The IAHPC Manual of Palliative Care

3rd Edition

TABLE OF CONTENTS

I. Principles and Practice of Palliative Care

DEFINITIONS
FAQS
THE NEED FOR PALLIATIVE CARE
THE GOALS OF PALLIATIVE CARE
PALLIATIVE CARE AND SUFFERING: INTERPROFESSIONAL CARE
MULTIDISCIPLINARY and INTERPROFESSIONAL TEAMS
PRINCIPLES OF PALLIATIVE CARE
COMMUNICATION WITH PATIENTS
ADVANCE CARE PLANNING
MODELS OF CARE
INTEGRATION OF PALLIATIVE CARE INTO CLINICAL CARE
BARRIERS TO PALLIATIVE CARE

II. Ethical Issues in Palliative Care

PRINCIPLES OF MEDICAL ETHICS
COMMUNICATION AND DISCLOSURE
WITHHOLDING AND WITHDRAWING TREATMENTS
ARTIFICIAL NUTRITION
ARTIFICIAL HYDRATION
EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE
ETHICS IN RESEARCH
JUSTICE AND RESOURCE ALLOCATION

III. Pain

INTRODUCTION
TYPES OF PAIN
CAUSES OF PAIN
FACTORS THAT MODIFY THE PERCEPTION OF PAIN
ASSESSMENT OF PAIN
GENERAL PRINCIPLES OF TREATMENT

PRINCIPLES OF USING ANALGESICS FOR CHRONIC PAIN
NON-OPIOID ANALGESICS
OPIOID ANALGESICS
    WEAK OPIOIDS
    STRONG OPIOIDS
ADJUVANT ANALGESICS
LOCAL ANAESTHETIC AND NERVE BLOCKS
PHYSICAL THERAPIES FOR PAIN
PSYCHOSOCIAL ASPECTS OF PAIN CONTROL
ANTICANCER THERAPY FOR PAIN

IV. Symptom Control

BREATHLESSNESS
COUGH
TERMINAL RESPIRATORY CONGESTION
NAUSEA AND VOMITING
ANTIEMETICS
BOWEL OBSTRUCTION
CONSTIPATION
LAXATIVES
ANOREXIA
WEIGHT LOSS
WEAKNESS AND FATIGUE
ACUTE CONFUSION AND DELIRIUM
TERMINAL RESTLESSNESS

V. Psychosocial

PSYCHOLOGICAL DISTRESS
DEPRESSION
ANXIETY
SPIRITUAL AND EXISTENTIAL DISTRESS
CARING FOR FAMILIES AND FRIENDS

VI. Organizational Aspects of Palliative Care

HOW TO START A PALLIATIVE CARE SERVICE
REGULATION AND ACCREDITATION IN PALLIATIVE CARE
EDUCATION AND TRAINING FOR SERVICE STAFF
EXTERNAL EDUCATION AND TRAINING
INFORMING PEOPLE ABOUT PALLIATIVE CARE
STRESS IN PALLIATIVE CARE

VII. Resources

JOURNALS
BOOKS
INTERNET

ABBREVIATIONS

The following abbreviations are used in the Manual

routes of administration

CSCI	continuous subcutaneous infusion
EP	epidural
IM	intramuscular
IT	intrathecal
IV	intravenous
PO	oral
PR	rectal
SC	subcutaneous
SL	sublingual
TD	transdermal
TM	transmucosal

time

sec	second
min	minute
h	hour
d	day
w	week
m	month

measures

μg	microgram
mg	milligram
g	gram
kg	kilogram
fl	fentilitre
μl	microlitre
ml	millilitre
dl	decilitre
l	litre

preparations

cap	capsule
inj	injection
mixt	mixture
supp	suppository
tab	tablet
IR	immediate release
SR	sustained release

frequency of administration

PRN (*pro re nata*)	as required
q (*quantum*)	frequency, e.g. q4h is every 4 hours

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

I. Principles and Practice of Palliative Care

DEFINITIONS
FAQs
THE NEED FOR PALLIATIVE CARE
THE GOALS OF PALLIATIVE CARE
PALLIATIVE CARE AND SUFFERING: INTERPROFESSIONAL CARE
MULTIDISCIPLINARY and INTERPROFESSIONAL TEAMS
PRINCIPLES OF PALLIATIVE CARE
COMMUNICATION WITH PATIENTS
ADVANCE CARE PLANNING
MODELS OF CARE
INTEGRATION OF PALLIATIVE CARE INTO CLINICAL CARE
BARRIERS TO PALLIATIVE CARE

DEFINITIONS

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 failure
    - 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 interprofessional 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 therapy for their underlying disease
- palliative care should **never be withheld until such time that all treatment alternatives 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 nor 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

http://www.who.int/cancer/palliative/definition/en/

FAQs

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

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 disease?

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**

Is Palliative Care just Terminal Care or 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**

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
- depression and psychosocial problems are frequent in patients making requests
- unrelieved or intolerable physical or psychosocial suffering should be infrequent if patients have access to modern interprofessional 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 of 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 unrelieved pain

    - with uncontrolled physical symptoms
    - with unresolved psychosocial and spiritual problems
    - in fear and loneliness
- this is the suffering that could be helped or prevented with palliative care
- the World Health Organization (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**

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 maximize the quality of life
- to provide psychosocial and spiritual care
- to support the family during the patient's illness and bereavement

PALLIATIVE CARE AND SUFFERING: INTERPROFESSIONAL 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 approach to care a necessity.

Suffering	**Care**
pain	treatment of pain
+ other physical symptoms	+ treatment of other physical symptoms
+ psychological problems	+ treatment of psychological problems
+ social difficulties	+ treatment of social difficulties
+ cultural issues	+ treatment of cultural issues
+ spiritual/existential concerns	+ treatment of spiritual/existential concerns
= Total Suffering	**= Multidisciplinary Palliative Care**

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 unrecognized or unresolved problems relating to one cause may cause or exacerbate other aspects of suffering

- unrelieved pain can cause or aggravate psychosocial problems
    - **these psychosocial components of suffering will not be treated successfully until the pain is relieved**
- pain may be aggravated by unrecognized or untreated psychosocial problems
    - **no amount of well prescribed analgesia will relieve the patient's pain until the psychosocial problems are addressed**
- **A multidisciplinary approach to assessment and treatment is mandatory**
    - failure to do this often results in unrelieved pain and unrelieved psychosocial suffering
    - no one individual can deal with the many problems encountered in palliative care and an integrated team is essential.

MULTIDISCIPLINARY and INTERPROFESSIONAL TEAMS

Successful palliative care requires attention to all aspects of a patient's suffering, which 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 **interprofessional 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
- **interprofessional** 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 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

Volunteers play an important role in many palliative care services

The ideal multidisciplinary team requires

- medical staff
- nursing staff
- social worker
- physiotherapist
- occupational therapist
- chaplain or pastoral care worker

Very useful, but not essential, are

- dietician
- psychologist (or liaison psychiatrist)
- clinical pharmacist
- music and art therapists
- volunteers
- other personnel, as required

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 medical practice

Principles of palliative care

- **Attitude to Care**
    - Caring attitude
    - Commitment
    - Consideration of individuality
    - Cultural considerations
    - Consent
    - Choice of site of care
- **Communication**
    - Communication amongst health care professionals
    - Communication with patients and families
- **The Care**
    - Clinical context: appropriate treatment
    - Comprehensive and multidisciplinary
    - Care excellence
    - Consistent
    - Co-ordinated
    - Continuity
    - Crisis prevention
    - Caregiver support
    - Continued reassessment
- **Advance Care Planning**

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 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

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

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
- good communication with patients and families is also essential

see Communication

Clinical context: Appropriate treatment

- **all palliative treatment should be appropriate to the stage of the patient's disease and the prognosis**
- over-enthusiastic therapy that is inappropriate and patient neglect are equally deplorable
- palliative care has been accused of the medicalization of death, and care must be taken to balance technical interventions with a humanistic orientation to dying patients
- 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 the patient’s expressed wishes
- 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

see Ethical issues

Comprehensive interprofessional 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

Coordinated care
- involves the effective organization of the work of the members of the interprofessional 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 used 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

Crisis prevention
- 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

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

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 individualized 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?

- 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** so the patient and 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 what you understand about your illness at the moment

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

Provide medical information, if necessary

- in a caring and sympathetic way, not abruptly or bluntly
- in a way they can understand
- clearly (avoid euphemisms and medical jargon)
- the medical situation
- 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)
- use trained interpreters

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, emphasize the positive aspects of symptomatic and supportive palliative care
- **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 achieve what is important to them
    - Recommend that family relationships and worldly affairs be attended to
    - Be prepared to answer questions about the process of dying. Remember, 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**

    - 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
    - If agreement is not reached, the intervention can be trialled 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
    - **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

Remember, death is the natural end to life and is not a failure of medicine

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

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 (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.

Models of Care

Palliative Care Services operate in one or more of the following ways, reflecting local practice and needs, but there is no "right" or "wrong" type of service.

In-patient beds

- an in-patient palliative care unit may be part of a hospital or an independent free-standing unit
  - a hospital unit may be either a special ward within the hospital or a separate unit built in the hospital grounds
  - a free-standing unit is physically separate from the hospital, but should still be able to access its staff and services
- patients may be admitted for
  - symptom management (physical or psychosocial)
  - terminal care
  - short duration rehabilitation/convalescence
  - to provide a period of respite for family carers
- in the UK, most units have few beds (6-30), an average length of stay of 2 weeks or less, and a discharge rate of 40-60%
  - these figures vary greatly around the world and depend on local needs and resources, and the relationship to other services

Community services

- there are various models for community based palliative care services
  - services providing specialist advice and support for the family doctors and community nurses managing the patients
  - services providing "hands-on" nursing and allied health services to patients at home, in co-operation with the patient's own doctor
  - comprehensive services providing medical, nursing and allied health care to patients and their families at home

Day Units

- known as Day Care, Day Hospice, Day Palliative Care Unit
- usually form part of a hospital or in-patient palliative care unit
- provide care, rehabilitation, support and respite during the day for people under care at home, who are still well enough to be transported to and from the Day Care Unit, often by volunteer transport

Hospital Palliative Care Teams

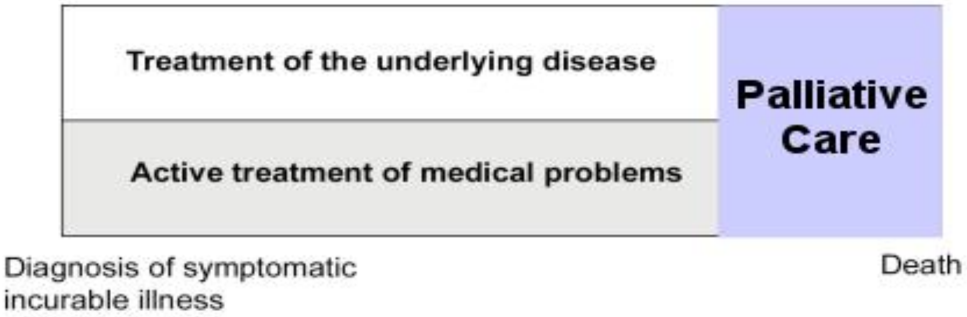
- operate in general and specialist hospitals
- are staffed by doctors and palliative care nurses
  - some also have a social worker or a pastoral care specialist
- provide consultative advice on patients referred to them in any department of the hospital
  - to advise on every aspect of palliation
  - provide support for family member
  - provide support and education for the staff
- facilitates the provision of high quality palliative care in all wards
  - where the patient is familiar with the staff and surroundings
  - without the need to be transferred to another unit
  - educates the ward staff about matters pertaining to palliative care

INTEGRATION OF PALLIATIVE CARE INTO CLINICAL CARE

Many health care workers believe that palliative care is the "soft option" adopted when "active" therapy stops

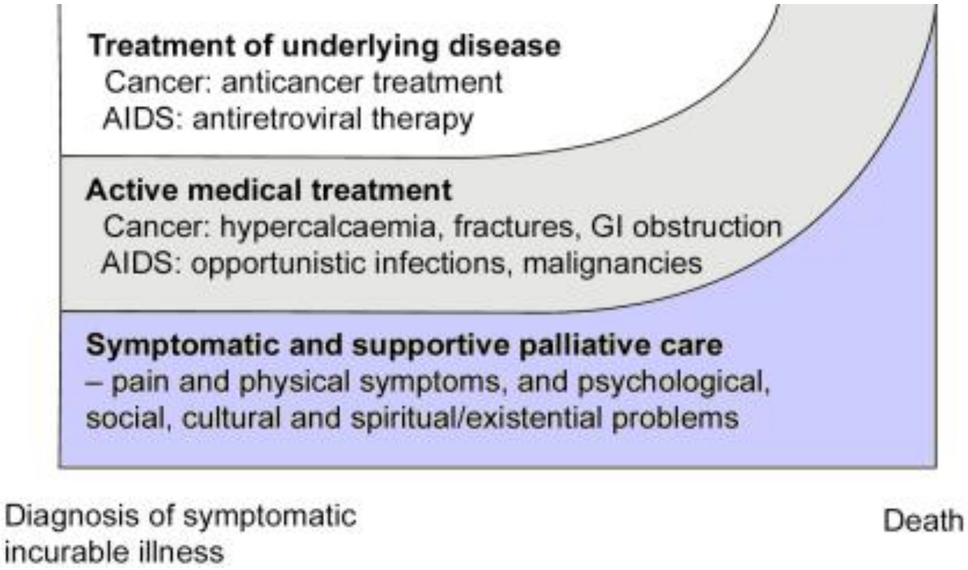
- **palliative care, addressing all the patient's physical and psychosocial problems, is active therapy**

Palliative care has in the past been regarded as the care employed when all avenues of treatment for the underlying disease are exhausted and further active medical treatment considered inappropriate.



Palliative care should be initiated when a patient becomes symptomatic of active, progressive, incurable disease

- it should *never* be withheld until such time as all modalities of treatment of the underlying disease have been exhausted
- it is active therapy that is **complementary** to active treatment of the underlying disease
- It should be **integrated in a seamless manner** with other aspects of care
- a **holistic approach** to care, encompassing all aspects of a patient's suffering and which is a prerequisite for successful palliative care, is often lacking in modern disease-orientated medicine.



[Diagrams reproduced with permission from Woodruff R. *Palliative Medicine*. 4th edition. Oxford University Press, 2004]

BARRIERS to PALLIATIVE CARE

Many patients with advanced disease do not receive palliative care and some are referred too late in the course of their disease to benefit from treatment. The reasons for this may relate to the physician, the patient, the family, or to societal factors.

Barriers related to the physician

- poor prognostication: does not recognise how advanced the patient's illness is
- may not recognise how much the patient is suffering
- lacks communication skills to address end-of-life issues
- believe they are already providing good palliative care and need no assistance
- misunderstands what a palliative care service does or has to offer
- does not want to hand over the patient's care: loss of control, loss of income
- opiophobia: worries the patient may become addicted to opioids or suffer severe side effects
- does not believe in palliative care
- does not know of the palliative care service

Barriers related to the relatives

- they may never have heard of palliative care or a local service
- they may not know whom to ask about it
- they may worry if they can afford it
- they may fear what relatives and neighbours will say about home care
- they may not want many professionals visiting the home
- there may be patient-family disagreement about treatment options
- they may feel unskilled and unable to care for their loved one at home
- they may want the patient to stay at home or the hospital ward they are currently in
- they may fear unexpected emergencies at home and not know if the palliative care service can cope with them
- they may fear it may mean telling the patient they are dying (which may have been previously resisted)
- they may think it is euthanasia by another name

Barriers related to the patient

- they may have unrealistic expectations about their disease and prognosis
- there may have been no advance care planning/discussions
- they may not have heard of hospice or palliative care
- they may suspect that it is dismal, gloomy and frightening with people dying all around you and everyone talking about death
- they may suspect that people die as a result of euthanasia
- they may worry about opioid addiction
- they may not want to leave home or the unit they are currently in

- they may not want to have to develop relationships with new professionals

Barriers related to society and culture

- ethnic minorities
- language barriers
- poor or underprivileged
- rural communities
- dying and death still remain, to a large extent, taboo subjects
- there is still a deeply held view that maintaining life—whatever its quality—is a prime responsibility of health care professionals and services.
- opiophobia

« Table of contents

« Table of contents

II. Ethical Issues in Palliative Care

PRINCIPLES OF MEDICAL ETHICS
COMMUNICATION AND DISCLOSURE
WITHHOLDING AND WITHDRAWING TREATMENTS
ARTIFICIAL NUTRITION
ARTIFICIAL HYDRATION
EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE
ETHICS IN RESEARCH
JUSTICE AND RESOURCE ALLOCATION

PRINCIPLES OF MEDICAL ETHICS

Ethics are the principles that should guide doctors and other health care professionals in their work and decision-making

- they are not laws but guiding principles; some things may be legal but are not ethical.
- they apply to all medical care but assume greater importance when caring for people at the end of life.
- unlike cultural issues that differ from country to country, the same ethical principles apply everywhere.

There are four main principles of medical ethics

Beneficence — is to produce benefit, to do good, to always act in the best interests of the patient

- whatever is done or said must be for the patient's good
- includes being honest with patients, which in nearly all circumstances will be of benefit to the patients
- patients should not be subjected to unnecessary investigations
- patients should not be subjected to unnecessary or futile therapies
- applies not only to physical good but also to psychological, social and existential well-being
- must be distinguished from paternalism ('doctor knows best')

Non-maleficence — is to minimise or do no harm

- whatever is done or said must not harm the patient, physically or psychologically

- includes being honest with patients; lying to patients or telling only part of the truth will very probably cause harm
- for every intervention, the potential benefits must be weighed against possible adverse effects
- treatments should not be prescribed unless there is a strong chance they will help the patient and only a small chance of unpleasant adverse effects. In palliative care, there is no place for the prescription of placebo.
- prescribing should aim to produce the minimum of adverse effects.

Autonomy — acknowledges patients' rights to self-determination, without prejudice

- treatments can only be given with patients' informed consent
- it is the patients' right to decide what treatments they do or do not wish to have
- patients have a right to be fully informed in order to make decisions.
- heath care professionals have an obligation to provide honest and complete information when it is requested. Opportunities must be given for them to ask questions and show that they understand what is being suggested to them
- applies not only to medical treatments but also to matters such as where they receive care, and who shall provide their care

Justice — refers to the equitable allocation of health care resources according to need

- not according to wealth, class, creed or colour
- unfortunately, observation of health care around the world shows much lack of justice
- many treatments are only available to the rich, or those with influence and power, or those articulate enough to ask for something better
- in some countries morphine is available only if the patient can afford it
- in some countries even palliative care has to be paid for and lack of money may mean dying in pain, possibly alone, without any dignity

In Clinical Practice

- situations arise where there is apparent conflict between different principles
- in assessing which principle is the more important
    - give priority to what is in the best interests of the individual patient
    - weigh the possible benefits against the potential adverse effects for each proposed therapy

COMMUNICATION AND DISCLOSURE

Patients have a right to an honest and full explanation of their situation

- patients should be told as much or as little as they want to know
    - patients have a right to decline information if they so wish. (There often comes a time in palliative care when a patient will say that they trust their professional carers and do not want more information or having to make difficult decisions).
- without information about the disease and prognosis, patients
    - cannot participate in their own treatment planning
    - cannot give informed consent to treatment
    - cannot make suitable plans for themselves and their families

Communication should be with the patient, unless

- the patient is not competent
- they have delegated the responsibility to a family member, something that should be confirmed or documented as a Power of Attorney.
- religious or cultural custom requires that the male head of the family is told

Communication about sensitive matters should be

- carried out in an understanding, sensitive and unhurried manner
- given in a way that can be understood
- performed honestly

see Communication with Patients

Telling patients nothing or lying to them is very likely to cause harm

- there is evidence from many different countries and cultures that terminally ill patients fear the unknown more than they fear the known and will suffer less, both physically and psychologically, when given the information they want
- even in countries where patients are traditionally not told the diagnosis and are thought not to know it, many patients have a good idea of the diagnosis and its prognosis even if they have not been explicitly informed about it
- will lead to loss of trust when the patient is informed of, or deduces the true situation

WITHHOLDING OR WITHDRAWING TREATMENTS

The goal of palliative care is to maintain the quality of life while neither

hastening nor postponing death

- death is the natural end of life
- there is no ethic, in any culture or religion, which say that a terminally ill patient must be kept alive by any means
- what matters is the quality of life left to the patient, not the time which is left to them
- palliative care must never become an exercise in prolonging life

Whether it is appropriate to offer or to withhold or withdraw a particular therapy depends on the balance between the possible benefits and the potential risks of the treatment, i.e. what is in the patient's best interests

- it will depend on individual clinical circumstances
- it is often difficult and complex
- futile therapy, with no chance of benefit ("You have to do *something*!"), can never be justified

<u>Example 1</u> Should a terminally patient receive antibiotics for chest infection?

