

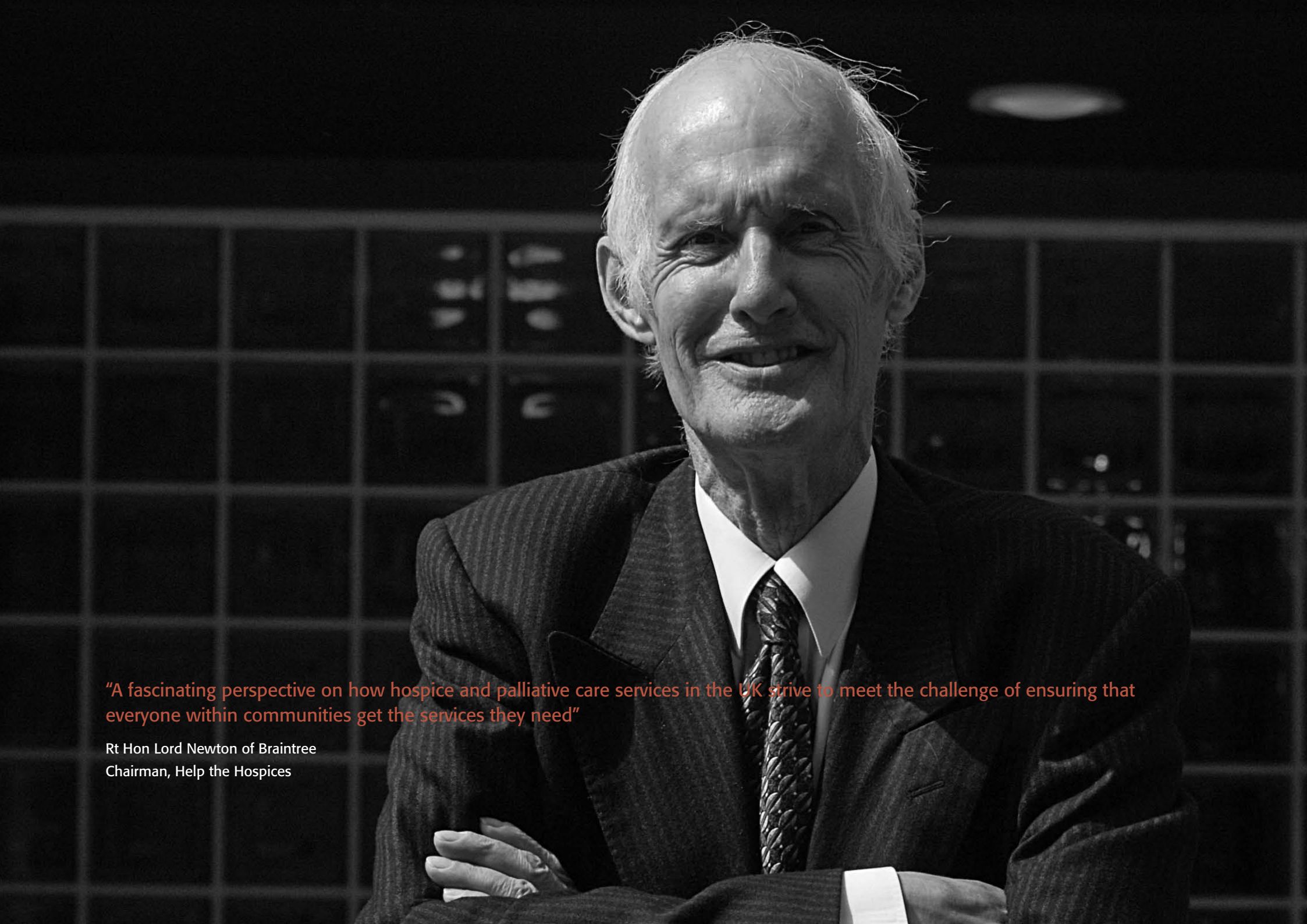


HOSPICE AND PALLIATIVE CARE - ACCESS FOR ALL

PUBLISHED BY



**help the
hospices**



"A fascinating perspective on how hospice and palliative care services in the UK strive to meet the challenge of ensuring that everyone within communities get the services they need"

Rt Hon Lord Newton of Braintree
Chairman, Help the Hospices



FOREWORD

In 2005, the first World Hospice and Palliative Care day was celebrated in over 75 countries around the world with more than 1,100 events. The theme for World Hospice and Palliative Care Day 2006 is access to care for all - highlighting the fact that everyone has a right to high quality end of life care but that more needs to be done to enable everyone to access it.

