

The principles of palliative care

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The development of palliative care

Introduction

This chapter explores the history and development of palliative care from the early days of the hospice movement through to the development of specialist palliative care and end of life care. It will track the extension of palliative care beyond cancer diagnosis, which is underpinned by the principle of provision of care according to need, not diagnosis. The differences between palliative care and other areas of care will be explored. The provision of palliative care for patients in minority groups is considered as well as the policies and strategies that have shaped the development of the speciality.

Learning outcomes

By the end of this chapter you will be able to

- identify key events in the development of hospice and palliative care;
- describe palliative care and specialist palliative care;

(continued)

Learning outcomes *(continued)*

- identify the key principles of palliative care;
- discuss the provision of palliative care across care settings;
- discuss the extension of palliative care services beyond cancer diagnosis;
- discuss some of the challenges facing hard-to-reach groups requiring palliative care.

What is palliative care?

Simply put, palliative care ‘focuses on the relief of pain and other symptoms and problems experienced in serious illness. The goal of palliative care is to improve quality of life, by increasing comfort, promoting dignity and providing a support system to the person who is ill and those close to them.’ (dying matters 2012).

Since the development of St Christopher’s hospice in 1967, the growth of palliative care has been driven by charities, health care providers and government policy. The significant early developments and key policies are presented in Figures 1.1 and 1.2.

Cicely Saunders the founder of the modern day hospice movement was driven by a profound Christian faith and a fundamental belief that ‘You matter because you are you, and you

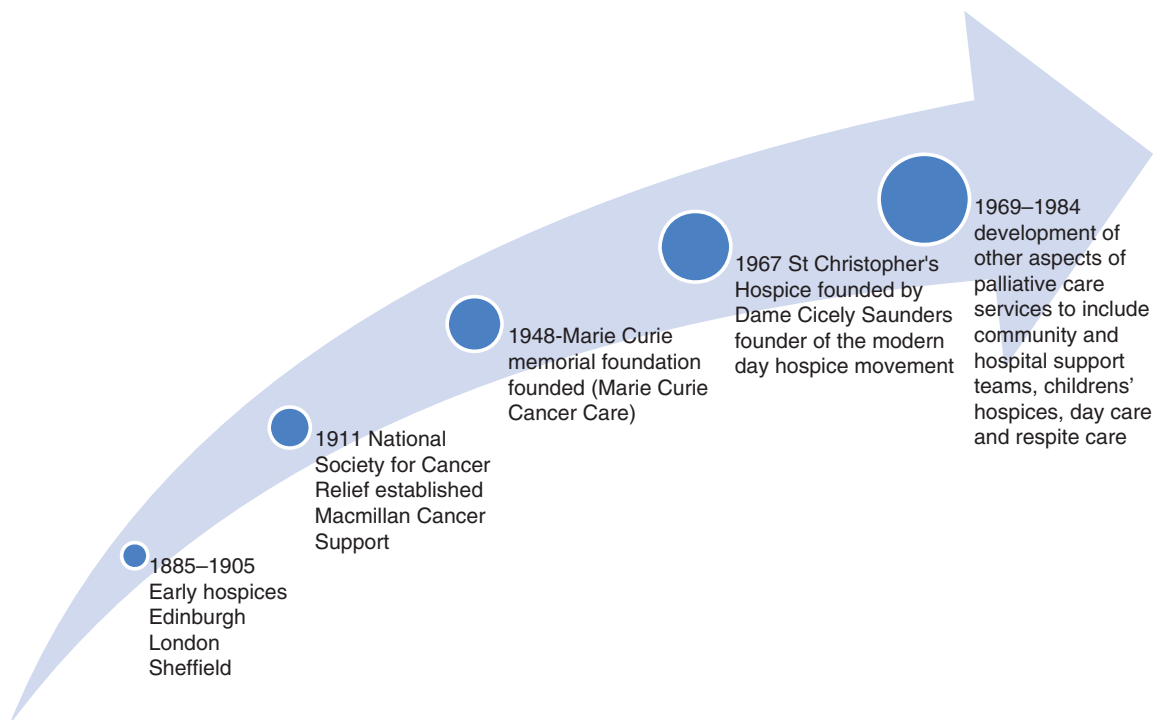


Figure 1.1 The early development of palliative care services in the United Kingdom.

