African Palliative Care Association

Palliative Care

A Handbook of
Palliative Care in Africa

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FOREWORD

In addition to addressing general HIV care and support needs, palliative care has a strong focus on pain and symptom control. As defined by the World Health Organization (WHO), palliative care is concerned with the assessment and management of pain and symptoms among patients with life limiting illnesses; it includes attention to physical, emotional and spiritual pain. PEPFAR supports the WHO definition of palliative care and has included it as a key component for all PEPFAR supported HIV care and treatment programs for persons and families with HIV disease in low resource settings.

With the huge burden of cancer and HIV disease among other life-limiting illnesses in Africa, there is a clear public health need for palliative care to enhance quality of life for the millions of people affected and to ensure freedom from suffering. The majority of problems can be controlled with adequate clinical knowledge and drug availability. To address the need for knowledge, the PEPFAR Care and Support Technical Working Group funded the African Palliative Care Association in collaboration with AIDSTAR- One to develop a handbook of palliative care.

This handbook, one of a series of books produced APCA, provides quick-reference information on the principles and practices of palliative care. This is with an aim of providing essential knowledge and skills on palliative care for the care and support providers, heads of health teaching institutions, policy makers and others involved in the care of patients with life-threatening illnesses.

The handbook of palliative care in Africa is underpinned by the philosophy of palliative care. Although the book uses internationally recognised principles of palliative care, it is written for an African audience and therefore discusses models of care appropriate for the African setting.

Not only does the book provide a clear rationale for the need for palliative care in Africa to ensure that such care is available to all who need it, but it also acts as an information tool for policy makers and palliative care advocates.

So why is there a need for this book? Unfortunately, palliative care as a concept and discipline is not well understood across Africa, and its development is still embryonic in many countries. Indeed, while there are many challenges that hinder palliative care development on the continent, a key challenge is the lack of knowledge and accurate information around palliative care. This handbook, as well others in the series, aims to address that challenge – although it is not intended to cover everything related to palliative care. The handbook focuses on both adults and children. In every chapter, information relating to children is included in a coloured textbox.

The handbook of palliative care in Africa is a vital tool for caring for people with life-threatening illnesses. Consequently, it is PEPFAR and APCA's sincere hope that this book will be a useful tool for practitioners and health planners who are implementing and planning palliative care services for those patients in need of it.

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CHAPTER 1:
AN INTRODUCTION TO PALLIATIVE CARE

Developing effective symptom control, openness, respect of the patient's own wishes and the needs and care for the family are the cornerstones of palliative care'

(Jay, 2007)

...as for our staff, they repeatedly tell me how grateful they are for palliative care. Before ... they felt helpless in the face of the suffering of their patients. Now they know something can be done.

(Carla Simmons, 2006)

A. General Palliative care principles

- Palliative care is 'an approach which improves the quality of life of patients and families facing the problem of life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.'
- It will enhance quality of life, and may also positively influence the course of illness.
- It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, or antiretroviral/opportunistic Infection (OI) therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO 2002).

Palliative care aims at:

- Providing relief from pain and other distressing symptoms;
- Affirming life and regarding dying as a normal process;
- Intending neither to hasten nor to postpone death;
- Integrating the psychological and spiritual aspects of patient care;
- Offering a support system to help patients live as actively as possible until death;
- Offering a support system to help the family cope during a patient's illness and in their own bereavement;
- Using a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Enhancing quality of life, and sometimes also positively influencing the course of an illness;
- Being applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation or antiretroviral therapy (ART), and being inclusive of those investigations needed to better understand and manage distressing clinical complications;
- Responding to people's beliefs and practices as well as their social and cultural values.
- A balanced approach to care is needed, balancing the benefits of investigation and treatment against the burdens of possible harm – and thus ensuring quality of life. The following questions should be considered:
    - Is there a reasonable chance of benefit to the patient?
    - Will the intervention be likely cause harm to the patient?
    - Is the intervention a proper use of available resources?
    - What are the patient's wishes?
- Respect for patient autonomy and choice is vital.
- There is a need for open and sensitive communication for all concerned.

Hope

- Hope is a dynamic inner power that enables transcendence of the present situation and fosters a positive new awareness of being.
- Hope is an important concept in palliative care, and yet sustaining hope can be a challenge as the focus may have changed (e.g. having a good night's sleep).
- Hope has long been associated with belief.

Dignity

- Dignity is the 'state of being worthy of honour or respect' (*Oxford English Dictionary*).
- Dignity is recognised as a human right.
- Dignity is threatened when there is loss of independence, a fear of becoming a burden, not being involved in decision-making, lack of access to care, spiritual matters and even the attitudes of staff towards the patient.
- Upholding the dignity of patients within a palliative care setting is essential for both the patient and their family.
- Often, patients with a life-threatening illness are vulnerable to a loss of dignity and feel they are no longer respected as the person they once were.
- Some patients may feel that their life has no worth, meaning or purpose.
- The ABCD framework for dignity addresses the aspects of Attitude, Behaviour, Compassion and Dialogue – and provides a framework for upholding, protecting and restoring dignity.

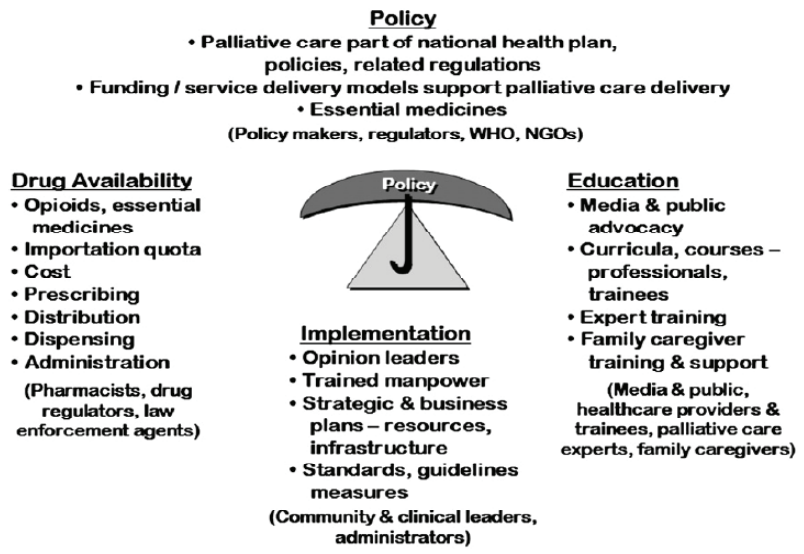
Resilience

- Resilience is about the ability to thrive in the face of adversity and stress: 'The capacity to withstand exceptional stress and demands without developing stress-related problems' (Carr, 2004).
- Strengths exist in everyone, and even people facing the end of their lives can be resilient.
- Resilience allows for psychological, social and spiritual development despite stressful circumstances.
- Resilience can be promoted at different levels – e.g., individual, families and carers, groups, communities, staff teams and organisations.
- Resilience is a dynamic process. It can change over time and is a combination of internal and external characteristics in the individual and their social, cultural and physical environment.

B. The need for palliative care

- The disease burden in Africa is great.
- By 2008 an estimated 22 million people in sub-Saharan Africa were living with the human immunodeficiency virus / acquired immune deficiency syndrome (HIV and AIDS), with 1.9 million new infections reported in that year alone.
- There were an estimated 7.6 million new cancer cases and 6 million cancer-related deaths in Africa in 2007, and these numbers are expected to increase dramatically in the years ahead.
- There is a growing concern that as people's lifestyle, nutritional preferences and non-sedentary work patterns on the continent change, Africa may experience an increase in the incidence of chronic life-limiting diseases.

C. The WHO enhanced Public Health model for palliative care



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- For palliative care to be developed using a public health approach, it must be founded on appropriate policy, drug availability, education and implementation strategies, including implementation at all levels of a nation's health service through an integrated approach to care.

Policy

- Adoption and implementation of appropriate health policies is key to the provision of palliative care.
- Policies may include a national health policy, an essential medicines policy and a palliative care policy.
- Policies need to include providers' roles and responsibilities regarding palliative care, including who can prescribe.

Drug Availability

- Access to palliative care medicines is crucial for ensuring effective pain and symptom management.
- Across Africa, many medicines required for palliative care remain unavailable – e.g. opioids such as morphine, which are critical to the effective relief of moderate to severe pain.
- Barriers to access to medicines include supply, legislation, education and practical issues such as distribution.
- Increasing access involves increasing prescribers, and there is a growing trend towards task shifting across the region.
- An essential medicines list for palliative care is a useful tool for enabling access to medications (See Appendix 1).

Education

- Palliative care education should target diverse audiences (e.g. policy makers, healthcare workers, non-professional health workers and the general public) to increase their awareness, skills and knowledge of, and to change their attitudes to, the discipline.
- Palliative care training needs to be ongoing. It should be provided during initial pre-registration training as well as during in-service and postgraduate training programmes, and tailored to the roles and responsibilities of different cadres of staff.
- As palliative care is relatively new across the African region, education and training is vital.

Implementation

- Without effective implementation, the other components of the enhanced WHO public health model are redundant.
- It is therefore important that African governments and donors ensure that there are sufficient funding and appropriate service-delivery models in place to support the expansion of palliative care in their respective countries.

D. The provision of palliative care

Models of care

- Palliative care can be provided across a range of care settings and models, e.g.:
  - Home based care
  - Facility-based care
  - Outpatient care
  - Inpatient care
  - Day care
  - Roadside clinics
- It can be provided in specialist as well as general settings and should be integrated into existing health structures.
- In generalist settings such as clinics, consider triaging services where palliative care patients are identified as higher priority and referred to the palliative care team where it exists or for faster access to services.
- The concept should be adapted to reflect unique local traditions, beliefs and cultures as long as they are not counter-productive to proven palliative care approaches. In such situations ethical principles should be applied to the interest of the patient.
- Palliative care should be provided by a multi-disciplinary team of caregivers, which may include nurses, doctors, social workers, community workers, traditional healers and others as appropriate.
- Trained community health workers and volunteers have a vital role to play in the provision of palliative care in the home care setting under the supervision of health professionals.
- Continuity of care across the different settings is important; therefore good referral systems must be put in place.
- End-of-life care is an important part of palliative care and usually refers to the management of individuals during their last few days, weeks or months of life.

Assessment

- Assessment is the process of gathering information to help guide patient care.
- A thorough initial assessment before starting palliative care interventions, as well as regular follow-up, is key to ensuring adequate relief of symptoms and distress and that the correct treatment is given.
- Assessment requires the health professional to listen well, ask relevant questions and be able to assimilate the information received.
- The patient is at the centre of the assessment, but it should involve the family and other caregivers as well.
- It is important to try to assess the cause of any pain or symptoms so that, where possible, the underlying cause can be treated i.e., treat the cause as well as manage the symptoms.

Palliative care for children

- Palliative care for children requires particular attention and sensitivity to the developmental stage of the child involved.
- Children often understand more about their illness than we acknowledge, and it is important to answer questions openly and honestly.
- The management of physical symptoms in children's palliative care has a lot in common with adults; however, there are differences in choice of medicines and the dosage given.
- It is important that children and their parents are supported with compassion and understanding combined with expert symptom assessment and management.
- Sometimes a child's wishes may differ from that of their adult carers, and special effort needs to be made to try to understand the needs and wishes of them all.
- More information can be found on palliative care in children in Chapter 6.

E. Special considerations related to HIV and AIDS

- Palliative care should be an integral part of the comprehensive care for people living with HIV and AIDS from the time of diagnosis.
- HIV and AIDS is complex clinical because of the course of the illness is unpredictable and the presentation is variable.
- Prevention and treatment of opportunistic infections (OIs) are key components of palliative care.
- Many patients with HIV and AIDS also have cancer.
- Antiretrovirals (ARVs) do not cure HIV but delay its natural progression. However, numerous pills, food restrictions, side effects, toxicities, drug-to-drug interactions and complex regimens affect quality of life.
- Many people in the African region do not have access to ARVs, and some of those who do will not respond well or will not adhere to the strict regimens required.
- The emotional, social and economic impact of the illness is substantial, with the challenges of fear, stigma, rejection, repeated bereavement and conflicting messages all of possible significance for an individual.
- Often, many people in the family will be infected and parents may be being cared for by young children, and in child-headed households, the children will be caring for other children. Both of these situations pose a challenge to the provision of care.
- As in other areas of palliative care, promoting quality of life is the focus, with excellent symptom control, effective communication and appropriate support for the patient and their family. However, fear and stigma can make this a challenge.

E. Be aware ...

- Palliative care should be available for all those with a life-threatening illness.
- Disease-modifying treatments can be offered together with palliative care appropriate to the needs of the patient.
- ART does not replace palliative care but is a vital part of palliative care.
- Care for people with HIV and AIDS must involve improving access to ART as well as access to palliative care.
- Palliative care is a relatively new field in some parts of Africa and so many health workers will not have received palliative care training.

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CHAPTER 2: ETHICS

Ethical issues in Palliative Care centre on decisions that ensure that our care will be guided by moral values that will enable us to satisfy the criteria for a peaceful and dignified death.

(Bruera et al. 2004)

A. Ethics principles

- Ethical principles in palliative care centre around autonomy, beneficence, non-maleficence and justice.
- However, these principles are sterile if they are not applied within a compassionate environment by wise, charitable and moral practitioners.
- What is particularly needed is the virtue of prudence, understood as 'practical wisdom'. Prudence plays a key role in disclosing the way in which the different classical ethical principles should be applied in individual situations.

B. The ethical framework for palliative care

Autonomy

- Autonomy is about the respect for a person's right to make decisions concerning their care. Autonomy promotes the development of a trusting relationship between a healthcare worker and a patient.
- It also means the patient becomes an active member of the management team, which restores a sense of control in the face of an illness that has deprived that person of control.
- In order to give due attention to this principle, several matters are involved, and these are set out next.

Communication

- The patient has a right to know about the diagnosis, the treatment that is proposed, its effects and any side effects.
- It is the responsibility of the healthcare worker to ensure that the patient is fully informed.
- This will involve an assessment by the healthcare worker both of the patient's understanding and of how much the patient wants to know.
- Failure to communicate honestly with the patient can isolate the patient, preventing a therapeutic sharing of the patient's fears, anxieties and other concerns.

Consent

- Once the patient is given sufficient information, they have the prerogative to accept or not accept the care or treatment offered.

Confidentiality

- Confidentiality protects the autonomy of the patient by allowing them to control information about themselves.

Privacy

- Central to a respect for personal autonomy is the concept that the privacy of the individual must be respected.

Beneficence

- To 'do good', health professionals should reflect on patient care decisions with this question in mind: 'Will this treatment benefit the patient?' This requires considering risks versus benefits and deciding whether the benefits outweigh the risks.
- Often, families will not want a patient to know their diagnosis, or perhaps want the patient cared for in hospital rather than at home. The healthcare worker needs to be familiar with both the patient and their situation in order to make a good assessment and so guide the patient and family.
- Knowing the patient's wishes is essential in deciding what will benefit them.
- The patients need truthful information from the health professional in order to make their own decisions.
- Although palliative care is concerned with the care of both the patient and the family, the healthcare worker must be careful not to subordinate the interest of the patients to the anxieties of relatives.
- It is often the case that family members want 'everything' done for their patient, not appreciating that, in fact, prolonging the patient's life with artificial hydration or other measures only acts to prolong their suffering.
- Families need to be informed about the consequences of different treatments and they also need to be encouraged to listen to what the patient wants.
- Palliative care is neither about shortening life nor prolonging the dying period.
- It is of greatest importance that the health professional establish, with the patient and the patient's family, the clinical goals at which they are aiming. One patient may desire only to die comfortably without pain, while another may want to live long enough to witness a particular event, a wedding, a birth etc. These different goals help the health worker to determine what is the best treatment decision to make in the case of each patient.

- In the case of a child patient, especially an older child, opinions and concerns are often not sought. This increases the child's pain.
- The child can be left to feel responsible for their illness and even for their parents' suffering.
- It is most important for the health professional to include the child in communications with the family about the illness and in decision-making.
- Parents are presumed to have the ability to make decisions regarding a child's 'best interests'.
- In general, the best interests of a child are presumed to be life preserving, but in the face of irreversible illness, this presumption requires careful exploration. 'Best interests' may require a plan that focuses on the child's need for comfort and symptom relief to ease the process of dying in a way that promotes the safety, comfort and dignity of the child.

Non-maleficence

- To 'do no harm', a health worker needs to have adequate education and knowledge to ensure that the treatment they offer will not harm or endanger a patient.
- In practice, many treatments carry some risk of harm and it is up to the health worker to weigh the risks versus the benefits.
- The principle of non-maleficence is not absolute, and must be balanced against the principle of beneficence (doing good – see above).
- In essence, the intended effect of treatment must be a good one. For instance:
  - Pain relief with opioids can possibly hasten death, but this is not the intention when prescribed. The intention is the relief of pain.
  - Artificial hydration at the end of life may appear to families to be good for a patient who is no longer taking oral fluids, whereas in fact it can cause great distress since the patient's body can no longer cope with these fluids.
- The principle of 'double effect' forbids the achievement of good ends by wrong means. It forbids doctors to relieve the distress of a dying patient by killing them, but it permits the use of drugs which relieve the distress of dying even when they may hasten death.

Justice

- Justice is concerned with the correct use of resources, and this is particularly pertinent when working in resource-poor settings such as in many areas of Africa.
- It is the principle by which competing claims may be decided in fairness and is concerned with fair distribution of resources. Here are two examples:
  - If a family has very limited resources, should the terminal patient be prescribed expensive treatment that will cause financial hardship for the rest of the family? In the days before antiretrovirals became free or more affordable, individuals sometimes sold all the families property to buy drugs for a limited period. The family was eventually left impoverished.
  - Should patients with terminal cancer being started on ART? This is often seen with HIV-positive women being started on ART when they have advanced cancer of the cervix. In places where ARVs are scarce, this is a case where drugs would be better used for patients who have a longer prognosis. This is also an example of futile treatment: ART is not going to have any curative effect on the cancer and in fact may prolong the woman's suffering without just cause.
- Prolonging the dying process may be justifiable if the patient and the family need that extra time to achieve important personal goals. However, the availability of medical technologies is not of itself an ethical command that these technologies be used.

C. Special considerations in HIV and AIDS

- Many ethical issues are particularly important in relation to patients with HIV or AIDS, such as the right to confidentiality about HIV status, the concerns of the public and the fears of the health professionals.
- Disclosure of a person's HIV status, even to another health professional, must be on a legitimate 'need to know' basis.

D. Be aware ...

- Ethics in palliative care is a matter of practical reasoning about individual patients, specific cases and unique situations.
- What may be ethical in one case may be unethical in another.
- A health professional at the bedside must understand the clinical situation in all its subtle medical and human complexity.
- The fundamental moral attitudes orienting the contemporary practice of palliative care are an unconditional respect for the dignity of each person and the acceptance of finitude.

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CHAPTER 3: COMMUNICATION IN PALLIATIVE CARE

Effective communication between care providers, patients and their families is very essential in palliative care. Identification and management of symptoms, physical and psychological, hinge on interaction.

(Holland and Chertkov, 2004)

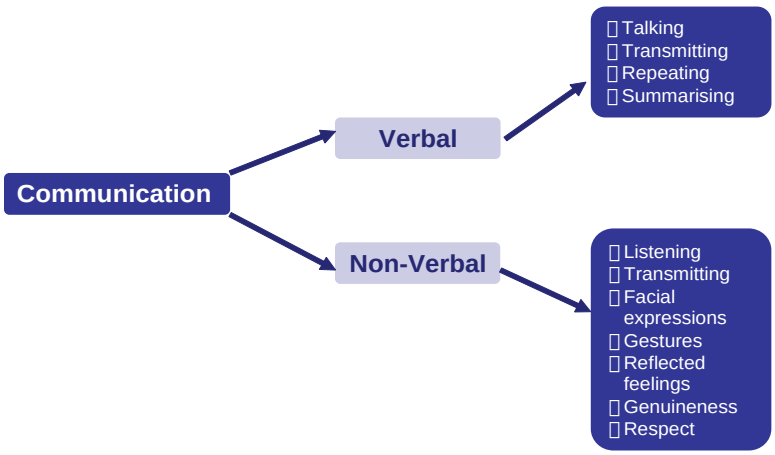
A. Communication principles related to palliative care

- *Effective communication:*
  - Identifies and aims to address all the needs of the patient, family and care provider (i.e. psychological, spiritual, social, cultural and physical issues);
  - Provides information according to the patient's preferences (whether good or bad news);
  - Invites the patient to share their agenda in a conversation;
  - Aims to communicate the truth by means of accurate essential information;
  - Facilitates appropriate referrals, inter-disciplinary assessment, continuity of care, discharge planning, end-of-life care and bereavement support, as well as conflict resolution and stress management;
  - Advises on the resources available to address holistic needs and concerns;
  - Provides patients with a sense of security, consistency and comfort;
  - Educates family members and care providers on how to manage pain, distress and other symptoms in the patient and how to communicate effectively;
  - Aims to improve relationships at all levels, including those involving family members, care providers and the community;
  - Documents as appropriate the main discussions with the patient, family and other care providers;
  - Ensures a good flow of information within and between organisations involved in service delivery;

- Uses an honest and open approach as the basis of all communication with a child and their family;
- Enables parents to be central to a child's well-being; and, where possible, they, or a designated carer, are present and involved in all aspects of the child's care, guided by the age and wishes of the child;
- Provides information to a child and their family about the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.

B. Types of communication

- *Communication* (as a generic process) is a two-way process between two or more persons in which ideas, feelings and information are shared, with the ultimate aim of reducing uncertainties and clarifying issues. Communication only becomes complete when there is feedback.
- *Verbal communication* is the exchange of ideas through spoken expression in words. It is a medium for communication that can entail using the spoken word, such as talking face-to-face, on a telephone, or through a formal speech; similar communication can occur through writing.
- *Non-verbal communication* involves the expression of ideas, thoughts or feelings without the spoken or written word. This is generally expressed in the form of body language that includes gestures and facial expressions and, where appropriate, touch.
- *Both verbal and non-verbal* communication is important in palliative care.



C. Key aspects that should be targeted by communication in palliative care

These cover:

- All aspects which make an individual complete, i.e. psychological, spiritual, social, cultural and physical aspects;
- Prognosis and goals of care, as these are essential for quality care;
- Disclosure, diagnosis, prognosis, transition to palliative care and the holistic care plan;
- A patient's fears and concerns;
- Disease progression and end-of-life care issues, such as the use of aggressive treatments in the end-of-life stage, decisions on readmission, review of medications, family rituals and the family's role;
- Patient and family styles and practices for coping with grief, loss and bereavement, and the support required from care providers;
- Discussions about the future, as this is vital if patients are to be permitted the dignity of deciding how to spend their remaining time

- The beliefs and values of a child patient and their family regarding death and dying, and assistance to prepare and plan for death by discussing expectations in order to reduce fear and encourage involvement;
- End-of-life issues and the anticipation of the death of a child patient, each being honestly discussed with the child and their family.
- Give the child the opportunity to say goodbye and express last feelings and wishes.
- Bereavement counselling and support for children.

D. Principles to help care providers communicate effectively

- Communicate with sensitivity, empathy, compassion and support to the patient and family.
- Listen attentively and allow tears and emotions to be expressed without rushing the patient.
- Check for understanding, because miscommunication is common as a result of language, culture, the environment and stress.
- Take into account the family and its ethnic, cultural and religious roots.
- Family meetings are useful for identifying and meeting the patient's and the family's informational and care needs, as well as for understanding the family's dynamics.
- Debriefing is available for caregivers who need support following the death of a patient whom they have been caring for.
- Pay attention to the patient, family members and fellow care providers.
- Be aware of the importance of non-verbal communication such as facial expressions.
- Use clear and suitable language (i.e. that which is understood by the patient), and use an interpreter where necessary.
- Ask appropriate questions and allow the patient and family to ask questions each time you see them.
- Ensure that the patient and family have understood what you are saying, and that you have understood what they are saying, by asking questions, paraphrasing, summarising etc.
- It is easy to unintentionally miscommunicate and not understand others, due to common physical, psychological and socio-cultural barriers such as language, culture, stress, environment etc. Care providers must identify and address any such barriers for effective communication to happen.

Basic communication skills

- *Active listening*: this can be defined as hearing with interest and attention, and understanding verbal and non-verbal messages that patients and their families are communicating. The indicators of attention are summarised as "ROLES":
  - Relax
  - Openness
  - Lean forward
  - Eye contact
  - Sit near (comfortably near).

Table 1: Reflection on listening

You are not listening to me when ...	You are listening to me when ...
· You do not care about me. · You say you understand before you know me well enough. · You have an answer for my problem before I have finished telling you what my problem is. · You cut me off before I have finished speaking. · You finish my sentence for me. · You feel critical of my vocabulary, grammar, or accent. · You are very eager to tell me about something. · You tell me about your experience, making mine seem unimportant. · You are communicating to someone else in the room. · You refuse my thanks by saying you have not really done anything.	· You come quietly into my private world and let me be. · You really try to understand me even if I am not making much sense. · You grasp my point of view even when it is against your own sincere convictions. · You realise that the hour I took from you has left you a bit tired and drained. · You allow me the dignity of making my own decisions, even though you think they might be wrong. · You do not take my problem from me, but allow me to deal with it in my own way. · You hold back your desire to give me good advice. · You do not offer me religious solace when you sense I am not ready for it. · You give me enough room to discover for myself what is really going on. · You accept my gift of gratitude by telling me how good it makes you feel to know you have been helpful.

(Source: Hospice Palliative Care Association of South Africa, 2005)

- *Check understanding* through paraphrasing and summarising the patient's story, and identifying and reflecting the person's feelings and emotions from the story.
- *Ask questions:* focus on questions that are purposeful to the patient and the care provider. They should aim to:
  - Get information
  - Assess knowledge
  - Direct and focus decisions
  - Get a deeper understanding of the person's problem
  - Prioritise issues
  - Set the pace of the dialogue with the person seeking assistance
  - Show that the care provider is trying to understand the person and the problem better.
- Use mainly *open-ended questions*, i.e. those that are thought provoking, that invite a person to talk and explain a situation, and that offer the opportunity for a variety of responses. Such questions might be 'What makes you feel bad?' 'How did you feel when you were diagnosed with cancer?' or 'What worries you the most?'
- You can use some *closed-ended questions* if necessary: these are brief and restricting and are used to obtain facts rather than knowledge of feelings – for instance, 'Does this part of your body hurt?'
- Avoid *leading questions*: these suggest a preferred answer or desired response – e.g., 'You must be feeling a lot of pain, mustn't you?'
- When answering questions:
  - Understand that behind every question is a story; therefore be honest and give accurate answers
  - Give correct information
  - Provide clear and simple information
  - Check for understanding or misunderstanding
  - Respect and reinforce important information.
- Use positive attitudes:
  - *Non-judgmental*: treat people as they are, with respect and dignity, and avoid condemning or criticising them.
  - *Confidential:* the care provider should not reveal any information that they get from their patient unless consent is obtained from the patient. Every patient has a right to confidentiality and should feel secure as they communicate.
  - *Empathetic:* put yourself 'in the patient's shoes' by understanding and accepting their situation.
  - *Caring:* this means giving attention or being concerned about someone's well-being. We show care by being approachable, welcoming, showing interest, etc. It entails making the patient feel at home and responding with interest to what they are saying.

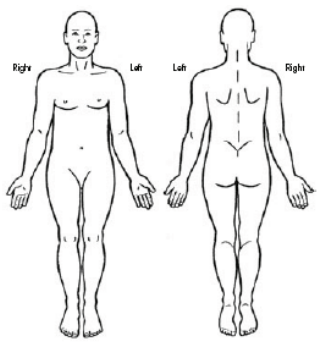
E. Breaking bad news

- Use language and media that children understand according to their age – e.g., drawing, pictures, music, dance and drama, or stories.

- The following steps to breaking bad news about an illness are helpful:
  - Prepare well. Know all the facts before meeting the patient/family.
  - Review how much the patient already knows by asking for a summary of events. You can ask, 'Can you bring me up to date me on your illness and how things are now?'
  - Check that the patient/family wants more information and how much more. You can say, 'We have more results now. Would you like me to give you an update on what we know? I will go step by step and you can stop me whenever you want.'
  - Indicate that the information to be given is serious. You can say, 'I am afraid it looks rather serious,' and then allow a pause for the patient to respond.
  - Encourage expression of feelings – this is the **key aspect** in terms of patient satisfaction with a session.
  - Give more information if requested, systematically and in simple language.
  - Listen to concerns and ask questions. You can say, 'what are your main concerns at the moment?' or 'What does this mean to you?'
  - Wind down the session by summarising issues that are raised and plan with the family the next steps.
  - Make yourself available to discuss the illness further, as needed.
- This process can be adapted when breaking news of the death of a loved one.

- When breaking bad news to a child, try to do it in an age-appropriate manner. Never underestimate what a child knows and can understand.

F. The importance of effective communication in palliative care



- Family members often recall in detail the sensitivity (or lack of it) of the doctor and staff as their relative was dying. These memories affect the grieving process: how the family was told about what was being done, how they were informed of the changes in the medical situation, and especially how attentive the doctor and staff were in controlling the patient's distress and physical symptoms.
- Effective communication fosters a very strong relationship between the caregiver and the patient as well as family members.
- Truthful communication about the future is also vital if patients are to be permitted the dignity of deciding how to spend their remaining time.
- Good communication maintains effective professional relationships, which fosters a high standard of care
- Communication is seen as a therapy, which is used to help the patient to either cope with or solve the problem.

G. Possible consequences of ineffective communication in palliative care

- Not communicating accurate essential information to patients may provoke greater problems.
- Protecting patients from the reality of their situation often creates further problems and can lead to inconsistent messages being given by other members of the inter-disciplinary team.
- Hiding the truth often leads to conspiracies of silence that usually build up to a heightened state of fear, anxiety and confusion, rather than provide one of calmness.
- Poor communication is a threat to patient care and can lead both to mistrust and to a source of staff stress.
- Communicating effectively is essential for engaging the patient and their family in their care.
- Not communicating about the nature and seriousness of an illness can lead to a lack of planning for the future – e.g. not writing a will, not planning who will take care of the children.

H. Special considerations in HIV and AIDS

- A diagnosis of HIV presents the affected individual with the prospect of a life-threatening illness along with the stigma associated with the disease.
- There are strong emotions associated with HIV and AIDS which increase anxiety and therefore impact on effective communication – e.g. the fear of rejection by others, the fear of infecting others, anger and a sense of betrayal, a sense of shame for having contracted the disease, worry about how to cope, worry about the family.
- Disclosure of their status is an important topic to explore with patients – they may be trying to maintain a position of respect with their children, or be afraid of being abandoned if the family finds out their status.
- Adherence to the specified drug regimen is key to the success of ART, and good provider–patient communication is key to adherence.
- Communication issues that are key to successful adherence include:
    - Proper education and counselling before initiation of ART
    - Information on HIV and its manifestations, benefits and side effects
    - Involvement of peer support in the patient's treatment
    - Psychosocial support to minimise stigma
    - Culturally appropriate adherence programmes.
- Support groups across the African region have proved to be successful in providing emotional and peer support, and in helping individuals to cope with HIV and AIDS.

- Disclosure is a particular challenge with children and adolescents, with their carers often not wanting them to know their diagnosis.
- Adherence in children, particularly if they are not aware of their illness, can be a challenge.

I. Be Aware ...

- Most attempts by service providers to protect patients from the reality of their situation create further problems for patients, their relatives, and their friends.
- Realistic hopes and aspirations can only be generated from honest disclosure.
- The extent to which patients and families cope with information relating to illness largely depends on how effectively it is delivered and the relationship created between them and the care provider.
- Considerable suffering is caused by poor communication; much of this is avoidable.

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CHAPTER 4:
MANAGEMENT OF COMMON SYMPTOMS AND CLINICAL PROBLEMS IN PALLIATIVE CARE

Putting life into their days not just days into their lives.

(Ruth Wooldridge)

A. Symptom and clinical management principles

- Managing symptoms is a crucial part of palliative care.
- A general principle of symptom management is to assess, plan, implement, evaluate and include the patient and family throughout the process.
- Good pain and symptom control is an essential component of all palliative care.
- Listen to what the patient and family are saying; both verbal and non-verbal communication is necessary.
- Holistic assessment underpins good symptom control, so excellent history and careful examination are both very important.
- Evaluate the symptom by thinking through the likely aetiology and underlying pathophysiology.
- Avoid unnecessary interventions.
- Formulate a management and treatment plan.
- 'Treat the treatable':
    - Consider radiotherapy and chemotherapy if available.
    - Consider antibiotics for reversible infections.
    - Drain a pleural effusion.
    - Tap ascetic fluid.
    - Clean and dress painful wounds.
- Prescribe essential medications:
    - Keep numbers of medications to a minimum.
    - Balance benefits of medications with possible side effects.
    - Remember affordability and accessibility.
    - Make sure you explain the reasons for prescribing the medications and how they should be taken.
- Remember to offer support and explanation to the family and empower their input.
- Review, re-evaluate, re-formulate plans; review, … .

B. The impact of symptoms

- Consider the following impacts of symptoms on a patient's overall situation:
    - When a patient is vomiting and confused, how can they talk about their fears and anxieties?
    - When a patient is frightened and lonely, how can they cope with their fungating wound when the smell makes everyone avoid them?
    - When a family listens to their loved one cough and fight for breath with no relief, how can they feel at peace?
    - When no one talks openly about what is happening, how do the patient and family decide what treatment to have and what they can afford?
- These are some of the key issues for palliative care providers, and the assessment of symptoms is key to trying to overcome some of them so that proper symptom management plans can be put in place.
- The best way to deal with these issues is to be prepared to take the necessary time to assess symptoms in a clear manner, so proper symptom management plans can be put into place with the client and his/her family

C. Assessment of symptoms

- Assessment must always precede treatment.
- There are a number of tools that can be used for assessment, and information about these can be found in the core texts used for this handbook.
- Regular assessment is important for setting treatment goals, for monitoring the response to specific treatment, for communicating between members of the healthcare team, and for quality control.

D. Common symptoms and clinical problems

- Most patients with advanced disease will have potentially devastating symptoms or clinical problems.
- Some common symptoms or clinical problems, described further below, include:
  - Pain (covered in chapter 5)
  - Anorexia and cachexia
  - Breathlessness
  - Confusion
  - Constipation
  - Dehydration
  - Diarrhoea
  - Distress
  - Fatigue
  - Insomnia
  - Malnutrition
  - Nausea and vomiting
  - Sore mouth
  - Wounds
- Some symptoms or clinical problems can be classified as emergencies within palliative care, and these will be covered in Chapter 7. They include:
  - Bone fractures
  - Choking
  - Haemorrhage
  - Hypercalcaemia
  - Seizures
  - Severe pain
  - Superior vena cava obstruction
  - Spinal cord compression
  - Stridor

Anorexia and cachexia

- Weakness, profound weight loss and poor appetite are common problems in advanced cancer, HIV and AIDS, and end-stage organ failure.
- Cachexia is not associated with hunger or thirst, nor will it improve by forced feeding or hydration.
- Cachexia is often debilitating and frustrating, particularly for families who may try to pressurise patients to eat so they can stay strong.
- ***Cause***
  - The underlying mechanisms are not fully understood and differ with different diseases.
  - There is release of inflammatory mediators including cytokines. These, along with alterations in metabolism, cause a catabolic state to be induced, with resultant profound weight-loss that involves both fat and skeletal muscle.
- ***General measures***
  - It is important to ensure that there is not anorexia or malnutrition due to a reversible cause such as;
    - Lack of available or digestible food
    - Dysphagia
    - Sore mouth or altered taste
    - Dyspepsia, or nausea and vomiting, or constipation
    - Pain

Metabolic disturbance – e.g. hypercalcaemia or uraemia

One that is secondary to treatment such as chemotherapy, radiotherapy or drugs.

  - Support should be given to the family and patient to understand the underlying process and to see food as something to enjoy rather than endure.
  - Presentation can be helpful with small, appetising meals and an emphasis on fluid intake.
  - Remember that as the terminal phase is reached, a reduction in food and fluid intake is very normal.
- ***Assessment and management***
  - Added nutritional supplements are expensive and seldom make a significant difference in advanced disease.

- Enteral nutritional support is occasionally useful in specific situations:

Where tumours of the head, neck and oesophagus exist and where swallowing is difficult despite good appetite and the disease is not far advanced.

Surgical placement of a feeding gastrostomy tube can be straightforward and helpful (refer to core texts for details).

May be associated with complications such as aspiration pneumonia and diarrhoea.

- Parenteral nutrition is seldom indicated and in any case is costly and burdensome.
- Corticosteroids (e.g. dexamethasone 2–4mg 5days po) may be of short-term benefit.

Assessment and management of symptoms in children

- Corticosteroids should not be used in children if anorexia/ cachexia is the only symptom that might benefit.
- There may be benefit from a short trial of corticosteroids in children with associated nausea, pain, asthenia or depressed mood.
- Dexamethasone dose in children is:
  - <10kg: 0.15mg/kg/dose BD
  - 10–20kg: 2mg po BD
  - 21–40kg: 4mg BD
  - >40kg: 8mg BD
- As an alternative, use Prednisone 0.05-2mg/kg divided 1–4 times a day.

Breathlessness

- Difficulty in breathing is a frightening experience.
- Think of the words that patients use to describe their experience, such as ‘suffocating’, ‘choking’, ‘could not get enough air’, ‘it felt like I was about to die’.
- ***Causes***
  - *Respiratory:* primary or secondary lung cancers, pleural effusion, pulmonary embolus, tracheal tumours, airway collapse, infection, lymphangitis carcinomatosa, chronic obstructive pulmonary disease (COPD), weak respiratory muscles;
  - *Cardiac:* superior vena cava obstruction, anaemia, cardiac failure, cardiomyopathy, pericardial effusion;
  - *Other:* ascites, secondary to treatment such as radiotherapy, chemotherapy or pneumonectomy.
- ***General care***
  - Adjust position – usually best to be sitting up, although in patients with a pleural effusion it is best that they lie on the affected side with the good lung upwards so as to maximise ventilation.
  - Ensure good ventilation by opening windows, using a fan or even fanning with a newspaper.
  - Adjust activity and help with slow, deep breathing.
  - Gently suction any excessive secretions
- ***Assessment and management***
  - Take a careful history, asking about severity, duration, and associated features such as breathing being worse when lying down or on exertion, pleuritic chest pain or haemoptysis.
  - Treat reversible conditions if possible, such as anaemia, heart failure, infection, pulmonary embolus or pleural effusion.
  - Address any underlying anxiety and panic.
  - Use medications to relieve symptoms:
  - Morphine 2.5–5mg orally every four hours (but if already taking oral morphine for pain, titrate dose and advise on taking extra doses as required);
  - Diazepam 2–5mg at night, especially for anxiety and panic;
  - Dexamethasone 8–12mg daily for specific causes, e.g. superior vena caval obstruction, lymphangitis carcinomatosa;
  - Consider other medications, such as broncodilators, diuretics or oxygen, depending on their availability and the cause of the breathlessness.

General care in children

- Gently suction any excessive secretions and in young babies ensure that their noses are unblocked using normal saline nose drops.
- As an alternative, use Prednisone 0.05-2mg/kg divided 1–4 times a day

Assessment and management

- In children, give morphine at 25–50% of the normal starting dose for pain (see Chapter 4 for more details). If the child is already on morphine, increase the dose by one-third.
- Add a benzodiazepine in children if breathlessness is severe. (**Note:** oral/rectal diazepam works as fast as parenteral, and you can use injectable diazepam rectally.) These might be:
  - Lorazepam 25–50mcg/kg as a single dose or 4–8hrly po/SL
  - Midazolam 200–500mcg/kg (max 10mg) SL, or intra-nasally as a single dose, or 100mcg/kg sc as a single dose, or 300–700mcg/kg over 24 hours as a subcutaneous infusion
  - Salbutamol nebuliser solution: 6months – 5 years 2.5mg prn, or 5–12 years 5mg prn but via nebuliser if bronchospasm is present.

Confusion

- This is one of the most distressing and difficult-to-manage symptoms.
- ***Causes***
  - Uncontrolled pain
  - Urinary retention or severe constipation
  - Changes in environment, leaving home, transfer from one ward to another
  - Metabolic disturbance: uraemia, hypercalcaemia, hyponatraemia
  - Infection: urinary tract infection, cryptococcal meningitis, other opportunistic infections
  - Hypoxia
  - Raised intracranial pressure, strokes
  - Medication-induced through opioids, antimuscarinics, corticosteroids
  - Withdrawal state such as alcohol, benzodiazepines, opioids
  - Dementia, delirium, HIV encephalopathy
  - Sudden sensory deprivation (blindness, deafness).
- ***General care***
  - Keep surroundings calm, reassuring and as familiar as possible.
  - Seek to remind the patient where they are and orientate them in time.
  - Remember that the patient may be very deaf and so only *seem* confused.
  - Avoid physical restraint unless for reasons of patients safety.
  - Support the family to be able to stay with the patient and express their worries and fears.
- ***Assessment and management:*** Consider the following questions;
  - Have new medications been started? – consider stopping these.
  - Are there any signs of infection? – treat appropriately.
  - Is the patient dehydrated? – give oral fluids and consider parenteral infusion.
  - Is there urinary retention or constipation? – relieve with urinary catheter or laxatives.
  - Is there any reversible organ failure? – assess and manage appropriately.
  - Use medications to relieve symptoms but take care not to sedate more than is necessary.
  - For mild agitation, give:
    - Diazepam 5–10mg daily
    - Or Lorazepam 1–2mg po/SL (give oral tablets via this route if available).
  - For severe delirium, give:
    - Haloperidol 1.5–5mg up to 8hrly until settled
    - Or Chlorpromazine 25–50mg po/pr if available
    - Add diazepam as above but do not use alone for severe delirium because it might worsen the confusion.

Assessment and management in children

- For children, start an antipsychotic – e.g. haloperidol 0.05–0.15mg/kg per 24hrs as a continuous infusion, or in divided doses twice or three times a day po/sc/IV.
- Give midazolam 500mcg/kg SL as a single dose, or 100mcg/kg sc as a single dose or 300–700mcg/kg over 24 hours by sc infusion
- Or Lorazepam 25–50mcg/kg (max 1mg) as a single dose or 4–8hrly po/SL.
- Don't use benzodiazepines alone, because they carry the risk of paradoxical agitation; however, they can be used in conjunction with antipsychotics to sedate children.

Constipation

- Constipation is defined as 'unduly infrequent and difficult evacuation of the bowels'.
- This is very common in palliative care and often can be predicted and prevented.
- ***Causes***
  - Direct effects of disease:
    - intestinal obstruction from tumours in the bowel wall or external compression from abdominal masses
    - damage to lumbosacral spinal cord
  - Secondary effects of disease:
    - decreased food intake and low-fibre diet
    - dehydration
    - general body weakness
    - metabolic abnormalities – hypokalaemia, hypercalcaemia
  - Medications:
    - opioids such as codeine or morphine
    - anticholinergic drugs such as tricyclic antidepressants
    - diuretics
  - Concurrent disease:
    - diabetes mellitus, hypothyroidism
    - haemorrhoids, anal fissures.
  - The two most common causes are related to the side effects of opioids and the effects of progressive disease.
- ***General care***
  - Encourage fluid intake and fruit, vegetables and fibre in the diet.
  - Remember that even if a patient is not eating much, they still need to move their bowels regularly.
  - Remember to anticipate constipation as a side effect of medications such as morphine and amitriptyline.
  - Prescribe prophylactic laxatives together with morphine, especially in adults.
- ***Assessment and management***
  - Remember to assess whether there is obstruction.
  - Rectal examination may be essential to determine whether there are hard faeces, impaction or high obstruction (rectum is empty and ballooned).
  - Oral treatments:
- Bisacodyl 5mg at night (up to 20mg)
- Senna 1 to 2 tablets at night
- Paw paw seeds dried and crushed: 1 teaspoon at night with water
- Vegetable oil or margarine: 1 tablespoon at breakfast
  - Rectal treatments:
    - Glycerol or bisacodyl suppositories if available
    - Use a pellet of soap softened and inserted with petroleum jelly
    - May need to consider digital removal of faeces.
  - Non-pharmacological management:
- Patient education and dietary advice, e.g. encouragement of a high-fibre diet.

- For children an osmotically active laxative (eg Lactulose) is preferable to a stimulant laxative (Bisacodyl) as the stimulants may cause severe abdominal pain in children.
  - For children, try to prevent constipation when starting opioids by adding laxatives, e.g.:
- Bisacodyl: 6–12 years 5–10mg once daily po
- Or Sennakot.
  - Suggested constipation management in children:
- Step 1: try lactulose, building the dose up over one week:
  - <1year 2,5ml BD
  - 1–5 years: 5mls BD
  - 6–12 years 10mls BD
- Step 2: if no improvement, add Senna
  - 2–6years –1 tablet BD po
  - 6–12 years 1–2 tablets BD po
- Step 3: If already on opioids, use step-2 drugs straight away.
  - If on rectal examination the stool is found to be hard, try a glycerine suppository. If soft but not moving, try a bisacodyl or senna suppository. If the rectum is empty, try a bisacodyl suppository to bring the stool down or a high-phosphate enema.
  - For severe constipation, try a phosphate enema or a bowel prep product (e.g. Movicol) if available.

Dehydration

- Dehydration is a common symptom.
- There is a need and desire for relatives and the medical or nursing team to want to keep patients well hydrated.

Diagnosis and prognosis

- Dehydration may occur when a patient has an intercurrent illness from which you expect them to recover, e.g. an episode of diarrhoea in a patient with lung cancer who has a prognosis of several months, or severe diarrhoea in an HIV and AIDS patient.
- Presence of other symptoms:

Dehydration may significantly impair drug excretion and so increase side effects. This is particularly true for morphine.

Try to stop unnecessary medication or reduce the dose while maintaining symptom control.

Supplementary fluids may be given for a short period of time to reduce distressing symptoms such as hallucinations or myoclonic jerks.

- Presence of a dry mouth rather than thirst:

See also the section below on mouth care.

The patient may report feeling thirsty but they appear well hydrated and their symptom may actually be a dry mouth.

If the patient is very thirsty and measures to keep their mouth moist are ineffective and they are unable to swallow, supplementary fluids should be considered.

Are they close to death?

- A patient who is nearing death will often struggle to manage oral fluids. They may even cough when they swallow.

- ***Assessment and management***
  - A dilemma occurs when the patient is very ill and entering the terminal phase. In most patients nearing death, a reduction in fluid intake is natural and appropriate. They no longer have a requirement for fluid and full explanation is likely to reassure the family and reduce the request for supplementary fluids.
  - Remember to keep the mouth and lips clean and moist, because dry oral mucosa may be a worse symptom than thirst.
  - There are, however, some situations in which it may be appropriate to consider artificial hydration. If so, aim to hydrate via the oral route but consider IV or SC infusions if needed. SC may be the least invasive and can even be given in a home situation.
  - Excessive hydration may result in fluid overload and necessitate venous cannulation, which can become painful and difficult. In deciding to give supplementary fluids, several factors should be considered:

Giving more than sips of oral fluids in this situation risks the complication of aspiration and pneumonia.

Often, families worry that the patient will be uncomfortable and will need hydration.

It is important to ensure the family and patient are aware that comfort can be maintained by keeping the mouth moist, that fluids are not needed and that they can cause harm in this situation.

Diarrhoea

- Diarrhoea is defined as the passage of more than three unformed stools within a 24-hour period.
- ***Causes***
  - Imbalance of laxative therapy
  - Drugs such as antibiotics, NSAIDs, ARVs
  - Faecal impaction – fluid stool leaks past a faecal plug or tumour mass
  - Radiotherapy involving the abdomen or the pelvis
  - Malabsorption
  - Colonic or rectal tumours
  - Concurrent disease
  - Odd dietary habits
  - HIV
- ***General care***
  - Increase fluid intake where possible.
  - Provide reassurance that most diarrhoea is self-limiting.
- ***Assessment and management***
  - Treat or exclude any specific causes.
  - Discontinue laxatives if prescribed and review.
  - If due to antibiotics, give metronidazole 400mg tds for 7–14 days.
  - Review other medications as appropriate.
  - If necessary, opioids such as loperamide, codeine and morphine can be used.

- In a child, diarrhoea refers to abnormal frequency as well as consistency.
- Breastfed babies may pass a stool after each feed; in this case, loose consistency is more important than frequency as a sign of disease.
- In bottle-fed infants more than seven stools per day indicates diarrhoea, while the indicator for toddlers is more than three.
- Can be caused by urinary tract or any other systemic infections in children.
- In children, temporary lactose intolerance may be a problem necessitating the use of lactose-free milks such as soya or the use of yoghurt with live cultures.
- If blood is present in a child's stool, give ciprofloxacin and add metronidazole in areas where amoebic dysentery is prevalent.

Distress

- Distress encompasses the psychological response to the challenge of a life-threatening illness.
- Screening tools for distress may be used; however, the key to dealing with distress is sensitive listening and supportive communication.
- Symptoms may include anxiety and low mood.
- Many people experience temporary symptoms as they adjust to the psychological challenges of their illness (adjustment disorder).

- ***General care***
  - Offer skilled counselling and support.
  - Recognise that when symptomatic, medication or psychiatric referral may be needed.
  - Unrelieved physical pain and symptoms will contribute to distress.
  - Depression may sometimes be interpreted as being due to supernatural forces – therefore careful explanations for behaviour will help the patient and their family to understand what is happening.

-

Depression

- Depression is often misunderstood, under-diagnosed and under-treated.
- Assessment and management:

The key factors which distinguish depression that may require anti-depressant medication and psychiatric referral include:

- Low mood more than 50% of each day
- Loss of any enjoyment or interest
- Excessive or inappropriate guilt
- Thoughts of suicide.
    - Ongoing support and counselling may be needed.
    - Antidepressants take several weeks to be effective, so should be tried for at least 2–4 weeks.

If depression does not respond to counselling, give anti-depressants:

- Amitriptyline – start with 25mg at night and increase gradually to 75–150mg. (The anti-depressant effect is unlikely to be seen at less than 75mg.) The main side effects are drowsiness, dry mouth and constipation.
- Imipramine, if available, is an alternative that might be less sedating.

Anxiety

- This may be a symptom of depression.
- Assessment and management:

Symptoms included feelings of panic, irritability, tremor, sweating, lack of sleep and a lack of concentration.
Ensure the patient is given an opportunity to talk about their fears and anxieties. Non-pharmacological interventions may help, such as massage and relaxation. If persistent symptoms are hindering quality of life, consider medication with benzodiazepams, e.g. diazepam 5–10mg at night.

Fatigue

- Chronic fatigue is very common in people with advanced disease.
- ***Causes***
    - Multiple causes, often obscured by coexisting disease processes
    - Anaemia
    - Pain
    - Emotional distress
    - Sleep disturbances
    - Poor nutrition.
- ***General care***
    - Try to manage lifestyle around the periods of greater energy or fatigue.
- ***Assessment and management***
    - Treat the underlying cause of the fatigue where possible – e.g. if anaemic, give a blood transfusion as appropriate.
    - Can give low doses of psychostimulants, e.g. methylphenidate (Ritalin) or antidepressants.
    - Non-pharmacological interventions include energy conservation and physical exercise, and stress reduction by relaxation and meditation.

Insomnia

- Insomnia is a subjective complaint of inadequate nocturnal sleep – manifested as difficulty initiating or maintaining sleep, early-morning awakening, non-restful sleep or a combination of all of these.
- It is common in those with advanced disease.
- ***Causes***
    - It may be transient or chronic:

Transient: secondary to life crisis, bereavement, illness
Chronic: associated with medical or psychiatric disorders, drug intake or maladaptive behavioural patterns.

- In advanced disease it emerges as a psychological or physiological side effect of diagnosis and/or treatment.

- ***General care***
  - Try to reduce the intake of nicotine, caffeine and other stimulants and avoid alcohol near bedtime.
  - Exercise regularly in the earlier part of the day.
- ***Assessment and management***
  - Benzodiazepines are the most commonly used hypnotic medications for sleep – they offer prompt symptom relief by decreasing time to sleep onset, improving sleep efficiency, and imparting a sense of restful sleep for most patients.
  - Intermediate-acting:
    - Temazepam 7.5–30mg; half-life 8–12 hours
    - Oxazepam 10–30mg; half-life 5–15 hours.
  - Long-acting:
    - Alprazolam 0.25–1mg; half-life 12–20 hours
    - Lorazepam 0.5–2mg; half-life 10–22 hours
    - Clonazepam 0.5–2mg; half-life 22–38 hours
    - Diazepam 2.5–10mg; half-life 20–50 hours.
  - However, these are not indicated for long-term treatment of chronic insomnia because of the risk of tolerance, dependency and other side effects. **Note:** despite being longer acting, Lorazepam has the least active metabolites of the benzodiazepines and this can therefore be used over a longer period, especially in older patients, without a cumulative drowsy effect.

- If insomnia in a child is not improved by addressing sleep hygiene, then the following medications may be considered:
  - Sedating antihistamines (e.g. Promethazine):
- Under 1 year: 5–10mg at night
- 1–5 years: 10–20mg at night
- 5–12 years: 20–25mg at night
  - Tricyclic antidepressants:
- Imipramine
- 5–8 years: 10–25mg po at night
- 9–12years: 25–50 mg po at night
- ⇢ 12 years: 25–75mg po at night
  - Amytriptaline:
- 2–12 years: 200–500mcg/kg (max 25mg) once daily at night
- 12–18 years: 10–25mg po at night
  - Benzodiazepam (for short-term use only)
  - Diazepam (Valium):
- 6 weeks – 1 year: 0.25–1mg at night
- 1–6 years: 0.5–3mg at night
- 6–14 years: 1–5mg at night
- Melatonin is a useful drug within children's palliative care, particularly for children with neurological disorders who struggle to sleep (including blind children). Dose: 0.5–10mg at night

Malnutrition

- Malnutrition is very common in many settings in Africa.
- ***Causes***
  - Poverty
  - Incorrect feeding practices, early weaning (birth of second child)
  - Anorexia associated with illness, mouth ulcers or oral thrush
  - Nutrient loss from malabsorption, diarrhoea or HIV enteropathy
  - Increased metabolic rate due to disease or infection (especially TB).
- ***General care***
  - Malnutrition is effectively a social not a medical disorder, although it causes medical problems.
- ***Assessment and management***
  - Stage 1 – initial treatment: life-threatening problems are identified and treated.
  - Stage 2 – rehabilitation: intensive feeding is given to recover weight loss, emotional and physical

stimulation is increased, and the carer is trained to look after the child.
  - Stage 3 – follow up.
  - Follow your national guidelines for the management of malnutrition, as appropriate.
  - Where available, refer to food and nutritional support programmes.

- Malnutrition is very common in many settings in Africa and in particular in children's palliative care.
- Malnutrition in children often leads to other distressing symptoms that add to the suffering – e.g. oral sores, angular stomatitis, dermatitis, corneal ulceration, gastric distension, irritability, hunger, headaches. These should be managed as outlined in the other sections of this handbook.

Nausea and vomiting

- Nausea is the unpleasant sensation of being about to vomit and can occur alone or can accompany vomiting.
- Vomiting is the forceful expulsion of gastric contents.
- This is a very common symptom with many different causes and may be very distressing.
- Patients have been known to say that nausea is worse than pain.
- ***Causes***
  - Pharmaceutical: opioids, digoxin, anticonvulsants, antibiotics
  - Toxic: infection, radiotherapy, chemotherapy
  - Metabolic: hypercalcaemia, ketoacidosis, renal failure
  - Intracranial: cerebral tumours, cerebral infections, meningeal mestastases, raised ICP
  - Gastrointestinal: gastric stasis, intestinal obstruction, constipation, candidiasis.
- ***General care***
  - Ensure the patient is in well ventilated areas, to avoid smells permeating which can trigger nausea and vomiting.
  - Avoid the eating of big meals and encourage small appetising meals.
  - Avoid spicy or fatty meals.
  - Ensure adequate fluids by mouth if possible.
  - Ginger may be useful, e.g. ginger tea.
- ***Assessment and management (see also Table 2 on the opposite page)***
  - Treat reversible conditions such as oesophageal candidiasis, raised intracranial pressure, constipation and gastro-oesophageal reflux and heartburn.
  - Review the medication to see whether any causal link exists, such as use of opioids, digoxin toxicity, chemotherapy, antiretrovirals or antibiotics.
  - Consider giving medication via a non-oral route if severe nausea or intractable vomiting occurs. Try the rectal or parenteral routes, then transfer back to oral administration when the symptoms are under control.
  - Use a step-wise approach to prescribing anti-emetic medication, depending on your assessment and the pattern of symptoms. You may only have limited access to medications, but still try to prescribe carefully and review.
  - Consider non-pharmacological approaches as appropriate – e.g. surgery, acupressure, cognitive therapy:

The acupressure point for nausea and vomiting is situated 2–3 fingers down from the top crease of the wrist in the groove between the two tendons.

Take your thumb and index or middle finger and press firmly on points on both sides of the wrist when nauseous feelings persist.

- Remember, patients may have more than one cause of nausea and may need more than one anti-emetic.

Table 2: Characteristics and treatment of nausea and vomiting

Pattern	Causes	Suggested medications in adults	Suggested medications in children
Gastric stasis or poor stomach emptying · Vomiting is main symptom · Vomiting often relieves nausea · Patient feels full quickly when eating · May have gastro-oesophageal reflux	· Medications such as morphine · Constipation · Squashed-stomach syndrome due to liver enlargement or large-volume ascites	· Metoclopramide 10–20mg 8hrly before meals · Domperidone 20–30mg 8hrly · Consider dexamethasone 8mg daily if squashed-stomach syndrome	· Metoclopramide: ° 1–12 years: 300mcg/kg po in three divided doses ° >12 years: <60kg: 5 mg po tds ° >12 years >60kg: 10 mg po tds · Manage GORD by thickening feeds, maintaining upright position after feeds and using an antacid
Blood chemistry disturbance or toxins: · Intractable nausea is the main symptom · Vomiting often does not relieve nausea	· Medications such as morphine · Renal failure · Hypercalcaemia · Liver failure	· Haloperidol 1.5 – 5mg at night · Prochlorperazine 5–10mg 8hrly	Haloperidol : · Oral: < 12 years: 0.025–0.05mg/kg per day in two or three divided doses. > 12 years: 1–4mg at night · SC infusion: Child 1 month to 12 years: 25–85mcg/kg over 24hrs. Child 12–18 years: 1.5–5mg over 24hrs · Odansetron or Granisetron for chemotherapy-related nausea and vomiting
Raised intracranial pressure: · May be worse in the morning · May be worse on movement · Vomiting does not relieve nausea	· Intracranial tumours or infections such as toxoplamosis · Meningitis such as TB or cryptococcus · Malaria	· Dexamethasone 8–16mg daily (give in the morning to avoid disrupting sleep, and take care in prescribing if untreated infections) · Promethazine 25mg 8hrly · Cyclizine 25–50mg 8hrly	· Dexamethasone: 0.03–0.2mg/kg per day in 2–4 divided doses · Haloperidol (as above)
Bowel obstruction: · Large-volume vomiting · May be partial when some flatus or faeces are passed · May be complete · Remember to consider surgery if patient is strong enough and single site of obstruction	· Abdominal or pelvic tumours · May be a single site of obstruction, such as the sigmoid colon, or many levels such as ovarian carcinoma with peritoneal spread	· Metoclopramide 10–20mg 8hrly (Avoid if complete obstruction or if it worsens abdominal colicky pain) · Hyoscine butylbromide 20–40mg 6hrly · Promethazine 25mg 8hrly · Cyclizine 25–50mg 8hrly · Best given by subcutaneous infusion · Octreotide if available	· Metoclopramide 0.1–0.2 mg/kg/dose 6hrly PO, SC or IV · Haloperidol sc infusion: Child 1 month to12 years: 25–85mcg/kg over 24hrs. Child 12–18 years: 1.5–5mg over 24hrs · Hyoscine butylbromide: 1month to 2years: 1.5mg/kg in three divided doses. 2–5 years: 5mg po tds. 6–12 years: 10mg po tds · Steroids may help to decrease oedema

Sore mouth

- Perhaps more than any other symptom, a sore mouth affects communication as well as comfort.
- A sore mouth is very common in palliative care and may be severe in patients with HIV and AIDS or who are receiving chemotherapy or radiotherapy.
- ***Causes***
  - Infection such as candidiasis or herpes
  - Mucositis due to radiotherapy or chemotherapy
  - Ulceration
  - General debility
  - Poor dental hygiene
  - Dry mouth due to medications, damage to salivary gland due to radiotherapy or tumour, or mouth breathing
  - Erosion of buccal mucosa by tumours, with possible fistula formation
  - Iron deficiency
  - Vitamin C deficiency.
- ***General care***
  - Most problems can be prevented by keeping the mouth clean and moist and treating any infections promptly.
  - Check the mouth, teeth, tongue, palate and gums regularly for dryness, inflammation, ulcers, infection or inflammation.
  - Ensure the patient and family know how to care for the patient's mouth using what is available.
  - Avoid harsh brushing; use a soft brush or a soft cotton cloth instead.
  - A simple mouthwash with sodium bicarbonate or saline (a pinch in a glass of water is sufficient) can be very effective.
  - Sucking ice or pieces of fruit such can help a dry mouth.
  - Use petroleum jelly on the lips after cleaning.
- ***Assessment and management***
  - Treat pain in accordance with the WHO analgesic ladder (see Chapter 4).
  - Remember that mucositis can cause severe pain and require oral morphine.
  - Treat oral candidiasis and remember you may not see white patches but only inflammation:
    Nystatin oral drops 1–2mls 6hrly after food and at night; hold dose in mouth to allow it to act topically.

    Fluconazole 50mg daily for five days; use higher doses (200mg daily for two weeks) if patient has difficulty swallowing and you suspect oesophageal candidiasis. Ketoconazole 200mg daily is an alternative, but watch for drug interactions.
  - Treat other infections:
    Apply Gentian Violet three times daily; useful for many sores. Metronidazole mouthwash, made by mixing crushed oral tablets or liquid for injection with fruit juice, helps with smelly sore mouths, especially with oral cancer. Consider acyclovir 200mg po for five days for herpes infection. Oral or parenteral medications may be needed to treat severe infections.
  - Treat inflammation:
    Consider the use of steroids, such as oral dexamethasone 4–8mg or prednisolone powder or solution, for ulceration and inflammation – but ensure that any infection is well treated as steroids may exacerbate them.

- For general care in children sucking ice or pieces of fruit such can help a dry mouth – use lollies for children.
- For children, give paracetamol prior to feeding.
- Commercially available teething gels (Teejel, Bonjela) may be useful for children with sore mouths.

Treat oral candidiasis and remember you may not see white patches but only inflammation:

- Nystatin oral drops 1–2mls 6hrly after food and at night; hold dose in mouth to allow it to act topically. Nystatin 1ml qds for children.
- Fluconazole 50mg daily for five days; use higher doses (200mg daily for two weeks) if patient has difficulty swallowing and you suspect oesophageal candidiasis. Fluconazole in children: 6mg/kg po stat and then maintenance of 3mg/kg per day for up to 21 days in severe cases.
- Treat inflammation:
  - Inhaled steroids (eg Bethamethasone) sprayed on an ulcer BD may be useful in children.

Wounds

Causes

- Fungating skin cancers (primary or secondary) such as breast, sarcoma, squamous tumours or melanoma
- Poor wound healing due to debility, poor nutrition and illness
- Pressure sores due to debility and immobility.

General care

- **Cleaning wounds:**
  - Use a simple saline solution made by boiling water and adding salt (a pinch for a glass or one teaspoon for 500mls).
  - Use salt-water baths for perineal wounds.
  - Avoid caustic cleaning agents such as hydrogen peroxide.
  - Consider leaving a wound exposed to air (though watch for maggots).
  - If needed, apply clean dressings daily, or more often if there is discharge.
  - Consider making simple dressings from local materials such as old cotton cloths washed and cut to size.
  - Help the patient's family to learn the skills to do the dressings daily.
  - Prevent pressure sores by changing the patient's position regularly.
  - Keep skin dry and clean.
  - Consider a water-filled surgical glove for pressure relief of critical areas.

Assessment and management

- Is there pain?
  - Use non-adherent dressings, and soak them off prior to changing.
  - Give analgesia 30 minutes before dressing changes.
- Is there an unpleasant smell?
  - Sprinkle crushed metronidazole tablets directly onto the wound (avoid enteric-coated tablets) or use metronidazole gel if affordable.
  - Consider using locally available remedies such as natural yoghurt, paw-paw and tried-and-tested local herbs.
  - Honey or sugar can be used temporarily on a dressing, for de-sloughing necrotic wounds. Dressings should be changed twice a day (as they become moist), but within a few days you can revert to dry dressings or metronidazole.
- Is there discharge?

Use absorbent dressings and change them frequently.

- Is there bleeding?
  - If the bleeding is severe, consider radiotherapy or surgery and use dark cloths to soak up the blood.
  - Clean the wound carefully to avoid trauma during dressing changes.
  - Consider crushed topical sucralfate g tablets, or tranexamic acid 500mg tablets.
- Are there maggots?
  - If suspected, use a pad soaked with turpentine oil held close to the wound but not touching.
  - Gently remove any maggots with forceps when they appear, and repeat every day till clear.

- In general care for child patients, disguise smells in the room using vanilla, incense, candles etc.

E. Special considerations in HIV and AIDS

- As the immune system becomes exhausted, an individual becomes susceptible to a wide range of infections, which in turn cause different symptoms. Thus prevention and treatment of OIs is an important part of good symptom control.
- Enabling access to medicines for symptom control is a challenge, particularly when the medicines are expensive.
- Recurrent or persistent diarrhoea can be a challenge in patients with advanced AIDS.
- Many of the patients with diarrhoea will have an identifiable infection, which should be treated.
- Chronic diarrhoea needs to be taken as seriously as pain – particularly in areas where there is a lack of proper sanitation and/or easily accessible sanitation.
- Sweating and fever are frequent throughout the course of AIDS – it is important to undertake careful assessment and treat any underlying conditions where possible.
- Almost all patients with AIDS will have some form of *skin problem* – e.g., dry skin and itching. In such cases:
    - Avoid excessive bathing.
    - Underlying infections (e.g. seborrhoeic dermatitis or scabies) should be treated.
    - Multiple purple-brown nodules scattered all over the body are characteristic of Kaposi's sarcoma.
    - Topical creams can help:
        - Aqueous cream (can be used as a substitute for soap)
        - Hydrocortisone 1% may help any inflammation
        - Chlorhexidine 0.5% solution can be used after bathing.
    - Antihistamines can help reduce itching:
        - Chlorphen-iramine 4mg tds.

	AZT	DDI	D4T	3TC/FTC	TDF	LOP/RIT	NEV	EFF
Taken with food					+	+		
Cell cycle activity	active	resting						
CNS penetration	60%	20%	30/40%	10%	13%	?	<45%	
Half-Life — Intracellular	3 hrs.	25–40 hrs.	3.5 hrs.	12/39 hrs.	10–50 hrs.	T1/2= 5–6 hrs.	T1/2= 25–30 hrs.	T1/2= 36–100hrs.
Side Effects:								
Anemia	+							
CNS								
• Headache	+							+
• Insomnia	+							+
• Dizziness								+
• Vivid dreams								+
• Depression								+
GI								
• N/V	+	+			+	+		
• Bloating						+		
• Diarrhea		+				+ 15–25%		
• Pancreatitis							+	
• Hepatic necrosis		(original formulation-diarrhea)					(body ≥ 250 CD4)	
Rash				(occasional hyper-pigmentation-soles/palms)			15–30%	15–27%
Nail-bed changes	+							
Fatigue/ Asthenia	+	+	+			+		
Peripheral Neuropathy		+	+					
Body Habitus								
• Facial wasting	+	+	++					
• Fatty deposits: Post. Neck & Abdomen						+		
Long Term								

Reprinted from Clinical Guide to supportive and palliative care for HIV/AIDS in sub-Saharan Africa *(with permission)*.

Promethazine 10–25mg at night

- Treat herpes zoster with Acyclovir 200mg at five a day for five days if available – it needs to be started within 72 hours of the rash first appearing.
- Good nutrition is essential for maintaining an adequate immune system.

Side effects of treatment (e.g. ART) please see table:

- ARVs are the best available form of palliative treatment for AIDS at present, and the decision as to when to start or stop ARVs and which combination to use is complex.
- ART is meant to reduce plasma viral load significantly and to increase CD4 levels, allowing for immune recovery and reducing the frequency of OIs. Quality of life is thus improved.
- Each country will have its own guidelines with regard to the use of ARVs and these should be followed as appropriate.
- Those on ART may well experience a range of symptoms, including:
  - Pain, including neuropathic pain
  - Diarrhoea
  - Fever
  - Neurological symptoms
  - Skin problems
  - Nutritional problems
  - Emotion and psychological symptoms
  - Social and spiritual issues.
- Palliative care therefore has a key role to play in the care of people on ART.

F. Be aware ...

- All symptoms and management options will not be covered here, so please use the References list towards the end of this handbook to access further information as needed.
- Priority has been given to affordable and available medications in an African setting.
- All symptoms must be managed on an individual basis.
- Many symptoms are subjective and the impact they have on the individual will vary from person to person.
- Symptom management can be complicated by factors such as malnutrition and decreased renal function.
- Care without adequate pain and symptom control is supportive care and not palliative care.
- Treatment using ARVs is a complex issue – it is beyond the remit of this handbook to describe how to start and manage someone on ARVs.

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CHAPTER 5: ASSESSMENT AND MANAGEMENT OF PAIN

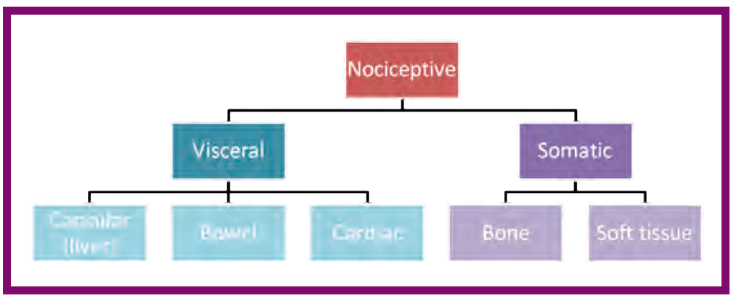
I think that the simplest and probably the best definition of pain is what the patient says hurts. I think that they may be expressing a very multi-faceted thing. They may have physical, psychological, family, social and spiritual things all wound up in this one whole experience. But I think we should believe people; and once you believe somebody, you can begin to understand, and perhaps tease out the various elements that are making up the pain.

(Dame Cicely Saunders)

A. Assessing and managing pain principles

- All areas of total pain (psychological, spiritual, social, cultural and physical) must be addressed.
- Pain can be caused by a disease (e.g. HIV), its consequences (e.g. opportunistic infections), treatment (e.g. chemotherapy) or concurrent disorders (e.g. arthritis).
- Palliative care aims to free patients from pain so that it doesn't affect their life.
- Pain is subjective – it is what the patient says it is.
- Pain should be managed according to the WHO guidelines and analgesic ladder.
- Particularly important in children are incident and procedural pain

- Both adults and children feel less distress when they understand what's happening and are involved in their care.
- Children (including newborns) suffer pain as much as adults, and younger children experience higher levels. Fear of treatment may prevent them expressing pain.
- Repeated painful procedures may cause children increased anxiety and pain perception.

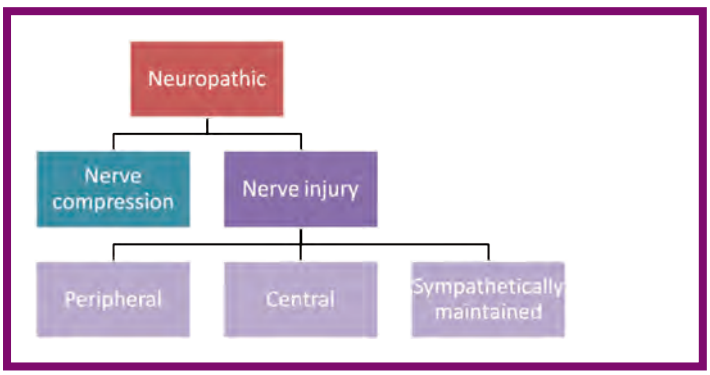


B. Types of pain

Nociceptive pain

This type of pain is produced by stimulation of specific sensory receptors in the viscera and somatic structures (the nerves are intact). Its characteristics are:

- Somatic pain: superficial (cutaneous) in skin, subcutaneous tissue or mucous membranes: sharp and well localised pain, deep muscles, tendons, joints: more diffuse and dull;
- Visceral pain from organs: dull and poorly localised – the sensation of pain may be referred to a cutaneous site, often associated with autonomic responses (e.g. sweating, nausea).



Neuropathic pain

This type of pain is produced by damage to the central or peripheral nervous system (the nerves are abnormal). Its characteristic are:

- Burning pain or shooting pain
- Aching sensation relieved by pressure applied to the affected area
- Increased sensitivity to a pain stimulus or to a stimulus that is not normally painful.

Situation

- *Breakthrough* – a transitory exacerbation of pain that occurs on a background of otherwise controlled pain;
- *Incident pain* – occurs only in certain circumstances e.g. after a particular movement;
- *Procedural pain* – related to procedures or interventions;

- Particularly important in children are incident and procedural pain.

Factors influencing pain

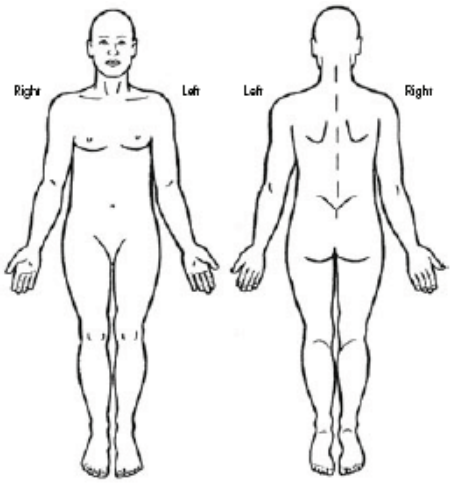
- Pain is influenced by psychological factors as well as spiritual issues and social circumstances. These factors can increase or decrease pain sensation.
- The concept of total pain reminds us that we need to holistically assess and manage chronic pain.
- The definition of pain by the International Association for the Study of Pain (IASP) draws attention to the emotional component of the pain experience.
- Pain is often expressed in emotional terms such as agonising, cruel, terrible etc.
- Integrated multi-disciplinary teams need to be involved in the management of chronic pain.
- Holistic support for a patient with chronic pain can have a profound effect on a patient's quality of life and may focus on addressing feelings of helplessness and on building resilience.
- Women experience pain differently from men as a result of biological, psychological and social factors. Men and women also respond differently to pharmacological and non-pharmacological pain management.
- For more information on the management of psychological, spiritual, cultural and social pain, refer to APCA's *Beating Pain* pocketbook, or the core texts listed in the references.

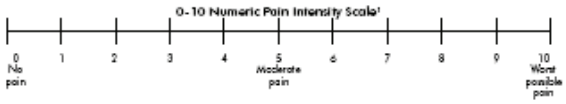
C. Pain Assessment

- As pain is subjective, self-reporting is central to assessment.
- Comprehensive clinical assessment is vital for effective pain management.
- A standard assessment guideline for pain is important to measure change over time.
- Several pain assessment tools are available – for instance: body diagrams to document the site of pain; and pain rating scales to follow pain and the effect of treatment (which are useful in managing difficult pain).
- Use the **PQRST** tool for questions to assess pain:
  - **P**recipitating and relieving factors: What makes your pain better/worse?
  - **Q**uality of pain: How would you describe your pain?
  - **R**adiation of pain: Is the pain in one place or does it move?
  - **S**ite and severity of pain: Where is your pain? How bad is it?
  - **T**iming and previous treatment: How often do you get the pain? When? Are you on pain treatment? Does it help?

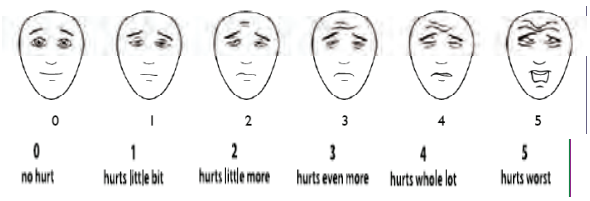
- Measure children's pain using the Faces Scale. Ask the child about their pain.
- For children less than three years of age, and for older non-verbal children, use the FLACC or TVP scales.

Body chart





Faces scale



Numerical rating scale

Visual analogue scale

D. Pain Management

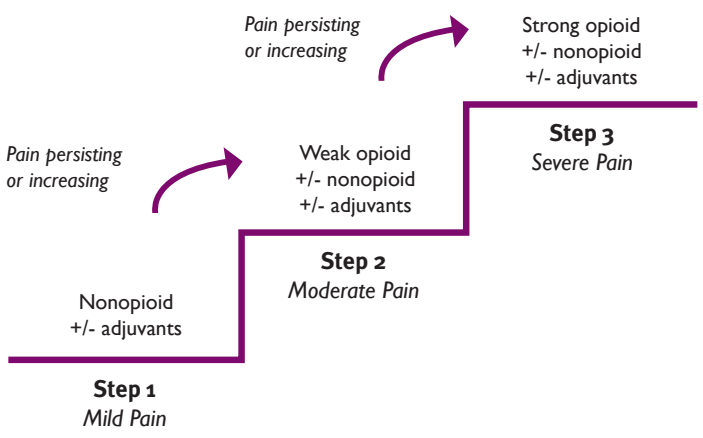
- Relieve pain as fast as possible and prevent its return.
- Use pharmacologic and/or non-pharmacologic methods.
- Control pain while treating the underlying cause (e.g. infection).
- Reassess pain regularly using assessment tools.

Non-pharmacological pain management

- This can be:
  - *Physical:* e.g. massage, exercise, physiotherapy, surgery
  - *Psychological:* strengthen the patient's coping mechanisms through counselling, relaxation therapies etc.
  - *Social:* help the patient resolve social or cultural problems through community resources, financial and legal support, etc.
  - *Spiritual:* e.g. religious counselling and prayer.

Pharmacological pain management

- Use WHO guidelines. Pain management should be by the:
  - *Mouth:* use the oral route where possible.
  - *Clock:* analgesia should be given at fixed time intervals. Give the next dose before pain recurs.
  - *Individual:* involve adults and children fully in their care. Link doses to their daily routine.
  - *Ladder:* choose analgesics according to the WHO analgesic ladder (see below), covering mild, moderate and severe pain.
- The choice of analgesic depends on the severity, site and type of pain. Start patients on Step 1 analgesics for mild pain; if ineffective, change to a Step 2 analgesic, then to Step 3 as required.
- If Step 1 or 2 analgesics don't work, don't switch to another analgesic at the same level: move up a step.
- A combination of a non-opioid and an opioid drug is effective (they have different modes of action). Don't combine weak with strong opioids.
- Other medications for managing pain (adjuvants) can be combined with Step 1, 2 or 3 drugs.
- If the oral route isn't possible, use alternative methods. These can include rectal, intravenous, nasogastric tube, transdermal and subcutaneous routes.
- The majority of patients can have their pain controlled in the home care/outpatient settings using the WHO analgesic ladder as a guide. Only in very severe cases may they need to be an inpatient.



The WHO Three-Step Analgesic Ladder

Step 1 Non-opioid (e.g., paracetamol, aspirin) ± adjuvant (e.g., antidepressant). If pain is not controlled by Step 1 analgesics, move to Step 2 by adding a weak opioid.

Step 2 Opioid for mild to moderate pain (e.g. codeine) ± non-opioid ± adjuvant. If an opioid for mild to moderate pain has been used to a maximum dose and the patient still has pain, then move to Step 3 by changing to a strong opioid.

Step 3 Strong opioid (e.g., morphine) ± non-opioid ± adjuvant.

(*Source: WHO 1996, reprinted with permission*)

Mild pain – Step 1

Paracetamol

- Adult dose: 500mg–1g po 6hrly; max daily dose 4g.
  - **Note:** hepatotoxicity can occur if more than maximum dose is given per day. Can be combined with a non-steroidal anti-inflammatory drug (NSAID).

Ibuprofen (NSAID)

- Adult dose: 400mg po 6–8hrly. Maximum dose 1.2g per day.

Caution: can cause serious side effects, e.g. gastro-intestinal (GI) bleeding or renal toxicity. If GI symptoms occur, stop and give H2 reception antagonist (e.g. Ranitidine).

Diclofenac (NSAID)

- Adult dose: 50mg po 8hrly. Maximum dose 150mg per day.

Moderate pain – Step 2 (weak opioids)

Codeine

- Codeine is the commonest weak opioid:
  - Adult dose: 30–60mg po 4 hrly (max dose 180–240mg per day)
- Codeine is often combined with Step 1 analgesics. Give laxatives to avoid constipation unless patient has diarrhoea.
- If pain relief is not achieved on the ceiling dose (max dose 240mg per day), move to a strong opioid (see Step 3 below).

Tramadol

- Adult dose: 50–100mg po 4–6hrly.
- **Note:** Start with a regular small dose and increase if no response observed. Dose limit is 400mg/day.

Severe pain – Step 3 (strong opioids)

Mild pain – Step 1 (non opioids)

- Paracetamol: Children under 1 year 10–15mg/kg po 6–8hrly; 1–5 years 10–15mg/kg po 6–8hrly; 5–12 years 250–500mg po 6–8hrly. Maximum dose 75mg/kg/day.
- Ibuprofen: In children: 5mg/kg po 6–8hrly. Max 30mg/kg/day in three or four divided doses.
- Diclofenac (NSAID): In children of 6 months to 12 years: 2–3mg/kg per 24hrs po in two or three doses.

Moderate pain – Step 2 (weak opioids)

- Codeine: Children over 6 months: 0.5–1mg/kg po 6hrly.
- Tramadol: Children over 12 years: 50–100mg po 4–6hrly.

Severe pain – Step 3 (strong opioids)

- Morphine: opioid-naive infants <6 months, starting dose 0.02mg/kg po 4hrly; opioid-naive infants >6 months, starting dose 0.04 mg/kg po 4hrly.
  - Children younger than six months are more sensitive to possible opioid-induced respiratory depression, so they need a lower starting dose.

- Fentanyl patch: The smallest Fentanyl patch for use in children is 12mcgm (which corresponds to a total daily dose 45mg of oral morphine).
  - Urinary retention and pruritis are side effects that are more common in children than in adults.

Morphine

- Morphine is the 'gold standard' against which other analgesics are measured.
- The correct morphine dose is the one that gives pain relief; there is no 'ceiling' or maximum dose, but any increase should be gradual.
- Starting dose is 2.5–20mg po 4hrly, the level depending on age, previous use of opiates, etc.
- Patients changing from regular administration of a Step 2 opioid should start on morphine 10 mg po 4hrly.
- If patient is cachexic, or not on Step 2 analgesics, start morphine at 5mg po 4hrly.
- Start frail/elderly patients on morphine at 2.5mg po 6–8hrly, due to the likelihood of impaired renal function.
- 'Breakthrough' or 'rescue' doses of morphine can be given as often as required (ideally the same as the 4hrly dose). Keep a record of each rescue dose.
- Titrate the regular dose of morphine over several days until the patient is pain free. Either add the total daily dose and the total breakthrough dose given in 24 hours and divide by six to get a new 4hrly dose, or give 30–50% increments (e.g. 5–10–15mg etc.) as 4hrly doses. Increments of less than 30% are ineffective.
- If needed, give a double dose of morphine at night to allow pain-free sleep.
- If the patient can't swallow, use other routes, e.g. rectal, subcutaneous, buccal, intravenous or gastrostomy tube.
- Ratio of morphine PO:SC is 2:1, e.g. 10mg of oral morphine equates to 5mg of SC morphine.
- Ratio of morphine PO:IV is 2–3:1, e.g. 30mg of oral morphine equates to 10mg of IV morphine.
- Explain common morphine side-effects to patients and prevent where possible:
    - *Constipation* – therefore always give with a laxative, e.g. bisacodyl 5mg at night increasing to 15 mg if needed. (Do not give laxative if the patient has diarrhoea.)
    - *Nausea and vomiting* – if this occurs, give metoclopromide 10mg 8hrly, or haloperidol 1.5 mg once a day.
    - *Drowsiness* – may occur in the first few days; if it does not improve after about three days, cut down on morphine dose.
    - *Itching* – less common but if it occurs, give chlorpheniramine.
- Patients on a stable morphine dose should not be sedated. If sedated, reduce the dose and consider adjuvants.
- Morphine is available in immediate-release and slow-release oral formulations. Use slow-release morphine once pain is controlled. Divide the total 24-hour dose into two to get the twice-daily dosage.
- Fentanyl patches can be started once pain is under control on morphine and you know the amount of analgesia the patient needs in 24 hours. Don't use Fentanyl for acute pain.

Adjuvant analgesics

- Although their primary purpose is not analgesic, these medications relieve pain through other mechanisms.
- Adjuvants are particularly useful in pain that is only partially sensitive to opioids, e.g. neuropathic and bone pain, smooth or skeletal muscle spasms, or pain related to anxiety.
- Use adjuvants alone or in conjunction with Step 1, 2 and 3 analgesics.
- The types of adjuvants that are relevant to palliative care are described further below and are:
    - Antidepressants
    - Anticonvulsants
    - Antispasmodics
    - Muscle relaxants / Anxiolytics
    - Corticosteroids.

Antidepressants

- Use for neuropathic pain, presenting primarily as burning or dysaesthesia. Eg:
    - Amitriptyline. Adult dose10–75mg at night, where you should start with a low dose and slowly increase it as needed. Can also be given in a dose of 0.5–2mg/kg at night.
- Side effects include dry mouth and drowsiness.
- Use with caution in the elderly and those with cardiac disease.

Anticonvulsants

- Use for neuropathic pain. Eg:
    - Carbamazepine. Adult dose should start at 100mg twice a day, and can be increased to 800mg twice a day.
    - Sodium valporate 200mg – 1.2g per day.

Gabapentin 100mg three times a day; increase up to 3.6g daily.

Note: Use Phenytoin in the absence of these drugs, at the rate of 100mg 2–3 times/day

- Use Phenytoin and Carbemazepine **with caution** because of the rapid metabolism of other drugs metabolised in the liver.

Antispasmodics

- Use for muscle spasm, e.g. colicky abdominal pain or renal colic. Eg:
  - Hyoscine Butylbromide (Buscopan) Dose: Adult: start at 10mg three times /day; Can be increased to 40mg three times/day
- NB. Can cause nausea, dry mouth and constipation

Muscle relaxants / Anxiolytics

- Use for skeletal muscle spasm and anxiety-related pain. Eg:
  - Diazepam. Adult dose 5mg orally 2–3 times/day.

Corticosteriods

- Use for bone pain, neuropathic pain, headache due to raised intracranial pressure, or pain associated with oedema and inflammation. Eg:
  - Dexamethasone. Adult dose 2–4mg per day for most situations, apart from raised intracranial pressure, nerve compression and spinal cord compression. For raised Intracranial pressure start at 24mg per day and reduce by 2mg daily to the lowest effective maintenance dose. For nerve-compression types of pain 8mg is often used, and for spinal cord compression 16mg is usually the starting dose.
  - If dexamethasone is not available, then adults can also be given prednisolone where a conversion rate of 4mg dexamethasone to 30mg prednisolone can be used.
- **Note:** In advanced disease, corticosteroids may improve appetite, decrease nausea and malaise, and improve quality of life. Adverse effects include neuropsychiatric syndromes, gastrointestinal disturbances and immunosuppression.

E. Special considerations in HIV and AIDS

- Pain in HIV and AIDS (see Table 3 below) is highly prevalent, has various syndromal presentations, can result from two or three sources at a time and has the potential of being poorly managed.
- Such pain may be directly related to HIV infection, immunosuppression or HIV therapy.
- In South Africa the prevalence of neuropathic pain in AIDS patients was 62% prior to antiretroviral therapy, with men more likely to experience pain than women.

Table 3: Common sources of pain in HIV and AIDS

Cutaneous/ Oral	Visceral	Somatic	Neurological/Headache
• Kaposi's Sarcoma • Oral cavity pain • Herpes zoster • Oral or oesophageal candidiasis	• Tumours • Gastritis • Pancreatitis • Infection • Biliary tract disorders	• Rheumatological disease • Back pain • Myopathies	• HIV-related headaches from encephalitis, meningitis etc • HIV-unrelated headaches from tension, migraine etc. • Iatrogenic (AZT) • Peripheral neuropathy • Herpes neuritis • Neuropathies associated with DDI, D4T toxicities • Alcohol, nutritional deficiencies *Modified from Carr*

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- Pharmacological pain management should be as per the WHO analgesic ladder (see earlier in the chapter).
- NSAIDs, tricyclic antidepressants, anticonculsants and non-pharmacological interventions are important – although NSAIDs could exacerbate bone marrow disease and worsen the gastro-intestinal effects of HIV and ARVs so should be used **with caution**.
- Many of the ARVs, especially the protease inhibitors, cause abdominal discomfort, nausea and vomiting.
- Headache and peripheral neuropathies are also common side effects of ART.
- Some antiretroviral medicines interact with analgesics and so **caution** needs to be used when giving analgesics to patients on ART. The main interactions occur with the adjuvant analgesics such as phenytoin, carbamazepine, dexamethasone and amitriptyline.
- Women with HV have unique pain syndromes of a gynaecologic nature specifically related to OIs and cancer of the pelvis and genito-urinary tract.
- African women with HIV are often young with babies and young children, and if they also have HIV this adds emotional, social and spiritual suffering to their physical pain.

F. Be aware ...

- Pain is often inadequately treated.
- Failure to assess pain levels and type causes poor pain control.
- A person with long-standing pain may not show the usual signs of pain.
- Never use slow-release opioids as rescue medication.
- Significant percentages of adults and children cannot metabolise codeine, so it may be ineffective.
- Patients will often have more than one pain.

- Involve adults and children fully in their care. Link doses to their daily routine.
- Children younger than six months are more sensitive to possible opioid-induced respiratory depression, so they need a lower starting dose.

- More detailed information about pain assessment and management, as well as interactions of analgesics with ARVs, can be found in the APCA pocketbook entitled *Beating Pain: A handbook for pain management in Africa*.

References:

- *British National Formulary* (2008). London: BMJ Group and RPS Publishing.
- Twycross R and Wilcock A (2007). *Palliative care formulary* (3rd edition). Nottingham, UK: palliativebooks.com.

CHAPTER 6:
PALLIATIVE CARE IN CHILDREN

Children's talent to endure stems from their ignorance of alternatives.

(Angelou, 1969)

Palliative care for children has been integrated throughout this pocketbook, and so for specific issues relating to children (e.g. pain and symptom control) please refer to the appropriate chapter in the book on that topic. Issues appropriate to children have been highlighted in red throughout the book for ease of identification.

A. Principles of Palliative care in children

- Palliative care for children is a special field, albeit closely related to adult palliative care.
- Palliative care in this context is the active, total care of the child's body, mind and spirit, and it also involves giving care to the family.
- Such care begins when an illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, or wherever the child calls home (WHO, 2002).
- Children are not little adults but young individuals – growing, developing and changing with their own unique and changing understanding of their condition and with their individual responses.
- The focus of palliative care for children is the relief of suffering and the promotion of the best possible quality of life for the child and the family.
- Children require honesty from their healthcare workers and their families.
- The family or primary caregiver is included in all care decisions.
- The family receives ongoing support throughout the course of the condition and into bereavement.
- The older child who has the capacity to understand has the right to be included in all care decisions.
- As far as possible, allow children some control over their care and treatment.
- Siblings require ongoing assessment and support.
- A child's friends and school colleagues will also require support.
- Palliative care for children can be provided from the perinatal and neonatal stages until young adulthood.
- Communication skills will change according to the child's age and developmental stage.
- The emotional impact of a seriously ill or dying child is often greater than that with an adult.
- Grief is often more severe after the death of a child.
- Children suffer grief and bereavement that is often poorly understood by healthcare professionals.
- All caring for children with life-limiting or life-threatening conditions requires specific training in palliative care for children.
- Children's rights must be protected at all times.

B. Assessment issues

- Establish a relationship of trust before beginning assessment. Show respect for the child even when that child is very young.
- Begin with careful explanations to the child and their family.
- Identify family, economic, community and cultural issues that may affect the assessment.
- As far as possible, try to assess the child at their level and try not to bend over them in a manner that could feel threatening. Sit on the floor or on a chair at their level.
- A child has three languages: verbal, non-verbal and play. All may be needed in assessment.
- Assessment of children requires knowledge and skills for each age or stage of development.
- Assessment requires knowledge of normal childhood development.
- As far as possible, involve the child and/or the primary caregiver in all aspects of the child's care and management.
- Remember to assess the child and family holistically – the physical, functional, emotional, social, spiritual, developmental and educational aspects.
- Spiritual assessment in children is frequently ignored or poorly assessed. Simple tools are available, so find one that you are comfortable using or develop one using words that a child will understand (refer to the book *Children's Palliative Care in Africa* for more information).
- Always use assessment tools that have been developed with children in mind.
- Carry a folder with these tools at all times.

- Tools for assessment may vary according to a child's developmental stage.
- Wherever possible, prevent or minimise procedural pain.
- Healthcare professionals and caregivers must be able to apply the tools and assess the responses correctly.
- Assess the need for both clinical and non-clinical interventions.
- Involve the primary caregiver when assessing the younger, non-verbal or developmentally delayed child.
- Communication with children may be more effective if carried out through play activities, art and stories.
- Listen to the child – even a very young child can often tell you more than you can observe.
- Examples of assessment tools include :
    - The HPCA Soweto CARES Score to assess the vulnerability of the child (see Appendix 4)
    - The Touch Visual Pain Scale developed for the African context for infants younger than one year (see Appendix 2)
    - The Revised Faces Scale (Chapter 5)
    - The FLACC Scale for non-verbal children and infants (Appendix 2)
    - Numerical pain scales using the fingers of one hand (Chapter 5).

C. Management issues

- The management of physical symptoms in children's palliative care has a lot in common with adults. However, there are differences in choice of medicines and the dosage given, and this has been integrated throughout the pocketbook.
- The management of psychological, social and spiritual issues needs special consideration for children.
- Providing emotional and psychological support for the sick child is as essential as providing relief of physical symptoms.
- Parents often want to protect their sick child from unpleasant facts, and yet the child often knows a lot about their illness and prognosis.
- Children sometimes ask health professionals difficult questions – e.g. 'Am I dying?' It can be helpful to respond with a question – e.g. 'What makes you ask me that?' and this will help you to clarify how to answer their question and what they are actually asking. The real question may sometimes be completely different.
- Where possible, normalise feelings of fear, anger and sadness and try not to dismiss a child's feelings and beliefs.
- Maintain the child's routine as much as possible so that they feel safe and secure.
- Maintaining hope and a supportive environment whilst advocating for the child's needs are important aspects of palliative care.
- A 'hope for the best, prepare for the worst' approach is often helpful.
- Children, like adults, need to attribute meaning to life and death and are capable of significant spiritual experiences.
- Involving the family in decisions and information sharing is extremely important.
- Often, the palliative phase for children is longer than for adults and there is often a lot of uncertainty around the prognosis.

D. Differences between children's and adults' palliative care

- An understanding of developmental issues is essential when providing children's palliative care.
- Infants and young children are completely dependent on adults and so depend on other people to make decisions for them.
- As children grow and develop, their capacity to care and to decide for themselves increases. Therefore care that is appropriate for a child of 11 may be inappropriate two years later.
- The natural desire of family and carers to protect a child with a devastating illness can lead to that child feeling stifled.
- The child's developmental level will particularly influence:
    - The communication of wishes, fears and symptoms
    - Their understanding of illness and death
    - An assessment of symptoms
    - The management of symptoms
    - Decision making
    - The importance of play as a means of understanding the world
    - The importance of school.

E. Special considerations in HIV and AIDS

- HIV has become a major cause of infant and child morbidity and mortality in Africa.
- 95% of children with HIV are infected by vertical transmission from mother to child. Therefore HIV and AIDS in Africa is a multi-generational disease of families, in which everyone in the family is affected by the disease.
- Support for children must be delivered as a comprehensive package within the context of family-centred care.
- Making a diagnosis of HIV in children in resource-limited settings is a challenge, especially in very young children, because of limited laboratory resources and the high cost of tests. Health professionals are therefore often reliant on clinical signs and symptoms.
- Younger children with HIV have different OIs than older children – as they get older they develop disease conditions caused by the reactivation of previous infections, as is often seen in adults.
- Treatment protocols vary from country to country, and in many countries it is difficult to get paediatric formulations of medicines.
- HIV and AIDS will impact on an HIV-positive child's development, with growth, motor skills, cognitive ability and socialisation all potentially being affected.
- The impact of the disease will depend on the developmental stage at which symptoms present.
- Parents tend to want to protect their children from the knowledge of their disease, yet evidence suggests that children allowed pertinent information and knowledge are better able to 'own' their disease, adhere to medication and deal with the discomfort of interventions etc.

F. Be Aware ...

- Children may respond differently to medications and dosages.
- Neonates, very young and very small children may require smaller doses of medication than their weight would suggest.
- Malnutrition and dehydration, as well as opportunistic infections, are often the most life-threatening conditions requiring immediate treatment.
- Paediatric formulations are more accurate for children than tablets that need to be divided.
- Certain formulations may require refrigeration, which may be a challenge in many areas.
- Always know a child's weight because this is the basis for deciding on dosages.
- Children's understanding of illness, dying and death changes with their developmental stages, and the healthcare worker's approach will therefore need to change at each developmental stage.
- The healthcare worker should have a paediatric palliative-care guideline to refer to for pain and symptom management – e.g. *Rainbow Children's Palliative Care Guidelines*, or the textbook *Children's Palliative Care in Africa* edited by Dr Justin Amery.
- Adolescents and young adults usually have sexual needs that should be discussed openly.
- Children are often very resilient and respond quickly to palliative interventions.
- All children have similar needs regardless of whether they are healthy or ill – treat the child as normally as possible.

References:

- EAPC Taskforce for Palliative Care in Children (2008). *Palliative Care for Infants, Children and Young People. The Facts*. Rome: Fondazione Aruzza Lefebvre D'Ovisio Onlus.
- Bikaako-Kajura W, Luyirika E, Purcell DW, Downing J, Kaharuza F, Mermin J, Malamba S and Bunnell R (2006). 'Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV-infected Children in Uganda' in *AIDS Behaviour* 10(Supp1, July): 85–93.

CHAPTER 7: PALLIATIVE CARE EMERGENCIES

These emergencies do not only mean situations that are eminently life threatening, but also those that could result in impaired quality of the patient's remaining life and that of the family in their bereavement.

(Cambridge and Huntingdon Palliative Care Group)

A. Emergency care principles

- A palliative care emergency is any change in a patient's condition that requires urgent and immediate intervention.
- Assessment must be prompt and complete if good results are to be achieved.
- The following should be considered during the management of a palliative care emergency:
  - The nature of the emergency
  - The general condition of the patient
  - The stage of the disease and prognosis
  - The availability of possible treatments
  - The affordability of possible treatments
  - The likely effectiveness and toxicity of available treatments
  - The patient's wishes
  - The carer's wishes.

B. Types of palliative care emergencies

- Major emergencies occurring in palliative care, described further in section D below, include:
  - Bone fractures
  - Choking
  - Haemorrhage
  - Hypercalcaemia
  - Seizures
  - Severe pain
  - Spinal cord compression (SCC)
  - Stridor
  - Superior vena cava obstruction (SVCO).

C. Assessment of the emergency

- What is the problem? It is important to make a proper diagnosis.
- Can the problem be reversed?
- What effect will the reversal of the problem have on the patient's overall condition?
- Can active intervention maintain or improve the patient quality of life?
- Is the treatment option in mind available and affordable?
- What is the patient's wish?
- What is the carer's wish?

D. Management of palliative care emergencies

Bone fractures

- Bone fractures can occur with no or minimal trauma, especially to weight-bearing bones such as the femur or vertebrae.
- **Causes**
  - Fractures are common when there are widespread bone mestastases in cancers such as lung cancer, breast cancer, renal cancer and myeloma.
  - Bone fracture may also be due to osteoporosis or trauma.
- **Signs and symptoms**
  - Severe pain around the site
  - Deformed limb
  - Pain on movement
  - Bone grating
  - Inability to use the limb
  - Patient may go into acute confused state.
- **Assessment and management**
  - Analgesia and efforts to immobilise the site of fracture comprise the first remedial steps.
  - Immobilise the limb where possible. This may mean applying a splint or a plaster-of-paris cast – though if

the patient is fit enough it may be possible to surgically stabilise the fracture.
- Internal or external fixation may be required.
- Radiotherapy can be given, and even a single fractional dose may be of benefit as it prevents further progression of bone metastasis.

Choking

- Choking is the inability to breathe as a result of acute obstruction of the pharynx, larynx or trachea.
- This can be due to local tumour or neurological swallowing difficulties, as well as a more general obstruction.
- *Assessment and management of choking from local tumours*
  - Acknowledge the patient's and family's fears.
  - Discuss interventions truthfully with the patient and family.
  - High-dose steroids may be useful to reduce the swelling around the obstructing tumour.
  - Palliative radiation, if available, may also help.
  - Midazolam 5mg sc can help to sedate the patient and reduce anxiety.
  - Rectal diazepam can be used, especially in the community.

- In children, especially with a sudden onset of choking, think about foreign bodies!

Haemorrhage

- Haemorrhage is profuse bleeding from one of the major blood vessels, e.g. the carotid artery.
- While uncommon, haemorrhage can be a frightening event for patient and carers.
- Haemorrhage is, however, often predictable and needs to be proactively managed – e.g., make medicines available in the home care setting in case the possible emergency occurs.

- **Causes**
  - Catastrophic bleeding from a large blood vessel due to tumour erosion from areas such as the head and neck, stomach, pelvis, bladder or lungs.
  - Patients with cirrhosis may also have torrential bleeding from oesophageal varices.
  - Many patients also have disorders of their blood-clotting systems.
  - Low platelets associated with malignancies (bone marrow infiltration) and HIV.
- **Assessment and management**
  - Communicate gently and truthfully and stay with the patient.
  - Use dark cloths to soak up the blood.
  - Pack a bleeding nose with gauze and BIPP or use nasal tampons. Adrenalin-soaked ribbon gauze may also help as it causes local vasoconstriction.
  - For small oral bleeds, crushed cyclocapron may help.
  - Sedation (such as diazepam 10mg PO/PR) is indicated if the patient is distressed.
  - Remember that if the bleeding is torrential, the blood pressure will drop quickly and so medications will not be effective.
  - The family or staff of a patient having the likelihood of a haemorrhage should be counselled about that possibility and advised what they should do in such a situation – as well as being offered support after the event if it occurs.

- Epistaxis (severe nose bleed) is particularly prevalent in children with haematological malignancies.
- In children, aim for rapid and complete sedation with benzodiazepines, and/or opioids if available; use parenteral routes.
- If able to swallow, give children double the usual dose of morphine with or without diazepam.
- If unable to swallow, give large doses of morphine and diazepam rectally. Rectal valium dose:
  - If weight is not known: <3years 5mg; >3years up to 10mg
  - If weight known: 0.5–1mg/kg up to a maximum of 10kg.

Hypercalcaemia

- Hypercalcaemia is a threatening metabolic disorder associated with cancer.
- It is common in patients with breast cancer, multiple myeloma, and head, neck and renal tumours.
- **Causes**
  - Lytic bone lesions, thus causing calcium to be released from the bone, along with a decrease in the excretion of urinary calcium.
- **Signs and symptoms**
  - General malaise
  - Nausea and vomiting
  - Anorexia
  - Constipation
  - Bone pain
  - Thirst and polyuria
  - Polydypsia
  - Severe dehydration
  - Drowsiness
  - Confusion and coma
  - Cardiac arrhythmias.
- **Assessment and management**
  - Treatment of hypercalcaemia can markedly improve symptoms even in patients with advanced disease.
  - Proper management of hypercalcaemia makes end-of-life care and management less traumatic for the patient and the carer.
  - The patient may be admitted for hydration and bisphosphonate therapy (e.g. disodium pamidronate 60–90mg in sodium chloride 0.9%, 500ml over 2–4hr). However, this treatment might not be available due to cost.

Seizures

- Seizures can be frightening and their occurrence is often unpredictable.
- People may attach significance to these events, such as being bewitched.
- Seizures can be generalised, with jerking of the whole body, or limited to a specific area such as an upper limb or face. The period of jerking is often followed by a period of unconsciousness.
- Most seizures are self-limiting and efforts can be made to prevent or limit future seizures.
- A prolonged seizure lasting more than 10 minutes or one that does not terminate needs more urgent treatment.
- **Cause**
  - Pre-existing epilepsy
  - Stroke
  - Trauma, including subdural haematoma
  - Primary or secondary brain tumour
  - Intracranial bleed
  - Biochemical disturbance, eg. hyponatraemia, hypoglycaemia, uraemia or hypercalcaemia
  - Infections such as cerebral toxoplasmosis, meningitis, malaria or encephalitis
  - Alcohol withdrawal.
- **General care**
  - Keep the patient safe and free of hazards until the seizure is complete.
  - Protect the airway of the patient so they can breathe – **but** do not place anything in their mouth (eg spoons, spatulas).
  - Loosen any tight clothing if possible.
  - After the seizure is over, place the patient in the recovery position and ensure someone stays with them.
  - Observe and record the length and frequency of the seizures.
  - Support the family and patient, and address their fears and concerns.
- **Assessment and management**
  - No treatment is needed for self-limiting seizures that last less than five minutes.
  - To stop more prolonged seizures:
    - Diazepam 10mg given per rectum or IM; repeat after 10 minutes
    - Midazolam 5mg sc is available; may also be given buccally
    - Paraldehyde 5–10mls diluted in saline as a rectal enema
    - Phenobarbitol 200mg IM if patient not responding to diazepam.
  - To prevent seizures or reduce their intensity and frequency:
    - Phenytion 150–300mg daily and titrate gradually, watching for toxicity and drug interactions
    - Sodium valproate 600mg daily in divided doses and titrate to maximum 1500mg; this is the medication of choice when there is concern about drug interactions, including those in patients on ARVs.

- In children, a suitable rectal valium dose would be:
  - If weight is unknown: <3years 5mg; >3years up to 10mg
  - If weight known: 0.5–1mg/kg up to a maximum of 10kg.
- Clonazepam (Rivotril) 0.02mg/kg per dose slow IV (max = adult dose of 1mg).
- Phenobarbital 20mg/kg IV or PO in neonates and 10mg/kg in infants and older children, then 4–6mg/kg/day IV, SC or PO.
- Midazolam 100mcg/kg SC over one minute, then if necessary 200–700mcg/kg over 24 hours by sc infusion.
- If available, paraldehyde 0.1–0,5ml/kg mixed with an equal amount of mineral oil in a glass syringe and administered rectally is an effective and safe drug for managing seizures in children who have not responded to the above measures, especially where are concerns around respiratory suppression.

Severe pain

- This should be assessed and managed as per the WHO analgesic ladder and is covered in Chapter 3.

Spinal cord compression (SCC)

- In SCC, the spinal cord is compressed causing neurological symptoms.
- Cord compression occurs when there is extrinsic or intrinsic obstruction to the spinal cord.
- If it is not managed quickly, it progressively turns into irreversible neurological damage (paralysis).
- Be alert for patients with new thoracic back pain.
- **Causes**
  - Vertebral metastases, leading to collapse, is the most common cause
  - Epidural infiltration
  - TB should be considered
  - Less often, there is a vascular interruption.
- **Signs and symptoms**
  - Backache – which may radiate circumferentially and where the patient may complain of a tight band around the waist
  - Weakness in the lower limbs
  - Abnormal sensation in the lower limbs – pins and needles, tingling sensations, crawling insects, etc.
  - Bladder symptoms
  - Constipation.
- **Assessment**
  - A quick yet proper assessment can help to arrive at an accurate diagnosis, which can help to maintain or restore motor functions in patients who would otherwise face disability for the rest of their life.
  - SCC is common in patients with advanced cancer of the breast, lungs or prostate gland.
  - A careful history and neurological examination should be made, including looking for what sensory level applies.
  - Ask about bladder and bowel sphincter function.
- **Management**
  - Most important is to think of the diagnosis and to start treatment before irreversible neurological loss occurs.
  - Start high-dose steroid dexamethasone 16mg in divided doses.
  - Arrange appropriate investigations such as x-ray, bone scan, CT myelogram or MRI scan, depending on availability.
  - Refer for urgent (within 1 day) radiotherapy if available.
  - Surgery may also be considered, depending on the patient's condition and the availability of facilities and surgeons.
  - Once neurological loss has occurred it is often irreversible, but good rehabilitation will maintain function and prevent complications.

Stridor

- A stridor is a high-pitched sound of breathing in partial laryngeal or major-way obstruction.
- It is common in head and neck tumours or mediastinum.
- It causes exhaustion from laboured breathing and anoxia.
- **Causes**
  - Pressure on the upper airways by extrinsic compression caused by such things as enlarged lymph nodes or primary tumour in the lungs, head or neck.
- **Management**
  - If impending obstruction is diagnosed, consider whether pre-emptive treatment with radiotherapy or tracheostomy is indicated.
  - Discuss the possible events with the patient and their family.
  - Offer sedation with morphine and benzodiazepines; 5–10mg morphine and 5–10mg diazepam given PO/SC/IV/PR depending on the patient's condition.
  - In hospital, and if facilities are available and the condition of the patient allows, consider:
- Bronchoscopy
- Chemotherapy

- In children, consider dexamethasone high dose 0.5mg/kg 1V over 2 minutes
- Nebulise children with adrenaline: 1ml of 1: 1000 added to 4mls of saline, with a minimum of 30 minutes between sessions.
- Give parenteral morphine and/or benzodiazepine if the breathlessness is severe (Note: oral/rectal diazepam works as fast as parenteral and so you can use injectable diazepam rectally.)

Superior vena cava obstruction (SVCO)

- SVCO is the partial or complete obstruction of blood flow through the superior vena cava into the right atrium.
- SVCO usually results in impairment of the venous return.
- **Causes**
  - External compression by tumour or lymph nodes, or thrombosis as a result of compression.
- **Signs and symptoms**
  - Dyspnoea
  - Facial/upper body including arms swell
  - Headaches
  - Visual changes
  - Unclear mind (muzziness)
  - Cough
  - Dysphagia.
  - Some patients may complain of a sensation of drowning. This condition is common in patients with tumours within the mediastinum, i.e. bronchial carcinoma, cancer of the breast and lymphoma.
- **Assessment**
  - Examination may reveal engorged conjunctivae, periorbital oedema, dilated neck veins and the collateral veins on the arms and chest wall.
  - Late signs include; pleural effusions, pericardial effusion and stridor.
- **Management**
  - In advanced disease the patient needs relief of their acute symptoms.
  - Give high-dose corticosteroids (e.g. dexamethasone 16mg PO/IV) and, if available, urgent radiotherapy .
  - At the same time, treat dyspnoea symptomatically with morphine (5mgs 4hrly) and/or a benzodiazepine.
  - Practical management of dyspnoea is also important – e.g., teach the patient how to breathe slowly, and encourage a calm environment.
  - Without treatment, SVCO carries a very poor prognosis.

E. Special considerations in HIV and AIDS

- In HIV and AIDS the most common palliative-care emergencies are SCC (often due to TB), seizures due to infections, and overwhelming sepsis.
- Treatment for such emergencies is as above, with special consideration of anti-infection agents.
- Overwhelming sepsis in a patient with HIV and AIDS may not display the typical signs of fever.
- Intracranial or meningeal infection should be considered when there is a rapid decrease in the level of consciousness.
- Opportunistic infections may present with sudden deterioration or collapse.

F. Be Aware ...

- While the required facilities to manage some palliative care emergencies may be limited in some African settings, health workers should always endeavour to undertake impeccable assessment, communicate with the patient and the family, and do whatever they can for the patient.
- Clear thinking is crucial in handling emergency situations, and calmness and patient comfort are paramount.

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CHAPTER 8: DEATH AND DYING

There is a time for everything, and a season for every activity under heaven:
A time to be born and a time to die,
A time to plant and a time to uproot,
A time to kill and a time to heal,
A time to tear down and a time to build,
A time to weep and a time to laugh,
A time to mourn and a time to dance.
(The Bible: Ecclesiastes chapter 3 verses 1–4)

A. Death and dying principles

- Death is a part of life, and people need to be allowed to die in peace and with dignity.
- During the dying phase, patients should continue to receive adequate pain and symptom control.
- Palliative care neither hastens nor postpones death and views dying as a normal process.
- It is important that palliative care is delivered in a culturally sensitive manner.
- Palliative care patients have had a diagnosis of a life-threatening illnesses such as HIV/AIDS and cancer; therefore there is usually a preparatory period for death.

- It is hard to watch and care for a dying child. It is important to support the parents and to encourage them to give the child special attention and demonstrate affection during his or her dying stages.

B. Preparing to care for the dying

Prepare yourself

- Contemplate your own death and preferences for dying – this can help you empathise with a patient who is losing everything known to them and the family who are losing a precious loved one. However, it is important not to apply your own preferences to the patient.
- Some principles for preparing yourself to care for the dying are as follows:
  - Where possible, get to know the patient and family for some time before death. If referred late, spend time with patient and family to gain their confidence.
  - Ensure the patient and family are aware that you will care for them.
  - Prepare the patient and family well in advance for death.
  - Be knowledgeable about the medical management of all possible events.
  - Be aware of spiritual aspects and needs, and provide for them.
  - Encourage the family to talk to the patient, reassure them and pray with them (as appropriate).
  - Find out whether the patient has any special requests for the family after death.
  - Be familiar with, and respect, religious and cultural rituals surrounding death and dying,
  - Facilitate bereavement support for the family.
  - Be aware of your own affection for the patient. You too have bereavement needs. Know how to address them with a trusted team member.
- Remember that autonomy will be a priority for adults with the cognitive capacity to understand decisions.

- Children have partial autonomy that increases in proportion to their increasing abilities to comprehend situations and accept responsibility for their decisions.

- **Prepare the patient and their family**
- Gently ensure that the patient and their family understand that death is near and explain some of the signs of dying – e.g.:
  - Gradual increase in drowsiness and/or weakness
  - Changes in breathing pattern
  - Death rattle
  - Cheyne–Stokes respiration
  - Skin colour changing as circulation changes
  - Possible terminal restlessness.
- The presence of a loved one, holding hands, touching, praying etc. can bring comfort to the patient.
- The importance of having friends and family needs to be recognised and respected.
- Reassure the patient and the family that dying is not usually uncomfortable – e.g. grunting is not a sign of pain.
- Be prepared to discuss cultural issues and support cultural needs as long as they do not cause suffering to the patient.
- Explore and discuss the issue of a patient writing a will and/or other inheritance issues to protect the bereaved.
- Facilitate the resolution of unfinished business.

- Hold family conferences to facilitate future placement of any children.

C. Management of the dying

- The holistic approach continues to the end of life and beyond.
- Help from other team members or organisations should be sought when indicated.
- There are different 'roads to dying' – see diagram below. The majority of patients take the 'usual' road; however, when the 'difficult' road is being trodden by the patient, it is important to be there to support them and their family.

Roads to dying:

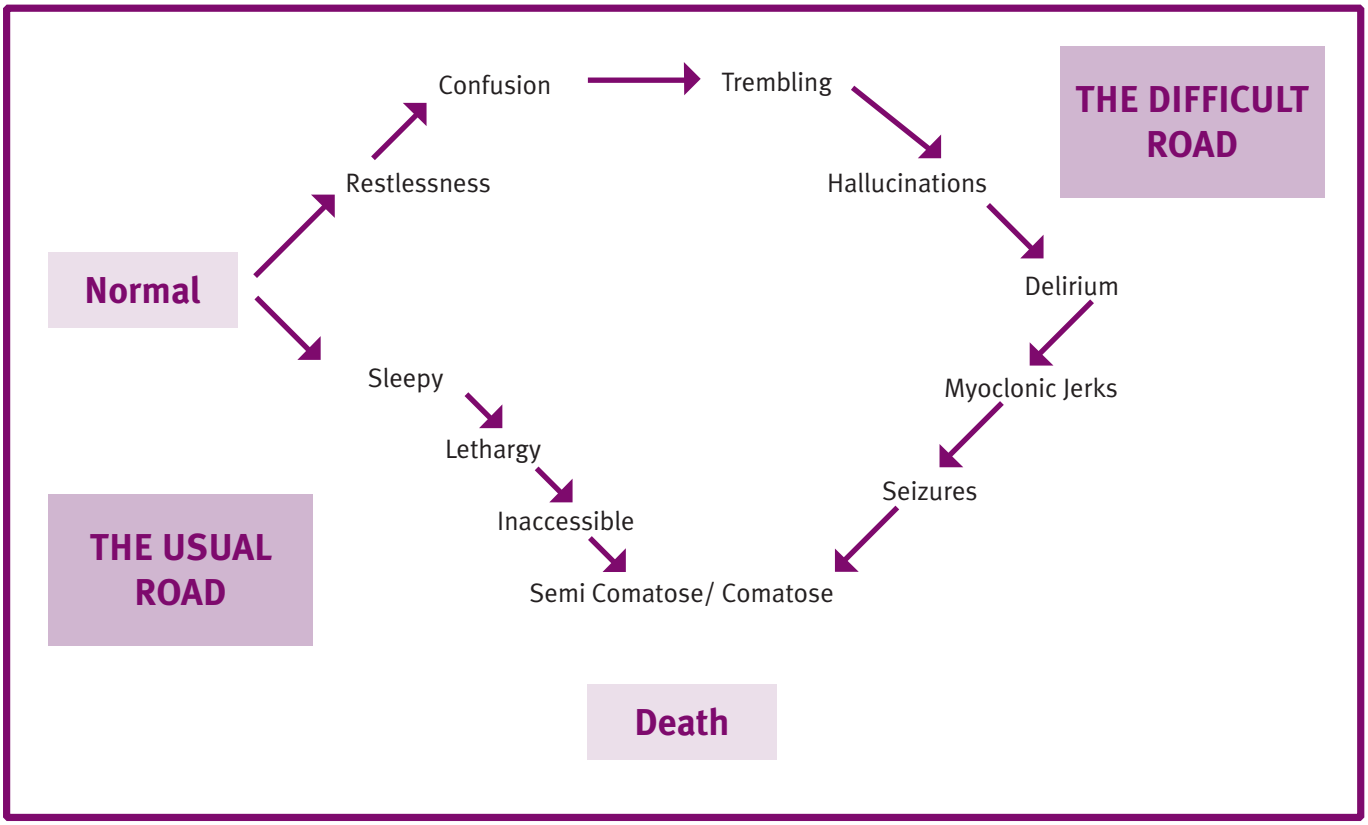
- It is not possible to accurately estimate the time of death; you can only say that death is getting closer.
- The dying person may remain aware of their surrounding until the moment of death. However, this awareness may be limited (e.g. confused about time, mumbling, staring into space, odd movements of the hands, seeming to see things).
- Hearing often remains intact so take care in conversation and include the patient if talking at the bedside even if they appear asleep or unconscious.
- Encourage the family to continue talking to the patient even when he/she is too weak to respond.
- Reduce unnecessary medications but continue with pain and symptom control.
- As the patient is dying, the body organs begin to decline.
- Near death, hepatic and renal function are reduced, so medications may linger in the body. Therefore the patient who had their pain controlled by regular doses of morphine may now manifest some of the side effects as the active ingredients accumulate in the bloodstream.
    - *Action:* stop the morphine for a day (with instructions for breakthrough pain) and then commence again at a lower dose or with longer hours between (e.g. extend intervals from 4-hourly to 6–hourly).

D. Special considerations for pain and symptom management at the end of life

- As the disease advances towards the end of life there may be an escalation in pain and other symptoms, requiring ongoing increases and adjustments to be made in drug therapies.
- If the patient has received good palliative care, their pain should be controlled before they enter the terminal stage of the illness. However, this will often not be the case.
- The pain and symptom assessment and management measures addressed in earlier chapters of this handbook are still appropriate for the terminal phase of illness, although several alternative methods of administering analgesics may be required as a result of decreased oral intake and consciousness.
- Such alternative methods of providing analgesia include:
    - Rectally
    - Sublingually or bucally
    - Transdermally via pain patches such as fentanyl
    - Subcutaneously – can be done at home
    - Via a nasogastric tube
    - Intravenously (in hospital).

Rectal analgesia

- Morphine suppositories are sometimes available.
- Long-acting morphine, such as MST 12-hourly, can be used by the rectal route.



Sublingual or buccal analgesia

- Morphine solution is absorbed from the buccal mucosa – however, because absorption is variable, a larger dose may be needed.
- Morphine solution can therefore be given in this way to moribund patients.

Subcutaneous analgesia

- The subcutaneous route is useful if the patient is unable to ingest medication.
- Intermittent dosing via a subcutaneous needle (butterfly) can be given, such as 4-hourly morphine.
- Syringe drivers, when available, can be used to administer analgesics and other symptom control drugs subcutaneously. This is a safe and relatively painless way. It is often used in a hospice or home care setting.
- There are different types of syringe drivers available. The most frequently used is the Graseby MS26 infusion pump that delivers a constant amount of analgesia through a butterfly needle inserted into the subcutaneous space over a 24-hour period.
- To deliver analgesia via a syringe driver, you need to:
    - Convert the dose of morphine from the oral dose to a subcutaneous dose – this is done by adding up the total oral dose over 24 hours and dividing it by two. For instance, 10mg 4hrly orally = 60mg per 24hrs orally = 30mg per 24hrs parentally.
    - Dilute the amount of parenteral morphine in a luer-lok syringe with normal saline/ sterile water and fill up the syringe to a fluid length of 48mm (around 8–9mls). (**Note:** normal saline should not be used with cyclizine as it causes crystallisation.)
    - If a Graseby MS26 syringe driver is used, then set it at a rate of 2mm/hr in order to provide 24 hours of continuous morphine.
    - Insert a butterfly needle under the skin over the abdomen, upper arm or thigh.
- Other drugs can also be given via the syringe driver, such as anti-emetics (e.g. Cyclizine), metoclopramide, haloperidol, hyoscine or midazolam.
- Care needs to be taken to ensure that if more than one drug is given via the syringe driver, they can be mixed safely. For instance, dexamethasone should not be mixed with other drugs as it will precipitate out.
- Challenges to the subcutaneous route are as follows:
    - In some places across the African region, the subcutaneous route has not been an acceptable method of pain control, while for others it has been. So the culture and environment needs to be considered when considering using this route.

- Involving the patient and their family – there is often fear about using the syringe drivers.
- Which machine to use – simplicity, convenience, availability and cost all need to be taken into account. The 'Springfusor' may be used instead of the Graseby pump, becasue it uses a spring so does not need batteries, and it is simpler and cheaper.
- Some drugs are too irritant to be given subcutaneously, e.g. diazepam, chlorpomazine and prochloperazine.
- Drugs need to be changed every 24 hours and the needle site checked, so the patient needs to be seen by a health professional every 24 hours – which may not be possible in some settings.

Decreasing intake of food and fluids

- The patient may not experience hunger and may feel very little thirst. There is no problem with this so long as their mouth is kept clean and moist.
- Usually patients do not need parenteral fluids or enteral feeding; however, on occasion this may be provided to help control symptoms of dehydration.
- Teach the family to clean the patient's mouth with a moist cloth and apply petroleum jelly to the lips in order to prevent drying and cracking.

Respiratory symptoms

- Death rattle – i.e. noisy, rattling breathing when a patient is deeply unconscious and close to death – can be a distressing problem for relatives. But it is rarely a problem for the patient.
- Death rattle is usually due to pooling of saliva, though there may also be respiratory tract infection, pulmonary oedema or gastric reflux.
- Explanation and reassurance for the family and staff are essential.
- Positioning to maximise postural drainage may help, depending on the cause.
- Suction is seldom needed and may be traumatic unless the patient is deeply unconscious.
- Antimuscarinic medications are effective when given early for salivary pooling.
- Hyoscine hydrobromide 20mg SC is usually the most available.
- Hyoscine hydrobromide SC 400mcg and glycopyrronium 200mcg SC are alternatives.
- Cheyne–Stokes breathing may alarm family members in the periods of apnoea. They need to be reassured that this can persist for some time before death.

- Hyoscine hydrobromide can be given to children aged 1–12 years: 10mcg/kg SC/IV as single dose, or 20–60mcg/kg over 24 hours in SC or IV infusion.
- Glycopyrronium 4–10mcg/kg 6hrly IV or SC (max 200mcg/dose) can be given.

Travelling the 'difficult' road

- Restlessness, confusion, hallucinations and delirium can be treated with haloperidol 1.5–2.5mg. First, though, exclude remediable causes such as a full bladder or rectum.
- Seizures should be treated with diazepam 5–10mgs IV (or, if not possible, IM). If available, midazolam 2.5–5mgs SC (which lasts up to three hours).
- Manage patient and family calmly, touching and holding the patient and family member as appropriate.

- A child dying is painful to watch and care for in any culture.
- Depending on the age of the child, death may be acknowledged, even feared; but many children are more trusting, more spiritual and accept death although fearing separation.
- It is important to support the parents and to encourage them to give special attention and demonstrate affection during the dying stages.

E. After death

- Immediately after death there will be rituals to be carried out according to custom or religion. Allow the family to take this over.
- Remember that burials in Africa will often take place within 48 hours; this is particularly important for Muslims, who have to be buried before sunset on the day they died.
- The body may need to be preserved and transported – this may be done in a mortuary or traditionally in the village. Such action can preserve the body so that the funeral can take place up to 10 days later.
- There are many different customs and rituals that will be upheld in different parts of Africa – e.g.:
    - Many cultures believe that the spirit is around for several days after death.
    - Friends and relatives may accompany the body for the first 24 hours. The body is never left alone but prayers, hymns and comfort are there for the body and the family.
    - In some cultures, food and precious belongings are put into the coffin.
    - The body may be buried in the ancestral home, in the garden.
- In some countries in Africa, cremation is rare.
- The extent and the depth of bereavement differs in every culture. This topic is addressed in Chapter 9.

F. Special considerations in HIV and AIDS

- A similar approach is needed for patients who are dying, regardless of their disease.
- The medication regimen needs to be simplified to only those medicines needed for good symptom control. This may therefore include stopping ARVs or anti-TB treatment.
- The provision of care through home-based care services and HIV support services is important.
- It is important that everyone caring for the patient is aware of universal precautions, particularly if handling bodily fluids.
- It can be hard to know when the end is really the end, because patients may be seriously ill with an OI, which is treated and then they recover.
- Signs and symptoms associated with decreased survival include:
    - Poor performance status, with more than half the daytime spent in bed
    - End-stage organ failure and anorexia
    - Decreased response to ART, or the development of resistance
    - Wasting and loss of >30% lean body mass
    - Very low CD4 count.
- However, actual survival time may vary from days to weeks, months or even years.

G. Be Aware....

- Whether we have met with death before or not, we all need to take time away to think about our death and what we would like if all things were equal.
- As we attend to our patient in this situation, we need to ask ourselves constantly, 'What would I want if I was dying like this?'
- Not everyone will have a peaceful death.
- Many of patients die at a young age. The commonest age range in many African countries is 30–40, a time when there is unfinished business, anxiety about the children, etc.
- Bringing someone to peace with their family and their God before death can be one of the most rewarding events in the life of a carer, professional or volunteer.

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CHAPTER 9: BEREAVEMENT

The purpose of bereavement is not to let go of the deceased and move on, but to find ways to remember the dead person that are safe, healthy and less painful as time goes on.

(Thomas and Jay, 1997)

Bereavement principles

- Helping the family, including children, to cope with grief and loss forms an integral part of palliative care.
- A comprehensive assessment (including a genogram – see Appendix 5) undertaken at initial contact with the family will provide information on family deaths, other losses, quality of relationships, coping mechanisms, depression, and any alcohol or substance abuse.

- Families are encouraged and equipped to include and inform children of all ages in understanding illness.
- Children are supported in their involvement with the patient and are prepared for bereavement.
- Special attention is paid to the bereavement needs of children of all ages. The explanation of death is age related and child sensitive within the family and cultural context.

Bereavement in general

- Bereavement is the normal process through which people adapt to a life without a loved one. However, complicated grief can lead to serious illness and requires professional intervention.
- Bereavement is a complex mix of individual feelings (grief) and a process that we show to others in ways that are strongly influenced by environment, culture and society (mourning).
- Feelings of grief during bereavement can be painful; physically, socially, spiritually and emotionally.
- Risk factors for complicated grief include multiple losses and dysfunctional relationships.
- There are three main areas relating to bereavement needs in palliative care:
    - Living w ith a life-threatening illness means facing loss of life and loss of a future.
    - Patients may have lost children, spouses and other relatives in the course of their lives from many causes. Emotional, social and spiritual care during the illness will explore bereavement for patient and family members so as to provide peace and resolution during the dying process.
    - Emotional, spiritual and practical support is provided to all family members who require help after the death of the patient for as long as is necessary.
- Periods of bereavement vary according to:
    - The manner of death (long illness, sudden death or traumatic death such as car accident, murder, medical mistake)
    - The age of the person who dies (a child's death often feels out of place; an older person has often had longer relationships)
    - The age of the bereaved (child development affects reaction; life stage is relevant)
    - Gender (women are often allowed more emotional expression than men)
    - Previous experiences of loss and their impact
    - Support systems
    - Personal coping styles
    - Family and cultural rules.
- In sub-Saharan Africa, the high incidence of cancer- and AIDS-related deaths means that many families experience multiple losses and hardships, such as unemployment, poverty and malnutrition, during their bereavement.

- Adults and children react differently in bereavement because of different levels of understanding of death and the ability to express things differently at various stages of life. By the time late childhood is reached, most people understand that death is:
    - Permanent and irreversible (the body cannot be revived)
    - Unavoidable (death is inevitable and cannot be escaped)
    - Universal (death happens to everyone).

Common reactions in bereavement

- There are physical, emotional, social and spiritual reactions to loss. These are experienced in a complex mix and change over time. Some examples follow.
- Physical reactions:
  - Aches and pains
  - Nausea and/or vomiting
  - Headaches
  - Confusion, weakness and numbness
  - Change in sexual needs (loss/increase of libido)
  - Vulnerability to infections, cold, illness (low immunity)
  - Changes in eating and sleeping patterns
  - Shortness of breath
  - Dry mouth
  - Sweating
  - Frequent urination.
- Emotional reactions:
  - Disbelief
  - Numbness
  - Sadness
  - Crying, even sobbing
  - Unexpected thoughts and feelings, often painful
  - Guilt
  - Panic and fear
  - Appearing distracted
  - Feelings of helplessness
  - Anger (at self and others)
  - Blame
  - Regret.
- Social reactions:
  - Needing to say goodbye (stay with the body, view the body)
  - Interaction with people at public gathering, funeral
  - Selecting and undertaking rituals
  - Self-absorption and anti-social behaviour
  - Needing to talk of the deceased
  - A sense of isolation from the world ('in a bubble')
  - Attempting to carry on as usual (social face)
  - Needing to be alone or need to be with others.
- Spiritual reactions:
  - Questioning why this has happened
  - Challenging the belief system (strengthening, decrease or change in beliefs)
  - Bargaining with a higher power
  - Talking to the deceased
  - Dreams that may have significance about the deceased
  - Review of the meaning of life
  - Consideration of ending own life.

- Children's reactions will depend on age, personal development and environment. An understanding of the meaning of death changes as a child gets older:
  - Children 0–2 years of age (infants and toddlers):
    - Miss the physical contact, security and comfort if a main caregiver dies.
    - Show upset by changes in sleeping or eating patterns, crying or irritability, and becoming withdrawn.
    - When toddlers, may be angry and have tantrums or go back to baby behaviour.
  - Children 3–6 years of age:
    - Are unable to understand that death is for ever and may ask when the dead person is coming back.

Confuse fact and fantasy and may think the death was caused by magic.

    - Grieve in bits and pieces – at times appearing to have forgotten about the death and able to play happily, then becoming upset again.
  - Children 6–9 years of age:
    - Are able to understand that death is for ever (permanent) and it happens to everyone (universal) but still imagine that death is avoidable.
    - Are interested in practical matters, for example what happens to the dead person's body.

May feel responsibility for causing the death because of behaviour or thoughts.

  - Children 9–12 years of age:
    - Have approximately the same understanding of death as adults: death will happen to everyone sooner or later (universal); no-one escapes it, including them (unavoidable); and death is for ever (permanent).
    - Understand that death can be sudden and can happen at any time (not just for the elderly and sick); may fear their own death.
    - Begin to think about the meaning of life and what happens after death.
  - Adolescents
    - Have as much understanding of death as adults.
    - May take risks to 'test' life.

Management of bereavement

- Ideally, bereavement planning starts before the death of the patient.
- Make contact as soon as possible to acknowledge the death and to offer condolences according to personal and cultural norms and customs. Some help with documentation such as a will or death certificate may be needed.
- Give information about the illness and the process of death if there is confusion about what happened. Use simple explanations and avoid medical jargon.
- Be there to listen, even when there is repetition – the latter is necessary for bereaved people to accept the reality of the death.
- Inform all family members about the bereavement process and what to expect physically, emotionally, socially and spiritually in this.
- Do not discourage the bereaved from expressing sadness, depression or anger by trying to comfort. These and other extreme emotions are all normal, although they can be distressing to witness.
- Allow periods of silence.
- Encourage talk of the deceased as much as is needed. Ask about the deceased and use their name to make it personal. Share memories by asking questions such as: 'Where did you meet?', 'What kind of child was she?', 'Can you tell me about him?'
- Explore the spiritual needs of each family member and facilitate discussion, networking with a traditional healer or religious leader as required. Do not assume faith will have remained the same as before the death.
- Some people express the pain of grief in tears, which can be very helpful. Others feel unable to cry easily (men are often discouraged from crying) and it is important to help them find alternative forms of emotional release. Physical activity is especially helpful, and may include walking, playing sports, hitting a punch bag, or gardening.
- Encourage regular physical activity for all bereaved persons as this helps the mind and body to process emotional pain.
- Suggest the family use journals and art, or create a memory book to share and express memories.
- Do not offer platitudes. These include 'It was for the best,' or 'He is in a better place now.' Also, do not say, 'I know exactly what you are going through,' because you do not know that this is true and it may certainly not be how the bereaved person is feeling.
- Bereavement can take a very long time, much longer than people imagine. Let bereaved persons know to expect that they may perhaps still be struggling some months or years later.
- Prepare families for times that may be especially hard, such as birthdays, death anniversaries, family celebrations and school/university events.

- Adults need to provide children with explanations, reassurance and the freedom to express emotions about death and loss.
- Encourage family members to include children in rituals, depending on cultural expectations.
- Guide adults away from using euphemisms such as 'she has gone to sleep' or 'he has gone away', because children will understand these literally.
- Encourage family members to use drawing and play with children to assist them in expressing confusion and pain at the loss.
- Help adolescents to talk when it is convenient for them. Often, a school friend or another adult will be chosen as a confidant(e).
- Orphans may need extra bereavement care because of their living conditions, as well as the emotional burden they bear without the support of close family elders.
- Establish and strengthen child-to-child activities, such as support or discussion groups, a 'buddy' or friend programme, sports and play activities, music, dancing and drama. Child committees can plan these activities either with or without the help of adults.
- Use traditional approaches to providing emotional support to children, for example storytelling by elders and mentoring.

Assessment of difficulties in bereavement

- Occasionally, people have complications that prevent a healthy resolution of the bereavement process and that require referral to a specialist. A few indicators include:
  - After a couple of years the bereaved cannot speak of the deceased without experiencing intense and fresh grief each time.
  - Material possessions belonging to the deceased remain totally untouched as a shrine.
  - A history of depression may make bereavement difficult to resolve.
  - Suicidal thoughts continue after a couple of years.
  - Phobias about illness or death intrude upon the daily life of the bereaved.
- A comprehensive psychosocial assessment and genogram of the family will highlight possible areas of concern.
- Complicated bereavements should be referred, with the consent of the bereaved, to a health practitioner and, where possible, someone trained in bereavement counselling.
- Risk factors for complicated grief include multiple losses and dysfunctional relationships.

F. Special considerations in HIV and AIDS

- The risk factors for complicated grief are high when an individual dies from AIDS – these include multiple losses, stigma, an individual's HIV status, and the death of a child.
- Loss and grief are hard to deal with at the best of times.
- Multiple deaths from HIV can leave individuals with little support, and ongoing loss has become a way of life.
- Sometimes there is little time for anything other than survival.
- Stigma also creates barriers within the wider community – it can lead to a breakdown of *ubuntu* – the mutual caring for others within a community.
- Bereavement through AIDS worsens people's circumstances and removes from communities those who might otherwise have helped their families.
- The excessive number of AIDS-related deaths in some families and communities can cause 'bereavement overload' and lead to unhealthy physical, emotional and spiritual responses.

G. Be aware ...

- Everyone will experience bereavement in their own unique way.
- There is no set formula for how people should behave in a time of bereavement – this will vary from culture to culture and person to person.
- Bereavement is a normal process and can be painful.

- Children must be allowed to grieve as well as adults.

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CHAPTER 10: SELF-CARE

The care we give to self is directly proportional to the quality of care we are able to give others. All caregivers therefore need to accept the responsibility for self-care.

(Source not known)

A. Self-care principle

- The holistic approach that incorporates physical, emotional, social and spiritual components pertains as much to self-care as it does to patient and family care.

B. Types of self-care

- The aim of self-care is to prevent burnout and to build resilience that enables caregivers to remain healthy, happy and compassionate even in the face of ongoing suffering, stigma, poverty and loss. There are several aspects to self-care, described next.

Physical

- A healthy lifestyle that includes a balanced diet, getting enough sleep, rest and exercise
- Knowing one's HIV and TB status – regular medical check-ups as indicated
- Preventing infection by putting universal precautions into practice, especially hand washing
- Knowing and using correct techniques when lifting or moving patients
- Knowing and responding to signs of bodily tension
- Balancing work, play and rest
- Being vigilant and taking sensible safety and security precautions.

Emotional

- Acknowledging and processing feelings associated with grief and loss
- Practising active relaxation and stress management
- Using self-reflection and acknowledging the positive impact of one's input on a daily basis
- Letting go of work after hours
- Being assertive and able to set personal boundaries and to say 'no' when indicated
- Never making unrealistic promises
- Celebrating your successes
- Accepting and loving yourself, 'warts and all'
- Seeking professional counsel if emotional distress persists.

Social

- Making time for family and friends
- Contributing generously to the team, helping co-workers and giving credit where it is due
- Finding a mentor and arranging regular meetings
- Implementing good interpersonal communication skills
- Caring enough to confront, and practising constructive conflict management
- Building your own support network
- Asking for help when needed
- Implementing good time management
- Having fun and committing to at least one enjoyable interest that has nothing to do with work.

Spiritual

- Respecting your own dignity and worth
- Developing/using your own spiritual resources
- Praying and meditating
- Joining a prayer group
- Participating in religious services
- Actively forgiving 'those who have trespassed against you'
- Forgiving your own frailty and mistakes
- Creating and nurturing inner peace
- Seeking help from your religious/spiritual adviser
- Spending time appreciating nature
- Listening to sacred music

- Surrounding yourself with people who have sound ethical principles
- Using gentle humour with oneself and others
- Actively striving for wholeness.

General and organisational Issues

- Knowing and insisting on your rights to have:
  - A clear current job description (role clarity)
  - Clear reporting lines and understanding of the structure of your organisation
  - Adequate training to maintain competence
  - Specific training regarding stress management
  - Sufficient time off
  - Access to supervision and support.

Being open

- Capitalising on opportunities for debriefing, support and supervision
- Ongoing learning
- New ways of doing things
- Sharing your own ideas with colleagues, including superiors
- Breaking big problems down into manageable pieces and working at them one step at a time
- Letting off steam in ways that do not cause harm to relationships
- Undergoing performance appraisal
- Accepting and learning from constructive criticism
- Comfortably admitting when you do not know
- Apologising for mistakes
- Dealing positively and non-judgmentally with stigma associated with HIV, AIDS and death
- Coping constructively with change – learning about change management and being open to new possibilities while acknowledging the loss and/or threat associated with moving out of one's comfort zone.

Ensuring that you:

- Are able to prioritise activities
- Accept that you can only change things within your control and cannot alleviate all suffering
- Tell superiors when you feel overloaded
- Set yourself realistic/achievable goals
- Monitor your workload
- Take leave regularly (short breaks during the year and one long break annually)
- Do not continuously work excessive hours of overtime
- Are not exposed to any unnecessary risks
- Monitor your own health and well-being.

C. Active management of self-care

Consider compiling a self-care plan. Some of the elements of such a plan are set out below:

Assessing the risk of burn out

- Lauton's Stress Barometer (see outline below) was developed to be used by a supervisor. It could, however, also be used on a monthly basis by individuals to monitor their own levels of stress.
- The barometer is a simple pointer in assessing one's risk for burn out and identifying the need to seek professional help.
- It could be a valuable tool in a self-care stress management plan.
- The user could simultaneously use it to monitor the value of self-care interventions by comparing scores when new stress management activities are introduced.
- It is also important that supervisors are on the lookout for signs of burn out in the people that they work with.

Name ..... Date .....

Circle the number that best represents your feelings:

1 definitely not coping

2 struggling to cope

3 coping but experiencing some problems

4 coping fairly well

5 coping well

How are you coping with the following?

Workload	1	2	3	4	5
Physical fatigue	1	2	3	4	5
Spiritual fatigue	1	2	3	4	5
Anger	1	2	3	4	5
Sadness	1	2	3	4	5
Helplessness	1	2	3	4	5
Have you accessed any professional support during this month?				YES	NO

A persistent score of less than 15 indicates that professional help or a change in occupation ought to be urgently considered.

Incorporating preventive measures against burn out

- These are as outlined in section B above.

Identifying and addressing symptoms pointing to burn out

- Decreased motivation
- An unwillingness to make decisions
- Diminished accomplishment and efficacy
- Overly critical of self and others
- Feeling exhausted and unable to sleep restoratively
- Frequent physical ailments
- Feelings of being trapped and helpless
- A poor self-image
- Crying frequently for no apparent reason.

Prioritising a few realistic life-affirming activities

- Take time off or going on holiday.
- Plan an enjoyable outing with friends or family.
- Spend time appreciating nature.
- Tap into your spiritual resources.
- Read uplifting material.
- Work at a creative hobby.
- Listen to your favourite music, or join a choir.
- Claim acknowledgement for yourself and give it to others when it is due.
- Let go of some areas of your work.
- Delegate to others as appropriate.
- Trust colleagues and show yourself to be trustworthy.
- Guard against the need to maintain total control at all costs.
- Actively seek help for difficult physical, emotional, social or spiritual problems.
- Maintain competence.
- Ask for additional training.

Encouraging healthy thought processes

- Think things through before acting.
- Prioritise and plan activities carefully.
- Allow sufficient time for preparation.
- Critically evaluate results in relation to the amount of time and emotional energy invested.
- Learn from experience and try not to repeat the same mistakes.
- Consider your energy levels as a valuable resource that deserves to be managed well.
- Guard against doubts and negative thoughts.
- Visualise a positive outcome in your mind.
- Get to the bottom of fears and anxieties, and face up to them.
- Think about the consequences of your actions before you take them, and how they could affect your well-being and the well-being of others.
- Accept responsibility for your actions and deal with the consequences constructively.
- Accept blame when you are in the wrong and then move on.
- Focus on hopeful thoughts.
- Accept the limitations of any given situation.
- Realise that you are never totally alone and there is always some help available.

D. Special considerations in HIV and AIDS

- Many countries have a health system that is ill equipped to cope with the scale of HIV and AIDS.
- In many countries across sub-Saharan Africa, a large proportion of the population is either infected or affected by HIV and AIDS and this includes health professionals.
- The sheer magnitude of the HIV epidemic has increased the challenges, burdens, costs and rewards of being a carer at any level of care provision.
- The challenges of caring for a person with HIV and AIDS include:
    - The incurability of HIV
    - Ethical dilemmas with difficult decisions
    - Limited access to ARVs
    - Stigma
    - Secrecy
    - Lack of resources
    - Lack of training on how to care for people with HIV and AIDS
    - Age – most patients with HIV are young
    - Lack of support – often the health worker has a large and demanding caseload
    - Illness – the health workers themselves may have HIV and AIDS and be struggling to cope with the physical demands of providing care.

E. Be aware ...

- When embarking on a self-care programme, it is wise to start working on areas that are the most appealing and least threatening.
- The more challenging aspects of self-care can wait until self-care becomes a habit that has been consciously integrated into daily living.
- Many of the suggested self-care activities belong in more than one category.
- Not everything mentioned in this brief chapter is for everybody, but the commitment to accepting the responsibility to care for oneself applies equally to employed and voluntary professional and non-professional caregivers, as well as administrative support staff in not-for-profit settings.

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APPENDICES

APPENDIX 1: THE INTERNATIONAL ASSOCIATION FOR HOSPICE AND PALLIATIVE CARE LIST OF ESSENTIAL MEDICINES FOR PALLIATIVE CARE

Amitriptyline[a]	50–150 mg tablets	Depression Neuropathic pain	24.2.1–Depressive disorders
Bisacodyl	10 mg tablets 10 mg rectal suppositories	Constipation	Not included
Carbamazepine[b]	100–200 mg tablets	Neuropathic pain	5–Anticonvulsants/antiepileptics 24.2.2–Bipolar disorders
Citalopram (or any other equivalent generic SSRI except paroxetine and fluvoxamine)	20 mg tablets 10 mg/5 mL oral solution 20–40 mg injectable	Depression	Not included
Codeine	30 mg tablets	Diarrhea Pain—mild to moderate	2.2–Opioid analgesics 17.5.3–Antidiarrheal
Dexamethasone	0.5–4 mg tablets 4 mg/mL injectable	Anorexia Nausea Neuropathic pain Vomiting	3–Antiallergics and anaphylaxis 8.3–Hormones and antihormones
Diazepam	2.5–10 mg tablets 5 mg/mL injectable 10 mg rectal suppository	Anxiety	1.3–Preoperative sedation short-term procedures 5–Anticonvulsants/antiepileptics 24.3–Generalized anxiety, sleep disorders
Diclofenac	25–50 mg tablets 50 and 75 mg/3 mL injectable	Pain—mild to moderate	Not included
Diphenhydramine	25 mg tablets 50 mg/mL injectable	Nausea Vomiting	Not included
Fentanyl (transdermal patch)	25 µg/h 50 µg/h	Pain—moderate to severe	Not included
Gabapentin	300 mg or 400 mg tablets	Neuropathic pain	Not included
Haloperidol	0.5–5 mg tablets 0.5–5 mg drops 0.5–5 mg/mL injectable	Delirium Nausea Vomiting Terminal restlessness	24.1—Psychotic disorders
Hyoscine butylbromide	20 mg/1 mL oral solution 10 mg tablets 10 mg/mL injectable	Nausea Visceral pain Terminal respiratory congestion Vomiting	Not included
Ibuprofen	200 mg tablets 400 mg tablets	Pain—mild to moderate	2.1—Nonopioids and NSAIMs
Levomepromazine	5–50 mg tablets 25 mg/mL injectable	Delirium Terminal restlessness	Not included
Loperamide	2 mg tablets	Diarrhea	Not included
Lorazepam[c]	0.5–1–2 mg tablets 2 mg/mL liquid/drops 2–4 mg/mL injectable	Anxiety Insomnia	Not included
Megestrol acetate	160 mg tablets 40 mg/mL solution	Anorexia	Not included
Methadone (IR)	5 mg tablets 1 mg/mL oral solution	Pain—moderate to severe	24.5–Substance dependence
Metoclopramide	10 mg tablets 5 mg/mL injectable	Nausea Vomiting	17.2–Antiemetics
Midazolam	1–5 mg/mL injectable	Anxiety Terminal restlessness	Not included
Mineral oil enema			Not included
Mirtazapine (or any generic dual action NaSSA or SNRI)	15–30 mg tablets 7.5–15 mg injectable	Depression	Not included
Morphine	IR: 10–60 mg tablets IR: 10 mg/5 mL oral solution IR: 10 mg/mL injectable SR: 10 mg tablets SR: 30 mg tablets	Dyspnea Pain—moderate to severe	2.2–Opioid analgesics Note: Only IR is included in the WHO Model List—SR morphine is not.
Octreotide	100 µg/mL injectable	Diarrhea Vomiting	Not included
Oral rehydration salts		Diarrhea	17.5.1–Oral rehydration
Oxycodone	5 mg tablet	Pain—moderate to severe	Not included
Paracetamol (acetaminophen)	100–500 mg tablets 500 mg rectal suppositories	Pain—mild to moderate	2.1–Nonopioids and NSAIMs
Prednisolone (as an alternative to dexamethasone)	5 mg tablet	Anorexia	3–Antiallergics and anaphylaxis 8.3–Hormones and antihormones 21.2–Anti-inflammatory agents
Senna	8.6 mg tablets	Constipation	17.4–Laxatives
Tramadol	50–100 mg IR tablets 10 mg/5 mL oral solution 50 mg/mL injectable	Pain–mild to moderate	Not included
Trazodone	25–75 mg tablets 50 mg injectable	Insomnia	Not included
Zolpidem (still patented)	5–10 mg tablets	Insomnia	Not included

Complementary: Require special training and/or delivery method

[a] Side effects limit dose

[b] Alternatives to amitriptyline and tricyclic antidepressants (should have at least one drug other than dexamethasone)

[c] For short-term use in insomnia

Abbreviations: IAHPC = International Association for Hospice and Palliative Care; WHO = World Health Organization; SSRI = selective serotonin reuptake inhibitor; NSAIM = nonsteroidal anti-inflammatory medicine; IR = immediate release; NaSSA = noradrenergic and specific serotonergic antidepressant; SNRI = serotonin norepinephrine reuptake inhibitor; SR = sustained release

Notes:

Nonbenzodiazepines should be used in the elderly.

NSAIMs should be used for brief periods.

Source: *IAHPC (2006). 'IAHPC List of Essential Medicines for Palliative Care' in The Journal of Supportive Oncology 4(8, September): 409–11.*

APPENDIX 2: PAIN ASSESSMENT TOOLS FOR CHILDREN

FLACC Scale **for use in children less than three years of age or older non-verbal children.**

- For use in children under 3 years or for older non-verbal children.
- Use like an Apgar score: evaluating each item and arriving at a total score out of 10.
-

DATE/TIME						
Face 0 – No particular expression or smile 1 – Occasional grimace or frown, withdrawn, disinterested 2 – Frequent to constant quivering chin, clenched jaw						
Legs 0 – Normal position or relaxed 1 – Uneasy, restless, tense 2 – Kicking, or legs drawn up						
Activity 0 – Lying quietly, normal position, moves easily 1 – Squirming, shifting back and forth, tense 2 – Arched, rigid, jerking						
Cry 0 – No cry (awake or asleep) 1 – Moans or whimpers, occasional complaint 2 – Crying steadily, screams or sobs, frequent complaints						
Consolability 0 – Content, relaxed 1 – Reassured by occasional touching, hugging or being talked to, distractible 2 – Difficult to console, comfort						
TOTAL SCORE						

Source: Merkel S, Voepel-Lewis T, Shayevitz JR and Malviya S (1997). 'The FLACC: A behavioural scale for scoring postoperative pain in young children' in Pediatric Nursing 23: 293–7.

The 10-point Touch Visual Pain (TVP) Scale for assessing pain and symptoms through touch and observation

Tactile and visual score	present
1.Toes bent down or upwards and tense under soles, ankles tightly crossed	
2.Knees tightly together or tightly crossed	
3.One leg protecting nappy area	
4.Thoracic or and irregular breathing, and /or mouth breathing and /or intercostal muscles and/or nasal flaring and/or crackles	
5.Heart rate increased and/or irregular	
6 Arms tight against body or guarding or crossed over face, chest or stomach	
7.Fists (not or difficult to open with finger)	
8.Neck asymmetrically positioned on shoulders, shoulders pulled up	
9.Head asymmetrical	
10.Facial tension (fearful or painful expression); tense mouth, eyes tense or anxious, distressed look	

- The 10-point TVP Scale uses touch and observation to assess not only a child's pain but also any anxiety or discomfort that may be experienced.
- It was developed in Africa.
- It is based on signs of pain and anxiety that can be observed, including an asymmetrical head, verbalisations of pain, facial tension, clenched hands, crossed legs, shallow breathing, and an increased or irregular heartbeat.

APPENDIX 3: THE ICPCN CHARTER OF RIGHTS FOR LIFE-LIMITED AND LIFE-THREATENED CHILDREN

1. Every child should expect indivualised, culturally and age-appropriate palliative care as defined by the World Health Organization (WHO). The specific needs of adolescents and young people shall be addressed and planned for.
2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.
3. The child's parents or legal guardians shall be acknowledged as the primary caregivers and recognised as full partners in all care and decisions involving their child.
4. Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.
5. A sensitive but honest approach will be the basis of all communication with the child and the child's family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.
6. Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends, and participate in normal childhood activities.
7. The child and the family shall be given the opportunity to consult with a paediatric specialist with particular knowledge of the child's condition where possible, and shall remain under the care of a paediatrician or doctor with paediatric knowledge and experience.
8. The child and the family shall be entitled to a named and accessible key worker whose task it is to build, coordinate and maintain appropriate support systems, which should include a multi-disciplinary care team and appropriate community resources.
9. The child's home shall remain the centre of care whenever possible. Treatment outside this home shall be in a child-centred environment by staff and volunteers who have trained in the palliative care of children.
10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.

(Adapted from the ACT Charter, ICPCN 2008)

Source: ICPCN (2008). 'The ICPCN Charter of Rights for life-limited and life-threatened children'. Downloadable from their website at www.icpcn.org

APPENDIX 4: THE SOWETO CARES SCORE:

ASPECT REQUIRING EVALUATION		GREEN: Class I	ORANGE: Class II	RED: Class III
C- Comfort	C1: Basic needs: food, shelter, warmth (clothing)	Completely met	Adequately met but at risk of not being adequate if challenged by stressor (eg: mother hospitalized, grant not collected, winter weather etc).	Not met (child often misses meals, clothing or shelter inadequate, homeless etc)
	C2: Pain	None	Mild-moderate	Severe
	C3: Symptoms other than pain	None	Mild-Moderate	Severe
A- Access	A1: Transport	Own vehicle, transport always available	Reliant on public transport but would be able to access transport in an emergency	No transport services, no money for transport
	A 2: Healthcare	Easily accessible, good level of care	Average access, reasonable level of care	Not accessible (too far or very poor healthcare facilities)
R- Resources	R 1:Primary caregiver	Good caregiver, responsible, loving, caring	Satisfactory caregiver but may need extra help in a crisis	Not satisfactory, caregiver not coping, elderly grandparent, childheaded household
	R 2: Financial resources	Well resourced	Adequate but could become a problem if challenged by an unforeseen crisis	Inadequate
E- Emotional needs	E 1: Child (the patient)	Happy, content	Coping but elements of stress, anxiety or depression observed	Uncontained, suicidal
	E 2: Caregiver	Happy, content	Coping but elements of stress, anxiety or depression observed	Uncontained, suicidal
S- Safety	S1: Abuse/neglect	None	Suspicion of abuse/neglect/exploitation	Confirmed abuse/neglect/exploitation
	S2: `Environment	Safe	Elements of concern but not life threatening	Unsafe living environment posing a threat to survival

Most young children (even healthy ones) require assistance with activities of daily living by virtue of their developmental immaturity. Also, all infants and young children need to be looked after by caregivers and vulnerability is dependent on the capacity of their caregiver to meet their needs. It was with this in mind that the 'CARES score for children' was proposed and tested in the Soweto Hospice Paediatric Palliative Care pilot site.

Classification

Level I: All green

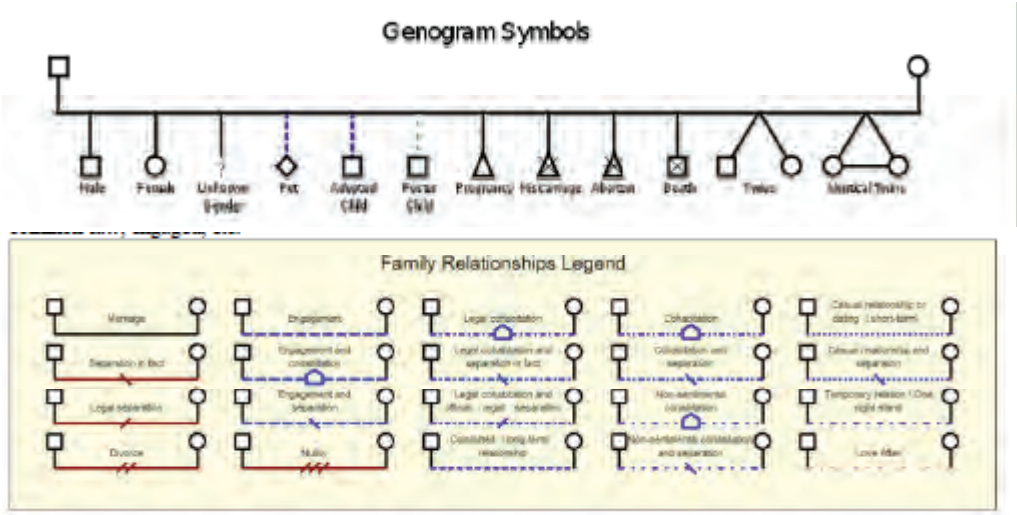
Level II: Any orange, some green, no red

Level III: Any red

If red for C1,R1, E1, E2 ,S1 or S2 : immediate notification of the relevant concern

Source: Soweto Hospice Paediatric Palliative Care. The HPCA Soweto CARES Score to assess the vulnerability of the child. Available from the Hospice and Palliative Care Association (HPCA) of South Africa via www.hpca.co.za

APPENDIX 5: EXAMPLE OF A GENOGRAM



Sources:

http://www.genopro.com/genogram/
http://en.wikipedia.org/wiki/Genogram

APPENDIX 6: LIST OF MEDICINES USED IN THE HANDBOOK

Medicine
Acyclovir
Alprazolam
Amitriptyline
Bisacodyl
Carbamazepine
Ciprofloxacin
Chlorpromazine
Clonazepam
Codeine phosphate
Co-trimoxazole
Cyclizine
Dexamethasone
Diazepam
Diclofenac
Disodium pamidronate
Domperidone
Fentanyl (Durogesic)
Fluconazole
Gabapentin
Glycerol suppositories
Glycopyrronium
Haloperidol
Hyoscine butylbromide (Buscopan/Scopolamine)
Ibuprofen
Ketaconazole
Lorazepam
Metoclopramide
Metronidazole
Midazolam
Morphine
Oxazapam
Paracetamol (Acetaminophen)
Phenytoin
Phenobarbitol
Prednisalone
Prochloperazine
Senna
Sodium Valporate
Temazepam
Tramadol

ACRONYMS

3TC	Lamivudine
ACT	Association for Children with Life-limiting and Life-threatening Conditions
AIDS	Acquired Immune Deficiency Syndrome
AIDSTAR	AIDS Support and Technical Resources
APCA	African Palliative Care Association
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
AZT	Zidovudine
BD	Twice daily
COPD	Chronic Obstructive Pulmonary Disease
CT	Computerised Tomography
D4T	Stavudine
DDI	Didanosine
EAPC	European Association of Palliative Care
FLACC	Faces, Legs, Activity, Cry, Consolability
FTC	Emtricitabine
HAU	Hospice Africa Uganda
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
HPCA	Hospice and Palliative Care Association of South Africa
Hrs	Hours
Hrly	Hourly
IASP	International Association for the Study of Pain
ICPCN	International Children's Palliative Care Network
IM	Intramuscular
IV	Intravenously
Kg	Kilogram
LOP	Loprinavir
Mcg	Micrograms
Mg	Milogram
MoH	Ministry of Health
MRI	Magnetic Resonance Imaging
NSAID	Non Steroidal Anti-Inflammatory Drug
OI	Opportunistic Infections
Po	Orally
Pr	Rectally
POS	Palliative Outcome Scale
qds	Four times a day
RIT	Ritonavir
Sc	subcutaneously
SCC	Spinal Cord Compressions
SVCO	Supervior Vena Cava Obstruction
TB	Tuberculosis
TDF	Tenoflovir
tds	Three times a day
TVP	Touch Visual Pain Scale
UN	United Nations
USAID	United States Agency for International Development
USG	United States Government
VAS	Visual Analogue Scale
WHO	World Health Organisation

ABOUT APCA

APCA is a non-profit-making pan-African membership organisation which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. APCA aims to support the scaling-up of palliative care provision across Africa through a public health approach that strives to balance coverage with quality. Its broad objectives are to:

- Promote the availability of palliative care for all in need, including orphans and vulnerable children
- Encourage governments across Africa to support affordable and appropriate palliative care, which is to be incorporated into the whole spectrum of healthcare services
- Promote the availability of palliative care drugs for all in need;
- Encourage the establishment of national palliative care associations in all African countries
- Promote palliative care training programmes suitable for African countries
- Develop and promote quality standards in palliative care training and service provision for different levels of health professionals and care providers.

AIDSTAR-One

The AIDS Support and Technical Resources (AIDSTAR) mechanism is an indefinite quantity contract (IQC) managed out of the Office of HIV/AIDS in USAID's Bureau for Global Health. AIDSTAR-One is a flexible mechanism available to US Government (USG) country teams, USAID/Washington operating units, missions, and other USG agencies to access technical expertise and implementation support across a broad range of technical areas related to HIV and AIDS. AIDSTAR-One may be used for:

- Long- or short-term technical assistance and programme implementation support in specialised HIV/AIDS technical areas, including: behaviour change; clinical and community-based services for HIV and AIDS; care for orphans and vulnerable children; monitoring and evaluation; and health systems strengthening that is specific to HIV and AIDS services
- Long- or short-term in-country support for coordination and scale-up for HIV and AIDS activities in support of US Government country strategies
- Documenting and disseminating successful innovative approaches and sustainable models; evidence-based best practices and lessons learned; and new approaches, tools and methodologies in HIV and AIDS programming.

PERSONAL NOTES

Further information about medicines used in palliative care can be found at www.palliativedrugs.com and those for children on www.icpcn.org

Further information about the handbook and the African Palliative Care Association can be found at www.apca.org.ug or by emailing info@apca.org.ug

PERSONAL NOTES

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