

# **Palliative Care in Residential Aged Care Facilities (RACFs)**

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## **Background**

Over the past 50 years, there have been increasing numbers of deaths in RACFs. This trend will continue because of further aging of the population, the breakdown of extended families to care for the elderly at home, limited beds in hospitals and hospices, and an increasingly frail RACF population. Possibly more deaths will occur in RACFs than in any other setting in the foreseeable future.

There are several impediments, however, to the provision of palliative care in RACFs:

- The number of available nursing hours falls well short of that required for labor-intensive terminal care.
- GP workforce shortages, the corporatisation of practices, the relatively poor remuneration of RACF consultations, and the lack of support systems (IT, limited medication imprests, lack of treatment rooms and equipment etc) results in many residents being poorly serviced.
- The knowledge and skills of nurses, carers and GPs for palliative and terminal care is suboptimal.
- Medical specialists usually do not attend RACFs, and specialist palliative services are less likely to be involved in the care of cancer patients who die in RACFs compared to cancer patients who die in other settings.
- The availability of allied health care services (social work, physiotherapy, occupational therapy etc) is also quite limited.

Although the Federal Government takes primary responsibility for funding and standards of care in RACFs, the SA Government has a vital interest in ensuring its citizens receive good end-of-life care in this setting, and that they do not have to be 'bailed out' of RACFs and transferred to hospitals. This concern is relevant to hospital avoidance strategies, including the Respecting Patient Choices Program, that enable residents to remain in RACFs when that is their preference.

Outlined below are strategies to better meet the palliative care needs of Australians with terminal illness in the RACF setting.

## **'Link Nurse' Model**

This model requires RACFs to nominate a nurse or nurses to lead the delivery of palliative care in their facility. The nurses are educated in workshops and seminars provided by Specialist Palliative Care Services (SPCSs) to improve their knowledge and skills in palliative care.

Feedback from link nurses demonstrates increased confidence in managing residents, an enhanced ability to engage in discussions with GPs and residents' families, and greater awareness of resources to help their residents (see attached *Palliative Care Resource Nurse in Aged Care Programme*).

For a modest investment each regional SPCS can educate and support link nurses from RACFs in their catchments. A position of Link Nurse Co-ordinator could be established with responsibility for implementing the model throughout South Australia (the possibility of Commonwealth funding should be explored). Close ties to the PEPA program would provide RACF staff with additional palliative experience.

### **Recommendation**

**The link nurse model should be extended throughout SA as a cost-effective means to improve palliative care in RACFs.**

### **Systematic use of Advance Directives (ADs)**

Satisfaction with care is improved when residents are given the opportunity to express their wishes about their management, and clinicians show a willingness to respect their wishes. The Respecting Patient Choices Program (RPCP) offers an established model for advance care planning that can be successfully implemented in RACFs.

Most residents who make an AD declare a wish to remain in the RACF for palliative care at the end of their lives. This will help to reduce pressure on hospitals. It is incumbent on the providers of care to ensure these residents get their palliative needs met in the setting of their choice.

Similar to the 'Link nurse' model, nurses from each RACF could be nominated to take responsibility for advance care planning as 'RPCP Consultants' – in some cases, palliative care resource nurses may also be RPCP Consultants. These nurses would be trained (over two days) to assist residents in making advance care plans, to document and disseminate the plans to relevant health care providers. Again, it is important to have statewide co-ordination of the program, and Commonwealth support should be explored.

### **Recommendation**

**The RPCP be systematically extended to give all RCAF residents the opportunity to make an AD and have an individualized advance care plan.**

### **Primary Care Hospice**

The range of needs of palliative patients demands a spectrum of services that includes Primary Care Hospices, which could alternatively be called 'Step-down' or 'Nurse-led' Hospices. They care for patients who are unable to be cared for at home, and who do not require ongoing care in a hospital or specialist palliative care unit, yet whose needs are far too great for a standard RACF. Such patients have high nursing needs with diagnoses such as motor neuron disease and brain tumors. Without

Primary Care Hospices there would be greater difficulty discharging such patients from hospitals and specialist palliative care units and an increased length of stay.

This model offers a cost-effective way for the State to support in-patient palliative care because it combines resources from:

- Commonwealth funding of RACF beds, GP services, and pharmaceuticals
- Providers of RACFs for capital works, organizational infrastructure etc.
- Resident contributions to bed costs (87.5% of standard pension) and pharmaceuticals
- State funding for additional nursing and allied care

The success of this model relies on a critical mass of support from local GPs who want to practice palliative care, the RACF provider and its nurses, and the regional specialist palliative care service (see attached submission from Western Adelaide Palliative Care).

The PKC Hospice at Largs Bay (western Adelaide) has been operating for 25 years as a unique demonstration model of a Primary Care Hospice. It has a stable, experienced corps of nurses dedicated to end-of-life care, local GPs who have been contracted to provide daily services, and support from the regional specialist palliative care service. PKC Hospice has potential to benefit the broader sector by offering examples of practice and education to generic RACF nurses (see submission from Southern Cross Care).

### **Recommendation**

**The Primary Care Hospice fulfills the needs of a certain group of terminally ill patients, and the model should be developed in the suite of palliative services for each region. A tendering process should consider the site, services and governance of prospective Primary Care Hospices.**

### **Care Packages**

Care packages can provide additional care for individual residents with defined palliative care needs to enable them to remain in a RACF for end-of-life care. To be effective, however, a skilled pool of nurses and GPs must be available, which is problematic in the current climate of workforce shortages. Discrete, scattered packages will not generate the critical mass of palliative care momentum that is possible with Primary Care Hospices (which can be thought of as bringing together a group of packages in one ward).

### **Recommendation**

**Care packages should be cautiously introduced and evaluated for their feasibility and cost-effectiveness in the RACF setting.**

## **Chair of Aged and Palliative Care**

Palliative care in the RACF setting has lacked status as a career path and worthy academic discipline. The establishment of a Chair of Aged and Palliative Care, perhaps in a School of Nursing, would improve career prospects, education and research in this area, and complement the 'Link nurse' and RPCP initiatives in RACFs.

### **Recommendation**

**A Chair of Aged and Palliative Care be established.**

## **Palliative Care Response Team**

A response team could 'trouble shoot' problems that arise in end-of-life care in RACFs. It would need to be attached to a call centre and be available after hours. The logistics and cost-effectiveness of such a team should be considered in conjunction with service developments for palliative patients at home.