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ACT PALLIATIVE CARE SOCIETY

PRE BUDGET SUBMISSION

2008-09

28/9

To: ACT Health Minister, Katy Gallagher, MLA

From

ACT Palliative Care Society Inc.

27 September 2007

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EXECUTIVE SUMMARY

ACT Palliative Care Society is pleased to provide this response and input to the ACT Government 2008-09 Budget. On 2 August 2007, ACT Health Minister Katy Gallagher launched the ACT Palliative Care Strategy 2007-11 which sets the direction for the delivery of palliative care services in the ACT. With the Strategy in mind, the Society has realistically looked at the needs of palliative care services in the ACT and prepared a short list of the most urgent recommendation in order of priority for your consideration.

There is no secret that an obvious gap exists in the area of residential aged care facilities for palliative care services and support of residents who are dying and especially during the last days of life. In the 2008-09 budget, the Society strongly recommends that provision be made for the employment of a full time independent palliative care/aged care clinical nurse consultant to liaise with the existing and growing number of residential aged care facilities and the allied health services and professionals to ensure equal access to expert palliative care services be available to these residents.

Funding to employ a Coordinator to implement a palliative care aged care volunteer program - as an adjunct to the Society's volunteer program - which would provide extra support for the above residents and family. There is a pool of volunteer resources waiting to be tapped and utilized for the greater good of the ACT community.

The number of people choosing to spend their last days in their own home environment is growing and Home-based palliative care is recognized as the most economical option of providing both generalist and specialist palliative care in the ACT as the infrastructure/facilities and physical maintenance issues are minimal. Therein is highlighted a number of areas requiring extra support for both the patients and carers. The Society recommends a Home-Based Overnight Palliative Care Nursing Service designated to provide temporary relief for carers to ease the constant strain and pressures the carers accumulate, particularly sleep deprivation, while caring for their loved ones. It also recommends that a Palliative Care Package not dissimilar to the Community Aged Care Packages be designed to provide for the complex needs of the Home-Based Palliative Care patients and family.

RECOMMENDATIONS

ACT Palliative Care Society makes the following recommendations:

1. Funding for a Palliative Care / Aged Care Clinical Nurse Consultant to be appointed to liaise with various ACT residential aged care facilities and the various allied palliative care services/primary care professionals. Such an appointee makes assessments and referrals for residents in the aged care facilities who are terminally ill and dying so that the residents and their family can access the appropriate palliative care services and support ACT has to offer.

2. Funding for a Coordinator to implement a palliative care aged care volunteer program in the residential aged care facilities to provide extra support to residents and family in these facilities.

3. Funding for a 'Home-based Overnight Palliative Care Nursing Service for Carer Relief' to provide relief, especially overnight, for carers in the patient's home.

4. Palliative Care Packages to be designed for home-based palliative care patients similar to the Community Aged Care Packages (CACPs).

1 – DEFINITIONS AND EXPLANATIONS

1.1 ACT PALLIATIVE CARE SOCIETY INC.

The ACT Palliative Care Society Inc. is the representative voice for palliative care in the Australian Capital Territory. Formed in 1985, it is a non-government community based organisation, a registered charity and a founding member of the national peak body Palliative Care Australia.

The Society' s major objective is to facilitate the provision and improvement of palliative care in the ACT. The principal purpose and objects for which the Society is established are to promote the prevention or control of disease in human beings and to facilitate the provision and improvement of palliative care in the ACT by:

(i) providing a forum for the exchange of ideas on matters relating to palliative care and to encourage the dissemination of such information to the community, health professionals, volunteers and caregivers through education and awareness campaigns;

(ii) to consult with ACT Government and the Health Department on the needs of those receiving or requiring palliative care and initiate action to meet those needs or act as an advocate on their behalf;

(iii) to promote the maintenance of palliative care standards across the ACT; and

(iv) to liaise and develop partnerships with other organisations which have like objectives that could improve palliative care in the ACT.

Palliative care,

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological, emotional and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death; and

- Offers a support system to help family and friends cope during the patient's illness and their bereavement

Volunteers are an integral part of the palliative care team at the ACT Hospice – Clare Holland House – and in home-based palliative care. The ACT Palliative Care Society implements a Volunteer Program and employs a professional team to train and co-ordinate over 100 volunteers who are committed to supporting people living with a terminal illness.

1.2 PALLIATIVE CARE EXPLAINED

Palliative care is care that 'palliates' or relieves pain and distress. It can be provided in conjunction with other treatments and is holistic in its focus, encompassing spiritual, emotional, social as well as physical care. It focuses on the individuality of each person. It is provided in a sensitive way taking into account individual and family uniqueness, cultural and spiritual beliefs, traditions and lifestyle patterns.

Setting may include:-

- The individuals own home
- The Palliative Care Unit located at Clare Holland House
- A hospital
- An aged care facility or other health care facility

The team that provides palliative care includes doctors, nurses, occupational therapists, social workers, pastoral carers and volunteers. They all bring knowledge, skills and understanding to caring for those with a life-limiting illness and their families. The team is there to honestly answer all the patients' and families' questions and to help the patient to make choices that are right for the person. The aim of palliative care is to help the patient to build an effective support network to meet his/her needs.

