

Palliative Care

See also separate articles [Helping Patients Face Death and Dying](#), [Looking after People with Cancer and Terminal Care](#).

The contemporary concept of palliative care has its origins in the modern hospice movement. Beginning with Dame Cicely Saunders and the opening of St. Christopher's Hospice in 1967, the underlying philosophy of palliation included holistic care (emphasising emotional, social and spiritual needs) taken hand-in-hand with a progressive approach to managing end-of-life symptoms medically. The movement's success is reflected in how universally accepted these goals now are, if not actually universally available yet.^[1]

Aims of palliative care:^[2]

- To affirm life but regard dying as a normal process.
- To provide relief from pain and other distressing symptoms.
- To neither hasten nor postpone death.
- To integrate psychological and spiritual aspects into mainstream patient care.
- To provide support to enable patients to live as actively as possible until death.
- To offer support to the family during the patient's illness and in their bereavement.

Many continue to be fearful of palliative care since they *wrongly* consider it synonymous with terminal care so it is important to understand its evolution:

- **Beyond cancer care to greater inclusiveness:**
 - For many years, palliative care largely meant the care of those with cancer and patients with progressive end-stage disorders besides cancer were denied access to these services despite prognoses and symptoms comparable to or worse than many cancers.
 - In the twenty-first century, palliative care is gaining expertise and becoming more inclusive of the many other diseases that afflict the population, such as [heart failure](#), [chronic obstructive pulmonary disease \(COPD\)](#) and [dementia](#).
- **Beyond providing symptom relief in the dying to the care and support of the living as well:**
 - The World Health Organization (WHO) defines palliative care as 'an approach that improves the quality of life of individuals 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'.^[3]
 - The case for early palliative care was emphasised by a survey of British cancer patients, two-thirds of whom had experienced pain at the time of their first hospital visits but this was either not elicited or inadequately treated.^[4]
- **From end-of-life care to providing care over the *entire* disease trajectory:**
 - Optimising quality of life for patients and their families via the use of symptom control and good supportive care may be relevant at any or all points along the disease continuum - from pre-diagnosis, through diagnosis and treatment, to recovery or death.
 - This change in perspective has been due partly to medical advances: many more individuals now 'survive' cancer or experience it as a chronic disease. The emphasis now lies on *living* with a 'killer' disease such as AIDS or cancer. Increasingly, individuals may receive palliation for diseases that will not be their ultimate cause of death.
 - Most medical conditions are not cured; rather, the symptoms are palliated and whilst, in practice, palliative care is usually reserved for those coping with life-threatening illness, the philosophy of palliation, supportive care elements and expertise in managing symptoms are widely applicable beyond this remit.

- **To the coexistence of palliative and treatment approaches:**

- Previously, palliative care was used as the only option for a patient when active treatment had failed. It is now appreciated that some aspects are applicable from much earlier in the patient's illness and can be used in combination with disease-modifying or curative treatments. ^[5]
- Patients and their families may equate palliative care with imminent death and 'hopelessness' so this should be explained carefully. Similarly, hospices are seen as places for people to die and frightened individuals may turn down admission for intensive symptom control or respite.
- Promote the capacity of palliative care to alleviate suffering and improve quality of life.

Epidemiology

Each full-time GP will have an average of about 20 patient deaths per annum. Typically, 5 will be due to cancer, 5-7 organ failure (cardiac, renal, COPD), 6-7 through dementia, frailty and decline and 1-2 sudden deaths. ^[6] Palliative care will be appropriate to many more patients in their care (the average GP has 40 patients with cancer, for example) at any stage in the disease and treatment path from pre-diagnosis to bereavement or survivor support.

Palliative care provision remains uneven in the UK. The 2004 House of Commons Health Committee's 'Inquiry into Palliative Care in England' found:

- Gross inequality of access to hospice and other specialist palliative care services by diagnosis (95% went to people with cancer).
- National Institute for Health and Clinical Excellence (NICE) guidance on 'Supportive and Palliative Care for Adults with Cancer' ^[7] should be fully implemented and its underlying principles should be extended to develop palliative care for patients suffering other life-threatening conditions.
- Issues surrounding choice of place of death:
 - Between 50-90% of patients with cancer wish to die at home but only 22% achieve this. ^[8] Approximately a quarter of people express a preference to die in a hospice, but only 17% of those with cancer and 4% overall die there.
 - There has been a downward trend in home deaths, falling from 31 to 18% between 1974 and 2003. If the trend continues, under 10% of deaths will occur at home by 2030. ^[9]
 - Dying at home is associated with low functional status, an expressed preference (and carer agreement), home care and its intensity, living with relatives and dependable extended family support. ^[8]

Initiatives such as the End of Life Care Strategy ^[10] have been announced in response to such findings.

