

PALLIATIVE CARE IN RURAL AND REMOTE AREAS



...good health and wellbeing in rural and remote Australia

Palliative care is care provided for people living with and dying from a terminal condition, and for whom the primary goal is quality of life. A variety of factors often make looking after people towards the end of their lives more challenging in rural and remote areas.



What is palliative care?

Palliative care is an approach which improves the quality of life of people facing life-limiting or life-threatening illness through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems. It is often associated with older people with terminal age-related conditions, but it can be required for people of any age, including young adults, teenagers and children who may also need palliative care for cancer and neurodegenerative conditions.

Palliative care ensures that people are comfortable and pain-free towards the end of their life, whether at home, in hospital or in a hospice. Requirements for end of life care encompass not only the physical needs of a patient but also their cultural and emotional needs and wishes, as well as the needs of the person's family and carers.

Australia was ranked second in the Quality of Death Index – an international study conducted by *The Economist* to ascertain how different countries rate in their provision of end of life care. However, not all parts of Australia have equal access to such care, which is available more readily in major cities and regional centres than in rural and remote areas.

Rural and remote Australia

About seven million people live outside the major cities, and they have shorter lives and higher levels of some illnesses and health risks than the majority of people in major cities. Mortality rates increase with increasing remoteness. According to the COAG Reform Council's *Healthcare 2010-11: comparing outcomes by remoteness*, rural and remote people also receive fewer subacute services in hospitals – such as geriatric evaluation and management, psycho-geriatric care and palliative care, all of which help older people remain in their own homes.

Not everyone wants to travel away from home to a specialised palliative care centre and to remain there at the end of their life. Many people, especially those living in rural and remote communities, would like to spend their last weeks at home or in a small hospital or aged care facility near to people they know, with the support of local primary care health professionals if they need it. For rural health professionals and their patients, it is important to have ready and timely access to specialised advice, equipment and practical suggestions as back up to local approaches to palliative care.

In rural and remote areas it may be the case that there is no local doctor to support the health professional(s) providing the palliative care, who may be a nurse, an allied health professional, an Aboriginal and Torres Strait Islander Health Practitioner or an Aboriginal Health Worker.

A holistic approach

To help people adapt to their changing life when they know that death is approaching requires a holistic approach. An important first step is to relieve pain from the start and through all its stages. When pain is managed it is possible to bring some peace, acceptance and even beauty to the process. It is important to focus on the facts about morphine and other opioid medicines, not the myths.

Obtaining supplies and advice about the use and disposal of medicines for palliative care can be challenging for people in rural and remote areas if there is not a pharmacist nearby. A brochure about morphine and other opioid medicines is available from the Palliative Care Australia website: www.palliativecare.org.au/portals/46/resources/FactsAboutMorphine.pdf Further information about medicines used in palliative care is available at the NPS Medicinewise website: www.nps.org.au/

The vital importance for both the patient and their loved ones of the patient being pain-free towards the end of life is demonstrated in the award-winning documentary, *Life Before Death*, produced by Sue Collins and Mike Hill, and available at www.LifeBeforeDeath.com

Understanding of palliative care should be part of basic training and continuing professional development for health care professionals who work in rural and remote areas. The care of an allied health professional may well be part of what is required to ensure that the patient has the best quality of life until the end. Having a social worker available can help patients achieve a satisfying sense of closure in relation to unfinished emotional business. Occupational therapy can help with strategies for maintaining daily living tasks such as washing, dressing and grooming. Grief and bereavement counselling is also a part of good palliative care. It makes an enduring beneficial difference to family and loved ones when a person leaves in peace and without pain.

CareSearch at www.caresearch.org.au is funded by the Australian Government Department of Health and Ageing as an online resource of palliative care information, with links to services for consumers, carers and health professionals

Cultural respect

Culturally safe care when addressing end of life needs is also an essential part of rural and remote palliative care, given the variety of cultural backgrounds of Australia's non-metropolitan population and the higher proportion of Aboriginal and Torres Strait Islander people outside the major cities.

Aboriginal and Torres Strait Islander people have strong connections to their country. Understanding this, and possible cultural obligations, would make final stages of life more comfortable for patients and their families.

Advance care directives

Research conducted by Southern Cross University suggests that fewer than 25 per cent of Australians have written an advance health care directive or have put in place an enduring power of attorney. An advance health care directive is a 'living will' – a witnessed document written at a time of wellbeing in preparation for a time when a person may no longer be able to exercise their own right to make choices about their care or consent to medical treatment.

Every competent person has the right to accept or reject any health care a health professional might suggest. A health

care directive is to give people confidence that their wishes about health care will be carried out if they can no longer speak for themselves.

Telehealth has the potential to have a positive impact on palliative care services in rural and remote areas. It can link people and their health care providers with specialist palliative care advice. Face-to-face consultation with a local health professional is important but a video consultation with a palliative care team or other specialist, facilitated and supported by local health professionals, can provide additional expertise and support.

The most effective hospitals and hospices have a supportive model of palliative care that considers the wishes of people with advanced life-limiting disease, taking into account the probable trajectories of their diagnosed conditions. The Personally Controlled E-Health Record (PCEHR) can help with this and the location of a health care directive can be included in a person's record.

Quality of life

"It is so important that people have access to good palliative care close to home and that it entails physical, emotional and spiritual support to the patient and also to their family."

Dr Jenny May, rural GP and lecturer at the University Department of Rural Health, Tamworth

For the person spending their final months, weeks or days at home, having the support of a nearby health service if they need it is reassuring. Temporary accommodation for the families of rural patients' families is available at some health services. Some aged care facilities and community services in rural areas have effective models of palliative care, and they serve as an inspiration to others. Overall, however, palliative care services are under-funded and not well distributed across the country.

Supporting quality of life for people near the end of their life is an important part of health service provision in rural and remote communities, as it is elsewhere in this country. Progress towards greater equality in this and other matters could be enhanced through development of a National Rural Health Plan.

Further information and advice about palliative care are also available from Palliative Care Australia: PO Box 24, Deakin West, ACT 2600; Tel: (02) 6232 4433; Web: www.palliativecare.org.au



Palliative Care Australia is the peak national organisation representing the goals of all who share the ideal of quality care at the end of life. The mission of Palliative Care Australia is to influence, foster and promote the delivery of quality care at the end of life for all.