

Palliative Care
for Women
With Cervical Cancer:
A KENYA FIELD MANUAL

USING THIS FIELD MANUAL

This field manual was developed for use in Kenya but may be reproduced or adapted to meet local needs. Trade names were used throughout this manual for the convenience of the users in Kenya and do not imply endorsement of any particular brand name product.

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JEY

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Foreword

Women in Kenya, like in many other countries, suffer from very high rates of cervical cancer due to the lack of an adequate screening program to detect and treat precancerous lesions of the cervix. Since most Kenyan women present with symptoms when cancer has spread beyond the cervix, this places heavy demands on the health care system. The most immediate need is for curative treatment in the form of pelvic surgery, radiotherapy, and chemotherapy, but at this time these treatments usually are not available or accessible, especially for poor women living in rural areas. Consequently, most women do not receive curative treatment and face a protracted and difficult illness.

This field manual is a first step in adequately caring for women who are suffering from cervical cancer that is terminal. The contents are the result of many years of palliative care experience in community and hospice settings, and this experience has been purposely distilled and simplified for use in the field by visiting nurses or health facility-based nurses and physicians. Practical advice on the drugs and techniques that are effective in the management of the most common problems confronting women and their families will lead to improvements in health service delivery. I believe that this manual will better equip health care workers with the necessary skills and hope that it will stimulate the further development, recognition, organization, and support of palliative care services in Kenya. Palliative care should be incorporated into the mainstream of the health agenda in the country.

A handwritten signature in black ink that reads "Nizar J. Verjee". The signature is written in a cursive style with a horizontal line underneath.

Dr. Nizar Verjee
Chair, Kenya Hospice Association
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Preface

In Kenya and most other 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 an identified need for a field manual for community nurses and medical doctors caring for women dying of advanced cervical cancer in the Busia District of Western Kenya. It complements *Palliative Care for Women With Cervical Cancer: A Field Manual*, produced by PATH and EngenderHealth in 2003, which provides information for global audiences. While both manuals focus on caring for women with cervical cancer, the information can be used when caring for any person with chronic pain nearing the end of life, no matter what illness or disease he or she has.

The observations and recommendations of nurses and medical doctors working in hospices in Eldoret, Kisumu, and Nairobi were invaluable in prioritizing problems and validating practical methods to manage them. Also, the community nurses, local pharmacies, and medical doctors in and around the rural district of Busia in Western Kenya provided very useful information about the availability and cost of drugs, the practicality of the management plans, and the language used in the text. Drugs have been chosen on the basis of the best evidence available on accessibility and effectiveness. The use of brand names does not imply the authors' endorsement of any particular brand; it is merely to make drugs more recognizable to providers who may not be familiar with generic names.

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 terminally 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 an attachment or practicum for up to one month with a hospice team. This 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, the local physicians who consulted on the manual felt strongly that they 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 a provincial gynecologist, who are, in turn, supported by a regional radiotherapy and chemotherapy center.

The authors of this manual have various backgrounds. Dr. John Sellors was in private family practice in a rural area of Canada for over 22 years and then was a Professor of Family Medicine at McMaster University before

joining PATH in 2000. Dr. Ketra Muhombe is a general practitioner and a consultant to the Kenya Cancer Association and PATH's country program in Kenya. Wendy Castro has been with PATH since 2000 and has been writing evidence-based materials that summarize the state of the art on various topics that relate to cervical cancer prevention. The work of all of the authors on this field manual has been supported by the Bill & Melinda Gates Foundation through the Alliance for Cervical Cancer Prevention.

Introduction

1

What Is Palliative Care?

The World Health Organization (WHO) defines palliative care as “the active total care of patients whose disease is not responsive to curative treatment.” One of the most valuable services that can be offered to terminally ill patients and their families is palliative care. It involves managing patients’ pain and relieving the discomfort from physical symptoms, as well as attending to the emotional and spiritual needs of patients to ensure that they are as comfortable as possible. Palliative care also 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 WHO, 1990.

The unit of care in palliative care is the patient and her family. Rather than focusing only on medical care, palliative care focuses on the things that may be important to a person as she nears the end of life. Attention to a person's 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 also 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 addressing social, emotional, and spiritual issues related to cancer. For the relief of physical signs and symptoms, drugs often are very effective.

The use of effective medications for the relief of physical problems such as pain and foul-smelling vaginal discharge is vital. These symptoms can

prevent a woman from participating in her community and carrying out her daily activities. It is important that the ill woman be able to visit with friends and continue her participation in activities such as prayer groups for as long as possible. Ways to help the woman meet the social, emotional, and spiritual challenges of living with advanced cervical cancer are dealt with in the final chapter 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 10 to 15 years. This abnormal area that precedes the development of cervical cancer is referred to as a precursor of cervical cancer or a precancerous lesion. 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 (VIA) were designed for detection of 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. Before age 30, many cases of CIN will regress to normal, but after age 30, CIN is more likely to progress. If CIN is present, 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 the adjacent 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 adjacent vagina—may be treated by total

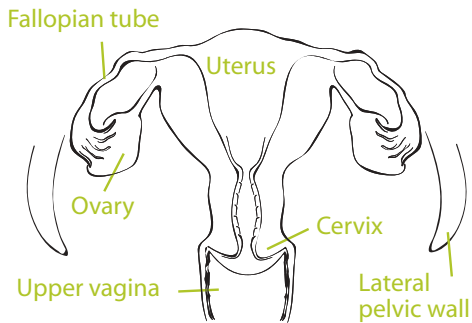
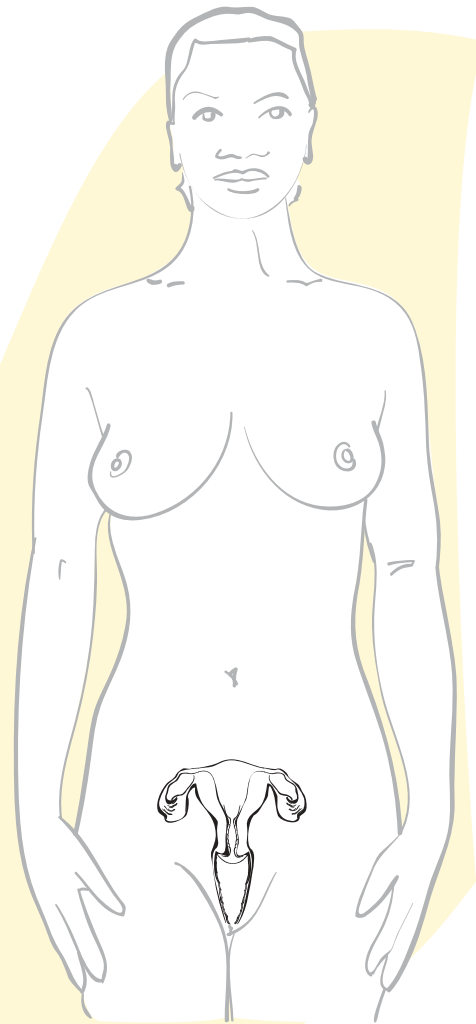


Figure 1

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 stages of cervical cancer, the extent of anatomical spread, the typical symptoms, and the possible treatments and outcomes are described in Appendix 1. 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 the 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

2

This chapter gives an overview of the most common symptoms a woman with advanced cervical cancer may have. 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.

Using Modern Medications to Relieve Pain

Most women with advanced cervical cancer will experience pain including backache 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 backache and need more drugs as her disease gets worse.

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 another type of 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 to hold off starting 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 the Table of Commonly Used, Available Drugs and Costs (Appendix 2). This list was developed by surveying local pharmacies in the rural area of Busia in Western Kenya for the availability and cost of drugs that are recommended (by local practitioners, hospices, and the World Health Organization) as useful in palliative care. Only drugs that are available and have been proven to be effective are shown, along with their prices. Dosages of the drugs are discussed, as well as costs, which can be prohibitive in some cases.

Note: The information on medications and dosages provided in this manual is for guidance only. Each patient's medical situation is unique, and all medications should be prescribed under the supervision of a qualified medical professional. The medication dosages provided in this manual are for a woman who weighs an average of 70 kilograms, has normal liver and kidney functions, and whose body weight has been stable over the past three months. If this does not appear to be the case, the correct medicine dosages should be established by a medical doctor.

Analgesics of varying strengths are effective for relieving pain (see Table). 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 in the section that follows.

Note: In many locales, prescriptions are not necessary for most drugs except opioids (opiates and synthetic narcotics, e.g., morphine). Palliative care centers and hospices typically are a good resource for morphine until policy changes can be made to allow greater access and availability. The Table of Commonly Used, Available Drugs and Costs (Appendix 2) provides costs from a survey of pharmacies in Busia, Kenya.

Table: Modern Medications to Relieve Pain

Category of pain severity	Analgesics in each category and examples of brand names (in parentheses)	Helper drugs for neuropathic pain or bone pain
Severe pain	A strong opioid such as morphine.	amitriptyline (Elavil®) ibuprofen (Brufen®)
Moderate pain	Paracetamol (Panadol®) and/or ibuprofen (Brufen®) 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 (Elavil®) ibuprofen (Brufen®)
Mild pain	Paracetamol (Panadol®) and/or ibuprofen (Brufen®).	amitriptyline (Elavil®) ibuprofen (Brufen®)

Adapted from WHO, 1996.

Note: Aspirin is not recommended since it may cause stomach problems such as 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 clean water (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 (sunrise, noonday sun, sunset) as directed. Near the equator, the timing of sunrise, noonday sun, and sunset do not vary much. Daily events in a village run on a normal cycle. Cues such as when the children come home from school (about 1:30 p.m.) or when the chickens come home each night can be used to time the administration of medications. Regular dosing is very important because each medication has a specific duration of effect. The recommended timing for each analgesic prevents "breakthrough" of the pain and 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 breakthrough 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 bones 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 (see Figure 2).

Drawing pictures can help explain the time that the medications should be taken. The pictures in Figure 2 mean that one tablet should be taken 4

times a day: one at sunrise, one at noon, one at sunset, and one at bedtime. The chart in Appendix 3 can be used to help caregivers keep track.

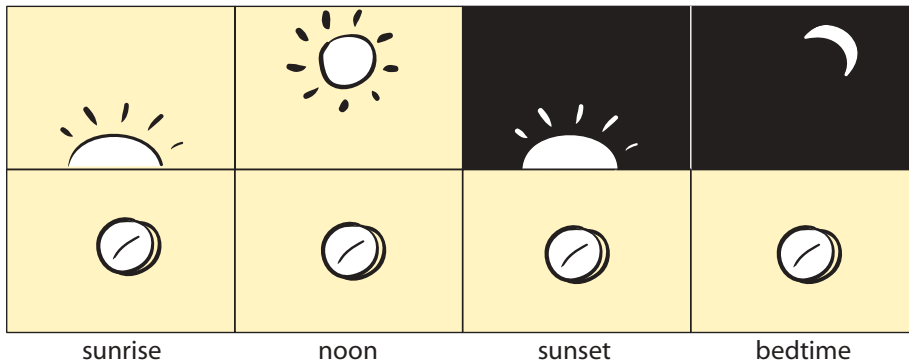


Figure 2

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 (also called Panadol®)

Paracetamol is widely available and relatively inexpensive. In patients with liver or kidney failure, paracetamol should be avoided since this drug is eliminated from the body by these two organs and it may accumulate in the body and cause problems. Nausea, vomiting, and

The dose of paracetamol is 325 to 650 mg by mouth every 4 hours regularly.

pain in the stomach could be signs that the patient 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.

Ibuprofen (also called Brufen®, Ibumex®)

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 out 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. Although 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 in the case of morphine, for example. 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 and be knowledgeable about their management (see “Nausea and vomiting” and “Constipation” sections).

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 (Narcan®) to help someone who has taken too much of a mild opioid.

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).

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 (Narcan[®]) 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 (Brufen[®], Ibumex[®]), 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.

Medication for neuropathic pain

Amitriptyline (Elavil®) 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.

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

1. 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. 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 paste or cream may be used.

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 (1 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. Vaginal douching (rinsing of the vagina) can be used once or twice a day for 5 days to decrease the amount of foul-smelling discharge due to bacterial overgrowth. Choose either a clean plastic juice or water bottle (preferably a bottle with a squirt top) and fill with one of the solutions discussed above (bicarbonate, vinegar, or metronidazole). Have the woman lie down with her bottom in a pan or dish, or on cloth or towels to catch the excess liquid (see Figure 3). Carefully insert the open end of the bottle into the opening of the woman's vagina. Gently squeeze the bottle to rinse the vagina with solution.

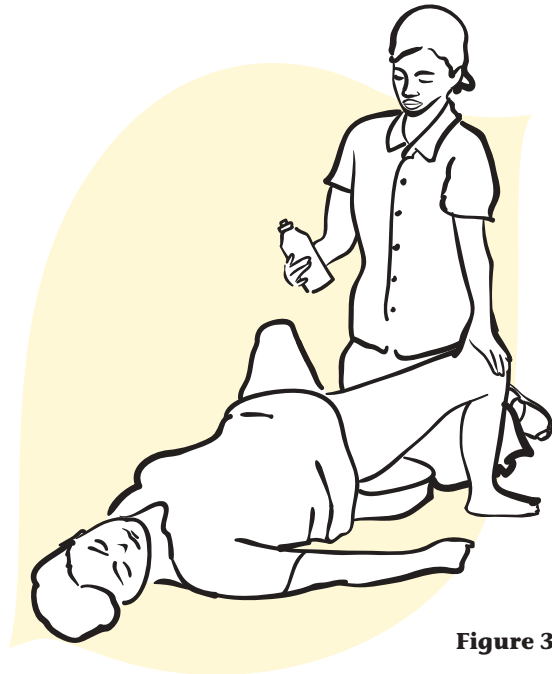


Figure 3

Some women may not be familiar with douching so teaching the process to the ill woman and her caregivers can be helpful. Rarely, vaginal douching may cause considerable or uncontrolled vaginal bleeding, so it should be used with caution.

4. To control the bacteria, broad-spectrum oral antibiotics may be used, such as:
 - Amoxicillin and metronidazole, taken together
 - or**
 - Doxycycline.

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.

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

The dose of doxycycline is 100 mg by mouth 2 times a day for 5 days. The dose of amoxicillin is 250 mg by mouth 3 times a day for 5 days. The dose of metronidazole is 400 mg by mouth 2 times a day for 5 days.

IMPORTANT NOTE

Antibiotics vary in the way that they work against specific bacterial infections and should be prescribed only if you are confident that the patient has this type of infection. It is especially important to explain to the woman and her caregivers that she should continue to take the full course of antibiotics prescribed even if she feels better.

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 in “Bacterial overgrowth”). 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 becomes sore, drying the area and applying zinc oxide paste or cream can provide relief.

Vaginal Bleeding

If severe, this symptom can be quite alarming for the patient and her family. Sexual intercourse or strenuous activity may provoke vaginal 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 or light uji, tea, soup, or clean water (water that has been boiled and allowed to cool).

Packets of oral rehydration salts for mixing with clean (boiled and cooled) 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 4).

Figure 4: Two Ways to Make “Home Mix” Rehydration Drink*

<p>1. WITH SUGAR AND SALT (Raw sugar or molasses can be used instead of sugar.)</p> <p>In 1 liter of clean WATER put several pinches of SALT and 3 rounded tablespoons of SUGAR.</p> <div style="display: flex; align-items: center;"> <div style="margin-right: 20px;"> <p>1 liter of clean WATER</p> <p>+</p> <p>Several pinches of SALT</p> <p>+</p> <p>3 rounded tablespoons of SUGAR</p>  </div> <div style="margin-right: 20px;"> <p>→</p> <p>→</p> <p>→</p> </div> <div style="text-align: center;">  <p>1 liter clean water</p> </div> </div> <p>Add half a cup of fruit juice, coconut water, or mashed ripe banana, if available. This provides potassium which may help the patient accept more food and drink.</p> <p>CAUTION: Before adding the sugar, taste the drink and be sure it is less salty than tears.</p>	<p>2. WITH POWDERED CEREAL AND SALT (Powdered rice is best. Or use finely ground maize, wheat flour, millet, sorghum, or cooked and mashed potatoes.)</p> <p>In 1 liter of clean WATER put several pinches of SALT and 5 rounded tablespoons (or 2 handfuls) of powdered CEREAL.</p> <div style="display: flex; align-items: center;"> <div style="margin-right: 20px;"> <p>1 liter of clean WATER</p> <p>+</p> <p>Several pinches of SALT</p> <p>+</p> <p>5 rounded tablespoons (or 2 handfuls) of powdered CEREAL</p>  </div> <div style="margin-right: 20px;"> <p>→</p> <p>→</p> <p>→</p> </div> <div style="text-align: center;">  <p>1 liter clean water</p> </div> </div> <p>Boil for 5 to 7 minutes to form a liquid gruel or watery porridge. Cool the drink quickly and start giving it to the patient.</p> <p>CAUTION: Taste the drink each time you give it to be sure it is not spoiled. Cereal drinks can spoil in a few hours in hot weather.</p>
<p>IMPORTANT: Adapt the drink to your area. If liter containers or tablespoons are not in most homes, adjust quantities to local forms of measurement. Where people traditionally give cereal gruels to the sick, add enough water to make it liquid and use that. Look for an easy and simple way.</p>	

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

Sips of rehydration drink or other liquids should be taken frequently (every 5 or 10 minutes) until the woman begins to produce normal amounts of urine. 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 the woman vomits.

Dehydration can cause the feeling of having a dry mouth. To relieve this feeling, the woman can suck on lozenges or candies, or can wipe the inside of her mouth with a cloth moistened with lemon and water.

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).
- Fast and deep breathing.
- Convulsions.
- No urine for over 24 hours.

NAUSEA AND VOMITING

Nausea and vomiting are a possible sign 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 pages 32-34).

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 uji, cooked bananas, or dry bread.

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

- If the cause of nausea is renal failure, prochlorperazine (Stemetil®) 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 prochlorperazine is 5-10 mg (tablets) by mouth 4 times a day.

The dose of metoclopramide is 10-20 mg (tablets) by mouth 4 times a day (before meals and at bedtime).

If severe vomiting and diarrhea make taking an oral medication impossible, a local health care provider may be able to give the woman a subcutaneous or intramuscular injection of metoclopramide or prochlorperazine. 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.
- If there are signs of severe dehydration (see page 26).

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 4, page 27).
3. If a woman with diarrhea is also vomiting or feels too sick to eat, refer to pages 26-29 for treatments for dehydration, nausea, and vomiting. Use an oral rehydration drink if possible.

The dose of loperamide is a 4-mg loading dose (2 tablets) at the start and one 2-mg tablet after each time the woman has diarrhea. Do not exceed the maximum daily dose of 16 mg (8 tablets).

4. Loperamide (Imodium®) 2-mg tablets can provide relief of diarrhea.
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 co-trimoxazole (80 mg trimethoprim/400 mg sulfamethoxazole) is 2 tablets by mouth 2 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 26).

FEVER

A temperature above 37° Celsius (C), read from a thermometer in the axilla, is considered a fever. If the patient has a high fever (above 39° C), 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 (Panadol®) 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 tepid sponging using 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 each insertion of the finger until it is not possible to remove any more stool.
 - 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 8 glasses of fluid a day will help prevent constipation.
 3. Give the sick woman fruits, green vegetables, and other foods with natural fiber, such as cassava (manioc), carrots, ground nuts, simsim (sesame seeds), and pumpkin to eat.
 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® (2 to 4 tablets at bedtime).
 - Dulcolax® (1 to 2 tablets at bedtime).
 - Milk of Magnesia® (1 to 2 tablespoons at bedtime).
 - Castor oil (1 to 4 tablespoons at bedtime).

Stool softeners such as liquid paraffin (1 to 3 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 motion 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 4 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 one 5-mg tablet by mouth 3 times a day.

The dose of dexamethasone is two or three 0.5-mg tablets, by mouth 4 times a day.

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 (see Figure 5).
- Corticosteroids (prednisone or dexamethasone) can be given to increase a feeling of well-being (see box on page 34 for dosage).

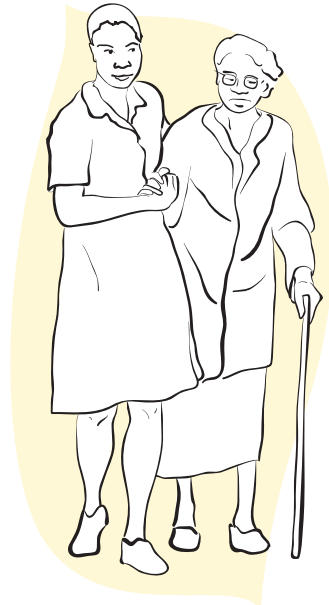


Figure 5

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 is advisable. When massaging the legs, start at the feet and ankles and massage towards the hips and body.
- 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 250-mg tablets by mouth 4 times a day or one penicillin V 500-mg tablet by mouth 4 times a day) is advisable. These antibiotics should be taken with a glass (250 ml) of clean water to avoid stomach upset. If after 3 days improvement is seen, antibiotics should be continued for 2 weeks.
- If available, a brief course of external beam radiotherapy directed at the swollen lymph glands may help reduce the swelling for a short while.

The dose of erythromycin is two 250-mg tablets by mouth 4 times a day.

The dose of penicillin V is one 500-mg tablet by mouth 4 times a day.

IMPORTANT NOTE

Antibiotics vary in the way that they work against specific bacterial infections and should be prescribed only if you are confident that the patient has this type of infection. It is especially important to explain to the woman and her caregivers that she should continue to take the full course of antibiotics prescribed even if she feels better.

When to consult a doctor or refer to the hospital:

- If an infection is not responding to antibiotic therapy after 3 days.

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 2 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. Help the sick person to turn over to a new position at least every 2 hours: face up, face down, or from side to side (see Figure 6).

2. Bathe her every day using mild soap, and massage her skin with petroleum jelly (Vaseline®), 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. Cushions or pillows can be made by placing old rags, clothes, raw cotton, leaves, grass, or any soft “filling” under a piece of material.

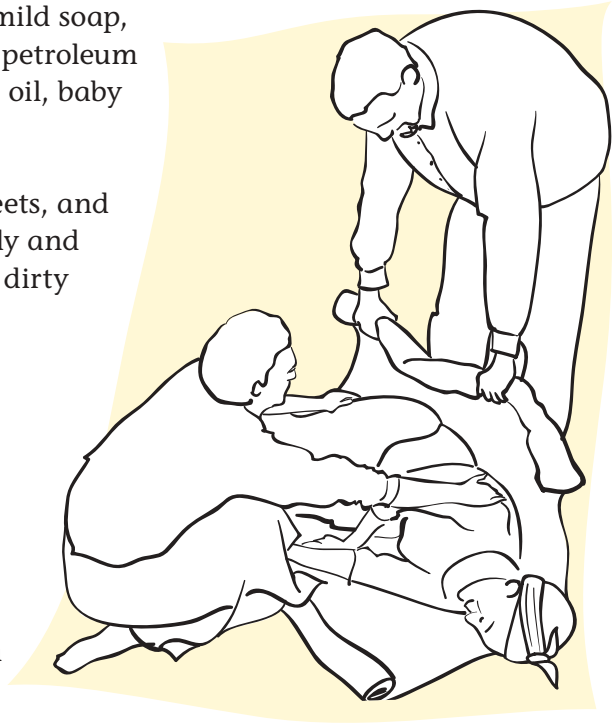


Figure 6

If the woman has bedsores:

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

Do not remove hard scabs—they should fall off on their own as the sore heals. Do not cover dry wounds (those that have a scab).

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 (pawpaw), or plain yogurt (sour milk) at least 2 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.

The dose of cloxacillin is two 250-mg capsules by mouth 4 times a day for 1 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. This can be made by mixing 1 part honey, 1 part lemon juice, and 1 part hot water. Take 1 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.

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).

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 late-stage cancer that has spread to the lungs, try to make the person as comfortable as possible.

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 2 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.

Social, Emotional, and Spiritual Issues

3

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

Good communication skills are essential to providing effective social, emotional, and spiritual support. Following the suggestion 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 (see Figure 7).
- Begin by talking about general topics before moving to personal ones.
- Ask open-ended questions (questions that do not have a “yes” or “no” answer).



Figure 7

- 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 the 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 are usually available at health centers or the district hospital.

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. “Burn out”—a state of mind in which you find the pressure and stress of the job make it impossible to continue working effectively—can be the end result. Some signs that you may be feeling burned out 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 you have less patience than usual, you get angry easily, and you 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.

Burnout 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:

- Helping them plan how they will manage the care of the sick woman and share tasks with others.
- Reminding them to make time for themselves so that they are able to get away and relax for short periods of time can give family and caregivers time to rest; respite care is available for up to two weeks at most hospices, e.g., Kisumu, Eldoret, Nairobi.
- 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, anger, and sadness can all be expressed during the time that you are visiting (see page 50 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.

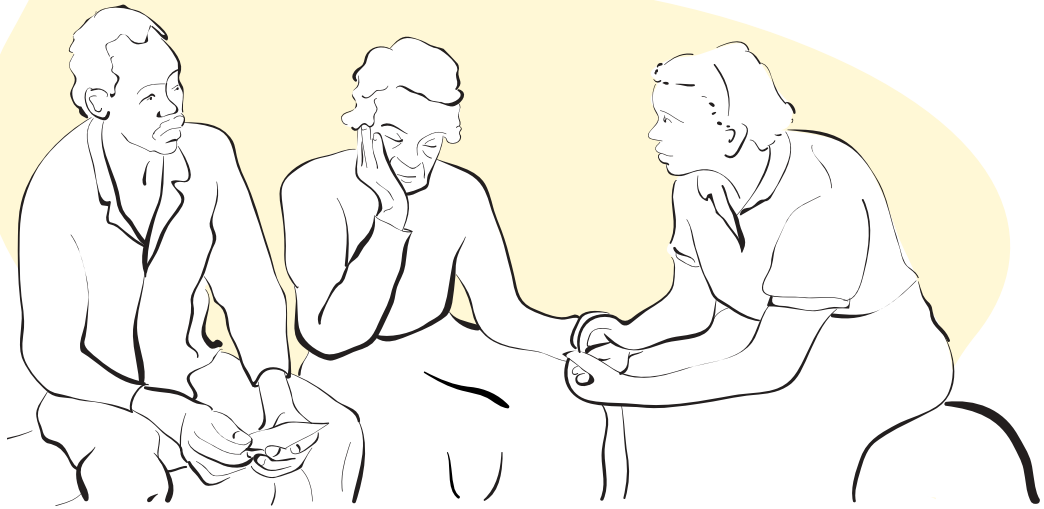


Figure 8

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. A harambee may be helpful in organizing friends, family, and others in the community 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 (see Figure 8). 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.

Emotional Support: Helping Sick Women and Their Caregivers Cope

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 in this section.

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

Women with advanced cervical cancer may feel rejected, unclean, and even untouchable. Touching the woman's arm while speaking to her, holding her hand, hugging her, and giving massage can provide great comfort and be emotionally healing (see Figure 9). 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.

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 viewed as a normal reaction, is usually not long-lasting, and for some it may be a more socially acceptable emotional reaction than anger. If her depression persists for longer than is viewed as normal, it may have progressed and become “endogenous” or “clinical depression.” Endogenous depression is important to recognize, since it can be debilitating and should be treated with counseling, antidepressant medication, and regular monitoring. A



Figure 9

woman may be suffering from endogenous 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, unusually quiet, or not interested in activities that she used to enjoy.
- 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 may admit 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, 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 4 to 6 months and then re-evaluated.

A typical regimen to start a woman on might be:
amitriptyline one 25-mg tablet by mouth at bedtime for 2 nights, then two 25-mg tablets at bedtime for 2 nights, then three 25-mg tablets at bedtime.

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 officer 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 officer in charge immediately.

ANGER

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 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, angry, or frustrated.

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 patient 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, a friend, a counselor, or a 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 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.

Relatives may feel guilt as well. The husband may feel as if he has neglected the woman and this has made her disease worse. 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 to care for the woman, 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 and religious beliefs of a patient and her family, no matter what religion they practice. 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. A 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 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 for the patient, her family, and caregivers. 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 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 woman. 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 or bladder. 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 laying out (preparing and displaying) the body of someone who has died. 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 patient, 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 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.

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APPENDIX 1: STAGES OF CERVICAL CANCER

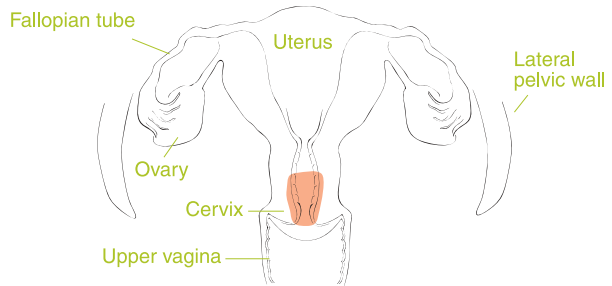
Stage I A

Carcinoma is strictly confined to the cervix, but can be diagnosed only 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.

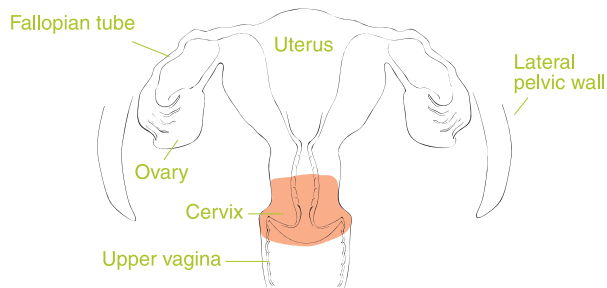
Stage II A

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

Usual Symptoms: Vaginal discharge may be serous, mucopurulent, bloodstained, 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%.



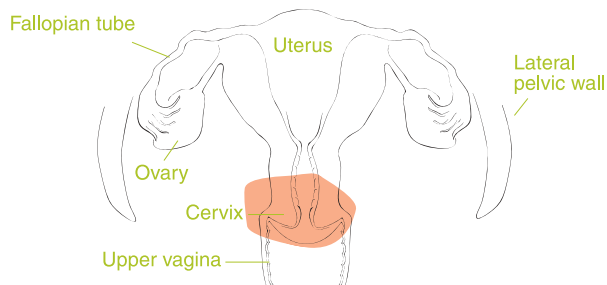
Stage II B

Cancer has spread beyond the uterus, 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 IIA, 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%.



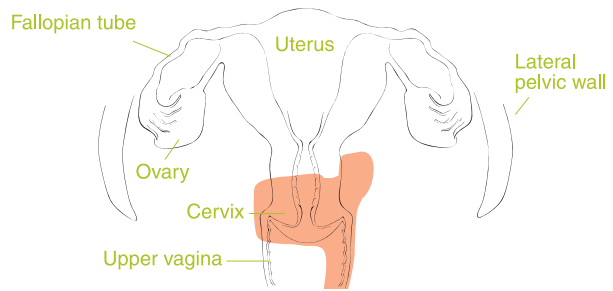
Stage III A

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: Radical radiotherapy with or without concurrent chemotherapy.*

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



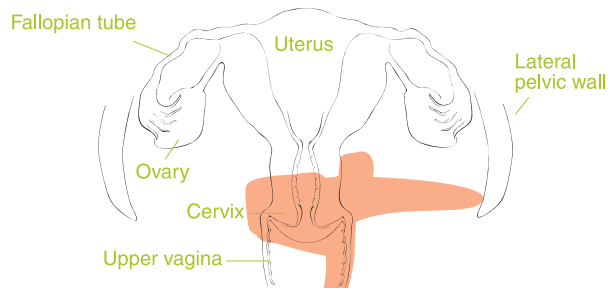
Stage III B

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

Usual Symptoms: Similar to III A, severe pain in lower abdomen and lower back, often one or both legs swollen. May be signs and symptoms of uraemia (chronic renal failure) due 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.

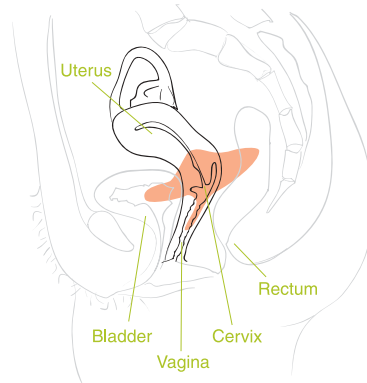
Stage IV A

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, recto-vaginal fistula.

Optimal 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 mid-back pain.
- Lungs—intractable, nonproductive cough.
- Liver—abdominal swelling (right upper quadrant pain and tenderness, jaundice).
- Skin—large, non-tender, nodular skin swellings.
- Lymph nodes—enlarged lymph glands.
- Brain—convulsions, confusion.

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

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

APPENDIX 2: TABLE OF COMMONLY USED, AVAILABLE DRUGS AND COSTS

Category	Medications commonly available in Busia	Approximate cost (Ksh) as of September 2002
Analgesics		
Non-opioid	Paracetamol 500-mg tablet	0.50
	Ibuprofen 200-mg tablet	0.50–1
Weak opioid	Codeine phosphate 30-mg tablet	7
	DF 118 tablet	20
Strong opioid	Morphine 10-mg/ml oral solution	3 per ml*
Helper drugs	Ibuprofen 200-mg tablet for bone pain	0.50–1
	Amitriptyline 25 mg for neuropathic pain	2†
Appetite stimulant (also used to increase sense of well-being)	Prednisone 5-mg tablet	0.50–1
Stimulant laxative	Senokot® tablet	1–3
	Dulcolax® tablet	1–6
Anti-nausea/ vomiting		
Opioid or physical obstruction to gastric outflow	Metoclopramide 10-mg tablet	1–2
	Domperidone 10-mg tablet	12
Uremia/hypercalcemia	Haloperidol 5-mg tablet	5–10†
	Stemetil 5 mg	6–10
Antibiotics	Erythromycin 250-mg tablet	5
	Amoxicillin 250-mg cap	3
	Doxycycline 100-mg tablet	1–4

* Kisumu Hospice

† Available at no charge at the district hospital.

Category	Medications commonly available in Busia	Approximate cost (Ksh) as of September 2002
Antibiotics cont.	Antibiotic powder (neomycin, bacitracin, gramicidin) 10 g	60
	Metronidazole 200-mg tablet IV solution 500 ml	0.67–1 30–65
	Cloxacillin 250-mg cap	5
	Cotrimoxazole (trimethoprim 160-mg/sulfamethoxazole 800-mg) tablet Penicillin V 500-mg tablet	1 2
Vaginal antiseptic	Betadine iodine pessaries	105–300
Oral rehydration	ORS sachet	10*
Skin care	Zinc oxide cream 100 g	30
	Petroleum jelly 50 g 100 g	25 45
Antidepressant	Amitriptyline 25-mg tablet	2*
Anti-fungal	Fluconazole 100-mg cap (1 by mouth daily x 7 days)	105–320 (7-day pack)
	Ketoconazole/Nizoral/Hitoral 200-mg tablet (1 by mouth daily x 7 days)	30–80 (7-day pack)
	Clotrimazole 100-mg vaginal pessary (1 daily x 6 days)	30–60 (6-day pack)
	Nystatin vaginal pessary (1 daily x 14 days)	60–120 (14-day pack)
Anti-diarrhea	Loperamide 2-mg tablet	4 - 6

* Available at no charge at the district hospital.

APPENDIX 3: PATIENT MEDICATION CHART–SAMPLE*

Medication name (attach tablet/capsule with cellotape)	Reason	Morning		Afternoon		Evening		Night	
		8 a.m.	10 a.m.	2 p.m.	4 p.m.	6 p.m.	8 p.m.	10 p.m.	Bed Time

* Nairobi Hospice, Kenya

APPENDIX 4: PALLIATIVE CARE PATIENT RECORD FORM—SAMPLE

WESTERN KENYA CERVICAL CANCER PREVENTION PROJECT

Palliative Care Patient Record

Assessment completed by: _____

Place of assessment: _____

Health facility where diagnosis was made: _____

Patient Information

ID/Number:	Palliative care ref. no.:	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 WKCCPP, to be filled in by MYWO district coordinators or nurses at the health center or district hospital for women needing palliative care. Women carry the form to the palliative care team at the Provincial General Hospital (PGH) or local hospice to use as an ongoing patient care and referral record.

Contact

Name of contact	Relationship	Postal address	Location	Sub-location
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				
Diarrhea				
Nausea + 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 & 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?” _____

Insight of Patient & 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

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

Palliative Care Plan

Enter each complaint/diagnosis separately and complete a management plan for each. Please refer to Chapter 2 for the management of each sign and 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.			
Other remarks:			

Follow-Up Sheet

Date: _____
DD / MM / YYYY

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

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

*Please tick according to severity.

2. Remarks:
3. Fill in new palliative care plan if required:
4. Overall impression:

