

**A NEEDS ASSESSMENT
FOR
PALLIATIVE CARE
IN THE EASTERN REGION**

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Executive Summary

The World Health Organisation has defined palliative care as the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment. Specialist palliative care services are those services with palliative care as their core speciality.

The aims of the study were to assess the needs for specialist palliative care services in the Eastern Region in respect of adult patients with **malignant and non-malignant disease** in line with the Report of the National Advisory Committee on Palliative Care and to project the likely future needs for specialist palliative care services in the Eastern Region.

The report begins with a review, which examines the delivery of specialist palliative care services, nationally and internationally, to allow comparison between Irish specialist palliative care services and other models. Information regarding morbidity and mortality from cancer and other diseases with a palliative care component is presented and population projections together with National Cancer Registry Ireland projections are applied to predict the need for services in the region over the next 10 years. A description of present services and their utilisation is also presented to compare the services throughout the region and to estimate current service use. Qualitative and quantitative research methods are employed to estimate the views of service providers regarding satisfaction with present services and to highlight priority areas for service development.

The population of the Eastern Region is projected to increase to 1.6 million by 2011 with marked increases in the 45-64 and over 65 year age groups. Older people are much more likely to develop cancer, with the risk doubling in every successive decade of life. Most patients are over 65 at the time of diagnosis and nearly three quarters of all cancer deaths also occur in those over 65.

Malignant disease accounts for approximately one quarter of all deaths in the Eastern Region. In the period 1994-1998 the total number of cancer cases (excluding non-melanoma skin cancers) in the Eastern Region was 20,912 giving a yearly average of 4,182 cases. The leading causes of cancer deaths in the region included cancer of the lung, colo-rectum, breast, prostate and stomach. In the 15 year period 2000-2015 there is a projected increase of 31% in the number of malignant cancer cases in the Eastern Region. This increase is sharpest in those aged 50 years and over.

Traditionally and in practice, palliative care in Ireland, as in other countries such as the UK, has focused on the terminal care needs of patients with cancer and generally about 95% of patients availing of the specialist palliative care services have some form of cancer. Admission to the specialist palliative care services in the region is more restrictive where non-malignant disease is concerned. Patients with AIDS and motor neurone disease are currently accepted but the limited number of specialist palliative care places available restricts the number of places available for these patients.

Based on population and cancer case projections together with the likely needs of non-cancer patients, the Eastern Region will need the capability of dealing with upwards of 2,000 admissions per year for both malignant and non-malignant conditions by 2011. Furthermore research would suggest that if the needs of all patients (cancer and non-cancer patients) for palliative home-based care are to be met then the Eastern Region will need the capability of dealing with as many as 5,000 patients and their families by 2011.

There are currently 55 specialist palliative care beds in the Eastern Region. To meet projected needs for in-patient palliative care for all patients the Eastern Region will need 128-160 specialist palliative care beds by the year 2011. The inevitable increase in demand for home based care will also require a significant expansion of current home care and day care services.

Notwithstanding the superb work currently being done by all those employed in the delivery of specialist palliative care the results of the survey of service providers revealed a relatively high level of frustration and dissatisfaction with current service capability. Areas of unmet need that were found consistently throughout the different groups of service providers included (a) the need for palliative care services for non-cancer patients (b) the need for more beds across all sectors of the service (c) the need for the expansion of day care and home care services (d) the need for improved staffing in the service (e) the need for better integration of services between acute hospital, hospice and community level.

The review of current palliative care services and their utilisation has highlighted the ever increasing demand being made of the service at acute hospital, hospice and the home and day care level. Current staffing and infrastructure falls significantly short of the recommendations of the National Advisory Committee on Palliative Care that reported in 2001.

Excluding capital investment and to meet the recommendations of the National Advisory Committee on Palliative Care by 2011 in the Eastern Region it will cost (in today's terms) upwards of €26 million per year. It rests with the Regional Development Committee to advise the Chief Executive Officer on prioritisation and the allocation of all statutory resources, both capital and revenue for new and developing services.

1. Introduction

The World Health Organisation (WHO) has defined palliative care as ***the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment.***

It has been recommended that palliative care services be structured in three levels of ascending specialisation. These levels are dependant on the expertise of the health care professionals delivering the palliative care services.

Level one-Palliative Care Approach: All health-care professionals should practice palliative care principals. The palliative care approach should be a core skill for every clinician at hospital and community level. Many patients with progressive disease can have their care needs met satisfactorily without referral to a specialist palliative care service.

Level two – General Palliative Care: At an intermediate level, a proportion of patients and their families will benefit in the hospital or the community setting from the expertise of health care professionals who have some additional training and experience in palliative care. Such expertise may be available in hospital or community settings.

Level three – Specialist Palliative Care: These are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs and consequently require a greater degree of training, staff and other resources.

Following on the 2001 report of the National Advisory Committee on Palliative Care this needs assessment has been done to estimate the need for palliative care services for patients with both malignant and non-malignant disease in the Eastern Region.

2. Aims and Objectives

In line with the recommendations of the Report of the National Advisory Committee on Palliative Care, the aims of the study were:

1. To assess the current needs for specialist palliative care services in the three Area Health Boards of the Eastern Region in respect of adult patients with malignant and non-malignant disease
2. To project the likely future needs for specialist palliative care services in the Area Health Boards.

These aims were achieved through a series of objectives:

1. To review the different models of specialist palliative care available
2. To present population projections for the Eastern Region
3. To present cancer case projections for the Eastern Region
4. To describe the epidemiology of all diseases with a possible palliative care component in their optimum management will be described
5. To outline current specialist palliative care services in the three Area Health Boards in the Eastern Region
6. To establish the current levels of service utilisation by patients with specialist palliative care needs
7. To present the views of major stakeholder groups on the current specialist palliative care services in the three Area Health Boards in the Eastern Region
8. To make recommendations for the future needs for specialist palliative care services in the Eastern Region.

3. Methodology

3.1 Scope of the study

The specialist palliative care needs of adult patients with malignancies and with non-malignant diseases with a palliative care component in their optimal management in the three Area Health Boards of the Eastern Region were assessed.

3.2 Population projections

The various projections available for the population of the Eastern Region were considered and compared to estimate the current population and the most likely population size and profile in 2011.

3.3 Epidemiology of diseases with a palliative care component in their management

Data from the National Cancer Registry were used to estimate the current morbidity and mortality resulting from malignant diseases in the Eastern Region. These rates were then used in conjunction with the population projections to estimate the likely burden of these diseases in 2011. The other main diseases with a palliative care component in their optimal management were identified by a literature search and in consultation with the palliative care consultants. Mortality data from the Central Statistics Office were then used to estimate the current and future burden of these diseases and their mortality rates.

3.4 Data sources

The following data sources were used:

- National Cancer Registry
- Public Health Information System
- Central Statistics Office (CSO)
- Hospital In-patient Enquiry
- Department of Health and Children
- Health Information Unit, Department of Public Health, Eastern Region
- Hospital Annual Reports together with other data from individual institutions and service providers

3.5 Models of specialist palliative care services

A literature search was undertaken to identify the range of models of palliative care service provision available.

3.6 Description of current specialist palliative care service provision and utilisation

In consultation with the Palliative Care Consultants, the specialist palliative care services which are currently provided to adults in the Eastern Region's three Area Health Boards and their utilisation were described in detail. These services consist of the in-hospice, day care and home care level 3 services available as well as the specialist palliative care services provided in acute hospital settings in each of the Area Health Boards.

3.7 Qualitative and Quantitative research

When carrying out research involving patients in receipt of specialist palliative care services, cognisance must be taken of the fact that patients may only be in contact with those services for short periods of time before they die and may also be very ill during those short periods. This can be a very distressing period for the patients and for their carers and relatives. As information had previously been gathered from these stakeholder groups for the 1999 needs assessment by questionnaires and focus group discussions, it was decided that it was not necessary to consult with them again at this time.

The various groups of service providers were consulted again in order to gain as broad a view as possible of the specialist palliative care services currently available in each of the Area Health Boards and their utilisation. In the three years since the last needs assessment there had been significant changes in the demand for specialist palliative care services in the EASTERN REGION, with more cancer patients living longer on newer regimes of chemotherapy and/or radiotherapy. Both quantitative and qualitative information was gathered.

The Palliative Care Consultants in each of the Area Health Boards (AHBs) were requested to provide statistical data on the specialist palliative care services currently available in each of their AHBs.

Questionnaires were circulated to specialist palliative care service providers, consultant oncologists, consultants in specialities where there may be a palliative care component in caring for their patients with terminal diseases, area managers, general practitioners, specialist public health nurses and public health nurses. In the absence of validated instruments suitable for use in an Irish setting, specially designed questionnaires were developed in consultation with the palliative care consultants. These questionnaires were based on those used in the 1999 needs assessment and on those being used in similar studies being undertaken at the same time in all of the other health boards in Ireland.

Each questionnaire contained a section on satisfaction with existing services. A rating scale was used whereby the respondent was asked to put an X along a line of satisfaction from zero to ten. Then questions were asked relating to the numbers of patients with palliative care needs, both with malignant and non-malignant diseases, that the respondent was treating or had contact with. Some open questions regarding the adequacy of the present services and ways in which the specialist palliative care services could be improved were raised and the questionnaires concluded with information regarding the location and setting that the respondent worked in.

All the information collected was treated confidentially and all questionnaires were anonymised before the data were analysed for each of the stakeholder groups consulted.

(a) Questionnaire for Palliative Care Consultants

A questionnaire was sent to all of the Consultants in Palliative Care Medicine in each of the Area Health Boards. Palliative care is a developing speciality and, even in the three years since the 1999 needs assessment was undertaken, there have been significant changes in what the speciality has to offer, in the numbers of patients availing of specialist palliative care services in each of the AHBs and in the numbers of patients who would benefit from specialist palliative care. Because of the importance of this group in the provision of specialist palliative care services and in the development of those services, a group of three consultants, one from each of the AHBs, was consulted on the study and questionnaire design, and to gather information on current services, and all of the palliative care consultants in the EASTERN REGION were sent questionnaires.

(b) Questionnaire for Medical Oncologists

A questionnaire was sent to all of the Consultant Medical Oncologists working in hospitals with and without a specialist palliative care service in each of the Area Health Boards. These consultants were included because of their regular dealings with the specialist palliative care services.

(c) Questionnaire for Consultants

A questionnaire was sent to all Consultants in specialities where there may be a palliative care component in caring for their patients with terminal diseases, in the major hospitals with and without a specialist palliative care service in each of the Area Health Boards.

(d) Questionnaire for Area Managers

A questionnaire was sent to the Chief Executive Officers of each of the Area Health Boards, which they were asked to fill in and also to copy to their Assistant CEOs with responsibility for Palliative Care Services and to the General Managers in each of the Community Care Areas in their AHB.

(e) Questionnaire for General Practitioners

Lists of all general practitioners practising in the three Area Health Boards of the EASTERN REGION were obtained from the Primary Care Managers in each of the Area Health Boards. A 20% random sample was identified from the GPs in each of the AHBs, both from the GMS doctors and the non-GMS doctors listed. This resulted in a total sample of 150 doctors, 44 from the East Coast Area Health Board, 54 from the South-Western Area Health Board and 52 from the Northern Area Health Board. General Practitioners are important providers and co-ordinators of palliative care services in the community who liaise with and use the specialist palliative care services. The views of the GP were, therefore, seen to be very important in this study.

(f) Questionnaire for Public Health Nurses

The Superintendent Public Health Nurse in each Community Care Area was asked to complete a questionnaire and to circulate copies of the questionnaire to the Specialist Public Health Nurses and the Public Health Nurses working in that Community Care Area. The Public Health Nurse plays an important

role in the provision of community services and liaises with GPs and home care nurses in the provision of palliative care services.

3.9 Ethics

Ethical approval was not felt necessary for this needs assessment.

3.10 Data analysis

The quantitative data obtained was analysed using Epi Info 2000

4. Models of palliative care service provision

Palliative care services have been criticised for providing specialist care for a privileged few, mainly comprised of patients with malignancies living in certain geographical areas. There is, however, no routinely available information to prove or refute these criticisms (Gray and Forster, 1997).

Different philosophies regarding the most appropriate mix of palliative care services and the balance between home and institutional care have developed. Despite the development of specialist palliative care services, it is widely recognised that most patients who have progressive illness, which is no longer responsive to curative treatment, receive much of their care from the primary care team and hospital staff. The development of domiciliary palliative care teams, home nursing services and day care have increased the support available for patients, their families and other community services (Higginson, 1997).

4.1 Hospice care

The classic studies of public hospitals in the USA conducted in the 1960s showed severe shortcomings in the institutional treatment of dying people (Seale, 1989). The development of the modern hospice movement dates from the opening of St Christopher's Hospice in 1967 and its home care team in 1969. Since then it has spread worldwide and has shown that the basic principles derived from many sources can be interpreted in a wide variety of settings and cultures (Saunders, 1996).

Essential components of a hospice are small autonomous units (maximum 50-70 beds) having a high nurse to patient ratio, a mixture of patients including some long-stay and some brief admissions for pain control as well as patients admitted for terminal care, a home-care programme serving patients at home, spiritual support for staff and patients, a tradition of flexibility and open communication between staff and patients, staff and families and staff and other staff, minute attention to the relief of pain and other symptoms, full use of volunteers from the local community, willingness to teach and conduct research and support for the patient's family before and, where necessary, after the patient's death (Parkes, 1979a).

It is important to know what happens in hospices in order to assess the claims of hospice practitioners to be providing something different from traditional care. Such claims have thus far been evaluated mainly by studies employing the method of outcome measurement (Seale, 1989). One randomised controlled trial of hospice care found no difference between hospice and hospital care on a number of outcome measures including patients' anxiety, depression, pain and other cancer related symptoms and anxiety and depression in bereaved spouses. This study suggests, like the study of Parkes, that 'the hospice movement may have made its contribution by sensitising [hospital] practitioners to their inadequacies' (Kane, Wales, Bernstein et al., 1984). Another study suggests that hospice patients are more likely to know that they are dying than other patients with cancer who are not in receipt of hospice care (Cartwright, 1991).

Little is known about whether the growth of the hospice movement has been accompanied by a general rise in the standards of terminal care for all cancer patients, not just for those who receive hospice care. The presence of St. Christopher's Hospice may have had beneficial effects on terminal care in local hospitals, but it is not known whether similar changes in the standard of terminal care have followed the introduction of hospice care in other areas (Addington-Hall, MacDonald, Anderson et al., 1991).

Some evidence exists from both British and American studies that hospital care may have come closer to the hospice approach in recent times. This may be due to the educational effect of the hospice movement, particularly in the area of pain control. Further evidence, largely from America, suggests that there is also pressure on hospices to become more like hospitals, both organisationally and in terms of patient care (Seale, 1989).

The hospice approach to the giving of medical therapies emphasises the palliative rather than the curative. The largest evaluation study of hospice care was the American National Hospice Study which involved 40 hospice care programmes compared with 14 conventional oncological care settings. The results of this study confirm that hospice care is different from conventional care. Fewer diagnostic tests and therapies such as surgery, X-rays, transfusions, chemotherapy, respiratory support and anti-emetics were recorded for hospice patients (Greer et al., 1986).

A cross-cultural comparison of hospice institutions in the USA, Germany and Japan found no differences in basic hospice tenets, including better care for dying patients, focus on palliative care and no resuscitation. There were some differences between countries but these were mainly organisational or related to cultural factors (Voltz et al., 1997).

The rapid growth of specialist domiciliary and in-patient hospice services has resulted in another referral interface between primary and secondary care and also between secondary care services. One study revealed a number of significant differences between hospital-based consultant referrals and community-based GP referrals to an in-patient hospice. Consultant referrals had been diagnosed for a shorter period of time before admission, had a higher requirement for terminal nursing care and were more likely to die during the admission than GP referrals. They were also more likely to have a subcutaneous infusion pump and urinary catheter in situ and to be less mobile on admission and throughout the whole admission. Conversely, GP referrals were more likely to require respite care and to be discharged to home (Seamark, Lawrence and Gilbert, 1996).

Communication can be improved by keeping records of the information that is given to and received from patients and relatives. Hospices often use a special coloured sheet of paper in the medical notes for details of conversations about diagnosis and prognosis. This may also encourage better contact with relatives before and after death (Hockley, Dunlop and Davies, 1988).

Critics of the provision of special in-patient units for the terminally ill point to three supposed disadvantages of such places:

- The 'death-house' image. It is suggested that such places are likely to get a reputation as places where 'nobody gets out alive' which deters others from accepting admission.
- The 'depressing' environment. This suggests that any ward which contains more than a few dying patients will become gloomy and depressing.
- The 'upsetting' effect of deaths on the ward. It is suggested that patients in a unit with a high death rate are more likely to become aware of the death of other patients than at other hospitals.

These disadvantages are discussed and largely refuted in an article written about the effects of the services provided by St. Christopher's Hospice on patients (Parkes, 1979a).

Reviews of evaluations of hospice and palliative care conclude by stating that hospice care is no worse than conventional care and in some special centres is better (Higginson and McCarthy, 1989).

4.2 Hospitals

Palliative care services initially developed separately from major hospitals, either as independent in-patient hospice units or as community based domiciliary services. This has been interpreted as pEastern Regionps indicating a lack of appreciation of the need for palliative care services in major hospitals in the past (Chan and Woodruff, 1991). Although hospitals have traditionally focused on treating episodic acute illness and prolonging life, 65% of adults in the United States now die in hospitals (Meier et al., 1997).

There are, however, economic and social reasons why a busy hospital ward is quite unsuited for the care of patients with end-stage cancer. There is a need for a deliberate management decision on the part of hospital authorities to allocate both ward space and special staff in order to provide a high quality service with suitable surroundings and continuity of personal nursing by those skilled in the provision of palliative care (Allbrook, 1984).

Concern about the quality of care for dying patients in general hospitals has been provoked by a number of studies. Problems identified include staff avoidance of dying patients, inadequate symptom control, lack of provision of basic nursing care, poor communication, a focus on physical needs at the expense of psychosocial needs and being too busy to provide adequate care. Some comparisons of hospice and hospital in-patient care have suggested that higher standards are obtained in hospices, although others have detected few marked differences (Seale and Kelly, 1997). Evaluation of hospice services suggests that conditions for the dying in hospitals may have improved in recent years (Seale, 1989).

Since the early 1970s, the importance of disseminating the expertise developed in hospices to acute hospitals has been stressed. By the mid-1970s the idea of a hospice team working within the acute hospital emerged

at St Luke's Hospital, New York (Hockley, 1992). The first hospital palliative care service, the St Thomas' Hospital Terminal Care Support Team, was established in the United Kingdom in 1977 (Bates, Clarke, Hoy et al., 1981). In Ireland, the first such service was introduced in 1989 (Igoe, Keogh and McNamara, 1997).

These specialist hospital palliative care teams aim to bring the principles and benefits of palliative care into acute hospitals. The teams usually work in an advisory capacity providing symptom control and psychological support to patients and carers as well as playing an important role in education and advice within the hospital (Higginson, 1997). They vary in the number and type of professionals involved. There is some evidence to support the claim that such teams may improve care standards (Ellershaw, Peat and Boys, 1995).

One study found that since the establishment of such a specialist team in an acute hospital, the number of patients referred to the team had gradually increased showing that the team was accepted by most of the consultants. The main reason for patient referrals was palliation of symptoms from advanced cancer. A more objective measure of the effect of the team was the dramatic reduction in the number of complaints relating to terminal care (Hockley et al, 1988).

Another study found that, following the introduction of a palliative care service in a hospital, prescribing and symptom control, particularly with respect to pain, appeared to improve (McQuillan, Finlay, Roberts et al., 1996). An English study showed that the hospital palliative care team improves symptom control, facilitates understanding of the diagnosis and prognosis and contributes to the appropriate placement of patients. Another study looking at two hospital support teams highlighted difficulties in the assessment of the financial and spiritual needs of patients, the management of dyspnoea and the relief of family anxiety (Higginson, Wade and McCarthy, 1992).

The first objective of a hospital palliative care service must be to assist in the relief of pain and other distressing physical symptoms. While it may be argued that this is not the most important aspect of palliative care, pain and physical symptoms must be addressed first, as it is not possible to assess or treat other factors (psychological, social, spiritual, financial etc.) in patients with unrelieved pain or other distressing physical symptoms (Chan and Woodruff, 1991).

It has been pointed out that the palliative care support team  the acute hospital must act as a role model rather than taking over care and "de-skilling" the hospital team (Hockley, 1992).

4.3 Home care

Home care has been promoted as a way of improving the quality of life for the dying and their families as well as being a more cost-effective option than hospitalisation (Roe, 1992). As well as reducing health care costs, it also reduces the demand on acute care beds. At present, however, many people who would prefer to die at home are admitted to hospital for terminal care

because of inadequate support in the community. Not everyone dying at home needs specialist palliative care, but access to such a service should be available to anyone who does (Thorpe, 1993).

The first home care team was established at St Christopher's Hospice London, in 1969 and evaluation showed it to be successful. Patients could stay at home until a later stage in their illness and the length of time they spent in hospital was almost halved. Families were also satisfied with the help given by the home care staff and reported improved peace of mind for both themselves and the patients. Finally, the cost of home care was considerably less than that of in-patient care with resultant savings to the NHS (Parkes, 1980a). However, research has also indicated that home care can lead to poorer symptom control and increased demands on families (Rafferty, Addington-Hall, MacDonald et al., 1996).

The provision of domiciliary palliative care services varies world-wide. There is increasing evidence to suggest that comprehensive services can be provided in the absence of a traditional family doctor system by appropriately trained specialist teams. These teams should be invited in only after consultation with the primary care team (Doyle, 1997). In Italy, given the limited number of hospices available, the palliative care services have developed principally as home palliative care services (Peruselli, Marinari, Brivio et al., 1997). The prerequisites for good domiciliary care include a loving family, committed health care professionals and putting the patients needs and dignity first (Doyle, 1997).

One review looked at the effectiveness of home care programmes on quality of life and on reducing the percentage of days spent in hospital from the start of care until death. After reviewing the results of nine prospective studies, the conclusion was that home care programmes did not have a negative influence on quality of life or time spent in hospital and in some studies had a positive influence on these outcome measures (Smeenk, Van Haastregt, De Witte et al., 1998).

There is a great advantage in a strong link between a home care service and a palliative care centre. There is then ready access to beds for symptom control, rehabilitation and respite care and when a crisis arises necessitating admission. Day care is provided and additional facilities, either for out-patients or for patients at home, can include physiotherapy, occupational therapy, complementary therapy and advice from social workers and chaplains (Thorpe, 1993).

4.4 Day care and out-patient care

The first purpose-built day hospice was opened in Sheffield in 1975. The 1998 hospice directory lists 245 day hospices, over two thirds of which are attached to in-patient palliative care units (St Christopher's Hospice Information Service, 1998). Most of the day care units in the United Kingdom are based in specialist palliative care units, operate on weekdays and cater for ten to fifteen patients each day. Those attending from home are brought by car or ambulance at 10am and taken home between 3 and 4pm (Doyle, 1997).

Few studies have been carried out on day care but subjective views of patients suggest that day care affirms living rather than dying and that its patients can go into long term remissions. What is equally important is the respite that it offers to the patients' relatives (Doyle, 1997).

