

Caring for Cancer Patients

A BOOKLET FOR CAREGIVERS OF
CANCER PATIENTS



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1.

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December, 2016

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3.

Introduction

If you are helping a person who has cancer, this book is written for you. It answers many questions you might have about cancer and how to care for your loved one.

It shares suggestions for supporting and caring for a person who has cancer from the time when they first learn about their disease, as well as during and after treatment.

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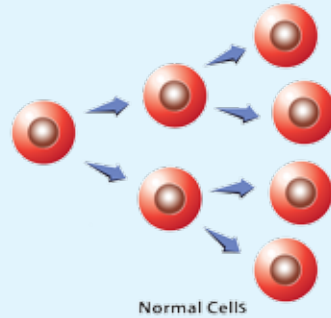
What is cancer?

Cancer is a disease where cells grow and multiply out of control. This makes it hard for the body to work the way it should.

What are cells?

The human body is made up of millions of tiny cells. Normal cells grow and divide to make new cells as the body needs them. Usually, when cells get too old or damaged, they die. Then new cells take their place.

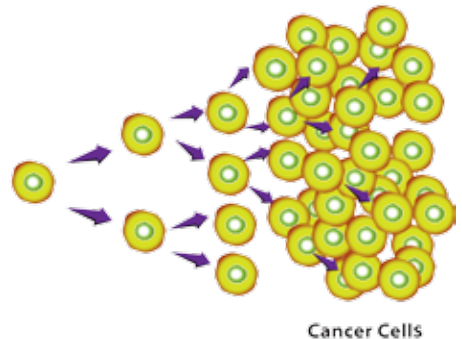
Normal Cell Division



Cancer cells are abnormal

They continue to grow and divide until there are too many. These cells crowd out normal cells. This causes problems in the part of the body where the cancer started. Cancer cells also move to other parts of the body, which a normal cell cannot do.

Cancer Cell Division



5.

Types of cancer

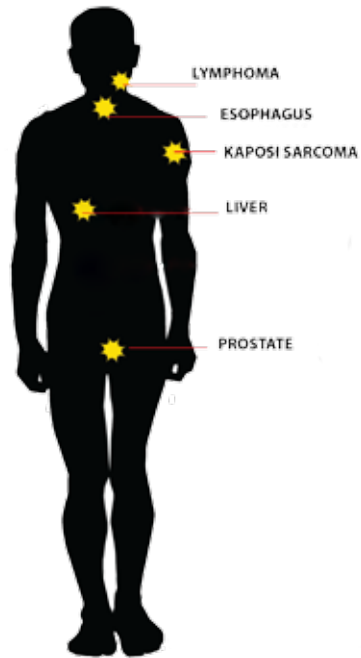
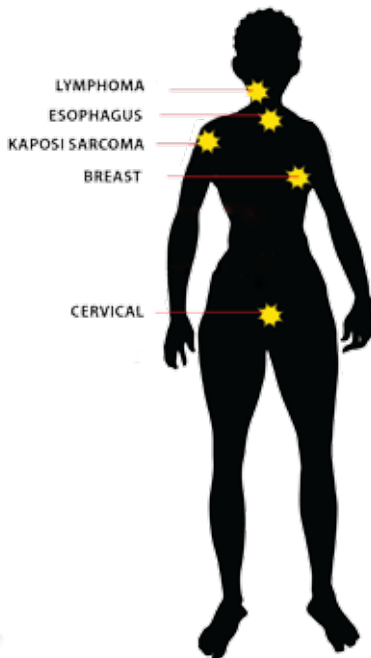
Cancer cells can start in any part of the body. They can also move to other parts of the body and grow there. The type of cancer is named after the place where it started. If cancer started in the breast, then it is called breast cancer.

There are many types of cancer. Some cancers grow and spread fast. Others grow more slowly. They also respond to treatment in different ways.

When someone has cancer, the doctor will want to find out what kind of cancer it is.

