

# The Palliative Care Handbook

Guidelines for clinical management  
and symptom control, featuring extensive  
support for advanced dementia



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# Psychosocial/spirituality

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## Quality of life .....

The primary goal of palliative care is to optimise the quality of life for patients and their families by preventing problems, delaying their onset and reducing their severity. There are many views on the nature of quality of life but one enduring view by Calman in 1984 (see 'Further reading') is that quality of life 'can be defined as subjective well-being reflecting differences or gaps between hopes and expectations and current experiences.'

The aim of care near the end-of-life is to

- provide 'appropriate' palliative care
- provide and maintain improvement in patients' quality of life
- achieve a 'good death' for the patient and family

However, health professionals and patients often have different views on what aspects of disease and treatment are important. There are many 'expert-derived' tools available such as:

- McGill Quality of Life questionnaire
- Schedule for the Evaluation of Individual Quality of Life (SEIQoL)
- Missoula-VITAS quality of life index - encompasses a number of domains and is user-friendly ([npccr.org/files/news/missoula\\_vitas\\_quality\\_of\\_life\\_index.pdf](http://npccr.org/files/news/missoula_vitas_quality_of_life_index.pdf)). It contains questions about
  - symptoms - the level of physical discomfort and distress
  - function - perceived ability to perform accustomed functions and activities of daily living and the emotional response, experienced in relation to expectations
  - interpersonal aspects - degree of investment in personal relationships and the perceived quality of one's relations/interactions with family and friends
  - well-being - the individual's internal condition i.e. a sense of wellness or unease, contentment or lack of contentment
  - transcendent - degree of connection with an enduring construct, and of a meaning and purpose

It has also been suggested that there are a number of developmental milestones to be reached near the end-of-life that are helpful for practitioners and patients alike to recognise including:

- a sense of completion of worldly affairs, of relationships with the community and family and friends
- a sense of meaning about our own life and life in general
- an experience of love of self and others
- an acceptance of the finality of life – of one's existence
- a sense of a new self (personhood) beyond personal loss
- a surrender to the transcendent, to the unknown – letting go

## Spirituality .....

Part of the 'task of dying' is to address spiritual concerns. Spiritual and existential concerns are important for most people at end-of-life. Spirituality should be routinely assessed, documented and addressed just as other elements of the patient's care are. Spiritual concerns may influence other symptoms. Spiritual care needs to be patient-led and should be a normal part of history taking and care plans at end-of-life.

- there is no universally agreed definition of spirituality. It includes the existential to the religious, means different things to different people and may involve a search for: ultimate beliefs/values; a sense of meaning/purpose in life; a sense of connectedness; identity and awareness; and for some people, faith and religion. Another suggestion is that 'spirituality is the way individuals seek and express meaning and purpose and experience their connectedness to the moment, to self, to others, to nature, to mortality and to the significant or sacred'
- spirituality is individually determined and culturally varied
- spiritual paths include nature (garden, sea, wilderness), relationships (self, family, friends, God), aesthetic pursuits (art, poetry, music), metaphysical pursuits (silence, prayer, ritual, philosophy)
- spiritual distress/pain is that caused by the threats to the extinction of the being/person and their meaning of 'self'. It is a similar construct to demoralisation, but not to clinical depression
- there is some agreement that religion and spirituality are different but related concepts, with religion being within the broader category of spirituality although religion has become disconnected from spirituality for some

### ***Spirituality assessment (or discernment)***

The majority of seriously ill patients are likely to want their spirituality attended to, however there are a proportion who will find this intrusive. Questions that may initiate conversations are:

- 'Are you at peace?'
- 'What does your illness mean to you?'
- 'Tell me about your faith?'
- 'How is your illness challenging your relationship with your God?'
- 'You must be wondering "Why me"?''
- 'Do you have a belief in an afterlife?'
- 'What gives your life meaning?'

