

Discussion Paper August-September 2009

Planning for the Future: Palliative Care in the Northern Territory 2010 Onwards

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DISCUSSION PAPER

PLANNING FOR THE FUTURE: PALLIATIVE CARE IN THE NORTHERN TERRITORY 2010 ONWARDS

The Department of Health and Families (DHF) is committed to the ongoing development and improvement of palliative care services in the Northern Territory. The first five year plan helped us achieve many things and this discussion paper is to support the development of the second five year strategic plan.

Planning for the future for Palliative Care services in the Northern Territory relies on what we have learnt and experienced about end of life care for those we have cared for or loved, or for planning our own care. Understanding the most important things to focus on for future planning in Palliative Care for the Northern Territory has been directed by many people's input already. The role of a strategic plan is to be visionary, conceptual, directional and consistent with national and best practice policy, guidelines and direction. This is in contrast to an operational plan, which is likely to be shorter term, tactical, focused, able to be implemented and easily measurable.

THE AIM of the plan is to achieve an agreed approach to end of life care which meets the realities, needs and priorities of Territorians.

WE ARE ASKING YOU FOR YOUR INPUT, TO MAKE SURE:

1. The information we have been collecting about what is most important is correct,
2. The way we are talking about what is important is in a way that everyone understands and can relate to; and
3. To give your ideas, expertise and experience about what we need to do to get where we say we would like to be.

1. Background

1.1 Understanding Where We Have Come From and Where We are Now

Assessment of the history and current position of Territory Palliative Care has been made by pulling together information from a lot of different areas. These include:

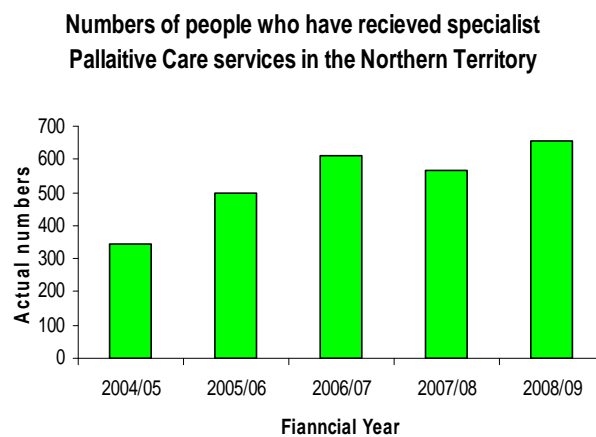
- The Clinical Reference Group (CRG) monitoring of the current Strategic Plan¹ and associated 'action' (Implementation) Plan. This includes data collected from both core operational service reports and project officer reports.
- Data showing changes in service delivery over time from specialist and community health staff input of service delivery through the NT government CCIS data systems.
- Data from Health Gains, NT government, used to gain an understanding of population need v's current service delivery to predict future service demand and therefore need for future growth planning against current national planning documents.
- Documentation and analysis gained through the half way evaluation of the NT Palliative Care Strategy in 2007.
- Questionnaire responses gathered at conferences and workshops in 2008.
- Project reports and associated recommendations.
- Historical service reviews.
- National documents outlining accepted standards and benchmarks, including research reports.
- Initial discussions with key individuals, stakeholders and groups.

¹ Palliative Care Strategy 2005-2009, Northern Territory Government, Department of Health and Community Services, April 2005

1.2 Services Provided to Territorians

A definition of Palliative Care which clearly identifies who the services are for ('target group') will be provided in the final Strategy document.

The graph below demonstrates growth recorded for Territorian palliative care services over the past five years.



654 Territorians were provided services through the Territory Palliative Care specialist team during 2008/09. This is an increase of 69.5%² since 2005/06.

Available data reports also show an increase in the percentage of Indigenous people receiving services and of people accessing palliative care with non-malignant related diagnoses.

Planning service delivery based on community needs and population in the Northern Territory, includes taking into account the specific and unique aspects of our population. Providing services according to Northern Territory population demographic and need often requires additional resources from standard service delivery models used in urban areas. Firstly, the need to support home based palliative care to people living in rural and remote area communities requires additional resources. The specialist palliative care team also provides an extensive training and education role within the community. Training is provided by staff to family and informal carers, communities, primary health care and other health professionals and through university courses teaching medicine, nursing and community services within the Northern Territory.

Although the NT has a younger population, understanding the impact of the relatively rapid rate of growth for our aged population and the impact of chronic disease rates in the Northern Territory, both of which are higher than any other jurisdiction in Australia, are also important.

A Guide to Palliative Care Service Development: A population based approach³, Palliative Care Service Provision in Australia: A Planning Guide⁴ and the

² This calculation reflects the total number in 2004/05 and the average of the following four years. Taking into account no recent staffing increases, it is likely service delivery has reached full capacity within current resource availability. This does not mean there is not increased demand.

³ Palliative Care Australia-A Guide to Palliative Care Service Development: A population based approach. PCA, Canberra, 2005.

⁴ Palliative Care Australia-Palliative Care Service Provision in Australia: A Planning Guide (2nd Edition). PCA, Canberra, 2003

*Standards for Palliative Care Provision*⁵ have been used as guiding frameworks and documents as closely as possible in their applicability to the Northern Territory work and living environments. These are currently considered the leading guidelines across Australian jurisdictions for service planning. The Australian Government has recently commissioned the Australian Institute of Health and Welfare (AIHW) to undertake a scoping project, which includes consideration of a range of methods related to service planning in Palliative Care. When available this information will assist in determining and recommending staffing needs to match quality service provision.