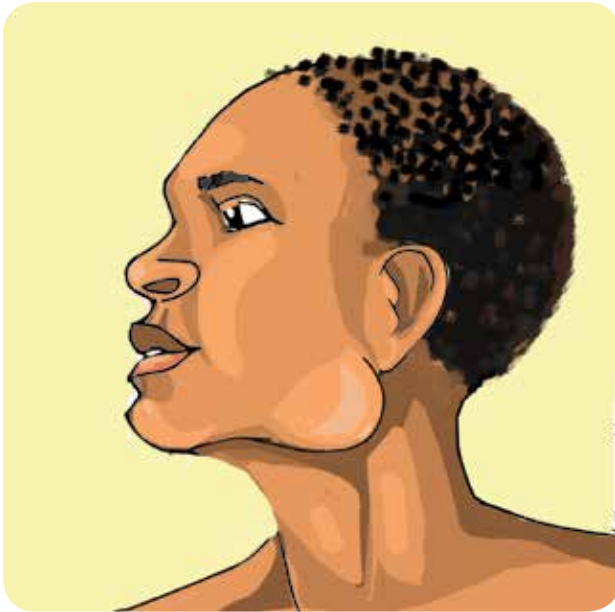
The 5 most common cancers in women in Uganda

The 5 most common cancers in men in Uganda



What is a tumour?

A tumour is a lump or swelling. Most cancers form tumours. But not all tumours are cancer. There are some cancers, like leukemia (cancer of the blood), that do not form tumours. Instead, they grow in the blood cells or other cells of the body.



Tip for caregivers: Make sure the patient understands what cancer is, and is not. Talk about it openly, and ask the health worker questions.

6.

What causes cancer?

There is no one cause of cancer. But, there are risk factors that increase one's chance of getting cancer. These include:

- ⚙ Some types of infections, such as HIV and human papillomavirus (HPV).



- ⚙ Breathing tobacco smoke, smoke from burning buveera or breathing in fumes from diesel engines.



- ⚙ Eating a diet without enough fruits and vegetables and being overweight.



- ⚙ Growing old. As our bodies age, our risk of cancer increases.



Cancer is NOT caused by witchcraft or a curse. It is NOT a punishment for something the cancer patient has done.

7. Is cancer contagious?

Cancer is NOT contagious. It does not spread from person to person like HIV.

You cannot get cancer by caring for a cancer patient, spending time with them or eating with them.

Some cancers may be caused by viruses and bacteria that can spread from person to person. However, the cancers caused by these germs cannot spread from person to person.



8.

Is cancer inherited?

Some cancers can run in families, but cancer isn't passed on from parent to child the same way that height is. Cancer also cannot be passed from mother to child in the same way as HIV. Cancer is caused by changes in the way cells divide. These changes almost always happen during a person's lifetime as a result of risk factors like smoke from tobacco or burning buveera.



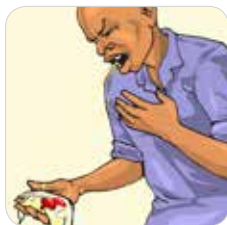
9.

What are common symptoms of cancer?

There are some symptoms and signs of cancer. These should not be ignored, especially if they have lasted a long time or get worse. Common symptoms of cancer include:



Unexplained weight loss



Unusual bleeding



Sores or changes to your skin that do not go away



A lump or swelling



Unexplained pain

These symptoms can also be caused by something other than cancer. However, it is always best to have them checked by a health worker, as soon as possible.

There are many other symptoms of cancer that are not listed here. If you notice any major changes in the way your body works or the way you feel – especially if it lasts for a long time or gets worse – get checked by a health worker.

10.

How is cancer diagnosed?

Usually, the patient first visits a health worker because they have a symptom of cancer. In other cases, the cancer is found during cancer screening.

What is cancer screening?

Sometimes, it is possible to find cancer before having symptoms. The Ministry of Health recommends check-ups and certain tests for cervical and breast cancer for women even though they have no symptoms. This helps find these cancers early, before symptoms start.

Tip for caregivers: If you have never been screened for cervical or breast cancer, now is a good time to do it. You can also share this information with other family members.

