

Getting Started



Guidelines and Suggestions for those
Starting a Hospice/Palliative Care Service
3rd Edition

Derek Doyle
IAHPC PRESS



**Getting Started: Handbook and Suggestions
for those Starting a Hospice/Palliative Care Service**
3rd Edition

Derek Doyle, OBE, MD

IAHPC Press
Houston, 2021
ISBN - 978-0-9989787-5-8

Preface to the 3rd Edition

How often one meets someone who says:

"We are determined to start a new hospice or palliative care service but don't know where to start? We all wish there was something somewhere where we could learn what to do and what not to do, written by people who have been through all this. We must get it right."

Well, the IAHPC has just that resource. It was first published in 2005, the second edition was published in 2009 and has since been read by thousands of people, many of whom have told us how helpful it was. It is the most consulted, downloaded document and visited page in the IAHPC website.

With this third edition, it has now been brought up to date - relevant for readers worldwide. It answers all the most asked questions. It stresses what not to do as much as what to do. It is free of jargon and is honest about the challenge that faces those "getting started".

Derek Doyle, OBE, MD

Edinburgh, 2021

Acknowledgments

The author is grateful for the review, valuable comments and contributions received from the following IAHPC Officers for this 3rd edition:

Liliana De Lima, MHA (USA)

IAHPC Executive Director

Tania Pastrana, MD (Germany)

IAHPC Research Adviser

Abbreviations/Acronyms

CEO	Chief Executive Officer
CPCS	Community Palliative Care Service
DNR	Do Not Resuscitate
GP	General Practitioner
HPCU	Hospice Palliative Care Unit
HPCT	Hospice Palliative Care Team
IAHPC	International Association for Hospice and Palliative Care
PAS	Physician Assisted Suicide
SHS	Serious Health-Related Suffering
UK	United Kingdom
VSM	Volunteer Services Manager
WHO	World Health Organisation

Table of Contents

1. Introduction	1
2. What is palliative care?.....	2
3. Principles of Palliative Care.....	10
4. How do you 'get started'?	15
5. Management of the Service.....	22
6. Hospital Palliative Care Unit	28
7. Hospital Palliative Care Team	31
8. Free-standing Inpatient Unit/Hospice	34
9. Home Care/Community Palliative Care Services.....	38
10. Hospice/Palliative Day Care Unit.....	43
11. Human Resources.....	48
12. Hospice/Palliative Care Volunteers.....	56
13. Orientation, Training and Education.....	61
14. Communication.....	69
15. Documentation	80
16. Resources.....	87
17. References.....	93

1. Introduction

Despite the tremendous engagement of the palliative care community, many patients in need do not have access to hospice and palliative care services.

It is tempting to see the enormous avoidable suffering of many patients with severe disease and at the late stages of life and, knowing that palliative care will be able to ease their suffering, rush into starting a palliative care service without planning. This can be disastrous. Spending time (even years) planning a palliative care service is always time well spent.

Governments have been urged to include palliative care as part of health policy; integrate palliative care training into the curricula of health professionals; ensure the availability and affordability of all essential medicines. However, there is inequity and significant gap in provision of palliative care worldwide.

Most countries worldwide do not have palliative care policies or integrated palliative care services. Even in countries with an adequate standard of care and well-developed health care services, access to palliative care is greater in urban areas and for patient groups, such as cancer patients. Many people do not know what hospice/palliative care is, and what it is not; what its essential features are and how it can be provided.

This series of brief papers has been prepared for those interested in starting palliative care services in low- and middle-income countries where knowledge about and funding for palliative care is limited, allowing access to palliative care services for all those patients and their family members that would benefit from this care. *'Getting Started'* has been produced by the IAHP and it does not aim to implant a particular model of care worldwide but provide guidance and advice on how to start a service.

2. What is palliative care?

The World Health Organisation (WHO) produced in 2002 a useful definition,⁽¹⁾ valuable when negotiating with local and national health departments who may not be familiar with the essential features of such care provision.

Based on it, the International Association for Hospice and Palliative Care ([IAHPC](#)) conducted a consensus process with over 400 participants from 86 countries, and after a series of discussions, rounds, and rankings, the participants agreed on the following [definition of palliative care](#) (2):

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.

Throughout 'Getting Started' palliative care will refer to the above definition.

In addition to the definition, the working group which spearheaded this effort, developed the following to describes what is palliative care, what it accomplishes and a set of recommendations to governments.

Palliative Care:

- Includes, prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. Whenever possible, these interventions must be evidence based.
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
- Is applicable throughout the course of an illness, according to the patient's needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient's illness, and in their own bereavement.

- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.

To achieve palliative care integration, governments should:

- Adopt adequate policies and norms that include palliative care in health laws, national health programs and national health budgets.
- Ensure that insurance plans integrate palliative care as a component of programs.
- Ensure access to essential medicines and technologies for pain relief and palliative care, including paediatric formulations.
- Ensure that palliative care is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation.
- Ensure access to adequate palliative care for vulnerable groups, including children and older persons.
- Engage with universities, academia, and teaching hospitals to include palliative care research as well as palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.

This is a reminder that palliative care is not disease-specific, is not restricted to a defined number of months or weeks of life and is centred on quality rather than quantity of life. Taken for granted in this definition is that the relatives must also be factored into the care programme because it is impossible to care for a critically ill person if the needs of relatives are not also addressed.

Palliative Care and Suffering

Suffering may be defined as the distress associated with events that threaten the intactness or wholeness of the person. Suffering is health related (SHS) when it is associated with illness or injury of any kind. Health related suffering is serious when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual and/or emotional functioning.

In clinical practice, it is helpful to have a simple classification of the causes of suffering, so that the complex problems presented by patients can be disentangled, to provide comprehensive palliation and relief of suffering caused by:

- Pain or other physical symptoms
- Psychological distress
- Social issues

- Spiritual issues

The components of palliative care, or the aspects of care and treatment that need to be addressed, follow logically from the causes of suffering. Each must be addressed in the provision of comprehensive palliative care, making a multidisciplinary team approach to care a necessity.

Treatment of pain and physical symptoms are addressed first because it is not possible to deal with the psychosocial aspects of care if the patient has unrelieved pain or other distressing physical symptoms.

The various causes of suffering are interdependent and unrecognised or unresolved problems relating to one cause may cause or exacerbate other aspects of suffering.

Pain and psychological suffering area inter-related:

- Unrelieved pain can cause or aggravate psychosocial problems. These psychosocial components of suffering cannot be treated successfully until the pain is relieved.
- Pain may be aggravated by unrecognised or untreated psychosocial problems. No amount of well prescribed analgesia will relieve the patient's pain until the psychosocial problems are addressed.

Different terms used about 'palliation'

It is important to differentiate among different (sometimes confusing) terms related:

Palliative care principles are the principles of all good clinical care, whatever the illness or condition, whatever the stage or prognosis, whatever the age, gender, race, class, or creed of the patient.

Palliative techniques or therapies are valuable components of modern palliative care, include medical and surgical therapies or procedures (e.g., radiotherapy, chemotherapy, insertion of stents, paracentesis, internal fixation of fractures, drainage of effusions, and even procedures as simple but valuable as catheterisation stenting). They are employed to palliate symptoms and ease suffering but are only a small part of the spectrum of care known as palliative care, because they are not in themselves comprehensive palliative care.

Specialist palliative care is that provided by a service or team (which may or may not have in-patient beds) where the principal clinicians (physicians, nurses, social worker and other team members) have an advanced training in the management of complex situations/cases. In a few countries where palliative medicine and palliative care nursing are recognised as medical and nursing specialties, the services in which they work are essentially secondary or tertiary referral services.

Is 'Palliative Care' the same as 'Hospice Care'?

In some countries these terms are used to distinguish home care services from hospital services, or volunteer-based services provided in the community from services provided by a professional team in a hospital. However, the principles are and should be the same.

The 'modern hospice movement' goes back to England in the 60's, and in 1973 was renamed 'palliative care' in Canada. Palliative care is the preferred term for health care professionals particularly since it became a nursing specialty and palliative medicine became a medical specialty in in few countries the UK in 1987. The concepts have experienced several transitions (3) and have acquired own characteristics, conserving key aspects/principles.

Hospice care is often related to a prognosis of six months or less and focused on care at the end of life, while palliative care patient at any time, at any stage of illness.

The word hospice is better known to members of the public than palliative care and have different meanings in different countries. It is variously used to refer to a philosophy of care, to the buildings where it is practised, to care offered by unpaid volunteers, or to care in the final days of life.

It is recommended that the term 'palliative care' be used in all professional communications and publications, since the term is understood by and used by health care professionals.

What palliative care is not?

Though the principles of palliative care are applicable in each of the following fields, they are NOT the same as palliative care services:

Care of the Elderly (Geriatrics)	General practice (Family Medicine)
Care of the Chronically Ill	Care of Cancer (Oncology)
Care of the Incurable	Pain Clinic/ Pain Relief Service

Most emphatically palliative care is not euthanasia or physician-assisted suicide (PAS). In 2017, the IAHPHC adopted a position statement against euthanasia and PAS which states: "IAHPHC believes that no country or state should consider the legalization of euthanasia or PAS until it ensures universal access to palliative care services and to appropriate medications, including opioids for pain and dyspnoea"(4).

Should a palliative care service provide care for patients with chronic diseases and conditions?

Depending on the level of health-related suffering. Many of the principles of palliative care are applicable to the management of patients with chronic diseases and should be available and accessible when the suffering requires it.

Should a palliative care service provide care for the older persons?

Depending on the level of health-related suffering. Many of the principles of palliative care are applicable for older persons and should be available and accessible when the suffering requires it.

Is palliative care just terminal care/care of the dying?

The provision of high-quality care during the final days and hours of life is an important component of palliative care. However, palliative care should be initiated when the patient becomes symptomatic of their severe disease/condition and should never be withheld until such time as all treatment alternatives for the underlying disease have been exhausted. Palliative care may be appropriate long before the final phase of the disease or condition.

Should palliative care stay separate from mainstream medicine?

No. Palliative care originated because of the belief that patients at the end of life were not receiving optimal care and there was for a long-time mutual distrust between the practitioners of palliative care and mainstream medicine. Palliative care should be integrated into mainstream medicine.

Palliative care is complementary to the active treatment of the underlying disease, and it will foster palliative care skills for other health care professionals, particularly better pain and symptom control and appreciation of the psychosocial aspects of care.

Is palliative care not just 'old-fashioned' care?

No. Palliative care was originally separate from mainstream medicine and was frequently practised by very caring individuals who knew little about medicine. However, palliative care has gradually integrated in many health systems and curricula in medical and nursing schools.

Is palliative care what you do when "nothing more can be done"?

No. No patient should ever be told "there is nothing more that can be done"— it is never true and may be seen as abandonment of care. It may be permissible to say there is no treatment available to stop the progression of the underlying disease, but it is always possible to provide care and good symptom control.

Does Palliative Care include euthanasia and physician-assisted suicide?

No. A request for euthanasia or assisted suicide is usually a plea for better care or evidence of unrelieved or intolerable physical or psychosocial suffering. Depression and psychosocial problems are frequent in patients making requests and both can respond to appropriate care.

Patients suffering intractable symptoms can be treated by sedation; this does not constitute euthanasia or physician-assisted suicide.

Is a palliative care service really a pain service and its doctors' pain specialists?

No. Most but not all patients needing palliative care have pain of one sort or another but there are usually many other reasons for their distress. Focusing on pain to the exclusion of the others does not help the patient. Palliative medicine doctors have all had advanced training in pain management but not necessarily in invasive measures (though these are less frequently used in palliative care).

Their training has embraced all aspects of suffering – physical, psychosocial, and spiritual –but their certification is in palliative medicine, not pain management. Nevertheless, many of the principles of palliative care are appropriate to the pain management.

Palliative Care Need

Over 56.8 million people are estimated to require palliative care every year including 31.1 million prior to and 25.7 million near the end of life and at least 7% are children.(5) It is estimated that only 7 million patients received palliative care in 2017.(6) Majority of adults (76%) and children (>97%) in need of palliative care live in low and middle income countries.

The most frequent conditions accounting for adult palliative care are cancer, HIV, cerebrovascular diseases, and dementia. HIV/AIDS, premature birth and birth trauma congenital anomalies, and injuries and cancers generates the greatest need for palliative care among children.(5)

In High and Low- and Middle-income countries alike, people are living and dying:

- in avoidable, unrelieved pain
- with uncontrolled but controllable physical symptoms
- with unresolved psychosocial and spiritual problems
- in fear and loneliness, often feeling unwanted burdens.

The World Health Assembly (2014) declared that "palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care", and called for palliative care to be included in every country's health services, as well recommended the access to essential medicines and promote ongoing education and training to care providers.(7)

Do many people suffer so much that palliative care needed?

Emphatically yes! There are many published reports, based on objective as well as subjective observations, showing poorly relieved suffering experienced by people with serious health related suffering and those in the final years and months of life (see Table 1).

They had much physical suffering including high levels of pain, breathlessness, weakness, loss of appetite, nausea and vomiting, constipation, insomnia, sores and convulsions.

Their psychosocial suffering included anxiety, fear and apprehension, depression, loss of dignity, loneliness, a sense of being a burden on others and no longer being valued as a person, feeling that their suffering was not always recognised or taken seriously by their care givers.

Their existential suffering included questions of meaning - of life, death, and suffering; questions about religious faith - its relevance to them, the place of prayer and sacraments, the need for forgiveness.

If health authorities are not impressed with the wealth of evidence from other countries demonstrating the need for palliative care, then research into the unmet suffering and needs of your country/district will need to be done and the evidence shown to the authorities.

Table 1: The spectrum of suffering in patients with advanced disease (8)

Symptoms	Cancer %	Chronic heart failure %	COPD %	AIDS %
Pain	30-94	14-78	21-77	30-98
Breathlessness	16-77	18-88	56-98	43-62
Anorexia	76-95		64-67	82
Constipation	4-64	12-42	12-44	9-35
Nausea/vomiting	2-78	2-48	4	41-57
Fatigue	23-100	42-82	32-96	43-95
Depression	4-80	56-57	17-77	17-83
Anxiety	3-74	2-49	23-53	13-76

The goals of palliative care

The goals of palliative care are:

- to maximise the quality of life
- to provide relief from pain and other physical symptoms
- to provide psychosocial and spiritual care
- to provide support to help the family during the patient's illness and in their subsequent bereavement.

The key features of palliative care

- Recognition and relief of pain and other symptoms, whatever their causes
- Recognition and relief of psychosocial suffering, including appropriate care and support for relatives and close friends.
- Recognition and relief of spiritual/existential suffering.
- Sensitive communications between professional care givers, patients, relatives, and colleagues.
- Respect for truth and honesty in all dealings with patients, relatives, and fellow professionals.
- Inter-professional/multi-disciplinary team caring where possible.

3. Principles of Palliative Care

The principles of palliative care might simply be regarded as those of good clinical practice. A holistic approach, incorporating the whole spectrum of care –medical, nursing, psychological, social, cultural, and spiritual– is good medical practice, whatever the patient’s illness, wherever the patient is under care, whatever his/her social status, creed, culture, or education. In palliative care, it is essential.

Box 1: Content 'Palliative care – its principles and practice'

- Communication: Setting goals – discussing realistic goals, how to achieve, how to record.
- The general principles of symptom diagnosis and assessment
- Pain control – diagnosis, assessment, analgesic ladder, routes of administration, dispelling opioid myths and misunderstandings.
- All other common symptoms
- Emotional care – causes of distress, diagnosis, pharmacological approaches, psychotherapeutic approaches, family conferences.
- Social issues - diagnosis, management approaches, the needs of relatives
- Spiritual/existential issues – expressions of suffering, fear or doubt, the role of pastoral care workers, searching for meaning. Cultural and religious differences.
- Grief and bereavement – features of/preparation for counselling.
- Relatives, including children, needs of, support of.
- Team caring, clarifying, and blurring of traditional roles, mutual respect, and support.
- Staff stress and 'burn out'.
- Ethical issues – confidentiality, resource allocation, advance directives, DNR, euthanasia and PAS, research, patient’s competence, 'right to die', power of attorney.
- Emergencies encountered in palliative care and how they are dealt with.
- Legal requirements, licensing, and norms on palliative care

Attitudes and principles required for successful palliative care

A caring attitude

- involves sensitivity, empathy, and compassion, and demonstrates concern for the individual.
- concern for all aspects of a patient's suffering, not just the medical, nursing, or social work problems.
- a non-judgmental approach in which personality, intellect, ethnic origin, religious belief, or any other individual factors do not prejudice the delivery of optimal care.

Consideration of individuality

- the practice of categorizing patients by their underlying disease, based on the similarity of the medical problems encountered, fails to recognize the psychosocial features and problems that make every patient a unique individual.
- these unique characteristics can greatly influence suffering and need to be considered when planning the palliative care for individual patients.

Caregiver support

- the relatives of patients with advanced disease are subject to considerable emotional and physical distress, especially if the patient is being managed at home.
- particular attention must be paid to their needs as the success or failure of palliative care may depend on the caregivers' ability to cope.
- Palliative care, whether at home or in a hospital, often succeeds or fails depending on the care and support provided for the caring relatives.

Cultural considerations

- ethnic, racial, religious, and other cultural factors may have a profound effect on a patient's suffering.
- cultural differences are to be respected and treatment planned in a culturally sensitive manner.

Consent

- the consent of a patient, or those to whom the responsibility is delegated, is necessary before any treatment is given or withdrawn.
- most patients want shared decision making although physicians tend to underestimate this.
- having assessed what treatment is appropriate or inappropriate, this is discussed with the patient.

- in most instances, adequately informed patients will accept the recommendations made if they have been explained in non-medical jargon.

Choice of site of care

- the patient and family need to be included in any discussion about the site of care.
- patients with a terminal illness should be managed at home whenever possible though in the developed world few do so, most dying in hospitals.

Communication

- good communication between all the health care professionals involved in a patient's care is essential and is fundamental to many aspects of palliative care. There is strong evidence that such communications are less than optimal.
- good communication with patients and families is also essential.

Clinical context: Appropriate treatment

- all (palliative) treatment should be appropriate to the stage of the patient's disease and the prognosis.
- over-enthusiastic investigations, inappropriate therapy and patient neglect are equally deplorable.
- Palliative care has been accused of the medicalisation of death, and care must be taken to balance technical interventions with a humanistic orientation to dying patients. This is where a team approach is essential, each member of the team being able to see different aspects of the patient's suffering, personality, and needs.
- the prescription of appropriate treatment is particularly important in palliative care because of the unnecessary additional suffering that may be caused by inappropriately active therapy or by lack of treatment.
- when palliative care includes active therapy for the underlying disease, limits should be observed, appropriate to the patient's condition and prognosis and expressed wishes which may be different from those of the clinicians.
- treatment known to be futile, given because "you have to do something", is unethical.
- where only symptomatic and supportive palliative measures are employed, all efforts are directed at the relief of suffering and the quality of life, and not necessarily at the prolongation of life.

Comprehensive inter-professional care

- the provision of total or comprehensive care for all aspects of a patient's suffering requires an interdisciplinary team.

Care excellence

- palliative care should deliver the best possible medical, nursing and allied health care that is available and appropriate.

Coordinated care

- involves the effective organization of the work of the members of the inter professional team, to provide maximal support and care to the patient and family.
- care planning meetings, to which all members of the team can contribute, and at which the views of the patient and the family are presented, are essential to develop a plan of care for each individual patient.

Continuity of care

- the provision of continuous symptomatic and supportive care from the time the patient is first referred until death is basic to the aims of palliative care.
- problems most frequently arise when patients are moved from one place of care to another and ensuring continuity of all aspects of care is most important. A useful means of delivering this is the Liverpool Care Plan [[See the Recommended Reading List](#)].

Consistent medical care

- consistent medical management requires that an overall plan of care be established, and regularly reviewed, for each patient.
- this will reduce the likelihood of sudden or unexpected alterations, which can be distressing for the patient and family. It may lessen the chance of crises or medical emergencies which can frighten the patient and relatives.

Crisis prevention (see Consistent medical care)

- good palliative care involves careful planning to prevent the physical and emotional crises that occur with progressive disease.
- many of the clinical problems can be anticipated and some can be prevented by appropriate management.
- patients and their families should be forewarned of likely problems, and contingency plans made to minimize physical and emotional distress.

Continued reassessment

- is a necessity for all patients with advanced disease for whom increasing and new clinical problems are to be expected.
- this applies as much to psychosocial issues as it does to pain and other physical symptoms.

Advance Care Planning

Advance care planning is a means for patients to record their end-of-life values and preferences, including their wishes regarding future treatments (or avoidance of them).

Advance care planning involves several processes:

- informing the patient
- eliciting preferences
- identifying a surrogate decision maker to act if the patient is no longer able to make decisions about their own care.
- it involves discussions with family members, or at least with the person who is to be the surrogate decision maker.

The principle of advance care planning is not new:

- it is common for patients aware of approaching death to discuss with their carers how they wish to be treated.
- however, these wishes have not always been respected, especially:
 - if the patient is urgently taken to hospital
 - if there is disagreement amongst family members about what is appropriate treatment.

The '[Respecting Choices](#)' program developed in Wisconsin is an example of advance care planning:

- employs trained personnel to facilitate the discussions and record the outcomes, which are in writing and signed, and kept in the front of the patient's file.
- the surrogate decision maker is involved in the discussions so that they have explicit knowledge of the patient's wishes; otherwise, they may feel burdened by the responsibility.
- there is less conflict between patients and their families if advance care planning has been discussed.

Health care provider should have the own advance care planning, then it helps with the conversation about with patients and family.

4. How do you 'get started'?

How do you 'get started' planning a palliative care service?

There is no one right or wrong model for the provision of palliative care. The best model is determined by local needs and resources, in consultation with the local health care providers and authorities.

IAHPC believes that each country should be encouraged and enabled to develop its own model of palliative care, appropriate to the needs of the local patients and the available resources, taking advantage of the experience and expertise accumulated in developed countries, and not be expected to copy models more appropriate to affluent countries.

Models of palliative care provision

The following include different models of palliative care provision, also recommended by the European Association for Palliative Care (EAPC) (9)

- Hospital palliative care unit (or in-patient palliative care unit) within a (secondary or tertiary referral) hospital, operating with dedicated beds.
- Hospital palliative care team/hospital mobile teams, operating without dedicated beds, in a secondary or tertiary referral hospital.
- In-patient hospices are detached or even distant from a hospital. Often termed a 'free-standing inpatient unit'.
- Community palliative care services/Home palliative care teams, caring for patients at home, in nursing homes or living with relatives.
- Day palliative care unit, caring for patients living at home but able to be brought in for clinical and social care on a day basis.

It is now widely accepted that no programme or service should be started before:

- There has been a well conducted needs assessment study.
- There has been discussion with local, regional, and possibly national health care planners.
- There has been discussion with all other local groups, statutory and voluntary, providing hospice/palliative care, whatever its model.

After that and for the selected model, there must be:

- Detailed analysis of financial aspects: Cost and capital need (expenses, operational costs) and projected sources of income (revenue from services, donations, grants).
- Detailed consideration of staffing implications and recruitment challenges
- Detailed consideration of the educational role of any planned service
- Detailed consideration of relations with local hospitals and clinics, sharing of facilities and the procurement of all necessary pharmaceuticals.

Box 2: Models of palliative care delivery at the hospital

There are 3 ways of delivering PC in the hospital setting:

- Consultation service
- Palliative care unit
- Combination of 1 and 2

There is no evaluative data to recommend one delivery system over another. Each delivery method should provide continuity of care between home, acute care, palliative care and local hospice and facilitate an integrated seamless programme of services for patients and families from diagnosis to death.

Choosing the right model of palliative care service with which to 'get started'

The matrix below illustrates the differing indications, based on the different levels of suffering and dependency of the patients. It must be emphasised, however, that it is not being recommended that at the stage of 'getting started' each model be started and developed simultaneously!

Table 2: Care Matrix for Different Palliative Care Models (based on patient needs and dependency)

Care Factor	In-patient Palliative Care Unit	Hospital Palliative Care Team	Community Palliative Care Service	Day Palliative Care Unit	Out-patient/ Ambulatory Consultation
Symptoms	Moderate/Severe	Moderate/Severe	Mild/Moderate	Mild	Mild
Psychosocial complexity/instability	Moderate/Severe	Moderate/Severe	Mild/Moderate	Mild/Moderate	Mild
Clinical instability	Unstable +++	+++/**	++	+	0
Require other intensive medical treatment	0/+	+++	0	0	0
Degree of nursing required	High	High	Intermediate	Low	Minimal
Degree of social support available	Low/Variable	Low/Variable	Available	Available at night-time	Available
Functional dependency	Dependent +++	Variable	++	+	0

In the chapters which follow different types of service are described with pros and cons of each.

What can you learn from others?

In the planning period it is good to visit other similar facilities existing in the country and to learn from their success and failures. If you are the first to open a palliative care service or hospice in your country and maybe you have been abroad and have been impressed with one specific hospice and have learnt about its functioning, policies and operational procedures be realistic in what you can use in your specific situation, what needs to be adapted and what needs to be left out. Do not try to clone a unit that has impressed you!

Search online for palliative care sites and official documents regarding certification and licensing for health services, seek advice from legal. Doing work in advance might save you from ending up with a building that cannot be registered in your country and is not suitable for the needs of the patients.

What must be emphasised is that there is no single model appropriate in all situations. Cloning a model found effective in one country or one culture, can be a recipe for disaster.

Needs Assessment

It is tempting to rush into starting a palliative care service without doing a needs assessment or giving thought to the topics mentioned above, knowing that we know how palliative care can ease the suffering of many patients. This can be disastrous.

Experience suggests that time spent in answering the following questions is always well spent.

Patients

- How many patients will likely benefit from the palliative care service at any one time?
- What is their age distribution?
- What is the prevalence of symptoms?
- What is the main cause of death?
- What are thought to be the other unmet needs of these patients?
- What is the trajectory of death?
- What proportion is dying at home and in hospital?
- Which diseases in a defined community are likely to benefit from palliative care?

Priorities

- Is the service primarily to provide care in the home, or to train family members to care better?
- Is the service primarily to provide care or to educate and train local health care professionals to provide better care, in the home or in local hospitals?
- Is the goal to enable more people to remain at home for longer periods?
- Is the goal to enable more people to die at home? (as distinct from wanting to remain at home if possible)

Models of care

- What are the obstacles to good palliation as perceived by health care workers in the area?
- Should the proposed service provide home care and /or inpatient care?
- Should there be a palliative care ward in the local hospital or a free-standing palliative care unit/hospice?
- Should a hospital palliative care service manage the patients or provide advice and support?
- Will education be provided and if so, which model of care provision will best facilitate it?

Relationships with other agencies

- What will be the relationship with any existing palliative care services?
- What will be the relationship with the local hospital?
- What will be the relationship with the local medical community?
- Who will prescribe and dispense medications and be responsible for opioid storage etc.?
- Will there be access to basic (non-sophisticated) diagnostic facilities and to case notes of all patients referred to the service?

How many beds will be needed?

For administrative/economic/efficiency reasons a unit smaller than 10 beds is not cost efficient unless catering, stores, supplies, central heating, security, pharmacy etc. are available on site or in an adjacent unit/hospital.

It is generally accepted that in a population of 1,000,000 the number who will need a palliative care bed is:

Table 3: Estimation of palliative care beds

Population	Per one million
With malignant disease	400-700
With non-malignant disease	200-700
Deaths of those with neurological diseases	170
Deaths of those with psycho-geriatric disease	40
Deaths of those with chronic cardiac/respiratory disease	5000

As guidelines, typical statistics for hospices in the West are:

- Average length of stay 11-14 days (lowest when there is a community palliative care service (CPCS))
- Average age 65
- Deaths at home 40-50% (not necessarily higher if there is a CPCS)
- Is the hospice going to have an incorporated outpatient/ambulatory clinic or maybe a day hospice/unit or other palliative care services? If so this will affect the number and type of rooms, toilets, ambulance and car access, wheelchair access, the need for activity rooms, treatment rooms and equipment.

Financial considerations

Experience shows that any hospice/palliative care service is considerably more expensive to operate than most planners had anticipated. Raising capital is easier than raising revenue.

The smaller the in-patient unit the higher, proportionately, is the cost. Eighty five percent of expenditure always goes on salaries and wages, whatever the type or size of service.

It is counter-productive in this work to try to reduce running costs by reducing staff. Small economies must be achieved through vigilance with telephone, postage, travel, catering, and printing costs.

When a palliative care service is to be independent of any national health service (even if it is a private not for profit foundations), it is prudent to consider the appointment of fundraiser or a fundraising committee to relieve other staff of any responsibility to generate income.

Palliative care has been shown to reduce direct costs of hospitals and health care system, while guarantee satisfaction with the care for patient and their caregivers.(10, 11)

Educational Responsibilities

Every palliative care service should be regarded as an educational facility for fellow professionals – not as the sole provider of palliative care. Educational outreach should be built in from the start of any service.

This may involve time allocated to teaching, room(s) for tutorials, a small library, budgeting for teaching equipment or even a member of staff designated primarily for education.

There must be discussions with local universities, colleges, and educational establishments on how the palliative care unit can collaborate with them in teaching modules even before a new service starts. It is perhaps unnecessary to point out that such work generates little if any income, essential as it is.

Discussion with planners

Remember that local/national health care managers may not know much about palliative care. They may need to visit established palliative care services or be presented with data from other services serving similar population groups.

They will want to be persuaded:

- that a palliative care service is needed, not duplicating an existing service.
- that its senior staff will cooperate with them rather than adopting a combatant attitude.
- that there is a real possibility of collaboration leading to mutual benefit.
- that the proposed new service may even reduce costs.
- that the proposed new service will fit seamlessly into existing care.

Discussions should be held with all other local health care providers who may be affected by the planned palliative care service. The key to successful collaboration in palliative care is partnership, not criticism or competition.

The local medical community

The palliative care service needs the cooperation of local medical doctors, to be able to work with them in providing better care for patients.

- Doctors who feel threatened by the service or feel their patients are being 'taken over' will not be supportive and will not refer patients who might benefit from palliative care.
- It is best to assume that even though some doctors may not know much about palliative care, they have their patients' best interests at heart and want to learn how to better care for them.

The local hospital

The relationship with the local hospital(s) must be clearly defined to foster co-operation and to avoid any antagonism.

- Will the palliative care doctors be permitted to see patients in the hospital?
- Will the hospital's diagnostic facilities be available for palliative care patients?
- Will medications be available from the hospital pharmacy?
- What charges will be levied for such services?
- If hospital patients are transferred to palliative care, will their records come with them?
Mail or electronic?

Other palliative care services

Avoid competition between palliative care providers. It wastes precious resources and may deprive some patients of the care they need and deserve. It can produce confusion in the minds of the public and local health care professionals.

- Each palliative care provider should define what service they can offer in a defined geographical area and then, in discussion with other providers, decide who does what.
- Explore together closer co-operation. For example, can they share a fund-raiser? Can they collaborate on purchasing pharmaceuticals to bring down the price? Can they share educational work, one teaching doctors, the other nurses?
- Can they co-operate in research and data collection?

5. Management of the New Service

If the new palliative care service is to be part of a larger health care facility (hospital, medical centre, or community service) its management structure will be dictated by the existing system. It then becomes essential that the palliative care service has at its head, someone with both an understanding of, and experience in, palliative care.

Governance

The Board of Directors /Trustees

A free-standing hospice or an independent unit will need to have a Board of Directors/Trustees, who will be legally responsible for the affairs and operation of the service. If the service is within a hospital, it is highly likely that there is already a Board of Directors/Trustees in place. This section refers to a Board of Directors /Trustees of a free-standing palliative care unit or hospice.

The legal responsibilities of such a Board will be laid down in the statute books of the country where the service is based. They are legally binding. Membership is laid down by its Articles of Memorandum and Constitution.

The chairperson is usually someone with a track record of such leadership, coming from any of the learned professions or commerce or academia. It is useful if the members can represent medicine, nursing, law, local or national government, the public, the media and the church. Sitting in on its meetings but not serving as trustees or governors or permitted to vote, can be the CEO (Chief Executive Officer) and the nursing, medical and administrative directors.

Professional Advisory Committee and its subcommittees

A professional advisory committee, non-executive but immensely important and influential group, reporting directly to the Directors/Trustees. Much of the efficiency and credibility of the unit will flow from this committee and its influence and guidance. Its membership, usually 10-12 in number, should be representative of specialist hospice/palliative care (both medical and nursing), general medicine, oncology, hospital and community nursing, social work, education, and research, as well as representatives of the church, and professionals allied to medicine. As with any committee much depends on the authority of the chairperson who must be able to meet regularly with the senior hospice staff. Its responsibility is to advise on all aspects of the professional work of the unit, including staffing levels, recruitment, documentation, protocols, audit, curricula, relations with other clinical services, research and possibly ethics etc.

This is one of the most useful committees yet seldom set up by those 'getting started'. Usually with 8-12 members, they should present general practice, hospital medicine, university, hospital and community nursing, social work, local clergy, professionals allied to medicine and specialist palliative medicine/care. Initially most members will be invited by the founders of the service because of their known interest in palliative care or their standing in their profession or locality.

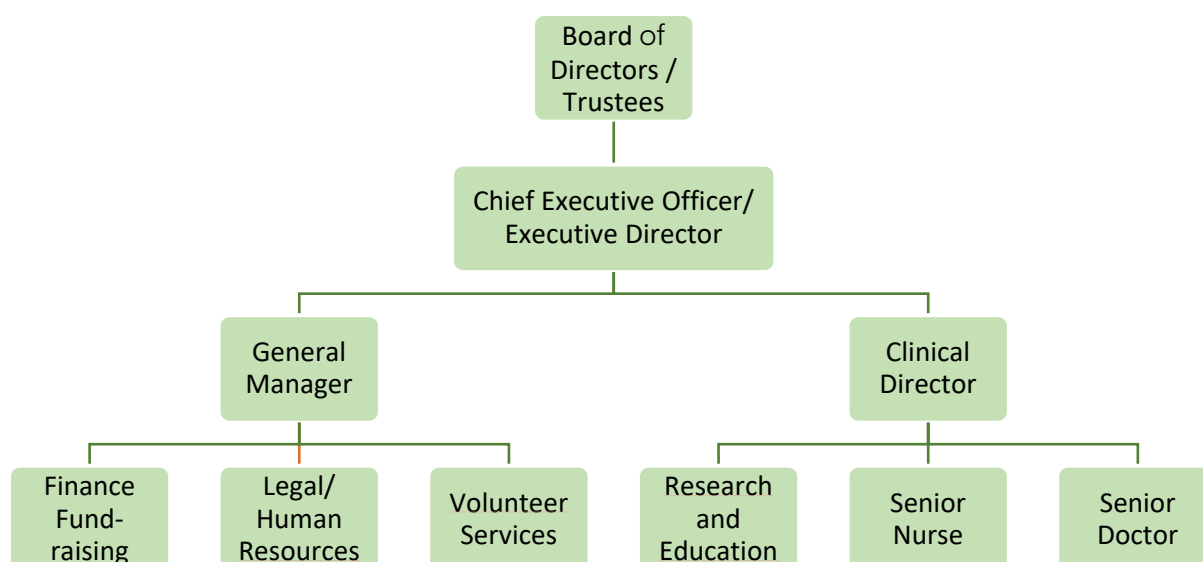
Such a committee usually meets quarterly for the first few years of a new service then twice yearly when it is well established. The period that members serve is decided by them in consultation with trustees. The selection of a chairperson is also usually left to the trustees.

The committee usually has no executive powers but is, as its name implies, an advisory body. It advises at the request of the clinicians of the new service and the Trustees/Governors on matters such as staffing, research, records, service provision and relations with other clinical services – anything that relates to the care programme of the new service. Some palliative care services have subcommittees of the Professional Advisory Committee advising on pastoral care and another advising on education.

Administration and Management

Example of an Organizational Structure

The following is an example of an organizational structure. The structure that works for the service depends on the level of resources, the needs, the existing organizational structure and legal or institutional norms.



The success of any team rests with the personality, the interpersonal skills, and the management skills of the Chief Executive Officer (CEO)/Executive Director.

Appointment of senior staff

Provided there is a Professional Advisory Committee and the Board of Directors / Trustees, the order in which senior staff are appointed hardly matters, though logically the senior administrator/chief executive should be given priority, followed by the senior medical and nursing staff, each of whom will then share in the recruitment and appointment of their own staff members.

It cannot be over-emphasized that even the smallest hospice/palliative care unit must be run on business-like lines, with well-defined lines of accountability and communication, written down procedures and protocols, review systems in each department, clinical and organizational audit systems which operate from Day 1, and a defined public relations policy.

Being well-meaning and compassionate (as are all people in hospice/palliative care) is essential, but this can never substitute for clinical and organisational efficiency, however small the in-patient unit.

If the service is 'free-standing' or 'independent' then it is important to choose the most appropriate and efficient management structure.

Strategic planning

It is recommendable to do a strategic plan for five years. It provides a sense of direction and outlines measurable goals. Strategic planning is a tool that is useful for guiding day-to-day decisions and for evaluating progress and changing approaches when moving forward. In addition, it helps to set priorities, focus energy and resources, strengthen operations, ensure that employees and other stakeholders are working toward common goals.

Leadership

Building a new palliative care service requires strong leadership to plan, develop, implement, and to continue, evolve and grow.

Being a good leader is not something everyone can do, but you can learn it! Every effective leader needs to possess and/or work towards their goals and vision. Leadership means creating and planning, securing resources, and looking out for and improving errors. Leadership is about inspiring and motivating people to work together and cooperate with themselves and in some cases, other teams, to achieve the common goal.

Human Resources

Each manager, as in any company or organisation, will be responsible for the support of staff under their control and direction. Such support may be unobtrusive but nevertheless must be tailored to the different needs of each member of staff, and details of major issues and formal meetings recorded.

Staff morale in any palliative care service is largely dependent on:

- Good overall leadership in the organisation and regular, informal visits to the unit by Trustees

- Good leadership in the unit, ward, or department
- Good communications so that key issues, problems, and decisions affecting staff are made known to all concerned. A staff newsheet/letter is useful and cheap to produce.
- Social interaction for example through an occasional party, dinner, barbecue to which partners are invited.

In addition, it is useful for every member of staff, no matter how small the staff, to be provided with an employee handbook. In it will be given information about the aims of the service, its staffing, its management structure, its committees, uniforms, discipline and appeal procedure, lines of responsibility and communication, vacations, holidays, sick leave, family leave, ethical guidelines etc.

Such a handbook is as much for the administrators/managers and trustees as for clinical staff members, enabling them all to feel part of this new and exciting venture. It should be so worded that readers feel welcome and excited to be part of something exciting.

Education

Very importantly a consultation service allows for teaching and support for others in healthcare (physicians, nurses, therapists) and can influence their care of other patients under their care but not referred for advice from the HPCT ('ripple' effect).

Continuing professional development

From the start of a new service each member of staff must be given the opportunity to develop their skills whether they are in management, teaching, or bedside care. Modest courses might be held in the unit. Others may be day-release study days or residential courses, ranging from modest updates to advanced training leading to higher qualifications. Financial budgeting is obviously essential. Few aspects of staff support yield so many benefits as professional betterment.

Ideally, but not often done, is for Directors /Trustees to have occasional (say annual) study days when they are brought up to date with the working of the service and developments in palliative care generally, hear talks by staff members, and collaborating colleagues in local hospitals.

It is extremely easy for Trustees and members of staff to become islands, less and less aware of the outside world, ignorant about palliative care nationwide and worldwide. Every effort must be made to prevent this happening.

Stress management

The surprising answer is 'probably not'. People working in palliative care for the first time expect it to be stressful because of the number of deaths, the level of grief and anger but research has shown that most stress is related to the obsessive, high expectations, critical personalities of the staff members. A short session chaired by a psychologist or psychiatrist, held every two weeks in the first year of a new unit, is usually all that is needed.

The realistic aim of a palliative care service is not to produce perfect care but to offer care better than people have experienced before, care that is always under review and gets better all the time.

Financial matters

Experience suggests that raising capital for hospice/palliative care is relatively easy when people already know what it is and how it can help them. The bigger challenge is raising sufficient revenue to maintain the service, particularly if there are in-patient beds.

The most expensive item is salaries, usually accounting for 80-85% of costs. Though hospice/palliative care beds are certainly slightly more economical than beds in acute or even long stay hospitals, they are still expensive. A good rule, when planning an in-patient service is to budget for revenue requirements only 10% less than current costs in local acute units.

Essential Package of palliative care and pain relief

The Lancet Commission on Palliative Care and Pain Relief designed a cost-effective, essential package of palliative care medicines, basic equipment, and human resources, which is the minimum requirement for a health system, though resource-constrained, should make universally accessible for alleviating much of avoidable suffering (12). Of course, this list can be adapted and expanded according to the local situation.

Box 3: Essential Package of palliative care and pain relief

Medicines

- Amitriptyline
- Bisacodyl (Senna)
- Dexamethasone
- Diazepam
- Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)
- Fluconazole
- Fluoxetine or other selective serotonin-reuptake inhibitors
- (sertraline and citalopram)
- Furosemide
- Hyoscine butylbromide
- Haloperidol
- Ibuprofen (naproxen, diclofenac, or meloxicam)
- Lactulose (sorbitol or polyethylene glycol)
- Loperamide
- Metoclopramide
- Metronidazole
- Morphine (oral immediate-release and injectable)
- Naloxone parenteral
- Omeprazole
- Ondansetron
- Paracetamol
- Petroleum jelly

Medical equipment

- Pressure-reducing mattress
- Nasogastric drainage or feeding tube
- Urinary catheters
- Opioid lock box
- Flashlight with rechargeable battery (if no access to electricity)
- Adult diapers (or cotton and plastic, if in extreme poverty)
- Oxygen

Human resources (varies by referral, provincial or district hospital, community health center, or home)

- Doctors (specialty and general, depending on level of care)
- Nurses (specialty and general)
- Social workers and counsellors
- Psychiatrist, psychologist, or counsellor (depending on level of care)
- Physical therapist
- Pharmacist
- Community health workers
- Clinical support staff (diagnostic imaging, laboratory technician, nutritionist)
- Non-clinical support staff (administration, cleaning)

What might be regarded as essential in one country might not even be used or available in another. The more sophisticated and affluent a country the more patients and their relatives will expect 'special' equipment. In other cultures, they will improvise and manage to make a patient feel comfortable and safe in conditions that might seem Spartan and inadequate in the West.

6. Hospital Palliative Care Unit

This refers to a bedded unit within a hospital – whether general or specialist, secondary or tertiary. HPCU admits patients whose conditions requires specialist palliative care. After stabilizing the situation, the patient is discharged or transferred to another care setting, if possible.

It differs from a Hospital Palliative Care Team (HPCT) in having beds whereas the HPCT is entirely advisory. Ideally a HPCU should be the base for a HPCT or, at least, the senior members of the Unit can go to advice in other wards. In many hospitals the beds are under the clinical direction of the specialists in the HPCT who use them for patients they have been asked to see in other parts of the hospital, patients who have complex nursing as well as major medical problems, all more easily cared for in the Palliative Care Unit beds. It can, of course, also function when there is no HPCT.

Advantages of a HPCU

- The senior medical staff are palliative medicine specialists
- The nurses are trained in palliative care and very experienced
- The patient does not need to be moved to a hospital or hospice unfamiliar to them
- The patients can still be visited by doctors and nurses from other units in the hospital
- The patient can usually return to their home ward when the palliation has been successful
- All clinical records are available in the hospital
- All diagnostic facilities are available in the hospital
- Special environment for care, closer control/monitoring
- Ideally medical students and junior doctors can follow the patient and his care regimen both in the original unit and through the HPCU – a rich educational experience.

Disadvantages of a HPCU

- It is often difficult to persuade management that more can be achieved by having a HPCU than by just having a HPCT advising on patients in the wards where they have been treated in the past. As a small unit with only 4-6 beds, it is expensive to operate, especially when the throughput is so fast.

- To be effective it needs the best possible nurse/patient ratio (as in all palliative care) but it is unrealistic and unhelpful to suggest what that should be. Senior management will seldom agree to the establishment of a HPCU which costs more than other comparable units in the hospital. A useful guide is to regard/describe the HPCU as a 'High Dependency Unit' and staff accordingly. That will be understood by administrators.
- Frequent visits from 'allied health professionals' including social work and pastoral care – all adding to the cost of running such a small unit.
- Staff may be more than usually anxious about what standard of care patients will receive when they leave the HPCU. Nurses may resent the fast through-put of patients in the HPCU, feeling that a longer spell there would have been good for them.

Questions that must be asked before planning a HPCU

- Will the small unit accept only from the other wards and units in the hospital or also admit from the community? This is particularly relevant when there is no well-staffed hospice in the community or no Community Palliative Care Service or few GPs willing/able to provide high quality palliative care in the community. This will materially affect the number of beds needed.
- What statistics about the benefits and disadvantages of a HPCU will be needed to persuade managers and planners that such a unit is needed? Equally sceptical will be clinicians who have yet to be convinced that any other doctors and nurses can provide better palliative care than they are currently doing in their Oncology or Renal Unit.
- What will happen to a patient admitted to the HPCU, now much improved, who cannot be transferred back to his original ward because there are no available free beds? Will he/she have to remain in HPCU or go to an unfamiliar ward?
- When a patient who has been in the HPCU is discharged home to the care of the general practitioner/family physician, which specialist will be responsible for follow-up? Ideally it should be the medical specialist in the HPCU because palliative care will be the focus of care from then on but this will need to be negotiated with other specialists involved. Transfer to the HPCU can easily be perceived as a subterfuge, taking a patient out of the care of another specialist.
- Are the community services well enough developed to take over the care of discharged patients? Are there other services with which you can establish links (social services, primary health care, other charities)?
- How do you prevent the HPCU getting the reputation of a 'Gloom and Doom Ward'? Experience of HPCUs in different parts of the world have demonstrated that, like all good hospices and palliative care units, they have a positive atmosphere, much humour, are often much livelier than general wards, and popular places to work for nurses and doctors – all much to the surprise of other staff within the hospital.
- Initially senior nursing and medical management may know so little about intensive palliative care that they will be uneasy having responsibility for the HPCU. This may affect

staff support, appraisals, and staffing levels – almost certainly better than elsewhere in the hospital. They will predictably want to keep costs down.

Do not resuscitate (DNR) policy

If the hospital has a clear policy, then it must be followed in the HPCU. If not, then one must prepare for the HPCU and presented to senior medical/nursing staff meetings for explanation and approval. There is likely to be vigorous opposition to what many would see as nihilism in the HPCU. ("You can't just let someone die – it's our duty to keep them alive by all means known to us.")

Auditing a HPCU

The need for clinical and management audit is as great as, if not more than, in any other palliative care service. It should be given the highest priority; its records kept transparent for all to see and question.

Before the launch of the new service

- Ensure that all staff of the hospital – junior and senior, nurses and doctors, social workers and pastoral care workers and all physiotherapists, occupational therapists, art and music therapists, clinical pharmacists and clinical psychologists – are sent details about the service, who will benefit from it and how it will operate.
- Ensure that notices about the service, giving all that information, are put on as many notice boards as possible, and as a minimum, one in each ward office and doctors' office.
- Ensure that it is announced at Grand Rounds – preferably by the lead clinician of the new service. As the service develops try to arrange for one session to be devoted to an update on the work and progress of the HPCT.
- Ensure that the hospital switchboard is fully informed about the service.
- Ensure that junior medical staff, and those in charge of their continuing medical education, know about the service because, very often, when things go wrong it is because they were not sure what was expected of them and whom they were meant to contact for guidance.

7. Hospital Palliative Care Team

Hospital Palliative Care Team (HPCT) –or consultation service– develops in response to the need for expert palliative care. The personnel for a consultation team can be simply a nurse or physician alone or combined with pharmacist, spiritual care or social worker. Those planning a consultation service should not be discouraged by lack of numbers at the outset. Special interest and expertise are essential, however.

Patients and families are seen in consultation only and the HPCT does not assume responsibility for providing care, despite the frustrations inherent in the inability to 'control' patient care. This is the best model if resources are limited or institutional needs minimal e.g., a small local hospital with no oncology service and for a 'start-up' palliative service. Funding is still required and should be arranged before any such service is started.

Once the service is established it is usually found that much time is spent advising on patients who are in the same unit as the one the team has been called to. Patients and families appreciate the extra time and expertise, do better and credibility produces more referrals.

The HPCT may be the contact point for Community Palliative Care Services if these are available and one team member should lead in this. If this is the case a HPCT can facilitate smooth transfer to hospital from home and vice versa.

Advantages HPCT over a dedicated HPCU

- No need to fight for space, equipment, facilities
- Minimal personnel commitment (no night call, no holiday relief unless readily available)
- Ability to train other disciplines by hands- on end of life care and example
- Use of pre-existing diagnostic and therapeutic resources and other hospital staff
- Use of the hospital pharmacy and its specialist pharmacists

Disadvantages of a HPCT

- the inability to develop team expertise in a dedicated unit such as a palliative care unit
- the inability to control medication administration
- the difficulty (though not the impossibility) of doing research
- the difficulty of doing formal bedside teaching when the HPCT does not have its 'own beds'

- the consultation services having to rely on the staff and resources of the institution to provide such services as physiotherapy, occupational-, music-, art -therapy and pastoral care
- Even before considering staffing, bear in mind some of the unique problems associated with this type of service and the stress they can produce.
- Experience shows that it is much more challenging to bring suffering under control in a general ward, even with a HPCT than in a HPCU with its dedicated palliative care staff, so familiar with every aspect of palliative care.

Problems and disappointments

Some examples of problems and disappointments associated with a service may illustrate this:

- Unfamiliar with opioids a ward doctor discontinues them when the patient vomits. It is a day or two later before the service learns of this.
- Trained to fear opioids because of 'addiction', 'tolerance' or 'narcosis', the consultant/specialist forbids their use in his "unit".
- Nurses are unhappy when the service suggests a meeting with relatives and patient to explain the care regimen and the prognosis.
- The routine of the unit does not make it easy/possible for a family group to remain near a dying patient.
- Staff in the unit have no experience of talking to/listening to a dying patient.
- Staff have never effectively managed 'death rattle' and fail to call for help.
- A patient develops intestinal obstruction and is immediately put on 'drip and suck' and the surgeons summoned.
- Junior staff are unclear whether to consult their senior doctor or the doctor of the HPCT when a crisis arises.
- Some senior doctors take offence when changes in a regimen are suggested feeling their authority is being undermined.
- Though the service is there to advise it is often used to find a terminal/palliative care bed somewhere.
- Occasionally the HPCT is called in to give ethical advice for patients not in need of palliative care.

Before planning a HPCT

For whatever reason you are considering starting a HPCT there are essential preliminary tasks:

- Perform a needs assessment to evaluate the wisdom of a palliative team e.g., if your hospital is a Maternity Hospital, it makes no sense. However, if it is a general hospital with an oncology service and possibly other specialists it makes good sense.
- Enrol nursing, medical, social work, pastoral, and other colleagues in a working group to develop a proposal for formal presentation to your institution.

- Find a sympathetic administrator/planner who will support your thinking and proposal.
- Meet with Hospital Administration and present your idea/proposal/costings.
- Get advanced training in palliative care, read, and surf the many good palliative sites on the internet if available.
- Meet with colleagues in other disciplines, oncology, surgery, medicine to introduce yourself and the concept of palliative care. Their understanding and collaboration are essential.
- Meet with pharmacy administration to enrol their support and inform them of the principles, practice, and pharmacopoeia of palliative care. You must be sympathetic to their concerns re: increased workload, overtime budget etc.

In summary, a HPCT is worth considering when there are not the resources to start and operate a bedded unit. However, it must be remembered that the members of the HPCT:

- must be highly experienced in hospital work, and aware of the workings of the hospital where the HPCT will operate.
- expert in the palliative care of patients with a wide range of conditions (and not just malignancy),
- possessed of considerable skills in diplomacy, tolerance and understanding of the needs and problems of the clinicians who refer patients to them.
- committed to, and happy to contribute to, teaching in almost every unit they are called to.

Future development of the HPCT may include:

- The creation of an in-patient bedded unit within the hospital backing up the HPCT.
- University affiliation
- Local national and international recognition, website
- Symposia and seminars
- Collaborative research with other PCUs, HPCTs and free-standing units

It is difficult to factor in all of these from start-up, but they should be considered as the unit develops expertise which they can share.

Groups contemplating starting such a service are often daunted by the complexity and expertise of services whose personnel they meet at seminars and on websites they visit. Some are tempted to feel it would be less threatening to start a free-standing unit/hospice, remote from the frenetic, sometimes aggressive atmosphere of a tertiary referral university teaching hospital. Remember others have been in the same position and it was no easier than now. However, it was worth it.

8. Free-standing Inpatient Unit/Hospice

A 'free-standing' unit is one not within a hospital, be it a general one or a specialist one. It may be in the grounds of a hospital or totally separate from a hospital, miles away in another part of the town or city. Whether it is called a palliative care unit, or a hospice is a decision that must be made by the Trustees establishing it, bearing in mind that the public (except in French speaking countries) still seem to prefer the term 'hospice' whilst health care professionals understandably prefer 'palliative care unit'. In some countries the name (and requirements) of the facilities is regulated.

What makes any palliative care unit or hospice different from a hospital is not its size (although most are small units with 14 - 30 beds), but the holistic, personalized, flexible programme, and the attitude and focused commitment of the staff.

When planning to open/build a free-standing in-patient unit the following questions must be addressed: *Why is a free-standing inpatient unit thought to be needed?*

There must be an identified need for care in a hospice according to the pattern of death, and the structure of the society. There must be good reasons why the palliative care unit cannot be within a hospital or palliative care be provided by a hospital palliative care team (HPCT).

A well conducted needs assessment is essential to define the target population, the major clinical problems, the existing services, and networks in the community being served. [[See Need Assessment](#)]

If it is a culture where family bonds are strong and families feel that it is their duty there to care for the patients no matter whatever the cost to them, and the patients want to die in their own beds then maybe it is better to have a second thought and ask if a community palliative care team might be more appropriate or a unit for short stay, for 'acute problems' combined with a such a community team. If patients want to remain at home as long as possible but not die there, a unit may be needed solely for end-of-life care' but it will soon be known as a death house.

If it is a community where there are few relatives to care for their loved ones at home, few nursing homes and poorly developed community services then a long-stay unit is the best solution for offering palliative care. It should be noted that even in a hospice/palliative care unit there can develop the problem of 'blocked beds' occupied by patients who might be better at home or in a nursing/care home, but no places are available.

Will it be a demonstration unit?

If you work in areas where palliative care is in the pioneering stage it might be necessary to demonstrate to the authorities the benefits of hospice, the costs associated with it, the impact of care on the patients and the families to convince them to accept the model and to integrate it into the existing health care system. Making the right choice for the model of care is critical.

The building

What if an existing building is offered or becomes available for purchase? Sometimes hospital buildings become available when re-organization takes place, and some existing buildings are found to be redundant. They may be offered for emerging hospice sometimes with the idea of keeping the workplace for staff who would otherwise be made redundant. Think of all the implications when accepting such an offer. It might not be the best decision for all concerned.

If it is a hospital building offered to set up a 'not-for-profit' unit would the hospice be obliged to forego its high staff/patient ratio, or accept hospital staff without any palliative care training into its interdisciplinary team, or student nurses on rotation through the unit? If yes, then this is not an option and you must find a way to convince your authorities that hospices are well recognized in the world and back up your case with recommendations made by international professional associations or official bodies like European Union, World Health Organization (WHO).

On the other hand, there are some benefits of having the hospice/palliative care unit within the grounds of (but not inside) a general hospital:

- Proximity to medical specialists such as surgeon, intensive care specialists etc.
- Laundry, laboratory, pharmacy, catering facilities close at hand.
- Junior medical staff to share out-of-hours calls.
- Proximity to diagnostic services, physiotherapy, occupational therapy, social work, pastoral care.
- Heating services and maintenance staff nearby.

Other essential considerations

What other essential things need to be considered at the planning stage?

- If it is to be a short stay hospice (most people being discharged within 14 days), what care services will they be able to access when they leave the hospice?
- Are the community services well enough developed to take over the care of discharged patients? Are there other services with which you can establish links (social services, primary health care, other charities)?
- What arrangements can be made for investigations (radiology, laboratory) or for receiving such further treatments (radiotherapy, surgery, chemotherapy)?
- Will the hospice have its own pharmacy and how/where will medications be ordered, procured, delivered, and stored (meeting all national legal requirements)?

