National Workshop for a uniform course in Palliative Care in India

World health organization workshop to Finalize the outline and content for a uniform course in Palliative care for doctors and nurse in India 10th & 11th February 2009 Jawaharlal Nehru University, New Delhi

REPORT
Developed under GOI-WHO collaborative programme (2008-09)

Institute of Palliative Medicine
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The concept of modern palliative care was introduced to India more than a quarter of a century ago. Individuals and organizations, both within and outside the country have since then been trying to introduce services for the incurably and terminally ill people in India. Despite all the efforts, a meager one percent of those who need palliative care in the country have access to appropriate services.

One of the major problems has been lack of awareness and skills in palliative care among health care professionals. There are only very few centers offering training for doctors and nurses in palliative care in India. The courses offered also vary in format, content, quality and frequency. Indian Association of Palliative Care, the national umbrella organisation in the country has been trying to evolve a basic uniform course for doctors and nurses in palliative care. The workshop on 10th and 11th February 2009 at Jawaharlal University, New Delhi was aimed at finalizing the course content and background material for this Basic Certificate Course in Essentials of Palliative Care. The workshop organized by Institute of Palliative Medicine was supported by a World health Organisation. Delhi’s National Initiative in Palliative Care played the role of local host.

The workshop was successful in formulating the outline and background material for the course. We are happy to note that this final version of the course has since then been approved by the National Faculty in Palliative Care in India and Indian Association of Palliative Care (IAPC).

The course is being offered by IAPC through more than 20 outlets from June 2009 in the format suggested by the Workshop.

25 April 2009

Dr Suresh Kumar
Director
Institute of Palliative Medicine

Foreword
National Workshop for a uniform course in Palliative Care in India

World Health Organisation Workshop to finalize the outline and content for a uniform course in palliative care for doctors and nurses in India
10th & 11th February 2009
Jawaharlal Nehru University, New Delhi

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National Workshop to finalize a uniform course in Palliative Care
10th & 11th February 2009, Jawaharlal Nehru University, New Delhi
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National Workshop to finalize a uniform course in Palliative Care
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A uniform course in Palliative Care in India

Course Outline

INTRODUCTION
The majority of health care professionals working in hospitals and the community look after patients with palliative care needs on a regular basis. This course is aimed at helping such professionals consolidate and develop their confidence and expertise in palliative care. The course is also designed to meet the needs of health care professionals new to palliative care services who wish to develop or consolidate specialist knowledge and skills.

At its heart palliative care involves team working, and the course is appropriate for both doctors and nurses. As most candidates will have professional daytime commitments, the eight-week course is home study based.

GENERAL INFORMATION

- The contact sessions and evaluation are compulsory for successful completion of the course.
- Course fee is not refundable, but a single time extension of the contact session and evaluation may be considered for the candidates having genuine reasons. In such situation the course will be carried forward to the next session. If the regional centre where they had registered previously is not hosting the course next time, the candidates will be offered the next nearest centre for the continuation of the course.
- If a candidate fails to qualify in the evaluation session, he/she can appear for the second time with same course fee. Further attempts need fresh registration.
- The expense for travel, accommodation for the contact sessions will have to be met by the candidates.

COURSE OUTLINE
This Course has eight weeks of distance learning and 15 hours of contact sessions during the course period. **Attendance of the contact session is mandatory for successful completion of the course.** There will be an evaluation at the end of the course. Successful candidates will be awarded a Certificate.

There is an optional second part of the course with ten days of clinical placement at a palliative care unit convenient for the candidate. The candidates who successfully complete the clinical component will be eligible to apply for license to stock and dispense oral morphine under modified narcotic rules. Please note that some of the centres charge a bench fee for the clinical placement. Check with your regional coordinators for details. The members of the National Faculty in Palliative Care, through different centres in India, will deliver the course.
During the contact sessions there will be lectures on the following topics:

- Concepts of palliative care
- Management of chronic pain
- Management of other symptoms in advanced diseases
- Management of palliative care emergencies
- Communication skills and emotional support
- Nursing care in patients with advanced diseases
- Care of the elderly
- Community participation
- End of life care and ethical issues

The course material provided contains seven sections, which covers the most essential principles in palliative care practice. As part of the course, the candidate needs to submit a reflective case history for evaluation. Format for writing the reflective case history is enclosed.

**Aims of the Course**

The programme of study aims to:

- Provide the candidate with an opportunity to develop clinical practice by integrating it with up-to-date and relevant theoretical palliative care knowledge. Particulars attention will be paid to the holistic, patient and family centred nature of palliative care, including grief and bereavement.
- Provide opportunities to develop personal and professional reflection about the management of a patient with palliative care needs.
- Develop the ability to change clinical practice in the light of increased theoretical knowledge and personal reflection.

**Learning Objectives**

The programme is divided into seven sections:

**Section One: - Palliative Care - An Introduction**

This section gives an idea about the basic concept of palliative care.

**Section Two: - Communication Skills and Psychological Issues**

By the end of this section, the candidate should be able to learn:

- the basic skills in communicating with a patient
- strategy for breaking bad news and handling reactions
- an overview of the psychological issues in a chronically ill patient and practical management of the same.

**Section Three: - Ethical & Spiritual Issues**

By the end of this section the candidate should be able to:

- understand the ethical issues in palliative care
- learn the concept of spiritual distress

**Section Four: - Management of Pain**

By the end of the section, the candidate should be able to...
• demonstrate knowledge relevant to assessment of pain
• identify the cause of pain
• discuss the psychological, social and spiritual factors contributing to total pain
• demonstrate the application of knowledge (especially in WHO analgesic ladder) can improve the management of chronic pain

Section Five: - Management of Other Symptoms

By the end of the section, the candidate should be able to
• identify the causes and plan the management for a patient with the common gastro intestinal and respiratory problems.
• identify the common nursing issues in chronically ill and bedridden patients and learn the practical management of the same.

Section Six: - Palliative Care Emergencies and Common Conditions Requiring Palliative Care

By the end of the section, the candidate should be able to
• identify the emergency situations in palliative care which requires prompt recognition and management
• have an understanding about the conditions other than cancer which needs long term care and plan appropriate management for the same.

Section Seven: - End of Life Care and Practical Issues Related to Death

By the end of the section the candidate should be able to
• recognize the signs and symptoms when death is approaching
• make a holistic assessment of the needs of the patient and their family in the terminal phase
• recognize the manifestation of the grieving process in bereaved adults and children and describe the ways to help them
• understand certain basic concepts of organ donation

EVALUATION

A: Theory Examination and ‘spotters’

B: Evaluation of case reflection

Theory examination includes short answer questions, multiple choice questions, and true/false questions:

Pass mark is 50%. The candidate has to score 50% for A and B separately.

The details of grading criteria for case reflection are given at the end.

THE CASE REFLECTION

The case reflection is a learning tool to reflect on the candidate’s own clinical practice, and improve his/her practice accordingly. This enables the learner to build on their own experience and improve practitioners’ ability to assess, make sense of and learn through work experience to achieve more desirable, effective and satisfying work.

A case reflection can help the learner to plan his/her learning needs, identify gaps in knowledge and record achievements.
The case reflection will need to contain personal and professional information and evidence demonstrating the candidate’s professional development, skill acquisition and knowledge growth.

**Aims of Case Reflection**
- To illustrate the candidate’s ability to integrate and develop his/her clinical practice with relevant theoretical palliative care knowledge, paying particular attention to the holistic, patient and family centered nature of palliative care, including grief and bereavement.
- To demonstrate personal and professional reflection about the management of a patient with palliative care needs.
- To illustrate the capacity to change clinical practice in the light of theoretical knowledge and personal reflection.

**Objectives of Case Reflection**
- To demonstrate understanding of the core reading material in the course handbook.
- To apply the theory of the handbook, supported by additional reading, to clinical practice.
- To demonstrate a patient centered approach to practice.
- To help you reflect on your own practice.

**Suggested Approach**
- Identify the patient. This may be a current patient or someone the candidate has cared for in the past. Do this as early as the learner can to give him/her the longest time possible to think about how he/she will approach and write up his/her case reflection. Seek help from a mentor if necessary.

**The ideal patient to select is one for whom the management was not straight forward.**

**STRUCTURE OF THE CASE REFLECTION**
Format of the case reflection will be given
- The case reflection must be presented clearly and should be typed.
- The case reflection is structured with questions, to aid reflection of the total care of a patient and their family. You are asked to identify situations that challenged your knowledge or you personally.
- Patient confidentially must be carefully observed. This includes withholding patient identifiers including workplaces and geographical area. Ideally, the consent of the patient (or family, if the patient has recently died) should be sought informing them of your wish to use their case for your case reflection.
- The candidate is expected to support his/her reflections with accurate literature references wherever possible.
- In the conclusion, the candidate is asked to provide evidence of a change in practice as a result of new learning. The report will be assessed for reflection and discussion of application of new knowledge.
- The word limit is 2000 words
Distribution of marks is as follows

**Reflection and Application of knowledge - 70%**
**Evidence/Literature - 20%**
**Style of presentation - 10%**

## GRADING CRITERIA FOR CASE REFLECTION

<table>
<thead>
<tr>
<th>Grade</th>
<th>Reflection 50%</th>
<th>Application of knowledge 20%</th>
<th>Evidence 20%</th>
<th>Presentation 10%</th>
</tr>
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<tbody>
<tr>
<td><strong>E</strong></td>
<td>Reaches conclusion that are effectively applied to areas of practice. Utilises reflection and presents a meaningful discussion. Analyses alternative strategies/innovations in practice and the consequences. Discusses how policies may be influenced.</td>
<td>Gives extensive range of evidence to demonstrate essential principles of palliative care. Demonstrates the holistic patient and family centered nature of palliative care, including grief and bereavement in a balanced way.</td>
<td>Wide and comprehensive selection of literature mostly from primary sources. Consistently demonstrates skills of analysis, interpretation and application to practice.</td>
<td>Clear, logical well organized work presented in accordance with guidelines format and word limit. Accurate references list.</td>
</tr>
<tr>
<td><strong>G</strong></td>
<td>Reaches conclusions that are integrated to area of practice. Utilises reflection. Discusses alternative strategies/innovations in practice. Briefly suggests how policies may be influenced.</td>
<td>Identifies and relates many of the essential principles of palliative care appropriately. Identifies the holistic, patient and family centered nature of palliative care.</td>
<td>Comprehensive selection of literature, some from primary sources used to enhance analysis. Evaluation of practice is supported by the effective use of literature.</td>
<td>Clear organized work presented in accordance with guidelines format and word limit. Accurate reference list.</td>
</tr>
<tr>
<td><strong>P</strong></td>
<td>Conclusions somewhat supported by evidence. Presented with some application. Utilises reflection. Some consideration of alternative strategies although this may be limited.</td>
<td>Identifies most essential principles of palliative care with an accurate account given. No uniform coverage of different aspects of palliative care.</td>
<td>Limited selection of appropriate reading material. Some analysis and evaluation of practice.</td>
<td>Clear work, presented in accordance with guidelines, format and word limit. Acceptable references list.</td>
</tr>
<tr>
<td><strong>P</strong></td>
<td>Conclusions not supported/appropriate to palliative care. Has not utilized reflection. No consideration of alternative strategies.</td>
<td>Insufficient relevant evidence provided to demonstrate principles of palliative care. Application of principles to practice severely limited.</td>
<td>Very limited, or no reference to literature.</td>
<td>Not as per the guidelines and the format inaccuracies in reference list.</td>
</tr>
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Section One
Palliative Care – An introduction

Palliative Care – the context:
Most countries of the World are experiencing health transitions, with a rapidly rising burden of chronic and incurable diseases. Even as infections and nutritional deficiencies are receding as leading contributors to death and disability, cardiovascular diseases (CVDs), cancers, diabetes, respiratory diseases, neuropsychiatric ailments, and other chronic diseases are becoming major contributors to the burden of disease. These are currently the major cause of death among adults in these countries and the toll is projected to increase further. 80% of chronic disease deaths occur in low and middle income countries where most of the world’s population is living. The age-specific death rates from non-communicable diseases are higher in developing than in developed countries.

India too illustrates this health transition, which positions Non Communicable Diseases (NCDs) as a major public health challenge of growing magnitude in the twenty-first century. In India, chronic diseases accounted for 53% of all deaths and 44% of disability-adjusted life-years (DALYs) lost in 2005. Long Term Care (LTC) for such patients is emerging as the major health care issue in countries like India. More NCD deaths in India occur in middle age (35–69 years) than in industrialised countries, where they occur largely in old age (>70 years). The rising levels of hypertension, diabetes, obesity, tobacco consumption, and blood lipids in Indian population groups have been well documented in recent years, pointing to a major rise in future NCD burdens in India.

Programmes for the prevention and control of NCDs need to adopt a ‘life span’ approach, attempt to reduce risk at stage of life through appropriate public health interventions. They also need to be variably integrated into different levels of health care (primary, secondary, and tertiary). The principal functions of such a programme would be: (a) to provide information and an enabling environment for increasing awareness and adoption of health living habits by the community; (b) early detection of persons with risk factors and cost-effective interventions for reducing risk; (c) early detection of persons with clinical disease and cost-effective care to prevent complications; (d) acute care, utilising low cost, high yield technologies; (e) secondary prevention to reduce, risk of the recurrent events; and (f) rehabilitation and palliative care, in cases where disease has resulted in complications or is incurable. Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by addressing physical, psychosocial and spiritual issues. Palliative care should be seen as part of a continuum of care involving all the components of prevention and management of chronic diseases. Most of the activities can be performed in primary care settings.
With a crude death rate of 6.24/1000 and a population of more than a billion, the total number of people dying every year in India is about seven million. Majority of them die in misery. According to WHO estimates, more than four million of them would benefit from palliative care. Less than one percent of those who need palliative care services have any access to such services in the country.

Issues surrounding the problem of chronic diseases illustrate the complex interactions between health and social ecology. There was a time when chronic illness was considered a problem of the well off. But recent studies have shown that the chronic disease burden greater among the poor. The collection and analysis of population based data on chronic and incurable diseases and the investigation of inequalities in disease occurrence and care requires an elaborate routine data collection system. Such an information infrastructure tends to exist only in high income countries. In turn, most of the inferences are based on data from these countries. The available information tends to show a class difference in the incidence and severity of chronic diseases.

Poor people are more vulnerable for several reasons, including material deprivation and psychosocial stress, higher levels of risk behaviour, unhealthy living conditions causing increased exposure to risks and limited access to good-quality health care. The documented social and economic difference in risk factor prevalence is prominent in high income countries, but is not limited to them. Neighbourhood segregation and wider societal discrimination have also been associated with poor health outcomes. Several studies among patients with different chronic disease conditions (cystic fibrosis, systemic lupus erythematosus, and rheumatoid arthritis) all have shown an association between severity of disease and lack of social support.

In addition, chronic diseases inflict an enormous direct and indirect economic burden on the poor, and push many people and their families into poverty. A similar situation exists in the case of chronic mental illness. Proper care for mentally ill persons is something that the poor cannot afford in developing countries, yet mental disorders are common among poor people.

The major difference between the care of the acutely ill and the chronically ill is the need for regular supportive care in the latter group. The complex nature of physical and psycho social problems faced by these patients demand good medical and nursing attention, but such a system of care alone is not adequate. The present medical establishment, with its hospital-centred services, is geared basically to look after patients with acute illness. This acute-care orientation is reflected in the current emphasis on illness diagnosis, patient-initiated consultations, and curative and/or symptom relieving treatments. Patients with chronic and incurable illness on the other hand need a regular system of support available in the community.
The complexity of the situation and the various social factors at play makes Long Term Care and Palliative Care areas in which success depends on a large extent in getting the needs of the individuals expressed and pursued in a social context. Successful management of the problem of chronic and incurable illness at the population level necessitates the integration of our knowledge about economics, health and human development. Overcoming the barriers to such integration at various levels is a key policy challenge for national governments today.

**Principles of Palliative Care:**

No single sphere of concern is adequate without considering relationship with the other two. This usually necessitates genuine interdisciplinary collaboration and social interventions. Palliative care relieves suffering and improves the quality of life of the living and dying. Palliative Care services, if implemented in a rational public health way, would quickly and dramatically improve the quality of life for cancer suffers, other patients dying of chronic diseases, the elderly terminally ill and people living with AIDS. Policies and recommendations for the implementation of palliative care in a rational public health way have been produced internationally and several detailed reports on how to put theory into practice when establishing National Palliative Care Programs or Initiatives are available.

What is needed is the political will to act, educate and train the health profession, involve the community and make the necessary affordable drugs easily available.

Most of the patients in need of palliative care and long term care will have to be looked after by health care professionals at the primary health care level. If these doctors and nurses are trained to improve their clinical and communication skills and supported by a net works of trained community workers and home care nurses, it can improve the care of the majority of these patients tremendously. The training of General Practitioners and other doctors in rural areas in pain relief and Palliative Care will be important as well as capacity building among of community volunteers and nurses.

The proposed model for Long Term Care (LTC) and Palliative Care (PC) Adapted with permission from Stjernsward 2005 (Indian Journal of Palliative Care 11(2))
Legislation introduced and funds allotted by the Government are important for establishing a stable system achieving a meaningful coverage, reaching all and for guaranteeing, together with referral institutions, continued care for patients discharged from specialist centres. Establishment of adequate and accessible palliative care facilities in the community will also mean freeing expensive hospital beds from incurable patients. It will also culturally be the most important for reassuring the citizen a dignified death where they want it most, namely at home. Good quality community based home care services can help in reversing the present trend of materially and emotionally expensive institutionalized dying. The strong family structure still observed in India will be useful if the families are trained to involve in the care of the patient at home. Emotional support, spiritual support, prophylaxis for avoiding bedsores, appropriate food, changing of bandages, etc are some of the important areas in which the family and local community can make a positive impact when empowered to do so.

Involvement of the local governments (Panchayaths) in the provision of care in the locality will be essential for ensuring sustainability of the projects at the primary health care system level. The same model can be adapted for other aspects of interventions in the area of Non Communicable Diseases including cancer.

**Definitions:**

**Palliative Care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation)

**The Palliative Care approach** aims to promote physical, psychosocial and spiritual well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

**Supportive care** helps the patients and their families to cope with their disease and treatment of it from pre-diagnosis, through the process of diagnosis and treatment, to cure, the state of being ill or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as best as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.

**Palliative Medicine** is the appropriate medical care of patients with active, progressive and advanced diseases for whom the prognosis is limited and the focus of care is the quality of life. Palliative medicine includes consideration of the family’s needs before and after the patient’s death.

**Hospice and Hospice Care** refers to a philosophy of care rather than a specific building or service and may encompass a programme of care and array of skills deliverable in a wide range of settings.

**Terminal Care** is an important part of palliative care and usually refers to the management of patients during their last few days, weeks or months of life, from a point at which it becomes clear that the patient is in a progressive state of decline.

**Rehabilitation** in the Palliative Care Setting aims to help patients gain opportunity, control, independence and dignity. It responds quickly to help people adapt to their illness. The main differences between mainstream rehabilitation and rehabilitation in the palliative care setting are; 1) the speed of response, 2) the speed of setting of realistic goals 3) the need to adapt constantly to changing circumstances, 4) the need for therapists to be able to support patients through the changes.
Section Two
Communication Skills and Psychological Issues

COMMUNICATION SKILLS
Communication skills are not commonly taught to health care professionals, yet are crucial to the way that our patients experience our service. The skills needed to communicate well with patients are not complex but they can make a significant difference to quality of life of both patient and professional.

Conversely poor communication can lead to increased stress for professionals and distress for patients and their families. It is often said by hard-pressed professionals that they do not have time to communicate properly. Studies show that it is not the quantity of time involved in communicating but the quality of communication that makes the difference. (Some of the busiest health care professionals in the world are also those with the best communication skills.)

It is a strange fact that although a huge percentage of professional time is spent in communicating with patients there is so little emphasis in learning the skills involved in training. This course can only outline the basics of communication but candidates are encouraged to make communication a priority in their practice. There is no such thing as neutral communication. It is either effective or ineffective, stress relieving or stress producing.

Examples of good and poor communication techniques

<table>
<thead>
<tr>
<th>Closed questions</th>
<th>Open questions</th>
</tr>
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<tbody>
<tr>
<td>“Is your pain OK today?”</td>
<td>“How are you feeling?”</td>
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<tr>
<th>Ignoring emotional factors</th>
<th>Empathic response</th>
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<tr>
<td>Pt. “I feel scared when I am breathless”</td>
<td>Dr. “Take these tablets for your breathing”</td>
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<tr>
<td>Dr. “Take these tablets for your breathing”</td>
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<tr>
<th>Sensitive truth telling</th>
<th>False reassurance</th>
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<tr>
<td>Pt. “The Doctor said my cancer is incurable”</td>
<td>Pt. “The Doctor said my cancer is incurable”</td>
</tr>
<tr>
<td>Dr. It must have been very hard to hear that “the cancer has spread, but we will do our best to help you in every way we can”</td>
<td>Dr. “Don’t worry about such things everything will be OK.”</td>
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<tr>
<th>Balancing hope and truth</th>
<th>Destroying hope</th>
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<tr>
<td>Dr. “I am sorry but there are no more treatments available to cure your disease, but we can start other medicines to help you be more comfortable so you can be at home with your family. If you need any help in the future ust come to the clinic.”</td>
<td>Dr. “There is nothing more we can do, your disease is incurable, so there is no point in staying in hospital”</td>
</tr>
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</table>
Breaking bad news is an important aspect of communication. It takes time and issues often need to be discussed further and clarified as more information is imparted.

**BREAKING BAD NEWS**

**Reflective learning**

*If you had a diagnosis of cancer would you want to be told?*

*How would you feel if your family chose to hide the news from you?*

There is increasing evidence that patients want to know about their illness. Many patients who have been denied this knowledge have difficulty in understanding why they are becoming weaker and are then relieved and grateful to be told the truth. They may be angry with the family who has known about the illness and have not thought it right to tell them. As professionals, we are often caught up in a potential ‘conspiracy of silence’, when the family catches us before we have had a chance to speak to the patient. They might say “Don’t tell him the diagnosis / prognosis because he would not be able to cope with it. We know him better than you do”. This can be an awkward situation. The family needs to know that we have understood their concerns of not wanting to cause any more hurt to the patient. They also need to know that we accept that some patients use denial as a way of coping.

However, they also need to know that it would be unwise for clinical staff to be untruthful if the patient wants to know the truth and was asking direct questions, because of the inevitable breakdown in trust that this could cause. Advising patients and families with regard to prognosis is important since they may want to organise their affairs and plan for the time that is left, but, it is impossible to be accurate.

Overestimating or underestimating the time that someone has to live can cause untold anguish. It is therefore more sensible to talk in terms of days/weeks, weeks/months, and months/years as appropriate. It is important to be aware that people have divergent attitudes to the receiving of bad news and that this needs sensitive handling.

As health professionals, we can be very critical of how our colleagues have passed on bad news. Some of this criticism may have validity, but before judging too quickly we need to remember that a patient’s understanding of what they have been told can differ greatly from what the nurse or doctor think they have said!
A STRATEGY FOR BREAKING BAD NEWS.
The actual process of outlining a strategy for breaking bad news is difficult because it turns a process, which should be natural and unforced into something which seems constrained and awkward. This outline is not intended to make you feel self-conscious but to give you an idea of what other people have found helpful so that you have more information with which to develop your own personal way of breaking bad news.

Before breaking bad news it is important to ask yourself the following questions:

Are you the right person to do so?
Do you have all the information that you need?
Is this the right time and place?
Does anybody else need to be present?
What is the management plan for this patient?

THE GOALS OF BREAKING BAD NEWS
The process of breaking bad news needs to be specifically tailored to the needs of the individual concerned, for every human being will have a different history and collection of fears and concerns. The goal of breaking bad news is to do so in a way that facilitates acceptance and understanding and reduces the risk of destructive responses. The ability to break bad news well involves skills which need to be coveted and trained for, audited and kept up to date with as much objective determination as that shown by a surgeon in acquiring surgical skills. The consequences of performing the process badly may have immediate and long-term damaging effects for all involved, every bit as catastrophic as surgery going wrong. Having awareness of strategies to complete the process well is vital, but breaking bad news must never become so mechanical that patients, or their families, detect little individual caring and compassion.

PREPARING TO TELL BAD NEWS
Acquire all the information possible about the patient and their family. A family tree can be useful in quickly assimilating the important people in the patient’s life, and the web of relationships within the family.

Read the patients notes for:
- diagnostic information.
- test results.
- understanding of the patient’s clinical history.
- clarifications regarding the plan of care, and the prognosis.
- the support system for the individual.
- background knowledge of the patient’s life.

Making basic mistakes will undermine the patient’s confidence.

Discuss with other members of the team, and then select the most appropriate team member to break the bad news. Decide which other member of the team should be present during the interview.

Check:
Place of privacy, and non-interruption. Time to carry out process of conveying the information.
Your own emotional energy to do so (better earlier in the day than late). Urgent tasks are
completed so that there will be minimal interruptions. Whom the patient would like to have present with him/her also should be ascertained.

**Plan:**
Prepare a rough plan in your mind of what you want to achieve in the communication, and what you want to avoid communicating. Having a rough goal will bring structure to the communication, though it is important to avoid imposing your agenda on the patient’s agenda.

**Setting the Context:**
Invite the patient to a place of privacy.
Introduce yourself clearly.
Let patient know that they have your undivided attention. If appropriate, also indicate when you must finish the meeting. Ensure that the patient is comfortable and is not distracted by pain or a full bladder etc.

Sit at the same level as each other within easy reach

**Listen:**
- How much does the patient know already?
- What is the information gap?
- How much does the patient want to know?
- How do the patients express themselves?
- How is the patient feeling?
- Is there anything that is concerning the patient which they are not verbalising?
- What mechanisms has the patient used in the past to deal with bad news?
- Does the patient have a particular outlook on life or culture, understanding underpinning their approach to dealing with the situation?
- Who are the important people in the patient’s life?
- to non-verbal as well as verbal clues.
- Encourage the patient to speak by listening carefully and responding appropriately.

**Sharing Information:**
- Having spent time listening, use the patient’s words to summarize what has happened so far
- Use the “warning shot” technique before bad news to help the patient prepare themselves.
- Using simple clear language, start from what the patient knows, to what he needs to know. Try to be brief, sensitive and clear. Do not be either too abrupt or too long.
- Avoid technical language and “short-forms” which are easily misunderstood. Pause after you have said the word e.g. “cancer”
- Be sensitive to the patient’s emotional reactions. Allow silence or questions. Listen to emotions of anger/grief/denial if expressed

**Check that the patient understands what is being said to ensure that:**
- the patient’s fear of having bad news suddenly unexpectedly dumped on them is reduced
- the patient is in control of the speed at which information is being passed on
- use diagrams to help patient, but only if it is appropriate, and the patient wants diagrams to better understand and retain the information
you address the patient’s real concerns, which may be very different from what you expect them to be

- do not bluff.

**Response:**
- You should respond to the patient’s feelings and response to the news
- You should acknowledge the patient’s feelings
- You should be prepared to work through the patient’s emotional response to the bad news with them.

**Draw up a plan with the patient, make concrete plans for the next step**

**Summarise:**
For the patient, to ensure they have understood.
For other health care professionals
- Record details of the conversation in the patient’s notes clearly

**Deal with questions:**
“Are there any questions which you would like me to deal with at this point?” Summarise again the key points.

**Contract for the future:**
Closing remarks and identification of support network, and times of easy access.

*Be clear about the time of the next meeting but also allow the patient the option to postpone it if they do not feel able to attend.*

**BREAKING BAD NEWS BACKGROUND READING**

**Books**

**Articles**
PSYCHOLOGICAL ISSUES
Palliative care is unique in that it is a specialty which defines itself by good quality psychosocial care. However, this should be more than just being kind to patients and being sympathetic to their suffering. Good communication skills are the starting point to identification of the emotional problems and psychological difficulties which accompany any major physical disease. There are many psychological constructs which are already used in palliative care. There is a wealth of clinical and research experience from the related branch of Psycho-oncology which can be drawn upon to inform and enhance psychosocial care in palliative care.

There are two ways of approaching psychological issues in palliative care.
The first would be familiar to members of the medical profession, used to recognizing ‘signs’ and ‘symptoms’ of disease in the many health complaints that patients bring to them. Doctors look for known patterns of signs and symptoms to make a ‘syndromal’ diagnosis, which may or may not be backed by knowledge of aetiology and pathology (e.g., migraine, pulmonary tuberculosis). If we follow a similar approach, we could look for the presence or absence of known psychiatric syndromes such as ‘depression’ or ‘depressive disorder’.

The second approach would be to identify the psychological issues relevant in a person’s life as they are going through the illness experience. People may experience emotions such as anxiety or anger or may be said to be in ‘denial’ when they are seen to be having difficulties accepting the reality of their plight.

Both approaches have their benefits and disadvantages. Making a diagnosis allows us to communicate easily. A diagnosis of ‘severe depressive episode’, if correctly made, can lead to a justifiable expectation that the person may respond to antidepressant medication. However, the downside is that psychiatric diagnosis have reliability problems, especially when made in the context of major physical ill health. They can also lead to inappropriate use of psychiatric medications and the even more serious problem of using medications instead of counseling or psychotherapy. Focusing on psychological issues such as ‘denial’ is often more appropriate to the reality of the situation but there is less clarity as to the course of action which should follow. Moreover, the same terms are used to mean different things and there is a problem of imprecision.

In the rest of this section, an attempt will be made to introduce both the basic psychological concepts as well the psychiatric syndromes which are commonly seen in palliative care patients.

COMMON PSYCHOLOGICAL SYMPTOMS & PSYCHIATRIC SYMPTOMS

1. ANXIETY & ANXIETY DISORDERS
Patients and families
Anxiety is a normal human response to perceived threat, which may improve our performance in the face of that threat. However, anxiety becomes a problem when either the threat can not be dealt with easily or the anxiety starts hampering our functioning. Therefore, the spectrum of anxiety ranges from ‘normal’ through to persistent and severe anxiety.

Anxiety may be acute or chronic and the implications are different for each. Many people have a life long history of experiencing anxiety in response to day to day stressors. For them the anxiety surrounding their physical disease is yet another manifestation of an anxiety problem which they have experienced all their lives. An acute episode of anxiety, on the other hand, may be the temporary response of someone overwhelmed by a major stress such as a new diagnosis of cancer or the news that there are no more curative options for their disease.
Anxiety is common in the terminally ill for a variety of reasons including the fear of uncontrolled symptoms and of being left alone to die. Many commonly used medications also cause anxiety as a side effect.

**Anxiety Disorders**
These are a group of disorders where anxiety occurs either in response to an object or a situation (phobic anxiety disorders) or anxiety occurs irrespective of the environmental situation (generalized anxiety disorder, panic disorder and mixed anxiety and depressive disorder).

It is not clear how common such disorders are in the palliative care population. Studies in cancer patients report unreliable prevalence figures because most studies do not make the full spectrum of diagnoses including adjustment disorders. Anxiety symptoms are common, but in terms of diagnoses, most patients with predominant symptoms of anxiety will actually be suffering with adjustment disorder or depression.

**Management:**

1. **Anxiety Assessment**
   - Are the common anxiety features such as excessive worrying, increased motor tension, autonomic hyperactivity and vigilance / scanning present?
   - Assessment of the nature of anxiety, acute or chronic and whether part of another psychiatric syndrome such as a depressive disorder. Is it pervasive?
   - Assessment of any reversible factors such as pain, or inappropriate medications. Stimulant drugs or excessive alcohol intake or withdrawal may exacerbate anxiety.
   - Understanding of unexplored worries. It is necessary to provide time and opportunity for patients to express their worries and concerns and for these concerns to be addressed honestly and clearly.

2. **Non-Pharmacological Management**
Relaxation therapies such as progressive muscular relaxation and other techniques such as distraction are very useful and should form the mainstay of anxiety management.

