



# Getting Started:

**Guidelines and Suggestions for  
those Starting a  
Hospice/Palliative Care Service  
2nd Edition**

**Derek Doyle**  
IAHPC Press



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for those Starting a  
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**IAHPC Press  
Houston**

2009

ISBN - 0-9758525-7-4

## Preface to the 2<sup>nd</sup> 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 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 IAHPD has just that book. It was first published a few years ago and has since been read by hundreds if not thousands of people many of whom have told us how helpful it was. It has now been brought up to date - relevant for readers worldwide. It answers all the most commonly 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, 2009

## Acknowledgments

The author is grateful for the review, valuable comments and contributions received from the following IAHPD Board Members:

Kan-sang Chan, MD (Hong Kong)  
Liliana De Lima, MHA (USA)  
Roberto Wenk, MD (Argentina)  
Roger Woodruff, MD (Australia)

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## Introduction

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. Spending time (even years) planning a palliative care service is always time well spent.

This series of short papers has been prepared for those interested in starting palliative care services in developing countries where knowledge about and funding for palliative care is limited.

**Most topics mentioned here are dealt with in detail in other sections**

### What is palliative care?

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

A more succinct definition is ***"Palliative care is the care of patients with active, progressive, far-advanced disease with a limited life expectancy, for whom the focus of care is the quality of life."*** 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.

### Different (sometimes confusing) terms used about palliation

The **principles of palliative care** are the principles of all good clinical care, whatever the illness, whatever the stage of it, whether or not it is life-threatening, whatever the age, gender, race, class or creed of the patient.

**Palliative procedures** are valuable components of modern palliative care but not in themselves comprehensive palliative care. They include radiotherapy, chemotherapy, the insertion of stents, the drainage of effusions, the stabilization of bones and even procedures as simple but valuable as catheterisation.

**Specialist palliative care** is that provided by a service (which may or may not have in-patient beds) where the principal clinicians (doctors, nurses, social worker and other team members) have all had advanced training in the principles of modern palliative care. (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.)

*Throughout 'Getting Started' palliative care will refer to the care defined in the shorter definition above*

### 'Hospice' or 'Palliative Care'? Are they the same thing?

Yes, in most respects they are. However the word *hospice* is better known to members of the public than *palliative care*. *Palliative Care* is the preferred term for health care professionals particularly since it became a nursing specialty in so many countries and palliative medicine became a medical specialty in the UK in 1987. Sadly some health care professionals regard *hospice* as care for the dying provided either by well-intentioned volunteers or the ultra-religious. In North America '*hospice*' is often used to describe not a building or care programme but a philosophy of care ("He is now so ill he needs hospice").

*It is recommended that the term 'palliative care' be used in all professional communications and publications.*

## What palliative care is not

Though the principles of palliative care are applicable in each of the following they are **NOT** palliative care services

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

**Most emphatically palliative care is not euthanasia or physician-assisted suicide, both of which focus on death rather than on the quality of life.**

## Models of palliative care provision

- **In-patient palliative care unit within a general** (secondary or tertiary referral) **hospital**
- **In-patient palliative care unit**, detached or even distant from a hospital. Often termed either a 'free-standing unit' or a 'hospice'
- **Community palliative care service**, caring for patients at home, in nursing homes or living with relatives
- **Hospital palliative care team**, operating with or without dedicated beds, in a secondary or tertiary referral hospital
- **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

The pros and cons of each will be discussed in separate sections of ***Getting Started***.

## 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 carers, 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

Do many dying 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 in the final years and months of life (see tables below).

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 carers.

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.

### Does palliative care have world-wide relevance?

Yes! No matter where people live, whatever their age, gender, education, class, race, language, culture, creed or disease - they describe the same suffering and the same needs, and respond equally well to *appropriate* palliative care, which takes into account their culture and their belief system.

The word 'appropriate' is the important one, and why **Getting Started** has been produced by the IAHPC which does not aim to implant western style medical care worldwide.

| The spectrum of suffering in cancer and cardiac patients |          |           |
|--|----------|-----------|
| Symptoms   | Cancer % | Cardiac % |
| Pain   | 75       | 78        |
| Breathlessness   | 40       | 61        |
| Anorexia   | 75       | 43        |
| Constipation   | 75       | 37        |
| Nausea/vomiting  | 45       | 32        |
| Convulsions/fits   | 45       | 59        |
| Fungating lesions  | 10       |           |
| Diarrhoea  | 5        |           |
|  | 4        |           |

### How do you "get started" planning a palliative care service?

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 even 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 there must be

- Detailed consideration of cost implications (capital and revenue), short-term and long-term;
- 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.

### Needs Assessment

**WARNING:** It is tempting to see the unnecessary suffering of many patients in 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 doing a needs assessment or giving thought to the topics mentioned above. **This can be disastrous.**

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

**Patients:**

- How many patients likely to benefit from palliative care are there at any one time?
- What is their age distribution?
- What is the prevalence of symptoms?
- What are thought to be the other unmet needs of these patients?
- 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 ultimate goal to enable more people to die at home? (as distinct from wanting to remain at home as long as 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 access to basic (non-sophisticated) diagnostic facilities and to case notes of all patients referred to the service?

**Discussion with Strategic Planners**

Remember that local / national health care managers may not know much about modern 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 co-operation of local doctors, in order 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 drugs 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?

### 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.**

Eighty five percent of expenditure always goes on salaries and wages, whatever the type or size of service.