- Will the hospice have its own mortuary, or will it be able to use the facilities of a neighbouring hospital?
- Depending on the law in your country will the hospice need to have a 'cold room'?
- How soon after a death must a death certificate be issued? This has relevance to the duty hours of medical staff.
- If post-mortems/autopsies are ever needed, where would they be done and how will bodies be transported there?

Target Patients

What type of patients will be admitted to your hospice?

- Is the hospice going to be for adults, for children or for both? If you plan to open a unit exclusively for children you are strongly urged to read about them, how they are run, the problems faced etc. in the many books and papers published by children's hospices worldwide. If children are to be cared for in a 'mixed unit' there will need to be special rooms or even an annexe set aside for them and nurses and doctors trained in paediatric palliative care.
- Patients at the end of life or might some have chronic, not-life-threatening conditions? Possible eligible patients are listed in Clinical Practice Guidelines for Quality Palliative Care National Consensus Project (13).

For example, will the unit:

- Accept children and adults with congenital conditions leading to dependence on life-sustaining treatments and/or long-term care be admitted?
- Will people be admitted if they have acute, serious but not necessarily life-threatening illnesses (such as severe trauma, leukaemia or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant nursing and care burdens?
- Will people be admitted with progressive chronic conditions (such as peripheral vascular disease, low-grade malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neuro-degenerative disorders and dementia).
- Will people be admitted with chronic and life-limiting injuries from accidents or other forms of trauma?
- Will people be admitted with advanced serious illnesses (end-stage dementia, AIDS, cancer or severe disabling stroke, cardiac, renal or respiratory failure), from which they are unlikely to recover, and for whom intensive palliative care is the predominant focus and goal of care for the time remaining.

Reading this list is a reminder that strict adherence to the definition of hospice/palliative care is of the utmost importance. It would be well-nigh impossible to care appropriately for many of the above groups in a small palliative care unit but the decision about them must be made before the unit opens.

One must decide if the unit is going to be for:

- patients expected to die within days.
- long stay patients.
- short stay patients admitted, for example, for 10-14 days to control severe symptoms or psychosocial problems (In most units in the West the average length of stay is 11-14 days).
- respite care to offer families a break from exhausting care. If so, will such stays be booked in advance or be offered as the need arises? The need for respite care is greatest when the unit is associated with a community palliative care service. One problem is that many such patients are admitted for 'respite' too late and do not return home but remain and die in the unit.

Once the unit is well known in the community there will soon be a waiting list for admission so apart from establishing in your admission criteria you have to establish the priority criteria for admission. It is useful to have a team responsible for the admissions so as not to put too much pressure on one individual.

Educational programmes

If so, there will need to be a seminar room for teaching, space for a library, storage space for equipment, toilets nearby, access separate from the in-patient unit as well as major staffing and therefore financial implications. [[See separate section for fuller discussion](#)]

Disadvantages of a free-standing unit

- Cost, generally higher than planners expect.
- Only able to accept a limited number of patients, a small proportion of the many who need its services.
- A management structure that might be unlike those of other local health care units
- Families might feel excluded because the patient is taken out of their care.
- It is still 'an institution' and as such, no matter how hard everyone tries, it is never 'Home'.
- Its practice and principles will not be seen and learned by the many doctors and nurses who work in general hospitals where 90% of the patients at the end of life are cared for.

9. Home Care/Community Palliative Care Services

This section will look at services caring for severe ill patients at the end of life in their own homes, the home of relatives, or care homes for the frail or aged.

Strong evidence from many countries suggests that with some exceptions, most people say that when they come to the end of their lives, they want to remain at home if possible, though not necessarily to die there.

Community care is one area of health care where there are wide variations between one country and another, and even within a country.

Some countries have well established primary care services staffed by general practitioners or family physicians supported by community nurses/'district nurses' and even nurses registered as specialists in paediatrics, palliative care, cardiology, renal medicine, chest medicine, diabetes, psychiatry and stoma care.

In contrast there are others where patients must travel to clinics many miles from their homes or wait for a travelling clinic which visits their village every few weeks at best, any acute illness necessitating them being taken to a distant hospital's Accident and Emergency Department.

If the doctors who care for people at home seldom make house visits, or have no training in palliative care, or cannot readily access and prescribe opioids, then end-of-life care is usually unsatisfactory.

Similarly, if family carers have not been taught how to care for someone so gravely ill, or there are no home-visiting nurses trained in palliative care, it can be difficult to ensure that dying is peaceful and dignified.

This section addresses some of the issues of caring for the severe ill or dying in their homes in the hope that readers will adapt its contents to their local or national situation. There are many models of care. None is a perfect model for all situations.

Models of Home Care

There are three models of Home Care/Community Palliative Care Services (CPCS) in common use and many modifications of each.

Palliative care consultation service

This assists GPs and community nurses who invite the advisory team to visit and advice on the care of patients at home. The staff of the advisory service does not accept invitations to become involved from anyone except the family doctor and community nurse.

The advisory team consists of a palliative medicine physician and a community palliative care nurse (and can usually call on the services of a social worker, an occupational therapist and other allied health professionals in the hospice/palliative care service). In many countries, the usefulness of the occupational therapist can hardly be exaggerated.

They visit homes, assess what modifications area needed, what equipment might help the patient and teach both patient and carers how to make best use of failing faculties.

Their role is entirely advisory, prescriptions being written by the GP and the practical nursing being done by the community nurse not the palliation nurse.

The benefits of such a service are that the patient (and often some relatives) remains under the care of doctors and nurses they know well but, at the same time, they are getting specialist advice. Additionally, there is no threat to the authority or autonomy of the GP and community nurses who, hopefully, will be encouraged and enabled to provide better palliative care for future patients.

The advisory team, usually based in a palliative care unit, facilitates admission there if needs be, and coordinates consultations and investigations in other units. There is evidence that such services enable more patients to remain at home longer and they may enable more to die at home (if they are called in early enough).

If, as is recommended, the service operates within a clearly defined geographical area with modest distances to travel a single nurse can usually be involved with 16-20 patients at any one time, seeing each 2-3 times/week and often telephoning frequently and regularly. The average time each patient is under care averages 2-3 months for cancer patients but double that for cardiac, respiratory and some patients with neurological disorders.

The 'success' or 'effectiveness' of such a service largely depends on:

- Members of the primary care team knowing when they and their patient might benefit from specialist medical or nursing advice from a community palliative care team. This requires that they know their own limitations.
- The ability of the GP assisted by the team to deal appropriately with emergencies occurring in the home.
- The availability of essential opioids
- The availability of the necessary equipment and aids
- The ready availability of back-up beds in either a palliative care unit or a hospital unit with which the patient is familiar.
- The extent to which relatives are supported, their needs addressed, and trained in basic nursing care.

Comprehensive Home Palliative Care Service

Operating in few places in the world this service provides a team of specially trained palliative medicine physicians and nurses who provide all care for the patient in his home. With following tasks: confirming the diagnosis, ordering whatever further investigations are needed, prescribing medications, involving home nurses, organising family support, and even performing such procedures as blood transfusion, paracenteses, some chemotherapy, and physiotherapy. Any necessary equipment is loaned from the palliative care service base (which need not have its own in-patient beds).

The benefits are that the patient is guaranteed high quality specialist medical and nursing care round-the-clock in his own home, with his well-supported family around him. Such as service is thought to enable more to die at home if that is what they wish.

The disadvantages are:

- the extremely high cost
- the possibility that GPs and community nurses will either be deskilled or not given the opportunity to practise better palliative care.
- because they have not been involved in this critical time in the patient's care, GPs might be less able to give appropriate bereavement care after the death.

Such a service can only be expected to operate successfully and amicably when its involvement does not financially disadvantage the GP when he/she 'hands over' a patient to the service.

Practical ('hands-on') Palliative Nursing Service

This is most appropriate where there are no other nurses working with patients in their own homes. Nurses, specially trained in palliative as well as community nursing, provide all the practical care a palliative patient needs, and demonstrate basic nursing care to the relatives. They may visit once or many times each day, depending on needs, often lending equipment from the palliative care service.

Useful as this service can be it is expensive to operate (salaries, equipment, and transport costs), and dependent on the cooperation and understanding of sympathetic GPs who may not know much about palliative care and the nursing needs of their patients. Without the cooperation of a knowledgeable GP this can be a lonely and stressful job for the palliative care nurse.

This form of Community Palliative Care Service does not offer any form of palliative care education for doctors or nurses. This is a major weakness.

A modification of the above...

The palliative care nurse(s) working without any medical support or back up palliative care beds and professional colleagues.

This is seen in many countries where palliative care is in its infancy. The reasons are obvious – there are more nurses available than doctors, they are usually more willing to work in the

community, their salaries are lower than those of doctors, they are well received and better understood by unsophisticated villagers than doctors might be.

However, it should be regarded as a short-term model of care provision to be replaced as soon as possible by one of the models described above.

The reasons are that:

- even the best palliative care nurse will encounter problems of pain and symptom management that are beyond her knowledge and experience.
- professional support (emotional, social and spiritual) is essential for all in palliative care.
- emergencies occur even when the best care is being provided and both medical input and hospital admission may be needed.
- palliative care is, and always has been, more than excellent nursing care. Doctors have a role to play and must be encouraged to learn about it – something they may not do with an all-nurse service.

CAUTION

In some countries The Community Palliative Care Team is expected to provide palliative care to serious ill patients alongside their general work with patients not in need of palliative care. This is almost impossible to do, does not help either group of patients and is to be discouraged because It is usually suggested by managers eager to save money, managers who know little or nothing about palliative care. It is exceedingly stressful for the team members, does not save money and usually results in poor quality palliative care.

Emergencies encountered in community palliative care

Much depends on whether those caring for a patient at home can deal with the following. If GPs and community nurses do not know how to deal with them, they need a Community Palliative Care Team:

- Extreme breakthrough pain
- Hypercalcaemia
- Haemorrhage
- Spinal cord compression
- Sudden dyspnoea
- Pathological fracture
- Acute paranoia
- Urinary retention
- Severe vomiting
- Oesophageal obstruction
- Subacute Intestinal Obstruction
- Status Epilepticus

Auditing a Community Palliative Care Service

As with every aspect of a palliative care service it is essential to audit it regularly. The audit should be a community team responsibility with time set aside for it, accurate records kept of all discussion at audit meetings. These might be chaired by a senior doctor or nurse or, preferably, by different members of the team in turn. Regular feed-back, critical appraisal from GPs and community nurses with whom the team works is essential.

One final observation: Whether a patient can stay at home and receive excellent palliative care there depends as much on the relatives as on all the professionals involved.

10. Hospice/Palliative Day Care Unit

A Day Care (sometimes termed Day Hospice or Palliative Care Day Unit) is a model of care designed for patients being cared for at home (or in the home of a relative or in a Nursing Home/Rest Home). It enables them to receive attention to all aspects of their illness and suffering; to receive physiotherapy and occupational/music/art therapy; to meet with others in similar situations to themselves in a friendly social/non-clinical environment.

Benefits of Day Care Unit

The patient is enabled to remain at home if possible (which is what most say they want) and by attending the Day Care Unit.

They benefit from seeing the palliative care nurse (and the medical specialist if the nurse deems that necessary), being encouraged to report every aspect of their suffering, ask all the questions they want to and get all the advice they need. When needed, they can have wound dressings done, constipation dealt with, bladder lavage and catheter change.

They benefit from seeing palliative care- trained physiotherapists, occupational/art/ music therapists for what is, in effect, rehabilitation – helping them to live life to the full within the limits set by their illness. Experience shows that they take up new hobbies and interests, become more positive in outlook, and consequently experience fewer symptoms.

Caring relatives benefit from a few hours free to do whatever they want to do, to have a well-earned rest or have time on their own with some of the palliative care team to ask questions, get advice and, above all else, feel supported.

It is very possible but not proven that patients attending a Day Unit are able to remain at home longer than would be the case if they had not attended one. The evidence base supporting day-services is dated and limited. Dying people find attending PDS a valuable experience that allows them to engage with others and to be supported in a restorative environment. (14, 15) There is much anecdotal evidence that relatives feel it is less stressful caring for a patient at home if the patient can, attend a Day Unit perhaps one or twice a week.

How does a Day Care Unit operate?

The most common model is where patients are brought from their homes in a car or 'minibus' (often driven by a volunteer) to the Day Care Unit at about 10.00 hrs, spend the middle of the day there and taken back home at about 15.00 hrs.

On arrival they are welcomed by a member of staff/volunteer, join the others attending for a cup of tea/coffee then spend time on creative activities of their choice under the guidance of the therapists, spend some time with the nurse or doctor. Lunch is leisurely, tailored to their needs and energy and often accompanied by a 'little drink' if that is what they enjoy. The time after lunch is spent in comfortable chairs, resting, or being entertained by visiting cooks, TV stars, Olympic champions with their medals, local actors, dancers, poets and musicians – most of whom have usually offered their time and services without any thought of payment.

What accommodation is needed for a Day Care Unit?

- A hall/room about the size of a large lounge or tennis court with a ramp and doors wide enough for wheelchair entry.
- Worktables that might also be used for meals and sufficient chairs for sitting at the table and easy chairs for lounging in.
- A small room large enough to accommodate an examination couch, small table, 2 chairs and (desirably) a hand basin.
- A small room with a table and 2 chairs, filing cabinet, (a computer if possible), and notice board of some sort for use as an office/interview room.
- A toilet which permits wheelchair entry. Ideally the toilet and hand basin should be designed for disabled users.

If funds and space permit it is useful to have two rooms rather than one large one – one for activities and crafts, the other for socialising. Equipment takes up much space so adequate storage space must be provided either in the unit or nearby. Not essential but useful is a small cloakroom where patients outdoor clothes can be left, and another small room where staff and volunteers can withdraw.

Where should a Day Care Unit be situated?

The Unit may be part of a hospital/hospice/ palliative care unit OR be in the grounds of a health care facility. It may be run in a church or community hall not otherwise being used during the day. Essential is that there must be easy vehicle access and that it must be convenient for access for the population being served. Long journeys even in comfortable cars, can be tiring for these patients.

What staff are needed for a Day Care Unit?

The key member of staff is the *Day Unit Coordinator* (or whatever title is selected). Their professional background is not as important as their skills, their sensitivity, and their

understanding of the principles of palliative care. Most have backgrounds in nursing or social work or occupational therapy but in the new role may not use the hands-on skills of those professionals as much as their 'person skills'.

A useful ratio is 1 staff member/volunteer to every 2 patients, depending on levels of dependency.

The nurse and each of the therapists may either work exclusively in the Day Unit or visit it from the wards of the hospice/palliative care unit/hospital if nearby, depending on how many patients there are, what their needs are, how much time needs to be spent with each etc.

The volunteers need careful selection and comprehensive training [[See Hospice/Palliative Care Volunteers section](#)]. They are directly accountable to, and report to, the Coordinator but are ultimately accountable to the Volunteer Services Manager of the hospice/palliative care service/hospital. They act as friends, assisting with handling frail patients, serving meals, and assisting with activities under the direction of the Coordinator or therapist. Or no account do they become involved in clinical matters or attempt to offer professional advice, no matter what their own background is.

'Creative activities' offered in a Day Care Unit

It depends on whether there is an occupational therapist and his/her skills and experience of palliative care; on the physical and financial resources of the unit, and the culture of the community it serves.

All that can be done here is list some of the activities to be found round the world:

Clay modelling	Crossword solving
Painting Pottery	Origami
Indoor gardening	Knitting
Carpentry	Dress making
Stamp collecting/sorting	Enamel jewellery
Computer programming	Making greeting cards
Rug making	Computer games

The important thing is that such activities are what the patient wants to do (and has often had as a long-time ambition) and not merely recreational – helping the patient forget their illness and fate. Everything done in a Day Unit is geared to enhancing quality of life, restoring dignity to it and giving patients as sense of being valued and useful.

The use of volunteers in a Day Care Unit

Usually, the volunteers working in a Day Unit have already worked in other clinical areas of the hospital or palliative care service where their sensitivity and calm presence had been noted. Only then are they selected for the Day Unit and undergo further orientation. They are taught the aims of the Unit, the conditions of the patients who will attend the spectrum of suffering

they may encounter and how the palliative care nurses and therapists will respond. Above all else they will be taught to be friends and companions to the patients rather than 'carers', encouraged to help create the most relaxed, informal atmosphere possible; the type of atmosphere so often described by patients as 'safe'.

For most volunteers, their time in the Day Unit will be the closest and most prolonged they will ever have had with people in the final months of life, many of them of similar age to them or their children. At one and the same time as they see some patients psychologically thriving in that atmosphere, they will also notice that they are getting frailer and near to death. Over the time they work in the Day Unit they will make many friends all of whom will eventually die, some much sooner than the volunteers had expected. Understanding support as well as sensitive supervision for volunteers is essential.

Can/should a Day Care Unit accept any type of patient?

Yes, but experience in units that have been operating for many years suggests that patients should be accepted on the understanding that their condition and how much they have benefited/might continue to benefit from attending, is reviewed every 12 weeks. They may then have a spell of not attending and then return after a few months if it is thought they might benefit. If this is not done the Unit may find itself with a patient whose condition does not require palliative care, coming to the Unit for years. This helps neither that patient nor the other patients.

Care must be taken with particularly young patients who may be discouraged if they attend on days when everyone else is elderly, sharing no common interests with them. Seeing such a young person with advanced illness can also be extremely distressing to older patients. Ways must be found to get around this problem.

Some units find it better to have separate days for the sexes with morning activities and afternoon visitors tailored to each group. For example, the men might have visiting football players talk to them whilst the ladies might have ballet dancers or a poet reading a new poem.

It does not seem to matter if people with different illnesses are put together – those with cancer mixing easily with those suffering cardiac or neurological problems. Invariably patients discuss with each other what they suffer from, what care they have had and how long they expect to live. Despite that, there is usually an exceedingly happy, positive atmosphere where everyone wants to help another. It follows, however, that there are times of sorrow when one of their number dies at home or must be admitted to an in-patient unit. If that unit is adjacent to the Day Unit, then they can, and usually do, come back to enjoy the Day Unit with old friends. This is one of the great advantages of any Day Unit being part of a hospital/ palliative care complex rather than free-standing.

Why should planners consider starting a Day Unit?

- It greatly helps in the care of patients receiving palliative care at home.
- It recognises the stress experienced by relatives and gives them a break for a few hours.

- It makes it less daunting when the time comes for a patient to leave home and be admitted for terminal care because they have seen such patients coming from the in-patient unit to the Day Unit.
- It is economical to operate, the only expenses being the salaries of the professional staff, the equipment, and materials for activities (finished articles are usually sellable to raise funds) and the costs of food and transport costs.

Can a Day Care Unit be financially self-sufficient?