Palliative care provision in the UK

There are two distinct groups of health and social care professionals involved in providing palliative care:

- 'Nonspecialists' involved in day-to-day care and support of patients and their **carers** in their homes and hospitals. This group should be able to assess and meet the patient care needs under ordinary circumstances or to seek advice from/refer to specialist palliative care services in more challenging situations.
- Specialist palliative care providers (eg consultant palliative care physicians or nurse specialists). Delivery of care may be via hospice, day centres, hospital or community teams or telephone advice services. Specialist palliative care funding comes in part from the state and much from voluntary organisations, charities and local-fundraising. Only 35% of adult hospice income comes from the NHS.

Management

Supportive care

There is a reductionist tendency of doctors to consider palliative care as symptom control. Whilst good symptom control is vital, other nondrug aspects of palliative care may be equally as important to the patient and their family. Anyone facing a life-threatening illness will require supportive care in addition to specific treatment for their condition. Elements of such care include: ^[11]

- Self-help and education
- User involvement
- Information giving
- Psychological support
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- End-of-life and bereavement care

Living with cancer (or other life-threatening illness)

From a patient's perspective, common issues include:

- **Emotional adjustments** - psychological issues surrounding diagnosis, impact of disease and treatment, effect on relationships, 'getting back to normal' after treatment and worries about recurrence and the future are very common. Help may include support groups, counselling, stress management and relaxation courses.
- **Communication** - patients and their families often find it difficult to talk openly about their feelings surrounding illness and may individually or collectively seek help or an outsider to listen. Particular difficulties may be experienced talking to children about illness.
- **Symptoms and side-effects of disease/treatment** - palliative care has traditionally concentrated on managing disease symptoms; it can also help patients cope with side-effects of treatment such as chemotherapy or radiotherapy.
- **Sex and sexuality** - sexual problems are common, often due to direct effects of the disease or its treatment, fatigue, anxiety or depression, altered body image and loss of self-esteem. Issues of fertility may also be important.
- **Work**^[12] - 100,000 people of working age are diagnosed with cancer in the UK every year. Many fail to get appropriate advice and support to help them remain or return to work.
- **Dietary advice** - loss of appetite, weight loss and the desire for good nutrition are all common.
- **Travelling** - this can become more complicated and patients may need help with practical matters such as assessing fitness to travel, advice on taking medications and seeking medical help abroad, and problems obtaining travel insurance.
- **Mortgages, pensions, loans and insurance** - developing a life-threatening illness usually impacts on one's financial position and help may be required to navigate financial services, whether claiming on previously held insurance policies or covering outstanding mortgage or loan payments. Having had such an illness, obtaining cover in the future may also be more problematic.
- **Financial support** - money concerns can often become very pressing and help can come from government **benefits** or charitable grants.

Best practice in community palliative care

Good primary care is about caring for individuals from 'cradle to grave'. Providing good palliative care to individuals in the community can be one of the more demanding but ultimately satisfying parts of a GP's job. The multidisciplinary team can be large and, most often, the district nurses are the key players in orchestrating services around an individual's changing needs. In addition to the standard primary healthcare team, specialist community palliative care teams' input may be sought - services may include hospice at home, respite admissions, Macmillan nurse specialists, Marie Curie nursing and day centres. However, the 'team' may be even broader encompassing:

- Informal carers (family, friends, neighbours, volunteers)
- Privately provided nurses or carers assisting the family
- Voluntary organisations and patient groups (may be accessed via the internet or local centres, where available, providing information and support)
- Counsellors, therapists (art and music therapy are used widely in palliative care), psychologists and psychiatrists (some may specialise in palliative care, eg psycho-oncologists^[13])
- Dieticians, occupational and speech therapists
- Complementary therapists (eg massage, **acupuncture**)
- Religious and spiritual care workers
- Social workers and benefit advisers

