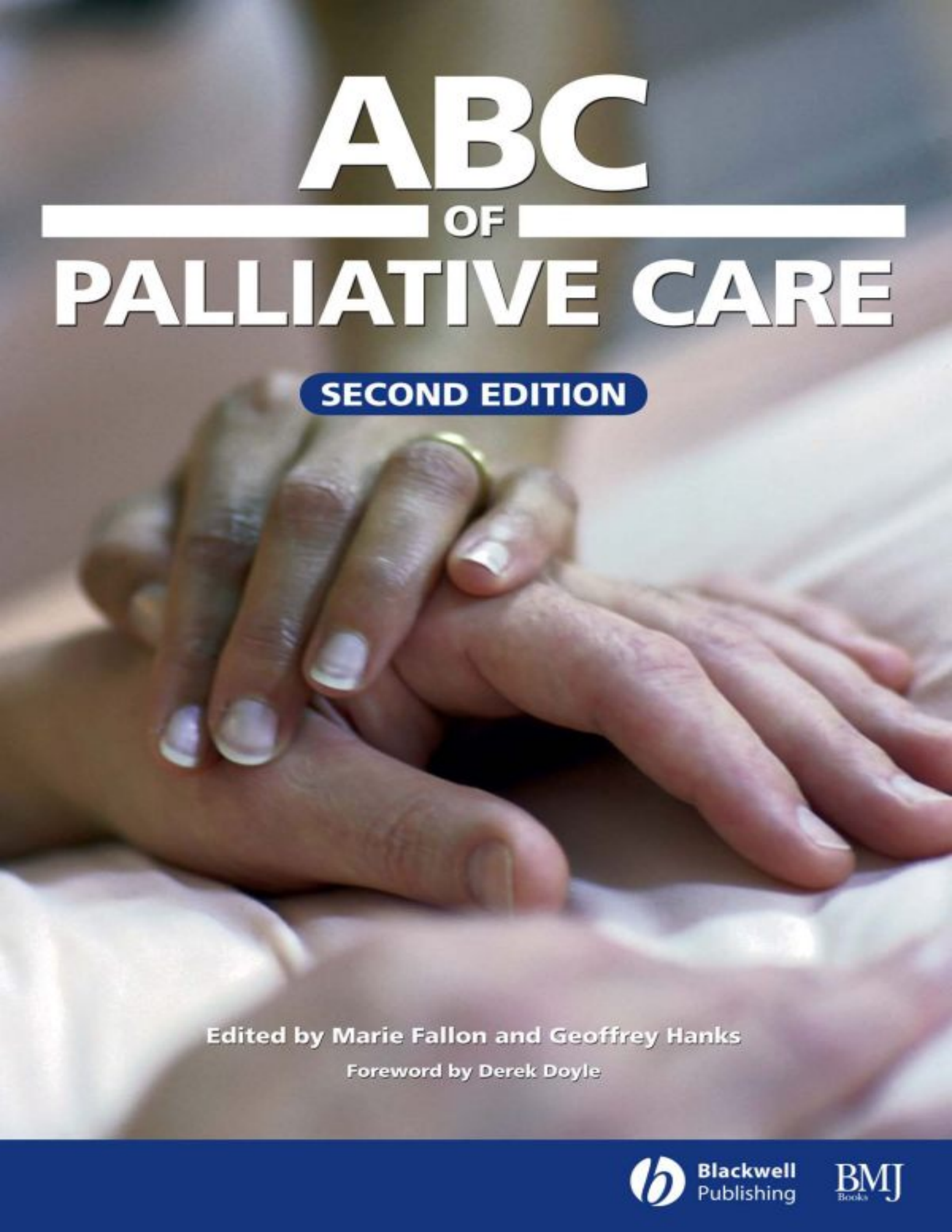
ABC
OF
PALLIATIVE CARE
SECOND EDITION
Edited by Marie Fallon and Geoffrey Hanks
Foreword by Derek Doyle
Blackwell Publishing
BMJ Books

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Second Edition

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BMJ Books

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Foreword

It is almost impossible for a health care professional to avoid being called upon to care for people getting frailer as life ebbs away, to care for them at their dying and to have to help and support their loved ones afterwards. Who can be insensitive to their pain, their breathlessness, their weakness and their fears? Who can forget how helpless they have felt at these times, how lost for words, how unskilled and unprepared. Doctors and nurses, whether generalist or specialist, can no more avoid these professional and personal challenges than they can deny or avoid death itself.