The smaller the in-patient unit the higher, proportionately, is the cost.

When a palliative care service is to be independent of any national health service (though not necessarily "private" in the sense of being "For profit") it is prudent to consider the appointment of an Appeals Officer or Fund-raiser to relieve other staff of any responsibility to generate income. The better an independent service blends in effectively with other health care providers in the locality, the more difficult it is to raise charity funds without great effort because it has lost its "independent" needy image.

**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.

**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, work load, distances to travel in the community, whether or not 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.**

| Care Factor                               | In-patient Palliative Care Unit | Out-patient/ Ambulatory Consultation | Community Palliative Care Service | Day Palliative Care Unit | Hospital Palliative Care Team |
|---|---------------------------------|--------------------------------------|-----------------------------------|--------------------------|-------------------------------|
| Symptoms                                  | Moderate/Severe                 | Mild                                 | Mild/Moderate                     | Mild                     | Moderate/Severe               |
| Psychosocial Complexity/Instability       | Moderate/Severe                 | Mild                                 | Mild/Moderate                     | Mild/Moderate            | Moderate/Severe               |
| Clinical Instability                      | Unstable +++                    | 0                                    | ++                                | +                        | +++                           |
| Functional Dependency                     | Dependent +++                   | 0                                    | ++                                | +                        | Variable                      |
| Require other intensive medical treatment | 0 / +                           | 0                                    | 0                                 | 0                        | +++                           |
| Degree of Social Support available        | Low/Variable                    | Available                            | Available                         | Available at night time  | Low/Variable                  |
| Degree of nursing required                | High                            | Minimal                              | Intermediate                      | Low                      | High                          |

**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. Having said that, it must be noted that the 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!**

## **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.**

## **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!

### **Care Matrix for Different Palliative Care Models (based on patient needs and dependency)**

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.

In the chapters which follow different types of service are described

## What is palliative care?

*[Note: this is also the opening section of the IAHPC Manual of Palliative Care available in <http://www.hospicecare.com/manual/IAHPCmanual.htm> ]*

**Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life.**

The following should be noted:

- **active disease:** this activity can be confirmed and measured objectively by clinical examination and investigations;
- **progressive disease:** this too can be assessed clinically;
- **far-advanced disease:** more difficult to define but examples are extensive metastatic disease in cancer, refractory cardiac, renal or respiratory failure and total dependency in neurodegenerative conditions or Alzheimer's Disease;
- focus on the **quality of life** is the key feature of the definition
- it is **person-oriented**, not disease-oriented;
- it is **not primarily concerned with life prolongation** (nor with life shortening);
- it is **not primarily concerned with producing long term disease remission**;
- it is **holistic** in approach and aims to address all the patient's problems, both physical and psychosocial;
- it uses a **multidisciplinary or inter professional approach** involving doctors, nurses and allied health personnel to cover all aspects of care;
- it is dedicated to the **quality of whatever life remains for the patient**
- palliative care is appropriate for **all patients** with active, progressive, far-advanced disease and not just patients with cancer;
- palliative care is appropriate for patients receiving continuing " active" therapy for their underlying disease.

Palliative care should never be withheld until such time that all "active" treatment regimens for the underlying disease have been exhausted.

The message of palliative care is that whatever the disease, however advanced it is, whatever treatments have already been given, there is always something which can be done to improve the quality of the life remaining to the patient.

### World Health Organization definition

**"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."**

### Palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

- Is applicable early in the course of illness, in conjunction with **other** therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

This definition is available in <http://www.who.int/cancer/palliative/definition/en/>

## Types of Care: the meaning of "Palliative"

It is important to differentiate:

- **palliative care principles** which apply to all care, whatever the disease suffered by a patient
- **palliative techniques or therapies** include medical and surgical therapies or procedures (e.g. stenting, paracentesis, internal fixation of fractures and radiotherapy) that are employed to palliate symptoms and ease suffering but are only a small part of the spectrum of care known as palliative care
- **specialist palliative care** in some countries is practised in units operated exclusively for palliative care by doctors and nurses who are accredited specialists in palliative care. Whether such specialisation is important or essential is something that can only be debated in the context of national needs and resources.

## Frequently asked questions

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

Yes, the principles are the same.

- hospice means different things 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 better to adopt and use the term palliative care, a term understood by and used by health care professionals

### Should a Palliative Care service provide care for patients with chronic diseases?

No, although their care is important.

- patients with chronic conditions such as rheumatoid arthritis, degenerative diseases, diabetes mellitus and similar conditions usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients with chronic diseases**

### Should a Palliative Care service provide care for patients with incurable diseases?

No, although their care is important.

- as with patients with chronic diseases, these patients usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients with incurable diseases**

### Should a Palliative Care service provide care for patients incapacitated by their not-life-threatening disease (eg stroke, post trauma disability)?

No, although their care is important.

- patients incapacitated by psychiatric illness, cerebrovascular accidents, trauma, dementia and the like deserve special care but they usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients incapacitated by their disease**

**Should a Palliative Care service provide care for the elderly?**

No, although their care is important.

- many patients needing palliative care are elderly but they need palliative care because of the underlying disease from which they are suffering, not because of their age
- nevertheless, **many of the principles of palliative care are appropriate to the management of the elderly** /geriatric medicine

**Is Palliative Care just Terminal Care / Care of the Dying?**

No.

- the provision of high quality care during the final days and hours of life is an important part of palliative care
- palliative care should be initiated when the patient becomes symptomatic of their active, progressive, far-advanced disease 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 terminal phase.