If the health worker thinks the patient might have cancer, they will ask them to have a biopsy to make sure. They may also ask them to have x rays, scans and blood tests. Often they will want them to have more than one of these tests.

11. What is a biopsy?

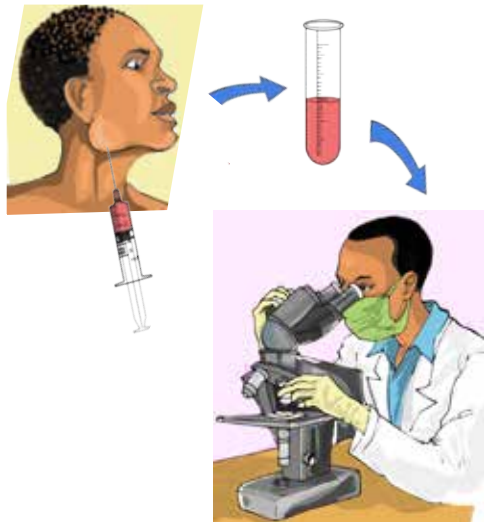
A biopsy is the only way to be sure whether cancer is present. During a biopsy, the doctor removes a small piece of the tumour and examines it under a microscope. Sometimes, this is done with a needle. Sometimes the doctor cuts out a small piece of the tumour. The doctor will give medication so that the patient will not feel pain during the procedure.

If there are cancer cells, the doctor can identify what type of cancer it is and how fast it is likely to grow.

- ⚙ Biopsies do NOT cause cancer to spread to other parts of the body.
- ⚙ Biopsies do NOT leave a big wound. Only a very small piece of the tumour is removed.

Tip for caregivers:

Often, patients avoid getting biopsies because they are afraid. Delays in getting biopsies cause delays in starting treatment. Meanwhile, the cancer will continue growing and may spread. Talk with the patient about their fears. Ask the health worker to explain clearly how the biopsy will be done, and answer all the patient's questions.



12.

Can cancer be cured?

Having cancer is not a death sentence. If the patient starts and completes treatment at an early stage, chances are good that they will survive.

Many factors affect how long a person survives after getting cancer. These include:

- ⚙ The type of cancer and where it is in the body
- ⚙ The stage of the cancer
- ⚙ If the cancer is fast or slow growing
- ⚙ The patient's age and how healthy they were before getting cancer
- ⚙ How they respond to treatment.

Ask the health worker what the patient can expect.

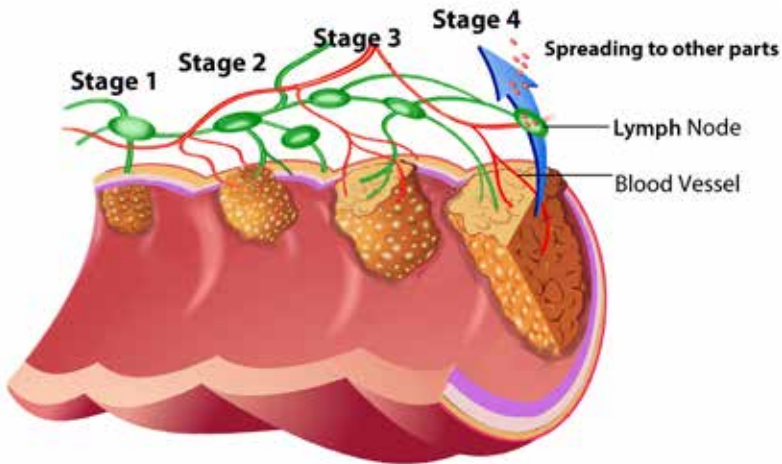
13. Staging

Once the patient is diagnosed with cancer, the doctor will determine how big the tumour is and whether or not the cancer has spread from where it started. This is called the cancer stage. Knowing the stage of the cancer helps the doctor decide what type of treatment is best, and helps determine the likelihood of cure.

