Chapter 10 – Australian Capital Territory

Overview of palliative care in the Australian Capital Territory

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

Recent history and context in ACT

ACT Health is currently developing a new palliative care strategic plan for the period 2004–2007. The goals of the new *ACT Palliative Care Strategic Plan* echo the National Strategy and aim to improve and enable:

- Awareness and understanding
- Quality and effectiveness, and
- Partnerships in care.

The ACT Palliative Care Partnership Team was established in 1999 to provide a mechanism for providers of palliative care in ACT to work collaboratively to achieve the Goals and Objectives of the *ACT Palliative Care Strategic Plan 1999–2001*.

The Team provides a mechanism to improve the co-ordination of palliative care services in ACT and to advise ACT Health on palliative care issues. It is a multidisciplinary advisory body that links community and hospital-based clinicians, volunteers and consumers with ACT Health.

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

Current arrangements in ACT

Introduction (Objectives 2.2, 3.2)

Palliative Care ACT is funded and managed through the Health Planning and Performance Unit of ACT Health. There is a full-time medical director of palliative care who has full status as a staff specialist at the Canberra Hospital.

Funding (Objective 2.2)

Funding for palliative care is principally provided through the Australian Health Care Agreements to the States and Territories on a proportional basis, and through additional funding from the relevant State or Territory health budgets. Like many States and Territories, ACT finds it difficult (and, indeed, misleading) to attempt to identify a ‘palliative care budget’, as many palliative care activities are not recorded as such, most notably those provided by Calvary Healthcare.

Other funding for research and time-limited projects is reported in 'Palliative care activity in the Australian Capital Territory' (page 103) and 'Commentary about the Australian Capital Territory' (page 108).

Service delivery structure (Objective 2.4)

The current model of service arrangements in ACT is characterised by:

- A hospice (Clare Holland House) funded as part of the annual purchase agreement between ACT Health and Calvary Healthcare for the operation of Calvary Hospital (not separately identified as line item for Hospice)
- Home-based palliative care funded as part of the annual grant paid to Calvary HealthCare.
- Provision of some palliative activities (e.g. symptom management, respite care) through public and private hospitals
- Provision of some funds to NGOs to provide education and information resources (ACT Eden – Monaro Cancer Support Group; ACT Palliative Care Society Inc; Cancer Council ACT; Diabetes Australia – ACT)

A report on the *ACT Palliative Care Strategic Plan 1999–2001* documented progress against the objectives and strategies of the plan and claimed that:

> 'Palliative care services are provided by a range of agencies and individuals in the ACT and appear to be generally well regarded by the ACT community. While there is no single overarching palliative care organisation in the ACT, the existing services are well integrated and generally provide a high level of co-ordinated care for patients and their families and carers.'

Services were purchased by ACT Health in 2003/04 to support, train and co-ordinate a volunteer support scheme to people with palliative care needs and children with cancer and their families.

Equipment (Objective 2.4)

The ACT Health Minister launched the Palliative Care Equipment Program for ACT in October 2003 at Clare Holland House. The contribution of the national Palliative Care Equipment Program is being co-ordinated in ACT by Calvary Healthcare.

Planned arrangements in ACT

See current development re new *ACT Palliative Care Strategic Plan* for the period 2004–2007.

Planning, data collection, monitoring and reporting in ACT

Planning (Objectives 2.2, 3.2)

The *ACT Health Clinical Services Plan 2004–2011* (Draft June 2004) provides the strategic framework for the delivery of public hospital and community health services for ACT up to 2011.

With respect to the growth in palliative care services, the plan has projected as follows:

- Service planning for hospice beds has been based on the assumptions of no change in the average length of stay for patients and 90% occupancy. On this basis, there will be a future need for 20 additional hospice beds. It also projects that hospice activity will increase from 341 to 466 admissions by 2011/12

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

- Service planning has been based on the assumption that home-based palliative care will continue to be the preferred model of care. An average 5% annual growth in home-based palliative care activity by Calvary Healthcare in respect of cancer outpatients has been projected for 2004–2011.

Data collection (Objective 2.3)

Home-based palliative care was provided by Community Health ACT until its transfer to Calvary Healthcare in September 2003. Data about home-based palliative care is not readily available.

The *ACT Palliative Care Strategic Plan 1999–2001* contained a number of strategies relating to data collection and monitoring. The plan included collaboration with other jurisdictions to develop a Palliative Care National Minimum Data Set and performance indicators; input to this is reported to be ongoing. In the absence of national agreement about AN-SNAP, there has been no implementation in ACT.

Advisory bodies (Objectives 2.2, 3.1, 3.2, 3.3)

The Palliative Care Partnership Team is a multidisciplinary advisory body that links community and hospital based clinicians, volunteers and consumers with ACT Health. It provides policy, planning, delivery and budgetary advice on the provision of current and projected palliative care services within ACT and the surrounding region.

The Team is the primary means of engagement with palliative care stakeholders. It meets bi-monthly. Secretariat support is organised through the Executive Director, Policy and Planning within ACT Health.

Members are representatives of:

- The Medical Director, Palliative Care ACT (The Canberra Hospital)
- Clare Holland House
- Carers ACT
- ACT Palliative Care Society (formerly ACT Hospice Palliative Care Society)
- Health Consumers Association
- ACT Health
  - Community Health
  - The Canberra Hospital
- Council on the Ageing
- ACT Division of General Practice
- Residential aged care facilities.

Reporting

The Palliative Care Partnership Team provides an annual summary of its functions and outcomes to ACT Health.

Chapter 10 – Australian Capital Territory

Key settings of care in ACT (Objectives 1.3, 2.4, 3.1)

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

Clare Holland House (hospice)

Clare Holland House opened on 5 February 2001 and provides specialist inpatient palliative care services. It is presently a 19-bed facility, having increased from 17 beds in May 2003 as a result of a 2002/03 ACT budget initiative. It was reported that the facility runs at a high bed occupancy rate of around 85% and that waiting times for admission are generally fairly short. Admissions average 340 per annum.[9]

The hospice also operates a day centre program for both inpatients and outpatients, to provide emotional, physical and social support for people receiving oncology or palliative care services and to provide respite for carers, relatives and friends.

Home-based

Home-based Palliative Care operates from a base at Clare Holland House; administrative responsibility for provision of home-based palliative care services transferred from Community Health (part of ACT Health) to Calvary Healthcare part way through 2002/03.

Acute care facilities

Support for symptom management, respite care, terminal care and outpatient services are also available through the range of acute care facilities in ACT. These comprise Canberra Hospital (public hospital), Calvary Hospital (both public and private), John James Memorial Hospital (private) and the National Capital Private Hospital.

Note re respite care

Respite in ACT is provided through Clare Holland House and acute care facilities such as the Canberra Hospital (public), Calvary Hospital (public and private), John James Memorial Hospital (private) and the National Capital Private Hospital.

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

Key relationships with specific population groups in ACT (Objectives 2.4, 3.2)

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

Children and young people

Some children who need cancer care go to Sydney for treatment, creating challenges around support issues for families. Paediatric palliative care has been foreshadowed as a priority area for future project resourcing.

---

[9] *Consultation Draft – ACT Health Clinical Services Plan 2004–2011*, p 50.

Aboriginal and Torres Strait Islander peoples

ACT does not yet have a strategy that focuses on Indigenous palliative care issues (e.g. there is no Aboriginal palliative care worker in Canberra), but has identified this as a priority area for future project resourcing.

People with specific cultural and linguistic needs

Indigenous palliative care has been foreshadowed as a priority area for future project resourcing.

People with cancer

A *Cancer Streaming Plan* is currently being prepared and contains elements relating to palliative care.

Key links with other strategies and frameworks in ACT (Objectives 3.2, 3.3)

In ACT, provision of palliative care services is an integral part of other health and support services. In addition to the *ACT Palliative Care Strategic Plan 1999–2001*, there are some other key strategies and operational frameworks in ACT which influence palliative care planning and practice:

- The Palliative Care Partnership Team and its links with various stakeholders
- The ACT Palliative Care Society
- The *Cancer Streaming Plan*
- The draft *ACT Health Clinical Services Plan 2004–2011*
- The *ACT Health Action Plan* (November 2002), which sets the directions for public health services in ACT for three to five years.

Palliative care activity in the Australian Capital Territory

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

Reform, training and research in ACT

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

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

National Contribution to ACT Reform in Palliative Care (Objective 2.4)

The Australian Government, through the National Palliative Care Program, has offered funding to assist each of the States and Territories to undertake strategic activities that would progress the reform agenda in palliative care and support the policy, Goals and Objectives of the National Strategy. ACT has considered four possible projects which will enhance the planning and delivery of palliative care.

Proposal 1: Scoping study to look at needs in ACT nursing homes (Objectives 1.5, 2.4)

This study would look beyond educational needs to determine what other supports may be required for palliative care for people in aged care residences. Key aspects to be covered would include issues around decision-making, outside-hours assistance and patients requiring specialised care.

Proposal 2: A scoping study to look at arrangements for patients transferring between acute, palliative and aged-care facilities (Objectives 3.1, 3.2)

Of particular concern are those people who fall between acute, geriatric and palliative care systems – for example, a person may require acute care services and then not be able to return to the aged care facility they consider to be their primary residence, thus effectively becoming homeless.

Proposal 3: Restructure of bereavement supports, including follow-up (Objectives 2.2, 3.1)

The Palliative Care Partnership Team is currently in the process of restructuring bereavement supports and this project would facilitate and expand this activity. Bereavement follow-up is required to ensure that people get the information they need when they need it. This may include specialised counselling, especially, for example, where a young person is dying or has died. Development of new education and training arrangements for volunteers is also proposed.

Proposal 4: Investigation of medications in the community (Objective 2.2)

This proposed project would include the design and implementation of a system to monitor ongoing trends in the demand for, and the delivery of, medications used in palliative care which are not funded under the PBS or through palliative care funding from the Australian Government. This system would be used to inform future policy on, and resourcing of, non-PBS palliative care medications.

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

This program is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The National Palliative Care Program has made funding available for PEPA, which provides primary health care practitioners with an opportunity to develop skills in the palliative care approach by undertaking a short and flexible program of planned work placement with a palliative care specialist service within a metropolitan or larger rural service.

Total PEPA funding received by ACT to date has been $67,407. Fourteen participants have been selected and, at 30 September 2004, seven placements have been completed. The placement program is managed by Calvary Healthcare. There is one occupational therapy placement and the remainder are either registered nurses or enrolled nurses. In addition, one PEPA placement from the Northern Territory undertook a one-week placement in February 2005 in Clare Holland House.

The *PEPA ACT Learning Guide* has been developed from the PEPA NSW guide and has been distributed to all participants.

Status	Funding available till June 2006
Evaluation	PEPA National Evaluation Framework
Reports, information, materials	Contact National Co-ordinator, (07) 3636 8197

Palliative Care Equipment Program (Objectives 2.2, 2.4)

The Palliative Care Equipment Program ($3.8 million over two years) is one of a number of national initiatives designed to achieve the Goals of the National Strategy. The initiative (being administered through Palliative Care Australia) provides grants to organisations in each State and Territory for the purchase of equipment that can be loaned to families and carers of people receiving palliative care at home, particularly organisations in rural or remote communities or those with links to residential aged care facilities. In ACT, Calvary Healthcare has taken on the co-ordination role, which includes managing a one-off grant of $124,000. This has been used to purchase new shower chairs, wheelchairs, recliner chairs, syringe drivers for managing doses of medication, and electric beds for when patients are extremely debilitated. The program aims to provide specialised palliative care equipment to allow individual patients and their families to manage symptoms comfortably at home while maintaining their independence for as long as possible.

Caring Communities Program projects in ACT (Objective 1.1)

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

Enhancing Community Understanding of Palliative Care (Objectives 1.1, 1.2)

This project aims to increase community understanding and awareness of palliative care through the delivery of a series of education sessions and the production of some community education resources.

Conducted by the ACT Palliative Care Society, two community resources have been produced, following feedback from two focus groups. These are a generic flyer which includes key contacts in ACT for palliative care, and a 12-page brochure which includes general and clinical palliative care information as well as a Frequently Asked Questions section. The initial print run is 1,000 copies of each. In early 2005, a series of clinical fact sheets will be produced. It is estimated that there will be 15–16 topics, targeted to patients and carers, who will receive a subset of these, selected for them by a clinician.

A community educator has developed and delivered a series of presentations to community groups, including professional organisations, to increase awareness of the role of palliative care. To date, three of four planned sessions have been held, with attendances at each ranging from 30 to 50 people.