1.3 2 LEVELS OF PALLIATIVE CARE SERVICES ROLE DELINEATION

Due to the relatively small population in the ACT, ACT Health has adopted the first 2 levels of palliative care service provision as developed by Palliative Care Australia and are illustrated as follow:-

Palliative Care Australia Role Delineation Framework

Level	Capacity	Typical Resource Profile
Primary Care	Clinical management and case coordination including assessment, triage and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care. Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care Level 1	Provides specialist palliative care patients, caregiver/s and families whose needs exceed the capacity of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. Has formal links to primary care providers and other levels of specialist palliative care providers to meet the needs of patients and family/carers with complex problems. Has quality and audit program.	Multi-disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.

2 – RECOMMENDATIONS IN DETAILS

2.1 PALLIATIVE CARE AGED CARE NURSE CONSULTANT

It is no secret that there is an obvious gap and a great need existing in the residential aged care facilities for palliative care services and support of residents who are dying and in their last days of life. Not everyone dying is diagnosed with cancer or other terminal illness: hence they are not registered as Palliative Care patients and do not receive palliative care service. Many people tend to have a gradual decline in their ability to function until they reach their final stage of life. These residents simply because they are old, many are living with dementia, are often cared for by untrained care workers NOT palliative care specifically trained workers.

In the 2008-09 budget, we strongly recommend provision be made for the employment of a full time independent palliative care/aged care clinical nurse consultant to liaise with the existing and growing number of residential aged care facilities and the allied health services and palliative care professionals so as to identify the needs of these residents and to ensure equal access to expert palliative care services be available to them as is already available to those who chose to remain in their own home environment or are admitted to Clare Holland House.

The palliative care aged care nurse consultant is an independent clinical nurse consultant who identifies the need of the individual aged care resident who is in the last stage of life — makes an assessment, gives advice on symptom management to help to ease pain, nausea and suffering for the resident. This person has access and contact with the specialist palliative care services and liaises with the GPs, specialist palliative care doctor or facility to provide timely and appropriate support for the aged care residents to ensure equitable delivery of quality care for those who are at the end of life.

2.2 PALLIATIVE CARE AGED CARE VOLUNTEER COORDINATOR

According to data released by Commonwealth CareLink Centre, there are 15 residential aged care facilities in the ACT region with some form of palliative approach facility. Some of these facilities may have their own team of volunteers helping out in the facility, but as far as the Society is aware, there is no established palliative care volunteer program implemented in any of these facilities. For most cases, it is impractical for these residential aged care facilities to provide their own palliative approach volunteer program due to financial or human resource constraints. Suitably screened, trained and matched volunteers have much to contribute in aged care facilities and can enhance the provision of a palliative approach to the residents.

In the 2008-09 Budget, the Society urges the Government to make provision for the employment of a Coordinator to train and implement a palliative care volunteer aged care program to serve in residential aged care facilities for those residents who are at the final stage of life. The Society has a substantial list of volunteers on its register waiting to be trained to serve as palliative care volunteers. Volunteers provide a broad range of support services which include companionship, assisting with meals, hand/foot massage, reading, conversation, listening and letter writing or simply ‘being there’. On request, volunteers can companion the residents during their last days or at the time of death. Most of all, volunteers choose to be there and bring their humanness with them in their interactions with the residents. Such contact, acceptance and support are extremely beneficial for the residents and their family.

2.3 HOME-BASED OVERNIGHT PALLIATIVE CARE NURSING SERVICE FOR CARER RELIEF

Figures indicate that increasing numbers of people choose to remain at home to live their last days and have a home death. This is viewed by healthcare agencies as a cost effective option. Despite the input offered by professional palliative care services, home-based palliative care patients generally rely on a family member or friend for all kinds of support. Without the assistance of these carers, home-based palliative care would be highly impractical. Commitment and dedication required by those who assume the carer role need to be appreciated. Awareness of the many stresses and potential physical, emotional, financial strains experienced by the carers need to be acknowledged and alleviated where ever possible. For example, a carer may need to maintain a constant presence by the patient's side thus becoming as housebound as the patient. Often these carers suffer from sleep deprivation and would welcome a short break even if it means a retreat into one's own bedroom.

The Society recommends attention be given to the carers needs as well as those of the patients. On request by the carer and prearranged with the home-based palliative care service, a palliative care nurse would stay overnight in the patients' home to supervise the patient, allowing the carer to get some rest and relief. This is no magic potion but it is a step towards providing some support and assistance for the carer, especially those who have been caring for a considerable period of time, enabling them to have some much needed rest.

2.4 PALLIATIVE CARE PACKAGES

Much like the Community Aged Care Packages, Palliative Care Packages would be individually planned and coordinated packages of care, tailored to assist Palliative Care patients remain living in their own homes. They are designed to help with individual care needs. The types of services may include:

- Personal care
- Home Help
- Meal preparation and
- Social support

Unlike the Community Aged Care Packages which are only available to people over the age of 65, Palliative Care Packages should be tailored for people of any age, since death and dying occur to people of all ages and not just people over the age of 65. Eligibility should be for those who have been diagnosed and subsequently registered as Palliative Care Home Based patients. Currently, palliative care patients who are under the age of 65 and choose to spend their last days at home are not eligible to access Community Aged Care Packages resulting in a greater burden – physical, emotional and possibly financial on the patient and the family at time of great distress and emotional unrest.

3 - Conclusion

The primary goal of palliative care is best 'quality of life' for patients, their families and friends. It should be made available regardless of location, age, income, diagnosis or prognosis, social or cultural background. Death and dying occur to people of all age and in particular the elderly and including those living with dementia. The challenge presented by increasing numbers of frail and aged people in the community — together with those with multiple, complex and chronic health care needs — has to be tackled.

The Society is pleased that the ACT Palliative Care Strategy is now in place. In addition to the already existing palliative care funding allocation, we urge the Government to continue to implement the Strategy by making specific provisions in the 2008-09 budget along the lines we suggest. This will narrow the disparity existing in the current system and make provision to meet the needs of the ACT community.

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ACT Health

ACT Palliative Care Strategy
2007 - 2011

Foreword by Katy Gallagher

Minister for Health

The ACT Palliative Care Strategy 2007-2011 sets the direction for palliative care services in the ACT for the next four years. The Strategy aims to provide direction for the delivery of palliative care services in the ACT, in line with the national palliative care standards developed by Palliative Care Australia.

Palliative care services provide crucial assistance to members of the ACT community and it is important that we develop a strategic direction for this sector of the health system. The Strategy sets out proposed activities under a range of key aims. These aims include improving community awareness and participation, further developing a comprehensive ACT palliative care service, strengthening provision of primary care through the palliative approach, strengthening specialist palliative care service, further developing a skilled workforce and improving information management and data collection.

We consulted widely with key stakeholders and the community during the development of the Strategy. This has enabled us to capture the ACT community's views on what they want from palliative care services, along with the views of key palliative care providers. We will continue to work with consumers and providers in the implementation of the Strategy.

I would also like to sincerely thank the members of the ACT Palliative Care Strategy Working Group. This group provided essential expertise to the development of the Palliative Care Strategy as well as giving generously of their time and support both to ACT Health and to each other.

I believe that the ACT Palliative Care Strategy provides an excellent direction for the delivery of quality palliative care services in the ACT and I am pleased to support its implementation.

Katy Gallagher

Katy Gallagher MLA
Minister for Health

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Introduction

The ACT Palliative Care Strategy aims to provide overarching direction for the delivery of palliative care services across ACT Health. The Strategy has been written in the context of the national palliative care standards developed by Palliative Care Australia (www.pca.org.au) and commits the ACT to deliver palliative care services in accordance with these standards. As part of its commitment to the national palliative care standards the ACT has also committed to develop a role delineation framework, which is contained in this Strategy.

The ACT Palliative Care Strategy has been developed, and will be implemented, in accordance with the following existing ACT plans and policies:

- ACT Primary Health Care Strategy 2006–2009
- Clinical Services Plan 2005-2011
- Health Action Plan 2002
- Discharge Planning Policy 2005
- ACT Health Workforce Plan 2005–2010

What is palliative care?

The World Health Organisation describes palliative care as:

"...an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates psychological and spiritual aspects of palliative 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 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" (World Health Organisation Definition of Palliative Care – www.who.int/cancer/palliative/definition/en.

The palliative approach is defined as

"an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of the patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision of physical, psychological, social and spiritual care. Application of the palliative approach to the care of an individual patient is not delayed until the end stages of their illness. Instead, it provides a focus on active comfort-focused care and a positive approach to reducing suffering and promoting understanding of loss and bereavement in the wider community. Underlying the philosophy of a palliative approach is the view that death, dying and bereavement are all an integral part of life." (www.pallcare.org.au; Standards for Providing Quality Palliative Care for all Australians, p11)

More definitions are provided in the glossary at Appendix B.

Principles and Vision

Vision

ACT Health will deliver palliative care as appropriate to people of all ages, respecting their choices and needs; ensuring care is provided in accordance with the standards developed by Palliative Care Australia (www.pallcare.org.au; 2005).

Principles

Person centred care – holistic care is provided respecting and empowering the individual and carers needs and choices and ensuring consumer and carer participation in health decision-making. Care provided is culturally competent and respects the individual needs of patients and carers.

Access and equity – safe, effective and appropriate services are provided to all people in need of palliative care in the ACT, and any inequalities in palliative care service provision are reduced.

Advocacy – on behalf of the expressed wishes of the dying person, caregiver/s, families, and communities.