**Should Palliative Care stay separate from mainstream medicine?**

No.

- palliative care originated because of the belief that terminally ill patients were not receiving optimal care and there was for a long time mutual distrust between the practitioners of palliative care and orthodox medicine
- modern palliative care should be integrated into mainstream medicine
- it provides active and holistic care that is complementary to the active treatment of the underlying disease
- 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
- modern palliative care is more integrated with other health care systems and calls for highly trained doctors and nurses, competent in a range of medical disciplines including internal medicine, pharmacology, communications skills, oncology and psychotherapy

**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 that more care and support are needed by relatives.
- depression and psychosocial problems are frequent in patients making requests and both can respond to appropriate care

- unrelieved or intolerable physical or psychosocial suffering should be infrequent if patients have access to modern inter-professional palliative care
- terminally ill 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 modern palliative care.). Their training has embraced all aspects of suffering – physical, psychosocial and spiritual –but their certification is in palliative medicine, not chronic pain management.

### **The need for Palliative Care:**

- fifty-two million people die each year
- it is estimated that tens of millions of people die with unrelieved suffering
- about five million people die of cancer each year, to which can be added the numbers of patients dying with AIDS and other diseases who might benefit from palliative care
- that many people die with unnecessary or untreated suffering has been well documented in many studies and published in hundreds of scientific papers and reports
- in developed and developing countries alike, people are living and dying
  - in unnecessary, unrelieved pain
  - with uncontrolled but controllable physical symptoms
  - with unresolved psychosocial and spiritual problems
  - in fear and loneliness, often feeling unwanted burdens.
- this is the suffering that could be helped or prevented with palliative care
- the World Health Organisation (1990) and the Barcelona (1996) declarations both called for palliative care to be included in every country's health services
- **the relief of suffering is an ethical imperative**
  - every patient with an active, progressive, far-advanced illness has a right to palliative care
  - every doctor and nurse has a responsibility to employ the principles of palliative care in the care of these patients
  - every patient has the right to die in a place of their choice

### **The Goals of Palliative Care**

For patients with active, progressive, far-advanced disease, the goals of palliative care are:

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

### **Palliative Care and Suffering: Inter professional Care**

**Suffering** may be defined as the distress associated with events that threaten the intactness or wholeness of the person. 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, in order to provide comprehensive palliation and relief of suffering:

- Pain

- Other physical symptoms
- Psychological
- Social
- Cultural
- Spiritual

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 has to 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

**A multidisciplinary/team approach to assessment and treatment is mandatory**

- 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.

## **Multidisciplinary and Inter professional Teams**

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.

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 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, Day



Unit, 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

More on staffing can be found in ***Getting Started*** (on this IAHP website)

## Principles of Palliative Care

- **Palliative care incorporates the whole spectrum of care — medical, nursing, psychological, social, cultural and spiritual. A holistic approach, incorporating these wider aspects of care, is good medical practice and in palliative care it is essential.**
- The principles of palliative care might simply be regarded as those of good clinical practice, whatever the patient's illness, wherever the patient is under care, whatever his / her social status, creed, culture or education.

### Attitudes and principles required for successful palliative care

#### A caring attitude

- involves sensitivity, empathy and compassion, and demonstrates concern for the individual
- there is concern for all aspects of a patient's suffering, not just the medical, nursing or social work problems
- there is 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 taken into account when planning the palliative care for individual patients

#### 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
- the majority of 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, therapy that is inappropriate 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

## 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.

## 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)

### 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

### 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**

### 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

see Advance Care Planning

### Communication with Patients

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 take into account 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 take into account 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 (i.e. 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 for geographic reasons
- **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 at the moment. 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?)
- use trained interpreters. (Strictly what you need is a translator, not someone who interprets what is being said and as a consequence 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 than 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

- Issues related to the appropriateness of artificial hydration and nutrition, antibiotics and other medications are dealt with in the section on Ethical Issues
- 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,**

### 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 a **number of 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.

### Models of Care

- 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

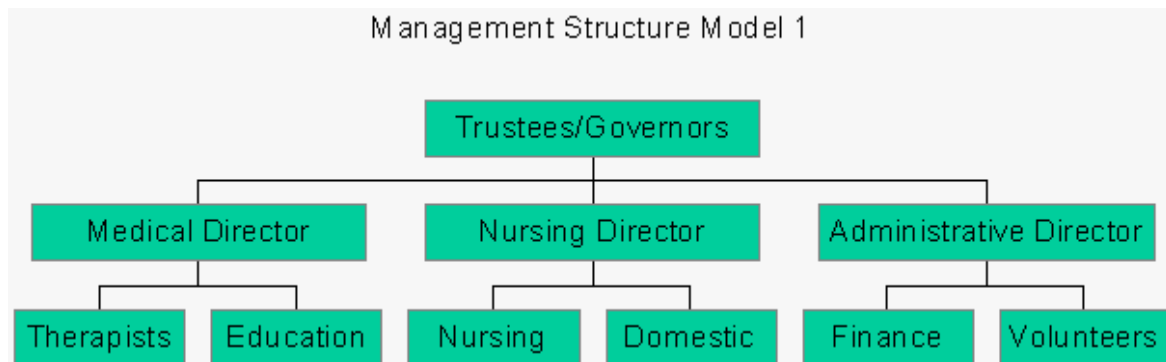
**IAHPC believes that each developing country should be encouraged and enabled to develop its own model of palliative care, appropriate to the needs of the local patients and the available resources, taking advantage of the experience and expertise accumulated in developed countries, and not be expected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