Guidance to improve community palliative care has come from a number of sources over the last decade, including NICE [7] and the Gold Standards Framework. [14] Key messages include:

- Patients with palliative care needs are identified using common criteria and management plans instituted after discussion with the multidisciplinary team.
- Regular assessment of patients and carers using validated assessment tools.
- Anticipated needs should be planned for.
- Patient and carer needs are communicated within the team and to specialist colleagues, where appropriate.
- Preferred place of care and death are openly discussed and noted and measures made to facilitate an individual's preferences where possible.
- There should be a named person within the primary care team to co-ordinate care.
- Relevant information should be available to out-of-hours carers, and drugs that may be needed should be left in the home.
- Care in the dying phase should follow a protocol, such as the Liverpool Care Pathway (LCP) for the dying patient, [15] to ensure that no aspect is overlooked.
- Carers should be involved, educated and supported to care for their loved ones in the ways they choose. Information is critical - whether medical, financial or on **bereavement support**.
- Audit, reflective practice, developing practice protocols, etc. are encouraged in order to promote individual and organisational development.

Implementation has been variable and further work is needed to assess direct impact on patients and carers. [16] Similarly, a recent Cochrane Review pointed out that whilst end-of-life care pathways (such as the LCP) are routinely used around the world, there have been few systematic studies providing good supportive evidence. [17]

The Qualities and Outcomes Framework (QOF) for 2009-2010 has also included two indicators for palliative care (each worth 3 points) requiring a practice to have: [18]

- A complete register of all patients in need of palliative care or support, irrespective of age.
- Regular (at least 3-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

Spiritual care

When confronted with serious illness, spiritual needs become more important and patients and carers consistently attach more importance to spiritual wellbeing than doctors. Providing spiritual care in a secular society is challenging, particularly to doctors and nurses trained in a biomedical model, who may feel out of their depth when confronted by spiritual needs. Most healthcare professionals have received no training in spiritual care - we find it difficult because it requires us to shift from the problem-solving, solution-finding approach that we apply to the rest of our jobs.

Spirituality is difficult to define but relates to the need we all have to make sense of the world and our experience of it. The 'soul' or 'spirit' creates internal resources that can sustain, motivate and transform an individual's experience of life. A common misunderstanding is that spirituality and religion are synonymous. Religion is actually a belief system linked to rituals and practices that may help some people to better spiritual understanding. Spiritual needs common to all are the need for love and meaning. Kindness, compassion and deep listening are the core skills for providing spiritual care and are those most appreciated by patients and their families.

Self-care [19]

Providing palliative care can be very demanding, particularly when it involves: [20]

- Complex needs
- Multiple visits
- Insufficient time or resources
- Challenging symptoms
- Lack of open communication about disease and prognosis

In order to provide good palliative care, we need to care for ourselves and our colleagues. A study of some American primary care doctors showed that their main methods for sustaining wellbeing were:

- Time with friends and family
- Religious or spiritual activity
- Self-care
- Finding meaning in work but also setting boundaries around it
- A positive-thinking outlook

It is also important to ensure that support is available within the practice team or from another professional when things are difficult. Deeper emotional insight into our practice can be fostered by personal development work, coaching, mentoring, Balint or other support groups.

Further reading & references

- [Treatment and care towards the end of life: good practice in decision making](#); General Medical Council, May 2010
 - [wIPADS Advance Care Planning](#); Palliative Care in Wales
 - [Marie Curie Cancer Care: Delivering Choice programme](#); Nationwide programmes to support patient choice to die at home
 - [Caring for someone who is terminally ill](#), Directgov
 - Sue Ryder
 - [Macmillan Cancer Support](#)
 - [Cruse Bereavement Care](#)
 - [Dame Cicely Saunders OM](#); Daily Telegraph Obituary
 - [Cancer counselling trust](#)
 - [The Balint Society - Balint groups](#); The aim of the Society is to help general practitioners towards a better understanding of the emotional content of the doctor-patient relationship.
 - [Maggie's](#); UK centres supporting cancer sufferers and their families; usually situated close to major treatment centres
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