Craft work produces many items that might be sold, the income helping the day unit. That list would include such things as stools, ornaments, enamel brooches, models, artificial flowers, calendars, Christmas cards. Experience shows that people, particularly friends of the Hospice or relatives, are happy to purchase them but the income usually scarcely covers the cost of purchasing the raw materials from which they are made. What is important though is that patients feel they are not only enjoying themselves but being useful and appreciated.

Audit of a Day Care Unit

It is essential to audit a Day Car Unit, for all members of its staff/team to take part and for its records to be accurate and open to scrutiny. Topics that might usefully be audited include:

Conditions of patients	Quality of life measurements
Reasons for referral	Occupational therapy activities and usefulness
Length of time attending unit	Reception of patients on arrival
Transport of patients	The work of the nurse
Views of GPs/family physicians	Finances
Value of different activities	Food likes and dislikes
Transport service	Bowel treatment needed
Work of volunteers	The views of community nurses
Views of relatives	Record keeping
Time spent with relatives	Dietary issues

11. Human Resources

Multidisciplinary and Inter professional Teams

A multidisciplinary/team approach to assessment and treatment is mandatory. Successful palliative care requires attention to all aspects of a patient's suffering. This requires input or assistance from a range of medical, nursing, and allied health personnel—a multidisciplinary approach.

Failure to do this often results in unrelieved pain and unrelieved psychosocial suffering. No one professional can deal with the many problems encountered in palliative care. An integrated team is essential.

Established palliative care services work as a multidisciplinary or inter-professional team:

- multidisciplinary is the term that used to be applied to palliative care teams, but if the individuals work independently and there are no regular team meetings, patient care may become fragmented and conflicting information given to patients and families.
- Inter-professional is the term now used for teams that meet on a regular basis to discuss patient care and develop a unified plan of management for each patient and provide support for other members of the team.

Where palliative care services have not yet been established, it is important for the few professionals providing such care to work as a team, meeting regularly, planning, and reviewing care, and supporting each other.

The patient may be considered a 'member' of the team (although they do not participate in team meetings), as all treatment must be with their consent, understanding and in accordance with their wishes.

The members of the patient's family can be also considered 'members', as they have an important role in the patient's overall care and their opinions should be included when formulating a plan of management, then fully explained to them.

Volunteers play an important role in many palliative care services. They receive no pay but may be offered expenses. They work in reception, coffee rooms, library, appeals office, flower arranging, transport, charity shops but in most units do not perform 'hand-on' role with patients. They work under the direction of a Volunteer Service Manager, a salaried member of the staff.

The ideal core multidisciplinary clinical team consists of:

- Physician(s)
- Nurses (for both in-patient care and community care)
- Social worker
- Physiotherapist
- Occupational therapist
- Chaplain or pastoral care worker

Very useful, but not essential, are:

- Clinical psychologist (or visiting liaison psychiatrist)
- Clinical pharmacist
- Music and/or art therapist

Essential documentation

- job descriptions for every member of staff – whole-time and part-time
- referral and acceptance policies and procedures
- explanatory leaflets on how the service will operate, who takes clinical responsibility, and patient and family brochures see [[see Communications section](#)]
- specimen reports and recommendations letters

There are compelling reasons for delivering palliative care in an acute-care setting and alongside other disciplines.

- Doing so keeps palliative care in the 'mainstream' which is good for both other specialists and disciplines who can learn better end-of-life care and symptom management, and for palliative care staff, who, under the watchful eye of their colleagues, are encouraged to use evidence-based principles and treatments and to use the expertise of their colleagues.
- Patients benefit by having access to consultation from other specialties, available imaging, radiotherapy, and other useful palliative modalities.
- A culture of trust and respect develops between palliative experts and others, fostering early, appropriate, and more numerous referrals. If designated beds are appropriate a centre of excellence and teaching can develop. The in-hospital bedded unit – the HPCU – is discussed in the [specific section](#).
- Any successful palliative care service should reflect the needs of the community it serves based on a needs assessment, and fit the requirements and resources (including financial) of the institution. The programme must be flexible and able to adapt to changing hospital priorities and patient needs with the goal of sustaining a long-term service.

- Seeing that high quality palliative care can be provided in a busy medical/surgical /gynaecological/oncology ward is a rich educational experience and personal challenge for junior doctors and nurses who may have thought that it was only possible in a hospice.

The hospital, and therefore its Trustees/Board and Managers, must be able to recognize a benefit for it as an institution by having defined palliative care services as well as benefit to the inpatient population. Those developing hospital PC services should encourage local administrative authorities to accept symptomatic and end-of-life care as a worthwhile investment in their communities as part of an overall plan for their region.

Consideration of Staffing and Recruitment

Good palliative care requires a high nurse/patient ratio. This applies to both in-patient care and community care. Ratios cannot be given because they are influenced by the diseases from which the patients are suffering (AML patients often having higher dependence and therefore requiring more nursing care than cancer patients, for example). The availability of other nurses working in patients' homes, workload, distances to travel in the community, whether there is a hospital palliative care team etc. all affect nurse: patient ratios. It is safer to over-estimate staffing needs when planning a service.

Palliative care, whether in hospital, hospice, or home, is always multi-professional. When attempts are made to reduce costs by excluding one professional group or another, the quality and comprehensiveness of the service deteriorates. It must be noted that the composition and roles of different professions vary greatly, depending on the type of service offered.

The physician plays a major and very prominent role in a hospital palliative care team, whereas in a day hospice the medical presence is almost subliminal. How much a doctor or a nurse does in a community palliative care service depends on the experience and roles of family doctors and community nurses, if available. Generally, professions allied to medicine (physiotherapy, occupational/ art/music/speech therapy) play an important role only in in-patient units and need not be factored into plans for community services.

Recruitment of staff may be expected to be difficult though many will apply. Personality, aptitude, and commitment are more important than professional experience.

All staff, whatever their profession, discipline, qualifications, and experience, will need comprehensive pre-service training before starting this work, much of it based in the new service and the rest in established palliative care services. No member of staff, junior or senior, should ever be expected to learn the basics of palliative care on the job!

Staffing the unit

In countries with no tradition of hospice/palliative care there be some initial difficulty in recruiting, but such is the attractiveness and professional satisfaction to be gained in palliative care that recruiting is soon not a problem. It goes without saying that staff selection, support,

pre-service training, and employment legal requirements must be as strict as in any other health care unit.

Nursing staff

A good rule is to aim for a nurse/patient ratio of not less than one nurse to 1.5 patients throughout 24 hours. At least 50% of nurses on duty at any one time should be registered (i.e. trained) nurses. The others nursing auxiliaries should undergone basic nurse training plus in palliative care nursing training.

Most experienced units do not use student nurses rotating through different specialties, able to spend only a few weeks in the palliative care unit, but have a permanent, designated palliative care staff.

Medical staff

How many physicians needed depends on:

- The number of beds, and whether it is a short-stay or a long-stay unit.
- Whether the doctor will also be involved in any community palliative care service.
- Whether the doctor will be responsible for advising in a Day Hospice
- Whether the doctor will also work as part of a hospital palliative care team
- The amount of education, research and management expected of the physician.
- Whether he/she will be supervising junior doctors
- Whether he/she will have administrative responsibility
- Whether he/she has time for research written into his contract

A rule of thumb is that one full time physician can:

- look after 10-15 beds.
- provide the medical input into a community palliative care service caring for 40 patients at any one time.
- be available to advise in a Day Unit and
- spend up to 3 hours/week on education.

A critical issue is 'out-of-hours' cover. For the sake of patients and nurses, it should not be provided by a doctor (senior or junior) lacking experience in hospice/palliative care. This cannot be overstressed.

Extensive experience in the United Kingdom shows that units with full-time physicians have a higher admission and discharge rate of patients, and provide more education, than units served by part-time visiting physicians.

Table 4 - Palliative Care Australia recommends the following medical and nursing staffing level for specialist palliative care services per 100,000. (16)

Position	Community-based service*	Consultative service**	Palliative care designated beds***	Comments
Medical				
Palliative care consultant	2.0	1.5		Specialist and registrar positions have both community and hospital responsibilities
Registrar	←-----1.0-----→			
Resident medical officer			0.25	Resident position attached to designated palliative care beds only
Liason psychiatry	←-----0.25-----→			It is expected that between 30-50% of the referrals will have a diagnosable mental illness
Nursing				
Clinical Nurse Consultants (CNC)	1.0 Plus 2 clinical nurses	0.75		Community and acute care consultation teams require CNC level nurses to act independently, provide consultation to primary carers (nursing and medical), and to coordinate, monitor and review patient care. Clinical Nurses are senior palliative care nurses who work under the direction of the CNC.
Registred (RN) and enrolled nurses (EN)			6.5 hours per patients per day	Designated palliative care beds require a mix of direct care. This care will include CNC, Clinical Nurses, RN and EN level nurses, with a predominance of RNs over ENs. Patient carers may also be part of the workforce mix
Discharge Liason	←-----0.25-----→			This role could be included in a nursing or social work position

Notes* Full-time equivalent per 100,000 population, ** Full-time equivalent per 125 beds, *** Full-time equivalent per 6.7 beds (within acute hospital)

The team

Will this be a 'doctor only' or 'nurse only' service or a genuine team of doctor, nurse, pharmacist and social worker and pastoral care worker? Bear in mind the steadily increasing workload of all, the salary implications, the stresses involved, the range of conditions they will be asked to advise on.

It is possible, and sometimes necessary, to have a nurse-only service but most undesirable. The nurse will be isolated, lonely, must persuade/convince and stand up to opinionated doctors not accustomed to taking advice from a nurse. Such a service is exceedingly stressful and to be avoided if possible.

Physician(s): How many, as explained elsewhere in *'Getting Started'*, depends on whether there will be an associated PCU, a Community Palliative Care Service, a Day Palliative Care Unit, educational and research components, and whether the doctor works in another specialty such as oncology. Advanced training in Palliative Medicine is not optional but essential.

Nurse(s): Registered nurses with extensive training (and preferably a diploma/degree) in palliative care nursing.

Social Worker: If, as should be the case, many of the social needs of the patient are already familiar to the unit's social worker here is less need for a fulltime social worker on the HPCT. Access to one with palliative care experience is extremely useful.

Psychologists: They can be accessed from their department in the hospital, or they can be part of the team. Access to one with palliative care experience is extremely useful.

Pastoral Care Worker: Again, invaluable but hopefully can be accessed in the hospital department.

Table 5 – Allied workforce levels for specialist palliative care services for allied health services (from Palliative Care Australia) (16)

Position	Community-based service*	Consultative service**	Palliative care designated beds***	Comments
Allied Health				
Social Work	0.5	0.25	0.25	
Psychology	0.25	0.1	0.1	
Bereavement Support	0.25	0.1	0.1	
Pastoral care	0.25	0.25	0.25	Pastoral carers offer spiritual support that is quite distinct from the psychological and social support offered by other professionals
Speech pathology	0.2	0.2	0.2	Speech pathologists assess and treat swallowing dysfunction, and support communication skills, particularly for people with worsening physical disability
Dietician	←-----0.2-----→			Dieticians with a particular skill and interest in palliative care can enhance quality of life by planning enjoyable and attractive food within the constraints imposed by the patient's condition

(continuation)

Position	Community-based service*	Consultative service**	Palliative care designated beds***	Comments
Physiotherapy	0.4	0.2	0.2	PT and OT are valued by patients for providing practical help and positive intervention. Ideally the two will work closely together help to keep patients mobile and safe, as well as providing short-term symptom relief for people with lung congestion, etc. ·OTs work with both patients and carers to promote the patient's function, safety and independence in the home and hospital environment · Lymphoedema symptom relief is shared between PT and OT.
Occupational Therapy	0.4	0.2	0.2	
Pharmacist		0.25	0.1	Both of these positions would have a role in supporting the community-based team. An extensive network of community pharmacists provides valuable primary healthcare for palliative patients in the community by assisting with advice, documentation of medication histories, dosage compliance, and the disposal of medications no longer required.

Notes: * Full-time equivalent per 100,000 population** Full-time equivalent per 125 beds *** Full-time equivalent per 6.7 beds (within acute hospital)

Social work staff

It is essential that every comprehensive palliative care service (which may include in-patient unit, community care, day care and even hospital palliative care team) has an experienced social worker on staff. It is, however, recognised that in many countries there are few, if any, social workers and even fewer with training/experience in palliative care. Their work will usually focus as much on staff as on patients and relatives, and be concerned with coping strategies, loss, and personality problems.

The 'simpler' tasks of a social worker, such as facilitating discharge, arranging help in the home, obtaining financial assistance, making special holiday arrangements etc. can usually be dealt with by someone appropriately trained, though not necessarily accredited/paid as much as a social worker.

Professionals allied to medicine

Any in-patient unit with more than 15 beds, regardless of other services it provides, will need a physiotherapist on staff. Units with 30+ beds need a full-time one. Good palliative care involves rehabilitation, not simply the aim of getting patients back to their homes and loved ones. For this a physiotherapist and, if possible, an occupational therapist are essential.

Especially useful but not strictly essential are clinical pharmacists, clinical psychologists, dentists, and podiatrists. Often, they offer their voluntary services for new hours a week.

Someone trained in pastoral care should be on staff or be readily available. Larger units (of > 25 beds) may need a full-time pastoral care worker. Others may use local clergy, according to the local needs/traditions. It must be remembered that this 'chaplain' will also support staff and volunteers, contribute to and organize educational courses, and conduct many funerals. In multi-faith societies it is necessary to have access to diverse religious/spiritual communities.

Skills required

The success of a palliative team depends on its members. They must be advocates, persuaders and highly trained, skilled clinicians. Above all else they must be consummate communicators. Other colleagues may oppose your plan to start a HPCT because of perceived threats to their autonomous care of their patient or their ability to care for palliative patients.

The characteristics that will win over sceptics include:

- Good communication skills i.e., follow-up consultations with a phone call or better still personal contact with the referring physician
- Excellent professional skills and use of evidence-based treatments.
- Improvement in patient and family condition and good 'outcome'
- Follow-up of patients
- Your sympathetic understanding of their work - its stresses, disappointments, and its problems.
- At all times bear in mind that the team is expected to provide skilled compassionate care in the acute hospital, supporting and advising other clinicians, and aiding support of relatives.

Professional stress

The stress experienced by those working in a palliative care is no greater than in any other palliative care service except in one respect – they are working in a unit within a hospital where there may be little if any understanding of what palliative care is. They will find that what they do is often misunderstood, seen as sentimental and unscientific, but at the same time other nurses and junior doctors in the hospital may envy their job satisfaction.

12. Hospice/Palliative Care Volunteers

In many countries there is a long-standing tradition of people volunteering to work for a few hours each week without remuneration in a charity of their choice. In others such use of unpaid workers is seen as exploitation – "if someone is worth employing, they are worth paying". Others claim that using volunteers is keeping someone out of a paid job and just a means of saving money. This section describes how volunteers can contribute to palliative care services from the early planning stages. Whether or not the service should work with volunteers must be a local decision, based on local traditions, laws and needs.

'Employee' or Volunteer?

It is important to understand that volunteers are not, in the legal sense, employees working without pay. Employees, and those who employ them, are subject to a range of laws in all developed countries. Volunteers are not subject to them, but there might be legislation specifically for volunteers. In practice this simply means that volunteers must NOT be termed employees in any documents, particularly legal ones.

However, it must be emphasised, most of the moral principles underlying 'employment laws' laws apply to volunteers (e.g., good working practices and conditions, fairness, equal opportunities, no racial or sexual discrimination etc).

In all other respects, they should be recruited, trained, supervised, supported, and (rarely) dismissed like anyone else working for the palliative care service. Put succinctly, volunteers should behave professionally, even though their volunteer role is not that of a professional. Those who supervise and support them should treat them, and expect of them, as if they were professionals.

What work do they do?

This may be divided into 'hands-on care' such as bathing, feeding, mobilising, moving them in bed and 'indirect care' many examples of which are listed below.

Before planning to work with volunteers it is prudent to ascertain what other units/services do, what laws relate to the work of volunteers in your country. What you decide will affect how the volunteers are managed and led, finances, professional staff numbers, legal issues and, finally, insurance.

Generally, volunteers do work that helps to create the friendly, homely, caring atmosphere that it is hallmark of a hospice/palliative care service. Some examples are:

- Receiving and welcoming patients and visitors when they come to the unit.
- Manning the telephone switchboard 'out-of-hours'.
- Transporting patients to/from Day Hospice or hospitals
- Working alongside the professionals in the Day Unit
- Flower arranging throughout the unit.
- Sitting with patients at home to relieve relatives.
- All manner of work related to fund-raising.
- Working in the charity shops of the charity
- Staffing the coffee rooms in the unit
- Running the patients' library and, if suitably experienced, the education library
- Public speaking on behalf of the hospice
- Taking grieving relatives home after a death
- Organising and helping to run the bi-annual Memorial Services.
- Helping patients with their hobbies (chess, draughts, modelling etc)

Volunteer Service Manager

This post is the key one if a unit intends to work with volunteers. The care needed for selecting such a person is no different from that for the medical or nursing directors. The appointee must be in post before volunteer recruitment starts.

This person must be salaried, be on the senior management team or reporting directly to one of that team or the CEO. Regular contact with senior nursing and medical staff (e.g. at weekly team or senior management meetings), as well as fund-raisers, and the volunteer leaders of all the teams into which the volunteers are divided. It is a position which demands a unique blend of skills and attributes – management, sensitive leadership, deep understanding of, and sympathy with, palliative care and knowledge of how to weld so many different people from varying backgrounds into an effective team, sometimes so large that it might be an army.

Recruiting volunteers

The intention to appoint volunteers will normally be passed on by word of mouth, announced in newspapers and church newsletters, and within hospitals. As for the appointment of a salaried member of staff there must be a 'Job Description', in this case not about a specific job, but about:

- the overall work of volunteers within the organisation.
- the ethos and objectives of the unit.
- where and how volunteers will contribute.
- what expenses will be paid?
- the range of work/service that is done by volunteers.
- what hours will be worked?

- line management and accountability.
- how they will be supervised and supported?

and, most importantly, what they will not be expected or allowed to do – hands-on patient care, counselling, offering practical advice etc. This same document will advise that if a person with professional clinical training and qualifications (medical, nursing, therapist etc.) wishes to offer their services, they will be invited to see the head of the department in which their skills might best be used.

Interviewing and appointing volunteers

Most units invite interested people to visit the unit, possibly spend a few hours seeing where volunteers work and whether they feel they could work there. Only after that do they come for formal interview by the VSM and one of her deputies/assistants.

What they will look for is personality, the ability to work alongside others, and a genuine understanding of what hospice/palliative care is. They will try to find what the volunteer feels they can contribute to the ethos. Those unlikely to be useful as volunteers are:

- those who have had a major loss in the preceding 12 months and are still working through their grief.
- those who cannot work with those of a different social 'class' or ethnic group.
- those who cannot respect confidentiality.
- those who enjoy organising others.
- those who enjoy counselling others.
- those who enjoy talking about their own problems, illnesses, and grief.
- those who see working in the hospice as a chance to evangelise.