- depends on many factors, including
    - the patient's nearness to death
    - the wishes of the patient and their family
    - the expected benefits from the patient's point of view
- if the antibiotics
    - will merely prolong the dying process, they are probably best withheld
    - will control distressing symptoms unresponsive to other measures, such as pyrexia or delirium, they may be of benefit

<u>Example 2</u> How should renal failure caused by ureteric obstruction due to advanced cancer be managed?

- if the patient was terminally ill because of cancer before renal failure supervened, active therapy is probably inappropriate
- if the patient was previously relatively well and has a reasonable life expectancy except for the effects of renal failure, consideration for stenting or nephrostomy insertion is appropriate

ARTIFICIAL NUTRITION

The question is whether or not a particular treatment or intervention will restore or enhance the quality of life for a particular patient

- if the answer is yes, and it can be justified on the best clinical grounds,

then it is ethically right to do it
- if not, it should not be done
- in developing countries, cost may be a major additional consideration
- **'You have to do *something!'* is never a justification for artificial nutrition**

Weight loss and wasting in advanced cancer

- is nearly always due to the **cachexia syndrome**
- is caused by changes to metabolism secondary to the cancer
- is never responsive to enteral or parenteral nutrition
  - i.e. they are futile
  - parenteral nutrition is also associated with
    - central venous catheterization
    - infections
    - expense
  - enteral nutrition is also associated with
    - abdominal cramps
    - diarrhoea
    - feeding tubes
- is occasionally due to **malnutrition and starvation**
  - patients with upper gastrointestinal obstruction, not terminally ill from their cancer warrant feeding by a nasogastric tube or gastrostomy
  - patients receiving therapy that will prevent them eating for 2 weeks or more warrant consideration for parenteral feeding
  - for patients with persistent or recurrent bowel obstruction, whether parenteral nutrition is warranted depends on individual clinical circumstances

ARTIFICIAL HYDRATION

The question is whether or not a particular treatment or intervention will restore or enhance the quality of life for a particular patient

- if the answer is yes, and it can be justified on the best clinical grounds, then it is ethically right to do it
- if not, it should not be done
- **'You have to do *something!'* is never a justification for artificial hydration**

Effects of dehydration in terminally ill patients

- dry mouth
  - but this can be well palliated topically

- thirst
    - although dying patients do not complain of thirst
- diminished conscious state
    - several reports and a single randomized controlled trial showed no correlation between hydration and cognition in these patients

Possible benefits of dehydration in terminally ill patients

- less urine output means less movement and less incontinence
- less pulmonary secretions reduce dyspnoea and terminal congestion
- less gastrointestinal secretions will lessen nausea and diarrhoea
- less problems with oedema and effusions

Possible disadvantages of artificial hydration in terminally ill patients

- may have the opposite effects to the benefits listed above and worsen the patient's situation
- may give an ambiguous signal or false hope to the patient or family
- drips act as a physical barrier between patient and family

Dehydration in patients not terminally ill

- causes thirst, dry mouth and postural hypotension
- patients unable to take or retain adequate fluids warrant parenteral hydration

EUTHANASIA AND PHYSICIAN ASSISTED SUICIDE

Euthanasia is a deliberate intervention undertaken with the express intention of ending a life so as to relieve intractable suffering

- if performed at the person's request or with their consent, it is voluntary
- otherwise it is non-voluntary

Physician-assisted suicide: the physician provides the knowledge and means necessary, but the act is completed by the patient

- from the physician's standpoint, it is a deliberate act with the express intention of ending life and should not be ethically distinguished from euthanasia

Palliative Care

- recognizes human suffering and seeks to relieve it

  - but it does not accept that euthanasia is ever the answer
- recognizes that a request for euthanasia is a plea for better care

Withholding or withdrawal of medical treatment

- terminally ill patients should not be subjected to futile therapies
- there is no requirement or justification to sustain life at all costs
  - a doctor has no right to prescribe a prolonged or lingering death
- withholding or withdrawal of futile treatment from the terminally ill does not shorten life or hasten death
  - it does not artificially prolong life
- **withholding or withdrawal of futile therapy from the terminally ill is not euthanasia**
  - the intention is to allow death to occur naturally, not to deliberately terminate life

'Double effects'

- medications given for the relief of distressing pain or symptoms may, on occasions, hasten the moment of death, the so-called 'double effect'
  - there is no evidence that good palliative medicine shortens life
  - effective symptom control is just as likely to extend as shorten life
  - studies indicate that the appropriate use of sedatives and opioids at the end of life is not associated with life-shortening
- **providing that appropriate drugs are given for appropriate medical reasons and in appropriate doses, this is not euthanasia**
  - the hastening of death may or may not be foreseen, but it is never intended

Palliative sedation

Palliative sedation is the use of sedating medications at the end of life to relieve refractory and intolerable symptoms (e.g. pain, dyspnoea, agitated delirium) after all other measures have failed.

- provided it is performed with the informed consent of the patient or surrogate decision-maker, employing appropriate drugs in appropriate doses and carefully titrated, it is ethically sound and is not euthanasia.
- the possibility of a 'double effect' exists, although studies of patients treated with palliative sedation in this manner do not demonstrate life-shortening.
- the practice of 'terminal sedation' (with the intention of keeping a patient unconscious until they die) and palliative sedation for 'existential distress', as reported from the Netherlands, probably constitute euthanasia.

Euthanasia may be requested or advocated for various reasons

- unrelieved pain and physical symptoms (or fear of)
    - which should occur infrequently given optimal multiprofessional palliative care
    - terminal sedation may be considered for patients with pain or other symptoms that are refractory to optimal palliative care; this does not constitute euthanasia
- severe anxiety and depression
    - which should be controlled given optimal multiprofessional palliative care
- intolerable suffering, existential distress
    - which should be controlled given optimal multiprofessional palliative care
- carer fatigue
    - is preventable
- autonomy and self determination
    - in modern society, the existence of a right to request and receive euthanasia is controversial—every 'right' is balanced by a responsibility
- iatrogenic - the 'nothing more can be done' syndrome
    - would not occur if patients were referred to a palliative care service
    - requires professional education

Uncontrolled suffering in the terminally ill should be considered a medical emergency and not an indication for euthanasia

Legalization of euthanasia is associated with risks

- voluntary euthanasia leads to non-voluntary euthanasia
    - reports from the Netherlands indicate that as many as a thousand patients a year are subjected to euthanasia without request, never mind consent
- euthanasia for the terminally ill leads to euthanasia for those not terminally ill
    - e.g. the Dutch reports of euthanasia for men with early AIDS and life expectancy measured in years
- euthanasia for the terminally ill leads to euthanasia for persons with potentially treatable conditions like depression
    - as documented in the Dutch and Australian reports
- the vulnerable will experience pressure to request euthanasia
    - the aged, the sick, the disabled and those who feel a burden
    - as reported from Holland

There is no place for euthanasia in a caring society that provides palliative care services

Further articles concerning euthanasia are to be found on the Ethics Page of the IAHPC website

ETHICS IN RESEARCH

Should terminally ill patients be recruited into clinical trials?

- Yes, if the trial objective is to improve the quality of life and
    - there is possible benefit
    - the potential for harm is low
    - the patient is fully informed of all that is involved
- No, if it is a phase 1 trial of an experimental anticancer agent or other intervention for which
    - the chance of benefit is very small
    - the potential for harm is significant

Informed consent for a clinical trial must include understanding of

- the purpose of the research
- any foreseeable risks
- any possible benefits
- any appropriate alternative procedures or treatments
- confidentiality of records
- participation being voluntary
- ability to withdraw at any time
- that continuing care is not dependent on participation in the trial

Palliative care patients are particularly vulnerable and susceptible to proposals to enrol in clinical trials

- they may be desperate for treatment options
- they may be physically ill and exhausted
- they may be depressed
- they may be cognitively impaired
- they may feel obliged to participate, to show their appreciation to the doctors caring for them

There is an ethical responsibility to protect palliative care patients from studies that are not in their best interests whilst preserving the informed patients' freedom of choice

- experience suggests that many terminally ill patients enjoy collaborating in ventures which might help others, feeling that they are still useful members of society

JUSTICE AND RESOURCE ALLOCATION

Justice

- refers to the equitable allocation of health care resources according to need
  - not according to wealth, class, creed or colour
- **all patients with active, progressive, far-advanced disease and a short life expectancy, for whom the focus of care is the relief and prevention of suffering and the quality of life, should have access to palliative care**

Resource Allocation

- some would argue that cure medicine should have priority because it aims to maintain life which may be economically and socially useful and productive
- others would argue that palliative care is more important because a society which is not concerned about its incurably ill is not a good society
- in many developing countries, the majority of patients are diagnosed with advanced stage disease and/or curative treatments are not available
- in some developing countries, expensive chemotherapy drugs and analgesic medications are available, but simple (and affordable) morphine mixture and injections are not

Palliative Care must be prepared

- to demonstrate the effectiveness of interventions on quality of life and symptom control and not just on patient satisfaction
- to show cost-effectiveness or at least cost parity with alternative forms of care
- to demonstrate not only the efficacy but also the efficiency of what it does

« Table of contents

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

III. Pain

INTRODUCTION
TYPES OF PAIN
CAUSES OF PAIN
FACTORS THAT MODIFY THE PERCEPTION OF PAIN
ASSESSMENT OF PAIN
GENERAL PRINCIPLES OF TREATMENT
PRINCIPLES OF USING ANALGESICS FOR CHRONIC PAIN
NON-OPIOID ANALGESICS
OPIOID ANALGESICS
    WEAK OPIOIDS
    STRONG OPIOIDS
ADJUVANT ANALGESICS
LOCAL ANAESTHETIC AND NERVE BLOCKS
PHYSICAL THERAPIES FOR PAIN
PSYCHOSOCIAL ASPECTS OF PAIN CONTROL
ANTICANCER THERAPY FOR PAIN

INTRODUCTION

Pain is one of the most common symptoms in palliative care. The aim of palliative care is to allow patients to be pain-free or for their pain to be sufficiently controlled that it does not interfere with their ability to function or detract from their quality of life. In palliative care, the treatment of pain needs to be part of a holistic and multidisciplinary approach to patient care.

- **Pain can cause or aggravate problems related to other causes of suffering and the pain has to be controlled before the other problems can be addressed and treated.**
    - It is not possible to have meaningful discussions about psychosocial concerns if a patient has uncontrolled pain.
- **Pain can be caused or aggravated by psychosocial concerns, which must be addressed before good pain control can be achieved.**
    - Where psychosocial or spiritual problems are causing or aggravating pain, no amount of well-prescribed analgesia will relieve the pain until the responsible psychosocial issues are identified and addressed.

Good pain control requires

- accurate and detailed assessment of each pain
- knowledge of the different types of pains
- a different therapeutic approach to chronic pain
- knowledge of which treatment modalities to use
- knowledge of the actions, adverse effects and pharmacology of analgesics
- assessment and treatment of other aspects of suffering that may aggravate pain
  - physical, psychological, social, cultural, spiritual
- fundamental to this is the availability of opioid analgesics

TYPES OF PAIN

Definitions

- **Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective.** (International Association for the Study of Pain).
- **Pain is what the patient says hurts.** It is what the patient describes and not what others think it ought to be.

Acute and chronic pain

Acute pain

- is usually due to a definable acute injury or illness
- it has a definite onset and its duration is limited and predictable
- it is accompanied by anxiety and clinical signs of sympathetic over-activity
- treatment is directed at the acute illness or injury causing pain, with or without the short term use of analgesics

Chronic pain

- results from a chronic pathological process
- it has a gradual or ill-defined onset, continues unabated and may become progressively more severe
- is said to exist if the pain persists longer than the expected healing time for the injury or illness in question
- the patient appears depressed and withdrawn
- there may be no sympathetic over-activity and patients are frequently labelled as "not looking like somebody in pain"
- requires treatment of the underlying disease where possible, regular use of analgesics to relieve pain and prevent recurrence, as well as

psychosocial supportive care

Incident pain

- occurs only in certain circumstances, such as after a particular movement or on standing
- should be regarded as chronic pain but, as it is intermittent, it is better managed with local measures where possible

Breakthrough pain

- is a transitory exacerbation of pain that occurs on a background of otherwise stable and controlled pain

Nociceptive, neuropathic and psychogenic pain

Nociceptive pain

- nociceptive or physiological pain is produced by stimulation of specific sensory receptors or nociceptors in the tissues
- the neural pathways involved are normal and intact
- somatic pain from the skin and superficial structures is usually well localized
- visceral pain is less well localized and there is often referred pain to cutaneous sites

Neuropathic pain

- is caused by peripheral or central nervous system injury
- pain occurs because the injured nerves react abnormally to stimuli or discharge spontaneously
- neuropathic pain is described as
  - a burning stinging feeling (dysaesthesia)
  - a shooting pain like an electric shock (lancinating)
  - an aching sensation often relieved by firmly squeezing or gripping the affected area
- is less responsive to non-opioid and opioid analgesics and may respond better to an adjuvant analgesic

Sympathetic pain

- is caused by damage to sympathetic nerves
- is characterized by burning pain and increased sensitivity
- there are signs of sympathetic dysfunction in the affected area
  - vasomotor instability (erythema, pallor, oedema)
  - sudomotor (sweating) abnormalities
  - trophic changes (thinning of the skin and atrophy of the subcutaneous tissue)

- is less sensitive to non-opioid and opioid analgesics
- often responds well to a regional sympathetic nerve block

Psychogenic pain

- is pain for which there is no physical basis in a patient who has other evidence of psychopathology
- in palliative care, patients are occasionally seen with psychosocial or existential distress in whom psychological factors and not the medical condition are judged to play the major role in the onset and maintenance of the pain, and for whom primarily psychological therapies may be appropriate
- however, all chronic physical pain is associated with some degree of psychological distress, for which the treatment should be primarily directed at the cause of the physical pain

Determination of the type of pain is an important part of assessment, as different types of pain may respond better to different treatments

see Principles of Treatment

CAUSES OF PAIN

In palliative care, there are many different possible causes of pain

Examples of the causes of pain in palliative care patients include pain

- due to the primary disease e.g.
    - tumour infiltration
    - nerve compression
- associated with treatment e.g.
    - diagnostic and staging procedures
    - surgery
- due to general debilitating disease e.g.
    - pressure sores
    - constipation
- unrelated to the primary disease or treatment e.g.
    - arthritis
    - ischemic heart disease

Determination of the cause of pain is an important part of assessment, as therapy directed at the cause may greatly improve pain control

see Assessment and Principles of Treatment

FACTORS THAT MODIFY THE PERCEPTION OF PAIN

Pain is always subjective and the perception of pain may be modified by problems or influences related to other physical or psychosocial causes of suffering
Pain caused by the disease or treatment is modified by these influences, making it either better or worse, resulting in the final clinical pain, which is what the patient says it is, and what has to be treated

The table lists examples of factors that might aggravate pain. Relief or successful management may have the opposite effect and improve pain.

pain	severe or progressive pain pain at multiple or an increasing number of sites pain that causes significant limitation at activity poor prior pain management
other symptoms	insomnia or fatigue persistent cough or vomiting other distressing symptoms
psychological	depression anxiety anger
social difficulties	problems with interpersonal relationships family problems financial and legal problems
cultural issues	culturally insensitive management language barriers
spiritual/existential	feelings of meaningless, guilt, regret unresolved religious questions

Interaction of Pain and the Other Causes of Suffering

Pain can cause or aggravate problems related to other causes of suffering—other physical symptoms, psychological problems, social difficulties, cultural issues, or spiritual/existential concerns

- in this situation, **pain has to be controlled before psychosocial problems can be addressed**
  - it is not possible to have meaningful discussions about psychosocial concerns if a patient has uncontrolled pain
- **alternatively, pain can be caused or aggravated by psychosocial concerns**
- in this situation, **the psychosocial concerns must be addressed before good pain control can be achieved**
  - where psychosocial or spiritual problems are causing or aggravating pain, no amount of well-prescribed analgesia will relieve the pain until the responsible psychosocial issues are identified and addressed

PAIN ASSESSMENT

Comprehensive clinical assessment is fundamental to successful treatment

- accept the patient's description
  - pain is always subjective and patients' pain is what they say it is and not what others think it ought to be
- thorough assessment of the pain
- patients should be asked to describe their pain, in their own words
  - their expression and any body language whilst describing their pain may provide useful information
- this information is supplemented by specific questions to define the exact nature of the pain
  - the site and radiation of the pain
  - the type of pain
  - the duration of the pain and whether it has changed
  - whether there are precipitating, aggravating or relieving factors
  - its impact on functional ability, mood and sleep
  - the effect of previous medications
- what the pain means to the patient
- physical examination, including neurological assessment, should be recorded both in writing and pictorially
- further investigations should be limited to those likely to have a significant bearing on treatment decisions
- assess each pain
  - many patients have more than one pain and each pain requires assessment
- evaluate the extent of the patient's disease
  - the underlying disease is the most frequent cause of pain, new or worsening pain requires the extent of the patient's disease be re-

evaluated

- assess other factors that may influence the pain
    - physical, psychological, social, cultural, spiritual/existential
- reassess
    - repeated reviews are necessary to both assess the effect of treatment and because the underlying disease is usually progressive

Pain measurement

Pain is a subjective phenomenon for which objective measurement is not possible.

- A variety of pain intensity scales have been developed to measure pain.
- The instruments in common use are unidimensional and consist of a visual analogue scale, a numerical rating scale, or a verbal descriptor scale:

Visual Analogue Scale

Mark on the line below how strong your pain is
No pain <______________________________> Worst possible pain

Numerical Rating Scale

On a scale of 0 to 10, how strong is your pain?
No pain = 0 1 2 3 4 5 6 7 8 9 10 = Worst possible pain

Verbal Descriptor Scale

Which word best describes your pain?
None   Mild   Moderate   Severe   Excruciating

- Note: they are used to compare one patient's pain at different times and are **not intended to compare one patient's pain with another's**.
    - can be used to follow the course of a patient's pain
    - can be used to assess the effect of treatment
    - may be seen by the patient as indicating concern about their pain

More complex multidimensional instruments are available

- e.g. the Brief Pain Inventory (BPI)
- includes affective and behavioural associations of pain and interference with function
- time consuming for both patients and staff and are best reserved for research projects

Pain in patients with **cognitive impairment or dementia** can be estimated using the Abbey Pain Scale (www.apsoc.org.au/PDF/Publications/). This is based on the score (0-3) given for six observations—vocalisation, facial expression, body language change, behavioural change, physiological change and physical changes.

