta Declaration also promoted comprehensive approaches to health development, settings for health, participation to sustain efforts in health promotion and health literacy (World Health Organisation, 1997).

Life-limiting illness

A term that describes 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 (Palliative Care Australia, 2005).

Morbidity

Any departure, subjective or objective, from a state of physiological or psychological well-being (Last, 1995, cited in World Health Organisation, 1998).

Mortality

Relative frequency of death, or death rate, as in a district or community (The Macquarie Dictionary, 1997)

Ottawa Charter

The Ottawa Charter identified three basic strategies for health promotion: advocacy, enabling and mediating. These strategies are supported by five priority action areas:

- Building healthy policy
- Creating supportive environments
- Strengthening community action for health
- Developing personal skills, and
- Re-orienting health services.

Pastoral Care

Pastoral care is responding to someone in need with help, encouragement and hope. The objective of pastoral care is to stimulate psychological and spiritual wellbeing by supporting a person's feelings and assisting with their reflections on life. Pastoral care enhances the total spectrum of health care (Benner, 1998).

Primary Care

“Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self reliance and self determination. It forms an integral part both of the country’s health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.” (World Health Organisation, 1978).

Primary care providers

Primary carers include general practitioners, community nurses, staff of residential aged care facilities and multipurpose centres. They also include 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 people with a life limiting illness. They are seen as the primary care service with specialist palliative care services involved on an “as required” basis. In general the substantive work of the primary care provider is not in palliative care. (Palliative Care Australia, 2005).

Specialist palliative care model

Specialist palliative care is based on the assumption that some clients require care beyond what primary or generalist providers can reasonably provide ie those with complex or resource intensive needs. Specialist care is often provided through consultancy with the client’s primary care givers. Specialist palliative care is inter-disciplinary and is provided across all three major settings—home, hospital and hospice. Services meet the needs of clients with complex or resource intensive needs that exceed capacity in primary care services. (Palliative Care Australia Draft Policy, 2004).

Volunteer

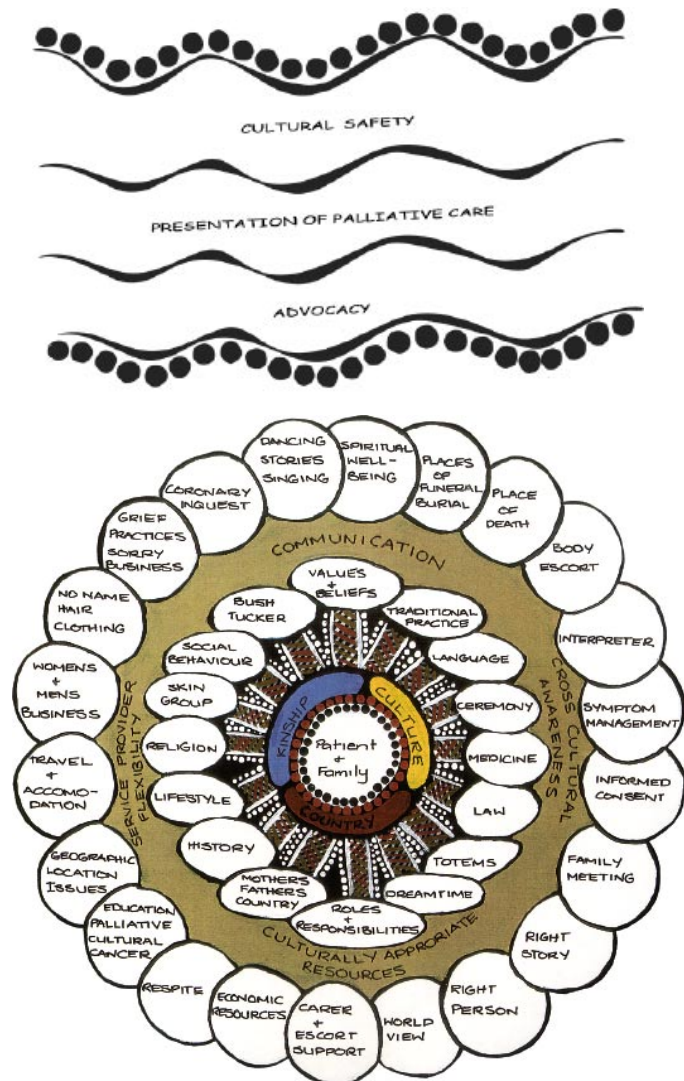
Volunteers are people who provide practical and emotional support for people with a life-limiting illness, their families and carers. They undergo recruitment, orientation and training and may fulfil such roles as making personal visits to the resident, listening, providing companionship and a supportive presence, and general support. (Australian Government Department of Health and Ageing, 2004).



Appendix

The model in action

An example of the model adapted for a palliative care service—diagram



(Derschow, adapted from McGrath et al, 2004)



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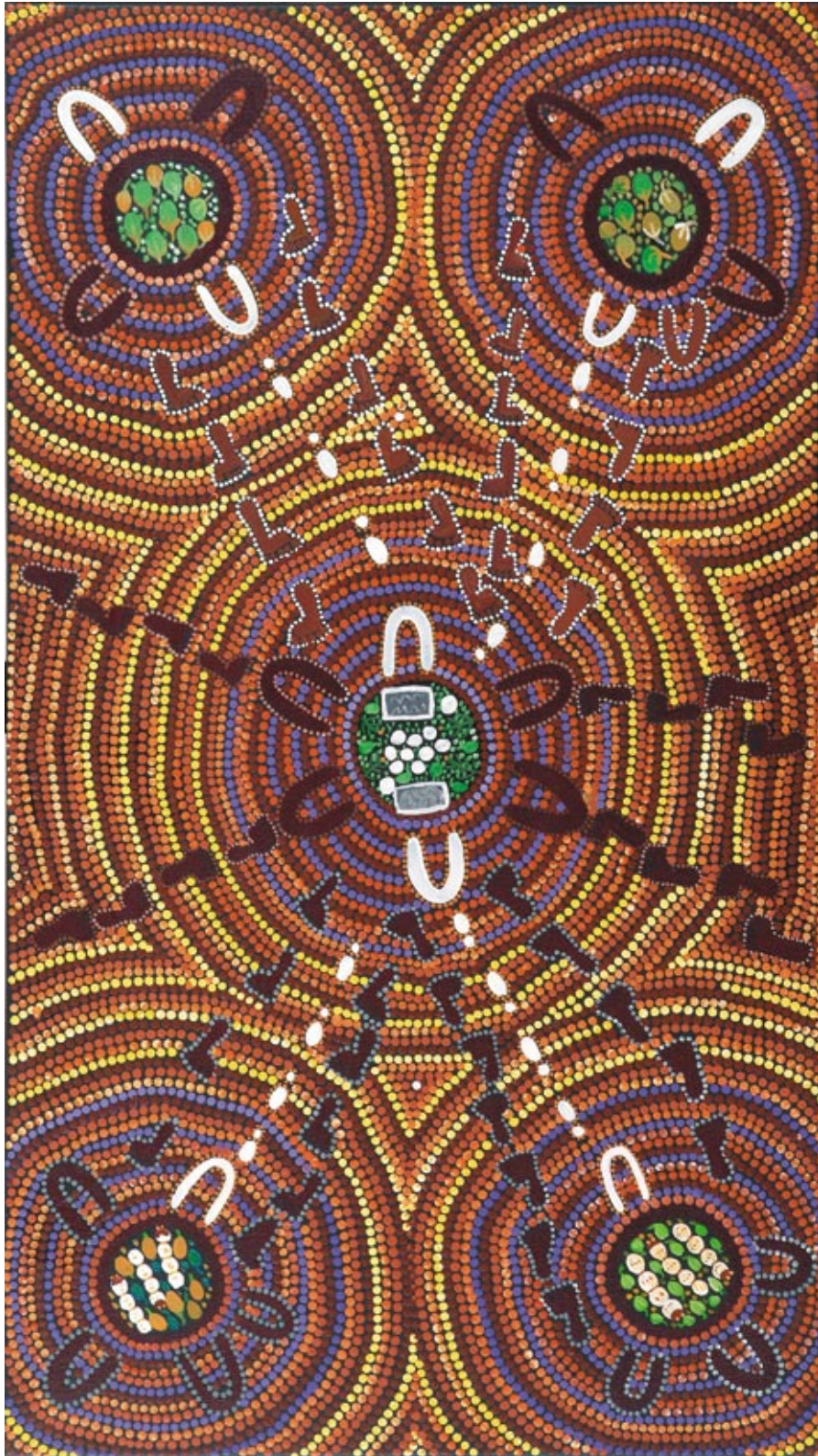
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'You need both types of medicine'

From the 'Many Ways of Caring: The Central Australian Aboriginal Palliative Care Painting Story'.

Jukkurpa Artist ~ Bessie Liddle.