In brief, those who might easily upset others because of insensitivity or wrong motivation, or who are themselves vulnerable because of their own recent loss.

In most units, the volunteers undergo a training course (about 3 hours per week for 12 weeks) during which they have lectures, talks, discussions, and demonstrations. The appointee is then put on probation for a period of 2-3 months so that they may leave without any embarrassment if they do not enjoy the work. In that time, they work under different team leaders and in different parts of the service depending on their skills and aptitudes.

If they stay in post, they will be given a copy of the Staff Handbook or, if there are sufficient volunteers to merit it, a copy of the Volunteer Workers Handbook specially prepared by the unit. The VSM will always keep in close touch with new recruits, spend some time with them at the end of the probation period and again at every anniversary of their appointment.

Management Issues

Ideally the volunteer service needs a small office of its own. If that is not possible then space must be found for the VSM and a room for private meetings and interviews.

A data base must be developed for all volunteers showing personal information, availability, aptitudes, particular skills and areas of interest, tasks they should not be asked to do and areas of the unit they do want to be in.

A pin board accessible to all volunteers is useful, listing the different teams (flowers, reception, coffee shop, drivers, Day Unit etc.) and who is on duty at any one time. Most units produce a news sheet exclusively for volunteers.

Expenses

It is usual for volunteers using their cars in the service of the unit (e.g. bringing patients to and from) to be given an agreed mileage allowance. Other out-of-pocket expenses are usually met on presentation of receipts/ tickets.

Uniforms

Volunteers seldom wear uniforms except perhaps an apron or overall, but all usually have name badges. Long service is usually marked by the presentation of a badge, worn every time they are on duty each succeeding 5 years being marked by a 'bar' to the ribbon or special badges.

Supporting Volunteers

Though volunteers are not always providing 'hands-on' care they nevertheless see much suffering, distress, grief and family sadness. Inevitably they are affected by it. They need sensitive, informed support from their team leader and the VSM.

Volunteers should have available to them the same levels of support as any member of the paid staff. Like them, they may need some time off, a few weeks break from their duties, opportunities to cry and ventilate their feelings. Like them they may have to be told that the work is not for them and be allowed to leave without any disgrace or embarrassment.

Problems encountered working with volunteers

- Many come to the work eager but, understandably, apprehensive about what they will see.
- Some want to help the patients with advice or, worse still, recounting their own experiences. They see themselves as counsellors or therapists despite what will have been said to them, in their orientation.
- Some, on learning that a patient or visitor has a legal, financial, or religious problem offer to put them in touch with a lawyer, accountant or minister they know "who will be delighted to help you without charging anything!".
- Many find it difficult to maintain confidentiality – believing that if they have not actually used a patient's name outside the unit, they have not breached confidence. This is a common problem.
- There may be personality conflicts with other volunteers in their 'team'.

- They may not respect the decisions and authority of the VSM.
- If they begin this work within a year of a bereavement, they may break down with their re-awakened sadness.

Key features of volunteers

- They help to create a homely atmosphere, in contrast to most hospitals.
- They are not professional carers so seem less daunting to patients and visitors.
- Their air of relaxed, genuine friendliness helps to create an atmosphere of peace and calm.
- They probably do not reduce the running expenses of a unit because, in most cases, they are not taking the place of salaried staff.

'Professional' volunteers

This term describes the nurses, physicians, physiotherapists, occupational therapists, and any other health care professionals who offer their unpaid services for a few hours every few weeks – working in their normal professional role. For example, a nurse might offer to work one night a week, a doctor be on call one night a week, a podiatrist come in one afternoon a fortnight and so on. Their contributions can be very considerable but

- they must report to and be accountable to the senior staff member of their profession (nursing director, medical director/senior consultant etc. – not the VSM though she/he may have been responsible for recruiting).
- they must adhere to all agreed clinical protocols and procedures in the unit.
- they must be insured by their professional defence union for the work they will do.

Finally, it has to be remembered that patients and relatives will not be able to distinguish an unpaid (professional volunteer) from a paid member of the professional staff. And will speak to them as they would to any other nurse, doctor, therapist, podiatrist etc.

These 'professional volunteers' will need the same support as is being offered to the salaried professional on the staff, and every effort made to ensure that they get the same 'job satisfaction' as the rest of the professional team.

Is it worth having volunteers?

Before deciding to use volunteers the hospice/palliative care unit must accept that though they undoubtedly enhance the homely, friendly, safe, caring atmosphere of the unit what money they may save on telephone operators, flower arrangers and fund raisers will be offset by the salary of the VSM and the considerable organisation and management needed. They can be a very great asset but need as skilled supervision and support as members of the salaried staff.

13. Orientation, Training and Education

Orientation

All staff about to start work in a new hospice/specialist palliative care unit will need orientation and training in two subjects:

- The new unit – how it will operate.
- Principles and practice of palliative care

The new unit – how it will operate

All new staff members should be in possession of the Staff Handbook before coming to these tutorials. The aim of the classes is to familiarise them with how the unit will be operated daily. The topics will include:

- Where the patients will come from (home, hospital, care home, nursing home etc.)
- Pre-admission assessment by a palliative care doctor or nurse
- The commonest conditions they will suffer from (malignancy, cardiac, neurological)
- What investigations and treatment they may already have had?
- The spectrum of suffering likely to be seen.
- What the patients may know of their condition and what additional information they may want on entering the palliative care unit.
- How crucially important information about the patient and/or relatives will be made known to team members who need updates.
- How care staff will be updated on new clinical developments and information about patients
- How the patient will be met at the hospice/HPCU door and made to feel welcome
- How the relatives will also be welcomed, and arrangements made for them to see around the unit and meet staff, see where they can go for peace and quiet, a shower or a light meal.
- What will happen as death approaches and when the patient actually dies, the role of the nurse/doctor at that time.
- Death certification, guidance to relatives, handing over possessions, saying goodbye.

- Other palliative care units/services or bereavement services in the same city or town
- The relationship between the new unit and pre-existing ones
- The different departments of the new unit and how they will relate to each other-
 - community palliative care service
 - day unit
 - hospital consultation service
 - bereavement service
 - educational work of the unit – who will the students be, will they see patients, who will teach them, how will this affect the patients, will they be able to refuse...

The Staff Handbook

Each hospice/palliative care unit must produce its own handbook to be given to every member of staff whether they work at the bedside or in the background, whole time or part-time. It will not be the same as the Useful Information for Patients and Visitors Booklet which will be described later. The two will have several sections in common, however.

Staff need to know about the following (not listed in any priority)

- Roles of different members of staff.
- Uniforms, who wears what and when.
- The importance of name badges.
- Times of duty shifts.
- Visiting times and their durations for different patients.
- Patient and staff mealtimes and arrangements
- Availability and use of alcohol by patients and visitors.
- Regulations about smoking by patients and visitors.
- Giving information about patients (phone and in person)
- Radio, TV, and computer games for patients (and visitors if permitted).
- Visiting by children and how they are welcomed and assisted (if needs be).
- Visiting by pets.
- Volunteers in and near the patients' care areas.
- Food being brought in by visitors.
- Flowers being brought in or sent after funerals.
- Laundering of patient's clothes.
- Security for patients' and staff possessions.
- The crucial importance of hygiene and preventing cross infections.
- Medication regimens, record keeping.
- Medications brought in by patients and their relatives.

Training

Pre-service training of staff

No matter how qualified and experienced in palliative care, new staff members should have a short period of training before they start work in the palliative care service, whether it is an in-patient one, a community one or a day care unit. For some it need be no more than a few days, for others less experienced, 3-4 weeks. So important is administration and management, this applies also to non-clinical staff whose courses will be tailored to their need.

The need for this aspect of preparation to be clinical and practical rather than theoretical and academic cannot be sufficiently stressed. Each new staff member must be left in no doubt that the unit will aim for the highest possible standard of care, something that is achievable when everyone works as a team.

Experience has shown that most professionals coming into this work feel that they know much of it already, only to be surprised at how little they know and must now learn. Again, experience suggests that teaching mixed professional groups (e.g. doctors and nurses) can be profitable and, some sessions conducted by both a doctor and a nurse, are a timely reminder of the mutual dependency and valuable cooperation possible in palliative care.

There is no need to develop a palliative care manual. There are many available in print and some may be downloaded from the internet (such as the IAHPC Manual on this website). Having such a resource facilitates standardisation of care on evidence-based principles.

The topics covered should include:

- The principles of palliative care
- The philosophy of the service
- The management structure of the service
- How the service operates
- Communications within the service
- Confidentiality
- Legal aspects of work in the service
- Day to day routines, paperwork, etc
- Staff support mechanisms in the service
- Health and safety regulations and routines
- Security matters
- Relationship with other health professions

Different disciplines may need additional subjects, depending on their work, experience, and the responsibilities they will have:

- Ward routines
- Working with syringe drivers, nebulisers and iv lines
- Communications between teams and members
- Data collection and record systems
- Team meetings
- Meals and food handling
- Policy regarding DNR orders, CPR, euthanasia, and PAS
- Issues related to visitors, counselling and giving information
- Discharge planning and policy
- Medication storage, handling, administering and records

In-service staff training

Topics that might usefully be included in sessions held every 6 - 8 months include:

- Update on the statistics of the service
- Therapeutic advances
- Changes in therapeutic routines
- New clinical and management routines
- New legislation and regulations
- Staff changes
- Local and national developments in palliative care

In addition, members of staff may be sent for further training in patient handling, counselling, teaching technology, computer skills, bereavement work, time utilisation, and other topics raised by members of staff with their line managers.

If, as is recommended, each member of staff has a record book covering all the time they work in the palliative care service (in addition to records routinely kept on data bases of management). They can record all the additional information felt needed, and then raise it in their in-service study days.

Tutorial staff for pre-service and in-service training

All the above training can be organised and taught by heads of departments – nursing, medical, and administration. It need not be the responsibility of education staff.

Training for volunteers will always be under the direction of the Volunteer Service Manager (VSM) with co-opted tutors for special topics. [[See separate chapter](#)]

Education

Education in the palliative care unit for health care professionals

It is common for those planning a palliative care service to focus exclusively on the clinical aspects of the work and to ignore education. Only after the clinical work has been progressing for several years do they begin to think about their responsibility to educate others. This is a bad policy. The palliative care needs of the world will only be met when sufficient physicians and nurses are aware of and practise its principles. Education needs advance planning, space allocation, appropriate staffing, budgeting, equipment, and well negotiated cooperation with other educationists. The time to start planning is when the palliative care service itself is being planned.

When training others in palliative care the most difficult task is to change attitudes and to acquire the right communication and practical skills. So practical training is a vital part of the education project and an in-patient unit is the place where this can best be done. Indeed, it can be questioned whether any palliative care service should ever be started if there are no plans to engage in education and training.

Key questions to be asked in the early planning days:

Which professional groups will need to be taught?

- medical students
- family physicians
- oncologists and surgeons
- trainee specialists
- hospital nurses
- community nurses
- clinical pharmacists
- clinical psychologists
- pastoral care workers
- Social workers
- Some therapists
- Nurse tutors

It is immediately apparent that a decision will need to be made about priorities!

Which kind of teaching?

At this stage of planning this decision need not be made except if there is a question about a tutorial room being provided near the patient care area. It can often be multi-functional doubling as a team meeting room, a library reading room.

It might be clinical (using patients and at the bedside), theoretical in a tutorial room or in the community in patient's homes.

The talks/lectures might be formal didactic or informal workshops and discussions. They each need different types/sizes of rooms. Contrary to what many people say, patients in hospices and palliative care units much appreciate being asked to speak with and share their experiences and insights with students and are highly effective teachers.

What space and equipment will be needed for educational activities?

This is a crucially important question at the planning stage.

Ideally there needs to be:

- A room to hold 25-30 with comfortable seats.
- At least one smaller room to hold up to 10 people.
- The ability to darken the rooms for films, slides, etc.
- A slide/video projector
- A screen or a wall made to act as a screen.
- A suitably equipped office for tutors and clerical assistants
- A library for journals and textbooks (essential, not a luxury)
- A laptop computer

It should be noted that the lecture room provided its use is well planned, can be used for staff meetings, committees, research groups, board meetings, fund-raising events, and much else in addition to its educational role.

What staff will be needed?

Provided use is made of the clinical and teaching skills of physicians, senior nurses, therapists, pastoral care staff and social worker a large comprehensive educational programme can be run with

- One nurse lecturer/tutor
- One clerical assistant/administrator

How will this education relate to other educational centres?

When there are so few palliative care workers and so many to educate and train it is essential to use the limited resources carefully and

- not to duplicate what others are doing (and probably doing well)
- not to do what someone else can do equally well (it does not need a palliative medicine physician or nurse to teach ethics, spirituality, or communication skills just because these are important in this work)
- not to take on an educational project solely because it is prestigious (e.g., running a degree course useful for few people)
- only teach a group or subject for which there are the necessary skills in the education team. Remember that most doctors and nurses have not had any training in teaching techniques and methodology.

In other words, find what others are doing. Identify gaps in education n and training. Find if you can employ staff able to fill those gaps. Start small and let the work grow.

Other questions often asked at this planning stage

Are there curricula and syllabi already available?

Yes, look at the websites listed in *'Getting Started'*. Excellent syllabi have been drawn and are in use in Europe, Asia, Africa, Eastern Europe and Latin America. There is no need to produce a new one for your unit!

How can doctors and nurses learn how to teach?

Several short courses (1-2 weeks in length) are run for this purpose. Details can be obtained from national palliative care organisations and the IAHPC. They are often called 'Teaching the Teachers' courses. In that short time future teachers/lecturers learn

- how to prepare lectures and talks,
- how to produce and use PowerPoint slides
- how to give public lectures
- how to set examinations
- how to do 'role play'

- how to conduct workshops and discussion groups
- how to evaluate their teaching and courses
- how and when to use acetates
- how to use 'hand-outs'
- how to conduct interviews
- when to use didactic teaching, small groups, one-to-one, workshops, role play and discussion groups for different subjects and students.

Who makes the decisions about whom to teach and train?

Ideally there should be an education team/committee/group within every hospice/palliative care service. The members would be the senior doctor, the senior nurse, the tutor, and a manager. They should have the responsibility of

- deciding what courses and study days to run
- deciding the content of the courses and study days
- estimating the financial implications
- defining the target audiences

Are external advisers useful?

Much is said elsewhere in *'Getting Started'* of the benefits of having a Professional Advisory Committee (PAC) for all clinical and professional matters. A subgroup of the PAC can act as education and training advisors, just as yet another small group can advise on research. Having such external experts to advise also raises the profile, credibility, and authority of the hospice/palliative care service when fellow professionals and academics see the calibre of those lending it their support and expertise. It is seldom difficult to recruit them for terms of service not exceeding three years.

What are the dangers and 'risk' implications of doing educational work?

- Trying to do too much with limited human resources.
- Trying to teach subjects in which you have insufficient experience.
- Using members of staff eager to help but without being able to supervise them or monitor their input.
- Making the teaching too sophisticated rather than keeping it simple
- If the 'students' (even long qualified) have more knowledge or experience than is the case
- Forgetting that the clinical staff helping with education have fulltime, stressful jobs as well as teaching.
- Leaving the senior tutor/lecturer isolated without sufficient support or well-defined lines of accountability.
- Under funding the educational work

- Expecting large amounts of money to come in from course fees, study days and conferences.
- Failing to win the hearts of the pharmaceutical industry to subsidise/under pin educational events.
- Failing to send key staff members to as many relevant courses in their specialties as possible.

Is there one message that best describes the aim of education and training in palliative care for health care professionals?

Yes. Strive to change attitudes rather than instilling facts and figures.

14. Communication

Good communications lie at the heart of palliative care and every palliative care service. Its importance cannot be exaggerated. Many new palliative care services are judged as much by the quality of communication as by the clinical care.

It is not only patients and relatives with whom palliative care workers must communicate. They must be skilled in explaining to the public, the media and their politicians what palliative care is, how it is practised. At this time when so many misunderstandings surround it, they must be able to explain that palliative care is not either euthanasia or physician-assisted suicide. On the quality of these communication skills will depend much of the success and effectiveness of the service and how much it is supported and valued.

Communicating with patients

Good communication skills are pre-requisites for palliative care, especially between the members of the palliative care team and their patients, and inside the team itself. If a patient or relative has not understood what a doctor or nurse has said, or not been encouraged to ask questions or feels he/ she is not listened to, their suffering will only increase. Few professionals have been taught to listen as carefully as they speak.

Such skills should be amongst the attributes to be looked for an interview. During the whole time of employment in any palliative care service managers must ensure that every opportunity is taken to further develop these skills.

Important and potentially difficult discussions are frequently necessary with palliative care patients who have active, progressive, far-advanced disease, regarding:

- breaking bad news
- further treatment directed at the underlying disease.
- communicating prognoses
- admission to a palliative care program
- artificial nutrition
- artificial hydration
- medications such as antibiotics.
- do-not-resuscitate orders.

Decisions must be individualised for each patient and should be made in discussion with the patient and family. The following guide is to help you plan for and hold such discussions.

Before the Discussion

Ask yourself these questions:

Would you be surprised if this patient died of their disease within 6 months?

Bear in mind that even doctors with long experience tend to over-estimate prognosis.

This may provide a better guide for decision-making, as attempting to prognosticate may be difficult and inaccurate. Alternatively, assess how much the patient's condition has deteriorated in the last month or six weeks, using observations by the team and objective measures such as x-rays and biochemistry. Observations by close relatives often help.

What specific therapies are available to treat the underlying disease?

- What are the percentage chances of significant clinical improvement?
- Does that consider the patient's age and any other diseases/co-morbidities?
- How long would the improvement last? Days, weeks or months?
- What are the percentage chances of serious adverse effects?
- Does that consider the patient's age and any other diseases/co-morbidities?
- On balance, do the potential benefits outweigh the potential burdens?

About the Patient and Family

- What is their understanding of the state of the disease and the prognosis?
- Do they understand the goal of any treatments to be discussed (e.g., palliative, not curative)?
- Do they understand the potential benefits and burdens of the treatment options?
- What are their expectations? What are they hoping for?
- What do you think their preferences are?

The Discussion

Appropriate setting

- Discussions should be held in person and not by telephone, except when face-to-face meetings are not possible.
- Privacy, prevent interruptions (leave your pager/mobile with someone else)
- Sitting down where the patient/relative can see your face (not standing over the patient's bed)
- Allow enough time.
- The patient has at least one family member or friend for support

Introduce the discussion:

- e.g., "We need to talk about your current problems and our goals for your care".

Find out what they understand:

- e.g., "Tell me in your own words what you understand about your illness now. Don't worry if you cannot remember medical terms".

Find out what they expect:

- e.g., "Tell me what you see happening with this illness in the future".
- e.g., "Tell me what things are important for you, perhaps things you've not mentioned before".
- e.g., "Tell me what you don't like about what we've done or said – we won't be upset or angry, I promise you".