GENERAL PRINCIPLES OF TREATMENT

Acute pain

- treatment of acute pain in palliative care is the same as for patients not requiring palliative care
- palliative care patients may recover more slowly and require analgesics for longer periods if their general condition is poor

Incident pain

- occurs only in certain circumstances, such as after a particular movement or on standing
- where possible, it should be treated with local measures
- analgesics may be used if the pain is mild and the side effects of constant administration tolerable
- if the pain is severe, modification of the patient's activity may be preferable to taking strong opioid analgesics on a regular basis for pain that occurs infrequently

Chronic pain

- the aim of treatment is the prompt relief of pain and prevention of its recurrence
- **the principles involved in the treatment of chronic pain are**
    - thorough assessment
    - good communication reassurance about pain relief
    - discourage acceptance of pain
    - encourage patient participation
- **the treatment of chronic pain in palliative care is**
    - an integrated part of the interdisciplinary plan of total care
        - including management of psychosocial issues
    - should be appropriate to the stage of the patient's disease
        - treatment for an ambulant patient will differ from one confined to bed
    - employs the appropriate modality or modalities
    - must be consistent, not variable
        - avoid repeated changes of analgesics; titrate each drug to its optimal level
    - requires continuity of care
    - involves repeated reassessment
- **the modalities of treatment available for chronic pain are**

  - treatment of the underlying disease
  - analgesics
  - adjuvant analgesics
  - neurostimulatory treatment
  - anaesthetic, neurolytic and neurosurgical procedures
  - physiotherapy
  - psychological therapy
  - lifestyle modification
  - treatment of psychosocial issues that cause or aggravate pain

PRINCIPLES OF USING ANALGESICS FOR CHRONIC PAIN

- the use of analgesics for the treatment of acute pain is the same as for non-palliative care patients
- it is the treatment of chronic pain that is often poorly managed and requires a different approach

CHOICE OF DRUG

The selection of which drug or drugs to use involves

- selecting a drug appropriate for the type of pain
- selecting a drug appropriate for the severity of pain
- using combinations of drugs, not combined preparations
- following the analgesic ladder
- using adjuvant analgesics
- never using placebo

Drug strength

- as it is important that pain be controlled as quickly as possible, it is preferable to start with a strong analgesic and subsequently wean the patient to a weaker drug

Type of pain

- different pains respond to different analgesics:

Nociceptive pain

bone, soft tissue	mild, moderate	non-opioid (opioid if required)
	severe	opioid + non-opioid
visceral	mild	non-opioid (opioid if required)
	moderate, severe	opioid ± non-opioid

Neuropathic pain

nerve compression	corticosteroid ± opioid
nerve infiltration, damage	antidepressant *or* anticonvulsant *or* oral local anaesthetic drug *or* NMDA receptor antagonist
sympathetic type pain	sympathetic nerve block
Other Pain	
raised intracranial pressure	corticosteroid
muscle spasm	muscle relaxant

Drug Combinations

- when prescribing more than one drug, the different drugs should be given independently and compound preparations avoided
- if it is necessary to escalate the dose of one of the drugs in a combined preparation, the dose of the second will also be increased and may cause unwanted toxicity

The analgesic ladder

- if the prescribed drugs do not produce adequate analgesia, treatment is escalated in an orderly manner
  - from non-opioid to weak opioid to strong opioid, as illustrated in the World Health Organization's "Analgesic Ladder"
- non-opioid analgesic should be continued when opioid drugs are commenced, as their action can be complementary and allow lesser doses of opioids to be used
- adjuvant analgesics should be used whenever indicated

WHO Analgesic Ladder

		Analgesics	*Drug of choice*	*Alternatives*
Step 1	Pain	**non-opioid ± adjuvant**	NSAID	paracetamol (acetaminophen)
Step 2	Pain persists or increases	**weak opioid ± non-opioid ± adjuvant**	codeine	oxycodone tramadol
Step 3	Pain persists or increases	**strong opioid ± non-opioid ± adjuvant**	morphine	hydromorphone oxycodone fentanyl

Placebo

- there is no place for the use of placebo medications in the treatment of chronic pain in palliative care

- it is unethical and will lead to distrust if discovered by the patient
- whether or not a response occurs provides no useful information

DRUG ADMINISTRATION

The **principles** of analgesic administration for chronic pain are

- give in adequate dosage
- titrate the dose for each individual patient
- schedule administration according to drug pharmacology
- administer on a strict schedule to prevent pain, not PRN
- give written instructions for patients on multiple drugs
- give instructions for treatment of breakthrough pain
- warn of, and give treatment to prevent, adverse effects
- keep the analgesic program as simple as possible
- use the oral route wherever possible
- review and reassess

Dose

- the selected drug or drugs are prescribed in a dose adequate to relieve the pain
- the dose needs to be titrated against the pain for each individual patient

Schedule

- drugs are given according to a strict schedule, determined by the duration of drug action, in order to prevent the recurrence of pain—**Not PRN**
- drugs given on an "as required" basis or *pro re nata* (PRN) usually results in poor pain control

Instructions for breakthrough pain

- it is essential to give instructions for the treatment of breakthrough pain
    - it is reassuring
    - avoids the despair that occurs if an analgesic program is ineffective
    - helps the patient feel in control

Keep it simple

- avoid multiple analgesics
- it is usually possible to simplify the analgesic program, even for patients with severe pain

Oral

- Oral medication should only be abandoned if the patient is unable to take or retain them

Reassessment

- continued reassessment is necessary and a number of dose modifications are often needed before optimal pain control is achieved

NON-OPIOID ANALGESICS

NSAIDs
ACETAMINOPHEN (PARACETAMOL)

NSAIDs

The **non-steroidal anti-inflammatory drugs (NSAIDs)** are a structurally diverse group of medications that share the ability to inhibit the enzyme prostaglandin synthetase (cyclo-oxygenase, COX).

There are two isoforms of the COX enzyme, COX-1 and COX-2

COX-1

- is constitutively expressed in most normal tissues
- produces the prostaglandins necessary for protective and regulatory functions
  - maintenance of the gastric mucosa
  - normal renal function
  - platelet aggregation
- inhibition of COX-1 produces the clinically troublesome adverse effects including gastrointestinal toxicity

COX-2

- is induced by inflammation
- produces the prostaglandins involved in the generation of pain
- is also constitutively expressed in the kidney, brain and premenopausal uterus
- inhibition of COX-2 is responsible for the analgesic and anti-inflammatory properties of NSAIDs

NSAIDs

---

non-selective COX-1 and COX-2 inhibitors
  salicylates
    aspirin
  non-selective NSAIDs

- acetates: indomethacin, sulindac
- propionates: flurbiprofen, ibuprofen, ketoprofen, ketorolac, naproxen
- oxicams: piroxicam, tenoxicam
- slightly selective NSAIDs
  - meloxicam, diclofenac
- highly selective COX-2 inhibitors (COX-2 specific inhibitors; coxibs)
  - celecoxib, etoricoxib
- centrally acting COX inhibitor
  - paracetamol (acetaminophen)

Non-selective COX inhibitors

- are effective analgesics in cancer pain
- have analgesic efficacy equivalent to 5-10mg of intramuscular morphine
- have a ceiling effect to their analgesic action, but not to their adverse effects
- show considerable variation in both efficacy and toxicity between individual patients
- the dose needs to be individually titrated and in all cases the lowest effective dose should be used
- treatment for several days is required to achieve stable plasma levels and maximal effect

General features of non-selective COX inhibitors

actions	anti-inflammatory, analgesic, antipyretic
mechanism	inhibition of COX-1 and COX-2 antipyretic action is central
pharmacology	well absorbed PO, some effective PR considerable pharmacokinetic variation between different drugs metabolized by a variety of pathways, mainly in the liver
indications	mild to moderate pain disease-related fever
contraindications	history of hypersensitivity or allergy to NSAIDs or aspirin
cautions	patients with history of peptic ulcer, erosions thrombocytopenia or other bleeding diathesis patients with asthma, nasal polyps, allergic predisposition
consider dose reduction	hypoalbuminaemia severe hepatic or renal dysfunction elderly or frail patients
adverse effects	
gastrointestinal	dyspepsia, erosion, ulceration, bleeding, perforation constipation
haemostasis	inhibition of platelet aggregation (not reversible with aspirin)
renal	fluid retention, renal impairment
cardiovascular	hypertension, cardiac failure, myocardial infarction, stroke
hepatic	elevated enzyme levels
neurological	headache, dizziness

skin	rashes
salicylism (aspirin)	nausea, vomiting, dizziness, headaches, tinnitus, deafness
hypersensitivity	allergic reactions

Gastrointestinal toxicity

- occurs commonly with non-selective COX inhibitors
  - particularly in palliative care patients
- the risk is **increased** with
  - advanced age (linear increase in risk)
  - history of peptic ulcer
  - higher doses of NSAID, or long-term use
  - systemic co-morbidity (e.g. diabetes, cancer, hepatic impairment)
  - co-prescription of
    - corticosteroids
    - anticoagulants
    - aspirin (including low dose aspirin)
  - bleeding disorder
    - thrombocytopenia, abnormal platelet function
  - *H. pylori* infection
- the risk is **reduced** by proton pump inhibitors (e.g. omeprazole, lansoprazole)
  - antacids and sucralfate may reduce symptoms but do not protect against ulceration
  - H_2-receptor antagonists protect the duodenal and oesophageal mucosa but not the stomach
  - misoprostol is effective but causes diarrheal
- **palliative care patients requiring continued NSAID therapy should also be treated with a proton pump inhibitor**

Selective COX-2 inhibitors (coxibs)

- were developed to minimize adverse events mediated by COX-1 inhibition
- have analgesic activity equivalent to traditional non-selective NSAIDs, both for acute pain and for the chronic pain associated with osteoarthritis and rheumatoid arthritis
- are associated with significantly less gastrointestinal toxicity
- have no effect on platelet function
- have the same renal effects as non-selective NSAIDs
  - patients with renal impairment, hypertension, or hypovolaemia are at increased risk
- can cause acute neuropsychiatric events including confusion, somnolence, hallucinations
- do not induce bronchospasm in patients with aspirin- or NSAID-induced asthma
- **Note**: rofecoxib, valdecoxib and paracoxib have been withdrawn from the

market in many countries because of an increased risk of cardiovascular side effects (myocardial infarction and stroke). Lumiracoxib was withdrawn because of hepatic toxicity.

Selective COX-2 inhibitors: celecoxib

actions	anti-inflammatory, analgesic, antipyretic
mechanism	inhibition of COX-2
pharmacology	well absorbed PO metabolized in the liver
indications	mild/moderate pain in patients unable to take non-selective NSAID thrombocytopenia or other bleeding diathesis
dose	100-200mg q12h
duration of action	12-24h
contraindications	urticaria or angioedema with NSAIDs or aspirin allergy to sulfonamides
cautions	patients with history of peptic ulcer, erosions renal impairment, hypertension, hypovolaemia cardiac failure severe hepatic or renal dysfunction elderly or frail patients
adverse effects	
gastrointestinal	nausea, dyspepsia erosion, ulceration, bleeding, perforation
renal	renal impairment, fluid retention, oedema
cardiovascular	hypertension, cardiac failure, myocardial infarction, stroke
hepatic	elevated enzyme levels
neurological	headache, dizziness
skin	rashes
hypersensitivity	allergic reactions

Acetaminophen (Paracetamol)

- does not cause gastric irritation or bleeding
- does not affect platelet function or cause gastric irritation or bleeding
- can cause hepatic toxicity, possibly more likely with
  - reduced glutathione stores e.g. poor nutritional status, the elderly
  - regular use of alcohol

Paracetamol (Acetaminophen)

actions	analgesic, antipyretic
mechanism of action	inhibition of prostaglandin synthesis in the CNS
pharmacology	well absorbed from small intestine, rectum conjugated in liver, excreted in urine
indications	mild to moderate skeletal and soft tissue pain fever hypersensitivity to aspirin, NSAIDs peptic ulceration or gastric intolerance of aspirin, NSAIDs

	significant thrombocytopenia or bleeding diathesis
dose	500-1000 mg q4-6h (maximum 4g/d)
duration of action	4-6h
contraindications	allergy to paracetamol (rare)
cautions	severe hepatic dysfunction
	elderly or frail patients
	alcoholic liver disease
adverse effects	allergic rash (rare)
	hepatic dysfunction
	constipation (mild)
drug interactions	potentiates warfarin
preparations	tablets, capsules, suspension, suppositories, IV solution

OPIOID ANALGESICS

CLASSIFICATION
EQUIANALGESIC DOSES
OPIOID SUBSTITUTION
OPIOID OVERDOSE
ADVERSE EFFECTS
TOLERANCE, PHYSICAL DEPENDENCE
AND PSYCHOLOGICAL DEPENDENCE
OPIOPHOBIA
WEAK OPIOIDS
STRONG OPIOIDS

The opioid analgesics are defined as drugs having morphine-like effects and act by interaction with the opioid receptors.

Classification

- **Weak opioids—opioids for mild to moderate pain**
  codeine
  tramadol
- **Strong opioids—opioids for moderate and severe pain**
  buprenorphine
  fentanyl
  diamorphine
  hydromorphone
  methadone
  morphine
  oxycodone
  meperidine (pethidine)

Equianalgesic doses of opioids

- The equianalgesic doses of different opioid drugs
  - are only approximations
  - do not take into account individual patient variation (differences in absorption, metabolism, excretion) some are derived from studies of single doses rather than continued therapy
- **Each drug must be titrated against pain and side effects for each individual patient**

Approximate equianalgesic doses of opioid analgesics

	Parenteral	**Oral**
morphine	**10 mg**	**30 mg**
buprenorphine	0.3 mg	0.4 mg SL
codeine	120 mg	240 mg
diamorphine	4-5mg	20-30mg
fentanyl	0.1 mg	
hydromorphone	1.5 mg	7.5 mg
methadone	10 mg	20 mg
oxycodone	10 mg	20 mg
pethidine	75 mg	300 mg
tramadol	100 mg	300 mg

Opioid substitution: switching from one drug to another

With the increasing availability of a range of opioid drugs, it has become common practice for patients with inadequate analgesia or troublesome adverse effects to be tried on a different drug. Substitution of one opioid drug for another has been termed **opioid switching** or **opioid rotation**. Opioid substitution results in improved analgesia and fewer adverse effects for many patients.

Guidelines for opioid substitution

calculate the equianalgesic dose of the new drug
decrease the dose by 25-50% to accommodate cross-tolerance
    reduce by 75% if changing to methadone
    do not reduce if changing to TD fentanyl
    initial opioid needs to be continued for 12-48h if changing to TD fentanyl
adjust according to prior pain control
    reduce less if patient in severe pain
adjust according to the patient's general condition
    reduce more if elderly, frail, or significant organ dysfunction
give 50-100% of the 4-hourly dose for breakthrough pain
reassess and titrate new opioid against pain and side effects

Opioid overdosage

Severe sedation or **narcosis**, with loss of consciousness and respiratory depression, can occur

- if the dose prescribed is too large
- if the patient takes an intentional overdose (likely to be more severe)

The **risk factors** for narcosis are

- elderly or frail patients
- renal impairment
- other causes of CNS depression, including other medications
- opioid naive patients
- patients with only mild pain
- patients whose pain has been acutely relieved by a procedure such as a nerve block

Opioid overdosage is very uncommon in palliative care if appropriate care is taken with selecting and titrating the dose.

Assessment of narcosis

- respiration rate (RR)
- oxygen saturation: SaO2. Is the patient cyanosed?
- is the patient rousable?
- has time of peak plasma level of last dose of opioid been reached?

Treatment of narcosis

- General
  - stimulate the patient
  - give oxygen
  - stop/withhold further opioid therapy
- **RR < 5/min**
  - naloxone 0.4mg IV or SC stat
- **RR 5-7/min ± barely rousable/unconscious ± SaO_2 <90%**
  - naloxone 0.4mg in 10ml saline: 1-2ml IV or SC, q2-3min
  - **the minimum effective dose of naloxone should be used**
  - **the aim is to improve respiratory function without causing recurrent pain or physical withdrawal**
- **RR = 8/min + rousable + SaO2 = 90%**
  - Careful observation

Adverse effects of opioids

- **Gastrointestinal**
  - nausea and vomiting
    - usually settles after several days

    - give antiemetic, either regularly or PRN
    - if persistent, change to a different opioid
  - constipation
    - **laxatives and dietary advice are required for the duration of opioid therapy**
  - gastric stasis
    - metoclopramide or cisapride
- **CNS**
  - narcosis - see Overdosage
  - sedation
    - may resolve after a few days
    - reduce opioid dose
    - withhold less necessary drugs that are CNS depressants
    - consider an alternative opioid
  - psychotomimetic (agitated delirium)
    - reduce opioid dose
    - haloperidol
    - consider an alternative opioid
  - myoclonus
    - reduce opioid dose
    - benzodiazepine
- **Respiratory**
  - severe respiratory depression - see Overdosage
  - mild/moderate respiratory depression
    - reduce opioid dose
    - withhold less necessary drugs that are CNS depressants
    - consider an alternative opioid
  - suppression of cough reflex

Tolerance, physical dependence and psychological dependence

Tolerance

- is a normal physiological response to chronic opioid therapy in which increasing doses are required to produce the same effect
- is uncommon in cancer patients with chronic pain in whom the need for increasing doses usually relates to disease progression
- is not a reason for "saving up" the use of opioid drugs until the terminal phase
- patients concerned that there will be "nothing left" for more severe pain should be reassured that the therapeutic range of morphine is very broad and that there is adequate scope to treat more severe pain if it occurs

Physical Dependence

- is a normal physiological response to chronic opioid therapy which causes withdrawal symptoms if the drug is abruptly stopped or an antagonist administered
- patients whose pain has been relieved by surgical or other means should have their opioid reduced by about 25% per day
- patients should be reassured that physical dependence does not prevent withdrawal of the medication if their pain has been relieved by other means, providing it is weaned slowly

Psychological dependence and addiction

- is a pathological psychological condition characterized by abnormal behavioural and other responses that always include a compulsion to take the drug to experience its psychic effects
- is rare in patients with cancer and pain
- even if it is anticipated that pain will be relieved by other means, opioids should not be withheld because of any concerns related to psychological dependence, although patients with a history of drug abuse should be managed carefully

In palliative care, concerns about tolerance, physical dependence or psychological dependence are never a reason to withhold opioid therapy if it is clinically indicated

The Underutilization of Opioids: Opiophobia

Professional opiophobia

Reasons why doctors underprescribe and nurses underadminister opioid drugs

- **belief that morphine hastens death**
  - morphine may be used for months or years and, correctly administered, is compatible with a normal lifestyle
  - used properly, it does not hasten death
- **fear of respiratory depression**
  - used properly, morphine should not cause respiratory depression, although care must be taken with patients who are at risk of respiratory depression for other reasons
- **"Morphine doesn’t work"**
  - morphine will be ineffective in controlling pain if
    - it is incorrectly administered
    - it is used for morphine-insensitive pain
    - matters of psychosocial concern have not been addressed
- **Morphine causes unacceptable side effects**
  - side effects should not be severe
  - respiratory depression is uncommon except in opioid naïve patients

    - commenced on parenteral therapy
    - constipation occurs inevitably and requires explanation and advice about diet and laxative therapy
    - somnolence and nausea usually improve after several days
- **Fear of tolerance, physical dependence, psychological dependence**
    - concerns about these are never a reason to delay treatment with an opioid if it is clinically indicated

Patient opiophobia

Patients and their families may express concerns about opioid therapy:

- **"That means I'm going to die soon"**
    - requires explanation that morphine can be used for months or years and is entirely compatible with a normal lifestyle
- **"Nothing left for when the pain gets worse"**
    - requires reassurance that the therapeutic range of morphine is sufficient to allow escalation of the dose if necessary
- **"I'll become an addict"**
    - requires explanation and reassurance about physical and psychological dependence
- **"The morphine didn't work"**
    - morphine may not relieve pain if
        - the dose was too low
        - it was given too infrequently
        - there were no instructions for breakthrough pain
        - it was given for opioid-insensitive pain
        - matters of psychosocial concern have not been addressed
- **"I couldn't take the morphine"**
    - unacceptable side effects should not occur
    - patients should be warned about somnolence and nausea and reassured that they are likely to improve after several days
    - constipation occurs inevitably and requires explanation and advice about diet and laxative therapy.
- **"I'm allergic to morphine"**
    - usually relates to nausea or vomiting that occurred when parenteral morphine was given to an opioid naïve patient for acute pain
    - immunological allergy to morphine is rare

Given explanation, reassurance and the cover of antiemetics, most patients can be started on morphine without ill effect.

