



# The misunderstood world of palliative care

There are many misconceptions about palliative care. For example, that it means death is imminent and, as such, is ‘God’s waiting room’. It may also be thought of as the withdrawal of all active or effective treatment, that health professionals have given up, that it hastens death, is just about pain relief and that it is only available in hospital or a hospice. In reality, it is none of these things, as Kate’s story illustrates (see case study, p. 24).

The World Health Organization defines palliative care as an approach to care that supports the physical, emotional, social and spiritual needs of a person with a life-limiting illness, their family and carers. This definition has been adopted by the Australian Government National Palliative Care Strategy ([bit.ly/2uVIETW](http://bit.ly/2uVIETW)) as well as Palliative Care Australia ([bit.ly/2ujkfOH](http://bit.ly/2ujkfOH)).

Palliative care is provided at any time point in the disease process for the purpose of alleviating physical, psychological and existential suffering by managing symptoms, enhancing quality of life, and providing interdisciplinary support to the person, their family and carers. It also help patients and their family to make difficult treatment decisions, particularly when the future becomes less certain. Universal access to care, as well as reliable and relevant information to support decision-making, is therefore vital.

Offering access to palliative care services can help people to remain in the place or community of their choice and where they feel they belong, enhancing their quality of life and preserving their dignity.

Palliative care should commence when a person with a life-limiting illness requires additional support to live an active and meaningful life. Palliative care should encompass care through to the later phase of an illness and dying. In the last stages of a life-limiting illness, palliative care includes terminal care, which may involve referral to a hospice, as well as supporting the family and carers in bereavement.

Hospices may be community-based or led by tertiary facilities, general practices, specialist clinics, aged care facilities and other organisations in which people may be living (such as correctional facilities and locations caring for people living with severe mental illness or severe disabilities).

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## Case study: *Kate*<sup>1</sup>

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Kate was a 42-year old woman diagnosed with metastatic lung cancer in 2017. She lived with her husband John and her 16-year old twin daughters, Lucy and Mia. Given the burden of Kate's symptoms and intensive treatment she was eventually forced to retire from her corporate role in local government. Once it became clear there were no more curative treatment options, Kate was referred to palliative care for symptom management and supportive care. At this point, John retired from full-time employment to become Kate's full-time carer.

Kate was visited regularly by the community palliative care nurses until her symptoms became unstable and too severe for John to manage at home. She was subsequently admitted to an inpatient palliative care service. On this first visit she remained there for 10 days.

A referral to the psychologist on the interdisciplinary palliative care team was quickly made because of the distress that both Kate and John were expressing to the medical and nursing staff. Although Kate did not meet DSM criteria for a mood or anxiety disorder, she reported symptoms such as fear of suffocating, and an increased heart and breathing rate around periods of dyspnoea (breathlessness). She was also feeling guilty about the burden her disease was placing on her family. Anticipatory grief regarding the losses she and her family would be experiencing before she died was also causing distress.

Unfinished business about a sexual trauma that had occurred during her university studies was also raised during this first appointment. Although the psychologist assessed her for PTSD she did not meet the criteria even though she had ruminated about this for 20 years and had never told anyone.

In conjunction with her psychologist, Kate prioritised her treatment goals as, (1) management of her dyspnoea, (2) unfinished business regarding her sexual abuse, and (3) adjustment to end of life, guilt regarding the burden on her family, and anticipatory grief.

After explaining the relationship between dyspnoea and anxiety, the psychologist introduced Kate to a range of distress reduction strategies. Kate found that mindfulness and basic breathing exercises were helpful for alleviating her dyspnoea. John was also taught these interventions and appreciated the help it gave him to ground himself. Kate and John were then encouraged to practise together on a daily basis.

Once Kate's symptoms had stabilised a family meeting was organised to discuss treatment and discharge planning. During that meeting with Kate and John and members of the palliative care interdisciplinary team, the psychologist referred the family to a private psychologist

with expertise in psycho-oncology and palliative care as her ability to provide support was limited. This referral was to assist Kate with her remaining treatment goals. Before discharge the palliative care social worker helped Kate and John to develop an advance care directive and provided advice regarding financial and other practical concerns.

Before discharge and with Kate's agreement, the palliative care psychologist and social worker conducted a family therapy intervention using the family-focused grief therapy approach. This enabled the family to express their feelings and concerns and have them validated. A plan to work on family relationship issues was also developed and follow-up appointments were scheduled to be conducted in Kate's home.

After discharge the community palliative care nursing team regularly visited Kate to provide symptom management. During the next six months the private psychologist worked with Kate on her unresolved trauma and emotional adjustment using a combination of acceptance and commitment therapy, and cognitive therapy. This enabled Kate to eventually let go of her self-blaming beliefs and to process her abuse with support and without judgment.

When Kate's symptoms became unstable she was readmitted to the inpatient palliative care unit where she and her family received ongoing support from all members of the interdisciplinary team. With input from the psychologist and palliative care volunteers, Kate developed a legacy document in the form of a recipe book for her daughters, as well as a brief biography that contained family photos. The Dignity Therapy framework was used to expedite this. Kate was also able to receive some input into the first draft of her funeral service and eulogy. She was anxious to ensure this was correct, as she did not want to cause offence and believed it would relieve the family of an unnecessary burden.

After Kate died several weeks later, the palliative care psychologist offered the family bereavement counselling. John and his daughters subsequently attended several sessions together and John had two individual consultations. Family-focused grief therapy also continued for several further visits.

In the following 12 months, the palliative care service contacted John to offer further bereavement counselling which he subsequently accepted for his daughters. In that period further support was provided by members of the palliative care team at the bi-annual memorial service held at the palliative care unit.

<sup>1</sup> Case study provided by Courtney Joy, clinical psychologist. [bit.ly/2HUHpDd](https://bit.ly/2HUHpDd)

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# “Palliative care not only incorporates physical and medical treatments, but also assessment and intervention to ensure the psychological wellbeing of the patient”

## **Palliative care in context**

Improvements in lifestyle and healthcare mean that Australians in general are living longer and in better health. However, a significant number of Australians live with multiple chronic conditions such as cancer, diabetes, heart disease and degenerative illnesses ([bit.ly/2T149OE](http://bit.ly/2T149OE)). Therefore, as they approach the end of their life they may also benefit from palliative care. Similarly, older people approaching their natural end of life (with or without chronic conditions) may also have palliative care needs. Although their conditions may not be life-limiting, the health status of this group may be such that they are likely to die in the foreseeable future.

Despite the overwhelming evidence for the role and benefits of palliative care in providing care to people at this difficult time, only around half (50.5%) of those who died in hospital in 2015–2016 received palliative care (Australian Institute of Health and Welfare, 2018). This shortfall in service provision, may in part be due to misconceptions about palliative care even among specialist medical staff. But it is also due to a shortage of palliative care services in Australia. According to the Australian Institute of Health and Welfare, for example, there are only 137 public acute hospitals with a dedicated palliative care service in the country, and one-third are in New South Wales. Regional, rural and remote communities are even more disadvantaged in terms of services.

## **The role of psychology**

The psychology profession supports the World Health Organization’s (2011) emphasis that palliative care not only incorporates physical and medical treatments, but also assessment and intervention to ensure the psychological wellbeing of the person, their family members, carers, as well as members of the palliative care interdisciplinary team. This team may consist of a palliative care physician, palliative care nurses, a physiotherapist, an occupational therapist, a dietitian, music and art therapists, social workers, pastoral service workers, a counsellor, or a psychologist. Most of these professionals will be employed by the palliative care service but some may work as private consultants.

The European Association for Palliative Care Task Force identified five broad areas of expertise that psychology can bring to a palliative care setting (Jünger, Payne, Costantini, Kalus, & Werth, 2010). These are psychological assessment; psychological therapy for individuals, families and groups; consultation; supervision; and staff support, education and research. While psychologists may have the skills to work across all these areas, their actual role is likely to be determined by their job description and negotiation with other members of the team. A mutual respect and understanding of the skills that each member brings to the palliative care team is essential.

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Depending on the course, postgraduate training equips psychologists with the tools to identify and assess common psychological issues in palliative care. These include adjustment to diagnosis and palliative care, depression, anxiety, demoralisation, coping, complicated grief reactions, cognitive dysfunction and suicidal ideation. Regardless of what postgraduate training covers, it is likely targeted and continuing professional development will be required.

## Exploring the interventions

Psychologists can offer a broad range of interventions to assist people, their families and carers. These include cognitive, expressive-supportive and meaning-based therapies for anticipatory, normal and complicated grief reactions. Psychologists may assist with stress and pain management, family therapy and couples counselling.

Psychologists might also be asked to assist with verbal or written life reviews. To provide a framework for this critical aspect of psychological care there are a number of specialist interventions designed specifically for the palliative setting (Chochinov et al., 2005; Lethborg et al., 2010; Rodin, 2015). These therapies are designed to help individuals to continue living as fully as possible in the face of impending death by bringing meaning and purpose to the fore. Training in these interventions, however, is critical as they are highly specialised approaches.

David Kissane and Sidney Bloch's (2002) family-focused grief therapy is another specialised intervention that our discipline can use, albeit with appropriate training. It is a form of family therapy that ideally should be introduced as soon as a person enters palliative care and continue into bereavement. It is intended to help families cope during the palliative care process, particularly those who are conflicted or sullen. Research results from a randomised control trial suggest that it can reduce complex grief reactions in family members (Kissane et al., 2006).

Psychoeducation is another strength of our discipline. Therefore, we can confidently offer psychoeducation to not only patients, families, carers but to palliative care staff. For example, we have expertise in topics such as stress, pain, sleep disturbance, fatigue, self-care, and carer support. Furthermore, our training is such that we can deliver debriefing to staff for simple or complex grief reactions, stress management, burnout and compassion fatigue as well as personal problems.

Other areas in which psychologists' skills are highly developed and prized are program development and evaluation, as well as research. Psychologists can, for example, offer consultation to the interdisciplinary team on the design, implementation and evaluation strategies of short- or long-term patient-focused or in-service programs. Psychologists have sound skills in the development of research questions, ethics

applications, grant applications, research design, statistical analyses, report writing, library searches and systematic literature reviews.

In conjunction with other members of the interdisciplinary team, either with the person or family, psychologists can be involved in planning care, and optimising function and independence. In family meetings they can assist with problem-solving for practical issues such as financial pressures and advance care directives at the same time as providing emotional support.

## Support at the end

Working with people at the end of life requires that psychologists acknowledge and address their own personal beliefs and issues about death and dying. Despite death being inevitable for everyone, Western society is ill-equipped to manage death and dying. This is partly due to over-medicalisation of care, meaning that people become more separated from the experience of dying, resulting in reduced death literacy and more stigma and denial about death. Effective care and the ability to discuss these issues openly and professionally may be severely compromised if psychologists have not done their own self-inquiry. This critical reflection, in combination with self-care, is important to minimise burnout and compassion fatigue.

For people approaching the end of their life it is common to experience shock, grief, anger, denial, demoralisation, anxiety, guilt, resignation and acceptance. But mostly it is the experience of loss which is predominant – which includes actual loss of mobility, ability to take part in daily activities, but also the anticipated loss of identity, family and relationships and a fear of missing out.

Working with people at the end of life is a privilege. The emphasis is about spending as much time as is required to help people come to terms with their mortality and adapting to many changes. It is about helping everyone involved to live their best possible lives until the person dies and continuing care into bereavement.

Palliative care is not limited to the final days of life. As palliative care encompasses functioning across the physical, psychological, social, emotional and existential domains, psychologists must have a broad range of skills at their disposal. It requires additional skills and training. These skills must be tailored and adapted to the specific needs of the people being cared for. As in any other specialisation in psychology, it is vital to keep up with new developments in physical and psychological treatments, and engage in evidence-based practice. Ongoing professional development, supervision and education will then provide the confidence and understanding required to work effectively with people in any care setting as people approach the end of their life.



Furthermore, with the introduction of assisted dying legislation in Victoria, psychologists will need to be aware of their own roles and responsibilities, as well as the ethical and legal implications. While palliative care is independent to assisted dying, it is vital that patients have access to the full range of care options and are fully supported in making their own decisions.

### **Evidence-based resources**

There are a range of quality resources for psychologists working in or considering a career in palliative care. Two key online resources in Australia are CareSearch ([bit.ly/2Ogscwb](http://bit.ly/2Ogscwb)) and palliAGED ([bit.ly/2qdYVG4](http://bit.ly/2qdYVG4)), which are Commonwealth funded. They pull together and consolidate evidence-based information and resources into accessible language and formats. CareSearch provides evidence-based palliative care information across the lifespan and across the health system, while palliAGED provides information for the aged care sector. The Allied Health section of CareSearch also offers information, tools and resources to support psychologists looking after a person with palliative care needs ([bit.ly/2OhRsmI](http://bit.ly/2OhRsmI)). Across both websites, the perspectives of healthcare professionals,

and of patients, carers, and their families are considered, and the materials are tailored to meet these needs. There are sections devoted to the information needs of allied health, nurses, general practitioners, residential aged care, researchers, Aboriginal and Torres Strait Islander care, and patients, carers, and families.

In addition to the websites, the ‘Psychology and End-of-Life’ special edition of the *Australian Psychologist* (October, 2017) contains articles on the role of psychology in palliative care; psychological interventions near end of life; a review of dignity therapy research; client’s perspectives on bereavement counselling; and carers’ experiences of end-of-life care. You can also access more resources and information about the work of the APS in relation to end of life on the APS website ([bit.ly/2Fqm82u](http://bit.ly/2Fqm82u)).

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