Palliative care – *"the care of patients with active, progressive, advanced disease where the prognosis is short and the focus of care is the quality of life"* – is a basic human right, not a luxury for the few. Its principles are not peculiar to the care of the dying but are the integral features of all good clinical care – freedom from pain and the alleviation so far as is possible, of all physical, psychosocial and spiritual suffering; the preservation of dignity; the utmost respect for honesty in all our dealings with these patients and their relatives.

The emergence in 1987 of palliative care as a medical sub-specialty (mentioned in the Preface to the first edition of this book) has brought about improvements in care, research, professional education and training, and in the understanding by the public and the politicians of what needs to be done and what can be done for those at the loneliest time on their life journey. It has also had a downside. Many have come to suspect that providing palliative care requires unique people to do justice to this demanding work, unique skills to do it well, and more time

than today’s doctors and nurses ever have. So easy is it to phone a palliative care specialist whether working in a hospital, a specialist unit or in the community, and get advice or an admission that some are leaving the palliative care of their patients to them. In fact only about 10% of terminally ill patients have problems so rare or so complex that specialist expertise is needed. All the others can be cared for by non-specialists if they learn the principles of palliative care, if they develop the right attitude to it, if they are willing to share themselves as well as their therapeutic skills… and if they study this book. One thing is undeniable – no-one is born with a built-in ability to provide excellent care. It has to be learnt from a book such as this, and hopefully from watching others with more experience, but that is a luxury some never have.

In situations where too often the knee-jerk response can be “there is no more we can do”, the reader will find that there is always a means of helping and of caring. It may be pharmacological or psychological, nursing or physiotherapy, occupational therapy, music or art therapy, or complementary medicine. Often it may be no more, no less than enabling patients to open their hearts in that atmosphere of safety created by the doctor or nurse who has learned to be honest, and is humble enough to listen and to learn.

The reader will be surprised at how richly rewarding palliative care can be; how surprisingly often terminally ill patients speak of the sense of safety they feel when suffering has been relieved and they know everyone is being honest with them and the loved ones they will leave behind. This can happen anywhere – in a hospital, in a hospice, in a nursing home or in someone’s home.

This excellent book produced by editors and contributors with international reputations deserves to be read by every

doctor and nurse who will ever offer palliative care – and that means most of us!

Derek Doyle

Retired consultant in palliative medicine

Vice President, National Council for Palliative Care

Founding Member and Adviser,

International Association for Hospice and Palliative Care

1

The principles of palliative care

Balfour Mount, Geoffrey Hanks, Lorna McGoldrick

Components of palliative care

Palliative care is recognised by individualised, holistic models of care, delivered carefully, sensitively, ethically, and therapeutically by using skilled communication with attention to detail, meticulous assessment, and advancing knowledge.

Wherever palliative care is used, its core ingredient is the quality of presence that the caregiver brings to the patient, a way of caring that enables discernment of the ongoing needs of the patient and family as they evolve and emphasises being alongside them. The focus is on all that is still possible in this time of multiple losses, the patient's and family's quest for meaning, and sustaining their experience of connectedness as they adapt to the challenges of the moment.

The term "palliative care" implies a personalised form of health care. It extends the healthcare professional's mandate beyond the biomedical model to the wider horizon necessary if one is to attend to suffering as well as the biology of disease, caring as well as curing, quality of life as

well as quantity of life. The patient and family or significant others are taken together as the unit of care in assessment of needs related to illness. The aim of palliative care is to support optimal quality of life and to foster healing—that is, a shift in response towards an experience of *integrity* and wholeness on the continuum of the quality of life.

Beyond the physical

Meticulous attention to the alleviation of symptoms is the foundation of care of the whole person. Important psychosocial and spiritual concerns may be eclipsed by the presence of uncontrolled pain, nausea, constipation, and the other symptoms of advanced disease. Optimal treatment demands careful assessment of the multiple contributory factors to each symptom. If increasing doses of opioid are prescribed in response to pain that is escalating due to unrecognised existential anguish, the result will be persistent pain, opioid toxicity, and ongoing distress for the patient, family, and caregivers. If we are body, mind, and spirit, those domains are inseparable and interdependent. Thoughtful assessment of each complaint should be considered in the context of the patient's total suffering; therefore thoughtful assessment is mandatory.