For most cancers, there are four stages:

- ⚙ Stage 1 or 2 means that the cancer has not spread to other parts of the body, and can more easily be treated.
- ⚙ Stage 3 means it has begun spreading, and will be more difficult to treat.
- ⚙ Stage 4 means the cancer has spread to many other places in the body and is unlikely to be cured.

The patient should ask the doctor to explain the stage of their cancer and what it means for them.



14. Treatment options

The types of treatment that the doctor prescribes will depend on the type of cancer, the stage of the cancer, and the patient's age and overall health.

Purposes of treatment

The purpose of treatment may be to cure the cancer, control it, or treat problems it is causing. You should ask the doctor what the purpose of treatment is.

Types of treatment

The most common treatments for cancer are surgery, chemotherapy and radiotherapy. A person with cancer may have any or all of these treatments.

Cost of treatment

The cost of treatment depends on the type of cancer and how long the cancer lasts. After treatment, cancer may come back again and require another type of treatment. If the patient lives far from the treatment facility, they need to be prepared to pay for transportation, food, and accommodation. Some organisations listed at the end of this booklet offer assistance to cancer patients during treatment.

Tip for caregivers:

Ask the patient if they want you to go along with them when they get their biopsy results. Most of the time people are shocked when they first hear that they have cancer. It may be hard for the patient to hear or remember anything else after that. So you will need to pay close attention to what the doctor says. You may want to write down what the doctor says. Later on, you may need to remind the patient about what was said.

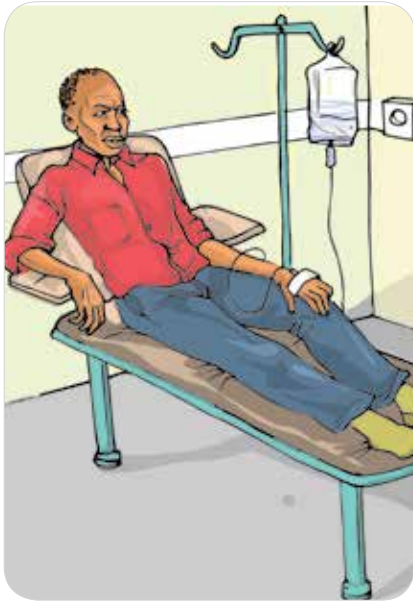
Surgery

Surgery can be used to remove the cancer. The doctor might also take out some or all of the body part the cancer affects. For breast cancer, part (or all) of the breast might be removed. For prostate cancer, the prostate gland might be taken out. Surgery is not used for all types of cancer. For example, blood cancers like leukemia are best treated with drugs. Surgery may be used to cure the cancer, control it, or treat problems it is causing.



Chemotherapy

Chemo (short for chemotherapy) is the medicine used to kill cancer cells or slow their growth. Some chemo is given by drip (into a blood vein through a needle), and others are given as pills. Because chemo travels to nearly all parts of the body, it is useful for cancer that has spread. Chemo may be given to cure cancer, control it, or treat problems it is causing.



Radiotherapy

Radiotherapy is also used to kill or slow the growth of cancer cells. Special equipment sends high doses of radiation to kill cancer cells in a part of the body. Radiation can harm normal cells near the cancer cells. But, normal cells can repair themselves, and cancer cells cannot. Radiotherapy does not feel hot and is not usually painful. It can be used alone or with surgery or chemo. Radiotherapy may be used to cure cancer, to slow the growth of cancer or to make the patient more comfortable.



15. What are side effects of treatment?

Surgery, radiotherapy and chemo can have side effects. It's hard to predict what side effects a person will have. Even when people get the same treatment they can have different side effects. Some can be severe and others mild. Most side effects of cancer treatment can be treated. The side effects one may experience after surgery differ depending on the type of surgery.

Radiotherapy side effects:

Radiation treatments are usually painless, but they can cause skin sores or rashes and extreme tiredness. Tiredness often lasts for many weeks after treatment ends. Other side effects can happen, too, depending on what part of the body is being treated.