Out-patient services enable the general practitioner to obtain specialist advice on any aspect of a patient's needs whilst still maintaining care at home. Such a facility should not be regarded as a substitute for a domiciliary service where the patient is visited at home by the palliative care team. Although it enables patients to be given specialist advice, it does not enable the team to see and assess the home situation nor to meet the relatives (Doyle, 1997).

4.5 Support teams

A support team is one which sees patients in hospital out-patients and wards and also assists the families of those who are caring for a terminally ill patient at home who may want to die at home. In 1975 there were two such teams in Great Britain whereas in 1980 this number had increased to 32 (Evans and McCarthy, 1984). The 1998 directory of hospice services lists 150 hospital palliative care/ support teams and 204 hospital support nursing services (St Christopher's Hospice Information Service, 1998).

The terminal support team is a multidisciplinary one whose aim is to provide skills in symptom relief and to support the patient and his family. The St Thomas' Hospital support team was established in 1976 to provide patient and family support so that patients who wished to do so could die at home. The team does not assume management of patients but will provide advice and family support when requested to do so by the patient's hospital doctor. The team will continue to see the patient after discharge with the general practitioner's permission. Regular meetings are held to discuss all cases. The team is available 24 hours a day but, due to the fact that clinical responsibility remains with the patient's doctor, most out of hours problems can be dealt with over the telephone (Bates et al., 1981).

The advantages of the terminal support team are that it is relatively inexpensive to run when compared with an in-patient hospice, it has great teaching potential and it can bring the principles of hospice care to patients at home and in the hospital at an early stage. One disadvantage may be the potential confusion over responsibility for patient care. The team must be backed up by doctors with experience in palliative care, and the ideal support team would include both a hospital doctor and a general practitioner (Bates et al., 1981).

5. Population Projections in the Eastern Region

Ireland

The total population of Ireland was 3.9 million in 2002 (Census 2002). By 2011 the national population is projected to reach 4.20 million (an increase of 8% over the next 9 years).

Eastern Region

The total population of the Eastern Region was 1.4 million in 2002 (Census 2002). By 2011, the Eastern Region population is projected to reach 1.5 million through natural increase alone and up to 1.6 million when migration flows are included (an increase of 14% over the next 9 years).

Key changes in individual age groups in the Eastern Region are as follows:

1. In the 15 year period 1996-2011 the under 15 year population in the Eastern Region, is projected to increase again in the Eastern Region .
2. In the 15 year period 1996-2011 the 15-44 year old population in the Eastern Region is projected to increase by 3% through natural increase alone and by between 13%-15% when migration flows are included which is similar to the 15% rise seen in the period 1981-1996.
3. In the 15 year period 1996-2011 the 45-64 year old population in the Eastern Region is projected to increase by 39% through natural increase alone and between 46%-48% when migration flows are included. Over the 30 year period (1981-2011), this age group is projected to have increased by 79% through natural increase, and approximately 90% when migration flows are included, making it the fastest growing age group in the region.
4. In the 15 year period 1996-2011 the over 65 year age population in the Eastern Region is projected to increase by between 25%-29% involving a further 31,000 persons through natural increase alone and approximately 35,000 persons when migration flows are included.
5. In the 15 year period 1996-2011 the over 75 year age group in the Eastern Region is projected to increase by a further 10,000 persons approximately.

Conclusion:

The population of the Eastern Region is projected to increase to 1.6 million by 2011 with marked increases in the 45-64 and over 65 year age groups.

Older people are much more likely to develop cancer, with the risk doubling in every successive decade of life. Most patients are over 65 at the time of diagnosis and nearly three quarters of all cancer deaths also occur in those over 65 (National Cancer Registry Ireland, 2001)

6. Cancer Case Projections in the Eastern Region

In the period 1994-1998 the total number of new cancer cases (excluding non-melanoma skin cancers) in the eastern region was 20,912 giving a yearly average of 4,182 cases. The leading types of cancer included cancer of the lung, colo-rectum, breast, prostate and stomach.

This data from the National Cancer Registry Ireland, in conjunction with the population projection presented in section 5, were then used to estimate the likely burden of all cancers (excluding non-melanoma skin cancers) in the Eastern Region in the years 2000, 2005, 2010 and 2015. See table 6.1

Table 6.1 No. cases of malignant cancers in the Eastern Region 2000-2015

Year	Eastern Region Total No. of malignant cancers
2000	4,559
2005	5,136
2010	5,826
2015	6,632

Figure 6.1 presents the projected number of cases of all malignant cancers for each 5 year age group in the Eastern Region.

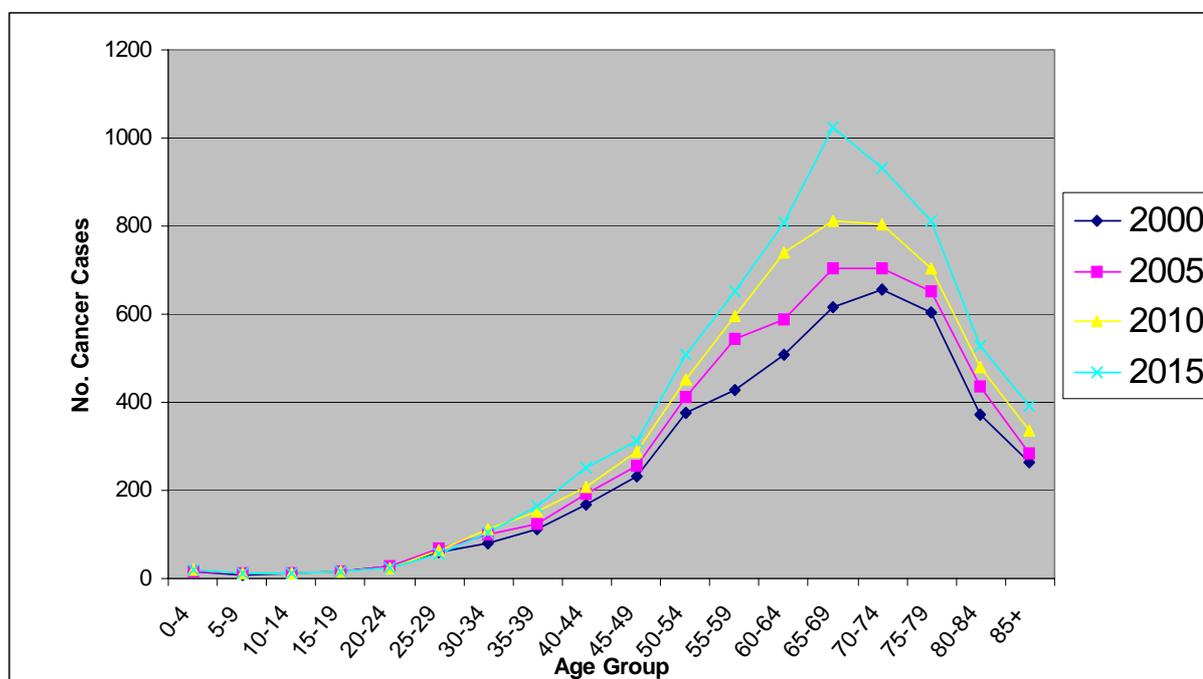


Figure 6.1 No. malignant cancer cases by age group in the Eastern Region 2000-2015

Conclusion

In the 15 year period 2000-2015 there is a projected increase of 31% in the number of malignant cancer cases in the Eastern Region. This increase is sharpest in those aged 50 years and over.

7. Epidemiology of diseases with a palliative care component in their optimum management

Traditionally and in practice palliative care in Ireland, as in other countries such as the U.K., has focused on the terminal care needs of patients with cancer and generally about 95% of patients availing of the specialist palliative care services have some form of cancer. Some patients with neurological conditions such as motor neurone disease or multiple sclerosis, and more recently some patients with AIDS, have been provided with palliative care but these still only represent a small fraction of those receiving palliative care. This is despite the fact that it is estimated that the palliative care needs of non-cancer patients may equal those of cancer patients, almost doubling the number of specialist palliative care beds required overall. This represents a huge area of unmet needs, which was emphasised in the report of the National Advisory Committee on Palliative Care.

Diseases with a palliative care component include:

1. Malignancies
2. Circulatory diseases
3. Respiratory diseases
4. Chronic liver disease
5. Renal disease
6. Neuromuscular & neurological disorders
7. AIDS
8. Children with life limiting disorders

7.1 Malignant Disease

During the years 1994-1998 the cancer incidence rates in the Eastern Region at 342/100,000 and 445/100,000 for males and females respectively, were 7% and 14% in excess of national levels. There was no significant change in cancer incidence or mortality rates overall between 1994-1998. It is projected that there will be a 31% increase in the number of cancer cases between 2000-2015, just over 2,500 more cases per annum (6,632 versus 4,559)

Data from the UK suggests that 15-25% of patients who die from cancer receive inpatient hospice care. Using the projected figures of malignant cancer cases for the Eastern Region and a figure of 20% that will require inpatient hospice care table 7.1 shows the total number of cancer cases and the number that will require inpatient hospice care in the Eastern Region.

Table 7.1 Projected total number of malignant cancer cases and the number requiring in-patient hospice care in the Eastern Region 2005-2015

Year	Eastern Region Total No. of Malignant Cancer Cases	Eastern Region Malignant cancer cases requiring hospice care
2005	5,136	1,027
2010	5,826	1,165
2015	6,632	1,326

7.2 Cardiac disease:

Cardiac failure affects 1-2% of the adult population, the prevalence increasing with age (>10% of those aged over 70). Up to 30% of patients with cardiac disease require hospitalisation.

7.3 Respiratory Disease

The commonest chronic respiratory disorder requiring palliative care is chronic obstructive pulmonary disease. Studies of the palliative care needs of patients with COPD reveal a poor quality of life related to the high degree of social isolation and emotional distress, associated with their physical symptoms and a poor degree of physical functioning and increasing disability.

7.4 Motor Neurone Disease:

Deaths attributed to neurological disorders are relatively rare and patients suffering from diseases such as motor neurone disease and multiple sclerosis have differing palliative needs to cancer patients and other non-cancer patients. A major difference is the long-term nature of the diseases during which palliative care may focus on the need for respite care, with only 20% of hospice referrals with motor neurone disease required for terminal care. The prevalence of symptoms in patients with MND is similar to that in cancer patients but at present in Ireland fewer are referred for symptom control/palliative care.

5.5 AIDS patients

With the advent of anti-retroviral treatment, AIDS patients are living longer. However, it is an ageing illness and, as it progresses, patients may become increasingly debilitated and dependent. A number will go on to develop AIDS dementia and require in-patient care in specialist units. Effective palliative care can help to avoid unnecessary suffering. (Wood C et al; ABC of palliative care: HIV infection and AIDS; BMJ; 1997; 315; 1433-1436). Generally it is recognised that AIDS patients as a group are considerably younger than other groups of patients requiring palliative care. Many may be homeless which makes home-based care problematic. Patients suffering from AIDS experience many different symptoms which may include pain together with other symptoms related to the pulmonary and gastrointestinal systems and skin problems. The prevalence of symptoms is frequently higher than in cancer patients and symptoms are moderate to severe in 35-70% of

cases. In one study in the UK, 21% of patients suffering from AIDS-related conditions died in a hospice, 57% in hospital and 22% at home.

7.6 Children with life limiting illnesses

The palliative care needs of children were not within the scope of the current study and are to be assessed at a national level in a separate needs assessment. Relative to adults, few children require palliative care and, for children with terminal diseases, the aim should be to support the family so that the child can die at home. Between one-quarter and one-third, of children with terminal diseases die in hospital. The annual mortality rate is approximately 1 per 10,000 for the population of children between 1-17 years of age. The prevalence of life limiting illnesses has been estimated as 10 per 10,000 for children 1-19 years of age. (Goldman, A; ABC of palliative care: Special problems of Children; BMJ 1998; 316; 49-52). There were 294,051 children aged 0-14 years in the eastern region in 1996 and using the PHIS projections there will be 319,891 children in this age range, in 2011. Using these data, it is projected that 28 children aged 0-14 years may die in 2011 and 240 children in the same age who may have a life limiting illness. At any time, about half of the children with a life limiting illness will need palliative care.