Provide medical information, if necessary

- in a caring and sympathetic way, not abruptly or bluntly
- in a way they can understand
- keep asking them to explain back to you what you have just tried to explain to them.
- clearly (avoid euphemisms and medical jargon)
- what treatments can be offered.
- the possible benefits and adverse effects of any treatments
- as much or as little information as they want. If unsure, ask them how much they want. "Am I telling you too much at one time to take in? Would you like me to go over any of that again but explaining it differently?".
- work with trained interpreters. Strictly, what you need is a translator, not someone who interprets what is being said and consequently gets it wrong.

Discuss realistic possibilities in the context of their view of the present and future:

- Discussing further active treatment for the underlying disease
- truthful discussion of what therapy is or is not available.
- the benefits and burdens of any therapies
- Never say "there is nothing more that can be done".
 - patients interpret this to mean no treatment for anything.
 - it is never true.
 - patients and families will feel abandoned.
- patients may be told there is no further therapy for the underlying disease, but the provision of continuing care and symptom control should be stressed.

- if further active therapy for the underlying disease is not appropriate, emphasise the positive aspects of symptomatic and supportive palliative care. Stress to the patient that he or she matters and is not a burden.

Discussing prognoses

- Explain the uncertainty in estimating an individual patient's prognosis.
- Avoid precise prognostication.
- Give a realistic time range.
- Provide realistic hope—helping them to achieve what is important for them.
- Recommend that family relationships and worldly affairs be attended to
- Be prepared to answer questions about the process of dying. Remember that most people are more afraid of dying that of death itself.
- Provide on-going support and counselling.
- Reassure about continuity of care.

Discussing admission to palliative care units/services

- discuss palliative care in the context of how it can help them achieve their goals.
- e.g., You have told me you would like to.... Palliative care may be able to help you achieve what you want.
- emphasize the positive aspects of palliative care.
- e.g., living as well as possible, for as long as possible; not 'giving up'

Discussing appropriate medical care

- Explain the possible benefits and burdens (or futility) of any intervention. Patients appreciate such honesty.
- If agreement is not reached, the intervention can be tried for a specified time.

Discussing 'Do-not-resuscitate' orders (DNR)

- Introduce the discussion
e.g. "We need to discuss something we discuss with all patients admitted to the hospital."
- Find out what the patient understands
e.g. "What do you understand about your current medical problems?"
- Find out what the patient expects, what their goals are
e.g. "What do you see happening in the future?"
- Discuss a DNR order in the context of the patient's view of their future
e.g. "You have told me you would like.... so, CPR would not seem appropriate if you died".

- If necessary, discuss:
 - futility of CPR (chances of surviving to discharge)
 - indignity of CPR
 - being on a respirator in ICU and unable to communicate
- Respond sympathetically to emotional reactions.
- Reassure patient that all other medical care will continue. Being left to suffer is what most patients dread, not death itself.
- If a patient clearly understands that they are dying and that the only care that they will receive is directed to their comfort, it may not be necessary to discuss DNR orders. If this is the case, it must be recorded in case-notes.

Respond sympathetically to emotional reactions:

- Agree on a plan, with provision that it can be modified if circumstances change.
- Offer to document the plan, including appointing an agent and regarding resuscitation.
- Remember, death is the natural end to life and is not a failure of medicine or any clinicians.

No more will be said here about this important feature of palliative care because it is dealt with in all major books on palliative care. It should always remain at the centre of attention, never being assumed to be better than it really is, hence regular audit of communications is essential.

As explained later in this section it is useful to produce leaflets explaining what the palliative care service is for, how it operates and is funded, how to recognise members of staff, how to contact it for help etc.

Communicating with (health care) professionals

Communications between the members of the palliative care team are crucially important but not an issue for those just 'getting started'. Here we look at communications between team members and their colleagues in the community and in hospitals.

Evidence suggests that such communications are often far from satisfactory. This may be because most doctors and nurses cannot explain things simply, or because they do not know what others want/need to know, or because they are poor listeners. There is also evidence that most doctors and nurses are aware how badly their colleagues communicate but think that they themselves are good communicators.

Doctor – Patient and family

In palliative care each doctor needs to know

- The diagnosis and how much the patient understands about it
- The treatment given and planned.
- The care plans for the immediate future

- The questions the patient has asked, and the answers given.
- The questions the relatives have asked, and the answers given.
- What each doctor feels they can/cannot contribute to future care
- It should be noted that these are all patient centred. There is no need to itemise investigations, blood results, details of operations.

Doctor – Nurse Communication

The content should be the same as above with the addition of

- What the doctor has explained to the patient.
- What questions the patient has asked the doctor.
- Anything said by the patient to the nurse but not the doctor.
- What the doctor has said to the nurse
- Nursing plans with details of any dressings, enemata, etc.

Communicating with relatives and friends of patients

It goes without saying that having obtained the permission of the patient to do so, all the information they want is conveyed to close relatives and, in the absence of relatives, close friends. What is not permissible, no matter how vigorously they ask for it, is to tell relatives or friends information that they do not need, that they might use inappropriately or that has not been conveyed to the patient. Well-meant offers by relatives or friends that they will break bad news or explain the situation to the terminally ill patient should usually be declined. The responsibility for such communications rests on the professionals.

Research shows that most relatives feel they were not kept up to date on the patient's condition, treatment, future, and understanding of his/her condition. They further report that they, the relatives, were not sufficiently told of help available to them – financial, practical, and emotional. It is helpful:

- For a 'communication' sheet to be inserted in the patient's notes detailing each occasion when a relative was spoken to, by whom, and the main points in the conversation.
- For a check list to be included in all case notes listing all the most important information that most relatives want to know (and space for dates when dealt with
 - Diagnosis and treatment, past, present, and future
 - How the relative(s) can help.
 - Assistance in the home (nursing, equipment, night assistance etc)
 - Financial assistance if needed.
 - Support systems put in place.

What every relative or close friend must have is a Visitors' Handbook (or whatever it is decided to call it). Its contents will include:

- A description of what the hospice/palliative care unit is, whom it serves, and who runs it.
- The relationship of the hospice/palliative care unit with other hospitals and family physicians (illustrating how closely they work together to offer seamless care)
- Visiting times and how to get up-to-date information about patients when phoning/visiting.
- Facilities for visitors – quiet room, prayer room, shower room, bedrooms, chairs for sitting beside the patient at night, kitchen for making/heating up their own food.
- Staff and how to identify different members, particularly non- uniformed members of staff.
- Volunteers, some of the roles they play, how they can be identified.
- How visitors can help in care e.g., bathing, feeding, reading to the patient
- Rules relating to food and drink brought into the patient.
- The bringing in of flowers.
- Rules relating to pets visiting.
- Rules relating to smoking by patients and visitors.
- Rules relating to hygiene, hand washing, infection control etc.
- Making donations or offering their own services
- Contact details – telephone, fax, e-mail, snail mail – and to whom they should be sent in the hospice/palliative care unit.

Communicating with the public

Many suggestions have already been made in this section to aid this. The most effective means are:

- Leaflets for use in public meetings, fund-raising events, lectures etc
- Talks about the palliative care service given to members of the public by a team of volunteer speakers (recruited and trained by the service)
- Maximum use of the press, radio and TV. (under the guidance of a PR specialist)
- Palliative care service's own website
- National palliative care service resource/association

Explanatory leaflets about the service are always valuable

Two types are needed:

A general-purpose leaflet explaining what the service offers, who it is for, whether any charges are made, how referrals are made, how it is staffed and where further detailed information can be obtained. It is designed to hand out to the media, to have in doctors' and lawyers' waiting rooms, to give to enquiring patients and relatives and to assist in fund-raising without being a 'begging' letter.

A patient-specific leaflet explaining the principles of palliative care, how it is offered in the service, how to identify members of staff, where to seek advice and help etc. Copies can be given to all patients admitted to the service whether in a unit or at home, displayed at the entrance or reception, and be carried by all staff and volunteers likely to be asked about the palliative care service.

Communicating with the press

When a palliative care services is started, particularly by a charity, there is often considerable media interest. Reporters from local papers want to film facilities and interview staff members and TV crews are soon there looking for 'interest stories'.

This can be stressful particularly for people unfamiliar with being interviewed, and even worse, when they ask to to/expect to interview and even photograph patients. Many who have started palliative care services report that one of the most stressful, distressing features of the early days of the work was the interest shown by the media, the benefits of which were often not obvious to any except the reporters.

However, experience shows that the media can and does do much good. If the senior staff of the service co-operate with them, they can be of enormous help, raising awareness of what palliative care can offer, what financial and other help the service needs and how the local community can assist it. Finally, the media can help to highlight ethical issues involved in palliative care and dispel any notion that it is a form of euthanasia – a very commonly held view.

Communication with the media

Ways to facilitate communication and co-operation with the media:

Appoint an appropriately qualified and experienced senior member of staff or volunteer to be the 'press officer', to answer questions, plan for interviews, shield the service from undue media pressures. The media always appreciate having such a 'contact person'.

Ensure that each newspaper and TV station is invited to all major events – fund raising, new buildings, special announcements – and made to feel welcome and wanted. The more often the service is mentioned in the media the higher will be its profile, and hopefully the better will be its voluntary income and recruitment of staff and volunteers.

Be prepared to issue press releases on all such occasions or when the service has a noteworthy event or piece of news - new senior staff appointments, a member of staff receiving an award or honour, breaking records of patients cared for, achieving a fund-raising target. Such a release should always be restricted to one side only of A4 paper, double-spaced, succinct and jargon-free. It might also have an embargo date and time which the media always respect and honour, never releasing the information prior to that time.

Restriction on media access

In advance of any approach from the press, radio or TV the Trustees/Governors or the directors/CEO acting on their behalf must make a policy decision about patient privacy and how it is to be respected.

Even the best journalists and interviewers will press to be able to interview patients or, as a second best, their relatives. They will use persuasive arguments to show how telling it would be for a patient to describe how they have been made welcome, made more comfortable, or in whatever way they choose to describe what a wonderful place it is.

In terms of patient autonomy, it is, of course, the patient who must decide whether they wish to be interviewed or filmed but few appreciate how long such interviews usually are, how exhausting, how upsetting to loving relatives, and how many thousands of people are, in a sense, brought into the intimacy of their rooms. Paternalistic as some might describe it, most palliative care units discourage patients from agreeing to meet the press.

Finally, when considering communication with the media, those not experienced in working with them usually forget that they:

- do not allow interviewees to see/edit the draft material of what they intend to publish or show on screen.
- may take statements out of context, often radically changing the meaning of what was said.
- usually reduce what an interviewee said, sometimes taking the sense out of it.
- may publish details from an interview under an inappropriate title over which the interviewee, and even the reporter, has no control.

Communicating with politicians

Politicians need to know about palliative care services because:

- they affect the constituents they represent.
- they are part of local and national health care provision for which they are responsible.
- they need revenue to operate - money from a health budget or charity money and politicians are interested in both.

Most politicians, certainly in regions or countries where palliative care is not yet established, know nothing about it. Evidence suggests that they want to learn about palliative care, many of them becoming deeply committed to it in one way or another.

Ways in which politicians can learn about palliative care

- They can be invited to make a private visit to the unit/service as soon as it opens, shown every aspect of it, told how it will serve the community, its budget, staffing, support structure etc.
- They can be sent a personal invitation to every public meeting/major fund-raising event organised by the service. Politicians are busy people with many similar invitations, but they appreciate being invited and for the chance to be seen by those who have voted for them.
- They can be sent a regular, but not too frequent, update on the life and affairs of the service - a newsletter perhaps, with the occasional invitation to contribute a few paragraphs.

Local politicians (as distinct from national ones in government/parliament/ assembly) like to host occasional events in local government offices/chambers. The expenses are met by the palliative care service but politicians like the opportunity to have a profile, show off where they work, and demonstrate their commitment to local enterprise.

Undoubtedly the best way to help, and win the support of, national politician and leaders is through an All-Party Parliamentary Palliative Care Group. (Inevitably its name will differ from country to country. Some refer to it as The Cross Party Parliamentary Palliative Care Group). Such groups now operate in several countries.

The crucial thing is that the group is non- political.

It needs a Member of Parliament (MP), Congressman, Senator or Member of a National Assembly to start it in cooperation with the palliative care services of the country (preferably a national association or federation of services). They then send letters to each MP asking if they would be interested in learning more about palliative care, if they would be willing to attend a meeting in a parliamentary building, lasting no longer than 1 hour every 3 months, and if they would be willing to receive a small information pack on each occasion.

At each meeting they have a 10 minute (or less) talk from a palliative care expert on topics as diverse as how existing services are coping, opioid availability, opioid myths and misunderstandings, palliative care in neighbouring and other countries, palliative care for minority and disadvantaged groups, education, and training in palliative care in schools and university, ethical issues. This is followed by questions to the speaker, then questions raised by their work or constituents, and finally discussion how best they can encourage and facilitate the development of palliative care in their country.

The 'information pack' contains details of new services, copies of any information or scientific papers they have requested and a small piece on palliative care internationally. Politicians like to feel they are comparing well with other countries.

A National Palliative Care Resource Centre/Officer

The public, the press and most politicians like to get most of the authoritative information they need from a central resource rather than contacting numerous units, services and agencies.

It therefore becomes a matter of urgency that when several palliative care services operate in a country or state such a resource is established, provided with all the statistics and information available. Whether that is then published in hardcopy or on a website or made available in other formats is a policy matter for the operating group or association.

Evidence coming from several countries suggests that support from public, press and politicians is greatly enhanced when there is a representative/co-ordinating body.

Auditing Communications

Every means possible must be used to check whether the quality of communications is as good as possible. Some form of audit should be built into the system from the start of the service as follows:

- When a patient dies/leaves the care of the service each clinician (family medicine or hospital, doctor, or nurse) can be asked to answer 5-10 questions on a check list about aspects of communication with the service.
- when a representative of the service visits a bereaved person 3 – 6 months after the death they too can be asked to answer 5 questions about what was said, how helpful it was, and where communications could have been bettered.
- An annual social event can be held to which are invited the representatives of the media seen most frequently in the past year and they too can be asked how communication and co-operations could be improved. (not a written check list in this case).

15. Documentation

It is essential to have a simple but efficient clinical documentation system for two reasons:

- It will be expected/demanded by local or national government health departments.
- It makes audit and research easier as well as comparability with other palliative care services and collecting and collating data at a national level.

Though it is possible to design a system it is much better to use one of the many Minimum Data Sets' computer programmes currently on the market, written for palliative care services. Details are obtainable from national bodies such as the UK's National Council for Palliative Care and the US National Hospice and Palliative Care Organisation as well as other national and regional bodies.

In-house documents (patient case-notes/records) can then be designed to obtain the information needed for the data sets without obtaining interesting but possibly unnecessary information. The possibility of trying to get too much information ("Might be useful one day") is thus avoided and time saved.

Medication documents

Pharmacy Records. Whether medications are stored and dispensed in the unit or brought in from another pharmacy (hospital or community)

- all records must meet the standards laid down by the law of the country.
- there must be regular, thorough checks that all legal requirements are being met. One senior member of staff (doctor, nurse, pharmacist) must be made responsible.

In-Patient medication charts/records. Again, it is preferable to use one of the models in common use in local hospitals. Unless there are compelling reasons why they should not be used it is best to use similar charts and records to those in the hospitals from which most patients will come. Staff will be familiar with them; it cuts down the possibility of confusion and makes comparability easier.

Community-based patients' medication charts/records for use in patients' homes. These are essential but some services, unwisely, try to do without them. They are needed to record medication for the benefit of patient, relatives and the many different professionals who may visit the home. Samples can be found in several textbooks of palliative medicine and community care [[See Recommended Reading](#)]

Clinical Records

Operational data should include such information as demographics, age, disease, symptoms, referral source, interventions, follow-up plans, and outcomes (using a validated scale). By having adequate statistics, you will be able to lobby for further funding and have a basis for research topics. Information about 'Minimum Data Sets' software can be obtained from national palliative care organizations and IAHPC.

Again, what is needed must be comprehensive yet simple and easy to use. Samples are available from most national and regional organisations. As a minimum the folder will need pages devoted to

- Personal details (name, address etc.)
- Past medical history
- Present medical history
- Investigations
- Medications
- Nursing reports and comments: enabling the records to be multi-professional used by all members of staff.
- Medical reports and comments: multi-disciplinary is hugely invaluable for team caring
- Correspondence about the patient, usually to/from fellow clinicians

A Communication sheet: what the patient said or asked, what reply, or explanation was given – completed by doctor, nurse, social worker, pastoral care worker) after every significant conversation. This is crucially important and is not usually found in non-palliative care clinical records.

So called 'Patient Held Records' have been tried and evaluated in several centres. It had been hoped that respecting patient autonomy and decision-making and their right to see all records, they would improve communication between the many professionals involved in the care. They were not found to do that and are therefore not recommended here.

Day-to-day clinical reports and updates, as used on the wards, should be for the shared use of all professionals involved in the care of that patient, doctors, and nurses (for example) writing in comments, observations, summaries of what they have told the patient (and been told by the patient) – all on the same pages. On the death or discharge of the patient they are all filed in the one folder.

The IAHPC developed a [Global Clinical Database](#) for the first palliative care consultation which may serve as a model.

Non-Clinical Records

Computer programmes are now on the market for the finance department, staff management, volunteer service management, pharmacy, and even pastoral care. Advice and assistance can usually be obtained from the national palliative care association.

It is better to select one of these than try to devise a new one as most new hospice and palliative care services tend to do.

Legal and ethical considerations

At the advanced planning stage, it is important to find out what are the legal requirements for records, archiving, the period they must be retained (and therefore what storage facilities will be needed), who has right of access to records and how much is covered by any 'Data Protection Act' operating in the country. It varies greatly from one country to another.

When doing so it is wise to get legal advice on the disposal of medications. How many provided they are still with their expiry date can be taken back into pharmacy and recycled. Which ones must be disposed of and by whom and with what records of doing so?

When so many members of staff representing so many professions and disciplines work together palliative care it is easy for confidential information to be leaked to people who have no right to know it. At the same time in most western countries, patients - but not their relatives - have a right to see their medical records. These issues will need to be considered when planning record systems and their security and access.

Records to assist Clinical Audit

No palliative care service, whether in the community or a hospital, should be established without planning for rigorous audit. It may be financial (as required by law), administrative or clinical. Such audit is not a luxury, not something that one does after the service has been running for a few years, not something that can be left until a visiting official enquires about it.

Documentation, whether hard copy (paper) or recorded and stored electronically, must be in place from Day 1. Much of what is needed will be obvious - personal details of each patient, pathology, investigations, treatments, clinical outcomes. Other information will depend on what seems important to know to justify the service, to measure its quality, to assess its efficacy and efficiency.

The Final Preparations

The unit has been built or a satisfactory old building adapted. Staff have been appointed and pre-service training started. Within weeks the first patients will arrive. What final preparations will be needed, many of them continuations of work done in the previous months and years?

They are listed here, mostly as questions, in no order of importance or priority.

