Palliative Care Curriculum



By Helen Neely RN

Palliative Care Curriculum

Palliative Care Curriculum Copyright 2003, by Helen Neely, RN All Rights Reserved

Palliative Care Table of Contents

Palliative Care Lesson One Introduction	4
Palliative Care Lesson Two Nutrition	10
Palliative Care Lesson Three Hygiene	13
Palliative Care Lesson Four Comfort Measures	15
Palliative Care Lesson Five Pain Relief	17
Palliative Care Lesson Six Support to Family Members	19
Palliative Care Lesson Seven Care for the Caregivers	22
Signs of Impending Death	23
Faith and Dying	24
Reference for Lesson Two Curative Foods	
Universal Precautions	27
Technique of Bed Bathing	28
Reference for Decubitus sites	29
Supply List	
Skin Diagram	32
Edmonton Symptom Assessment Numerical Scale	
Body Diagram	34
Modified Edmonton Symptom Assessment Scale	35
Palliative Care Worksheet	37
Reference for HIV/AIDS	39
HIV Care in Children	42
Reference for Wound Care Guide	48
Bibliography	52

Palliative Care Lesson One Introduction

What is the goal of Palliative Care?

To educate people and promote awareness regarding end of life care. Teaching caregivers to provide compassionate care, centered on the spiritual and physical well being of the patient. How does that happen?

- 1. By teaching the caregiver to provide comfort measures to patients.
- 2. By teaching caregivers to treat patients with dignity and compassion.
- 3. By teaching caregivers to provide a healthy, sanitary environment for the patient.

This program consists of seven lessons. Each one contains a different aspect of Palliative care. In training caregivers, it is important that each lesson be taught and reviewed so that the learner is confident in passing along this knowledge to others. This is information to be shared but for it to be shared correctly, all seven lessons should be attended. Ideally, this program can be used by organizations, churches and individuals to teach caregivers to provide qualified care to the homebound seriously or terminally ill patient.

What is Palliative care?

Palliative care is measures taken to keep a terminally ill person as comfortable as possible by providing good nutrition, good hygiene, comfort measures, and support to family members of the patient.

What does it mean to "caregive"?

Caregiving is providing the care for the person in a well trained and compassionate manner. They should provide holistic care that encompasses emotional, physical, and spiritual needs.

Who are Caregivers?

Caregivers are people; they can be friends, family members, men, or women that care for the needs of ill or injured persons.

Caregivers should assess patients thoroughly, documenting findings to provide good continuity of care.

Caregivers should obtain accurate history from Patient and/or family members.

A caregiver is a minister. He or she ministers to the patients physically as well as spiritually. They should be caring and compassionate.

They should be available to help with patient care as needed.

They should be concerned for the spiritual as well as the emotional and physical needs of their patients.

The caregiver is needed to provide in-home care to sick, injured or dying patients.

Dying and sick people need trained, compassionate care.

Other persons can also benefit by the teachings of a caregiver, such as concerned neighbors and family members of the patient.

Caregivers are needed to provide relief for over-worked family members caring for the patient.

Caregivers are needed because some patients do not have family nearby or a support system to rely on for assistance.

Who are the terminally ill?

A terminally ill person is someone that is dying from an illness or injury with no chance of recovery. Not all terminally ill people have the same illness.

What are the needs of a terminally ill person?

They have a need to have pain relieved.

All terminally ill people need to be shown love and support.

They need to be treated respectfully.

They need to have their wishes and needs observed.

They need trained and compassionate caregivers to provide them with;

- Comfort measures
- A dignified, peaceful end to their lives.
- -They and their families have a right to privacy.
- -They have a need to die with dignity

How to assess the needs of a patient.

It is very important to do a physical assessment of the patient at the beginning of each visit. Knowing your patient's vital statistics and documenting changes in their health is very helpful in providing good care for your patient.

Initial request- there will be an initial request made of you for information or your opinion on the condition of a sick person. When you get the initial request, it is helpful if you ask some questions in advance to help you in making decisions on what actions you should take.

- 1. Find out the location of the sick person.
- 2. How long has the person been ill?
- 3. Has the illness changed in any way?
- 4. What does the family need from you (what type of assistance)?
- 5. What have they done for the sick person before they called on you?

It should be problem focused, address the initial complaint. If the person is only complaining of a cough, you need to make sure that that issue is examined during the assessment. Gather the information as you are assessing each area.

There may be other questions that you may think of to ask to help you to decide on your course of action. It helps greatly to be well informed in these situations. (Example knowing the nature of an illness like TB and how to protect yourself)

As you reach the place where the sick person is, it would be very good if you could examine the person outside **if possible**.

- 1. The risk of contagious illness is less outdoors.
- 2. Daytime lighting makes examinations easier to perform.

We will discuss how to perform a simple head to toe assessment.

1. Neurological- First, determine the patient's mental status. Are they awake, do they awaken easily?

You can do that by asking them 3 questions:

- 1. What is your name?
- 2. Where are you (where do you live?)
- 3. Is it day or night?

The answers to those questions should help you to determine if the patient is confused or aware of his/her surroundings. Confusion can mean many things from stroke, to drug use, to chemical imbalance, to lack of oxygen, to advanced stages in many diseases (like syphilis or AIDS and some types of cancer)

In a person that does not speak, or a small child, you need to watch for non-verbal cues to identify pain location or mental status.

2. Breathing- Second, assess their breathing status.

Are they breathing rapidly or slowing, is their breathing labored? Respiratory rate (number of breaths a minute) should be between **12-20**. Up to 30 breaths per minute is normal for children. Breathing should be even, quiet, unlabored and in a regular rhythm.

High fevers can cause respiratory rate to be faster. More than 40 breaths per minute (Shallow in nature) and 60 for children can mean pneumonia. Slow rate, less than 12-20 can indicate a severe illness that is life-threatening.

Do their nostrils flare with taking a breath? Flaring shows a struggle to inhale during breathing.

Does their chest wall retract (suck in)? This means that the person is having trouble getting air into their lungs. Chest wall should be even when expanded during breathing in. Trachea (windpipe) should be in the middle of the throat (if it is pushed to the side it can be a collapsed lung or advanced TB) chest even, expansion, listening, dressings

Do you hear noises when they breathe in or out? Sounds in breathing pattern can be a sign of illness. A crackling sound may be pneumonia, whistling or wheezing may show asthma. A wet or gurgling sound can mean fluid in lungs or in trachea that is blocking good air exchange.

Ask about coughing. How long? Dry or wet? What color is mucus that is coughed up? Is the cough worse at a certain time? Is the cough painful?

3. Cardiac- Thirdly, assess the circulation. Hands and feet cool? Are the lips pale on the inside? Lips blue tinged? Swelling (edema) in face, hands and feet could mean the heart in early failure. Heart should sound like "lub-dub lub-dub..." in a regular rhythm. Heart rate- take pulse in side of neck (carotid artery) wrist, in a child check pulse in upper arm. A weak rapid heart rate can mean a person is in shock (due to internal injury, too much post delivery bleeding, head injury, septic shock (bacteria in blood) or due to severe dehydration, Even a severe emotional shock can cause physical effects. Evaluate the medical history for cause of shock and refer as needed.

A rapid, slow or irregular heart rate can mean heart problems. Refer these people to a clinic for evaluation. A slow heart rate with a high fever may mean the person has Typhoid. The normal body response is for the temperature to rise when there is an infectious illness. (20 beats per minute for every degree Centigrade rise in fever.

If you place your index finger on the area of your wrist on the inside below your thumb, you can feel a rhythmic beating, that is your heart rate. If you time this for a full minute, that tells how fast your heart is beating. A normal adult resting heart rate is **60-80** beats per minute. Children have a faster heart rate normally **80-100** and babies **100-140**.

- 4. **Head:** -Level of consciousness (awake? hard to awaken? asleep?)
- -Eyes: describe, pupil size even? (uneven pupils can show stroke, head injury-usually sick person's medical history will reveal injury, or glaucoma- eye with larger pupil will be painful) any significant difference in size of pupils should be considered an emergency if injury is suspected or not. Drainage from eyes? (Yellow drainage can be conjunctivitis very contagious), open eyes evenly (drooping eyelid can show stroke, Bell's palsy, facial nerve damage)
- -Ears: describe, discharge? Difficulty hearing? (Is the white a different color like red or yellow?) Babies with ear infections may pull at ears.
- -Nose: describe, discharge (in head injuries ears and/or nose can bleed or drain clear fluid)
- -Mouth: describe, lips and gums color?, moisture?, tongue, teeth (Pellegra has swollen, sore tongue, malnutrition can show tongues with large ridges, thrush is white coating in mouth, dehydration will show very dry mouth. Tooth abscesses can cause other problems like fever and infections of blood.

A stiff jaw, that will not open (not including jaw injury) can mean Tetanus, in a person with a stiff neck look for Meningitis (verify with other symptoms and history, these two illnesses are medical emergencies)

- 5. **Abdomen**: -describe, soft, flat, distended, firm, hard to touch (acute abdomen is medical emergency-appendicitis, peritonitis, incisions, dressings, time or date of last bowel movement. If person complains of pain in abdomen, ask where it is, have the sick person point to it. Press abdomen in four locations upper-left- lower-left, upper-right, lower-right, appendicitis-pain at navel then, check rebound (when the pressure is released from pressing lower right abdomen)
- 6. **Extremities:** -evenness, strength, (person can squeeze fingers of examiner, push with feet against hands) flexibility, joint movement, colour, warmth, skin turgor (check for tenting in dehydration), pressure areas, dressings, wounds, gait, co-ordination (if able to walk), Pulses (in feet and wrist). Unequal movement or strength in adults may be stroke, head injury, back injury, brain tumor. Overall weakness in a child could be polio or malnutrition.
- 8. **Skin**: What is their skin color like?

Skin color can tell many things like these;

1. Pale lips, pale inside of eyelids-anemia

- 2. bluish-tinge -can mean lack of oxygen or heart problems
- 3. Yellow-tinge- malaria or jaundice from another kind of illness
- 4. Lighter color than normal-TB, malnutrition
- 5. Red face- high blood pressure, texture, skin breakdown, lesions, rashes. Loss of feeling near spots on the body or loss of feeling in hands or feet can mean Leprosy. Other reasons for loss of feeling in extremities could be Diabetes or nerve damage from a back injury. The sick person may be conscious or unconscious. You may have to rely on family members for an accurate history if the patient is unable to answer questions. Always talk to the patient even if they are not conscious. History will determine whether advanced medical care is advisable. (Example a person unconscious due to stroke that has not changed compared to child that fell and lost consciousness)

There is a difference between sleeping and being unconscious. If the person is sleeping, do not awaken them for an exam. The person is unconscious when they unable to be awakened. Use the family as the information source in this matter.

Whatever the assessment findings are, should tell you that;

- 1. That the sick person should be referred to clinic for more intensive care
- 2. That the person can be cared for at home.

Considerations of Contagious Illnesses

The patient may have a contagious illness such as HIV or Tuberculosis. It is important to know about these diseases so you can provide the best care possible to your patients and also to prevent infection to yourself and family. **Education** is a tool that can be used to correct false ideas about contagious diseases such as HIV and TB.

What is HIV?

AIDS (Acquired Immunodeficiency Syndrome) is a disease cased by a virus called HIV (Human Immunodeficiency Virus). AIDS is the disease, and HIV is the virus that causes the disease. People may be infected with HIV for many years without signs of illness; but once they become ill from the virus, we say they have AIDS. HIV causes illness by attacking the part of the body that usually defends it from infection: the immune system. When bacteria come into the body, a healthy immune system can usually fight them off, and the person gets well.

If a person has AIDS, his or her immune system is weakened. People with AIDS can become very ill or die of illnesses that healthy people fight off, like diarrhea. HIV usually lives in the body for years without causing any visible or obvious illness, but HIV can be transmitted to others from the moment a person becomes infected, before AIDS and obvious illness develop.

Sooner or later, as the immune systems weaken, people infected with HIV start to feel more tired than usual and to lose weight. They may suffer from common illnesses like diarrhea or coughs that do not go away with treatment. At this point, they may have developed the disease AIDS. For some people it takes 10 years or more to go from HIV infection to AIDS. For others, it takes as little as six months.