## Management of the New Hospice/Palliative Care 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.

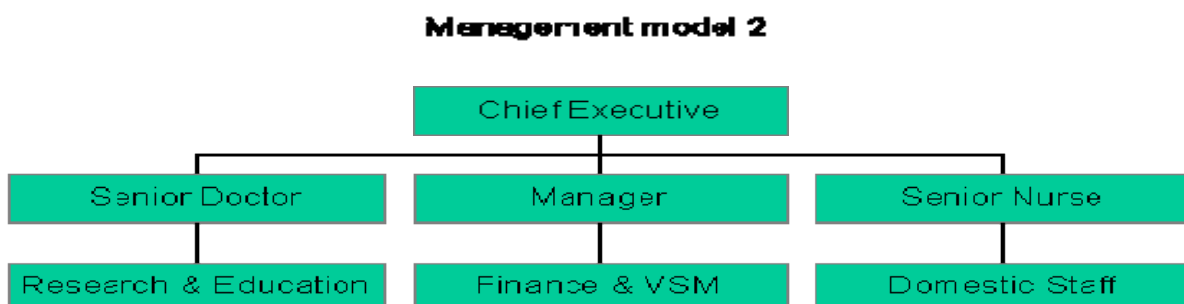
If the service is 'free-standing' or 'independent' then it is important to choose the most appropriate and efficient management structure. Basically there are 3 models

### Model 1



It is assumed that, whatever the management model, there is a Board of Governors / Trustees with overall legal responsibility for the running of the service. Under them and answering to them is a triumvirate of Medical Director (responsible for medical matters, education, research), a Nursing Director (responsible for nurses, domestic matters) and an Administrative Director (responsible for administration, finance, public relations). In this model management decisions are shared equally without one person having to bear too heavy a responsibility. The model breaks down if relations are poor between the directors or one dominates.

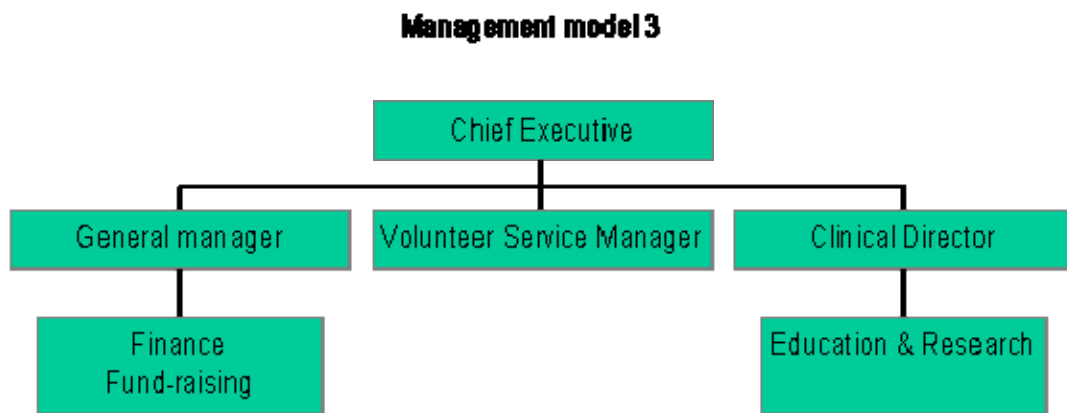
### Model 2



In this model there is a single Chief Executive Officer (CEO) / General Manager in overall charge of the unit and directly accountable and answerable to the Board of Governors / Trustees... Beneath him / her and answerable to the CEO are the Senior Doctor and Senior Nurse and, sometimes a third manager for Finance (and fund-raising). This is an effective model when the CEO is both an experienced and capable manager and knowledgeable about palliative and health care services generally. It can, however, leave medical, nursing and other staff feeling that their work and needs are not understood and that they are powerless to influence decisions. It places almost total power in the hands of one person.



### Model 3



This 3<sup>rd</sup> model is very different from the others. The person with control over all aspects of the service is the Chief Executive Officer, someone with management and administrative training and skills; from any background – medical, nursing, social work, management, commerce, law etc.

All clinicians are represented by a Clinical Director (usually alternating every two year between a nurse and a senior doctor) also responsible for research and education. Also reporting directly to the CEO is a general manager overseeing finance, fund-raising, and all non-clinical aspects of the unit.

The success of this model - whether it succeeds or fails – rests with the personality, the interpersonal skills and the management skills of the CEO. It can reduce the time that senior clinicians spend on committees but with only one clinical director there can be less-than-optimal communication and cooperation between the health professions and resentment that clinical matters were not brought directly to the CEO from the clinical discipline concerned.

### The Board of Trustees / Governors

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 general 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 and the nursing, medical and administrative directors.

### Professional Advisory Committee and its subcommittees

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.

### **Staff Handbook (see also chapter on Orientation and Training)**

By law every member of staff must be given a legally binding contract. This will be drawn up by the trustees and their representatives with the guidance of a legal / human resources adviser.

In addition it is useful for every member of staff, no matter how small the staff, to be provided with a 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, 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.

### **Staff Support**

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.

### **Are special stress management sessions usually needed?**

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.

## **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 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 very 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.

## A Hospital Palliative Care Unit (HPCU)

This refers to a **bedded unit within a hospital** – whether general or specialist, secondary or tertiary. It differs from a Hospital Palliative Care Team (HPCT) in having beds whereas the HPCT is entirely advisory. 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.

