

# Care and support for people with HIV and AIDS



This chapter has information on helping people with HIV and AIDS to stay healthy, as well as providing home-based care and emotional support to people with HIV and AIDS. It also has a reference guide for caregivers.

# 1. Home-based care



## Session objectives

By the end of this session, participants will be able to:

- Explain what is meant by home-based care.
- List advantages of home-based care for people with HIV and AIDS, their families and communities.
- List signs that caregivers should look for when caring for a person with HIV and AIDS.



## Session guide

1. **Ask:** What does home-based care mean? [Answer: Home-based care (HBC) is the care of people infected and affected by HIV and AIDS that extends from the hospital or health facility to the patient's home through family participation and community support. HBC combines clinical care, nursing care, counselling and psycho-spiritual care, and social support.]
2. **Ask:** What is the purpose of providing HBC to people with HIV and AIDS? [Possible answers: To prevent and care for any problems that may emerge as a result of being infected or affected, to encourage timely treatment of new infections or illnesses, and to reduce stigma and discrimination of people with HIV and AIDS and their families.]
3. **Explain** that when people with HIV and AIDS return home from the hospital, they are usually cared for by untrained relatives who do not have any support. These caregivers are most often women and children with no training in nursing the sick or protecting themselves or other family members from infections from handling infected material. People with HIV and AIDS need quality care to live longer, healthier lives and reduce suffering. HBC is one way to ensure that quality care can be provided outside a facility.
4. **Divide** participants into four groups. Assign each group one of the following: people with HIV and AIDS, families, communities, and health system. Ask each group to think about all of the advantages of HBC for their group.
5. **Bring** participants back together and ask for a representative from each group to share the advantages they talked about. The following should be mentioned:

People with HIV and AIDS	Family	Community	Health system
Receive care in a familiar, supportive environment. Stay healthy longer. Continue to participate in family matters. Maintain sense of belonging to social groups.	Holds family together. Helps family accept someone's positive status. Makes it easier to provide care/support. Can reduce medical costs.	Promotes awareness about HIV prevention. Helps community understand the disease and respond to myths and misconceptions. Can reduce costs.	Does not require the creation of extra services where resources and services are already inadequate. Helps ease demand on health system.

People with HIV and AIDS	Family	Community	Health system
Makes it easier for them to accept their condition and live positively.	Makes it easier for family members who provide care to attend to other responsibilities.	Encourages the sustainability of the care services.	Extends responsibility to family and community.
Maximizes emotional health.		Makes it easier to provide support.	
Helps them adhere to TB and ARV drugs.		Can help the community maintain a sense of togetherness.	

Allow participants from other groups to add other advantages while the groups are presenting.

6. **Explain** that caregivers can prevent many problems by being aware of danger signs of illness. It is important to learn what is normal and report any changes.
7. **Ask:** What signs should caregivers pay attention to when caring for a person with HIV and AIDS? Be sure the following are mentioned:
  - Mood: Alert, sleepy, irritable, jumpy, withdrawn
  - Colour: Normal, white, yellow, blue fingernails
  - Skin: Rash, dry ulcers, blisters, sweaty, loose
  - Body: Feverish, cold, sweating
  - Breathing: Fast, slow, difficult, noisy
  - Other: Fast or irregular heartbeat, odd body odour
8. **Ask:** Does anyone know someone who is caring for a family member that has HIV and AIDS? What are some of the challenges they face? How can we support the caregiver? Allow participants to discuss.



## Main messages

- The purpose of home-based care for people with HIV and AIDS is to prevent and care for any problems, to encourage timely treatment of new infections or illnesses, and to reduce stigma and discrimination of people with HIV and AIDS and their families.
- It is important for people who are providing care to people with HIV and AIDS to pay attention to and recognize what is and is not normal for the people they are caring for. If caregivers notice changes in mood, skin conditions, body temperature, breathing, heartbeat, and colour of skin and fingernails, they should encourage them to visit a health worker.

## 2. Helping people with HIV and AIDS stay healthy



### Session objectives

By the end of this session, participants will be able to:

- Explain why it is especially important for people with HIV and AIDS to eat well.
- Describe what eating well means and list ways to help people with HIV and AIDS to eat well.
- List ways for people with HIV and AIDS to remain active.
- Explain the risks of re-infection for people who are already HIV infected.



### Session guide

1. **Ask:** Why is it important for people with HIV to eat well? What happens when people with HIV do not eat well? [Answer: It is important for people with HIV and AIDS to eat a healthy diet to fight infection and disease and to stay energetic, strong, and productive.]
2. **Ask:** What does nutrition mean? [Answer: The kind of food that we eat and how our bodies use that food.] **Ask:** What does malnutrition mean? [Answer: Malnutrition means someone who is not eating enough food or someone who is not eating enough of the right kinds of food. A person is malnourished if they do not eat enough protein, energy, vitamins, and minerals and have frequent infections and disease. How well-nourished a person is depends on the food he or she eats, his or her overall health, and the environment where he or she lives.]
3. **Explain** that nutrition and HIV are strongly related to each other. People who are malnourished are more likely to progress faster to AIDS, because their bodies are weak and cannot fight infection. People with HIV and AIDS are at risk of malnutrition because they eat less, have infections that require more energy, and their bodies do not use food effectively. People with HIV and AIDS need to eat more than people who are not infected. Eating small meals often and a variety of foods can help people with HIV and AIDS to get all the energy and nutrients they need.
4. **Ask:** Are there any foods that people with HIV and AIDS should eat? Are there any foods they should avoid? Why? Allow participants to discuss. Encourage them to give examples of specific foods and meals that are healthy.
5. **Explain** that it is important for people with HIV and AIDS to eat different kinds of foods to be sure the body gets all the nutrients it needs. The main food groups people need to eat to live a healthy life are bodybuilding foods, protective foods, and energy foods.

Body-building foods	Protective foods	Energy foods	Foods to avoid
<p>Beans, lentils, peas, nuts, milk, yogurt, cheese, fish, eggs, chicken, meat, wheat, maize, and rice.</p> <p><i>These foods contain protein for cell repair and growth, help build strong bones and cells, and help to fight infection and repair the body.</i></p>	<p>Greens, spinach, cabbage, mango, paw paw, sweet potato, carrots, tomato, avocado, oranges, lemons, and bananas.</p> <p><i>These foods help the body absorb and use protein and carbohydrates and help fight infections and digest nutrients.</i></p>	<p>Maize, ugali, rice, matoke, millet, cassava, taro root, potato, and sweet potato.</p> <p><i>These foods provide the body with energy so it will work and people can stay active.</i></p>	<p>Raw eggs, milk immediately from a cow, undercooked meat or chicken, sweets, alcohol, coffee, expired food, oily foods, fatty meats, fried food, and acidic foods.</p> <p>Smoking should also be avoided.</p>

6. **Ask:** What advice would you give to someone with AIDS who said it is difficult for him or her to eat enough food? [Possible answers: Eat smaller meals more often, snack during the day, and eat softer foods.]
7. **Ask:** Should people with HIV avoid activity or be active? Why? Are there any activities they should avoid? [Answer: It is important for people with HIV and AIDS to stay active because it improves appetite, develops muscle, reduces stress, increases energy, and helps to maintain overall physical and emotional health. Social and everyday activities such as walking, cleaning, and collecting firewood and water are important. People with HIV and AIDS should be encouraged to be active and continue with their daily routine as long as they are physically able to do so.]
8. **Ask:** Once people know they are HIV-positive should they try to find someone else who is positive to have sex with? Allow participants to discuss.
9. **Ask:** If both partners are HIV positive, is there any reason to use a condom?
10. **Explain** that it is important for people with HIV and AIDS to use condoms and avoid unprotected sexual intercourse. Even if someone is already infected, being exposed to HIV over and over again can make the infection progress to AIDS more quickly. Having protected sex can lead to healthier and more productive lives by:
  - Reducing further spread of the virus.
  - Reducing the risk of repeated exposure to HIV infection.
  - Preventing exposure to other sexually transmitted infections.
  - Avoiding pregnancy, which puts a greater strain on a woman's health and risks possible HIV infection of the baby.
  - Avoiding infection in women and therefore the possibility of transmitting HIV to their babies.



## Main messages

- It is important for people with HIV and AIDS to eat a healthy diet to fight infection and disease and to stay energetic, strong, and productive.
- HIV and nutrition are strongly connected to each other. People who are malnourished are more likely to progress faster to AIDS, because their bodies are weak and cannot fight infection. People with HIV and AIDS are at risk of malnutrition because they eat less, have infections that require more energy, and their bodies do not use food effectively. It is important that people with HIV and AIDS eat more than people who are not infected.
- It is important for people who are HIV infected to practice protected sex to protect themselves against re-infection and protect their partners.



