

ANALYSIS



Palliative care from diagnosis to death

Evidence is growing that people can benefit from palliative care earlier in their illness, say **Scott Murray and colleagues**, but care must be tailored to different conditions

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Many people still associate palliative care with care in the terminal stage of cancer, and patients with cancer remain more likely to receive it than those with other illnesses.¹ It is often delayed until the last weeks or days of life once the illness is advanced and disease focused treatments are no longer effective. However, late palliative care is a missed opportunity to do better for patients, families, and health services. In high income countries, up to 80% of people who die could benefit from palliative care much earlier in their illness.²

The World Health Organization adopted a resolution on early palliative care in 2014. It states that palliative care should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future.³ Palliative care can improve the quality of life of patients and their families through timely identification of deteriorating health, holistic assessment of needs, management of pain and other problems (physical, psychosocial, and spiritual), and person centred planning of care.

By embracing the principles of palliative care in their routine practice, clinicians can meet the multidimensional needs of people with deteriorating health more effectively. Palliative care specialists can provide support, training, additional advice, and direct involvement in more complicated or unstable situations.⁴

What is the evidence for early palliative care?

Randomised controlled trials and other studies show multiple benefits from early palliative care. A landmark randomised trial comparing standard care with outpatient specialist palliative care integrated with oncology for patients with advanced or metastatic disease improved quality of life and, for some people, longevity.⁵ Further recent trials and a systematic review report that early systematic provision of palliative care by many clinicians, not just by palliative care specialists, can improve

quality of life of people with cancer and other advanced life limiting conditions.⁶⁻⁸ It can also help avoid burdensome interventions of low benefit.⁹ Studies of older people in Australia and people with chronic disease in Canada showed significant reductions in hospital admissions.¹⁰⁻¹²

Patients have been shown to have palliative care needs from diagnosis.¹³ Although trials do not explain which aspects of palliative care are the most important, helping people to make choices aligned with their priorities seems to be the key.¹⁴

Below we set out a rationale for early palliative care based on the three typical trajectories of functional decline towards the end of life (rapid, intermittent, and gradual)^{15 16} and suggest how it can be incorporated into disease specific care.

Rapid functional decline

In people with advanced cancer, social functioning typically declines in parallel with physical decline, whereas psychological and spiritual wellbeing often fall together at four key times: around diagnosis, at discharge after initial treatment, as the illness progresses, and in the terminal phase (fig 1⇓). Patients and family members report that the time around diagnosis is one of the most traumatic, psychologically and existentially, with further emotional turmoil as the patient gets more ill.¹⁷

All people whose cancer may be life limiting, but not necessarily untreatable, should be considered for palliative care from diagnosis. They can benefit from holistic care and support as well as planning care even when they may be relatively well physically. Patients report finding it supportive for professionals to simply acknowledge that this initial time can be very challenging. Some also value being told about the likely course of events for people with their condition. Waiting for physical decline misses the opportunity to provide well coordinated palliative care integrated with other treatments. Triggers for a review of palliative care needs include discharge from hospital

after treatment, poorly controlled symptoms, falling performance, and other clinical evidence of disease progression

Intermittent decline

In people with life limiting, long term conditions or multiple illnesses, the dynamic “four dimensional” pattern of needs is different from that for most progressive cancers. Social and psychological decline both tend to track the physical decline, while spiritual distress fluctuates more and is modulated by other influences, including the person’s capacity to remain resilient (fig 2).¹⁶ People may die suddenly during an exacerbation or when still functioning relatively well, so death is often perceived as unexpected, although it has actually been a predictable risk for some years.¹⁸

During the increasingly frequent exacerbations of conditions such as heart failure, liver failure, or chronic obstructive pulmonary disease, patients and their carers are anxious, need information, and often have social problems. Support for these needs might be more effective and likely to reduce hospital admissions than interventions focusing on disease management or physical wellbeing, especially as multimorbidity is the norm in these conditions. Planning for exacerbations should include dealing with multidimensional needs and communicating current plans and patient wishes regularly and routinely to out-of-hours care providers and hospitals. This facilitates appropriate management during and after such crises.¹⁹

Gradual decline

People who have frailty, dementia, or a progressive neurological disease, including those with long term disability after a severe stroke, typically experience a gradual physical decline from a limited baseline and a diminishing social world.²⁰ Psychological and existential wellbeing sometimes fall in response to changes in social circumstances or an acute physical illness but a decrease in social, psychological, or existential wellbeing can herald global physical decline or death (fig 3). Some older people reach a tipping point when they feel unable to live usefully or with dignity and experience increasing psychological and existential distress before dying.²¹

Actions to promote optimum physical health should be combined with help to engage with social support and care that let frail older people maintain a sense of self and purpose even in the face of increasing dependence. Allowing older people to raise and discuss their greatest fears—of losing independence, dementia, or being a burden to others—is person centred early palliative care. Anticipating and planning for deteriorating health in older age can reduce distress while promoting a realistic understanding of normal ageing and how death occurs at the end of a long life. People with early dementia or progressive neurological conditions need holistic palliative care and support to plan ahead from the time of diagnosis.

Early palliative care for all conditions

Lack of timely identification of people who may benefit is the greatest barrier to early palliative care. In the same way that we screen for cardiovascular risk factors or for diabetes, we should routinely and systematically consider whether our patients might benefit from early palliative care. Signs of decline in general health or specific conditions can be combined with triggers such as unplanned admissions, poorly controlled symptoms, or increasing need for carer support. Screening can happen at treatment reviews, at hospital admission or discharge, or at annual medical examinations in older people. Various

identification tools—such as the Supportive and Palliative Care Indicator Tool, Necesidades Paliativas, and Gold Standards Framework guide—are available and increasingly popular internationally.^{22–23} Action before the last weeks or days of life means accepting prognostic uncertainty instead of relying on mortality prediction tools that do not work for individuals.^{1–24}

Good conversations

Early conversations suggesting that it is helpful to start talking about what might happen in the future and available treatment and care options should be introduced sensitively.¹⁴ Explaining the inherent uncertainties of life limiting illness is different from breaking bad news. It requires an ongoing discussion about what might happen and what could help.²⁵ There are many well validated guides to help clinicians to explore people’s understanding, share individualised information, respond to emotions, and acknowledge loss so that care is tailored to each person’s needs and priorities. The content and the context of such conversations should be relevant to the person’s current state and involve those close to them (box 1).^{14–28}

Many clinicians find it challenging to raise palliative care with patients because it is associated with imminent death. In Canada and the UK some palliative medicine physicians use the term “supportive care” to promote access.²⁹ In one study many patients who experienced early palliative care thought it should be renamed.³⁰ Practical aspects of doing this have recently been reviewed.³¹ A natural experiment of using the term “anticipatory care” throughout Scotland found that it enabled earlier conversations. Planning for possible deterioration made it much easier to discuss and plan for likely events in the illness trajectory, including dying. More patients subsequently received this planned holistic care before dying.¹⁹

Integration with ongoing disease management

Integration is the only way that early palliative care can be widely available and acceptable to most people. Open dialogue and planning should occur in the community, care homes, and hospital wards, so that everyone who needs it can benefit.³² Communication between settings is vital. Hospital specialists, specialists in palliative care, general practitioners, community nurses, patients and carers, and providers and commissioners of care must all be included.

Several such initiatives have already been implemented in health systems throughout Europe.³³ A WHO web platform dedicated to integrated people centred palliative care (www.integratedcare4people.org/communities/integrated-people-centred-palliative-care/) has been launched to share good practice, experiences, and lessons.

By considering each dimension of need, palliative care may promote kinder and more realistic medicine, preventing unnecessary treatment.⁹ An open conversation mapping out the likely course of the illness and future needs with the patient and family can allow an earlier focus of care on quality of life and managing symptoms. Initiatives to promote a public discourse about death and dying are underway in Scotland (www.goodlifedeathgrief.org.uk), England (www.dyingmatters.org), and Ireland (<http://hospicefoundation.ie/programmes/public-awareness>). These include telling people how early palliative care can help them live well from diagnosis onwards.

Early palliative care requires doctors to be alert to the opportunity to introduce it, to listen to what the person thinks is important, and to offer ongoing support. Understanding typical patterns of decline and distress enables professionals, patients, and their carers to share a realistic view and include palliative

Box 1: Introducing early palliative care

- Talk about why starting a conversation about what is happening is important:
When someone has this sort of health problem, we usually plan to have a talk together about what is happening and what help they might like to have now or in the future...
The treatment has helped this time and I am glad you feel better, but I am worried you may get unwell again so can we talk about how we might plan for that...?
- Ask who should be involved:
What would be the best way for us to talk about this? People often like us to involve a family member or close friend...
- Talk about the main aims of the conversation:
We want to find out about the things that are important for you like what you'd like to be able to do now and in the future...
We can talk about your current situation and what you want to know about your health problems...How have you been doing recently?
This is a good time for us to talk about any thoughts or worries you might have about the future...
- Ask what the person knows, has been told, and thinks could happen to them
- Talk about what might happen linked to this understanding and awareness using short "chunks" with pauses and time for questions or reactions
- Ask what matters most so that good plans can be made to help
- Talk about getting advice from a colleague who can help you look after them well if the situation is more complicated or unstable.
Explain that palliative care is all about what we can do to help people stay as well as possible

care to prevent as well as treat distress. Explanation about when practical, emotional, and existential issues might occur, and the help available, helps empower patients and provides real hope. Early palliative care is therefore about doing more for the person, not less. Indeed it might be best not to call it palliative care, but just good patient centred care and planning, to which we should all aspire.

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Key messages

Palliative care should start at diagnosis and not be confined to the very end of life

Early palliative care improves quality of life by focusing on living well with deteriorating health

All health professionals need to incorporate holistic palliative care into their practice

An understanding of typical, multidimensional illness trajectories can help doctors know what to offer and when

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Figures

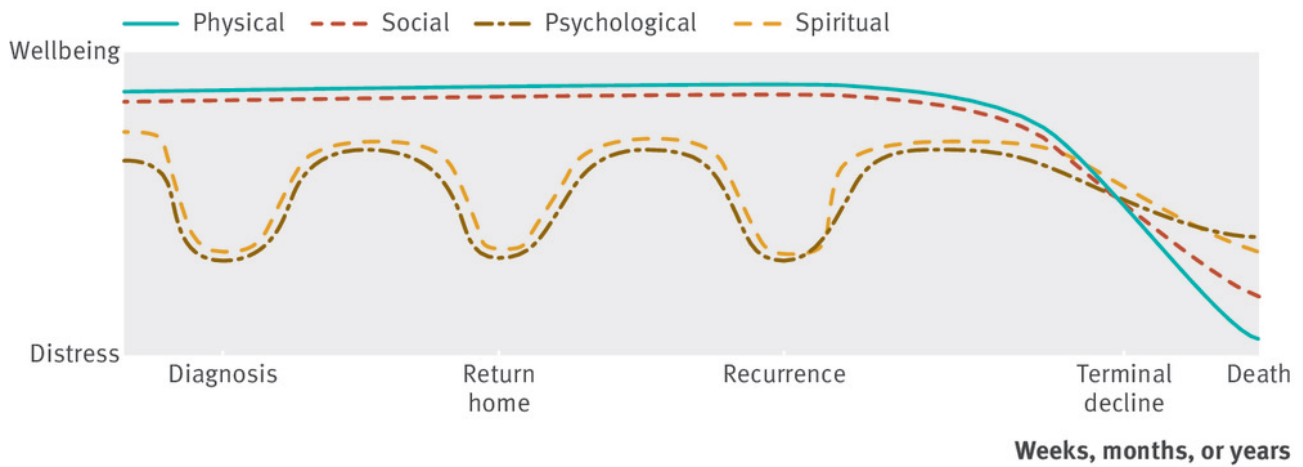


Fig 1 Wellbeing trajectories in patients with conditions such as cancer causing rapid functional decline

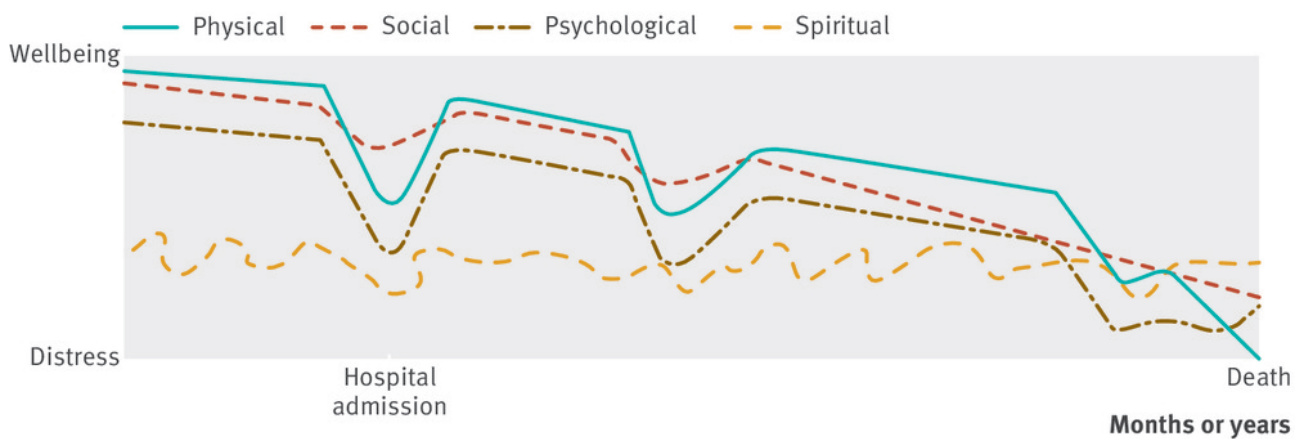


Fig 2 Wellbeing trajectories in patients with intermittent decline (typically organ failure or multimorbidity)

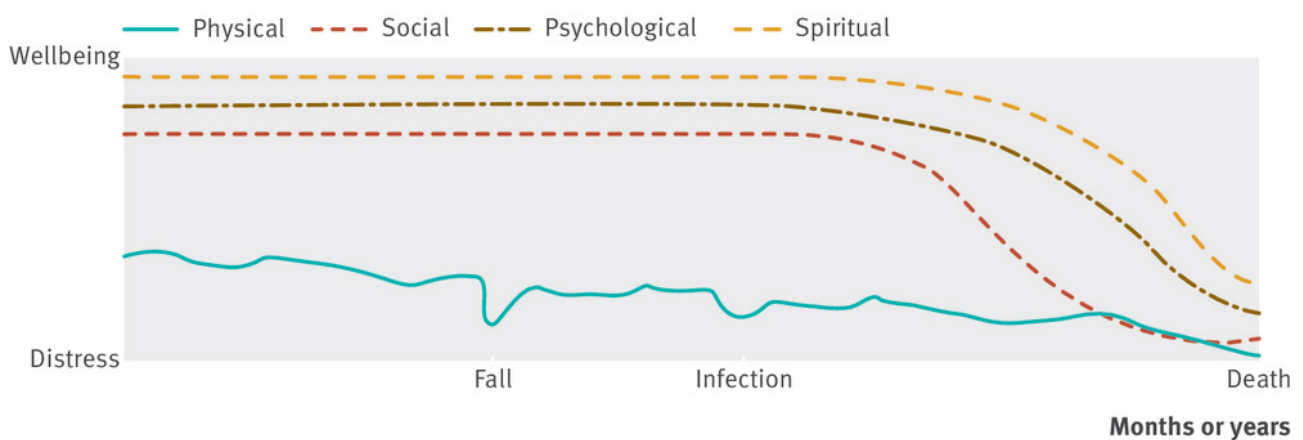


Fig 3 Wellbeing trajectories in patients with gradual decline (typically frailty or cognitive decline)