Not just symptom control

Control of symptoms in palliative care commonly involves the concurrent use of six to eight or more medications. The goal is consistently to prevent rather than treat symptoms. Effective management depends on frequent adjustment to consistently sustain the minimal effective doses of medication and an emphasis on skilled nursing care as well as the use of the complementary skills of an interdisciplinary team experienced in end of life care.

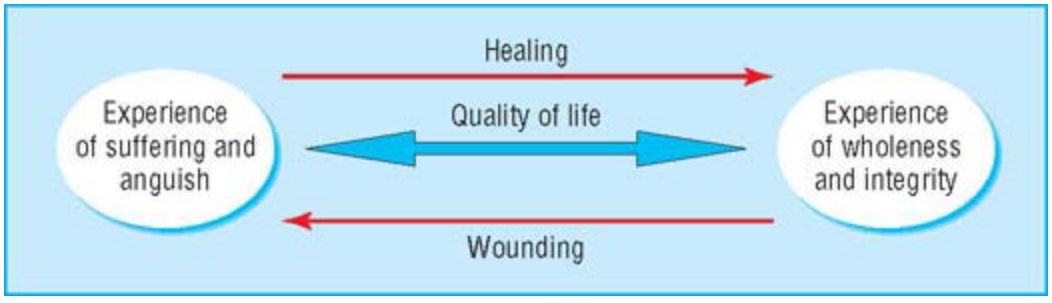
Laboratory investigations—and even such non-invasive routines as monitoring blood pressure, pulse, and

temperature—are undertaken only if doing so may lead to interventions that will enhance the quality of life.

Palliative care is founded on a philosophy that promotes sensitivity to cultural, religious, sexual, and other defining perspectives from the patient's point of view; the intent to meet patients where they are rather than where the caregivers feel they should be; sensitivity to the determinants of coping, particularly concerning major existential challenges for the patient, family, and caregivers (death; isolation; freedom—the absence of external structure; meaning); attention to the meaning of the illness for the patient, family, and caregivers; and attention to the need for relating to people in an empathic way.

Palliative care is the 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 (World Health Organization, 2005)

The quality of life continuum



Palliative care: selected philosophical perspectives and assumptions

- Nothing matters more than the bowels (Cecily Saunders)
- Humanise, personalise, de-institutionalise
- Clinical care grounded in qualitative and quantitative inquiry
- Experience of illness viewed as a narrative: relational, meaningful, filled with potential
- Assist progressive understanding of reality at a rate acceptable to the patient
- “Reality” as illusion; subjectivity of experience; acknowledgment of mystery
- Quiet efficiency, not hustle and bustle
- Focus on quality of living in the present moment, not death
- Accompaniment: empathic presence to the other in the moment
- Team: led by the patient; egalitarian rather than hierarchical
- Environment: centred on the patient, welcoming, peaceful
- Uniqueness, limitations, defences of the patient/family
- Healing of psyche: an innate potential
- Potential for adaptation, integration, reconciliation, transcendence
- Importance of compassion, celebration, community, paradox, humour
- With unresolved symptoms, “Review! Review! Review!” (Robert Twycross)

Application

The early successes of hospice care in alleviating the suffering of patients with cancer and those with motor neurone disease and some other neurodegenerative diseases at the end of life has led now to broad agreement concerning the relevance of palliative care across the spectrum of disease and healthcare settings.

Care delivery

Considerations in the provision of palliative care include a seamless continuity of care appropriate to the needs of the patient and the family, with options that include home care; chronic inpatient care; acute, specialised inpatient (tertiary) care; consultation services available for those still receiving

treatment to modify the disease; day care with resources for multidisciplinary assessment; bereavement support for those at risk of a complicated grief reaction.

Specialist role

General palliative care is practiced widely in specialties other than palliative care. Multiprofessional teams who work full time in palliative care, and are trained beyond the basic level, deliver specialist palliative care. They aim to care for those patients and carers who have complex physical, psychosocial, or spiritual needs that are difficult to manage. Their role is primarily about advice, support, and education when they work alongside other specialties. Hospices and hospice wards have more direct management of patients and carers in an inpatient setting. Role modelling, service development in line with local, national, and WHO guidelines, education, and research are further components of the role.

Multidisciplinary teams

Caring for patients and carers at a difficult time is synonymous with palliative care. Each patient and carer will require a unique and individualised approach to incorporate all their biopsychosocial and spiritual needs. There cannot be a universal optimum model for the delivery of care; adaptability and flexibility is paramount, and this is an increasing challenge in today’s healthcare systems.