### The benefits 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
- 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.

### The downside 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
- It will sometimes be asked by sceptics if having a HPCU will not deskill junior medical and nursing staff who would learn palliative care better in the original unit rather than in a small specialist unit. There is some evidence that this can happen. It places a heavy responsibility on the staff of the HPCU to demonstrate what they do and how they do it to all who want to visit the unit. 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.

### 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 / is not 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.
- 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 very 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 be prepared 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.

### **Professional stress in a HPCU**

The stress experienced by those working in a HPCU 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 in the HPCU.

Staff may be more than usually anxious about what standard of care patients will receive when they leave the HPCU. Nurses in particular may resent the fast through-put of patients in the HPCU, feeling that a longer spell there would have been good for them.

## Hospital Palliative Care Team (HPCT)

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 PCU – is discussed in a separate section of *Getting Started*
- 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 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.

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

1. consultation service – Hospital Palliative Care Team
2. palliative care unit (tertiary or acute) (See separate section in *Getting Started*)
3. combination of i) and ii)

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.

### Consultation Service - Hospital Palliative Care Team (HPCT)

A 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.

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). 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 visa versa.

**Advantages of a Consultation Team (HPCT) over a dedicated Hospital Palliative Care Unit (HPCU) include:**

- 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 Consultative Service (HPCT) include:**

- 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.

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 is 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 there concerns re: increased workload, overtime budget etc.

**Staffing of a HPCT**

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

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

- Unfamiliar with opioids a ward doctor discontinues them when the patient vomits. It is a day or two later before the HPCT learns of this.
- Trained to fear opioids because of 'addiction', 'tolerance', 'narcosis' 'the consultant / specialist forbids their use in his unit '
- Nurses are unhappy when the HPCT 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 properly 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 physician 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 HPCT 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.

**The skills required in a HPCT**

The success of a palliative team depends on its members. They have to be salespersons, 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

**Doctor and nurse working alone or as a 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 HPCTs, 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. He/she will be isolated, lonely, have to 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.

**Doctor(s):** How many, as explained elsewhere in Getting Started, depends on whether or not 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 however very useful

**Therapists:** They are not needed on the team if they can be accessed from their departments in the hospital.

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

### **Documentation (see separate section in *Getting Started*)**

Documentation and statistics gathering is easier to establish at the outset of a programme. Data is useful for research, audit and justification. Drug records and administration charts must comply with hospital practice and legal requirements)

#### **Essential startup documentation:**

- job descriptions for every member of staff – whole-time or 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 Communications section in *Getting Started*)
- specimen reports and recommendations letters

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**

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.

### **Before the launch of the new Consultation 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

In summary, a HPCT is worth considering when there are not the resources to start and operate a bedded unit. However, It has to 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 then than now. However it was worth it.

## The '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 general public (except in French speaking countries) still seem to prefer the term 'hospice' whilst health care professionals understandably prefer 'palliative care unit'.

What makes any palliative care unit or hospice different from a hospital is not its size (although most are small units with 20- 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. Annual mortality statistics are the starting point:

- What is the total number of people who died in that community?
- What is the main cause of death
- Where do people die? Own home, care home, home of relatives, hospital?
- Where do they say they want to die? (Almost all will say 'home')
- What is the trajectory of death? (Slow decline, alternating highs and lows etc.)

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 'terminal 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 in order 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.

### **Will the unit engage in professional education and training?**

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 or not any palliative care service should ever be started if there are not plans to engage in education and training.

### **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 palliative care services 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.

### **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 drugs 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?

### **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 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!**

Go on the Internet and look for palliative care sites and official documents regarding palliative care like Rec (24) 2003 of the European Council. 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 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.
- Will they all patients be in the terminal stages of illness 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). p.4

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 terminal illnesses (end-stage dementia, AIDS, vCJD, terminal 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 has to 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.

### **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:

- With malignant disease .....400-700 per 1,000,000 population
- With non-malignant disease.....200-700 per 1,000,000 population
- Deaths of those with neurological diseases .....17/100,000 population
- Deaths of those with psycho-geriatric disease.....4/100,000 population
- Deaths of those with chronic cardiac / respiratory disease..... 500/100,000 population

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.

### **Will there be an educational programme?** (See separate section for fuller discussion)

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

### **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 (ie trained) nurses, the others nursing auxiliaries who have 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 doctors 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.

Junior doctors who rotate through the unit for experience should not be regarded as service providers because they require so much of the senior physician's time in supervising and teaching. 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.*

### **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.

Very useful but not strictly essential are clinical pharmacists, clinical psychologists, dentists and podiatrists. Often they offer their voluntary services for new hours a week. (See "Volunteers")

### **Pastoral care staff**

It is axiomatic that a hospice/palliative care service and its team pay due and equal attention to the spiritual needs of the patients as to their physical and psycho-social needs. This generally means that a priest, clergyman or someone trained in pastoral care should be on staff, or be readily available. Larger units (of > 25 beds) need a *full time* pastoral care worker if possible. Others may use local clergy. It must be remembered that this "chaplain" will also support staff and volunteers, contribute to and organize educational courses, and conduct many funerals. In increasingly multi-faith societies it is necessary to have access to Rabbis, Imams, Hindu teachers etc.

## **Volunteers (see separate section)**

### **Administration and Management**

From the earliest planning days three important groups of people are needed

**A planning group** composed of mature people familiar with (though not necessarily expert in) hospice/palliative care, able to contribute experience and skills in management, building, law, health care administration, medicine, nursing and spiritual care. Once the unit is operational this group may stand down.

**A trustee group** who will be legally responsible for the affairs and operation of the unit, advised by the planning group and

**A professional advisory committee**, non-executive but immensely important and influential group, reporting directly to the 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.

### **Appointment of senior staff**

Provided there is a Professional Advisory Committee and the 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.

### **Financial matters** (for the building and for the day-to-day running of the unit)

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 very 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.

### **Disadvantages of a free-standing unit**

- Cost, usually 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 terminally ill are cared for.

### **Recommended reading**

Gomes B, Higginson IJ 1(2008) Where people die (1974-2030) Past trends, future projections and implications for care. Palliative Medicine 22(1)pp 33-41.

## Hospice / Palliative Day Care Unit

What is meant by Day Care (sometimes termed Day Hospice or Palliative Care Day Unit)?

It 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

### What benefits can Day Care offer?

The patient is enabled to remain at home as long as possible (which is what most say they want) and by attending the Day 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. 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. Again there is anecdotal evidence that patients feel more positive, more able to cope, less depressed when they attend a Day Unit.

### How does a Day 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 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 Unit?

- A hall / room about the size of a large lounge or tennis court with a ramp and doors wide enough for wheel chair entry
- Work tables 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 very 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 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. (again depending on how many patients there are, what their needs are, how much time needs to be spent with each etc)

The volunteers need very careful selection and comprehensive training (see below). 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 is their own background.

### **What "creative activities" are offered in a Day Unit?**

The answer depends on whether or not 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 'divert ional' – 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 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 is not terminal coming to the Unit for years. This helps neither that patient nor the other patients.

Care has to 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 terminally ill person can also be extremely distressing to older patients. Ways have to 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. In spite of 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 has to 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             | OT 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                   |

## Community Palliative Care Services (CPS)

This section will look at services caring for terminally ill patients in their own homes or the home of relatives, or care homes for the frail or aged – patients **not** in a hospital or in-patient palliative care unit.

Strong evidence from many countries suggests that except where houses are too small for anyone with a mortal illness to be cared for there, almost everyone says that when they come to the end of their lives they want to remain at home as long as 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 / 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 modern palliative care, or cannot readily access and prescribe opioids, then terminal 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 terminally ill 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 Community Palliative Care Service

There are three models in common use and many modifications of each

#### 1. Advisory 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
- 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.

## 2 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 nursing a terminally ill 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.**

## 3 Comprehensive Community 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 terminally ill patient in his home. – 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 a service is thought to enable more to die at home if that is what they wish.

The disadvantages are many:

- the very 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.**

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 terminally 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 or not 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

### **Equipment useful (but not always essential) for community palliative care**

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.

### **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 or not a patient can stay at home and receive excellent palliative care there depends as much on the relatives as on all the professionals involved.**

**Recommended reading:** Papers by Higginson and Gomes on issues related to palliative care in the community, patients' wishes and modern trends.

## Pre-Service Orientation and Training

**All staff without previous experience in modern palliative care, about to start work in a new hospice / specialist palliative care unit will need orientation and training in two subjects:**

- Modern palliative care- principles and practice
- The new unit – how it will operate

### Modern palliative care – its principles and practice

- The principles of holistic care of the terminally ill
- Setting goals – discussing realistic goals, how to achieve, how to record.
- Team caring, clarifying and blurring of traditional roles, mutual respect and support
- The general principles of symptom diagnosis and relief
- Pain control – diagnosis, assessment, analgesic ladder, modern analgesics, routes of administration, dispelling opioid myths and misunderstandings
- All other common symptoms encountered in end stage malignant and non-malignant conditions
- The place of intravenous infusions, parental feeding, blood transfusion and invasive investigations in palliative care
- 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.
- Staff stress and “burn out”
- Ethical issues – confidentiality, resource allocation, euthanasia and PAS, research, patient’s competence, “right to die”, power of attorney.
- Emergencies encountered in palliative care and how they area dealt with.

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.

### 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 on a daily basis. 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 / PCU 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 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.

## Professional Education and Training

This section will deal with:

1. Training of staff and volunteers
2. Education of health care students and professionals

### 1. Pre-service training of staff

No matter how well 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 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, past 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 with regard to DNR orders, CPR, euthanasia and PAS
- Issues related to visitors, counselling and giving information
- Discharge planning and policy
- Drug 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 and methodology, 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)

## **2. 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 doctors 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.

### **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! (see later). 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.*]

#### **Will there be bedside instruction?**

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.

#### **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
- The ability to darken the rooms for films, slides, etc.
- A slide / PowerPoint projector
- An overhead 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 DVD / video cassette recorder and player
- A laptop computer

Useful but not essential is a heated food trolley for serving meals.

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 doctors, senior nurses, therapists, pastoral care staff and social worker a very 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 (*For example 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 (*For example 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, Help the Hospices and the IAHP. 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 very 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
- Assuming that 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 it a useful thing to have junior medical and nursing staff (and even experienced family physicians) working in the hospice / palliative care service to gain valuable experience?**

This question can be left until the service is up and running. The experience can be a very valuable one for them, and their contribution to the service a useful one **but** they must be supervised, taught, have time to ask questions and to study, and statutory time off. That can add greatly to the work load of the senior professional staff.