In Africa, death usually occurs within six months of diagnosis with AIDS, but this can vary widely. That is because many times people wait until symptoms of the disease are present before they are tested. Much can be done to delay or treat the infections caused by AIDS, but at the present time, there is **no cure for AIDS itself.**

How is HIV/AIDS spread?

It is spread through direct contact with the blood or body fluids of an infected person. It can be through sexual intercourse, blood transfusion, childbirth, accidental exposure through contact with infected fluids, through breast milk to an infant from an infected mother, or sharing needles with an infected person.

It is NOT spread through hugging, kissing, or by mosquito bites. It is also not spread by giving care to someone with the disease.

What is Tuberculosis?

Tuberculosis is a contagious disease caused by the bacteria Mycobacterium tuberculosis. It usually affects the lungs, but can affect many organs in the body, such as the bones, skin, eyes and spine.

What are the symptoms of TB?

The common signs of TB are;

- -a chronic cough especially after just awakening.
- -mild fever in the afternoon and sweating at night
- -pain in the chest and /or upper back
- -chronic weight loss and increasing weakness
- -dark skin can appear lighter in color, especially in children

Advanced symptoms are

- -coughing up blood
- -voice sounds hoarse

In children the cough may come late in disease so look for these symptoms;

- -steady weight loss
- -fever that comes often
- -skin lighter than usual in color
- -neck that looks swollen

TB can also occur on the skin and can cause large sores that do not heal easily. It can also occur in different parts of the body like the eyes, and can cause blindness. Spinal TB cause weakness or paralysis

How is TB spread?

TB infection is spread by coughing the germ, Mycobacterium tuberculosis, into the air where it may be inhaled by persons sharing the same breathing space. Only one in ten infected by the germ actually develops active symptomatic TB. The remainder have a healthy immune system which contains the infection in a dormant state. However, many years or decades later, dormant infections may reactivate and cause disease when the immune system fails.

It is estimated that as much as one third of the world's 6 billion population (1.9 billion) has been infected (not active, but infected). The chance that anyone person will become ill with TB after infection is low (one in ten). In patients already infected with HIV, TB spreads much more quickly and is more life-threatening because of the patient's weakened immune system.

Diagnosis and Treatment

Diagnosis of TB can be made by a Tuberculin skin test (if the person has not had a BCG vaccine), a Sputum culture and an X-ray of the chest. There is treatment for TB in the form of medications. It can take as long as 6 months to treat the disease because the bacteria are very

slow-growing. The TB in the lungs is treated with the same medications as the TB that can happen in other locations in the body. It is curable with correct medication, taken for the right amount of time.

A BCG vaccine is commonly given to children and adults in countries where there are high percentages of people with Tuberculosis. It is given for prevention of some types of TB. It will not prevent all strains of TB, especially the drug-resistant forms of the disease. When a person has had a BCG vaccine, their Tuberculin skin test will very likely show up positive, due to the antibodies the body has made. This vaccine is not to be given to children who have had symptoms of AIDS infection due to adverse reactions that have been documented. But each case should be individually examined.

The reason we have discussed these two diseases is that these two are commonly seen in terminally ill patients here. It is very important for the caregivers to be aware of the transmission and prevention of these illnesses. Not every patient will be infected with a contagious illness; but for your own personal safety. It is best to treat all patients with universal precautions. That will be discussed more thoroughly in lesson three.

Palliative Care Lesson Two Nutrition

What makes up Palliative care?

Palliative care is made up of measures performed to keep a terminally ill person as comfortable as possible. By providing **good nutrition**, good hygiene, comfort measures, assist with pain relief, and support to family members of the patient.

For the very ill, nutrition plays a major role in the well-being, comfort, length and quality of life. It is very important that the terminally ill patient has someone who can provide nutritious foods for them and adequate and proper hydration (clean water). There are many ways to have good nutritious foods available for the patient at inexpensive costs. As a caregiver, part of the responsibility that you have is in arranging meals for your patient with family, neighbors or church members of your patient. It is not your responsibility to provide the food, but it is your responsibility to teach how important good nutrition is to the patient's well-being. Some foods that we can eat actually have health benefits like medications. They can help with

Some foods that we can eat actually have health benefits like medications. They can help with nausea, diarrhea and other medical issues the patient may complain of.

(See reference on curative foods in back of manual)

Eating a well balanced diet, one that includes a main food as well as fruits and vegetables and a protein source, can keep a person healthier and avoid many illnesses.

Children especially can suffer from malnutrition if their diet is not adequate.

It is important also for pregnant mothers and elderly to have a good diet, as they are also prone to becoming malnourished more easily than a healthy adult.

Signs of malnutrition

Mild malnutrition- children can appear small for age; weak, not able to fight off illnesses. A measurement of the upper arm can show if a child is malnourished. Any child older than 1 year of age whose upper arm measures less than 13 ½ cm around is malnourished, no matter if they look

"fat" or not.

Severe malnutrition- there is two types

Dry (Marasmus) - has the face of an old man, always hungry, potbelly (looks fat in the belly), very thin arms and legs, very underweight.

Wet (Kwashiorkor)- hands and feet appear swollen, "moon face", color loss in hair and skin, stopped growing, sores and peeling skin, wasted muscles, thin upper arms.

These people need a good diet; these conditions can be corrected if the person has a change in the way they are eating. These symptoms can happen more quickly and more severely in young children.

We will look at the types of nutrients needed by the body for maintenance of good health. Foods contain several kinds of nutrients. These include;

- 1. Carbohydrates and Fats and Oils- These provide energy for the body
- 2. Protein- This is necessary for the healthy growth of the body including the bones, muscles, and brain.
- 3. Vitamins and Minerals- They help the body to work properly and keep it healthy. Minerals are necessary for healthy blood, bones and teeth.

Vitamins are an important part of our diet. They are food substances which we need in very small quantities but are vital for good health. They are labeled by the letters of the alphabet. Vitamins A, B, C and D are the most important.

Vitamin A is found in dark green, leafy vegetables; fruits and vegetables colored red and yellow (carrots, papaya and mango, guava). If a person goes a long time without vitamin A they can go blind. An early symptom of this is night blindness. Later, the eye becomes dry and changes so much that the eyes go blind.

Vitamin B this includes several different vitamins in the B group. These are found in cereals, especially the brown cereals. White rice and plain flour contain fewer vitamins so they are not as healthy as un-milled rice or wheat flour or enriched flour.

Vitamin C is found in oranges, lemons, guavas and green vegetables. Lack of vitamin C can cause many medical problems. Wounds can be slow to heal and scar tissue does not form properly. Bleeding from the mouth and gums can happen. Eating plenty of fruits and green vegetables can prevent these problems.

Vitamin D is made in people's skin through the action of sunlight. This is also in milk. It is necessary for the proper formation of bones. People can lack vitamin D if they do not get exposed to the suns rays. Some Muslim women who cover their bodies totally when outside suffer from this deficiency. Lack of vitamin D may cause Ricketts, this is a condition where the bones do not form properly or become soft and pliable. Children may have a "bowlegged" appearance.

Minerals such as Iodine and Iron are also very important in maintaining good health. A lack of Iron in the diet can lead to anemia and a lack of Iodine can cause a goiter, or large growth on the thyroid gland, seen on the lower part of the neck. Iron can be found in beans, green vegetables and meat, especially red meat and liver. Iodine can be found in salt that has it added, and small amounts can be found in shellfish.

Here is a list of some healthy food options. It is good to include some from each food group for each meal if possible.

Go foods (energy helpers)

Fats (oil, ghee, lard)
Fat rich foods (cheese, fatty neat, coconut)
Nuts (cashews, pumpkin seeds, ground nuts)
Oil seeds (sesame, sunflower)
Sweet foods (fruits, sugar, sugarcane, honey)

Main foods (the center of the meal)

Cereals and grains (enriched cornmeal, wheat, millet, rice, maize) Starchy roots (taro, cassava, potato) Starchy fruits (banana)

Glow foods (vitamins and minerals or protective helpers)

Vegetables (dark leafy plants, tomatoes, carrots, sweet potatoes, papayas, peppers, pumpkin, leeks, turnips, kale, avocado, eggplant-impwa)

Grow foods (proteins or body building helpers)

Legumes (beans, peas, lentils)

Nuts (cashews, almonds, ground nuts, pumpkin seeds)

Oil seeds (sesame, sunflower)

Animal products (milk, cheese, lacto, meat, fish, chicken, small animals, insects)

Nsima is a major part of the diet in this part of Africa. The corn meal by itself does not contain much nutritional value. To add calcium to the diet, egg shells may be crushed finely and added to the cooking nshima. Calcium is very helpful in keeping a person's bones strong, and also by helping prevent some muscle cramping caused by lack of calcium in the diet. Iron helps prevent anemia (thin, pale blood) food with lots of iron includes, meat (especially liver and organ meat) fish chicken and eggs.

These other foods have some iron: dark leafy vegetables, yams, cabbage, beans and potatoes. You can also cook in iron pots and add lemon juice or tomatoes to the pot and it pulls iron out of the pot and into the food. Iron pills are also available from most clinics. They also can be called ferrous sulfate, ferrous glutamate, and ferrous fumerate. Doses of Iron and Folic acid should be 60 mg of Iron, 1 mg of Folic acid. Iron pills can cause constipation, so the person needs to drink extra water when taking them. Too much iron can be poisonous, so you never should take more than is recommended. Folic acid is known to cut down on the risk of neural

tube defects in babies (Spina Bifida). These are conditions where the spine does not develop

in the correct way, leading to physical handicaps.

With regards to hydration, it is very important that the person has enough clean drinking water every day. Proper hydration does many things to help a person stay healthier longer, some of these include; it helps the person feel stronger, protects the skin from becoming dried and cracked, helps the kidneys continue to work well, and it keeps the circulation system (pulse, blood pressure) working properly.

When a person is dehydrated they will become very weak. Their pulse can also become weak and thready, and their blood pressure can be low, you may also see the urine output become less frequent in amount. Vomiting and diarrhea in a person causes very rapid dehydration. The fluid should be replaced as they lose it. That may mean that they sip water or an oral rehydration drink all day to replace what has been lost. Even when a patient is vomiting they need to sip the drink, their bodies will absorb some of the liquid.

There is also a change in their skin turgor, (that is the stretch and elasticity of the skin). It will look dry, scaly and when it is pinched up, it will stay in the "tenting" position. Their eyes will appear sunken, and with children the anterior fontanel (soft spot in the front of the head) will be sunken.

The person can also become listless, and confused when dehydrated.

A person is not getting enough water when they "feel" thirsty. Feeling thirsty is the body's way of telling us when it needs more fluid. A person should ideally have 6 to 8 glasses of clean water every day.

Water can be cleaned by filtration, using Clorin as directed, and by boiling for at least 5 minutes. Water can also be placed in a clear plastic container and placed in direct sunlight for several hours to kill bacteria.

In children, it is very important that they have enough fluid because they will dehydrate very quickly, especially if they have vomiting or diarrhea. Children will die from loss of fluids very quickly if the fluid is not replaced with clean water or the oral rehydration drink.

Here is the formula for the rehydration drink;

1 liter clean water

2 tablespoons of sugar (open handful)

1/2 teaspoon salt (3-finger pinch)

This drink should taste no saltier than your tears. Too much salt can cause more vomiting. The dehydrated person should sip this drink every 5 minutes day and night until they begin to urinate normally.

Malnutrition and dehydration alone can kill. If a person develops the signs of either of these, it is very important to treat these conditions immediately.

They are preventable conditions.

Food preparation is also important. Hygiene is a crucial part of staying healthy. If foods are contaminated they can lead to illness. Food can be contaminated by;

Not cooking meat long enough to kill possible bacteria or parasites.

Allowing food to be left uncovered and flies contaminate it with bacteria.

Eating food that has been left out, (not kept cool), and has become contaminated with bacteria. Bacteria grow quickly and easily in warm, moist environments.