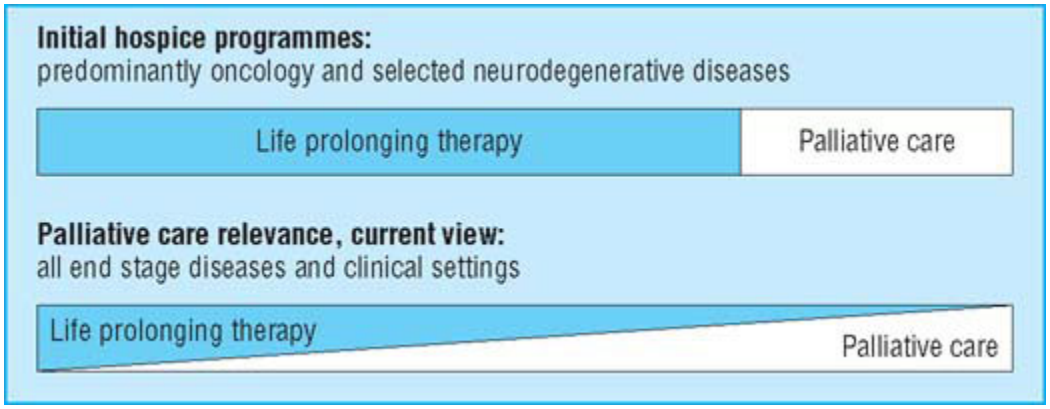
A single profession, like a single model of care, can only fail to meet the holistic fluctuating needs of patients and carers. The knowledge and skill of many professions—medical, nursing, pharmacy, social work, physiotherapy,

occupational therapy, and chaplaincy—held together by endless communication and teamwork is vital.

Future challenges

New and evolving challenges in palliative care are emerging as patients live longer with improved palliative tumoricidal treatments. Symptoms that are difficult to control and are chronically debilitating test the resilience and resources of weary patients, carers, and providers of health care. Education and robust multiprofessional support are necessary to equip those working in palliative care with the sustainable resilience demanded by an unwavering quality of presence that continues to effectively focus on quality of life and care and attend to suffering of patients with longer and more difficult experiences.

Changes in allocation of resources with the development of palliative care



Palliative care

- Affirms life and regards dying as a normal practice
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the families of patients cope during the patient’s illnesses and in their own bereavement

Essential components of palliative care

- Control of symptoms
- Effective communication
- Rehabilitation
- Continuity of care
- Terminal care
- Support in bereavement
- Education
- Research

Dame Cecily Saunders, founder of St Christopher’s Hospice (reproduced with permission)

Without research, advances in the science of control of symptoms and quality of care will stagnate and palliative care will cease to meet the future needs of patients with advanced life threatening illnesses and their carers. Though there are numerous epidemiological surveys outlining problems, few researchers do good quality interventional studies or try to extend knowledge through collaboration with basic science. More collaborative research involving basic science and other appropriate specialties is needed urgently.

The late Dame Cecily Saunders and her vision of combining optimum care, observation, and appropriate research established the essential ingredients of modern palliative care; this should remain our basis for the future.

Further reading

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2

The principles of control of cancer pain

Marie Fallon, Geoffrey Hanks, Nathan Cherny

Pain is a complex phenomenon which is the subjective endpoint of a variety of physical and non-physical factors. For most patients, physical pain is only one of several symptoms of cancer. Relief of pain should therefore be seen as part of a comprehensive pattern of care encompassing the physical, psychological, social, and spiritual aspects of suffering. Physical aspects of pain cannot be treated in isolation from other aspects, nor can patients' anxieties be effectively addressed when patients are suffering physically. The various components must be addressed simultaneously.

Our understanding of the basic mechanisms of pain has improved considerably over the past few years. This understanding has included a greater appreciation of the relationship between the physical injury, pain pathways, and our emotional processing of this information; these factors are interlinked in the nervous system, rather than working in parallel. We now understand from basic science more of the mechanisms of total pain than ever before. It is clear that anxiety, fear, and sleeplessness feed into the limbic system and cortex. In turn, the brain talks back to the spinal cord modifying pain input at spinal levels. This then feeds back to the brain and a loop is established.