**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.



## 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 use 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. However, it must be emphasised, most of the moral principles underlying "employment laws" laws apply to volunteers (eg good working practices and conditions, fairness, equal opportunities, no racial or sexual discrimination etc). In practice this simply means that volunteers must NOT be termed employees in any documents, particularly legal ones.

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 they 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 use volunteers it is prudent to ascertain what other units / services do, what laws relate to the use / 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, last but not least, insurance.

As a general rule 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 –VSM**

This post is the key one if a unit intends to use 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( eg 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 or not 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 cannot work with those of a different social 'class' or ethnic group
- 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
- those who cannot respect confidentiality
- those who have had a major loss in the preceding 12 months and are still working through their grief

*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 (eg. bringing patients to and from) to be given an nationally-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 using 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 in spite of 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 out 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 very 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

### **The advantages of having volunteers**

They probably do not reduce the running expenses of a unit because, in most cases, they are not taking the place of salaried staff.

- 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

### **"Professional" volunteers**

This term describes the nurses, doctors, 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 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

## **Communicating with Patients, Public, Professionals, Press and Politicians**

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.

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.

It is not only patients and relatives with whom palliative care workers must communicate. They must be skilled in explaining to the general 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.

Such skills should be amongst the attributes to be looked for at 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. 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 remain at the centre of attention at all times, 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 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 / 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. Last but not least, 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 and co-operation with the media can be facilitated in the following ways:**

- Appoint an appropriately qualified and experienced senior member of staff or volunteer to be the “press officer”, to answer questions, make arrangements 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.

**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 or not any charges are made, how referrals are made, how it is staffed and where further more 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

**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 or not 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 interest 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-party-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 very 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 such as euthanasia, PAS, and patient autonomy. 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 / 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.

### **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 - Doctor correspondence / direct communication**

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 Communications**

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,



## **Doctor / nurse to relatives**

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

## **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.

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 pastoral care, social workers and non-uniformed members of staff.
- Volunteers, some of the roles they play, how they can be identified
- How visitors can help in care eg bathing, feeding, reading to the patient
- Rules relating to food and drink brought in to 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 General 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

### **Auditing Communications**

Every means possible must be used to check whether or not 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)

## Documentation: Patient's clinical records and other essential documents

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 drugs 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

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: again **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.**

### **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 [See appendix at the end of this section]

### **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 taken into account 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 making arrangements 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.

**Do NOT try to design your own forms or soft wear programme. Contact your national palliative care association OR the IAHPC OR the National Hospice Organisation in Washington OR Hospice Information, London for sample documentation, and details of other sources of help and suppliers of soft wear, tried and tested in palliative care services.**

## Appendix

### Minimum Data Sets - Software Suppliers (UK)

The following companies are known to supply patient administration software relevant to hospice and specialist palliative care services in the UK. Mention in this list in no way implies any recommendation on the part of the National Council. Enquirers are recommended to ask for a list of palliative care services which are using the software and to contact such services for their opinions on suitability etc.

Software Medical Informatics Ltd  
4 Edison Village  
Nottingham Science Park  
University Boulevard  
Nottingham  
NG7 2RF  
UK  
Tel : 0845 370 7879  
Email : [support@smicare.net](mailto:support@smicare.net)  
System: Pal.Care

Kirstin Lodge  
iSOFT  
Daventry Road  
Banbury OX16 3JT  
UK  
T: 0870 050 8901/01295 274200  
F: 01295 275131  
Email: [kirstin.lodge@isoftplc.com](mailto:kirstin.lodge@isoftplc.com)  
System: OPMAS-P by Isoft (previously marketed as HCAS by Eider computers)

Healthy Software Limited  
Merlin House, Stainer Way, Wyvern  
Business Park,  
Derby DE21 6BF  
UK  
Tel: 01332 680 022  
Email: [rob.england@healthysoftware.co.uk](mailto:rob.england@healthysoftware.co.uk)  
System: Crosscare

Chameleon Information Management  
Services Ltd.  
59-61 High Street  
Rickmansworth WD3 1 RH  
UK  
Tel: 01923 896939  
Direct Line: 01923 890707  
Fax: 01923 896526  
<http://www.infoflex-cims.co.uk>  
Email [DDickens@infoflex-cims.co.uk](mailto:DDickens@infoflex-cims.co.uk)  
System: InfoFlex Palliative Care System.

Capstone Systems Ltd  
Oak Mead  
Malting Row, Honington  
Bury St Edmunds IP31 1RE  
UK  
Tel: 01359 268711  
Email: [dcg@capstonesystems.co.uk](mailto:dcg@capstonesystems.co.uk)  
System: ReadyRiter

The Phoenix Partnership  
Mill House, Troy Road  
Horsforth  
Leeds LS18 5TN  
UK  
Tel: 0113 20 50083  
Email: [cairen.ball@tpp-uk.com](mailto:cairen.ball@tpp-uk.com)  
System: SystemOne Palliative Care

If you have any queries or comments relating to this list please contact:

Ann Eve  
Minimum Data Sets Data Project Manager  
National Council for Palliative Care  
UK  
Tel 020 7697 1520 / Direct line: 01883 344458  
Email [mds@ncpc.org.uk](mailto:mds@ncpc.org.uk)  
Updated Nov 2008

## 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? 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 is to be done with them when the patient dies?
- What arrangements have been made for records of patients admitted from their homes?
- What about x-rays? Will they be sent to / lent to the palliative care unit or sent electronically as images?