WEAK OPIOID DRUGS

Weak opioid drugs are opioid drugs for mild to moderate pain

CODEINE
TRAMADOL

Codeine

pharmacology	active PO, SC, IM metabolized in liver, excreted in urine duration of action 4-6h Ineffective with poor or blocked CYP2D6 metabolism
indications	mild to moderate pain diarrhoea cough
cautions	severe hepatic or renal impairment other causes of CNS depression
adverse effects	qualitatively similar to morphine - generally mild
dose	analgesic 30-60mg PO q4-6h antitussive 8-20mg PO q4-6h
dose equivalence	240mg PO is equivalent to morphine 30mg PO
preparations	tablets, syrup, injection combined preparations with aspirin, acetaminophen or NSAID N.B. some combined preparations have subtherapeutic doses of codeine

Tramadol

pharmacology	active PO, PR, SC, IM, IV actions: opioid agonist, monoamine re-uptake inhibitor metabolized in liver, excreted in the urine duration of action 4-6h
indications	mild and moderate pain
contraindications	patients taking MAOIs serotonergic agents (e.g. SSRIs, venlafaxine, mirtazapine)
cautions	severe hepatic or renal impairment epilepsy, drugs that reduce seizure threshold e.g. TCAs, SSRIs SSRIs, TCAs: risk of serotonin syndrome
adverse effects	qualitatively similar to morphine - generally mild, less constipating dizziness, postural hypotension (uncommon) neuropsychiatric syndromes serotonin syndrome
dose	50-100mg PO q4-6h or 100-200mg SR PO q12h
dose equivalence	100mg IM is equivalent to morphine 10mg IM 300mg PO is equivalent to morphine 30mg PO
preparations	IR capsules, SR tablets, injection

STRONG OPIOID DRUGS

Strong opioids are opioid drugs for moderate or severe pain

- BUPRENORPHINE
- DIAMORPHINE
- FENTANYL
- HYDROMORPHONE
- METHADONE
- MORPHINE
- OXYCODONE
- PETHIDINE (MEPERIDINE)

Buprenorphine

pharmacology	active SL, IM, TD metabolized in the liver, excreted in bile and urine
duration of action	6-9h (SL, IM), patch 7d
indications	moderate and severe pain
cautions	opioid dependence monoamine oxidase inhibitors (MAOIs)
adverse effects	qualitatively similar to other opioids respiratory depression may be poorly responsive to naloxone
dose	0.3-0.6mg IM or 0.4-0.8mg SL, q6-8h
dose equivalence	0.3mg IM is equivalent to morphine 10mg IM 0.4mg SL is equivalent to morphine 30mg PO 20μg/h TD (480μ/d) is equivalent to morphine 48mg/d PO
preparations	injections, sublingual tablets, transdermal patch

Diamorphine (heroin)

pharmacology	active PO, PR, SC, IM, IV, spinal and topical metabolized to 6-acetylmorphine and morphine duration of action: 3-4h
indications	moderate and severe pain
cautions	severe hepatic or renal dysfunction other causes of severe respiratory impairment other causes of CNS depression
adverse effects	similar to morphine
dose equivalence	4-5mg IM is equivalent to morphine 10mg IM 20-30mg PO is equivalent to morphine 30mg PO
preparations	tablet, liquid, injection

Fentanyl

Parenteral Fentanyl

pharmacology	active IV, IM, SC and spinal metabolized in liver, excreted in the urine
duration of action	0.5-1h (IV), 1-3h (SC)
indications	moderate and severe pain
- single dose	painful procedures, prevention of incident pain
- CSCI	inadequate pain relief with other opioid unacceptable toxicity with other opioid renal failure
adverse effects	qualitatively similar to morphine
dose	no standard dose for chronic pain titrated against pain and adverse effects for each individual patient
dose equivalence	0.1mg IV equivalent to morphine 10mg IV (but lasts <1h)

Transdermal Fentanyl

pharmacology	well absorbed: bioavailability 92% onset of action 12-24h continued action after patch removal 12-24h duration of action 72h (<72h in 24% of patients)
indications	intolerable adverse effects of other opioid unable to take or retain oral analgesia renal failure
contraindications	severe pain requiring rapid analgesic titration acute pain pain unresponsive to morphine or other *μ*-agonist patients taking MAOIs
caution	patients with disease-related fever significant pulmonary disease other causes of CNS depression old age, debility Medications inhibiting CYP3A4
warnings	do not heat the patch area do not cut patch or use damaged one dispose of used patches with care
adverse effects	qualitatively similar to morphine—less constipation, sedation skin reactions
dose	patient on strong opioids - calculate previous 24h dose as mg/d of PO morphine - divide by 3 and choose nearest patch strength in *μ*g/h patient on weak opioid or opioid naïve - start with 25*μ*g/h patch
titration	each 72h, according to response pain at 48-72h, not relieved by higher dose: change patch q48h
preparation	TD patches delivering 12.5, 25, 50, 75 and 100*μ*g/h fentanyl

Oral transmucosal fentanyl citrate (OTFC)

description	‘lozenge on a stick’ containing fentanyl in a hard sweet matrix
pharmacology	bioavailability 50%: half by transmucosal, half by slower GI absorption onset of action 5-10 min duration of action 1-3.5h, longer with higher doses
indication	breakthrough pain
adverse effects	somnolence, dizziness, nausea
dose titration	OTFC dose not predicted by opioid dose for background pain 1. Patient uses one 200μg lozenge over 15 min ± second 200μg lozenge after 15 min if analgesia inadequate no more than two lozenges per episode of pain 2. Repeat this dose for 2-3 episodes of pain effective dose is pain relief with a single lozenge 3. If ineffective, increase to next strength lozenge repeat steps 1 to 3
preparations	200, 400, 600, 800, 1200, and 1600μg lozenges

Note: 25% of patients either do not achieve analgesia with the highest dose (1600μg) or suffer unacceptable adverse effects
Note: OTFC lozenges are expensive

Hydromorphone

pharmacology	active PO, PR, SC, IM, IV and spinal metabolized in the liver, excreted in urine
duration of action	4h
indications	moderate and severe pain morphine intolerance
cautions	renal impairment severe hepatic dysfunction significant pulmonary disease other causes of CNS depression old age, debility
adverse effects	similar to morphine
dose	no standard dose for chronic pain titrated against pain and adverse effects for each individual patient
dose equivalence	1.5mg IM is equivalent to morphine 10mg IM 7.5mg PO is equivalent to morphine 30mg PO
preparations	Tablets (IR & SR), liquid, suppositories, injection

Methadone

pharmacology	active PO, PR, IM, IV, SC actions: μ opioid agonist, NMDA receptor antagonist

	metabolized in liver, mainly excreted by faecal route
	bioavailability PO 80%, but considerable interindividual variation
duration of action	4-6h initially, 8-12h with continued use
indications	moderate and severe pain
	pain poorly responsive to morphine, especially neuropathic pain
	intolerance to morphine or other opioid
	renal failure
cautions	frail, elderly, confused
	significant hepatic or renal impairment
	significant pulmonary disease
	other causes of CNS depression
adverse effects	similar to morphine
	cumulative toxicity heralded by sedation
drug interactions	CYP3A4 inhibitors cause increased methadone levels and toxicity
	e.g. erythromycin, ketoconazole, ciprofloxacin, SSRIs
	CYP3A4 inducers cause decreased methadone levels and effect
	e.g. phenytoin, carbamazepine, phenobarbital, corticosteroids
dose	calculated from previous therapy, adjusted for effect and toxicity
	frequency: q4-6h for first 1-3d, then q6-12h
dose equivalence	20mg PO is equivalent to morphine 30mg PO
	10mg IM is equivalent to morphine 10mg IM
preparations	tablet, mixture, injection
N.B.	**Methadone has cumulative toxicity due to the progressive prolongation of the half-life with continued therapy. It is necessary to reduce both the dose and the frequency after the first few days. Failure to do this will result in narcosis.**

Morphine

pharmacology	active PO, PR, SC, IM, IV, spinal and topical
	metabolized in the liver, excreted in urine
	duration of action 3-4h; longer with renal impairment
indications	moderate and severe pain
	dyspnoea
	cough
	diarrhoea
contraindications	genuine morphine intolerance
cautions	renal impairment
	severe hepatic dysfunction
	significant pulmonary disease
	other causes of CNS depression
	old age, debility
adverse effects	
neuropsychological	sedation, drowsiness, confusion, narcosis, coma
	dysphoria and psychotomimetic effects

	myoclonus miosis
gastrointestinal	dry mouth, nausea, vomiting, delayed gastric emptying, constipation biliary colic
respiratory	suppression of cough reflex respiratory depression
cardiovascular	postural hypotension
urological	urgency, retention
dermatological	flushing, sweating, pruritus
dose	no standard dose for chronic pain titrated against pain and adverse effects for each patient
dose equivalence	see **Equianalgesic Dose** table
preparations	Tablets, capsules, mixture (IR and SR), injection

Oxycodone

pharmacology	active PO, PR, SC, IM, IV metabolized in liver, excreted in urine
duration of action	4-6h (IR), 12h (SR)
indications	mild to moderate and severe pain
cautions	renal impairment severe hepatic dysfunction significant pulmonary disease other causes of CNS depression old age, debility
adverse effects	qualitatively similar to morphine
dose	calculated from previous therapy, adjusted for effect and toxicity
dose equivalence	20mg PO or PR is equivalent to morphine 30mg PO 10mg SC oxycodone is equivalent to morphine 10mg SC
preparations	IR and SR tablets, suppository, injection

Oxycodone/Naloxone

pharmacology	both drugs are SR
duration of action	12h
Indications	Moderate or severe pain, complicated by constipation
contraindications	moderate or severe liver dysfunction patients taking MAOIs
cautions	mild liver impairment others: as for oxycodone
adverse effects	diarrhoea (at commencement) withdrawal symptoms switching from other opioids
dose	as for oxycodone SR

preparations		tablets 5/2.5, 10/5, 20/10, 40/20mg oxycodone/naloxone
	Note	combined preparation is more expensive
	Note	combined preparation should prevent abuse by opioid-dependent persons (e.g. crushing and injecting IV)

Pethidine (Meperidine)

pharmacology	active IV, IM, PO, PR metabolized in the liver, excreted in the urine duration of action 2-3h
indications	moderate and severe pain NOT RECOMMENDED for chronic usage in palliative care
contraindications	patients taking MAOIs renal impairment
adverse effects	qualitatively similar to morphine but less constipating not antitussive CNS toxicity due to norpethidine accumulation - agitation, tremor, sedation, narcosis - myoclonus, seizures (unresponsive to naloxone)
dose	not recommended for chronic usage
dose equivalence	75mg IM is equivalent to morphine 10mg IM 300mg PO is equivalent to morphine 30mg PO
preparations	IR tablet, injection
N.B.	**Pethidine is NOT RECOMMENDED for chronic pain because of its neurotoxicity and shorter duration of action**

THE ADJUVANT ANALGESICS

- are not analgesics in the true pharmacological sense, but may contribute significantly to pain relief when used either alone or in combination with other analgesics
- they are of particular use for opioid-insensitive pain, particularly neuropathic pain
- include
  - **corticosteroids**
  - **drugs for neuropathic pain**
    - antidepressants
    - anticonvulsants
    - oral local anaesthetic agents
    - NMDA receptor antagonists
  - **drugs for bone pain**
    - bisphosphonates

    - radioisotopes
- **psychotropic drugs**
    - neuroleptics
    - anxiolytics
    - psychostimulants
    - cannabinoids
- **muscle relaxants**
    - benzodiazepines
    - baclofen
    - dantrolene

Corticosteroids

actions	peripheral: anti-inflammatory
	central (evidenced by the effect on mood and appetite)
mechanism of action	peripheral: nonselective COX inhibition
	central: mechanism not defined
indications	neurological
	- raised intracranial pressure
	- spinal cord compression
	- nerve compression or infiltration
	bone metastases
	capsular stretching
	- liver metastases, other visceral metastases
	soft tissue infiltration
	- head and neck tumours, abdominal and pelvic tumours
contraindications	no absolute contraindications
	side effects are often dose-limiting
cautions	peptic ulceration
	diabetes mellitus
	cardiac failure and oedematous states
adverse effects	
general	Cushingoid facies: moon face, hirsuitism
	body habitus: truncal obesity, interscapular hump
gastrointestinal	gastric erosion, ulceration, bleeding
	increased appetite, weight gain
metabolic	hyperglycaemia, aggravation of diabetes
	sodium and fluid retention
	hypokalaemia and muscle weakness
cardiovascular	oedema, hypertension
	thrombosis
musculoskeletal	improved muscle strength (subjective)
	proximal myopathy
infection	predisposition to infection
psychological	euphoria, improved sense of well-being
	emotional lability, agitation, dysphoria
	depression, steroid psychosis

dermatological	impaired wound healing easy bruising, purpura		
neurological	insomnia		
preparations	**hydrocortisone**	**prednisolone**	**dexamethasone**
dose equivalence (glucocorticoid effect)	100mg	25mg	4mg
mineralocorticoid effect	++	+	-

Drugs for Neuropathic Pain

Antidepressants

- antidepressants are indicated for the treatment of neuropathic pain
- they act by blocking the presynaptic re-uptake of serotonin and noradrenaline in the central nervous system, enhancing the action of the descending inhibitory pathways
- the character of the neuropathic pain does not determine whether a response will occur
  - there is no evidence that antidepressants are more effective than other agents for the burning dysaesthetic type of pain
- compared to the antidepressant action, the analgesic effect of tricyclic antidepressants (TCAs)
  - is usually seen with lower doses (e.g. 50-100 mg/d amitriptyline)
  - occurs more quickly (response should be evident within 5-7 days)
  - has been documented in patients with no features of depression
- a TCA (amitriptyline, imipramine or doxepin) is started at a dose of 10-25 mg at night, increasing to 50-100 mg
- if there is no benefit in 1-2 weeks the drug is stopped
- there is considerable individual variation in patients' responses to different drugs, and a trial of a second antidepressant is sometimes successful
- TCAs are probably more effective at relieving neuropathic pain than the newer antidepressants, but have double the rate of adverse effects
- drugs that affect both serotonin and noradrenaline re-uptake [serotonin noradrenaline re-uptake inhibitors (SNRIs, e.g. venlafaxine) and noradrenergic and specific serotoninergic antidepressants (NSSAs, e.g. mirtazepine)] are likely to have greater analgesic effect than selective serotonin re-uptake inhibitors (SSRIs)
- The adverse effects of TCAs (sedation, anticholinergic effects and postural hypotension) are usually mild when used in low dose for neuropathic pain, but may nevertheless be troublesome in palliative care patients.

Anticonvulsants

- anticonvulsants are indicated for the treatment of neuropathic pain
- they act by suppressing the spontaneous neuronal discharges and neuronal hyperexcitability that occur after nerve injury and may also have a central effect
- the character of the neuropathic pain does not determine whether a response will occur
  - there is no evidence that anticonvulsants are more effective than other agents for the shooting lancinating type of pain
- drugs used frequently are gabapentin, carbamazepine, sodium valproate and clonazepam.
  - gabapentin may be no more effective than carbamazepine, but causes less troublesome adverse effects
- the dose and the initial titration are the same as for anticonvulsant therapy
  - there is no data relating blood levels and analgesic activity
- the dose is increased step-wise until a response occurs or toxicity ensues
  - serum levels can be checked and the drug should be stopped if there is no response when the levels are in the therapeutic range for anticonvulsant therapy
- there is considerable lack of cross-resistance between the drugs and treatment with a second anticonvulsant is sometimes successful
- the adverse effects of the different anticonvulsants are similar, with gastric intolerance (nausea and vomiting), sedation, ataxia, dizziness and confusion being the most common
  - carbamazepine can cause leucopenia and the white blood cell count should be checked periodically

Local anaesthetic agents

- are indicated for neuropathic pain refractory to other therapy
- act by neuronal membrane stabilization by sodium channel blockade, probably at both peripheral and central sites
- **lignocaine** infusions (2-5mg/kg IV over 30 minutes) can be used to predict whether there will be a response to mexiletine
  - lignocaine infusions (IV or SC) may be useful for rapidly controlling severe neuropathic pain
- **mexiletine** is the preferred oral local anaesthetic-type drug
  - it is commenced at a dose of 150 mg/d and increased by 150mg each few days up to a maximum of 750 mg/d
  - the dose and blood levels of mexiletine do not correlate with pain relief
  - it must be given with particular caution to patients with ischemic heart disease or cardiac arrhythmias
  - the **adverse effects** of mexiletine include dizziness, sedation, tremor, and unsteady gait; nausea and indigestion can be lessened by taking the medication with food.

NMDA receptor antagonists

- are indicated for the treatment of refractory neuropathic pain and other severe pain when opioid tolerance is a concern
    - the NMDA (N-methyl D-aspartate) receptors in the spinal cord are activated by continuing stimuli in nociceptive afferents, leading to sensitization of the dorsal horn cells and causing perpetuation of the sensation of pain and reduced opioid sensitivity
    - this mechanism is believed to underlie opioid tolerance and the relative opioid-insensitivity of neuropathic pain
    - the NMDA receptor antagonists ketamine, dextromethorphan and methadone inhibit this process
- **ketamine** is a dissociative anaesthetic used for short surgical procedures
    - subanaesthetic doses has been shown to improve the effect of opioids in relieving refractory neuropathic pain or other opioid-insensitive pain
    - it can be given PO, IV or by CSCI
    - is usually started at 100mg/d and titrated up by 100mg/d, up to 500mg/d
    - **adverse effects:** psychotomimetic effects, may be treated or prevented by the co-administration of a benzodiazepine or haloperidol
        - more likely if titration too rapid, liver metabolism is slowed or the oral route is used

Adjuvant drugs for bone pain

Bisphosphonates

- are chemical analogues of pyrophosphate that inhibit bone resorption
- are effective in the treatment of hypercalcaemia associated with cancer
- have been shown to reduce pain and skeletal events in patients with bone metastases
- act by inhibiting osteoclast activity, blocking mineral dissolution
- the more recently introduced nitrogen-containing bisphosphonates (**pamidronate, ibandronate, olpadronate and zoledronic acid**) are more potent than the non-nitrogen-containing compounds **etidronate and clodronate**
- systematic reviews indicate that there is improvement in the pain related to bone disease that occurs over time
    - there is insufficient evidence to recommend bisphosphonates for immediate analgesia

Radioisotopes

- the systemic administration of the bone-seeking radioisotope, **89-Strontium**, is effective in controlling bone pain related to metastases
- it is preferentially taken up in osteoblastic metastases, which show increased uptake on bone scan
- improved pain control is reported in up to 80% of patients
- responses are usually evident in 2-3 weeks and last for 3-6 months
- compared to local radiotherapy, strontium reduces the number of new pain sites for about four months following treatment
- the main **adverse effect** is myelosuppression, which is usually mild and not clinically significant
  - must have adequate haematological reserve before treatment is given
  - 10% of patients suffer a transient flare reaction with increased pain following treatment, which settles spontaneously

Psychotropic drugs

Neuroleptics

- standard neuroleptic drugs (e.g. **chlorpromazine, haloperidol**) have no analgesic action
  - aid treatment of pain by reducing anxiety and improving night-time sedation
  - same benefits can be obtained with a benzodiazepine, without the potentially troublesome anticholinergic and extrapyramidal side effects, unless the neuroleptic drugs are specifically indicated for the treatment of delirium or nausea

Anxiolytics

- **benzodiazepines**
  - e.g. diazepam, oxazepam and lorazepam
  - aid treatment of pain by virtue of their anxiolytic effect
  - also useful for muscle spasm or acute musculoskeletal pain
  - **adverse effects:** sedation, weakness and postural hypotension

Psychostimulants

- **methylphenidate**
  - does not have an analgesic action
  - can be used to counteract severe sedation caused by opioids
  - **adverse effects:** dysphoria, tolerance and dependence

Cannabinoids

- cannabinoids are no more effective than codeine in treating pain
- **adverse effects** of cognitive impairment and sedation limit their use

Muscle relaxants

- **benzodiazepines**
    - effective for muscle spasm
    - main adverse effects are weakness and sedation

- **baclofen**
    - acts at a spinal level
    - started at 5mg/d and cautiously titrated against effect up to a maximum of 100mg/d
    - main adverse effects are weakness and sedation
    - must be withdrawn slowly to avoid withdrawal syndrome and seizures

- **dantrolene**
    - acts directly on muscle
    - started at 25mg/d and titrated against effect to a maximum of 400mg/d
    - main adverse effects are weakness, sedation and hepatotoxicity

LOCAL ANAESTHETIC AND NERVE BLOCKS

Local Infiltration

- **painful bone metastases**
    - infiltration with local anaesthetic for palpable bone metastases
    - addition of corticosteroid will prolong the effect
- **neuromas**
    - injection with local anaesthetic
    - addition of a long-acting corticosteroid preparation will prolong the effect
- **myofascial pain**
    - is characterized by local pain and tenderness in muscles, associated with pain radiating in a non-dermatomal distribution
    - there are local trigger points, palpation of which produce or aggravate the symptoms
    - injection of the trigger point with local anaesthetic, with or without corticosteroid, usually produces complete relief

Peripheral Nerve Blocks

- **peripheral nerve blocks**
    - the only peripheral nerve block performed frequently is that of intercostal nerves for chest and abdominal wall pain

    - severe limb pain, which in the past might have been treated with plexus blocks, can now be treated with measures that are more selective for sensory nerves (epidural local anaesthetic) and pain (spinal opioids)
- **autonomic nerve blocks**
    - a **coeliac plexus** block is indicated for severe pain from disease in upper abdominal viscera
        - provides immediate relief of pain for about 80% of patients
        - relief lasts a number of months for most
    - a lumbar sympathetic plexus block is of benefit for some patients with pelvic visceral pain or sympathetic type pain in the lower limb

Spinal nerve blocks

- **epidural anaesthetic blocks**
    - injection of local anaesthetic into the epidural space will provide excellent analgesia over several spinal segments
    - either by a single injection or by the temporary or permanent placement of a catheter in the epidural space at the desired level
- **neurolytic blocks**
    - injection of alcohol or phenol into the epidural or subarachnoid space
    - motor and autonomic nerves may also be damaged, causing limb weakness or paralysis and bladder or bowel dysfunction
    - neurolytic blocks have been largely replaced by epidural anaesthetic blocks and intraspinal opioid drugs, which produce the same benefits without the attendant risks

PHYSICAL THERAPIES FOR PAIN

Surgery

- **surgical internal fixation for bone metastases is indicated for**
    - pathological fracture
    - medullary lesion > 50% diameter of bone
    - cortical lesion > 50% cortical width eroded
    - lesions causing persisting pain after radiotherapy
- **pain related to visceral obstruction**
    - oesophageal: laser resection, endo-oesophageal tube
    - intestinal: bypass surgery
    - colonic: bypass surgery, defunctioning colostomy
    - biliary: bypass surgery, stenting
    - urinary: ureteric stenting, percutaneous nephrostomy

Heat Therapy

- relieves pain as a counter-irritant and by direct effect on the tissues treated
  - the sensation of heat acts to reduce the transmission of pain signals in the dorsal horn of the spinal cord and may also induce inhibitory stimuli from the brain stem
  - the local effects of heat include muscle relaxation, increased blood flow and tissue compliance
- heat therapy is of particular benefit in the treatment of muscle spasm, myofascial pain and the general musculoskeletal discomfort associated with immobility and debility
- heat therapy to **superficial tissues** is achieved with hot packs, hot water bottles, electric heating pads or radiant heat lamps
- heating of **deeper tissues** may be achieved with ultrasound, short wave diathermy and microwave treatment
- heat therapy can cause tissue damage and should not be used
  - near metal or plastic prostheses or areas where bone cement has been used
  - in areas where there is diminished sensation or paralysis or where tissues are ischemic
  - where there is infection
  - directly over tumour tissue