Alternatively, a spiritual wellbeing survey may be used, for example:

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Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	Not at all	A little bit	Some-what	Quite a bit	Very much
I feel peaceful	0	1	2	3	4
I have a reason for living	0	1	2	3	4
My life has been productive	0	1	2	3	4
I have trouble feeling peace of mind	0	1	2	3	4
I feel a sense of purpose in my life	0	1	2	3	4
I am able to reach down deep into myself for comfort	0	1	2	3	4
I feel a sense of harmony within myself	0	1	2	3	4
My life lacks meaning and purpose	0	1	2	3	4
I find comfort in my faith or spiritual beliefs	0	1	2	3	4
I find strength in my faith or spiritual beliefs	0	1	2	3	4
My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
I know that whatever happens with my illness, things will be okay	0	1	2	3	4

### ***Dealing with spiritual distress***

- a non-judgemental approach involving presence, compassion, and empathic and contemplative listening should be used
- the creation of space ('a safe place to suffer'), being with and listening to ('to be with and to bear witness'), touch and encouraging experiencing the natural and artistic worlds are useful approaches
- spiritual care is generally agreed to be the role of all those involved in care, with the need to involve a specialist as important as any other aspect of health care
- more specialised interventions include retreats, group therapy, meditation and religious rituals
- theological beliefs and conflicts should be referred to a chaplain/pastoral care worker
- ethical spiritual care is critical. Proselytizing is widely understood to be unethical

## **Negative effects of spirituality**

Not all effects associated with spirituality in the health setting are positive. The negative aspects of spirituality are mostly to do with 'religious spirituality'. These include punishment or abandonment by God, religious pressure, guilt, stress, afterlife questions, and malign spirit visitations. The latter, and other unexplained phenomena are quite common and need to be heard compassionately. In most cases referral to a spiritual specialist is recommended

## **Advance care planning (ACP) and Advance directives (AD)**

ACP is the process of discussion and planning for future health care in the context of anticipated deterioration of health. Not everyone will choose to participate in ACP.

Health care practitioners can become familiar with the particular legal requirements in their country, state or territory by contacting relevant guardianship authorities for up-to-date information. In Australia, each state and territory has different requirements. Advance care planning

- involves the patient, health care professionals and family/carers
- incorporates the patient's beliefs, values, culture, preferences for care, current and anticipated medical status and treatment options
- needs a competent patient to participate
- should take place early in the course of a terminal illness but can happen at anytime
- may result in
  - a conversation and shared understanding between patient and health professionals
  - documentation of an ACP plan
  - the writing of an Advance Directive (see below)
  - the appointment of an enduring power of attorney/surrogate decision-maker
- is the articulation of wishes, preferences, values and goals
- respects personal autonomy and medical reality
- should be used to inform decision-making, even in acute medical emergencies
- should be regularly reviewed and updated – it is a flexible 'living' document
- is open to change, revision, and cancellation
- is not confined to medical issues – may include spiritual or interpersonal issues

## **Barriers to ACP**

- it is time consuming
- advanced cognitive impairment (e.g. from dementia). Currently, fewer than 1% of those with a diagnosis of dementia are felt to have an ACP in place. The formulation of an Advanced Care Plan should be done as early as possible in the course of a dementing illness so that the affected individual retains a greater degree of capacity to enable its completion.
- there is sometimes a reluctance to discuss death and dying and the conversation may be difficult to initiate
- some patients prefer benign paternalistic medical care
- there may be an element of misinformation about the processes/rights/law
- acute/emergency interventions may not allow for consideration of the patient's

history

- the 'disability paradox' - with age and emerging health disabilities (especially cognitive) there is a tendency to moderate the assertiveness of stated care wishes

### **Advance directive (AD) ('Living will')**

- an AD is a written or oral directive/instruction about preferences for future care
- the process for completing advance directives should be raised early in the course of an illness when the patient is competent, free of undue influence and sufficiently informed
- the existence of an AD document or conversation needs to be established
- it becomes effective if the person loses capacity
- it may encompass refusal of, or consent to, a particular treatment
- there is no medical obligation or duty to provide treatments not offered, not effective or unavailable
- clinicians are obliged to give effect to an AD but in emergencies medical indications to save life may take priority (if AD not known about)
- in some states of Australia, directives are legally binding on health professionals. There may also be the provision for patients to nominate legal proxies who can make decisions on their behalf

### **Competency or capacity**

- an individual's ability to perform a particular task at a particular point in time e.g. a decision regarding their current or future health care includes competency and capacity
- all adults are presumed to have capacity unless it is proven otherwise
- in order to demonstrate capacity, three elements must be met:
- the person is able to understand and appreciate key basic facts that are relevant to the decision to be made
- the person is able to weigh the risks and benefits of any given course of action
- the person is able to express a choice that is made in the absence of coercion
- competency may fluctuate depending on the issues under consideration
- the patient needs to be able to understand information relevant to the decision, to reason and deliberate, to retain the information (even for only a short time), to communicate by any means
- capacity does not necessarily imply rationality
- if capacity is not possessed decisions must be taken by others in that person's best interests and in the least restrictive manner possible
- Legally authorised proxy/surrogate decision-maker
- refer to guidelines available for each country, state or territory as variations in the law in different areas exist
- the preferable surrogate is a close and mature relative. It is a difficult role
- All decisions must be made with the patient's best interest in mind and tend to be conservative and life-affirming.

## **Testamentary Capacity**

- this is the legal and mental ability to make or alter a valid will
- the testator must have knowledge of extent and value of their property, knowledge of their natural beneficiaries, and the ability to communicate this knowledge

## **Grief and loss** .....

Grief is the distressing emotional response initiated by the death of a loved and attached person, or a loss. It is a normal, adjustment process. Spontaneous recovery occurs over time for the majority.

- grief begins at loss/diagnosis
- there are no specific stages of grief. Grief is never fully resolved
- modern society is death-denying and death-defying
- symptoms include sadness, anger, waves of distress, tearfulness, initial insomnia, pining, haunting reminiscences, fleeting auditory or visual pseudo-hallucinations or a sense of presence of the departed
- mourning is the behavioural responses of grieving. Culture and social norms are determinants. Mourning customs serve to organise, protect and support the grief-stricken
- grief is age-influenced. Children do not develop the capacity to appreciate the permanency of death until aged 9-10. In the elderly grief may be curtailed if the death is expected
- grief therapy may be ineffective and potentially harmful, except in distressed/complicated grievers

## **Grief and loss in dementia**

Dementia has been characterised as 'the long goodbye'. Due to personality changes and a decline in the ability of a person with dementia to recognise even close relatives, family members can feel as though they lost the person long before the time of their death, perhaps due to the person being perceived as physically present but psychologically absent for some years prior to death. Feelings of ambivalence and guilt are common, and the grief of a close relative of someone with dementia can occur in a vacuum of social isolation if the wider social circle of an affected family member has drifted away during their loved one's decline.

Relatives may become affected by a phenomenon known as disenfranchised grief, where their grief is not validated by others in circumstances where their relationship with the departed is not recognised and their loss unacknowledged. In a similar vein, stigma against those with dementia may lead to a disenfranchised or devalued death, where the value of the departed's very personhood is no longer acknowledged by others who might otherwise lend support.

Depression rates in family caregivers of people with dementia can be as high as 50%. The grief of dementia caregivers frequently goes unrecognised by attending health professionals.

## ***Complicated grief***

- intense and/or protracted (> 1-2 years)
- it is characterised by prolonged longing and yearning for the deceased, intrusive thoughts or images, anger, guilt, emotional numbness, avoidance of reminders and difficulties redefinition
- it occurs in 10-15% of bereaved people
- it is accompanied by increased psychological and physical morbidity, substance abuse and suicide
- risk factors include sudden, unexpected, traumatic death, pre-existing dependant or ambivalent relationship, psychological/psychiatric vulnerability, disenfranchised grief (the hidden grief of those socially unable to express their response), compounded by major depression or substance abuse

## ***Management of grief***

- 'death talk' (anticipatory grief) and advance care planning may mitigate/moderate grief
- early identification of those at high risk for bereavement follow-up
- support, empathy, normalisation, offer pragmatic information/education
- encouraging adaptation and restructuring of a world without the lost one, acknowledgement of the emotional 'scar'
- short term mild hypnotic medication if marked insomnia
- specific counselling e.g. Cognitive Behavioural Therapy if complicated grief, perhaps with antidepressant medication
- cathartic expression of distress is of minimal, if any, benefit