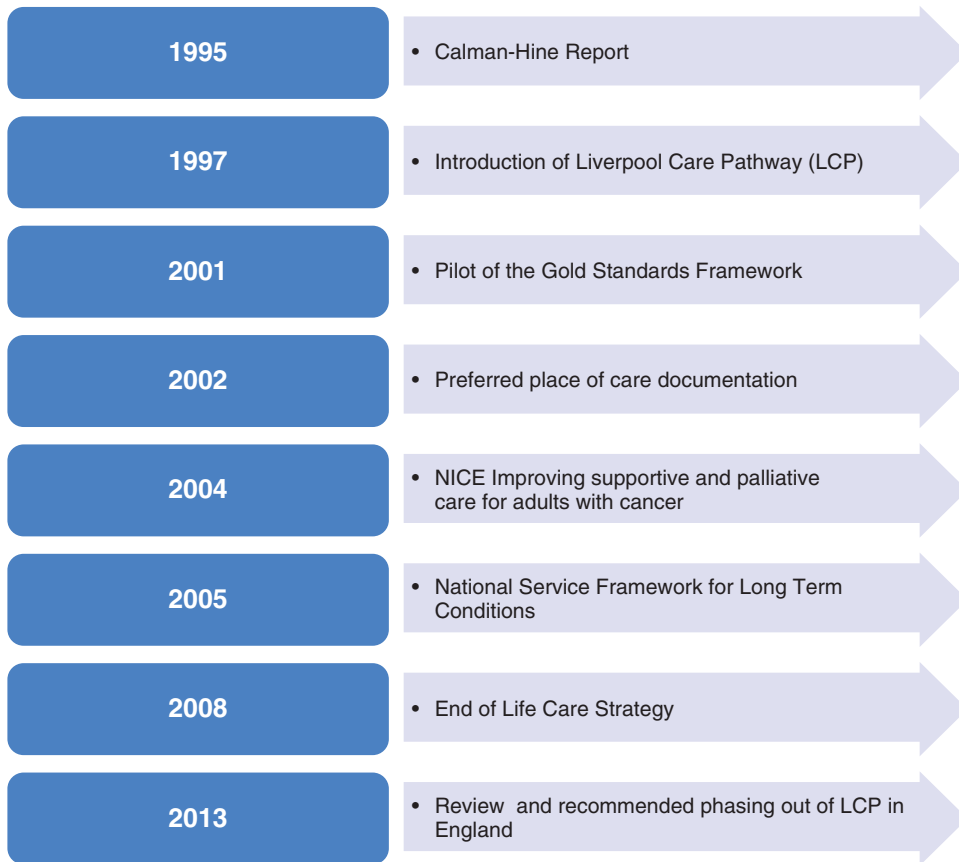


Figure 1.2 Key policy developments in palliative care in the United Kingdom.

matter to the last moment of your life'. Whilst the influence of religion has diminished over time the central belief of the value of people is paramount to palliative care. Today there are over 200 inpatient units and palliative care is provided in a number of other care settings, including hospitals, the community and day care centres. Most hospices are independent, local charities, only receiving a minority of their funding from the NHS.

There are a number of definitions relating to the provision of palliative care and each is discussed in the following text.