Electrical Therapy: Transcutaneous Electrical Nerve Stimulation (TENS)

- involves electrical stimulation of nerves, using electrodes applied to the skin
- causes electrical activity in the large afferent fibres that override pain signals in the dorsal horn or the spinal cord
- electrode placement and choice of frequency and intensity of stimulation should be performed by an experienced operator
  - optimal settings are different for each patient
  - when operating, TENS produces paraesthesiae in the painful area
- is useful in treating mild to moderate musculoskeletal pain but is ineffective against visceral pain
- is **contraindicated** in patients with a cardiac pacemaker
- results in a high initial response rate, although only 15-20% of patients will obtain long-term benefit
- if successful, it will reduce the requirement for systemic analgesics and has the advantages of being cheap, easy to use and relatively free of complications

Topical counter-irritants

- act by stimulating neuronal activity that inhibits the passage of pain signals

in the dorsal horn of the spinal cord
- heat and cold therapy and massage relieve pain by counter-irritation
- some commercially available analgesic ointments work in the same way
- capsaicin cream causes transient burning or stinging and may act partly by counter-irritation

Acupuncture

- is used to relieve pain by mechanisms that are incompletely understood
- involves needle insertion at classical acupuncture points or in painful areas
- its role in the treatment of pain in the palliative care setting is not defined
- it is relatively cheap and safe and, if successful, will reduce the requirement for systemic analgesics

Mechanical Therapies

- **massage:** can relieve pain due to muscle spasm, myofascial syndromes or the general musculoskeletal discomfort associated with immobility and debility
- **exercise:** passive and active exercises may improve pain control and lessen the general musculoskeletal discomfort associated with inactivity or debility
- **hydrotherapy** is particularly useful for patients with pain related to weight bearing
- **manipulation:** physical manipulation by chiropractors, osteopaths and physiotherapists is the most commonly practiced treatment for non-malignant back pain
    - patients with cancer often seek such treatment but manipulation should be performed with great care in the presence of vertebral metastases
- **orthotic devices:** braces and supporting devices will relieve and prevent pain by stabilizing or immobilizing painful tissues are of particular benefit for pain related to movement and weight bearing
- **mobility aids:** walking sticks, crutches and walking frames are of value in preventing pain associated with movement and walking
- **immobilization:** patients suffering severe pain despite the use of optimal analgesia and the physical supports described above may be forced to accept the use of a wheelchair or bed rest

PSYCHOSOCIAL ASPECTS OF PAIN CONTROL

- **psychosocial factors can play an important role in the aggravation (or amelioration) of pain**

- psychosocial factors must be assessed in the evaluation of any patient with chronic pain, necessitating a multidisciplinary approach
- **unrecognized or untreated psychosocial problems may lead to unrelieved pain**
- **pain unrelieved by apparently appropriate therapy should prompt a search for unrecognized psychosocial problems**

Psychological distress

- is often described in terms of just anxiety or depression but may manifest in a number of other ways including anger and frustration, hopelessness and helplessness, denial, grief, sadness or withdrawal
- management is primarily directed at facilitating the patient's adaptive and coping mechanisms
- if successful, it may have a profound effect on pain control and quality of life
- in palliative care, supportive counselling in a caring, considerate and unhurried manner is the mainstay of treatment

Psychological therapy for pain

- psychological approaches to the treatment of pain in palliative care include
  - general psychological supportive care
  - providing information
  - support groups
  - relaxation therapy
  - meditation
  - distraction therapy
  - coping skills training
  - cognitive therapy
  - anxiolytics, antidepressants
  - brief psychotherapy
  - hypnosis
- more complex techniques used for chronic non-malignant pain are of limited value in the palliative care
  - operant techniques
  - cognitive-behavioural therapy

Social Problems

- treatment or resolution of social problems may greatly facilitate pain control
  - supportive counselling to facilitate coping is the mainstay of treatment
  - practical assistance such as the provision of aids for daily living and accessing community resources and services

    - assistance with financial and legal matters

Cultural Issues

- patients of differing cultural backgrounds vary greatly in their response to pain
- management of cultural issues that might cause or aggravate pain is primarily preventive
    - palliative care should be conducted in a culturally appropriate and sensitive manner
    - language barriers can complicate the treatment of pain and professional interpreters should be used

Spiritual and Religious Concerns

- resolution of religious and spiritual/existential concerns may greatly help pain control

- see **Spiritual and Religious Issues**

ANTICANCER THERAPY FOR PAIN

For palliative care patients with cancer, the appropriate and judicious use of anticancer therapy is sometimes the most effective means of controlling pain, even for patients with very advanced disease**.**

Radiotherapy

- is a most effective means of controlling pain due to local tumour infiltration
- for each individual patient, the potential benefits must be weighed against the possible adverse effects as well as the inconvenience of transporting the patient to and from a radiotherapy facility
- the concept of "radioresistant tumours" relates to radiocurability of the cancer and not to palliative radiotherapy
    - local pain due to tumour infiltration usually responds to local radiotherapy, irrespective of the histological type or tissue of origin of the tumour
- palliative radiotherapy should employ the minimum dose of radiotherapy required to achieve the desired result, given in the minimum number of treatment fractions

Chemotherapy

- can be considered for palliation of pain in patients with chemosensitive tumours and widespread disease
- chemotherapy given for the palliation of pain should be geared to produce

manageable and acceptable side effects

  - single agents or combination chemotherapy in reduced doses may be appropriate

« Table of contents

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

IV. Symptom Control

respiratory	BREATHLESSNESS
	COUGH
	TERMINAL RESPIRATORY CONGESTION
gastrointestinal	NAUSEA AND VOMITING
	ANTIEMETICS
	BOWEL OBSTRUCTION
	CONSTIPATION
	LAXATIVES
constitutional	ANOREXIA
	WEIGHT LOSS
	WEAKNESS AND FATIGUE
neurological	ACUTE CONFUSION AND DELIRIUM
	TERMINAL RESTLESSNESS

BREATHLESSNESS OR DYSPNOEA

Breathlessness or dyspnoea is the unpleasant awareness of difficulty in breathing

- dyspnoea, like pain, is subjective and involves both the perception of breathlessness and the reaction of the patient to it
- dyspnoea is always associated with some degree of anxiety, which in turn will make the breathlessness worse

Causes

- **airway obstruction**
    - tracheal
        - tumour
        - tracheo-oesophageal fistula
    - bronchial
        - tumour
        - chronic bronchitis
        - acute infection, bronchitis
        - bronchospasm: bronchitis, asthma
- **reduction in functional lung tissue**

    - surgical resection
    - tumour
    - fibrosis: pre-existing, radiation
    - pleural effusion
    - infection
    - haemorrhage
    - pulmonary embolism
    - chronic obstructive pulmonary disease
- **impaired ventilatory movement**
    - chest wall weakness, motor impairment, general debility
    - chest wall pain
    - elevated diaphragm: ascites, hepatomegaly, phrenic nerve lesion
- **cardiovascular**
    - congestive cardiac failure, cardiomyopathy
    - pericardial effusion, constrictive pericarditis
    - shock, haemorrhage, septicaemia
    - anaemia
- **anxiety**

Assessment

- clinical history and examination, together with knowledge about pre-existing lung disease, are usually sufficient to determine the cause of dyspnoea
- whether investigations should be performed, looking for a reversible cause, depends on
    - what stage the patient is at on the terminal illness trajectory
    - their identified goals of care

Treatment

- treatment directed at the **specific cause**, where possible and appropriate
- **general measures**
    - calm, reassuring attitude
    - nurse patient in position of least discomfort
    - physiotherapy
    - improve air circulation
    - distraction therapy
    - relaxation exercises
    - breathing control techniques
    - counselling
- **oxygen**
    - if hypoxic
    - if it improves symptoms (terminal care situation)
- **bronchodilators**
    - if there is a reversible element to the bronchial obstruction

- **corticosteroids**
    - effective bronchodilators
    - for dyspnoea due to multiple metastases, lymphangitis carcinomatosis and pneumonitis
- **opioids—the most useful agents in the treatment of dyspnoea**
- **nebulised morphine**
    - effective for some patients, although controlled studies do not support its use
    - risk of bronchospasm
- **aid expectoration**
    - steam, nebulised saline
    - mucolytic agents
    - expectorants
    - physiotherapy
- **reduce excess secretions**
    - anticholinergics
- **antitussives** if dyspnoea exacerbated by coughing
- **anxiolytics**

Examples of drug therapy

- **bronchodilators**
    - salbutamol by metered aerosol or 2.5-5 mg by nebuliser, q4-6h
    - ipratropium by metered aerosol or 250-500 μg by nebuliser, q6h
    - aminophylline, theophylline PO

- **corticosteroids**
    - prednisolone 40-60 mg/d PO or dexamethasone 8-12 mg/d PO
    - wean to the minimum effective dose after a few days

- **opioids**
    - morphine 5-10 mg PO, q4h or 4-hourly PRN and titrate
    - 50% increase in dose for patients on morphine for pain
    - nebulised morphine not recommended

- **anxiolytics**
    - diazepam 2 mg PO q8h ± 5-10 mg nocte
    - alprazolam 0.25-0.5 mg SL, q1-2h
    - lorazepam 0.5-1 mg SL, q4-6h

- **mucolytics (for sputum retention)**
    - humidified air (steam, nebulised saline)
    - acetylcysteine 10%, 6-10 ml by nebuliser, q6-8h

- **anticholinergics (for excessive secretions)**
  - glycopyrrolate 0.2-0.4mg SC q2-4h or 0.6-1.2mg/24h CSCI
  - hyoscine hydrobromide 0.2-0.4mg SC q2-4h or 0.6-1.2mg/24h CSCI

- **Terminal Care**
  - treatment should be purely symptomatic in the last week or days of life
  - investigations should be avoided
  - antibiotic therapy is usually not warranted
  - if of benefit, bronchodilator therapy can be continued by mask.
  - unconscious patients who still appear dyspnoeic should be treated with morphine SC

COUGH

Cough is the physiological reflex employed to clear irritant, foreign or particulate material from the respiratory tract

Cause

- **airway irritation**
  - atmosphere: smoke, fumes, dry atmosphere
  - tumour: endobronchial tumour, extrinsic bronchial compression
  - aspiration
    - vocal cord paralysis
    - reduced gag reflex
    - tracheo-oesophageal fistula
  - gastro-oesophageal reflux
  - infection: post-nasal drip, laryngitis, tracheitis, bronchitis
  - increased bronchial reactivity: ACE inhibitors, asthma
  - sputum retention
  - excess sputum (bronchorrhoea)
- **lung pathology**
  - infection
  - infiltration: primary or secondary cancer, lymphangitis carcinomatosis
  - pneumonitis: radiation, chemotherapy
  - pulmonary fibrosis
  - chronic obstructive pulmonary disease
  - pulmonary oedema: congestive heart failure, pericardial effusion
- **irritation of other structures associated with the cough reflex:**

pleura, pericardium, diaphragm

Assessment

- the clinical history, physical examination and chest x-ray will usually define the cause
- whether investigations should be performed, looking for a reversible cause, depends on
  - at what stage the patient is on the terminal illness trajectory
  - their identified goals of care

Treatment

- treat the **specific causes** where possible and appropriate
- **general symptomatic measures**
  - avoid smoke, fumes
  - atmospheric humidification
  - nurse patient in position of least discomfort
- **aid expectoration if cough productive**
  - may be contraindicated for patients who are weak or debilitated
  - steam or nebulised saline are as effective as inhalations containing menthol or eucalyptus
  - the chemical mucolytic agent acetylcysteine
  - atmospheric humidification
  - physiotherapy
  - bronchodilators if bronchospasm present
  - antibiotics if infection present
- **cough suppressants for persistent dry cough**
  - opioids
  - opioid analogues
  - nebulised local anaesthetics
  - corticosteroids for lymphangitis carcinomatosis
- **sedation** may be useful, especially at night

Examples of medications used

protussive therapy	
mucolytics	
topical	nebulised saline 2.5ml q4-6h & before physiotherapy steam inhalations e.g. menthol and eucalyptus
irritant	ammonium chloride, potassium iodide
chemical	acetylcysteine 10%, 6-10ml by nebuliser, q6-8h
bronchodilators	if bronchospasm present
antibiotics	if infection present

antitussive therapy

opioid analogues	dextromethorphan 10-20mg PO q4-6h
	pholcodine 10-15mg PO q4-6h
opioids	codeine 8-20mg PO q4-6h
	dihydrocodeine 10-15mg PO q4-6h
	hydrocodone 5-10mg PO q4-6h
	morphine 2.5-5mg PO q4-6h
local anaesthetics	lignocaine 2%, 5ml by nebuliser q6-8h
	bupivacaine 0.25%, 5ml by nebuliser q6-8h
other antitussives	benzonatate 100-200mg PO q8h
bronchodilators	if bronchospasm present
antibiotics	if infection present
corticosteroids	pulmonary metastases, lymphangitis carcinomatosis
anticholinergics	to reduce secretions

Terminal Care

- treatment should be purely symptomatic in the last week or days of life
- treatment of persistent cough is with an opioid drug, which will also reduce respiratory secretions
- investigations should be avoided
- antibiotics and vigorous physical therapy are inappropriate
- sedatives may be of benefit, especially at night
    - **haloperidol** or **levomepromazine**, which will dry respiratory secretions by their anticholinergic effect, are preferable to a benzodiazepine
- if of benefit, bronchodilator therapy can be continued by mask.
- unconscious patients who are still coughing should be treated with morphine SC

TERMINAL RESPIRATORY CONGESTION

"DEATH RATTLE"

Terminal respiratory congestion is the rattling, noisy or gurgling respiration of some patients who are dying

Cause

- accumulation of pharyngeal and pulmonary secretions in patients who are unconscious or semi-conscious and too weak to expectorate

Treatment

- **therapy is often more for the comfort of the relatives and other patients, as most of the patients are no longer aware of their surroundings**

- position the patient on their side
- oropharyngeal suction should be reserved for unconscious patients
- **anticholinergic drugs** to suppress the production of secretions
  - **hyoscine hydrobromide**
    - 0.4mg SC, ± repeat at 30min, then q2-4h or 0.6-1.2mg/24h CSCI
    - antiemetic; sedative; occasional agitated delirium
  - **glycopyrrolate**
    - 0.2-0.4mg SC, ± repeat at 30min, then q4-6h or 0.6-1.2mg/24h CSCI
    - less central and cardiac effects
  - **atropine**
    - 0.4-0.8mg SC q2-4h
    - may cause tachycardia after repeated injections
  - **transdermal scopolamine patches**
    - hyoscine hydrobromide 1.5mg patch q72h
    - onset of action is delayed for several hours during which other anticholinergic treatment needs to be given
- **reassure relatives that the noisy breathing is not causing any added suffering for the patient**

NAUSEA AND VOMITING

Cause - frequently due to multiple causes

- **irritation, obstruction of the gastrointestinal tract**
  - cancer
  - chronic cough
  - oesophagitis
  - gastritis
  - peptic ulceration
  - gastric distension
  - gastric compression
  - delayed gastric emptying
  - bowel obstruction
  - constipation
  - hepatitis
  - biliary obstruction
  - chemotherapy
  - radiotherapy
- **via chemoreceptor trigger zone**
  - biochemical abnormality
  - hypercalcaemia

    - liver failure
    - renal failure
    - sepsis
    - drugs e.g. opioids, antibiotics
- **via vestibular system**
    - drugs e.g. aspirin
- **via cortical centres**
    - psychological factors, anxiety
    - sites, smells, tastes
    - conditioned vomiting
    - raised intracranial pressure

Treatment

- **assess for and treat underlying cause(s)**
- **dietary measures**
    - liquid and soft foods, selected by the patient
    - small meals, eaten slowly
- **general measures**
    - avoidance of noxious or suggestive smells and odours
    - relaxation techniques
- **use of antiemetics (see below)**
    - drug selected on basis of presumed causative mechanism
    - commence before vomiting starts if possible
    - in adequate doses
    - in combination if necessary
    - by parenteral route if necessary
    - if unresponsive
        - assess for psychological factors
        - reassess for missed physical causes
        - try different antiemetics and/or combinations
- **nasogastric intubation and intravenous hydration should be avoided**
    - in patients whose symptoms can be controlled by other means
    - in the terminally ill

ANTIEMETICS

phenothiazines	examples	prochlorperazine, chlorpromazine, levomepromazine
	action	antidopaminergic effect at the CTZ*
	adverse	EP, sedation and hypotension
butyrophenone	example	haloperidol
	action	antidopaminergic effect at the CTZ
	adverse	sedation, EP

orthopromides	examples	metoclopramide, domperidone
	actions	antidopaminergic at CTZ, direct gastrokinetic effect
	adverse	sedation and EP; domperidone - no central effects
anticholinergic	examples	hyoscine hydrobromide
	actions	anticholinergic at VC, reduces GI secretions, motility
	adverse	whole spectrum of anticholinergic effects
antihistamines	examples	cyclizine, diphenhydramine
	action	at VC; will potentiate dopamine antagonists
	adverse	sedation and dry mouth
cannabinoids	examples	nabilone, dronabinol
	action	at a cortical level - antiemetic effect parallels euphoria
	adverse	drowsiness, dysphoria and delusions
corticosteroids	examples	prednisolone, dexamethasone, hydrocortisone
	action	undefined mechanism
	adverse	see corticosteroids
benzodiazepines	examples	diazepam, alprazolam, lorazepam
	action	at a cortical level
	adverse	sedation
$5HT_3$ antagonists	examples	ondansetron, granisetron, tropisetron
	action	prevents vagal stimulation; ? also central action
	adverse	constipation, headache
prokinetic agent	example	cisapride
	action	increases GI peristalsis
	adverse	colic, diarrhoea
NK-1 antagonist	example	aprepitant
	action	substance-P neurokinin-1 (NK1) receptor antagonist
	adverse	anorexia, dyspepsia, fatigue

*Abbreviations: CTZ - chemoreceptor trigger zone, EP - extrapyramidal side effects, GI - gastrointestinal, VC - vomiting centre.

Use of antiemetics

Which antiemetic(s) is prescribed depends on

- whether the cause can be determined
- what drugs are available
- the effects of antiemetics already given

Metoclopramide

- is a good first-line antiemetic
- has central antidopaminergic activity and is effective for many of the chemical causes of nausea
- has a gastrokinetic effect useful in delayed gastric emptying and functional bowel obstruction
- is contraindicated in high small bowel obstruction

If there is no improvement after 12-24 hours

- other drugs can be substituted, e.g.

    - levomepromazine has a broad spectrum of antiemetic activity
    - haloperidol has strong antidopaminergic effects
    - cyclizine is both antihistaminic and anticholinergic and is useful in mechanical bowel obstruction
- other drugs can be added, e.g.
    - dexamethasone if there is raised intracranial pressure
    - benzodiazepine if there is excessive anxiety
    - a 5HT3 receptor antagonist if vomiting is related to surgery, chemotherapy or radiotherapy

BOWEL OBSTRUCTION

Cause

- **mechanical obstruction**
    - luminal obstruction: cancer, constipation, faecal impaction
    - wall infiltration, stricture formation: cancer, radiation, surgery, benign (peptic ulcer)
    - extrinsic compression: cancer, adhesions (surgical, malignant)
- **paralytic (functional) obstruction**
    - autonomic neuropathy
    - retroperitoneal infiltration
    - spinal cord disease
    - drugs: opioids, anticholinergics
    - postoperative
    - peritonitis
    - metabolic: hypokalaemia, hypercalcaemia, hyperglycaemia
    - radiation fibrosis

Treatment

The management of bowel obstruction is traditionally based on surgical intervention but for patients in palliative care, particularly those with advanced cancer, conservative therapy for subacute and incomplete bowel obstruction will produce equivalent results.