Skilled Workforce – commitment to building a workforce that is skilled in the palliative approach/palliative care and supported by specialist tertiary level services.

Collaboration – an interdisciplinary approach is taken to care and collaboration occurs between ACT Health services, GPs, allied health, non-government organisations and complementary health practitioners in palliative care.

Resource Management – services are structured to make effective and efficient use of available resources.

ACT Palliative Care Services – 2007

Palliative care services in the ACT are delivered to all people in need, regardless of diagnosis. The primary and specialist palliative care services currently provided in the ACT are of high quality and deliver excellent care to the ACT community. More details are provided on the services below.

Primary palliative care services

ACT Government, through ACT Health, is responsible for the provision of many health care services for palliative care patients, including allied health services and community nursing. These professionals are considered "primary care" providers under the national standards. Primary care services are also provided by a range of people who are specialists in other areas, such as oncologists, renal, cardiac and respiratory physicians and staff in acute hospitals. These health care providers support large numbers of people needing palliative care and their carers in the ACT.

Other health service providers, including General Practitioners, Winnunga Nimmityjah Aboriginal Health Service, private medical specialists, Home and Community Care (HACC) services, residential aged care facilities and private hospitals, form essential components of ACT primary palliative care service provision.

There is also a range of publicly-funded not for profit organisations that provide services to palliative care clients and their carers. These include ACT and Australian Government funded organisations that provide services such as home assistance and carer support to palliative care clients and their families/carers.

Primary care providers are able to support people needing palliative care in any setting through offering a "palliative approach" rather than specialist palliative care and are appropriate for people with less complicated needs. Primary care providers can also care for people with more complicated needs, if the provider is particularly experienced or where specialist consultancy services are available to provide advice.

Specialist palliative care services

ACT Government, through ACT Health, provides funding for the inpatient, outpatient and community based specialist palliative care services in the ACT. These are:

- **Clare Holland House** – an interdisciplinary service including a 19 bed in-patient hospice, specialist outreach services to people's homes (Home Based Palliative Care), consultancy services to hospitals, a nurse educator, bereavement services and the Program of Experience in the Palliative Approach (PEPA) program, all managed by Calvary Health Care ACT
- **The Canberra Hospital** – palliative care liaison nursing services at The Canberra Hospital managed by the Capital Regional Cancer Service
- **ACT Palliative Care Society** – a non-government, not for profit organisation for the facilitation and promotion of excellent palliative care in the ACT, the Society professionally trains and supports palliative care volunteers

ACT Palliative Care Role Delineation

Palliative Care Australia has developed a role delineation framework to describe the levels of palliative care service provision. Role delineation frameworks are important because they provide a mechanism by which health service planners and providers can agree upon a level of resourced capability for specific service provision. This enables service planning around realistic and reasonable expectations. Role delineation also ensures that comparative studies and other quality activities such as benchmarking are measuring and comparing like with like. The Palliative Care Australia Role Delineation Framework sets out four levels of palliative care service provision: primary care and specialist palliative care levels 1, 2 and 3. The ACT has developed an ACT-specific role delineation framework, as part of its commitment to the national standards. The ACT's role delineation framework is based upon Palliative Care Australia's framework but, due to the small size of the ACT's specialist palliative care services and workforce, the ACT role delineation has been set out against only two levels of palliative care service provision: primary care services and specialist care services. This role delineation and the Palliative Care Australia framework can be found at Appendix A.

The Strategy

Aims

The overarching aims of the Strategy are that, in partnership, ACT Health, stakeholders, the community and consumers will improve the palliative care services available to the ACT community by:

1. Improving Community Education, Awareness and Participation

2. Further Developing a Comprehensive ACT Palliative Care Service

3. Strengthening Provision of Primary Care Through the Palliative Approach

4. Strengthening Specialist Palliative Care Services

5. Further Developing a Skilled Workforce

6. Improving Information Management and Data Collection

Aim 1 – Improving Community Education, Awareness and Participation

The Strategy aims to improve community awareness of, and participation in, palliative care. Key objectives under this aim will include education for the community and supporting the role of volunteers within the palliative care sector. Under this section, it is crucial to ensure that the needs of carers and families are considered and appropriate education and information is provided to carers and families. Education and information for the community will also include the provision of information on issues such as advance care planning.

Support for a strong volunteer sector is a key component of an effective palliative care program. A strong volunteer service not only adds considerable value to the palliative care service but also increases the participation of the broader community in palliative care. It is important to ensure that equity is a key principle in the provision of volunteer services and that volunteers can be accessed by people, regardless of where they are located in the palliative care sector.

1.1 Education and Information for the Community

Education will be provided to the community to raise awareness of palliative care issues and increase community skills around grief and loss. Education and information provided to the community will be culturally appropriate.

Actions:

- Ensure appropriate information about palliative care services is available to the community, including on websites, and that more specific information is available for carers and families
- Develop and implement palliative care education services especially regarding normal grief and loss, and how to support people who are grieving
- Investigate the possibility of establishing a palliative care fundraising program, in line with existing ACT Health fundraising structures

1.2 Palliative Care Volunteers

The importance of palliative care volunteer services to patients and carers, both through the ACT Palliative Care Society volunteer program and volunteer services provided by other non-government organisations, is recognised and will be supported.

