



Palliative Care Council of South Australia Inc

Annual Report

1 July 2004 – 30 June 2005

Chair's Annual Report

Palliative Care Council of South Australia

Financial Year 2005 was another period of change at the Palliative Care Council of South Australia.

Andrew Taylor

Andrew Taylor served as the Council's Executive Officer from October 1997 until his sudden death on 14 April 2005. Much has already been written about Andrew's untiring efforts to promote palliative care, his quiet and unassuming style, the vast range of ways in which he contributed to his community and the gap his passing left at the Council. Now, several months on, with new staff at the Council and with all of us over our initial shock and disbelief, we are still discovering the extent of Andrew's networks and influence, his reputation and capacity to get things done.

Will Hallahan, who previously worked with Palliative Care Australia in Canberra, has been appointed to the role of Executive Officer.

Finances

The Council recorded a modest surplus in Financial Year 2005. The Balance Sheet at 30 June 2005 shows that we have made provision for an additional staff position for the Financial Year ending 30 June 2006, and Robyn Rouvray was recruited in late June 2005 to fill the position of Project Officer. It is expected that Financial Year 2006 will show an operating deficit.

Palliative care in South Australia

SA Health system reform

The South Australian Government commissioned the Intergenerational Health Review in 2002, which recommended a substantial restructure of the state's health system. More budget and management responsibility has been devolved to larger regions, which are charged with improving integration and coordination of services. The theory is that services can be better tailored to meet the needs of local populations and bureaucratic overheads will be reduced. We are yet to see the long-term outcomes of the reform, but recognise that as an organisation we have to adapt to the new policy, planning and management environment.

Workforce

Our members report that the demand for palliative care services increases all the time. The existing palliative care workforce – especially those in the country – face additional stresses to meet demand.

The Council supports national and state-based efforts to grow and develop the entire healthcare workforce to provide better end of life care, and in Financial Year 2006 will work with the State Government to help promote the Program of Experience in a Palliative Approach (PEPA), which helps to educate the non-palliative care workforce. In late Financial Year 2005, working with Dr David Panter and Dr Kay Challinger at the Central Northern Adelaide Health Service, the Council was able to secure the funding for a palliative care doctor at the Modbury Hospice.

Special thanks

The South Australian Department of Health supported the Council, funding us to provide a palliative care resource and information service. Particular thanks are due to Minister for Health Lea Stevens, Dr Tom Stubbs, Ms Meryl Horsell and Ms Jean Murray of Health System Management.

The Cancer Council of South Australia have helped the Palliative Care Council of South Australia for many years. In Financial Year 2005 CEO Brenda Wilson and her team have helped us manage our information technology, payroll, and administration, and provided us with accommodation. But most valuable has been their friendly support and encouragement. This was particularly evident after Andrew Taylor's death.

The Governor of South Australia, Her Excellency Marjorie Jackson-Nelson, AC CVO MBE, is our Patron, and her interest and support, especially during National Palliative Care Week, is always greatly appreciated.

John Harley, the Public Advocate, is an esteemed partner in our shared mission to promote advance care planning in South Australia.

Lastly, on behalf of all at the Council, I thank members and volunteers for all they contributed in the past year to help make this organisation healthy, resilient and forward looking. I look forward to your ongoing support in years to come.

Dr James Cooper
Chair

Executive Committee Members**At 30 June 2005**

- Dr James Cooper – Chair
- Dr Judy Zollo – Deputy Chair
- Mrs Elizabeth Keam – Honorary Treasurer
- Ms Aine Greene – Honorary Secretary
- Mr David Macklin – Immediate Past Chair
- Mrs Kaye Coats
- Mrs Helen Lee
- Mrs Marilyn Paris
- Ms Megan Hender
- Dr John Sniatynskyj.

Ex-Officio Members as at 30 June 2005

- Dr Mary Brooksbank – Central Adelaide Palliative Services
- Dr Greg Crawford – Lyell McEwin Palliative Care Service
- Prof David Currow – Southern Adelaide Palliative Services
- Dr Roger Hunt – Western Palliative Care Service
- Ms Sara Fleming – Paediatric Palliative Care
- Ms Di Roughton – Royal District Nursing Service
- Mrs Di Ollino – Modbury Hospice.

Life Members

- The Mary Potter Foundation
- Mrs Margaret Beare
- Ms Jennifer Cashmore AM
- Mr Peter Fisher
- Sr Christina Lloyd
- Emeritus Professor Ian Maddocks AM
- Mr Lange Powell
- Dr Margaret Skene
- Mrs Joan Snyder
- Dr Mary Brooksbank.

Community Supporters

Several local businesses and organisations sponsor and support the activities of the Council, and we extend especial thanks to:

- Harrisons Funerals
- White Lady Funerals
- Janesce
- Pan Print
- Coopers Brewery
- Community Benefit SA.

Executive Officer's Annual Report

This is my first Annual Report. I started in the Executive Officer's role on 27 June 2005 – so I was at the Palliative Care Council of South Australia Inc for only four days of Financial Year 2005.

James Cooper has already paid tribute to the work of my predecessor, Andrew Taylor. After Andrew's death, Elizabeth Keam, the Honorary Treasurer, acted as Executive Officer in a voluntary capacity. James, Elizabeth and others on the Executive Committee have given me wonderful support during my first three months in Adelaide, while members have been encouraging and welcoming. I thank you all.

Robyn Rouvray joined the staff in mid July 2005 as Project Officer. Robyn has been involved in palliative care as a volunteer and volunteer manager in the past. You can see from my report, the format of which reflects the Council's current *Strategic Plan*, that with the our busy 2006 work program, Robyn will have lots to do. Welcome Robyn.

Advocacy

Health system reform

The advocacy landscape changed considerably during Financial Year 2006. The Government of South Australia instituted restructures, which saw the devolution of management and budget responsibility for palliative care to enlarged regional health services. Previously a section of the (now) Department of Health had system-wide responsibility, working with regional health services, for the implementation of the statewide palliative care plan, the current version of which lapses in 2006.

Strategies

- Monitor relevant government and health industry papers, occasional and annual reports of health authorities and departments, and the Government's palliative care policy.
- Develop a Council response to issues which may require action by government.
- Remain alert to policy directions or initiatives which emerge from forums, and which may warrant follow-up by the Council.
- Promote ways of better meeting the needs of people who are dying in residential aged care facilities.

The restructures mean that the Council's advocacy model has been redesigned to better ensure issues and concerns are brought to the attention of those empowered to make decisions in each of the state's health regions.

Priorities

Within this changed context the Council can report an important success in its advocacy activities during Financial Year 2006. The Council worked with the management of the Central and North Adelaide Regional Health Service to secure funding for a specialist palliative care doctor and a level three nurse at the hospice located at Modbury Hospital. These new appointments will bolster the clinical management of this large and growing service and help meet the palliative care needs of the area's population.

The Council maintained its active interest in the support and resourcing of palliative care in country South Australia. Rural palliative care coordinators were surveyed in early 2005 to gather information about staffing levels and compare them to levels recommended by recent Palliative Care Australia policy. The picture which emerged is that staffing levels have not changed to meet emerging population needs in most regions, while several areas have seen an erosion of palliative care staff capacity over a number of years.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- seek to provide high-level input and advice for the next statewide palliative care strategic plan, due to be released in mid 2006
- continue to work with regional health services to help ensure palliative care services meet population needs
- revise and develop standard position papers on a range of policy issues in palliative and end-of-life care and service provision.

Awareness

Public forums

A key awareness-raising strategy employed by the Council is the staging of public forums and awareness events:

- *Intimacy in palliative care* – 08 July 2004
- *The emerging challenge: Palliative care of non-cancer related illness in the aged care sector* – 03 August 2004
- *Caring for the carer* – 27 September 2004
- *Adolescence and palliative care* – 04 November 2004
- *Ambiguous Loss* – 08 March 2005
- *Genetic rust and familial cancer* – 07 April 2005
- *A one day conference for volunteers in palliative care* – 27 May 2005.

Strategies

- Maintain a palliative care resource and information service.
- Produce new resource materials.
- Hold public forums
- Monitor community awareness of palliative care.
- Promote professional awareness of palliative care.
- Maintain contact with MPs, government officers, and with the media, in order to position the Council as a reliable and readily accessible source of information and advice on palliative care.

A collection of carers' stories entitled *A journey lived*, published by Palliative Care Australia, was launched in South Australia on 04 May 2005 and generated some welcome media interest.

National Palliative Care Week

The Council was very busy during National Palliative Care Week, 22-28 May 2005. The theme was *Partners in Caring*, chosen to emphasise two critical concepts – that palliative care services are able to assist the carers of people who are dying, and that carers are indispensable partners in the provision of quality end of life care in the community in modern Australia. The Council thanks the Australian Government Department of Health and Ageing for providing funds to conduct National Palliative Care Week activities:

- the South Australian Launch – hosted by Her Excellency Governor Marjorie Jackson – 24 May 2005
- *Partners in caring – A hypothetical* – 25 May 2005
- banners and displays – including signage on Adelaide buses
- merchandise and posters – highlighting the question 'what is palliative care?' and a national 1800 number (SA calls answered by the Council in Adelaide).

Special thanks are also due to those many speakers, presenters and volunteers (especially the Council's Forums and Promotions Committee) who helped make our forums and National Palliative Care Week activities such a success in the past year.

Palliative care resources and information

The Council continues to respond to a growing number of requests for information about palliative care, and in particular about the provisions of the South Australian *Consent to medical treatment and palliative care act 1995*, from the general community and a range of health care providers.

The Council's website at www.pallcare.asn.au grew in popularity and in the quality of information included on it. This shows that the website address is increasingly widely known, that the content generates more search engine referrals, and that the Council has consolidated the website's 'go-to' status within the Australian palliative care community.

The Council maintains a library of palliative care resources, books and reports, which is mostly accessed by students.

The Executive Officer conducted information sessions on palliative care at several residential aged care facilities during Financial Year 2006. This is a growing part of the Council's work and results from an increasing understanding of end of life care issues in the aged care sector.

The Council published four editions of its regular newsletter *Palliative Profile SA*. Many thanks to all contributors and the editorial team.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- conduct at least four public forums in Adelaide and elsewhere around the state
- celebrate the inaugural World Hospice and Palliative Care Day on 08 October 2005 (visit www.worldday.org.au)
- consolidate links with and provide information to media and palliative care stakeholders – including health professionals whose primary role is not palliative care
- continue to support the SA Palliative Care Nurses Professional Forum in their educational activities
- encourage more aged care facilities and services to join the Council as members
- review and republish several of the Council's informational resources.

A common voice

The Council has, over the years, refined the way it engages with palliative care services in South Australia.

Regular input is sought from services at the highest level. Metropolitan palliative care services are all represented on the Executive Committee of the Council, which meets monthly. The Executive Officer attends the meetings of the Rural Palliative Care Group of South Australia and reports developments at each Executive Committee meeting.

Strategy

- Provide services with an opportunity to present their own needs, to suggest initiatives, and to assess the statewide position of palliative care so that a view can be put to government that is backed by the collective authority of the Council.

Services are also encouraged, as collective members of the Council, to attend the Annual General Meeting, which is a forum in which issues of concern can be put forward for discussion.

In addition to participating in regular mechanisms for input, rural palliative care services were surveyed in early 2005 about their staffing levels and support and resourcing needs.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- continue to provide services all around South Australia with opportunities to air concerns, issues and ideas about palliative care in the state and nationally
- seek the input of member services on Council's next three-year *Strategic Plan*, due for release in mid 2006.

Working together

Palliative Care Australia

The Council supports Palliative Care Australia (PCA). During Financial Year 2005 Dr Greg Crawford and Andrew Taylor attended two PCA Council meetings as South Australia's nominated Delegates. Council Chair, Dr James Cooper, spoke at PCA's March 2005 meeting about governance issues and the need to revise the PCA Constitution. Andrew Taylor served on the PCA Promotions and Marketing Committee and contributed articles for *Palliative News*, PCA's newsletter.

Strategies

- Communicate state issues to Palliative Care Australia.
- Communicate Palliative Care Australia policies within South Australia to members of the Council, services, and state health authorities.
- Identify and seek funding for projects that will be of value to people who are dying and to those who care for them, and which can be carried out more appropriately or effectively by the Council than by any other body.
- Maintain a close relationship with the Department of Health.
- Ensure that topics and programs for general meetings of the Council involve members in discussion, debate, presentation of ideas and policy suggestions.
- Undertake projects which advance palliative care within Aboriginal and culturally and linguistically diverse communities

The Council has also supported the introduction of recent PCA policies, including new *Standards for providing quality palliative care for all Australians* and *Palliative care service development: A population based approach*.

Projects

Funding was secured to undertake a number of projects, most of which will be completed in Financial Year 2006:

- revision and reprint Council publications *Faced with a life-threatening illness, Palliative caring at home, Palliative care nursing – A community perspective* (in conjunction with the Palliative Care Nurses Professional Forum)
- the translation of information about advance care planning into 14 community languages (to be completed in Financial Year 2006)
- staging the *One day conference for volunteers in palliative care* in May 2005.

Department of Health and Government of South Australia

The Chair and Executive Officer represented the Council on the Department of Health's Palliative Care Liaison Group during Financial Year 2005. Elizabeth Keam, the Council's Honorary Treasurer, served on the Carers Ministerial Advisory Committee, which has recommended legislation recognising carers which will be presented to parliament in the latter half of 2005. The Council is particularly appreciative of the ongoing support of Ms Meryl Horsell and her team at the Department, and of the Government of South Australia which provides funding for the Council to maintain a resource and information service.

Working with Aboriginal and other culturally and linguistically diverse communities

Andrew Taylor formed close links with the Pika Wiya Aboriginal community at Port Augusta and provided information about palliative care in several information sessions for members of that community. The Council and Pika Wiya have developed a joint project to create palliative care resources in formats appropriate to that community, and it is hoped funding for the project can be sourced in Financial Year 2006.

Andrew also provided information for Aboriginal groups and health workers at the Aboriginal Health Council, and at Noarlunga and Whyalla.

The Executive Officer also participated as a member of the steering committee for the Shared Bereavement Care in the West Caring Communities Program project. This project has seen the development of information for mainstream palliative care and non-palliative care health care providers about the cultural needs of Italian, Vietnamese and Aboriginal communities in the western suburbs of Adelaide. The Executive Officer served on a Department of Health committee reviewing and evaluating national Indigenous palliative care education and training resources.

The Diana Rudd Fellowship

South Australian Governor, Her Excellency Marjorie Jackson, presented Kangaroo Island community nurse Sharon Clarke with the inaugural Diana Rudd Fellowship at the launch of National Palliative Care Week in May 2005. Sharon will use the award to travel to London to participate in training at St Christopher's Hospice.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- continue to actively support Palliative Care Australia
- develop and implement strategic projects which meet real needs in the community, the health system and in palliative care
- work with Aboriginal and culturally and linguistically diverse communities to advance palliative care within those communities
- assist the Rural Palliative Care Group of South Australia to stage their August 2006 Rural Conference.

Standards

The Council supports Palliative Care Australia's *Standards for providing quality palliative care for all Australians* and its companion documents: *Palliative care service development: A population based approach* and *Palliative care service provision in Australia: A planning guide*.

Strategy

- Provide education and concise written information about standards and quality improvement to health care providers.

Both documents were developed using a consultative approach and the Council, through the Executive Committee and via South Australia's two PCA Council Delegates, participated in this process, providing feedback and advice for PCA's consideration.

The new *Standards* were launched by the Australian Government Minister for Health and Ageing, Tony Abbott, at National Palliative Care Week on 24 May 2005. PCA, at the same time, announced a comprehensive national education program about the new *Standards* which includes a workshop in Adelaide in July 2005.

Since their launch, the Council has received numerous requests for the *Standards* from South Australian health care providers.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- encourage South Australian regional health services to adopt the population based palliative care service planning approach underpinning the new *Standards* and the companion documents
- provide members with information about the new *Standards* and any state or national quality improvement initiatives
- participate in national discussions and debates about quality improvement and standards in palliative care.

Networking

The Council enjoys excellent working relationships with many organisations, including:

- The Cancer Council of South Australia – who assist the Council with accommodation, administrative and moral support
- the Aboriginal Health Council
- the Rural Palliative Care Group of SA
- palliative care services in South Australia
- the Office of the Public Advocate
- South Australian academic centres – universities and TAFE colleges
- aged care providers
- numerous palliative care project teams working in a variety of settings.

Strategies

- Form cooperative ventures with other organisations, including interstate and national.
- Seek sponsorship for activities and initiatives of the Council.
- Promote the Council through newsletters circulated by a range of community organisations.

Financial Year 2006 Activities

In Financial Year 2006 the Palliative Care Council of South Australia will:

- review and refine our extensive mailing and contact list of stakeholder organisations – peak bodies, professional associations, disease groups etc to ensure Council information is efficiently disseminated to interested parties
- cultivate mutually beneficial relationships with a variety of Council sponsors and supporters
- continue to produce a quality regular newsletter (*Palliative Profile SA*) and regular emailed State Bulletins (both available on www.pallcare.asn.au).

Financials

The Financial Report for the period 01 July 2004 to 30 June 2005 has been audited by DW Johns & Co.

The Report is available at www.pallcare.asn.au/news.php or in hardcopy from the Palliative Care Council of South Australia Inc – call 08 8291 4137 or email pallcare@pallcare.asn.au.

How to support the Palliative Care Council of South Australia

The Palliative Care Council of South Australia is a non-profit community organisation which aims to promote palliative care in South Australia.

Objectives

The Council is constituted to:

- be an independent, community-based, representative organisation for palliative care in South Australia
- advocate the needs, rights and interests of people who are dying and those who care for them
- foster and promote community awareness of palliative care philosophies and services
- present to government an independent voice on issues and directions for palliative care in South Australia
- facilitate the working together of government, health authorities, service providers and community groups to meet the needs of dying people and those who care for them
- support and facilitate professional development and education
- promote the use of recognised standards for palliative care
- liaise and network with similar organisations elsewhere in Australia and overseas.

How your gift helps

Your gift assists the Council to provide palliative care information and resource materials to the general community, health care professionals and palliative care services, and to advocate on behalf of people who are dying and those who care for them.

Bequests

Making your will need not be a sombre or sad occasion – it's an opportunity to plan exactly what should happen to your hard-won assets after you die. Professional help is available to help ensure your will work as you intended – solicitors and accountants can advise you.

A bequest is a gift specified in a will, which reserves part of an estate for a particular beneficiary. Bequests can be given for use at the discretion of the Executive Committee of the Council, which gives the greatest flexibility, or can be directed to a specific purpose.

Please consider contacting us here at the Council on 08 8291 4137 when you've made your bequest – and give us a chance to thank you for your generosity!

Donations

The Council has been awarded Deductible Gift Recipient status by the Australian Tax Office. This means that you can deduct the value of any donations you make to the Council from your annual income for tax purposes. The Council provides an official receipt and thank-you letter to all giftmakers who provide details.

Post your gift to:

The Palliative Care Council of South Australia
202 Greenhill Road
EASTWOOD SA 5063,

or call 08 8291 4137 to discuss your options or to donate by credit card.

Volunteering

Please contact us on 08 8271 4137 to discuss how you can volunteer in palliative care or at the Council. Palliative care volunteers work with local services, who provide full training, to enhance the ability of dying people, their families, friends and communities to live as fully as possible.

What is palliative care?

Palliative care is care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.

The World Health Organisation describes palliative care as:

An approach that improves quality of life of patients and families facing the problems associated with life-threatening illness, through the prevention of suffering by the early identification and impeccable assessment and treatment of pain and other symptoms, physical, psychological and spiritual.

Palliative care:

- *provides relief from pain and other distressing symptoms*
- *affirms life and regards dying as a normal process*
- *intends neither to hasten or postpone death*
- *integrates psychological and spiritual aspects of patient care*
- *offers a support system to help patients live as actively as possible until death*
- *offers a support system to help the family cope during the patient's illness and in bereavement*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated*
- *will enhance the quality of life, and may also positively influence the course of illness*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

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