A BRIEF summary related to changing trends in palliative care will be provided in the final strategy document. This will include:

- Information about the general population numbers and health needs, geographical and cultural demographic information,
- Information about who is accessing the specialist palliative care services and community health services for end stage care and;
- Information about the work community health are doing in providing end stage care and support.

Data summaries will provide references to let those people who want to, access more in depth data and will site original sources.

1.3 Staffing as a Major Resource

Staffing is the most important resource in service provision for Palliative Care. Recommendations for staffing numbers and expertise, per 100,000 population for Palliative Care consultancy services is provided in 'Palliative Care Service Provision in Australia: A Planning Guide.'⁶

Reliance upon the planning guide raises two issues:

- Although the planning guide is not currently endorsed by the Australian Government, it is currently the benchmarking tool used in multiple jurisdictions across Australia. Detailed staffing information is viewed to be more relevant to the second level of planning (operational).
- No recommendations for primary or community health resource allocation for palliative care service provision are made in the planning guide.

The guide identifies a range of factors, likely to result in the need for additional resources. Many of these factors are directly relevant to the challenges faced by service providers in the Northern Territory, including:

- The nature of disease and related longer term support needs,
- Demographics of the client population,
- Increased acute care admissions due to carer crisis (lack of respite care availability),

⁵ Palliative Care Australia-Standards for Palliative Care Provision (3rd Edition). PCA, Canberra, 1999.

⁶ Note 2 @ pp25-31

- Number of people who do not have partner, family or friend/carer support available,
- Infrastructure limitations,
- Cultural differences leading to increased time needed for interpreters, consultation and cultural advice,
- Distance and remoteness noted to lead to 'some economies of scale' may not be achievable in services catering for small populations spread over wide geographical areas, and higher staffing levels may be needed'.

Additionally, staff report increased demand and expectation from the health sector and from the general community. This has been described to be a result of increased availability of services, word of mouth and positive experiences with the service, networking and promotion of palliative care services and projects.

Some factors related to our population, identified by Territory Palliative Care specialist staff, which result in high levels of complexity and increased workload include:

- Clients having few or no informal care networks,
- Additional time and travel costs required in ensuring access to services for remote locations.
- Cultural aspects of connecting, understanding and working with Aboriginal people requires the need for specialist visits to community for relationship building, knowledge and skills sharing and support, as well as specialist and direct service provision.
- Constraint upon resources is experienced by all care providers and directly impacts all service providers including specialist palliative care team, General Practitioners, community health professionals, community support services and other primary care providers.

These factors have a direct impact on planning for ongoing Palliative Care service delivery.

Much has been achieved in the past five years, including successful creation of and recruitment to identified positions. Total permanent staffing numbers in the specialist Territory Palliative Care service (not including hospice only staff) are approximately 16.7 equivalent full-time positions. Staff provide services to individuals and families in the Hospice, in our acute care hospitals and in the community, in both urban and remote settings. Approximately 29.9% of current staff are employed in Central Australia and the remainder (70.1%) are based in the Top End. This is consistent with current population demographics which indicate a 30% and 70% weighting for Central Australia and Top End respectively.

Additional staff are employed working within the service conducting project work, which is funded by the Department of Health of Ageing, with further funding provided to support program administration and policy within Health House. Hospice staffing is a separate service delivery and funding model (pooled from Royal Darwin Hospital) from the specialist consultancy teams.

Analysis of current staffing positions mapped against recommended staffing levels using the formulas for population, acute care beds and hospice allocated beds in the Northern Territory indicate significant growth is still required in staffing resource to meet the needs of our population as recommended in the *Palliative Care Service Provision Planning Guide*⁷.

The limitations on staffing numbers indicate a number of important things to consider in future planning. These include understanding current national approaches to staffing resource allocation and how this applies to workforce development in the Northern Territory. Whilst staff numbers remain limited the expectation that services will be able to continue expanding service delivery and training and develop new service areas requires consideration. This includes realistic planning to include the extent to which valuable resources can be realistically focussed on administration related to the national priorities of data and quality focussed outcomes within current resources.

Creative thinking and discussion about various staff resource issues include:

- how to develop and maintain specialist skills,
- how to best support staff and carers in providing direct palliative care services,
- the levels to which the skill development is desirable across all settings,
- strategies related to staff turnover and staff support and;
- the development of a clear approach to allocation of identified specialist positions, generalist champions and shared staff position resources across all services.

The overall staffing shortage highlights the vital importance of the ongoing need for strong relationships, partnerships, understanding and respect between the specialist teams, community health and primary health service providers, community care and support services and community volunteers.

⁷ Note 2.

2. Having a Shared Understanding and Approach

2.1 The Vision

The first step is to develop a realistic 'Vision' for Territory Palliative Care for the next stage of service strengthening and development in the Northern Territory. What will the service look like, how big will it be, who will be involved and what services will be delivered to our local communities.

2.2 The Mission

The nature of a service or organisation is often expressed in terms of its 'Mission'. This would describe the purpose and activities of core service delivery for Territory Palliative Care.

An example of this might be: *'Our Mission is to provide specialist palliative care, advice and services to ensure end of life care is of the highest possible quality, and suitable to the person and their circumstances, in the Northern Territory'*.

The central purpose and role of Territory Palliative Care is defined as:

- Clinical consultation services,
- training and education to family and informal carers, communities, primary health care and other health professionals, support service staff and within academic courses training a range of health professionals (medical, nursing, community services)
- clinical assessment,
- direct services provision,
- supporting and advocating for the wishes of a person who has a terminal condition in decision making, as far as practical, with respect to receiving care in the location of their choice,
- provision of support services that are to cultural, spiritual and bereavement needs of all involved with the service.

Our focus is the person with a terminal condition and their informal and formal care networks, be it their family, or others. We value a community-centred and informed decision making approach.

2.3 Values & Principles

Values and Principles guide the way day to day work is conducted including staff and organisational relationships with the general community, customers, families, carers, local community providers and other stakeholders.

Examples of this is the values of the Department of Health and Families⁸ being:

- Respect and cooperation,
- Responsibility to society,
- Pride in our work and;
- We are here for our clients.

DHF Corporate Strategic Plan underpins the values of Territory Palliative Care specialist services and community health services provided by the department. It may not however clearly show that the strategic plan is made up from what all stakeholders are working towards.

FOCUS QUESTION 1

How can palliative care services in the Northern Territory be made better in the next five years?
What do you think are the most important things that can be done to make services better?

⁸ Department of Health and Families Corporate Plan 2009-2012, Healthy Territorians Living in Healthy Communities, launched July 31st 2009.

3. Having a Shared Understanding of Main Purpose: What We Do and Why We Do It

Aside from assisting in the provision of palliative care services to clients, objectives should relate to the expectations and requirements of all the major stakeholders, including employees, and should reflect the underlying reasons for the funding of Palliative Care services.

3.1 The Objectives

Objectives need to be expressed in terms of the outcome or results we need and/or want to achieve in the medium to long term.

Some longer term objectives of a Palliative Care Strategy in the Northern Territory could be summarised as:

- To ensure Territorians are able to access quality end of life care.
- To support and ensure community education and support is provided and available for everyone involved in providing end of life care to people within their communities.
- To meet national standards and best practice expectations in the delivery of specialist services for end of life care in the Northern Territory.
- To ensure funding providers understand the demand for service and plan accordingly.
- To ensure Territory Palliative Care services, primary health care and chronic disease frameworks work together to support Territorians.
- Ensure we are engaged in best practice for skilled staff recruitment, support, training and retention in Territory Palliative Care services.
- Ensure partnerships are developed through relationship with providers in the care network and roles are clear.

FOCUS QUESTION 2

What do you like about palliative care services in the Northern Territory? What are the main important things they do and/or provide?

4. Developing Strategies from Shared Analysis

Future strategies are developed directly from the Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis. It is anticipated that in any complex system, the information from the analysis suggests a series of strategies or combinations of tactics that will address each of the main factors identified. SWOT analysis helps to identify possible strategies as follows:

- **Build** on strengths
- **Resolve** weaknesses
- **Exploit** opportunities
- **Avoid** threats

4.1 The Strategies Identified from the initial SWOT

Strategies provide effective guidelines by which the vision, mission and objectives can be achieved. They can cover Palliative Care in the Territory as a whole, or reflect priorities in particular operational or organisational areas in the provision of services to our population.

Attachment A provides information received from eight main stakeholder representatives and feedback from the Clinical Reference Group. From this information, tentative strategies have been identified. These might change if your feedback shows different priorities.

4.2 Key Strategies

- a) We need to develop an approach to remote area service provision in partnership with Primary Health Care (PHC) and other service providers such as Aboriginal Medical Services Alliance NT (AMSANT), Community Health Clinics and community nursing and General Practice Network, NT (GPNNT).
- b) We need to show that the services we are providing are of the best quality and within national frameworks for best practice
- c) We need to support and strengthen our workforce-that is: all the people providing services across the NT
- d) We need to make sure management and leadership is strong
- e) We need to develop, strengthen and formalise partnerships involved in the care matrix. This includes across all other specialist and general health programs such as renal, cancer and chronic disease.

The following important strategies were also identified:

- We need to advocate strategically for increased funding to meet increased need/service demand.
- In partnership with Aboriginal communities, organisations and leaders we need explore and embed our work in research and evidenced based frameworks. This would include working with national bodies for and creating national leadership opportunities in Indigenous Palliative Care.

- We need to identify and understand cultural expertise competencies and position in palliative care specialist service delivery in NT.
- We need to build a model to introduce cultural competency into service delivery.
- We need to develop contact lists and networks for specialised areas of palliative care eg: paediatric, unusual presentations-clinical, renal, cardiac, etc both intrastate and interstate.
- We need to develop an approach to bereavement and support for service users and service providers (including staff) in NT Palliative Care.

FOCUS QUESTION 3

What do they do best?

FOCUS QUESTION 4

Do you think there needs to be any changes made to palliative care service delivery? How could this be done?

FOCUS QUESTION 5

Is there anything you don't like about palliative care services?

5. Understanding the Priorities

A lot of information is already available to help us understand the priorities for planning in end of life care for the future in the Northern Territory. Some information is from past reports and some information is from what service providers, consumers and carers have already told us through questionnaires and interviews.

One of the most important things in asking for your feedback is making sure what we are saying is most important from the information we have is correct for now and the future.

5.1 Project Outcomes & Review Recommendations

Past reviews and projects in Palliative care have provided much guidance in how to develop the service over time. For the development of this discussion paper recommendations, identified priorities and outcomes have been summarised from:

- a) *Independent Review of Top End Palliative Care Services* by Professor David Currow, January 2004
- b) *Independent Review of Central Australian Palliative Care Services* by Professor David Currow, July 2004
- c) 2005-2009 NT Palliative Care Strategy Consultative Approach
- d) *Strengthening Partnerships in Palliative Care: Integration of Palliative Care Services Across the Northern Territory*, 2006
- e) *Interim Evaluation of the Palliative Care Strategy*, 2007
- f) Questionnaire Responses Summary, 2008

Most early recommendations have been achieved and therefore are no longer relevant. There are some recommendations however, that continue to be sources of concern for stakeholders and are yet to find comfortable and workable solutions and/or resources. It is worth examining whether they remain priorities for palliative care in the Northern Territory and if so, how can we understand what has stopped the successful implementation of the previous recommendations to assist new forward planning.

Major achievements & ongoing areas identified from past recommendations are summarised in the table below. It is important to note that many recommendations require ongoing and continual effort and will adapt and change over time.

Previous recommendations have been placed in categories or 'themes' which may help us understand how we can talk about how we group actions together into 'priority areas'.

GENERAL AREAS	ACHIEVEMENTS	ONGOING FOCUS REQUIRED
Strategy & Approach	Strategic planning across NT developed	Resource allocation by population, transparent process for allocation of resources, staff exchange, and clinical protocols to ensure equity
Service development & strengthening	<p>Consultative role and team developed which including the development of leadership and expertise.</p> <p>A service delivery model and role delineation model has been developed</p> <p>Indigenous service delivery model and resources have been developed.</p> <p>Service planning and funding includes remote area travel and outreach.</p> <p>Aboriginal Health Worker roles have been incorporated into the holistic team model of service provision.</p>	<p>Continuous data processes to support understanding service delivery and needs, planning, provision of streamlined care and able to demonstrate quality processes are not as developed as anticipated.</p> <p>Robust and responsive bereavement services. Need to link with social and emotional wellbeing services in primary health care.</p> <p>Three major areas of ongoing concern related to access to services are Equipment, Transport and Respite Care.</p> <p>Increased strengthening is desirable in Aboriginal Health Worker and cultural representation in services and resources.</p>
Working together & partnerships	<p>Strong NT wide network is operating.</p> <p>Hospital admission rights operating.</p> <p>Links with professional organisations both intrastate and nationally has occurred. This has included NT involvement in national data collection activities, pilot projects and presentations of project learning's at national conferences.</p>	Development and maintenance of partnerships
Education and Training and support for our care providers	Education is being provided in urban and remote areas.	Formal and clear staff support, debriefing and psychosocial support systems not developed.

Most of the areas above, which have been identified as requiring further action, are challenging for palliative care services in all Australian states and territories and some are current national priorities. This is particularly in the areas of:

- formal service provider support models,
- bereavement support and services,
- data collection for planning, quality improvement and management of services.

There are several national and local projects and reports that add to the information we have about what is required and how to do things well in planning and providing palliative care services. These include:

- the National Indigenous Palliative Care Needs Study,
- the Research Study into the Educational, Training and Support Needs of General Practitioners in Palliative Care,
- the 2009 Senate Inquiry Report ‘Who Cares...Report on the Inquiry into better support for carers’ and,
- local current projects in Program of Experience in Palliative Approach (PEPA) and remote renal service provision.

Copies and links to reports and information will be provided on the updated website.

5.2 Achievements and Unmet Goals Based on Previous Implementation Plan

The current strategy and Implementation Plan was monitored by the Palliative Care Clinical Reference Group across the six priority action areas. Some actions for Implementation applied to several of the priority action areas. The multiple achievements have been possible due to the work of Territory Palliative Care specialist staff, value added to by numerous Department of Health and Ageing funded projects and the commitment of community health and primary health care providers. A short summary highlighting the major achievements of the past five years is provided below. This has included highlighting areas where the expected outcomes were not achieved and more work is required.

Priority One: Territorians have improved access to palliative care services as required

<p>✓ People living across all health regions in the Northern Territory have had access to specialist services. Out patient services, services to people in hospital, hospice, residential care, home and community settings are provided.</p>	
<p>✓ Culturally appropriate resources and model have been developed.</p>	<p>! More work in Indigenous culturally appropriate service delivery required and remote service delivery models to be developed further.</p>

Priority Two: A flexible, holistic service model offering continuum of care

<p>✓ Care planning is occurring.</p>	<p>! Cares planning to be further developed and include supporting documentation.</p>
<p>✓ Advance care planning and involvement in national discussions has been ongoing.</p>	<p>! Advance care planning will require legislative changes, community education and broader implementation.</p>
<p>✓ NT wide networks have been developed, the Clinical Reference Group has stakeholders from relevant government and non-government service provision and policy areas working together.</p>	<p>! Strengthening of common standards and pathways developed with specialist and primary health providers is required.</p>
<p>✓ A bereavement project was completed, bereavement services are offered through both social work and pastoral care roles within the specialist team.</p>	<p>! A planned approach in bereavement and in particular, Indigenous specific bereavement approaches is still required.</p>
<p>✓ Holistic service model has been developed with integration of numerous professionals in the teams. This includes the addition of Aboriginal Health Worker roles in the specialist teams.</p>	<p>! Logistic difficulties such as limited access to respite, transport and equipment continue to impact on flexibility of service able to be provided to people in their home and communities. This often takes away from the educational and cultural brokerage expertise of the Aboriginal Health Worker roles.</p>

Priority Three: The needs of people in rural and remote areas are reflected in palliative care and support services.

<p>✓ Visits by specialist staff now occur in remote area communities. Linkages have been developed with key people in communities. Visits are supported through teleconferencing providing clinical support and discussion. A 24 hour number is available across the NT.</p>	<p>! Further development of linkage with community health workers and leaders and teleconferencing is required.</p> <p>! Information to support access to traditional medicine and healers requires further development.</p>
<p>✓ The Program of Experience in the Palliative Approach (PEPA) Project has enabled remote area and Indigenous staff to attend training and receive work experience and support. This has included the provision of education to communities across the NT.</p>	<p>! Aboriginal Health Worker role to incorporate education requires additional resources.</p> <p>! A sustainable model, process and resource information to support primary carers in remote communities needs development.</p>

Priority Four: A skilled, committed and competent workforce is developed and nurtured.

<p>✓ Staff have been appointed as identified as priority positions in the specialist team. Hospice staffing has been stabilised.</p>	<p>! Staffing numbers remain below national planning guide recommendations.</p> <p>! Difficulties in recruiting skilled staff when people leave is ongoing.</p>
<p>✓ Education and Training Opportunities have been made available through the PEPA Project and staff have been involved and presented at national conferences.</p>	<p>! Education and Training opportunities overall would benefit from increased coordination and a more planned and sustainable approach.</p>
<p>✓ A strong volunteer program exists in the Top End, based at the hospice.</p>	<p>! Development of a volunteer program in Central Australia is to be explored.</p>
	<p>! Formal processes for clinical supervision, regular debriefing and options for counselling and spiritual and cultural support for specialist and primary health care staff require development and implementation.</p>

Priority Five: Territorians have an improved awareness and understanding of palliative care.

<p>✓ Overall there has been a greatly increased knowledge and understanding of palliative and end stage care across the NT.</p>	<p>! More opportunities required to develop, promote and conduct education, training and information sessions and programs in local communities.</p>
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Priority Six: Data, evaluation and evidence base development

<p>✓ A Palliative Care Information Management Group (PCIMG) has been established. Staff have access to computers. Territory Palliative Care have participated in the national palliative care data collection surveys and report annually on the four National Palliative Care performance indicators. Team keep client data updated in CCIS.</p>	<p>! Data is not collected to demonstrate many outcomes and achievements in palliative care. Data reporting requires defining and development.</p> <p>! Baseline data is required for future monitoring.</p> <p>! Gaps in data have not been identified and a plan for approach in data set development is still required.</p>
<p>✓ A Quality officer position has been identified and Territory Palliative Care have participated in national pilot projects for Standards-quality reviews and audits</p>	<p>! Demonstrating quality is reliant upon many aspects of how we use data, and as above, defining and development of data related to quality is required.</p>
<p>✓ Relationships with research schools have been developed.</p>	<p>! Relationships require development for local evidence based outcomes.</p>

A challenge for us is to understand, if the priorities for the previous plan are still current, what needs to occur to ensure they can be achieved? This is more relevant to the second level of planning.

5.3 The Mid-Way Evaluation of the Strategy

An evaluation was conducted midway through the five year strategy⁹.

Overall:

- People were very pleased with palliative care services and thought skill and competence in providing palliative care services had improved.

⁹ The evaluation, conducted 2007 and was facilitated by use of some of the tools from: 'The Palliative Care Evaluation Tool Kit' developed at the University of Wollongong @ http://chsd.uow.edu.au/palliative_care.html

People also let us know:

- Knowledge about palliative care and available services was limited in remote areas.
- Education for health professionals across all areas of service delivery setting was requested.
- The role delineation model developed in 2005 was not well understood.
- Following the Palliative Care Integrated Service Delivery model was very difficult in remote areas due to limited generalist and specialist staff and services.

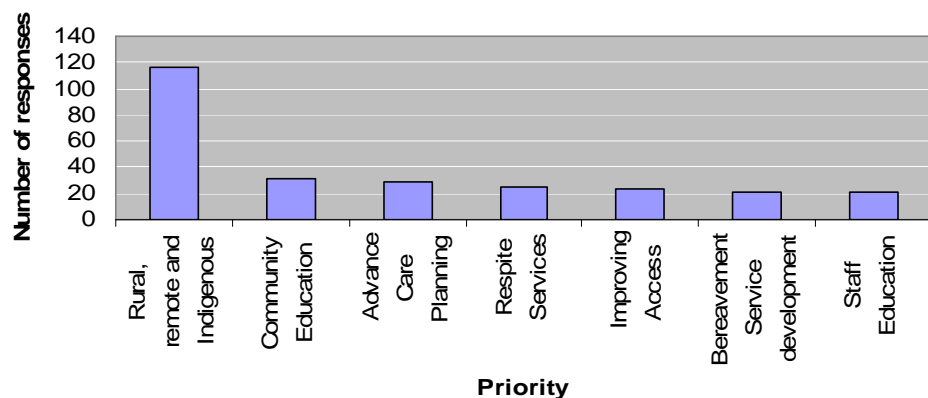
5.4 Questionnaire Results

Seventy-nine people¹⁰ completed questionnaires during 2008 at various conferences and meetings where Palliative Care was the main focus¹¹.

What people said the most important areas of focus (in order of frequency) for future planning were:

- 1 Rural, remote and Indigenous service delivery-overwhelming response¹²
- 2 More education to the community about palliative care
- 3 Advance care planning
- 4 Respite options and services
- 5 Improving access¹³.
- 6 Bereavement service development.
- 7 More educational opportunities for staff.

The six most common responses



¹⁰The 79 participants were: 67% service providers from work areas identified as: clinical 54.4%, counselling 6.3%, policy 2.5% and admin 3.8% and 23% 'other' and participants were located in: Darwin (57%) Alice Springs (12.6%) and NT Other and no response (30.4%).

¹¹ People completing the questionnaire could fill in more than one area of importance for future planning.

¹² This category includes four responses were put together to get the overwhelming area of priority related to remote and Indigenous service delivery. These were: Rural and remote palliative care issues, Better access for clients in remote and rural areas, Engaging Indigenous clients and; Remote area visiting.

¹³ This could have been added to rural, remote and Indigenous category, but was left as a separate issue.

The area of remote area service delivery and Indigenous service delivery are consistent priorities across many areas of health. It is not surprising that this was identified as the major priority by stakeholders completing questionnaires.

How this and other priorities are translated into the strategy and how real outcomes in the priority areas can be achieved deserves considerable discussion.

It is hoped the strategy can focus on areas that will create real improvements in these areas.

Some information is also available from three small scale surveys and interviews conducted with people receiving palliative care services and their families over the previous few years¹⁴.

The information provided mostly relates to the experience of clinical and supportive care provided by the palliative care team. This included the majority of people stating they are very happy with the services provided by palliative care, including clinical input, symptom management, emotional and spiritual support, case management and respect for and involvement of patient and family in decision making. The information also tells us about common experiences such as feelings of sadness and anxiety related to both being a patient and a family member, the experience of some lack of confidence in relation to understanding medications, the high value placed on having information about treatment, peoples experience of pain management and understanding what to expect with respect to death and dying.

This valuable information highlights the importance of consumer and carer input into informing the specialist team of individual and family experiences and needs to assist ongoing improvement in quality service provision. However, the information only offers some hints about what people see as important in future planning.

5.4 Summary

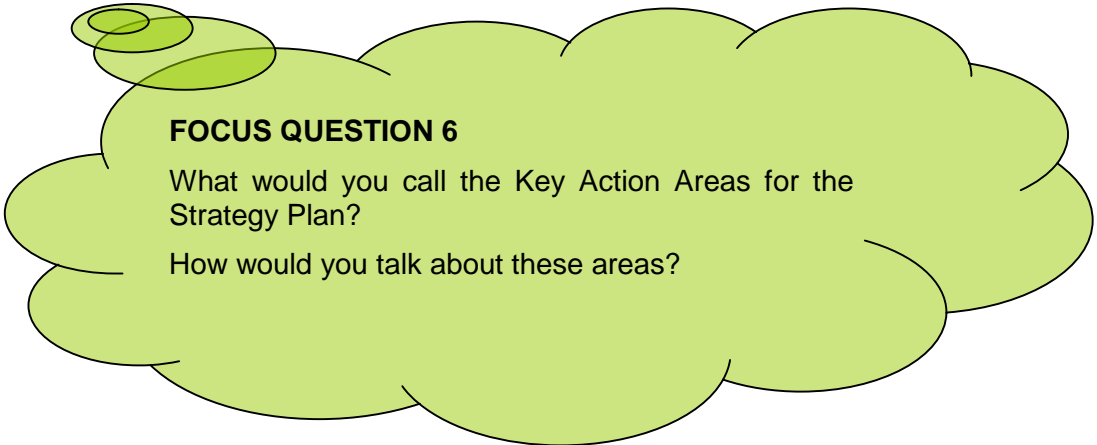
The things people said were the most important for the next five years was to strengthen palliative care services in Remote areas and to Indigenous people. People who provide services think together we can work out ways to do this better.

Priority areas for Palliative care include knowing what services are provided are the best possible, ensuring people understand and can make choices that suit their values and lives, access to informal and formal supports, not having to negotiate multiple services to receive information or services, being honest and open about what can and can't be provided and understanding who needs palliative care services, what people are benefiting from and what we need to develop further.

¹⁴ These include twenty-two returned carer surveys and information from eleven patient and ten family evaluations of Palliative Care services conducted by the Top End team as part of the National Standards Assessment Program Pilot. Information about NSAP Project is available at <http://www.standards.palliativecare.org.au/Default.aspx?tabid=1794>

Below are some suggested ways of talking about Action areas. The main priority of remote and Indigenous could be placed as a second part within each of these.

1. Community awareness, empowerment and informed decision making and choices for end of life care.
2. Strengthen provision of quality services
3. Strengthen and formalise Partnerships
4. Strengthen and support the Workforce
5. Strengthen Management, planning and accountability



FOCUS QUESTION 6

What would you call the Key Action Areas for the Strategy Plan?

How would you talk about these areas?

6. What Will Happen Next?

6.1 Pulling Everything Together

All the information you provide, will be put with the information we already have and the final strategy document will be written. The members of the CRG and any other interested people can be sent a draft for final comment before it is published.

Copies of the final document will be made available in hard copy and on the website early in 2010.

6.2 Programs and Organisations

Implementation plans for the key strategies are established by the organisations & programs responsible for monitoring and overseeing them. Implementation planning needs to include a consideration of available and planned resource use and allocation, objectives, time-scales, deadlines, budgets and performance targets.

The Palliative Care Clinical Reference Group (PCCRG) will oversee the implementation of the NT Strategy. There are a number of options in how this can be achieved:

- (1) This strategy incorporates whole of Territory Palliative Care program areas of responsibility. It is also suggested that the operational areas of Hospice, Top End Palliative Care Services and Central Australia Palliative Care services, bereavement support and volunteer training, support and development assume responsibility for the development of appropriate implementation planning, reporting and evaluation relevant to their core business and local needs within the overall Strategy.
- (2) Implementation of the strategy is shared by all the stakeholders involved in the PCCRG. How this would be monitored and information shared for measurable outcomes would have to be agreed by all participating individuals and agencies (stakeholders).

A main challenge in this approach is to ensure the mission, objectives, values, strategies and goals remain inter-linked and consistent with each other whilst providing a robust framework for the flexibility required by the various operational areas of Territory Palliative Care services and all stakeholder organisations involved in endorsing the NT Palliative Care Strategy.

6.3 Goals

Once the Strategy has been accepted and endorsed by DHF planning the best way forward will be the next step. Goals are specific interim or ultimate time-based measurements to be achieved by implementing strategies in line with the agreed objectives in the overall NT Palliative Care Strategy. Goals are measurable, consistent, realistic and achievable. These will be developed by Territory Palliative Care specialist services and as appropriate, by all collaborating stakeholder groups. This will help guide everyone in working towards the same 'bigger picture' ideas talked about in the strategy.

Department of Health and Families will let people see the Implementation plan for the Strategy by posting them on the website. Links can be provided to plans made by any other partner or stakeholder organisations in relation to palliative care.

When other areas or services, for example: cancer, renal, or chronic disease have plans that include palliative care, links will be provided on the website.

An annual report of the progress and activities of Palliative Care services will be produced to update all stakeholders on progress over the five years.



Strengths, Weaknesses, Opportunities & Threats (SWOT)

Attachment A

Eight key stakeholders representing specialist areas and organisations provided information to help develop the proposed strategies.

Strengths and weaknesses are essentially **internal** to organisations and relate to matters concerning resources, programs and organisation in key areas. This relates to the Department of Health and Family and Territory Palliative Care, in particular.

The external threats and opportunities confronting a service or organisation, can exist or develop in the areas of international, national, and local changes in palliative care. This can include funding approaches, Consumer demand which may be altering due to health, economic or social factors, Competing interests or competing resource priorities and new technologies, resources, approaches and ways of doing things are being introduced and research is being conducted which will influence Palliative Care service delivery in the future.

The most commonly identified have been provided in the table below.

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> • Services have expanded and passionate staff are working in the services. • Vision and leadership in Palliative Care exist in Territory Palliative Care. • Holistic/multidisciplinary teams have been created. • A relationship between service areas and communities has been developed. • Territory Palliative Care is recognised as providing high quality services. • Highly committed CH staff who provide great majority of hands-on care. 	<ul style="list-style-type: none"> • Current staff struggle to meet current and increasing demand for services, including increased workload related to accountability and quality activities. • Central Australia and Top End operational differences remain as a result of growth from two separate organisations. • All the services and the quality of services are not consistently demonstrated through data and reporting systems. • Logistic difficulties remain re: accessing equipment, transport and respite services • Career pathways are not clear in current service structure. • Specialist model is reliant upon resourced community health, care and primary health Care, which does not acknowledge resource and staffing issues across all areas of service delivery. • Communication processes and understanding of roles could always be improved between TPC and CH.

OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> • Leadership role in the development and delivery of Indigenous and Renal Palliative Care Services in Australia. ? role of nurse practitioner/Aboriginal health Workers. • Primary Health care and closing the gap priority in the NT is consistent with priority area in Palliative care re: remote service delivery. Aboriginal PHC in remote communities is receiving increased funding and so capacity to work in partnership with palliative care should increase? • CRG membership comprises of main stakeholders and has potential to clarify and support partnership arrangements and agreed approaches and processes for service delivery. Includes building on relationships developed through both project work and service delivery. • Access to and participation in forums to share experience and knowledge in inter-jurisdictional settings. • Value adding to service as a result of national projects with practical outcomes eg: PEPA and Rural 	<ul style="list-style-type: none"> • Need all stakeholders on same page. • Project work and service expansion have resulted in increased expectations in community. • Lack of additional funding for staffing increases and service expansion to meet need of Territorians. And staff training ie leadership and management. • Geographical isolation for remote service delivery and high turn over of staff in remote areas. • Workforce issues across all settings and organisations include high turnover, directly impacting on skill maintenance and continuous training demand. • Poor planning for ageing population in general.

Developing Strategies

Future strategies are developed directly from the SWOT analysis. It is anticipated that in any complex system, the information from the analysis suggests a series of strategies or combinations of tactics that will address each of the main factors identified. SWOT analysis helps to identify possible strategies as follows:

- **Build** on strengths
- **Resolve** weaknesses
- **Exploit** opportunities
- **Avoid** threats

The Strategies

Strategies provide effective guidelines by which the vision, mission and objectives can be achieved. They can cover the Territory Care Services as a whole, or reflect priorities in particular operational areas of the service.

Key Strategies

The following critical strategies will be pursued by Territory Palliative Care:

A. Develop an approach to remote area service provision in partnership with Primary Health Care (PHC) and other service providers (chronic disease, chronic disease, renal, mental health and wellbeing).

- Build on Strength: A relationship between service areas and communities has been developed.
- Resolve weakness: Specialist model is reliant upon resourced community health, care and primary health Care, which does not acknowledge resource and staffing issues across all areas of service delivery.
- Avoid threat: Need all stakeholders on same page.
- Avoid threat: Geographical isolation for remote service delivery and high turn over of staff in remote areas.
- Avoid threat: Workforce issues in primary health include high turnover, directly impacting on skill maintenance and continuous training demand.
- Exploit opportunities: Primary health care and closing the gap in the NT is consistent with priority area in Palliative Care re: remote area service delivery.
- Exploit opportunities: CRG membership comprises of main stakeholders and has potential to clarify and support partnership arrangements and agreed approaches and processes for service delivery.
- Exploit opportunities: Leadership role in the development and delivery of Indigenous and Renal Palliative Care Services in Australia.

B. We need to show that the services being provided are of the best quality and within national frameworks for best practice.

- Build on Strength: Expanded services and staff positions are now available.
- Build on Strength: Territory Palliative Care are recognised as providing high quality services.
- Build on strengths: Territory Palliative Care has good national linkages and standing.
- Resolve weaknesses: Service provision and work conducted are not consistently demonstrated in record and data reports currently readily available.
- Avoid Threat: Lack of additional funding for staffing increases and service expansion to meet need of Territorians.
- Exploit Opportunities: Leadership role in the development and delivery of Palliative Care in Australia re: Indigenous and Renal Palliative Care.

C. We need to support and strengthen our workforce-across all settings: Ensure staff are adequately resourced and are able to appropriately prioritise workload and respond to unmet need. Ensure staff are supported by robust and transparent systems (case conferencing, referrals, access to equipment and transport needs of clients). Ensure all existing staff have access to workforce planning and development opportunities and career opportunities are developed for TPC.

- Build on strength: Services have expanded and passionate staff are working in the services.
- Build on strength: Leadership positions, vision and guidance have been developed in Territory Palliative Care.
- Build on Strength: Holistic/multi-disciplinary teams have been created.
- Resolve Weakness: Current staff are struggling to meet current and increasing demand for services.
- Resolve Weakness: Logistic difficulties remain re; equipment and transport and access to respite, which impact on specialist service delivery.
- Resolve Weakness: Central Australia and Top End operational differences are not support by transparent and consistent processes .
- Resolve Weakness: Clear career pathways are not in current service structure.
- Avoid threat: Project work and service expansion have resulted in increased expectations in community.

D. We need to make sure management and leadership is strong

- Build on strengths: Territory Palliative Care has strong national linkages and standing.
- Resolve weaknesses: Central Australia and Top End differences are not always supported by transparent processes.
- Resolve weakness: service provision and work conducted are not demonstrated in record and data reports currently readily available.
- Resolve weaknesses: Logistic difficulties remain re: equipment and transport and access to respite, which impact on service delivery.
- Avoid threat: Lack of additional funding for staffing increases and service expansion to meet needs of Territorians.

E. Develop, strengthen and formalise partnerships involved in the care matrix. This includes all specialist and general health programs such as renal, cancer and chronic disease.

- Build on strengths: Territory Palliative Care is recognised as providing high quality services.
- Build on Strengths: Territory Palliative Care has good national linkages and standing.
- Build on Strengths: A relationship between service areas and communities has been developed.
- Resolve weaknesses: Specialist model is reliant upon availability of PHC, which is not always available.
- Avoid Threat: Need all stakeholders on the same page.
- Exploit Opportunity: Leadership role in the development and delivery of Palliative Care Services re: Indigenous in Australia.
- Exploit Opportunity: CRG Membership comprises of main stakeholders and has potential to clarify and support partnership arrangements and agreed approaches and processes for service delivery.

The following important strategies were also identified:

- Develop a strategic approach to ensure advocacy for increased funding to meet increased need/service demand. (Major sub-section of Strategy D: Management and Leadership)
- In partnership with Aboriginal communities, organisations and leaders we need to explore how to embed our work in research and evidenced based frameworks. This would include working with national bodies for creating national leadership opportunities in Indigenous Palliative Care. (Major sub-section for Strategy B: Quality and Evidence based services)
- Identify and understand cultural expertise competencies and position in palliative care specialist service delivery in NT. (Major sub-section of Strategy C: Strengthen our workforce)
- Build model to introduce cultural competency into service delivery. (Major sub-section of Strategy C: Strengthen our Workforce)
- Develop and contact list and network to support specialised areas of palliative care eg: paediatric, unusual presentations – clinical, renal, cardiac, both intra and interstate. (Major sub-section of Strategy E: strengthen and formalise partnerships involved in the care matrix.)
- Develop an approach to bereavement and support for service users and service providers (including staff) in NT Palliative Care (Major sub-section of Strategy B: Embed existing core service delivery in best practice)