Cooking food with unwashed hands can lead to contamination.

Unclean food preparation areas can also lead to contamination. An example of this is, cutting up a chicken on the same surface that the vegetables are prepared on without cleaning the surface well in between. Chicken can carry bacteria, Salmonella,

that can be transferred to the raw vegetables. This can lead to serious illnesses like, gastroenteritis.

A good diet with many different food options, not just one main food, and good hygiene when preparing food, along with good hydration, are all components of keeping healthy.

Palliative Care Lesson Three Hygiene

What makes up Palliative care?

Palliative care is made up of measures performed to keep a terminally ill person as comfortable as possible. By providing good nutrition, **good hygiene**, comfort measures, assist with pain relief, and support to family members of the patient.

Good Hygiene

It is very important to use good hygiene in the care of your patient, not only in the direct patient care by keeping them clean, but also for your own well-being and good health. To provide some protection against the spread of contagious disease there is a set of parameters that can be used to protect yourself in direct patient care, these are called Universal Precautions.

Use Universal Precautions.

(See reference in back of manual)

- 1. Use gloves for direct contact with patient's broken skin or body fluid. If no gloves are available, plastic bags may be substituted.
- 2. Wear mask if patient has cough that may be contagious. (Situation permitting)
- 3. Wash hands thoroughly with soap and clean water before and after contact with patient.
- 4. Change clothes if they become soiled by patient's blood or body fluid.

The patient should be kept clean and if they soil themselves should be bathed as soon as possible. Urine and stool will cause skin irritation very quickly. It is also uncomfortable for the patient to be lying in this condition.

The caregiver should use gloves, when available, when in contact with patient's blood or body fluids. They will protect the caregiver from being exposed to a blood-borne disease. It is very important that the caregivers use good hand washing procedures. The germs on the hands are a major way of passing infection from person to person. Proper hand washing can reduce the chance of picking up infection and transferring from one source to another. Proper hand washing includes the use of clean water, soap and proper friction. Also if clean drying towel is not available, allow hands to air-dry.

Demonstrate hand washing technique (Hands-on practical skill)

Good hand washing techniques

There are 3 ways we will do hand washing in this handout.

- 1. The first one will be with running water from tap and soap.
 As the water is running (hot or cold), put your hands under the running water to get them wet.
 Then you get the bar of soap and lather up your hands with good friction.
 Rub and cleanse your hands for 15-30 seconds, then rinse well under the running water.
 Use a clean towel or cloth to dry hands, or air dry if none available.
- 2. If no running water available, you may use a pan of clean water and soap. Wet your hands and lather up, not over the pan. Use same time as above to clean hands with friction. Rinse hands well in pan. Dry as stated above.
- 3. If no water available, use a liquid antiseptic to cleanse hands, such as Dettol or Savlon, but hands should be rinsed as soon as possible as these chemicals are strong on the skin.

When should hands be washed?

- a. Wash hands before and after direct contact with Patient.
- b. Wash hands before and after eating meals.
- c. Wash hands after taking care of toilet needs of yourself and others.

It is also important to present yourself in a professional manner by being clean and wearing clean clothing.

Bathing the Patient

(See reference practical skill)

Bathing protects the patient as well as the caregiver from unneeded infection. Bathing is an excellent way to promote good hygiene in the patient.

Bed bathing can be done in a patient that is too weak to sit or stand.

Bathing should be given everyday or more often if needed.

Providing for patients modesty is very important during bathing by keeping them covered, only uncover the part of the body that is to be cleansed. We must respect our patient.

The best thought on care-giving is to treat the patient in the way vou would like to be treated.

Ask visitors to leave until bathing is finished, unless the patient wishes for them to assist or you are teaching a family member to bathe the patient.

Allow patient to wash what they are able to wash. This helps them to feel more independent. Use clean, warm water changing it as needed.

Use soap to clean patient's body, starting from cleaner areas to dirty.

Partial bathing when necessary. If only certain parts of the body need to be washed, then a partial bath can be given.

Tub or shower bathing if it is possible for patient to do this. Supervision is needed in case of falling due to weakness.

The patient can use a chair to bathe in, if he/she is strong enough to sit.

Providing safety measures is an important part of being a caregiver.

You must provide physical assistance to your patient.

You should also prevent over-tiring by allowing patient to rest often during any physical activity.

The patient should be redressed in clean clothing. Bathing helps in many ways, such as pain relief, infection control, soothing and relaxing patient and benefiting skin protection.

Good hygiene is helpful to you as well as your patient. Infections that cause many deaths among immune compromised patients can be greatly reduced if good hygiene techniques, such as proper hand washing are done regularly.

Palliative Care Lesson Four Comfort Measures

What makes up Palliative care?

Palliative care is made up of measures performed to keep a terminally ill person as comfortable as possible. By providing good nutrition, good hygiene, **comfort measures**, assist with pain relief, and support to family members of the patient.

Comfort Measures

Comfort measures are the means by which someone is given care that provides for their feeling of well-being. By teaching the caregiver to provide comfort measures to patients they not only make the patient feel more comfortable but also by providing much needed physical therapy. A common problem for long-term bed bound patients is muscle wasting or atrophy and contractures. Muscle wasting happens when the person is immobile for prolonged periods of time and the muscle tissue actually begins to wither away from lack of use. Contractures happen when muscles are left without exercise and begin to pull arms, hands, legs, feet and even neck upward and inward. The muscles become resistant to stretching and difficult to move.

These both can be prevented by proper exercise (passive or active) and by adequate support of the joints to eliminate shortening and tightening of muscles and surrounding tissues.

Exercises

Range of motion exercises

- -Passive ROM- where the caregiver does the exercise with the patient not assisting.
- -Active ROM-where the patient can assist with the exercise, such as pushing against the caregivers hand with their foot, as a strengthening tool.

Deep breathing exercises- where patient is advised to take deep breaths in through the nose and out through the mouth to expand lung capacity.

Relaxation techniques- These techniques range from singing, praying, listening to soothing music, to the bathing and massage techniques.

Short walks if patient is able- This is a good distraction for the patient if they are able to walk. The exercise is also very beneficial for their health.

Massaging patient

- -Helps them relax
- Helps them to rest
- Provides endorphin release for feeling of well-being (endorphins are chemicals released by the brain)
- -Helps to relieve pain by loosening sore, stiff joints and muscles

Change linens daily, or more often if soiled.

-Linens should be washed in hot water and dried thoroughly before remaking patient's sleeping surface (ironing linen will remove the risk of putsi or mango fly infestation.)

Repositioning patient who is in either a sitting or lying down position;

- -Every two hours or more
- -to help alleviate pain
- -to increase circulation
- -to prevent bed sores

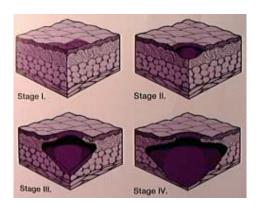
What are bed sores?

There are progressive levels of sores that can develop on a patient's body that is not being cared for properly. Also called Decubitus ulcers or pressure sores, they usually occur in a person with very limited mobility that has less than adequate nutrition, and less than ideal hygiene. There are three ways that pressure sores are caused. The first way is by pulling the

patient up and causing his or her skin to "shear" against itself that they are lying on. The second is normal pressure from the skin being squashed, causing blood circulation to be cut to the areas, especially under bony prominences. Thirdly is "friction" from poor lifting techniques.

(See reference on common decubitus sites)

These can be prevented with many of the measures being taught. We will discuss the 4 levels of ulcers and how they can be treated.



Level 1 the ulcer appears as a defined area of persistent redness in lightly pigmented skin, whereas in darker skin tones, the ulcer may appear with persistent red, blue, or purple hues. These can be treated easily once an area is identified. Good skin care, adequate turning and pressure relief (off of affected area). These will heal without medical intervention if found early in the stage

Level 2 Partial thickness skin loss involving epidermis, dermis, or both. The ulcer is superficial and presents clinically as an abrasion, blister, or shallow crater. At this stage, medical intervention is necessary. This stage of wound needs cleansing with a saline (salt solution) or a weak Chlorine solution. Area must be cleansed and a clean wound dressing put on the site at least once daily. Skin care then resumed as in stage 1. (See wound care section in back of manual for more information)

Level 3 Full thickness skin loss involving damage to, or necrosis of, subcutaneous tissue that may extend down to, but not through, underlying fascia. The ulcer presents clinically as a deep crater with or without undermining of adjacent tissue. Skin damage at this stage will not heal without medical attention. Most stage 3 ulcers require surgical debridement if possible. If that is not an option, care for this ulcer like stage 2.

Level 4 Full thickness skin loss with extensive destruction, tissue necrosis, or damage to muscle, bone, or supporting structures (e.g., tendon, joint, capsule). Undermining and sinus tracts also may be associated with Stage IV pressure ulcers. At this stage medical intervention is the only option. A patient with stage 4 is very likely to become septic (sick from bacteria entering bloodstream), from the wound. A patient can die from a septic stage 4 ulcer.

Providing for the comfort of the patient is a very important part of Palliative care. The comfort of our patient should be a very high priority for all caregivers. The patient will be more confident in your care, as will the family members. A compassionate and caring attitude in your care giving can help give your patient and their family members comfort and security that you are giving the best care possible. A gentle touch and a kind word will go a long way. As a caregiver, you will required to have a certain amount of supplies with you when you are doing your home visits. We will outline some of the necessary items you should bring with you on visits. (See reference for supply list)

Palliative Care Lesson Five Pain Relief

What makes up Palliative care?

Palliative care is made up of measures performed to keep a terminally ill person as comfortable as possible. By providing good nutrition, good hygiene, comfort measures, **assist with pain relief**, and support to family members of the patient.

IV. Assist with Pain Relief

How to assess pain in the patient

Ask the patient to describe symptom characteristics, including site (for pain and some other symptoms); frequency; severity; and associated distress or how bothersome the symptom may be for the patient. It is important to ensure that, where possible, reports of symptoms, especially of associated distress, are based on the subjective experience of the patient. Occasionally a patient may have a degree of mental impairment and may not be able to provide such detail.

If possible, ask the patient to explain the symptom in some way to provide a baseline for ongoing evaluation. Pain and fatigue, for example, can be described on a severity scale of 0 to 10, and similar scales can be used for other symptoms. Words can also be helpful, such as "mild." "moderate." or "severe."

Explore the degree to which each symptom, or its treatment, helps or makes worse other physical or psychological symptoms (e.g., Does the fatigue become more severe on the days that you also have high fevers? Do you find that the pain makes you depressed?)

Document the result of treatment on each symptom. Especially with palliative interventions, it is important in symptom assessment to investigate the impact of specific therapies on each symptom to find out which medications or treatments a patient has tried and how well they relieved the symptom. (For example, with the symptom of pain, did pain treatments provide you with *any* relief, and if yes, how much relief? For this question, a pain scale can help the patient to report on a scale of 0 to 10 his or her pain level before the medication or treatment and pain level after the treatment or medication.)

A system of charting can help you and other caregivers maintain good continuity of care for the patients. It can tell if the treatments have helped your patient to be more comfortable and also let others who may assisting you know how to provide the same quality of care that has been successful for you, the primary caregiver.

Your organization can decide how and if charting will be a part of your responsibility. There should be a person that can coordinate the charting and review the care for quality assurance. Quality assurance means making sure that care is being done in the best possible manner. To assess for changes and to utilize other options of care for the patients needs if necessary. This all works together to make a system of accountability in care giving. A care giver needs to know if or if not their efforts in providing adequate care have been successful. Charting is one method that can be used to determine this.

Here are some examples of charting to assess pain that uses a checklist, instead of a number scale to determine levels of discomfort in the patient.

(See references on pain assessment)

Edmonton Symptom Assessment Tool Numerical Scale

Modified Edmonton Symptom Assessment Scale

Pain relief

Pain relief may be controlled by medicinal means.

- Paracetamol may be given to reduce pain and also reduce fever.
- Codeine products can be given for more severe pain.

Pain relief may also be accomplished by non-medicinal means.

- -Applying warm or cold compresses to painful areas.
- -Making a warm compress out of cloth and warm water, refreshing the warmth often. Check first that temperature is not too hot and will burn patients skin.
- -The use of cold cans or bottles works well, roll them over the painful area.
- Cool water soaked cloths are also helpful.
- -Distraction techniques can also be used to provide non-medicinal comfort.
- -Singing songs or telling stories with patients
- -Praying and providing ministerial support
- Trans-visualization works by allowing the patient to visualize themselves in a place "away from their pain" encourage them to think of a peaceful, calm place when they are experiencing pain or discomfort.
- -Sitting patient up in bed will also help with shortness of breath. It is common for patients with end-stage illnesses to experience shortness of breath. Sitting them up increases the space in the chest wall cavity, allowing more room for lung expansion, therefore, better air-exchange.

Pain relief should be a main concern for a caregiver. If your patient is comfortable, they will rest better, eat better and have a more positive outlook.

The family will also be more comfortable if the patient is having their pain relieved. This is an excellent way for the family members to be involved in the care of the patient. They can report the patient's rest patterns and how pain was handled when the care giver is not present. This assistance by the family can also help them feel like they are a vital part of the caregiving process.

Many times at a person's death, the family will feel a sense of guilt over not doing enough to help their loved one. In including family members, the guilt feeling will hopefully not be an issue.

Also another tip is to always listen to the family in regards to your patient. Many times they are aware of changes in the health status before the health care worker is. They may pick up on a change in respiratory pattern or a change in the patient's appetite more quickly than a caregiver. They are more likely to be with the person more hours in the day than anyone else. Be very in tune with the verbal (things said) and the nonverbal (actions, facial expressions, body position), things that the patient may show. The nonverbal, especially in children are very helpful in assessing pain levels and whether the pain relief measures are working for them.

Palliative Care Lesson Six Support to Family Members

What makes up Palliative care?

Palliative care is made up of measures performed to keep a terminally ill person as comfortable as possible. By providing good nutrition, good hygiene, comfort measures, assist with pain relief, and **give support to family members** of the patient.

Give Support to Family Members of Patient.

The Family of the patient also needs the attention of the care giver at this time. They need to be included in your plan of care. Allow them to participate in care of family member. By doing so helps them in the grieving process. The grief process was explained well by Swiss-born psychologist Elisabeth Kübler -Ross. She stated that there are levels of grief that a person needs to go through to deal with loss in a healthy manner. The person who is ill will also be grieving, so these levels will also apply to them as well.

The Five Stages of Grief

DENIAL

The first characterization, which Kübler-Ross calls the stage of shock and denial, is usually at the point of initial disclosure of serious illness. Patients and those close to them in this stage are unable to admit to themselves that they might die and/or suffer the loss death represents.

They typically respond by saying "It's not true," "You must be mistaken" or "Are you sure? Can I get another opinion?" The reality of the disclosure is too shocking to admit and disbelief is the most immediate defense.

Denial may represent itself by many reactions ranging from loud, verbal protests to inappropriate lack of concern or even cheerfulness. The important point to remember is that in denial, the patient is saying to him/herself and others, "No, it can't be me! It is not possible that I should die!"

Denial is a way of cushioning the shock of the disclosure of probable death. For a few, it is needed until death. For most, it provides needed time to begin to understand the news and marshal more lasting coping mechanisms.

ANGER

The second type of reaction those affected might have is rage and anger. When they have begun to admit to themselves that the patient might die and denial is no longer an effective way of coping with the fact, the patient and loved ones ask "Why me?" This usually is expressed as anger toward each other, you and other health professionals, and, very often, God for allowing or making this happen.

This reaction of patients will be particularly difficult for you to handle personally because they will be quite irritable, complain about everything and blame you for their predicament. These patients are called "difficult and ungrateful" and frequently receive angry reactions from those who try to care for them.

The patients in the stage of rage and anger are asking "Why should this happen to me?" or "How could you let this happen? Why can't you help?"

Rage and anger provide a cathartic means of expression and of accepting the significance of probable death. At this stage one begins to ask questions about his/her death - who is to blame and what it means. By enabling one to externalize these questions, to put the blame on God or doctors, this device helps to handle the questions more easily.

BARGAINING

In the stage of bargaining the patient and others are no longer angry and difficult but are quite cooperative. They will now begin to "make deals" with you and God that "if I take all my medicine" or "if I am a good Christian will I get well?" They state "Yes me, but ..." They look for a cure and promise anything for the prolongation of the patient's life.

Bargaining represents a last effort at overcoming death by "earning" longer life. It may also represent feelings of guilt - that the may deserve his/her fate because of some failure, e.g., moral failure before God, failure to take care of his/her body or failure to be a good parent, spouse or friend. This keeps open hopes for cure necessary for one to face his or her problems and provides a way of working out this guilt."

DEPRESSION

Once the patient and others admit that there is no cure, the statement "Yes me, but ..." becomes "Yes me." At this point the full impact of imminent death strikes them and they enter the stage of depression.

It is most important to realize that this depression is not inappropriate but is a response to the overwhelming sense of loss death represents. You may recall or might imagine the sense of loss you may have felt when someone close to you died. Remember that the dying patient is about to experience the loss of all those close to him or her.

Depression is very difficult for most people to handle because the patient frequently cries or otherwise expresses great sorrow. The patient frequently wants to be alone and not be bothered.

Depression with its releases for frustration and loss in expressions of grief, such as crying, provides a means by which those in grief can admit the full impact of their loss with appropriate seriousness.

ACCEPTANCE

Kübler-Ross calls the fifth stage acceptance. Here the grieving person comes to grips with the fact of the patient's death and makes preparation for it. The patient frequently settles business affairs, makes a will, and calls in friends and family for the last time.

This is not the same as resignation which is a bitter giving up. It is a feeling of peace, of having finished all unfinished business, and of being "ready to go." The patient is not happy over this great loss, but neither is he/she extremely sad as in depression. The patient rests quietly, demands little and wants only one or two of those who are closest to care of him/her.

The stage of acceptance describes how the patient may positively deal with loss by fully admitting it and preparing for it. The acts of finishing unfinished business, of "closing all accounts" so to speak, help to fulfill important responsibilities as friend, parent, employee and so forth, and transfer concern to the patient's own dying and the prospect he/she believes it holds.

These stages reflect the needs of the dying patient and others and the devices they use to cope with them. It is most important for you to remember that the loss by death to and of the patient is probably the greatest loss those affected will ever experience. The prospect of death, then, will be the greatest crisis one can face. For most people, this crisis can be endured only with at least the temporary help of coping devices like those suggested by the stages. Teach them to perform the tasks that you have learned to provide around the clock care for the patient. This empowers the family to feel like they have been an important part of the patients' care. This can help alleviate some "guilt" feelings that some families experience when a family member is dying.

Encourage them to express their emotions about their family member's illness. The family members should feel free to talk about their loved one who is ill. Sometimes getting them to recall fond memories with the patient can help them cope better with the illness and encourage them in their care giving.

Encourage them to take care of themselves by eating properly and getting adequate rest. This is important for all caregivers. People are susceptible to illness when they become overtired or are not eating properly.

Teach family about voluntary HIV testing if applicable. This is a subject that has to be approached case by case. It is very helpful for family members to know of their HIV status if the patient is infected by the illness. This will assist in knowing the plan of care for the family unit

Encourage family to seek support of local Church fellowship. This can be extremely helpful in all aspects of Palliative care, from helping the family in physical ways and to ministering to them spiritually. Support from a church can serve as a great source of encouragement to a terminally ill patient as well as the family.

When death comes it is important not to leave the dying person alone.

Many people are very afraid of dying alone. Many people have a fear of the unknown, especially if they do not have eternal security in their belief system. They want to have loved ones there to be with them. Many dying patients become very talkative, sing songs, talk about their life, and want to discuss with the family what they should do after the death. Respect should be given to rituals, observances, and customs related to laying out the body. Family members and mourners can be given time alone with the body if they wish. However, all persons should be warned about the risk of contamination.

Bereavement counseling

Families and friends often have little social support, or may have become isolated while caring for the patient. Bereavement support should be made available before the person dies, and for as long afterwards as people need it. People react to death in different ways, and need different types of support. For some, it can take months or years to come to terms with loss. Additionally, people's responses may be affected by the way the person died: for example, whether the patient died alone and in pain, or died peacefully, surrounded by loved ones. Those left behind often blame themselves if they think they could have done more to ease suffering or if they feel that they had not spent enough time with their loved one.

Bereavement counseling should:

- 1. Give people an opportunity to talk about events leading up to the death, about the death itself, and the observance and rituals immediately after the death.
- 2. Reassure people that feelings of disbelief, denial, sadness, pain, and anger are normal.
- 3. Allow people to express their feeling and concerns, especially if it is difficult for them to do this with friends and family.
- 4. Enable people to accept their loss and start to look to the future.

There is some documentation that can be done as a way to review the care that has been given. It is a death questionnaire. This tool can be used to determine how the palliative care was viewed by family, whether the patient died with the desired outcome initially projected. This tool can be very helpful in guiding future care giving.

Palliative Care Lesson Seven Care for the Caregivers

The psychological needs of caregivers

Caregivers need proper training. Without proper training they can be lacking the confidence needed in providing well-balanced care for patient and family members. They are responsible for training family members to care for terminally ill patients so they need to be well prepared to handle a range of medical problems as well as psychological challenges such as bereavement counseling.

Home-based care works best when combined with support groups and if needed, counseling for people with HIV and their families, so that HIV positive people do not see the disease as an instant death threat, but are encouraged to live healthily and responsibly.

Caregivers need regular debriefings as the work that they do is draining and can be very depressing. It is advisable to meet with other caregivers and support persons to discuss strategies and to express feelings with people sharing similar experiences.

There also needs to be an organizational structure put into place where the caregiver knows he or she can refer to in case of questions or problems that may arise. A primary caregiver should be the one used as a resource person for others to ask questions of. This person should be in a position to access the proper channels for assistance, such as telephoning clinics or hospitals, knowing pharmacy availability, and have had successfully completed a training course for caregivers. This person could also be responsible for coordinating the patient work load and maintaining quality assurance in documentation in patient care, i.e. pain assessment sheets, and interviews with patients. It is imperative for good continuity of care for documentation to be reviewed. This is the guideline for determining whether the care for the patient has been adequate, or if revisions in techniques need to be done. Having a primary caregiver gives reassurance to the caregivers that they are not "doing this alone." It gives them someone that they can refer to with additional advice to help them in their care.

For additional information there are resources available upon request

Signs of Impending Death

When a person has a terminal illness, dying often occurs slowly (over several days or a week or so), but it also can happen quickly (in a few hours). You should be prepared for either situation.

Each day, the person grows weaker and usually sleeps more, especially if his or her pain has been eased. Many families do not know when dying is taking place, and they are not always sure when death itself has happened. Over the past 100 years, more people have died in hospitals. Death has become less of a natural event in family life, and fewer see the process from beginning to end. People with illnesses once died at home, and families were accustomed to watching for signs that the end of life was near. Today, many families are choosing to be like their grandparents and to help someone they love through the final weeks and days of life at home.

Near the very end of life, you can expect the person's breathing to become slower - sometimes with very long pauses in between breaths. Some pauses may last longer than a minute or two. This type of breathing frequently occurs if the person is in a coma; you will know a person is in a coma because he or she cannot be awakened. In rare cases, however, the person may open his or her eyes. This may surprise you. He or she usually does not talk but is awake for a short time. In other words, some people come out of, and go back into, comas. The skin will be cool, especially around the feet and hands, and it also will be a different color at these places - usually blue, gray, or some combination of both. If the person's skin is naturally dark, such as for an African, it will become dusky. Finally, the patient also may become incontinent (not able to control) of urine or stool. Usually, however, the person has had so little to drink that this does not amount to much.

At the end of dying is death itself. You will know this has happened because the chest will not rise and you will feel no breath from the nose. The eyes may be glassy (if they are open). You will not feel any pulse in the places where you felt it before. When you realize someone has just died, it is a very "still" and quiet moment.

Faith and Dying

By Helen Neely RN

Dying is something that most people fear. It can be a fear of the unknown, especially if they are not believers in Christ. It is very important that we discuss the need for eternal security with our patients and their family members. If your patient is not a believer, it can be difficult for them and the family members to "let go" of this earthly life. With hope of eternal life in Heaven after death, death can be easier to accept for a believer. There will still be much sorrow for the family left behind, but we know as followers of Jesus Christ, that we will be reunited again with our Christian brothers, sisters, mothers, and fathers. This is the greatest service we can offer our patients, the gift of hope through our Lord, Jesus Christ.

Psalm 30:5"...weeping may remain for a night, but rejoicing comes in the morning." That is a promise from the Lord. Yes, it is always painful to lose someone that you love. Nothing or no one can tell you otherwise. God promises us that He will be there with us through our pain and weeping. As Christians we need to share that news with our brothers and sisters that do not have that hope. The impending death of a person or family member is a time where people who need answers will look to you as a Christian to provide them.

We should speak with tenderness and sincerity. When we minister to the dying or grieving, we must ask God to guide our words. St Patrick, who was a strong man of God, was said to have this prayer inscribed on his breastplate;

"God be in my head, And in my understanding; God be in my eyes, And in my looking; God be in my mouth, And in my speaking; God be in my heart, And in my thinking; God be at mine end, And at my departing".

As a minister of the gospel, as all Christians are, it is our responsibility to determine the eternal security of our patients. We must take the opportunity to ask them if they have peace about dying. If the answer is yes, Halleluiah! If the answer is no, then ask them if they would like to know how to have eternal life. Explain the gift that God gave us through Jesus Christ, and lead them in a prayer to accept Jesus Christ as their Savior.

We should explain that all of us sin, and we all have the need of a savior. Jesus came in the flesh, died on the cross for our sins, and rose from the dead to overcome sin and death so we may have eternal life when we die. God gave the gift of eternal life to ALL people. We do not have to do anything to earn it: we just must accept the gift of salvation.

One useful tool in explaining our need for a savior is using these scriptures.

Romans 3:23 "for all have sinned and fall short of the glory of God,"

Romans 6:23 "For the wages of sin is death, but the gift of God is eternal life in Christ Jesus our Lord."

Ephesians 2:8-9 "For it is by grace you have been saved, through faith—and this not from yourselves, it is the gift of God--not by works, so that no one can boast."

John 1:12 "Yet to all who received him, to those who believed in his name, he gave the right to become children of God"

Revelation 3:20 "Here I am! I stand at the door and knock. If anyone hears my voice and opens the door, I will come in and eat with him, and he with me."

Another set of scriptures we will call the **H B T C** scriptures. They are as following;

HOPE: Jeremiah 29:11-13 "For I know the plans I have for you," declares the LORD, "plans to prosper you and not to harm you, plans to give you hope and a future. Then you will call upon me and come and pray to me, and I will listen to you. You will seek me and find me when you seek me with all your heart."

BELIEVE: **John 3:16** "For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life.

TURN: Acts 3:19 "Repent, then, and turn to God, so that your sins may be wiped out, that times of refreshing may come from the Lord."

CALL: **Romans 10:9-10,13** "That if you confess with your mouth, 'Jesus is Lord,' and believe in your heart that God raised him from the dead, you will be saved. For it is with your heart that you believe and are justified, and it is with your mouth that you confess and are saved. Everyone who calls on the name of the Lord will be saved."

Here is a sample prayer if the person decides to accept Jesus' gift of eternal life. "Dear God, I know that I am a sinner. Please forgive me of my sins. I believe Jesus came to Earth and died on the cross. I believe that He rose from the dead and is living now with you in Heaven. I ask you to come and live into my heart and life so that I may have eternal life in Heaven with you. In Jesus Christ's name I pray, Amen."

Reference for Lesson Two Curative Foods

	Common Uses	How Taken
Garlic	Improves immune function	Chopped raw or steamed cloves are used in cooking, vaginal garlic implants are used to treat infection, rectal garlic implants are used to treat diarrhea or fever
Yogurt	Restores normal flora	Eaten daily to prevent or treat diarrhea and candida
Lemon	Stimulates liver function, cleans the digestive tract, prevents infections	Lemon juice in hot water improves digestion, grated lemon or lemon juice on fatty foods promotes weight gain
Fermented Milk	Improves digestion, diarrhea, candida, weight gain	Taken as a daily beverage
Cabbage	Improves immune function, heals skin lesions, improves digestion	Leaves used for inflammation of the skin, sour cabbage is used for digestive problems
Carrots	Antioxidant, skin lesions, visual disturbances, diarrhea	Used in vegetable dishes, carrot soup used for diarrhea
Dark Leafy Greens	Strengthens the liver, antioxidant	Steam greens or eat them raw
Avocado	Promotes blood and tissue regeneration	Add to salads or vegetable dishes or eat whole
Yellow and Orange Fruits and Vegetables	Antioxidant, soothes the stomach, heals inflammation	Incorporate pumpkin, squash, yams, mangoes, paw-paw, apricots and melons into the diet
Onions	Antioxidant, restores normal flora, colds, cough, bronchitis	Use raw onion in salads, use in cooking, drink onion water daily
Pineapple	Aids in digestion, nausea, vomiting, diarrhea	Eat the raw form
Paw-Paw	Aids in digestion of proteins, ulcers	Eat the raw form
Coconut	Weight gain, aids in digestion, fever	Sprinkle on foods to promote weight gain, coconut milk used for digestive problems
Banana	Diarrhea, weight gain, oral ulcers	Eat in raw form
Nuts and seeds	Provide energy, weight gain	Eat seeds and nuts raw
Seaweed	Promotes healing, stimulates immune function, provides energy	Use in salads and with other foods
Fish	Reduces inflammation, promotes immune function	Fatty fish from cold, deep water such as sardines, mackerel, herring, salmon, tuna and hake are best
Sorghum	Aides in digestion, vomiting, diarrhea	Serve as a grain dish

Universal Precautions

Barrier protection should be used at all times to prevent skin and mucous membrane contamination with blood, body fluids containing visible blood, or other body fluids (cerebrospinal, synovial, pleural, peritoneal, pericardial, and amniotic fluids, semen and vaginal secretions).

Barrier protection should be used with <u>ALL</u> tissues.

The type of barrier protection used should be appropriate for the type of procedures being performed and the type of exposure anticipated. Examples of barrier protection include disposable aprons, gloves, and eye and face protection.

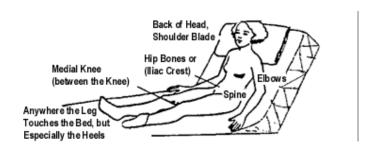
- 1. **Gloves** are to be worn when there is potential for hand or skin contact with blood, other potentially infectious material, or items and surfaces contaminated with these materials.
- 2. Wear **face protection** (face shield) during procedures that are likely to generate droplets of blood or body fluid to prevent exposure to mucous membranes of the mouth, nose and eyes.
- 3. Wear **protective body clothing** (disposable apron)) when there is a potential for splashing of blood or body fluids.
- 4. **Wash hands or other skin surfaces** thoroughly and immediately if contaminated with blood, body fluids containing visible blood, or other body fluids to which universal precautions apply.
 - 5. Wash hands immediately after gloves are removed.
- Avoid accidental injuries that can be caused by needles, razors or any other sharp instrument.
- 7. Used needles, disposable syringes, scalpel blades, pipettes, and other **sharp items are to be places in puncture resistant containers** marked with a biohazard symbol for disposal.

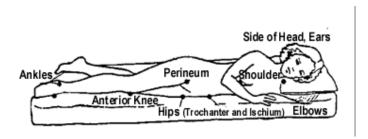
(Practical skill)

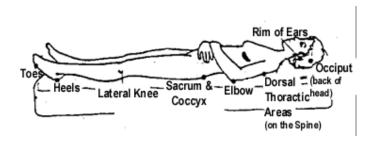
Technique of Bed Bathing

- 1. Gather supplies that will be needed. Basin with warm water, soap, towel, washcloth. Dry clothes for patient. Clean linens for bed changing. Lotion or Vaseline, if available.
- 2. Tell the patient exactly what you are preparing to do.
- 3. Patient may either stay in bed for bath, or sit in chair if possible.
- 4. Only expose the body part that will be washed to prevent patient being chilled.
- 5. Use gentle pressure when washing, no scrubbing as that could damage skin especially over bony prominences
- 6. Wash and dry patient starting from face, then to chest, then arms, legs, and then back, underarms, and then genital area, which should be last. Wash the person from cleanest part to least clean.
- 7. When washing the face, clean eyes from inner to outer edges of eyes, ask patient to close their eyes to avoid getting soap in them.
- 8. Change the water any time during bath if necessary.
- 9. Allow patient to help with bathing if they are able, especially with genitalia.
- 10. Massage lotion or Vaseline into patient's skin. This will provide comfort for them and also will promote good circulation in the skin. Use care if there are areas of breakdown seen.
- 11. Dry patient thoroughly. Do not rub skin, but pat dry to avoid breakdown.
- 12. Redress the patient in clean, dry clothes.
- 13. If wound care needs to be done, change dressings at this time. Document changes in wound and when dressing change was done.
- 14. Change the bed linen either with patient assisting while in bed, or if patient can sit in a chair.
- 15. Assist patient with oral care, clean water, tooth cleanser and basin to spit in.

Reference for Common Locations for the Development of Decubitus Ulcers or "Bedsores" or "Pressure-Sores" When Someone is Primarily Bed-Bound.







Preventive Measures:

- Change the person's position **every 2 hours** and more frequently if redness or irritation of the skin develops.
- Use soft pads and pillows to protect the skin.
- Keep the skin clean and dry.

Reference

Supply List for Caregivers

A carry bag to carry your supplies.

Soap - for general hygiene

Bleach (such as Jik) - for disinfecting and cleaning

Salt- for disinfecting and cleaning wounds

Gauze and cotton wool - to clean and cover sores and wounds

Toilet paper - to help with going to the bathroom and keeping the patient clean

Bandages - to keep sores and cuts clean

Adhesive tape - to secure gauze

Plastic sheeting - for bed baths to keep the patient's bed clean and dry

Gloves - to protect the patient and the caregiver and caretakers

Antiseptic (such as Dettol or Savlon) - for cleaning surfaces, basins,

and any items that have body fluids on them

Nail clippers - to trim the patient's finger and toenails

Scissors - to cut gauze

Waste disposal bags - to safely dispose of contaminated items

Apron (extra chitenge) - to keep the caregiver dry and clean during bed baths or when handling body fluids

Thermometer - to check the patient's temperature for fever

Vaseline - to give massages or keep wetness away from the skin to prevent rashes.

Talcum powder - used for massage (only when the patient doesn't have open sores)

Umbrella and Gum boots - to help the caregiver get from house to house when it is raining

Medications for the kit:

Calamine lotion - to ease itchy skin and sores

Antibiotic skin ointment (such as Bacitracin or Tetracycline ointment) -

to treat skin infections

Hydrocortisone ointment - for skin itching and eczema

Aspirin and/or Paracetemol - for general pain relief, teaching must be done on dosage and frequency.

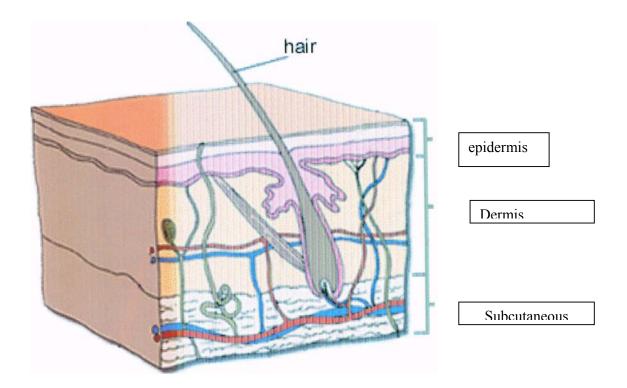
Eye drops - to sooth irritated, dry or infected eyes

Multivitamins - to help the patient stay healthy, teaching done on dosage must be done.

Iron tablets - for anemia, especially for pregnant women proper dosage must be taught.

*Refer patient to clinic if he or she need to receive antibiotics or anti-malarial medicines.

Reference for Lesson Four Skin diagram

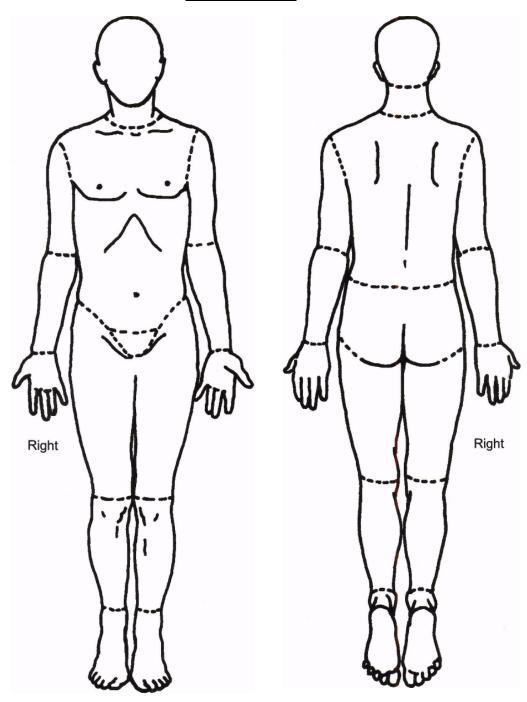


Reference for Lesson Five Edmonton Symptom Assessment Numerical Scale

Edmonton Symptom Assessment System: Numerical Scale Regional Palliative Care Program

										P	lease	circle the number that best describes:
No pain	1	2	3	4	5	6	7	8	9	10		Worst possible pain
Not tired	1	2	3	4	5	6	7	8	9	10		Worst possible tiredness
Not nauseat	ted 1	1 2	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depre	essed	1 1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	s 1	2	3	4	5	6	7	8	9	10		Worst possible anxiety
Not drowsy	,	1	2	3	4	5	6	7	8	9 1	10 V	Worst possible drowsiness
Best appetit	te 1	l	2	3	4	5	6	7	8	9	10	Worst possible appetite
Other proble	em	0	1	2		3	2	4	5	6	7	8 9 10
Patient's Na	ame											
ratient s ina	1111C _											
Completed	l by (checl	c on	e) Pa	atier	nt						Caregiver
Family men	nber_							_				
Date			Tiı	me								

BODY DIAGRAM



Please mark on these pictures where the pain is.

Reference for Lesson Five Modified Edmonton Symptom Assessment Scale

1a.	Please rate your <u>pain</u> now. 1. No pain 2. Mild pain 3. Moderate pain 4. Severe pain
1b.	Please rate your <u>pain</u> over the past 3 days. 1. No pain 2. Mild pain 3. Moderate pain 4. Severe pain
1c.	Is your pain control acceptable to you?
	 Very acceptable Acceptable Not acceptable
2.	How would you describe your <u>activity level</u> during the last 3 days? 1.
3.	How would you describe the amount of <u>nausea</u> during the last 3 days? 1. Not nauseated 2. Mildly nauseated 3. Moderately nauseated 4. Very nauseated
4.	How would you describe your level of <u>constipation</u> in the last 3 days? 1. No constipation 2. Mild constipation 3. Moderate constipation 4. Severe constipation
4a.	When was your <u>last bowel movement</u> ? 1.
5.	How would you describe your feelings of <u>depression</u> during the last 3 days? 1. Not depressed 2. Mildly depressed 3. Moderately depressed 4. Very depressed
6.	How would you describe your feelings of <u>anxiety</u> during the last 3 days? 1. Not anxious 2. Mildly anxious 3. Moderately anxious 4. Very anxious
7.	How would you describe your level of <u>fatigue</u> during the last 3 days? 1.

	3.
8.	How has your <u>appetite</u> been during the last 3 days? 1.
9.	How would you describe your sensation of well being during the last 3 days? 1.
10.	How short of breath have you been during the last 3 days? 1. No shortness of breath 2. Mild shortness of breath 3. Moderate shortness of breath 4. Very short of breath
11.	How has your physical discomfort been during the last 3 days? 1. No physical discomfort 2. Mild physical discomfort 3. Moderate physical discomfort 4. Severe physical discomfort

Reference for Lesson Six Palliative Care Worksheet

Name						
Location						
Date of Assessment _	//					
Demographic Informa	tion					
Age	tion	Sex	(m)	(f)		
1-50		SCA	(III)	(1)		
Religion	Protestant	C	Catholic			
_	Jewish	C				
Education	(0-9)	(9	9-12)	>12		
Marital status_	Single	V	Vidow(er)	Married		
Major diagnoses						
				YES NO		
Was a Palliative Care pl	an in place at time o	of death?				
vvus a rumanve care pr	an in place at time o	r death.				
Information about the Date of Death	Person's Death					
Was death expe	cted? YesN	No				
Location of Dea	nth					
Was Hospice In No	volved?		Yes			
Medical Treatments (d		f life)	Cł	neck if applicable		
Was customer to	reated with:		Vaa	No		
Pain medication	Pain medication			YesNo		
Hospital Admission or 1. Date Reason	ER visit (specify wh					
2. Dat	e/					
Reason	e/					
3. Dat	e/					
Reason						
Terminal Events						
During Last Ty	wo Months of Life					
Skin breakdown	Stage 1 2	3 4 (ci	rcle stage)			

Did the individual have any of the following s	ymptoms?		
Please check:			
Drinking/swallowing problem			
Falls			
Infection			
<u>Terminal Events</u> Pain	Last week	Last 24 hours	
Alert			
Agitated			
Weakness/lethargy			
Anorexia			
Nausea			
Short of breath			
Was individual comfortable?			
Were they afraid?			
Moment of Death	Ye	es No	
Was the person alone?			
Was the family satisfied with care?			
Name of Caregiver(s)			
Date			

rev. 2.0

Reference for HIV/AIDS

AIDS (Acquired Immunodeficiency Syndrome) is a disease caused by a virus called HIV (Human Immunodeficiency Syndrome). AIDS is the disease, and HIV is the virus that causes the disease. People may be infected with HIV for many years without signs of illness, but once they become ill from the virus, we say they have AIDS. HIV causes illness by attacking the part of the body that usually defends it from infection: the immune system. When bacteria come into the body, a healthy immune system can usually fight them off, and the person gets well.

If a person has AIDS, his or her immune system is weakened. People with AIDS can become very ill or die of illnesses that healthy people fight off, like diarrhea. HIV usually lives in the body for years without causing any visible or obvious illness. But HIV can be transmitted to others from the moment a person becomes infected, before AIDS and obvious illness develop.

Sooner or later, as their immune systems weaken, people infected with HIV start to feel more tired than usual and to lose weight. They may suffer from common illnesses like diarrhea or coughs that do not go away with treatment. At this point, they may have developed the disease AIDS. For some people it takes 10 years or more to go from HIV infection to AIDS. For others, it takes as little as six months.

In Africa, death usually occurs within six months of diagnosis with AIDS, but this can vary widely. Much can be done to delay or treat the infections cause by AIDS, but at the present time, there is no cure for AIDS itself.

Adapted from: Pathfinder International, 2000. A comprehensive training course: Prevention and management of reproductive tract infections (RTIs). Vol. 12. Watertown, MA: Pathfinder International.

Women get HIV more easily than men do.

Women are the receptive partners during sex. More HIV is present in semen than in a woman's vaginal fluids, and when a man ejaculates inside a woman, the semen remains in contact with the vaginal wall for a long period of time. The vagina provides a large surface area of mucous membrane that absorbs the virus more easily than does a man's penis. Thus, men infected with HIV transmit it to women two to fives times more easily than women infected with HIV transmit it to men.

Women are blamed unfairly for the spread of AIDS.

Because of different standards of behavior for men and women, commercial sex workers are often blamed for spreading HIV, while their customers escape any responsibility. As a result, sex workers often are stigmatized.

Commercial sex workers in developing countries rarely have access to health services and are commonly treated poorly by health care providers. Many married women whose only sex partners are their husbands get infected with HIV. Women with HIV may suffer violence, divorce, and disinheritance as a result of their HIV status.

Many pregnant women are infected with HIV, and they can pass it on to their babies.

An HIV-positive mother can transmit HIV to her baby during pregnancy, labor and delivery, and through breastfeeding.

Being pregnant and having HIV at the same time can be a double burden. A woman may worry that her baby might be born with HIV infection. Pregnancy and childbirth can make the HIV-positive woman's health worse. If her baby is born infected, the infant will require extra care. The mother may have no alternative to breastfeeding and know that this too could transmit HIV infection. A decision no to breastfeed may result in increased cost and stigma, as well as the risk of diarrheal disease and death for the baby.

An HIV-positive woman should have ready access to family planning counseling before she becomes pregnant so that she can make choices based on the real risks of pregnancy for her and her baby.

Women are usually the ones who care for family members who are sick with AIDS, even if they are sick themselves.

Caring for a loved one who is ill and dying causes stress, extra work, and usually loss of income for the family. Often here is no one to help bear this burden. Children, most often girls, are sometimes taken out of school to care for sick adults. For the rest of their lives these children are affected by having had their education cut short.

Women are affected at a younger age than men.

Young women and girls are less able to refuse unwanted unprotected sex. Immature genital tracts are more prone to tearing, bleeding, and infection.

Adapted from: Pathfinder International, 2000. A comprehensive training course: Prevention and management of reproductive tract infections (RTIs). Vol. 12. Watertown, MA: Pathfinder International.

Men and HIV infection

Shame and stigma directed towards infected men are widespread.

Men who are still healthy but infected may lose their jobs, their friends, and their social status.

Most existing reproductive health services don't have a strong component for men.

Although there are some STD services for men, access to care is often difficult, and men's knowledge of their own reproductive systems is often limited. They may not seek medical care for STDs, but might buy antibiotics on the street for urethritis (swelling in the penis), for instance, and not receive counseling on prevention or the necessity of treating their sexual partners.

Social conditions affect men's vulnerability to infection.

Poor economic conditions, war, and environmental problems all play a part in separating men from their families. Wherever there are large populations of single men-on plantations, in mines, or in the military-men are more prone to casual and risky sexual relationships.

Social norms affect men's behavior.

Men often feel they are expected to have sex on a regular basis or that multiple partners or trips to a brothel are signs of manhood. Young men are particularly vulnerable to the opinions of their peers, and may be less knowledgeable about how to protect themselves from infection.

The high rate of infected men affects families and communities where HIV prevalence is high.

The illness and death of men who would otherwise be working and helping to care for their families has had a devastating economic impact in many developing countries, resulting in families with no means of support.

Adapted from: Pathfinder International, 2000. A comprehensive training course: Prevention and management of reproductive tract infections (RTIs). Vol. 12. Watertown, MA: Pathfinder International.

Many Myths exist about how HIV is transmitted. Part of the stigma associated with AIDS stems from people's fears that everyday social contact with an infected person will result in becoming infected. Health workers are understandably concerned that their work will put them at risk of HIV infection. Although there are risks for providers and other staff in a health care setting, the risk of infection is often greater for patients than for providers when infection prevention guidelines are not followed carefully. Following infection prevention guidelines will prevent most health-care-related HIV transmission.

How HIV/AIDS Is Not Spread

HIV can live outside of the human body for no more than a few minutes. It cannot live on its own in the air or in water.

One cannot give or get HIV in these ways:

- Touching, kissing, or hugging someone with HIV or AIDS (unless there is blood in the saliva of the infected person)
- Sharing food with someone with HIV or AIDS

- Sharing a bed with someone with HIV or AIDS
- From the bites of mosquitoes, bedbugs, or other insects or animals
- Caring for someone with AIDS, as long as simple precautions are taken
- Sharing clothes, towels, sheets, latrines, or toilets

How HIV Is Spread

Most HIV (85-90%) is transmitted by having unprotected sex with someone who has the virus. The virus is spread when blood, fluids from the vagina, or semen from an infected person gets into the body of another person.

Intravenous (IV) drug users who share needles and the sex partners of IV drug users are especially vulnerable to HIV infection. Their risk of infection can be reduced by providing them with access to clean needles and syringes through exchange programs or by teaching them to clean needles and syringes with bleach and providing them with prevention information.

Another vulnerable group is men who have sex with men, especially those who have many sex partners and do not practice safer sex. This group must use condoms to protect their partners and themselves.

HIV Is Spread in These Ways:

- Unprotected sexual intercourse (85-90%)
- Using an unclean needles or syringe, or any other tool that pierces the skin that was recently used by an
 infected person
- Through the blood of an infected mother to her unborn child
- Through the breast milk of an infected mother to her baby
- From transfusions of HIV-infected blood where the blood supply is not tested
- Getting blood from an infected person into your body through an open wound or mucous membrane (for example, splashed into the eyes.)

Note: It is safe to live with someone who has AIDS and to share his or her life if the person infected with HIV is careful with open sores, bloodstained clothing or sheets, toothbrushes, and razors.

Reference for HIV care in Children

The number of children under 15 who have lived or are living with HIV since the start of the epidemic in the late 1970's has reached about 4.8 million - 3.6 million of them have already died. Nearly 600,000 children were infected with HIV in 1999, mostly through their mothers before or during birth or through breast feeding (vertical transmission).

HIV infection can be transmitted to:

- the unborn child (in utero infection)
- neonates during labor and delivery (intra partum infection)
- neonates, when exposed to infected maternal birth fluids
- infants, after birth, through breast milk (post partum infection) (30 percent risk of transmission)

Other sources of HIV transmission to infants and children include:

- transfusion with HIV-contaminated blood or blood products
- use of non-sterile (unclean) equipment in health care facilities
- -use of non-sterile equipment by traditional healers (surgeries,
- -male and female circumcisions, scarification)
- -sexual abuse

rev. 2.0

- -injecting drugs
- -sexual initiation practices involving sex workers
- -child prostitution

The lives of children who do not have HIV themselves are affected when family members have AIDS. Families face increased poverty and stress because adults have to leave their paid employment, or are too sick to farm their land. Women may be ill themselves, as well as caring for other sick family members and looking after young children.

Girls in particular often become the care providers for sick relatives and their brothers and sisters. Sometimes children have to leave school to look for work or care for other family members. In addition, denial or neglect of girls' human rights results in gender discrimination, giving young women little access to socioeconomic opportunities.

These girls (and boys to a lesser extent) often become vulnerable to commercial sex and to the drug trades

• Common symptoms of HIV infection in children HIV-infected children have an increased frequency of common childhood infections such as ear infections and pneumonia. In developing countries, diseases such as chronic gastroenteritis and tuberculosis are also frequent. In HIV-infected infants, the symptoms common to many treatable conditions, such as recurrent fever, diarrhea and generalized dermatitis, tend to be more persistent and severe. Moreover, HIV-infected infants do not respond as well to treatment and are likely to suffer life-threatening complications. Enlarged lymph nodes and an enlarged liver are common in children infected with HIV. Opportunistic infections occur as the immune system becomes more affected, and most of these children have some type of

42

neurological involvement, such as developmental delay or infection in the brain.

When administering medicines, it is important to consider the amount to be prescribed (depending on the infant/child's size and body weight), and its suitability for use in children.

• The course of HIV in infants/children

The majority of infected infants develop disease during the first year of life and have a high mortality rate. With recent research and new antiretroviral therapies (ARVs), there has been significant improvement to child mortality in countries where this treatment is available and accessible.

The diagnosis of pediatric AIDS is difficult. In addition, in developing countries, diagnostic procedures might not be available or routinely used. Different countries might show slightly different patterns of the opportunistic infections that are common in HIV-infected children.

The signs and symptoms most commonly found in HIV-infected children include:

- Weight loss
- Chronic diarrhea
- Failure to thrive (small for age, weak)
- Oral thrush (This often recurs after treatment and can be the first indication of HIV infection.)
- Fever
 - Making a diagnosis of AIDS in children when HIV testing is not available In infected women, the maternal HIV antibody is passively transmitted across the placenta to the fetus during pregnancy. This antibody can persist in the infant for as long as 18 months. Consequently, during this period, the detection of HIV antibody in infants does not necessarily mean that an infant is infected. Therefore, a case definition for AIDS is made in the presence of at least 2 major, and 2 minor signs.

Major signs:

- -weight loss of 10 % or more of body weight or abnormally slow growth
- -chronic diarrhea for more than 1 month
- -prolonged fever for more than 1 month
- -generalized lymph node enlargement (seen as lumps at front of neck on either side, either side of groin or under either armpit)
- -Tuberculosis

Minor Signs:

- -fungal infections of mouth and/or throat
- -recurrent common infections (eg. ear, throat)
- -persistent cough (will not go away)
- -generalized rash (over a big area of the body)

Please note: Confirmed HIV infection in the mother counts as a minor criterion.

• Care for infants and children with HIV-related illness Most HIV-related illness is caused by common infections which can be prevented or treated at home or in a health centre. However, the illnesses often last longer in HIV infected children, and are slower to respond to standard treatments. The standard treatments are nevertheless the most appropriate treatments. The following general recommendations should be used in the management of HIV infected infants/children and in teaching/counseling mothers and other care-givers.

Maintain good nutritional status in weight loss and failure to thrive In most countries of the developing world, HIV-infected mothers are still breast-feeding their infants. However, with the knowledge that HIV can be passed through breast milk (approximately 30% risk), this practice might be changing. In some countries, substitutes for breast milk may be recommended for infants of HIV-infected mothers. However there needs to be a safe and adequate supply of affordable breast milk substitutes, access to a clean water supply and adequate means to boil water and to sterilize equipment. In some communities, where supplies and equipment are limited or unavailable, the risk of babies dying if not breastfed will be greater than the risk of passing on HIV. In countries where ARV is available, breast milk substitutes will probably be recommended. Nurses and midwives are encouraged to refer to local policies and practices on nutritional counseling and breast feeding. Regular growth monitoring (preferably every month) is an appropriate way to monitor nutritional status. If growth falters, additional investigations should be done to determine the cause. Provide early and vigorous therapy for common pediatric infections as early as possible

All infants with HIV antibodies should be treated vigorously for common pediatric infections such as measles and middle ear infections.

Because the immune systems of children with HIV infection are often impaired, these diseases may be more persistent and severe, and the children may respond poorly to therapy and develop severe complications. Consequently, the mothers of all HIV-positive infants should be encouraged to take their infants for examination and treatment as soon as possible whenever symptoms of common pediatric infections develop.

Pediatric infection Treatment

Oral thrush (Often recurs after treatment and can be the first indication of HIV infection)-Treat with gentian violet application, polyvidone iodine and chlorhexidine mouthwash, and antifungal tablets and lozenges (depending on child's age)

Other skin diseases- Calamine, topical steroids, antibiotics orally or topically

Unexplained fever- Paracetamol; aspirin (in children older than 6 years of age)

Sexually transmitted diseases in the newborn- Antibiotics such as benzylpenicillin, kanamycin, erythromycin and others have been found to be effective for newborn treatment of syphilis, gonorrhea, and chlamydia

Otitis media(ear infections)- Broad Spectrum antibiotics

Emphasize early diagnosis and treatment of suspected TB for all family TB is one of the most common and deadly opportunistic infections and the HIV positive child is very susceptible to contracting this disease. Every effort should be made to ensure that TB prevention and treatment is available to family members.

Immunize according to standard schedules

All infants and children should be immunized according to standard schedules. The only exception is that infants with clinical symptoms of HIV infection should not be given tuberculosis vaccine (BCG). It is important that correct sterilization procedures for immunization equipment be strictly followed

Ensure the child has good quality of life

Most infants of HIV infected mothers are not infected with HIV. In addition, many of those who are infected will have months of asymptomatic life. Some will live for years without developing symptoms. Every effort should be made by members of the child's family and by the health care professional to help the HIV-infected child to lead as normal a life as possible.

Basic nursing care for the HIV-infected child with an opportunistic infection

Infection control

Maintain good hygiene. Always wash hands before and after care. Make sure linen nappies and other supplies are well washed with soap and water. Burn rubbish or dispose of in containers. Avoid contact with blood and other body fluids and wash hands immediately after handling soiled articles.

Skin problems

Wash open sores with soap and water, and keep the area dry. Salty water can be used for cleansing. Use medical treatment, such as prescribed ointment or salve, where available. Local remedies, oils, and calamine lotion might also be helpful.

Sore mouth and throat

Rinse the child's mouth with warm water at least three times daily. Give soft foods that are not too spicy.

Fevers and pain

Rinse body in cool water with a clean cloth or wipe skin with wet cloths. Encourage the child to drink more fluids (water, tea, broth, or juice) than usual. Remove thick clothing or too many blankets. Use fever reducers and analgesics such as aspirin, Paracetamol, acetaminophen, etc.

Cough

Lift the child's head and upper body on pillows to facilitate breathing, or assist the child to sit up. Place the child where she/he can get fresh air. Vaporizers, humidifiers can provide symptomatic relief.

Diarrhea

Treat diarrhea immediately to avoid dehydration, using either oral rehydration salts (ORS), or intravenous therapy in severe cases of dehydration. Ensure that the child drinks more than usual, and continues to take easily digestible nourishment. Cleanse the anus and buttocks after each bowel movement with warm soap and water and keep the skin dry and clean. Antibiotics used for other infections can worsen the diarrhea. Remember to wear gloves or other protective covering when handling fecally contaminated material.

Local Remedies

There are often local remedies that alleviate fevers, pains, coughs, and cleanse sores and abscesses. These local remedies can be very helpful in relieving many of the symptoms associated with opportunistic infections. In many countries women's associations or home care programs compile information on local remedies which alleviate symptoms and discomfort.

rev. 2.0 45

Assessing the family's ability to care for a child with HIV and HIV-related illness

The ability of a family to care for a child with HIV-infection or related illness is affected by their socio-economic status and their knowledge and attitudes about HIV infection. The following questions will help the health care worker to determine what care can be expected from family members and what care must be obtained from other sources.

What does the family know about HIV infection? Do they know how HIV is transmitted and how to prevent transmission? Can the family acknowledge that the child is HIV-infected, in order to access appropriate services? What is the parents' state of health, including their emotional condition? Are they physically able to care for the child? Which individuals can offer support to this family? What is their state of health? Are they able and willing to help care for the child? What is the social service system like to support this family? What is the family's economic situation?

What is the condition of their living space? What does the child eat? Is there a food shortage? Is clean drinking water freely available?

Children orphaned by AIDS

Approximately 8.2 million children around the world have been orphaned by the HIV/AIDS epidemic. AIDS orphans, defined as children who have lost their mother or both parents to AIDS before reaching the age of 15, are predicted to number 41 million worldwide by 2010. Nine out of ten (90%) maternal orphans are presently living in sub Saharan Africa. The extended family system, which would traditionally provide support for orphans, is greatly strained in communities most affected by AIDS. This is especially true in populations which migrate. Nurses and midwives can play an important role in orphan care. This care could include direct physical care, being an advocate on behalf of the child, and helping to influence policy changes to respect the rights and dignity of children.

When children are cared for by other family members, this places an added financial burden on these care givers. After their parent's death, children can lose their rights to the family land or house. Without education, work skills or family support, children may end up living on the streets. These children are especially vulnerable, often becoming sexually active at an early age and at risk from HIV themselves. Poverty is an overwhelming problem. These orphans not only lack money, but basics such as clean water, drugs, food, shelter and medical supplies. They do not have information about how to protect themselves, and have poor access to doctors, nurses, and other health care workers and facilities. Finally, these orphans often lack human rights and dignity. The magnitude of this problem will have to be addressed at international, national, local, and community levels. Government, non-governmental organizations (NGO) and other institutions and organizations will have to

combine their efforts to provide effective programs and strategies to care for orphaned children. Nurses and midwives can play an important role in orphan care. This care could include direct physical care, being an

rev. 2.0

advocate on behalf of the child, and helping to influence policy changes to respect the rights and dignity of children.

• Strategies for the care of orphaned children

Strategies for the care of orphaned children include the following, in order of preference:

The extended family: Every reasonable attempt must be made to trace relatives.

Substitute or foster care families: Placement with non-relative family units after careful caregiver selection, or foster care on an informal basis, recognizing traditional norms and values.

Family type group: Paid foster mothers living together with small groups of orphans or similar arrangements.

Child-headed households: Adolescents caring for younger siblings with the support of the community.

Orphanages: As a last resort when all other options are inappropriate or unavailable. However, there is a limited role for orphanages, for example, in caring for abandoned babies or for very young children needing care until alternative solutions can be found for them.

rev. 2.0 47

Reference for Wound Care Guide

Wounds

A wound is a break in the tissues of the body. Some injuries, like cuts and scrapes, are called open wounds; others, like deep bruises, are called closed wounds. They are usually caused by external forces such as motor vehicle accidents, falls, and the mishandling of sharp objects, tools, machinery and weapons.

This Wound Care Guide is to help you learn self-care and first aid for your minor wounds. By learning the basics of minor wound care, you can help to prevent infections and reduce the complications of injuries.

Types of Wounds:

<u>Abrasions</u> — These wounds are generally caused by scraping of the skin's outer layers. Bleeding is usually minimal. Often, there is foreign matter (such as dirt or gravel) imbedded in the skin. If not properly removed, immediately after the injury, dirt or matter left in the skin may cause a permanent tattooing effect. These wounds often become infected.

<u>Incisions</u> — These types of cuts are commonly caused by knives, metal edges, broken glass or other sharp objects. The amount of bleeding depends on the depth and extent of the cut.

<u>Lacerations</u> — These are jagged, irregular cuts or tears of the skin. Most lacerations are serious in nature and bleeding may be heavy. The chance of infection may be increased due to the extent and cause of the laceration.

<u>Punctures</u> — These types of wounds are caused by an object piercing the skin layers, creating a small hole. Some punctures are superficial and some are very deep, depending on the source and cause of it. Common causes are wood splinters, pins, nails and glass. Infections are common, due to the difficulty of cleaning into the puncture site.

The most important aspect of new wound care is to clean the wound thoroughly and examine it closely, as soon as possible. You must decide if the wound is severe in nature or if it is a minor wound. Then you must decide if you need to seek professional medical care, or if you can provide minor care.

Seek medical attention for <u>any</u> of the following:

- a wound that has blood spurting from it or wounds that continue to bleed after applying direct pressure for 5 full minutes.
- a puncture wound occurring from a nail, pen or other sharp object, whether the object is still impaled or is removed.
- a gaping wound, or any wound you think might need stitches.
- a wound that has a fatty layer, white tissue or muscle that is exposed.
- a wound that has visible foreign material or the material visible is gravel, dirt, glass or metal
- any type of burn.
- any type of bite animal or human.
- any wound causing severe pain.

- any wound which causes numbness or loss of movement below the wound.
- new wounds, if you are a patient with a chronic medical condition such as diabetes or a bleeding disorder.
- if you are not sure about the status of your tetanus immunization

. . . . if it has been 10 years since your last tetanus shot.

..... if your last tetanus shot was more than 5 years ago, and the wound has been contaminated with dirt or debris.

The two most important steps in the prevention of tetanus are immunization and the thorough cleansing of wounds, with removal of all foreign material.

TREATMENT FOR YOUR MINOR WOUNDS

The basics of wound care for small scratches, cuts and abrasions can be divided into 3 steps: cleansing the wound, cleansing the skin around the wound, and protecting the wound from further contamination.

<u>Wash your hands</u> — If your hands are not clean, you may spread bacteria (germs) into a new wound. When washing your hands, use soap and water, work up a good lather and rinse thoroughly.

<u>Cleansing the wound</u> — Gentle scrubbing with a mild soap and water, followed by flushing with lots of clean water, is the most effective method of cleansing the wound itself. The cleansing of the wound should be done carefully, to avoid further injury, but must be effective enough to

remove foreign materials, such as dirt and gravel. Dead tissue and foreign matter in the wound provide an excellent medium for bacterial growth, so this is the most important step.

Some wounds are best left to the professional to clean; for example, deep puncture wounds, severe lacerations, burns, and wounds with extensive skin loss or damage. Such wounds should be protected with a sterile covering, if possible, and immediate treatment from a physician should be obtained.

<u>Cleansing the skin around the wound</u> — It is important to clean the skin around the wound to remove other dirt and oils that may enter the wound. Clean this area with soap and water also, and rinse well. Cleaning the wound with salt water also aids in the healing process.

<u>Protecting the wound</u> — A covering of sterile, "breathable" bandage material is ideal for new wounds. This will help to keep further bacteria out of the wound and prevent infection. The bandage should not be airtight, since this traps the normal moisture given off by the skin and encourages bacteria to grow and may delay healing.

If the wound is more of a scrape than a cut, one of the non-stick dressings may be helpful. For most wounds, a scab will form in a few days..

<u>Changing bandages</u> — It is important that wounds be kept clean and dry. Change bandages frequently, cleansing the wound in between, and allowing the wound exposure to air. This helps the healing. A suggested schedule would be to cover the wound during heavy activity and at times when dirt may enter the wound. Air the wound during quiet, less active times, like the evening or at night while you sleep. If the bandage becomes wet, apply a clean, dry bandage.

Use care in applying new bandages. Clean your hands first, and open the bandage carefully so that the pad that covers the wound is not touched or contaminated in any way.

If a bandage becomes stuck to the wound, use care when removing. Do not rip the bandage off, as this can reopen the wound. You can soak the bandage in clean, warm water or

hydrogen peroxide to soften the point of attachment. Then, clean and dry the wound and apply a new bandage.

<u>About ointments</u> — Ointments are often promoted as aids in healing wounds, but this should <u>not</u> be taken to mean they speed healing. Antibiotic type ointments can be overused and can cause skin reactions and allergic responses, as well as set up a resistance-bacterial growth cycle. If you do prefer the use of an ointment on your minor wounds, follow these suggestions

- Choose the ointment carefully. Consult with your health care provider if you are unsure about which type to use. They are best suited for use with small, minor wounds. If you have a wound with a large area of skin damage, you are urged to talk with your health care provider before applying any ointment.
- Always apply ointments to a well-cleaned wound to avoid "sealing in" bacteria.
- Apply a very thin layer of ointment. This will coat and protect the wound. Large
 amounts of ointment are not beneficial because the moisture can attract bacteria.
- Apply the ointment with a clean swab or gauze. Do not apply ointments directly from the tube, to avoid contamination of the tube and any future wounds. Use a cotton swab (cotton bud) for application of ointment.
- You may use ointments up to three times daily; however, you should always clean the
 wound before new applications of ointment.
 Remember, poor healing can result when ointments and bandages are overused.
 Exposing minor wounds to air each day will promote healing.

MISCELLANEOUS WOUNDS AND ADVICE

Bee stings and insect bites - Stings from insects can be serious. A non-allergic person may experience various reactions, ranging from mild irritation and itching to swelling of an entire extremity. Persons who are highly sensitive to the venom released by insects may be subject to a serious systemic (anaphylactic) reaction that is very dangerous. It is best, in cases of moderate to severe reactions, to seek immediate medical care. It is helpful to apply ice to bee stings to reduce inflammation and pain. Be sure to place a cloth under the ice pack to prevent freezing the skin.

<u>Animal or human bites</u> - Bites can be very traumatic and dangerous. These wounds can be difficult to clean and the chance of infection is very high. It is important to have a history taken by a medically trained professional about the conditions surrounding any type of bite, so that proper care can be provided. Please note that any break in the skin caused by teeth (i.e., a cut on a hand, sustained in a fight), should be treated as though it was a bite. Rabies and Tetanus need to be considerations in this situation.

<u>Wounds with foreign or impaled objects</u> - The importance of having a medically trained specialist provide care to this type of wound cannot be over-emphasized. Often, x-rays are needed to ensure that all foreign bodies are removed. Any impaled objects (such as a fishhook or nail through a finger) should not be removed, except by a professional, to avoid further damage.

Wounds requiring stitches - Any wound that gapes open should be evaluated by a doctor. It is very important to have such wounds evaluated as soon as possible or within 6 hours of injury. A delay in seeking care may mean that the wound can not be sutured due to infection — and this can cause difficulty with healing, scarring and serious complications. If your wound requires stitches, your doctor will provide instructions about the care and follow-up needed. If the wound is small and the edges are "neat", clean the wound thoroughly, and apply two coats of super-glue as the edges of the wound are pressed together in closure. Beware not to glue

rev. 2.0

the fingers of the helper to the injured person's wound! (Nail polish remover is a good emergency stand-by)

Wounds of the eyes, ears, nose, face or head - Any type of laceration, injury or foreign object affecting these body parts should be professionally evaluated. Infection or trauma can cause serious and permanent damage to the cartilage of the nose and ears. Eyes need particular care to ensure that permanent damage is avoided and facial scarring may be avoided with special care. Head injuries should always be considered serious.

Injuries of the hand - Hand wounds deserve special mention because of the important functions the hands perform. Relatively close to the surface of the skin are the tendons and nerves that make the hands work and feel. The large majority of hand wounds are superficial and cause few problems. However, infection or damage caused by cuts and punctures of the hand can cause serious complications to the tendons and nerves. Permanent functional impairment can occur from hand injuries left unattended. If you question whether your hand injury is serious, or if there is any loss of motion or sensation to your hand or fingers, it is very important to have a professional evaluation.

Complications:

Serious complications may occur to neglected wounds and, at times, to even the best cared-for wounds. If you notice any of these signs when examining your wounds or injuries, you should see a doctor immediately:

- Redness, excessive swelling, tenderness, or increased warmth of the skin around the wound.
- Throbbing pain or tenderness in the wound area.
- Red streaks in the skin around the wound or progressing away from the wound.
- Pus or watery discharge collected beneath the skin or draining from the wound.
- Tender lumps or swelling in your armpit, groin, or neck.
- Foul odor from the wound.
- Generalized chills or fever.

Prevention of Wounds:

An ounce of prevention is worth a pound of cure. At home, at work, at play or on your way to wherever, keep in mind the actions you can take to prevent wounds from occurring:

- Wear seat belts (and helmets if appropriate) when traveling. Wear goggles or glasses when riding a scooter if you choose not to wear a helmet. Drive defensively, do not drink and drive, and do not drive if you are tired.
- Use sharp objects only for their intended purpose, handle with care and keep out of reach of children.
- Do not run with objects in hand such as glass bottles, wooden sticks or other penetrating devices.
- Use appliances and tools following the manufacturer's instructions.
- Unplug unused electrical items.
- Always sweep up broken glass promptly and carefully.
- Remove nails from boards and dispose of them properly.

Bibliography

www. AIDSmeds.com,.

www.medicaledu.com

www.disabledliving.org.uk

www.paraquad.nsw.asn.au

www.pathfind.org

www.yalenewhavenhealth.org

AHCPR Publication No. 92-0050, <u>Pressure Ulcers in Adults: Prediction and Prevention</u>. For copies of this booklet, call 202-512-1800 or 800-358-9295.

Where There Is No Doctor a village health care handbook for Africa, Werner, David Macmillan Publishers 1979, reprint 1988

<u>The Merck Manual of Medical Information Second home edition,</u> Merck &Co. Inc. copyright 2003

Genesis Eldercare 06/00

Edmonton Assessment Scale, Capital Health Care

Network of African People Living with HIV/AIDS; Food for People Living with HIV/AIDS Earthware. Cape Town, South Africa, 1995

Backer, B., Hannon, R., & Russell, N. (1994). <u>Death and Dying: Understanding and Care</u>, 2nd ed. Albany, NY: Delmar Pub.

<u>HIV Curriculum for The Health Professional</u>, Baylor College of Medicine, copyright 2003

Current Thinking in Wound Management, Nursing Times, pp 78-80, 1993

Emergency Nursing - Principles and Practices, pp 255-261, 1992

Dressings and Wound Infections, AMJ, Surgery, pp 215-305, 1994