Mood disturbance is common in patients with uncontrolled cancer pain and may need specific management, however,

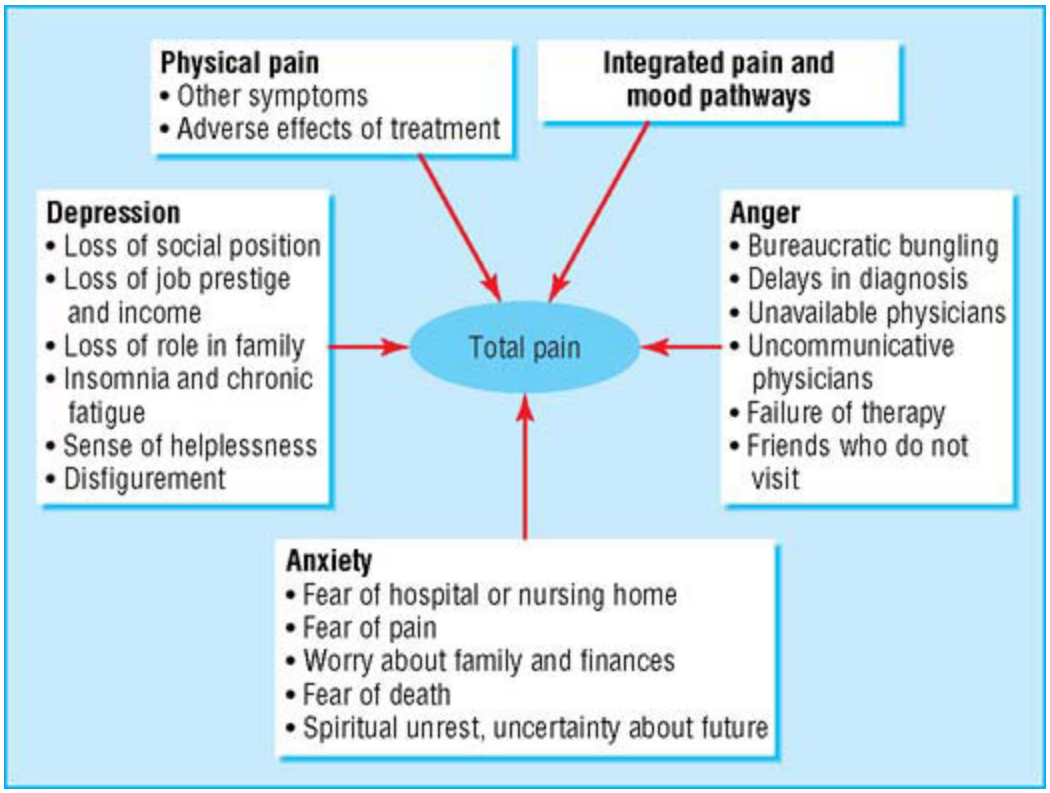
sometimes it will improve dramatically with effective resolution of pain. Hence the first principle of managing cancer pain is an adequate and full assessment of the cause of the pain, bearing in mind that most patients have more than one pain. With effective assessment and a systematic approach to the choice of analgesics using the WHO's three step analgesic ladder, over 80% of cancer pain can be controlled with the use of inexpensive drugs that can be self administered by mouth at regular intervals.

The WHO analgesic ladder

The analgesic ladder remains the mainstay of our approach to analgesia, though this was never designed for use in isolation. Surgery, radiotherapy, and appropriate tumoricidal treatments will have an important role in some patients, as will non-drug treatments. A combined approach can lead to optimum analgesia with minimum side effects.

Analgesic drugs do, however, remain key in managing cancer pain. The choice of drug should be based on the severity of the pain, not the stage of disease. Drugs should be administered in standard doses at regular intervals in a stepwise fashion. If a non-opioid or, in turn, an opioid for moderate pain is not sufficient, an opioid for severe pain should be used.

When a non-opioid drug is used with an opioid for moderate pain, many patients find combination formulations more convenient to use. Care must be taken with the dose of each drug in the formulation; some combinations of codeine or dihydrocodeine with aspirin or paracetamol (including co-codamol and co-dydramol) contain subtherapeutic doses of the opioid. The decision to use an opioid for severe pain should be based on severity of pain and not on prognosis.



Factors affecting patient's perceptions of pain (adapted from Twycross RG, Lack SA, *Therapeutics in terminal disease*, London: Pitman, 1984)

Analgesic drugs commonly recommended for cancer pain

Mild pain

- Aspirin 600 mg four times a day
- Paracetamol 1 g four times a day

Moderate pain

- Codeine 60 mg (plus non-opioid drug) four times a day

Severe pain

- Morphine 5–10 mg (starting dose) every four hours