

Chapter 14 – Western Australia



Overview of palliative care in Western Australia

This section provides an overview of the context, structure, planning, delivery and monitoring of palliative care services in Western Australia (WA).

Recent history and context in WA

The provision of specialist palliative care services in WA began in 1981 with the opening of the Palliative Care Unit at the Repatriation General Hospital (now Hollywood Private Hospital). This was followed in 1982 by a palliative care home support service in the metropolitan area, initiated by the Silver Chain Nursing Association and the Cancer Foundation of Western Australia.

Since this time, a range of government and non-government services have developed.

In 1993, the State Planning Committee was established by the Commissioner of Health in WA to develop a framework for the provision of palliative care services, *Planning for Palliative Care in Western Australia* (Department of Health 1993). This was the first attempt in WA to plan for a comprehensive, statewide, high quality network of services for terminally ill people.

The committee made 27 recommendations. Key elements of these recommendations included: emphasis on the patient and family as paramount; guiding principles and philosophy; development of regional plans; the need for integrated services with cooperation between public and private sectors; a focus on community-based provision incorporating the role of GPs; and the importance of standards, education, research and evaluation.

In 1997, this was followed up by the WA Government report *Palliative Care – The Plan for Western Australia*, which remains the major framework guiding strategy in WA. Key initiatives in the plan were to expand the scope of palliative care services, develop a palliative care investment strategy and evaluate the plan by annual reviews of implementation.

Western Australia was a party to the National Palliative Care Strategy (National Strategy), which was launched in October 2000 as a commitment of the Australian, State and Territory Governments (along with other stakeholders) to the development 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.

More recently a submission by Palliative Care WA (Inc) to the WA Government Health Reform Committee (August 2003) outlined provision of palliative care services in WA and included issues of future trends and sustainability. This committee has reported back via the *Health Reform Committee Report* (March 2004), making recommendations for future initiatives to establish hospice care services at the four metropolitan general hospitals. This recommendation has been given a long-term priority in the recommendations timeline.

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Current arrangements in WA

Introduction (Objectives 2.2, 3.2)

The WA Government has a palliative care program operating within the Department of Health. The preferred model of care is for integrated service provision with a focus on community-based care, with admitted patient care available for those not able to be cared for at home.

Funding (Objective 2.2)

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

In the 2003/04 financial year, the budget for the WA Palliative Care Program was approximately \$18 million. Monies are allocated mainly to purchase admitted patient services and to support community-based care in metropolitan and rural locations:

- In metropolitan areas, the Department of Health allocates the funding directly
- In regional areas, the WA Country Health Service allocates the funding.

Resources provided for palliative care services relate to agreed volumes of activity and to the values of the various types of services. Funds were committed during the WA State election to increase bed-day prices and to address priority issues such as the development of new models of service delivery for residents in the East Metropolitan area and for groups with special needs.

Other funding for research and time-limited projects is reported in 'Palliative care activity in Western Australia' on page 159.

Service delivery structures (Objectives 2.4, 3.2)

The current model of service arrangements in WA is as follows:

- Palliative care is available to patients in their homes, as outpatients, or as inpatients in hospices or hospitals. These services are provided by a range of professionals and ancillary workers and in some settings supported by volunteers. All providers share common goals of excellence and have a strong history of partnerships.
- In practice, palliative care services may be provided directly by the Department of Health through Government Health Services; through the Australian Departments of Health and Ageing and Veterans Affairs (e.g. in aged care facilities); through private health providers (e.g. St John of God Healthcare and Ramsay Health Care); or through NGOs (e.g. the Cancer Foundation of WA, Silver Chain Nursing Association, Murdoch Community Hospice, and the Carers Association of WA). Of the NGOs, the Silver Chain Nursing Association is the biggest and, in most cases, the sole provider of community care services in both rural and metropolitan areas.
- An on-call telephone consultation service is available for nurses and GPs in rural and remote areas.
- A Palliative Care Education Centre is funded to provide education to staff, volunteers, health professionals and carers throughout WA.