Chemo side effects:

Side effects of chemo usually only last while the patient is taking chemo and can often be treated. Common side effects can include:



nausea and vomiting



bleeding or bruising after minor cuts or injuries



appetite loss



extreme tiredness



temporary hair loss



mouth sores



higher risk of infection



diarrhoea or constipation



tingling pain in hands or feet.



fever

Most chemo side effects go away after treatment ends. For example, hair lost during treatment grows back after treatment is over. In the meantime, most patients use wigs, scarves, or hats to cover their heads.

Dealing with mouth sores

Mouth sores are little cuts or ulcers in the mouth. The sores may be very red, or may have small white patches in the middle. They may bleed. Mouth sores can be so painful that your patient will not want to eat or drink anything.

What caregivers can do

- ⚙ Use a torch to check the patient's mouth for red areas or white patches, which often become sores.
- ⚙ Offer liquids with a straw, which may help bypass the sores in the mouth.
- ⚙ Offer soft foods. Mash foods to make them easier to eat.
- ⚙ Ask the doctor for medicine to coat mouth sores with before meals to numb them during eating.
- ⚙ Offer pain medicines 30 minutes before mealtime.

16. What is remission?

After treatment, some patients go into remission and some are cured. Remission means that the signs and symptoms of cancer are reduced. Remission can be partial or complete. In a complete remission, all signs and symptoms of cancer have disappeared. If a patient remains in complete remission for 5 years or more, the doctor may say they are cured. Cure means that there are no traces of cancer after treatment.



17. Palliative care and pain management

Palliative care focuses on relieving pain, stress, and discomfort caused by cancer. It should be given together with treatment. Palliative care is not intended to cure the illness.

Pain is common with cancer. But, it can be controlled or relieved with medication.

Many people think that they will become addicted to pain medication. This is not true with the dosages and types of medicine used in Uganda. If the patient is in pain, you need to tell the health worker so they can prescribe or adjust the dose of pain medication.



How to help your patient cope with pain

- ⚙ Talk with the doctor or nurse so that you understand which medicines are for pain and how each is to be used.
- ⚙ Check with the doctor or nurse before you crush or dissolve pain pills to make them easier to swallow. Some pills can cause a dangerous overdose if broken.
- ⚙ Help the patient remember when pain medicines are due.
- ⚙ Watch the patient for signs of pain, including grimacing, moaning, tension, or reluctance to move around in bed.
- ⚙ Watch for signs that the patient is taking too much pain medicine: sleeping too much, and difficulty waking up.
- ⚙ Try warm baths or warm washcloths on painful areas, but avoid areas where radiation was given. Gentle massage or pressure might also help some types of pain.
- ⚙ Suggest fun activities to distract the patient from their pain.
- ⚙ Offer plenty of drinking water.
- ⚙ Keep pain medicines away from others, especially children and pets.

18. Caring for patients

Cancer patients need different kinds of care depending on which stage of the disease they are in. Patients who have just learned they have cancer have very different needs from a patient who is taking treatment or one who is facing the final stage of life.



Immediately after diagnosis

Patients react to the news that they have cancer with shock, sadness, anger, and denial. Sometimes the patient may take out their anger on family, friends, or anyone who happens to be around at the time. As the caregiver, you need to be patient and not take the patient's anger personally. With time, anger will pass.

Some patients deny that they have cancer, even when they have been told by the health workers. Patients who are in denial can be very difficult to deal with because they may refuse to follow the doctor's instructions, or to discuss their disease with their families. As their caretaker, you need to gently remind them of what their doctor has said, and the decisions they need to make.

Dealing with anger and denial.

You can help the patient accept they have cancer and make plans based on their likelihood of survival. Ask the patient if you can accompany them when they see the doctor. Listen carefully to what the health worker says, and ask questions if you do not understand. Try to understand your patient's cancer stage, chances of cure and survival and the treatment options available to them. Afterwards, you will be able clarify things for the patient, and remind them of what the doctor has said.

Adopting a healthy lifestyle.

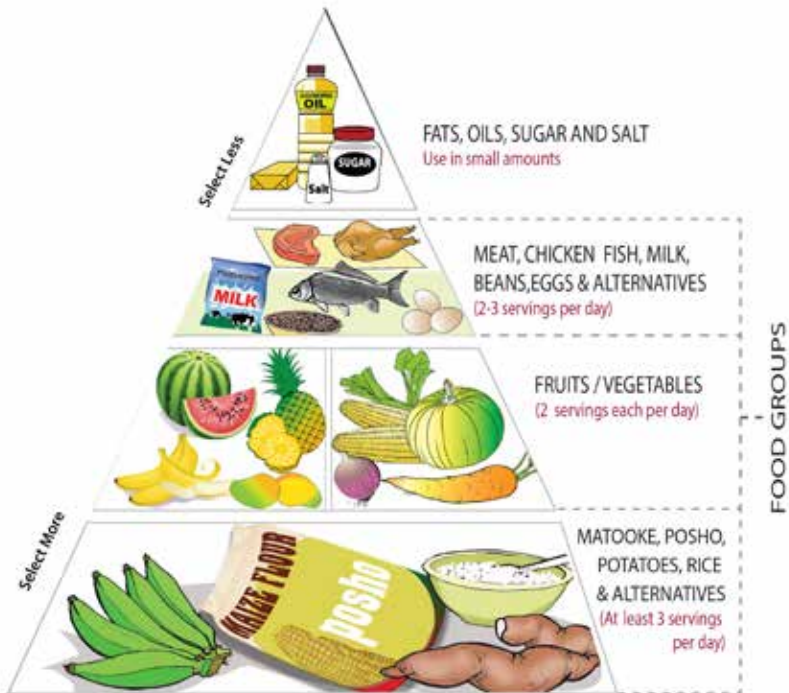
You can help the patient stay strong, and improve their chances of survival by promoting a good diet, regular exercise, and avoiding alcohol and cigarettes.

Diet.

If cancer patients adopt a good diet from the beginning, it will help them greatly as the disease progresses and when they are on treatment. As a caregiver, you can prepare meals that contain a variety of foods, and offer enough food to help the patient maintain their weight.

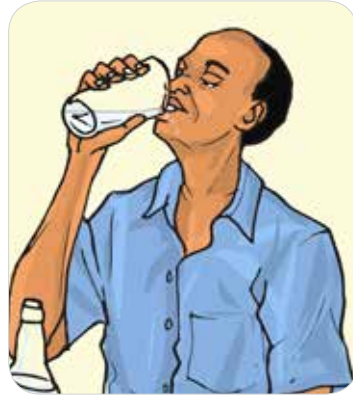
Eating well means eating foods from the three food groups at least three times each day.

The pyramid below shows how much of each food group one should eat each day. People should eat less of the foods at the top and more of the foods at the bottom. Oils, fats, salt and sugar can be dangerous to health in large quantities, so the patient should not eat much of these.



Water.

Offer the patient water and healthy drinks like fruit juice frequently. People need to drink at least eight large glasses of water each day. They may need extra fluids if they are vomiting, have diarrhoea, or if they are not eating much. Patients should avoid drinking alcohol and sodas.



Exercise.

Physical activity can help keep the patient strong, and it can help reduce stress, tiredness, nausea, and constipation. It can also improve their appetite.

If the patient is not used to regular exercise, and their doctor approves, encourage them to start exercising 5 to 10 minutes each day. If they exercised regularly before learning that they have cancer, and their doctor approves, encourage them to continue their exercise routine. Talk to their doctor before they start any type of exercise program.



During treatment

Some patients do well on treatment and others have a very difficult time. You can help patients cope with side effects, and recognize when they need to seek medical assistance. Most side effects can be relieved.

Often, people will lose their appetite when on treatment. They may eat much less than normal or may not eat at all. Here are some things you might try to help the patient eat more.

- ⚙ Try giving the patient six to eight small meals and snacks each day.
- ⚙ Offer starchy foods, such as posho, Irish potatoes, chapatti, with chicken, meats, fish, eggs, peas, or beans.
- ⚙ Offer fruit juices, tea with milk, or soup when the patient doesn't want to eat.
- ⚙ Keep cool drinks and juices within the patient's reach.
- ⚙ Try plastic forks and knives if the patient is bothered by bitter or metallic tastes.
- ⚙ Don't blame yourself if the patient refuses food or can't eat.
- ⚙ Be encouraging, but try not to fight about eating.