3. **Pharmacological Management**

**Benzodiazepines**
Medications if used for anxiety management should be limited to the short term. These are useful to break the anxiety cycle, to restore sleep, and to reduce the suffering of the situation where a patient feels he is “losing control”. They are not a substitute for taking the time to allow patients to ventilate their fears except in the rare circumstances when there is no time or ability to communicate.

- **Lorazepam** 0.5-2mg p.r.n.p.o, SL
  - Lorazepam is short acting, rapidly anxiolytic sublingually and less sedating than diazepam. It may be more addictive on a longer term basis. It has particular benefit in anxiety caused by breathlessness.
- **Diazepam** 2.5-5mg p.r.n. p.o, SL
  - Diazepam has a longer half life and may therefore accumulate and be sedative. It should be possible to give it once a day, at night. Its main function is as a mixed sedative/anxiolytic

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Midazolam 2.5-5mg p.r.n. SL, SC Useful for emergency sedation.
Clonazepam 0.25-0.5mg p.o Useful in breathlessness associated with anxiety and controlling panic attacks.

**Professional team**
It is important for all members of the palliative care team to be aware of the “infectious” nature of anxiety and for the team to avoid being driven to management extremes because of the anxiety of the patient or their family. Anxiety can be a problem for the palliative care team, when individual team members feel unsupported in their work and are confronted with stressful situations for which they perceive their options are very limited. No team is immune from anxiety and strategies need to be devised to provide ongoing support for team members where such issues can be talked over and dealt with concertedly, i.e. debriefing, identifying stress, reflective practice, stress management, training and support.

2. **LOW MOOD & DEPRESSIVE DISORDERS**
Just as anxiety is ubiquitous in palliative care and a symptom of many psychiatric conditions, so is low mood. The low mood of depression is different to feeling sad; in fact various features such as anhedonia, hopelessness, helplessness, a flattening of feeling and feeling a loss of feeling characterize the mood state seen in a depressive disorder. Anhedonia is the inability to enjoy things or experience pleasure.

**Depressive disorders**
Depressive disorders in cancer and palliative care have been better studied than anxiety disorders. Estimates of the prevalence of depression vary greatly but it used to be said that at least 25% may develop a significant mood disorder in advanced cancer. A review of 12 articles reported a range of depression rates from 3-69%. Certain types of cancer, such as pancreatic cancer are associated with an increased incidence of depression. However, now there is more clarity in that a spectrum ranging from sadness to adjustment disorder to depressive illness is recognized. It is now clear that if adjustment disorders are classified separately, the prevalence of depression might fall to less than 10%.

There is concern that depressive conditions including adjustment disorders may be under diagnosed. This may be due to a number of reasons including a diurnal variation in symptoms such that it may be missed, social ‘cover up’, or presentation with physical symptoms. Other confounding factors may be presentation with overriding anxiety or slowly developing worsening of personality traits which may go unnoticed. Physical features such as fatigue, decreased energy, weight loss and lethargy are not reliable as features of depression in patients with terminal illness and greater emphasis must be placed on psychological and behavioural features. Depressed mood, irritability, loss of interest in daily activities, feelings of worthlessness, lack of hope and suicidal ideation are important features.

Depression may be successfully treated in a high proportion of patients. Management includes ensuring that any reversible causative factors, such as distressing symptoms, are eliminated and that adequate emotional support and counseling is available so that fears and concerns can be explored and channeled appropriately.

**ANTIDEPRESSANTS**
**Tricyclic antidepressants** such of as amitriptyline or imipramine² are still sometimes used as first line anti depressants and they are often used as anxiolytics in “sub-antidepressant” dosages. Tricyclic antidepressants may take several weeks to lift anxiety/depression. Amitriptyline is relatively sedative in comparison with imipramine and dothiepin.
They all have antimuscarinic properties to a greater or lesser degrees and therefore may be associated with symptoms such as hypotension, dry mouth and difficulty in micturition. Doses should gradually be increased to avoid unnecessary side effects.

**BOX**
There is an increased risk of cerebrovascular accident reported in patients using risperidone and olanzapine particularly if they are elderly with dementia. They should be used only after careful consideration in any patient with history of or risk factors for cerebrovascular disease.

Selective serotonin reuptake inhibitor (SSRI) antidepressants such as paroxetine and or citalopram are good alternatives which have less reported side effects and also have anxiolytic properties. Common doses are:

- Sertraline 50 – 150 mg o.d.
- Citalopram 10 – 40 mg o.d.
- Fluoxetine 20 – 40 mg o.d.

Care must be taken when using SSRIs such as fluoxetine which can initially increase anxiety. Unfortunately their positive benefits may take up to three weeks to develop. These drugs are less sedative than tricyclic antidepressants and have few antimuscarinic effects, low cardio toxicity and may have a faster onset of action than the tricyclics. Gastrointestinal side effects such as nausea are dose-related. Fluoxetine, in particular, may cause restlessness and anxiety and should be used with caution in patients who are anxious.

More recently, Mirtazepine, 15-30mg noite, an antidepressant with noradrenergic and specific serotoninergic activity has been highlighted because it has been claimed to work more rapidly than others.

Complex depressive disorders with psychosis may be more suitably treated with neuroleptics such as haloperidol or the newer antipsychotic drugs such as risperidone, olanzapine or quetiapine. Supervision by a specialist psychiatric team would be ideal if available.

### 3. ADJUSTMENT DISORDERS

Of late, there is a growing understanding that most of the psychiatric morbidity in palliative care is best understood using the concept of adjustment disorders. They form the single largest group of patients with significant psychological problems when standard diagnostic methods and classifications are used. It is estimated that around 20% of palliative care patients will manifest adjustment disorders at any given point in time. This group of patients could have been misclassified as suffering with depressive disorders in previous studies giving rise to inflated prevalence figures for depressive disorders, commonly quoted in palliative care literature. If a diagnosis of adjustment disorder is considered, the prevalence of depression usually halves.

**The concept**

Adjustment disorders are a group of disorders which:

- occur in response to stress
- are usually acute and short-lasting
- are characterised by distress & emotional turmoil
- and result in impairment of functioning

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The diagnosis of adjustment disorders is, like all psychiatric diagnoses, a clinical judgment which is made when the onset is within 1-3 months of a stressor and usually lasts less than 6 months if the stressor resolves. It is sometimes a problematic judgment because it has to be decided that the distress is ‘excessive’ and results in significant impairment. The levels of distress can be variable at different times. Mostly affective symptoms are prominent but they do not meet the criteria for other disorders such as anxiety or depressive disorders.

**The significance of Adjustment Disorders**

If a diagnosis of adjustment disorders is considered in palliative care patients, fewer people would be given a diagnosis of depression as, quite rightly, a narrow definition of depression would be used. This might lead to fewer patients being prescribed antidepressant medications and counselling or psychotherapy options being considered more often. There is growing evidence for its validity as a diagnostic category in cancer patients. The outcomes are generally considered better than for disorders such as depression and psychotherapy is seen to be effective.

**Management**

While pharmacotherapy might have a role when sleep is disturbed or anxiety is extremely troublesome, on the whole, psychotherapy is the treatment of choice. Every effort should be taken to:

- spend time talking to patients on their own
- understand their concerns
- help them find solutions
- resolve conflicts
- facilitate better communication
- and deal with family and social issues

More formal approaches such as Problem Solving Therapy or Cognitive Behaviour Therapy may be used. It is possible to train some members of the team to deliver such therapies in the absence of easy availability of trained specialists. DISTRESS

All psychiatric diagnoses carry stigma. Apart from this, as seen in the case of adjustment disorders, there is a lack of reliability when diagnoses are made, which could possibly give rise to wrong treatment decisions. In order to get away from these problems, the National Comprehensive Cancer Network (NCCN) in the United States, has proposed that a broad-based concept of ‘Distress’ be used instead. The idea is to try to capture a global measure of psychological distress that a person experiences at any point in time during their illness. This would help identify, amongst all patients, those who require more psychological help.

**Definition**

Distress has been defined as a multifactorial unpleasant emotional experience of a psychological, social or spiritual nature that interferes with coping with cancer. It extends along a continuum and once identified, further delineation of psychiatric syndromes may be done.

**Screening for distress**

It is well known that there is under-recognition and under-detection of psychological morbidity in cancer patients. This has led to the suggestion that we need to actively screen our patients for the presence or absence of psychological disorders. Many questionnaires have been used for this purpose but recently most attention has been focused upon the ‘Distress Thermometer’. Prior to deciding to screen your patients, thought must be given as to whether you are in a position to offer psychological help to those who are detected to have psychological problems.
Distress thermometer

This is a visual analogue scale along with a list of common problems or issues that patients face. A global rating of psychological distress is made first. The list of problems, which might have to be modified locally, is then used to decide where to focus interventions.

5. OTHER COMMONLY USED CONCEPTS

Denial
This is a commonly used concept in palliative care, often used in the same way as a diagnosis is used. The concept of denial has its roots in psychoanalytic literature where it is described as one of many, usually unconscious, defense mechanisms. In palliative care, this term is used when patients are seen not to accept and agree with the treating team’s, usually negative, views of the diagnosis or prognosis. Rather than see this as a ‘disorder’ to be treated, it is best to view this as one of the many ways people adapt to bad news and cope. It is often an expression of distress where the priority should be to manage the various aspects of distress as a whole.

BACKGROUND READING

Books

Articles
Section Three
Ethical and Spiritual Issues

ETHICAL ISSUES

Ethics and communication
We live in a world which has become increasingly complex. Ethical issues that arise towards the end of life are often fraught with difficulty in an (increasingly technological) age in which the process of dying may be prolonged. In health care, there is often no “right” or “wrong” decision, but only a consensus view of a clear aim, considered on the basis of ethical principles. This ethical framework is comprised of the following principles:

- Autonomy (the patient should be informed and involved in decision making)
- Beneficence (do good)
- Nonmaleficence (do no harm)
- Justice (balancing the needs of individuals with those of society)

It is very useful to have a framework with which to deal with ethical crises. The following clinical scenarios are examples which occur commonly. Applying the principles of ethics in order to reach a balanced compromise can provide a path through uncertainty.

“My father has eaten very little. Why aren’t you giving intravenous fluids?”

Ethical issues

Beneficence: Will artificial hydration help the patient?

Non maleficence: Will giving or not giving artificial hydration cause the patient harm?

Autonomy: Does the patient want a ‘drip’?

It is instilled in all of us from childhood years, that food and drink are essential for life. There are clinical situations in palliative care when extra systemic fluids might be useful, for instance in hypercalcaemia or profuse diarrhoea and vomiting. These may be salvageable clinical situations where we are expecting the patient to return to his normal, albeit generally deteriorating, state of health.

Sometimes, there may be a specific goal the family is aiming towards e.g. a wedding the next week.

However, routinely giving systemic fluids may not be in the patients’ best interests when the patient is dying.

Background Information

There are a few studies addressing this issue and no proof that either the giving or withholding of fluids interferes with the length of remaining life or affects comfort. Biochemical parameters show that only 50% of patients have any evidence of dehydration within the final 48 hours of life and even if present only in mild to moderate degree. The extensive experience of nurses working in hospices suggest that systemic fluids at best make no difference and, at worst, may actually contribute to suffering at the end of life.
The more fluid available, the more likely that it will gather in lungs and other dependant parts of the body particularly in the presence of hypoalbuminaemia which is common in advanced malignancy.

Artificially increasing fluids at the end of life may lead to worsening respiratory secretions, increased vomiting, raised intracranial pressure in the presence of intracerebral disease, and an uncomfortable urinary output.

Families have to spend precious time worrying about drips running out and causing discomfort instead of concentrating on quality time with the patient.

**Discussion**

Withholding systemic fluids is inevitably a very sensitive issue as it may be for the first time to the family that their loved one is now entering the final stages. In practice, patients are often able to take small amounts of fluids until shortly before death. It should be explained to families that the body is gradually shutting down, does not need as much food and fluid as before and is unable to handle an extra fluid load. They need to be aware that the patient will not be allowed to suffer from pain or other discomfort. They will need explanations of the measures that will be taken to avoid discomfort which will include medication where necessary and most importantly meticulous mouth care to prevent the common symptoms of a dry mouth. Occasionally, families cannot bring themselves to accept the inevitability of death and insist on artificial hydration. Although health care professionals must only act in the best interests of their patients, it would be unwise to ignore the views of the family who have to go on surviving with vivid memories of the dying phase. On occasion, if it is felt that extra fluids will not adversely affect comfort, it is sometimes helpful to have a contract with the family for a relatively small volume of fluid to be used subcutaneously or intravenously for a defined short period on the understanding that it would be discontinued at any time if it was thought to be causing the patient distress. As in most ethical crises, a balance has to be made, in this situation, between the harm caused by withholding or giving artificial hydration.

- Acknowledge family distress.
- Explore concerns.
- Discuss above points.
- Reassure that the patient will be looked after and kept comfortable whether fluids are given artificially or not.

**“How long will I live?”**

**Ethical Issues:**

**Autonomy :** Has every attempt been made to inform the patient adequately?

This type of question usually relates to prognosis. However, it is always important to make sure that you have entirely understood the question To enter into a conversation about how long a patient has to live when all they want to know is when they are going to leave hospital can cause unnecessary distress. When you are sure that the patient is talking about prognosis, firstly find out what they already know, how they see the situation, why they are asking the question and how much they really want to know. Use questions such as:

- “What have the doctors told you so far?”
- “What has prompted you to ask this question now?”
- “Are there other specific issues, related to how long there is left, would you like to talk about?”
“Are you the kind of person who likes to know everything?”

In practice, patients often say that they have not been told anything by the doctors but these questions can usually explore what they understand. Patients often want to achieve goals such as settling their property or conducting a family wedding.

Help from us is needed in planning the limited time that is left by setting realistic and achievable goals. Before addressing the prognosis directly, it is important to be aware of the full medical history and to build up a picture of clinical deterioration.

Questions such as “I believe you have not been feeling so well recently” or “the doctors/your medical notes tell me that life has become more difficult for you over the past few weeks” open up these issues giving you and the patient a chance to estimate prognosis.

**Background**

Literature on determining prognosis is available especially for patients with cancer. For a population presenting with a defined stage, grade, and cancer type and histology, 5-year survival rates are available and often quoted to families. Many other factors have been studied singly and in combination in an attempt to categorise patients into prognostic groups, which can be helpful in broad terms. However, in practice it is not possible to accurately predict prognosis for an individual since there are so many different factors including psychosocial, emotional and existential all of which evade measurement of any kind. Studies show that health professionals tend to overestimate prognosis. Despite these pitfalls, it is still important to answer the patient’s question. It is still relatively common for a precise prognosis for example “6 months” to be given and this is always inaccurate. If the patient dies before the due date, the family feel cheated of time that they would otherwise have spent differently had they known that time was so short. If the patient survives longer than the due date, both patient and family may feel proud that they have defeated the odds. On the other hand if the family have altered their life styles including giving up work to look after a patient remains stable, this can create financial and other stresses. It is not helpful to give a precise date, which patients and families often take literally, but to talk in terms of days/weeks, weeks/months and months/years. It is also important to say that even within these broad terms we may still be inaccurate. It is also useful to talk about the pace of deterioration and to say that the pace may continue at the same rate but it may also stabilise for a while.

* We don’t want our mother to know her diagnosis*

**Ethical Issues:**

**Autonomy:** “Does the patient have a right, if she wants to know regardless of what the family think?”

**Beneficence:** “Would it help the patient to know her diagnosis?”

**Non maleficence:** “Would it harm the patient to know her diagnosis? Would it harm her to remain a state of uncertainty where she can sense that the family is hiding things from her?”

It is common to be caught in the corridor by anxious relatives who have been told that their relative has cancer before this information has been given to the patient. There is increasing evidence that patients want to know what is wrong with them and to be involved in decisions. Generally speaking, we have moved away from a paternalistic approach in truth telling whereby doctors often avoided telling patients they had cancer, to a more open approach, respecting the principle of autonomy.

However, the family have known the patient over many years and have seen how the patient has responded to bad news in the past and they may feel that there is no point in discussing the diagnosis particularly if the patient is very elderly and there is no available treatment.
For understandable reasons they want to protect the patient from bad news but very often they want to protect themselves from further hurt and the reality that the patient may now be entering the last stages of life. It needs to be acknowledged with the family that this is a difficult area but that the patient may have important things to say or do or opinions regarding their management.

The family also need to know that patients pick up non-verbal clues from professionals and family and are already often aware of the diagnosis and are not very shocked if it is confirmed. The family need to be aware that patients may find it easier once they understand why they are not getting better, and that this is not because of inadequate treatment, or a lack of interest from the family to take them to “another hospital”.

Families need to know that it becomes more difficult to conceal the truth from the patient as time goes on and as more professionals, family members and friends share the secret. There are increasing opportunities for the truth to slip out and for the patient to lose trust in the family for not having been honest to him/her. It is very important not to lie to the patient since this breaks all communication and confidence.

If there are no particular decisions to be made, the patient has dealt with his/her affairs and he/she is living with the family, there may be no pressing need to try to discuss the issue and invite family dispute. However, if the patient starts to ask direct questions, the family should be advised not to lie. The family also needs to be aware that family tensions reduce considerably when there are open discussions about diagnosis. The professional is able to override family views if it is clearly in the interests of the patient to do so. However it is always advisable to listen to and to take account of the views of the family. If it is felt important to discuss the diagnosis it is usually acceptable to families to say that we will try to find out what the patient understands by their illness and whether or not they would like more information.

“I want full resuscitation if my heart or lungs fail.”

**Ethical Issues:**

*Autonomy: Does the patient have the right to demand treatments from nursing and medical staff?*

*Beneficence: Would it be in the patient's best interests to initiate resuscitation?*

*Non-Maleficence: Would it do the patient any harm to initiate resuscitation?*

*Justice: Would it be an appropriate use of resources to initiate resuscitation measures?*

**Background**

Patients and families are increasingly aware of the many ethical issues surrounding cardiopulmonary resuscitation. These have been highlighted recently with “DNR”(Do Not Resuscitate) notices being recorded in patients’ notes without the patients being aware about it. This has caused much concern particularly among the weakest and most vulnerable sections of the community. Inappropriate attempts at resuscitation have also led to patient discomfort and financial burdens on the family. Many of these problems can be avoided by consistent and sensitive communication regarding prognosis, and the limitations of interventions so that the patient and family have the time to make decision. Litigation anxiety can cause a dilemma and increase the strain on staff to make the right decision. The need to document the resuscitation status of patients, following full discussion, itself lead to increased stress for all involved in handling what can be a very distressing issue.

**Autonomy:**

Patients have the right to ask for whatever treatment they choose; however, medical and nursing staff are not obliged to comply with such expressed wishes if they feel that it is not
going to be in the best interests of the patient or if the intervention is deemed to be futile. Good practice would dictate that such matters are addressed by the whole multiprofessional team, though the senior doctor has ultimate responsibility for the decision.

**Beneficence:**
Would the patient be helped by initiating full cardiopulmonary resuscitation? If the resuscitation was successful what would happen then? Is there a likelihood that the patient will leave the hospital alive, or are we prolonging the dying phase on a ventilator? Would any “quality life” be restored by “CPR”.

**Non Maleficence:**
Would initiating CPR rob the patient and their family of the peace, dignity and intimacy of a non-medicalised death?

**Justice:**
Is it justifiable to drain the family’s resources, or to reserve a scarce intensive care bed for a patient with a terminal prognosis?

**ETHICAL ISSUES BACKGROUND READING**

**Articles**


**SPIRITUAL ISSUES**

Addressing the spiritual issues of the patients has long been recognized as an integral part of palliative care. Since spirituality is usually considered to be linked to religious beliefs people tend to believe that spiritual distress are the result of conflict with one’s own religious faith. Accordingly, clergy assumed an important role in western model of hospice care. In situations where the faith of the patient and the care giver differ, any attempt on the part of the care giver to offer spiritual support to the patient through religious motifs will invariably be counter productive and ethically indefensible. So in a pluralistic society we need to develop a spiritual concept which is secular.

As a first step we have to differentiate between spirituality and religion. Religion is a shared framework of theistic beliefs and rituals which give expression to spiritual concerns (Robert Twycross). It is difficult to define spirituality. Spirituality may be defined as an awareness of the whole of which one is a part, which help one to transcend the tangible to reach new meaning and purpose. In every deliberation on spirituality certain themes often recur. They are,

- Ultimate meaning and purpose in life
- An awareness of oneself as part of the whole
- A sense of connectedness to fellow beings and to the universe
- A sense of mystery and awe

Man is essentially a spiritual being. Every human endeavor aspires to reach this ultimate height. In other words every human endeavor has a spiritual dimension which gives it meaning.
and value.

Spirituality gets its expression in the following:

- Altruistic actions
- Unconditional love
- Compassion
- Kindness
- Forgiveness
- Creative expressions: In the height of creativity the delight an artist feels is spiritual. Same is true about appreciation of a work of art.

Spirituality can be understood as a deeper plane of our own awareness, the surface plane being the mundane level. The deeper plane is absolute, changeless, unconditional and an infinite source of strength and freedom. What ever we experience in the mundane plane can be connected to the deeper plane where we can discover new meaning and purpose for it. These are the moments of transcendence which every body experience for brief or long periods in their day to day life. This is how we make sense of the world. All religions identify this domain and express it through various names: “Christians and Jews call it “God”. Hindu call it “Self”, “Brahman”, Sufi mystics name it “The Hidden Essense” and the Buddhists call it “Buddha Nature”. At the heart of all religions is the certainty that there is a fundamental truth, and that this life is a sacred opportunity to evolve and realize it.”- The Tibetan Book of Living and Dying by Sogyal Rinpoche.

How do we know that one patient is in spiritual distress?

- It can present as intractable symptoms which can not be relieved by usual methods of treatments.
- Or it may present as psychological distress like fear, anxiety, panic, depression, despair, helplessness, hopelessness, and meaninglessness.

Spiritual suffering in a patient can be seen as his/her inability to connect his/her illness experience into the deeper plane where they can derive new meaning for it. According to Victor Frankl, “Man is not destroyed by suffering. He is destroyed by suffering without meaning”. 

**How to respond to spiritual distress**

It is important to understand that we don’t have a ready made solution to the patient’s problem. Patients can find a way out by him/her self and all that we need to do is to provide a safe environment for him/her. This can be done by providing good symptom relief, good psycho social support, and being there with the patient as a human companion. Accept the patient as he/ she is. Respect their religious convictions or the absence of it. Provide religious support when asked. Never try to impress the patient with our own religious convictions. Instead provide opportunity for the patient to remember experiences, places or persons that had given some meaning to his/her life in the past.

It is also important to explore the significance of spirituality in our own life as care givers. Try to enrich the spiritual domain by practices acceptable to one’s own cultural background and/or religious faith.

**Further reading:**

- Introducing palliative care: Robert Twycross (Forth edition) part 1
- The Tibetan book of living and dying: Sogyal Rinpoche
- A place of healing: working with suffering in living and dying: Michael Kearney
Section Four
Management of Pain

“Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. In other words, pain is a somatopsychic phenomenon”.4

Pain is a complex physiological and emotional experience and not a simple sensation.
The most comprehensive review of the evidence based palliative medicine pain management is to be found in the Scottish Intercollegiate National Guidelines.5,6

Pain is a common symptom and is purely subjective. Patients with palliative care needs most commonly have chronic malignant pain. However patients with acute pain or chronic non-malignant pain sometimes require the help of palliative care services. It is important to assess each specific pain and to identify the likely causes.

ASSESSMENT OF PAIN
Assessment of a patient’s pain is a crucial skill, which requires a structured approach, actively listening ears and sharp eyes. Accurate assessment is also helped by experience, and is not a “one off” event, but constantly needs to be re-evaluated by the health care team as they gather more information and understanding.

Many patients have more than one pain.
Assessment questions
There are many approaches to assessing pain, and each professional will develop his/her own approach to taking a pain history. What is important while taking a pain history is that you should have an outline/scheme with which you are confident, and which works. Having a good assessment technique is the basis for prompt and appropriate management of a patient’s pain.

5 http://www.sign.ac.uk (last accessed 26.01.06)
PAIN CLASSIFICATION

It is useful to classify the pain into predominantly nociceptive and neuropathic categories in order to determine the correct management.

1. NOCICEPTIVE PAIN

This refers to pain resulting from stimulation of peripheral nerves through nociceptors. Pain impulses enter the spinal cord through the dorsal horn, where they ascend to higher centres.

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in the brain. Inhibitory impulses block transmission at the dorsal horn in the spinal cord, preventing further transmission of the pain impulse.

2. NEUROPATHIC PAIN

Neuropathic pain refers to pain arising from injury in the peripheral or central nervous system. Clinically it may present with sensations such as burning or stabbing in areas of sensory loss i.e.

*Hyperalgesia – An increased response to a normally painful stimulus*

*Allodynia – Pain caused by a stimulus that does not normally provoke pain*

1. **Peripheral neuropathic pain**
   Peripheral neuropathic pain is caused by damage within the peripheral nervous system. There is often an associated area of altered sensation along the course of the nerve.

2. **Central neuropathic pain**
   Central neuropathic pain is neuropathic pain caused by damage within the central nervous system. There is usually an area of altered sensation incorporating the area of pain. Cerebrovascular accident, or spinal cord damage may be associated with central pain.

3. **Sympathetically maintained pain**
   Sympathetically maintained pain is due to sympathetic nerve injury. Essential features are pain (often burning) and sensory disorder related to a vascular as opposed to neural distribution. In patients with cancer such pain is more common in the lower limbs, and is usually associated with disease in the pelvis. Such pain is also associated with reduced sweating and dry shiny skin within the affected area.

PAIN MANAGEMENT

Pain is traditionally classified into different modalities:- physical, psychosocial and spiritual. Exploring a patient’s anxieties and frequent misconceptions related to these modalities can be very beneficial. Pain will not be adequately managed unless patients feel a degree of participation/control over their situation. To ignore such psychological aspects of care may often be the reason for persisting pain. Having prescribed analgesics and/or adjuvant medication, the patient’s pain should be constantly re-evaluated and the response to treatment reviewed regularly.
MANAGEMENT OF NOCICEPTIVE PAIN

Up to 90% of patients can have their pain controlled by application of the WHO Ladder

WHO Analgesic Ladder

<table>
<thead>
<tr>
<th>Cancer related</th>
<th>Treatment related</th>
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<tbody>
<tr>
<td>Bone</td>
<td>Surgery - post-operative scars/adhesions</td>
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<td>Nerve compression/ infiltration</td>
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<tr>
<th>Associated Factors</th>
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<tr>
<td>Post-herpetic neuralgia</td>
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“Total Pain” – the term used when psycho social, physical, and spiritual distress combine to affect the patient

CAUSES OF PAIN IN CANCER

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<thead>
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HOW TO USE THE ANALGESIC LADDER

STEP 1 (Mild pain) Non-Opioid ± adjuvant
Start treatment with paracetamol 500mg - 1g 6 hourly (q.d.s.) regularly. If step 1 medications are not adequate in 24 hours, proceed to step 2.

STEP 2 (Mild to moderate pain) Weak Opioid ± step one medication
Start treatment with a combined preparation of paracetamol with dextro-propoxyphene or codeine, or tramadol.

Dextropropoxyphene is available in combination with paracetamol. One capsule contains 65mg of dextropropoxyphene, approximately equivalent to 5mg of morphine. The usual daily dose

is one capsule six hourly, which gives a total daily dose of 260mg of dextropropoxyphene. If step 2 medications are not adequate in 24 hours, proceed to step 3.

**STEP 3 (Moderate to severe pain) Strong Opioid ± step onen medication**

If step two medication is inadequate consider starting oral morphine. For a patient taking 260mg dextropropoxyphene a day, a *minimum* of morphine 5mg four hourly/ six times a day, i.e. a daily total of 30mg of morphine is required.

**Note:**
A. Once the patient is started on the analgesic ladder it is very important that they are reviewed regularly to correctly titrate the exact dose requirements. If pain is not controlled, see the section on poorly controlled pain
B. Though higher doses of dextropropoxyphene can be used the cost will be greater than using oral morphine.

Caution should be exercised in patients who are elderly or in renal failure since kidney excretes active morphine metabolites. Thus it may be necessary to decrease the dose or increase the time interval between doses. Patients should be titrated with immediate release (i/r) morphine either as i/r tablets or solutions depending on patient preference.

**Once Pain is Controlled:**
If modified release morphine preparations are available and affordable (twice the price of normal release preparations) it is possible to change over to twice daily dosing.¹⁰

**Method:**
Calculate the 24 hour dose of 4 hourly (i/r) oral morphine needed, and split into 2 equal doses of 12 hourly (m/r) morphine.

e.g. morphine 20mg 4 hourly = morphine 120mg in 24 hours. Therefore give MST 60mg b.d

**ADJUVANT ANALGESICS (CO-ANALGESICS)**

An adjuvant analgesic drug is a drug which is not an analgesic in its prime function but in combination with an analgesic can enhance pain control. Few examples of adjuvant analgesics are given below

1. **Secondary analgesics**
   - Corticosteroids - pain caused by oedema
   - Antidepressants - neuropathic pain
   - Anticonvulsants - neuropathic pain
   - Muscle relaxants - muscle cramps
   - Antispasmodics - bowel colic
   - Antibiotics - infection pain

2. **Psychotropic medication**
   - Night sedatives - when lack of sleep is decreasing pain threshold
   - Anxiolytics - when anxiety is aggravating pain
   - Antidepressants - when depressed mood is contributing to pain

**MANAGEMENT OF NEUROPATHIC PAIN**

Up to 40% of cancer-related pain may have a neuropathic mechanism involved. Neuropathic pain may be difficult to control, so a wide variety of treatments may be needed:

**DRUGS USED IN NEUROPATHIC PAIN**

**OPIOIDS**

Opioids are usually partially effective in both cancer-related and non-malignant neuropathic pain. Opioids other than morphine have been shown to be effective are tramadol and fentanyl.

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<tr>
<th>1st line</th>
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<tbody>
<tr>
<td>Opioids</td>
<td>Ketamine</td>
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<tr>
<td>Antidepressants</td>
<td>Ligocaine infusion</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>Spinal analgesia (epidural or intrathecal)</td>
</tr>
<tr>
<td>NSAIDs</td>
<td>TENS</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Neurolytic procedures (coeliac plexus block, chemical lumbar sympathectomy)</td>
</tr>
<tr>
<td>Corticosteroid</td>
<td>Capsaicin</td>
</tr>
</tbody>
</table>

Opioids are used as first-line drugs in cancer-related neuropathic pain because:
- Many patients will have a co-existing nociceptive pain
- There may be a nociceptive element to the pain
- Opioids alone may control a third of neuropathic pains, and partially control a further third

If the pain is not responding well to first-line opioid and/or opioid side effects are developing:
- An alternative opioid analgesic may be tried (tramadol, fentanyl)
- Management of side effects can be tried (haloperidol to reduce hallucinations)

**TRICYCLIC ANTIDEPRESSANTS**

The mechanism of analgesic action is principally by facilitation of descending inhibitory pain pathways. (They inhibit pre synaptic reuptake of norepinephrine and serotonin)

e.g. amitriptyline 25-100mg imipramine 25-100mg

**Note:** Amitriptyline can increase the bioavailability of morphine leading to opioid side effects. Start with amitriptyline 25mg (10mg in the elderly) nocte. If there is no response by day 5, increase the dose or according to clinical circumstances, consider changing to an anticonvulsant.

Some patients do not see benefit until after 4-6 weeks of treatment, and/or doses of up to 100mg/day. Severity of pain and the patient's prognosis will dictate how long to prescribe antidepressants. Many patients do not tolerate amitriptyline especially in higher doses, therefore consider changing to imipramine. Lower doses of tricyclic antidepressants are found to produce pain relief and faster response when compared with their doses used in depressive

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11 Department of Health & SPSS Northern Ireland General Palliative Care Guidance for control of pain in patients with cancer. 2003
illnesses. Other antidepressants which are used include venlafaxine, Mirtazapine\textsuperscript{12}

**ANTICONVULSANTS** \textsuperscript{1,3}

These drugs work by dampening abnormal electrical signals in the central nervous system e.g.