In WA, volunteers continue to provide significant service for both inpatient and home-based community care in NGOs. There is general agreement that volunteers play a significant role in the delivery of services to palliative care patients.

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.

Murdoch Community Hospice is piloting and evaluating their train-the-trainer program for volunteer governance. The hospice has a pool of 200 volunteers of various types, including professional volunteers who provide services such as massage, reiki, beautician, meditation and reflexology. All these volunteers are qualified in their fields.

Loss, grief and bereavement education and professional counselling services are provided through the Cancer Council of WA (included in the contract between the Department of Health and the Cancer Council).

Other organisations providing grief support are Silver Chain Grief Support Services, Motor Neurone Disease Care Advisor and the Compassionate Friends.

Equipment (Objective 2.4)

In WA, the provision of equipment for palliative care includes equipment pertaining to medical and nursing interventions but does not include equipment pertaining to activities of daily living. The contribution of the national Palliative Care Equipment Program is being co-ordinated in WA by Silver Chain (see further details in 'Palliative care activity in Western Australia' on page 159).

Planned arrangements in WA

The Health Reform Committee report, *A Healthy Future for Western Australians* (2004), recommended that purpose-built facilities be established in four designated general hospitals for inpatient, day and ambulatory palliative care hospice services.

Planning, data collection, monitoring and reporting in WA

Planning (Objectives 2.2, 3.2)

The Department of Health is currently proposing to undertake planning to review demand for palliative services in WA to inform decisions relating to future service development and reconfiguration of existing services.

Data collection (Objectives 2.1, 2.2, 2.3)

Service usage data for inpatient and hospice care is collected via bed-day data for the Department of Health. Statewide data on community-based palliative care services is generally poor; it appears to be only intermittently collected, rarely collated and reported – the exception is in the metropolitan area, where Silver Chain collects community-based data for its delivery.

The University of Western Australia (funded by the NHMRC) has developed the WA Health Linked Database, providing information on 26,000 deaths in WA in a one-year period. This is one of only six similar databases worldwide. All hospital and health contacts over a two-and-a-half-year period are documented. From this information, diagnostic groups and categories of care can be extracted to give accurate data on those receiving palliative care services and those who did not.

Monitoring and reporting (Objective 2.3)

Monitoring and reporting of palliative care information and activity may be more robust in the future with the WA Health Linked Database information.

Advisory body (Objectives 2.2, 3.2)

In WA, there is a Western Australian Palliative Care Advisory Group, with representatives from all stakeholders. Currently, the function and composition of this group is being reviewed.

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Key settings of care in WA (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 WA's approach to these settings.

Home and community settings

Home-based palliative care services are well developed in metropolitan areas and regional towns. In metropolitan areas, the two major providers of home palliative care services are the Silver Chain Hospice Service and the Hollywood Home Care Service (the latter is funded by the Department of Veterans Affairs and provides services to veterans at the Hollywood Hospital Hospice). Peel Health Service also has a home palliative care service.

Twenty-four-hour care is offered by teams, which include nurses, hospice care doctors (who are mainly GPs), care aides, chaplains, counsellors and volunteers. In-home care includes home nursing, personal care and other general and specific support services (e.g. symptom control).

Community-based care – aged care residential facilities

People living in residential aged care facilities may have palliative care available through the local palliative care team, supported by clinical consultancy/advisory services. Silver Chain Nursing provides five days of no-cost advisory assistance to staff in residential aged care, but no equipment is supplied. Education is client specific.

Inpatient palliative care beds and units – admitted patient care

Admitted patient care is integrated with community-based services to facilitate access when needed. The intention is to provide a more appropriate and cost-effective alternative to an acute hospital environment.

Inpatient hospice services are offered at:

- Hollywood Private Hospital Palliative Care Unit
- Cancer Foundation Cottage Hospice
- Murdoch Community Hospice.

