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TB CARE II

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Comprehensive Guidelines for TB and DR-TB Palliative Care and Support

University Research Co., LLC

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Some of the content for this guideline was adapted from a publication titled: “Clinical Practice Guidelines for Providing Palliative Care to Patients with Tuberculosis” developed by KNCV Tuberculosis Foundation for the Ministry of Health of the Kyrgyz Republic and is used with permission.

The document draws on USAID/TB CARE I and WHO background references.

2. List of Abbreviations and Abbreviations

AFB (KB)	Acid-fast bacteria (Koch's bacillus)
AM	Amikacin
ATBD	Antituberculosis drugs
CM/KM	Capreomycin/ Kanamycin
CP	Chemoprophylaxis
CPR	Cardiopulmonary resuscitation
CS	Cycloserine
DR-TB	Drug-resistant tuberculosis
DST	Drug susceptibility test
DS-TB	Drug-sensitive tuberculosis
DT	Dignity therapy
FICA	Faith, Important, Community, Assist
FLDs	First-line drugs
HADS	Hospitality Anxiety and Depression Scale
HIV	Human immunodeficiency virus
IC	Infection control
IDTPOC	Interdisciplinary Team Plan of Care
INH	Isoniazid
MDR-TB	Multidrug-resistant tuberculosis
MP	Maintenance phase of treatment
MTB	Mycobacterium tuberculosis
PAS	Para-aminosalicylic acid
PHC	Primary health care
PR-TB	Poly-resistant tuberculosis
RMP	Rifampicin
SLDs	Second-line drugs
SSRI	Selective Serotonin Reuptake Inhibitor
TB	Tuberculosis
URC	University Research Co., LLC
USAID	United States Agency for International Development
WHO	World Health Organisation
XDR-TB	Extensively drug-resistant tuberculosis
Z	Pyrazinamide

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3. Introduction

Tuberculosis (TB) is an infectious airborne disease caused by *Mycobacterium tuberculosis).*[1] The main source for transmission of the disease is through a contagious person infecting those who share air space with him/her. Multidrug-resistant tuberculosis (MDR-TB) is defined as tuberculosis caused by *M. tuberculosis in vitro* resistant to the first-line treatment drugs isoniazid (INH) and rifampicin (RMP).[2] The most resistant form of TB, extensively drug-resistant tuberculosis (XDR-TB), includes resistance to isoniazid and rifampicin, fluoroquinolones, and at least one of three second-line injectable drugs (SLDs) (amikacin (AM), Capreomycin (CM) or kanamycin (KM).[i] In the case of XDR-TB, all anti-tuberculosis drugs currently available may not be able to cure a patient. Additionally, as XDR-TB patients are the most difficult to treat effectively, relevant clinical and social settings may contribute to whether or not the patient is successfully treated. In the above situations, there is a need for provision of palliative care to patients.

In 2013, the Department of Health of the Republic of South Africa published policy guidelines on the *Management of Drug-Resistant Tuberculosis*[ii] that included reference to the need for palliative care to be integrated into the national TB program. Palliative care is defined by the World Health Organisation (WHO) as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[iii] Palliative care provided to patients with TB and M/XDR-TB must be based on recommendations of national guidelines and protocols, international guidelines on TB and principles of palliative care.[iv,7] The main problems related to TB and M/XDR-TB are the high level of contagiousness of patients, the difficulty in maintaining adherence to curative treatment, and the management of severe side affects associated with the disease and its treatment. Palliative care has the promise of helping not only to relieve suffering for patients for whom treatment has failed but also to help patients to more effectively adhere to treatment leading to better outcomes.

In November 2010, a palliative care meeting for tuberculosis control experts was held in Geneva, Switzerland. The meeting resulted in a call for action to reinforce efforts and incorporate palliative care into the global standards of M/XDR-TB treatment. The Declaration on Palliative Care and M/XDR-TB[v] included the following tenets:

1. That access to palliative care for individuals (adults and children) with MDR/XDR-TB is a human right and promotes dignity.
2. That palliative care is an essential component of the provision of care for individuals (adults and children) with MDR/XDR-TB, wherever in the world that they are receiving care.

3. That palliative care should be strengthened where being provided, and integrated alongside the prevention and treatment of MDR/XDR-TB.
4. That palliative care in the context of MDR/XDR-TB should be integrated into the management of MDR/ XDR-TB from the time of diagnosis until the patient reaches cure or the end of life. The problems faced by MDR/XDR-TB patients and families span multiple physical, psychological, social and spiritual dimensions. We believe that the existing WHO definition of palliative care is highly appropriate for patients with drug resistant TB.
5. That palliative care strengthens the Stop TB strategy.
6. That, as experts on MDR/XDR-TB and palliative care, we are keen to learn from each other.
7. That we are committed to developing the agenda on palliative care in MDR/XDR-TB, and improving access to care, medications, training and capacity building, and collaborating to improve the knowledge base through research.

4. Tuberculosis and Multi-drug/Extensively Drug-Resistant Tuberculosis

Incidence, Mortality and Definitions of Tuberculosis and Multidrug/Extensively Drug-Resistant Tuberculosis

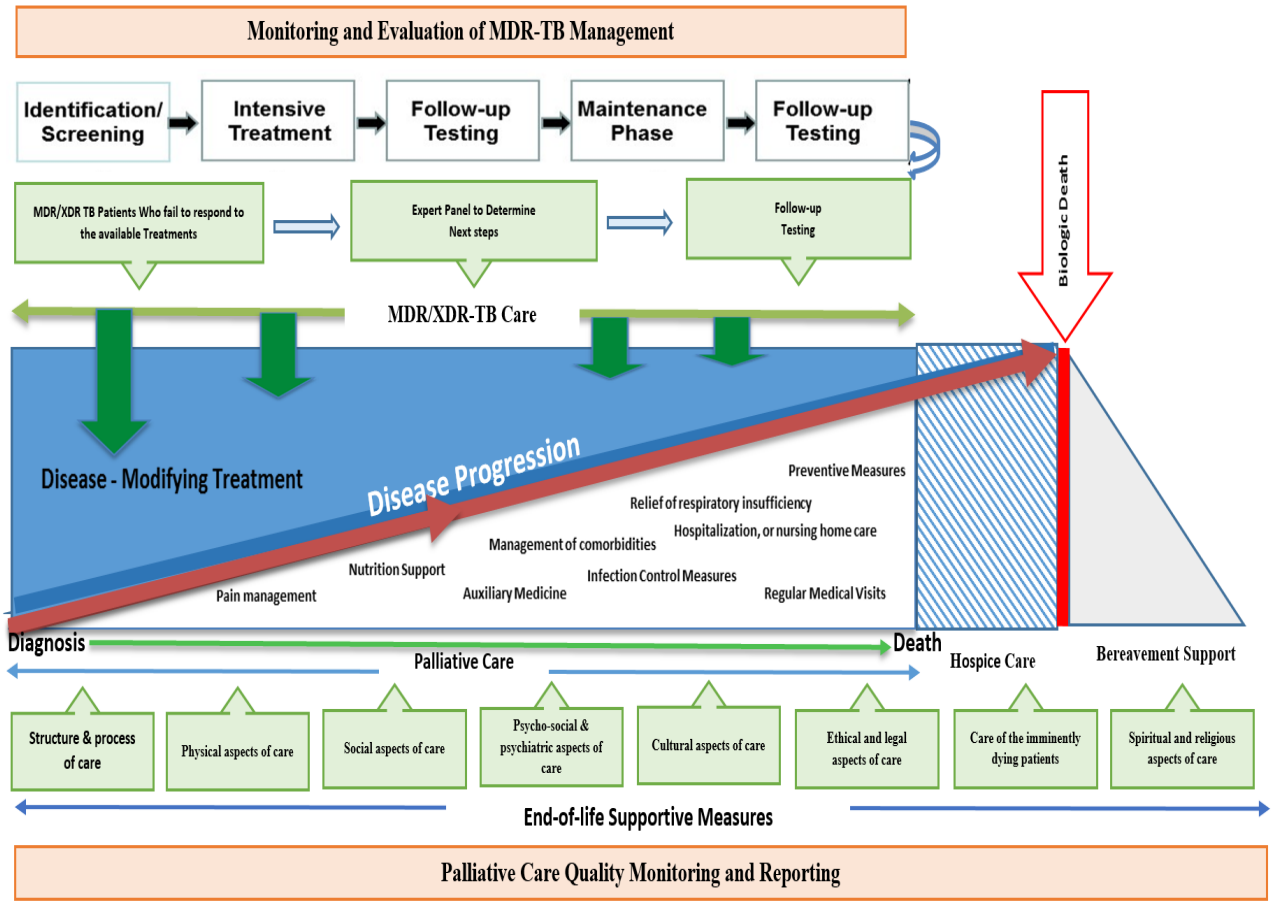
Tuberculosis (TB) is an infectious airborne disease caused by *Mycobacterium tuberculosis*. The most effective method for preventing the transmission of TB is early detection of new cases and immediate initiation of patients onto effective treatment. The transition from initial TB infection to the development of active disease, and the degree of success of treatment are influenced by several factors including: the etiologic agent, host organism, clinical treatment and socioeconomic issues. All of these factors should be considered when treating tuberculosis.[vi]

In 2013, according to WHO estimates, the global incidence of tuberculosis was 9 million cases. During 2013, about 1.1 million people died from TB (excluding deaths attributed to TB-HIV co-morbidity.)[vii] The majority of cases occurred in the WHO regions of South-East Asia, the Western Pacific and Africa. As the human immunodeficiency virus (HIV) greatly increases susceptibility to tuberculosis, HIV is a major factor contributing to the growth of the TB epidemic. Indeed, HIV and TB carriers accounted for 13% of all global tuberculosis cases in 2013, and accounting for a staggering 78% of all estimated cases in the WHO African region. In the same year, there were 0.36 million TB deaths among HIV-positive people, accounting for 25% of the estimated 1.5 million deaths from HIV/AIDS globally.[9] The prevalence of HIV co-infection among TB patients is highest in the African Region. Of the 1.1 million TB patients with an HIV test result in 44 countries across the African Region, 41% tested positive.

Over the last few decades the prevalence of drug-resistant tuberculosis has increased significantly. Apart from spontaneous mutations of the *Mycobacterium tuberculosis* strain, inadequate treatment and/or poor adherence to treatment are the main causes of drug resistance. In 2013 an estimated 480,000 patients fell ill with MDR-TB worldwide.[9] MDR-TB requires prolonged therapy and administration of expensive and less effective anti-tuberculosis second-line drugs (SLDs).

South Africa has the third highest TB burden in the world. The WHO estimates that 1.8% of new TB cases and 6.7% of TB retreatment cases have MDR-TB (WHO Global TB Report, 2013) in South Africa. In 2013, 328,896 notified cases of tuberculosis were diagnosed in South Africa (36,671, 0-14 years), with 26,023 of these identified as MDR. The estimated TB incidence for this year was 410,000 – 520,000,[9] while the total number of TB deaths is not known due to a lack of vital registration.

Improper use or mismanagement of SLDs may result in the development of XDR-TB. Nearly 9.0% of all MDR-TB cases were estimated to have XDR-TB. South Africa accounted for 59% of XDR-TB patients with outcomes reported in 2011. Treatment success was only 15% and 40% of patients died; 36% were lost to follow up or not evaluated. High mortality is likely related to high levels of HIV co-infection.



Logical Framework for Integrating Providing Palliative Care into MDR/XDR TB Care

Draws on the work of the Canadian Palliative Care Association and Frank Ferris, MD.

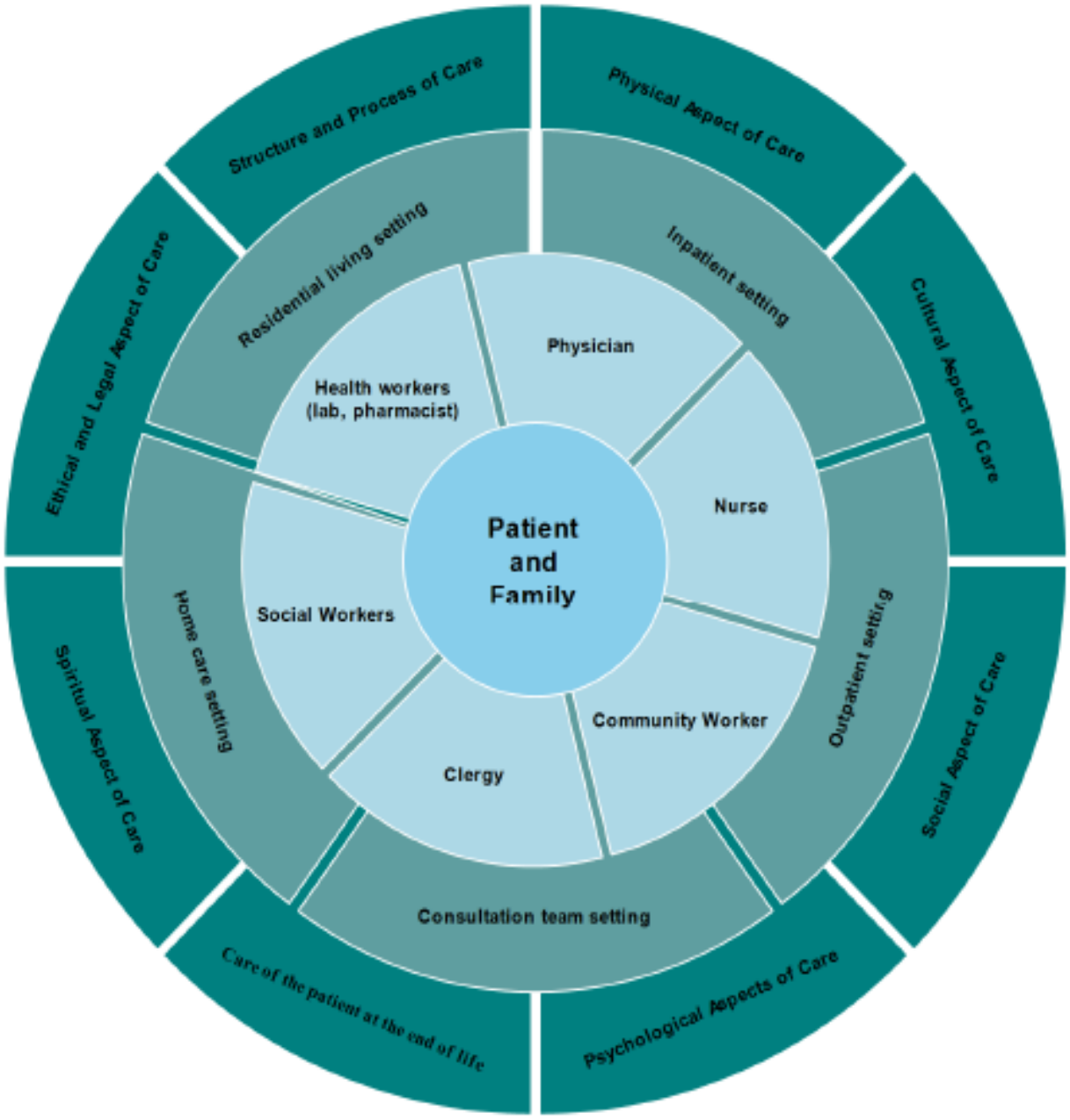
5. What is Palliative Care?

Definition and Philosophy

The World Health Organization defines palliative care for adults and children as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." [viii]

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.


Structure and Process of Care
Physical Aspect of Care
Cultural Aspect of Care
Social Aspect of Care
Psychological Aspects of Care
Care of the patient at the end of life
Spiritual Aspect of Care
Ethical and Legal Aspect of Care
Residential living setting
Inpatient setting
Outpatient setting
Consultation team setting
Home care setting
Physician
Nurse
Community Worker
Clergy
Social Workers
Health workers (lab, pharmacist)
Patient and Family

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not 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 multidisciplinary 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 centers and even in children's homes.

Recently the definition was clarified to note that palliative care is needed in chronic as well as life-threatening/life-limiting conditions, that there is no time or prognostic limit on the delivery of palliative care, that palliative care is needed at all levels of care, and that palliative care is not limited to any one setting. Further palliative care is never a substitute for curative care and should be integrated alongside curative care including care for drug-resistant TB (Pg. 31-33). [7]

Palliative care philosophy is person-centered and draws its roots from humanism and existential theories with an emphasis on holistic care and meaning making. Family systems theory also informs palliative care as the affected person and family are always together the focus of care.[ix]

Domains of Care

A consensus on which domains are important to the development and delivery of palliative care exists and will be used in these guidelines to organize the content of the material.[x] These domains and recommendations are as follows:

- Structure and Process of Care
    - Comprehensive interdisciplinary assessment of patient and family
    - Addresses identified and expressed needs of patient and family
    - Interdisciplinary team consistent with plan of care
    - Education and training
    - Emotional impact of work
    - Team has relationship with hospices
    - Physical environment meets needs of patient and family.

- Physical Aspects of Care
  - Pain, other symptoms, and treatment side effects are managed using best practices
  - Team documents and communicates treatment alternatives permitting patient/family to make informed choices
  - Family is educated and supported to provide safe/appropriate comfort measures to patient

- Psychological Aspects of Care
  - Psychological and psychiatric issues are assessed and managed
  - Team employs pharmacologic, non-pharmacologic, and complementary therapies as appropriate
  - Grief and bereavement program is available to patients and families

- Social Aspects of Care
  - Interdisciplinary social assessment
  - Care plan developed
  - Referral to appropriate services

- Religious, Spiritual, and Existential Aspects of Care
  - Assesses and addresses spiritual concerns
  - Recognizes and respects religious beliefs-provides religious support
  - Makes connections with community and spiritual/religious groups or individuals as desired by patient/family

- Cultural Aspects of Care
  - Assesses and aims to meet the culture-specific needs of patients and families
  - Respects and accommodates range of language, dietary, habitual, and ritual practices of patients and families
  - Team has access to/uses translation resources
  - Recruitment and hiring practices reflect cultural diversity of community

- Care at the End-of-Life
  - Signs and symptoms of impending death are recognized and communicated
  - As patients decline, team introduces or reintroduces hospice
  - Signs/symptoms of approaching death are developmentally, age, and culturally appropriate

- Ethical and Legal Aspects of Care
  - Patient's goals, preferences, and choices are respected and form basis for plan of care
  - Team is aware of and addresses complex ethical issues
  - Team is knowledgeable about relevant statutes and regulations.

Standards of Practice and Operation

No universal international standards exist for the organization and delivery of palliative care, however over 70 countries have developed standards of practice for palliative care and a general consensus exists as to what should be included in palliative care program operation.

- Background on country palliative care development including history, philosophy, important developments, summary of identified needs.
- Governance and management of palliative care services
- Eligibility for palliative care
- Description of the interdisciplinary team including all disciplines that are required or optional
- Description of the qualifications and training required to work in a palliative care service.
- Description of the types of services that must be provided by each discipline
- Recommended staffing ratios and caseload
- Education, training, and staff support
- Clinical assessment and interdisciplinary plan of care development
- Recordkeeping requirements and medical record maintenance
- Safety and infection control policies
- Medication, supplies, and equipment
- Continuity of care
- Ethical issues
- Quality assessment and performance improvement
- Palliative care in different settings (inpatient, clinic, day care, home care)
- Palliative care to special populations (Children, communicable diseases, non-cancer patients, stigmatized populations)

Home and Community Based Care

Palliative care around the world is mainly provided in residential settings. Wherever the person calls home. An interdisciplinary team of professionals, volunteers and community health workers visit the patient and family regularly to provide care and support. Inpatient facilities should be available for crises or severe symptom management. The professionals include physicians, nurses, social workers, psychologists, therapists, and others as needed. Support from the community, in terms of volunteers and family caregivers is vital to palliative care delivery as is community awareness of palliative care and the importance of the relief of suffering.

6. Palliative Care for TB

Although TB is curable in most cases M/XDR-TB cure rates are much lower at present and mortality rates are high during treatment (7-17%), especially with HIV positive patients.[xi] Therefore palliative care is a necessary part of the continuum of care for TB patients.

What Makes Tuberculosis a Unique Palliative Care Situation?

- **TB and M/XDR-TB is a very contagious disease,** and if not treated properly, it threatens the surrounding people, including healthcare workers and the patient's family. Since the symptoms of tuberculosis develop slowly, the patients usually would have had symptoms and been the carriers of infection for a long time before they are diagnosed with tuberculosis. During this time, the family has possibly been infected, and provision of in-home palliative care to patients with TB or M/XDR-TB involves less treatment if proper infection control measures have been taken.

- Due to the risk of infection, **it is difficult to employ and retain the staff** for provision of palliative care. Healthcare workers exposed to higher risk of tuberculosis disease, e.g. people with immune system disorders (HIV-positive or receiving immunosuppressive therapy) should not provide care to patients with TB and M/XDR-TB.[xii]

- The **indications for referral and provision of palliative care** to patients with difficult to treat TB are challenging to define. In general patients who fail treatment or whose treatment fails them are all candidates for palliative care and should be referred. All staff caring for TB patients should have some familiarity with palliative care and those regularly caring for patients with MDR & XDR TB need competent training in palliative care so that general palliative care principles are available to all patients. At MDR treatment facilities, MDR or XDR-TB patients that are unable to convert to sputum negative status may be considered for curative treatment discontinuation by the treating facility "consilium." Such decisions should be done with the involvement of the TB patient and family. Once a decision is taken to discontinue the patient should be referred for formal palliative care and a complete referral form should be completed that notes the reasons for treatment discontinuation and referral recommendations.

- **Social stigmatisation***:* People with TB and M/XDR-TB, as well as their family members, suffer from discrimination and stigmatisation, zero tolerance and social isolation during treatment, especially if treatment has no positive outcome.

- **Antisocial behaviour of patients***:* Development of TB and M/XDR-TB and the progress of TB and M/XDR-TB are closely connected to lifestyle, cigarette smoking, alcohol and drug abuse, lower levels of education, social marginalisation,

and poverty.[xiii,xiv] Alcohol abuse and smoking are major factors of unsuccessful outcomes of treatment and mortality rate in tuberculosis patients.[xv] Therefore, antisocial behaviour is seen frequently in TB and M/XDR-TB patients, and, moreover, in those whose TB and M/XDR-TB treatment failed.

- **Ethical dilemmas*:*** ethical dilemmas in provision of palliative care to very contagious patients with TB and M/XDR-TB concern all parties to the dilemma, healthcare workers, educators, patients and the patient's families and other members of the community.

Which TB patients should receive palliative care?

In general patients with multi-drug and extreme drug resistant TB should have access to palliative care. In some DST patients' palliative care may also be needed including those co-infected with HIV and those with extra pulmonary TB. Formal palliative care services should be available to all patients that have failed TB treatment.

When should TB patients receive palliative care?

Palliative care symptom relief should be available to all patients suffering from significant symptoms including shortness of breath, pain, gastrointestinal dysfunction, night sweats, hemoptysis, etc. Formal palliative care should be available following a console decision to discontinue active TB treatment.

Generalist v. specialized palliative care services

It is helpful to distinguish between a generalized palliative care 'approach' and the provision of specialized or formal palliative care services. All TB professionals should be familiar with basic palliative care principles and symptom management and should use these skills while caring for their patients. When a patient has difficult to manage symptoms or reaches the point where TB treatment is ended it may be best to offer a transition to specialized palliative care services. Specialized palliative care services may be available in the community or may be provided within the government run TB facilities and programs. A specialized service will have an interdisciplinary team and will meet standards for palliative care operation.

7. Structure of Care

Organization of palliative care services

How palliative care is integrated into the TB continuum of care

In South Africa patients with TB or M/XDR-TB may be provided with palliative care in home settings, at hospice for palliative TB care, in palliative care facilities, in TB hospitals and/or general hospitals, and in primary healthcare facilities. An interdisciplinary team that is comprised of primary health care workers, nurses, social workers, and physicians should provide palliative care. Other specialists including physical therapists, nutritionists, pharmacists, psychologists, psychiatrists, religious workers and so forth should provide counseling as required.

Although treatment of TB and M/XDR-TB may not be provided for various reasons, it does not mean that healthcare services and/or emergency medical treatment should not be provided. The major problem of palliative care provided to patients with TB or M/XDR-TB is the high contagiousness of the disease, which should be considered during treatment of these patients in specialised TB facilities, departments, and hospices or homes of patients, and in general hospitals.

Hospitalization in TB treatment facilities

When patients with TB and M/XDR-TB join the palliative care program, they receive outpatient therapy; the interdisciplinary team in palliative care provided to TB and M/XDR-TB patients should establish contact with the hospital(s) that would provide care if the patient cannot receive in-home therapy due to changed conditions or if there is a need for emergency care. The role and responsibilities of the palliative care team and referral to hospitals should be discussed and set forth so that all the parties concerned are aware of their tasks and establish cooperation. When referring the patient to the clinician, the latter should be notified at least within 24 hours to be prepared to receive such patient. Medical staff and visitors should wear N95 respirators. Healthcare workers with compromised immunity must not be appointed to take care of such patients. Therapy shall be provided in the general hospital.

The level of emergency medical aid provided to the patient of the palliative TB and M/XDR programme must be also agreed and ordinary invasive procedures such as bronchoscopy, intubation are not recommended. The hospital should be informed of the patient – member of the TB and M/XDR-TB programme of palliative care in their area and be ready to receive him/her, if necessary. The facility should have in place the tuberculosis infection control programme, and it is necessary that the standard operating procedures of hospitalisation of highly contagious TB or M/XDR-TB patients (short term) are implemented.

Appropriate wards (isolation for patients with airborne diseases) should be available for immediate isolation of such patients. The ward should be isolated from the rest of patients (box-type) and have separate ventilation through the open window with the

possibility of changing the direction of the airflow, e.g. via fans or individual active ventilation system. Patients with TB and M/XDR-TB that have joined the palliative care programme may be discharged from the general hospital (or tuberculosis hospital) with home-based care support once acute situation is resolved.

Hospitalization in specialized TB and M/XDR-TB facilities

Criteria for hospitalization of patients with TB or M/XDR-TB to hospices providing palliative care to TB patients, facilities for patients, staff and respective healthcare facilities:

Criteria for healthcare facility

The patient can be admitted to a specialised TB and M/XDR-TB palliative care facility if no infection control measures can be provided in home setting, i.e. there is no separate room for the patient (without separate sleeping arrangements);

The issues that will be considered by a specialised TB and M/XDR-TB palliative care facility:

- If possible, natural ventilation with the possibility to open windows, as well as fans located in necessary places;
- Possibility of isolation of the room with windows that open out;
- Patients should be restricted to move to certain zones of isolation;
- The staff and visitors should wear N95 respirators.

Criteria for patients

- Failure to ensure TB control measures at the patient's home, i.e. no separate room for the patient (no separate sleeping arrangement);
- The patient lives alone and cannot take care of him/herself;
- The patient has no place for recreation;
- Other social and clinical conditions, on a case-by-case basis.

Criteria for the staff

- It is vital to ensure open communication so that the staff understands the principles of proper infection control and at the same time it is necessary to provide compassionate care;
- Proper infection control should become a daily task;
- Encouragement in finding out own HIV status;
- The staff with HIV must not be involved in the provision of care to such patients.[xvi] Note: palliative care facilities may contribute by holding palliative care trainings to the staff working in these public institutions.

Primary Health Care

Home based care & mobile teams

Palliative care may be provided not only in the hospital, but also in home settings or at the place of residence by an interdisciplinary team that includes nurses, caregivers, physicians, social workers and other specialists as needed. In fact palliative care is provided much more in the home setting than in institutions.

Prior to admission of the patient with TB or M/XDR-TB to the in-home palliative care program; the patient should be visited at home for objective assessment of physical, psychosocial, spiritual, and economic condition of the patient and family. This assessment includes checking for available separate sleeping arrangement, caregiver availability, and whether infection control measures are in place. It is essential to investigate contacts especially children under 5.

It is important to establish communication channels with the patient and family and to ensure they have access to counselling. It is necessary to needs for medications and supplies and to discuss plans for visits by the palliative care doctor/nurse and nearest pharmacy. The role and responsibilities of all parties involved should be discussed and specified.[xvii] Each patient should have an individualized team plan of care based on need that will identify problems to be managed, treatments, how frequently home visits will occur and how to reach the palliative care service if a problem arises.

Outpatient & satellite clinics

For palliative care patients that are stable and that do not need regular home visitation access to services in an outpatient or satellite clinic setting should be available. Services should include symptom management and psychosocial support.

Hospice facilities

Palliative care patients can be successfully managed at home with proper education and support. However new problems arise, crises can occur, and some patients may need to be transferred to an inpatient facility for care if they cannot continue to be managed at home. In some cases the person may not want to spend their final days at home. Where available an inpatient hospice facility may be needed to manage palliative care. This may be a community-based facility or a unit at a TB hospital designed to provide hospice inpatient care.

Hospice facilities should be designed to be more home like less institutional settings. There should be accommodation for a family member to be able to stay and the patient should be able to bring pictures and other personal items from home. Where possible patients actively dying should be able to have a private room. Active psychosocial and spiritual support should always be available.

Standards of operation for Palliative Care services

Specialized providers of palliative care services should meet the standards established by the Hospice Palliative Care Association of South Africa.

Staffing of palliative care services

Staffing of palliative care services in residential settings should exceed the recommended staffing for mobile teams defined in the Management of Drug Resistant TB Policy Guidelines[4] in that access to physician, social work, and psychology services must be included. Nursing and community caregiver staffing levels are appropriate but interdisciplinary team services are required.

Funding for palliative care services

Community based organizations providing palliative care services for TB patients should be eligible for grant funding through their usual funding sources but also from government sources. Government run health programs providing palliative care should be funded through the usual annual budgeting process.

Provision of essential palliative care medications including opioids

The WHO Model List of Essential Medicines[xviii] includes a section for pain and palliative care medicines that should be available in all countries. The list includes non-opioids and non-steroidal anti-inflammatory medicines, opioid analgesics, and medicines for other common symptoms in palliative care. The opioids include codeine and morphine. Morphine should be available in slow release granules, injection, oral liquid, slow release tablets 10-200 mg, and immediate release tablets 10 mg.

Oral morphine is the standard of practice for pain relief in palliative care and should be available along with non-opioid analgesics for TB patients with moderate to severe pain. Opioids are also used for treatment of shortness of breath (see clinical guidelines).

Training of Medical Staff and Other Persons Providing Palliative Care

Curricula for teaching generalized palliative care

All TB workers should have a basic understanding of palliative care. A curriculum for teaching the basics of palliative care is available for up to 40 hours of classroom and practicum instruction. This curriculum is designed for physicians and nurses. A shorter one-day course can be taught to paramedical workers and volunteers. The basic course for professionals includes the following modules:

- Introduction to palliative care & WHO policy on palliative care & TB
- Human rights
- PC Assessment
- DR-TB treatment
- Breaking bad news
- Ethics
- Psychosocial and spiritual issues and effective communication
- Pain assessment/management & treatment of adverse effects
- Dyspnea treatment
- Nausea treatment
- Dermatology
- Constipation & GI symptoms
- Delirium management
- Haemoptysis management
- Anxiety and depression treatment
- Infection control

- Burnout prevention
- Grief, loss, & bereavement support
- Community engagement

Curricula for teaching specialized palliative care

A growing number of countries recognize palliative care as an area of medical specialization, usually as a sub-specialty. Qualifying as a palliative care specialist usually takes one year of fellowship training that includes some classroom training but is primarily done in practice settings under the mentorship of a qualified specialist. Palliative care is not yet recognized as a medical specialty in South Africa.

Education of family members and community on palliative care

Public awareness of palliative care is important to ensure that services are accessed by those in need. There are also many myths about palliative care that need to be dispelled including that it is only for people at the end-of-life, that patients will be over-medicated, that it means giving up. All of these are false. Palliative care education helps empower families to participate in caregiving and to anticipate problems before they occur leading to better quality of life for all.

Monitoring and Evaluation of Palliative Care

The process of monitoring and evaluating patients with DR-TB is described in the *Policy Guidelines for Management of Drug-Resistant Tuberculosis* (2013). The focus of monitoring and evaluation (M&E) during treatment is different than for patients requiring specialized palliative care. The goals of care shift from cure to care, and there is a need to understand and assess the patient's qualify of life (QoL). QoL is affected by many things that may or may not be related to the provision of palliative care, but it is still necessary to recognize the dimensions of QoL that are important for each person (See section 8.1.4.2) and to use the clinical measurement tools to document symptom severity, quality of life, and respect patient choices and involvement in care. The Home Data Management System should include palliative care data so each palliative care service can compare outcomes. M&E data should also be used for ongoing quality improvement activities.

8. Process of Car

Introducing Palliative Care as part of the continuum of care from diagnosis

Since it is never clear which patients will experience non-response to treatment, a general introduction to palliative care should be provided to all those with TB, including drug-sensitive patients, with counselling included. The goal is to normalize palliative care as part of the continuum of care for TB patients. In the packet initiating TB treatment a short description of palliative care should be included that emphasizes the importance of relief of suffering, improving adherence, and assuring that patients unable to be cured will not be abandoned. The special needs of children must also be addressed from admission.

Transition to specialized palliative care service

Criteria for Suspension of TB treatment

While there is no single indicator that determines whether treatment is failing, a point will be reached when it is clear that the patient is not going to improve. Signs that indicate treatment failure include:

- Persistent positive smears or cultures after 8 months of treatment;
- Extensive and bi-lateral lung disease with no option for surgery;
- High-grade resistance with no option to add additional agents; and
- Deteriorating clinical condition that usually includes weight loss and respiratory insufficiency.

All these signs need not be present to declare failure of the treatment regimen; nevertheless, cure is highly unlikely all exist. It is important to note that the epidemiological definition of treatment failure for recording outcomes is often different from the process of suspending treatment in a patient when it is failing. The epidemiological definition is an outcome to account for the patient in treatment cohort analysis. The clinical decision to suspend treatment is one made after all other options have been explored, and cure of the patient has been determined to be highly unlikely.
MDR or XDR-TB treatment can be terminated provided that appropriate counselling has been offered to the patient, and the patient has been given an opportunity to speak before a final decision is made. Termination of treatment should be considered in the following circumstances:

- Where the patient no longer consents to treatment.
- Where there is negligible chance of success, even where the patient wishes the treatment to continue. This would apply to those who are chronic defaulters in whom the treatment may not be effective, may result in amplification of resistance or treatment failure, and in patients with advanced terminal disease.

Suspension of treatment should only be considered after all other options for treatment have been explored. Because this is such a difficult decision for family members and caretakers, and especially for the patients themselves as treatment is often viewed as his/her only hope, it is imperative that psychosocial support must be rendered to the patient and family.

If the DR-TB clinical management team is confident that all medications have been taken and that there is no possibility of adding other drugs or surgery, the treatment should be considered a failure and suspension of therapy recommended along with the provision of palliative care.

The decision to suspend treatment should be made by the provincial TB review committee based on all the evidence provided on the patient. The team should recommend a continuum of care plan that is inclusive of palliative care. Conditions under which treatment may be suspended include:

- The patient's quality of life is poor, particularly when taking medications used in DR-TB treatment have considerable side effects and continuing them while the treatment is failing may cause additional suffering.
- Continuing treatment that is failing can amplify resistance in the patients strain, resulting in resistance to all available anti-tuberculosis drugs. This super-resistant strain can be transmitted to others.

A consultative process with the patient and family should take place. Both parties should be made to understand and accept the decision for suspension of treatment and alternative care offered. Depending on the patient's condition this can be provided at home, hospital, or hospice. Usually this process takes a number of visits and occurs over several weeks. Home visits during the process offer an excellent opportunity to talk with family members and the patient in a familiar environment. Treatment should not be suspended before the patient understands and accepts the reasons to do so, and agreed with the supportive care offered. The household should be assessed for risk of infection and family educated on measures to take to minimize transmission risk of infection and patients should be advised to avoid contact with the general public and especially susceptible persons such as young children or HIV infected individuals." (adapted from Management of Drug-Resistant Tuberculosis: Policy Guidelines, 2013 pp-99-100).

Refusal or discontinuation of treatment does not mean cessation of care. Palliative care must be offered to all those who will not be continuing active TB/MDR-TB treatment to ensure they can continue to live with minimum suffering and without loss of sense of dignity. In such cases, decisions made by the community and household should be considered. It is essential to support the family by providing in-home palliative care.

Criteria for Initiation of specialized palliative care services

Any patient where the decision is taken to discontinue treatment should be eligible to receive specialized palliative care services. At the time of initiation of palliative care services a comprehensive assessment should be conducted to identify the patients

current problems and needs and a care plan is developed according to need. For patients with high symptom burden and deteriorating condition the care plan and service delivery should begin immediately. For patients that are asymptomatic and stable the initiation of education and monitoring can be initiated and services increased over time as the needs increase. Palliative care may be initiated in inpatient or residential settings.

Procedures for working with patients and families to understand discontinuation of treatment & initiation of palliative care

The involvement of the patient and family with the consilium is essential in the process of discontinuing treatment and initiating formal palliative care provision. This process must be done with careful care and consideration (as noted above). The procedures for breaking bad news (see section 8.2) should be followed and time taken to ensure that the patient fully understands the situation and knows what the plan is going forward. The inter-disciplinary team caring for the patient is responsible for sharing bad news on outcomes for the patient and this should be done as a team, ensuring that a designated person is present that the patient trusts. Bad news should be conveyed earlier rather than late in the process. Breaking bad news to children requires a broad team, age appropriate communication, and strong family psychological support. All health care workers must communicate the same message, and understand that the end of curative treatment is not the end of care. This must be emphasized to the patient and carried out by the PHC team to ensure access to ongoing care and support.

Initial Assessment, care planning and record keeping

Initial assessment of patients with TB and M/XDR-TB requiring palliative care includes medical history, examination and assessment of any active problem or other issues requiring intervention or supervision. Assessment should consider such specific symptoms of pulmonary tuberculosis, which are the most common symptoms among tuberculosis patients, as cough, haemoptysis, shortness of breath, as well as such non-specific symptoms that are common for any site of tuberculosis, as fatigue and malnutrition, night sweats and types and levels of pain. Moreover, assessment focused on palliative care should detect essential physical symptoms, emotional, psychological and spiritual questions, as well as any family or social problems. Initial assessment allows the creation of a comprehensive palliative care plan for patients. Moreover, comprehensive initial and ongoing assessment helps to detect immediate and long-term targets of care for every individual. Decisions should be carefully explained to adult patients or a person appointed by them as decision-maker. A record of all services provided and visits made to the patient is maintained including patient/representative signature acknowledgement.

Refer to Annex #2: Assessment Tools

Medical History

A medical history for the patient is needed either from a recent hospital admission or done by the admitting nurse or physician. The history should include:

- Current diseases and prescribed treatment
- Medical history including all concurrent diseases and previous diseases, HIV and others;
- Primary diseases, hospitalisation, surgical interventions and date of TB or HIV diagnosis;
- Prescribed drugs;
- Drug abuse and dependence, including treatment;
- Family history;
- Social history;
- Social resources;
- Financial issues;
- Current symptoms (i.e. pain, loss of weight, anorexia, fatigue, fever, night sweats, insomnia, despondency, anxiety, shortness of breath, cough, nausea/vomit, diarrhoea);
- Chronology of symptoms;
- Aggravating and mitigating factors;
- Drug taken or other treatment of symptoms;
- Reason, type and level of pain (pain scale must be from 0 to 10, where 0 means no pain, 10 means worst pain);
- Reason of symptoms, type and peculiar characteristics. Impact of (1) symptoms on functional capabilities, (2) symptoms on each other, (3) specific therapy on every symptom, (4) symptoms on the quality of patient's life;
- History of mental health and treatment (e.g., depressions, anxious disorders, delirium, psychosis). And any current problems with mental health.

Refer to Annex #2: Assessment Tools

Physical Examination

A physical examination of the patient is done during the admission process regardless of the patient's setting. During this visit a complete assessment is done of all physical systems and includes:

- Full clinical examination
- Systemic interview includes:
  - Constitutive (fatigue, anorexia, fever, loss of weight)
  - Neurological
  - Mental status
  - Dermatological
- Other tests and research, as required.

Psychosocial Assessment

Psychosocial assessment is a critical part of a comprehensive palliative care assessment. The following are common components of this assessment:

- Demographic information
- Social support system
- Impacts of illness on daily living and relationships
- Work/education history, skills and interests
- Strengths and coping strategies
- Self-care activities, e.g., meditation, exercise, prayer, etc.
- Understanding of diagnosis and prognosis
- Experience and comfort level with health care system
- Goals/hopes/expectations
- Fears/concerns
- Previous and/or anticipated losses
- Communication and information needs
- Psychological issues and support needs

Refer to Annex #2: Assessment Tools

The Interdisciplinary Team Plan of Care (IDTPOC)

Each person receiving specialized palliative care should have an IDTPOC. The plan is based on initial and on going assessments of the affected person. The IPTPOC should include at least the following elements:

- Problem list
- Medications & orders for treatments
- Needed equipment and supplies
- Goals for care
- Plans for visit/contact frequency

Tuberculosis and Multidrug/Extensively Drug-Resistant Tuberculosis in Special Cases

Tuberculosis and Multidrug/Extensively Drug-Resistant Tuberculosis in Children

Treatment of children with tuberculosis or M/XDR-TB under the palliative care program is based on the same principles applied to adults. Parents and educators should be informed about tuberculosis and the importance of observing infection control measures. If in-home care is provided, the child should have a separate room or, at the least, separate sleeping arrangements with the possibility of frequent window opening to reduce the amount of infections particles.

A child's parents should be sufficiently trained and effectively supported in treatment of their child. Parental worries about the ill child should not be underestimated. Increased counselling and psychosocial support to the whole family is often indicated.

Co-infected children require specialized care that is stable and appropriate. Counselling must include the family and must be structured and documented. If treatment fails, the patient and family's belief system must be respected. Support from the Department of Social Development and the Department of Education should be included.

Children may have difficulty expressing their pain and may need the help of adults to detect it depending on age. Adults must try to help identify the level of pain by numbers with the help of scales, for example smiling or sad faces. Adults must differentiate pain from anxiety. In the case of lasting pain, they should look for behavioural signs of pain:

- Irritation;
- Crying
- Unwillingness to be active;
- Loss of interest;
- Reduced concentration;
- Sleep problems;
- Changes in child's movements;
- Anxiety;
- Increased breathing rate and heart rate.
- Touching or guarding an affected part of the body

HIV-positive Patients with Tuberculosis and Multidrug/Extensively Drug-Resistant Tuberculosis

Among HIV-positive patients, TB is a main cause of death. Particular attention should be paid to diagnosing tuberculosis or M/XDR-TB among HIV-positive patients in order to avoid late diagnosis and, hence, to reduce treatment possibilities. Both diseases, tuberculosis and HIV, are associated with strong social stigma. The holistic approach to the patient, family and community is necessary to ensure significant help to TB/HIV-positive patients. One of the main cornerstones is the provision of adequate and actual information to avoid misunderstanding and misconception.

In the event of TB/HIV, the infected person may have more need for palliative care. In such cases, procedures of TB treatment relating to HIV care should apply:

- Due to high contagiousness of the patient, particular attention should be paid to infection control measures;
- Primary examination of patients includes medical history, physical examination and assessment of any active problem or other issues requiring intervention or supervision.
- Assessment should consider the peculiar characteristics of specific TB and HIV symptoms.

Control over TB or M/XDR-TB symptoms must be based on treatment provided and symptoms of HIV infection according to the relevant guidelines

Care and Support

Family and Staff Care and Support

The relatives of patients with advanced disease are subject to considerable emotional and physical distress, especially if the patient is being managed at home. Particular attention must be paid to their needs as the success or failure of palliative care may depend on the caregivers' ability to cope.[xix]

Healthcare staff should visit the patient at home since caregivers may need technical and emotional support. Find out when and why such support is needed, even if it has not been planned. The healthcare staff of the medical department in charge of in-home palliative care must supply drugs and medical supplies without interruptions.

It is essential to take care of staff caregivers and detect possible job burnout – irritability, anger, sleep disturbances, poor concentration, denial of others – avoiding patients and problems, fatigue, emotional numbness – no pleasure, alcohol and drug abuse, fear of grief (refer to Annex: *Psychological Assessment of Patient, Family and Caregiver*). In such cases, psychological support must be provided. Ensure that the healthcare worker has skills and resources to take care of the caregiver(s). It is very important to take care of TB caregivers. If you take care of the staff they can take care of the patients.

Caregivers must decide themselves what is significant and valuable in the process of care. It is essential to discuss the problems that are encountered with the healthcare worker that controls in-home care. Know what causes stress and try to avoid it by using the strategies focused on the problems, not emotions.

If necessary, change the approach to the caregiver:

- Split the tasks (little help);
- Ask others to help;
- Ask the head caregiver to find a substitute for one or few days;
- Encourage patient's self-care.

Take care of your own life apart from the care of the patient.

- Develop your own network of psychological support (e.g., caregivers support team);
- Take care of your own health;
- Take regular breaks and do other things, spend time with the family, friends;
- Know that you cannot do everything and you need help;
- Share the problems with your colleagues;
- Organise community work.[xx]

9. Clinical Palliative Care

PLEASE REFER TO THE HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA CLINICAL GUIDELINES FOR ADDITIONAL GUIDANCE ON PALLIATIVE SYMPTOM MANAGEMENT[xxi]

10. Physical Aspects of Care

Palliative Care Physical Symptom Management

The main target of palliative care is to improve quality of life for the patient with the help of symptomatic treatment and relief of suffering. The following symptoms occur often in progressive tuberculosis: cough and shortness of breath, haemoptysis and bleeding, anorexia and cachexia, pain, night sweats, anxiety and depression.

Patients with M/XDR-TB may differ from those with TB by the intensity of conditions and specific symptoms. It is essential to detect the cause of symptoms in order to treat the symptoms and, if possible, offer effective recovery care. It is important that palliative care be available when medical and/or recovery treatment starts.

Cough and Shortness of Breath

Shortness of breath is the subjective symptom of asphyxia that occurs in pulmonary disease or other diseases. Shortness of breath often causes anxiety in patients and persons that take care of patients. In the case of pulmonary tuberculosis, including M/XDR-TB, cough is persistent. During the course of the disease, bloody sputum or haemoptysis may occur. Nevertheless, cough may be caused by other reasons such as non-specific pulmonary infections, influenza, chronic bronchitis and bronchiectasis, pulmonary tumour (Kaposi's sarcoma, non-Hodgkin lymphoma in HIV-positive patients with tuberculosis), aspiration, sinusitis following treatment with nasal drops, reflux, spontaneous pneumothorax, etc...[xxii] The cough reflex may reduce if treated with opioid antitussive drugs and opioid analgesics such as morphine. Sodium cromoglicate inhaler may prevent cough in patients with TB and M/XDR-TB.

Cough Control

For cough caused by mucus hyper-production, use:

- Steam inhalations;
- If the volume of sputum exceeds 30 ml per day, forced expiration technique with postural drainage should be applied.

For watery mucus, use:

- Hyoscine 10 mg in every 8 hours. Hyoscine butylbromide: 20 - 120 mg in oral doses taken at certain intervals, or via continuous subcutaneous infusion.

- Scopolamine transdermal patch: 1.5 mg; 1 - 3 patches applied every 72 hours
- Antihistamines, e.g., diphenhydramine, 25 - 50 mg, every 4-6 hours

For cough caused by bronchial spasm, use bronchodilators (e.g., salbutamol inhaler) or inhaled or systemic corticosteroids.

For cough caused by gastric reflux, use proton-pump inhibitors (omeprazole) or H2-receptor antagonists (ranitidine).

For dry, non-productive cough, use:

- General cough mixture;
- Codeine 10–20 mg every 4 hours; dextromethorphan - 25 mg or more tds; morphine – starting from 2.5 mg every 4 hours;
- Lidocaine inhalation 3–5 ml 2% solution (without epinephrine) 3–4 times a day or bupivacaine 0.25% (5ml) 3–4 times a day. Inhalations should not be made before or within one hour after eating or drinking.

For productive cough in patients who cannot cough effectively, use:

- Inhalations with 2.5% saline solution – 5 ml every 2-6 hours, or humidifying;
- Mucolytics – acetylcysteine, bromhexine.

For productive cough in weak patients, use:

- Codeine 10–20mg every 4 hours, not more than 60 mg a day;
- Morphine 2.5mg-5mg every 4 hours;
- Dextromethorphan 25–50 mg 3–4 times a day.

Refer to Annex #3: Postural Drainage

Management of Shortness of Breath

The most effective drugs for treatment of shortness of breath are opioid analgesics such as morphine. Respective doses of opioid analgesics can reduce the intensity of shortness of breath without reducing the breathing rate. Patients taking opioids will have less shortness of breath, yet they may have rapid breathing. This information must be conveyed to the families since relatives may interpret tachypnea as a sign of shortness of breath.

Additional oxygen may be especially useful for patients with hypoxia. The air is supplied by a fan or an open window, which can reduce shortness of breath by stimulating sensory receptors on the face and in the epipharynx.

Refer to Annex #4: Pharmacological Management of Shortness of Breath

Refer to Annex #5: Non-pharmacological Management of Cough and Shortness of Breath

Haemoptysis

Haemoptysis is a particularly alarming symptom for both patients and their relatives and usually requires immediate counselling by healthcare workers or a specialised hospital. Haemoptysis is usually caused by TB; however, it can be as well related to bronchitis, thromboembolism, or tumour. Usually haemoptysis requires emergency care; however, in the case of palliative care, such procedures as intubation, bronchoscopy and bronchial artery embolisation are not recommended. Instead, it is recommended to use strong opioids and midazolam or diazepam to reduce fear and anxiety.[xxiii, xxiv]

The use of red towel, dark sheets and blood collection containers can calm the patients with severe haemoptysis down. [xxv] Dark colour makes blood less noticeable, which, in turn, makes the patient and his/her family less stressed. If the patient has high risk of bleeding or fear of secondary asphyxia due to haemoptysis, it will be useful to have a syringe prefilled with short-acting benzodiazepines such as midazolam, or lorazepam. The families must be aware of a possibility of excessive bleeding and must be instructed on how to inject a tranquilising agent, if there is a need to mitigate the patient's suffering.

Fatigue and Extreme Emaciation

This is one of the most frequent problems in tuberculosis patients. Increased food intake can hardly solve the problem of significant loss of weight related to tuberculosis since cachexia (extreme emaciation) is a syndrome caused by metabolic disorders. Tuberculosis-associated cachexia is not a result of ordinary calorie imbalance and rarely responds to aggressive parenteral or enteral nutrition. It is important to manage the symptoms of pain and depression in addition to fatigue and cachexia.

The social values of food must be maintained even if patients consume small amounts of food. The families should be provided with information that patients do not starve, they rather suffer from expected metabolic effects of tuberculosis.

- Psycho-stimulants and antidepressants may be useful in managing subjective symptoms of fatigue;
- Patients with anemia may be helped with blood transfusion, if available;
- Prednisolone 5-15mg a day, up to 6 weeks, can be useful in the event of severe anorexia and asthenia;
- Vitamin B1 should be administered daily since it plays a core role in production of energy from carbohydrates and is involved in RNA and DNA production;
- In the event of nausea and vomiting, prescribe antiemetic agents;
- Offer small but frequent portions of favorite food to the patient; do not force the patient to eat. Food should be taken in small portions until appetite revives.

Night Sweats

Night sweats are a common non-specific symptom that accompanies TB and M/XDR-TB. There are several reasons for night sweats such as fever; a damaged lung must work harder in order to maintain the required level of oxygen in blood.

Night sweats management:

- Treatment of fever: paracetamol, drink plenty of water
- Frequent change of bed sheets and pajamas.

Pain

Pain may have various origins in patients with TB and M/XDR-TB, i.e. they can be associated with the organ affected by tuberculosis, as well as for other reasons. It is essential to identify the source of the pain and to manage it properly.
Pain caused by tuberculosis or M/XDR-TB is usually easily managed by opiates and non-steroidal anti-inflammatory drugs. The causes of pain in the event of tuberculosis or M/XDR-TB may be as follows:

- Pulmonary or pleural inflammatory infiltration, or other internal organs;
- Muscle tension due to severe cough;
- Bone pain due to TB infiltration in the vertebral column or bones;
- Pain caused by arthralgia or septic arthritis.

Pain management (Please also refer to HPCA Clinical Guidelines 2012):

- Mild pain: Paracetamol 2 x 500mg every 4–6 hours (not to exceed 4g/day);
- Moderate pain: Codeine phosphate 30–60mg every 4 hours;
- Severe pain: Morphine sulphate 5–10mg every 4 hours, titrated to comfort;
- Bone pain: Ibuprofen 200–400mg every 8 hours;
- Neuropathic pain: Vitamin B6 (pyridoxine) 100mg and tricyclic antidepressants (amitriptyline 25mg before bed).

Other Symptoms

Including:

- Gastro-intestinal symptoms
- Constitutional symptoms
- Urinary symptoms
- Wound care
- Vascular and haematological disorders
- Palliative Care Emergencies
- Mouth care

Please also refer to HPCA Clinical Guidelines 2012

Other co-morbidities including diabetes, silicosis, hearing loss, etc.

Comorbidities are common in patients with tuberculosis and should be taken into consideration when deciding on treatment. The prevalence rate of diabetes in TB patients has been found to be 29% (8.3% new cases). Hearing loss related to treatment with aminoglycosides (amikacin, kanamycin, & apreomycin) for resistant TB is estimated at 18%. The co-existence of silicosis and TB is known as silico-tuberculosis. Miners, silica mill workers, and slate pen workers exposed to silica dust are at high risk of developing the condition as silica causes renewed multiplication of bacilli in healing TB lesions.

Prevention and treatment of these co-morbidities should be done using existing protocols. Diabetic care procedures should be followed, hearing loss can be ameliorated with hearing aids and other measures. There is no specific treatment for silicosis other than symptomatic interventions, including cough medicine, bronchodilators, and oxygen.

11. Psychological Aspects of Care

12. Psychological & Psychiatric care

The availability of qualified mental health professionals including psychologists, psychiatrists, social workers, and counsellors is limited in South Africa. Efforts to fund and recruit staff with these skills is an important part of the integration of palliative care into the TB treatment system. An interdisciplinary team is incomplete without the inclusion of mental health professionals. If only physicians, nurses, and community health workers are involved in treatment then an important element is missing as psychological and psychiatric support could be considered, in many respects, the most important element to successful treatment outcomes. Nonetheless, there will continue to be variability in access to competent mental health workers so it is incumbent on medical workers to develop mental health skills. All health care workers should become familiar with the following guidelines to ensure that patients and families receive the counselling and support they need both during treatment and when treatment fails.

Anxiety

Anxiety/agitation in patients with advanced disease is often due to stress from the diagnosis itself. The diagnosis may raise fears about anticipated symptoms related to treatment and side effects and associated with progressive loss of autonomy leading to death. Anticipatory anxiety is often seen before tests and procedures or while waiting for test results.

Factors contributing to anxiety include previous or underlying anxiety disorder, unmanaged pain, or medical factors.

Assessment of anxiety

Ask the patient about the following:

- Bothersome physical symptoms;
- Psychological distress (fears and concerns);
- Previous experiences of anxiety and coping mechanisms;
- Awareness of condition and prognosis.

Examination may reveal the patient to be:

- Diaphoretic, pale or flushed;

- Hypertensive, tachycardic, tachypneic;
- Irritable, worried, fearful;
- Apprehensive, tremulous, jittery, tense, inattentive;
- Labile, hyperalert/hypervigilant.

The decision to intervene with behavioural or pharmacological therapies is based on the patient's level of distress and ability of the patient to participate in treatment or function adaptively. For example, if a patient's fear of needle insertion for a biopsy is creating a delay in the procedure, pharmacological or behavioural interventions are appropriate.

When anxiety symptoms do not interfere with treatment or are not intolerable to the patient, no specific interventions are required beyond the reassuring and empathic responses of staff members. Supportive counselling or behavioural techniques may help patients with intolerable anxiety. Medication or a combination of behavioural and medication therapies should be considered in some cases.

The Hospital Anxiety and Depression Scale (HADS) [xxvi] is a useful screening tool for anxiety and depression and is widely used within the palliative care setting. (**See Annex #2 Assessment Tools**)

Management of Anxiety

Anxiety in the patient with advanced disease can be managed as follows:

- Treat underlying physical problems and discontinue offending medications;
- Assess and aggressively manage pain (if any);
- Offer reassurance, sensitively address concerns and fears, enable the patient to express his/her thoughts and feelings about the situation, and empower the patient with helpful information;
- Suggest relaxation techniques;
- Prescribe anxiolytic medications judiciously.

The choice of anti-anxiety medications is usually made based on the severity of the symptoms. Anxiety in patients who are dying is often brought on by one of the many physical complications at the end of life. It is important to remember the psychological causes of anxiety, especially with patients who are alert and not confused. These patients may have fears about disability and dependence. The fear associated with death (death anxiety) is a normal part of the human condition. It is the fear of non-being, life's ultimate existential concern. In particular, patients may fear the isolation and separation of death. Although these issues are often troubling for staff they should not be avoided. Eliciting assistance from trained spiritual counsellors is also an important part of caring for a dying patient.

Supportive counselling is an important intervention for the terminally ill and should be provided by trained professionals. Many fears and concerns of the terminally ill may be too painful to reveal to family and friends. Thus, the goal of supportive counselling at the

end of life may be described as helping patients achieve comfort or peace of mind. An open and frank discussion about death and dying may alleviate fears and anxieties by detoxifying or demystifying the experience.
Unique qualities of skilled counselors in this setting include active listening, giving supportive verbal feedback, and eliciting light-hearted conversation about the patient's life and experiences rather than focusing solely on death and dying. This type of counseling requires someone who is adept at stimulating interaction and actively listening with interest rather than somber and emotionally distant.

Pharmacological Management[xxvii]
There is a lack of robust evidence to support the use of any specific medications in the management of anxiety within the palliative care population.[xxviii]

Benzodiazepines
These are widely regarded as the mainstay of treatment for anxiety but have addictive potential. They are traditionally divided between compounds, which have more sedating effects and those which have more anxiolytic actions. However there is considerable overlap on the anxiety/sedating spectrum. They are useful to break the anxiety cycle, to restore sleep, and to reduce the suffering of the situation where a patient feels that he/she is "losing control". They are not a substitute for taking the time to allow a patient to ventilate their fears.

Diazepam	1 - 5mg PRN PO	Diazepam has a long half-life and may therefore accumulate and be sedative. It should be possible to give it once a day at night.
Lorazepam	0.5 - 2mg PRN PO or SL	Lorazepam is short acting, rapidly anxiolytic and less sedating than diazepam. It may be more addictive on a longer term basis.
Midazolam	5 - 10mg PRN SC or buccal	Useful for emergency sedation.

Antidepressants
Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants such as paroxetine are recommended by NICE for the management of generalized anxiety disorder. Doses used are often lower than the doses for depression. The time for effect may be up to 6 weeks, which may limit their use amongst palliative care patients. It is also important to warn patients of the potential for an initial worsening of symptoms.
Tricyclic antidepressants such as imipramine, are less commonly used and again usually at "sub-antidepressant" doses.[xxix] Other drugs have been used in the management of anxiety e.g. anti-histamines, buspirone and antipsychotics. Complex anxiety states with depression and psychosis may require the help of a psychiatric team.

Depression

Emotional distress is a normal response to the fatal event that the incurability diagnosis represents. For most patients, this distress is transient, and the patient and family are able to adapt with time and general supportive care.
The diagnosis of depression is often difficult to ascertain. The most obvious problem is that sadness and grief are expected responses to the diagnosis and at various transition points in the disease. Another is that the physical signs of depression (such as fatigue) may be attributable to the disease itself.

The best starting point for assessing mood dysfunction in patients is a careful history and physical examination and a simple question: "Have you recently been bothered by feeling down, depressed, or hopeless?" Another useful question is: "Have you often been bothered by having little interest or pleasure in doing things?" The first question targets depressed mood, while the latter is an indicator of anhedonia or inability to feel any pleasure.

Management of Depression

Step 1: Perform a thorough initial assessment (Refer to Annex 2):

- Note previous depressive episodes;
- Consider the patient's family history of depression or suicide;
- Ascertain any current or prior substance abuse (refer to annex: CAGE questionnaire);
- Directly ask the patient whether he or she is contemplating suicide;
- Rule out delirium.

Step 2: Facilitate effective communication:

- Anticipate and allow sufficient time for breaking bad news to the patient if necessary(this usually works better near the end of the day);
- Make follow-up assessments of fragile patients more frequent (this is more effective than lengthy but infrequent assessments);
- Get the setting right (i.e. make sure the patient is comfortable and accompanied by family/friends);
- Provide information to the patient directly and without jargon;
- Respond to the patient's emotions with empathy, but avoid giving unrealistic expectations. A useful phrase for empathising with the patient and acknowledging disappointing facts is to simply state, "I wish things were different".

Step 3: Consider psychological interventions:

- Allow the patient a safe opportunity to express his/her concerns and fears about TB and the end of life. If some of the patient's family members hinder such expression, consider a split counselling session. Provide referral to the clinician or contact information of a place where care can be obtained.

Step 4: Evaluate the patient for significant major depression:

  - Look for profound levels of worthlessness, guilt, anhedonia, and hopelessness;
  - Ask about suicidal ideation. If the patient has active suicidal ideation, refer the patient to a behavioural health professional;
  - Consider possible medical causes of depression:
- Drugs;
- Poorly controlled pain.

Step 5: Use antidepressants appropriately.

- Antidepressants may be used to manage mild, moderate or severe depressive symptoms. However, their optimal use is still poorly defined.
- It is often useful to choose a specific antidepressant whose side effects best suit the patient's situation. For instance, a patient with psychomotor retardation might benefit from a more activating agent, such as methylphenidate (i.e. Ritalin) or fluoxetine. An agitated and depressed patient may do better with a more sedating drug such as tricyclic antidepressants (e.g. nortriptyline) or noradrenergic and specific serotonergic antidepressants (mirtazapine).

Medication Management[xxx]

Under-treatment of depression is common.[xxxi] Psychological therapies can be effective but may need to be brief due to limited life expectancy. Cognitive Behavioral Therapy has been increasingly used and can improve some outcomes in palliative care. Evidence is limited concerning the effectiveness of antidepressant medication in terminally ill patients but they are recommended in moderate to severe depression.[xxxii, xxxiii]

Psycho-stimulants are very rarely used despite some evidence of benefit.[xxxiv]

Selective Serotonin Reuptake Inhibitors (SSRIs)

- Sertraline 50mg o.d.
- Citalopram 20mg o.d.
- Paroxetine 20mg o.m.
- Fluoxetine 20mg o.m.

Recommendations are that sertraline and citalopram are well tolerated and should be considered for first line treatment starting at a low dose and slowly titrating up. SSRIs are less sedative than tricyclic antidepressants and have few anti-muscarinic effects, low cardio-toxicity and may have a faster onset of action than the tricyclics.
Gastrointestinal side effects such as nausea are dose-related.

Fluoxetine in particular may cause restlessness and anxiety and should be used with caution. Consider using a benzodiazepine as a short-term adjunct on commencement. There is some evidence of an increased incidence of gastrointestinal bleeding in combination with NSAIDs or aspirin.

Mirtazepine 15-45mg o.n. - Mirtazepine is an alpha adrenoceptor antagonist and increases central noradrenaline and serotonin transmission. It may increase appetite, and cause sedation during initial treatment.

Tricyclic antidepressants

- Amitriptyline 10 - 150mg per day
- Dosulepin 25 - 150mg per day
- Imipramine 10 - 150mg per day
- Lofepramine 70 - 210mg per day

Tricyclic antidepressants may take several weeks to lift depression. Amitriptyline and dosulepin are relatively sedative in comparison with imipramine and lofepramine. They all have anti-muscarinic properties to greater or lesser degrees and therefore may be associated with symptoms such as hypotension, dry mouth and difficulty in micturition. Doses should gradually be increased to avoid unnecessary side effects.

Pre-existing or new psychiatric diagnoses

There are a host of other potential psychiatric diagnoses that can affect the medically ill. In some cases pre-existing conditions can be exacerbated by a stressful medical condition such as TB. Patients may have a history of mood disorders, schizophrenic conditions, character disorders, or developmental disorders, and it is not uncommon for patients to experience adjustment disorders in response to their medical illness. A careful assessment is needed to uncover new or pre-existing diagnoses. When TB patients manifest acute psychosis or other psychiatric conditions that require hospitalization, a determination is needed on whether the condition can be treated at a TB facility or if psychiatric hospitalization is necessary. It is preferable if such patients can be effectively treated in TB hospitals, but these hospitals need access to psychiatric consultation in order for this to occur. If a situation occurs where the patient must be cared for in psychiatric facilities, the TB team should be able to attend to the patient to ensure that the patient is isolated and that infection control measures are instituted for any staff caring for the patient.

Other psychological issues

*D*enial

Facing the possibility of dying is very difficult for most human beings. The first reaction is often to deny or disbelieve the reality of the diagnosis or condition. Denial can be a kind of psychic shock absorber to allow a person time to develop more adaptive ways of coping. For those with limited inner resources for coping denial may be necessary to cope but for most it has more to do with interpersonal relationships. We decide not to talk about the seriousness of the condition out of fear that those we care about will abandon us or we don't want to deal with the emotions that come from facing the truth. In palliative care we help patients come to terms with their illness at their own pace and we create opportunities for open communication with family to promote growth and reconciliation.

Quality of Life

Maintaining or improving quality of life is the principal goal of palliative care yet it is often hard to measure and is affected by many factors that have little to do with the care the patient receives. It is generally held that the following five dimension of experience are most relevant to patients needing palliative care. [xxxv]

1. Symptoms
2. Functional ability
3. Interpersonal
4. Well Being
5. Transcendent

Breaking Bad News[xxxvi]

Patients and relatives need time to absorb information and to adapt to bad news. Health care professionals need good communication skills, including sensitivity and empathic active listening.

Breaking bad news takes time and issues often need to be discussed further and clarified as more information is imparted.

There is increasing evidence that most patients want to know about their illness. Many patients who have been denied this knowledge have difficulty in understanding why they are becoming weaker and are then relieved and grateful to be told the truth. Patients may be angry with the family who have known about the illness all along and have not thought it right to tell them.

As professionals, we often become entangled in a potential 'conspiracy of silence' situation when the family demands information before we have had a chance to speak to the patient. They might say, "Do not tell him the diagnosis / prognosis because he would not be able to cope with it. We know him better than you do". This can be an awkward situation. The family needs to know that we have understood their concerns of not wanting to cause any more hurt to the patient. They also need to know that we accept that some patients use denial as a way of coping. However, they also need to know that it would be unwise for clinical staff to be untruthful if the patient appeared to want to know the truth and was asking direct questions, because of the inevitable breakdown in trust that this could cause.

Some patients and their families may ask about prognosis and then it is important to be sure what information they are really wanting from you. If they want an idea of prognosis so that they can organize their affairs and plan for the time that is left, it is sensible to talk in terms of days/weeks, weeks/months, and months/years as appropriate. It is however, **impossible to be accurate** and overestimating or underestimating the time that someone has to live can cause untold anguish.

There is a balance to be made between fully informing the patient about their disease and prognosis, completely overwhelming them with facts and figures or providing only minimal and inadequate information. While it is important to avoid being patronizing, it is also important not to cause distress by "information overload."

It is important to be aware that people have divergent attitudes to receiving bad news and that this needs sensitive handling. Furthermore, people respond badly to being told bad news in a hurried, brusque and unsympathetic manner with no time to collect thoughts and ask questions. As health care professionals, we can be very critical of how our colleagues have imparted bad news.
Some of this criticism may have validity, but before judging too quickly we need to remember that:

- We are hearing one side of the story
- The impact of the news can obliterate a great deal of the communication that took place
- A patient's understanding of what they have been told can differ greatly from what the nurse or doctor think they have said!

A strategy for breaking bad news

This strategy outlines what other people have found helpful. Individuals should develop their personal ways of breaking bad news based on these principles. Practice and critical self-reflection are necessary to continue to improve this basic but essential skill.

Break bad news well and you will always be remembered, break bad news badly and you will never be forgotten.

The Goals of Breaking Bad News

The process of breaking bad news needs to be specifically tailored to the needs of the individual concerned, for every human being will have a different history and collection of fears and concerns. The goal of breaking bad news is to do so in a way that facilitates acceptance and understanding and reduces the risk of destructive responses.

Preparing To Tell Bad News

Acquire all the information possible about the patient and their family. A genogram (family tree) is particularly useful in quickly assimilating the important people in the patient's life, and the web of relationships within the family.
A "warning shot" is concerned with preparing a patient that bad news is coming. This allows them to be more receptive than if it comes "out of the blue". An example would be, "I'm sorry to say that the results were not as good as we had hoped."

LET THE PATIENT SPEAK FIRST
Use open questions, such as:
"How are you feeling today?"

"Can you tell me how this all came about?"
"How do you see things going from here?"

Read the patient's notes for:

- Diagnostic information
- Test results
- Full details of the patient's clinical history
- The support system for the individual
- Background knowledge of the patients life. Making basic mistakes will undermine the patient's confidence
- Discuss with other members of the team and then select the most appropriate team member to break the bad news.
- Decide which other member of the team should be present during the interview.

Check

- Place of privacy. Tissues, jug of water and glasses
- Time to carry out process
- Your own emotional energy to do so (better earlier in the day than later)
- Pressing tasks are completed so that there will be minimal interruptions. (Unplug the telephone and switch off the mobile phone etc.)

When breaking news to a patient make sure that he / she is appropriately dressed so he / she is able to engage in conversation without feeling embarrassed or at a disadvantage.

Plan

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

Setting the Context

- Introduce yourself clearly.
- Let the patient know they have your attention and how long you have got.
- Ensure that the patient is comfortable and not distracted by pain or a full bladder etc.
- Give "warning shot" indication that this is not a social or routine encounter.
- Sit at the same level as the patient within easy reach and not behind an obstacle such as a desk.

Assess

- How much the patient knows already
- How much the patient wants to know
  "Are you the sort of person who likes to know everything?"
- How the patient expresses themselves verbally and non-verbally
- What words and ways of understanding their situation they use

Acquire empathy with patient

- What would it be like to be the patient?
- How is the patient feeling?
- Is there anything that is concerning the patient?
- What mechanisms has the patient used in the past to deal with bad news?
- Does the patient have a particular outlook on life or cultural understanding?
- Who are the important people in the patient's life?

*Respond to **non-verbal** as well as **verbal** cues.*
Encourage the patient to speak by listening carefully, not interrupting (time permitting!) and responding appropriately.

Sharing information

- Having spent time listening, use the patient's words to recap. The story of the journey so far, checking regularly with the patient that you have heard the story correctly
  "Would you mind if I repeated back to you what I have heard you tell me to make sure I have understood things correctly?"
- Slowly and gradually draw out the information from the patient while regularly checking that they are not misunderstanding what you are saying
- Use the "warning shot" technique to preface bad news
- Use diagrams to help patient, but only if it is appropriate, and the patient wants diagrams to better understand and retain the information
- Avoid jargon and acronyms which are easily misunderstood
- Do not bluff
  It is acceptable to say: "I do not know, and I will need to try to get an answer for you for our next meeting."

Remember to ensure that:

- The patient understands what you are saying and the implications
- The patient is in control of the speed at which information is being imparted
- The patient can see that you are being empathic to their emotional response. It can be very appropriate to say something like:
  "Being told something like this can seem overwhelming...."

- You address the patient's real concerns, which may be very different from what you expect them to be

Response

- You should respond to the patient's feelings and response to the news by reflecting back to them words or body language that they have used
- You should acknowledge the patient's feelings
- You should be prepared to work through the patient's emotional response to the bad news with them

Draw up a plan with the patient

"Your appointment to see Mr. Brown, the oncologist, is provisionally booked for next Thursday at 2 o'clock. How would that fit in with your other arrangements?"

Make concrete plans for the next step

Immediate plans

The questions below can help the patient to start formulating the answers that they will need for their family or friends.

- *What are you doing now?*
- *How are you getting home?*
- *Who will you tell?*
- *How will you tell them?*
- *What will you say?*
- *How will they cope"?*

Summarize

For the patient

- Try to get the patient to repeat the key points to ensure they have understood

For other health care professionals

- Record details of the conversation in the patient's notes clearly
- Convey information quickly to those who need to know

Deal with questions:-

"Are there any questions which you would like me to deal with at this point?"

Future Plans

Closing remarks and identification of support network, including contact telephone numbers and times of easy access. For example:

> "I know the news today was not what you were hoping for but you are not going to go through this on your own. We are there for you, your family is there for you and we are going to go through this together. Mr. Brown will be seeing you next Thursday and I'll see you back here on Monday morning."

Be fairly concrete about the next meeting but also allow the patient the option to postpone if they do not feel able to attend.

Effective communication skills

Some verbal communication skills at the helper or volunteer's disposal include:

- Silence---give yourself permission to wait 1, 2, or 3 seconds before you respond. This technique may give you a chance to think of a more empathetic response

and the person you are speaking to more time to attend to their inner experience.

- Minimal encouragers and repetitions---"tell me more", "hmm", or restate some of the exact words the person said to highlight the important part of their message

- Paraphrases---freshly restate the content of the person's message as a way to communicate understanding using some of the persons words

- Summarizations---reflect the content of several statements or ideas and shows that you have understood what the person has been telling you.

- Reflections of feeling---a direct reference to the emotional part of the person's message. "You feel (feeling word) because of (source or context of the feeling)". Be careful you are responding to feelings and not thoughts. Feelings can usually be expressed in one word.

- Questions---too many, or in rapid succession can be unhelpful. Open questions that begin with how, what, could or why elicit a range of responses. Closed questions elicit a "yes" or "no" answer. "How" questions are best for eliciting feelings.

- Self disclosure---high level skill that you must always ask yourself: "for whom am I doing this?" The answer should always be to help the other person. Too much self disclosure may be distressing to the person being helped.

Adapted from The Helper's Journey, Dr. Dale Larson[xxxvii]

13. Social Aspects of Care

Social Care

Family and relational issues

Family support is one of the keys to successful palliative care. When we take care of families they are better able to care for the ill person. To effectively support the family we need a good understanding of the family system and its dynamics. As part of interdisciplinary assessment a genogram is usually done for at least three generations. This helps us to understand who is in the family and their history of loss. A basic genogram includes age, sex, children (biological, foster, adopted, miscarried, or stillbirth), marriages & divorces, year of death. It can also include emotional relationships, sexual orientation, conflicts, estrangements and so forth. Palliative care philosophy is generally humanistic and accepts people of all social strata and culture. Families need a great deal of education to be prepared to delivery care and need to know they can communicate with their caregivers whenever needed.

Work, housing, and poverty reduction

Illness often disrupts employment and income, especially a contagious disease like TB. The affected person may not be able to work or may be discharged. Patients undergoing long-term treatment and months of hospitalization need to remain active and it is critical to have activity programs for patients to remain productive and to have a sense of worth and purpose. Loss of work and social stigma can sometimes lead to homelessness. It is critical that people living with TB have shelter and a safe place to live. Social work services are very important to ensure that the patient has effective advocacy for basic needs and should be available to all palliative care patients. Opportunities for micro-finance and small business activity should continue and be supported even for patients with serious illness to reduce poverty.

Grief & Bereavement Support to the Patient and Family

When a person is diagnosed with a life-threatening disease like M/XDR-TB, he/she may feel shock, fear and distress about the future. Taking into account all potential losses that people may experience in the course of the disease, grievous loss begins with the diagnosis itself and continues after death. Early detection of persons at high risk of complicated grief and mourning is a critical aspect of holistic care.

The following specific factors may be associated with M/XDR-TB and bereavement:

- Stigma around death caused by M/XDR-TB, as well as TB (it can prevent the relatives of deceased patients from sharing their grief, or talking about what happened);
- Feeling of family's shame after death (if the patient behaved irresponsibly, which caused death);
- Long-term hospitalisation and isolation of the patient (it can affect the family's attitude and grief);
- Death of tuberculosis infection (since it can be the reason of their own death);
- Duration of the disease (especially in long-term and severe process);
- Hidden losses that cannot be openly mourned;
- The process of grief may depend on the culture and system of beliefs in the society, age of the deceased and his/her personality, gender, habitual alcohol or drug abuse for coping with personal hardship, previous mental disorders, system of support (family, friends, religious communities), financial problems, simultaneous pressure increase, other family members that may be ill.

Support to the families of the deceased comprises all practical, social and emotional issues. The family might need assistance in practical issues such as funeral assistance, child allowance or care grants, where applicable, insurance payable (if applicable), communication with the organisation providing care to children and families. The families need to show their denial, disbelief, confusion, shock, sadness, yearning, anger, humiliation, despair, guilt, superstition, isolation, loneliness, and rejection, as well as receive bereavement counselling.[xxxviii] Not only families, but possibly patients will require bereavement counselling. Reactions of denial, disbelief, confusion, shock, sadness,

bargaining, yearning, anger, humiliation, despair, guilt, and acceptance can be caused by diseases and related behaviour. The communication should be as open as possible and maintained in such form as convenient for the patient. Practical support may be necessary to help the patient in making a will, in solving old quarrels, planning for children's custody. It is important to know and respect their will to die. Reactions of people to loss are as different as people are. Therefore, no one can fit in a certain grief model, although certain topics of grief agree to some extent.

It is generally thought that bereavement is an active process through which the mourners pass when they struggle to adapt and cope with their changed reality, both intrinsic and extrinsic. Application of some or other model may be useful to help patients and family members to cope with the new situation.[xxxix]

Refer to Annex #8: Grief Models

Sudden, unexpected, and untimely deaths are more likely to be associated with difficult outcomes than are anticipated deaths, although death from slow terminal illness may also in some cases lead to difficult outcomes. Bereavement support and counselling, as necessary, should be provided as a core part of palliative care by professionals and volunteers.

Differences in responses between expected and sudden deaths	
Expected	Sudden
Anticipatory grieving possible	No time to say goodbye
Unfinished business attended to	Many possible regrets
Varying levels of acceptance of inevitability of death	Shock
Future preparations possible	Family thrown into disarray
Exhaustion due to long-term care - Did we do enough?	

14. Religious, Spiritual, Existential, & Cultural Aspects of Care

Spiritual care

Palliative care is based on caring for the 'whole' person and also includes the family and close careers. This approach therefore considers: the physical, emotional, social and spiritual aspects of people's lives as they and their loved ones live with life limiting illness and approaching death.

Definitions

As in other areas of life, terminology changes due to a variety of factors. In order to be inclusive, the government Equality Act 2010 adopted the terms 'Religion and Belief' to denote those who hold a philosophical belief as opposed to a 'faith' in something. It would however be true to say that in general most people still talk in terms of 'faith/belief', 'religion' and 'spirituality'. The following are useful definitions to help clarify the differences and overlaps in these terms:

Religion - That which 'binds' (Religio = to bind together) a group of people together with a shared view of God, including the same 'sacred text' and similar practices in worship.

Religious Care - Supporting, as far as is reasonable in the healthcare setting, those practices which will aid and facilitate the patient and their relatives in the expression of their religion.

Spirituality - That which gives 'breath' to a person's life in terms of meaning and purpose. This may or may not include a belief in a particular God but would include a power or force greater than themselves. Such beliefs are often held individually and are not necessarily expressed in formal worship with others. Spirituality can also be defined as how people make sense of their joys and difficulties in life.
Spiritual care - Provides appropriate support in order for people to express their thoughts and feelings in regard to their spirituality.

Belief - Belief is the psychological state in which an individual holds a proposition or premise to be true. Beliefs may be theistic, atheistic or agnostic. This includes those who would not wish to describe that which gives their life meaning in terms of what is 'spiritual' or religious as they do not believe in a 'higher power'. This would include people who might describe themselves as humanists, or secularists.

Belief support - Provides appropriate support in order for people to express their thoughts and feelings in regard to their beliefs.

Meaning and Purpose - Whilst traditional religious categories might mean a lot to some; they may have little meaning for others. Directly asking patients and relatives what gives their life meaning can be helpful in exploring what is of real significance to them and avoids making assumptions which are much more likely to cause offence than asking.

Key Principles

In order to provide good healthcare, it needs to be acknowledged that for a number of patients, relatives and staff there is a very real need to address issues of religion and belief. These issues affect not only dignity and comfort, but human rights and deeply held values.

Even amongst patients and carers for whom religion plays a relatively small part in their life when they are well, questions of meaning, purpose and hope can take on a larger profile during times of illness.
When providing spiritual care:

- You need to be aware of your own concerns, anxieties and ambivalence about discussing patients spiritual needs as this may hinder you asking patients and relatives what they feel and want.
- It is important to acknowledge your role and limitations in regard to what is expected of you within the team and within your profession and to know whom to refer to if you feel that a patient or relative would appreciate talking to someone about their religious or spiritual needs.
- Accepting your own limitations in terms of knowledge and understanding will enable you to refer to others, but it also needs to be stated that the majority of spiritual care in the health care setting is probably delivered without the carer realizing it through good quality patient centered support and compassion.
- Choose a way of ensuring that you are able to include questions of spiritual need within your assessment which can give you confidence in making sure that all patients are treated equally so that their beliefs and spiritual needs, which may differ from your own, can still be addressed.

Spiritual Assessment

The following tool was developed by Dr. Christine Puchalski and is based on remembering a simple four-letter acronym.

F I C A — Spiritual Assessment

F	Do you have a religious **faith**? Or do you have any philosophy or a set of beliefs that helps you, or what gives your life meaning and purpose?
I	How **important** is your faith/beliefs to you?
C	Are you part of a **community** that offers you support such as: a church, a mosque, temple or any other group of people you see regularly?
A	How can we **assist**? Are there things we need to be aware of — prayer times, diet, etc? Can we contact anyone? What would best support you now?

(For more information please go to the GWISH website www.gwish.org)

Religious Issues

Ask the patient and relatives what they need in order to fulfill their religious practices or obligations. Asked in a supportive way this can give people the sense that you really want to help and support and do not want to assume what is needed.
Whilst these needs should be affirmed it might not be possible to always comply and you need to clear about what is and what is not practical i.e. candles burning close to oxygen cylinders, or incense near smoke alarms, or chanting in the presence of other patients etc.

Some religions and cultures may require relatives staying with the patient throughout the time that they are ill. This may need to be limited to the capacity of the ward or room that the patient is in. Clear guidance to staff and families is needed.

Guidance may also be needed if an interpreter is required. Can family members ever be acceptable interpreters for the patient? There might be a policy about this but where there is not the staff team need to discuss their needs in terms of nursing and medical care and what is best for the patient. Such issues need to be discussed with the patient and family.

As death approaches it is even more important to ask the patient and family what they require and expect and as far as possible this should be adhered to. Some religions require that burial or cremation is performed as quickly as possible. This will mean that the Medical Certificate of Cause of Death and any contact with the Coroner and Registry Office should be conducted as quickly as possible. Any delays should be explained to the family.

Spiritual Care Interventions

Life Review

Life review is an element in many psychotherapy approaches, in which people recount and reevaluate their personal life history and in so doing reframe their present difficulties in a way that enables them to make therapeutic changes to their thoughts, feelings or behavior. Therapists center life review therapy around life themes or by looking back on certain time periods. These include childhood, parenthood, becoming a grandparent, or working years. Other themes include:

- Education and schooling
- Experiences in aging
- Health
- Literature
- Milestones such as marriage
- Major historical events
- Major turning points
- Music
- Purpose
- Values

Narrative Therapy[xl]

Narrative therapy finds ways of developing insight into the stories of the client's life. A therapist using narrative therapy is interested in the history of their client. They are searching for an in depth account of the problems that are affecting the client's life. Narrative therapy is sometimes identified as having the client "re-authoring" or "re-storying" their experiences. These descriptions emphasize that the stories of people's lives are pivotal to an understanding of the individual.

Dignity Therapy[xli]

Dignity therapy (DT) is a unique, individualized, short-term psychotherapy that was developed for patients (and their families) living with life-threatening or life-limiting illness. DT helps patients to create a narrative life history.

Dignity Therapy Questions:

- Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important. When did you feel most alive?"
- "Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?"
- "What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?"
- "What are your most important accomplishments, and what do you feel most proud of?"
- "Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?"
- "What are your hopes and dreams for your loved ones?"
- "What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, others)?"
- "Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future?"
- "In creating this permanent record, are there other things that you would like included?"

Traditional Health Practitioners

Traditional health practitioners are a valuable and sustainable resource that already exists in most communities. The training and utilization of these practitioners in primary health care, working in close collaboration with conventional health staff, can be expected to contribute, in many countries substantially, to obtaining more practical, effective, and culturally acceptable health systems for communities. The WHO has developed guidelines for training traditional health practitioners in primary health care.[xlii]

Traditional healers of South Africa are practitioners of traditional African medicine in Southern Africa. They fulfill different social and political roles in the community, including divination, healing physical, emotional and spiritual illnesses, directing birth or death rituals, finding lost cattle, protecting warriors, counteracting witches, and narrating the history, cosmology, and myths of their tradition. There are two main types of traditional healers within the Nguni, Sotho-Tswana and Tsonga societies of Southern Africa: the diviner (*sangoma*), and the herbalist (*inyanga*). These healers are effectively South African shamans who are highly revered and respected in a society where illness is thought to be caused by witchcraft, pollution (contact with impure objects or occurrences) or through neglect of the ancestors. It is estimated that there are as many

as 200,000 indigenous traditional healers in South Africa compared to 25,000 Western-trained doctors. Traditional healers are consulted by approximately 60% of the South African population, usually in conjunction with modern biomedical services

Cultural Aspects of Care[xliii]

The health care provider must have a clear understanding and recognition of the unique and specific influences culture has on a patient's behavior, attitudes, preferences, and decisions around end-of-life care. It is important to remember that simply because a person is identified as a member of a particular ethnic group or practices a particular religion it does not necessarily mean that the person or person's family maintains beliefs that may be associated with the ethnicity or religion. Additionally, an assessment should be made of how acculturated a person and their family are, their language skills, and whether an interpreter is needed. Be aware of some of the overall cultural values of the community and then explore the pertinent themes as they relate to providing health care for individual patients. Remember there is great diversity within a community. Experiences will vary greatly depending, for example, on whether people lived in rural or urban communities in their countries of origin, how long they have been in the country, their immigration experiences, former occupations, and levels of education. Keep in mind that patients are individuals.

Cultural Competency
The following are the key process elements that require a health care provider to commit to lifelong learning in order to enhance health care services:

Cultural Desire is the process of wanting to become culturally competent. It is the motivation that is behind the health care provider's desire to actively engage and commit to becoming culturally competent. Humility is the key factor in this process. Humble health care providers have a genuine desire to discover what the patient is thinking and feeling. Also of critical importance is seeing each individual as a unique and worthy person to be treated with dignity, fairness, and deserving of quality of care.

Cultural awareness is the process of becoming more sensitive, respectful, and attentive to the patient's cultural beliefs and practices. Through this process the health care provider becomes cognizant and reflective of his or her own cultural identity, attitudes, biases, and prejudices and how they shape his or her behavior, specifically in the provision of health care services.

Cultural knowledge is the process of developing an understanding of the differences and similarities between and within cultural groups. This includes learning about various cultural groups' values, beliefs, lifestyle practices, and perspectives on life. Culture is a powerful determinant of behavior towards illness.

Cultural skill is the process of cultural assessment, which obtains relevant information about the patient's beliefs, values, and practices. A critical component of cultural skill is

the development of interpersonal communication skills that convey respect, appreciation, and sensitivity to other cultures.

Cultural collaboration is the process that requires a partnership approach between the health care provider, the patient, and the family. An important part of the collaboration is the development of mutually agreeable goals between the health care provider, patient, and family.

Cultural encounter is the process of obtaining cultural experience through active engagement and, if possible, immersion in another culture. Meaningful encounters require being open to learning, understanding, and appreciating the other person's viewpoint.

Working within the cultural context of the patient and family is an essential underpinning of end-of-life care. Cultural influences can significantly impact the patient's reaction to the dying process and the decisions the patient and family make.

15. Care at the End-of-Life

End-of-life Care

The purpose of end-of-life care is to provide physical and emotional comfort and open, honest communication. End-of-life care comprises alleviation of respiratory distress, pain control; nutritional support, current social and psychological support (for the patient and family members, as well as caregivers), adjuvants, care (personal hygiene, prevention of bed sores, prevention of muscle contractions), and infection control measures.[xliv]

As a carer be prepared to discuss spiritual matters if patient would like to.

- Learn to listen with empathy;

- Understand reactions to the losses in their life (the different stages of grief);
- Be prepared to "absorb" some reactions, for example anger projected onto the health worker;
- Connect with spiritual counsellor or pastoral care according to the patient's religion and wishes;
- Do not impose your own views. If you share religious beliefs, praying together may be appropriate;
- Discuss worrying issues such as custody of children, family support, future school fees, old quarrels, funeral costs;
- Encourage communication within the family;
- Make sure patient gets help with feelings of guilt or regret;
- Protect your patient from overenthusiastic evangelists;
- For some patients, it is better to talk about meaning of their life, rather than directly about spirituality or religion.

Encourage support by the family by providing knowledge and skills.

The presence of the carer is essential during palliative care as well: move slowly by holding hand, if it is culturally relevant, your visits should be regular and expected. Keep the patient clean and dry, and prepare for incontinence of bowel and bladder. Moisten lips, mouth, eyes. Only give essential medications, control symptoms with medical treatment. Skin care - turning every 2 hours or more frequently. Eating less is OK.

Signs & symptoms of approaching death

The signs of imminent death are:

1) Decreased social interaction - sleeps more, acts confused, coma;
2) Decreased food and fluid intake - no hunger or thirst;
3) Changes in elimination -reduced urine and bowel movements, incontinence;
4) Respiratory changes - irregular breathing, "death rattle";
5) Circulatory changes - cold and greyish or purple extremities;
6) Decreased heart rate and blood pressure.[xlv]

The signs of death are:

1) breathing stops completely
2) Heartbeat and pulse stop
3) Totally unresponsive to shaking, shouting
4) Eyes fixed in one direction, eyelids open or closed
5) Changes in skin tone – white to grey.[xlvi]

Infection control measures and education

Persons with contagious forms of TB and M/XDR-TB and without active treatment may receive palliative care both in hospitals (general or special unit) and in home settings. Healthcare workers and other persons providing care are at high risk of contracting TB due to frequent communication with contagious patients.

Proper measures of infection control have major impact on prevention of TB transmission and reduction of the risk of tuberculosis spread in hospitals and home settings. If production of infectious droplet nuclei containing Mycobacterium tuberculosis can be prevented in hospitals, the risk of infection for patients, staff and other people will also be eliminated, and no further control will be needed.

However, since it is impossible to eliminate the total risk of infection, additional measures of environmental control should be taken to reduce the concentration of potentially infectious droplet nuclei and personal protective equipment should be used to avoid the inhalation of infectious droplet nuclei.

Patients, family members and healthcare workers must be trained to take simple but effective measures of environmental control at any time, and they must become a part of routine daily care.
Good working practice in the hospital means:

1) Elaborated plan of infection control;
2) Continuous training of all IC workers;
3) Regular assessments to evaluate the risk of infection and quality of IC measures;
4) Education of patients, their families about prevention and control of tuberculosis;
5) Raising public awareness;
6) Communication with the tuberculosis control program, in case of TB/MDR-TB, palliative care shall be provided in the general hospital or in home settings.

Infection Control Plans

Infection control (IC) of tuberculosis must be included into the IC plan of an entity. It should comprise the following:

1) All family members and other contact persons must be screened for tuberculosis by asking 4 questions: (1) Coughing for 2 weeks; (2) Sweating a lot at night; (3) Fever; (4) Losing weight in the past four weeks. Any persons suspected for tuberculosis should be referred to the nearest healthcare facility for further assessment;
2) Anyone (patient, family member, healthcare workers) who is coughing must be given advice on respiratory hygiene/cough etiquette and provided with a surgical mask or tissues to cover the mouth and nose. Tissues and masks should be disposed of in the appropriate waste containers;
3) Optimal ventilation should be provided (mechanical or natural);
4) Safe sputum collection and disposal should be ensured.
5) Hand washing is particularly important.

6) All staff, family members and other persons involved should be trained on TB IC;[xlvii]
7) Particular attention must be paid to families to control infection at home.

Education of Patients and their Families

TB IC must become a part of education of patients, families and communities to recognize the symptoms of tuberculosis and to seek healthcare on time. TB investigations should be routine in the communities where TB/MDR-TB patients receive treatment or palliative care. Moreover, patients must understand how to protect themselves and others from exposure to TB by simple cough hygiene measures.[xlviii]

Refer to Annex #9: Infection Prevention

Environmental Control Measures

Controlled natural ventilation can reduce the risk of spreading M. tuberculosis. It is necessary that the patient that receives palliative care have separate room with a window opening out.

Natural ventilation relies on open doors and windows to bring in air from the outside. "Controlled" implies that checks are in place to make sure that doors and windows are maintained in an open position that enhances ventilation. Fans may also assist to distribute the air. Fans should be directed to blow air towards an open window or door leading to the outside of the building.[xlix]

Individual Protection

A visit can be made after careful IC measures, e.g. ventilated room or, if weather permits, outside. The patient should always wear a surgical mask. Clinician and/or visitor, when in the same room with the TB patient, should wear an N95 respirator.

16. Ethical & Legal Aspects of Care

Ethical Values

Ethical issues that arise towards the end of life are often fraught with difficulty in an increasingly technological age in which the process of dying may be prolonged. In health care, there is often no "right" or "wrong" decision, but only a consensus view of a clear aim, considered on the basis of ethical principles. The most widely used ethical principles in health issues in the West are:

- **Autonomy** (patients should be informed and involved in decision making)
- **Beneficence** (do good)
- **Non-maleficence** (do no harm)
- **Justice** (balancing the needs of individuals with those of society).

Ethics Issues

Ethical problems in TB and M/XDR-TB include various issues, such as:[l]

- Do patients have the right to refuse treatment?
- Is it ever legitimate to isolate contagious patients against their will?
- Do healthcare workers have an obligation to provide care, even when it involves significant health risks?
- Should a patient's TB status ever be disclosed to third parties against his or her will?
- Should patients be diagnosed in the absence of adequate treatment?
- What are the obligations towards patients who cannot be cured?

Treatment, including provision of care to patients with TB and M/XDR-TB, raises the problems of balance of individual rights of an infected person against the community in general. Here appear the obligation and responsibility of the authorities to ensure effective treatment and humane and dignified way to end their lives.

Patient and Caregiver Rights

The Patients' Charter for Tuberculosis Care[li] describes the rights and responsibilities of all parties concerned. The first two rights are the rights to free and equitable access to tuberculosis care. The rights of TB patients should be treated with respect and dignity. Responsibilities outlined in the Charter include the patient's responsibility to follow the prescribed treatment plan and to contribute to community well-being.

Refer to Annex #1: Patients' Rights

The best way to manage MDR-TB is to prevent it. Therefore, every healthcare worker should update his/her knowledge of TB and its treatment. The organisations providing healthcare services should contribute to effective measures of infection control on every phase of treatment and care.

One of the most frequent ethical dilemmas in palliative care is the question of truth telling to terminally ill patients. Unwillingness to be honest with the patient about his/her diagnosis or prognostication is often associated with cultural issues. Although healthcare workers tend to think that patients should be told truth about tests and outcomes of treatment, family members sometimes ask not to disclose truth to their relatives thinking that it is harmful for the patient.[lii]

Treatment decisions

Informed consent

Informed consent is the process by which the treating health care provider discloses appropriate information to a competent patient so that the patient may make a voluntary

choice to accept or refuse treatment (Appelbaum, 2007)[liii] It originates from the legal and ethical right the patient has to direct what happens to his or her body and from the ethical duty of the physician to involve the patient in health care decisions. Informed consent is more than just getting a signature and includes a discussion of the following elements:

- The nature of the decision/procedure
- Reasonable alternatives to the proposed intervention
- The relevant risks, benefits, and uncertainties related to each alternative
- Assessment of patient understanding
- The acceptance of the intervention by the patient

As an ethical concept, informed consent refers to the process of engaging patients as partners in the treatment process by giving them relevant information and an opportunity to make decisions for themselves.

The ethical aspect of informed consent should not be confused with legal mechanisms, such as consent forms, that some health-care providers and researchers use to document patients' decisions. Such legal mechanisms are sometimes criticized as adding unnecessary administrative complexity, or as being threatening to patients who fear they are being asked to sign away their legal rights. Whatever the merits of these objections, they do not undercut the importance of adhering to the fundamental ethical requirement of engaging patients as partners by ensuring that their decisions are voluntary and informed.[liv]

Nutrition and hydration[lv]

Palliative care aims to relieve suffering in all stages of disease and is not limited to the end of life. Patients in palliative care range from fully functional (especially if newly diagnosed with an incurable illness) to extremely limited (particularly at the end of life). Palliative services, including setting patient-centered achievable goals for medical care and aggressive symptom management, should be routinely offered alongside curative and disease-modifying treatments for patients with serious illnesses.

Medically-assisted nutrition and hydration should be considered medical interventions rather than a basic provision of comfort. Promoting early discussions with the patient and family about the goals of care and treatment choices, including the expected benefits and burdens of artificial nutrition and hydration based upon the best available evidence, is ethically appropriate, respects family and patient autonomy, and facilitates informed decision making.

Resuscitation and life support

Cardiopulmonary resuscitation (CPR) is intended to prevent sudden, unexpected death.

CPR is not indicated in cases of:

1) Terminal, irreversible illness where death is expected, or
2) In certain medical situations where CPR is deemed ineffective.

For many people resuscitation is unwanted, unneeded and impossible. Depending on the situation and the person's preferences, CPR may be inappropriate, futile and undignified.

Involuntary isolation and detention[lvi]

In general, TB treatment should be provided on a voluntary basis, with the patient's informed consent and cooperation. As explained above, engaging the patient in decisions about treatment shows respect, promotes autonomy, and improves the likelihood of adherence. Indeed, non-adherence is often the direct result of failure to engage the patient fully in the treatment process.

While there has been a great deal of publicity about isolated cases of TB patients unwilling to undergo treatment, it is important to remember that these cases are highly infrequent occurrences. Individuals who have been properly counselled about the risks and benefits of TB treatment rarely refuse care, and adherence is not usually a problem if appropriate support is provided. The reason many countries are struggling with high rates of TB infection is not that a few individuals refuse to take their TB medications, but rather that access to high-quality TB diagnosis and treatment is too often unavailable.

Detention should never be a routine component of TB programmes. However, in rare cases, despite all reasonable efforts, patients will not adhere to the prescribed course of treatment, or will be unwilling or unable to comply with infection control measures. In these cases, the interests of other members of the community may justify efforts to isolate or detain the patient involuntarily. As explained below, involuntary isolation and detention must be carefully limited and used only as a very last resort.

Legal Issues

Getting affairs in order

The term getting your affairs in order refers to the need to organize one's legal and financial documents in case death or disability renders one unable to and leaves family members unprepared to act on your behalf. This applies as well to anyone with a life-threatening illness. The main steps involved include:

- **Put your important papers and copies of legal documents in one place.** You could set up a file, put everything in a desk or dresser drawer, or just list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check each year to see if there's anything new to add. Important papers include a will or trust, advanced directives for health care, general and durable powers of attorney. Also personal and financial records and passwords.

- **Tell a trusted family member or friend where you put all your important papers.** You don't need to tell this friend or family member about your personal affairs, but someone should know where you keep your papers in case of an emergency. If you don't have a relative or friend you trust, ask a lawyer to help.

- **Give consent in advance for your doctor or lawyer to talk with your caregiver as needed.** There may be questions about your care, a bill, or a health insurance claim. Without your consent, your caregiver may not be able to get needed information. You can give your okay in advance to Medicare, a credit card company, your bank, or your doctor. You may need to sign and return a form.

Euthanasia[lvii]

Etymologically, the term euthanasia derives from the ancient Greek, eu - meaning good and thanatos - meaning death, thus a "good death". Today, the term euthanasia refers to the administration of death, the active intentional ending of life. We must not forget that patients are often making decisions regarding euthanasia on the basis of inadequate prognostic information, since medical science as yet cannot identify accurately when an individual patient will die naturally.
Some proponents of euthanasia feel that:

"Euthanasia is the only alternative to avoiding a painful death."
Although the control of pain is not perfect, patients can usually achieve a degree of relief acceptable to them. Public education has started to erode the myth that all patients with cancer inevitably die in considerable pain, although this fear is still held strongly by some. In practice, even patients with distressing symptoms and an apparent high level of suffering rarely consistently request euthanasia.

"Euthanasia is the only answer to the fear of being kept alive at all costs."
Extraordinary advances in medicine over the last few centuries have pushed forward the frontiers, extending the quantity of life and potentially, therefore, the extension of a poor quality of "unacceptable" life. However, medical ethics has also advanced, allowing competent patients to refuse treatment and supporting the concept that burdensome, futile treatment is bad medicine. Assuming that health care professionals act with multidisciplinary support within an ethical framework, the fear of being kept alive at all costs should be minimized.

"Euthanasia is the only way to die with dignity."
Families are torn between not wanting to see their loved ones deteriorate and wanting them to survive as long as possible to maximise precious time. A natural death and all the potential healing and strengthening of family unity that so often occurs during the final days is surely worthwhile and dignified, a sentiment supported by most health care professionals experienced in the care of the dying. Furthermore, the efficacy of drugs used to carry out euthanasia is unpredictable. There are literature reports of failure to achieve coma and patients reawakening in considerable discomfort, which can hardly be described as dignified.

"Euthanasia should be legalised to uphold the principle of autonomy."
Comment In the West, individual rights have been elevated to a central tenet of society, implying that the individual has the right to control his/her own destiny. However, in society, others also have rights and the concept of a health care professional delivering euthanasia as a technical act may not be in the best interests of individuals or society.
Euthanasia, if carried out, should rightly occur only when the patient is fully competent and consistently requests it. However, patients who are ill, often bed bound, unable to care for themselves and wholly reliant on others for care may feel a burden and under pressure to acquiesce.
A diagnosis of a reversible clinical depression may be missed if families and health care professionals are slow to recognise it. The concept of the "slippery slope" argument in which patients may be subjected to euthanasia without their expressed consent and within a short time of having had the discussions has already been reported in the literature.
Whatever the arguments, the fundamental principles are that life is infinitely precious and that the vulnerable deserve protection. We should always consider the views of our competent patients and act in the best interests of those who are not able to give consent.
It is also fundamentally important to recognize what is NOT euthanasia, which includes the following where the primary intention is to prevent suffering:

Euthanasia is not:

- Withholding or withdrawing futile, burdensome treatment including nutrition and hydration if the patient is unable to swallow
- Giving opioids, or any other medications, to control symptoms including pain, fear and overwhelming distress
- Sedating a patient in the terminal stages if all other practical methods of controlling symptoms have failed
- Issuing a "Do Not Resuscitate" order

Key points

- Ethical principles are guiding principles that should direct doctors and other health care professionals in their work and decision making
- Ethical conflicts occur in end-of-life care when ethical principles are in conflict with each other, or with fundamental tenets such as the sanctity of life
- In most countries, actively killing a patient, or actively assisting a patient to take his or her own life, is illegal. It is legal in some other parts of the world
- Allowing a patient to die naturally but more rapidly than would otherwise have occurred due to care being withheld, or withdrawn, or due to the 'double effect' is both legal and moral, as long as it is in the patient's best interest
- Wherever possible respect the patient's wishes, even if the patient is not competent to make a decision, but where the patient's advance wishes are known. The only exception to this is if there is any doubt about the patient's wishes, when you should err in the direction that maintains the patient's choices for the future.

Advance Care Planning

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences, often by putting them into an *advance directive*. An advance directive is a legal document that goes into effect **only** if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want. It also allows you to express your values and desires related to end-of-life care. You might think of an advance directive as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

17. Annex #1: Patients' Rights

Patient has the right to:

Medical care:

- The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.
- The right to receive medical advice and treatment which fully meets the new clinical standards for tuberculosis care, centering on patient needs, including those with multidrug-resistant tuberculosis or tuberculosis-human immunodeficiency virus (HIV) co-infections and preventative treatment for young children and others considered to be at high risk.
- The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Dignity

- The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by healthcare workers and authorities.
- The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

Information

- The right to information about what healthcare services are available for tuberculosis and what responsibilities, engagements, and direct or indirect costs are involved.
- The right to receive a timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives.
- The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side effects, and its possible impact on other conditions or treatments.
- The right of access to medical information which relates to the patient's condition and treatment and to a copy of the medical record if requested by the patient or a person authorised by the patient.
- The right to meet, share experiences with peers and other patients and to voluntary counselling at any time from diagnosis through treatment completion.

Choice

1) The right to a second medical opinion, with access to previous medical records
2) The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease

3) The right to choose whether or not to take part in research programs without compromising care

Confidence
1) The right to have personal privacy, dignity, religious beliefs, and culture respected
2) The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent

Justice
1) The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly
2) The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome

Organisation
1) The right to join, or to establish, organisations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society
2) The right to participate as "stakeholders" in the development, implementation, monitoring, and evaluation of tuberculosis policies and programmes with local, national, and international health authorities

Security
1) The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment
2) The right to nutritional security or food supplements if needed to meet treatment requirements

Patient's Responsibilities

The patient has the responsibility to:

Share information:
- The patient has to provide the healthcare organisation (clinic) as much information as possible about present health, past illnesses, any allergies, and any other relevant details;
- The patient has to provide information to the healthcare organisation (clinic) about contacts with immediate family, friends, and others who may be vulnerable to tuberculosis or may have been infected by contact.

Follow treatment (follow prescriptions of attending doctor):
- The patient has to follow the prescribed and agreed treatment plan and to conscientiously comply with the instructions given to protect the patient's health, and that of others;
- The patient has to inform of any difficulties or problems with following treatment or if any part of the treatment is not clearly understood.

Contribute to community health (contribute to community health, propagate healthcare):

- The patient has to contribute to community well-being by encouraging others to seek medical advice if they exhibit the symptoms of tuberculosis;
- The patient has to show consideration for the rights of other patients and healthcare providers, understanding that this is the dignified basis and respectful foundation of the tuberculosis community.

Show solidarity:

- Every patient has the moral responsibility of showing solidarity with other patients, marching together towards cure;
- Every patient has the moral responsibility to share information and knowledge gained during treatment and to pass this expertise to others in the community, making empowerment contagious;
- Every patient has to join in efforts to make the community tuberculosis free.

http://www.who.int/tb/publications/2006/patients_charter.pdf

18. Annex #2: Assessment Tools

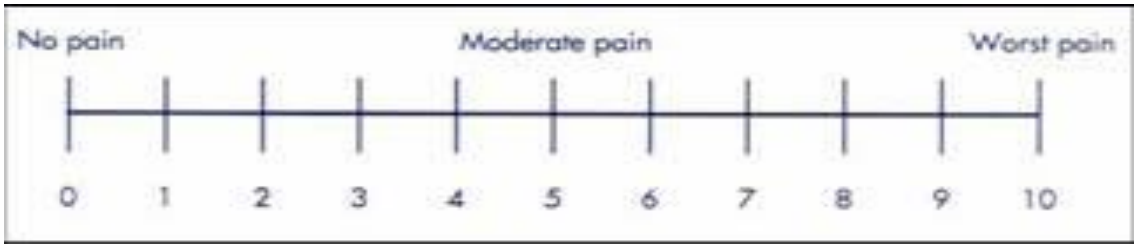
Palliative Performance Scale Version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

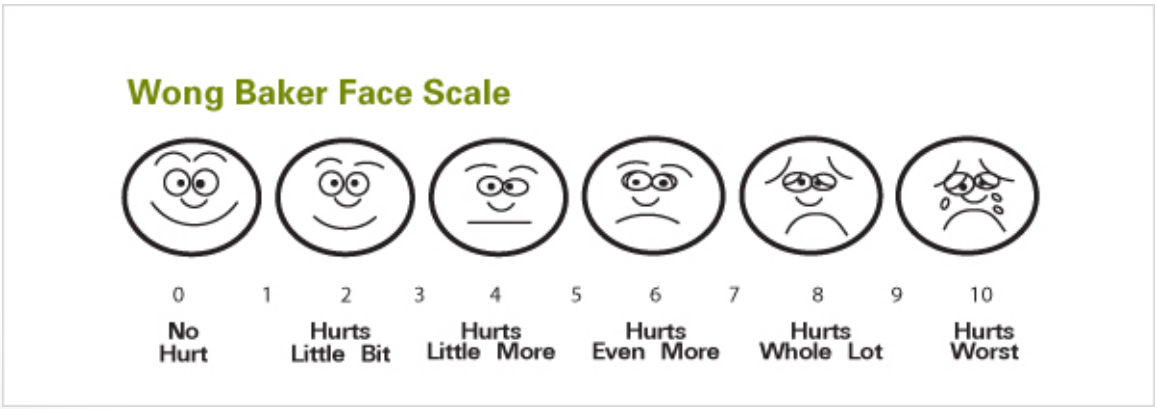
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Numeric Pain Rating Scales

Adult



Children



Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Drowsiness
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Nausea
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Lack of Appetite
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Wellbeing
No _____ Other Problem *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible _____

Patient's Name _____

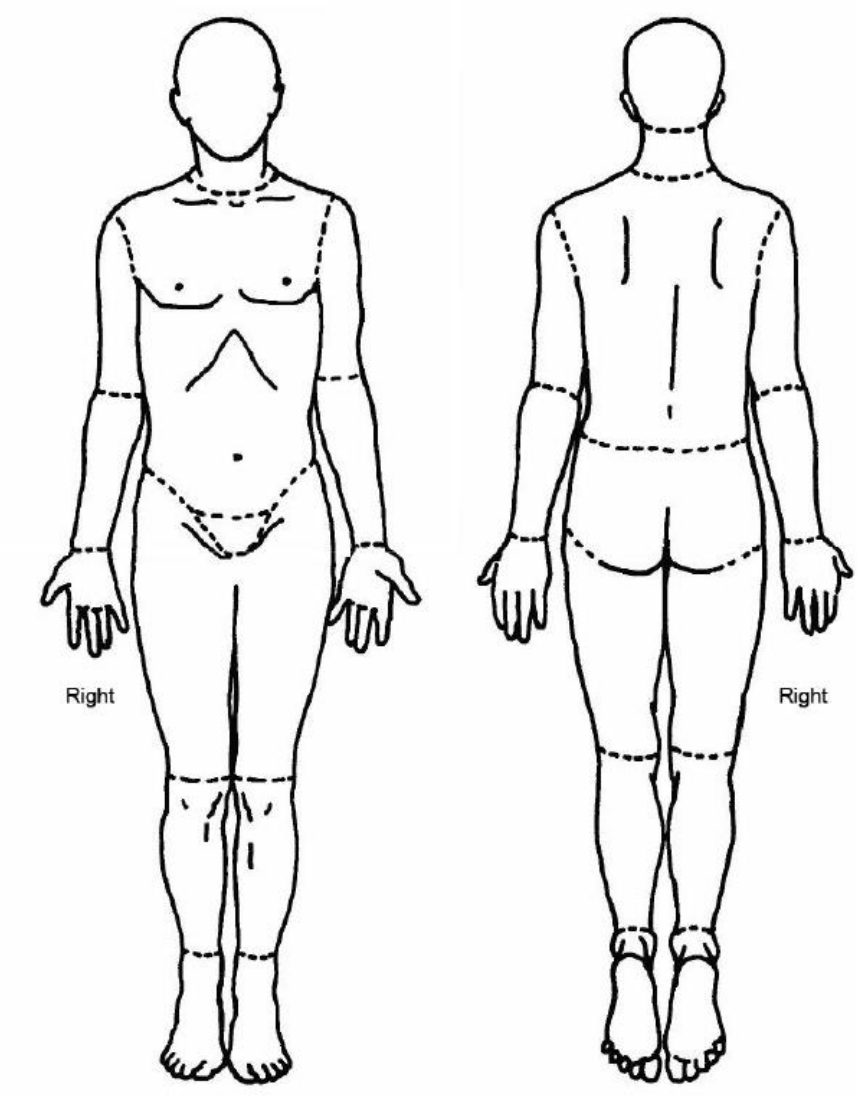
Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

ESAS-r
Revised: November 2010

Please mark on these pictures where it is that you hurt:



Victoria Hospice

Psychosocial Assessment

_____
(Print patient name or place patient label here)

TEAM ALERT Date of First Assessment: _____ initial: _____

_____

_____

_____

PRACTICAL CONSIDERATIONS

P.O.A.: enduring / bank / other: _____ Who is POA? _____

Decision Maker: _____ Relationship _____ Rep Agreement: yes no

Financial Support/Pensions: Income Assist ☐ CPP (disability) ☐ DVA ☐ Other _____

Financial/Housing/Employment concerns: _____ No financial concerns apparent ☐

Last Will & Testament: Discussed ☐ Estate Plan package given ☐ Will Completed ☐

Funeral Planning: Discussed ☐ F/M Plan package given ☐ Funeral Home _____

TIME OF DEATH

Details _____

Family/others requesting to be present at time of death _____

Special requests/rituals for time of death _____

SPIRITUAL CARE

Religious/Spiritual affiliation _____

Patient's description of their Spirituality _____

_____

_____

_____ Referral for Spiritual Care ☐ Date _____

INFORMATION GIVEN: (to whom)

- ☐ Anticipatory Grief _____
- ☐ Children & Grief _____
- ☐ When Death Occurs _____
- ☐ Final Gifts _____
- ☐ Other _____

Patient Assessment

Life Review (careers, interests, etc.)

Cultural Beliefs & Practices Relevant to Care

Community Supports

Strengths / Coping and Decision-making Styles / Self Care

Current Awareness of Illness / Goals / Expectations / Hopes

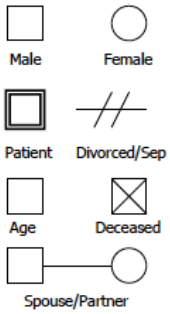
Fears / Concerns

Intimacy / Sexuality Issues

Losses experienced by Patient and Family

Anticipated losses

FAMILY MAP



CAREGIVER ASSESSMENT

Primary Caregiver Name _____ Relationship _____Employed _____

Physical/Psych/Medical _____

_____

Strengths/Coping/Self Care _____

_____

Concurrent Demands _____

Hopes/Fears/Other _____

Other Caregiver Name _____ Relationship _____ Employed _____

Physical/Psych/Medical _____

_____

Strengths/Coping/Self Care _____

_____

Concurrent Demands _____

Hopes/Fears/Other _____

FAMILY FUNCTIONING (communication patterns, decision making, family roles, etc.)

_____

_____

_____

_____

_____

Hospital Anxiety and Depression Scale

Name: Date:

Instructions: Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and **place a firm tick** in the box opposite the reply which comes closest to **how you have been feeling in the past week**. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or 'wound up':		**A**	**8. I feel as if I am slowed down:**	**D**	
Most of the time		3	Nearly all of the time	3	
A lot of the time		2	Very often	2	
Time to time, occasionally		1	Sometimes	1	
Not at all		0	Not at all	0	
2. I still enjoy the things I used to enjoy:	**D**		**9. I get a sort of frightened feeling like 'butterflies in the stomach':**		**A**
Definitely as much	0		Not at all		0
Not quite so much	1		Occasionally		1
Only a little	2		Quite often		2
Not at all	3		Very often		3
3. I get a sort of frightened feeling like something awful is about to happen:		**A**	**10. I have lost interest in my appearance:**	**D**	
Very definitely and quite badly		3	Definitely	3	
Yes, but not too badly		2	I don't take as much care as I should	2	
A little, but it doesn't worry me		1	I may not take quite as much care	1	
Not at all		0	I take just as much care as ever	0	
4. I can laugh and see the funny side of things:	**D**		**11. I feel restless as if I have to be on the move:**		**A**
As much as I always could	0		Very much indeed		3
Not quite so much now	1		Quite a lot		2
Definitely not so much now	2		Not very much		1
Not al all	3		Not at all		0
5. Worrying thoughts go through my mind:		**A**	**12. I look forward with enjoyment to things:**	**D**	
A great deal of the time		3	A much as I ever did	0	
A lot of the time		2	Rather less than I used to	1	
From time to time but not too often		1	Definitely less than I used to	3	
Only occasionally		0	Hardly at all	2	
6. I feel cheerful:	**D**		**13.I get sudden feelings of panic:**		**A**
Not at all	3		Very often indeed		3
Not often	2		Quite often		2
Sometimes	1		Not very often		1
Most of the time	0		Not at all		0
7. I can sit at ease and feel relaxed:		**A**	**14. I can enjoy a good book or radio or TV programme:**	**D**	
Definitely		0	Often	0	
Usually		1	Sometimes	1	
Not often		2	Not often	2	
Not at all		3	Very seldom	3	

Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'.

Source: http://www.sadness101.com/HAD.html

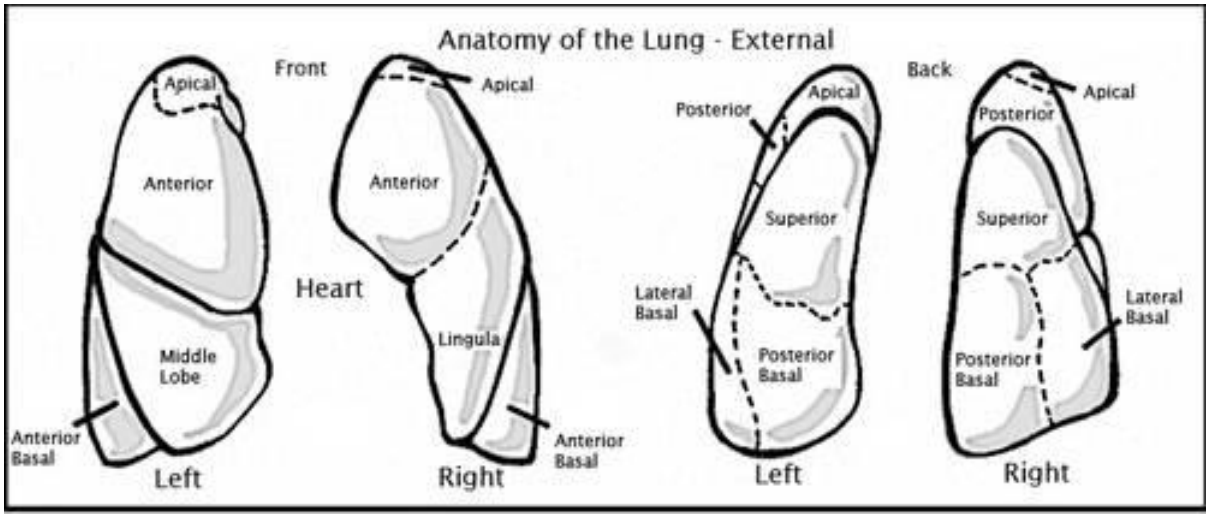
19. Annex #3: Postural Drainage [3]

Postural drainage is an airway clearance technique that, along with chest percussion and vibration, helps patients with respiratory illnesses like COPD, clear mucus from their lungs. The lungs consist of 5 lobes - 3 on the right and 2 on the left side of the chest cavity, each of which are further divided into segments.

The following diagrams show a variety of postural drainage positions that are meant to facilitate drainage from each specific segment of the lung. In each picture, the shaded black dots demonstrate the place where your caregiver should apply chest percussion (a clapping movement that is performed with cupped hands) and vibration (a vibrating movement done with flat hands).

Chest physiotherapy is generally performed for 3 to 5 minutes on each segment. During this time, the patient is encouraged to take a slow, deep breath followed by a vigorous cough in an attempt to clear the airways of mucus. This technique should be repeated several times during the chest physiotherapy session.

It is important to note that some postural drainage positions may cause an increase of heartburn and acid reflux and/or vomiting, particularly those positions where the head is lower than the stomach. Not only can this cause discomfort and possible wheezing, but vomiting may lead to a lung infection which may cause further lung damage.



[33] Leader D, Russel C. Positions Used for Postural Drainage. [Internet: About.com.COPD [assessed on 30 May 2013].

http://copd.about.com/od/copdtreatment/ig/Postural-Drainage-Positions/Lungs-labeled.htm

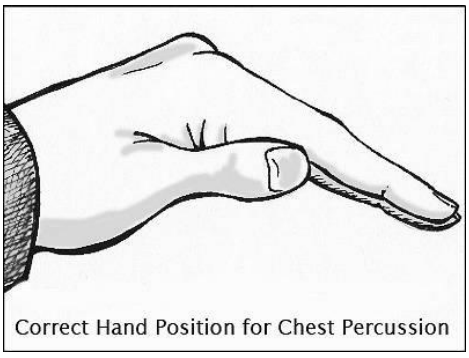
Chest percussion involves using a cupped hand and alternately clapping with both hands on the patient's chest wall. This should be performed over the lung segment that is to be drained. Your hand should NOT be flat, but cupped at all times, as if you were holding liquid in it.

The percussion technique should be vigorous and rhythmical, but it should not involve pain. If the patient does complain of pain, this means that your hand may not be cupped properly and needs to be softened or readjusted. When done properly, you should hear a hollow sound with each percussion.

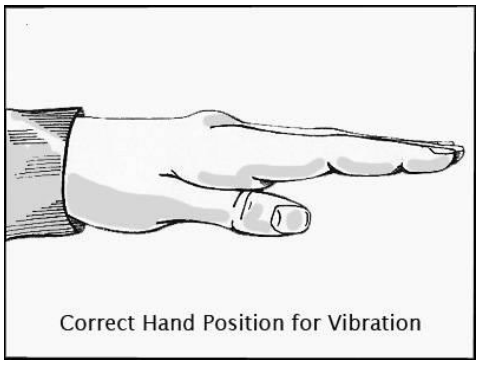
Chest percussion should be done over the ribs, with careful attention to avoiding percussing over the spine, breastbone, or lower back to prevent damage to internal organs. Percussion may, or may not, be accompanied by vibration. Mechanical percussive devices are also available as an alternative to manual chest percussion.

Vibration is an airway clearance technique that, coupled with chest percussion, is applied during postural drainage to help patients clear mucus from the airways. Vibration helps to gently shake mucus and secretions into the large airways, making them easier to cough up.

During vibration, place your flat hand firmly against the chest wall, atop the appropriate lung segment to be drained. Stiffen your arm and shoulder, apply light pressure and create a shaking movement, similar to that of a vibrator. Tell the patient to breathe in deeply during vibration therapy, and exhale slowly and completely. Taking a deep breath and then exhaling slowly and forcefully without straining will hopefully stimulate a productive cough.

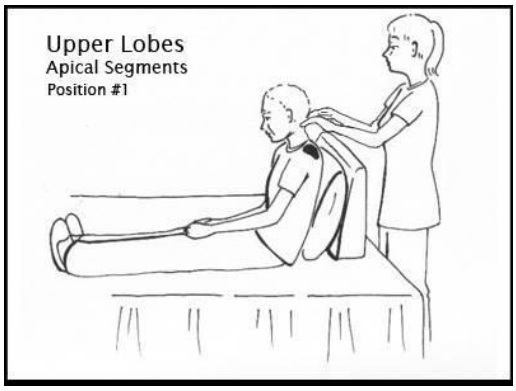


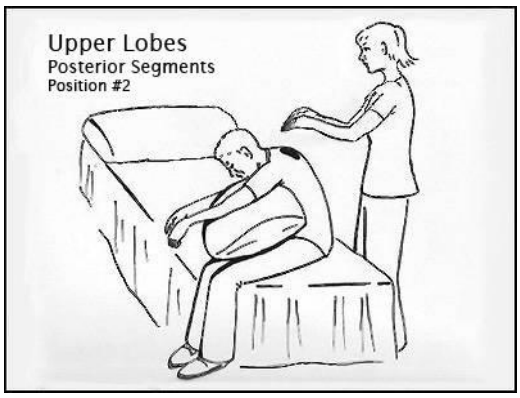
Correct Hand Position for Chest Percussion



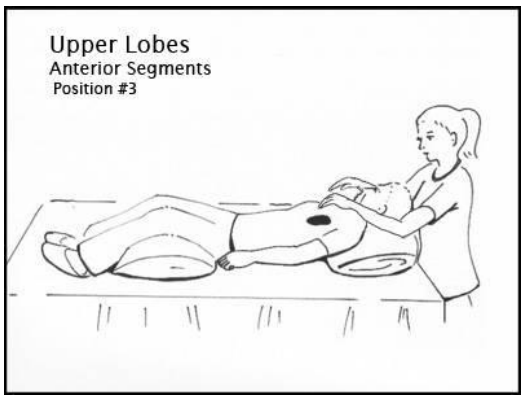
Correct Hand Position for Vibration

Positions 1 & 2. Upper lobe apical segments. To drain mucus from the upper lobe apical segments, the patient sits in a comfortable position on a bed or flat surface and leans on a pillow against the headboard of the bed or the caregiver. The caregiver percusses and vibrates over the muscular area between the collar bone and very top of the shoulder blades (shaded areas of the diagram) on both sides for 3 to 5 minutes. Encourage the patient to take a deep breath and cough during percussion in order to help clear the airways. Do not percuss over bare skin.

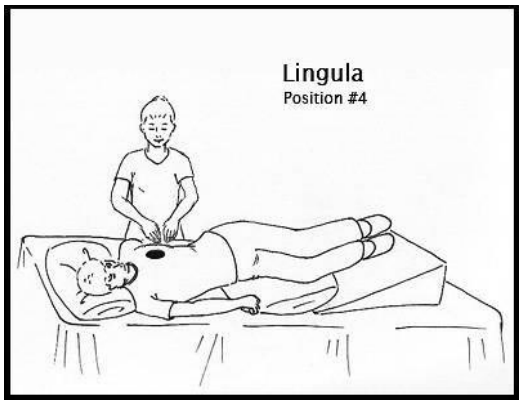




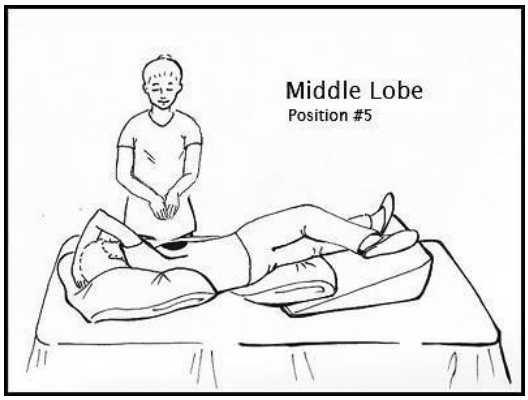
Position 3. Upper lobe posterior segments. The patient sits comfortably in a chair or the side of the bed and leans over, arms dangling, against a pillow. The caregiver percusses and vibrates with both hands over upper back on both the right and left sides.



Position 4. Lingula. The patient lies with his/her head down toward the foot of the bed on the right side, hips and legs up on pillows. The body should be rotated about a quarter-turn towards the back. A pillow can also be placed behind the patient and their legs slightly bent with another pillow between the knees. The caregiver percusses and vibrates just outside the nipple area.

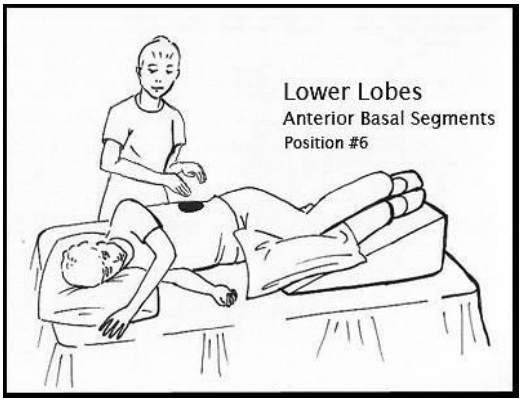


Position 5. Middle Lobe. The patient lies head-down on his/her left side, a quarter-turn toward the back with the right arm up and out of the way. The legs and hips should be elevated as high as possible. A pillow may be placed in back of the patient and between slightly bent legs. The caregiver percusses and vibrates just outside the right nipple area.

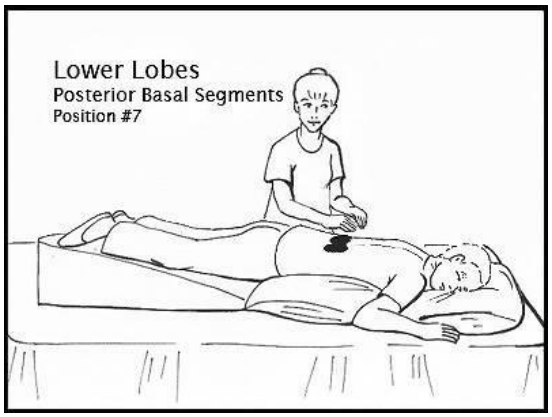


Position 6. Lower Lobes Anterior Basal Segments. The patient lies on his/her right side with his/her head facing the foot of the bed and a pillow behind his back. The hips and legs should be elevated as high as possible on pillows. The knees should be slightly bent and a pillow should be placed between them for comfort.

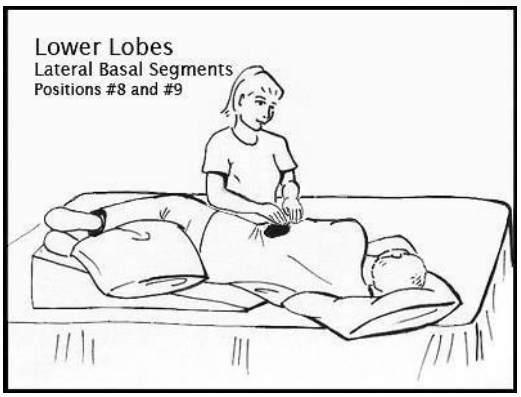
The caregiver percusses and vibrates over the lower ribs on the left side, as shown in the shaded part of the diagram. This should then be repeated on the opposite side, with percussion and vibration over the lower ribs on the right side of the chest.



Position 7. Lower Lobes Posterior Basal Segments. The patient lies on his/her stomach, with the hips and legs elevated by pillows. The caregiver percusses and vibrates at the lower part of the back, over the left and right sides of the spine, careful to avoid the spine and lower ribs.

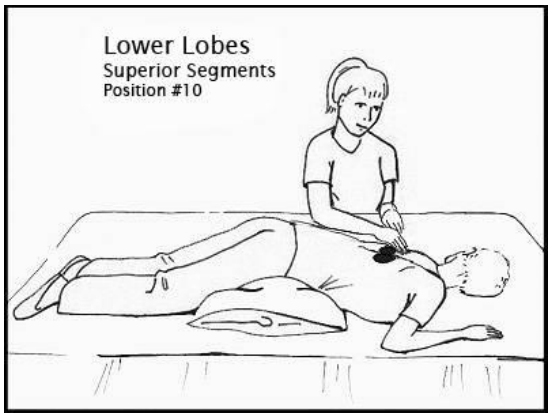


Positions 8 & 9. Lower Lobes Lateral Basal Segments. The patient lies on his/her right side, leaning forward about one-quarter of a turn with hips and legs elevated on pillows. The top leg may be flexed over a pillow for support and comfort.



The caregiver percusses and vibrates over the uppermost portion of the lower part of the left ribs, as shown in the shaded area. This should then be repeated on the opposite side, with percussion and vibration over the uppermost portion of the right side of the lower ribs.

Position 10. Lower Lobes Superior Segments. For this position, the patient lies on his/her stomach on a flat bed or table. Two pillows should be placed under the hips. The caregiver percusses and vibrates over the bottom part of the shoulder blades, on both the right and left sides of the spine, avoiding direct percussion or vibration over the spine itself.



20. Annex #4: Pharmacological Management of Shortness of Breath[lviii]

A combination of an opioid and a sedative anxiolytic is very effective in managing shortness of breath.

- Opioids: to relieve shortness of breath 2.5-5mg oral morphine solution every 4 hours. If necessary, titrate the dose upwards. Morphine improves the quality of breathing and decreases anxiety. In a patient who is unable to swallow, opioids can be given subcutaneously, sublingually or rectally. For the patient who already takes morphine – the dose should be increased by 25%. If no effect follows, increase the dose by 25% more.
- Anxiolytics: lorazepam (0.5-1mg po or sublingual 6-8 hourly), diazepam (2.5mg tds, then 5mg daily), midazolam (from 15mg / 24 hours by continuous subcutaneous infusion, parenteral benzodiazepine).

Table 1. Guidelines for Management of Shortness of Breath[lix]

Little shortness of breath	Moderate shortness of breath	Severe shortness of breath
Treatment of primary disease[a]	Treatment of primary disease	Treatment of primary disease
Treatment of psychosocial factors[b]	Treatment of psychosocial factors	Treatment of psychosocial factors
	Pulmonary rehabilitation[c] Anxiolytic	Pulmonary rehabilitation Cooling the face (by fan) Anxiolytic Opioids (see cough) Non-invasive ventilation

[a] *Treat primary disease including anaemia, pleural fluid , congestive cardiac failure, reversible obstructive airway disease, hypoxemia, bronchial obstruction.*

[b] *Treat psychosocial factors: to manage anxiety, use relaxation techniques, distraction, modification of activity, behavioural change, and breathing techniques. To manage depression, use cognitive therapy, antidepressants, or combination of both.*

[c] *Pulmonary rehabilitation includes training exercises, psychological support, nutritional management, and self-control training, including breathing re-training, use of additional oxygen, pharmacological therapy (to relieve airway obstruction), and panic management.*

Table 2. Initial opioid doses [a] and their lasting effect on patients who have taken opioids earlier to relieve severe pain or shortness of breath[4]

	Adults	Adults	Children	Children[b]	
Medication	IV	Per os	IV	Per os	Duration
Oxycodone	N/A	5–10 mg	N/A	0.05–0.15 mg/kg	4–6 hrs
Methadone	2.5–10 mg	5–10 mg	0.1 mg/kg	0.1 mg/kg	4–12 hrs
Morphine	2–10 mg	5–10 mg	0.1–0.2 mg/kg	0.2–0.5 mg/kg	3–4 hrs
Hydromorphone	0.3–1.5 mg	2–4 mg	0.015–0.03 mg/kg	0.03–0.08 mg/kg	3–4 hrs
Fentanyl	50–100 mg	N/A	1–2 mg/kg	N/A	0.5–1 hrs

[a] These dosage recommendations do not apply to the patients who have earlier taken opioids because their doses will be higher and must be prescribed individually. The proper dose and opioid dosing intervals in all patients mean the dose that eliminates shortness of breath or pain without side effects. It does not have upper limit, i.e. the dose should be increased as much as is needed to achieve the desired effect or until side effects become intolerable. Reassessment of the medication effect on the patient and titration of opioids are the basis of successful treatment.

[b] Note: paediatric dose (adjusted to body weight) must not exceed the respective dose of the adult. These dosage recommendations do not apply to newborns that have special pharmacokinetics.

IV: intravenous; N/A: not available.

21. Annex #5: Non-Pharmacological Management of Cough and Shortness of Breath[lx]

- Oxygen if hypoxic. Home oxygen is often not available and once a patient has started oxygen, it is very difficult to stop due to psychological dependence, therefore use with caution;
- A cool stream of air in the face is often as effective as oxygen via a mask;
- Positioning should be determined by patient preference. The patient's head should be elevated and when one lung is obstructed, lying on one side or the other may help;
- Relaxation techniques and distraction;
- Reassurance, explanation and company;
- Breathing re-training;
- Physiotherapy.

General measures:

- Local soothing remedies such as honey and lemon or steam with Eucalyptus leaves;
- Frequent re-positioning (avoid supine position);
- Position semi-prone to encourage postural drainage;
- To help the patient sit in the best position:
- Use extra pillows or some back support;
- Open windows to allow in fresh air;
- Fan with a newspaper or clean cloth;
- Give patient water frequently (it loosens sputum).
- Practice cough etiquette,
- Open windows to allow in fresh air and good ventilation of the room,

Educate on most efficient use of remaining lung function:

- How to plan activities to accommodate breathlessness;
- Avoid crowding, cooking and smoking in the room of the patient;
- Explanation and reassurance for caregivers;
- Reserve suctioning for unconscious patients or for suctioning of oral cavity only;
- For safe handling and disposal of sputum:
    - Handle sputum with care to avoid spreading infection;
    - Use a tin with ash for spitting, then cover it;
    - Empty container in a pit latrine and wash with detergent or clean the tin with boiled water.

When providing nursing or any help associated with any other kind of palliative care ask the patient to wear the surgical mask, while you should wear N95 respirator (to be supplied under the healthcare programme) and open windows to air the room.

22. Annex #6: Grief Models [lxi]

There are several models that help understand the process of bereavement. Grieving, whilst regarded as a painful yet normal and healthy process with its individually determined path, often proceeds for the bereaved with a number of extra challenges.

The John Bowlby Model

The John Bowlby Model implies how attachments influence our interpersonal relationships. There are secure and insecure attachments. Insecure attachments can lead to problems grieving. Insecure attachments include:

- Too strong – leading to anxiety and prolonged grieving
- Too weak – leading to inability to express grief
- Disorganized – need reassurance and permission to show grief

According to Bowlby, grief is set in motion when the bereaved observe that the object of their affection or attachment will no longer exist. The bereaved may deny the reality of the separation (death) and attempt to retain the attachment to the deceased. This model of "working through" the grief is continual reality testing until the energy is gradually released, and the attachment broken.

- Grief is an adaptive response to loss;
- The reality of the loss must be confronted and accepted;
- Grieving is an active process and takes time.

The William Worden Model

This model specifies four tasks that the bereaved must complete in order to reconcile their grief.

1) Accept the reality of the loss;
2) Work through the pain of grief, experience the pain of loss. This pain is physical, emotional and spiritual. The avoidance of this pain prolongs the course of mourning;
3) Adjust to life without the deceased developing the skills needed to cope with life's new demands, and taking on new and often unwanted roles;
4) Emotionally relocating the deceased and moving on with life, reinvesting in a "new reality", withdrawing the emotional energy that had been invested in the relationship with the deceased and re-focusing this.

The Therese Rando Model

The "6 R Processes" model portrays the grief process as consisting of six individual but interacting processes:

1) Recognize the loss - acknowledge the death;
2) React to the separation of the loss - experience the pain and express the emotions;
3) Recollect and re-experience all the feelings involved including the negative aspects of the relationship with the deceased;
4) Relinquish attachments to the deceased and the old world;
5) Readjust to the 'new world' without forgetting the deceased;
6) Re-invest the 'freed up' energy in a new life or identity.

The Dual Process Model

Developed by Margaret Stroebe and Henk Shut in the Netherlands. Problems with grieving occur when the bereaved are unable to vacillate between their grief experience and their need to attend to the demands of living without the person that has died. When people get stuck either in their grieving or avoidance of grieving and are only focused on daily living there are problems with grief. This is depicted in the following figure.

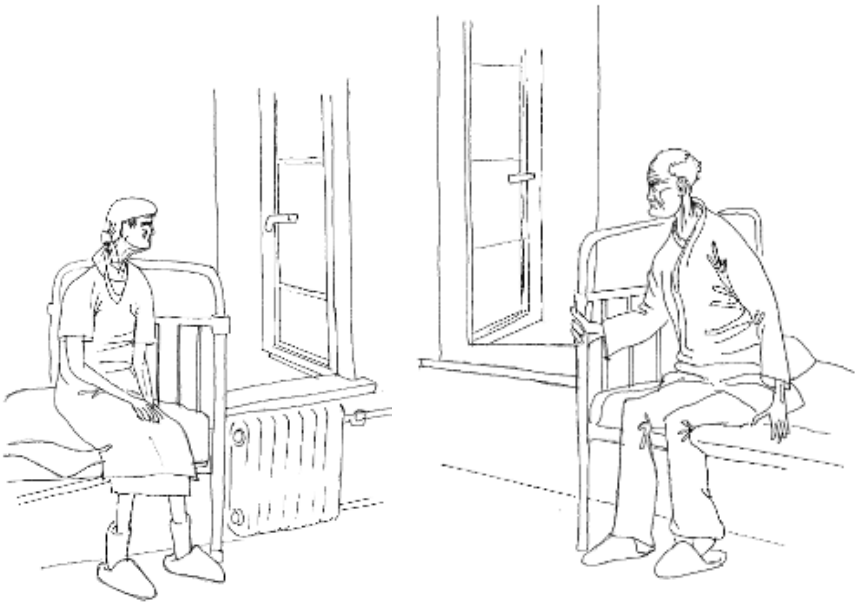


23. Annex # 7: Infection Prevention

POSTER: TB Infection Control

1. Ventilation

Try to keep the window open as long as possible regardless of weather conditions and time of day.

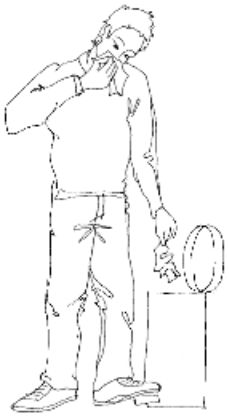


2. Cough hygiene

1) U*se a tissue or the upper sleeve, not your hands, to cover coughs and sneezes.*



2) *Put all used tissues in the garbage.*



3) *Clean your hands after coughing or sneezing by washing with soap or using an alcohol-based hand cleaner.*



4) *Wear a surgical mask in contacts with other people*



24. Annex #8 Educational Booklets

BOOKLET #1: Palliative Care for TB Patients

Some facts about the disease: What Is Tuberculosis?

Tuberculosis (TB) is an infectious airborne disease transmitted when the patient coughs. Tuberculosis is known to be curable. However, some patients may need palliative care.

It is important to decide: Whether people should be told that the patient has incurable form of tuberculosis or not

Severe forms of TB are known to cause shock, fear, distress, anger, and anxiety. This news may cause agitation and deep emotion in the patient's family and relatives. They may also need support.

It is important to know: What Is Palliative Care?

You should know: What Is Palliative Care

Palliative care implies help and relieving suffering, various expressions of the disease. Palliative care is focused on supporting physical, emotional, social, cultural and spiritual needs and demands of the patient.

Palliative care includes: nursing, medical counselling by clinician, nutritional advice, provision of necessary equipment (for a while), physiotherapy, services of social workers, support of the bereaved, spiritual support.

You can receive palliative care in hospitals and home setting. The choice of place will depend on a variety of factors: level of contagiousness; nature of the disease; level of in-home support, etc.

Infection control measures must be taken for palliative care

You should remember that you may infect your family.
Therefore:

1. Patients must observe cough etiquette: covering the mouth and nose when coughing, or sneezing.
2. Ventilate the room regardless of weather conditions and time of day;
3. During nursing procedures, a TB patient must wear a surgical mask. Healthcare worker, caregiver and/or other visitors being in the same room with the patient must use the respirator (special mask protecting the healthy person from infection).

If necessary, a special waste container for the disposal of used tissues should be available in the patient's room; there also may arise the need to have a special bed with seating support and head support – in case of shortness of breath in the patient, when he/she needs to be in a vertical position.

In the course of disease, complications or aggravations may occur. You can write down your questions about physical or emotional sensations, which you can later on discuss with the healthcare worker.
It is important to talk openly with a clinician, nurse or a caregiver. They can choose the appropriate medication and treatment regimen for you to alleviate your suffering.

It is essential to help: Yourself, Your Family and Friends

Death will come to us all. This thought can frighten us, but if we go on the final journey prepared, it can make the situation less painful.

- Make a log of personal data about yourself, your spouse, your parents and children; a person in charge of funeral arrangements will need this information;
- State your heirs of land, property;
- State your vision of your family affairs management;
- Let people know what they mean for you;
- Designate a person who will be carrying out your wishes as you die.

Consider what is most important to you and do it first. The more you talk about what's on your mind and heart, the easier you will cope with problems.
What would you like to do before you die?

If you have any questions or concerns, please contact your clinician, nurse or caregiver:

Name /Surname: .....
Hours of work: ....
Phone: .....

For reference only

- Palliative care, Victoria, 2007- available at: www.pallcarevic.asn.au
- NAM's, available at: www.aidsmap.com
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BOOKLET #2: Palliative Care (*for those who provide care to TB Patients)*

Some facts about the disease: What is Tuberculosis?

Tuberculosis (TB) is an infectious airborne disease transmitted when the patient coughs. Tuberculosis is known to be curable. However, some patients may need palliative care.

Severe forms of TB are known to cause shock, fear, distress, anger, and anxiety in patients and their relatives.

You may have questions arising when you provide care to the TB patient.

You should know: What is Palliative Care?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering. Palliative care is focused on treatment of the physical, emotional, social, cultural and spiritual needs of patients.

Palliative care includes nursing, medical counselling by clinician, nutritional advice, provision of necessary equipment (for a while), physiotherapy, services of social workers, support of the bereaved, spiritual support.

Who can provide care to TB patients?

The main problem of provision of palliative care to the patients with communicable diseases is the possible transmission of the disease; therefore, this possibility should be hindered.

There are a few infection control measures that should be observed:

1) You and your family members should be screened for TB;
2) Make sure that the patient uses tissues and observes cough etiquette;
3) Arrange an isolation room with a window that opens to the exterior of the building;
4) Ventilate the room. Or leave the window open;
5) Personal visits must be made only after all windows have been opened and the room has been ventilated well; if the weather permits, the visit should be made outdoors;
6) During nursing procedures, the TB patient should wear a surgical mask. The caregiver or a visitor should wear N95 respirator when staying in the same room with the TB patient.

If necessary, a special waste container for the disposal of used tissues should be available in the patient's room; there also may arise the need to have a special bed with seating support and head support – in case of shortness of breath in the patient, when he/she needs to be in a vertical position.

You should know: about reliving suffering of TB patients in palliative care

In the case of an incurable form of TB, the following symptoms are often seen:

- Persistent cough
- Shortness of breath, dyspnoea
- Haemoptysis or streaks of blood in the sputum
- Chest pains

These symptoms may cause mental and physical exhaustion. Therefore, outbursts of aggression, depression, blocking, vision and hearing loss may follow.

- For in-home palliative care provision: you should make changes and transformations to make the house more comfortable for the patient so that he/she could move on his/her own and take care of him/herself.

- If a person you take care of finds it difficult or has problems, the mobile equipment, such as rails and wheelchair ramp may make the house safe for both of you. The furniture should be arranged in a simple and consistent manner. Also, it can be useful to get rid of soft carpets, and keep the edges of carpets from curling up.

- If a person you take care of gets confused, try not to make any changes into his/her environment, use leaflets and reminders. Night lamps may be placed in the hall and WC.

- Gain support of the person you trust and to whom you can tell about previous incidents; and also try to get competent advice (consult a clinician or a nurse) on the methods and possibility of coping with aggression

- Remember that aggression can be either physical or mental violence.

- If a person you take care of has lost his/her memory, it is important that he/she always carries identification information including name and address and contact person for emergency contacts.

- If a person you take care of has vision problems, leave all items on their previous places, if any item has to be moved, tell the patient about the place where it is moved.

- Be particularly careful when doing the housework: everything can be potentially dangerous – vacuum cleaner cord, wet floors, a mop and a bucket. Close all doors fully or leave them open and place back the items to their original state. Take the patient around the room.

You should help: Yourself, Your Family and Friends –You Should Take Care of Yourself

Care for someone with severe disease requires much effort. Therefore, it is essential to take care of yourself and your health. Have enough rest, keep to your diet, and avoid excessive consumption of caffeine, alcohol, nicotine.

Manage time for rest and sleep properly.

Create your own support team. Involve your friends, relatives and neighbours into nursing. Contact them regularly, i.e. every week, call them.
Try to share your concerns and feelings before they overwhelm you. If you have shouted at the patient, or treated him/her abusively, ask for help immediately.

Take time for your own needs. Think about your needs, make a plan and try keeping to it. The plan may include daily communication and contacts that can be performed over phone or email, book reading.
Sleep need may become a problem for caregivers. Do not make important decisions if you are burned out. If the patient falls asleep during the day, use this free time to rest or take a nap.

If there are still too many things to do, ask your friends and family for help. Ask everyone do some things. It is possible that someone can start doing laundry, sending letters, paying bills, gardening for you. Right now you have significant job, and, foremost, self-concern.

Sometimes people on whom you rely cannot help you in certain circumstances, possibly, due to their fears and stress.

If you have any questions or concerns, please contact:

Name /Surname: .....
Hours of work: ....
Phone: .....

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BOOKLET #3: Palliative Care (*for those support caregivers*)

Some facts about the disease: What is Tuberculosis?

Tuberculosis (TB) is an infectious airborne disease transmitted when the patient coughs. Tuberculosis is known to be curable. However, some patients may need palliative care.

Severe forms of TB are known to cause shock, fear, distress, anger and anxiety in patients and their relatives.

You may have questions arising when you provide care to critically ill patients with TB.

You should know: what is palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering. Palliative care is focused on treatment of the physical, emotional, social, cultural and spiritual needs of patients.

Palliative care includes nursing, medical counselling by clinician, nutritional advice, provision of necessary equipment (for a while), physiotherapy, services of social workers, support of the bereaved, spiritual support.

Who can provide care to TB patients?

Caring for the critically ill patients can cause the burnout syndrome, when a person feels he/she is weak, all his/her intentions are useless, etc. But you can always help him/her to overcome or relieve his/her suffering and make it bearable.

Let him/her know you are beside him/her to support him/her no matter what happens. Be honest and frank with them.

As a rule, people with incurable disease make some adjustments to their way of life. They and their family members keep their hope alive. Be ready to listen. You can help them not feel lonely.

- Learn to listen to him/her
- Do not blame yourself

Caring for the critically ill person may be tiring. Caregivers try to handle the situation as usually in unusual situation. The roles may change. Relations can be exposed to difficulties since people get used to new life. The life of your friend has possibly changed. Listen to him/her and learn to accept his/her understanding and change the attitude to this new situation.

Your friend wants to stay in touch and feel as part of the world. Help him/her avoid isolation by adapting to social activity. Learn about appropriate time and plan the meeting or take him/her for a walk when he/she needed.

A person you know wants you to keep talking to him/her on equal terms. Encourage memories and value friendship he/she provides. Know that you can change the situation by offering your support and asking how you can help.

Accepting practical help may be difficult at first sight. Let the patient and his/her family make decisions and reach agreements. You may provide help in many terms – cooking or working in the garden, bringing books, or helping with visits necessary for treatment.

You should know: After death – What I can tell to the caregiver

Even when death is imminent, it causes shock. It is even harder when people stay apart or tell nothing. There is no solution to that. The process of grief is actually a part of curing. Value the relations you have had. Take time to grieve. Stay close with your friends and family to get support.

If you have any questions or concerns, please contact:

Name /Surname: .....
Hours of work: ....
Phone: .....

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