Chapter 13 – South Australia

Overview of palliative care in South Australia

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

Recent history and context in SA

Strategic Plan for Palliative Care Services

The SA Department of Human Services launched the *Strategic Plan for Palliative Care Services 1998–2006* (Strategic Plan) in April 1998 to drive development and set the direction for mainstreaming SA's palliative care services. The Strategic Plan was developed following extensive consultation with key service providers, consumer groups, particular population groups and key stakeholders, and was informed by national and state-level reviews and reports. An independent consultant undertook a demand analysis (using population data and epidemiological cancer-related deaths data) as a base to project current and future demand for palliative care. Key themes addressed in the Strategic Plan included models of care, needs of particular community groups, service development, funding strategies, indicators of performance and future priorities.

The Strategic Plan has three overall aims:

- To promote improved access to palliative care services for all South Australians
- To ensure ongoing development of a comprehensive service delivery model
- To plan adequate resourcing of services.

The Strategic Plan reflects the shift in palliative care services in SA away from a traditional, institutional hospice model of care, to one of networked services linking care in the home with a range of inpatient care options in hospital settings in order to meet the needs of patients and their carers.

The underlying principles of palliative care are relevant to specialist palliative care services and generalist service providers. Specialist palliative care services should support and complement generalist services and, together, achieve comprehensive support for those who die in our community and their carers and loved ones.

The Strategic Plan was reviewed in 2001, with continued endorsement given to many of its main features. A revised Strategic Plan to take palliative care services beyond 2006 has been deferred pending a Generational Health Review and subsequent implementation of a widespread health reform program. The updated Strategic Plan for palliative care will reflect the new health governance structures being implemented.

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.

Legislative framework

The *Natural Death Act* came into effect in SA in 1983. This Act provided competent adults over the age of 18 years with the opportunity of giving medical practitioners a notice of direction regarding their wishes should they at some time in the future become terminally ill. The Act was repealed with the proclamation of the *Consent to Medical Treatment and Palliative Care Act 1995* (Consent Act).

The Consent Act was proclaimed in SA on 30 November 1995 after more than two years of consultation with the public, and with health and other professionals. The Consent Act covers medical practice generally and makes special provision for the care of people who are dying.

Of the six major provisions included in the Consent Act, four emphasise the obligation of medical and dental practitioners to respect a person's right of self-determination. The other two provisions cover Medical Power of Attorney, allowing a person to appoint a medical agent to speak on their behalf, and Anticipatory Directives, which enable a person to stipulate what level and type of treatment they want to receive should they subsequently be in the terminal phase of a terminal illness or in a persistent vegetative state and unable to make decisions for themselves.

National Palliative Care Strategy

South Australia 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 of palliative care policies, strategies and services that are consistent across Australia and to the delivery of quality palliative care that is accessible to all people who are dying.

Since 2002, SA has worked collaboratively with the Australian Government to advance the National Strategy and implement a number of new funding initiatives. With funding from the National Palliative Care Program, a range of projects and research activities are being undertaken within SA or with SA as a collaborative partner with other States; these are aimed at extending the reach of palliative care programs, supporting people if they wish to die at home, and developing the palliative care skills of a broad range of clinicians and carers. To date, SA has received in the vicinity of $3 million under the National Palliative Care Program to undertake a range of project and research initiatives aimed at improving the standard of palliative care offered in local communities.

SA will be developing a stronger evidence base for palliative care by pulling together the outcomes of the many national projects and research being undertaken as part of the National Palliative Care Program and incorporating the key learnings into the development of directions for palliative care provision in SA.

Peak body formation

The Palliative Care Council of South Australia (the Council) commenced in 1980, as one of the first peak bodies in Australia. The Council acts as a statewide advocacy group for palliative care and is involved in raising community awareness of palliative care issues.

Its two main objectives are to provide a common voice for hospice and palliative care in SA and to be the statewide community-based representative organisation for palliative care in SA.

The Council receives some funding from the SA Department of Health and other funds through the fees of individuals and 'collective' members. A full-time chief executive officer was appointed in 1997.

A key role of the Council is as a resource and information service for both service providers and consumers. It conducts information forums (both professional and public), maintains a library of palliative care references (print based as well as a website), produces a bi-monthly newsletter and promotes palliative care through speaking engagements. The Council has produced a great deal of written information, often partnering with Palliative Care Australia or other peak bodies (e.g. Palliative Care Victoria).

The Council hosted the first National Palliative Care Conference in 1990, which saw the commencement of the National Palliative Care Association. The secretariat function for this national body was located at the Council until Palliative Care Australia moved to Canberra in 1998.

Current arrangements in SA

Current governance structure

Within the Department of Health, palliative care is managed across a range of departments and departmental sections, with principal responsibility sitting with the Acute Care and Clinical Service section of the Metropolitan Health Division. However, policy and strategic management structures will be revised according to the new Department of Health and regional structure during 2005.

As part of its commitment to the Australian Health Care Agreements, SA will continue to focus on improving palliative care, in particular to 'improve the provision of palliative care services'.

Palliative care in SA continues to be aligned with the Strategic Plan, which is based on a continuum of care approach.

Advisory group (Objectives 2.2, 3.2, 3.3)

The Palliative Care Liaison Group was established to provide advice to the Department of Health on the implementation of the Strategic Plan. Membership includes core stakeholders such as the Council, directors of palliative care services, and nurses. It does not have representation from broader interests, such as aged, disability or neuorology.

Funding for palliative care

Public palliative care services in SA are funded from a variety of national and State funding sources. Quantifying a total SA budget allocation is difficult (and indeed, misleading) as many palliative care activities are not recorded as such. (Note that other specific funding for research and time-limited projects is reported in 'Palliative care activity in South Australia' on page 146.)

Since 1998, palliative care has been identified as a priority area within the Australian Health Care Agreements, with all States provided with a dedicated allocation for palliative care. The allocation for palliative care in the 2003–2008 Australian Health Care Agreements uses a formula based on the last year of the previous (1998–2003) Australian Health Care Agreements grant with adjustments for weighted population (based on Australian Bureau of Statistics population estimates for SA) and the Australian Wage Cost Index.[10]

Inpatient palliative care is funded from SA's global health budget using either casemix principles or on an occupied bed day rate for hospice care (Daw House Hospice and Mary Potter Hospice).

The Department of Health contracts two non-government sector organisations (Calvary Hospital and Southern Cross Care (SA) Inc) to provide hospice care for public patients. Inpatient episodes in both metropolitan and country hospitals are funded according to the An-DRG classification of the patient on discharge.

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10. Australian Health Care Agreement between the Commonwealth of Australia and the State of South Australia 2003–2008.

The palliative care community outreach services are funded as specific grants to the health services that provide specialist palliative care services.

The Royal District Nursing Service and domiciliary care services in SA are also grant-funded to provide primary care level service provision for palliative care (within their broader service agreement with the Department of Health).

Several of the rural-based palliative care services are funded through the HACC program. Palliative care is also provided within some of the HACC-funded programs. HACC projects generally identify multiple service types, making it difficult to distinguish the amount spent directly on providing palliative care services. SA also assumes (in HACC-funded services) that palliative care service delivery may also be a component of community nursing. However, there is no way of knowing what percentage of community nursing can be identified as palliative care.

Charitable trusts and foundations play an important role in adding often substantial financial support to some palliative care services, in particular the hospices and services providing respite care.

The Medical Specialist Outreach Assistance Program (funded under the National Palliative Care Program) provides some funding for palliative care medical specialists from metropolitan services to undertake visits to country areas for the purposes of upskilling and providing professional support for health professionals in regional and rural areas. Funding for this program has been reduced from 2005.

Complementary activity in palliative care is carried out by a range of other means, including public and private hospitals, private palliative care services (Nurselink and Independent Home Nurses provide a degree of specialisation in palliative care), welfare agencies and community health services.

A funding grant is provided to the Council for provision of six specific functions, including a resource and information function and advice to the Department of Health.

Service delivery structure

Palliative care is available for people of all ages whose condition has progressed beyond the state where curative treatment is effective and cure is attainable, or who choose not to pursue curative treatment. The person must have (a) been diagnosed as having a terminal illness and/or (b) a progressively deteritorating condition and/or a significantly shortened life expectancy.

Palliative care is delivered by an integrated network of providers, across home, residential care facility, hospital and hospice locations. Providers include both palliative care specialists and generalist/generic providers. There continues to be a strong focus on supporting the dying person’s wish to remain within their home for as long as possible.

In the metropolitan area, palliative care services are formally aligned with acute health services. Most are either located within the hospital itself or are located on the grounds of the hospital/health service. In country SA, most palliative care services are attached to local community health services.

A paediatric palliative care service commenced formally in 1999 with the appointment of a paediatric palliative care co-ordinator at the Women’s and Children’s Hospital. This service operates as a statewide consultative service.

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The palliative care team within specialist palliative care services takes a multidisciplinary approach to the provision of palliative care and encompasses the skills and commitment of medical practitioners, nurses, allied health workers, volunteers and family members. The size of the palliative care team varies depending on the population size and profile for which it provides services. The community-based team typically provides a consultancy service (expert advice and treatment, co-ordination, training and equipment) 24 hours a day, 7 days a week to mainstream service providers of health. However, in some smaller rural areas, providing a 24-hour consultative service is not achievable.

Services are provided across four settings of care; the network of care may be provided through different service structures depending on the actual services in place. Palliative care services are comprenhensive and include management of people in inpatient and community-based care settings. Wherever possible, palliative care is provided in the setting of the person's choice. Within SA, palliative care services are provided in:

- Community settings – the person's home, which includes residential care facilities
- Acute hospital care
- Designated palliative care beds, including hospice.

Other key features of the palliative care system in SA include:

- Recognition of five levels of care: stable, unstable, deteriorating, terminal, and bereaved
- Provision of palliative care services as an integral part of other health and support services
- Recognition of the patient, family and carers as the unit of care
- Recognition of the important role of bereavement support for the patient, family and carers.

Inpatient palliative care includes:

- Short admissions for diagnosis, assessment of symptoms and/or symptom control
- Longer-stay admissions during the end-of-life period for people for whom dying at home is either not preferred or is not an option
- Short-term respite admissions
- 'Step down' or longer-stay admissions for patients who are not able to be managed at home and who require a residential care option but whose care needs exceed that able to be provided in a residential care facility.

Inpatient care may be provided in a:

- General acute bed, where clinical management is provided by a physician or other clinical specialist or GP; consultancy may or may not be provided by the specialist palliative care team
- Dedicated palliative care bed in a hospital where the clinical management is provided by a palliative care specialist, but other staff providing direct care may or may not have palliative care qualifications
- Dedicated palliative care unit or hospice; hospice care may be provided in either a separate facility or a dedicated inpatient unit, and it is generally accepted that staff working in a hospice have palliative care qualifications or are experienced in the provision of the range of palliative care services.

Inpatient care for palliative care patients is available across all regions in SA, although the type of care varies. Hospice care continues to be a key element of best practice palliative care. Hospice care is short-term inpatient care that facilitates stabilisation of symptoms and development of a palliative care plan, as well as care during the end stage of life. Hospice care is not considered to be a long-term inpatient care option. While the availability and type of hospice care varies across the metropolitan area, residents in the northern metropolitan area have least access to hospice care.

The relatively small number of children with a life-limiting illness indicates that SA does not warrant a free-standing hospice. The community-based approach to providing paediatric palliative care in SA is considered to represent the most effective and appropriate model of care for children.

The capacity for rural and remote regions to provide hospice care is also determined by the population profile of the region. In most rural areas, the number of people dying who want or require hospice level care is not enough to support a hospice. The use of family suites in local hospitals that facilitate family members participating more actively in the care of the dying person is supported as an appropriate alternative.

The palliative care Medical Specialist Outreach Assistance Program also assists in supporting increased numbers of rural people to remain within their local community. However, where preferred, country residents are supported to access hospice facilities in metropolitan regions.

The role of primary health care providers in the provision of palliative care is an integral component of service provision. The role of the GP is essential in providing practical and emotional support at a local level both before and after the person's death.[11] This is particularly the case in the country areas, where the GP is a constant in the lives of family members and has the potential to be a critical element in bereavement support.

Specialist palliative care services

There are five metropolitan palliative care services providing both inpatient and community palliative care services. Within country SA, there are 13 specific funded palliative care programs across the seven country regions. The nature and structure of the services in country areas varies depending on population size and allocated resources.

Generalist providers and primary palliative care providers

The provision of palliative care extends beyond specialist palliative care services. Palliative care is provided by a network of generalist providers, which includes both acute care and community-based organisations. The increasing profile of palliative care within the community makes the role of the generalist care providers particularly important.

All metropolitan hospitals provide palliative care as a component of their core business. Not all patients with palliative care needs are managed by palliative care specialists, with some specialists from disciplines such as oncology, respiratory and cardiac care choosing to maintain ongoing management of their patients. Community-based palliative care is also provided by the Royal District Nursing Service, with domiciliary care services contributing to the range of services available for people with palliative care needs.

Community services and agencies such as the Options Co-ordination and the Crippled Children's Association are also widely recognised for the role they play in supporting community-based care. Child and Adolescent Mental Health Services, Child and Youth Health, respite centres, and various disease specific support groups such as Canteen or the Muscular Dystrophy Association also contribute to the provision of holistic care for people with palliative care needs.

11. Paediatric Palliative Care: Distinctive Needs and Emerging Issues, JL Hynson. SM Sawyer, *Journal of Paediatric Child Health* (2001), 37, 323-325.

The primary care provider network includes GPs, who manage palliative care patients often in collaboration with specialist palliative care providers.

Palliative care is provided by all domiciliary care services to existing clients as part of meeting their continuing needs and to new clients who are referred by a hospital or agency. All domiciliary care clients with palliative care needs are given priority in assessment and in provision of services and equipment. A comprehensive range of equipment is available from domiciliary care services to support palliative care clients managed in their own home. Counselling and limited respite is provided for carers.

The Royal District Nursing Service works collaboratively with palliative care services across SA. Each of its regions has palliative care co-ordinators as well as using the community-based skills of their generalist providers. Palliative care services are provided on a 24-hour basis, every day of the year.

The Cancer Council South Australia contributes to the provision of end-stage respite for palliative care patients with a cancer-related diagnosis. Financial assistance is provided for people who wish to die in their home or spend time at home during their final stage with the support of palliative care staff. The Cancer Council also runs a Cancer Help Line, which provides advice on palliative care.

Volunteers

Volunteers form an integral part of most palliative care services in SA. Volunteer training and co-ordination is provided by the palliative care service.

The Strategic Plan recognises the reliance placed on availability and involvement of volunteers, and acknowledges that palliative care services would not be able to meet the needs of clients without the numbers of volunteers.

The Department of Health also has a volunteer strategy for SA which includes palliative care volunteers.

Equipment (Objectives 2.2, 2.4)

The provision of equipment for palliative care includes both domiciliary services (funded by the Department of Health) and the role of the Palliative Care Council in co-ordinating the national Palliative Care Equipment Program.

In practical terms:

- Equipment to support palliative care patients being cared for at home is provided through the metropolitan domiciliary care services
- In country areas, some palliative care equipment is stored and distributed through local palliative care co-ordinators. Most metropolitan palliative care services also keep small stocks of smaller equipment items (e.g. medication pumps)
- Charitable organisations and donations also contribute to the equipment supplies utilised by palliative care services for community-based clients.

Planned arrangements in SA

The reform process of the Department of Health[12] will result in changes in metropolitan structures for health services. Three regional metropolitan health services have been estblished, including a statewide Child, Youth and Women's Health Service. The regional health structure across rural and remote SA remains the same.

It is not anticipated that this new strucutre will change the current pattern of publicly funded palliative care service in SA.

[12] Based on document – *Advancing Health Reform – Building a Better Organisation.*

Planning, data collection, monitoring and reporting in SA

Planning (Objectives 2.2, 2.4)

The need for palliative care services is estimated using population information and its projected changes combined with an understanding of the levels and mix of different forms of palliative care services. This is translated into activity levels and the price, volume and mix of services to be purchased by each region.

The planning model for palliative care services in 1998:

- Relied on average annual age-specific and gender-specific mortality rates for cancer (with some allowance for the impact of other diagnostic groups)
- Estimated that up to 60% of terminally ill people would choose to access some form of home-based or community-based palliative care service
- Estimated that approximately 30% of people referred to palliative care services will die in a hospice or palliative care bed.

Data collection (Objectives 2.1, 2.2, 2.3)

South Australia developed a Palliative Care Client Management System which has been upgraded and incorporated into CME, the client database common to community care clients in the Department of Health. A Palliative Care Users Group (a sub-group of the Palliative Care Liaison Group) meets to identify and manage matters relating to software and data coding definitions.

South Australia was a participant in the trial of the SNAP classification and costing system.

Inpatient palliative care activity is collected through the SA hospital morbidity system (ISAAC), which defines a palliative care episode. The palliative care code is not uniformly used in all hosptials.

Reporting (Objective 2.3)

The Department of Health has been working towards the development of a more comprehensive corporate dataset for palliative care to support monitoring of the services. Given the increasing demand for palliative care, information regarding activity levels, patient demographics and the nature of services required is essential for long-term service planning.

Palliative care services provide the Department of Health with quarterly data on community-based activity. The Department of Health produces a six-monthly *Palliative Care Bulletin*, designed as a reporting tool for community outreach activity within specialist palliative care services. Each bulletin summarises client and activity data collected by the services and is designed to provide tangible information to assist service monitoring and evaluation.

Metropolitan and country bulletins, which aggregate data from respective services, have also been developed for Department of Health monitoring purposes.

Each service, with the exception of the paediatric palliative care service, uses the CME program to document client details and track activity. The level of detail in the bulletins reflects the level of data collected and recorded. There is a requirement to enter at least one piece of activity data per client to generate the reporting process.

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Key settings of care in SA (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. Within the current Stategic Plan, settings of care are described slightly differently as home, hospice, hospital, and residential care. The palliative care team plays a major role in providing integration across these settings.

The SA model of care describes the service in each of the four settings through variations in eight parameters: levels of care (stable, unstable, deteriorating, terminal, and bereaved), personnel/services required, co-ordination, frequency, volunteers, possible innovation, education/support, and access.

Considerable detail is available about each of the eight paramaters for each setting; however, a brief summary is as follows:

Home	Offers all five levels of palliative care and links with access to inpatient palliative care where required.
Hospice	Inpatient care in a designated palliative care facilitiy and day services; offers all levels of care. There are three hospices funded by the Department of Health (Mary Potter Hospice at Calvary Hosptial, Daw House Hospice at Repatriation General Hospital, and Phillip Kennedy Centre Hospice within Phillip Kennedy Centre). Modbury Hospital has a discrete ward referred to as Modbury Hospice.
Hospital	Palliative care is provided on an inpatient or outpatient basis. There are inpatient beds or units in metropolitan hospitlas. In rural areas, most hospitals have palliative care or family rooms accessed by palliative care clients and their families as needed.
Residential care	Offers all levels of care to residents of nursing homes and hostels on the basis that it is 'their home'.

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. SA has four such CCRCs. Inpatient and day respite is provided through the hospices.

The funding to the CCRCs in SA has increased their focus on the respite care needs associated with palliative care. A 'palliative care network' in one region has recently been established to improve pathways and access for respite for carers. In practice, most respite booked through these CCRCs for palliative care appears to relate to planned respite rather than emergency care.

The Cancer Council also provides funding for cancer patients for some end-stage respite. In addition, a significant proportion of respite care is provided by volunteers within many of the palliative care services.

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

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

Aged care

Many of the residential care facilities in SA are developing palliative care protocols to assist their care workers to more effectively manage the end-of-life care needs of their residents.

In 1998/99 a project, Palliative Care Nurse Practitioner in Aged Care Facilities, was funded in acknowledgement of the palliative care needs of the older person. The aim was to encourage aged care facilities to become key providers of palliative care by increasing palliative care confidence, knowledge and skills of all staff in aged care facilities. SA reports that this work has made a positive impact on the quality of palliative care received by residents of aged care facilities.

The Phillip Kennedy Centre Hospice in the western metropolitan area is located within a residential care facility. The facility receives additional funding to convert some of its residential aged care beds to hospice beds.

One of the Caring Communities Program projects in SA, Establishing the Care-worker Role in Palliative Care – Education, Support and Integration with Palliative Care Teams, focuses on the education and support needs of care workers who provide care and support to people receiving Community Aged Care Packages.

Children and younger people

The Strategic Plan recognises that the needs of children and their families are essentially similar to those of older adults but that the actual services provided will vary in their components, intensity, timing and frequency. The Strategic Plan also acknowledges the often complex need for psychosocial and bereavement support because of the web of relationships that young people have with family, friends, school and community.

A paediatric palliative care service is based at the Women's and Children's Hospital (formally commencing in 1999 with the appointment of a paediatric palliative care co-ordinator). It operates as a statewide service.

Aboriginal and Torres Strait Islander peoples

A report in 1997, *Developing an Aboriginal Palliative Care Strategy for South Australia,* made a number of recommendations about palliative care for Aboriginal and Torres Strait Islander peoples. The findings of this report informed the development of the Strategic Plan.

The Department of Health currently has a project consulting with the Aboriginal community about the appropriateness of the materials (particularly the 'cultural safety' aspects) developed by the Indigenous Palliative Care Resource Kit Project (a National Palliative Care Program initiative). The Practice Principles from that project are also out for consultation in SA with mainstream community care providers. The results of these consultations will lead to a clear response by the Department of Health to the palliative care needs of Aboriginal people in SA.

The Council has produced material specifically related to palliative care in Aboriginal communities. The Council also provides assistance to Aboriginal health workers to attend the Palliative Care Rural Conference. The Council is also progressing work on developing supportive material relating to the use of Advanced Care Directives (see 'Reform, training and research in SA' on page 146) to extend Advanced Directives to people of Aboriginal or Torres Strait Islander background.

People with specific cultural and linguistic needs

A report in 1996, *Palliative Care Needs Study on Non-English Speaking Background People in SA*, made a number of recommendations which also informed the development of the Strategic Plan.

Provision of care to people with specific language and cultural needs is part of the core requirement of all palliative care services funded by the Department of Health.

The Council has been active in developing resource material for culturally and linguistically diverse communities. The development of such material (and provision of this in 20 languages on their website) has resulted in many national and international contacts for material in other languages.

The Council has also provided grants to multicultural palliative care practitioners to attend rural palliative care conferences.

People with HIV/AIDS

The provision of palliative care for people with HIV/AIDS is part of the general business of palliative care serices. All people with palliative care needs are able to access palliative care services, irrespective of diagnosis.

People with cancer

Specialist palliative care services have developed close links with cancer services.

The Cancer Council advocates for, and provides leadership in, cancer control; facilitates education and awareness; provides support and information; and facilitates high quality research. Its support and information function has close links with the palliative care sector. The Cancer Council runs a Cancer Help Line, has an active resource centre and provides respite for carers of people with cancer who choose to die at home.

A statewide *Cancer Control Plan* currently being developed for SA is inclusive of palliative care in the cancer journey.

Activities in rural and regional SA

The Strategic Plan recognises that there are differences in levels of care across geographic regions. There are varying levels of knowledge and skill regarding palliative care among rural GPs, and the impact of travel can create inequities in some regions.

There are 13 palliative care services spread across rural SA providing community-based palliative care. Most rural palliative care services are attached to the local community health service.

The Medical Specialist Outreach Assistance Program has been taken up enthusiastically in SA but there is some frustration that peri-urban areas are not eligible.

A Rural Palliative Care Co-ordinators Group meets quarterly, comprising rural palliative care nurses and bereavement co-ordinators. The meetings provide a clinical forum to discuss palliative care issues pertinent to the rural sector, provide a professional support network and enable professional development with educational input from speakers. The group also has representation on the Palliative Care Liaison Group.

Inpatient care is provided within local hospitals. Few country hospitals have dedicated palliative care beds but many of the hospitals have established 'family' suites that are used by palliative care clients and their families as needed. These family rooms greatly increase the capacity for family members to more actively participate in the care of the dying person. These suites have often been developed with significant input from local fundraising activities.

Carers

The Strategic Plan makes specific mention of the respite needs of carers.

The Carers Association of SA Inc produced a discussion paper, *Developing a Whole of Government State Carers Policy in South Australia* (July 2003), which makes specific mention of carers in relation to palliative care.

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

In addition to the Strategic Plan, there are some other key strategies and operational frameworks in SA which influence palliative care planning and practice:

- The *Palliative Care Service Delineation Framework*. This framework describes the complexity of patient care, facilities and support services, staffing, service links, teaching, research and statewide roles for services providing palliative care. The aim of developing the framework has been to provide a consistent language which health care providers and planners can use to describe health services. There are four levels of complexity of palliative care services within the framework – levels 1, 2, 4 and 6 (there is no level 3 or 5). Level 1 is primary care with level 6 being tertiary centre specialist palliative care. The framework is one of 40 similar frameworks being developed for a range of services providing clinical support, critical care, medical, surgical, maternal and child services as well as integrated community and hospital services.
- The *Statewide Cancer Control Plan*. This includes palliative care, although palliative care will continue to be a service in its own right.
- The International Institute of Palliative and Supportive Studies, a research centre of Flinders University based at Repatriation General Hospital.
- The presence of the Chair of Palliative Care Australia in SA.
- The Palliative Care Council of South Australia.

Workforce (Objectives 1.3, 1.4)

The palliative care workforce is not currently addressed separately or as a separate stream within other health workforce strategies in SA. At the local level, workforce issues are managed by the funded palliative care services.

A palliative care rotating registrar position is funded by the Department of Health. This position operates across the metropolitan palliative care services as a means of extending palliative care knowledge within the medical profession.

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Palliative care activity in South Australia

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

Reform, training and research in SA

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

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

National Contribution to South Australian 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.

South Australia has used these funds to conduct a project designed to disseminate the findings of the National Palliative Care Program projects and research to the broad palliative care community, and identify actions to allow the learnings to be used by the palliative care community to advance and/or extend their service. The objective was to report key strategic and service provision issues in palliative care arising from the National Palliative Care Program. The project was conducted by the Joanna Briggs Institute and examined the conclusions arising from projects funded by the National Palliative Care Program. Of the 33 projects examined, 20 were considered either not assessable, not specific to palliative care, educational in nature, incomplete or superseded by a subsequent project. Thirteen were thus examined further for their conclusions or recommendations.

The report outlined 211 ‘conclusions’ which could be grouped into 47 categories. These were then subjected to in-depth analysis and review to create 13 ‘synthesis statements’ which are, in essence, conclusions whose strength is demonstrated across programs and projects.

Status	Interim report completed; not yet released
Evaluation	Not relevant
Reports, information, materials	*The Development of an Evidence Base to Underpin Palliative Care in South Australia: A Comprehensive Review of Key Learnings from the National Palliative Care Program*

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.

Status	Ongoing
Reports, information, materials	Information for community, professionals; new forms; new pamphlets at www.dh.sa.gov.au/consent/

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 SA, the Adelaide Hills Division of General Practice has received funding and has developed a 'GP advisor' role to act as a champion and facilitate collaborative work with the (very experienced) palliative care nurses.

Status	Ongoing
Evaluation	Yes
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 Strategy. The initiative (being administered through Palliative Care Australia) provides grants to organisations in each State and Territory for the purchase of equipment that can be loaned to families and carers for people receiving palliative care at home, particularly organisations in rural or remote communities or those with links to residential aged care facilities. In SA, the Council has taken on the co-ordination role. In the first round of this program, equipment for metropolitan services went through the domiciliary care services, while equipment for rural services was identified individually with the service. In the second round of the program, equipment for both metropolitan and regional palliative care services was negotiated on a needs basis with the individual service. Note: the agreements re equipment require that the service be responsible for maintenance.

Status	Completed
Reports, information, materials	Equipment now available for loan

Changes to the Consent to Medical Treatment and Palliative Care Act (Objectives 2.2, 3.1)

South Australia has recently made some changes to the Consent Act, particularly in relation to Advanced Directives. The changes primarily update the relevant forms and allow for separate witnessing on the Medical Power of Attorney Form. The former Schedule 1 and 2 forms have moved out under regulations.

The following aspects have not changed: Duty to Explain, Protection for Medical Practitioners, Care of the Dying. New explanatory material has also been developed. Additional consultation is occurring with people of Aboriginal or Torres Strait Islander background.

Status	Ongoing
Reports, information, materials	Information for community, professionals; new forms; new pamphlets at www.dh.sa.gov.au/consent/ Palliative Care Australia reported to the National Palliative Care Program in October 2003

CareSearch – Supporting Evidence-based Palliative Care (Objectives 1.3, 1.4, 2.1, 2.5)

This national initiative (with funding to Flinders University through the National Palliative Care Program) has designed and developed a searchable electronic database to store palliative care literature and report abstracts and evaluations. It has developed a website as an 'electronic resource for palliative care researchers and clinical specialists providing care for people with a life-limiting illness'. The website has areas on 'finding the literature', 'generating the evidence' and 'supporting the evidence'.

Status	Website developed. Electronic databases commenced
Reports, information, materials	www.caresearch.com.au

Knowledge Network (Objectives 1.3, 1.4)

This national initiative (with funding to Flinders University through the National Palliative Care Program) is scoping the viability of developing a Knowledge Network – a virtual community of practice – to enable funders, service providers and the broader community to access information about palliative care. Extensive consultation has occurred to investigate a conceptual model, as well as to identify resources and support for implementation.