- **Valproate**: 100-600mg b.d.
- **Carbamazepine**: 100-400mg t.d.s.
- **Clonazepam**: 1-4mg o.d.
- **Gabapentin**: 100-600mg t.d.s.
- **Pregabalin**: 25-150mg b.d.

Anticonvulsants have been considered better than tricyclic antidepressants for lancinating or paroxysmal pain, but evidence from studies does not support this.

There is little to choose overall between antidepressants and anticonvulsants for neuropathic pain in terms of efficacy or adverse effects.

There is little data to compare anticonvulsants in terms of efficacy, although in one trial comparing the efficacy of different anticonvulsants for lancinating pain, the results suggested that clonazepam was superior to phenytoin, valproate and carbamazepine.\textsuperscript{14}

**Carbamazepine** was used extensively, but clinical experience in the palliative care setting suggested it was often tolerated poorly by elderly, frail or ill patients, and had numerous drug interactions. Carbamazepine tends to result in more side effects particularly when used in combination with other drugs. Doses should be built up slowly to minimize adverse effects.

**Valproate** has been recommended as an alternative to Carbamazepine for use in palliative care, but more data on its efficacy is needed.

**Clonazepam** has been used in cancer-related neuropathic pain, where there is an add element of anxiety.

**Gabapentin and Pregabalin** are licensed for all types of neuropathic pain. Trials have shown benefit in non-malignant and cancer-related pain. Doses of gabapentin up to 2400mg/day have been used successfully (with a few studies up to 3600mg/day). Pregabalin may be as effective with fewer side effects than gabapentin. Some physicians titrate the dose up from 25mg b.d. to minimize the risk of drowsiness. Unlike the antidepressants, anticonvulsants are pharmacologically diverse in their actions, and there is good theoretical reason to try alternative anticonvulsants. All anticonvulsants are used in their typical ‘anticonvulsant’ doses. e.g. Start with Valproate- Day 1 200mg nocte, Day 3-6 400mg, Day 7-10 600mg up to a maximum daily dose of 1200mg or until pain is controlled.

- Some patients do not see full benefit from anticonvulsants until after 4-6 weeks of treatment
- The severity of pain and the patient’s prognosis will dictate how long to prescribe anticonvulsants.


**CORTICOSTEROIDS**

Corticosteroids (usually dexamethasone) may help cancer related neuropathic pain, either by reducing inflammatory sensitization of the nerves, or by reducing pressure on nerves caused by oedema. A high initial dose for a short (three-day) trial should indicate if it will be useful. The dose should then be rapidly reduced to the minimum that maintains benefit.

Although long-term corticosteroids are best avoided, they can sometimes buy useful time whilst allowing other methods (e.g. radiotherapy or antidepressants) to work.

Hydrocortisone has a high mineralocorticoid effect (causes salt and water retention)

Dexamethasone has a relatively high equivalent corticosteroid dose per tablet and less mineralocorticoid effects than prednisolone, or methylprednisolone with consequently less problems with fluid retention.

Prednisolone causes less proximal myopathy than dexamethasone

If steroids are not helpful within three days, consider stopping.

**Relative anti-inflammatory steroid doses (approximate)**

<table>
<thead>
<tr>
<th>Steroid</th>
<th>Administration</th>
<th>Equivalent dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dexamethasone</td>
<td>Oral / SC / i/v</td>
<td>2mg</td>
</tr>
<tr>
<td>Prednisolone</td>
<td>Oral / Rectal</td>
<td>15mg</td>
</tr>
<tr>
<td>Hydrocortisone</td>
<td>Oral / i/v</td>
<td>60mg</td>
</tr>
<tr>
<td>Methylprednisolone</td>
<td>Oral / i/v</td>
<td>12mg</td>
</tr>
</tbody>
</table>

**NSAIDS**

NSAIDs are sometimes effective in cancer-related neuropathic pain, as well as nociceptive pain either because there is mixed nociceptive pain or because they reduce inflammatory sensitisation of the nerves. NSAIDs exert an anti-inflammatory action by inhibiting prostaglandin synthesis through the cyclo-oxygenase (COX) pathways. NSAIDs can be divided into drugs which act on all the COX receptors and therefore may have more associated side effects, and those which selectively inhibit COX – 2 pathways may be associated with less, predominantly gastrointestinal side effects.

The benefits of a lower incidence of gastrointestinal side effects from using COX-2 NSAIDs is reduced by concurrent use of low dose aspirin. This makes the use of COX-2 NSAIDs hard to justify when low dose aspirin is being concurrently administered.

**Non-selective NSAIDs**

- *e.g.:* ibuprofen 200-400mg t.d.s. (p.o.)
- diclofenac 50mg t.d.s. (i/m or suppository)
- naproxen 250-500mg b.d. (p.o. or suppository)
- ketorolac 10-30mg q.d.s (SC, p.o.)

Maximum dose of ketorolac is 60mg for elderly. Maximum duration is 2 days as it has higher incidence of gastrointestinal side effects.

Elderly patients or those with a past history of peptic ulceration, GI bleeding or gastro duodenal perforation are more at risk from side effects. A proton pump inhibitor such as omeprazole has been shown to reduce this risk.

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15 Mims 2003 Handbook of pain management p76
COX–2 Selective NSAIDs

Not commonly used as there are reports of higher incidence of thrombotic episodes

Serious concerns have been raised about the use of COX-2 inhibitors, and their association with myocardial ischemia and cerebrovascular diseases. The European Medicines Agency reviewed all available data on cardiovascular safety and found an increased risk of thrombotic events for COX-2-selective inhibitors as a class, plus data to suggest that the risk of such cardiovascular events increases with high doses and prolonged treatment.

While prescribing COX–2 selective NSAIDs the following recommendations are to followed

- COX-2 selective inhibitors must not be used in patients with ischaemic heart disease or cerebrovascular disease or in patients with peripheral arterial disease
- Caution is required when prescribing COX-2 selective inhibitors to patients
- with risk factors for heart disease, such as hypertension, hyperlipidaemia diabetes and smoking
- Use the lowest effective dose for the shortest possible duration of treatment
- Hypersensitivity reactions and rare but serious (and sometimes fatal) skin reactions can occur with all COX-2 selective inhibitors. In the majority of cases these occur in the first month of use and patients with a history of drug allergies may be at greater risk

OTHER DRUGS

Topical Lignocaine

Topical lignocaine may be useful for superficial localised areas of pain such as fungating wounds for short periods of time. A combination of lignocaine gel with morphine may also help pain. Prolonged use may lead to skin sensitisation.

Ketamine In lower doses, ketamine can be useful in refractory pain, especially neuropathic in character. Use of ketamine is best carried out under specialist supervision.

MANAGEMENT OF POORLY CONTROLLED PAIN

Reassess pain and re-evaluate treatment on a regular basis. Patient's symptoms can have frequent change, and consideration of changing dose or adding an adjuvant analgesic should be kept in mind.

<table>
<thead>
<tr>
<th>PAIN</th>
<th>ADJUVANT/ CO-ANALGESIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache due to cerebral oedema</td>
<td>Dexamethasone</td>
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<tr>
<td>Painful wounds</td>
<td>antibiotic</td>
</tr>
<tr>
<td>Liver capsule pain</td>
<td>dexamethasone</td>
</tr>
<tr>
<td>Gastric mucosa irritation</td>
<td>omeprazole, pantoprazole</td>
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<tr>
<td>Gastric distension</td>
<td>dimethicone+metoclopramide</td>
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<tr>
<td>Skeletal muscle spasm</td>
<td>baclofen/diazepam</td>
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<tr>
<td>Cardiac pain</td>
<td>nitrates/nifedipine</td>
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<td>Oesophageal spasm</td>
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<tr>
<td>Intestinal Colic</td>
<td>hyoscine butyl bromide</td>
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**BREAKTHROUGH PAIN**

Breakthrough pain is a flare in pain of rapid onset, moderate to severe intensity and of short duration. It does not include pain that occurs because the dose has been inadequately titrated (end of dose failure).

Includes:

- **Incident pain**, when pain occurs in response to a specific activity e.g. standing up, walking, changing wound dressings, rectal examination, manual evacuation.

- **Spontaneous pain**, when pain occurs without an obvious aggravating cause.

**END OF DOSE FAILURE PAIN**

If pain is experienced before the 4 hourly dose of (i/r) opioid is due, the patient should be given a rescue dose of 100% of the 4 hourly dose. If rescue doses are required more than twice a day on a regular basis, then this is an indication to increase the regular 4 hourly doses.

When prescribing for continuous pain, remember,

- **By the Clock** – Regular intervals, not p.r.n
- **By the Mouth** – Safe, cheap and convenient
- **By the Ladder** – Proven method to control 90% of pain

**INCIDENT PAIN**

**Activity management**

- Analysis and avoidance of precipitating activities if possible

**Drugs**

- Oral morphine sulphate 20-30 minutes prior to procedure NSAID taken prior to movement, but note that NSAIDs can not be taken as and when required
- Inj. ketamine (0.25-0.5mg/kg) taken p.o/SL 15 minutes prior to the procedure

**Other Therapies**

- Hypnotherapy
- Distraction

**BONE PAIN**

A single fraction of radiotherapy aimed at a localised area in the skeleton may prove beneficial in the relief of bone pain, whereas more widespread bone pain may be improved by wider field radiotherapy or by treatment with a bone seeking isotope e.g. radioactive Sumarium. NSAIDS (Non-Steroidal Anti-Inflammatory Drugs) - see previous NSAID section.

**Bisphosphonates**

The bisphosphonates (e.g. pamidronate, zoledronate, ibandronate, clodronate, and alendronate) are potent inhibitors of osteoclast-mediated bone resorption. There is good evidence that these are useful for reducing the incidence of fractures in bone metastases particularly due to multiple myeloma and breast carcinoma. However first line treatment for bone pain remains NSAIDs combined with opioids, if necessary. Pamidronate and zoledronate are administered intravenously.

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Clodronate, alendronate and ibandronate may be used orally. Studies have shown some promise with oral ibandronate in reducing the incidence of bone pain.\textsuperscript{19}

**HEADACHE**
Headache due to raised intracranial pressure often responds well to the use of steroids. These may have to be given in large doses (16-32mg dexamethasone per day, before 3pm and titrate according to response.). Headaches are semi resistant to opioids, hence paracetamol can be tried along with steroids.

**INTESTINAL and URINARY TRACT COLIC**
Pain due to bowel cramps is largely insensitive to morphine but can be eased by smooth muscle relaxants such as hyoscine butyl bromide.

**LIVER CAPSULE PAIN**
The pain is caused by stretching of the peritoneum on the liver surface and can often be eased by the use of steroids (dexamethasone 4-6 mg) to reduce oedematous distension

**MUSCLE SPASM**
This can be hard to control, but the use of skeletal muscle relaxants such as diazepam 2mg t.d.s. or baclofen 5mg t.d.s. may be effective.

**OPIOID SIDE EFFECTS**
Patients should be warned about the possible side effects of morphine such as nausea and sleepiness which are usually short lived. If sleepiness continues after a few days, other possible causes (uraemia, hypercalcaemia) or toxicity from other medication should be excluded. Constipation is predictable and most patients need prophylactic laxatives.

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<tr>
<td>Vomiting</td>
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<tr>
<td>Myoclonus</td>
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<tr>
<td>Pin Point pupils</td>
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<tr>
<td>Urinary retention</td>
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If unacceptable toxicity occurs, reduce morphine dose. The patient may need to miss several doses and restart at a lower dose. For the occasional patient who cannot tolerate morphine, it may be useful to consider alternative opioids in equivalent doses.

**GENERAL MANAGEMENT OF OPIOID SIDE EFFECTS**
A number of different approaches may be used to manage persistent opioid-related side effects:

- Treat the side effect
- Use an alternative opioid
- Use an alternative analgesic method, such as spinal opioids, which may cause less systemic or central side effects

SPECIFIC MANAGEMENT OF OPIOID SIDE EFFECTS

Opioid induced Drowsiness & Cognitive impairment
- Initial mild drowsiness on initiating opioid therapy will often abate over a few days as the patient adjusts. It is often appropriate to continue opioids and wait for the drowsiness to wear off.
- For persistent drowsiness, sedation or cognitive impairment, opioids are stopped temporarily and other causes for drowsiness have to be ruled out. Alternative opioids are another option. Psycho stimulants also may be tried.

Common Misunderstandings about Morphine Use
- Should be given only in the very last stage.
- Always causes addiction.
- Never give to patients with COPD.

Opioid-induced Hallucinations or Delirium
Reduce dose of opioid and consider adding adjuvants. (haloperidol 2.5-5mg nocte p.o/SC)

Opioid-induced Myoclonus
- Renal failure alone can cause myoclonus, but also causes opioid metabolites to accumulate which increase the risk of opioid toxicity. Myoclonus may be more likely in patients also taking antidepressants.
- Parenteral rehydration, if appropriate Reviewing other medication which may exacerbate myoclonus.
- Alternative opioid.
- Clonazepam 1-2mg/24h. Diazepam or midazolam are probably less effective than clonazepam but may be appropriate if sedation is also desirable.

Opioid - induced Constipation
- Constipation can usually be treated acceptably with laxatives.
- A stimulant laxative such as bisacodyl 10mg nocte increased to tds if required. Softeners such as liquid paraffin can be added.

Opioid - induced Nausea & Vomiting
Initial nausea may wear off after a week and usually responds to:
- haloperidol 1.5 – 2.5mg nocte
- metoclopramide 10mg tds

Opioid - induced Pruritus
More common with spinal than systemic opioids.
- 5-HT3 antagonists (e.g. ondansetron) or paroxetine

Opioid - induced Respiratory Depression
UNCOMMON WITH ORAL MORPHINE
Reduction of the dose is usually all that is required immediately.

If the patient is receiving morphine through CSCI, it should be temporarily stopped to allow plasma levels to decrease, before restarting at a lower dose.

Naloxone is only indicated if significant respiratory depression is present; opioid withdrawal symptoms and pain can be severe if long-term opioids are abruptly stopped.

It is important to titrate the dose of naloxone carefully, to avoid acute opioid withdrawal.
Naloxone has a half-life of 5-20 minutes. As the half-life of most opioids is longer than this, it is important to continue assessment of the patient and give naloxone at further intervals if necessary.

**NALOXONE**

**Indications for naloxone**
- Respiratory rate <8 breaths/min, or
- <10-12 breaths/min, difficult to rouse and clinically cyanosed, or
- <10-12 breaths/min, difficult to rouse and SaO2 <90% on pulse oximeter

**Use of naloxone**
- Dilute naloxone 0.4mg in 10ml of 0.9% sodium chloride for injection
- Use an i/v cannula or butterfly needle
- Administer 0.5ml i/v every 2 minutes until respiratory status improves satisfactorily. Repeat further doses as needed

**Opioid -induced Increase in Generalized Pain (Rare)**
- Hyperalgesia and allodynia have been reported with high-dose opioids. It is usually associated with myoclonus, and an increase in the opioid dose may lead to worsening of the pain and opioid toxicity
  - Substitution of an alternative opioid often resolves the symptoms
  - Alternatively, reduction of dose and the addition of a coanalgesic may be useful

**Note:** If side effects of opioids are unacceptable and/or pain is not controlled review the cause of the pain.

**OPIOID RESISTANT CANCER PAIN**

**Pseudo-resistant**
- Under dosing
- Poor absorption (ileostomy)
- Poor intake (vomiting)
- Ignoring psychological aspects

**Semi-resistant**
- Bone pain
- Raised intracranial pressure
- Neuropathic pain
- Activity related pain

**Resistant**
- Muscle spasm
- Abdominal cramps
- Psychosocial pain
- Spiritual pain*

*As stressed earlier, patients with chronic unremitting pain from a deteriorating condition are particularly at risk of spiritual pain which needs to be addressed. Referral for psychological/
spiritual support is important. Using Hay’s model assessment, “spiritual pain” can be broken down into:

- spiritual suffering - interpersonal or intrapsychic anguish
- inner resource deficiency - diminished spiritual capacity
- belief system problem - lack or loss of personal meaning
- religious request - a specifically expressed religious need

**ALTERNATIVE OPIOIDS TO MORPHINE**

Rarely when patients develop intolerable side effects such as nausea, itching, confusion, myoclonic jerks, bronchospasm etc. an alternative opioid might be of help.

Of the following opioid alternatives only fentanyl is currently available in India.

1st line morphine
2nd line oxycodone, fentanyl, hydromorphone
3rd line methadone

Opioids control pain by blocking receptors (mainly mu and kappa), which are present predominantly in the dorsal horn of the spinal cord but also in the brain stem and in the peripheral nerves. Different opioids have different pharmacological profiles because of the different ways in which they bind to the different opioid receptors.

Patients who are in renal failure are in danger of opioid toxicity, since morphine metabolites, which are normally excreted by the kidney, get accumulated. Dose and frequency of opioids must be monitored meticulously in such patients for signs of opioid toxicity.

It is worth considering switching from oral morphine to subcutaneous morphine if patients are unable to swallow.

Genuine morphine intolerance is limited to a very small number of patients.

<table>
<thead>
<tr>
<th>DIFFERENT TYPES OF OPIOID DRUGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine &amp; similar drugs</td>
</tr>
<tr>
<td>Morphine</td>
</tr>
<tr>
<td>Diamorphine</td>
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<tr>
<td>Hydromorphone</td>
</tr>
<tr>
<td>Oxycodone</td>
</tr>
<tr>
<td>Fentanyl &amp; similar drugs</td>
</tr>
<tr>
<td>Fentanyl</td>
</tr>
<tr>
<td>Alfentanil</td>
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<tr>
<td>Sufentanil</td>
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<tr>
<td>Methadone</td>
</tr>
<tr>
<td>Methadone</td>
</tr>
<tr>
<td>Opioid of intermediate strength</td>
</tr>
<tr>
<td>Tramadol</td>
</tr>
<tr>
<td>Other opioids</td>
</tr>
<tr>
<td>Buprenorphine (rarely used)</td>
</tr>
<tr>
<td>Weak opioids</td>
</tr>
<tr>
<td>Codeine, Dextropropoxyphene</td>
</tr>
</tbody>
</table>

Not recommended in Palliative Care-Pethidine and Pentazocine (Fortwin)

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**FENTANYL (Transdermal and Injectable)**
- Fentanyl is a selective mu receptor agonist, unlike morphine which is less selective.
- In India it is available in a 72-hour transdermal patch formulation.
- Fentanyl is unsuitable for patients with unstable pain
- Fentanyl is expensive

Transdermal Fentanyl patches deliver 25,50,75 or 100 micrograms per hour over three days. Peak plasma concentrations are achieved after 12-24h and a depot remains in the skin for some 24h after the patch is removed. Breakthrough doses of opioid will be necessary during the first 24h of application.

One in ten patients who have had their pain controlled by morphine may experience a withdrawal reaction when converted to fentanyl. They may require oral morphine on a p.r.n. basis to manage the withdrawal symptoms for a day or two. A reduction of laxative may be necessary when converting from morphine to fentanyl as the latter may cause less constipation.

*Patients cannot have their pain titrated using patch delivery systems which take up to 36 hours to reach a steady state in the body. Pain control must first be achieved using oral morphine before switching to a fentanyl patch.*

**METHADONE (Not available for clinical use in India)**
Methadone is a long acting synthetic opioid which may have a part to play in treating non-specific cancer pain as well as neuropathic pain, although the evidence is still equivocal. The use of methadone as an alternative opioid should only be initiated as an in-patient by a specialist in palliative care because its dosing regime is unusual, and there is wide inter-patient variability preventing reliable equi-analgesic dose predictions.

The major danger is overdosing as methadone has a very long half-life.

**TRAMADOL**
Tramadol may be classed somewhere between the weak and strong opioids. It has additional pharmacological actions to its opioid effects. It is not classed as a ‘controlled drug’ which has some practical prescribing advantages.

Tramadol is a synthetic analogue of codeine that binds to mu opioid receptors and also inhibits nor epinephrine and serotonin reuptake at the neuromuscular junction. It is rapidly absorbed after oral doses and is metabolized in the liver. Analgesia begins within one hour and starts to peak in two hours. In studies comparing equianalgesic doses of oral tramadol (up to 400 mg/ day) and oral morphine for moderate cancer pain, constipation, nausea, neuropsychiatric symptoms, and pruritus were reported more frequently with morphine. Slow release formulations have also been shown to provide effective relief of moderate pain.

**BUPRENORPHINE (Available in only in some parts of India)**
- Tablet strength: 0.2mg.
- Dose range: 0.2- 0.6mg 6-8 hourly

Antiemetics are always required for the first week of therapy. Some palliative care physicians have been concerned about the use of buprenorphine. This is due to the fact that although buprenorphine is a very potent analgesic and strongly binds to opioid receptors

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displacing other opioids it is a less effective analgesic. However, within commonly used dose ranges this risk may have been more theoretical than actual, and the introduction of buprenorphine patches has caused such concerns to be reviewed.

For patients using buprenorphine patches, other opioids such as oral morphine immediate release and buprenorphine immediate release can be used for breakthrough pain. Ensure that the patch is sticking well to the skin of those patients who use to sweat heavily

- For opioid naïve patients the starting dose recommended by the manufacturers is 35 micrograms/h
- Not more than two patches should ever be applied at one time
- The maximum dose is 140 micrograms/h
- The patch should be changed every three to four days.

**COMMON OPIOID CONVERSIONS**

1. Oral dextropropoxyphene to oral morphine
2. Oral codeine to oral morphine
3. Immediate release oral morphine to modified release oral morphine
4. The breakthrough dose of oral morphine
5. 24h oral morphine to 24h CSCI morphine
6. Oral morphine to transdermal fentanyl

### 1. Oral dextropropoxyphene to oral morphine

Dextropropoxyphene is a weak opioid. The conversion factor between dextropropoxyphene and morphine is 12.

**i.e. a patient who is taking proxyvon (paracetamol / dextropropoxyphene 65mg) 1 cap 6 hourly should get morphine equivalent of 22mg a day. If that is inadequate to control the pain, the patient should be switched over to oral morphine 5mg 4 hourly (30mg per day)**

### 2. Codeine to oral morphine

Codeine is a weak opioid. The conversion factor between codeine and morphine is 10.

**i.e. a patient who is taking codeine tablets 40mg 4 hourly gets a total dose of 240 mg of codeine/24h To convert this dose of codeine to an equivalent dose of oral morphine, divide the codeine dose by 10. This gives a total morphine dose per 24 hours of 240mg/10 = 24mg oral morphine.**

### 3. Immediate release oral morphine to modified release oral morphine

Oral morphine is available in immediate release (i/r) preparations which work over 4 hours. Oral morphine is also available in modified release (m/r) preparations such as MST (12 hours). Immediate release (i/r) morphine is used for patients who have unstable pain to assess their opioid needs. It is safer to titrate the dose against the patient’s pain with short acting preparations.

**i.e. a patient who is being titrated on immediate release oral morphine requires 6 doses of 5mg for 24 hours. To convert this to a modified release preparation, work out the total 24 hour dose consumed- ( 5mg X 6 doses = 30mg). For a 12h preparation such as MST, use total 24 h dose/ 2 = 30mg/2 = 15mg b.d.**

### 4. The rescue dose of oral morphine

The rescue dose of oral morphine is always given in an immediate release formulation. The breakthrough dose is generally calculated in relation to the patient’s overall 24 hour morphine...
requirements if under dosing or over dosing are to be avoided. The breakthrough dose is
generally calculated at the dose equivalent to a 4 h dose (1/6th) of the patient’s current
opioid dose.

i.e.a patient who is receiving 60 mg of morphine every 24h, should have a breakthrough
dose of 60mg/6 = 10mg of immediate release morphine.

5. 24 h oral morphine to 24h CSCI morphine
Morphine subcutaneously is 2 times more potent than oral morphine. i.e. a patient who is no
longer able to swallow is currently on MST 120mg b.d. To work out the equivalent dose of
morphine to be used subcutaneously for 24h,

   a) work out the total dose of oral morphine per 24h = 120 X 2 = 240mg oral morphine.

   b) The equivalent dose of morphine SC=240/2 =120 mg morphine/ 24h CSCI.

6. Oral Morphine to Fentanyl Patch
First ensure pain is stabalised using oral morphine before considering switching to a patch.
10mg oral morphine four hourly (60 mg/ 24hours) is approximately
equal to a 25 mcg/h transdermal fentanyl patch applied once in three days.

WRITING PRESCRIPTIONS FOR OPIOIDS
Legal requirements for writing opioid prescriptions may vary from state to state in India.

Every prescription should contain the following information as a minimum.

1. The patient’s name, age and hospital number
2. Name of drug, strenght, route, dose and frequency
3. Number of days for which the drug is prescribed
4. Physician’s name, signature and registration number

NERVE BLOCKS
This may be appropriate if pain is not well controlled, or if drug side effects are a problem,
and may be particularly useful if pain is localised in a segmental distribution.

Common anaesthetic techniques in patients with terminal cancer include:

Temporary analgesia : - local anaesthetics, steroids etc. are used to produce temporary
analgesia

   e.g. myofascial pain (trigger point injection)
        solitary rib metastasis
        axial skeletal metastases
        sacroiliac pain (sacroiliac joint injection)
        chest wall pain (paravertebral block)
        fractured neck of femur (lumbar plexus block)
        head and neck pain (cervical plexus block)
        postherpetic neuralgia

Neurolytic analgesia :- aqueous phenol, alcohol are used to produce permanent analgesia

These techniques are usually only applied after a successful trial with temporary analgesia.

Spinal analgesia :- epidural or intrathecal analgesia. Local anaesthetics and steroids are
common agents used.
NON-PHARMACOLOGICAL INTERVENTIONS
A range of techniques exist to complement the pharmacological approaches. These techniques are not just an adjunct to medication but point to the centrality of holistic patient-centred care. Not all approaches will be appropriate for every patient, but there are patients for whom traditional medicine has little to offer.

<table>
<thead>
<tr>
<th>Complementary Therapies</th>
<th>Other Non-Pharmacological Interventions</th>
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<td>Reflexology</td>
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<td>Touch therapy</td>
<td>Good communication</td>
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<tr>
<td>Aromatherapy</td>
<td>Diversional therapy</td>
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<tr>
<td>Art therapy</td>
<td>Splinting of a fractured limb</td>
</tr>
<tr>
<td>Music therapy</td>
<td>Psychological support</td>
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<tr>
<td>Hypnotherapy</td>
<td>Relaxation</td>
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<tr>
<td></td>
<td>Joint mobility - passive &amp; active</td>
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<tr>
<td></td>
<td>Spiritual counselling</td>
</tr>
</tbody>
</table>

PAIN MANAGEMENT BACKGROUND READING

Books
Abingdon: Radcliffe Medical Press
CONCEPT OF PALLIATIVE CARE AND MANAGEMENT OF PAIN
QUESTIONS

These questions can be used as an aid to revision.

1. How would you define palliative care, terminal care and hospice care?
2. What is the difference between nociceptive and neuropathic pain and why is this difference important?
3. What is the WHO analgesic ladder?
4. For pain management, give two examples each of:
   - Weak opioids
   - Non-opioids
   - Adjuvant/ co-analgesics
   - Strong opioids
5. For a patient receiving MST 120mg b.d, what is the appropriate dose for breakthrough medication?
7. What is spiritual pain?
8. What classes of drugs are used to treat neuropathic pain?
9. What are the routes by which opioids can be administered?
10. What advice would you give to patient starting opioids?
11. Describe the steps that you would advise to convert MST 100mg b.d. to a fentanyl patch.
Section Five
Management of other Symptoms

GASTRO INTESTINAL SYMPTOMS

The Guiding Principles:

- Anticipation of problems before they occur.
- Ongoing assessment of treatments and their effectiveness.
- Appropriate prescribing of background medications as well as medication for “breakthrough” symptoms

A sizeable proportion of palliative care is concerned with the management of gastrointestinal symptoms. Traditionally such symptoms have received less attention than pain management, yet the same principles apply.

Patients with pain usually show a response or a lack of response to treatment within hours. Patients with gastrointestinal symptoms on the other hand may take several days to respond to interventions and the temptation is thus to have a more lax attitude to monitoring gastrointestinal problems. In reality the doctor and nurse need to be much more attentive to these issues which deceptively cause great patient morbidity, yet may not declare themselves, until they have become major management difficulties.

An example of such an issue arises every time a patient is prescribed a strong opioid for the first time. Waiting to see if the patient will become nauseated or constipated may lead to major problems.

1. The patient may become so nauseated that he/she refuses all opioids.
2. The patient may become severely constipated with serious and unpleasant consequences.
3. The patient and family may lose trust in the health care professional. Such trust is one of the strongest tools in helping patients and may be difficult or impossible to repair if it is shaken so fundamentally.

Every time an opioid is prescribed for the first time, or the dose of a strong opioid is markedly increased, always prescribe or increase the dose of a laxative. Antiemetics should be prescribed for the first five to ten days of a strong opioid being started or a higher dose being initiated, but after five days can, and should, be stopped as nausea due to the opioid side effects wears off. In practice, if patients have tolerated analgesics on step two of the analgesic ladder, without antiemetics they will probably not need antiemetics when changing to strong opioids

ORAL PROBLEMS

Saliva is composed of mucinous, as well as serous fluid, which helps keep the mouth moist and healthy. Mucin has many actions including antibacterial activity. Each day around 1.5 litres of saliva should be produced in the healthy population, to keep the mouth, teeth and gums healthy. This is often not the case in patients with palliative care needs.
Patients with palliative care needs are particularly at risk of oral problems even in the absence of local disease because:

- fluid intake tends to be lowered
- nutritional state is often reduced
- patients are often taking medicines, which dry up secretions
- associated interventions such as radiotherapy in the face and neck and chemotherapy predispose to poor oral health. (Head and neck cancers have a very high incidence in India)
- the patient’s capacity to take care of his/her own oral hygiene may be reduced
- there is frequent acceptance that oral problems, “aren’t serious enough to mention”

Ninety percent of patients in the palliative setting have oral problems of varying severity. The underlying cause should be sought and treated appropriately.

ASSESSMENT:

- Assess symptoms and signs of problems such as altered taste, oral pain, dry mouth, halitosis, ulcers, oral or pharyngeal candidiasis or dental problems
- Regular examination of lips, tongue, teeth and oral mucosa
- Involve local dental team if necessary
- Assess patient’s ability to carry out own mouth care effectively

GENERAL MOUTH CARE

The aim of good mouth care is to prevent problems before they arise and to control unpleasant symptoms. Mouth care should be undertaken routinely in all patients every 2-4 hours whether or not they are able to care for themselves. Particular attention needs to be paid to patients who are comatose, on steroid therapy, receiving nasogastric tube feeding and mouth breathing. Other patients who are less at risk need less frequent, but regular, mouth care. Care includes cleaning the teeth with toothpaste and soft tooth brush after meals, regular mouth rinsing, keeping the mouth moist, and looking and inquiring for evidence of problems such as altered taste, halitosis, oral candidiasis, ulcers, denture problems and oral pain. It can be anticipated that a diligent search will often reveal a need for more meticulous mouth care.

Review of general dental hygiene should be done and request for professional help from a dental surgeon should be sought if necessary.

1. ORAL CANDIDIASIS (ORAL THRUSH)

This is a condition where there is candidal infection of the oral mucosa causing pain and difficulty in swallowing. There will be intense inflammation which gives reddish appearance to the mucosa and white patches in the mucous membrane which may bleed on removal.

