UNITED KINGDOM

Population: 60,609,153

Current Directory:

Printed version	*	Hospice and Palliative Care Directory UK and Ireland (2005)
Online version	*	http://www.hospiceinformation.info/

None identified

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Palliative Care Services

NK = not known

Number of Palliative Care Services

	Inpatient Palliative Care Units	Hospices	Consultant Teams in Hospitals	Home Care Teams	Day Centres	Total
Adult/Children	63	158	305	356	257	**1139**
Paediatric only	0	34	112	112	0	**258**

	Inpatient Palliative Care Units/ hospices	Chronic Hospitals /Nursing Homes	Total
Number of beds allocated to adult palliative care inpatients	2515	665	**3180**
	Adults	**Children**	**Total**

Number of Bereavement Support Teams	350	48	**398**

Comments/Sources

- **The number of beds allocated to adult palliative care inpatients in chronic hospitals/nursing homes is estimated from the figures given by hospital support teams. There are other beds in small local hospitals where patients may be cared for by a general practitioner or specialist nurses.**
- **The number of paediatric hospital/home care teams are based on an estimated joint figure of 224 for both services provided by the Association for Children with life-threatening or terminal conditions and their families (ACT) (representing the number of teams held on their database). There will be other teams not included within this figure.**
- **Many palliative care units and teams provide bereavement support as part of their work. Referrals may also be made to other bereavement support organisations which are not exclusively connected with palliative care.**

[Hospice and Palliative Care Directory UK and Ireland 2006]

[Association for Children with life-threatening or terminal conditions and their families]

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Adult Palliative Care Population

95%	of patients receiving palliative care have a cancer diagnosis
5%	of patients receiving palliative care have other incurable conditions

	Cancer	**(n)**
Number of patients who die at home	NK	NK
Number of patients who die in a general hospital	NK	NK
Number of patients who die in other healthcare institutions	NK	30,000

Comments/Sources

- **Number of patients who die in other healthcare institutions is an estimate only.**
- **Percentage of patients receiving palliative care that have other incurable conditions is for in-patient units only; hospital-based teams see an average of over 11% non-cancer patients.**

[Minimum Data Sets project survey 2004]

[Deaths in hospices and palliative care units – MDS survey 2004]

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Palliative Care Workforce Capacity

	Full-time	**Part-time**	**Total**
Physicians	442	316	**758**
Nurses	NK	NK	**4950**
Social Workers	NK	NK	**200**
Psychologists	NK	NK	**NK**
Physiotherapists	NK	NK	**112**
Occupational Therapists	NK	NK	**107**
Spiritual/Faith leaders	NK	NK	**202**
Volunteers	NK	NK	**70,000**

Comments/Sources

- **The number of spiritual/faith leaders is a minimum estimate based on membership of the Association of Hospice Chaplains. There are many more spiritual/faith leaders who work with palliative care patients.**
- **The number of volunteers is a minimum estimate based on Davis Smith (2004).**

[Association for Palliative Medicine of Great Britain and Ireland]

[2005 *National Workforce Survey of Specialist Palliative Care Staff* carried out by The National Council for Palliative Care on behalf of The National Partnership Group]

[Association of Hospice and Palliative Care Social Workers]

[Association of Chartered Physiotherapists in Oncology and Palliative Care]

[Specialist Section of Occupational Therapists working in HIV/AIDS, Oncology and Palliative Care Education]

[Davis Smith, J. (2004) *Volunteering in UK hospices: looking to the future*. London: Help the Hospices]

[Association of Hospice Chaplains]

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Funding of palliative care services	
Total number of palliative care services funded by the government	**NK**
Total number of palliative care services funded privately or by NGO's	**NK**

Comments/Sources

- **Palliative care services funded by the government: Inpatient care 30%; Home care 59%; Day care 23%; Hospital Support 83%**
- **Palliative care services supported by a combination of private and public funds: Inpatient care 70%; Home care 40%; Day care 77%; Hospital Support 27%.**

[Hospice Information Directory database, 2005]

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Perceived use of main opioids in palliative care

Order of frequency	Opioid	Estimated cost per month (€)
First opioid	Morphine (oral)	€8
Second opioid	Diamorphine (subcutaneous infusion)	€43
Third opioid	Fentanyl (transdermal)	€83

Comments/Sources

[Data given by Hospice Pharmacist]

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Key issues and challenges

- The main barrier to the development of palliative care is also the reason it has developed as a distinct specialism in the first place. It is the tendency of mainstream health services to focus on curing disease and saving lives and this results in care of the dying not being given priority. Because improvements in quality of life are difficult to measure, palliative care has tended not to feature in national NHS targets. The tendency to focus on curing disease has also meant that many healthcare professionals perceive death to be a poor outcome and may not be comfortable discussing palliative care with patients because it is associated with dying. We are now seeing the mainstreaming of palliative care into generalist healthcare and hopefully this will start to change the situation.
- The availability of a skilled palliative care workforce: the UK is currently facing shortages of healthcare staff and this has an effect on palliative care amongst other specialisms. Even when funding has been made available to support palliative care, services are not always able to grow as quickly as they would like to because of the time and resources that are required to train new specialists.
- There is a need for more training for generalist healthcare staff in palliative

care. Progress has been made in this area, with statutory funding now available for training district nurses in palliative care, and for rolling out the Macmillan Gold Standards Framework in GP practices. We hope to see improvements in the skills of generalist healthcare staff as a result of these initiatives.

- There is currently insufficient funding of both generalist and specialist palliative care in the UK and also a lack of clarity and transparency in the way in which statutory funding is made available. Palliative care in the UK was pioneered by local hospice charities and was originally funded entirely from voluntary income. Over time, palliative care services have developed in both the NHS and the voluntary sector and the NHS has increased the contribution it makes to palliative care services. However, services in both sectors still receive a significant proportion of income from charitable sources. The NHS contribution is variable around the country, and tends to be a contribution towards costs rather than payment for a specific level of services.
- There is a lack of availability of controlled drugs outside of standard working hours.
- The high-profile conviction of Dr Harold Shipman (a GP who murdered over 215 of his patients using Diamorphine), may have made GPs more reluctant to prescribe morphine for patients.

[EAPC Palliative Care Euro-Barometer 2005]

Palliative care accreditation

- "Palliative Medicine was recognised as a specialty in 1987 when specialist medical training programmes were established for doctors. Historically, most nurses working in palliative care undertook Care of the Dying courses validated by the English National Board for Nursing. Now, many nurses working in palliative care will have a first degree, and a smaller number will have a master's degree or a doctorate based exclusively in palliative care or incorporating palliative care modules in curricula."

[EAPC Palliative Care Facts in Europe Questionnaire 2005]

Palliative care milestones

- *2000:* The NHS Cancer Plan is published, promising £50m additional investment per annum for specialist palliative care.
- *2004:* The National Institute for Clinical Excellence guidance on *Improving Supportive and Palliative Care for Adults with Cancer* sets out the services that should be available and each of the 34 cancer networks in England produces an action plan to implement this guidance over the next few years. This provides the basis for commissioners to undertake local needs assessment to see how closely current services match what should be available. It also provides a basis for peer review of services and for the development of clear commissioning and funding arrangements for palliative care.
- *2004:* End of Life Care Programme for England is launched with a budget of £12 million over three years.
- *2004:* Help the Hospices marks the publication of the Council of Europe (2003) report on palliative care (Recommendation 24 of the Committee of Ministers to member states on the organisation of palliative care) by printing the report in the UK, circulating it at the Korea World Summit of National Associations for Palliative Care, and making it available at the European

Health Forum.

[EAPC Palliative Care Euro-Barometer 2005]

Health policy

- The National Partnership Group for palliative care in England brings together the Department of Health, national hospice and palliative care charities, local NHS trusts and service providers from the NHS and voluntary sector, with the aims of ensuring that funds are spent appropriately and developing a future funding framework for specialist palliative care.
- There has been an increase in statutory funding in the last three years, following the publication of the NHS Cancer Plan 2000 and also the creation of the End of Life Care Initiative. It is hoped that the Payment by Results system which is currently being developed will result in more statutory funding being made available and provide much needed clarity about funding of specialist palliative care. The Government has recently begun to provide specific funding for the development of palliative care services provided by generalists, but more resources will be needed to really mainstream palliative care practice across generalist healthcare.
- The palliative care needs of patients with a wide range of conditions have been addressed through the implementation of the various National Service Frameworks. Following the publication of the NICE guidance (2004), minimum service specifications for specialist palliative care services are now under development which will set out what should be commissioned locally. The NICE guidance does not cover the needs of people with life threatening illnesses other than cancer or of children. However, it is seen as a starting point for the development of further guidance addressing the palliative care needs of other groups.
- There has been increasing interest from the public and civil society in hospice and palliative care and in issues relating to the end of life more generally. Patient representative organisations and other charities such as older people's organisations are taking an interest in the availability of palliative care for their stakeholders. There has also been an increase in media interest in palliative care and care at the end of life. This interest offers an opportunity to generate greater awareness of palliative care and to generate political momentum for further service development.
- The thriving voluntary sector has allowed services to be developed locally and flexibly to meet needs. The level of investment through personal donation has enabled palliative care services to develop more rapidly than they would have done if they had been entirely reliant on public funding. The disadvantage has been that these developments have been located where there was a public will and the means to do so, rather than following any strategic plan. This may have left some areas underprovided for compared with others. The commitment of local communities to develop and sustain local services is highly relevant. Funding from major charities has supported other aspects of growth (such as specialist palliative care clinicians) through charitable funding to fill prime posts in areas of need.
- Help the Hospices has not participated in any way in the Council of Europe discussions about euthanasia (the Marty Report).
- A draft Bill to legalise physician assisted suicide and euthanasia was

considered by a select committee of the House of Lords, which reported in April 2005. The Bill did not proceed any further due to the general election.
[EAPC Palliative Care Euro-Barometer 2005]

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