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# 1. SCOPE OF PALLIATIVE CARE

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## DEFINITIONS

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Palliative care is the *active total care* of patients with an incurable progressive life-threatening condition, and their families, by a multiprofessional team. Palliative care extends far beyond physical care, as is emphasized in the definition from the World Health Organization (Box A). The word 'palliative' is derived from the Latin word 'pallium' meaning 'a cloak'. Thus in palliative care, symptoms are 'cloaked' with treatments whose primary aim is to promote comfort.

### **Box A** WHO definition of palliative care<sup>1</sup>

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening 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.

Palliative care:

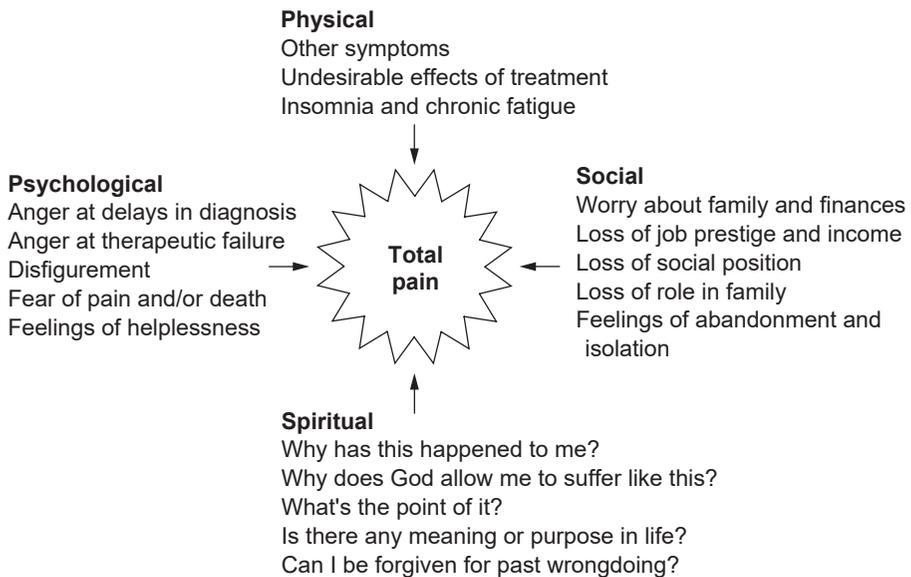
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Patients can live for many years with an incurable, progressive but ultimately fatal condition, and the need for palliative care is not defined by a set time limit. Nonetheless, most patients referred to specialist palliative care services will be in their last 6–12 months of life, and increasingly the term ‘end-of-life care’ is applied to the care of patients within this time frame. ‘Terminal care’ is now generally restricted to the care of patients when it becomes clear that they are going to die in the next few weeks or days.

‘Supportive care’ is an umbrella term used to describe the provision of all aspects of care from pre-diagnosis to bereavement, whether physical or non-physical, and curative or palliative in intent.<sup>2</sup> It is also used more narrowly to describe measures to combat the undesirable effects of disease-modifying treatment.<sup>3</sup>

In paediatric palliative care (see p.287), the terms ‘life-limiting condition’ and life-threatening condition’ are used. A life-limiting condition is defined as a condition for which there is no reasonable hope of cure and from which a child (or young adult) will die. A life-threatening condition is one for which curative treatment may be feasible but can fail, such as cancer.<sup>4</sup>

Palliative care is a form of care in which the patient’s physical, psychological, social and spiritual needs are regarded as equally important, and which emphasizes the inextricable link between them. This is well illustrated by the concept of *total pain*, initially proposed by Cicely Saunders, which emphasizes that a patient’s suffering can relate to any or all of the four dimensions (Figure 1).



**Figure 1** The four dimensions of total pain

A 'listening ear', notably that of a doctor or other health professional, is just as necessary as the right drugs, *either alone is not enough*. For example, anxiety about family finances can increase the severity of a patient's pain-related distress. If so, optimal benefit will result from the provision of financial advice and support, not just the progressive increase in analgesic dose (see p.81).

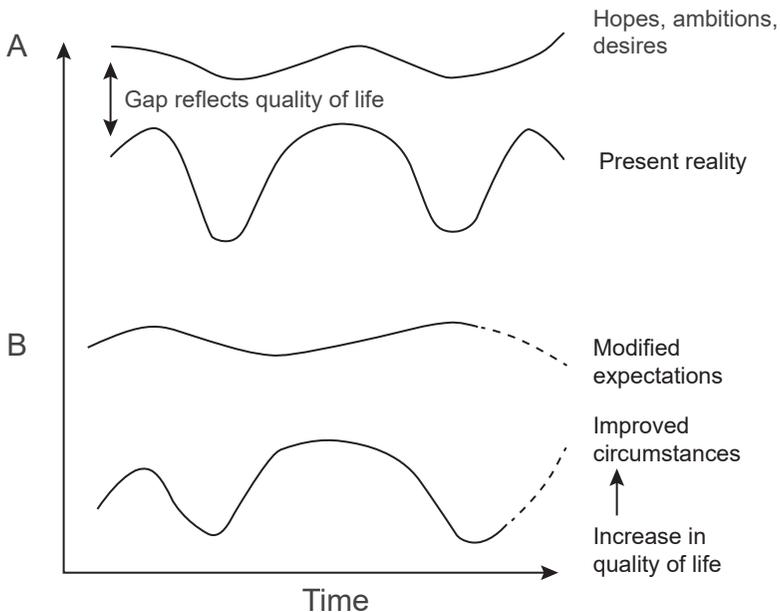
## QUALITY OF LIFE

*'Quality of life is what a person says it is.'*

Palliative care is about quality of life, and includes rehabilitation. It seeks to help patients achieve and maintain their maximum potential physically, psychologically, socially and spiritually, however limited these may have become as a result of disease progression.

Quality of life relates to an individual's overall subjective satisfaction with life, and is influenced by all aspects of personhood.<sup>5</sup> In essence, there is good quality of life when the aspirations of an individual are matched and fulfilled by present experience.

There is poor quality of life when there is a wide divergence between aspirations and present experience.<sup>6</sup> To improve quality of life, it is necessary to narrow the gap between aspirations and what is possible (Figure 2). Palliative care aims to do this.



**Figure 2** A representation of the gap between reality and hopes (A); an improvement in quality of life reflects either a reduction in expectations or a change in present reality (B).<sup>6</sup>

Thus, a tetraplegic ex-gymnastics instructor is able to say, 'The quality of life is excellent, though to see me you wouldn't believe it. I've come to terms with my loss and discovered the powers of my mind'. And a 30-year-old man dying of disseminated osteosarcoma complicated by paraplegia comments, 'The last year of my life has been the best'.

## **DEVELOPMENT OF PALLIATIVE CARE**

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Palliative care is a relatively new concept in modern medicine. In its early stages, it was synonymous with 'hospice care'. (Historically, hospices were 'houses of rest and entertainment for pilgrims, travellers, or strangers'.) In the mid-late 19<sup>th</sup> century, hospices in Dublin and London were set up by nuns to offer care to the 'dying poor'. However, there was relatively little medical input. Other similar establishments opened during the middle years of the 20<sup>th</sup> century.

In the late 1950s, Cicely Saunders, a recently qualified doctor and research fellow in pharmacology went to St Joseph's Hospice in East London to study pain in dying cancer patients, and to provide the necessary medical input. Having previously worked as a nurse and then a social worker, Saunders had resolved to dedicate her life's work to improving the care of the dying. Motivated by her Christian faith, she went on to found St Christopher's Hospice in South London in 1967. She was a passionate advocate of 'efficient loving care' for dying patients, and she is universally recognized as the founder of the modern palliative care.<sup>7</sup>

Palliative care is now a well-established element of healthcare provision, with over 8,000 hospice and palliative care programmes in more than 100 countries. In the UK, palliative care has been a medical specialty since 1987, with specialist services available in hospitals, hospices and the community. There is increasing recognition of the importance of generalist and other health professionals providing high quality palliative care within their own care settings and specialties.

In 2014, the World Health Assembly adopted a landmark resolution emphasizing the importance of palliative care as an ethical responsibility of healthcare, and called for both individual countries and the WHO to take action to improve provision globally.

## **CURRENT CHALLENGES IN PALLIATIVE CARE**

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Annually worldwide:

- 54 million people die (all causes)
- 30 million die from progressive organ failure or other degenerative diseases
- 8.5 million die from cancer
- 1.5 million die from HIV/AIDS.

With technological advances in public health and healthcare provision, life expectancy is increasing rapidly in many parts of the world. Globally currently almost 1 in 10 people are over 60; by 2050, this proportion will have risen to 1 in 5. An ageing

population brings with it a rise in chronic conditions and multiple co-morbidities, and an increased need for palliative care.<sup>8</sup>

At its inception, palliative care had a strong focus on cancer, particularly in younger patients. In recent years, the importance of other chronic progressive conditions, such as cardiorespiratory disease and dementia, has been increasingly recognized. However, with less predictable disease trajectories, access for non-cancer patients to palliative care services is still relatively poor.

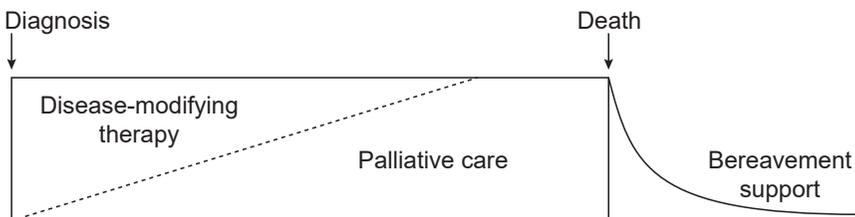
In the UK, end-of-life care has been subject to damaging media coverage, with controversy about the way in which the *Liverpool Care Pathway for the Dying Patient* was sometimes implemented. A subsequent report highlighted the need for care to be more than an unthinking 'tick-box' exercise but, instead, based on adequate training and sensitive communication with patients and families.<sup>9,10</sup> New NICE guidelines stress the need for an individualized approach and the need for frequent review, at least on a daily basis.<sup>11</sup>

Coping with uncertainty at the end of life is a key challenge for health professionals, patients and families. It has inevitable ethical implications (see p.13) as well as impacting on communication strategies (see p.35).

In many countries, more deeply ingrained barriers remain, such as limited access to strong opioid analgesics (because of overly restrictive governmental control on narcotic drugs) and 'opiophobia' (fear of opioids) among many clinicians. In many developing countries, healthcare is massively underfunded and unable to provide basic preventive and curative treatments, and certainly not palliative care.

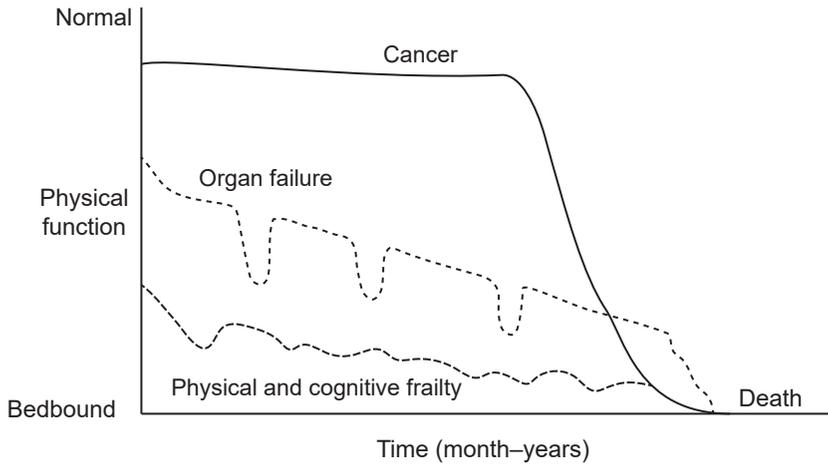
## WHO IS A 'PALLIATIVE PATIENT'?

Often, there is *not* a clear-cut division between disease-modifying therapy and palliative care (Figure 3). However, once disease-modifying treatments are no longer available or appropriate, the primary focus will shift to palliative care.



**Figure 3** The relationship between disease-modifying therapy and palliative care in a patient with an incurable progressive condition.

Clinicians' estimates of prognosis in cancer can be very inaccurate, and are commonly over-optimistic. In non-cancer patients, in whom the illness trajectory is less predictable, prognosis is even harder to estimate. Different groups of patients have different trajectories of functional decline towards death (Figure 4).



**Figure 4** Disparate trajectories in progressive conditions.

Cancer deaths tend to follow a fairly predictable course, with a long period of relatively good physical function, followed by a steady, rapid and progressive decline towards death.

In contrast, deaths from organ failure (heart, lung, liver) tend to follow a course of progressive decline with unpredictable acute exacerbations. In many cases, the patient makes a good recovery from each exacerbation, but there will ultimately be an episode from which they will not recover, and they may die fairly rapidly. It is very difficult to foresee which exacerbation will be the final blow.

Chronic frailty associated with dementia, degenerative neurological disease or old age is even more unpredictable with a prolonged progressive decline in physical and mental function. Thus, when talking with patients and their families about the future, it is important to communicate the uncertainty surrounding prognosis (see p.42).

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## WHO PROVIDES PALLIATIVE CARE?

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Teamwork and partnership are central to palliative care: between different members of the multiprofessional team, and between clinicians and patients and their families.

### Teamwork

*'Together Everyone Achieves More'*

A climate of mutual respect and trust where hierarchy is minimized and each individual is empowered to provide the best possible care is fundamental. Because there is an overlap of roles, co-ordination is an important part of teamwork.

Conflict inevitably erupts from time to time in a team of highly motivated, skilled professionals. One of the challenges of teamwork is how to handle conflict constructively and creatively.

Most palliative care is delivered by doctors and nurses who are not specialists in palliative care. With the growing needs of an ageing population, it is neither possible nor appropriate for all palliative care to be provided by specialists. Thus, all health and social care professionals need to be equipped with appropriate skills in order to provide good palliative care (Table 1), with specialist services involved for the more difficult and complex cases.

**Table 1** Roles of health professionals in providing palliative care

<i>Role</i>	<i>Description</i>
General Practitioner	Co-ordinates care in the community, ensuring all appropriate professionals are involved. Normally the lead doctor for patients at home or in residential and nursing homes. On average, a GP in the UK will have 20 patient deaths per year: five from cancer, six from organ failure, seven from chronic frailty and two from sudden death.
Hospital Consultant	Consultants in specialties such as Oncology, Chest Medicine, Cardiology or Care of the Elderly usually remain in overall charge of a patient's specialist care when inpatients or in outpatient clinics. They may transfer patients directly to a palliative care service but, more commonly, will discharge them back to the GP to provide continuing care.
Palliative Medicine Consultant	Generally involved only in more complex cases. Responsible for a patient's care when admitted to a palliative care unit/hospice. In the community or hospital, they generally provide an advisory service, with ultimate responsibility for the patient's care remaining with the GP or other hospital consultant.
Non-consultant grade doctors (e.g. junior doctors, staff grade, associate specialists)	Provide palliative care in all settings in various ways with the support of a consultant/GP, e.g. co-ordinating the day-to-day care of inpatients and optimization of their medical management, review of patients in outpatients, day care, GP clinics and at home. In hospital, a junior doctor is likely to be the first to be called to see dying patients out of hours, and to confirm death.
Inpatient Nurse	In hospital or care home, the nurses and healthcare assistants provide the physical care and administer drugs. In hospices and other clinical areas where dying patients are cared for regularly, nurses become confident in administering 'as needed' drugs.
District Nurse	Provides regular nursing care in the community; available 24/7 in most areas of the UK. Will regularly visit a patient to monitor physical symptoms and nursing needs, provide nursing care, arrange equipment in the home such as a hospital bed, arrange overnight nursing care and administer drugs such as morphine by injection or syringe driver.

*continued*

**Table 1.** Contd.

<i>Role</i>	<i>Description</i>
Macmillan Nurse/ Clinical Nurse Specialist in Palliative Care	Specialist nurses whose role is to provide information and advice regarding the patient's care and condition, and provide emotional support to patients and families. Do not provide hands-on nursing care and are generally not available 'out-of-hours'.
Marie Curie Nurse and Hospice at Home service	Nurses or Healthcare Assistants who provide hands-on nursing care in the home, often co-ordinated by the patient's District Nurse. They aim to support a patient to remain in their own home for as long as possible, frequently staying with patients for several hours overnight.
Home Carer	Community-based carers (Social Services or agency) attend to a patient's hygiene, toileting, eating and drinking needs, and support the family. They may get to know the patient very well, and thus may identify subtle changes in their condition.
Physiotherapist and Occupational Therapist	Maximizes a patient's functional ability for as long as possible, either through exercises or home modifications. May also advise in the non-drug management of symptoms such as breathlessness or anxiety.
Social Worker	Responsible for advising on and arranging community care packages, including home carers and access to care homes. Provide advice on the financial aspects of care, and the availability of grants.
Chaplain/Religious leader	Spiritual care practitioners are particularly helpful for patients who have a religious faith. Also helpful for the non-religious who have existential questions they would like to talk through in a non-religious framework.
Complementary Therapist	Complementary therapies may be available, particularly in hospices. Relaxation techniques are often used in the management of anxiety and insomnia.
Volunteers	Although not health professionals, volunteers are an integral part of most palliative care services, providing 'added value' as a result of their own life experiences and skills. They help with a wide range of tasks, including serving food and drink, co-ordinating activities for patients, and being an additional listening ear for patients and families. They also form an important link with the wider community.