Management:

- nystatin suspension 1-2ml 4 hourly
- fluconazole 150mg daily for 7-14 days
- Clotrimazole mouth paint

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2. STOMATITIS (SORE MOUTH)

Stomatitis refers to painful, inflammatory/infective/ ulcerative conditions affecting the mucous membranes lining the mouth and may be caused by:

- infection (including Herpes simplex, Candida albicans)
- ulceration (malignant/non malignant ulcers)
- mucositis (post radiotherapy or chemotherapy)
- iron deficiency (angular stomatitis and glossitis)
- vitamin C deficiency (gingivitis and bleeding)
- dry mouth

Other causes of oral pain include:

- tumour infiltration
- dental problems

Management:

General measures:

- Frequent sipping of water and semi-frozen drinks
- Sucking ice-chips
- Chewing pineapple pieces
- Sugar-free chewing gum
- Petroleum jelly applied to lips
- Vegetable oil
- Consider saliva substitutes (expensive) especially pre-meals
- Good oral hygiene
- Avoid foods that trigger pain e.g. acidic foods
- Avoid tobacco and alcohol

Specific Measures

- Treat underlying cause if possible (e.g. infection)
- ENT/oncology review

Drug management:

Local anaesthetic agents such as 2% lignocaine jelly or 4% viscous, and choline salicylate gel (Zytee) can be used. Ulcers may also be helped by soluble aspirin/ prednisolone

3. DRY MOUTH (XEROSTOMIA)

Xerostomia is the subjective feeling of a dry mouth and is often associated with difficulties with speech, chewing or swallowing, the need to keep drinking and loss of taste. This is a common problem in advanced cancer and appropriate management may involve the use of both saliva stimulants and substitutes.

Causes:

- Drugs e.g. antimuscarinic, antidepressants, opioids, Diuretics
- Candidiasis
- Dehydration
- Anxiety
- Mouth breathing
- Radiotherapy
- Oxygen therapy (non-humidified)
Management:
- Keep mouth as moist as possible
- Treat underlying cause if possible
- Review medications
- Basic oral care regimen (see previous page)

4. HALITOSIS
Halitosis means foul smelling breath. There can be many causes for this condition. Few examples are
- Oral Causes: - Poor orodental hygiene, Dental caries, Gingivitis, Malignant ulcers/growths
- Sinusitis, Malignant growths in the sinuses
- Suppurative lung diseases

Diagnose cause, if oral
- Metronidazole gargle
- Frequent mouth wash
- Meticulous dental care

Occasionally a systemic course of metronidazole is required

ORAL PROBLEMS BACKGROUND READING

Books

Articles
NAUSEA AND VOMITING

“Nausea is an unpleasant feeling of the need to vomit often accompanied by autonomic symptoms”

“Vomiting is the forceful expulsion of gastric contents through the mouth”

Twycross

Nausea and vomiting are the symptoms which can cause patients and their relatives deep distress. Of the two, nausea causes most misery. Many patients can tolerate one or two episodes of vomiting a day while prolonged nausea is profoundly debilitating. Causes of nausea are multiple and it is important to analyse the likely cause so that appropriate therapy can be initiated.

There are many receptors involved in transmitting the neural impulses connected with nausea and vomiting. These include those for histamine, acetylcholine, hydroxytryptamine and dopamine which are located in varying concentrations largely in the vomiting centre and the chemo receptor trigger zone (CTZ) in the mid brain. In simple terms, neural impulses from a variety of emetic stimuli are relayed to these sites in the brain stem triggering the vomiting reflex. Hydroxytryptamine is also found in high concentration in the gut lining, and can be released through bowel distension, radiotherapy, chemotherapy etc.

OPIOID-INDUCED NAUSEA & VOMITING

Opioids can cause nausea and vomiting through a number of different mechanisms. These include stimulation of the chemo receptor trigger zone, increased vestibular sensitivity, gastric stasis or impaired intestinal motility and constipation.

Haloperidol is usually recommended as the first-line drug for opioid-induced nausea and vomiting, however metoclopramide (for gastric stasis), may be effective in certain patients. 5-HT3 antagonists have also been shown to be useful but are expensive for long term use. It is worth considering reducing the opioid dose. If nausea and vomiting are distressing, try another opioid. ²⁴

The priority is to treat the nausea and vomiting aggressively, if necessary with more than one anti emetic before reducing opioid doses and causing the return of pain.

MANAGEMENT

Non-Pharmacological Management of Nausea and Vomiting

Control of malodour from colostomy, fungating tumour or decubitus ulcer etc..

A calm, reassuring environment away from the sight and smell of food

Avoid exposure to foods, which precipitate nausea

Small snacks, e.g. a few mouthfuls given frequently are often more effective than infrequent large meals.

If the patient is the household cook, someone else may need to take on this role

Acupuncture. There is some evidence for its use.²⁵


# Pharmacological Management of Nausea and Vomiting

<table>
<thead>
<tr>
<th>Causes of vomiting</th>
<th>Choice of antiemetic Drug</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug or toxin induced</td>
<td>Haloperidol 1.5-2.5 mg nocte/b.d., metoclopramide 10mg tds</td>
</tr>
<tr>
<td>Radiation</td>
<td>Ondansetron up to 8mg t.d.s., granisetron 1mg stat then 1mg b.d., haloperidol 1.5 nocte or b.d. ondansetron 4-8mg tds</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Granisetron 1mg stat then 1mg b.d., dexamethasone 4-8mg o.d.(often as part of a chemotherapy regime), metoclopramide up to 20mg q.d.s.</td>
</tr>
<tr>
<td>Metabolic / hypercalcemia</td>
<td>Haloperidol 1.5mg nocte or b.d.</td>
</tr>
<tr>
<td>Raised intracranial pressure</td>
<td>Dexamethasone 16-32mg in morning (dose is to be titrated)</td>
</tr>
<tr>
<td>Delayed gastric emptying</td>
<td>Metoclopramide 10-20mg q.d.s. (gradually increased till prokinetic effect is satisfactory or extrapyramidal symptoms develop), domperidone 10-20 mg q.d.s</td>
</tr>
<tr>
<td>Gastric irritation</td>
<td>PPI (Omeprazole). Stop gastric irritants (NSAID)</td>
</tr>
</tbody>
</table>

A single antiemetic may be adequate to suppress symptoms, but if there are different causes of vomiting, it may be necessary to combine drugs. For instance, if the causes of vomiting are thought to be raised intracranial pressure and uraemia, it may be necessary to combine e.g. metoclopramide and haloperidol and an adjuvant, e.g. dexamethasone.

It may be possible to control nausea with oral medication but persistent vomiting requires drug delivery by an alternative route or more reliably subcutaneously by means of stat doses or continuously via a syringe driver.

All antiemetics have side effects with which it is necessary to be familiar. It is very easy to overlook minor extrapyramidal effects of the dopamine antagonists and thus add to a patient’s distress. For instance, haloperidol and metoclopramide may cause restlessness and inability to keep still (akathisia). More marked signs include parkinsonian effects such as stiffness and tremor. The effect can be reversed by reducing or stopping the drug. If necessary a small dose of a benzodiazepine can be given to reverse the symptoms.

**Note:**
- Prokinetic drugs such as metoclopramide or domperidone should be used with care if bowel obstruction is suspected since they may increase gut colic and worsen vomiting.
- Octreotide (expensive) dries up gastrointestinal secretions tending towards constipation.
- Ondansetron and granisetron also are associated with constipation.

**Identify the causes of nausea and vomiting that can best be treated specifically**
- Constipation - remember to do a rectal examination.
- Gastritis - epigastric discomfort & tenderness?
- Raised intracranial pressure - headache & neurological signs?
- Oropharyngeal candidal infection?
- Hypercalcaemia - dehydration, confusion, thirst?
- Drug-induced - recent introduction of morphine?
- Intestinal obstruction
- Renal Failure

If the first choice drug is unsuccessful or only partially successful after 24h, increase dose or use different antiemetic(s)
- Nausea & vomiting in cancer are often multifactorial
- If confident that there is a single cause for the nausea and vomiting, consider increasing the dose of antiemetic (especially metoclopramide), or changing to a second-line specific antiemetic (e.g. ondansetron for chemotherapy-induced nausea)
- If not confident of cause, empirically try one of the other first-line antiemetics (metoclopramide, haloperidol)
- Combinations of antiemetics which act at different receptor sites are often needed if using more than one antiemetic, one from each class of antiemetics should be used
- Antispasmodic drugs such as hyoscine butylbromide (buscopan) may antagonise the prokinetic metoclopramide, and should not be used together

General points
- Always give antiemetics regularly -not p.r.n.
- If vomiting is preventing drug absorption, use an alternative route e.g. subcutaneous
- Dexamethasone 4mg daily often contributes an antiemetic effect for nausea and vomiting of unknown mechanism
- Check blood urea and electrolytes, liver function tests and calcium

Renal failure - consider lowering the dose of opioids, or changing to an opioid that is better tolerated in renal failure (e.g. fentanyl)

Hypercalcaemia - should be treated first with rehydration then intravenous bisphosphonates if available.

**NAUSEA AND VOMITING BACKGROUND READING**

**Books**


**Articles**

CONSTIPATION

Constipation is characterised by difficult or painful defaecation, and is associated with infrequent bowel evacuations, and hard, small faeces.

Constipation can be extremely debilitating and can become the patient’s overriding concern. A good history is required, particularly as constipation is subjective and depends on the patient’s normal bowel habit, and how the patient defines “constipation”. Patients will need full explanations of the cause of their constipation and reassurance regarding management. Stool frequency varies considerably in the normal population; 45% of patients are constipated in the palliative care setting. Complications of constipation include a general feeling of bloating and rectal fullness, pain, bowel obstruction, overflow diarrhoea and urinary retention all of which cause great distress and every effort must therefore be made to avoid them.

CAUSES

Disease Related
- Immobility leads to decreased peristalsis
- Decreased food intake
- Low residue diet

Fluid Depletion
- Poor fluid intake
- Increased fluid loss (vomiting, polyuria, fever)

Weakness
- Inability to raise intra-abdominal pressure (general debility, paraplegia)
- Inability to reach toilet when urge to defecate occurs

Drugs
- Opioids (90% of patients taking opioids need laxatives)
- Diuretics
- Somatostatin analogues (octreotide)
- Antimuscarinics (phenothiazines, tricyclic antidepressants)
- Hyoscine derivatives
- Serotonin inhibitors (ondansetron)

Biochemical causes
- Hypercalcaemia
- Hypokalaemia

Others
- Embarrassment in public setting
- Pain on defecation (fissure in ano)
**MANAGEMENT**

**Non-Pharmacological Management of Constipation**

Access and ability to get to the toilet may be more important than a supply of laxatives

Timing and privacy–impatience from patients and carers leads to straining and bracing

Straining compromises defaecation and damages pelvic floor function

A squatting position facilitates efficient funnelling of the pelvic floor, favouring defaecation

Put feet underneath knees, if necessary using a step/ pillow to bring knees above hip level

Rest forearms on thighs, curling upper body forward, with head drooping slightly forward

Look at the hands resting on thighs. No tension should be felt in the shoulder girdle

Blow silently, slowly and gently. At the end of the breath feel the upper abdominal muscles pulling in

Wait and repeat the slow blowing as often as necessary

*As far as possible patients should be encouraged to eat a normal balanced diet and drink plenty of fluid. This may not be possible for all the reasons outlined previously.*

**PHARMACOLOGICAL MANAGEMENT OF CONSTIPATION**

**LAXATIVES**

1st line: **Stimulants** (senna, bisacodyl)

Avoid stimulant drugs if there is the possibility of intestinal obstruction. Bisacodyl is useful with a softener such as docusate for opioid induced constipation

2nd line Faecal softeners (docusate or liquid paraffin)

These are useful in conjunction with a stimulant (docusate + bisacodyl)

(It may be safer to use docusate alone in resolving intestinal obstruction).

3rd line: **Osmotic Agents** (lactulose, magnesium salts, macrogols)

Polyethylene glycol in the palliative setting is commonly used particularly in intractable constipation and faecal impaction\(^{26}\). Sufficient intake of fluid may reduce the dehydrating effect sometimes seen with osmotic laxatives.

**Bulk Forming Agents** (methylcellulose, ispaghula husk Fybogel). Patients are rarely started on these preparations in the palliative care setting since they may aggravate constipation when used with reduced fluid intake. They are also unpalatable and may aggravate anorexia.

**Rectal agents** (glycerol suppository, bisacodyl suppository) Bisacodyl is a rectal stimulant and should be placed in direct contact with the rectal mucosa. If appropriately placed, it should stimulate evacuation within one hour.

Glycerol is a faecal lubricant which facilitates defaecation by softening the stool, with which it should be placed in contact. Glycerol also acts as a rectal stimulant through its mildly irritant action.

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For more severe constipation:
Phosphate enema (proctoclys) is used to stimulate bowel clearance. This can be repeated daily until effective bowel movement occurs.
Rectal laxatives are sometimes necessary but should never take the place of an appropriate prescription of an oral laxative.

Treatment of faecal impaction
The treatment of faecal impaction is usually managed in stages. Generally, only one stage should be implemented in each 24 hour period, but assessment of a patient’s individual need and his/her normal bowel habit should be taken into consideration first. Macrogols (Movicol) are also licensed for use in faecal impaction.

Soft Faeces Palpable in Rectum
- Bisacodyl suppositories

Hard Faeces Palpable in Rectum
- Bisacodyl and glycerol suppositories
- Plain warm water/saline enema
- Sodium phosphate enema and increase oral laxatives
- Gentle manual evacuation with lubrication

Do not attempt manual evacuation of impacted stool without considering sedation or analgesia if the patient is distressed.
In circumstances of intractable constipation, close consultation between nursing and medical colleagues is vital and a clear strategy for managing the problem should be achieved.

Rectum empty but ballooned (beware as mechanical intestinal obstruction could be present)
- Stage 1 Plain warm water enema
- Stage 2 Sodium Phosphate enema and increase oral laxatives

LAXATIVES FOR CONSTIPATION

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>EXAMPLES</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stimulant Laxatives</td>
<td>Bisacodyl</td>
<td>Senna and rely on bacterial transformation in the large bowel to produce active derivatives and so have little effect on small intestine.</td>
</tr>
<tr>
<td>bisacodyl</td>
<td>senna</td>
<td></td>
</tr>
<tr>
<td>Osmotic laxatives</td>
<td>Lactulose</td>
<td>Mild irritant on rectal</td>
</tr>
<tr>
<td></td>
<td>Polyethylene glycols</td>
<td>Osmotic laxatives are not absorbed from the gut and retain water in the lumen by osmotic action.</td>
</tr>
<tr>
<td>Faecal softeners</td>
<td>Docusate</td>
<td>Acts to reduce surface tension and improves water penetration into the stools</td>
</tr>
</tbody>
</table>
ONSET OF ACTION OF COMMON LAXATIVES

- Bisacodyl tab. -10-12 hours
- Bisacodyl supps. - 20-60 minute
- Senna - 8-12 hours
- Lactulose - 48 hours
- Docusate - 24-48 hours
- Glycerin supps. - 1-6 hours
- Phosphate enema - 20 minutes
- Polyethylene glycol (Movicol) - 48 hours

Comments
Stimulant laxatives can cause abdominal cramps and should be avoided in patients with intestinal obstruction. Faecal softeners can cause abdominal distension and abdominal cramps.

DIARRHOEA
Diarrhoea is the passage of frequent loose stools. It has been defined as the passage of more than three unformed stools within a 24-hour period. As with constipation, patients can understand “diarrhoea” in different ways and clarification of the term is always required.

Prevalence
Diarrhoea is less common than constipation in patients requiring palliative care. Up to 10% of patients with palliative care needs complain of diarrhoea. (in particular, 27% of HIV infected patients are reported as having diarrhoea)

THE MOST COMMON CAUSES OF DIARRHOEA IN THE PALLIATIVE CARE SETTING

1. Imbalance of laxative therapy especially when laxatives have been increased to clear severe constipation.

   Diarrhoea should settle within 24 hours if laxatives are stopped and reintroduced at a lower dose

2. Drugs such as antibiotics, antacids, NSAIDS iron preparations, chemotherapeutic agents etc.

3. Faecal impaction may be associated with fluid stool which leaks past a faecal plug or a tumour mass (“overflow diarrhoea”)

4. Radiotherapy involving the abdomen or pelvis is likely to cause diarrhoea especially in the second or third week of therapy.

5. Malabsorption of fat or water

   Carcinoma of head of pancreas with blockage of the passage of pancreatic secretions into the gut. Steatorrhoea will result since fat is not absorbed adequately, as a consequence.

   Gastrectomy resulting in poor mixing of food with pancreatic secretions and consequent steatorrhoea.

   Vagotomy can cause increased water secretion into colon

   Ileal resection reduces the ability of the small intestine to reabsorb bile acids. These acids increase fluid in the colon and contribute to explosive diarrhoea. Resection of over 100-cm of terminal ileum will outstretch the liver’s capacity to compensate for the bile salt loss, and fat malabsorption will again compound the diarrhoea.
Colectomy Immediately following surgery for a total or a near total colectomy, the water in the gut cannot be adequately absorbed. Although this tends to settle over a week, the bowel seldom returns to its pre-surgical function. The small intestine is unable to adequately compensate for the loss of this colonic water-absorbing capacity. This can lead to an ongoing daily loss of an extra 400–1000ml of gut fluid rectally. Such patients often require an ileostomy and need an extra litre of fluid and 7g of extra salt a day with vitamin and iron supplements.

6. Bowel fistulae
7. Colonic or rectal tumour can cause diarrhoea through causing partial bowel obstruction or through increased mucus secretion.
8. Endocrine tumours (rare), which secrete hormones causing diarrhoea. e.g. carcinoid tumour

DIAGNOSIS OF DIARRHOEA PATTERNS
Defaecation described as "diarrhoea" experienced only two or three times a day without warning suggests anal incontinence. Profuse watery stools are characteristic of colonic diarrhoea. Sudden onset of diarrhoea after a period of constipation raises suspicion of faecal impaction.

Alternating diarrhoea and constipation suggests poorly regulated laxative therapy or impending bowel obstruction.

Pale, fatty offensive stools (steatorrhoea) indicate malabsorption due to either pancreatic or ileal disease.

INVESTIGATIONS
Faecal impaction needs to be excluded by a rectal and abdominal examination. Persistent watery diarrhoea requires investigation as appropriate.

TREATMENT
Cause for the diarrhoea should be sought prior to giving antidiarrhoeal agents. The presence of fever or blood in the stool should prompt further discussion to ensure that the most appropriate treatment is given.

General Measures
- Increase fluid intake, frequent sipping of water.
- Reassurance that most diarrhoea is self-limiting.

SPECIFIC DRUG TREATMENT

<table>
<thead>
<tr>
<th>Causes</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fat malabsorption</td>
<td>Pancreatin</td>
</tr>
<tr>
<td>Radiation diarrhoea</td>
<td>Ondansetron</td>
</tr>
<tr>
<td>Pseudomembranous colitis</td>
<td>Metronidazole 400mg t.d.s. or vancomycin 125mg q.d.s.</td>
</tr>
<tr>
<td>Profuse secretory diarrhoea</td>
<td>Somatostatin analogues (octreotide) although very expensive, have a place in the management of severe, profuse, secretory diarrhoea, such as that associated with HIV infection, when other agents have failed to work. It is best given via asyringe driver.</td>
</tr>
</tbody>
</table>

Non-Specific Drug Treatment

Opioids, such as codeine or loperamide
These act via gut opioid receptors to reduce peristalsis and increase anal sphincter tone. Loperamide alone does not cross the blood brain barrier and is the antidiarrhoeal opioid of choice.

INTESTINAL OBSTRUCTION
This most commonly occurs with carcinoma of the ovary or bowel. The obstruction may be intramural, intraluminal, or extraluminal due to surrounding peritoneal disease, and is often at multiple sites. In addition, there is often a clinical obstruction in the absence of a mechanical lesion (“functional obstruction”). A plain X-ray abdomen may be helpful in excluding constipation.

In the presence of advanced peritoneal disease, the most likely cause of obstruction is malignant tumour. However, the cause may also be due to benign factors such as adhesions. If the patient is fit enough, a surgical opinion should be sought and the advantages and disadvantages of laparotomy assessed. The potential mortality and morbidity associated with surgery should be weighed against quality of life in a patient whose prognosis may only be predicted to be a few weeks or months.

If surgical intervention is inappropriate, symptomatic measures using medication are the mainstay of treatment. The evidence for the standard ‘drip and suck’ approach is lacking; it may cause considerable distress, and is ineffective in 80% of patients.

MANAGEMENT OF INTESTINAL OBSTRUCTION IN PATIENTS WITH ADVANCED DISEASE
The management of intestinal obstruction requires close attention to detail and clinical experience because treatment options will change according to the patient’s response.

1. Reduce Bowel Wall Oedema:
Dexamethasone 8-16mg SC (before 3.00pm as late administration may interfere with sleep) is given for three-day trial. If this is helpful and vomiting subsides, it may be useful to consider continuing with oral steroids. If dexamethasone is not helpful after three days, it should be stopped (unless the patient has been on longer term steroids (more than a week) in which case it should be tailed off slowly).

2. Stimulate Gut Motility:
Metoclopramide 30-120mg/24h via subcutaneous infusion. Commence with 10mg tds SC. The dose can be steadily increased on a day by day basis until patient is relieved of obstruction or they develop colic or extrapyramidal side effects. Beware of any increase in gut colic and stop if obstruction is not resolving. Such a trial should be initiated early in the day when the patient can be closely monitored. For complete obstruction or obstruction not resolving with the above measures in 24-48 hours, focus on treating symptoms rather than the underlying cause.

3. To Reduce Colic and Intestinal Secretions:
Hyoscine butylbromide. 40-240mg/24h via subcutaneous infusion

4. **Nausea and Vomiting:**
Haloperidol 2.5 - 5mg/24h via subcutaneous infusion Promethazine 25mg t.d.s SC

5. **Constipation:**
Ensure that reversible constipation is not contributing to the obstruction Gentle rectal measures or a small dose of a faecal softener such as docusate may be used particularly if there is no colic and obstruction is thought to be colonic and subacute.
More vigorous measures should be avoided for fear of aggravating symptoms.

**Other Measures for management of intestinal obstruction:**
1. **Reduce or encourage reabsorption of gut secretions and reduce intestinal motility using:**
   - hyoscine butylbromide (Buscopan) 40-240mg/24h via subcutaneous infusion
   - octreotide 300-600 micrograms/24h via subcutaneous infusion

2. **Nasogastric Tube**
If vomiting is not subsiding, or if very distressing and/or faecal, it may be necessary to use a nasogastric tube after full discussion with the patient and carers. This is a very infrequent practice in a hospice setting.

3. **Venting Gastrostomy**
With the advent of somatostatin analogue therapy e.g. octreotide, the need for venting gastrostomy has been reduced. In occasional situations, with clinically stable patients who are distressed by vomiting but who have a prognosis of at least weeks, and who are keen to resume oral intake, it may be an option to discuss a venting gastrostomy, fluids and possibly nutritional support.

**CONSTIPATION, DIARRHOEA & INTESTINAL OBSTRUCTION BACKGROUND READING**

**Books**

**Articles**

GASTROINTESTINAL SYSTEM QUESTIONS

These questions can be used as an aid to revision
1. Describe briefly the mechanism of nausea and vomiting.
2. Where in the brain is the vomiting centre situated?
3. What is special about the chemo receptor trigger zone?
4. Which antiemetic covers the widest range of vomiting receptors?
5. Which drugs (other than opioids) commonly cause vomiting?
6. Should 5HT3 inhibitors such as ondansetron be used for vomiting in any patient with cancer?
7. What are the metabolic causes of nausea and vomiting?
8. Name one antiemetic, which improves gastric emptying.
9. What diagnosis is suggested by sudden onset of diarrhoea after a period of constipation?
10. Name three non-pharmacological interventions for constipation.

RESPIRATORY SYMPTOMS

BREATHLESSNESS

The pathophysiology of breathlessness is complicated and not fully understood. Normal breathing is maintained by regular rhythmical activity in the respiratory centre in the brain stem. This is stimulated by mechanical receptors (stretch receptors in the airways, lung parenchyma, intercostal muscles and diaphragm) and by hypoxia and high levels of CO₂ (detected by chemo receptors in the aortic and carotid bodies and in the medulla). In malignant lung disease, breathlessness is usually due to distortion and stimulation of the mechanical receptors, and blood gases are often normal.

MANAGEMENT

Look for Reversible Causes of Breathlessness.

Do not assume that it is directly caused by cancer. Reversible causes of breathlessness, such as congestive heart failure, an exacerbation of chronic obstructive pulmonary disease

Breathlessness occurs in 50% of patients referred for palliative care, and is experienced most commonly with cancers of the lung, breast, prostate, colon and rectum, although in 25% of these patients there may be no evidence of lung or pleural involvement. In cancer, breathlessness is interpreted as having a sinister significance and may therefore cause more distress than the same degree of breathlessness in a control


(COPD), cardiac arrhythmias, anaemia, pleural/pericardial effusions, bronchial infection and pulmonary emboli, should be treated appropriately.

Breathlessness due to lung cancer per se, can be alleviated in a high proportion of patients with radiotherapy or chemotherapy.

**SYMPTOMATIC TREATMENT**

**Bronchodilators**

Even in the absence of obvious “wheeze”, there may be an element of reversible bronchoconstriction.

- oral salbutamol 2-4mg t.d.s or terbutaline 2.5 - 5mg t.ds,
- deriphyllin 100mg t.d.s or 150mg b.d.salbutamol 2.5-5mg q.d.s via nebuliser or 2puffs q.d.s via spacer device.

*Try* Beware of increased anxiety, tremor and tachycardia if used regularly. Ipratropium 250-500 micrograms 6 hourly via nebuliser or 2puffs q.d.s via spacer device / Saline, via a nebuliser may help to loosen tenacious secretions

**Steroids**

Reduction of peri-tumoral oedema may improve breathlessness due to multiple lung metastases and lymphangitis. Benefit should be apparent within 7 days.

*Try* dexamethasone 4-8mg p.o. daily, for a one week trial. If there is no improvement stop.

**Opioids**

Morphine reduces inappropriate and excessive respiratory drive and substantially reduces the ventilatory response to hypoxia and hypercapnia. By slowing respiration breathing is made more efficient, and the sensation of breathlessness is reduced.

Morphine does not cause CO retention if used appropriately and is useful in patients with cancer and with terminal respiratory failure due to chronic obstructive pulmonary disease. In such circumstances a trial of oral morphine 2.5mg 4 hourly is appropriate. The dose may be escalated if well tolerated but doses above 10-20mg 4 hourly are unlikely to produce further benefit. Morphine modified release (MST) seems to be less effective for breathlessness than immediate release morphine preparations given 4 hourly. Nebulised morphine is still used in some units but its effects have been shown to be equal to that of nebulised saline, which also has some benefit

**Benzodiazepines**

Benzodiazepines with shorter half lives can be useful in crisis situations but there is then a risk of reactive agitation and anxiety as the effect wears off quickly. Panic with hyperventilation and the fear of suffocation may worsen breathlessness. Trial of lorazepam 1-2mg SL p.r.n.is beneficial (works fast and is well absorbed sublingually). Midazolam 2-5mg SC as a stat dose is another choice.

**Theophyllines**

These can significantly reduce the sensation of breathlessness in the absence of any bronchodilator effect. Try theophylline m/r 200mg b.d. The half-life of theophylline may be increased in hepatic impairment, heart failure and with certain drugs including cimetidine, ciprofloxacin, and erythromycin.

The half-life is decreased in smokers, heavy drinkers and by phenytoin, carbamazepine and barbiturates.
Other Measures
Drainage of pleural effusions may be appropriate, even though fluid reaccumulates within a few days.
Relaxation techniques, physiotherapy in the form of breathing exercises etc. may be very helpful
- Directing a stream of air over the face can reduce the sensation of breathlessness
- Explanation that the awareness of breathing will be reduced by the drugs and that they can feel more in control, is essential.
- Breathing techniques
- Teaching clients coping strategies and relaxation skills
- Occupational therapists can also help patients to manage their everyday activities through advice on energy conservation and use of appropriate adaptive equipment
- As a symptom, breathlessness tends to cause more concern among health care professionals than other common distressing symptoms such as pain.
- A calm, positive, logical approach can do much to alleviate the distress of the patient and their family.
- Occasionally breathlessness is very difficult to control despite the above measures especially in the terminal situation. Sedation may then be necessary, with the primary intention of reducing the patient’s suffering.
- Managing dyspnoea at home is particularly challenging and carers need to be taught how best to support the patient. It is helpful to let the family know that the terminal event in patients with dyspnoea is not a sudden inability to breathe but a gradual sleeping away.
- Simple measures including
  - ensuring good ventilation
  - use of a fan to encourage a flow of air across the face
  - calm environment
  - avoid tight clothes
  - keeping mouth moist
- Small regular amounts of oral morphine 2.5mg 4-6hourly
- Lorazepam 0.5 - 1mg SL can be very effective for acute exacerbations

OXYGEN
Oxygen is often only helpful if there is hypoxia and cyanosis. Pulse oximetry could be used to confirm hypoxia and an improvement in oxygen saturation with treatment. Oxygen may help in sudden episodes of hyperventilation due to panic, pulmonary oedema or pulmonary embolus and may be of benefit in COPD or lymphangitis. The costs of initiating oxygen therapy are considerable in financial, social, psychological, logistical and safety terms. It should not be undertaken lightly and only after a full discussion of the cost benefits have been explored.

DYSPNOEA BACKGROUND READING
Books


**Articles**


**NURSING ISSUES**

**WOUND CARE**

Skin infiltration with subsequent ulceration or fungating wounds can be distressing. A small metastatic skin nodule is a visual reminder of disease progression and a fungating carcinoma with malodour, discharge and bleeding add to the misery of advanced and uncontrolled metastatic disease. Loco-regional skin involvement (e.g. breast fungation) should be distinguished from generalised skin metastases; the latter implies very late disease. Local extension of malignant tumour leads to embolisation of blood and lymphatic vessels compromising tissue viability. Infarction of the tumour leads to necrosis with subsequent infection, particularly anaerobic.

The ideal aim is complete healing through either local or systemic treatment, which may involve surgery, radiotherapy, hormonal manipulation or chemotherapy. If such treatment is inappropriate or unsuccessful (often the case), then care is directed to minimisation of pain, infection, bleeding, odour and psychological trauma. Treatment should be realistic and acceptable to the patient and carers. The primary aim is the promotion of comfort (as opposed to healing) and the enhancement of quality of life which may hitherto have been severely impaired.

Following assessment of the problems, choose a dressing regime to meet the needs of the patient. Be prepared to change and experiment since there are no ‘rights’or ‘wrongs’. Vaseline gauze or a simple dressing material, which can be sterilized in a “pressure cooker” at home are affordable options. The aim is to contain problems and improve quality of life. There are

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Choosing a Wound Care Regime

- Pain
- Exudate
- Necrotic tissue
- Bleeding
- Odour
- Infection
- Comfort
- Cosmesis
- Patient lifestyle
- Psychological effects
Numerous commercially available products. The simplest products may be the best and the most cost-effective. The criteria are comfort, acceptability, and availability.

**Pain:** Ensure that pain is caused neither by infection nor the dressing itself. Try to stick to simple regimes, limiting the frequency of dressing changes. Dressings must be soaked prior to removal to reduce pain and also the loss of crucial healing cells from the wound. If painful, prior to applying the dressing, use short acting analgesia e.g. immediate release morphine or, under supervision, ketamine.(p.o/SL)

**Exudate:** Use dressings with high absorbency and further packing on top in addition to plastic pads to protect clothing. Change the top layer as often as necessary, avoiding frequent changes of dressings placed directly over the wound. Protect the surrounding good skin with zinc oxide paste or karaya powder paste.

In some cases wounds will become infested with maggots. This may be distressing for patients and families, though maggots can also be very effective at removing dead tissue and exudates. Turpentine is effective for removing maggots.