Actions:

- Investigate volunteer demand and capacity for additional volunteer coordinator support for volunteers, including consideration of the need for volunteers in particular population groups such as Aboriginal and Torres Strait Islander people.

Aim 2 — Further Developing a Comprehensive ACT Palliative Care Service

This Strategy requires palliative care services in the ACT to work together to offer a cohesive, readily accessible network of best practice, appropriate palliative care to people, their families and carers. This means that the various elements of the specialist palliative care service will act as a unified service and will interact effectively with each other and with primary care providers.

Care will be tailored to patient and carer needs and the service's primary focus will be to ensure best outcomes for people needing palliative care and their carers. This Strategy aims to support people to die where they choose to die, whenever possible and clinically appropriate. Palliative care services in the ACT at the primary or specialist level, including bereavement services, should be available according to need, not according to the location of care.

The further development of a comprehensive palliative care service will be pursued in line with the national standards developed by Palliative Care Australia. Issues that are particularly important for the further development of a comprehensive service include bereavement and respite services, provision of services to Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people and children, and the development of service agreements and links between the palliative care service and other organisations.

2.1. Palliative Care Services Plan

The Strategy identifies the need to undertake more detailed palliative care service planning in the ACT. It is also acknowledged that a number of the actions identified in the Strategy may best be addressed through the Palliative Care Services Plan. The Steering Committee that will be established to guide the implementation of the Strategy will also provide advice on the development of the Plan and will assist in identifying which of the Strategy's actions should be addressed as part of the Plan.

Actions:

- Develop a Palliative Care Services Plan to guide development of palliative care services and identify unmet needs and the mix of services required over coming years.

2.2. Respite

Appropriate respite services are particularly important for palliative care clients and their families and carers. It is also important that respite services are flexible and can be accessed in a range of forms such as inpatient respite and at home respite.

Actions:

- Develop and maintain appropriate levels of allocated respite care for palliative care patients, including the flexibility for respite to be provided at home as well as at inpatient and residential aged care facilities
- Investigate options for providing additional carer support, in consultation with consumers and carers. This will include working to develop strong links between consumer, carer and volunteer organisations such as the Health Care Consumers Association, Carers ACT and the ACT Palliative Care Society.

2.3. Bereavement

It is important that bereavement services are available to families and carers and are available at both the primary and specialist level.

Actions:

- Examine current bereavement services and ensure that appropriate bereavement services are maintained across the whole of the ACT, including in the primary palliative care sector. This review will refer to the recommendations from the report "Review of bereavement services for palliative care at Clare Holland House and in the ACT" 2006.

2.4. Aboriginal and Torres Strait Islander People

It is important that palliative care services delivered to Aboriginal and Torres Strait Islander people take account of any specific needs of the patient and carer/family group. There are a number of issues that may have an impact upon the needs of Aboriginal and Torres Strait Islander people when accessing palliative care.

For all leading causes of ill health indicators, many of which affect an older Australian population, Aboriginal people continue to be over represented at considerably younger ages, which impacts on the palliative care needs of these patients and their families. There also needs to be recognition by health service providers of the importance to Aboriginal people of "the whole-of-life-view" that includes the "cyclical concept of life-death-life" a belief that is tied to the land and traditional beliefs" (A National Aboriginal Health Strategy 1989 preface page 10).

The challenge for mainstream palliative care services is recognising and adjusting existing and future services to accommodate Aboriginal people(s) access and needs to appropriate palliative care services.

Actions:

- Ensure that palliative care services provided to Aboriginal and Torres Strait Islander people are culturally appropriate and take into account any special needs that individual people and families may have.

- Ensure that the posters, brochures, workbooks and cultural protocols developed as part of the Aboriginal and Torres Strait Islander palliative care project are distributed and implemented among palliative care service providers
- Consider the need for additional Aboriginal and Torres Strait Islander palliative care initiatives, such as a 'return to country' protocol and further opportunities for palliative care workers to develop knowledge of culturally appropriate palliative care service provision.

2.5. Culturally and Linguistically Diverse People

People from culturally and linguistically diverse backgrounds may face a range of unique needs when accessing palliative care. Issues such as language barriers and cultural/religious beliefs and practices surrounding death and dying need to be addressed in order to ensure that appropriate palliative care services are provided.

Actions:

- Ensure that palliative care services provided to people from culturally and linguistically diverse backgrounds are culturally appropriate and take into account any special needs that patients, carers and families may have.
- Ensure, where necessary, that interpreter services are available and utilised.
- Ensure that specific palliative care material is available in appropriate languages for the main culturally diverse groups in the ACT.