Help the Hospices is marking the day with this report - offering a fascinating perspective on how hospice and palliative care services in the UK strive to meet the challenge of ensuring that everyone within communities get the services they need.

A terminal diagnosis can be so overwhelming, and our healthcare system so bewildering and impersonal, that one often doesn't know where to turn or whom to trust. Many people, unfortunately, do not know what choices they have.

This new report showcases the many success stories of how hospice and palliative care has been provided in the most difficult settings. It also provides food for thought on how services can be made more accessible. The report aims to reflect the diversity of our society and the different beliefs and values, interests and attitudes to care that people have.

The format blends technical detail with practical examples and resources. We hope it will be valuable to health professionals, policy makers and anyone with an interest in hospice and palliative care and that it will provide inspiration for us all.

Rt Hon Lord Newton of Braintree
Chairman, Help the Hospices

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“Our vision is of a world in which the best possible care is available to all people at the end of life, whatever their circumstances”

Mission statement of Help the Hospices

INTRODUCTION

The Widening Access Group of Help the Hospices recently published its statement of intent, its aspiration for the future.

“Hospice care is free and is for those living with a progressive and life threatening illness. Hospices are unique and valuable local resources and the hospice movement is committed to ensuring their services are accessible to all who would benefit.

To make this a reality we are committed to promoting equity of access to hospice care. It is the aim of all independent hospices that no one should be discriminated against, directly or indirectly, on any grounds including their age, gender, race, religion, sexuality or their particular physical or mental illness or disability. Hospices are seeking to ensure that they provide full and appropriate communication to those with any language or communication difficulties. Hospices are working

to remove existing barriers to access, to develop services that are appropriate to all, and to extend the spread of high quality palliative care through education and training.”



WHAT IS PALLIATIVE CARE?

Palliative Care has been defined as:

'....an approach that improves the quality of life of patients and their families facing the problem 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 ⁽¹⁾.'

Palliative care aims to:

- ♦ provide relief from pain and other distressing symptoms
- ♦ affirm life and regard dying as a normal process
- ♦ integrate the psychological and spiritual aspects of patient care
- ♦ offer a support system to help patients live as actively as possible until death
- ♦ offer a support system to help the family cope during the patient's illness and in their own bereavement.



PALLIATIVE CARE IN THE UK

Modern palliative care could be said to have begun with the founding of St Christopher's Hospice in South London by Dame Cicely Saunders in 1967. It developed in response to the often very poor care provided to dying cancer patients, often with very distressing symptoms, and introduced a research-based medical model to control pain and other symptoms, addressing the needs of the whole patient.

Although palliative care started with the hospice movement, it is now provided in a variety of different settings, including large teaching hospitals and small rural hospices, patients' homes and in residential and nursing homes. Although hospice and palliative care is provided in a large part by independent and voluntary hospices, there are also a number of NHS hospices and community palliative care teams. In addition, many hospitals have palliative care support teams that provide

specialist advice to other teams caring for the patient.

Largely because of their history and development, hospices have concentrated principally on the care of patients with cancer, although there is now an increasing interest and emphasis in extending care to patients with other illnesses.

Facts & Figures

- ◆ There were 583,082 deaths in the United Kingdom in 2004, of which 153,660 (26%) were from cancer. ⁽²⁾
- ◆ Of those deaths not from cancer, many were from diseases that may have a prolonged period of deterioration that would respond to palliative care.
- ◆ The proportion of patients suffering from diseases other than cancer that are cared for by hospices remains at just over 5%, with a range of 0 - 31%. ⁽³⁾



“I had a firm belief that a hospice was a place where you went to die, but I don’t think I would have been here without the hospice... I valued every minute of it... they have given us back our lives”

Patient at Hospiscare, Exeter

Facts & Figures

- ♦ In the UK the voluntary sector provides 158 (71%) out of a total of 221 adult palliative care inpatient units, and all of the 34 children’s inpatient units. ⁽⁴⁾
- ♦ Nearly half of all people admitted to a hospice return home again - the average length of stay is just 13 days.
- ♦ All care is provided free of charge to patients and families.
- ♦ The UK Government contributes an average of 33% of running costs for adult hospices⁽⁵⁾ and 2.7% for children’s (England)⁽⁶⁾ - the rest is dependent on voluntary contributions.
- ♦ In 2005, adult hospices in England raised £245 million from charitable means to pay for the services they provided.
- ♦ St Ann’s Hospice in Manchester, one of the UK’s largest hospices, has to raise £16,000 every day from charitable sources to fund its services.

ABOUT HOSPICE CARE

Hospices aim to improve the quality of life of people with a terminal illness, helping them to make the most of every moment, in whatever way works best for them.

Hospices care for the whole person, aiming to meet all needs - physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them.

Hospices provide a range of services - pain control, symptom relief, skilled nursing care, counselling, complementary therapies, spiritual care, art therapy, music therapy, physiotherapy, reminiscence, beauty treatments and bereavement support.

Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer dignity, peace and calm and freedom from pain.

Hospices have developed in response to locally identified needs and all place a different emphasis on how they provide care. Sometimes this will depend on the profile of the community; sometimes the geography of the area will be key.

The core of the service is to manage the physical symptoms, such as pain, but symptom management is not just about drugs and medication. The emphasis on holistic care, addressing emotional and spiritual needs as equally important, lies at the heart of the hospice movement’s approach.



“I was really impressed with the way everyone involved communicated with each other - the hospice staff, the GPs and the district nurses. It was as if she was being held all the way through by other people and this took the strain off us. The hospice staff were key, bearing much of the weight of what we were going through. They softened the process, making Mum’s journey much easier, much more gentle. It would have been a lot more traumatic and exhausting without them. Until you’ve walked that road, you just don’t know what its like.”

Daughter of a patient who received care from two local hospices, both at her home and in a hospice. Her mother died very peacefully at home with her family.

HOW HOSPICES OFFER CARE

Care at home

Care at home comes in various forms; the hospice community team provides support and advice to the GP and district nurse in the community, who have overall responsibility for managing patients in their own homes or in care homes. In addition, the team provides emotional and practical support to patients and carers. In some cases they also provide additional skilled nursing to patients who wish to remain in their own homes, but who require a greater level of care than is available from district nurses or their formal or informal carers.

Day care

The role of day care is evolving: it is an important component of hospice care. Day care may offer outpatient treatment, emotional and psychosocial support through counselling, nurse advisors, volunteers and complementary therapies, as well as

considerable peer support. Art and music therapies can also play an important role in helping patients come to terms with their illness.

Inpatient care

Inpatient units offer assessment, symptom management and control, respite and end of life care. Many patients are admitted for short periods only, for a specific problem, and are able to go home again following assessment and treatment.

Bereavement care

Hospices offer bereavement care to whole families following the death of a relative in the care of the hospice. This can take the form of psychosocial support ranging from trained counsellors to volunteer support, memorial services and sympathy letters.

Facts & Figures

In 2004/5:

- ◆ 160,000 patients received palliative care at home
- ◆ Over 32,000 people benefited from day care
- ◆ Nearly 38,000 new patients were admitted to palliative care inpatient beds. ⁽³⁾

A district nurse, acknowledging that nurses can find it difficult to care for patients and families with different cultural and social views of dying said, after attending a course in palliative care skills at a local hospice:

“I have always tried to respect all families, but the course helped me to do it in difficult situations. I had time to explore my own feelings”⁽⁸⁾

LIVING AND DYING AT HOME

The majority of patients are cared for in their own homes for most of their final illness. Research with patients and their families suggests that over half expressed a wish to die at home⁽⁷⁾, and that many more want to spend their last months at home. Hospices and palliative care services make a very significant contribution to supporting patients to achieve these wishes.

Patients’ families and carers, together with their GPs, district nursing teams and social services, provide most of the day to day patient care at home, supported and advised by specialist palliative care teams and Hospice at Home teams.

Hospices and palliative care teams across the country have worked together very successfully providing training programmes to strengthen the palliative care skills of their local district nurses and care home staff.

Facts & Figures

In the UK:

- ◆ 65% of people want to die in their own home⁽⁷⁾
- ◆ in 2003 22% of cancer patients died at home and 16% died in a hospice
- ◆ in 2003 18% of all deaths took place at home and 4% in a hospice.⁽²⁾



ACCESS FOR ALL

In 2004 the House of Commons Health Committee reported that:

"...a major concern (of the Department of Health) is the lack of equity in the provision of palliative care."⁽⁹⁾

The report indicated that there were considerable inequalities in provision across the country. It showed that:

- ♦ areas of social affluence had better access to palliative care services than socially deprived areas
- ♦ services mainly addressed the needs of cancer patients
- ♦ services appeared to be underused by members of the black and minority ethnic communities, by the elderly and by people with complex needs.

Historically, in the absence of a national strategy for palliative care, hospices developed to serve locally identified needs, funded by the local communities. The Government has recently announced the development of a new strategy for improving end of life care, which should go some way to addressing some of these inequities.

Hospices wish to make their care more accessible to groups such as:

- ♦ minority ethnic groups
- ♦ people of faiths other than Christianity
- ♦ gypsies and travellers
- ♦ prisoners
- ♦ homeless

- ♦ gay men and lesbians
- ♦ people with learning disabilities
- ♦ people with serious mental illness
- ♦ refugees and asylum seekers
- ♦ people with limited English language skills
- ♦ older people
- ♦ people living in institutional care
- ♦ people with sensory deprivation.





WHY ACCESS TO CARE MAY BE INEQUITABLE

To gain access to hospice or specialist palliative care, patients are usually referred by a healthcare professional. There can be barriers at all stages of referral, and these barriers can include personal, professional and organisational factors ⁽¹⁰⁾.

Some of these factors include:

- ♦ physical difficulties, including geographical distance
- ♦ professional obstacles; a lack of knowledge of hospice services or a reluctance to refer; the perception that hospices may not be able to care for patients with complex needs
- ♦ emotional and psychosocial difficulties, including negative perceptions of hospice or palliative care by some patients and families
- ♦ social, cultural, or religious barriers; the taboo nature of death and dying among some communities; the social exclusion of groups such as the homeless, travellers and prisoners; the perception that hospices may not meet the religious or cultural needs of the patient or family
- ♦ a diagnosis of a disease other than cancer may limit access to palliative care.



THE CHALLENGE OF GEOGRAPHY

Geographical barriers to access are particularly pronounced in the more rural areas of the country including parts of Scotland, Wales and South West England. Transport links are poor and community teams cover large, sparsely populated areas.

Highland Hospice faces specific challenges in the delivery of specialist palliative care to the Highland region of Scotland, which covers almost one fifth of the UK landmass. In particular, due to the geographical diversity of the area, the hospice delivers services to city and urban locations as well as to often remote and isolated smaller communities.

Highland Hospice has developed unique and innovative approaches to help overcome some of the challenges and to provide support to patients and families, primary care teams and the local district and community hospitals throughout the

area. Hospice consultants visit outlying areas on a monthly basis, visiting community hospitals and patients in their own homes and providing education sessions for health professionals. They work very closely with the locally based Macmillan nurses and community healthcare teams. They also run monthly internet conferences with the primary care teams, discussing current clinical topics and case management. The hospice also provides a 24-hour, seven day a week telephone support service.

Facts & Figures

- ◆ Scotland - Highland Hospice in Inverness provides all the dedicated palliative care beds for Highland Region.
- ◆ Wales - There are no inpatient units in either Powys or Ceredigion in Wales, with hospices concentrated in the more populated north and south of the principality. ⁽⁴⁾.



THE CHALLENGE OF THE ORGANISATION AND DISTRIBUTION OF CARE

The level of provision of services in relation to population size and needs have a clear impact on fair access to care. The House of Commons report states that: ‘...the (palliative care) network with highest estimated need has one of the lowest ratios of beds to population... Two of the networks with the least need have two of the highest ratios of beds ...’

However, some care needs to be taken with equating bed numbers directly with service provision; some hospices have taken a decision to limit or dispense with beds altogether and increase the care available in the community.

West Cumbria Hospice at Home was founded in 1987 with the aim of creating ‘a hospice in the home’. The vision was to provide all the facilities of an inpatient hospice but to base those services in

the patient’s own home rather than in a separate building. The hospice provides a specialist Home Nursing Service 24 hours per day, seven days per week, thus making staying at home a realistic choice for patients and carers. It also works closely with the NHS, providing other hospice services such as day care, lymphoedema clinics, drop in centres, bereavement counselling and provides specialist palliative care advice.

Hospice care for older people in care homes

Many older people living in nursing homes can have difficulties in accessing palliative care. Although many care homes provide a high standard of care, there is evidence that not all homes have appropriate expertise in palliative care ⁽¹¹⁾, or knowledge of how to access specialist palliative care advice or hospice services.

St Raphael’s Hospice and Orchard House nursing home in South London work together to improve the palliative care skills of the care staff through a training programme and by using a form of the Gold Standards Framework*. This led to the very successful care of Madge, a 96 year old lady with dementia. The use of GSF ensured that her care was planned in advance in accordance with her wishes, and her known desire to stay in the home were recognised and recorded. When she deteriorated unexpectedly, she was reviewed briefly in hospital, but was able to return to the home, where she died peacefully the following day in the comfort of her familiar surroundings. Both her daughter and the care staff felt that the best possible outcome had been achieved.

*The Gold Standards Framework (GSF) is described more fully on page 27



THE CHALLENGE ASSOCIATED WITH MEETING COMPLEX NEEDS

There is evidence that people with complex needs such as those with learning disabilities, mental health problems or dementia may face considerable difficulties in accessing palliative care, and in an appropriate form for their needs.

Professionals may overlook their physical needs, attributing symptoms to their existing difficulties. They may have communication and behavioural difficulties that prove challenging for both the referrers and the palliative care professionals. Their behaviour may also cause concern or disruption to other people accessing day care or inpatient services, and staff may lack the skills to help them ⁽¹²⁾.

Most people with complex needs live in their own home, sometimes with family, or in small residential homes, supported by care workers. They have important relationships and familiar faces around

them. Inpatient care in hospices may not be the satisfactory answer to their care requirements and some hospices are working with other key agencies to provide solutions.

St Oswald's Hospice and Macmillan Cancer Support have collaborated with Northumberland Tyne and Wear NHS Trust, to develop a seamless service for people with learning disabilities who have developed life threatening /life limiting illnesses such as cancer/dementia.

Dorothy Matthews is a specialist Macmillan nurse who has a learning disability nursing background; it is her particular remit to work with this group of patients. She supports them through investigation and diagnosis, and should they reach the point when they need palliative care, she works with professionals in the palliative care services to ensure that, wherever the patient is living,

whether in their own home, in a small group home, in a residential or nursing home, palliative care follows the patient, wherever they may be.

THE CHALLENGE OF CULTURE AND PERCEPTION

Health beliefs, culture and emotional and psychosocial factors can play an important role in the uptake of services. For some minority ethnic groups, cancer can be a very stigmatising illness, with issues of blame that can lead to difficulties in disclosure to family and friends and to a reluctance to accept hospice care. There can be important cultural issues around discussions of death and dying, where the patient wants to die, and who is responsible for care during the final illness ⁽¹³⁾.

For some groups, there is a strong belief that they will 'care for their own', which may result in inadequate referrals to palliative care, and there may not be enough information available to families on how hospices can support them while caring for a family member at home.

There can be misconceptions amongst people from all communities and faiths about the role of hospices, sometimes seen only as 'places where people go to die', rather than an appreciation of the much wider range of services, often used for a much longer time. There may also be perceptions among some minority communities that hospices would not be able to meet their needs, whether for food, privacy or spiritual care.

LOROS

LOROS, a large hospice in Leicester, serves a city that has almost a third of its population of South Asian origin. To encourage this group to make greater use of their services, the hospice has appointed a cultural support worker from the Asian community, whose role is to provide cultural and diversity training to professionals and volunteers. Among other activities, the hospice has held workshops and training seminars on 'death and dying in different cultures', and is working hard to raise awareness of the hospice and its services.



MULTI FAITH HOSPICE CARE

Kumadben was a devout Hindu and Gujarati speaker who was cared for at LOROS Hospice. Anjana Vaja, the cultural support worker, provided support to Kumadben and her extended family over the period she spent at the hospice. During the festival of Diwali, Kumadben and her family and the hospice invited a Hindu priest to say prayers, light candles and offer Indian sweets as 'prashad' – blessed food. The event was open to all and many came to share the very happy occasion.

Her daughter Priya says: *"Upon hearing the news that my mum was being transferred to nearby LOROS Hospice, my heart sank and anxiety set in. I attribute my initial opinion (of LOROS) to a stigma I believe it has: of being the place where people stop fighting against the horrible disease that is cancer. The support provided by LOROS enhanced the quality of life for my mum. From the moment*

we stepped through the doors we felt at home, with staff providing understanding, compassion, warmth and concern. Anjana was able to speak to my mother in her native Gujarati, and got the chef to prepare ethnic meals for her, as she was a vegetarian. The fact that LOROS makes an effort to support patients and families through a difficult time, with the families' religious and cultural beliefs in mind, far exceeded our expectations".

Most hospices have professionals who are charged with providing and coordinating spiritual care for all patients; for patients of all faiths, and for patients of none.



THE CHALLENGE OF SOCIAL EXCLUSION

There are several groups of people who might be seen as being 'outsiders', because of who they are, or how or where they live.

Gypsies and travellers, the homeless and prisoners have been identified as unpopular and stigmatised groups who have some common factors that could prevent or impede their access to palliative care:

- ♦ where they live
- ♦ poor primary care provision
- ♦ communication challenges
- ♦ negative attitudes towards them from the public as a whole.

Gypsies and travellers have considerable problems with accessing the healthcare system, partly through the practical problems rising from their nomadic

way of life, but also due to reluctance among many GPs to register travellers, or visit their sites. Communication difficulties are common between the travellers and health workers, with Gypsies and travellers having a high expectation of racism and prejudice ⁽¹⁴⁾.

The homeless share many of these difficulties. In addition, their irregular life styles, with high levels of mental illness, drug and alcohol abuse, make them difficult to reach ⁽¹⁵⁾. Where individuals have added problems of mental illness, drug or alcohol abuse, this creates additional barriers to access.

CARE OF THE HOMELESS

The Mission Hospice Programme in Ottawa in Canada is an imaginative programme that recognises that people live in different ways and has used this recognition to develop a programme that meets the needs of its constituency.

This programme provides dedicated palliative care to homeless people in a shelter in the inner city. It provides a home where people can live well for their remaining days, improving both quality of life and life expectancy.

The programme provides high quality medical, nursing and personal care, rehabilitation and spiritual care. Challenging behaviour and mental health problems, including drug and alcohol abuse, are supported and managed in a safe and familiar environment. Patients' biological and street families are encouraged to take part in their care, and many

patients have been reunited with long estranged families. The hospice provides support for end of life planning, and those who wish to die at home in their hostel can do so surrounded by family, friends and volunteers.

Facts & Figures

- ◆ There were 3,112 known rough sleepers in London during 2004.⁽¹⁶⁾
- ◆ There were 14,000 people living in hostels in London in 2004.
- ◆ 18% of rough sleepers are over 50 years of age.

GERRY'S STORY

Gerry had been homeless since the age of 13, spending years on the streets or in prison. Long estranged from his family, he lived with a multiplicity of illnesses and addictions coupled with a severe and persistent mental illness. He had spent most of his life excluded from services because of his behaviour and mental illness. Despite this, he became a favourite with clients, staff and volunteers at the hospice, and the sense of belonging and acceptance that he gained there brought incredible joy in his life. With the help of the hospice staff, he was able to be reunited with his family, and they were with him when he died peacefully in the hospice. He said that being in the hospice was the happiest time of his life.

“This programme does more than simply take care of the dying: it has strengthened our community and brought dignity and meaning to the end of life for a group of people who desperately need and deserve it”

Wendy Muckle, Project Director,
Ottawa Inner City Health Initiative





CARE OF PRISONERS

Prisoners do have access to healthcare, now provided by the NHS through their local primary care trusts (PCTs). Services are predominantly focused on mental health and drug and substance abuse programmes. There is a lack of awareness of the needs of older prisoners⁽¹⁷⁾ but, with changes in sentencing policy, the number of older prisoners is growing every year. Despite a requirement for a palliative care policy for each prison, not all were in place by the end of 2004 ⁽¹⁷⁾.

St Catherine's Hospice in Preston works closely with the PCT responsible for the four prisons in its catchment area. The palliative care nurse specialist will visit the prisons on request and provide advice to the prison healthcare team on symptom control and support and advice to the patient. Recently, a long stay prisoner spent 10 days in the hospice for symptom management and pain control. At his own request, he then returned to the prison, which

he felt was his home and where he had friends, and there he spent his last days. Another prisoner nearing the end of his life wanted to return to the city of his birth. The hospice helped to arrange a transfer to the hospice near his original home and family, where he died peacefully.

Facts & Figures

- ◆ In England and Wales in 2003 there were 1,469 prisoners over the age of 60 years.
- 83% of prisoners over 60 years of age have a longstanding illness or disability. ⁽¹⁸⁾



THE CHALLENGE OF DIAGNOSIS

The great majority of patients cared for currently by hospices and palliative care services have cancer. Palliative care and hospice services developed in response to the very real needs of dying cancer patients for pain and symptom control and to their need for emotional, psychological and spiritual care, but there is now a recognition that people with other life limiting illnesses share many of the symptoms and needs of the cancer patient ⁽¹⁹⁾.

More work is now needed to understand the best way to provide care to give them the best possible quality of life. Some hospices already provide care for a range of illnesses and hospices are increasingly interested in extending and developing care, for example, to patients with motor neurone disease, heart failure and respiratory disease. Palliative care professionals have much to offer these patients, but there is concern about staff having the necessary expertise and anxiety about the capacity of the

current services to provide for them without compromising the care of their existing patients.

A number of projects based in hospices have developed different strategies to extend care to the patient with a condition other than cancer, not only to provide a service but to understand the different needs of these patients and the most appropriate ways of delivering the care.

Weston Hospicecare in Somerset has developed a programme to provide palliative care for patients with respiratory disease. The aspect of the care most appreciated was the physiotherapy input to relieving the very distressing symptom of breathlessness. Control of breathlessness has improved patients mobility, independence and quality of life. Patients have also been taught strategies to deal with panic and anxiety. Complementary therapies have been very useful in promoting relaxation.

WHAT THE HOSPICE MOVEMENT IS DOING TO IMPROVE ACCESS

Many individual hospices are working very hard to ensure that their local communities are made welcome and that their services take account of the needs of often very diverse communities.

Help the Hospices is funding a project working with a wide range of professionals and independent hospices to improve access to marginalised or disadvantaged groups in our society. The project has developed a series of workshops to help hospices work with their local health communities to identify the factors that are inhibiting access to their services and then set in place structures and systems that will ensure access for all, no matter who they are or what their difficulties.

Involving the community

St Luke's Hospice and the hospital Macmillan team in Basildon gathered together a group of people from a range of communities and groups, including representatives from different faith groups and people with disabilities. The resulting Valuing Local Diversity Group will drive forward the development of appropriate services, responding to the expressed wishes of the local communities. Small working groups have been formed, and included in their plans are awareness sessions intended to improve information about palliative care, open days at the hospice and the development of a local resource pack giving information on local community services and support and translation services. The initiative has had wide support, including that of the South Essex supportive and palliative care management group.

Identifying the needs of specific groups

St Gemma's Hospice in Leeds held a multidisciplinary meeting to review the needs of people with severe mental illness and palliative care needs. Among the recommendations for supporting this group of people through their cancer journey included providing an advocate to support the patient through the diagnostic and treatment process, developing skills in palliative care among mental health staff and improving the palliative care team's understanding of patients' mental health needs.



WORKING IN PARTNERSHIP

Despite the many problems in access to services, there are a number of initiatives across the country, and internationally, to bring improvements to the care of patients.

One of the most important initiatives is the Gold Standards Framework (GSF) ⁽²⁰⁾, developed by a GP and now being rolled out across the country. The primary aim of GSF is to improve the organisation and quality of care for patients in the last stages of life in the community, so that more live and die well in their preferred place of care. Hospices and palliative care teams are key players in the successful implementation of GSF.

The two key tools are simple:

- ♦ develop and maintain a register of patients with palliative care needs

- ♦ meet as a team to assess, plan and communicate the care of these patients.

Epsom GP Amanda Free says: "I introduced the GSF into our practice in June 2003. We have had the support of the community team from the Princess Alice Hospice from the beginning, and without this support I don't believe that the project would have been as successful as it has been.

We are a large training practice with 16 partners and 25,000 patients. In such a large practice communication and coordination can be difficult. By using GSF we have managed successfully to work together as a team to provide the best care possible for our patients. The team includes the hospice palliative care nurse, primary healthcare team members and the Home Services Officer from Social Services.

In the words of a patient whose husband died at home, *'Everyone who was involved with his care worked so effectively together, providing excellent and seamless care. I felt everyone was sensitive to our needs and worked to get the correct balance between being there when needed but not being over-intrusive.'*

Through using GSF I feel we have truly achieved collaborative working between primary care and hospice, working as one team, with the patient at the centre of it. The commitment and enthusiasm of all involved has been heartening".

WHAT MORE NEEDS TO BE DONE?

It is essential to ensure that everyone can get the care they need, wherever they are in the country - and this should be a right for all, not a luxury.

- ♦ All parts of the healthcare system should reach out to marginalised and vulnerable groups to ensure that their palliative care needs are assessed and addressed, based on their individual needs and preferences. A concerted programme of projects aimed at specific groups needs to be rolled out across the country, learning from best practice.
- ♦ Healthcare providers and networks should ensure that appropriate and effective palliative care referral systems are in place and that effective coordination of care takes place at all levels.
- ♦ Hospices and palliative care services should ensure that they provide good quality information on the full range of their services to healthcare professionals, patients, their families and carers and to the general public, including those from marginalised groups and minority communities.
- ♦ Government should recognise, encourage and adequately fund the role of hospices as resource centres for providing education and training to generalists. This is a key contribution that hospices make to the wider health economy and is one mechanism for driving up quality of care in hospitals and nursing homes.
- ♦ Adequate study of palliative care should be integrated into the education programmes of all healthcare professionals during initial training and through continuous professional development.
- ♦ Government should act urgently to ensure that independent hospices receive the full costs they incur from providing end of life care services for the NHS. Currently the Government contributes an average of 33% of adult hospice costs in England. The remainder is raised through public donations.



"Our vision is of a world in which the best possible care is available to all people at the end of life, whatever their circumstances"

Help the Hospices

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RESOURCES AND CONTACTS

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Tel: 020 7520 8200
Email: info@helpthehospices.org.uk
Website: www.helpthehospices.org.uk

Hospice Information

Hospice House
34-44 Britannia Street, London WC1X 9JG
Tel: 0870 903 3 903 (national rates apply)
Email: info@hospiceinformation.info
Website: www.hospiceinformation.info

National Council for Palliative Care

The Fitzpatrick Building
188-194 York Way, London N7 9AS
Tel: 020 7687 1520
Email: enquiries@ncpc.org.uk
Website: www.ncpc.org.uk

The Scottish Partnership for Palliative Care (SPPC)

1a Cambridge Street, Edinburgh EH1 2DY
Tel: 0131 229 0538
Email: office@palliativecarescotland.org.uk
Website: www.palliativecarescotland.org.uk

Marie Curie Cancer Care

89 Albert Embankment, London, SE1 7TP
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Email: info@mariecurie.org.uk
Website: www.mariecurie.org.uk

Association of Children's Hospices

First Floor, Canningford House, 38 Victoria Street,
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Tel: 0117 989 7820
Email: info@childhospice.org.uk
Website: www.childhospice.org.uk

Childhood Bereavement Network

8 Wakley Street, London EC1V 7QE
Tel: 020 7843 6309
Email: cbn@ncb.org.uk
Website: www.childhoodbereavementnetwork.org.uk

National Network for Palliative Care of People with Learning Disabilities

PO Box 522, Cambridge CB1 0BL
Tel: 01223 460473
Email: LindaMcEnhill@natnetpald.org.uk
Website: www.helpthehospices.org.uk/NPA/learningdisabilities

Sue Ryder Care

Second Floor,
114-118 Southampton Row, London WC1B 5AA
Tel: 020 7400 0440
Email: via website
Website: www.suerydercare.org

Macmillan Cancer Support

89 Albert Embankment, London SE1 7UQ
Tel: 020 7840 7840
Email: via website
Website: www.macmillan.org.uk

Cancer Black Care

79 Acton Lane, London, NW10 8UT
Tel: 020 8961 4151
Email: info@cancerblackcare.org
Website: www.cancerblackcare.org.uk

Cancerbackup

3 Bath Place, Rivington Street, London EC2A 3JR
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Email: info@cancerbackup.org.uk
Website: www.cancerbackup.org.uk

The Neurological Alliance

Stroke House, 240 City Road, London EC1V 2PR
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Website: www.neural.org.uk

British Heart Foundation

14 Fitzhardinge Street, London W1H 6DH
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Helpline: 08450 70 80 70
Email: via website
Website: www.bhf.org.uk

British Lung Foundation

73-75 Goswell Street, London EC1V 7ER
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