Palliative Care

See also the separate Helping Patients Face Death and Dying, Looking after People with Cancer and End of Life Care articles.

Definitions and aims of palliative 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.

Aims of palliative care[1, 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.

The National Institute for Health and Care Excellence (NICE) defines palliative care as: "The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support are paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments."[3]

Many continue to be fearful of palliative care since they wrongly consider it synonymous with end-of-life 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 21st 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."[2]

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 co-existence 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. The WHO definition above goes on to add that palliative care “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 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. Health professionals can promote the capacity of palliative care to alleviate suffering and improve quality of life.

Epidemiology

Around 1% of the population die each year, so a GP with a list size of 2,000 patients will have an average of about 20 patient deaths per annum. The majority of these should be predictable. 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. 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 2015 House of Commons Health Committee’s report into end-of-life care found great variation in quality and practice across both acute and community settings. Other conclusions included:

- 24-hour access to specialist palliative care in hospitals and the community would greatly improve treatment of people with life-limiting conditions and their families, and their expertise should be more equitably available to those with a non-cancer diagnosis.
- In 2013 80% of those who died were people aged over 65. One third of all deaths are people aged 85 and over, but only 15% of those who receive specialist palliative care are in this age group.
- The current situation is unlikely to improve unless clinicians feel confident to identify people who may be near the end of life and to start conversations with their patients about their wishes. The large majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia, so predicting and planning should be achievable.
- Most people who express a preference, would like to die at home but that is made more difficult by the shortfall in community nurses and specialist outreach palliative care in addition to the lack of early identification allowing proactive care.
- 53% of deaths occur in NHS hospitals, with around 21% occurring at home, 18% in care homes, 5% in hospices and 3% elsewhere, even though 63% of people say that they would prefer to die at home, while 29% would prefer to die in a hospice.

Palliative care provision in the UK

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

- ‘Non-specialists’ 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

Whilst good symptom control is vital, other non-drug 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:

- 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-limiting 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** - 750,000 people with cancer in the UK are of working age[9]. Many fail to get appropriate advice and support to help them remain in 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 - e.g., psycho-oncologists[10]).
- Dieticians, occupational and speech therapists.
- Complementary therapists (e.g., 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 period of a decade, including NICE and the Gold Standards Framework[3, 4]. 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 locally approved protocol for the dying patient, 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[11]. Similarly, a recent Cochrane Review pointed out that whilst end-of-life care pathways are routinely used around the world, there have been few systematic studies providing good supportive evidence[12].
Further reading & references

- The Qualities and Outcomes Framework (QOF) over recent years has also included indicators relevant for palliative care for example, requiring a practice to have:\[13\]
  - A complete register of all patients in need of palliative care or support, irrespective of age.
  - Regular (at least three-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.
  - A register of patients diagnosed with cancer, and a requirement to have reviewed them within six months of diagnosis.

Spiritual care

When confronted with serious illness, spiritual needs become more important and patients and carers consistently attach more importance to spiritual well-being 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

Providing palliative care can be very demanding, particularly when it involves\[14\]:

- 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 well-being were\[15\]:

- 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.

Palliative care work puts professionals at risk of stress and burnout.\[16\] No intervention has been found convincingly to prevent this, and one meta-analysis of studies in this area concluded further research is urgently needed\[17\].

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Document ID: 7213 (v5) Last Checked: 29/01/2019
Next Review: 28/01/2024

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