Note that some other hospitals admit patients for palliation (e.g. some other private hospitals in the metropolitan area) and there are some hospice-based services in rural areas such as Albany, Geraldton and Bunbury. They may have palliative care beds available, but these are generally a small number of beds set aside in a ward, rather than as a separate palliative care unit.

Palliative care consultancy services are also provided to inpatients where they have been admitted through other inpatient units. This occurs at Royal Perth Hospital, Sir Charles Gairdner Hospital, Fremantle Hospital and St John of God Hospital Subiaco.

In many rural WA centres the most cost-effective provision of palliative care is in the local public hospital. Hospitals are encouraged to provide palliative care in a home-like environment.

Acute hospital care

Consultative services are provided by Royal Perth Hospital, Sir Charles Gairdner Hospital, Hollywood Private and Fremantle Hospital.

Note re respite care

The Commonwealth Carer Respite Centres (CCRCs), funded across Australia through the Ageing and Aged Care Division of the Department of Health and Ageing, 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. WA has nine such CCRCs.

In WA, inpatient respite services are provided by admittance to a hospice (e.g. the Cottage Hospice and Murdoch Hospice), admittance to hospital, day respite (e.g. at Crawford Day Centre at Shenton Park or the Murdoch Community Day Centre), or at home.

Respite care services are provided by some of the disability groups, such as the Multiple Sclerosis Association and Muscular Dystrophy Association, but these are not specific palliative care respite centres and staff do not necessarily have specific palliative care training.

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

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

Aged care

Palliative care patients who are older are able to access all four key settings of care. Although people living in residential aged care facilities all have access to palliative care services, it can be difficult to ensure appropriate education of staff and access to palliative consultative services (e.g. specialist GPs and nursing staff), particularly where the aged care services are not part of one of the major aged care providers. (Note, for major providers, awareness of access to education is often more systematic.)

Children and young people

Providers of paediatric and adolescent palliative care are faced with the challenges of meeting protracted access requirements often accompanying childhood illness, location of suitable accommodation, and assembling the specific age-appropriate range of expertise required in supporting dying children and teenagers and their families. In WA, paediatric palliative care is largely provided by the Princess Margaret Hospital for Children. Palliative care services are primarily for oncology patients. Seriously ill children from country areas are transported by air or road to the hospital and the hospital provides accommodation for country parents and families.

See also current work on paediatric palliative care needs in 'Palliative care activity in Western Australia' on page 159.

There is also specialist accommodation for Indigenous families.

Planning for Palliative Care in Western Australia, 1993 outlines standards for the supportive care of the dying child and following the child's death. As Princess Margaret Hospital is the major specialist primary care centre for children in WA, adolescents who have been treated at the hospital as children may still be admitted for palliative care services as young adults.

Aboriginal and Torres Strait Islander peoples

Three of the five current Caring Communities Program projects in WA (see 'Palliative care activity in Western Australia') are in rural or remote areas where there are significant Indigenous populations. Each of these three projects (covering the Eastern Goldfields, Kimberley and Fitzroy Valley regions) is looking at developing awareness and systems specific to improving palliative care for Indigenous people.

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In these rural and remote areas, issues of not dying at home (because relatives then need to vacate the house) versus not wanting to go to hospital (because of associations with death) continue to make awareness of the concept of palliative care difficult to practise. The Fitzroy Crossing Caring Communities Project is attempting to set aside a room at the hospital that can be used for palliative care and have elders carry out smoking ceremonies to cleanse the room following a death.

Awareness of cultural issues related to grief, death and dying in Indigenous populations is better understood in rural and remote areas than in metropolitan settings.

A project jointly funded by Silver Chain and the Western Australian Aboriginal Community Controlled Health Organisation (WACCHO) and Derbyl Yerrigan is currently underway to improve palliative care services to Aboriginal people within the metropolitan area of Perth (see 'Reform, training and research in WA' on page 159).

People with specific cultural and linguistic needs

There appear to be no specific palliative care services for people with specific cultural and linguistic needs in WA; however there are residential aged care services for people with specific cultural and linguistic needs which can access the services of the Silver Chain Association palliative care team.

People with HIV/AIDS

There are no longer any specific palliative care services or centres for people with HIV. The hospice for HIV/AIDS patients closed in 1992 as treatments changed and a philosophy towards using generic services was introduced.

Palliative care for patients with HIV is provided through general palliative care services, with most hospice patients admitted to either The Cottage Hospice or Murdoch Hospice. Home care services are provided through the Silver Chain Association.

People with cancer

Western Australia reports that currently 90% of people who use palliative care services have malignancies. The Cancer Council provides four palliative care services:

- Cancer Council Cottage Hospice (provided under contract to the Department of Health). The Cottage Hospice is a community-based health service, providing specialist palliative care to individuals with a progressive illness for which there is no known cure. Although funded by the Cancer Council, it admits palliative care patients from all groupings, not solely cancer patients.
- Day therapy services – a support centre.
- The Palliative Care Education Centre – provides palliative care education to meet the needs of the staff of the Cancer Council and its volunteers, as well as health professionals and carers throughout WA.
- Loss, grief and bereavement education and professional counselling services.

People with post-traumatic stress disorders

No specific services are available.

People with pre-existing disabilities

People with disabilities such as muscular dystrophy, motor neurone disease and multiple sclerosis access generic community services for palliative care. The Cottage Hospice and Murdoch Hospice provide admitted patient care, and Silver Chain provides home care. Respite may be provided by some of the special respite care accommodation managed through disability groups, but this is not specific palliative care respite.

Activities in rural and regional WA

Palliative care services in rural and remote regions of WA are provided mainly at the primary care level. Inpatient services in rural centres range from well developed to limited, and home-based palliative care services are offered in some areas following a variety of service models. Silver Chain provides home care and community-based services in most major rural towns.

Economies of scale are always an issue in regional WA – numbers of patients may be very small and sporadic in nature. However, other complementary supports are available:

- Telephone medical consultation services are provided by a group of six Perth-based palliative care specialists who are available on-call to provide advice to rural GPs and nurses for advice re palliative care issues in rural areas. So far the usage of the telephone consultation system has not been high, but has been evaluated as extremely helpful by those who have used it.
- Telephone consultation services for nurses in rural and remote areas are provided by Silver Chain.
- The Cancer Foundation and Silver Chain provide education in palliative care that can be delivered in rural settings, including short courses using video for health professionals. The Carers Association of WA also provides resources and information.
- Edith Cowan University also runs short courses and modules on palliative care for nurses in major regional towns.

Awareness of palliative care in rural areas may not be as strong as in metropolitan areas. The three Caring Communities Program projects in regional WA (see 'Caring Communities Program projects in WA' on page 161) all commenced with very small numbers, but all have shown a steady increase in demand for services as awareness has increased.

Carers

The Carers Association of WA provides resources and information as well as education and training for carers. It is jointly funded through HACC by both the Australian and WA governments.

The Carers Association has recently completed a pilot project at Fremantle Hospital where it provided information sessions, packages of materials and direct work with carers on the patient's admission to hospital. The carers work in conjunction with the Social Work Department of the hospital. Funding has been made ongoing after 1 July 2004 for all admissions to five particular wards at the hospital; the proportion of these patients who are palliative is unknown at this stage.

The project will continue beyond the pilot and will also be implemented at Sir Charles Gairdner Hospital in 2005.