### 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 or not 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?

- 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 very 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 very 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 is the appetite of people with advanced disease 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 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

- 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 carers.
- 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
  - a press pack is produced and given to all attendees. Brevity is of the essence!
  - 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 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 Drug Squad checking the security of the Pharmacy / Drug 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.



## 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](http://www.apca.co.ug)
- Asia Pacific Hospice and Palliative Care Network (APHN)  
[www.aphn.org](http://www.aphn.org)
- Canadian Hospice and Palliative Care Association - Norms and Standards of Practice  
<http://www.chpca.net/initiatives/norms-general.htm>
- Center to Advance Palliative Care (CAPC)  
<http://www.capc.org/>
- European Association for Palliative Care (EAPC)  
[www.eapcnet.org](http://www.eapcnet.org)  
[eapc@istitutotumori.it](mailto:eapc@istitutotumori.it)
- Hospice Information  
[www.hospiceinformation.info](http://www.hospiceinformation.info)  
[info@hospiceinformation.info](mailto:info@hospiceinformation.info)
- International Association for Hospice and Palliative Care (IAHPC)  
[www.hospicecare.com](http://www.hospicecare.com)  
[info@iahpc.com](mailto:info@iahpc.com)
- International Observatory on End of Life Care  
[www.eolc-observatory.net](http://www.eolc-observatory.net)  
[info@eolc-observatory](mailto:info@eolc-observatory)
- Latin American Association for Palliative Care (ALCP)  
[www.cuidadospaliativos.org](http://www.cuidadospaliativos.org)  
[info.administracion.alcp@gmail.com](mailto:info.administracion.alcp@gmail.com)
- Macmillan Cancer Relief  
[www.macmillan.org.uk](http://www.macmillan.org.uk)  
[cancerline@macmillan.org.uk](mailto:cancerline@macmillan.org.uk)
- National Council for Palliative Care of England, Wales and Northern Ireland  
[www.ncpc.org.uk](http://www.ncpc.org.uk)  
[enquiries@ncpc.org.uk](mailto:enquiries@ncpc.org.uk)
- National Hospice and Palliative Care Organisation (NHPCO) (USA)  
[www.nhpco.org](http://www.nhpco.org)  
[info@nhpco.org](mailto:info@nhpco.org)
- UK forum for hospice and palliative care worldwide (an arm of Help the Hospices)  
[information@helpthehospices.org.uk](mailto:information@helpthehospices.org.uk)

## Recommended Reading

Those “getting started” are reminded that the IAHPIC has its own regularly updated list of recommended books on almost every aspect of Hospice and Palliative Care, most available from Amazon. Each has been reviewed by experienced and eminent members of the IAHPIC 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 F J. (2000) [\*Nursing Practice: Hospice and Home - The Adult\*](#). 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)

Booth S, Bruera E, Oliver D. (2004) [\*Palliative Care Consultations in Primary and Metastatic Brain Tumours\*](#). Oxford University Press, Oxford.

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

Bruera E, Higginson I, Ripamonti C and Von-Gunten C. (2006) *Palliative Medicine*. Arnold Publishers, UK.

Bruera E, De Lima L, Wenk R, Farr W. (2004) [\*Palliative Care in Developing Countries : Principles and Practice\*](#). IAHPIC Press.

Buckman R. (1988) [\*I don't know what to say - how to help and support someone who is dying\*](#). Macmillan, London.  
(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)

Dickman A, Schneider J, Varga J. (2005) [\*The Syringe Driver: Continuous Subcutaneous Infusions in Palliative Care\*](#). 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)

Doyle D, Hanks G W, Cherny, N, Calman KC. (2004) [\*The Oxford Textbook of Palliative Medicine\*](#). 3rd Edition. Oxford University Press, Oxford.  
(The definitive reference book on every aspect of palliative medicine. The 4<sup>th</sup> edition is due 2009).

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. A new edition will be published in 2009)

Ellershaw J, Wilkinson S. (2003) [\*Care of the Dying: A Pathway to Excellence\*](#). Oxford University Press, Oxford.  
(The best book on care pathways – the Liverpool Pathway)

Fallon M, Hanks GWC (2006) ABC of Palliative Care. Balliere Publishing.  
(A book for doctors and nurses as well as students)

Ferrell B, Coyle N. (2005) [Textbook of Palliative Nursing](#). Oxford University Press, Oxford.  
(Probably the best text for nurses specialising in palliative care)

Faull C, Carter Y, Woof R. (1998) [Handbook of Palliative Care](#). Blackwell Science, London.  
(A multi-professional book excellent for nurses as well as doctors)

Goldman, A. (1998) [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 Garner S. (2007) *Palliative Care Nursing: Improving End of Life Nursing*. Balliere Tindall.

Lugton J and McIntyre R. (2006) *Palliative Care – The Nursing Role*. Churchill Livingstone.

MacDonald N, Hagan N, Oneschuk D. (2005) [Palliative Medicine: a case-based manual](#). 2<sup>nd</sup> edition Oxford University Press, Oxford.  
(Ideal for teaching medical students and junior doctors)

Payne S, Seymour J, Ingleton C. (2008) *Palliative Care Nursing: Principles and Evidence for practice* (2ed) Maidenhead: Open University Press.

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).

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, Lucas C, Hoy A, Black I. (2005) [Oxford Handbook of Palliative Care](#) 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):

- 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](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 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/>

A comprehensive list of all the journals in, or related to the field of palliative care is available in the IAHPHC website in [http://www.hospicecare.com/journals\\_publications.htm](http://www.hospicecare.com/journals_publications.htm)