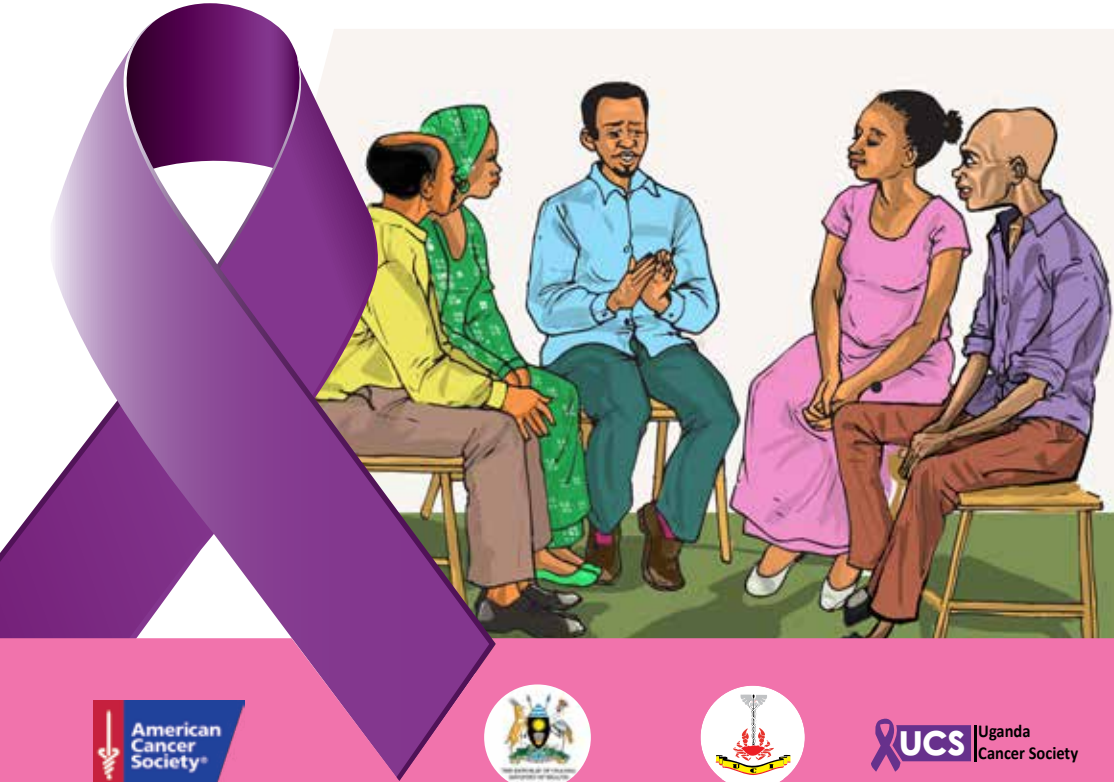


Coping with Cancer

A BOOKLET FOR CANCER PATIENTS



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December, 2016

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“I have been a breast cancer survivor for 16 years and...I would be dead if I had not braved surgery and gone for treatment.”

Outreach worker, Uganda Women's Cancer Support Organisation

1.

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2.

Introduction

Finding out you have cancer brings many changes and you may have lots of questions.

Here, we answer many questions about cancer and cancer treatment. We hope this information will help you and your family.

This is not meant to replace the advice of your doctor or nurse. Talking with them is the best way to understand what is going on with your body and how treatment will work.

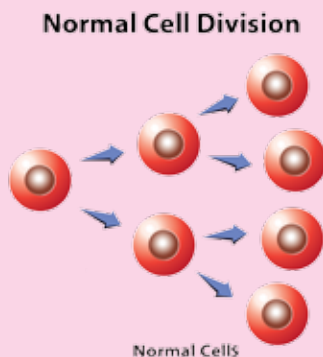
3.

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.

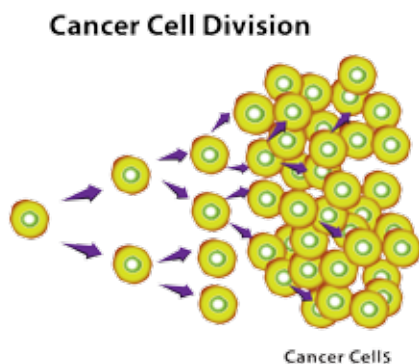
What are cells?

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.



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.



4.

Types of cancer

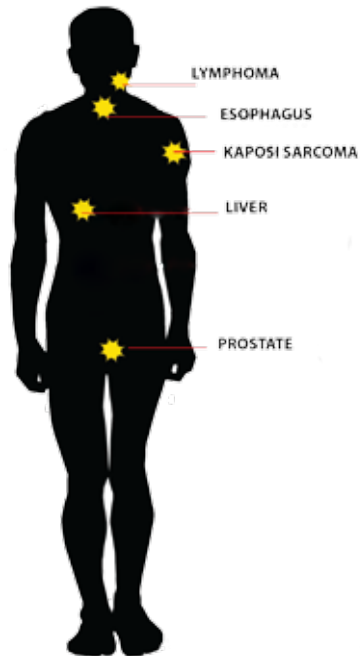
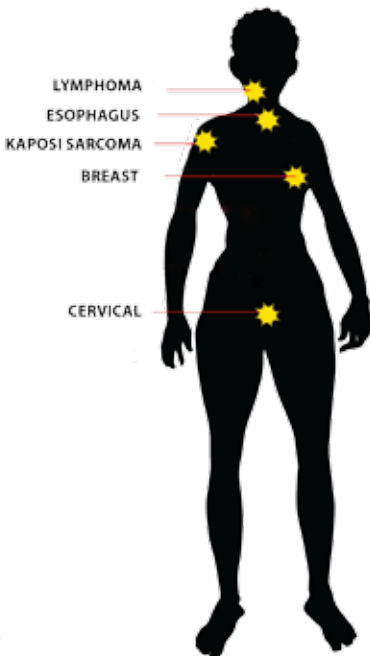
Cancer cells can start in any part of the body. They can also move to other parts of the body and grow there. The type of cancer is named after the place where it started. If cancer started in the breast, then it is called breast cancer.

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

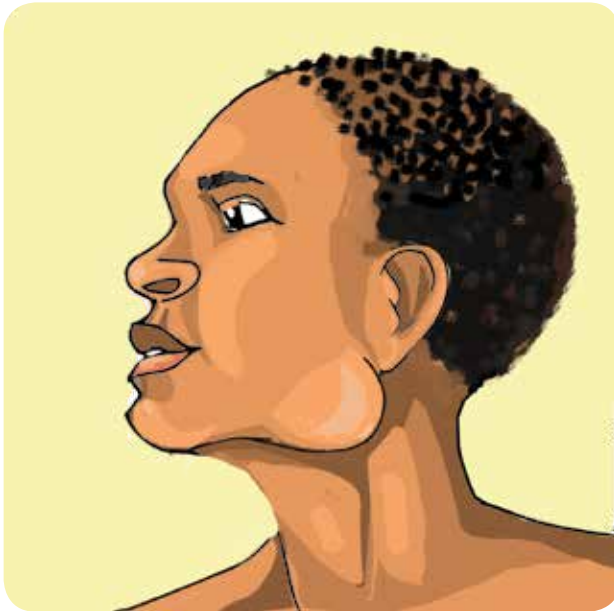
The 5 most common cancers in men in Uganda



What is a tumour?

A tumour is a lump or a swelling. Most cancers form tumours. But not all tumours are cancer. Lumps that are not cancer are called benign. Lumps that are cancer are called malignant.

There are some cancers, like leukemia (cancer of the blood), that do not form tumours. They grow in the blood or other parts of the body.



5.

What causes cancer?

There is no one cause of cancer. 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 any supernatural force. Cancer is a disease that can affect anyone, anywhere, in any country, at any time.

6.

Is cancer contagious?

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

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.



7.

Is cancer inherited?

With some cancers, abnormal cells can be inherited from one's parents. In such families, more than one person may get the same cancer. But, cancer is not passed from parent to child the same way that height, eye color and HIV are.

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.