2.6. Children

Infants, children and adolescents who need palliative care may have a number of particular needs and requirements, as may their parents and families. Palliative care services in the ACT will deliver services that acknowledge the specific needs of children. Appropriate liaison will occur between palliative care services, and other specialist services such as oncology and paediatric services. It is also important to ensure that liaison occurs with interstate hospitals where ACT children may be required to undergo treatment, such as Sydney Children's Hospital and Children's Hospital Westmead.

Actions:

- Ensure that palliative care services provided to children take account of their needs and appropriate liaison occurs between relevant services.

2.7. Service Agreements and Links

The comprehensive palliative care service will develop links with other appropriate services in order to ensure that palliative care service provision is integrated and seamless. These links will be developed with both organisations and programs, such as the Respecting Patient Choices Program. A key area of linkage in this area will be to ensure that the specialist service has strong links at a system level with primary care providers, in particular community nursing and general practice.

Actions:

- Develop and maintain appropriate links between the specialist palliative care service and other providers of palliative care. This will include the development of service level agreements or Memorandum of Understandings
- Clarify admission criteria and transfer and discharge processes for all elements of the palliative care service

Aim 3 – Strengthening Provision of Primary Care through the Palliative Approach

Under the definitions developed by Palliative Care Australia a primary care provider is any provider who has a primary level of contact with the patient and includes GPs, community nurses and specialists in other fields such as oncology.

In line with the national palliative care standards, the majority of palliative care service in the ACT will be provided in the primary care sector, using a palliative approach and with appropriate supports. The palliative approach to care will be practised across all health care settings, and health care professionals will be provided with support to ensure that they are skilled in the palliative approach.

Predominantly, palliative care in the community and at home is provided by Community Health and General Practice services. As such, primary care nurses and GPs will be acknowledged as the key providers of palliative care and are strongly supported to undertake this care.

In the ACT, the GP will be the responsible clinician unless a person has been admitted to hospital or the hospice. Discharge from either a hospital or hospice setting will be back to the GP, with support from other providers as appropriate, and specialist to specialist (including hospital to hospice) referrals will ensure that the GP is also informed. This includes people discharged to residential aged care.

Community nurses will provide nursing care to people needing palliative care in the community, within an appropriate scope of practice. Community nurses will receive support from the specialist service where necessary and if patients have complex needs will be able to request that the specialist service provide patient care.

It is also important to acknowledge the role of other services including allied health providers, non-government organisations, Home and Community Care providers, residential aged care providers, volunteers, self-help organisations and community supports, including community and religious organisations.

Under this aim, the Program of Experience in the Palliative Approach (PEPA) is a particularly important education model. PEPA is an Australian Government program providing generalist health care workers the opportunity to develop their skills and confidence in the palliative approach for the care of people at the end of their life.

It is also important to ensure that primary care providers are equipped to assist patients in recording their wishes through methods such as advanced care planning. The Respecting Patient Choices program is a particularly important tool in this area.

Actions

- Strongly support and educate GPs and other primary health care providers to participate in the provision of palliative care in the community
- Build capacity and strengthen the use of the palliative approach across primary services

Aim 4 – Strengthening Specialist Palliative Care Services

The specialist palliative care service in the ACT, delivered from Clare Holland House and the Canberra Hospital, will care for the most complex patient needs and work as a consultancy and support service to primary care providers. The specialist palliative care service, incorporating all specialist resources regardless of where they are physically located, will operate as a unified service. Specialist service provision will include complex patient care and provision of complex bereavement services. Strategies will also be put in place to reduce the amount of primary care services that the specialist service is asked to provide.

Actions:

- Ensure that the specialist service leads quality and audit activities within the service
- Ensure that the specialist service provides a consultancy and support service to primary care services
- Ensure that the specialist service operates as a unified service
- Devise strategies to reduce the amount of primary care services that the specialist service is asked to provide
- Consider the potential and need for a more extensive trainee registrar program
- Consider establishing a palliative care professorial position

4.1 Research

The specialist palliative care service will also be responsible for developing a research program for the ACT.

Actions:

- Review the research needs and potential within the ACT and begin to develop a palliative care research program in the ACT.

4.2 Regional Relationship

Greater Southern Area Health Service (GSAHS), as part of its current restructure process, is working towards being more self sufficient in the provision of palliative care services and this will be made increasingly possible by the upgrade of Queanbeyan hospital which will include dedicated palliative care beds.

ACT Health acknowledges it has a regional role and will work with GSAHS to support the establishment of a more independent palliative care Level 1 service in surrounding NSW. The ACT specialist palliative care service offers support through medical consultation and inpatient care, in collaboration with GSAHS Palliative Care CNC, specialist palliative care and primary care nurses in GSAHS.

Actions:

- Establish and maintain formal regular communication meetings between ACT Health and GSAHS.
- Establish clear roles and responsibilities for palliative care service provision between ACT and GSAHS

Aim 5 – Further Developing a Skilled Workforce

The workforce that provides palliative care in the ACT consists of both specialist and generalist professionals, as well as volunteers. Importantly, the combined skills of the interdisciplinary team of allied health and psychosocial professionals as well as nurses, medical officers and volunteers need to be developed and enhanced.