Conclusion

The population of the Eastern Region in 2011 is projected to be 1.6 million. The projected number of cancer cases in 2010 is 5,826 (See table 6.1). Data from the UK suggest that approximately 20% of patients who die from cancer actually receive inpatient hospice care, i.e. 1,165 patients in the Eastern Region in 2011 will need in-patient hospice care. This figure equates well to the work of Franks et al (2000). He has suggested that 40-70 cancer patients per 100,000 population will require in-patient care. Using this assumption, the Eastern Region will need to provide in-patient palliative care for 640-1120 cancer patients by the year 2011

Higginson has estimated that there will be 690 deaths/100,000 population due to progressive non-malignant disease, i.e. 11,040 deaths in Eastern Region in 2011. Franks et al (2000) has suggested that 20-70 non-cancer patients per 100,000 population will require in-patient care. Using this assumption the Eastern Region will need to provide in-patient palliative care for 320-1120 non-cancer patients by the year 2011.

A total of 960-2,240 admissions per year for both malignant and non-malignant conditions will be required by 2011 i.e. 1.5 - 4 times the current level of admissions.

Based on a review of available international data, The National Advisory Committee on Palliative Care recommended;

- Malignant cancer patients
 - 5 beds/100,000 population
- Malignant cancer patients plus patients with non-malignant conditions
 - 8-10 beds/100,000 population.

There are currently 55 specialist palliative care beds in the Eastern Region. Based on international recommendations the projected need is for 128-160 specialist palliative care beds by the year 2011. Franks et al (2000) also suggested 70-180 cancer patients per 100,000 population and 35-140 non-cancer patients per 100,000 population would require palliative care support at home. That is, if the needs of all patients for palliative home-based care are considered in the Eastern Region in 2011, 1,680-5,120 patients will require support at home.

8. Current service provisions for palliative care in the Eastern Region

8.1 Introduction

The population of the Eastern Region, which includes the counties of Dublin, Wicklow and Kildare, was 1.4 million in the 2002 census. The provision of palliative care services for this population varies between the different Area Health Boards. The palliative care services currently being delivered in the Health Authority are as follows:

8.2 Our Lady's Hospice, Harold's Cross

- **In-Patient Units**

Our Lady's Hospice was founded in 1879 by Mother Mary Aikenhead and the Irish Sisters of Charity. It is based in Harold's Cross which lies in the South-Western area of the Eastern Region.

Patients are generally admitted to the palliative care in-patient unit for pain and symptom control, respite care and terminal care. This unit has thirty-six in-patient beds for the provision of specialist palliative care services to patients suffering from malignant and non-malignant disease. Although the vast majority of in-patients are suffering from malignant disease, patients with HIV/AIDS, progressive neurological disease and other chronic non-malignant diseases have also been admitted to the unit in the past. However due to the demand on beds, hospice in-patient admission policy is quite restrictive in the admission of patients with non-malignant conditions.

A range of paramedical services is provided for hospice patients in Our Lady's Hospice including physiotherapy, occupational therapy and complementary therapy. Other ancillary services include social work, pastoral care and bereavement counselling.

- **Home care service**

Our Lady's Hospice has been providing home care services since 1985. Home care services are provided for those patients who are in need of specialist palliative care advice and input at home. The majority of patients seen have malignant disease. This is a 24 hour a day, seven day a week service which ensures that a member of the home care team is contactable at all times. An on call service is provided for problems that arise outside of regular working hours (i.e. 4.30pm-8.30am Monday to Friday and 24 hours during weekends). One nurse is on call every night with two nurses on-call during the day at weekends.

The nurses providing the home care service are split into three teams, each team covering a specific geographical area. Teams meet each morning to discuss management problems and a weekly meeting is held between representatives of the home care team and the oncology service in St Vincent's Hospital to discuss patients known to both services. Plans for services at Merrion/Blackrock are currently being developed.

Along with medical and nursing services, the services provided include occupational therapy, physiotherapy, social work and bereavement counselling. Occupational therapy services are provided by the community occupational therapist. The home care team usually accesses this service by consulting and discussing individual cases with the local public health nurse who then recommends referral to the community occupational therapy service. Physiotherapy services are arranged at community level, usually through the patient's general practitioner. Some patients of the home care team also attend the day care service where they may receive physiotherapy. There is no formal pastoral care service attached to the home care service and patients' spiritual needs are often met through the services of a local priest or minister. The home care nurses provide bereavement services.

Home care services may be accessed in a number of ways. Patients who are in-patients in a hospice or an acute hospital may be referred to the home care service on discharge for assessment. GPs may also refer directly to the home care service.

- **Day Care Service**

The day care service in Our Lady's Hospice, Harold's Cross commenced in February 1995. It offers a change of environment for patients and provides respite for their families and carers. Most patients availing of this service are suffering from malignant disease or HIV/AIDS.

The day care service can accommodate 42 patients over a three day week. Volunteers are actively involved in the provision of day care services. They transport patients to and from the hospice, they share their skills with the patients and help with the various outings and parties. A chaplain and a social worker also support the day care programme.

Day care activities include nursing procedures and advice, personal care, physiotherapy, occupational therapy, complementary therapies (e.g. aromatherapy and massage), relaxation, music and outings. Other activities requested by individuals can also be arranged.

Referrals to day care may be made by home care and by hospice doctors. All referrals are acknowledged or assessed within one week of receipt. A place is then offered to the patient as soon as one becomes available. The GP and public health nurse are informed of the patient's referral to day care by the home care team. All external day care patients remain under the care of the home care team.

- **Outpatient Services**

There is an increasing numbers of referrals to the multidisciplinary outpatient Palliative Care service. Patients are initially assessed at a medical/nursing clinic. From there patients can be referred on to complementary and supportive therapies, occupational therapy, physiotherapy or social work on an outpatient basis.

Table 8.1 Staffing levels (Whole Time Equivalents) of current specialist palliative care services in Our Lady's Hospice

	IN-PATIENT UNITS	HOME CARE (if applicable)	DAY CARE (if applicable)
<i>Doctors</i>	21 Consultant Sessions 4xNCHD	3.45xNCHD	3 Consultant sessions
<i>Nurses</i>	30.5	17.0	2.0
<i>Nurses Aides/Care Assistants</i>	22.5	0	1.0
<i>Occupational Therapists</i>	1.7	0	1.0
<i>Physiotherapists</i>	1.0	0.5	.5
<i>Complementary therapist</i>	2.4	0	1.0
<i>Pharmacist</i>	1.0	0	0
<i>Social Workers</i>	2.0	2.0	1.0
<i>Pastoral Care</i>	0.3	0.33	0.33
<i>Administrative staff</i>	2.0	1.5	0.54
<i>Volunteers</i>	30.0	0	10.0
<i>Other (please specify)</i>			
Number of beds/places	36	180 places	42 over a 3 day week
Waiting list (days vs weeks vs months)	2 weeks approx	2-3 weeks approx	2 weeks approx
Diagnosis of patients (malignant/non-malignant conditions)	99% / 1%		

8.3 St Francis Hospice, Raheny

- **In –Patient Units**

St Francis Hospice was originally founded in 1989 as a home care service for patients with cancer in north Dublin. It now provides a range of palliative care services, including in-patient specialist palliative care, for patients from the Eastern Region's Northern Area Health Board area.

The service has 19 beds for those in need of specialist palliative care. Most patients are admitted for symptom control or terminal care. Patients are also admitted for respite care. This unit accepts patients with malignant disease and with motor neurone disease.

As well as medical and nursing services ancillary services provided in St Francis Hospice include physiotherapy, occupational therapy, pastoral care, bereavement support and social work.

- **Home care service**

The home care service in St Francis was established in 1989. It provides support and expertise to people with advanced malignant disease and motor neurone disease and their families. In September 2001, the service took over the care of patients in the North West area of Dublin including Castleknock, Clonsilla, Blanchardstown and Mulhuddart from Our Lady's Hospice.

The service offered includes routine visits seven days per week with out of hours visits from 7.30-9.00 and 17.00-23.00 hours and overnight telephone contact with the In-Patient Unit staff. The home care team meets on a daily basis to discuss problems arising from patient management.

The initial assessment is carried out by a home care doctor and arrangements are then made for follow-up visits by nurses, as often as required. Permission to visit the patient is obtained from the patient's GP. Other sources of referral to the home care service include hospitals, day care, hospice in-patient wards and family members.

- **Day care**

The day care service in St Francis Hospice was established in 1994 and provides skilled care and offers companionship to those suffering from malignant disease and motor neurone disease and also provides respite for their carers.

The day care facility can cater for 64 patients over a 4 day week. Activities include medical and nursing care or advice, physiotherapy, complementary therapy (e.g. aromatherapy, relaxation therapy and art therapy), beauty therapy and social activities.

The majority of referrals to day care are made by home care but referrals are also accepted from the in-patient unit and hospitals or general practitioners. An initial assessment is carried out by a nurse in the patient's home to assess suitability for day care. Approval is also obtained from each patient's general practitioner.

Table 8.2 Staffing levels (Whole Time Equivalents) of current specialist palliative care services in St. Francis Hospice, Raheny.

	IN-PATIENT UNITS	HOME CARE (if applicable)	DAY CARE (if applicable)
<i>Doctors</i>	2.5	3	
<i>Nurses</i>	23	13.5	3.5
<i>Nurses Aides/Care Assistants</i>	13.5		2
<i>Occupational Therapists</i>	0.5		
<i>Physiotherapists</i>	0.5		
<i>Complementary therapist</i>	-		
<i>Pharmacist</i>	0.5		
<i>Social Workers</i>	1.5	2	.5
<i>Pastoral Care</i>	1.5	.5	
<i>Administrative staff</i>	20.5	2	1
<i>Volunteers*</i>	84	3	52
<i>Other (please specify) Domestic</i>	4		
<i>Fundraising Project Officer</i>	1		
<i>Volunteer Co-Ordinator</i>	1		
Number of beds/places	19	126	64 over 4 day week
Waiting list (days vs weeks vs months)	1-3 weeks**	Days	Days
Diagnosis of patients (malignant/non-malignant conditions)	Cancer – 98% : Motor Neurone Disease – 2%		
Any Comments:			
* Not possible to give whole time equivalent for Volunteers			
** Urgent patients can be admitted within days			

8.4 Palliative care services within general hospitals

8.4.1 St Vincent's University Hospital, Elm Park

Public Hospital

This palliative care service was established in 1989 with the appointment of a palliative care physician. A full-time nurse specialist in palliative care medicine was appointed to the service in 1991. The team is currently composed of a Consultant in Palliative Medicine for nine sessions a week (though these sessions will be split between St Vincent's University Hospital and Blackrock Hospice, when the latter opens), one full time clinical nurse specialist and two job-sharing clinical nurse specialists, and a registrar in palliative care medicine. The full-time clinical nurse specialist was funded by the Irish Hospice Foundation from July 1996 until August 1998.

The palliative care team accepts referrals from all hospital specialties. Most of the patients referred suffer from malignant disease but those with non-malignant disease are also referred (comprise approximately 15% of all new referrals), particularly those with cystic fibrosis as St Vincent's Hospital is the National Centre for Cystic Fibrosis. The commonest reasons for referral include pain and symptom control and community palliative care post discharge. The palliative care team refers patients to other services such as physiotherapy and occupational therapy.

This team is involved in the provision of education regarding palliative care on both a formal and an informal basis in the hospital setting. While the registrar and clinical nurse specialists give formal tutorials to junior doctors, the nurse specialists engage in ward-based teaching of both nursing and medical staff on a more informal basis as various issues arise in patient management.

Data regarding the number and source of referrals, the reasons for referral, the diagnoses of the patients referred and the outcome of referrals is recorded and presented in the hospital's annual report.

Private Hospital

The palliative care team is comprised of a full-time specialist nurse (funded by the Hospital) in palliative care with consultant sessions. The majority of patients referred are suffering from malignant disease and, although referrals are accepted from all specialties, most come from the oncology service. Referrals are usually for symptom control.

8.4.2 St James's Hospital

The palliative care service in St James's Hospital was established in 1995. The team is currently composed of a Consultant in Palliative Medicine for three sessions per week (0.27 WTE), an SpR in Palliative Medicine for three session per week, two clinical nurse specialists and a half time secretary.

Patients referred to the service include those with malignant disease, HIV/AIDS and end-stage non-malignant disease. Reasons for patient referral include symptom control, terminal care, home care and hospice admission.

The palliative care team accept referrals from all hospital specialities and, in turn, make referrals to services such as social work, pastoral care, occupational therapy and anaesthetics.

The palliative care team meets with Our Lady's Hospice home care team on a weekly basis to discuss individual patients, thus facilitating continuity of care. The team also liaises with patients' general practitioners where home care is needed.

8.4.3 Beaumont Hospital

The palliative care service in Beaumont Hospital was established in 1995. The team is currently composed of a Consultant in Palliative Medicine for three sessions per week (0.27 wte), two clinical nurse specialists, one Senior Social Worker and one Grade 3 clerical officer.

The majority of patients referred to this service suffer from malignant disease. The main reasons for patient referral include symptom control, discharge planning particularly with a view to availing of hospice in-patient or home care facilities and family and patient support.

Referrals are accepted from all specialities in the hospital. Patients may be seen by one of the nurses first but every new patient is also seen by the consultant.

The team is involved in formal and informal education of hospital staff. The consultant is involved in both undergraduate and postgraduate education.

8.4.4 St Luke's Hospital

The palliative care service at St. Luke's Hospital is an advisory service to patients under the care of referring Radiotherapists of Consultant Oncologists. The palliative care team is currently composed of a Consultant in Palliative Medicine for six sessions per week (.54 wte), an SpR in Palliative Medicine for eight sessions per week and two whole time clinical nurse specialists. The team have access to services in the hospital including physiotherapy, complementary therapy, social workers and pastoral care. There are no designated palliative care beds in St Luke's.

8.4.5 James Connolly Memorial Hospital

The palliative care team is currently composed of a Consultant in Palliative Medicine for three sessions per week (0.27 wte), one whole time clinical nurse specialist, 1 Senior Social Worker and a one Grade 3 clerical officer.

8.4.6 Cherry Orchard Hospital

There are currently no staff employed in specialist palliative care services in Cherry Orchard Hospital. However an 18 bed unit which provides respite and terminal care for patients with HIV/AIDS has been operational since 1990.

The unit is staffed by three/four nurses. A hospital physiotherapist holds relaxation classes for patients of the unit and recreational classes in areas

such as painting and massage are held. Voluntary agencies continue to support this unit through fundraising and visitations.

Referrals to the unit can be made by general practitioners in the community and in HIV/ satellite clinics and by Consultants in Infectious Diseases/AIDS. Patients are also referred by drug treatment counsellors and social workers. Some patients self refer to the unit.

The staff in the unit communicates with the specialist palliative care service providers when issues regarding palliative or terminal care arise and the hospice home care teams visit patients in the unit on request. Patients may be transferred to an acute general hospital such as St James's Hospital for acute care when clinically necessary.

8.5 Other palliative care services in the EASTERN REGION

- **Wicklow home care service**

This service is provided by two nurses with palliative care training and is managed by the local Superintendent Public Health Nurse. There is no specialist medical input into this service. One of the nurses is based in Bray and covers north Wicklow while the second nurse is based in Wicklow town and covers the south of the county. The home care needs of patients in west Wicklow are covered by the Kildare/West Wicklow (St Brigid's) home care service.

The two nurses provide this service within normal office hours only. There is no on-call or weekend service. Palliative care problems arising at night or during weekends are dealt with by local general practitioners. Similarly, there is no cover available when nurses are on sick leave or annual leave. If one nurse is on leave, the other will provide telephone advice for patients in the other catchment area but will not be able to visit due to her own workload and the large geographical spread of the catchment area of the service.

One palliative care bed is provided in Rathdrum and two are provided in Wicklow Hospital. Four beds are also available in Baltinglass Hospital when needed. These hospitals do not, however, have specialist medical input. Patients with more difficult management problems are admitted to Our Lady's Hospice, Harold's Cross.

- **Kildare/West Wicklow home care service**

The home care service is provided by three nurses; one public health nurse and two registered general nurses, who work closely with local public health nurses and general practitioners in the provision of palliative care services for patients in the catchment area.

The home care service is provided during normal working hours. An on-call service is available at weekends between 10am and 12pm. During these hours the home care nurse on call will answer queries from public health nurses and general practitioners and will make house calls where necessary.

The palliative care nurses meet with local hospice staff including the medical director and a senior public health nurse in the hospice unit on a weekly basis.

A part time bereavement counsellor provides a local counselling service. Other paramedical services are provided by community occupational therapists and physiotherapists. Pastoral care is provided by the chaplain from the Drogheda Memorial Hospital, when needed, or by local clergy. The local Director of Public Health Nursing acts as co-ordinator of palliative care services in the community care area.

The Drogheda Memorial Hospital in the Curragh is a 24 bedded welfare home which provides in-patient hospice services (not specialised palliative care services) for four patients in the region. There are plans to increase the number of hospice beds to six in the near future. A local general practitioner acts as medical director of the home care team and the hospice unit. There is no specialist medical input into this hospice unit.

The Friends of the Hospice is a local organisation which raises funds for the Kildare/West Wicklow palliative care services. This organisation funds one and a half nurses in the area. It also provides funding for a night nursing service which supplements the service provided by the Irish Cancer Society. The Irish Cancer Society funds one full-time nursing post in the area.

There is no waiting list for the palliative care services in Kildare. On receipt of a referral, the home care nurse will call, often with a public health nurse who may already be familiar with the patient. Both nurses liaise closely in the co-ordination of services for each patient.

- **Services provided by general practitioners**

The general practitioner has a primary role in the provision and co-ordination of palliative care services in the community, as the patient spends most of his/her last year of life at home. The home care team requests the general practitioner's permission before taking on the care of his or her patients. The GP's permission is also sought before a patient is accepted for day care. Clinical responsibility for the patient remains with the GP and while the home care team makes suggestions regarding medication and other aspects of patient care, prescribing of medication remains the responsibility of the GP.

A palliative care fellow was appointed by the Irish College of General Practitioners (ICGP) in 1996. The College through its post graduate resource centre provides courses in palliative care. The standard course provides modules on all the major areas of palliative care. Course is varied to suit the requirements of participants and local needs. A distance learning course is provided.

- **Services provided by public health nurses**

The services provided by public health nurses vary from area to area. In some areas such as Kildare/ West Wicklow, the home care service is staffed by public health nurses along with registered general nurses. In Dublin, which is served by hospice home care teams, the public health nurse liaises with the

home care nurse in the provision of services for the terminally ill. Community paramedical services such as physiotherapy and occupational therapy are often only accessible through the Health Board with the result that home care nurses communicate with public health nurses for patient referral purposes.

The public health nurse often carries out a psychosocial support role as well as a nursing role due to the lack of community social workers. She communicates with local general practitioners regarding patient care issues. The public health nurse may be assisted in her task by registered general nurses.

8.6 Services provided by voluntary agencies

- **Irish Cancer Society**

The Irish Cancer Society, founded in 1963, is financed entirely by voluntary contributions from the public and receives no government funding. The Irish Cancer Society, is the national charity dedicated to preventing cancer, saving lives from cancer and improving the quality of life of those living with cancer through patient care research and education. The main work of the Society is the delivery of nursing services to patients with cancer throughout Ireland. These services include; funding hospital based Oncology Liaison Nurses, community based Night Nursing for patients in their home, and Home Care Nursing teams. Additionally the Society operates a FreeFone Cancer Helpline, staffed by fully qualified nurses. This Cancer Helpline receives almost 6,000 calls annually

- **Irish Hospice Foundation**

The Irish Hospice Foundation (IHF), founded in 1986, is a support organisation for the development and improvement of palliative care services in Ireland. It aims to make palliative care available to all on the basis of need and need alone.

In the past the IHF provided £1.6 million for the construction of an Education and Training Centre at Our Lady's Hospice, Harold's Cross. It also provided £1.3 million towards the setting up of a palliative care service in Raheny serving the needs of the north side of the city and county. The IHF works closely with the Irish Cancer Society in supporting and encouraging the setting up of hospice services throughout the country.

The Irish Hospice Foundation Bereavement Service provides comprehensive counselling and support for the bereaved in the two Dublin Hospices. The IHF runs a number of courses to train volunteers in bereavement counselling and holds bereavement workshops. It also provides training courses in child bereavement.

9. Utilisation of Palliative Care Services in the Eastern Region

9.1 Introduction

This section examines the utilisation of the specialist palliative care services and also looks at waiting lists for the various services. This enables the identification of areas where present services are failing to meet demand which, although it does not necessarily equate with need, can help in the assessment of needs.

9.2 Our Lady's Hospice Harold's Cross

- **In-Patient Units**

The palliative care unit in Our Lady's Hospice has 36 beds for in-patient palliative care.

The admission summary over the last 5 years is shown in table 9.1.

Table 9.1 Admission summary for in-patient palliative care

	1997	1998	1999	2000	2001
No. of admissions	415	424	427	448	427
Occupied bed days	10,750	10,968	10,518	10,643	11, 337
Percentage Occupancy	81.8%	83.4%	80.5%	80.7%	86.2%
Average length of stay (days)	25.9	25.8	24.6	23.7	26.4

The admission and discharge summary for 2001 is shown in figure 9.1

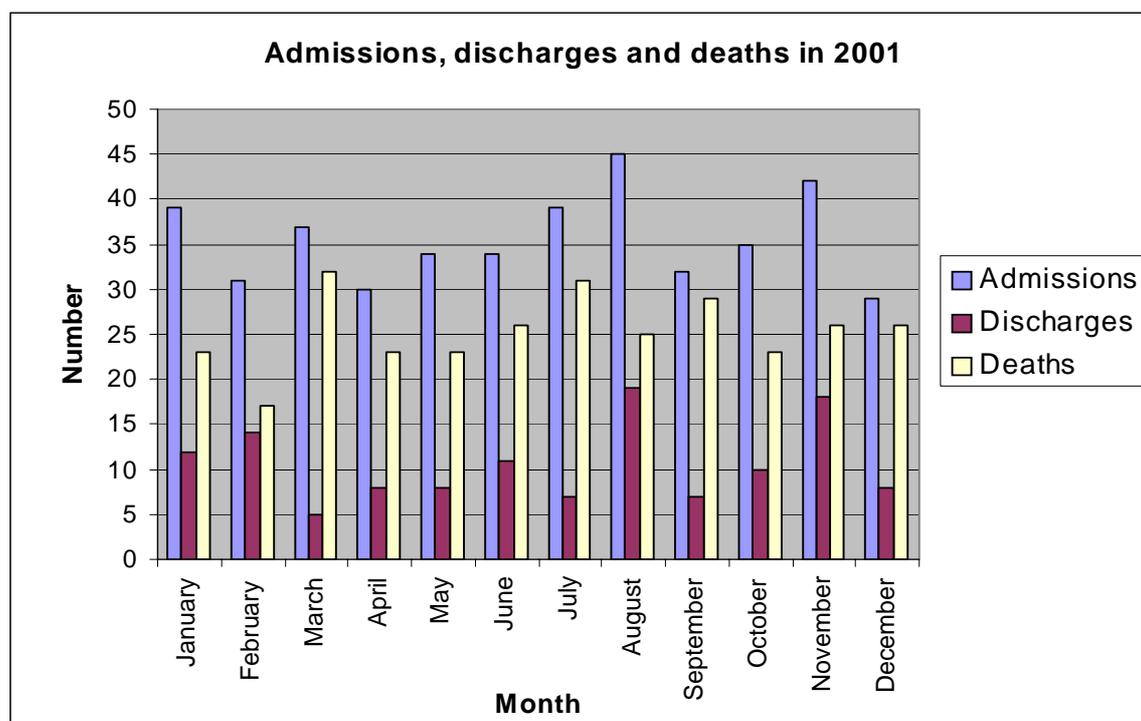


Figure 9.1 Admissions, discharges and deaths, Our Lady's Hospice, 2001

The area of residence of the patients admitted yields important information for those involved in service planning. See table 9.2.

Table 9.2 Area of residence of patients admitted to Our Lady's Hospice, 2001

Address	No. of admissions (%)
Dublin 2-24	270 (63%)
Dublin 1-15	33 (8%)
South Co. Dublin	73 (17%)
West Co. Dublin	13 (3%)
North Co. Dublin	2 (0.5%)
Kildare	8 (1.9%)
Wicklow	11(2.6%)
Meath	5 (1.2%)
Wexford	3 (0.7%)
Kerry	1 (0.2%)
Tipperary	3 (0.7%)
Westmeath	2 (0.5%)
Roscommon	1 (0.2%)
Clare	1 (0.2%)
UK	1 (0.2%)
Total	427(100%)

427 admissions=370 patients

The sources of the 427 referrals are shown in table 9.3

Table 9.3 Referral sources for 2001 admissions to Our lady's Hospice

Referral Source	Number (%)
Home	272 (64%)
St. James's Hospital	49 (11%)
St. Vincent's Hospital	29 (7%)
St. Luke's Hospital	18 (4%)
St. Vincent's Private Hospital	16 (4%)
Tallaght Hospital	11 (2.6%)
Blackrock Clinic	6 (1.4%)
Mater Hospital	4 (0.9%)
St. Columcilles	4 (0.9%)
Beaumont	3 (0.7%)
Nursing Home	3 (0.7%)
James Connolly	2 (0.5%)
Mount Carmel	2 (0.5%)
Other	8 (1.9%)
Total	427 (100%)

- **Day Care Unit**

The day care service can accommodate 42 patients over a three day week. The activity levels seen in the day care unit are shown in table 9.4.

Table 9.4 Day Care Statistics, Our Lady's Hospice 2001

Day Care Statistics 2001	No. (%)
Number of referrals	130 (100%)
Number of referrals who attended	63 (48%)
Number of referrals who died before receiving day care	19 (15%)
Declined offer/in-patient/on hold/other	42 (32%)
Number on waiting list at end of 2001	6 (5%)

- **Out Patient Services**

Referrals to outpatient services continue to climb. The total number of attendees to end of 2001 was 1,288.

- **Home Care**

Home Care can accommodate 180 patients. In 2001, over 650 new referrals were made to the service, which represent the busiest year ever for home care.

9.3 St Francis Hospice, Raheny

- **In Patient Services**

The palliative care unit in St Francis Hospice provides accommodation for 19 in-patients. There were 270 admission to St. Anne's In-Patient Unit in 2001 which represented an 8% increase on 2000.

Approximately 75% of admissions were referred from either home care or day care while the remainder of patients were referred from hospitals.

- **Day Care Services**

The day care service can accommodate 64 patients over a four day week. During 2001 there were 125 new patients referred to Day Care. The total yearly attendances at day care were 1,943, with 483 patients cared for.

- **Home Care Services**

The number of patients cared for by the Home Care team in 2001 was 565 an increase of almost 15% on 2000.

Figure 9.1-9.3 show the breakdown of patients attending St. Francis Hospice in 2001 by gender, age profile and community care area of residence.

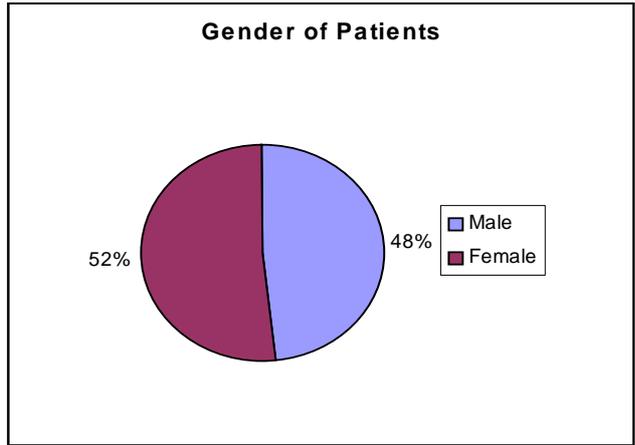


Figure 9.1 Gender of Patients, St. Francis Hospice, 2001

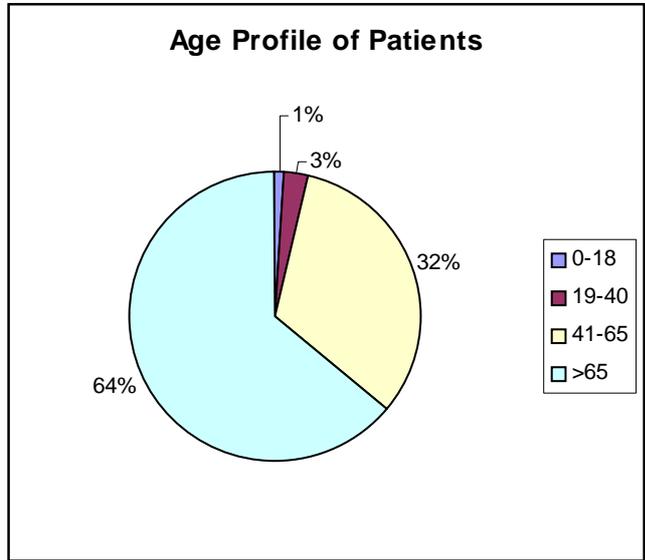


Figure 9.2 Age Profile of Patients, St. Francis Hospice, 2001

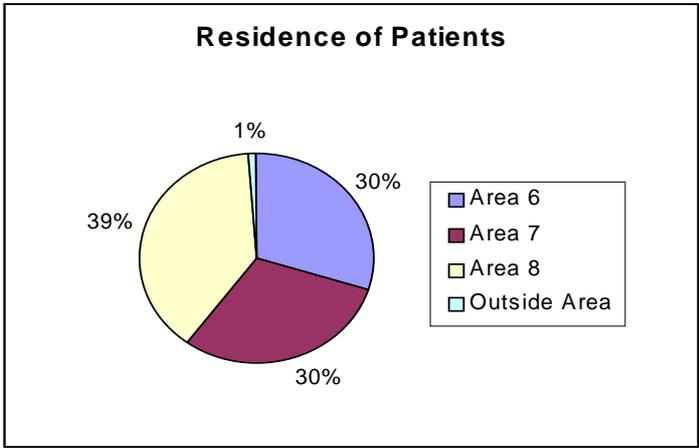


Figure 9.3 Community Care Area of Residence, 2001



9.4 Beaumont Hospital

The Palliative Care Service has been in operation in Beaumont Hospital since 1996. The number of referrals to the service have risen from 193 in 1996 to 585 in 2001, an increase of over 200% in 5 years.

Referrals are received from all specialties with the greatest number of referrals coming from the Medical Oncology team. While most of the patients referred to the service have a malignancy (85%) there is a steady increase in the number of patients with other progressive fatal diseases (15%).

9.5 St. Vincent's Hospital

In 2001, a total of 389 patients were referred to the palliative care service, an increase of 44 patients (12.8%) on the previous year. Of these 342 were new patients while 47 patients were re-referrals.

Most of the 342 new patients referred to the service have a malignancy (86%) but there is a steady increase in the number of patients with other progressive fatal diseases (14%). The outcome for patients referred to the palliative care service in 2001 is shown in table 9.5.

Table 9.5 Outcome of Referrals to Palliative Care Service, St. Vincent's Hospital, 2001

Patient Outcome	Number (%)
Discharged Home with community palliative care	148 (39%)
Died in St. Vincent's Hospital	137 (35%)
Transferred to Our Lady's Hospice, Harolds Cross	26 (7%)
Transferred to other hospitals	20 (5%)
Died in St. Vincent's Hospital while awaiting transfer to Our Lady's Hospice, Harold's Cross	15 (4%)
Transferred to St. Vincent's Private Hospital	15 (4%)
Discharged home without community palliative care	13 (3%)
Discharged from the palliative care team	13 (3%)
Discharged to Nursing Homes with community palliative care	12 (3%)
Transferred to other hospices	5 (1%)
Total	389 (100%)

9.6 St. James Hospital

This palliative care service was established in 1995 with the appointment of a palliative care physician.

In 2000 there were 411 new referrals to the palliative care service. The average number of referrals per month was 34. The outcome for patients referred to the palliative care service in 2000 is shown in table 9.6.

Table 9.6 Outcome of Referrals to Palliative Care Service, St. James's Hospital, 2000

Patient Outcome	Number (%)
Died in St. James Hospital	164 (40%)
Referred for home care at Our Lady's Hospice, Harold's Cross	98 (24%)
Referred for other home care services	50 (12%)
Transferred to Our Lady's Hospice, Harold's Cross	41 (10%)
Referred home-no palliative care follow up	33 (8%)
Referred in abeyance	25 (6%)
Total	411 (100%)

9.7 St Luke's Hospital

A specialist palliative care nurse was appointed in St Luke's Hospital in early 1998 and had 113 referrals in her first three months. The three main reasons for referral to the service included pain/symptom control, psychological support and discharge planning.

9.8 Irish Cancer Society Night Nursing Service

In 2001, a total of 338 families in the Eastern Region availed of the night nursing service provided by the Irish Cancer Society: 273 from Dublin, 51 from Kildare and 14 from Wicklow. The average number of nights per patient was 3-5. The cost is €145 for an 8 hour shift Monday-Friday, €160 for an 8 hour shift Saturday and €200 for an 8 hour shift on Sunday.

10. Outcome of Survey of Palliative Care Service Providers

10.1 Survey of Consultants in Palliative Care Medicine

All of the six questionnaires distributed were returned giving a response rate of 100%. There were 2 respondents each from the NAHB, ECAHB and SWAHB.

10.1.1 Workload (at time of study)

- The mean number of patients with *malignant* disease receiving in-patient specialised palliative care was **17.5**
- The mean number of patients with *non-malignant* disease receiving in-patient specialised palliative care was **1.8**
- The mean number of patients with *malignant* disease receiving outpatient specialised palliative care/support was **130.3**
- The mean number of patients with *non-malignant* disease receiving outpatient specialised palliative care was **1.3**

Consultants were asked about the non-malignant conditions that they were currently providing palliative care services for. These conditions included the following conditions:

- HIV & AIDS
- Motor Neuron Disease
- End stage lung/cardiac/renal disease
- Peripheral Vascular Disease
- Parkinsons Disease
- Cystic Fibrosis
- Cerebrovascular disease

10.1.2 Satisfaction levels

Table 10.1 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of the present services.

Table 10.1 **Mean satisfaction ratings**

Area	Mean Satisfaction Rating
No. of staff working in your section of palliative care service	3.6
No. beds available for patients with malignant disease	3.8
No. beds available for patients with non-malignant disease	1.4
No. of respite care beds for patients with malignant disease	3.8
No. of respite care beds for patients with non-malignant disease	2.2
Communication with GPs regarding palliative care issues	5.5
Stage of disease at which you get involved	5.0
Level of education/training that you received in palliative care	7.4
Availability of assistance/ advice from colleagues when needed	7.6
Communication with charitable agencies (e.g. Irish Cancer Society)	4.6

10.1.3 Service Provision

Fifty per cent (50%) of palliative care physicians have and follow protocols for patient management. These include (a) pain management (b) referral to home care (c) pain management (d) admission and discharge and (e) patient wills.

Fifty per cent (50%) of palliative care physicians audit their activities. This includes (a) retrospective patient chart review (b) Activity levels (c) patient demographic details (d) planned admissions.

Thirty three per cent (33%) of palliative care physicians have formal complaints procedures for seeking and dealing with complaints relating to palliative care services.

10.1.4 The Future Of Palliative Care

All of the respondents are of the opinion that palliative care services are currently inadequate in their respective health boards. Areas of unmet need that were identified included:

- Services for patients with non-malignant disease
- Community and home care services
- Education & training /audit/research in the field of palliative care
- Paediatric palliative care services

There were a number of priority areas identified. These included:

- Development of services for patients with non-malignant disease
- More beds across the service (hospice, respite, day care)
- Sufficient resources (hospice/community/paramedical/nursing) to manage current and future workloads
- Strengthening links between acute hospitals, palliative care units and community services with the aim of providing a seamless service

10.2 Survey of General Practitioners

Seventy four of the 150 questionnaires circulated were returned giving a 50% response rate. Twenty two respondents (29.7%) were from the ECAHB. Twenty six respondents (35.1%) were from the NAHB and twenty three respondents (31.1%) were from the SWAHB. This data was missing from three respondents (4.1%).

10.2.1 Liaison with specialist palliative care services

Table 10.2 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of the present services.

Table 10.2 Mean satisfaction ratings

Area	Mean Satisfaction Rating
Access to palliative care beds for patients with malignant disease	5.9
Access to beds for patients with non-malignant disease	3.2
Access to beds for respite care	5.0
Access to beds for crisis situations	5.3
Communication with home care team regarding patient progress	6.8
Communication with in-hospice care team	7.9
Advice from palliative care teams when requested	8.2
Access to palliative care consultant when needed	6.9
Overall adequacy of local specialist palliative care service	6.9
Support from public health nurses in the provision of services	6.6
Health Board reimbursement for palliative care services	3.0

10.2.2 Palliative Care Services provided

- The mean number of patients with *malignant disease* with palliative care needs that the GP was seeing at the time of the study was **6.3** (Range 1-20). In 1999 the mean figure was 2.5.
- In the previous 12 month period the mean number of patients that they provided services for was **7.5** (Range 1-100). In 1999, the mean figure was 5.9.
- The mean number of patients with *non-malignant disease* with palliative care needs that the GP was seeing at the time of the study was **4.5**.
- In the previous 12 month period the mean number of patients with non-malignant disease that they provided services for was **3.2** (Range 0-50).

The non-malignant conditions that required palliative care services included (a) Multiple Sclerosis (b) Motor Neurone Disease (c) Chronic Lung/cardiac/renal disease (d) HIV (e) Parkinson's disease (f) Severe rheumatoid arthritis and (e) cerebrovascular disease

10.2.3 The Future of Palliative Care

Overall 43.2% of GPs are satisfied with palliative care services in their Area Health Boards as opposed to 48.6% who are not. Areas of unmet need that were identified included:

- Access to beds/availability of more beds/better access to beds
- Needs of non-malignant disease patients
- Respite care

There were a number of priority areas identified. These included:

- Early/easy/more timely/access to beds
- Development of services for patients with non-malignant disease
- Improved staffing (community/nurses/consultants)/funding and reimbursement for services
- Improved communication across and between services
- Education and Training (symptom control, pain control, paediatric palliative care, bereavement counselling, stress management)

10.2.4 Training

Twenty (27%) respondents have received post-graduate training in palliative care. Fifty one (68.9%) have not. In most cases the Irish College of General Practitioners provided training. Other training resources included Our Lady's Hospice in Harold's Cross and St. Lukes Hospital. There was a desire for further training in (a) symptom control (b) pain control (c) paediatric palliative care (d) bereavement counselling and (e) stress management.

10.3 Survey of Hospital Consultants

Twenty seven of 80 questionnaires circulated were returned giving a 34% response rate. Questionnaires were sent to hospital consultants in specialties where there may have been a palliative care component.

10.3.1 Occupation and Location

Specialties that responded included (a) cardiology (b) respiratory medicine (c) care of the elderly (d) renal medicine (e) neurology (f) general surgery (g) gastroenterology and (h) rheumatology.

Seventeen consultants (63%) were from the NAHB, nine (33%) from the ECAHB and 1 (4%) from the SWAHB. All were working in acute general hospitals.

Seven (26%) consultants had received education/training in palliative care, three at undergraduate level and four at postgraduate level.

10.3.2 Provision of Specialist Palliative Care Services (at time of study)

- The mean number of patients with *malignant disease* under their care and actually receiving specialised palliative care at the time of the study was **3.5** (Range 0-20).
- The mean number of patients under their care with *malignant disease* that would benefit from specialised palliative care was **12.3** (Range 1-70).
- The mean number of patients with *non-malignant disease* under their care actually receiving specialised palliative care at the time of the study was **3.5** (Range 0-15).
- The mean number of patients with *non-malignant disease* under their care that would benefit from specialised palliative care was **10.3** (Range 0-40).

The non-malignant conditions that consultants felt would benefit from specialised palliative care services included (a) Multiple Sclerosis (b) Motor Neurone Disease (c) Chronic Lung/cardiac/renal disease (d) HIV (e) Parkinsons disease (f) Rheumatoid arthritis (e) Creutzfeld-Jakob Disease and (f) Cerebrovascular disease.

The vast majority of consultants (85.2%) have access to on-site specialist palliative care services. The staffing composition of these services generally involved a Consultant in Palliative Medicine supported by a nurse specialist. The main reasons for referral to the specialist palliative care services were (a) pain control (b) Optimising all-round care (c) Psychological support (d) symptom control and (e) Counselling.

10.3.3 Satisfaction levels

Table 10.3 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of the present services.

Table 10.3 Mean satisfaction ratings

Area	Mean Satisfaction Rating
Availability of palliative care services for patients with malignant disease	6.9
Availability of palliative care services for patients with non-malignant disease	5.3
Quality of on-site specialist palliative care services	6.7
Communication between specialist palliative care services and own specialty	7.4
Access to specialist palliative care beds for patients with malignant disease	4.5
Access to specialist palliative care beds for patients with non-malignant disease	2.6
Counselling /bereavement services available to patients	5.4

10.3.4 The Future Of Palliative Care

While 25% of respondents felt that palliative care services were adequate a large majority-67%-of respondents felt that palliative care services were inadequate.

Areas of unmet need that were identified included:

- Services for patients with non-malignant disease

- Development of home care services
- Increase in hospice beds and staffing
- Counselling services

There were a number of priority areas identified. These included:

- Services for patients with non-malignant disease
- Access to services-seamless integration between services
- Medical and paramedical staffing

10.4 Survey of Public Health Nurses

Twenty two questionnaires were returned from Public Health Nurses.

10.4.1 Occupation and location

Specialist areas of nursing that responded included (a) cardiology (b) respiratory medicine (c) hepatology (d) renal medicine (e) neurology (f) general surgery and (g) care of the elderly.

Fifteen PHNs (68%) were from the ECAHB, three (14%) from the SWAHB and 2 (9%) from the NAHB. Data was missing from two respondents (9%). All respondents were primarily based in the community.

Ten PHNs (46%) had received education/training in palliative care at undergraduate or postgraduate level.

10.4.2 Current Palliative Care Services

Table 10.4 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of current services.

Table 4 Mean satisfaction ratings

Area	Mean Satisfaction Rating
Communication with hospice home care team/progress reports	5.3
Communication with in-hospice or hospital palliative care teams	4.1
Communication with GPs regarding palliative care issues	4.2
Availability of assistance and advice from colleagues when needed	7.0
Overall adequacy of local specialist palliative care services	5.8
Provision of community ancillary services for palliative care needs	4.7
Availability of equipment for those with palliative care needs	7.2
Local provision of night nursing services for palliative care needs	4.8

10.4.3 Palliative Care Services Provided

- The mean number of patients with *malignant disease* that PHNs were providing palliative care services for at the time of the study was **4.2** (Range 1-13).

- In the preceding 12 months the mean number of patients with *malignant disease* that PHNs provided palliative care services for was **7.2** (Range 1-20).
- The mean number of patients with *non-malignant disease* that PHNs were providing palliative care services for at the time of the study was **3.6** (Range 1-11).
- In the preceding 12 months the mean number of patients with *non-malignant disease* that PHNs provided palliative care services for was **8.7** (Range 1-25).

The non-malignant conditions that required palliative care services included (a) Multiple Sclerosis (b) Motor Neurone Disease (c) Chronic Lung/cardiac/renal disease (d) cerebrovascular disease (e) Alzheimers disease (f) burn injuries.

10.4.4 The Future Of Palliative Care

While 37% of public health nurses are satisfied that palliative care services are adequate over 50% are not (data missing on 13%).

Areas of unmet need that were identified included:

- Palliative care needs for non-malignant conditions
- Night Nurse Services/sitting services
- Day care/respice care
- Counselling and support for families
- Waiting times for assessment

There were a number of priority areas identified. These included:

- Home care/day care/respice care
- Development of services for non-malignant conditions
- Improving communication links between community/hospice/hospital/GPs
- Counselling services
- Education and training for PHNs

10.4.5 Education and Training

Ten (45.5%) respondents have received training in palliative care. Twelve (54.5%) have not. There was a desire for further training in (a) symptom control (b) pain control (c) paediatric palliative care (d) bereavement counselling and (e) stress management.

10.5 Survey of Consultant Oncologists

Two out of 7 questionnaires circulated were returned giving a 29% response rate.

10.5.1 Location and Workload

Both of the oncologists work in acute general hospitals in the SWAHB.

- The mean number of patients under their care that required palliative care at the time of the survey was **35** (Range 20-50)
- The mean number of patients that were actually receiving palliative care at the time of the survey was **22** (Range 20-25)

10.5.2 Satisfaction Levels

Table 10.5 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of the present services.

Table 10.5 Mean satisfaction ratings

Area	Mean Satisfaction Rating
Number of staff working in your section of the palliative care service	2.8
No. of beds available for palliative care needs of patients with malignant disease	1.3
Number of beds for respite care needs of patients with malignant disease	0
Communication with GPs regarding palliative care issues	5.8
Stage of disease at which you get involved in patient management	9
Level of education/training which you received in palliative care	7.3
Availability of assistance from colleagues	5.8
Communication with charitable agencies	3.0

10.5.3 Service Provision

Both respondents have and follow protocols for patient management. These include terminal care provision in the acute hospital setting and the active management of cancer.

Neither respondent has a formal complaints procedure for seeking and dealing with complaints relating to the palliative care services.

10.5.4 The Future of Palliative Care

Both of the respondents feel that palliative care services are currently inadequate.

Areas of unmet need that were identified included:

- Recognition that a need for palliative care services will increase
- More beds
- More staff (medical and paramedical)
- Integration with acute hospital service
- More medical input into home care

There were a number of priority areas identified. These included:

- Increase in the number of palliative care beds and day care places
- Expansion of palliative care units
- Linkage with acute hospitals
- Medical input into home care

10.6 Survey of Area Managers

A total of five questionnaires were returned from Area Managers.

10.6.1 Occupation and Location

All of the respondents worked in the ECAHB and consisted of 3 Directors of Nursing, 1 Physiotherapy Manager and 1 Project Manager for Palliative Care Services.

10.6.2 Satisfaction Levels

Table 10.6 lists the mean satisfaction ratings on a scale from zero (very dissatisfied) to 10 (very satisfied) with various aspects of the present services.

Table 10.6 Mean satisfaction ratings

Area	Mean Satisfaction Rating
Number of staff working in your Area Health Board/Community Care Area	2.3
Number of beds for palliative care needs of patients with malignant disease	0.75
Number of beds specialist palliative care needs of patients with non-malignant disease	0.75
Number of beds available for respite care	2.5
Communication with GPs	2.8
Communication with consultants in acute hospitals regarding palliative care issues	2.1
Communication with specialist palliative care consultants regarding palliative care issues	5.0
Communication with charitable agencies	4.6
Level of education/training received in specialist palliative care	3.0

10.6.3 The Future of Palliative Care

All respondents (100%) felt that specialist palliative care services are inadequate. Some of the comments expressed included the following: *“an excellent service...but long wait”....“improving”....“needs of patients with non-malignant disease haven’t been met”....“not enough services”*

There were a number of priority areas identified. These included:

- Better communication systems between hospitals and community services
- Access to beds across the service
- Development of services for non-malignant conditions
- Specialist nurses

11. Implications and Costings of the National Advisory Committee on Palliative Care Recommendations

11.1 Bed Requirements

A capacity for 960-2,240 admissions per year for both malignant and non-malignant conditions will be required by 2011 in the Eastern Region.

The international recommendation of the number of beds required for both malignant cancer patients and patients with non-malignant conditions is 8-10 beds/100,000 population.

Based on population and cancer case projections for the region and to have the capacity to deal with the projected increase in admissions the **Region will require 128-160 specialist palliative care beds by the year 2011**. This is 2.5 to 3 times the current number of 55 beds.

11.1 Staffing Recommendations

The Report of the National Advisory Committee on Palliative Care made recommendations with regard to staffing levels and are those referred to in the subsequent sections. See also table 11.1

11.2. Medical Staff

- **Consultants**

It is recommended that there should be 1 whole time equivalent (WTE) Consultant in Palliative Medicine per 160,000 population, with a minimum of 2 consultants in each health board area.

With the population of the Eastern Region projected to increase to 1.6 million by 2011, **10 Consultants in Palliative Medicine will be required in the Eastern region**.

Cost estimate: €1.45 million

- **NCHDs**

It is recommended that for each consultant in palliative medicine there should be at least 3 NCHDs.

30 NCHDs will be required in the Eastern Region

Cost estimate: €1.3 million

11.3. Specialist Palliative Care Nurses

- **Specialist Palliative Care Nurse in a Specialist Inpatient Unit**

It is recommended that there should be a ratio of not less than one WTE specialist palliative care nurse to each bed

128-160 Specialist Palliative Care Nurses in Specialist Inpatient Units will be required.

Cost estimate: ~~€5.3-€6.6~~ million

- **Specialist Palliative Care Nurses in the Community**

It is recommended that there should be at least one WTE specialist palliative care nurse per 25,000 population

64 Specialist Palliative Care Nurses in the Community will be required

Cost estimate: ~~€2.6~~ million

- **Specialist Palliative Care Nurse in an Acute General Hospital Team**

It is recommended that there should be at least one hospital based specialist palliative care nurse per 150 beds

Excluding obstetrics and psychiatry there are 4,076 acute hospital beds. Therefore 28 Specialist Palliative Care Nurses in the Acute Hospital will be required

Cost estimate: €1.2 million

- **Specialist Palliative Care Nurse in a Day Care Centre**

It is recommended that in each day care centre there should be at least one specialist palliative care nurse per 7 daily attendees

Currently there are 106 day care places per week available. If bed needs are projected to triple over the next 10 years it is a reasonable assumption that day care places should also increase in line with this i.e. 300 plus day care places per week by 2011

43 Specialist Palliative Care Nurse in Day Care Centres will be required

Cost estimate: €1.8 million

11.4 Physiotherapy

- It is recommended that there should be at least one WTE physiotherapist per 10 beds in the specialist palliative care unit

13-16 physiotherapists will be required in specialist palliative care units in the Eastern region by 2011

Cost estimate: ~~€466K-€573K~~

- It is recommended that there should be at least one WTE community physiotherapist specialising in palliative care per 125,000 population

13 community physiotherapists will be required in the Eastern Region by 2011

Cost estimate: €466K

11.5 Occupational Therapy

- It is recommended that there should be at least one WTE occupational therapist per 10 beds in the specialist palliative care unit

13-16 occupational therapists will be required in specialist palliative care units in the Eastern Region by 2011

Cost estimate: €454K-€559

- It is recommended that there should be at least one WTE community occupational therapist specialising in palliative care per 125,000 population

13 community occupational therapists will be required in the Eastern Region by 2011

Cost estimate: €454K

11.6 Social Workers

- It is recommended that there should be at least one WTE social worker employed per 10 beds in the specialist palliative care unit.

13-16 social workers will be required for palliative care services in the Eastern Region by 2011

Cost estimate: €651K-€801K

- It is recommended that there should be at least one WTE community social worker specialising in palliative care per 125,000 population.

13 community social workers will be required for palliative care services in the Eastern Region by 2011

Cost estimate: €51K

- It is recommended that there should be at least one WTE specialist palliative care social worker in acute general hospitals that have a specialist palliative care team

7 specialist palliative care social workers will be required in acute general hospitals in the Eastern Region

Cost estimate €351K

11.7 Speech and Language Therapy

- It is recommended that there should be regular speech and language therapy session in each specialist palliative care unit with a minimum of one session per week

Cost estimate: €7K per palliative care unit

Clinical Nutritionists

- It is recommended that there should be at least one clinical session in each specialist palliative care unite per week

Cost estimate: €8K per palliative care unit

11.8 Pharmacists

- It is recommended that there should be at least one WTE pharmacist in each specialist palliative care unit

Cost estimate: €36.2K per specialist palliative care unit

11.9 Care Attendants

- It is recommended that there should be not less than 0.5WTE care attendants to each bed in a specialist palliative care unit

65-80 Care attendants will be required in specialist palliative care units by 2011

Cost estimate: €1.6-€1.9 million

11.10 Volunteers

- It is recommended that every specialist palliative care unit should have a volunteer coordinator

Cost estimate: €29K per specialist palliative care unit

11.11 Librarian & Educational Staff

- It is recommended that specialist palliative care services should have a librarian and educational personnel

Cost estimate: €300K

11.12 Administrative Staff

- It is recommended that specialist palliative care services should have an appropriate level of administrative staff **Cost estimate: €1.8-2 million**

11.13 Non Pay Costs

The costing estimates outlined previously do not take into account the non-pay costs. The National Advisory Committee recommended that each health board should have a sufficient back of equipment to meet the needs of palliative care patients in the community. It was also recommended that palliative care units should have their own small bank of aids and appliances to facilitate rapid access to equipment. Non pay costs would also refer to items such as medications, dressings and travel costs. The national estimate of non pay costs was estimated at €9.2 million. The Eastern Region would be expected to account for at least one third of this i.e. €3 million

11.14 Capital Expenditure

The need and scale of capital developments to support the development of specialist palliative care services will be determined by the interpretation and implementation of the findings of this report and the report of the Expert Group on Design Guides for Specialist Palliative Care Settings.

Table 11.1 Approximate Annual Pay Costs for Whole Time Equivalents in Specialist Palliative Care, EASTERN REGION, 2011

Criteria	National Advisory Committee on Palliative Care Recommendations	Eastern Region Requirements by 2011	Current Position	Estimated cost of recommendations (Euro)
Beds	8-10 beds per 100,000 population	128-160 beds	55	
Consultants	1 WTE Consultant per 160,000 population	10	6	1.45 million
NCHDS	3 NCHDs per Consultant	30		1.3 million
Nurses	(a) 1 WTE per bed in specialist palliative care unit (b) 1 WTE per 25,000 population in the community (c) 1 specialist nurse per 150 beds in an acute general hospital (d) 1 specialist nurse per 7 daily attendees in day centres	263-295	61.5	10.9-12.2million
Physiotherapist	(a) 1 WTE physiotherapist per 10 specialist palliative care beds (b) 1 WTE community physiotherapist per 125,000 population	26-29	3.5	0.8-1 million
Occupational Therapist	(a) 1 WTE OT per 10 specialist palliative care beds (b) 1 WTE community OT per 125,000 population	26-29	3.2	0.8-1 million
Social Workers	(a) 1 WTE social worker per 10 specialist palliative care beds (b) 1 WTE community social worker per 125,000 population (c) 1 WTE in acute general hospitals	33-36	17	1.6-1.8 million
Speech and Language Therapy	1 session per week in each specialist palliative care unit	Per Unit	Not specified	7K per unit
Clinical Nutritionist	1 session per week in each specialist palliative care unit	Per Unit	Not specified	8K per unit
Pharmacist	1 WTE pharmacist in each specialist palliative care unit	Per Unit	3.5	36K per unit
Care Attendants	(a) 0.5 WTE Care Attendants per specialist palliative care bed (b) Care attendants/sitters should be available to support families	65-80	39	1.6-1.9 million
Volunteers	Each specialist palliative care unit should have a volunteer coordinator	Per Unit	1	29K per unit
Librarian	Each specialist palliative care unit should have a librarian and educational personnel	Per Unit	Not specified	300K
Administrative Staff	Each specialist palliative care unit should have an appropriate level of administrative staff	Per Unit	30.5	1.8-2 million
Non-pay costs				3 million
Total				23.5-25.9 million

12. Conclusions & Recommendations

(a) An increased need for palliative care services is inevitable

The population of the Eastern Region is projected to increase to 1.6 million by 2011 with marked increases in the 45-64 and over 65 year age groups. Older people are much more likely to develop cancer, with the risk doubling in every successive decade of life. Nearly three quarters of all cancer deaths occur in those over 65 years.

(b) Malignant cancer cases will increase by 31%% in Eastern Region by 2011

There is a projected increase of 31% in the number of malignant cancer cases in the Eastern Region. The major increase will be in those aged 50 years and over.

(c) Experience has shown that 15-25% of patients who die from cancer actually receive inpatient hospice care

The Eastern Region will need the capability for up to 1,165 cancer patient admissions for palliative care by the year 2011

(d) Inpatient palliative care services for non-cancer patients is required

Between 20-70 non-cancer patients per 100,000 population will require inpatient care. The Eastern Region will need the capability for up to 1,120 non-cancer patient admissions for palliative care by the year 2011.

(e) Admissions for cancer and non-cancer patients for palliative care will increase significantly

As many as 2,285 admissions per year for both malignant and non-malignant conditions will be required by 2011.

(f) Specialist Palliative Care Beds need to be increased

The Eastern Region needs between 128-160 specialist palliative care beds by the year 2011 to meet the needs of cancer and non-cancer patients

(g) Demand for palliative home-based care will increase

It has been reported that 70-180 cancer patients per 100,000 population and 35-140 non-cancer patients per 100,000 population will require palliative care support at home. The Eastern Region will need the capability for meeting the home care needs of up to 5,000 patients and their families

(h) A high level of dissatisfaction was expressed amongst different service providers with current palliative care services in the Eastern Region

(i) Different service providers identified common areas of unmet need

- Palliative care needs of non-cancer patients
- More beds across all sectors i.e. acute hospital, hospice, respite care, day care
- Day care and home care services
- Medical, nursing, paramedical and administrative staffing
- Communication between acute hospital, hospice and community palliative care service

(j) Current palliative care services in the Eastern Region fall short of the National Advisory Committee Recommendations on Palliative Care

A major increase in staffing across all sectors of the service will be required to meet the palliative care needs of the Eastern Region by 2011

(k) In today's terms it will cost upwards of €26 million per year to meet the staffing recommendations alone of the National Advisory Committee on Palliative Care by 2001 in the Eastern Region

It must be acknowledged that this is an estimate of pay and non-pay costs. It does not include any necessary capital costs.

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