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

One of the features of palliative care services in WA is the provision of palliative care as an integral part of other health and support services. In addition to *Palliative Care – the Plan for Western Australia* (1997) there are some other key strategies and operational frameworks in WA which influence palliative care planning and practice:

- The Health Reform Committee in WA, which has recommended that:
'Purpose built facilities to provide for inpatient, day and ambulatory palliative care hospice services should be incorporated into the four designated general hospitals. These services should form an integrated network with existing community-based palliative care services, including supporting end-of-life care in aged care residential facilities.'
- The Palliative Care Advisory Group of WA, which provides advice to the Department of Health

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- Palliative Care WA, which is the voluntary association for all stakeholders in the palliative care field
- A range of strategies and initiatives address workforce issues
- The Centre for Cancer and Palliative Care Research at Edith Cowan University.

Workforce (Objectives 1.3, 1.4, 2.5)

Many parts of the primary health care sector are experiencing an ageing workforce; this is particularly so in the aged care area, where palliative care in residential aged care is endeavouring to become well established. Edith Cowan University has found that offering short courses (initially at certificate level) in palliative care is an effective way of getting older nursing staff involved in postgraduate education.

Recruitment to rural and remote areas in all areas of the health services is frequently difficult for all health services. In the Kimberley region there is currently a 300% turnover of registered nurses, affecting palliative care initiatives among others. Finding and retaining Indigenous staff at all levels is also very difficult as currently experienced by the Caring Communities Program projects working with Indigenous people in WA.

WA has thus developed a range of strategies to support an effective workforce infrastructure, as follows.

Nursing staff – A range of education programs (centre-based, on-site and distance learning) is provided by the Cancer Foundation of WA and the Silver Chain Association and Edith Cowan University.

Medical staff – A medical teaching program includes community-based training placements for palliative care and education programs for GPs. There are also services to link medical practitioners with palliative care consultants via telephone or through site visits.

Metropolitan nurse consultancy – Metropolitan hospitals and residential aged care facilities with 24-hour registered nurse staffing can access this service, which supports staff in relation to individual patient care needs. The service is co-ordinated by a clinical nurse consultant and a hospice care medical consultant. The service includes a site visit from a registered nurse specialising in palliative care to:

- Provide nursing advice related to an individual patient's care
- Teach relevant procedures to those involved with patient care
- Perform nursing procedures that the facility staff do not have the skills to provide.

Country staff – Education and team support is available for staff working in country areas with Silver Chain, the Cancer Foundation and Edith Cowan University often co-operating to provide joint educational programs in palliative care.

The Nurse Consultancy telephone help service for palliative care is managed by Silver Chain.

Telehealth and Westlink programs are interactive video services which provide consultation between medical and nursing staff on health issues in rural and remote areas through the State network of telecentres. Westlink covers other areas as well as health and is more education oriented.

An upgrade/installation of the PalCIS software is available for country sites.

Palliative care activity in Western Australia

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

Reform, training and research in WA

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

In particular the universities have been major drivers of research and training.

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

National Contribution to Western Australian State Reform (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. Western Australia has used these funds to conduct PalCIS workshops in country areas. WA also intends to use some of these funds to look at models of care and the applicability of palliative care service models developed by Palliative Care Australia. This work will commence in 2005.

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.

The first round of PEPA placement in WA accepted 23 participants – 16 registered nurses, two enrolled nurses, three allied health workers, one Aboriginal health worker and one nursing assistant. Supervised clinical placements are available for 50 primary care practitioners in WA during 2004 and 2005.

Rural Palliative Care Program (Objectives 1.4, 2.2, 2.5, 3.1, 3.2)

The Rural Palliative Care 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 over a three-year period to support eight Divisions of General Practice across Australia in the development and implementation of collaborative models, demonstrating improved access to multidisciplinary care for rural communities. In WA, the Pilbara Division of General Practice and the Eastern Goldfields Division of General Practice have received funding.

The Pilbara Project (South Burnett) is focusing on provision of an after-hours service, effective case-conferencing, the use of PalCIS, significant education and training, and the use of patient-held records.

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The Eastern Goldfields Project focuses on an integrated multidisciplinary approach. It has also invested heavily in a GP education program and developed a GP resource kit.

Reports, information, materials Further information at www.adgp.com.au

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 Palliative Care Program.