**Necrotic Tissue:** Surgical debridement may be necessary to remove dead tissue if absolutely necessary.

**Bleeding:** Gauze soaked in adrenalin 1:1000 (may cause hypertension and rebound bleeding if applied over a large area) or sucralfate liquid may be used over bleeding points. Gentle removal of dressing after soaking with saline or water is attempted. It is preferable to use dressings that can be left in place for a few days to prevent frequent dressing changes and aggravating bleeding. Gentle and uniform pressure applied over the wound may stop mild bleeding and in such condition, pressure dressing can be used. Ethamsylate 250 – 500mg(p.o/ i/v) tid – q.d.s is another option

**Odour:** Use systemic or topical metronidazole (or both). Charcoal dressings are useful and the wound should be sealed. The smell can be disguised with incense or perfumes if agreeable to the patient and the family.

**Infection:** This is usually chronic and localised. The wound should be cleaned with normal saline or preferably under running water. If the surrounding areas are inflamed, especially if there is spreading inflammation, antibiotic(s) should be used. The commonest organisms grown in fungating, cancerous wound and in pressure sores include coliforms, anaerobes, staphylococcus aureus and group G beta- haemolytic streptococcus. Staphylococcus aureus is probably the commonest pathogen.

Antibiotics such as ciprofloxacin, trimethoprim or erythromycin should cover most common infections but metronidazole may be needed for anaerobic infections and topical metronidazole gel/solution or even powdered metronidazole tablets mixed with lignocaine gel is particularly useful for eradicating the associated noxious smell. Remember that agents such as cephalosporins, which cover a wider spectrum of bacterial infections, increase the risk of Clostridium difficile diarrhoea.

**Comfort:** By trial and error, a combination of dressings and top packing that will be most comfortable will need to be found for an individual patient.

**Cosmesis:** The best cosmetic effect possible should be achieved, in order to boost confidence.

**Psychological effects:** Attention to detail and in particular ensuring leakproof/odourproof appliances and giving information and explanation will lessen the sense of isolation and enhance confidence and morale.
SUMMARY:
Remember the principles
Address the problems
Seek help from a wound care expert, if available

WOUND CARE BACKGROUND READING
Books

STOMA CARE
An ostomy is a surgical procedure preformed when normal function of hollow viscera is interrupted by birth defects, disease or injury. Conditions that may require an ostomy include colorectal cancer, traumatic injury to the bowel or bladder, diverticulitis, inflammatory bowel disease and removal of bladder. Stoma is an artificial opening made surgically in the hollow viscera to the exterior
Types of stoma – Input and Out put
Input – Tracheostomy, gastrostomy, jejunostomy etc
Output – Colostomy, ileostomy etc
Colostomy may be temporary or permanent. The consistency and frequency of the discharge from the stoma depend on the types of colostomy performed. There are four main types: ascending, transverse, descending and sigmoid

Management
Pre operative Management
Site marking and planning for post operative rehabilitation

Post operative management
1. Discomfort and strain
Liquid diet is given initially followed by soft diet.
- Avoid certain food that causes gas and malodour.
  Eg.Onion, cabbage, spicy foods meat and egg.
- Team work- patient, family, surgeon and nurse therapist.
- Bag care- correct size bag, proper cleaning with soap and water. Empty the bag when ¾ full.

2. Bowel Management
Habit formation by daily irrigation at a fixed time for 21 days and this has to be continued throughout life. It is usually done with tap water (about 1 to 1.5litres) using an irrigation set. Irrigation can be started 3 weeks to 3months after surgery/ RT/CT.

3. Management of nursing problems
Constipation
Laxatives, enema, suppositories.

Diarrhoea
Increase intake of fluid and hospitalization as early as possible.
**Bleeding**
It is usually seen at the time of cleaning or changing the bag. Apply local pressure for 10 minutes followed by sucralfate powder application.

**Prolapse**
Prolapse is diagnosed when
- stoma size 1 to 1.5 cm outside skin level in colostomy
- stoma size 3 to 3.5 cm outside skin level in ileostomy
Prolapse above 5 cm needs surgical intervention.

**Retraction**
If there is no interference with bowel movement no intervention is needed. Otherwise surgical correction advised. Special attention is to be given to peristomal skin.

**Skin care**
- Daily cleaning with soap and water
- Skin should be mopped with a soft towel
- If skin erosion is present apply karaya powder mixed with egg white for 2 to 3 days.
- Zinc oxide can be used instead of karaya powder
- Use correct size bag to avoid leaking and soiling of skin

**Malodour**
It can be prevent by putting charcoal in the colostomy bags.

**Sexual life**
- Support and encouragement, counseling to spouse
- Avoid pressure being applied on stoma.

**Games**
Avoid outdoor rough games.

**Clothing**
Any type of clothes which are loose and cover the stoma can be used

**Traveling**
Protect the stoma from injury by using an article which is light and handy (book/hand bag)

**TRACHEOSTOMY**
Stoma made in the trachea for breathing.

**Routine Care**

**Cleaning**

**Inner tube**

Thorough cleaning of the inner tube should be done with soap and water
Sterilization of the tube in boiling water for 10 minutes or in betadine / hydrogen peroxide solution also is advised

**Outer tube**

Should not be removed. Clean the tube plates with gauze soaked in saline thoroughly.

**Skin care**
Clean the skin around the tracheostomy with gauze soaked in saline. Protect the skin with a gauze pad, which is cut in the middle so that it can be placed in between the outer tube and skin (Vaseline gauze can be used).
**Suction**
Careful suction may be done for not more than 5 seconds. It is indicated only if copious secretions present.

**Humidification of air**
Place wet sterile gauze on the tracheostomy tube. This helps in humidifying the inhaled air and filters the dust.

**Changing the tie**
Tie is used to fix the tube in position. Tie should be changed when it is dirty. Preferably black tie should be used. The tie should not be too tight or loose. There should be one finger gap between the tie and the skin.
- Train the patient to clean the tube by him/herself using a mirror.
- Speech therapy and communication - The patient is advised to take deep breath then close the stoma with finger and speaks.

**LYMPHOEDEMA**
Lymphoedema is accumulation of lymph in the interstitial space of sub cutaneous tissue or is an excessive and persistent accumulation of extra vascular and extra cellular fluid and proteins in tissue spaces. It occurs when lymph volume exceeds the capacity of the lymph transport system and it is associated with the disturbance of the water and protein balance across the capillary membrane.

**Classification**

**Primary**
Congenital malformation – lymphatic aplasia or hypoplasia or by congenital vascular incompetence.

**Secondary**
Infection and inflammation: - lymphangitis, lymphadenitis etc.
Obstruction or Fibrosis: - trauma, disease (cancer), surgery, radiotherapy

**Signs and symptoms**
Swelling: Usually unilateral unless the disease/ trauma is extensive, slow onset, non pitting oedema
Skin changes. Dry thickened skin, Deep creases. Peau d’ orange appearance,
Stemmer’s sign - inability to pinch a fold of skin at the base of second digit.
- Hyperkeratosis
- Papillomatous lesion
- Lymphorrhoea
- Joint stiffness and muscle strain
- Discomfort and pain

**Psychological issues**
- Altered body image
- Anxiety
- Depression
- Reduced adjustment to illness
- Difficult in wearing clothes
• Reduced working capacity
• Reduced social contact
• In cancer, fear of recurrence and reminder of the disease

**Four corner stones of Management**
1. Skin care
2. Compression bandage
3. Massage
4. Exercises

**Skin care:** Keep the skin clean and supple. Use oil or moisturizers. Avoid injuries and treat infections promptly.

**Compression Bandage:** Helps in limiting fluid accumulation in the subcutaneous tissue. It also provides the muscles with a firm outer casting by stimulating lymph flow.

**Massage:** Stimulates contraction of the skin lymphatics which are usually intact thus improving superficial lymph drainage.

**Exercises:** Wearing compression bandages during exercise enhances lymph flow and protein reabsorption more efficiently. Exercise reduces soft tissue oedema and improves joint mobility which enhances the efficiency of the lymphatic pump.

**References**
1. Management of Lymphoedema by Robert Twycross, Caroline Badger (Research sister BA RGN)
3. Text book of Palliative Nursing Edited by Belty Rolling Neua Coyle

**CARE OF BED RIDDEN PATIENT**
Nursing care in bed ridden patients is the quite challenging for nurses. Patient may be conscious or unconscious, where the nurse helps the individual to perform activities of the daily living. For a conscious/unconscious patient complete care has to be given. A patient becomes bedridden due to a disease or aging. In both the cases, a patient needs complete care like

• Personal hygiene
• Nutrition
• Exercise
• Communication
• Treatment
• Education.

The major problems in a bedridden patient (conscious/ unconscious) are

• Corneal ulcer
• Pressure sore
• Malnutrition
• Psychological problems
• Electrolyte imbalance.
Nursing care for an unconscious patient:
- Airway clearance
- Adequate fluid intake (Nasogastric tube or IV fluid to maintain fluid electrolyte balance
- Incontinence urine/ faeces
- Personal hygiene
- Impairment of mobility resulting in development of foot drop, muscle wasting and thrombophlebitis.
- Alterations in body temperature
- Impaired communication
- Impaired skin integrity which makes skin vulnerable to pressure sore.

MOUTH CARE
Mouth care is provided to maintain the integrity of the patient’s teeth, gum, mucus membrane and lips.
- If the patient is conscious, assist the patient but encourage him/her to do mouth care by self

In unconscious patient
- Place the patient preferably in lateral position as it allows any secretion collected in the mouth to drain through the corner of the mouth.
- Place Kidney tray close to the cheek
- Wrap gauze piece around the forceps and moisten the gauze with cleaning agent and swab the teeth gently.
- To clean the inner of the mouth, use a mouth gag to open the mouth and then clean the tongue.
- Use fresh gauze piece for each stroke.
- When the teeth and tongue are cleaned well, stop the procedure, wipe the lips and face with the towel.
- Apply glycerin or any other emollient on the lips and tongue to keep them soft and moist

Solutions used
- Add potassium permanganate crystals to a glass of water to make the solution light pink in colour. Use freshly prepared solution each time
- Hydrogen peroxide solution (1:8)
- Sodium chloride (table salt/ common salt) solution. Add 1 teaspoon to 500ml of water to prepare the solution.
- Consult a doctor and treat oral problems accordingly.

BED BATH
Bathing is an important intervention to promote hygiene. Bed bath means bathing a patient who is confined to bed and who does not have the physical and mental capability of taking bath by self. Patients confined bed but able to do some self care, needs assistance for back and legs. Bathrooms should be equipped with some types of signaling device and the patient needs to be instructed to call for help when feeling uncomfortable

Purpose
- To clean the dirt from the body
- To increase elimination through the skin.
- To prevent pressure sores.
- To stimulate circulation.
- To induce sleep.
- To provide comfort
- To relieve fatigue.
- To give the patient a sense of well being.
- To regulate body temperature.
- To provide active and passive exercises.

**There are some additional points**
- To observe objective symptoms
- To give the nurse an opportunity for health teaching.
- To establish an effective nurse-client relationship.

**General Instructions for Giving a Bed Bath**

1. Maintain privacy of the patients by means of screens, curtains or drapes.
2. Explain the procedure to win the confidence and the cooperation of the patient.
3. Wash hands before and after the procedure.
4. All articles used for bed bath should be absolutely clean.
5. Patient’s unit should be warm and free of draughts.
6. All needed equipment should be at hand and conveniently placed before beginning the bed bath so as to avoid leaving the patient unnecessarily.
7. Avoid giving unnecessary exertion to the patient.
8. Remove the soap completely to avoid the drying effect.
9. Only small area of the body should be exposed and bathed at a time.
10. The washed clothes should be held with the corners tucked securely on the palm of the hand to avoid dragging its cold and wet ends on the skin.
11. Each stroke should be smooth and long rather than short and jerky.
12. Support should be given to the joints while lifting the arms and legs for washing and drying these areas.
13. Provide active and passive exercises whenever possible unless it is contraindicated.
14. Wash the hands and feet by placing them in the basin because it promotes thorough cleaning of the finger nails and toe nails.
15. Cut short the nails, if they are long.
16. A thorough inspection of the skin especially at back should be done to find out the early signs of pressure sore. Redness in the skin, an excoriation of the skin etc., should be reported immediately and treated adequately to prevent development of pressure sores.
17. All the skin surfaces should be included in the bathing process with special care in cleaning and drying the creases and folds and the bony prominences etc. as these parts are most likely to be injured by moisture, pressure, friction and dirt.
18. Special attention is given to axillae and groins to prevent disagreeable body odours.
19. Cleaning is done from the cleanest area to the less clean area, e.g. upper parts of the body would be bathed before the lower parts.
20. Avoid bathing a patient immediately after a meal as it may reduce the blood supply to
the digestive organs and interfere with the digestion.
21. Frequency and the time at which bath is given should be adjusted according to the
comfort of the patients and on the physician’s orders. A critically ill patient may not
tolerate a full bath.
22. Do not touch the body with hands. It is unpleasant to some patients.
23. The temperature of the water should be adjusted for the comfort of the patient and the
water should be changed at intervals to maintain a comfortable temperature. The
temperature for the sponge bath should be 110 to 115°F (43.3 to 46.1°C). For tub
baths or bathroom bath the temperature of the water should be 90 to 100°F (32.2 to
37.8 °C).
24. Powders are used to prevent friction and to absorb moisture but they should not be
used on open draining areas, as powder can make or form crust, causing skin irritation.
25. Use only a small amount of spirit for the back care. The rapid evaporation of spirit
causes rapid and excessive cooling of the body and also causes drying of the skin.
26. Use soaps which contain less alkali.
27. Creams or oils are used to prevent drying and excoriation of the skin.
28. The nurse should maintain good posture and balance of the body during bed bath.
   Keep the patient near the edge of the bed to avoid over reaching and strain of the
   back of the nurse

BACKCARE
- Patients who are prone to pressure sores, must have their back care two hourly or
  more frequently.
- Back is washed with soap and water, dried and massage with powder or any other
  lubricant to prevent friction.
- Massaging helps to increase the blood supply to the area and thereby prevent pressure
  sore.
- Attention to the pressure points.
- Dry the area by patting and not by rubbing.
- Stocking with both hands on the back.

CARE OF HAIR
HEAD BATH
The appearance of one’s hair and the skin reflects the general health of a person. Hair
needs care in order to keep them clean and healthy. Hair needs light and fresh air. Stimulation
of circulation by massage and brushing is essential to maintain the hair healthy. Illness,
worry, grief etc affects the health of the hair, often by loss of hair. Clean hair and scalp keep
lice away.

Purpose
- To keep the hair clean and healthy
- To promote the growth of hair
- To prevent loss of hair
- To prevent itching and infection
- To prevent accumulation of oil, dirt and dandruff
- To prevent tangles.
To provide a sense of well-being.
To stimulate circulation.
To destroy lice
To appear well groomed

POINT TO REMEMBER
- Protect the bed linen and pillow cover with a towel and mackintosh
- Place a mackintosh under the neck and head and its end in a bucket to receive the water.
- Wash thoroughly with soap or shampoo.
- Rinse thoroughly and dry the hair. Braid into two one on each side of the head behind the ears to make the patient more comfortable when lying on her back.

CARE OF EYES
- The common problem of the eyes is secretions that dry on the lashes. This may need to be softened and wiped away.
- Each eye is cleaned from the inner to the outer canthus with separate swabs.

CARE OF NOSE AND EARS
- The nose and ears need minimal care in the daily life. Excessive accumulation of secretions makes the patient sniff or blows the nose. For patients who cannot remove the secretions, assistance is needed to clear the congestion and protect the mucosa. External crusted secretions can be removed with a wet cloth or a cotton applicator moistened with oil, nominal saline or water.
- When there is poor hygiene of the ears, debris may accumulate behind the ear and in the anterior aspect of the external ear. Another common problem of the ears is the collection of cerumen or ear wax which can be easily removed by instilling vegetable oil or warm liquid paraffin. When it cannot be removed consult ENT surgeon.

CARE OF PERINEUM
- Perineal hygiene involves cleaning the external genitalia and surrounding area. The area is prone to the growth of pathogenic organisms because it is warm, moist and is not well ventilated. Thorough cleaning is essential to prevent bad odour and to promote comfort.
- The most pertinent principle for the perineal care is to clean the perineum from the cleanest to the less clean area. The urethral orifice is considered as the cleanest area and the anal orifice is considered as the dirtiest area.
- Perineum should be cleaned after each urination and defecation. Hands should be cleaned after giving perineal care
- The following patients require special attention to perineal area:
  - Patients who are unable to do self care.
  - Patients with genito-urinary tract infections.
  - Patients with incontinence of urine and stool.
  - Patients with excessive vaginal discharge.
  - Patients with indwelling catheters.
  - Women in the post partum period.
  - Patients after surgery of the genito-urinary system.
  - Patients with injury, ulcer or surgery on the perineal area.
1. How would you manage a patient oozing blood from a fungating breast carcinoma?
2. What factors, directly related to a lung cancer, might contribute to a patient becoming more breathless?
3. When might oxygen be appropriate for breathlessness?
4. What measures could you use for malodorous wounds?
Section Six
Palliative Care emergencies and Common conditions requiring Palliative Care

It is important to have a clear understanding of the management of emergencies in palliative care. Clear thinking is crucial in handling an emergency and a sense of calm authority can provide a family, transforming a crisis situation. All health care professionals involved in the care of patients with palliative care needs must have awareness of the few emergency situations which require a prompt response.

DELIRIUM
Delirium (acute confusional states) can cause severe distress to patients as well as to relatives and staff. Often, the patient becomes suddenly disturbed, agitated and sometimes aggressive. Delirium is characterized by fluctuating levels of consciousness (mental clouding or drowsiness), with disturbances of comprehension, decreased attention, disorientation and other cognitive impairments.

Delirium has been defined as, "an aetiologically non-specific, global, cerebral dysfunction characterised by concurrent disturbances of level of consciousness, attention, thinking, perception, memory, psychomotor behaviour, emotion and the sleep-wake cycle".31

Though the stereotype of the delirious patient is one of agitation and hyperactivity, in practice the hypoactive and mixed subtypes are more common. The prevalence may be as high as 85% for hospitalised terminally ill patients and is particularly common in elderly patients. It may be exacerbated by deafness and poor vision. While delirium is normally a reversible process, there may not be time for it to improve in terminally ill patients. In such situations, irreversible processes such as multiple organ failure may be causing the delirium.

The differential diagnosis includes dementia, which is a more chronic condition, is not associated with mental clouding, and is irreversible.


<table>
<thead>
<tr>
<th>Simplified Mentaltest</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Exact age in years</td>
</tr>
<tr>
<td>2. Date and month of birth</td>
</tr>
<tr>
<td>3. Exact current year</td>
</tr>
<tr>
<td>4. Time to nearest hour</td>
</tr>
<tr>
<td>5. Home address</td>
</tr>
<tr>
<td>6. Current chief minister</td>
</tr>
<tr>
<td>7. Independence day</td>
</tr>
<tr>
<td>8. Count back from 20</td>
</tr>
<tr>
<td>9. Recognition of two people poor concentration and short and their correct roles term memory loss are typical.</td>
</tr>
<tr>
<td>10. Recall three-point addresses at start and end of test.</td>
</tr>
</tbody>
</table>

Each item scores 1. 
total of <7 = risk of confusion
The diagnosis of delirium may be obvious with a rapid onset of altered behaviour and incoherent rambling speech. Reduced awareness, drowsiness, disorientation, The symptoms may fluctuate and there may be some (e.g. 42 West Street, Bangalore) degree of insight.

Psychotic features such as delusions and hallucinations often mark the clinical picture. It is essential to understand that the patient is experiencing distress and to expect that the patient is able to comprehend what is going on. It is important to explore possible reasons for the symptoms, to allay fears and to always give explanations. Any reversible causes should be sought and treated appropriately.

It may be appropriate, if done sensitively, to carry out a simplified mini-mental score test to help management and to monitor clinical progress.

**MANAGEMENT OF DELIRIUM**

1. **Treat underlying cause where possible**
   Systematic, frequent, initial and subsequent assessments are required. Medical causes such as hypoxia, fluid/electrolyte imbalance, bowel/bladder dysfunction and pain may be reversible. Elimination of unnecessary medications, mobilization and prevention and treatment of postoperative complications are also important.

2. **Non-pharmacological management**
   **Explanation to Patient**
   Mild confusion is often missed by treating teams. They are often worried by what is happening to them and will be relieved to discuss their feelings with the health care professional. They need to know that there is often a reversible cause for the confusion and that they are not “going mad”. Those who are more severely muddled need careful handling, gentle explanation and reassurance.

   **Explanation to Relatives**
   Relatives need to know that there is a reasonable chance of the delirium being reversible and that their presence, if possible, would be a real comfort to the patient who will respond best to familiar people.

   *The family also need to know that the patient, who is behaving out of character, does not mean everything that he/she is communicating.*

   **Nursing and environmental modifications**
   Good lighting levels are essential. Regular and repeated visible and verbal clues as to orientation (e.g. clocks, calendars) will help with re-orientation. Continuity of care from treating staff, if possible, can go a long way in helping patients make sense of what is happening around them. Maintenance or restoration of normal sleep patterns should be one of the aims. Approach and handle gently confused patients. Try to eliminate unexpected and irritating noises. Minimise catheters and physical restraints. Encouraging visits from familiar friends and relatives is important.

3. **Pharmacological management**
   Haloperidol is the drug of choice in delirium. Dosages required vary depending on the level of agitation. A common starting dose is 1.5 to 2.5 mg stat orally or SC and titrated as necessary, usually two or three times daily. It has been suggested that the newer atypical antipsychotic medications such as risperidone or olanzapine may be useful with the added benefit of causing less extra pyramidal side effects. Disappointingly, they have not lived up to their initial promise. These medications are to be avoided in patients with a history of or risk factors for cerebrovascular thrombosis.
Medications for insomnia should be given only after an attempt to remove other causes of insomnia. These include fear, noisy surroundings, unrelieved pain, nocturia and stimulant medication such as steroids. It is best to avoid benzodiazepines as much as possible. If they have to be used, try Lorazepam in combination with Haloperidol. Doses of 0.5 mg to 1 mg repeated up to 4 times a day may be necessary.

Management of restlessness in the terminal phase may require:

- midazolam 10-100mg SC over 24 hrs
- phenobarbitone 200-600mg SC over 24 hrs

**Question**

How would you manage a patient with an acute confusional state?

**CONFUSIONAL STATES BACKGROUND READING**

**Books**


**Articles**


**SEPSIS IN THE NEUTROPENIC PATIENT**

As more and more patients undergo chemotherapy and radiotherapy, we all need to be aware of the risks of lowered immune response, typically in the second week after chemotherapy. Manifestation of sepsis in a patient who is undergoing oncological treatment can be minimal, and there should be a high index of suspicion. The routine signs of raised temperature, fast pulse, sweating etc. may be absent. Without such vigilance, patients may suddenly deteriorate and become septicemic which, for a significant proportion, will be fatal.

**MANAGEMENT**

- Awareness of the risk for patients who have recently undergone oncological treatments
- Prompt checking of white cell count to confirm the risk in susceptible patients.
- Admission to a unit where intravenous antibiotics can be given and appropriate monitoring carried out.
- Empirical treatment of an ill neutropenic patient while blood culture results are awaited

*Treatment options should be discussed with the local bacteriologist, as antibiotic regimes will vary across the country, and should include antibacterial, fungal and viral aetiology*

**2. SPINAL CORD COMPRESSION.**

Spinal cord compression (SCC) occurs in 3-5% of patients with cancer and 10% of patients with spinal metastases develop cord compression, the frequency being highest in multiple myeloma\(^{33}\) and cancers of the prostate, breast and bronchus. Those looking after such


patients should always be vigilant in checking for early signs and symptoms of spinal cord compression.

It is important for all health professionals to have a high index of suspicion for possible spinal cord compression because of the catastrophic consequences of a delay in diagnosis. Back pain, a sensation of weakness in the legs and often vague sensory symptoms may be the early manifestations.

For those presenting with profound weakness, a sensory ‘level’ and sphincter disturbances which are relatively late features the outcome is poor and the compression is much less likely to be reversible. 80% of cases are caused by extradural deposits due to direct extension from the vertebral body into the anterior epidural space. Lesions above L1 (lower end of spinal cord) will produce upper motor neuron signs and often sensory level signs, whereas lesions below L1 will produce lower motor neuron signs and perianal numbness (cauda equina syndrome)

MANAGEMENT
While managing spinal cord compression consider the following aspects

1. Does this patient have a reasonable likelihood of having spinal cord compression?
   Even the most skilled clinician is unable to diagnose spinal cord compression with absolute certainty. Often by the time clinical signs are “classical” it is too late. Once the compression has fully developed treatment outcome is very poor. Thus if intervention to prevent paraplegia is to be meaningful, spinal cord compression needs to be diagnosed early

2. Would this patient benefit from instituting emergency investigation and treatment?
   Once the possibility of spinal cord compression has been raised the patient may be urgently transferred to a specialized unit where an MRI scan can be carried out (if affordable) and radiotherapy performed. Deciding whether this course of treatment is appropriate for a particular patient involves an overall assessment

\[ \text{Where suspicion of spinal cord compression is high, it is best to involve the oncological team who have been managing the patient, who will be able to co-ordinate the necessary scan and appropriate treatment rapidly} \]

If the patient is still walking, emergency treatment provides some chance of regaining muscle power and treatment should be started immediately with dexamethasone 16mg-24mg daily orally or intravenously while arrangements are made for urgent transfer to an oncology centre.
Prognosis
Overall, 30% of patients may survive for one year. Function will be retained in 70% of patients who were ambulant prior to treatment but will return in only 5% of those who were paraplegic at the onset. Return of motor function is better in those with an incomplete cord damage and particularly with partial lesions of the cauda equina. Loss of sphincter function is a bad prognostic sign.

In practice, most patients with an established diagnosis are relatively unwell and have multiple metastases, and will be referred for palliative radiotherapy.

Management of patients with spinal cord compression
Such patients provide great challenges to the multi-disciplinary team. These challenges are mobility management, within the limits considered safe for the compromised spinal cord.
- skin care in a patient confined to bed.
- bowel interventions.
- bladder interventions.
- psychosocial support
- occupational and physiotherapy assessments
- practical advice and support on environmental changes
- passive movements to maintain joint range
- teaching carers on how to correctly undertake handling activities to maximise patient function and safety
- Prevention of bedsores, catheter care and bowel care

SUPERIOR VENA CAVA OBSTRUCTION.
Superior vena cava obstruction (SVCO) is due to compression or invasion of the SVC by mediastinal lymph nodes or tumour in the region of the right main bronchus. It is caused most commonly by carcinoma of bronchus (75%) and lymphomas (15%). Cancers of the breast, colon, oesophagus and testis account for the remaining 10%. Symptoms of SVCO include breathlessness (laryngeal oedema), headache (cerebral oedema), visual changes, dizziness and swelling of the face, neck and arms, orthopnoea and stridor.

Signs include engorged conjunctivae, peri-orbital oedema, non-pulsatile dilated neck veins and dilated collateral veins (chest and arms) without treatment, acute SVCO can progress
over several days leading to death.

Prognosis is poor in a patient presenting with advanced SVCO unless the primary tumour is responsive to radiotherapy or chemotherapy. Patients with chronic SVCO often have a longer history and dilated collaterals and may not have symptoms of headache, stridor and orthopnoea.

**MANAGEMENT**

**Emergency treatment** (needed for advanced, acute SVCO) Patients may benefit from sitting upright

Oxygen trial may be used especially if patients or their family are requesting.

Maintain calmness, or consider low dose midazolam to reduce anxiety.

- dexamethasone 16mg p.o. or i/v
- furosemide 40mg p.o. or i/v

Emergency radiotherapy (or chemotherapy for chemo sensitive tumours such as small cell carcinoma of bronchus, lymphoma or testicular cancer), can be given with steroid cover (e.g. dexamethasone 16 mg daily). Survival may be prolonged for several months by treatment but a recurrence may be more difficult to control. Intraluminal stents, only available in major centres, inserted via the femoral vein, can also be considered in consultation with the local oncologist and radiologist.

Young patients with acute SVCO may have a reasonable prognosis with a primary such as lymphoma, which can respond dramatically to certain oncological therapy.

**HAEMORRHAGE**

Haemorrhage may be directly related to the underlying tumour or caused by treatments such as steroids or non steroidal anti-inflammatory drugs resulting in gastric/duodenal erosion. A generalised clotting deficiency, seen in thrombocytopaenia, hepatic insufficiency or anti-coagulation with warfarin, are also contributory factors in patients with cancer.

Treatment for **non-acute** haemorrhage include oncological, systemic and local measures. Palliative radiotherapy is useful for superficial tumours and those of the bronchus and genito-urinary tract. If radiotherapy is not appropriate, coagulation should be enhanced with oral tranexamic acid 1g t.d.s., but caution is necessary with haematuria since clots may form in the bladder resulting in further problems. The risks of encouraging hyper-coagulation need to be considered carefully in patients with a history of cerebrovascular disease or ischaemic heart disease. Local measures such as topical tranexamic acid, pressure, or adrenalin (1:1000) soaks may be useful. Sucralfate may stop stomach mucosal bleeding although it will inhibit the absorption of a proton pump inhibitor such as omeprazole. Ethamsylate is another option which can be administered either orally or i/v at a dose of 250 –500 mg tid

Erosion of a major artery can cause **acute** haemorrhage, which may be a rapidly terminal event. It may be possible to anticipate such an occurrence and appropriate medication and a dark blanket to reduce the visual impact should be readily available. Relatives or others who witness such an event will need a great deal of support. If the haemorrhage is not immediately fatal such as with a haematemesis or bleeding from the rectum, vagina or superficially ulcerated wound, the aim of treatment

**QUIET WARNING**

The health care team need to balance the anxiety of alerting the family to the possibility of an acute bleed, with the likelihood of such an event occurring and the need for the family to be prepared for it. If the patient prefers to be at home managing acute haemorrhage needs to be discussed with the family and the home care team and a clear plan should be worked out.
is local control if possible. If necessary sedation of a shocked, frightened patient is important. Midazolam 2.5 mg SC or lorazepam 0.5-1mg SL act quickly.

It may be appropriate to have emergency medication in the home to sedate the acutely bleeding patient, but such a strategy can only be arrived at after discussion with the family, carers and needs to be documented clearly.

**CONVULSIONS**

Convulsions are usually associated with patients with primary or secondary brain tumours and present with generalised (grand mal) or focal epilepsy. Emergency management includes the correct positioning of the patient, if possible, and the administration of midazolam i/v/SC. Relatives will need support since it is very frightening to witness a convulsion.

Generalised myoclonic twitching may occur in the terminal stages and in uremia and may be treated in the same way. When a dying patient is unconscious and no longer able to take oral anticonvulsant medication, suitable alternatives should be given subcutaneously to prevent further cerebral irritability.

Useful drugs in syringe driver:
- midazolam 20 - 100mg/24 hours SC
- phenobarbitone 200 - 600mg/24 hours SC
- clonazepam

Avoid using drugs that may increase cerebral irritability such as phenothiazines (e.g chlorapromazine) if possible.

**HYPERCALCAEMIA**

Hypercalcaemia occurs as a result of increased osteoclastic activity, which releases calcium from bone in addition to a decrease in excretion of urinary calcium. This is attributed to locally active substances produced by bone metastases or by factors such as ectopic parathyroid hormone related protein (PTHrP) or cytokines, and occurs in 10% of the cancer population. The tumours most commonly associated with hypercalcaemia include squamous cell carcinoma of the bronchus, carcinomas of the breast and prostate, multiple myeloma and other squamous cell tumours.

A corrected plasma calcium concentration of greater than 2.6 mmol/litre defines hypercalcaemia. It is often mild and asymptomatic and significant symptoms usually only develop with levels above 3.0 mmol/litre. Levels of 4.0 mmol/litre and above will cause death in a few days if left untreated. Eighty percent of patients with cancer-related hypercalcaemia survive less than one year.