Treatment options include

- **nasogastric intubation and IV fluids as a temporary measure**
    - preoperative
    - pending a decision regarding surgery
    - whilst systemic therapy is initiated
    - acute phase of recurrent obstruction
- **surgery**
    - resection or bypass of obstruction

  - creation of colostomy, ileostomy
  - percutaneous gastrostomy as venting procedure
  - endoscopic laser resection (colorectal)
- **symptomatic**
  - medications (see below)
  - relieve and prevent constipation
  - small meals, reduced roughage, served when the patient requests

Examples of medications used for symptomatic management

- **antiemetics**
  - metoclopramide 10mg PO q4-6h or 30-60mg/24h CSCI
  - cyclizine 50mg PO, PR q8h or 150mg/24h CSCI
  - haloperidol 0.5-1mg PO q6h or 3-5mg/24h CSCI
  - levomepromazine 6.25-12.5mg SC or 12.5-50mg/24h CSCI
- **analgesic**
  - morphine PO, PR or SC infusion
- **anticholinergics**
  - hyoscine butylbromide 20mg PO q6h or 60-120mg/24h CSCI
  - hyoscine hydrobromide 0.4mg SC q6h or 0.6-1.2mg/24h CSCI
- **prokinetic agent**
  - cisapride 10mg PO q6-8h
- **somatostatin analogue**
  - octreotide 0.1mg SC q8h or 0.2-0.3mg/24h CSCI
- **corticosteroid**
  - dexamethasone 8-16mg/d PO or 8-16mg/24h CSCI

CONSTIPATION

Constipation means infrequent or difficult defecation and implies a significant variation from the normal bowel habit of an individual patient

Cause - frequently due to multiple causes

- **general**
  - immobility, inactivity
  - muscular weakness, debility
  - confusion, sedation
  - inability to access or use toilet facility
- **nutritional**
  - decreased intake
  - low residue diet
  - poor fluid intake
- **metabolic**

    - dehydration
    - hypercalcaemia
    - hypokalaemia
- **neurological**
    - cerebral tumour
    - spinal cord disease
    - sacral nerve route infiltration
- **psychological**
    - depression
    - fear of diarrhoea, incontinence
- **colorectal**
    - obstruction
    - pelvic tumour mass
    - radiation fibrosis, stricture
    - painful anorectal condition
- **drugs**
    - opioid analgesic
    - antidiarrhoeals
    - non-opioid analgesics
    - anticholinergic drugs or anticholinergic adverse effects
        - anticholinergics
        - antispasmodics
        - antidepressants
        - phenothiazines
        - haloperidol
    - antiemetics e.g. 5HT3 antagonists

Treatment

Established constipation requires the use of suppositories and enemas to clear the lower bowel before a normal bowel pattern can be established with oral medication

- absent rectal tone, reflex or sensation: neurogenic bowel (see below)
- no neurological abnormality
    - faeces in rectum
        - hard faeces: glycerine PR, microenema, enema, disimpaction
        - soft faeces: bisacodyl or docusate PR, microenema, enema, disimpaction
    - empty rectum: do plain x-ray
        - no bowel obstruction: bisacodyl or docusate PR, oral medications
        - bowel obstruction: appropriate therapy

Prevention of constipation

- factors and situations that predispose to constipation are well known
- **preventive treatment** should be introduced before clinical problems develop
- **general measures** (where feasible)
    - increased food intake
    - increased dietary fibre or bulk forming laxative
    - increased fluid intake
    - encourage activity
- **laxatives**
    - docusate 240-480mg nocte or bisacodyl 10-20mg nocte
    - ± senna 15mg nocte
    - ± lactulose 30ml nocte
    - and titrate the dose against the clinic effect
- explanation to patient, family
- treatment of painful rectal conditions
- ensure access and ability to use toilet facilities
- avoid constipating drugs if possible
- keep a record of bowel actions

Management of neurogenic bowel

- **spinal cord lesion** - spastic bowel, hypertonic anal sphincter, sacral reflexes intact
    - adequate fluid and fibre intake
    - oral laxatives (avoid laxatives that cause excessive softening)
    - rectal suppositories or stimulation leads to increased peristalsis and sphincter relaxation
- **sacral nerve root lesion** - reduced peristalsis, flaccid sphincter, sacral reflexes absent
    - adequate fluid and fibre intake
    - oral laxatives
    - rectal suppositories or stimulation may lead to evacuation
    - straining and abdominal massage
- **patients with a short life expectancy,** for whom bowel training is not feasible
    - dietary fibre is reduced and bulk laxatives avoided
    - constipation is induced with codeine or loperamide
    - regular bowel evacuations are planned once or twice weekly using suppositories or enemas

Terminal care

- significant symptoms of constipation are rare in the last days or week of life
- oral intake is frequently limited and laxatives can usually be discontinued
- a suppository or microenema can be used

    - if the patient has pain, feels the urge to defecate but is unable to do so
    - if there is faecal incontinence due to impaction

LAXATIVES

bulk forming laxatives	
includes	psyllium, ispaghula, sterculia, methylcellulose, dietary fiber supplements
action	retention of intraluminal fluid - softens faeces and stimulates peristalsis
precautions	must drink extra fluids - unsuitable for elderly, debilitated and those with partial bowel obstruction
adverse effects	unpalatable, colic, flatulence
faecal softener and stimulant	
includes	docusate, poloxamer
action	faecal softener and stimulant: promotes secretion of fluid into bowel
contact (stimulant) laxatives	
includes	polyphenolics: phenolphthalein, bisacodyl, senna, cascara, danthron
action	promotes secretion of fluid - softens faeces and stimulates peristalsis
adverse effects	dehydration and electrolyte imbalance
osmotic laxatives	
includes	magnesium salts: sulfate (epsom salts), hydroxide (milk of magnesia) non-absorbable sugars: lactulose, sorbitol, mannitol, polyethylene glycol
action	draws fluid into bowel by osmosis - softens faeces and stimulates peristalsis
precautions	patients must drink extra fluids - unsuitable for elderly, debilitated
adverse effects	colic, flatulence, dehydration and electrolyte imbalance
rectal suppositories	
includes	glycerine, bisacodyl
action	faecal softener (glycerine), contact stimulant (bisacodyl)
use	glycerine inserted into faecal matter, bisacodyl against mucosa

ANOREXIA

Anorexia is a reduced desire to eat

Cause - often due to multiple causes

- **cancer**
- **pain**
- **disordered taste, smell**
    - cancer
    - stomatitis
    - malodorous ulcer or fungating tumour
- **gastrointestinal**

    - stomatitis, xerostomia, mucositis, infection
    - oesophagitis, dysphagia
    - small stomach: gastrectomy, linitis plastica
    - gastric compression: hepatomegaly, ascites
    - gastric distension: delayed gastric emptying
    - bowel obstruction, constipation
    - hepatic metastases, liver disease
    - chemotherapy, abdominal radiotherapy
- **intracranial disease**
    - metastases, radiotherapy, infection
- **metabolic**
    - abnormalities of sodium, calcium, glucose
    - organ failure: liver, kidney, adrenal
- **infections**
- **medications**
- **psychological**
    - anxiety, depression, confusion, dementia
- **organisational**
    - poor food preparation or presentation
- **religious or cultural customs**

Treatment

Treatment of anorexia is important as

- it will improve patient morale
- it will reduce family anxiety
- preservation of optimal nutrition may delay the onset of cachexia

Treatments

- **treat or palliate the underlying cause**
- **activity, exercise**
- **dietary**
    - dietary advice – the assistance of a dietician may be invaluable
    - visually appealing food
    - tasty small frequent meals
    - what they want, when they want it
    - sitting up, at a table, in a room free of odours
- **appetite stimulants**
    - alcohol
    - corticosteroids, e.g. prednisolone 15-30mg/d, dexamethasone 2-4mg/d
    - progestogens, e.g. megestrol 160mg/d
- **explanation, counselling**

Counselling

- anorexia and poor food intake frequently cause much distress for patients and families, requiring careful discussion and explanation
- when advanced and progressing cancer is the prime cause, it needs to be explained that enteral or parenteral nutrition will not be of benefit

WEIGHT LOSS & CACHEXIA

Cause

- in patients with **advanced cancer**, this is primarily due to alterations in protein, carbohydrate and lipid metabolism caused by inflammatory cytokines released by the tumour
- in patients with **AIDS**, it usually relates to systemic infections and chronic gastrointestinal dysfunction

The causes of weight loss include

- **malnutrition**
  - poor intake due to anorexia
  - functional blockage: mouth, oesophagus, stomach
  - malabsorption
  - vomiting, diarrhoea, fistulas
  - protein loss: ulceration, haemorrhage, repeated paracenteses
- **metabolic abnormalities secondary to cancer (cancer cachexia)**
- **increased energy expenditure**
  - systemic infections
  - chronic fevers
  - tumour metabolism

Treatment

The treatment options for weight loss include

- **correct or palliate cause of malnutrition, anorexia**
- **treat tumour where feasible**
- **drug treatment**
  - there is no satisfactory drug therapy for cachexia
  - **corticosteroids** and **alcohol** may reduce anorexia but have no effect on the metabolic abnormalities of cancer cachexia
  - **progestogens** may exert an anabolic effect and reduce or prevent weight loss
  - **dronabinol** is effective in maintaining weight for some patients with AIDS
- **dietary measures**
  - small frequent meals

    - what the patient wants and when they want it
    - dietary supplements
- **enteral nutrition**
    - will not reverse or prevent cancer cachexia
    - may be appropriate for patients with upper gastrointestinal obstruction who may otherwise suffer starvation
    - may cause fluid overload, abdominal cramps and diarrhoea
- **parenteral nutrition**
    - will not reverse or prevent cancer cachexia
    - is appropriate for patients who are temporarily unable to eat for two weeks or more because of anticancer treatment
    - is associated with significant complications and cost
- **management of the psychosocial consequences**

Counselling

- for both the patient and the family, progressive weight loss and cachexia represents progression of the disease
- counselling and discussions may facilitate acceptance and understanding
- the family needs to be dissuaded from trying to force the patient to eat, as this will only cause physical distress and guilt
- the family needs to be helped to show love to the patient by means other than feeding them or pressuring them to eat

WEAKNESS AND FATIGUE

Asthenia is generalized weakness associated with fatigue and lassitude

Cause

In palliative care, asthenia is most frequently associated with progression of the cancer or other underlying disease, but other causes need to be considered, as some are amenable to treatment or palliation. Most relatives attribute weakness to poor eating or to medications.

- **neuromuscular**
    - cachexia-related loss of muscle mass
    - cachexia-related muscular dysfunction
    - polymyositis
    - overactivity, prolonged immobility
    - polyneuropathy
    - intracranial tumour, paraneoplastic encephalopathies
    - acute confusion or delirium
- **metabolic**
    - electrolyte imbalance, dehydration

    - renal, hepatic failure
- **endocrine**
    - adrenal insufficiency
    - ectopic ACTH secretion, diabetes
- **malnutrition**
    - inanition, malabsorption
- **anaemia**
- **infection**
- **psychological**
    - anxiety, depression, dependency, boredom, insomnia
- **anticancer therapy**
    - radiotherapy, chemotherapy, interferon
- **drugs**
    - opioids, tranquillisers, sedatives, antidepressants diuretics, antihypertensives, hypoglycaemics and others

Treatment

- **treatment of underlying cause, where possible**
- **drug therapy**
    - corticosteroids
        - symptomatic improvement, improved feeling of well-being
        - proximal myopathy with continued therapy
    - amphetamines and methylphenidate
- **physical therapy**
    - encourage exertion and activity, physiotherapy
        - within the patient's physical limitations
        - may help maintain dwindling muscle strength
    - encourage activities providing diversion from a patient's feeling of weakness
    - assistance with the activities of daily living
    - physical aids
    - reorganization of the immediate environment to accommodate reduced mobility
- **counselling**
    - supportive therapy: physical and psychological
    - redefinition of goals and expectations

ACUTE CONFUSION OR DELIRIUM

Acute confusion or delirium is an organic brain syndrome characterized by the acute onset of disturbance of the conscious state associated with disordered attention, cognition, perception and psychomotor behaviour

Clinical features of delirium

onset	acute or subacute
conscious state	usually impaired
cognitive impairment	global
attention deficit	always
mood (affect)	released
impaired perception	common
hallucinations	common
incoherent speech	common
course	fluctuating, worse at night
reversibility	often reversible

Cause – multifactorial in many cases

- **intracranial pathology**
    - tumour
    - haemorrhage
    - encephalopathy - radiation, chemotherapy
    - infection - abscess, meningitis, encephalitis
    - post-seizure
    - cerebrovascular disease, stroke
- **metabolic**
    - respiratory failure - hypoxia, hypercapnia
    - liver failure, hepatic encephalopathy
    - renal failure
    - acidosis, alkalosis
    - electrolyte disturbance - sodium, calcium
    - hyperglycaemia, hypoglycaemia
    - adrenal, thyroid and pituitary dysfunction
- **infection, fever**
- **circulatory**
    - dehydration
    - hypovolaemia
    - heart failure
    - shock
- **anaemia**
- **nutritional**
    - general malnutrition
    - vitamin B1, B6, B12 deficiency
- **drug withdrawal**
    - alcohol, benzodiazepine, barbiturate, opioids, nicotine
- **drugs**
    - alcohol, anticholinergics, anticonvulsants, antidepressants, antiemetics (phenothiazines, metoclopramide, nabilone), antihistamines, antiparkinsonian, antipsychotics, anxiolytics and

hypnotics (benzodiazepines, barbiturates), corticosteroids, NSAIDs, opioid analgesics, stimulants (amphetamine, methylphenidate, cocaine) and, less frequently, many other drugs

Other potentially reversible contributing factors that may precipitate or aggravate delirium

- anxiety, depression
- pre-existing cerebral disease, dementia general debility
- pain, discomfort
- sleep deprivation
- altered environment

Treatment

- **treatment of the cause**
  - identify and treat the underlying cause
  - withhold all non-essential medications
  - consider alternatives for essential drugs
  - alcohol or drug withdrawal
    - consider allowing continued use
    - nicotine skin patches
- **general measures**
  - appropriate physical environment
  - quiet and well lit room, night light
    - minimize number of different staff having contact
    - avoid disturbances
    - presence of a family member or trusted friend
  - develop a regular daily routine
  - repeated calm reassurance and explanation
  - do not move from familiar surroundings
  - avoid physical restraints
    - restless patients can be allowed to ambulate if accompanied
    - habitual smokers should be allowed to smoke with supervision
  - reassure family and patient that the confusional state is due to organic disease
- **drug therapy**
  - **haloperidol**
    - is the most frequently used drug for delirium in medically ill patients
    - improves cognitive function and provides sedation
    - mild delirium: 1-5 mg/d PO, in divided doses
    - severe delirium: 2-5 mg IV or SC, q30-60 min, if required
  - **alternatives**
    - chlorpromazine

        - levomepromazine
    - **benzodiazepines**
        - can be given in addition to haloperidol
        - **given alone cause sedation without any effect on cognitive function and may aggravate confusion**

TERMINAL RESTLESSNESS

Terminal restlessness is an agitated delirium that occurs in some patients during the last few days of life

Clinical features

- agitation, restlessness
- impaired conscious state
- muscle twitching
- multifocal myoclonus
- seizures
- distressed vocalizing

Treatment

- **exclude restlessness due to**
    - anxiety, fear
    - unrelieved pain
    - urinary retention, faecal impaction
    - drug, alcohol or nicotine withdrawal
- **review opioid use**
- **benzodiazepines**
    - **clonazepam** 0.5mg SL or SC q12h or 1-2mg/24h CSCI and titrate
    - **midazolam** 2.5-10mg SC, q2h or 20-60mg/24h CSCI and titrate
    - **diazepam** 5-10mg IV or 10-20mg PR, q6-8h and titrate
    - **lorazepam** 1-2.5mg SL, q2-4h and titrate
- **for benzodiazepine failure**
    - **haloperidol** 5mg SC, followed by 20-30mg/24h CSCI and titrate
    - **levomepromazine** 12.5-50mg SC q4-8h and titrate; continue as CSCI
    - **phenobarbitone** 100-200mg SC q4-8h and titrate; continue as CSCI

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

V. Psychosocial

PSYCHOLOGICAL DISTRESS
DEPRESSION
ANXIETY
SPIRITUAL AND EXISTENTIAL DISTRESS
CARING FOR FAMILIES AND FRIENDS

PSYCHOLOGICAL DISTRESS

Some psychological distress will occur with any life-limiting illness. The ability to recognize and relieve this is an essential skill in palliative care.

Factors predisposing to psychological distress

- **the disease**
    - rapidly progressive, clinical features changing frequently
    - present and anticipated disabilities, disfigurement, dependency
    - physical dependence
    - protracted illness with physical and psychological exhaustion
- **the patient**
    - not fully understanding the disease, treatment or what lies ahead
    - made worse when no simple explanations are given
    - fear of pain, dying, disfigurement
    - loss (or fear of loss) of control, independence, dignity
    - helplessness, hopelessness, dependency
    - insight regarding (or fear of) poor prognosis
    - anxious personality, pre-existing personality traits
    - pain and doubts whether suffering can be relieved
    - lack of confidence in medical and nursing attendants
    - unrelieved pain
- **symptoms**
    - uncontrolled or poorly controlled symptoms
    - perceived lack of interest in medical attendants
    - unaware of the cause of different symptoms
- **treatment**
    - diagnostic delays, multiple failed treatments
    - side effects of therapy
- **treatment team**
    - poor communication

    - lack of continuity of care
    - exclusion of family, carers
- **social**
    - loss (or fear of loss) of job, social position, family role
    - feels isolated (actual or perceived)
    - feels a burden on family and carers
    - unfinished business: personal, interpersonal, financial
    - financial hardship
    - fears for family
- **cultural**
    - cultural differences in attitude to sickness, suffering, loss, and death
    - language barriers
- **spiritual**
    - religious issues
    - spiritual issues, e.g. remorse, guilt, unfulfilled expectations, meaninglessness, sense of life and suffering having no meaning

Clinical features

- psychological distress is often described in terms of anxiety or depression but most patients suffer a range of other emotional problems
- these do not necessarily or commonly reflect psychopathology and some, like denial, are best regarded as the clinical manifestations of coping mechanisms
- agitation, restlessness and mood swings are particularly common

Examples of psychological distress

anxiety
depression
anger, frustration, irritability
hopelessness, despair
helplessness
regression
denial
guilt
fear
grief
passivity
avoidance
sadness, misery, remorse
withdrawal, apathy
inappropriate compensation (joyful)
lack of co-operation with carers
unresponsive pain

Denial

- is the most frequently seen coping mechanism
- does not necessarily indicate the patient has not had everything explained
- is not necessarily abnormal or pathological
    - it is so common that it could be regarded as a normal feature of life-threatening illness
- allows patients time to come to terms with their situation
- an alternative description is ‘suppression of information’ which emphasizes its protective function
- should not prompt team members to force information on the patient, but alert them to a defence mechanism

- is often cited by relatives as evidence that the patient does not know or does not want to know and that information should not be forced upon them
- may result in the patient behaving differently with different people—with close relatives they may appear to know nothing of the illness or its seriousness, but are able to discuss it openly with another relative or a professional carer

The level of psychological distress depends on patients' ability to cope

Factors predictive of poor coping

- **personal**
  - anxious or pessimistic personality
  - poor coping with previous illnesses, stresses, losses
    - most patients cope better than might be expected from their previous history of coping
  - adverse experiences with cancer in relatives or friends
  - history of recent personal losses
  - low personal esteem
  - multiple family problems, obligations
  - marital problems
  - history of psychiatric illness
  - personality disorder
  - history of alcohol or substance abuse
- **social**
  - few social supports, resources; isolated
  - lower socioeconomic class
  - sense of not being valued or understood
- **cultural**
  - certain cultural traditions, usually related to stoicism, showing emotions, being undemonstrative
- **spiritual**
  - not religious; no alternate value system

Treatment

Treat underlying causative factors before rushing to prescribe anxiolytics or antidepressants

- **general measures**
  - caring, considerate, unhurried, non-judgemental approach
  - good listening, good communication
  - reassurance about continuing care
  - respect for the person and individuality
  - allow discussion of fears regarding future suffering, life expectancy

    - even patients ‘in denial’ appreciate such discussions
- **control pain and physical symptoms**
    - most psychological distress lessens when physical suffering is competently relieved
- **social**
    - address social issues, encourage social supports
    - provide support for family and carers
    - their support needs are usually different from those of the patient
    - many carers say they did not receive all the information they felt they needed
- **cultural**
    - respect cultural differences: diet, rituals, customs
- **spiritual**
    - address religious or spiritual concerns and respect belief systems
- **other measures**
    - general supportive counselling
    - support groups
    - relaxation therapy
    - meditation
    - distraction
    - socialization
- **psychological therapies**
    - stress management techniques
    - coping skills training
    - cognitive therapy
    - anxiolytics, antidepressants (as a last resort)
    - supportive psychotherapy

Effective treatment of psychological distress in patients with life-threatening illness may greatly improve the quality of life

Time spent listening is never wasted. A truism of palliative care is that ‘nothing is trivial’. Everything the patient says, everything they experience, is worthy of our attention.

DEPRESSION

Significant symptoms of depression are reported to occur

- in about 25-35% of patients with advanced cancer
- in a similar number of patients with other life-limiting illnesses
- the incidence is probably higher in patients with advancing disease, increasing physical disability, or troublesome pain

In palliative care

- many patients with depression are not diagnosed or treated appropriately
  - the diagnosis is missed
  - it is wrongly thought to be inevitable
  - it is regarded as unlikely to respond to antidepressants
- some are started on antidepressants in the last few weeks of life when there is insufficient time for the medication to have any therapeutic effect

Diagnostic criteria

The American Psychiatric Association's DSM-IV criteria for **diagnosis of depression in physically healthy individuals** requires

- at least one of two core symptoms
  - **depressed mood**
  - **anhedonia** (diminished interest or pleasure in activities)
- at least four other symptoms from the list
  - **weight change**—unintentional weight gain or loss (>5% body weight in a month)
  - **sleep disturbance**—insomnia or hypersomnia
  - **psychomotor problems**—agitation or retardation
  - **lack of energy**—fatigue or loss of energy
  - **excessive guilt**—feelings of worthlessness or inappropriate guilt
  - **poor concentration**—diminished ability to think or concentrate, indecisiveness
  - **suicidal ideation**—recurrent thoughts of death or suicide, or suicide attempt
- each symptom needs to be
  - severe (most of the day, nearly every day)
  - durable (more than two weeks)
  - be judged to cause clinically significant distress or impairment
  - not be attributable to the patient's medical condition or therapy.