Supportive care

Palliative care has come to be regarded as part of supportive care formally introduced by the National Institute for Clinical Excellence (NICE) in 2004. Supportive care describes all care provided to patients, friends and family throughout their illness, including the time before diagnosis has been reached, when patients may be undergoing a number of investigations. The aim of supportive care is to help the patients and their families to cope with their condition and treatment. It helps the patient to maximise the benefits of treatment and to live as well

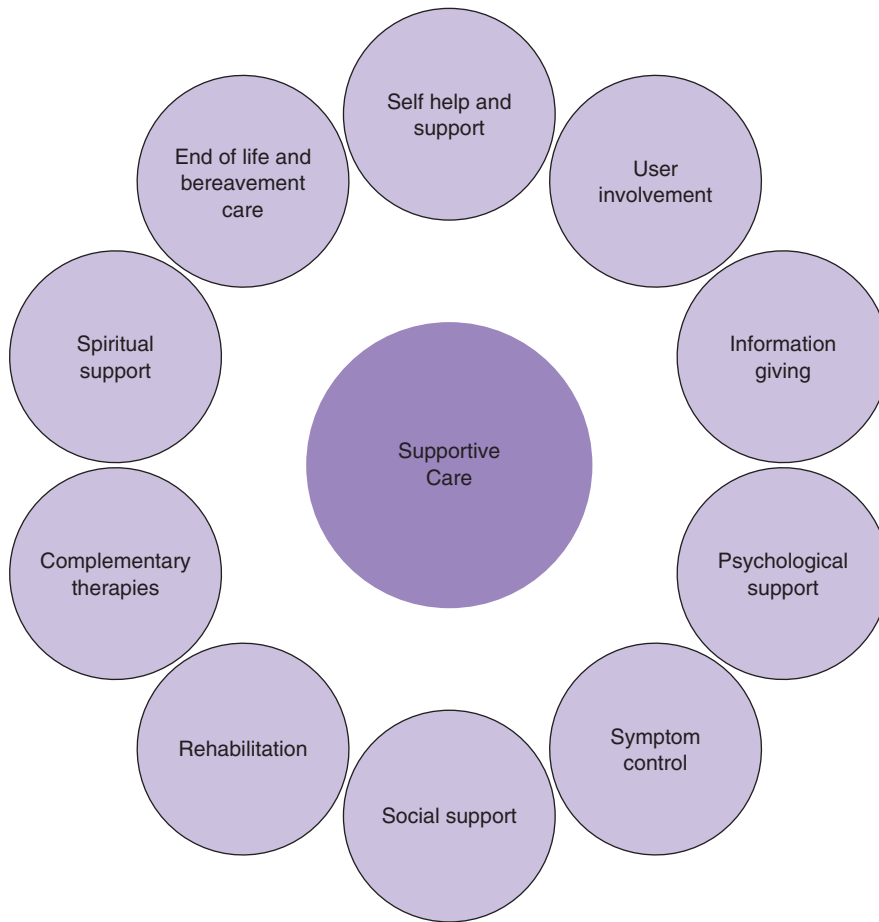


Figure 1.3 The components of supportive care.

as possible with the effects of the disease (National Council for Palliative Care (NCPC) 2010). Figure 1.3 shows the components of supportive care.

Palliative care

Palliative care is defined in Fact Box 1.1.

Fact Box 1.1

The World Health Organization (WHO) (2014) defines palliative care as:

‘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.

The WHO principles of palliative care are listed in Fact Box 1.2:

Fact Box 1.2

The principles of palliative care

WHO principles of 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.

These principles highlight an holistic, humanistic approach to caring for the whole person throughout their illness, rather than focusing on the disease or condition. Palliative care responds to the changing needs of the patient and family over time, recognising that the disease progression and the associated experiences are unique to each person.

Specialist palliative care

As the palliative care movement developed and grew there was an expressed need to differentiate between palliative care and specialist palliative care to ensure that patients and their families were receiving the most appropriate care. It was acknowledged that a minority of people with complex needs would require direct or indirect input from specialist teams, identified as 'those services with palliative care as their core speciality with a high level of professional skills from trained staff and a high staff: patient ratio' (NCHSPCS, 1995).

Once the differences between palliative and specialist palliative care had been established there was an expectation that everyone living with a life-threatening illness was entitled to receive appropriate palliative care regardless of health setting; therefore, each health professional has a duty to practice the palliative care approach as an integral component of good clinical practice, referring to specialist palliative practitioners when necessary (NCHSPCS, 1997).

End of life care

As the meaning of palliative care has developed beyond care provided for those who are dying it became necessary to coin a new definition – 'end of life care'. This is acknowledged

by the Department of Health (2008) as care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

Where is palliative care provided?

Palliative care services have extended far beyond the hospices of the early movement (Figure 1.4).

As stated by NCHSPCS (1997) fundamental palliative care should be provided by the patient's primary carers, be it the ward teams or the district nurses or GPs. Specialist palliative care practitioners may be involved in the management of more challenging situations such as complex pain or symptom problems or complex psychological needs or family dynamics. Specialist practitioners should withdraw once the problem has settled or if the patient is admitted for specialist palliative care. Nowadays, hospices are used for specialist palliative care rather than respite, which was not the case in the early days. Respite is often provided by nursing homes, or by Marie Curie nurses who provide periods of respite overnight or during the day in the patient's home. Hospice at home teams may become involved towards the very end of the patient's life to enable them to die at home.

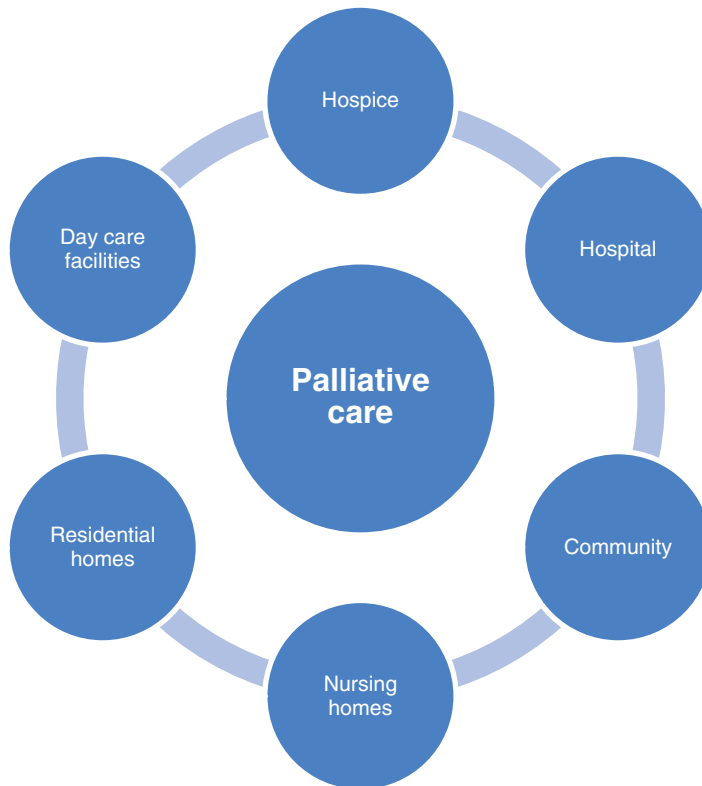


Figure 1.4 Sites of palliative care provision.

Widening access

Activity 1.1

- Make a list of people/patient groups who you have seen receive palliative care nursing
- Make a list of other people who you think might have unmet palliative care needs
- Why do you think this might happen?

Traditionally, palliative care was only offered to patients with a diagnosis of cancer; thankfully in 1998 the government stipulated that the principles and practice of palliative care should become needs led, integral to NHS practices and available to patients, wherever they are, irrespective of diagnosis (DH, 1998). This belief is echoed in the National Service Frameworks (NSF); for example, it is noted that people with heart failure have a worse quality of life than people with most other common medical conditions. There is marked impairment of psychosocial function and over a third of people with heart failure experience severe and prolonged depressive illness (Lynn *et al.*, 1997, Sharpe and Doughty, 1998 both cited in DH, 2000). It is anticipated that most people dying from a non-malignant disease will require palliative care as opposed to specialist palliative care (O'Connor *et al.*, 2011).

In respect to widening access it is also important to ensure that palliative care is available to groups of people who have traditionally been marginalised in relation to the provision of palliative care. These include older people, those with learning disabilities and people from black and ethnic minorities.

Palliative care for older people

Demographics and an increase in long-term conditions and chronic diseases mean that there is a rise in the age of those requiring palliative care (Gardiner *et al.*, 2011). Older people tend to die from one of a few diseases:

- cancer
- cardiovascular
- cerebrovascular
- chronic lung disease
- dementia.

Advanced care planning is vital for older patients to enable them to express their wishes about the care they do and do not receive as their condition progresses. Many older people express an unfulfilled wish to die in their own homes, as most die in care homes or hospitals and a few die in hospices (Gomes *et al.*, 2011).

It is not clear why access to palliative care should differ according to age, but there seems to be a belief amongst some professionals that older people do not have the same palliative care needs as younger people. There is a persistent association between palliative care and cancer diagnosis and those dying from non-malignant diseases are not referred (Gardiner *et al.*, 2011). Health care professionals need to acknowledge that older people have the same palliative care needs as others and should seek out education about caring for older people with palliative care needs.

Challenges increase when providing care for an older person living with dementia. People living with dementia experience symptoms similar to people living with cancer, and experience them for a longer period (WHO, 2011). People living with dementia do not receive adequate palliative care, either because of problems of confirming prognosis or inadequate professional perception of palliative care needs. Communication is difficult which makes assessment and management of symptoms challenging. Advanced care planning needs are to be initiated early on in the disease process (WHO, 2011). Guidelines for the management of symptoms such as agitation, constipation and pain have been introduced on a small scale with some benefit (Lloyd Williams and Payne, 2002)

People living with learning disabilities

People living with learning disabilities experience a number of health inequalities (Emerson and Baines, 2010).

People with learning disabilities are one of the most socially excluded groups in Britain. With poorer health than the general population, they face specific challenges when trying to access end of life care. While people with learning disabilities have more similarities to the rest of the population rather than differences, they cannot access services as easily. Problems of access include challenges of

- lack of awareness of the need for palliative care for the person or their carer;
- lack of confidence of palliative care providers to work with people having learning disabilities;
- informed consent;
- communication – good communication is the key to effective end of life care, yet 50%+ of people with learning disabilities have communication impairment;
- interpretation of behaviour;
- uncertainty of how to raise sensitive issues with people having learning disabilities.

Read and Morris (2008)

Clear communication with family, friends and familiar carers is the key in order to gain information about the person. Carers need to be made aware of when illness or deterioration might be suspected and advised to contact their GP if concerned. Health care professionals need to work at developing creative ways of communicating openly and honestly with people with learning disabilities so that they understand as much as possible and are empowered to make informed choices. This can be achieved by working with the family or familiar carers. Consent, mental capacity and the person's best interests need to be assessed.

Black and ethnic minorities

There is an acknowledged need to extend racially and culturally sensitive palliative care services to the minority ethnic communities, who, because of a lower incidence of most cancers, have historically been unfamiliar with palliative care services. Professional perceptions of how the minority ethnic families respond to life-limiting illnesses have compounded underuse of palliative care service. There is a belief that families care for their own relatives. Whilst the incidence of cancer may be lower in the minority ethnic groups there are a number of

life-limiting diseases such as heart and cardiovascular diseases experienced by these groups. There is a clear need for palliative and specialist palliative care (Gunaratnam, 2007). In order to promote equity of timely access to appropriate services, care for these groups should mirror that of the other groups and be informed by the same frameworks and pathways. It is important to promote sensitive responsive services, through working with relevant bodies (Gunaratnam, 2006).

The changes in the focus and provision of palliative care have partly been influenced by government reports and related strategies. These have shaped the development of services since the early days.

Influential documents and strategies

The first attempt to rationalise and coordinate cancer services was through the Calman Hine report (Expert advisory group, 1995) in which it was recognized that palliative care needed to be integrated with other aspects of cancer care. It raised the difference between generalist and specialist palliative care, identifying that both were equally important. These recommendations were adapted by each of the four nations to meet a more local need, for example, the Cameron report (Welsh Office, 1996).

The focus on cancer care has been perpetuated by the NICE guidelines for supportive care (2004) but aspects of these have been adapted to fit non-malignant conditions (NCPC, 2010).

Gold Standards Framework (GSF)

This framework was introduced in 2000 to enable primary care practitioners to improve the supportive and palliative care offered to patients with any end stage illness (Thomas, 2003). It is a systematic evidence-based approach to optimising the care delivered by general health care practitioners to patients nearing the end of their lives. The framework is now used by many practitioners to improve the quality and co-ordination of care provided in a number of settings and aims to enable people to die comfortably in the place of their choice. The GSF has been introduced to a number of different settings including care homes, acute hospitals, community hospitals and prisons and is supported by a comprehensive programme of education, resources and audit. The framework has continued to develop around the seven C's of the community GSF which are the key tasks of patient care (Figure 1.5)

End of life care pathways

The first end of life care pathway introduced was the Liverpool Care Pathway (LCP) which was introduced in England to ensure the delivery of appropriate, evidence-based holistic care for hospital patients in the last days of life. This pathway was also adopted in Scotland and Northern Ireland. Wales developed its own pathway – the All Wales Integrated Care Priorities for the Last Days of Life.

The LCP was developed to facilitate optimal care to dying patients, who were not being cared for in a hospice. It initially focussed on care in the acute sector and was then rolled out into all care settings. In many cases use of the LCP approach to end of life care ensured that patients received appropriate treatment and had a dignified, peaceful death. Unfortunately over the past few years it would appear that implementation of the LCP has not always been appropriate or

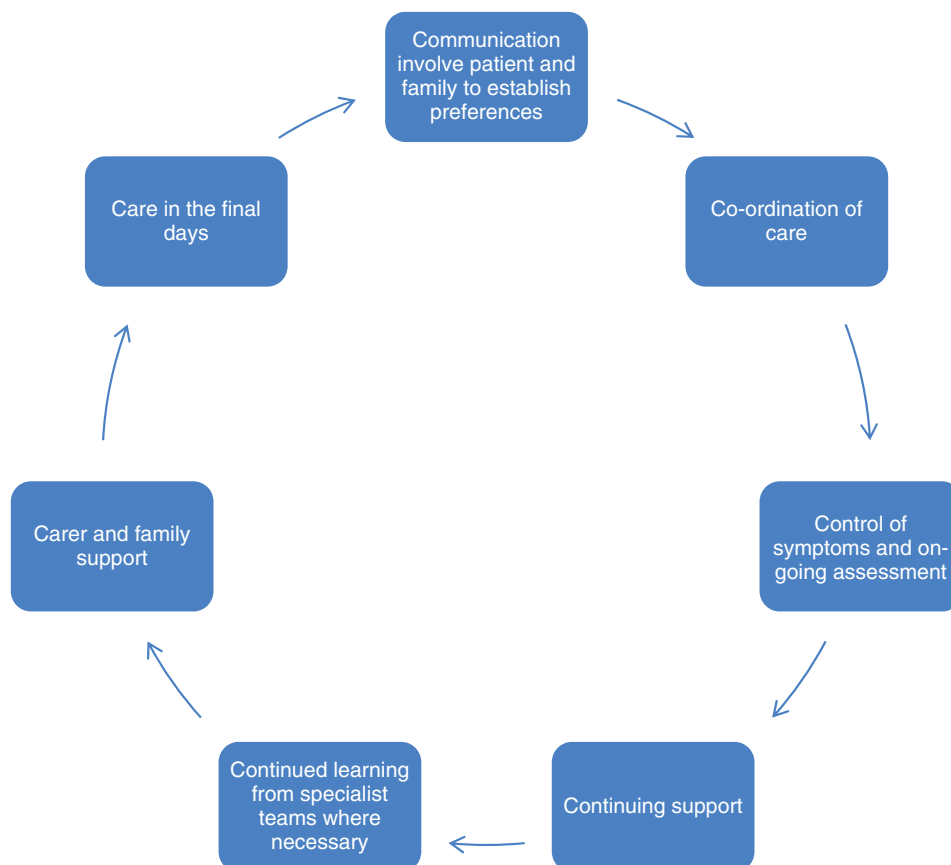


Figure 1.5 The key tasks of patient care (GSF, 2012).

correct because of practitioners' lack of understanding of the approach to care, poor communication skills and lack of knowledge about end of life care. Increasing concerns from media, carers, relatives and professionals over the past couple of years led to a review of the use and experience of the LCP in England.