Symptoms include drowsiness, confusion, nausea, vomiting, thirst, polyuria, dehydration, weakness and constipation.

**MANAGEMENT**

Treatment is only necessary if there are symptoms, or a high likelihood of symptoms developing, and is unnecessary if the patient is very near to death.

**FLUID REPLACEMENT**

Intravenous hydration is necessary for acute therapy for severe or symptomatic hypercalcaemia.34

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BISPHOSPHONATES
Bisphosphonates inhibit osteoclast activity and thereby inhibit bone resorption. Because of poor alimentary absorption, they are usually given intravenously initially. Disodium pamidronate or sodium clodronate are effective in 70-80% of patients for an average of two to three weeks e.g: pamidronate 60-90mg in sodium chloride 0.9%, 500ml over 2-4 hours/ sodium clodronate 1.5g in sodium chloride 0.9%, 500ml over 4 hours/ zoledronic acid 4mg in 50ml over 15 minutes intravenously.\(^{35}\)
Ibandronate 50 mg p.o. o.d. may be an option in this situation when infusion is not possible\(^{36}\)
Plasma calcium levels should start to fall after 48 hours and fall progressively for up to 6 days. Oral sodium clodronate has been reported to delay the recurrence of hypercalcaemia and may be important for maintenance (see bone pain section in management of pain)

PALLIATIVE CARE EMERGENCIES BACKGROUND READING

Books

Articles

MANAGEMENT OF PALLIATIVE CARE EMERGENCIES

QUESTIONS

These questions can be used as an aid to revision.

1. What factors in a patient’s history alert you to the risk of spinal cord compression?
2. What treatment would be appropriate for the management of spinal cord compression?
3. Which cancers are most likely to cause Superior Vena Cava Obstruction (SVCO)?
4. How would you manage patients with SVCO?
5. What is the treatment of hypercalcaemia?
6. How would you prepare the family of a patient who is at risk of an acute haemorrhage?
7. A 50 year old patient with a cerebral glioma has had several fits recently. How would you manage this situation?
COMMON CONDITIONS REQUIRING PALLIATIVE CARE

Currently the majority of patients receiving specialist palliative care services have are those with cancer. However there is now increasing recognition of the unmet need in patients with other progressive, incurable, non-malignant diagnoses diseases and HIV/AIDS. The development of palliative care services in India has recognized this and is trying to respond to this need. Patients with end stage non-malignant disease suffer from as many distressing symptoms as those with cancer. Cancer patients’ symptoms may be more severe, but those of non-cancer patients tend to be more prolonged. However, there remains a lack of confidence in looking after patients with these illnesses. This may stem partly from the fact that the dying phase is often different from that seen in cancer. Patients dying from cancer tend to deteriorate gradually over time and it is usually obvious when the terminal phase has been entered and when the emphasis of treatment and interventions can be altered towards ensuring comfort. The condition of patients dying from chronic heart or lung disease, on the other hand, tends to deteriorate over a longer period of time, interspersed with acute episodes which may well be better managed within the hospital environment with appropriate and readily available access to acute care management. This may highlight educational and training issues but does not mean that the palliative care team should take over the role of other specialist teams. The skills and philosophies of palliative care should be extended to all care settings. This is optimally delivered by those working in their own specialty - such as neurology, cardiology, and respiratory medicine. However if this is not possible then there should be a good interface with palliative care, and they should work alongside specialists in other fields ensuring that the principles of palliative care are upheld and that patients and families receive the best possible treatment. The main causes of mortality are chronic heart diseases, cerebrovascular diseases, chronic respiratory diseases and cancer.

The percentage of the population over 65 years has increased and will continue to do so in coming years. Palliative care teams need to find a way to deliver appropriate care to all patients regardless of diagnosis. With increasing dialogue, partnership, research and funding, the vision of providing services where they are needed should be a realistic aim. The following outline of several non-malignant conditions is obviously not exhaustive but covers conditions which are experienced by patients increasingly referred to palliative care services.

End-stage respiratory diseases

Chronic heart failure

Debilitating Advanced or progressive neurological diseases

- Cerebrovascular diseases
- Parkinson’s disease
- Traumatic paraplegia
- Multiple sclerosis
- Motor neuron diseases

End stage renal disease

End stage liver disease

Tuberculosis

HIV/AIDS

Cognitive and physical frailty

END-STAGE RESPIRATORY DISEASES

Respiratory disease is a major cause of morbidity and mortality in India. The course of chronic respiratory disease is often marked by slow, inexorable decline with prolonged periods
of disabling breathlessness, reducing exercise tolerance, recurrent hospital admission and premature death.

This decline is associated with a loss of dignity, social isolation and psychological problems for the individual in addition to pressure on the family and carers. There is therefore potentially much to gain through the application of a holistic approach to their care. The inability to predict disease trajectory in patients with non-malignant terminal disease can make end of life decisions difficult. Symptoms which present in the final weeks and months of life are similar to symptoms experienced by patients with lung cancer and include;

- dyspnoea
- cough
- fever
- haemoptysis
- stridor
- chest wall pain

**Dyspnoea**

Dyspnoea can be defined as difficult, uncomfortable or laboured breathing or the sensation by the individual of needing more air. It is the most frequently experienced symptom in those with end-stage respiratory disease and is multifactorial in origin. A person’s emotional state, personality and cognitive function also influence its perception. A good history and examination are invaluable. (see management of dyspnoea in respiratory symptoms)

**Recurrent Aspiration**

This is often a feature as the patient progresses to respiratory failure

There may be a bulbar cause (MND, CVA) or there may be repeated micro-aspiration leading to bronchiectasis.

The right main bronchus is the most direct path to the lungs, hence aspiration leads more commonly to right lower lobe infections

Less than 5% of patients with non-malignant disease die in hospices compared to at least 20% of patients with lung cancer as more palliative care services are available to cancer patients.

**Management Includes:**

- nursing in semi recumbent position
- semisolid foods
- nasogastric tube
- treatment of the associated pneumonia with antibiotics and chest physiotherapy

**MANAGEMENT OF END STAGE RESPIRATORY DISEASES**

**Respiratory Failure**

This is defined as the inability of the respiratory system to maintain arterial oxygenation or to clear CO₂. In COPD (Chronic Obstructive Pulmonary Disease) the end-stage is not easy to recognise but usually comprises:

75% of patients with respiratory failure will have persistent dyspnoea despite maximal therapy poor mobility increased frequency of hospital admission decreased improvements with repeated admission expressions of fear, anxiety panic attacks concerns expressed about dying.
**PHARMACOLOGICAL TREATMENTS**

**Anxiolytics**
Anxiety can exacerbate breathlessness. Clinical experience suggests that low dose anxiolytics e.g. oral diazepam 2.5 mgs or sublingual lorazepam 1mg can result in improvements despite a lack of evidence.

**Antidepressants**
Tricyclic antidepressants (TCAs) and selective serotonin re-uptake inhibitors (SSRIs) have been shown to be beneficial.

**Oral Opioids**
Site of action may be central (brainstem) or peripheral. They may also decrease anxiety. Opioids can cause side effects such as CO₂ retention, nausea, drowsiness and respiratory depression if not used carefully.

A trial of opioid in COPD patients without CO₂ retention is appropriate with close monitoring. If used appropriately oral morphine does not cause CO₂ retention. Low doses and small increments should be used e.g. morphine 2.5mg 4 hourly. In the terminal phase opioid therapy is justified for treatment of dyspnoea even in the presence of CO₂ retention.

**Nebulised Opioids**
Currently there is no good evidence to support this.

**Mucolytics**
- N-Acetylcysteine
- nebulised saline
- steam inhalation (if acceptable to the patient)
- bromhexine
- ambroxol

**NON-PHARMACOLOGICAL MEASURES**

**General measures**
- General nursing care - fan, open windows, regular repositioning, relief of constipation
- Good nutrition and hydration
- Physiotherapy - forced expiratory technique, controlled coughing, chest percussion
- Psychological support - help patient cope, provide strategies to relieve symptoms and maximise quality of life etc
- Controlled breathing techniques - pursed lip/ slow expiration etc.

**Palliative Oxygen Therapy**
A significant proportion of patients will have resting hypoxia, although its degree may not correlate with the level of dyspnoea. Symptoms may be improved by oxygen. When oxygen therapy is initiated, the cost, the place where it will be given and how long it is to be given for should be considered. A trial of a flow of air across the face may provide similar benefit.

**NEUROMUSCULAR, RESTRICTIVE AND CHEST WALL DISEASES**
These cause respiratory muscle weakness or loss of compliance in the respiratory cage. Muscular function can be affected at various sites from spinal cord to the muscles themselves. Features that characterise some of these conditions include:

- Increased ventilatory drive with inadequate ventilatory response
- Sleep disorders
- Unbalanced weakness of spinal and thoracic muscles leading to kyphoscoliosis
- Diaphragmatic paralysis
- Pulmonary embolism (secondary to immobility)
Supportive treatments:
- Oxygen
- Techniques to clear secretions
- Antibiotics
- Inspiratory muscle training
- Physiotherapy
- Beta-2 agonists (e.g. salbutamol)

END OF LIFE CARE

In the terminal stages, the emphasis changes from active interventions to supportive and symptomatic measures.

Drugs for palliating symptoms may depress respiration but are often unavoidable. This possible double effect should be explained to patient and relative.

The oral route should be used where possible, but failing this, drugs may be given by the subcutaneous route.

The ‘rattle’ associated with loose or pooled respiratory secretions, although probably not distressing to the patient, may be addressed by repositioning, or by the use of hyoscine butylbromide or glycopyrronium bromide. As some patients approaching death will have uncontrolled dyspnoea, sedation and opioid use should not be withheld because of an inappropriate fear of respiratory depression. The risks and benefits must be carefully considered and the justification for palliative sedation clearly defined. Such decisions are often made by teams rather than individuals and it is appropriate that patients and families are fully involved.

In the terminal phase, simple measures are important:
- constant draught from fan or open window
- regular sips of water
- comfortable position

CHRONIC HEART FAILURE

Definition
Chronic heart failure is a progressive, fatal disease and is the final common pathway of many cardiovascular diseases. Heart failure is defined by the European Society of Cardiology as the presence of symptoms of heart failure at rest or during exercise and objective evidence of cardiac dysfunction (usually on echocardiography).

Incidence
Heart failure is the only major cardiovascular disease with increasing incidence. It is predominantly a disease of old age (mean 75 years). A diagnosis of heart failure has huge cost implications because of hospital admissions and long term use of medication.

Prognosis
40% of patients die within 1 year of diagnosis. 50% of patients die suddenly and 25% without worsening of their heart failure symptoms. This can occur at any stage of the disease. There are no reliable prognostic models either for poor/overall prognosis or sudden death.

Relevant Pathology and Physiology
Coronary artery disease and hypertension are the commonest causes of heart failure. The direct insult is of mechanical pump failure, but this initiates an ongoing, complex cascade of haemodynamic, metabolic, neuroendocrine and renal dysfunction that is the syndrome of
chronic heart failure.

**Clinical Features**

Breathlessness and fatigue are the classic symptoms of heart failure. Orthopnoea is a sensitive ‘measure’ of fluid overload. Fluid retention causes not only breathlessness, cough and dependant oedema, but also anorexia, nausea, abdominal bloating and pain.

Other common symptoms which are poorly recognized and therefore frequently not treated include:

- pain (common, severe, prolonged and distressing.
  - Probably due to a combination of angina, liver capsule distension, lower limb swelling and co-morbid disease e.g. arthritis
- anxiety and depression (severe in a third of hospitalized patients. Depression adversely affects mortality and hospital readmission)\(^{37}\)
- disordered sleep
- memory loss and confusion
- anorexia, nausea, vomiting and constipation
- weight loss (usually mild, but severe cachexia is a poor prognostic sign)
- loss of libido

Poor information, communication and understanding for patients are widespread and contribute to psychological morbidity. Significant functional impairment in activities of daily living and social isolation are common long before the end of life. The pattern of functional decline is slow, compared to the classic patient with cancer who exhibits a rapid decline from approximately 5 months before death.\(^{38}\)

**Disease Burden**

The burden of chronic heart failure has physical, psychological and social dimensions. These needs have been demonstrated to be prevalent, severe, prolonged and usually unrecognised and unrelieved. There is a disparity in symptom control and support offered to those dying from heart failure compared to cancer which are described shockingly by those who have lost a parent to each disease.

**New York Heart Association (NYHA) functional classification (summary)**

<table>
<thead>
<tr>
<th>Class</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Heart disease present, but no undue dyspnoea</td>
</tr>
<tr>
<td>II</td>
<td>Comfortable at rest; dyspnoea on ordinary activities</td>
</tr>
<tr>
<td>III</td>
<td>Less than ordinary activity causes dyspnoea, which is limiting</td>
</tr>
<tr>
<td>IV</td>
<td>Dyspnoea present at rest; all activities causes discomfort</td>
</tr>
</tbody>
</table>

**Management**

**Disease specific management**

Education of patients and carers including diet (salt intake, alcohol), weight reduction, abstinence from smoking and exercise

The cornerstones of drug treatment are angiotensin-converting enzyme (ACE) inhibitors and beta blockers. They both improve symptoms and slow disease progression. Diuretics are used to control fluid overload.

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Symptom management

1. Ensure specific heart failure treatments are optimal. This is the first step in achieving good symptom control. Diuretics may need quite frequent dose changes to control fluid overload. Avoid overuse of diuretics, which may cause dizziness, nausea, poor sleep and fatigue.

2. Avoid where possible drugs which may worsen cardiac function. These include some drugs commonly prescribed in cancer palliative care practice. (see table)

3. Actively seek out and manage other likely symptoms. Bear in mind the likely causes of symptoms in a patient with heart failure and poor renal function.
   - pain: follow the WHO ladder. Avoid NSAIDs and alter opioid dosing schedules as for patients with impaired renal function
   - nausea: try haloperidol for a biochemical cause and metoclopramide for gastric stasis
   - anxiety and depression: treat conventionally (with or without drugs.) Newer classes of antidepressant such as sertraline (a selective serotonin reuptake inhibitor) and mirtazepine are safer than tricyclics. They are less likely to affect cardiac conduction, cause postural hypotension or interact with other drugs
   - breathlessness: this may include correction of anaemia, low dose opioids and the non-pharmacological approaches used in respiratory rehabilitation and lung cancer management

4. Adopt a palliative approach to psychological, social, spiritual, information and communication needs, actively pursuing and managing identified needs. Patients and carers may need help to manage the uncertainty of a future with a high chance of sudden death.

END OF LIFE CARE
Diagnosing dying in heart failure is extremely difficult. The disease trajectory is of a steady decline punctuated by unexpected sudden death. Features suggested as characterising a subgroup of patients with a poor prognosis are39

- previous admissions with worsening heart failure
- no identifiable reversible precipitant
- optimum tolerated conventional drugs
- deteriorating renal function
- failure to respond soon after admission to changes in vasodilators or diuretics. In these patients, invasive treatments and monitoring should be reviewed and emphasis on palliation should predominate. Discontinuation of cardiac drugs may be appropriate.

MODELS OF CARE
Chronic heart failure is increasingly being managed across the community/hospital interface by multiprofessional heart failure teams. These teams should aim to address the disease management and supportive and palliative care needs of the majority of patients with heart failure. The minority of patients with extraordinary palliative needs may require direct involvement from specialist palliative care services, often working together with active heart failure teams. Mutual support and education, plus joint management by heart failure and specialist palliative care teams should be objectives for the future.

Key drugs to avoid if possible in heart failure patients:

<table>
<thead>
<tr>
<th>Drugs</th>
<th>Reason for avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDs</td>
<td>Salt and water retention and worsening of renal function</td>
</tr>
<tr>
<td>Tricyclic antidepressants</td>
<td>Cardio toxic</td>
</tr>
<tr>
<td>Lithium</td>
<td>Salt and water retention</td>
</tr>
<tr>
<td>Steroids</td>
<td>Water retention</td>
</tr>
<tr>
<td>Progestogens</td>
<td>Water retention</td>
</tr>
</tbody>
</table>

**BACKGROUND READING**

**Books**

**Articles**
Heart Failure

**PROGRESSIVE NEUROLOGICAL DISEASE**

Although Multiple Sclerosis and Motor Neuron Disease are uncommon in India the management of various issues in them is helpful to manage similar problems in other progressive neurological diseases.

**MULTIPLE SCLEROSIS (MS)**
- In the majority (70-80%), the course of the disease is relapsing and remitting in nature at the onset. Half of these patients will enter a progressive phase within 10 years (secondary progressive MS)
- In a smaller group of patients the disease is progressive from the onset (approximately 15%)
- In a population of patients with MS (approximately 20-30%) have marked paraparesis, hemiparesis or paraplegia, 15% are wheelchair bound and 5% have severe cognitive impairment.
- It is estimated that only about 25% of patients who are severely disabled are alive at 10 years after diagnosis.
- Death is commonly due to secondary complications of MS (e.g., aspiration pneumonia, pulmonary embolus).
- If sudden neurological deterioration occurs, precipitating factors such as infection should be looked for. If there is no resolution of symptoms, a course of steroids is usually given which has a high chance of improving symptoms for a further year or so.

**IMMOBILITY**
Walking is usually affected if the disease is progressive, through a combination of weakness, spasticity, fatigue, disuse, pain, cerebellar ataxia and sensory loss particularly proprioception. Immobility inevitably becomes a problem towards the end of life, leading to many problems, which need to be addressed by the majority of members of the multidisciplinary team.

**PAIN**
- **Chronic pain** may be present in 60% and some studies have shown inadequate control in 40% of patients, with significant adverse effect on quality of life. Neuropathic pain, which may present as a persistent burning discomfort often affecting the lower limbs, is usually treated with standard agents for neuropathic pain such as tricyclic antidepressants.
- **Trigeminal neuralgia** is common and is classically treated with carbamazepine. Being an anticonvulsant, carbamazepine has an effect on nerve conduction and may lead to a perception of muscle weakness and a decrease in overall function. Gabapentin has also been used, but is an expensive option.
- **Lhermitte’s sign** is a syndrome of intermittent burning sensations or “electric shocks” occurring on neck flexion. It is probably due to demyelination in the posterior columns of the spinal cord and can occur in up to two thirds of patients at some time during the course of the disease. It is often self-limiting but, if persistent, acervical collar and carbamazepine may be needed.
- **Musculoskeletal pain** is common, particularly back pain, and results from prolonged immobility, poor posture and gait abnormalities. It is probably caused by a combination of spasticity leading to muscular pain and abnormal stresses resulting in mechanical pain.
- **Osteoporotic pain** should also be considered and treated as appropriate. Simple analgesics or NSAIDs can be prescribed.
- **Physiotherapy** is needed to improve poor posture and to ensure that correct seating and wheelchair adaptations are provided. Passive and active exercises, TENS (Transcutaneous Electrical Nerve Stimulation), massage and acupuncture may also be helpful.

**SPASTICITY**
Increased muscle tone occurs in the majority of patients with MS. It may cause difficulty with function of the affected limb, painful muscle spasms and, when severe, difficulty in nursing care. Neuro- physiotherapists teach patients and their carers stretching techniques for shortened spastic muscles and passive joint exercises to maintain movement which should be carried out regularly. Splints may be used and TENS may alleviate the frequency of painful muscle spasms and improve sleep. Aggravating factors such as urinary tract infections, pressure sores and constipation should be avoided and/or treated.
**Baclofen** can be built up slowly by 5mg every 3-4 days starting from 5mg t.d.s. up to a maximum of 80mg daily. Transient mood and gastrointestinal symptoms may occur. Reduction of baclofen should be gradual to avoid fits or hallucinations. Benzodiazepines such as diazepam can be given at night if painful spasms disturb sleep.

**Diazepam**, 2.5-5mg t.d.s, is an inexpensive option but is associated with sedation.

**Tizanidine**, an alternative to baclofen, is associated with less muscle weakness than baclofen or diazepam. The starting dose is 2mg increased every 3-4 days in 2mg increments up to 24mg daily in divided doses. It can cause sedation and dry mouth and liver function should be monitored for the first 4 months.

**Gabapentin** is an alternative.

**Tendotomies** (surgical release of tendons) or nerve blocks may be tried in patients who do not show adequate response. Most commonly performed nerve blocks are obturator, perineal, adductor, or pudendal.

**ATAXIA AND TREMOR**
Feeding, correct seating and head control can be very difficult. The role of the occupational therapist is crucial. There is some evidence, although minimal, for the benefits of propranolol and clonazepam.

**URINARY SYSTEM**
**Assessment and treatment** is important in order to improve symptoms and to minimise complications such as pressure damage to the kidneys, urinary tract infections and skin breakdown secondary to incontinence.

**Incontinence** can lead to profound embarrassment and social breakdown. Adequate fluid intake, bladder emptying (particular if residual volume is more than 100ml) and treatment of infection are the principal priorities.

**Hyperreflexia of the bladder** is associated with a low volume capacity bladder and possible symptoms of mild urgency, frequency and incontinence. Treatment is usually with anticholinergic drugs such as oxybutinin. Incomplete bladder emptying, induced by these drugs, may require intermittent self-catheterisation. Nocturnal incontinence may be relieved with desmopressin nasal spray 10-40 micrograms at night, but the cost makes this a rare option. Bladder drained through a condom catheter is another but less preferred option.

**Bladder hypotonia and sphincter incoordination** (sphincter contracts when voiding) results in incomplete bladder emptying, about which the patient may be unaware. Catheterisation will be needed. Intermittent catheterisation, if performed cleanly, is associated with less risk of UTI than a permanent indwelling catheter. However permanent indwelling catheter may be needed if all other methods fail to fully empty the bladder frequently enough to avoid problems. Even with a permanent catheter, an anticholinergic may still be needed for bladder spasm. If all else fails a urinary diversion may be the only viable option.

**CONSTIPATION**
Constipation is common due to delayed gut transit time, immobility and anticholinergic medication. Adequate dietary fibre and fluid intake are important and regular oral laxatives, suppositories/enemas are frequently needed.

**FATIGUE**
Fatigue is severe and disabling in the majority of patients reflecting muscle weakness and sleep interruption (e.g. from nocturia or spasms).
It presents as overwhelming tiredness which is not relieved by exercise or rest. It does not necessarily directly correlate with mood disturbance or the severity of the MS.

Precipitants such as exposure to hot baths and hot weather should be avoided.

Explanation, reassurance, and advice on modification in lifestyle such as pacing activities, taking rest periods and gentle exercise are essential.

**MOOD/COGNITIVE DISTURBANCE**

Clinical depression is common in MS. The estimated lifetime risk of developing depression is 50% and the risk of suicide is 7.5 times that of the healthy population.

Depression is contributed to by many factors including the breakdown in family relationships, public embarrassment, social isolation and other losses (work, money, sexual abilities and confidence). Antidepressants should be selected according to their side effect profile; for example, a tricyclic antidepressant might be used if an overactive bladder and neuropathic pain are also a problem. Conversely, an SSRI which is less sedating than a tricyclic would be preferable if the patient feels fatigued.

There is some degree of cognitive impairment in 50-60% of patients. The most common deficits relate to short term memory, attention and speed of processing information and impaired learning. Personality and behaviour may change. Moderate to severe dementia is seen in 10% of patients with longstanding MS. Pathological laughing and crying is a problem in 10% for which amitriptyline may be tried.

Multiple sclerosis is usually managed in advanced stage of the disease by palliative care teams although these patients may have an earlier role in providing respite. The principles of palliative care apply through the illness.

**MULTIPLE SCLEROSIS BACKGROUND READING**

**Articles**


**MOTOR NEURONE DISEASE (MND)**

When I wake each morning I decide...

This can be a good day or a bad day - my choice.

I can be happy or sad - my choice.

I can complain or I can cope - my choice.

Life can be a chore or a challenge - my choice.

I can take from life or give to life - my choice.

If all things are possible,

How I deal with those possibilities is - my choice.

*Steve Shackel*- diagnosed with MND, alternatively referred to as amyotrophic lateral sclerosis (ALS)

Motor Neuron Disease (MND) is a disease of unknown aetiology in which there is progressive degeneration of both upper and lower motor neurons, leading to wasting of muscles and weakness. The average survival is 40% at 5 years although older patients presenting predominantly with bulbar signs may have a worse prognosis and conversely, younger patients...
with largely lower motor neuron involvement may have a better than average prognosis. The mean age of onset is 56 years.

**Upper Motor Neuron** involvement leads to generalised spasticity, hyperreflexia and often emotional lability.

**Lower Motor Neuron** involvement leads to flaccidity, muscle wasting and fasciculation. Involvement of **bulbar** innervated muscles leads to dysarthria and dysphagia. Interestingly the third, fourth and sixth cranial nerves and those of the lower segments of the spinal cord are usually spared such that eye movements, bladder, bowel and sexual function are generally unaffected. Furthermore intellect, memory, sight and hearing are also usually preserved.

### Symptoms in MND are often similar to patients with cancer and include:

<table>
<thead>
<tr>
<th>Weakness</th>
<th>Insomnia</th>
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<tbody>
<tr>
<td>100%</td>
<td>40-50%</td>
</tr>
<tr>
<td>65%</td>
<td>40-50%</td>
</tr>
<tr>
<td>50-60%</td>
<td>50-60%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Depression</td>
</tr>
</tbody>
</table>

In addition problems related to mobility, communication and psychosocial issues both for the patient and their families must be addressed necessitating a fully multidisciplinary approach.

**WEAKNESS**
Attention to individual needs for maximum comfort is crucial in order to prevent pain and other problems such as skin trauma, contractures and joint dislocation. The role of the physiotherapist is important not only for the patient but also to educate and advise relatives. Although it is important to maintain muscle function and to keep joints mobile, overenthusiastic physiotherapy may tire the patient and be counter-productive.

**INSOMNIA**
It is important to ascertain as far as possible the cause of insomnia which may range from pain and depression to the overwhelming anxieties of choking and the fear of dying. There is a general reluctance to prescribe night sedatives to patients with MND for fear of respiratory depression. In practice this rarely happens and is insignificant in relation to the morbidity associated with chronic fatigue.

**PAIN**

**Management of cause of pain**
- Stiff joints - careful positioning/physiotherapy
- Inflammation - NSAID
- Joint pains – intra articular steroid injections
- Muscle spasm - diazepam/baclofen
- Skin pressure – repositioning using special beds (water bed/air bed)

**DYSPHAGIA**
- The speech therapist will help in analysing the exact cause of dysphagia in order to recommend specific techniques to aid swallowing. A common cause is spasticity of the tongue causing difficulty in propelling a food bolus to the pharynx.
- The subject of artificial feeding via a gastrostomy tube should be discussed with the patient and the advantages and disadvantages outlined. In the end stages of the disease, tube feeding may not necessarily prolong life.
However, earlier in the disease, particularly if the patient is ambulant, gastrostomy feeding may slow the inevitable weight loss and its associated weakness and depression.

The dietician can advise on food consistency and general nutritional requirements and the timing of an endoscopic percutaneous gastrostomy tube.

**DYSARTHRIA**
- The speech therapist should be involved early to teach the patient various techniques relevant to their own special needs
- Various aids are available and include light writers with or without synthesized voice function
- Other computerised systems are available from specialised centres including electronic equipment, telephone devices and communication boards which may be adapted to the physical abilities of the individual patient
- It is essential to plan ahead since motor function may deteriorate rapidly

**BREATHELESSNESS**
- This is due to diaphragmatic and respiratory muscle weakness.
- The physiotherapist may suggest breathing techniques and help with chest drainage if appropriate. Antibiotics may be useful in controlling symptoms but if the patient is in a terminal stage they may be inappropriate serving only to prolong the dying period.
- Nocturnal hypoventilation is characterised by poor sleep and nightmares, early morning headaches and daytime tiredness with subsequent impaired concentration. At an early stage in the disease, it may be appropriate to consider some form of limited ventilatory assistance, such as non-invasive positive pressure ventilation to aid respiration at night time (NIPPV). As breathing becomes weaker, this form of ventilation may be continued during the day time.
- More invasive ventilation through a tracheostomy is generally not used in U.K. The wishes of patients for respiratory support should be discussed well in advance of acute problems arising
- Patients with MND may die suddenly and unexpectedly with respiratory failure. This can be very traumatic for family and professional carers

**USE OF OPIOIDS IN MND**
- There has been a reluctance to prescribe opioids for fear of respiratory depression in patients whose lung function may already be compromised. However, one study showed that over 80% of patients had been treated with morphine without detriment

**CHOKING**
- The normal reflexes which protect the airway are impaired so that swallowing food or saliva may result in choking although it is a common fear, patients die rarely as a result of choking
- Speech therapists may help by advising different techniques for protecting the airway such as chewing carefully and slowly, breathing in, swallowing and then deliberately coughing. This technique serves to clear the larynx and to minimise the possibility of choking
- Some patients find suction to the upper airways useful. For others it is avoided since it not only causes trauma, fright and discomfort but may also be very distressing for the relatives to witness

**THE MULTIDISCIPLINARY TEAM**
Care of patients with MND is a team work. The team includes the neurologist, physiotherapist, occupational therapist, speech therapist, dietician, local physician nurse, social worker, palliative physician and palliative home care team.
The Motor Neuron Disease Association (MNDA) in the UK provides an invaluable service not only in terms of liaising, supporting and educating patients and carers but also by facilitating the loan of equipment and helping financially.

**MOTOR NEURON DISEASE BACKGROUND READING**

**Book**

**Articles**


**End Stage Renal Disease (ESRD)**

**Chronic kidney disease (CKD)** differs somewhat from other advanced diseases in that there is a specific measure of disease severity (glomerular filtration rate- GFR) which can be used as an indicator of how advanced the disease is. When estimated GFR falls below 15 mL per minute per 1.73 m body surface area, the CKD patient has reached Stage 5, the most advanced stage of chronic kidney disease. At this point, renal replacement therapy (in the form of dialysis or renal transplant) must be considered if the patient is to survive in the long term, although a small proportion of patients with slow decline in renal function may not develop symptoms of uremia (and so need renal replacement) for weeks, months or (rarely) years after first reaching Stage 5.

**End-stage renal disease (ESRD)** is irreversible decline in kidney function, severe enough to be fatal in the absence of dialysis or Transplantation (i.e. it refers to the time when renal replacement is actually needed).

**Which renal patients need palliative care?**
Patients whose palliative and supportive care needs should be considered are those with Stage 5 CKD who:

- Decline renal replacement therapy (dialysis or transplant) through their own preference
- Are advised against renal replacement therapy because the burden of frequent dialysis is felt to outweigh likely survival and quality of life benefits (a complex and difficult decision likely to apply more often to those with poorer prognoses)
- Have been on dialysis but are now withdrawing or about to withdraw from dialysis
• Are ON dialysis but with a poor prognosis, often because of co-morbid conditions (especially cardiac disease)

The patient-centred (rather than disease-centred) approach of palliative care, with attention to psychological, social and spiritual (as well as physical) needs may have much to offer patients with ESRD and their families. Most patients with ESRD needing palliative care are older people, with high levels of co-morbidity. They have variable and often complex needs, with symptoms which are often unaddressed. A systematic literature review of symptom prevalence in ESRD identified evidence mainly from dialysis populations, but illustrates the high prevalence of symptoms experienced by these patients.

**Dialysis withdrawal:** Recent reviews of the evidence in those withdrawing from dialysis identify mean survival from withdrawal as 8-10 days, with a range of 1-44 days, but also highlight the dearth of evidence on palliative needs. Retrospective review suggests palliative needs may be considerable. In one of the few studies prospectively assessing symptoms in those withdrawing from dialysis, Cohen and colleagues show that a significant minority have distressing symptoms in the last 24 hours, although most deaths were viewed as peaceful by relatives.

**Conservative (non-dialytic) management:** Conservative management has only emerged as a specific management option relatively recently. There has been little evidence about the palliative needs of those managed without dialysis, although this is gradually changing and recent studies are beginning to show that the symptom burden is as high as that of cancer patients. Some preliminary evidence about survival is also emerging, with 1- and 2-year survival (from first reaching stage 5 CKD) of 68% and 47% respectively.

Pain can be managed by Tramadol or Fentanyl. Morphine if used will need reduction of dose and also increase in dosing interval. Control of nausea and vomiting can be a challenge and may require combination of anti-emetics like Haloperidol and Ondansetron. For distressing pulmonary oedema palliative sedation must be considered. Uremic coma usually results in a peaceful death.

**Useful websites for further reading on Palliative Care for non-malignant conditions**


ABC of palliative care Non-malignant conditions — O’Brien et al_316 (7127) 286 — BMJ.mht

Palliative care for patients with non-malignant end stage respiratory disease — HILL and MUERS 55 (12) 979 — Thorax.mht


NLH - Later Life - Dementia Knowledge Week 2007 Palliative Care- End of Life Care.mht

http://www.capc.org/

Palliative Care in the ICU – Center to Advance Palliative Care.mht
CHRONIC MENTAL ILLNESSES

One in four of us can expect to develop a significant neuropsychiatric disorder at some point in our life, according to the World Health Organisation. Some time ago, the National Human Rights Commission pointed out that 7 crore Indians have significant mental disorders. The National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore says that around 2 crore people need treatment for “serious mental disorder”. Studies have shown that “morbidity on account of mental illness is set to overtake cardiovascular diseases as the single largest health risk in India by 2010.” Under the circumstances, it is timely and appropriate to consider bringing chronic mental disorders under the umbrella of chronic incurable diseases that are taken care of in palliative care.

Clinical presentations

People with chronic mental illnesses exist in our midst but at the peripheries of our society. The wandering homeless people we see on our roads are the most extreme example of the untreated serious mental illnesses. Around us live people with long term disabilities caused by untreated or partially treated psychotic illnesses.

Psychoses are serious psychiatric disorders where, to various degrees, the contact with reality is lost. The schizophrenic disorders and bipolar affective disorders (manic depressive psychosis) are the best known examples of psychoses. Organic psychoses due to primary or secondary brain dysfunction form another important group.

Depressive disorders, some of which might also exhibit psychotic features, perhaps form the largest group amongst severe mental disorders. They are much more common than psychoses such as schizophrenia and cause huge morbidity as mentioned above.

People with ‘neurotic’ conditions such as anxiety may be less visible in the society but again suffer with long term disabilities.

Management

Pharmacotherapy of mental disorders has progressed a lot in the last few decades. Proper treatment with medications forms the base on which lives can be rebuilt. There are relatively simple psychological interventions which can go a long way to ease the suffering of people with mental conditions. Compared to many of the chronic medical conditions, the management options in chronic mental disorders are cheaper and more rewarding. However, managing the stigma that people with mental illnesses face, is far more difficult. Providing mental health care as part of palliative care may be one of the ways of combating stigma.

Palliative Care in HIV/AIDS

Introduction: When AIDS first emerged as a clinical problem, some 27 years ago, many patients died early from acute illnesses such as Pneumocystis carinii pneumonia. Cumulative experience and increased awareness have led to the use of prophylaxis, earlier diagnosis, and more effective treatments for HIV itself with anti-retroviral drugs. Also the many complications of HIV infection and AIDS are now more effectively managed. As a result, patients with HIV now have improved survival but are more likely to experience months or years of increasing dependency, punctuated by episodes of acute illness.

Definition of Palliative Care in HIV (OGAC)

Aims to achieve optimal quality of life for PLHA and families and minimize suffering through mobilizing clinical, psychological, spiritual, supportive and preventive care services throughout the entire course of HIV infection

Not limited to clinical management of complications of HIV/AIDS and terminal care
**Why palliative care for people with HIV/AIDS?**
- Dramatic changes in HIV/AIDS care in the past decade
- Increasing body of knowledge and expanded definition of palliative care
- Shift in the trajectory of dying from HIV/AIDS
- Patients with HIV/AIDS have palliative care needs at each stage of the illness

**HIV/AIDS: Pre-HAART era**
- Rapidly fatal course
- Emphasis on treating opportunistic infections and on providing palliative care
- Physicians and other care providers received specific training in end of life care

**HIV/AIDS in the HAART era**
- Chronic, manageable disease for many
- Unpredictable course with more prognostic uncertainty
- Complex treatment regimen requiring specific expertise
- Multiple symptoms with complex etiologies
- Focus of care and training on HAART and not on palliative care

**Importance of palliative care in HIV/AIDS**
- Co-morbidities of Hepatitis B & C and malignancies can be fatal
- HAART is not a cure and has many side effects
- Many symptoms throughout the disease impact quality of life
- Complex psychosocial issues such as psychiatric illness and substance abuse
- HIV/AIDS disproportionately impacts minority and marginalized populations
- These groups often enter care later in the disease progression
- Some groups have less access to HAART
- Some lack the support system to adhere to a complicated medication regimen

**HIV/AIDS palliative care**
- Integrated with disease - modifying therapies
- Interdisciplinary approach
- Patient & family-centered
- Focus on quality of life
- Multidimensional focus - physical, emotional, social, spiritual
- Collaboration with patient to develop care goals

In developing and transitional countries, 7.1 million (20%) people are in immediate need of life-saving AIDS drugs; of these, only 2.015 million (28%) are receiving the drugs.
- Over all 5.7% out of 35M in dev world get HIV drugs (emphasis added)

In India of the 64000 pregnant women who need ART to prevent mother to child transmission only 14% get it. This is a highly motivated group and the intervention is for a limited period. In spite of this only 14% benefit from ART. Of the total number of 3.2 M HIV in India only 5% are receiving ART.

Comparing HIV / AIDS with other life limiting illnesses
- Cancer – 20% helped by curative treatments
- End stage renal disease - 6% helped by transplant
- HIV /AIDS (dev W) – 6% helped by ART

In all the above situations the need is for good comprehensive Palliative care, throughout the entire course of the illness.

OGAC guidance on HIV/AIDS Palliative Care

(OGAC - Office of the U.S Global AIDS Co-ordinator)
Types of Palliative Care

- Clinical Care
- Psychological Care
- Spiritual Care
- Supportive Care
- Preventive Services

The clinical care services include:

- Prevention and treatment of TB/HIV
- Prevention and treatment of other opportunistic infusions
- Alleviation of HIV-related symptoms and pain
- Nutritional rehabilitation for malnourished PLHA

Psychological care involves:

- Mental health counseling
- Support groups
- Diagnosis and treatment of HIV related psychiatric illnesses
  - Depression and related anxieties
- Bereavement services

Spiritual care: This includes culturally-sensitive services that support individuals and families through faith and ritual:

- Counseling on
  - Hope
  - Fear
  - Meaning of life
  - Guilt
  - Forgiveness
- Life review
- Life Completion tasks

Supportive care: Assists individuals and families to link with the following services:

- Child care
- Adherence to treatment
- Legal services – rights, inheritance
- Housing
- Food support
- Income Generation Program

Prevention Services

- Interventions for sero-discordant couples including VCT and ongoing counseling
- Community and clinic-based support groups
- Case management and provider delivered prevention messages focused on disclosure
- Correct and consistent use of condoms and mutual fidelity

Specific issues in palliative care of AIDS patients

Medical

- Multiple infections
- Chronic suppressive therapy
- Increased risk of adverse drug reactions
- Continued prophylaxis
- Multiple medications
- The need for vigilance around reversible or treatable conditions

**Psychosocial**
- Young patients (usually)
- Marginalized or minority groups
- Partners and carers often infected
- Family members often infected
- Often well informed
- Stigmatized
- Confidentiality
- Infected peer networks
- Multiple bereavements
- Fears of “contagion”

**Conclusion:**
Comprehensive palliative care is essential to the health and well-being of people living with HIV/AIDS (PLWHA) and is an integral part of the President’s Emergency Plan for AIDS Relief (the Emergency Plan).

Palliative care has traditionally been associated with terminal or end-of-life care. However, current thought and practice and Emergency Plan policy take the broader view that palliative care encompasses care provided from the time that HIV is diagnosed and throughout the continuum of HIV infection.

It is important that we learn from the African experience which is summarized by Dr Mwangi-Powell as –

“Palliative care is now spoken in the same breath as HIV/AIDS management and that is a significant achievement”,

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CARE OF THE ELDERLY

Advances in medical science and improved social conditions during the past few decades have increased the life span of man. The expectation of life at birth in developed countries is over 70 years. The age structure of the population in the developed countries has so evolved that the number of old people is continually on the increase. These trends are appearing in all countries where medical and social services are well developed and the standard of living is high.

Between 2002 and 2025, the total number of people = 65 years of age is expected to increase by 11 to 70% in European countries and by up to 170% in some developing countries. By 2025, the countries with the highest percentage of people = 65 are expected to be Japan (with 28%), Italy (with 24.7%), and Germany (with 24.6%). However, because developing countries such as China and India have the largest total populations, they have and will continue to have the largest absolute number of elderly people. In 2002, the greatest number of people = 80 lived in China, followed by the US and India. By 2025, the world’s population is expected to include over 830 million people = 65; most will live in developing rather than developed countries.

The exceptional growth in the percentage of the elderly worldwide is related to the substantial decrease in birth rates during the past 25 yr in many countries, the migration of younger people out of certain areas because of economic reasons, and the decrease in overall mortality (including that due to infectious diseases in developing countries and that due to coronary artery disease and stroke in European and other developed countries).

Physical, emotional and socio economic implication of this fact is beyond the mere arithmetic of this statistical statement. Most of these countries are already burdened with diseases of poverty and lower socio economic living. For India the second largest population in the world with its already existing disease burden (the largest number of tuberculosis, leprosy, malaria, filarial and the HIV–AIDS patients and 30 % of population still under the poverty line) its aging population demands well orchestrated and non conventional approaches for tackling the problems of aging population.

Not all aged people are all the same and all are not frail and incapacitated as generally believed. But the rapidly changing socio economic order and social values, changing family structure from joint family to nuclear families, mass migrations looking for job and better living conditions, wars and natural catastrophes make things less easy for the aging population. Their care poses bigger challenges for the health and welfare system managers.

The process of aging

Aging is a process of gradual maturation and is thought to have the positive component of development (eg, increased wisdom, experience, and expertise) and the negative component of decline. The term senescence is the most common term for the decline component and refers only to changes that are deleterious.

The changes that occur with aging can be categorized as those that result from aging itself and those that result from diseases, lifestyle, and exposures. People age very differently: Some acquire diseases and impairments, and others seem to escape disease altogether and are said to have died of "old age."

Successful (healthy) aging refers to a process by which deleterious effects are minimized, preserving function until senescence makes continued life impossible. People who age successfully avoid experiencing many of the undesirable features of aging and, whether they have a disease or not, remain functional both physically and mentally.
Disease vs. aging: It is important to understand that old age is not a disease. With aging, many physiologic functions decline. Many of these declines are attributed to aging itself; in other words, they are considered normal, not disease-related. For example, renal impairment may be a part of aging but renal failure is not. Also urinary incontinence is not part of normal aging, but it is a disease that may occur at any age and is frequently treatable.

Health problems of the aged

The disability statistics shows 50% of the 65+ individuals have some kind of disability. One important aspect of the expressions of disease pattern in old age is that multiple diseases coexist and the disease presentation is atypical and complex. The changing trends in disease pattern shows a gradual take over by the degenerative diseases from infections and communicable diseases. This trend is attributed mainly to the improvement in living conditions and aging population. Age related changes and increased physical vulnerability are responsible for most of the diseases in elderly. The diminishing reserve also contributes the ill health.

1. Problems due to the aging process: these are due to the decline in the functioning of different organs of the body as age advances, and include diminished vision (mainly due to cataract), deafness, osteoporosis affecting mobility, changes in mental outlook etc.

2. Problems associated with long term illness: certain chronic diseases are more frequent among the older people.
   a. Degenerative diseases of heart and blood vessels. Deposits in the inner walls of the arteries lead to narrowing of the blood vessels leading to diminished blood supply to different organs, rupture of blood vessels and high blood pressure. This may lead to heart attack, stroke etc. The process can be prevented or delayed by a reduction in body weight and modification of habits of life.
   b. Cancer is by and large, a disease of old age. The incidence of cancer is on the rise because of increased number of older people along with other factors like change in life style and better diagnostic techniques.
   c. Accidents are very common in the elderly and majority occur in the home than outside. Visual and hearing impairment and decline in mobility make the aged more vulnerable. The bones become fragile due to decalcification and break easily.
   d. Diabetes is more common in elderly and is a long term cause of diseases like heart attack, kidney diseases, stroke and cataract.
   e. Diseases of the locomotor system like arthritis limit the mobility of the aged considerably and contribute to accidents.
   f. Diseases of the respiratory system like asthma, chronic bronchitis and emphysema are common in old age especially in smokers.
   g. Genito-urinary and bowel problems. Difficulty in passing urine, loss of control and frequent urination are common problems. Lack of exercise and change in dietary habits result in constipation.

3. Psychological problems:
   a. Mental changes. Impaired memory, rigidity of outlook, and dislike of change are some of the mental changes in the aged.
   b. Sexual adjustment. There is cessation of reproduction in the women between 40 and 50 and diminution of sexual activity in men. Many physical and emotional disturbances are associate d with this phase.
   c. Emotional disorders result from social maladjustment. Failure to adapt to the process of aging and physical and financial dependence can result in bitterness, withdrawal, depression, and even suicide. Dementia, one of the dreaded problems facing the elderly, contributes to the psychological problems.
4. **Social problems:** these are probably the most neglected area in the care of the elderly. Because of the physical decline

a. Most of these people who are living in developing countries live and work in un-organized sector in an unprotected environment. They have no social security or social welfare system to take care of them when they are unwell or unable to work. So they are forced to work even when their health declines. The lack of pension or insurance makes them all he more vulnerable as the physical health deteriorates. The health care needs and spending are more compared to the young. On the one hand they cannot work, on the other they need more money for taking care of their failing health and there is no welfare system to take care of them.

b. Disintegration of joint families leaves the care of the elderly to the mercy of nature. Even in joint families when the issue of resource allocation comes the elderly of the family get less preference than the children and more productive groups.

c. A significant number of the elderly lose their partners in their old age. As men usually marry woman of lesser age and women outlive men in life expectancy, woman outnumber men in widowhood. The social stigmas and economic dependence of these women add on to their social distress.

d. Neglect and ill treatment of the elderly: elderly are subjected to physical and emotional ill treatment and neglect. Sexual abuse is also not rare.

e. The demographic transition due to declining birth rate and increased life expectancy leads to alteration in caregiver – cared ratio. It is estimated that each potential caregiver may be responsible for at least 6 elderly people.

f. Decreasing physical health, visual, hearing and mental impairment may lead on to increased isolation from the environment and regression to one self.

g. Most of the physical and psychological issues related to aging are mistakenly considered as inevitable and are so left unattended, due to lack of awareness.

h. Loss of role is another issue that adds to frustration. Persons who have been the decision makers in the family or work suddenly finds that he is not consulted in important matters. This makes them angry, irritable or depressed.

5. **Spiritual issues:** This is also the time they have to meet with the multiple loses in their life. Loss of spouses, peers and near ones causes enormous emotional and spiritual distress to the patient. Death and after death issues are also an important concern for many of them at this age.

**Care of the elderly**

Geriatrics is the branch of medicine that focuses on health care of the elderly. It aims to promote health and to prevent and treat diseases and disabilities in older adults. There is no set age at which patients may be under the care of a geriatrician. Rather, this is determined by a profile of the typical problems that geriatrics focuses on. The term geriatrics differs from gerontology. This is the study of the aging process itself.

Geriatrics differs from adult medicine in many respects. The body of an elderly person is substantially different physiologically from that of an adult. Old age is the period of manifestation of decline of the various organ systems in the body. This varies according to the reserve in the organs (e.g. Smokers consume their respiratory system reserve early and rapidly). The decline in physiological reserve in organs make elderly vulnerable to diseases (such as dehydration from a mild gastroenteritis) and liable to complications from mild problems (Fever in elderly persons may cause confusion leading to a fall and fracture of the hip bone). Functional ability, dependence and quality of life issues are of greater concern in this group.

Another major difference between geriatrics and adult medicine is that elderly persons
sometimes cannot make decisions for themselves. The issues of power of attorney, privacy, legal responsibility, advance directives and informed consent must always be considered geriatric procedure. Elder abuse is also a major concern in this age group.

Elderly people have specific issues related to medications. Elderly people particularly are subjected to polypharmacy due to many causes. Some elderly people have multiple medical disorders; some use many herb & OTCs; some adult physicians just prescribe medications to their specific specialty without reviewing other medications used by the elder patient. The polypharmacy may result in many drug interactions and may be some drug adverse reactions. Drugs are excreted mostly by kidneys or liver which maybe impaired in elderly and medication might need adjustment.

Also presentations of diseases in elderly persons may be vague and non-specific or present with delirium of falls (Pneumonia may present with fever, low grade fever, dehydration, confusion or falls). Also some elderly people may find difficulty verbally describing their symptoms, especially if the disease is active and causing confusion or if they have cognitive impairment. Delirium in elderly may be caused from a minor problem as constipation to a serious life threatening problem as myocardial infarction.

The best place for the elderly to be cared is their own home. The familiarity with the physical and emotional environment of the home is reassuring to the patient. Short term institutional care may be advisable when the patient is acutely sick or when patient or family needs a break. For those who have been living in non conventional places, they have to be cared where they feel to be comfortable.

The role of family is paramount. Family has to be trained in providing physical care, as well as emotional support. Physical, emotional and social care has to be supplemented through community resources. Professional caregivers have a role in helping patients when and where there is a need and in training the family and the community in providing care.

**Preventive measures in elderly care**

Prevention of diseases can be at different levels. The objective of primary prevention is to stop disease before it starts, often by reducing or eliminating risk factors. By adopting a healthier life style, the risk of developing many diseases can be reduced (e.g. smoking cessation). In secondary prevention, disease is detected and treated at an early stage, before symptoms or functional losses occur, thereby minimizing morbidity and mortality (e.g. early detection and treatment of diabetes and hypertension). In tertiary prevention, an existing symptomatic, usually chronic disease is appropriately managed to prevent further functional loss (e.g. appropriate management of diseases like arthritis, visual and hearing impairment may prevent falls).

The possible areas of intervention are:

- a. **Diet and nutrition**: A healthy diet from early in life is important in delaying or preventing the diseases of old age. The diet should be balanced with less saturated fat and oils, should contain lots of fruits and vegetables, salt and sugar should be less and should be fibre rich.

- b. **Exercise** helps to control weight, improves emotional well being and relieves stress, improves blood circulation, increases flexibility, lowers blood pressure, improves bone density and thus helps prevent fractures, lowers blood sugar levels.

- c. **Obesity** (over weight) is an important factor in heart disease, stroke, hypertension, diabetes, arthritis and breast cancer.

- d. **Smoking** is associated with a wide range of diseases like various cancers (mainly lung cancer), diseases of the respiratory and cardiovascular systems.
e. **Alcohol** is associated with liver diseases, stomach ulcers, depression, heart disease, diabetes and hypertension.

f. **Social activities** create a sense of belonging. The support derived from social interactions is helpful in preventing physical and emotional problems and also in recovering from illness.

g. **Prevention of accidents and falls**: treating specific conditions like visual impairment, joint problems etc can improve mobility and balance. Modifications in the living atmosphere like providing walking sticks and railings for the stair may have tremendous influence on quality of life.

**Health status of the aged in India**
The government of India announced a national policy on older persons in January 1999. The principal areas of intervention are financial security, health care, nutrition, shelter, education, welfare and protection of life and property of older citizens. The policy also provides scope for collaboration between government and NGOs and aims for active and productive involvement of older parsons, and not just their care.

As part of the National Social Assistance Programme, old age pension is being provided. Tax concessions and travel concessions are available for senior citizens. The national rural health mission has identified elderly care as one of the main areas.

*Help Age India* is the largest voluntary organisation working for the care of older people. Help Age India supports free cataract operations, mobile medicare units, income generation and microcredit, old age homes and day care centers, Adopt-a-gran and disaster mitigation.

**PARALYTIC DISEASES OF BRAIN AND SPINAL CORD**

**SPINAL CORD INJURY**

- Traumatic spinal cord injury (SCI) is a common problem in our community that cripples thousands of young population, leaving most of them bedridden for the rest of their life. Non traumatic diseases of the spine and spinal cord also contribute to this.

- SCI is a devastating event that brings about a drastic change in the life of those affected, and is a major physical and psychological challenge to the patients, who requires empathetic support. Rehabilitation programmes plays a major role in renewing a sense of independence and confidence, and bringing back hopes to their lives.

Rehabilitation is to be started within days after the injury and to be continued in home based care, with constant supervision from professionals and support from the community. But unfortunately, the few Physical Medicine and Rehabilitation (PMR) centres in India have facilities that are too meagre to meet the demands of the large population of patients in need.

- Data about the incidence and prevalence of SCI are not available in our country, but a study based on data from palliative units of Kerala reveals the following

  1. Incidence is estimated to be much higher compared to developed countries ( more than 100 per million, and much high in certain regions)

  2. Causes: Most common cause is fall from height. (Manual labourers who fall from trees, fall from buildings during construction works, and fall into wells are affected most.) Fall of head load and road traffic accidents are other common causes.

    Non traumatic causes like transverse myelitis, ischaemic spinal cord injury, tumours of spinal cord and spinal canal, tuberculosis of spine etc also contributes.

  3. Gender: Males are affected most ( male, female ration is more than 5:1)

  4. Age: Most of the patients are affected at a young age (20-40 years)
5. Socio economic status: Vast majority of patients come from lower socio economic group. Most of them are unskilled manual labourers, who have not completed primary education.

6. Anatomical considerations: Injuries of cervical cord causes Quadriplegia and below this causes Paraplegia.

Most common site of injury- T11, T12, L1 Vertebrae
(Spinal segments lie 1 or 2 levels above the corresponding vertebral bodies in thoracic vertebrae. Spinal cord ends (conus medullaris) at L1-L2 interspace and below L2 only cauda equina traverses spinal canal.

The injury may be complete with no motor /sensory function below the level or may be in complete with partial preservation of motor and sensory function.

**Physical Problems of Patients with Spinal Cord Injury**

1. **Urinary problems:**

   Neurogenic bladder: Many of the patients have UMN bladder (In lesions above conus medullaris) is a low volume spastic bladder. There is detrusor sphincter dyssynergia and patients are at risk of upper urinary tract complication due to back pressure into ureters and renal pelvis.

   In patients with lesion of cauda equina a high volume bladder with little or no contractile force from detrusor muscle.

   In both the cases, most of the patients loses control over micturition, with absent bladder sensation, are incontinent, and requires intervention.

**Management strategies:**

- Timed voiding, bladder stimulation:
  - Credes manoeuvre (manually applied pressure over bladder)
  - Valsalva manoeuvre (Increasing Intra abdominal pressure by straining)
  - Suprapubic Jabbing

(These measures carry risk of back pressure and upper urinary tract damage)

- Urine collection devices:
  - Diapers
  - Condom catheter (risk of penile skin break down)
  - Indwelling catheter (urethral /suprapubic)

Clean self intermittent catheterisation (CSIC) - Patients and family members should be trained in clean and proper techniques. Start with 4-6 hourly catheterisations as a trial and adjust the intervals according to the holding capacity. Urine volume should be less than 400-500ml at each time. It should be done minimum three times a day.

   Problems: UTI, Urethral trauma, incontinence

Drugs: Drugs like anticholinergics, alpha agonists, tricyclics, alpha blockers, muscle relaxants etc are used for various conditions like hyper reflexic bladder, sphincter incontinence, sphincter contraction-retention etc.

Complications of voiding dysfunction:

- UTI
- Vesico ureteric reflux
- Hydronephrosis
Renal stones
Bladder stones
Pyelonephritis
Autonomic dysreflexia
Peno-scrotal complication like abscess, fistula, strictures

(UTI in SCI may present as dysuria, frequency, new onset of incontinence, haematuria, fever, uneasiness, malaria, lethargy, increase in spasticity, cloudy or odorous urine or automatic dysreflexia. Treatment of asymptomatic bacteruria in SCI with long term antibiotics is controversial. General view is to treat asymptomatic bacteruria only if complications like hydronephrosis or reflex are present.)

2. Bowel Problems:
Neurogenic bowel: It is a major medical and social concern for patients with SCI.
UMN bowel: Lesion above conus medullaris is associated with longer intestinal transit time, resulting in hard stools, increased sphincter tone, absent sensation, incontinence etc. They are usually constipated and need mechanical/chemical triggers to defecate.
LMN bowel: Sphincter tone is lost, and incontinence is a major problem together with constipation.
Patients with SCI usually need laxatives and rectal measures. Patients and family needs training in making a bowel plan apt for them and practicing it.

3. Skin Care:
Many factors can contribute to the development of pressure sores in patients with SCI, like
a. Insensitive skin
b. Decreased muscle mass
c. Poor nutrition
d. Pressure over bony prominences
e. Excessive sitting or lying
f. Shear forces while transferring
g. Spasticity or contractures
Some of the complicated stage IV pressure sores requires surgical intervention. Others require nursing care. (See section on pressures sores.)

4. Spasticity:
Phasic and tonic stretch reflexes develop after a period of spinal shock. It is seen in patterns involving extensors/ flexors. Noxious stimuli like pressure ulcers/ bladder stimuli lead to sudden flexor reflexes.
Spasticity interferes with function such as transfers, ADL, sleep, perineal care, seating and requires management.

5. Autonomic Dysreflexia (AD): is an acute syndrome of uninhibited sympathetic discharge as a result of noxious stimuli below the lesion. Seen in lesions at the level of T6 or above. Common causes include bladder distension, UTI, impacted bowel, pressure sores, ingrown toe nail, fractures etc.
Manifests as paroxysmal hypertension, bradycardia/ tachycardia, headache, flushing and sweating above the level of lesion. If left untreated, AD can result in hypertensive crisis, seizure, arrhythmias, stroke and other complications of hypertension. With drugs or alpha 1 agonists to suppress such episodes is required.
6. Pain in SCI:
There are various potential causes for pain in patients with SC. It can be nociceptive or neuropathic. Radicular pain and paraesthesia are common, especially in the zone of partial preservation. Hyperesthesia and allodynia are also commonly seen. Neuropathic pain below complete lesion described as burning/cold or “pins and needles” in non-dermatomal pattern is very common.

Overuse injuries (especially of shoulder, rotator cuff), other musculoskeletal pains, compressive neuropathies, complex regional pain syndrome (CRPS) etc also can cause pain.

7. Deep vein Thrombosis: Risk is increased up to 1 year, highest in first two weeks. Such patients may require long term prophylaxis for DVT and pulmonary embolism.

8. Metabolic and bone complications like deconditioning osteoporosis, Fractures heterotrophic ossification, Immobilisation hypercalcemia are not uncommon.

9. Sexual Problems: In a study on sexual issues of traumatic paraplegia patients majority of patients reported issues related to denied sexuality are of utmost concern to them, affects their family life and marital harmony in various ways, still, these problems are very often unexplored and unaddressed. Lack of knowledge and misconcepts about sexuality in SCI patients is prevalent even among medical professionals.

Many of the patients report major problems related to erection tumescence, ejaculation, positioning and other problems. Some of the problems have a major psychological element. Even if some of the problems related to erection and inter course cannot be treated, a positive attitude towards other forms of sexual relation and emotional bonding can be encouraged.

Psychosocial Problems:
Compared to other patients’ population in palliative care setting, SCI patients are relatively young, mentally active, upper half of body is unaffected in many of them and they are destined to spend a very long time in bed. They suffer from loneliness, social isolation. Unemployment, loss of role in family and society. They are denied of opportunities to entertain themselves in any productive activities. Therefore, attempts on effective rehabilitation should give emphasis on possible vocational training and opportunities for earning from such activities.

Stroke
The term ‘stroke’ or ‘Cerebro Vascular Accident’ (CVA) is applied to acute and chronic manifestations of cerebro vascular diseases. It includes a number of syndromes with diverse aetiology, epidemiology, prognosis and treatment. It is a common problem that leaves many people with life-altering functional and neurological deficits, causing both physical and mental crippling.

- WHO definition of stroke: “Rapidly developing clinical signs of focal(or global) disturbances of cerebral function, lasting for more than 24 hours or leading to death, with no apparent cause other than vascular origin.”
- It is the third leading cause of death world wide, after ischemic heart disease and cancer.
- Incidence is estimated to be two per 1000 population per year in many developing countries (WHO study), but there is no reliable information on stroke in India.
- 10-12% of deaths in these countries are due to stroke.
- WHO study shows that more than 1/3 of patients with stroke died within one year.
- ¾ of the cases occur in age >65 year.
- After age of 55, risk of stroke doubles in each decade.
- Incidence is 30-50% higher in males, compared to females.
In India about 1/5 of all strokes occur below the age of 40 years. (Called stroke in the young.)

It is one of the major affecting factors for the national resources due to the prolonged hospital stay, slow recovery and residual neurological deficits.

Nearly 20% of the patients have recurrent stroke in one year.

Continuing rehabilitation from the acute phase throughout the medical course and beyond is essential to maximise recovery and restore function.

More than 1/3 of the patients are permanently disabled.

Temporal classification
1. Transient Ischemic Attack (TIA)- Temporary neurological deficits, lasting for less than 24 hours, resolving completely
2. Reversible Ischemic Neurological Deficits (RIND) - temporary neurological deficits, lasting more than 24 hours, but with eventual resolution.
3. Stroke: Neurological deficits lasting more than 24 hours and are lasting.

Disease mechanism (causes)
A. Ischemic (85%)  
    Thrombosis 60%  
    Embolism 20%  
    Others 5%
B. Hemorrhagic (15%)  
    Intra cerebral 10%  
    Subarachnoid: 5%

Pathogenesis:
Most common pathology is atherosclerosis. It is a slowly evolving degenerative disorder of multifactorial origin. Multiple risk factors contribute to the development of atherosclerosis. It evolves through fatty streaks, fibrous plaques, atheromatous stenosis and then thrombosis.

WHO Study shows that nearly ¾ of all patients had associated diseases mostly in the CVS or related to diabetes.

Major risk factors:
Non modifiable : age  
    Gender  
    Genetic predisposition  
    Ethnic factor

Modifiable :  
    Hypertension  
    Diabetes  
    Dyslipidemia  
    Smoking, tobacco abuse  
    Obesity  
    Cardiac diseases (LVH, dilatation, valvular diseases, atrial fibrillation)

Primary prevention of stroke: Guidelines
1. Control of Hypertension (SBP< 140, DBP<90 mmHg) with weight control, physical activity, moderate sodium intake and if required antihypertensive drugs.
2. Control of diabetes
3. Cessation of smoking
4. Control of dyslipidemia
5. Physical Activity
6. Diet modification: Increased fruits and vegetables, moderation of alcohol use
7. Control atrial fibrillation

**Clinical features:**
The manifestations (acute and chronic) differ, in the form of various neurological symptoms and signs that are related to extent and site of the area involved, and to the underlying cause.

These include coma, Hemi/para/monoplegia, multiple paralysis, cranial nerve paresis, sensory impairment, speech disturbances (like motor/sensory/conduction aphasia, anosmia, jargon speech, dyslexia, mutism, slowness, delay, intermittent interruptions) gait disturbances, bowel bladder incontinence, mental changes, apraxia, visual disturbances etc. These depend mainly on the arterial territory involved (anterior/middle/posterior cerebral arteries vertebrobasilar syndrome etc)

Of these, hemiplegia constitutes the main disorder in about 90% of patients.

**Medical problems of patients with stroke**
Many of the focal or global neurological outlined above many persist, some of them with partial resolution. They cause motor weakness, sensory disturbances, gait abnormalities and dependence on ADL. Apart from these, the chronic problems that are challenging to the rehabilitation team are:

1. Increased incidence of deep vein thrombosis and pulmonary embolism.
2. Increased incidence of pneumonia (often secondary to clinical/sub clinical aspiration.)
3. GI problems like constipation, nausea, dysphagia incontinence.
   (Neurogenic bowel: uninterrupted cerebral input between cortex, pons and spinal defecation centre causing uninhibited reflex emptying-incontinence.)
4. Nutritional problems, difficulty in feeding
5. Genitourinary problems: Neurogenic bladder in early stage, flaccid, atonic bladder.
   Later, detrusor hyperreflexia and low capacity bladder inhibition from cerebral cortex.
   Bladder sensations are often absent.
6. Skin problems: Prevention and management of pressure sores
7. Spasticity: Mass contraction of multiple muscle groups seen in flexor and extensor patterns. Can be painful, may enhance development of pressure sores, and impede functional rehabilitation.
8. Language and communication problems: Seen in approximately 30% of stroke survivors.
   May affect expression, fluency, comprehension, naming, reading, writing and repetition.
9. Cognition: Approximately 25% of stroke survivors have a cognitive deficit, in areas like consciousness, orientation, memory, language and reasoning.
10. Increased incidence of delirium
11. Depression: About 1/3 of affected patients may develop major depression. Possible causes include disruption of catecholamine systems (decreased nor adrenaline and serotonin), grief reaction to loss, medication side effects, hypothyroidism, infection or pre-existing psychiatric condition.
Diagnosis may be difficult, especially in patients with aphasia or cognitive impairment. Other organic problems like emotional lability, flat affect may co exist. Clinical signs symptoms include decreased sexual desire, feeling of worthlessness, impaired concentration, behavioural changes, suicidal thoughts, and decreased/increased appetite. Depression can negatively affect rehabilitation programmes, causing greater cognitive deficits.

12. Seizures
13. Pain:
   a. Central post stroke pain: Occur in 2% of patients.
   b. Shoulder pain: possible causes include spasticity, bursitis, shoulder subluxation, tendonitis, traction neuropathies, CRPS etc.
14. Hydrocephalus: communicating hydrocephalus (secondary to impaired absorption of CSF) is more common.
15. Increased risk of fall
16. Other problems of deconditioning – like orthostatic hypotension, decreased respiratory capacity and atelectasis, generalized muscle weakness, joint contractures, osteoporosis, impaired glucose tolerance etc are not uncommon in stroke patients.

**Treatment of CVA**
Stroke patients require hospitalization and management of acute post stroke problems in the initial few days or weeks for saving life and speeding recovery. But the long term care (rehabilitation and measures to prevent recurrence) has to be planned in domiciliary (or home based) care, in the community, by training and enabling family and primary health care team.

**Phase I: Emphasis on saving life and speedy recovery.**
- Maintain vital signs, patent airway
- Decision on anticoagulation – in ischemic stroke (Hemorrhagic stroke is to be ruled out, with the help of investigations.)
- Tissue plasminogen activator or heparin is used
- Blood pressure management
- Maintain body temperature, prevent fever.
- Maintenance of fluid & electrolyte balance
- Nutritional support (NG tube feeding may be required)
- Prevention and management of complication like aspiration, seizures, DVT, thrombophlebitis, pressure sores etc)
- Good general medical and nursing care

**Phase II : Rehabilitation to achieve adaptation**
Physical, occupational and social rehabilitation have to be planned, involving the family with realistic goals appropriate to the situation. Rehabilitation is started in the acute inpatient setting, extended to outpatient reviews and the home based care

**Phase III : Secondary prevention**
Emphasis is on prevention of recurrence of stroke. Control of hypertension, diabetes and dyslipidemia, cessation of smoking, weight reduction, treatment with oral anticoagulants (if embolic foci are suspected) and antiplatelet drugs (aspirin/ clopidogrel) are all combined.
Section Seven
The last 48 hours of life, Practical issues and bereavement

TERMINAL PHASE

Prognosis

It is notoriously difficult to predict when death will occur; patients will readily tell you stories of what others have told them in response to the question, “How long have I got?” Avoid the trap of predicting prognosis unless absolutely pushed to do so. At that point, avoid specific times that will be remembered by patients and relatives long after you have forgotten. Talk in terms of ‘days’, ‘weeks’ or ‘months’

“When we see someone deteriorating from week to week, we are often talking in terms of weeks; when that deterioration is from day to day then we are usually talking in terms of days, but everyone is different”

Research has shown that nurses and relatives are often better at predicting the approach of death than medical staff.

Signs and Symptoms of Death approaching

The clearest signs of approaching death are picked up by the day by day assessment of deterioration.

- Profound Weakness
- Bedbound
- Needs assistance with all care
- Diminished intake of food and fluids
- Drowsy/reduced cognition
- May be disorientated in time and place
- Difficulty in concentrating
- Scarcely able to co-operate with carers
- Gaunt appearance
- Difficulty swallowing medicine

Should such symptoms develop suddenly over a matter of days instead of the usual weeks, it is important to exclude a reversible cause of deterioration such as infection, hypercalcaemia, or change in medications

Participation by patient, family and friends.

It is very important to continually seek the patient’s views on, and feelings about treatment while they remain conscious, even when their weakening state makes communication difficult.

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41 National Council for Hospice and Specialist Palliative Care Services (1997) Changing Gear – Guidelines for Managing the Last Days of Life in Adults. London: NCHSPCS: 7. The terminal phase is defined as the period when day to day deterioration, particularly of strength, appetite and awareness, are occurring.
Relatives also need to be given time to have their questions, concerns, and requests for information listened to and answered as clearly as possible. As the patient deteriorates the family’s advocate role becomes more important, though their wishes need to be balanced with the palliative care team’s views of the patient’s needs.

At the end of life families are crucial in providing the needed support and care for their loved ones and the professionals should understand their role as being to empower the family to fully manage all aspects of care. While most people will be dying at home in the event of patients dying in hospital carers should be invited to stay, if they want to, while nursing and medical procedures are carried out.

Relatives should determine who and how the body is dealt with after death. This is a very important part of their last ‘duty’ on behalf of their relative and should not be medicalised. The events and the ‘atmosphere’ which are present at the time of a patient’s death can greatly influence the grieving process of those left behind.

**Different Cultures**

Different religious and cultural groupings have different approaches to the dying process. It is important to be sensitive to these particular cultural and religious beliefs. If in doubt, ask a family member. You are more likely to cause offence by not asking than by asking.

**Patients’ Wishes**

Dying is a very special and unique event for each individual. Helping to explore a patient’s wishes about death and dying should be an earlier part of the palliative care approach than in the last 24 hours. However, following wishes that the patient has expressed about such things as place of death can bring great comfort to the family. The wish to die at home is very common and training the carers to be able to provide the care necessary to allow this to happen, with support if possible from local hospital and community services, is an important part of palliative care responsibility.

Studies have shown that by recording a patient’s choice of where they would like to die helps improve the chance of patients being where they want to be for this crucial time. Raising the question with patients is not easy, particularly for those who do not know the family very well. However, over the course of a developing relationship it may be possible to ask, “If your condition deteriorated where would you prefer to be looked after”. 42

**Collaborative Multi-professional approach**

Effective terminal care has been shown to require a team approach. No individual, no matter how committed or gifted, can meet all the palliative care needs of a patient and their family. Thus, if you are working on your own, you need to gather a team of fellow workers who can combine with you so that together you can provide a more holistic service. Such a team might include doctors, nurses, volunteers, social workers, and others with suitable gifts.

**ASSESSMENT OF A PATIENT’S NEEDS**

The focus of assessment in the last 48 hours is to discover what the patient perceives to be his or her problems, and to try and find out which concerns need to be addressed and how they should be prioritised. Beware of patients who under-report their symptoms and families who misinterpret their relatives’ symptoms.

---


**Physical needs?**
What are the symptom control issues which need to be addressed?

**Psychological needs?**
Is anxiety or agitation developing?
Is the patient “comfortable”?

**Spiritual needs?**
Are their particular religious tasks to be accomplished? Is there spiritual distress or pain?

### Formal Inquiry
Particularly about areas such as nausea, constipation, pain, oral problems, sleep disturbance, pressure sores and appetite.

### Informal Inquiry
Assessment is not just a recording process but involves looking for insights into what the patient is feeling, and thinking. Many problems are displayed through non-verbal clues, and relatives can often shed light on what is happening.

### Physical examination
- Examination at this stage is kept to the minimum to avoid unnecessary distress.
- site of pain
- Mouth
- Relevant body areas suggested by history or non-verbal signs.

### Psychological assessment
The key to psychological assessment is finding out what the patient wants to know. Gently assessing how the patient feels about their disease and situation can shed light on their needs and distress. How the patient interprets their disease and its symptoms may be a cause of suffering itself. However, deep probing at this stage is inappropriate as the goal is psychological comfort and peace.

Some patients want to know everything, and studies suggest that this is by far the majority, but some would prefer not to have things spelled out.

### Causes of non-physical distress

#### Anxiety can be increased in patients if:
- they are unaware of the diagnosis, but feel that people are lying to them
- they have certain symptoms such as breathlessness, haemorrhage and constant nausea or diarrhoea
- if there is a “weak” religious faith. (It is said that convinced believers and convinced nonbelievers have less anxiety)
- if there are young dependant children or other dependant relatives they have “unfinished business” to attend to such as an unmarried daughter or incomplete house construction.

#### Talking about death and dying
As a taboo subject, few people feel comfortable about discussing death, even though it is natural, certain, and is happening all around us all the time. Opening up discussion can be very liberating to patients who often feel that they are not given permission to talk about dying as this would be admitting defeat. Sometimes the direct question “are you worried
“About dying?” is most appropriate. Often the patient’s biggest fears are groundless and reassurance can be given. Where reassurance cannot be given, it is helpful to break the fear down into constituent parts and try to deal with the aspects of the fear which can be dealt with.

**Terminal anguish and spiritual distress are**
characterised by overwhelming distress often related to unresolved conflict, guilt, fears or loss of control

**Dignity**
The palliative care team need to have as a goal the maintenance of the patient’s dignity in a manner which is appropriate to that particular patient. What is dignified for one patient may not be for another.

**Investigations**
Any investigation at the end of life should have a clear and justifiable purpose such as excluding reversible conditions where treatment would make the patient more comfortable. The need for investigations in the terminal stage of illness are very few.

**Treatment of patient’s symptoms.**
Dying patients are very weak. They require:
excellence in nursing care prevention of new problems developing. –use of appropriate mattresses and prevention of bed sores
treatment of specific symptoms such as a dry mouth
expectation of their probable needs so that immediate response can be made when the time comes As the patient becomes less aware, it is the relatives and the nursing staff who become the patient’s advocate. At this point a clear plan of goals needs to be agreed between the doctors, nurses and family members.
the potentially sedative side effects of analgesia needs to be explained
the use of alternative routes of medication need to be discussed, as the oral route may be more difficult
the treatment plan should define clearly what should be done in the event of a symptom breakthrough

**Routes for Medicine in the Terminal Phase**
The intramuscular route for injections should be avoided as it is painful. If buccal medicines are given, it is important that the mouth is kept moist. The rectal route can be very useful for certain patients, though it is more or less accepted by different cultures. Transdermal fentanyl patches should be avoided in the terminal stage unless they have been used before this time since it takes too long to titrate against a patient’s pain. If available, a syringe driver, containing morphine and other drugs are used so that adjustments can be made more finely in accord with the patient’s changing state.

**Review of medication**
At this stage comfort is the priority. Unnecessary medication should be stopped but analgesics, antiemetics, anxiolytics/ antipsychotics and anticonvulsants will need to be continued. Diabetes can be managed with a short acting insulin as needed. If the patient is unable to swallow essential medicines, an alternative route of administration is necessary. These changes needs to be explained to relatives who may become anxious that tablets which the patient has had to take for years have now suddenly stopped.
COMMON SYMPTOMS IN LAST 48 HOURS

- Noisy, moist breathing See below
- Urinary dysfunction See below
- Pain Refer to Section 1
- Restlessness / Agitation See below
- Breathlessness Refer to Section 3,4
- Nausea /Vomiting Refer to Section 3

NOISY, MOIST BREATHING (DEATH RATTLE)
This is very distressing to relatives and should be treated prophylactically as it is easier to prevent secretions forming than removing secretions that have gathered in the upper airways or oropharynx. Patients themselves are rarely distressed by noisy secretions and it is helpful for the family to know this; equally, The family should be told that the patient is not choking. Despite re-positioning the patient, and using all available medication, some patients will continue to have noisy breathing

Management:
General measures include re-positioning the patient and giving reassurance to the relatives. It is rarely if ever necessary to use suction, which can be traumatic. Glycopyrronium bromide 0.6-1.2mg/24h subcutaneously Hyoscine butylbromide 20mg-60mg/24h subcutaneously This is well tolerated and non-sedative. Suction is rarely done as it can be traumatic

URINARY DYSFUNCTION
As patients become weaker their ability to pass urine normally is affected by weakness and tiredness. Some patients will prefer to have catheter while for others the thought of a catheter or pads is very undignified. Patient’s wishes need to be taken into account. However in the situation when a patient becomes unconscious it is important to ensure bladder care is part of the overall patient care plan. If not, a patient may become distressed because their bladder is distended or they may develop skin problems from incontinence. If such patients are managed at home, the family members need to be given clear instructions on how to handle these sensitive issues. They can be easily taught how to manage an indwelling catheter at home as well as the use of pads.

RESTLESSNESS / AGITATION IN THE TERMINAL PHASE
Eliminate all possible reversible causes with particular attention to pain and discomfort from a full bladder or rectum. If it is necessary to consider sedation, this should be discussed with the patient and family. The following drugs may be useful:

- midazolam 10-100mg/24hours SC
- phenobarbital 200-600mg/24 hours SC

When oral administration is no longer possible
In most of the patients oral administration of drugs for symptom management can be maintained till the end of life. However in some patients this will not be possible and the health professionals must devise a plan for prescribing by another route.

INDICATIONS FOR SWITCHING FROM ORAL ROUTE:
1. Intractable vomiting
2. Severe dysphagia
3. Patient too weak to swallow oral drugs
4. Decreased conscious level
5. Poor alimentary absorption (rare)
The common routes practised in India for patients at home include:
Subcutaneous Injections
Placing a subcutaneous needle to allow for intermittent bolus injections
Nasogastric Tube

The common routes practised in India for patients in hospital include:
In addition to above measures, Continuous Sub Cutaneous Infusions (CSCI) via syringe drivers, intravenous injections In patients with upper gastrointestinal obstruction, feeding gastrostomy/jejunostomy can be one, but this is much less preferred option. The use of subcutaneous butterfly needles has had a major impact in allowing patients to receive injectable medication at home. These needles can be kept in situ for up to one week and can provide a route for injection which can be used by members of the family who have been trained.

SYRINGE DRIVERS
Experience in the use of syringe drivers has been limited in India and tends to be confined to specialist in-patient units.

PRACTICAL ISSUES
“Do we need to ask his son to come back from Gulf?”
Since the opportunities for meaningful communication diminish as the patient approaches death, families, expressing a wish to be present at the time of death should be advised to visit as soon as you detect a deterioration.

“Do we need to have one of the male members of the family staying all the time?” (If the patient is hospitalized)
It is hard to predict accurately but it is important to be aware of the signs of imminent death to be able to advise the family of a serious deterioration.

- Extremities become cold
- Nails and lips may develop bluish tinge.
- Pulse may become thready and difficult to feel.
- Breathing pattern will change, with long gaps between breaths
- Eye balls become sunken and lose their luster

“I think it is finished, please can you come and check?”
When you are sure the breathing has stopped, and there is no heart sounds after auscultating for 30 seconds, and there is no carotid pulse tell the family clearly. It is important to use explicit language

“Gopal has died”
It is also very important at this point not to leave the room immediately but to spend a few minutes, even in silence, acknowledging the family’s loss, and if necessary offering practical support as the family prepare for the funeral.

Books
CARE PATHWAY FOR DYING
Adapted from Liverpool Care Pathway

Template:
Instruction for use

- Goals are in bold and suggestions are in italics
- Intended as guide only, you should always use your clinical judgement, but if you record ‘No’ anywhere, it should be recorded at the back as a variance’

Criteria for putting patients on the LCP:
- All reversible causes have been considered for current condition
- Team agrees that the patient is dying
- Two of the following apply:

Patient is:
- [ ] Semi-comatose
- [ ] Unable to take tablets
- [ ] Bed-bound
- [ ] Only able to take sips of fluids

Staff involved in care

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Signature</th>
<th>Date</th>
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</tbody>
</table>
1. Initial Assessment

<table>
<thead>
<tr>
<th>Name:</th>
<th>Age:</th>
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<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Sex: Male</th>
<th>Female</th>
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Review of main symptoms

<table>
<thead>
<tr>
<th>Pain</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resp. Tract secretions</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dyspnoea</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conscious</td>
<td>Y</td>
<td>N</td>
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<table>
<thead>
<tr>
<th>Nausea</th>
<th>Y</th>
<th>N</th>
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<tbody>
<tr>
<td>Oriented</td>
<td>Y</td>
<td>N</td>
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<table>
<thead>
<tr>
<th>Vomiting</th>
<th>Y</th>
<th>N</th>
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<tbody>
<tr>
<td>Confused</td>
<td>Y</td>
<td>N</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Bowel problems</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary problems</td>
<td>Y</td>
<td>N</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Restlessness</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catheterised</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problems with oral intake</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insomnia</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

| Other.................. | Y | N |

[If you chart No, please fill in the reason in the Variance sheet at the back]

### Goal

<table>
<thead>
<tr>
<th>1. Medication reviewed and non-essentials stopped</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider changing to s/c route if appropriate</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>2. Stop unnecessary interventions</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood tests</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>IVs</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>Oxygen</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>NG feeding</td>
<td>N</td>
<td>N/A</td>
</tr>
</tbody>
</table>

As appropriate following discussions with family

Not for cardiopulmonary resuscitation

Signature: Date:

<table>
<thead>
<tr>
<th>3a Stop unnecessary nursing interventions</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vital signs</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>Turning regimens</td>
<td>N</td>
<td>N/A</td>
</tr>
<tr>
<td>Lymphoedema care</td>
<td>N</td>
<td>N/A</td>
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</table>

<table>
<thead>
<tr>
<th>3b Syringe driver set up within 4 hours of doctors order</th>
<th>Y</th>
<th>N</th>
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<tbody>
<tr>
<td></td>
<td>N</td>
<td>N/A</td>
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</tbody>
</table>
4. Ability to communicate in XXX language
   i) Patient
   ii) Family
   (C= Comatose)
   | Y | N | C | Y | N |

5. Insight into condition assessed
   - Aware of diagnosis
     i) Patient
     ii) Family
   - Recognition of dying
     i) Patient
     ii) Family
   - Coping with present situation
     i) Patient
     ii) Family
   | Y | N | C | Y | N |

6. Religious / spiritual needs assessed
   i) Patient
   ii) Family
   | Y | N | C | Y | N |

7. Family details
   Name and address checked
   | Y | N |

8a Family given orientation to hospice
   | Y | N |

8b Family involved in care discussed
   | Y | N |

9. XXX (eg. Link Centre) informed of patient’s admission
   | Y | N |

10. Plan of care explained and discussed with:
    i) Patient
    ii) Family
    | Y | N |

11. Family understand plan of care
    | Y | N |

Signature
Doctor........................................... Nurse.................................
Date........................................... Date.................................
2. Ongoing Assessment

4th Hourly

<table>
<thead>
<tr>
<th>Goal</th>
<th>6am</th>
<th>10am</th>
<th>2pm</th>
<th>6pm</th>
<th>10pm</th>
<th>2am</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient is pain free</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Patient is not restless</td>
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<tr>
<td>Respiratory tract secretions are not a problem</td>
<td></td>
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<tr>
<td>Patient is not nauseated or vomiting</td>
<td></td>
<td></td>
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<tr>
<td>Patient does not appear breathless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth is moist and clean</td>
<td></td>
<td></td>
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<tr>
<td>No urinary problems</td>
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<tr>
<td>Medication given as prescribed</td>
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12th Hourly

<table>
<thead>
<tr>
<th>Goal</th>
<th>10 am</th>
<th>10 pm</th>
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<tbody>
<tr>
<td>Position comfortable for patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consider mattress for pressure area care</td>
<td></td>
<td></td>
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<tr>
<td>No bowel problems</td>
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<td></td>
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<tr>
<td>Appropriate psychological and social support</td>
<td></td>
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<tr>
<td>given to:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) Patient</td>
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<td></td>
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<tr>
<td>ii) Family</td>
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<td></td>
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<tr>
<td>Appropriate religious and spiritual support</td>
<td></td>
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<td>given to:</td>
<td></td>
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</tr>
<tr>
<td>i) Patient</td>
<td></td>
<td></td>
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<tr>
<td>ii) Family</td>
<td></td>
<td></td>
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<tr>
<td>Needs of the family addressed</td>
<td></td>
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</tr>
<tr>
<td>Family happy with level of involvement in care</td>
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<tr>
<td>Aware of patient’s condition</td>
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Signature

Day............................................. Night......................................
### Notes

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#### 3. After Death Care

**Confirmation of death**

Date of death:  
Team of death:  
Notes:  

Signature:  
Position:  

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<tr>
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<tbody>
<tr>
<td>12</td>
<td>XXX (eg. Link Centre) informed of patient’s death</td>
</tr>
<tr>
<td>13</td>
<td>Body laid out as appropriate</td>
</tr>
<tr>
<td>14</td>
<td>Procedures after death</td>
</tr>
<tr>
<td>15</td>
<td>Care of the family</td>
</tr>
<tr>
<td>16</td>
<td>Return of meditation or borrowed items</td>
</tr>
<tr>
<td>17</td>
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National Workshop to finalize a uniform course in Palliative Care  
10th & 11th February 2009, Jawaharlal Nehru University, New Delhi  
Supported by World Health Organization
### Variance Analysis

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**Signature**

Doctor............................... Nurse.................................

Date.................................. Date.....................................

N/A
TISSUE DONATION
The subject of tissue donation should be discussed with the patient and family much in advance, if possible. The regulations and possibilities for donation of organs will vary from state to state and according to the proximity to transplant centres. In India, usually such individuals who had decided for tissue donation might have registered their names. Otherwise the family, after death of the patient may express the wish gives consent for tissue donation.

THE TRANSPLANTATION OF HUMAN ORGANS ACT, 1994 ACT NO. 42 OF.- (1) Any donor may, in such manner and subject to such conditions as may be prescribed, authorise the removal, before his death, of any human organ of his body for therapeutic purposes. (2) If any donor had, in writing and in the presence of two or more witnesses (at least one of whom is a near relative of such person), unequivocally authorised at any time before his death, the removal of any human organ of his body, after his death, for therapeutic purposes, the person lawfully in possession of the dead body of the donor shall, unless he has any reason to believe that the donor had subsequently revoked the authority aforesaid, grant to a registered medical practitioner all reasonable facilities for the removal, for therapeutic purposes, of that human organ from the dead body of the donor.

Donor Criteria For Non-Heart-Beating Donor
There are few absolute contra-indications to tissue donation. Patients with untreated systemic infection, HIV (or high risk factor for HIV), Hepatitis B or C, Alzheimer’s disease, diseases of unknown aetiology, Motor Neuron disease cannot be considered. Blood is taken from potential donors (after death) for HIV and Hepatitis B and C testing. Relatives must be informed of this.

DEATH CERTIFICATION
All patients dying in hospital need to have a death certificate issued from the local self government office closest to the hospital. This can only be done after a ‘death report’ has been filled in by the duty doctor. The ‘death report’ should be filled in as early as possible to avoid further distress to the relatives. Clear statements of the disease process should be given in the report to avoid ambiguity Abbreviations should not be used. If the patient dies at home it is the family’s responsibility to inform the local government office.

BEREAVEMENT
Grief is a normal reaction to death (bereavement) or other major loss. Its manifestations will vary from person to person but will often include physical, cognitive, behavioural and emotional elements. For a close personal bereavement, grief is likely to continue for a long time may recur in a modified form, stimulated by anniversaries, future losses or other reminders. People are likely to be changed by the experience of grieving but most in time find that they are able to function well and enjoy life again.

Ways Of Helping A Bereaved Person
• Being there for them
• Non-judgemental listening, encouraging them to talk about the deceased, giving permission for the expression of feelings, offering reassurance about the normality of feelings and experiences
• Providing information, when requested, about the illness and death of their loved ones and also about the range of grief responses
• Educating others (family members and other support networks) about how best to help the bereaved person
• Becoming familiar with your own feelings about loss and grief
Normal Manifestations of Grief

Physical Manifestations. Symptoms experienced by a bereaved person may include “hollowness” in the stomach, tightness in the chest or throat, over sensitivity to noise, feeling shortness of breath, weakness in the muscles, lack of energy, dry mouth and a sense of depersonalisation. These are usually quite normal but if there is doubt, a medical opinion should be sought.

Emotional Manifestations. For many, sense of shock and numbness is the initial emotional response to bereavement. Feelings of anger (directed at family, friends, medical staff, God, the deceased or no one in particular) and feelings of guilt (real or imagined) are common, as is a desire for the return of the deceased. Anxiety and a sense of helplessness and disorganisation are also normal responses. Sadness is the most commonly recognised manifestation of grief, but the great depths of sadness, something similar to depression, is often not reached. Feelings of relief and freedom may also be present, although people may then feel guilty for having these feelings.

Cognitive Manifestations. Disbelief and a sense of unreality are frequently present early in a bereavement. For a while elements of denial may be present which also be present. The bereaved may be preoccupied with thoughts about the deceased. It is also common for people to have a sense (visual, auditory etc.) of the presence of the deceased. Short term memory, the ability to concentrate and sense of purpose are frequently detrimentally affected by a bereavement.

Behavioural Manifestations. Appetite and sleep may be disturbed following a bereavement and dreams involving the deceased, with their emotional impact for the bereaved, are not infrequent. The bereaved person may withdraw socially, avoid reminders of the deceased or act in an absent-minded way; they may also engage in restless over-activity, or visit places or carry objects which remind them of the deceased. Some people contemplate rapid and radical changes in their lifestyle (e.g. anew relationship/job transfer), which may represent a way of avoiding the pain of bereavement. Such rapid changes soon after a bereavement are not normally advisable.

Grief Pathway

Various models have been developed to help us understand people’s experiences of grief. Some writers have described stages or phases of grief through which bereaved people pass:

Kubler-Ross (1970) - shock/denial, anger, bargaining, depression, acceptance. (Formulated from her work with dying people, but often applied to grief.)


Worden (1991) - refers to ‘tasks’ of mourning:

Task 1 - To accept the reality of the loss
Task 2 - To experience the pain of grief
Task 3 - To adjust to an environment in which the deceased is missing
Task 4 - To emotionally relocate the deceased and move on with life

Stroebe (1992) - in her dual process model of coping with grief suggested that bereaved people tend to oscillate between ‘loss oriented experiences’ and ‘restoration oriented activity’

Factors making grief more difficult include:

Interpersonal: relationship with was ambivalent or dependant
Circumstantial: “bad death”, sudden death, absent at the time of death
Historical: previous unresolved losses and history of depression
Personality: limited ability to tolerate emotional stress; self image as being a ‘strong coper’
Lack of social support
and that both are necessary to allow adaptation to continued life without the deceased.

Walters (1996) and Klass et al (1996) have explored continuing bonds for the bereaved person, emphasising the importance of incorporating the memory of the dead into their ongoing lives, recognising the enduring influence of the deceased.

Factors which may affect the grieving process
Each person’s grief is individual. Various factors may affect how a person grieves. These include:

- the nature of the death
- the nature of the relationship with the deceased
- family history, including earlier losses
- the temperament of the bereaved individual
- the availability of a supportive network
- subsequent problems following the death
- social, cultural and religious framework

BEREAVED CHILDREN
Children experience emotions and other reactions which are not dissimilar to those experienced by adults. Reactions may include:

- **denial** - the child talking about the dead person as if they are still alive.
- **guilt** - children may feel that something they said or did caused the death.
- **anger** - perhaps directed at peers who have not had a close bereavement, at the surviving parent or at the deceased.
- **anxiety** - that other caregivers also may die or that no one will take care of them.

Physical Complaints, including loss of appetite, nightmares or symptoms which the deceased had previously experienced. Children may need help to understand these reactions and those of others around them, as they have little or no previous experience of death. One feature of the grief of most children is that they do not sustain grief over continuing periods of time, but tend to dip in and out of grief jumping in and out of puddles, rather than wading through the river of grief. Children’s understanding, responses and needs will be affected by many factors including their previous experiences of loss and how these were handled. It is important also to consider the age of the child, although any attempt to consider responses according to age will require flexibility and there is considerable crossover between the ages.

Children under the age of 2-3 years may have little concept of death, but will be aware of separation and may protest against this by detachment or regressive behaviour. Children of this age need a consistent care giver, familiar routines and the meeting of their physical needs.

To help children cope with their grief, adults should consider the following:

**information** - keep children informed about what is happening, answer their questions honestly and in words they can understand. Don’t be afraid to say that you don’t know, and consider offering them the opportunity to talk to somebody who might help.

**involvement** - do not exclude children. Offer them the opportunity to participate, explaining in advance what will be happening (e.g. when viewing the body, at the funeral).
Children aged between 3 and 5 do not see death as irreversible. Their concerns will relate to separation, abandonment and the physical aspects of death and dying. Their response may include aggressive and rejecting behaviour, becoming withdrawn or an increase in clinging or demanding behaviour. There may also be regression to infant needs. Comfort, reassurance and a simple answering of their questions will help a child of this age. Allow them to participate in family rituals and to keep mementoes of the deceased. Be aware of the words you use (e.g. do not associate death with sleep or a long journey).

Children age between 6 and 8 seek causal explanations. A whole range of behaviours may be evidence of their response to grief – withdrawal, sadness, loneliness, depression, acting out behaviour or becoming a ‘perfect’ child. Short, honest, concrete explanations will help a child of this age, as will maintaining contact with friends and normal activities. Allow short term regression and dependence on other adults and reassure the child that they will always be cared for. Involvement in the family’s grief related rituals will also help.

Children in the pre-teenage group appear to have a calmer, more accepting attitude to death. They often have a good factual understanding of what has happened. Encouraging the child to talk about the deceased, providing them with clear and truthful answers to their questions, not hiding your own feelings and providing the child positive reassurance.

Children in the teenage years are engaged in a search for meaning and purpose in life and for identity. They feel that they have deep and powerful emotions that no one else has experienced. Teenagers may exhibit withdrawal, sadness, loneliness and depression, or they may act-out in an angry, hostile and rejecting way. They may seek to cover up fears with joking and sarcasm. Young people of this age need as much support as possible, involvement, boundaries, a sense that their feelings are being taken seriously and reassurance that their feelings are normal. Continuing contact with their peers should be encouraged. Young people may identify someone, with whom they feel comfortable to talk.

General approach

Adults attempt to shield children from death and dying people by telling them little or nothing about what is happening. However, children are never too young to sense when something is wrong from the behaviour of those caring for them. In their own, many children are not able to understand the reality of death and the feelings they are having. They may be confused and feel rejected and abandoned at a time when they most need support, understanding and security. Adults, struggling to cope with their own emotions, may feel inadequate or totally helpless in dealing with grieving children. Children may express themselves physically rather than verbally and tend to grieve in spurts, going through periods of time seemingly unaffected.

BEREAVEMENT BACKGROUND READING

Books


**Articles**
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<td>angiotensin converting enzyme</td>
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<td>acquired immune deficiency syndrome</td>
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<td>b.d.</td>
<td>twice daily</td>
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<td>Equivalent Daily Dose of Morphine</td>
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<td>immediate release</td>
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<td>OTFC</td>
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