FACTSHEET

End-of-life Doulas and Palliative Care

Palliative care peak bodies from all Australian states and territories and Flinders University have developed this *End-of-life Doulas and Palliative Care Factsheet*. The factsheet is designed to assist palliative care services work with their clients and their end-of-life doulas, to achieve the best possible outcomes for their clients and their families.

Definitions

To provide clarity on the terms used in this factsheet, the following terms and definitions are used.

An end-of-life doula is engaged (usually for a fee) to support a person who has a life limiting diagnosis. The support provided is not medical and is offered to ensure the person is aware of their choices and to provide non-medical support and comfort. Services vary but may include provision of emotional and physical support, assistance with navigation around care and support options, assistance in completing paperwork, and advocacy for the needs of people who are dying and their families. An end-of-life doula may also assist post death with end-of-life rituals. End-of-life doulas are not registered and there are no minimum training requirements. An end-of-life doula may also be referred to as a death doula, death midwife or death-care doula. The term end-of-life doula will be used in this statement to represent all these names.

Palliative Care[1] affirms life and regards dying as a normal process that intends neither to hasten nor to postpone death. It improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Specialist palliative care services: People will have different levels of need for palliative care. People with more complex and persistent needs should be able to access support provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience, and training in palliative care. Palliative Care Australia (PCA) refers to this type of care that is provided by specialist palliative care services as 'specialist palliative care'.[2] PCA has specified service delivery standards for specialist palliative care.[3]

Generalist palliative care services: Generalist palliative care is care provided to people living with a life-limiting condition, their families and carers by healthcare providers who are not specialist palliative care providers. The medical management and coordination of care for people living with a life-limiting illness may be undertaken by a wide range of health professionals including GPs, geriatricians, physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists, and other specialists. Other essential team members will include nurses, allied health professionals, Aboriginal and Torres Strait Islander Health Workers and Liaison Officers, and pharmacists. These health professionals are 'generalists' with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline.[4]

1 Australian Governments: The National Palliative Care Strategy 2018 , p30, https://www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf
2 PCA Palliative Care Service Development Guidelines, 2018, p7, https://palliativecare.org.au//wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf
3 PCA, National Palliative Care Standards, 5th ed. 2018 https://palliativecare.org.au/publication/standards/
4 PCA, National Palliative Care Standards for All Health Professionals and Aged Care Services: For professionals not working in specialist palliative care, 2022, p36, National Palliative Care Standards for All Health Professionals and Aged Care Services - Palliative Care Australia

Background

In Australia, the number of people practicing as end-of-life doulas is growing.[5] [6] [7] The services of an end-of-life doula may be an option available to people at the end of their life. Currently end-of-life doulas work independently and without oversight.

If a person chooses to engage an end-of-life doula to support themselves or a loved one, it is a negotiated arrangement. The support to be provided by the doula may attract a fee and/or a private contractual arrangement.

In Australia, palliative care services do not employ end-of-life doulas. Where a person receiving palliative care has engaged the services of an end-of-life doula under a private arrangement, the palliative care service will work collegiately with the end-of-life doula to support the wishes and care needs of the person.

Palliative care services often utilise the services of palliative care volunteers to provide additional non-medical help and assistance to people receiving palliative care and their families. Some end-of-life doulas work in a voluntary capacity with clients and families, and this should not be confused with palliative care volunteers, who are trained, supported and managed by palliative care services.

There is no one definitive description of what services an end-of-life doula will provide because it is not an accredited profession. There is a large degree of personal autonomy for end-of-life doulas in what services they offer. Further, most arrangements between a person and an end-of-life doula are a private arrangement, making oversight difficult.

In general terms however, end-of-life doulas may provide support and an advocacy role for patients and their families including:

- Supporting people with life-limiting illness and families with information and support in navigating services and making end-of-life plans.
- Providing an independent source of support and compassion to people with life limiting illness and family members.
- The opportunity to provide culturally safe support and care to families who are receiving care in a westernised healthcare system.
- After death care.

End-of-life doulas are not registered by a Board under the National Regulatory and Accreditation Scheme administrated by the Australian Health Practitioner Regulation Agency (AHPRA). End-of-life doulas are regulated by the National Code of Conduct for unregistered health care workers (the National Code for HealthCare workers), which is administered by the Health Complaints Commissioners in those States and Territories which have passed the relevant laws to bring the National Code into effect.[8] Those States and Territories which have not enacted the National Code are in the process of developing such legislation. The National Code sets out the minimum standards of conduct and practice.

Palliative care services should be aware that health professionals, for example, nurses who are registered with AHPRA and are also engaged in a private capacity as an end-of-life doula, must still meet the requirements of their Board in whatever capacity they are working, for example, the Nursing and Midwifery Board of Australia.

5 Rawlings, Tieman, Miller-Lewis, Swetenham, What role do Death Doulas play in end-of-life care? A systematic review, 2018. Health Soc. Care Community, 2018;00:1–13. https://doi.org/10.1111/hsc.12660

6 Rawlings, Litster, Miller-Lewis, Tieman, Swetenham, The voices of death doulas about their role in end of life care, 2020, Health and Social Care in the Community. 2020 Jan; 28(1):12-21. https://doi.org/10.1111/hsc.12833

7 Rawlings, Litster, Miller-Lewis, Tieman, Swetenham, End-of-Life Doulas: A qualitative analysis of interviews with Australian and International death doulas on their role, 2020, Health Soc Care Community. 2020;00:1–14. https://doi.org/10.1111/hsc.13120

8 This has become the Code of Conduct for Certain Health Care Workers in SA and the National Code of Conduct for HealthCare workers in other states. https://www.hcscc.sa.gov.au/code-of-conduct-for-unregistered-health-practitioners/

Palliative Care services working with patients who have employed an end-of-life doula

People receiving palliative care have the right to engage an end-of-life doula to support them if that is their choice. People receiving palliative care can be vulnerable as they enter the last stage of their life. Due to this vulnerability, palliative care services and health professionals may consider the following actions to safeguard their clients.

- Provide information to end-of-life doulas when approached, on local palliative care and primary health services, so end-of-life doulas can provide an informed description of benefits and services to their clients and families and encourage uptake of referrals to palliative care.
- Facilitate two-way feedback (provided to end-of-life doulas by palliative care services and vice versa) to help improve the quality of both services, with communication a priority when providing care for the same patient.
- Acknowledge and ensure patients know that end-of-life doulas work within a non-medical framework, and, while retaining their independence, they usually work collaboratively with the clinical and other support offered by multi-disciplinary specialist or generalist palliative care teams and other care providers.
- Ensure patients and their families are aware that the end-of-life doula role is defined as non-medical and non-clinical support. End-of-life doulas cannot dispense or discuss palliative care medications. They do not diagnose, and cannot provide advice, only options.
- Acknowledge that end-of-life doulas may be able to help patients and families to navigate the complexities of the needs and planning associated with care for someone at the end stage of life and seek to work in collaboration with them and other services.
- Palliative care services are not required or obligated to provide information or referrals to end-of-life doulas.
- If a palliative care service is providing care to a person also using the services of an end-of-life doula, the service should seek information about the agreed role of the end-of-life doula in supporting the person.

Palliative care peak bodies from all Australian states and territories as well as Flinders University have developed this document:

Palliative Care NEW SOUTH WALES
PalliativeCare VICTORIA Living, dying & grieving well
PalliativeCare SOUTH AUSTRALIA
PalliativeCare QUEENSLAND
PalliativeCare WESTERN AUSTRALIA
PalliativeCare TASMANIA
PalliativeCare AUSTRALIAN CAPITAL TERRITORY
PalliativeCare NORTHERN TERRITORY
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