Patients' Records

- Has it been negotiated that each patient being transferred from a hospital will bring his/her up-to-date case notes?
- What arrangements have been made for records of patients admitted from their homes?
- Has permission been granted for the palliative care unit to keep them whilst the patient is under care there or are they to be returned to the hospital after copies have been made of relevant section?
- What about x-rays? Will they be sent to/lent to the palliative care unit or sent electronically as images?
- What is to be done with them when the patient dies?

Investigations

- In the case of a free-standing palliative care unit has it been negotiated that patients may be sent to a nearby hospital for diagnostic procedures such as x-ray, MRI, CAT scan, PET scan, and specimens be sent there for bacteriological, biochemical, and haematological tests?
- Will the palliative care unit be billed, or the bill be sent directly to the patient?
- Has it been agreed who will read/interpret scans and other sophisticated procedures?
- What transport arrangements have been made for patients needing to go to and from the hospital? Once again, who will be billed?
- Will they be accompanied by a nurse or a volunteer? If the patient is a woman, will it be necessary to have another lady as a chaperone?

Autopsies/Post-mortems

These are not often requested in palliative care but are recognised as being of considerable value in elucidating the cause of inexplicable symptoms. In certain circumstances they may be required by law.

- Where will they be done and by which pathologists?
- What transport will be used?
- Will they be traditional cause of death' examinations or "What caused the following inexplicable symptoms?".

Relationship with Morticians/Funeral Directors

Close and mutually helpful working relationships are essential if, after death as much as before it, the patient is accorded every possible dignity. Prior discussion with local Funeral Directors is never wasted time.

- Has a meeting been held with representatives of all local Funeral Directors where the ethos of the hospice/palliative care service was explained, when they were shown the entrance for funeral cars, the mortuary and how there will always be a nurse present when they came to uplift a body? [It should be remembered that in hospitals there is always a mortuary attendant on duty]
- Has it been discussed whether a body may remain in the unit until the day of the funeral?
- What arrangements have been made for Jewish, Islamic, Hindu, and Sikh patients to be cared for after death according to their beliefs, culture and traditions or wishes?
- Has it been discussed what is to happen to the flowers from a funeral, if the family have requested that they be brought to the hospice? Will members of the Hospice Volunteer Flower Team be ready to come in daily (or oftener) to deal with the hundreds of flowers brought from funerals, many of them not suitable for placing in vases?
- Will it be permissible for ashes to be scattered/buried in the grounds of the Palliative Care Unit after a cremation? This is best discussed before the first request is received.

Visiting Guidelines

The questions surrounding visitors for patients are perhaps more difficult and sensitive than many people realise. They require careful thought and must then be explained to staff (as well as being in the Staff Handbook) and visitors.

The key issue is that patients have limited energy, are easily exhausted yet want to see loved ones and friends and do not want to disappoint anyone. Much as relatives will say they want to be with their loved 24/7. In fact, they too become exhausted, find it ever more difficult to leave the bedside, and need a break. Further problems arise in HPCUs in general hospitals; having different visiting times from that of other wards and departments is seen as unfair.

- Will it be limited to specific times except when special permission for other times has been granted? This is probably preferable provided there is flexibility and explanations for decisions are given to all concerned.
- Will it be unlimited, visitors being free to come at any time and stay for as long as they want? Sounds good but is exhausting for patients and not all visitors are sensitive to their feelings but sensitive to their own 'rights'.
- Will it be at any time during the day but not at night, with a time limit on how long anyone may stay unless special permission is granted by the senior nurse? This works well.
- Will children be allowed to visit with an adult? Will a playroom or crèche be provided for little ones? There is substantial evidence that children both want to visit and can do so

responsibly with no adverse effect on them provided they have been sensitively told what is happening to the person they are visiting.

- What food and drink will visitors be permitted to bring in? Will they be permitted to give it directly to the patient or, in the first place, to report what it is and give it to the senior nurse on duty? This seldom a problem because people understand how limited the appetite of people with advanced disease is, but they may not appreciate how alcohol may be contra-indicated with many medications.
- Will a favourite pet, in particular a well-behaved dog, be permitted to visit occasionally? This is now common practice and many palliative care units arrange visits by Pet-a-Dog.

Information for Professional Colleagues

Detailed discussions will have taken place for months or even years before the palliative care service starts – discussions about what care it will offer, the type of patients who might benefit from it, the experience and expertise of its senior medical and nursing staff etc. Now is the time to ensure that all doctors (hospital and family medicine), nurses (hospital, community and private) know everything they will need to know about the new service and what it will offer them. The following questions might be asked:

- Will information leaflets or packs about the palliative care service be sent to all senior medical and nursing staff (hospital; and family medicine) a week or so before the service starts. Will the service accept referrals via completed application forms sent by mail (often too slow a process in the rapidly changing condition of many patients needing palliative care), over the phone or by email? Will each referral be assessed by a palliative care doctor or nurse prior to admission? What is the minimum information the service will expect when a patient is admitted? How will emergencies be dealt with?
- Have discharge forms been produced to ensure that all relevant information about a patient can be in the hands of professional care providers.

Launch

- Will there be a reception in the palliative care unit (wherever it is – hospital or community) before it opens to patients to which are invited all local colleagues? They can meet palliative care staff, see facilities, discuss collaboration and mutual support, and ask all the questions they have. Experience worldwide has shown that there is initially much ignorance and misunderstanding about hospice/palliative care, considerable scepticism about what it can achieve, and professional fears that existing inadequacies will be highlighted by the new service. Winning their professional support and understanding is crucially important.
- Have other key people in the community, and often in the lives of patients, been told about the new service – clergy, local and national politicians, social workers?
- Has a press/media conference been planned so that representatives may come to learn what the service offers and does not offer? For this to be a success it is essential that.
- the event is planned with the help of a public relations expert.

- senior staff are chosen to respond to questions and briefed accordingly. They must be prepared for difficult questions on current standards of terminal care in the city or county, euthanasia, physician-assisted suicide, DNR, Living Wills”, litigation, falling standards of care etc.
- every opportunity is given for photographers to film the unit.
- photographs are made available to them of senior staff together with mini biographies.
- a press pack is produced and given to all attendees. Brevity is of the essence!
- a brief history of hospice/palliative care worldwide is in the press pack.

The final 'dress rehearsal'

Before patients are admitted the local Fire Department, Ambulance Service and Police Department must be informed. Each will want to send representatives to see the unit:

- The Fire Department ascertaining the fastest route to reach it, the escape exits, the fire alarm control board, positioning of hydrants, dangerous chemicals etc.
- The Ambulance Service will also plan routes, position of entry doors, where trolleys area parked etc.
- The Police may have already been through the whole building, its Medication Squad checking the security of the Pharmacy/Medication Store, others checking security, staff screening etc.

In the last week before the service starts, particularly if it there are to be in-patient beds there must be a rehearsal involving a 'patient' being brought to the unit, being welcomed by the nurse who will be looking after him/her, receiving the accompanying relatives, going through the admission process, explaining the routine of the unit, meals, visiting, how important every little detail is in this care, the doctor introducing him/herself, what happens at night. Every effort must be made to make it realistic, even to the extent of finding weaknesses, staff making mistakes, forgetting to mention fire drills and routes of escape, potential difficulties, patients unwilling to stay, relatives who misunderstand hospice care and think it is euthanasia etc.

16. Resources

Sources of Useful Information

Each organisation listed below produces authoritative, up-to-date information, invaluable not only to those starting a hospice/palliative care service but to those well-established, making it all essential reading.

African Association for Palliative Care (APCA)

www.apca.co.ug

Asia Pacific Hospice and Palliative Care Network (APHN)

www.aphn.org

Center to Advance Palliative Care (CAPC)

<http://www.capc.org/>

European Association for Palliative Care (EAPC)

www.eapcnet.org

International Association for Hospice and Palliative Care (IAHPC)

www.hospicecare.com

International Observatory on End-of-Life Care

<https://www.lancaster.ac.uk/health-and-medicine/research/ioelc/>

International Children's Palliative Care Network (ICPCN)

<https://www.icpcn.org/>

Latin American Association for Palliative Care (ALCP)

www.cuidadospaliativos.org

Palliative Care in Humanitarian Aid Situations and Emergencies (PallCHASE)

<https://www.ed.ac.uk/global-health>

Respecting Choices

<https://respectingchoices.org/>

World Health Organization (WHO) - WHO infographics

<https://www.who.int/health-topics/palliative-care>

<https://www.who.int/ncds/management/palliative-care/pc-infographics/en/>

Worldwide Hospice Palliative Care Alliance (WHPCA)

<https://www.thewhpca.org>

Recommended Reading

Those 'getting started' are reminded that the IAHPC has its own regularly updated list of recommended books on almost every aspect of Hospice and Palliative Care. Each has been reviewed by experienced and eminent members of the IAHPC who understand the needs of all working in palliative care.

Listed below is only a small selection of highly recommended books, all ideal for new libraries:

Alexander M F, Fawcett J N, Runciman P J. (2006) *Nursing Practice: Hospice and Home - The Adult*. 3rd Edition. Churchill Livingstone, Edinburgh. (Written for both student nurses and those returning to nursing, with an excellent section on palliative care. A useful book for the new library).

Allison Michael, Kaye Jude. (2015). *Strategic Planning for Nonprofit Organizations: A Practical Guide for Dynamic Times* (Wiley Nonprofit Authority) 3rd Edition. Wiley, USA.

Beecher R and Gamlin R. (2004) *Palliative Care Nursing: Fundamental Aspects of Nursing*. Mark Allen Publishing.

Bruera E, Dalal S (2018) *The M.D. Anderson Supportive and Palliative Care Handbook*. The University of Texas, Houston.

Bruera E, Higginson I, Ripamonti C and Von-Gunten C Morita T. (2006) *Textbook of Palliative Medicine*. 3rd Edition. CRC Press, USA.

Bruera E, De Lima L, Wenk R, Farr W. (2004) *Palliative Care in Developing Countries: Principles and Practice*. IAHPC Press, USA.

Buckman R. (1992) *I don't know what to say - how to help and support someone who is dying*. Vintage. (Invaluable for those faced with this challenge and as a teaching text).

Buckman R. (1993) *How to break bad news - a guide for health care professionals*. Macmillan, London. (Excellent for students, junior doctors and family doctor),

Bryson John. (2018) *Strategic Planning for Public and Nonprofit Organizations: A Guide to Strengthening and Sustaining Organizational Achievement*. Wiley, USA.

Currow D, Clark K (2010) *Emergencies in Palliative Care and Supportive Care*. Oxford University Press, Oxford.

Dickman A, Schneider J, Varga J. (2016) *The Syringe Driver: Continuous Subcutaneous Infusions in Palliative Care*. 4th Edition. Oxford University Press, Oxford. (The authoritative text on syringe drivers/pumps).

Doyle D. (2002) *Volunteers in Hospice and Palliative Care: a handbook for volunteer service managers*. Oxford University Press, Oxford. (New edition due 2009).

- Cherny NI, Fallon M, Kaasa S, Portenoy RK, Currow D. (2015) *The Oxford Textbook of Palliative Medicine*. 5th Edition. Oxford University Press, Oxford. (The definitive reference book on every aspect of palliative medicine).
- Davidson Glen (Editor) (2013) *The Hospice: Development and Administration (Death Education, Aging and Health Care)* 2nd Edition, Routledge, USA.
- Doyle D, Jeffrey D. (2000) *Palliative Care in the Home*. Oxford University Press, Oxford. (Written exclusively for non-specialist doctors and nurses working in the community).
- Fallon M, Hanks G (2006) *ABC of Palliative Care*. 2nd Edition. BMJ Books/Blackwell Pub, Oxford. (A book for doctors and nurses as well as students).
- Ferrell B, Paice J (2019) *Textbook of Palliative Nursing*. Oxford University Press, Oxford. (Probably the best text for nurses specialising in palliative care).
- Faull C, DeCastecke S, Nicholson A, Black F. (2012) *Handbook of Palliative Care*. 3rd Edition. Blackwell Science, London. (A multi-professional book excellent for nurses as well as doctors).
- Goldman, A. (1994) *Care of the Dying Child*. Oxford University Press, Oxford. (Written by a specialist in paediatric palliative care - Essential reading for anyone called upon to care for children).
- Higginson, I J. (1993) *Clinical Audit in Palliative Care*. Radcliffe Press, Oxford.
- Higginson I J. (1997) *Health Care Needs Assessment: Palliative and Terminal Care*. Radcliffe Medical Press, Oxford.
- Kinghorn S and Gaines S. (2007) *Palliative Care Nursing: Improving End of Life Nursing*. 2nd Edition. Balliere Tindall, London.
- Kouzes James M, Posner Barry (2012). *The Leadership Challenge: How to Make Extraordinary Things Happen in Organizations*. Jossey-Bass: USA.
- Lugton J and McIntyre R. (2005) *Palliative Care: The Nursing Role*. Churchill Livingstone, Edinburgh.
- MacDonald N, Herx L, Boyle A. (2021) *Palliative Medicine: a case-based manual*. 4th edition Oxford University Press, Oxford. (Ideal for teaching medical students and junior doctors).
- Palliative Care Australia (2018). *Palliative Care Service Development Guidelines*.
- Payne S, Seymour J, Ingleton C. (2008) *Palliative Care Nursing: Principles and Evidence for practice (2nd Edition)* Maidenhead: Open University Press.
- Pizam A. (2019) *International Encyclopedia of Hospitality Management*. Elsevier.
- Pynes Joan. (2013) *Human Resources Management for Public and Nonprofit Organizations: A Strategic Approach* 4th Edition. Jossey-Bass: USA.
- Randall F, Downie RS. (2006) *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford University Press, Oxford. (Comprehensive coverage of all major ethical issues encountered in palliative care).

- Robbins M. (1998) *Evaluating Palliative Care: Establishing the Evidence Base*. Oxford University Press, Oxford.
- Sims R, Moss VA (1995) *Palliative Care for People with AIDS* Edward Arnold, London. (Highly recommended for all called upon to provide palliative care to patients with AIDS).
- Stahl Michael J. *Encyclopedia of Health Care Management* (2003) SAGE: UK.
- Walsh D, Foley KM, Glare P, Caraceni AT, Fainsinger R, Goh C, Lloyd-Williams M, Nuñez Olarte JM, Radbruch L. (2008) *Palliative Medicine*. Saunders, UK.
- Watson M, Ward S, Vallath N, Wells J, Campbell R. (2019) *Oxford Handbook of Palliative Care*. 3rd Edition. Oxford University Press, Oxford. (Comprehensive, compact and based on the Oxford Textbook of Palliative Medicine).
- Woodruff R. (2004) *Palliative medicine: Evidence-based Symptomatic and Supportive care for Patients with Advanced Cancer and AIDS*. 4th edition. Oxford University Press, Oxford. (Comprehensive, authoritative and reasonably priced).
- Woodruff R, Doyle D. (2009) *IAHPC Manual of Palliative Care - Read Online at IAHPC* (The basics - Completely revised and brought up-to-date).

Recommended Journals

Each is international but the country where it is published is shown here (in alphabetical order):

American Journal of Hospice and Palliative Medicine (USA)

<https://journals.sagepub.com/home/ajh>

Annals of Palliative Medicine (China)

<https://apm.amegroups.com/>

BMC Palliative Care (UK)

<https://bmcpalliatcare.biomedcentral.com/>

BMJ Supportive & Palliative Care (UK)

<https://spcare.bmj.com>

Current Opinion in Supportive and Palliative Care (USA)

<https://journals.lww.com/co-supportiveandpalliativecare/pages/default.aspx>

Death Studies (UK)

<https://www.tandfonline.com/>

International Journal of Palliative Nursing (UK)

<http://www.ijpn.co.uk/>

Journal of Pain and Symptom Management (US)

http://www.elsevier.com/wps/find/journaldescription.cws_home/505775/description

Journal of Hospice and Palliative Nursing (US)

<http://www.jhpn.com/>

Journal of Palliative Care (US)

<https://journals.sagepub.com/home/pala>

Journal of Palliative Medicine (US)

<http://www.liebertpub.com/Products/Product.aspx?pid=41&crit=Palliative+Medicine>

Journal of Palliative and Supportive Care (US)

<http://journals.cambridge.org/action/displayJournal?jid=pax>

Omega: The Journal of Death and Dying (US)

<http://www.baywood.com/Journals/PreviewJournals.asp?Id=0030-2228>

Palliative Medicine (UK)

<http://pmj.sagepub.com/>

17. References

1. World Health Organization. National Cancer Control Programmes. Policies and managerial guidelines. Geneva: WHO; 2002.
2. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnagar S, et al. Redefining Palliative Care-A New Consensus-Based Definition. *J Pain Symptom Manage*. 2020;60(4):754-64.
3. Gómez-Batiste X, Connor S, Murray S, Krakauert E, Radbruch L, Luyirika E, et al. Principles, Definitions and Concepts. In: Gómez-Batiste X, Connor S, editors. *Building Integrated Palliative Care Programs and Services*. Catalonia: Liberdúplex; 2017. p. 45-60.
4. De Lima L, Woodruff R, Pettus K, Downing J, Buitrago R, Munyoro E, et al. International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide. *J Palliat Med*. 2017;20(1):8-14.
5. Knaul F, Radbruch L, Connor S, De Lima L, Arreola-Ornelas H, Mendez O, et al. How many adults and children are in need of palliative care worldwide? In: Connor S, editor. *Global Atlas of Palliative Care 2nd Edition* 2020. p. 17-32.
6. Clark D, Centeno C, Clelland D, Garralda EL, J, Downing J, Varghese C, et al. How are palliative care services developing worldwide to address the unmet need for care? In: Connor S, editor. *Global Atlas of Palliative Care 2nd Edition* 2020. p. 45-58.
7. World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19) 2014. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf?ua=1.
8. Moens K, Higginson IJ, Harding R. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *J Pain Symptom Manage*. 2014;48(4):660-77.
9. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 2. Recommendations from the European Association for Palliative Care. *European Journal of Palliative Care*. 2010;17(1):22-33.
10. Herrera E, Rocafort J, De Lima L, Bruera E, García-Peña F, Fernández-Vara G. Regional palliative care program in Extremadura: an effective public health care model in a sparsely populated region. *J Pain Symptom Manage*. 2007;33(5):591-8.

11. Payne SK, Coyne P, Smith TJ. The health economics of palliative care. *Oncology (Williston Park)*. 2002;16(6):801-8; discussion 8, 11-2.
12. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report. *The Lancet*. 2018;391(10128):1391-454.
13. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med*. 2018;21(12):1684-9.
14. Stevens E, Martin CR, White CA. The outcomes of palliative care day services: a systematic review. *Palliat Med*. 2011;25(2):153-69.
15. Bradley SE, Frizelle D, Johnson M. Patients' psychosocial experiences of attending Specialist Palliative Day Care: a systematic review. *Palliat Med*. 2011;25(3):210-28.
16. Palliative Care Australia. Palliative Care Service Development Guidelines 2018. Available from: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf.