Chapter 1
Historical and cultural perspectives on the evolution of palliative care

KEY POINTS

- **Introduction**: palliative care is one of the success stories in the health service. In a death-denying society, as a result of work in the hospice movement, good-quality palliative care is now high on the government’s agenda.
- **Death in society**: as health care has improved, death has been marginalised. Today society grapples with Victorian Romanticism, which portrays death of a loved one as unbearable, and twentieth-century denial, which sees death as a failure (Aries 1983). Death is a normal part of living.
- **Dame Cicely Saunders and the origins of contemporary palliative care**: Dame Cicely became a doctor with the intention of making a difference to the quality of dying for cancer patients. Her remarkable story has led to the modern-day organisation and approach to the care of people who are dying.
- **An international perspective**: international networking and some of the initiatives that exist to keep palliative care high on the international agenda are explored.
- **Definitions**: these shape our attitude and approach to the work that we do. Current definitions are presented and some discussion is raised about their implications. Definitions should implicate the patient’s role. When they do not, are they disempowering? A health-promoting approach is encouraged.
- **End-of-life care**: the End-of-Life Programme examines current initiatives concerned with providing equity, continuity and choice to patients who receive palliative care. The tools used for this are the Gold Standards Framework, Preferred Place of Care initiative and Liverpool Care Pathway.
- **Culture**: in a multicultural society information about, and access to, palliative services among many minority ethnic groups cause some concern. Aspects of research in this area are highlighted. The tensions that can exist in professional roles as a result of dominant philosophical approaches are discussed.
- **Service user involvement**: recent legislation has set the scene for service users to be involved at all stages in shaping services. It is hoped that this will lead to less need for patient groups taking an adversarial role. Local initiatives in involving service users are important.
INTRODUCTION

This first chapter aims to provide a historical and cultural perspective on the evolution of palliative care; it then goes on to describe and discuss definitions and frameworks for the delivery of contemporary palliative care. The twentieth century heralded enormous advances in medical science and the introduction of the National Health Service. The health of the nation’s people was being valued as never before. Diagnosis, cure and health promotion dominated in this new health-care system. Death was marginalised. Intellectually we all know that we are going to die, but emotionally perhaps we deny this. Possibly this is why health-care professionals have, over the years, failed to give good end-of-life care. Dying is not a dress rehearsal.

In the middle of the twentieth century Dame Cicely Saunders and other committed colleagues, both in this country and around the world, challenged a death-denying health-care system. The hospice movement was born. Palliative care is considered to be one of the great success stories in health care over the past 40 years. The challenge now is to continue to transfer and embed what has developed in the hospice sector into the mainstream NHS (Ellershaw and Murphy 2005).

The document Building on the Best: Choice responsiveness and equity in the NHS (Department of Health or DH 2003a) highlighted that patients and carers want choice over care at the end of their lives. In another recently published government report, Our Health, Our Care, Our Say: A new direction for community services (DH 2006), there was recognition that more investment is needed in end-of-life care and a statement to endorse an earlier call that is relevant to increased expenditure. The government is on board; the scene is set; provision of a high-quality palliative care service is the remit of every health-care professional working in all areas of health care.

DEATH IN SOCIETY

Historical perspective

Advances in public health, e.g. understanding infection control, the importance of clean water and the introduction of immunisations for all, have meant that, since the second half of the twentieth century, the death of children and young adults is rare. It is over 60 years now since the end of World War II. In this country we have a society that is less ‘used’ to death than ever before. In line with many parts of Europe, North America and Australia, death now is less often sudden and unexpected, and more often associated with chronic disease of long duration (Clark 2004).

Political initiatives over the past 20 years have encouraged people to take greater charge of their own health, e.g. Promoting Better Health (DH 1987) and The Health of The Nation (DH 1991a). Against this backdrop and a continuing focus on health promotion, coupled with the media’s almost obsessive preoccupation with the ‘body beautiful’, it probably makes it emotionally more difficult now, than ever before, to accept ill health and dying. Conversely the efficiency of the media can make us witness to the atrocities of violent death in our own society and around the world, sometimes on the scale of genocide. Deaths from famine, natural disasters and
manmade disasters are also brought to our attention all too regularly. It is impossible to make a blanket statement on what effect this dichotomy may have on each person’s attitude to mortality.

Sociologists have been commenting on the depersonalisation of death for some years. They identify a process in which the care of those who are dying and of death has been taken out of the hands of family and friends, and put into the hands of health-care professionals and funeral directors. With this process, the customary mourning practices have disappeared (Gorer 1955; Aries 1983; Walter 1994; Clark 2005b). Gorer (1955) pinpoints the beginning of the end of mourning customs to World War I, when the magnitude of the number of deaths and the need to keep the war effort going hindered mourning.

Spiritual care

Historically the spiritual care of those who are dying was of paramount importance and this was often portrayed in literature by the clergy, who had a predominant role at the deathbed. The events of World War I diminished the role of spirituality in dying, according to Walter (1994). In a Christian religious context, absolution from sin before death represents spirituality. Who would not absolve a soldier dying in terrible circumstances for his country? There was a sense of the clergy feeling humbled and inadequate. Doctors and public health workers have supplanted priests at the bedside of those who are dying (Walter 1994). Although we know that a person’s spirituality does not necessarily exist in a religious context, it has been represented by clergy in the formal structure of society.

Today society grapples with the influence of Victorian Romanticism which portrayed the death of a loved one as unbearable and twentieth-century denial that sees death as a failure (Aries 1983). Gorer’s (1955) statements about a society that reports death daily and proliferates media and journal articles about death, also being a society that finds it difficult to talk about their own personal grieving seem as relevant now as they did then.

DAME CICELY SAUNDERS AND THE ORIGINS OF CONTEMPORARY PALLIATIVE CARE

Historically contemporary palliative care services are embodied within the hospice movement, which was launched by the opening of St Christopher’s Hospice (a registered charity) in Sydenham, south London on 24 July 1967. This was the first teaching and research hospice of its kind in the world. The founder of the hospice movement was Dame Cicely Saunders. Dame Cicely, first a nurse and then a social worker, trained in medicine with the sole intention of challenging the dominant model that valued cure at the expense of being responsive to the individual experiences of those who are dying.

In the 1950s, around the world about a dozen homes had been set up as charities to care for dying people. It was while working as a volunteer in one such home, St Luke’s Hospital in Bayswater, that Dame Cicely witnessed pain being controlled
much more effectively than in general hospice wards, and ‘much more besides’. At this time she worked as an almoner at St Thomas’ Hospital. She spoke to the surgeon for whom she worked about this. He told her that there was much more to learn about pain and that she would only be frustrated in any efforts to make a difference unless she was a doctor. It was then that she decided to enter medical school and he helped her with this (Clark 2006).

A patient, David Tasma, who died of cancer in London’s Archway Hospital in 1947, has been credited as being the inspiration for Dame Cicely’s work with dying people (Clark 2006). He was a young man who had been in the Warsaw Ghetto. Cicely, as an almoner, was drawn to him and their relationship intensified ‘into a fragile loving friendship’ (Clark 2006). The two discussed the idea of creating more ‘home like’ places where people could die. David had said to her, ‘I want only what is in your mind and in your heart’. Clark (2006) describes this combination of emotion and intellect as being the guiding theme in her subsequent work. David Tasma left Dame Cicely £500 in his will, saying that ‘I’ll be the window in your home’. In her Templeton Prize speech, given in 1981, Dame Cicely said:

Here was a commission from a dying man who felt he had made no impact on the world, a commission to give meaning to his life by creating a home dedicated to openness and to the balance of mind and heart, of skill and friendship.

Saunders in Clark (2006, p 158)

It was a momentous achievement that 19 years later St Christopher’s was opened. Dame Cicely has described it as building the home around the window (Clark 2006, p xvi).

For the first 18 years of its existence Dame Cicely was the medical director at St Christopher’s. During this time she developed a home care service and a specialist education unit. She continued to research pain control and the effectiveness of the hospice. She was well known for her international lecture tours and she regularly published – some 220 works in total. She also taught in the education unit. She left no stone unturned. On a study day I ran recently a delegate described how Dame Cicely had visited her primary school in south London to explain the work of the hospice. She remembers it as having death explained clearly to her and fear being removed.

Notably her writings are almost always firmly grounded in practice. In her paper on the treatment of intractable pain, she writes of keeping analysed detailed records of 900 patients who had died (Saunders 2006a). She regularly tape-recorded interviews with her patients in order that she could reflect on their descriptions of physical pain and their experiences of facing death. Many of her earlier articles, in particular, are based on case histories.

Other palliative pioneers

Dame Cicely is not the only person responsible for palliative care becoming part of mainstream medical and health care. Many have made valuable contributions, but notably Eric Wilkes, Robert Twycross, Neil MacDonald, Derek Doyle, Elisabeth Kübler-Ross, Balfour Mount and Colin Murray Parkes and, I’m sure, many others
working on both sides of the Atlantic. Significant landmarks that can be attributed to their efforts are the General Medical Council according palliative medicine a specialist status in 1987 and the inception of the National Council for Specialist Hospice and Palliative Care Services shortly afterwards, which, from 2004, has been known as the National Council for Palliative Care (NCPC). It is important now to stop seeing hospices as buildings and to see them rather as representing a philosophy of care.

Future challenges

One challenge for the future is to continue to develop a palliative approach in all health-care settings – in hospitals, care homes and at home. In *Building on the Best: Choice, responsiveness and equity in the NHS* (DH 2003a) it is highlighted that patients and carers want choice over end-of-life care. The End-of-Life Programme (NHS Confederation 2005) is committed to taking forward training programmes, so that all adult patients nearing the end of life will have access to high-quality palliative care. One aim of the programme is that people will have a choice about where they die. This initiative is being managed by strategic health authorities (SHAs).

The second future challenge is concerned with the considerable body of knowledge and research that has built up over the years. Historically this is embedded in cancer care because this is where it all began. We need to continue to examine and, where appropriate, transfer knowledge and evidence accrued in cancer care to the care of people with all other life-threatening illnesses. It is also important to keep developing the evidence base for all aspects of care. How far things have come since Dame Cicely first met David Tasma in 1947.

The National Council for Palliative Care

It is appropriate here to look at the aims of the NCPC and what the provision of specialist palliative care services in the UK is at this time. The NCPC aims to:

- identify and develop policy proposals that enable improved palliative care and wider access to this
- influence the policies of the governments in England, Wales and Northern Ireland to this end
- identify good clinical practice management and disseminate.

The strategy is (NCPC 2005a):

- to promote improvement in the quality and availability of palliative care to patients with cancer, their families and carers
- to promote the extension of palliative care to patients with other life-threatening conditions, their families and carers.

The current provision of specialist palliative care services, as of January 2006 in England, Wales and Northern Ireland, was (NCPC 2005b):
• 193 specialist inpatient units providing 2774 beds, of which 20% were NHS beds
• 295 home care services; at present this figure will include both primary advisory services delivered by hospices or NHS-based community palliative care teams and more sustained care delivered in patients’ homes
• 314 hospital-based services
• 234 day-care services
• 314 bereavement support services.

AN INTERNATIONAL PERSPECTIVE

From the inception of the idea of St Christopher’s, international links were made. In 1967 an American colleague wrote to Dame Cicely from New York:

I think you should realise that you have two obligations. One is to continue your work which you are doing in the development of your own centre at St Christopher’s and the other is to teach the world what you have learned.

Clark (2005a, p 11)

In the period 1959–67 her published letters include correspondence with colleagues in many different parts of the USA, Switzerland, Sri Lanka, the Netherlands, France and South Africa. As Medical Director at St Christopher’s she visited North America regularly and made strong professional bonds with Balfour Mount at the palliative services at the Royal Victoria Hospital in Montreal. She was a regular visitor to the international conferences that he has hosted every 2 years from 1976. She also visited many other countries, including Yugoslavia, Belgium, Australia, Israel and South Africa (Clark 2005a). There are many examples of international collaboration in the palliative care arena. The Oxford Textbook of Palliative Medicine is now in its third edition (Doyle et al. 2005) and it contains contributions from all members of the multidisciplinary team around the world.

World Health Organization

The United Nations Specialised Agency for Health, i.e. the World Health Organization (see www.who.int/cancer/palliative/pain_ladder/en/index.html), has a remit for palliative care. The WHO is governed by 192 member states throughout the world assembly. In collaboration with the International Organization for the Relief of Pain, the WHO has established the three-step pain relief ladder that is generally adopted by all specialist palliative care units and based on the early work of Dame Cicely and her colleagues.

Some 52 million people die in the world each year with approximately one in ten of these deaths being from cancer. Millions more suffer from other life-threatening illnesses such as AIDS. Often the need is greatest where resources are poor. Barriers to caring for those who are dying include lack of financial resources, non-availability of vital medicines, no opportunity for training or support, and long-standing
conflicts and natural disasters. In spite of these obstacles, it is now estimated that palliative care services exist, or are being developed, in 100 countries (Help the Hospices 2006).

The Hospice Information Bulletin is a magazine produced jointly by St Christopher’s and Help the Hospices. Through this publication 6000 people in over 100 countries in the world are contacted (Help the Hospices 2006). Help the Hospices, in partnership with palliative care associations around the world, has produced a report called Suffering at the End of Life – The state of the world and it was published by the Help the Hospices (2005). This report highlights current issues by using facts and figures, case studies and photographs. Below are some extracts from it.

**Facts and figures**

There are currently more than 13 million children under 15 years of age who have lost one or both parents to AIDS. Most live in sub-Saharan Africa. By 2020, the number is expected to increase to more than 25 million. AIDS brings psychosocial distress and material hardship to children. They may be pressed into service to care for ill and dying parents, required to drop out of school to help with farm or household work, or experience declining access to food and health services. Many are at risk of exclusion, abuse, discrimination and stigma.

Help the Hospices (2005, p 11)

Table 1.1 summarises the findings of 64 studies and shows the symptoms experienced by patients with specific diseases (Solano et al. 2006).

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Cancer</th>
<th>AIDS</th>
<th>Heart disease</th>
<th>COPD</th>
<th>Renal disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>3–77</td>
<td>10–82</td>
<td>9–36</td>
<td>37–71</td>
<td>5–60</td>
</tr>
<tr>
<td>Anxiety</td>
<td>13–79</td>
<td>8–34</td>
<td>49</td>
<td>51–75</td>
<td>39–70</td>
</tr>
<tr>
<td>Confusion</td>
<td>6–93</td>
<td>30–65</td>
<td>18–32</td>
<td>18–33</td>
<td>?</td>
</tr>
<tr>
<td>Fatigue</td>
<td>32–90</td>
<td>54–85</td>
<td>69–82</td>
<td>68–80</td>
<td>73–87</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>10–70</td>
<td>11–62</td>
<td>60–88</td>
<td>90–95</td>
<td>11–62</td>
</tr>
<tr>
<td>Insomnia</td>
<td>9–69</td>
<td>74</td>
<td>36–48</td>
<td>55–65</td>
<td>31–71</td>
</tr>
<tr>
<td>Constipation</td>
<td>23–65</td>
<td>34–35</td>
<td>38–42</td>
<td>27–44</td>
<td>29–70</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>3–29</td>
<td>30–90</td>
<td>12</td>
<td>?</td>
<td>21</td>
</tr>
<tr>
<td>Anorexia</td>
<td>30–92</td>
<td>51</td>
<td>21–41</td>
<td>35–67</td>
<td>25–64</td>
</tr>
</tbody>
</table>

From Solano et al. (2006). Reproduced with the permission and help of the authors. AIDS, acquired immune deficiency syndrome; COPD, chronic obstructive pulmonary disease.
Hospice or palliative care has been identified as a relatively cheap and effective means of meeting the needs of those nearing the end of their lives, thereby ensuring that they do not suffer unnecessarily.

The case of Uganda shows that palliative care is not just for wealthy industrialised nations. Uganda was the first African country to make palliative care for people with AIDS and cancer part of its national health plan (2000–2005). A clear national policy has been established, with appropriate education for health professionals at all levels. Affordable morphine has been made easily available in the country.

Help The Hospices (2005, p 19)

The role of governments

The role of governments in developing and promoting palliative care is crucial. Hospice and palliative care associations from around the world drew up a Declaration on Hospice and Palliative Care in March 2005, which asked governments to take 15 actions, including the following:

- Include hospice and palliative care as part of all governmental health policy, as recommended by the WHO.
- Make access to hospice and palliative care a human right.
- Make resources available for hospice and palliative care programmes and services.
- Make necessary drugs available, including affordable morphine to the poorest.

www.wwpca.net

The global community must act now to meet the enormous challenge of providing palliative care for all who need it. To ensure that suffering at the end of life is not inevitable, let each and every one of us play our part. We all stand to benefit.

Help The Hospices (2005, p 26)

DEFINITIONS

Definitions are important although we often pay them little regard. Definitions may well help to shape our attitude and approach to the work that we do. For an equitable and coordinated approach to care, we all need to have a common understanding of the what, why, how, when and where of palliative care.

Health

Illich’s definition of health embraces the concept of a ‘healthy death’. He stated that ‘health designates the ability to adapt to changing environments, to growing up and ageing, to healing when damaged, to suffering and to the peaceful expectation of death. It also embraces the future and therefore includes anguish and the inner
resources to live with it’ (Illich 1975). Viewing health as a process of adaptation, rather than simply an absence of disease, can create a useful approach to palliative care. The emphasis is on supporting people in their adaptation and helping them to remain in control of their illness experience for as long as possible (Buckley 2002a).

**Palliative care**

Perhaps the most widely quoted definition of palliative care is the one published by the National Institute for Health and Clinical Excellence (NICE), which leans heavily on NCHSPC (1995). It is as follows:

> Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and the provision of psychological, social and spiritual support is paramount. The goal of palliative care is the best possible quality of life for patients and their families.

*NICE (2004b, p 20)*

This definition has quickly become recognised as appropriate for the care of patients with any life-threatening/long-term condition.

The definition, as quoted here, can carry an implicit suggestion of disempowerment. There is no real suggestion of the contributions that the ill person and their friends and relatives might make to their illness management. However, within the NICE manual (2004b), there is such a suggestion. It states, for example, that ‘patients, families and other carers should play the central role in making decisions about the care they receive’ (NICE 2004b, p 21) and ‘user empowerment must therefore underpin good supportive and palliative care’ (NICE 2004b, p 21). This definition is also given in NCPC (2005b). However, as in the NICE guidelines, this document goes on to describe a more active role for patients.

**Holism**

The increasing use of the word holism is also of some concern. It is a word that is becoming embedded in nursing theory, e.g. in philosophies of care, curricula and writing. An analysis of the literature suggests that its emergence as an ideal is dogged by lack of clear definitions (Smart 2005). In many instances it simply seems to mean consideration of the whole, i.e. psychological, social and spiritual, as well as physical. Within the discipline of complementary therapies, the heart of holism is seen as supporting people in utilising their own inner resources; thus patients are experts on themselves (Daniel 2001b). A definition should have purpose and clarity; including the word holism has the potential to hamper that.

By adopting a definition that contains the words holism, psychological, social, spiritual and physical, particularly with a poorly defined sense of what holism means, we are in danger of being intrusive and controlling for some of our patients. Holism and its tool, individualised palliative care, has granted us permission to peel
away the layers of the onion that is patient care, but perhaps we do not always need
to do so because the knowledge that we gain may not be necessary for the care of
a patient and may have costs to them as a person (Smart 2005).

This is not to devalue the philosophy of an approach that encompasses understand-
ing patients’ perceptions and feelings, and supporting their coping styles. Nor
does it devalue the notion of supporting the physical, psychological, social and
spiritual needs. It is simple to recognise that not everyone wants or needs this full-
on approach.

An alternative definition presented here is:

The aim of palliative care is to support the patient, their family and friends in adapting
to embracing a peaceful expectation of death. To this end expert assessment skills are
paramount. Control of pain and difficult symptoms are a priority. Expert support should
be offered where needed and wanted in all areas, physical, psychological, social and
spiritual. The goal of palliative care is achievement of the best quality of life for patients,
their family and friends and the creation of precious memories in the dying trajectory.

Terminal care

It has been suggested that the use of the word ‘palliative’ has replaced the word
‘terminal’ and that this may be indicative of a death-denying society (Praill 2000).
Perhaps it is more indicative of the evolution of a palliative service rather than a
substitution of words. ‘Terminal care’ is a term used within palliative care. It refers
to a period when, despite the best efforts of patients, carers, friends, relatives and
the multidisciplinary team, symptoms become more difficult to manage. Typically
it is heralded by loss of energy, no interest in eating, and some psychological with-
drawal from family and friends. The onset and duration of this period are as unique
as every human being. Indeed, some people do not have a ‘terminal phase’ either
as a result of an acute occurrence or because they simply do not experience it. It is
an important period to recognise. Sometimes a palliative approach, e.g. small appe-
tising meals, managed exercise and organising anticipated enjoyable activities, can
become a burden to the patient. They may not want to dampen the enthusiasm of
friends, relatives and professionals in their attempts to care. Relatives and friends
may need additional support at this time. When a loved one no longer wants to eat,
for example, they may need help to understand this. Preparing food translates into
nurturing and eating is often a mutually enjoyable event. Relinquishing this may
feel like withdrawing love and friendship at some level.

Generalist and specialist palliative care

Good quality palliative care is the remit of every health-care professional. The
NCPC (2005b) sees two distinct categories of health-care and social-care profes-
sionals providing palliative care: generalist and specialist palliative care teams. They
provide day-to-day care for patients, relatives and friends in the community hospi-
tals, care homes and indeed all care settings. Generalists do not nurse dying people
Historical and Cultural Perspectives on the Evolution of Palliative Care

exclusively – they are only part of their caseload. Specialist palliative care teams will usually have had extra training and will be caring for people with life-limiting disease only. Traditionally, these teams have been hospice and hospital based.

Generalists should be able to assess and meet the physical, psychological, social, spiritual and informational needs of patients and families in their care. Importantly they should be aware of their own limits in knowledge, skills and competency in palliative care, and know when to seek advice from a specialist palliative care team (NCPC 2005b).

Specialist palliative care is provided by a specialist multidisciplinary care team. Such a service should include the following:

- Assessments of, advice for and care of patients, families and friends in all care settings, including hospitals and care homes.
- Specialist inpatient facilities in hospital or hospice.
- Intensive coordinated home support for patients with complex needs who wish to stay at home. This may be a specialist service providing advice alongside the GP and district nurse or perhaps a hospice-at-home service, i.e. specialist nursing, medical advice and access to all other members of the care team in the patient’s home.
- Day-care facilities offering a range of opportunities for assessment and review of all needs. They can provide support and friendship groups, and also complementary and creative therapies.
- Advice and support to all people involved in patient care.
- Bereavement support care.
- Education and training in palliative care.

The specialist teams should include palliative medical consultants, palliative care nurses, physiotherapists, occupational therapists, dietitians, pharmacists, social workers, and those able to give psychological and spiritual support (NCPC 2005b). Integral to most specialist palliative care services is a complementary therapy service and, in many, a well-defined creative therapies service. There is overwhelming anecdotal evidence, and a growing more formal evidence base, that these therapies help to enhance quality of life for the dying person.

Supportive care

The term ‘supportive care’ is recent but is now firmly established on the health-care agenda, largely as a result of the NICE (2004b) manual Improving Supportive and Palliative Care for Adults with Cancer, and its accompanying publication Supportive and Palliative Care: The research evidence (NICE 2004a). Supportive care in the past has been piecemeal and patchy and still is. It is hoped that the 20 key recommendations from the NICE manual (2004b) can start to rectify this, not just for cancer patients, their relatives and friends, but for all facing progressive disease.

The definition of supportive care quoted here is from the NICE manual (2004b) and has been adopted by the NCPC (2005b):
Supportive care helps the patient and their family to cope with cancer and the treatment of it from pre diagnosis, through the process of diagnostics and treatment, to cure, continuing illness or death and bereavement. It helps the patient to maximise the benefits of treatment to life and correlate as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. Supportive care should be fully integrated with diagnosis and treatment. It encompasses:

- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Rehabilitation
- Complementary therapies
- Spiritual support
- End of life bereavement care.

Three exciting nationally coordinated initiatives – the Gold Standards Framework, the Preferred Place of Care document and the Liverpool Care Pathway – are an important part of a supportive and palliative care approach in the UK. The NHS End-of-Life Care Programme has been established to promote the spread of these three frameworks into the cancer and non-cancer populations.

END-OF-LIFE CARE NATIONAL PROGRAMME

The Gold Standards Framework

The Gold Standards Framework (GSF) has grown from a local initiative by Dr Keri Thomas, a GP Macmillan Facilitator in Huddersfield. The original project involved 12 GP practices in Huddersfield. In 2006 the GSF was being used by over 2000 primary care teams in the UK covering a quarter of the population (Thomas 2005).

The GSF is an evidence-base programme of assessment and care, developed for the use of primary health-care teams. It provides a home pack for patients to facilitate sharing of information. Assessment tools, e.g. pain assessment and other symptom assessments, have also been developed for use with it. The aim of the GSF is to improve and optimise the quality of life for patients, their families and friends in the last year of life. It aspires to providing equal opportunity, good quality, end-of-life care regardless of location and diagnosis. By using the GSF, practices should be able to improve communication and teamwork. Each practice nominates a key nurse and GP for each patient whom they place on a practice-based palliative care register. Each practice should have a monthly meeting to review patients on this register. Improvement of the seven Cs is frequently quoted as being the main goals:

- Communication
- Control of symptoms
- Continuity of care
- Coordination
• Care support
• Care of those who are dying
• Continued learning.

The GSF practices should also hold 6-monthly significant events meetings and attend central meetings to share experiences and develop protocols. It is from these meetings that the ‘toolkit’ previously referred to, containing a variety of assessment tools, and guidelines for practice have been developed (Thomas 2003).

A central NHS GSF team provides continued support for SHAs, primary care trusts (PCTs) and cancer networks.

Using GSF in the community can improve communication advance care planning and monitoring of patients enabling more patients to die where they choose. It has also been shown to reduce un-needed hospital admissions.

There is evidence of strong central government support for the GSF. It was mentioned in the House of Commons Select Committee Report in July 2004, the Labour and Conservative Party Manifestos in April 2005 and is embedded in the National Service Frameworks, e.g. for chronic heart disease and chronic renal disease (Thomas 2005).

The Preferred Place of Care/Preferred Priorities of Care

The NHS Cancer Plan (DH 2000b) stated that cancer patients should be able to live and die in a place of their own choosing where this is possible. Nationally 56% of us would prefer to die at home, but only 20% of us actually do (NCPC 2003).

The Preferred Place of Care/Preferred Priorities of Care (PPC) is the initiative of the Lancashire and Cumbria Cancer Network. The aim is to put the patient at the centre of care planning, in the hope that autonomy and control will be fostered: ‘Many patients feel these factors are taken away in the terminal stages of their illness’ (Storey 2003). Some sections of the PPC documentation are designed to be completed by carers and some by health professionals. The document is divided into four parts, as follows:

Section 1

Family profile – explains details relating to dependence and identifies who key carers will be.

Section 2

Records discussions of the patients’ and families’ understanding of the diagnosis and possible outcomes.

It is here that the practitioner proceeds to discuss what consideration has been given to where and by whom, they would like to be cared for when their condition deteriorates.
Section 3

Provides a comprehensive assessment of health and social services available to the patients and any services currently being accessed.

Section 4

This is a variance sheet allowing space for patients and professionals to document changes.

Storey (2003)

It is impressed upon patients that they can change their mind at any time. An accompanying NHS leaflet also explains that choices may not always be honoured for various reasons, e.g. a change of physical condition, a carer becoming ill or tired, and a lack of resources to meet a particular need (Department of Health 2004b).

By collecting documents after the death of a patient, it is hoped to gather data on what actually happens. Why do people who wish to die at home die in hospital? Is it lack of resources or poor communication between professionals? Or is it not listening to patients and relatives? These data will be invaluable and will help determine whether it is a reality to offer home as a choice of place to die. Do we have enough resources in the right places?

The Liverpool Care Pathway

The stimulus for the development of care pathways in this country was the government’s White Paper – *A First Class Service – Quality in the New NHS* (DH 1998). Embodied within this paper were initiatives that created the expectation that quality of delivered care must be benchmarked, audited and inspected to ensure compliance. This paper was the launch of clinical governance, the NICE and the Commission for Health Improvement (CHI). A care pathway is an agreed plan of care ideally constructed by a multidisciplinary team. It provides a central organising tool for all clinical care and is designed to replace all other documentation and become a multiprofessional document. ‘The care pathway includes expert opinion, guidelines, protocols, evidence-based practice and research and development where possible’ (Ellershaw and Murphy 2005, p 132). The Liverpool Care Pathway (LCP) was developed as a joint initiative between the Marie Curie Hospice in Liverpool and the Royal Liverpool Hospital. It was developed 10 years ago as a tool to enhance education programmes for the care of those who are dying (Ellershaw and Wilkinson 2003). It is designed for use in the last days of life.

The fundamentals incorporated in the LCP are not complex. The diagnosis for those who are dying includes easily demonstrable criteria, e.g. the patient is bed bound, semi-comatose, only taking sips of fluid, can no longer swallow tablets. The multiprofessional team must agree that two or more of these criteria have been met to stimulate the implementation of the LCP. In a well-run area this should avoid conflicting messages being given to relatives and friends about whether or not the patient is dying.

One of the first actions that the LCP recommends is to review all medications, discontinue non-essential medicines and prescribe medication for potential
symptoms as needed, e.g. pain, nausea. These are very simple and easy steps to follow. As someone who frequently listens to multidisciplinary team members practising generalist palliative care, issues of continuing with all medications and being unable to get prompt consultations re difficult symptoms when they arise, are factors that still cause a good deal of distress to patients, relatives, friends and professional carers.

The LCP was developed for use in hospitals but is increasingly being used in the community as a natural extension of the GSF.

In the NICE supportive care manual (NICE 2004b, p 11), key recommendation 14 states:

> In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The Liverpool Care Pathway for the Dying provides one mechanism for achieving this.

So, similar to the GSF, there is evidence that the LCP is being adopted by mainstream NHS organisations. It is estimated that over 25% of hospices in the UK are now using the LCP. Evaluation has shown that, in the generic health-care setting in Liverpool, over 50% of patients on the LCP are non-cancer patients (Ellershaw and Murphy 2005). This trend has also been demonstrated in other hospitals (Murtagh et al. 2004; Mirando 2005).

As with the GSF there is a national team to support the LCP, based at the Marie Curie Palliative Care Institute in Liverpool. An audit and research team supports four continuing associated programmes. They are: non-cancer, benchmarking, education and international. An annual national conference focuses on research and new developments.

‘It is well recognised within our society and within the healthcare system that hospice care is synonymous with quality care of the dying’ (Ellershaw and Wilkinson 2003, p xi). In a society where over 56% of people die in hospital (NCPC 2003), it is exciting to think that the LCP could be at the fingertips of all health-care professionals wherever they are. It provides the framework for a good quality of dying.

**CULTURE**

**Multicultural Britain**

In the mid-1990s there was concern that uptake of hospice and other specialist palliative care services among black and minority ethnic (BME) patients was low. Research identified several factors that constituted this perceived low uptake. There was a lack of accurate data on ethnicity of people using services. At this time, in many units cancer was still the focus for palliative care. Deaths from cancer occur mainly in the population of people aged 55 years and over. There was a smaller proportion of BME groups in this age range and many may emigrate back to their country of origin in later life, which could help to account for low uptake. Added to this, cancer is not the main cause of illness among the black and Asian communities. It was also found that there is little or no information available to BME patients or their carers about palliative services (Hill and Penso 1995).
The research, called Opening Doors (Hill and Penso 1995), targeted three specific sites for an indepth analysis – Brent, Newham and Birmingham. It concluded by making 11 recommendations. This summary by Baroness Cumberlege from the report highlights some of the main areas for concern and action:

One of the most important aspects of the report is the evidence it shows of an understanding of the particular needs of the black and ethnic minority communities for hospice and specialist palliative care. However, awareness on its own is not enough. Although much progress has been made, access to, and knowledge of these services by people for ethnic minority communities is still not as good as it should be. The report shows that better liaison between agencies involved and more information on current needs are necessary. Training in cultural awareness, interpreting services and targeting information in appropriate languages are some of the ways services can be made friendlier to their users.

Hill and Penso (1995, p 4)

A follow-up study commissioned by the then National Council for Hospice and Specialist Palliative Care Services (Firth 2001) made further recommendations: it suggested more availability of culturally sensitive tools, e.g. pain assessment charts, more sensitivity to different cultural practices, e.g. large family gatherings and mourning rituals. It also suggested regular meetings of health-care professionals, community leaders and patient groups, and the subject of more culturally sensitive recruitment of nurses was raised. This study makes 11 recommendations for practice and 5 for further research, including looking at beliefs and attitudes to illness and death, care and the role of carers, attitudes to disclosure, autonomy and informed consent, attitudes and responses to pain, and referral patterns (Firth 2001).

Neuberger (2003) highlights that her experiences in terminal care demonstrate that, on occasion, services can be totally culturally appropriate. However, in conditions once considered terminal and now viewed as chronic, e.g. some cancers, HIV, heart disease, she views cultural sensitivity as often lacking. Despite several national attempts to encourage better end-of-life care incorporating psychological, social and spiritual considerations, ‘services are still patchy and depending too much on individual enthusiasts’ (Neuberger 2003, p 208).

Interprofessional culture

Offering a service to patients that recognises them as unique human beings presents a challenge. It requires a good deal of individual motivation and excellent communication within the team, which must include patients and their families/friends. As human beings, we operate on an intellectual and emotional level. Sometimes we make intellectual decisions that conflict with our emotions, e.g. a mother giving a baby up for adoption may be making an intellectual decision that carries emotional suffering. Similar things happen in health care, often with very little professional awareness of it. However, the suffering as a result of ‘faulty’ decision-making is not that of the professionals but that of the patient, family and friends. This is vividly demonstrated by continuation of aggressive futile treatments.
**Doctors**

Western doctors traditionally work within a strong philosophical framework based on curing. When making decisions about active treatment in the face of futility, experience supports ignoring hard evidence. The doctor may operate at an emotional level and continues futile treatments. The consequences for patients, relatives and friends are far reaching. Essentially, because of invasive painful procedures, they are robbed of their last moments together. This cannot be reversed. Anguished moments replace potentially precious ones.

**Nurses**

Nurses work in a philosophical framework of caring. They often ‘come into their own’ when a patient cannot be cured. I heard a doctor gently talking to an elderly woman who had an aggressive chest infection. He sensitively explained that antibiotic therapy could be optional. She understood. She replied that she had a daughter and three grandchildren who loved her and she loved them and life. He prescribed the antibiotics. The conversation with the patient was stimulated by nurses advising him not to prescribe. The nursing staff were critical of him in spite of knowing that he had spoken to the patient. In their opinion, she had suffered enough. Their philosophical framework of care in this instance was misguided and created unnecessary tension. It begs the question of how it may have impinged on their relationship with the patient.

**Therapists**

Maintaining independence when disease is progressing can be synonymous with maintaining hope (Buckley and Herth 2004). Physiotherapists, occupational therapists and speech and language therapists have a vital role to play in this important aspect of care. Although they know their value at this critical time, they often find themselves with feelings of sadness and failure when patients can no longer remain independent and their role becomes redundant.

These are complex issues. Developing a stronger sense of personal and professional awareness is crucial to our decision-making and this is addressed in Chapter 4. Having a good knowledge of what patients understand and feel about a situation is also a vital component of decision-making; this is discussed in Chapter 3.

We can do a good day’s work caring for our patients physically and organisationally. However, supporting patients emotionally and spiritually requires added energy and motivation. Those who are dying do not have a strong voice in the main, so the personal motivation of their carers becomes an even more vital factor. Health professionals need to feel supported to be able to keep caring for those who are dying. Staff support systems and self-care are vital and are discussed in Chapter 4.
SERVICE USER INVOLVEMENT

A new system of patient and public involvement in health care has been implemented in recent years. Community health councils have been replaced by patient and public involvement forums (PPIFs). These forums have many responsibilities, including monitoring and reviewing services and seeking patient views. Every PCT and NHS trust has a patient advice and liaison service (PALS), with members who monitor trends and highlight gaps in services. A national independent public body, the Commission of Patient and Public Involvement in Health, provides a voice for patients and the public; it advises on systems of patient and public involvement and on major issues that arise. In addition, local authorities with responsibilities for the Social Services have an overview and scrutiny committee to take on the role of scrutinising health services, including the NHS (DH 2003b). A strong philosophy behind the new framework is that patients and the public will be included in shaping services, e.g. assessing need and writing policies. It is hoped that this will shape a more user-friendly service and the new patient organisations will be less involved in adversarial roles, as was often the case for community health councils.

Historical perspective

One could say that palliative care as we know it today has been shaped around patient involvement, e.g. the giving of regular morphine was a result of an extensive study by Dame Cicely Saunders (2006a), during which she analysed 900 records and tape-recorded patients’ stories of pain and response to pain relief. A doctor remarked to her at a symposium in 1963 ‘I always thought that regular giving was the answer’. ‘Patients’ voices have provided the answer’ (Saunders 2006a, p 6), was Dame Cecily’s reply.

Contemporary initiatives

At St Christopher’s, two patient groups have been set up: one for ward-based patients and one for home-based patients. The Beacon project in Brighton, which provides a service for people with HIV and AIDS, has a user forum so that service users are involved at all stages of the service provided there (Munroe and Oliviere, 2003). These are just two examples of practice.

It may be perceived that user involvement in palliative care presents a particular challenge because of limited life expectancy, and some specialist palliative care teams are resistant to forming user groups. Munroe and Oliviere (2003) warn against this type of stereotyping. It should not be assumed that, as patients pass from active to palliative care, they are not well enough to take part in user activity. This has the potential to create a divide between patients and staff, particularly if patients are coming from areas where they have had active user involvement. In Chichester, patients are involved in planning and delivering study days for health-care professionals. These are in their infancy but so far have proved to be valuable learning experiences.
Palliative care service users are already involved in a wide range of activities: self-help groups, education groups, user consultation forums. The challenge for the future is to extend these activities and evaluate the effectiveness in terms of impact on both service and patients involved.

CONCLUSION

This chapter has given an overview of the history of and cultural perspectives on the evolution of the modern palliative care movement. The challenge is now to continue to develop frameworks and approaches that will extend a good-quality palliative service to people dying of any illness, in any setting, in any country of the world.

MAIN IMPLICATIONS FOR PRACTICE

- It is important to understand what the philosophical approach to palliative care is in your place of work. If the approach in practice does not match the philosophy or, indeed, if palliative care is not included in your philosophy or mission statement, raise these points at an appropriate forum, e.g. ward meetings.
- A palliative approach should, where possible, aim to help people use their own inner resources and avoid disempowerment.
- Be mindful that sometimes rehabilitative aspects of care and, indeed, lifesustaining activities (e.g. eating) can become burdensome in the terminal stage of someone’s illness.
- All health-care professionals practising generalist palliative care should know how to contact their local specialist teams for advice.
- Services should be culturally sensitive and all health-care organisations should design policies and educational approaches that will help to establish this as a routine part of care. This important aspect should not depend on the enthusiasm of individuals.
- Interprofessional culture is important when making individual and group decisions. Understanding of our own profession’s philosophical approach and that of our colleagues is a fundamental step in understanding our decision-making.
- User involvement is as important in palliative care as in active care. It should not be assumed that, because people are receiving palliative care, they will not feel well enough for user involvement. Assumptions are disempowering for patients, friends and relatives, and may lead to social isolation.

SUGGESTED FURTHER READING

Websites

www.helpthehospices.org.uk
www.ncpc.org.uk
For information on the Preferred Place of Care initiative contact www.cancerlancashire.org.uk.
www.goldstandardsframework.nhs.uk
www.endoflifecare.nhs.uk
www.who.int