The initiative (being administered through Palliative Care Australia) provides grants to organisations in each State and Territory for the purchase of equipment that can be loaned to families and carers for people receiving palliative care at home, particularly organisations in rural or remote communities or those with links to residential aged care facilities. In WA, this initiative is managed by the Silver Chain Association.

Reports, information, materials Palliative Care Australia reported to the National Palliative Care Program in October 2003

Metropolitan Indigenous Palliative Care (Objectives 1.3, 1.4, 2.4)

A project jointly funded by Silver Chain and the Western Australian Aboriginal Community Controlled Health Organisation (WACCHO) and Derbyn Yerrigan is currently underway to improve palliative care services to Aboriginal people within the metropolitan area of Perth. This is a four-month project designed to develop awareness and provide education to staff at inpatient facilities or at home. Project staff have been involved in giving talks, sending flyers to the Divisions of General Practice and visiting clients at inpatient facilities. An Aboriginal liaison worker has been employed and at this stage ongoing funding is being sought. Referrals have increased in the duration of the current project.

Centre for Cancer and Palliative Care Research at Edith Cowan University (Objectives 2.4, 2.5)

Edith Cowan University has a Centre for Cancer and Palliative Care Research in the Faculty of Health Sciences, offering educational programs and collaborative research opportunities for professionals in the field.

Research projects from the University have highlighted the need to provide models of service delivery for the non-cancer patients, volunteer use, children's palliative care and rural service delivery models.

The National Palliative Care Program has created a research agenda and the University has undertaken a number of these national projects, particularly linked to palliative care in aged care:

- The Australian Palliative Residential Aged Care (APRAC) team at the University has developed guidelines and a national palliative care education program for palliative care in residential aged care facilities. This material is now being progressed and implemented via other initiatives
- The University is also developing a model to support palliative care volunteers in residential aged care (VPRAC)
- The University is evaluating workshop materials for the specific Caring Communities Program project 'Learn now, Live Well'.

Reports, information, materials Copies of the guidelines at www.pallcare.gov.au, or email palliativecare@health.gov.au
Information re volunteers project at www.vprac.org

Children with Palliative Care Needs (Objectives 2.2, 2.4, 3.3)

The Princess Margaret Hospital palliative care team is developing a Needs Assessment of Paediatric Palliative Care in WA (funded by the NHMRC but not specifically through the National Palliative Care Program). This needs assessment relates to oncology patients only.

However, there is also a white paper being developed (jointly funded by the Department of Health, the NHMRC, Edith Cowan University and Princess Margaret Hospital) investigating the paediatric palliative care needs of all children in the State (i.e. looking at all children with palliative care needs, not only oncology patients). There are 400 children identified to date and the group is due to report mid-2005.

Caring Communities Program projects in WA (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 those patients are cared for in the setting of their choice and to improve their satisfaction with care. Four projects from WA were successful in receiving funding.

Fitzroy Valley Palliative Care Service (Objectives 1.1, 1.2, 1.3, 2.4)

This project aims to develop a culturally and spiritually appropriate palliative care service for the Indigenous population of the area, to enable, where possible, people to remain in their own country. The project will meet the palliative care needs of the people of the Fitzroy Valley and enhance services being offered by the Fitzroy Valley and Kimberley Palliative Care Service in joint partnership with the Aboriginal Health Service. There has been some delay in the project due to staffing matters. Activities primarily involve consultation with elders and general awareness of palliative care.

Status Was due to complete June 2004, now April 2005

Evaluation Through the national cluster evaluation of the Caring Communities Program

Reports, information, materials Policies and protocols now available; may produce video

Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities (Objectives 1.1, 1.2, 1.3, 2.4)

There is a lack of access to palliative care services in the Kimberley region, and community needs fluctuate in an unpredictable manner (as does staff turnover). Hence the requirement for service delivery that can best be met with a decentralised service where local people and resources can be activated to deliver palliative care when the need arises.

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This project will address the lack of access to a comprehensive palliative care service, increase the knowledge of palliative care services and establish a support and information network to enable the provision of palliative care in remote Aboriginal communities. Since commencement, there has been steady rise in referrals from both Indigenous and non-Indigenous clients. The project has assumed an educative role re generic medical services.

Status	Commenced July 2003 and will be completed in October 2005
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Have produced a video, posters and leaflet materials, and presented at the State Conference

Kalgoorlie–Boulder Palliative Care Co-ordination Project (Objectives 1.1, 2.4)

The aim of this project is to provide co-ordination, education, cultural awareness and Indigenous liaison and interpretation to support the development of an integrated and cooperative palliative care service which will enhance the delivery of palliative care to the Kalgoorlie–Boulder region and surrounding areas. The project has employed a palliative care co-ordinator and an Indigenous liaison worker, who are raising awareness, providing education and forging partnerships.

Status	Current, commenced April 2003, due to complete April 2005. Six partners in the project
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	Report early 2005. Submitting business plan for sustainability beyond April 2005 Have acquired equipment for community clients, developed Volunteers Training Material for six-hour workshop

Learn Now, Live Well: An Educational Program for Patients and Caregivers Living with and affected by Life Threatening Illness (Objectives 1.1, 1.2)

This project aims to increase support for family members caring for palliative care patients at home, through an education and support program. The Learn Now, Live Well project has been specifically designed to enhance carers' sense of empowerment and increase confidence in their role as carers. The program consists of six education modules that can be delivered as a full program or stand-alone unit covering areas such as pain, exercise and nutrition, communication, the physical side of caring, symptom control and medications. The program is not specifically cancer focused, but aims to meet the needs of caregivers caring for people with non-malignant disease. The program will be delivered at Hollywood Private Hospital and three other community locations throughout the metropolitan area of Perth.

Marketing is being addressed and the project has had good collaboration with Edith Cowan University.

Status	The pilot has been completed and the workshop materials are currently being evaluated by Edith Cowan University Project due to be completed in March 2006
Evaluation	Workshop materials evaluated by Edith Cowan University Project also being evaluated through the national cluster evaluation of the Caring Communities Program

South West Perth Collaborative Community Palliative Care Project (Objectives 1.1, 1.2)

This project aims to trial and evaluate a new interface model that seeks to improve the transition between community and inpatient care through enhancing communication, collaboration and co-ordination between two services – Murdoch Community Hospice and Silver Chain Hospice Care Services. This will be achieved through a multi-pronged approach involving: new and improved documentation; involvement of Murdoch staff before patient admission (meeting patient at home); information and education for GPs, particularly in ‘crisis anticipation management plans’; and strengthening the assessment skills of community-based teams.

Evaluation	Project being evaluated through the national cluster evaluation of the Caring Communities Program
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The peak body – Palliative Care WA (Objectives 1.1, 1.2, 3.2)

Palliative Care WA is the group representing individuals and organisations who provide palliative care services throughout WA. It plays a major role in:

- Providing palliative care information to the public, government and health professionals
- Providing a united voice for palliative care providers
- Promoting and supporting palliative care research
- Facilitating the ongoing development of palliative care policies, standards and services.

Palliative Care WA has input at a national level to palliative care issues and policies through its affiliation with the national peak body, Palliative Care Australia.

Palliative Care WA uses a number of committees to progress its work and to represent the specific needs and interests of members. The views of these members are directed through to the executive committee, which has ultimate decision-making responsibility.

These committees include:

- the Quality and Standards Committee, which is committed to promoting awareness and understanding of the need for the highest quality and standards in palliative care
- The Research Group, which encourages and supports the development of palliative care research in WA and fosters nationwide research connections
- The Rural Reference Group.

Commentary about Western Australia

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

Palliative care is available in WA to patients in their homes, as outpatients, or as inpatients in hospices or hospitals. Generally, palliative care services are well developed in metropolitan areas and rural towns; in rural and remote regions, palliative care is provided mainly at the primary care level.

Some of the strengths of palliative care provision in WA have been:

- The strong partnerships which have evolved between the government and non-government sectors. The non-government associations involving carers and volunteers have also collaborated with mainstream hospital services to provide complementary service provision in the palliative care field.
- The University of Western Australia has been the driver for data collection and analysis.
- The Department of Health has responded to rural and remote needs with the provision of the two telephone services for nurses and medical practitioners and facilitating the implementation of the PalCIS software.

Matters influencing palliative care in WA appear to be the following (many reported in the *Palliative Care Program, Resource Management Plan 2003/2004*, prepared by Ruth Foley).

Undergraduate training in palliative care (medicine and nursing):

Nursing – Edith Cowan University provides undergraduate training for nurses. Palliative care is embedded throughout the undergraduate degree, and begins with a six-week unit on aged and palliative care in the first year. In the second year there is a two-week practical placement in a palliative care setting.

At the postgraduate level – Edith Cowan University offers Certificate, Diploma and Masters level courses in Clinical Nursing (Palliative Care). As a result of its decision to attract older, experienced nurses, particularly from the aged care sector, Edith Cowan offers short courses and modules within the postgraduate courses. Students often then go on to further study. Some of these courses are also offered in regional areas on a costs only basis. This strategy has been successful in significantly increasing student numbers in the aged care/palliative care areas.

Medicine – the University of Western Australia undergraduate medical training provides some training in palliative care and has a required rotation in palliative care.

Special needs of children with terminal illness. Palliative care for children is currently directed towards the needs of oncology patients; some efforts are currently being made to assess and respond to the needs of all children with palliative care needs.

Awareness of Aboriginal issues with respect to grief, death and dying. Awareness of cultural issues in palliative care is better understood in rural and remote regions, but staff turnover continues to be a problem. Within Aboriginal and Torres Strait Islander communities, there is much variation in beliefs and practices, which can cause confusion. The Cancer Council of WA reports that low referral rates and language barriers impact on cancer outcomes for Indigenous Australians and that referral for palliative care is affected by lower referral rates for treatment, and poor access to services. In the metropolitan region, the current WACCHO/Silver Chain project is beginning to address these issues.

Access to appropriate services for patients with longer-term needs who are unable to be cared for at home. This remains an issue not currently being specifically addressed. Most patients with longer-term needs are cared for in institutional settings other than a hospice, such as residential aged care or disability residential centres (e.g. the ParaQuad Centre, or Rocky Bay for muscular dystrophy patients). Edith Cowan University is currently researching the needs of patients with motor neurone disease through an NHMRC grant.

Palliative care models. Further exploration of palliative care models in WA is required around specific patient group needs, such as children with terminal illness who are not oncology patients, Aboriginal and Torres Strait Islander groups, remote services generally, people with pre-existing disabilities and people with specific cultural and linguistic needs. Future models are likely to be more community-based, probably utilising more respite care (including night respite care).

Commentary summary

Other issues have been noted that were not cited as issues in the Resource Management Plan:

- Awareness of palliative care and attitudes towards end-of-life issues among patients, their families, and those caring for them medically are important in planning new palliative care initiatives.
- The new WA Health Linked Database should assist more accurate alignment of needs and resources in the future.
- Patients with cancer are generally well represented within current palliative care services and any future models are likely to point to unmet needs among other groups of patients, particularly the long-term degenerative disease group.

Further information

Palliative Care – The Plan for Western Australia, WA Department of Health, 1997

Palliative Care Program – Resource Management Plan 2003/2004, WA Department of Health, June 2003

A Healthy Future for Western Australians – Report of the Health Reform Committee, WA Department of Health, March 2004

Who Receives Specialist Palliative Care in Western Australia – and Who Misses Out, McNarara B, Rosenwax L, D'Arcy Holman C and Nightingale E, 2004