## Activity: Meal and activity planning

Divide participants into groups of three. Ask each group to create a 5-day plan for an imaginary person who is HIV positive. This plan should list all of the food he or she will eat and all of the physical activity he or she will do during the 5 days. Give participants 10 minutes to create their plans. Encourage participants to have a lot of variety and be realistic based on what is available in their community.

After the groups have completed their plans, ask for a representative from each group to share their ideas. Allow other participants to ask questions and offer suggestions after each group has presented.

After each of the groups have presented, share information from the Background Notes as needed.

### 3. Keeping clean and safe



#### Session objectives

By the end of this session, participants will be able to:

- Describe why keeping our bodies, food, and houses clean are especially important for people with HIV and AIDS.



#### Session guide

1. **Ask:** What is meant by hygiene? [Answer: keeping clean in order to preserve health and prevent the spread of disease.] What practices do you know about that promote good hygiene? [Possible answers: hand washing, boiling water, treating water, using pit latrines, etc.]
2. **Ask:** Why is practicing good hygiene especially important for people with HIV and AIDS? [Answer: It is especially important for people with HIV and AIDS because they have weak immune systems and are more vulnerable to infection. Handle and store food and water properly to avoid contamination and further infection.]
3. **Explain** that practicing good hygiene is important for everyone to avoid infection and illness. There are many different parts of hygiene. There is keeping water clean, keeping food safe, keeping our bodies clean, and being around animals in a safe way.
4. **Divide** participants into four groups. Assign each group one of the following areas: water, food, our bodies, and our animals. **Ask** each group to answer the following questions:
  - How can we keep this clean and safe?
  - What are challenges to keeping this clean and safe?
  - How can we overcome those challenges?
5. **Bring** the groups back together and allow a representative from each group to report on what the group talked about. Allow other participants to ask questions or give additional information. Be sure the following come out:

Water	Food	Our bodies	Animals
Be sure water is from a clean source.	Cook meat, chicken, fish, and eggs at high temperatures until cooked completely.	Take baths everyday to keep the body clean.	Keep animals and pets outdoors.
Boil water for at least 5-10 minutes to kill germs.	Do not eat soft-boiled eggs or meats that still have red juice.	Wear shoes to avoid small injuries that could result in infection.	Do not clean up after animals, especially cats, kittens, chickens, and other birds.
Store water in a container with a lid.	Thoroughly wash utensils and surfaces used with uncooked foods.	Brush teeth after meals.	Wash hands after handling pets and animals.
	Cover meat, poultry, or fish with a clear cover or cloth and keep it separate from other foods.		
	Use clean water to wash all fruits and vegetables that will be eaten raw or remove the skin.		

Water	Food	Our bodies	Animals
Always wash hands with soap before and after touching food.	Remove the bruised parts of fruits and vegetables to avoid any mould. Use a clean table or chopping board to prepare food. Make sure areas for preparing and eating food are free of flies. Cover food that is not eaten. Keep hot foods hot and cold foods cold. Do not eat food after the expiry date. Store cooked food at most for one day and re-heat before eating. Use clean and dry bowls, plates, glasses, and utensils.	Wash hands with soap after going to the toilet.	Avoid contact with young animals and animals with diarrhoea.

6. **Ask:** Do families caring for a person with HIV need to take any precautions? [Answer: They should avoid contact with the infected person's body fluids, blood, or diarrhoea.]
7. **Ask:** What are specific things they should do? Be sure the following are mentioned:
- Wash hands with soap and water after changing soiled bed sheets and clothing, or having contact with body fluids.
  - Use gloves, or a piece of plastic or paper, while attending to the sick person (especially if the person has open sores).
  - Cover any wounds (on the infected person or caregiver) with a bandage or cloth.
  - Keep the infected person's bedding and clothing clean.
  - If cleaning clothes or sheets stained with blood, diarrhoea, or other body fluids:
    - Keep these items separate from other household laundry.
    - Hold the unstained part and rinse off any blood or diarrhoea with water.
    - Wash in soapy water, dry, or iron as usual. Bleach or boiling water is not needed.
  - Properly dispose of soiled materials, excretions, and body secretions.
  - Clean body fluid spills with soapy water and bleach (jik) if available but do not touch them directly (cover hands as described above).
  - Do not share any sharp instruments, razors, needles, or toothbrushes that can come into contact with blood. If it is necessary to share these items, boil them first.
8. **Explain** that sharing a home and everyday activities are not a risk for families living with a person with HIV. For example, there is no risk of HIV from touching; hugging; sharing plates, utensils, glasses, towels, or other items; or being sneezed or coughed on by a person with HIV and AIDS.



## Main messages

- Sharing a home and every day activities are not a risk for families living with a person with HIV. You can not be infected by hugging, coughing, sneezing, sharing plates, utensils, glasses, towels or other items.
- Keeping the body, food, cooking utensils, and homes clean is especially important for people with HIV and AIDS.
- Caregivers should be sure to avoid contact with an infected person's bodily fluids.



## Activity: Cleanliness role plays

Ask for volunteers to role play the following scenarios in front of the group. One person plays the role of a person trying to use a persuasive argument to try to persuade the other person to change behavior.

After each role play ask participants to talk about them. Ask for another pair to role play the same scenario but with a different approach to addressing the issue. Facilitate another discussion around that role play.

Ask for two new volunteers to role play another scenario and follow the same steps for the first role play. Continue until all of the scenarios have been acted out and discussed.

Example role play scenarios:

- You know your brother John does not wash his hands after going to the bathroom. How could you convince him to change his behavior?
- Your sister, Evelyn, does not brush her teeth often and sometimes refuses to take baths. What would you say to her to get her to practice these things more often?
- Your neighbor, Margaret is mother of three small children. She is very busy and does not always clean her fruits and vegetables with clean water. You have noticed this. What would you say?
- Robert comes home late from work each night and doesn't want to spend time boiling water for drinking. He drinks it directly from the tap. What would you advise?

## 4. Staying healthy and getting treatment on time



### Session objectives

By the end of this session, participants will be able to:

- List ways people with HIV can stay healthy.
- List symptoms that are a sign a person with HIV and AIDS should go to a doctor.
- Explain what living positively means.
- Describe what opportunistic infections are.
- Explain that not everyone with TB has HIV.



### Session guide

1. **Ask:** What things can people with HIV do to stay healthy? Allow participants to discuss.

Be sure they mention the following:

- Eating a healthy diet
  - Doing physical activity
  - Getting enough sleep
  - Practicing good hygiene
  - Avoiding smoking
  - Avoiding alcohol
  - Having protected sex
  - Going to the doctor immediately for treatment of illness and infection
  - Only taking medications given by a doctor and follow the directions carefully
2. **Explain** that it is very important for people with HIV and AIDS to go to the doctor as soon as they have symptoms of infection or fall ill. Illness and infection are signs that the body is weak. If left untreated, they can make the body even weaker. When signs of illness begin, an HIV-infected person should seek treatment if available. Quick attention to early signs of illness can prevent further damage to the body.
3. **Ask:** What are signs that a someone with HIV should go see a health worker right away? Allow participants to discuss and be sure they mention the following information from the table on the next page:

## Signs to go for treatment at a health facility

<p><b>Head and body</b></p>	<p>He or she has pain that is new, different, and much worse. The pain does not respond to paracetamol. He or she has high fever and a stiff neck. He or she is unconscious or having fits (convulsions). He or she has a high fever that does not go down. He or she has head and body aches. He or she has chills and sweats. He or she has lost a lot of weight. He or she has a sudden change in his or her ability to think or move.</p>
<p><b>Skin</b></p>	<p>He or she has skin sores that are large, red, very swollen, and tender. He or she has skin sores that are not getting better with treatment. His or her skin feels itchy.</p>
<p><b>Eyes</b></p>	<p>The white part of his or her eyes is yellow. He or she is having difficulty seeing. His or her vision has changed. He or she sees floating dark spots. He or she has spots or blisters on the eye lids.</p>
<p><b>Breathing</b></p>	<p>He or she has pain that makes it hard to breathe. His or her breathing is very fast and noisy. He or she coughs up sputum/spit with blood. He or she coughs up sputum/spit that is greyish-yellow or green. He or she has a cough that lasts for more than 3 weeks. A child is breathing faster than normal and has a fever.</p>
<p><b>Mouth and stomach</b></p>	<p>He or she is very thirsty but cannot eat or drink. He or she cannot swallow or has pain when swallowing. He or she cannot eat enough to maintain strength. He or she has a burning pain in the chest. He or she is urinating less than normal. He or she has many, very watery stools a day. He or she has blood in the stool. He or she is vomiting for more than 24 hours. The vomit has blood in it. He or she has a swollen belly. A child does not want to eat or drink.</p>
<p><b>Reproductive health</b></p>	<p>She is pregnant or has just given birth, and has a fever. He or she has pain when urinating. He or she has genital warts or sores. He or she has very smelly or strange coloured discharge from the vagina or penis. A woman has pain in her lower belly, especially if she also has a fever. A woman stops getting her monthly bleeding or it is not regular. He has swelling or pain in the scrotum.</p>
<p><b>Feelings</b></p>	<p>He or she feels or seems much more tired than usual. He or she is depressed and cannot do anything.</p>