In **palliative care**

- the significance of somatic symptoms is questionable as all may be attributable to the disease or treatment
  - they might be considered significant if clearly out of proportion to the physical illness
- others have advocated other criteria as indicators of depression in the terminally ill:

Indicators of depression in terminally ill patients

psychological symptoms

- dysphoria
- depressed mood
- sadness
- tearfulness
- lack of pleasure
- hopelessness
- helplessness
- worthlessness
- social withdrawal
- guilt
- suicidal ideation

other indicators

- intractable pain or other symptoms
- excessive somatic preoccupation
- disproportionate disability
- poor cooperation or refusal of treatment

history related indicators

- history of depression
- history of alcoholism or substance abuse
- pancreatic cancer

Reproduced with permission from Block SD for the ACP-ASIM End-of-Life Care Consensus panel: Assessing and Managing Depression in the Terminally Ill Patient. Annals of Internal Medicine 2000; 132: 209-218.

Clinical spectrum

- **normal depressive symptoms**
  - symptoms of depression and anxiety that occur as part of a normal psychological stress response at times of crisis
  - last one to two weeks
  - resolve spontaneously with time and appropriate supportive care
- **reactive depression—adjustment disorder with depressed mood**
  - differs from the normal stress response in either degree or duration
  - the response
    - is maladaptive
    - is greater than would be expected as a normal reaction
    - lasts longer than expected (more than two weeks)
    - may be more severe or intense, causing more disruption and interference with daily functioning, social activities, and relationships with others
- **major depressive disorder**
  - symptoms are usually more severe
  - the mood is incongruent with the disease outlook
  - does not respond to support, understanding, caring or distraction
  - correlates with a desire for death in the palliative care population
- **organic brain syndromes**
  - patients with acute confusion (delirium) or early dementia may exhibit features of depression
  - mental state examination will reveal evidence of organic brain dysfunction
  - delusional thoughts and hallucinations, features of psychotic depression, may occur

Assessment

- the structured clinical interview is the gold standard for the diagnosis of depression
- the use of a single question "Are you depressed?" correctly identified the eventual diagnostic outcome in a series of 197 palliative care patients
    - physicians unfamiliar with palliative care do not ask the question, feeling the answer is bound to be ‘Yes’

Treatment

- **diagnose and treat organic brain syndrome,** if present
    - exclude adverse effects of drugs and drug interactions
        - particularly those associated with opioids, steroids and benzodiazepines
- **treat any causative or aggravating factors**
    - pain, other physical symptoms, social, cultural, spiritual
- **general support**
    - caring and empathy
    - reassurance of continued care and interest, which many palliative care patients fear they may lose
    - provision of any information about the illness requested by the patient
    - explore patients’ understanding and fears about illness, prognosis
    - encourage, strengthen family and social supports
        - many patients worry more about their relatives than about themselves
- **brief, supportive psychotherapy**
    - resolution of issues regarding disease, treatment, future, coping, etc.
    - family, group therapy
        - particularly useful for a dysfunctional therapy
    - behavioural techniques
- **antidepressants**
- **other drugs**: hypnotics, anxiolytics, neuroleptics

Antidepressants classified by principal actions

SNRIs - serotonin and noradrenaline re-uptake inhibitors
  TCAs: amitriptyline, imipramine, dothiepin
  venlafaxine
SSRIs - selective serotonin re-uptake inhibitors
  fluoxetine, paroxetine, sertraline, citalopram
NRIs - noradrenaline re-uptake inhibitors
  TCAs: desipramine, nortriptyline
  reboxetine
NaSSA - noradrenergic and specific serotoninergic antidepressant
  mirtazapine

Serotonin $5HT_2$ receptor antagonists
- nefazodone
- mianserin

Mono-amine oxidase inhibitors
- Non-selective MAOIs: isocarboxazide, phenelzine
- RIMAs - reversible inhibitor of mono-amine oxidase-A: moclobemide

Psychostimulant
- methylphenidate

Tricyclic antidepressants (TCAs)

- antidepressant medication is considered for any patient with significant depression
- adverse effects are common and can be clinically troublesome in elderly or frail patients (particularly dry mouth, constipation)
- different TCAs are more suited to certain situations
  - patients with agitation or insomnia are treated with a sedating drug such as amitriptyline or doxepin
  - patients with psychomotor slowing require a less sedating drug such as desipramine or imipramine
  - patients with problems related to intestinal motility or urinary retention need a drug with less anticholinergic effect such as desipramine or nortriptyline
- TCAs are usually started at a dose of 25-50 mg at night and increased gradually over several weeks
  - 2 to 4 weeks is required for clinical response
  - adults without physical illness require doses of 150-300 mg/d
  - elderly or debilitated patients may only be able to tolerate much lower doses
  - a systematic review of RCTs of TCAs given at low dose (<100mg/d) showed
    - these drugs are effective at lower doses when compared to placebo
    - that increasing to standard doses did not improve the response rate but did produce more adverse effects

Selective serotonin re-uptake inhibitors (SSRIs)

- have little sedative, anticholinergic or cardiac side effects
- can cause transient anxiety, insomnia, nausea and diarrhoea for the first few weeks
- sertraline is possibly the best drug for patients with physical illness
- paroxetine is more likely to cause drug interactions
- fluoxetine has a slow onset of action
- a Cochrane review of antidepressants in patients with medical illness showed that TCAs might be more effective than SSRIs but were

associated with more adverse effects

Mono-amine oxidase inhibitors (MAOIs)

- **non-selective MAOIs should not be used in palliative care because of the need for dietary restrictions and the frequency of interactions with other drugs**
- less drug interactions occur with the reversible inhibitor of mono-amine oxidase-A, moclobemide, but there is little to recommend its use in palliative care.

Noradrenergic and specific serotoninergic antidepressant (NaSSA)

- **mirtazapine** was effective in a small trial of patients with advanced cancer
- acts more quickly than traditional TCAs
- adverse effects are sedation, dry mouth and weight gain

Serotonin and noradrenaline re-uptake inhibitors (SNRIs)

- **venlafaxine** does not have the sedative, anticholinergic or cardiac effects of amitriptyline and acts more quickly
- adverse effects are dizziness, dry mouth, nausea and insomnia

Psychostimulants

- **methylphenidate** has been used for patients with advanced disease and a life expectancy of weeks to a few months
- it is effective in the majority of patients
- serious adverse effects are uncommon
- should be given earlier in the day (5mg PO at 0800 and 1200h) to avoid insomnia
- effect is often seen within two to three days
- it has beneficial side effects
    - counteracting opioid-related sedation
    - improving appetite
    - improving cognitive function
    - counteracting the feelings of weakness and fatigue
    - promoting a sense of general well being

St John's wort

- is an extract of *Hypericum perforatum*
- is a popular over-the-counter antidepressant
- some studies report activity equivalent to other antidepressants with fewer adverse effects
- there are three RCTs that report it to be no better than placebo

ANXIETY

anxiety is a normal and universal emotion

- occurs frequently in patients with physical disease
- includes a continuous clinical spectrum ranging from normal to psychiatric

abnormal (maladaptive) anxiety is distinguished from normal anxiety by

- anxiety out of proportion to the stress
- persistence of symptoms for more than two weeks
- severe physical symptoms or recurrent panic attacks
- disruption to normal functioning

Clinical spectrum

- **normal anxiety**
  - in response to the stress and crises associated with disease
  - more frequent in the terminal phases of the disease
- **reactive anxiety—adjustment disorder with anxious mood**
  - lasts longer than expected (more than 2 weeks)
  - exceeds the level that is regarded as normal and adaptive
  - follows a defined incident or stress
  - depressive symptoms frequently coexist
- **generalized anxiety disorder**
  - characterized by chronic unrealistic worries with autonomic hyperactivity, apprehension and hypervigilance
  - the anxiety is more pervasive and persistent, occurring in many different situations
  - patients have more severe and disabling symptoms, which appear inappropriate or out of proportion to the medical situation
- **panic disorder**
  - repeated sudden, unpredictable attacks of intense fear and physical discomfort
  - attacks follow a crescendo pattern, reaching a maximum in a few minutes
  - may occur in many different situations.
- **phobic anxiety**
  - anxiety provoked by exposure to a specific feared object or situation
  - usually results in an avoidance response.
- **organic anxiety syndromes**
  - uncontrolled pain
  - hypoxia, respiratory distress
  - hypoglycaemia

  - any uncontrolled or severe physical symptoms
  - acute confusional state or delirium
  - drug adverse effects: corticosteroids, metoclopramide, bronchodilators
  - drug withdrawal: opioids, barbiturates, benzodiazepines, alcohol, nicotine

Treatment

- treat the cause of organic anxiety syndrome, if present
- exclude adverse effects of drugs and drug interactions
- treat other factors that may cause or aggravate anxiety
  - pain, other physical symptoms, social, cultural, spiritual
- treat depression, if present
- general support (see Depression)
- brief, supportive psychotherapy (see Depression)
- psychological behavioural therapies
  - relaxation training, hypnosis, cognitive-behavioural therapy, biofeedback
- distraction therapies
  - music therapy, art therapy, socialization
- drug therapy: anxiolytics, hypnotics, antidepressants, neuroleptics

SPIRITUAL AND EXISTENTIAL DISTRESS

What is Spirituality?

- every human being, religious or not, possesses spirituality
- spirituality encompasses the purpose and meaning of an individual’s existence
- it involves relationships with, and perceptions of, people and all other things and events
- it is unique to each person
- it is founded in cultural, religious and family traditions, and is modified by life experiences
- it is the basis for an individual’s attitudes, values, beliefs, and actions
  - for people with religious faith, spirituality is usually encompassed within their religion, but spirituality and religion are not the same thing

What is spiritual or existential distress?

- questions pertaining to spiritual and existential issues may arise as the result of any life event, but occur most frequently (probably invariably) in response to terminal illness

- spiritual and existential problems are an important source of clinical suffering
    - they may cause or aggravate pain and psychosocial problems
    - they can cause an anguish all their own
- recognition and successful management of spiritual and existential problems is an important part of palliative care

Spiritual and existential problems encountered by the terminally ill can be broadly grouped

- **relating to the past**
    - how the patient sees their life, work, relationships, achievements, failures
    - value and meaning of a person's life
    - worth of relationships and effect of failed relationships
    - value of previous achievements or sense of not achieving anything
    - painful memories or shame
    - guilt about failures, unfulfilled aspirations
- **relating to the present**
    - disruption of personal integrity
    - physical, psychological and social changes
    - increased dependency
    - meaning of a person's life
    - meaning of suffering
- **relating to the future**
    - impending separation
    - hopelessness
    - meaninglessness
    - concerns about death
- **relating to religion**
    - strength of their faith
    - whether they have lived according to, and not disgraced, their faith
    - existence of after-life

How is spiritual or existential distress manifest?

- it is most often manifest as physical or psychological problems
- pain or other symptoms unresponsive to appropriate therapy should alert the clinician to the possibility of unrecognized spiritual or existential problems
- the patient may remain sad, withdrawn or 'depressed' when all physical and psychosocial suffering have been relieved
- it is seldom expressed verbally unless the patient is asked about spiritual issues and invited to talk about them. There usually follows immense relief.
- when asked about spiritual matters, most patients assume you are talking

about religion. It is important to stress that at some time in life *everyone* asks existential questions—Why do people suffer? Is there a God who cares? Is my illness because of what I did in my life?

How do you deal with spiritual or existential distress?

- **reassure** the patient that
    - everyone has spiritual problems at some stage in their life
    - everyone asks the same questions—Why this? Why that?
    - everyone tries to find reasons for all that has happened in their life and is happening now
    - that you regard their spiritual/existential concerns every bit as important as every other aspect of their care and will be taken very seriously
    - that unlike other aspects of their suffering, there may not be answers to spiritual/existential questions
        - but ventilating some of the Why questions can make the physical problems seem less
- **patients** vary greatly in their desire to pursue spiritual/existential issues
    - some will not discuss it
    - others just need the presence of a sympathetic person to listen (not necessarily a religious person or a pastoral care worker)
- spiritual care is person-centred and begins at the level of the patients' own insight
- most people are helped by knowing that the questions and doubts that are troubling them are shared by many others

What is Religious Faith?

- religion is the relationship between an individual and God, characterized by belief in, reverence for, and desire to please that God
- for patients who profess a religious faith, their spirituality is usually closely allied with their religion
- patients with religious faith are less likely to have unmet spiritual concerns if their religious needs are met
- patients with religious faith may have as much pain as any other patient but may report it less because their faith may confer some stoicism
- in the **palliative care** setting, a person's faith, no matter how strong or weak, will influence, and be influenced by, everything they experience as death approaches

Can religious faith help the dying?

- most faiths teach that biological death is not the end of life
- believers are comforted
    - that there is something after death

    - that their wrong doings can be forgiven and their good deeds be credited
    - that God will look after those left behind
    - that God is forgiving rather than condemning and punishing
- families sharing the same faith
    - may help them cope better looking after a terminally ill relative
    - may be a source of comfort to the dying patient, confident that faith will help those left behind
- people with a deep religious faith often find it grows as death approaches
- for those with a less well-developed/less tested faith, impending death can be a major challenge to their faith

Can religious faith cause problems for the dying?

- religion does not make living or dying easier, though it may make both meaningful
- religion does not provide all the answers people seek
- people with unrealistic expectations of their religion are usually disappointed
    - some people expect miracles
    - some expect answers to unanswerable questions
    - some expect immediate and sympathetic answers to their prayers
- when these are not forthcoming they may
    - blame their religion or even their God
    - direct their anger or disappointment against clergy and/or their professional carers

How should religious issues be handled in palliative care?

- there should be unreserved respect for an individual's religious beliefs and practices
    - the patient or family should be asked about religious matters including prayer, diet, and routines of personal hygiene
    - sacred practices including prayer, sacraments, anointing with oils, the burning of incense, periods of fasting or self-denial, special diets, baptism and many others are both respected and facilitated
- the manner in which individuals practice their religion must be respected
- a patient's religious needs are assessed on an individual basis
    - no two people of the same faith are likely to have exactly the same religious needs
    - facilitate arrangements for their priests and teachers to visit them
    - support them when their faith feels inadequate for what they are experiencing
- reassure them that the rites of their religion and culture will be fully respected after their death
- many patients, having previously denied any religious faith, may change

as their illness worsens, and be comfortable talking about religious and spiritual matters with doctors or nurses but may be reluctant to do so with clergy or religious personnel

CARING FOR FAMILIES AND FRIENDS

Care of the relatives and close friends is an integral feature of good palliative care

Meeting with relatives is an essential part of palliative care, whether at home or in a hospice/hospital palliative care unit.

Good care of the patient helps the relatives cope, but they also have their own needs and anxieties that must be addressed, including:

- **to do with the patient's illness and care**
    - what exactly is wrong with the patient
    - why the patient is receiving certain treatment
    - what will happen next
    - what is the prognosis or life expectancy
    - whether his illness is infectious or contagious
    - about visiting in hospital
    - about talking to children and friends about the patient's illness
    - how to deal with unsolicited advice from relatives and friends
- **to do with care at home**
    - whether they can or should care for the patient at home
    - what other people will think about their caring
    - what professional help is available
    - how long they will be able to care for the patient at home
    - whether their health will be adequate for them to do this caring
    - whether they will cope with any emergencies that might arise
    - when to call the doctor and what help or advice to ask for
    - how to give medications
    - how to feed the patient
    - whether they will be blamed if the patient has to be admitted to hospital or hospice
    - how to restrict home visitors without offending anyone
    - what to say to visitors
    - how to get some rest as the patient's condition deteriorates
- **to do with their own personal feelings and needs**
    - their own health but feel they cannot mention it
    - family tensions and how to deal with them

    - unresolved interpersonal problems from the past
    - unresolved grief from a recent bereavement
- **looking to when the patient dies**
    - whether they have " done the right thing "
    - how to behave after the death
    - how to arrange a funeral
    - how they will manage—where will they live, who will care for them, where will the money come from
    - legal and financial matters

How should these anxieties be addressed?

- **short meetings with the doctor and/or nurse**
    - to explain everything they want to know about the patient's illness and care
    - to ask questions about the illness, treatment and details of what lies ahead
    - to ask for information about whatever agencies there are to assist their caring
    - to express their fears about the present and both the immediate and distant future
    - to talk about their own health and other needs
    - to express any anger, resentment, and sadness about the illness and care
    - the relatives must feel these meetings are solely for them and their problems
    - most relatives and close friends will appreciate and benefit from these short meetings
- **family conferences**
    - useful/necessary for dysfunctional families or if family tensions are high or there is feuding within the family
    - should be chaired by the doctor with the nurse and social worker in attendance
    - the purpose of the meeting is explained and the absolute necessity for all to contribute and to put personal feelings aside
    - the whole family are given details about the patient's illness, investigations, treatment and prognosis then invited to ask questions
    - each family member is then invited to express their feelings, including their anger
    - the doctor can then explain how their anger or feuding is not only not helping each of them at this painful time but also affecting the final days of their loved one
    - they are asked to put interpersonal differences behind them, to try to love or at least tolerate each other, remembering that each of

    them is suffering grief, disappointment and apprehension
  - finally they are asked to appoint one person to be the communications link between them and the treatment team

At every stage, the palliative care team must ensure that the relatives are being given the care, the attention and the time they need

« Table of contents

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

VI. Organizational Aspects of Palliative Care

HOW TO START A PALLIATIVE CARE SERVICE
REGULATION AND ACCREDITATION IN PALLIATIVE CARE
EDUCATION AND TRAINING FOR SERVICE STAFF
EXTERNAL EDUCATION AND TRAINING
INFORMING PEOPLE ABOUT PALLIATIVE CARE
STRESS IN PALLIATIVE CARE

HOW TO START A PALLIATIVE CARE SERVICE

see Getting Started. Derek Doyle's booklet is available on this website and provides more detailed information than what follows here—everything you need to know when planning to start a new hospice/palliative care service

The eventual success and effectiveness of a palliative care service depends very largely on how well it is planned

- the need for a palliative care service is often so great that those eager to establish it do not always give it the thoughtful planning that is needed
- the planning stage may take much longer than expected, sometimes years

Local factors are most important in planning a palliative care service

- the situation will vary greatly from one country to another and even within a single country
- IAHPC believes that each developing country should be encouraged and enabled to develop its own model(s) of palliative care, taking advantage of the experience and expertise accumulated in developed countries, and not be expected to copy models more appropriate to affluent countries

The planning of any palliative care service requires

- a well-conducted needs assessment (subjective assessment of need is never adequate)
- discussion with local, regional and even national health care planners (who may not know what palliative care is)
- discussion with all other local groups (statutory and voluntary) providing

palliative care in any form (duplication of services is wasteful and counterproductive)

- consideration of the model(s) of care which might best meet local needs
- consideration of staffing implications and recruitment issues
- consideration of the educational role of any planned service
- consideration of relations with local hospitals, clinics and diagnostic facilities
- consideration of the availability of equipment and pharmaceuticals
- consideration of capital investment needs, funding requirements, reimbursement issues

Needs Assessment

Examples of questions to be asked include

- **Patients**
  - which diseases in a particular community are likely to benefit from palliative care
  - how many potential patients are there
  - what is their age distribution
  - what is the prevalence of symptoms
  - what are thought to be the unmet needs of these patients
  - what proportions are dying at home or in hospital
- **Priorities**
  - is the service to provide care or to train family members to care better
  - is the service to provide care or to educate and train local health care professionals to provide better care
  - is the service to provide care or simply assist the doctors and nurses already managing the patients in the community or hospital
  - 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
- **Models of care**
  - what are the obstacles to good palliation as perceived by health care workers in the area
  - should it provide home care or inpatient care
  - should there be a palliative care ward in the local hospital or a free-standing hospice
  - should a hospital 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
        - the local hospital
        - the local medical community
    - are medications available
    - is there access to basic diagnostic facilities
    - will medical records in other hospitals be made available
    - will fees be charged for the use of any of these facilities

Discussion with Strategic Planners

- those planning a new palliative care service often complain that strategic planners and health care managers do not want to listen to them and seem to be ignorant about palliative care
    - co-operation with them may not be easy but it is never wasted time
    - the planners may need to visit established palliative care services or be presented with data from other services serving similar population groups
    - the closer the collaboration, the better the eventual service
- the aims of these discussions are
    - to inform each other of needs and possible responses
    - to prevent duplication of activities and waste of precious resources
    - to foster co-operation rather than competition and conflict
- a well planned service, fitting neatly into a local or regional plan, will enable patients, whether at home or in a hospital, to receive seamless palliative care

Discussion with Other Providers

Discussions should be held with all other local health care providers who may be affected by the planned palliative care service

- **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 must be clearly defined to foster co-operation and to avoid any antagonism
    - will 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?
    - if hospital patients are transferred to palliative care, will their records come with them?
- **other palliative care services**
    - to avoid unhealthy competition between palliative care providers
        - competition usually wastes precious resources and may deprive some patients of the care they need and deserve
        - competing services can produce confusion in the minds of the public and the local health care professionals
    - each provider to define what service they can offer and then, in discussion with other providers, decide who does what
        - catchment areas can be defined
        - agreement can be reached on the types of patients accepted by each service (e.g. non-malignant disease, AIDS, etc)
    - to foster co-operation in
        - the use of specialized services e.g. lymphoedema treatment
        - education and training
- **the community**
    - appointment of a local fund-raiser will raise the image of the new palliative care service and hopefully bring in essential income for its development
        - ideally, this should be someone with no clinical responsibilities

There is no one way to handle all these potential conflicts and problems. They call for patience, tact, diplomacy and courtesy.