It is important that the workforce is appropriately educated, qualified, experienced and trained, and is supported to achieve appropriate levels of qualification, knowledge and ongoing professional development. Specialist palliative care providers need to be appropriately qualified and trained in palliative care and primary health care providers need to be educated in the palliative approach. For specialist palliative care providers it is important that whole of career pathways in palliative care are developed and appropriate support is provided to specialist palliative care professionals.

Actions:

- Undertake a needs analysis of the current workforce and if necessary develop an action plan to restructure the workforce to better meet the needs of the ACT community. This review will consider issues such as establishing a palliative care nurse practitioner position, establishing a palliative care nurse coordinator at Calvary and increasing the number of palliative medicine trainees
- Undertake a palliative care skills audit for all nursing, medical and allied health professionals – to ensure that the skills of the workforce are developed and maintained and to identify what elements an education strategy needs to address in order to enhance the provision of the palliative approach
- Ensure appropriate education and practice and professional development opportunities are provided to primary and specialist palliative care staff, across whole of career pathways.
- Support training and development of the volunteer workforce, including provision of information to volunteers on self care while providing palliative care services.

Aim 6 – Improving Information Management and Data Collection

It is important to ensure that there are system-based relationships and processes so that information can be exchanged effectively across the palliative care sector. It is also important that links are built across the palliative care sector.

High quality care planning and information sharing are essential in order that palliative care services can be delivered in accordance with patient and carer needs, across the care continuum.

It is also important that information and data are recorded in a manner that enables it to be utilised effectively for purposes such as patient care management and service planning.

Actions:

- Ensure secure availability and transfer of clinical information, across the continuum of palliative care.
- Develop a data collection system for palliative care, consistent with national minimum data set requirements where appropriate and acknowledging local service needs.

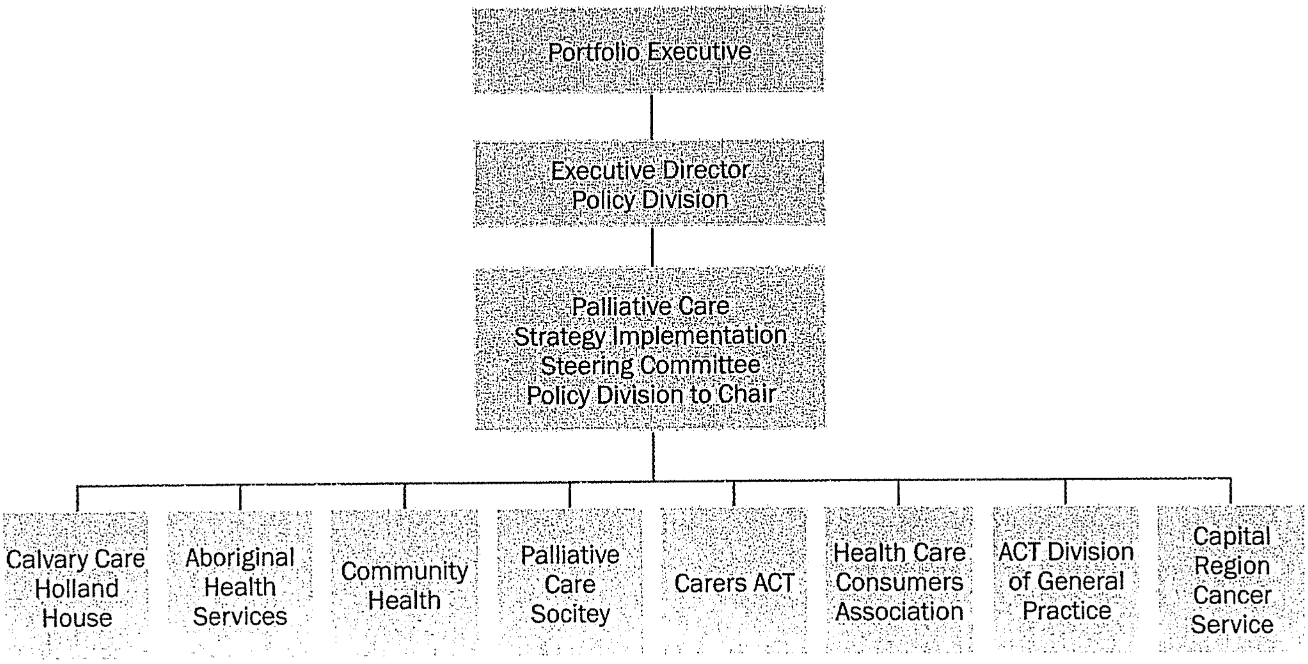
Implementation Phase

The principles and actions detailed in this Strategy will provide planning direction for palliative care in the ACT for the next four years. Implementation will be overseen by a Steering Committee. Diagram 1 illustrates the governance and reporting lines for the implementation of the Strategy.