Status	Project due for completion in April 2005
Evaluation	Evaluation will occur as part of the national cluster evaluation of the Caring Communities Program; training sessions had their own feedback sheets
Reports, information, materials	Generic flyer 12-page brochure Fact sheets (available 2005)

Education Link – Palliative Care (Objectives 1.1, 1.2, 1.3)

Carers ACT, in collaboration with the ACT Palliative Care Society, is offering a free three-and-a-half-hour workshop for service providers, community groups, volunteers, and residential aged care facilities who are either supporting or working alongside families and individuals who are, or may be, receiving palliative care. The training includes:

- Information about what support palliative care provides and how it is provided
- Understanding the experience of loss, grief and bereavement
- Practical ways to support families who are receiving palliative care
- Raising awareness of the need to look after themselves in this work, and discussing ways of managing self care.

To date, ten workshop sessions have been held at venues throughout ACT, with 100 participants involved.

Each workshop utilises a range of training methods, including lectures and stories, overheads, small group discussion, brainstorming, individual activities such as drawing and reflection, a video (*Palliative Care – More Than Just Pain Control*), large group discussion and handouts. A book list and resource list are distributed at the end of the session. The book list was developed after a request by one of the participants.

This project is being run by Carers ACT.

Status	Current project runs February 2004 – February 2006
Evaluation	Participants complete an evaluation immediately after attending a workshop and again two months later. Assistance with evaluation design has been provided by the University of Wollongong Evaluation will also occur as part of the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Summary report of collated evaluations available end of 2004

Shared Understandings: Improving Palliative Care for People with Dementia (Objectives 1.1, 1.3, 1.4, 3.1)

The aim of this project, undertaken by Alzheimer's Australia, was to improve palliative care services for people with dementia through producing an education resource and improving relationships between dementia care workers, aged care workers and palliative care specialists. Five residential aged care facilities are involved in the project – three ACT and two rural facilities.

The project utilised a learning circle approach to develop a shared understanding between palliative care and dementia care specialists on ways to improve palliative care for people with dementia. Activities included a bi-monthly meeting of a group of residential aged care staff and palliative care staff, a survey of all staff working in the aged care facilities, and a series of face-to-face interviews with families who had experienced the death of a family member with dementia in the last 12 months. Aged care and palliative care workers then received education sessions which were run through the ACT Hospice and included training in strategies developed from the learning circle process. Strong linkages have now been built between the residential aged care sector and palliative care in ACT. An education resource kit is to be developed for use by aged and palliative care workers, incorporating a range of accessible resource material.

Status	Current
Evaluation	Currently underway – the evaluation is being conducted by Dr Mike Bird, Clinical Psychologist, Southern Area Health Service, and Gerard Mallor, ANU, and is expected to be completed early in 2005 Evaluation will also occur as part of the national cluster evaluation of the Caring Communities Program
Reports, information, materials	A stand-alone resource kit to support palliative care for people with dementia will be available to aged care facilities Two Palliative Care Help Sheets are to be produced for inclusion in the suite of help sheets on dementia published nationally by Alzheimer's Australia

The peak body – the ACT Palliative Care Society (Objectives 1.1, 1.2, 3.2)

The ACT Palliative Care Society (formerly ACT Hospice Palliative Care Society) is affiliated with Palliative Care Australia.

The Society is a member of the Palliative Care Partnership Team and sees advocacy and lobbying on palliative care matters in ACT as part of its role. In addition, it provides education services to the ACT community about palliative care and the services available as well as providing professional training for ACT palliative care volunteers who are part of the volunteer program run by the Society.

Commentary about the Australian Capital Territory

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

There is a new *ACT Palliative Care Strategic Plan* under development. Drivers of palliative care in ACT appear to be:

- **The demographics of ACT.** This population (approximately 320,000) and its geography (a number of discrete town centres, with poor public transport which tends to be organised along the corridors between the town centres, making cross-suburb travel difficult without access to a car) will continue to influence the best way to provide palliative care services.
- **Projected service growth.** The Draft *ACT Health Clinical Services Plan 2004–2011* projects ACT hospice activity will increase from 341 to 466 admissions by 2011/12. Assuming no change in the average length of stay for patients and 90% occupancy, there will be a future need for 20 additional hospice beds.
- **Service planning.** This has been based on the assumption that home-based palliative care will continue to be the preferred model of care. An average 5% annual growth in home-based palliative care activity by Calvary Healthcare in respect of cancer outpatients has been projected for 2004–2011.

Further information

www.health.act.gov.au/c/health

ACT Palliative Care Strategic Plan 1999–2001