Status	A decision about the Knowledge Network will be made based on a business plan
Reports, information, materials	A needs assessment survey is at www.mortonblacketer.com.au/SurveyASP/takeSurvey.asp?surveyID=7 Other information is at www.caresearch.com.au

Treasure Boxes (Objectives 1.1, 1.2)

This initiative, supported by a grant from Community Benefit SA, is being conducted by the Council. It provides a 'Treasure Box' for children and adolescents to assist them to mourn a person who has died. The Treasure Box can consist of different items, most commonly: (1) a 'pocket book' which provides common simple information about death, dying and loss; (2) a soft comfort heart; and (3), for younger children, a colour book and pencils or, for older children, a candle and a book.

This provides a tangible and helpful way to assist children and teenagers to express their grief in a way that supports and acknowledges their feelings, thoughts and memories.

Status	Ongoing
Reports, information, materials	www.pallcare.asn.au

Caring Communities Program projects in SA (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. Four projects from SA were successful in receiving funding.

Partnering with Rural Communities to Improve Access and Education in Palliative Care (Objectives 1.1, 1.2, 1.3)

This initiative aims to improve the community awareness of palliative care services among health professionals and provide education for health professionals, community members and carers. Understanding, knowledge and skill levels are being enhanced through discussions and interviews, both face to face and online.

Status	Ongoing
Evaluation	Through the national cluster evaluation of the Caring Communities Program
Reports, information, materials	www.unisa.edu.au/why/Disciplines/nursing/pallliativecare/default.asp

Kangaroo Island Palliative Care Project (Objectives 1.2, 2.4, 3.1)

This initiative aims to develop a volunteer support program to provide long-term practical and emotional assistance for people who are dying, complementing professional services. The goal is that volunteer support is available in homes, residential facilities or acute inpatient facilities.

Evaluation	Through the national cluster evaluation of the Caring Communities Program

Shared Bereavement Care in the West (Objectives 1.2, 3.1)

This initiative aims to develop partnerships and strengthen links between specialist and primary health providers of palliative care in order to provide culturally appropriate bereavement support. In particular, it will focus on collaboration between specialist and primary palliative care providers and Aboriginal and cultural and linguistically diverse organisations to ensure there is a co-ordinated and culturally appropriate palliative care bereavement service.

Status	Ongoing
Evaluation	Through the national cluster evaluation of the Caring Communities Program

Establishing the Care-worker Role in Palliative Care – Education, Support and Integration with Palliative Care Teams (Objectives 1.2, 1.4, 2.4)

This initiative aims to explore the education and support needs of care workers who provide care and support to people receiving Community Aged Care Packages. It will do this by: (1) establishing the role of Community Aged Care Packages for care workers/support workers in palliative care; and (2) developing, trialling and evaluating a self-directed learning package on palliative care for care workers/home support workers.

The three-year project commenced in March 2003 as a collaborative project between the Royal District Nursing Service, the International Institute of Palliative and Supportive Studies (part of Flinders University) and a group of palliative care providers.

The project aims to promote an integrated service delivery model where care workers have access to education and support, enabling them to continue to provide support services for their clients during the palliative care phase.

Status	Ongoing
Evaluation	Through the national cluster evaluation of the Caring Communities Program

Commentary about South Australia

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

Drivers of palliative care in SA appear to be:

- The early establishment (1980) and strong position of the **Palliative Care Council** and its growth. It has blended the functions it undertakes for the Department of Health (specified under service agreement) with broader project, advocacy and liaison roles
- The **Palliative Care Liaison Group**, whose members are appointed by, and provide advice to, the Department of Health
- The **Rural Palliative Care Group**, which has not only provided a rural focus for SA palliative care but has assumed a 'national' role in harnessing interest and directing matters related to rural palliative care issues (particularly through its biennial conference)
- The emergence of **Flinders University** as an important research focus for palliative care
- The establishment in the 1990s of a **professorial chair in palliative care** at Flinders University
- The nature of the **geography and population distribution in SA**, including the practicalities of providing effective care in diverse settings
- The **change in the interest/demand for palliative care services**, including the growth of interest from clients who have neurological conditions.

Further information

www.health.sa.gov.au

Strategic Plan for Palliative Care Services in South Australia 1998–2006, Department of Human Services, 1998