4. **Ask:** What are opportunistic infections? [Answer: Infections that attack the body when the immune system is weak. A person with a healthy immune system would be able to fight it off, but people with HIV have a weaker immune system and are not able to. Most opportunistic infections are curable, so it is important to visit the doctor early.]
5. **Ask:** Do all people with tuberculosis (TB) have HIV? Allow participants to discuss.
6. **Ask:** Do all people with HIV have TB? Allow participants to discuss.
7. **Explain** that some people are sick with only TB, some people are sick with only HIV, and some people are sick with TB and HIV at the same time. Having TB does not mean someone has HIV and having HIV does not mean someone has TB. With the right medicine, TB can be cured whether or not someone has HIV. HIV weakens the immune system. Someone who is HIV infected and infected with TB is much more likely to become sick with TB than someone infected with TB who is not infected with HIV. TB speeds up HIV disease. TB is a leading cause of death among people with HIV.
8. **Ask:** What does living positively mean? Allow participants to discuss. **Ask:** What are examples of things a person who is living positively would say or do? Allow participants to share and discuss.
9. **Explain** that living positively is more than having a positive attitude. The goal of living positively is to be free of illness, to be productive, and to stay emotionally and physically healthy.
10. **Explain** that people with HIV and AIDS also need emotional support to live positively. **Ask:** What are ways that we can support people who are HIV positive? Allow participants to discuss.
11. **Divide** participants into pairs. Assign each pair a letter, either a, b, or c, so that each pair has a letter. Assign the following scenario to each pair according to their letter.
  - a. You are visiting your sister who is HIV positive and the mother of three small children. That morning you saw her yell at the children for making too much noise when they were playing outside. You have never seen her yell before and you want to talk to her about her feelings.
  - b. You and your friend are sitting next to each other waiting for the bus to Nairobi. He has been sitting quietly for some time, and then you notice that he is breathing quickly and sweating. You ask him what is wrong and he starts to tell you how he found out he is HIV positive and he is worried about telling his wife. He then starts to complain about pains in his chest.
  - c. You are walking home from the market and you see your neighbour. Her husband died yesterday and everyone says that he had AIDS. She is walking with her head down and it looks like she is crying. In thinking about her you remember that very few people have been to visit her over the past month. You have always been friendly and want to see if there is any way you can help.
12. After 5 to 10 minutes, **ask** participants to switch roles and this time have the other person play the person with HIV. Assign new role plays according to their letter.
  - a. You and your friend are sitting next to each other waiting for the bus to Nairobi. He has been sitting quietly for some time, and then you notice that he is breathing quickly and sweating. You ask him what is wrong and he starts to tell you how he found out he is HIV positive and he is worried about telling his wife. He then starts to complain about pains in his chest.
  - b. You are walking home from the market and you see your neighbour. Her husband died yesterday and everyone says that he had AIDS. She is walking with her head down and it looks like she is crying. In thinking about her you remember that very few people have been to visit her over the past month. You have always been friendly and want to see if there is any way you can help.
  - c. You are visiting your sister who is HIV positive and the mother of three small children. That morning you saw her yell at the children for making too much noise when they were playing outside. You have never seen her yell before and you want to talk to her about her feelings.
13. After 5 to 10 minutes, bring participants back together and **facilitate** a discussion about how they can support people infected with and affected by HIV and AIDS.



## Main messages

- To stay healthy, people with HIV and AIDS should eat a healthy diet, continue to do physical activity, get enough sleep, practice good hygiene, go to the doctor immediately for treatment of illness and infection, and only take medications given by a doctor and follow the directions carefully.
- Caregivers should be able to recognize symptoms that require immediate attention and encourage people with HIV and AIDS to get prompt treatment for illness.



## Background notes

Home-based care (HBC) is the care of persons infected and affected by HIV and AIDS that extends from the hospital or health facility to the patient's home through family participation and community support. HBC combines clinical care, nursing care, counselling and psycho-spiritual care, and social support.

The purpose of providing home-based care to people with HIV and AIDS is to:

- Prevent and care for any problems resulting from being infected or affected.
- Encourage timely treatment of new infections or illnesses.
- Reduce stigma and discrimination of people with HIV and AIDS and their families.

### Why HBC?

When people with HIV and AIDS are discharged from hospital they return home, where they are usually cared for by untrained relatives who do not have any support. These caregivers are most often women and children with no training in nursing the sick or protecting themselves or other family members from infections from handling infected material (e.g., body fluids). They also do not know how to protect people with HIV and AIDS from common infections. People with HIV and AIDS need quality care to live longer, healthier lives, but limited resources and hospital restrictions affect the care that is given. All these issues mean that people with HIV and AIDS cannot get the care they need. HBC is one way to ensure that quality care can be provided outside a facility.

### Advantages of HBC

Organized home-based care has many advantages for people with HIV and AIDS, their families, the community, and the health-care system.

People with HIV & AIDS	Family	Community	Health system
<p>Receive care in a familiar, supportive environment.</p> <p>Stay healthy longer.</p> <p>Continue to participate in family matters.</p> <p>Maintain sense of belonging to social groups.</p> <p>Makes it easier for them to accept their condition and live positively.</p> <p>Maximizes emotional health.</p> <p>Helps them adhere to TB and ARV drugs.</p>	<p>Holds family together.</p> <p>Helps family accept someone's positive status.</p> <p>Makes it easier to provide care and support.</p> <p>Makes it easier for family members who provide care to attend to other responsibilities.</p>	<p>Promotes awareness about HIV prevention.</p> <p>Helps community understand the disease and respond to myths and misconceptions.</p> <p>Can reduce costs.</p> <p>Makes it easier to provide support.</p> <p>Can help the community maintain a sense of togetherness.</p>	<p>Does not require the creation of extra services where resources and services are already inadequate.</p> <p>Helps ease demand on health system.</p> <p>Extends responsibility to family and community.</p>

### Parts of HBC

**Clinical management:** Includes early diagnosis, treatment, monitoring HIV status, and planning for follow-up care of HIV-related illnesses.

**Nursing care:** Includes care to promote and maintain good health, hygiene, and nutrition, and ultimately to provide comfort, reduction of pain, and palliative care.

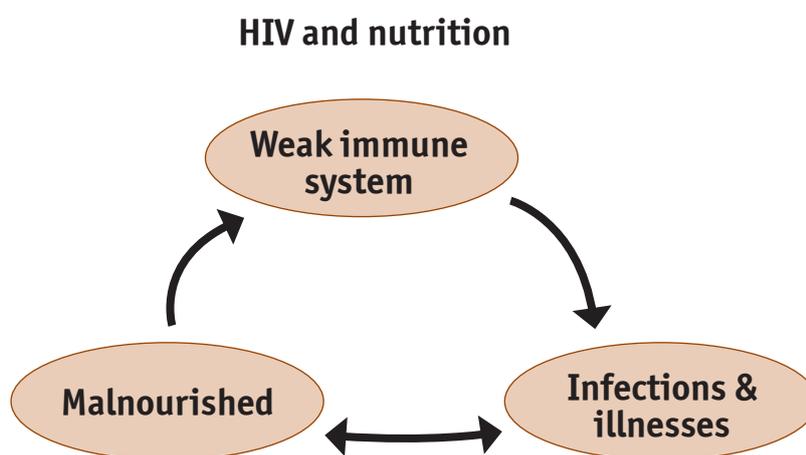
**Counselling and psycho-spiritual care:** Includes reducing stress and anxiety, promoting positive living, and helping individuals make informed decisions on HIV testing, making future plans, behaviour change, managing grief and loss as a result of their status, and involving families in decision making.

**Social support:** Includes information and referral to support groups, social and welfare services, and legal advice for individuals and families, including surviving family members.

## Nutrition and HIV

It is important for people with HIV and AIDS to eat a healthy diet to fight infection and disease and to stay energetic, strong, and productive. Nutrition means the kind of food that we eat and how our bodies use that food.