After surgery

Patients who have had surgery may worry about how they will look afterwards. Breast cancer patients who have surgery are particularly concerned about this. It might be helpful to ask someone from the Uganda Women's Cancer Support Organisation (UWOCASO) to speak with your patient. UWOCASO provides artificial breasts for women who have had surgery for breast cancer.

Caring for patients during the final stage of life

Some people have cancer that no longer responds to treatment and must face the fact that they will soon die. This is scary for the person who is sick and for those around them. The person with cancer may be in pain, may be bedridden, may be able to walk only a few steps, or may be confused.

Helping patients to eat:

Patients often lose their appetites as the disease worsens. Offer them small portions of food frequently. If the patient is unable to feed themselves, you will need to help them. Make sure the patient is sitting up so they do not choke. Use a small spoon, and give the patient time to chew and swallow before offering another.



Helping with personal hygiene:

As the patient weakens, you will need to help them bathe, change bedding, and change clothes. If the patient can get out of bed, it is good to have them sit from time to time. If the patient cannot leave the bed, help them change position frequently. Make sure the patient does not lay in the same position for longer than a few hours.

Loss & bereavement:

As your patient nears death, both you and they may feel angry, sad, and scared. No matter how hard it may be, it is important to try to be there for the person with cancer. Just staying close and listening with a smile or gentle touch shows you care.

Some patients want to talk about dying. They may ask you what to expect. Will it be painful? How long with it last? The patient may ask, "Why is this happening to me?" It is very hard to hear these question because there is no answer. You can simply say, "I don't know." Holding your patient's hand and letting them cry or talk about their sadness and regrets is the best you can do.



19. Caring for yourself

Caring for a cancer patient can be tiresome, worrying, sad and lonely. You should not spend every spare minute thinking about or being with your patient. You need relief and rest to stay emotionally and physically fit and to help the person with cancer.

Asking for help and taking time off

Plan time for yourself. Ask friends or other family members for help. Tell them exactly what they can do to help. This can take some of the pressure off and allow you time to take care of yourself.



Tip for caregivers:

Look for areas where you need help. Make a list. Hold regular family meetings to keep everyone up to date. Include the patient. Ask family and friends when they can help and what jobs they think they can do. Be very clear about what you need.

Stay healthy:

Exercise, eat well, and get enough rest. Eat three meals each day with foods from all the three food groups. Take regular exercise and avoid becoming overweight. If you smoke cigarettes, stop. Avoid drinking excessive amounts of alcohol.

Protect yourself and your family from cancer:

Get screened for breast and cervical cancer. If you have any signs of cancer, see a doctor for a check up. Share all that you know about cancer, its prevention, and its signs with your family and friends.



20.

Where to go for more information and services

Cancer treatment services

Uganda Cancer Institute (UCI): Old Mulago Road, Uganda Cancer Institute Campus, Kampala; phone: 0414 540 410; provides detection and screening, specialised diagnostics, chemotherapy and radiotherapy treatment, and palliative and rehabilitation programmes.

St. Francis Hospital Nsambya: Plot 57 Nsambya Road, Kampala; phone: 0414 267012; provides cancer treatment through chemotherapy and referrals for radiotherapy.

Case Hospital: Plot 69/71 Buganda Road, Kampala; phone: 0414 250362; 0701 250362; provides cancer diagnostic and treatment services, including chemotherapy, surgery, and referrals for radiotherapy.

Nakasero Hospital: Plot 14A Akii Bua Road, Nakasero, Kampala; phone: 0392 346152; 0392 346153; 0312 531400; Provides cancer diagnostic and treatment services, including chemotherapy, surgery, palliative and rehabilitation programmes.

International Hospital Kampala: Plot 4686 St Barnabas Road, Kisugu – Namuwongo, Kampala; phone: 0312 200400; 0414 309800; 0772 200400; 0712 200400; provides detection and screening, specialized diagnostics, chemotherapy, surgery, and palliative and rehabilitation programmes.

Cancer support services

Uganda Women's Cancer Support Organisation (UWOCASO): Plot M3 Suuna Road Ntinda Stretcher, Kampala; phone: 0414 590

897; provides artificial breasts/bras to women survivors of breast cancer, provides transport to UCI for cervical and breast cancer patients, and provide client education about breast and cervical cancer.

Uganda Women Health Initiative: Bethel House, Mildmay Centre, Lweza, Entebbe Road, Uganda; phone: 0772 501 700; free screening and treatment for cervical cancer to women of all ages.

Cancer Charity Foundation/Haven hostel: LRV 1428, Folio 12 Land Kyadondo Block 273, Plot 1021, Namasuba, Kampala; phone: 0312 111467; 0702 970749; provides free accommodation for patients who live outside Kampala during treatment.

Women's Hostel at Mulago: P.O Box 3935, Kampala; phone: 074 761064; 0705 907078; provides accommodation for patients with cervical and breast cancer during chemotherapy and radiotherapy.

Bless a Child Foundation Uganda: P.O. Box 36152, Kampala; phone: 0200 905945; provides basic physical needs like hygiene, shelter, clothes, hostel accommodation whilst undergoing treatment and terminal care for children with cancer and their families.

Palliative care

Kagando Mission Hospital [KARUDEC]: Off Fort Portal-Mpondwe Road, Kasese; 0772 425150; provides cancer screening and palliative care for cancer patients.

Kawempe Home Care: Erisa Zone, Kyebando, along Gaya Road, Kawempe Division, Kampala; phone: 0414 530414; provides holistic home care to people living with tuberculosis, HIV/AIDS and cancer. Provides transportation, meals and accommodation for cancer patients

Hospice Africa Uganda (HAU): 130 Mobutu Road, Makindye, Kampala; phone: 0414 266867; 0704 161120/1/3; provides holistic palliative care for cancer patients.

Makerere Palliative Care Unit (MPCU); Mulago Hospital, Kampala; phone: 0772 595672; offers a palliative care and patient navigation service for inpatients across Mulago Hospital, Uganda Cancer Institute and Women's Hostel at Mulago.

St. Francis Nagalama Hospital, Nagalama, Mukono- Kayunga Road, Mukono; phone: 0772 593665; offers palliative care for cancer patients.

Kitovu Hospital Mobile: P.O. Box 270, Masaka; phone: 0481 420113; provides holistic palliative care for cancer patients.

Hospice Tororo: Old Administration offices at Tororo General Hospital, Tororo; phone: 0703 916997; provides palliative care for cancer patients.

Rays of Hope, Hospice Jinja: Jinja; phone: 0774 485 099; provides palliative care for cancer patients in Busoga region.

Christian Outreach Mission and Evangelism (COME): Mulago Hospital, Kampala; phone: 0414 389 116; volunteer staff offer destitute and needy cancer patients care: bathing them, feeding them, giving them clothes and bedding, and locating relatives.

Joy Hospice Mbale: Buwasunguyi Clinic, Mbale; provides palliative care for cancer and end-stage AIDS patients.

Little Hospice Hoima: 2A Kijungu Hill, Hoima, 430; phone: 036 2260000; provides care to terminally ill patients with cancer, HIV or AIDS through outpatient and home care services. Services include pain relief, nutritional support, financial support, family counselling and bereavement support.

Patient Relief Mission: Plot 1408 Kawempe Mbogo, Mumyuka Road Block 208; phone: 0392 943 221/0753 848 986; provides accommodation, meals and transport for female cancer patients and their caregivers during treatment.

Online Resources

Uganda Cancer Society: <http://ugandacancersociety.org/>

American Cancer Society: <http://www.cancer.org/>

MacMillan Cancer Support: <http://www.macmillan.org.uk/>

National Cancer Institute (USA): <http://www.cancer.gov/>

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