



# The precious gift

Throughout Australia, free palliative care services offer support to people with life-limiting illnesses and to their carers. Dr Websdale-Morrissey writes about her family's experience of this surprisingly unheralded service.

My father taught me to swim, to play tennis, to love reading and to approach the world with curiosity and humour. Last year, he taught me that there can be dignity in death.

He had been ill for two years, but the last weeks were hard. My 82-year-old mother did much of the nursing on her own, lovingly tending to his increasing needs. Dad worried about her, he hated "being a nuisance". I came to stay bringing my past nursing experience, but this was very different from nursing a stranger. We were all distressed.

Then my sister heard about a local service, Banksia Palliative Care, which provides help in such circumstances. Suddenly we were not alone. Within a couple of days of our initial call, we had all the aids we needed – bed frame, recliner chair that also helped to stand him upright, walking frame, dressing packs – they identified needs we hadn't considered and within hours had filled them. They involved the Royal District Nursing Service (RDNS) and liaised with Dad's doctor about pain management. Importantly we could call Banksia for advice 24 hours a day and immediately the desperate nights of uncertainty seemed manageable.

Their support extended beyond the accompaniments of illness. They offered hairdressers, massages, respite care

#### What is palliative care?

Palliative care is about assisting the dying to remain in their homes for as long as possible, or to die at home if that is their wish. Most palliative care services can access beds in local hospitals and hospices if patient and family so choose.

As is evidenced by the range of supports it provides, palliative care's focus is holistic health care for people living with life-limiting illnesses. It achieves its goals by managing six dimensions of care:

- pain control
- disability management
- social aspects
- psychological aspects
- sexuality
- cultural and spiritual needs.

Everyone in Australia is within reach of some palliative care services. Not all local providers work with the same model of care, or offer the same range of complementary services, but at least basic palliative care is available for everyone who needs it. Palliative Care Australia is the body that guides the various state member organisations throughout Australia (see box). Its Acting Executive Director,

ago, the Federal Government gave \$58 million for a number of excellent projects, but operational funding has remained virtually static, creating strain on individual services. Funding is currently under review and a decrease would be disastrous – such services are expensive to run and, even now, at least 20 per cent of Banksia's operating costs are met by donations and fundraising efforts such as raffles and cake stalls. Some providers have an even greater shortfall to meet.

#### How does it work?

Most palliative care services operate by appointing each new patient a case manager who goes into the home and undertakes a holistic assessment. As Dad's case manager, nurse Jenny Lumadon sat with us and chatted about his needs, but also about his garden and the family. During this time, she watched carefully, looking for indications of needs beyond the family's assessments. "I'm looking listening to them, watching them move, their facial expressions," she says of her initial and subsequent interactions with client and family. In our case, she drew up a care plan that included visits from the RDNS nurse, who would have showered him daily if required, and a number of mobility aids that made life much easier for everyone. She helped Dad to understand his pain relief options and

# of palliative care

volunteers. Had Dad been less ill, we could have called on a music or art therapist to help him through long hours of inactivity. When Dad died, Banksia's counsellors offered bereavement support to my mother.

And all this – all of it – was free, yet it is a service that has gone largely unheralded. My only regret is that we did not bring them in earlier because we did not know they existed.

Donna Daniels' says that its overarching purpose is to improve access, equity and quality of palliative care across Australia.

It was not always thus. A century ago, only the privileged could afford hospices for the dying. Since then, services have become far more wide-reaching and for many years palliative care has been growing in significance and range. Three years

watched Mum carefully, ensuring that she was coping.

Dad mentioned that his hair needed trimming, the next day a mobile hairdresser arrived. Would he like a relaxing massage? Would we like a volunteer respite carer to come in to sit with him? We were overwhelmed.

Many more, like us, feel they are almost collapsing under the strain of loving and

caring and loving. When Jerry arrived with his amazingly beautiful basket of resources and staffing support, we felt almost physically held up – increased against the impending collapse – and found the strength to continue. Sadly, Dad soon needed palliative care for long but for the two weeks that he did, it was heaven-sent.

When the time came, we called Benita and told them that dad needed hospitalisation. They immediately arranged a bed in the palliative care ward of our local hospital and sent an ambulance to transport him there. No fuss, no waiting on trolleys, no anxiety beyond that of our losing him.

It was unbearable watching Dad slip from us, but he was 64 and had lived a strong and wonderful life. Sadly many palliative care clients are very young. Their needs and the needs of their

parents, siblings, extended family friends and teachers are quite different. Often art and/or music therapy helps these children to express their emotions and this helps those around them. A resource called Journeys is available through Palliative Care Australia for young people and their carers (see resource link). Donna Donnelly says that it was produced by carers and professionals who have been through this ordeal as a gift for those who might yet go through it.

And in the end, palliative care is just that, a gift in every sense, one provided by government funding and community generosity and delivered by skilled carers to people wanting their last days to be less about caring and instead, where possible, about the life they will have. 🌻