## Partnership

Palliative care is based on partnership between the multiprofessional team and the patient and family. Consultations should be seen as a meeting of experts: patients are the experts about how they feel and the overall impact of the illness, and health professionals are the experts in diagnosis and management. Partnership emphasises equality rather than hierarchy, and requires mutual respect (Box B).

<b>Box B</b> Partnership with the patient	
Be courteous and polite	Explain
Listen	Agree priorities and goals
Don't be condescending	Discuss treatment options
Be honest	Accept treatment refusal

## PLACE OF CARE

In recent years, significant emphasis has been placed on the patient's preferred place of care and preferred place of death. Although the majority of the *general public* say they would prefer to die in their own home, among *patients* there is a wide range of preferences, many of whom are undecided or view issues such as symptom management as a greater priority than the place of their care and death.<sup>12</sup>

It is important that patients and their families are aware of all the options, how to access them urgently if necessary, and be assured that they have not failed should they change their minds about remaining at home.

The most common place of death in the UK is still the acute hospital. This discrepancy between preferred and actual place of death has been one of the drivers behind Advance Care Planning, where people record their wishes before becoming seriously ill, e.g. to avoid unwanted emergency hospital admissions (see p.268).

## Home

High quality care at home is often possible, particularly if social networks are strong and family members are able to be closely involved. A good support network is essential: ready access to medical and nursing care at all times of day and night, access to specialist advice when needed, and equipment or adjustments to the home speedily available.

Planning for the last days of life is particularly important, in which possible outcomes are discussed sensitively, and family and carers are appropriately prepared. A 'just-in-case' set of drugs enables health professionals to administer drugs rapidly should distressing symptoms develop (see p.273). Well co-ordinated teamwork among the various professionals involved is vital to avoid a succession of disjointed visits (very tiring for the patient) and ensuring continuity of care.

Despite initially expressing a wish to be cared for at home, many patients and families change their minds as the illness progresses, with preference for home care declining over time.<sup>13</sup> Caring is far more demanding than most people imagine, and exhaustion is an ever-present threat.

### **Hospice day care**

Hospices often also provide day care 1–2 days per week for patients in the community. This may be for a limited period of time because of restrictions on numbers. It is very beneficial for patients who are socially isolated or whose family need some respite. Day care patients often receive complementary and relaxation therapies alongside more traditional medical and nursing care, enabling them to remain in their own homes for longer.

### **Nursing or residential care homes**

These provide a significant amount of palliative care, particularly for patients with chronic frailty and dementia. Care homes look after people on a long-term basis, in a constant environment; they become familiar with the staff, who get to know their preferences. The nurses can also become expert at detecting troubling symptoms, and involving other health professionals when appropriate.

### **Hospice/palliative care unit**

Hospices are centres of excellence providing specialist palliative care. The majority of patients have a cancer diagnosis, reflecting their historical focus. They typically receive considerable amounts of charitable funding (sometimes well over 50% of their running costs), and often provide various additional services such as complementary therapies. The number of hospice beds in the UK is limited and allocation of this scarce resource is a challenge. Inpatient beds are generally reserved for patients with complex physical, psychological, social or spiritual needs which cannot be met elsewhere. Average duration of stay is 10–14 days, typically with the aim of improving symptom control. About half will die at the hospice, with the remainder discharged back to their own home or to a care home.

### **Hospital**

Patients approaching the end of life are often admitted to hospital when crises arise, and many never recover sufficiently to be discharged before their death. Early in a patient's disease process it may be entirely appropriate for them to be admitted to hospital, particularly if they are still receiving curative treatment. However, the busy environment of a hospital ward is less appropriate for patients near the end of their lives. Often, staff looking after acutely ill patients do not have sufficient time also to care adequately for the rapidly changing needs of dying patients.

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## CONCLUSION

Over the past 50 years, palliative care has developed into an important clinical specialty, but is also fundamental to the role of all health professionals, regardless of specialty. On average, in their first year post-qualification, a UK FI doctor will care for around 40 dying patients. It is thus vital that they have a good understanding of palliative care.

Further, over half of all medical graduates become GPs, who have a central role in the care of the 40% of UK patients who die at home or in care homes. With only one chance to get it right, caring for dying patients is both hugely challenging and hugely rewarding.

Clinical, pharmacological, communication and team-working skills are crucial. As one family member wrote to a junior doctor:

*'We will never forget the calm and reassuring way that you looked after mum in her last few days. Your quiet confidence that you would keep it comfortable for her, and that you knew where to get advice, made our painful loss so much easier to bear. Thank you.'*

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