Nutrition and HIV are strongly related to each other. People who are malnourished are more likely to progress faster to AIDS, because their bodies are weak and cannot fight infection. People with HIV and AIDS are at risk of malnutrition because they eat less, have infections that require more energy, and their bodies do not use food effectively.



People with HIV and AIDS need to eat more than people who are not infected. Eating small meals often and a variety of food can help people with HIV and AIDS to get all the energy and nutrients they need.

### **What is malnutrition?**

Malnutrition means “badly nourished” but it is more than just what people eat or do not eat. A person is malnourished if they do not eat enough protein, energy, vitamins and minerals and have frequent infections and disease. A person’s nutritional status is determined by the food he or she eats, overall health, and the environment where he or she lives.

### **Eat small meals often**

It may be difficult for people with HIV and AIDS to eat enough food because of mouth sores, appetite loss, or poor nutrient absorption. Encourage people with HIV and AIDS to eat smaller meals more often and to snack during the day. It may help to offer softer foods to those who are ill.

### **Eat a variety of food**

It is important for people with HIV and AIDS to eat a variety of foods to be sure the body gets the energy, protein, and vitamins and minerals it needs. The main food groups people need to eat to live a healthy life are bodybuilding foods, protective foods, and energy foods.

Body-building foods	Protective foods	Energy foods
Beans, lentils, peas, nuts, milk, yogurt, cheese, fish, eggs, chicken, meat, wheat, maize, and rice.	Greens, spinach, cabbage, mango, paw paw, sweet potato, carrots, tomato, avocado, oranges, lemons, and bananas.	Maize, ugali, rice, matoke, millet, cassava, taro root, potato, sweet potato
<i>These foods contain protein for cell repair and growth, help build strong bones and cells, and help to fight infection and repair the body.</i>	<i>These foods help the body absorb and use protein and carbohydrates and help fight infections and digest nutrients.</i>	<i>These foods provide the body with energy so it will work and people can stay active.</i>

Just as there are foods that people with HIV and AIDS should eat, there are those that should be avoided, including: raw eggs, milk immediately from a cow, undercooked meat or chicken, sweets, alcohol, coffee, expired food, oily foods, fatty meats, fried food, and acidic foods. Smoking should also be avoided.

### **Eating during and after illness**

Illnesses such as fever and diarrhoea cause the body to not use food properly, which can result in weight loss. It is important to continue to eat during illness. When recovering from illness, it is important to eat more to make up for the lost nutrients and weight.

### **Encourage activity**

For people with HIV and AIDS, being active plays an important role in maintaining good health. Physical activity improves appetite, develops muscle, reduces stress, increases energy, and helps to maintain overall physical and emotional health. Social and everyday activities such as walking, cleaning, and collecting firewood and water are important. People with HIV and AIDS should be encouraged to be active and continue with their daily routine as long as they are physically able to do so.

### **Avoiding re-infection**

It is important for people with HIV and AIDS to use condoms and protect themselves and their partners during sexual intercourse. Having protected sex can lead to healthier and more productive lives by:

- Reducing further spread of the virus.
- Reducing the risk of repeated exposure to HIV infection.
- Preventing exposure to other sexually transmitted infections.
- Avoiding pregnancy, which puts a greater strain on a woman's health and risks possible HIV infection of the baby.
- Avoiding infection in women and therefore the possibility of transmitting HIV to their babies.

Being exposed to HIV over and over again can make HIV progress to AIDS more quickly.

Protect against HIV re-infection by:

A – **Abstaining** from sexual intercourse.

B – **Being faithful** to one partner and having protected sex.

C – Using **condoms** correctly for every sexual act.

### **Keeping clean and safe**

Practicing good hygiene is important for everyone to avoid infection. It is especially important for people with HIV and AIDS because they have weak immune systems and are more vulnerable to infection. Handle and store food and water properly to avoid contamination and further infection.

### **Water**

- Be sure water is from a clean source.
- Boil water for at least 5-10 minutes to kill germs.
- Store water in a container with a lid.
- Always wash hands with soap before and after touching food.

### **Animal products**

- Cook all animal products (meat, chicken, fish, and eggs) at high temperatures until thoroughly cooked.
- Do not eat soft-boiled eggs or meats that still have red juice.
- Thoroughly wash utensils and surfaces used with uncooked foods, especially meats, before handling other food.
- Cover meat, poultry, or fish with a clear cover or cloth and keep it separate from other foods.

### **Fruits and vegetables**

- Use clean water to wash all fruits and vegetables that will be eaten raw.
- If it is not possible to wash fruits and vegetables properly, remove the skin.
- Remove the bruised parts of fruits and vegetables to avoid any mould or bacteria.

### **General food storage and handling**

- Use a clean table or chopping board to prepare food.
- Make sure there are no flies in areas for preparing and eating food.
- Cover food that is not eaten.
- Keep hot foods hot and cold foods cold.
- Do not eat food after the expiry date.
- Store cooked food at most for one day and re-heat before eating.
- If there is a refrigerator, put all leftover foods in it.
- Use bowls, plates, glasses, and utensils that have been cleaned and well dried.

### **Keeping clean**

Infections can be avoided by practicing good personal hygiene.

- Take baths every day to keep the body clean.
- Wear shoes to avoid small injuries that could result in infection.
- Brush teeth after meals.
- Wash hands with soap after going to the toilet.

Hygiene is also important around animals.

- Keep animals and pets outdoors.
- Do not clean up after animals, especially cats, kittens, chickens, and other birds.
- Wash hands after handling pets and animals.
- Avoid contact with young animals and animals with diarrhoea.

### **Caring for people with HIV and AIDS**

Families caring for a person with HIV need to learn the following simple rules that will protect uninfected members from HIV transmission.

The main message of these rules is to prevent contact with the infected person's body fluids, blood, or diarrhoea.

- Wash hands with soap and water after changing soiled bed sheets and clothing, or having contact with body fluids.
- Use gloves, or a piece of plastic or paper, while attending to the sick person (especially if the person has open sores).
- Keep any wounds (on the infected person or in exposed areas of the caregiver) covered with a bandage or cloth.
- Keep the infected person's bedding and clothing clean.
- When cleaning clothes or sheets stained with blood, diarrhoea, or other body fluids:
  - Keep these items separate from other household laundry.
  - Hold the unstained part and rinse off any blood or diarrhoea with water.
  - Wash in soapy water, hang to dry, fold, or iron as usual. The use of bleach or boiling water is not necessary.
- Properly dispose of soiled materials, excretions, and body secretions.
- Clean body fluid spills with soapy water and bleach if available but do not touch them directly (cover hands as described above).
- Do not share any sharp instruments, razors, needles, or toothbrushes that can come into contact with blood. If it is necessary to share these items, boil them first.

Sharing a home and everyday activities are not a risk for families living with a person with HIV. For example there is no risk of HIV from touching; hugging; sharing plates, utensils, glasses, towels, or other items; or being sneezed or coughed on by a person with HIV and AIDS.

### **Self care for people with HIV and AIDS**

To stay healthy people with HIV and AIDS need to make decisions to avoid infections and illnesses and go to the doctor early to treat infections and illnesses.

Ways to stay healthy and avoid infections and illness:

- Eat a healthy diet.
- Do physical activity.
- Get enough sleep.
- Practice good hygiene.
- Avoid smoking.
- Avoid alcohol.
- If having sex, use a condom.
- Go to the doctor immediately for treatment of illness and infection.
- Only take medications given by your doctor and follow the directions carefully.

Go to the doctor if experiencing any of the following symptoms:

- Feeling dizzy.
- Vision loss or changes.
- Difficulty breathing.
- Frequent, very painful headaches.
- High fever (38° Celsius) for more than one day.
- Feeling more and more tired for no reason.
- Cough lasting over 2-3 weeks.

- Watery diarrhoea more than 4 times a day for more than 3 days.
- Vomiting for more than 24 hours.
- Blood in stools or vomit.
- Problems with balance, walking, or speech.
- Losing weight for no reason
- Severe stomach pain.
- Pain during sexual intercourse or urination.

People with HIV and AIDS can live long, healthy lives if they take care of themselves by eating well, practicing good hygiene, staying active, and going to the doctor as soon as they have symptoms of infection or fall ill. Living positively means more than having a positive attitude. The goal of living positively is to be free of illness, to be productive, and to stay emotionally and physically healthy.

### **Avoiding and treating illnesses and infections**

Illness and infection are signs that the body is weak. If left untreated, they can make the body even weaker. When signs of illness – like those listed above – begin, an HIV-infected person should seek treatment without waiting. Quick attention to early signs of illness can prevent further damage to the body.

#### ***Opportunistic infections***

Infections that attack the body when the immune system is weak are called opportunistic infections. Most common opportunistic infections are curable, so it is important to visit the doctor early.

Tuberculosis (TB) is the most common opportunistic infection. Up to half of HIV patients will develop TB disease. TB is the leading cause of AIDS-related deaths in Africa. HIV weakens the immune system, making the body more likely to get active TB. Symptoms include fever, long-lasting cough with bloody sputum, and weight loss. Tuberculosis affects the lungs and can also affect other organs such as lymph nodes and skin. Tuberculosis is curable; therefore early detection and immediate treatment are important. Covering the mouth when coughing decreases the spread of the disease. Keep the home well ventilated.

### **Emotional care and support**

Emotional health can be just as important as physical health for people with HIV and AIDS. A positive attitude and supportive friends and family can help people choose healthy behaviours and decide to go for medical treatment early.

The reference section in the back of this chapter offers suggestions on how to help people with HIV and AIDS to feel good emotionally in order to maintain and improve their physical health.

People with HIV and AIDS need emotional and physical support in order to live positively. The goal of living positively is to be free of illness, to be productive, and to stay emotionally and physically healthy.

#### ***Testing positive***

When people learn they are HIV positive, it is normal for them to have many different emotions. Some may feel shock, worry, and denial. Others may be angry, irritated, or afraid of what the future will be like. They may feel embarrassed, lonely, withdrawn, guilty, depressed, or want to attempt suicide.

Each person who tests positive for HIV will react differently. Two factors that influence how a person reacts are:

- Emotional strength - his or her way of thinking, and dealing with emotions and problems.
- Emotional support and life circumstances - having a warm and understanding family and relationships, or having no financial problems may allow the person to be better able to manage his or her own feelings.

If people with HIV and AIDS can find their own solutions to the problems they face and have someone who understands their challenges, they may be able to accept their status and continue their lives with hope. Whenever they fall ill the feelings may come back, so it is important for them to have a supportive environment.

Positive thinking, exercise, laughter, and general good feelings release helpful hormones and other chemicals in the body. Stress can cause the release of hormones that may decrease immunity. If people with HIV and AIDS can reduce their feelings of stress, their immune system may function better, helping to fight HIV and other infections.

### ***Helping people to feel better***

How to help...

- Give people with HIV and AIDS support by sincerely showing your compassion, warmth, and caring.
- Listen and show them that you understand (or want to understand) what they are thinking and feeling.
- Let them know that their feelings are normal.
- Do not condemn, judge, or give unsolicited advice. Help them to identify options so they can make decisions.

### ***When to get professional help***

People with HIV and AIDS may have emotional problems that are too serious for friends and family members to handle alone. Encourage people with HIV and AIDS to see a health worker if they experience any of the following:

- Depression lasting longer than two weeks.
- Attempting suicide.
- Mental disorders, like hallucinations (auditory or visual) and delusions.

### ***How to listen***

Listening well and asking the right questions will encourage people to share their feelings. It is important for people with HIV and AIDS to be able to talk about their feelings, discuss their fears, and talk with someone about the future. Someone with good communication skills can make people feel comfortable talking about their feelings.

We communicate using words, sounds, silence, voice, body, eyes, and face. Half of communication is said to be unspoken – this is sometimes called body language. In addition to being aware of your own body language, it is important to pay attention to the other person's body language as well.

### ***Body language for good communication***

- Sitting in a friendly way (leaning toward the person who is talking).
- Nodding or smiling slightly to encourage someone to talk or share an opinion.
- Using appropriate facial expressions (sad face for sad stories).

### ***Body language that can block good communication***

- Nodding too often.
- Not looking at the person who is talking.
- Acting disinterested.
- Allowing interruptions.
- Smiling or frowning inappropriately.

### **Good listening skills**

- Accept people as they are. Do not judge them.
- Listen to what people say and also how they say it. Notice their tone of voice, choice of words, facial expressions, and movements.
- Imagine yourself in their place as you listen.
- Keep silent sometimes. Give them time to think, ask questions, and talk.
- Listen carefully to what they are saying instead of thinking about what you will say next.
- Every now and then repeat what you have heard, to be sure that you understood.
- Sit comfortably. Avoid distracting movements.
- Look directly at them when they speak.
- Pay attention to the person's facial or eye expressions and movements.
- Ask questions like "How have you been lately?"
- Ask the person's family or friends about his or her behaviour.

## **Information on common symptoms among people with HIV and AIDS**

The following pages have information that you can share with caregivers of people with HIV and AIDS. This information should be used as a guide, but it is important to refer people to health centres for treatment.

Because people with HIV and AIDS have a weakened immune system, they often get attacked by different infections. Caregivers can prevent many problems by being aware of danger signs and illness. It is important to learn what is normal and report any changes. They should pay attention to:

- Mood: Alert, sleepy, irritable, jumpy, withdrawn
- Colour: Normal, white, yellow skin; normal, bluish fingernails
- Skin: Rash, dry ulcers, blisters, sweaty, loose
- Body: Feverish, cold, sweating
- Breathing: Fast, slow, laboured, noisy
- Other: Fast or irregular heartbeat, odd body odour

The following pages have information on common symptoms for people with HIV and AIDS and what caregivers can do.

- |                          |                                       |
|--------------------------|---------------------------------------|
| 1. Fits/seizures         | 7. Mouth sores and sore throat        |
| 2. Problems seeing       | 8. Coughs                             |
| 3. Fever and headache    | 9. Joint and muscle pain              |
| 4. Diarrhoea             | 10. Loss of appetite and weight loss  |
| 5. Nausea and vomiting   | 11. Feeling weak and trouble sleeping |
| 6. Skin rashes and bumps | 12. Feelings and emotions             |

### **1. Fits/seizures**

Seizures are disorders of brain function, resulting from fungal meningitis, brain injuries, or heredity

#### **Care at home**

There is no specific treatment for seizures or spasms from fungal meningitis. Affected persons usually recover eventually from the seizure. Providing care when seizures occur will prevent potential injury.

## Care during seizures

- Care should be taken to protect the person from collisions or falls.
- Clear the area around the person so there is nothing in the way.
- Roll the person onto one side to ease breathing.
- Loosen clothing and take off glasses.
- Place a pillow under the head.
- Stay with the person throughout the seizure.



## Care after the seizure

- Comfort or inform the person of the seizure to hasten consciousness.
- Ensure sufficient rest until the person has regained complete consciousness.

## When to visit the doctor?

- When the person has recurring seizures or becomes unconscious.
- When the seizure lasts longer than 15 minutes.

## Remember

- Do not put a solid object or spoon in the mouth as this might cause an oral injury.
- Do not tie up or attempt to fight with the affected person.
- Do not feed during the seizure or immediately afterwards because of choking risk.
- Stress and sleeplessness can cause or worsen seizures.

## 2. Problems seeing

People with weak immune systems often lose their sight because of Cytomegalovirus (CMV). Initially it causes visual abnormalities, such as seeing floating dark spots. CMV is very serious and likely to cause swift blindness.



## Preventing vision loss

- Maintain a healthy immune system.
- Visit a doctor immediately if having trouble seeing.

## When to visit the doctor?

- Immediately after experiencing vision loss, abnormal vision, or regularly seeing floating dark spots.

## Remember

- Without quick treatment, CMV can cause blindness.
- Medication for vision loss can have some side effects, including diarrhoea, fatigue, and fever, if they occur visit the doctor immediately.
- Eat fish, chicken, soybeans, and garlic to enhance immunity.

## 3. Fever and headache

Fever and headache can be caused by the flu or the common cold. They may also be symptoms of HIV infection or other opportunistic infections.

## Care at home

- Drink plenty of water and other fluids (boiled water, weak tea, soup, juice) to avoid dehydration.
- Soak a wet towel in cold water and rub the whole body, especially the chest and forehead.
- Get plenty of rest.
- Take analgesics to reduce fever:
  - Paracetamol 500 mg, 1-2 tablets, every 4 – 6 hours
  - Aspirin 325 mg, 1 tablet, every 4 – 6 hours



## When to visit the doctor?

- High fever (above 38° Celsius) or fever for three days after treatment at home.
- Fever, coughing, and weight loss during the last month.
- A combination of fever, dry mouth, severe headache, convulsion, yellow eyes (jaundice), or diarrhoea.
- A combination of severe headache, fever, drowsiness, stiff neck, and vomiting.



## Remember

- Do not take more than 8 paracetamol tablets a day.
- Aspirin should be taken immediately after meals, with plenty of water to prevent stomach upset.
- If experiencing only headache and no fever, exercise to enhance blood circulation.