Concerns highlighted in the review related to perceptions around

- premature/inappropriate withdrawal of nutrition and hydration;
- hastening of death through excessive use of opiates or sedation;
- poor communication about patient's deterioration and prognosis;
- lack of professional compassion, respect, care and knowledge.

The review panel reviewed verbal and oral evidence of care relating to use of the LCP (Department of Health, 2013) and made 44 recommendations. The review found great disparity in the quality of care provided to patients in the LCP:

It would seem that when the LCP is operated by well trained, well-resourced and sensitive clinical teams, it works well.

Where care is already poor, the LCP is sometimes used as a tick box exercise, and good care of the dying patient and their relatives or carers may be absent.

DH (2013: p. 3)

The overarching recommendation was that:

Use of the Liverpool Care Pathway should be replaced over the next 6–12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.

DH (2013, p. 10)

This recommendation was underpinned by others, advocating that

- senior clinicians are involved in any clinical decision making and in discussing end of life decisions with relatives and carers, and documenting that discussion;
- all professionals receive education, training and professional development in end of life care;
- The Nursing and Midwifery Council issues guidance for nurses on good practice in decision making in end of life care;
- named nurses and doctors take responsibility for patient care.

Whilst these recommendations currently apply only to England, it is likely that Scotland and Northern Ireland will review their use of the LCP. Guidance has been issued to guide practice during the re-organisation of end of life care (NCPC, 2013). While the LCP will be phased out it is important that the key principles of end of life care advocated by the end of life care strategy are incorporated in the care plans for patients.

End of Life Care Strategy

This strategy was launched in 2008 with the aim of increasing accessibility to high quality care for all people approaching the end of their life. The strategy, which currently only relates to care in England, is informed by key initiatives such as GSF, advanced care planning and preferred priorities of care. The central tenets are enhanced choice, quality, equality and value for money informed by 10 objectives (DH, 2008):

- increased public awareness and discussion of death and dying;
- people to be treated with dignity and respect at the end of their lives;
- to ensure pain and suffering are minimised and optimal quality of life maintained;
- all people to have access to physical, psychological, social and spiritual care;
- individual needs, priorities and preferences for end of life care to be identified, documented, reviewed, respected and acted upon wherever possible;
- services well coordinated to ensure seamless service;
- high quality care to be provided in the last days of life and following death, in all settings;
- carers to be supported during a patient's illness and after their death;
- health and social care professionals receive the necessary education and training to enable them to provide high quality care;
- services to provide good value for money for the tax payer.

Conclusion

Since the time St Christopher's hospice was opened by Cicely Saunders palliative care has never stopped developing. A number of key policies have shaped the growth and direction of services. There are a number of voluntary and charitable organisations committed to the provision of the best quality palliative care. Supportive and palliative care can be provided in any care setting by well educated health care professionals providing good fundamental care. Specialist palliative care teams may become involved to help care for patients who are faced by complex situations or experiencing symptoms which are particularly hard to resolve. Supportive and palliative care is no longer restricted to patients living with cancer, care must be available according to need, not diagnosis and clear strategies need to be introduced in order to guarantee equity of access for traditionally marginalised groups.

Glossary

Advanced care planning

Documented discussions between patients and professionals to enable patients to express their preferences for their care in the final months of life.

End of life care

Care that helps all those with advanced, progressive and incurable illness to live as well as possible until they die.

Palliative care

The active, holistic care of patients with advanced progressive illness in order to achieve best possible quality of life for patients and their families.

Specialist palliative care

Specialist care provided to a minority of people with complex needs.

Specialist palliative care team

Teams with palliative care as their core speciality, with high level of professional skills and a high staff patient ratio.

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