The Steering Committee will include representatives from Clare Holland House, Home Based Palliative Care, the Capital Region Cancer Service, the Canberra Hospital palliative care service, general practice, Community Health, the Palliative Care Society, Carers ACT and Health Care Consumers Association of the ACT. The Steering Committee will be chaired by ACT Health Policy Division, who will also provide secretariat services. The Committee will report to the Deputy Chief Executive, ACT Health and will provide six-monthly reports through the Deputy Chief Executive to ACT Health Portfolio Executive on the progress of implementation.

It is proposed that for each 12-month period of the life of the Strategy, a list of priority actions be agreed for implementation within that time, and that progress against the priority actions be reviewed six-monthly, and an updated list of priority actions be agreed annually.

Diagram 1 – ACT Palliative Care Strategy Governance



Appendix A – ACT Palliative Care Role Delineation

Level	Role	Staffing	Formal Service links	Services Accessible	Education of others	Research	Quality Activities
Primary Care	Provision of palliative care to people who have uncomplicated needs. The service may be provided to people needing palliative care in: • their place of residence • a community health facility • a hospital setting • a residential aged care facility	Primary healthcare providers competent in providing a palliative approach	Specialist consultative palliative care services	Aged Care Residential Care Facilities Aged Care and Rehabilitation Service General Practice Public Hospitals Private Hospitals Medical Specialists Community Nursing Allied Health Winnunga Nimmityjah Aboriginal Health Service Volunteer Services NGOs including ACT Palliative Care Society, Council on the Aging and Health Care Consumers Association Carers ACT Link Team Complementary medicine Aboriginal and Torres Strait Islander Liaison Service Community Pharmacy CIT Skills for Carers course	People needing palliative care/carer education Nursing and aged care workers Allied health students Trainee aboriginal health workers Medical students and advanced trainees GPs	May initiate their own research and audit activities if indicated	Participates in quality activities

Level	Role	Staffing	Formal Service links	Services Accessible	Education of others	Research	Quality Activities
Specialist palliative care (Level 2 against Palliative Care Australia role delineation framework)	To provide: • Inpatient palliative care • Specialist consultative services • Specialist outreach services • Palliative care volunteers • Education services	Palliative Care Physician/s Registered and Enrolled Nurses experienced in palliative care with tertiary qualifications Allied Health Staff Pastoral Care Bereavement staff Volunteer Coordinators Education Coordinator PEPA project officer	Canberra Afterhours Locum Medical Service Funded Organisations (ACT Palliative Care Society)	Diagnostic imaging and pathology Consulting Anaesthesia Clinical psychology Medical and Radiation Oncology Liaison Mental Health Services	Education to people needing palliative cares/carers Leadership role in broader educational activities Formalised medical, nursing and allied health programs Opportunities for registrars/ trainees/ students Volunteer Training	Initiates and collaborates with activities to develop the palliative care service Contributes to policy development at a Territory-wide and national level	Individual specialist palliative care staff participate in their own ongoing

Format taken from the Northern Territory Department of Health and Community Service

Palliative Care Australia Role Delineation Framework

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

Appendix B – Glossary

Life limiting illness — The term life limiting illness is used here to describe illnesses where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and nonmalignant nature. A life limiting illness might be expected to shorten an individual's life. This differs from chronic illness where, even though there may be significant impact on the patient's abilities and quality of life, there is likely to be a less direct relationship between the illness and the person's death.

Patient — The word patient is used to describe the primary recipient of palliative care. "People needing palliative care" is also used in this document to describe the same group of people where the context and language allow for it.

Carer – The carer is generally in the close kin network of the patient and is usually self identified, eg spouse, partner, adult child, parent or friend. This person undertakes to provide for the needs of the patient and may take on additional tasks of a technical nature to provide ongoing care for the patient, eg administration of medications.

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

Primary care providers — primary care providers is taken to include all those health services and staff that have a primary or 'first contact' relationship with the patient with a life limiting illness. The use of the term 'primary care provider' in this context refers to general practitioners, community nurses, staff of residential aged care facilities and multi-purpose centres. It also includes other specialist services and staff, for example oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals and services. These staff, while specialist in their own areas, may undertake an ongoing role in the support of patients with life limiting illness by adopting a palliative approach to the care they provide. In this context they are seen as the primary care service, with specialist palliative care services involved on an 'as required' basis only. In general the substantive work of the primary care provider would not be with people who have a life limiting illness.

Specialist palliative care provider — specialist palliative care provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available) who provides consultative or ongoing care for patients with a life limiting illness, and support for their caregiver/s and family. Specialist palliative care builds on the palliative approach adopted by primary care providers, and reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first, by providing direct care to referred individuals and their families; and second, by providing a consultancy service to primary care providers and therefore supporting their care of the patient and family.

Interdisciplinary team — An interdisciplinary team is a team of health care providers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs of the target population. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may also be part of the team.

(These definitions are based on those used by Palliative Care Australia in "Standard for providing Quality Palliative Care for all Australians, p11–12).