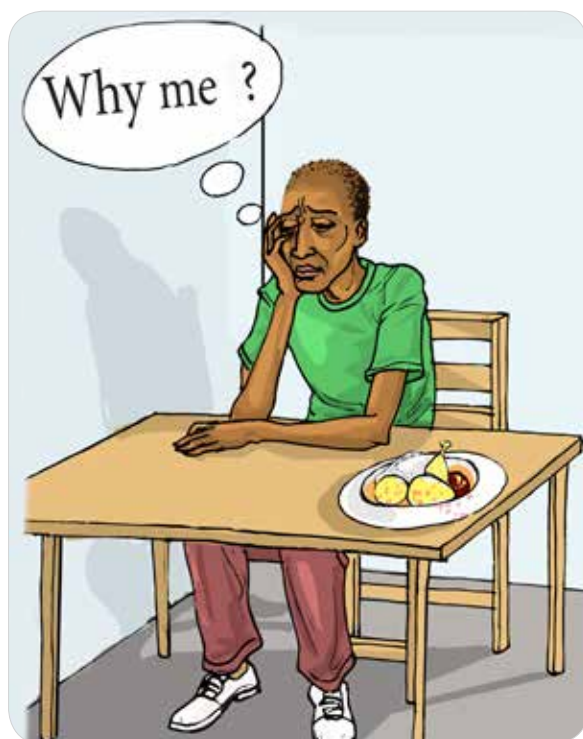


8.

Why me?

People with cancer often ask, “Why me?,” “What did I do wrong to get cancer?” Some people believe that cancer is a punishment for something they did or did not do in the past.

If you’re having these feelings, you’re not alone. Thoughts and beliefs like this are common for people with cancer. You need to know that cancer is not a punishment for your past actions. Try to not blame yourself or focus on looking for ways you might have prevented cancer. Instead, focus on taking good care of yourself now.



9.

How does the doctor know I have cancer?

Most likely, you first went to the doctor when you had some problem. The doctor then checked you for signs of cancer.

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



Screening for breast and cervical cancer

Sometimes, it's 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, when they are easier to treat and cure.

Common symptoms of cancer

There are some symptoms you should always have checked. Don't be scared about getting symptoms checked by a health worker. The earlier cancer is found, the more likely it is to be cured. You won't be wasting your time. Common symptoms of cancer include:



Unexplained weight loss



A lump or swelling



Unusual bleeding



Unexplained pain



Sores or changes to your skin that do not go away

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.

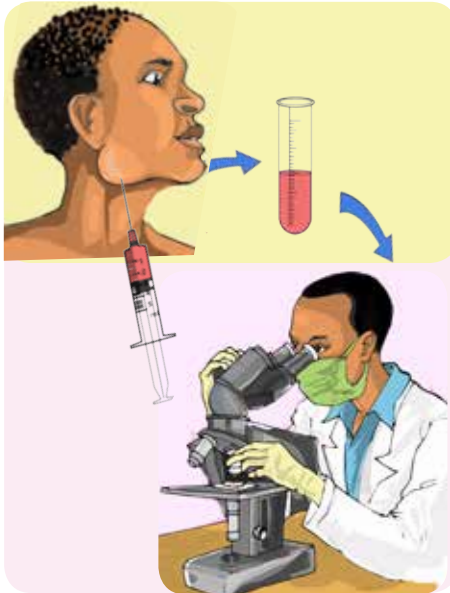
There are many other symptoms of cancer that are not listed here. If you notice any major changes in the way your body works or the way you feel – especially if it lasts for a long time or gets worse – get checked by a health worker.

10. 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 to examine it under a microscope. Sometimes, this is done with a needle. The doctor will give medication so that you 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.

11.

What are stages of cancer?

Once you are 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.

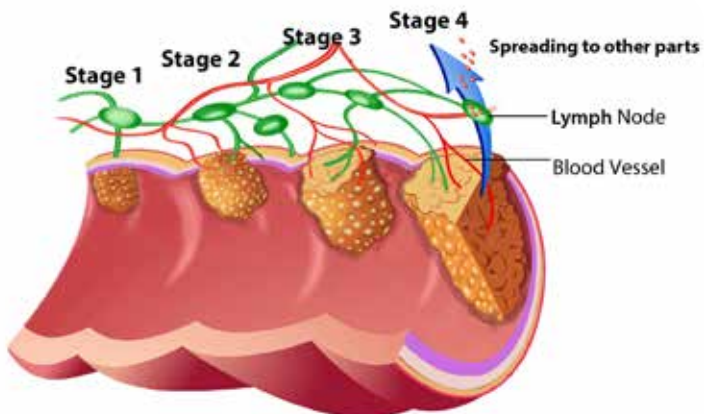
For most cancers, there are four stages.

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 that the cancer has spread to other parts of the body and is unlikely to be cured.

Ask your doctor to explain the stage of your cancer and what it means for you.



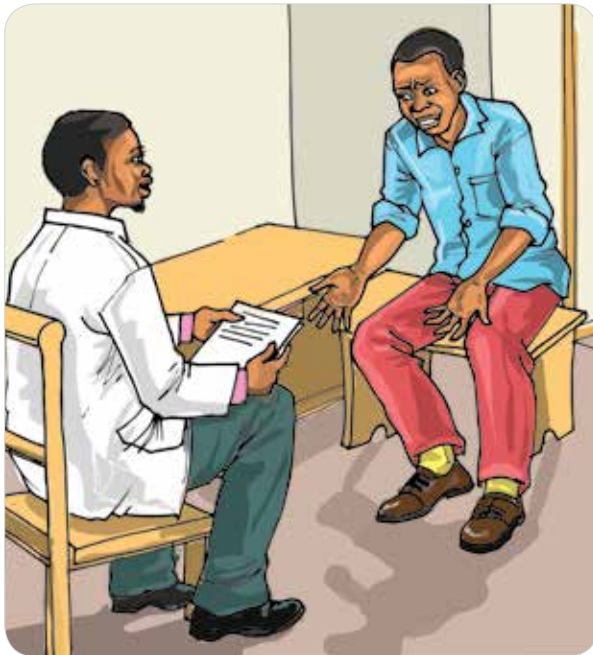
12.

Will I die from my cancer?

Having cancer is not a death sentence. If you start and complete treatment at an early stage, chances are good that you will survive.

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

- ◆ The type of cancer and where it is in your body
- ◆ The stage of the cancer
- ◆ If your cancer is fast or slow growing
- ◆ Your age and how healthy you were before getting cancer
- ◆ How you respond to treatment.



13. How is cancer treated?

The types of treatment that the doctor prescribes for you will depend on the type of cancer you have, the stage of the cancer, and your 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 your doctor what is the purpose of your treatment.

Types of treatment

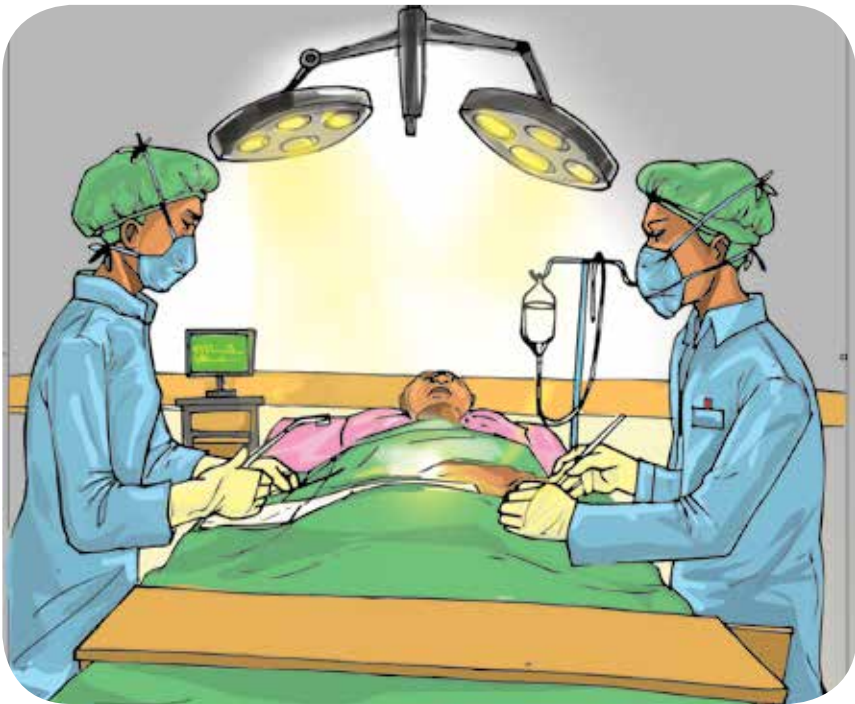
The most common treatments for cancer are surgery, chemotherapy and radiotherapy. A person with cancer may have any or all of these treatments.

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 you live far from the treatment facility, you should also 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.

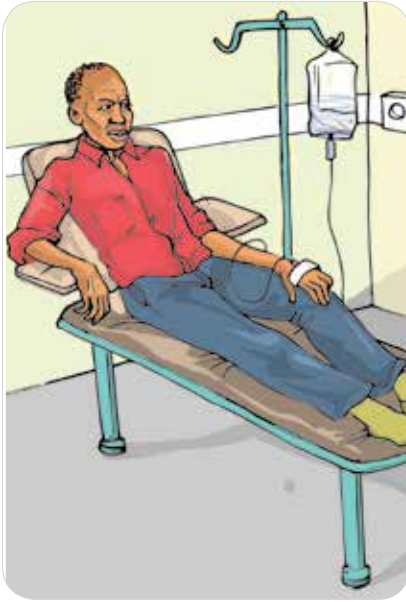
Surgery

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 may be used to cure the cancer, control it, or treat problems it is causing. Surgery is not used for all types of cancer. For example, blood cancers like leukemia are best treated with drugs.



Chemo

Chemo (short for chemotherapy) is medicine that kills cancer cells or slows their growth. Some chemo is given by drip (into a blood vein through a needle), and others are pills you swallow. 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 also harm normal cells near the cancer cells. But, normal cells can repair themselves, and cancer cells cannot. Radiotherapy does not feel hot and is usually not 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.



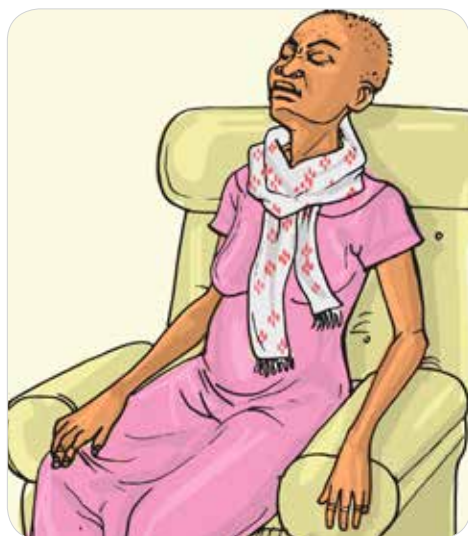
14.

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. Some people have a tough time with cancer treatment, but many others manage quite well. And 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 completely painless, but they can cause skin sores or rashes, loss of appetite 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 you are 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



diarrhoea or constipation



mouth sores



fever



higher risk of infection



tingling pain in hands or feet

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 are able to use wigs, scarves, or hats to cover, warm, or protect their heads.

15. Will I have pain ?

Many patients worry about pain from biopsies, treatment, and from the cancer itself.

Health workers give patients medicine to prevent pain before taking biopsies or operating. So, these procedures are not usually painful. Radiotherapy and chemotherapy are not usually painful.

Pain from the cancer can be controlled with medication. So, you should not think that pain is a normal part of cancer.

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 you are in pain, tell your health worker so they can give you pain medication.



16. What is palliative care?

Palliative care focuses on relieving pain, stress, and discomfort caused by cancer. It is not intended to cure the illness.

Some people think that palliative care is only for people who are dying. This is not true. Palliative care should be provided along with cancer treatment.



17.

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 you remain in complete remission for five years or more, your doctor may say you are cured. Cure means that there are no traces of cancer after treatment.



18. How will I cope?

People cope with cancer just like they cope with many other problems in life – each person does it in their own way. With time and practice, most people find ways to go on with their work, hobbies, and friendships. They find new or different ways to live their lives.

As you look for a way of coping that works for you, you may want to try some of these ideas:

Learn as much as you can about your cancer and its treatment.

Some people find that learning about their cancer and its treatment gives them a sense of control over what's happening.



Take care of yourself.

Take good care of your body and your mind. Eat and sleep well. Get some exercise. Take time to do something you enjoy every day. Spend time with a friend or loved one, meditate, volunteer to help others, or listen to your favorite music or radio show.



Reach out to others.

It's very hard for any one person to handle having cancer all alone. Joining a cancer support group can help. When we talk to other cancer patients we can share ideas on treatment and caring. This will help us to recognize we are not the only one experiencing this. These people can help you feel less alone.



19. Talking with family and friends

It is important to tell your loved ones that you have cancer and how they can help. It is very hard to cope with cancer all alone. And, hiding your cancer can make it harder to get treatment and follow your doctor's instructions.

Many patients fear that their family or friends will reject them if they learn they have cancer. In fact, this is not usually the case.

Your loved ones may also have a hard time talking about cancer. They may not know what to say to help you or make you feel better.



Here are some tips to help you and your loved ones deal with cancer:

- ◆ Tell your family and friends about your cancer as soon as you feel up to it. Sooner or later, they'll all know you have cancer. They might feel hurt or left out if they haven't heard about it from you.
- ◆ When you talk to them, explain what kind of cancer you have and how it will be treated. Let them know that no one can catch it from you.
- ◆ Allow friends and family to help you, and tell them what kind of help you need.
- ◆ Tell the people who are closest to you how you feel. This may not be easy, but it can be a very important way to get the support you need when you need it most.
- ◆ You may not be able to do things you were doing before you got cancer. If that is true, let your family and friends know.
- ◆ It's best for your family and friends to keep doing the things they did before you had cancer. They should not feel guilty about doing this.
- ◆ If you're feeling sad or depressed, talk to your doctor, nurse, or religious leader.

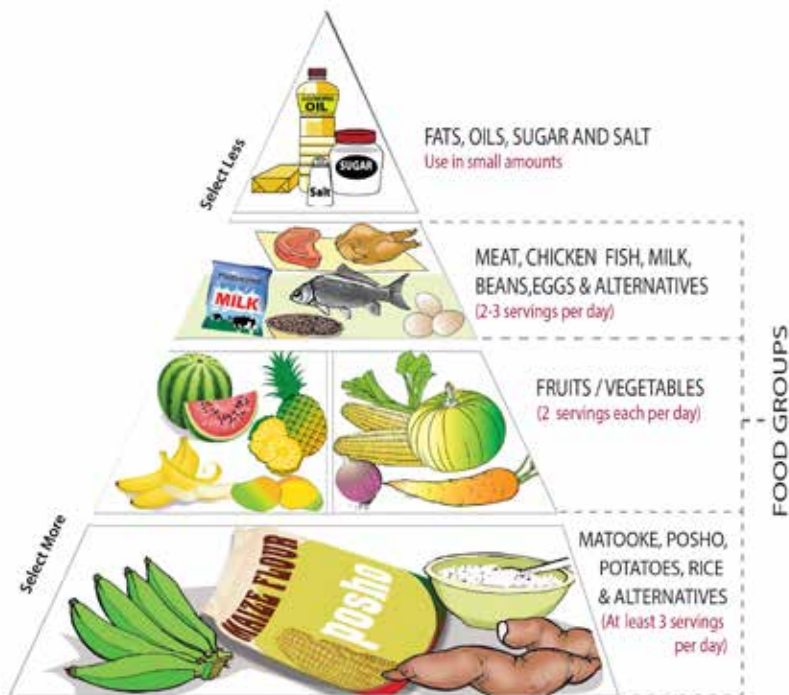
20.

Staying healthy

Eating a good diet, exercising, and avoiding unhealthy activities like smoking or drinking excessive alcohol can help you feel better and stay stronger.

Diet: Eating a well-balanced diet before, during, and after treatment can help maintain your body weight, deal with side effects of treatment, and heal and recover faster.

A well-balanced diet means eating at least three meals each day that contain foods from each of the three food groups shown here. You should eat less of the foods at the top and more of the foods at the bottom. Limit the amount of oils, fats, salt and sugar you eat, as these can be dangerous to your health in large quantities.



During treatment, you may lose your appetite. But, you should still try to eat a well-balanced diet. When suffering from nausea, try eating smaller meals more frequently. Eat what you like to eat. If you cannot eat solid foods, try drinking fruit juices, milk or soups.

Water and fluids are vital to health. Try to drink about eight large glasses of water each day. You may need extra fluids if you're vomiting, have diarrhoea, or if you are just not eating much. You should avoid artificially sweetened drinks, sodas, and alcohol.

Exercise:

Physical activity helps keep you strong, and it can help reduce stress, tiredness, nausea, and constipation. It can also improve your appetite.

If you are not used to regular exercise, and your doctor approves, start small (5 to 10 minutes each day). If you exercised regularly before learning that you have cancer, and your doctor approves, continue your exercise routine.



Listen to your body, and rest when you need to.

- ◆ Talk to your doctor before you start any type of exercise program.
- ◆ Start slowly.
- ◆ Try short periods of exercise with frequent breaks.
- ◆ End your session with stretching or flexibility exercises.

Here are some ways to add physical activity to the things you do every day.

- ◆ Walk around your neighbourhood after dinner.
- ◆ Take a friend dancing, or dance in your home.
- ◆ Sweep and clean your home.
- ◆ Work in your garden.
- ◆ Get off the taxi or boda several stops early and walk the rest of the way.
- ◆ Or walk if it is not too far, rather than taking a boda or taxi.



Healthy lifestyle:

Living a healthy lifestyle is not only about eating a healthy diet and exercising. It also means changing habits that are not good for your health. Two important habits to change are smoking and drinking a lot of alcohol.

There is no safe form of tobacco.

If you smoke cigarettes, cigars or shisha or chew tobacco, stop! Encourage the people around you to quit. Breathing in tobacco smoke, whether your own or another person's, damages your lungs, heart and other parts of your body. Tobacco smoke also increases cancer risk for smokers and everyone near them.



If you drink alcohol, limit the amount you drink.

Alcohol is a poison that causes emotional, social and health problems when taken in excess. For cancer patients, alcohol abuse makes treatment less effective, can cause depression, and may isolate you from friends and family.



21.

How will cancer affect my sex life?

Cancer can change your desire for sex. Some cancer patients have little or no change in their sexual desire and others find that they have less interest in sex. This may be caused by stress, feeling tired, and other treatment side effects.

Some types of cancer, like cancer of the cervix or bladder, may cause bleeding in the private parts. If this bleeding is worse after sex, talk with your doctor.

If you have surgery, ask your health worker how long you should wait to have sex.

Cancer is not contagious. Your partner cannot catch it from you. And, you cannot pass it on to your baby if you get pregnant.

22. Will cancer make me infertile ?

Pregnancy is possible while receiving chemo or radiotherapy. However, radiation and chemotherapy can cause birth defects. So, men and women should avoid pregnancy by using family planning during treatment, and even for a few weeks or months after treatment is done. Women should tell their doctor if they are pregnant.

Women may find that their periods become irregular or stop while getting treatment. This doesn't mean that they cannot get pregnant. In men, the treatments may reduce or damage sperm cells. Even so, men often become fertile again after treatment is done.

Radiotherapy and chemotherapy for prostate, cervical or ovarian cancer often cause permanent infertility. Some cancer surgeries can also cause infertility. If surgery involves removal of your sexual organs, then you will most likely become infertile.



It is normal to worry about how treatment will affect your fertility. Talk to your doctor before treatment starts about any concerns you have.

23.

Where to get cancer services and information

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 accommodation, transportation and meals 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/>