Considerations of Staffing and Recruitment

- **palliative care must be multiprofessional or interprofessional**
    - optimal palliative care requires the co-ordinated input from doctors, nurses and various allied health professionals
    - no one profession can provide palliative care on its own, no matter how committed they are
    - palliative care promoted as nursing care, without any need for medical involvement, will not be recognized by doctors
- **there is often much healthy overlap of roles in an interprofessional team**
    - for example nurses can be as effective at counselling as most doctors, but neither may be as good as a social workers or pastoral care specialists
    - this requires staff to be flexible to avoid conflicts between the different professions

    - there is no place for territorialism in palliative care
    - relatives taught to do some nursing care should be seen as complementing the trained nurses rather than replacing them
- **planning the nursing establishment**
    - depends primarily on the level of dependency of the patients
        - patients with different diseases have different nursing needs
        - e.g., patients with motor neurone disease (ALS) often need more nursing care than most cancer patients
    - for community-based services, other factors relate to
        - the case load
        - the distances to be travelled
        - whether other community nurses are available
        - the availability of doctors with a knowledge of palliative care
        - whether the palliative care nurses will do nursing tasks or are primarily support/resource/advisory nurses
- **consider the possibility of sharing staff with other medical services**
    - sharing social workers, occupational therapists, pastoral care workers and other allied health personnel, which
        - can be an educational experience for each group
        - may reduce expenses
    - the possibility should always be considered for nurses to rotate between the hospital and the community palliative care service once they have been adequately trained
- **do not underestimate the need for both pre-service and in-service training**
    - many health care professionals (doctors, nurses, and allied health personnel) think that palliative care is simple
        - something that can be done without training, something that we all do naturally
        - others think of it as care of the chronic sick or of the elderly
        - some think of it as merely offering psychological support
    - the result is that many who apply to work in palliative care services are totally unsuited for the work
    - all personnel working in palliative care for the first time will need training
- **what personal and professional qualities should be looked for when recruiting staff?**
    - personality is far more important than anything else
        - the undoubted stresses of palliative care are more related to the personalities of the staff than to the work itself
    - they are able to work harmoniously with others
    - they are flexible and able to compromise
    - previous experience of palliative care, geriatric care and psychotherapy are not essential

            - everyone will need training
            - a sense of humour is essential

Educational Responsibilities

- every palliative care service must be prepared to offer an educational service
    - varies from an occasional meeting to a full scale course, according to local needs and resources
- to share palliative care skills, expertise and enthusiasm with other (non-palliative care) health care professionals
    - it is to be hoped that they are the ones who will provide most of the palliative care in the future

Clinical Collaboration

- the ultimate goal in planning a palliative care service is for patients to receive optimal palliative care wherever they are (in hospital, hospice or at home), and care which continues in a seamless manner when they are moved between places of care
- all local health care providers who may be affected by the palliative care service should be involved in the planning stage, or at least kept well informed
- details must be discussed from the early planning stages of
    - which patients should be referred
    - when and how they should be referred
    - how the new service will integrate with hospital services
    - how the new service will integrate with general practitioners
    - availability of diagnostic services

REGULATION AND ACCREDITATION IN PALLIATIVE CARE

The aim should be to have palliative care recognized as a part of routine health care provision and funded in a similar manner

- this requires that palliative care services be audited and the professional staff accredited as for any other health care service

Organizational accreditation

- in some countries, national palliative care associations have developed criteria or standards of care by which palliative care services are judged or accredited
    - these standards are designed to assess

        - whether a service is operating efficiently (to satisfy government agencies or whoever is funding the service)
        - whether a service is meeting the needs of its patients (to maintain the good name of palliative care and satisfy members of the community)
- accreditation audits are usually performed every 3 to 5 years

Professional accreditation

- in some countries, professional medical and nursing organisations have established postgraduate qualifications for specialists in palliative care
    - the criteria to obtain these qualifications varies, but might include
        - a specified number of years working in palliative care
        - attendance at regular courses of continuing education
        - studying for a specialist diploma or degree in palliative care
- in any particular country, the accreditation of doctors and nurses in palliative care should be the same as for any other specialty
- as in all other medical and nursing disciplines, continuing professional education is essential and must be factored into staff management plans

EDUCATION AND TRAINING FOR SERVICE STAFF

All doctors, nurses and allied health professionals working in palliative care for the first time will need training

- routine professional education and training does not adequately equip them to offer the best standard of palliative care

Minimum requirements for a doctor include

- knowledge of modern methods of pain and symptom management
- understanding of the complex psychosocial needs of the terminally ill and their relatives
- understanding of spirituality in relation to palliative care
- understanding of cultural and ethnic issues in relation to palliative care
- communication skills in relation to palliative care
- understanding of the ethical issues in palliative care
- bereavement care
- working as an member of an interprofessional team

Minimum requirements for a nurse include

- same requirements as above

- less emphasis on pharmacological methods in pain and symptom management
- greater focus on observing and recording patients' suffering

In service and continuing education

- are needed to
    - to maintain skills
    - keep up-to-date with new developments
- include
    - clinical meetings and case discussions
    - journal clubs
    - invited speakers
    - conferences, including reporting-back sessions after the meeting
    - visits to other units, particularly if they are of similar size and scope of work
- should be co-ordinated by one member of staff
    - program development
    - ensuring that each staff member is given the opportunity to attend appropriate courses or conferences
    - encouraging all personnel to keep a record book of professional development
- there should be budgetary provision for continuing education
- each member of staff should keep a record of their specialist training, courses and conferences attended, etc

Library facilities

Access to a library is essential in palliative care

- **textbooks** are useful but are expensive and go out of date
- **journals** of particular use include
    - Palliative Medicine
    - European Journal of Palliative Care
    - Journal of Pain and Symptom Management
    - Journal of Palliative Medicine
    - Progress in Palliative Care
    - Journal of Palliative Care
    - International Journal of Palliative Nursing

- **Internet access**
    - many internet sites now provide access to a lot of palliative care information

see Resources

EXTERNAL EDUCATION AND TRAINING

Every palliative care service must provide education and training in the principles and practice of palliative care to other health care professionals. This is an ethical imperative.

- this should be planned from inception
- it is too often left until after the clinical work and budget are established

In planning an outreach education program

- set up a committee to oversee the educational work of the unit (e.g. palliative care doctor, nurse tutor, local GP, hospital specialist, all with an established interest in palliative care and some experience of teaching)
- be clear what the palliative care unit can offer in terms of time and available expertise
- cater for all groups, not just doctors
- discuss perceived needs with the groups
- always obtain feedback after all teaching sessions
- involve local colleges and teachers, especially for topics about which the palliative care unit does not have expertise
- provide coverage of all aspects of palliative care, not just pain control
- don’t expect it to generate income
- use all available teaching techniques and models including didactic, discussions, role play, case studies, patient-led, journal club, film and video
- where it is available and not too expensive, consider video-conferencing

Models

- each palliative care service must design its own model for education, appropriate to local needs and local resources, in co-operation with other providers, be they universities, colleges, other palliative care units, governments or charitable agencies
- use modern technology if it is available but do not assume that it replaces a gifted teacher
- keep the teaching simple
- palliative care need not be made to sound sophisticated to be worthwhile
- principles are more important than the minutiae

Priorities

- if resources are limited, which professional groups should be given priority for education and training?
- priorities can only be decided locally, but
    - for palliative care to succeed, the doctors must be won over and

    give it their enthusiastic support
    - the younger the doctors and nurses being offered training, the quicker change occurs in local palliative care practice

INFORMING PEOPLE ABOUT PALLIATIVE CARE

Palliative care workers often report that politicians, the press, fellow professionals and even the public do not know much about palliative care. What do they need to know and how can we ensure that they are well informed?

Informing politicians

They should know about palliative care because

- it affects the people they represent
- it requires money over which they have some control
- it is an integral part of modern health care
- issues raised by it - quality of life, value of life, euthanasia - are important issues in modern society
- issues related to the availability of opioids and other medications are important issues in developing countries

They can be helped to know more about palliative care by

- establishing an All Party Parliamentary Palliative Care Group. Such groups meet quarterly to hear a very brief talk, are given regular briefings on all topics central to palliative care provision in that country (funding, staffing, resources, opioid availability, etc) and sent an information pack several times a year to keep them up-to-date.
- inviting every local politician to visit the palliative care units in their constituency and attend all public functions.
- inviting the parliamentarians to open new buildings, launch new projects, present prizes - so as to keep their names and the work of the palliative care unit before the public

Informing the press

If kept well-informed the press can be the friends and allies of palliative care not its critics or detractors

- they influence public opinion
- they influence politicians
- they can help to raise funds and public awareness
- they offer a platform to deal with key issues such as euthanasia, resource allocation, and opioid availability

They can be helped to know about palliative care by

- being sent regular press briefings by a professional Press / PR Officer employed by the National Palliative Care Association. This ensures high quality briefings and saves individual units trying to prepare press statements
- by inviting local and national press to all palliative care events, big or small
- by having a national panel of palliative care experts willing and able to speak on radio or appear on TV when matters related to palliative care are being discussed
- by inviting photographers to all public-interest events in a palliative care unit
- by having press briefings, preferably chaired by someone with PR experience, when new palliative care projects / services / courses are being launched
- by keeping them informed of what is happening in the rest of the world of palliative care. (There are few better incentives to improve services than learning how much better other countries seem to be doing it)

Informing the Professionals

Fellow professionals need to know what palliative care is, how they can access it, how it might or might not help their patients and how they might practice it themselves

- there are often misunderstandings about what palliative care is. It is seen as terminal care or geriatric care or care of the incurable or care of the chronic sick or as being appropriate only to oncology patients or a dignified and well-intentioned form of euthanasia.

They can be helped to know about palliative care

- by seeing the nature and effectiveness of palliative care when we are called to see their patients. Beyond doubt this is the best demonstration that can be offered
- by the quality of our correspondence about patients, our clinical presentations, our professional papers in peer-reviewed journals and our talks at conferences and meetings
- by being invited to visit palliative care units either as visitors or to advise on patients or to attend ‘grand rounds’ or clinical meetings
- by the quality of our clinical and organizational audits and standard setting
- by the quality of published papers emanating from palliative care services

Informing the General Public and Patients

To many people hospice / palliative care is care of the dying. Being sent to such a place is proof that death is imminent. Word gets round that the care is good and the staff deeply caring but few people know what a high proportion of patients are discharged home, how palliative care teams operate in many general and specialist hospitals, and that doctors and nurses are increasingly being taught it before qualifying. Even fewer will have heard of Day Hospices and fewer still know what it costs to operate a palliative care service.

They can be helped to know about palliative care

- by hearing about it on the media, reading about it in the press
- by meeting people who have received it or whose relatives have received it
- by reading explanatory leaflets about it in the offices of their family doctors and in hospital waiting rooms
- by reading how they can help it financially in leaflets prepared for their legal adviser's offices
- by reading the special leaflets prepared for every patient, every visitor to each palliative care service in the country

STRESS IN PALLIATIVE CARE

Working in palliative care *is* stressful, although possibly no more than in other specialties.

Causes of stress in palliative care

- **organizational**
    - poor administration
    - lack of goal definition
    - inadequate funding for infrastructure, personnel, medications
    - lack of resources, poor allocation
    - failure to recognize clinical team's achievements
    - no opportunity to develop new skills
- **team**
    - poor leadership
    - poor definition of goals
    - unreasonable clinical workloads
    - reimbursement issues
    - poor communication
    - role ambiguity: interdisciplinary conflict
- **patients**
    - difficult patients
    - difficult dysfunctional families
    - emotional attachment to patients

- **unrealistic goals**
  - attempting to solve all problems
  - attempting to deal with long-standing family problems
- **personal stresses**
  - personal
  - marital
  - family

In practice, most of the stress relates to unrealistic goals and personal stresses.

How do you deal with stress in palliative care?

- address and remedy organizational problems
- ensure that the goals of the team as a whole and its individual members are realistic
- workers have to take some responsibility for their own psychological health
- whatever the cause, a service has to have adequate support systems in place
- a new service should have a formal staff support system
  - a monthly multiprofessional meeting led by an experienced facilitator
  - may no longer be required after about two years when the staff are comfortable with each other and their goals realistic
- importance in staff selection: can the person recognize stress, do they have other interests, have they worked in a team, are they flexible?

While no-one will deny that working in palliative care can be stressful, there is no evidence that it is more stressful than most other medical and nursing specialties, and it is probably equally enjoyable and rewarding.

« Table of contents

The IAHPC Manual of Palliative Care *3rd Edition*

« Table of contents

VII. Resources

JOURNALS
BOOKS
INTERNET

JOURNALS

A number of journals are available that specialise in palliative care, including

- Palliative Medicine
- European Journal of Palliative Care
- Journal of Pain and Symptom Management
- Journal of Palliative Medicine
- Progress in Palliative Care
- Journal of Palliative Care
- International Journal of Palliative Nursing

BOOKS

Hundreds of books about various aspects of palliative care have been published in the last 10 years, perhaps a sign that palliative care has come of age. Those listed (alphabetically) here are amongst the best. You can read reviews of these and many other books in the Book Reviews section.

GENERAL

Berger, Shuster and Von Roenn (Eds). **PRINCIPLES AND PRACTICE OF PALLIATIVE CARE AND SUPPORTIVE ONCOLOGY 4e**. Lippincott, Williams and Wilkins, 2013.

Bruera, Higginson, Ripamonti and von Gunten (Eds). **TEXTBOOK OF PALLIATIVE MEDICINE.** Hodder Arnold, 2007.

Ferrell and Coyle (Eds). **OXFORD TEXTBOOK OF PALLIATIVE NURSING 3e.** Oxford University Press, 2010.

Hanks, Cherny, Christakis, Fallon, Kaasa and Portenoy (Eds). **THE OXFORD TEXTBOOK OF PALLIATIVE MEDICINE 4e.** Oxford University Press, 2009.

Matzo and Sherman (Eds). **PALLIATIVE CARE NURSING 3e. Quality Care to the End of Life.** Springer Publishing Company, 2010.

Regnard and Dean. **A GUIDE TO SYMPTOM RELIEF IN PALLIATIVE CARE 6e.** Radcliffe Publishing, 2010.

Sykes, Edmonds and Wiles (Eds). **MANAGEMENT OF ADVANCED DISEASE 4e.** Arnold, 2004.

Twycross and Wilcock (Eds). **PALLIATIVE CARE FORMULARY 4e.** Palliativedrugs.com Ltd, 2011.

Twycross, Wilcock and Toller. **SYMPTOM MANGEMENT IN ADVANCED CANCER 4e.** Palliativedrugs.com Ltd, 2009.

Walsh, Caraceni, Fainsinger, Foley, Glare, Goh, Lloyd-Williams, Olarte and Radbruch (Eds). **PALLIATIVE MEDICINE.** Saunders Elsevier, 2008.

Watson, Lucas, Hoy and Wells. **OXFORD HANDBOOK OF PALLIATIVE CARE. 2e.** Oxford University Press, 2009.

Woodruff R. **PALLIATIVE MEDICINE. Evidence based symptomatic and supportive care for patients with advanced cancer 4e**. Oxford University Press, 2004.

PAIN

Bruera and Portenoy (Eds). **CANCER PAIN. Assessment and Management 2e.** Cambridge University Press, 2010.

Davis, Glare, Quigley and Hardy (Eds). **OPIOIDS IN CANCER PAIN 2e.** Oxford University Press, 2009.

Dickman and Schneider. **THE SYRINGE DRIVER 3e. Continuous Subcutaneous Infusions in Palliative Care.** Oxford University Press, 2011.

Dworkin and Breitbart (Eds). **PSYCHOSOCIAL ASPECTS OF PAIN. A HANDBOOK FOR HEALTH CARE PROVIDERS.** International Association for the Study of Pain (IASP), 2004.

Sykes, Bennett and Wuan (Eds). **CANCER PAIN 2e.** Hodder Arnold, 2008.

PSYCHOLOGICAL

Chochinov and Breitbart (Eds). **HANDBOOK OF PSYCHIATRY IN PALLIATIVE MEDICINE 2e.** Oxford University Press, 2009.

Holland, Breitbart, Jacobsen, Lederberg, Loscalzo and McCorkle (Eds). **PSYCHO-ONCOLOGY 2e.** Oxford University Press, 2010.

SOCIAL

Altilio and Otis-Green (Eds). **OXFORD TEXTBOOK OF PALLIATIVE SOCIAL WORK.** Oxford University Press, 2011.

SPIRITUAL

Cobb, Puchalski and Rumbold (Eds). **OXFORD TEXTBOOK OF SPIRITUALITY IN HEALTH CARE.** Oxford University Press, 2012.

Puchalski. **A TIME FOR LISTENING AND CARING. Spirituality And The Care Of The Chronically Ill And Dying.** Oxford University Press, 2006.

COMMUNICATION

Kissane, Bultz, Butow, and Finlay (Eds). **HANDBOOK OF COMMUNICATION IN ONCOLOGY AND PALLIATIVE CARE.** Oxford University Press, 2010.

CHILDREN

Goldman, Hain and Liben (Eds). **OXFORD TEXTBOOK OF PALLIATIVE CARE FOR CHILDREN 2e.** Oxford University Press, 2012.

Wolfe, Hinds and Sourkes (Eds). **TEXTBOOK OF INTERDISCIPLINARY PEDIATRIC PALLIATIVE CARE.** Saunders (Elsevier), 2011.

ETHICS

Berlinger, Jennings and Wolf (Eds). **THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE 2e.** Oxford University Press, 2013.

INTERNET RESOURCES

There is a wealth of information available on the internet. This list just touches the surface; sites are listed alphabetically.

Care Search – bibliography of systematic reviews, with commentary

http://www.caresearch.com.au/caresearch/ClinicalEvidence/tabid/65/Default.aspx

Center to Advance Palliative Care

http://www.capc.org/

Cochrane Pain, Palliative and Supportive Care Review Group (PaPaS)

http://papas.cochrane.org/welcome

Department of Pain Medicine and Palliative Care, Beth Israel Medical Center

www.StopPain.org

End of Life Palliative Education Resource Center (EPERC)

http://www.eperc.mcw.edu/EPERC

European Society for Medical Oncology (ESMO) pain guidelines

http://annonc.oxfordjournals.org/content/22/suppl_6/vi69.long

Fast Facts: End of Life Palliative Education Resource Center (EPERC)

http://www.eperc.mcw.edu/EPERC/FastFactsIndex

Innovations in End of Life Care

http://www2.edc.org/lastacts/

Liverpool Care Pathway

http://www.sii-mcpcil.org.uk/lcp.aspx

National Cancer Institute – PDQ Supportive and Palliative Care

http://www.cancer.gov/cancertopics/pdq/supportivecare/

National Consensus Project for Quality Palliative Care

http://www.nationalconsensusproject.org/

National Institute for Health and Care Excellence – Palliative Cancer Care

http://cks.nice.org.uk/

National Palliative Care Research Center (NPCRC)

http://www.npcrc.org/

NCCN Clinical Practice Guidelines in Oncology – Palliative Care

http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

Palliative Care Formulary.

www.palliativedrugs.com

Palliative.Info – an up-to-date collection of links to palliative care resources

http://www.palliative.info/

PCC4U – Palliative Care Curriculum for Undergraduates

http://www.pcc4u.org/

Promoting Excellence in End-of-Life Care

http://www.promotingexcellence.org/

Scottish Intercollegiate Guidelines Network – Pain in Adults with Cancer

http://www.sign.ac.uk/guidelines/fulltext/106/index.html

Shaare Zedek Cancer Pain and Palliative Medicine Reference Database

http://www.chernydatabase.org/

<< Table of Contents