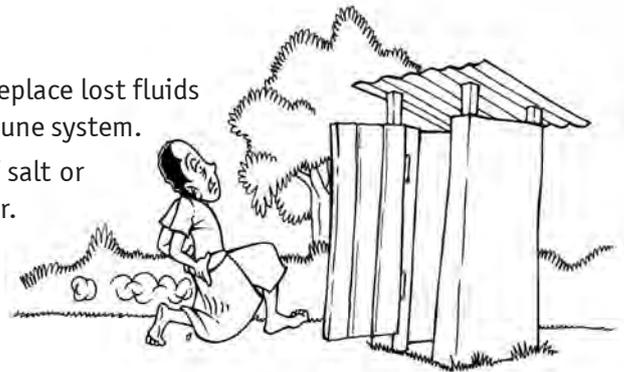
## 4. Diarrhoea

Diarrhoea can be from an infection from food or water, stress, or a weak immune system.

### Care at home

Diarrhoea is easily treated by drinking plenty of water to replace lost fluids and by trying to eat, in order to strengthen the body's immune system.

- Dissolve 2 tablespoons of sugar and ½ teaspoon of salt or oral rehydration salts (ORS) in a bottle of boiled water. Drink the solution instead of drinking water often after defecation.
- Drink plenty of fluids (boiled water, weak tea, soup, juice) to avoid dehydration.
- Eat soft, cooked, and clean food that is nutritious and easily digested. Food that is well cooked, mashed or ground and yoghurt, bananas, and melon.
- Eat small meals every two hours.
- Avoid fats, oils, and milk products (except yoghurt), citrus fruits, and spicy foods.
- If experiencing stomach cramps or pain, use a hot water bottle wrapped in a towel to reduce the pain.



## When to visit a doctor?

- Symptoms do not improve.
- Fever.
- Watery diarrhoea lasting three days.
- Blood or mucus in stool.
- Weakness, nausea or vomiting, or unable to drink or eat.
- Severe abdominal pain.

## Remember

- After defecation, clean the anus properly – soak in warm water mixed with salt, then dry and apply body lotion.
- Avoid milk while the diarrhoea is active, it may worsen the symptoms or cause gas.
- ORS solution should be prepared daily and drunk on the day it is prepared.

## 5. Nausea and vomiting



### Care at home

- Avoid cooking smells.
- Eat plain foods that are easily digested.
- Eat small amounts of food often, rather than one or two large meals.
- Eat soups (using the cooking water for vegetables) or food that is soft and mashed.
- Drink plenty of fluids (boiled water, weak tea, soup, juice) to avoid dehydration.

### When to visit the doctor?

- Vomiting that lasts for more than 24 hours.
  - Blood in the vomit.
  - Severe pain in the stomach.
  - Fever.
- Dehydration.
  - Unable to eat or drink.

## 6. Skin rashes and bumps

Skin problems are common among people with HIV and AIDS. These may be conditions that last for a long time and are difficult to cure. However they can be prevented and treated.

### Care at home

#### Dry and itchy skin or itchy rashes

- Apply a clean, wet towel to reduce itching.
- Avoid dryness by applying body lotion or Vaseline if skin feels very dry.
- Try not to use soaps or detergents.
- Lie in the sun in the early morning or late afternoon for half an hour to relieve rashes on the arms and legs.
- Try not to scratch, and keep fingernails short to avoid further wounds.
- Medication:
  - Calamine lotion: apply 2 – 3 times a day
  - Chlorpheniramine: take 2 (2 mg) tablets every 4 – 6 hours



## Wounds, infected wounds, abscesses, or swollen wounds

- For abscesses, infected open sores, and swollen wounds, apply a warm compress for 20 minutes, four times a day.
- For infected wounds with abscesses: clean with saline solution, apply povidone-iodine and dress the wound.
- When using aloe (snake plant), cut a thin slice and only use the gel inside the leaves to cover the wound.
- Wash non-infected and infected open sores with cooled, boiled water mixed with salt (1 tsp salt/per litre of water) three to four times a day, keep them dry and cover them with a gauze bandage or loose cloth.
- Change any dressing at least once a day.
- Prevent more sores, such as bedsores, by changing position at least four times a day.

## Herpes zoster rash (shingles)

- Apply calamine lotion twice a day to reduce itching, relieve pain, and promote healing.
- Wash the affected area with normal saline solution to prevent infection.
- Keep sores dry and do not let them be rubbed by clothes.
- Wear clean, loose-fitting, cotton clothing.
- Bathe sores in warm salt water three-four times a day to prevent infection.
- Apply gentian violet solutions once a day or antibiotic skin creams or ointments, if available, to prevent infection.
- Do not eat groundnuts or any dish containing groundnuts because they may make symptoms worse.
- Take aspirin or paracetamol for pain; if the pain is severe, use stronger prescribed medicines as painkillers and as sedatives at night.

## When to visit the doctor?

- If the irritation or surrounding area is red and swollen and there is fever.
- When there are many wounds or abscesses.
- If the affected area smells bad, bleeds, or becomes black.
- If it is very painful.
- If the face is affected.
- If a rash appears along the limbs or on the face after taking antibiotics.



## Remember

- The best way to prevent skin diseases is to keep the skin dry, using soap and water to keep it clean.
- Always wash hands with soap and water before dressing a wound. Avoid contamination with blood and pus.
- Cover an infected or bleeding wound. It is not necessary to cover a dry wound.
- Eat fish, chicken, soybean, garlic and vitamin B complex to nourish the skin.
- Take paracetamol 500 mg, 1-2 tablets every 4-6 hours for pain relief.

## 7. Mouth sores and sore throats

White patches may appear on parts of the mouth or throat. They may cause a sore throat when swallowing.

### Care at home

- Clean mouth and teeth more often with floss, picks, or a tooth-cleaning stick. Make toothpaste of salt and bicarbonate of soda (or charcoal) in equal amounts, used with a soft, wet toothbrush.
- Rinse the mouth with saline solution (Mix  $\frac{1}{2}$  spoon of salt with 1 cup of water) often or after meals.
- Drink plenty of warm water.
- Wear a scarf to keep warm.
- Eat healthy, soft foods. Avoid food with sugar or yeast.
- Do NOT scrape the mouth.
- If the tongue is affected, follow these instructions:
  - Clean the tongue and gums with either a soft toothbrush or cotton buds dipped in normal saline solution.
  - Rinse with saline solution or warm water.
  - Get plenty of rest.

### When to visit the doctor?

- Severe sore throat or unable to swallow water or food.
- Burning pain in the chest.

### Remember

- Drink plenty of water.
- Eat soft foods, and avoid spicy food.
- Eat plenty of vegetables, cereals (wheat, maize), and garlic.
- Drinking through a straw may help to avoid the burning sensation experienced when drinking.

## 8. Coughs

People with HIV and AIDS often suffer from coughs, shortness of breath, wheezing, or chest pains as a result of colds (homa), asthma, tuberculosis or lung infections.

### Care at home

- Keep the home well ventilated.
- Soothe the throat with tea and honey, or cough syrup.
- Take short walks, do simple exercises for the legs and arms, and deep breathing exercises to promote drainage in the lungs.
- Cover the mouth when coughing.
- Carefully dispose of soiled cloth that has been coughed in or is wet with mucus.

### Coughs

- Drink lime juice mixed with salt, or tea with sugar.
- Take fresh garlic, onion, and sunflower seeds.
- Frequently sip warm water.
- Suppress the cough at night with cough suppressants.



## Wheezing or shortness of breath

- Keep the head upright while resting or sleeping – support the head with pillows or cushions.
- In order to enhance breathing, try the following exercise: while sitting, bend the body forward, supporting the chin with the patient's hands and with the elbows on the lap.
- Stay in well-ventilated areas and avoid dusty areas.

## If diagnosed as TB

- Patients should take medication regularly and continuously.
- Take every precaution to prevent transmission of the disease.
- Consume foods high in protein, energy, iron and vitamins.

## Remember

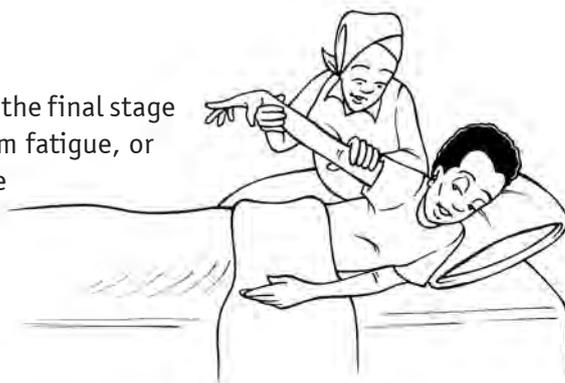
- Do not eat or drink anything while the symptoms are severe; wait 1 – 2 hours after they have passed and then start slowly with either water or tea.
- Avoid eating while lying down.
- Some medicines may cause drowsiness.

## When to visit the doctor?

- Unable to eat.
- Severe dryness in the mouth, weakness, or blackout.
- High fever.
- Severe chest pain.
- Grey, yellow, green, or bloody mucus.
- Difficulty breathing.
- Cough lasting for more than three weeks.

## 9. Joint and muscle pain

Joint and muscle pain can occur at any stage of HIV including the final stage when people living with AIDS can no longer work, suffer from fatigue, or have to stay in bed. Lying still and not being able to move affects blood circulation, which can cause joint and muscle pain. Relieving the pain will make people with HIV and AIDS feel better.



## Care at home

- Take pain-relieving medicines (paracetamol).
- Gently massage the arms, legs and back of the patient. Warm the hands by rubbing them with olive oil, body lotion, or talcum powder beforehand to reduce skin abrasion.
- Gently stroke the limbs with both palms, starting from the upper arms to the fingertips and the thighs to the toes. Repeat the stroke, adding more pressure this time, alternating between arms and legs until the skin feels warmer when touched.
- Move the finger joints, toe joints, and the elbows. Bend the arms at the elbows, lifting up to the shoulders, and release. Lift arms up and down. Bend the legs at the knees and hips, if the patient cannot exercise on their own, move their arms and legs for them.
- Rub only the muscles, asking where it hurts. Gently feel the spot and use the thumbs or a hot compress to press the area, apply as much pressure as they can stand, counting 1 to 5, then release the pressure.

## 10. Loss of appetite and weight loss

Stress, worry, and feeling sad can all cause people to lose their appetite. Some illnesses also cause people to not feel hungry. Mouth sores can also make eating difficult. HIV and fever can increase the body's energy needs.

### Care at home

- Treat or relieve any complications that cause loss of appetite.
- Stimulate appetite by:
  - Eating small amounts more often.
  - Eating while the food is still warm.
  - Eating favourite foods.
  - Avoiding strong smelling foods.
- Keep the mouth clean by brushing the teeth often or by rinsing with saline solution (Dissolve 1/2 teaspoon salt in 1 cup of water) after meals.
- Take vitamins such as multivitamins or Vitamin B complex to stimulate appetite, 1 tablet should be taken 2 to 3 times a day.
- Add vegetable oil or groundnut paste to food for extra nutrition.
- Eat foods that are rich in protein, vitamins and carbohydrates.
  - Foods that are rich in carbohydrates and provide energy include: cereals, starchy roots and tubers, such as potatoes, yams, cassava, taro, plantains, wheat, rice, millet, and maize.
  - Foods that are rich in vitamins and protect the body from infection include: all fruits and vegetables, especially dark green leafy vegetables and orange coloured vegetables, and fruits.
  - Foods that are rich in protein and contain iron and calcium include: dairy products, peas, beans, soya, groundnuts, eggs, and poultry.



### When to visit the doctor?

If unable to eat at all or losing weight quickly.

### Remember

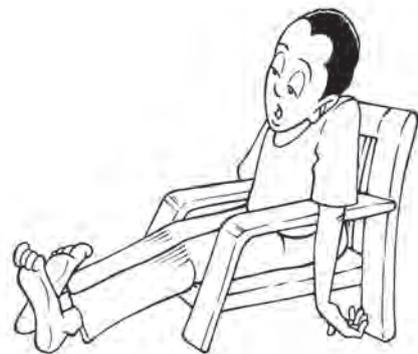
If he or she cannot eat a lot of food in one sitting, encourage them to eat small amounts more often to strengthen the body's immunity.

## 11. Fatigue and trouble sleeping

Both fatigue (weakness) and insomnia (unable to sleep well) can be caused by anaemia, heart disease, asthma, or opportunistic infections. Anxiety or lack of rest can also cause symptoms.

### Care at home

- Get adequate rest.
- Try to eat more food or small amounts more often.
  - Eat foods that are high in calories and are easily digested : juice or syrup.
  - Take vitamins such as multivitamins or vitamin B complex to stimulate appetite. One tablet should be taken 2 or 3 times a day.
- Avoid drinks with caffeine (like tea, coffee, and sodas).



## When to visit the doctor?

- If feeling very weak or feeling weak for a long time.
- If feeling very stressed or unable to sleep for a long time.

## Remember

- Sleeping tablets and tranquilizers should only be taken under a doctor's advice.
- Some medicines like Chlorpheniramine or Dimenhydrinate can cause drowsiness, and may help people to sleep.

## 12. Emotions and feelings

It is normal for people with HIV and AIDS to have many different feelings and emotions at different times after learning they are positive. Below are ways to identify different feelings and ways to support someone.

### Anger

Signs of anger include frowning, talking loudly, avoiding eye contact, tightened lips, shouting at family members or friends, restlessness, pacing, unusual quietness, self abuse, violence towards others, and uncooperative behaviour.

#### Do

- Allow the person to discuss his or her anger. Try to show your understanding of his or her situation by describing it. For example, say, "You are angry that your husband infected you."
- When the person has calmed down, help the person to realize the consequences of his or her anger. Ask questions like, "What would happen if you stay angry?"
- Try to identify other sources of his or her anger and work with the person or resolve these.

#### Don't

- Ignore the person's feelings, or make comments like, "It is useless to get angry," "Just accept it," or "Forget it."
- Argue with the person or express your own frustration by making comments like, "I cannot help if you stay angry."
- Pressure the person to explain his or her emotions.
- Use your own life or experiences as a model for the person to follow.



### Fear or worry

Signs of fear or worry include chest pain, shortness of breath, faster heartbeat, sweating, restlessness, dizziness, fainting, and not being able to sleep. People with HIV and AIDS may mention that they are afraid of dying or losing control. They may say that they are upset or worried. Other noticeable signs include worried facial expressions or not being able to focus on tasks or do them well. Fear is more serious than worry.

#### Do

- Pay attention to the person's feelings.
- Encourage him or her to talk about feelings and express fear or worry.
- Identify the source of fear or worry by asking, "What are you afraid of?"
- Identify ways to address fear or worry. For example, if the person is afraid of dying when he or she falls ill or has an infection, suggest visiting a health clinic.

- Suggest activities that may take the person's mind off his or her fear or worry, like housework, keeping fit, or visiting family and friends.
- Provide moral support, by saying, "Other people with HIV and AIDS share your fears," or "Parents can accept HIV-positive children," or "You are still in good physical condition. If you take good care of your health, you can lead a long and normal life."



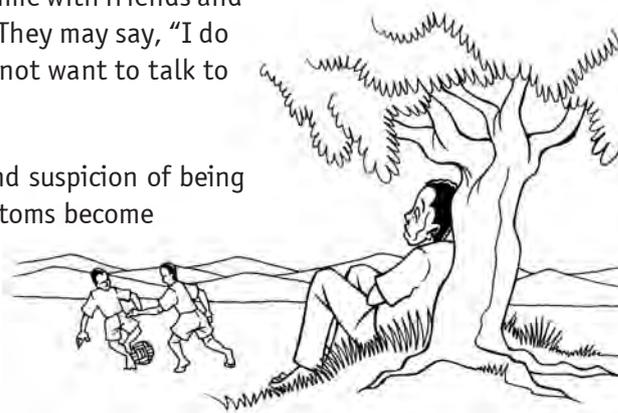
### Don't

- Neglect or ignore the person's fear or worry.
- Belittle the person's fear or worry by saying, "This is nothing, don't worry about it."
- Worry or feel tense because you cannot help him or her.

### Loneliness or stigmatization

Signs include avoiding eye contact, no longer spending time with friends and family, speaking little, and feeling lonely and deserted. They may say, "I do not want to see anyone," "I want to be alone," or "I do not want to talk to anyone."

Stigmatization arises from fear of social discrimination and suspicion of being watched and gossiped about. It usually begins when symptoms become apparent or when someone's partner dies of infections. Loneliness comes when people with HIV and AIDS feel they have no one to share their problems with or that no one would understand them. They feel lonely and worthless.



### Do

- Meet, talk with them, and spend time together regularly.
- Pay attention to or stay with the person, even though he or she may not want to chat.
- Listen and show understanding and support. Let him or her know that your conversations are private and confidential.
- Identify the cause of stigmatization. Encourage the person to think positively and point out his or her strengths that make people accept him or her.
- Talk with family members and encourage them to accept and support the person.
- Give moral support by providing information on resources, such as support groups and health services within the community.

### Don't

- Ignore or make fun of feelings of loneliness.
- Add to his or her feelings by saying things like, "Don't worry too much, otherwise your symptoms could get worse."
- Provide too much support too soon, because he or she may already feel uncomfortable and become even more uncomfortable.

### Depression

Common signs of depression are sadness, withdrawal, unusual quietness, loss of appetite, insomnia, feeling tired, memory loss, inability to focus, and moving slowly.

People suffering from chronic illnesses, especially those without a cure, often feel guilty, worthless, and hopeless.

Fear of loss can also be a cause of depression, especially about the loss of life, health, social status, a spouse or partner, or economic stability.



## Do

- Express friendly concern and care to the person, even though he or she might not want to share personal thoughts and feelings.
- Pay attention and encourage the person to discuss personal feelings. Give moral support when he or she can solve the problem. Ask, "How did you solve other problems in the past?"
- Listen, try to imagine you are in his or her position, show you care, and take his or her words seriously.
- Identify the causes of depression and provide proper assistance to resolve them. For example, if the person feels worthless, help to identify personal strengths.

## Don't

- Ignore or brush aside the person's feelings by saying, "Don't worry, everything will be fine."
- Give advice without listening to the person's feelings.
- Try to counsel at a level beyond your capacity or neglect to seek professional help.

## Suicide

Some people who are really depressed may want to die or feel that they are worthless. They may stop caring about things that were once important to them and stop taking care of themselves. Some people may attempt suicide because they are angry with their family members or because they feel ashamed or guilty.

## Warning signs of suicide

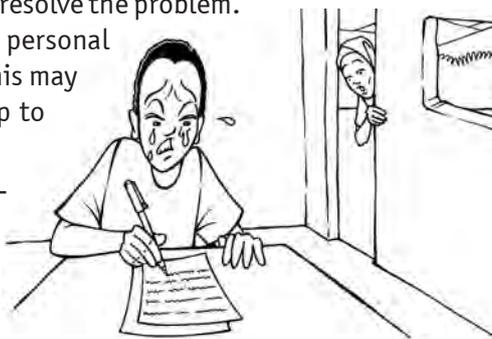
- Saying he or she wants to die.
- Signs of planning such as writing farewell letters or giving away treasured possessions.
- Comments suggesting impending death such as, "Please take care of my children," or "This is the last time we'll meet."
- In some cases, suddenly feeling better after a long depression might mean that the person has decided to commit suicide.



## Do

- Ask the person about his or her thoughts and feelings. For example:  
"How are you feeling?"  
"Have you ever felt that you no longer want to live?"  
"Have you ever thought of hurting yourself?"  
"Have you ever hurt yourself?"
- Continue to listen and provide support, and talk to a health worker for advice.
- Watch the person closely, especially if he or she has a plan, but has not made any arrangements or prepared any equipment.
- Get professional help from health workers and take the person to the hospital or health clinic if he or she has a specific plan and equipment to carry it out.

- Identify the causes of suicidal behaviour in order to properly resolve the problem. For example, if the person feels worthless, help to identify personal strengths or identify a person he or she cares for, because this may give him or her the will to live. If the person is angry, help to manage the anger to reduce suicidal risks.
- Watch the person to see if he or she shows signs of self-destructive behaviour. Be careful and always keep potential suicidal equipment such as sharp objects, ropes, hazardous chemicals, and drugs away from the person.



## Don't

- Ignore the person's feelings by saying, "Don't worry, everything will be fine."
- Try to calm, advise, or teach without paying any attention to the person's feelings.
- Assume that he or she is joking or will not have enough courage to attempt suicide.
- Use religious arguments, like "Committing suicide is sinful."
- Make fun of unsuccessful suicide attempts by saying, "Next time do it properly."
- Try to counsel at a level beyond your capacity or neglect to seek professional help.

## Getting professional help

If, despite your efforts, there is no improvement in the person's condition, you should immediately encourage him or her to see a specialist who can closely watch him or her and prescribe treatment or medication if necessary.

After he or she has received treatment, continue to visit him or her to see how they are doing. Should he or she begin to show renewed suicidal tendencies, continue to provide help and take him or her to see a health worker. Remember that he or she still needs your help.

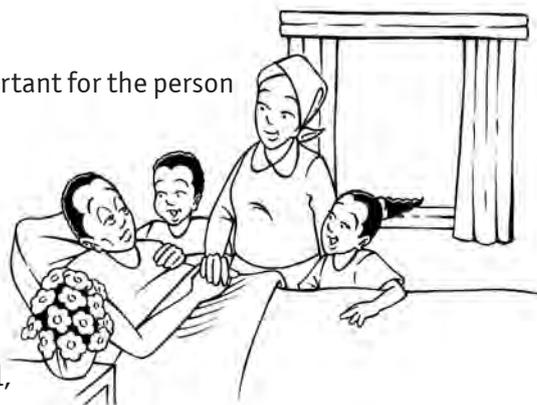


## Helping people who are dying

Making sure someone feels comfortable in their last days is important for the person and his or her family.

### Physical support

- Keep the person clean.
- Be sure he or she is breathing easily and is not in pain.
- The use of touch can be comforting and provide support.
- Make sure the person's surroundings are familiar, peaceful, and that family is close by.



### Mental support

- Discuss his or her fears and worries.
- Allow him or her to have traditional or religious rites.
- Show a friendly and positive physical presence as death approaches. Be sure his or her hand is held.
- Make the person aware that he or she is not alone and that friends and family are close by.
- Allow him or her to talk, and assure the person that any requests will be carried out.



If the person is unable to talk, consider using closed questions, asking the patient to move the face or eyelid for “yes” and “no” or to write his or her answer. If the patient is unconscious, whisper or speak quietly.

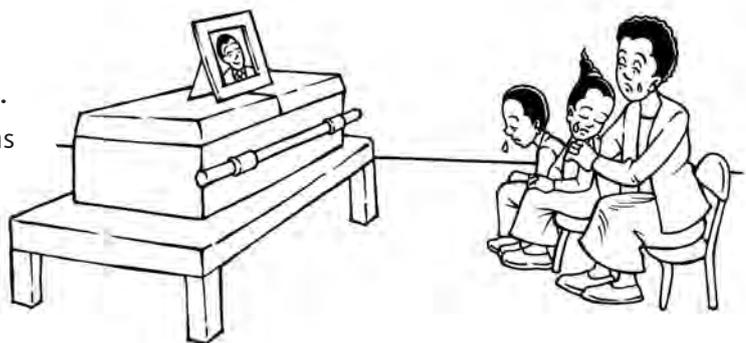
### Don't

- Interrupt them when they are talking.
- Ignore them if they are unconscious or seem confused.

### Helping bereaved families

#### Do

- Listen.
- Tell them you are sorry.
- Help them make funeral arrangements.
- Coordinate with other organizations that offer support.



#### Don't

- Rush in to support without thinking of the family's needs or feelings.
- Ignore or trivialize the family's feelings.

### Memory books

People with HIV and AIDS often worry that they will not be able to see their children grow up. Some people make “Memory Books” for their children. In the memory book they write about their lives, their dreams, and their hopes for their children. They also write about their family, where they grew up, where they went to school, what their children were like when they were young, and other things that parents share with their children.

They may write about how they hope their children will be when they grow up, the values they will have, the kinds of decisions they will make, and other aspects of their characters. They can also write about family health problems that are important to know. If they can afford it, sometimes people include photos of themselves, their home, or their children.

The book can be a simple exercise book. What is important is that it gives children a record of their parent's life and is a physical expression of their love.



It is good for children to know their family history, however painful this might be, as long as this history is told in a loving and accepting setting. If children know the history of their parents, they are better able to overcome the suffering caused by their parents' illness or death. Parents and caregivers often assume that their children are "too small to understand." Yet a conversation between adults and children around sickness and death can help. Families need to talk about these issues. Children should be encouraged to talk about their feelings.



## Gender and home-based care and support

Women and girls are traditionally responsible for taking care of ill or elderly family members. Although organized home-based care may be the better option, gender norms giving husbands financial decision making power, and obligating women to be responsible for family members may be a significant barrier to getting such care. Families may also be less willing to spend resources on home-based care for women who are ill, especially elderly ill women, because of gender norms. Family members need to discuss the options available for home-based health care and make decisions together.

## References

This chapter is adapted from *Stay Fit – Feel Good: A Community Manual for Physical and Psychosocial Care for People Living with HIV/AIDS*, developed by Lampang Provincial Health Office in cooperation with PATH and the Ratananurak Center with financial support from Horizons/USAID through the Population Council.

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