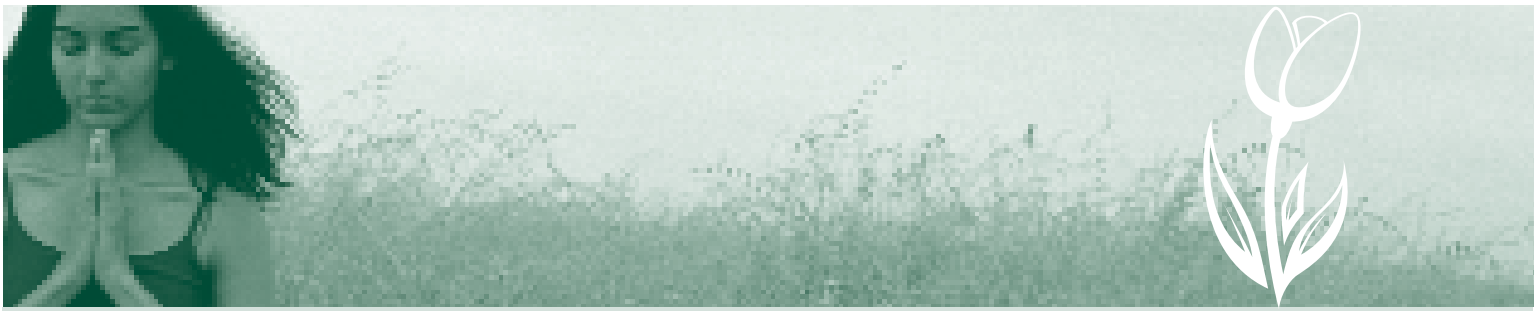
Chapter 15 – Northern Territory



Overview of palliative care in the Northern Territory

This section provides an overview of the context, structure, planning, delivery and monitoring of palliative care services in the Northern Territory (NT).

Recent history and context in NT

Dedicated palliative care funding has been in place in NT since 1995. Funding was allocated to NT to ensure that appropriate palliative care services were in place to better meet the growth in demand of clients seeking palliative care. The funding led to the establishment of a palliative care specialist service – Territory Palliative Care – with one team based in Darwin for the Top End and another in Alice Springs for Central Australia. The *Rights of the Terminally Ill Act* required additional palliative care services to be in place. The service has been guided by the Palliative Care Policy endorsed by Territory Health Services in 1999. In recent years the NT Hospice and Palliative Care Association has been a small but active advocacy group for palliative care services and in particular the establishment of a hospice in Darwin.

With a small population spread throughout regional and remote areas and a significant Indigenous population (nearly 30%) which is highly mobile, provision of quality and timely health services in home and community settings and access to hospital care is very challenging. Retaining a skilled health workforce, especially in regional and remote areas, is difficult. For people from remote communities there can be significant language and cultural barriers in accessing health services.

At one time NT had a more transient population, with younger people moving to NT to work and then leaving in their retirement. There is now a trend for older people to continue living in NT. Hence the overall population profile is increasing in age and there will be increasing demand for aged care and palliative care.

The Northern Territory was a party to the National Palliative Care Strategy (National Strategy) which was launched in October 2000 as a commitment of the Australian, State and Territory governments (along with other stakeholders) to the development of consistent palliative care policies, strategies and services, and to the delivery of quality palliative care that is accessible to all people who are dying.

Current arrangements in NT

Palliative care services are funded and managed through the Acute Care section of the Department of Health and Community Services (DHCS). Following a review of DHCS, the specialist palliative care teams have been brought under the management of the Acute Care stream of services rather than the Community Health stream where they were previously located.

Note that in Chapters 7–15, reference is made, where relevant, to numbered Objectives of the National Strategy. The Objectives are presented in full in Chapter 3.

A recent independent review of palliative care services has resulted in the creation of the position of Director of Palliative Medicine. This position is based at Royal Darwin Hospital and is responsible for palliative care services across the whole Territory. This role will strengthen leadership for palliative care and improve collaboration and co-ordination of services across NT.

Palliative care services aim to provide 'high quality services that are accessible through NT and responsive to the cultural and spiritual needs of clients'.[13]

Funding (Objective 2.2)

Funding for palliative care is principally provided through the 2003–2008 Australian Health Care Agreements to the States and Territories on a proportional basis, and through additional funding from the relevant State or Territory health budgets.

In 2004/05 the Australian Government allocated $700,000 for palliative care in NT and the NT Government also committed $700,000. This funds the two palliative care specialist teams. Palliative care is also one of the services provided by DHCS primary care providers that include community health nursing, allied health, hospitals – and some NGOs who receive funding from the NT Government. This is not separated out as specific palliative care funding.

Capital funding has been allocated for the construction of a 12-bed hospice on the Darwin Hospital campus by July 2005. From July 2005, Royal Darwin Hospital will have specific funding for up to 12 palliative care beds in the hospice. The current framework document for DHCS, *Building Healthier Communities*, commits to the construction of the hospice and to the 'development of palliative care services elsewhere in NT'.

Other funding for research and time-limited projects is reported in 'Palliative care activity in the Northern Territory' (page 171).

Service delivery structure (Objective 2.4)

The DHCS website has comprehensive information on palliative care principles, eligibility, access, client rights and the current Territory palliative care model.

There are two specialist palliative care teams, based in Darwin and Alice Springs. The two teams provide consultative services to clients, their families and carers in community, home and inpatient settings. The teams may assist with the provision of direct care when required. They also provide consultancy to primary care providers throughout NT. There are also a number of NGOs that deliver a range of services such as domiciliary nursing and respite care for palliative patients in the community.

The model proposed in the *NT Palliative Care Strategic Plan 2005–2009* (Draft Plan) is an integrated service delivery model with four levels of care through which patients may move over time and depending on their choices and needs. The model is based on strengthening partnerships between palliative care providers to ensure a holistic continuum of care for clients. The model is based on the review of the Tasmanian Palliative Care Service in 2004 and the population-based service planning document from Palliative Care Australia.

Equipment (Objective 2.4)

In NT, both specialist teams provide equipment for palliative care needs in the home, including to remote communties. The contribution of the national Palliative Care Equipment Program is being co-ordinated in the Territory by the NT Hospice and Palliative Care Association (see further details in 'Palliative care activity in the Northern Territory').

13. www.nt.gov.au/health/comm_health/palliative/palliative.html

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Planned arrangements in NT

The Department of Health and Community Services (DHCS) has undertaken a major strategic planning process in palliative care which has been funded by the Department of Health and Ageing from November 2003 to November 2004. The Northern Territory Palliative Care Clinical Reference Group has been given the responsibility of overseeing the development and implementation of a palliative care strategic plan for 2005–2009. Focus group consultations have been held across NT and by November 2004 a draft plan will have been circulated and consultation on the draft completed. The final plan should be released in May 2005. DHCS is then likely to seek funding for an implementation phase that will seek to promote the plan and to clarify the roles of different services in implementing the plan.

Planning, data collection, monitoring and reporting in NT

Planning (Objectives 2.2, 2.4)

The planning of palliative care services will be driven by the Draft Plan, which is currently being finalised.

Data collection and reporting (Objectives 2.1, 2.2, 2.3)

Hospitals in NT report on palliative care patients through the National Minimum Dataset. Community health services also provide data on palliative care patients. In late 2004 there will be a review of reports generated to assess whether managers are receiving the most useful data.

As part of the Draft Plan there is a proposed strategy to 'develop reporting mechanisms to identify the extent and scope of palliation services'.

Advisory bodies (Objectives 2.2, 2.3)

The NT Palliative Care Clinical Reference Group will oversee the development and implementation of the Draft Plan. The group includes clinicians, health service managers and NGO representatives, including Aboriginal community controlled health organisations.

Key settings of care in NT (Objectives 1.2, 1.3)

There are four settings of care identified in the National Strategy: home, community settings, inpatient palliative care beds and units, and acute hospital care. The following describes NT's approach to the settings.

Hospital and communities

Primary care providers working in community health centres and Indigenous communities provide palliative care, as do acute hospitals in Darwin, Alice Springs, Katherine, Tennant Creek and Nhulunbuy. There are a number of NGOs that deliver a range of services such as domiciliary nursing and respite care for palliative patients in the community. There is a Director of Palliative Medicine in NT. The two specialist palliative care teams provide consultative services to clients, their families and carers in the community, home and inpatient settings. The teams may assist with the provision of direct care when required. They also provide consultancy to primary care providers throughout NT.

The Top End team has an Aboriginal health worker and a clinical nurse consultant who travel to remote communities to provide consultative services. From Darwin they can also provide teleconferencing, discharge planning, education, advocacy and support for people in remote communities. Supply of equipment is an important part of the service. The team also has a registrar, a

part-time resident medical officer, two clinical nurse consultants, a part-time occupational therapist, a social worker and a pastoral care worker.

The Central Australian team is located in the community health centre and has a part-time medical officer, a clinical nurse consultant and a nurse, as well as the capacity to call on allied health staff from community health.

There is an 1800 number with 24-hour advice and support from the specialist teams available across NT.

About 87% of patients seen by the Top End team and 64% seen by the Central Australian team have malignancy. The higher case load of patients with non-malignancy seen by the Central Australian team includes people with renal failure and chronic disease. The difference in rates between the two teams is partly due to the fact that renal patients in Darwin tend to continue their care with the renal team from Darwin Hospital.

Hospice

The hospice will be a free-standing facility in the grounds of Royal Darwin Hospital. It has been planned with the needs of the Indigenous population taken into account. The recent NHMRC-funded research project (see 'Reform, training and research in NT' on page 171) made a series of detailed recommendations on providing palliative care to Indigenous people and communities, including suggestions for making the hospice a culturally safe and appropriate facility. It is also expected that one of the Caring Communities Program projects which involves carrying out volunteer training and co-ordination will assist in planning for volunteer capacity at the hospice.

Note re respite care

The Commonwealth Carer Respite Centres (CCRCs), funded across Australia through the Ageing and Aged Care Division of the Department, provide information, referral, access and co-ordination of respite services (including in relation to palliative care). In 2003, specific funding for palliative care (nationally $11 million over four years) was added to the 'brokerage component' of CCRCs, requiring that 6% of brokerage money be spent specifically on respite related to palliative care. NT has three such CCRCs. The Draft Plan recognises the need to improve access to respite services in rural and remote areas.

Volunteers

The Draft Plan includes a strategy to 'encourage volunteers and consumers in the involvement of palliative care'. It also recognises the importance of engaging more Indigenous people in a range of different ways in palliative care from volunteer caring to reference group participation. The experience of the Caring Communities Program project in Darwin has suggested that only a small proportion of individuals and families currently accept formal volunteer involvement.

Key relationships with specific population groups in NT

A number of different population groups are identified in the National Palliative Care Strategy. NT's current approach to the key population groups is as follows.

Aged care

Only a small percentage of the clients currently seen by the specialist palliative care teams die in an aged care facility (6% in Darwin and 17% in Alice Springs). People in their care are more likely to die in hospital or at home. However, in some places residential aged care may be a source of respite care for palliative care patients.

Children and young people

The number of children requiring palliative care services is very small in NT. Over the last few years there have been about six children in need of care. While they are recognised as having special needs, there are no designated services for them.

Aboriginal and Torres Strait Islander peoples

About 40% of the clients seen by the Darwin-based specialist palliative care team are Indigenous people and about 40% of their clients are from rural and remote communities. In Central Australia, 45% of the clients are Indigenous and 33% of clients are from remote areas.

The NHMRC-funded project Indigenous Palliative Care Service Delivery – A Living Model (July 2004) conducted extensive consultation and research across rural and remote parts of NT (see 'Reform, training and research in NT' opposite). The study identified eight important principles that should underpin service delivery and be incorporated into a flexible model that can be applied in diverse situations but which is founded on 'advocacy for resources and infrastructure and cultural awareness' as a basis for providing Indigenous palliative care. The principles are:

1. Cultural safety
2. Equity in service delivery
3. Autonomy
4. Importance of trust
5. Humane, non-judgemental care
6. Seamless care
7. Emphasis on living
8. Respect.

The findings are being applied in the development of the NT *Palliative Care Strategy 2005–2009*.

Two of the Caring Communities Program projects (see 'Palliative care activity in the Northern Territory' opposite) are specifically about access of Indigenous communities to palliative care.

People with specific cultural and linguistic needs

There are large numbers of people in NT for whom English is not a first language, including many Indigenous peoples. There is also great diversity in cultural backgrounds, including long-established populations such as Chinese, Greek and Italian and more recent arrivals such as East Timorese. The palliative care teams use interpreters when needed, provide information in other languages and have respect for cultural safety and practices around death and dying.

People with cancer

The Northern Territory currently has no radiation services – cancer patients must travel interstate for radiation treatment. Alice Springs has a visiting oncologist from Adelaide. Hence cancer patients in NT may be linked into cancer services from other States. Palliative care services work at maintaining strong links with all cancer services, including oncology specialists, the Cancer Council and interstate services, so that there can be a smooth transition into palliative care for cancer patients when needed. In Darwin, 87% of the patients cared for by the palliative care team have been cancer patients.

People with HIV/AIDS

The number of people with HIV/AIDS in need of palliative care is currently low. The NT AIDS Council provides mainly education and prevention services but there are no NGOs or services specialising in palliative care services for this group.

People with post-traumatic stress disorders

The Northern Territory has no specific services for this group – each person referred to the palliative care service is assessed and services provided according to their individual needs.

People with pre-existing disabilities

Each person referred to the palliative care service is assessed and services provided according to their individual needs.

Activities in rural and regional NT

Rural and regional areas are a key population group within the National Strategy. In reality, the NT approach to palliative care is built around the impact of the Territory's relative isolation, the total size of its population and the spread of its population.

Carers

The Draft Plan notes that single-person families are common in NT and hence people may not have a family carer. Relationships among Indigenous families can also be complex. Although many people may be present in the home or community of an Indigenous client, there may be only one person who has responsibily for caring for that person or assisting in passing on information and decision-making. The Draft Plan suggests that strong partnerships between services and flexible service models are needed to help strengthen the role of families and communities as carers.

Key links with other strategies and frameworks in NT (Objective 3.2)

One of the features of the Draft Plan is the provision of palliative care services as an integral part of other health and support services. In addition to the Draft Plan there are some other key strategies and operational frameworks in NT which influence palliative care planning and practice:

- The current DHCS framework, *Building Healthier Communities*
- The NT Palliative Care Clinical Reference Group
- Cancer services
- Palliative Care NT
- The Palliative Care Reference Group (Central Australia).

Palliative care activity in the Northern Territory

This section provides additional information about projects, research, initiatives and influences in the broader palliative care sector in NT.

Reform, training and research in NT

There is a range of reform, training and research initiatives which have occurred, or are occurring, in NT. Some are funded through the National Palliative Care Program and are being conducted in NT; some are funded by DHCS; others arise through various grant and research arrangements.

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Some of the more significant initiatives in NT are described below.

National Contribution to Northern Territory Reform in Palliative Care (Objective 2.4)

The Australian Government, through the National Palliative Care Program, has offered funding to assist each of the States and Territories to undertake strategic activities that would progress the reform agenda in palliative care and support the policy, goals and objectives of the National Strategy. NT has used these funds to undertake the strategic planning process, which will result in the NT *Palliative Care Strategic Plan 2005–2009*.

Status	The Draft Plan is to be signed off by mid-2005
Evaluation	Evaluation undertaken throughout the project. The Plan will be evaluated in 2007.
Reports, information, materials	A website for the development of the Draft Plan was established in March 2004. Updates were posted on the site bi-monthly throughout the project A draft of the Plan for comment was posted on the website in the first week of November 2004 at www.nt.gov.au Reports provided to the Department of Health and Ageing

Program of Experience in the Palliative Approach (PEPA) (Objectives 1.3, 1.4)

This program provides primary health care practitioners with an opportunity to develop skills in the palliative care approach by undertaking a short and flexible program of planned work placement with a palliative care specialist service within a metropolitan or larger rural service.

There is a minimum of 50 weeks of supervised clinical placements available for NT primary care practitioners. The placements are predicted to be completed by May 2006. Of the total 37 weeks allocated, 45% of participants are registered nurses, 15% enrolled nurses or personal care assistants, 25% allied health professionals and 10% Aboriginal health workers. The placements are from five regional areas of NT; approximately 50% of the placements are from either remote or very remote localities according to ARIA (Accessibility/Remoteness Index of Australia).

The Northern Territory has applied for the expanded phase of PEPA (which will make PEPA available to GPs and other medical practitioners). They are seeking to provide three-to-four day placements within a metropolitan or larger rural service to 15 medical officers and eight specialist palliative care positions.

Status	A two-year program, with final completion May 2006
Evaluation	The evaluation of PEPA is provided through a nationally developed framework. All evaluations are forwarded through to the national co-ordinator
Reports, information, materials	Information, application forms, newsletter available on DHCS website www.nt.gov.au Reports to the Department of Health and Ageing

National Palliative Care Equipment Program (Objectives 2.2, 2.4)

The Palliative Care Equipment Program ($3.8 million over two years) is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The initiative (being administered through Palliative Care Australia) provides grants to organisations in each State and Territory for the purchase of equipment that can be loaned to families and carers for people choosing to die at home – particularly organisations in rural or remote communities or those with links to residential aged care facilities. In the Territory, the NT Hospice and Palliative Care Association has taken on the co-ordination role.

Status	In Central Australia, equipment has been purchased to the value of $50,000 from the first grant provided. In the Top End, the Association has acquitted the funding from the first grant. A second grant has been received.
Reports, information, materials	Palliative Care Australia reported to the National Palliative Care Program in October 2003

National Health and Medical Research Council (NHMRC) – Indigenous Palliative Care – a Living Model (Objectives 2.4, 2.5)

The National Palliative Care Program has created a research agenda (see Chapter 7) which includes activities occurring through the NHMRC. In NT, the NHMRC funded a project, Indigenous Palliative Care Service Delivery – A Living Model (July 2004). This project conducted extensive consultation and research across rural and remote parts of NT. The project grew from a collaboration between the specialist palliative care team and the principal investigator, an academic at Charles Darwin University, and had a national reference group. The consultation with communities was conducted by the Aboriginal health worker from the specialist team.

The key research questions were:

- What palliative care services are provided and are they meeting clients' needs?
- How can services be modified to deliver a culturally appropriate, innovative and exemplary model?
- What strategies are needed to develop and apply the model developed?

The study identified eight important principles that should underpin service delivery:

1. Cultural safety
2. Equity in service delivery
3. Autonomy
4. Importance of trust
5. Humane, non-judgemental care
6. Seamless care
7. Emphasis on living
8. Respect.

These principles are incorporated into the model described in the report which essentially is a flexible model that can be applied in diverse situations but which is founded on 'advocacy for resources and infrastructure and cultural awareness' as a basis for providing Indigenous palliative care.

Status	Project completed. The findings are being applied in the development of the Draft Plan
Reports, information, materials	Report at www.mcgrathresearch.net.au

Implementation of Indigenous Palliative Care Practice Principles

This project will be tailoring a learning guide developed by Wodonga TAFE. The goal of the training package is to upskill service providers to deliver culturally appropriate palliative care services to Indigenous people of Australia. The project plan in NT is to consult stakeholders and training facilities in NT to contribute to the modification of the training package to ensure relevance for the delivery of culturally appropriate palliative care to NT Aboriginal people.

Status	The program commenced in October 2004 and is funded until October 2005
Evaluation	Evaluation processes are being defined
Reports, information, materials	Information, application forms, newsletter available on DHCS website www.nt.gov.au Reports to the Department of Health and Ageing

Caring Communities Program projects in NT (Objective 1.2)

The National Palliative Care Program has provided one-off funding through the national Caring Communities Program for individual projects to improve the capacity of their communities to care for someone with a life-limiting illness – specifically to improve the proportion of time for patients to be cared for in the setting of their choice and improve satisfaction with care. Four projects from NT were successful in receiving funding.

Groote Palliative Care Support Service (Objectives 1.1, 1.2, 1.3, 1.5)

This initiative aims to respond to the particular needs of Groote Island, where there is a group of people with a rare hereditary and degenerative condition who are likely to need a range of services in the future. Hence the project is assisting to build the capacity of local people and services to manage future needs. The project is about forming partnerships with medical staff and developing carer teams and skills among primary care and aged care workers and family members. An Indigenous cultural consultant assists non-Indigenous staff to understand specific cultural requirements around palliative care and helps to develop protocols.

Status	Finishes July 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Six-monthly reports to the Department of Health and Ageing; developed a culturally appropriate flyer translated into language to raise awareness and understanding of palliative care

Greater Darwin Palliative Care Volunteer Support Project (Objectives 1.1, 1.2, 1.4)

This initiative aims to recruit, train, support and co-ordinate volunteers to work in palliative care in Darwin. It is being carried out by a project officer employed by the NT Carers Association. While recruitment and training have been successful, the demand for volunteers from patients and their families has not been as strong as first estimated. It is anticipated that volunteers trained through this project will be ready and available to provide support when the hospice is opened.

The original proposal was also to include Katherine. An Honours student from Darwin University was to conduct a feasibility study in Katherine regarding the viability of a volunteer program; however this was unable to proceed. Consultation with key stakeholders in the Katherine region concluded that the provision of a palliative care volunteer program was not viable in Katherine at this stage. Similar to findings from other areas, it was found that formal recruitment and training of volunteers in small country towns may not be viable where there are strong family and social networks which may not accept assistance outside of that network. However the project officer and members of the Top End Territory Palliative Care team are conducting a seminar in Katherine in April 2005 to promote the palliative care service and increase awareness and understanding of palliative care.

Status	April 2003 – May 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Six-monthly reports to the Department of Health and Ageing; brochures and posters developed

Visiting Specialist Program (Objectives 1.1, 1.2, 1.4)

This initiative aims to improve peer support for health professionals and co-operation and co-ordination between agencies in delivery of palliative care services through offering palliative care education to all health providers in central Australia.

Central Australia has a Division of Primary Care (rather than a Division of General Practice) and the project is managed by the Division. Education and training is being provided locally for specialists, primary health care workers and the community by bringing specialists from a range of associated palliative care fields to Alice Springs.

A series of topics have been identified and are being addressed in different ways – case presentations, workshops, conferences, resource development.

Status	June 2003 – July 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Six-monthly reports provided to the Department of Health and Ageing. Project officer assisted in the development of an Indigenous bereavement booklet.

Northern Care Frontier Services (Objectives 1.1, 1.2, 1.3, 1.4)

This initiative aims to identify and empower non-professional and professional people in palliative care in three Indigenous communities. The project is effectively trialling some of the components of the Guidelines for Palliative Care in Residential Aged Care (APRAC) specific to care of Indigenous people. The project has looked at choices for palliative care for Indigenous people.

Frontier Services, a division of the Uniting Church health and community services, is the largest provider of residential aged care in Central Australia. Phase 1 (consultation and action research) has been completed and actual trialling of the curricula has been completed.

Status	May 2003 – May 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Six-monthly reports; culturally appropriate educational material developed for palliative care

The peak body – NT Hospice and Palliative Care Association (Objectives 1.1, 1.2, 3.2)

The NT Hospice and Palliative Care Association has a membership mainly of service providers and is a small voluntary group with a branch in Alice Springs and Darwin. The Association has been active in lobbying on palliative care and raising community awareness of palliative care. It also distributes information for Palliative Care Australia on relevant projects. Members were involved in the equipment project and have played a part in National Palliative Care Week. The organisation has no government funding and no paid staff position. The NT Carers Association currently provides meeting space.

Commentary about the Northern Territory

This section provides a summary of the trends and influences emerging in palliative care in NT.

One of the advantages for NT in having a small population and limited services is that the key players in palliative care are easily identified, have a stronger potential to establish partnerships in planning and service delivery, and are generally well informed of the range of initiatives underway in palliative care.

The drivers of palliative care in NT appear to relate to:

- **Population demographics.** At one time NT had a more mobile population with younger people moving to NT to work and leaving in their retirement. There is now a trend for older people to continue living in NT. Hence the overall population profile is increasing in age and there will be increasing demand for aged care and palliative care.
- **Specific matters relating to the Indigenous population.** The Indigenous population continues to carry a significant burden of chronic disease. The NHMRC project has been important to progressing education and consultation on palliative care across NT Indigenous communities.

- **Rural and remote matters.** The challenges for palliative care in NT are similar to those for the delivery of any health services to rural and remote communties. Improving partnerships and service co-ordination, retaining skilled staff, managing travel for patients and families to hospital care or to home country, and having adequate resources for people to be cared for and to die at home are all ongoing challenges for communities and service providers. The opening of the hospice in Darwin will present new opportunities for delivering palliative care services to the people of NT.
- **Role of primary health care.** The proposed integrated model of palliative care may put a greater emphasis on the specialist teams to provide education and support for primary health care providers.

Further information

www.nt.gov.au/health/comm_health/palliative/palliative.shtml

Palliative Care Services homepage, Department of Health and Community Services at www.nt.gov.au/health

Indigenous Palliative Care Service Delivery – A Living Model. Report and Executive Summary. Funded by NHMRC (Research team: McGrath P, Watson J, Derschow B, Murphy S and Rayner R, July 2004)

Northern Territory Palliative Care Strategy, draft on www.nt.gov.au/health, November 2004