Palliative Care for Women With Cervical Cancer: A FIELD MANUAL





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ACKNOWLEDGMENTS

The authors extend sincere thanks to the following individuals who reviewed the document at various stages:

Berna Basimira, Hospice Uganda Michele Burns, PATH, USA Rachel Dipio, Hospice Uganda Dr. Martha Jacob, EngenderHealth, USA Dr. Suphannee Koonsaeng, National Cancer Institute, Thailand Dr. Anne Merriman, Hospice Uganda Dr. Rengaswamy Sankaranarayanan, International Agency for Research on Cancer, France

The authors thank Connie Sellors, B.Sc.Phm., for her review of information on medicines and dosages. In addition, the authors thank the following individuals in Bolivia for participating in focus group discussions of the material:

Dr. Jesus Andia, Hospital Nicolas Ortiz Antelo Dr. Nelson Bejar, Instituto Oncológico del Oriente Boliviano Lic. Victoria Acho Castro, Hospital Nicolas Ortiz Antelo Dr. Hugo Cuellar, PROSALUD Lic. Olga Galván Gamón, Hospital Alfonso Gumucio Reyes Lic. Mery Yupanqui Huayta, Hospital María Daza C. Minero Lic. Juan Cayoja Llampa, CARE Lic. Roxana Lobo P., Hospital Nuestra Señora del Rosario Dr. Jesús Méndez, Hospital Nuestra Señora del Rosario Dr. Gaby Orellana, Hospital Alfonso Gumucio Reyes Lic. Marina Isabel Orozco, PROSALUD Lic. Melffy Rosa Vargas Rosado, Hospital Alfonso Gumucio Reyes Dr. Elsa M. Subero, Microhospital La Guardia Lic. Irma Villegas Torrico, PROSALUD Dr. Tereza Pablita Escalante Vargas, PROSALUD

Any inaccuracies are the sole responsibility of the authors.

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Support for the development of this document was provided by the Bill & Melinda Gates Foundation through the Alliance for Cervical Cancer Prevention (ACCP).

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USING THIS FIELD MANUAL

The use of trade names throughout this manual does not imply endorsement of any particular brand name product.

The authors of this Field Manual have made every attempt to ensure that information contained here is accurate and complete. However, in light of

the possibility of human error or changes in medical sciences, readers are encouraged to confirm information (particularly that related to medicines and dosages) with other reliable sources.

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A Kenyan edition of this handbook, called *Palliative Care for Women With Cervical Cancer: A Kenya Field Manual*, is available from PATH at the address above.

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Preface

In most developing countries, more women are dying of cervical cancer than any other cancer. This places a large burden on the women, their families, their communities, and their health care providers—especially in poor, rural regions. Cervical cancer poses unique psychosocial and medical challenges that can be met most effectively by health care workers who have practical knowledge and skills. This manual was developed to address a need identified by health care providers, such as community nurses and medical doctors who care for women who are dying of advanced cervical cancer or who do not have access to treatment options. The manual focuses on recommendations for providing supportive care for women with cervical cancer, but these techniques can be applied when caring for any person with chronic pain nearing the end of life, no matter what illness or disease he or she has.

This document is not an exhaustive text on the subject, but rather a field manual to which nurses and medical doctors can refer while providing home-based care to very ill women. The manual is not a replacement for training of nurses or medical doctors in palliative care; ideally, they should have specialized practical training by attending a one-week course given by a hospice and supplemented by a practicum for up to one month with a hospice team. The manual is not meant to imply that nurses should work unsupervised. A nurse using this manual should be able to refer to and consult with a registered medical doctor (such as the local medical officer), and they should work as a team. Indeed, physicians who reviewed this manual felt strongly that they too should have access to the manual to facilitate teamwork. Ideally, nurse/medical doctor teams working in the rural areas should have backup from a regional hospice and gynecologist, who are, in turn, supported by a regional radiotherapy and chemotherapy center.

Introduction

What Is Palliative Care?

Most people want to die with dignity and in peace. One of the most valuable services that can be offered to terminally ill people and their families is palliative care. Palliative care is the active total care for a person with terminal illness who is near the end of his or her life. Palliative care involves support of patients whose disease is in advanced stages and does not respond to curative treatments; this includes the provision of terminal care.

Palliative care:

- Sees dying as part of the normal life cycle.
- · Does not quicken or delay death.
- Provides relief from pain and other upsetting symptoms.
- Includes the psychological, social, and spiritual aspects of care.
- Offers a support system to help ill people live as actively as they can until death.
- Offers a support system to help family members cope during the sick person's illness and in their own grief and mourning.

- Adapted from the World Health Organization, 1990.

The recipients of palliative care are the patient and her family. In developing countries, most palliative care is provided in the patient's home because hospice or hospital care may not be accessible, affordable, or feasible. In addition, many women would rather die in their own surroundings than in an unfamiliar environment. Rather than focusing only on medical care, palliative care also addresses a woman's non-medical concerns as she nears the end of life. Attention to emotional, social, and spiritual needs can help to relieve much of the distress and loneliness of a person nearing death. The basic comfort of the sick person is important. A terminally ill woman should be kept clean, and her position in bed should be changed every few hours to help prevent skin and lung problems. Nutrition is important, and there should be adequate access to liquids and appetizing food.

This field manual focuses on understanding cervical cancer, relieving the physical problems associated with it, and coping with the social, emotional, and spiritual issues related to cancer. The use of effective medications for the relief of physical problems such as pain and foul-smelling vaginal discharge is vital. These symptoms often prevent women from socializing and continuing with their regular activities. It is important that women be able to visit with friends and continue participation in regular activities for as long as possible. Ways to help women meet the social, emotional, and spiritual challenges of living with advanced cervical cancer are discussed in Chapter 5 of this manual.

Understanding the Natural History of Cervical Cancer

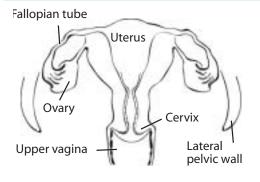
It is helpful for health care providers to be well educated about cervical cancer—with a good understanding of how cancer develops and how it attacks the body. Before cervical cancer occurs, an area on the cervix will have been abnormal for ten to fifteen years. This abnormal area that precedes the development of cervical cancer is referred to as a precursor of cervical cancer or "precancer." Pathologists refer to a precancerous lesion as *cervical intraepithelial neoplasia* (CIN) and grade it as mild, moderate, or severe (CIN 1, 2, or 3). Screening tests such as the Pap smear and visual inspection with acetic acid were designed to detect CIN, since it is easily treated with an outpatient procedure. This is why such importance is placed on having screening done after the age of 30 but before the age of 40 to 50 years. Before age 30, many cases of CIN will regress to normal, but after age 30, CIN is more likely to progress. If CIN is detected, it can be eliminated by treatment such as cryotherapy and the woman's risk of getting cervical cancer is greatly reduced.

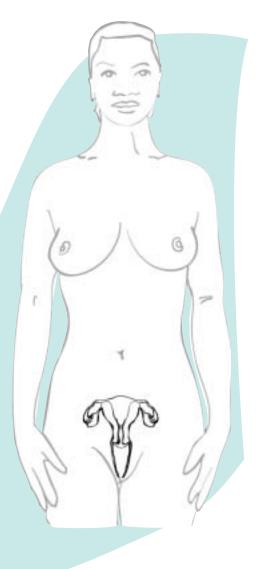
Without treatment, a small proportion of women with CIN will have a cancer develop in the abnormal area, invading the rest of the cervix and nearby tissues. The cancer grows slowly in the area of the cervix, vagina,

and uterus at first, but then it spreads to the other pelvic soft tissues and bones. A woman may have cervical cancer for years before she develops severe pelvic and low back pain and severe vaginal discharge. Death may occur due to blockage of the ureters (renal failure) or severe vaginal bleeding (anemia).

Women with early stages of cervical cancer—cancer that has not spread beyond the cervix or vagina—may be treated by total abdominal hysterectomy (removal of the uterus) with or without removal of pelvic lymph nodes and radiotherapy if these treatments are available and affordable. Similarly, those with cancer confined within the pelvis may be treated with radiotherapy and chemotherapy if these are affordable and available. For many women with cervical cancer, the disease is so advanced by the time it is detected, it cannot be cured. In these cases, providing palliative care to relieve the symptoms often is the best thing that can be done to help the woman and her family.

The advancing spread of cancer within the body is described by stages, numbered from I to IV, and decisions on whether curative or palliative therapy should be given are based on the stage of the cancer. The extent of anatomical spread, typical symptoms, and possible treatments and outcomes for the stages of cervical cancer are described in Appendix 3. It is important for the community nurse and registered medical doctor to understand where and how the cancer may be affecting a woman's body so that therapy is appropriate and the patient's needs are anticipated. The basic anatomy of the female reproductive system is illustrated in Figure 1.







Managing Physical Signs and Symptoms



This chapter gives an overview of the most common symptoms a woman with advanced cervical cancer may feel. It explains each symptom; describes possible treatments, including medications; and advises on when to seek additional medical help, such as admission to the hospital. In settings where curative treatments such as surgery and radiotherapy are not available or affordable, palliative care is the only possible management for patients with cervical cancer.

IMPORTANT NOTE!

Information in this manual about medications and dosages is provided for general guidance only. Each sick person's medical situation is unique and all medicines should be prescribed under the supervision of a qualified medical professional.

The medication dosages given throughout this manual are for an average woman who weighs 70 kilograms, has normal liver and kidney functions, and whose body weight has been stable over the past three months. Please bear in mind that these assumptions may not hold true for women with cervical cancer. If this appears to be the case or if the woman's stable weight is considerably greater or less than 70 kilograms, the correct medicine dosages should be established by a medical doctor.

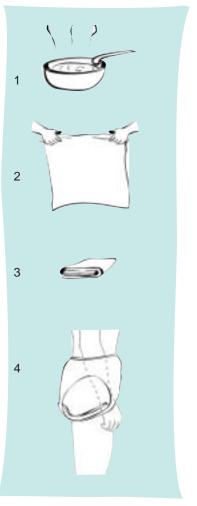
Financial barriers and limitations often prevent women from accessing treatment for cervical cancer, even when it is available. Although this is generally beyond your control as a health care provider, you can help by learning about potential local resources that subsidize the cost of services or provide some economic suport to enable women to access treatment, medicines, transportation, and other critical components of care.

Vaginal Discharge and Its Causes

Women with cervical cancer may experience watery, straw-colored, bloody, or foul-smelling vaginal discharge. This discharge can be composed of blood, pus, tissue, urine, stool, or any combination of these. This symptom is often a result of bacteria that are attracted to the unhealthy cervical cancer tissue in the vagina. These bacteria produce particularly foul-smelling gases. The bacteria cannot be eliminated permanently. Although efforts to relieve this symptom will have only temporary effect, there are ways to help the woman and her caregivers deal with vaginal discharge.

BACTERIAL OVERGROWTH

- If a sick woman has a lot of discharge, she may want to use clean strips of cloth or bundles of cotton in her panties, to absorb the discharge (see Figure 2). Sanitary pads, like those used for menstruation, also can be used. Cloths or pads should be changed as often as needed to keep the woman as dry and free of bad smells as possible. If the skin is very sensitive, petroleum jelly or zinc oxide cream may be applied.
- 2. To decrease the amount of bacterial overgrowth, gently pack the woman's vagina with clean cloths soaked with a solution of clean water mixed with bicarbonate of soda powder (one tablespoon in 500 ml of warm water) or table vinegar (1 part vinegar to 4 parts water), or metronidazole I.V. solution. Metronidazole solution can also be made by dissolving 5 to 10 crushed metronidazole 200-mg tablets in 500 ml of clean (boiled) water. The cloths should be left in the vagina for no more than a few hours at a time. This can be repeated twice a day for 5 days.





- 3. Periodically, vaginal douching (rinsing the vagina with a solution from a clean plastic juice bottle or syringe) can be used, once or twice a day for 5 days to decrease the amount of bacterial overgrowth. The solutions discussed above (bicarbonate, vinegar, or metronidazole) can be used for douching. Some women may not be familiar with douching, so teaching the process to the ill woman and her caregivers can be helpful. Vaginal douching may cause considerable vaginal bleeding however, so it should be used with caution.
- 4. If you determine that bacterial overgrowth is likely, broad-spectrum oral antibiotics may be used, such as:
 - Doxycycline
 - Amoxicillin and metronidazole, taken together

Note: Fungal vaginitis (yeast, candida) may occur as a side effect of using antibiotics, orally or topically in the vagina. This can be treated with antifungals. Common antifungals are: fluconazole 100 mg by mouth daily for 7 days; ketoconazole 200 mg by mouth once a day for 7 days; and 1 nystatin vaginal pessary daily for 14 days. The dose of doxycycline is 100 mg by mouth two times a day for 5 days. The dose of amoxicillin is 250 mg by mouth three times a day for 5 days. The dose of metronidazole is 400 mg by mouth two times a day for 5 days.

5. Although not widely available, radiotherapy (external beam) is also effective for controlling vaginal discharge. It also temporarily results in shrinking of the tumor.

IMPORTANT NOTE!

Antibiotics vary in the way that they work against specific bacterial infections and a medical doctor should prescribe them only when confident that the ill woman has this type of infection. It is essential to explain to the woman and her caregivers the importance of taking the complete course of antibiotics prescribed. Explain that not taking the full course of medicine (even if she feels better) can make the problem much worse.

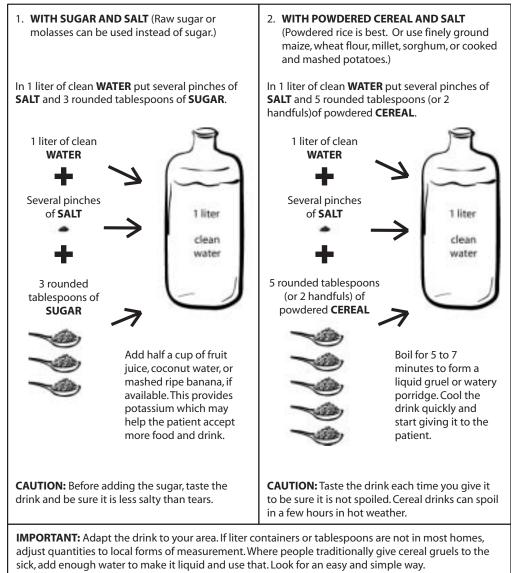
VESICO-VAGINAL AND/OR RECTO-VAGINAL FISTULA

The cancer may cause a fistula—a hole between the vagina and the bladder—causing urine to leak uncontrollably from the vagina. Sometimes the hole is between the rectum and the vagina, and stool escapes from the vagina. No drugs can stop the leakage of urine or stool caused by a fistula. Surgery is usually not successful and is seldom performed for women with cervical cancer, especially since fistulae tend to occur during the late stage of illness. Placing clean cloths in the woman's panties can help absorb the discharge (see Step 1 on page 11). Covering the bed with a plastic sheet or newspaper can help to protect the linens or bed cloths and the bed itself. It is important to focus on making the woman as comfortable and clean as possible in coping with this symptom. If the skin around the vagina or anus becomes sore, protect it by drying the sore areas then applying zinc oxide cream or petroleum jelly.

Vaginal Bleeding

If severe, this symptom can be quite alarming for the patient and her family. Sexual intercourse or strenuous activity may provoke vaginal

TWO WAYS TO MAKE 'HOME MIX' REHYDRATION DRINK*



* Adapted from Where There is No Doctor: A Village Health Care Handbook, The Hesperian Foundation, 1992.

Figure 3

bleeding. It often subsides with simple bed rest. If needed, vaginal packs effectively control bleeding as well.

When to consult a doctor or refer to the hospital:

- If bleeding is severe and persistent, the woman should be referred to the nearest medical facility for possible blood transfusion.
- If it is available, radiotherapy (intracavitary or external beam) may be effective in controlling bleeding.

Dehydration and Its Causes

Dehydration happens when the body loses more water than it takes in. Diarrhea, vomiting, high fever, or being too sick to eat or drink enough can cause dehydration. In hot climates, it is easier to become dehydrated because sweating causes the body to lose water. Signs of dehydration include:

- Thirst.
- Little or no urine.
- Very dry mouth.
- Sunken, dry eyes.
- Loss of elasticity of the skin.

When a person has diarrhea, vomiting, or high fever, do not wait for signs of dehydration—act right away to prevent it! Give lots of liquids to drink to replenish the losses of water. Use the following types of liquids:

• Oral rehydration salts or a rehydration drink.

• Watery cereal, porridge, tea, soup, or water that has been boiled and allowed to cool.

Packets of oral rehydration salts for mixing with clean water may be available in pharmacies. Homemade drinks—especially cereal drinks made from finely powdered rice, maize, wheat flour, sorghum, or cooked and mashed potatoes—are often cheaper and also effective when correctly prepared. (See Figure 3).

Sips of rehydration drink or other liquids should be taken frequently (every 5 or 10 minutes) until normal amounts of urine are produced. Give the woman a cup of the drink to keep by her bedside and encourage her to drink if she wakes up at night. Keep giving the drink in small sips, even if vomiting occurs.

When to consult a doctor or refer to the hospital:

Intravenous fluids and hospitalization are needed urgently if, in addition to the physical signs of dehydration (thirst, little or no urine, dry mouth, sunken eyes, loss of skin elasticity), any of these signs are present:

- A rapid pulse (more than 100 beats per minute) or a weak pulse.
- Fast and deep breathing.
- Convulsions.
- No urine for over 24 hours.

NAUSEA AND VOMITING

Nausea and vomiting are possible signs of many different problems. Vomiting may result from sickness with high fever, severe pain, infection in the stomach, or food poisoning from eating spoiled food. Nausea and vomiting may also be side effects of opioid analgesics and of radiation or chemotherapy treatment. If constipation and impaction occur, they should be treated, since they cause nausea (see page 20).

Although rehydration drinks are ideal, ginger tea, ginger ale, or cola drinks may be tolerated better than other fluids if there is nausea and vomiting. Small sips should be taken every 5 or 10 minutes. When the vomiting seems to have stopped, small amounts of unspiced food can be eaten, such as cooked bananas or dry bread.

An antiemetic medication may be effective against nausea and vomiting. Two of the most commonly used are metoclopramide and prochlorperazine.

- If the cause of nausea is renal failure, prochlorperazine may work best.
- If the cause is gastric stasis (delayed emptying of the stomach) as a side effect of opioid analgesics, metoclopramide works best.

Note: Most patients on morphine should be given an antiemetic on a regular basis (not as needed) to prevent nausea. The dose of metoclopramide is 10 to 20 mg (tablets) by mouth four times a day (before meals and at bedtime).

The dose of prochlorperazine is 5 to 10 mg (tablets) by mouth four times a day.

If severe vomiting and diarrhea make taking an oral medication impossible, a subcutaneous or intra-muscular injection of metoclopramide or prochlorperazine can be given. Metoclopramide 20 mg or prochlorperazine 10-mg rectal suppositories are also effective, though not universally acceptable or commonly stocked in local pharmacies.

When to consult a doctor or refer to the hospital:

- If severe vomiting lasts more than 24 hours and the woman is unable to take fluids.
- If a woman vomits blood in large amounts or repeatedly.
- If there are signs of severe dehydration (see page 15).

DIARRHEA

Diarrhea has many causes. The most common cause is infection from bad food or water. Follow the steps below for relief of diarrhea:

- 1. Sometimes a woman will be too weak to clean herself and will need help. Use plastic bags or clean disposable rubber gloves on your hands if available. Wash your hands well with soap and water after helping to clean her. Encourage household caregivers to use plastic bags on their hands when cleaning up after diarrhea.
- 2. Allow the woman to eat whatever she feels like eating. Fatty, greasy, or highly spiced foods appear to worsen the diarrhea for some people. Maintain her fluid intake by giving her an oral rehydration drink if possible (see Figure 3, page 14).
- 3. If a woman with diarrhea is also vomiting or feels too sick to eat, refer to pages 15–17 for treatments for dehydration, nausea, and vomiting. Use an oral rehydration drink if possible.
- 4. Loperamide 2-mg tablets can provide relief of diarrhea.

The dose of loperamide is a 4-mg loading dose (two tablets) at the start and 2 mg after each time the woman has diarrhea. Do not exceed the maximum daily dose of 16 mg. 5. If there is blood mixed in with the stool (and it is not from the vagina/cervix) or there is a fever (and it is not malaria) for more than 24 hours, start presumptive treatment for bowel infection with cotrimoxazole. Inform the supervising medical doctor that this has been done.

The dose of cotrimoxazole (80 mg trimethoprim/400 mg sulfamethoxazole) is two tablets by mouth two times a day for 10 days.

When to consult a doctor or refer to the hospital:

- If diarrhea lasts for more than 3 days or keeps coming back.
- If diarrhea lasts for more than 3 days after antibiotics have been started.
- If there are signs of severe dehydration (see page 16).

FEVER

A temperature above 37° Celsius (C), read from a thermometer in the axilla, is considered a fever. If a person has a high fever (above 39°), the most important thing to do is reduce her body temperature quickly. A very high fever (above 40° C) can cause convulsions and, rarely, permanent brain damage. The following steps should be taken to reduce a fever:

1. Give paracetamol 325-mg by mouth every 4 hours as needed—an effective treatment for fever. If a person with a



fever cannot swallow the tablets, the pills may be chewed or ground up and mixed with water.

Note: Using medication to reduce a fever often causes shivering, but this should pass.

- 2. Uncover the woman, and remove her clothing, if necessary, to allow a fresh breeze to reach her.
- 3. Give her lots of cold liquids to drink.
- 4. If she has a high fever, try sponging her with lukewarm wet cloths until the fever goes down.

When to consult a doctor or refer to the hospital:

- If a high fever does not go down after 48 hours.
- If the fever is accompanied by signs of meningitis (stiff neck and persistent headache), jaundice, persistent confusion, or pneumonia.
- If convulsions occur.

Constipation

If a person has dry, hard stools that are difficult to pass or she has gone much longer than her normal time without a bowel movement, she is said to be constipated. Constipation is a common side effect for women who are bedridden or taking opioids. The following steps should be followed:

- 1. Sometimes the cause of constipation is fecal impaction (blockage of stool in the lower rectum); this should be checked by performing a rectal examination. If the bowel is impacted, a nurse will need to remove the blockage of stool. Follow these steps for rectal examination and disimpaction:
 - Make sure the woman is lying on her side.
 - Cover your hand with a clean plastic bag or rubber glove.
 - Put oil on your index finger (vegetable oil, petroleum jelly, or liquid paraffin work well).
 - Insert oiled finger into the anus as far as your finger can reach.
 - Remove as much stool as possible with the finger.
 - This procedure may be repeated one more time, a day later, if no bowel motion has occurred.
- 2. Give the woman lots of fluids to drink. Drinking at least eight glasses of fluid a day will help prevent constipation.
- 3. Give the sick woman fruits; green vegetables; and foods with natural fiber, such as cassava (manioc), carrots, ground nuts, sesame seeds, and pumpkin.
- 4. Opioid analgesics can cause constipation. If the patient is taking an opioid analgesic, give her a laxative that stimulates the bowel to move on a regular basis. Do not wait until she needs the laxative. Commonly available laxatives include:
 - Senokot[®] (two to four tablets at bedtime).
 - Dulcolax[®] (one to two tablets at bedtime).
 - Milk of Magnesia[®] (one to two tablespoons at bedtime).
 - Castor oil (one to four tablespoons at bedtime).

Stool softeners such as liquid paraffin (one to three tablespoons at bedtime) also may help relieve constipation.

Note: Never give laxatives to anyone who has diarrhea, is suspected to have a bowel obstruction, or is dehydrated. Uncontrolled constipation can be an important cause of nausea.

When to consult a doctor or refer to the hospital:

- If constipation continues and is accompanied by a constant, severe pain in the abdomen and/or vomiting with great force. This could be a bowel obstruction.
- If the steps outlined above fail to produce a bowel movement after 4 days. This could mean that the cervical cancer may have spread to the lower colon or rectum, causing bowel obstruction.
- If two consecutive disimpactions over four days plus the use of laxatives fail to produce a bowel movement, then oil-retention enemas followed by saline or tap-water enemas may be required. For convenience, it is advisable to move the patient to a health care facility for this to be done.

Appetite Loss and Wasting

People who are ill lose interest in eating. Appetite loss can be caused by many things, including illness, anxiety, or depression. Significant weight loss is called wasting. For a woman with cervical cancer, these symptoms may signal the last stage of her life. Certain actions may be taken to reduce appetite loss and wasting:

- 1. The way in which the food is presented may be important in stimulating appetite. Avoiding exposure of the patient to the smells of cooking also may help.
- 2. Give her foods that she usually enjoys and accepts. Fresh foods; fruit juices; and fruits, particularly oranges or watermelon, may help.
- 3. Give her smaller amounts of food she likes, more often.
- 4. Corticosteroids (prednisone or dexamethasone) may be helpful in stimulating her appetite. If one of these drugs is used, it should be used early in the course of advanced illness rather than waiting to use it as a last resort. The family should be told that, although the patient is not likely to gain weight, she will likely regain some appetite and feel generally better.

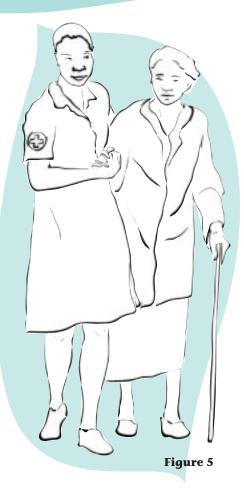
The dose of prednisone is 5 mg (tablet) by mouth three times a day for as long as necessary.

The dose of dexamethasone is 1.0 or 1.5 mg (tablets) by mouth four times a day for as long as necessary

Weakness and Fatigue

Weakness and fatigue will increase as a person reaches the end of her life. This may happen because she is not eating or drinking enough, is anemic, is anxious, or has not rested enough. Fatigue is common in women who have had radiation treatment. Several things may help increase a woman's energy:

- Encourage her to eat the foods she likes the best.
- Ensure she gets adequate rest.
- Assist her to move about, walk, and stretch if she feels able.
- Corticosteroids (prednisone or dexamethasone) can be given to increase a feeling of wellbeing (See box on previous page for dosage).



Leg Swelling

Many women with advanced cervical cancer may experience painless, severe swelling (lymphoedema) in one or both legs, usually accompanied by swollen inguinal (groin) glands that are causing a blockage in the flow of fluid (lymph) from the limb(s). No treatment is very successful for this, but the following is suggested:

- Raising her legs or wrapping with an elastic bandage (not tightly applied) or using a support stocking, if available, may provide some relief.
- Skin care with gentle bathing and massage with petroleum jelly are advisable.
- If an area of skin overlying the swollen leg becomes reddened, red streaks are present, and the lymph nodes in the groin are tender, this suggests a serious infection (lymphangitis). A trial of therapy with an antibiotic (erythromycin two 250mg tablets by mouth four times a day or one penicillin V 500-mg tablet by

The dose of erythromycin is 500 mg (tablets) by mouth four times a day. If after 3 days improvement is seen, continue use for 2 weeks.

The dose of penicillin V is 500 mg (tablets) by mouth four times a day. If after 3 days improvement is seen, continue use for 2 weeks.

IMPORTANT NOTE!

Antibiotics vary in the way that they work against specific bacterial infections and a medical doctor should prescribe them only when confident that the ill woman has this type of infection. It is essential to explain to the woman and her caregivers the importance of taking the complete course of antibiotics prescribed. Explain that not taking the full course of medicine (even if she feels better) can make the problem much worse. mouth four times a day) is advisable. These antibiotics should be taken with a glass (250 ml) of clean water to avoid stomach upset. If after three days improvement is seen, antibiotics should be continued for two weeks.

When to consult a doctor or refer to the hospital:

- If an infection is not responding to antibiotic therapy after 3 days.
- If available, a brief course of external beam radiotherapy directed at the swollen lymph glands may help reduce the swelling for a short while.

Note: Painless swelling of both legs may also be an early sign of advanced kidney failure. If this is the case, generalized swelling of the body will eventually occur.

Bed Sores

Keeping the sick person clean can prevent infection and help her feel emotionally healthy. She should be bathed every day. If she is too sick to get out of bed, she should be washed while in bed with a sponge or cloth and lukewarm water. Her clothes, sheets, and covers must be kept clean and dry. A person who is very weak and cannot turn over by herself in bed should be helped to change position at least every two hours. This helps prevent bedsores (also called pressure sores). Bedsores are most often seen on the buttocks, back, shoulders, elbows, or feet, and they can take a long time to heal. Caregivers can be taught how to prevent bedsores and how to keep them clean if they develop. To prevent bed sores:

- 1. Assist the sick person to move to a new position at least every 2 hours: face up, face down, or from side to side.
- 2. Bathe her every day using mild soap; and massage her skin with petroleum jelly, unscented oil, baby oil, or other lotion.
- 3. Use a soft mattress, bed sheets, and padding. Change them daily and each time the bedding gets dirty with urine, stool, or vomit.
- 4. Put cushions or pillows under the person in such a way that bony body parts rub less (see Figure 6). Cushions or pillows can be made by placing old rags, clothes, raw cotton, leaves, grass, or any soft "filling" under a piece of material.



If the woman has bedsores:

Figure 6

- 1. When changing her position, try to avoid having her lie directly on any sores.
- 2. Wash the sores two times a day with dilute hydrogen peroxide (2% solution), if available. Toilet soap (mild soap) and clean water, or povidone iodine or betadine solution may also be used to bathe the wound. Gently remove any dead tissue using clean tweezers or cloths. Rinse well with cool, clean water that has previously been boiled, and then cover the sores with clean bandages or cloths.

- 3. To fight infection and speed up healing, clean the sores and cover them with one of the following: sugar, honey, molasses, fresh mashed papaya, or plain yogurt (sour milk) at least two times a day.
- 4. Clean disposable gloves or plastic bags should always be worn when touching open wounds. The person taking care of the wounds should also wash his or her hands both before and after cleaning and dressing the wounds.
- 5. If sores begin to smell because they are heavily infected, an antibiotic powder (gramicidin, bacitracin, neomycin mixture) or metronidazole powder (made from crushing 200 mg tablets of metronidazole) can be sprinkled into the wound to assist in controlling the smell and healing the infection.
- 6. If the bedsores are obviously infected (tenderness, redness, pus, with or without foul smell) and the patient develops a fever, oral antibiotics (cloxacillin) should be given.

Do not remove hard scabs—they should fall off on their own as the sore heals. Do not cover scabs.

The dose of cloxacillin is 500 mg (capsules) by mouth four times a day for one week.

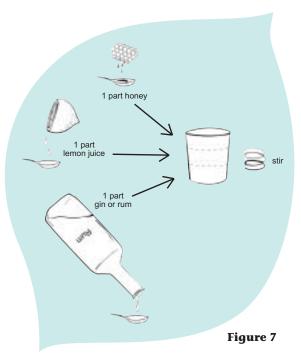
When to consult a doctor or refer to the hospital:

• If the sore has pus, swelling, heat, pain, or red streaks around it, an abscess may have formed. The woman should be examined at the local health center or district hospital and considered for incision and drainage of the abscess.

Cough or Breathing Difficulties

Coughing or other breathing difficulties, such as shortness of breath, can hurt the throat, make the person tired, and prevent sleep. Coughing is not a sickness in itself, but is a sign of possible infection in the chest (pneumonia or bronchitis). Although it is rare, coughing could be a sign that cancer has spread to the lungs. Persistent hiccups may be a sign of kidney failure. Shortness of breath may be a sign of heart failure, anemia, asthma, or chest infection. The following actions can be taken to address coughing or breathing problems:

- 1. It is usually easier to breathe in a sitting or standing position. Helping the ill woman to walk about or sit up can reduce breathing difficulty.
- 2. A homemade cough syrup can help all kinds of coughs, especially a dry cough (see Figure 7). This can be made by mixing one part honey, one part lemon juice, and one part gin or rum. Give one teaspoon every 2 or 3 hours. Another option is an equal mix of honey and ginger root mixed with hot water, or honey and wine (or whiskey).
- 3. Breathing may become so difficult that the ill woman becomes frightened. In this case, sit her up and stay with her.



- 4. If a woman has a severe dry cough that interferes with her sleep, codeine in tablet or syrup form may be effective. If a chest infection is suspected, do not use codeine.
- 5. As with all symptoms, try to find out what is causing the cough and treat that sickness directly. If it is a sickness that cannot be treated, such as latestage cancer that has spread to the lungs, try to make the person as comfortable as possible.

The dose of codeine is 30 to 60 mg (tablets or syrup) by mouth every 4 hours regularly. Dihydrocodeine is twice as potent, per milligram, as codeine phosphate (i.e., dihydrocodeine 15 mg = codeine phosphate 30 mg).

When to consult a doctor or refer to the hospital:

- If the person has constant difficulty in breathing that becomes severe or lasts longer than two weeks.
- If she is coughing up blood or foul-smelling pus, a chest infection is likely.
- If she is losing weight, has a persistent fever, and chest pain, a chronic chest infection such as tuberculosis may be the cause.
- If both legs are swollen and shortness of breath worsens when the woman lies flat, congestive heart failure could be the cause.

Using Modern Medications to Relieve Pain

Most women with advanced cervical cancer will experience pain at some time during their illness. Pain from late-stage cervical cancer may last until the sick woman dies. She may have more pain and need more drugs as her disease gets worse. It is important that strategies be put into place to strengthen follow-up and referral systems and ensure that women have continuous access to medications.

IMPORTANT NOTE!

Again, please note that the medication dosages given throughout this manual are for an average woman weighing 70 kilograms and who has normal liver and kidney functions (see page 10 for additional information). Consult with a qualified medical professional if you have questions or need guidance.

Medications often are very effective for relieving physical symptoms. Before starting the use of a drug it is important to check with the woman for a history of allergies to the medication (such as history of swelling, rash, or difficulty in breathing). Many people may not recall that they are allergic or had a reaction to a drug, but may recall that they have been told not to take a certain medication. If there is any doubt, it is better not to start a new drug and to seek advice from a registered medical doctor or a

pharmacist. A reference list of drugs, listed by category of use, is given in Appendix 1 (Table of Commonly Used, Available Drugs). This list was developed according to recommendations of practitioners, hospices, and the World Health Organization as being useful in palliative care. Only drugs that are available and have been proven to be effective are shown.



Figure 8

Analgesics of varying strengths are effective for relieving pain (see Table 1). The least amount of medication, of the appropriate strength, should be given at regular intervals so that the pain is eliminated entirely, if possible. If pain is mild, a drug such as paracetamol can be used on a regular basis, with or without ibuprofen. If pain increases, the dosage of medication should be increased to counter the pain. Once the maximum dosage of a medication is reached, it is time to move to another category of pain control: this involves adding a new drug to what the patient is already taking or replacing one drug with another. The use of analgesics is explained further on pages 34–39.

Note: In many places prescriptions are not necessary for most drugs except opioids (opiates and synthetic narcotics such as morphine).

Category of Pain Severity	Analgesics in Each Category and Examples of Brand Names (in parentheses)	Helper Drugs for Neuropathic Pain Bone Pain
Severe pain	A strong opioid such as morphine.	Amitriptyline Ibuprofen
Moderate pain	Paracetamol and/or ibuprofen plus a weak opioid such as codeine phosphate or dihydrocodeine (DF 118). Dihydrocodeine is twice as potent, per milligram, as codeine phosphate (i.e., dihydrocodeine 15 mg = codeine phosphate 30 mg).	Amitriptyline Ibuprofen
Mild pain	Paracetamol and/or ibuprofen.	Amitriptyline Ibuprofen

Table 1

Adapted from: Cancer Pain Relief, Second Edition, WHO, 1996.

Note: Aspirin is not recommended since it may cause stomach problems and bleeding, especially when used in combination with ibuprofen. Paracetamol is as effective as aspirin.

Use of Analgesics

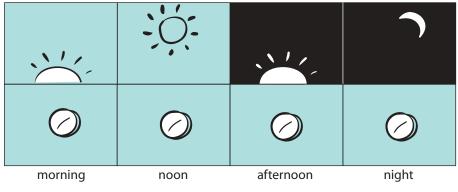
There are five important things caregivers should know about the use of analgesics for the control of chronic pain.

- 1. *Oral dosing*. Analgesics given by mouth in the form of tablets, capsules, and syrups work just as well as injections and are easier to administer. Either way, the analgesic will enter the person's body and be effective. It is usually recommended that tablets and capsules be taken with a glass of water that has been boiled and cooled.
- 2. *Regular administration*. Analgesics should be given at regular intervals "by the clock" (if a watch, clock, or radio is available) or using some other regular daily event such as sunrise (morning), midday sun (noon), late day sun (afternoon), and sundown (night or bedtime) as directed. Near the equator, the timing of sunrise, noonday sun, and sunset do not vary much. Daily events in a community often run on a normal cycle. In some communities, cues such as when the children come home from school or when the chickens come home each night can be used to time the administration of medications. In other communities, other cues might be more appropriate. Regular dosing is very important because each medication has a specific duration of effect. The recommended timing for each analgesic ensures that the pain does not come back.
- 3. *Bedtime dose*. Sleeping can be a problem if a medication is to be given more frequently than every 8 hours (e.g., every 4 or 6 hours). Rather than waking a patient (and the caregiver) during the night to administer a dose of an analgesic, the bedtime dose of the drugs can be doubled. This usually prevents pain without disturbing sleep.
- 4. *Helper drugs*. Other drugs that help with nerve or bone pain can also be given. Sometimes late-stage cervical cancer causes nerve damage

and women may feel stabbing pain or burning pain on their skin. This kind of "neuropathic" pain may not be stopped by opioids alone. Amitriptyline (commonly used for depression) can help stop nerve pain. Similarly, the cancer may invade the pelvic bone and cause pain because of an expanding tumor within the bone. An anti-inflammatory drug such as ibuprofen can reduce the swelling within the bone and thereby help to relieve the pain.

5. *Monitoring and adjustment*. Analgesics should be given based on the sick woman's need. If a medication no longer stops the pain, three possible actions can be taken: (1) increasing the dose, (2) adding another drug, or (3) switching to a new drug. In any case, the nurse should communicate the change to the medical doctor who is supervising the care of the patient. The health workers should watch and listen to the ill woman so that they can safely determine the amount and type of medication she needs in order to prevent pain. In some situations, only some of the pain will be relieved through medications despite everyone's best efforts.

To help women with advanced cervical cancer and their caregivers keep track of the different medications to control pain, be sure to explain the medications thoroughly.





- 1. Explain what each medication is for, how it should be taken, and for how long. Give instructions written in the local language for each recommended medication, if possible.
- 2. Use pictures to help explain instructions.

Pictures can help explain the time that the medications should be taken. The pictures in Figure 9 mean that one tablet should be taken four times a day: one at sunrise, one at noon, one at sunset, and one at bedtime. The chart in Appendix 2 can be used to help caregivers keep track of the medications administered.

If a woman vomits immediately after taking a drug (liquid or tablet), the dose should be repeated. But if she vomits several minutes after taking the drug, the dose should be repeated only if the tablet can be seen in the vomit.

Use of Non-Opioid Analgesics

Two of the most common non-opioid analgesics (paracetamol and ibuprofen) are described below.

PARACETAMOL

Paracetamol is widely available and relatively inexpensive. Its use should be avoided in patients with liver or kidney failure, since this drug is eliminated from the body by these two organs and may accumulate in the body and cause problems. Nausea, vomiting, and stomach pain could be signs that the patient

The dose of paracetamol is 325 to 650 mg by mouth every 4 hours regularly. has taken too much. If these signs occur, reduce the dosage or stop giving the drug, and make sure the woman drinks lots of water.

Like paracetamol, ibuprofen can be used to reduce fever and to relieve moderate pain. Since ibuprofen also reduces swelling and inflammation, this drug can help to reduce pain caused by cancer that has spread to bone. Ibuprofen should not be given to women who have stomach ulcers.

The dose of ibuprofen is 400 to 600 mg by mouth 4 times a day regularly.

Use of Opioid Analgesics to Control Moderate to Severe Pain

When non-opioid medications no longer control pain, opioid medications should be used. Codeine and morphine are examples of these drugs. A registered medical doctor should supervise their use. It is important to take codeine exactly as prescribed and to be very careful when measuring dosages to avoid overdosing (taking too much).

Once a woman with advanced cervical cancer starts taking an opioid, she will need to continue opioid use to control pain until she dies. Because she will need to take the medication for chronic pain, there is no need to worry about addiction—addiction is not a concern in terminally ill patients. The most important thing is to make sure that she takes enough medication to be free from pain. A key feature of opioid analgesics is that the dosage will gradually need to be increased.

The goal of treatment should be the continuous (24-hour) relief of pain, using regular dosing. More convenient, longer-acting forms of opioid medications are sometimes available, but these do not provide better pain control. In hospital settings, injectable (parenteral) opioids are sometimes available. The dose is usually half of the oral dose, given subcutaneously. Rectal doses of opioids are equal to oral doses but are neither universally acceptable to patients and providers nor commonly stocked in local pharmacies.

Note: Since nausea, vomiting, and constipation are common side effects of opioid medications, the patient should be monitored closely for these symptoms. It is advisable for the health care worker to anticipate these problems, be knowledgeable about their management, and tell caregivers how to prevent or minimize these problems (see sections on nausea, vomiting and constipation).

CODEINE AND DIHYDROCODEINE

Codeine and dihydrocodeine (DF 118) are mild opioid analgesics that reduce moderate pain. Mild opioids often cause constipation. Drowsiness, nausea, vomiting, itching, and headaches are other possible side effects. Seek medical help immediately if someone has taken too much. Taking too much can cause death. In some settings, a doctor may be able to administer an injection of naloxone to help

The dose of codeine is 30 to 60 mg (tablets or syrup) by mouth every 4 hours regularly. Dihydrocodeine is twice as potent, per milligram, as codeine phosphate (i.e., dihydrocodeine 15 mg = codeine phosphate 30 mg).

someone who has taken too much of a mild opioid.

MORPHINE

Morphine is the strongest opioid analgesic available. It should be used only if other medications described above are no longer effective. Because it is so effective, every effort should be made to see that morphine is available to women with terminal cervical cancer who have severe pain not controlled by other analgesics. Like codeine, morphine should be taken "by the clock" and not just when the patient complains of pain. Since morphine usually causes constipation, patients taking it should also use laxatives, eat a high-fiber diet, and drink lots of liquids. Nausea and vomiting are other common side effects, though they may lessen after a few days.

The starting dose of morphine is 10 to 15 mg by mouth every 4 hours; if necessary, the dose can then be increased until the patient is pain-free throughout the 4-hour intervals.

Very shallow breathing, stupor, coma, or respiratory arrest are signs of taking too much morphine. As in the case of codeine, in some settings, a doctor may be able to administer naloxone as an injection to reduce the effects of an overdose.

Helper Drugs

MEDICATION FOR BONE PAIN

A woman with terminal cancer may feel severe pain in her bones if her cancer has spread to the bones (typically the pelvic bones). Most drugs

for mild pain usually have no effect on bone pain, but ibuprofen, which reduces swelling, is sometimes helpful. Stronger pain medication may be needed in addition to ibuprofen.

The dose of ibuprofen is 400 to 600 mg by mouth 4 times a day regularly.

MEDICATIONS FOR NEUROPATHIC PAIN

Amitriptyline is a commonly available medication that is used to treat depression. In some women with advanced cervical cancer that is invading nerve tissue, this drug helps to relieve the very unpleasant neuropathic type of pain that results. Like bone pain, neuropathic pain can be very hard to relieve unless a helper drug is used along with analgesics.

The starting dose of amitriptyline is 10 to 25 mg by mouth at bedtime, gradually increasing to 150 mg at bedtime, if necessary.

Promoting Good Nutrition

Good nutrition is an important part of everyone's health. Eating nutritious food can help people stay healthy and prevent some common problems that arise from poor nutrition such as weakness, diarrhea, and headaches. Good nutrition can help a person with a terminal illness keep her strength and have a longer, more comfortable life. As you provide care to sick women and their families you may have the opportunity to teach them about nutrition. Everyone can benefit from this information, whether they are sick or healthy. Good nutrition can help caregivers and family members remain healthy, even when things are difficult for them.

In families with little money, land, or food, decisions are sometimes made to limit the amount of nutritious food given to someone who is very ill so that more is available for others who are healthy. It is important to explain to families that sick people need to continue to eat as much nutritious food as possible to keep up their strength. There is hardly ever a good reason to limit or reduce the amount of healthy food eaten by a person with a terminal illness. These decisions can be very difficult for a family, and you will need to approach the situation with your own knowledge of these issues and each family's circumstances.

This chapter provides information on foods that are high in nutrition but do not cost a lot, which may help you to work with families to continue to provide sick people with good, nutritional food. This chapter also gives examples of different types of foods and explains why they are healthy to eat. Foods that have a lot of certain vitamins or minerals are also described. You may know of other examples of nutritional foods that can be helpful.



Figure 10

Helping a sick person eat:

People who are very sick should eat small meals many times a day to help them get the nutrition they need. For people who are very sick, grinding or mashing their food may make it easier for them to swallow and digest.

Eating right helps the body fight sickness. Good nutrition can help sick people feel better and healthy people stay healthy.

Main Foods and Helper Foods

In most parts of the world, people eat one main low-cost food with almost every meal. Depending on where you live, the main food may be rice, maize, millet, wheat, cassava, potato, sorghum, breadfruit, or banana. This main food usually provides most of the body's daily food needs.

But the main food alone is not enough to keep a person healthy. Certain helper foods are needed. These foods add nutrition to a meal and provide protein, energy, and vitamins. Growing children, people who are sick, women who are pregnant or breastfeeding, and older people especially need these helper foods to stay healthy. There are many kinds of helper foods. The different types are presented below, with examples for each group.

HIGH-ENERGY HELPER FOODS

High-energy helper foods can be added to main foods to supply extra energy. This group includes:

- Fats such as vegetable oils, butter, ghee, and lard.
- Foods rich in fats, such as coconut, olives, and fatty meat.
- Nuts such as groundnuts (peanuts), almonds, walnuts, and cashews.
- Oil seeds such as pumpkin, melon, sesame, or sunflower seeds.
- Sugars such as sugar, honey, molasses, sugar cane, and jaggery.

BODY-BUILDER FOODS

Body-builder foods are also known as proteins and can help give strength. This group includes:

- Legumes, including beans, peas, and lentils.
- Nuts, including groundnuts (peanuts), almonds, walnuts, and cashews.
- Oil seeds, including sesame and sunflower seeds.
- Animal products, including milk, eggs, cheese, yogurt, fish, chicken, meat, small animals such as mice, and insects.

PROTECTIVE FOODS

Protective foods supply important vitamins and minerals that help to protect the body. This group includes:

- Vegetables such as dark green leafy plants, tomatoes, carrots, pumpkin, sweet potato, and peppers.
- Fruits such as mangoes, oranges, papayas, and bananas.

Better Foods at Low Cost

Many people eat a lot of bulky, starchy main foods without adding enough helper foods to provide the extra energy, body-building, and protection they need. This is partly because many helper foods are expensive especially those that come from animals, such as milk, eggs, or meat. In some places, people may not eat certain foods from animals because of religious or social beliefs.

A family that cannot afford the more expensive helper foods from animals can be better nourished if it grows or buys foods such as beans, peas, lentils, and groundnuts, together with a main food such as maize or rice. But where family finances and local customs permit, it is wise to eat some food that comes from animals, when possible. This is because even plants high in protein (body-building helpers) often do not have all of the different proteins the body needs.

It is important for a terminally ill woman to try to eat a variety of foods. Different plants supply the body with different proteins, vitamins, and minerals. For example, beans and maize together meet the body's needs much better than beans or maize alone. If other vegetables or fruits are added, this is even better. The nutritional benefits of certain types of foods are listed below.

- *Eggs and chicken*. In many places, eggs are one of the cheapest and best forms of animal protein. Even eggshells can be boiled, finely ground, and mixed with food to provide calcium, an important mineral for bones. Chicken is a good, often cheap, form of animal protein—especially if the family raises its own chickens.
- *Liver, heart, kidney, and blood.* These are especially high in protein, vitamins, and iron (for anemia), and are often cheaper than other meat.
- *Fish.* Fish is high in protein, often cheaper than other meat, and just as nutritious.

- *Beans, peas, lentils, and other legumes.* These foods are a good, cheap source of protein. If allowed to sprout before cooking and eating, they are higher in vitamins.
- *Dark green leafy vegetables.* Dark leafy greens have some iron, a lot of vitamin A, and some protein. The leaves of sweet potatoes, beans, peas, pumpkins, squash, and baobab are especially nutritious. They can be dried or powdered.
- *Cassava (manioc) leaves.* These leaves contain seven times as much protein and more vitamins than the root. If eaten together with the root, they add nutrition at no additional cost. The young leaves are best.
- *Rice, wheat, and other grains.* These foods are more nutritious if their outer skins are not removed during milling. If the skins remain, they may require a longer time for cooking. The protein in wheat, rice, maize, and other grains can be better used by the body when they are eaten with beans or lentils.
- *Fruits and berries.* Many fruits and berries are rich in vitamin C as well as natural sugars. They provide extra vitamins and energy.

Cooking Tips

• Cook vegetables, rice, and other foods in little water and do not overcook. This way, fewer vitamins and proteins are lost. Be sure to drink the leftover water or use it for soups or in other foods. • Cooking in iron pots or putting a clean piece of old iron or a clean horseshoe in the pan when cooking beans and other foods adds iron to the food and helps prevent anemia. Even more iron can be obtained if you add tomatoes.



Special Diets for Specific Health Problems

Chapter 2 discusses several different common physical symptoms. Some additional information is provided here on how to provide the best nutrition in response to some of these symptoms.

ANEMIA, WEAKNESS, FATIGUE, DIZZINESS

Eat protective foods—that is, foods rich in vitamins and iron. This group includes:

- Animal foods, including meat, blood, chicken, eggs, fish, grasshoppers, crickets, and termites.
- Beans, lentils, potatoes, yams, and peas.
- Tomatoes, cabbage with dark-colored leaves, turnips, dark green leafy vegetables, and pineapples.
- Sunflower seeds.

NAUSEA AND VOMITING:

- Drink lots of liquids to avoid dehydration.
- Eat crackers or dry bread.
- Eat small amounts of food several times a day.
- Avoid spicy or greasy foods.

DIARRHEA

• Drink lots of liquids to avoid dehydration.

If the person feels well enough to eat, try a selection of the following foods or similar ones:

- Ripe or cooked bananas
- Crackers

For nausea, vomiting, and diarrhea do NOT eat or drink:

- · Fatty or greasy foods
- Most raw fruits
- Any kind of laxative or purge
- Highly seasoned or spicy foods
- Alcoholic drinks

- Rice, oatmeal, or other well-cooked grain
- Fresh maize (well cooked and mashed)
- Potatoes
- Applesauce (cooked)
- Papaya
- Chicken (boiled or roasted)
- Eggs (boiled)
- Meat (well cooked, without too much fat or grease)
- Beans, lentils, or peas (well cooked and mashed)
- Fish (well cooked)

CONSTIPATION

Eat more fruits, vegetables, and foods with natural fiber, including:

- Whole-grain bread, wheat bran, sorghum, millet, and rye.
- Cassava, carrots, and turnips.
- Raisins, nuts, and pumpkin or sunflower seeds.

Including these foods in your diet will decrease the need for laxatives. It also helps to add a little vegetable oil to food.

Social, Emotional, and Spiritual Issues



This chapter addresses the social, emotional, and spiritual aspects of advanced cervical cancer and identifies ways to help women with cervical cancer and their families deal with these issues.

Communicating With a Sick Woman and Her Family

Staying in regular contact with a sick woman and her family is a very good way to demonstrate your commitment to her physical and emotional wellbeing. Good communication skills are essential to providing effective social, emotional, and spiritual support. Following the suggestions given below, you can help build a trusting relationship with an ill woman and may help her feel comfortable talking about her feelings.

- Greet the woman and her family politely and warmly, and shake hands with them.
- Begin by talking about general topics before moving to personal ones.



Figure 12

- Ask open-ended questions (questions that do not have a "yes" or "no" answer).
- Follow up on the patient's answers with more questions.
- Listen carefully to what the woman has to say.
- Repeat or summarize important points that the patient makes.
- Assure the patient that conversations will be kept private.
- Use simple medical terms that the patient can easily understand.

Ignoring or belittling a woman or pressuring her to get over her feelings can just add to her frustration. Sometimes a woman will be very irritable or depressed and she will not feel like talking to you. Be patient and give her time. Empathize with the woman. If she will not open up to you or you feel you cannot help her with her problems, it is important to try not to get annoyed with her or upset with yourself, or feel that you have failed. Trained counselors or social workers are usually available at health centers or the district hospital.

What if the Woman Has Not Been Told That She Has Cancer?

In some cultures, health care providers or family members may think that a woman with a terminal illness should not be told about her disease. They may believe that the news would be too hard for her to bear and that she would become sick more quickly or give up trying to get better. Sometimes, family members think that not telling her will be easier because then no one will have to talk about it. This is a very difficult situation for everyone.

It is important to respect cultural values and traditions, but it is also important to know that they can sometimes complicate a situation or even be harmful. Over time, most women who are sick with cervical cancer understand that they are very ill and will probably die. Not giving a woman the chance to discuss her illness and plan for her death can take away her dignity. Explaining this to family members can help them understand that even though telling her may be hard, it almost always helps everyone cope with the situation.

Caring for Yourself

Providing care and support to a terminally ill woman and her caregivers can be physically and emotionally demanding. It is important to be aware of your own feelings and take care to avoid overextending yourself so much that you find the pressure and stress of the job make it impossible to continue working effectively. Some signs that you may be feeling overwhelmed and need to take care of yourself include:

- No longer being enthusiastic about your work. Your work begins to feel like a chore and visiting families and providing care feels tiresome.
- Experiencing an increase in physical problems. You may feel generally unwell, tired, or achy. You may be experiencing frequent headaches, stomach problems, or disturbances in sleep patterns.
- No longer being able to relate to patients in a positive and supportive manner. You may find your patience is less than usual, you get angry easily, and take offense at small things. This also may affect your relationships with your coworkers and your own family.
- Experiencing a lack of confidence and loss of self-esteem. As you feel more and more drained and experience physical problems, you may begin to feel that you no longer are good at your job or that people no longer like you. This can further reduce your efficiency at work and can lead to depression.

It is always advisable to ask a trusted colleague or, preferably, a trained counselor for advice if you are feeling depressed.

Feelings of being overwhelmed can be avoided by recognizing signs and developing strategies to care for yourself. It is important to find ways to let go of work at the end of the day.

- Find ways to relax. This may mean finding a quiet place to sit, talking with a close friend or partner, reading, listening to the radio or music, or watching TV.
- Hobbies and exercise can also help alleviate stress and give people pleasure. Take time to do the things you enjoy.
- Take care of your social relationships. It can be extremely helpful to have a close friend, partner, or relative with whom you can talk, laugh, and share both good and bad experiences.
- Take time out if you need it. Occasionally, it may be helpful to take a few days away from work, especially if a patient has died recently or the workload has increased significantly. It is important to recognize your own needs.

Remember that there will be times when you feel frustrated or helpless in your work. You will not be able to solve every problem and make everything better. But being available to offer care and support to an ill woman and her family is vital and helpful in itself.

Caring for Caregivers

Family members or friends who are taking care of a very sick woman at home usually have their own special needs during the course of the woman's illness and after her death. Many caregivers will feel better if they know that they are doing a good job of keeping the sick woman as comfortable as possible. Teaching them how to provide supportive care can help them feel they are making a difference. Some ways you can help caregivers include:

- Reminding them to make time for themselves so that they are able to get away and relax for short periods of time.
- Helping them plan how they will manage the care of the sick woman and share tasks with others.
- Encouraging them to talk about feelings and assuring them that their feelings are normal.
- Helping them find someone in the community (such as a trusted friend or a counselor) to support them during this hard time.

Family members and caregivers may experience many of the same emotions for many of the same reasons that the woman with cervical cancer feels. Fear, anxiety, sadness, and anger can all be expressed during the time that you are visiting (see page 59 for more information on emotional issues).

Social Support: Having an Illness That Cannot Be Cured Can Change Relationships

Having an illness that cannot be cured can change the way a sick woman and her family members treat each other. There is no "right" or "wrong" way to cope with an illness. What is important is that people are able to talk to one another and get help when they need it.

Family stress. As a woman becomes very ill, she will have to depend a lot on her family and friends for care and support. Relationships within families will have to change, and people will need to take on new responsibilities.



This can be difficult for everyone because people may not know how to take on these new roles or they may not want to change. Supporting the family and discussing these things with them can help ease this transition.

In some cases, a sick woman's husband may spend less and less time at home as her illness gets worse. He may abandon her when he learns that she is dying. He may not want to take care of her, or he may feel so upset that it is too painful to stay and watch her get sicker and weaker. Whatever the reason, it will be important to comfort the woman and provide her with emotional, social, and spiritual support.

It is important to remember that young children in the family may be very worried and upset about their mother's health and will require counseling to help them cope with the situation.

Stigma and avoidance. Some family members and friends may avoid seeing or being with a very sick person if they are afraid that the illness may

be contagious. They may not want to help because of their fears. It is important to explain that cancer is not contagious to lessen their anxiety about visiting or caring for the ill woman.

Economic strain. The sick woman and her caregivers may need help to find ways to get food, pay for her housing, or pay for her medications and medical care. Sometimes friends, family, and others in the community can be organized to support the woman and raise the necessary funds.

Sexuality. Because cervical cancer is a disease that affects a woman's reproductive system, it may change the way she feels about her body and even how she feels about being a woman. As the disease gets worse, the woman will probably feel some pain or have vaginal discharge or bleeding that may cause her to decide that she no longer wants to have sex. Or

she may not want to have sex because of how she feels emotionally. Talking with a couple may help them better understand what is happening and help them decide what is best for them. If the couple is comfortable discussing these issues with you, you could suggest alternatives to sexual intercourse such as mutual masturbation or simulating sexual intercourse and ejaculating between the woman's thighs.



Figure 14

Emotional Support: Helping Sick Women and Their Caregivers

When a woman finds out she has terminal cervical cancer she may experience many strong emotions such as shock, anger, guilt, anxiety, and depression. Some of the difficult emotional issues that may come up when caring for very sick women are discussed here.

Sometimes the emotional problems she experiences may be too severe for her relatives and the nurse providing palliative care to handle by themselves. If her emotional problems become severe, she can be referred to a district hospital or health center where some of the staff may have counseling training.

Women with advanced cervical cancer may feel rejected, unclean, and even untouchable. Touching her arm while speaking, holding her hand, hugging her, and giving massage can provide great comfort and be emotionally healing. Cervical cancer is not contagious so it should be made clear to the woman, her family, and her friends that there is absolutely no danger in touching someone with this disease.

Helping Sick Women Stay Active and Involved

Most women with a terminal illness will want to stay involved in activities and make choices about their lives for as long as they can. One of the hardest things for a woman with a terminal illness is the feeling that she is losing control over what is happening to her. Caregivers who mean well may think they should make all decisions about a sick woman's life once she becomes ill. They may prevent her from making important decisions or from continuing her regular activities because they are trying to protect her. But sick women should be encouraged to stay involved in all the normal activities of their lives prior to illness, such as socializing and participating in community events, to the extent that they desire. Some women may want to make their own choices about what should happen near the end of their lives or after they die. A very sick woman may feel strongly about the type or amount of medicine she takes. She may want to make special plans for her children. Or she may want to make decisions about the type of ceremony she would like to have after she dies. For example, she may want certain songs to be sung or prayers to be said.

Helping a woman stay involved in activities and decision making can help her feel in control of her changing life. During the last stage of her life, a woman with cervical cancer can lose her independence and her social position in her community and her role in her family can change. Helping her cope with these losses and changes can be an invaluable service.



DEPRESSION

Depression is a common emotional reaction to losses in life. Depression is especially common when a person is dealing with death, either their own impending death or that of someone they care about. This is a normal reaction, is usually not long-lasting, and for some may be a more socially acceptable emotional reaction than anger. If depression persists for longer than is viewed as normal, it may have progressed to "clinical depression." Clinical depression is important to recognize, since it can be debilitating and should be treated with counseling, antidepressant medication, and regular monitoring. A woman may be suffering from clinical depression if she has several of these signs:

- She feels that life is not worthwhile and no longer gets pleasure out of the people, activities, or things that she used to enjoy.
- She feels very sad or empty for a long period of time.
- She cries or feels like crying most days.
- She is withdrawn or unusually quiet.
- She is tired, feels slow, or does not have energy.
- She has changes in her eating patterns (more than usual or less than usual) and corresponding weight gain or loss.
- She has difficulty falling asleep and/or wakes up early and cannot get back to sleep.
- She has a hard time concentrating or making decisions.
- She neglects personal hygiene.
- When questioned directly, she admits to thoughts about killing herself and may have an actual way planned and the means available.

If the woman has two or more of the above symptoms and the depression has lasted for longer than expected, then consideration should be given to the use of an antidepressant medication such as amitriptyline. It may take 3 to 4 weeks for the antidepressant to work. A health worker should continue to visit the woman regularly—at least every week, if possible. The visits should be used to evaluate whether the woman is responding to the medication, to give supportive counseling,

A typical regimen to start a patient on might be: amitriptyline one 25-mg tablet by mouth at bedtime for two nights, then two 25-mg tablets at bedtime for two nights, then three 25-mg tablets at bedtime. and to monitor and report back to the medical officer in charge. If trained mental health counselors are available, it would be helpful if the woman could be seen, preferably in her own home, with access to her family members. Antidepressant medication is usually continued for at least four to six months and then re-evaluated.

IMPORTANT NOTE!

There are many different types of antidepressant medications and each has unique dosage recommendations and side effects, and they vary in terms of how quickly they begin to have an effect on depression. Antidepressants should only be prescribed under the close monitoring of a qualified health professional.

A person who is very depressed may think about suicide. Some common warning signs that the person is thinking about suicide include complete withdrawal and repeated expressions of wanting to die. Be aware that, in some cases, a very abrupt recovery after a long period of depression can indicate that the person has decided to commit suicide. Also, if the woman talks about a specific and feasible way to kill herself, this often indicates that she will try it. She will need to be watched carefully to prevent her from harming herself.

When to consult a doctor or refer to the hospital:

- Any depressed patient who appears to have a more prolonged and severe depression than what would be expected with a reactive depression should be discussed immediately with the medical provider in charge to determine whether she is clinically depressed and in need of antidepressant medication.
- If there is a voiced threat or other reason to be concerned about suicide, the nurse should consult the medical provider in charge immediately.



When a woman becomes very ill, loses control over her own life and decision making, or is in a situation where she can not make sense of what is happening, anger is a common reaction. She may be angry with herself or with others and these feelings may not always be easily understood by those around her.

People who are very angry usually will calm down after they have let their anger out. Try to get the woman to talk about her anger. Try to show her that you understand her situation. When she has calmed down, try to help her identify the sources of her anger and work with her to resolve them. Sometimes caregivers or family members who mean well may think they should make all decisions about a woman's life once she becomes ill. Health care providers should help the family understand that preventing her from making important decisions can cause a sick woman to feel powerless, upset, frustrated, or angry.

When people are very angry, it is best not to confront or argue with them. Arguing may make them angrier or make them direct their anger at you. If there is a risk that an angry person will hurt someone or hurt herself, it is very important to seek outside support to help deal with the situation. This outside support could come from a family member, friend, counselor, or community leader.

ANXIETY AND FEAR

Anxiety and fear are usually caused when someone is unsure about a situation or unsure about how it will affect them. Anxiety and fear are common feelings that women and their caregivers may have when faced with cancer. A woman who is dying of cervical cancer may experience fear or anxiety because of:

- Changes in family roles and positions.
- Uncertainty about her relationship with her husband and friends.
- Loss of control over her everyday life.
- · Lack of money for medications.
- Fear of suffering, pain, or death.
- Fear of the unknown.

Talking with the ill woman about her feelings often helps to lessen anxiety and fear. Try to help her identify the source of her anxiety or fear and identify ways to resolve it.

GUILT

A woman with cervical cancer may feel guilty if she thinks that she has done something bad that has caused her to have cervical cancer or that someone has placed a curse on her. She may feel guilty because other people have to take care of her or because her illness has made things difficult for people close to her. For example, she may feel badly about the family's lack of money and that her medical needs are using up the family's resources.

In some cases, the sick woman may feel guilty because of something harmful she said or did to another person recently or in the past. This can be a good time to honestly apologize for hurtful actions or words that still cause guilty feelings. Making peace in this way can help everyone feel better.

Both the woman who is sick with cancer and her caregivers may need reassurance and support so that they are not overwhelmed with guilty feelings. They should be reassured often that, despite all their best efforts, all life ends in death.

Spiritual Issues

When a woman is dying, religion and spiritual beliefs can be very comforting, but they also can be the source of questions and doubts. She may have thoughts and questions about her life and what will happen to her after she dies. She may believe that it is important to make peace with her god or do things to keep her soul or spirit safe after she dies.

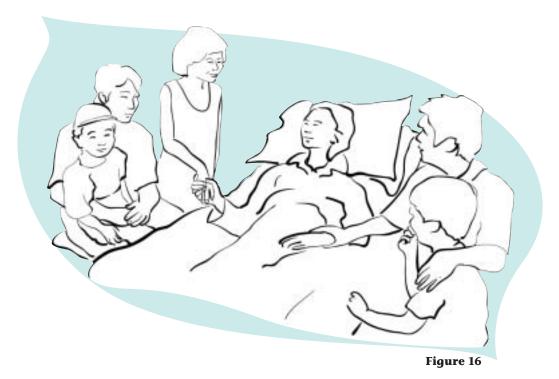
It is important to be respectful of and responsive to the spiritual beliefs of a woman and her caregivers. There are many things that can be done to help a person who has a terminal illness find spiritual peace and to bring her comfort and help her accept her death. She may know of someone in her community whose spiritual advice or wisdom could help her find peace. The very ill woman may need someone to help arrange for that person to spend time with her. There also may be groups in the community, such as a prayer group or a women's group from her place of worship, that can provide spiritual comfort.

Some women may not want to speak with a spiritual or religious person, but they may want to discuss spiritual issues with someone they respect. It may be helpful to try to find a person, such as a church elder or other respected person, who may be able to offer support.

Preparing for Death

THE GRIEVING PROCESS

Grieving is the process of accepting loss. The grieving process often begins once a sick woman and her family understand she is dying. The process can involve strong emotions. Sometimes feelings of grief and loss can be so



overwhelming that a person is unable to carry on with her normal activities. A person who is grieving may feel sadness that leads to depression. Support from others is very important in this situation. Support can remind grieving people that grief is normal and that there are many good things yet to experience in their lives. Having someone simply sit quietly and listen to the woman or hold her hand and provide sympathy can be very comforting.

As a woman with cervical cancer nears the end of her life, there are certain things that may help her die in peace and help her caregivers to cope with her death. As a woman gets sicker:

- Encourage her to talk about her wishes and feelings.
- Involve her in planning and making decisions to lessen anxiety and provide peace.

- Speak with her honestly about what to expect as the disease progresses.
- Reassure her that family and caregivers will do everything possible to keep her comfortable.
- Allow her to lie down in a familiar place that lets her watch and be included in conversations and daily activities with family members.
- Be aware that if she is very ill, she may prefer to be somewhere quiet.
- If she wants, make sure her friends and family are around to comfort her.
- Watch to make sure visitors do not distress or tire her.

When Death Comes

During the last hours of a woman's life, caregivers should focus on keeping her as comfortable as possible. The ill woman should not be left alone during this time—many people are afraid of being alone when they die. Ensure that the family is nearby and that someone is sitting quietly with the dying person. Holding her hand, sitting with her, or praying with her can all be comforting to her, her family, and her caregivers.

When people are approaching death, they usually become very weak and cannot move. They stop eating and drinking and are drowsy or asleep much of the time. It is normal for people who are very near death to lose control of their bowels and bladders. Therefore, in order to avoid soiling the bed, place a large piece of plastic or newspaper underneath the sheets. It will be very important to explain these things to the ill woman's family members and caregivers so that they can know what to expect and how to provide the best care possible.

After Death Has Come

The family may need or appreciate help in making funeral arrangements. Respect the rituals and customs related to preparing and displaying the body. Offering the family your sympathy and listening to them if they need to talk about the deceased can provide them with comfort and support.

Once several days have passed since the death of a woman, it is a good idea to stop by her home to see how her caregivers and family members are coping with her death. It will be important at this time to find out how they are feeling, and to be prepared to provide them with linkages to other groups, such as a bereavement support group, that offer social, emotional, or spiritual support.

Family members and caregivers may feel depressed for a long time after the death of a loved one. This is normal during the grieving process. Most family members will come to accept the death of a loved one and will recover from depression over time. Sometimes caregivers can become very depressed, and may also need support or treatment for depression.

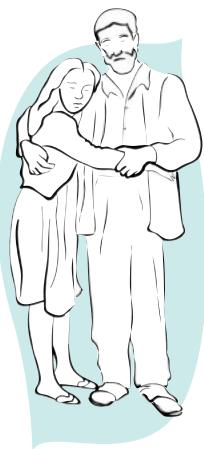


Figure 17

Conclusion

6

Providing palliative care can be a
very powerful experience. You join
people in what is usually a very
difficult emotional journey. They
may look to you for advice and
courage. You may develop close
friendships with ill women, family
members, and other caregivers
during this time and you may share
tears and even laughter together.
A person who provides good
palliative care can know that she
has helped others through one of
life's greatest challenges.

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APPENDIX 1: TABLE OF COMMONLY USED, AVAILABLE DRUGS

Category	Medicines Commonly Available	
Analgesics		
Non opioid	Ibuprofen	
Non-opioid	Paracetomol	
Weak opioid	Codeine phosphate	
Weak opioid	Dihydrocodeine (DF 118)	
Strong opioid	Morphine	
Holperdrugs	Amitriptyline for neuropathic pain	
Helper drugs	Ibuprofen for bone pain	
Appetite stimulant (also used to	Dexamethazone	
increase sense of well-being)	Prednisone	
Stimulant laxative	Dulcolax®	
Stimulant laxative	Senokot®	
Anti-nausea/vomiting		
Opioid or physical obstruction	Domperidone	
to gastric outflow	Metoclopramide	
	Haloperidol	
Uremia/hypercalcemia	Stemetil	
	Amoxicillin	
	Antibiotic powder (gramicidin, bacitracin, neomycin mixture)	
	Cloxacillin	
Antibiotics	Cotrimoxazole (160 mg trimethoprim/800 mg sulfamethoxazole)	
	Doxycycline	
	Erythromycin	
	Metronidazole	

Category	Medicines Commonly Available		
Vaginal antiseptic	Betadine iodine		
Oral rehydration	Oral rehydration salts sachet		
Skin care	Petroleum jelly		
Skin care	Zinc oxide cream		
Antidepressant	Amitriptyline		
	Clotrimazole		
Anti-fungal	Fluconazole		
	Nizoral/Hitoral		
	Nystatin vaginal pessary		
Anti-diarrhea	Loperamide		

APPENDIX 2: SAMPLE PATIENT MEDICATION CHART*

APPENDIX 3: STAGES OF CERVICAL CANCER

Stage I A

Carcinoma is strictly confined to the cervix, but can be only diagnosed by microscopy (not clinically visible).*

Usual Symptoms: None (asymptomatic).

Optimal Treatment: Total abdominal hysterectomy.

5-year survival (with optimal treatment): 90%–100%.
 Stage I B
 Carcinoma is strictly confined to the cervix, and a macroscopically (clinically)

visible lesion is present.

Usual Symptoms: May be a watery, pale, straw-colored vaginal discharge and postcoital bleeding.

Optimal Treatment: Radical surgery (radical hysterectomy with bilateral pelvic lymphadenectomy or radical radiotherapy).

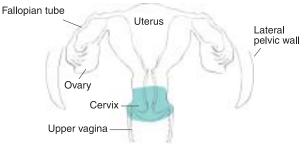
5-year survival (with optimal treatment): 80%–90%.

* All staging descriptions based on FIGO nomenclature.

Stage II A

Cancer has spread beyond the cervix, but does not involve the pelvic wall, lower third of the vagina, or the parametrium.

Usual Symptoms: Vaginal Cervi discharge may be serous, Upper vagina mucopurulent, blood stained, and sometimes foul-smelling. Recurrent vaginal bleeding including postcoital.



Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy; in selected cases, radical surgery plus radiotherapy.

5-year survival (with optimal treatment): 75%.

Stage II B

Cancer has spread beyond the cervix, but not as far as the pelvic wall or the lower third of the vagina. There is obvious parametrial involvement.

Usual Symptoms: Similar signs and symptoms as II A, often with pain in lower pelvis and lower back. Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy.

5-year survival (with optimal treatment): 50%–60%.

Stage III A

The tumor invades the lower third of the vagina, with no extension to the pelvic wall.
Usual Symptoms: Similar to II B, often with painful intercourse.
Optimal Treatment:
Fallopian tube
Uterus
Uteru

Radical radiotherapy with or without concurrent chemotherapy.*

5-year survival (with optimal treatment): 20%–40%.

Stage III B

The tumor involves the lower third of the vagina *and* extends to the pelvic wall or hydronephrosis or nonfunctioning kidney occurs.

Usual Symptoms: Similar Fallopian tube Uterus to III A, severe pain in Lateral pelvic wall lower abdomen and lower back. often one or both legs swollen. May be signs Ovarv and symptoms of uremia Cervix (chronic renal failure) due Upper vagina to obstruction of one or both ureters.

Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy.*

5-year survival (with optimal treatment): 20%-40%.

* These are radical treatments with curative intention, not palliative treatments. One-third of Stage III patients are cured with radical radiotherapy with or without concurrent chemotherapy.

Stage IV A

Cancer has spread beyond the pelvis to the adjacent organs (bladder and/or rectum).

Usual Symptoms: Similar to III B, often with haematuria (blood in the urine), dysuria, anemia, weight loss, and sometimes vesico-vaginal fistula or recto-vaginal fistula.

Treatment: Palliative radiotherapy and/ or palliative chemotherapy and symptom control; radical radiotherapy with or without concurrent chemotherapy in selected cases.



5-year survival (with optimal treatment): 5%–10%.

Stage IV B

Cancer has spread to distant organs.

Usual Symptoms: Same as IV A, but with additional signs and symptoms according to site of metastatic spread:

- Kidneys severe midback pain.
- · Lungs intractable, nonproductive cough
- Liver abdominal swelling (right upper quadrant pain and tenderness), jaundice.
- Skin large, nontender, nodular skin swellings.
- Lymph nodes enlarged lymph glands.
- Brain convulsions, confusion.

Treatment: Palliative radiotherapy and/or palliative chemotherapy and symptom control.

5-year survival (with optimal treatment): 0%.

APPENDIX 4: SAMPLE PALLIATIVE CARE PATIENT RECORD*

Palliative Care Patient Record

Assessment completed by: ______
Place of assessment: ______

Health facility where diagnosis was made:_____

Patient Information

ID/Number:	Palliative Care Ref. N.:	Date first seen by nurse: (DD/MM/YY)
Patient first name:	Patient last name:	Marital status:
Date of birth: (DD/MM/YY)	Age:	District:
Division:	Location:	Chief:
Sub-location	Sub- chief:	Village/Headman:
Educational level:	Occupation:	Family sources of income:

* This form was designed for the Western Kenya Cervical Cancer Prevention Project, to be completed by district health coordinators or nurses at the health center or district hospital for women needing palliative care. Women bring the form to the Provincial General Hospital palliative care team to use as an ongoing patient care and referral record. This sample patient care and referral form can be adapted for use by health care providers offering palliative care to women with cervical cancer.

Contact

Name of contact	Relationship	Postal address	Location	Sublocation
Next of kin:				
Other family/friend:				
,				

Referral For Palliative Care

Patient referred by:_____

Reason for referral:_____

History of illness given by: _____

Present Medical History (See symptom/complaint list in Chapter 2.)

Symptom/complaint*	Mild	Moderate	Severe	Duration (weeks)
Pain				
Vaginal discharge				
Vaginal bleeding				
Diarrhoea				
Nausea and vomiting				
Constipation				
Fever				
Appetite loss				
Lymphoedema				
Bed sores				
Shortness of breath				
Depression				
Insomnia				
Other (specify below)				

*Please tick according to severity.

Diagnosis

Diagnosis:_____

Site(s) of secondary spread:_____

Other present medical conditions:

Current Medications

Type of medication	Name	Dose	Frequency	Number of days	Total amount given
Prescription					
Over-the-counter					
Alternative					

Past Medical History

Condition	If yes, describe below
Any previous related illnesses?	
Is patient taking any drugs for previously diagnosed problems?	
Any allergies?	
Is she able to move around?	

(Be sure to speak in a caring manner when asking patient the following questions below.)

Social Aspects and Bereavement

"What kinds of expectations does your family have for you?" (home, work, your relationships)

"What are your interests?" (what sorts of things to you like to do? What are you able to do?)

"In what ways has this illness affected your health, your life?"_____

Insight of Patient and Family Concerning Prognosis

"Have things changed for you and your family? If so, in what ways?" _____

"How is your family dealing with your prognosis?"_____

Spiritual Aspects of Patient's Life

"Do you have any links with a church or religious community?"_____

(if NO) "Would you like to be involved with a church or religious community in some way?"_____

"How important are your links with church or the religious community?"

Physical Examination

Write all clinical findings on examination according to related symptoms.

Appearance and mental state:

Diagnosis

Diagnosis (of current problems/complaints) in order of severity:		
1.		
2.		
3.		
4.		

Caregiver Difficulties

1.		
2.		
3.		
4.		

Possible Causes of Pain or Discomfort

2. 3.	1.			
	2.			
	3.			
4.	4.			

Palliative Care Plan (List Each Complaint/Diagnosis)

Please refer to the Palliative Care Field Manual for the management of each symptom.

Date	Complaint/ diagnosis	Nursing care	Current medications (Dose, frequency, total amount given, number of days each dose, and when new supply needed for each medication.)
1.			
2.			
3.			
4.			
5.			
Other rer	narks:		

Follow Up Sheet

Date: ______ DD / MM / YYYY

1. Symptom/Complaint List (Refer to Chapter 2.)

Symptom/complaint*	Mild	Moderate	Severe	Duration (weeks)
Pain				
Vaginal discharge				
Vaginal bleeding				
Diarrhea				
Nausea and vomiting				
Constipation				
Fever				
Appetite loss				
Lymphoedema				
Bed sores				
Shortness of breath				
Depression				
Insomnia				
Other (specify below)				

*Please tick according to severity.

3. Fill in new care plan if required:

4. Overall impression: